Contract No.: Q146901

MPR Reference No.: 8349-223



5/12/4

# Evaluation of the Cash and Counseling Demonstration

Baseline Instrument

June 14, 2001

#### Submitted to:

Center on Aging University of Maryland 1240 HHP Building Valley Drive College Park, MD

Project Officer:

Kevin Mahoney, Ph.D.

# Submitted by:

Mathematica Policy Research, Inc. P.O. Box 2393
Princeton, NJ 08543-2393
Telephone: (609) 799-3535
Facsimile: (609) 799-0005

Project Director:

Randall Brown, Ph.D.

# LIST OF MODULES

		Page
ľ	INTRODUCTION	1
A	HOUSEHOLD	18
В	UNPAID HELP	20
C	PAID HELP, UNMET NEED, AND SATISFACTION	32
D	USE OF OTHER HOME- AND COMMUNITY-BASED SERVICES	45
E	CLIENT HEALTH AND FUNCTIONAL IMPAIRMENT	49
F	PREDICTING DROPOUT AND CLIENT CHARACTERISTICS	55

#### I. INTRODUCTION

>i1< Hello, I'm calling about the [PROG] program. My name is [fill INTERVIEWER'S FULL NAME] from Mathematica Policy Research in Princeton, New Jersey. May I please speak to (a parent or guardian of) [fill Mr./Ms.] [fill FCNM] [fill LCNM])?

INTERVIEWER: IF ONE PARENT OR GUARDIAN IS UNAVAILABLE, ASK TO SPEAK TO THE OTHER PARENT OR GUARDIAN BEFORE ASSIGNING A STATUS.

- <1> SPEAKING TO CLIENT/PARENT [goto i4]
- <2> WANTS MORE INFORMATION [goto i2]
- <3> CLIENT/PARENT UNAVAILABLE [goto cb]
- <4> CLIENT/PARENT COMES TO THE PHONE [goto i3]
- <5> CLIENT/PARENT 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> CLIENT/PARENT IN HOSPITAL [goto i12]
- <9> CLIENT/PARENT IN NURSING HOME OR ICF/MR [goto i14]
- <10> CLIENT/PARENT MOVED (NOT IN NURSING HOME)[goto i20]
- <11> WRONG NUMBER [goto bdph]
- <12> PROBLEMS-LANGUAGE, SUPERVISOR REVIEW
- <r> REFUSAL/ HUNG UP DURING INTRODUCTION [goto ref]

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

>i2< (A parent or guardian of) [fill Mr./Ms.] [fill FCNM][fill LCNM] should have received information about a study of (the care of older people/help for people [of all ages] with disabilities). We are calling people who recently decided to sign up for a program, [fill PROG], in which they might receive a MONTHLY from Medicaid. (A parent or guardian of) [fill Mr./Ms.][fill FCNM] [fill LCNM] already agreed to a telephone interview. I'd like to begin the interview at this time.

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.

PROBE IF RESPONDENT IS RELUCTANT: As you may remember (a parent or guardian of) [fill Mr./Ms.][fill FCNM] [fill LCNM] needs to complete this interview to have a chance to participate in the (cash program/PROG program).

- <1> CLIENT/PARENT COMES TO THE PHONE [goto i3]
- <2> CLIENT/PARENT IS ON THE PHONE AND WANTS TO CONTINUE [goto i4b]
- <3> CLIENT/PARENT UNAVAILABLE [goto cb]
- <5> CLIENT/PARENT PHYSICALLY OR MENTALLY UNABLE TO RESPOND ON THE TELEPHONE [goto i8]
- <6> CLIENT AT HOME IN A COMA (VOLUNTEERED)[goto i14b]
- <7> CLIENT DECEASED [goto i11]
- <8> CLIENT/PARENT IN HOSPITAL [goto i12a]
- <9> CLIENT/PARENT IN NURSING HOME OR ICF/MR [goto i14a]
- <10> CLIENT/PARENT MOVED (NOT IN NURSING HOME)[goto i20a]
- <11> WRONG NUMBER [goto bdph]
- <12> PROBLEMS--LANGUAGE, SUPERVISOR REVIEW [goto prob]
- <r> REFUSAL/HUNG UP DURING INTRODUCTION [goto ref]

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

===>

>i3< Hello, I'm calling about the [PROG] program. My name is [fill INTERVIEWER'S FULL NAME] from Mathematica Policy Research in Princeton, New Jersey.

TYPE <g> TO CONTINUE

You should have received information about a study of (the care of older people/help for people [of all ages] with disabilities). We are calling people who recently decided to sign up for a program, [fill PROG], in which they might receive a MONTHLY from Medicaid. You may remember agreeing to be interviewed over the telephone. The questions we are asking are about the services you have been receiving recently.

IF NECESSARY: All of the answers will be held in strict confidence, and reported only as averages for groups of people. Participation in the study is voluntary. We very much appreciate your willingness to be interviewed.

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.

PROBE IF CLIENT IS RELUCTANT: As you may remember, you need to complete this interview to have a chance to participate in the (cash program/ PROG program).

TYPE <g> TO CONTINUE

===>

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

- <1> BEGIN INTERVIEW [goto i30]
- <2> NOT A GOOD TIME--SKIP TO CALLBACK [goto cb]
- <3> DID NOT RECEIVE OR DOES NOT RECALL INFORMATION [goto i5]
- <r> CLIENT/PARENT REFUSAL [goto ref]

===>

>i5< The materials explained that you would be telephoned as one of the people who decided to sign up for a program, [fill PROG]. Some people participating in this program will be randomly selected to receive a MONTHLY.

PROBE: As you may remember, your consent form states that completion of this interview is necessary for participation in the (cash program/PROG program).

- <1> BEGIN INTERVIEW [goto i30]
- <2> NOT A GOOD TIME--SKIP TO CALLBACK [goto cb]
- <3> WANTS MORE INFORMATION [goto i6a]
- <r> CLIENT/PARENT REFUSAL [goto ref]

===>

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

CURRENT ADDRESS IS: [fill Mr./Ms.][fill FCNM] [fill LCNM] [fill ADDR] [fill CITY] [fill ST] [fill ZIP:0] INTERVIEWER: IF DIFFERENT, RECORD CLIENT/PARENT ADDRESS BELOW. STREET ADDRESS:\_\_\_\_\_ CITY: STATE: ZIP CODE: ===> [goto cb] (A parent or guardian of) [fill Mr./Ms.][fill FCNM] [fill LCNM] should have received information about a study of (the care of older people/help for people [of all ages] with disabilities). We are calling people who recently decided to sign up for a program, [fill PROG], in which they might receive a MONTHLY from Medicaid. (A parent or guardian of) [fill Mr./Ms.][fill FCNM] [fill LCNM] may remember agreeing to be interviewed over the telephone. The questions we are asking are about the services people have been receiving recently. 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. TYPE <g> TO CONTINUE Will (a parent or guardian of) [fill Mr./Ms.][fill FCNM] [fill LCNM] be able to talk on the

>i8< Will (a parent or guardian of) [fill Mr./Ms.][fi telephone if I call back in a day or two?

<1> YES

<0> NO [goto i14b]

<d> DON'T KNOW [goto i14b]

===>

>i7<

>i9< When would be a good time to call to see if (he/she) is up to it?

INTERVIEWER: RECORD DAY AND TIME ON CONTACT SHEET.

TYPE <g> TO CONTINUE

===> [goto cb]

>i10< I am very sorry to hear that (he/she) is so ill. (A parent or guardian of) [fill Mr./Ms.][fill FCNM] [fill LCNM] should have received information about the study of (the care of older people/help for people [of all ages] with disabilities). We are calling people who recently decided to sign up for a program, [fill PROG], in which they might receive a MONTHLY from Medicaid.

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 i14b]

>i11< I am very sorry to hear that (he/she) passed away. I was calling about a study of (the care of older people/help for people [of all ages] with disabilities). There is no need for us to disturb you further. Thank you very much for your time.

===> [goto fs:deceased]

>i12< (A parent or guardian of) [fill Mr./Ms.][fill FCNM] [fill LCNM] should have received information about a study of (the care of older people/help for people [of all ages] with disabilities). Do you expect (a parent or guardian of) [fill FCNM] [fill LCNM] to come home from the hospital within a day or two?

