



Quality of Life Survey

Respondent Information

Respondent Name:

Respondent Street Address:

Respondent City:

Respondent State:

Respondent ZIP Code:

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

Social Security Number:

Date of death:

NOTE: If respondent has died, go to last page.

Please select the correct option to identify this QOL:

Baseline

First follow up

Second follow up

****Be sure to fill in the blanks below****

Hello, my name is _____ and I am from (LO/facility abbreviation) _____. I'm here to ask for your help with an important study of Medicaid beneficiaries in the state of California. The Quality of Life Survey, sponsored by the Centers for Medicare & Medicaid Services (CMS) and the state of California, 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 California 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 I will record "REFUSED" 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

Answer "ALL" parts of "EACH" question unless directed to go on to the next question indicated at the right of each answer.

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 _____ Don't know _____ Refused _____

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

2. Interviewer: Does sample member live in a group home or a nursing facility?

3. Do you like where you live?

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

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

If "yes"	go to question 6
If "no"	go to question 5a
If "don't know"	go to question 6
If "refused"	go to question 6

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

MODULE 2: CHOICE AND CONTROL

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

7. Can you go to bed when you want?

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

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

10. Can you choose the foods that you eat?

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

12. Can you watch TV when you want to?

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?

- | | |
|-----------------|--------------------|
| If "yes" | go to question 13a |
| If "no" | go to question 14 |
| If "don't know" | go to question 14 |
| If "Refused" | go to question 14 |

13a. [AFTER TRANSITION ONLY]

In the last 12 months, what help or equipment did you buy with this allowance?

Modified home

Modified car

Special equipment

Paid help

Transportation

Household goods

Security deposit

Other

Don't know

Refused

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.

If "yes"	go to 14a and 14b
If "no"	go to question 15
If "don't know"	go to question 15
If "refused"	go to question 15

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

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

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

If "yes"	go to questions 15a and 15b
If "no"	go to question 16
If "don't know"	go to question 16
If "refused"	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?

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.

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

If "yes"	go to questions 16a and 16b
If "no"	go to question 17
If "don't know"	go to question 17
If "refused"	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?

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.

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

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

If "yes"	go to questions 17a and 17b
If "no"	go to question 18
If "don't know"	go to question 18
If "refused"	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?

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

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

If "yes"	go to questions 18a and 18b
If "no"	go to question 19
If "don't know"	go to question 19
If "refused"	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?

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

Probe: Please include any help received by another person, including queing or standby assistance.

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.

If "yes"	go to questions 19a and 19b
If "no"	go to question 20
If "don't know"	go to question 20
If "not applicable"	go to question 20
If "refused"	go to question 20

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

Don't know

Refused

19b. [AFTER TRANSITION ONLY]

Did you get the equipment or make the changes you needed?

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?

21. [AFTER TRANSITION ONLY]

During the last week, did any family member or friends help you with things around the house?

- If "yes" go to question 21a.
- If "no" go to question 22
- If "don't know" go to question 22
- If "refused" 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?

Hours
Don't know
Refused

Probe: Your best estimate is fine.

Interviewer: If less than one hour, enter 1 hour.

MODULE 4: RESPECT AND DIGNITY

Note: If the response to question 14 was No, Don't know, or refused, begin at question 27. If the answer was Yes, begin at question 22.

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?

If "yes"	go to question 23
If "no"	go to question 22a
If "don't know"	go to question 23
If "refused"	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?

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

If "yes"	go to question 24
If "no"	go to question 23a
If "don't know"	go to question 24
If "refused"	go to question 24

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

Although these questions are optional, ask all parts if the participant chooses to respond.

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.

If "yes"	go to questions 24a and 24b
If "no"	go to question 25
If "don't know"	go to question 25
If "refused"	go to question 25

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

Don't know
Refused

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

of Times
Don't know
Refused

Probe: Your best guess is fine.

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?

If "yes"	go to question 25a
If "no"	go to question 26
If "don't know"	go to question 26
If "refused"	go to question 26

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

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

If "yes"	go to question 26a
If "no"	go to question 27
If "don't know"	go to question 27
If "refused"	go to question 27

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

of Times
Don't know
Refused

Probe: Your best guess is fine.

MODULE 5: COMMUNITY INTEGRATION AND INCLUSION

Please answer all parts of the following questions unless instructed to go to the next one.

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.

If "yes"	go to question 27a
If "no"	go to question 28
If "don't know"	go to question 28
If "refused"	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?

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

- If "yes" go to question 28a
- If "no" go to question 29
- If "don't know" go to question 29
- If "refused" 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?

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

- If "yes" go to questions 29a and 29b
- If "no" go to question 30
- if "don't know" go to question 30
- If "refused" go to question 30

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

Don't know
Refused

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

Don't know
Refused

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

- If "go out independently" go to question 31
- If "need help" go to question 30a
- If "don't know" go to question 31
- If "refused" 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?

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

Probe: Do you get any money for doing work?

- If "yes" go to question 32
- If "no" go to question 31a
- If "don't know" go to question 32
- If "refused" go to question 32

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

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?

- If "yes" go to question 33
- If "no" go to question 32a
- If "don't know" go to question 33
- If "refused" 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?

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?

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?

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?

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.

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?

If "happy"	go to question 37a
If "unhappy"	go to question 37b
If "don't know"	go to question 38
If "refused"	go to question 38

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

Go to question 38

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

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

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

Go to question 39

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

MODULE 7: HEALTH STATUS

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

If "yes"	go to question 39a
If "no"	go to question 40
If "don't know"	go to question 40
If "refused"	go to question 40

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

40. During the past week have you felt irritable?

If "yes"	go to question 40a
If "no"	go to question 41
If "don't know"	go to question 41
If "refused"	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.

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

If "yes"	go to question 41a
If "no"	go to question 42
If "don't know"	go to question 42
If "refused"	go to question 42

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

CLOSEOUT

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.

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?

44. Interviewer: Record date the interview was completed:

Add additional comments here: