



**NATIONAL CORE INDICATORS –
AGING AND DISABILITIES**

**CONSUMER SURVEY
2015-2016**

Full version (for individual receiving services)

Notes on survey organization:

- Do not read response options unless the instructions specifically state so.
- Instructions are gray-highlighted and in CAPS.
- Parts of questions/responses that should not be read out loud are in CAPS.
- Box **PROXY** next to the question indicates that proxy responders are allowed. If there is no **PROXY** box, only individual receiving the services should be responding.
- Questions 1-8 should be asked only of the individual receiving services (not a proxy) and should be used to determine whether to use the proxy or the full version of the survey.

Survey code _____

HOME

I would like to begin by talking about where you live.

1. How long have you lived here? _____

2. In general, do you like where you are living right now?

2 YES - **GO TO QUESTION 4**

1 IN-BETWEEN, MOST OF THE TIME

0 NO

98 DON'T KNOW - **GO TO QUESTION 4**

100 UNCLEAR/REFUSED/NO RESPONSE - **GO TO QUESTION 4**

3. What don't you like about where you live? **(CHECK ALL THAT APPLY)**

50 **N/A- LIKES WHERE LIVES**

1 ACCESSIBILITY OF HOUSE/BUILDING

2 FEELS UNSAFE IN/ DISLIKES THE NEIGHBORHOOD

3 FEELS UNSAFE IN HOME

4 HOME/BUILDING NEEDS REPAIRS OR UPKEEP

5 DOES NOT FEEL LIKE HOME

6 LAYOUT/SIZE OF HOME/BUILDING

7 PROBLEMS WITH NEIGHBORS/OTHER RESIDENTS/HOUSEMATES/ROOMMATES

8 PROBLEMS WITH STAFF

9 INSUFFICIENT AMOUNT/ TYPE OF STAFF

10 WANTS MORE INDEPENDENCE AND CONTROL

11 WANTS MORE PRIVACY

12 WANTS TO BE CLOSER TO FAMILY/FRIENDS

13 FEELS ISOLATED FROM THE COMMUNITY/ FEELS LONELY

14 OTHER **(FILL IN)** _____

98 DON'T KNOW

100 UNCLEAR/REFUSED/NO RESPONSE

4. Would you prefer to live somewhere else? *We are not talking about geography, but rather the kind of place you'd like to live in.*

_2 YES

_1 MAYBE

_0 NO - **GO TO QUESTION 6**

_100 UNCLEAR/REFUSED/NO RESPONSE - **GO TO QUESTION 6**

5. Where would you prefer to live? *Again, we are not talking about geography, but rather the kind of place you'd like to live in.*

_50 **N/A – WOULD NOT PREFER TO LIVE SOMEWHERE ELSE**

_1 DIFFERENT OWN HOUSE/APARTMENT

_2 FAMILY MEMBER'S HOUSE/APARTMENT

_3 ASSISTED LIVING FACILITY

_4 GROUP HOME

_5 ADULT FAMILY HOME, SHARED LIVING

_6 NURSING FACILITY

_7 OTHER **(FILL IN)** _____

_98 DON'T KNOW

_100 UNCLEAR/REFUSED/NO RESPONSE

RELATIONSHIPS

I am going to ask you about family and friends.

6. Do you have friends or family (*who do not live with you*) who are involved in your life? **(IF THE PERSON LIVES WITH FAMILY, ASK ABOUT OTHER FAMILY MEMBERS THAT DO NOT LIVE AT HOME)**

_2 YES

_0 NO - **GO TO QUESTION 9**

_98 DON'T KNOW - **GO TO QUESTION 9**

_100 UNCLEAR/REFUSED/NO RESPONSE - **GO TO QUESTION 9**

7. Can you see or talk to your friends and family (*who do not live with you*) when you want to?

_50 N/A - NO FAMILY OR FRIENDS, OR NO FAMILY INVOLVEMENT

_2 YES, ALWAYS, OR CHOOSES NOT TO - **GO TO QUESTION 9**

_1 MOST OF THE TIME, USUALLY, OR SOME FAMILY AND/OR FRIENDS

_0 NO, OR ONLY SOMETIMES

_98 DON'T KNOW - **GO TO QUESTION 9**

_100 UNCLEAR/REFUSED/NO RESPONSE - **GO TO QUESTION 9**

8. Why not/ why only sometimes? **(CHECK ALL THAT APPLY)**

_50 N/A - NO FAMILY OR FRIENDS, OR NO FAMILY INVOLVEMENT

_51 N/A – CAN SEE/TALK TO FAMILY AND FRIENDS AS OFTEN AS WANTS TO, OR CHOOSES NOT TO

_1 AVAILABILITY OF TRANSPORTATION

_2 ACCESSIBILITY

_3 STAFFING/PERSONAL ASSISTANCE UNAVAILABLE

_4 HEALTH LIMITATIONS

_5 SOMEONE PREVENTS FROM, OR THERE ARE RULES THAT RESTRICT SEEING OR TALKING TO FRIENDS OR FAMILY

_6 OTHER **(FILL IN)** _____

_100 UNCLEAR/REFUSED/NO RESPONSE

PROXY1. WAS THE PERSON RECEIVING SERVICES ABLE TO RESPOND TO ABOVE QUESTIONS?

_2 YES

_0 NO

IF “YES” – CONTINUE TO REST OF SURVEY. IF “NO” - DO NOT CONTINUE SURVEYING THE PERSON AND SWITCH TO “PROXY SURVEY” (IF A PROXY IS AVAILABLE TO ANSWER QUESTIONS FOR THE INDIVIDUAL)

SERVICE SATISFACTION

Let's talk about the services and supports you are receiving. We are not talking about medical services. We are talking about what is called "long-term care services" – that is, services that help you with your everyday life, such as homemaker services, transportation services, personal care assistance, meals and nutritional assistance, home health, etc. To clarify, we are talking about formal services – services that the State, Medicaid or Medicare pays for, services for which you or your family do not pay the whole cost out of pocket.

