



**Department of Health and Human Services  
Division of Community Based Care Services  
Bureau of Elderly and Adult Services**

**New Hampshire Participant Experience Survey**

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**Report prepared by:**

**University of New Hampshire Survey Center**

**in collaboration with**

**University of New Hampshire  
Institute of Health Policy and Practice  
Institute on Disabilities**

**and**

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

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**I.**

**EXECUTIVE SUMMARY**

The 2010 Participant Experience Survey (PES) was the second PES conducted by the Bureau of Elderly and Adult Services (BEAS) of the New Hampshire Department of Health and Human Services, the first being conducted in 2008. The survey was designed by Thompson-Reuters, formerly the MEDSTAT Group, and the Centers for Medicare and Medicaid Services (CMS) for states to use to monitor the quality of their home and community based care (HCBC) waiver programs for the elderly and chronically ill population. The survey consisted of 316 in-person interviews with randomly selected adults who receive home based services.<sup>1 2</sup> Since this is the second time the survey has been conducted, the opportunity is presented for some comparative analysis.

BEAS contracted with the University of New Hampshire (UNH) and worked with the UNH Survey Center, Institute on Disability (IOD) and Institute for Health Policy and Practice (IHPP) to hire and train surveyors, conduct the survey and draft the results. The results for all questions are provided in the figures and tables in the appendices.

Overall, there have been few significant differences in survey responses between the 2008 and 2010 surveys. These differences are specifically noted on the figures and tables in the appendices where a significant difference is noted (see questions 5, 14, 16, 17, 20, 22, 23, 25, 26, 27, 28, 33, 36-40, 40, 41, 43, 44, 59, 66, 68, 72, 73). A statistically significant difference means the differences are unlikely to have occurred by chance. The significance of a result is called its p-value which represents the probability that random chance could explain the result. The smaller the p-value, the more significant the difference is. In this report, p-values of .05 or less indicate statistical significance. For questions where the p-value was not provided, the p-values were higher than .05 indicating no statistically significant differences between the 2008 and 2010 surveys.

The major findings of the survey are as follows:

Activities

The HCBC population is most likely to need help in more physical activities, especially buying groceries, with transportation, doing housework, doing laundry, bathing, and preparing meals. They are less likely to need assistance dressing, getting out of bed, and eating. They are least likely to report needing help going to the bathroom or taking their medication.

- However, a high percentage of recipients who say they need help, typically between 10% and 15%, say that they have been unable to complete the activity because they did not have help.

Choice and Control

Waiver recipients report a modest degree of interest in choosing who provides their services.

- Nearly half (47%) of all respondents report that they pick the people who help them.
  - There has been a significant increase in this indicator since 2008, when only 32% said they helped pick the people who help them.

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<sup>1</sup> See Chapter II for more information about the program.

<sup>2</sup> See Chapter III for complete survey methodology.

## Participant Experience Survey 2010

- The majority of the people who say they do not pick the people who help them (60%), said they would not like to help pick the people who help them.
- Three in four (78%) say they know they can change the people who help them if they want to.
- Overall, 97% of recipients say that the people paid to assist them spend all the time with them that they are supposed to.
- 84% of recipients say they tell the people who help them what to help them with.
  - This represents a significant decline since 2008 when 94% said they did, but the percentage who said they sometimes do this increased from 4% in 2008 to 10% in 2010.
- Only two-thirds of recipients say they contact their case manager when they have a problem, a decline from 79% in 2008.
- 84% of recipients can name their case manager and 90% say they can sometimes or always talk to their case manager when they need to.
  - Three in five recipients say their case manager helps when they ask for something.

### Respect and Dignity

Service recipients report a high degree of satisfaction with the people who help them.

- Nearly all recipients (98%) say the people who help them treat them respectfully.
- Similarly, the great majority of recipients (88%) say the people who help them listen carefully to what they are asked to do.
- Almost no recipients (3%) report having been injured by any of the people who are paid to help them
- Similarly, only 2% report that any of the people who help them are mean to them and only 4% report having anything taken by the people who help them.

### Outside of Home

- Only 12% of recipients report going to a day program outside of their homes.
- Most (54%) say they do not ride a van or use other transportation sources.
- Half of respondents (52%) say there are things they would like to do outside of their homes that they do not do now (see appendix for responses to survey question # 59)
  - This has increased significantly since 2008 when only 27% responded that there are things they would like to do outside of their homes
- Only 3% of respondents say they are currently working, and all of whom say they are working report they like their jobs.
  - Of those eligible to work, 43% say they want to work (see appendix for responses to survey question #66).

### Plan for Services

- Only 61% of respondents say they have been provided with a copy of their plan for services. However, 85% believe their plan addresses all of their service needs and concerns
- Only 53% report that their role in developing their plan for services has been explained to them, but 78% say they feel they have had enough say about the development of their plans for services.
- Four in five (80%) say they are receiving all of the services listed in their plans, and another 15% say they are unsure.
- Overall, recipients are quite satisfied with the services they receive from this program – 62% are very satisfied and another 29% are somewhat satisfied.

### Systems Transformation Grant Questions

Several new questions were added to the 2010 survey as part of the evaluation of the Systems Transformation Grant. These questions focused on the recipients' ability to direct the case management agencies who provide their care. Most survey respondents (86%) have been on the waiver for more than a year.

- Only 38% of recent waiver recipients say they were informed about how long it would take to process their application, only 47% were given information about the steps in the application process, and only 39% received information about the status of their application while waiting to learn of their eligibility.
- However, 81% of recent enrollees said they were able to get information about the status of their application and 70% said the information about the application process was helpful to them.

## Participant Experience Survey 2010

- More than half of recent enrollees (59%) said they were given a choice about receiving services in a nursing home or receiving them in their community.
- Only 36% said they were able to choose their case management agency.

### Other Issues

- Most respondents (76%) answered all of the survey questions themselves. Very few respondents were not able to complete at least half of the survey themselves.

## **II. SURVEY METHODOLOGY**

The Participant Experience Survey (PES) project is based on a random 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 (CFI) program.

A February 2010 report of CFI participant cases that were open for at least six months reflected 2520 cases and further calculation indicated that a randomized and representative sample of 183 would yield a 5% confidence interval at the 95% confidence level, for a statewide sample.

Notification letters were sent to all HCBC-ECI waiver participants (N=2520) notifying them that they may be randomly selected to participate in the Participant Experience Survey. Ultimately, 316 interviews were actually completed. All Participant Experience Surveys (PES) 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 30 minutes.

The initial survey team consisted of eight interviewers with past experience working with the older adult and disabled population. The PES survey team received training and technical assistance from the PES developer, the Healthcare Business of Thomson Reuters, formerly known as the MEDSTAT group, which developed the survey under contract with the Centers for Medicare and Medicaid Services (CMS) and the University of New Hampshire Survey Center who coordinated the 2010 implementation of the PES survey in collaboration with the Division of Community Based Care quality management and BEAS Long Term Care offices.

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. participant is unable to participate per provider, guardian or family member/advocate
3. participant is unable to be contacted
  - a. three attempts made
  - b. telephone number checked with BEAS support staff; if different try again
4. surveyor is unable to arrange for interpreter or adequate proxy
5. conducting the survey would present an unsafe situation for the surveyor (as determined by the surveyor)

## Participant Experience Survey 2010

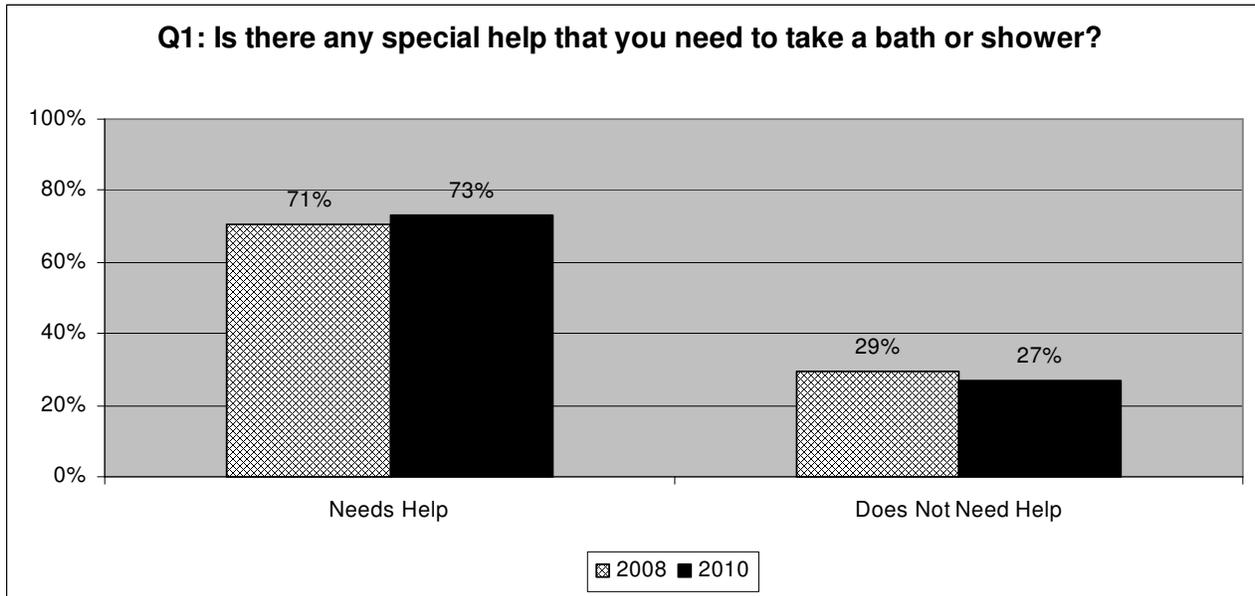
6. participant is known to the surveyor; participant to be transferred to another surveyor
7. other, e.g., participant who schedules multiple times and cancels multiple times
8. death of participant

A particular challenge was undelivered notification letters at a return rate of at least 8%. Letters that were returned undeliverable were re-mailed with new contact information. In addition, a significant number of participants' telephone numbers were incorrect in the Bureau of Elderly and Adult Services information system, Options, making it necessary to check other resources such as New Heights, the system managed by the Division of Financial Assistance and which in several cases had more current contact information. BEAS has identified this issue as a concern and will be working with the case management agencies and the department's information technology staff to that ensure that accurate and current contact information is available and accessible.

**Appendix I: 2008-2010 Tables and Graphs**

**ACCESS AND CARE**

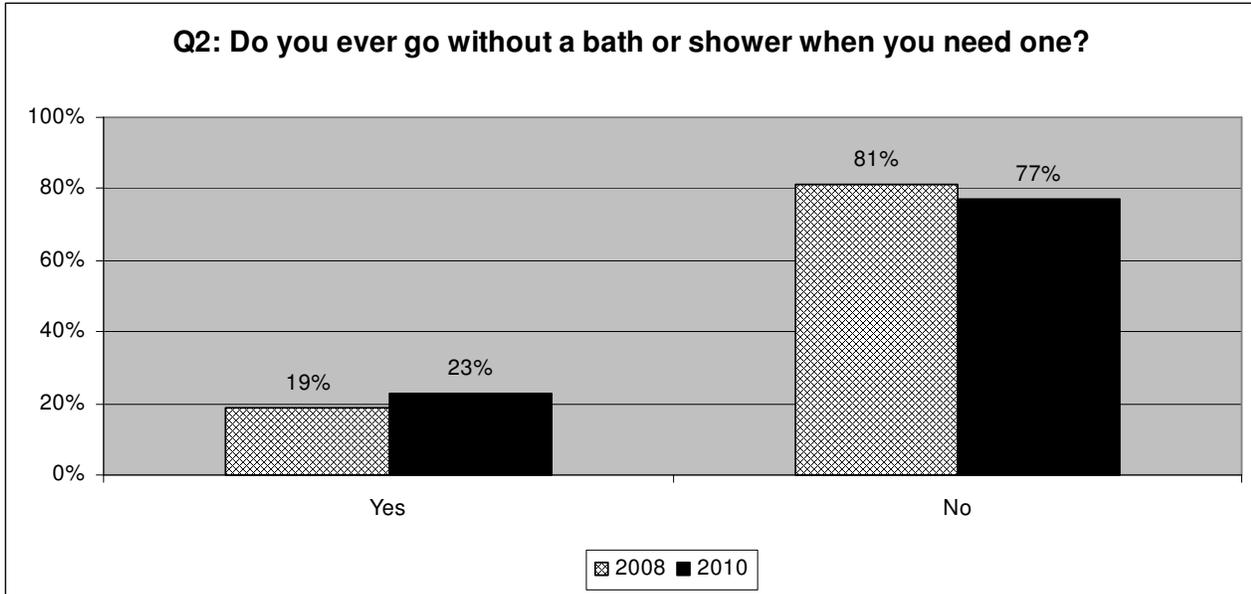
### Bathing



**Q1: Is there any special help that you need to take a bath or shower?**

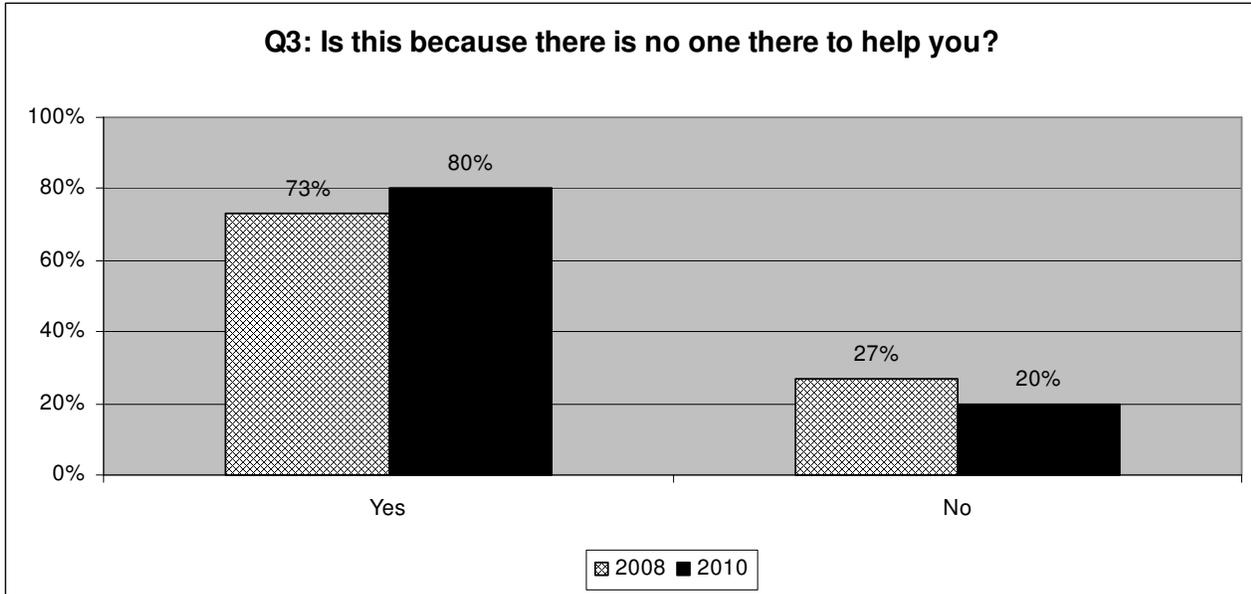
	Year	
	2008	2010
<b>Needs Help</b>	71%	73%
<b>Does Not Need Help</b>	29%	27%
<b>Total responses</b>	279	311

Participant Experience Survey 2010



**Q2: Do you ever go without a bath or shower when you need one?**

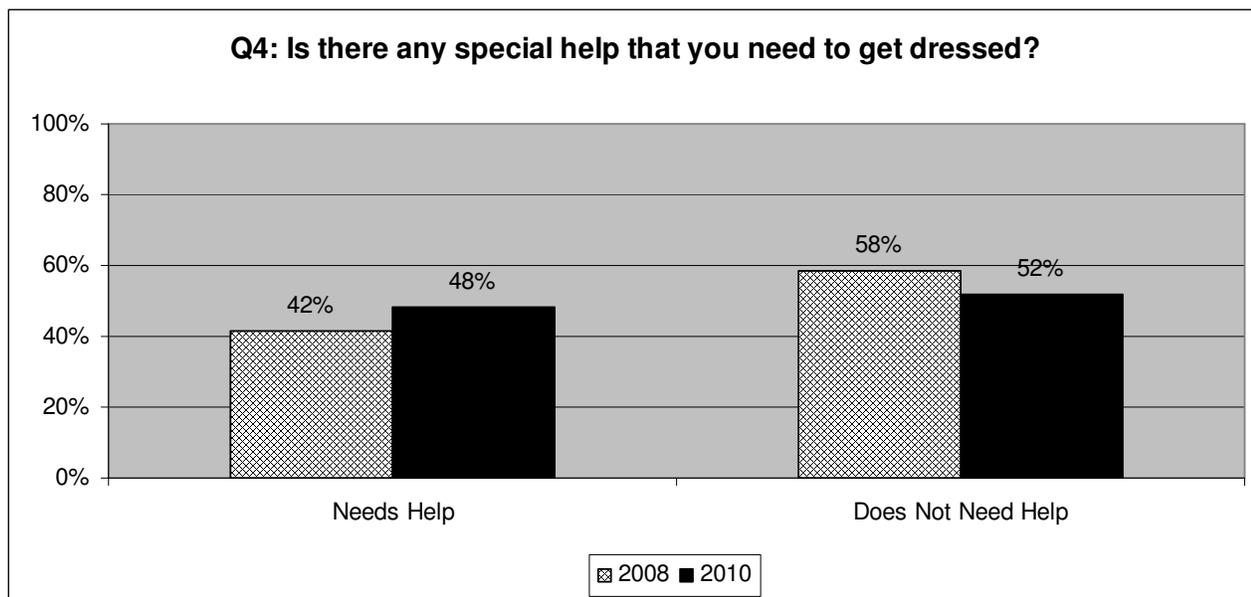
	Year	
	2008	2010
Yes	19%	23%
No	81%	77%
<b>Total responses</b>	195	225



**Q3: Is this because there is no one there to help you?**

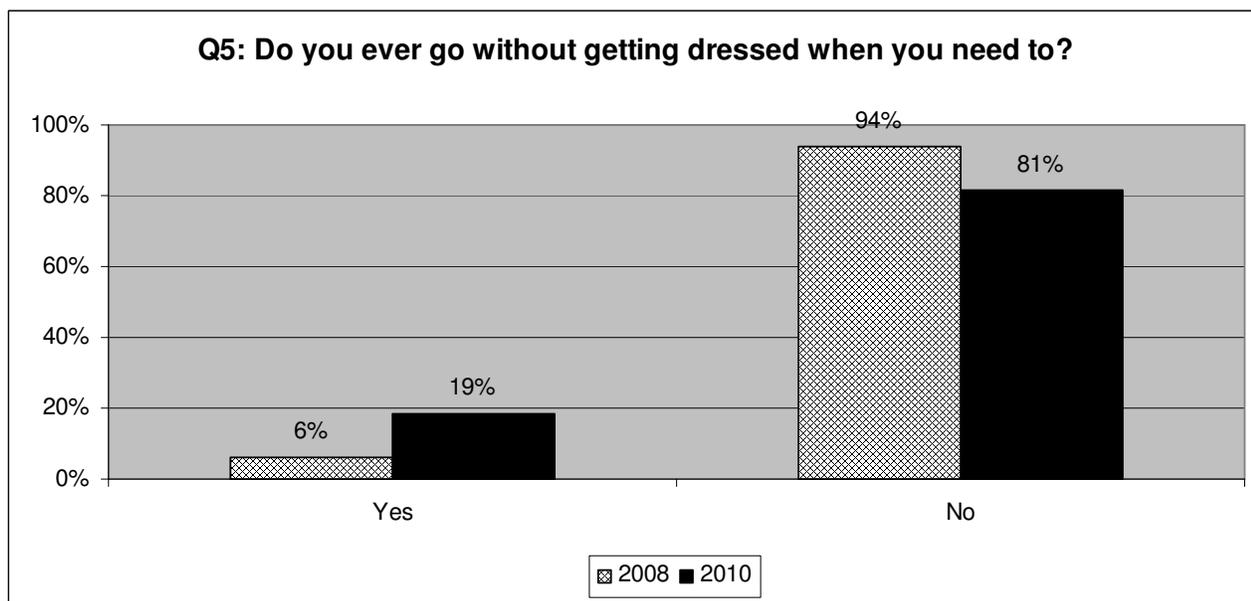
	Year	
	2008	2010
<b>Yes</b>	73%	80%
<b>No</b>	27%	20%
<b>Total responses</b>	37	51

### Dressing



**Q4: Is there any special help that you need to get dressed?**

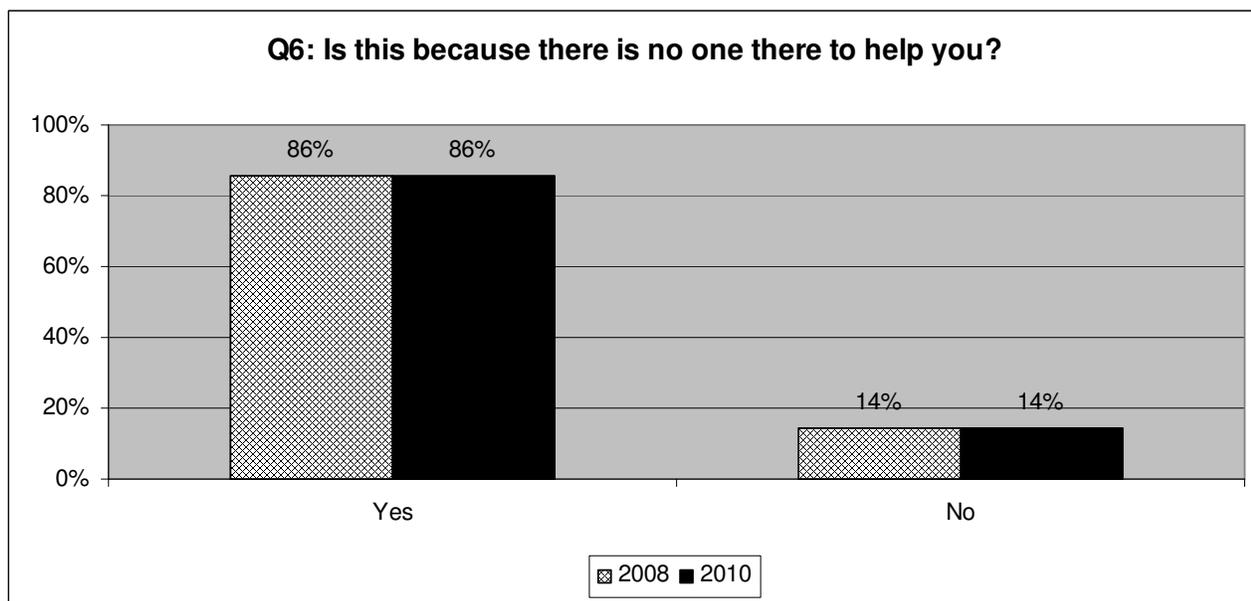
	Year	
	2008	2010
<b>Needs Help</b>	42%	48%
<b>Does Not Need Help</b>	58%	52%
<b>Total responses</b>	274	315



**Q5: Do you ever go without getting dressed when you need to?**

	Year	
	2008	2010
<b>Yes</b>	6%	19%
<b>No</b>	94%	81%
<b>Total responses</b>	113	150

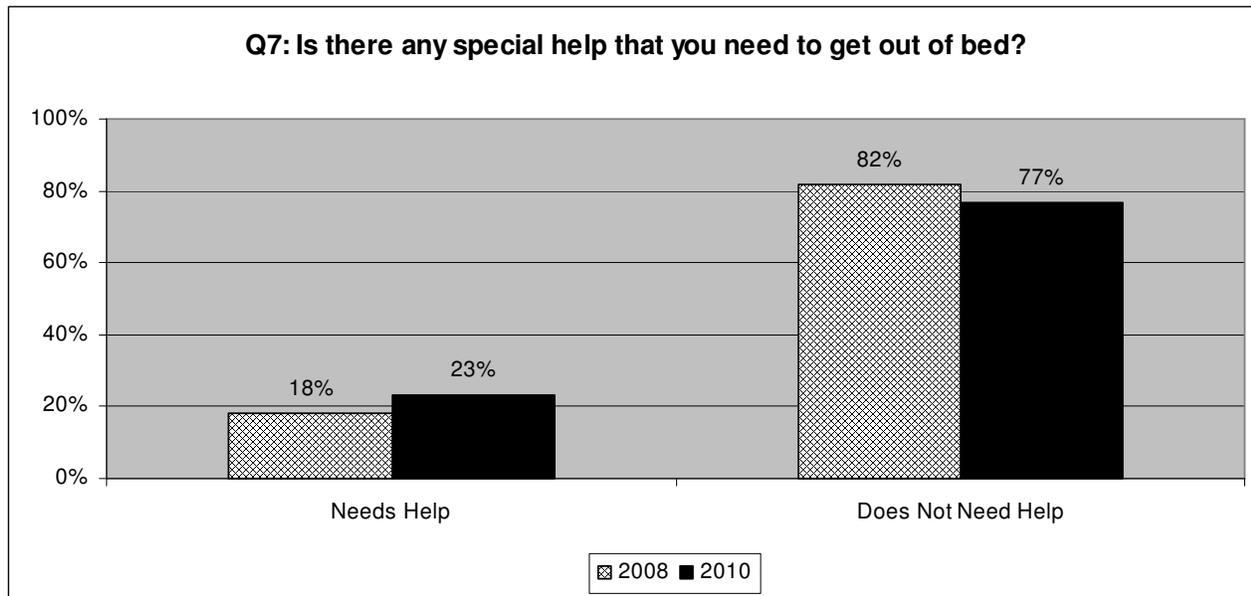
$\chi^2$  (df=1)=8.689, p=.003



**Q6: Is this because there is no one there to help you?**

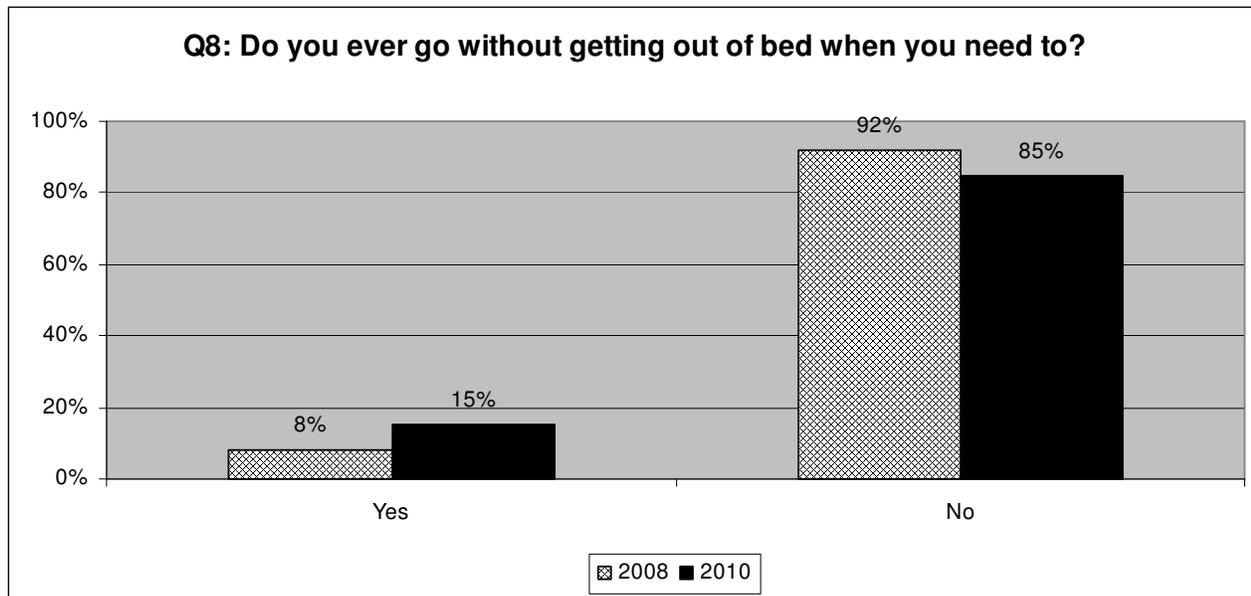
	Year	
	2008	2010
Yes	86%	86%
No	14%	14%
<b>Total responses</b>	7	28

### Transferring



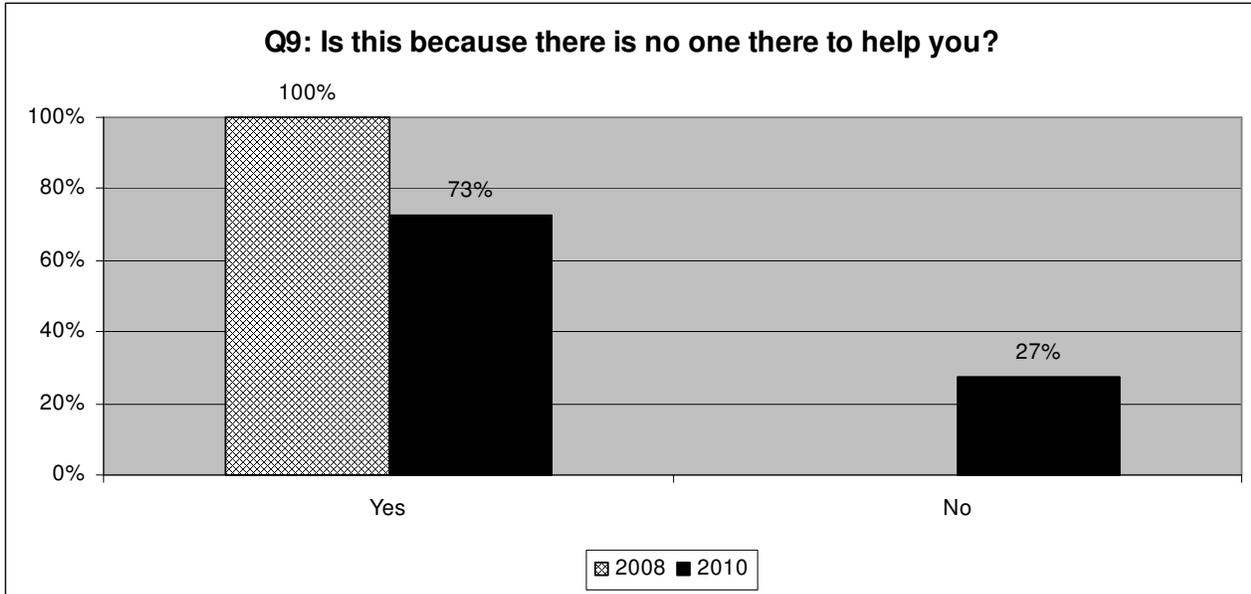
**Q7: Is there any special help that you need to get out of bed?**

	Year	
	2008	2010
<b>Needs Help</b>	18%	23%
<b>Does Not Need Help</b>	82%	77%
<b>Total responses</b>	278	313



**Q8: Do you ever go without getting out of bed when you need to?**

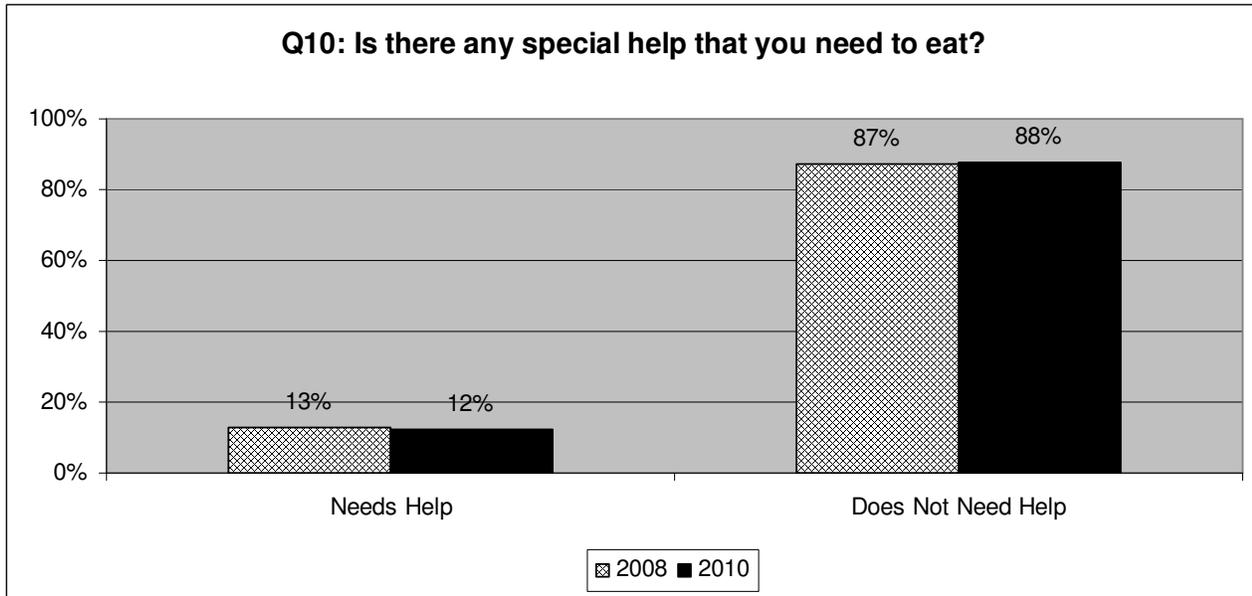
	Year	
	2008	2010
<b>Yes</b>	8%	15%
<b>No</b>	92%	85%
<b>Total responses</b>	50	73



**Q9: Is this because there is no one there to help you?**

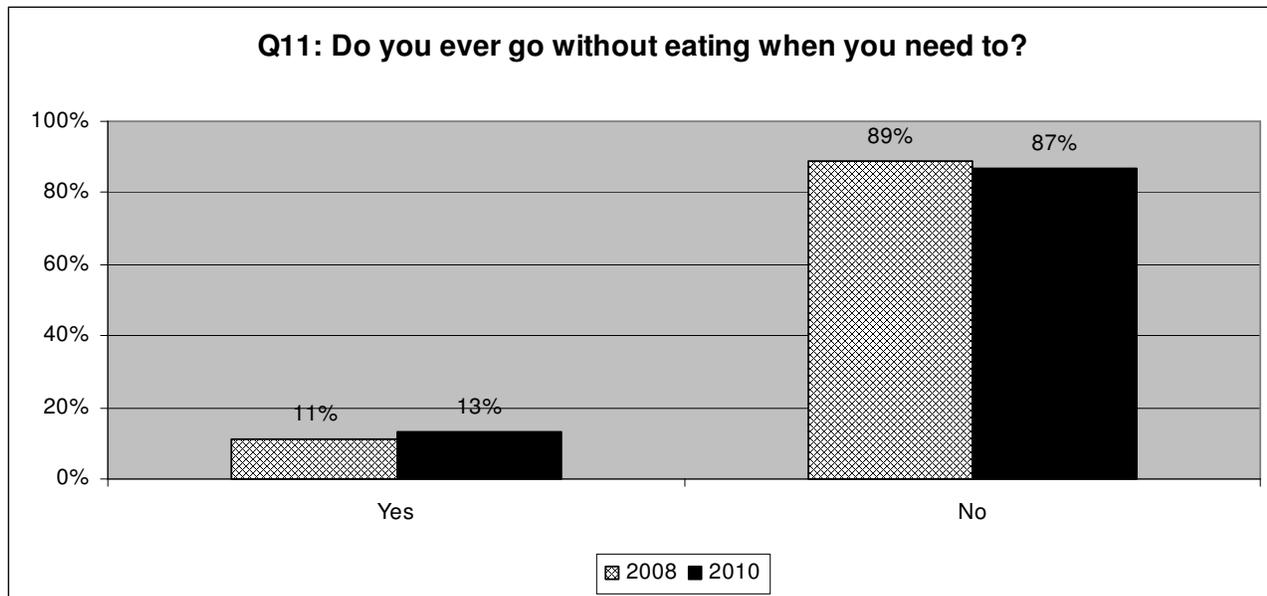
	Year	
	2008	2010
Yes	100%	73%
No		27%
<b>Total responses</b>	4	11

### Eating



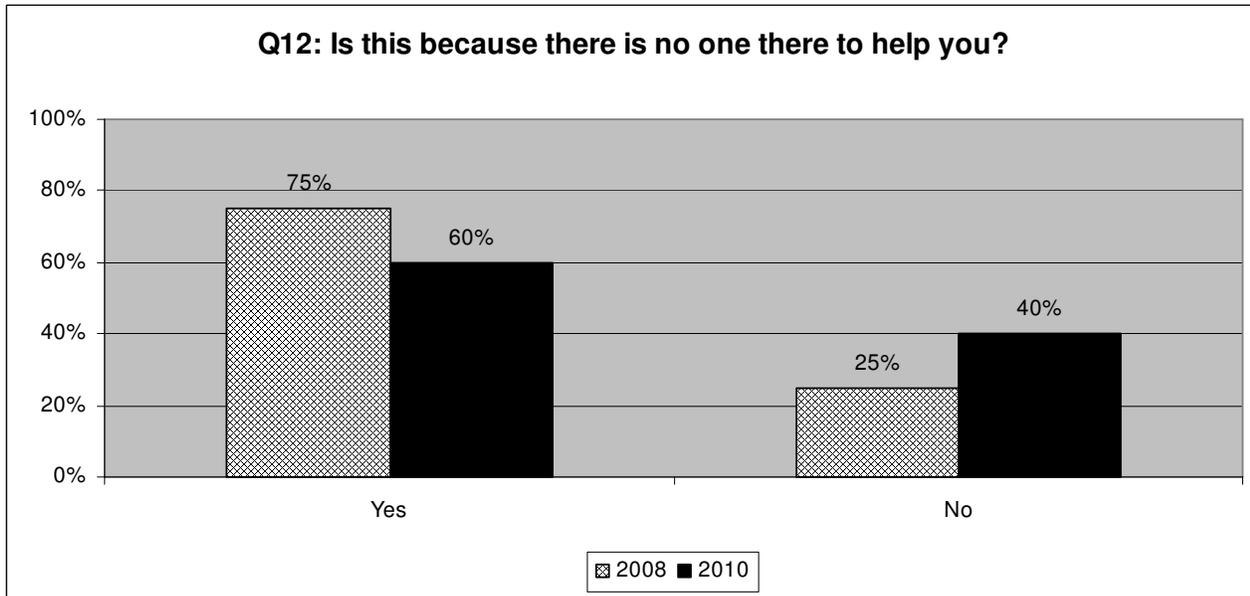
**Q10: Is there any special help that you need to eat?**

	Year	
	2008	2010
<b>Needs Help</b>	13%	12%
<b>Does Not Need Help</b>	87%	88%
<b>Total responses</b>	277	314



**Q11: Do you ever go without eating when you need to?**

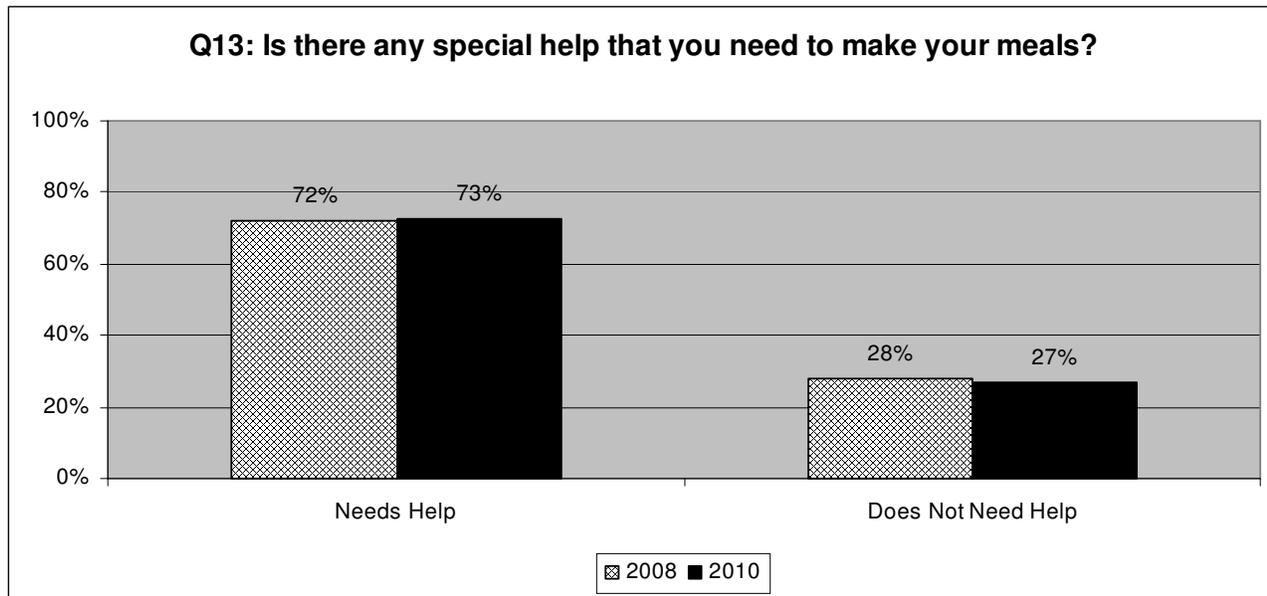
	Year	
	2008	2010
<b>Yes</b>	11%	13%
<b>No</b>	89%	87%
<b>Total responses</b>	36	38



**Q12: Is this because there is no one there to help you?**

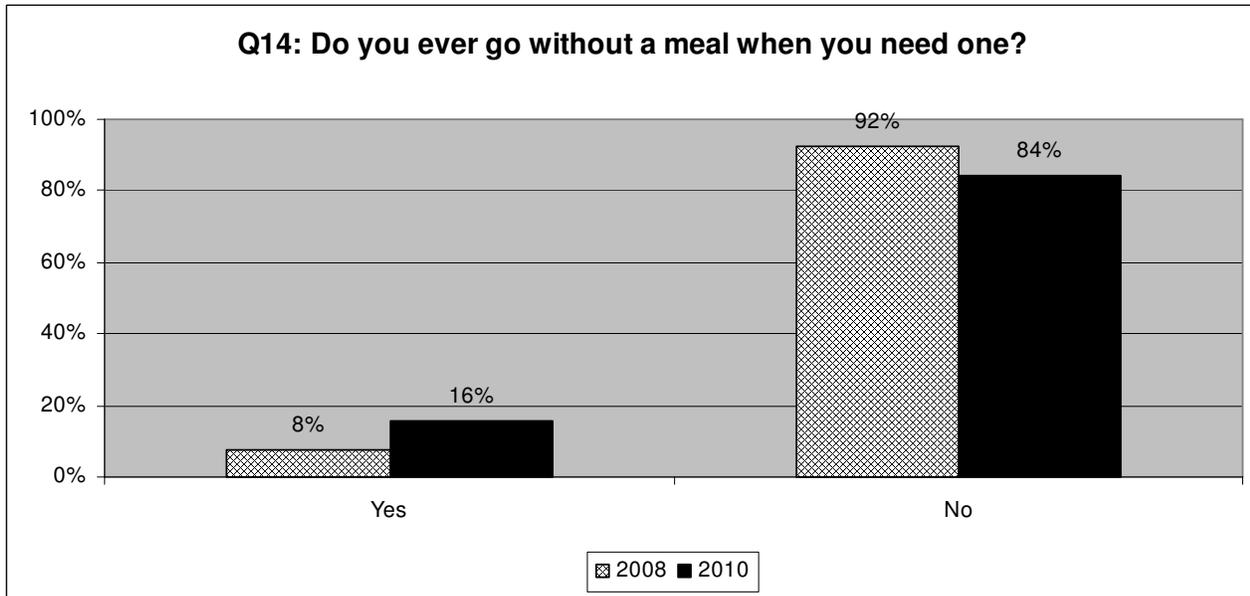
	Year	
	2008	2010
Yes	75%	60%
No	25%	40%
<b>Total responses</b>	4	5

### Meals



**Q13: Is there any special help that you need to make your meals?**

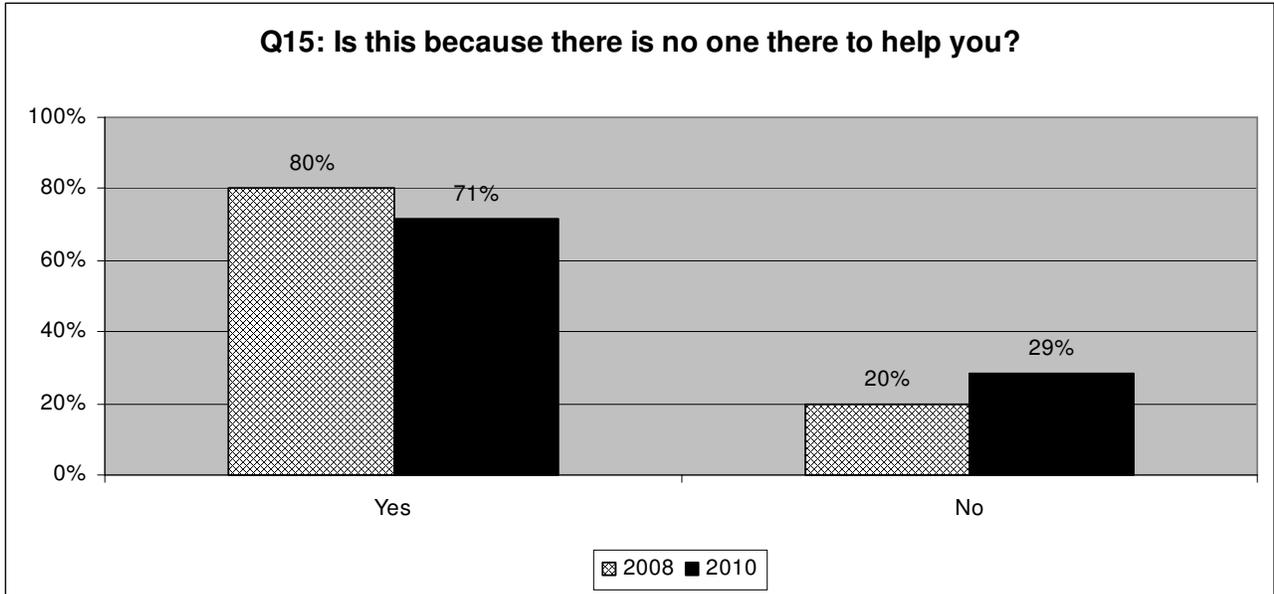
	Year	
	2008	2010
Needs Help	72%	73%
Does Not Need Help	28%	27%
<b>Total responses</b>	271	311



**Q14: Do you ever go without a meal when you need one?**

	Year	
	2008	2010
<b>Yes</b>	8%	16%
<b>No</b>	92%	84%
<b>Total responses</b>	195	225

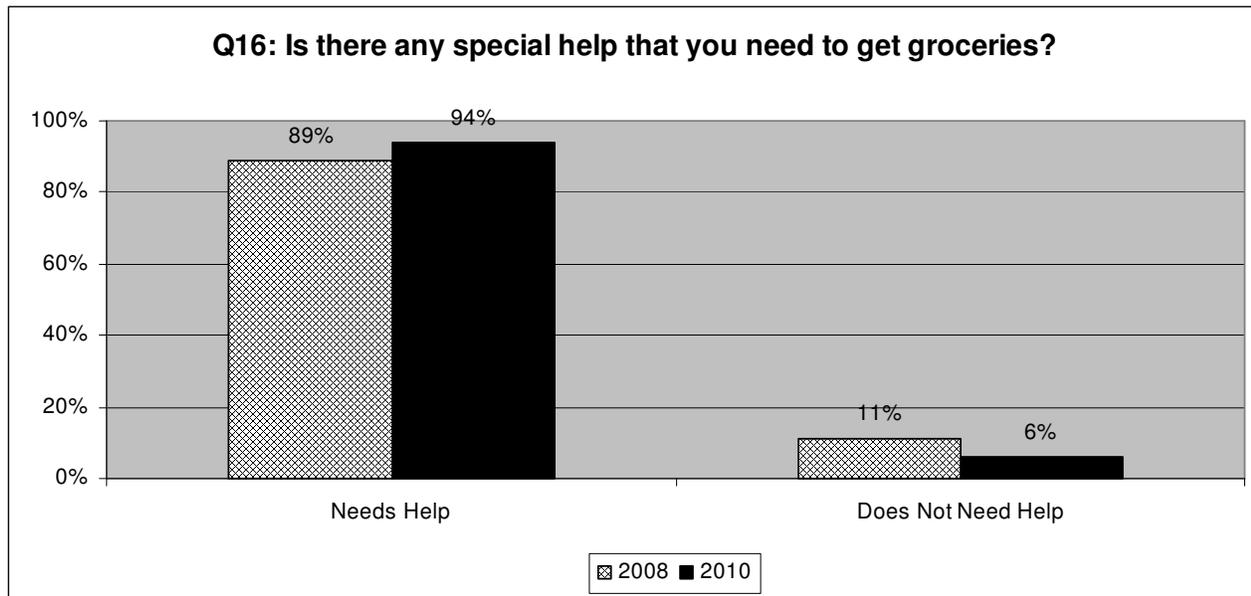
$\chi^2$  (df=1)=6.159, p=.013



**Q15: Is this because there is no one there to help you?**

	Year	
	2008	2010
Yes	80%	71%
No	20%	29%
<b>Total responses</b>	15	35

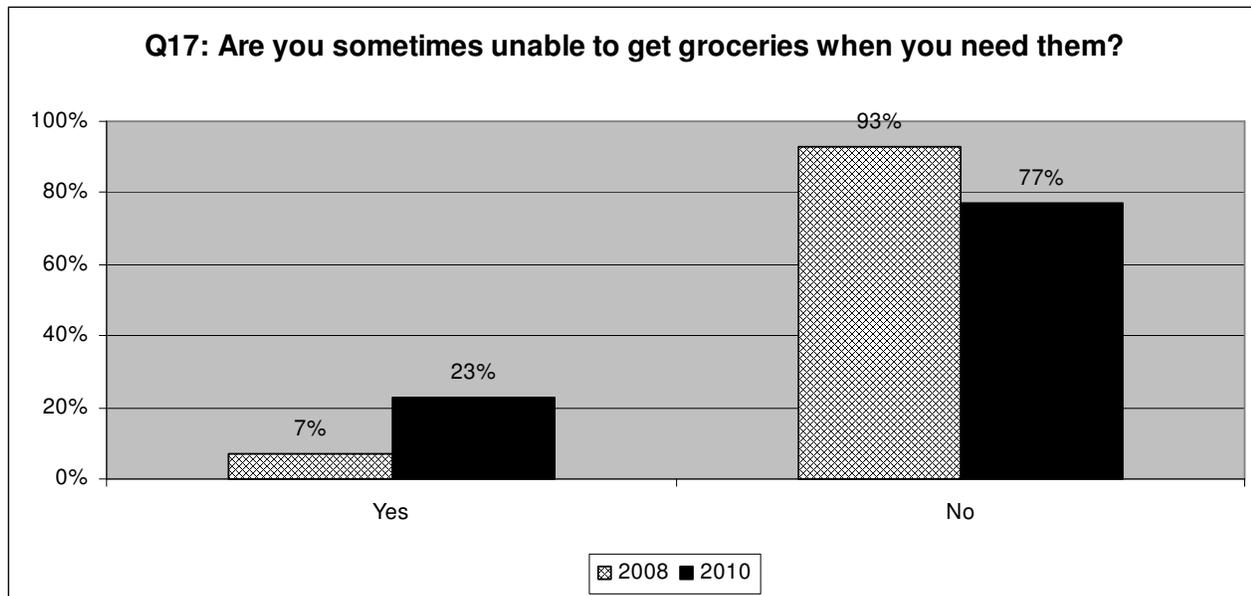
### Groceries



**Q16: Is there any special help that you need to get groceries?**

	Year	
	2008	2010
<b>Needs Help</b>	89%	94%
<b>Does Not Need Help</b>	11%	6%
<b>Total responses</b>	271	309

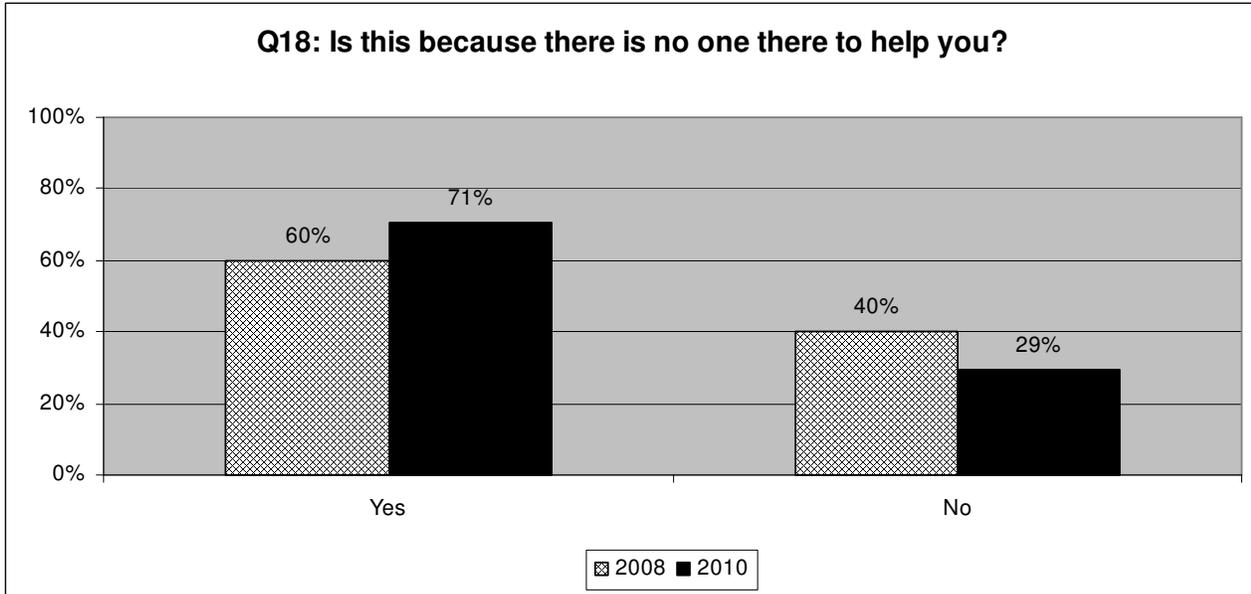
$\chi^2$  (df=1)=4.521, p=.033



**Q17: Are you sometimes unable to get groceries when you need them?**

	Year	
	2008	2010
<b>Yes</b>	7%	23%
<b>No</b>	93%	77%
<b>Total responses</b>	239	289

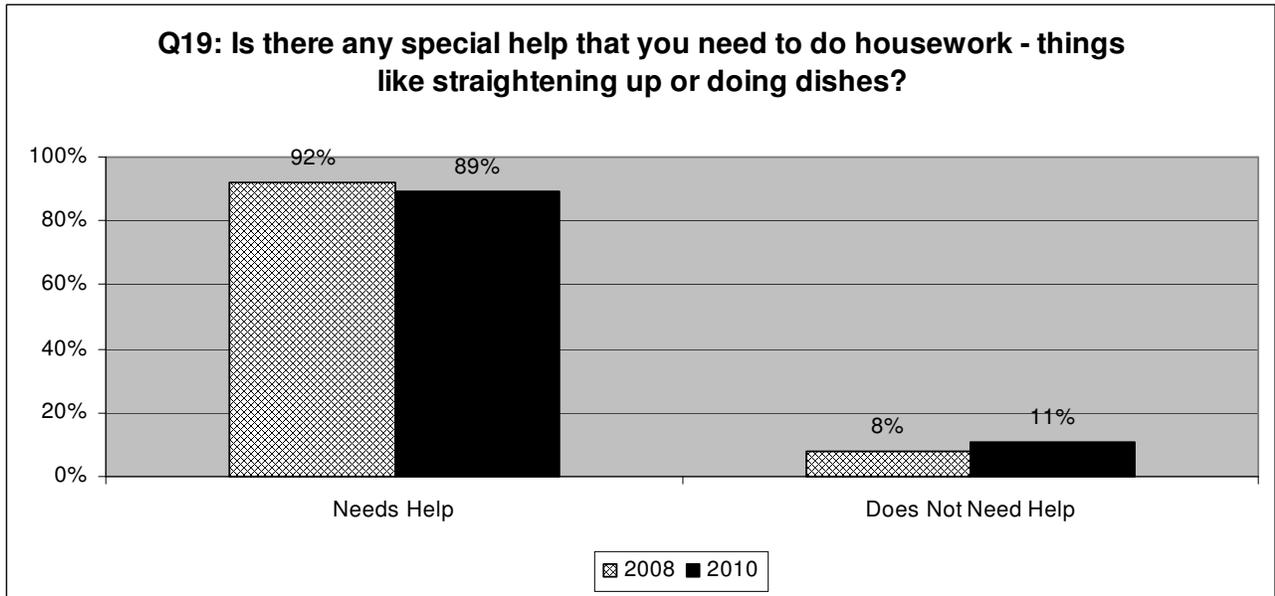
$\chi^2 (df=1)=24.414, p=.000$



**Q18: Is this because there is no one there to help you?**

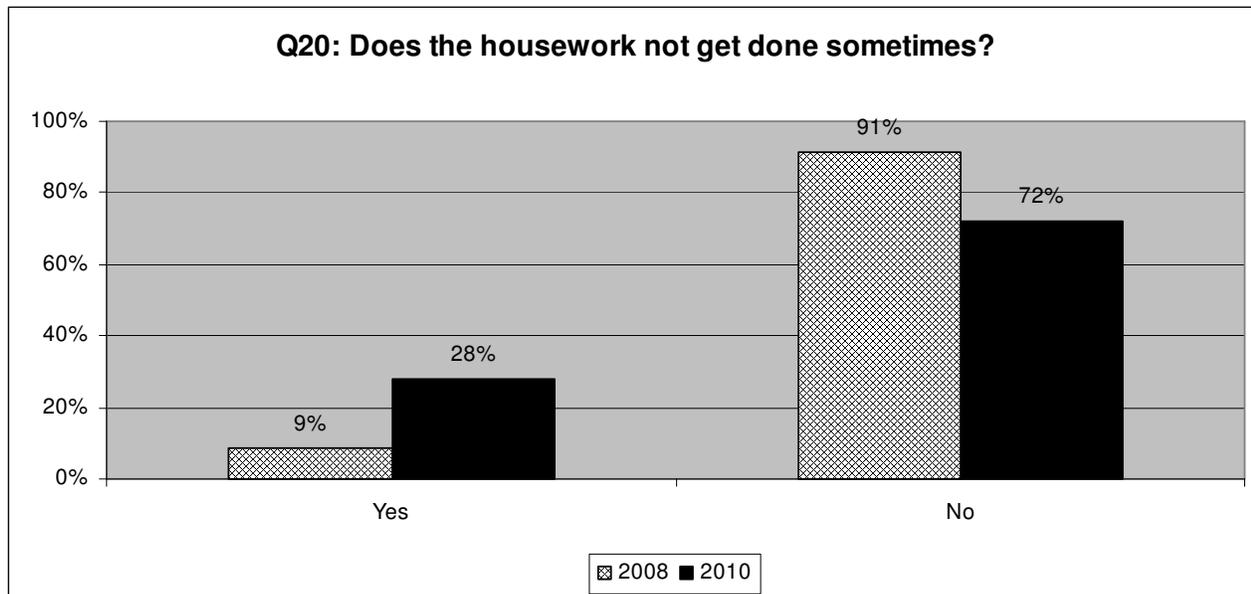
	Year	
	2008	2010
<b>Yes</b>	60%	71%
<b>No</b>	40%	29%
<b>Total responses</b>	65	15

### Housework



**Q19: Is there any special help that you need to do housework – things like straightening up or doing dishes?**

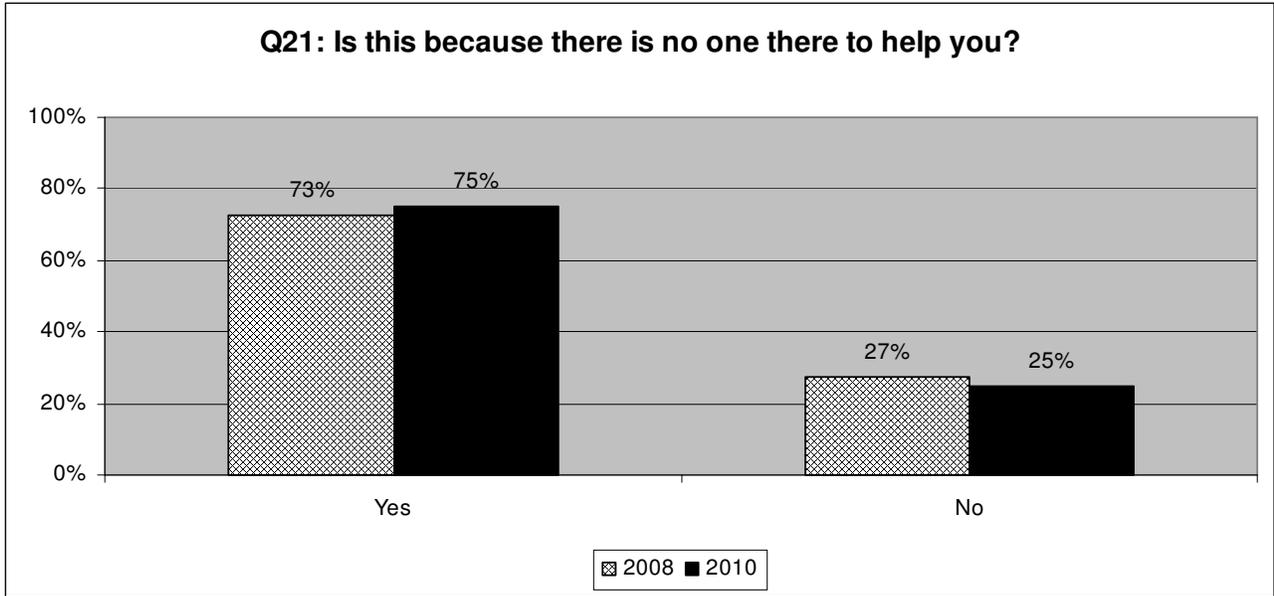
	Year	
	2008	2010
<b>Needs Help</b>	92%	89%
<b>Does Not Need Help</b>	8%	11%
<b>Total responses</b>	272	313



