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# Personal Experiences with MaineCare Services from People Who Use Elder and Adults with Disabilities Waiver and Private Duty Nursing/Personal Care Services.

Julie T. Fralich MBA

*University of Southern Maine, Muskie School of Public Service*

Louise Olsen

*University of Southern Maine, Muskie School of Public Service*

Katherine Rosingana

*University of Southern Maine, Muskie School of Public Service*

Jennifer Pratt

*University of Southern Maine, Muskie School of Public Service*

Mark Richards BS

*University of Southern Maine, Muskie School of Public Service*

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**Authors**

Julie T. Fralich MBA, Louise Olsen, Katherine Rosingana, Jennifer Pratt, Mark Richards BS, and Vanessa Bell

# Personal *Experiences*



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## With **MaineCare** Services

From people who use:

- Private Duty Nursing and Personal Care Services
- Home and Community Based Waiver Services

**Prepared for:**

The Maine Department of  
Health and Human Services

**Prepared by:**

Muskie School of Public Service  
University of Southern Maine

**Funded by:**

Maine Health Access Foundation and  
Maine Department of Health  
and Human Services

January 2012

# **Personal *Experiences*** **With MaineCare Services**

## **From people who use:**

Elder and Adults with Disabilities Waiver  
Private Duty Nursing/Personal Care Services

## **Prepared For:**

Maine Department of Health and Human Services

## **Prepared By:**

Julie Fralich  
Katie Rosingana  
Mark Richards  
Vanessa Bell  
Louise Olsen  
Jennifer Pratt

Muskie School of Public Service  
University of Southern Maine

## **Funded by:**

Maine Health Access Foundation  
Maine Department of Health and Human Services

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Staff from the Maine Health Access Foundation (MEHAF) provided overall guidance and input into the purpose and use of the survey. Elizabeth Gattine and Romaine Turyn from the Office of Elder Services, Maine Department of Health and Human Services provided advice on the questions related to medical services, home care services and care coordination services. Michelle Probert from the Office of MaineCare Services provided input and feedback on the questions related to transportation services. Staff from MEHAF asked that questions related to the use and need for medical and assistive devices be included. Staff from DHHS and MEHAF provided input on the questions related to the intersection of the medical and long term care systems.

Staff from the Office of Elder Services also provided support in identifying service users and mailing the surveys.

We appreciate the guidance and attention to detail offered by these individuals. Their perspectives and advice strengthened the survey design and helped to focus the scope and depth of the questions that were included. We would like to thank them for their assistance in making this report become a reality.

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## EXECUTIVE SUMMARY

Policy makers at the state and federal level are focusing on the need to improve the quality and cost effectiveness of services for people with chronic conditions. Older adults and adults with disabilities receive care from physicians, specialists and long term service providers that is often fragmented and uncoordinated. Federal and state initiatives to develop primary care medical homes, health homes, and integrated financing mechanisms for members who are eligible for both Medicaid and Medicare are being promoted and considered in many states, including Maine.

This report provides the results from a survey and personal interviews that were conducted with MaineCare members who use long term services and supports -- specifically those who are on the Elder and Adults with Disabilities Waiver and those using Private Duty Nursing (PDN) Services. People who are eligible for these services generally need nursing care and assistance with a combination of activities of daily living (e.g. eating, toileting, mobility, transfer) and instrumental activities of daily living (e.g. meal preparation, grocery shopping, housework). People on the Waiver are medically eligible to be in a nursing home.

The purpose of the survey and interviews was to provide information on the experience of members and their use of medical services; the coordination between the medical and home care systems; care transition services (e.g. from the hospital to home); home care services; and use of transportation services. The surveys also include information on the satisfaction of members with their workers, their use and need for assistive technology devices, and their access to other community resources.

### **A summary of key results from the survey follows:**

A total of 1500 surveys were sent to Waiver and PDN recipients. A total of 462 people (31%) responded. Based on the data collected from these respondents, the key highlights are as follows.

### **People with long term support needs are also high users of medical and specialty services.**

Almost all (99%) of MaineCare survey respondents using long term services and supports have a primary care physician and more than 90% have visited their physician at least once in the prior six months. Many of the respondents had visited their physician two or more times in the last six months and 20% of the PDN respondents reported visiting their physician 5-9 times in the last six months.

Although almost 90 percent of respondents reported that they could get a medical appointment as quickly as they needed it, 28% of Waiver respondents and 38% of PDN respondents indicated that they had been to the emergency room at least once in the last six months because they could not see their doctor when they needed to.

Respondents also reported using many specialty services. Almost half reported seeing 1-2 specialists in the last six months; 15% of the Waiver respondents and 22% of the PDN respondents had seen three or more specialists in that time period.

### **People with long term support needs are frequently admitted to the hospital.**

Approximately 40% of the respondents had stayed overnight in a hospital in the last six months.

About three quarters of those who left the hospital received information on the services they might get at home; and 67% of respondents on the Waiver Program and 80% of respondents on the PDN program found the information very helpful. About two-thirds of the respondents felt very prepared to go home.

### **People are generally satisfied with their home care services.**

About three quarters of respondents were very satisfied with the services they received at home. About 18% were somewhat satisfied.

### **People know their care managers.**

Approximately 90% of the respondents knew their care manager and could talk to their care manager when they needed to.

The percent of people who had talked with their care manager about unmet needs varied from 71% of the Waiver respondents to 54% of the PDN respondents.

### **Information exchange across the medical, home care and community service systems is limited.**

Approximately 56% of respondents indicated that their primary care doctor had asked about the services they need or were getting at home.

Only 13% of the respondents indicated that they had asked their care manager to talk with their doctor about services they are getting or need at home.

Less than half of the respondents indicated that their care manager had given them information on their local Area Agency on Aging.

### **People appreciate their workers, but there are areas for improvement in training and reliability.**

Almost 8 out of 10 respondents were very satisfied with their workers. Twenty percent of Waiver respondents and 24% of PDN respondents had a worker **not** show up in the last 30 days. Many had not talked with their care manager about a back-up plan to follow if a worker did not show up.

### **Many simple assistive devices can help people at home.**

A number of simple devices were mentioned that could help people at home, including lights that go on automatically when you enter a room; temperature controls; and large numbers on telephones and TVs. Respondents receiving Private Duty Nursing services mentioned the need for Emergency Response Systems, which is not a covered service under this program.

### **Transportation**

Approximately 7 out of 10 respondents report that they always got help from a transportation agency when they asked for it.

About half of the PDN respondents indicated that they had always been picked up on time; and 68% of Waiver participants indicated they had always been picked up on time.



## **Interview Results**

The themes from the interviews were consistent with the results from the surveys; however many people talked about their medical conditions during the interviews even though none of the interview questions asked specifically about their medical needs. People spoke about the relationship between their medical care and their needs at home. Many had been hospitalized or used a nursing home in the past year.

### **Special Note about Physician Home Visits**

Although we did not ask any questions about home visits by physicians, a number of people mentioned having (and others wanting) home visits from physicians in their open ended response to questions. When we reviewed the surveys, we found that 12 people had mentioned having a home visit from a physician. This was not limited to a particular county but was a trend across the state. This seems noteworthy and perhaps worth further discussion or inquiry.

## INTRODUCTION

Policy makers at the state and federal level are focusing on the need to improve the quality and cost effectiveness of services for people with chronic conditions. Older adults and adults with disabilities receive care from physicians, specialists and long term service providers that is often fragmented and uncoordinated. Financial incentives built into the payment system promote siloed of care delivery rather than a team based approach. There is often little coordination or communication between medical providers, care managers and community based service providers.

Evidence from recent studies is showing the efficacy of team-based care, integrated care delivery, robust information systems and access to new technologies that support home-based care.<sup>1</sup> Policymakers and providers are developing new models of health care delivery and financing of services for people with chronic health conditions that recognize the importance of coordinating care across services and settings; the need for effective communication between providers; and the importance of care transition assistance (e.g. hospital and nursing home transitions). Transportation to timely primary and urgent care services is also a critical component of the delivery system.

The federal government and many states, including Maine, are promoting and considering primary care medical homes, health homes, and integrated financing mechanisms for individuals who are eligible for both Medicaid and Medicare.

The surveys and interviews that were conducted for this report provide baseline information on the experience of older adults and adults with physical disabilities who use MaineCare funded long term services and supports. Previous surveys of home care users have focused primarily on member satisfaction with their home care services and workers. The surveys and interviews in this report broadened this scope to include many aspects of services and supports that people are receiving including their access to medical services; the coordination between the medical system and the home care system; care transition services (e.g. from the hospital to home); home care services; and use of transportation services. The surveys also include information on the satisfaction of members with their workers, their use and need for assistive technology devices; and their access to other community resources.

This report focuses specifically on members who receive services under the Elder and Adults with Disabilities Waiver and those who use Private Duty Nursing/Personal Care Services (PDN). People who are eligible for these services generally have need for a nursing service and assistance with a combination of activities of daily living (e.g. eating, toileting, mobility, transfer) and instrumental activities of daily living (e.g. meal preparation, grocery shopping, housework). People on the Waiver are medically eligible to be in a nursing home.

