

Division of Community Based Care Services

Bureau of Elderly and Adult Services

Participant Experience Survey

2008

Prepared by:

**Division of Community Based Care Services
Quality Management**

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Overview

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The goal of the Participant Experience Survey (PES) project was to complete a survey with a representative sample of Home and Community Based Care Services Elderly and Chronically Ill waiver participants about the services and supports they receive. The Home and Community Based Care Services Elderly and Chronically Ill waiver program, formerly known as HCBC-ECI, has been named the Choices for Independence (CIF) program.

A December 2007 report of CIF participant cases that were open for at least six months reflected 2142 cases and further calculation indicated that a randomized and representative sample of 326 would yield a 5% confidence interval at the 95% confidence level, which remained the goal of the project. To determine the sample size, NH followed the guidelines in the *Sampling, A Practical Guide for Quality Management in Home & Community-Based Waiver Programs* which describes a probability sample as one in which “everyone in the target population has a known, non-zero probability (or likelihood) of being included in the sample. That is, everyone in the target population has a chance of being selected into the sample, and their chances of selection (likelihood) are greater than zero. A probability sample is considered ‘representative’ of the population, and therefore the findings based on the sample can be generalized to the population overall.”¹

The project was designed to establish a statewide baseline rather than regional or stratified results, such as by case management agencies, by county, by ServiceLink Resource Center (SLRC) catchment areas or by the Department of Health and Human Services’ twelve District Offices. Future surveys may be organized regionally such as by SLRCs or by county though to do so would require a much larger sample than a statewide sample.

Introductory letters were sent to an oversample of 472 CIF participants, with the goal of completing at least 326 interviews. Ultimately, 288 interviews were actually completed. All PESs were completed as face-to-face interviews in CFI participants’ homes and/or residences based on appointments arranged by the trained surveyors. Surveyors reported that, on average, interviews took approximately 30 minutes.

The initial survey team consisted of five Bureau of Elderly and Adult Services (BEAS) state office personnel. Eventually two additional state office staff joined the team and two contractors were hired, one for one month and the second for two for a total of nine surveyors. The PES survey team received training and technical assistance from the PES developer, the Healthcare

¹ Developed for Centers for Medicare and Medicaid Services, March 2006 by Human Services Research Institute and The MEDSTAT Group, Inc, pg. 14

business of Thomson Reuters, which developed the survey under contract with the Centers for Medicare and Medicaid Services (CMS).

New Hampshire used Version 1.0 of the PES E/D, designed for elders and adults with physical disabilities. This tool consists of four domains, listed below. In addition, BEAS developed a fifth domain, Plan for Services, which also provides a source of information for the Real Choice System Transformation Grant:

1. Access to Care
2. Choice and Control
3. Respect and Dignity
4. Community Integration

Most questions had the following forced choice response pattern:

- Yes
- No
- Unsure
- Unclear response
- No response

Participants' comments on several questions from the 288 completed surveys are included in the Appendix. In addition estimates for a number of performance indicators developed by Thomson Reuters are included in the Appendix.

Not all CFI participants in the sample were available or interested in participating in the PES. The surveyors recorded the reason a selected CFI participant did not complete a PES based on the following list of non-survey reasons.

1. participant does not wish to participate
2. unable to participate per provider, guardian or family member/advocate
3. unable to contact
 - a. 3 attempts made
 - b. check telephone number with support staff; if different try again
4. unable to arrange for interpreter or adequate proxy
5. unsafe for surveyor (as determined by the surveyor)
6. surveyors not to survey people known to them; will transfer to another surveyor
7. other, e.g., participant who schedules multiple times and cancels multiple times
8. death

One observation is that the over sample size of 472 should have been larger as more people than anticipated either chose not to participate, were otherwise unavailable or were unable to be located. A particular challenge was undelivered introductory letters at a return rate of at least 8%. In addition, a significant number of participants' telephone numbers were incorrect making it necessary to check other resources and, if contact

information was not available, those CFI participants were crossed off the list and other participants were selected from the randomized sample list.

Challenges and Opportunities

Establishing the survey team proved to be a significant challenge. The Bureau could not use volunteers due to liability issues around travel and visiting people's homes and residences. Eventually a number of state office staff were recruited to participate, and two minor contracts were established to expand the total interview team to nine. The positive side to having staff as surveyors is the increased ability to sustain the PES as a standing quality management activity. Conversely, the challenge with using staff in this capacity was the conflict with their existing workload, which at times slowed the rate of survey completion.

Equipment posed an additional challenge. Shortly before the survey was to be initiated, automobile chargers were ordered so the laptop computer batteries could be charged between surveys – a recommendation made by other staff that relied on laptop computers to perform assessments in peoples' homes. The equipment delivery took several weeks.

As noted earlier, two related issues were returned mail and incorrect telephone numbers for sampled respondents. When introductory letters were returned and/or telephone information was missing or incorrect, attempts were made to access correct information, re-mail the letters and contact the participants in the order in which their names were listed on the randomized list.

Surveyors' feedback

The surveyors were presented with a brief questionnaire about their experiences with the project. Narrative responses to two of the questions are included below.

Thinking back, what was good about being a PES surveyor?

- It was an opportunity to meet some of the individuals who participate in the program for the sole purpose of hearing from them and how they were helped (or not), and how their preferences were honored. It was very interesting – and revealing – to me, personally to hear people identify what they needed help with.
- Meeting the folks in their homes.
- I enjoyed being a surveyor. I think it was very helpful that it was state employees doing the interviewing. It was important to be able to read the spoken and unspoken language. I think it was an advantage for employees to do the interviewing.
- Going into the community to work with a variety of clients and giving them a sense of empowerment/voice.
- Meeting people who receive services and hearing their stories.
- Getting out in the “field” and working closely with clients.

What was one of your personally rewarding experiences?

- Spending some time with the mother of an individual receiving services, listening to her frustrations trying to get the services her son needs.... but hearing about her persistence to help him tracking down resources on her own in spite of our system.
- I was able to get additional information for a consumer I had interviewed. It was nice to meet the consumers who utilize Medicaid and I heard more than once that it was nice for the consumers to meet a state representative (without an issue being involved).
- Surveying a resident in a dementia unit that was described as being uncooperative in talking to people..... he talked (with me).
- Hearing from people about how much of a difference the program has made in their lives.

Analysis

Per feedback from the Thomson Reuters' consultant, the margin of error is acceptable (less than 5 percent) given the population of 2142, a sample of 288 completed surveys, and the indicators' estimates included in the Appendix.

For reference a blank Participant Experience Survey is included in the Appendix. In addition survey results by domain, e.g., Access to Care, the performance indicators and narrative responses to several questions are also included in the Appendix.

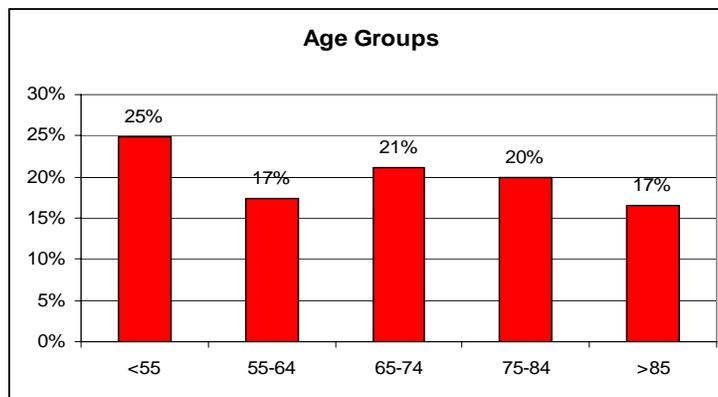
APPENDICES

Demographic Data	Page 6
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PES Results (by domain; excluding narrative responses).....	Pages 19 – 39
Performance Indicators	Pages 40 – 46
Narrative Responses.....	Pages 47 – 61

Demographics data²

Age groups

Age range	# of respondents	
< 55	60	25%
55-64	42	17%
65-74	51	21%
75-84	48	20%
>85	40	17%
<i>Total</i>	<i>241</i>	<i>100%</i>



Gender

Male	86	30%
Female	202	70%

Race

Race	Total recorded	
White	188	97%
Black or African American	1	0%
American Indian or Alaska Native	1	0%
Asian	0	0%
Hispanic or Latina	2	1%
Native Hawaiian or Other Pacific Islander	3	2%
Hispanic or Latino AND one or more races	0	0%
More than one race	0	0%
<i>Total responses</i>	<i>195</i>	<i>100%</i>

² The demographic data fields were not completed for all of the completed surveys.

PARTICIPANT EXPERIENCE SURVEY³
ELDERLY/DISABLED (ED) VERSION
Version 1.0
August 1, 2003

A. Access to Care	
1.	<p>Is there any special help that you need to take a bath or shower?</p> <p><input type="checkbox"/> Needs help from another person</p> <p><input type="checkbox"/> Does not need help from another person (skip to q.4)</p> <p><input type="checkbox"/> Unclear response (skip to q.4)</p> <p><input type="checkbox"/> No response (skip to q.4)</p>
2	<p>Do you ever go without a bath or shower when you need one?</p> <p><input type="checkbox"/> Yes</p> <p><input type="checkbox"/> No (skip to q.4)</p> <p><input type="checkbox"/> Unsure (skip to q.4)</p> <p><input type="checkbox"/> Unclear response (skip to q.4)</p> <p><input type="checkbox"/> No response (skip to q.4)</p>
3	<p>Is this because there is no one there to help you?</p> <p><input type="checkbox"/> Yes</p> <p><input type="checkbox"/> No</p> <p><input type="checkbox"/> Unsure</p> <p><input type="checkbox"/> Unclear response</p> <p><input type="checkbox"/> No response</p>
4	<p>Is there any special help that you need to get dressed (specify)</p> <p><input type="checkbox"/> Needs help from another person</p> <p><input type="checkbox"/> Does not need help from another person (skip to q. 7)</p> <p><input type="checkbox"/> Unclear response (skip to q. 7)</p> <p><input type="checkbox"/> No response (skip to q. 7)</p>
5.	<p>Do you ever go without getting dressed when you need to?</p> <p><input type="checkbox"/> Yes</p> <p><input type="checkbox"/> No (skip to q. 7)</p> <p><input type="checkbox"/> Unsure (skip to q.7)</p> <p><input type="checkbox"/> Unclear response (skip to q.7)</p> <p><input type="checkbox"/> No response (skip to q.7)</p>

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Developed by: The Medstat Group, Inc.
 For the: Centers for Medicare & Medicaid Services, an Agency of the Department of Health & Human Services; Contract #500-96-0006 T.O. #2