**Q20: Does the housework not get done sometimes?**

	Year	
	2008	2010
<b>Yes</b>	9%	28%
<b>No</b>	91%	72%
<b>Total responses</b>	249	277

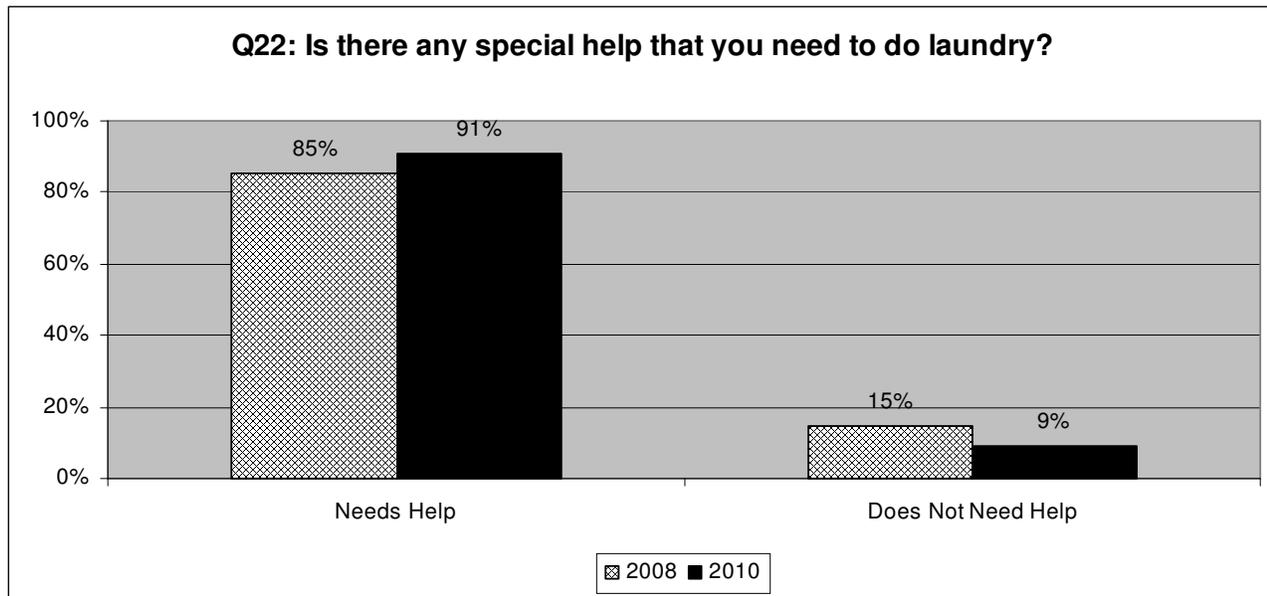
$\chi^2 (df=1)=30.860, p=.000$



**Q21: Is this because there is no one there to help you?**

	Year	
	2008	2010
Yes	73%	75%
No	27%	25%
<b>Total responses</b>	22	76

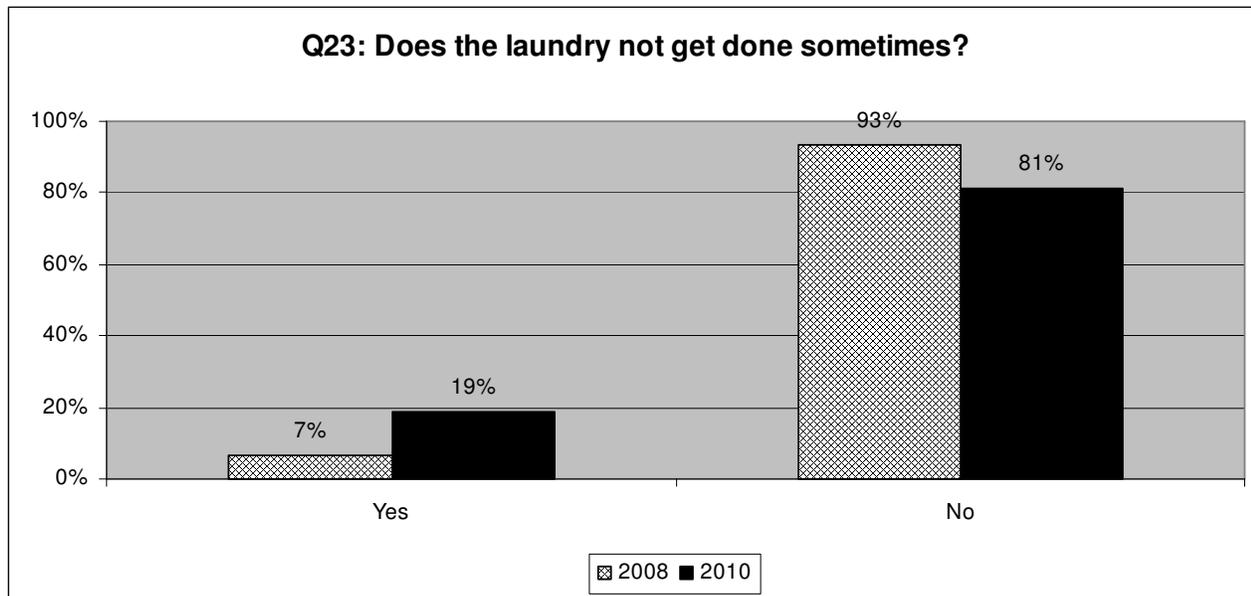
### Laundry



**Q22: Is there any special help that you need to do laundry?**

	Year	
	2008	2010
<b>Needs Help</b>	85%	91%
<b>Does Not Need Help</b>	15%	9%
<b>Total responses</b>	277	312

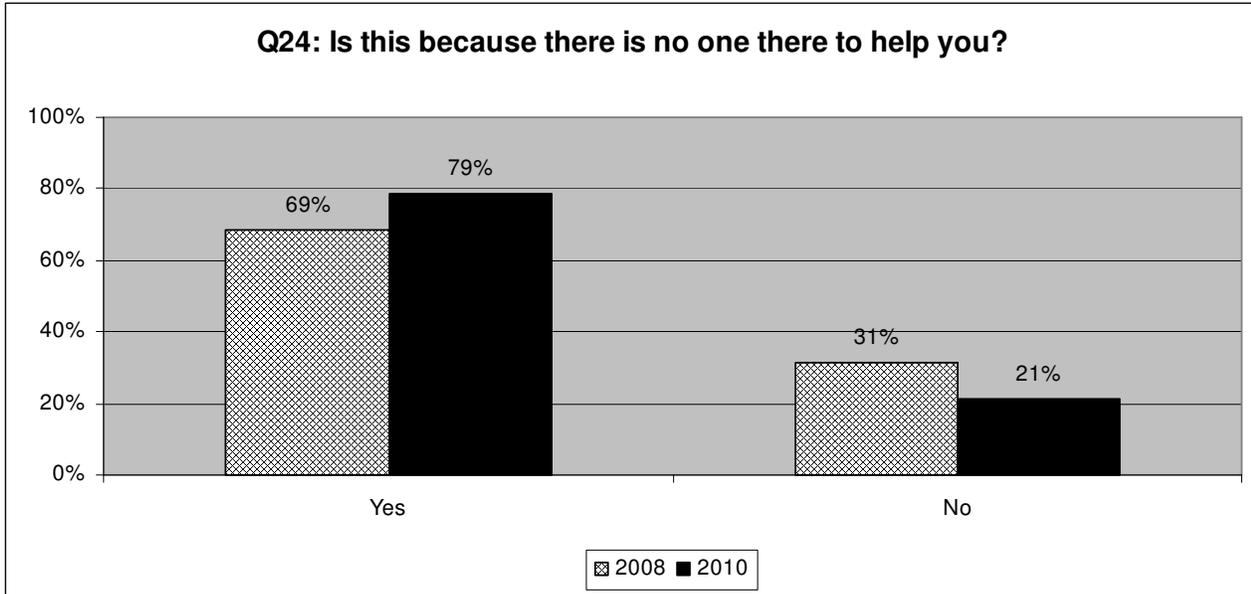
$\chi^2$  (df=1)=4.817, p=.028



**Q23: Does the laundry not get done sometimes?**

	Year	
	2008	2010
<b>Yes</b>	7%	19%
<b>No</b>	93%	81%
<b>Total responses</b>	237	279

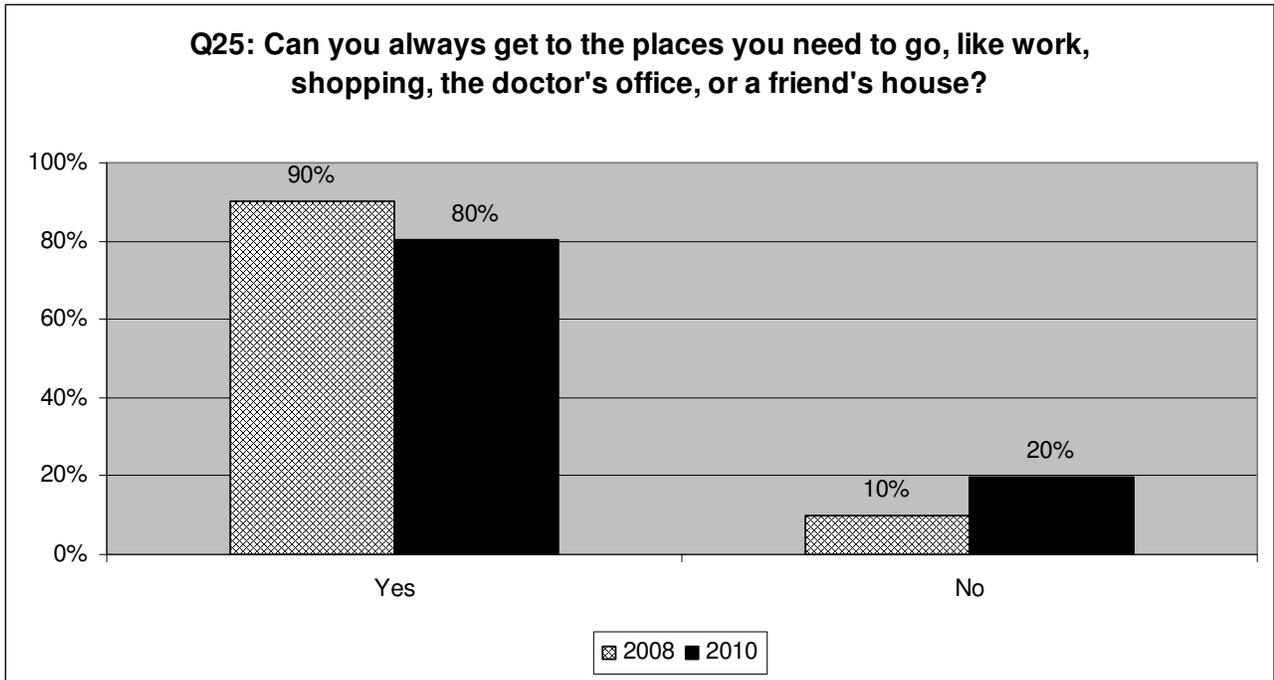
$\chi^2 (df=1)=15.825, p=.000$



**Q24: Is this because there is no one there to help you?**

	Year	
	2008	2010
<b>Yes</b>	69%	79%
<b>No</b>	31%	21%
<b>Total responses</b>	16	52

### Transportation

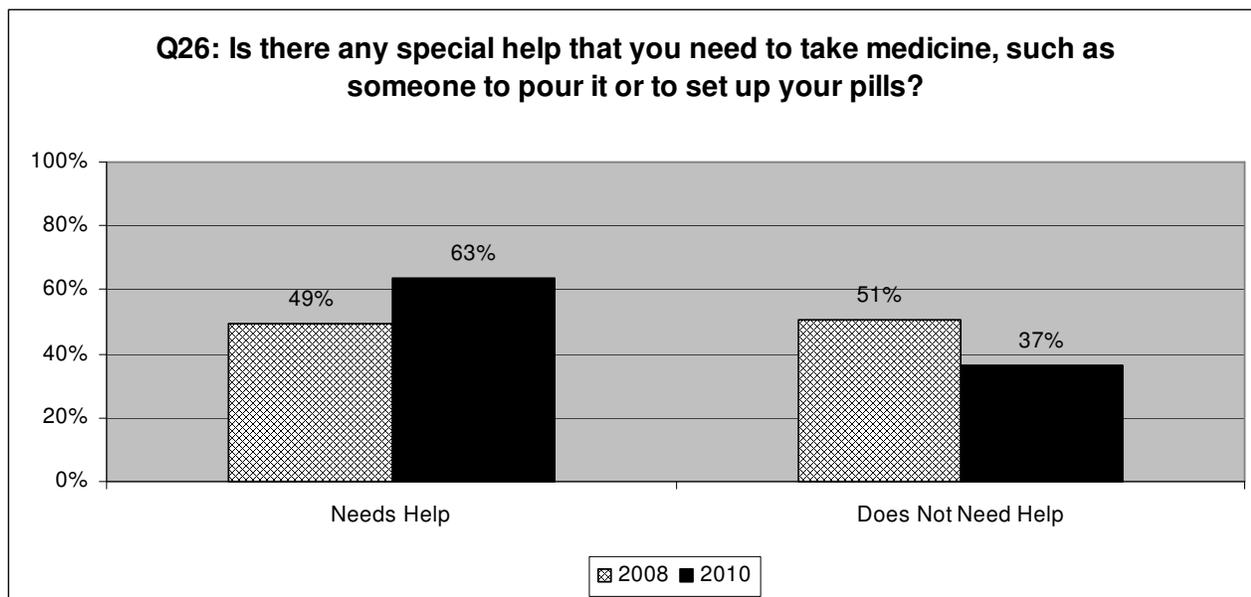


**Q25: Can you always get to the places you need to go, like work, shopping, the doctor's office, or a friend's house?**

	Year	
	2008	2010
Yes	90%	80%
No	10%	20%
<b>Total responses</b>	276	310

$\chi^2 (df=1) = 11.201, p = .001$

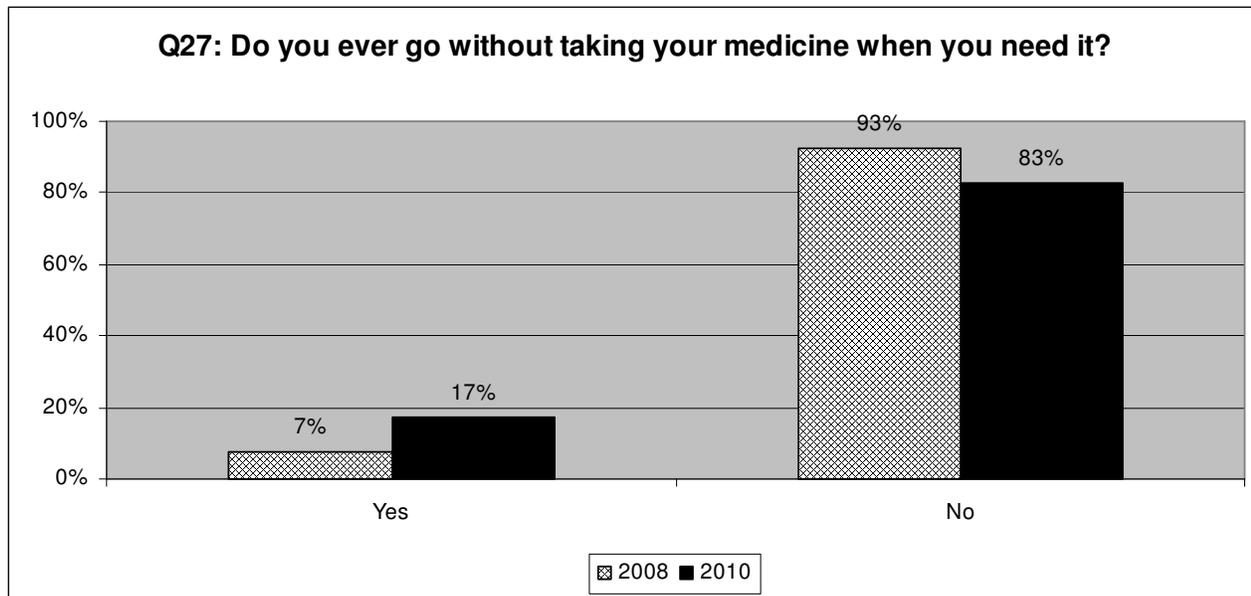
### Medication



**Q26: Is there any special help that you need to take medicine, such as someone to pour it or to set up your pills?**

	Year	
	2008	2010
<b>Needs Help</b>	49%	63%
<b>Does Not Need Help</b>	51%	37%
<b>Total responses</b>	272	315

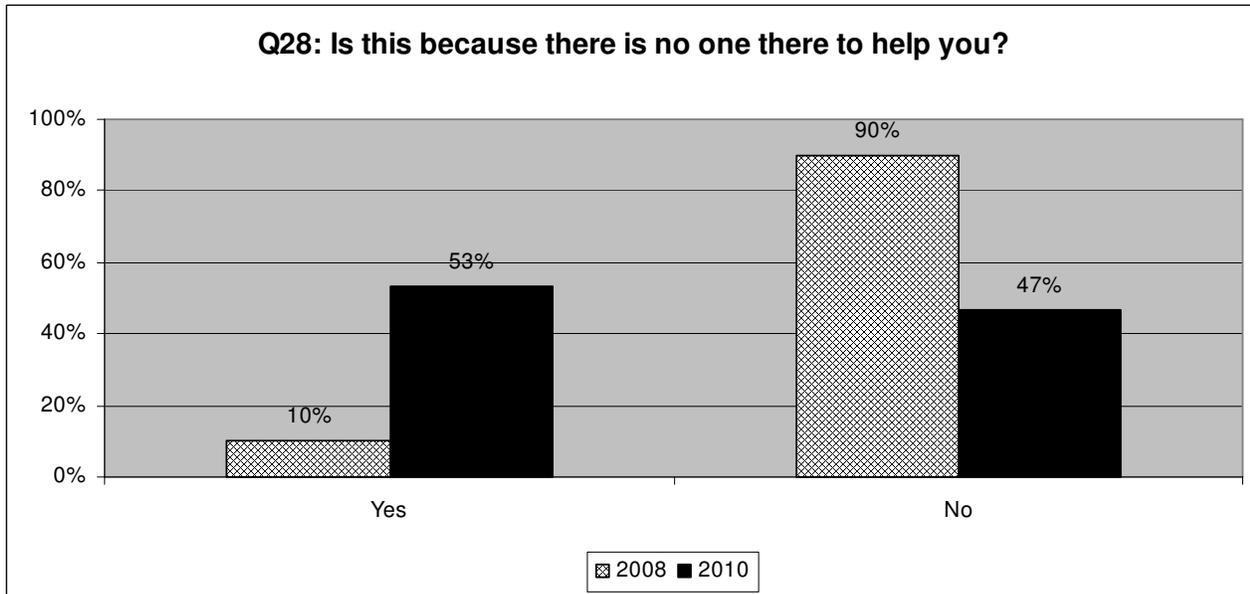
$X^2$  (df=1)=12.048, p=.001



**Q27: Do you ever go without taking your medicine when you need it?**

	Year	
	2008	2010
<b>Yes</b>	7%	17%
<b>No</b>	93%	83%
<b>Total responses</b>	134	193

$\chi^2 (df=1)=6.430, p=.011$

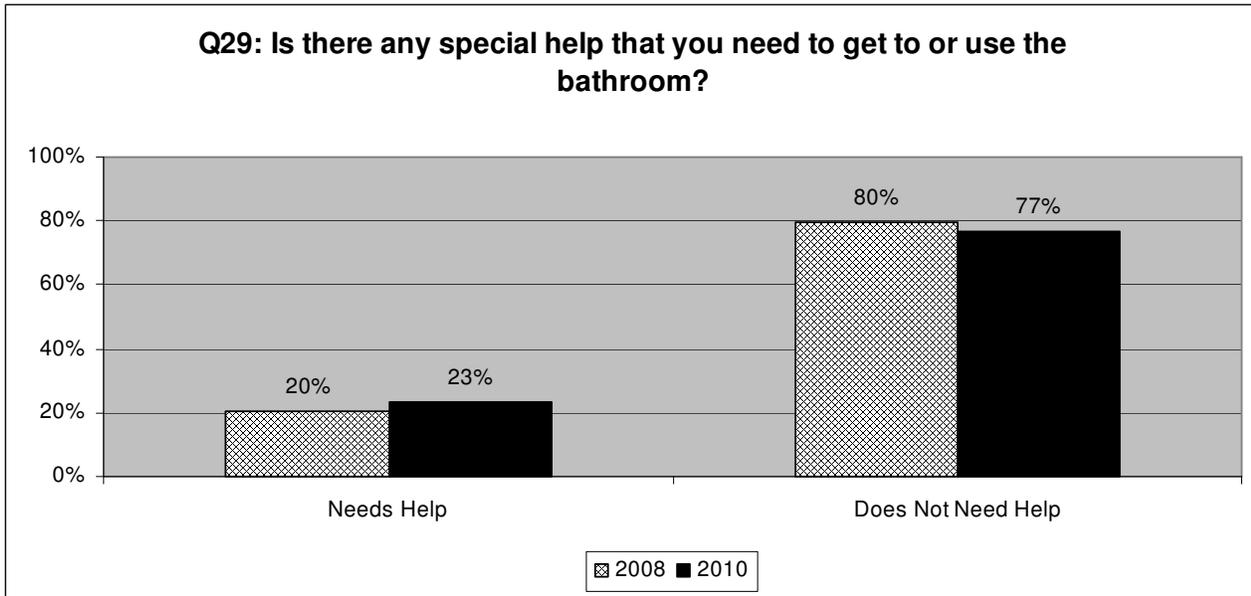


**Q28: Is this because there is no one there to help you?**

	Year	
	2008	2010
<b>Yes</b>	10%	53%
<b>No</b>	90%	47%
<b>Total responses</b>	10	32

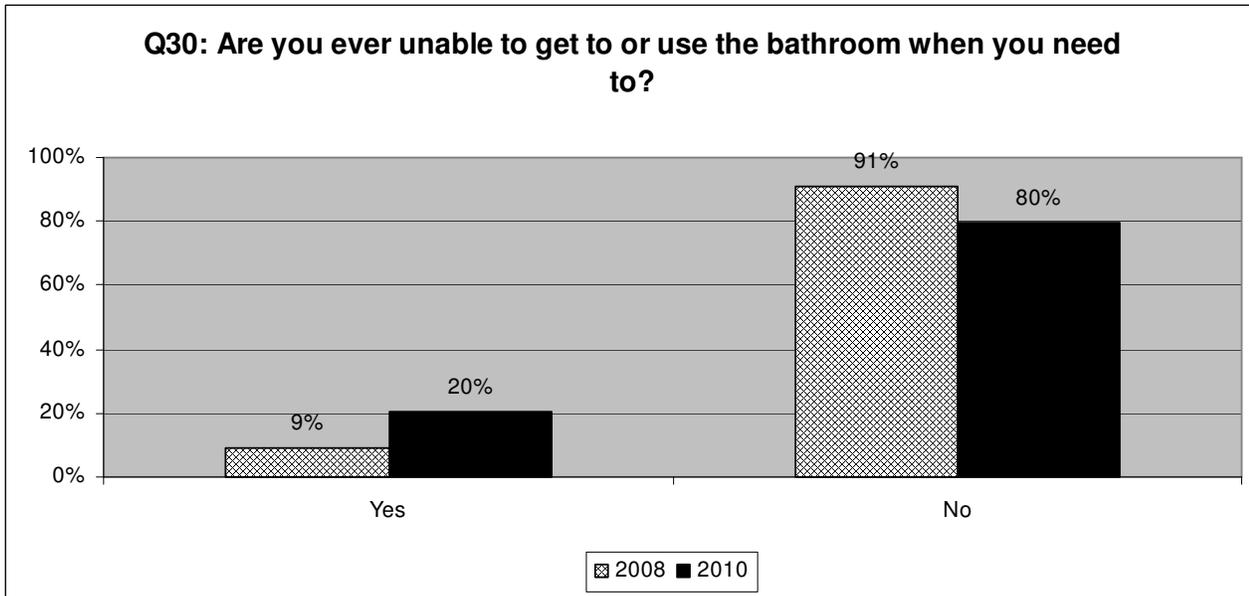
$\chi^2 (df=1)=5.786, p=.016$

### Toilet



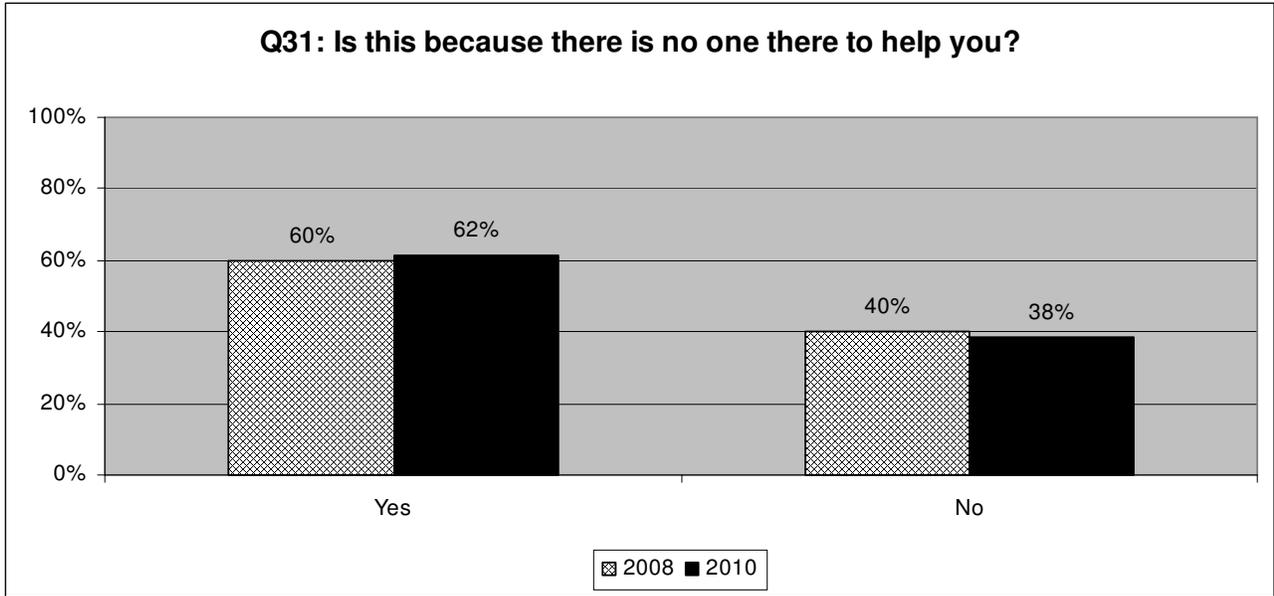
**Q29: Is there any special help that you need to get to or use the bathroom?**

	Year	
	2008	2010
<b>Needs Help</b>	20%	23%
<b>Does Not Need Help</b>	80%	77%
<b>Total responses</b>	276	314



**Q30: Are you ever unable to get to or use the bathroom when you need to?**

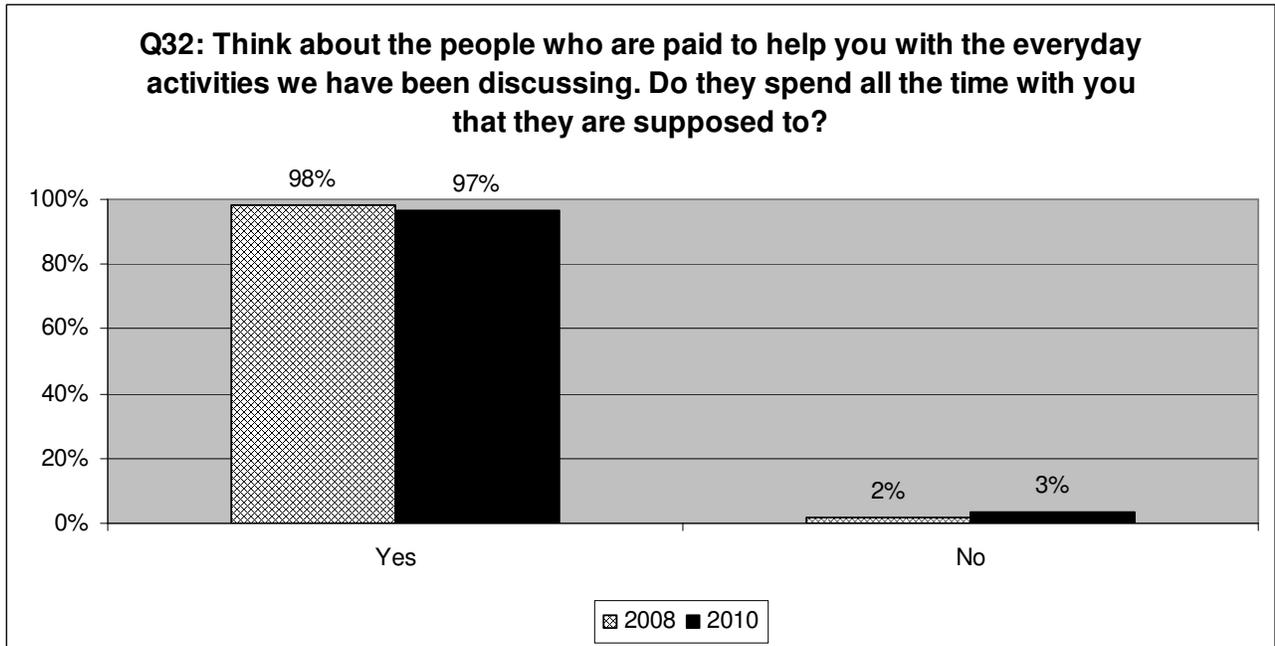
	Year	
	2008	2010
<b>Yes</b>	9%	20%
<b>No</b>	91%	80%
<b>Total responses</b>	56	69



**Q31: Is this because there is no one there to help you?**

	Year	
	2008	2010
Yes	60%	62%
No	40%	38%
<b>Total responses</b>	5	13

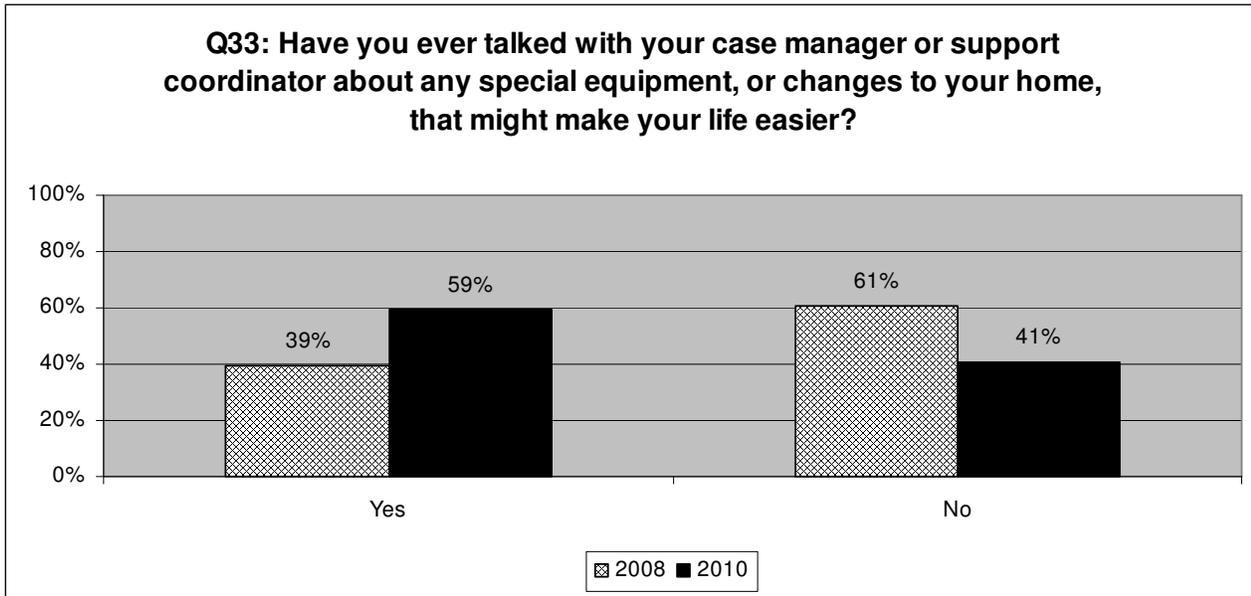
### Staff Time



**Q32: 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?**

	Year	
	2008	2010
<b>Yes</b>	98%	97%
<b>No</b>	2%	3%
<b>Total responses</b>	263	302

**Equipment:**



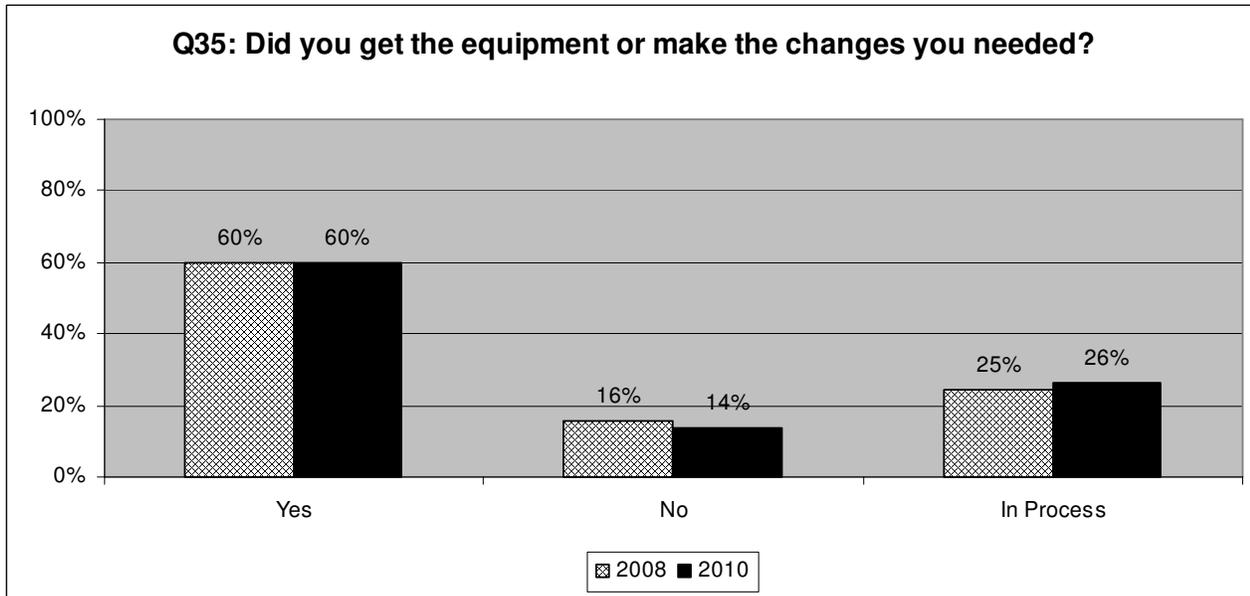
**Q33: Have you ever talked with your case manager or support coordinator about any special equipment, or changes to your home, that might make your life easier?**

	Year	
	2008	2010
<b>Yes</b>	39%	59%
<b>No</b>	61%	41%
<b>Total responses</b>	268	308

$X^2$  (df=2)=22.727, p=.000

**Q34: What equipment or changes did you talk about?**

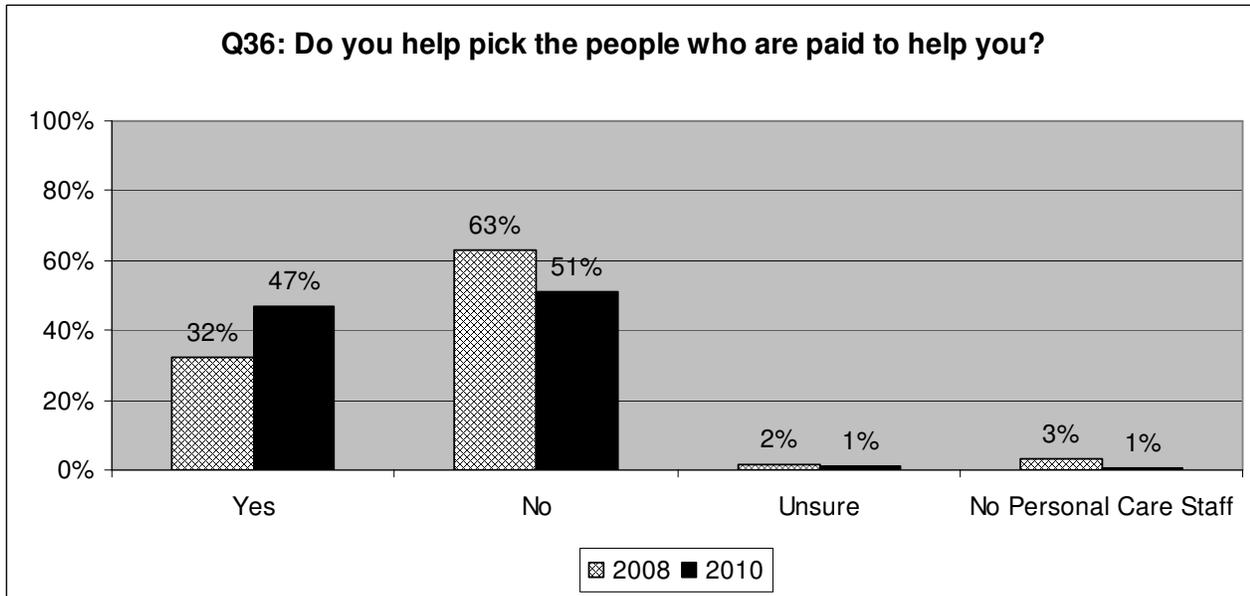
See appendix for responses to this question.



**Q35: Did you get the equipment or make the changes you needed?**

	Year	
	2008	2010
<b>Yes</b>	60%	60%
<b>No</b>	16%	14%
<b>In Process</b>	25%	26%
<b>Total responses</b>	102	167

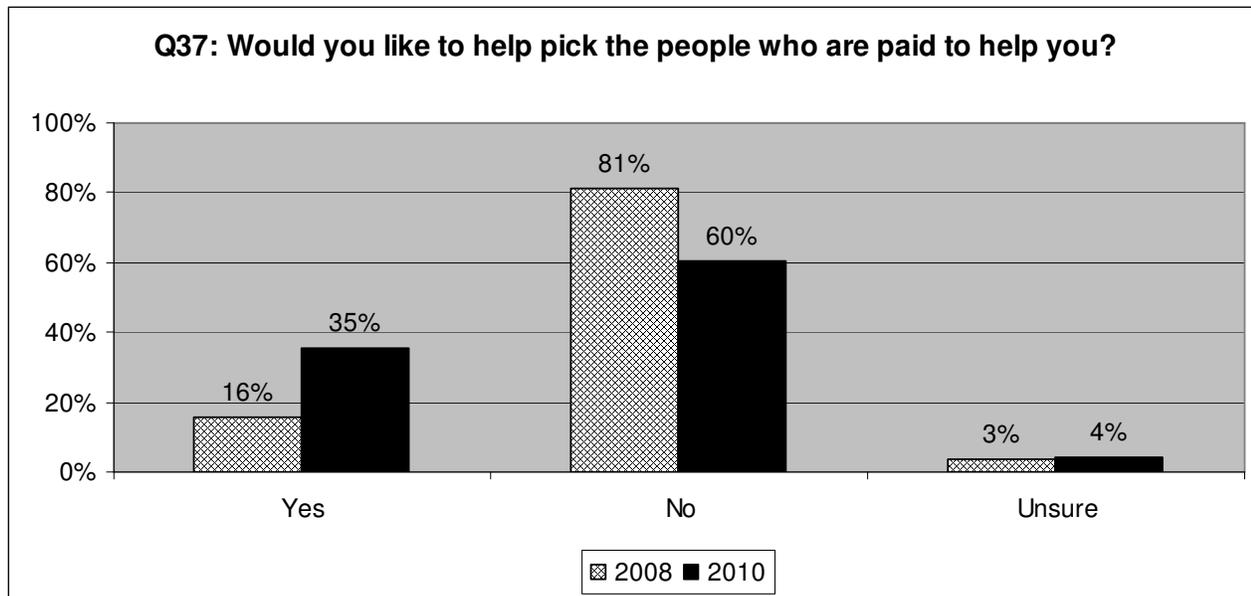
## **CHOICE AND CONTROL**



**Q36: Do you help pick the people who are paid to help you?**

	Year	
	2008	2010
<b>Yes</b>	32%	47%
<b>No</b>	63%	51%
<b>Unsure</b>	2%	1%
<b>No Personal Care Staff</b>	3%	1%
<b>Total responses</b>	277	312

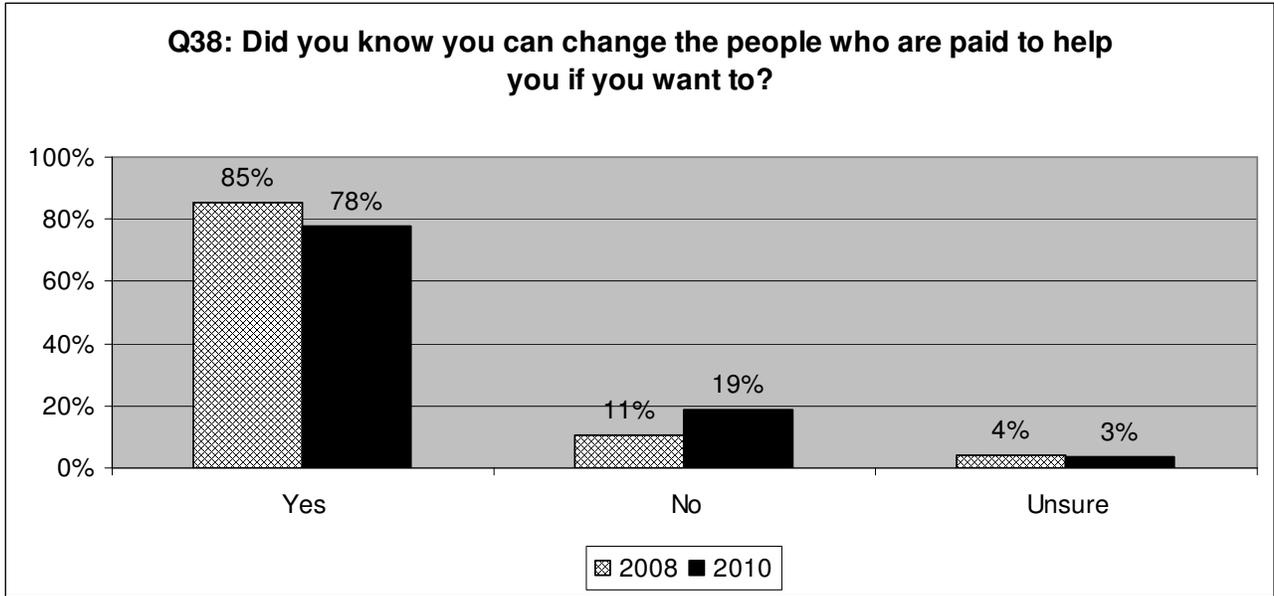
$\chi^2$  (df=3)=17.779, p=.000



**Q37: Would you like to help pick the people who are paid to help you?**

	Year	
	2008	2010
Yes	16%	35%
No	81%	60%
Unsure	3%	4%
<b>Total responses</b>	174	161

$X^2 (df=2)=18.449, p=.000$



**Q38: Did you know you can change the people who are paid to help you if you want to?**

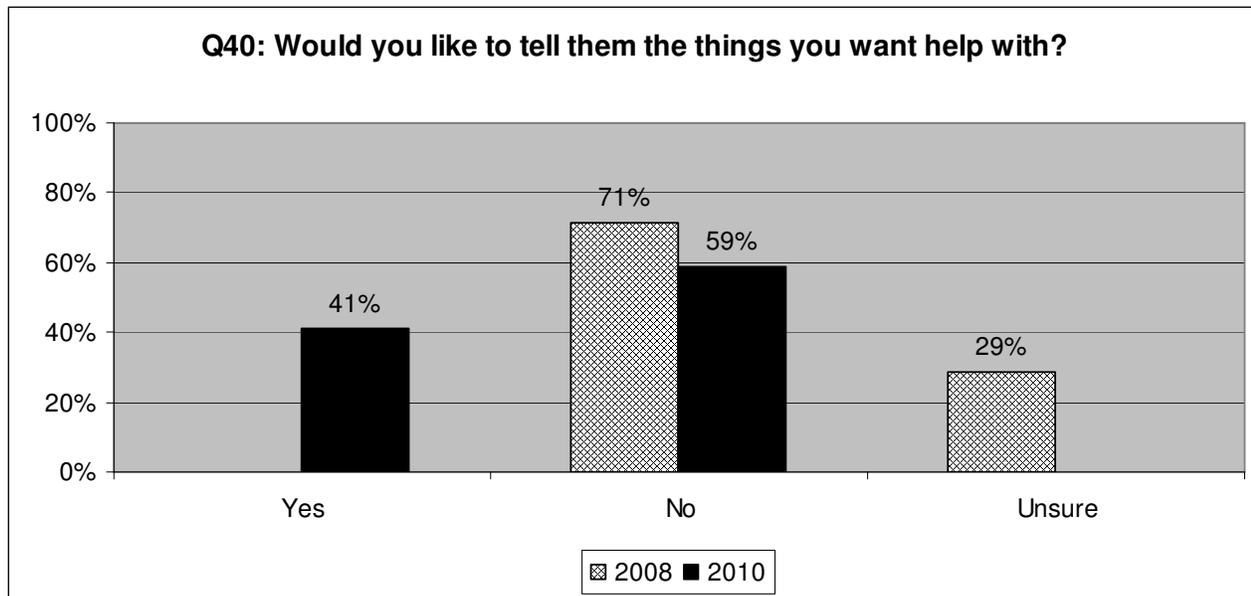
	Year	
	2008	2010
<b>Yes</b>	85%	78%
<b>No</b>	11%	19%
<b>Unsure</b>	4%	3%
<b>Total responses</b>	266	308

$\chi^2 (df=2) = 7.843, p = .020$

**Q39: Thinking again about the people who are paid to help you, do you tell them what to help you with?**

	Year	
	2008	2010
<b>Yes</b>	94%	84%
<b>No</b>	2%	6%
<b>Sometimes</b>	4%	10%
<b>Total responses</b>	265	308

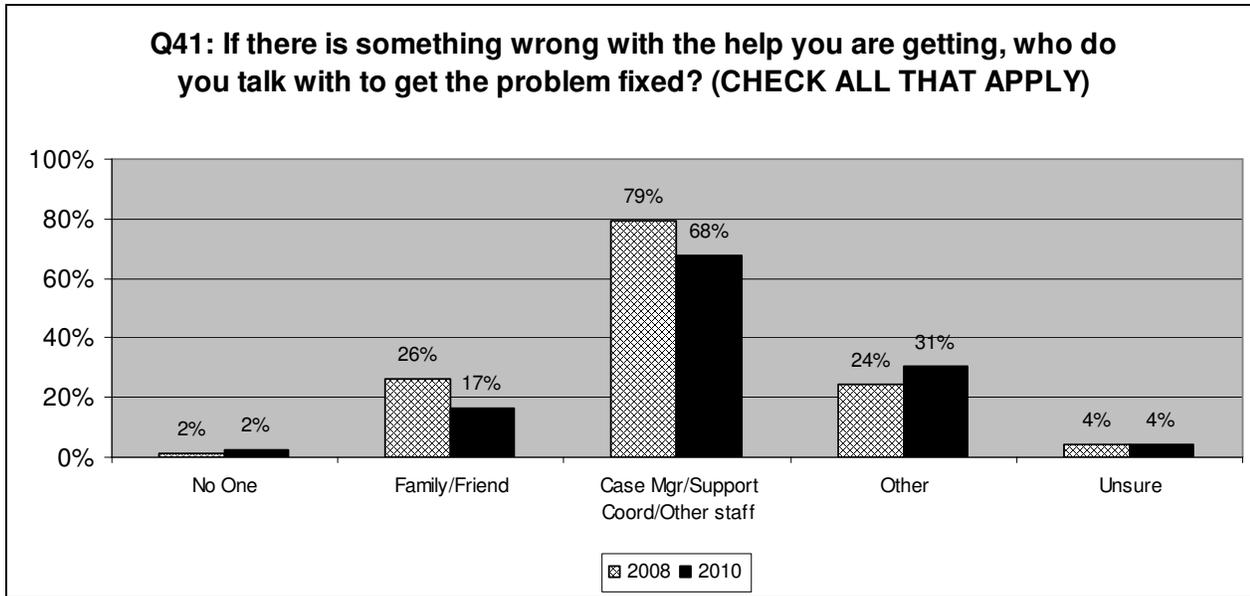
$\chi^2$  (df=2)=13.833, p=.001



**Q40: Would you like to tell them the things you want help with?**

	Year	
	2008	2010
Yes		41%
No	71%	59%
Unsure	29%	
<b>Total responses</b>	7	17

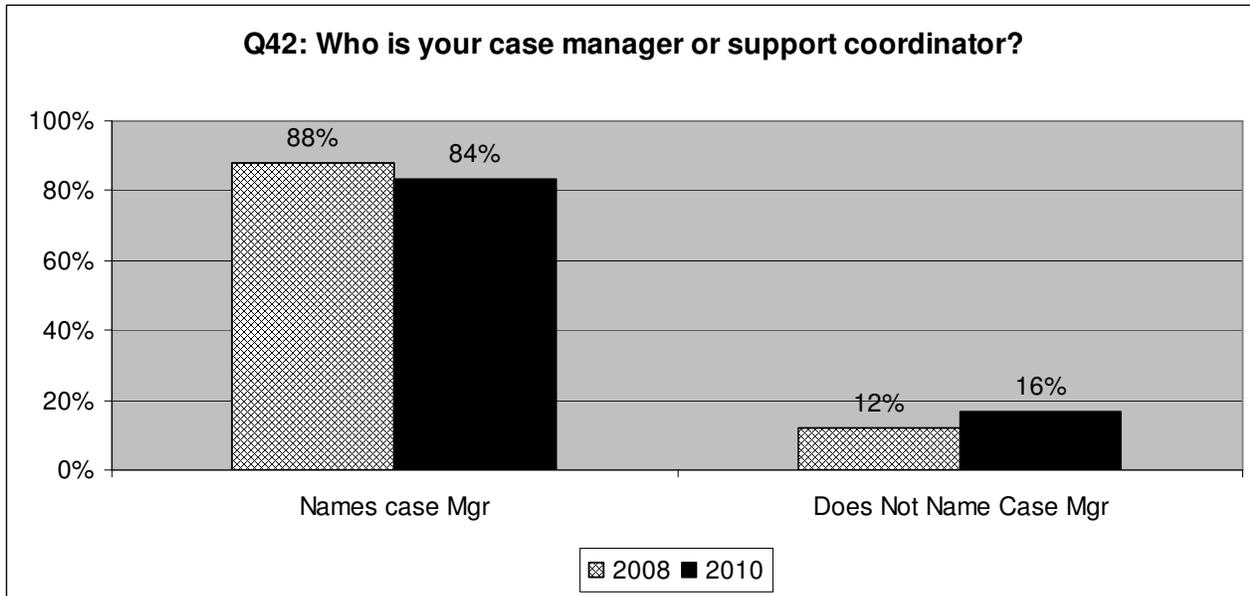
$\chi^2 (df=2)=7.886, p=.020$



**Q41: 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)**

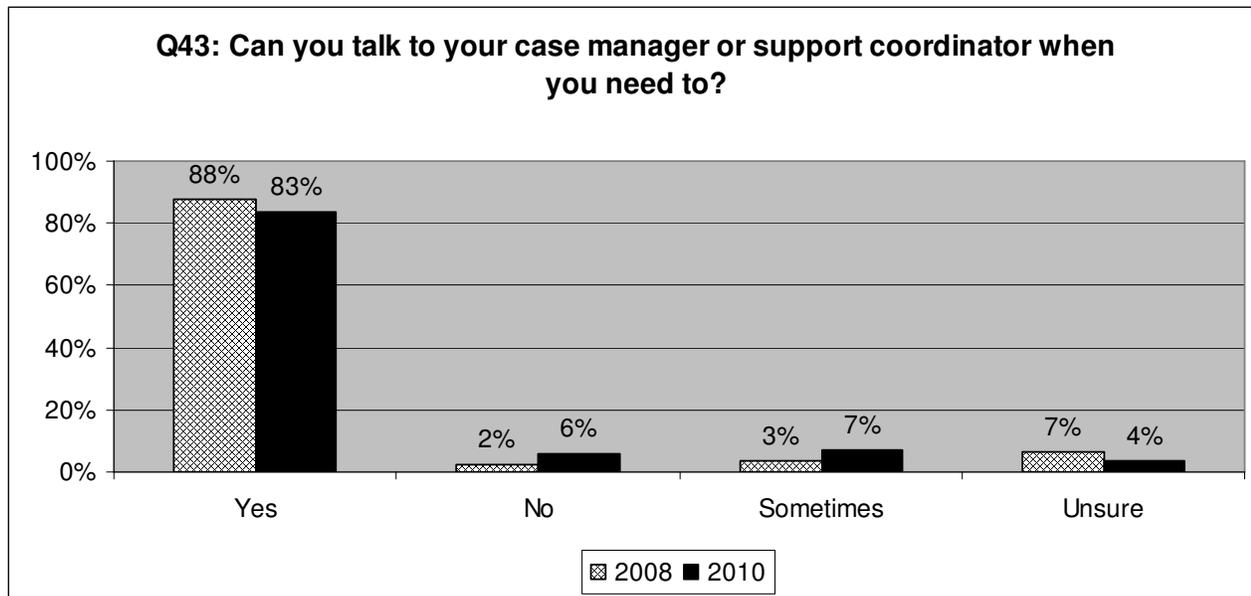
	Year	
	2010	2008
No One	2%	2%
Family/Friend	17%	26%
Case Mgr/Support Coord/Other staff	68%	79%
Other	31%	24%
Unsure	4%	4%
<b>Total responses</b>	<b>314</b>	<b>274</b>

$\chi^2$  (df=8)=44.780, p=.000



**Q42: Who is your case manager or support coordinator?**

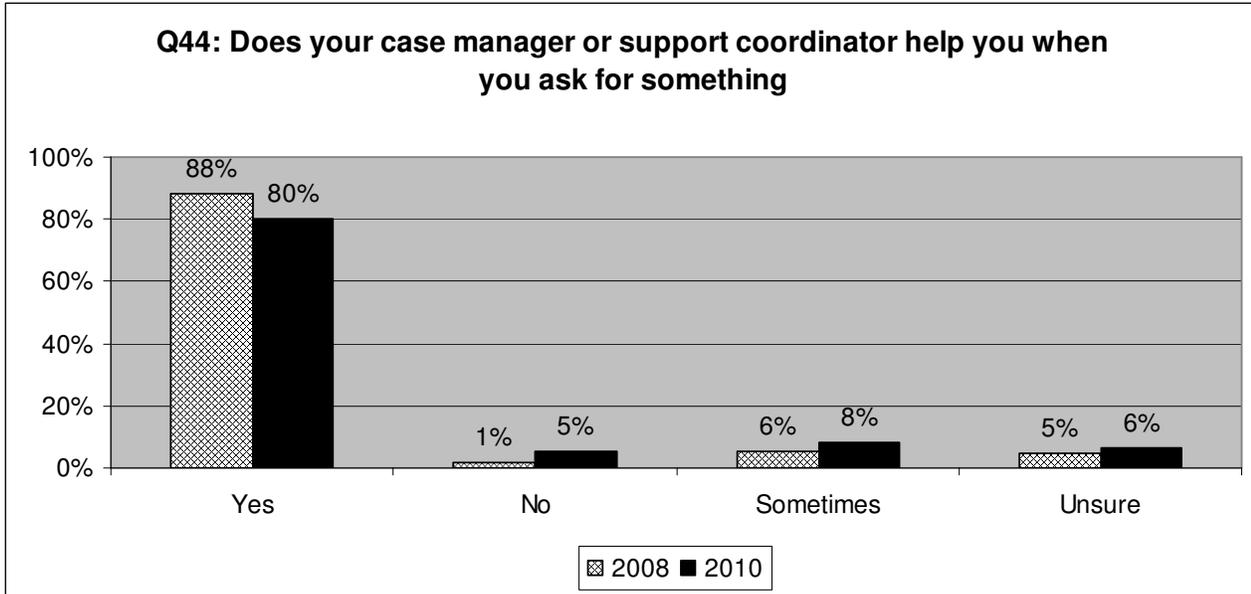
	Year	
	2008	2010
<b>Names case Mgr</b>	88%	84%
<b>Does Not Name Case Mgr</b>	12%	16%
<b>Total responses</b>	270	304



**Q43: Can you talk to your case manager or support coordinator when you need to?**

	Year	
	2008	2010
Yes	88%	83%
No	2%	6%
Sometimes	3%	7%
Unsure	7%	4%
<b>Total responses</b>	<b>272</b>	<b>307</b>

$\chi^2$  (df=3)=11.652, p=.009

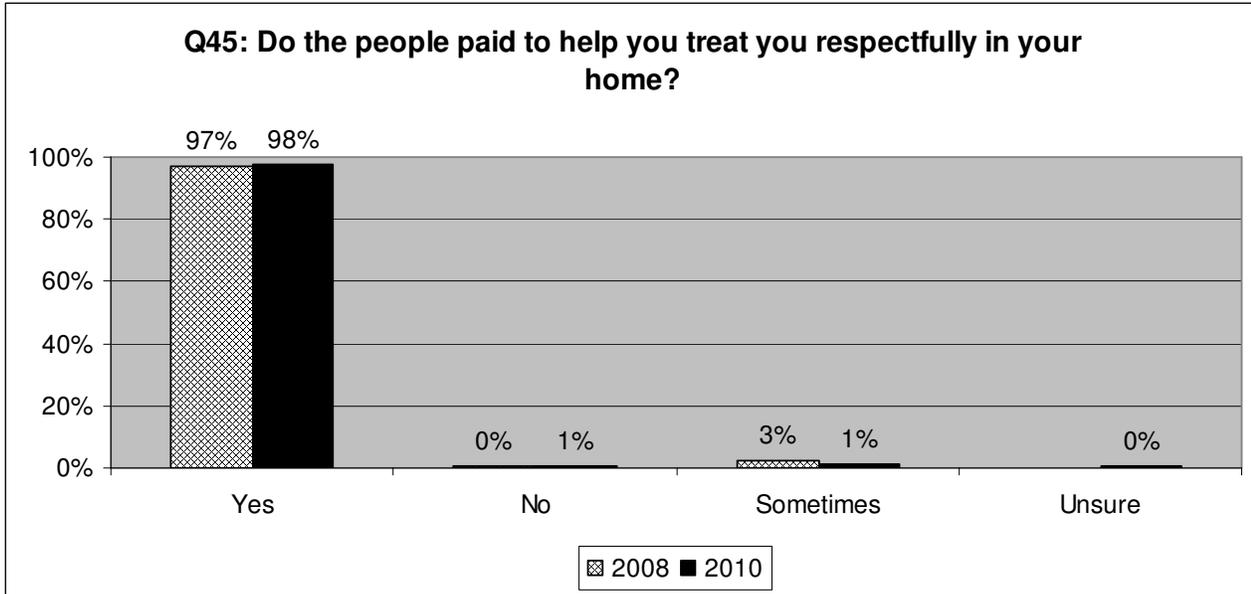


**Q44: Does your case manager or support coordinator help you when you ask for something?**

	Year	
	2008	2010
<b>Yes</b>	88%	80%
<b>No</b>	1%	5%
<b>Sometimes</b>	6%	8%
<b>Unsure</b>	5%	6%
<b>Total responses</b>	271	311

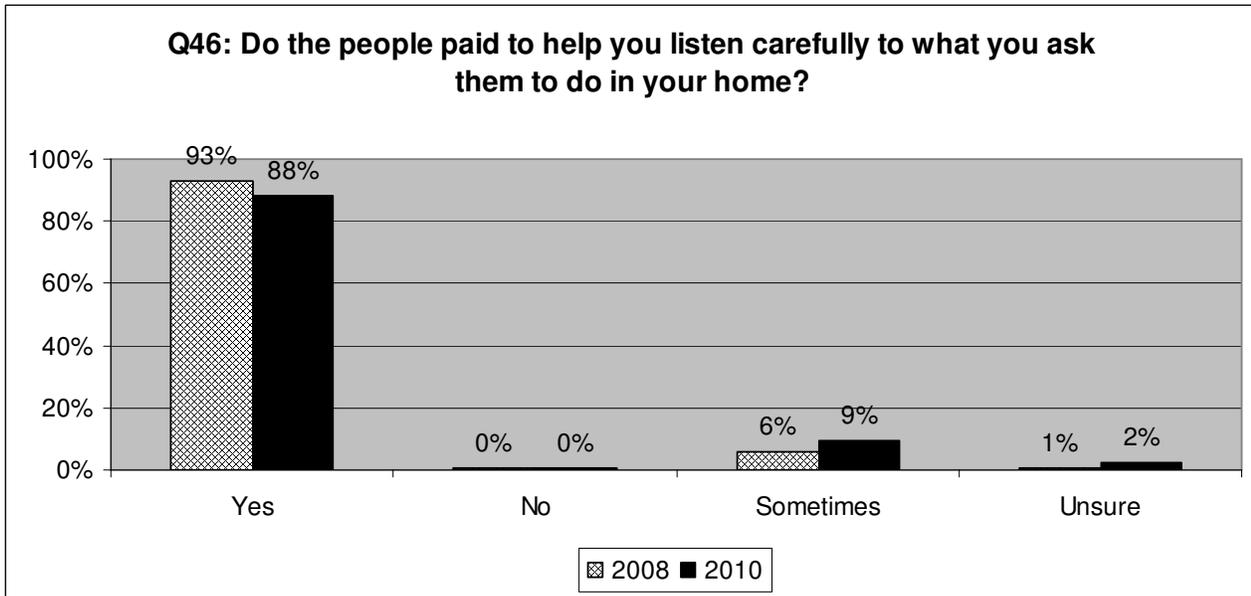
$\chi^2(df=3) = 9.135, p = .028$

**RESPECT AND DIGNITY**



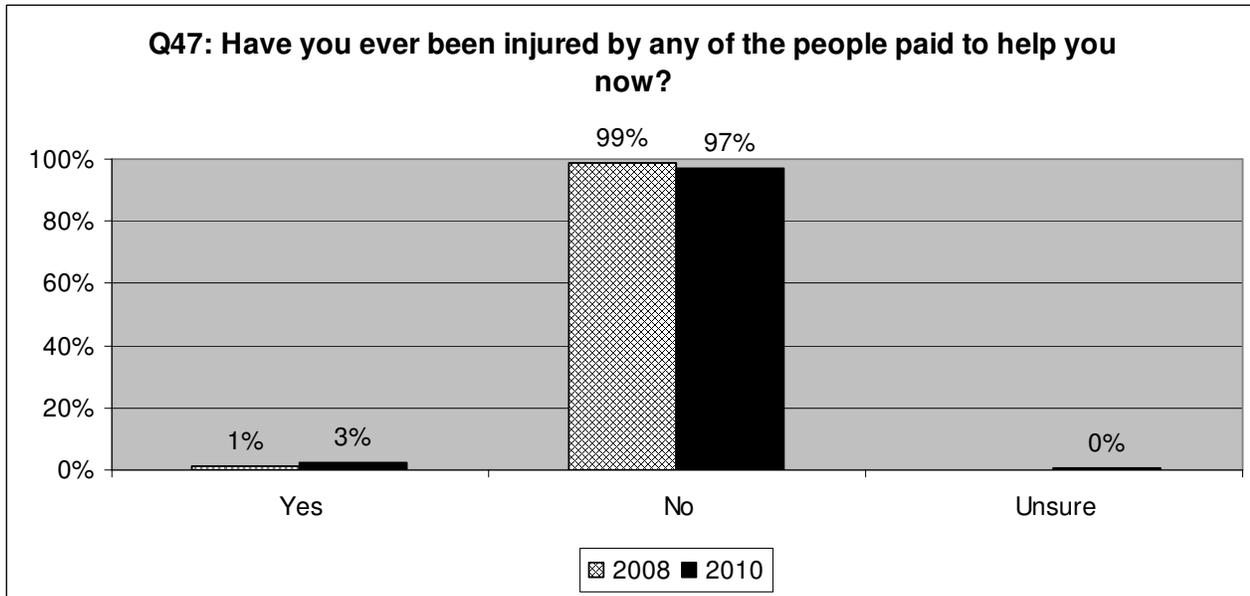
**Q45: Do the people paid to help you treat you respectfully in your home?**

	Year	
	2008	2010
Yes	97%	98%
No	0%	1%
Sometimes	3%	1%
Unsure		0%
<b>Total responses</b>	273	313



**Q46: Do the people paid to help you listen carefully to what you ask them to do in your home?**

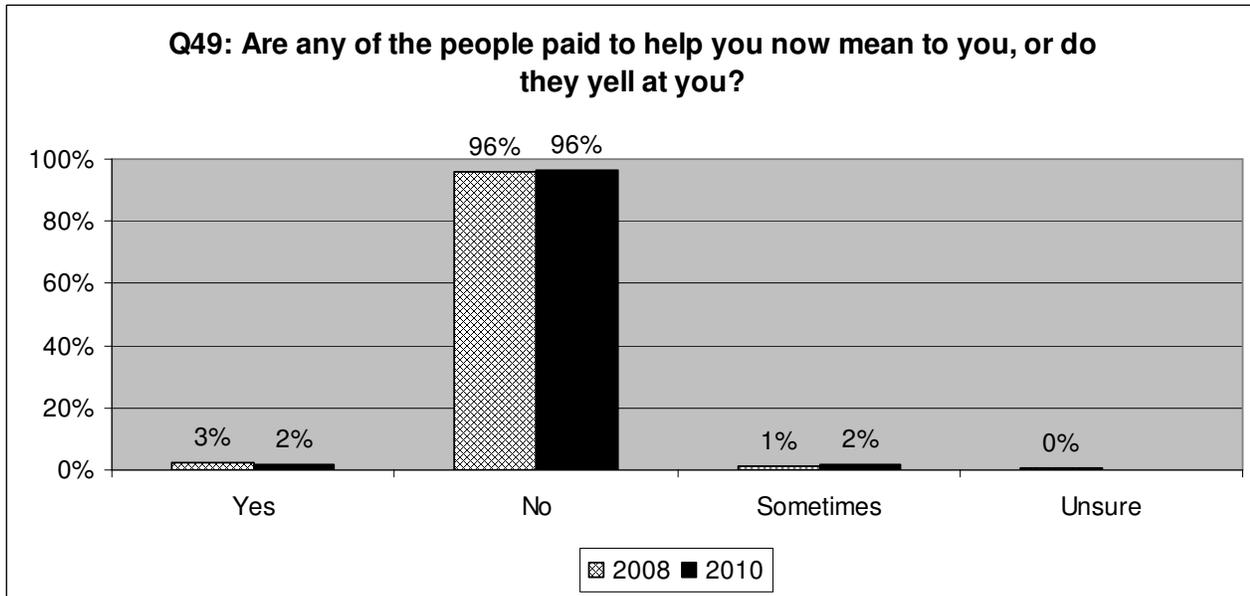
	Year	
	2008	2010
Yes	93%	88%
No	0%	0%
Sometimes	6%	9%
Unsure	1%	2%
<b>Total responses</b>	<b>268</b>	<b>313</b>



**Q47: Have you ever been injured by any of the people paid to help you now?**

	Year	
	2008	2010
Yes	1%	3%
No	99%	97%
Unsure		0%
<b>Total responses</b>	274	311

**Q. 48 What happened? When? Would you like any help with this problem?**  
 See appendix for responses to this question.

