PARTICIPANT EXPERIENCE SURVEY

ELDERLY/DISABLED (E/D) VERSION

USERS' GUIDE

Version 1.0
August 1, 2003

A Technical Assistance Tool for States

ACKNOWLEDGEMENTS

The *Participant Experience Survey, Elderly/Disabled Version* (PES E/D) represents the joint efforts of several organizations and individuals.

Questions and comments about this guide should be directed to Sara Galantowicz at (617) 492-9348. To receive any subsequent versions of the Users' Guide or the PES E/D, please register via e-mail to **sara.galantowicz@medstat.com**. Issues addressed in future versions may include specific disability concerns, the relationship between personal assistance and work, and choices in staffing.

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APPENDICES

1. Purpose of the Survey

The purpose of the PES E/D is to provide State officials with information about program participants' experience with the services and supports they receive under the 1915(c) waiver program — the Medicaid Home and Community Based Services waivers.

● The PES E/D is a technical assistance tool that States may consider using as part of their quality management program to monitor quality in their waiver programs.

● Target population is elderly and non-elderly adults with physical disabilities.

● The PES provides indicators of program participants' experience in four priority areas:

   ■ **Access to Care:** Are program participants' needs for personal assistance, adaptive equipment, and case manager access being met?

   ■ **Choice and Control:** Do program participants have input into the types of services they receive and who provides them?

   ■ **Respect/Dignity:** Are program participants treated with respect by providers?

   ■ **Community Integration/Inclusion:** Do program participants participate in activities and events of their choice outside their homes when they want to?

● The PES E/D can be used to calculate 33 performance indicators, within these priority areas, for quality monitoring and intervention. These indicators can be calculated for the entire sample, or for different sub-samples, such as program participants residing in different counties or served by different providers, and compared across groups. *Section 7* lists the indicators and includes information on calculating and interpreting them.

PES E/D and the Quality Improvement Process

Addressing quality within HCBS waiver programs entails following the basic quality improvement process common to all intervention efforts. This process includes five basic steps:

● Identify problem areas.

● Brainstorm remediation strategies.

● Develop quality intervention activity or activities.

● Measure the impact of your intervention.

● Evaluate effectiveness of your strategy.

The PES E/D and the performance indicators can be useful for the first and fourth steps in this process, *identifying problem areas* and *measuring the impact of your intervention.* Quality improvement interventions are most credible when they are grounded in evidence. When program dollars are scarce, the PES data can be used to identify areas where program participants are experiencing unmet need or other problems. Any problems can then be addressed systematically across the waiver as a whole, as well as on an individual basis. For more detailed guidance on developing quality improvement projects, see **Work Book: Improving the Quality of Home and Community Based Services and Supports**,[1] developed by the Muskie School under contract to CMS. States may also request assistance from the National Quality Contractor in designing and implementing quality improvement projects.

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[1] Maureen Booth and Julie Fralich "Work Book: Improving the Quality of Home and Community Based Services and Supports." Prepared for the Centers for Medicare and Medicaid Services. 2003.

2.   Selecting Your Sample

Before selecting a sampling frame (the group of people from whom you will select your sample), it is important to clarify goals and constraints for the survey process. Some questions to consider:

- What do you want to be able to say based on the results?

  - Do you want to profile your entire waiver population, or only a subset?

  - Do you want to compare sub-groups within the waiver population?

- Who will be your audience for the results?

  - Policymakers, providers, program participants, advocacy groups, CMS?

  - What are their expectations for the survey?

- What are your constraints for the survey process?

  - Financial and staffing constraints?

  - Geographic constraints? – Reaching a geographically dispersed population can be expensive.

  - Political and other constraints?

- Do existing data from other sources suggest a specific target population?

  - Additional information may indicate the need to look only at a particular type of program participant.

  - Example: residents of rural areas, managed care enrollees, program participants over age 85.

Guidelines for determining sample size and composition, following this clarification process, are outlined below.

- Random samples are ideal.

  - Allow you to draw inferences about your entire waiver population.

  - May not be financially or logistically possible.

- Larger samples allow for greater precision in estimates.

  - Precision is a function of confidence level and confidence interval.

  - Sample size calculator available at **http://www.surveysystem.com/sscalc.htm**.

- Analysis of sub-groups may require larger samples

  - May need to stratify sample by dimension of interest.

  - Stratifying ensures you have enough respondents of each type to make valid estimates of a subpopulation.

  - Examples of dimensions: provider or provider type, county, age.

  - Stratifying can be a complicated process – local academic experts or survey professionals may be able to help.

Any criteria you select for including or excluding program participants from the sampling frame must be consistently applied and explicitly articulated. Your findings will **only** apply to those who meet your criteria. For example, if you exclude program participants who do not speak English, then you can only present your results as representative of the English-speaking waiver population.

Addressing Cognitive Impairments

For the sake of simplicity, States may be tempted to limit the survey sample to cognitively intact program participants. However, we recommend against this approach for several reasons. First, the PES E/D was designed to be accessible to the largest number of program participants possible, including those with cognitive limitations. The language and response patterns have been extensively tested to insure that they are straightforward and concrete. Second, as an explicitly *participant survey*, with no proxy version, the goal of the instrument is to allow program participants to comment directly on their experiences whenever possible. Finally, it may not be possible or practical to determine in advance which participants are cognitively intact.

3.   Choosing and Training Interviewers

Survey findings are only as good and credible as the combination of the instrument and how it was administered. Indeed, poor interviewing can distress clients and possibly decrease satisfaction. Therefore, selecting and training interview staff is a key component of the survey process.

Choosing Interviewers

- The PES E/D is designed to be administered in person.

  - Interview staff with strong interpersonal skills are essential.

- You may face trade-offs between cost, skill, and experience.

  - Extensive interview experience may be less important than personality and experience relating to people with disabilities and the elderly.

- Some important factors to consider when choosing interviewers:

  - Interviewers must be experienced and comfortable with people with disabilities and with the elderly.

  - They should be able to develop and maintain rapport throughout the interview.

  - Interviewers should be appreciative of the program participants' perspective and be able to address any anxieties around the interview process.

  - Good interviewers will understand their role is to gather information and not to address service problems during the interview.

  - Neutrality is paramount: interviewers should not have their own agendas with respect to the information gathered.

  - Interviewers must also be sensitive to the cultural issues and setting of the program participants with whom they will be meeting.

An ideal interviewer will be warm, respectful, caring, and professional. S/he should be a good listener who understands the purpose of the survey process, and who can engage program participants and stay focused on the topic despite interruptions and distractions. S/he should respect the differing cultures of the program participants.

> **Important**
>
> Interviewers should never be anyone involved with direct provision of services to the program participant being interviewed. Case managers, supports coordinators, or direct care staff should not function as interviewers because of a potential conflict of interest, and the need to provide a safe environment for program participants to answer honestly.

Training Interviewers

- Training should be in-person.