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 i14b]

>i12a< Do you expect [fill Mr./Ms.][fill FCNM] [fill LCNM] ('s parent or guardian) to come home from the hospital within a day or two?

<1> YES

<0> NO [goto i14b]

<d> DON'T KNOW [goto i14b]

===>

>i13< Would (a parent or guardian of) [fill Mr./Ms.][fill FCNM] [fill LCNM] be able to talk on the telephone about the services (he/she) has been receiving recently if I called back in a day or two?

<1> YES [goto cb]

<0> NO

<d> DON'T KNOW

===> [goto i14b]

>i14< I am calling about a study of (the care of older people/help for people [of all ages] with disabilities). (A parent or guardian of) [fill Mr./Ms.][fill FCNM] [fill LCNM] should have received information about the study.

Would [fill Mr./Ms.][fill FCNM] [fill LCNM] ('s parent or guardian) be able to talk on the telephone about the services (he/she) has been receiving recently?

PROBE: If I called him/her 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 i23]

<0> NO

<d> DON'T KNOW

===> [goto i14b]

>i14a< Would (a parent or guardian of) [fill Mr./Ms.][fill FCNM] [fill LCNM] be able to talk on the telephone about the services (he/she) has been receiving recently?

PROBE: If I called him/her at the nursing home.

<1> YES [goto i23]

<0> NO

<d> DON'T KNOW

===>

>i14b< CATI CHECK: IS CLIENT LESS THAN 18 YEARS OF AGE?

<1> YES

<0> NO [goto i14e]

===>

>i14c< CATI CHECK: IS CLIENT IN A COMA?

<1> YES [goto i14e] <0> NO [goto i15]

===>

>i14e<

(I am sorry to hear that.) Because CLIENT is unable to respond for him/herself, I would like to speak to (a parent or guardian of [fill FCNM] [fill LCNM]/ the person who is most knowledgeable) about the services [fill Mr./Ms.][fill FCNM] [fill LCNM] has been receiving lately. Is he/she/that person available at this time?

IF NECESSARY: (A parent or guardian of) [fill Mr./Ms.][fill FCNM] [fill LCNM] should have received information about a study of (the care of older people / help for people [of all ages] with disabilities). We are calling people who recently decided to sign up for a program, [fill PROG] in which they might receive a MONTHLY from Medicaid. (A parent or guardian of) [fill Mr./Ms.][fill FCNM] [fill LCNM] already agreed to a telephone interview. I would like to begin the interview now.

- <1> SPEAKING TO PARENT/MOST KNOWLEDGEABLE PERSON (OR COMES TO PHONE)
- <2> NO, PARENT/MOST KNOWLEDGEABLE PERSON UNAVAILABLE AT THIS TIME [goto i14f]
- <3> NO, PARENT/MOST KNOWLEDGEABLE PERSON UNAVAILABLE DURING FIELD PERIOD [goto i15]

<r> REFUSED [goto ref]

===>

>i14f< CATI CHECK: IS CLIENT LESS THAN 18 YEARS OF AGE?

<1> YES AND i14e=1 [goto i30] <2> YES AND i14e=2 [goto cb] <0> NO [goto i16aa]

===>

>i15<

(I am very sorry to hear that.) Perhaps you could answer some questions on behalf of (a parent or guardian of) [fill Mr./Ms.][fill FCNM] [fill LCNM]. Are you knowledgeable about the services [fill FCNM] has been receiving lately?

INTERVIEWER: CODE IF KNOWN.

<1> YES [goto i16aa]

<0> NO

<d> DON'T KNOW

<r> REFUSED

===>

>i15a<

Is there another family member for friend who could answer questions on behalf of [fill Mr./Ms.][fill FCNM][fill LCNM] ('s parent or guardian)?

PROBE: Is there a family member or friend who is knowledgeable about the services [fill Mr./Ms.][fill FCNM][fill LCNM] has been receiving lately?

- <1> YES
- <0> NO [goto i26]
- <d> DON'T KNOW [goto i26]
- <r> REFUSED [goto ref]

===>

>i15b< Is he/she 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.

(A parent or guardian of) [fill Mr./Ms.][fill FCNM] [fill LCNM] should have received information about a study of (the care of older people/help for people [of all ages] with disabilities). We are calling people who recently decided to sign up for a program, [fill PROG], in which they might receive a MONTHLY from Medicaid. (A parent or guardian of) [fill Mr./Ms.][fill FCNM] [fill LCNM] already agreed to a telephone interview.

I am sorry to hear that (a parent or guardian of) [fill Mr./Ms.][fill FCNM][fill LCNM] is ill. You were suggested as the person most knowledgeable about the services [fill FCNM] has been receiving lately. Would you mind doing the interview on his/her behalf?

- <1> BEGIN INTERVIEW
- <2> NOT A GOOD TIME
- <r> REFUSED [goto ref]

===>

>i16aa<

(In that case, I would like to record your/his/her name and address so I know who to ask for when I call back.) 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]

===>

>ti16aa< INTERVIEWER CHECK: IS RESPONDENT THE CLIENT'S REPRESENTATIVE? DOES [NAME FROM I16aa]= RNAM?

<1> YES SET PROXY=R

<0> NO SET PROXY=X

>i16ab<	(In that case, I would like to record his/her phone number and address so I know how to contact him/her.) May I please (confirm/have your/his/her) telephone number?				
	<0> SAME AS CLIENT'S [goto i16d]				
	<y> ENTER TELEPHONE NUMBER &lt; &gt;-&lt; &gt;</y>				
	<d> DON'T KNOW [goto LOC] <r> REFUSED [goto ref]</r></d>				
	===>				
>i16ac<	And what is (your/his/her) address?				
	INTERVIEWER: RECORD PROXY'S ADDRESS BELOW.				
	<y>ENTER ADDRESS &lt; &gt;</y>				
	ENTER CITY, STATE < >				
	ENTER ZIP < >				
	<d> DON'T KNOW</d>				
	<r> REFUSED [goto cb]</r>				

>i16d< How (are you/is fill i16a/this person) related to [fill Mr./Ms.][fill FCNM] [fill LCNM]?

PROBE IF RESPONDENT IS CLIENT'S CHILD: (Are you/Is he/she) CLIENT's (daughter or daughter-in-law/son or son-in-law)?

- <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/this person is your/CLIENT's (fill i16d)

<1> YES

<0> NO [goto i16d]

===>

- >i17< CATI CHECK: WHO ARE/WILL WE (BE) CONDUCTING THE INTERVIEW WITH AND WHETHER WE ARE CONTINUING WITH THE INTERVIEW NOW.
  - <1> CONTINUING INTERVIEW WITH PROXY OF ADULT WITH A REPRESENTATIVE [goto 127]
  - <2> CONTINUING INTERVIEW WITH REPRESENTATIVE OR PROXY OF a) ADULT WITHOUT REPRESENTATIVE OR b) CHILD WITHOUT PARENT AVAILABLE [goto i30]
  - <3> CALLING BACK FOR REPRESENTATIVE OR PROXY [goto cb]

>i20< (A parent or guardian of) [fill Mr./Ms.][fill FCNM] [fill LCNM] should have received information about a study of (the care of older people/help for people [of all ages] with disabilities). Do you know how we can reach (a parent or guardian of) [fill Mr./Ms.][fill FCNM] [fill LCNM]? 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 i21] <0> NO, SPECIAL SEARCH NEEDED <d> DON'T KNOW <r> REFUSED [goto ref] ===> [goto LOC] Do you know how we can reach (a parent or guardian of) [fill Mr./Ms.][fill FCNM] [fill >i20a< LCNM1? <1> YES [goto i21] <0> NO, SPECIAL SEARCH NEEDED <d> DON'T KNOW <r> REFUSED [goto ref] ===> [goto LOC] >i21a< May I please have his/her telephone number and address? PROBE: For (a parent or guardian of) [fill Mr./Ms.][fill FCNM] [fill LCNM]. <y> RECORD PHONE NUMBER <</p> <d> DON'T KNOW <r> REFUSED >i21b< <y> RECORD ADDRESS < > <d> DON'T KNOW