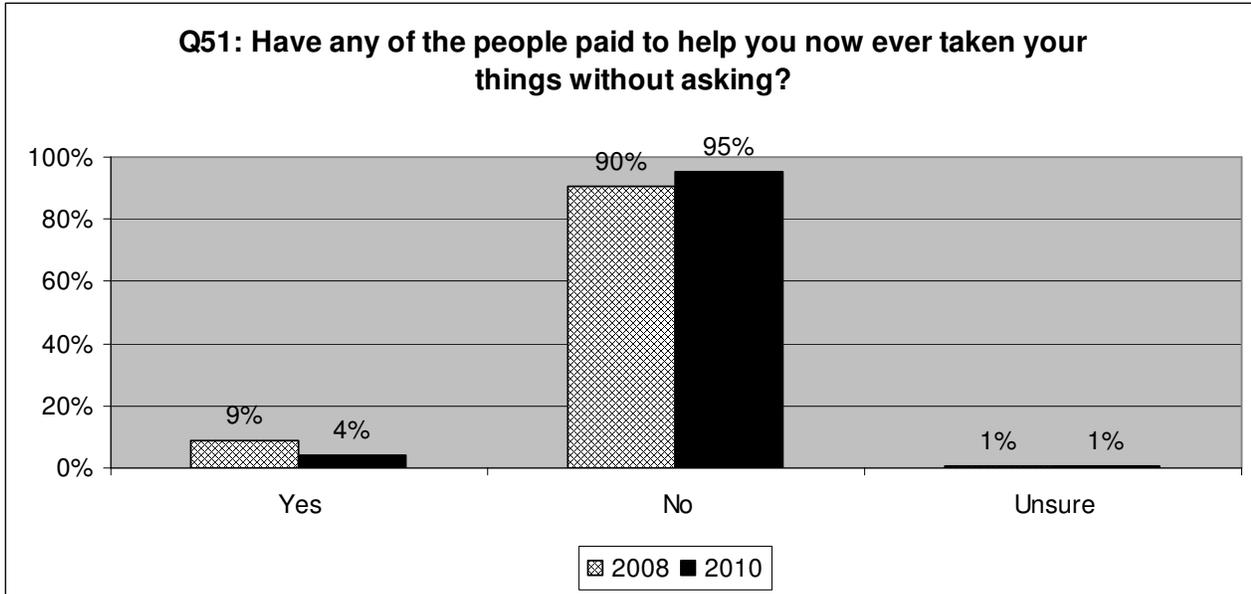


**Q49: Are any of the people paid to help you now mean to you, or do they yell at you?**

	Year	
	2008	2010
Yes	3%	2%
No	96%	96%
Sometimes	1%	2%
Unsure	0%	0%
<b>Total responses</b>	273	312

**Q. 50: What happens? Would you like any help with this problem?**

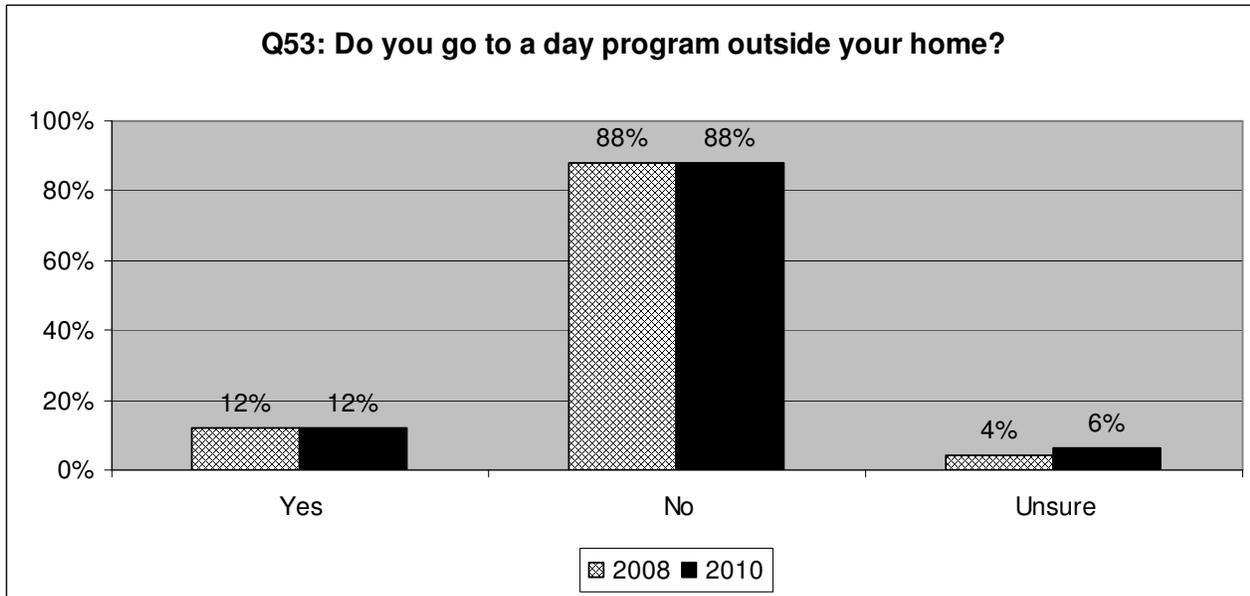
See appendix for responses to this question.



**Q51: Have any of the people paid to help you now ever taken your things without asking?**

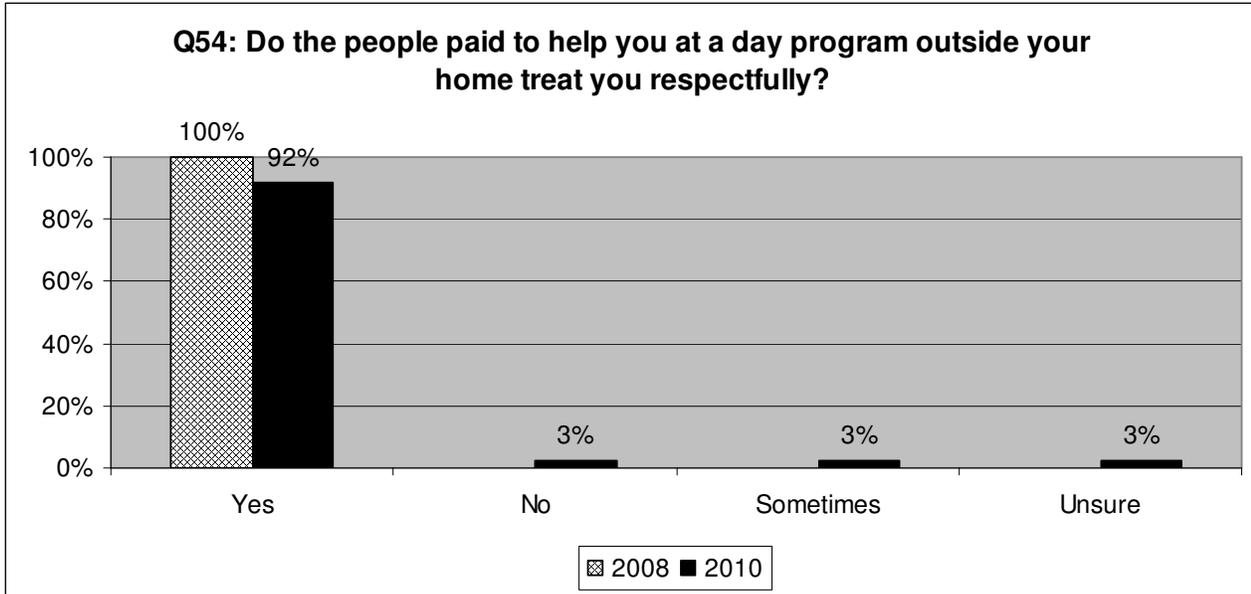
	Year	
	2008	2010
Yes	9%	4%
No	90%	95%
Unsure	1%	1%
<b>Total responses</b>	270	311

**Q. 52: What happened? When? Would you like any help with this problem?**  
 See appendix for responses to this question.



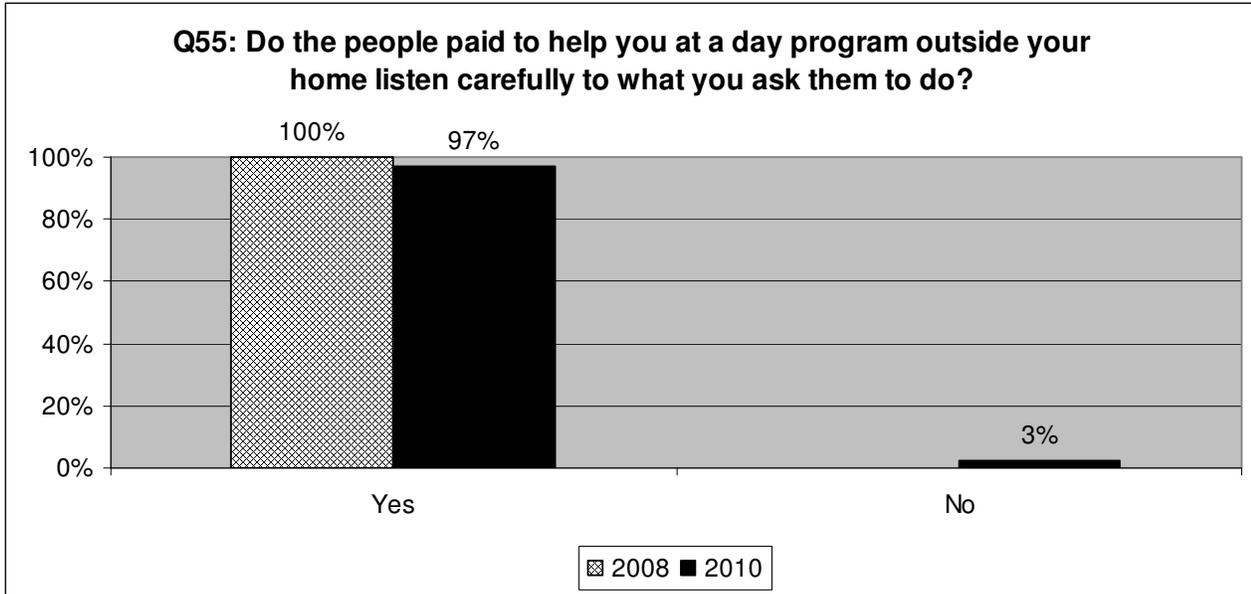
**Q53: Do you go to a day program outside your home?**

	Year	
	2008	2010
<b>Yes</b>	12%	12%
<b>No</b>	88%	88%
<b>Unsure</b>	4%	6%
<b>Total responses</b>	272	311



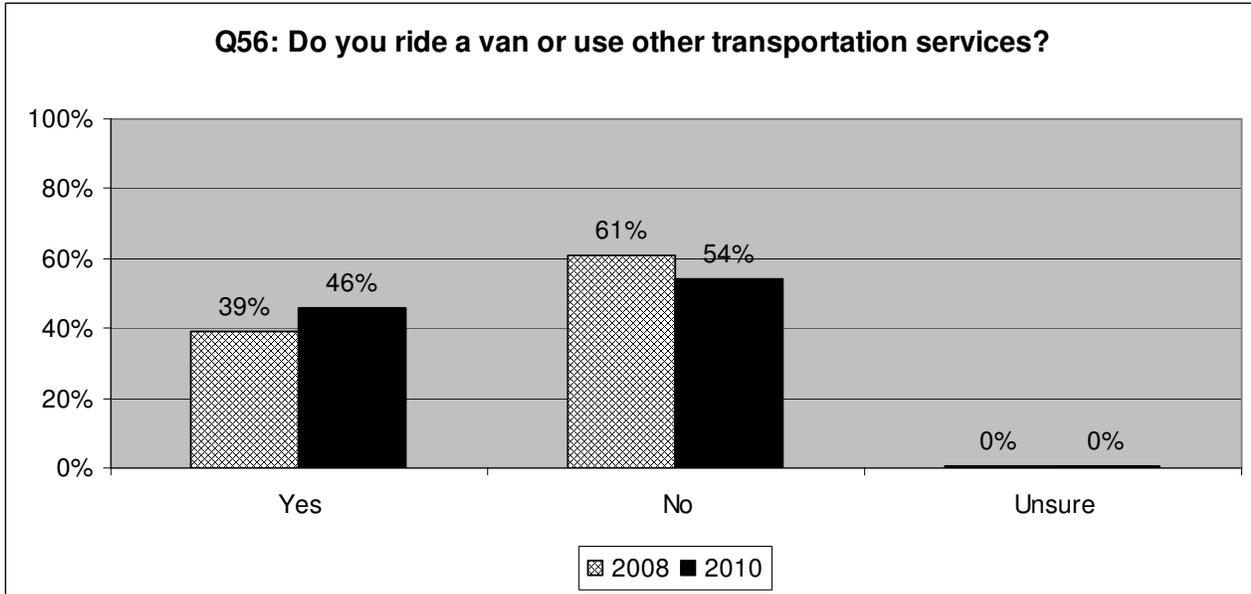
**Q54: Do the people paid to help you at a day program outside your home treat you respectfully?**

	Year	
	2008	2010
Yes	100%	92%
No		3%
Sometimes		3%
Unsure		3%
<b>Total responses</b>	32	38



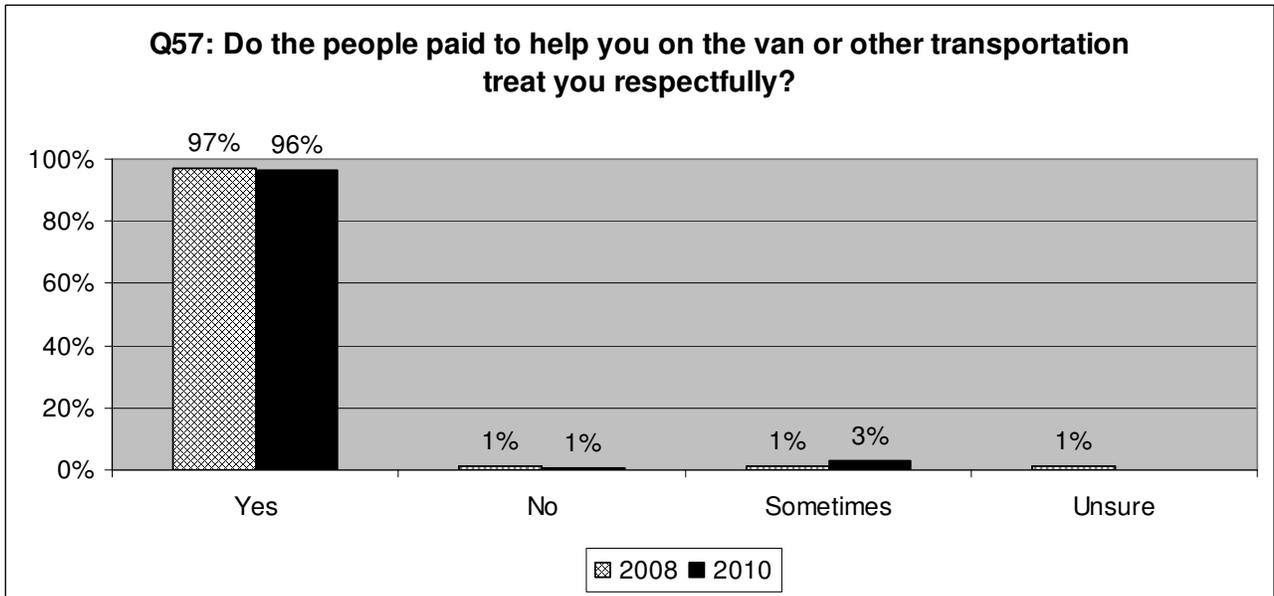
**Q55: Do the people paid to help you at a day program outside your home listen carefully to what you ask them to do?**

	Year	
	2008	2010
Yes	100%	97%
No		3%
<b>Total responses</b>	32	38



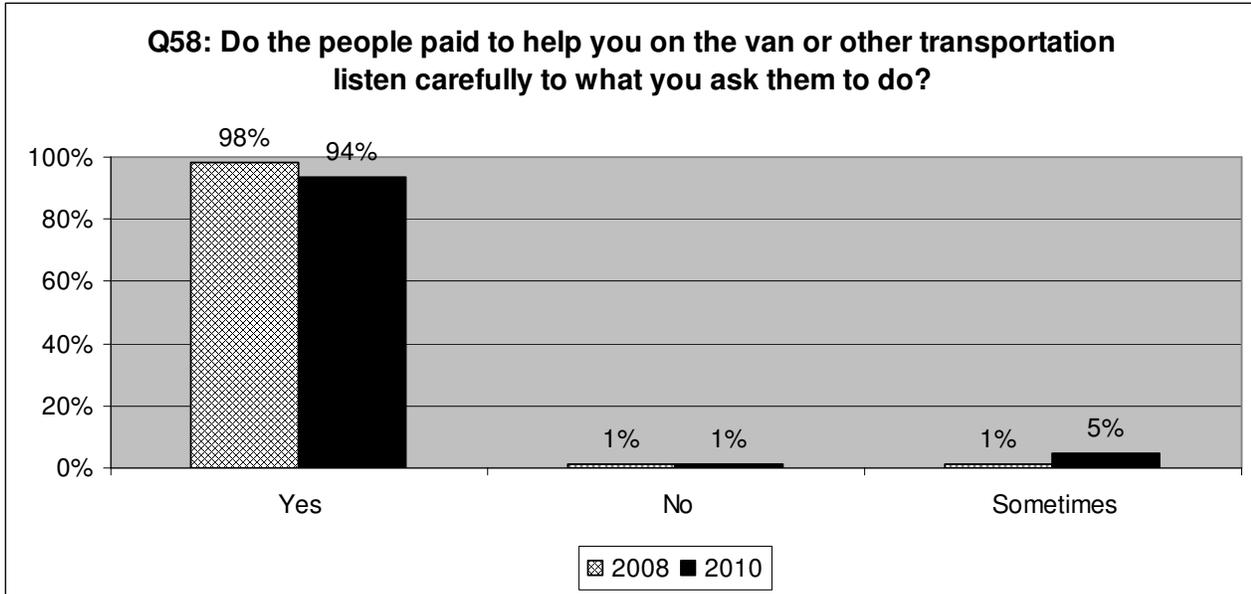
**Q56: Do you ride a van or use other transportation services?**

	Year	
	2008	2010
<b>Yes</b>	39%	46%
<b>No</b>	61%	54%
<b>Unsure</b>	0%	0%
<b>Total responses</b>	273	311



**Q57: Do the people paid to help you on the van or other transportation treat you respectfully?**

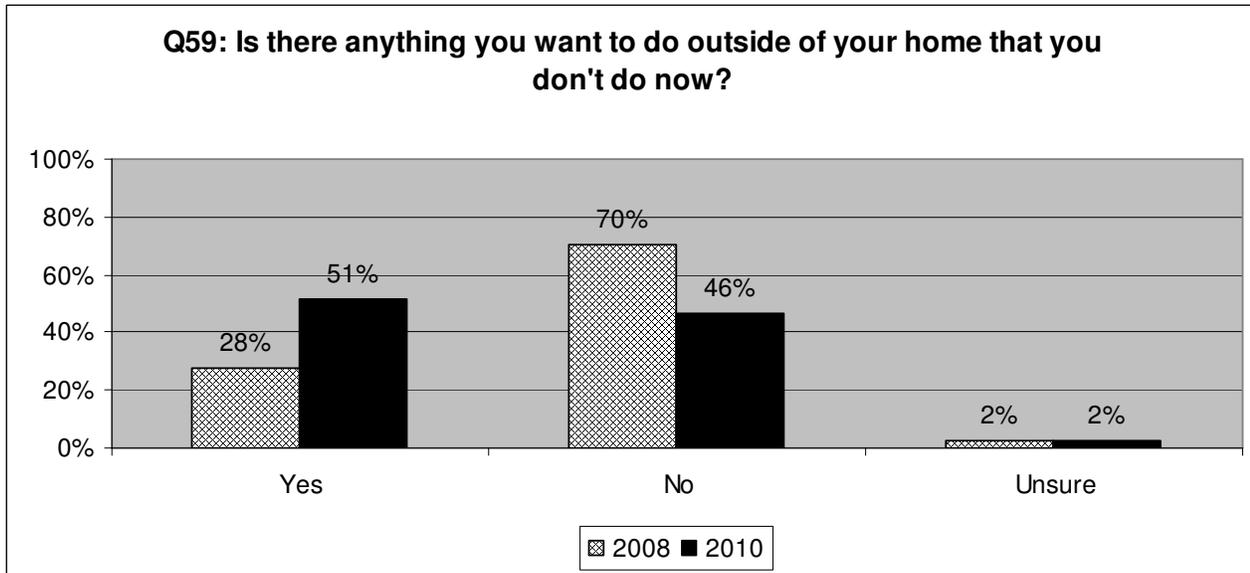
	Year	
	2008	2010
<b>Yes</b>	97%	96%
<b>No</b>	1%	1%
<b>Sometimes</b>	1%	3%
<b>Unsure</b>	1%	0%
<b>Total responses</b>	106	140



**Q58: Do the people paid to help you on the van or other transportation listen carefully to what you ask them to do?**

	Year	
	2008	2010
<b>Yes</b>	98%	94%
<b>No</b>	1%	1%
<b>Sometimes</b>	1%	5%
<b>Total responses</b>	105	142

## **COMMUNITY & INCLUSION**



**Q59: Is there anything you want to do outside of your home that you don't do now?**

	Year	
	2008	2010
<b>Yes</b>	28%	51%
<b>No</b>	70%	46%
<b>Unsure</b>	2%	2%
<b>Total responses</b>	268	313

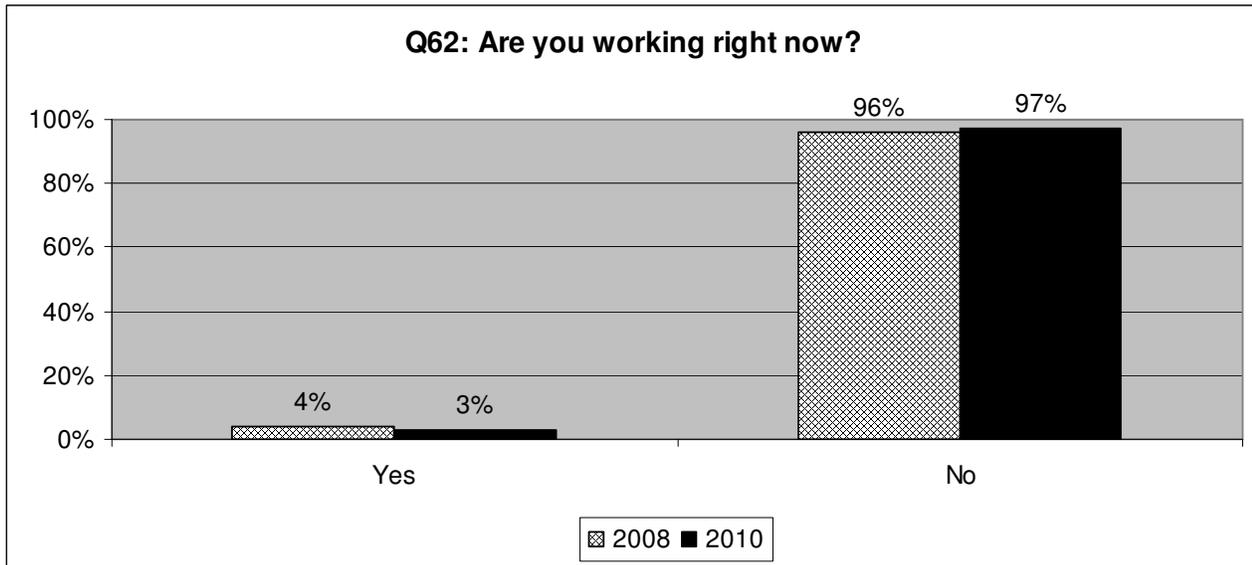
$\chi^2$  (df=2)=34.560, p=.000

**Q. 60: What would you like to do? What do you need to make this happen?**

See appendix for responses to this question.

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

See appendix for responses to this question.

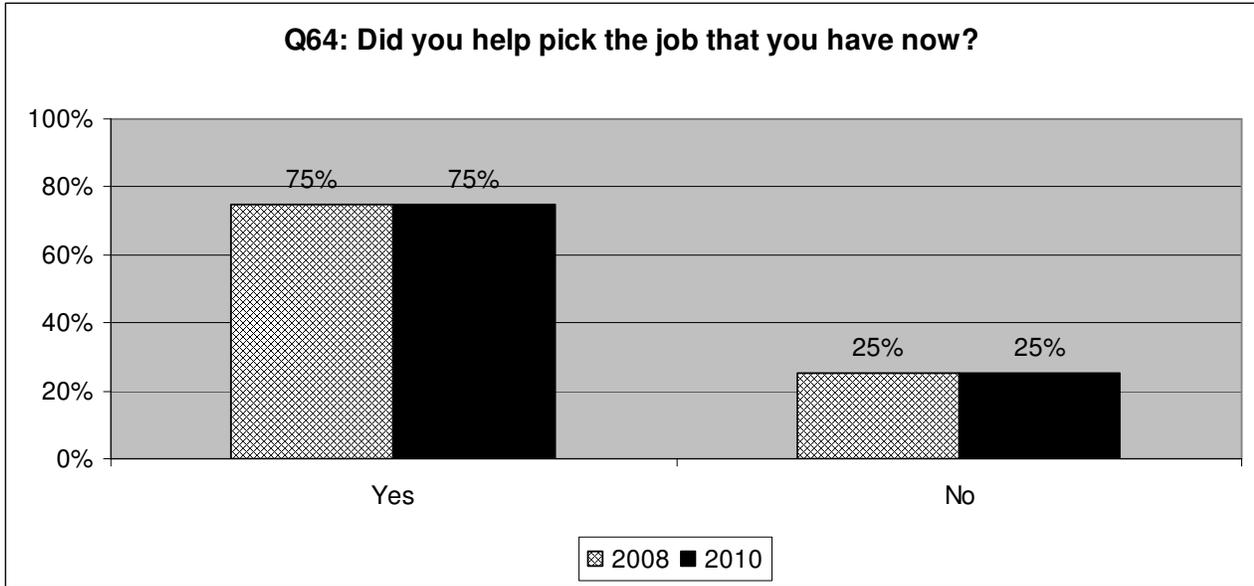


**Q62: Are you working right now?**

	Year	
	2008	2010
Yes	4%	3%
No	96%	97%
<b>Total responses</b>	96	131

**Q. 63: What kind of work do you do?**

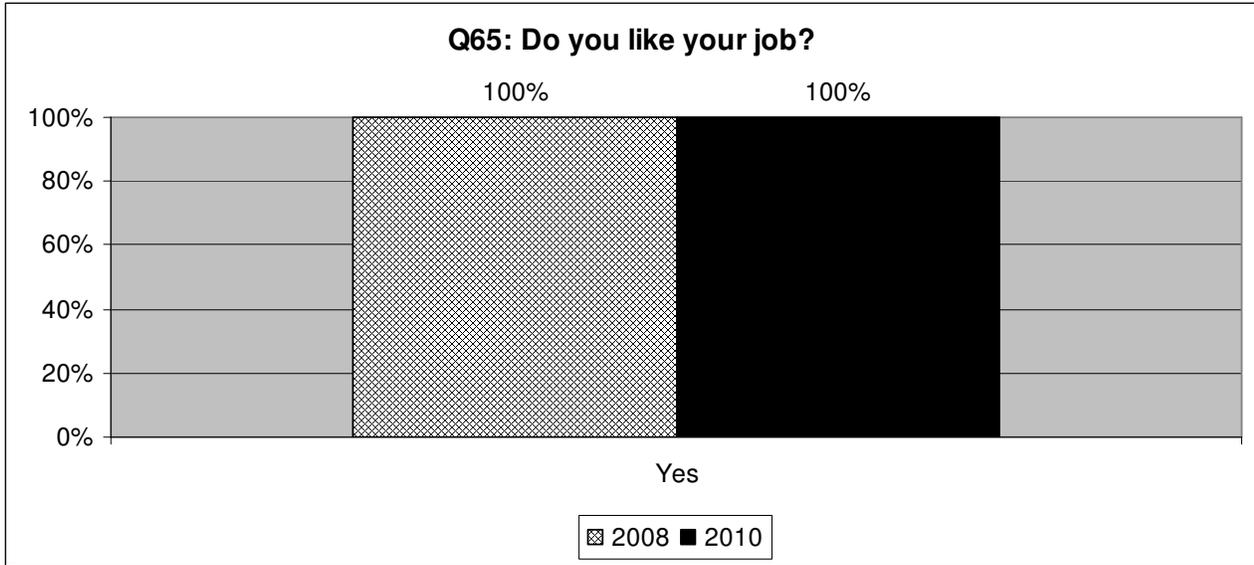
See appendix for responses to this question.



**Q64: Did you help pick the job that you have now?**

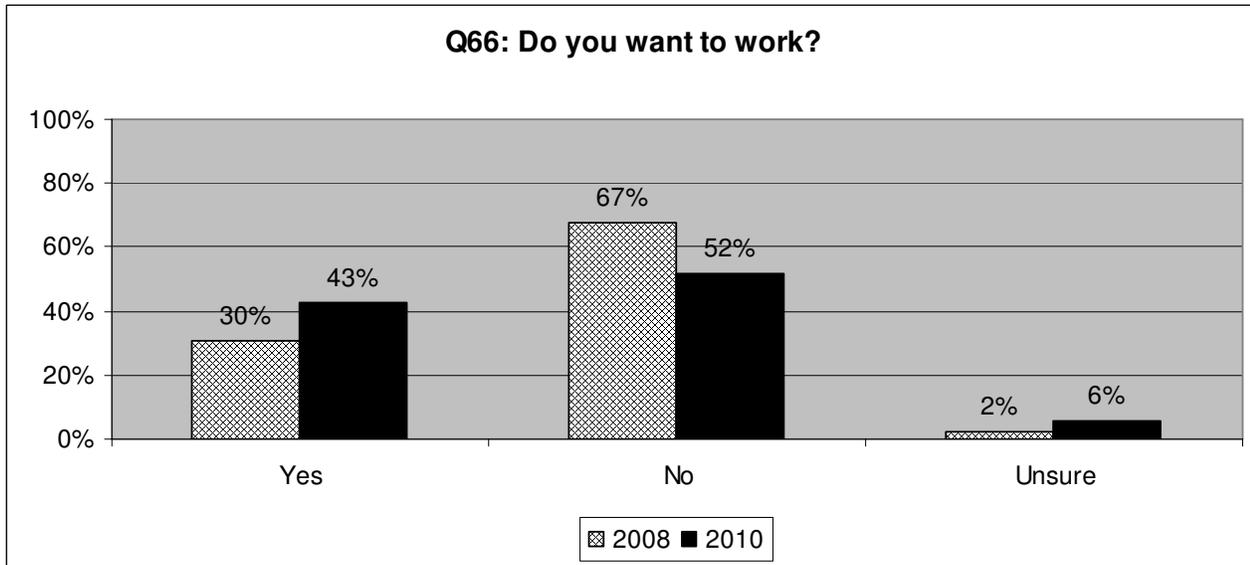
	Year	
	2008	2010
<b>Yes</b>	75%	75%
<b>No</b>	25%	25%
<b>Total responses</b>	4	4

Participant Experience Survey 2010



**Q65: Do you like your job?**

	Year	
	2008	2010
<b>Yes</b>	100%	100%
<b>Total responses</b>	4	4

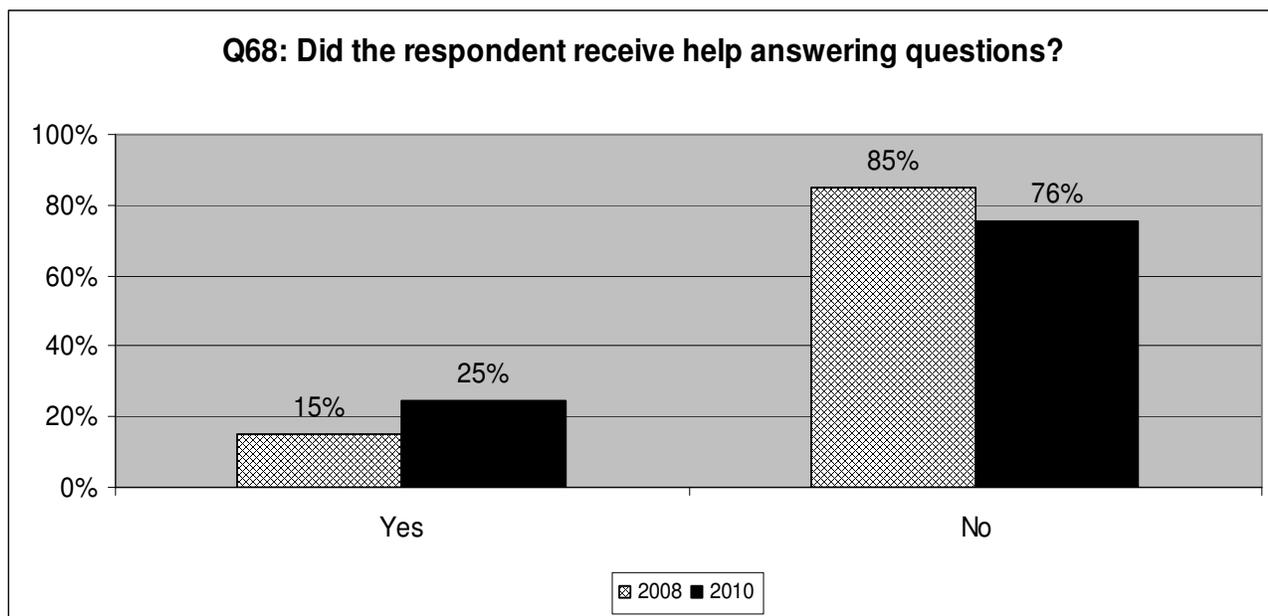


**Q66: Do you want to work?**

	Year	
	2008	2010
Yes	30%	43%
No	67%	52%
Unsure	2%	6%
<b>Total responses</b>	92	122

$\chi^2 (df=2)=5.896, p=.052$

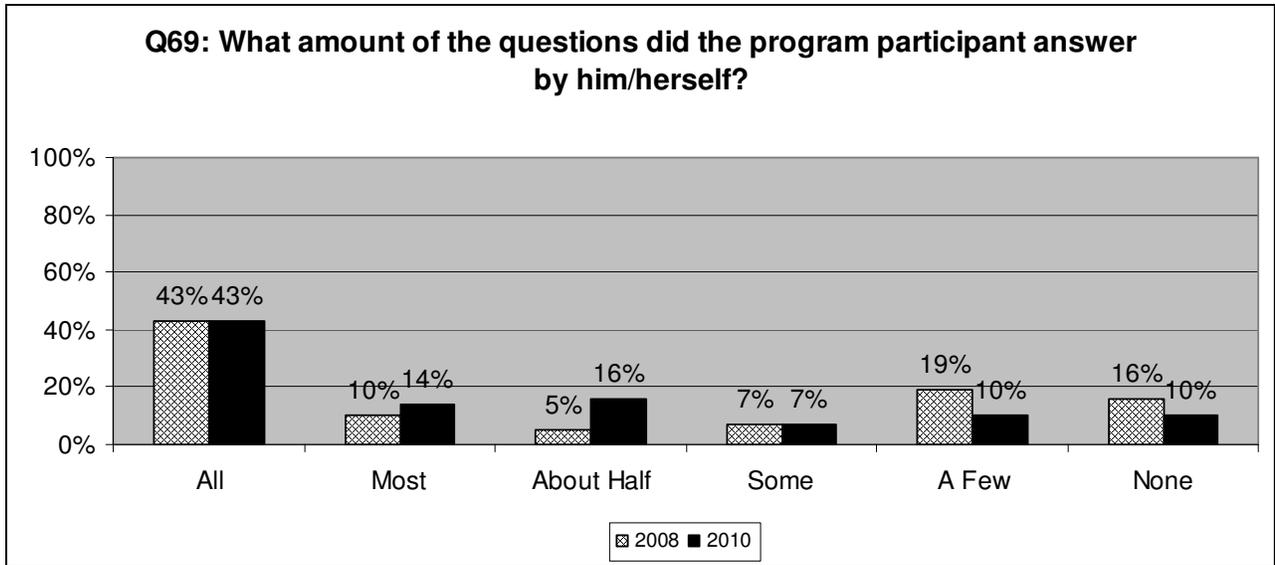
**Q. 67: There is no question #67**



**Q68: Did the respondent receive help answering questions?**

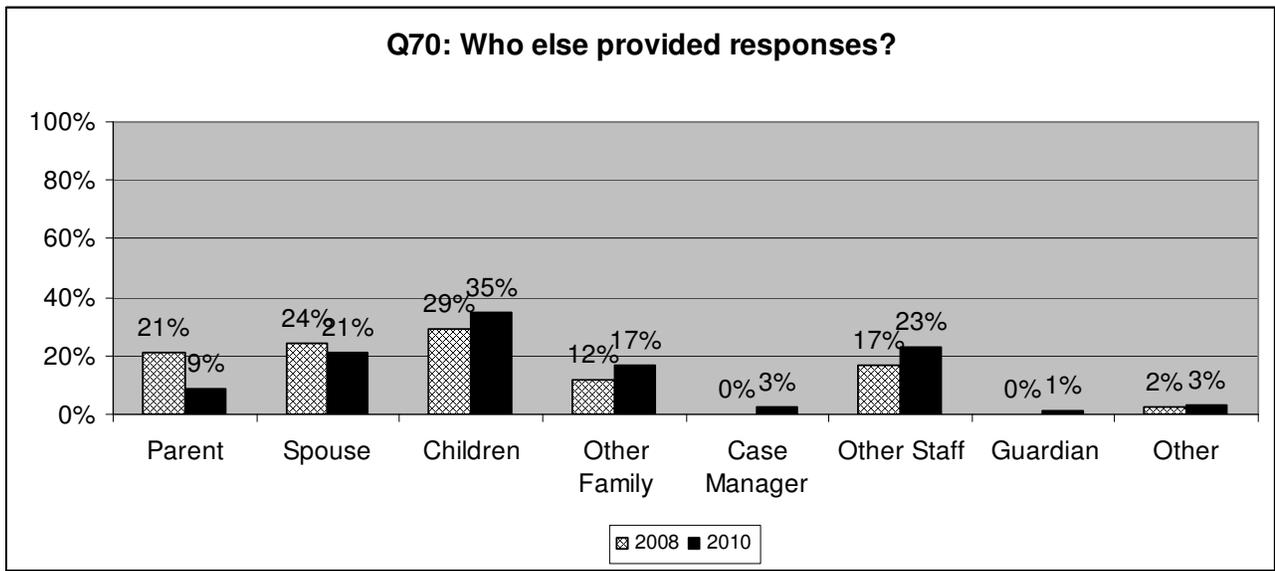
	Year	
	2008	2010
<b>Yes</b>	15%	25%
<b>No</b>	85%	76%
<b>Total</b>	276	310

$\chi^2(df=1)=7.850, p=.005$



**Q69: What amount of the questions did the program participant answer by him/herself?**

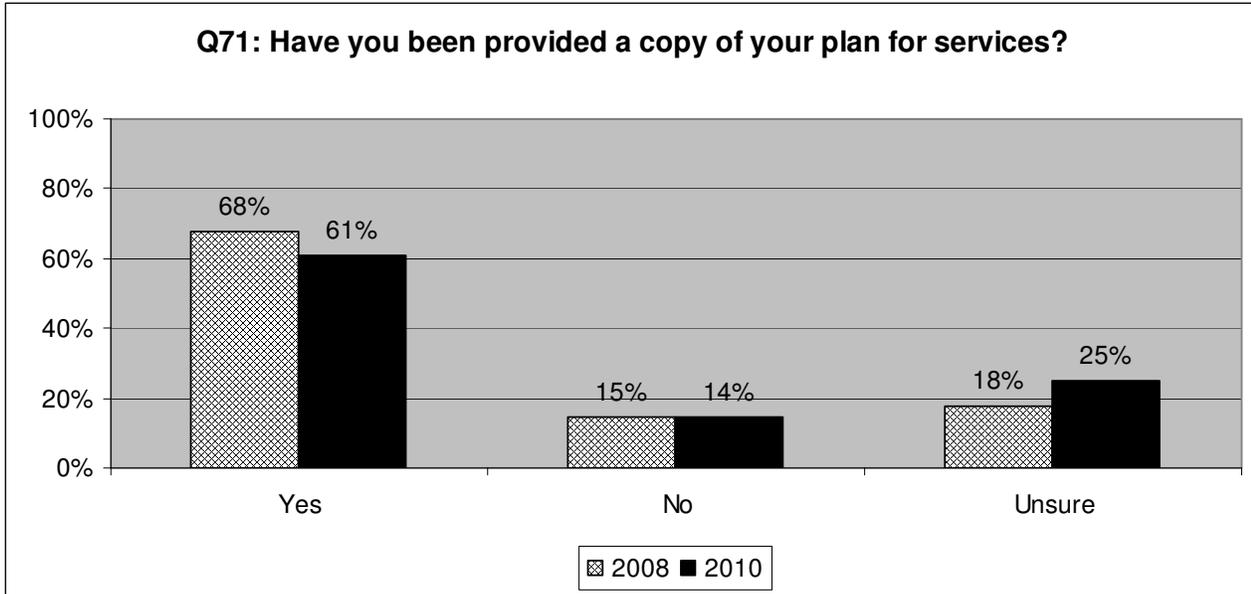
	Year	
	2008	2010
All	43%	43%
Most	10%	14%
About Half	5%	16%
Some	7%	7%
A Few	19%	10%
None	16%	10%
<b>Total responses</b>	42	77



**Q70: Who else provided responses? (If applicable)**

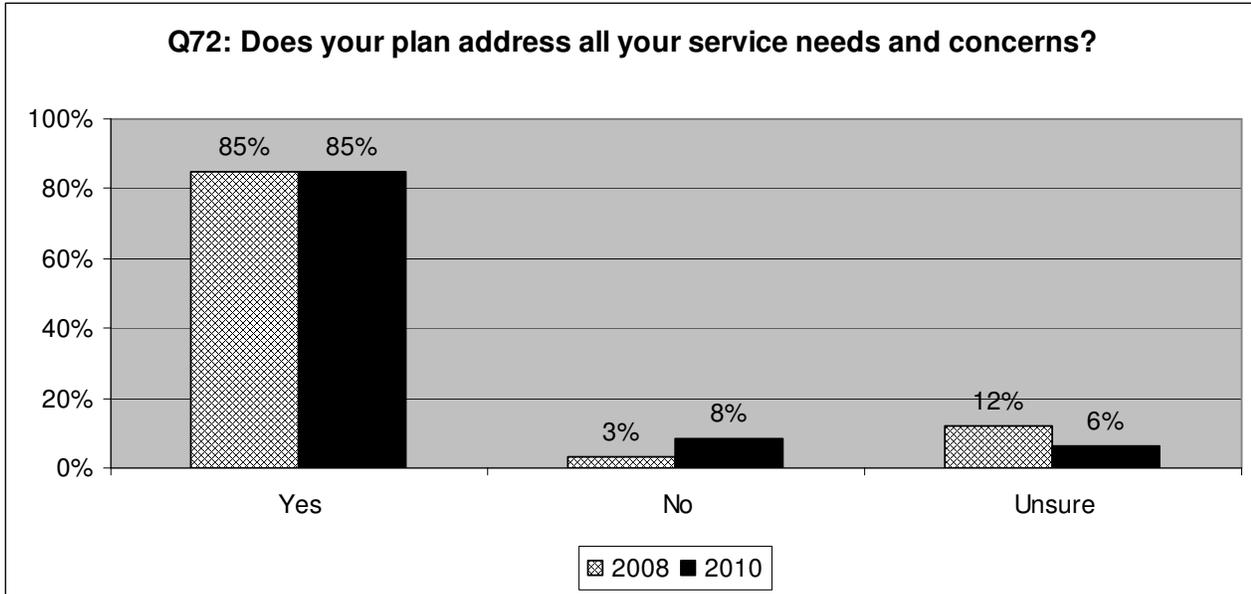
	Year		Total
	2008	2010	
<b>Parent</b>	21%	9%	16
<b>Spouse</b>	24%	21%	26
<b>Children</b>	29%	35%	38
<b>Other Family</b>	12%	17%	18
<b>Case Manager</b>	0%	3%	2
<b>Other Staff</b>	17%	23%	24
<b>Guardian</b>	0%	1%	1
<b>Other</b>	2%	3%	3
<b>Total</b>	42	75	117

## **PLAN FOR SERVICES**



**Q71: Have you been provided a copy of your plan for services?**

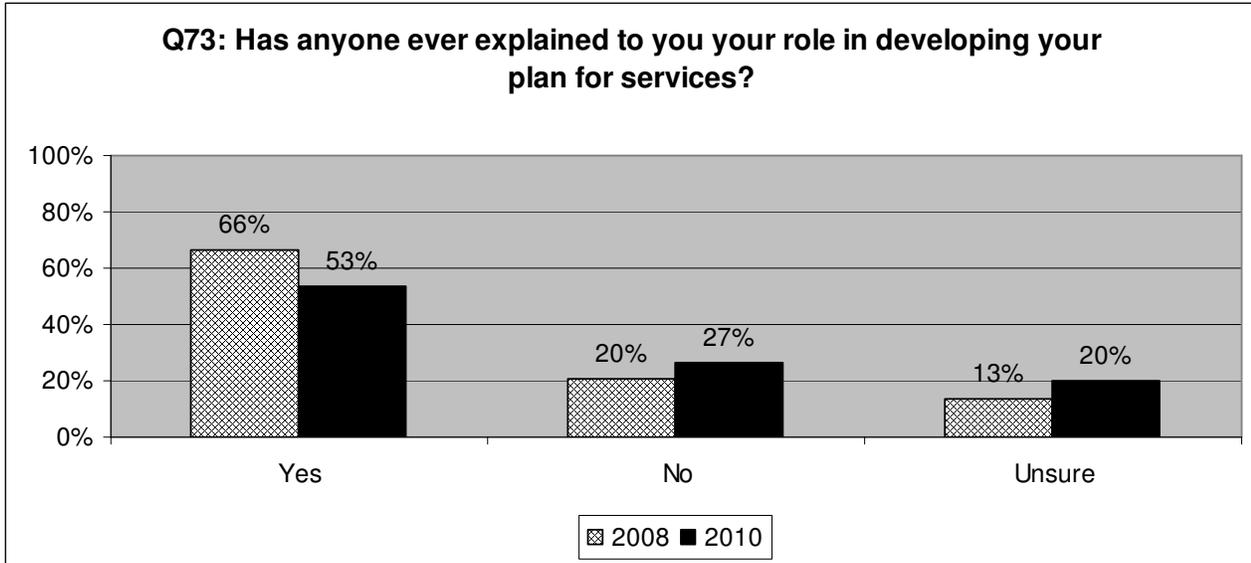
	Year	
	2008	2010
Yes	68%	61%
No	15%	14%
Unsure	18%	25%
<b>Total responses</b>	277	311



**Q72: Does your plan address all your service needs and concerns?**

	Year	
	2008	2010
<b>Yes</b>	85%	85%
<b>No</b>	3%	8%
<b>Unsure</b>	12%	6%
<b>Total responses</b>	270	307

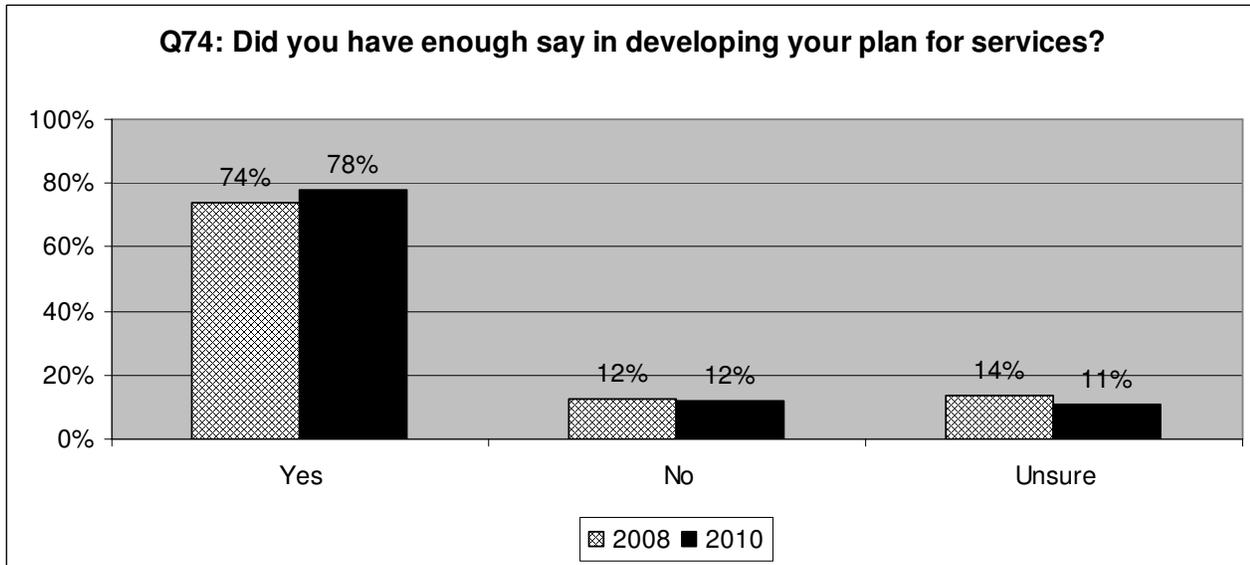
$\chi^2 (df=2)=11.301, p=.004$



**Q73: Has anyone ever explained to you your role in developing your plan for services?**

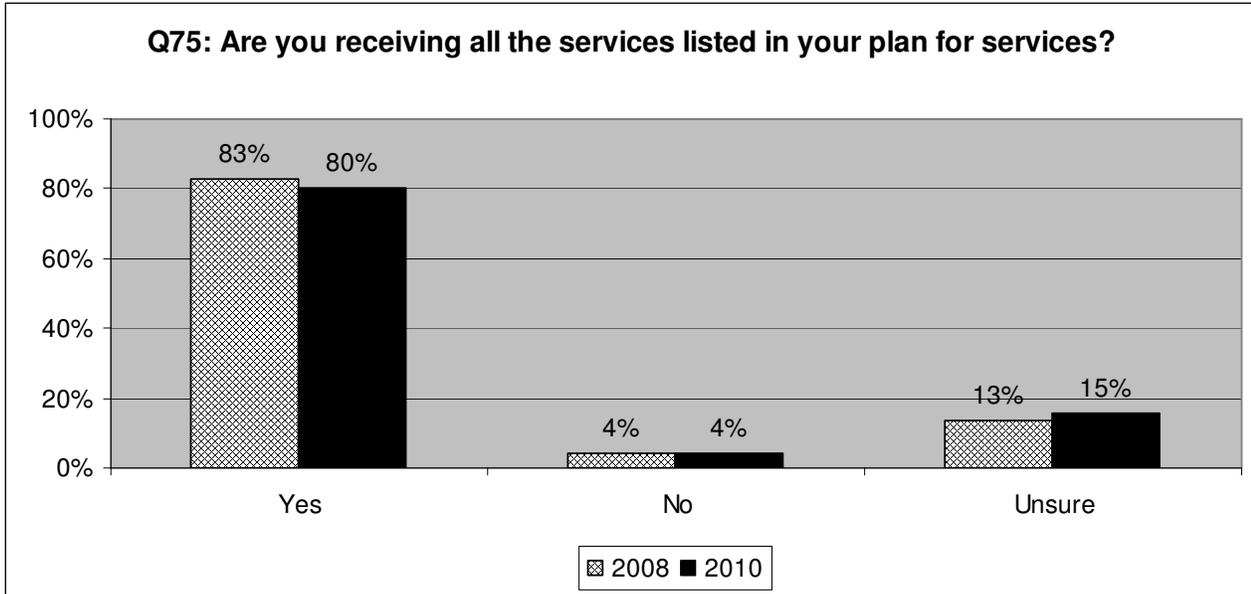
	Year	
	2008	2010
<b>Yes</b>	66%	53%
<b>No</b>	20%	27%
<b>Unsure</b>	13%	20%
<b>Total responses</b>	270	307

$\chi^2 (df=2)=10.089, p=.006$



**Q74: Did you have enough say in developing your plan for services?**

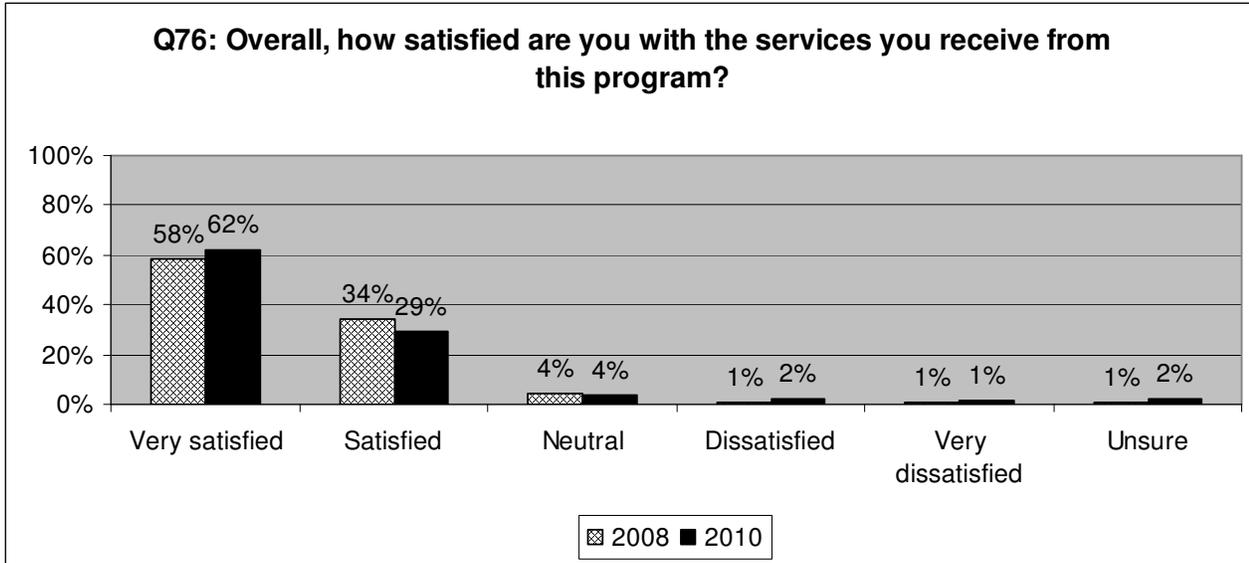
	Year	
	2008	2010
Yes	74%	78%
No	12%	12%
Unsure	14%	11%
<b>Total responses</b>	274	308



**Q75: Are you receiving all the services listed in your plan for services?**

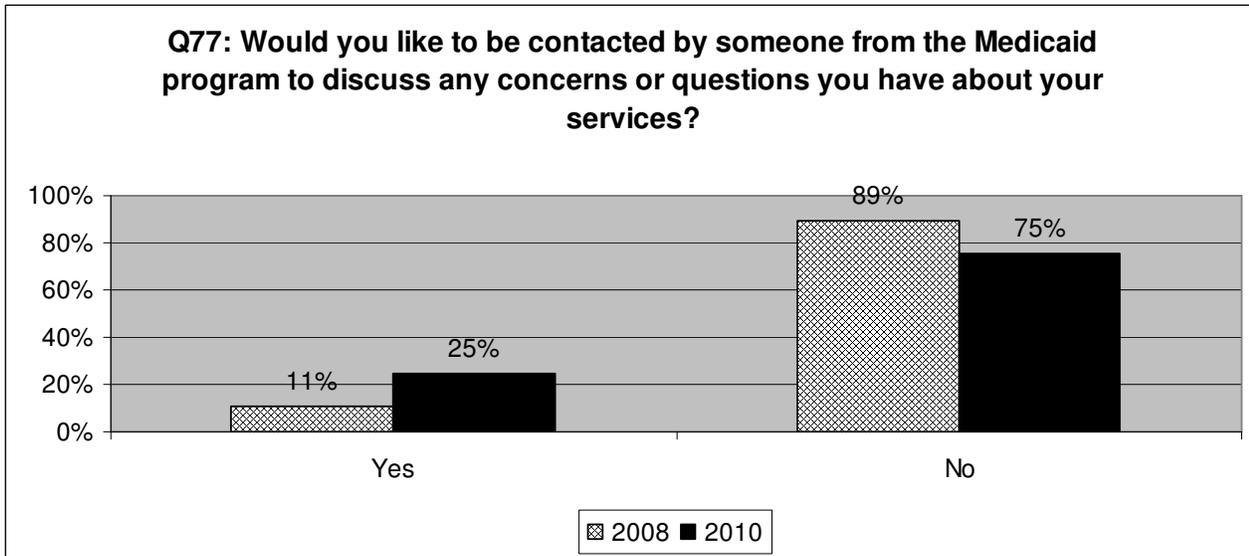
	Year	
	2008	2010
Yes	83%	80%
No	4%	4%
Unsure	13%	15%
<b>Total responses</b>	276	310