9. Are you currently getting any of these paid services and supports? **(READ RESPONSE OPTIONS) (CHECK ALL THAT APPLY) PROXY**

Respondent: () 1-individual () 2-child () 3-spouse/partner () 4-other family () 5-PCA () 6-Friend () 7- Other

- 1 **Personal care assistance, personal care services** (like assistance with dressing, bathing, eating)
- 2 **Homemaker/ chore services** (like assistance buying groceries, cleaning the house, cooking meals, shoveling snow)
- 3 **Companion services** (like assistance with planning community outings, staying connected with friends)
- 4 **Healthcare home services, home health** (medical or nursing care in your home)
- 5 **Home delivered meals** (prepared meals sent to your home)
- 6 **Congregate dining** (a meal provided in the community)
- 7 **Adult day services** (place where you go during the day that provides social or health-related activities to promote your well-being)
- 8 **Transportation** (either actual transportation or a voucher or pass for public transit)
- 9 **Other services (FILL IN)** _____
- 50 PERSON SAID THEY ARE NOT RECEIVING ANY OF THE ABOVE SERVICES - **GO TO QUESTION 18**
- 98 DON'T KNOW - **GO TO QUESTION 18**
- 100 UNCLEAR/REFUSED/NO RESPONSE - **GO TO QUESTION 18**

10. How did you first find out about the services available to you? **(TRY TO CLASSIFY) (CHECK ALL THAT APPLY)**

Respondent: () 1-individual () 2-child () 3-spouse/partner () 4-other family () 5-PCA () 6-Friend () 7- Other

50 N/A – PERSON SAID THEY ARE NOT RECEIVING SERVICES

PROXY

1 FRIEND

2 FAMILY

3 AREA AGENCY ON AGING

4 AGING AND DISABILITY RESOURCE CENTER

5 CENTER FOR INDEPENDENT LIVING

6 NEWSPAPER/ADVERTISEMENT/BILLBOARD

7 PROVIDER (E.G. HEALTH CARE AGENCY, NURSING HOME, HOME HEALTH WORKER, PERSONAL ATTENDANT)

8 STATE OR COUNTY AGENCY (E.G. DIVISION OF AGING, COUNTY OFFICE ON DISABILITY)

9 DOCTOR

10 MANAGED CARE ORGANIZATION

11 CASE MANAGER OR CARE COORDINATOR

12 OTHER **(FILL IN)** _____

98 DON'T KNOW

100 UNCLEAR/REFUSED/NO RESPONSE

11. **(ONLY ASK PERSONS WHOSE PREFERED LANGAUGE IS NOT ENGLISH)** Do you receive information about your services in the language you prefer? **PROXY**

Respondent: () 1-individual () 2-child () 3-spouse/partner () 4-other family () 5-PCA () 6-Friend () 7- Other

50 N/A – PERSON SAID THEY ARE NOT RECEIVING SERVICES

51 N/A – ENGLISH IS PERSON'S PREFERED LANGAUGE

2 YES, ALL INFORMATION

1 SOME INFORMATION

0 NO

98 DON'T KNOW

100 UNCLEAR/REFUSED/NO RESPONSE

12. Do you have a case manager or care coordinator– someone whose job it is to help set up and coordinate services with you? **PROXY**

Respondent: () 1-individual () 2-child () 3-spouse/partner () 4-other family () 5-PCA () 6-Friend () 7- Other

__50 N/A – PERSON SAID THEY ARE NOT RECEIVING SERVICES

__2 YES

__0 NO - GO TO QUESTION 14

__98 DON'T KNOW - GO TO QUESTION 14

__99 UNCLEAR RESPONSE - GO TO QUESTION 14

__100 REFUSED/NO RESPONSE - GO TO QUESTION 14

13. **(ONLY ASK IF PERSON SAID THEY HAVE A CASE MANAGER OR CARE COORDINATOR IN QUESTION 12)** Can you reach your case manager/care coordinator when you need to? **PROXY**

Respondent: () 1-individual () 2-child () 3-spouse/partner () 4-other family () 5-PCA () 6-Friend () 7- Other

__50 N/A – PERSON SAID THEY ARE NOT RECEIVING SERVICES

__51 N/A – PERSON SAID THEY DO NOT HAVE A CASE MANAGER

__2 YES, ALWAYS

__1 MOST OF THE TIME, USUALLY

__0 NO, OR ONLY SOMETIMES

__98 DON'T KNOW

__100 UNCLEAR

14. If you have a complaint about the services you are getting right now, do you know whom to call? **PROXY**

Respondent: () 1-individual () 2-child () 3-spouse/partner () 4-other family () 5-PCA () 6-Friend () 7- Other

__50 N/A – PERSON SAID THEY ARE NOT RECEIVING SERVICES

__2 YES

__1 MAYBE, NOT SURE

__0 NO

__100 UNCLEAR/REFUSED/NO RESPONSE

15. If your needs change and you need new or different types of services and supports, do you know whom to call or how to get information? **PROXY**

Respondent: () 1-individual () 2-child () 3-spouse/partner () 4-other family () 5-PCA () 6-Friend () 7- Other

__50 N/A – PERSON SAID THEY ARE NOT RECEIVING SERVICES

__2 YES

__1 MAYBE, NOT SURE

__0 NO

__100 UNCLEAR/REFUSED/NO RESPONSE

These next few questions are about the level of control and choice you have over your services and the people who provide them to you.

16. Can you choose or change what kind of services you get and determine how often and when you get them?

Respondent: () 1-individual () 2-child () 3-spouse/partner () 4-other family () 5-PCA () 6-Friend () 7- Other

__50 N/A – PERSON SAID THEY ARE NOT RECEIVING SERVICES

PROXY

__2 YES, ALL SERVICES

__1 SOMETIMES, OR SOME SERVICES

__0 NO

__98 DON'T KNOW

__100 UNCLEAR/REFUSED/NO RESPONSE

17. Can you choose or change who provides your services if you want to?

PROXY

Respondent: () 1-individual () 2-child () 3-spouse/partner () 4-other family () 5-PCA () 6-Friend () 7- Other

__50 N/A – PERSON SAID THEY ARE NOT RECEIVING SERVICES

__2 YES, ALL SERVICES

__1 SOMETIMES, OR SOME SERVICES

__0 NO

__98 DON'T KNOW

__100 UNCLEAR/REFUSED/NO RESPONSE

DIRECT CARE WORKERS/DAILY ACTIVITIES

Now let's talk about what your everyday life looks like.

18. How much assistance with everyday activities do you generally need? *(Things like preparing meals, housework, shopping or taking your medications)* **(READ RESPONSE OPTIONS)**

PROXY

Respondent: () 1-individual () 2-child () 3-spouse/partner () 4-other family () 5-PCA () 6-Friend () 7- Other

_2 A lot

_1 Some

_0 None - **GO TO QUESTION 20**

_98 DON'T KNOW - **GO TO QUESTION 20**

_100 UNCLEAR/REFUSED/NO RESPONSE - **GO TO QUESTION 20**

19. Do you always get enough assistance with your everyday activities when you need it?

PROXY

Respondent: () 1-individual () 2-child () 3-spouse/partner () 4-other family () 5-PCA () 6-Friend () 7- Other

_50 **N/A – DOES NOT NEED HELP**

_2 YES, ALWAYS

_0 NO, NOT ALWAYS

_98 DON'T KNOW

_100 UNCLEAR/REFUSED/NO RESPONSE

20. How much assistance with self-care do you generally need? *(Things like bathing, dressing, going to the bathroom, eating or moving around your home)* **(READ RESPONSE OPTIONS)**

PROXY

Respondent: () 1-individual () 2-child () 3-spouse/partner () 4-other family () 5-PCA () 6-Friend () 7- Other

_2 A lot

_1 Some

_0 None - **GO TO QUESTION 22**

_98 DON'T KNOW - **GO TO QUESTION 22**

_100 UNCLEAR/REFUSED/NO RESPONSE - **GO TO QUESTION 22**

21. Do you always get enough assistance for self-care when you need it?

PROXY

Respondent: () 1-individual () 2-child () 3-spouse/partner () 4-other family () 5-PCA () 6-Friend () 7- Other

- 50 N/A – DOES NOT NEED HELP**
- 2 YES, ALWAYS**
- 0 NO, NOT ALWAYS**
- 98 DON'T KNOW**
- 100 UNCLEAR/REFUSED/NO RESPONSE**

I would like to talk to you about people who may be helping you - like family members, personal care attendants or personal assistants, other direct care workers, or whoever helps you with everyday life, regardless of whether or not they get paid for it.

