

**Cash and Counseling
Nonparticipation Study
Client**

Draft Questionnaire

November 3, 2004

Please reference previous study with OMB control number 0990-0223 (Evaluation of the Cash and Counseling Demonstration), expiration date 12/31/03.

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INTRODUCTION/SCREENER

S1. Hello. My name is [INTERVIEWER NAME] from Mathematica Policy Research, Inc. in Princeton, New Jersey. We're calling New Jersey residents who are eligible to receive Medicaid personal care services at home.

May I please speak with [CLIENT NAME]?

- SPEAKING TO CLIENT.....01 → **GO TO S2**
- CLIENT COMES TO PHONE.....02
- CLIENT TEMPORARILY UNAVAILABLE.....03 → **GO TO S7**
- CLIENT PHYSICALLY/COGNITIVELY UNABLE TO SPEAK ON THE PHONE.....04 → **GO TO S3**
- CLIENT IN A NURSING HOME OR HOSPITAL.....05 → **GO TO END 2**
- CLIENT DECEASED.....06 → **GO TO END 3**

S1a. Hello. My name is [INTERVIEWER NAME] from Mathematica Policy Research, Inc. in Princeton, New Jersey. We're calling New Jersey residents who are eligible to receive Medicaid personal care services at home.

S2. We would like to speak to the person who makes the decisions about the Medicaid personal care services you receive at home, or to someone who would make decisions about benefits you might be eligible for. Would you make those decisions, or would someone else?

- CLIENT ONLY.....01 → **GO TO S8**
- SOMEONE ELSE.....02 → **GO TO S5**
- MORE THAN ONE PERSON.....03

S2a. Who has primary responsibility for making these decisions?

INTERVIEWER: IF RESPONDENT HAS TROUBLE DECIDING AND CLIENT IS ONE OF THE DECISION MAKERS, CHOOSE CLIENT.

- CLIENT.....01 → **GO TO S8**
- SOMEONE ELSE.....02 → **GO TO S5**

S3. We would like to speak to the person who makes the decisions about the Medicaid personal care services [CLIENT] receives at home, or to someone who would make decisions about benefits [CLIENT] might be eligible for. Would [CLIENT] make those decisions or would someone else?

CLIENT ONLY.....	01	→	GO TO S4
RESPONDENT, NOT CLIENT.....	02	}	→
SOMEONE ELSE.....	03		
MORE THAN ONE PERSON.....	04		GO TO S5 , OTHER DM

S3a. Who has primary responsibility for making these decisions?

INTERVIEWER: IF RESPONDENT HAS TROUBLE DECIDING AND CLIENT IS ONE OF THE DECISION MAKERS, CHOOSE CLIENT.

CLIENT.....	01		
RESPONDENT, NOT CLIENT.....	02	}	→
SOMEONE ELSE.....	03		
			GO TO S5 , OTHER DM

S4. Since [CLIENT] makes (his/her) own decisions about Medicaid personal care services, but is unable to speak on the phone, we would like to talk to the person who knows the most about the services [CLIENT] may receive at home or benefits [CLIENT] might be eligible for. Would that be you or someone else?

RESPONDENT.....	01		
SOMEONE ELSE.....	02		
DON'T KNOW.....	d	}	→
REFUSED.....	r		
			GO TO END 2

S5. What is (your/this person's) name?

NAME: _____

S5a. How (are you/is [he/she]) related to ([CLIENT]/you)?

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

- SPOUSE.....01
- MOTHER.....02
- FATHER.....03
- DAUGHTER.....04
- DAUGHTER-IN-LAW.....05
- SON.....06
- SON-IN-LAW.....07
- SISTER/SISTER-IN-LAW.....08
- BROTHER/BROTHER-IN-LAW.....09
- GRANDPARENT.....10
- GRANDCHILD.....11
- OTHER RELATIVE.....12
- OTHER NON-RELATIVE.....13
- DON'T KNOW.....d
- REFUSED.....r

S5b. (Do you/does [he/she]) live with [CLIENT]?

- YES.....01
- NO.....00

**INTERVIEWER: IF TALKING TO DESIRED RESPONDENT NOW
(S3(a)=02 OR S4 = CODE 01), GO TO S8. ELSE ASK S6.**

S6. Is [NAME IN S5] there now?

- YES.....01
- NO.....00 → **GO TO S7**

S6a. Would it be possible to speak with [NAME IN S5]?

- YES.....01 → **GO TO S1a**
- NO.....00

S7. When would be a good time to reach [CLIENT/NAME IN S5]?

RECORD TIME OF DAY.

|_|_|:|_|_| AM/PM

S7a. What would be the best phone number to reach [CLIENT/NAME IN S5] at?

RECORD PHONE NUMBER.

(|_|_|_|_|) - |_|_|_|_| - |_|_|_|_|
AREA CODE

SAME NUMBER DIALED.....01
REFUSED.....r
DON'T KNOW.....d

GO TO END 1

S8. According to our records, you are currently eligible to receive Medicaid personal care services at home. Have you received any help like that from Medicaid in the last two weeks?

PROBE: Has a home health aid or personal care attendant come to your home to help you bathe, get dressed, fix meals, clean, shop, or other things like that?

PROBE: Do *not* include Medicaid skilled nursing services.

YES.....01 → **GO TO A1**
NO.....00
DON'T KNOW.....d
REFUSED.....r

S8a. Have you had help like that from Medicaid at any time during the last month?

YES.....01 → **GO TO A1**
NO.....00
DON'T KNOW.....d
REFUSED.....r

S9. Sometimes people *try* to get help with personal care, but none is available. During the last month, did you *try* to get help like that through an agency or from someone else who was paid?

YES.....01
NO.....00
DON'T KNOW.....d
REFUSED.....r

S9a. Why didn't you receive those services (or *try* to obtain services) during the last month?