6.	<p>Is this because there is no one there to help you?</p> <p><input type="checkbox"/> Yes</p> <p><input type="checkbox"/> No</p> <p><input type="checkbox"/> Unsure</p> <p><input type="checkbox"/> Unclear response</p> <p><input type="checkbox"/> No response</p>
7.	<p>Is there any special help that you need to get out of bed?</p> <p><input type="checkbox"/> Needs help from another person</p> <p><input type="checkbox"/> Does not need help from another person (skip to q. 10)</p> <p><input type="checkbox"/> Unclear response (skip to q. 10)</p> <p><input type="checkbox"/> No response (skip to q. 10)</p>
8.	<p>Do you ever go without getting out of bed when you need to?</p> <p><input type="checkbox"/> Yes</p> <p><input type="checkbox"/> No (skip to q. 10)</p> <p><input type="checkbox"/> Unsure (skip to q. 10)</p> <p><input type="checkbox"/> Unclear response (skip to q. 10)</p> <p><input type="checkbox"/> No response (skip to q. 10)</p>
9.	<p>Is this because there is no one there to help you?</p> <p><input type="checkbox"/> Yes</p> <p><input type="checkbox"/> No</p> <p><input type="checkbox"/> Unsure</p> <p><input type="checkbox"/> Unclear response</p> <p><input type="checkbox"/> No response</p>
10.	<p>Is there any special help that you need to eat?</p> <p><input type="checkbox"/> Needs help from another person</p> <p><input type="checkbox"/> Does not need help from another person (skip to q. 13)</p> <p><input type="checkbox"/> Unclear response (skip to q. 13)</p> <p><input type="checkbox"/> No response (skip to q. 13)</p>
11.	<p>Do you ever go without eating when you need to?</p> <p><input type="checkbox"/> Yes</p> <p><input type="checkbox"/> No (skip to q. 13)</p> <p><input type="checkbox"/> Unsure (skip to q. 13)</p> <p><input type="checkbox"/> Unclear response (skip to q. 13)</p> <p><input type="checkbox"/> No response (skip to q. 13)</p>
12.	<p>Is this because there is no one there to help you?</p> <p><input type="checkbox"/> Yes</p> <p><input type="checkbox"/> No</p> <p><input type="checkbox"/> Unsure</p> <p><input type="checkbox"/> Unclear response</p> <p><input type="checkbox"/> No response</p>

13.	<p>Is there any special help that you need to make your meals?</p> <ul style="list-style-type: none"> <input type="checkbox"/> Needs help from another person <input type="checkbox"/> Does not need help from another person (skip to q. 16) <input type="checkbox"/> Unclear response (skip to q. 16) <input type="checkbox"/> No response (skip to q. 16) <input type="checkbox"/> Not applicable, tube fed (skip to q. 19)
14.	<p>Do you ever go without a meal when you need one?</p> <ul style="list-style-type: none"> <input type="checkbox"/> Yes <input type="checkbox"/> No (skip to q. 16) <input type="checkbox"/> Unsure (skip to q. 16) <input type="checkbox"/> Unclear response (skip to q. 16) <input type="checkbox"/> No response (skip to q. 16)
15.	<p>Is this because there is no one there to help you?</p> <ul style="list-style-type: none"> <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unsure <input type="checkbox"/> Unclear response <input type="checkbox"/> No response
16.	<p>Is there any special help that you need to get groceries?</p> <ul style="list-style-type: none"> <input type="checkbox"/> Needs help from another person <input type="checkbox"/> Does not need help from another person (skip to q. 19) <input type="checkbox"/> Unclear response (skip to q. 19) <input type="checkbox"/> No response (skip to q. 19) <input type="checkbox"/> Not applicable, tube fed (skip to q. 19)
17.	<p>Are you sometimes unable to get groceries when you need them?</p> <ul style="list-style-type: none"> <input type="checkbox"/> Yes <input type="checkbox"/> No (skip to q. 19) <input type="checkbox"/> Unsure (skip to q. 19) <input type="checkbox"/> Unclear response (skip to q. 19) <input type="checkbox"/> No response (skip to q. 19)
18.	<p>Is this because there is no one there to help you?</p> <ul style="list-style-type: none"> <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unsure <input type="checkbox"/> Unclear response <input type="checkbox"/> No response
19.	<p>Is there any special help that you need to do housework – things like straightening up or doing dishes?</p> <ul style="list-style-type: none"> <input type="checkbox"/> Needs help from another person <input type="checkbox"/> Does not need help from another person (skip to q. 22) <input type="checkbox"/> Unclear response (skip to q. 22) <input type="checkbox"/> No response (skip to q. 22)

20.	<p>Does the housework not get done sometimes?</p> <ul style="list-style-type: none"> <input type="checkbox"/> Yes <input type="checkbox"/> No (skip to q. 22) <input type="checkbox"/> Unsure (skip to q. 22) <input type="checkbox"/> Unclear response (skip to q. 22) <input type="checkbox"/> No response (skip to q. 22)
21.	<p>Is this because there is no one there to help you?</p> <ul style="list-style-type: none"> <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unsure <input type="checkbox"/> Unclear response <input type="checkbox"/> No response
22.	<p>Is there any special help that you need to do laundry?</p> <ul style="list-style-type: none"> <input type="checkbox"/> Needs help from another person <input type="checkbox"/> Does not need help from another person (skip to q. 25) <input type="checkbox"/> Unclear response (skip to q. 25) <input type="checkbox"/> No response (skip to q. 25)
23.	<p>Does the laundry not get done sometimes?</p> <ul style="list-style-type: none"> <input type="checkbox"/> Yes <input type="checkbox"/> No (skip to q. 25) <input type="checkbox"/> Unsure (skip to q. 25) <input type="checkbox"/> Unclear response (skip to q. 25) <input type="checkbox"/> No response (skip to q. 25)
24.	<p>Is this because there is no one there to help you?</p> <ul style="list-style-type: none"> <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unsure <input type="checkbox"/> Unclear response <input type="checkbox"/> No response
25.	<p>Can you always get to the places you need to go, like work, shopping, the doctor's office, or a friend's house?</p> <ul style="list-style-type: none"> <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unsure <input type="checkbox"/> Unclear response <input type="checkbox"/> No response
26.	<p>Is there any special help that you need to take medicine, such as someone to pour it or set up your pills?</p> <ul style="list-style-type: none"> <input type="checkbox"/> Needs help from another person <input type="checkbox"/> Does not need help from another person (skip to q. 29) <input type="checkbox"/> Unclear response (skip to q. 29) <input type="checkbox"/> No response (skip to q. 29)

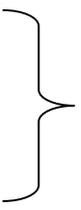
27.	<p>Do you ever go without taking your medicine when you need it?</p> <p><input type="checkbox"/> Yes</p> <p><input type="checkbox"/> No (skip to q. 29)</p> <p><input type="checkbox"/> Unsure (skip to q. 29)</p> <p><input type="checkbox"/> Unclear response (skip to q. 29)</p> <p><input type="checkbox"/> No response (skip to q. 29)</p>
28.	<p>Is this because there is no one there to help you?</p> <p><input type="checkbox"/> Yes</p> <p><input type="checkbox"/> No</p> <p><input type="checkbox"/> Unsure</p> <p><input type="checkbox"/> Unclear response</p> <p><input type="checkbox"/> No response</p>
29.	<p>Is there any special help that you need to get to or use the bathroom?</p> <p><input type="checkbox"/> Needs help from another person</p> <p><input type="checkbox"/> Does not need help from another person (skip to q. 32)</p> <p><input type="checkbox"/> Unclear response (skip to q. 32)</p> <p><input type="checkbox"/> No response (skip to q. 32)</p>
30.	<p>Are you ever unable to get to or use the bathroom when you need to?</p> <p><input type="checkbox"/> Yes</p> <p><input type="checkbox"/> No (skip to q. 32)</p> <p><input type="checkbox"/> Unsure (skip to q. 32)</p> <p><input type="checkbox"/> Unclear response (skip to q. 32)</p> <p><input type="checkbox"/> No response (skip to q. 32)</p>
31.	<p>Is this because there is no one there to help you?</p> <p><input type="checkbox"/> Yes</p> <p><input type="checkbox"/> No</p> <p><input type="checkbox"/> Unsure</p> <p><input type="checkbox"/> Unclear response</p> <p><input type="checkbox"/> No response</p>
32.	<p>Think about the people who are paid to help you with the everyday activities we have been discussing.</p> <p>Do they spend all the time with you that they are supposed to?</p> <p><input type="checkbox"/> Yes</p> <p><input type="checkbox"/> No</p> <p><input type="checkbox"/> Unsure</p> <p><input type="checkbox"/> Unclear response</p> <p><input type="checkbox"/> No response</p>
33.	<p>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?</p> <p><input type="checkbox"/> Yes</p> <p><input type="checkbox"/> No (skip to q. 36)</p> <p><input type="checkbox"/> Unsure (skip to q. 36)</p> <p><input type="checkbox"/> Unclear response (skip to q. 36)</p> <p><input type="checkbox"/> No response (skip to q. 36)</p>

34.	What equipment or changes did you talk about (specify)?
35.	Did you get the equipment or make the changes you needed? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> In process <input type="checkbox"/> Unsure <input type="checkbox"/> Unclear response <input type="checkbox"/> 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? <input type="checkbox"/> Yes (skip to q. 38) <input type="checkbox"/> No <input type="checkbox"/> Unsure <input type="checkbox"/> Unclear response (skip to q. 38) <input type="checkbox"/> No response (skip to q. 38) <input type="checkbox"/> No personal care staff (skip to q. 41)
37.	Would you like to help pick the people are paid to help you? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unsure <input type="checkbox"/> Unclear response <input type="checkbox"/> No response
38.	Did you know you can change the people who are paid to help you if you want to? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unsure <input type="checkbox"/> Unclear response <input type="checkbox"/> No response
39.	Thinking again about the people who are paid to help you, do you tell them what to help you with? <input type="checkbox"/> Yes (skip to q. 41) <input type="checkbox"/> No <input type="checkbox"/> Sometimes (skip to q. 41) <input type="checkbox"/> Unsure <input type="checkbox"/> Unclear response (skip to q. 41) <input type="checkbox"/> No response (skip to q. 41)
40.	Would you like to tell them the things you want help with? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unsure <input type="checkbox"/> Unclear response <input type="checkbox"/> No response

41.	<p>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)</p> <ul style="list-style-type: none"> <input type="checkbox"/> No one <input type="checkbox"/> Family/friend <input type="checkbox"/> Case manager/support coordinator/other staff <input type="checkbox"/> Other (specify) _____ <input type="checkbox"/> Unsure <input type="checkbox"/> Unclear response <input type="checkbox"/> No response
42.	<p>Who is your case manager or support coordinator?</p> <ul style="list-style-type: none"> <input type="checkbox"/> Names case manager/support coordinator <input type="checkbox"/> Does not name case manager/support coordinator <input type="checkbox"/> Unclear response <input type="checkbox"/> No response
43.	<p>Can you talk to your case manager or support coordinator when you need to?</p> <ul style="list-style-type: none"> <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Sometimes <input type="checkbox"/> Unsure <input type="checkbox"/> Unclear response <input type="checkbox"/> No response <input type="checkbox"/> Not applicable – have not tried
44.	<p>Does your case manager or support coordinator help you when you ask for something?</p> <ul style="list-style-type: none"> <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Sometimes <input type="checkbox"/> Unsure <input type="checkbox"/> Unclear response <input type="checkbox"/> No response <input type="checkbox"/> Not applicable-have not asked
<p>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.</p>	
45.	<p>Do the people paid to help you treat you respectfully in your home?</p> <ul style="list-style-type: none"> <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Sometimes <input type="checkbox"/> Unsure <input type="checkbox"/> Unclear response <input type="checkbox"/> No response <input type="checkbox"/> No staff in home (skip to q. 47)