    - Trainers should include program staff, as well as survey and interviewing experts.

    - Include a model interview with a volunteer program participant if possible.

- Sections 4, 5, and 6 of this guide are designed as a template for interviewer training. *Appendix I* provides more details on the survey experience for respondents.

Monitoring Interviewers

As essential as training interviewers is, monitoring their work and providing appropriate guidance and feedback is just as critical. Some techniques for interviewer guidance and monitoring:

- Use mentors: Have new interviewers accompany more experienced interviewers to observe before going out on their own. Also, have more experienced interviewers observe the first few interviews done by new staff. Multiple interviewers should compare coding afterwards, and discuss any differences in their interpretation of responses.

- Tape interviews and review with a more experienced interviewer for feedback and suggestions.

- Solicit feedback directly from selected program participants about their interview experience.

- Validate interviewer accuracy by having a more experienced interviewer repeat the interview at a later date.

NOTE: The following three sections are designed to be a training guide for interviewers administering the PES E/D instrument. This guidance is directed specifically at the people who will be conducting the interviews. The pages with a 🗨 icon can be removed from this guide and used separately.

4.   Scheduling and Preparing for the Interviews

Collecting Pre-Survey data

● **Complete first section of the face sheet.**

Prior to contacting the program participants selected into the sample, have the case manager or other agency staff complete the first section of the face sheet for each selected individual. The face sheet includes items helpful for arranging interviews, such as the program participant's address and phone number. A copy of the face sheet is attached in *Appendix II*. The face sheet should be modified, if necessary, to reflect program specifics.

Scheduling Interviews

● **Call program participants or send a letter to introduce survey.**

Call or send a letter to program participants selected into the sample, letting them know who will be contacting them about their interest in the survey and to schedule an interview. A sample letter is included in *Appendix III*.

● **Contact the guardian if necessary.**

If a guardian's consent is required, this consent should be obtained prior to meeting or speaking with the program participant. Contact the guardian first to introduce the survey and its use. Case managers can play an important role in obtaining guardian consent.

● **Call the program participant.**

Use the face sheet information to call the program participant, or the appropriate designee, and introduce yourself and the PES. A suggested script is included below. For any individuals with cognitive disabilities, it may be preferable to arrange interviews through agency staff or an informal caregiver.

"Hello, my name is _____. I am calling on behalf of the State of _____ to see if you are willing to answer some questions about the services you receive from agencies like _____ (name agency.) Did your case manager let you know I might be calling?

These questions ask if you are satisfied with the help you receive, if staff treat you well, and if you are getting the help you need. Your state wants to use this information to evaluate their program providing help to people like you living in the community, and to determine if any changes need to be made.

These questions should take about 15 minutes of your time. It is your choice whether or not you answer these questions. Answering them will not affect the help you receive in any way. If you are willing to answer them, we can meet at a time and place that is convenient for you.

I am really interested in hearing your opinions and about your experience. When is a convenient time for us to talk?"

● **Arrange an interview time and location.**

If the program participant is willing to participate, arrange a time to meet with him/her at a location that is both convenient and comfortable.

- Possible locations include the program participant's home or place of work, if applicable, or a local mall.

- Try to accommodate other obligations in the program participant's life, such as scheduled visits from home care staff, doctor's visits, employment duties, etc.

● **Get directions to the interview location.**

If appropriate, get directions during the initial call. Case managers or other staff can also provide directions. In addition, maps and Internet sites can be used to supplement verbal directions. The face sheet (*Appendix II*) includes room to record directions, as well as details about the interview time, date, and location.

● **Provide contact information.**

Be sure to leave contact information with the program participant, in case s/he needs to cancel or change the arranged interview. Confirm the time, date, and location of the interview at the close of the conversation.

● **Remind the program participant.**

If possible, call the program participant a day or two in advance of the scheduled interview to remind him or her of the upcoming appointment. A letter or reminder card can also help insure the program participant is available when you make your visit.

Special Situations

- **Program participant declines.**

  Answering the survey questions should be a voluntary activity for program participants. If the selected individual declines to participate, mark the reason given on the face sheet.

- **Program participant has significant problems with waiver.**

  If you determine during your initial phone call that the program participant has significant concerns or problems with waiver services, refer him or her to the appropriate program personnel for follow-up. Or, you may determine that it is appropriate for state staff to initiate follow-up. There is space on the face sheet to record details about any needed follow-up by program personnel.

- **Program participant has behavioral or other issues.**

  If case management staff indicates any behavioral or other issues relevant to arranging the interview, such as the program participant can be violent, or fears strangers, you should address them. For example, if the program participant should not be seen alone, then arrange to have the appropriate staff present.

- **Program participant needs special arrangements.**

  Use the information from the face sheet to make any special arrangements necessary, such as the presence of a translator or individual knowledgeable in sign language.

5.   General Interviewing Guidelines

BEFORE THE INTERVIEW

● **Review face sheet and instrument.**

Review both documents before you meet with the program participant. It is important to know the instrument well, so that you can spend most of your time looking at the program participant and not at the instrument. Also, there is information on the face sheet you will need when conducting the interview, such as the case manager's name.

● **Assign a case ID.**

■ The case ID must be unique to that program participant interview.

■ Copy this number on the first page of the survey.

■ Can be done in advance of the actual interview.

AT THE INTERVIEW

● **Introduce yourself and help program participant feel at ease.**

■ Remind program participant again of the purpose of the survey (to learn about his or her experiences and determine if program improvements are needed).

■ Underscore that there are no "correct" answers nor will honest responses affect his or her benefits.

■ Discuss confidentiality of responses, if appropriate.

■ Allow time to answer any questions the program participant may have before starting.

■ See suggested script, which can be paraphrased, below.

"My name is _____ and I am from the State of _____. Thank you for agreeing to spend some time talking to me. I would like to ask you some questions about your experience with the help you receive.

Your state wants to hear your opinions to learn how well their program is meeting the needs of people like you. There are no correct answers to these questions — I am interested in hearing about *your* experience. Nothing you say will change the help you receive. And, we can stop any time you like.

Do you have any questions for me before we begin? If something I ask is confusing, please let me know."

- **Address the presence of others.**

  Check with the program participant to see if the presence of any other people during the interview is consistent with his/her wishes. Some program participants may feel more comfortable with staff or family members present. Others may prefer to talk to you in private, but may need your help in asking others present to give you and the program participant some privacy.

- **Make sure that you and the program participant are comfortable.**

  Try to minimize distractions for yourself and the program participant, such as television and radio. Your focus should be on the instrument and the program participant.

- **When in doubt, ask; do not skip.**

  Ask every question on the survey, unless a skip pattern indicates to do otherwise. Program participants may choose not to answer any question they wish. That is their prerogative.

- **Do not leave any questions blank.**

  If the program participant does not answer, record "No Response."

- **Ask the questions as they are written.**

  This ensures that each person gets asked the question the same way. If you need to, after reading the question in the original form, you may repeat or rephrase the question to help clarify the question's intent, as long as the meaning of the question does not change.