NO LONGER ELIGIBLE FOR MEDICAID
PERSONAL CARE SERVICE.....01 → GO TO END 4
CLIENT WAS/IS IN A NURSING HOME.....02
AGENCY WAS UNABLE/UNWILLING
TO PROVIDE A WORKER.....03
CLIENT'S DECISION (NO LONGER WANTED). .04
NOT AT HOME ALL OR MOST OF
THE TIME RECENTLY.....05 → GO TO A1
OTHER (SPECIFY).....96

DON'T KNOW.....d
REFUSED.....r

END 1: IF UNAVAILABLE

I'll try calling back at another time. Thank you for your time.

END 2: IF CLIENT IS IN HOSPITAL, NURSING HOME, OR RESPONDENT REFUSES

Thank you, I'll make note of that. I appreciate your time. Goodbye.

END 4: IF CLIENT NOT ELIGIBLE FOR MEDICAID

We are only interviewing people who are eligible for Medicaid personal care services right now. Thank you for your time. Good-bye.

Begin Time: |__|__|:|__|__| AM/PM

A. AWARENESS OF CASH AND COUNSELING

A1. First, I would like to ask you whether you have ever heard of a program called Personal Preference. It is a Medicaid program for people who need personal care services. Have you ever heard of it?

PROBE IF NO/DK/REF: People who participate in Personal Preference receive a monthly allowance to manage their own personal care services. Many people use the allowance to hire family members and friends to provide personal care. Have you ever heard of this program?

PROBE: Personal care includes help with bathing, dressing, preparing meals, transportation, things around the house and community, and other daily activities.

YES.....01
NO.....00
DON'T KNOW.....d
REFUSED.....r

→ **GO TO B1**

A1a. Have you ever participated in this program?

PROBE IF DK: Have you ever received a monthly allowance so that you can manage your own care?

YES.....01 → **GO TO ENDER**
NO.....00 → **GO TO B4a**
DON'T KNOW.....d
REFUSED.....r

→ **GO TO ENDER**

ENDER. We are only interviewing people who have not participated in Personal Preference. Thank you very much for your time and interest. Good-bye.

B. LEVEL OF INTEREST IN CASH AND COUNSELING

B1. **INTERVIEWER: IF HAS NOT HEARD OF PERSONAL PREFERENCE➔
GO TO B2**

B2. Now, I am going to read a short description of Personal Preference, and ask you if it sounds interesting. Personal Preference provides an allowance along with training and advice to let participants manage their own personal care services, and to buy supplies and equipment to help them be more independent. Participants receive the allowance instead of agency personal care services. Many people decide to use the allowance to pay family members and friends to help them with bathing, preparing meals, or doing other things around the house. Each participant’s allowance is based on the number of hours of care they qualify for.

Now that you have heard a little about Personal Preference, how interested in the program are you? Would you say you are . . .

- Very interested (in this program),.....01
- Somewhat interested,.....02
- Not very interested, or.....03
- Not at all interested?.....04
- DON'T KNOW.....d
- REFUSED.....r

B3. Next I am going to describe some specific features of Personal Preference. Please tell me whether each feature sounds very appealing, somewhat appealing, somewhat unappealing, or very unappealing to you.

PROBE: Is this a very appealing, somewhat appealing, somewhat unappealing, or a very unappealing feature?

	VERY APPEALING	SOMEWHAT APPEALING	SOMEWHAT UNAPPEALING	VERY UNAPPEALING	DON'T KNOW
a. Receiving an allowance every month instead of receiving agency personal care services.....	01	02	03	04	d
b. Being able to hire family members, friends, or neighbors to help you with your personal care...	01	02	03	04	d
c. Deciding whom to hire, how much to pay, when they would work, and what they would do.....	01	02	03	04	d
d. How appealing would it be to choose a family member or friend to help make those decisions?	01	02	03	04	d
e. How appealing would it be to be able to use the allowance to buy personal care supplies, such as adult diapers or disposable gloves?.....	01	02	03	04	d
f. (How appealing would it be...) to be able to use the allowance to buy special equipment to help you around the house, such as a microwave oven?.....	01	02	03	04	d
g. (How appealing would it be...) to be able to use the allowance to modify your home, such as installing grab bars for the bathroom?.....	01	02	03	04	d
h. (How appealing would it be...) to be able to ask program consultants for training and advice about how to manage the allowance.....	01	02	03	04	d
i. (How appealing would it be...) to be able to ask program bookkeepers to write checks for the people you pay and the things you buy with the allowance.....	01	02	03	04	d

INTERVIEWER: IF B2 = 03 OR 04 (NOT (VERY) INTERESTED), ASK B4. ELSE GO TO E1.

B4. Earlier, you told me that you were not (very) interested in the Personal Preference program. What is the main reason that you are not interested?

CIRCLE ONE ONLY

- CHANGED MIND/IS INTERESTED SINCE HEARING MORE ABOUT PROGRAM.....01
- SATISFIED WITH CURRENT ARRANGEMENTS.....02
- DOESN'T WANT TO CHANGE.....03
- WOULD NOT HAVE ANYONE TO HIRE TO PROVIDE PERSONAL CARE.....04
- PROGRAM SOUNDS LIKE TOO MUCH RESPONSIBILITY/TOO DIFFICULT.....05
- THE ALLOWANCE IS TOO SMALL.....06
- OTHER (SPECIFY).....96
- _____
- DON'T KNOW.....d
- REFUSED.....r

INTERVIEWER: GO TO E1.

B4a. How did you hear of Personal Preference?

PROBE: Does anything come to mind?

PROBE: Any other ways?

CIRCLE ALL THAT APPLY

- FAMILY MEMBER.....01
 - AGENCY OR AIDE THAT PROVIDES
YOUR MEDICAID PERSONAL CARE OR
WAIVER SERVICES.....02
 - CASE MANAGER.....03
 - FRIEND.....04
 - NEWS STORY (E.G., ON TV, RADIO, WEB).....05
 - DIRECT MAILING (E.G., LETTER OR
BROCHURE FROM GOVERNOR).....06
 - OTHER (SPECIFY).....96
-
- DON'T KNOW/DON'T REMEMBER.....d
 - REFUSED.....r

B5. Please tell me which statement best describes your reaction when you first heard about Personal Preference. Were you. . .

PROBE: Please think about the first time you heard about the program.

