

MFPDAC Quarterly Meeting
January 9, 2009
2:00 pm – 4:00 pm

Brown-Heatly, Room 1410

- Welcome and Introductions
- Review Minutes of Last Meeting (October 10, 2008) MFPDAC
- MFP Demonstration Update
 - MFPD Financial Reports Steve Ashman
 - MFPD Semi-Annual Report Due to CMS Steve Ashman
 - Amendment #1 to Operational Protocol Steve Ashman
 - Amendment #2 to Operational Protocol Steve Ashman
 - Behavioral Health Pilot Dena Stoner
 - Overnight Companion Services Ric Zimmerman
 - ICF/MR Voluntary Closure Marc Gold
- Review of MFPD Reports MFPDAC
- TDHCA Housing Issues Brenda Hull
- Quarterly Activities (October through December, 2008) Steve Ashman
- Public Comments
- Next Meeting Date – April 10, 2009, Brown-Heatly, Room 1410

Toll Free Dial-In Number: (877) 226-9790
Access Code: 1822660

For more information, please visit: <http://www.dads.state.tx.us/providers/pi/index.html> or e-mail us at MFP-Project@dads.state.tx.us.

January 9, 2009 MFP Demonstration Advisory Committee Meeting

(figures are through November 30, 2008)

Total MFPD Enrollments									
March	April	May	June	July	Aug	Sep	Oct	Nov	
6	68	127	179	261	393	466	560	663	
% Change	1033.33%	86.76%	40.94%	45.81%	50.57%	18.58%	20.17%	18.39%	

MFPD Enrollment Activity by Program										
Program	March	April	May	June	July	Aug	Sep	Oct	Nov	
Wiaver CBA	3	8	23	39	69	79	94	109	132	
MDCP	0	0	1	1	1	4	11	12	13	
CLASS	0	0	0	0	0	0	0	0	0	
HCS	0	49	61	89	115	157	173	205	237	
DBMD	0	0	0	0	0	0	0	0	0	
STAR+Plus	3	10	31	33	55	85	109	127	145	
ICM SSI	0	0	2	3	7	14	11	12	17	
ICM MAO	0	0	6	9	10	38	46	57	71	
CWP	0	0	0	0	0	0	0	0	0	
Total	6	67	124	174	257	377	444	522	615	

Type of Facility Transitioned From Community ICF/MR	Count	Percent
	136	20.51%
Nursing Facility	400	60.33%
State Hospital	13	1.96%
State School	92	13.88%
Other/Unknown	22	3.32%
Totals	663	100.00%

Type of Facility Transitioned To Community- Alt. Living/Res. Care	Count	Percent
	101	15.23%
Community - W/Other Waiver Participants	12	1.81%
Foster/Companion Care	49	7.39%
Own Home/Family Home	307	46.30%
Residential Support	132	19.91%
Supervised Living	49	7.39%
Other/Unknown	13	1.96%
Totals	663	100.00%

Transitions by CMS Type of Residence

Definition - NF Waivers	Count	Percent
Home Owned or Leased by Individual	307	73.10%
Apartment	12	2.86%
Group Home - 4 or fewer people	101	24.05%
Total	420	100.00%

Transitions by CMS of Type of Residence -

ICF/MR Waivers	Count	Percent
Supervised Living	49	21.30%
Residential Support	132	57.39%
Foster/Companion Care	49	21.30%
Total	230	100.00%

Waiver CBA	< 21	22-64	65+	Female	Male
	0	55	77	74	58
MDCP	13	0	0	5	8
CLASS	0	0	0	0	0
HCS	61	167	9	85	152
DBMD	0	0	0	0	0
STAR+Plus	0	87	58	71	74
ICM SSI	0	14	3	9	8
ICM MAO	0	30	41	38	33
CWP	0	0	0	0	0
Totals	74	353	188	282	333
			615		615

Contract No.: HHSM-500-2005-0025I
MPR Reference No.: 6352-800

MATHEMATICA
Policy Research, Inc.

**Money Follows the Person
Quality of Life Survey
Trainer's Manual**

May 1, 2008

*Matt Sloan
Sara Skidmore
Debra Wright*

Submitted to:

Centers for Medicare and Medicaid Services
Division of Advocacy and Special Initiatives
Disabled and Elderly Health Programs
7500 Security Blvd.
Baltimore, MD 21244-1850

Project Officer:

Mary Beth Ribar

Submitted by:

Mathematica Policy Research, Inc.
P.O. Box 2393
Princeton, NJ 08540
Telephone: (609) 799-3535
Facsimile: (609) 799-0005

Project Director:

Randall Brown

CONTENTS

Chapter	Page
I	INTRODUCTION TO THE STUDY1
A.	DESCRIPTION OF MONEY FOLLOWS THE PERSON INITIATIVE1
1.	Program Goals1
2.	Program Sponsor.....1
B.	DESCRIPTION OF MFP EVALUATION2
C.	IMPORTANCE OF STUDY2
II	INTERVIEWING GUIDELINES.....3
A.	BEFORE THE INTERVIEW3
1.	Call the respondent and arrange for a time and place to interview the respondent in person.3
B.	AT THE INTERVIEW4
1.	Interviewers must verify that they are interviewing the correct person.4
2.	Interviewers must introduce herself or himself and the survey.4
3.	Before starting, interviewers should make sure that they and the respondent are comfortable.4
4.	Administering the questionnaire:4
5.	Close the Interview5
C.	GENERAL INTERVIEWING GUIDELINES.....5
1.	Establishing rapport5
2.	Talk to interviewers about knowing and sharing their limits.....6
3.	Program participants in immediate danger7
D.	GAINING COOPERATION7

CONTENTS *(continued)*

Chapter	Page
II	<i>(continued)</i>
E. INTERACTING WITH PEOPLE WITH SPECIAL HEALTH CARE NEEDS	7
1. Fatigue.....	7
2. Cognitive Impairment	8
F. DATA SECURITY AND CONFIDENTIALITY OF RESPONDENT INFORMATION.....	8
III DATA COLLECTION OVERVIEW	10
A. WHEN THE DATA WILL BE COLLECTED	10
B. MFP PARTICIPANTS TO BE INTERVIEWED	10
C. PROXY AND ASSISTED INTERVIEWS	11
1. Determining when a assisted interview or proxy may be necessary	11
2. Conducting a proxy interview.....	13
D. THE INFORMATION TO BE COLLECTED	13
E. WHERE THE SURVEYS WILL BE CONDUCTED.....	14
F. HOW THE SURVEYS WILL BE CONDUCTED	14
IV MONITORING DATA COLLECTION.....	15
APPENDIX A: MFP QUALITY OF LIFE SURVEY QUESTION BY QUESTION OVERVIEW	16
APPENDIX B: MONEY FOLLOWS THE PERSON QUALITY OF LIFE SURVEY FREQUENTLY ASKED QUESTIONS.....	35
APPENDIX C: EXAMPLE CONFIDENTIALITY PLEDGE.....	38

I. INTRODUCTION TO THE STUDY

This section familiarizes interviewers with the study purpose, background, and importance. Trainers should provide interviewers with a description on the Money Follows the Person initiative and the current evaluation. In general, the key to a successful survey is a motivated interviewer. Studies have shown that interviewers who understand the reason behind a survey and who believe that it is an important effort, collect higher quality data and have higher response rates. As such, we suggest that you start the interviewer training by reviewing the Money Follows the Person (MFP) program and focusing on why the Quality of Life Survey is an important element of that program. This should also include a description of your state's program. Each state's MFP program is very different and it will help motivate interviewers if they understand the specific goals and objectives of your program.

Goal: Interviewers leave the training highly motivated with a basic understanding of the program being evaluated.