22. Is there anyone who helps you at home or in the community on a regular basis (at least once a week)? *We are talking about any kind of help – either with self-care needs, or everyday activities.*

PROXY

Respondent: () 1-individual () 2-child () 3-spouse/partner () 4-other family () 5-PCA () 6-Friend () 7- Other

- 2 YES**
- 0 NO – GO TO QUESTION 30**
- 98 DON'T KNOW - GO TO QUESTION 30**
- 100 UNCLEAR/REFUSED/NO RESPONSE - GO TO QUESTION 30**

23. Who is the person who helps you most often? **(SELECT ONE)**

PROXY

Respondent: () 1-individual () 2-child () 3-spouse/partner () 4-other family () 5-PCA () 6-Friend () 7- Other

- 50 N/A - NOBODY PROVIDES SUPPORT ON A REGULAR BASIS**
- 1 PAID SUPPORT WORKER WHO IS NOT A FRIEND OR RELATIVE**
- 2 PAID FAMILY MEMBER OR SPOUSE/PARTNER**
- 3 PAID FRIEND**
- 4 UNPAID FAMILY MEMBER OR SPOUSE/PARTNER**
- 5 UNPAID FRIEND OR VOLUNTEER**
- 6 OTHER (FILL IN) _____**
- 98 DON'T KNOW - GO TO QUESTION 30**
- 100 UNCLEAR/REFUSED/NO RESPONSE - GO TO QUESTION 30**

24. Who else provides assistance for you when you need help? **(CHECK ALL THAT APPLY)**

PROXY

Respondent: () 1-individual () 2-child () 3-spouse/partner () 4-other family () 5-PCA () 6-Friend () 7- Other

__50 N/A - NOBODY PROVIDES SUPPORT ON A REGULAR BASIS

__1 PAID SUPPORT WORKER WHO IS NOT A FRIEND OR RELATIVE

__2 PAID FAMILY MEMBER OR SPOUSE/PARTNER

__3 PAID FRIEND

__4 UNPAID FAMILY MEMBER OR SPOUSE/PARTNER

__5 UNPAID FRIEND OR VOLUNTEER

__6 OTHER (FILL IN) _____

__7 NO ONE ELSE PROVIDES SUPPORT

__98 DON'T KNOW

__100 UNCLEAR/REFUSED/NO RESPONSE

ASK QUESTIONS 25 THROUGH 29 ONLY IF THERE ARE PAID SUPPORT WORKERS, PAID FAMILY MEMBERS OR PAID FRIENDS IN EITHER QUESTION 23 OR 24. IF THERE ARE NO PAID SUPPORT PERSONS, GO TO QUESTION 30.

IF PAID SUPPORT WORKERS (OR THE PAID FRIEND OR FAMILY MEMBER) ARE PRESENT AT THIS INTERVIEW, ASK THEM TO STEP OUT OF THE ROOM. IF THEY DO NOT STEP OUT OR THE PERSON NEEDS THEM TO BE PRESENT, DO NOT ASK QUESTIONS 25 THROUGH 29 AND GO TO QUESTION 30

25. **(DO NOT ASK IF PAID SUPPORT WORKERS ARE PRESENT OR IF THERE ARE NO PAID WORKERS)** Do the people who are currently paid to help you change too often?

PROXY

Respondent: () 1-individual () 2-child () 3-spouse/partner () 4-other family () 5-PCA () 6-Friend () 7- Other

__50 N/A - NO PAID SUPPORT PERSONS

__51 N/A - QUESTION NOT ASKED BECAUSE PAID SUPPORT PERSONS ARE PRESENT

__52 N/A – PAID SUPPORT PERSON/S ARE LIVE-IN

__2 YES

__1 SOME, OR SOMETIMES

__0 NO

__98 DON'T KNOW

__100 UNCLEAR/REFUSED/NO RESPONSE

26. **(DO NOT ASK IF PAID SUPPORT WORKERS ARE PRESENT OR IF THERE ARE NO PAID WORKERS)** Do the people who are paid to help you show up and leave when they are supposed to? **PROXY**

Respondent: () 1-individual () 2-child () 3-spouse/partner () 4-other family () 5-PCA () 6-Friend () 7- Other

- __50 N/A - NO PAID SUPPORT PERSONS**
- __51 N/A - QUESTION NOT ASKED BECAUSE PAID SUPPORT PERSONS ARE PRESENT**
- __52 N/A – PAID SUPPORT PERSON/S ARE LIVE-IN**
- __2 YES, ALL PAID SUPPORT WORKERS, ALWAYS OR ALMOST ALWAYS**
- __1 SOME, OR USUALLY**
- __0 NO, NEVER OR RARELY**
- __98 DON'T KNOW**
- __100 UNCLEAR/REFUSED/NO RESPONSE**

27. **(DO NOT ASK IF PAID SUPPORT WORKERS ARE PRESENT OR IF THERE ARE NO PAID WORKERS)** Do you feel that the people who are paid to help you treat you with respect?

- __50 N/A - NO PAID SUPPORT PERSONS**
- __51 N/A - QUESTION NOT ASKED BECAUSE PAID SUPPORT PERSONS ARE PRESENT**
- __2 YES, ALL PAID SUPPORT WORKERS, ALWAYS OR ALMOST ALWAYS**
- __1 SOME, OR USUALLY**
- __0 NO, NEVER OR RARELY**
- __98 DON'T KNOW**
- __100 UNCLEAR/REFUSED/NO RESPONSE**

28. **(DO NOT ASK IF PAID SUPPORT WORKERS ARE PRESENT OR IF THERE ARE NO PAID WORKERS)** Do the people who are paid to help you do things the way you want them done?

- __50 N/A - NO PAID SUPPORT PERSONS**
- __51 N/A - QUESTION NOT ASKED BECAUSE PAID SUPPORT PERSONS ARE PRESENT**
- __2 YES, ALL PAID SUPPORT WORKERS, ALWAYS OR ALMOST ALWAYS**
- __1 SOME, OR USUALLY**
- __0 NO, NEVER OR RARELY**
- __98 DON'T KNOW**
- __100 UNCLEAR/REFUSED/NO RESPONSE**

29. **(DO NOT ASK IF PAID SUPPORT WORKERS ARE PRESENT OR IF THERE ARE NO PAID WORKERS)** Do you feel safe around the people who are paid to help you?