The report provides the results of a survey that was sent out in August 2011 and personal interviews that were conducted with a sample of members in the fall of 2011. By highlighting the experience and satisfaction of members who use long term services and supports, the report is intended to inform policy discussions about areas for improvement in the care and services people receive.

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<sup>1</sup> Holahan J, Schoen C, McMorro S. *The Potential Savings From Enhanced Chronic Care Management Policies*. (Issue Brief): Urban Institute Health Policy Center; November 2011.

## METHODOLOGY

The survey was mailed in August 2011 to people using either the Elder and Adults with Disabilities Waiver or those using Private Duty Nursing (PDN)/Personal Care Services. At that time, there were 882 people on the Elder and Adults with Disabilities Waiver and 964 people receiving Private Duty Nursing Services.

These programs are available to low-income people who are eligible for services under MaineCare and who have needs that require some level of nursing and/or personal care assistance. Most program participants receive services from personal care and home health agencies. A small number of people on both programs direct their own personal support services through a self-directed option within each program. The two programs and the services they provide are:

Program	Services	Medical Eligibility
<b>Elder and Adults with Disabilities Waiver<sup>2</sup></b>	Personal Support, Skilled Services, Emergency Response, Adult Day, Respite, Environmental Modifications	Nursing facility level of care eligibility that requires a need for nursing care on a weekly basis and assistance with a combination of Activities of Daily Living (ADLs)* and Instrumental Activities of Daily Living (IADLs)**
<b>Private Duty Nursing/Personal Care Services<sup>3</sup></b>	Personal Support, Skilled Services	Eligibility that requires a need for nursing care on a monthly basis and assistance with a combination of Activities of Daily Living (ADLs)* and Instrumental Activities of Daily Living (IADLs)**

\*ADLs for Waiver include bed mobility, transfer, locomotion, eating, toilet use.

\*ADLs for PDN include the above 5 ADLs plus bathing and dressing.

\*\*IADLs include: main meal preparation, routine housework, grocery shopping or laundry.

In order to protect the confidentiality of people completing the survey, the survey was mailed from the Office of Elder Services, which is the office that manages these programs. People were asked not to put their name or any other identifiable information on the survey that was returned. The completed surveys were provided to the Muskie School of Public Service.

### Survey Instrument

The survey instrument includes questions from a number of existing surveys that had been tested or used by others. In a few instances, the evaluation team developed new survey questions. One of the challenges was the lack of a standard questionnaire that captured the full array of domains of interest. Most commonly used instruments (e.g. the Medicare Consumer Assessment of Health Providers Systems (CAHPS)<sup>4</sup> survey or the HCBS Participant Experience Survey<sup>5</sup>) focus on the

<sup>2</sup> MaineCare Benefits Manual. *Home and Community-Based Benefits for the Elderly and for Adults with Disabilities. Chapter 101, Section 19.* Available at: <http://www.maine.gov/sos/cec/rules/10/ch101.htm>.

<sup>3</sup> MaineCare Benefits Manual. *Private Duty Nursing and Personal Care Services. Chapter 101, Section 96.* 2012. Available at: <http://www.maine.gov/sos/cec/rules/10/ch101.htm>.

<sup>4</sup> Agency for Healthcare Research and Quality (AHRQ). *CAHPS Survey.* 2012. Available at: <http://www.cahps.ahrq.gov/Surveys-Guidance.aspx>.

<sup>5</sup> MEDSTAT and Centers for Medicare and Medicaid Services (CMS). *Participant Experience Surveys (PES).* 2003. Available at: <http://www.hcbs.org/moreInfo.php/doc/652>.

experience of a consumer with one part of the health or long term care system. In this survey, we tried to capture the experience of home and community based consumers across a spectrum of services (e.g. medical, hospital, emergency room, care transitions, home care, assistive technology and transportation). For this reason, we had to combine questions from a number of different instruments and design some new questions.

### Survey Sample and Response

We mailed 797 surveys to people on the Elder and Adults with Disabilities Waiver and 700 surveys to people using Private Duty Nursing. We also sent 100 letters to a separate group of Waiver and PDN recipients asking if they would be willing to be interviewed.

The following table provides a summary of the surveys that were sent, the number of completed surveys, and the response rate. The response rates for both surveys were exactly the same, or 31%. This was somewhat lower than expected but still reasonable given the level of disability and impairments of people receiving these services and the length of the survey instrument.

**Table 1: Survey Response Rates**

Program	Surveys Mailed	Completed Surveys	Response Rate
Elder & Adults Waiver	797	247	31%
Private Duty Nursing Personal Care Services	700	215	31%
<b>Total</b>	<b>1500</b>	<b>462</b>	<b>31%</b>

### Characteristics of Survey Respondents

The following table provides a summary of the age ranges of the survey and sample respondents.

**Table 2: Age Ranges**

Age Range	Elder and Adults Waiver Respondents (n = 239)	Elder and Adults Waiver Sample (n = 797)	PDN/ Personal Care Respondents (n = 205)	PDN/ Personal Care Sample (n = 700)
	Percent	Percent	Percent	Percent
18 to 24	3%	5%	0%	0.4%
25 to 44	13%	16%	6%	6%
45 to 64	27%	29%	24%	34%
65 to 74	19%	17%	23%	24%
75 to 84	21%	18%	26%	21%
85 or older	17%	15%	20%	14%
Total	100%	100%	100%	100%

The age distribution of people in the samples and the age distribution of people who responded are very similar. The percent of respondents in the age 45-64 age range for the Private Duty Nursing Program was lower (24%) than the percent in that age group from the sample; and the percent of respondents in the 85 and over age group was somewhat higher than the percent in the sample in that age range. The percent of respondents and percent in the sample population were comparable in the other age groups.

People of all ages use the services offered by the Elder and Adults Waiver and the Private Duty Nursing Program. As indicated in Table 2, approximately 57% of the Waiver respondents are over the age of 65 and 69% of PDN respondents are over the age of 65. While a high percentage of the respondents were over 65, approximately one quarter of the respondents were age 45-65. Sixteen percent of the Waiver respondents were in the age range of 18 to 44.

The following table shows the percent of respondents who live alone. More respondents receiving Private Duty Nursing/Personal Care were apt to live alone. Those on the Waiver with increased care needs were more likely to live with others.

**Table 3: Living Arrangement**

	<b>Elder and Adults Waiver (n = 240)</b>	<b>Private Duty Nursing Personal Care (n = 206)</b>
	<b>Percent</b>	<b>Percent</b>
<b>Live Alone</b>	20%	63%

For those who were not living alone, the people using the Waiver were most likely to be living with a spouse or companion (43%); while 26% of those using PDN live with a spouse/companion. In both groups, slightly over half report living with family members.

**Table 4: Living Arrangement For Those Who Do Not Live Alone, They Live With:**

	<b>Elder and Adults Waiver (n = 174)</b>	<b>Private Duty Nursing Personal Care (n = 74)</b>
	<b>Percent</b>	<b>Percent</b>
Spouse or companion	43%	26%
Family	51%	53%
Friend	3%	14%
Other	3%	8%
<b>Total</b>	<b>100%</b>	<b>100%</b>

The following table shows how people rated their own health.

**Table 5: Self-Rated Health**

	<b>Elder and Adults Waiver (n = 232)</b>	<b>Private Duty Nursing Personal Care (n = 199)</b>
	<b>Percent</b>	<b>Percent</b>
Excellent	4%	3%
Very Good	14%	6%
Good	26%	28%
Fair	34%	44%
Poor	22%	20%
Total	100%	100%

Respondents using Private Duty Nursing Services were more apt to rate their health as fair or poor. Almost two-thirds of the respondents using Private Duty Nursing Services rated their health as fair or poor compared with 56% of those on the Waiver. People receiving Waiver services rated their health status higher than those receiving PDN. Approximately 18% of the people on the Waiver rated their health as excellent or very good compared to 9% on PDN.

We asked if the respondent had help completing the survey. The following table shows who filled out the survey.

**Table 6: Survey Respondents**

	<b>Elder and Adults Waiver (n = 236)</b>	<b>Private Duty Nursing Personal Care (n = 200)</b>
	<b>Percent</b>	<b>Percent</b>
Filled out myself	24%	53%
I answered, someone else filled out	31%	28%
Someone else answered and filled out	45%	19%
Total	100%	100%

Forty-five percent of the surveys from Waiver recipients were answered and filled out by someone other than the consumer. Only 24% of the Waiver recipients filled out the survey by themselves. In comparison, more than half of the surveys from the PDN recipients were completed by the individual recipients. For both groups, a high number of surveys (31% and 28%, respectively) were answered by the individual but filled in by someone else.