A. DESCRIPTION OF MONEY FOLLOWS THE PERSON INITIATIVE

1. Program Goals

The Money Follows the Person (MFP) initiative is the newest component of the president's New Freedom Initiative. The initiative is a nationwide effort to remove barriers to community living for people of all ages with disabilities and long-term illnesses. It represents an important step in working to ensure that all Americans have the opportunity to learn and develop skills, engage in productive work, choose where to live and participate in community life. Several key elements of MFP are that:

- Many Medicaid beneficiaries currently residing in institutions, such as nursing homes and intermediate care facilities for the mentally retarded, want to live in the community and could do so if they had adequate support.
- Caring for Medicaid beneficiaries in the community is less costly than caring for them in an institution.
- If states transition Medicaid beneficiaries from institutional facilities into the community where they can be served in their home, their independence and ties to their community may be preserved and their quality of life will improve.

2. Program Sponsor

To support states in altering their long-term care systems so that more Medicaid beneficiaries who need long-term care services can be served in community settings, the Centers for Medicare & Medicaid Services (CMS) has awarded MFP demonstration grants to 31 states to

assist states in developing and implementing strategies to reform their long-term care financing and service design.

- The grants are intended to assist states in:
 - Making home and community-based services (HCBS) available in a manner that permits funding to “follow the person” to the most appropriate and preferred long-term care setting.
 - Offering services to adequately support those individuals transitioning to community-based settings.

B. DESCRIPTION OF MFP EVALUATION

To evaluate the MFP initiative, CMS has provided funding to states to:

- Set up reporting systems to enable CMS and states to track performance of MFP programs as well as developing mechanisms to help states with reporting requirements.
- Assess the effects of the MFP grants program on Medicaid beneficiaries on states’ efforts to rebalance their long-term care systems toward HCBS, and on implementing system changes.
- Collect information on beneficiaries’ quality of life before and after the transition. This is of particular importance given that the purpose of the MFP initiative is to improve quality of life of beneficiaries. The key measure of this is the Quality of Life survey.

C. IMPORTANCE OF STUDY

This evaluation is an important study designed to collect information from Medicaid beneficiaries transitioning out of institutional care. Congress allocated over \$1.7 billion to the MFP program and required a thorough evaluation of this program. Policymakers believe understanding how well MFP achieves its goal to help states transition long-term institutionalized Medicaid beneficiaries to community settings and restructure their long-term care systems is critical to determining future programs and policies. The study is being conducted to help CMS evaluate how well the MFP initiative is meeting the needs of beneficiaries and what changes may need to be made. The results of this demonstration will be summarized in a report to Congress. Most importantly, the results of the study will be used to improve the program and provide the best possible services to beneficiaries in the community.

II. INTERVIEWING GUIDELINES

This section discusses training interviewers to provide information about correct interviewing techniques, revivifying that they have the correct program participant, establishing rapport, and gaining cooperation.

Goal: Interviewers will understand how to properly contact and interview respondents.

A. BEFORE THE INTERVIEW

1. Call the respondent and arrange for a time and place to interview the respondent in person

States should create a script for interviewers to use to contact the respondent and introduce himself or herself and the QOL survey. This script can be used (or modified):

Hello, my name is _____ and I am from _____. Thank you for letting me come talk with you. I'd like to ask you a few questions about your life and how satisfied you are with the assistance you get. This information will help us evaluate the "Money Follows the Person" [or local name] program so that it meets the needs of people like you. I'd like to schedule a time and place that we could speak for a few minutes.

- When contacting a person in an institution, interviewers may need to make initial contact with a staff member to make arrangements for the time of the interview. Interviewers must be prepared to respond to concerns about privacy (HIPAA) or legitimacy by reviewing the Frequently Asked Questions in Appendix B (FAQ).
- Interviewers should be ready to provide contact information. It is important to give contact information to the respondent in case they need to cancel or change the arranged interview. Interviewers should confirm the time, date, and location of the interview at the close of the conversation. This information could also be included in a follow-up letter to confirm the interview.
- If interviewers cannot reach the respondent to arrange an interview time by phone, they should attempt to contact the respondent in person.

B. AT THE INTERVIEW

1. Interviewers must verify that they are interviewing the correct person

When first contacting a respondent, interviewers must verify his or her name, address, and date of birth. If the respondent's name, address, and birthday don't match the information the interviewer has, they should talk to a supervisor before continuing the interview. Since administrative records are not always correct, supervisors should have a decision rule to use to determine if the information does not match.

2. Interviewers must introduce herself or himself and the survey

Interviewers should be prepared to introduce themselves and the survey.

- If necessary, interviewers can remind the respondent of the purpose of the survey (to learn about his or her experiences and determine if program improvements are needed).
- Interviewers should underscore that there are no "correct" answers nor will honest responses affect his or her care or benefits. Best guesses are okay.
- Interviewers must discuss confidentiality of responses. Once they start the interview, they need to be sure to read the entire script concerning the content of the survey and the assurance of confidentiality. Interviewers should sign a confidentiality pledge that prohibits divulging any personally identifiable information before starting work. More detailed information about confidentiality can be found in Section F of this chapter.
- Interviewers should allow time to answer any questions the respondent may have before starting. They should not rush the respondent.

3. Before starting, interviewers should make sure that they and the respondent are comfortable

- Interviewers should try to minimize distractions for themselves and the respondent, such as television and radio. The interviewers' focus should be on the instrument and the respondent.
- It is preferable to interview the respondent in private. However, in some cases the respondent might ask for a family member or caseworker to be present which is acceptable. The interviewer may need to gently remind others that the respondent is the person we wish to hear from.

4. Administering the questionnaire

- Every question on the survey must be asked, unless a skip pattern indicates to do otherwise.

- If in doubt about whether a question should be skipped, interviewers should ask the question. We can always drop a response later.
- Respondents may choose not to answer any question they wish.
- Interviewers should not leave any questions blank (unless it a skip pattern indicates it should not be asked). If the respondent does not answer record “refused.”
- Interviewers must ask the questions exactly as they are written (verbatim). This ensures that each person gets asked the question the same way. Interviewers can use the probes or the Question-by-Question Overview in Appendix A to clarify the question’s intent. They may repeat or rephrase the question as long as the meaning of the question does not change. They should not rephrase questions until they have tried using the original one.
- Interviewers can try to clarify unclear answers. If a respondent’s answer is unclear, they may probe in a neutral manner to gain further understanding. An example of a neutral probe is, “Could you say more about that?” However, try not to impose your interpretation on the respondent. An example of a leading probe is, “Do you mean ...”. They may simply mark the response as “unclear” if the respondent’s response is unclear.
- Except in an assisted interview (described below), if others present during the interview attempt to answer for the respondent, interviewers should gently remind them that we are interested in hearing directly about the respondent’s experience. If other people provide a response, interviewers should verify the respondent’s answer before recording.
- Interviewers should be sensitive to the respondent’s physical and emotional state. They may want to ask how she or he is feeling, or if she or he would like to continue. If the respondent seems tired, or in pain, they can always offer to take a break from the questions. Respondents also have the right to stop the interview altogether at any time. In this case, interviewers should thank them for their time and end the visit.

5. Close the interview

At the end of the interview, interviewers should thank the respondents for his or her participation. They should also leave contact information for the state survey director (or other designated person) so that the respondent can contact someone knowledgeable if she or he has additional questions.

C. GENERAL INTERVIEWING GUIDELINES

1. Establishing rapport

Establishing a friendly and respectful rapport with respondents is critical to getting accurate and honest answers. Respondents will feel more at ease when interviewers are:

- Understanding,
- Honest and accurate in responding to questions about the survey (see FAQ),
- Non-judgmental,
- Respectful of their culture, and
- Appreciative of the information provided.

Conversational, open-ended questions are included in the survey as opportunities to build rapport between interviewers and the respondent. Interviewers may also ask additional questions, and use “small talk” to increase rapport, however, the interview questions are always the primary focus, and should not be altered or dropped. Making and maintaining eye contact is another way of building rapport and indicating respect, when it is culturally appropriate.

Although it may be tempting, interviewers should avoid expressing opinions or commiserating with respondents. It is important to respond neutrally to the responses the respondent provides so that you do not influence his or her answers. The following guidelines will assist interviewers in approaching respondents and establishing rapport:

- Speak clearly.
- Present yourself as a straightforward, self-confident, trustworthy person on legitimate business. Show respect for the lives and privacy of the people with whom you interact. Avoid talking about other respondents.
- Be aware of your facial expressions and body language and how others might perceive them. Avoid personal comments such as remarks about a person’s surroundings, children, or personal possessions.
- Observe and consider the informant’s facial expressions and body language as a clue to your success in completing an interview.

