

NCI – AD

Consumer Survey

SERVICE SATISFACTION

Let's talk about the services and supports you are receiving... Let's start by talking about the people who help you arrange for services.

Q1. (I23) Do you know who your service coordinator *(can use state-specific term)* is? PROXY

- Yes
- No
- Not sure

If no or not sure, ask about "someone" instead of "service coordinator" in questions 2, 4, 5, 6.

Q2. (I27) When you need to talk about your services, can you get in contact with your service coordinator/someone quickly and often enough? PROXY

- Always
- Usually
- Sometimes
- Never
- Don't know
- N/A – never needs to talk about services or get in contact

If does not know who the service coordinator is and says something other than never or don't know to question 1, ask question 3:

Q3. Who is that person? _____

Q4. (I45) Does the service coordinator/that person/someone give you enough information to make informed decisions about your services? PROXY

- Always
- Usually
- Sometimes
- Never
- Don't know
- N/A

Q5. (I24) Do you feel that your service coordinator/that person/someone listens to you and knows about your goals and what you want?

- Always
- Usually
- Sometimes
- Never
- Don't know
- N/A

Q6. (I25) Does your service coordinator/that person/someone ask you whether you have any needs that are not being met? PROXY

- Always
- Usually
- Sometimes
- Never
- Don't know
- N/A

Now we are going to talk about your services in general...

Q7. (I23) If you have a question or a complaint about the services you are getting, do you know whom to call? PROXY

- Always
- Usually
- Sometimes
- Never
- Don't know
- N/A

Q8. (I50) Do you have access to information about your services and programs in the language you prefer? PROXY

- Always
- Usually
- Sometimes
- Never
- Don't know

Q9. (I30) Do the services you receive address what's important to you?

- Yes
- No
- Don't Know

Q10. (I19) Do you get all services that you need?

PROXY

- Always
- Usually
- Sometimes
- Never
- Don't know

If "always", skip question 11 and go on to question 12. If not "always", ask question 11:

Q11. (I19) What kind of services do you need (that you are not getting)? _____ PROXY

SELF-DIRECTION OF CARE

Q12. (I86) Has someone talked with you about the services available to you?

- Yes
- No
- Don't know

Q13. (I28) Were you able to participate in planning the services you receive?

- Yes, planned all services
- Yes, was involved in planning
- No
- Don't know

Q14. (I85) Do you feel that you are in charge of your services (for example, can you determine who helps you, what kind of services you get?)

- Yes
- No
- Don't know

If "yes", skip questions 15, 16 and 17 and go on to question 18.

Q15. (I84) Has anyone told you that you can be in charge of your services?

- Yes
- No
- Don't know

Q16. (I85) Would you like to be in charge of your services?

- Yes
- Some services
- No
- Don't know

If not "No", skip question 17 and go on to question 18.

Q17. (I85) Why not? _____

SUPPORT WORKERS

I would like to talk to you about support workers. Do you have people who provide care for you on a regular basis? If yes - now we want to talk to you about those people. *If no, skip questions 18 through 35 (mark N/A) and start at question 36.*

Q18. (I92) Who are the people who provide care for you the most/most often? (*Select one*) PROXY

- Unpaid relative
- Paid relative
- Unpaid friend
- Paid friend
- Unpaid volunteer
- Paid support worker who is not friend or relative
- N/A - no support workers

Q19. (I92) Who else provides care for you when you need help? (*MARK ALL THAT APPLY*) PROXY

- Unpaid relative
- Paid relative
- Unpaid friend
- Paid friend
- Unpaid volunteer
- Paid other support workers
- None
- N/A - no support workers

Q20. (I20) Do you like your support workers/the people who provide care for you?