Despite the fact that both groups had a lot of help answering the questions and completing the surveys, we decided to include all the surveys in our analysis, regardless of whether they were completed by the individual or someone else. Ideally, it is preferable to hear the views and opinions of consumers directly and not have them interpreted by another person. But many people served by these programs have significant cognitive or other impairments that make it difficult to answer questions and complete a survey instrument. We felt that it was important to include all the answers, many of which may have come from family members or friends. In the case of people receiving home care services, the experience of the person caring for or closest to the individual is also an important voice to be heard.

The following table provides percent of respondents by county.

**Table 7: Respondents by County**

	Elder and Adults Waiver		Private Duty Nursing Personal Care Services	
	n	Percent	n	Percent
<b>Androscoggin</b>	16	7%	14	7%
<b>Aroostook</b>	29	12%	37	19%
<b>Cumberland</b>	29	12%	15	8%
<b>Franklin</b>	13	6%	6	3%
<b>Hancock</b>	4	2%	3	2%
<b>Kennebec</b>	21	9%	11	6%
<b>Knox</b>	1	.4%	2	1%
<b>Lincoln</b>	3	1%	8	4%
<b>Oxford</b>	10	4%	12	6%
<b>Penobscot</b>	32	14%	31	16%
<b>Piscataquis</b>	5	2%	4	2%
<b>Sagadahoc</b>	4	2%	2	1%
<b>Somerset</b>	17	7%	15	8%
<b>Waldo</b>	14	6%	5	3%
<b>Washington</b>	8	3%	10	5%
<b>York</b>	30	13%	22	11%
<b>Total</b>	236	100.0%	197	100.0%

The distribution of respondents by county is consistent with the distribution of people using the services in each county. For example, approximately 13% of Waiver participants reside in Penobscot county and 14% of Waiver respondents indicate they live in Penobscot county.

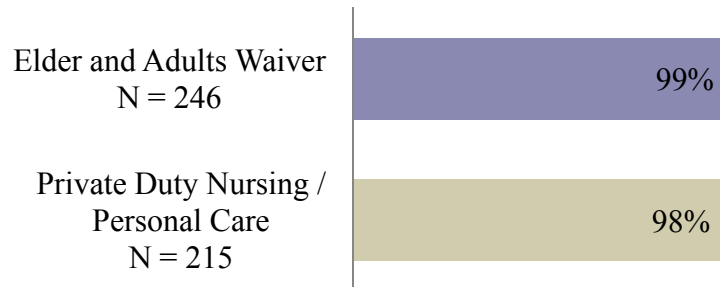
## SURVEY RESULTS

The following graphs provide the results of the two surveys that were administered to the people using the Elder and Adults Waiver and the Private Duty Nursing/Personal Care programs.

### ACCESS TO MEDICAL SERVICES

#### Do you have a primary care doctor? (Yes Responses)

*“My doctor comes to my house every 3 months.”*



Across both of these programs, virtually all respondents indicated they have a primary care doctor. Across both surveys, only six people indicated they did not have a primary care doctor.



**In the last 6 months, how many times did you visit your primary care doctor to get care for yourself?**

	<b>Elder and Adults Waiver (n = 240)</b>	<b>Private Duty Nursing Personal Care (n = 207)</b>
	<b>Percent</b>	<b>Percent</b>
None	10%	4%
1 time	25%	20%
2 times	30%	24%
3 times	15%	17%
4 times	10%	15%
5 to 9 times	11%	20%
Total	100%	100%

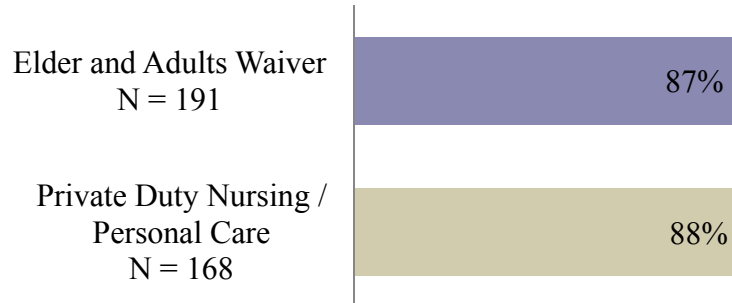
People on both programs are seeing their doctors very frequently. Ninety percent of Waiver respondents and 96% of PDN respondents had seen their primary care doctor at least once in the last six months. Both groups of respondents were likely to see their doctor more than once in that time period. Thirty-six percent of Waiver respondents and 52% of PDN respondents had seen their doctor three or more times in the last six months. Twenty percent of PDN respondents had been 5 or more times.

**Who went with you to the doctor’s office?**

	<b>Elder and Adults Waiver (n = 216)</b>	<b>Private Duty Nursing Personal Care (n = 199)</b>
	<b>Percent</b>	<b>Percent</b>
I went by myself	8%	32%
Family member/spouse/friend	87%	75%
Direct Care worker (PCA, PSS)	31%	14%
Other	8%	13%

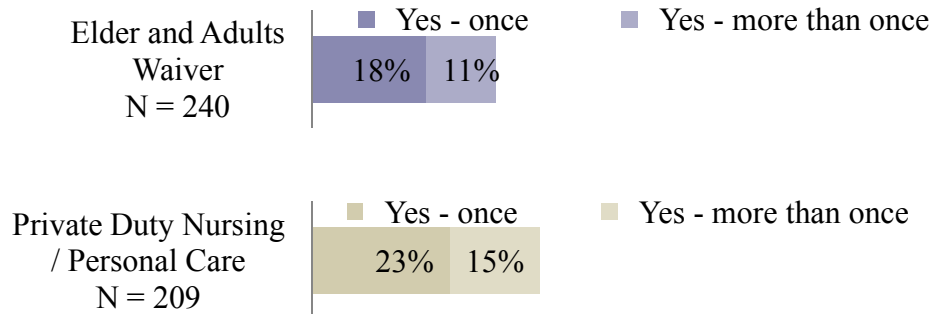
Most respondents are accompanied by a family member or spouse when they go to the doctor’s office. Waiver recipients are more likely to rely on their Direct Care workers than are the PDN service users. The category ‘Other’ included specific relatives not captured under the Family member/spouse category.

**In the last 6 months, when you needed medical care right away, did you get an appointment as quickly as you needed it?  
(Yes Responses)**



People seem to be able to get an appointment with their doctors. Almost nine out of 10 respondents indicated that when they needed medical care right away, they could get an appointment as quickly as they needed.

**In the last 6 months, did you go to the hospital emergency room because you could not see your doctor when you needed?**



Despite the fact that respondents seem to be able to get an appointment when they need medical care right away (see previous graph), they are still using the emergency room because they can't get to their doctor. Between 29% and 38% of all respondents went to the hospital emergency room at least once in the prior six months because they could not see their doctor when they needed. Although it is difficult to interpret these somewhat contradictory results, it may be related to the urgency with which the person needed medical attention or to the hours of operation of their primary care providers. As indicated in the table below, almost half of the Waiver recipients and slightly more than a third of the PDN respondents who went to the emergency room were transported by an ambulance.

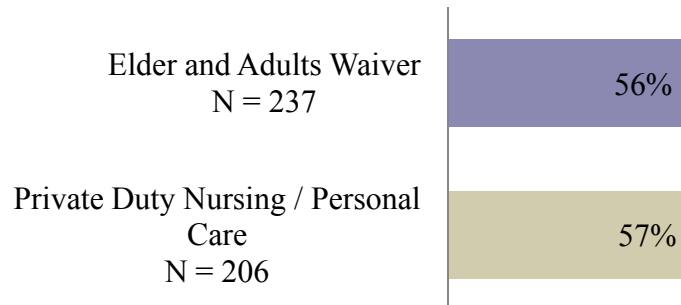
**If YES, how did you get to the hospital emergency room?**

*"I used a wheelchair car service."*

*"My PCA took me."*

	<b>Elder and Adults Waiver (n = 77)</b>	<b>Private Duty Nursing Personal Care (n = 90)</b>
	Percent	Percent
Drove myself	4%	2%
Family member drove me	42%	36%
Friend or neighbor drove me	1%	16%
Ambulance	49%	37%
Other	4%	10%
Total	100%	100%

### In the last 6 months, did your primary care doctor ask you about any services you need or are getting at home? (Yes Responses)



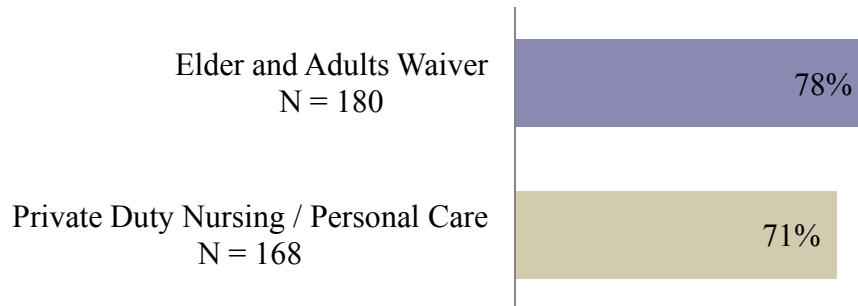
Although all of the respondents to this survey were receiving services at home, doctors do not appear to be routinely asking people about these services. Just over half of the respondents indicated that their primary care doctor had asked about the services they needed or were getting at home.

