

Participant Experience Survey

Determining the quality of home and community based services for the elderly and disabled has always been difficult to ascertain. Indeed, the only measurement that AHRQ was able to settle on after a year of careful study was based on readmission or admission to the hospital.

Background

In late December, NASUAD conducted a survey of state agencies on aging and disability to determine if they conducted participant experience surveys. This survey was done at the request of West Virginia. States were asked four basic questions: if the state conducts participants experience survey; the frequency of conducting the survey; how the survey was completed; and who conducts the survey.

To date, 24 states have responded to the survey and this report is based on the sampling from those 24 states. NASUAD will update the report as more states respond.

National Surveys and Tools

In 2003, the Centers for Medicare and Medicaid Services developed a tool for states to administer to clients participating in the Home and Community Based Services Program. The CMS developed survey focuses on four areas: access to care; choice and control; respect/ dignity; and community integration/ inclusion.

The survey was designed to be collected through face to face interviews with the recipients of the services. A copy of the actual survey instrument can be found at http://www.hcbs.org/files/28/1387/3_PES_ED.pdf.

AHRC also developed a survey users' guide for the CMS survey which includes information about the purpose of the survey; how to select the sample; how to choose and train interviewers; how to schedule and prepare for interviews; general interviewing guidelines; how to code the responses; how to analyze the results; and how to act on the findings. A copy of the survey users' guide can be found at <http://www.innovations.ahrq.gov/content.aspx?id=1443>

The administrators of the developmental disability waiver have long had survey instruments in place that ask the individual waiver client their views on the services that they are receiving. In fact, a group of state Developmental Disabilities Directors began a project in 1997 with the goal of encouraging and supporting state Developmental Disabilities agencies to develop a standard set of performance measures that could be used by states to manage quality and across states for making

comparisons and setting benchmarks. 15 states were in the initial phase of the project but each year the number of participating states has grown and they now have 25 states participating and have recently received funding to support the remaining states efforts to join the collaborative.

The Developmental Disabilities directors' core indicators project assesses 100 performance and outcome indicators organized across the following components: individuals outcomes; family outcomes; health, welfare and rights; and system performance. One of the primary data sources for the National Core Indicators project is to gather information directly from service recipients and their families or other representatives. States are expected to interview at least 400 individuals. Additionally, three Family Surveys are administered by mail to collect data on family and guardian perspectives of the quality of services and supports received by adults living at home, adults living outside the home, and children living at home. For each of the Family Surveys, states typically send out 1,000 to 1,200 surveys in order to obtain a target of 400 completed surveys. For a review of the 2009-2010 analysis, visit <http://www.nasdds.org/pdf/2009-2010NCI-Report.pdf>.

Participant Experience Surveys for HCBS for Elderly and Disabled Clients

In programs for the elderly and individuals with disabilities, states do not have the same national toolkit as the developmental disabilities directors have had access to. Many of the states however have collected the data using their own tools. Of the responding states, most of the states reported that the surveys were conducted for the Medicaid HCBS waiver clients and not consumers who receive the broader array of services for the aging and individuals with disabilities such as programs funded through the Older Americans Act.

Frequency of delivery of services

Using the responses of a recent national survey, it was determined that in the states that use a participant experience survey most of the states do the survey annually. A few states indicated that they had done the survey annually but have had to scale back due to state budget reductions.

Types of questions asked in the participant surveys

The questions asked in the survey were generally similar to the categories developed by the Centers for Medicare and Medicaid Services. The majority of states attempt to gather information around the following criteria: overall consumer satisfaction with the

services rendered, satisfaction with the workers who provide the services to the consumer; and the impact of the services rendered.

- Below you will find a list of the questions that the state of Florida uses. Copies of other state agency surveys can be found in the appendix of this document.
- How satisfied are you with how often services are received?
- How satisfied are you with the length of the service visits?
- How satisfied are you with the time of day that services are provided?
- How satisfied are you with the days of the week services are provided?
- Overall, how satisfied are you with the quality of the services you received?
- How satisfied are you that your workers have the knowledge and skills needed to help you?
- How satisfied are you with the way your workers treat you?
- How satisfied are you with the way you and your workers communicate?
- Does your worker usually arrive at the scheduled time?
- Can you usually expect the same person to come help?
- Overall, would you say that the services you receive meet your needs?
- Do these services help you to maintain or improve our quality of life?
- Do these services help you to stay in your home?
- Overall, how satisfied are you with the services you receive?

How the survey is completed

Many states indicated that they were deliberate in their decision making about how the survey is completed and focused on two main factors: conflict free interviewers, and ease of the survey. States reported three main ways of conducting the surveys: by phone, in person, or mail. There were nearly equal numbers of states reporting that they conducted the survey via mail as doing in person face to face interviews. The least reported method of doing the survey was over the phone.

In the states that had face to face interviews or phone interviews, the majority of states used state staff to conduct the interviews. The types of state staff who conducted the surveys varied widely and could include social workers not assigned to the case, nurses, or administrative assistants. One state reported having a university conduct the survey and a few states reported hiring an outside contractor. Minnesota used volunteers with the Ombudsman program who were screened and trained to conduct the survey.

In the states that mailed the surveys out to the recipients most reported taking steps to ensure completion of the survey. For example, prior to sending the survey out case workers would reach out to the clients and indicate that a survey was about to be sent. When the surveys were sent nearly all of the states reported that they mailed the surveys with a stamped envelope to ensure ease of use. The survey instrument in the

states that mailed the surveys out tended to have fewer questions than the surveys conducted by professional state staff and were written in plain easy to understand text.

Conclusion

As the culture of the Aging and Disability Network changes from one in which we were trained to “protect the vulnerable elders and individuals with disabilities” to one focused more on consumer choice and control, so too will the need to be accountable to those consumers for the quality of care that they receive. Conducting participant experience surveys could be one step in that direction.

Appendix 1: State Responses

State	State Has Participant Experience Survey	Frequency	How Survey Is Completed			Survey Performed By
			Face to Face	Phone	Mail	
Alabama						
Alaska						
Arizona						
Arkansas	Have in the past but not at this time					
California	No					
Colorado	Not at state level, but some locals do					
Connecticut						
Delaware						
DC						
Florida	Yes	Annually		X		Department staff
Georgia	Yes					Department staff
Hawaii						
Idaho						
Illinois						
Indiana	Yes	Continually	X			Contractors
Iowa	Yes	Annually			X	Clients with help from family or caregivers
Kansas						
Kentucky						
Louisiana						

State	State Has Participant Experience Survey	Frequency	How Survey Is Completed			Survey Performed By
			Face to Face	Phone	Mail	
Maine						
Maryland						
Massachusetts	Yes	Annually			X	Recipient unless they need ASAP assistance
Michigan	Yes	Quarterly	X	X		Waiver agent staff
Minnesota	Yes	Every 2-3 years	In person's home or where they choose			Volunteers with the MN Ombudsman for LTC
Mississippi						
Missouri	No					
Montana						
Nebraska						
Nevada	Yes	Annually	X			Trained staff
New Hampshire	Yes	20,082,010	X			Nurses, QA staff and the University of NH
New Jersey	Yes	Every other year			X	
New Mexico	Yes	Annually, depending on resources	In recipient's home			State staff
New York	Yes	Annually	X	X	X	Regional Resource Development Center staff
North Carolina	No – planned for summer 2012					
North Dakota	Yes	In 2009		X		The survey was sent to the client and completed by the client or whoever designated
Ohio	Yes	Did 2011, but skipped 2009 and 2010 due to budget constraints		X		

State	State Has Participant Experience Survey	Frequency	How Survey Is Completed			Survey Performed By
			Face to Face	Phone	Mail	
Oklahoma						
Oregon						
Pennsylvania						
Rhode Island						
South Carolina						
South Dakota						
Tennessee						
Texas	Yes	Biennially	X			Contracted/Nurses and social workers
Utah						
Vermont	Yes	Yes		X	X	Contracted
Virginia						
Washington	Yes	Yes		X		Program management staff
West Virginia						
Wisconsin	Yes		Focus Groups	X		
Wyoming						
CNMI	In the process of doing an assessment for all home bound Home Delivered Meals clients					Nurses

State Surveys

- **Indiana**
- **Iowa**
- **Massachusetts**
- **Minnesota**
- **New Hampshire**
- **New Jersey**
- **New Mexico**
- **New York**
- **North Dakota**
- **Ohio**
- **Texas**

Indiana:

Iowa:

SENECA AREA AGENCY ON AGING
OCTOBER 2011
CASE MANAGEMENT REVIEW –ELDERLY WAIVER

In order to provide our Case Management participants with better service and to help us know where improvements need to be made, **please answer the following questions as honestly as possible.**

Please check the appropriate response box	Yes	No
1. Was the Case Management program thoroughly explained to you?		
2. Were your questions answered completely and in a timely manner?		
3. Is your Case Manager friendly, courteous, and professional?		
4. Has receiving these services made your life better?		
5. Did you receive information concerning Seneca AAA grievance procedure?		
6. Did <u>YOU</u> choose which services you wanted and whom you wanted to provide them?		
If you answered "no" to question number 6 who chose the services/provider?		
Do you provide care to an individual helping meet their needs to allow them to remain living in their own home?		

➤ How did you find out about this service?

➤ Comments:

Thank you for taking the time to complete this survey. Your response is important to us!

F:\Users\Peggy\evaluations.serv\Service Evaluations 2011\Case management review 11.doc

Iowa:

Dear Sir or Madam,

You are a Case Management client of _____ Agency on Aging. We would like to find out if you are satisfied with this program and the agencies that have been serving you. Please circle the appropriate answers on this form and return it in the envelope enclosed by December 31, 2011. Thank you.

Program Director

_____ is your Case Manager. She visited you in your home and completed an assessment of your needs. She developed a service plan with you and/or your family to set up services to assist you from area providers.

1. Is your Case Manager courteous and polite?

Yes No Unsure

2. Does your Case Manager answer your questions and assist you with problems?

Yes No Unsure

3. Did your Case Manager tell you about different services that could assist you?

Example: meals, homemaker, emergency response system

Yes No Unsure

4. Were you allowed to pick which agency would provide your service(s)?

Yes No Unsure

5. Are you satisfied with the service you are receiving from the provider(s) assisting you in your home?

Yes No Unsure

Use the lines below for comments or to explain your answers:

Massachusetts:

**Client Satisfaction Survey
Care Management**

Thank you for completing the following survey. This survey is designed to help HESSCO Elder Services ensure that the care management service that we provide is of the highest quality.

Please mark the box with an X that most appropriately describes the quality of service that you receive.

Please return in the enclosed envelope by August 20.

My Care Manager Is: Terry Tomasello

	Yes Definitely	Often	Sometimes	No	Not Applicable
1. My Care Manager follows up to see if the services I get are helpful or need to be changed.					
2. My Care Manager returns calls promptly.					
3. My Care Manager does not listen to what I tell her.					
4. My Care Manager does a good job of helping me get services.					
5. I do not know who my Care Manager is.					
6. My Care Manager understands and cares about me.					

Additional Comments:



Who is filling out this survey? Client Other (List relationship below)

(Example: daughter, niece, son, nephew, friend)

If other, will the client participate in responses? Yes No (If no, briefly explain)

(Example: Communication/memory impaired from illness)

- Instructions -

The next four pages ask about 3 services you may be receiving through your state home care plan and the companies that provide these services.

- (1) Read the descriptions of the services listed below and check off the boxes for the services you receive; **everyone** receiving this survey receives case management and will complete **page one**.
- (2) Fill out the pages of the survey listed next to the services you checked off, **and** the two questions under heading Greater Springfield Senior Services' Staff on page 4.
- (3) If you **do not know** the name of your case manager, personal care worker or homemaker's employer call 781-8800 ask for Mary Beth Dowd.

Case Management (Complete page 1)

Your case manager is from Greater Springfield Senior Services. He or she visits or contacts you every three months to review and update your care plan. They ask about changes to your medications, if you have new doctors, and if you are satisfied with your services. Your case manager adjusts your plan as needed.

List your case manager's name here: _____

Personal Care (Complete pages 2 and 4)

A **personal care worker** helps with hygiene tasks like bathing, dressing, washing your hair foot care, shaving, and cleaning your teeth. They may help you on/off the toilet up and down from a chair and support you as you walk. If you have a homemaker this may be the same person.

Homemaking (Complete pages 3 and 4)

A **homemaker** helps with tasks like making a meal, grocery shopping, cleaning the kitchen and bathroom, vacuuming and making a bed. If you have a personal care worker this may be the same person.

Personal Care Worker/Homemaker Employer. (Complete questions on page 4)

Your **personal care worker or homemaker's employer** notifies you of your worker's schedule, changes in their schedule or service cancellations and makes other arrangements for service with your consent.

List your worker's employer here: _____

- You are ready to begin the questionnaire -



Case Management Services

*In this section, we want to know about your experience with **Greater Springfield Senior Services' case management service.** Your **case manager** either visits or contacts you every three months to review and update your care plan. She or he asks about changes to your medications, if you have any new doctors, and if services are continuing to meet your needs. Your case manager adjusts your plan as needed.*

Instructions:

- (1) Clearly mark the box that best describes your experience. **Choose only one answer.**
- (2) If you respond **Yes to questions 10 and/or 12** please briefly explain on the line provided.
- (3) Responses are kept confidential; your name will not be shared with your case manager.