Participant Experience Survey 2010



**Q76: Overall, how satisfied are you with the services you receive from this program?**

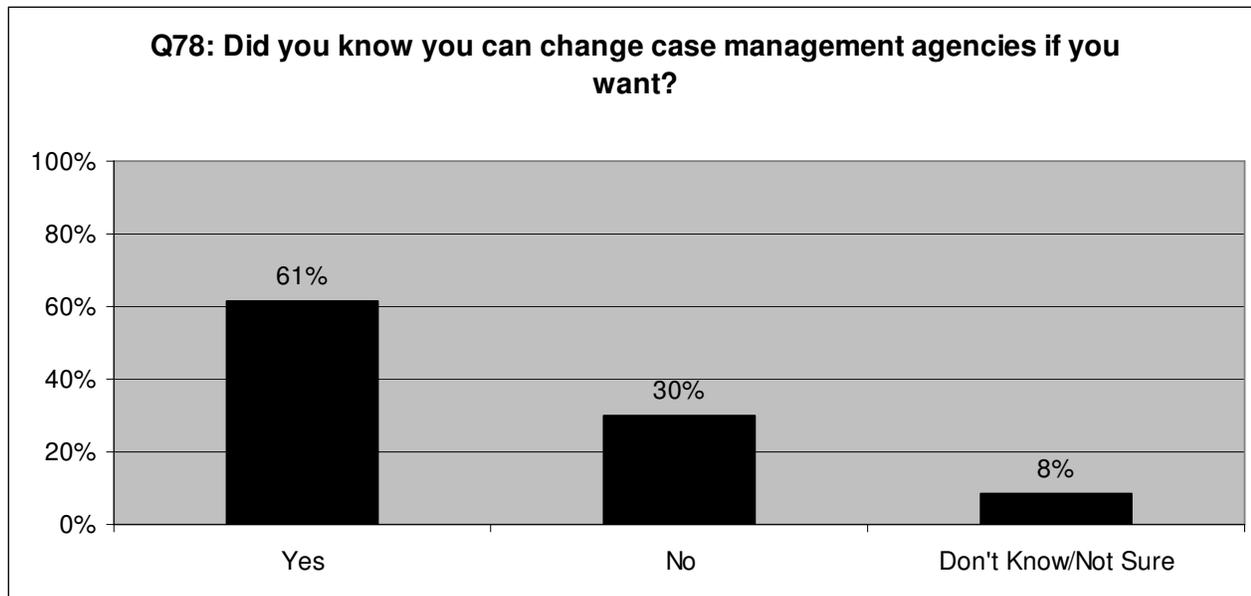
	Year	
	2008	2010
Very satisfied	58%	62%
Satisfied	34%	29%
Neutral	4%	4%
Dissatisfied	1%	2%
Very dissatisfied	1%	1%
Unsure	1%	2%
<b>Total responses</b>	<b>277</b>	<b>314</b>



**Q77: Would you like to be contacted by someone from the Medicaid program to discuss any concerns or questions you have about your services?**

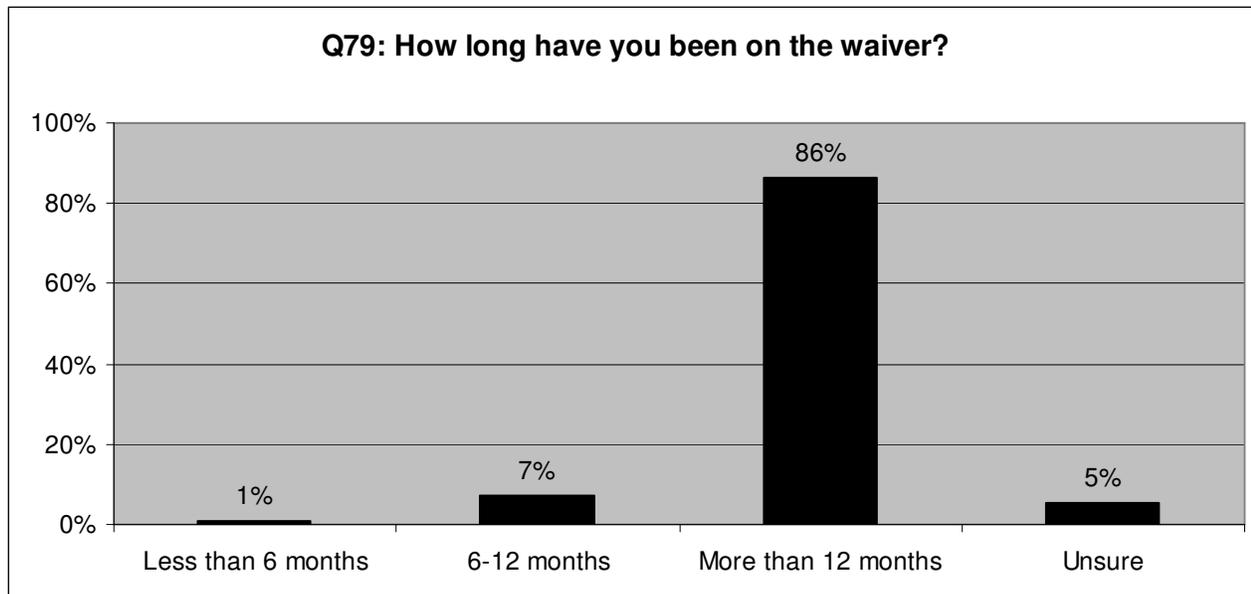
	Year	
	2008	2010
Yes	11%	25%
No	89%	75%
<b>Total responses</b>	267	310

## **2010 QUESTIONS**



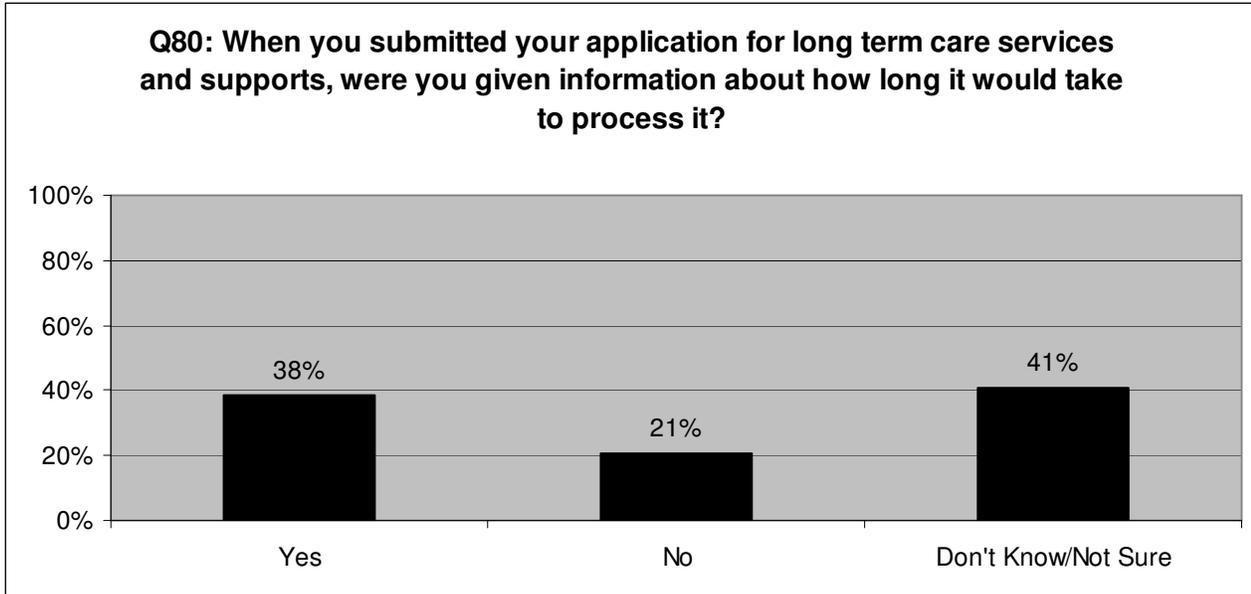
**Q78: Did you know you can change case management agencies if you want?**

	Year	Total
	2010	
Yes	61%	190
No	30%	93
Don't Know/Not Sure	8%	26
<b>Total responses</b>		<b>309</b>



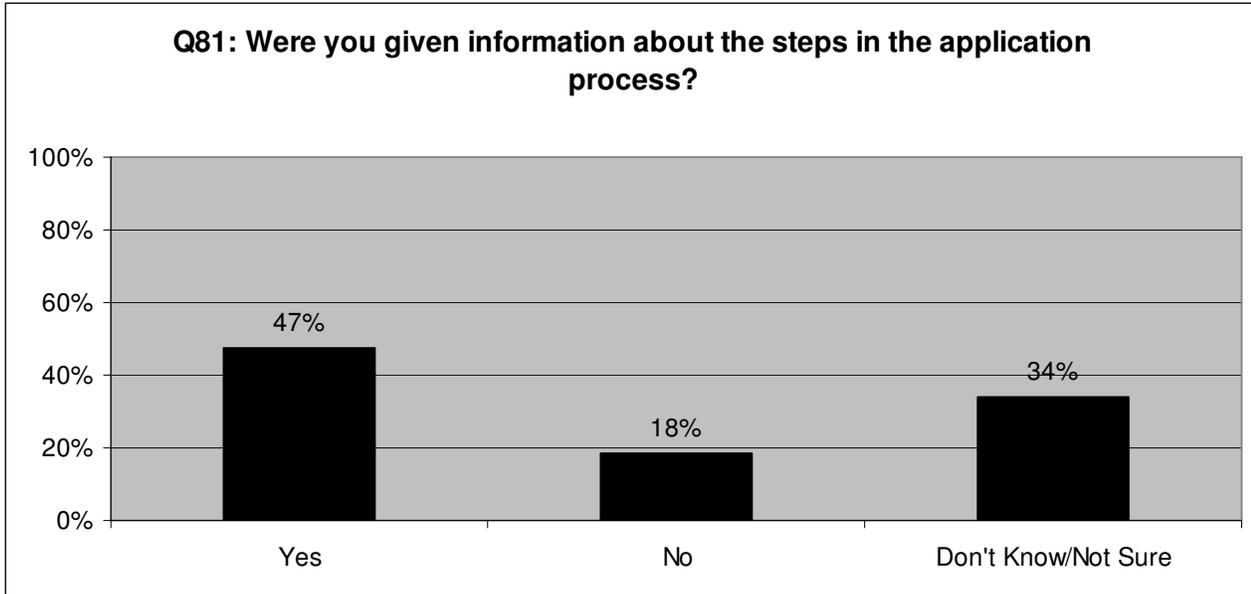
**Q79: How long have you been on the waiver?**

	Year	Total
	<b>2010</b>	
<b>Less than 6 months</b>	1%	3
<b>6-12 months</b>	7%	23
<b>More than 12 months</b>	86%	273
<b>Unsure</b>	5%	17
<b>Total responses</b>		316



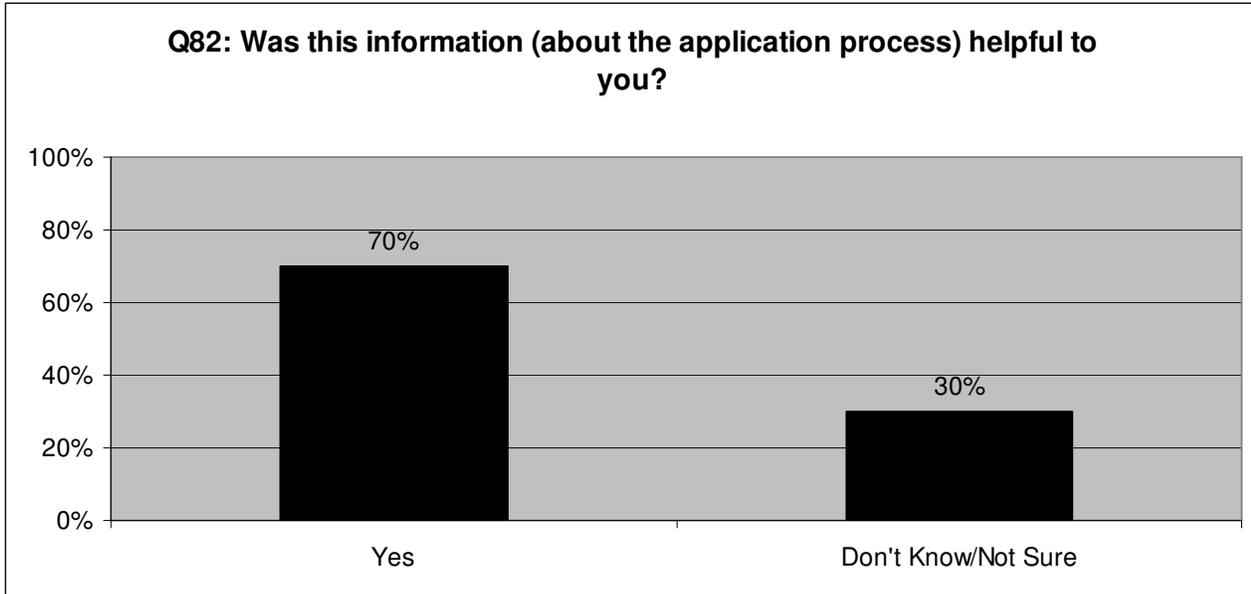
**Q80: When you submitted your application for long term care services and supports, were you given information about how long it would take to process it?**

	Year	Total
	2010	
Yes	38%	18
No	21%	7
Don't Know/Not Sure	41%	13
<b>Total responses</b>		<b>38</b>



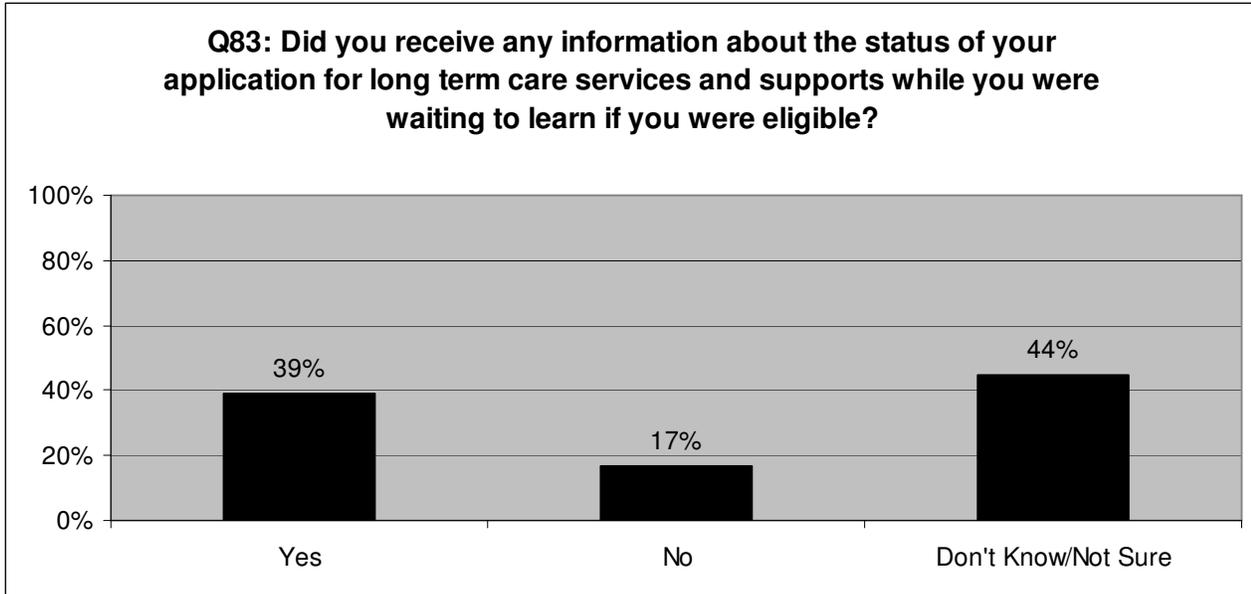
**Q81. Where you given information about the steps in the application process?**

	Year	Total
	2010	
Yes	47%	18
No	18%	7
Don't Know/Not Sure	34%	13
<b>Total responses</b>		<b>38</b>



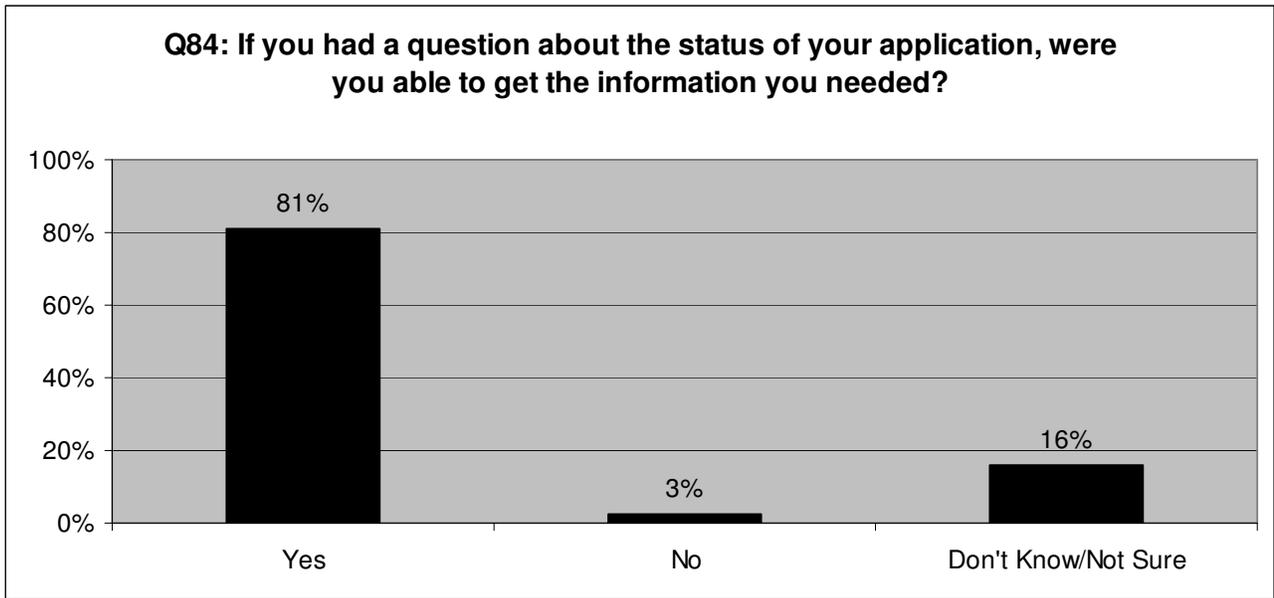
**Q82: Was information (about the application process) helpful to you?**

	Year	Total
	<b>2010</b>	
<b>Yes</b>	70%	21
<b>Don't Know/Not Sure</b>	30%	9
<b>Total responses</b>		30



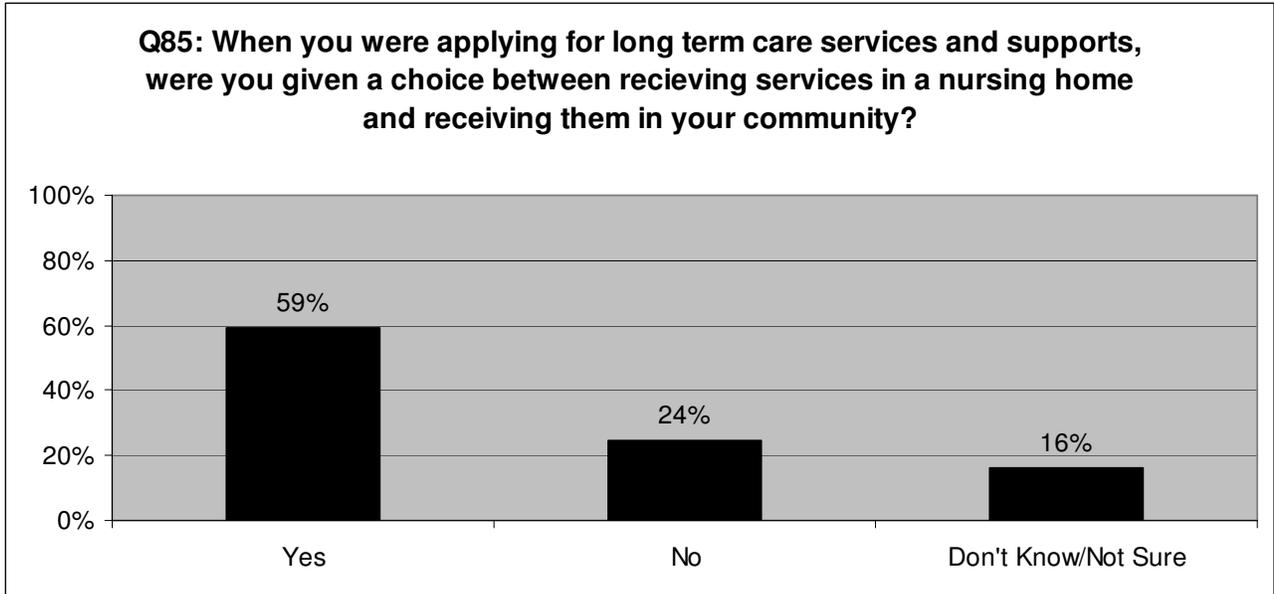
**Q83: Did you receive any information about the status of your application for long term care services and supports while you were waiting to learn if you were eligible?**

	Year	Total
	2010	
<b>Yes</b>	39%	14
<b>No</b>	17%	6
<b>Don't Know/Not Sure</b>	44%	16
<b>Total responses</b>		36



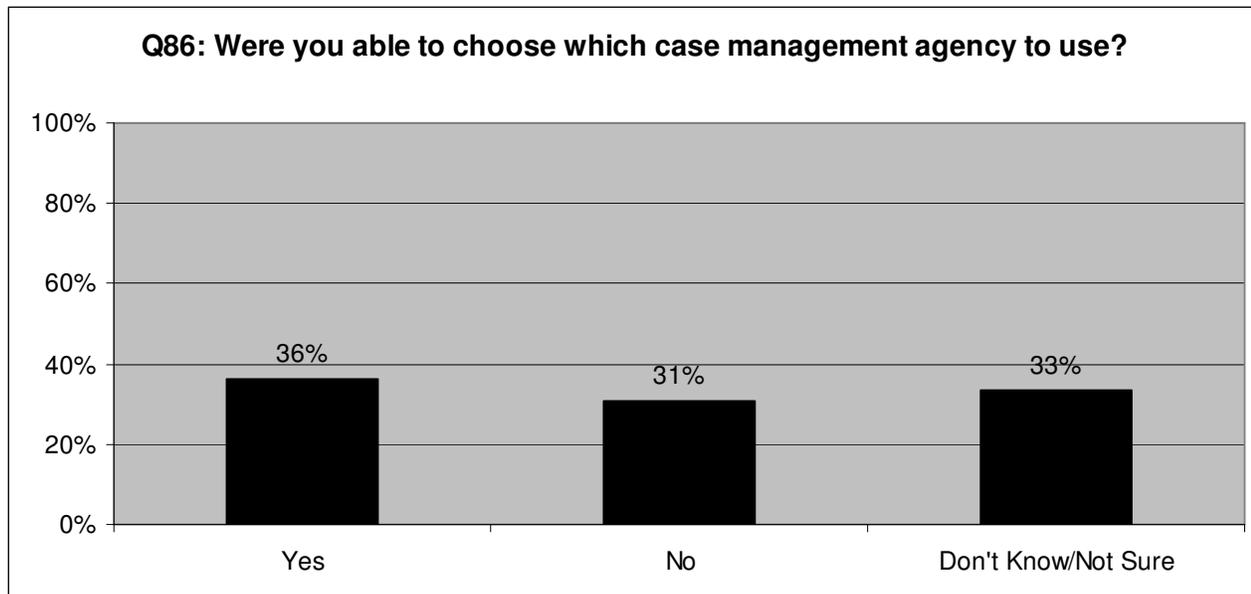
**Q84: If you had a question about the status of your application, were you able to get the information you needed?**

	Year	Total
	<b>2010</b>	
Yes	81%	30
No	3%	1
Don't Know/Not Sure	16%	6
<b>Total responses</b>		<b>37</b>



**Q85: When you were applying for long term care services and supports, were you given a choice between receiving services in a nursing home and receiving them in your community?**

	Year	Total
	2010	
Yes	59%	22
No	24%	9
Don't Know/Not Sure	16%	6
<b>Total responses</b>		<b>37</b>



<b>Q86: Were you able to choose which case management agency to use?</b>		
	<b>Year</b>	<b>Total</b>
	<b>2010</b>	
<b>Yes</b>	36%	13
<b>No</b>	31%	11
<b>Don't Know/Not Sure</b>	33%	12
<b>Total responses</b>		36

## **Appendix II: 2010 Demographic Tables**

## Participant Experience Survey 2010

### Q1: Is there any special help that you need to take a bath or shower?

	Needs Help	Does Not Need Help	Number Responding
<b>Surveyed Adults</b>	<b>73%</b>	<b>27%</b>	<b>311</b>
<b>Age*</b>			
55 or younger	84%	16%	58
55 to 64	68%	32%	75
65 to 74	79%	21%	72
75 to 84	62%	38%	60
85 or older	74%	26%	46
<b>Gender**</b>			
Male	63%	38%	96
Female	78%	22%	215
<b>Region/County*</b>			
Carroll & Coos	80%	20%	51
Cheshire, Sullivan & Grafton	71%	29%	34
Belknap & Merrimack	72%	28%	29
Hillsborough	84%	16%	91
Rockingham & Strafford	63%	37%	102
<b>Help w/ Questions*</b>			
Yes	84%	16%	73
No	70%	30%	232

## Participant Experience Survey 2010

### Q2: Do you ever go without a bath or shower when you need one?

	Yes	No	Number Responding
<b>Surveyed Adults</b>	<b>23%</b>	<b>77%</b>	<b>225</b>
<b>Age</b>			
55 or younger	27%	73%	49
55 to 64	35%	65%	52
65 to 74	16%	84%	55
75 to 84	11%	89%	37
85 or older	22%	78%	32
<b>Gender</b>			
Male	24%	76%	59
Female	22%	78%	166
<b>Region/County</b>			
Carroll & Coos	18%	82%	38
Cheshire, Sullivan & Grafton	17%	83%	23
Belknap & Merrimack	29%	71%	21
Hillsborough	23%	77%	77
Rockingham & Strafford	25%	75%	64
<b>Help w/ Questions</b>			
Yes	18%	82%	60
No	24%	76%	160

## Participant Experience Survey 2010

### Q3: Is this because there is no one there to help you?

	Yes	No	Number Responding
<b>Surveyed Adults</b>	<b>80%</b>	<b>20%</b>	<b>51</b>
<b>Age</b>			
55 or younger	92%	8%	13
55 to 64	89%	11%	18
65 to 74	100%	0%	9
75 to 84	50%	50%	4
85 or older	29%	71%	7
<b>Gender</b>			
Male	79%	21%	14
Female	81%	19%	37
<b>Region/County</b>			
Carroll & Coos	57%	43%	7
Cheshire, Sullivan & Grafton	75%	25%	4
Belknap & Merrimack	83%	17%	6
Hillsborough	83%	17%	18
Rockingham & Strafford	88%	13%	16
<b>Help w/ Questions</b>			
Yes	64%	36%	11
No	87%	13%	38

## Participant Experience Survey 2010

### Q4: Is there any special help that you need to get dressed?

	Needs Help	Does Not Need Help	Number Responding
<b>Surveyed Adults</b>	<b>48%</b>	<b>52%</b>	<b>315</b>
<b>Age***</b>			
55 or younger	73%	27%	59
55 to 64	55%	45%	76
65 to 74	51%	49%	72
75 to 84	21%	79%	61
85 or older	36%	64%	47
<b>Gender</b>			
Male	41%	59%	97
Female	51%	49%	218
<b>Region/County</b>			
Carroll & Coos	40%	60%	52
Cheshire, Sullivan & Grafton	38%	62%	34
Belknap & Merrimack	55%	45%	29
Hillsborough	51%	49%	92
Rockingham & Strafford	51%	49%	104
<b>Help w/ Questions</b>			
Yes	51%	49%	76
No	47%	53%	233

## Participant Experience Survey 2010

### Q5: Do you ever go without getting dressed when you need to?

	Yes	No	Number Responding
<b>Surveyed Adults</b>	<b>19%</b>	<b>81%</b>	<b>150</b>
<b>Age</b>			
55 or younger	16%	84%	43
55 to 64	26%	74%	42
65 to 74	20%	80%	35
75 to 84	23%	77%	13
85 or older	0%	100%	17
<b>Gender</b>			
Male	10%	90%	40
Female	22%	78%	110
<b>Region/County</b>			
Carroll & Coos	10%	90%	21
Cheshire, Sullivan & Grafton	8%	92%	13
Belknap & Merrimack	19%	81%	16
Hillsborough	27%	73%	45
Rockingham & Strafford	19%	81%	53
<b>Help w/ Questions*</b>			
Yes	8%	92%	39
No	23%	77%	108

## Participant Experience Survey 2010

### Q6: Is this because there is no one there to help you?

	Yes	No	Number Responding
<b>Surveyed Adults</b>	<b>86%</b>	<b>14%</b>	<b>28</b>
<b>Age</b>			
55 or younger	86%	14%	7
55 to 64	82%	18%	11
65 to 74	100%	0%	7
75 to 84	67%	33%	3
<b>Gender</b>			
Male	100%	0%	4
Female	83%	17%	24
<b>Region/County</b>			
Carroll & Coos	100%	0%	2
Cheshire, Sullivan & Grafton	100%	0%	1
Belknap & Merrimack	100%	0%	3
Hillsborough	83%	17%	12
Rockingham & Strafford	80%	20%	10
<b>Help w/ Questions</b>			
Yes	100%	0%	3
No	84%	16%	25

## Participant Experience Survey 2010

### Q7: Is there any special help that you need to get out of bed?

	Needs Help	Does Not Need Help	Number Responding
<b>Surveyed Adults</b>	<b>23%</b>	<b>77%</b>	<b>313</b>
<b>Age***</b>			
55 or younger	46%	54%	57
55 to 64	29%	71%	76
65 to 74	17%	83%	72
75 to 84	8%	92%	61
85 or older	17%	83%	47
<b>Gender</b>			
Male	27%	73%	95
Female	22%	78%	218
<b>Region/County</b>			
Carroll & Coos	25%	75%	51
Cheshire, Sullivan & Grafton	26%	74%	34
Belknap & Merrimack	24%	76%	29
Hillsborough	23%	77%	93
Rockingham & Strafford	21%	79%	102
<b>Help w/ Questions**</b>			
Yes	34%	66%	76
No	19%	81%	231

## Participant Experience Survey 2010

### Q8: Do you ever go without getting out of bed when you need to?

	Yes	No	Number Responding
<b>Surveyed Adults</b>	<b>15%</b>	<b>85%</b>	<b>73</b>
<b>Age</b>			
55 or younger	15%	85%	26
55 to 64	23%	77%	22
65 to 74	8%	92%	12
75 to 84	0%	100%	5
85 or older	13%	88%	8
<b>Gender</b>			
Male	19%	81%	26
Female	13%	87%	47
<b>Region/County</b>			
Carroll & Coos	8%	92%	13
Cheshire, Sullivan & Grafton	0%	100%	9
Belknap & Merrimack	14%	86%	7
Hillsborough	24%	76%	21
Rockingham & Strafford	19%	81%	21
<b>Help w/ Questions</b>			
Yes	12%	88%	26
No	18%	82%	44

## Participant Experience Survey 2010

### Q9: Is this because there is no one there to help you?

	Yes	No	Number Responding
<b>Surveyed Adults</b>	<b>73%</b>	<b>27%</b>	<b>11</b>
<b>Age</b>			
55 or younger	100%	0%	4
55 to 64	60%	40%	5
65 to 74	100%	0%	1
85 or older	0%	100%	1
<b>Gender</b>			
Male	80%	20%	5
Female	67%	33%	6
<b>Region/County</b>			
Carroll & Coos	100%	0%	1
Belknap & Merrimack	0%	100%	1
Hillsborough	60%	40%	5
Rockingham & Strafford	100%	0%	4
<b>Help w/ Questions</b>			
Yes	33%	67%	3
No	88%	13%	8

## Participant Experience Survey 2010

### Q10: Is there any special help that you need to eat?

	Needs Help	Does Not Need Help	Number Responding
<b>Surveyed Adults</b>	<b>12%</b>	<b>88%</b>	<b>314</b>
<b>Age***</b>			
55 or younger	22%	78%	58
55 to 64	21%	79%	76
65 to 74	1%	99%	72
75 to 84	5%	95%	61
85 or older	13%	87%	47
<b>Gender</b>			
Male	11%	89%	97
Female	13%	87%	217
<b>Region/County</b>			
Carroll & Coos	16%	84%	51
Cheshire, Sullivan & Grafton	3%	97%	34
Belknap & Merrimack	34%	66%	29
Hillsborough	8%	92%	93
Rockingham & Strafford	12%	88%	103
<b>Help w/ Questions**</b>			
Yes	21%	79%	75
No	9%	91%	233

## Participant Experience Survey 2010

### Q11: Do you ever go without eating when you need to?

	Yes	No	Number Responding
<b>Surveyed Adults</b>	<b>13%</b>	<b>87%</b>	<b>38</b>
<b>Age</b>			
55 or younger	8%	92%	13
55 to 64	20%	80%	15
65 to 74	0%	100%	1
75 to 84	33%	67%	3
85 or older	0%	100%	6
<b>Gender</b>			
Male	20%	80%	10
Female	11%	89%	28
<b>Region/County</b>			
Carroll & Coos	14%	86%	7
Cheshire, Sullivan & Grafton	0%	100%	1
Belknap & Merrimack	20%	80%	10
Hillsborough	0%	100%	7
Rockingham & Strafford	17%	83%	12
<b>Help w/ Questions</b>			
Yes	7%	93%	15
No	18%	82%	22

## Participant Experience Survey 2010

### Q12: Is this because there is no one there to help you?

	Yes	No	Number Responding
<b>Surveyed Adults</b>	<b>60%</b>	<b>40%</b>	<b>5</b>
<b>Age</b>			
55 or younger	100%	0%	1
55 to 64	33%	67%	3
75 to 84	100%	0%	1
<b>Gender</b>			
Male	50%	50%	2
Female	67%	33%	3
<b>Region/County</b>			
Carroll & Coos	100%	0%	1
Belknap & Merrimack	50%	50%	2
Rockingham & Strafford	50%	50%	2
<b>Help w/ Questions</b>			
Yes	100%	0%	1
No	50%	50%	4

## Participant Experience Survey 2010

### Q13: Is there any special help that you need to make your meals?

	Needs Help	Does Not Need Help	Number Responding
<b>Surveyed Adults</b>	<b>73%</b>	<b>27%</b>	<b>311</b>
<b>Age</b>			
55 or younger	80%	20%	59
55 to 64	77%	23%	75
65 to 74	70%	30%	70
75 to 84	65%	35%	60
85 or older	72%	28%	47
<b>Gender</b>			
Male	69%	31%	95
Female	75%	25%	216
<b>Region/County</b>			
Carroll & Coos	82%	18%	50
Cheshire, Sullivan & Grafton	68%	32%	34
Belknap & Merrimack	79%	21%	29
Hillsborough	64%	36%	91
Rockingham & Strafford	76%	24%	103
<b>Help w/ Questions**</b>			
Yes	85%	15%	73
No	69%	31%	232

## Participant Experience Survey 2010

### Q14: Do you ever go without a meal when you need one?

	Yes	No	Number Responding
<b>Surveyed Adults</b>	<b>16%</b>	<b>84%</b>	<b>225</b>
<b>Age</b>			
55 or younger	21%	79%	47
55 to 64	16%	84%	57
65 to 74	22%	78%	49
75 to 84	8%	92%	38
85 or older	6%	94%	34
<b>Gender</b>			
Male	11%	89%	66
Female	18%	82%	159
<b>Region/County</b>			
Carroll & Coos	10%	90%	41
Cheshire, Sullivan & Grafton	9%	91%	23
Belknap & Merrimack	22%	78%	23
Hillsborough	25%	75%	57
Rockingham & Strafford	13%	87%	77
<b>Help w/ Questions***</b>			
Yes	3%	97%	62
No	21%	79%	159

## Participant Experience Survey 2010

### Q15: Is this because there is no one there to help you?

	Yes	No	Number Responding
<b>Surveyed Adults</b>	<b>71%</b>	<b>29%</b>	<b>35</b>
<b>Age</b>			
55 or younger	80%	20%	10
55 to 64	78%	22%	9
65 to 74	82%	18%	11
75 to 84	33%	67%	3
85 or older	0%	100%	2
<b>Gender</b>			
Male	71%	29%	7
Female	71%	29%	28
<b>Region/County</b>			
Carroll & Coos	50%	50%	4
Cheshire, Sullivan & Grafton	100%	0%	2
Belknap & Merrimack	60%	40%	5
Hillsborough	79%	21%	14
Rockingham & Strafford	70%	30%	10
<b>Help w/ Questions</b>			
Yes	100%	0%	2
No	70%	30%	33

## Participant Experience Survey 2010

### Q16: Is there any special help that you need to get groceries?

	Needs Help	Does Not Need Help	Number Responding
<b>Surveyed Adults</b>	<b>94%</b>	<b>6%</b>	<b>309</b>
<b>Age</b>			
55 or younger	93%	7%	59
55 to 64	97%	3%	74
65 to 74	92%	8%	71
75 to 84	90%	10%	60
85 or older	98%	2%	45
<b>Gender**</b>			
Male	88%	12%	93
Female	96%	4%	216
<b>Region/County</b>			
Carroll & Coos	94%	6%	50
Cheshire, Sullivan & Grafton	94%	6%	34
Belknap & Merrimack	93%	7%	28
Hillsborough	95%	5%	92
Rockingham & Strafford	94%	6%	101
<b>Help w/ Questions</b>			
Yes	96%	4%	74
No	93%	7%	229

## Participant Experience Survey 2010

### Q17: Are you sometimes unable to get groceries when you need them?

	Yes	No	Number Responding
<b>Surveyed Adults</b>	<b>23%</b>	<b>77%</b>	<b>289</b>
<b>Age*</b>			
55 or younger	26%	74%	54
55 to 64	30%	70%	71
65 to 74	31%	69%	65
75 to 84	13%	87%	54
85 or older	9%	91%	45
<b>Gender</b>			
Male	19%	81%	80
Female	24%	76%	209
<b>Region/County</b>			
Carroll & Coos	10%	90%	48
Cheshire, Sullivan & Grafton	16%	84%	32
Belknap & Merrimack	19%	81%	26
Hillsborough	30%	70%	86
Rockingham & Strafford	26%	74%	94
<b>Help w/ Questions**</b>			
Yes	10%	90%	71
No	28%	72%	213

## Participant Experience Survey 2010

### Q18: Is this because there is no one there to help you?

	Yes	No	Number Responding
<b>Surveyed Adults</b>	<b>71%</b>	<b>29%</b>	<b>65</b>
<b>Age</b>			
55 or younger	71%	29%	14
55 to 64	81%	19%	21
65 to 74	74%	26%	19
75 to 84	29%	71%	7
85 or older	75%	25%	4
<b>Gender</b>			
Male	73%	27%	15
Female	70%	30%	50
<b>Region/County</b>			
Carroll & Coos	40%	60%	5
Cheshire, Sullivan & Grafton	80%	20%	5
Belknap & Merrimack	60%	40%	5
Hillsborough	73%	27%	26
Rockingham & Strafford	78%	22%	23
<b>Help w/ Questions</b>			
Yes	71%	29%	7
No	71%	29%	58

## Participant Experience Survey 2010

### Q19: Is there any special help that you need to do housework - things like straightening up or doing dishes?

	Needs Help	Does Not Need Help	Number Responding
<b>Surveyed Adults</b>	<b>89%</b>	<b>11%</b>	<b>313</b>
<b>Age</b>			
55 or younger	93%	7%	58
55 to 64	88%	12%	76
65 to 74	92%	8%	72
75 to 84	82%	18%	61
85 or older	93%	7%	46
<b>Gender</b>			
Male	88%	13%	96
Female	90%	10%	217
<b>Region/County</b>			
Carroll & Coos	90%	10%	52
Cheshire, Sullivan & Grafton	94%	6%	34
Belknap & Merrimack	93%	7%	28
Hillsborough	91%	9%	92
Rockingham & Strafford	86%	14%	103
<b>Help w/ Questions</b>			
Yes	92%	8%	76
No	88%	12%	231

## Participant Experience Survey 2010

### Q20: Does the housework not get done sometimes?

	Yes	No	Number Responding
<b>Surveyed Adults</b>	<b>28%</b>	<b>72%</b>	<b>277</b>
<b>Age**</b>			
55 or younger	43%	57%	51
55 to 64	30%	70%	66
65 to 74	30%	70%	67
75 to 84	22%	78%	50
85 or older	9%	91%	43
<b>Gender**</b>			
Male	17%	83%	84
Female	33%	67%	193
<b>Region/County*</b>			
Carroll & Coos	13%	87%	46
Cheshire, Sullivan & Grafton	23%	77%	31
Belknap & Merrimack	44%	56%	27
Hillsborough	30%	70%	84
Rockingham & Strafford	30%	70%	87
<b>Help w/ Questions</b>			
Yes	19%	81%	67
No	30%	70%	204

## Participant Experience Survey 2010

### Q21: Is this because there is no one there to help you?

	Yes	No	Number Responding
<b>Surveyed Adults</b>	<b>75%</b>	<b>25%</b>	<b>76</b>
<b>Age</b>			
55 or younger	64%	36%	22
55 to 64	80%	20%	20
65 to 74	90%	10%	20
75 to 84	50%	50%	10
85 or older	100%	0%	4
<b>Gender</b>			
Male	69%	31%	13
Female	76%	24%	63
<b>Region/County</b>			
Carroll & Coos	50%	50%	6
Cheshire, Sullivan & Grafton	71%	29%	7
Belknap & Merrimack	75%	25%	12
Hillsborough	96%	4%	24
Rockingham & Strafford	65%	35%	26
<b>Help w/ Questions</b>			
Yes	58%	42%	12
No	81%	19%	62

## Participant Experience Survey 2010

### Q22: Is there any special help that you need to do laundry?

	Needs Help	Does Not Need Help	Number Responding
<b>Surveyed Adults</b>	<b>91%</b>	<b>9%</b>	<b>312</b>
<b>Age</b>			
55 or younger	97%	3%	58
55 to 64	92%	8%	75
65 to 74	86%	14%	73
75 to 84	90%	10%	59
85 or older	91%	9%	47
<b>Gender</b>			
Male	91%	9%	95
Female	91%	9%	217
<b>Region/County</b>			
Carroll & Coos	88%	12%	52
Cheshire, Sullivan & Grafton	94%	6%	34
Belknap & Merrimack	86%	14%	29
Hillsborough	92%	8%	92
Rockingham & Strafford	92%	8%	101
<b>Help w/ Questions</b>			
Yes	95%	5%	76
No	90%	10%	230

## Participant Experience Survey 2010

### Q23: Does the laundry not get done sometimes?

	Yes	No	Number Responding
<b>Surveyed Adults</b>	<b>19%</b>	<b>81%</b>	<b>279</b>
<b>Age*</b>			
55 or younger	25%	75%	55
55 to 64	25%	75%	68
65 to 74	21%	79%	62
75 to 84	10%	90%	52
85 or older	7%	93%	42
<b>Gender**</b>			
Male	9%	91%	85
Female	23%	77%	194
<b>Region/County</b>			
Carroll & Coos	13%	87%	45
Cheshire, Sullivan & Grafton	7%	93%	30
Belknap & Merrimack	28%	72%	25
Hillsborough	25%	75%	83
Rockingham & Strafford	17%	83%	93
<b>Help w/ Questions*</b>			
Yes	9%	91%	70
No	22%	78%	205

## Participant Experience Survey 2010

### Q24: Is this because there is no one there to help you?

	Yes	No	Number Responding
<b>Surveyed Adults</b>	<b>79%</b>	<b>21%</b>	<b>52</b>
<b>Age</b>			
55 or younger	86%	14%	14
55 to 64	76%	24%	17
65 to 74	77%	23%	13
75 to 84	100%	0%	5
85 or older	33%	67%	3
<b>Gender</b>			
Male	88%	13%	8
Female	77%	23%	44
<b>Region/County</b>			
Carroll & Coos	33%	67%	6
Cheshire, Sullivan & Grafton	100%	0%	2
Belknap & Merrimack	86%	14%	7
Hillsborough	86%	14%	21
Rockingham & Strafford	81%	19%	16
<b>Help w/ Questions</b>			
Yes	67%	33%	6
No	80%	20%	46

## Participant Experience Survey 2010

**Q25: Can you always get to the places you need to go, like work, shopping, the doctor's office, or a friend's house?**

	Yes	No	Number Responding
<b>Surveyed Adults</b>	<b>80%</b>	<b>20%</b>	<b>310</b>
<b>Age</b>			
55 or younger	81%	19%	57
55 to 64	73%	27%	74
65 to 74	75%	25%	73
75 to 84	88%	12%	59
85 or older	89%	11%	47
<b>Gender</b>			
Male	83%	17%	95
Female	79%	21%	215
<b>Region/County</b>			
Carroll & Coos	90%	10%	51
Cheshire, Sullivan & Grafton	91%	9%	34
Belknap & Merrimack	71%	29%	28
Hillsborough	77%	23%	92
Rockingham & Strafford	77%	23%	101
<b>Help w/ Questions*</b>			
Yes	88%	12%	75
No	77%	23%	229

## Participant Experience Survey 2010

**Q26: Is there any special help that you need to take medicine, such as someone to pour it or to set up your pills?**

	Needs Help	Does Not Need Help	Number Responding
<b>Surveyed Adults</b>	<b>63%</b>	<b>37%</b>	<b>315</b>
<b>Age*</b>			
55 or younger	71%	29%	59
55 to 64	55%	45%	76
65 to 74	58%	42%	73
75 to 84	62%	38%	60
85 or older	79%	21%	47
<b>Gender</b>			
Male	68%	32%	97
Female	61%	39%	218
<b>Region/County</b>			
Carroll & Coos	71%	29%	52
Cheshire, Sullivan & Grafton	50%	50%	34
Belknap & Merrimack	69%	31%	29
Hillsborough	62%	38%	93
Rockingham & Strafford	64%	36%	103
<b>Help w/ Questions***</b>			
Yes	82%	18%	76
No	58%	42%	233

## Participant Experience Survey 2010

### Q27: Do you ever go without taking your medicine when you need it?

	Yes	No	Number Responding
<b>Surveyed Adults</b>	<b>17%</b>	<b>83%</b>	<b>193</b>
<b>Age</b>			
55 or younger	23%	77%	39
55 to 64	24%	76%	41
65 to 74	19%	81%	42
75 to 84	6%	94%	35
85 or older	11%	89%	36
<b>Gender</b>			
Male	20%	80%	65
Female	16%	84%	128
<b>Region/County</b>			
Carroll & Coos	5%	95%	37
Cheshire, Sullivan & Grafton	13%	87%	15
Belknap & Merrimack	22%	78%	18
Hillsborough	21%	79%	57
Rockingham & Strafford	20%	80%	64
<b>Help w/ Questions*</b>			
Yes	10%	90%	62
No	21%	79%	128

-note \* p=.051

## Participant Experience Survey 2010

### Q28: Is this because there is no one there to help you?

	Yes	No	Number Responding
<b>Surveyed Adults</b>	<b>53%</b>	<b>47%</b>	<b>32</b>
<b>Age</b>			
55 or younger	44%	56%	9
55 to 64	63%	38%	8
65 to 74	63%	38%	8
75 to 84	67%	33%	3
85 or older	25%	75%	4
<b>Gender</b>			
Male	46%	54%	13
Female	58%	42%	19
<b>Region/County</b>			
Carroll & Coos	50%	50%	2
Cheshire, Sullivan & Grafton	50%	50%	2
Belknap & Merrimack	40%	60%	5
Hillsborough	67%	33%	12
Rockingham & Strafford	45%	55%	11
<b>Help w/ Questions</b>			
Yes	50%	50%	6
No	54%	46%	26

## Participant Experience Survey 2010

### Q29: Is there any special help that you need to get to or use the bathroom?

	Needs Help	Does Not Need Help	Number Responding
<b>Surveyed Adults</b>	<b>23%</b>	<b>77%</b>	<b>314</b>
<b>Age***</b>			
55 or younger	43%	57%	58
55 to 64	28%	72%	76
65 to 74	15%	85%	73
75 to 84	7%	93%	60
85 or older	26%	74%	47
<b>Gender</b>			
Male	26%	74%	95
Female	22%	78%	219
<b>Region/County</b>			
Carroll & Coos	33%	67%	52
Cheshire, Sullivan & Grafton	18%	82%	33
Belknap & Merrimack	31%	69%	29
Hillsborough	20%	80%	92
Rockingham & Strafford	21%	79%	104
<b>Help w/ Questions***</b>			
Yes	39%	61%	74
No	18%	82%	234

## Participant Experience Survey 2010

### Q30: Are you ever unable to get to or use the bathroom when you need to?

	Yes	No	Number Responding
<b>Surveyed Adults</b>	<b>20%</b>	<b>80%</b>	<b>69</b>
<b>Age</b>			
55 or younger	18%	82%	22
55 to 64	14%	86%	21
65 to 74	45%	55%	11
75 to 84	0%	100%	4
85 or older	18%	82%	11
<b>Gender</b>			
Male	13%	88%	24
Female	24%	76%	45
<b>Region/County</b>			
Carroll & Coos	13%	88%	16
Cheshire, Sullivan & Grafton	0%	100%	6
Belknap & Merrimack	25%	75%	8
Hillsborough	28%	72%	18
Rockingham & Strafford	25%	75%	20
<b>Help w/ Questions</b>			
Yes	22%	78%	27
No	18%	83%	40

## Participant Experience Survey 2010

### Q31: is this because there is no one there to help you?

	Yes	No	Number Responding
<b>Surveyed Adults</b>	<b>62%</b>	<b>38%</b>	<b>13</b>
<b>Age</b>			
55 or younger	50%	50%	4
55 to 64	33%	67%	3
65 to 74	100%	0%	4
85 or older	50%	50%	2
<b>Gender</b>			
Male	50%	50%	2
Female	64%	36%	11
<b>Region/County</b>			
Carroll & Coos	100%	0%	1
Belknap & Merrimack	50%	50%	2
Hillsborough	60%	40%	5
Rockingham & Strafford	60%	40%	5
<b>Help w/ Questions</b>			
Yes	40%	60%	5
No	86%	14%	7

## Participant Experience Survey 2010

**Q32: Think about the people who are paid to help you with the everyday activities we have been discussing. Do they spend all the time with you that they are supposed to?**

	Yes	No	Number Responding
<b>Surveyed Adults</b>	<b>97%</b>	<b>3%</b>	<b>302</b>
<b>Age</b>			
55 or younger	97%	3%	59
55 to 64	95%	5%	74
65 to 74	100%	0%	67
75 to 84	95%	5%	59
85 or older	98%	2%	43
<b>Gender</b>			
Male	96%	4%	94
Female	97%	3%	208
<b>Region/County</b>			
Carroll & Coos	100%	0%	51
Cheshire, Sullivan & Grafton	100%	0%	32
Belknap & Merrimack	93%	7%	29
Hillsborough	97%	3%	88
Rockingham & Strafford	96%	4%	98
<b>Help w/ Questions</b>			
Yes	99%	1%	71
No	96%	4%	225

## Participant Experience Survey 2010

**Q33: 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?**

	Yes	No	Number Responding
<b>Surveyed Adults</b>	<b>59%</b>	<b>41%</b>	<b>308</b>
<b>Age**</b>			
55 or younger	79%	21%	56
55 to 64	64%	36%	75
65 to 74	57%	43%	72
75 to 84	43%	57%	60
85 or older	51%	49%	45
<b>Gender</b>			
Male	59%	41%	91
Female	59%	41%	217
<b>Region/County</b>			
Carroll & Coos	60%	40%	50
Cheshire, Sullivan & Grafton	50%	50%	34
Belknap & Merrimack	52%	48%	29
Hillsborough	69%	31%	91
Rockingham & Strafford	57%	43%	100
<b>Help w/ Questions</b>			
Yes	66%	34%	74
No	57%	43%	228

## Participant Experience Survey 2010

### Q35: Did you get the equipment or make the changes you needed?

	Yes	No	In Process	Number Responding
<b>Surveyed Adults</b>	<b>60%</b>	<b>14%</b>	<b>26%</b>	<b>167</b>
<b>Age</b>				
55 or younger	52%	17%	31%	42
55 to 64	61%	14%	25%	44
65 to 74	65%	14%	22%	37
75 to 84	60%	16%	24%	25
85 or older	63%	5%	32%	19
<b>Gender</b>				
Male	61%	17%	22%	54
Female	59%	12%	28%	113
<b>Region/County</b>				
Carroll & Coos	45%	21%	34%	29
Cheshire, Sullivan & Grafton	69%	13%	19%	16
Belknap & Merrimack	60%	13%	27%	15
Hillsborough	61%	14%	25%	57
Rockingham & Strafford	64%	10%	26%	50
<b>Help w/ Questions</b>				
Yes	62%	9%	29%	45
No	59%	15%	26%	119

## Participant Experience Survey 2010

### Q36: Do you help pick the people who are paid to help you?

	Yes	No	Unsure	No Personal Care Staff	Number Responding
<b>Surveyed Adults</b>	<b>47%</b>	<b>51%</b>	<b>1%</b>	<b>1%</b>	<b>312</b>
<b>Age</b>					
55 or younger	66%	34%	0%	0%	59
55 to 64	49%	50%	1%	0%	74
65 to 74	47%	51%	1%	1%	73
75 to 84	37%	62%	2%	0%	60
85 or older	35%	63%	0%	2%	46
<b>Gender**</b>					
Male	59%	38%	3%	0%	95
Female	42%	57%	0%	1%	217
<b>Region/County</b>					
Carroll & Coos	51%	49%	0%	0%	51
Cheshire, Sullivan & Grafton	47%	53%	0%	0%	34
Belknap & Merrimack	52%	48%	0%	0%	29
Hillsborough	47%	49%	1%	2%	91
Rockingham & Strafford	44%	54%	2%	0%	103
<b>Help w/ Questions*</b>					
Yes	54%	43%	0%	3%	74
No	45%	54%	1%	0%	232

## Participant Experience Survey 2010

### Q37: Would you like to help pick the people who are paid to help you?

	Yes	No	Unsure	Number Responding
<b>Surveyed Adults</b>	<b>35%</b>	<b>60%</b>	<b>4%</b>	<b>161</b>
<b>Age</b>				
55 or younger	47%	47%	5%	19
55 to 64	41%	59%	0%	39
65 to 74	34%	55%	11%	38
75 to 84	34%	63%	3%	38
85 or older	22%	74%	4%	27
<b>Gender</b>				
Male	46%	49%	5%	39
Female	32%	64%	4%	122
<b>Region/County</b>				
Carroll & Coos	15%	85%	0%	26
Cheshire, Sullivan & Grafton	35%	65%	0%	17
Belknap & Merrimack	50%	50%	0%	14
Hillsborough	31%	58%	11%	45
Rockingham & Strafford	44%	53%	4%	57
<b>Help w/ Questions</b>				
Yes	42%	58%	0%	31
No	35%	60%	6%	127

## Participant Experience Survey 2010

### Q38: Did you know you can change the people who are paid to help you if you want to?

	Yes	No	Unsure	Number Responding
<b>Surveyed Adults</b>	<b>78%</b>	<b>19%</b>	<b>3%</b>	<b>308</b>
<b>Age</b>				
55 or younger	83%	17%	0%	59
55 to 64	79%	19%	1%	73
65 to 74	81%	19%	0%	72
75 to 84	75%	15%	10%	59
85 or older	69%	24%	7%	45
<b>Gender</b>				
Male	81%	17%	2%	95
Female	77%	20%	4%	213
<b>Region/County</b>				
Carroll & Coos	73%	23%	4%	52
Cheshire, Sullivan & Grafton	82%	18%	0%	34
Belknap & Merrimack	79%	21%	0%	28
Hillsborough	88%	8%	4%	89
Rockingham & Strafford	70%	26%	4%	101
<b>Help w/ Questions</b>				
Yes	81%	15%	4%	74
No	76%	21%	3%	229

## Participant Experience Survey 2010

### Q39: Thinking again about the people who are paid to help you, do you tell them what to help you with?

	Yes	No	Sometimes	Number Responding
<b>Surveyed Adults</b>	<b>84%</b>	<b>6%</b>	<b>10%</b>	<b>308</b>
<b>Age</b>				
55 or younger	81%	3%	15%	59
55 to 64	77%	11%	12%	73
65 to 74	88%	4%	8%	72
75 to 84	90%	3%	7%	60
85 or older	86%	5%	9%	44
<b>Gender</b>				
Male	85%	7%	9%	92
Female	84%	5%	11%	216
<b>Region/County</b>				
Carroll & Coos	88%	8%	4%	50
Cheshire, Sullivan & Grafton	85%	12%	3%	33
Belknap & Merrimack	89%	0%	11%	28
Hillsborough	93%	2%	4%	91
Rockingham & Strafford	74%	6%	21%	102
<b>Help w/ Questions</b>				
Yes	89%	7%	4%	73
No	82%	5%	13%	229

## Participant Experience Survey 2010

### Q40: Would you like to tell them the things you want help with?

	Yes	No	Number Responding
<b>Surveyed Adults</b>	<b>41%</b>	<b>59%</b>	<b>17</b>
<b>Age</b>			
55 or younger	50%	50%	2
55 to 64	56%	44%	9
65 to 74	33%	67%	3
75 to 84	0%	100%	1
85 or older	0%	100%	2
<b>Gender</b>			
Male	43%	57%	7
Female	40%	60%	10
<b>Region/County</b>			
Carroll & Coos	60%	40%	5
Cheshire, Sullivan & Grafton	40%	60%	5
Hillsborough	0%	100%	1
Rockingham & Strafford	20%	80%	5
<b>Help w/ Questions</b>			
Yes	17%	83%	6
No	55%	45%	11

## Participant Experience Survey 2010

**Q41: If there is something wrong with the help you are getting, who do you talk with to get the problem fixed? (CHECK ALL THAT APPLY)**

	No One	Family/Friend	Case MNGR/Staff	Other	Unsure	Number Responding
<b>Surveyed Adults</b>	2%	17%	68%	31%	4%	314
<b>Age</b>						
55 or younger	2%	12%	83%	31%	0%	59
55 to 64	3%	16%	72%	33%	1%	75
65 to 74	3%	11%	75%	23%	3%	73
75 to 84	2%	21%	52%	34%	7%	61
85 or older	2%	26%	48%	33%	13%	46
<b>Gender</b>						
Male	5%	10%	67%	33%	2%	97
Female	1%	19%	68%	29%	5%	217
<b>Region/County</b>						
Carroll & Coos	2%	12%	52%	31%	8%	52
Cheshire, Sullivan & Grafton	3%	3%	74%	21%	6%	34
Belknap & Merrimack	0%	24%	62%	59%	0%	29
Hillsborough	1%	13%	77%	16%	3%	93
Rockingham & Strafford	4%	25%	64%	38%	4%	104
<b>Help w/ Questions</b>						
Yes	1%	33%	58%	18%	5%	76
No	3%	11%	71%	34%	4%	232

## Participant Experience Survey 2010

### Q42: Who is your case manager or support coordinator?

	Names case Mgr	Does Not Name Case Mgr	Number Responding
<b>Surveyed Adults</b>	<b>84%</b>	<b>16%</b>	<b>304</b>
<b>Age*</b>			
55 or younger	91%	9%	58
55 to 64	86%	14%	76
65 to 74	90%	10%	68
75 to 84	73%	27%	60
85 or older	74%	26%	42
<b>Gender</b>			
Male	84%	16%	93
Female	83%	17%	211
<b>Region/County</b>			
Carroll & Coos	81%	19%	48
Cheshire, Sullivan & Grafton	88%	13%	32
Belknap & Merrimack	96%	4%	28
Hillsborough	87%	13%	91
Rockingham & Strafford	78%	22%	101
<b>Help w/ Questions</b>			
Yes	80%	20%	74
No	84%	16%	224

## Participant Experience Survey 2010

### Q43: Can you talk to your case manager or support coordinator when you need to?

	Yes	No	Sometimes	Unsure	Number Responding
<b>Surveyed Adults</b>	<b>83%</b>	<b>6%</b>	<b>7%</b>	<b>4%</b>	<b>307</b>
Age					
55 or younger	88%	3%	9%	0%	58
55 to 64	84%	5%	8%	3%	75
65 to 74	83%	6%	7%	4%	71
75 to 84	80%	8%	7%	5%	59
85 or older	82%	7%	5%	7%	44
Gender					
Male	84%	7%	4%	4%	95
Female	83%	5%	8%	3%	212
Region/County					
Carroll & Coos	77%	12%	2%	10%	52
Cheshire, Sullivan & Grafton	88%	6%	6%	0%	33
Belknap & Merrimack	81%	12%	8%	0%	26
Hillsborough	88%	2%	7%	3%	91
Rockingham & Strafford	81%	5%	11%	3%	101
Help w/ Questions					
Yes	92%	3%	4%	1%	75
No	80%	7%	8%	4%	228

## Participant Experience Survey 2010

### Q44: Does your case manager or support coordinator help you when you ask for something?

	Yes	No	Sometimes	Unsure	Number Responding
<b>Surveyed Adults</b>	<b>80%</b>	<b>5%</b>	<b>8%</b>	<b>6%</b>	<b>311</b>
<b>Age</b>					
55 or younger	81%	5%	10%	3%	59
55 to 64	83%	4%	13%	0%	75
65 to 74	83%	6%	7%	4%	72
75 to 84	75%	5%	7%	13%	60
85 or older	76%	7%	2%	16%	45
<b>Gender</b>					
Male	81%	5%	11%	3%	95
Female	80%	5%	7%	8%	216
<b>Region/County</b>					
Carroll & Coos	79%	10%	4%	8%	52
Cheshire, Sullivan & Grafton	94%	6%	0%	0%	33
Belknap & Merrimack	72%	3%	21%	3%	29
Hillsborough	88%	0%	5%	6%	93
Rockingham & Strafford	71%	7%	13%	9%	100
<b>Help w/ Questions</b>					
Yes	89%	3%	0%	8%	76
No	77%	6%	11%	6%	229