**How many specialists have you seen in the last 6 months?**

	<b>Elder and Adults Waiver (n = 242)</b>	<b>Private Duty Nursing Personal Care (n = 209)</b>
	<b>Percent</b>	<b>Percent</b>
0	36%	33%
1-2	49%	46%
3-4	13%	15%
5 or more	2%	7%
Total	100%	100%

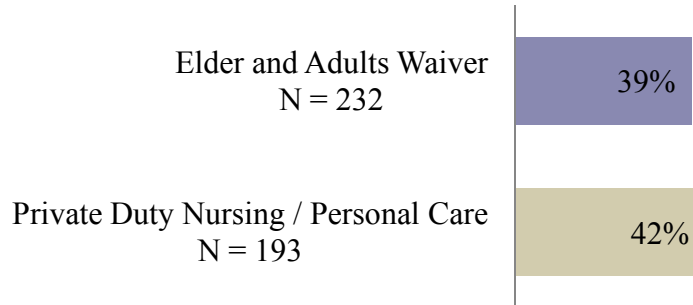
Respondents on the Waiver and PDN Program are high users of specialist services. Almost two-thirds of respondents in both programs had seen at least one specialist in the last six months; and 15% and 22% respectively of the Waiver and PDN program had seen three or more specialists.

**In the last 6 months, did your primary care doctor seem informed and up to date about the care you got from specialists? (Yes Responses)**



Almost 80% of respondents on the Waiver program indicated that their doctor seemed informed about the care provided by their specialists. The somewhat lower percent (71%) of people on the PDN program who thought their doctor was informed of specialist care may be related to the higher number of specialists that people on this program are using. Seven percent of PDN respondents indicated seeing five or more specialists compared to 2% of the Waiver respondents.

**In the last 6 months, did you stay overnight in a hospital? (Yes responses)**



Respondents on both programs are high users of hospital services. Approximately 40% of all respondents indicated they had an overnight stay in the hospital in the last six months.

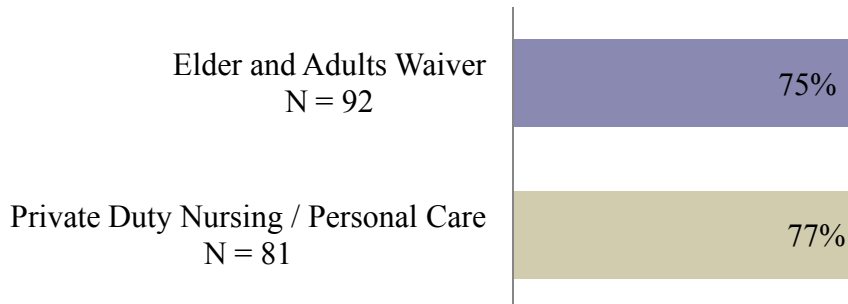
**When you left the hospital, where did you go?**

*“After 4th or 5th time to the emergency room, I went to rehab.”*

	Elder and Adults Waiver (n = 91)	Private Duty Nursing Personal Care (n = 83)
	Percent	Percent
Directly home from hospital	73%	68%
Rehab/nursing facility	24%	27%
Other	3%	6%
Total	100%	100%

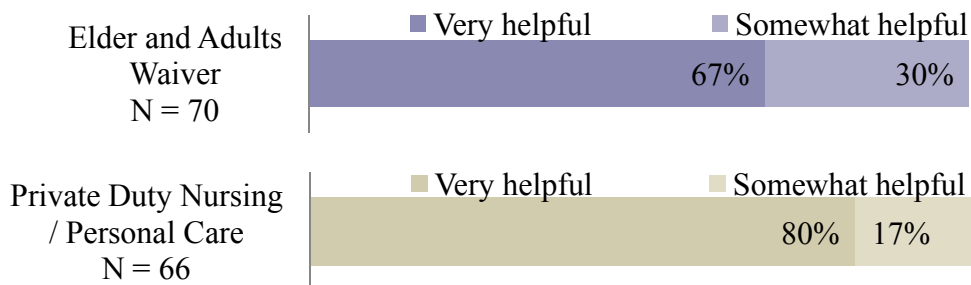
Most respondents indicated they went directly home from the hospital. About one fourth of respondents went to a rehab facility or a nursing home from the hospital before returning home.

**When leaving the hospital or rehab/nursing facility, did you receive information about services you might get at home? (Yes responses)**



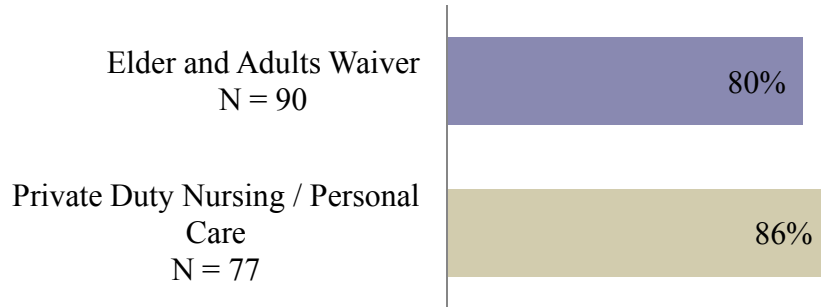
Three quarters of those having a hospital stay received information about home care services prior to leaving the hospital or rehab/nursing home.

**IF YES, how helpful was the information?**



Two-thirds of the people on the Waiver program found the information they received very helpful. Thirty percent of Waiver respondents found it only somewhat helpful. More of the respondents on the PDN program (80%) found the information very helpful.

**Did anyone arrange for you to have services when you returned home? (Yes responses)**



5

Eighty percent or more had someone help arrange for home care services upon discharge. Family members, hospital, rehab, or nursing home staff, and care managers were most apt to help with arrangement of services.

**IF YES, who arranged for these services?**

*“Health Reach.”*

*“My doctor”*

*“The rehab nursing facility messed up coordination of services.”*

	Elder and Adults Waiver (n = 72)	Private Duty Nursing Personal Care (n = 66)
	Percent	Percent
I did	6%	5%
Family members and/or spouse	47%	23%
Hospital staff	40%	33%
Nursing facility or rehab staff	19%	23%
EIM Care Manager	57%	50%
Other	6%	6%

People seemed to get help in arranging post hospital services from a variety of sources. The Elder Independence at Home (EIM) Care manager arranged for services post discharge for almost 60% of the Waiver respondents. Similar results were seen for those people who went directly home and those who went to the rehab or nursing facility. Family members were also mentioned by almost half of the Waiver respondents as arranging care post discharge. Hospital staff were mentioned as arranging services for only 40% of the Waiver respondents.

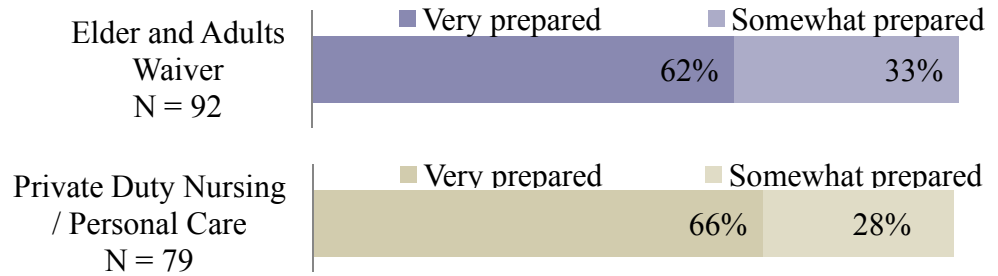
Respondents on the PDN program responded that EIM arranged services 50% of the time; hospital staff were only mentioned as arranging services 33% of the time.



*“Arranging post hospital transportation can be very difficult.”*

*“After having surgery to my left shoulder, I could really use some more help.”*

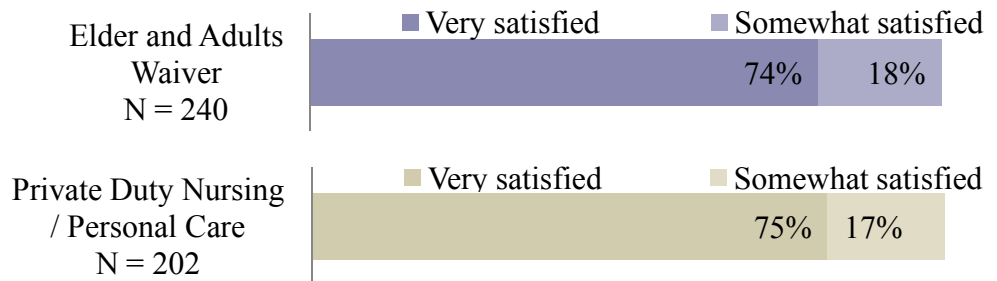
**Overall, how prepared did you feel to go home?**



While 62% - 66% of respondents felt very prepared to go home, approximately thirty percent felt only somewhat prepared.