46.	<p>Do the people paid to help you listen carefully to what you ask them to do in your home?</p> <p><input type="checkbox"/> Yes</p> <p><input type="checkbox"/> No</p> <p><input type="checkbox"/> Sometimes</p> <p><input type="checkbox"/> Unsure</p> <p><input type="checkbox"/> Unclear response</p> <p><input type="checkbox"/> No response</p>
47.	<p>Have you ever been injured by any of the people paid to help you now?</p> <p><input type="checkbox"/> Yes</p> <p><input type="checkbox"/> No (skip to q. 49)</p> <p><input type="checkbox"/> Unsure (skip to q. 49)</p> <p><input type="checkbox"/> Unclear response (skip to q. 49)</p> <p><input type="checkbox"/> No response (skip to q. 49)</p> <p><input type="checkbox"/> Not applicable (does not interact with any paid staff)(skip to q. 59)</p>
48.	<p>What happened? When? Would you like any help with this problem?</p>
49.	<p>Are any of the people paid to help you now mean to you, or do they yell at you?</p> <p><input type="checkbox"/> Yes</p> <p><input type="checkbox"/> No (skip to q. 51)</p> <p><input type="checkbox"/> Sometimes</p> <p><input type="checkbox"/> Unsure (skip to q. 51)</p> <p><input type="checkbox"/> Unclear response (skip to q. 51)</p> <p><input type="checkbox"/> No response (skip to q. 51)</p>
50.	<p>What happens? Would you like any help with this problem?</p>
51.	<p>Have any of the people paid to help you now ever taken your things without asking?</p> <p><input type="checkbox"/> Yes</p> <p><input type="checkbox"/> No (skip to q. 53)</p> <p><input type="checkbox"/> Unsure (skip to q. 53)</p> <p><input type="checkbox"/> Unclear response (skip to q. 53)</p> <p><input type="checkbox"/> No response (skip to q. 53)</p>
52.	<p>What happened? When? Would you like any help with this problem?</p>
53.	<p>Do you go to a day program outside your home?</p> <p><input type="checkbox"/> Yes</p> <p><input type="checkbox"/> No (skip to q. 56)</p> <p><input type="checkbox"/> Unsure (skip to q. 56)</p> <p><input type="checkbox"/> Unclear response (skip go q. 56)</p> <p><input type="checkbox"/> No response (skip to q. 56)</p>

54.	<p>Do the people paid to help you at a day program outside your home treat you respectfully?</p> <p><input type="checkbox"/> Yes</p> <p><input type="checkbox"/> No</p> <p><input type="checkbox"/> Sometimes</p> <p><input type="checkbox"/> Unsure</p> <p><input type="checkbox"/> Unclear response</p> <p><input type="checkbox"/> No response</p>
55.	<p>Do the people paid to help you at a day program outside your home listen carefully to what you ask them to do?</p> <p><input type="checkbox"/> Yes</p> <p><input type="checkbox"/> No</p> <p><input type="checkbox"/> Sometimes</p> <p><input type="checkbox"/> Unsure</p> <p><input type="checkbox"/> Unclear response</p> <p><input type="checkbox"/> No response</p>
56.	<p>Do you ride a van or use other transportation services?</p> <p><input type="checkbox"/> Yes</p> <p><input type="checkbox"/> No (skip to q. 59)</p> <p><input type="checkbox"/> Unsure (skip to q. 59)</p> <p><input type="checkbox"/> Unclear response (skip to q. 59)</p> <p><input type="checkbox"/> No response (skip to q. 59)</p>
57.	<p>Do the people paid to help you on the van or with other transportation treat you respectfully?</p> <p><input type="checkbox"/> Yes</p> <p><input type="checkbox"/> No</p> <p><input type="checkbox"/> Sometimes</p> <p><input type="checkbox"/> Unsure</p> <p><input type="checkbox"/> Unclear response</p> <p><input type="checkbox"/> No response</p>
58.	<p>Do the people paid to help you on the van or with other transportation listen carefully to what you ask them to do?</p> <p><input type="checkbox"/> Yes</p> <p><input type="checkbox"/> No</p> <p><input type="checkbox"/> Sometimes</p> <p><input type="checkbox"/> Unsure</p> <p><input type="checkbox"/> Unclear response</p> <p><input type="checkbox"/> No response</p>
<p>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.</p>	

59.	<p>Is there anything you want to do outside your home that you don't do now?</p> <ul style="list-style-type: none"> <input type="checkbox"/> Yes <input type="checkbox"/> No (skip to q. 61) <input type="checkbox"/> Unsure (skip to q. 61) <input type="checkbox"/> Unclear response (skip to q. 61) <input type="checkbox"/> 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?
<p>Work Experience [If respondent is under 65 years of age, ask q. 62. Otherwise end the interview]</p> <p>The last few questions I'd like to ask you have to do with your work experiences.</p>	
62.	<p>Are you working right now?</p> <ul style="list-style-type: none"> <input type="checkbox"/> Yes <input type="checkbox"/> No (skip to q. 66) <input type="checkbox"/> Unsure (end of interview) <input type="checkbox"/> Unclear response (end of interview) <input type="checkbox"/> No response (end of interview)
63.	What kind of work do you do? (specify)
64.	<p>Did you help pick the job you have now?</p> <ul style="list-style-type: none"> <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unsure <input type="checkbox"/> Unclear response <input type="checkbox"/> No response
65.	<p>Do you like your job?</p> <ul style="list-style-type: none"> <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unsure <input type="checkbox"/> Unclear response <input type="checkbox"/> No response <div style="display: inline-block; vertical-align: middle; margin-left: 20px;">  <div style="border: 1px solid black; padding: 5px; display: inline-block;">End of interview.</div> </div>
66.	<p>Do you want to work?</p> <ul style="list-style-type: none"> <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unsure <input type="checkbox"/> Unclear response <input type="checkbox"/> No response

Plan for Services: Additional questions developed by NH BEAS	
71.	<p>Have you been provided with a copy of your plan for services?</p> <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unsure / can't remember <input type="checkbox"/> I don't know what this is <input type="checkbox"/> Unclear response <input type="checkbox"/> No response
72.	<p>Does your plan address all your service needs and concerns?</p> <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unsure / can't remember <input type="checkbox"/> Unclear response <input type="checkbox"/> No response
73.	<p>Has anyone ever explained to you your role in developing your plan for services?</p> <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unsure / can't remember <input type="checkbox"/> Unclear response <input type="checkbox"/> No response
74.	<p>Did you have enough say in developing your plan for services?</p> <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unsure / can't remember <input type="checkbox"/> Unclear response <input type="checkbox"/> No response
75.	<p>Are you receiving all the services listed in your plan for services?</p> <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unsure / can't remember <input type="checkbox"/> Unclear response <input type="checkbox"/> No response
76.	<p>Overall, how satisfied are you with the services you receive from this program?</p> <input type="checkbox"/> Very satisfied <input type="checkbox"/> Satisfied <input type="checkbox"/> Neither satisfied or dissatisfied (neutral) <input type="checkbox"/> Dissatisfied <input type="checkbox"/> Very dissatisfied <input type="checkbox"/> Unsure <input type="checkbox"/> Unclear response <input type="checkbox"/> No response

77.	Would you like to be contacted by someone from the Medicaid program to discuss any concerns or questions you have about your services? <input type="checkbox"/> Yes <input type="checkbox"/> No
-----	---

E. Interviewer Comments and Observations

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

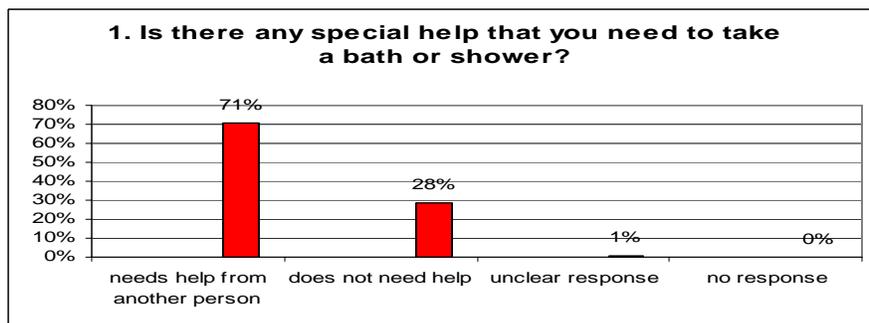
- All
- Most
- About half
- Some
- A few
- None

Who else provided responses? (If applicable)

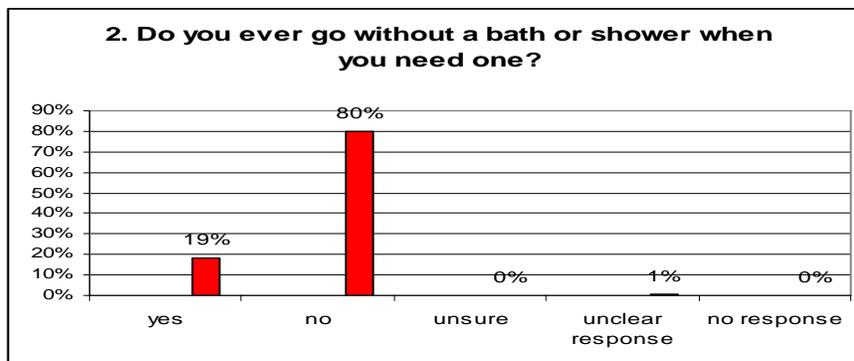
Results

(responses to questions requiring narrative are not included in following tables)

1 Is there any special help that you need to take a bath or shower?					
a	needs help from another person			204	71%
b	does not need help			82	28%
c	unclear response			2	1%
d	no response			0	0%
				Total responses	288



2 Do you ever go without a bath or shower when you need one?					
a	yes			39	19%
b	no			163	80%
c	unsure			0	0%
d	unclear response			2	1%
e	no response			0	0%
				Total responses	204

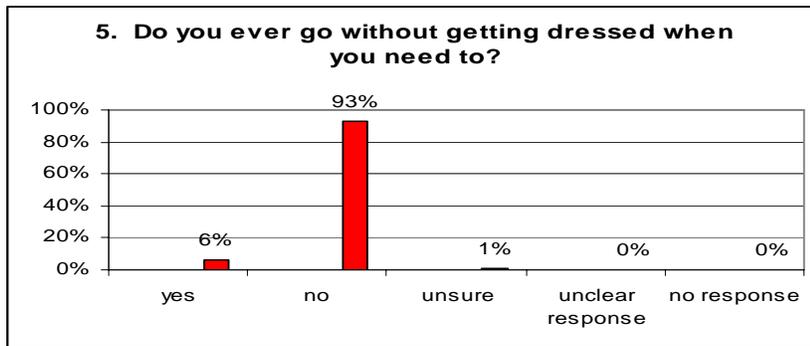


Results (cont.)