- **Try to clarify unclear answers.**

  If a program participant's answer is unclear, you may probe to gain further understanding. However, try not to impose your interpretation on the program participant. You may simply mark the response as "unclear" if the program participant's response is unclear.

- **Record only responses provided by the program participant.**

  This instrument is designed to be a *participant* experience survey. If other people provide a response, verify the program participant's answer before recording. You can gently remind family, friends, etc. who are trying to help with information that we are interested in hearing directly about the program participant's experience. If you do record any proxy responses, note this in the *Interviewer Comments* section at the end of the survey.

- **Be sensitive to the program participant's physical and emotional state.**

  You may want to ask how s/he is feeling, and if s/he would like to continue. If the program participant seems tired, or in pain, you can always offer to take a break from the questions. Program participants also have the right to stop the interview altogether. In this case, thank them for their time and end the visit.

● **Amend previous answers, if appropriate.**

If the program participant provides additional or new information later in the interview which changes a previous answer, return to that answer and amend it. For example, if you learn or observe during the interview that the program participant does require assistance with an ADL, even if s/he initially states s/he did not, return to that question and follow the appropriate skip pattern. Also, if s/he remembers additional information, such as a case manager's name, note that information where relevant.

● **Close the interview.**

At the end of the interview, thank the program participant again for his or her participation. Leave contact information so that the program participant can contact someone knowledgeable if s/he has additional questions.

● **Complete the *Interviewer Comments.***

Use the space at the end of the survey to make any comments about the interview you feel are important, including the program participant's comfort level, any non-verbal cues or items you observed, or whether someone else provided responses on the program participant's behalf.

Improving the Interview by Building Rapport

Establishing a friendly and respectful rapport with interview subjects is critical to getting accurate and honest answers. Program participants will feel more at ease when you are:

■ understanding
■ non-judgmental
■ respectful of their culture
■ appreciative of the information provided

Conversational, open-ended questions are included in the survey as opportunities to build rapport between you and the program participant. You may also ask additional questions, and use "small talk" to increase rapport. The interview questions are always the primary focus, and should not be altered or dropped. However, indicating an interest in family pictures, pets, etc. through appropriate comments and questions will help set a friendly, more congenial tone. Similarly, making and maintaining eye contact is another way of building rapport and indicating respect, when it is culturally appropriate.

Some Things to Remember

Know and Share your Limits

Interviewers should be clear about the purpose of the visit: to administer the survey instrument. Too much social interaction can sidetrack the interview, or misrepresent the visit as a social call. In addition, you should be clear about the limits of your ability to change the program participant's living situation, services, etc. Your goal is to gather information only; requests for assistance, or complaints about existing services should be directed to the program participant's case manager. When program participants raise concerns or ask for help, encourage them to talk to their case managers. Otherwise, the individual may be left with the impression that you will "fix things" for them.

Program Participants in Immediate Danger

Intervention may be warranted for program participants whose health, safety, or well-being seems threatened. If you believe the program participant is in immediate jeopardy, through abuse, neglect, unsafe living conditions, or inadequate services, contact the appropriate state or program representative.

6. Coding Responses

Throughout the survey, you, the interviewer, must make judgments about the information the program participant gives you. For example, you must decide how to code a response or if a skip pattern must be followed. This section provides guidance, by priority area, on how to interpret and code individual items.

A. Access to Care

Unmet need: Questions #1 – #31

The purpose of the unmet need section is to determine if a program participant is going without any personal assistance s/he might require to do everyday activities - activities of daily living (ADLs) and instrumental activities of daily living (IADLs). These are some of the performance indicators which can be calculated from the PES. All the questions in this section follow the format shown below, with the exception of transportation (question #25).

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

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

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

The first questions in each ADL or IADL group address whether the program participant needs personal assistance to accomplish the activity. Listening to the program participant, you will need to make a judgment as to whether the respondent needs *or* routinely receives personal assistance, based on their narrative response. If there is any indication that any help is received from another person or that someone else routinely performs the task, code as "Needs help from

another person." This includes stand-by assistance and cueing help, as well as hands-on assistance. Research has shown that people with functional limitations tend to underestimate their need for assistance from others. Therefore, it is important to be attuned to any indication that the program participant receives or requires any help from another person, even it is only occasional.

If you code the program participant as needing assistance, ask the following question to see if the program participant is going without performing certain activities. The third question in each series ("Is this because . . .") is only for those program participants who indicate they sometimes go without performing the ADL and IADL. The purpose of the last question is to determine if lack of personal assistance is the reason for going without.

For further clarification, see the examples below. These examples were drawn from actual pretests of the PES.

→ **EXAMPLE:** When asked if she took a bath or shower by herself, an elderly woman replied that she did, but only when her homemaker was in the apartment, due to her fear of falling.

  ✎ **How to code:** Because she relied on the standby presence of another person, she was coded as requiring assistance with bathing.

→ **EXAMPLE:** A man with an acquired brain injury told the interviewer he could put his own clothes on, but that his mother laid them out for him.

  ✎ **How to code:** Because he received this cognitive assistance from another person, he was coded as requiring help from another person, and asked the follow-up questions.

→ **EXAMPLE:** During pretests, many program participants reported they could prepare their own meals, but received Meals on Wheels.

  ✎ **How to code:** The fact that they received help overrides any self-reporting of the ability to accomplish the task on their own. These program participants were asked the follow-up questions.

IMPORTANT

In addition, if the program participant is physically and cognitively capable of an activity, but another person still routinely does it, s/he should still be asked the follow-up questions. For example, during pretesting some men noted that their wives did all the cooking, even though they were capable. It is better to err on the side of coding program participants as needing/receiving assistance, even if they may not.

Assistive technology and environmental modifications: Questions #33 – #35

The purpose of these questions is to assess unmet need for specialized equipment or home modifications requested by program participants.

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

Some program participants may find these terms or concepts confusing. *Appendix IV* lists examples of assistive technologies available for people with disabilities. This appendix can be used to provide examples to help clarify the concepts of special equipment and changes to the home.

In some cases, a request for equipment or changes may still be open. If so, check the "in process" option for question #35.

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

Choosing staff and services: Questions #36 – #40

The purpose of the items in this section is to assess if program participants can exercise control or make choices about who helps them and what they receive help with. While the Medicaid program requires program participants have a choice among agencies that serve them, it does not require that program participants be able to choose among staff from an agency. Similarly, participants may not always be able to change individual staff when they want. There may be good reasons, such as staffing shortages or program policy, which make changes in staffing difficult or unlikely.

Nonetheless, program participants who indicate that they would like more choice and control regarding staffing are another important measure of program performance. This section seeks to answer:

● Do program participants have options for selecting staff?

● Can program participants at least partially direct the type of assistance they receive?

This can be a difficult concept for some individuals. Items may require rephrasing or the provision of examples.