- Very interested in participating,.....01
- Somewhat interested in participating,.....02
- Not very interested in participating, or.....03
- Not at all interested in participating?.....04
- DON'T KNOW/DON'T REMEMBER.....d
- REFUSED.....r

B6. After you first heard about Personal Preference, did you try to get more information about the program?

- YES.....01
 - NO.....00
 - DON'T KNOW.....d
 - REFUSED.....r
- } → **GO TO C1**

B7. Now I'm going to ask you about the ways you might have tried to get information about Personal Preference. Please tell me whether you tried any of them.

PROBE: Did you search for information in other ways? Is there anything else?

Did you . . .

	YES	NO	DON'T KNOW	REFUSED
a. Call, e-mail, or write to the program to get more information?.....	01	00	d	r
b. Look on the World Wide Web or the internet site for Personal Preference?.....	01	00	d	r
c. Talk to the agency or aide that normally provides your Medicaid personal care or waiver services?...	01	00	d	r
d. Talk to your Medicaid case manager?.....	01	00	d	r
e. Talk to a Medicaid beneficiary who was participating in the program?.....	01	00	d	r
f. Talk to a family member or friend?.....	01	00	d	r
g. Do something else? (SPECIFY).....	01	00	d	r

B8. Did you get the information you wanted from (this/any of these) source(s)?

YES.....01
 NO.....00
 DON'T KNOW.....d
 REFUSED.....r

} → **GO TO C1**

**INTERVIEWER: IF B7a=YES, ASK B9.
 ELSE GO TO INSTRUCTION BOX ABOVE
 B11.**

B9. I'm going to read you some types of information you may have received from the Personal Preference program itself. Please tell me whether you received each type of information. When you contacted the program, did you receive . . .

CIRCLE YES OR NO FOR EACH

	YES	NO	DON'T KNOW	REFUSED
a. Information by phone?..... PROBE: This includes someone calling you back or information from an automated system.	01	00	d	r
b. Written materials such as a letter or brochure?.....	01	00	d	r
c. A video to watch about the program?	01	00	d	r
d. Did a program staff member come to your home to explain the program?.....	01	00	d	r
e. Anything else? (SPECIFY)..... _____	01	00	d	r

**INTERVIEWER: IF ANY OF B9 = YES, ASK B10.
ELSE GO TO INSTRUCTION BOX ABOVE B11.**

B10. In general, how useful was the information you received? Would you say it was . . .

- Very useful,.....01
- Somewhat useful,.....02
- Not very useful, or.....03
- Not at all useful?.....04
- DON'T KNOW.....d
- REFUSED.....r

INTERVIEWER: IF B7b = 1, ASK B11. ELSE GO TO BOX BEFORE B12.

B11. You mentioned that you visited the website for Personal Preference. How useful was the information on the website? Would you say it was . . .

- Very useful,.....01
- Somewhat useful,.....02
- Not very useful, or.....03
- Not at all useful?.....04
- DID NOT FIND THE NEEDED INFORMATION.....05
- DON'T KNOW.....d
- REFUSED.....r

INTERVIEWER: IF B7c OR B7d = 1, ASK B12. ELSE GO TO C1.

B12. You mentioned that your personal care agency, aide or case manager gave you information about Personal Preference. Did this person say that it might be a good idea to participate in Personal Preference, a bad idea to participate in Personal Preference, or did they not offer an opinion?

- GOOD IDEA.....01
- BAD IDEA.....02
- NO OPINION.....03
- DON'T KNOW.....d
- REFUSED.....r

C. REASONS FOR NOT PARTICIPATING

Next, I'm going to ask you about the reasons you are not participating in Personal Preference.

C1. Why did you decide not to participate in Personal Preference program?

PROBE: Could you be more specific please?

PROBE: Anything else?

CIRCLE ALL THAT APPLY

- SATISFIED WITH CURRENT ARRANGEMENTS/
DOESN'T WANT TO CHANGE.....01
- WOULD NOT HAVE ANYONE TO HIRE TO
PROVIDE PERSONAL CARE.....02
- PROGRAM SOUNDS LIKE TOO MUCH
RESPONSIBILITY.....03
- INSUFFICIENT ALLOWANCE.....04
- CASE WORKER/AGENCY DISCOURAGED
PARTICIPATION.....05
- COULD NOT HIRE SPOUSE OR LEGALLY
LIABLE RELATIVE.....06
- FEAR OF LOSING MEDICAID.....07
- FEAR OF LOSING NURSING CARE.....08
- FEAR OF LOSING OTHER PUBLIC BENEFITS.....09
- PROGRAM DECISION.....10
- DIDN'T KNOW HOW TO GET
MORE INFORMATION.....11
- DID NOT THINK WOULD BE RECEIVING
PERSONAL CARE SERVICES FOR
VERY LONG.....12 → **GO TO E1**
- OTHER (SPECIFY).....96
- _____
- DON'T KNOW.....d
- REFUSED.....r

INTERVIEWER: IF C1 = 07, ASK C1a. ELSE GO TO C2.

C1a. If participating in Personal Preference would not affect your public benefits, would you be more interested in the program, or would your level of interest remain the same?

- MORE INTERESTED.....01
- NO CHANGE/INTEREST THE SAME.....03
- DON'T KNOW.....d
- REFUSED.....r

C2. Who made, or helped you make, the decision not to participate in Personal Preference?

PROBE: Is there anyone else?

CIRCLE ALL THAT APPLY

- CLIENT/SELF..... 01
- SPOUSE.....02
- MOTHER.....03
- FATHER.....04
- SON..... 05
- DAUGHTER.....06
- SON-IN-LAW.....07
- DAUGHTER-IN-LAW.....08
- SISTER.....09
- BROTHER.....10
- DOCTOR.....11
- AIDE.....12
- CASE MANAGER.....13
- PROGRAM REPRESENTATIVE.....14
- OTHER FAMILY MEMBER (SPECIFY).....15
- _____
- OTHER (SPECIFY).....96
- _____
- DON'T KNOW.....d
- REFUSED.....r

D. KNOWLEDGE OF PROGRAM FEATURES

D1. Next, I'm going to ask you about what you think of the different program features.

When you eventually decided not to participate in the Personal Preference program, were you aware . . .