- All support workers
- Most support workers
- Some support workers
- None of the support workers
- Don't know
- N/A - no support workers

Q21. (I20) Do you think your support workers have had enough training to work with you? PROXY

- All support workers
- Most, but not all support workers
- Some support workers, but not most
- None of the support workers – all need more training
- Don't know
- N/A - no support workers

Q22 (I20) Do your support workers change often? PROXY

- Yes
- No
- Don't Know
- N/A - no support workers

Q23. (I3) Can you change the people who provide care for you if you want to? PROXY

- Yes
- No
- Don't know
- N/A - no support workers

Q24. (I50) Do your support workers speak your preferred language? PROXY

- Always and all support workers
- Usually or most support workers
- Sometimes or some support workers
- Never or none of the support workers
- Don't know
- N/A - no support workers

Q25. (I50) Do your support workers understand and respect your religious and cultural beliefs? PROXY

- Always and all support workers
- Usually or most support workers
- Sometimes or some support workers
- Never or none of the support workers
- Don't know
- N/A - no support workers

Q26 (I93) Do your support workers arrive and leave when they are supposed to? PROXY

- Always or all support workers
- Usually or most support workers
- Sometimes or some support workers
- Never or none of the support workers
- Don't know
- N/A - no support workers

Q27. (I93) Do you have a back-up plan/do you know what to do if they don't show up or leave too early?

- Yes PROXY
- No
- Don't Know
- N/A - no support workers

Q28. (I93) In the last 30 days, have your support workers ever not shown up when they were supposed to? PROXY
 Yes
 No
 Don't Know
 N/A - no support workers

Q29. (I94) Have you had a problem with your support workers in the last 30 days? PROXY
 Yes
 No
 Don't Know
 N/A - no support workers

If not "yes", skip question 30 and go on to question 31.

Q30. (I94) Did you get the help you needed to work out the problem? PROXY
 Yes
 In-between
 No
 Don't Know

Q31. (I94) If you ever have a problem with your support workers, do you know what to do? PROXY
 Yes
 No
 Don't Know
 N/A - no support workers

Q32. (I81) Do you feel that your support workers treat you with respect?
 Always or all support workers
 Usually or most support workers
 Sometimes or some support workers
 Never or none of the support workers
 Don't know
 N/A - no support workers

Q33. (I81) Do your support workers do things the way you want them done?
 Always or all support workers
 Usually or most support workers
 Sometimes or some support workers
 Never or none of the support workers
 Don't know
 N/A - no support workers

Q34. (I54) Are you ever concerned for your safety around your support workers?

- Always and all support workers
- Usually or most support workers
- Sometimes or some support workers
- Never or none of the support workers
- Don't know
- N/A - no support workers

Q35. (I3) Do you decide what kind of help you get from your support workers?

- Always
- Usually
- Sometimes
- Never
- Don't know
- N/A - no support workers

If no support workers, start here.

Q36. (I104) Do you get enough help to do basic self-care things like bathing, dressing, going to the bathroom, eating, moving around your home? PROXY

- Yes
- No
- Don't know
- Not applicable – don't need help

Q37. (I104) Do you get enough help with everyday things like taking your medications, housework, shopping? PROXY

- Yes
- No
- Don't know
- Not applicable – don't need help

Q38. (I105) Do you get enough help managing your money and finances? PROXY

- Yes
- No
- Don't know
- Not applicable – don't need help

HOME

Now let's talk about where you are living. You live here _____

Q39. (I43) Lots of people use in-home modifications like grab bars, ramps, emergency response systems, bathroom modifications, remote monitoring, etc. Are you using any of these kinds of

modifications that help you move and function around your home right now)? PROXY
 Yes
 No
 Don't know

If "no" or "don't know", skip question 40.

Q40. (I43) Have these modifications met your needs? PROXY
 Yes
 No
 Don't know

If "yes", skip question 41.

Q41. (I43) What changes to your home do you need that you do not have? _____ PROXY

Q42. (I12) Do you like this place _____ where you are living right now?
 Yes
 No
 Not Sure/Don't Know

If "no" or "don't know", skip questions 43, 44 and 45 and go on to question 46:

Q43. (I19) Without the services and supports you receive, would you have to live somewhere else? PROXY
 Yes
 No
 Not Sure/Don't Know

Q44. (I19) To continue living here, do you need more or different types of support? PROXY
 Yes
 No
 Not applicable - does not want to continue living here
 Don't know

If not "yes", skip question 45 and go on to question 46.

Q45. What kind of supports? _____ PROXY

Q46. (I12) Would you prefer to live somewhere else?
 Yes
 No
 Not Sure/Don't Know

If "no" or "don't know", skip question 47 and go on to question 48.

Q47. (I12) What prevents you from living somewhere else? _____

Q48. (I77) Do people ever enter your home without permission?