	<u>Yes</u> <u>Definitely</u>	<u>Yes,</u> <u>I Think</u> <u>So</u>	<u>Maybe</u> <u>Yes,</u> <u>Maybe No</u>	<u>No,</u> <u>I Don't</u> <u>Think So</u>	<u>No,</u> <u>Definitely</u> <u>Not</u>
1. I know I can contact my case manager if I need to.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. The services arranged by my case manager meet my needs.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. My case manager is respectful of me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. My case manager is very knowledgeable about the services that are available.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. When I call GSSSI and leave a message my call is returned within 2 days.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. I helped develop my homecare plan.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. My case manager ignores what I tell her about what things I need.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. My case manager is sensitive and responsive to customs and traditions of my culture or background.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. I can talk to my case manager about my homecare needs.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. I would like more choices about the types of services I get.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
* <i>If yes, briefly describe:</i> _____					
11. Seeing the same case manager for a long time is important to me.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. I wish my case manager could do more things for me that I need to have done.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
* <i>If yes, briefly explain:</i> _____					



Personal Care Services

*In this section we want to know about your experiences with your **personal care service**. A **personal care worker** helps you take care of your hygiene tasks like bathing, dressing, washing your hair, foot care, shaving, and cleaning your teeth. Also they may help you on/off the toilet, up and down from a chair and support you when you walk. If you have a homemaker this may be the same person.*

Instructions:

- (1) Clearly mark the box that best describes your experience. **Choose only one answer.**
- (2) If you respond with a **Yes to question 9**, please briefly explain on the line provided.
- (3) Responses are kept confidential; your name will not be shared with your worker or employer.

	<u>Yes, Definitely</u>	<u>Yes, I Think So</u>	<u>Maybe Yes, Maybe No</u>	<u>No, I Don't Think So</u>	<u>No, Definitely Not</u>
1. My personal care worker is respectful of me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Generally my personal care worker knows what to do.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. I usually have the same personal care worker.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. In general my personal care worker takes an interest in me as a person.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. My personal care worker is sensitive and responsive to customs and traditions of my culture or background.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. My personal care worker arrives late.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. I worry that my personal care worker will be replaced.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. My personal care worker is very thorough.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. I wish my personal care worker could do more things that I need to have done.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
* If yes, please list: _____					
10. My personal care worker ignores what I tell her about the way I like things done.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. My personal care worker leaves too early.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. I would recommend my personal care worker to a friend.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>



Homemaker Services

*In this section we want to know about your experiences with your **homemaking service**. A **homemaker** helps with tasks like making a meal, grocery shopping, cleaning the kitchen and bathroom, vacuuming and making a bed. If you have a personal care worker this may be the same person.*

Instructions:

- (1) Clearly mark the box that best describes your experience. **Choose only one answer.**
- (2) If you respond with a **Yes to question 2**, please briefly explain on the line provided.
- (3) Responses are kept confidential; your name will not be shared with your homemaker or their employer.

	<u>Yes, Definitely</u>	<u>Yes, I Think So</u>	<u>Maybe Yes, Maybe No</u>	<u>No, I Don't Think So</u>	<u>No, Definitely Not</u>
1. My homemaker is very thorough.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. I wish my homemaker could do more things that I need to have done.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
* If yes, please list: _____					
3. My homemaker is respectful of me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Generally my homemaker knows what to do.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. I usually have the same homemaker.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. In general my homemaker takes an interest in me as a person.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. My homemaker is sensitive and responsive to customs and traditions of my culture or background.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. My homemaker leaves too early.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. I worry that my homemaker will be replaced.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. My homemaker ignores what I tell her about the way I like things done.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. My homemaker arrives late.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. I would recommend my homemaker to a friend.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>



Personal Care Worker/Homemaker's Employer

*In this section we want to know about your experience with the agency that employs your personal care worker and/or homemaker. **The employer** notifies you of your worker's schedule, any changes in their schedule or service cancellations and makes other arrangements for service with your consent.*

Instructions:

- (1) Clearly mark the box that best describes your experience. **Choose only one answer.**
- (2) Responses are kept confidential; your name will not be shared with your worker or their employer.

	<u>Yes, Definitely</u>	<u>Yes, I Think So</u>	<u>Maybe Yes, Maybe No</u>	<u>No, I Don't Think So</u>	<u>No, Definitely Not</u>
1. My personal care worker/homemaker's employer notifies me ahead of time when she or he is not coming.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. My personal care worker/homemaker's employer offers me a substitute when my regular worker cannot come.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. I am treated with respect when I contact my personal care worker/homemaker's employer.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. My personal care worker/homemaker's employer returns my calls promptly.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. My personal care worker/homemaker's employer is rude to me.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. My personal care worker/homemaker's employer takes into account my needs and preferences for the time and day of service.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Greater Springfield Senior Services Staff

In this section we want to know your overall experience with Greater Springfield Senior Services.

	<u>Yes, Definitely</u>	<u>Yes, I Think So</u>	<u>Maybe Yes, Maybe No</u>	<u>No, I Don't Think So</u>	<u>No, Definitely Not</u>
1. I am treated with respect by the staff at Greater Springfield Senior Services.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. I would recommend Greater Springfield Senior Services to a friend.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

We sincerely thank you for participating in the Greater Springfield Senior Service 2008 Home Care Survey, and look forward to continuing our commitment to provide services which enable you or someone you love stay at home.

Minnesota:

2009 Elderly Waiver Consumer Experience Survey

Interviewer Instructions

THANK YOU FOR INTERVIEWING THIS CONSUMER OF MINNESOTA WAIVER SERVICES. IN GOING THROUGH THE FOLLOWING SURVEY, PLEASE BE AWARE THAT THE SURVEY IS FORMATTED AS FOLLOWS:

- *All items in **bold** are to be read aloud.
- *All items in CAPS are special instructions for the interviewer.
- *When a series of questions might be skipped, the first question of the series is highlighted with a grey box.
- *Conditional questions are shaded grey because you will only ask that question based on the previous question.

FOR MULTIPLE CHOICE QUESTIONS, PLACE AN "X" IN THE BOX NEXT TO THE ANSWER.

FOR OPEN-ENDED QUESTIONS, CLEARLY WRITE THE RESPONSE IN THE PROVIDED BOX. DO NOT WRITE OUTSIDE OF THE BOX

PLEASE ONLY CHECK ONE ANSWER FOR MOST OF THE QUESTIONS, UNLESS "CHECK ALL THAT APPLY" IS INDICATED IN THE INSTRUCTIONS. IF YOU HAVE ADDITIONAL NOTES, PLEASE WRITE THEM ON A POST-IT NOTE AND PLACE ON THE SURVEY

PLEASE BEGIN FILLING OUT THIS SURVEY BY COMPLETING THE INFORMATION BELOW. WRITE ONLY ONE LETTER/NUMBER IN EACH BOX. THE SURVEY ID # CAN BE FOUND ON YOUR COVER SHEET FOR THIS PARTICIPANT.

Q1	CONSUMER'S INITIALS (FIRST, LAST)	<table border="1" style="border-collapse: collapse; width: 50px; height: 30px;"> <tr> <td style="width: 25px;"></td> <td style="width: 25px;"></td> </tr> </table>					
Q2	CONSUMER'S 3-DIGIT SURVEY NUMBER	<table border="1" style="border-collapse: collapse; width: 80px; height: 30px;"> <tr> <td style="width: 30px;"></td> <td style="width: 25px;"></td> <td style="width: 25px;"></td> </tr> </table>					
Q3	INTERVIEWER INITIALS (FIRST, MIDDLE, LAST)	<table border="1" style="border-collapse: collapse; width: 80px; height: 30px;"> <tr> <td style="width: 30px;"></td> <td style="width: 25px;"></td> <td style="width: 25px;"></td> </tr> </table>					
Q4	INTERVIEW DATE (08 15 07) (numbers only)	<table border="1" style="border-collapse: collapse; width: 100px; height: 30px;"> <tr> <td style="width: 20px;"></td> <td style="width: 20px;"></td> <td style="width: 20px;"></td> <td style="width: 20px;"></td> <td style="width: 20px;"></td> </tr> </table>					

Survey Introduction and Agreement to Participate

Hello, my name is _____. I am an Ombudsman Office volunteer working with the Minnesota Department of Human Services. How are you today? Thank you again for letting me come talk with you. I am very interested in hearing about how things are going in your life and what you think about the services you receive. Before we start the survey, I have some information I'd like to go over with you in case you have questions about my visit today.

You don't have to answer any questions that you don't feel comfortable with. There are no right or wrong answers, just your opinions. All of your answers will be kept confidential. They will not be shared with your program staff or anyone else associated with your care or services. In addition, your participation will not affect any services you are receiving.

You should know, however, that I am a mandated reporter. This means that if I see or learn something that makes me concerned about your health or safety, I am required by law to report this to the Department of Human Services so that someone can make sure that you are safe.

Your name will not be attached to your answers. The report we develop combines the answers from all the people we are visiting and talking with.

The Department of Human Services sent you a letter explaining the survey. On the back of that letter is a Privacy Notice which explains your privacy rights.

Again, I am a volunteer with the Ombudsman Office. I am not connected with your services. If you have questions or concerns about your services, I will be able to give you resources at the end of the interview, but I won't be able to address your questions directly.

Do you agree to participate in this survey? If you could please review and sign this agreement form, so that we have a written record of your agreement. I will leave a copy with you. (HAND COPY OF AGREEMENT FORM TO PARTICIPANT, REVIEW CONTENTS. IF CONSUMER VERBALLY AGREES BUT DOES NOT SIGN, WRITE "AGREES TO PARTICIPATE" AT SIGNATURE LINE". GIVE CONSUMER A COPY OF THE FORM).

Are you ready to begin? 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.

**INTERVIEWER: COMPLETE QUESTIONS BY PLACING AN "X" IN THE APPROPRIATE BOX.
DO NOT WRITE ON SURVEY OUTSIDE OF PROVIDED ANSWER BOXES.**

General Satisfaction Questions

The first set of questions I am going to ask you have to do with your home and your life in general, and how things are working out for you.

Q5 Please tell me how you generally think or feel about the following questions. In general....

		Generally No	Generally Yes	No Response/ Refused	Can't Code	N/A no family (Q5g only)
Q5a	*****Do you like where you're living now?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Q5b	Is your room/apartment/home how you like it to be?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Q5c	Is the place in good condition?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Q5d	Can you get around inside your (room/apartment/home) as much as you need to?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Q5e	*****Are you satisfied with how you spend your free time?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Q5f	*****Can you usually get to the places where you want or need to go, like shopping, for a visit, to church, to get your hair done, to play cards, or to a ball game?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Q5g	*****Are you satisfied with the amount of contact you have with your family?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Q5h	*****Are you satisfied with the amount of contact you have with friends?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Q5i	Is there someone you can count on in an emergency?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Q5j	*****Are you as socially active as you'd like to be - like participating in community activities?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Daily Living

The next questions are about everyday activities, like getting dressed and shopping. Some people can do these things by themselves; others need somebody to help them sometimes with some work, and others need help with most of these things most or all of the time. For the following questions, please think about the last year.

Q6 Thinking about getting **HOUSEWORK** done, would you say...

- | | | | |
|---|---|--|---|
| <input type="checkbox"/> You do your housework yourself | <input type="checkbox"/> Someone helps you with your housework some of the time | <input type="checkbox"/> Someone helps you most or all of the time with your housework | <input type="checkbox"/> No Response/ Refused |
| | | | <input type="checkbox"/> Can't code |

Q7 Have there been times in the last year when you didn't get **HOUSEWORK** done that you would have liked to have done because there was no one to help you?

- | | | | |
|-----------------------------|------------------------------|---|-------------------------------------|
| <input type="checkbox"/> No | <input type="checkbox"/> Yes | <input type="checkbox"/> No Response/ Refused | <input type="checkbox"/> Can't code |
|-----------------------------|------------------------------|---|-------------------------------------|

Q8 Thinking about getting **GROCERIES OR OTHER SHOPPING** done, would you say...

- | | | | |
|--|--|--|---|
| <input type="checkbox"/> You do your shopping yourself | <input type="checkbox"/> Someone helps you with your shopping some of the time | <input type="checkbox"/> Someone helps you most or all of the time with shopping | <input type="checkbox"/> No Response/ Refused |
| | | | <input type="checkbox"/> Can't code |

Q9 Have there been times in the last year when you haven't gotten **GROCERIES OR OTHER SHOPPING** done when you wanted or needed to because there was no one to help you?

- | | | | |
|-----------------------------|------------------------------|---|-------------------------------------|
| <input type="checkbox"/> No | <input type="checkbox"/> Yes | <input type="checkbox"/> No Response/ Refused | <input type="checkbox"/> Can't Code |
|-----------------------------|------------------------------|---|-------------------------------------|

Q10 Thinking about **MAKING MEALS** would you say...

- | | | | |
|---|---|--|---|
| <input type="checkbox"/> You make your meals yourself | <input type="checkbox"/> Someone helps you make your meals or makes your meals for you some of the time | <input type="checkbox"/> Someone helps you make your meals or makes your meals for you most or all of the time | <input type="checkbox"/> No Response/ Refused |
| | | | <input type="checkbox"/> Can't code |

Q11 Have there been times in the last year when you haven't gotten a **MEAL** when you wanted to because there was no one to help you?

- | | | | |
|-----------------------------|------------------------------|---|-------------------------------------|
| <input type="checkbox"/> No | <input type="checkbox"/> Yes | <input type="checkbox"/> No Response/ Refused | <input type="checkbox"/> Can't code |
|-----------------------------|------------------------------|---|-------------------------------------|

Q12 Have there been times in the last year when you have gone hungry?

- | | | | |
|---|------------------------------|---|---|
| <input type="checkbox"/> No (GO TO Q14) | <input type="checkbox"/> Yes | <input type="checkbox"/> No Response/ Refused (GO TO Q14) | <input type="checkbox"/> Can't code (GO TO Q14) |
|---|------------------------------|---|---|

Q13 IF YES, why?

Q14 Thinking about doing LAUNDRY would you say...

You do your laundry yourself
 Someone helps you with your laundry some of the time
 Someone helps you most or all of the time with your laundry
 No Response/Refused
 Can't code

Q15 Have there been times in the last year when you haven't gotten LAUNDRY done that you needed to get done because there was no one to help you?

No
 Yes
 No Response/Refused
 Can't code

Q16 Thinking about getting DRESSED, would you say...

You get dressed by yourself
 Someone helps you get dressed sometimes
 Someone helps you get dressed most or all of the time
 No Response/Refused
 Can't code

Q17 Have there been times in the last year when you couldn't get DRESSED when you wanted to because there was no one to help you?