<r> REFUSED

>i21c<	CATI CHECK: IS ADDRESS OUT OF STATE?
	<1> YES [goto fs: moved out of state] <0> NO
	===>
>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 &lt; &gt;</y>
	<d> DON'T KNOW <r> REFUSED [goto ref]</r></d>
	===>
>i23b<	At what telephone number and address can (a parent or guardian of)[fill Mr./Ms.][fill FCNM] [fill LCNM] be reached?
	<y> RECORD PHONE NUMBER &lt; &gt;</y>
	<d> DON'T KNOW <r> REFUSED [goto ref]</r></d>
	===>
>i23c<	<y> RECORD ADDRESS &lt; &gt;</y>
	<d> DON'T KNOW <r> REFUSED</r></d>
	===>

#### >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]

>i27< NO i27 THIS VERSION

>i28< NO i28 THIS VERSION

>i29< NO i29 THIS VERSION

>vi29< NO vi29 THIS VERSION

# >i30< [INTERVIEWER: ASK FOR NAME OF RESPONDENT AND RECORD ON CONTACT SHEET.]

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. A computer will randomly select people to get the [MONTHLY]. Your answers will not affect whether or not you are/CLIENT is selected. (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.)

TYPE <g> TO CONTINUE

>cb<	(We'll call back in a few days to make sure you've received the materials.)			
	When would be the best time to reach (a parent or guardian of) [fill Mr./Ms.][fill FCNM] [fill LCNM]([fill PROXY NAME])?			
	INTERVIEWER:	RECORD DAY AND TIME ON CONTACT SHEET. IF INFORMATION REQUESTED, PLACE IN "NEEDS MATERIALS" FOLDER.		
	TYPE <g> TO CONTINUE</g>			
	===>			
>thnx<	Thank you very much for your time.			
	===>			
>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:			
	REPRESENTATIV	VE'S ADDRESS:		

#### A. HOUSEHOLD

>A1< First, I have a few questions about your/CLIENT's household.

PRESS ENTER TO CONTINUE

===>

>A1a< CATI CHECK: IS THE CLIENT 18 YEARS OF AGE OR GREATER?

<1> YES

<0> NO [goto A3]

===>

>A2< (Do you / Does CLIENT) live with others or do you/does he/she live alone?

PROBE: Please include anyone living in the same household as you/CLIENT at the present time.

PROBE: We mean your/CLIENT's permanent residence where you/he/she keep your/keeps his/her belongings.

PROBE: We will be asking about help with things around the house that may benefit other members of your/his/her household as well as you/CLIENT. We would like to know how many people might potentially benefit.

- <1> YES/WITH OTHERS
- <0> NO/ALONE [goto A4]
- <r> DON'T KNOW/REFUSED [goto A4]

>A3< Including yourself/CLIENT, how many people live in the same household?

PROBE: Please include anyone living in the same household as you/CLIENT at the present time.

PROBE: Please count yourself/CLIENT even if (you were/he/she was) temporarily not at home last week.

PROBE: We mean your/CLIENT's permanent residence where you/he/she keep your/keeps his/her belongings.

<1-20> PEOPLE

<r> DON'T KNOW/REFUSED

===>

>A3a< CATI CHECK: IS THE CLIENT 18 YEARS OF AGE OR GREATER?

<1> YES

<0> NO [goto B1]

===>

>A4< CODE WITHOUT ASKING IF KNOWN: (Even though [you are / he/she is] living alone) (are you / is CLIENT) married at this time?

PROBE IF PROXY: To the best of your knowledge.

<1> YES

<0> NO

<d> DON'T KNOW

<r> REFUSED

#### B. UNPAID HELP

>B1< The next questions are about help you/CLIENT may have received during the last week from people who are *not* paid to help you/him/her, like family members, friends, and volunteers. I will ask about paid helpers later.

===>

>B1a< CATI CHECK: IS THE CLIENT UNDER 5 YEARS OF AGE?

<1> YES [goto B3]

<0> NO

===>

>B2< During the last week, (have you / has CLIENT) received help with personal care such as eating or bathing, from people who were *not* paid to help? (Please include your(self)/his/her husband/wife/CLIENT's parents.)

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

PROBE: Some other examples of personal care are help with getting out of bed, using the toilet, dressing, and brushing your/his/her hair or teeth.

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

PROBE: Please include help from any parent.

<1> YES

<0> NO

<r> DON'T KNOW/ REFUSED

>B3< During the last week, has anyone who was *not* paid, driven you/CLIENT somewhere or helped you/him/her ride public transportation, such as a bus, taxi, or special van? (Please include your(self)/his/her husband/wife/CLIENT's parents.)

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 you/CLIENT or helping you/him/her on or off, other than the driver.

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

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

PROBE: Please include help from any parent.

PROBE IF CHILD: Did someone who was not paid help with taking this child places?

<1> YES

<0> NO

<r> DON'T KNOW/ REFUSED

===>

>B4< During the last week, (have you / has CLIENT) received help, from people who were *not* paid, with routine health care, such as checking blood pressure, doing exercises, and (taking medicines, including reminders to take it/medications)? (Please include your(self)/his/her husband/wife/CLIENT's parents.)

PROBE: Please include filling pill trays, preparing syringes, and changing dressings.

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

PROBE: Please include help from any parent.

PROGRAMMER: USE "medications" FOR CHILDREN UNDER 5 AND COMATOSE PATIENTS. USE "taking" FOR ALL STATES.

<1> YES

<0> NO

<r> DON'T KNOW/ REFUSED

===>

>B5< NO B5 THIS VERSION

>B6< During the last week, (have you / has CLIENT) received help with things around the house or community, such as preparing meals, housework, (yardwork,) and shopping for you/him/her, from people who were *not* paid? (Please include your(self)/his/her husband/wife/CLIENT's parents.)

(PROBE: Some other examples of help with things around the house and community are paying bills and doing laundry.)

(PROBE: For example, by preparing meals in home or bringing meals that CLIENT ate. Include people who sometimes prepare meals that are eaten at your/CLIENT's home or in someone else's home.)

PROBE: Help includes someone doing these things for you/CLIENT.

PROBE: Please include help from any parent.

<1> YES

<0> NO

<r> DON'T KNOW/ REFUSED

===>

>B7< CATI CHECK: WAS ANY UNPAID HELP REPORTED IN B2, B3, B4, or B6?

<1> YES

<0> NO [goto B17]

===>

>B8< Now, please think about all the different family members, friends, or others who were not paid and who helped you/CLIENT in the last week. How many different people is that? (Please include your(self)/his/her husband/wife/CLIENT's parents.)

PROBE: Please include help from any parent.

<1-15> NUMBER OF UNPAID HELPERS

<r> Cr> DON'T KNOW / REFUSED

# >B9< CATI CHECK: DOES CLIENT LIVE ALONE (A2=0)?

<1> YES [goto B12]

<0> NO

===>

>B10< During the last week, did (this person / any of these NUMBER people) live in the same household as you/CLIENT? Please include anyone staying in (your/CLIENT's) household at least three nights last week. (IF YES: How many?)

INTERVIEWER: CONFIRM IF KNOWN.

PROBE: Do not include people who come and stay overnight just to help you/CLIENT,

but who live elsewhere.

PROBE: The family members, friends, or others who helped without pay.

<0> NO/NONE

<1-15> UNPAID HELPERS IN SAME HOUSEHOLD

<r> DON'T KNOW/ REFUSED

PROGRAMMER: IF B8=1, SUPPRESS "IF YES: HOW MANY." ALSO, CHANGE RESPONSE CATEGORY TO <1> YES

===>

>B12< CATI CHECK: IS THERE ONLY ONE UNPAID CAREGIVER?

<1> YES, ONLY ONE

<0> NO, MORE THAN ONE [goto B14]

>B13< You/(A parent or guardian of) CLIENT may recall being told when you/he/she/he or she applied for the (cash program/ PROG program) that, in about nine months, we may interview the family member or friend who is *not* paid and who helps you/CLIENT. Who is this person?

PROBE: The person who helped you/CLIENT during the last week.