PROBE: When you eventually decided not to participate in the program.

CIRCLE YES OR NO FOR EACH

	YES	NO	DON'T KNOW	REFUSED
a. that you would receive an allowance every month instead of receiving personal care services from an agency?.....	01	00	d	r
b. that the amount of the monthly allowance would be based on the number of hours of personal care that you qualify for?.....	01	00	d	r
c. that the monthly allowance could be used to pay family members, friends, neighbors, or other people of your choice, to help you with personal care?.....	01	00	d	r
d. that you would make decisions about whom to hire, how much to pay, when they would work, and what they would do?.....	01	00	d	r
e. that you could choose a family member or friend to help you make these decisions?.....	01	00	d	r
f. that the monthly allowance could be used to purchase personal care supplies such as adult diapers or disposable gloves?.....	01	00	d	r
g. that the monthly allowance could be used to purchase special equipment to help you around the house, such as a microwave oven?.....	01	00	d	r
h. that the monthly allowance could be used to make modifications to your home, such as installing grab bars for the bathroom?.....	01	00	d	r
i. that program consultants would be available for training and advice about how to manage the monthly allowance?..	01	00	d	r
PROBE: Consultants would help you decide things like whom to hire or how much to pay them.				
j. that program bookkeepers would be available to write checks to pay workers or make other purchases?.....	01	00	d	r
IF C1=07, CIRCLE 'NO' IN D1k WITHOUT ASKING.				
k. that signing up for the program would not affect your other Medicaid benefits, or any Supplemental Security Income (SSI) or food stamps you may receive?.....	01	00	d	r

<p>INTERVIEWER: COUNT NUMBER OF "YES" RESPONSES. IF ALL 11=YES, GO TO D4 IF 8-10 YESES, GO TO D2A IF 0-7 YESES, GO TO D3</p>

INTERVIEWER: IF D1a NOT YES, ASK D2a.

D2a. If you knew that you would receive a monthly allowance instead of agency services, would you be more interested in the Personal Preference program, less interested in the program, or would your interest remain the same?

- MORE INTERESTED.....01
- LESS INTERESTED.....02
- NO CHANGE/INTEREST THE SAME.....03
- DON'T KNOW.....d
- REFUSED.....r

INTERVIEWER: IF D1b NOT YES, ASK D2b.

D2b. If the allowance were enough to let you buy about the same number of care hours you currently qualify for, would you be more interested in the Personal Preference program, less interested in the program, or would your interest remain the same?

- MORE INTERESTED.....01
- LESS INTERESTED.....02
- NO CHANGE/INTEREST THE SAME.....03
- DON'T KNOW.....d
- REFUSED.....r

INTERVIEWER: IF D1c NOT YES, ASK D2c.

D2c. If you knew that you would be allowed to pay family members, friends, neighbors, or other people of your choice to help you with personal care, would you be more interested in the Personal Preference program, less interested in the program, or would your interest remain the same?

- MORE INTERESTED.....01
- LESS INTERESTED.....02
- NO CHANGE/INTEREST THE SAME.....03
- DON'T KNOW.....d
- REFUSED.....r

INTERVIEWER: IF D1d NOT YES, ASK D2d.

D2d. If you knew that you could decide whom to hire, how much they would work and what they would do, would you be more interested in the Personal Preference program, less interested in the program, or would your interest remain the same?

- MORE INTERESTED.....01
- LESS INTERESTED.....02
- NO CHANGE/INTEREST THE SAME.....03
- DON'T KNOW.....d
- REFUSED.....r

INTERVIEWER: IF D1e NOT YES, ASK D2e.

D2e. If you knew that you could have someone help you make decisions, would you be more interested in the Personal Preference program, less interested in the program, or would your interest remain the same?

- MORE INTERESTED.....01
- LESS INTERESTED.....02
- NO CHANGE/INTEREST THE SAME.....03
- DON'T KNOW.....d
- REFUSED.....r

INTERVIEWER: IF D1f NOT YES, ASK D2f.

D2f. If you knew that you would be allowed to purchase personal care supplies with the allowance, would you be more interested in the Personal Preference program, less interested in the program, or would your interest remain the same?

PROBE: Care supplies such as adult diapers or disposable gloves.

- MORE INTERESTED.....01
- LESS INTERESTED.....02
- NO CHANGE/INTEREST THE SAME.....03
- DON'T KNOW.....d
- REFUSED.....r

INTERVIEWER: IF D1g NOT YES, ASK D2g.

D2g. If you knew that you would be allowed to purchase special equipment to help you be more independent, would you be more interested in the Personal Preference program, less interested in the program, or would your interest remain the same?

PROBE: Special equipment such as an emergency response system, a touch lamp, or a microwave oven.

- MORE INTERESTED.....01
- LESS INTERESTED.....02
- NO CHANGE/INTEREST THE SAME.....03
- DON'T KNOW.....d
- REFUSED.....r

INTERVIEWER: IF D1h NOT YES, ASK D2h.

D2h. If you knew that the monthly allowance could be used to make modifications to your home, would you be more interested in the Personal Preference program, less interested in the program, or would your interest remain the same?

PROBE: Modifications such as installing grab bars for the bathroom.

- MORE INTERESTED.....01
- LESS INTERESTED.....02
- NO CHANGE/INTEREST THE SAME.....03
- DON'T KNOW.....d
- REFUSED.....r

INTERVIEWER: IF D1i NOT YES, ASK D2i.

D2i. If you knew that program consultants would be available to help you, would you be more interested in the Personal Preference program, less interested in the program, or would your interest remain the same?

- MORE INTERESTED.....01
- LESS INTERESTED.....02
- NO CHANGE/INTEREST THE SAME.....03
- DON'T KNOW.....d
- REFUSED.....r

INTERVIEWER: IF D1j NOT YES, ASK D2j.

D2j. If you knew that bookkeepers would be available to help you, would you be more interested in the Personal Preference program, less interested in the program, or would your interest remain the same?

PROBE: Bookkeepers to write checks to pay workers or make other purchases and to file payroll taxes for the people hired.

- MORE INTERESTED.....01
- LESS INTERESTED.....02
- NO CHANGE/INTEREST THE SAME.....03
- DON'T KNOW.....d
- REFUSED.....r

INTERVIEWER: IF D1k NOT YES, ASK D2k.

D2k. If you knew your benefits would not be affected by participating in Personal Preference, would you be more interested in the program, less interested in the program, or would your interest remain the same?

- MORE INTERESTED.....01
- LESS INTERESTED.....02
- NO CHANGE/INTEREST THE SAME.....03
- DON'T KNOW.....d
- REFUSED.....r

GO TO D4

D3. If you knew that all the features I just mentioned would be available to you, would you be more interested in the Personal Preference program, less interested in the program, or would your interest remain the same?

PROBE: Features such as receiving an allowance instead of agency services, being able to pay family members or friends, being able to make decisions about hiring and firing, being able to purchase special equipment, having consultants available, and the program not affecting your other benefits.

MORE INTERESTED.....01
LESS INTERESTED.....02
NO CHANGE/INTEREST THE SAME.....03
DON'T KNOW.....d
REFUSED.....r

Attitudes About Paying Family

D4. Have you ever had any interest in paying family or friends to provide care for you?

PROBE: Either now or earlier.

YES.....01 → **GO TO E1**
NO.....00
DON'T KNOW.....d
REFUSED.....r

D5. Can you tell me why you have no interest in paying family or friends to provide care for you?

CIRCLE ALL THAT APPLY

- NO NEED (THEY WILL DO IT FOR FREE).....01
- TOO DIFFICULT TO KEEP TRACK.....02
- DON'T KNOW HOW TO DO TAXES/
REPORTING TO IRS.....03
- DON'T KNOW HOW MUCH TO PAY.....04
- WON'T BE ABLE TO PAY ENOUGH.....05
- AFRAID CAREGIVERS WILL LOSE PUBLIC
BENEFITS.....06
- NO ONE AVAILABLE.....07
- CONCERN THAT IT MAY CREATE PROBLEMS
AMONG FAMILY MEMBERS/BE AWKWARD.....08
- NEVER THOUGHT ABOUT IT/
DIDN'T KNOW IT WAS AN OPTION.....09
- DON'T KNOW.....d
- REFUSED.....r

E. CURRENT USE OF PERSONAL CARE SERVICES

Living Arrangements

E1. The (next/first) questions are about you and the people who help with your personal care. First, I'm going to ask you about your living arrangements during the last two weeks.

Do you live with others or do you live alone?

PROBE : We mean your permanent residence where you keep your belongings and receive your calls.

- LIVES WITH OTHERS.....01
- LIVES ALONE.....00 → GO TO E3
- DON'T KNOW.....d
- REFUSED.....r

E2. Including yourself, how many people live in your household?

PROBE: Live in the same household as you.

- |_|_| PEOPLE
- DON'T KNOW.....d
- REFUSED.....r

E3. (IF E1=00: Even though you are living alone...) Are you married at this time?

PROBE: To the best of your knowledge.

- YES.....01
- NO.....00
- DON'T KNOW.....d
- REFUSED.....r

Informal (Unpaid) Care

E4. The next questions are about help you may have received during the last two weeks from people who are not paid to help you like family members, friends, and volunteers. I will ask about paid helpers later.

During the last two weeks, have you received help with personal care such as eating, bathing, or dressing, or help with routine health care, transportation, or things around the house or community from people who were *not* paid to help? Please include your husband/wife, if married.

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

PROBE: For example, a volunteer from a church or service organization.

YES.....01
NO.....00
DON'T KNOW.....d
REFUSED.....r

→ **GO TO E10**

E5. During the last two weeks, *how many different* family members, friends, or others who were *not* paid, helped you? Please include your husband/wife, if married.

|_|_| NUMBER OF UNPAID HELPERS
DON'T KNOW.....d
REFUSED.....r

INTERVIEWER: IF CLIENT LIVES ALONE (E1=0), GO TO E8.

E6. During the last two weeks, did (this person/any of these [NUMBER FROM E5] people) live in the same household as you?

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

YES.....01
NO.....00 → **GO TO E8**
DON'T KNOW.....d
REFUSED.....r

INTERVIEWER: IF E5 = 1, GO TO E8. ELSE, CONTINUE WITH E7.

E7. How *many* of them lived in the same household as you during (the last/those) two weeks?

INTERVIEWER: CODE WITHOUT ASKING IF KNOWN.

PROBE: The same household as you?

|_|_| UNPAID LIVE-IN HELPERS

DON'T KNOW.....d

REFUSED.....r

E8. During a typical week, of the unpaid people who help you, who helps you the most with personal care, doing things around the house or community, transportation, or with routine health care at home?

PROBE: What is the name of this person?

INTERVIEWER: CODE WITHOUT ASKING IF KNOWN.

_____ FIRST NAME OF PERSON OR
RELATIONSHIP

E8a. How is [FILL FROM E8] related to you?

PROBE IF PRIMARY INFORMAL CAREGIVER IS CLIENT'S CHILD: Is [he/she] your [daughter or daughter-in-law/son or son-in-law]?

INTERVIEWER: CODE WITHOUT ASKING IF KNOWN.

CIRCLE ONLY ONE

- SPOUSE.....01
- MOTHER.....02
- FATHER.....03
- DAUGHTER.....04
- DAUGHTER-IN-LAW.....05
- SON.....06
- SON-IN-LAW.....07
- SISTER/SISTER-IN-LAW.....08
- BROTHER/BROTHER-IN-LAW.....09
- GRANDPARENT.....10
- GRANDCHILD.....11
- OTHER RELATIVE.....12
- NON RELATIVE.....13
- DON'T KNOW.....d
- REFUSED.....r

E9. Is [FILL FROM E8] employed at the present time?

PROBE: Is (he/she) working for pay??

PROBE: Other than caring for you.

- YES.....01
- NO.....00
- DON'T KNOW.....d
- REFUSED.....r

INTERVIEWER: IF S8 = CODE 00 (NO PAID HELP IN LAST TWO WEEKS) OR d OR r, GO TO E18.

