



PARTICIPANT EXPERIENCE SURVEY



ELDERLY/DISABLED (E/D) VERSION

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A Technical Assistance Tool for States

DEVELOPED BY
The MEDSTAT Group, Inc.
FOR THE
Centers for Medicare & Medicaid Services
AN AGENCY OF
The Department of Health & Human Services
CONTRACT #500-96-0006 T.O. #2

THOMSON

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CENTERS for MEDICARE & MEDICAID SERVICES

Survey Instructions

- * Make sure you have the respondent's face sheet available when conducting the interview, since you are directed to refer to it at various points during the interview.
- * Text read to the respondent is in mixed case. Text just for you is in all CAPS (with the exception of the Interviewer Comments Section).
- * Please answer every question by checking **one** box, unless instructed to "Check all that apply," in which case multiple boxes may be checked.
- * Do not leave any questions blank. If the respondent does not answer an item, check the box for "No Response."
- * Record **only** responses provided by the respondent.
- * Some questions require you to write in the respondent's answer, like the example below. Please record the respondent's verbatim response as best you can.

66. What kind of work do you do? (SPECIFY)

- * Some questions are skipped over in this survey. When this is necessary, an arrow directs you to the next question to be asked, like the example below.

- | | | |
|---|--------------------------|--------------------------------|
| 1 | <input type="checkbox"/> | YES |
| 2 | <input type="checkbox"/> | NO →Skip to Q.15 |
| 7 | <input type="checkbox"/> | UNSURE →Skip to Q.17 |
| 8 | <input type="checkbox"/> | UNCLEAR RESPONSE →Skip to Q.17 |
| 9 | <input type="checkbox"/> | NO RESPONSE →Skip to Q.17 |

- * If there is **no** arrow next to a response category, like the "YES" response above, please continue with the very next item in the sequence.
- * Some items have instruction boxes, like the example below. These boxes are intended to provide you with additional information or instructions. Do not read these to the respondent.

Refer to the face sheet for the case manager's or support coordinator's name.

- | | | |
|---|-------------------------------------|------------------------------------------------|
| 1 | <input type="checkbox"/> | NAMES CASE MANAGER/SUPPORT COORDINATOR |
| 2 | <input checked="" type="checkbox"/> | DOES NOT NAME CASE MANAGER/SUPPORT COORDINATOR |
| 8 | <input type="checkbox"/> | UNCLEAR RESPONSE |
| 9 | <input type="checkbox"/> | NO RESPONSE |

PARTICIPANT EXPERIENCE SURVEY E/D

Hello, my name is _____ and I am from _____. How are you today? Thank you again for letting me come talk with you. I am very interested in hearing about your life and how satisfied you are with the assistance you get from the people paid to help you. 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. Are you ready to begin?



Case ID#: _____

Interviewer Name: _____

Date: _____

A. Access to Care

The first set of questions I am going to ask you have to do with some everyday activities, like getting dressed and taking a bath. Some people have no problem doing these things by themselves. Other people need somebody to help them.

1. Is there any special help that you need to take a bath or shower?

If respondent indicates any help is received from another person, including cueing or standby assistance, check "Needs Help."

REVIEW RESPONSE ABOVE AND THEN CODE AS APPROPRIATE BELOW.

- 1 NEEDS HELP FROM ANOTHER PERSON
- 2 DOES NOT NEED HELP FROM ANOTHER PERSON →Skip to Q.4
- 8 UNCLEAR RESPONSE →Skip to Q.4
- 9 NO RESPONSE →Skip to Q.4

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

- 1 YES
- 2 NO →Skip to Q.4
- 7 UNSURE →Skip to Q.4
- 8 UNCLEAR RESPONSE →Skip to Q.4
- 9 NO RESPONSE →Skip to Q.4

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

- 1 YES
- 2 NO
- 7 UNSURE
- 8 UNCLEAR RESPONSE
- 9 NO RESPONSE

4. Is there any special help that you need to get dressed? (SPECIFY)

If respondent indicates any help is received from another person, including cueing or standby assistance, check "Needs Help."

REVIEW RESPONSE ABOVE AND THEN CODE AS APPROPRIATE BELOW.