Assistance with problems: Question #41

The purpose of this question is to determine if the program participant has someone to whom they believe they can take concerns, questions, requests, and complaints. To code this question, you will need to know the relationship of the named individual to the program participant.

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 determine in which category the named individual should be placed.

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

● Although this is a "check all that apply" question, some response categories are mutually exclusive. Respondents who answer "no-one," or are "unsure" of whom they would contact, cannot have responses in more than one category. Similarly, if "unclear response" is checked, no other response should be filled in.

Case manager access: Questions #42 – #44

The goal of the first question in this section, #42, is to determine if program participants can correctly identify their case manager. If program participants cannot name their case manager, they are less likely to be able to contact that individual when they need assistance. You can use the information on the face sheet to verify the accuracy of the response to this question. Code this question as "names case manager" if the program participant can correctly name his/her case manager or indicates in any way s/he knows the case manager's identity. For example, participants may show a card with contact information, or describe the individual. If not, or if the program participant is unsure, code the question as "does not name case manager."

42. Who is your case manager or support coordinator?

| | | Refer to the face sheet for the case manager's name. |

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

For questions #43 and #44, if the program participant states s/he has not tried to contact his/her case manager, or has not asked the case manager for assistance, record his/her response as "not applicable."

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

Abuse and theft: Questions #47 – #52

The goal of these questions is to determine if program participants are being physically or verbally abused, or robbed, by the staff that care for them. The focus of these items is on current abuse – reports of past problems which have been resolved should not be recorded. Each item in this section follows the same format.

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

<table>
<tr><td>1</td><td>☐</td><td>YES</td></tr>
<tr><td>2</td><td>☐</td><td>NO → Skip to Q.49</td></tr>
<tr><td>7</td><td>☐</td><td>UNSURE → Skip to Q.49</td></tr>
<tr><td>8</td><td>☐</td><td>UNCLEAR RESPONSE → Skip to Q.49</td></tr>
<tr><td>9</td><td>☐</td><td>NO RESPONSE → Skip to Q.49</td></tr>
<tr><td>95</td><td>☐</td><td>NOT APPLICABLE (DOES NOT INTERACT WITH PAID STAFF) → Skip to Q.59</td></tr>
</table>

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

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

_____

_____

Some program participants may find the questions about theft and physical and emotional abuse to be offensive or difficult to answer.

- Be sensitive around these questions.

- Reassure individuals that they are asked of everyone.

- Be attuned to any indications of abuse.

- Work to make program participants comfortable discussing their concerns.

- Use the follow-up probe question to get as much information as possible about any alleged incident, to determine its severity and if the respondent would like any assistance or intervention.

IMPORTANT

Despite any pledge of confidentiality you may have made, you may be required by state law or policy to report some incidents of alleged abuse or neglect described to you. Refer to your state's policy regarding legal and ethical responsibilities around reportable incidents of abuse.

Respectful treatment outside the home: Questions #53 – #58

These six questions address respectful treatment by staff in settings other than the program participant's home, if relevant.

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

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

● Use the screening questions, #53 and #56, to determine if the program participant attends a day program or uses transportation services. Only those who do should be asked the follow-up questions.

● You should have information about the service plan on the face sheet.

D. Community Integration/Inclusion

Community integration: Questions #59 and #60

These two questions are designed to broadly assess unmet need for community involvement.

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)

_____

_____

Record the response to the follow-up question. However, interviewers should make it clear to program participants that they (the interviewer) cannot personally make the changes or secure the services or items the program participants say they want. Instead, encourage program participants to talk to their case managers as appropriate.

Wrap-up: Question #61

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

_____

_____

Refer program participants to case managers or other agency personnel if appropriate.

Employment: Questions #62 – #66

This set of questions about choices and satisfaction regarding work is only for the non-elderly population (those under age 65). When interviewing elders, stop the interview at question #61.

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   → **END OF INTERVIEW**
    8 ☐ UNCLEAR RESPONSE
    9 ☐ NO RESPONSE

66. Do you want to work?

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

The definition of "work" here is very broad, and includes any productive activity.

- Paid employment, volunteer work, training classes, and sheltered workshops should all be considered as work.

- Use these examples to help program participants who might think "work" is limited to paid employment.

- If the program participant is working, ask question #63 through #65.

- For those non-elderly individuals who report no "work", skip to question #66.

7.   Analyzing Your Results

Data from the PES E/D can be used to calculate 33 performance indicators for the waiver program. These indicators are listed below. Program staff can use these indicators to identify potential problem areas in waiver program quality. Detailed instructions on how to calculate each indicator are listed in *Appendix V*.

Access to Care

1. **Bathing:** Percent of program participants requiring personal assistance with bathing who report they are sometimes unable to bathe or shower because there is no one there to help them.

2. **Dressing:** Percent of program participants requiring personal assistance with dressing who report they are sometimes unable to dress because there is no one there to help them.

3. **Transferring:** Percent of program participants requiring personal assistance with transferring who report they are sometimes unable to get out of bed because there is no one there to help them.

4. **Eating:** Percent of program participants requiring personal assistance with eating who report they are sometimes unable to eat because there is no one there to help them.

5. **Meal Preparation:** Percent of program participants requiring personal assistance with meal preparation who report they sometimes go without a meal because there is no one there to help them.

6. **Groceries:** Percent of program participants requiring personal assistance with grocery shopping who report they are sometimes unable to get groceries because there is no one there to help them.

7. **Housework:** Percent of program participants requiring personal assistance with housework who report the housework does not get done sometimes because there is no one there to help them.

8. **Laundry:** Percent of program participants requiring personal assistance with laundry who report the laundry does not get done sometimes because there is no one there to help them.

9. **Transportation:** Percent of program participants who report not always having transportation when needed.

10. **Medication:** Percent of program participants requiring personal assistance with taking medications who report they sometimes go without taking medications because there is no one there to help them.

11. **Toileting:** Percent of program participants requiring personal assistance with using the bathroom who report they are sometimes unable to get to or use the bathroom because there is no one there to help them.

12. **Staff Time:** Percent of program participants who report care staff do not spend all the time they are supposed to with the program participant.

13. **Adaptive Equipment or Environmental Modifications:** Percent of program participants who requested special equipment or environmental modifications who report not receiving them.

Choice and Control

14. **Choice in Staff:** Percent of program participants who do not help choose their care staff, but would like to.

15. **Changing Staff:** Percent of program participants who did not know they could change their paid staff.

16. **Directing Staff:** Percent of program participants who do not help direct their staff, but would like to.

17. **Contact for Reporting Staffing Problems:** Percent of program participants who would report staffing problems to "no one" or are unsure to whom to report problems.

18. **Ability to Identify Case Manager:** Percent of program participants who are unable to identify their case manager when asked.

19. **Ability to Contact Case Manager:** Percent of program participants who report they cannot always talk with their case manager when they need to.