INTERVIEWER: CONFIRM IF KNOWN

- <1> RESPONDENT IS PRIMARY INFORMAL CAREGIVER
- <2> SOMEONE OTHER THAN RESPONDENT

<r> DON'T KNOW/REFUSED [goto B17]

===> [goto B14nam]

>B14< Now please think about *all* the family members and friends who helped you/CLIENT during the last week, and who were *not* paid. (Please include your(self)/his/her husband/wife.)

You/ (A parent or guardian of) CLIENT may recall being told when you/he/she/he or she applied for the (cash program/PROG program) that, in about nine months, we may interview the family member or friend who helped you/CLIENT the *most* during the last week with personal care, things around the house or community or routine health care at home.

Who is this person?

PROBE: Including (people who live in the same household as you/he/she and) those who came to help.

PROBE: Personal care such as eating or bathing.

PROBE: Things around the house and community such as preparing meals, housework, shopping, and transportation.

PROBE: Please do not include anyone who is paid to help.

<1> RESPONDENT IS PRIMARY INFORMAL CAREGIVER

<2> SOMEONE OTHER THAN RESPONDENT

<r> DON'T KNOW/REFUSED [goto B17]

PROGRAMMER: IF CLIENT LESS THAN 18, SUPPRESS "THINGS AROUND THE HOUSE OR COMMUNITY" AND RELATED PROBE.

===>

>B14nam<(In that case, can I confirm your name?/May I please have this person's name?)
INTERVIEWER: RECORD NAME BELOW.

< > ENTER NAME

>B11< CATI CHECK: IS CASE IN INFORMAL CAREGIVER SAMPLE?

<1> YES

<0> NO [goto B15]

>B14add< And what is your/his/her address and telephone number?

> ENTER ADDRESS

- < > ENTER CITY, STATE
- < > ENTER ZIP
- < > AREA CODE
- > PHONE NUMBER
- <7> SAME AS CONTACT SHEET
- <w> WILL CHECK WITH PERSON IF OKAY TO GIVE ADDRESS

===>

>B15< How (is PRIMARY INFORMAL CAREGIVER / are you) related to you/CLIENT?

INTERVIEWER: CODE IF KNOWN.

PROBE IF PRIMARY INFORMAL IS CLIENT'S CHILD: (Are you/ Is he/she) CLIENT's/ your (daughter or daughter-in-law / son or son-in-law)?

PROGRAMMER: YOU REFERS TO RESPONDENT WHO IS THE PRIMARY INFORMAL CAREGIVER.

- <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

<r> DON'T KNOW/ REFUSED

===>

>vB15< So PRIMARY INFORMAL CAREGIVER is your/CLIENT's [fill B15]?

<1> YES

<0> NO [goto B15]

>B16< (Is PRIMARY INFORMAL CAREGIVER / Are you) employed at the present time?

PROBE: Are you/ Is he/she working for pay?

<1> YES

<0> NO

<r> DON'T KNOW /REFUSED

===>

>B17< As you may know, the Medicaid program, LOCAL PROGRAM NAME, allows people to pay (certain) *family members* to help them. How important was that to you / CLIENT / CLIENT's parents in deciding to apply for the PROG program? Would you say very important, somewhat important, or not important?

PROBE IF ARKANSAS: I realize that certain family members, such as spouses and legal guardians, cannot be paid under the cash program.

PROBE: Please consider (your/CLIENT's/CLIENT's parents') views as well as the views of anyone acting on your/his/her/their behalf.

PROBE: Some people were asked to fill out a questionnaire about their *main* reasons for deciding to apply for the (cash program/ PROG program). We hope you won't mind answering a few more specific questions about that.

- <1> VERY IMPORTANT
- <2> SOMEWHAT IMPORTANT
- <3> NOT IMPORTANT
- <7> CLIENT AND PROXY OR PARENTS OF MINOR DIFFERED ON IMPORTANCE
- <r> DON'T KNOW /REFUSED [goto B17a]

==> [goto B18]

PROGRAMMER: USE "YOU" IF RESPONDENT IS CLIENT OR IF CLIENT IS LESS THAN 18 AND PARENT IS RESPONDENT. USE "PARENTS" IF CLIENT IS LESS THAN 18 AND RESPONDENT IS NON-PARENT PROXY.

>B17a< INTERVIEWER: DID RESPONDENT SAY "IMPORTANT?"

<1> YES

<0> NO

>B18< The PROG program also allows people to pay *friends* to help. How important was that to you/CLIENT/CLIENT's parents in deciding to apply?

PROBE: Would you say very important, somewhat important, or not important?

PROBE: Please consider (your/CLIENT's/CLIENT's parents') views as well as the views of anyone acting on your/his/her/their behalf.

- <1> VERY IMPORTANT
- <2> SOMEWHAT IMPORTANT
- <3> NOT IMPORTANT
- <7> CLIENT AND PROXY OR PARENTS OF MINOR DIFFERED ON IMPORTANCE
- <r> DON'T KNOW /REFUSED [goto B18aa]

PROGRAMMER: USE "YOU" IF RESPONDENT IS CLIENT OR IF CLIENT IS LESS THAN 18 AND PARENT IS RESPONDENT. USE "PARENTS" IF CLIENT IS LESS THAN 18 AND RESPONDENT IS NON-PARENT PROXY.

==> [goto B18a]

>B18aa< INTERVIEWER: DID RESPONDENT SAY "IMPORTANT?"

<1> YES <0> NO

>B18a< CATI CHECK: IS THERE A PRIMARY INFORMAL CAREGIVER?

<1> YES

<0> NO [goto B20]

>B19< (Has PRIMARY INFORMAL CAREGIVER / Have you) ever expressed an interest in being paid to help you/ CLIENT?

PROBE IF ARKANSAS: I realize that certain family members, such as spouses and legal guardians, cannot be paid under the cash program.

PROBE: Before now.

<1> YES

<0> NO

<r> DON'T KNOW /REFUSED

===>

PROGRAMMER: USE "YOU" IF RESPONDENT IS PRIMARY INFORMAL CAREGIVER.

>B20< In deciding to apply for the (cash program/ PROG program), how important was it to you / CLIENT / CLIENT's parents to have a choice about *when* your/his/her helpers come? Would you say very important, somewhat important, or not important.

PROBE: Choice about the times of the day and days of the week they come?

PROBE: Please consider (your/CLIENT's/CLIENT's parents') views as well as the views of anyone acting on your/his/her/their behalf.

- <1> VERY IMPORTANT
- <2> SOMEWHAT IMPORTANT
- <3> NOT IMPORTANT
- <7> CLIENT AND PROXY OR PARENTS OF MINOR DIFFERED ON IMPORTANCE
- <r> DON'T KNOW /REFUSED [goto B20a]

===> [goto B21]

PROGRAMMER: USE "YOU" IF RESPONDENT IS CLIENT OR IF CLIENT IS LESS THAN 18 AND PARENT IS RESPONDENT. USE "PARENTS" IF CLIENT IS LESS THAN 18 AND RESPONDENT IS NON-PARENT PROXY.

#### >B20a< INTERVIEWER: DID RESPONDENT SAY "IMPORTANT?"

<1> YES <0> NO

>B21< How important was it to have a choice about what *types* of help or services you/CLIENT receive(s)?

PROBE: Would you say very important, somewhat important, or not important.

PROBE: Please consider (your/CLIENT's/CLIENT's parents') views as well as the views of anyone acting on your/his/her/their behalf.

- <1> VERY IMPORTANT
- <2> SOMEWHAT IMPORTANT
- <3> NOT IMPORTANT
- <7> CLIENT AND PROXY OR PARENTS OF MINOR DIFFERED ON IMPORTANCE
- <r> DON'T KNOW /REFUSED [goto B21a]

===> [goto C1]

### >B21a< INTERVIEWER: DID RESPONDENT SAY "IMPORTANT?"

<1> YES

<0> NO

## C. PAID HELP, UNMET NEED, AND SATISFACTION

#### Paid In-Home Care

>C1< The next questions are about help you/CLIENT may receive from people who *are paid* to help you/CLIENT.

TYPE <g> TO CONTINUE

>C2< During the last week, (have you/has he/she) received any help at home from someone who is paid **under Medicaid or some other public program?** Please include paid help with personal care, things around the house or community, routine health care at home, or transportation.