3 Is this because there is no one there to help you?						
a	yes				29	74%
b	no				10	26%
c	unsure				0	0%
d	unclear response				0	0%
e	no response				0	0%
					Total responses	39

4 Is there any special help that you need to get dressed?						
a	needs help from another person				117	41%
b	does not need help				165	58%
c	unclear response				3	1%
d	no response				1	0%
					Total responses	286

5 Do you ever go without getting dressed when you need to?						
a	yes				7	6%
b	no				109	93%
c	unsure				1	1%
d	unclear response				0	0%
e	no response				0	0%
					Total responses	117



6 Is this because there is no one there to help you?						
a	yes				6	86%
b	no				1	14%
c	unsure				0	0%
d	unclear response				0	0%
e	no response				0	0%
					Total responses	7

Reports (cont.)

7 Is there any special help that you need to get out of bed?						
	a	needs help from another person			49	17%
	b	does not need help			236	82%
	c	unclear response			2	1%
	d	no response			1	0%
				Total responses	288	

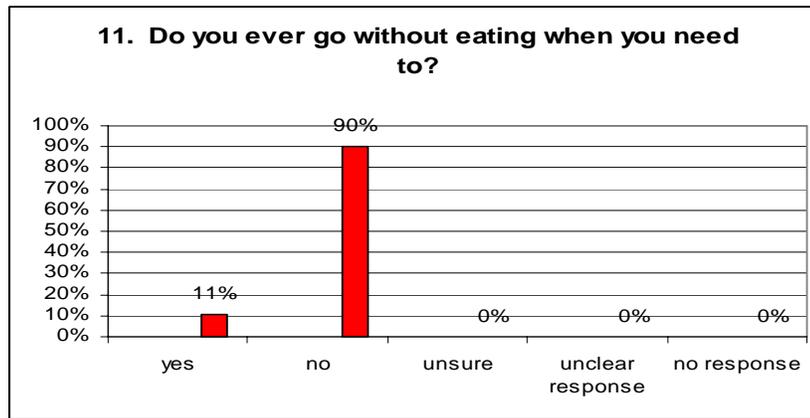
8 Do you ever go without getting out of bed when you need to?						
	a	yes			4	8%
	b	no			45	92%
	c	unsure			0	0%
	d	unclear response			0	0%
	e	no response			0	0%
				Total responses	49	

9 Is this because there is no one there to help you?						
	a	yes			4	100%
	b	no			0	0%
	c	unsure			0	0%
	d	unclear response			0	0%
	e	no response			0	0%
				Total responses	4	

10 Is there any special help that you need to eat?						
	a	needs help from another person			37	13%
	b	does not need help			249	86%
	c	unclear response			1	0%
	d	no response			0	0%
				Total responses	287	

11 Do you ever go without eating when you need to?						
	a	yes			4	11%
	b	no			33	90%
	c	unsure			0	0%
	d	unclear response			0	0%
	e	no response			0	0%
				Total responses	37	

Reports (cont.)



12 Is this because there is no one there to help you?							
a	yes					3	75%
b	no					1	25%
c	unsure					0	0%
d	unclear response					0	0%
e	no response					0	0%
				Total responses		4	

13 Is there any special help that you need to make your meals?							
a	needs help from another person					202	70%
b	does not need help					78	27%
c	unclear response					2	1%
d	no response					2	1%
e	not applicable, tube fed					3	1%
				Total responses		287	

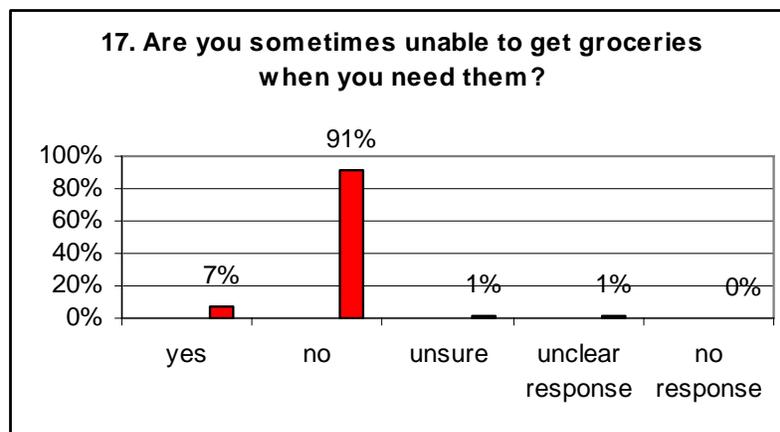
14 Do you ever go without a meal when you need one?							
a	yes					15	7%
b	no					186	92%
c	unsure					0	0%
d	unclear response					1	1%
e	no response					0	0%
				Total responses		202	

Reports (cont.)

15 Is this because there is no one there to help you?						
a	yes				12	80%
b	no				3	20%
c	unsure				0	0%
d	unclear response				0	0%
e	no response				0	0%
Total responses					15	

16 Is there any special help that you need to get groceries?						
a	needs help from another person				249	88%
b	does not need help				31	11%
c	unclear response				0	0%
d	no response				2	1%
e	not applicable, tube fed				0	0%
Total responses					282	

17 Are you sometimes unable to get groceries when you need them?						
a	yes				18	7%
b	no				228	91%
c	unsure				2	1%
d	unclear response				3	1%
e	no response				0	0%
Total responses					251	



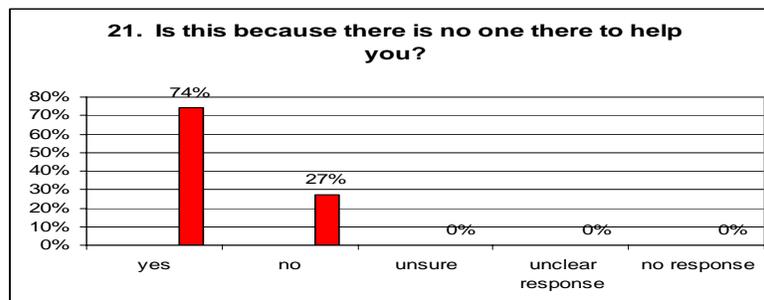
Results (cont.)

18 Is this because there is no one there to help you?						
a	yes				10	56%
b	no				6	33%
c	unsure				1	6%
d	unclear response				1	6%
e	no response				0	0%
Total responses					18	

19 Is there any special help that you need to do housework-things like straightening up or doing dishes?						
a	needs help from another person				259	90%
b	does not need help				22	8%
c	unclear response				4	1%
d	no response				2	1%
Total responses					287	

20 Does the housework not get done sometimes?						
a	yes				23	9%
b	no				234	90%
c	unsure				3	1%
d	unclear response				0	0%
e	no response				0	0%
Total responses					260	

21 Is this because there is no one there to help you?						
a	yes				17	74%
b	no				6	27%
c	unsure				0	0%
d	unclear response				0	0%
e	no response				0	0%
Total responses					23	



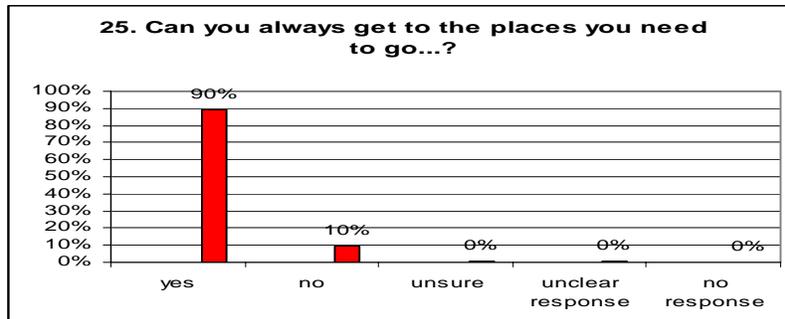
Results (cont.)

22 Is there any special help that you need to do laundry?						
	a	needs help from another person			243	85%
	b	does not need help			42	15%
	c	unclear response			2	1%
	d	no response			0	0%
				Total responses	287	

23 Does the laundry not get done sometimes?						
	a	yes			17	7%
	b	no			227	93%
	c	unsure			0	0%
	d	unclear response			0	0%
	e	no response			0	0%
				Total responses	244	

24 Is this because there is no one there to help you?						
	a	yes			11	65%
	b	no			5	30%
	c	unsure			0	0%
	d	unclear response			1	6%
	e	no response			0	0%
				Total responses	17	

25 Can you always get to the places you need to go, like work, shopping, the doctor's office, or a friend's house?						
	a	yes			256	90%
	b	no			29	10%
	c	unsure			0	0%
	d	unclear response			1	0%
	e	no response			0	0%
				Total responses	286	



Results (cont.)

26 Is there any special help that you need to take medicine, such as someone to pour it or set up your pills?						
	a	needs help from another person			136	48%
	b	does not need help			144	50%
	c	unclear response			5	2%
	d	no response			1	0%
				Total responses	286	

27 Do you ever go without taking your medicine when you need it?						
	a	yes			10	7%
	b	no			126	92%
	c	unsure			0	0%
	d	unclear response			1	1%
	e	no response			0	0%
				Total responses	137	

28 Is this because there is no one there to help you?						
	a	yes			1	10%
	b	no			9	90%
	c	unsure			0	0%
	d	unclear response			0	0%
	e	no response			0	0%
				Total responses	10	

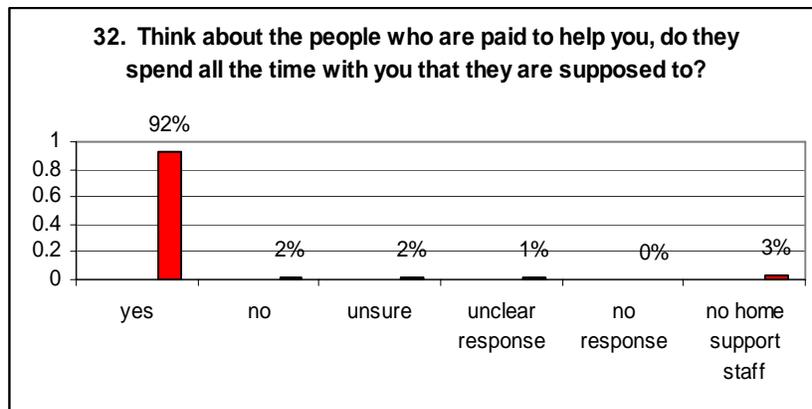
29 Is there any special help that you need to get to and use the bathroom?						
	a	needs help from another person			56	20%
	b	does not need help			228	79%
	c	unclear response			2	1%
	d	no response			1	0%
				Total responses	287	

30 Are you ever unable to get to and use the bathroom when you need to?						
	a	yes			5	9%
	b	no			51	91%
	c	unsure			0	0%
	d	unclear response			0	0%
	e	no response			0	0%
				Total responses	56	

Results (cont.)