20. **Case Manager Helpfulness:** Percent of program participants who say their case managers do not always help them when they ask for something.

Respect/Dignity

21. **Respect by Home Care Staff:** Percent of program participants who report staff do not treat them respectfully in their homes.

22. **Careful Listening by Home Care Staff:** Percent of program participants who report home care staff do not listen carefully to their requests for assistance.

23. **Physical Abuse by Staff:** Percent of program participants who report being injured by current staff.

24. **Verbal Abuse by Staff:** Percent of program participants who report being verbally abused by current staff.

25. **Theft by Staff:** Percent of program participants who report theft by current staff.

26. **Respect by Day Program Staff:** Percent of program participants in day programs who report staff do not treat them respectfully in programs outside their homes.

27. **Careful Listening by Day Program Staff:** Percent of program participants in day programs who report staff do not listen carefully to their requests for assistance in programs outside their homes.

28. **Respect by Transportation Staff:** Percent of program participants who use transportation services who report staff do not treat them respectfully while using these services.

29. **Careful Listening by Transportation Staff:** Percent of program participants who use transportation services who report staff do not listen carefully to their requests for assistance while using transportation services.

Community Integration/Inclusion

30. **Community Involvement:** Percent of program participants who report an unmet need for community involvement.

31. **Demand for Employment:** Percent of non-elderly program participants who are not currently working, but would like to work.

32. **Choice in Employment:** Percent of working, non-elderly program participants who did not choose their current job.

33. **Satisfaction with Employment:** Percent of working, non-elderly program participants who do not like their current job.

8.   Reporting and Acting on Findings

Collecting program participant data using the PES is only the first step in the quality improvement process. When the results have been collated and analyzed, two key questions arise:

● How and to whom should the results be reported?

● What programmatic actions do the results suggest?

Reporting Results

While States may consider the PES an internal quality improvement exercise, there may be expectations around how the results will be shared as well as advantages to sharing them. Indeed, reporting issues should be addressed before data collection begins, so that an effective and systematic strategy for sharing results is developed in advanced.

● Some key questions to address in advance:

■ Who are your audiences?

■ What are they likely to do in response to the results you share? What do you want them to do?

■ How well do they understand the waiver program?

■ How comfortable do you think they are with statistical data?

● Different potential audiences will have different expectations of, and uses for, the results.

■ Results can be used to monitor, compare, or motivate providers.

■ Policymakers and legislators may want the results for accountability purposes.

■ Department heads may want the data to support funding requests.

■ Advocates may also see the results as a way to assess waiver performance.

■ Program participants and their family members will be interested in the results, possibly as a basis for making choices in the program.

● These different audiences will require several different reporting products.

- For each audience there are several key questions:

  - What format is best (print or electronic or verbal)?

  - How long and how much detail?

  - What kinds of graphics and explanatory text?

  - What can you assume about the technical knowledge and literacy level of audience members?

- Disseminating the results also raises issues of:

  - Timing

  - Media and promotion

  - Appropriate messengers

  - Spokespeople to explain and reinforce the message

- Evaluating the effectiveness of reporting is valuable guidance for future efforts.

- Assistance in collecting and reporting quality/performance data is available at: **www.talkingquality.gov**.

Acting on Findings

When examining PES performance indicators for potential problem areas, there are a few important questions to ask before deciding to intervene.

- How much do I care about this problem?

  - Is it priority within this program?

  - Does it have political relevance?

  - Is it within my jurisdiction?

● What do the results mean?

   ■ Are the results statistically significant?

      ➤ Meaningful and measurable differences exist between groups.

   ■ Are the results accurate?

      ➤ Estimates can be more or less accurate depending on sampling errors.

   ■ Are the results practically significant?

      ➤ Results are considered unacceptably high.

   ■ Do results warrant intervention, even if statistically significant?

      ➤ Is the incidence of problems considered acceptable?

      ➤ Are the data compelling enough to justify spending quality dollars?

      ➤ Are the results supported by data from other sources?

      ➤ Are they amenable to quality improvement interventions?

The quality improvement process, outlined in *Section 1,* should be the template for acting on any problem areas indicated by the performance indicators. If action is deemed warranted, the appropriate personnel should be involved in brainstorming interventions or program changes to address the perceived problem. After intervening, repeating the survey can provide valuable information about the impact of your intervention, through changes in the performance indicator values. For more information about the quality improvement process, see **Work Book: Improving the Quality of Home and Community Based Services and Supports.** Again, assistance for states is also available through the National Quality Contractor.

Additional Data Sources

PES E/D data can also be combined with other data sources, both to determine the scope and prevalence of problem areas and to measure the impact of quality interventions. Data from other sources can help corroborate PES findings, or provide additional information about the problem area.

Appendix I:
Background on the Survey Experience

How people answer survey questions — the process of formulating a response

In answering a survey question, people must go through four cognitive steps:

- Comprehension

- Retrieval

- Estimation/Judgment

- Response

First people must ***understand what is being asked*** — comprehension. Then they must ***retrieve from memory information*** relevant to what they are being asked. Using this information, they have to formulate or ***estimate an answer***, and then ***convey their answer*** to the person asking the question. The accuracy of a person's response can be affected at every step of this process. In addition, people with disabilities receiving home and community supports may also have multiple staff coming in and out of their homes to provide support, further complicating the interview. An interviewer's sensitivity to the issues outlined below can help limit their impact on the interview process.

Comprehension: Comprehending a question requires that the respondent first know the individual words. Health literacy — understanding of health terms and concepts such as managed care or case manager — can be limited in many populations. But respondents also have to have a practical understanding of what the question is really asking and what the interviewer's intention is. For both elderly and non-elderly people with disabilities, pain associated with their conditions, possible sensory impairments, and general fatigue can also interfere with comprehension.

Retrieval: Research indicates that people tend to group experiences in their memories, and that only abnormal events stand out. In general, the elderly may have less recent experience with retrieving information and responding to surveys.

Estimation/Judgment: When information is retrieved, the respondent may have to evaluate that information, make comparisons with other information, and fit that information into one of the provided categories. This can also be challenging.

Response: Finally, even after arriving at a response internally, individuals may edit their spoken or written response for reasons of social desirability or self-presentation. In general, people want to try to reflect prevailing social norms in their answers rather than actual personal experience. In interviews, people don't want to be embarrassed, or seem abnormal, or unintelligent.

Research has also shown that this bias is an important factor in interviewing elderly clients about home care. Older respondents may choose to agree with what they perceive to be the desired answer, and may also fear reprisal and loss of services if they express dissatisfaction. As a result, emphasizing confidentiality and anonymity, when appropriate, is key. In addition, people may be more honest if they do not associate the interviewer with the agency providing services. Finally, elderly and chronically ill subjects have shown the tendency to agree with statements, regardless of their content.