No
 Yes
 No Response/Refused
 Can't code

Q18 Does someone help you use the BATHROOM

No (can perform independently with no help)
 Yes (needs help with this activity)
 No Response/Refused
 Can't code

Q19 Have there been times in the last year when you couldn't use the BATHROOM when you needed to because there was no one to help you?

No
 Yes
 No Response/Refused
 Can't code

Q20 Does someone help you take a BATH OR SHOWER

No (can perform independently with no help)
 Yes (needs help with this activity)
 No Response/Refused
 Can't code

Q21 Have there been times in the last year when you couldn't take a BATH OR SHOWER when you wanted to because there was no one to help you?

No
 Yes
 No Response/Refused
 Can't code

Q22 Does someone help you GET OUT OF BED?

No (can perform independently with no help)
 Yes (needs help with this activity)
 No Response/Refused
 Can't code

Q23 Have there been times in the last year when you couldn't GET OUT OF BED when you wanted to because there was no one to help you?

No
 Yes
 No Response/Refused
 Can't code

Q24 Does someone help you EAT? (NOTES FEEDING; DOES NOT INCLUDE MEAL PREPARATION)
 No (can perform independently with no help) Yes (needs help with this activity) No Response/ Refused Can't code

Q25 Have there been times in the last year when you couldn't EAT when you wanted to because there was no one to help you?
 No Yes No Response/ Refused Can't code

I will now read several statements about MEDICATIONS.

Q26 Do you take any MEDICATIONS- including pills, injections or other types of medications?
 No (GO TO Q32) Yes No Response/ Refused Can't code

IF YES, ASK THE FOLLOWING QUESTIONS. IF NO, GO TO Q32.

Q27 IF YES, Does someone set up your pills for you? (CODE YES, IF ANY AT ALL)
 No (sets them up on own or does not take pills) [GO TO Q29] Yes No Response/ Refused Can't code

Q28 IF YES, have there been times when you haven't been able to get someone to set up your pills for you?
 No Yes No Response/ Refused Can't code

Q29 Does someone help you take your medication, such as giving you an injection or putting the pills in your mouth or hand? (NOTES ADMINISTRATION OF MEDICATION- CODE YES, IF ANY AT ALL)
 No (administers to self) (GO TO Q31) Yes No Response/ Refused Can't code

Q30 IF YES, have there been times when you haven't been able to take your medication when you needed to because someone couldn't give it to you?
 No Yes No Response/ Refused Can't code

Q31 Do you ever have problems getting your medication? (Such as there is no one to pick them up for you from the pharmacy or they cannot be delivered?)
 No Yes No Response/ Refused Can't code

Informal Caregivers

The next few questions are about the people who might help you with the activities we talked about a little while ago. I'd like you to first think about any **FAMILY** or **FRIENDS** who might help you in your daily life with things such as cleaning, eating, bathing or any of the other activities we just discussed.

Q32 Do any of your **FAMILY** or **FRIENDS** regularly help you with any of the activities we just discussed? SUCH AS CLEANING, EATING, BATHING

- No (SKIP TO Q 38)
 Yes
 No response- (SKIP TO Q38)
 Can't code- (SKIP TO Q38)

REMEMBER, THIS SECTION IS ASKING ABOUT INFORMAL CAREGIVERS. DO NOT COMPLETE THIS SECTION ABOUT A PAID STAFF PERSON (UNLESS IT IS A FAMILY MEMBER THAT IS ALSO PAID TO HELP THE CONSUMER).

Q33 What is the name of the family member or friend who provides you with the **most** help? (WRITE DOWN FIRST NAME)

INSERT CAREGIVER'S FIRST NAME FROM Q33 INTO QUESTIONS 35-37.

Q34 What is this person's relationship to you?

- | | | | |
|---|--|-----------------------------------|---|
| <input type="checkbox"/> Wife | <input type="checkbox"/> Son | <input type="checkbox"/> Grandson | <input type="checkbox"/> Friend |
| <input type="checkbox"/> Husband | <input type="checkbox"/> Daughter-in-law | <input type="checkbox"/> Sister | <input type="checkbox"/> No Response/ Refused |
| <input type="checkbox"/> Domestic partner/boyfriend or girlfriend | <input type="checkbox"/> Son-in-law | <input type="checkbox"/> Brother | <input type="checkbox"/> Can't code |
| <input type="checkbox"/> Daughter | <input type="checkbox"/> Granddaughter | <input type="checkbox"/> Neighbor | <input type="checkbox"/> Other |

Q34a IF OTHER LIST HERE:

Q35 Does _____ help you with... ASK EACH ACTIVITY INDIVIDUALLY.
CHECK IF ANSWER IS YES

- | | |
|--|--|
| <input type="checkbox"/> Housework/cleaning | <input type="checkbox"/> Setting up or taking medicine |
| <input type="checkbox"/> Home or yard maintenance | <input type="checkbox"/> Getting dressed |
| <input type="checkbox"/> Finances (banking, paying bills) | <input type="checkbox"/> Using the bathroom |
| <input type="checkbox"/> Making appointments | <input type="checkbox"/> Bathing or showering |
| <input type="checkbox"/> Transportation (rides around town) | <input type="checkbox"/> Getting out of bed or chairs |
| <input type="checkbox"/> Laundry | <input type="checkbox"/> Eating (not meal preparation) |
| <input type="checkbox"/> Getting groceries or other shopping | <input type="checkbox"/> Anything else? |
| <input type="checkbox"/> Making meals | |

Q35a IF ANYTHING ELSE, WRITE IN HERE:

Q36 Is _____ paid to provide this help for you? YOU CAN ALSO ASK CAREGIVER IF THEY ARE PRESENT

- | | | |
|---|-------------------------------------|--|
| <input type="checkbox"/> Yes (for everything I mentioned above) | <input type="checkbox"/> No | <input type="checkbox"/> No Response/Refused |
| <input type="checkbox"/> Yes (for some help) | <input type="checkbox"/> Don't know | <input type="checkbox"/> Can't code |

SKIP TO QUESTION 52 IF CAREGIVER OR FAMILY IS PRESENT AT INTERVIEW

Q37 Overall, how would you rate the quality of care or help that you get from _____?

- | | | | | | |
|------------------------------------|-------------------------------|-------------------------------|-------------------------------|--|-------------------------------------|
| <input type="checkbox"/> Excellent | <input type="checkbox"/> Good | <input type="checkbox"/> Fair | <input type="checkbox"/> Poor | <input type="checkbox"/> No Response/Refused | <input type="checkbox"/> Can't Code |
|------------------------------------|-------------------------------|-------------------------------|-------------------------------|--|-------------------------------------|

Experience with Paid Staff

Earlier we talked about things you need help with. The next questions are about the people who may be paid to come and help you with the things you need. (IF NEEDED, REMIND CONSUMER OF THE THINGS THEY INDICATED THEY NEED HELP WITH.)

Q38 Is anyone paid to help you with any of these things?

No (GO TO Q52)
 Yes
 Don't Know (GO TO Q52)
 No Response/Refused (GO TO Q52)
 Can't Code (GO TO Q52)

IF "YES" THE PERSON HAS PAID HELP, ASK THE FOLLOWING QUESTIONS. IF THE PERSON DOES NOT HAVE PAID HELP, SKIP TO QUESTION 52.

INTERVIEWER: IF PAID STAFF IS PRESENT AT INTERVIEW, DO NOT COMPLETE THIS SECTION AND GO TO Q52

Q39 Did you help choose the people who are paid to help you?

No
 Yes (GO TO Q41)
 Don't Know
 No Response/Refused
 Can't code

Q40 IF NO, would you like to pick the people who are paid to help you?

No
 Yes
 Don't know
 No Response/Refused
 Can't code

For the next few questions, I'd like you to think about the people paid to help you in the last year and if they ALWAYS, USUALLY, SOMETIMES, or NEVER do these things.

Q41 In the past year, did the people who are paid to help you.....

	Always	Usually	Sometimes	Never	No Response/Refused	can't code
Q41a Come when they are supposed to?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Q41b Stay as long as they are supposed to?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Q41c Respect your privacy?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Q41d Do the things that you want them to do?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Q41e Treat you respectfully?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

In the past year...

Q42 Did staff do things that you didn't want them to do?

No
 Yes (INCLUDES SOMETIMES)
 No Response/Refused
 Can't code

Q43 Did staff ever throw things away without asking you first?

No
 Yes (INCLUDES SOMETIMES)
 No Response/Refused
 Can't code

Q44 Have there been changes in staff that have been a problem for you?

No
 Yes (INCLUDES SOMETIMES)
 No Response/Refused
 Can't code

Q45 How would you rate the overall quality of the paid help you receive?
 Excellent Good Fair Poor No Response/Refused Can't code

Q46 Would you recommend the people who are paid to help you to someone else?
 No Yes Some staff yes, some staff no No Response/Refused Can't code

Q47 Compared to what you expected, would you say that the paid help you get is BETTER than you expected, ABOUT THE SAME as you expected or WORSE than you expected?
 Better About the same Worse Don't know No Response/Refused Can't code

Q48 Who would you call or talk to if you wanted to change the services you receive in your home? (IF ANSWER IS "NO ONE", WRITE THAT IN)

Q49 What is this person's relationship to you?
 Family (spouse, child, grandchild, other family) County case manager/Health Plan care coordinator Other community coordinator (from church or other organization) No Response/Refused
 Friend or neighbor Staff from provider agency Other
 IF OTHER LIST HERE:

Q50 Who would you call or talk to if you wanted to complain about the services you receive in your home? (IF ANSWER IS "NO ONE", WRITE THAT IN)

Q51 What is this person's relationship to you?
 Family (spouse, child, grandchild, other family) Health Plan care coordinator/ County case manager Other community coordinator (from church or other organization) No Response/Refused
 Friend or neighbor Staff from provider agency Other
 IF OTHER LIST HERE:

Experience with Care Management

As you know, there is a person called a care coordinator or case manager who works for a health plan or for the county social services or public health office. Our records indicate that your current care coordinator/case manager is _____ [ENTER NAME OF CARE COORDINATOR/CASE MANAGER FROM RESOURCE SHEET HERE].

_____ is responsible for working with you to make sure you get the services or supports you need to stay in your home.

Q52 Is _____ the person who works with you?
 No (GO TO Q53) Yes (GO TO Q55) No Response/Refused (GO TO Q53) Can't code (GO TO Q53)

Q53 IF NO, do you know _____ ?
 No (GO TO Q54) Yes (GO TO Q55) No Response/Refused (GO TO Q54) Can't code (GO TO Q54)

Q54 IF NO, who is your case manager?

IF THE CONSUMER CAN IDENTIFY THEIR CASE MANAGER (EVEN IF DIFFERENT FROM ABOVE), COMPLETE THIS SECTION. OTHERWISE SKIP THIS SECTION AND GO TO Q64.

IF YES, When answering the next questions, please think of _____

Q55 Thinking about the last year, about how often has _____ contacted you by phone or visited you?
 More than once a month Every few months Not at all No Response/Refused
 About once a month About once a year Don't know Can't code

Q56 Has _____ helped you solve a problem that you have told them about?
 No Yes (GO TO Q58) Not applicable (Never asked. Never had a problem) Don't know No Response/Refused Can't code

Q57 (IF NO, N/A OR DON'T KNOW) Do you feel that _____ would help you if you did have a problem?
 No Yes Don't know No Response/Refused Can't code

Q58 Have you ever talked with _____ about any special equipment or change to your services that might make your life easier?
 No (GO TO Q60) Yes No Response/Refused (GO TO Q60) Can't code (GO TO Q60)

Q59 IF YES, Did he/she make the changes you asked for?

- No
 Yes
 Somewhat
 No Response/Refused
 Can't code

Q60 When talking to you about your services, has _____ ever given you information about the providers you can choose from to help you with your needs?

- No
 Yes
 Don't know
 No Response/Refused
 Can't code

Q61 Have you had a change in case managers/care coordinators in the past year?

- No (GO TO Q64)
 Yes
 No Response/Refused (GO TO Q64)
 Can't code (GO TO Q64)

Q62 IF YES, has this been a problem for you?

- Very much so
 Somewhat
 Not at all (GO TO Q64)
 No Response/Refused (GO TO Q64)
 Can't code (GO TO Q64)

Q63 IF VERY MUCH SO or SOMEWHAT please explain:

Housing

The next set of questions are about where you live.

Q64 I don't want to presume anything. What kind of home do you live in?

- Your own house or condo that you own
 Your own house or apartment that you rent
 The home of family or friends
 Assisted living or housing with services
 Adult Foster Care
 No Response/Refused
 Can't code
 Other?

Q64a

IF OTHER LIST HERE:

Q65 Approximately how long have you lived here?

- Less than 1 year
 1-3 years
 4-5 years
 6-10 years (SKIP TO Q69)
 over 10 years (SKIP TO Q69)
 No Response/Refused
 Can't code

IF THE CONSUMER HAS LIVED IN THEIR CURRENT HOME FOR 5 YEARS OR LESS, ASK THE FOLLOWING QUESTIONS, OTHERWISE SKIP TO Q69.

Q66 (IF 5 YEARS OR LESS) Where did you live before you came here?