- 50 N/A - NO PAID SUPPORT PERSONS
- 51 N/A - QUESTION NOT ASKED BECAUSE PAID SUPPORT PERSONS ARE PRESENT
- 2 YES, ALL PAID SUPPORT WORKERS, ALWAYS
- 1 SOME, OR USUALLY BUT NOT ALWAYS
- 0 NO, NEVER OR RARELY
- 98 DON'T KNOW
- 100 UNCLEAR/REFUSED/NO RESPONSE

PHYSICAL ENVIRONMENT

30. Many people make changes to their homes, for example, adding grab bars, ramps, or bathroom modifications to make it easier for you to live at home. Do you have or need any of the following changes made to your home (or an upgrade to the one you have)? *To clarify, we are not talking about general repairs to the house, but rather specialized modifications.* **(READ EACH MODIFICATION OPTION)** **PROXY**

Respondent: () 1-individual () 2-child () 3-spouse/partner () 4-other family () 5-PCA () 6-Friend () 7- Other

	3 - NEEDS ONE	2 - HAS ONE, BUT NEEDS UPGRADE	1 - HAS ONE, AND DOESN'T NEED UPGRADE	0 - DOES NOT NEED	98 - DON'T KNOW	100 - UNCLEAR/REFUSED/NO RESPONSE
Grab bars (either in the bathroom or elsewhere in home)						
Other bathroom modifications						
Specialized bed						
Ramp or stair lift (either inside or outside of the home)						
Remote monitoring (a system like a video or a computer camera or a radio that checks that you are okay)						
Personal emergency response system (like a button you can push in case of an emergency)						
Other home modification (FILL IN) _____						

SAFETY/SECURITY/PRIVACY

I would like to ask you some personal questions about how you feel about your safety and security.

31. Do you have an emergency plan in place? For example, do you know what to do in case of a natural disaster, disease outbreak or another wide-scale emergency? **PROXY**

Respondent: () 1-individual () 2-child () 3-spouse/partner () 4-other family () 5-PCA () 6-Friend () 7- Other

__2 YES

__0 NO

__98 DON'T KNOW

__100 UNCLEAR/REFUSED/NO RESPONSE

32. Are you able to get to safety quickly in case of an emergency like a fire or a natural disaster? **PROXY**

Respondent: () 1-individual () 2-child () 3-spouse/partner () 4-other family () 5-PCA () 6-Friend () 7- Other

__2 YES

__0 NO

__98 DON'T KNOW

__100 UNCLEAR/REFUSED/NO RESPONSE

33. Do you or somebody else have concerns about you falling or being unstable? **PROXY**

Respondent: () 1-individual () 2-child () 3-spouse/partner () 4-other family () 5-PCA () 6-Friend () 7- Other

__2 YES, OFTEN

__1 SOMETIMES

__0 NO – **GO TO QUESTION 35**

__98 DON'T KNOW

__100 UNCLEAR/REFUSED/NO RESPONSE

34. Has somebody talked to you or worked with you to reduce your risk of falling or being unstable? **PROXY**

Respondent: () 1-individual () 2-child () 3-spouse/partner () 4-other family () 5-PCA () 6-Friend () 7- Other

__51 **N/A – PERSON IS NOT AFRAID OF FALLING OR BEING UNSTABLE**

__2 YES

__0 NO

__98 DON'T KNOW

__100 UNCLEAR/REFUSED/NO RESPONSE

35. Do you feel safe at home/where you live?

- _2 YES, ALWAYS
- _1 MOST OF THE TIME
- _0 RARELY OR NEVER
- _98 DON'T KNOW
- _100 UNCLEAR/REFUSED/NO RESPONSE

36. Are you ever worried for the security of your personal belongings?

- _2 YES, OFTEN
- _1 SOMETIMES
- _0 NO, NEVER
- _98 DON'T KNOW
- _100 UNCLEAR/REFUSED/NO RESPONSE

37. Has anyone used or taken your money without your permission?

- _2 YES
- _1 MAYBE, NOT SURE
- _0 NO
- _100 UNCLEAR/REFUSED/NO RESPONSE

38. Do people ask your permission before coming into your home/room? **(DETERMINE WHETHER TO SAY HOME" OR "ROOM" BASED ON WHERE THE PERSON LIVES)**

- _2 YES, ALWAYS
- _1 USUALLY, BUT NOT ALWAYS
- _0 SOMETIMES/RARELY, OR NEVER
- _98 DON'T KNOW
- _100 UNCLEAR/REFUSED/NO RESPONSE

SAFETY/SECURITY/PRIVACY – GROUP SETTING

ASK QUESTIONS 39 THROUGH 47 ONLY IF THE PERSON LIVES IN GROUP SETTING ACCORDING TO QUESTION BI-8 (GROUP HOME, ADULT FAMILY HOME/FOSTER HOME/HOST HOME, ASSISTED LIVING FACILITY OR NURSING HOME). IF PERSON LIVES IN OWN HOME OR IS HOMELESS, GO TO QUESTION 48.

The next few questions are about your privacy at home. Some of these questions may seem like they do not apply or may not seem relevant to you. However, they are important for many people, so please try to answer them as best you can.

39. Are you able to lock the doors to your room if you want to?

- 50 N/A – DOES NOT LIVE IN GROUP SETTING**
- 2 YES
- 0 NO
- 98 DON'T KNOW
- 100 UNCLEAR/REFUSED/NO RESPONSE

40. Do you have enough privacy in your home? (*Can you have time to yourself?*)

- 50 N/A – DOES NOT LIVE IN GROUP SETTING**
- 2 YES, ALWAYS
- 1 USUALLY, BUT NOT ALWAYS
- 0 SOMETIMES/RARELY, OR NEVER
- 98 DON'T KNOW
- 100 UNCLEAR/REFUSED/NO RESPONSE

41. Are you able to decide how you furnish and decorate your room?

- 50 N/A – DOES NOT LIVE IN GROUP SETTING**
- 2 YES
- 1 IN-BETWEEN, ABLE TO DECIDE SOME WAYS
- 0 NO
- 98 DON'T KNOW
- 100 UNCLEAR/REFUSED/NO RESPONSE