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

PROBE: That is, help from someone not paid by you/CLIENT or your/CLIENT's family. PROBE: Include Medicaid personal assistance services, ElderChoices and Alternatives.

<1> YES

<0> NO [goto C4]

<r> DON'T KNOW/REFUSED [goto C4]

PROGRAMMER: NOTE "ELDER CHOICES AND ALTERNATIVES" ARE PROGRAMS SPECIFIC TO ARKANSAS.

>C3< About how long (have you / has CLIENT) been receiving paid help at home under Medicaid or some other public program? READ IF NECESSARY: Has it been six months or less, more than six months to less than a year, one to three years, or more than three years?

PROBE: Please include paid help with personal care, things around the house or community, routine health care at home, or transportation.

- <1> SIX MONTHS OR LESS [goto C3a]
- <2> MORE THAN SIX MONTHS TO LESS THAN ONE YEAR
- <3> ONE TO THREE YEARS
- <4> MORE THAN THREE YEARS
- <d>DON'T KNOW [goto C3b]
- <r> REFUSED
- ===> [goto C4]

>C3a< How many months (have you/has CLIENT) been receiving paid help like that?

INTERVIEWER: CODE IF KNOWN

<0> LESS THAN ONE MONTH

<1-6> MONTHS

<r> DON'T KNOW/REFUSED

===> [goto C4]

>C3b< Has it been three months or less, that's since MONTH OF YEAR?

- <1> YES
- <0> NO

<r> DON'T KNOW/ REFUSED

>C4< During the last week, (have you/ has CLIENT) received help from someone who is paid by you/him/her or your/his/her family, or private insurance to help you/him/her at home with personal care, things around the house or community, routine health care at home or transportation?

PROBE: Private insurance includes insurance obtained through a current or former employer or union, or insurance bought on your own or through an association or trade group.

<1> YES

<0> NO

<r> DON'T KNOW/ REFUSED

===>

>C4a< CATI CHECK: DID CLIENT RECEIVE PAID HELP IN LAST WEEK (DOES C2 OR C4=YES)?

<1> YES

<0> NO [goto C12]

===>

>C5< Now I have a few questions about the help (you/CLIENT) received in the last week from all those who were paid to help (you/CLIENT), including (those paid by you/CLIENT, your/his/her family or private insurance and those paid by public programs). During the last week, how many **different** paid workers have helped you/CLIENT?

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

<1-10> NUMBER OF PAID WORKERS

<r> DON'T KNOW / REFUSED

PROGRAMMER: IF C4=1, USE "THOSE PAID BY YOU/CLIENT, YOUR FAMILY OR PRIVATE INSURANCE". IF C2=1, USE "THOSE PAID BY PUBLIC PROGRAMS."

>C6< Did (this person / any of these paid workers) live in the same household as you/CLIENT? (IF YES: How many?)

PROBE: Do not include people who come and stay overnight just to help you/CLIENT,

but who live elsewhere.

PROBE: Please count anyone staying in your/CLIENT's household at least three nights

last week.

PROBE: During the last week.

<0> NO/NONE

<1 - 3> NUMBER OF PAID WORKERS LIVING IN HOUSEHOLD

<r> DON'T KNOW/ REFUSED

PROGRAMMER: IF C5=1, SUPPRESS "IF YES: HOW MANY." ALSO, CHANGE RESPONSE CATEGORY TO <1> YES.

===>

>C7< During the last week, (have you / has he/she) received help with *personal care*, such as eating and bathing, from a home-care-agency worker or others who are *paid* to help you/him/her?

PROBE: Some other examples of personal care are help with getting out of bed, using

the toilet, dressing, and brushing your/his/her hair or teeth.

PROBE: Please include anyone you/he/she or your/his/her family hired privately.

PROBE: Please include staying nearby just in case (you need/CLIENT needs) help.

<1> YES

<0> NO

<r> DON'T KNOW/ REFUSED

>C8< During the last week, has anyone who was *paid*, driven you/CLIENT somewhere or helped you/him/her ride public transportation, such as a bus, taxi or special van?

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

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

PROBE: For example, a ride to the doctor or to shopping.

PROBE: Include help riding ambulettes and ambulances.

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

PROBE: Include people who helped by accompanying you/CLIENT or helping you on

or off, other than the driver.

PROBE: Please include staying nearby just in case (you need/CLIENT needs) help.

<1> YES

<0> NO

<r> DON'T KNOW/ REFUSED

===>

>C9< During the last week, (have you / has CLIENT) received help with routine health care, such as checking blood pressure, doing exercises, and (taking medicines, including reminders to take it/medications) from home-care-agency workers or others who were paid to help?

PROBE: Please include filling pill trays, preparing syringes, and changing dressings.

PROGRAMMER: USE "medications" FOR CHILDREN UNDER 5 AND COMATOSE PATIENTS. USE "taking" FOR ALL STATES.

PROBE: Please include staying nearby just in case (you need/CLIENT needs) help.

<1> YES

<0> NO

<r> DON'T KNOW/ REFUSED

>C11< During the last week, (have you / has CLIENT) received help with *things around the house or community*, such as preparing meals, housework, (and) shopping(, and yardwork) from home-care-agency workers or others who were *paid* to help?

(PROBE: Some other examples of things around the house and community are paying bills and doing laundry.)

(PROBE: For example, by preparing meals in home or bringing meals that CLIENT ate.)

PROBE: Help includes someone doing these things for you/CLIENT.

PROBE: Please include staying nearby just in case (you need/CLIENT needs) help.

<1> YES

<0> NO

<r> DON'T KNOW/ REFUSED</ri>

===>

>C11a< About how many hours did (this person/these people) help you/CLIENT with personal care, transportation, (or) routine health care, or things around the house and community in the last week?

PROBE: Your best estimate is fine.

INTERVIEWER: READ CATEGORIES IF NECESSARY.

<1> 1-2 HOURS <5> 21-30 HOURS

<2> 3-5 HOURS <6> 31-40 HOURS

<3> 6-10 HOURS <7> 41-60 HOURS

<4> 11-20 HOURS<8> 61 OR MORE

<r> DON'T KNOW/REFUSED

PROGRAMMER: PLEASE FILL BASED ON RESPONSES TO C7, C8, C9, AND C11.

===>

#### **Unmet Need**

>C12< CATI CHECK: WAS ANY PAID OR UNPAID ASSISTANCE REPORTED WITH PERSONAL CARE IN B2 or C7?

<1> YES

<0> NO [goto C14]

>C13< Now, please think about *all* the help you/CLIENT received during the last week with *personal care* (from people who were *not* paid / from people who were paid / both from people who were paid and not paid).

(Do you / Does CLIENT) need *more* help with personal care than (you are / he/she is) now receiving?

PROBE: Some examples of personal care are help with eating, getting out of bed, using the toilet, dressing, grooming, and bathing.

PROBE (PROXY ONLY): In your opinion.

PROBE IF PARENT OF CHILD UNDER 5: Do you need more help providing personal care to your child?

<1> YES

<0> NO

<r> DON'T KNOW/ REFUSED

PROGRAMMER: IF B2=1 AND C7=0, USE "PEOPLE WHO WERE NOT PAID." IF B2=0 AND C7=1, USE "PEOPLE WHO WERE PAID." IF B2=1 AND C7=1, USE "BOTH FROM PEOPLE WHO WERE PAID AND UNPAID."

===> [goto C15]

>C14< I understand you/CLIENT haven't/hasn't received any help recently with personal care. (Do you / Does CLIENT) *need* help with that?

PROBE: At the present time?

PROBE: Some examples of personal care are help with eating, getting out of bed, using the toilet, dressing, grooming, and bathing.

PROBE IF PARENT OF CHILD UNDER 5: Do you need help with providing personal care to your child?

<1> YES

<0> NO

<r> <r> DON'T KNOW/ REFUSED</ri>

===>

>C15< CATI CHECK: WAS ANY PAID OR UNPAID ASSISTANCE REPORTED WITH TRANSPORTATION IN B3 OR C8?