- | | | | |
|---|---|--|-------------------------------------|
| <input type="checkbox"/> In my own home | <input type="checkbox"/> Assisted living or housing with services | <input type="checkbox"/> Nursing home | <input type="checkbox"/> Can't code |
| <input type="checkbox"/> With family or friends | <input type="checkbox"/> Adult foster care | <input type="checkbox"/> No Response/Refused | <input type="checkbox"/> Other |

Q66a

IF OTHER LIST HERE:

Q67 Why did you move here? (CHECK ALL THAT APPLY)

- | | | | |
|--|--|---|--|
| <input type="checkbox"/> I couldn't get the services I needed | <input type="checkbox"/> I didn't feel safe living there | <input type="checkbox"/> It was too expensive to live there | <input type="checkbox"/> Other |
| <input type="checkbox"/> I was having a hard time keeping up with housework and chores | <input type="checkbox"/> I didn't have the transportation I needed to get around | <input type="checkbox"/> I wanted to be closer to my family | <input type="checkbox"/> No Response/Refused |
| | | <input type="checkbox"/> My family wanted me to | <input type="checkbox"/> Can't code |

IF OTHER LIST HERE:

Q68 Thinking about the decision for you to move here, would you say

- | | | | | |
|--|--|--|--|-------------------------------------|
| <input type="checkbox"/> I made the decision all by myself | <input type="checkbox"/> I made the decision with help from others | <input type="checkbox"/> Someone else made the decision for me | <input type="checkbox"/> Other | <input type="checkbox"/> Can't code |
| | | | <input type="checkbox"/> No response/Refused | |

Q68a

IF OTHER LIST HERE:

Q69 Have you thought about moving

- | | | | |
|---|------------------------------|--|-------------------------------------|
| <input type="checkbox"/> No (GO TO Q71) | <input type="checkbox"/> Yes | <input type="checkbox"/> No Response/Refused | <input type="checkbox"/> Can't code |
|---|------------------------------|--|-------------------------------------|

Q70 (IF YES) Why would you move? (CHECK ALL THAT APPLY)

- | | | | |
|---|---|---|--|
| <input type="checkbox"/> I can't get the services I need here | <input type="checkbox"/> I don't feel safe living here | <input type="checkbox"/> It is too expensive to live here | <input type="checkbox"/> Other |
| <input type="checkbox"/> I am having a hard time keeping up with housework and chores | <input type="checkbox"/> I don't have the transportation I need to get around | <input type="checkbox"/> I want to be closer to my family | <input type="checkbox"/> No Response/Refused |
| | | <input type="checkbox"/> My family wants me to | <input type="checkbox"/> Can't code |

Q70a

IF OTHER LIST HERE:

Your Safety

The next set of questions I have for you are about your safety. I'd like for you to think about how you generally feel about the next questions.

- Q71 *****In general, do you feel safe here in your home?
- Generally no
 Generally yes (GO TO Q73)
 No Response/Refused
 Can't code

Q72 IF NO, why not?

- Q73 In general, do you feel like your belongings are safe here?
- Generally no
 Generally yes (GO TO Q75)
 No Response/Refused
 Can't code

Q74 IF NO, why not?

- Q75 In general, do you feel safe when you go out?
- Generally no
 Generally yes (GO TO Q77)
 No Response/Refused
 Can't code

Q76 IF NO, why not?

Next I am going to ask you some questions about how you are treated by others. You can choose whether or not to answer these questions. I want to remind you that I am a mandated reporter so that if you tell me something that worries me, I will need to tell someone about it to make sure that you are safe.

- Q77 In the last year, has anyone said mean things to you, yelled at you, or threatened you?
- No (GO TO Q80)
 Yes
 Unsure (GO TO Q80)
 No Response/Refused (GO TO Q80)
 Can't Code (GO TO Q80)

- Q78 IF YES, who has done this? (CHECK ALL THAT APPLY)
- Spouse or significant other
 Someone paid to help you
 A stranger
 No Response/Refused
- Family member
 A friend or acquaintance
 Unknown
 Can't code

Q79 IF YES, can you tell me what happened?

Q80 In the last year, have you been hit or hurt by anyone?

No (GO TO Q83) Yes Unsure (GO TO Q83) No Response/Refused (GO TO Q83) Can't code (GO TO Q83)

Q81 IF YES, who has done this? (CHECK ALL THAT APPLY)

Spouse or significant other Someone paid to help you A stranger No Response/Refused
 Family member A friend or acquaintance Unknown Can't code

Q82 IF YES, can you tell me what happened?

Q83 In the last year, has anyone taken (or stolen) money from you or put pressure on you to give them money?

No (GO TO Q83) Yes Unsure (GO TO Q83) No Response/Refused (GO TO Q83) Can't code (GO TO Q83)

Q84 IF YES, who has done this? (CHECK ALL THAT APPLY)

Spouse or significant other Someone paid to help you A stranger No Response/Refused
 Family member A friend or acquaintance Unknown Can't code

Q85 IF YES, can you tell me what happened?

Wrapping Up

We just have a few more questions to go through.

Q86 Thinking overall, would you say that the help you receive has made your life....NOTE "HELP" MAY INCLUDE MEDICAL DEVICES/EQUIPMENT AS WELL AS DIRECT SERVICES

Better
 About the same
 Worse
 No Response/Refused
 Can't code

Q87 Are there other kinds of services you think would help you that you don't have now?

No (GO TO Q89)
 Yes
 No Response/Refused (GO TO Q89)
 Can't Code (GO TO Q89)

Q88 If so, what services would be helpful to you?

Q89 Are there any types of equipment or devices you think would help you that you don't have now?

No (GO TO Q91)
 Yes
 No Response/Refused (GO TO Q91)
 Can't Code (GO TO Q91)

Q90 If so, what equipment or devices would be helpful to you?

Q91 Are there any changes to your home you think would help you that you don't have now? (IF EXAMPLES ARE NEEDED, CAN GIVE "SUCH AS A RAMP or WIDENED DOORWAYS")

No (GO TO Q93)
 Yes
 No Response/Refused (GO TO Q93)
 Can't Code (GO TO Q93)

Q92 If so, what changes to your home would be helpful to you?

Q93 Are you getting any services or help that you'd rather NOT have?

No (GO TO Q95)
 Yes
 No Response/Refused (GO TO Q95)
 Can't code (GO TO Q95)

Q94 IF YES, can you tell me about that?

I am just going to take a minute to review some of your answers to see if there's anything I missed.

INTERVIEWER: REVIEW CONSUMER'S ANSWERS TO Q87-94. IF CONSUMER INDICATED A NEED IN ANY AREA, ASK FOLLOWING QUESTION:

Q95 You noted that you have a need for _____ (or don't want _____). Have you told your case manager about this?

No
 Yes
 No Response/Refused
 Can't code

Q96 *****That's all the questions I have for you. Is there anything else you'd like to tell me about?

Thank you for taking the time to talk with me. Before I go, I want to give you this. GIVE THANK YOU CARD AND PEN TO PARTICIPANT.

Here is a resource sheet with your case manager's name and phone number and some other resources. [GIVE CONSUMER RESOURCE SHEET. IF CONSUMER RAISED ANY CONCERNS DURING INTERVIEW, MENTION THESE AND TELL CONSUMER THEY SHOULD CALL CASE MANAGER.]

After I leave, if you think of other information that you'd like to share, you can call someone in our office or your case manager or care coordinator.

Thank you again for your cooperation. It was nice talking to you!

INTERVIEWER: PLEASE COMPLETE THE FOLLOWING. ENTER ONE NUMBER/LETTER IN EACH BOX.

Q97 Length of time to complete survey (exclude time spent visiting or not on survey)

Time Started
(ex: 9:45AM)

--	--	--	--	--	--	--	--

Time Finished
(ex: 10:30AM)

--	--	--	--	--	--	--	--

New Hampshire:

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.

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

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

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)

- 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?

- 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?

- 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?

- 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?

- 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?

- 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

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

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?

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?

- 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?

- 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

42. Who is your case manager or support coordinator?

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

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?

- 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?

- 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

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

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

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

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?

ASK Q.62 IF RESPONDENT IS UNDER 65 YEARS OF AGE,
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

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

E. Interviewer Comments and Observations

What amount of the questions did the program participant answer by him/herself?

ALL

MOST

ABOUT HALF

SOME

A FEW

NONE

Who else provided responses? (If applicable)

New Jersey:

- The person completing this form is:
- Enrolled in the Global Options for Long-Term Care Medicaid Waiver program (GO)
 - A caregiver of someone enrolled in GO
 - Previously enrolled in GO

Please mark the answer that fits your response to the following statements:

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1. It was easy to apply for the Global Options (GO) program.					
2. I am treated with respect and courtesy.					
3. The GO program was explained to me.					
4. I participated in creating my Plan of Care.					
5. My personal goals are in my Plan of Care.					
6. I had a choice of services.					
7. I received services quickly.					
8. I am getting the services I need.					
9. When my condition and care needs change, my Plan of Care is updated.					
10. I had a choice of providers.					
11. I am satisfied with my providers.					
12. I can contact my Care Manager when needed.					
13. My Care Manager is helpful and clearly understands my needs.					
14. My Care Manager reviewed with me what to do in case of an emergency & helped me create a back-up plan for such situations. <input type="checkbox"/> N/A*					

Please mark the answer that fits your response to the following statements:	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
15. I know what to do if I have a problem with a service or need to make a complaint/grievance.					
16. I would refer a friend to this program.					
17. I feel safe and secure where I live.					
18. Through this program, I would like to hire a friend or relative to help me.					
The next two (2) questions apply ONLY for those GO participants residing in an Assisted Living facility or Adult Family Care home - (Optional to indicate facility name: _____)					
19. The facility staff is helpful and supportive.					
20. My Co-Pay is acceptable. <input type="checkbox"/> N/A*					
The last four (4) questions are for ALL survey respondents:					
21. Prior to enrolling on GO, did you ever consider living in a nursing facility as an option?	<input type="checkbox"/> YES	<input type="checkbox"/> NO			
22. Currently, if you didn't receive help through the GO program, might you need to live in a nursing facility?	<input type="checkbox"/> YES	<input type="checkbox"/> NO	<input type="checkbox"/> MAYBE		
23. What do you like most about the Global Options (GO) program?					
24. What can be done to improve the Global Options (GO) program?					
If you would like to talk to a State program representative, please call: 1-800-792-8820 or if you want someone to contact you, please provide the following information: NAME: _____ PHONE#: () - - -					

Please return this survey by mail to:

N.J. Department of Health and Senior Services, Division of Aging and Community Services
 P.O. Box 807, Trenton, N.J. 08625-0807

New Mexico:

CoLTS (1915c) Waiver - Participant Quality Review

Reviewer: _____ Date: _____

Participant Name: _____

Respondent: _____

Relationship: _____

A. Service Coordination Questions:

1. Do you know the name of your Service Coordinator and how to contact them?

- Yes
- No
- Unsure

SC Name: _____

2. Can you talk to your Service Coordinator when you need to?

- Yes
- No
- Sometimes

2a. How long do they take to get back to you?

- Within 2 days
- 3 to 7 days
- More than a week
- Never

3. Do you know who to talk to if your Service Coordinator is not available?

- Yes
- No
- Unsure

4. Have you had a specific medical or behavioral health issue?

- Yes
- No [if no, skip question 5]

4a. If yes, did you contact your service coordinator about this issue?

- Yes
- No

4b. If yes, did your service coordinator respond to the issue?

- Yes
- No

4c. How long did it take for your service coordinator to get back with you?

- Within 2 days
- 3 to 7 days
- More than a week
- Never

5. Have you ever talked with your Service Coordinator about any special equipment, or changes to your home that might make your life easier?

- Yes
- No

5a. If yes, what happened? _____

6. Did your Service Coordinator give you a 'rights and responsibilities' form to sign and explain it to you?

- Yes
- No
- Unsure

7. Were you ever told by your Service Coordinator, that you may be eligible to receive 'value added benefits' at no additional cost?

- Yes
- No
- Unsure

7a. If yes, what types of 'value added benefits' have you received? _____

Note: some participants might not know what these benefits are -provide the handout depending on the relevant MCO.

8. Do you believe that you are being treated with respect by your Service Coordinator?

- Yes
- No
- Sometimes

8a. If no, can you briefly tell me what happened? _____

B. Service Plan Questions:

For this next section please explain the level of care (LOC) assessment. This is the assessment done by the nurse from Molina or the service coordinator.

1. Do you believe that the result of your 'level of care assessment' identifies your real needs?

- Yes
- No
- Unsure

2. Do members of your family or friends provide a portion of your care each week?

- Yes
- No
- Sometimes

2a. If the answer is no or sometimes, have you made a request for a family member to provide a portion of your care that went unaddressed?

- Yes
- No

2b. If yes, please explain: _____

3. Did you participate in the creation of your Individualized Service Plan (Plan of Care)?

- Yes
- No
- Unsure

4. Were you given a copy of your latest Individualized Service Plan (Plan of Care) at the time it was completed?

- Yes
- No
- Unsure

5. Have you ever experienced any period of time where you could not receive services?

- Yes
- No
- Sometimes

5a. If yes, can you briefly describe what happened? _____

6. Do you believe that you are receiving all of the services and supports that are specified on your plan?

- Yes
- No
- Unsure

6a. If no, pick one of the following that best describes the issue:

- Reduced hours
- No provider in the area
- Staff does not show up
- Transportation
- Other _____

Note: “Supports” are any services that are not paid by Medicaid. This could include: family, friends, neighbors, church, community organizations, senior centers, Meals on Wheels, etc.

7. Do you believe that you are receiving all the hours that are specified in your Individualized Service Plan (Plan of Care)?

- Yes
- No
- Sometimes
- Unsure

7a. If the answer is no or sometimes, please explain: _____

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

- Yes
- No
- Sometimes

8a. If the answer is yes or sometimes, please explain the reason: _____

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

- Yes
- No

- Sometimes

9a. If yes, pick one:

- No money for co-pay
- Meds not covered by plan
- No Transportation
- No one to pick it up
- Other _____

10. Have you ever had an unresolved problem with your care where you chose to request a fair hearing?

- Yes
- No
- In Process

10a. Did the fair hearing occur

- Yes
- No

C. Provider and Community Access Questions

1. Do you feel safe in your home?

- Yes
- No

1a. Explain the reason for either answer: _____

2. Do you feel safe while you are out in your community or neighborhood?

- Yes
- No

2a. Explain the reason for either answer: _____

3. 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?