31 Is this because there is no one there to help you?						
a	yes				3	60%
b	no				2	40%
c	unsure				0	0%
d	unclear response				0	0%
e	no response				0	0%
Total responses					5	

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?						
a	yes				266	92%
b	no				5	2%
c	unsure				5	2%
d	unclear response				4	1%
e	no response				0	0%
f	no home support staff				8	3%
Total responses					288	

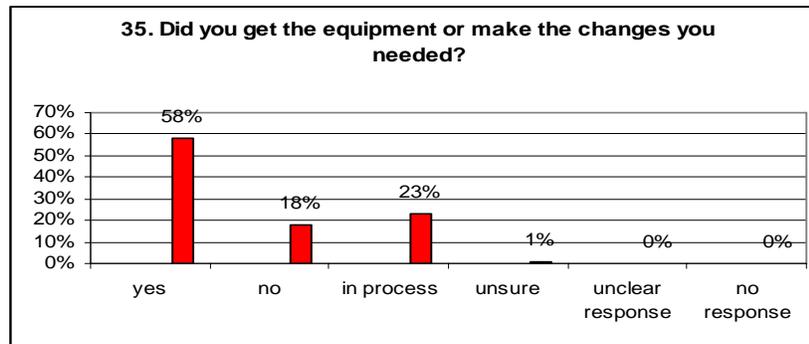


33 Have you ever talked with your case manager or support coordinator about any special equipment, or changes to your home, that might make your life easier?						
a	yes				110	38%
b	no				167	58%
c	unsure				8	3%
d	unclear response				2	1%
e	no response				1	0%
Total responses					288	

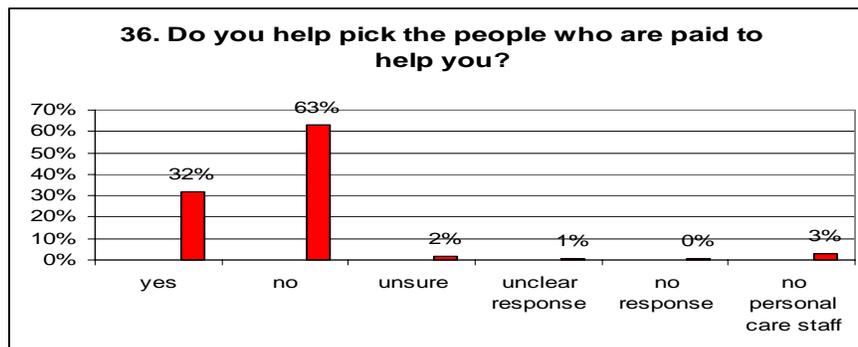
Results (cont.)

34 What equipment or changes did you talk about?					
		See narrative responses.			

35 Did you get the equipment or make the changes you needed?					
a	yes			63	58%
b	no			19	18%
c	in process			25	23%
d	unsure			1	1%
e	unclear response			0	0%
f	no response			0	0%
Total responses				108	

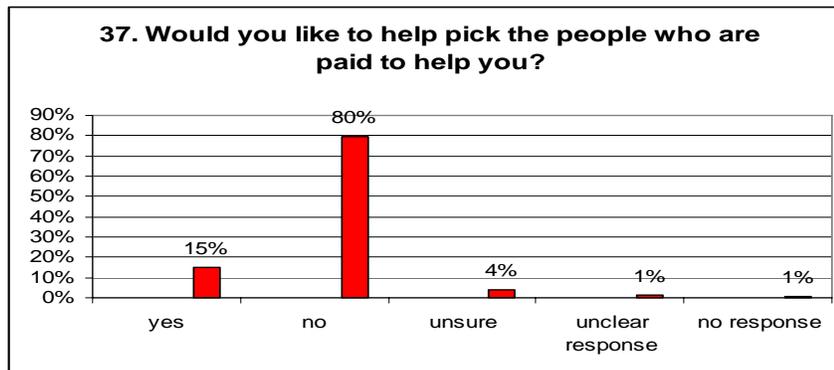


Choices and Control					
36 Do you help pick the people who are paid to help you?					
a	yes			92	32%
b	no			180	63%
c	unsure			5	2%
d	unclear response			2	1%
e	no response			1	0%
f	no personal care staff			7	3%
Total responses				287	



Results (cont.)

37 Would you like to help pick the people who are paid to help you?						
a	yes				27	15%
b	no				146	80%
c	unsure				7	4%
d	unclear response				2	1%
e	no response				1	1%
Total responses					183	



38 Did you know you can change the people who are paid to help you if you want to?						
a	yes				235	84%
b	no				29	10%
c	unsure				11	4%
d	unclear response				3	1%
e	no response				3	1%
Total responses					281	

39 Thinking again about the people who are paid to help you, do you tell them what to help you with?						
a	yes				255	91%
b	no				6	2%
c	sometimes				13	5%
d	unsure				1	0%
e	unclear response				3	1%
f	no response				3	1%
Total responses					281	

Results (cont.)

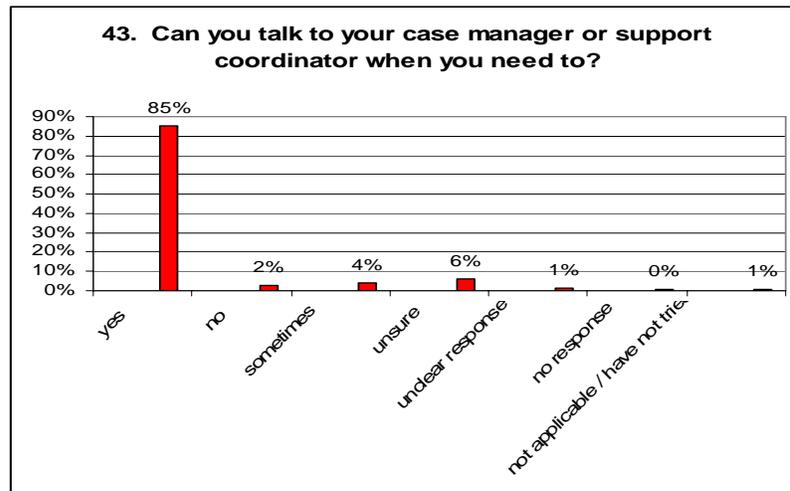
40 Would you like to tell them the things you want help with?						
a	yes				0	0%
b	no				5	71%
c	unsure				2	29%
d	unclear response				0	0%
e	no response				0	0%
					Total responses	7

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)						
a	no one				4	1%
b	family / friend				76	20%
c	case manager/support coordinator/other				223	57%
e	other (specify)				69	18%
f	unsure				11	3%
g	unclear response				4	1%
h	no response				1	0%
					Total responses	388

42 Who is your case manager or support coordinator?						
a	names case manager/support coordinator				246	86%
b	does not name case manager/support coord.				33	12%
c	unclear response				5	2%
d	no response				2	1%
					Total responses	286

43 Can you talk to your case manager or support coordinator when you need to?						
a	yes				245	85%
b	no				6	2%
c	sometimes				12	4%
d	unsure				18	6%
e	unclear response				3	1%
f	no response				1	0%
g	not applicable / have not tried				2	1%
					Total responses	287

Results (cont.)



44 Does your case manager or support coordinator help you when you ask for something?						
a	yes				245	85%
b	no				4	1%
c	sometimes				16	6%
d	unsure				14	5%
e	unclear response				2	1%
f	no response				4	1%
g	not applicable / have not asked				2	1%
Total responses					287	

Respect and Dignity						
45 Do the people paid to help you treat you respectfully in your home?						
a	yes				274	95%
b	no				1	0%
c	sometimes				7	2%
d	unsure				0	0%
e	unclear response				1	0%
f	no response				1	0%
g	no staff in home				2	1%
Total responses					286	

46 Do the people paid to help you listen carefully to what you ask them to do in your home?						
a	yes				257	91%
b	no				1	0%
c	sometimes				17	6%
d	unsure				2	1%
e	unclear response				4	1%
f	no response				3	1%
Total responses					284	

Results (cont.)

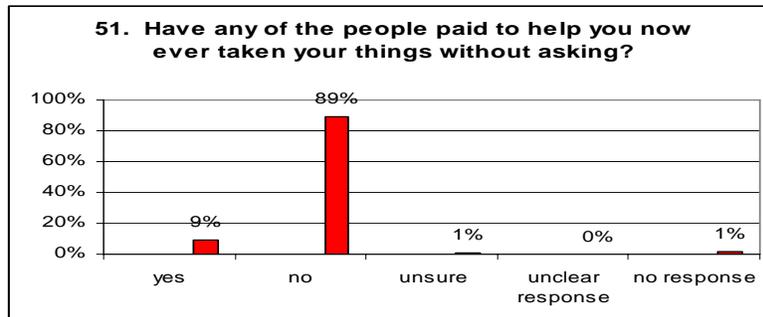
47 Have you ever been injured by any of the people paid to help you now?						
a	yes				4	1%
b	no				279	97%
c	unsure				0	0%
d	unclear response				1	0%
e	no response				0	0%
f	not applicable/does not interact with paid staff				3	1%
Total responses					287	

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

49 Are any of the people paid to help you now mean to you, or do they yell at you?						
a	yes				7	3%
b	no				271	95%
c	sometimes				3	1%
d	unsure				1	0%
e	unclear response				2	1%
f	no response				0	0%
Total responses					284	

50 What happens? Would you like any help with problem?				
See narrative responses.				

51 Have any of the people paid to help you now ever taken your things without asking?						
a	yes				25	9%
b	no				252	89%
c	unsure				2	1%
d	unclear response				1	0%
e	no response				4	1%
Total responses					284	



Results (cont.)

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

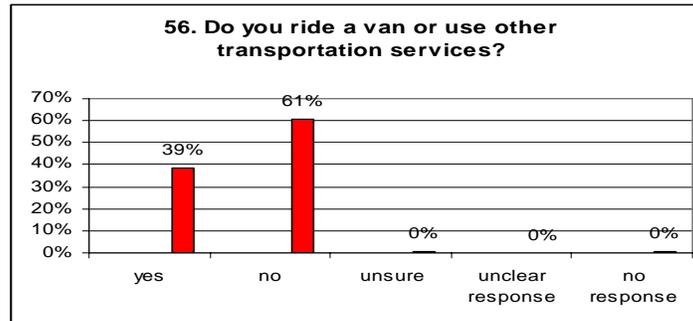
53 Do you go to a day program outside your home?						
a	yes				31	11%
b	no				249	88%
c	unsure				1	0%
d	unclear response				0	0%
e	no response				1	0%
Total responses						

54 Do the people paid to help you at a day program outside your home treat you respectfully?						
a	yes				31	100%
b	no				0	0%
c	sometimes				0	0%
d	unsure				0	0%
e	unclear response				0	0%
f	no response				0	0%
Total responses					31	

55 Do the people paid to help you at a day program outside your home listen carefully to what you ask them to do?						
a	yes				31	100%
b	no				0	0%
c	sometimes				0	0%
d	unsure				0	0%
e	unclear response				0	0%
f	no response				0	0%
Total responses					31	

56 Do you ride a van or use other transportation services?						
a	yes				109	39%
b	no				172	61%
c	unsure				1	0%
d	unclear response				0	0%
e	no response				1	0%
Total responses					283	

Results (cont.)