**In general, how satisfied are you with the services you receive?**

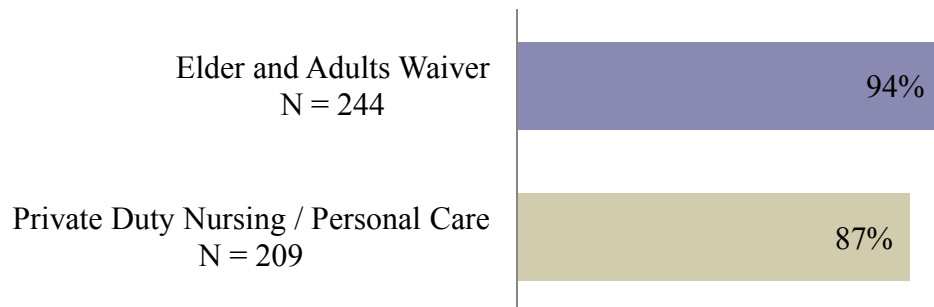
*“Without my worker I couldn't manage to do a lot of the household duties. She has been a God send to me.”*



Ninety-two percent of all respondents are very or somewhat satisfied with the services they receive at home. Many respondents expressed appreciation for the program and workers who help them remain at home.

**Do you know who to call if you have a complaint about any of your services? (Yes Responses)**

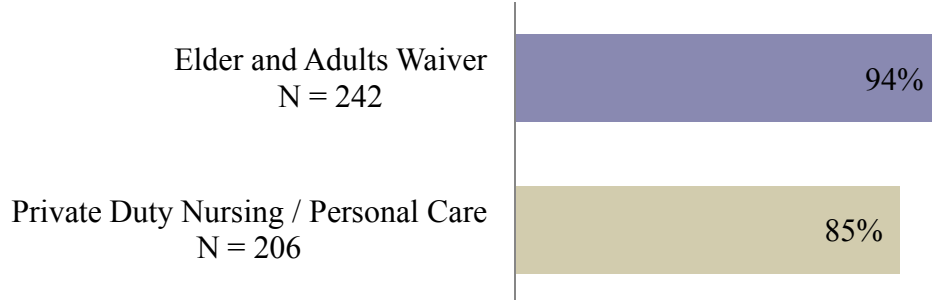
*“Because good help or any help at all is hard to come by, I'm afraid if I complain I'll be left without help.”*



Most respondents seemed to know how to file a complaint.

*“EIM is coordinating switching agencies.”*

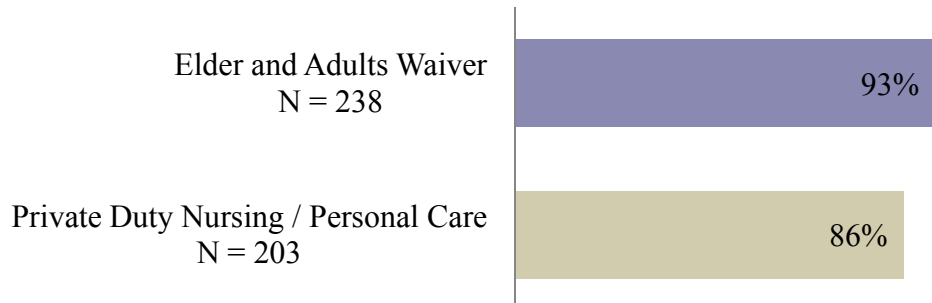
**Do you know the name of your care manager at Elder Independence at Home (EIM)?  
(Yes Responses)**



About 94% of the respondents using the Waiver know the name of their care manager. This compares with 85% of the PDN respondents.

*“My care manager is hard to contact. Have to leave a message and wait for him to call back.”*

**Can you talk to your care manager when you need to?  
(Yes Responses)**

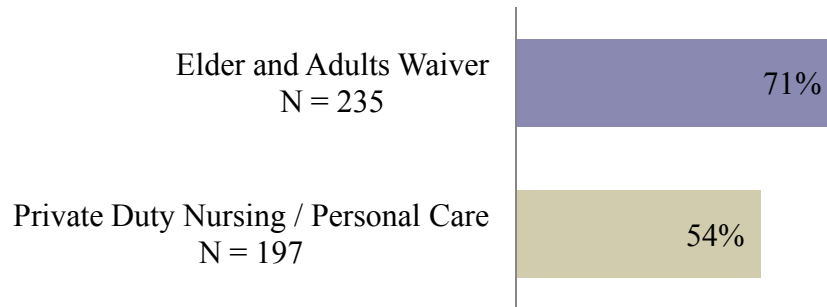


Eighty-six to ninety-three percent of respondents say they can talk with their care manager when they need to.

*“Would be difficult not to have EIM contracted services.”*

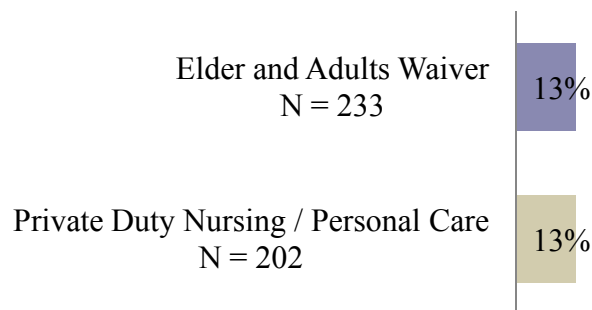
*“EIM workers are great to me! Get along just fine with all of them.”*

**In the last 6 months, has your care manager talked with you about any needs you may have that are not being met? (Yes Responses)**



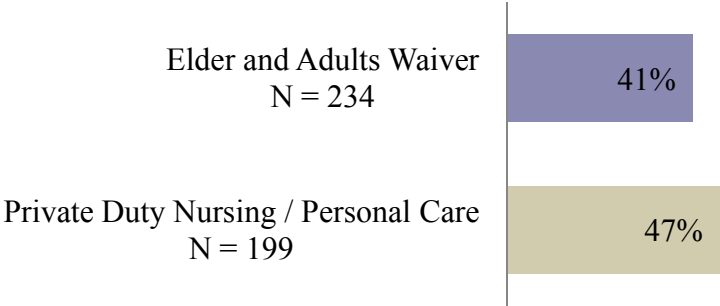
Waiver respondents were more likely to have talked with their care manager about their unmet needs. Seventy-one percent of the Waiver respondents had talked with their care managers compared with only 54% of the PDN respondents.

**In the last 6 months, have you asked your care manager to talk with your primary care doctor about the services you need or are getting at home? (Yes Responses)**



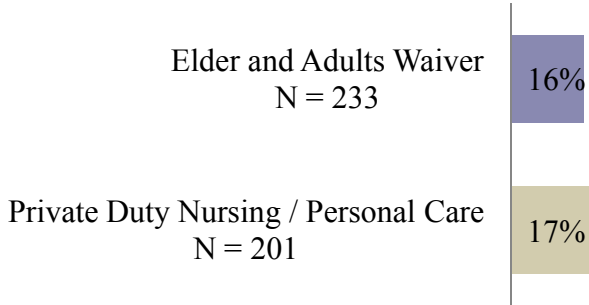
Most respondents do not ask their care manager to talk with their primary care doctor about services they are getting at home.

**Has your care manager given you information about your Area Agency on Aging? (Yes Responses)**



The Area Agencies on Aging provide information and referral, options counseling, Meals on Wheels, Medicare Part D education, and caregiver support. Less than half of the respondents had been referred by their care manager to someone at their Area Agency on Aging.

**In the last 6 months, have you contacted anyone at the Area Agency on Aging? (Yes Responses)**



Less than 20% of the people on these programs have contacted anyone at the Area Agency on Aging in the last six months.

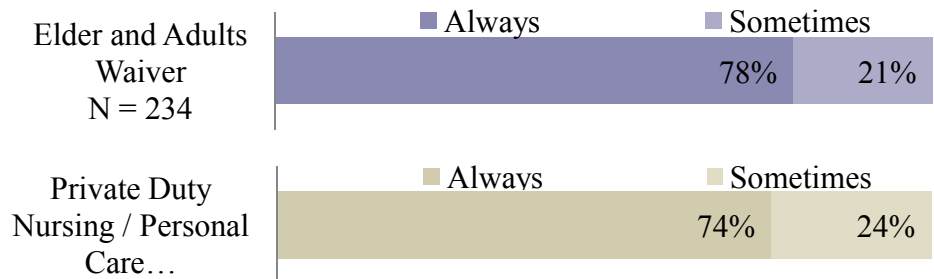
## WORKER PERFORMANCE

### Does the worker who comes to help you do things the way you want them to be done?

*“My daughter does my care & she knows my needs well.”*

*“Workers come in my home knowing nothing about me.”*

*“The help I receive is very poor, not trained too well. She cannot even make a bed.”*



People are generally satisfied with their worker’s performance although there are areas where they think workers could use more training. Seventy-four to seventy-eight percent of the people surveyed responded that the worker always does things the way they want them done.

About a quarter of the respondents on both programs thought there were areas where their worker could use more training.