- 1 NEEDS HELP FROM ANOTHER PERSON
- 2 DOES NOT NEED HELP FROM ANOTHER PERSON →Skip to Q.7
- 8 UNCLEAR RESPONSE →Skip to Q.7
- 9 NO RESPONSE →Skip to Q.7

5. Do you ever go without getting dressed when you need to?

- 1 YES
- 2 NO →Skip to Q.7
- 7 UNSURE →Skip to Q.7
- 8 UNCLEAR RESPONSE →Skip to Q.7
- 9 NO RESPONSE →Skip to Q.7

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

- 1 YES
- 2 NO
- 7 UNSURE
- 8 UNCLEAR RESPONSE
- 9 NO RESPONSE



7. Is there any special help that you need to get out of bed?

If respondent indicates any help is received from another person, including cueing or standby assistance, check "Needs Help."

REVIEW RESPONSE ABOVE AND THEN CODE AS APPROPRIATE BELOW.

- 1 NEEDS HELP FROM ANOTHER PERSON
- 2 DOES NOT NEED HELP FROM ANOTHER PERSON →Skip to Q.10
- 8 UNCLEAR RESPONSE →Skip to Q.10
- 9 NO RESPONSE →Skip to Q.10

8. Do you ever go without getting out of bed when you need to?

- 1 YES
- 2 NO →Skip to Q.10
- 7 UNSURE →Skip to Q.10
- 8 UNCLEAR RESPONSE →Skip to Q.10
- 9 NO RESPONSE →Skip to Q.10

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

- 1 YES
- 2 NO
- 7 UNSURE
- 8 UNCLEAR RESPONSE
- 9 NO RESPONSE

10. Is there any special help that you need to eat?

If respondent indicates any help is received from another person, including cueing or standby assistance, check "Needs Help."

REVIEW RESPONSE ABOVE AND THEN CODE AS APPROPRIATE BELOW.

- 1 NEEDS HELP FROM ANOTHER PERSON
- 2 DOES NOT NEED HELP FROM ANOTHER PERSON →Skip to Q.13
- 8 UNCLEAR RESPONSE →Skip to Q.13
- 9 NO RESPONSE →Skip to Q.13

11. Do you ever go without eating when you need to?

- 1 YES
- 2 NO →Skip to Q.13
- 7 UNSURE →Skip to Q.13
- 8 UNCLEAR RESPONSE →Skip to Q.13
- 9 NO RESPONSE →Skip to Q.13

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

- 1 YES
- 2 NO
- 7 UNSURE
- 8 UNCLEAR RESPONSE
- 9 NO RESPONSE



13. Is there any special help that you need to make your meals?

If respondent indicates any help is received from another person, including cueing or standby assistance, check "Needs Help."

REVIEW RESPONSE ABOVE AND THEN CODE AS APPROPRIATE BELOW.

- 1 NEEDS HELP FROM ANOTHER PERSON
2 DOES NOT NEED HELP FROM ANOTHER PERSON →Skip to Q.16
8 UNCLEAR RESPONSE →Skip to Q.16
9 NO RESPONSE →Skip to Q.16
95 NOT APPLICABLE , TUBE FED →Skip to Q.19

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

- 1 YES
2 NO →Skip to Q.16
7 UNSURE →Skip to Q.16
8 UNCLEAR RESPONSE →Skip to Q.16
9 NO RESPONSE →Skip to Q.16

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

- 1 YES
2 NO
7 UNSURE
8 UNCLEAR RESPONSE
9 NO RESPONSE

16. Is there any special help that you need to get groceries?

If respondent indicates any help is received from another person, including cueing or standby assistance, check "Needs Help."

REVIEW RESPONSE ABOVE AND THEN CODE AS APPROPRIATE BELOW.

- 1 NEEDS HELP FROM ANOTHER PERSON
- 2 DOES NOT NEED HELP FROM ANOTHER PERSON →Skip to Q.19
- 8 UNCLEAR RESPONSE →Skip to Q.19
- 9 NO RESPONSE →Skip to Q.19
- 95 NOT APPLICABLE, TUBE FED→Skip to Q.19

17. Are you sometimes unable to get groceries when you need them?

- 1 YES
- 2 NO →Skip to Q.19
- 7 UNSURE →Skip to Q.19
- 8 UNCLEAR RESPONSE →Skip to Q.19
- 9 NO RESPONSE →Skip to Q.19

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

- 1 YES
- 2 NO
- 7 UNSURE
- 8 UNCLEAR RESPONSE
- 9 NO RESPONSE



19. Is there any special help that you need to do housework – things like straightening up or doing dishes?

If respondent indicates any help is received from another person, including cueing or standby assistance, check "Needs Help."