Use of Paid Care

E10. The next questions are about care you may have received from people who were paid to help during the last two weeks. This could be someone employed by an agency, even if you did not have to pay the agency.

How many *different* people who were paid, helped you with personal care, doing things around the house or community, transportation, or routine health care at home, during the last two weeks?

PROBE: Please include personal care, such as eating and bathing; doing things around the house or community, such as preparing meals, housework, laundry, shopping, yardwork, and transportation; and routine health care at home, such as taking medicine, checking blood pressure, and doing exercises.

|_|_| PAID HELPERS

NONE.....	00	} → GO TO E18
DON'T KNOW.....	d	
REFUSED.....	r	

INTERVIEWER: IF CLIENT LIVES ALONE (E1=00), GO TO E13. ELSE GO TO E11.

E11. Did (this person/any of these paid workers) live in the same household as you?

- YES.....01
 - NO.....00
 - DON'T KNOW.....d
 - REFUSED.....r
- } → **GO TO E13**

E12. How many live in the same household as you?

PROBE: Do not include people who come and stayed overnight just to help you, but who live elsewhere.

PROBE: During the last two weeks.

|__|__| NUMBER OF PAID WORKERS
LIVING IN HOUSEHOLD

- NONE.....00
- DON'T KNOW.....d
- REFUSED.....r

E13. During the last two weeks, have you received help with *personal care*, such as eating and bathing, from a home-care-agency worker or others who are paid to help you?

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

PROBE: Please include anyone you or your family hired privately.

- YES.....01
- NO.....00
- DON'T KNOW.....d
- REFUSED.....r

E14. During the last two weeks, have you received help with transportation from home-care-agency workers or others who were paid to help?

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

YES.....01
NO.....00
DON'T KNOW.....d
REFUSED.....r

E15. During the last two weeks, have you received help with taking medicines or other routine health care at home, such as checking blood pressure and doing exercises, from home-care-agency workers or others who were paid to help?

PROBE: Please include filling pill trays, preparing syringes, and reminders to take your medicine.

YES.....01
NO.....00
DON'T KNOW.....d
REFUSED.....r

E16. During the last two weeks, have you received help with *things around the house or community*, such as preparing meals, housework, 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.

YES.....01
NO.....00
DON'T KNOW.....d
REFUSED.....r

E17. In the last two weeks, on how many *days* did you receive paid care from (this person/these people)?

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

|__|__| DAYS IN LAST TWO WEEKS (1-14 RANGE)

DON'T KNOW.....d

REFUSED.....r

E17a. During the last two weeks, about how many *hours* of paid care did you receive in all from (this person/these people)?

PROBE: Please include paid help with personal care, (or) transportation, (or) routine health care, or things around the house and community in the last two weeks.

PROBE: Your best estimate is fine.

PROBE: How many hours per day per person?

INTERVIEWER: HELP R TO CALCULATE TOTAL HOURS.

- 1-5 hours.....01
- 6-10 hours.....02
- 11-15 hours.....03
- 16-20 hours.....04
- 21-25 hours.....05
- 26-30 hours.....07
- 31-35 hours.....08
- 36-45 hours.....09
- 46-60 hours.....10
- 61 or more hours.....11
- DON'T KNOW.....d
- REFUSED.....r

E18. **IF NOT CURRENTLY RECEIVING PAID CARE (S8 = CODE 00, d, OR r), ADD AT BEGINNING:** Although you have not had help recently. . .

About how long have you 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 but 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.

PROBE: How long since you first became eligible?

- SIX MONTHS OR LESS.....01
- MORE THAN SIX MONTHS TO LESS THAN ONE YEAR.....02
- ONE TO THREE YEARS.....03
- MORE THAN THREE YEARS.....04
- DON'T KNOW.....d
- REFUSED.....r

E19. During the last two weeks, have you received help from someone who is paid by you or your family, or by *private* insurance to help you 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.

YES.....01
NO.....00
DON'T KNOW.....d
REFUSED.....r

F. SATISFACTION WITH PAID CARE

INTERVIEWER: THESE QUESTIONS SHOULD ASSESS THE DECISION MAKER'S SATISFACTION. USE "you" IF RESPONDENT IS DECISION MAKER, ELSE USE CLIENT'S NAME.

F1. IF NOT CURRENTLY RECEIVING PAID CARE (S8 = CODE 00, d, OR r), ADD AT BEGINNING:

When you last received paid care . . .

Please think about all the people who (are/were) paid to help you, including anyone from a home care agency.

Are/Were you satisfied or dissatisfied with the *times of day* that people who (are/were) paid come/came to help you?

IF CURRENTLY RECEIVING CARE (S8 = CODE 01), ADD: If someone who is paid is with you now, please answer with a 1 for satisfied or 2 for dissatisfied.

SATISFIED.....01

DISSATISFIED.....02

NEVER RECEIVED PAID CARE.....03 →

.....

GO

TO F8

DON'T KNOW.....d

REFUSED.....r

→ **GO TO F2**

F1a. Would that be very (satisfied/dissatisfied) or somewhat (satisfied/dissatisfied)?

PROBE: (Dis)Satisfied with the times of day.

VERY.....01

SOMEWHAT.....02

DON'T KNOW.....d

REFUSED.....r

F2. Are/Were you satisfied or dissatisfied with the way people who are paid, carry out their tasks?

PROBE: For example, how satisfied are you that the work is done the way you want it.

- SATISFIED.....01
 - DISSATISFIED.....02
 - DON'T KNOW.....d
 - REFUSED.....r
- } → GO TO F3

F2a. Would that be very (satisfied/dissatisfied) or somewhat (satisfied/dissatisfied)?

PROBE: (Dis)Satisfied with the way they carried out their tasks.

- VERY.....01
- SOMEWHAT.....02
- DON'T KNOW.....d
- REFUSED.....r

F3. Do/Did you feel that you were *ever neglected or abused* by people who were paid to help?

PROBE: For example, you may feel that you were left alone for a long time when you needed care, or that an important task was not done for a long time.

PROBE: People who were paid to help with personal care, doing things around the house or community, transportation, or routine health care at home.

PROBE: Please think about all the people who were paid to help.