<1> YES

<0> NO [goto C17]

===>

>C16< (Do you / Does CLIENT) need *more* help getting rides or using public transportation than (you are / he/she is) now receiving?

PROBE: Such as rides to go shopping or to a doctor's office.

PROBE: Public transportation like a bus, taxi or special van.

PROBE IF PARENT OF CHILD: Do you need more help taking your child places?

<1> YES

<0> NO

<d> DON'T KNOW

<r> REFUSED

==> [goto C18]

>C17< I understand that you/CLIENT haven't/hasn't received any help recently with getting rides or using public transportation. (Do you / Does CLIENT) need help with that?

PROBE: At the present time.

PROBE IF PARENT OF CHILD: Do you need help taking your child places?

PROBE: Such as rides to go shopping or to a doctor's office.

PROBE: Public transportation like a bus, taxi or special van.

<1> YES

<0> NO

<d> DON'T KNOW

<r> REFUSED

>C19< CATI CHECK:

WAS ANY PAID OR UNPAID ASSISTANCE REPORTED WITH THINGS AROUND THE HOUSE AND COMMUNITY IN B6 OR C11?

<1> YES

<0> NO [goto C21]

===>

>C20< Please think about *all* the help you/CLIENT received during the last week with *things* around the house or community, besides transportation, (from people who were *not* paid / from people who were paid / both from people who were paid and unpaid).

(Do you / Does CLIENT) need *more* help with things around the house or community than (you are / he/she is) now receiving?

(PROBE: Some examples of things around the house and community are preparing meals, doing housework, laundry, shopping, yardwork and other chores, and paying bills.)

(PROBE: Some examples of things around the house and community are housework, shopping, preparing meals in home or bringing meals that CLIENT ate.)

<1> YES

<0> NO

<r> DON'T KNOW/REFUSED

PROGRAMMER: IF B6=1 AND C11=0, USE "PEOPLE WHO WERE NOT PAID." IF B6=0 AND C11=1, USE "PEOPLE WHO WERE PAID." IF B6=1 AND C11=1, USE "BOTH FROM PEOPLE WHO WERE PAID AND UNPAID."

===> [goto C22]

>C21< I understand you/CLIENT haven't/hasn't received any help with things around the house or community recently. (Do you / Does CLIENT) *need* help with that?

PROBE: At the present time?

(PROBE: Some examples of things around the house and community are preparing meals, doing housework, laundry, shopping, yardwork and other chores, and paying bills.)

(PROBE: Some examples of things around the house and community are housework, shopping, preparing meals in home or bringing meals that CLIENT ate.)

<1> YES

<0> NO

<r> DON'T KNOW/ REFUSED

===>

#### Satisfaction

>C22< CATI CHECK: IS THERE ANY PAID HELP IN C7, C8, C9 OR C11?

<1> YES

<0> NO [goto D1]

===>

- >C23< CATI CHECK: IS THE RESPONDENT--
  - <1> CLIENT 18 YEARS OF AGE OR OLDER [goto C27]
  - <2> PARENT FOR CLIENT UNDER 18 [goto C27]
  - <3> REPRESENTATIVE OR PROXY

>C24< We would like to know whether or not (CLIENT is/CLIENT's parents are) satisfied with the assistance (he/she has/they have) been receiving from people who are *paid* to help. Would you be able to answer a few specific questions about that?

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

- <1> YES [goto C27]
- <0> NO
- <7> CLIENT MENTALLY UNABLE TO FORM OPINION
- <d> DON'T KNOW
- <r> REFUSED [goto D1]

===>

>C25< In that case, we would like to know about *your* satisfaction with the services that CLIENT has been receiving recently from people who are paid to help.

PRESS ENTER TO CONTINUE

===>

- >C26< MISSING FROM THIS VERSION.
- >C27< (The next questions are about (your / CLIENT's / CLIENT's parents') satisfaction with services (you have / he/she/CLIENT has) been receiving recently from people who are paid to help.)

People may be uncomfortable answering these questions if someone who is paid to help is nearby. If this is the case, you can answer with a 1 for satisfied, or a 2 for dissatisfied.

PROBE: It is important that we ask the questions the same way for everyone.

PROGRAMMER: IF MINOR CLIENT, USE "parents" IF RESPONDENT IS NON-PARENT PROXY; USE "your" IF RESPONDENT IS THE CLIENT'S PARENT.

PRESS ENTER TO CONTINUE

===>

>C29< CATI CHECK: if C7=1 goto C30; otherwise goto C31.

>C30< Please think about *all* the people who are *paid* to help you/CLIENT, including anyone from a home care agency.

(Are you / Is CLIENT / Are CLIENT's parents) satisfied or dissatisfied with the *times of day* that people who are paid come to help you/CLIENT?

PROBE:

You can answer with a 1 for satisfied and a 2 for dissatisfied.

PROBE IF MINOR CLIENT AND NON-PARENT PROXY: Are CLIENT's parents satisfied or dissatisfied, considering both of their views?

- <1> SATISFIED
- <2> DISSATISFIED
- <7> PARENTS OF MINOR DIFFERED ON SATISFACTION [goto C30b]
- <n> PROXY CANNOT REPORT CLIENT'S (PARENT'S) SATISFACTION [goto C24]
- <d> DON'T KNOW [goto C3Ob]
- <r> REFUSED [goto C3Ob]

===>

>C30a<

Would that be very (dis)satisfied or somewhat (dis)satisfied?

<1> VERY

<2> SOMEWHAT

<d> DON'T KNOW

<r> REFUSED

===>

>C30b<

How difficult would it be for you/CLIENT to change the times when people who are paid, help you/him/her?

Would you/he/she say.....

- <1> Very difficult,
- <2> Somewhat difficult, or
- <3> Not at all difficult?
- <4> DON'T THINK CAN DO THAT
- <d>DON'T KNOW
- <r> REFUSED

PROBE: Either the day or the time of day.

PROBE: Either when workers come to your/CLIENT's home or when they perform a task when they are there.

# >C31< CATI CHECK: DID CLIENT RECEIVE PAID HELP WITH PERSONAL CARE, THINGS AROUND THE HOUSE OR COMMUNITY, OR ROUTINE HEALTH CARE IN LAST WEEK (C7=1 OR C9=1 OR C11=1)?

<1> YES <0> NO [goto D1]

===>

>C32< (Are you / Is CLIENT / Are CLIENT's parents) satisfied or dissatisfied with the way people who are paid, carry out their tasks in helping you/him/her?

PROBE: You can answer with a 1 for satisfied or a 2 for dissatisfied.

PROBE: For example, how satisfied (are you/is CLIENT/are CLIENT's parents) that

the work is done the way you/he/she/they want it.

PROBE IF MINOR CLIENT AND NON-PARENT PROXY: Are CLIENT's parents satisfied or dissatisfied, considering both of their views?

<1> SATISFIED

<2> DISSATISFIED

<7> PARENTS OF MINOR DIFFERED ON SATISFACTION [goto D1]

<d> DON'T KNOW [goto D1]

<r> REFUSED [goto D1]

===>

>C32a< Would that be very (dis)satisfied or somewhat (dis)satisfied?

<1> VERY

<2> SOMEWHAT

<d> DON'T KNOW

<r> REFUSED

#### D. USE OF OTHER HOME- AND COMMUNITY-BASED SERVICES

>D1< The next questions are about services you/CLIENT may have received *in the last year*. (Have you / Has CLIENT) during the last year attended a/an (adult) day care center or other day program (such as a sheltered workshop) with staff to help you/him/her with personal care?

PROBE:

That's since MONTH of YEAR.

PROBE:

People typically go to this type of program during the day and come home at

night.

PROBE:

Some day care programs provide health care.

PROBE:

Even if you/he/she only attended once.

PROBE:

Some examples of personal care are help with eating or bathing, getting out of

bed, using the toilet, and dressing.

PROBE:

Please include (adult) day care centers that provide supervision, even if they

do not generally provide personal care.

PROGRAMMER:

INCLUDE REFERENCE TO "sheltered workshop" FOR FLORIDA.

<1> YES

<0> NO

<d> DON'T KNOW

<r> REFUSED

===>

>D2< During the last year, have you/ has CLIENT attended social or recreational group programs, such as those in community (or [senior/youth]) centers or in schools or churches? Please do not include attending religious services.