42. Are your visitors able to come at any time, or are there only certain times of day that visitors are allowed?

50 **N/A – DOES NOT LIVE IN GROUP SETTING OR NO VISITORS WHO VISIT HOME**

2 YES, VISITORS CAN COME ANY TIME

0 NO, VISITORS ALLOWED ONLY CERTAIN TIMES

98 DON'T KNOW

100 UNCLEAR/REFUSED/NO RESPONSE

43. Do you have privacy with visitors at home if you want it?

50 **N/A - DOES NOT LIVE IN GROUP SETTING OR NO VISITORS WHO VISIT HOME**

2 YES, ALWAYS HAS PRIVACY

1 USUALLY HAS PRIVACY

0 NO, NEVER OR RARELY HAS PRIVACY OR THERE ARE RULES AGAINST BEING ALONE WITH VISITORS

98 DON'T KNOW

100 UNCLEAR/REFUSED/NO RESPONSE

44. Can you use the phone privately whenever you want to?

50 **N/A – DOES NOT LIVE IN GROUP SETTING, OR DOESN'T USE PHONE**

2 YES, CAN USE PRIVATELY ANYTIME, EITHER INDEPENDENTLY OR WITH ASSISTANCE

1 CAN USUALLY USE PRIVATELY

0 NO, NEVER OR RARELY CAN USE PRIVATELY OR THERE ARE RULES/RESTRICTIONS/ INTERFERENCE WITH PRIVATE USE OF PHONE

98 DON'T KNOW

100 UNCLEAR/REFUSED/NO RESPONSE

45. Do you have access to food at all times of the day? *Can you get something to eat or grab a snack when you get hungry?*

50 **N/A – DOES NOT LIVE IN GROUP SETTING**

2 YES

0 NO

98 DON'T KNOW

100 UNCLEAR/REFUSED/NO RESPONSE

46. Do people read your mail or email without asking you first?

50 N/A – DOES NOT LIVE IN GROUP SETTING, OR DOES NOT GET MAIL/EMAIL

2 YES, PEOPLE READ MAIL/EMAIL WITHOUT PERMISSION

0 NO, PEOPLE NEVER READ MAIL/EMAIL WITHOUT PERMISSION

98 DON'T KNOW

100 UNCLEAR/REFUSED/NO RESPONSE

47. **(ASK THIS QUESTION ONLY IF PERSON SHARES UNIT WITH ANOTHER PERSON)** Are you able to choose who your roommate is here?

50 N/A – DOES NOT LIVE IN GROUP SETTING, OR DOES NOT HAVE ROOMMATE

2 YES

0 NO

98 DON'T KNOW

100 UNCLEAR/REFUSED/NO RESPONSE

COMMUNITY

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

48. Are you able to do things you enjoy outside of your home when and with whom you want to? (*For example, visit with friends or neighbors, go shopping, go to a movie or a show or out to eat, to religious functions, to volunteer in the community*)?

50 N/A – DOESN'T WANT TO - **GO TO QUESTION 50**

2 YES - **GO TO QUESTION 50**

1 SOMETIMES

0 NO

98 DON'T KNOW - **GO TO QUESTION 50**

100 UNCLEAR/REFUSED/NO RESPONSE - **GO TO QUESTION 50**

49. Why not (*why only sometimes*)? Is it any of the following? **(READ RESPONSES 1-9) (CHECK ALL THAT APPLY)**

50 N/A – CAN DO THINGS OUTSIDE OF HOME WHEN WANTS TO

51 N/A – DOES NOT WANT TO

1 Cost/money

2 Transportation

3 Accessibility/lack of equipment

4 Health limitations

5 Not enough help/staffing/personal assistance

6 Feeling unwelcome in the community

7 Feeling unsafe

8 No community activities outside of home available

9 Lack of information/doesn't know what type of community activities are available

10 Other **(FILL IN)** _____

98 DON'T KNOW

100 UNCLEAR/REFUSED/NO RESPONSE

50. Do you have transportation when you want to do things outside of your home, like visit a friend, go for entertainment, or do something for fun? **PROXY**

Respondent: () 1-individual () 2-child () 3-spouse/partner () 4-other family () 5-PCA () 6-Friend () 7- Other

50 N/A – DOES NOT WANT TO

2 YES

1 SOMETIMES

0 NO

98 DON'T KNOW

100 UNCLEAR/REFUSED/NO RESPONSE

51. Do you have transportation to get to medical appointments when you need to? **PROXY**

Respondent: () 1-individual () 2-child () 3-spouse/partner () 4-other family () 5-PCA () 6-Friend () 7- Other

50 N/A – DOES NOT GO TO MEDICAL APPOINTMENTS (OR DOCTOR COMES TO HOME)

2 YES

1 SOMETIMES

0 NO

98 DON'T KNOW

100 UNCLEAR/REFUSED/NO RESPONSE

52. Many people use devices like a cane, walker, scooter, or a wheelchair to help them get around or things like hearing aids, glasses or communication devices to help with their everyday lives. Do you have or need any of the following (or an upgrade to the one you have)? **(READ EACH DEVICE)** **PROXY**

Respondent: () 1-individual () 2-child () 3-spouse/partner () 4-other family () 5-PCA () 6-Friend () 7- Other

	3 - NEEDS ONE	2 - HAS ONE, BUT NEEDS UPGRADE	1 - HAS ONE, AND DOESN'T NEED UPGRADE	0 - DOES NOT NEED	98 - DON'T KNOW	100 - UNCLEAR/REFUSED/ NO RESPONSE
Walker						
Scooter						
Cane						
Wheelchair (or power chair)						
Hearing aids						
Glasses						
Communication device						
Portable oxygen						
Other device (FILL IN) _____						

EVERYDAY LIVING

Now let's talk about what your typical day looks like.

53. Do you have a paying job in the community, either full-time or part-time? **PROXY**

Respondent: () 1-individual () 2-child () 3-spouse/partner () 4-other family () 5-PCA () 6-Friend () 7- Other

2 YES, FULL-TIME

1 YES, PART-TIME

0 NO - **GO TO QUESTION 55**

98 DON'T KNOW - **GO TO QUESTION 55**

100 UNCLEAR/REFUSED/NO RESPONSE - **GO TO QUESTION 55**

54. Does your job pay at least minimum wage? **PROXY**

Respondent: () 1-individual () 2-child () 3-spouse/partner () 4-other family () 5-PCA () 6-Friend () 7- Other

50 **N/A – DOESN'T HAVE A JOB**

2 YES - **GO TO QUESTION 57**

0 NO - **GO TO QUESTION 57**

98 DON'T KNOW - **GO TO QUESTION 57**

100 UNCLEAR/REFUSED/NO RESPONSE - **GO TO QUESTION 57**

55. (ASK THIS QUESTION ONLY IF PERSON DOES NOT HAVE A FULL- OR A PART-TIME JOB IN QUESTION 53)

Would you like a job?