PROBE: In your opinion.

- YES.....01
 - NO.....00
 - DON'T KNOW.....d
 - REFUSED.....r
- } → GO TO F4

F3a. Have you had that problem during the last six months?

PROBE: Being neglected or abused by people who were paid to help.

YES.....01
NO.....00
DON'T KNOW.....d
REFUSED.....r

F4. Do/Did you ever feel that paid workers took money or other belongings without asking?

PROBE: People who were paid to help with personal care, doing things around the house or community, transportation, or routine health care at home.

PROBE: Please think about all the people who were paid to help.

PROBE: In your opinion.

YES.....01
NO.....00
DON'T KNOW.....d
REFUSED.....r

GO TO F5

F4a. Have you had that problem during the last six months?

PROBE: That paid workers took money or other belongings without asking.

YES.....01
NO.....00
DON'T KNOW.....d
REFUSED.....r

F5. About how often (do/did) people who were paid, *perform or complete* the tasks they were supposed to? Would you say . . .

PROBE: Tasks that (he/she/they) (are/were) supposed to perform.

PROBE: Please remember that all the information you give us will only be reported as averages for groups of people.

- Rarely,.....01
- Sometimes,.....02
- Usually, or.....03
- Always?.....04
- DON'T KNOW.....d
- REFUSED.....r

F6. Other than what I just mentioned, have you been *dissatisfied with any (other)* aspects of your paid help since you have been receiving Medicaid personal care services at home?

PROBE: Any aspects other than neglect, abuse, theft or not completing tasks.

PROBE: Even if it's only a problem sometimes.

PROBE: Even if the problem has been resolved.

PROBE: Even if it only pertains to one paid helper and not to the others.

- YES.....01
 - NO.....00
 - DON'T KNOW.....d
 - REFUSED.....r
- **GO TO F8**

F7. Please tell me about the problems you had, what aspects of the services you were unhappy with.

PROBE: Someone who was paid to help you with getting dressed or bathing, doing things around the house, or routine health care at home.

PROBE: Anything you tell me will be confidential and will not be reported to Medicaid or your aide.

PROBE: Can you be a little more specific please?

PROBE: What kinds of problems?

PROBE: Are there any other problems? Are there any other aspects you are dissatisfied with?

|__|__|

NONE.....00
DON'T KNOW.....d
REFUSED.....r

F7a. Have you had that problem during the last six months?

PROBE: [REPEAT VERBATIM RESPONSE FROM F7].

YES.....01
NO.....00
DON'T KNOW.....d
REFUSED.....r

F8. For the next question, please think about all the different types of help and any special equipment you use.

Are you satisfied or dissatisfied *overall* with the arrangements for your care and equipment?

PROBE: Equipment for meal preparation or housekeeping, equipment to help with personal activities (a lift to help get out of bed, raised seat for the toilet, tub seat for bathing, wheelchair or scooter), equipment to help with communication, and equipment to help keep you safe.

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

SATISFIED.....01
DISSATISFIED.....02
DON'T KNOW.....d
REFUSED.....r

→ GO TO G1

F8a. Would that be very (satisfied/dissatisfied) or somewhat (satisfied/dissatisfied)?

VERY.....01
SOMEWHAT.....02
DON'T KNOW.....d
REFUSED.....r

G. UNMET NEEDS

G1. Now, please think about *all* the help with personal care you received during the last two weeks from people who were either paid or unpaid.

Do you need *more* help with personal care than you are currently receiving?

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

- YES.....01
 - NO.....00
 - HAVE NOT RECEIVED HELP RECENTLY.....02
 - DON'T KNOW.....d
 - REFUSED.....r
- **GO TO G2**
 → **GO TO G2**

G1a. I understand you haven't received any help recently with personal care. Do you *need* help with that?

PROBE: At the present time?

- YES.....01
- NO.....00
- DON'T KNOW.....d
- REFUSED.....r

G2. Now, please think about all the help with *transportation* you received during the last two weeks.

Do you need *more* help getting rides or using public transportation than you are now receiving?

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

PROBE: Public transportation like a bus or taxi.

PROBE: Please think about both paid and unpaid help that you may have received.

- YES.....01
 - NO.....00
 - HAVE NOT RECEIVED HELP RECENTLY.....02
 - DON'T KNOW.....d
 - REFUSED.....r
- **GO TO G3**
 → **GO TO G3**

G2a. I understand that you haven't received any help recently with getting rides or using public transportation. Do you *need help* with that?




PROBE: At the present time.

YES.....01
NO.....00
DON'T KNOW.....d
REFUSED.....r

G3. Now, please think about all the help with *routine health care* you received at home during the last two weeks.

Do/Did you need (help/more help than you are/were receiving with *taking medicine* or with *other tasks*, such as checking blood pressure or doing exercises?

PROBE: Please think about both paid and unpaid help that you may have received.

YES..... GO TO G4¹
NO.....
HAVE NOT RECEIVED HELP RECENTLY.....02
DON'T KNOW..... GO TO G4
REFUSED.....

G3a. I understand that you haven't received any help recently with *routine health care*. Do you *need help* with that?

PROBE: At the present time.

YES.....01
NO.....00
DON'T KNOW.....d
REFUSED.....r

G4. Now, please think about all the help with *things around the house or community*, besides transportation, you received during the last two weeks.

Do you need *more* help with things around the house or community than you are now receiving?

PROBE: Some examples are preparing meals, doing housework, laundry, shopping, yardwork and other chores, and paying bills.

PROBE: Please think about both paid and unpaid help that you may have received.

YES..... → GO TO G5⁰¹
NO.....
HAVE NOT RECEIVED HELP RECENTLY.....02
DON'T KNOW..... → GO TO G5
REFUSED.....

G4a. I understand you haven't received any help with things around the house or community recently. Do you *need* help with that?

PROBE: At the present time?

YES.....01
NO.....00
DON'T KNOW.....d
REFUSED.....r

G5. Do you need more supplies for your personal care than you can currently afford?

PROBE: For example, incontinence pads, adult diapers, ostomy and feeding bags, and disposable gloves.

PROBE: Please don't count medicine.