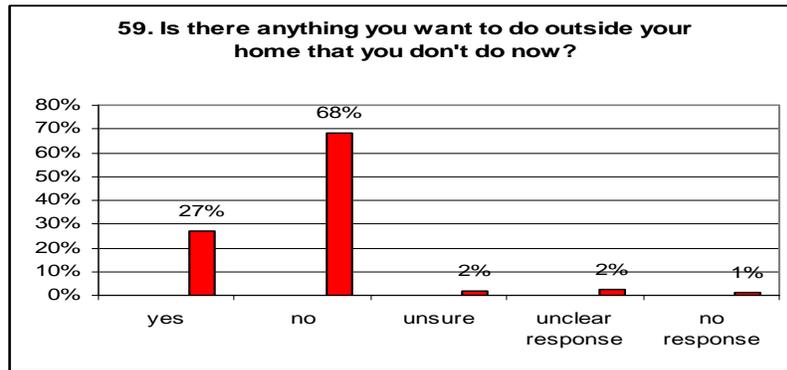


57 Do the people paid to help you on the van or with other transportation treat you respectfully?						
a	yes				107	97%
b	no				1	1%
c	sometimes				1	1%
d	unsure				1	1%
e	unclear response				0	0%
f	no response				0	0%
Total responses					110	

58 Do the people paid to help you on the van or with other transportation listen carefully to what you ask them to do?						
a	yes				107	97%
b	no				1	1%
c	sometimes				1	1%
d	unsure				0	0%
e	unclear response				1	1%
f	no response				0	0%
Total responses					110	

Community Integration						
59 Is there anything you want to do outside your home that you don't do now?						
a	yes				77	27%
b	no				194	68%
c	unsure				6	2%
d	unclear response				7	2%
e	no response				3	1%
Total responses					287	

Results (cont.)



60 What would you like to do? What do you need to make this happen?					
		See narrative responses.			

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

For respondents under 65 years of age, see questions 62-66.

62 Are you working right now?						
a	yes				4	4%
b	no				95	96%
c	unsure				0	0%
d	unclear response				0	0%
e	no response				0	0%
Total responses					99	

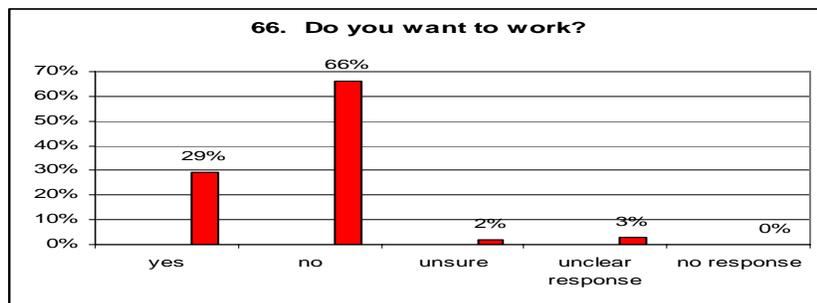
63 What kind of work do you do?					
		See narrative responses.			

64 Did you help pick the job you have now?						
a	yes				3	75%
b	no				1	25%
c	unsure				0	0%
d	unclear response				0	0%
e	no response				0	0%
Total responses					4	

Results (cont.)

65 Do you like your job?							
	a	yes				4	100%
	b	no				0	0%
	c	unsure				0	0%
	d	unclear response				0	0%
	e	no response				0	0%
						Total responses	4

66 Do you want to work?							
	a	yes				28	29%
	b	no				64	66%
	c	unsure				2	2%
	d	unclear response				3	3%
	e	no response				0	0%
						Total responses	97



67 What do you want to do?							
		See narrative responses.					

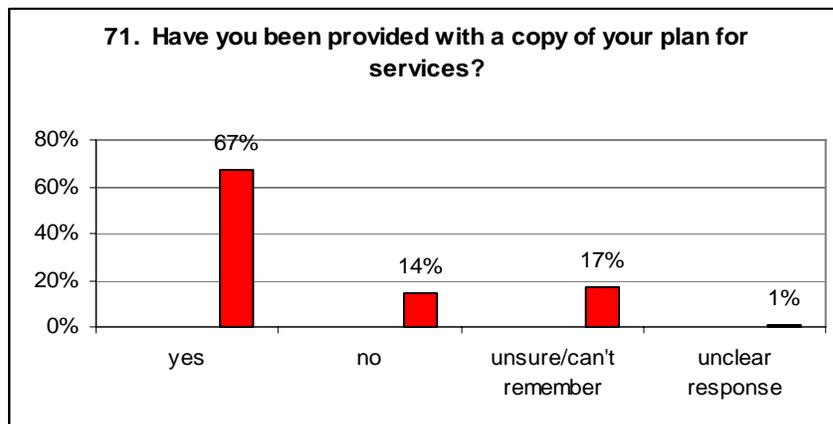
68 Were any of the answers recorded by someone other than the program participant?							
	a	yes				42	15%
	b	no				242	85%
						Total responses	284

69 What amount of the questions did the program participant answer by him/herself?							
	a	almost all				19	44%
	b	most				4	9%
	c	about half				2	5%
	d	some				3	7%
	e	a few				8	19%
	f	none				7	16%
						Total responses	43

Results (cont.)

70 Who else provided responses? (check all that apply)						
a	parent				9	18%
b	spouse				11	22%
c	children				11	22%
d	other family				7	14%
e	case manager				0	0%
f	other staff				9	18%
g	guardian				2	4%
h	other				1	2%
Total responses					50	

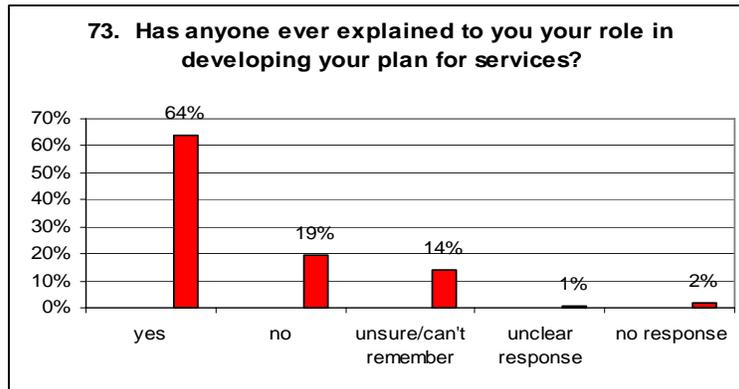
Plan for Services: developed by NH BEAS						
71 Have you been provided with a copy of your plan for services?						
a	yes				191	67%
b	no				41	14%
c	unsure/can't remember				49	17%
d	unclear response				3	1%
Total responses					284	



72 Does your plan address all your service needs and concerns?						
a	yes				239	84%
b	no				8	3%
c	unsure/can't remember				37	13%
d	unclear response				1	0%
Total responses					285	

Results (cont.)

73 Has anyone ever explained to you your role in developing your plan for services?						
a	yes				183	64%
b	no				55	19%
c	unsure/can't remember				39	14%
d	unclear response				2	1%
e	no response				5	2%
Total responses					284	

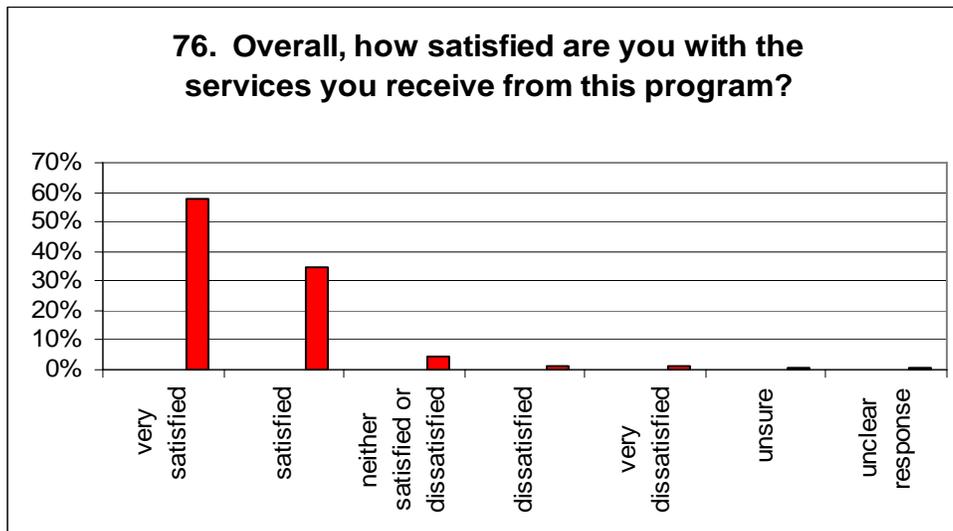


74 Did you have enough say in developing your plan for services?						
a	yes				206	73%
b	no				33	12%
c	unsure/can't remember				42	15%
d	unclear response				4	1%
Total responses					285	

75 Are you receiving all the services listed in your plan for services?						
a	yes				234	82%
b	no				10	4%
c	unsure/can't remember				39	14%
d	unclear response				1	0%
e	no response				1	0%
Total responses					285	

Results (cont.)

76 Overall, how satisfied are you with the services you receive from this program? Would you say you were very satisfied, satisfied, neither satisfied or dissatisfied, or very dissatisfied?						
a	very satisfied				165	58%
b	satisfied				98	35%
c	neither satisfied or dissatisfied				12	4%
d	dissatisfied				3	1%
e	very dissatisfied				3	1%
f	unsure				2	1%
g	unclear response				1	0%
Total responses					284	



77 Would you like to be contacted by someone from the Medicaid program to discuss any concerns or questions you have about your services?						
a	yes				32	12%
b	no				241	88%
Total responses					273	

PES Performance Indicators

The PES software established 33 performance indicators based on the questions in each of the four domains: Access to Care, Choice and Control, Respect and Dignity and Community Integration, e.g., the calculation for the Access to Care, Bathing Performance Indicator, included responses from questions #1 through #3.⁴

The following tables list the percentage of adverse outcome and of positive outcome responses to each Performance Indicator.

Performance Indicator: Access to Care

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.

Indicator 1: Bathing
[questions 1-3]

Experiences adverse outcome		Experiences positive outcome	
Count	Percent	Count	Percent
29	14%	175	88%

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.

Indicator 2: Dressing
[questions 4-6]

Experiences adverse outcome		Experiences positive outcome	
Count	Percent	Count	Percent
6	5%	111	95%

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.

Indicator 3: Transferring
[questions 7-9]

Experiences adverse outcome		Experiences positive outcome	
Count	Percent	Count	Percent
4	8%	45	92%

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.

Indicator 4: Eating
[questions 10-12]

Experiences adverse outcome		Experiences positive outcome	
Count	Percent	Count	Percent
3	8%	34	92%

⁴ Participant Experience Survey, Elderly/Disabled (E/D) Version, Users' Guide, Version 1.0, August 1, 2003; pg 26-28, 44-48.

Performance Indicator: Access to Care (cont.)

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.

Indicator 5: Meal Prep
[questions 13-15]

Experiences adverse outcome		Experiences positive outcome	
Count	Percent	Count	Percent
12	6%	190	94%

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.