- Yes
- No

4. Do you feel safe with the people (providers) that come into your home to provide your services?

- Yes
- No
- Sometimes

4a. If no or sometimes, please explain: _____

5. Can you always get to the places you need to go, like the doctor's office, or visit your family?

- Yes
- No
- Sometimes

5a. If no, pick the reason why:

- No Transportation
- Unreliable Transportation
- Need assistance
- Other _____

6. Do you have enough money to pay your basic living expenses so you can stay in your home?

- Yes
- No
- Sometimes

6a. If no or sometimes, please explain: _____

7. Do you believe that you are being treated with respect by your health care providers?

- Yes
- No
- Sometimes.

7a. If no or sometimes, please explain: _____

D. Incident Reporting

1. Did your Service Coordinator explain what abuse, neglect or exploitation is?

- Yes
- No

1a. Did she/he explain what you should do if you believe you have been abused, neglected or exploited?

- Yes

No

2. In the last 12 months, have you suspected that you've been abused, neglected or exploited?

Yes

No

2a. If yes, can you briefly describe what happened? _____

2b. Did you file an incident report about it?

E. Other Questions/Comments:

1. Are there other things you would like to tell us about?

- [Comment Section]
-
-

New York:

August XX, 2011

Dear Nursing Home Transition and Diversion Waiver Participant:

The State Department of Health is conducting a voluntary survey of participants in the Nursing Home Transition and Diversion (NHTD) Medicaid Waiver. The purpose of the survey is to get feedback on how satisfied you are with the services you receive from the waiver.

We appreciate your taking the time to complete the survey; your input and comments are important to us and your participation in the survey will help us improve the program for everyone. The survey

is voluntary and will be kept confidential. Please complete the survey, place it in the self-addressed return envelope and mail it back by **XXXXXX**.

If you have any questions, please contact **(XXXX RRDS NAME)** at **(XXX) XXX-XXXX (RRDS phone number)**. We appreciate your time and cooperation and thank you in advance for your assistance.

Sincerely,

[LEAD RRDS]

[RRDC ADDRESS]

Long Term Home Health Care Program (LTHHCP)

AIDS Home Care Program (AHCP)

Consumer Satisfaction Survey

NAME: _____ CIN#: _____ DATE: _____
(Optional) (Optional) (Required)

Please complete the following if you are currently enrolled in the LTHHCP/AHCP waiver.

*Your opinions are important to help improve the program. Responses to these questions will **not** affect your ongoing participation in the LTHHCP or AHCP.*

Are you satisfied with the LTHHCP or AHCP overall?

Yes No N/A

Are you satisfied with the services you have received in the LTHHCP or AHCP?

Yes No N/A

Are you satisfied with the LTHHCP agency/staff?

Yes No N/A

Comments: _____

Thank you for your assistance. You may request a copy of this survey for your records.

Care at Home (CAH) I/II Waiver Program *Satisfaction Survey - March 2010*

1. Today's date: ____/____/____ 2. Child's Date of Birth: ____/____/____
month day year month day year

3. Gender of CAH participant: 4. County of Residence _____

Male Female

5. Your relationship to CAH Participant:

Parent Aunt/Uncle
 Grandparent Foster Parent
 Guardian Other (Specify: _____)

6. Where did you first learn about the CAH Waiver Program?

Hospital Pediatrician Clinic
 Neighbor/friend Case Manager Internet
 Other (Specify: _____)

7. How often do you contact your child's Case Manager?

More than once a week Once a week Twice a month
 Once a month Once every two months Once every three months
 Less than once every three months

8. How often does your child's Case Manager visit your home or call you regarding your child's status or needs?

More than once a week Once a week Twice a month
 Once a month Once every two months Once every three months
 Less than once every three months

9. Is this enough contact to meet the needs of your child?

- Yes, just the right amount No, would like more contact No, would like less contact

10. How effective is your child's Case Manager in addressing his/her needs?

- Very Ineffective Ineffective Effective Very effective

11. Are you considering changing your Case Manager or Case Management Agency?

- No Yes → Case Manager
 Case Management Agency

12. Do you know how to make a complaint or voice a concern about the CAH Waiver Program?

No

Yes → Have you ever made a complaint or voiced a concern about the CAH Waiver Program?

No

Yes → Were you satisfied with the outcome? No Yes

13. Is information about CAH Waiver program readily available?

- No Yes

Please explain:

14. Do feel that you have a choice of providers?

Yes

No → Why not?

15. Is there anyone besides yourself who is trained to and currently helps care for your child?

No

Yes→ Who? (Please check all that apply)

Spouse

Grandparent

Aunt/uncle

Sibling

Friend

Other (Who? _____)

Other (Who? _____)

How often do you rely on the above to help when you are unable to be with your child?

More than once a week

Once a week

Once a month

Twice a month

Once every two months

Once every three months

Less than once every three months

For what reasons do you use the above care giver(s)? (Check all that apply)

Not enough nursing hours

Family time with other children

Paid help does not show as scheduled

Personal time

Other (specify: _____)

16. Are there other types of respite services you would like to have?

No

Yes→ What? (Please check all that apply)

In home

Out of home

Other (specify: _____)

17. Has your child received a vehicle modification in the past year?

No

Yes→ Were you satisfied with the outcome? No Yes

18. Has your child received a home adaptation in the past year?

No

Yes→ What type? (Please check all that apply)

Bathroom

Door widening

Electrical updating

Other (specify: _____)

Other (specify: _____)

Were you satisfied with the outcome? No Yes

19. How has your child's participation in the CAH waiver affected your satisfaction or dissatisfaction with the following?

	<i>Very Dissatisfied</i>	<i>Dissatisfied</i>	<i>Satisfied</i>	<i>Very Satisfied</i>
Your health	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Your sleep	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Your relationship with your child	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Your personal relationships with others	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Your capacity to work	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The conditions of your living place	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Your child's access to health services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Your transportation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Your child's quality of life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Your quality of life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

20. Has your child's enrollment in the CAH Waiver Program made it easier for you to care for him/her?

No Yes

Please explain:

21. What is your child's primary disability/ diagnosis?

Please specify: _____

22. Are you aware of pediatric palliative care services available in your community?

No Yes

The CAH I/II Waiver Program has been approved to provide five new palliative care services to help waiver participants, and their family members, cope with the child's end-of-life experience.

23. As a parent of a CAH participant, how much interest do you have in the following?

	<i>No Interest</i>	<i>Some Interest</i>	<i>A lot of Interest</i>
Pain and symptom management services to relieve or control suffering related a CAH child's end-of-life experience.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Expressive therapy to help a CAH child better understand, and creatively express, his/her emotions related to his/her end-of-life experience.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Art	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Music	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Play	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Expressive therapy to help sibling(s) of a CAH child better understand and creatively express their emotions related to their siblings' end-of-life experience.

Art	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Music	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Play	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Bereavement services to help a CAH child and his/her family cope with grief related to the child's end-of-life experience

Child	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Family	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Massage therapy to help manage a CAH child's muscle pain, and relieve fear and stress associated with his or her end-of-life experience.

For the Child	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
For the Family	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Family palliative care education providing personal instruction and guidance in the principles of end-of-life care and access to available resources.

24. Do you think palliative care service(s) will help keep your child at home?

- No
 Yes
 Unsure
 Not Applicable

Please explain:

25. In the future would you prefer to complete a web based participant satisfaction survey?

No Yes

26. Any comments about the CAH I/II Waiver Program?

Thank you for your time!

Please return this survey to the NYS DOH Care At Home Program using the included self-addressed envelope.

Traumatic Brain Injury (TBI) Waiver Program Participant Satisfaction Survey

1. Today's date: ____/____/____
month day year

2. Who is completing this survey? (Please check only one)

- Person who has sustained brain injury (without any assistance) Spouse/ significant other assisting
- Parent assisting assisting Child/ sibling/ other family member
- Other (Specify : _____)

3. Did you choose to live in the community instead of living in an institution?

- Yes
- No→ Why not? _____

4. Overall, are you satisfied with the TBI Waiver Program?

- Yes
- No→ Why not? _____

5. Do you know what is in your Service Plan?

- No
- Yes→ Are you receiving the services that are in your Service Plan?
- No
- Yes→ Were you satisfied with the outcome? No Yes
- Have you ever requested other services?
- No
- Yes→ Which one? _____
- Which one? _____
- Which one? _____

Are you receiving the other services you requested?

No

Yes→ Which one? _____

Which one? _____

Which one? _____

Did you have a choice in your services and service providers?

No

Yes→ Were you satisfied with the outcome? No Yes

6. How often do you have contact with your Service Coordinator...

	<i>More than once a week</i>	<i>Once a week</i>	<i>Twice a month</i>	<i>Once a month</i>	<i>Once every two months</i>	<i>Once every three months</i>	<i>Less than once every three months</i>
By phone?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
In person?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

7. How much do you agree or disagree with the following?

	<i>Disagree</i>	<i>Somewhat Disagree</i>	<i>Somewhat Agree</i>	<i>Agree</i>
My Service Coordinator helps me when I ask for something.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My Service Coordinator is helpful in arranging the services that I need.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My Service Coordinator has a good attitude.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My Service Coordinator returns my calls.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

8. Do you currently receive Home and Community Support services?

No (Skip to question 11)

Yes→ Did you choose this service? Yes

No→ Explain? _____

How much do you agree or disagree with the following?

	<i>Disagree</i>	<i>Somewhat Disagree</i>	<i>Somewhat Agree</i>	<i>Agree</i>
The aide is helpful.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The aide comes as scheduled.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am satisfied with this service.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

If you are not satisfied with this service, please explain:

9. Do you currently receive Community Integration Counseling?

No (Skip to question 12)

Yes → Did you choose this service? Yes

No → Explain? _____

How much do you agree or disagree with the following?

	<i>Disagree</i>	<i>Somewhat Disagree</i>	<i>Somewhat Agree</i>	<i>Agree</i>
The counselor teaches me how to cope with changes in my life.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The counselor comes as scheduled.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am satisfied with this service.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

If you are not satisfied with this service, please explain:

10. Do you currently receive Independent Living Skills Training?

No (Skip to question 13)

Yes → Did you choose this service? Yes

No → Explain? _____

How much do you agree or disagree with the following?

	<i>Disagree</i>	<i>Somewhat Disagree</i>	<i>Somewhat Agree</i>	<i>Agree</i>
I choose the tasks I need to work on to become more independent.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I feel this service has helped me to learn how to do things on my own.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
ILST staff comes as scheduled.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am satisfied with this service.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

If you are not satisfied with this service, please explain:

11. Do you currently receive Assistive Technology services?

No (Skip to question 14)

Yes→ Did you choose this service? Yes

No→ Explain? _____

How much do you agree or disagree with the following?

	<i>Disagree</i>	<i>Somewhat Disagree</i>	<i>Somewhat Agree</i>	<i>Agree</i>
I received the assistive technology that I needed.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I helped choose the type of assistive technology that I received.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am satisfied with this service.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

If you are not satisfied with this service, please explain:

12. Do you currently receive Structured Day Program services?

No (Skip to question 15)

Yes→ Did you choose this service? Yes

No→ Explain? _____

How much do you agree or disagree with the following?

	<i>Disagree</i>	<i>Somewhat Disagree</i>	<i>Somewhat Agree</i>	<i>Agree</i>
There are a variety of activities.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I participate in the activities.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Transportation to the program is reliable.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The program's hours are convenient.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am satisfied with this service.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

If you are not satisfied with this service, please explain:

13. Do you currently receive Environmental Modification services?

No (Skip to question 16)

Yes → Did you choose this service? Yes

No → Explain? _____

How much do you agree or disagree with the following?

	<i>Disagree</i>	<i>Somewhat Disagree</i>	<i>Somewhat Agree</i>	<i>Agree</i>
I received the home modifications that I needed.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
This service was completed.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am satisfied with this service.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

If you are not satisfied with this service, please explain:

14. Do you currently receive Vehicle Modification services?

No (Skip to question 17)

Yes → Did you choose this service? Yes

No → Explain? _____

How much do you agree or disagree with the following?

	<i>Disagree</i>	<i>Somewhat Disagree</i>	<i>Somewhat Agree</i>	<i>Agree</i>
I received the vehicle modifications that I needed.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
This service was completed.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am satisfied with this service.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

If you are not satisfied with this service, please explain:

15. Do you currently receive Community Transitional services?

No (Skip to question 18)

Yes→ Did you choose this service? Yes

No→ Explain? _____

How much do you agree or disagree with the following?

	<i>Disagree</i>	<i>Somewhat Disagree</i>	<i>Somewhat Agree</i>	<i>Agree</i>
I received the basic items I needed to set up my home.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am satisfied with this service.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

If you are not satisfied with this service, please explain:

16. Do you currently receive Positive Behavioral Intervention and Supports (PBIS) services?

No (Skip to question 19)

Yes→ Did you choose this service? Yes

No→ Explain? _____

How much do you agree or disagree with the following?

	<i>Disagree</i>	<i>Somewhat Disagree</i>	<i>Somewhat Agree</i>	<i>Agree</i>
The PBIS staff helps me manage my behaviors.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The aide comes as scheduled.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am satisfied with this service.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

If you are not satisfied with this service, please explain:

17. Do you currently receive Respite services?

No (Skip to question 20)

Yes → Did you choose this service? Yes

No → Explain? _____

How much do you agree or disagree with the following?

	<i>Disagree</i>	<i>Somewhat Disagree</i>	<i>Somewhat Agree</i>	<i>Agree</i>
Someone relieved my primary caregiver.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The aide is helpful.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The aide comes as scheduled.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am satisfied with this service.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

If you are not satisfied with this service, please explain:

18. Do you currently receive Substance Abuse services?

No (Skip to question 21)

Yes → Did you choose this service? Yes

No → Explain? _____

How much do you agree or disagree with the following?

	<i>Disagree</i>	<i>Somewhat Disagree</i>	<i>Somewhat Agree</i>	<i>Agree</i>
The substance abuse treatment plan is helpful.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am satisfied with this service.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

If you are not satisfied with this service, please explain:

19. Do you currently receive Waiver Transportation (Social Transportation) services?

No (Skip to question 22)

Yes→ Did you choose this service? Yes

No→ Explain? _____

How much do you agree or disagree with the following?