2. Talk to interviewers about knowing and sharing their limits

Interviewers should be clear about the purpose of the visit: to administer the survey instrument. Too much social interaction can sidetrack the interview or misrepresent the visit as a social call. In addition, they should be clear about the limits of their ability to change the program participant’s living situation or services.

The interviewer’s goal is to gather information only; requests for assistance, or complaints about existing services should be directed to the program participant’s case manager. When program participants raise concerns or ask for help, interviewers should encourage them to talk to their case managers. Otherwise, the individual may be left with the impression that the interviewer will “fix things” for them.

3. Program participants in immediate danger

Intervention may be warranted for program participants whose health, safety, or well-being seems threatened. Despite any pledge of confidentiality made, you may be required by state law or policy to report some incidents of alleged abuse or neglect described. Establish a clear procedure to follow if interviewers believe a program participant is in jeopardy, through abuse, neglect, unsafe living conditions, or inadequate services. In general, interviewers should report these instances to the state survey director (or other designated person). State survey directors can then rely on legal advice to determine how these reports should be handled.

D. GAINING COOPERATION

Respondents are not required to complete the survey. However, grantees are expected to complete interviews with a high proportion of respondents to ensure that responses are representative. As a guideline, we expect baseline interviews to be completed with over 90 percent of respondents. Our experience with this population and this topic indicates that these are reasonable goals.

Interviewers should approach respondents with the attitude that the respondents will want to complete the survey in order for the grantee to assess and monitor their well-being and for CMS to identify ways to better serve program participants. Most program participants will be interested in participating once the purpose of the survey is explained to them. Some program participants may have additional concerns that can be addressed by assuaging concerns about confidentiality and the interview process. Interviewers should carefully review the FAQ before speaking with any respondents.

E. INTERACTING WITH PEOPLE WITH SPECIAL HEALTH CARE NEEDS

Individuals in this population are likely to have health needs that may require some accommodation to complete the interview. The two most common health care issues that may affect participation include fatigue and cognitive impairment.

1. Fatigue

Some people in this sample will tire easily. Interviewers should listen for voice tone, frequent pauses or sighs. Does the respondent seem less alert than earlier? It is better to stop the interview and come back later rather than continue with a tired and perhaps inattentive respondent. Interviewer should follow these guidelines:

- Assess the respondent's ability to continue as the interview progresses. If you are not sure if the respondent is feeling fatigued, simply ask. Do not hesitate to stop and come back another time.
- Use the following probes to determine if the respondent is fatigued:
 - Are you feeling tired or can we continue?

- Would you like to take a break? I can hold on.
- Would you like to continue the interview another time?

2. Cognitive Impairment

Some respondents may have difficulty processing questions and responses, lack complete or specific knowledge, or are confused about the role of the interview. Interviewers can use these guidelines for interacting with respondents with limited cognitive ability:

- Use probes or repeat the question text if the respondent does not understand the question.
- Help keep the respondent free from distractions. If you hear background activities, suggest that the respondent move to a quieter place. You may need to come back another time.
- Say the person's name often to keep their attention and focus on the interview.
- Speak slowly and clearly, but don't exaggerate the inflection or tone of your voice. Exaggerations call attention to themselves rather than what you are saying and can be distracting and confusing.
- Check frequently to be sure the person understands you. It is usually not helpful to simply ask, "Do you understand?" Instead, you might try asking the respondent to repeat the question. This will give you the opportunity to identify the source of confusion.
- Be an active listener and provide neutral feedback such as "I see" or "I understand." These phrases indicate that you are interested and encourage the respondent.
- Be prepared to wait. People with cognitive impairments may process information slowly. Never attempt to finish sentences for the respondent.

F. DATA SECURITY AND CONFIDENTIALITY OF RESPONDENT INFORMATION

States collecting data for the Money Follows the Person project have a legal and moral obligation to keep all information gathered about sample persons in the strictest confidence. This responsibility starts with interviewers, but everyone involved in the project must adhere to the principles that guide our confidentiality procedures. These principles are described below.

1. Survey data must not be released to anyone outside the project. When survey data are presented, they will only be presented in summary form and will be stripped of any identifying information.
2. Access to individual identifying information must be limited to those whose roles demand it and only for the period required. Physical safeguards such as locked file cabinets protect the data and prevent unauthorized access.

3. No identifying information can be published or released to anyone, except as may be required by law, regulation, or subpoena.
4. Data collected from respondents will be used for research purposes only.

Because the Money Follows the Person project has a strong commitment to protecting the identity of our respondents and any data they might give us, all interviewers should receive, sign, and return a Confidentiality Pledge before leaving training (see Appendix C for an example). A confidentiality pledge obligates interviewers to keep the names of sample members and the information collected from them in confidence.

Interviewer guidelines. All information that can be used to identify a respondent must be kept confidential. When an interviewer receives information about a person they will be interviewing (such as name, address, phone number, birth date), he or she is receiving confidential information about that sample member. Interviewers must follow these protocols to protect this information:

- Always keep respondent contact information and survey responses in a folder or envelope which conceals the information from others.
- Never leave materials in a car (case materials are easily stolen from automobiles).
- Never leave materials where anyone could pick them up and read them.
- Do not leave materials out in the open, even in your own home – keep them in a drawer or locked cabinet out of the family “traffic.”
- Do not discuss the sample member or respondent with *anyone* outside the project.
- Take very seriously the distinction between the sample person and informants or contacts you may meet when trying to interview the sample person. You should not reveal any information that could cause a breach of the sample member’s confidentiality to an informant. For example, do not mention that the study concerns people who applied for or receive Medicaid benefits.

Returning Survey Materials. Each state should develop a system for receiving and tracking completed survey questionnaires and case assignment materials. Completed surveys and case assignment materials are highly confidential because they contain sample person contact information and responses to potentially sensitive questions. Materials may be sent via USPS on an ongoing basis to a specific contact person but should be tracked to ensure the appropriate person receives them. At the training, provide interviewers with specific instructions for packing and sending these materials. If materials are not returned, the state should follow-up with the interviewer to retrieve them. At the end of the project, all such information must be retrieved from interviewers and stored securely or destroyed.

III. DATA COLLECTION OVERVIEW

This section provides an overview of the data collection protocol including timing of the data collection, study population, and the survey. Because the grantee states will each be responsible for collecting MFP Quality of Life survey interviews, it is extremely important that a standard set of procedures be used. Sometimes, even minor changes in data collection procedures may cause differing responses that have nothing to do with the data. For example, if one grantee state only interviewed respondents during the day, that state would likely miss respondents who were more active and thus unavailable during the day than other states who attempted to contact respondents during the day and evening.

Goal: Interviewers will understand the specific procedures for how this study will be conducted.

A. WHEN THE DATA WILL BE COLLECTED

MFP participants will be interviewed three times:

- At “Baseline”: after they have been accepted into the MFP program but just before they are discharged from the institution to the community
- At “First followup”: about 11 months after discharge to the community,
- At “Second follow-up”: about 24 months after discharge to the community

This training focuses on conducting the baseline interviews. Additional trainings will be held to discuss the follow-up interviews closer to when they will be conducted. It is important for interviewers to remember, however, that respondents will be contacted in the future. Good contact information must be obtained so that respondents can be located for follow up interviews. And, interviewers must be sure to leave a good impression so that respondents will be willing to participate again in the future.

B. MFP PARTICIPANTS TO BE INTERVIEWED

Baseline interviews will be administered to all MFP participants in each state who enter the program during the first three years of operation. Follow-up interviews must be attempted for everyone who receives a baseline interview. If a respondent does not complete a baseline interview we will not attempt follow up interviews. Interviewers should understand that uncompleted interviews not only hurt the data in this round, but in future rounds as well.