PROBE:

Even if you/he/she only attended once.

<1> YES

<0> NO

<d> DON'T KNOW

<r> REFUSED

>D3< During the last year, did you/CLIENT use transportation services provided by an organization or agency, such as *special vans or buses [,or special school buses]*?

PROBE:

Even if you/he/she only used these services once.

PROBE:

Transportation intended for [CLIENT>65: older people] [OW: people with disabilities]. for which arrangements must be made.

<1> YES

<0> NO

<d> DON'T KNOW

<r> REFUSED

===>

>D4< During the last year, did you/CLIENT receive home-delivered meals from Meals-on-Wheels or a program like that?

PROBE:

Even if you/he/she only received home-delivered meals once.

<1> YES

<0> NO

<d> DON'T KNOW

<r> REFUSED

===>

>D5< During the last year, (have you or your family / has CLIENT or his/her family / has CLIENT's family) modified your/his/her home to make it easier for you/him/her to do things, such as adding a ramp, grab bar, shower stall, elevator, or remote control device, or modified your/CLIENT's home to make it safer for you/CLIENT?

PROBE:

Or arranged for someone to modify the home.

<1> YES

<0> NO

<d> DON'T KNOW

<r> REFUSED

>D6< During the last year, (have you or your family / has CLIENT or his/her family / has CLIENT's family) modified a car or van or purchased a modified car or van so that you/he/she could (drive it or) ride in it more easily?

PROBE: Or arranged for someone to modify the car or van.

PROBE: Or some other kind of vehicle.

<1> YES

<0> NO

<d> DON'T KNOW

<r> REFUSED

===>

44

>D7< During the last year, (have you or your family / has CLIENT or his/her family / has CLIENT's family) purchased equipment to help you/him/her with personal activities, equipment to make it easier for you/him/her to do things around the house, or equipment to improve your/his/her communication or safety?

PROBE:

Some examples of equipment to help with personal activities are a lift to help get out of bed, raised seat for the toilet, tubseat for bathing, or a wheelchair or scooter for getting around.

PROBE:

Some examples of household equipment are a washer and dryer for laundry and a microwave oven.

PROBE:

Some examples of communication equipment are computers, hearing aids, braille materials, speech devices, special telephone systems, and flashing lights.

PROBE:

Some examples of safety equipment are personal emergency response systems and alarm systems which are activated when someone wanders off.

PROGRAMMER:

IF SPEAKING TO ADULT CLIENT OR PARENT OF MINOR CLIENT, USE "you or your family." IF SPEAKING TO PROXY FOR ADULT CLIENT, USE "CLIENT or his/her family." IF SPEAKING TO PROXY FOR MINOR CLIENT, USE "CLIENT's family."

<1> YES

<0> NO

<d> DON'T KNOW

<r> REFUSED

>D8< CATI CHECK: DID CLIENT HAVE ANY PAID IN-HOME HELP, COMMUNITY SERVICES OR EQUIPMENT?

(REFER TO C7, C8, C9, C11, D1-D7)

<1> YES

<0> NO [goto F4a]

>D9< Please think about all these different types of help and any equipment you/he/she have/has.

(Are you / Is CLIENT / Are CLIENT's parents) satisfied or dissatisfied overall with the arrangements for your/his/her care?

PROBE:

You can answer with a 1 for satisfied or a 2 for dissatisfied.

PROBE:

Please include any type of equipment, regardless of how long you have had it.

PROBE IF MINOR CLIENT AND NON-PARENT PROXY: Are CLIENT's parents satisfied or dissatisfied, considering both of their views?

- <1> SATISFIED
- <2> DISSATISFIED
- <7> PARENTS OF MINOR DIFFERED ON SATISFACTION [goto F4a]
- <d> DON'T KNOW [goto F4a]
- <r> REFUSED [goto F4a]

PROGRAMMER:

IF RESPONDENT IS PROXY FOR ADULT CLIENT, CHECK C24

FOR WHETHER TO ASK CLIENT'S SATISFACTION OR

PROXY'S SATISFACTION.

===>

>D9a< Would that be very (dis)satisfied or somewhat (dis)satisfied?

- <1> VERY
- <2> SOMEWHAT
- <d> DON'T KNOW
- <r> REFUSED

===>

>F4a< CATI CHECK: IS RESPONDENT CLIENT OR PARENT OF CLIENT WHO IS LESS THAN 18?

- <1> YES
- <0> NO [goto E0]

===>

>F5< Overall, how satisfied are you with the way (you are / your child is) spending your/his/her life these days? Would you/he/she say very satisfied, somewhat satisfied, somewhat dissatisfied, or very dissatisfied?

- <1> VERY SATISFIED
- <2> SOMEWHAT SATISFIED
- <3> SOMEWHAT DISSATISFIED
- <4> VERY DISSATISFIED
- <d> DON'T KNOW [goto F5a]
- <r> REFUSED

===> [goto E0]

PROGRAMMER: USE "your child" IF RESPONDENT IS PARENT.

>F5a< INTERVIEWER: DID RESPONDENT SAY "SATISFIED" OR "DISSATISFIED?"

- <1> SATISFIED
- <2> DISSATISFIED
- <3> NEITHER

# E. CLIENT HEALTH AND FUNCTIONAL IMPAIRMENT

#### Client Health

>E0< CATI CHECK: IS CLIENT IN A COMA?

<1> YES [goto F13]

<0> NO

===>

>E1< Now, I have some questions about your/CLIENT's overall health.

First, relative to other people your/his/her age, how would you rate your/CLIENT'S health now? Would you say it's. . .

<1> Excellent

<2> Good

<3> Fair, or

<4> Poor

<r> DON'T KNOW/REFUSED

===>

PROBE:

Considering everything.

>E2< Compared with a year ago, is your/CLIENT's health better, worse, or about the same?

PROBE:

Your/His/Her health now compared to a year ago.

PROBE IF CLIENT IS SERIOUSLY ILL: You may have already given me information on

CLIENT's health, but I need to ask these questions of everyone. (PROGRAMMER: DISPLAY ON PROXY SCREEN ONLY)

<1> BETTER

<2> WORSE

<3> ABOUT THE SAME

#### <r> DON'T KNOW/REFUSED

===>

- >E3< Compared with a year ago, (are you /is CLIENT) more physically active, less physically active, or about the same?
  - <1> MORE PHYSICALLY ACTIVE
  - <2> LESS PHYSICALLY ACTIVE
  - <3> ABOUT THE SAME
  - <r> DON'T KNOW/REFUSED

===>

>E4< During the *next* year, do you expect your/CLIENT's health will get better, get worse, or stay the same?

PROBE:

In your opinion.

- <1> BETTER
- <2> WORSE
- <3> STAY THE SAME
- <d> DON'T KNOW
- <r> REFUSED

===>

### **Client Functional Impairment**

>E5< CATI CHECK: IS THE CLIENT UNDER FIVE YEARS OF AGE?

<1> YES [goto F13]

<0> NO

>E6< Now, I would like to ask about how (you get /CLIENT gets) along day to day.

During the last week, did any person help you/CLIENT get in or out of bed, did you/he/she do that by yourself/himself/herself, or didn't you/he/she get out of bed at all for any reason?

PROBE: That's

That's since DAY OF WEEK of last week.

- <1> GOT HELP [goto E8]
- <2> NO HELP
- <3> DID NOT GET OUT OF BED AT ALL [goto E8]
- <r> DON'T KNOW/REFUSED [goto E8]

===>

>E7< Did someone stay nearby just in case you/he/she might need help getting in or out of bed?

PROBE:

Did any person stop what he or she was doing to be near in case

you/he/she might need help?

PROBE:

During the last week.

PROBE:

For half or more of the times you/he/she got out of bed or a chair.

<1> YES

<0> NO

<r> DON'T KNOW/REFUSED

===>

>E8< 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 last week, did any person help you/CLIENT bathe, did you/he/she do that by yourself/himself/herself, or (were you / was he/she) not able to bathe at all?

- <1> GOT HELP [goto E10]
- <2> NO HELP
- <3> DID NOT BATHE AT ALL [goto E10]
- <r> DON'T KNOW/REFUSED [goto E10]

===>

>E9< Did someone stay nearby just in case you/he/she might need help bathing?