Appendix II:
Sample Face Sheet

Participant Experience Survey — Elderly/Disabled Version
Face Sheet

I.   BACKGROUND (To be filled out by the case manager or other appropriate program personnel)

I-1. Program Participant's Name: _____

I-2. Social Security Number: _____

I-3. Program Participant's Medicaid Number: _____

I-4. Program Participant's Address: _____

_____

_____

I-5. Program Participant's Tel. No: ___ ___ ___-___ ___ ___-___ ___ ___ ___

I-6. County of Residence: _____

I-7. Date of Birth (MM/DD/YY): ___ ___/ ___ ___ / ___ ___

I-8. Contact for Scheduling Interview

If program participant should be contacted directly, check here _____

Name: _____   Relationship: _____

Daytime Phone: __ __ __- __ __ __- __ __ __ __   Evening Phone: __ __ __- __ __ __- __ __ __ __

Pager: __ __ __- __ __ __- __ __ __ __   Cellular Phone: __ __ __- __ __ __- __ __ __ __

E-mail address: _____

I-9. Special Instructions

Any special instructions for the interviewer in arranging the interview?

_____

_____

_____

I-10. Legal Guardian

Does the program participant have a legal guardian? _____ Yes _____ No

Legal Guardian's Name: _____

Legal Guardian's Address: _____

_____

_____

Legal Guardian's Tel. No. : __ __ __- __ __ __- __ __ __ __

I-11. Case Manager _____

Case Manager's Name: _____

Case Manager's Agency: _____

Case Manager's Tel. No. : __ __ __- __ __ __- __ __ __ __

Please indicate if case manager is known by another title, e.g., support coordinator.

_____

I-12. Communication Needs

Does the program participant need any special communication accommodations to participate in the interview? For example, is his/her primary language something other than English? Does s/he use sign language or a communication device? Please explain what arrangements would be needed for the interview.

_____

_____

_____

I-13. Service Plan

Please check all the services that the program participant receives through the waiver.

_____ Personal care/personal attendant services/home health aide/homemaker

_____ Chore/home maintenance

_____ Home-delivered meals

_____ Home modifications

_____ Day program

_____ Visiting nurse/OT/PT/Speech

_____ Employment assistance

_____ Assistive technology/durable medical equipment

_____ Family support/caregiver training/respite

_____ Transportation

_____ Community support

_____ Case management

_____ Other _____

I-14. Support Staff

If there are any people who are paid to assist the program participant in his/her home, such as home health aides or homemaker staff, please indicate their first names. If there are several workers, please list those staff that spend the most time with the program participant.

Names of home support staff: _____

If there are any people who are paid to assist the program participant outside his/her home, such as day program staff or an attendant at work, please indicate their first names. If there are several workers, please list those staff that spend the most time with the program participant.

Names of day program/employment staff: _____

If there are any people who are paid to provide assistance with transportation services, please indicate their first names. If there are several workers, please list those staff that spend the most time with the program participant.

Names of transportation staff: _____

I-15.   Other Helpful Information

Is there anything else that would be helpful to the interviewer who will be arranging for, and conducting, the interview? For example, might this person be uncomfortable talking with a stranger? Are there any reasons this person should not be interviewed alone?

_____

_____

_____

II.   SCHEDULING THE INTERVIEW (To be completed by the interviewer)

II-1. Dates Individual Contacted: _____

_____

_____

II-2. Willingness to Participate

Agrees to interview? Circle **YES** and complete rest of this page only.

Declines interview? Circle **NO** and compete last page only.

II-3. Scheduled Interview Date and Time: _____

II-4. Actual Interview Date and Time (if different): _____

II-5. Location: _____

_____

II-6. Driving Directions:

_____

_____

_____

_____

II-7. Case ID#   _____

II-8. Is Program Follow-Up Needed?

____ Yes, immediate follow-up   ____ Yes, but need is not immediate   ____ No

Who should follow up and why?

_____

_____

_____

II-9.   Reason Interview Refused (check all that apply)

_____   Too busy   _____   Hospitalized

_____   No longer on waiver   _____   Communication issues

_____   Family/other refused   _____   Not comfortable/other concerns

_____   Not interested   _____   No reason given

_____   Waiver participant has concerns/problems with program, staff, or services

II-10. Is Program Follow-Up Needed?

____ Yes, immediate follow-up   ____ Yes, but need is not immediate   ____ No

Who should follow up and why?

_____

_____

_____

Appendix III:
Sample Program Participant Letter

November 26, 2002

Dear :

I hope you can help me out.

I am conducting a survey of people in the Medicaid Home and Community-Based Services Waiver Programs in _____. The purpose of the survey is to get feedback from people like you about how satisfied you are with the help you receive from organizations like X, and with the people who are paid to help you.

We are looking for people like you who can tell us if you are satisfied with the help you receive.

Would you be willing to meet with me and allow me to ask a few questions about the help you get? It would take about 20 minutes of your time.

We can meet at your convenience — the date, time and place are up to you.

I will not be sharing any of the information you give me with anyone who is paid to help you. The information you give to me will be kept confidential.

I will call you in about a week to set up a convenient meeting time if you are interested, or you may call me at _____.

Thank you.

Sincerely,

Appendix IV:
Assistive Technology Examples

Below are several examples of assistive technologies and devices, as well as environmental modifications, currently available for people with disabilities. They are grouped both by impairment type and by everyday living activity. They can be used as examples when asking question #33 on PES E/D.

I. Assistive Technology by Impairment Type

Mobility
>Wheelchairs — both motorized and portable (lightweight)
>Ramps to enter your home, job, or school
>Canes and walkers, including walkers with pouches or shelves for carrying things
>Grab bars to hold on to so you don't fall down
>Lifts to move a wheelchair up or down stairs

Communication
>Computer software to help you learn words for things and places in your town
>Computer software that lets you practice talking with another person
>Little machines that play the messages you want when you press a button
>Talking cards to let people know what you want
>A special board with pictures that tell people what you want
>Toys and other devices that make your speech clearer and louder

Visual Devices
>A machine that lets you use a telephone to surf the World Wide Web and hear information
>Large print address books
>Talking maps to help you explore your neighborhood
>Braille keyboards, rulers, and speaker phones
>Special devices that make everything on the television look larger
>Videos which describe the action in the movie
>A phone that tells you the day, time, and phone number of someone calling you
>Talking dictionaries, thermometers, VCRs

II. Technologies for Everyday Living

Cooking/Meal Preparation
Special, simple cookbooks which use pictures to help you
Cookbooks recorded on tapes, written in Braille, or with large print
Picture cards to use when ordering food in a restaurant
Grippers that make it easier to hold on to things like tools and cooking utensils
Pots and pans which are easy to lift if you have weak arms
A buzzer that tells you when you have filled a cup or pot to the top
A cutting board that makes it easier to see the food
Devices that tell you when a pot is boiling
Special knobs for stoves and microwaves for people who can't see well
Talking kitchen timers and microwave ovens
Special tools for opening jars and bottles and for pouring milk
Appliances and counters low enough to use if you are in a wheelchair