REVIEW RESPONSE ABOVE AND THEN CODE AS APPROPRIATE BELOW.

- 1 NEEDS HELP FROM ANOTHER PERSON
- 2 DOES NOT NEED HELP FROM ANOTHER PERSON →Skip to Q.22
- 8 UNCLEAR RESPONSE →Skip to Q.22
- 9 NO RESPONSE →Skip to Q.22

20. Does the housework not get done sometimes?

- 1 YES
- 2 NO →Skip to Q.22
- 7 UNSURE →Skip to Q.22
- 8 UNCLEAR RESPONSE →Skip to Q.22
- 9 NO RESPONSE →Skip to Q.22

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

- 1 YES
- 2 NO
- 7 UNSURE
- 8 UNCLEAR RESPONSE
- 9 NO RESPONSE

22. Is there any special help that you need to do laundry?

If respondent indicates any help is received from another person, including cueing or standby assistance, check "Needs Help."

REVIEW RESPONSE ABOVE AND THEN CODE AS APPROPRIATE BELOW.

- 1 NEEDS HELP FROM ANOTHER PERSON
- 2 DOES NOT NEED HELP FROM ANOTHER PERSON →Skip to Q.25
- 8 UNCLEAR RESPONSE →Skip to Q.25
- 9 NO RESPONSE →Skip to Q.25

23. Does the laundry not get done sometimes?

- 1 YES
- 2 NO →Skip to Q.25
- 7 UNSURE →Skip to Q.25
- 8 UNCLEAR RESPONSE →Skip to Q.25
- 9 NO RESPONSE →Skip to Q.25

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

- 1 YES
- 2 NO
- 7 UNSURE
- 8 UNCLEAR RESPONSE
- 9 NO RESPONSE

25. Can you always get to the places you need to go, like work, shopping, the doctor's office, or a friend's house?

- 1 YES
- 2 NO
- 7 UNSURE
- 8 UNCLEAR RESPONSE
- 9 NO RESPONSE



26. Is there any special help that you need to take medicine, such as someone to pour it or set up your pills?

If respondent indicates any help is received from another person, including cueing or standby assistance, check "Needs Help."

REVIEW RESPONSE ABOVE AND THEN CODE AS APPROPRIATE BELOW.

- 1 NEEDS HELP FROM ANOTHER PERSON
2 DOES NOT NEED HELP FROM ANOTHER PERSON →Skip to Q.29
8 UNCLEAR RESPONSE →Skip to Q.29
9 NO RESPONSE →Skip to Q.29

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

- 1 YES
2 NO →Skip to Q.29
7 UNSURE →Skip to Q.29
8 UNCLEAR RESPONSE →Skip to Q.29
9 NO RESPONSE →Skip to Q.29

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

- 1 YES
2 NO
7 UNSURE
8 UNCLEAR RESPONSE
9 NO RESPONSE

29. Is there any special help that you need to get to or use the bathroom?

If respondent indicates any help is received from another person, including cueing or standby assistance, check "Needs Help."

REVIEW RESPONSE ABOVE AND THEN CODE AS APPROPRIATE BELOW.

- 1 NEEDS HELP FROM ANOTHER PERSON
- 2 DOES NOT NEED HELP FROM ANOTHER PERSON →Skip to Q.32
- 8 UNCLEAR RESPONSE →Skip to Q.32
- 9 NO RESPONSE →Skip to Q.32

30. Are you ever unable to get to or use the bathroom when you need to?

- 1 YES
- 2 NO →Skip to Q.32
- 7 UNSURE →Skip to Q.32
- 8 UNCLEAR RESPONSE →Skip to Q.32
- 9 NO RESPONSE →Skip to Q.32

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

- 1 YES
- 2 NO
- 7 UNSURE
- 8 UNCLEAR RESPONSE
- 9 NO RESPONSE



32. Think about the people who are paid to help you with the everyday activities we have been discussing. Do they spend all the time with you that they are supposed to?

- 1 YES
- 2 NO
- 7 UNSURE
- 8 UNCLEAR RESPONSE
- 9 NO RESPONSE
- 95 NO HOME SUPPORT STAFF

33. Have you ever talked with your case manager or support coordinator about any special equipment, or changes to your home, that might make your life easier?