	<i>Disagree</i>	<i>Somewhat Disagree</i>	<i>Somewhat Agree</i>	<i>Agree</i>
The driver came as scheduled.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Transportation is reliable.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am satisfied with this service.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

If you are not satisfied with this service, please explain:

20. Do the people who help you with your services ever do mean things to you?

No

Yes→ Like what? (Please check all that apply)

Use your things without your permission

Yell at you

Embarrass you

Direct you to do things that make you uncomfortable

Hit you

- Push you
- Take your things without your permission
- Use profanity

21. Have you ever felt unsafe or disrespected by any of the people involved with your services?

No

Yes→ Please check all that apply

- Service Coordinator
- Home and Community Support
- Community Integration Counseling
- Independent Living Skills Training
- Assistive Technology
- Structured Day Program
- Environmental Modification
- Vehicle Modification
- Community Transitional
- Positive Behavioral Intervention and Support
- Respite
- Substance Abuse
- Waiver Transportation

22. Do you know who to call to make a complaint or voice a concern about the services you receive?

Yes

No→ Why not? _____

23. Have you ever made a complaint or voiced a concern about any of the services that you receive?

No

Yes→ Which one? _____

Were you happy with the way the complaint was handled?

Yes

No→ Why not? _____

24. Are there activities outside your home you are unable to do now (For example, church, shopping, visiting friends/family)?

No

Yes→ What? _____

What stops you from doing this? _____

25. Is there anything else you'd like to tell us about your experience as a TBI Waiver participant? Your responses will be used to help improve the program.

Overall, How would you rate the quality of the services you receive through the Traumatic Brain Injury Medicaid Waiver:

Excellent Very Good Good Poor

Name (Optional) _____

Would you like us to contact you regarding this survey? Yes No

Contact information: _____

Thank you for your time!

**Nursing Home Transition and Diversion (NHTD)
Participant Satisfaction Survey 2011**

NAME: _____
(Optional)

DATE: _____
(Required)

Our records show you are/were enrolled in the Nursing Home Transition and Diversion (NHTD) waiver. Please complete the following. You can provide additional information in #6 below if needed.

*Your opinions are important to help improve the program. Responses to these questions will **NOT** affect your ongoing participation in the NHTD program.*

1. Are you satisfied with the NHTD program overall?

Yes No NA

2. Are you satisfied with the services you have received in the NHTD program?

Yes No NA

3. Are you satisfied with your NHTD service providers?

Yes No NA

4. Do you know how to report abuse, neglect and/or exploitation regarding the NHTD waiver services?

Yes No NA

5. Have you ever had to report an abuse, neglect and/or exploitation regarding the NHTD waiver services?

Yes No NA

6. Additional comments:

7. May the [INSERT RRDC] contact you for further information regarding your experiences with NHTD waiver program?

Yes No

[ID) (Unique

North Dakota:

PARTICIPANT EXPERIENCE SURVEY

NORTH DAKOTA DEPARTMENT OF HUMAN SERVICES
MEDICAL SERVICES

PRELIMINARY CONSUMER INFORMATION

Client First Name

Client Last Name

County

The following describes the Home and Community Based Services you are receiving and that were approved for you by the County Case Manager.

Services

A. ACCESS TO CARE

The first set of questions deal with some everyday activities. Some people have no problem doing these things by themselves. Other people need somebody to help them.

1. Think about the people who are paid to help you and the services you are receiving, such as housekeeping, shopping, and laundry. Do your paid helpers spend all the time with you that they are supposed to?

- Yes
- No
- Unsure
- The Services I Receive Don't Take Place In My Home (such as emergency response button)

2. Are you satisfied with the services you are receiving?

- Yes
- No

3. Did you ever go without any of the services when you needed them?

- Yes
- No

If your answer is NO skip to Question 5.

4. Is this because the person who was supposed to provide the care didn't show up?

- Yes
- No

5. Do the services offered by the County Case Manager or County Social Worker meet your needs?

- Yes
- No

B. CHOICE AND CONTROL

6. Did you help pick the people or agencies that are paid to help you with the services approved by the County Case Manager or County Social Worker?

- Yes
- No

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 County Social Worker.

7. Do you know you have the right to choose the people or agencies that are paid to help you if you want to?

- Yes
- No

**8. 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)**

- No One
- Family/Friend
- Case Manager/County Social Worker/Other Staff
- Other (Specify):
- I Don't Know Who To Talk To
-

9. Do you know the name of your Case Manager or County Social Worker?

- Yes
- No

10. Do you know how to contact your Case Manager or County Social Worker when you need to?

- Yes
- No

11. Does your Case Manager or County Social Worker help you when you ask for something?

- Yes
- No
- Sometimes

B. RESPECT/DIGNITY

The following questions concern how you are treated by the people who are paid to help you.

12. Does your Case Manager or County Social Worker treat you with respect?

- Yes
- No
- Sometimes

13. Do the people paid to help you with the services that were approved for you by the County Case Manager or County Social Worker, treat you with respect?

- Yes
- No
- Sometimes

14. Do the people paid to help you with the services that were approved for you by the County Case Manager or County Social Worker, listen carefully to what you ask them to do?

- Yes
- No
- Sometimes

15. Have you ever been injured by any of the people who are still being paid to help you with the services that were approved for you by the County Case Manager or County Social Worker?

- Yes
- No

If your answer is NO skip to Question 17.

16. Would you like us to contact the Medical Services Division so they can follow up with you?

- Yes
- No

17. Are any of the people who are still being paid to help you with the services that were approved for you by the County Case Manager or County Social Worker, mean to you, or do they yell at you?

- Yes
- No

If your answer is NO skip to Question 19.

18. Would you like us to contact the Medical Services Division, so they can follow up with you?

- Yes
- No

19. Have any of the people who are still being paid to help you with the services that were approved for you by the County Case Manager or County Social Worker, taken your things without asking?

- Yes
- No

If your answer is NO skip to Question 21.

20. Would you like us to contact the Medical Services Division, so they can follow up with you?

- Yes
- No

21. If the person paid to help you now uses your things or supplies to complete their work with you, have they ever broken your things or not handled your things the way you want them to?

- Yes
- No

If your answer is NO skip to Question 23.

22. Would you like us to contact the Medical Services Division, so they can follow up with you?

- Yes
- No

D. ACCESS TO COMMUNITY ACTIVITIES

The following questions concern things you do in your community and the help you get to do these things.

23. Do you feel your social needs are being met (such as participating in community events, visiting friends/family, going to church)?

- Yes
- No

24. Please use the space below to tell us about anything else you would like us to know about the services you receive.

25. If you did not complete this survey on your own, please tell us who else completed the survey (mark all that apply)

- Client
- Family Member
- Friend
- Other (Specify):

Ohio:

YOUR RESPONSE CAN MAKE SERVICES BETTER!

The purpose of the PASSPORT Program is to offer basic services to qualified older adults who might otherwise need to go to a nursing home. Case managers' work with individuals to plan for services based on what he or she needs and what the PASSPORT Program regulations allow.

For the following questions, please fill in the circle **O** in front of the answer that best represents your feelings and experiences. You may use either a pencil or a black or blue pen. Fill in only one circle for each question.

- **this is the correct way to mark your response**
- ⊗ **this mark will not “count”—please fill in the circle**

1. First, please tell me who is answering this survey.

- Consumer only
- Consumer with family member
- Consumer with another person/ unrelated person
- Family member alone
- Other person alone/ unrelated person

2. Overall, how satisfied are you with the PASSPORT Program?

- Extremely satisfied: “I receive everything I need.”
- Very satisfied: “Everything lives up to my expectations.”
- Somewhat satisfied: “My expectations are being met with some exceptions.”
- Not satisfied: “My expectations are not being met.”
- No opinion

3. How satisfied are you with how well the PASSPORT program meets your needs?

- Extremely satisfied
- Very satisfied
- Somewhat satisfied
- Not satisfied
- No opinion

4. How satisfied are you with how well your PASSPORT case manager takes care of your problems, complaints, or concerns?

- Extremely satisfied
- Very satisfied
- Somewhat satisfied
- Not satisfied
- No opinion

5. How satisfied are you with how courteous your PASSPORT case manager is to you?

- Extremely satisfied
- Very satisfied
- Somewhat satisfied
- Not satisfied
- No opinion

6. How satisfied are you with how available your PASSPORT case manager is when you need to talk with him/her?

- Extremely satisfied
- Very satisfied
- Somewhat satisfied
- Not satisfied
- No opinion

7. How satisfied are you with how well the service choices offered by your PASSPORT case manager fit your needs?

- Extremely satisfied
- Very satisfied
- Somewhat satisfied
- Not satisfied
- No opinion

8. How satisfied are you with how well your PASSPORT case manager understands your specific needs?

- Extremely satisfied
- Very satisfied
- Somewhat satisfied
- Not satisfied
- No opinion

9. If a friend were in need of similar help, would you recommend the PASSPORT program to him or her?

- Definitely
- Likely
- Maybe
- Probably not
- No opinion

You are almost finished, just one more page to go.

SPECIFIC PROBLEMS OR CONCERNS ABOUT THE SERVICES YOU ARE RECEIVING?

If you want your local PASSPORT agency to follow-up on a specific problem or request, please let us know in the space below. Please add your name, address, and telephone number. However, you may use this page for any positive comments that you would like to provide. We will detach this page from your survey answers and send it to your local PASSPORT agency for assistance if need be.

Please tell us about or explain your concern or problem:

Thank you for letting us know !

Please print.

Name: _____

Address: _____

_____ Zip Code: _____

Ohio:

YOUR RESPONSE CAN MAKE SERVICES BETTER!

The purpose of the Assisted Living Waiver Program is to offer basic services to qualified older adults who might otherwise need to go to a nursing home. Case managers' work with individuals to develop a care plan to meet the identified needs and select an assisted living waiver facility that can provide the required care.

For the following questions, please fill in the circle O in front of the answer that best represents your feelings and experiences. You may use either a pencil or a black or blue pen. Fill in only one circle for each question.

- **this is the correct way to mark your response**
- ⊗ **this mark will not “count”—please fill in the circle**

9. First, please tell me who is answering this survey.

- O Consumer only**
- O Consumer with family member**
- O Consumer with another person/unrelated person**
- O Family member alone**
- O Other person alone/unrelated person**

Over, please

10. Overall, how satisfied are you with the ASSISTED LIVING WAIVER Program?

- O Extremely satisfied: “I receive everything I need.”**
- O Very satisfied: “Everything lives up to my expectations.”**
- O Somewhat satisfied: “My expectations are being met with some exceptions.”**
- O Not satisfied: “My expectations are not being met.”**
- O No opinion**

11. How satisfied are you with how well the ASSISTED LIVING WAIVER program meets your needs?

- Extremely satisfied**
- Very satisfied**
- Somewhat satisfied**
- Not satisfied**
- No opinion**

12. How satisfied are you with how well your ASSISTED LIVING WAIVER case manager takes care of your problems, complaints, or concerns?

- Extremely satisfied**
- Very satisfied**
- Somewhat satisfied**
- Not satisfied**
- No opinion**

Over, please

13. How satisfied are you with how courteous your ASSISTED LIVING WAIVER case manager is to you?

- Extremely satisfied**
- Very satisfied**
- Somewhat satisfied**
- Not satisfied**
- No opinion**

14. How satisfied are you with how available your ASSISTED LIVING WAIVER case manager is when you need to talk with him/her?

- Extremely satisfied**
- Very satisfied**
- Somewhat satisfied**

No opinion

15. How satisfied are you with how well the care plan your ASSISTED LIVING WAIVER case manager helped you to developed, does it fit your needs?

Extremely satisfied

Very satisfied

Somewhat satisfied

Not satisfied

No opinion

please

Over,

8. How satisfied are you with how well your ASSISTED LIVING WAIVER case manager understands your specific needs?

Extremely satisfied

Very satisfied

Somewhat satisfied

Not satisfied

No opinion

9. If a friend were in need of similar help, would you recommend the ASSISTED LIVING WAIVER program to him or her?

Definitely

Likely

Maybe

Probably not

No opinion

You are almost finished, just one more page to go.

SPECIFIC PROBLEMS OR CONCERNS ABOUT THE SERVICES YOU ARE RECEIVING?

If you want the local agency that operates the ASSISTED LIVING WAIVER program to follow-up on a specific problem or request, please let us know in the space below. Please add your name, address, and telephone number. However, you may use this page for any positive comments that you would like to provide. We will detach this page from your survey answers

and send it to the local agency that operates the ASSISTED LIVING WAIVER program for assistance if need be.

Please tell us about or explain your concern or problem:

Thank you for letting us know !

Please print.

Name: _____

Address: _____

_____ **Zip Code:** _____

Telephone number: (_____) _____

Ohio:

YOUR RESPONSE CAN MAKE SERVICES BETTER!

The purpose of the Choices Program is to offer basic services to qualified older adults who might otherwise need to go to a nursing home. Case managers' work with individuals to plan for services based on what he or she needs and what the Choices Program regulations allow.

For the following questions, please fill in the circle **O** in front of the answer that best represents your feelings and experiences. You may use either a pencil or a black or blue pen. Fill in only one circle for each question.

- **this is the correct way to mark your response**
- ⊗ **this mark will not “count”—please fill in the circle**

16. **First, please tell me who is answering this survey.**

- Consumer only
- Consumer with family member
- Consumer with another person/unrelated person
- Family member alone
- Other person alone/unrelated person

17. **Overall, how satisfied are you with the Choices Program?**

- Extremely satisfied: “I receive everything I need.”
- Very satisfied: “Everything lives up to my expectations.”
- Somewhat satisfied: “My expectations are being met with some exceptions.”
- Not satisfied: “My expectations are not being met.”
- No opinion

18. **How satisfied are you with how well the Choices program meets your needs?**

- Extremely satisfied
- Very satisfied
- Somewhat satisfied
- Not satisfied
- No opinion

19. How satisfied are you with how well your Choices case manager supports you when you have problems, complaints, or concerns?