C. PROXY AND ASSISTED INTERVIEWS

A proxy respondent is a person who answers the survey questions on the program participant's behalf, often because the program participant is unable to do so. However, program participants are the best judge of their own experiences and whenever possible their responses should be solicited. Often times proxy respondents give the impression that the respondent is less healthy than he or she actually is. However, it is permissible to allow the respondent to be assisted by a friend or family member if they require help to complete the survey or, if necessary, to conduct the interview with a proxy who is very familiar with the program participant's situation and agrees to answer on his or her behalf.

Remind interviewers that while the sample person should respond for him or herself whenever possible, a proxy response is better than no response and program participants should not be badgered to complete the interview.

1. Determining when a assisted interview or proxy may be necessary

There are three situations in which an assisted interview or proxy may be necessary:

1. The program participant wants to complete the interview, but the interviewer believes that he or she is not capable of understanding the questions;
2. The program participant requests that a proxy complete the interview for them; or
3. A family member indicates that the program participant cannot complete the interview him or herself.

In each situation, the interviewer should first attempt to conduct the interview with the program participant rather than a proxy if at all possible. Second, interviewers should can offer the option of assisted interviews in which a family member or friend helps the program participant to understand the question or accommodate concerns. As a last resort, interviewers may interview a proxy on the program participant's behalf. In each situation, the interviewer should gently encourage the program participant to attempt to complete as much of the interview possible him or herself.

The following guidelines should be used in determining whether a proxy interview should be allowed:

a. **The program participant wants to complete the interview, but the interviewer believes that the participant is not capable of understanding the questions:**

- Interviewers should try a few questions with the program participant to assess whether he or she will be capable of responding. If the respondent appears to understand the questions but takes a long time to answer them, this is okay and a proxy is probably not necessary. If the program participant does not seem to understand the questions or gives answers that don't seem relevant, interviewers should seek a proxy.

- Interviewers should determine whether a language interpreter or other accommodation such as taking breaks would help the program participant complete the survey.
 - Interviewers can ask if there is someone available who can help answer the questions, and if so, proceed with an assisted interview. Sometimes only some questions pose a problem for the respondent and so occasional assistance, rather than a proxy, will suffice. For example, a respondent may know details of his or her day-to-day life, but may not know whether the people who help him are paid. In this case another person may be able to answer this particular question.
 - If an assisted interview is not possible, interviewers should ask the program participant if there is a person who is familiar with the program participant's day-to-day life who can participate in the survey on the program participant's behalf and proceed with a proxy interview.
- b. The program participant insists that a proxy complete the interview for them even though the interviewer suspects the program participant is capable of completing it him or herself:**
- Interviewers should first gently encourage the program participant to try to answer the survey questions. They can tell him or her that we want to hear what he or she has to say, that there are no right or wrong answers, and that his or her responses will help improve services to people like them.
 - Interviewers can offer to do the interview in short sessions so as not to tire the respondent.
 - If the respondent still feels uncomfortable, interviewers should offer an assisted interview, in which the respondent answers the questions, but is able to seek help from others to better understand the questions.
 - If the program participant still does not want to participate, interviewers should identify a person who is familiar with the program participant's day-to-day life and proceed with a proxy interview.
- c. A family member insists that the program participant cannot do the interview or would be adversely affected by it:**
- Interviewers should tell the family member it's important we hear from the program participant directly if at all possible. The family member can remain nearby while the interview is being conducted in case the program participant needs assistance.
 - Interviewers can ask the family member if they would be willing to assist the program participant in responding.
 - If an assisted interview is not possible, interviewers should proceed with a proxy interview with the family member.

2. Conducting a proxy interview

If an interviewer determines that a proxy is necessary, it is important that they select a proxy who is familiar with the respondent's situation. Generally, the best approach is to ask the respondent him or herself if there is a person, such as a family member, who can fill that role:

- “Is there someone who could answer questions about your health and daily activities?”

If the respondent is unable to identify someone, an interviewer might ask a caseworker if he or she can identify someone or if he or she can serve as a proxy. Once a proxy has been identified, interviewers will need to persuade the proxy to participate on the respondent's behalf. A sample script should be provided:

Hello, my name is _____ and I am calling on behalf of _____. [Respondent name] has been selected to participate in an important study we are conducting for _____. I was told that you are the most knowledgeable person to respond to the survey on behalf of [respondent name]. I'd like to ask you a few questions about his/her life, and how satisfied he/she is with the assistance he/she gets. This information will help us evaluate the “Money Follows the Person” [or local name] program so that it meets the needs of people like him/her. I'd like to schedule a time and place so that we could speak for a few minutes.

When conducting the interview with a proxy interviewers must remember that:

- The objective is to obtain the program participant's point of view, not the proxy's point of view. They may need to instruct the proxy, “Please remember that when answering these questions you are responding on the program participant's behalf and should respond as much as possible from his or her point of view, even if your own opinions differ.”
- The question language will need to be modified for proxy respondents (for example changing “you” to the program participant's name).
- Proxy interviews should not be conducted for program participants who have died.

D. THE INFORMATION TO BE COLLECTED

The MFP Quality of Life instrument is based on the Participant Experiences Survey (PES), which is widely used for assessing quality of life for recipients of HCBS. The MFP instrument incorporates several modifications to reflect the need for greater gradation of answers and to capture additional information not included on the PES. The MFP Quality of Life instrument will be asked at all three interviews (with minor modifications for the follow-ups) and covers the following quality of life topics:

- Participants' freedom of choice and control over their lives
- Satisfaction with housing, care, and life in general
- Access to care and unmet needs
- Feelings about being treated with adequate respect and dignity
- Ability to engage in and enjoy community activities
- Health status

The same instrument will be used for all target populations. The Question-by-Question overview of the survey provides additional information about specific questions. A key part of training interviewers will be to review the Question-by-Question overview carefully. This must be done before any attempt to conduct interviews.

E. WHERE THE SURVEYS WILL BE CONDUCTED

The baseline interview will be conducted while the program participant is in the institution. In general, try to select a location where the respondent will be able to focus on the interview and where you can conduct the interview in private. For example, activity rooms or dining rooms may not be private and may have too many distractions.

F. HOW THE SURVEYS WILL BE CONDUCTED

- Baseline interviews will be conducted in person.
- Multiple attempts should be made to contact respondents. In general, up to 15 attempts should be made. These attempts should be made at different times and on different days of the week in order to find a time that the respondent can complete the survey. After 15 attempts, the case should be reviewed to determine if it is viable. In some instances another attempt might make sense, but in most cases efforts should be terminated at this point. To avoid needing multiple attempts, interviewers should attempt to make firm appointment times during initial contacts.
- Respondents who refuse to complete the survey should be placed on hold for two weeks and reviewed to determine the best follow up approach. After that, experienced interviewers should attempt to interview the respondent. If the respondent refuses a second time, effort on the case should cease and it should be coded a final refusal. Generally, you should expect to convert up to 25% of initial refusals.
- The survey will be translated into Spanish and other languages for which there is significant need. Grantees will be required to find interviewers who speak the additional languages and train them on conducting the interviews in those languages.
- In-person interviews will be conducted electronically on a laptop or by hand, using hard copy. Hard copies need to be entered into an Excel spreadsheet by grantees.

IV. MONITORING DATA COLLECTION

As essential as training interviewers is, monitoring their work and providing appropriate guidance and feedback is just as critical. Some techniques for interviewer guidance and monitoring:

- Establish reasonable goals for your interviewers. If an interviewer can work 10 hours a week and you think that each case takes about an hour to work each week, don't give your interviewer more than 10 or so cases. Also, let him or her know that you expect 6-7 of those cases to be completed each week. Do not give more cases if goals are not met.
- Devise a tracking system. This will vary by site, but you should be able to track each interviewer's cases and the status of those cases. Information tracked could include:
 - Unique Case Identifier and other identifying information such as name, address, telephone number, and date of birth.
 - Appointment details.
 - Case status that indicates whether contact has been attempted, completed, or refused.
 - Number of attempts.
- Make sure that all cases are being worked. If it appears that a case has not been worked in over a week, speak to the interviewer and address any of his or her concerns. Sometimes interviews will work "easier" cases and not work "harder" cases. It is extremely important that all cases be worked so as not to bias the results.
- Be sure that cases are spread evenly across interviewers. If possible, interviewers should have a mix of easier and harder cases and a mix of newly released cases and refusals.
- Meet with each interviewer regularly and review each of his or her cases with him or her.
- Discuss problems recording the data or dealing with difficult situations.