## Participant Experience Survey 2010

### Q45: Do the people paid to help you treat you respectfully in your home?

	Yes	No	Sometimes	Unsure	Number Responding
<b>Surveyed Adults</b>	<b>98%</b>	<b>1%</b>	<b>1%</b>	<b>0%</b>	<b>313</b>
<b>Age</b>					
55 or younger	97%	0%	3%	0%	58
55 to 64	97%	1%	1%	0%	76
65 to 74	96%	1%	1%	1%	72
75 to 84	100%	0%	0%	0%	60
85 or older	100%	0%	0%	0%	47
<b>Gender</b>					
Male	98%	0%	2%	0%	96
Female	98%	1%	1%	0%	217
<b>Region/County</b>					
Carroll & Coos	96%	0%	2%	2%	52
Cheshire, Sullivan & Grafton	100%	0%	0%	0%	34
Belknap & Merrimack	93%	3%	3%	0%	29
Hillsborough	99%	0%	1%	0%	91
Rockingham & Strafford	98%	1%	1%	0%	103
<b>Help w/ Questions</b>					
Yes	99%	0%	1%	0%	74
No	97%	1%	1%	0%	233

## Participant Experience Survey 2010

**Q46: Do the people paid to help you listen carefully to what you ask them to do in your home?**

	Yes	No	Sometimes	Unsure	Number Responding
<b>Surveyed Adults</b>	<b>88%</b>	<b>0%</b>	<b>9%</b>	<b>2%</b>	<b>313</b>
<b>Age</b>					
55 or younger	90%	0%	10%	0%	58
55 to 64	89%	0%	9%	1%	75
65 to 74	84%	1%	7%	8%	73
75 to 84	90%	0%	10%	0%	61
85 or older	89%	0%	11%	0%	46
<b>Gender</b>					
Male	92%	0%	7%	1%	97
Female	87%	0%	10%	3%	216
<b>Region/County</b>					
Carroll & Coos	90%	2%	2%	6%	50
Cheshire, Sullivan & Grafton	91%	0%	6%	3%	34
Belknap & Merrimack	83%	0%	14%	3%	29
Hillsborough	90%	0%	9%	1%	93
Rockingham & Strafford	86%	0%	13%	1%	103
<b>Help w/ Questions</b>					
Yes	92%	1%	4%	3%	75
No	87%	0%	11%	2%	232

## Participant Experience Survey 2010

### Q47: Have you ever been injured by any of the people paid to help you now?

	Yes	No	Unsure	Number Responding
<b>Surveyed Adults</b>	<b>3%</b>	<b>97%</b>	<b>0%</b>	<b>311</b>
<b>Age</b>				
55 or younger	0%	100%	0%	59
55 to 64	4%	96%	0%	75
65 to 74	4%	94%	1%	72
75 to 84	3%	97%	0%	60
85 or older	0%	100%	0%	45
<b>Gender</b>				
Male	3%	97%	0%	96
Female	2%	97%	0%	215
<b>Region/County</b>				
Carroll & Coos	12%	88%	0%	51
Cheshire, Sullivan & Grafton	0%	100%	0%	32
Belknap & Merrimack	7%	93%	0%	29
Hillsborough	0%	100%	0%	92
Rockingham & Strafford	0%	99%	1%	103
<b>Help w/ Questions</b>				
Yes	4%	96%	0%	74
No	2%	97%	0%	231

## Participant Experience Survey 2010

### Q49: Are any of the people paid to help you now mean to you, or do they yell at you?

	Yes	No	Sometimes	Number Responding
<b>Surveyed Adults</b>	<b>2%</b>	<b>96%</b>	<b>2%</b>	<b>312</b>
<b>Age</b>				
55 or younger	2%	95%	3%	59
55 to 64	4%	92%	4%	76
65 to 74	0%	100%	0%	72
75 to 84	2%	98%	0%	59
85 or older	2%	98%	0%	46
<b>Gender</b>				
Male	3%	96%	1%	97
Female	1%	97%	2%	215
<b>Region/County</b>				
Carroll & Coos	4%	94%	2%	49
Cheshire, Sullivan & Grafton	0%	100%	0%	34
Belknap & Merrimack	0%	93%	7%	29
Hillsborough	0%	100%	0%	92
Rockingham & Strafford	4%	94%	2%	104
<b>Help w/ Questions</b>				
Yes	0%	99%	1%	73
No	3%	96%	2%	233

## Participant Experience Survey 2010

### Q51: Have any of the people paid to help you now ever taken your things without asking?

	Yes	No	Unsure	Number Responding
<b>Surveyed Adults</b>	<b>4%</b>	<b>95%</b>	<b>1%</b>	<b>311</b>
<b>Age</b>				
55 or younger	7%	93%	0%	58
55 to 64	3%	97%	0%	76
65 to 74	1%	97%	1%	70
75 to 84	5%	95%	0%	61
85 or older	7%	91%	2%	46
<b>Gender</b>				
Male	1%	99%	0%	97
Female	6%	93%	1%	214
<b>Region/County</b>				
Carroll & Coos	6%	92%	2%	50
Cheshire, Sullivan & Grafton	9%	91%	0%	34
Belknap & Merrimack	7%	93%	0%	29
Hillsborough	1%	99%	0%	91
Rockingham & Strafford	4%	95%	1%	103
<b>Help w/ Questions</b>				
Yes	0%	100%	0%	72
No	5%	94%	1%	233

## Participant Experience Survey 2010

### Q53: Do you go to a day program outside your home?

	Yes	No	Number Responding
<b>Surveyed Adults</b>	<b>12%</b>	<b>88%</b>	<b>309</b>
<b>Age</b>			
55 or younger	12%	88%	58
55 to 64	11%	89%	75
65 to 74	8%	92%	71
75 to 84	12%	88%	60
85 or older	20%	80%	45
<b>Gender</b>			
Male	11%	89%	97
Female	12%	88%	212
<b>Region/County</b>			
Carroll & Coos	8%	92%	51
Cheshire, Sullivan & Grafton	15%	85%	34
Belknap & Merrimack	4%	96%	28
Hillsborough	11%	89%	91
Rockingham & Strafford	16%	84%	101
<b>Help w/ Questions*</b>			
Yes	19%	81%	73
No	10%	90%	230

## Participant Experience Survey 2010

### Q54: Do the people paid to help you at a day program outside your home treat you respectfully?

	Yes	No	Sometimes	Unsure	Number Responding
<b>Surveyed Adults</b>	<b>92%</b>	<b>3%</b>	<b>3%</b>	<b>3%</b>	<b>38</b>
<b>Age</b>					
55 or younger	100%	0%	0%	0%	7
55 to 64	100%	0%	0%	0%	8
65 to 74	86%	14%	0%	0%	7
75 to 84	100%	0%	0%	0%	7
85 or older	78%	0%	11%	11%	9
<b>Gender</b>					
Male	91%	9%	0%	0%	11
Female	93%	0%	4%	4%	27
<b>Region/County</b>					
Carroll & Coos	100%	0%	0%	0%	4
Cheshire, Sullivan & Grafton	100%	0%	0%	0%	5
Belknap & Merrimack	100%	0%	0%	0%	1
Hillsborough	91%	0%	0%	9%	11
Rockingham & Strafford	88%	6%	6%	0%	16
<b>Help w/ Questions</b>					
Yes	100%	0%	0%	0%	14
No	88%	4%	4%	4%	24

## Participant Experience Survey 2010

**Q55: Do the people paid to help you at a day program outside your home listen carefully to what you ask them to do?**

	Yes	No	Number Responding
<b>Surveyed Adults</b>	<b>97%</b>	<b>3%</b>	<b>38</b>
<b>Age</b>			
55 or younger	86%	14%	7
55 to 64	100%	0%	8
65 to 74	100%	0%	7
75 to 84	100%	0%	7
85 or older	100%	0%	9
<b>Gender</b>			
Male	100%	0%	11
Female	96%	4%	27
<b>Region/County</b>			
Carroll & Coos	100%	0%	4
Cheshire, Sullivan & Grafton	100%	0%	5
Belknap & Merrimack	100%	0%	1
Hillsborough	91%	9%	11
Rockingham & Strafford	100%	0%	16
<b>Help w/ Questions</b>			
Yes	93%	7%	14
No	100%	0%	24

## Participant Experience Survey 2010

### Q56: Do you ride a van or use other transportation services?

	Yes	No	Unsure	Number Responding
<b>Surveyed Adults</b>	<b>46%</b>	<b>54%</b>	<b>0%</b>	<b>311</b>
<b>Age</b>				
55 or younger	58%	42%	0%	59
55 to 64	47%	53%	0%	76
65 to 74	51%	49%	0%	71
75 to 84	41%	58%	2%	59
85 or older	26%	74%	0%	46
<b>Gender</b>				
Male	49%	50%	1%	96
Female	44%	56%	0%	215
<b>Region/County</b>				
Carroll & Coos	46%	54%	0%	50
Cheshire, Sullivan & Grafton	29%	71%	0%	34
Belknap & Merrimack	46%	54%	0%	28
Hillsborough	53%	46%	1%	92
Rockingham & Strafford	45%	55%	0%	103
<b>Help w/ Questions</b>				
Yes	38%	62%	0%	74
No	48%	51%	0%	232

## Participant Experience Survey 2010

### Q57: Do you ride a van or use other transportation services?

	Yes	No	Sometimes	Number Responding
<b>Surveyed Adults</b>	<b>96%</b>	<b>1%</b>	<b>3%</b>	<b>140</b>
<b>Age</b>				
55 or younger	91%	3%	6%	33
55 to 64	97%	0%	3%	35
65 to 74	97%	0%	3%	36
75 to 84	100%	0%	0%	24
85 or older	100%	0%	0%	12
<b>Gender</b>				
Male	94%	2%	4%	47
Female	98%	0%	2%	93
<b>Region/County</b>				
Carroll & Coos	100%	0%	0%	23
Cheshire, Sullivan & Grafton	89%	0%	11%	9
Belknap & Merrimack	92%	8%	0%	12
Hillsborough	100%	0%	0%	49
Rockingham & Strafford	93%	0%	7%	46
<b>Help w/ Questions</b>				
Yes	93%	0%	7%	27
No	97%	1%	2%	111

## Participant Experience Survey 2010

**Q58: Do the people paid to help you on the van or other transportation listen carefully to what you ask them to do?**

	Yes	No	Sometimes	Number Responding
<b>Surveyed Adults</b>	<b>94%</b>	<b>1%</b>	<b>5%</b>	<b>142</b>
<b>Age</b>				
55 or younger	91%	3%	6%	33
55 to 64	92%	3%	6%	36
65 to 74	94%	0%	6%	36
75 to 84	96%	0%	4%	25
85 or older	100%	0%	0%	12
<b>Gender</b>				
Male	94%	4%	2%	47
Female	94%	0%	6%	95
<b>Region/County</b>				
Carroll & Coos	100%	0%	0%	23
Cheshire, Sullivan & Grafton	90%	0%	10%	10
Belknap & Merrimack	85%	8%	8%	13
Hillsborough	96%	0%	4%	49
Rockingham & Strafford	91%	2%	7%	46
<b>Help w/ Questions</b>				
Yes	96%	0%	4%	27
No	93%	2%	5%	113

## Participant Experience Survey 2010

### Q59: Is there anything you want to do outside of your home that you don't do now?

	Yes	No	Unsure	Number Responding
<b>Surveyed Adults</b>	<b>51%</b>	<b>46%</b>	<b>2%</b>	<b>313</b>
<b>Age</b>				
55 or younger	68%	32%	0%	57
55 to 64	57%	42%	1%	76
65 to 74	48%	49%	3%	73
75 to 84	44%	52%	3%	61
85 or older	37%	59%	4%	46
<b>Gender</b>				
Male	52%	47%	1%	95
Female	51%	46%	3%	218
<b>Region/County</b>				
Carroll & Coos	54%	42%	4%	52
Cheshire, Sullivan & Grafton	48%	48%	3%	33
Belknap & Merrimack	59%	41%	0%	29
Hillsborough	50%	48%	2%	92
Rockingham & Strafford	50%	48%	2%	103
<b>Help w/ Questions</b>				
Yes	42%	54%	4%	76
No	54%	44%	2%	231

## Participant Experience Survey 2010

### Q62: Are you working right now?

	Yes	No	Number Responding
<b>Surveyed Adults</b>	<b>3%</b>	<b>97%</b>	<b>131</b>
<b>Age</b>			
55 or younger	5%	95%	57
55 to 64	1%	99%	74
<b>Gender</b>			
Male	6%	94%	52
Female	1%	99%	79
<b>Region/County</b>			
Carroll & Coos	0%	100%	17
Cheshire, Sullivan & Grafton	0%	100%	10
Belknap & Merrimack	6%	94%	16
Hillsborough	6%	94%	36
Rockingham & Strafford	2%	98%	49
<b>Help w/ Questions</b>			
Yes	4%	96%	27
No	3%	97%	101

## Participant Experience Survey 2010

### Q64: Did you help pick the job that you have now?

	Yes	No	Number Responding
<b>Surveyed Adults</b>	<b>75%</b>	<b>25%</b>	<b>4</b>
<b>Age</b>			
55 or younger	100%	0%	3
55 to 64	0%	100%	1
<b>Gender</b>			
Male	67%	33%	3
Female	100%	0%	1
<b>Region/County</b>			
Belknap & Merrimack	100%	0%	1
Hillsborough	100%	0%	2
Rockingham & Strafford	0%	100%	1
<b>Help w/ Questions</b>			
Yes	100%	0%	1
No	67%	33%	3

Participant Experience Survey 2010

Q65: Do you like your job?

	Yes	Number Responding
<b>Surveyed Adults</b>	<b>100%</b>	<b>4</b>
<b>Age</b>		
55 or younger	100%	3
55 to 64	100%	1
<b>Gender</b>		
Male	100%	3
Female	100%	1
<b>Region/County</b>		
Belknap & Merrimack	100%	1
Hillsborough	100%	2
Rockingham & Strafford	100%	1
<b>Help w/ Questions</b>		
Yes	100%	1
No	100%	3

## Participant Experience Survey 2010

### Q66: Do you want to work?

	Yes	No	Unsure	Number Responding
<b>Surveyed Adults</b>	<b>43%</b>	<b>52%</b>	<b>6%</b>	<b>122</b>
<b>Age</b>				
55 or younger	57%	33%	10%	51
55 to 64	32%	65%	3%	71
<b>Gender</b>				
Male	54%	44%	2%	48
Female	35%	57%	8%	74
<b>Region/County</b>				
Carroll & Coos	35%	65%	0%	17
Cheshire, Sullivan & Grafton	40%	60%	0%	10
Belknap & Merrimack	25%	67%	8%	12
Hillsborough	56%	38%	6%	32
Rockingham & Strafford	40%	52%	8%	48
<b>Help w/ Questions</b>				
Yes	30%	70%	0%	23
No	45%	48%	7%	96

## Participant Experience Survey 2010

### Q68: Did the respondent receive help from someone else to answer these questions?

	Yes	No	Number Responding
<b>Surveyed Adults</b>	<b>25%</b>	<b>75%</b>	<b>310</b>
<b>Age</b>			
55 or younger	18%	82%	57
55 to 64	23%	77%	75
65 to 74	21%	79%	72
75 to 84	22%	78%	60
85 or older	46%	54%	46
<b>Gender</b>			
Male	27%	73%	96
Female	23%	77%	214
<b>Region/County</b>			
Carroll & Coos	36%	64%	50
Cheshire, Sullivan & Grafton	39%	61%	33
Belknap & Merrimack	14%	86%	28
Hillsborough	28%	72%	92
Rockingham & Strafford	15%	85%	103

## Participant Experience Survey 2010

### Q69: What amount of the questions did the program participant answer by him/herself?

	All	Most	About Half	Some	A Few	None	Number Responding
<b>Surveyed Adults</b>	<b>43%</b>	<b>14%</b>	<b>16%</b>	<b>6%</b>	<b>10%</b>	<b>10%</b>	<b>77</b>
<b>Age</b>							
55 or younger	50%	10%	10%	0%	20%	10%	10
55 to 64	71%	12%	0%	0%	12%	6%	17
65 to 74	33%	7%	27%	20%	7%	7%	15
75 to 84	38%	15%	23%	0%	8%	15%	13
85 or older	27%	23%	18%	9%	9%	14%	22
<b>Gender</b>							
Male	62%	8%	12%	0%	4%	15%	26
Female	33%	18%	18%	10%	14%	8%	51
<b>Region/County</b>							
Carroll & Coos	44%	11%	22%	0%	11%	11%	18
Cheshire, Sullivan & Grafton	36%	21%	36%	7%	0%	0%	14
Belknap & Merrimack	75%	0%	0%	0%	25%	0%	4
Hillsborough	31%	19%	4%	12%	15%	19%	26
Rockingham & Strafford	60%	7%	13%	7%	7%	7%	15
<b>Help w/ Questions</b>							
Yes	42%	14%	16%	7%	11%	11%	76

## Participant Experience Survey 2010

### Q70: Who else provided responses (if applicable)?

	Parent	Spouse	Children	Case MGR	Other Children	Other Staff	Guardian	Other	Number Responding
<b>Surveyed Adults</b>	9%	21%	35%	17%	3%	23%	1%	3%	75
<b>Age</b>									
55 or younger	60%	0%	0%	20%	0%	30%	0%	0%	10
55 to 64	6%	35%	18%	18%	0%	35%	0%	6%	17
65 to 74	0%	36%	36%	0%	7%	29%	0%	0%	14
75 to 84	0%	17%	33%	42%	8%	17%	8%	0%	12
85 or older	0%	14%	64%	14%	0%	9%	0%	5%	22
<b>Gender</b>									
Male	12%	27%	23%	15%	0%	27%	4%	0%	26
Female	8%	18%	41%	18%	4%	20%	0%	4%	49
<b>Region/County</b>									
Carroll & Coos	6%	6%	47%	12%	12%	18%	0%	6%	17
Cheshire, Sullivan & Grafton	0%	36%	29%	7%	0%	21%	0%	7%	14
Belknap & Merrimack	25%	25%	75%	0%	0%	0%	0%	0%	4
Hillsborough	12%	20%	28%	28%	0%	28%	4%	0%	25
Rockingham & Strafford	13%	27%	27%	20%	0%	27%	0%	0%	15
<b>Help w/ Questions</b>									
Yes	9%	22%	35%	18%	3%	23%	1%	1%	74

## Participant Experience Survey 2010

### Q71: Have you been provided a copy of your plan for services?

	Yes	No	Unsure	Number Responding
<b>Surveyed Adults</b>	<b>61%</b>	<b>14%</b>	<b>25%</b>	<b>311</b>
<b>Age</b>				
55 or younger	73%	7%	20%	59
55 to 64	59%	15%	27%	75
65 to 74	59%	18%	23%	73
75 to 84	55%	17%	28%	58
85 or older	59%	15%	26%	46
<b>Gender</b>				
Male	64%	11%	25%	96
Female	60%	16%	25%	215
<b>Region/County</b>				
Carroll & Coos	59%	27%	14%	51
Cheshire, Sullivan & Grafton	56%	13%	31%	32
Belknap & Merrimack	64%	14%	21%	28
Hillsborough	71%	9%	21%	92
Rockingham & Strafford	54%	13%	34%	104
<b>Help w/ Questions*</b>				
Yes	70%	5%	25%	76
No	58%	17%	25%	229

## Participant Experience Survey 2010

### Q72: Does your plan address all your service needs and concerns?

	Yes	No	Unsure	Number Responding
<b>Surveyed Adults</b>	<b>85%</b>	<b>8%</b>	<b>6%</b>	<b>309</b>
<b>Age</b>				
55 or younger	83%	10%	7%	58
55 to 64	82%	10%	8%	72
65 to 74	84%	10%	7%	73
75 to 84	92%	3%	5%	60
85 or older	87%	9%	4%	46
<b>Gender</b>				
Male	89%	7%	3%	94
Female	83%	9%	8%	215
<b>Region/County</b>				
Carroll & Coos	90%	4%	6%	51
Cheshire, Sullivan & Grafton	85%	9%	6%	34
Belknap & Merrimack	86%	14%	0%	28
Hillsborough	93%	1%	6%	88
Rockingham & Strafford	76%	14%	10%	104
<b>Help w/ Questions</b>				
Yes	92%	3%	5%	74
No	83%	10%	7%	229

## Participant Experience Survey 2010

### Q73: Has anyone ever explained to you your role in developing your plan for services?

	Yes	No	Unsure	Number Responding
<b>Surveyed Adults</b>	<b>53%</b>	<b>27%</b>	<b>20%</b>	<b>307</b>
<b>Age</b>				
55 or younger	62%	22%	16%	58
55 to 64	61%	24%	15%	75
65 to 74	54%	30%	17%	71
75 to 84	40%	28%	33%	58
85 or older	47%	31%	22%	45
<b>Gender</b>				
Male	63%	20%	17%	94
Female	49%	30%	21%	213
<b>Region/County</b>				
Carroll & Coos	52%	31%	17%	52
Cheshire, Sullivan & Grafton	52%	30%	18%	33
Belknap & Merrimack	64%	21%	14%	28
Hillsborough	56%	19%	25%	88
Rockingham & Strafford	49%	31%	20%	102
<b>Help w/ Questions</b>				
Yes	61%	18%	22%	74
No	51%	30%	20%	227

## Participant Experience Survey 2010

### Q74: Did you have enough say in developing your plan for services?

	Yes	No	Unsure	Number Responding
<b>Surveyed Adults</b>	<b>78%</b>	<b>12%</b>	<b>11%</b>	<b>308</b>
<b>Age</b>				
55 or younger	75%	14%	11%	57
55 to 64	75%	14%	11%	76
65 to 74	86%	7%	7%	72
75 to 84	75%	16%	9%	57
85 or older	74%	7%	20%	46
<b>Gender</b>				
Male	80%	10%	11%	93
Female	77%	13%	11%	215
<b>Region/County</b>				
Carroll & Coos	85%	6%	10%	52
Cheshire, Sullivan & Grafton	76%	12%	12%	34
Belknap & Merrimack	79%	14%	7%	29
Hillsborough	83%	6%	11%	87
Rockingham & Strafford	70%	19%	12%	102
<b>Help w/ Questions</b>				
Yes	85%	5%	9%	74
No	75%	14%	11%	228

## Participant Experience Survey 2010

### Q75: Are you receiving all the services listed in your plan for services?

	Yes	No	Unsure	Number Responding
<b>Surveyed Adults</b>	<b>80%</b>	<b>4%</b>	<b>15%</b>	<b>310</b>
<b>Age</b>				
55 or younger	84%	4%	12%	57
55 to 64	77%	9%	14%	74
65 to 74	82%	4%	14%	72
75 to 84	85%	0%	15%	61
85 or older	72%	2%	26%	46
<b>Gender</b>				
Male	85%	3%	12%	94
Female	78%	5%	17%	216
<b>Region/County</b>				
Carroll & Coos	76%	2%	22%	50
Cheshire, Sullivan & Grafton	85%	0%	15%	34
Belknap & Merrimack	76%	7%	17%	29
Hillsborough	84%	2%	13%	90
Rockingham & Strafford	79%	7%	15%	103
<b>Help w/ Questions</b>				
Yes	89%	1%	9%	75
No	78%	5%	17%	229

Participant Experience Survey 2010

**Q76: Overall, how satisfied are you with the services you receive from this program?**

	Very satisfied	Satisfied	Neutral	Dissatisfied	Very dissatisfied	Unsure	Number Responding
<b>Surveyed Adults</b>	<b>62%</b>	<b>29%</b>	<b>4%</b>	<b>2%</b>	<b>1%</b>	<b>2%</b>	<b>314</b>
<b>Age</b>							
55 or younger	49%	34%	12%	3%	0%	2%	59
55 to 64	68%	23%	3%	0%	3%	4%	75
65 to 74	63%	29%	0%	4%	3%	1%	73
75 to 84	70%	25%	2%	2%	0%	2%	60
85 or older	57%	38%	2%	2%	0%	0%	47
<b>Gender</b>							
Male	65%	27%	5%	1%	2%	0%	96
Female	61%	30%	3%	3%	1%	3%	218
<b>Region/County</b>							
Carroll & Coos	64%	34%	2%	0%	0%	0%	50
Cheshire, Sullivan & Grafton	65%	26%	6%	0%	3%	0%	34
Belknap & Merrimack	55%	34%	3%	0%	7%	0%	29
Hillsborough	70%	26%	3%	0%	0%	1%	93
Rockingham & Strafford	55%	30%	4%	7%	0%	5%	104
<b>Help w/ Questions</b>							
Yes	65%	34%	0%	0%	1%	0%	74
No	61%	28%	5%	3%	1%	3%	234

## Participant Experience Survey 2010

**Q77: Would you like to be contacted by someone from the Medicaid program to discuss any concerns or questions you have about your services?**

	Yes	No	Number Responding
<b>Surveyed Adults</b>	25%	75%	310
<b>Age</b>			
55 or younger	40%	60%	57
55 to 64	21%	79%	76
65 to 74	22%	78%	73
75 to 84	21%	79%	58
85 or older	22%	78%	46
<b>Gender</b>			
Male	25%	75%	95
Female	25%	75%	215
<b>Region/County</b>			
Carroll & Coos	19%	81%	52
Cheshire, Sullivan & Grafton	15%	85%	34
Belknap & Merrimack	45%	55%	29
Hillsborough	22%	78%	88
Rockingham & Strafford	28%	72%	103
<b>Help w/ Questions</b>			
Yes	15%	85%	73
No	29%	71%	231

## Participant Experience Survey 2010

### Q78: Did you know you can change case management agencies if you want?

	Yes	No	Number Responding
<b>Surveyed Adults</b>	<b>67%</b>	<b>33%</b>	<b>283</b>
<b>Age</b>			
55 or younger	76%	24%	58
55 to 64	69%	31%	70
65 to 74	66%	34%	65
75 to 84	60%	40%	53
85 or older	62%	38%	37
<b>Gender***</b>			
Male	81%	19%	85
Female	61%	39%	198
<b>Region/County</b>			
Carroll & Coos	58%	42%	45
Cheshire, Sullivan & Grafton	62%	38%	29
Belknap & Merrimack	68%	32%	28
Hillsborough	72%	28%	83
Rockingham & Strafford	69%	31%	94
<b>Help w/ Questions</b>			
Yes	75%	25%	64
No	65%	35%	213

## Participant Experience Survey 2010

### Q79: How long have you been on the waiver?

	Less than 6 months	6-12 months	More than 12 months	Unsure	Number Responding
<b>Surveyed Adults</b>	1%	7%	86%	5%	316
<b>Age</b>					
55 or younger	0%	3%	95%	2%	59
55 to 64	0%	13%	82%	5%	76
65 to 74	1%	3%	86%	10%	73
75 to 84	2%	13%	79%	7%	61
85 or older	2%	2%	94%	2%	47
<b>Gender</b>					
Male	2%	6%	87%	5%	97
Female	0%	8%	86%	5%	219
<b>Region/County</b>					
Carroll & Coos	0%	4%	94%	2%	52
Cheshire, Sullivan & Grafton	0%	9%	85%	6%	34
Belknap & Merrimack	0%	10%	86%	3%	29
Hillsborough	2%	10%	77%	11%	93
Rockingham & Strafford	1%	6%	91%	2%	104
<b>Help w/ Questions</b>					
Yes	1%	9%	87%	3%	76
No	1%	6%	86%	6%	234

## Participant Experience Survey 2010

**Q80: When you submitted your application for long term care services and supports, were you given information about how long it would take to process it?**

	Yes	No	Number Responding
<b>Surveyed Adults</b>	<b>65%</b>	<b>35%</b>	<b>23</b>
<b>Age</b>			
55 to 64	75%	25%	8
65 to 74	57%	43%	7
75 to 84	57%	43%	7
85 or older	100%	0%	1
<b>Gender</b>			
Male	100%	0%	4
Female	58%	42%	19
<b>Region/County</b>			
Carroll & Coos	50%	50%	2
Cheshire, Sullivan & Grafton	50%	50%	2
Belknap & Merrimack	50%	50%	4
Hillsborough	80%	20%	10
Rockingham & Strafford	75%	25%	4
<b>Help w/ Questions</b>			
Yes	83%	17%	6
No	59%	41%	17

## Participant Experience Survey 2010

### Q81. Where you given information about the steps in the application process?

	Yes	No	Number Responding
<b>Surveyed Adults</b>	<b>72%</b>	<b>28%</b>	<b>25</b>
<b>Age</b>			
55 or younger	100%	0%	1
55 to 64	82%	18%	11
65 to 74	75%	25%	4
75 to 84	50%	50%	8
85 or older	100%	0%	1
<b>Gender</b>			
Male	83%	17%	6
Female	68%	32%	19
<b>Region/County</b>			
Carroll & Coos	100%	0%	2
Cheshire, Sullivan & Grafton	50%	50%	2
Belknap & Merrimack	25%	75%	4
Hillsborough	89%	11%	9
Rockingham & Strafford	86%	14%	7
<b>Help w/ Questions</b>			
Yes	86%	14%	7
No	67%	33%	18

## Participant Experience Survey 2010

### Q82: Was information (about the application process) helpful to you?

	Yes	Not Applicable	Number Responding
<b>Surveyed Adults</b>	95%	5%	22
<b>Age</b>			
55 or younger	100%	0%	1
55 to 64	100%	0%	9
65 to 74	83%	17%	6
75 to 84	100%	0%	5
85 or older	100%	0%	1
<b>Gender</b>			
Male	100%	0%	5
Female	94%	6%	17
<b>Region/County</b>			
Carroll & Coos	100%	0%	2
Cheshire, Sullivan & Grafton	100%	0%	1
Belknap & Merrimack	100%	0%	1
Hillsborough	92%	8%	13
Rockingham & Strafford	100%	0%	5
<b>Help w/ Questions</b>			
Yes	100%	0%	7
No	93%	7%	15

## Participant Experience Survey 2010

**Q83: Did you receive any information about the status of your application for long term care services and supports while you were waiting to learn if you were eligible?**

	Yes	No	Number Responding
<b>Surveyed Adults</b>	<b>70%</b>	<b>30%</b>	<b>20</b>
<b>Age</b>			
55 or younger	50%	50%	2
55 to 64	60%	40%	10
65 to 74	67%	33%	3
75 to 84	100%	0%	5
<b>Gender</b>			
Male	67%	33%	6
Female	71%	29%	14
<b>Region/County</b>			
Carroll & Coos	50%	50%	2
Cheshire, Sullivan & Grafton	100%	0%	2
Belknap & Merrimack	100%	0%	2
Hillsborough	63%	38%	8
Rockingham & Strafford	80%	20%	5
<b>Help w/ Questions</b>			
Yes	67%	33%	6
No	71%	29%	14

## Participant Experience Survey 2010

**Q84: Did you receive any information about the status of your application for long term care services and supports while you were waiting to learn if you were eligible?**

	Yes	No	Number Responding
<b>Surveyed Adults</b>	<b>97%</b>	<b>3%</b>	<b>31</b>
<b>Age</b>			
55 or younger	100%	0%	1
55 to 64	100%	0%	13
65 to 74	100%	0%	6
75 to 84	91%	9%	11
<b>Gender</b>			
Male	86%	14%	7
Female	100%	0%	24
<b>Region/County</b>			
Carroll & Coos	100%	0%	2
Cheshire, Sullivan & Grafton	100%	0%	3
Belknap & Merrimack	100%	0%	4
Hillsborough	93%	7%	14
Rockingham & Strafford	100%	0%	7
<b>Help w/ Questions</b>			
Yes	100%	0%	7
No	96%	4%	23

## Participant Experience Survey 2010

**Q85: When you were applying for long term care services and supports, were you given a choice between receiving services in a nursing home and receiving them in your community?**

	Yes	No	Number Responding
<b>Surveyed Adults</b>	<b>71%</b>	<b>29%</b>	<b>31</b>
<b>Age</b>			
55 or younger	100%	0%	2
55 to 64	83%	17%	12
65 to 74	67%	33%	9
75 to 84	43%	57%	7
85 or older	100%	0%	1
<b>Gender</b>			
Male	88%	13%	8
Female	65%	35%	23
<b>Region/County</b>			
Carroll & Coos	50%	50%	2
Cheshire, Sullivan & Grafton	75%	25%	4
Belknap & Merrimack	67%	33%	3
Hillsborough	63%	38%	16
Rockingham & Strafford	100%	0%	5
<b>Help w/ Questions</b>			
Yes	88%	13%	8
No	68%	32%	22

## Participant Experience Survey 2010

### Q86: Were you able to choose which case management agency to use?

	Yes	No	Number Responding
<b>Surveyed Adults</b>	<b>54%</b>	<b>46%</b>	<b>24</b>
<b>Age</b>			
55 or younger	67%	33%	3
55 to 64	57%	43%	7
65 to 74	43%	57%	7
75 to 84	57%	43%	7
<b>Gender</b>			
Male	33%	67%	3
Female	57%	43%	21
<b>Region/County</b>			
Carroll & Coos	100%	0%	1
Cheshire, Sullivan & Grafton	100%	0%	1
Belknap & Merrimack	0%	100%	2
Hillsborough	53%	47%	15
Rockingham & Strafford	75%	25%	4
<b>Help w/ Questions</b>			
Yes	60%	40%	5
No	50%	50%	18

## **Appendix III: 2010 Verbatim Responses**

## ACCESS AND CARE

### Bathing

#### **Q1: Is there any special help that you need to take a bath or shower?**

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- Best when someone washes my back and feet lest I fall when bending over
- I don't take a shower or a bath unless someone is here. I am too unsteady and can't react quick enough if I were to fall
- Monitor and assist
- Aide stands by for safety reasons
- Aids wash me, transfer,
- An aide assists with a sponge bath
- Assist and monitoring due to poor balance
- Can do that by himself. Have chair in bath tub.
- Can go to bathroom without any problems, but needs help with shower and shampoo
- Caregiver stands by in case she feels wobbly.
- Caretaker helps with the tub
- CNA help me w/ my shower
- Daughter helps
- Daughter in law stands by in case she's unsteady.
- Does have someone wash her hair but showers on her own.
- Does it by herself but likes to have someone in the house when she does it.
- Does take sponge baths now
- Due to weakness and vertigo
- Except to adjust water temp.
- For safety in getting out of the tub
- For safety mostly, b/c I am very unsteady. I have a tumor behind this eye and it knocks me off a bit.
- Get SOB easily and avoids showers
- Getting in and out
- Grand daughter is paid to help. Can't wash feet or back
- Had caretakers to sit beside her. Get dizzy
- Has an aid
- Has bath aid 3X weekly
- Has help every week
- Has poor sense of balance so needs to have help from aide
- Have shower lady that comes Mon & Thurs.
- Have to have someone take off prosthetic leg and have help turning on water because the shower head is on the opposite wall of her shower seat. Everything else she can do.
- Health aid/ 3x a week
- Husband helps gets in tub, legs in and legs out
- Husband helps.
- I am not that disabled
- I can't really take a bath, I have osteoporosis, so I really can't take a bath, but I shower myself alone. They want someone in the house in case I fall.
- I can't take a bath, I can't get out of the tub, claw foot, deep.
- I don't want anyone to help me in the shower, but it takes a long time to do. It takes me awhile to get everything set up, but I can do it

## Participant Experience Survey 2010

- I do get assistance
- I get a sponge bath
- I have a girl come in who helps me do the whole thing.
- I have a home health aide
- I have a nurse that comes Monday, Wednesday, and Friday to help me shower
- I have an aide
- I have an aide who helps me twice a week, I do it sometimes on my own, but I have a transfer chair. I do sponge baths in between times.
- I have help 5X weekly
- I have help twice a week
- I just need somebody to stand by me because I have trouble standing/walking
- I need someone there in case I fall, I fell once, but no one was here
- I need an extra hand
- I try to do it myself, but once in a while, my aide will help me if I really want my back scrubbed or my leg. I have my handicapped bathroom so I can do it myself.
- I usually take it when she is here, for balance in case I fall.
- I wash in front of the sink, never take a bath or shower
- Just somebody here in case I fall
- Just with feet and oversight for safety; and to see things due to legal blindness
- Left sided paralysis, I need help, aides come in twice a day.
- Monitored while bathing to reduce risk of falling
- Most days I have a nurse, usually every day.
- My aide helps me twice a week, I've got my chair in there
- My back, I get dizzy spells once in a while. My daughter is my caregiver.
- My daughter is my caretaker, she gets everything set up for me and makes sure she's there for safety.
- My granddaughter does that for me. She and my grandson are my caretakers.
- My nurses' aides take care of that for me. I have a problem w/other girls seeing me naked. One girl does my showers.
- Need 100% help
- Need aide because of fear of being alone and falling
- Need an aide to get in and out of the shower
- Needs a lot of help, max assist
- Needs help getting in and out of the tub
- Needs help to get into tub
- Needs help with her back and her shampoo
- Needs the assistance of an aide
- Needs to have someone in the home at the time.
- Not really, I have someone that comes in to help me, but I could do it myself. I'd have trouble shaving b/c of grip, neuropathy
- Nurse does that in the morning, 5 days a week
- Nurse that comes every day
- Nurses prn, I wouldn't do it by myself, I'd be crazy to.
- Old fashioned bath tub, needs help
- On good days, she can do everything except back and hair.
- On bad days, can do nothing.
- PCSP (personal care service provider)
- Per son - is unstable, but does it herself using her chair and handles
- R..... comes to watch me b/c I fell down once.

## Participant Experience Survey 2010

- Safety reasons
- Shampoo and back
- She does need help getting in. She shampoos her hair, I do her legs and her back. I need to be there for safety.
- She has to put the chair in when I don't feel like I can stand and she helps wash me down, my back and my butt.
- She helps me get in and out and sets out clothes for me, because I can't breathe that well anymore.
- Agency comes twice a week
- Shower has 3 bars that are sturdy and work well
- Sister is the unpaid caregiver and is the one who helps
- Some assistance. Always has someone is in the house when he takes a shower.
- Some days needs help.
- Someone comes 2 times a week to give shower - Mon & Wed
- Would prefer Mon or Tues AND Thurs. or Fri.
- Someone comes 3 days a week
- Someone helps with bathing in the morning.
- Someone stands next to her while she showers but she can do it herself if she had to.
- Sometimes I have to have help, once in awhile I get syncope. I can do it myself depending on the day.
- Sometimes needs help from his son
- Sometimes yes and sometimes no
- Sometimes yes, sometimes no; nature of the MS, sometimes I need to sit in a shower chair, sometimes I need help getting over the edge of the tub, sometimes I'm okay.
- Spouse does it
- The girl comes in Mondays, Wednesdays and Fridays and sits right in the bathroom with me. She's just there for safety, but I wouldn't take one without someone here. On the weekends, my kids will help me.
- The tub is really low for me to take a bath but a shower is fine
- They're right there though if I need them
- Usually wife helps. Has some physical limitations for getting wet.
- We have a homemaker for 3 hours and 5 days a week for that
- Well, they send me people here, but they send me people one of them 3 times a week. But you need to remember that I need to take a shower every day, so I take one by myself. I take a little longer when no one is here.
- Well, yes there is, but if I could get one of those things, I could do it myself. I have a problem reaching around to the top of my butt or down there with all this flab. I have been doing it myself.
- Wife gives a hand
- Yes,
- Yes, I fall over, balance issues, strength issues, I can no longer wash my own hair, and it sucks
- Getting out of tub is downright dangerous
- Yes, I need assistance to get in and out, I also have difficulty washing my back, my LNA takes care of that
- Yes, well I have severe COPD, so I need help, I am very unsteady on feet and short of breath.
- Yes. Visiting Nurses

### **Q2: Do you ever go without a bath or shower when you need one?**

---

- Because she refuses; she is getting a lot of bed baths
- Disgusting
- Have it down to a science
- He either receives services or we help, we have a lady coming in 3 times a week, and family helps if he needs it in the meantime and once on the weekend

## Participant Experience Survey 2010

- I get Monday through Saturday.
- I know how to sponge bathe, I can do that
- I need her handle bar inside the shower perpendicular to the bar on right outside the shower stall; I am afraid to go into the stall as it is because of my right leg weakness and the pressure of my weight
- I never go without a shower, but I do go without baths. My daughter offered to bathe me a couple of time, but I can't get out of the tub, but since I can shower myself, I just do that. I take a shower and I do my hair.
- I postpone my shower depending on how I feel
- I take a sponge bath
- I usually wash myself in the morning and the girl comes in the evening and showers me. She comes T, W and Th., and once in a while on Friday. And I have one that comes to take me to the doctors, does my food shopping, and stuff.
- If I absolutely need one, my wife can assist me.
- If Mom is injured or no LNA available
- If they don't come than I do, yes
- My daughter helps me
- My husband will help me with that
- My personal care attendant helps me with a sponge bath every two days
- Not all the time but sometimes
- Once in a blue moon
- Once in awhile
- One a week or every two weeks; sponges bath in between
- Sometimes
- Sometimes I just take a sponge bath
- Sometimes like when they're fixing the shower and the water is turned off.
- Sometimes they are short of help
- Sometimes, if I'm not up to standing and there is no nurse here
- Take sponge baths when no one around
- The aide helps me with my shampoo
- They always come
- They come Tues. And Thurs. Very gentle and take good care of her. Help her sit in tub.
- Try to make sure to get one every 3rd day, try not to ask for help a lot b/c it is a production
- Tuesdays and Thursdays, I don't take one. Saturday I did it by myself but I get nervous doing it myself. I used to get one 5 days a week but my nurse discontinued that last week
- Very rarely
- We're waiting for them to come in and modify the apartment to make it more handicapped accessible.
- With previous provider, she went 6 months without...but current one (about 2 months) she gets them 2 days a week
- Yes

### **Q3: Is this because there is no one there to help you?**

---

- Bbecause damn vna is really responsible
- Doesn't want to make her husband look bad, nature of the MS, it's not that he wouldn't help it's just that sometimes if they're in a rush, etc.
- Has help five days a week but would like to shower every day because of a skin condition.
- I know I could ask for a bathe aide but prefer not to; the steam in the bathroom is hard on my breathing as well as the exertion required
- I wait until my daughter is around and I get her to help

## Participant Experience Survey 2010

- If I do it's because I don't feel like it
- No, I get lazy
- On weekends when he has no assistance
- The help only comes M, W, F

## Dressing

### Q4: Is there any special help that you need to get dressed?

---

- A little w/ my socks and shoes.
- All clothes
- All clothing
- All clothing
- As long as the clothes are clean!
- Bra and stockings.
- Can get dressed but it takes a while.
- Can get dressed on her own but it is very hard
- Can't put on socks and shoes. Trousers sometimes
- Clothes are laid out, but can dress herself. Need help tying shoes.
- Could do it herself but is easier if someone helps
- Daughter helps dress
- Depends on what I am dressing. I am just getting to the point where it is difficult to do buttons. I don't button my shirts
- Does some by herself because she's modest.
- Dresses herself
- Getting dressed to go out; getting shoes on
- Getting things over my head
- Hardly ever
- Has help in the morning and evening.
- Have to have socks and shoes put on
- Have trouble getting things onto right leg, can't put socks and shoes on - daughter-in-law usually helps (lives in house)
- Husband helps me thread arms through my clothes
- I am kind of lame from arthritis. It starts in my back and now it goes up my spine
- I can do it myself, but when they are here, they help me. They put my socks on, bras, underwear.
- I cannot put on socks and shoes because of my hip
- I do it myself, sometimes it takes me about 45 minutes, but I get it done.
- I do my dressing myself, but at nighttime my granddaughter helps me get into my nightgown and helps me get into bed b/c it's hard for me to manipulate into bed.
- I do pretty good getting dressed, the only thing is not being able to find things that match! The girls try to help me put things together for me.
- I do some of it and my aid helps me
- I have adaptive equipment like a long handled grabber
- I just need help getting my socks on, I do it myself, or I go without my socks.
- I manage to do it by myself with my barbecue tongs to reach things
- I still do it myself, but it's easier w/ help
- I usually dress myself completely, unless I have a button down shirt, then the fingers don't always work right, so I wear mostly pullovers
- I'd have to bend over too far for safety
- If the nurse is not here my aunt will help me, b/c I can't move that much
- In mornings, help with dressed.
- It varies
- Just help with lower body - socks and pants

## Participant Experience Survey 2010

- Just socks & shoes
- Just to help me put my socks and shoes on, can't bend over, so they help me
- Just tying my shoes
- Leg brace and stockings.
- Like today would be a day that I'm going to stay like this all day today (pjs) till it's time for bed and I'll take a bath or whatever, I can't pull my legs up to put my clothes on
- Lower body dressing, pants included, and some of the upper body, shoulders are effective
- Mainly putting on foot brace for flat foot
- Most of their time she prefers to stay in her night dress
- MS affects my cognition and ability to remember and organize/complete tasks
- My arm is too stiff
- My wife helps me a lot b/c I can't put my prosthesis on, pants on, belt, she helps me a lot when I'm dressed up I would say a lot. If I'm just home, I wear sweats and I do it myself.
- Need an extra hand
- Need help from your aide
- Need help with buttons, but can put clothes on herself.
- Need some help getting otherwise it takes her all day
- Needs help with everything.
- Needs help with everything.
- Needs help with top half of clothes.
- Needs prompts, and set up, assistance.
- No longer needs help. I needed help two years ago but through determination I can do all those things by myself.
- No, I'm fine with that
- Not enough mobility to dress from waist down
- Not right now, when I have surgeries I need help
- Only bra and bending over for shoes and socks
- Only when I wear a bra
- Pants
- Pants, socks
- Partial help due to arthritis
- Requires the assistance of an aide
- Safety and clasps, bad balance and vertigo, pulling up pants is tough, b/c I lose my balance.
- She dresses me. Nurse.
- She likes help but she doesn't need it. She likes it for putting shoes and socks on
- She sets them up for me, usually I mostly stay in the nightgown things b/c they do the legs
- Shoes and socks
- Shoes, socks, pants
- Sister or care worker help her with all items of clothing.
- Socks and shoes
- Socks and shoes or shirts up over my head
- Someone puts on underwear and pants. The rest, she can do.
- Sometimes
- Sometimes depending on my pain level and my cramping level
- Sometimes needs some help
- Sometimes to put coat and shoes. Mostly shoes
- Sometimes with shoes and socks
- Sometimes, my feet, socks and shoes

## Participant Experience Survey 2010

- Sometimes. Needs help with shoes and jackets.
- Sometimes I can't do it
- Usually I'm okay by myself, sometimes I need to sit and husband needs to put my pants on and I pull them up, sometimes he helps to tie my shoes
- Spouse sometimes helps
- Spouse does it
- Still able to get dressed but it takes me a while
- Taking compression hose on and off and shoes; can't comb hair very well
- The only thing I can't do is put on my shoes and socks. Sometimes I have to have someone button up something, and I'm slow. Someone usually helps me. It was 4 mornings a week, then I have a nurse and a homemaker.
- There are things that I don't wear because I can't get it on
- They do my back, they do my legs, and I do my upper front...I can put on my clothes up here (hands on chest) they do my legs...it's like neuropathy, my fingers
- They have to help me with getting stuff over the head
- They put on everything like my bra, my shirt
- Total assist
- Total assist
- Total help
- Tying shoes or putting on my pants
- Usually does it by himself. Occasionally wife helps with buttons.
- Usually with legs, socks and feet if he needs help
- Waist down
- Will get help with shoes occasionally
- Yes, socks and shoes, b/c of my back problems I can't reach my feet
- Yes, that's why I don't get dressed!

### **Q5: Do you ever go without getting dressed when you need to?**

---

- (hesitant response) Some days I should be getting dressed but I just don't bother
- Both daughters live right near me, so I just call them and they'd be right here.
- Can do a little myself but can't do as much
- Can manage if she has to
- Don't wear pants b/c they're too much of a hassle but I always get dressed every morning
- I cover myself up w/ a thing they make for people in wheelchairs that ties in the back.
- I stay in my nighties sometimes
- I try to get dressed every day unless I'm really sick
- I wear my nightclothes
- If Mom or LNA is not available
- I'll get dressed and if I can't put my shoes on, I'll just work around it and wear my slippers or sandals.
- Live-in caretaker has been with R for ten years, he puts in a lot more hours than they say
- Sometimes
- Sometimes the aides do not come when I need them
- Weekends I don't have help
- When my mother is not home I can't pull my pants up with my one hand
- Wife is there

**Q6: Is this because there is no one there to help you?**

---

- And it's scary
- But it is never long. My daughter comes as soon as I call
- Exactly
- I'm just not in the mood. I have bipolar, so I'm in a bad depression now. I just don't want to get up.
- Most of the time

## Transferring

### **Q7: Is there any special help that you need to get out of bed?**

---

- Well I've got this ladder here and people are worried b/c my bp is going crazy" describes multiple hip and arm injuries
- Aid comes in the morning, she picks me up and turns me/twists and puts in chair
- Always need help - usually husband.
- Always needs help out of bed.
- Another person and a lift
- Because I have a hospital bed and they taught me how to get out. If I was in a regular bed than I could not get out
- Bed is high enough that she can get out on her own.
- But it is very hard work for her
- Depends on situation, sometimes needs help
- Electric bed so that's been a saving grace, sometimes if I'm really stiff I do but most of the time I have the electric bed
- Except a lot of willpower!
- Has a hospital bed so she does not need a person
- Has a trapeze attached to bed
- Has assist. Can stand and pivot, but has someone there watching in case she falls.
- Has hospital bed but doesn't need another person to help.
- Have a hospital bed, railings to help me get out
- He says he "should" have help getting out of bed, but only has help once in a while. He can't wait for someone to get here because they don't come until later and he has to get up to let them in the door. Sounds like he may be capable, not really sure.
- Hell no
- Help lifting up sometimes by my partner
- I have a bed rail
- I have a bar that I use.
- I have a hospital bed which comes up
- I have a hospital bed.
- I have a Hoyer lift and sometimes my brother does the lifting.
- I have a trapeze bar
- I have days, I have days that I can't move my right side at all
- I have my walker there, I always have that with me
- I have railings on the bed, if my back is out I just wind up staying in bed
- I manage to get from the bed b/c my chair is inside the room when I go to bed, I am able to manage my leg at least to be able to get out of bed myself.
- I need him to go to sleep earlier. I need to get my sleep b/c I'm up with him at night.
- I need to use a bed rail to get up
- I roll pretty good
- I sleep in this chair, and I can get out with my cane. And the chair lifts me up.
- I use a bedrail and leg lifter to assist
- If my wheel chair is not near the bed I can't get out of bed
- It depends on the rainy weather and the winter.
- It depends; if my back pain gets bad or my knees get locked my husband has to help me

## Participant Experience Survey 2010

- It takes me a good 15 to 20 minutes to get out of bed b/c my legs hurt so bad
- There's time that I have, it all depends on the weather, so I have to have somebody help me sometimes, it's not all the time"
- Just don't wake me up. It would be nice if the bed went up and down and not just putting my legs up
- Just needs help with prosthetic leg but can get out of bed by himself.
- Mother has to do all the transfers; they have a lift that will not fit into her bedroom and is now stored away with the hope that it could be used in a future home location or adaption
- Need someone to put her leg on. After her leg is on, she can get up by herself.
- No
- Not anymore, unless I'm sick
- Not as a rule
- Not really, it takes me a little bit, but I can do it. But sometimes when I fall on the floor, a lot of the times I do the best I can to get up off the floor, but if not, I call lifeline. They usually get here real quick.
- Not yet
- Nurse helps me, I had a stroke
- Occasionally if she has health problems.
- Only supervision
- Physically he gets out of bed himself, but he needs prompting or he would stay in bed past medication time.
- Requires the assistance of an aide
- Sleeps in a recliner and can get up from that by herself. Can't sleep in bed.
- So far I can get up with the help of my motorized chair
- Sometimes
- Sometimes
- Sometimes
- Sometimes
- Sometimes family members help but usually does it by himself.
- Sometimes I am weaker than other days
- Sometimes I do need help and sometimes not
- Sometimes I have to fight to get up
- Sometimes I need to have my arm pulled over
- Sometimes I need help, sometimes I sleep down here if I can't possibly make it up the stairs and I need to lean on chairs or something to balance myself, if I can make it upstairs to our bed, I can kind of do the same, lean on chairs/wall
- Sometimes, when having a hard time, chronic pain also, husband helps me, he is my main caregiver
- Sometimes. I overdo it and the next day I can't
- Son is here at night to help get into bed.
- Transfer to sit up
- Uses a walker for stability but doesn't need another person.
- Using bar on bed to get out of bed.
- Very occasionally, I need little assistance to get into a sitting position, my wife usually helps, maybe 2-3 times a month

### **Q8: Do you ever go without getting out of bed when you need to?**

- Because she doesn't like getting up but we are able to get her up the large majority of days
- I have
- If someone calls out, it may take a while before they can get s replacement
- Once in a while if they are late they won't put me in the chair.

## Participant Experience Survey 2010

- She comes every day
- Sometimes when I want to get up very early
- There is someone here 7 days a week 6 hours a day.
- We don't let him, we're always here. We want him to get out of bed every day.

### **Q9: Is this because there is no one there to help you?**

---

- B/c of depression, my husband is always with me.

## Eating

### Q10: Is there any special help that you need to eat?

---

- Assist
- Can eat and cook herself.
- Can feed herself, but has someone cook for her.
- Cut up my food
- Cutting food only
- Cutting meat only help she needs.
- Except for cutting up meat and things like that, they make sure that it is cut up bite sized for me b/c I don't have any teeth. Medicare won't pay for false teeth, and neither will Medicaid.
- For safety and prompting, physically can do
- Gets meals on wheels but can make self something for supper
- Has a hard time eating. Has anxiety problem. Has a hard time swallowing.
- Has in the past been unable to eat when she had the jerks, but currently can feed herself.
- Husband will usually cut food up b/c I can't do that myself,
- I can't do it neatly but I do it
- I don't need to be fed, but I have very bad motion in my shoulders, I have to eat out of a mug or something, no plates; aid puts in mug and R heats, etc.
- I had my stomach stapled so I have problems digesting so the food usually has to be soft, not pureed or nothing, just I don't do very well with meats
- I have no teeth so it is hard for me to eat
- I have to be careful not to make my food too hot
- I just have to be careful. Sometimes I wear a little more than I eat!
- I need someone to prepare food or I eat junk.
- Eating alone makes me nervous, I tend to choke
- I sit here and do my cooking myself, I use a rolling chair
- I think so, I've been doing it for years
- I try to eat w/ my left hand
- I used to have a hard time controlling my hands, but now the meds help me.
- I'm a chef
- It's debatable, daughter says depends on what's to eat, sometimes it's just cutting, sometimes its special things
- Just need help with slicing meat
- Luckily I have a little peripheral vision in my left eye
- My daughter gives me verbal direction and then I fish around on the plate to get it
- Need help cutting foods, like meat, but can otherwise feed herself.
- Need someone to cut food for me sometimes.
- Need to have my meat cut
- Needs a lot of prompts/encouraging
- Needs help cutting food
- No
- No, thank god for that. I love to eat. That's one thing I'll miss when I die.
- Not right now. Eventually I will need someone to cook my meals
- Only to cut meat.
- Other than cutting up meat sometimes.
- Pureed food

## Participant Experience Survey 2010

- Requires the assistance of an aide
- She has a feeding tube with a pump and can take some soft foods orally
- She needs to have her meat cut for her
- Sister: yes we do help arrange food. Participant is blind
- Sometimes I can't swallow things, I can only have soup or pasta, I can't chew and swallow as well, eat soup, but that's not really well
- Special
- That's why they're here!
- (name) cuts food into smaller pieces for her, but she can eat herself
- To cut up meat
- Usually my aunt feeds me
- Well let me tell you, I get food from meals on wheels and I try to lose some weight, I've been doing it for the past 2 1/2 months, I decided to cut my food in half, my sugar was crazy, now it's ok
- Yes and no, that's actually gotten better with therapy

### **Q11: Do you ever go without eating when you need to?**

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- Everything looks terrible to me
- I can't b/c I am diabetic.
- Only by choice, so no
- Rarely. If aide doesn't show up
- Sometimes don't feel like eating what she on hand
- Sometimes you don't feel like eating
- Try not to but there are sometimes that I'm so sick that I just can't, do fluids etc.

### **Q12: Is this because there is no one there to help you?**

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- Because of my medication. Changes flavor of food
- Scary when I'm throwing up and my husband has to come up b/c there's nobody here or they can't get in b/c I can't open the door

## Meals

### **Q13: Is there any special help that you need to make your meals?**

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- Aide prepares all his meals
- (name) does the cooking, doctor doesn't want me to be near the stove b/c diabetic attacks are dangerous.
- But it is difficult
- Can cook own meals - has been for last 2 months
- Can get my meals but have meals on wheels. Get my own at night
- Can make simple meals
- Can't feel the difference between hot and cold
- Can't make meals.
- Can't see well enough to find things in the refrigerator.
- Can't stand long enough to prepare a meal
- Caretaker makes meals
- Caretakers make meals
- Cook breakfast every morning. Doesn't eat lunch, but cooks himself supper.
- Cooks for herself on Sundays
- Daughter cooks and cleans. She takes care of all kitchen responsibilities
- Daughter does most of the cooking
- Daughter in law cooks but she can get a meal on her own
- Daughter prepares all the meals
- Daughter-in-law (personal care provider also), (name) makes meals
- Daughter-in-law cooks for her or makes meals ahead.
- When trying to cook she burns herself.
- Do not make meals, my husband does it, I don't go near the gas stove, I used to love to cook
- Does not cook his own meals
- Does not use another person. Eats frozen or delivered food.
- Does own cooking
- Daughter and participant share food prep
- Eats in dining room of assisted living facility but can get breakfast cereal by himself.
- Everything cut cut cut, and my dressings for my salads either seafood salad, chicken salads, or sauces on my fish or chicken need to be done all at home, and they all need what I already said, some very serious issues
- Family does it for him
- Get Meals on Wheels
- Get Meals on Wheels and then cooks other meals herself
- Gets meals on wheels and aids try to cook for me Mon., Wed and Fri
- And in between I use the microwave
- Has meals on wheels
- Has a girl to come in from the (name of agency) to prepare meals. Can't get meals on wheels because she has help.
- Has someone help make meals. Uses a food processor to take care of food for his meals.
- He does it (name)
- Her son lives next door and cooks for her
- His aide currently cooks his meals
- House staff cooks all his meals
- Husband does meals for her

## Participant Experience Survey 2010

- Husband makes meals.
- Husband.
- I am not allowed to cook because I won't remember if I have put food on the stove
- I can do it, well it depends on the hours they're coming. I've got one that comes in the morning, and I get meals on wheels, so I have that for lunch. I cook my own dinners. I can use the stove myself. It's all handicapped situation.
- I can't take the heat of the stove because of my breathing problem
- I can't use the stove because I have had sudden seizures
- I cook like a whirlwind, I do my own.
- I do all my own cooking w/ one hand. Of course I was a chef anyways.
- I do my own cooking and we get meals on wheels. Some of those meals are something else.
- I don't cook and like I was saying I can't cut my food up, I can't use a knife or nothing
- I don't cook, I just eat cold stuff.
- I don't have full sensation of hot and cold, very shaky and clumsy, not allowed near stove.
- I don't know how to cook, I can burn water
- I don't need help, but they mostly do the cooking.
- I get meals on meals and I get my supper myself
- I get meals on wheels
- I get meals on wheels and my aide will make lunch for me if I ask
- I get meals on wheels Monday through Friday. I actually usually get something from (name of local church) church, someone picks it up for me for the weekends.
- I have a friend that comes and he helps make dinner every night. And I have the old microwave! I wouldn't dare use the stove.
- I have meals on wheels; without that it would very difficult; I'd probably have to eat cereal
- I have two girls who come in and do some of the cooking
- I get frozen meals from meals on wheels
- I like help when it is here.
- I still cook
- I usually don't eat big meals, soup or a sandwich. Homemaker brings meals
- I will soon but not now
- If (name) doesn't do it, my husband will. You can already tell I like her! She's great.
- I'm actually a pretty good cook! I like to eat decent food.
- I'm too tired to cook any more
- It ain't easy but I do it
- It definitely helps. I can do it but it helps to have someone
- (name) does
- Makes some of his meals. Gets some meals on wheels
- Meal preparation,
- Meals are brought and otherwise can make meals herself.
- Meals are made at the facility
- Meals are provided at facility
- Meals on wheels
- Meals on wheels comes or my kids will come and they'll make something for me. I can cook simple things myself.
- Meals on wheels and I buy most of it
- Meals on wheels and purchases prepared foods
- Meals on Wheels at noon. Prepares dinner for herself.
- Meals on Wheels but often cooks himself.