Indicator 6: Groceries
[questions 16-18]

Experiences adverse outcome		Experiences positive outcome	
Count	Percent	Count	Percent
10	4%	239	96%

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.

Indicator 7: Housework
[questions 19-21]

Experiences adverse outcome		Experiences positive outcome	
Count	Percent	Count	Percent
17	7%	242	93%

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.

Indicator 8: Laundry
[questions 22-24]

Experiences adverse outcome		Experiences positive outcome	
Count	Percent	Count	Percent
11	5%	232	95%

Transportation: percent of program participants who report not always having transportation when needed.

Indicator 9: Transportation
[question 25]

Experiences adverse outcome		Experiences positive outcome	
Count	Percent	Count	Percent
29	10%	256	90%

Performance Indicator: Access to Care (cont.)

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.

Indicator 10: Medication
[questions 26-28]

Experiences adverse outcome		Experiences positive outcome	
Count	Percent	Count	Percent
1	1%	135	99%

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.

Indicator 11: Toileting
[questions 29-31]

Experiences adverse outcome		Experiences positive outcome	
Count	Percent	Count	Percent
3	5%	53	95%

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

Indicator 12: Staff Time
[question 32]

Experiences adverse outcome		Experiences positive outcome	
Count	Percent	Count	Percent
5	2%	271	98%

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

Indicator 13: Adaptive Equipment/
Environmental Modifications
[question 35]

Experiences adverse outcome		Experiences positive outcome	
Count	Percent	Count	Percent
19	18%	89	82%

Performance Indicator: Choice and Control

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

Indicator 14: Choice in Staff
[question 37]

Experiences adverse outcome		Experiences positive outcome	
Count	Percent	Count	Percent
27	15%	153	85%

Performance Indicator: Choice and Control (cont.)

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

Indicator 15: Changing Staff [question 38]	Experiences adverse outcome		Experiences positive outcome	
	Count	Percent	Count	Percent
	40	15%	235	85%

Directing Staff: percent of program participants who do not help direct their staff, but would like to do so.

Indicator 16: Directing Staff [question 40]	Experiences adverse outcome		Experiences positive outcome	
	Count	Percent	Count	Percent
	0	0%	7	100%

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.

Indicator 17: Contact for Reporting Staffing Problems [question 41]	Experiences adverse outcome		Experiences positive outcome	
	Count	Percent	Count	Percent
	15	4%	357	96%

Ability to Name Case Manager: percent of program participants who are unable to identify their case manager when asked.

Indicator 18: Ability to Name Case Manager [question 42]	Experiences adverse outcome		Experiences positive outcome	
	Count	Percent	Count	Percent
	33	12%	246	88%

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

Indicator 19: Ability to Contact Case Manager [question 43]	Experiences adverse outcome		Experiences positive outcome	
	Count	Percent	Count	Percent
	18	6%	263	94%

Performance Indicator: Choice and Control (cont.)

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

Indicator 20: Case Manager Helpfulness [question 44]	Experiences adverse outcome		Experiences positive outcome	
	Count	Percent	Count	Percent
	20	7%	259	93%

Performance Indicator: Respect and Dignity

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

Indicator 21: Respect by Home Care Staff [question 45]	Experiences adverse outcome		Experiences positive outcome	
	Count	Percent	Count	Percent
	8	3%	274	97%

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

Indicator 22: Careful Listening by Home Care Staff [question 46]	Experiences adverse outcome		Experiences positive outcome	
	Count	Percent	Count	Percent
	18	6%	259	94%

Physical Abuse by Staff: percent of program participants who report being injured by current staff.

Indicator 23: Physical Abuse by Staff [question 47]	Experiences adverse outcome		Experiences positive outcome	
	Count	Percent	Count	Percent
	4	1%	279	99%

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

Indicator 24: Verbal Abuse by Staff [question 49]	Experiences adverse outcome		Experiences positive outcome	
	Count	Percent	Count	Percent
	10	4%	272	96%

Performance Indicator: Respect and Dignity (cont.)

Theft by Staff: percent of program participants who report theft by current staff.

Indicator 25: Theft by Staff
[question 51]

Experiences adverse outcome		Experiences positive outcome	
Count	Percent	Count	Percent
25	9%	254	91%

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.

Indicator 26: Respect by Day
Program Staff
[question 54]

Experiences adverse outcome		Experiences positive outcome	
Count	Percent	Count	Percent
0	0%	31	100%

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.

Indicator 27: Careful Listening
by Day Program Staff
[question 55]

Experiences adverse outcome		Experiences positive outcome	
Count	Percent	Count	Percent
0	0%	31	100%

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

Indicator 28: Respect by
Transportation Staff
[question 57]

Experiences adverse outcome		Experiences positive outcome	
Count	Percent	Count	Percent
2	2%	108	98%

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.

Indicator 29: Careful Listening
by Transportation Staff
[question 58]

Experiences adverse outcome		Experiences positive outcome	
Count	Percent	Count	Percent
2	2%	107	98%

Performance Indicator: Community Integration and Inclusion

Community Involvement: percent of program participants who report an unmet need for community involvement.

Indicator 30: Community Involvement
[question 59]

Experiences adverse outcome		Experiences positive outcome	
Count	Percent	Count	Percent
77	28%	200	72%

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

Indicator 31: Demand for Employment
[question 66]

Experiences adverse outcome		Experiences positive outcome	
Count	Percent	Count	Percent
28	30%	66	70%

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

Indicator 32: Choice in Employment
[question 64]

Experiences adverse outcome		Experiences positive outcome	
Count	Percent	Count	Percent
1	25%	3	75%

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

Indicator 33: Satisfaction with Employment
[question 65]

Experiences adverse outcome		Experiences positive outcome	
Count	Percent	Count	Percent
0	0%	4	100%

Narrative Responses

Question 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?

Question 34: What equipment or changes did you talk about?

Equipment	# of responses
Hoyler lift	6
Chair lift	3
Lift	1
Lift in tub	1
Ramp	5
Wheelchair	25
Electric wheelchair	2
Commode	2
Grab bars in bathroom	3
Toilet with grab bars	1
Shower chair	9
Grab bars in bedroom	1
Hand-held shower / accessible shower	3
Incontinence pads	5
Bathroom help	1
Bathroom modifications	1
Hospital bed	8
Bed with railings	2
Mattress	3
Recliner	1
Rails	3
Cane	4
Scooter	7
Walker	8
Vision equipment (has macular degeneration)	1
Breathing machine / nebulizer	3
Oxygen tank	3
Rehab. Equipment	1
Helmet	1
Blood pressure machine	1
Night breathing machine	1
Prosthesis for leg	1
Hot water heater	1

Equipment	# of responses
Pressure cushion	1
Diabetic shoes	1
Hearing aid	1
Dental care	1
Van with toilet and lift	1
Van	3
Food stamps	1
Day care – more days	1
New apartment	4
Help with taxes	1
Carpentry	1
Water heater repair	1
Wheel chair repair	1
Wheelchair environmental controls (for lights, phone, door opener, etc)	1

Question 35: Did you get the equipment or make the changes you needed?

Fifty-eight percent responded yes; 23% responded “in process” and 18% said no; comments recorded are as follows:

Too expensive.

Has chair and they are working on the ramp.

Waiting to see if it will be covered.

Supposed to be getting the wheelchair.

Visiting nurses came, assessed and approved her needing a larger walker.....

Needs a new hospital bed and a new chair.

Not yet.working on it.

Went through with flooring change, is not ready to make house changes required for ramp, etc.

She got one but doesn't like it, as it is too tall and uncomfortable. She has sent it back and learned that she was denied getting a scooter.

Yes, lift and wheelchair, no mattress so far.

Nothing happens.

Needs new mattress.

Was told Medicaid would not pay for them.

Question 47: Have you ever been injured by any of the people paid to help you now?
One percent responded yes, 97% responded no.

Prior worker left her alone; participant fell.

Risk behaviors and rudeness have caused them to dismiss staff.

Has injured herself by falling.

Never even come close.

Came close once before

No.

Oh, lord no.

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

Mother complained to the office when she found out that the worker went home for an hour every day; then had her no longer because, after the report, the worker was unpleasant.

Worker was shaving her in the shower, accidentally cut participant.

Question 49: Are any of the people paid to help you now mean to you, or do they yell at you? *Three percent responded yes; 95% responded no.*

Has had to insist the worker wore gloves; required reminders.

At first seemed to indicate that this happened in the past, then it seemed she (the participant) meant current workers.

They called her clumsy, etc.

So far, so good.

They are always very gracious.

Wouldn't dare.

Thinks not; but has ignored her in the past.

No, I'm not putting up with that!

Very kind and helpful.

In the past.

Can't imagine.

Mostly no, but has gone back and forth a few times.

Sometimes they are over worked and they yell.

No complaints.

There is one individual who does.

Past homemaker stole things and yelled at participant.

A worker in the past yelled at her; she was fired.

Last PCSP before she quit.

Never.

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

Housekeeper yelled at her when she didn't feel like working; case manager was called and housekeeper was replaced immediately.

I don't know; I have a bad memory; I don't remember. Once in awhile they have been mean.

They call her clumsy when she bumps into something with her walker; doesn't feel she can say anything for fear they will kick her out.

Got new caregivers.

Some people have argued with him; he feels he can hold his own.

Blows over; needs no help now.

Homemaker would yell at her and call her awful names. She contacted (agency) and had her replaced two weeks ago. When she told her case manager, she was angry as well and told her to call her (the case manager) first and that she did not have to go to the individual agencies for help. News was greatly appreciated.

I fall; they think I blame them.

Already taken care of.

She quit.

Question 51: Have any of the people paid to help you now or ever taken your things without asking? *Nine percent responded yes; 89% responded no.*

Prior worker took pain meds, mother was not sure if it was the worker, but was pretty sure. Worker stopped coming.

A past worker had.

Not to my knowledge.

Had money stolen by part-time staff and she's no longer here; nothing stolen recently.

Not that I know of.

In past, has lost a couple of rings.

The one she reported had taken some pillowcases.

Earrings by housekeeper 6 months ago; she is not with them anymore; but I couldn't do anything because I couldn't prove it.

No.

He had been concerned about this at the beginning but there has been no problem.

Had problem in the past.

Well, only one.

Not that I know of.

No but I always misplace my glasses.

Prior PCSP was; (name of agency) is investigating.

One may have moved things so she couldn't find them.

Past homemaker stole comforter and mixer. Participant reported that the homemaker was upset by the participant having a mixer while she (the worker) did not.

Same person who yelled at her took something.

Cannot prove.

But I caught her trying to take some of my meds.

Husband's medication stolen.

Not that I know of.

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

Pain meds began disappearing; saw the worker put the meds by her pocketbook instead of near the participant.

He had an individual that worked for him that took a picture frame but she no longer works for him.

Same housekeeper drank her soda.

Could not prove it but got rid of her. I think the company fired her.

Money and a camera; told case manager and it is being investigated.

In past, mother discovered a couple of rings were missing but did not know when so could not make an accusation; did not take action.

Police did not help.

Took something of hers; she talked to the person and prayed.