APPENDIX A: MFP QUALITY OF LIFE SURVEY QUESTION BY QUESTION OVERVIEW

RESPONDENT INFORMATION

Respondent Information is to be completed by the interviewer prior to or at the start of the interview.

Respondent Name: _____

Respondent Street Address: _____

Respondent City: _____

Respondent State: _____

Respondent ZIP Code: _____

Medicaid ID number: _____

Check here if the Sample Member is deceased and record date of death:

[_____] [_____] [_____] ➔ **GO TO END**

Month

Day

Year

Hello, my name is _____ and I am from _____. I'm here to ask for your help with an important study of Medicaid beneficiaries in the state of _____. The Quality of Life Survey, sponsored by the Centers for Medicare & Medicaid Services (CMS) and the state of _____, is an essential part of an evaluation of the Money Follows the Person Program, a program designed to help Medicaid beneficiaries transition out of institutional care into the community. I'd like to ask you some questions about your housing, access to care, community involvement, and your health and well-being. Results from the study will help CMS and the state of _____ evaluate how well its programs are meeting the needs of Medicaid beneficiaries like you.

Before we begin, let me assure you that all information collected will be kept strictly confidential and will not be reported in any way that identifies you personally. Your answers will be combined with the answers of others and reported in such a way that no single individual could ever be identified. Further, the information collected will not be used by anyone to determine your continuing eligibility for Medicaid benefits. We are collecting this information for research purposes only. However, I may be required to report any instances of abuse or neglect that you tell me about to authorities. Your participation is completely voluntary and if we come to any question you prefer not to answer, just tell me and we'll move on to the next one.

If you have any questions, please stop me and ask me. Also, please let me know if you do not understand a question or if you would like me to repeat it.

MODULE 1: LIVING SITUATION

1. I'm going to ask you a few questions about the place you live. About how long have you lived (here/in your home)?

PROBE: Your best estimate is fine.

INTERVIEWER: IF RESPONDENT INDICATES LESS THAN 1 MONTH, ENTER 1 MONTH.

[_____] [_____] ➔ **GO TO QUESTION 2**
 Years Months

DON'T KNOW DK
 REFUSED R

Approximate dates are better than no information. You can use seasons or life events (e.g. birthdays, elections, etc.) to help the respondent narrow down an answer. For example, "Do you remember who was president when you moved in" or "Did you move in the summer or winter?"

If respondent has returned to live a place where they lived previously, record only the length of time of their current stay. Do not count hospital stays as such gaps.

- 1a. Would you say you have lived here more than five years?

YES 01
 NO 02
 DON'T KNOW DK
 REFUSED R

2. INTERVIEWER: DOES PROGRAM PARTICIPANT LIVE IN A GROUP HOME OR NURSING FACILITY?

- YES 01
- NO 02
- DON'T KNOW DK
- REFUSED R

This question is not read to the respondent but is based on interviewer observation. This information is important in determining whether certain following questions should be asked.

3. Do you like where you live?

- YES 01
- NO 02
- SOMETIMES..... 03
- DON'T KNOW DK
- REFUSED R

This question refers to where the respondent currently lives and applies to the respondent's institution, home or the surrounding neighborhood.

4. Did you help pick (this/that) place to live?

- YES 01
- NO 02
- DON'T KNOW DK
- REFUSED R

Code any input the respondent had as "yes".

5. Do you feel safe living (here/there)?

- YES 01 ➔ GO TO QUESTION 6
- NO 02
- DON'T KNOW DK ➔ GO TO QUESTION 6
- REFUSED R ➔ GO TO QUESTION 6

If respondent replies "Sometimes," code 5 as "Yes" and 5a as "Sometimes".

5a. How often do you feel unsafe living (here/there)?

- SOMETIMES..... 01
- MOST OF THE TIME 02
- DON'T KNOW DK
- REFUSED R

6. Can you get the sleep you need without noises or other disturbances where you live?

- YES 01
- NO 02
- SOMETIMES..... 03
- DON'T KNOW DK
- REFUSED R

Noises can be from any source inside or outside the home.

MODULE 2: CHOICE AND CONTROL

In this series of questions, we want to know if the respondent is permitted to do these things when he or she wants to. These items are not intended to assess physical ability to engage in these activities or ability to pay for things.

7. Can you go to bed when you want?

- YES 01
- NO 02
- SOMETIMES..... 03
- DON'T KNOW DK
- REFUSED R

If a respondent does not sleep in a bed, ask if they are able to go to sleep at night when they want.

8. Can you be by yourself when you want to?

- YES 01
- NO 02
- SOMETIMES..... 03
- DON'T KNOW DK
- REFUSED R

9. When you are at home, can you eat when you want to?

- YES 01
- NO 02
- SOMETIMES..... 03
- DON'T KNOW DK
- REFUSED R

"Home" means where the respondent lives, whether in an institution or in their own home.

10. Can you choose the foods that you eat?

- YES 01
- NO 02
- SOMETIMES..... 03
- DON'T KNOW DK
- REFUSED R

Note that this question does not include dietary restrictions that may constrain the respondent.

11. Can you talk on the telephone without someone listening in?

- YES 01
- NO 02
- SOMETIMES..... 03
- NO ACCESS TO TELEPHONE.....NA
- DON'T KNOW DK
- REFUSED R

This question refers to whether the respondent can have private telephone conversations. If the respondent does not have a telephone, code "NO ACCESS TO PHONE".

12. Can you watch TV when you want to?

- YES 01
- NO 02
- SOMETIMES..... 03
- NO ACCESS TO TV.....NA
- DON'T KNOW DK
- REFUSED R

If the respondent does not have a television or access to a television, code "NO ACCESS TO TV".

13. **[AFTER TRANSITION ONLY]** Some people get an allowance from the state to pay for the help or equipment they need. Do you get an allowance like this?

- YES 01
- NO 02 ➔ GO TO QUESTION 14
- DON'T KNOW DK ➔ GO TO QUESTION 14
- REFUSED R ➔ GO TO QUESTION 14

This question is not asked at baseline. By allowance, we mean money from the MFP program not social security benefits or other sources of income.

13a. **[AFTER TRANSITION ONLY]** In the last 12 months, what help or equipment did you buy with this allowance?

[Code all that apply]

- MODIFIED HOME..... 01
- MODIFIED CAR..... 02
- SPECIAL EQUIPMENT 03
- PAID HELP 04
- TRANSPORTATION..... 05
- HOUSEHOLD GOODS..... 06
- SECURITY DEPOSIT 07
- OTHER..... 08
- DON'T KNOW DK
- REFUSED R

This question is not asked at baseline.

MODULE 3: ACCESS TO PERSONAL CARE

14. Now I'd like to ask you about some everyday activities, like getting dressed or taking a bath. Some people have no problem doing these things by themselves. Other people need somebody to help them. First, does anyone help you with things like bathing, dressing, or preparing meals?

PROBE: Please include any help received by another person, including cueing or standby assistance.

- YES 01
- NO 02 ➔ **GO TO QUESTION 15**
- DON'T KNOW DK ➔ **GO TO QUESTION 15**
- REFUSED R ➔ **GO TO QUESTION 15**

Note that in this section questions about "help" refers to help with personal care, not monetary assistance and "cueing and standby" means reminders and staying nearby in case you need help.

14a. Do any of these people get paid to help you?

- YES 01
- NO 02 ➔ **GO TO QUESTION 15**
- DON'T KNOW DK ➔ **GO TO QUESTION 15**
- REFUSED R ➔ **GO TO QUESTION 15**

This includes services paid for by either the respondent or others.

14b. Do you pick the people who are paid to help you?

- YES 01
- NO 02
- DON'T KNOW DK
- REFUSED R

If the respondent has any choice at all in who is paid to help him or her, code "YES".