## Participant Experience Survey 2010

- Meals on wheels or family provides food.
- Meals on wheels, neighbors help
- Meals on wheels, they just do my lunch, I got stuff for the microwave, I buy those dinners and stuff
- Meals on wheels; 7 days a week.
- Meals provided by facility
- Meals provided by facility where he lives.
- Mostly because of energy level and reaching cupboards.
- My daughter cooks for me usually, but if she wasn't here, I could do it myself. She's been taking care of me for over a year
- My daughter is my paid caregiver. She makes my meals
- My daughter is usually here to help me, I can't have lots of things going at once, and I need help reaching things high up. I burn a lot of my food
- My daughter lives with me and helps me
- My daughter usually does our cooking
- My husband does it, he's a good cook
- My partner usually makes the meals
- My son does all the cooking, for safety.
- My worker does that
- Neighbors and family help
- NH Visually Handicapped provided cooking class so he can cook. Does make breakfast and lunch. Can reheat. Sister does help with dinner. He is learning to do it on his own.
- No, we get meals on wheels and my husband does the rest of the cooking
- Not really, just getting around it sometimes.
- On occasion during a flare up, I am laid up in bed, so my homemaker will cook something for me.
- Parents do that
- Receives lunches from Meals on Wheels. Gets help for dinner.
- Receives meals at assisted living facility
- Receives meals from assisted living facility.
- Receives Meals on Wheels
- Receives senior meals five days a day
- Regency makes meals
- Requires her aide to cook. Family members serve as back up
- Sends out for a lot of meals. Didn't like senior meals because they are too dry and too bland
- (name) cooks it, and CNA reheats it
- She can't cook, she'll forget that she left the stove on.
- She does the cooking for me, but if I had to get a small snack after she has left, I can if I don't have to stand up too long. I couldn't cook a roast or something like that.
- She does the cooking in the household
- Sister does the cooking
- Somebody cooks for me.
- Somebody prepares meals for me
- Sometimes
- Sometimes - getting things together
- Sometimes I request things that are not on the menu. I am perfectly able to cook at this home provides meals.
- Sometimes I'm able to cook and sometimes my husband gets it all together and gives me a plate like I'm a princess, I'm the queen
- Sometimes my homemaker helps me, but I mostly cook my own meals. I cook whatever I want

## Participant Experience Survey 2010

- Sometimes needs help. Grease sometimes makes me choke
- Sometimes she needs help from her daughter
- Sometimes, sometimes I can't breathe well enough to do any cooking or back hurts too much
- Sometimes. My husband and I do it together
- The cooking is done for us
- There are times that I have to have someone make my meals
- They help me cook, like if I'm cooking spaghetti, I can't lift the pot myself, so they do things like that.
- Trying to stay on the diet given by my gastroenterologist; intolerance/sensitivity to fiber
- Uses microwave and get my own meals; stove safety desired by my son whom I live with; they make supper when home from work
- Usually has help with supper - hard to get everything out and cook everything all at the same time. Can do breakfast and lunch. Twice a week lunch receives meals on wheels (tues & thurs).
- Usually mom cooks, but you could cook simple things, if you knew how to cook, I could. I can read directions
- Usually prepared ahead of time by someone
- Usually don't cook, because she doesn't like to cook meals for herself only. Sons bring meals on weekends or she will cook for them. Other days makes meals for herself.
- Well, I get meals on wheels, boy I'm not happy with that, some of the meals are terrible, so I don't eat them. I get them 5 days a week, and then double on Friday for the weekend. I can cook for myself, once a month I cook a good boiled dinner.
- Well, where she is in the kitchen, she makes the meals. I make my lunches, breakfasts, but I could do it myself.
- When he feels up to it he cooks, but usually not
- Yeah sometimes
- Your meals are prepared for you

### **Q14: Do you ever go without a meal when you need one?**

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- A lot of time because she can't swallow.
- Because I wouldn't eat what they were serving
- Because when it is hot and humid the meal goes right through me. I am on insulin and the food doesn't stay in me long.
- (name) is always here
- But I may not eat the proper thing
- But sometimes I just snack
- Can get to the fridge but not a full meal
- Fairly often by choice
- I also have meals on wheels
- I do a lot b/c my stomach knots up and I can't swallow.
- I get meals on wheels for lunch, I usually don't eat breakfast. The only time I eat breakfast is when (name) is here.
- I have to be careful about my eating because I am insulin dependent - 3-5 shots a day
- I never need one, not hungry, but diabetic, so need to eat. All the meds make me not hungry
- If worst comes to worst I can pour myself some cereal or make myself a peanut butter and jelly. It is a project, but I can do it.
- I'll find something to eat, but a prepared meal sometimes, will find snacks and I do keep some frozen dinners but they're not the most palatable
- My aide always prepares my meals for me
- Needs to be driven to the market

## Participant Experience Survey 2010

- No b/c I really don't have the urge to eat most of the time
- On my good days I can still cook
- She gets meals and wheels
- Some days I can't swallow, my throat muscles don't work
- Sometimes don't feel like eating
- Sometimes I forget to eat breakfast, sometimes I learn to go without if I need it and I don't have it.
- Sometimes if she doesn't feel like it, but not because she doesn't have food or isn't able to get it
- Sometimes when I am out and about I forget to eat but generally, no.
- Sundays they no longer have meals here, they are cutting back so they no longer have meals on the weekend. Some of the food is cooked by (name of agency) and I can't eat it
- Try not to, b/c it's not good for me, unless I'm on npl and then I do ice chips and syrup on the ice chips so that I don't get dehydrated and lose any more weight
- Twice a week

### **Q15: Is this because there is no one there to help you?**

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- Because she can't swallow
- I can do everything, it's just that when my stomach locks up, it comes right back out.
- I have a choking problem so I don't eat when there is no one home
- Sometimes
- Sometimes too tired or weak
- Sometimes. Homemaker does make a sandwich and I can put a frozen dinner in the oven but it can be too much
- Yes, my husband has to get up early for work and I just stay in bed

## Groceries

### Q16: Is there any special help that you need to get groceries?

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- A friend takes her to store.
- Absolutely
- Aide does shopping for him
- Always. Does not drive.
- An aide or family get the groceries
- (name) gets groceries, I can't walk the stores, my back.
- (name) brings me and reaches for the higher things b/c I can't do that b/c of torn rotator cuffs in both shoulders.
- Can drive van to get to and from store.
- Can't drive, mom does shopping, nothing preventing me from shopping
- Can't drive, so sister buys groceries.
- Can't push a cart
- Can't see to get groceries.
- Caregiver does all grocery shopping
- Caregiver does shopping.
- (name) my paid helper helps me pick out stuff cause I can't read
- Daughter gets them
- Daughter does it all. And my errands
- Daughter does that shopping
- Daughter takes her shopping.
- Daughter usually does her shopping
- Daughter-in-law gets them or takes him
- Daughter-in-law goes with her to do shopping. She can go to stores if they have a motorized cart. Sometimes try to use her walker with a seat for stores without motorized carts, but otherwise daughter-in-law will do the shopping by herself.
- Depends on a friend
- Does not apply. Meals provided by facility
- Does not do shopping
- Does not need groceries.
- Does not shop anymore
- Does occasional shopping with her daughter
- Doesn't have a car, so has to find someone to take her - says it's hard to find people
- Daughter does shopping
- Family does shopping.
- Family does that for him
- Family members get groceries
- Family members or care workers will take care of it
- Family members take care of it. Sometimes they take him to the grocery store.
- Family takes care of groceries.
- Family takes him to the store
- Food is bought by staff
- Food provided by facility
- For driving and safety, but I go with her
- Gets all meals at facility

## Participant Experience Survey 2010

- Gets help from daughter in law
- Gets help from care worker or family but transportation sometimes an issue.
- Goes with care provider every Friday
- (name) brings me once a week, he drives me crazy, he reads every label, I drive him crazy too. If someone puts together a meal for me I can put it in the oven.
- Has a friend that helps
- Has assistance when he goes shopping
- Has grocery store deliver.
- Has someone take her to the store.
- He does the grocery shopping, I don't do the grocery shopping
- Her aide drives me to market and to pay my bills. I choose my own food
- Her aides do her shopping because she can't walk the stores
- Her daughter buys the groceries. The food at the assisted living facility is too spicy
- Her son does her shopping or her aides
- Homemaker does it
- Homemaker does shopping for me
- Homemaker does shopping, no car, no driving
- Homemaker gets them. Sometimes I go on the shopping bus if I feel up to it
- Homemaker helps her - takes her shopping
- Homeowner provides the groceries
- House staff does all the grocery shopping
- Housekeeper gets them.
- How can anybody get groceries when they're like a robot to begin with and then they leave me with a mess in the kitchen
- Husband
- Husband does all shopping
- Husband does shopping
- I call in my order on Tuesdays and they deliver
- I call the, 3 rides a month, go to grocer with aids
- I can do it alone but it is a difficult and taxing effort
- I don't drive anymore
- I don't drive. My caregiver takes me to the grocery store so I can pick out what I want.
- I don't drive. I need help getting there and home. I need help putting stuff in my cart
- I don't get groceries
- I get help at the grocery store. I use the electric shopping cart
- The home health aide takes me"
- I go w/ the aides in the afternoon
- I go with her and I use the electric chair in the grocery
- I have a hard time walking, I haven't found anybody yet, I do it myself, but it's hard
- I have a homemaker that does that, or I have my daughter or son in law will go do a big shopping day for us. My wife is having a hard time w/ her lungs so she can't really shop.
- I have a homemaker who gets them for me.
- I have a mims worker that helps me do everything on the outside, bank, pharmacy, groceries.
- I have to have someone take me and to help me remember what I need to get
- I have to sit in a power chair when I go
- My daughter does the shopping 80% of the time
- I like going to the store b/c it's time out
- I make the list and he does the shopping

## Participant Experience Survey 2010

- I need assistance to get to the car and then I need a motorized cart
- I need money. I get food stamps but I am on a restricted diet and food stamps doesn't allow for restrictions so I can't change. My granddaughter has to bend and help put stuff in the cart.
- I need to be driven and I get dizzy spells. My girlfriend or my daughter takes me
- I take a taxi back. I go myself. Whenever I call the person who is supposed to take me, she is busy, so I go myself.
- I use the power chairs in the grocery store
- I usually try to combine my trips out to my support group, to the pharmacy and food pantry or the store
- I usually go with my worker to get groceries
- I walk to the corner
- Is driven to store by care worker.
- Is no longer able to drive
- It depends on the day if my arthritis is bad then I need help
- (name) goes grocery shopping
- My aide does all the shopping and errands
- My aide does it.
- My aide does my grocery shopping
- My aide does that for me, I am not allowed to go with her, I can't go in her car, I make a list and she goes for me. I'd love to go with her.
- My aide takes me there too, and if I don't feel like going, she'll go for me.
- My caregivers do my shopping
- My daughter brings me because I don't drive
- My daughter comes with me and does the groceries with me, she'd like to spend more time, but she works herself.
- My daughter does all that
- My daughter does most of my shopping
- My daughter helps me. I can do it if I need to but it is difficult. I need people to help me in the store because I can't reach anything.
- My daughter take me every month or so. I have to ride in a battery cart to do shopping
- My daughter usually gets my groceries
- My daughter usually, sometimes I send the homemaker
- My daughter-in-law does all our marketing
- My family locally helps me
- My husband does that for us
- My husband does the shopping and he does a good job
- My husband still gets our groceries
- My mom usually goes for groceries.
- My neighbor, son and granddaughter gets them for me
- My roommate always goes shopping for me b/c I can't breathe well enough to go and do it
- My son does most of my grocery shopping
- My son does my grocery shopping for me, sometimes I go along for the ride.
- My son gets them for me
- I can't walk in the store. My legs give out
- My son in law does all the grocery shopping.
- My son shops for me, but I go sometimes to get out of the house
- My wife does the shopping once a week. When I have a chance, I go to the soup kitchen in my electric chair. We get what we need from the soup kitchen, but we don't shop much. Food for the cat.
- Need a ride to the grocery store

## Participant Experience Survey 2010

- Need to be driven to the grocery store
- Needs a ride to the market
- Needs a ride to the market but does own shopping
- Needs help putting groceries in the cart and taking them out. Can't carry them from the car to
- Needs someone to drive her.
- Needs someone to go with him. Once in a while he goes blind or gets blurry vision.
- Not applicable
- Not applicable - food provided
- Not at this present time
- Nurses' aides do shopping, I have no vehicle and they are not able to drive me due to their contract. I just write a list, and they go get it.
- Only in inclement weather
- Only need help for transportation and carrying groceries in
- Parents help with groceries.
- PCSP
- Person who comes on Monday gets groceries or her family members
- Phones in her order when she needs groceries to supplement the two meals she receives daily
- She'll come and goes shopping on a Tues or Friday for me, depends on when I get my food stamps. And if I need something in between, one of the other girls will get it for me. I'm pretty well set.
- Shopper does it once a week.
- Sister does the shopping
- Sister helps her
- Sometimes I have to send someone for groceries, if the syncope is acting up, there's nothing I can do.
- Son does grocery shopping
- Son takes her shopping.
- Spouse takes me and I can push the cart
- That is the sticking point. There is a bus once a month that goes to the (name of store) in Concord but I am unable to go to that. I can shop by myself but it is just getting there.
- The girl from (name of agency) takes her or gets the groceries
- The girl gets my groceries, medication, laundry and housecleaning.
- There's a housekeeper that comes. She comes to my husband 3 times a week, 3 hours at once for me. It's not enough if you ask me!!
- They do that, they get the groceries and they make the meals
- Transport and carry back
- Transport to and from
- Transportation to get there, but do it by self once there
- (name of agency) does shopping and get Meals on Wheels
- Usually daughter
- Very upset the hours were cut for caregiver. Used to have three hours now has two hours. This is not enough time to get grocery shopping done. She can't move quickly. This makes shopping overwhelming.
- (name of agency) come one a week day to do grocery shopping.
- We plan it out once a week. We go through the sales.
- Weighs too much or out of reach
- Wife and paid helper goes to grocery; wife would like to have more help
- With shopping due to back pain
- Yes, sometimes. Has homemaker who does grocery shopping.
- Yes, we have a person who does the grocery shopping b/c my husband is also sick

**Q17: Are you sometimes unable to get groceries when you need them?**

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- Absolutely, I've been known to go days w/o food.
- And I just have to wait for the girls, that's all. It's nothing horrific. Except for my cigarettes, but I have my daughter pick that up.
- And my husband is also
- Because it is too hot for me to go out.
- Can drive and go by herself if need be
- Due to money
- Especially in winter. Can't get to the store on her own.
- Family members help out
- Gets meals on wheels or daughter helps
- Granddaughter also can run to the store.
- Has 2 care providers who will take him when he needs to.
- Her neighbors are willing to fetch things for her if she runs out
- Her son is very reliable
- He's right next door!
- I actually get so many things from meals on wheels, I even have some that's in the freezer from them.
- I don't drive anymore my PCSP does a very good job but I can't go out without a ride
- I have friends or family who can always take me when I need something
- I have to plan carefully so I don't run out of things
- I haven't had that problem.
- I just wait till they can come get me some. You always have plenty on hand, I have a freezer, I'm from the north country, you learn to survive.
- I make sure I've got enough
- I seem to be fine. Probably later on today she'll go to the store and I'll give her the money to pick up what I need. Most of the time I do go with her, but I have church this afternoon.
- I was living in the number (street address) street, but after my daughter left, they cut me off b/c they claimed that we make too much money, SS too much money? I don't think so.
- If I can't go, my house mate goes
- If I have the money, I don't have a problem
- If my help is not here
- If she has doctors appt that interferes with the grocery time then it doesn't get done. Family can help but they are not close by and she doesn't want to burden them.
- In wintertime
- It's difficult
- It's happened.
- I've always got somebody. And my homemaker if she is here, she'll go to the store for me, or my kids will stop at the store for me.
- I've never had any problems, I get 12 dollars a month and that takes care of my milk and stuff
- Kitchen is always well stocked
- My aide is very reliable.
- My care givers come every day
- My daughter gets my groceries for me
- My husband and my girlfriend do the shopping for me
- My husband can always do it if we need something. I only have her Wednesdays and Saturdays.
- My partner does my shopping

## Participant Experience Survey 2010

- My son or my daughter will take me
- Neighbors will get anything I need including medicine and my son helps
- Never without food but someone is not always available when the shopping needs to get done.
- No, they are always there
- Not really, before she runs out she arranges with housekeeper or someone else to help her when she buys groceries.
- Not too often
- Occasionally
- Occasionally.
- One of the daughters does the handling of the money and if I'm short on money, I might not be able to get them.
- Only in the winter
- She has friends who'll help if she needs something.
- Sometimes
- Sometimes runs out but I don't have anybody to go get it
- Sometimes.
- The home owner keeps a full pantry
- The money that I receive from the disability, I have it all mapped out, so I usually can get groceries. I'm not used to living on chump change.
- I can't get to the store.
- Unless he drives me there, there's no way of me getting there
- Usually I have enough in the fridge. Sometimes I can't open cans, I usually have aides do that before they leave.
- Usually we have a friend or someone that can get them if we're out of something. And on occasion my wife has gone in on her power scooter to get a few things. I haven't been to the store in over a year.
- Well, it's like now I've run out of money! It's impossible to get everything even if you do a big shop. Like a loaf of bread, I'm out of bread.
- Yes, because if I want something special and if the aides are not here, I can't send them.

### **Q18: Is this because there is no one there to help you?**

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- And due to lack of food stamps
- Because I'm not able to drive
- Can't get anybody who has a car, so has to go without until she can find somebody.
- I can only ask my husband to do so much and he can only do so much
- I run out of funds
- It's because I run out money at the end of the month
- Money runs out
- My son helps me also
- No money, economic situation not good. Simply I have to support my daughter until she is 21, it's the law in (names another country)
- Other circumstances
- See previous
- Sometime other needs like doctors appt will interfere with the time she has with caregiver. Doesn't have enough time with caregiver.
- Sometimes but has ways to get groceries if necessary.
- That and funds
- There are always groceries in the house
- Transportation is the biggest issue.

## Participant Experience Survey 2010

- Usually I forgot something or ran out of something, I have help twice a week
- Yeah. There is a lady at church that I can call if I really need it
- Yes and because I need transportation

## Housework

### Q19: Is there any special help that you need to do housework – things like straightening up or doing dishes?

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- A girl comes and does my heavier cleaning. I do my own dishes and make my own bed.
- Aide and family members do all her housework
- Angels help
- anything bending over, cleaning the floor, sometimes it causes dizziness
  
- Sometimes need help w/ dishes
- As you notice, I have a lot of clutter, I'm a hoarder. But my house is clean
- Can do dishes and some dusting. It's hard to get into corners to get things out. Hard to vacuum because legs get caught in cord.
- Can do dishes but cannot do other housework due to physical limitations.
- Can do dishes but care worker does housework.
- Can do dishes, but needs someone to mop and sweep floors.
- Can do the dishes, but always has live-in care giver or daughter do it.
- Can straighten up and do dishes, but no vacuuming or things like that
- Can't do any of it. (name) does it all.
- Caregiver and husband take care of it.
- Caretaker does it for me
- Comes Mon and Thurs
- (name) , daughter-in-law/personal care provider.
- Daughter does the cleaning
- Daughter in law does some; and homemaker does some and my son has done a lot as well
- Dishes, vacuuming, making bed, washing floors
- Does dishes and bed herself. Has assistance to clean floors and do laundry.
- Does dishes, but not all housework
- Does dishes, but no housework.
- Does have someone change bedding.
- Done by facility staff
- Daughter and participant and granddaughter share responsibility
- Everything
- Generally (name) does dishes at night before he leaves. Sometimes I say leave them b/c I really need to be able to do things. The homemaker comes once a week to do heavy cleaning. And I love the people I have.
- Gets tired easily, but can do most of it. (name) helps with laundry.
- Girl who comes each morning does the cleaning
- Has a dishwasher and wife takes care of that
- Has a homemaker
- Has an aide come in to help
- Has an aide who comes in to clean his house
- Has problem standing at one time so does need help.
- He does it
- Help comes in on Friday
- Her aides and her son do the work for her
- His aide does the dishes and the housework

## Participant Experience Survey 2010

- Home provider does the house keeping
- Homemaker
- Homemaker comes in once a week to do cleaning. Does some light homemaking, some dishes, some clean up, etc.
- Homemaker comes to sweep and wash the floor. A lady comes and cleans all the bathrooms in the building. I empty the trash in the building.
- Homemaker does that, I can do my own dishes sometimes
- Homemaker does that, she vacuums, she dusts, does dishes.
- Homemaker does that, she's good.
- Homemaker helps with vacuuming and dusting. She makes her own bed and takes care of animals.
- Homemaker or husband
- Homemaker straightens up and I do dishes
- House staff does all the housekeeping
- Housekeeper does everything but dishes
- Housekeeper helps
- Housekeepers from the facility
- Housework is done the staff
- I am not very good at it and I don't like it so help is appreciated
- I can do most things myself, but she does it. I take care of my room.
- I can't bend well enough to pick things up. I can't move around well to do house work.
- I can't do any of that, I can't mop the floor
- I can't do anything
- I can't stand too long on my feet. Can't do laundry. I have trouble breathing since I have COPD
- I do a little picking up, dusting here and there, bending over and picking things up, I don't dare to do it, b/c I might go right over like I have before.
- I do it myself. But my daughter helps with the heavy cleaning like washing the floors.
- I do light housecleaning, dishes and straightening up and stuff, other than that, (name) does the cleaning.
- I do my own dishes too.
- I do the dishes and I pick up the kitchen and at times I vacuum. The housekeeper comes too, but I don't kill them. They do some stuff, heavier cleaning.
- I don't do dishes, I can't get to the sink, I can't reach the knobs anymore b/c I don't stand so, the faucet I can't turn, I can't push a vacuum cleaner or make my own bed
- I don't have to worry about that, they do that for me
- I get someone from (name of agency) on Tuesdays and Thursdays cleaning for me and changing my bed sheets and all that stuff. I can do some things myself like a few dishes.
- I have a helper 2X 3.5 each time and (name) does whatever else needs doing
- I have a housekeeper
- I have a housekeeper who comes in because I can no longer stand at the sink
- I have bad balance
- I have pain when standing at the sink or doing house work; I have to do it bit by bit or not at all.
- I make my own bed and they don't want me to help with washing dishes or doing laundry b/c I have chemical infections and I can't wear globes
- I need help making my bed, doing my floors, cleaning the bathrooms, tub and everything, vacuuming.
- I need help with most everything, I can't stand up very long.
- Is physically able but does get assistance.
- I've been having help, but I can do it myself. They haven't shown up for over a week.
- (name) does it
- Knees are very bad, needs help with laundry

## Participant Experience Survey 2010

- (name) , PCP
- Lives with family
- My aide and my nephew (name) does the trash and makes the bed. He's a good kid
- My aide does it
- My aide does the housework
- My aide does the cleaning. She gets paid for that
- My aides do my cleaning
- My helper does some of the housework
- My homemaker does that, she cleans for me.
- My mother insists on dusting
- (name) is the caretaker here
- Needs help making my bed
- Needs help with everything since she can't stand for any length of time
- Needs help with vacuuming and heavy cleaning
- Neighbor, (name) (paid help), comes down 5 days a week (20 hours)...does the dishes, vacuums, changes bed and does laundry.
- No, I can do the dishes, I can't sweep up or vacuum or anything, our homemaker does all that.
- Nurse does that
- Nurses aid does that
- Oh yeah, she does everything. She takes care of all housework, I can't do anything
- PCSP
- (name) comes on Tuesday morning, she does the heavy cleaning for me. Changes my bed, does the floors and bathroom, and my son lives with me and he takes care of his own things. He just lost his job.
- Says she doesn't need help but does get help from caregivers.
- She comes 8 hours a week, usually 2 hours at a time. She takes me to doctor's, counselors, groceries, etc.
- She does some cleaning. Staff does other. She said that the doctor said she shouldn't even be cleaning.
- Someone from (name of agency) does it
- Sometimes, I do all the dishes myself, but some cleaning I can't do. Vacuuming, laundry, and cleaning are hard b/c of my contractures.
- Sometimes, sometimes it's the same sort of things, I try to be the normal mom and doing things and often my husband and my daughter do things
- The only things she does is do dishes, only exercise that she gets.
- The staffers do that here but I am capable of doing. I have lots of things crammed in my little room but I keep it tidy and I keep a fire lane. I have my dust pan and hand broom that I sweep with
- They clean my room, they do my laundry
- They do it when they come 3 days a week. I can do my own dishes, but they do the heavy cleaning and scrubbing.
- They leave it all to me, I'm supposed to be the patient, then I'm the good Samaritan, then I'm supposed to be the cook, the housekeeper, etc.
- Uses a walker but cannot do housework
- Vacuuming and cleaning
- We have a homemaker that comes in
- We have help for that
- Well, (name) does the deep cleaning, I do my own dishes, it takes
- Whoever is here does it. I have (name) the housekeeper once a week who does the floors and the heavy cleaning.
- Yes that's what I have aides for
- Yes, I have a homemaker that comes twice a week

**Q20: Does the housework not get done sometimes?**

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- Always done
- Because I don't do a lot of housework
- Done every week
- Everything I want done gets done
- Had hours cut last year by three hours and that made a big difference.
- (name) is here and we get stuff done. My kids are doing their own things, so they don't have time to come over at night and do things, if I needed them, they'd be here. And I went through (name of agency) b/c my daughter was working there at the time.
- Her daughter and her father help out so it is done well
- His aide is reliable
- Homemaker is there twice a week, so it stays pretty well picked up
- I can't say it doesn't get done, the problem is I have the small space and I have 8 rooms of furniture
- I have a homemaker that comes twice a week so I try to hold off until she can get here but my husband is here to help somewhat
- I have had several aides who do not work to my standards
- I keep it pretty well clean, the guy next door complains about the cockroaches and says they come from me, but I don't see none. The other guy don't flush the toilet either.
- I make sure she does it
- I was brought up in a way that you don't have a dirty house and even when it kills me I get things done; Sometimes I have to lean hard against something I do that
- If she can't come or if she is sick, it doesn't get done
- If they don't have enough help to send someone
- If we are doing other things during the two hours, it doesn't get done
- It doesn't get done period, unless someone comes in and does it for me
- It gets done
- It gets done every time she comes here. That's what I like. I had to tell her the first time, but now she knows exactly what needs to be done. I couldn't be more happy with that company, (name of agency) .
- It hasn't been done in over 12 – 14 months
- It would be cleaner if I were doing it but she does a lot here including yard work
- It's always done
- It's always done
- It's always done once or twice a week
- It's done regularly, not the way I want it done, but I'm too persnickety about it.
- It's usually pretty good.
- (name) does everything, I make sure that I don't make any mess.
- Most of the time
- Need more hours of help
- Needs a homemaker 2x a week. I haven't cleaned up my couch or table for a really long time because I have no room. There is a cart I can put things on but I have to ride up and down the elevator and that exhausts me
- Oh there's time when it don't get done. He makes an awful mess, I get after him though and he's getting better I guess. He had stuff everywhere, it would drive you crazy.
- On days that the housekeeper isn't there, some things don't get done because (name) isn't supposed to be lifting too much. She tries, but can't do much.
- On the weekends when no one is here.
- Once a week I have a homemaker come to help clean, shop, laundry, etc.

## Participant Experience Survey 2010

- Only if I am in a hurry to go somewhere I ask my helpers to wait for another time to clean
- Only on the weekend
- Only when (name) not here
- She always gets it finished. The only time we have to skip it, is when she has to take me to the doctors, but then she comes back the next day and gets it all done.
- She comes 2x a week
- She does a good job and works well.
- She's really organized, right after my shower, she's right on it.
- Someone comes 2 times a week
- Sometimes there are days when there's not enough time to do it because of appointments, etc.
- Son will help with housework when aide can't help
- There's always someone here those 3 days, so it usually gets done
- They keep a very clean house
- Unusual that it does not get done.
- Usually once a week on average.
- Very rarely
- When the aide is not here
- When they don't come, she doesn't do it.
- When they're not here
- Would like it cleaner than it is
- Yes because my housekeeper needs to do other important errands for me such as pick up groceries or medicine and that takes away from cleaning time.

### **Q21: Is this because there is no one there to help you?**

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- B/c (name) and (name) sometimes take a day off
- Busy going to appointments or doing other things.
- Gets frustrated and cries when there's housework to be done and she doesn't feel like she is able to do it.
- Has a lot of doctors appts and those take up time with caregiver.
- Homemaker here 3 times a week.
- Hours cut
- Housekeeper only comes 2-3 days a week
- If no one comes, she doesn't do it
- It's a matter of timing and priorities
- It's just clutter and things
- Just because we get tired
- My aide often sits and does very little – she does not finish the chores
- Not enough time with caregiver to get everything done.
- Once in a while the health aid will help do dishes
- 
- Sometimes
- Sometimes there just isn't enough time with the people who help her.
- Son lives here and does some but not always timely
- There is too much for one person to do in allotted time but she is a multitasker and does okay
- When outside help is not here

## Laundry

### Q22: Is there any special help that you need to do laundry?

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- “I do it if I can”. Sounds like his care provider is supposed to, but he says he’s stubborn so tries to do things himself.
- Aide does it
- Aide does that too
- (name) does it
- Because machines are in the basement
- (name) does it. I can’t reach the clothes in the washer b/c it’s a deep tub
- Brother in law did laundry
- Can’t even get there myself
- Can’t stand that long .Don’t have the stamina.
- Caretaker
- (name)
- Daughter does it.
- Daughter takes care of it
- Daughter-in-law does his laundry
- Do that all by myself. I have to have a special detergent
- Does need help with the washer
- Does receive help from staff.
- Doesn’t do laundry
- Done by aide
- Done by facility
- Done by facility staff.
- Driver does laundry, she’s a big help
- Everyone helps get laundry done, she likes to help fold clothes
- Facility staff does laundry.
- Girl does the laundry 1 day a week
- Has someone do it, because she can’t get to the washer and dryer – they’re positioned too low that she can get to them.
- He does some of his laundry and the aide does the rest
- He does the laundry, he’s hired for 35 hours a week and he works more than 40 hours a week easily, just to keep the basics and my doctor’s appointments
- He puts it in the washer but has a little trouble bending over to put the load in the dryer
- Her housekeepers do her laundry and heavy housework
- Her laundry is done by her aides
- Home health aide does laundry
- Homemaker and daughter does it all
- Homemaker does it
- Homemaker does it for me
- Homemaker does laundry. Can’t carry it down to the laundry room.
- Homemaker does that for me
- Homemaker, I can’t push the thing down to the laundry by myself and I can’t see enough to put the quarters in. I did used to do all the laundry.
- Housekeeper does it
- House staff does his laundry

## Participant Experience Survey 2010

- Housekeeper
- Housekeeper does it, but if she's not there for 3 days, then (name) does it herself...it's difficult to carry laundry – tries to use walker to carry laundry
- Husband does the laundry, that I can't do, I did it before but it gets too hot and wipes me out
- I am not allowed to use the machine
- I can do some but I cannot stay on my feet too long.
- I do it myself most of the time. I don't do it every single day, I may wait a week b/c it's only me.
- I do some laundry in the sink. My aide does loads of wash in the laundromat
- I don't do it at all
- I don't do laundry
- I don't do laundry, the homemaker does it for me, or my husband does
- I don't do stairs.
- I don't do the laundry, they do it for me when my basket gets full
- I feel very guilty about not doing the things I CAN do
- I go to the laundromat across the street
- I have a washer and dryer down the hall and somebody does it for me. .
- I like to have help, but I've been doing it. All of the sudden, no one shows up.
- I need help for the sheets and bedding, any heavier laundry, but I do the rest myself.
- I still hang it outside except my towels
- I use the washer on my good days
- Is able to put wash in, her aides do the folding
- (name) does it; washer/dryer is downstairs and (name) does not allow her to go downstairs
- (name) does the laundry, we have enough clothes so we can get it done.
- Laundry downstairs and cannot get downstairs.
- Laundry downstairs, so homemaker does it
- Laundry is done for him
- Laundry needs to be taken downstairs and she needs help with that – usually tries to get help from her children. Tries to hand wash things herself.
- Live-in daughter does laundry
- Mom does laundry, someone brings it up for me and I put it away. I can't carry it upstairs.
- Mondays the housekeeper does laundry
- My aides do the laundry twice a week
- My daughter and the housekeeper do the laundry
- My daughter does my laundry
- My daughter does my laundry
- My daughter does my laundry – I can sit and fold the clothes at a moderate rate
- My homemaker does that
- My homemaker helps me with that
- My husband usually does it
- My son helps me take the clothes out of the washer
- Never has the money to do laundry. Kids help out
- No my aide does that too, she takes it upstairs and does it.
- Not allowed to do the laundry
- Nurse
- Nurse does laundry
- PCP does it
- Paid helper assists

## Participant Experience Survey 2010

- (name) helps me and then she plays cards with me or whatever while we watch the laundry and people steal your stuff.
- She does my laundry but it's been in the drier two days
- She does my laundry, but I put it away.
- She helps me fold them, washes, dries, folds, and puts them away
- Sister
- Some days I need help but I try to do it
- Sometimes we do it by ourselves, if we want to
- Spouse and participant do it and if any left over then (name) , home health aide pitches in
- To carry it downstairs to the laundry room, but then stays to help with doing the laundry.
- (name of agency) does the laundry.
- We have a certain day that's set out... Wednesday, I had a care plan drawn up
- When I get paid, I got a lot of clothes, so what she's actually washing is my old clothes, my good clothes I take to the cleaners. My girlfriend takes them to the cleaners
- Wife does housework and laundry.
- Wife gets the homemaker service, but it benefits me too
- Yes
- Yes, I don't do stairs, she does it. Whatever needs to be done, she does it all, it's hard for me to do anything

### **Q23: Does the laundry not get done sometimes?**

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- It makes me livid.
- Has a system in place where homemaker does it every 2 weeks
- Homemaker has been out, so my daughter has been doing it.
- I can't move but everything gets done
- I have the best people, I don't care what anybody else says, mine are the best.
- I make sure it gets done on a regular basis
- I try to do it sometimes, but I get very short of breath. I don't want to completely stop doing everything, b/c it takes away my independence.
- Once in a great while it does not get done
- I usually do my laundry every month
- If for some reason not able to come, family does it for him.
- If one person doesn't do it, the other one does.
- If there was ever a week where she couldn't come, (name) would not happily do it, or one of the girls would come take it home and do it.
- I'm actually good about it.
- It always gets done – either hand washed or machine washed.
- It gets done at least once a week.
- It gets done every week.
- It gets done everyday...workers have a schedule
- It gets done.
- It's pretty good. Sometimes I put them in the tub and let them soak overnight, but they go out and put them on the clothesline for me. If it wasn't for these gals, I'm telling you, I couldn't exist.
- May be postponed one day but gets done
- Mom does laundry every day
- Mom helps with daily things as well as the aides
- My aide knows just what to do. She's wonderful.
- My daughter helps with my laundry

## Participant Experience Survey 2010

- My mom does our laundry
- Not so far
- Oh sometimes it don't b/c they do this, see, in 3 hours, it's not enough time. We just lost our best girl.
- Only if (name) is not here. I can have (name) carry it down for me, but I can't stand to do it
- Only if they cancel and I don't want someone new to come in
- Only when I tell her I don't need it! When she comes in, she asks two things, do you have laundry and do you want your bed changed, then she just goes and does everything
- She does it
- She does it herself when housekeeper isn't available to do it, but she struggles to do it.
- She does it once a week
- She has a regular routine and she keeps up with it.
- She keeps the laundry up well. Washes and folds and puts away.
- She's here on a regular basis.
- She's right on top of that
- Sometimes goes longer than I want it to
- Sometimes I don't have quarters for the machine
- Sometimes I have to call her to remind her because she comes when I am at the dining room
- Sometimes if I haven't been able to get to the bank
- Sometimes. Try to do it once a week
- Very rarely
- With the help we have now, everything gets done, but before we had them, things didn't get done

### **Q24: Is this because there is no one there to help you?**

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- And I don't have the facilities
- Because no one does it
- Can't find anyone to help her
- Caregiver isn't here long enough to get it done.
- I think I could do it, its' just been awhile. I used to always go to the laundromat
- If no one does it, She has to go outside to do it and she doesn't want to do that
- It is because I need to use the machines in the building and sometimes I don't have enough money or I do not have access to get change.
- It's b/c we don't have the money
- Or they ran out of time, the biggest one
- Sometimes it gets postponed but that might be because there aren't enough washers and dryers in the apt complex.
- Sometimes not enough HCBC hours to get everything done
- Sometimes she runs out of time. If it doesn't happen 1 day, it happens the next.
- They won't stay extra, b/c of money.

## Transportation

### Q25: Can you always get to the places you need to go, like work, shopping, the doctor's office, or a friend's house?

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- Aide drives him to doctor's appts.
- All I really go to is doctor's, hospital, wound care.
- Always arranged through service
- Always have (name of agency) van help me
- Because of transportation. Program needs work on transportation issues outside of the city
- (name) drives me. I'm all done driving.
- Can drive himself
- Can get to doctor's appts but doesn't get to go visiting friends or family because of difficulty with chair.
- Care provider takes him
- Care worker or son takes her to doctor's appt.
- Caregivers needs two weeks notice. I go by para
- Care worker and family provide transportation
- Church- sometimes has a hard time getting there
- Daughter takes her everywhere
- Daughter takes her
- Depends on the weather, if it's raining out, I can't go nowhere, my wheelchair is electric, I can't push myself.
- Doctor, (name of agency) ambulance will only take people to doctor, not pharmacy or anywhere else. That's their policy.
- Doctors always b/c the vans will take me there b/c it's part of my Medicaid/re thing, (name of agency) bus has only 2 wheelchair slots and the facility has many people with chairs, transportation isn't good, and I'm not able to get in and out of cars
- Doctor's office, yes. Everywhere else, no.
- Doctor's or shopping but for nothing else like pharmacy. Sometimes can't get medication when it's ready and has to wait.
- Doctor's yes, b/c I can use my wheelchair and (name of agency) ambulance
- Friend's house, sometimes depending on how feeling. I can drive my car.
- Does still drive but not long distance.
- Drives
- Drives himself.
- Daughter provides transport; once in a while my son will take me if my daughter can't
- Daughter takes me out 1-2X weekly and (name) in office can set up other transportation
- Either my case manager takes me or the nurse at the home
- (name of agency) usually can take her.
- Facility staff
- Family members give her rides
- Family members take him to appts.
- Family members will drive her.
- For the most part, yes. I have a driver that brings me to work and to school.
- Generally. Between PCSP or bus service
- Get his rides from family members
- (name of agency) has wheel chair van that he uses.
- Has hard time getting to doctor's. Usually sister will take her places.

## Participant Experience Survey 2010

- Has to plan far in advance. Doesn't get out much, but would LOVE to...it has to be really important like a doctor's to be able to find a ride.
- Her doctor makes home visits because it is not handicapped accessible
- His daughter takes him
- Home providers reliably provide transportation
- Husband still drives and can take her. Or can use van service, (name of agency)
- Husband usually
- Husband usually takes her but sometimes his health prevents it
- I can get a ride
- I can go almost everywhere, (name) takes me everywhere I need to go. I really don't see friends except for at daycare.
- I can no longer walk so my doctor makes house calls
- I can use my power chair to go to the local doc
- I can't always
- I don't work, (name) helps me do the shopping, I'm not up for driving sometimes not awake enough to drive.
- A lot of times I can't get things done when I need to, food shopping, pick up meds"
- I even went to the Ice Capades. I go to Bingo sometimes. My aide takes me.
- I have to ask for special stops but the van from (name of agency) will take me
- I have someone that takes me, usually on Tuesdays. I just make everything for Tuesdays when she comes.
- I have to pay attention to my scheduling
- I have to scheme and plan – there are very few people I will ask
- I haven't been able to find any company that is equipped to take me out other than my MD appts.
- I only drive once in a while and my car is broken. My granddaughter takes me to the doctor's.
- Just was able to get out of bed this past Feb.
- I only have one transportation agency and that takes me to my medical appts and that's it, the rest I have to wait for weekends or nights for my husband's schedule, or they visit me
- I schedule things when she's going to be here. We're busy, three hours sometimes.
- I take the city bus
- I use (name of agency)
- If I don't have a driver I can't go and sometimes it's a pain in the neck to call my helpers in and sometimes I have to wait until the next day
- I'm not safe to drive, do not have a license
- Impossible to get to doctor – uses (name of agency)
- In home caregiver or brother will take her to doctor's appts.
- (name) drives her.
- (name) does that
- (name of agency) provided my trans. With planning
- Locally I can get to in my power chair. Other places I have to take the bus
- (name) always takes her.
- Most of the time, they all come here!
- Most of the time
- My aide always reminds me when I have an appointment
- My case manager provides the rides
- My daughter and granddaughter both take me
- My daughter takes me to all my appointments
- My daughter takes me to the doctor – she lives in (name of town)
- My daughter takes me to the doctor's office. But recently she hasn't had much time for me

## Participant Experience Survey 2010

- My daughter in law comes and takes me to the doctor's. I don't have a hard time for a lot of things I need, my kids are very good. I've got one son that leaves me alone unless he wants to borrow money, so I don't see him.
- My daughter takes me
- My family has a van w/ a lift, one time I took paratransit for the last appointment when van was out getting fixed
- My friend from church is taking me tomorrow to the doctor's
- My helper takes me shopping and my friend up the street used to give me rides
- My husband drives me everywhere, every appointment
- My son has been doing it lately, or my helper
- (name) drives her, can't leave her alone
- Needs help for shopping. Drives herself to doctor's appts as long as the appts are in same town.
- Needs to be planned
- No because sometimes I have no transport
- Not always
- Say to the doctor's, on the 19<sup>th</sup> of this month at 7:30 in the morning I have lab work, and I have not found anybody to take me. I have family that I rely on, and it's very hard.
- (name of agency) sometimes but they have caused her to miss appts because of misunderstandings.
- Shopping, no. Doctor's office, definitely. I don't work. I am not supposed to work because of my disability. (It is a yes and no situation)
- Sister or van service
- Sister still drives
- Sister takes her.
- So far I've been able to go with (name) but they've been saying you have to have an ambulance or something to go back, pay for ambulance
- Sometimes I put off asking for help because it's a long walk to where the staff is and there is no intercom
- Sometime I don't have the energy to drive
- Sometimes he has to walk
- Sometimes I can and sometimes I can't b/c it depends on whether my other granddaughter or my grandson are available. I just have to cancel if they aren't able to do it.
- Sometimes I feel like I'm ready to fall down on the street. I go myself, I can't afford a taxi so I walk. People borrow my money and don't give it back, so I have to walk. They want me to take a taxi, but I don't.
- Sometimes not, my homemaker was off on an emergency leave
- Sometimes the w/c van is already booked up
- Son and (name) drive me. I get to where I need to go.
- Son drives her to Dr. appointments
- Sons takes her
- Thanks to my son
- That daughter takes me to the eye doctor and then (name) takes me to my regular doctor.
- The doctor's office I have transportation, Medicaid pays for that; (name) has a motorized wheelchair and likes to stay independent
- The friend's house is difficult. (name of agency) takes me to the doctor and day program, a van.
- The only wheelchair transportation service is not always available
- The problem is starting to get to be that I don't have the money for gas.
- (name) takes her
- They take us
- To major places

## Participant Experience Survey 2010

- Transport problem
- Transportation is an issue but can get to doctor's appts.
- Uses (name of agency) shuttle or a cab
- Uses (name of agency) transportation system
- Usually my daughter can take me, but I take a bus to dialysis.
- Usually. Uses (name of agency)
- Van service to doctors appts
- Van transportation for medical things only
- Vans not always available at her facility.
- Wants to use (name of agency) but can't always get them. Uses them sometimes. Depends on friends to get rides.
- We have a ramp van
- Well, not always b/c the person, we set appointments at an early time so she can drive me, b/c I am legally blind. My wife drives me when she is not at work.
- We've had to cancel doctor's appointments lately. We used to have an arrangement with (name) , but she's gone now. It's a lot of money to take a cab. I just don't go, but we should keep doctor's appointments.
- When my wife was sick, we needed help
- With the exception of social visits, church, I'm working on it, I called the church to see if someone could pick me up.
- Would like access to other places. Can get to doctor's appts. Difficult to arrange for a van ahead of time. Would like to go to the movies, for instance.
- Would like to go out shopping more often but she can't do it
- Yeah, I go if I want to go
- Yes
- Yes most of the time unless weather bad.
- Yes, homemaker or neighbor takes her or she calls caregivers

## Medication

### Q26: Is there any special help that you need to take medicine, such as someone to pour it or to set up your pills?

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- A lady stops by to organize my pills
- A nurse sets up his pill boxes
- Administers shots using self injection kit. Has trouble remembering sometimes.
- Again, depending on how I feel, when I have syncope, I can't see, it's very blurry
- An aide sets up her pills weekly
- (name) sorts pills by days in case for her.
- Daughter likes to supervise her so she knows that she remembers
- Daughter sets out pills
- Do those all myself
- Does not need help
- Daughter sets up pill box
- Daughter sets up planner and grandkids sometimes help
- Family takes care of that.
- Fills pill box by self, timed pill box
- Follows directions from nurse
- Full assist
- Has a nurse who sets up her medication boxes, then she takes her pills as prescribed
- Has visiting nurse
- He does that, I was doing it and it seemed that somehow I managed to overdose a few times so my nurse will be here in a little while and she set up a sheet with when to take my pills, he gives me my shots, she set everything up
- Home provider dispenses the medication
- (name of agency) puts his pills in apple sauce because I have a hard time swallowing
- Husband
- Husband sets up pills
- I do all that myself, I'm quite cognizant about all my meds. I do my own sugar testing and insulin and everything. I'll need help eventually as my eyesight gets worse, but not right now.
- I do that myself, my husband sets it out for me
- I do that myself. I've been doing it so long, I could probably do it w/ my eyes closed.
- I have a nurse that comes in once a week to set up my meds
- I have a little tray, and I separate them myself.
- I have a med planner w/ an alarm to remind me and my nurse sets it up
- I have a nurse that does that, she does it once a week, she takes my vitals, BP, checks my breathing and stuff like that. Fills my meds.
- I have poor eyesight
- I just need a cookie to eat my premarin
- I need reminders, use my iPhone. Alarms set to go off when I need to take my meds
- I set up her pills and give them to her
- I set up his and mine.
- Just to pick it up for me
- Just to remind her to do it
- Just to set up pills in a pillbox, but I take it myself.
- (name) sets out pillbox and then he takes it

## Participant Experience Survey 2010

- Loosens the pill bottle caps
- (name) sets them out and gives them to her. She wouldn't know what to take and when otherwise.
- Medicines come well packaged so it's easy to administer
- Mother/guardian carefully administers her meds.
- My aide brings my medication
- My aide prepares my pill box
- My daughter bought me a really nice pill box
- My daughter organizes my meds for me
- My husband does it
- My husband does that for me b/c I can't open the bottles
- My husband sets up my pills, I get very confused
- My husband takes care of my medication for me
- My nurse sets up my pills two weeks at a time and my aide reminds me when to take them
- My RN does that
- My son in law does that and they bring it here and it's all right there in each day in a pill box, b/c I made the mistake one time of overdosing
- My wife does it for me, she is in charge of all that.
- My wife does that for me, if anything happened to her, I'd need help
- My wife sets them up
- My wife sets up my pills and sets up my insulin, I mostly do my own shots, but my wife does it a few times a week to rotate the sites of the shots.
- Needs help opening package
- Needs help remembering as he has memory problems
- Needs help to be reminded.
- No
- Nurse comes every 2 weeks
- Nurse comes here and does it for me, injections, betaseron
- Nurse comes in and sets up pills – 2 times a week
- Nurse comes in every 2 weeks to set up pills, check blood pressure and feet and vitals
- Nurse comes in once a week to set up meds
- Nurse comes in the set up medicine because she takes so much.
- Nurse comes in to do that
- Nurse comes once a week.
- Nurse fills my pills and orders them and I take them by myself. I got a pill box
- Nurse on a weekly basis. Matter of fact, she was just here today and I have a week long planner and she hooked it all up for me, so I'm all set for a week.
- Nurse sets it up a week at a time
- Nurse sets up pills for her
- Only takes 1 aspirin a day and Metamucil.
- Parents do it
- Pill box is loaded by RN
- Pill box, my nurse sets it up for me.
- RN come 1X weekly for that
- Set up pills
- Set up pills for me, remind me
- Sets them up herself
- Sets up his own pills.
- Setting them out

## Participant Experience Survey 2010

- She set me up in the first place, but then I do it now.
- She takes of it for me, I only have three prescriptions so they're not hard to keep up with.
- Someone sets up medicines and gives them to her
- Someone sets up my pills
- Someone sets up pills for her
- Sometimes need help if having a bad day. (name) will do it on her own time if necessary. (name) wakes her up every night to take meds.
- Son sets out pills for her
- Spouse fills pill box
- Spouse sets up pills and makes sure I get them
- Staff brings her the medication she needs
- Staff prepares his medication box
- Takes her pills and box to the day out program once a week and the woman there fills it for her, but (name) takes them herself each day.
- Takes no medicines except ibuprofen PRN
- That's what I need the most help with. I can't pick it up myself, but I can read the dosage
- The nurse comes in 3 times a week
- The nurse comes in every week on Wednesday to set up my meds
- The nurse fills her medication boxes
- The nurse sets up my pills for me once a week
- The (name of agency) does it and they have to come once a week to check my Coumadin and set up my pills.
- The only thing he needs help with is the nebulizer because he can't pour with his disability. Pills can do by himself
- The only things I got are two big pills bottles, I take a lot of 'em, aide fills bottles and (name) takes
- The pharmacy does this for me for free
- The pharmacy prepackages my meds. According to MD orders so no one needs to fill boxes
- The staffers do present the medicines to us but I take care of my own supplements.
- They give us our medicine
- They have to set them up. I can't even see them anymore. If I do it myself, I usually take the wrong pill
- They organize for me
- They stand over you at the table to make sure that you take them and make sure you take the right ones, that's why I like it here b/c they do things that no one else do, I've been here 9 years so far
- Usually my husband does that
- Visiting RN sets up pill
- When I can't see well because my sugar goes up
- Wife helps him and reminds him.
- Wife sets it up every day for him

### **Q27: Do you ever go without taking your medicine when you need it?**

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- At times
- But does forget sometimes
- Every now and then I forget
- Forgets sometimes. (name) is off duty at 3:00 or 4:00, but does set out the pills.
- I can't do that
- I do go without medication b/c I forget sometimes, I can sit in here talking to you and suddenly I forget it.
- I forget once in a great while
- I have forgotten it

## Participant Experience Survey 2010

- I have refused medicine in the past because I felt I didn't need it anymore. I talked to my doctor about it and it was used as an interim step. Due to NH law I can do that until my doctor re-examines my medications
- I mostly take them
- I occasionally forget
- I take it at 9 and 9
- I try to take my pills when I get up in the morning
- (name) says that sometimes they forget b/c it's every 2 hours; when they forget, she moves slower
- May forget to take it but can administer herself.
- Maybe a time or two if I have run out but the pharmacy can't fill it
- Not unless I forget, and the only time I forget is say we've been out or something, but that's generally not the case.
- Oh no, I take it when I need it
- Oh no, never, I make sure of that, I keep a close eye on the clock
- Once in a while I miss it
- Once in a while I might take it late
- Only if she doesn't feel well
- Only if she's vomiting.
- Only the lasix if I have to be out and no rest room is immediately available
- Only when I'm confused. I use an alarm clock to remind me.
- Only when she forgets occasionally
- She has dementia, so sometimes she thinks she has taken it and she hasn't, I don't force the issue unless the doctor wants me to
- Sometimes
- Sometimes I experiment with things
- Sometimes I forget especially at night
- Sometimes I forget to take it
- Sometimes I forget it.
- Sometimes I forget to take it, yeah, but I don't really need it sometimes, it don't even work sometimes.
- Sometimes I get distracted even when I get the reminder by emergency response
- Sometimes it takes a week for the pharmacist to get prior authorization
- Sometimes late taking it b/c I'm waiting on someone to help me, actually my daughter does that for me on weekends b/c I have so many pills to take, (name)the homemaker is not trained to do that and the visiting nurse doesn't come all the time
- There are times when I don't get to the pharmacy and miss taking my meds; I don't recognize each type of pills and sometimes I don't remember to take them
- Used to but doesn't anymore. (surveyor comment: Seemed like it was intentional not to take medicine)
- Very rarely but it does happen because he forgot to take it. If he is out he may forget to take it with him
- Very seldom; I only miss my lasix if I have to go out; lasix makes me need to go to toilet every 20 mins
- Very unusual
- When I don't get the medicine sorted out, I actually forget a lot of times to take my evening pills, my shots,
- Will occasionally refuse his pill

### **Q28: Is this because there is no one there to help you?**

---

- Because she forgets, but the pills are set out by (name) .
- Forgets
- He can't afford to buy his medications over the counter

## Participant Experience Survey 2010

- I might need a medication reminder by phone or get another adaptive device
- I need reminders, usually (name) will remind me, but sometimes I'll still forget
- I play with my pills to get the best combination
- If (name) doesn't do it, I don't take them
- Its b/c I am trying to do too many things at once.
- It's because my stroke caused me to lose concentration
- Need help opening bottles and reaching
- Sometimes I forget
- That or the med planner isn't filled up and I don't know what to take. I have trouble seeing from diabetes
- When I get home from dialysis I am so wiped out that I forget and fall asleep

## Toilet

### **Q29: Is there any special help that you need to get to or use the bathroom?**

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- Again, it depends on the day, I have actually crawled to the bathroom.
- I have nurses and people who come 24 hours a week.
- Aide does here and when she's not here my husband, when no one's here I'll pee myself
- Always someone here to help. Just needs someone nearby.
- An aide assists
- Bathroom all set up for safety
- But I don't always make it
- Does not use bathroom. Has permanent colostomy. bag.
- Had special commode and could do it himself.
- Has a commode in bedroom
- Has assistance from (name) for safety reasons.
- He is able to ambulate and go to the bathroom, feels the urge, gets himself there. We have to help him once every couple of days.
- Help in and out of wheelchair and onto toilet.
- I hate asking for help, b/c it feels like I'm asking for a favor.
- I have a cane
- I have a chair on the toilet. I have a wheelchair because I can't walk far
- I have a chair that I can use when I need it; also have a chair in my tub
- I have a walker if I'm real bad, I have a wheelchair.
- I just use my walker
- I say they should have made the bathroom a little bigger.
- I use a bedpan and urinal, do not use bathroom
- I use my cane or my walker
- I use my cane, but sometimes my granddaughter helps me get into and out of the bathroom b/c of the long cord on the oxygen. But I can get there myself, b/c I do at nighttime
- I use the commode in the bedroom
- If I'm sick, yes, I get wobbly, I get shaky, and my husband has to help me or I have to wait till somebody does, if I have a leakage problem, we'll try to use paper towels, or I have to wait till someone gets here, which is really scary as well
- I'm happy to say I can still do that myself!
- Incontinent
- Is able to walk to the bathroom; uses some assistance with wiping
- Is nervous getting in and out of the tub, but does it herself.
- I've got a colostomy and a superpubic
- Needs help to change everything, clean, etc.
- Just walker or wheelchair
- Mom irrigates her bladder and when colostomy needs to be changed, mom does it.
- I am able to do it, but it's really difficult.
- Mostly I squawk because I don't go that much, bowel movements. I had one about a week ago, but sometimes it's 7 weeks or something. I got messed up in the hospital.
- My son helps me when I need it
- No person just a bar to hold on to
- No they built a bathroom down here so it would be easier for me to get to.
- No, I have a cane and a walker

## Participant Experience Survey 2010

- Not unless I'm sick, no
- Not wheelchair accessible or she could do it on her own
- Nurse helps me at home
- Only for bowel care and on a regular schedule
- Requires assistance from her son
- She has a walker, but I follow her for safety
- She is a fall risk so she likes to have someone there beside her. Not totally dependent on them but for safety and peace of mind she has them so she doesn't fall
- Sister and care worker added that she probably should be getting help using toilet but can get to the bathroom on her own.
- Sometimes
- Sometimes I have a little accident
- Sometimes I use my cane or my husband can take me
- Sometimes needs help
- Sometimes wife help for stability.
- Sometimes, depending on
- They lift me up to go to the bathroom
- Transfers and for bowel movements
- Uses her walker
- Usually I use my forearm crutches, other than my legs being swollen and hurting today, I'm able to use his arm to get there
- Wears depends and is bedbound; mother helps her with all this
- When he is out he needs help finding the bathroom

### **Q30: Are you ever unable to get to or use the bathroom when you need to?**

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- At times
- Caretaker helps or I use the stool in my bedroom
- I always have my bathroom bag with me
- I don't have to go into the bathroom, b/c of the catheter
- I roll out of bed and crawl
- Is confined to bed
- Lately he is not feeling the urge as much, and he's been sleeping more soundly, we've been putting him on a schedule.
- Participant unable to use bathroom
- Shakes head no but see previous answer and says "there's always someone"
- She is incontinent, I remind her that she needs to go and she'll go, but most of the time she is incontinent and wears adult diapers.
- Sometimes
- Sometimes
- Sometimes
- That's kind of a complicated question to me, b/c I have constipation b/c I always have time to contact people, in terms of urination, I can do that myself
- Wears diapers.
- Well, if I have a leakage problem, that means I haven't been able to get to the bathroom
- Would like better access outside the home

**Q31: is this because there is no one there to help you?**

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- Equipment failure is largest issue
- I hold it too long
- No it's just the lack of feeling, the lack of sensitivity, I often don't really feel like I have to pee until I'm peeing and I say oh, I didn't make it, things like that

## Staff Time

**Q32: 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?**

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- For the most part
- 12:30-4:30 Monday
- (name)
- 2 hrs a day 2x wk to 3hr 1x weekly; I was recently cut back due to budget cuts
- Always says he can call if he needs something else.
- And extra
- And more, one night they had an emergency with (name) (caregiver),
- And then some
- And then some
- And they're all real nice too. I did nursing when I was younger, so I know what people feel like
- As a matter of fact I have one that extends her time beyond just to help out
- But my time has been cut short because of budget cuts.
- But the two hours twice a week is not enough.
- Definitely
- Definitely and more! I mean I myself think it's really not fair about the fee thing, but she really doesn't mind doing it and welfare won't pay for it.
- Has only had 3 weeks of in home help. Benefit from this program is Day care at (name of agency)
- Her dementia makes it hard for (name) to understand some of the questions
- How in god's name can they do it in 2 hours, can you do that all in two hours?
- Husband is paid caregiver, they joke that he spends more than he's paid to with her, they only pay for 3 hours a day b/c she's not bedridden; he doesn't make minimum wage b/c he's a husband
- I did have someone who came from (name of agency) , but my mother wasn't eating and wasn't happy with her, she struggled. I gave up hours at my job and now I get paid to help her.
- I don't get that many hours but they are here when they are supposed to
- I have a nurse that comes once a week to check on me
- I have (name of agency) , I have a worker that works 3 days a week, which they're going to be cutting her hours, and I know she's gonna quit, and I'm worried about it.
- I have had a problem in the past, but good currently
- I think so
- If they don't do what's expected, then they go to 1-800 # to call for a back up or that's why I have my husband,
- (name) spends most of the time with me but the kids take up a lot of time
- Mom/guardian is paid in-home provider through two different agencies
- More
- Most of the time
- My daughter does over but I am not sure how long the nurse is supposed to be here
- No one comes on a regular basis, just to check in every 6 weeks or so.
- No, this week no one's come at all
- Not all of them
- Often spend more time than they are supposed to
- Oh yeah, sometimes a little more.
- (name) comes Tues & Thur, does bath.
- Perfectly happy with that

## Participant Experience Survey 2010

- Some do, some don't.
- Some of people don't spend all the time here that they are supposed to
- Sometimes I don't need them as long, then I tell them they can leave.
- Sometimes I wish my homemaker had more time and could come 2x a week
- Sometimes she gets done early if he doesn't have enough work to keep her busy.
- Sometimes stays longer
- Sometimes longer
- Suppose they do.
- (name) said they're excellent.
- The caregiver is okay. The lady that hires her, I have a problem with. She thinks I'm a child.
- The caregiver is paid for 2.5 hours during the week and 1.5 on the weekends. And she does.
- The homemaker, she's here 4 hours a week, 2 on Wed and 2 on Fri, she does good, she knows the routine
- The in home people are fine. The administrators of the 3<sup>rd</sup> party service providers are uniformly poor
- There is shortage of staff since I moved in; anyone here would tell you they don't have enough help for the people they have
- The lack of flexibility in her hours is a problem – she finishes her work despite their schedule
- The LNA helps me with other things if I am feeling sluggish. She is very helpful
- The owners have fired so many people and they were all young girls. The owners are never here and the dishwasher on first floor is leaking. I wish there was something useful for me to do here. I could repair a lot things.
- The people who come to help to do a specific job, come and do the job, then go.
- They have other things to do
- They are both awesome
- They are here, but they aren't necessarily working. They don't work very hard
- They do now, I had one girl who is no longer here
- They usually call me if they can't make it and then they call someone else to come.
- Think there's no home support staff – just staff provided at living facility
- Visiting nurse comes in every two weeks to check me, does BP, cuts toenails, etc. If I need blood work done, she does it for me, instead of going up to the lab.
- Well that I need to watch more. I need to check it more closely. I think if you don't watch them, they'll flip out on you a little bit! I told the girl yesterday and I counted my clothes before I send my laundry. I get the same amount back.
- Well, when the girl comes, the only really cleaning she does is cleaning the floors, she dusts too. I just feel strange having people do it for me all the time. I help her too.
- Yes and then some.
- Yes, they are always there for me

## Equipment:

### **Q33: 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?**

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- A scale needed to monitor my weight but (name of agency) can't cover it
- Actually I'm going to be doing that this week, but we're always talking about stuff
- Apt is not well appointed for wheelchair bound individuals; have my name in at (name of agency) and waiting
- Bariatric recliner,
- Because they have been proactive. There will come a time when I might need a change but they have anticipated what I need so far.
- (name) comes every other month to check on me to see if I need anything. So far I haven't really needed anything.
- (name) was trying to get me a lift chair because my chair is too low and I can't get up
- But they didn't happen
- Ceiling lift. (name of agency) made in possible.
- Chair for the tub
- Case manager helped get smaller shower chair for my small bathroom
- Didn't know who case manager was
- Do not want bars in the bathroom
- Every 8 yrs or so I have to get a new wheelchair, cushions
- Got shower stool and a porta-potty for his bedroom
- Grab bars and shower bench and handled toilet seat
- Grab bars in the bathroom
- Have requested his own apartment. His case manager has been putting it off – his name is on the list
- Have talked about a computer for the blind.
- His daughter acts as his advocate with his doctor
- Homemakers have a physical therapist and she's the one who arranged for me to get a wheelchair, but that's about it, as far as my home is concerned, I don't think there's anything they could do there
- I bought a shower seat and a roller walker, and I bought my husband's rollator. They didn't get it for me.
- I did, it took a long time, it took a couple of years, I was trying to get a bathroom with a shower that I could wheel my chair right into
- I didn't know I could
- I don't know what to ask, b/c I am afraid to ask for anything. I'm on Medicaid and so.
- I don't think I had to, once they set me all up, everything went pretty well.
- I have
- I have everything in here that'll make me alright.
- I have everything, I have a shower chair, he put me up a rail, I have a toilet extender, so I think I've managed to give me everything that I need
- I have things already, wheelchair, raised toilet, hospital bed
- I have told her about the problem with our shower which we now are not allowed to use and must go downstairs to shower
- I need a new mattress for my hospital bed and she said it should be coming soon
- I really don't need to.
- I talk with the visiting nurses and they get the papers signed
- I wish I had a handicapped toilet
- I would like my furniture moved so I can see out my window