- Extremely satisfied
- Very satisfied
- Somewhat satisfied
- Not satisfied
- No opinion

Over, please

20. How satisfied are you with how courteous your Choices case manager is to you?

- Extremely satisfied
- Very satisfied
- Somewhat satisfied
- Not satisfied
- No opinion

21. How satisfied are you with how available your Choices case manager is when you need to talk with him/her?

- Extremely satisfied
- Very satisfied
- Somewhat satisfied
- Not satisfied
- No opinion

22. How satisfied are you with how well the Choices services fit your needs?

- Extremely satisfied
- Very satisfied
- Somewhat satisfied
- Not satisfied
- No opinion

Over, please

23. How satisfied are you with how well your Choices case manager understands your specific needs?

- Extremely satisfied
- Very satisfied
- Somewhat satisfied
- Not satisfied
- No opinion

9. If a friend were in need of similar help, would you recommend the Choices program to him or her?

- Definitely
- Likely
- Maybe
- Probably not
- No opinion

You are almost finished, just one more page to go.

SPECIFIC PROBLEMS OR CONCERNS ABOUT THE SERVICES YOU ARE RECEIVING?

If you want your local Choices agency to follow-up on a specific problem or request, please let us know in the space below. Please add your name, address, and telephone number. However, you may use this page for any positive comments that you would like to provide. We will detach this page from your survey answers and send it to your local Choices agency for assistance if need be.

Please tell us about or explain your concern or problem:

Thank you for letting us know!

Please print.

Name: _____

Address: _____

_____ Zip Code: _____

Telephone number: (_____) _____

Texas: **PARTICIPANT**

**EXPERIENCE
SURVEY**

(ELDERLY/DISABLED)



Developed by
The MEDSTAT Group, Inc.

for the
Centers for Medicare and Medicaid Services



TEXAS
2010 version 6.00

Pre-Survey Form

BI-1. Survey Code: _____
(ID number)

Note: This code should be provided by the state project coordinator and is for data analysis purposes only. A unique code number should be assigned to each person. Do not use a number that could possibly identify the person (do NOT use social security numbers).

P.1 Interviewer code: ____ ____

P.2 Interview Date: ____/____/____ mm/dd/yyyy

P.3 Reason for Not Participating in Survey:

1. ____ **Participant Declined**

2. ____ **Guardian declined**

3. **Reason for declining (specify)** _____

Guardian Information (If Applicable)

Note... In the event the participant has a guardian, the guardian must be contacted prior to conducting the interview for consent and scheduling purposes.

Guardian Name: First _____ Last _____

Relationship: _____ **Phone:** _____

PS-1. Contact... Who should the interviewer call to arrange an interview with this person (consumer, parent/guardian, service coordinator, day or residential program staff, etc.)?

Name: First _____ Last _____

Relationship: _____ Daytime Phone: _____

Evening Phone : _____ Cell Phone: _____

Note... We would like to talk to people alone, when appropriate. Some people may feel uncomfortable with strangers, may have community protection issues, or may have medical or behavioral issues that require them to be under constant supervision by a trained caregiver.

Do you recommend that a caregiver be present while this person is interviewed?

2. ___ Yes 1. ___ No

PS-2. Communication needs... Does this person have any special communication needs? (Examples: primary language other than English, sign language, communication board.) Please explain what arrangements are needed for the interview.

PS-3. Case Manager/Service Coordinator... What is the name and phone number of this person's case manager/service coordinator?

Name: First _____ Last _____
Phone: _____ Cell Phone: _____

PS-4. Advocate... If this person has someone who helps represent him/her at planning meetings and in making important decisions, please provide the advocate's name and relationship. (Note: this may include staff, family, friends, or guardians who are involved in the person's life.)

Name: First _____ Last _____
Relationship: _____

PS-5. Other Interviewees... If this person is unable or unwilling to complete Section II of the survey, please indicate the name(s) and number(s) of others who know the person well and could respond on his/her behalf.

Name: First _____ Last _____
Relationship: _____ Phone: _____

PS-6. Living Arrangement... Please indicate who this person lives with.

1. ___ lives alone
2. ___ lives with parent/relatives
3. ___ lives with others (e.g., foster care, group home, etc.)
4. If applicable, provide first names of roommates or housemates _____

PS-7. Support Staff in the Home and During the Day... If there are any people who are paid to provide supports in this person's home, please indicate their first names. If there are several workers, please list the primary staff who spend the most time with this person. Also indicate the first names of any day and/or job support staff.

Home Support Staff: First Name _____
Day Support Staff/Job Support Staff/Coach: First Name _____

PS-8. Job/Day Activities... If applicable, please indicate what this person calls his/her job, school or day activity program.

Place of work: _____

DAY SUPPORT

Instructions: For the most recent month possible, please complete S1 and S2. If you check yes for any row, complete the other columns.

Type of activity Definitions: <u>Community-based setting</u> is a place where most people do not have disabilities. <u>Facility-based setting</u> is a place where most people do have disabilities.	A) Was this person engaged in this activity during the one-month period?	B) If Yes, what was the number of hours spent at this activity in the last month?	C) Does this person get publicly-funded services or supports to participate in this activity?	D) Is the job or activity done primarily by a group of people with disabilities?
S1. Unpaid activity in a community-based setting (e.g., volunteer activities, skills training, community experiences)	__1 No __2 Yes __3 Don't Know	---	__1 No __2 Yes __3 Don't Know	__1 No __2 Yes __3 Don't Know
S2. Unpaid activity in a facility-based setting (e.g., day habilitation, prevocational, seniors program)	__1 No __2 Yes __3 Don't Know	---	N/A	N/A

PS-9 **Self-Advocacy Organization...** What self-advocacy groups are active and well-known in the person's area? (Examples: AARP, Advocacy Inc., Adapt, Coalition of Texans with Disabilities, The ARC, etc.)

- BI-7. Does this person have a legal guardian or conservator appointed?** (check one)
- 1 No, person is independent of guardianship (legally competent or presumed competent)
 - 2 Yes, person has private guardian or conservator (including parent/relative or non-relative)
 - 3 Yes, person has public guardian or conservator
 - 4 Don't know

- BI-9. Marital status:** (check one)
- 1 Single, never married
 - 2 Married
 - 3 Single, married in past
 - 4 Don't know

- BI-12. What is this person's primary language?** (What language does s/he understand?)
- 1 English
 - 2 Spanish
 - 3 Other _____

- BI-13. What is this person's primary means of expression?** (check one – most frequently used)
- 1 Spoken
 - 2 Gestures/body language
 - 3 Sign language or finger spelling
 - 4 Communication aid/device
 - 5 Other
 - 6 Don't know

- BI-14. How would you describe this person's mobility?** (check one)
- 1 Can move self around environment; walks (with or without aids) or uses wheelchair
 - 2 Non-ambulatory, needs assistance to move around environment
 - 3 Don't know

- BI-16. Does this person currently take medications for...**
(check one column for each question):
- | | | | | |
|----------------------------|----------------------------|----------------------------|------------|---|
| | no | yes | don't know | |
| <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | | Mood disorders? [Includes any drug prescribed to elevate or stabilize mood (reduce mood swings), e.g., to treat depression, mania, or bipolar disorder.] |
| <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | | Anxiety? [Includes any drug prescribed to treat anxiety disorders (including obsessive disorders and panic disorders) or to reduce anxiety symptoms.] |

1 2 3 **Behavior problems?** [Includes any drug prescribed for a behavior modification purpose (such as a stimulant, sedative, or beta-blocker), e.g., to treat ADHD, aggression, self-injurious behavior, etc.]

1 2 3 **Psychotic disorders?** [Includes any drug (e.g., anti-psychotic or “neuroleptic”) used to treat psychotic disorders such as schizophrenia or psychotic symptoms such as hallucinations.]

BI-17. If this person has seizures, how often do they occur? (check one)

- 0 NOT APPLICABLE -- does not have seizures
- 1 Less frequently than once/month
- 2 At least once/month, but not once a week
- 3 At least once/week, or more frequently
- 4 Don't know or not available in records

BI-37. Does this person need support to prevent self-injury? “Self-injury” refers to attempts to cause harm to one’s own body, for example, by hitting or biting self, banging head, scratching or puncturing skin.

- 1 No
- 2 Yes
- 3 Don't Know

BI-37a. If yes, how often does the person need support to manage this behavior? (check one)

- 1 Needs occasional support, less frequently than once/month
- 2 At least once/month, but not once a week
- 3 At least once/week, or more frequently
- 8 Not applicable (no support needed or don't know)

BI-38. Does this person need support to prevent disruptive behavior?

“Disruptive behavior” refers to emotional outbursts that interfere with the activities of others, for example, by starting fights, laughing or crying without apparent reason, yelling or screaming, cursing, throwing objects, or threatening violence.

- 1 No
- 2 Yes
- 3 Don't Know

BI-38a. If yes, how often does the person need support to manage this behavior? (check one)

- 1 Needs occasional support, less frequently than once/month
- 2 At least once/month, but not once a week
- 3 At least once/week, or more frequently
- 8 Not applicable (no support needed or don't know)

BI-38b. Has this person been restrained in the last 30 days?

- _1 No
- _2 Yes
- _3 Don't Know

BI-38c. If yes, what type(s) of restraints were used? (check all that apply)

- _1 **Mechanical** – the use of a device that restricts the free movement of part or all of a person's body. Such a device does not include one used to provide support for functional body position or proper balance, such as a wheelchair belt, or one used for medical treatment, such as a helmet to prevent injury during a seizure.
- _2 **Personal** – the application of pressure, except physical guidance or prompting for brief duration, that restricts the free movement of part or all of a resident's body.
- _3 **Chemical** – the use of chemicals, including pharmaceutical, through topical application, oral administration, injection, or other means, to control a person's activity.
- _8 **Not applicable** (no restraint needed or don't know)

BI-38d. What alternatives were tried to prevent the use of restraints?

(check all that apply)

- _1 Verbal de-escalation or redirection
- _2 Interpersonal physical separation
- _3 Environmental remediation
- _4 Other
- _8 Not applicable (no restraint needed or don't know)

Please indicate who provided all of this pre-survey (PS) and background (BI)

information: (check yes to all that apply and no to all that do not apply)

- | | | | |
|----------------|--------------------------------|---------------------------------|--|
| BI.99.1 | 1. <input type="checkbox"/> no | 2. <input type="checkbox"/> yes | Person receiving services |
| BI.99.2 | 1. <input type="checkbox"/> no | 2. <input type="checkbox"/> yes | Advocate, Parent, Guardian, Personal Representative, Relative |
| BI.99.3 | 1. <input type="checkbox"/> no | 2. <input type="checkbox"/> yes | Staff who provides supports where person lives |
| BI.99.4 | 1. <input type="checkbox"/> no | 2. <input type="checkbox"/> yes | Staff who provides supports at a day or other service location |
| BI.99.5 | 1. <input type="checkbox"/> no | 2. <input type="checkbox"/> yes | Case Manager, service coordinator, social worker |
| BI.99.6 | 1. <input type="checkbox"/> no | 2. <input type="checkbox"/> yes | Other Person |
| BI.99.7 | 1. <input type="checkbox"/> no | 2. <input type="checkbox"/> yes | State data system |

Survey Instructions

- Make sure you have the respondent’s pre-survey information available when conducting the interview, since you are directed to refer to it at various points during the interview.
- Please answer the questions by checking ONE box, unless instructed to “Check all that apply”, in which case multiple boxes may be checked.
- 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.

Example:

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 pre-survey information 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 |
| 8 | <input type="checkbox"/> | COORDINATOR |
| 9 | <input type="checkbox"/> | UNCLEAR RESPONSE |
| | | NO RESPONSE |

Interviewer Instructions: Take a few minutes to introduce yourself and make the person feel comfortable. Read or paraphrase the following introduction. Pause after each statement, making sure the respondent understands.

🗣️ Dialogue:

“Hi, my name is _____ and I'm from NACES Plus Foundation. I'm here to conduct a survey for the Texas Department of Aging and Disability Services also known as DADS. I'd like to ask you some personal questions about your day-to-day activities, where you live, where you work, your friends and family, and the people who help you. By answering these questions, you are helping DADS figure out how people in Texas are doing, and how to make services and supports better.”

“This is not a test, and there are no right or wrong answers to these questions. If you don't understand a question, let me know and I'll try to explain it. It's okay if you don't know how to answer.”

“I'd like to know your opinions and how you feel about things but you don't have to answer any questions that you don't want to. Whatever you tell me will be kept private, so you can be honest.”

“Before we get started, I need to let you know that if you tell me that someone is hurting you, exploiting you, neglecting you, or if I think that any of that is happening to you, I need to report it.”

“Are you ready to get started?”

Interviewer Instructions: If yes, then begin with dialogue on next page. If no, try to determine if the individual needs more time or additional information. If the individual still does not want to participate, do not continue with the interview.

A. PREVENTIVE MEASURES

💡 DIALOGUE: This group of questions I'm going to ask you is about your health and how you stay healthy. Remember, you don't have to answer any questions that you don't want to.

A.1 **How often do you require medical care?** (check one) (Medical care refers to care that must be performed or delegated by a nurse or physician. Do not include medication administration.)

- 1 Less frequently than once/month
- 2 At least once/month, but not once a week
- 3 At least once/week, or more frequently
- 4 Don't know, unclear, or no response

A.2 **When was your last physical exam?** (check one)

- 1 In the past year
- 2 Over one year ago
- 3 Don't know, unclear, or no response

A.3 **(If female), when was your last OB/GYN exam?** (check one)

- 0 NOT APPLICABLE -- male
- 1 In the past year
- 2 Over one year ago
- 3 Has never had an OB/GYN exam
- 4 Don't know, unclear, or no response

A.4 **(If female), when was your last mammogram screening?** (check one)

- 0 NOT APPLICABLE – male
- 1 In the past year
- 2 In the past 2 years
- 3 More than 2 years ago
- 4 Never
- 5 Don't know, unclear, or no response

A.5 **When was your last dentist visit?** (check one)

- 1 In the last six months
- 2 In the last 7 to 12 months
- 3 Over 12 months ago
- 4 Don't know, unclear, or no response

A.6 When was your last eye examination/vision screening?