15. Do you ever go without a bath or shower when you need one?

- YES 01
- NO 02 ➔ **GO TO QUESTION 16**
- DON'T KNOW DK ➔ **GO TO QUESTION 16**
- REFUSED R ➔ **GO TO QUESTION 16**

A "bath or shower" includes sponge baths. These questions refer to times the respondent wants to have a bath or shower, but there is no one to help them do so. If respondent replies "Sometimes," code 15 as "Yes" and 15a as "Sometimes".

15a. How often do you go without a bath or shower when you need one? Would you say only sometimes or most of the time?

- SOMETIMES..... 01
- MOST OF THE TIME 02
- DON'T KNOW DK
- REFUSED R

15b. Is this because there is no one there to help you?

PROBE: Please include any help received by another person, including cueing or standby assistance.

- YES 01
- NO 02
- DON'T KNOW DK
- REFUSED R

Note that in this section questions about "help" refers to help with personal care, not monetary assistance and "cueing or standby" means reminders or staying nearby in case you need help.

16. Do you ever go without a meal when you need one?

- YES 01
- NO 02 ➔ **GO TO QUESTION 17**
- DON'T KNOW DK ➔ **GO TO QUESTION 17**
- REFUSED R ➔ **GO TO QUESTION 17**

A meal includes snacks or other food whenever the respondent is hungry and wants to eat. If respondent replies "Sometimes," code 16 as "Yes" and 16a as "Sometimes".

16a. How often do you go without a meal when you need one? Would you say only sometimes or most of the time?

- SOMETIMES..... 01
- MOST OF THE TIME 02
- DON'T KNOW DK
- REFUSED R

16b. Is this because there is no one there to help you?

PROBE: Please include any help received by another person, including cueing or standby assistance.

YES 01
NO 02
DON'T KNOW DK
REFUSED R

Note that in this section questions about “help” refers to help with personal care, not monetary assistance and “cueing or standby” means reminders or staying nearby in case you need help.

17. Do you ever go without taking your medicine when you need it?

PROBES: Medicines are pills or liquids that are given to you by a doctor to help you feel better.

YES 01
NO 02 ➔ **GO TO QUESTION 18**
DON'T KNOW DK ➔ **GO TO QUESTION 18**
REFUSED R ➔ **GO TO QUESTION 18**

“When you need it” means according to the prescription. If respondent replies “Sometimes,” code 17 as “Yes” and 17a as “Sometimes”.

17a. How often do you go without taking your medicine when you need it? Would you say only sometimes or most of the time?

SOMETIMES..... 01
MOST OF THE TIME 02
DON'T KNOW DK
REFUSED R

17b. Is this because there is no one there to help you?

PROBE: Please include any help received by another person, including cueing or standby assistance

YES 01
NO 02
DON'T KNOW DK
REFUSED R

Note that in this section questions about “help” refers to help with personal care, not monetary assistance and “cueing or standby” means reminders or staying nearby in case you need help.

18. Are you ever unable to use the bathroom when you need to?

YES 01
NO 02 ➔ **GO TO QUESTION 19**
DON'T KNOW DK ➔ **GO TO QUESTION 19**
REFUSED R ➔ **GO TO QUESTION 19**

“Using the bathroom” means getting to and using a toilet when the respondent needs to. This is not intended to address times the respondent is physically unable to go to the bathroom when at the toilet or when someone has a catheter or colostomy bag. If respondent replies “Sometimes,” code 18 as “Yes” and 18a as “Sometimes”.

18a. How often are you unable to use the bathroom when you need to? Would you say only sometimes or most of the time?

SOMETIMES..... 01
MOST OF THE TIME 02
DON'T KNOW DK
REFUSED R

18b. Is this because there is no one there to help you?

PROBE: Please include any help received by another person, including cueing or standby assistance.

YES 01
NO 02
DON'T KNOW DK
REFUSED R

Note that in this section questions about “help” refers to help with personal care, not monetary assistance and “cueing or standby” means reminders or staying nearby in case you need help.

19. **[AFTER TRANSITION ONLY]** Have you ever talked with a case manager or support coordinator about any special equipment or changes to your home that might make your life easier?

PROBE: Equipment means things like wheelchairs, canes, vans with lifts, and automatic door opener.

YES 01
NO 02 ➔ **GO TO QUESTION 20**
DON'T KNOW DK ➔ **GO TO QUESTION 20**
NOT APPLICABLE N/A ➔ **GO TO QUESTION 20**
REFUSED R ➔ **GO TO QUESTION 20**

This question is not asked at baseline.

19a. **[AFTER TRANSITION ONLY]** What equipment or changes did you talk about?

DON'T KNOW DK
REFUSED R

This question is not asked at baseline.

19b. **[AFTER TRANSITION ONLY]** Did you get the equipment or make the changes you needed?

- YES 01
- NO 02
- IN PROCESS 03
- DON'T KNOW DK
- REFUSED R

This question is not asked at baseline.

20. **[AFTER TRANSITION ONLY]** Please think about all the help you received during the last week *around the house* like cooking or cleaning. Do you need more help with things around the house than you are now receiving?

- YES 01
- NO 02
- DON'T KNOW DK
- REFUSED R

This question is not asked at baseline. "Help" refers to both paid help (paid for by either the respondent or others) and unpaid help by friends and family.

21. **[AFTER TRANSITION ONLY]** During the last week, did any family member or friends help you with things around the house?

- YES 01
- NO 02 ➔ **GO TO QUESTION 22**
- DON'T KNOW D ➔ **GO TO QUESTION 22**
- REFUSED R ➔ **GO TO QUESTION 22**

This question is not asked at baseline.

21a. **[AFTER TRANSITION ONLY]** Please think about all the family members and friends who help you. About how many hours did they spend helping you yesterday?

PROBE: Your best estimate is fine.

INTERVIEWER: IF LESS THAN ONE HOUR, ENTER 1 HOUR.

[_____] Hours

- DON'T KNOW DK
- REFUSED R

This question is not asked at baseline. Q.21 By "help" we mean family members and friends who provided help themselves, not those who paid someone else to provide assistance. Friends can include neighbors. "Things around the house" refers to tasks such as cooking, cleaning, laundry, etc.

MODULE 4: RESPECT AND DIGNITY

Note: If Q14 = No, DK or R → **GO TO QUESTION 27**

This module is skipped if the respondent receives no help (based on Q14).

INTERVIEWER: FOR QUESTIONS IN THIS MODULE, REFER TO YOUR STATE'S POLICY ON REPORTING ANY SUSPECTED INCIDENTS OF ABUSE AND NEGLECT. FOR THIS SURVEY, RECORD ONLY REPORTS OF CURRENT ABUSE.

22. You said that you have people who help you. Do the people who help you treat you the way you want them to?

YES 01 → **GO TO QUESTION 23**
NO 02
DON'T KNOW DK → **GO TO QUESTION 23**
REFUSED R → **GO TO QUESTION 23**

"Treat you the way you want them to" means being treated respectfully. If respondent replies "Sometimes," code 22 as "Yes" and 22a as "Sometimes".

- 22a. How often do they not treat you the way you want them to? Would you say only sometimes or most of the time?

SOMETIMES..... 01
MOST OF THE TIME 02
DON'T KNOW DK
REFUSED R

23. Do the people who help you listen carefully to what you ask them to do?

YES 01 → **GO TO QUESTION 24**
NO 02
DON'T KNOW DK → **GO TO QUESTION 24**
REFUSED R → **GO TO QUESTION 24**

If respondent replies "Sometimes," code 23 as "Yes" and 23a as "Sometimes".

- 23a. How often do they not listen to you? Would you say only sometimes or most of the time?

SOMETIMES..... 01
MOST OF THE TIME 02
DON'T KNOW DK
REFUSED R

24. **[Optional]** Have you ever been physically hurt by any of the people who help you now?

PROBE: Physically hurt means someone could have pushed, kicked, or slapped you.

- YES 01
- NO 02 ➔ **GO TO QUESTION 25**
- DON'T KNOW DK ➔ **GO TO QUESTION 25**
- REFUSED R ➔ **GO TO QUESTION 25**

Each state will determine whether or not to include this series of questions (Q24 – Q26a). If included, interviewers may need to report incidences of abuse as required by law.