## Participant Experience Survey 2010

- I'm actually going to be moving out to a place that's handicapped accessible. I can't even fit my wheelchair in.
- Just finances
- Just got a grant to renovate my bathroom and will be able to roll into the shower
- Never had to because she can have the maintenance man can install equipment
- No, I haven't, but it would be nice to have an electric stair chair, can't get all the way up without stopping to rest.
- Not recently, has talked about a ramp in the front of house, but hasn't gone any further than that
- Occasionally, usually just for advice.
- Other than dentures, no. They can't find any agencies that will take Medicare.
- Ramp
- She did not discontinue my 4.5 hours since December, 5 months I've gone without services; changes to home or special equipment have to be done through physical/occupational therapy or neurologist
- She purchased her own equipment.
- She wanted me to have a transfer bench in the tub, but bathroom is too small
- Shower grab bar, shower chair
- Sister has discussed a lift
- (name of agency ) through fuel assistance, came to do weatherization last year and put in exhaust fan over stove and in bathroom and did some weatherization.
- Special glasses and a lamp
- That's what we're working with the lift, called my social worker about a shower hose, the removable one, my HCBC worker for my shower chair
- The only thing (name) requested was if there could be railings on the front steps, but they weren't able to do that.
- The (name of agency) takes care of it for me
- The walker and the cane, shower chair, now we're working on the power chair
- They have talked about some things but at the time she doesn't need anything.
- They talk to me about that and I always said I like it here, I like the people too
- This is a rental place
- Toilet lift chair
- Walker
- Wants to try to get her a chairlift – landlord has okayed it. Has not been able to get it installed-thinks it's the money
- We have just about everything, a shower chair and railing, bars in shower and around toilet, lifeline, etc.
- We talk about it, she comes and we visit, and we go over things. (name) has her number.
- We're in the process of that now, automatic door to apartment, also bathroom lift for shower, to reduce transfers. We've qualified, we're trying to find someone to do the work.
- We're working on my posture, I'm sacral sitting, the toilet seat has got to go. I need to get it replaced. The back to my wheelchair went, and I got it replaced, but I still need to be sitting up straighter.
- When (name) was my CM he got me a walker
- Will have a ramp built in the near future

### **Q34: What equipment changes did you talk about? (SPECIFY)**

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- A bed and a plastic slide.
- Modified car
- A bench in my bath tub
- A lift chair
- A lift because stairs are difficult

## Participant Experience Survey 2010

- A new wheel chair and a new walker
- A shower bench
- Rails
- Hand held shower head
- Adjustable bed,
- Adjective bed and cpap machine
- An electric wheel chair and a hospital bed
- An outdoor lift
- Shower/tub change
- New hospital bed
- Ask landlord to fix the step because I fell.
- Back up wheel chair and replacement electric
- Bariatric recliner
- Bathroom adoptions
- Bathroom renovations.
- Bed rails and air conditioner
- Ceiling lift.
- Chair for the tub
- Walker
- Chair inside the bath tub
- Chair.
- Commode and dental work
- Computer but they are just talking about it right now.
- Computer with voice for communication.
- Crutches, a walker and now a wheel chair
- Cut a piece out of the bathtub out so I can get my legs over.
- Dentures
- Electric bed. Bars in the bathroom. Sometimes they suggest things to her.
- Electric Hoyer lift. Service dog.
- Electric Wheelchair
- Lift chair
- Bed
- Electric Wheelchair
- Shower stool
- Getting a two bedroom apt to store medical equipment
- Handicapped bath has all the railings
- Got a new wheelchair
- Got all the things I asked for and now I am not needing the shower bench at times
- Got me a walker
- Got me a walker and a special chair
- Grab bar for bathroom
- Bath chair
- Lift chair
- Grab bar in the shower, a railing on the stairs
- Grab bars
- Grab bars, adjustable bed,
- Grab bars, shower seat
- Had a walk in shower installed

## Participant Experience Survey 2010

- Hand grips outside door and on inside door. Higher toilet seat and handles on toilet to help using toilet and getting into shower, which is nearby.
- Handicapped bathroom, new wheelchair,
- Handle in shower
- A stand to help get into bed
- Has special equipment in her bathroom
- Hearing aide
- Home traction device to pull my spine and aid in rebuilding the disc material
- A motorized travel
- A lymphedema pump
- Housing
- Hoya lift. Wheelchair.
- I asked for special grab bars for the shower about 11 months but I don't know what happened about that
- I do need to replace my toilet parts
- I got my walker and my power chair through them
- I have a recliner that helps me stand up
- I have CPAP machine to help me sleep.
- I have asked for a walker with a seat on it but I have been denied
- I have the help I've fallen and I can't get up necklace, ramp out the back slider (someone advocated for it for her), that bed thingy, fancy toilet stand (fancy arm rests on either side)
- I need a railing, car modifications and making my bathroom handicapped equipped
- I need another smaller wheel chair that fits in the bathroom, the entire bathroom is too small and needs to be remodeled there isn't enough room for my assistant to safely help me moving around my w/c and using the lift;
- I need to move to first floor apt; stairs here are dangerous and I have already fallen several times; this building is not handicapped accessible
- I have also be discussing a scooter with my MD and CM
- I need sanitary pads
- Wheelchair
- I talked to them about getting a new chair b/c this one is very uncomfortable on my back, there is a steel bar right in the middle. I need to get a note from my doctor.
- I wanted a power chair and a new shower in the bathroom
- I'm getting a new shower stall for my bathroom
- I've been asking for a wheelchair but they won't give me one
- I've talked to my nurse and she wants this rug rolled up and out of the way, she checks to make sure there's no mats in the bedroom and she gave me a sewing machine to try to keep me busy.
- I've talked to (name) to get a 2 hour travel one, and they got us all set up after pacemaker change.
- Just being prepared to switch out wheelchairs
- Just got a new walker. Also has a lift chair and a lift chair. Case mgr. very good about getting what she needs.
- Just the shower chair
- Last year when she was very sick she filled out an application for a ramp. But the ramp was too expensive to put in so it did not get done. She will need \$7000.
- Lift chair in place of her regular recline because she couldn't put the recliner up and down. Was told they couldn't find the money for it.
- Lift chair The recliner is too low
- Modify the bathroom
- Wheelchair ramp

## Participant Experience Survey 2010

- Modifying kitchen and bath. Rolling shower and shower chair
- Motorized w/c, bathroom adoptions, Hoyer lift
- Motorized wheelchair if and when I need it
- Moving
- My oxygen that I have in the bedroom. It's not oxygen, it's like an air purifier thing.
- My wheel chair, my ramp outside on the porch
- Need new bath seat for the bathtub; need railings and a lift to put her in the tub; Hoyer lift for bedroom as well. PT cam
- Needs a chair lift on the stairs
- New hospital bed to sleep on because of back problems.
- New mattress only
- New portable shower head. CM didn't get the rest of the equipment I have; it was ordered by rehab before I returned home
- New walker
- New wheelchair
- New wheelchair and had to fix the bed
- New wheelchair. Bench seat.
- Office upstairs used to be down here, we have the rules that we have to follow
- I think R might have misunderstood question and is focusing on rules and not physical/equipment changes
- Oh gosh, laughs, the list is so long, actually, getting a new walker and arm lifts, um, and actually this is partly at the recommendation of the occupational therapy from the VNA , a new handheld shower, draw pulls on my cupboards, computer set
- Only bed rail
- Outside rail
- New shower head
- Wheelchair
- Walker
- Outside ramp to the front door
- Oxygen tank
- Bedside commode
- Bathtub seat
- Breathing aid
- Personal alarm
- Physical therapy
- Pull up, lift for bed
- Put in a new shower and a brand new bath tub
- Railings
- Railings and ramp discussed but never got them
- Railings, shower seat adjusted, etc.
- Ramp for outside now installed
- Wheel-in shower stall and fix for my wheelchairs are in process but very slow. My case mgr. has done all she can to speed things up but we still haven't heard anything
- Ramp for the scooter and referral to Assoc. For the Blind
- Ramp to deck; hearing aids;
- Ramp w/c handicapped bathroom walker and scooter
- Renovate the bathroom to make it more accessible
- Renovated the bathroom and bought a shower chair
- Scale was not approved but I can purchase that

## Participant Experience Survey 2010

- Scale. Commode. Cane. Wheelchair. Health buddy.
- See previous, the only thing I've asked for that I haven't gotten is a new set of teeth, I've had these teeth for 15, 20 years
- She doesn't need any currently
- She gets me a new scooter and other bathroom equipment
- She helped me get to see a neurologist b/c they had to know if I physically needed things like my pads for free and all kinds of things. I was able to get that cleared up too and that helped.
- She is getting the bathroom remodeled – will have a walk in tub
- Shower
- Shower bench, automatic door set up,
- Shower chair
- Personal lift
- Van lift
- Shower grab bar and chair and adjustable bed
- Some kind of switch activated help call line
- Special mattress. Received advice from case mgr.
- Stair lift
- Walker
- Recliner
- Stairmaster. Bars in bathroom. Transfer seat for the shower.
- Talked about the disability with getting in and out of the van. The neuropathy makes it difficult to get in and out of van some days
- That's what we're working with the lift, called my social worker about a shower hose, the removable one, my HCBC worker for my shower chair
- The bathroom has been renovated
- A Hoyer lift
- The case manager helped us get a two bedroom apartment
- The hospital bed. One that raises up and down
- The very beginning I needed a potty chair and a shower bar. I needed a wheel chair and a motor chair
- There's one thing that I guess I can't do it, but we've talked about a stair chair, but b/c I'm a renter, they won't fund it for me. Even though I'm not planning on moving, b/c I don't own the place.
- They brought her a seat for her toilet and bathtub. She asked for meals on wheels but they said she couldn't get it because she has the (name of agency). She can't see why
- They got me a walker and they made changes to my bathroom and a handicapped toilet. The state built the ramp
- They put a bar by the shower to help me get in
- They put in shower rails b/c I had none.
- They talked about bars in the bathroom and a longer bench in the bath tub
- Toilet seat and the commode
- Transfer bench for tub
- Trapeze
- Tried to get a ramp but was able to move to handicapped accessible apartment in about a year; CM helped through the whole time working with the VA and RHA
- Trying to get a Beazy (sp) Board, a portable power chair and (Invacare ATM)
  
- Waiting for another wheelchair.
- Walker only
- Walker w/ a bed, toilet chair, high toilet commode, right now she's trying to help us get a side rail for bed.

## Participant Experience Survey 2010

- Walker with a seat and an automatic door. Hospital bed and motor chair.
- Walker with a seat, emergency response button, wheelchair,
- Walker
- Lift chair for toilet
- Walker
- Tub apparatus
- Wheelchair
- Mattress
- Walker, cane, shower chair, and working on power chair
- Walker, I don't need any particular changes to my home but I had needed a walker that she did end up helping me get
- Walker, leg lifter, grabber
- We are getting a seat for the tub.
- I would really wish we had a handle in the tub
- We do talk off and on, we check and make sure we have the railings we need and so far I have everything I need.
- We got Depends and a wheel chair
- We talked about a lift system and a handicapped van. I have found her to be responsive
- We talked about a wheelchair ramp for her and her husband. Her husband is paraplegic so they needed a ramp.
- Well, they got me a commode and my church lent me wheelchair, my daughter lent me a walker. I tried walking to the bathroom w/o using my walker the other day and that was a mistake.
- We've talked with (name) about moving to Littleton to be closer to our family members
- Wheelchair
- Wheelchair
- Wheelchair lift
- Wheelchair ramp (through case manager), fixing the floors with plywood and new linoleum (in process)
- Wheelchair
- Hospital bed
- Shower chair
- Nebulizer
- Wheelchair
- Walker
- A bar in the bathroom
- I asked for a new bed
- Wheelchair, shower bench,
- Wheelchair, toilet seat
- Wheelchairs
- Widen the doorways
- Modify the shower
- Add wheelchair accessible sink & counter
- Wall protection
- Change to phone link
- Widening the bathroom door
- Replacing the bathroom sink
- Safety bars in the bathroom
- Will have the ramp built very soon

**Q35: Did you get the equipment or make the changes you needed?**

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- A motorized scooter would be very helpful
- After a very long process
- Because he is not that bad yet. Did get one thing to help warm up his legs
- Bed rails in process
- Case manager is working on getting the money
- CM submitted paperwork for approval at least 6 months ago.
- Did not get wheelchair, lift chair
- Discussing door and walker with seat. Has hospital bed and chair.
- Except for meals on wheels
- Except scale – in process
- For the walker yes, haven't asked about the others yet
- Frustrated she has to fight for the items.
- Got a better apartment - handicap accessible
- Got a scooter and a new washing machine; is getting a new one handed wheel chair
- Got the equipment and tried it, but it doesn't work
- Got them quickly
- Has not received the wheel chair he needs
- Has some but are old and need replacement
- Have not found the equipment which covers my needs
- Have the equipment that I want
- Haven't gotten the lift chair yet
- He is living in a new home for him and he needs some adaptive equipment
- I can't get prior approval for the equipment which would be helpful
- I got most equipment but the power chair still needs to be fixed.
- I have been indecisive about it
- I have to ask about extra grab bar again with apt management, if no cooperation I will ask (name) to help get it
- I wanted a handicapped van but there are no funds. If I had that I would be able to do what I want and would need to burden my daughter who is sick herself
- I'm very lucky to have (name of agency) , it's extremely good.
- It cost \$7000 which she does not have
- Just started talking about the lift for the bed. Case mgr. is looking into it.
- (name of agency) helping me
- Mattress is pending
- My bath bench broke but they didn't want to pay for it also discussed adding more tracking but it would be expensive
- My case manager was finally able to get me a donation, but it wasn't from our program
- My wife is making the calls, and I would like that before winter. I need to talk to the landlord about getting a door that closes more slowly so I can get out easier in my chair.
- New floors are in process. Wheel chair ramp has been installed.
- No, bathroom too small
- No, funding wasn't there at the time.
- Nothing in process at this time
- Ramp is complete
- Shower stall and fuses to my wheel chair still in process very slow waiting to hear
- Received the Hoyer lift.

## Participant Experience Survey 2010

- She has received everything except the hand held shower
- She made sure that I got the appointment and that stuff, the caseworker
- Some I have, in process with others
- I got a work out machine from the state, so I can start exercising a little
- Still on the waiting list for an independent apartment.
- Still working on the chair
- Thank goodness for my insurance.
- The furniture hasn't been moved yet
- The ramp is getting put in on July 5<sup>th</sup>. Children and teenagers from over the state are putting it in for her
- Told there was no money available.
- Told unlikely to be paid for
- We followed their recommendations
- We're working on it, I've got a doctor's appointment on the 26<sup>th</sup> to discuss it with my doctor.
- We've had fans and air conditioners come in, I have a fan b/c the a/c gets my feet aching and I get the aching with too much air
- When needed
- Would like a chair to help her stand but it is not in the budget
- Wouldn't approve it
- Yes
- Yes but (name) had to pay for the bed herself. The government won't pay for the function on the hospital bed that she needed
- Yes for bed and slider
- No for car
- Yes to shower
- No to stand
- Yes to all
- Yes to all
- Yes to first 3
- Mattress in process
- Yes to lift, no to others
- Yes to wheelchair and walker
- No to bed and bathroom bar

## CHOICE AND CONTROL

### **Q36: Do you help pick the people who are paid to help you?**

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- Always
- Asked for a special person from (name of agency)
- But it turned out to be an excellent choice
- But there are nice ones who come in
- But we are allowed to feedback to management and we do that all the time. I like (name) . She is an LNA and she is wonderful
- Daughter in law is the in-home care person
- Does not apply
- Doesn't have a choice, but basically the ones that have come have been nice and cooperative, but hasn't seen anyone come for several months.
- Doesn't pick them but is happy with all of them.
- Every once in a while, my favorite LNA can't come, so then they send somebody else, and I really don't have a choice which one I get for that one time. I was satisfied with all the replacements. They were courteous and helpful.
- Family cares for me. They asked me if I wanted them.
- For (name of agency) , yes
- Had the same one for a year. I did change one in the past.
- I can hire or fire, if I don't like someone I can just say I don't want them anymore, but so far I haven't had a problem w/ that
- I can yes, I'm free to do that
- I did with the personal care person
- I feel better to pick them myself
- I interview them and hire and fire them myself
- I made the choices when it first happened. I don't know. When they told me (name) could be my caretaker, I wanted that to happen. They had a state worker come in and I chose not to have that one, so the answer would be yes.
- I never picked no body
- I picked my daughter but not anyone else that helps me
- I take who I get. But I did have a big meeting and I'm supposed to get more services from (name of agency) . I'm gonna have somebody that helps me be able to go to my parent's house, go to a movie, etc. It's great.
- I tell them at (name of agency) the service, I tell them I hope they're not prejudice b/c I like wearing women's clothes, skirts and blouses.
- I think, I don't do that, I feel comfortable w/ the people they send, b/c I want to make sure that the person they send here feels comfortable.
- If I didn't like my homemaker, I could tell her to hit the road, but everything is great
- If I don't like them, I get rid of them.
- If I like them, I tell them, they're not going any place!
- I'm told
- I'm with (name of agency) , I hire them;
- (name) been with me 10 years, (name) been with you 5 years, and (name) been with me 5 years
- In fact she just told me one was coming and I said I don't want her for nighttime.
- I've got no qualms about throwing somebody out
- Mom does

## Participant Experience Survey 2010

- My daughter was already the caregiver so when I went on the program she stayed on.
- My PCSP I get to choose, I got to hire her through (name of agency), they pay her through the state. I got to choose my agency through (name of agency) , which is (name of agency) I got to say that I wanted the same person every day, same homemaker too.
- Never seen them until they come
- No I have no control over who they send
- On some occasions.
- Personal care attendants, yes. Morning care and visiting nurse, he doesn't pick but can say no to certain people
- Right now we've got good ones
- Same people come and the family expresses whether they like someone and will request that person continue to come.
- She is very nice.
- (name) said she helped interview them.
- There is a supervisor at (name of agency) that has a list of homemakers and health aids and she picked
- They are just sent to me
- They came and they got along fine, so she went with it.
- They just came to see me, I mean they send them to me you know
- They just come in
- They just send someone
- They know who I would prefer to have and I've had the same ones for a while. I have requested.
- They pick them for me. I am satisfied with the ones I have
- They picked the right choice for me
- They picked them and sent them over, there's only one that I rejected, she spoke nothing but Spanish, and I couldn't understand a word she was saying, not that I'm against that, but we couldn't communicate
- They send me someone and usually if that person... I try to accommodate them, there was one I didn't get along with
- They send out the people
- They send someone and if I didn't care for them, I'd call (name of agency)
- They send whoever
- They were going to get me an LNA but I never wanted an LNA b/c (name) was helping me at that time
- They've come and so far it's been okay
- Transportation only
- Two different people had to leave because they were not doing their job; I didn't want to get anyone in trouble but my CM worked to help me get this corrected
- We fine-tuned it.
- Well they send out an evaluation sheet or whatever and they go by what the client says
- Well I never asked for nothing
- We've interviewed them. They just send the (name of agency) and we keep them if we are happy with them.
- When I don't like one I tell them to send me another one
- Yeah, I pick them out
- Yes, kinda...he can help fire or hire them.
- Yes, thank goodness I got the person I wanted to have

### **Q37: Would you like to help pick the people who are paid to help you?**

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- I don't think I'd amount to very much
- If I had someone who slapped me on the butt and was rough, I would complain.

## Participant Experience Survey 2010

- Because he is very satisfied with the people who help
- Because they've been pretty good
- Been satisfied so far
- Does not apply
- Happy with her new agency.
- Happy with people who help
- Happy with the people I have
- Happy with who she has
- I am very happy
- I don't know anybody anyways
- I don't know, I just take the people they give me, and if there is a problem, I tell them.
- I don't really have a need to help pick them, I've been pretty happy so far.
- I don't see how if I picked someone it would really make a difference, b/c they are total strangers.
- I don't want to lose this one
- I got pretty good people, I'm happy with them.
- I guess I would. They ask me periodically if I am satisfied. They ask me that about once a month or every two months when I get recertified by the nurse RN.
- I have good ones right now
- I like the ones I got right now.
- I like who I have
- I'm afraid to say something b/c they might take it away from me
- I think sometimes. We can fire whoever we have technically b/c they are working for us.
- I wouldn't know who to pick anyway and the people they have sent are wonderful. They know who will work well with me
- If I really had to.
- If she needed to change but she is satisfied with the people she has. Very much so!
- I'm satisfied with who I have
- In a way
- It's okay as long as they're not prejudice
- My sister does these chores for me
- No need to. Likes the people
- No, she's very satisfied.
- People she has are fantastic
- Satisfied with people so doesn't need to change.
- Satisfied with the ones she has
- She has been very satisfied
- She likes to do a lot herself, but if she needed someone else she would tell her case manager and she would take care of it.
- She would not have the mental capacity to do so.
- Shrug
- So far everyone is very good. Even the ones who substitute
- So far she has been satisfied
- Sometimes, but if you get used to them, sometimes they're not that bad
- Sometimes. I have a good nurse so I will keep her
- That would be neat
- That's the only way they know what to do
- Too much of a judgment thing. Likes having them chosen for her. Had some problems with people about two years ago. Very happy with the person she has now.

## Participant Experience Survey 2010

- Umm, not really, but I'll have input once they come to meet me.
- Used to have (name of agency) . She was happy with them. Had three hours at a time. They took them away from her. She was attached to them.
- Very happy with the people who come now.
- Very happy with the people. Would not change them.
- Very satisfied. No need to.
- We haven't really had a problem, only w/one we didn't like.
- Well yeah, if I could.
- We're satisfied w/ the people
- Would like the agency to choose but also wants final say.
- Yeah, that'd be a better idea

### **Q38: Did you know you can change the people who are paid to help you if you want to?**

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- Assumed that you could
- (name) told me one time, usually his first choice is (name of agency) , so that speaks well of the company
- Blank stare
- But I don't do that, I am lucky.
- But I don't want to change
- But I hate to do it!
- But it's hard to find good people.
- But that's okay, I'm happy w (name) or (name) or (name)
- But would never change
- Daughter has taken care of that.
- Didn't it, but thought she would be able to if something went wrong.
- Has requested an aide to be changed and her request was honored
- Have had no problems
- I already changed from one other place to here but still have many little problems with the services
- I can't have anything to say, if I do I'll get kicked out; I have to keep my mouth shut; that's why I get all these letters saying they're concerned that I'm alone all the time
- I did not know that. There was one person who was verbally abusive to people and was stealing food. I got together with the managers and she was let go
- I did, I just asked if they could send a person who spoke English!
- I didn't even know that. When you're getting a handout, you don't complain.
- I didn't know before but we had some problems with an LNA and (name) told me I could change and I am hoping I can get a girl that I'd had before
- I didn't know that
- I don't want to change the ones I have, I've had my worker for 3 years and my nurse for more than 3 years. I call them the A team b/c their names start w/ A.
- I don't want to change my aide. She is suitable to my needs and she puts in extra. She helps me with everything
- I have a couple of times
- I have a couple of times. They just didn't work out, but they replaced them right away.
- I have a problem w/ (name) . She has been very rude and nasty
- I have been told this but it doesn't work that way
- I have done it a number of times
- I have in the past, but the people I have now are good. The nurse's aide I have had for 3 years, and my nurse about the same. They call me mother. They're wonderful.

## Participant Experience Survey 2010

- I have once, there was someone they sent me one time, she was in training and she wanted to stay with me after the trainer left, and then she wanted to take some of my meds.
- I know that I can say that we don't get along but I try not to make any waves
- I wouldn't change for anything
- I'll fight them, I have in the past
- Is satisfied.
- Is very aware he has control and would not hesitate to voice his opinion if caregivers are not doing what they are supposed to do.
- I've done that in the past. They know who the boss is.
- I've had to do that in the past by the way, with people who I've hired who just didn't work out for one reason or another, one stole money and she paid me back so I didn't call the police but I did fire her
- I've heard that. I hope they never take my aide, (name) away.
- (name) explained everything to me. Am very happy with (name)
- Like the ones I have
- (name) spoils us, we spoil her too! She almost feels like a daughter
- Sister – yes, but wouldn't want to. Very happy with current person.
- So far has been very happy.
- (name) was aware that this was in the paperwork.
- The only one I changed was one woman
- There is no need to change
- There was one nurse who we did not care for, my dog growled at her the whole time. Then I had an LNA, I called and asked that they never send her again. She refused to brush my hair, shave me, etc.
- Unclear, she said yes but previously stated that she could not pick the people who are paid to help her
- Ya, one quit on me because I called her a name. She was pretty good to me too.
- Yes, but feels guilty for asking for a change.

### **Q39: Thinking again about the people who are paid to help you, do you tell them what to help you with?**

- And I show them how to do it the first few times, I tell them how I want my clothes done. I get everything ready for them so they have enough time to do the whole wash and dryer cycle.
- Ask
- At first, but after a few times they just know. They know what I need and where everything else is.
- At this point they know what they are supposed to do
- Because I am so independent
- (name) just knows everything, and sometimes she even brings me a healthy drink. She never takes money for it either. She's more than a helper, she's like a family member.
- But by now they've been with my awhile, so they pretty much know what I need.
- But I don't really have to, she already knows what to do. She wouldn't go to the store and get something I wouldn't want. And I tell her don't get anything else, just that, and she's very good that way.
- But sometimes they don't like it, that's what that meeting was about. I had spilled raspberries on my shoes, and I asked her to wipe it off, but she told me it wasn't a part of her job. She made a big issue of me being rude to her.
- Describes schedule, and deviations due to sickness issues
- Do what they have to do but she tells them if she needs anything extra
- Don't even have to ask - they just know.
- Haven't had to though
- I've tried to tell them but it doesn't change
- I asked her to cut my toenails.

## Participant Experience Survey 2010

- I don't need to, they know. I will tell (name) tomorrow that I need some help making American chop suey. So they help with that if I need it. And they always ask, do you need anything cooked this week?
- I make a list, b/c this lady is a little hard of hearing anyways. I just write it down for her. She's real nice, a wonderful person.
- I never ask them, they just know
- I speak up with I need something
- I tell my homemaker what I want done.
- I tell them, I need to tell you what I need. They are always wonderful.
- I usually don't have to because she knows what to do. The only thing is when I want to get dressed, I might tell her, b/c she doesn't know
- I'd prefer continuity of staff I have 4 different people coming on 4 different days
- If she needs to – like cutting peppers or onions
- I'm not someone who asks for things
- I'm not used to having a housekeeper so I don't usually tell them what to do
- In a way
- It's not too often that I ever have to ask for anything
- Many times she sees what needs doing and just does it
- Most of the time
- Most of them just know what to do, because they've been with her so long.
- Mostly they know what to do.
- No usually I don't have to, by now he basically knows what to do
- (name) said no but then stated: they just help me with whatever I need to do
- She knows almost everything, it's been almost two years, then I tell her new and different things that come up.
- She writes it down too
- She's young so sometimes he has to "guide her", but she's good. He pointed out that it was dirty under his bedroom table so she cleaned it.
- Tell her to do whatever she thinks needs to be done, like it was her own home
- That's the only way they would know what to do
- They always ask you what she wants
- There are certain things that they have
- There is one girl who doesn't work hard; she is a lazy brat
- They already know. That's a no brainer. If they didn't do their job, I wouldn't have them here in the first place. To me, they are the cat's meow! These people do everything for me and I don't even have to ask them to do it, they do it automatically.
- They ask and they also have a routine they know of the basic list of housework that needs doing
- They ask me and I tell them, I says, I'm the boss
- They ask me and I'll tell them. My kids help me a lot too. If I had my way, I'd do everything myself, but I don't have my way.
- They ask me what I want them to do next.
- They know
- They know by now b/c they've been with me 3 years or so, my driver has only been with me for 8 months.
- They know the routine now.
- They know what to do
- They pretty well know the routine now and usually I have a list when they come
- They pretty well know what to do
- They pretty well know, they've been coming for a while so they know what to do. At first I didn't want any help, then I realized that I did need help, I have no balance at all

## Participant Experience Survey 2010

- They seem to know what they're supposed to do. She doesn't need to tell them.
- They usually ask me what I want done
- They usually ask what she wants done.
- They usually know already b/c they've been doing it all along. If there is something extra, I tell her.
- Usually
- Usually I tell them what needs to be done
- Usually leave her a list
- We don't leave anything up to chance. We leave good instructions so they do it the way we want it.
- We'll discuss it the day before or that morning.
- Well, I feel like they're working for us. I straightened her out quick on that yesterday, she wanted to make the hours herself and I told her we do that together. Oh yeah, I'll tell them they need to do the wash.
- Well, we ask
- When necessary. Like my homemaker, I have to tell her, this week will be shopping, floors, etc. As far as everyone else goes, they know what to do.
- When they come they just ask what I need them to do. I just tell them
- Will make a list and she'll do it.
- Yes but she knows automatically what to do.
- Yes, sometimes we have little projects that we do

### **Q40: Would you like to tell them the things you want help with?**

---

- I have no one to help me since my wife died and parents died
- I have no problem now
- I'd just like to have someone to come over here once in a while. Someone was supposed to come to do the laundry, but nobody showed up.
- Usually they just do it without asking
- In the beginning she asked them to put on her talking watch for her, but usually they notice the extra things to do and there is no need to ask.
- She does an excellent job
- Sometimes
- They know what to do and I don't have to tell them
- They've worked with him long enough so they know what to do.

### **Q41: 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)**

---

- (name)
- (name) at (name of agency)
- (name) at (name of agency)
- (name) at (name of agency)
- (name) at (name of agency) or (name)
- (name), the case manager, I like (name)
- (name) the administrator (of the home). Next I would go to my guardian who manages my care
- Brother (name) and (name)
- But I haven't had to
- Call (name) - case manager
- (name) CM @ (name of agency)
- (name) who is in the office here at (name of agency)
- Case mgr. and/or staff of (name of agency)
- Case manager, mother and sisters

## Participant Experience Survey 2010

- CM, (name of agency) supervisor and mother
- (name of agency)
- Daughter
- Daughter or son-in-law
- Daughter-in-law who is caregiver
- Doesn't have any problems, but would just go to the office and tell someone what was wrong
- Doesn't know who to talk to and she previously had a problem, but it was reported by someone else
- (name)
- (name of agency) if I need to
- Facility manager at (name of agency)
- Family member, and then go to the case manager if they feel it's necessary
- First caretaker, my person, if that doesn't work, I go to her supervisor, but I'm very fortunate, she was the first one I met and we hit it off, she's been with me almost 2 years now
- First of all I'd talk to the girl and if that didn't work, I'd talk to the supervisor or the owners at (name of agency) .
- First she talks to the person and then the case manager
- First she would talk to the care providers, then go to the case manager if it wasn't resolved.
- First talk it over with the individual and if it doesn't get resolved I have had to fire a couple of people. I have had over 100 paid caregivers in my lifetime I pretty much like to resolve problems myself
- First the person themselves, then the CM from (name of agency) and then (name)
- First we ask the visiting nurse, then the case mgr.
- First whoever the problem is with and secondly, who their boss is. Fortunately, I have never had that problem
- (name of agency) , the area agency that they work for
- (name) , facility administrator
- Go to my son
- Go to the person's supervisor
- (name of agency) or (name of agency)
- (name of agency) case manager
- (name of agency), (name)
- Hands up in distress, other-(name) , case manager said she did not decrease hours
- Has never had a problem. Very happy with services.
- Has never had any problems.
- Has never needed to contact someone.
- Hasn't had any problems but would try to work out problems with the person directly and then go to the case mgr.
- Haven't had any problems
- Her boss
- Her name is (name)
- House Case mgr.
- I don't feel like they pay too much attention to the client's needs.
- I don't know who the hell to talk to, b/c nobody's there
- I have no words to say because the caretaker takes good care of me
- I imagine it would be (name) , the boss
- I miss (name) who used to be the supervisor
- I talk to my nurse and the nurse tells the supervisor. Sometimes I will call
- I TRUST my home provider
- I try talking to the person themselves

## Participant Experience Survey 2010

- I try to talk with the person I am having problems with; if not I go to (name) (CM)
- I try to work it out with them
- I usually tell them
- I would call my nurse
- I would call (name of agency) and talk to them. (name) usually handles the cases, so if I have a complaint I would talk to her to get it figured out, but so far there have been no problems.
- I would call (name of agency) , I go through (name) first, she is a sweetheart.
- I would call the agency, I would call the state, my social worker.
- I would discuss the issue with the person providing the care
- I would either call my case worker or call (name) that is head of (name of agency) that she works under.
- I would either talk to (name) at (name of agency) or someone from (name of agency)
- I would go the head of the program
- I would probably talk with my doctor
- I would start w/(name of agency) , and if I had to I'd call (name)
- I would talk to (name) who runs the home
- I would talk to the head office
- I would talk with my CM or the person themselves and if that didn't work I'd have to go over their head
- I would tell the aide directly
- I would tell the person to leave
- I'd call (name of agency)
- I'd call (name) , he's the person at (name of agency) , but I haven't had to. He just came today to pay me a visit and they got a new director, so he introduced me.
- I'd call the agency
- I'd call the office, b/c I called the office on that woman that time.
- I'd go to the head of the (name of agency)
- I'd just call the office in the building.
- I'd probably talk to them first, and if I wasn't satisfied, then I'd probably talk to (name) . If you want to hire somebody, you have to be able to talk to them, if you can't communicate, then...
- I'd say we'd have to talk to (name) I forget her title over there at (name of agency)
- If that's the case I call my supervisor, (name) .
- In home caregiver.
- Intern, that's who sends me the help.
- It's hard for me to imagine she has been helping me for so long
- (name) from social services and sometimes (name)
- (name) in office , daughter (name) , sometime CM
- (name) , mgr.
- (name) and (name) and (name) at (name of agency)
- (name)
- (name) head of (name of agency)
- (name) (daughter) mentions: tells (name of agency) , (name of agency) , me, bus driver; most of the time no problems but feels comfortable going to all of those people if there is a problem
- (name), staff at (name of agency) , daughter of owner
- (name) the nurse supervisor
- Like I said, I try not to make waves
- Lives with (name) , daughter in law, who is also the paid caregiver.
- (name)
- (name) , live-in care giver, who would then talk to case manager.
- (name)

## Participant Experience Survey 2010

- (name) , Mgr, (name of agency)
- (name) - Adult Services worker
- (name of agency) staff
- (name) (case manager), (name) (works with (name of agency) )
- (name) , she is the scheduler, so if I have a problem I talk to her or my case manager
- My daughter, my granddaughter and great great granddaughter
- My head nurse
- My nurse or her supervisor, but my nurse is fabulous.
- My wife (name) when she is not in the hospital or rehab, my case manager (name) and (name) at (name of agency)
- Never had any problems.
- No problems. Would talk to children.
- Not really sure but knows she can talk with case mgr.
- Nurse
- (name of agency) or (name of agency) , I feel very fortunate I have these services. I don't think I'd be home if I didn't.
- (name of agency) . I haven't had no problems, but that's who I'd call. I called (name) last week
- Office staff but it seems they are often not there so I give up and my memory isn't the best
- Office on which agency supervisor depending
- Often deals with the manager of the organization before the case manager.
- Or head of provider agencies
- Other (name) , Coordinator at (name of agency)
- Pastor
- PCAs from (name of agency) , call the head nurse and let her know
- Person first then goes to case manager and if that doesn't help he goes to the state. Doesn't have an issue with (name of agency) because he hired them himself
- (name of agency)
- Probably (name of agency), , (name)
- Probably either my case manager or the one at (name of agency)
- Program coordinator
- (name) who takes the information back to her supervisor
- (name)
- (name) probably, the man in charge
- (name)
- Schedule manager at (name of agency) , and CM
- She discussed the problems directly with the person providing the help
- Sister
- Sister, (name) RN from (name of agency)
- Sisters or (name of agency) organization
- Speaks with care worker directly
- (name of agency) services, we'd go to their manager or we'd go to (name of agency) , we know who to go to.
- Staff at facility
- Staff first, then supervisor
- Bringing problems to the staff has worked for her
- Staff member calls her every Monday
- Staff of assisted living facility
- Staff of (name of agency) assisted living

## Participant Experience Survey 2010

- Started talking about building manager at living facility and the problems with the laundry center. Never got a clear response in regards to the actual help she's getting.
- (name) administrator, my sister or my CM
- Supervisor
- Takes care of it himself.
- Talk with the person who I have to problem with;
- Talks to (name)
- The administrator (name)
- The agency. It depends on who the problem was with.
- The aide herself
- The aide's supervisor
- The first person I would talk to is my nurse
- The head ones I guess, I never had a problem, so I don't know. I broke my ankle, and I called the lifeline and they sent an ambulance over and the guy said they couldn't take me to the hospital, so I had to stay here.
- The individual first and if that doesn't change the problem, then talk with their supervisor
- The lady that works here (name)
- The nurse owner of the home
- The one that causes the problem
- The one that's in charge of the help, which is (name of agency) The owner of the house
- The person themselves; if changes are not made, I go above them to their supervisor
- The staff at (name of agency)
- The supervisor
- The (name of agency) scheduler and my therapist and my daughter
- Their boss and my spouse
- Their bosses, the ones at (name of agency) or (name of agency) , but I've had the same aides now for several years. I had one for two visits, but he had no immune system. One time they sent a little old lady that can't even lift my wheelchair.
- This is a new situation and (name) has been taking care of her for two months now.
- (name) from (name of agency) .
- (name) owner of facility and the nurses
- Usually I thought I might have to talk to (name) my guardian, is who I thought I would talk to about that stuff. (Name) says she would probably talk to the nurse, (name) .
- Usually (name) or (name)
- Would usually tell family or if she knew who the person in the area was to call, she would call them

### **Q42: Who is your case manager or support coordinator?**

---

At least 150 clients provided the first name of their case managers or support coordinators. A few, approximately 26, provided their case managers or support coordinators names and the names of the agencies. Several provided names and comments about their case managers and support coordinators; several entries were comments only.

- god only knows
- you're going to ask me her name", my social worker is (name) .
- (Has the paper in his wallet with all the names that he needs)
- (name)
- (name)
- (name)
- (name)

## Participant Experience Survey 2010

- (name)
- As for names, I can't remember a lot of names.
- Asks (name) , have discussion about the fact that there are so many
- At this time it is (name) with (name of agency)
- (name)
- (name)
- (name)
- (name)
- (name)
- (name)
- (name) ; husband: she's going above and beyond; had to evacuated b/c of neighbors with bedbugs, husband was out of town (for work?), she came in and helped with all the packing and moving before the spraying
- (name) , I don't know his last name, he's in charge of the services.
- (name)
- (name) at (name of agency)
- (name) from (name of agency)
- (name)
- (name)
- (name) Does not know last name.
- (name) Does not know last name.
- (name)
- (name)
- (name) - hcbc
- (name)
- Case manager, (name)
- (name of agency)
- Very nice
- (name)
- (name) - it's just changed
- (name) from (name of agency)
- (name)
- (name)
- (name)
- (name)
- (name) - asked her aide what the name of her case manager is
- (name)
- (name)
- (name) and (name)
- (name)
- Couldn't remember last name

## Participant Experience Survey 2010

- (name) , (name of agency)
- (name)
- (name of participant) named (name)
- (name)
- (name)
- Did not name immediately but was able to find business card in wallet. (name)
- Didn't know.
- (name) was prompting her, saying that she comes every other month...you know who she is.
- But she couldn't come up with the name or identify the person.
- Didn't remember his name, but knew that he comes once a month and knew that he was the case manager
- Doesn't think he's ever spoken with case mgr.
- Daughter helped her remember
- (name)
- (name) of (name of agency)
- (name)
- She always is checking up on me"
- (name)
- (name)
- Gave the name of (name) , who supervises homemaker, then gave the name of (name) , who may be his HHS case manager.
- Had to think about it, but then came up with his name.
- Has had a recent change and can't remember her name
- (name of agency) (name)
- (name of agency) ; (name)
- I can't remember right now
- I don't think so
- I have 2
- I have a program coordinator from (name of agency) , that's (name)
- (name) is my case manager from (name of agency) , she's been with me a long time too
- It used to be (name) , but they fired her. I don't know what (name)'s last name is, but. My HCPC person is (name)
- It used to be (name) , now someone named (name) that does the Concord area, but last I knew (name) still had my bios and stuff
- It's either (name) or (name)
- It's (name) or (name)
- (name) . Can't think of last name
- (name) from (name of agency) , she's wonderful, I couldn't ask for anyone better
- (name)
- (name)
- (name) at (name of agency)
- (name) for driving
- (name) at (name of agency) , and (name) at (name of agency)
- (name) , and then we would also talk to (name) from (name of agency) . Wife named, (name) agreed.
- (name)
- (name)
- (name)
- (name)
- (name) , from (name of agency)





## Participant Experience Survey 2010

- (name) , that's his last name, that's what he goes by.
- (name) and (name)
- (name) from (name of agency)
- (name) don't know her last name. Couldn't find her card
- (name)
- (name)
- (name)
- (name)
- (name)
- (name)
- Sisters handle that
- Son named her. (name of client) didn't know
- (name)
- (name) , she is a real nice lady
- (name)
- (name) , husband named it for her
- (name) or (name) who just got married, she's with (name of agency) , or (name) at (name of agency)
- (name) did not know last name.
- (name)
- (name) - she comes every so often
- (name)
- (name)
- There are 4 of them from (name of agency)
- (name)
- (name)
- (name)
- (name)
- (name)
- She is very good. She got me extra help with medical expenses"
- They have changed many times in the last few years. I have the number in the kitchen
- Thinks it (name) but hasn't talked to her in a long time.
- Through HCBC, (name) (very good)
- (name of agency) , (name) (real good too)
- (name)
- (name) - had to look up name
- (name)
- Was (name) but new girl now and I can't think of her name
- Went and got the paper off of the refrigerator. (name)
- with reminder, named (name)
- I'm not quite comfortable with him - he's loud

- Woman

**Q43: Can you talk to your case manager or support coordinator when you need to?**

---

- 24 hours a day, 7 days a week, I have her home phone, cell phone, etc. If I had to call her at 2 in the morning I could. I wouldn't change her for anything in the world
- Always
- Always, she's great
- And when they're available, sometimes with (name) I get her voice message b/c she'll be out in the field with one of her clients, (name) always available
- Anytime
- Anytime I need to
- Anytime I need to. If I reach his machine, he calls me immediately right back when he gets into the office.
- Anytime, I have their cell phone numbers and things like that and they call right back when I call them.
- Basically yes, if she's not in she usually returns the call within a short period of time.
- (Name) has even told me to call her at home
- Can call her or (name)
- Comes in often
- Could talk to them if someone dialed the phone, but she'd have to be told the name of her case manager so she knew what it was.
- Daughter deals with case mgr. She is not aware of case mgr. or the agency.
- (Name) calls her for me because I have a difficult time using the phone; and she usually checks in every couple of months to see if there is anything need
- Doesn't know who it is
- Doesn't know who they are because she hasn't seen someone for a long time
- Email or call
- (Name) has her phone number. I mean it doesn't do any good for me to have any phone numbers! I can get hold of my family or whoever, and 411 I can call for numbers and b/c I'm blind I don't have to pay for it.
- Has never contacted her.
- Has never needed to.
- Has phone number
- Have her number and if she needs her she'll call
- Have phone and cell number
- He'll be here next month to check in. How things are going in the house, we had a problem once where everybody got kicked out, but then things smoothed over.
- He's comfortable talking with (name) his aide
- I call her
- I can send her a message, but she never answers it most of the time. She answers it sometimes.
- I can talk with her, I don't know how to get in touch with her. I do like the independence idea, I like it, you know, as far as that goes. (Name) is the one who has been helping me all along with that stuff. He helped me find this place.
- I don't know, I haven't had the need. I have her card.
- I don't really hear from her (quite unclear)
- I feel she doesn't have time; she is very sweet but when she asks me on the phone if I have problems I feel I have to say everything is fine because she is so busy
- I have a memory problem and that's one of the reasons I am here; I am bad at remembering names
- I have both her office number and her cell phone

## Participant Experience Survey 2010

- I have called him occasionally on a couple for things that I wanted to find out about. He's another one, he's an absolute sweetheart
- I have her email.
- I have her number, I know how to get hold of her.
- I just call her and she gets back to me, she's here once a month too
- I leave a message. But she is on overload. But she does get back to me all the time.
- I needed to talk to my case manager today but I couldn't get a hold of her. She is hard to get a hold of
- I really don't like to talk
- I talk with my boss, the one that does the paperwork, 3 of them
- I think so, {hesitant}
- If I contact her, she's never in her office. She never calls me back. I don't need you.
- If I have to leave a message, she calls me right back that same day. I have bad trust issues, and she's another one that I like and really trust.
- If leaves a message, she usually calls back the same day and sometimes after hours.
- Iffy. I am in the process of changing my case manager. It is not easy to reach her.
- Just needs to call and gets fast response
- (Name) I call, we leave messages, she's very hard to get a hold of
- Most of the time
- Most of the time I can; if I leave a message she usually gets back to me
- Most of the time if she calls, (name) will return her calls quickly.
- Most of the time, I can always leave messages if she is not available.
- Most of the time, I have her cell phone
- No issues there
- No, it doesn't seem like it lately, I know she's been sick too though.
- Not always there but always returns call.
- On the Phone only
- Never met her in person
- Per son
- Play phone tag but yes
- Pretty much
- Really like her
- She comes here about every 3rd month
- She comes out if I need to talk to her, I needed help w/ my electric, she tried to help w/ that. She's very good.
- She comes to visit me once a month
- She gave me her cell phone, so if I need to reach her I can, she always calls me back when I leave a message.
- She hasn't for a while but yes
- She is good about returning my calls
- She states that she has many clients, is busy, she has all these issues and (name of agency) has maybe 10 case managers, I have been to the head, somebody who was younger, sent to other person,
- She's always there for me. I just make a phone call.
- She's coming tomorrow
- She's very good. And then (name) comes to see me too, he works for elderly and adult services. He's wonderful to me too.
- Sometimes she is hard to get a hold of
- Sometimes, if she is not there, I leave a message and then she calls me back, it might be a couple of days.
- That (name) , she's a good egg.

## Participant Experience Survey 2010

- Unsure of whether or not he has her phone number
- Usually my son does all that because when I first got home from the hospital and I couldn't focus
- Usually she is in the office. She is on vacation right now but she tells me when she is going to be on vacation
- Very good communication with case mgr.
- Very much, he was just here on Thursday. We set up a nurse coming in to check her BP every two weeks.
- Whenever I call her, she'll come, if I need her to help me fill out papers and stuff.
- Would go to (name) from the facility and (name) would call case mgr.
- Yes or leave a message
- Yes, he's a really nice fellow. He makes himself right at home.

### **Q44: Does your case manager or support coordinator help you when you ask for something**

---

- (a little hesitant on the response)
- A much as she can; if something came up, I could call.
- All the time
- Always
- Always
- Always
- And she bugs me and calls me and says do you need anything and I say no stop calling me (laughing)
- Anything I want
- As far as she knows, she hasn't asked for anything.
- As much as is possible
- (name) is very good.
- Because I don't ask; someone at (name of agency) helps me when I bring up any concerns
- But I don't always like his attitude
- Can't recall (name of agency) or cm coming to see me but I probably just don't remember
- Case mgr. does think she'll be able to get Stairmaster.
- (name) is only human but seemed aggravated when I moved out of assisted living; I have told her a thousand times that I called about using local transport
- Depending on what it is
- Doesn't know who it is
- Doesn't speak to case mgr.
- Done a hell of a job!
- Except I really don't ever ask for something. I'm very content, I'm happy for what I have, very grateful for what I have.
- Explains things and what she can do
- Has had to do things on her own.
- Has never asked for anything.
- Has never contacted her. She calls him occasionally.
- Hasn't asked for anything.
- Haven't ever asked her for anything - didn't know how to contact her
- Haven't really had to ask for too much.
- I don't remember the case manager much. The caretaker the most
- I feel she doesn't always do what I ask her
- I go to my head nurse. I've had her for 10 years
- I haven't seen any changes; I've told her about the shower and the food being served raw
- I kept getting a bill from (name of agency) and she straightened it out
- I know she would, I have never needed to.

## Participant Experience Survey 2010

- I never ask her
- I suppose, I never have to ask for anything
- I tell her when I have a problem
- I tried to talk to her about moving out but she didn't really get it.
- I would never make a bad report nobody, so far it's been about a year or more that I've been receiving these services, and I've had 2 people only that have been not wonderful
- If I need something, she helps me. My caseworker. (Name) , not so much. I hardly talk to her.
- If I'm having an issue they'll try to fix it sometimes.
- If it's possible for her
- If there's anything I need I just ask, but I don't' really need that much. My problem is, I'm very independent.
- If they can they will, I have a lot of respect for both of them, I think it depends on what I ask for
- Is very happy with case manager. Is very accessible.
- I've asked to move to Berlin where my family is
- Like now, I was supposed to get a license for social security the social security card and..., case manager said let me know if I can help or maybe (name) can do it, so (name) did it
- Most of the time
- Most of the time; there is some stuff I might ask for that is not covered
- Never had to ask her for something.
- Never needed to call her
- She doesn't ask for anything.
- She either, a lot of times she helps me with all the paperwork and tells me what to send in and that kind of thing.
- She helped me get a print out of my birth certificate when I needed one
- She helps right away and visits regularly
- She is very nice
- She tries really hard. Right now I'm trying to get housing. I've been on the list for a while, but my husband has been out of work since August. So right now we struggle month by month. Section 8, rental assistance.
- She tries.
- She was the one who was able to get my nurse onto Medicaid.
- She will try
- She would come whenever I need her.
- She would help me look for funding but nothing ever panned out
- She's more my mother's friend than my friend
- She's pretty good that way, when I ask her for more hours. I don't want to take anything away from anyone else, but if we need something we need to get it.
- She's very helpful. Helped with a social security issue. Very appreciative of that.
- The nurse (name) came over and took my blood twice today and I have to go to the lab b/c it was getting too thick up here, but I don't want to.
- There are times she doesn't listen and I feel uncomfortable with her
- There's nothing that I need
- They try the best they can.
- Unclear
- Usually
- Usually
- Usually
- Usually

## Participant Experience Survey 2010

- Usually
- Yes and no
- Yes, if she's not that busy

### **Q45: Do the people paid to help you treat you respectfully in your home?**

---

- Absolutely
- Absolutely or they wouldn't be here.
- But sometimes their make under the breathe comments
- Current staff
- Definitely
- Definitely. Does not want to lose any of them!
- Depends (said jokingly, referring to his granddaughter)
- Everyone treats him good
- Everything's good
- Given the pool of people to hire from, they are not always respectful
- Had one aide who was difficult and I got rid of her
- I couldn't ask for better people. I love them dearly.
- I get hugs every time they leave!
- I guess ii would say yes b/c they're hasty, the timing, especially the (name of agency), and they're more concerned with how they're going to get paid, how the health insurance company's going to pay them and then my conversation is null and void
- I had problems with one and I had to fire her
- I'd say so. They'd better
- If they don't they get thrown out, literally
- If they don't, I would tell them
- I've had mixed results.
- We want everyone to make an appointment and respect our time
- Oh god yes, she treats me like a grandmother. And I love that. .
- Oh yes definitely
- Oh yes they do!
- Oh yes!
- Problems in past one time but no problems now I learned from that
- Sometimes people can be rude, one time people really rude came and was just complaining about everything. Some people feel bothered by my aunt.
- The nurse who checks on me does
- There great
- They are so good they are like family.
- They are very nice
- They have to
- They pick on me! Ha ha
- Utmost respect
- Very
- Very
- Very good at treating me well
- Very good.
- Very much so
- Very much so!
- Very much so.

## Participant Experience Survey 2010

- Very respectfully
- Very! Whatever questions you got about the nurses and homecare, it's 110%, I couldn't be happier. And that is what makes part of my life.

### **Q46: Do the people paid to help you listen carefully to what you ask them to do in your home?**

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- Absolutely
- Comme se comme ca, normally I'd say
- For the most part; some do some don't
- Had to set the house cleaner straight when I need to
- He tries to
- I don't know if they hear and understand sometimes
- I don't say much
- I had a nurse before that didn't but now I have a new RN
- I had one that didn't listen to me so I reported her and they found me someone else
- I have to repeat sometimes
- I let her do it on her own. She does a great job and asks for my input but I just tell her to do what she does and she does a great job. My late wife didn't take care of the house as good as she does
- I usually don't even have to ask them anymore.
- I will repeat myself if they don't get it right
- If I need to I repeat it
- If they are here they listen; sometimes the kids don't listen
- May sometimes have to remind them.
- Most of them, the ones I have regularly
- Mostly
- Mostly yes
- No problem communicating
- Not as carefully as they should at times
- Some of the per diem people from the (name of agency) have taken a lot more time to listen to my needs and but their hands are tied b/c of all the bureaucratic crap, I've heard some have lost their jobs b/c they've tried to communicate with their patients
- Sometimes one person won't let me be helpful
- Sometimes the RN doesn't listen
- Sometimes they forget but I just remind
- Sometimes they do it their way
- (Name) and (name) listen very intently.
- The last girl that didn't got fired
- There was one gal who seemed not to listen and there may have been a language barrier
- They are mostly young and don't have the life experience to know how to handle situations
- They ask for clarification when they don't understand
- They don't always do what they are asked to do. Her cell phone is always ringing
- They know the routines, but the homemaker will do something different if we ask them to.
- They know what they should be doing and they do it with gracefulness
- Very much so
- We kid around a lot
- Well, I think she does. I think I'm supposed to be talking to (name) . Like I need help with the nurse for the medicine

**Q47: Have you ever been injured by any of the people paid to help you now?**

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- I would never ever let that happen, they hurt me inside a lot of them, my self-esteem yes, my pride yes
- I'd injure them right back! Oh no, they're very respectful of me.
- Just once, not able to tell me more
- Laughs, might have been the opposite
- Not yet!
- Not yet!
- She is very gentle, but other people have hurt me, at (name of agency) , that's why I got away from them.
- They keep joking with me, but just kidding
- They're all still alive
- Those people have too much compassion, they wouldn't do that, they love me
- Yes, in the past

**Q48: What Happened? Would you like any help with this problem?**

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- I tell my helpers to be careful of my feet and legs because I have to hang them up and near the edge of the bed due to diabetic neuropathy; one time a paid caregiver carelessly walked too abruptly

**Q49: Are any of the people paid to help you now mean to you, or do they yell at you?**

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- (a little hesitant)
- (Long pause and hard thinking). There are three main people who are out
- But I did have that problem before. I can't have people yell at me, I have post traumatic stress disorder and anxiety and it really affects me.
- Don't remember, but if they did she would speak up to tell them she doesn't appreciate it
- Exactly the opposite, they are all really nice
- Except one person in the kitchen who raises her voice
- God no!!!
- I had a couple in the beginning when I was first starting with the (name of agency) and I hope I never have them again; not now, in the past, I won't have that ever again
- I think they know better
- I worked as a nurse for 22 years so I appreciate the care we get
- I would never tolerate that.
- If they did I wouldn't have them back
- In the past
- It wouldn't do any good b/c I'd yell right back, when (name)'s not around the other lady that will come and help, they give all they really do they give all
- Just one time and I told her to stop or you are out the door; she stopped immediately
- (Name) sometimes yells to sit back so she can hear her speak but is not mean to her
- Last Monday (name) a staffer at (name of agency) raised her voice toward me because I hadn't gotten the breakfast I wanted and she said it was too late
- May want to but don't
- No they're fantastic
- Not any more. I did have to speak up to the house cleaner
- Not really, they just do it in a fun way!
- Occasionally a little sarcasm
- Oh good lord, no! They're the dearest things you ever saw!
- Oh no, they're very good.

## Participant Experience Survey 2010

- One of my daughters who is paid to help me is bipolar and sometimes she has a bad day but I know what she is going through
- People in NH are very professional.
- (Name) tried to force me to go to the ER, but I didn't want to go. I told her I'd be okay after a while.
- She wouldn't allow it
- They aren't mean
- They know better
- They say I yelled at them
- They talk to me
- They wouldn't be here!
- They wouldn't dare yell at me!
- They'd better not!
- They're very nice, actually, they've both got families of their own
- We had one that was, and she doesn't work for us anymore
- Well, one did, and I shit-canned her!!!! I got that psoriasis on the leg and I used to scratch, she saw me and she used to come over and smack my arm to stop scratching.
- Yes one of my daily helpers has little patience with me at times she criticism she shouldn't work in health

### **Q50: What happens? Would you like any help with this problem?**

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- A helper was mean to me about my needing the shades down
- For her own good, she says. They are never disrespectful.
- I don't need any help with handling her
- I let my counselor know at (name of agency) but I haven't let my CM know because I know I am moving to assisted living in (name of city) in the next few months
- I suggested she take the summer off and re-apply in the fall and when she returned here as a caregiver she was a new person and did very well
- If I need to I'll talk to (name)
- (Name) sometimes yells to sit back so she can hear her speak but is not mean to her
- She would like help, b/c (name) s frustrated with her
- (name) is concerned for safety and gets frustrated when (name) does not sit back and so she yells
- She had to learn that he's the boss in his own home
- The spoke harshly to me and I complained and they took care of the problems; the company I have now, (name of agency), is the best I have had
- The worker is overly strict and cross sometimes. I don't feel I need help. It is a day to day work in progress and disagreements about day to day finer points. I don't think it needs to be taken further

### **Q51: Have any of the people paid to help you now ever taken your things without asking?**

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- A few people have in the past
- A piece of candy and soda but we talked about it and I told her just to ask first and she could have it. She is from another country so she may not have known. She is nice and we are ok now.
- Did have a problem in the past. Currently no problems.
- Has in the past
- I can't prove it. Last Friday I was \$20 short when we got back from the grocery store
- I give them gifts because I am very appreciative of what they do for me
- I had one nurse who stole a flashlight from me - I told her to leave
- I lost almost a \$1000 dollars and I can't find it. I called the police and the aide was fired
- I thought maybe another resident might have taken my (nothing specified) from my drawer
- I trust the A team completely

## Participant Experience Survey 2010

- In the past, yes.
- Never noticed anything missing
- Not currently, but true in the past
- Not now
- Not that I know of, one time we thought that they might have, but we don't know.
- Some have, like soda
- Someone took my hand lotion
- Sometimes laundry gets mixed up
- Trusts (name) completely
- When I first came here I lost a \$20 bill. You have to make sure that you keep your wallet with you

### **Q52: What happens? Would you like any help with this problem?**

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- I fired my homemaker about 1 month ago; because she stole from me; I let her go because she stole a hearing aid, s 24 pack of soda, jewelry box, Crayola stand etc.
- Just small things. Participant says she is working this out with the people in charge. Has many agencies working for her.
- Last December two 40 dollar gift cards; that person is no longer working
- My brother in law replaced my money.
- My roommate used to handle my music boxes
- One of my workers stole \$420
- Resident took my lipsticks and snoops around my bedroom sometimes but not any more
- See above
- She took a soda and piece of candy without asking. It wasn't anything that mattered and we worked through it. I told her just to ask and now it is all worked out. I don't need help with this
- Sometimes other residents aren't well enough mentally to know if an item is theirs or not; staff is looking for my missing item
- Sometimes that nurse would sneak in here
- The girl in (name of city) , I know

**Q53: Do you go to a day program outside your home?**

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- 3 days a week.
- 4 days a week – (name of agency)
- At home 24-7
- Both physical therapist and an occupational therapist come to the home
- But I am going to start one
- Community resources such as (name of agency) and a program at (name of agency) public housing
- Could if she wanted to, but doesn't want to currently.
- (name of agency)
- Day program at the facility
- Dialysis 3x weekly
- (name of agency)
- (name of agency) 3x week
- (name of agency) but doesn't care for it.
- (name of agency) day program 3 days
- Everything is here at facility
- Go to the community center occasionally
- He says he has everything he needs in his home
- I can but I haven't
- I get the hell out of here whenever I can, I walk around downtown
- I've been here for over 30 years, if I sit here all day long, it drives me crazy
- I go out with an outreach worker
- I go to (name of agency)
- I go to church
- I have dialysis 3 days a week. Which I don't like, but it keeps me alive. I had asked about a transplant, but I've got so many things wrong, it wasn't a good idea.
- I keep myself busy
- I participate in the activities that our scheduled
- I used to go to a group at the hospital, but all they talk about is sex and sports and I'm not interested in that, I got fed up.
- I used to, but I stopped. I used to go to (name of agency) daycare, but I stopped during the winter b/c it was too cold for me. The bus came to get me and it was too cold. I don't want to go right now.
- I used to, I haven't been going, it was winter and I just stopped going. I'd like to go back to (name) high school soon.
- I wish I could afford the fees at the gym. I want to be able to use the equipment which I choose to use. I don't want to have a trainer tell me what to do
- Language barrier, I don't think she would go anyways.
- (name) Senior Center occasionally to play bingo but it's hard to get around now. Tried (name of agency) last year but hated it.
- (name of agency) , where we met today. Good.
- Not able to anymore, had been going to one.
- Not clear what a da
- Off & on
- Once a week I go to (name of agency) to play bingo.
- (name of agency) Senior Center to play bridge.
- (name of agency) Day Care
- She had in the past but not at this time

## Participant Experience Survey 2010

- She is supposed to but has been sick.
- Sometimes I go to the senior center - I used to be a volunteer
- Sometimes spends a day at the nursing home foster care
- (name of agency)
- The closest is Keene and that is too far
- There are no programs in Berlin that are suitable for her
- There is a senior activity center but I have never gone to them
- They're boring
- Too much trouble
- Tried (name of agency) but sight impairment prevented her from participating
- Fully
- Tried it but didn't like it
- Used to and misses it terribly
- Used to go to daycare at (name of agency) , she hated it
- We go to a congregate meal at the community center
- We were working on that when I got very sick, but I do want to go one day a week, I think that's all I'm up to.
- Wed. mornings gets picked up to go to (name) Senior Center and go to the music room to listen to people play music. She dances and sings.
- Would be interested in trying something though. Was in a mental health day program but couldn't go enough so he couldn't handle it
- Wouldn't be able to get there, it would be very difficult to use the bus, my energy is easily sapped

### **Q54: Do the people paid to help you at a day program outside your home treat you respectfully?**

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- One person was mean to me at Bingo
- Sister - yes they spoil her and she loves it there.
- Some do, some don't
- They are like a family. They are very sweet and always helpful

### **Q55: Do the people paid to help you at a day program outside your home listen carefully to what you ask them to do?**

---

- Ya, they cut my meat and things

### **Q56: Do you ride a van or use other transportation services?**

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- (name) takes me in her van
- Ambulance service for wheelchairs
- Aren't any available in the area.
- Bus
- Bus or a cab, that's all I got
- Cab and (name of agency) shuttle
- (name of agency) for medical transportation but have no other van service
- (name of agency)
- (name of agency)
- Caregiver takes her where she needs to go or can ask a friend.
- Caregivers
- Car ride
- Car ride for medical appointments
- (name of agency) shuttle, caregivers

## Participant Experience Survey 2010

- (name of agency)
- Daughter takes her to doctor's appts.
- Don't have a public van
- Driven by staff of facility
- Drs. appt and once a week grocery shopping
- (name of agency) Bus
- Family care of all the transportation and he can drive.
- Family or visiting angels staff provide transportation.
- Family takes her
- Family takes me
- Do not use services
- Family took him
- For fun
- Goes in wheelchair around town, or drives or gets rides
- (name of agency) wheelchair van is main transportation to doctors appointments and other things.
- Has her license
- Has her own van. Husband drives to doctor's appts, etc.
- Have own van
- Haven't used wheelchair van in years.
- He is still driving
- His van is his vehicle not public
- I can still drive my pickup
- I can take the para transit bus, but usually my husband take me
- I can't afford it; the only one available has a very tight schedule and needs a weeks' notice.
- I can't get into the van that the (name of agency) offers. I don't really get a chance to sign up because some of us don't get a chance to go for a ride
- I go in (name) car and if I need to, I have to go in the hospital van, just once I went b/c I had to have 2 gall stones out
- I have a driver
- I have a driver that is paid to drive me, doesn't qualify for special needs van, so we do a driver
- I have (name). I was lucky to find him, I've known him for 7 years.
- I have in the past
- I have my car
- I have my own car and my daughter drives it for me
- I have my own jeep w/ hand controls
- I have my own van
- I have used car ride for an appointment if no one else is around.
- I have, you have to call 48 hours in advance and then if your appointment is done, you have to wait for them to come back to get you, sometimes it takes way too long. I try not to use it. And it costs money, and I don't have money on me all the time.
- I just use my truck
- I just use (name of agency) ambulance wheelchair assistance.
- I only ride (name 's car), company car
- I own the van and my caregivers drive it
- I use private cars.
- I use (name of agency)
- I use the (name of agency) van and sometimes I take a taxi or use the bus. Mostly I use my power chair
- I use they wheel chair services when I need to go to the doctor or grocery store

## Participant Experience Survey 2010

- I used to, but they don't consider home pick up a priority anymore. I have supplies that I need for my prosthetics, but I can't get them. (name of agency) used to bring me there whenever I needed to go, but now they won't.
- I'm thinking about it, I'm going to call someone about that
- Just family
- Just rides with (name)
- Just the van from (name of agency)
- (name of agency) wheel chair service
- Medical reasons only
- My aide has a van and gives me rides. My father gives me rides
- My family or friends say they will take me
- My home care provider provides me with my rides
- My wife does that stuff
- (name)
- (Name) drives her in minivan
- Neighbor gives me rides
- No, b/c I never have the money for it.
- Not allowed to. I can only go with staffers or family
- Not if I don't have to. It's such a hassle, b/c you have to call them so many days in advance, and then you have to wait and it's hard to schedule
- Not now
- Occasionally
- Occasionally
- Occasionally (name of agency) . Would like to find another transportation service.
- Occasionally uses church volunteers but that is available sporadically.
- Only once a month with (name of agency)
- Daughter takes me everywhere
- Only uses live-in care giver, friends, and family for rides.
- Owns his own van and has PCSPs who can drive it to get around
- (Name of agency), not happy with them, don't have much choice, you do what you gotta do.
- Provided by (name of agency) , residential facility.
- Rarely
- Recreation
- Rides in car
- (Name of agency) county ambulance wheelchair van
- Also, occasionally I'll use (name of agency) paratransit, once or twice a year at the most."
- (name of agency)
- (name of agency)
- (name of agency)
- (name of agency)
- (name of agency) for doctor's appts
- (name of agency)
- (name of agency) sometimes.
- She can use (name of agency) but hasn't had to yet.
- Sister drives her
- Sometimes she takes the service if we aren't available
- Sometimes, but usually my own van. I have used the city bus too.
- (name of agency) bus

## Participant Experience Survey 2010

- (name of agency) provides transportation
- The house has a wheel chair van. We go out for Chinese food sometimes. We'll do more activities this summer
- The van or trolley
- There's one woman who was very sarcastic, but I'll never use her again, on the van, not from this outfit.
- (name of agency)
- (name of agency)
- (name of agency)
- (name of agency)
- (name of agency) for doctor's appts. Doesn't use them for shopping.
- Use my own van
- Use own van
- Use (name of agency) for my doctors
- Use the bus or a cab if needed
- Used to but not now
- Uses (name of agency) when medical situation warrants it. Otherwise she still drives her car.
- Uses Mom's modified van
- Uses (name of agency) program through the (name of agency)
- Usually call (name of agency) ambulance, they have wheelchair vans
- Usually family provides transportation. Occasionally a care giver will provide a ride.
- Usually my family helps me or my helper.
- Van
- Van
- Van to get back & forth to day program
- (name of agency)
- We do it ourselves. I have a car and my caregiver helps me.
- We don't have any transportation other than (name)
- We have a car, but we don't drive that often. I take that to get a prescription or doctor. Usually the nurse will pick up prescriptions for us, especially when it's hot and humid.
- We have the (name of agency) van when I need to go out of town
- We take her in the car and I have a wheelchair for her.
- Wheelchair accessible van
- Wheelchair van to appts.
- (name of agency)
- When I go to the hospital for testing. I also have caregivers that help the elderly and keep them company.
- When I have an appointment, the nurse takes care of that for me. It's a NH thing. A bus that takes you or people that volunteer.
- When someone can't bring me, I ride (name of agency)
- Would like to go places, but says she doesn't have the opportunity to go anywhere

### **Q57: Do you ride a van or use other transportation services?**

- Depending on who is driving.
- Does that include (name of agency)? I get a lot of attitude from people on (name of agency) a lot of times, they don't want to pick you up b/c they have to use the lift and lift you up and hook
- It's a great time!
- One does very nicely and the other one has left, there's another one who confidentially is a perpetrator and I refuse to go through them
- Service provide by (name of agency)

## Participant Experience Survey 2010

- The driver just secures my chair. I take an aide with me as a buffer to the world
- They certainly do
- They even walk me inside the appointment, they always get wheelchairs for me.
- They know I can't see good, so they help me buckle and stuff like that
  
- Very much so
- Very much, that's about 120%, there's one guy (name) , he kind of treats me like his brother. He is such a good egg.