Eating
Plate guards to keep the food from being pushed off your plate
Special utensils for eating

Bathing
Shower stool so you can sit down in the shower
Hand-held shower head
Grab bars in shower

Dressing
Markers you can feel for matching your clothes
Clothes with Velcro closings
Special hooks or other tools for buttoning buttons
A tool to help you put on bracelets or necklaces
A tool to help you tie your shoes
A tool to help you use a razor
A tool that makes it easier to pull a zipper
Magnified mirror for putting on makeup

Taking Medication
A special alarm clock to remind you when to take your medicine
Special syringes you can fill with insulin even if you can't see well or at all

Transportation
Vans with lifts to carry your wheelchair
Cars or vans that you can drive using just your hands (no foot pedals)

Computer Devices

A computer keyboard with large colored keys

A computer mouse that attaches to your head, so you can control the computer by moving your head

A computer mouse that you use with your feet

A machine that lets you work your computer by talking (telling it what to do)

Special glasses that let you control your computer with your eyes

A talking keyboard for the computer

A talking computer which takes notes for you

Other

A device that lets you attach a camera to a wheelchair

Large light switches that are easy to use/switches you can turn on with your tongue

Special tools that help you turn a key, squeeze toothpaste, and other daily activities (fine motor tasks)

A scanner which tells you the amount of your paper money ($1, $5, $10, etc.)

Appendix V:
Calculating the Performance Indicators

The table below shows the numerator and denominator for each of the 33 performance indicators.

Indicator Number	Indicator	Numerator	Denominator
ACCESS TO CARE			
1	Bathing: Q1–Q3	Number of "yes" (1) responses to Q3. Do not include "unsure" (7), "unclear" (8), or "no response" (9) to Q3.	Number of "needs help" (1) responses to Q1. Do not include respondents needing help in Q1 who provided an "unsure" (7), "unclear" (8), or "no response" (9) to Q2 or Q3.
2	Dressing: Q4–Q6	Number of "yes" (1) responses to Q6. Do not include "unsure" (7), "unclear" (8), or "no response" (9) to Q6.	Number of "needs help" (1) responses to Q4. Do not include respondents needing help in Q4 who provided an "unsure" (7), "unclear" (8), or "no response" (9) to Q5 or Q6.
3	Transferring: Q7–Q9	Number of "yes" (1) responses to Q9. Do not include "unsure" (7), "unclear" (8), or "no response" (9) to Q9.	Number of "needs help" (1) responses to Q7. Do not include respondents needing help in Q7 who provided an "unsure" (7), "unclear" (8), or "no response" (9) to Q8 or Q9.
4	Eating: Q10–Q12	Number of "yes" (1) responses to Q12. Do not include "unsure" (7), "unclear" (8), or "no response" (9) to Q12.	Number of "needs help" (1) responses to Q10. Do not include respondents needing help in Q10 who provided an "unsure" (7), "unclear" (8), or "no response" (9) to Q11 or Q12.
5	Meal Preparation: Q13–Q15	Number of "yes" (1) responses to Q15. Do not include "unsure" (7), "unclear" (8), or "no response" (9) to Q15.	Number of "needs help" (1) responses to Q13. Do not include respondents needing help in Q13 who provided an "unsure" (7), "unclear" (8), or "no response" (9) to Q14 or Q15.
6	Groceries: Q16–Q18	Number of "yes" (1) responses to Q18. Do not include "unsure" (7), "unclear" (8), or "no response" (9) to Q18.	Number of "needs help" (1) responses to Q16. Do not include respondents needing help in Q16 who provided an "unsure" (7), "unclear" (8), or "no response" (9) to Q17 or Q18.

Indicator Number	Indicator	Numerator	Denominator
ACCESS TO CARE, continued			
7	Housework: Q19-Q21	Number of "yes" (1) responses to Q21. Do not include "unsure" (7), "unclear" (8), or "no response" (9) to Q21.	Number of "needs help" (1) responses to Q19. Do not include respondents needing help in Q19 who provided an "unsure" (7), "unclear" (8), or "no response" (9) to Q20 or Q21.
8	Laundry: Q22-Q24	Number of "yes" (1) responses to Q24. Do not include "unsure" (7), "unclear" (8), or "no response" (9) to Q24.	Number of "needs help" (1) responses to Q22. Do not include respondents needing help in Q22 who provided an "unsure" (7), "unclear" (8), or "no response" (9) to Q23 or Q24.
9	Transportation: Q25	Number of "no" (2) responses to Q25. Do not include "unsure" (7), "unclear" (8), or "no response" (9) to Q25.	Number of "yes" (1), "no" (2), and "unsure" (7), responses to Q25. Do not include "unclear" (8) or "no response" (9) to Q25.
10	Medication: Q26-Q28	Number of "yes" (1) responses to Q28. Do not include "unsure" (7), "unclear" (8), or "no response" (9) to Q28.	Number of "needs help" (1) responses to Q26. Do not include respondents needing help in Q26 who provided an "unsure" (7), "unclear" (8), or "no response" (9) to Q27 or Q28.
11	Toileting: Q29-Q31	Number of "yes" (1) responses to Q31. Do not include "unsure" (7), "unclear" (8), or "no response" (9) to Q31.	Number of "needs help" (1) responses to Q29. Do not include respondents needing help in Q29 who provided an "unsure" (7), "unclear" (8), or "no response" (9) to Q30 or Q31.
12	Staff Time: Q32	Number of "no" (2) responses to Q32. Do not include "unsure" (7), "unclear" (8), or "no response" (9) to Q32.	Number of "yes" (1), "no" (2), and "unsure" (7), responses to Q32. Do not include "unclear" (8) or "no response" (9) to Q32.
13	Adaptive Equipment or Environmental Modifications: Q35	Number of "no" (2) responses to Q35. Do not include "in process" (3), "unsure" (7), "unclear" (8), or "no response" (9) to Q35.	Number of "yes" (1), "no" (2), "in process" (3), and "unsure" (7) responses to Q35. Do not include "unclear" (8) or "no response" (9) to Q35.