- 1 YES
- 2 NO →Skip to Q.36
- 7 UNSURE →Skip to Q.36
- 8 UNCLEAR RESPONSE →Skip to Q.36
- 9 NO RESPONSE →Skip to Q.36

34. What equipment or changes did you talk about? (SPECIFY)

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

- 1 YES
- 2 NO
- 3 IN PROCESS
- 7 UNSURE
- 8 UNCLEAR RESPONSE
- 9 NO RESPONSE

B. Choice and Control

These next few questions are about how much choice you have in the help you get, and the assistance you receive from your case manager or support coordinator.

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

*Include anyone
paid to provide
assistance in any
setting.*

- 1 YES →Skip to Q.38
- 2 NO
- 7 UNSURE
- 8 UNCLEAR RESPONSE →Skip to Q.38
- 9 NO RESPONSE →Skip to Q.38
- 95 NO PERSONAL CARE STAFF →Skip to Q.41

37. Would you like to help pick the people who are paid to help you?

- 1 YES
- 2 NO
- 7 UNSURE
- 8 UNCLEAR RESPONSE
- 9 NO RESPONSE

38. Did you know you can change the people who are paid to help you if you want to?

- 1 YES
- 2 NO
- 7 UNSURE
- 8 UNCLEAR RESPONSE
- 9 NO RESPONSE

39. Thinking again about the people who are paid to help you, do you tell them what to help you with?

- 1 YES →Skip to Q.41
- 2 NO
- 3 SOMETIMES →Skip to Q.41
- 7 UNSURE
- 8 UNCLEAR RESPONSE →Skip to Q.41
- 9 NO RESPONSE →Skip to Q.41

40. Would you like to tell them the things you want help with?

- 1 YES
- 2 NO
- 7 UNSURE
- 8 UNCLEAR RESPONSE
- 9 NO RESPONSE

41. If there is something wrong with the help you are getting, who do you talk with to get the problem fixed? (CHECK ALL THAT APPLY)

- 1 NO ONE
- 2 FAMILY/FRIEND
- 3 CASE MANAGER/SUPPORT COORDINATOR/OTHER STAFF
- 4 OTHER (SPECIFY) _____
- 7 UNSURE
- 8 UNCLEAR RESPONSE
- 9 NO RESPONSE

*Probe,
if necessary,
to place the
response in the
appropriate
category.*

42. Who is your case manager or support coordinator?

Refer to the face sheet for the case manager's or support coordinator's name.

- 1 NAMES CASE MANAGER/SUPPORT COORDINATOR
- 2 DOES NOT NAME CASE MANAGER/SUPPORT COORDINATOR
- 8 UNCLEAR RESPONSE
- 9 NO RESPONSE

43. Can you talk to your case manager or support coordinator when you need to?

- 1 YES
- 2 NO
- 3 SOMETIMES
- 7 UNSURE
- 8 UNCLEAR RESPONSE
- 9 NO RESPONSE
- 95 NOT APPLICABLE – HAVE NOT TRIED

44. Does your case manager or support coordinator help you when you ask for something?

- 1 YES
- 2 NO
- 3 SOMETIMES
- 7 UNSURE
- 8 UNCLEAR RESPONSE
- 9 NO RESPONSE
- 95 NOT APPLICABLE – HAVE NOT ASKED



C. Respect/Dignity

Now I would like to ask you about how you are treated by the people who are paid to help you. The next two questions are about people who come to your home.

45. Do the people paid to help you treat you respectfully in your home?

- 1 YES
- 2 NO
- 3 SOMETIMES
- 7 UNSURE
- 8 UNCLEAR RESPONSE
- 9 NO RESPONSE
- 95 NO STAFF IN HOME →Skip to Q.47

46. Do the people paid to help you listen carefully to what you ask them to do in your home?

- 1 YES
- 2 NO
- 3 SOMETIMES
- 7 UNSURE
- 8 UNCLEAR RESPONSE
- 9 NO RESPONSE

47. Have you ever been injured by any of the people paid to help you now?

- 1 YES
- 2 NO →Skip to Q.49
- 7 UNSURE →Skip to Q.49
- 8 UNCLEAR RESPONSE →Skip to Q.49
- 9 NO RESPONSE →Skip to Q.49
- 95 NOT APPLICABLE (DOES NOT INTERACT WITH ANY PAID STAFF)→Skip to Q.59

Reminder:
Refer to your state's policy on reporting for any suspected incidents of abuse or neglect. Record only reports of current abuse.