50 N/A – HAS A JOB

2 YES

1 MAYBE, NOT SURE

0 NO – GO TO QUESTION 57

100 UNCLEAR/REFUSED/NO RESPONSE – GO TO QUESTION 57

56. Has someone talked to you about job options?

50 N/A – HAS A JOB

51 N/A – DOES NOT WANT A JOB

2 YES

0 NO

98 DON'T KNOW

100 UNCLEAR/REFUSED/NO RESPONSE

57. Do you do any volunteer work?

PROXY

Respondent: () 1-individual () 2-child () 3-spouse/partner () 4-other family () 5-PCA () 6-Friend () 7- Other

2 YES

0 NO

98 DON'T KNOW

100 UNCLEAR/REFUSED/NO RESPONSE

58. Do you like how you usually spend your time during the day?

2 YES, ALWAYS, OR ALMOST ALWAYS

1 SOME DAYS, SOMETIMES

0 NO, NEVER

98 DON'T KNOW

100 UNCLEAR/REFUSED/NO RESPONSE

59. Do you get up and go to bed at the time when you want to? (*no one else decides for you when you get up or go to bed, and you get the help you need to get up and go to bed when you want to?*)

2 YES, ALWAYS, OR ALMOST ALWAYS

1 SOME DAYS, SOMETIMES

0 NO, NEVER

98 DON'T KNOW

100 UNCLEAR/REFUSED/NO RESPONSE

60. Can you eat your meals when you want to? (*no one else decides for you when you eat*)

- _2 YES, ALWAYS, OR ALMOST ALWAYS
- _1 SOME DAYS, SOMETIMES
- _0 NO, NEVER
- _98 DON'T KNOW
- _100 UNCLEAR/REFUSED/NO RESPONSE

61. Do you ever have to skip a meal due to financial worries?

PROXY

Respondent: () 1-individual () 2-child () 3-spouse/partner () 4-other family () 5-PCA () 6-Friend () 7- Other

- _2 YES, OFTEN
- _1 SOMETIMES
- _0 NO
- _98 DON'T KNOW
- _100 UNCLEAR/REFUSED/NO RESPONSE

62. Do you have access to healthy foods like fruits and vegetables when you want them?

PROXY

Respondent: () 1-individual () 2-child () 3-spouse/partner () 4-other family () 5-PCA () 6-Friend () 7- Other

- _2 YES, OFTEN
- _1 SOMETIMES
- _0 NO, NEVER
- _98 DON'T KNOW
- _100 UNCLEAR/REFUSED/NO RESPONSE

HEALTH AND WELLNESS

Now let's talk about your health

63. How would you describe your overall health? (**READ RESPONSE OPTIONS**)

PROXY

Respondent: () 1-individual () 2-child () 3-spouse/partner () 4-other family () 5-PCA () 6-Friend () 7- Other

- _5 Excellent
- _4 Very good
- _3 Good
- _2 Fair
- _1 Poor
- _98 DON'T KNOW
- _100 UNCLEAR/REFUSED/NO RESPONSE

64. Compared to 12 months ago, how would you say your health is? **(READ RESPONSE OPTIONS)** **PROXY**

Respondent: () 1-individual () 2-child () 3-spouse/partner () 4-other family () 5-PCA () 6-Friend () 7- Other

- 5 Much better
- 4 Somewhat better
- 3 About the same
- 2 Somewhat worse
- 1 Much worse
- 98 DON'T KNOW
- 100 UNCLEAR/REFUSED/NO RESPONSE

65. During the past 12 months, do you forget things more often than before? Does it seem to be getting worse?

Respondent: () 1-individual () 2-child () 3-spouse/partner () 4-other family () 5-PCA () 6-Friend () 7- Other

- 2 YES **PROXY**
- 0 NO - **GO TO QUESTION 67**
- 98 DON'T KNOW
- 100 UNCLEAR/REFUSED/NO RESPONSE - **GO TO QUESTION 67**

66. Have you or somebody else discussed your forgetting things with a doctor or a nurse? **PROXY**

Respondent: () 1-individual () 2-child () 3-spouse/partner () 4-other family () 5-PCA () 6-Friend () 7- Other

- 50 **N/A – DOES NOT FORGET THINGS MORE OFTEN**
- 2 YES
- 0 NO
- 98 DON'T KNOW
- 100 UNCLEAR/REFUSED/NO RESPONSE

67. How often do you feel lonely, sad or depressed? **(READ RESPONSE OPTIONS)**

- 3 Often
- 2 Sometimes
- 1 Not often - **GO TO QUESTION 69**
- 0 Never or almost never - **GO TO QUESTION 69**
- 98 DON'T KNOW - **GO TO QUESTION 69**
- 100 UNCLEAR/REFUSED/NO RESPONSE - **GO TO QUESTION 69**

68. During the last 12 months, have you talked to someone about feeling sad and depressed? *This could be a friend, a family member, a doctor or nurse.* **(CHECK ALL THAT APPLY)**

- 50 **N/A – DOES NOT OFTEN OR SOMETIMES FEEL SAD OR DEPRESSED**
- 3 YES, FRIEND
- 2 YES, FAMILY MEMBER
- 1 YES, DOCTOR OR NURSE
- 0 NO
- 98 DON'T KNOW
- 100 UNCLEAR/REFUSED/NO RESPONSE

69. Do you take any medications that help you feel less sad or depressed?

PROXY

Respondent: () 1-individual () 2-child () 3-spouse/partner () 4-other family () 5-PCA () 6-Friend () 7- Other

- 2 YES
- 0 NO
- 98 DON'T KNOW
- 100 UNCLEAR/REFUSED/NO RESPONSE

HEALTHCARE

70. Do you have a primary care doctor? *(a regular doctor or nurse practitioner that you see)*

PROXY

Respondent: () 1-individual () 2-child () 3-spouse/partner () 4-other family () 5-PCA () 6-Friend () 7- Other

- 2 YES
- 0 NO - **GO TO QUESTION 72**
- 98 DON'T KNOW - **GO TO QUESTION 72**
- 100 UNCLEAR/REFUSED/NO RESPONSE - **GO TO QUESTION 72**

71. Can you get an appointment to see your primary care doctor when you need to?

PROXY

Respondent: () 1-individual () 2-child () 3-spouse/partner () 4-other family () 5-PCA () 6-Friend () 7- Other

- 50 **N/A – DOES NOT HAVE A PRIMARY CARE DOCTOR**
- 2 YES, ALWAYS
- 1 USUALLY
- 0 SOMETIMES OR RARELY
- 98 DON'T KNOW
- 100 UNCLEAR/REFUSED/NO RESPONSE

72. In the past year, have you gone to the emergency room for any of the following reasons: **(READ EACH REASON)** **PROXY**

Respondent: () 1-individual () 2-child () 3-spouse/partner () 4-other family () 5-PCA () 6-Friend () 7- Other

Tooth or mouth pain

_2 YES _0 NO _98 DON'T KNOW _100 UNCLEAR/REFUSED/NO RESPONSE

Falling or losing your balance

_2 YES _0 NO _98 DON'T KNOW _100 UNCLEAR/REFUSED/NO RESPONSE

Any other reason

_2 YES _0 NO _98 DON'T KNOW _100 UNCLEAR/REFUSED/NO RESPONSE

73. In the past 12 months, have you stayed overnight in the hospital or a rehab/nursing facility (*and were discharged*)? **(CHECK ALL THAT APPLY)** **PROXY**

Respondent: () 1-individual () 2-child () 3-spouse/partner () 4-other family () 5-PCA () 6-Friend () 7- Other