### If YES, in which areas of the job do you think your worker could use more training?

*Areas where worker could use training:*

*“On stroke problems.”*

*“Being on time.”*

*“General knowledge of in-home medical equipment & medications.”*

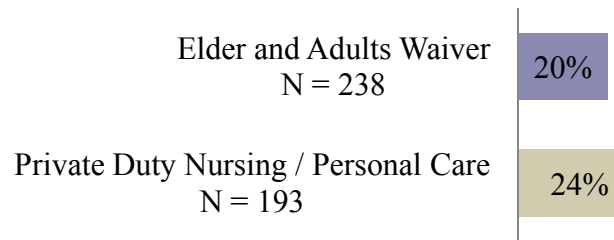
	Elder and Adults Waiver (n = 120)	Private Duty Nursing Personal Care (n = 207)
	Percent	Percent
Personal care tasks	68%	28%
Housekeeping tasks	62%	68%
Communication	40%	30%
Attitude/professional courtesy	35%	28%
Appearance/cleanliness	9%	4%
Other	40%	30%

For this survey question, people could respond to more than one area where they thought workers could use more training. Personal care and housekeeping tasks are top areas identified where more training is needed.

## WORKER PERFORMANCE

### During the past 30 days, did the worker paid to help you not show up? (Yes Responses)

*“Agency does not have a fill-in PCA for when my PCA goes on vacation or regular PCA calls in sick or with an emergency.”*



Twenty percent of the respondents on the Waiver and 24% on PDN report that a worker did not show up at least once during the past 30 days.

### If the worker did not show up, what did you do?

*“Called the agency that provides home care.”*

*“She always shows up.”*

*“Family/legal guardian took care of it.”*

*“Paid someone to come in.”*

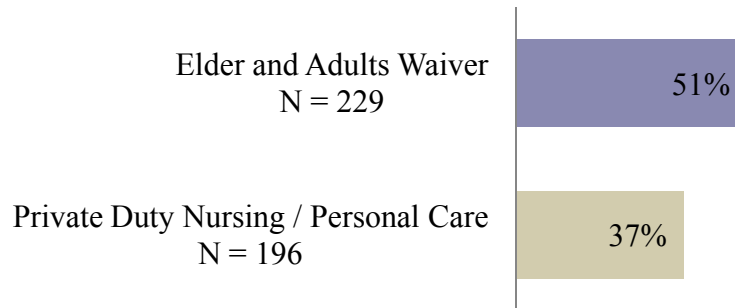
*“She made up 2 hours the next day.”*

	Elder and Adults Waiver (n = 47)	Private Duty Nursing Personal Care (n = 47)
	Percent	Percent
Called family member	53%	21%
Called neighbor or friend	13%	15%
Called agency	43%	53%
Called EIM	30%	21%
Went without help	60%	79%
Other	47%	45%

For this survey question, people could check multiple responses if they did several different things on the occasion(s) when their worker did not show up. Most respondents call EIM or the agency when a worker does not show up. Over 50% of Waiver respondents and 21% of PDN respondents call a family member and 60-79% go without help for the time when a worker is supposed to be there.

## BACK-UP PLAN

**Have you talked with your care manager at EIM about a backup plan you should follow if your worker does not show up? (Yes Responses)**



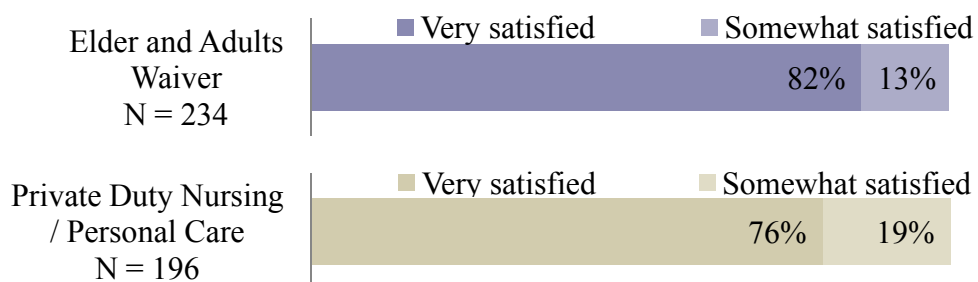
About 50% of respondents receiving services from the Waiver have talked with their care manager about having a backup plan when a worker does not show up. Only 37% of the respondents on PDN indicated having that conversation with their care manager.

## WORKER PERFORMANCE

**Overall, how satisfied are you with the worker who provides most of your care?**

*“My worker is the best I have had. She is very neat, clean and very courteous. She knows my needs very well. I don't ever want to lose my worker. She is great.”*

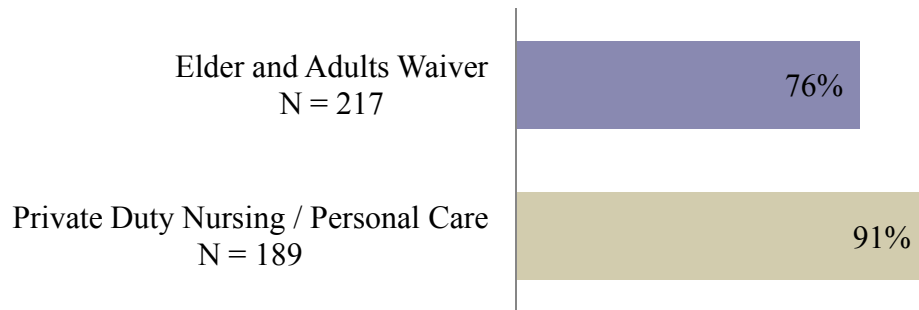
*“I just wish that she could get a raise. She really needs it.”*



Approximately eighty percent of all respondents are very satisfied with the worker who provides most of their care.



**Can you move around your house and get to the rooms and items that you need? (Yes Responses)**



Although a high percentage of people indicated they could get around the house and get to the rooms and items they needed, there were a number of simple changes to the home that many mentioned would be helpful including lights that go on automatically when you enter the room, temperature controls and large numbers on the phone and TV. (See Table 8 on next page).

## IN HOME MOBILITY AND ASSISTIVE DEVICES

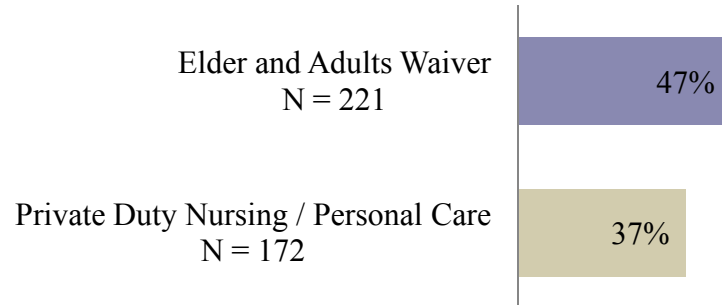
**Table 8: DEVICES THAT WERE MENTIONED AS TOP 10**

<b>Do not have device but think it would be helpful</b>	<b>Elder and Adults Waiver</b>	<b>Private Duty Nursing Personal Care</b>
Lights that go on automatically when you enter a room	✓	✓
Temperature controls that change when it gets hotter or colder	✓	✓
Large numbers on the telephone/easy to read TV controls	✓	✓
Emergency Response		✓
Devices for people who have a hearing impairment		✓
Automated call system to call and check on you daily		✓
Devices for people who have a visual impairment		✓
Motorized wheelchair	✓	✓
Touch screen computer	✓	
Different bed (e.g. a hospital bed)	✓	
Special devices to help with getting dressed	✓	
Wider doorways so wheelchairs can get through	✓	
Better handles on doors and faucets	✓	✓

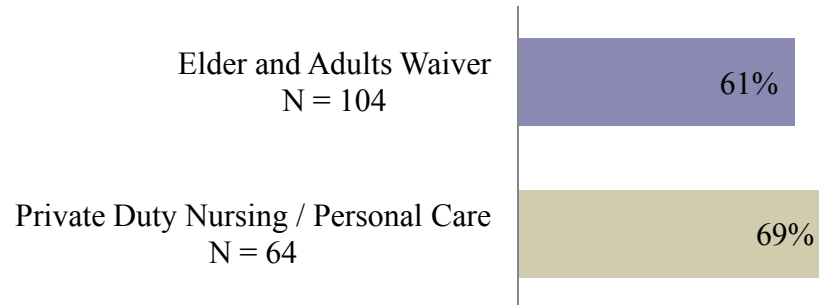
The top ten assistive devices that respondents believe would be helpful vary somewhat by program. This variance may be due to availability of funding for certain items. For example, respondents on Private Duty Nursing/Personal Care (PDN) mention Emergency Response System which is not a covered service under this program while it is covered, and not mentioned as a need, under Elder and Adults Waiver. All of the respondents mentioned ‘lights that go on automatically when you enter a room’, ‘temperature controls’, ‘large numbers on the telephone’ and ‘easy to read TV controls’.