Indicator Number	Indicator	Numerator	Denominator
CHOICE AND CONTROL			
14	Choice in Staff: Q37	Number of "yes" (1) responses to Q37. Do not include "unsure" (7), "unclear" (8), or "no response" (9) to Q37.	Number of "yes" (1), "no" (2), and "unsure" (7) responses to Q37. Do not include "unclear" (8) or "no response" (9) to Q37.
15	Changing Staff: Q38	Number of "no" (2) and "unsure" (7) responses to Q38. Do not include "unclear" (8), or "no response" (9) to Q38.	Number of "yes," (1) "no" (2) and "unsure" (7) responses to Q38. Do not include "unclear" (8), or "no response" (9) to Q38.
16	Directing Staff: Q40	Number of "yes" (1) responses to Q40. Do not include "unsure" (7), "unclear" (8), or "no response" (9) to Q40.	Number of "yes" (1), "no" (2), and "unsure" (7) responses to Q40. Do not include "unclear" (8) or "no response" (9) to Q40.
17	Contact for Reporting Staffing Problems: Q41	Number of "no one" (1) and/or "unsure" (7) responses to Q41. Do not include "unclear" (8) or "no response" (9) to Q41.	Number of "no one" (1), "family/friend" (2), "case manager…" (3), "other" (4), and/or "unsure" (7) to Q41. Do not include "unclear" (8) or "no response" (9) to Q41.
18	Ability to Identify Case Manager: Q42	Number of "does not name case manager" (2) responses to Q42. Do not include "unclear" (8) or "no response" (9) to Q42.	Number of "names case manager" (1) and "does not name" (2) responses to Q42. Do not include "unclear" (8) or "no response" (9) to Q42.
19	Ability to Contact Case Manager: Q43	Number of "no" (2) and "sometimes" (3) responses to Q43. Do not include "unsure" (7), "unclear" (8), "no response" (9), or "not applicable" (95) to Q43.	Number of "yes" (1), "no" (2), "sometimes" (3), and "unsure" (7) responses to Q43. Do not include "unclear" (8), "no response" (9), or "not applicable" (95) to Q43.
20	Case Manager Helpfulness: Q44	Number of "no" (2) and "sometimes" (3) responses to Q44. Do not include "unsure" (7), "unclear" (8), "no response" (9), or "not applicable" (95) to Q44.	Number of "yes" (1), "no" (2), "sometimes" (3), and "unsure" (7) responses to Q44. Do not include "unclear" (8), "no response" (9), or "not applicable" (95) to Q44.

Indicator Number	Indicator	Numerator	Denominator
RESPECT / DIGNITY			
21	Respect by Home Care Staff: Q45	Number of "no" (2) and "sometimes" (3) responses to Q45. Do not include "unsure" (7), "unclear" (8), "no response" (9), or "not applicable" (95) to Q45.	Number of "yes" (1), "no" (2), "sometimes" (3), and "unsure" (7) responses to Q45. Do not include "unclear" (8), "no response" (9), or "not applicable" (95) to Q45.
22	Careful Listening by Home Care Staff: Q46	Number of "no" (2) and "sometimes" (3) responses to Q46. Do not include "unsure" (7), "unclear" (8), or "no response" (9) to Q46.	Number of "yes" (1), "no" (2), "sometimes" (3), and "unsure" (7) responses to Q46. Do not include "unclear" (8) or "no response" (9) to Q46.
23	Physical Abuse by Staff: Q47	Number of "yes" (1) responses to Q47. Do not include "unsure" (7), "unclear" (8), "no response" (9), or "not applicable" (95) to Q47.	Number of "yes" (1), "no" (2), and "unsure" (7), responses to Q47. Do not include "unclear" (8), "no response" (9), or "not applicable" (95) to Q47.
24	Verbal Abuse by Staff: Q49	Number of "yes" (1) and "sometimes" (3) responses to Q49. Do not include "unsure" (7), "unclear" (8), or "no response" (9) to Q49.	Number of "yes" (1), "no" (2), "sometimes" (3), and "unsure" (7), responses to Q49. Do not include "unclear" (8) or "no response" (9) to Q49.
25	Theft by Staff: Q51	Number of "yes" (1) responses to Q51. Do not include "unsure" (7), "unclear" (8), or "no response" (9) to Q51.	Number of "yes" (1), "no" (2), and "unsure" (7) responses to Q51. Do not include "unclear" (8) or "no response" (9) to Q51.
26	Respect by Day Program Staff: Q54	Number of "no" (2) and "sometimes" (3) responses to Q54. Do not include "unsure" (7), "unclear" (8), or "no response" (9) to Q54.	Number of "yes" (1), "no" (2), "sometimes" (3), and "unsure" (7), responses to Q54. Do not include "unclear" (8) or "no response" (9) to Q54.
27	Careful Listening by Day Program Staff: Q55	Number of "no" (2) and "sometimes" (3) responses to Q55. Do not include "unsure" (7), "unclear" (8), or "no response" (9) to Q55.	Number of "yes" (1), "no" (2), "sometimes" (3), and "unsure" (7), responses to Q55. Do not include "unclear" (8) or "no response" (9) to Q55.

Indicator Number	Indicator	Numerator	Denominator
RESPECT / DIGNITY, continued			
28	Respect by Transportation Staff: Q57	Number of "no" (2) and "sometimes" (3) responses to Q57. Do not include "unsure" (7), "unclear" (8), or "no response" (9) to Q57.	Number of "yes" (1), "no" (2), "sometimes" (3), and "unsure" (7), responses to Q57. Do not include "unclear" (8) or "no response" (9) to Q57.
29	Careful Listening by Transportation Staff: Q58	Number of "no" (2) and "sometimes" (3) responses to Q58. Do not include "unsure" (7), "unclear" (8), or "no response" (9) to Q58.	Number of "yes" (1), "no" (2), "sometimes" (3), and "unsure" (7), responses to Q58. Do not include "unclear" (8) or "no response" (9) to Q58.
COMMUNITY INTEGRATION / INCLUSION			
30	Community Involvement: Q59	Number of "yes" (1) responses to Q59. Do not include "unsure" (7), "unclear" (8), or "no response" (9) to Q59.	Number of "yes" (1), "no" (2), and "unsure" (7) responses to Q59. Do not include "unclear" (8) or "no response" (9) to Q59.
31	Demand for Employment: Q66	Number of "yes" (1) responses to Q66. Do not include "unsure" (7), "unclear" (8), or "no response" (9) to Q66.	Number of "yes" (1), "no" (2), and "unsure" (7) responses to Q66. Do not include "unclear" (8), or "no response" (9) to Q66.
32	Choice in Employment: Q64	Number of "no" (2) responses to Q64. Do not include "unsure" (7), "unclear" (8), or "no response" (9) to Q64.	Number of "yes" (1), "no" (2), and "unsure" (7) responses to Q64. Do not include "unclear" (8) or "no response" (9) to Q64.
33	Satisfaction with Employment: Q65	Number of "no" (2) responses to Q65. Do not include "unsure" (7), "unclear" (8), or "no response" (9) to Q65.	Number of "yes" (1), "no" (2), and "unsure" (7) responses to Q65. Do not include "unclear" (8) or "no response" (9) to Q65.

Some guidelines to keep in mind when analyzing the survey results:

● Be aware of skip pattern violations.

   ■ Questions answered inappropriately (i.e. those which should have been skipped) can be recoded as missing, and not included in the numerator or denominator.

   ■ Questions which were inappropriately skipped cannot be recoded (not enough information to impute the program participant's response).

● Responses that are coded as "unclear response" or "no response" cannot be included in the numerator or denominator of the performance indicators. They are treated as missing observations.

   ■ There is not enough information about these individuals to determine if they do or do not possess a given trait.