PROBE:

Did any person stop what he or she was doing to be near in case

you/he/she might need help?

PROBE:

During the last week.

PROBE:

For half or more of the times you/he/she bathed.

<1> YES

<0> NO

<r> DON'T KNOW/REFUSED

===>

>E10< During the last week, did any person help you/CLIENT get to or use the toilet or commode, did you/he/she do that by yourself/himself/herself, or didn't you/he/she use the toilet or commode at all?

PROBE:

Please include arranging clothes, transferring on and off the toilet or

commode, and cleaning yourself/herself/himself.

PROBE:

For example, a commode at your/his/her bedside (or a potty chair).

PROGRAMMER: INCLUDE REFERENCE TO POTTY CHAIR FOR CHILDREN.

<1> GOT HELP [goto F13]

<2> NO HELP

<3> DID NOT USE TOILET OR COMMODE AT ALL [goto F13]

<4> COMBINATION OF SELF-TOILET AND HELP WITH DIAPERS

<r> DON'T KNOW/REFUSED [goto F13]

>E11< Did someone stay nearby just in case you/he/she might need help using the toilet or commode?

PROBE:

Did any person stop what he or she was doing to be near in case

you/he/she might need help?

PROBE:

During the last week.

PROBE:

For half or more of the times you/he/she used the toilet or commode.

<1> YES

<0> NO

<r> DON'T KNOW/REFUSED

## 6. CLIENT CHARACTERISTICS

F1-4; F6-12 deleted from this version

### **Client Characteristics**

>F13< The next questions are about where (you live / CLIENT lives). Some people have a difficult time finding someone to help them because of the area in which they live.

(Do you / Does CLIENT) live on a farm or in the country?

PROBE:

Do you live in a rural area?

PROBE (PROXY ONLY):

In your opinion.

<1> YES [goto F17]

<0> NO

<d> DON'T KNOW [goto F17]

<r> REFUSED [goto F17]

===>

>F14< How hard is it to get public transportation to where (you live / CLIENT lives)? Would you say . . .

- <1> Very hard,
- <2> Somewhat hard, or
- <3> Not hard at all?
- <d> DON'T KNOW [goto F14aa]
- <r> REFUSED

PROBE:

Such as a city bus, taxi or special van.

PROBE:

In your opinion.

===> [goto F14a]

>F14aa< INTERVIEWER: DID RESPONDENT SAY "HARD?"

<1> YES <0> NO

>F14a<Do you/Does CLIENT live in a city?

<1> YES

<0> NO [goto F17]

<d> DON'T KNOW [goto F17]

<r> REFUSED [goto F17]

===>

>F15< NO F15 THIS VERSION.

>F16< Would you say that (CLIENT lives/you live) in a high-crime neighborhood?

PROBE:

By neighborhood, we mean right around where (you live/CLIENT lives). About

five blocks in any direction.

PROBE:

In your opinion.

<1> YES

<0> NO

<d> DON'T KNOW

<r> REFUSED

>F17< Last, I have a few background questions. (Have you / Has CLIENT / either of CLIENT's parents) ever worked for pay?

PROBE: At any time during your/CLIENT's/their lifetime(s).

PROBE: A parent or guardian of CLIENT.

<1> YES

<0> NO [goto F21]

<r> DON'T KNOW/REFUSED [goto F21]

===>

PROGRAMMER: FOR F17, F19, F20, F21, F22 AND F23, USE "YOU" IF

RESPONDENT IS ADULT CLIENT OR REPRESENTATIVE, OR IF CLIENT IS LESS THAN 18 AND PARENT IS RESPONDENT. FOR F17, F21, AND F22, USE "EITHER PARENT" IF CLIENT IS LESS THAN 18 AND RESPONDENT IS NON-PARENT PROXY.

>F18< CATI CHECK: ARE WE SPEAKING TO CLIENT OR NON-REPRESENTATIVE PROXY AND IS CLIENT OLDER THAN 75?

<1> YES [goto F21]

<0> NO

>F19< (Do you / Does CLIENT/Do either of CLIENT's parents) work for pay now?

<1> YES

<0> NO [goto F21]

<d> DON'T KNOW [goto F21]

<r> REFUSED [goto F21]

===>

>F20< How many hours per week (do you / does CLIENT/do either of CLIENT's parents) usually work now?

PROBE:

Half the time or more during the last month.

PROBE IF BOTH PARENTS WORK: Pick the higher of the two.

<1-80> HOURS WORKED FOR PAY

<d>

DON'T KNOW

<r>

**REFUSED** 

===>

>F21< (Have you / Has CLIENT / either of CLIENT's parents) ever supervised another person as part of (your/his/her/his or her paid work or in) volunteer work you/he/she/he or she may have done?

PROBE:

At any time during your/his/her/their lifetime.

PROBE:

A parent or guardian of CLIENT.

<1> YES

<0> NO

<d> DON'T KNOW

<r> REFUSED

>F22< (Have you / Has CLIENT / either of CLIENT's parents) *ever* hired someone privately, for example someone to assist with housework, yardwork, or personal care (, or to care for a child while you were/he/she was /they were working)?

[PROBE: A parent or guardian of CLIENT.]

<1> YES

<0> NO

<d> DON'T KNOW

<r> REFUSED

===>

>F22a<CATI CHECK: IS CLIENT LESS THAN 18 YEARS OF AGE AND RESPONDENT NON-PARENT PROXY?

<1> YES [goto F24]

<0> NO

===>

>F23< How many grades or years of schooling did you/CLIENT complete?

INTERVIEWER COMPLETE a OR b.

a. PRIMARY AND SECONDARY YEARS OF SCHOOLING

<0><1-12> YEARS

b. HIGH SCHOOL GRADUATE AND HIGHER

<h>HIGH SCHOOL GRADUATE OR GED

<c> SOME COLLEGE/VOCATIONAL TRAINING

<br/>
<br/>
COLLEGE BACHELOR'S DEGREE

<g> COLLEGE GRADUATE WORK OR PROFESSIONAL DEGREE

<d> DON'T KNOW

<r> REFUSED

>F24< (Do you / Does CLIENT) consider yourself/himself/herself/CLIENT to be of Hispanic or Latino origin, such as Mexican, Puerto Rican, Cuban, or other Spanish background?

<1> YES

<0> NO

<d> DON'T KNOW

<r> REFUSED

===>

>F25< I'm going to read you a list of five race categories. Please choose one or more races that (you/CLIENT) consider(s) (yourself/himself/herself) to be?

INTERVIEWER: (1) READ ALL CATEGORIES . CODE UNLISTED, RESPONDENT-OFFERED CATEGORIES IN "OTHER"

PROBE IF RESPONDS "HISPANIC" OR "LATINO": Would that be White Hispanic/Latino, African American Hispanic/Latino, or something else?

#### CODE ALL RACES

- <1> White
- <2> African American Or Black
- <3> American Indian Or Alaska Native
- <4> Asian
- <5> Native Hawaiian Or Other Pacific Islander
- <6> OTHER [SPECIFY]
- <n> NO FURTHER RESPONSES
- <d> DON'T KNOW
- <r> REFUSED

>vAdd< Finally, I'd like to verify your/CLIENT's name and address:
The correct spelling of your/CLIENT's name is: [fill CLIENT NAME]
ENTER <y> IF CORRECT <n> TO MAKE CORRECTIONS

And your/his/her address is:

INTERVIEWER: HIT ENTER OR MAKE CORRECTIONS

ADDR : [fill add1] ADDR : [fill add2]

CITY : [fill city] STATE : [fill stat] ZIP : [fill zip]

And your/his/her phone number is:

PHONE # : [fill ph] < > < > < >

END. That's all the questions I have. Thank you so much for your time. Now that the interview is completed, a computer here at Mathematica will randomly select people who will (continue to) participate in the traditional home care program or the new [PROG] program. We will notify your state program officials of the result, and they will notify you within the next few weeks whether you were/CLIENT was selected for the [PROG] program or the traditional home care program. We will be calling again in several months to see how [you are / CLIENT is] getting along.