- Never**
- Sometimes or some people**
- Usually or most people**
- Always or everyone**
- Don't know**

Q49. (I77) Are you able to be alone at home with visitors if you want to?

- Always**
- Usually**
- Sometimes**
- Never**
- Don't know**
- N/A – doesn't want to or does not have visitors**

Q50. (I77) Do you feel that you have enough privacy in your home?

- Always**
- Usually**
- Sometimes**
- Never**
- Don't know**

Q51. (I77) Do people ever open your mail/email without permission?

- Never**
- Sometimes or some people or some mail**
- Usually or most people or most mail**
- Always or everyone or all mail**
- Don't know**
- N/A**

Q52. (I77) Can you use phone/internet whenever you want to?

- Always**
- Usually**
- Sometimes**
- Never**
- Don't know**
- N/A**

Q53. (I55) Are you ever scared or worried for the safety of your belongings?

- Always**
- Usually**
- Sometimes**

- Never
- Don't know

Q54. (I55) Is someone using your money in a way that you did not give them permission to?

- Always
- Usually
- Sometimes
- Never
- Don't know
- N/A

Q55. (I51) Are you ever concerned for your safety at home?

- Always
- Usually
- Sometimes
- Never
- Don't know

Q56. (I52) If you ever feel concerned for your safety, do you have somebody to talk to that could help you feel safe?

- Yes
- No
- Don't know
- N/A

Q57. (NEW1) Do you ever have to cut back on heating or cooling (not have the temperature in your home the way you want it) because you can't afford it?

PROXY

- Always
- Usually
- Sometimes
- Never
- Don't know
- N/A

Q58. (I113) Do you ever have to eat less than you'd like because you can't afford it?

PROXY

- Always
- Usually
- Sometimes
- Never
- Don't know
- N/A

COMMUNITY

Now let's talk about the community you live in....

Q59. (I2) Have you been able to participate in some sort of social activity outside of your home in the last 30 days?

Yes

PROXY

No

Don't know

N/A

Q60. (I2) Do you get to do things outside of your home when you want to (like visit friends, go for entertainment, go to a movie or a show, out to eat, to religious functions, etc)?

Always

PROXY

Usually

Sometimes

Never

Don't know

N/A – doesn't want to

Q61. (I41) Do you have transportation when you want to visit a friend, go to a movie, or do something for fun?

PROXY

Always

Usually

Sometimes

Never

Don't know

N/A

Q62. (I41) Do you have transportation to get to medical appointments and grocery shopping? PROXY

Always

Usually

Sometimes

Never

Don't know

N/A

Q63. (I51) Are you ever concerned for your safety when out in the community?

Always

Usually

Sometimes

Never

Don't know

N/A

EVERYDAY LIVING

Now let's talk about what your typical day looks like... What does a typical day look like for you?

Q64. (I16) Do you like what you typically do during the day?

Yes

No

Not Sure/Don't Know

Q65. What would you do during the typical day if you could do anything? _____

Q66. (I3) Do you set your own schedule during the day, like decide when you get up, when you go to bed, when you eat your meals, when you go outside, etc?

Always

Usually

Sometimes

Never

Don't know

Q67. (I95) Do you have a paying job, either full-time or part-time?

PROXY

Yes, full-time

Yes, part-time

No

Don't know

If not "no", skip question 68 and go on to question 69. If "no", go to question 68 and skip question 69.

Q68. (I101) Would you like a job?

Yes

No

Don't know

Q69. (Q100) Can you afford to retire if you want to?

PROXY

Yes

No

Don't know

N/A

RELATIONSHIPS

I am going to ask you about family and friends...

Q70. (I7) Can you see your friends when you want to?

- Always
- Usually
- Sometimes
- Never
- Don't know
- Not applicable (no friends)
- Not applicable (does not want to)

Q71. (I7) Can you see your family members when you want to? (THOSE FAMILY MEMBERS WHO DO NOT LIVE WITH YOU)

- Always
- Usually
- Sometimes
- Never
- Don't know
- Not applicable (no family involvement)
- Not applicable (does not want to)

Q72. (I7) How often do you see your friends and family?

PROXY

- Every day
- A couple of times a week
- Once a week
- A couple of times a month
- Once a month
- Less than once a month
- Don't know
- N/A

Q73. (I8) Do you ever feel lonely?