- 1 Within the past year (anytime less than 12 months ago)
- 2 Within the past 2 years (more than 1 year but less than 2 years ago)
- 3 Within the past 3 years (more than 2 years but less than 3 years ago)
- 4 Within the past 5 years (more than 3 years but less than 5 years ago)
- 5 5 or more years ago
- 6 Has never had a vision screening
- 7 Don't know, unclear, or no response

A.7 When was the last time you had a hearing test?

- 1 Within the past 5 years (anytime less than 5 years ago)
- 2 5 years ago or more
- 3 Has never had a hearing test
- 4 Don't know, unclear, or no response

A. 8 During the past 12 months, have you had a flu vaccination?

- 1 No
- 2 Yes
- 3 Don't know, unclear, or no response

A.9 Have you ever had a pneumococcal vaccine?

- 1 No
- 2 Yes
- 3 Don't know, unclear, or no response

A.10 Have you ever been diagnosed with high blood pressure and if so, how often is it checked?


- 1 Not applicable, does not have high blood pressure
- 2 Daily
- 3 Weekly
- 4 Monthly
- 5 Yearly
- 6 Every 2 years
- 7 Don't know, unclear, or no response

A.13 Do you smoke or chew tobacco?

- 1 No
- 2 Yes
- 3 Don't know, unclear, or no response

- A.14** **How often do you exercise?** (Prompt: Exercise can include any physical activity such as housework, yard work, exercise programs, or physical therapies.)
- 1 At least 5 times a week
 - 2 At least weekly
 - 3 At least monthly
 - 4 Never
 - 5 Don't know, unclear, or no response
- A.15** **How many servings of fruits and vegetables do you normally eat in a day?**
- 1 5 to 7 servings
 - 2 2 to 4 servings
 - 3 1 serving
 - 4 None
 - 5 Don't know, unclear, or no response
- A.16** **How long have you lived in your current home?**
- 1 Less than 1 year
 - 2 1-2 years
 - 3 3-5 years
 - 4 Over 5 years
 - 5 Don't know, unclear, or no response
- A.17** **Who owns or leases the place where you live?** (check one)
- 1 Family, guardian, or friend
 - 2 Private agency or home provider/foster family
 - 3 State or County agency
 - 4 Person rents home (name is on the lease)
 - 5 Person owns home (name is on the title)
 - 6 Don't know, unclear, or no response
 - 7 Other

B. ACCESS TO CARE

 Dialogue: For this set of questions, I am going to ask you about your everyday activities, like getting dressed and taking a bath.

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"

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

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

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

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

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

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

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

- 1 YES or SOMETIMES
- 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 or SOMETIMES
- 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"

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

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

- 1 YES or SOMETIMES
- 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 or SOMETIMES
- 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"

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

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

- 1 YES or SOMETIMES
- 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 or SOMETIMES
- 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"

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

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

- 1 YES or SOMETIMES
- 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 or SOMETIMES
- 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"

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

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

- 1 YES or SOMETIMES
- 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 or SOMETIMES
- 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"

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

20. Does the housework not get done sometimes?

- 1 YES or SOMETIMES
- 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 or SOMETIMES
- 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"

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

23. Does the laundry not get done sometimes?

- 1 YES or SOMETIMES
- 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 or SOMETIMES
- 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 or SOMETIMES
- 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"

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

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

- 1 YES or SOMETIMES
- 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 or SOMETIMES
- 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"

- 1 NEEDS HELP FROM ANOTHER PERSON
- 2 DOES NOT NEED HELP FROM ANOTHER PERSON →Skip to Q.31a
- 8 UNCLEAR RESPONSE
- 9 NO RESPONSE

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

- 1 YES or SOMETIMES
- 2 NO →Skip to Q.31a
- 7 UNSURE →Skip to Q.31a
- 8 UNCLEAR RESPONSE →Skip to Q.31a
- 9 NO RESPONSE →Skip to Q.31a

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

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

31.a Does your doctor give you instructions on how you can improve your health?

(Prompt: For example, testing your blood sugar, following a special diet, or doing certain exercises.)

- 1 YES or SOMETIMES
- 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.b Do you ever not follow those instructions?

- 1 YES or SOMETIMES
- 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.c Is this because there is no one there to help you?

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

32a. Do you think your services and supports address your health and well being?

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

32b. Do you think your services and supports help you achieve your personal goals?

(Prompt: Are you able to accomplish what you want with the help of your services and supports?)

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

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 or SOMETIMES
- 2 NO →Skip to Section C
- 7 UNSURE →Skip to Section C
- 8 UNCLEAR RESPONSE →Skip to Section C
- 9 NO RESPONSE →Skip to Section C

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

C. Choice and Control

 Dialogue: The next group of questions is about how much choice and control 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
- 9 NO RESPONSE
- 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

38a. Were you told you could hire, train and fire the people who are paid to help you if you want to?

- 2 YES
- 0 NO
- 9 NO RESPONSE, UNCLEAR, DON'T KNOW

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
- 7 UNSURE
- 8 UNCLEAR RESPONSE
- 9 NO RESPONSE

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)

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

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

42. Who is your case manager or support coordinator?

Refer to the pre-survey information 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

43a. When you leave a message with your case manager or support coordinator, do they return your call right away?

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

43b. Does your case manager or service coordinator ask you about your preferences?
(Prompt: Does your case manager or service coordinator ask you what you do and do not like?)

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

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 TRIED

44a. Do you get to help other people? *(Prompt: Do you get to teach things to other people?)*

- 2 YES
- 1 SOMETIMES
- 0 NO
- 9 NO RESPONSE, UNCLEAR, DON'T KNOW

44b. Can you have a close relationship if you want one? *(Prompt: Can you have a boyfriend or girlfriend?)*

- 2 YES
- 1 SOMETIMES
- 0 NO
- 9 NO RESPONSE, UNCLEAR, DON'T KNOW

44c. Do you have spending money to buy the things that you want?

- 2 YES
- 1 SOMETIMES
- 0 NO
- 9 NO RESPONSE, UNCLEAR, DON'T KNOW

44d. Are you free to take risks when you want to? *(Prompt: Do you feel like it's okay if you make mistakes or try new things?)*

- 2 YES
- 1 SOMETIMES
- 0 NO
- 9 NO RESPONSE, UNCLEAR, DON'T KNOW

44e. Do you have control over your transportation? *(Prompt: Can you plan a trip or decide when to go out?)*

- 2 YES
- 1 SOMETIMES
- 0 NO
- 9 NO RESPONSE, UNCLEAR, DON'T KNOW

44f. Do you get to decide who comes in and out of your home?

- 2 YES
- 1 SOMETIMES
- 0 NO
- 9 NO RESPONSE, UNCLEAR, DON'T KNOW


44g. Have you ever participated in a self-advocacy group meeting, conference or event?

- 2 YES → Skip to Section D
- 0 NO
- 9 NO RESPONSE, UNCLEAR, DON'T KNOW

44h. Do you want to participate in self-advocacy group meetings, conferences or events?

- 2 YES
- 0 NO
- 9 NO RESPONSE, UNCLEAR, DON'T KNOW

D. Respect/Dignity

 Dialogue: Now I would like to ask you about how you are treated by the people who are paid to help you. The next group of 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. Thinking about the people who are paid to help you *right now*, have you ever been injured by any of them?

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 or SOMETIMES
- 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.53

48. What happened? When?

49. Thinking about the people who are paid to help you *right now*, are any of them 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 happened? When?

51. Thinking of the people who are paid to help you *right now*, have any of them ever taken your things without asking?

Reminder:	1	<input type="checkbox"/>	YES or SOMETIMES
<i>Refer to your</i>	2	<input type="checkbox"/>	NO →Skip to Q.53
<i>state's policy on</i>	7	<input type="checkbox"/>	UNSURE →Skip to Q.53
<i>reporting for any</i>	8	<input type="checkbox"/>	UNCLEAR RESPONSE →Skip to Q.53
<i>suspected</i>	9	<input type="checkbox"/>	NO RESPONSE →Skip to Q.53
<i>incidents of</i>			
<i>abuse or neglect.</i>			
<i>Record only</i>			
<i>reports of current</i>			
<i>abuse.</i>			

52. What happened? When?

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

- 1 YES →Skip to Q.54
- 2 NO
- 7 UNSURE
- 8 UNCLEAR RESPONSE
- 9 NO RESPONSE

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

- 1 YES →Skip to Q.56
- 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?

Use specific information from the pre-survey information about services provided outside the home.

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

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

Use specific information from the pre-survey information about services provided outside the home.

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

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

- 1 YES
- 2 NO →Skip to Section E
- 7 UNSURE →Skip to Section E
- 8 UNCLEAR RESPONSE →Skip to Section E
- 9 NO RESPONSE →Skip to Section E

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

Use specific information from the pre-survey information about services provided outside the home.


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

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

Use specific information from the pre-survey information about services provided outside the home.

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

E. Community Integration/Inclusion

 Dialogue: The last group of 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.60a
- 7 UNSURE →Skip to Q.60a
- 8 UNCLEAR RESPONSE →Skip to Q.60a
- 9 NO RESPONSE →Skip to Q.60a

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

60.a. How did you find information about the services you receive? (check all that apply)

- 1 STATE AGENCY WEBSITE
- 2 LOCAL AGENCY (E.G. AREA AGENCY ON AGING, MENTAL RETARDATION AUTHORITY, STATE AGENCY OFFICE)
- 7 ADVOCACY ORGANIZATION
- 8 UNCLEAR RESPONSE
- 9 NO RESPONSE
- 99 OTHER _____

61. Did you get enough information about the services available to you?

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

61a. Did you get enough information on how to apply for services?

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

61b. Was it easy to apply for services?

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

62. Are you working right now?

- 1 YES →Skip to Q.64
- 2 NO
- 7 UNSURE
- 8 UNCLEAR RESPONSE
- 9 NO RESPONSE

63. Do you want to work?

- 1 YES →Skip to Q.73
- 2 NO →Skip to Q.73
- 7 UNSURE →Skip to Q.73
- 8 UNCLEAR RESPONSE →Skip to Q.73
- 9 NO RESPONSE →Skip to Q.73

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

66. Do you have a community-based or facility-based job? (Prompt: Community-based setting is a place where most people do not have disabilities. Facility-based setting is a place where most people do have disabilities.)

- 1 COMMUNITY-BASED SETTING
- 2 FACILITY-BASED SETTING
- 7 UNSURE
- 8 UNCLEAR RESPONSE
- 9 NO RESPONSE

67a. How many hours did you work in the past month?

— — —

67b. What were your gross wages in the past month before taxes and deductions?
(Prompt: How much did you make in the past month?)

\$__ __ __ __ . __ __

67c. Did you get publicly-funded services or supports to do your job?

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

68. What agency or program pays for the employment or day supports that you receive? (Please check all that apply)

- 1 HCBS Waiver Program
- 2 State MR/DD Agency (non-waiver)
- 3 Vocational Rehabilitation Agency
- 4 ICF/MR Day Program
- 5 Other (e.g., Social Security Ticket to Work)
- 6 NOT APPLICABLE – does not receive employment supports or day services

Interviewer Instructions:

If Question 66 is checked “Community-based”, please answer Question 69 - 72.

If Question 66 is “Facility-based”, skip to Question 73.

<p>69. Did you work 10 out of the last 12 months in a community job? (Person may have changed jobs or had periods of unemployment/transition.)</p>	<p><input type="checkbox"/> 1 No <input type="checkbox"/> 2 Yes <input type="checkbox"/> 3 Don't Know</p>
<p>70. Do you receive paid vacation and/or sick time at your job?</p>	<p><input type="checkbox"/> 1 No <input type="checkbox"/> 2 Yes <input type="checkbox"/> 3 Don't Know</p>
<p>71. How long have you been working at your current job?</p>	<p><input type="text"/> <input type="text"/> years <input type="text"/> <input type="text"/> months</p>
<p>72. What type of job do you have (where do you work or what do you do)? Check ONE option that best fits based on the answer given.</p> <p><input type="checkbox"/> 0 Person does not work</p> <p><input type="checkbox"/> 1 Agriculture, Forestry, Fishing, and Hunting</p> <p><input type="checkbox"/> 2 Construction/Manufacturing</p> <p><input type="checkbox"/> 3 Wholesale/Retail</p> <p><input type="checkbox"/> 4 Transportation/Warehousing</p> <p><input type="checkbox"/> 5 Information</p> <p><input type="checkbox"/> 6 Finance and Insurance</p> <p><input type="checkbox"/> 7 Administrative and Support</p> <p><input type="checkbox"/> 8 Waste Management and Remediation Services</p> <p><input type="checkbox"/> 9 Educational Services</p> <p><input type="checkbox"/> 10 Health Care and Social Assistance</p> <p><input type="checkbox"/> 11 Arts, Entertainment, and Recreation</p> <p><input type="checkbox"/> 12 Accommodation and Food Services</p> <p><input type="checkbox"/> 13 Other industry (specify) _____</p>	

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

Dialogue: “Thank you for your help. It’s been very nice talking to you. You’ve been very helpful.”

INTERVIEWER FEEDBACK SHEET

Interviewer Instructions:

Please take a few minutes to complete a feedback sheet after each interview you complete.

99. What amount of the questions did the program participant answer by him/herself?

- 1 ALL
- 2 MOST
- 3 ABOUT HALF
- 7 SOME
- 8 A FEW
- 9 NONE

99a. Who else provided responses? (If applicable)

99b. Where did the interview take place? (check one)

- ___1 Participant's home
- ___2 Participant's day program
- ___3 Other (specify)_____

99c. Was a language translator used?

- ___1 Yes
- ___2 No

99d. Were there any questions that were problematic?

- ___1 Yes
- ___2 No

99e. If yes, indicate the question number(s) below and describe the problem and any suggestions you have for improvement.

E. Interviewer Comments and Observations