24a. **[Optional]** What happened when the people who help you now physically hurt you?

- DON'T KNOW DK
- REFUSED R

24b. **[Optional]** How many times have you been physically hurt by the people who help you now?

PROBE: Your best guess is fine.

[_____] TIMES

- DON'T KNOW DK
- REFUSED R

25. **[Optional]** Are any of the people who help you now mean to you or do they yell at you?

PROBE: Do they treat you in a way that makes you feel bad or do they hurt your feelings?

- YES 01
- NO 02 ➔ **GO TO QUESTION 26**
- DON'T KNOW DK ➔ **GO TO QUESTION 26**
- REFUSED R ➔ **GO TO QUESTION 26**

25a. **[Optional]** How often are they mean to you? Would you say only sometimes or most of the time?

- SOMETIMES..... 01
- MOST OF THE TIME 02
- DON'T KNOW DK
- REFUSED R

26. **[Optional]** Have any of the people who help you now ever taken your money or things without asking first?

- YES 01
- NO 02 ➔ **GO TO QUESTION 27**
- DON'T KNOW DK ➔ **GO TO QUESTION 27**
- REFUSED R ➔ **GO TO QUESTION 27**

This question asks if the people who currently help the respondent have ever stolen from him or her or borrowed something without asking.

26a. **[Optional]** How many times have they taken your money or things without asking first?

PROBE: Your best guess is fine.

[_____] TIMES

- DON'T KNOW DK
- REFUSED R

MODULE 5: COMMUNITY INTEGRATION AND INCLUSION

27. I'd like to ask you a few questions about things you do. Can you see your friends and family when you want to see them?

INTERVIEWER: CODE "YES" IF RESPONDENT INDICATES THAT THEY HAVE EITHER GONE TO SEE FRIENDS OR FAMILY OR THAT FRIENDS AND FAMILY HAVE COME TO VISIT THEM.

- YES 01
- NO 02 ➔ **GO TO QUESTION 28**
- DON'T KNOW DK ➔ **GO TO QUESTION 28**
- REFUSED R ➔ **GO TO QUESTION 28**

This question refers to either the respondent visiting friends and family and the respondent's family visiting him/her at their place of residence.

27a. How often do you see your friends and family when you want to see them? Would you say only sometimes or most of the time?

- SOMETIMES 01
- MOST OF THE TIME 02
- DON'T KNOW DK
- REFUSED R

28. Can you get to the places you need to go, like work, shopping, or the doctor's office?

- YES 01
- NO 02 ➔ **GO TO QUESTION 29**
- DON'T KNOW DK ➔ **GO TO QUESTION 29**
- REFUSED R ➔ **GO TO QUESTION 29**

This question refers to problems the respondent may have getting transportation to these places or personal assistance needed. People who have trouble getting out due to health should answer "no".

28a. How often do you get to the places you need to go, like work, shopping, or the doctor's office? Would you say only sometimes or most of the time?

- SOMETIMES..... 01
- MOST OF THE TIME 02
- DON'T KNOW DK
- REFUSED R

29. Is there anything you want to do outside [the facility/your home] that you can't do now?

- YES 01
- NO 02 ➔ **GO TO QUESTION 30**
- DON'T KNOW DK ➔ **GO TO QUESTION 30**
- REFUSED R ➔ **GO TO QUESTION 30**

29a. What would you like to do that you don't do now?

- DON'T KNOW DK
- REFUSED R

29b. What do you need to do these things?

- DON'T KNOW DK
- REFUSED R

30. When you go out, can you go by yourself or do you need help?

- GO OUT INDEPENDENTLY 01 ➔ **GO TO QUESTION 31**
- NEED HELP 02
- DON'T KNOW DK ➔ **GO TO QUESTION 31**
- REFUSED R ➔ **GO TO QUESTION 31**

"Help" means personal assistance with walking or driving or other assistance to go out.

30a. Please think about *all* the help you received during the last week with *getting around the community*, such as shopping and going to a doctor's appointment, do you need *more* help getting around than you are receiving?

- YES 01
- NO 02
- DON'T KNOW DK
- REFUSED R

Help refers to transportation and personal assistance someone needs to use transportation, not help with personal assistance due to a health issue.

31. **[AFTER TRANSITION ONLY]** Are you working for pay right now?

PROBE: Do you get any money for doing work?

- YES 01 ➔ **GO TO QUESTION 32**
- NO 02
- DON'T KNOW DK ➔ **GO TO QUESTION 32**
- REFUSED R ➔ **GO TO QUESTION 32**

This question is not asked at baseline.

31a. **[AFTER TRANSITION ONLY]** Do you want to work for pay?

- YES 01
- NO 02
- DON'T KNOW DK
- REFUSED R

This question is not asked at baseline.

32. **[AFTER TRANSITION ONLY]** Are you doing volunteer work or working without getting paid?

PROBE: Are you doing work but not getting any money for it?

- YES 01 ➔ **GO TO QUESTION 33**
- NO 02
- DON'T KNOW DK ➔ **GO TO QUESTION 33**
- REFUSED R ➔ **GO TO QUESTION 33**

This question is not asked at baseline.

32a. **[AFTER TRANSITION ONLY]** Would you like to do volunteer work or work without getting paid?

PROBE: Would you like to do work without getting paid for it?

- YES 01
- NO 02
- DON'T KNOW DK
- REFUSED R

This question is not asked at baseline.

33. I'd like to ask you a few questions about how you get around. Do you go out to do fun things in your community?

PROBE: These are things that you enjoy such as going to church, the movies or shopping.

- YES 01
- NO 02
- DON'T KNOW DK
- REFUSED R

34. When you want to go somewhere, can you just go, do you have to make some arrangements, or do you have to plan many days ahead and ask people for help?

- DECIDE AND GO 01
- PLAN SOME 02
- PLAN MANY DAYS AHEAD 03
- DON'T KNOW DK
- REFUSED R
- N/A.....NA

This question refers to day trips only. Making some arrangements includes making phone calls to schedule paratransit or other transportation services such as a taxi that do not require several days notice.

35. Do you miss things or have to change plans because you don't have a way to get around easily?

PROBE: Do you have to miss things because it is hard for you to get there?

- YES 01
- NO 02
- SOMETIMES..... 03
- DON'T KNOW DK
- REFUSED R

This question is asking about transportation rather than personal health limitations.

36. Is there any medical care, such as a medical treatment or doctor's visits, which you have not received or could not get to within the past month?

PROBE: The medical care includes doctor visits or medical treatments that you may need.

YES 01
NO 02
DON'T KNOW DK
REFUSED R

This question refers to medical care received outside the home. The focus is on transportation and personal assistance someone needs to use transportation, not help with personal assistance due to a health issue.

MODULE 6: SATISFACTION

37. Taking everything into consideration, during the past week have you been happy or unhappy with the help you get with things around the house or getting around your community?

HAPPY 01 ➔ **GO TO QUESTION 37A**
UNHAPPY 02 ➔ **GO TO QUESTION 37B**
DON'T KNOW DK ➔ **GO TO QUESTION 38**
REFUSED R ➔ **GO TO QUESTION 38**

This question refers to help received either in the community or in the home.

- 37a. Would you say you are a little happy or very happy?

A LITTLE HAPPY 01 ➔ **GO TO QUESTION 38**
VERY HAPPY 02 ➔ **GO TO QUESTION 38**
DON'T KNOW DK ➔ **GO TO QUESTION 38**
REFUSED R ➔ **GO TO QUESTION 38**

- 37b. Would you say you are a little unhappy or very unhappy?

A LITTLE UNHAPPY 01
VERY UNHAPPY 02
DON'T KNOW DK
REFUSED R

38. Taking everything into consideration, during the past week have you been happy or unhappy with the way you live your life?

HAPPY 01 ➔ **GO TO QUESTION 38A**
UNHAPPY 02 ➔ **GO TO QUESTION 38B**
DON'T KNOW DK ➔ **GO TO QUESTION 39**
REFUSED R ➔ **GO TO QUESTION 39**

We are interested in whether the respondent is generally happy or unhappy right now.