- Always
- Usually
- Sometimes
- Never
- Don't know

HEALTH AND WELLNESS

Let's talk about your health

Q74. (I65) Do you use tobacco products? PROXY

- Yes, often
- Yes, sometimes
- No

Q75. (I65) Do you exercise on a regular basis? PROXY

- Yes
- No
- Don't know

Q76. (I106) Do you eat as much vegetables and fruit and healthy foods as you want? PROXY

- Always
- Usually
- Sometimes
- Never
- Don't know
- N/A

Q77. (I66) Have you participated in _____ (INSERT EVIDENCE-BASED HEALTH PROMOTION AND DISEASE PREVENTION ACTIVITY)? PROXY

- Yes
- No
- Don't know

Q78. (I67) How would you describe your overall health? PROXY

- Excellent
- Very good
- Good
- Fair
- Poor
- Don't know

Q79. (I43) Have you been told that you need a wheelchair or other devices that help you get around, like a cane or a walker or a scooter? PROXY

- Yes
- No
- Don't know

Q80. (I43) Do you use devices that help you get around? PROXY

- Yes
- No
- Don't know

If "yes" to question 79 and "no" to question 80, ask question 81. Otherwise: If "yes" to question 80, go to question 82; if "no" or "don't know" to question 80, skip to question 83.

Q81. Why not? _____ PROXY

If no or don't know, skip the next question. If yes, ask:

Q82. (I43) Are these devices providing adequate support? PROXY

- Yes
- No
- Don't know

If "yes" to question 82, skip question 83 and go to question 84.

Q83. (I43) What devices do you need that you don't have? _____ PROXY

Q84. Do you generally need help with (CHECK ALL THAT APPLY): PROXY

- taking a bath/shower
- going to the bathroom
- dressing
- walking
- eating/feeding yourself
- getting in and out of bed
- preparing meals
- going shopping
- riding in a car or using public transportation
- using the phone
- paying bills
- doing light housework or household chores

Q85. Over the past 2 weeks, have you felt down, depressed, or hopeless?

- Yes
- No
- Don't know

Q86. Over the past 2 weeks, have you felt little interest or pleasure in doing things?

- Yes
- No
- Don't know

If “no” or “don’t know” to both questions 85 and 86, skip question 87 and go to question 88 . If “yes” to either, ask question 87:

Q87. (I62) Do you have someone with a medical background you can talk to when you feel that way, like a doctor or a nurse, or a psychiatrist?

- Always
- Usually
- Sometimes
- Never
- Don’t know

Q88. (I62) Do you take any medications that help you to feel less sad, angry, or depressed? PROXY

- Yes
- No
- Don’t know

Q89. Do you have trouble remembering basic things (like where you are, where you left something, what date it is, what you did earlier, who people are, what you just said, etc)?

- Often PROXY
- Sometimes
- Never
- Don’t know

Q90. Do you or your family have concerns about your memory, thinking, or ability to make decisions?

- Often PROXY
- Sometimes
- Never
- Don’t know

If “never” to both questions 89 and 90, skip question 91 and go to question 92. If “often” or “sometimes” to either, ask question 91.

Q91. (I71) Have you talked to someone about having trouble remembering things? PROXY

- Yes
- No
- Not applicable – don’t want to
- Don’t know.

Q92. Have you fallen in the last six months?

- Yes PROXY
- No
- Don’t know

Q93. (I56) Are you afraid of falling?

- Always
- Usually
- Sometimes
- Never
- Don't know

If "no" to question 92 and "never" to questions 92 and 93, skip questions 94 and 95 and go to question 96. If "yes" to question 92 or "always" or "usually" or "sometimes" to question 93, ask question 94 and 95

Q94. (I56) Have you talked to anyone about falling or being afraid of falling?

PROXY

- Yes
- No
- Don't know

Q95. (I56) Has anything been done to help prevent you from falling in the future?

PROXY

- Yes
- No
- Don't know

HEALTHCARE

Q96. In the last 6 months, have you stayed overnight in the hospital or rehab/nursing facility? PROXY

- Yes
- No
- Don't Know

If "no" or "don't know", skip questions 97, 98 and 99 and go to question 100.

Q97. (I31) When leaving the hospital or rehab/nursing facility, did you receive information about services you might get at home?