The person was let go from the home care agency.

Could not prove it; had her replaced.

Took some food out of the refrigerator and he fired her.

Took electric toothbrush but the battery was dead; it might have been taken by mistake.

Some cash was missing; they were fired.

One person kept throwing things away without asking and she (the participant) uses things twice or as long as they have life in them before throwing them out. The person is no longer helping her.

Years ago, someone stole his credit card.

Got a new LNA.

Stole and were fired.

Could not prove theft.

Person replaced immediately.

This occurred during prior year (2007). Participant reported problem to case manager who went to worker's employer, who was friend of worker's family member and did not believe thefts.

At first they were not sure it was her, but a diamond ring disappeared. Thought it was someone else and fired that person, mainly because she was also drinking on the job. Finally realized who was the thief and fired her, felt that worker was "not right" otherwise, anyway.

Last one took her money she was to pay her bills for her; case manager helped her.

Medication was missing.

Called the police; nothing happened.

Question 59: Is there anything you want to do outside your home that you don't do now? *Twenty-seven percent responded yes; 68% responded no.*

Go to the beach; visit her brother.

Not really.

Would like to walk more but cannot because of arthritis.

Socialize.

Gets out on occasion; is on a ventilator.

Wishes she could walk farther than she is now able.

Fishing, cookouts.

I can't think of anything; trying to get a 4-wheel walker to go out walking.

Maybe go shopping more; transportation is a problem.

Has already been where he wants to go, is tired, wants to stay home and not have to go out.

Would like to go to the wellness center to keep up physical activity.

Lots of time would like to get out and go to a store, shop, limited to what she can lift.

Get out more.

Go to church.

Pointed to leg brace and wheelchair; said she has trouble going out, but gets out sometimes. Did not say there was anything she wanted to do that she cannot.

A lot – if I could see.

Liked to walk but can't now.

Not really.

Wants to go to day program.

In too much pain; would like to do a lot of things.

Quite a few things.

Go to church sometimes

No, they take me anywhere I want to go.

Is walking more outside.

Likes to get out but ability to do so is limited.

Sister takes her out.

Wants to get back to going to church; however the church has a long flight of stairs.

Would like to work.

Want to get a handicapped accessible van that would help me become much more independent. There is much I cannot do without my motorized wheel chair and it won't fit in a car – only a handicapped van. I want to take my service dog to the hospitals to help others the way she has helped me.

I'd like to go a library, browsing, shopping.

Would like to get to go to a restaurant; just get out.

Is able to go outside the home if she wants; her daughter drives.

There are many things; time is a factor.

Would like to go for a walk.

Not that I can think of.

Would like to get out of the building more; like go for a ride.

Wants to drive but can't now due to physical disability.

No, not really.

A lot of things; go fishing.

Needs respite care so parents can take a break.

Would like to get out to walk more.

Go camping a lot.

Likes to go to the fireworks.

I would love to go to social activities that my building plans. But there is no transportation to get there because I'm in a wheelchair. I would prefer someone like my aide to bring me in her car. There is no group transportation: too many germs.

Would like to do things on the spur of the moment, without planning on transportation, no bus on weekends.

A lot of things but I can't because of my sight.

I like to see my daughter who lives in (nearby state). Does not come down at all. I don't get many personal visitors. Sometimes the girls come in with something to eat, they put it on the tray table and come in and take the dishes away and stuff. My daughter has Power of Attorney but I don't hear from her very often - I would say not at all right now.

When the weather is nice; to go for a walk with somebody.

No. I haven't asked them for anything special. If I did I could get in the van. Every now and then you want to pack and leave. It has nothing to do with the place and the people.

Does not know – guess not.

Miss going to the movies.

Would like to go out at night but isn't able to leave husband alone.

She is able to get out when she wants with her mom (who is also a provider).

Would like to get out more and take rides in a car.

Wants good weather so she can get out to get some fresh air.

I don't think so.

Just be able to get out.

Go out more.

Wants a car; wants to play bridge.

Not really.

Swimming lessons.

Would like to get out and about.

Wants to get a part-time job.

Lots of things if I were more mobile.

Use to have a workshop but can't do it any more.

Sometimes

Attends children's school concerts and games.

Very mobile.

No, husband always takes her.

Can't wait for the nice weather so she can get out.

Can't do my flowers in the spring due to physical problems.

Work, drive and run.

Would like to go swimming but cannot due to disability.

I have my daughter and granddaughter; they take me out.

Can't get around; unsteady on my feet.

Can't think of anything off hand; maybe go to more Red Sox games.

Not much for going out.

Not any more.

Very content; family comes often.

Limited by available services.

Would like a senior companion to go for coffee or a movie or chat; I get lonesome.

A lot.

They get us where we need to go.

Nothing I can think of.

Priest comes here but I would like to go to church in good weather.

Would like to get out more but has a lot of appointments so cannot now.

Sometimes goes bowling with van driver or other places.

Question 60: What would you like to do? What do you need to make this happen?

Weather has restricted using walker.

Transportation (7 responses).

Transportation on weekends (2 responses)

Needs a car.

Needs wheelchair van (2 responses)

Want to get a handicapped accessible van that would help me become more independent. There isn't much I can do without my motorized wheel chair but it won't fit in a car.

Need a ramp for wheelchair.

If husband had more time to take her.

If I could see (2 responses)

Seizures prevent him from going to church social events, shopping, concerts.

Need a better scooter; one she has is too small and her knees cannot bend.

Church has a chair to get up a long flight of stairs but she gets scared.

I need someone to help me shop for clothes; I cannot read the labels.

Personal care workers need to get paid mileage.

Fix van and need an available driver. Needs to have a sore drained and be able to tolerate sitting.

Miss driving my own car; that was the worst when they took away my independence.

Would like driver's license back; would be able to get a vehicle if had license; would have better access to library, etc.

Needs someone to take her (3 responses)

Can't get out because of physical condition.

Need a scooter.

Would like more exercise; would like a bike.

Part-time work that won't "mess up" check.

Plans to return to work; wants to drive and return to running.

No social activities available in apartment complex.

Would like to do the grocery shopping herself; would need transportation and someone to help her.

Can't afford to go to museums, concerns, shows, etc.

Would like to go to the senior center but is not strong enough yet to get herself there.

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

Happy with the services.

Would like to get dental care for Medicaid recipients.

Gets good services

Transportation is #1; spends a lot of time arranging for transportation.

Would like to have alternate respite other than nursing home.

Need more food stamps; more money for food (3 responses)

Would like a 4-wheel walker.

I think more hospitals and social workers should make the public aware of HCBC services.

More than pleased with everything they have received and been directed to.

Would like to inquire about Meals on Wheels

Participant was fearful of going back to facility; feared she would not get the help she needs.

Son helps a lot; can he get paid?

Other than getting a van, I would like to get subsidized housing all on one level.

Everything is ok.

No, I'm quite happy here.

Can't think of anything; no complaints.

Wonders about a care dog; was told nothing would be paid for beyond the bathroom door and needs railing and shower chair.

No, I have been very happy here for a long time.

Improve communication between providers and participants. If a worker complains to the agency, the agency should talk with the participant and family so it can be addressed. Instead, agencies have said they could not provide workers but did not explain why.

Universal precautions are not consistently followed. Service providers need more training.

Several times a month personal care workers are unable to provide care at the last minute. And there is no back-up assistance provided.

When discharged from the hospital, someone should come to see her that day and not wait until the next day. She goes home alone and often needs something.

Would be helpful if all the social service agencies were consistent in their assistance to the public they serve, especially DHHS.

My veins. I showed my doctor but she doesn't do anything.

I am pretty content here and have been since 1994.

No, very content.

Wants case manager replaced; she has never followed through with anything. Thinks she may be overwhelmed.

Very happy with care; they call before they come.

Wishes there was a routine dental plan and help with getting dentures.

Has Meals on Wheels 5x a week; likes the food.

No, all very good.

Human services saved my life. BEAS came into my life and saved me. I am alive today because of human services.

No, everything is going well.

Nothing. Thank you.

No, services are good.

Everything is going ok.

No, nothing. I am very happy with her (caregiver).

No, will talk to nurse during recertification about Medicaid paying for Depends.

Likes her apartment and has been told she can stay.

Needs a chair lift.

These young girls don't seem to want to do anything; sometimes don't do the dishes.

Would like to pursue availability of local van services.

No problems; they are very good workers.

No complaints.

Would like to see more investigation of people hired.

Door needs to be widened.

Feels like a home away from home: a family.

Just health problems but you live with it.

Would like to have social activities in complex; would like to live in complex that offers more services that would be more appropriate for you.

Feels that without this program she wouldn't be able to stay in her home.

Has had issues in the past with service providers not showing respect, taking things, unresponsive. Service provider agencies should be recognized for the good job that they do.

Couldn't ask for anything better than this.

Question 63: What kind of work do you do?

Office work in own business.

Work in family owned store.

Volunteer work.

Vending machine manager; it's a small job but it feels great.

Question 66: Do you want to work?

Twenty nine percent responded yes; 66% responded no.

Tried to apply several times; never given job.

If I could do something which would not change my social security income.

Can't afford it; would lose too much.

I cannot work (12 responses).

Would like to do volunteer work (2 responses)

Tried (door-to-door) but can't get around.

Thinking about it (2 responses)

Looking.

Taking degree course online.

Working with Voc. Rehab.

Is attending college for a business degree.

I guess it depends. Right now, no. Have not thought about it much.

But not worth it; no one to take me to work.

No one would hire me with my body problems.

Has health issues but plans to work part-time after recovers from surgery.

Question 76. Overall, how satisfied are you with the services you receive from this program? *Fifty eight percent responded very satisfied; 35% responded satisfied and 4% responded neither satisfied or dissatisfied.*

Very grateful also

Feels the system is incomplete

Wish she had some week-end help

Feels alone sometimes

Some workers have not been satisfactory, but very satisfied with the program overall.

Pretty good but for the food, gets frozen foods for week-end

No one bothers me - I am happy where I am. Hopes to not have to go to a nursing facility, hopes to avoid amputations and to not have another stroke.

Happy

But there is nothing we can do the make it better

Would like to add snow shoveling - now PCA does it

Participant expressed his appreciation for the program and for the help provided by his daughter.

Feels does not need as much help as her daughter and case manager want her to have. New homemaker is better than the last one.

Every thing is fine now, had problems scheduling the van.

Thankful for it

We are all brothers and sisters here

Son says that he did not say "very satisfied" because there he does not know everything.

Very satisfied with (name of case management agency) - unsatisfied with homemakers.

Is convinced that her recovery progress is due to the help she has received through the program.

Satisfied

I would have said "very satisfied" until you asked about the service plan.

Yes, by all means satisfied

Not satisfied with home help care

Very dissatisfied with case manager.

I love the program

Couldn't ask for a better bunch of workers

Super satisfied

I can't complain, they are all very nice to me

Have to make the best of it

Every thing is going really well

I have no problem with you guys, couldn't ask for better

With the present worker I have; sometimes the "fill in" doesn't do what I need

Very, very

Happy with HCBC; other services lacking