YES.....01
NO.....00
DON'T KNOW.....d
REFUSED.....r

H. HEALTH AND DEMOGRAPHICS

INTERVIEWER: THESE QUESTIONS SHOULD ASSESS THE CLIENT'S CHARACTERISTICS.

Health and Functioning

H1. Next, I have some questions about your overall health.

First, relative to other people your age, how would you rate your health now? Would you say it is . . .

Excellent,.....01
Very good,.....02
Good,.....03
Fair, or.....04
Poor?.....05
DON'T KNOW.....d
REFUSED.....r

H2. Now, I would like to ask about how you get along day to day.

During the past week, did any person help you get in or out of bed, did you do that by yourself, or did you not get out of bed at all?

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

PROBE: For half or more of the times you got out of bed.

SOMEONE HELPED.....01 → GO TO H3
DID NOT NEED HELP.....02
DID NOT GET OUT OF BED AT ALL.....03
DON'T KNOW.....d
REFUSED.....r

→ GO TO H3

H2a. Did someone usually stay nearby just in case you might need help getting in or out of bed?

PROBE: During the past week.

PROBE: For half or more of the times you got out of bed.

YES.....01
NO.....00
DON'T KNOW.....d
REFUSED.....r

H3. 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 bathe, did you do that by yourself, or were you not able to bathe at all?

INTERVIEWER: CODE 01 IF GOT HELP WITH ANY OF THE ACTIVITIES MENTIONED.

SOMEONE HELPED.....01 → **GO TO H4**
DID NOT NEED HELP.....02
DID NOT TAKE A BATH AT ALL.....03
DON'T KNOW.....d
REFUSED.....r

→ **GO TO H4**

H3a. Did someone usually stay nearby just in case you might need help bathing?

PROBE: During the past week.

PROBE: For half or more of the times you bathed.

YES.....01
NO.....00
DON'T KNOW.....d
REFUSED.....r

H4. During the past week, did any person help you get to or use the toilet or commode, did you do that by yourself, or did you not use the toilet or commode at all?

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

PROBE: For example, a commode at your bedside.

SOMEONE HELPED.....	01	→	GO TO H5
DID NOT NEED HELP.....	02		
DID NOT USE THE TOILET.....	03	}	→ GO TO H5
DON'T KNOW.....	d		
REFUSED.....	r		

H4a. Did someone usually stay nearby just in case you might need help using the toilet or commode?

PROBE: During the past week.

PROBE: For half or more of the times you used the toilet or commode.

YES.....	01
NO.....	00
DON'T KNOW.....	d
REFUSED.....	r

H5. At this time, do you 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.

YES.....	01
NO.....	00
DON'T KNOW.....	d
REFUSED.....	r

H6. **INTERVIEWER: CODE CLIENT'S GENDER WITHOUT ASKING IF KNOWN.**

IF NECESSARY: First, would you mind telling me whether you are male or female? I cannot be sure from your name alone.

MALE.....01
FEMALE.....02
REFUSED.....r

H7. How old are you?

|_|_| CLIENT'S AGE

DON'T KNOW.....d
REFUSED.....r

H8. Next, I'm going to ask you about your background. Do you consider yourself to be of Hispanic origin, such as Mexican, Puerto Rican, Cuban, or other Spanish background?

YES.....01
NO.....00
DON'T KNOW.....d
REFUSED.....r

H9. I'm going to read you a list of five race categories. Please choose one or more races that you consider yourself to be.

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

CIRCLE ALL THAT APPLY

White.....01
African American or Black.....02
American Indian or Alaska Native.....03
Asian.....04
Native Hawaiian or Other Pacific Islander.....05
Some other race (SPECIFY).....96

DON'T KNOW.....d
REFUSED.....r

H10. Some people have a difficult time finding someone to help them because of the area in which they live. The next questions are about where you live.

Do you live on a farm or in the country?

PROBE: Do you live in a rural area?

YES.....01→ **GO TO H11**
NO.....00
DON'T KNOW.....d
REFUSED.....r

H10a. Do you live in a city?

YES.....01
NO.....00
DON'T KNOW.....d
REFUSED.....r

H11. How hard is it to get public transportation from where you live? Would you say . . .

PROBE: In your opinion.

PROBE: Do not include transportation services provided by an organization or agency, such as special vans or buses.

Very hard,.....01
Somewhat hard, or.....02
Not hard at all?.....03
DON'T KNOW.....d
REFUSED.....r

H12. Would you say that you live in a high-crime neighborhood?

PROBE: In your opinion.

YES.....01
NO.....00
DON'T KNOW.....d
REFUSED.....r

Work and Education

H13. Have you ever worked for pay?

PROBE: At any time during your life.

PROBE: Have you ever had a paid job?

- YES.....01
 - NO.....00
 - DON'T KNOW.....d
 - REFUSED.....r
- } → **GO TO H15**

H14. Do you work for pay now?

- YES.....01
- NO.....00
- DON'T KNOW.....d
- REFUSED.....r

H15. Have you ever supervised another person (as part of your paid work) or (as part of) volunteer work you may have done?

PROBE: At any time during your life.

- YES.....01
- NO.....00
- DON'T KNOW.....d
- REFUSED.....r

H16. Have you ever hired someone privately, for example someone to assist with housework, yardwork, or personal care (or to care for a child while you were working)?

- YES.....01
- NO.....00
- DON'T KNOW.....d
- REFUSED.....r

H17. How many grades or years of schooling did you complete?

INTERVIEWER: COMPLETE a OR b.

a. DID NOT GRADUATE HIGH SCHOOL

|_|_| YEARS

DON'T KNOW.....d

REFUSED.....r

b. HIGH SCHOOL GRADUATE AND HIGHER

HIGH SCHOOL GRADUATE OR GED.....01

SOME COLLEGE.....02

COLLEGE BACHELOR'S DEGREE.....03

COLLEGE GRADUATE WORK OR
PROFESSIONAL DEGREE.....04

DON'T KNOW.....d

REFUSED.....r

Those are all the questions I have for you. Thank you for your time. Good-bye.

End Time: |_|_|:|_|_| AM/PM

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Jen revised for Barbara Carlson