PROXY

- Yes
- No
- Don't know
- N/A

Q98. (I32) When leaving the hospital or rehab/nursing facility, did you feel prepared to go home?

PROXY

- Yes
- No
- Not sure/Don't know
- N/A

Q99. (I34) After leaving the hospital or rehab/nursing facility and going home, did someone follow-up with you to make sure you had what you needed? PROXY

- Yes
- No
- Don't know
- N/A

Q100. (I36) In general, do you get enough help with setting up your medical appointments? PROXY

- Always
- Usually
- Sometimes
- Never
- Don't know
- N/A

Q101. (I61) When you need to go to a doctor, can you get an appointment as quickly as you need it? PROXY

- Always
- Usually
- Sometimes
- Never
- Don't know
- N/A

Q102. (I49) In the past 6 months, did you have to go the emergency room because you could not see your doctor when you needed to? PROXY

- Yes
- No
- Don't know
- N/A

Q103. (I48) Do you feel that your health care providers (doctors, nurses, etc) listen to you? PROXY

- Always
- Usually
- Sometimes
- Never
- Don't know
- N/A

Q104. (I63) Do your health care providers give you enough information for you to make decisions about your healthcare and medications? PROXY

- Always
- Usually
- Sometimes

- Never
- Don't know
- N/A

Q105. (I36) Do you get enough help with following the advice/recommendations your doctor gives you?

- Always PROXY
- Usually
- Sometimes
- Never
- Don't know
- N/A

Q106. (I57) Are you getting care for all you chronic conditions (*list from background*)? PROXY

- Yes
- No
- Don't know
- N/A

Q107. (I59) Have you had _____ (INSERT PREVENTIVE CARE PROCEDURE) in the last _____?

- Yes PROXY
- No
- Don't know
- N/A

Q108. (I73) Has anyone ever reviewed your medications with you?

- Yes
- No
- Don't know
- N/A

Q109. (I36) Do you get enough help with understanding and taking your medications? PROXY

- Always
- Usually
- Sometimes
- Never
- N/A – don't need help
- Don't know

Q110. (I75) How often do you split or skip a pill? PROXY

- Always
- Usually
- Sometimes

- Never
- Not applicable (not taking any medications)
- Don't know

If "never" or "n/a" or "don't know", skip question 111 and go to question 112.

Q111. (I75) Why?

PROXY

- Forget
- Price
- Don't like side effects
- Pill too big
- Other _____

PLANNING FOR FUTURE

Let's shift gears and talk about how you feel about your future

Q112. (I116) Do you worry about not getting enough help in the future?

- Yes
- Sometimes
- No
- Don't know

Q113. (I117) Have you thought about your future and how to plan for it?

PROXY

- Yes
- No
- Don't know

Q114. (I117) Have you planned for any of these events:

PROXY

	Yes	No	Don't know
Long-term care			
Medical emergencies			
Burial			
Other unexpected circumstances			

Q115. (I117) Do you have the following:

PROXY

- Living Wills
- Wills
- Special Needs Trust
- Trust
- Medical Power of Attorney
- Financial Power of Attorney
- Out of Hospital Do Not Resuscitate (DNR) Order/ Physician's Orders for Life Sustaining Treatment
- Long-Term Care Insurance

- Financial Planning
- Medicaid
- Medicare
- Veterans Benefits
- Retirement Benefits

Q116. (I117) Do you know how to get information or help when you are planning for your future?

- Yes PROXY
- No
- Not sure/Don't know

INDEPENDENCE/FUNCTIONAL COMPETENCE

Finally, I want to ask a few more questions about you...

Q117. (I119) Is personal autonomy and being independent very important to you?

- Yes
- In-between
- No
- Don't know

Q118. (I119) Do you feel you are as independent as you want to be?

- Always
- Usually
- Sometimes
- Never
- Don't know

Q119. Please tell me how important these things are to you right now

	Not very important	Somewhat important	Very important
CHOICE			
RELATIONSHIPS			
COMMUNITY INVOLVEMENT			
SAFETY			
YOUR HEALTH AND HEALTHCARE			
BEING RESPECTED/DIGNITY			
HAVING ENOUGH HELP			
AUTONOMY/DOING THINGS FOR YOURSELF			