*“I could use a phone for my pacemaker”*

**Is there a computer you use in your home? (Yes Responses)**



**Do you use your computer for the internet (such as email, Skype, browsing the web)? (Yes Responses)**



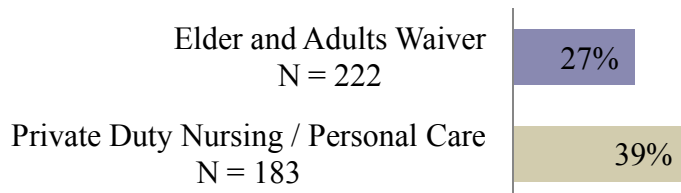
Less than 50% of the respondents have a computer.  
Between sixty and seventy percent of those who have a computer use it for the internet.

## TRANSPORTATION

MaineCare helps its members with transportation to get to doctors' offices or clinics.

### **In the last six months, did you call a regional transportation agency in your area to get help with transportation? (Yes Responses)**

*"I didn't have an appointment and I can't get out of my house as I am a shut-in."*



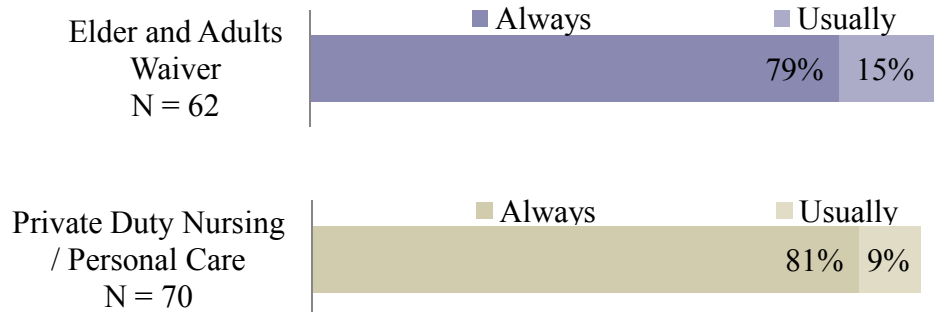
Approximately one third of these respondents have called their regional transportation agency (RTA) within the last six months.

### **Which of the regional transportation agencies below did you contact?**

	<b>Elder and Adults Waiver (n = 58)</b>	<b>Private Duty Nursing Personal Care (n = 65)</b>
	<b>Percent</b>	<b>Percent</b>
ARTS	15%	30%
Coastal Trans Inc	5%	3%
Community Concepts	3%	12%
KVCAP	15%	17%
Penquis	10%	6%
RTP	10%	5%
Waldo	5%	2%
WHCA	5%	6%
WMTS	19%	5%
YCCAC	7%	9%
Not Sure	3%	6%
<b>Total</b>	<b>100%</b>	<b>100%</b>

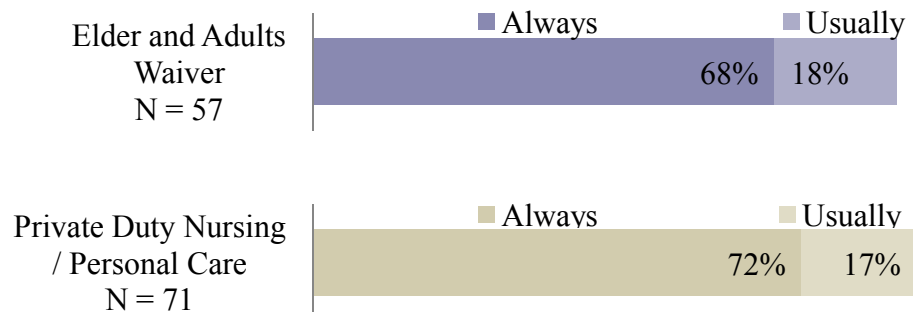
Most of the respondents using regional transportation in the last six months called ARTS in northern Maine, WMTS in western Maine or KVCAP in central Maine.

**In the last 6 months, how often have you felt that you were treated with respect by the persons who work for the regional transportation agency?**



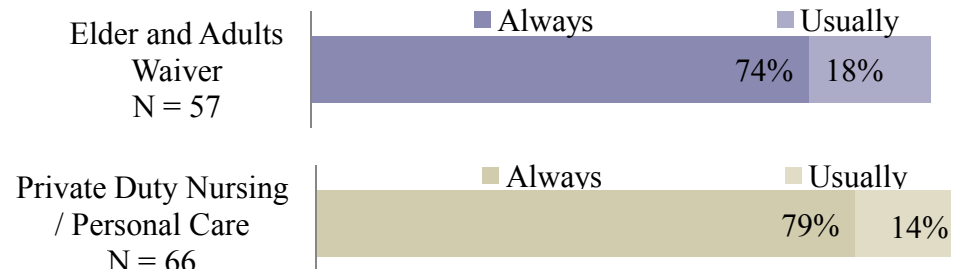
Eight in ten of those respondents using regional transportation feel they were always treated with respect by persons working for the transportation agency.

**In the last 6 months, when you called the transportation agency to get help with transportation, how often did you get it?**



About 70% of those respondents who called for transportation within the last six months always got help with their transportation needs.

**In the last 6 months, how often has the help you received for transportation met your needs?**



*“They have canceled on me.”*

*“Attempted contacting (transportation agency) - needed too much info in time before appointment.”*

## TRANSPORTATION

*“The only problem is sometimes the volunteer has to pick up the other people for appointment and it may result in a LONG TRIP. Instead of just taking me to my appointment, she sometimes has to go way out of the way to accommodate these (other folks) for their appointment. Just can be very uncomfortable due to the long ride.”*

### In the last 6 months, what type of help with transportation did you receive?

	Elder and Adults Waiver (n = 60)	Private Duty Nursing Personal Care (n = 72)
	Percent	Percent
Ride from a volunteer driver	20%	43%
Bus or van ride from RTP	23%	26%
Wheelchair van ride	48%	13%
Public bus pass, payment or voucher	2%	1%
Taxi payment or voucher	2%	3%
Payment for mileage	23%	19%
Other	15%	11%

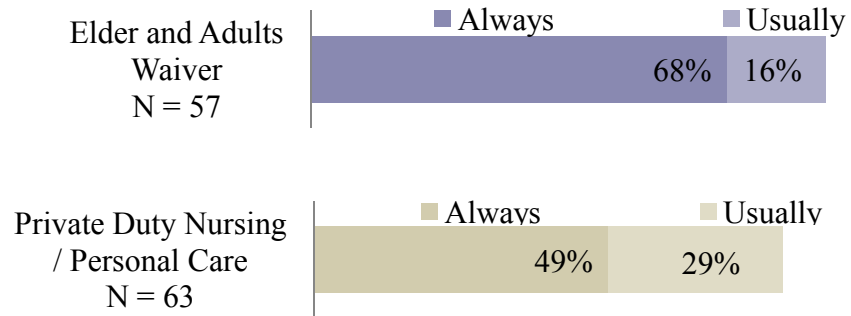
Most Waiver respondents received wheelchair van rides while most PDN respondents received a ride from a volunteer driver.

### Who contacts your regional transportation agency to arrange for help with transportation for your MaineCare appointments?

	Elder and Adults Waiver (n = 72)	Private Duty Nursing Personal Care (n = 81)
	Percent	Percent
I do it myself	35%	78%
Family member or spouse	34%	13%
Friend or neighbor	1%	7%
Direct Care worker (PSS,PCA)	14%	7%
Care manager at EIM	1%	3%
Other	5%	9%
Total	100%	100%

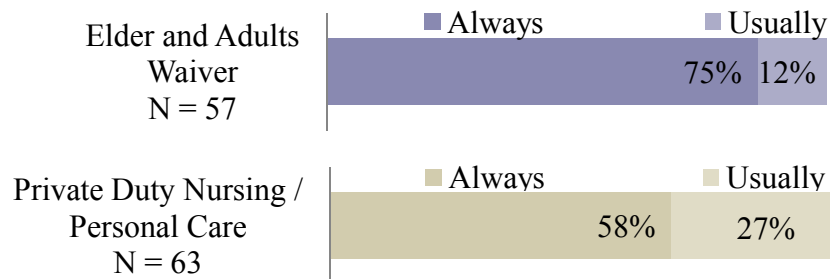
PDN respondents were most likely to contact the regional transportation agency on their own while Waiver respondents either contacted the regional transportation agency themselves or a family member contacted the agency on their behalf.

**Thinking about the help you received with transportation in the last 6 months, how often did the volunteer, bus or van pick you up on time?**



Sixty-eight percent of Waiver respondents and 49% of PDN respondents were always picked up on time.

**Thinking about the help you received with transportation in the last 6 months, how often did the volunteer, bus or van get you to your medical appointments on time?**



Seventy-five percent of Waiver respondents and fifty-eight percent of PDN respondents always got to their medical appointments on time.