_2 YES, HOSPITAL

_1 YES, REHAB/NURSING FACILITY

_0 NO - **GO TO QUESTION 76**

_98 DON'T KNOW - **GO TO QUESTION 76**

_100 UNCLEAR/REFUSED/NO RESPONSE - **GO TO QUESTION 76**

74. When leaving the hospital or the rehab/nursing facility, did you feel comfortable and supported enough to go home? **PROXY**

Respondent: () 1-individual () 2-child () 3-spouse/partner () 4-other family () 5-PCA () 6-Friend () 7- Other

_50 **N/A – HAS NOT STAYED IN HOSPITAL OR REHAB/NURSING FACILITY IN PAST 12 MONTHS**

_2 YES

_1 IN-BETWEEN

_0 NO

_98 DON'T KNOW

_100 UNCLEAR/REFUSED/NO RESPONSE

75. After leaving the hospital or rehab/nursing facility and going home, did anyone follow-up with you to make sure you had the services, supports and help you needed? *This could be a doctor, case manager, social worker, or others.* **PROXY**

Respondent: () 1-individual () 2-child () 3-spouse/partner () 4-other family () 5-PCA () 6-Friend () 7- Other

_50 **N/A – HAS NOT STAYED IN HOSPITAL OR REHAB/NURSING FACILITY IN PAST 12 MONTHS**

_51 **N/A – DID NOT NEED OR WANT FOLLOW-UP CARE**

_2 YES

_0 NO

_98 DON'T KNOW

_100 UNCLEAR/REFUSED/NO RESPONSE

76. Have you had the following preventive care? **(READ EACH EXAM)**

PROXY

Respondent: () 1-individual () 2-child () 3-spouse/partner () 4-other family () 5-PCA () 6-Friend () 7- Other

Physical exam/wellness visit (past year)

__50 N/A (E.G. NOT RECOMMENDED) __2 YES __1 NO __98 DON'T KNOW __100 UNCLEAR/REFUSED/NO RESPONSE

Hearing exam (past year)

__50 N/A (E.G. NOT RECOMMENDED) __2 YES __1 NO __98 DON'T KNOW __100 UNCLEAR/REFUSED/NO RESPONSE

Vision exam (past year)

__50 N/A (E.G. NOT RECOMMENDED) __2 YES __1 NO __98 DON'T KNOW __100 UNCLEAR/REFUSED/NO RESPONSE

Flu shot (past year)

__50 N/A (E.G. NOT RECOMMENDED) __2 YES __1 NO __98 DON'T KNOW __100 UNCLEAR/REFUSED/NO RESPONSE

Routine dental visit (past year)

__50 N/A (E.G. NOT RECOMMENDED) __2 YES __1 NO __98 DON'T KNOW __100 UNCLEAR/REFUSED/NO RESPONSE

Cholesterol screening done by a doctor or nurse (in past 5 years)

__50 N/A (E.G. NOT RECOMMENDED) __2 YES __1 NO __98 DON'T KNOW __100 UNCLEAR/REFUSED/NO RESPONSE

77. Have you been diagnosed with a chronic condition or conditions? *Some examples are diabetes, asthma or respiratory disease, arthritis, heart disease, high blood pressure, pressure or bed sores but it could be other conditions that last several months or longer?*

PROXY

Respondent: () 1-individual () 2-child () 3-spouse/partner () 4-other family () 5-PCA () 6-Friend () 7- Other

__2 YES

__0 NO - GO TO QUESTION 79

__98 DON'T KNOW - GO TO QUESTION 79

__100 UNCLEAR/REFUSED/NO RESPONSE - GO TO QUESTION 79

78. Do you know how to manage that chronic condition or conditions?

PROXY

Respondent: () 1-individual () 2-child () 3-spouse/partner () 4-other family () 5-PCA () 6-Friend () 7- Other

__50 N/A – HAS NOT BEEN DIAGNOSED WITH A CHRONIC CONDITION

__2 YES

__1 IN-BETWEEN, OR SOME CONDITIONS

__0 NO

__98 DON'T KNOW

__100 UNCLEAR/REFUSED/NO RESPONSE

79. Do you take or are supposed to take any prescription medications?

PROXY

Respondent: () 1-individual () 2-child () 3-spouse/partner () 4-other family () 5-PCA () 6-Friend () 7- Other

- _2 YES
- _0 NO - **GO TO QUESTION 81**
- _98 DON'T KNOW - **GO TO QUESTION 81**
- _99 UNCLEAR RESPONSE - **GO TO QUESTION 81**
- _100 REFUSED/NO RESPONSE - **GO TO QUESTION 81**

80. Do you understand why you take your medications and what they are for?

PROXY

Respondent: () 1-individual () 2-child () 3-spouse/partner () 4-other family () 5-PCA () 6-Friend () 7- Other

- _50 **N/A – DOES NOT TAKE MEDICATIONS**
- _2 YES
- _1 IN-BETWEEN, OR SOME MEDICATIONS
- _0 NO
- _98 DON'T KNOW
- _100 UNCLEAR/REFUSED/NO RESPONSE

PLANNING FOR FUTURE

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

81. Do you have any of the following forms of decision-making assistance? **(READ RESPONSE OPTIONS) (CHECK**

ALL THAT APPLY)

PROXY

Respondent: () 1-individual () 2-child () 3-spouse/partner () 4-other family () 5-PCA () 6-Friend () 7- Other

- _1 Durable power of attorney (you voluntarily appointed someone to make legal and financial decisions on your behalf if something happens to you)
- _2 Health care proxy (you voluntarily appointed someone to make health care decisions on your behalf if something happens to you)
- _3 Supported decision making (you voluntarily appointed someone to assist you with making decisions about your life)
- _4 Court-appointed legal guardianship (someone else was appointed by the court to make decisions for you in at least one of these areas: medical, personal or financial)
- _5 Living will (written instruction for end of life care)
- _6 NONE OF THE ABOVE
- _98 DON'T KNOW
- _100 UNCLEAR/REFUSED/NO RESPONSE

82. Do the services you receive meet your needs and goals?

PROXY

Respondent: () 1-individual () 2-child () 3-spouse/partner () 4-other family () 5-PCA () 6-Friend () 7- Other

- 50 N/A – PERSON SAID THEY ARE NOT RECEIVING SERVICES**
- 3 YES, COMPLETELY, ALL NEEDS AND GOALS - GO TO QUESTION 85**
- 2 MOSTLY, MOST NEEDS AND GOALS**
- 1 SOMEWHAT, SOME NEEDS AND GOALS**
- 0 NO, NOT AT ALL, NEEDS OR GOALS ARE NOT MET**
- 98 DON'T KNOW - GO TO QUESTION 85**
- 100 UNCLEAR/REFUSED/NO RESPONSE - GO TO QUESTION 85**