### **Q58: Do the people paid to help you on the van or other transportation listen carefully to what you ask them to do?**

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- Absolutely and they never forget either
- Asks the driver to put her walker in the back and he always does it.
- City bus is an issue. DOT rule. Other van is fine.
- Doesn't need to ask
- Except they don't avoid the pot holes which really hurt my back
- I don't have to ask them to do much
- I had a run in with one guy who was obstinate a long time ago. He isn't driving anymore
- I had trouble with one person, but he got fired
- I just get on and then get off, they just tell you to put your seatbelt on and that's it.
- Most of the time
- Oh god yeah! We get into heavy conversations
- One of them does but the others don't give a damn
- Pretty much
- She's good, I think she gets lost
- The driver did not help me get in
- The people who are driving listen carefully, but I wish they didn't have to wait so long to pick me back up, it's not the drivers, it's the people in charge.
- The wheel chair service is great. I had a bad experience with the city bus so I don't use them anymore
- They kind of know what to expect.
- Usually I will have to ask for help, the seats are low and I have an awful time getting up, I tell them exactly how I need help, like to help on my left side, etc. They come door to door. Very courteous and nice.

## COMMUNITY & INCLUSION

### **Q59: Is there anything you want to do outside of your home that you don't do now?**

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- Need to get my van set up to take my power chair so I could go to a fair or a store
- Swimming pool in yard
- (smiles wryly) No I guess not, besides get a job, get a life
- A lot of things I'd like to do, but I just can't do them anymore
- Aide takes him for hair cuts and to the bank
- Anything! Like volunteer work.
- B/c I'm waiting for my lift
- Beach. Would like to get errands done in one trip. The van just goes to one place at a time and has to sign up a week in advance.
- (name of agency) provides van service for residents. They often go on outings to events, the beach, etc.
- But my body won't
- Doesn't go anywhere now - is a hermit - and says he would like to, but he can't get out. Says if he went out then "trouble would follow him". I can't really get out of him clearly if he wants to get out or not. I think he's happy being home.
- Drive my own van. Used to but wrecked it
- Everything!
- I miss going into stores. It is too hard to keep pushing the wheelchair
- Fishing
- Fishing, walking around Prescott park, I miss Portsmouth
- Generally would like to get out more.
- Get out to shop on her own. The beach. Or anything non-medical. Family can get her to special family events on the weekends.
- Go to a movie
- Go to church
- God yes! I'd like to be able to drive again, or I'd like to be able to take walks, I can't do these things, go to art museums
- Happy at home with books, TV and company
- Happy with transportation to doctor's appts but would like to get around more.
- He wants to stay in his chair.
- He's a "stay at home type of person".
- Hike, swim
- Husband still drives so they can get around.
- I am a homebody
- I am really busy, there's 5 days in a week and I'm busy 4 of them. I go to a day program and church.
- I can do everything now; I used to be stuck in the house and now my pains are under control
- I can't think of anything
- I can't wash the outside of the windows
- I did like to poke through the stores, which I can't do now. I'm getting my treadmill back, so I'll be able to walk whenever I can.
- I get to go to family functions and bingo every once in a while and church every week.
- I go out to sit on the bench but there's a guy who feeds the animals and I'm afraid to go and sit with them out there begging
- I had to give it all up
- I like to go to the firehouse and sit in the trucks

## Participant Experience Survey 2010

- I love to go to the grocery store, but everybody has to do that for me.
- I miss driving, riding my motorcycle; I'd like
- shoot billiards, bowling, my mother and I are going to visit my grandmother in Bar Harbor which I am looking forward to it for a couple of days; I haven't seen my grandmother for 2 yrs.;
- I need transport for non-medical outings
- I used to go hunting or fishing, but other than that I'm fine. I'd like to be able to walk a little more
- I used to like to go to the fair, but I haven't been to them in years.
- I wish I could do my own yard works
- I want to be able to go shopping again and that's why I'm doing the physical therapy
- I want to go to Meals on Wheels 2 days instead of one.
- I want to play basketball, football, lots of things.
- I wish I could be a nurse
- I wish I could drive my truck; however, I have many friends and family visiting so I don't need to go anywhere
- I wish I could get out to eat or out to Wal-Mart
- I wish I could go camping. I can only go a place which has handicapped
- I wish I could still go yard sailing
- I wish I could still work as a nurse
- I wish I could still take a walk
- I wish I could work outside
- I wish I felt a bit better; I'd like to sit in the park or go to the beach, window shop
- I wish that my body would let me work
- I would just love to have a van because I could shop, skydive. And because I only completed the 8th grade because of my polio so I'd love to get my HS diploma and do some volunteer work in my community; I'd go for road trips to visit family.
- I would like a smokers' shed on the property so smokers would have a shelter to go to
- I would like to attend church and social activities, my granddaughter's graduation party - I can't get transportation there
- I would like to be able to dig in my garden
- I would like to be able to fish from a boat. All the fish have been caught from the handicapped accessible spot
- I would never be home if I had a boat
- I would like to be able to help (name) in the garden
- I would like to be able to swim. I do participate in an adaptive ski program
- I would like to feel well before I go out
- I would like to get back into cardiac rehab at the hospital
- I would like to get over to the senior center and do crafts.
- The worse thing I ever did was give up my car
- I would like to go fishing but I can't really walk
- I would like to go skiing
- I would like to go to the grocery store but my daughter took my car away from me
- I would like to run but I can't run or walk. There is pool therapy that I was going to at (name of agency) but I am not doing that anymore. The pool made my legs feel warm and really helped me. I don't do that anymore but I really liked that.
- I would like to socialize more with like-minded people; I just a swimming program, I'd like a gym program and personal trainer or PT.
- I would love to go to the lakes district. I really feel stuck inside a lot. I would love to go fishing
- I'd like to be able to get out more, but now I can't physically do the things I'd to do.

## Participant Experience Survey 2010

- I'd like to be able to go out to eat at a restaurant, but we can't b/c my wife has a hard time too.
- I'd like to drive
- Play bingo"
- I'd like to get out and meet more people and I'd like to learn more about my computer
- I'd like to get back to my job is my number one thing.
- I'd like to get out in the yard and feed the birds but my scooter gets stuck in the grass
- I'd like to go fishing - my aide is going to take me
- I'd like to go for walks more often away from the city
- It gets stuffy in here
- I'd like to go up to the mall, but I can't do that
- I'd like to straighten up my yard and have it look nice
- If I had money I'd go to the store and buy a snack or to the movies or other recreational activities
- If there's something she wants to do, she just asks her sister.
- I'm happy
- I'm not really an outside person
- In process now, movies, parent's house, etc.
- Just get out more. Van services are for doctor's appts. and other necessities.
- Just go for a ride, said wistfully
- Just things that I can't do, things that are impossible for me to do. We go out to eat, I belong to the senior chorus, so I still sing. (name) is the pianist that's how we met.
- Just to get out of here, that's all
- Lake
- Mall shopping
- Like to go first class to Hawaii
- Like to go fishing, shopping, visit my wife in rehab
- Like to go to day program more often. Would like to go to pool for therapy.
- Loves being at home.
- Loves TV, Loves day program
- More outings, more recreation; visit friends and relatives in Maine;
- More walking with the walker
- Movies, theatre, live performances, go camping
- Not really
- Not that I can think of
- Nothing I can think of. I can't bowl anymore.
- Nothing in particular but just wants to get out more often because she can't drive anymore
- Occasional outings to interesting places. With animals
- Output counseling; visit my family in Mass.,
- Recreational activities
- Resume Day Program,
- Senior activities of any kind would be so nice; we have no daily activities here
- She likes to go outside and walk, sit out, take dogs for walk
- Shop, sight see, be around people
- Shopping, out to eat,
- Skate. Play hockey.
- So far things are pretty good
- Something outside the home on weekends
- Sometimes.
- The beach - feel the breeze, smell the ocean.

## Participant Experience Survey 2010

- The pool but needs an aide. Is working on getting an aide to go with her. And will need transportation.
- The things I used to do, gardening, walking, going out
- There is a lot of things I'd like to do, but...no
- There's a lot of things!
- To see my grandnephews and grandniece, visit friends
- Tons. I can't dance
- Travel
- Umm, well I only get a person once a week for 2 hours to do anything I need myself to do outside the house rather than sending someone else
- Used to be able to do sightseeing but I can't anymore because the oxygen tanks don't last very long
- Visit my daughter
- Walk around but no there isn't anything she wants to do.
- Want to garden, but can't take care of it now. Never leaves the house unless to go grocery shopping or visit her husband at (name of agency) (across the street).
- Want to get a ramp because she can't climb stairs
- Wanted to get out to register to vote. Shopping.
- We go to the doctors and the psychiatrists, and shopping, and once he's taken me up to the cemetery where my husband and mother are. I don't ask her to do that anymore b/c she's busy
- Wife can take him on drives and can get out for special occasions.
- Work part time
- Would like to be able to work in my garden
- Would like to get out more.
- Would like to get out to play bingo more often but has a hard time walking.
- Would like to go the laundromat on her own.
- Would like to go with friends in their cars to places but doesn't have the right type of chair.
- Would like to walk
- Would love to be able to work in her garden but isn't able to physically
- Would love to garden. I can't afford to go to plays so I can't go.
- Yeah, I want to go to work
- Yes, shopping and other community activities

### **Q60: What would you like to do? What do you need to make this happen?**

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- A job
- References
- a new spine, a new body
- I'd like to go back to work, if they tell me I can make whatever my income is, I'm working on trying to get a part time job
- Be able to get out more. I go to church. Sometimes someone to drive me, my daughter's good about it, but I can't ask her all the time. No I think I'm very fortunate. Some people's kids don't bother with them. I have 3 that live nearby.
- Bike riding, horseback riding, skiing, ice skating, swimming
- Call the sarge at Salvation Army and ask him to take me
- Camping. Go to the beach. Go on a drive. Swimming.
- Can't as I can't walk or stand very long
- Can't happen. Lost a leg.
- Church, I'd like to go to Greeley park, they have events in the evening
- Crafts activates, outing or trip for luncheon sightseeing
- Currently physically unable.

## Participant Experience Survey 2010

- Drive my own van. Used to but wrecked it. Would need \$40,000, possibly less to get a van. That would expand job opportunities
- Finish (BS- social work at UNH) school, I don't think I need anything, I deliberately took the summer off
- Fish at a handicapped accessible fishing spot
- Fishing, camping, canoeing.
- Go to an art museum, but somebody would have to push me in a wheelchair and get me there
- I'd like to go shopping for clothes, someone to take and help you, can't walk long enough to do it
- Garden
- Garden
- Garden
- Gardening
- Gardening, outing, shopping, have fun
- Gardening, that's an easy one...need long handled equipment and long handled things, if I can sit some
- Generally would like to be more mobile. Go to Boston or enjoy events in the area. Has a handicap van but cannot drive.
- Get out and shop more
- Get out of the house more
- Get to family gravesites to lay flowers and pay respects; I would love to visit some friends but because I have lost control
- Go fishing
- Go fly fishing and we have it planned
- Go for rides
- Have a day when she is up for it
- Day care but could not spend the whole day due to serious health problems
- Go for walks- allowed to take short walks but would like to take longer walks
- Go shopping myself, just to go out and be normal, go to the things downtown, son's school had a fair, can't do that
- (name) needs them to put the lift in, b/c can't get outside house
- Go swimming, ride my horse, be healthy again
- Go to a restaurant and get clams. Water Country. Can't do these things because he doesn't have a car.
- Go to Boston; get out of Dover; go to Delaware to visit my friend; sports events etc.
- Go to church on Sunday, walking through stores, just get out to experience the world.
- Go to Foxwoods
- IGgo to Hawaii
- Save some money
- Go to school
- Bus/transportation - need
- Go to the mall, I need someone to walk with me so I don't fall.
- Have a ramp built
- Have my physical coordination back
- I am writing a children's book and would like to go back to my school. I need help arranging that, getting me there and help on the computer.
- I can't turn back the clock. I do go to legion meetings because they help me coming and going
- I don't have good affordable transport here
- I have a great big bag of duck food to feed the ducks, but I can't. I'd have to get better physically. I have a scooter, I just can't use it right now.
- I like to go on the hobo train
- I need to get younger

## Participant Experience Survey 2010

- I need reliable W/C transport to go shopping, recreation and activities. The only time I get out is to MD appts. cause their doesn't seem to be any companies that can take my chair
- I need to find a PT group or 1:1 mentor to help me keep moving; I am afraid my car will breakdown because it is on its last leg
- I need to get transportation to get to the place where I want to walk, but you know, I don't really think that it would...it would be really hard to arrange that
- I want to get our van repaired so I can go out shopping
- I want to get out more, I would need a scooter. I'd like to do a lot of things, like going to the movies or shopping, transportation is what I'd need.
- I wish I could still work
- I wish my short term memory could be restored
- I wish they would make the theater handicapped accessible
- I would like Medicaid to pay for transport to an outing to shop or eat even once in a while.
- I would like to be able to go shopping. I would like to be able to
- I would like to be able to walk more but I have bad breathing
- I would like to go on a vacation more
- I would like to go out shopping more
- I would like to go outside to the yard and empty the trash
- Need a ramp and an electric wheelchair.
- I would like to go places and see different things. I need people to take me around to do that
- I would like to go shopping and look at movies
- I would like to just shop more and go to stores. I need lower cost transportation.
- I would like to see of my kids who live down south
- I would need more money and I don't have it
- I'd like to be able to go places, I mean I'm not talking about travel,
- I'd like to eat out and meet more people that are more and I'd like to learn more about my computer (like I had in 2006), more people that are positive
- I'd like to go shopping. Haven't been in a store for over 5 years.
- Access to a van that I don't have to pay for. It's too expensive
- I'd like to plant my garden. But I do the best I can.
- It would take somebody to come over and dig a trench and plant them. I'm gonna do it myself now.
- I'd like to take walks and I can't even do that. I'd need a better wheelchair than what I've got. I can't push it with my hands.
- I'd like to visit my daughter at Glencliff, it's two hours away. I miss visiting some of my family
- I'd love to go out to dinner once in a while. I would need transportation and money.
- In general would like to get out more.
- Just get out more
- Live my life
- Look for a job part time and go to college full time.
- Job - response to her resume that she has submitted
- Mom needs more time and energy to take her
- More help, more money
- More mobility to go with friends in their cars to places beyond what is offered in the van service. Needs the Beasy board and the portable chair.
- (name) is going to help me go to the YMCA so I can swim
- If I could walk around, I would garden and go to the shore and stuff like that
- Most of things I want to do are not realistic
- Mount Sunapee

## Participant Experience Survey 2010

- Movies or just go out other than doctor's office.
- Mow the lawns
- My daughter tells me to write to Oprah Winfrey
- Needs to make arrangements to get an aide to go to the pool and will need transportation.
- Not sure. Lot of things are closed on the weekends. Has joined (name of agency) twice in previous years, but found the other visitors there acted "above her".
- Nothing, I can't. I haven't even driven for a long time. I don't even own a car. So, there's nothing that I'd like to do.
- I'd like to go back to work, but it's impossible.
- Often she depends on friends or volunteers to take her on errands. Loves the van services but it's sometimes not convenient.
- Other than being on the grass, nothing else
- Physically limited
- Play bingo
- Go to Senior Center
- Mall
- Need transportation for wheelchair and someone to stay with me at bingo
- Play golf but is blind.
- Play pool, play golf, socialize, etc.
- I would need to be able to drive, but I need a car with hand controls.
- Part time work,
- Regain sense of balance and have knees improve
- Restaurant. Usually we get to go w/ our daughter and son in law, they will help us get in and out, deal with our walkers and the bathroom.
- Resume Day Program, more outings and opportunities for social and recreational
- School plays and concerts, church, I cannot predict when I may become too fatigued so this is about it
- I have TV and help 5X weekly
- I just need to make up my mind and call them and the van will come and pick me up
- My goal is to have surgery so I can move better. I just got a new doctor.
- She would like to get her hair done once a week. She would like to get someplace to buy something special for people who are kind to her. Small trips for special occasions.
- Shop, activities, see people, recreation
- Shop, yard sales, doctors house, etc. but I have company so I don't really feel bad
- Shopping
- Sometimes a friend takes him.
- Swimming pool
- Cannot get out of wheelchair or off oxygen - not possible
- Talked about the beach a lot. This was emotional subject. Wishes there was a program to take people on special trips like nursing homes do for their residents.
- The drivers have to volunteer to provide rides as it is their personal time
- There is pool therapy that I was going to at (name of agency) but I am not doing that anymore. The pool made my legs feel warm and really helped me. I don't do that anymore but I really liked it
- There's things she'd like to do now but she can't do them b/c she can't do them, for example mountain climbing
- (name) wrote a book in 19\_\_
- To ride in the front seat of the w/c van so I don't get nauseous, get a ride to MD in Rochester,
- Transportation, but I don't see them paying for me to have a wheelchair ride to RI, when there's people who need it for medical reasons

## Participant Experience Survey 2010

- Visit friends and family
- Walk but eyesight, hip and breathing are prohibitive
- Walk the dog, I walk pretty good. They got me a power chair, okay? But it's a 350 lb. chair. What I'd like is a portable scooter. Then I could get out more with my family. The chair is for inside, we can't get it in and back.
- Working out at the gym
- Would like to be able to do some gardening but can't physically.
- Would like to be able to go for walks but it's too painful.
- Would like to be more active but is physically limited
- Would like to go to day program more often. Would like to get to pool for therapy.
- Would like to go to rehab for a pool for pool therapy. Has discussed with VNA and physical therapist. Must apply for services, find the time.
- Would like to go to the laundromat on her own but is unable physically.
- Would like to visit a friend who's in rehab. Would like to just get out sometimes. Family can take care of transportation needs but it would be nice to get out.
- Would love to go to attractions in the area but is wheelchair bound and it's hard to get around.
- Would love to go to church but has no transportation to there.
- Need transportation
- Yard cleanup;
- Yeah but it takes money and it takes a program, I'd like to go back to painting, I'm a crafts person
- Yes activities of all kinds like going to the beach, seeing the sights fireworks, music, ballgames etc. I want to live an active normal life

### **Q61: Is there anything else you want to talk to me about?**

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- (this happened after I asked the work questions) Wants to learn but can't afford to pay for it or for the loans b/c she can't get a job to pay for the loans (began tearing up), feels she stagnates
- Can't think of anything.
- Can't think of anything
- Communication is not so good with new CM at (name of agency) .
- Concerned about cuts in mileage allowed for staff of (name of agency) to transport him to gym, appts., shopping.
- Dentures
- Everything is ok
- Explain to me again about this survey
  
- I also get help from my daughters
- I am happy with what I have but I could use a little more help
- I am home alone a lot
- I am sleep deprived and don't usually cry but today it's all coming to the surface (participant is teary today)
- I am very happy with my services and who I have now; they changed the ones who were not working out.
- I am wondering what the doctor is gonna tell me about my cirrhosis; I am scared
- I don't go very far from the house. I get too tired. The people that help me are very prompt and kind. They are decent people.
- I don't have any help on the weekends and that's been very hard, especially on the weekends. I am left here all alone. That's hard.
- I don't know if there are other things I would qualify for like a ramp or more transport but now I will ask my CM

## Participant Experience Survey 2010

- I don't like certain foods
- I don't think so. I would like it to be easier to get my toenails cut. Only the nurse can do it and not the aids so it is hard to get them cut. I can't do them myself
- I don't trust anyone in the system
- I have had a fortunate year and although I had hours cut back I just have to watch my budget and I would like to pursue LNA training if it can work into my doctors needs for care; I know that if I need anything I can ask CM
- I have my faith, that's very important. It has saved me.
- I know that Medicaid is having financial problems so I'm not gonna push on the wheelchair things but really it's been breaking down a lot lately and the worse time it was broken for a month and a half
- I like everyone that comes here
- I like the food here
- I love this place; I am gonna stay here till my dying days!! My daughter is also so good to me
- I need more help getting to the MD, shopping, laundry and errands
- I need teeth to eat better and no one can seem to help me with this.
- Can't afford them.
- A lot of foods I can't eat b/c I have no teeth.
- Digesting is hard b/c you can't chew my food properly.
- I push to do for myself independently and don't want to burden my kids. So far the paid help are great for the most part. A couple haven't worked out but (name) has coached me on how to teach my paid helpers exactly how and what needs doing.
- I quit smoking and I chew Nicorette gum. I don't think I should have to pay for it myself.
- I should be living in a different type of place where I have opportunities for socialization and work
- I think that I have pretty much everything I need
- I want (name) back from (name of agency) because she is the most patient of all the helpers; she gets a lot done and goes the extra mile for me
- I wish I could get out more
- I wish I could still go swimming
- I would like a resource for affordable transportation and I'd like to attend a day program a couple a days a week.
- I would like to get my arm amputated and I get it done. I have a spinal cord injury and the doctor's still want to try to save it
- I'd be totally at a loss without the services I have
- I'm just scared what's going to happen to us if I lose my husband's income as he is very ill and may go to a nursing home full time.
- I feel very stuck right here.
- I'm lonely, my son just died.
- I'm pretty well set
- I'm trying to get a first floor apartment b/c I don't like the stairs, then I'll be able to go outside more.
- Instead of sending Mom the caregiver away on vacation, provide a trusted and qualified person to come and stay so Mom can have a break. Even just twice a year for a weekend
- Is there a place to get a will (referred to 211 and Service Link); has a health care proxy but no will
- The life span of my family doesn't seem to be very long lately; (name) was 32 when she died, (name) just turned 50, my mom lived to be 74
- It is a taxing effort to go out with my medical condition
- It is going to be difficult to lose my nighttime help because I cannot take off my compression hose.
- It would be nice to have people to prepare meals, because (name of agency) sucks, it's horrible food
- I've got a shoulder which needs to be rebuilt

## Participant Experience Survey 2010

- Just that this place is not as good as (name of agency) but I couldn't stay there because the room they gave us was tiny and I was required to share a room. It's been hard to find an assisted living facility that really meets all the needs of seniors.
- (name of agency) won't leave the meals if he is not home. They also won't leave the meal with his wife. They feel this is ridiculous because he isn't always in charge of how fast he gets back from things and his wife is there to take it for him.
- Mostly concerned about losing the three hours. That has made a big difference. Would like to get those three hours back. Very happy with the people
- Mostly that I am hanging in the balance to stay here. I am still an achiever, limited but I don't want that to be taken away.
- My biggest fear is that the funding will stop and I will not be able to continue my life and keep going.
- My helpers are very loving.
- I need someone to wash my windows
- My medications and how I've been labeled, my medications have been taken away from me, my strong medications re my morphine from Lahey - a pain center, I was sick and I had the VNA come in and assist me
- 40 responses were "No"
- No complaints.
- No from (name)
- Wife wanted to
- No I think I'm doing alright
- No other services that I want now
- No, everything is fine
- No, I think we covered it all.
- No, I'm not much of a complainer
- No, I'm pretty satisfied, pretty happy about it
- No, I've pretty much said everything, I've taken up all your time
- No, my caretaker does good.
- No, she is happy. Just if health would get better.
- No, we're all set
- Nope
- Nope
- Nope
- Not really
- People with Medicaid need dental work, people on Medicaid need dental; hasn't seen dentist since 16 years old, can't find a dentist to see
- Right now she has one person come to help out. If that person can't make it no one fills in and she has no one here to help. It would be nice to have more than one person available to help.
- Right now she says she's very lucky because everything is fine.
- She really wants to go to the grocery store with the caregiver but doesn't have enough time to get it done. This is her only opportunity to get out and she can do it physically.
- Sometimes feel really down because she can't get out much and feels out of touch with the real world. Can't find rides to go places when she wants to.
- Sometimes they want to know too much about my private life and don't stay focused on why they are here; i.e. my CM thought I shouldn't have a certain individual helping me but I think that should be between my (name of agency) CM myself and HCBC CM

## Participant Experience Survey 2010

- Son present for interview. From family perspective this program is great and very helpful. Fills in the gaps when family can't be here to help. Initially worried that this survey may have something to do with decreasing or eliminating the program.
- Stroke on LT side, legally blind, diabetes.
- The people will do whatever you ask of them; if you can't be at home, this is a very good place to be.
- The son feels there is an unfairness in that caregivers who are power of attorney cannot be paid for their time
- There are times I am stuck here at home.
- There is a situation that is developing now, we love it that the state gives us 20 days of respite. We have family medical things going on. We need the time away to help out there
- Think it's a wonderful program and just hope it stays funded b/c the alternative would be assisted living for me and , I'm too young for that.
- Thinking then shake their heads
- Transportation is biggest issue
- Used to get snow plowing and gardening done - would like that again.
- Very happy with services and program
- Wants to get out of nursing home
- We are glad we have the services; it sure helps
- We had a Father's Day celebration here and it was fun.
- We just lost our best girl (name) , we had her for 6 months and we really liked her. Change is hard, it's hard to get used to a new person. She was sweet and nice to get along with.
- Wheel chair repair has been delayed but I am going again
- Tomorrow to try to get it fixed right this time
- Witnessed some neglect during her year and a half stay in a nursing home. Wishes Medicare was aware.
- Would be happier living back in Manchester where he had more freedom
- Would like care in her home on Saturdays.
- Would like (name of agency) or another van services to provide transportation to doctor's appts and AA mtgs.
- Yes there is an area of weakness
- Yes, stop cutting the goddamn fucking budget!
- I worked all my life, I didn't ask for this to happen, now I have to sit here and take handouts. It doesn't make me happy

### **Q62: Are you working right now?**

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- I haven't worked in the last 8 years.
- As a volunteer, no paid work.
- She did have a job at (name of business), but they cut her hours back too much so it didn't make sense.
- Can't work.
- Haven't worked since '82
- I can't even walk
- I can't, I'm blind. I used to fix machinery, you need stability and you need your vision.
- I counsel my aides, but not for pay
- I did work somewhere for a short time, just checking tickets.
- I don't work, I think my desire has always been to work, but it's not possible b/c I don't want to work in a production line, I can't stand long b/c of my prosthesis, I can't see well enough to do much either.
- I empty the trash, but they don't pay me, I just do it.
- I haven't for about 4 years
- I own my own business

## Participant Experience Survey 2010

- I wish I was
- I work at (name of business)
- I'm retired.
- No, I am fully retired now
- Temp, part time seasonal
- Volunteer job for (name of business) sales person, but that will end in July. Donates the money she could earn to buy toys and things for (name of agency) and (name of agency) and other organizations.

### **Q63: What kind of work do you do? (SPECIFY)**

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- Clerical work, vender at the (name of business) . 3-4 hours at a time. And tax prep, self-employed
- Early autism intervention program.
- I take down data, data collection, film collection ,and I spend time to do damage control, make sure kids are where they are supposed to be, copies, and on Fridays I actually play with the kids.
- Sell candles wholesale
- Webmaster and list master

### **Q64: Did you help pick the job that you have now?**

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- I was picked by the former director through the access office
- It started as an internship, so mom helped me, they will hire me if I get a license and a car
- Went, applied and got hired and they call him back each year

### **Q65: Do you like your job?**

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- I do, I get to see those cute little faces
- Someday, used to love it but in 2008 it became routine

### **Q66: Do you want to work?**

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- As long as I could do it, of course I would! It's extra money, I'd work, yeah.
- At this point no, in the beginning yes, now no. At that time it was hard for him to adjust. He's got a lot of pain now, and it's too much, too tired now. I think if they told him he had to work now, he'd cry
- But can't physically
- But I can't
- But is unable.
- Can't because of physical limitations
- Every time I've tried to work, even volunteer work, I end up right back in the hospital. Mental health wise.
- With all the appointments I have, that's a job!
- Hard time with concentration. Has chronic pain.
- Has worked at different jobs in the past, but b/c of the MS, she can't type or hold things; husband thinks she would be great as an MSW working with people or kids; had so much fun as a parent liaison/coordinator when kids were in Head Start
- (name) is going to be bringing me to a part time thing like at Wal-Mart for a greeter or something for a few hours just to get me out. It will help my insurance, not doing this yet, but soon.
- I can't
- I can't; I got heart failure.
- I do make flower arrangements
- I don't know if I'd be able to.
- I don't know, there's a lot of worrisome that goes along with
- I have tried to work; I tried to work

## Participant Experience Survey 2010

- I haven't been able to work for 4 years
- I know I couldn't because I can't read and everything today is run by computer
- I was thinking about being a greeter at Wal-Mart. There isn't much I can do
- I was working right up until I had the accident. I have diabetes and my sugar got too low. I do, but no one will hire me. I used to be a cashier at a gas station overnight.
- I wish I could, but I can't
- I would like to get back to chambermaid work
- I would love to work but with my problems I cannot
- I'd like to return to work, but at this point, I'm physically unable to.
- I'd like to work a few hours as long as it's local and I have medical needs that sometimes require me to have somebody around
- I'd love to work
- I'd love to work!!! I can't do this crap no more, none of it. I might, as long as it's wheelchair accessible.
- I'd love to work, any project at the school I like to help
- I'd love to work, I had a great career, I can't work though, I'd love to be still doing my career
- If I could find a job that you could do, I would
- If I could I would
- I'm not able to work
- I'm retired
- It would be really hard for me to work, cognition is not there, stamina not there, I can't stand, I can't sit long. But I would LOVE to work!
- It's tough to find something I can do.
- Maybe part time
- Not physically able.
- Not possible
- Not while I am living here
- Receives disability benefits and has restricted earnings.
- Someday I hope to
- Sometimes I wish I could but I know I can't, I'm not able to work anymore, about the only thing I can get to work right now is my mind, (lists physical problems)
- That way I wouldn't be broke like I am now
- Totally disabled
- Unable physically
- Would be too difficult
- Would if she could
- Would like to work but doesn't think he can physically.
- Would like to, but doctor told him he has to go to school to learn a new trade.
- Wouldn't be safe. Has short term memory issues along with being a falling hazard
- Yes and no, if I were feeling good yes, sometimes I look at this writing thing I think maybe I could write and sell articles but I'm just hunting and pecking (typing) b/c these fingers (about 3 fingers on each hand) don't work, it's not realistic for me

## PLAN FOR SERVICES

### **Q71: Have you been provided a copy of your plan for services?**

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- By the (name of agency) ? What do they mean by services, I don't understand that, there's a lot of services
- Daughter probably has it
- (Name) gives us a paper every so often with our rules and regulations
- (Name) didn't remember, but (name) said yes
- Every time they send a brand new copy of everything, my med list, diagnosis, services, everything
- From (name of agency)
- Get copies of HIPPA but do not get copies of the monthly meeting
- Got it from homemaker's boss
- Have plans for individual organizations but not a comprehensive plan
- I don't know, I might have, it's all in there
- I got it a long time ago
- I got it right here
- I have a handbook
- I have a lot of paper work. I don't like to read. My daughter handles that stuff
- I probably have but don't ask me where it is
- I probably was somewhere.
- Informally yes.
- Initially but does not think it has been updated
- Is likely here at home in a folder
- I've got it somewhere I think, I'm sure I have, there's so many things here I don't know half the time what I'm doing.
- (Name) keeps my treatment plan for me
- May but don't recall
- Most likely. I have a bunch of papers
- My daughter handles it for me
- My mother takes everything
- My wife has one.
- Never, these people they never, they just say this person is in charge, I never got nothing.
- Not sure, everything (name) gets she gives to (name), b/c she can't read
- Not that I know of. If I did it was way back 4 years ago, I don't remember
- Oh yeah, I have all the information. Actually in September I'm going to have to fill out everything she does and what she is doing when she's here. Like how long it takes her to do everything.
- Probably when first started. But nothing else
- Probably, I lose everything.
- Probably; husband says yes every year, she gets another one
- The nurse checks with him before each visit
- Thinks her sister has it
- (Name) says she has the books in her room if she needs to look at them.
- We get so much paperwork, I shove it in the drawer
- Well, the girls gave me one one time, but I don't know where it is.
- What kind of plan would that be?
- What plan?
- Yes

**Q72: Does your plan address all your service needs and concerns?**

---

- About.
- As far as she knows it does.
- As far as she knows it does.
- As far as she knows, yes.
- As well as it can
- At this point in time
- Because it is rewritten as needed
- Big transportation gap
- But I'm not too keen on some of the advice given to my mother
- CM is working on setting up PT
- Daughter waiting for answer about recent request for resumption of RN visitations
- Easy transport without getting nauseous
- Everything but money
- Except for two things cleaning rugs and windows; I have to hire someone
- Except the toenail trimming
- Except transport and ramping
- Getting all the help she needs
- His case manager does make sure he gets the services he needs
- I am having a hard time getting forearm crutches, but other than that, yes.
- I believe so
- I don't know
- I don't know what the plan is
- I don't know what they offer so I cannot answer that question.
- I get everything I need
- I guess
- I guess so
- I guess, I don't remember!
- I haven't read it but I imagine so
- I needed a ramp and a railing which I didn't get
- I read it when they gave it to me, but that was then and this is now
- I really can't complain
- I see my nurse case manager once a month. We review the elements of my plan and any events such as a fall.
- I think the one I'll be calling is (name) , he'd rather see me go to an independent set up.
- I'd say so.
- If I have a question I can always call my case manager
- If we could get equipment we need, it would be better
- It might need to be upped
- Just sometimes it is a little slow but she sticks with me till the problem is solved
- Laundry is a big issue; I said to the girl that it's not getting done and I hate the smell
- Most of his needs, but underestimated the time it takes
- Most of them
- Most of them not all
- Mostly, but not everything
- Needed clarification, didn't know what I was talking about
- Needs more time with caregiver.

## Participant Experience Survey 2010

- Not always the right kind of care.
- Pretty much,
- She helps me get many things which I need
- She would like more housekeeping time
- The Medicaid program does not have sufficient flexibility to address my atypical needs
- They asked me what my goals, what I want done what I need done daily, that's how they determine how many hours a day I need, bathrooms, housework,
- They're quite upset that I don't have a wheelchair to move around in. I want some freedom.
- Would like Meals on Wheels for evening meal. Depends on son who sometimes works at night.
- Would like more frequent help. Doctor recommends 4 days a week.
- Yes

### **Q73: Has anyone ever explained to you your role in developing your plan for services?**

---

- I suppose they did.
- Again does not have a plan
- At the time I didn't have a place to live, they found me a roommate, that's what they found for me. At the time, I wasn't as capable as I am now. I had gotten hurt and everything and it was harder getting by.
- At the very beginning
- Basically leaves it in the hands of case manager by choice
- Do you know, I don't know
- Doesn't know if he could have other services he's not getting. This would be helpful to know but not sure or can't remember if this was ever explained to him. As far as he knows, he is getting what he should be getting.
- Don't remember, probably
- Family took care of that.
- Her daughter is a very strong advocate
- I did that
- I don't know, just to be here, I do what I do
- I don't think so.
- I have a good idea b/c I work with (name) , we're always going over that and the agency that I work with too
- I have to set up my own schedule and I'm not sure what you are asking me.
- I honestly can't remember, but I'm pretty sure I had some say b/c they are always pretty attentive
- I learned by walking through the pieces of my plan
- I'm sure they did but I can't remember
- I'm very independent, I should have had help long before I did.
- (Name) understands her role because of her nursing background
- (Name) explains for us
- (Name) explained it.
- Maybe not quite as well as they should have
- My caseworker did and another lady came from the state to explain
- My son acts as my advocate. He has power of attorney
- Not exactly, a little bit
- Nurse and case manager
- Probably
- Probably, yeah
- Probably. There is so much of this stuff, I don't even try to remember it anymore
- Seemed confused by the question

## Participant Experience Survey 2010

- She participates in meetings with case manager and state person
- Son and daughter took care of that.
- Son includes father in all issues relating to his care. But son makes most of the decisions
- Son takes care of all paperwork.
- (Name) said it was explained to her.
- The case manager tells me how I can participate
- The nurse goes over everything with me
- They check to see if everything is the way I want it
- They have discussed it with her; the intake person would come and ask her what she wanted
- They probably have
- They talk to me all the time about it
- They told me how they felt about what I needed, then they asked me if I agreed and I was able to add anything.
- Thinks so
- To (Name) and (name), (name) isn't cognizant
- To some degree
- We just get what we need, we don't try to take more than we need
- Well that lady (name) , she tries to come every 2 months I think it is and she comes and talks to me and tells me about the new things and what's going on w/ the company.
- When I first moved into my apartment a long, long time ago
- Yeah I think (name) did from (name of agency) when I first got on the program.
- Yes
- Yes and no, (name of agency) its their demand, their control, their way of saying 1, 2, 3, 4 and that's it

### **Q74: Did you have enough say in developing your plan for services?**

---

- Absolutely
- As far as she knows.
- But because of budget cuts some of my services have been eliminated
- CM and I argue about this back and forth
- Cold fish is my reaction
- Daughter handles this
- Does not understand what the "plan" means
- Doesn't think so. Says that she would like more help and has requested it.
- Everything he requested, he received
- Family handled that
- He thinks he remembers in the hospital talking about what he needed help with
- Her brother set her up in the program
- Her son took care of it.
- How do I answer that one?
- I guess
- I had input but I am unhappy with my plan
- I have the entire say
- I just accepted what I got, I'm easy to please. If I'm not happy, I'll let them know.
- I just told them what I like and what I don't like.
- I kept having to ask what the parts of the plan were for. It was done by the higher ups.
- I sometimes get confused about what I need..
- I think I did
- I tried to

## Participant Experience Survey 2010

- I was never asked or included
- I'm thinking about my physical therapy
- If I need anything all I have to do is call (name) , my CM
- If there is something I don't like I let them know and there are some things that are not covered that I think really should be covered
- It varies; sometimes yes sometime no
- Maybe, they didn't exactly ask me.
- More than enough
- Mostly yes, my brother helps me with the rest of what I need
- My husband
- My youngest daughter acts as an advocate for me. She doesn't let anything go.
- Not always
- Oh definitely.
- (Name) was very kind to me, the owner. We sat in my apartment.
- Says when he doesn't like something or needs something
- She wouldn't be able to participate
- Someone came in the beginning and sat down with her to explain everything.
- Sometimes feel like they don't understand what I'm saying with my words
- They changed my medications without telling me
- They just called me outright and I had to do it
- They tell you what you are gonna get and that's it
- Thinks yes, but unsure
- Trust me, I got my way.
- Usually
- Was basically told how it was going to be and what she would be getting - not in a forceful way, but she wasn't asked if things were alright with her.
- We give 5 dollars for the woman who does our hair, etc.
- Well, I guess a lot of things I'd been saying to the ones I need to say it to, I feel that this girl gets underpaid for what she does for me, she does more than she's supposed to do. I don't think that's fair.
- When I came home from the hospital they sat down with her and she is satisfied
- Yes
- You don't really have a choice. You are kind of limited. Here is what you can get, take it or leave it.

### **Q75: Are you receiving all the services listed in your plan for services?**

- All except transportation to buy food
- All that I know of
- Answered just about, but then added that she can't think of anything else she needs
- As far as he knows
- As far as he knows.
- As far as I know
- As far as I know
- As far as I know I am.
- As far as I know. I really don't read my plan.
- As far as she knows but doesn't remember the plan. Has everything she needs.
- As far as she knows, yes.
- As far as she knows.
- As far as she knows.
- B/c I'm allowed to tell them

## Participant Experience Survey 2010

- Because of her living situation she does not use all of the services she is eligible for such as food stamps
- But there were cutbacks and changes in personnel that I didn't agree with but I was told there was no other options
- Doesn't know what they are
- Except for meals on wheels since he has a sleep disorder and often one of his kids accepts the meals
- Except transport and ramping
- Haven't read the plan for a long time
- I believe I am
- I can't answer that one b/c I don't know
- I choose not to have meals on wheels due to my dietary conditions.
- I don't know because I really haven't seen the complete plan
- I don't think I have even seen my plan. I only talk with my case manager
- I get NH EBT every month
- I guess
- I guess I'm getting what I need. I get the aides and the meals on wheels, but I don't have transportation. That's the biggest thing.
- I guess so
- I have no idea
- I imagine so. There is not much I need right now but I really don't know
- I think so
- I think so; asks husband, he says yeah.
- I wish I didn't get cut the extra 3 hrs. a week because it really helped
- I would say pretty much, I'd have to look at it again, but I'd have to say pretty much and then what they don't, visiting nurse does
- If I don't get what I want I scream loudly
- Most of them, if I need extra, I can let him know, but I don't take anything I don't need.
- Mumbling about NY and services, the government, etc.
- Not familiar with current plan of services from which to answer this question
- Not sure what else she might get
- Not sure what's in it.
- Nurses come every 2 weeks, the case manager comes, everything is good
- She assumes she is.
- Still waiting on PT plan;
- (Name) said there are a lot of extra services listed that she doesn't utilize.
- They take very good care of me, I can't say enough good about them. They are the top of the top. And they know that I'm very outspoken, I'll tell them if I'm not happy.
- They attend to my needs. Very responsive to my needs or whatever the hell you want to call it
- Unless someone gets sick
- Unsure. Doesn't remember what is in her plan.
- Yes

### **Q76: Overall, how satisfied are you with the services you receive from this program?**

---

- 100%
- 100% satisfied
- 110%
- 99 and 9/10, I have no complaints there.
- A+!!!
- About as satisfied as I can get.

## Participant Experience Survey 2010

- Awesome!! You get the right people, put them into place, talk to them, and it works out. The only thing I really worry about is if they're gonna cut budget or services
- Because I don't really know what's available or not available
- But I often worry if my bills will be paid
- By and large due to (name) other comments about weaknesses in the program not withstanding
- Definitely very satisfied.
- Depends on the aide you have. Sometimes the meals don't come when they said they would.
- Dissatisfied with some things like the nurse I had before and the transportation problem
- (Name) and (name) are good
- Dissatisfied with day program. Would like more activities
- (name of agency)
- Everything's fantastic. Couldn't complain about a thing
- Excellent and professional
- Excellent satisfied
- Feels many of her needs are not being met. PCA program good but not happy with (name of agency) Doesn't get satisfactory response when asking for additional services.
- Good
- Good. Very good.
- Great
- Her in home caregiver is like a daughter to her. She loves her.
- I am not allowed in the kitchen, can't use my own bathroom, can't have a computer with internet, can't live a normal life here because there is nothing to do, no one to provide transportation for things
- I am very satisfied w/ the independent living, I'm very satisfied with that.
- I couldn't be happier!
- I give them a 10!
- I have no complaints
- I have two good girls coming in
- I like it, it's very good.
- I love it, I don't want to leave this place, this is my home for good
- I never want to lose (name) . She is so valuable to me and she doesn't treat me like I'm some kind of jerk.
- I think that I'm very fortunate to even be on it.
- I would say 100%, they all take very good care
- I'm saying I don't know, I don't got an answer.
- In the beginning things were great, but then things (services) began to dwindle.
- It's good
- Knows she can call case manager and she will provide if it is in her reach
- Like more time out and meals on wheels
- Mostly satisfied but has developed some new conditions.
- My only complaint is that my frozen food is soggy
- Ok
- Only complaint is not being notified if caregiver cannot make it. Does not happen often but is very disruptive when it happens especially if he has to go somewhere and has to get ready himself.
- Outstanding!
- She is happy with some of the people. Unhappy with others.
- Simply amazing what they are doing.
- Some of them do better than others.
- The agency is short staffed so if my regular worker is out, I don't get any services

## Participant Experience Survey 2010

- The only thing is I think it's not enough pay for the workers or if she could get paid for more hours to be here. She does it anyways b/c she's my daughter, but if it was someone else, maybe not.
- The program from (name of agency) is very helpful
- There is significant variation in the quality of the care
- Very good
- Very grateful for the services.
- Very happy when care worker is here but needs more time.
- Very pleased with the help she gets.
- Very proud of it, very content, right now, I couldn't ask for anything better, I had a girl who was 18, but she ended up going somewhere else
- Very satisfied
- Very satisfied with the person who helps her but is not satisfied with the service because she doesn't have enough service.
- Very satisfied with everything
- Very satisfied with (name) , but overall satisfied.
- Very satisfied - no complaints
- Well yes when I get somebody like (name) , I'm satisfied. They try. But I hear they don't pay much and if you don't pay much you ain't gonna get much, but they do go out of their way.
- We're just grateful for whatever we can get and we can manage
- With the new company and (name of agency) it's great; in the past I had to trouble shoot
- Would be in a nursing home without the help

### **Q77: Would you like to be contacted by someone from the Medicaid program to discuss any concerns or questions you have about your services?**

---

- Absolutely, a.s.a.p., (hand clap)
- Any questions - ask case manager
- As long as they are gonna help me and not make things any harder
- Ask about dentures
- By Medicaid and Medicare
- Call to discuss unpaid bills, contact (name) , son.
- Concerns about wheelchair.
- Does not have any concerns.
- Doesn't have any issues. Can deal with case mgr. about anything.
- Everything has been explained to me in good detail already.
- Food, meals
- I actually have someone that calls me once every 4 or 6 months, she sends me a business card, if I have problems just call
- I called for my MS medication yesterday, and they're telling me they have a \$120.00 balance b/c Medicaid isn't paying my co pays.
- I can talk with (name)
- I can't think of any concerns
- I clam up because I get overwhelm and I feel very uncomfortable with the way some people act
- I don't have any though, but yeah.
- I don't hear good over the phone
- I don't want to be contacted by anyone
- I guess I do have a couple of questions about what Medicaid will pay for.
- I have no concerns
- I have the number for them if we need them

## Participant Experience Survey 2010

- I just want to get the Medicaid number, the Medicaid card, I just want them to send me the card on the social security and the Medicaid
- I know how to get hold of them
- I usually call them when I need something
- I want the diaper situation resolved
- I would like to find out if I could work part time to be able to pay up some of my bills
- I would like to talk to someone about getting teeth.
- I would rather do it face to face because I'm hard of hearing and can't make out what people are saying on the phone
- I'd like to know why I have such a hard time getting stuff sometimes, like forearm crutches and stuff.
- If they want to call me that's fine
- I'm a little bit confused about this insurance thing, it has to do with my prescription plan. It says to call social security or something.
- I'm being recertified so I'll be going there
- I'm not too fond of Medicaid. That program I'm on. They told me I'm not to pay for nothing, but I get sent bills.
- I'm putting in a request for a hearing aid; they've been taking money from me for years.
- It would be alright, but I don't have any questions right now
- It's pretty self-explanatory; read the book.
- Just started
- Keep all them people away from me
- (Name) answers all her questions
- Meals on wheels
- Medicaid calls her regularly
- My services are fine. I'm very pleased with what I get.
- No
- No questions or concerns
- Not unless they plan on giving me more
- Regarding access to my inhaler; I would like a job part time
- Sure
- Sure if they have the time to talk with me
- That's not necessary b/c I don't have no concerns, they're working out fantastic.
- There is not much I need right now but I know there are more services out there. (Name) tells me to call her if there is anything I need. She takes care of me
- To discuss my fear of losing funding and losing services that would change my life not concerns about current services
- To talk about wheelchair and van services

### **Q78: Did you know you can change case management agencies if you want?**

---

- But no agencies will touch me
- No, but I figured I probably could
- Also knows about changing nursing agency option
- Also with (name) , if I'm not satisfied with (name) , I could hire someone else if I don't want her.
- But I don't have no reason to.
- But I don't need to
- But I don't want to
- But is satisfied
- But my daughter probably knows because she's smart, she goes to college

## Participant Experience Survey 2010

- But she wouldn't want to
- Couldn't remember, but (name) knew you could.
- Did not know at first but knows it now.
- Did not know she can change agencies.
- Did not know that
- Didn't know she could change agencies. Did know she could change managers. Has had many managers over the years but not because she has requested the changes.
- Didn't know, but likes her agency
- Does not want to change
- Happy with what I've got
- Husband says there's no competition in Strafford, two agencies talk about combining
- I am aware of that
- I am in the process of doing it
- I did have to switch care services, but we have been w/ (name of agency) for a while, but yes, I know I can.
- I didn't know that
- I do know that
- I don't know who talk to
- I guess so, I did. My homemaker I changed to (name of agency) . I had terrible luck before.
- I have already changed my agency once
- I have in the past
- I haven't been so happy with (name) because she has changed appts with me over and over and didn't seem to care that I told her I had plans to go out which I rarely do
- I like the (name of agency)
- I still run that boat
- I wouldn't want to make a change
- If I knew of another service I could go to I would
- Let me tell you, is anybody can offer something better than this, maybe I refuse to take it!
- Like what I have
- No, but I figured you could.
- None of that was explained to me.
- Not really, b/c there ain't nobody around that I know of
- She wasn't aware of that
- This is my third one, I went through (name) , then there was (name of agency) , and now (name of agency)
- Would never want to change. Is happy with people.
- Would not want to change
- Yes
- Yes, but they're doing a good job.

### **Q79: How long have you been on the waiver?**

---

- 14 years
- 2 years
- 2 years
- 5 years
- 5 years
- 6 years
- A couple of years I think
- A good four years

## Participant Experience Survey 2010

- A year and a couple of months.
- About 25 years I guess, I don't know
- About 4 years
- About 7 or 8 years
- Almost a year
- Almost two years, in fact it is probably two years.
- At least 3 years.
- (name) started getting paid in 2007 about.
- Ever since I came out of Manchester, (name of agency) for rehab about 3 years ago.
- Forever
- Going on three years
- I don't know exactly
- I got here July 12th, I met (name) then when I moved here.
- I guess since 2008, they were the first we had
- I think I came out here in 2003 or 2004 and I applied then and I think I've had it since then.
- I'd say a good three or four years easy, might be longer
- I'd say at least 2 years, I've been on it ever since I got out of the hospital.
- I'm not sure what (name) said, sounded like I've been on since long ago
- It's got to be two years anyway.
- Just hit one year
- Maybe a couple of years or longer?
- Maybe three years
- More than 1 year
- More than a year. .
- Oh god, I honestly don't remember, probably 3 years or more.
- Oh, I think since like, a long time, I don't know
- Okay, I've been with somebody for about 10 years now, but I don't remember how long I've been with this one.
- Quite a while. I have had my home health aide for 3 years, so it has to be longer than that.
- Since 2007
- Since I came home from getting my pacemaker in April.
- Since I came out of rehab, so in 2000 or so
- Since June of 2005
- The MS affects my memory. It affects everything.
- Well actually, let's see, now my husband died in January and I didn't really have (name) until after that b/c I mean I was able to help him somewhat, not very much, but some.
- What waiver?
- (Name) since 2004
- What's a waiver?

### **Q80: When you submitted your application for long term care services and supports, were you given information about how long it would take to process it?**

---

- Another person who works with her took care of it. Not sure of that person's title.
- Doesn't think they discussed it but it was very short period of time
- Forever!
- Human services asked all kinds of questions and I don't remember
- I believe that they worked on it as quickly as they could so I could get the help I needed at that time.
- I don't think I did

## Participant Experience Survey 2010

- It was pretty quick, (name) has always been pretty good about keeping up w/ everything.
- Probably I don't remember.
- Still doesn't know
- Was quicker than she was told

### **Q81: Were you given information about the steps in the application process?**

---

- I don't think I did
- It was pretty much you need it, here you go, (name) said.
- My daughter took care of the details and it was quick
- No because the people helping to get the program for me didn't know for sure and time frames were unavailable but I was surprised at how quickly and smoothly it all went
- Says she must have been
- She did her part

### **82: Was this information (about the application process) helpful to you?**

---

- All information is helpful
- At the time was not too "with it". Not quite as clear as it is now
- Somewhat

### **Q83: Did you receive any information about the status of your application for long term care services and supports while you were waiting to learn if you were eligible?**

---

- Don't remember
- Did not take long though
- Happened quickly
- I didn't even know I was going to receive it until the case worker came
- I didn't have to wait for anything
- It happened very quickly.
- They told me exactly when I would be notified or when (name) was gonna start working

### **Q84: Did you receive any information about the status of your application for long term care services and supports while you were waiting to learn if you were eligible?**

---

- Didn't have a question
- If I need something, I call (name) . I came out of a nursing home and I was just put here and on all of these programs
- I'm sure I was.
- (name) is wonderful, she's always spending times asking me, she usually comes for a visit to see how everything is going.
- Oh yeah. Like I said I have those numbers and such.
- We had a social worker who helped us; without him, we probably wouldn't know what was out there. He worked very closely for us.

### **Q85: When you were applying for long term care services and supports, were you given a choice between receiving services in a nursing home and receiving them in your community?**

---

- A nursing home was not mentioned
- Chose to stay at home, we discussed that at length
- Doesn't remember, but from the start she knew she wanted to be at home
- He was applying so he wouldn't have to go to a nursing home.

## Participant Experience Survey 2010

- I chose to live at home b/c at the time my husband was still here and he didn't want to go to a nursing home either.
- I got the choice to stay at home, I plan on dying at home, staying right here
- I told them, I am NOT going in a nursing home
- I wanted to stay in the nursing home but I was talked into this apartment. I wanted to be around people and more help. They kept saying that I had to try this.
- I'm not going to a nursing home
- Never came up because she has lived with family for over 7 years and daughter in law is caregiver
- No one's ever asked me whether I wanted it or not. I don't need no nursing home
- She doesn't want to be anywhere else (i.e. wants to stay in home)
- The woman from (name of agency) was very considerate and careful to get me the services that was appropriate
- They mentioned assisted living as I would not qualify for a nursing home
- Wanted to stay at home.
- When she had her hip done, she went to rehab, then comes home
- Ya, they threatened me with that
- My mother helps me most of the time

### **Q86: Were you able to choose which case management agency to use?**

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- Anyone would do (I think that's what (name) said?)
- (name of agency) was the only one that called him back though. Everyone else didn't seem to want to help or return their call but (name) was very nice to them and they love them
- I didn't specify anybody, I could have. I said whoever
- I don't know how it works, all I know is that (name) called everyone at the time.
- I don't think so. I went into the hospital everything switched automatically. I came out of the hospital and everything was set up with (name of agency) and (name) .
- I think so
- She was given 2 or 3 options
- They assigned me one and I have been happy for it.
- They just gave me one
- We were so involved w/ a lot of workers that we knew already, that we just kind of connected in w/ what they offered us.

### **Q88: Additional Comments**

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- (Name) was a very effective case manager. He used to work at the Conway office for DHHS - he was a real loss.
- (Name) grew tired of trying to answer the questions. It was clearly hard for her to focus on them.
- I am afraid for what will happen to us if I lose my house.
- I am lucky to have what I have
- I am quite happy with what I'm getting
- I am very satisfied with the girl who comes in now. I don't want any changes.
- I could have more help, but I do my own bedroom because you have to do something. My knees get shaky
- I did have one aide who was not satisfactory and I let her go. Now I have two girls who are fine.
- I feel that the system has failed me. I only appreciate the work of my aide
- I feel very fortunate because they are so good to me
- I hated to turn 80. It's too old. I appreciate that I am still relatively healthy. I had 10 children and I needed to go the doctor. I had my stroke 2 years after my husband died of lung cancer
- I like the services and I especially like my aide.

## Participant Experience Survey 2010

- I think that the program is wonderful and I am glad that it is out there for us.
- I want to know if I can get a new arm.
- I would a new case manager. I don't like the way (name) talks to me
- I would rather live closer to family
- I wouldn't trade my aides for any amount of money. I recommend them highly.
- I'm satisfied with the program and what they do for me
- She lives at (name of agency) . Mostly happy about the people who assist her but would like to get out more. Has van service for doctor's appts but also has friends offering to drive her places.
- It would be nice if more people knew about this service. I know a lot of people who could have used this service during their last years. I learned about it from my daughter's social worker
- It's been a life saver for my mother and me. It has exceeded my expectations
- It's been wonderful to me
- My services are going very well
- Services she receives are wonderful and very helpful
- She affects a very little girl attitude when answering
- The choices which allow independence are absolutely wonderful
- The people who come to help me are really wonderful. They bring me happiness when they come. They are very positive
- The people who do come in are super great
- The staff are a group of very dedicated services who love doing their job
- The state works well
- There is a significant limitation in the coverage for atypical devices which harms my care
- Wants transportation
- We are very satisfied and they help us find new services
- We would like to get some oxygen for my husband when he is having a hard time breathing and I really need some bars in the tub to hold onto. My husband could really use a motorized chair