38a. Would you say you are a little happy or very happy?

- A LITTLE HAPPY 01 ➔ **GO TO QUESTION 39**
- VERY HAPPY 02 ➔ **GO TO QUESTION 39**
- DON'T KNOW DK ➔ **GO TO QUESTION 39**
- REFUSED R ➔ **GO TO QUESTION 39**

38b. Would you say you are a little unhappy or very unhappy?

- A LITTLE UNHAPPY 01
- VERY UNHAPPY 02
- DON'T KNOW DK
- REFUSED R

MODULE 7: HEALTH STATUS

39. During the past week have you felt sad or blue?

- YES 01
- NO 02 ➔ **GO TO QUESTION 40**
- DON'T KNOW DK ➔ **GO TO QUESTION 40**
- REFUSED R ➔ **GO TO QUESTION 40**

If the respondent replies "Sometimes," code 39 as "Yes" and 39a as "Sometimes."

39a. How often have you felt sad and blue? Would you say only sometimes or most of the time?

- SOMETIMES 01
- MOST OF THE TIME 02
- DON'T KNOW DK
- REFUSED R

40. During the past week have you felt irritable?

PROBE: Irritable means grumpy or easily upset about things in your life.

- YES 01
- NO 02 ➔ **GO TO QUESTION 41**
- DON'T KNOW DK ➔ **GO TO QUESTION 41**
- REFUSED R ➔ **GO TO QUESTION 41**

If the respondent replies "Sometimes," code 40 as "Yes" and 40a as "Sometimes."

40a. How often have you felt irritable? Would you say only sometimes or most of the time?

PROBE: Irritable means grumpy or easily upset about things in your life.

- SOMETIMES..... 01
- MOST OF THE TIME 02
- DON'T KNOW DK
- REFUSED R

41. During the past week have you had aches and pains?

- YES 01
- NO 02 ➔ **GO TO QUESTION 42**
- DON'T KNOW DK ➔ **GO TO QUESTION 42**
- REFUSED R ➔ **GO TO QUESTION 42**

If the respondent replies "Sometimes," code 41 as "Yes" and 41a as "Sometimes."

41a. How often do you have aches and pain? Would you say only sometimes or most of the time?

- SOMETIMES..... 01
- MOST OF THE TIME 02
- DON'T KNOW DK
- REFUSED R

CLOSEOUT

42. Those are all the questions I have for you now. We would like to talk with you in about a year or so to find out how you are doing. In case we have trouble reaching you, what is the name, address, and phone number of a close relative or friend who is not living with you and is likely to know your location in the future? For example, a mother, father, brother, sister, aunt, uncle, or close friend.

- NO CONTACT AVAILABLE 01 ➔ **GO TO QUESTION 43**
- CONTACT AVAILABLE 02

Partial information for a contact is ok. Even a name may help locate the respondent for follow up interviews. Addresses can include intersections or nearby landmarks (e.g. across from the Piggly Wiggly on Route 1). Any information is better than no information. Verify spelling if possible.

If the interview was completed with a proxy, record the proxy's information here and note that the interview was completed with a proxy in Q43.

42a. Contact Name: _____

42b. Contact Street Address: _____

42c. Contact City: _____

42d. Contact State: _____

42e. Contact ZIP: _____

42f. Contact Phone: _____

43. *Interviewer: Did you complete the interview with the sample member alone, the sample member who was assisted by another, or with a proxy?*

SAMPLE MEMBER ALONE..... 01
SAMPLE MEMBER W/ ASSISTANCE 02
PROXY..... 03

45. *Interviewer: Record date the interview was completed:*

[] [] []
Month Day Year

➔ END INTERVIEW

APPENDIX B: MONEY FOLLOWS THE PERSON QUALITY OF LIFE SURVEY FREQUENTLY ASKED QUESTIONS

What is this study about?

The evaluation of the *Money Follows the Person* initiative is an important study sponsored by the U.S. Department of Health and Human Services, Centers for Medicare and Medicaid Services, to collect information from Medicaid beneficiaries transitioning out of institutional care. The study is being conducted to help CMS and your state evaluate how well the Money Follows the Person initiative is meeting the needs of beneficiaries like yourself. I will not ask for a donation or try to sell you anything.

What kinds of questions will you ask me?

The questions relate to your quality of life, including questions about your housing, access to care, community involvement, and your health. Your answers will help CMS identify ways to better serve beneficiaries such as yourself.

Why did you choose me?

We are interviewing all MFP participants and your name was on a list of MFP participants in your state.

Will my answers be confidential?

Protecting people's privacy is one of our major concerns. Your answers will be used only for research and evaluation of this program. Further, your answers will be combined with the answers of others and reported in such a way that no single individual could ever be identified. However, I may be required to report any instances of abuse or neglect that you tell me about.

Am I required to participate?

Your participation is completely voluntary and you may refuse to answer any question you don't want to answer. Once we start the interview, we can stop at any time.

It may be difficult for me to be interviewed. Can I still participate?

We can make special arrangements for you to participate. We can conduct the interview in Spanish or provide an interpreter for another language if necessary. If needed, someone can help you answer the questions or we can conduct the interview with a family member or other representative who answers on your behalf. Your participation is important to us. We will work with you to make sure your experiences and opinions are included in the study.

Why should I participate?

It is important for us to hear from you so that CMS and the state can monitor your well-being and identify ways to better serve people like you. We hope that you will decide to help us. This is your chance to tell us what you think and make your voice heard.

How long will this take?

The interview will take about 15 minutes to complete. We can schedule the interview at a time convenient for you.

I've never been interviewed before and don't think I'll like it

There are no right or wrong answers to these questions. Your answers are extremely important and your participation is needed to make this study a success. I think you will find the questions in this survey interesting. Let's start and you will see.

I'm too busy

I understand that your time is limited, but your participation is very important to helping CMS and the state understand how its programs are doing. Let's start now and see how far we get. We can reschedule to finish the rest of the survey anytime that is convenient for you.

I don't like (government) surveys

This is a very important survey for Medicaid beneficiaries. CMS and the state want to learn about the experiences and needs of beneficiaries in order to learn how their programs are doing. The survey will help CMS and the state make their programs more effective and help them serve people better.

APPENDIX C: EXAMPLE CONFIDENTIALITY PLEDGE

CONFIDENTIALITY PLEDGE

I understand that the names, and any other identifying facts or information, of individuals, businesses, organizations, and families participating in projects conducted by _____ or its subsidiaries are confidential information. I agree that I will not reveal such confidential information, regardless of how or where I acquired it, to any person unless such person has been authorized by the cognizant _____ Project Director to have access to the information.

I further understand that the unauthorized access to, use, or disclosure of any confidential information is a breach of the terms of my employment, or my consultant agreement, with _____ and may subject me to court action by any interested party or to other sanctions by _____. I acknowledge that this agreement shall continue to bind me even after the project(s) is (are) completed and/or even though my employment or my consultant agreement with _____ has terminated.

Other than in the course of my authorized employment or my consultant agreement, I further agree that I will not use, nor facilitate the use by any third party, in any way any information deemed confidential by the terms of any contract or other written agreement between _____ and any other organization, except by written authorization by both parties. It is my understanding that _____ and the contracting organization(s) have the exclusive right to all information acquired or developed under such a contract or other written agreement. I acknowledge that I acquire no right, title, or interest in and to any data or information to which I have access by reason of my employment or my consultant agreement and that I may not remove such data from my assigned work location without prior authorization.

I agree to promptly notify the cognizant _____ Project Director of any unauthorized disclosure, use, or alteration of confidential information that I observe.

Nothing herein shall be construed to prevent divulgence of information to any court or governmental agency, provided such divulgence is required by law. However, if I am subpoenaed, or if I have reason to believe that I may be called upon to make such divulgence, I agree to notify the _____ Project Director promptly in writing and, upon his request, to cooperate in all lawful efforts to resist such divulgence.

Name: _____

Signature: _____

Date: _____