83. What additional services might help you? **(TRY TO CLASSIFY) (CHECK ALL THAT APPLY) (FOR ANSWERS THAT MAY FIT INTO TWO CATEGORIES, CODE THE MORE SPECIFIC ANSWER WHEN POSSIBLE)**

PROXY

Respondent: () 1-individual () 2-child () 3-spouse/partner () 4-other family () 5-PCA () 6-Friend () 7- Other

- 50 N/A – SERVICES MEET ALL NEEDS**
- 1 PERSONAL CARE ASSISTANCE, PERSONAL CARE SERVICES (LIKE HELP WITH DRESSING, BATHING, EATING)**
- 2 HOME MAKER/ CHORE SERVICES (LIKE HELP BUYING GROCERIES, CLEANING THE HOUSE, COOKING MEALS, SHOVELING SNOW)**
- 3 COMPANION SERVICES (LIKE HELP WITH PLANNING COMMUNITY OUTINGS, STAYING CONNECTED WITH FRIENDS)**
- 4 HEALTHCARE HOME SERVICES, HOME HEALTH (MEDICAL OR NURSING CARE IN YOUR HOME)**
- 5 HOME DELIVERED MEALS (PREPARED MEALS SENT TO YOUR HOME)**
- 6 CONGREGATE DINING (A MEAL PROVIDED IN THE COMMUNITY)**
- 7 ADULT DAY SERVICES (PLACE WHERE YOU GO DURING THE DAY THAT PROVIDES SOCIAL AND HEALTH-RELATED ACTIVITIES TO PROMOTE YOUR WELL-BEING)**
- 8 TRANSPORTATION (EITHER ACTUAL TRANSPORTATION OR A VOUCHER OR PASS FOR PUBLIC TRANSIT)**
- 9 ASSISTIVE TECHNOLOGY, SPECIALIZED MEDICAL EQUIPMENT (ITEMS, DEVICES, OR PRODUCT SYSTEMS TO INCREASE OR MAINTAIN A FUNCTIONAL STATUS)**
- 10 HOME AND/OR VEHICLE MODIFICATIONS (PHYSICAL CHANGES TO A PRIVATE RESIDENCE, AUTOMOBILE, OR VAN, TO ACCOMMODATE THE PARTICIPANT OR IMPROVE HIS OR HER FUNCTION)**
- 11 RESPITE/FAMILY CAREGIVER SUPPORT**
- 12 HEALTH CARE**
- 13 MENTAL HEALTH CARE**
- 14 DENTAL CARE**
- 15 HOUSING ASSISTANCE (PAYING FOR, FINDING, MAINTAINING, OR CHANGING HOUSING)**
- 16 HEATING/COOLING ASSISTANCE**
- 17 OTHER (FILL IN) _____**
- 98 DON'T KNOW**
- 100 UNCLEAR/REFUSED/NO RESPONSE**

84. **(ONLY ASK IF PERSON SAID THEY HAVE CASE MANAGEMENT/CARE COORDINATION IN QUESTION 12)** Has your case manager/care coordinator talked to you about services that might help with your needs and goals?

Respondent: () 1-individual () 2-child () 3-spouse/partner () 4-other family () 5-PCA () 6-Friend () 7- Other

50 N/A – PERSON SAID THEY DO NOT HAVE A CASE MANAGER

PROXY

51 N/A – SERVICES MEET ALL NEEDS

2 YES

0 NO

98 DON'T KNOW

100 UNCLEAR/REFUSED/NO RESPONSE

85. Do you want any help planning for your future need for services?

2 YES

0 NO

98 DON'T KNOW

100 UNCLEAR/REFUSED/NO RESPONSE

INDEPENDENCE

86. Do you feel in control of your life?

2 YES

1 IN-BETWEEN

0 NO

98 DON'T KNOW

100 UNCLEAR/REFUSED/NO RESPONSE

87. **(OPTIONAL)**. Please tell me, out of these four things **(READ LIST BELOW OUTLOUD)**, which one is the most important to you right now? **(MARK '1' NEXT TO THE ONE CHOSEN)** Okay, now out of the three remaining things **(READ OUTLOUD)**, which is the most important? **(MARK '2' NEXT TO THE ONE CHOSEN)** Okay, now there are two left **(READ OUTLOUD)** – which is more important to you right now? **(MARK '3' NEXT TO THE ONE CHOSEN AND MARK '4' NEXT TO THE REMAINING ONE)**

Health

Safety

Being independent

Being engaged with your community and friends

98 DON'T KNOW

100 UNCLEAR/REFUSED/NO RESPONSE

88. (OPTIONAL). Is there anything else you'd like to tell me that we did not cover today? Keep in mind, this is confidential and anonymous.

THANK YOU!!!!

INTERVIEWER FEEDBACK SHEET

Please take a few minutes to complete a feedback sheet after each interview you complete. Please do not include any personally identifying information regarding yourself or the individual surveyed.

Interviewer's Initials or Code: _____

Survey Code: _____

1. Date of interview: (mm/dd/yyyy) ___ / ___ / _____

2. How long did it take to complete the direct interview (in-person section only)?

__ __ Hours __ __ Minutes

3. Where did the interview take place?

1 Person's home

2 Place other than person's home (FILL IN) _____

4. How difficult was it to gain access to the person?

1 Very difficult

2 Somewhat difficult

3 Not difficult

5. Were there any questions that were problematic, either in the Background Information Section of the survey, or the main Survey itself?

Yes No

If yes, indicate the question number(s) below and describe the problem and any suggestions you have for improvement.

Question: Problem/Suggestions:

_____	_____
_____	_____
_____	_____
_____	_____

6. Who was present during the interview? (CHECK ALL THAT APPLY)

- 1 Person receiving services
- 2 Spouse
- 3 Child
- 4 Other family
- 5 Personal care attendant/direct care worker
- 6 Friend
- 7 Other _____

7. Indicate all respondents during the interview (CHECK ALL THAT APPLY):

- 1 Person receiving services
- 2 Spouse
- 3 Child
- 4 Other family
- 5 Personal care attendant/direct care worker
- 6 Friend
- 7 Other _____

8. Could questions where no proxies are allowed be completed?

- 1 Yes, person answered independently or with some assistance
- 2 Yes, person answered using alternate/picture response format
- 3 No, person could not communicate sufficiently to complete these questions
- 4 No, person was unwilling to participate
- 5 No, other reason

9. In your opinion, did the individual appear to understand most of these questions or not?

- 8 N/A – questions where no proxies are allowed were not completed
- 2 Yes, appeared to understand most questions (even if prompted) and could give an opinion
- 1 Not sure
- 0 No, appeared to have very little understanding or comprehension

10. In your opinion, did the individual seem to answer these questions in a consistent manner? (Do you feel his/her responses were valid?)

- 8 N/A – questions where no proxies are allowed were not completed
- 2 Yes, seemed to give consistent and valid responses
- 1 Not sure
- 0 No, did not seem to give consistent and valid responses

11. Please note anything you or the respondent feels is not covered in the survey