48. What happened? When? Would you like any help with this problem?

49. Are any of the people paid to help you now mean to you, or do they yell at you?

Reminder:
Refer to your state's policy on reporting for any suspected incidents of abuse or neglect. Record only reports of current abuse.

- 1 YES
- 2 NO →Skip to Q.51
- 3 SOMETIMES
- 7 UNSURE →Skip to Q.51
- 8 UNCLEAR RESPONSE →Skip to Q.51
- 9 NO RESPONSE →Skip to Q.51

50. What happens? Would you like any help with this problem?

51. Have any of the people paid to help you now ever taken your things without asking?

Reminder:
Refer to your state's policy on reporting for any suspected incidents of abuse or neglect. Record only reports of current abuse.

- 1 YES
- 2 NO →Skip to Q.53
- 7 UNSURE →Skip to Q.53
- 8 UNCLEAR RESPONSE →Skip to Q.53
- 9 NO RESPONSE →Skip to Q.53



52. What happened? When? Would you like any help with this problem?

53. Do you go to a day program outside your home?

- 1 YES
- 2 NO →Skip to Q.56
- 7 UNSURE →Skip to Q.56
- 8 UNCLEAR RESPONSE →Skip to Q.56
- 9 NO RESPONSE →Skip to Q.56

54. Do the people paid to help you at a day program outside your home treat you respectfully?

- 1 YES
- 2 NO
- 3 SOMETIMES
- 7 UNSURE
- 8 UNCLEAR RESPONSE
- 9 NO RESPONSE

Use specific information from the face sheet about services provided outside the home.

55. Do the people paid to help you at a day program outside your home listen carefully to what you ask them to do?

- 1 YES
- 2 NO
- 3 SOMETIMES
- 7 UNSURE
- 8 UNCLEAR RESPONSE
- 9 NO RESPONSE

Use specific information from the face sheet about services provided outside the home.

56. Do you ride a van or use other transportation services?

- 1 YES
- 2 NO →Skip to Q.59
- 7 UNSURE →Skip to Q.59
- 8 UNCLEAR RESPONSE →Skip to Q.59
- 9 NO RESPONSE →Skip to Q.59

57. Do the people paid to help you on the van or with other transportation treat you respectfully?

- 1 YES
- 2 NO
- 3 SOMETIMES
- 7 UNSURE
- 8 UNCLEAR RESPONSE
- 9 NO RESPONSE

Use specific information from the face sheet about services provided outside the home.

58. Do the people paid to help you on the van or with other transportation listen carefully to what you ask them to do?

- 1 YES
- 2 NO
- 3 SOMETIMES
- 7 UNSURE
- 8 UNCLEAR RESPONSE
- 9 NO RESPONSE

Use specific information from the face sheet about services provided outside the home.

D. Community Integration/Inclusion

The last few questions I'd like to ask you are about things you do in your community and the help you get to do these things.

59. Is there anything you want to do outside your home that you don't do now?

- 1 YES
- 2 NO →Skip to Q.61
- 7 UNSURE →Skip to Q.61
- 8 UNCLEAR RESPONSE →Skip to Q.61
- 9 NO RESPONSE →Skip to Q.61

60. What would you like to do? What do you need to make this happen? (SPECIFY)

61. Is there anything else you want to talk to me about?

BOX 1
IF RESPONDENT IS UNDER 65 YEARS OF AGE,
ASK Q.62
OTHERWISE END INTERVIEW.

The last few questions I'd like to ask you have to do with your work experiences.

62. Are you working right now?

- 1 YES
- 2 NO →Skip to Q.66
- 7 UNSURE →End of interview
- 8 UNCLEAR RESPONSE → End of interview
- 9 NO RESPONSE → End of interview

63. What kind of work do you do? (SPECIFY)

64. Did you help pick the job you have now?

- 1 YES
- 2 NO
- 7 UNSURE
- 8 UNCLEAR RESPONSE
- 9 NO RESPONSE



65. Do you like your job?

- 1 YES
- 2 NO
- 7 UNSURE
- 8 UNCLEAR RESPONSE
- 9 NO RESPONSE



→ End of interview

66. Do you want to work?

- 1 YES
- 2 NO
- 7 UNSURE
- 8 UNCLEAR RESPONSE
- 9 NO RESPONSE

Thank you for talking with me today. I really appreciate all your help. If you have other questions, here is information on how you can contact me. INFORMAL PARTING OF YOUR CHOICE – GOOD-BYE, TAKE CARE, HANDSHAKE, ETC.

