



**CONFIDENTIALITY STATEMENT
MONEY FOLLOWS THE PERSON (MFP) DEMONSTRATION
QUALITY OF LIFE SURVEY**

I understand that the names, and any other identifying facts or information, of individuals and families participating in the Quality of Life Survey 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 Money Follows the Person Demonstration Project Director to have access to the information.

I acknowledge that this agreement shall continue to bind me even after the project is completed.

I acknowledge that I acquire no right, title, or interest in and to any data or information to which I have access.

I agree to promptly notify the Money Follows the Person Demonstration Project Director of any unauthorized disclosure, use, or alteration of confidential information that I observe.

Name: _____

Signature: _____ Date: _____



MONEY FOLLOWS THE PERSON QUALITY OF LIFE SURVEY

The Money Follows the Person Quality of Life Survey (QoL) was designed to measure quality of life in seven domains: living situation, choice and control, access to personal care, respect/dignity, community integration/inclusion, overall life satisfaction, and health status. The target population for the survey includes people with disabilities and long-term illnesses who are transitioning from institutionalized care to a care setting in the community. The survey is to be administered to all participants at three points in time—just prior to transition, about 11 months after transition, and about 24 months after transition.

The QoL takes approximately 15 to 20 minutes to complete. A few questions are asked only before or after the transition, although most are asked at all three interviews. The survey is intended to be administered by an interviewer, in person, and in a private setting (e.g., an office in a nursing facility). Depending on the individual circumstances and the abilities of the participant, however, a proxy respondent or an assisted interview may be necessary. A proxy respondent is a person who answers the survey questions on the participant's behalf. In an assisted interview, a third person is present to help the participant answer questions. This survey also has been translated into Spanish.

The development of the QoL survey was funded by the Centers for Medicare and Medicaid Services (CMS) under contract HHSM-500-2005-00025I (0002). The majority of questions are based on the Participant Experience Survey (Version 1.0 of Mental Retardation/Developmental Disabilities 2003, MEDSTAT Group, Inc.), although a few items are drawn from other instruments (ASK ME!, Cash and Counseling, National Core Indicator Survey (NCI), Quality of Life Enjoyment and Satisfaction Questionnaire—Short Form, and the Nursing Home Consumer Assessment of Health Plans Survey (NH CAHPS)).

The survey is free and available for use by the public; no one can use the survey for monetary purposes. Users are expected to include the following citation:

Sloan, Matt, and Carol Irvin. Money Follows the Person Quality of Life Survey. Prepared for Centers for Medicare and Medicaid Services (CMS). Washington, D.C.: Mathematica Policy Research, Inc., 2007.

MFP QUALITY OF LIFE SURVEY

RESPONDENT INFORMATION

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:

[_____] [_____] [_____]
Month Day Year

➔ GO TO END

Interviewer Name: _____

Survey Type

- Baseline
- First Follow-up (11-month)
- Second Follow-up (24-month)

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 **New York**. The Quality of Life Survey, sponsored by the Centers for Medicare & Medicaid Services (CMS) and the state of **New York**, 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 **New York** 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.

[_____]
Years

[_____]
Months

➔ **GO TO QUESTION 2**

DON'T KNOW DK
REFUSED R

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 sample member live in a group home or nursing facility?*

Yes 01
No 02
Don't Know DK
Refused R

3. Do you like where you live?

- Yes 01
- No 02
- Sometimes 03
- DON'T KNOW DK
- REFUSED R

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

- Yes 01
- No 02
- DON'T KNOW DK
- REFUSED R

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

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

MODULE 2: CHOICE AND CONTROL

7. Can you go to bed when you want?

- Yes 01
- No 02
- Sometimes 03
- DON'T KNOW DK
- REFUSED R

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

10. Can you choose the foods that you eat?

- Yes 01
- No 02
- Sometimes 03
- DON'T KNOW DK
- REFUSED R

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

- Yes 01
- No 02
- Sometimes 03
- No access to telephone..... 04
- DON'T KNOW DK
- REFUSED R

12. Can you watch TV when you want to?

- Yes 01
- No 02
- Sometimes 03
- No access to TV 04
- DON'T KNOW DK
- REFUSED R

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
 - DON'T KNOW DK
 - REFUSED R
- ➔ GO TO QUESTION 14
➔ GO TO QUESTION 14
➔ GO TO QUESTION 14

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

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**

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**

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

- Yes 01
- No..... 02
- Don't Know DK
- Refused..... R

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**

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

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**

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

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**

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

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**

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

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**

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

DON'T KNOW DK
REFUSED R

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

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

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
DON'T KNOW DK
REFUSED R

➔ GO TO QUESTION 22
➔ GO TO QUESTION 22
➔ GO TO QUESTION 22

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

MODULE 4: RESPECT AND DIGNITY

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

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**

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**

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. 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

24a. What happened when the people who help you now physically hurt you?

- DON'T KNOW DK
- REFUSED R

24b. 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. 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. 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. 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

26a. 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**

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**

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**

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

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**

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

- Yes 01
- No 02
- DON'T KNOW DK
- REFUSED R

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**

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

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

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

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

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

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**

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**

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**

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**

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 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

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 with Assistance 02
Proxy 03

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

[_____] [_____] [_____]
Month Day Year

➔ END INTERVIEW