## TRANSPORTATION

*“In the past (the transportation agency) waited till the very day of appointment (to call back) and couldn't provide transportation even though I called in advance at least 2 weeks.”*

**Thinking about the most recent time you received help with transportation, how many days were there between when you called the transportation agency and when you received the ride?**

	<b>Elder and Adults Waiver (n = 50)</b>	<b>Private Duty Nursing Personal Care (n = 55)</b>
	<b>Percent</b>	<b>Percent</b>
Same day	14%	16%
The next day	12%	20%
2-3 days	44%	27%
4-7 days	20%	18%
8 days or more	10%	18%
Total	100%	100%

Most respondents called 2-3 days prior to when they received their ride.

*“Had a ride sometimes with a friend”*

*“Have my case manager do it because it is easier to get in & out of her vehicle.”*

*“I knew they were unable to transport me as I am unable to sit upright in wheelchair.”*

*“I have a handicap van that only works occasionally. If it is not running, I call RTP.”*

**In the last 6 months, if you did not call a regional transportation agency to get help with transportation for your travel to and from medical appointments, why not?**

	<b>Elder and Adults Waiver (n = 203)</b>	<b>Private Duty Nursing Personal Care (n = 166)</b>
	<b>Percent</b>	<b>Percent</b>
Don't need help with transportation	35%	30%
Did not have medical appointments in last 6 months	7%	5%
Did not know these services were available	5%	4%
Too difficult to arrange these services	6%	8%
Other	30%	30%
Total	100%	100%

About a third of those who did not call, did not need help with transportation.



## SATISFACTION

At the end of the survey, we asked people to share any other comments about the services they receive at home. We received pages and pages of hand written comments. Many of these have been included throughout this report. The following is a selection of some of the other comments we received. The notes from people receiving services, as written in their own words, are often more powerful than the charts and graphs from a survey. People were overwhelmingly grateful for the services they receive at home and thankful that they were able to remain at home with the help of these services.

*“Very pleased with maintaining same person and schedule. Thank you. Very professional, courteous and hard worker, please don't change anything. I'm a very nervous person and having the same worker is reassuring to me. Again, thank you.”*

*“I have a very pleasant friendly, efficient care taker and a great nurse. I do not have to tell them what to do. They come in, do their job well and always ask if there is anything more I would like to have them do for me.”*

*“My home care worker is wonderful. She does everything and does not need to be told. She's very thoughtful, kind and dependable. I don't know what I'd do or how I would get by without her.”*

*“I am fortunate to have this home care - they are good workers, cheerful and compassionate. I also appreciate the office workers who are in charge and contact me if and when a worker cannot come in and give me the name of the replacement. It's a great program. Thank you.”*

*“I like my worker. She makes me feel comfortable and is easy to talk to. Also, any questions I may have, she takes the time to help me out. She's compassionate, friendly and has a great attitude. Thank you.”*

*“Even my substitutes have been wonderful, except for one.”*

*“It is very difficult for me to walk. I'm waiting to be admitted to an assisted living facility. My PCA is wonderful but comes only until noon. I spend most of my time sitting on my sofa.”*

*“Workers are great to me! Get along just fine with all of them.”*

*“I like all of them, they give me a hard time about taking my meds, paying my bills, not hording but they are trying to keep me in my own home.”*

*“I need the help and she gives me the best of care. She has a very good attitude and listens to what I have to say.”*

*“Finally was able to get a competent care giver who knows what she is doing”*

*“I love my new worker!”*

*“I could not do without her help and care. She is great. She goes far beyond my expectations.”*

*“There is no backup plan. Not enough workers to cover. We need consistency in workers. Three or four workers a week is the norm. We recently changed agency due to inadequate, not qualified workers.”*

*“I would not be able to remain at my home without the services. I certainly appreciate the way the program is available to help those like myself that receive them.”*

*“Got rid of one and found a better one; the new worker excels at completing tasks and attitude and being proactive - she is a rarity and a gem!”*

*“It would be better if hours were more flexible during the week.”*

*“Caregiver time card requires TOO MUCH information. It needs to be simplified.”*

*“They take very good care of me.”*

## **SPECIAL NOTE ON HOME VISITS BY DOCTORS**

We noticed in the comments on the surveys that a number of people mentioned having home visits by their doctors. We did not ask a specific question on home visits and yet it was noted by more than one respondent. When we reviewed the survey instruments again, we found that 12 people had mentioned home visits; 10 from people on the Waiver program and 2 on the PDN program. The visits were not concentrated in any one county but spread across the state. We found this noteworthy and may prompt further inquiry.

## INTERVEIWS WITH MAINECARE MEMBERS USING LONG TERM SERVICES AND SUPPORTS

### **Purpose**

In October and November of 2011, the Muskie School of Public Service conducted interviews of fourteen (14) MaineCare members who receive long term services and supports (LTSS) in their home. The overall goal of these interviews was to provide qualitative information to supplement the quantitative responses from mail surveys that were sent to members in August 2011. The results of the mail surveys were reported in the first section of this report.

The personal interviews focused on the experience of people who receive MaineCare-funded services through the Elder and Adults with Disabilities Waiver program and the Private Duty Nursing program. During the interviews, people were asked about their experience in getting medical services, in-home services, care transition services and transportation services. They were also asked about their satisfaction with the workers who care for them, their use of assistive technology and medical devices, and their ability to get to the grocery store, and other recreational and social activities. Interviewers asked people to comment on those things that were working well and areas where things were not working well.

### **Methodology**

Participants for these interviews were recruited via a letter from the Office of Elder Services (OES), sent to their homes in August 2011. Persons under guardianship were screened out. In total, one hundred letters were sent to people receiving long term service and supports through two programs at OES: the Elder and Adults with Disabilities Waiver program and the Private Duty Nursing program. To avoid duplication, interviewees were from the same population receiving services from OES, however, this group was only invited to participate in the interviews, not the mail survey. Efforts were made to assure geographic distribution of the interviews; OES staff sent the recruitment letter to people in all sixteen counties in the state.

Upon receiving the letter, interested persons sent back their name and contact information to the Muskie School. Staff from the Muskie School then contacted interested individuals to schedule interviews. Persons not able to answer questions on their own behalf (i.e. interviewees had a proxy who was willing to speak for them) were not included in this effort. Some interested individuals were not interviewed due to scheduling conflicts, illness or because Muskie staff was unable to establish contact. Twenty-five people returned the form to the Muskie School, and ultimately fourteen were able to complete the interview. Ten people were interviewed in their homes and four were interviewed over the phone. Those who completed the interview received a \$25 gift card to Hannaford as a thank you for their participation.

Of the fourteen interviewees, there were nine females and five males. They live in a variety of settings. Six live in rural areas, while nine live in an urban area or an urban cluster area, as defined by the U.S. Census Bureau. There was a mix of private residences and congregate housing, i.e. housing structures subsidized by state, local or federal funds.

The following report provides a summary of the themes that emerged from the interviews. These themes were organized and the results analyzed using a qualitative software program called NVIVO. The software allows users to classify, sort and arrange information, as well as examine relationships in the data to categorize themes that arise from the interviewees' responses.

The themes are presented in order by the volume of comments and conversations in the interview transcripts. These themes are not meant to fully represent all the issues and concerns that face people who receive in-home long term services and supports in the state. They do help provide a context for interpreting some of the results of the mail survey, point to areas where people face particular challenges, highlight areas where things are working well, and focus attention on those things that people who receive services at home most value.

In order to protect the privacy of the interviewees, results are presented in the format of common themes that were discussed throughout most, if not all, of the interviews.

## THEMES FROM INTERVIEWS

### 1. Members want qualified direct care workers who show up consistently.

Members talked extensively about their direct care workers. Frequent topics included what workers do, how they help, and what they can do to improve. Members report being very satisfied with their direct care workers: all fourteen interviewed each had something very positive to say about the services provided by these workers. Most stressed the importance of good training, the difficulties created by high turnover rates, and the lack of staff to serve as back-up when regularly scheduled workers cannot make their shift. The themes related to workers are grouped into: worker performance, training, and availability.

- **Worker Performance**

Members discussed the performance of their workers. Over all, the people we interviewed are happy to have the help, and some workers are exemplary, but some workers do not always do the job to the complete satisfaction of the member.

*“She does a great job. But I think, you know, I don’t want to say nothing to her because sometimes they get mad and walk right out and leave you.”*

*“I am happy with 80 percent of them.”*

*“Right now I have a regular person who knows her job, who loves her job, who is excellent at her job.”*

- **Worker Training**

Many members discussed the fact that they had to train their workers. Some of this is expected as each person has individual needs, tastes, likes and dislikes for how things are done. However, some members thought that their worker could have been trained better on common things such as housekeeping.

*“Most of them (are) lacking the training when they come in and it takes at least two consecutive days to pick up enough from me to continue training them on my own.”*

*“She is basically looking to me every single time she comes for ‘what do you need done?’ So she doesn’t have the intuition that okay there is about an inch of dust all over the tables, but she can’t see it.”*

- **Worker Availability**

Worker no-shows were a common theme among members, with several explaining how this creates chaos in their schedules and daily activities. Members who have had workers not show up for work discussed the fact that in most cases, they don’t know the worker isn’t coming until their scheduled arrival time. There is frustration when a scheduled worker does not show up, and the member is “on their own” trying to find a replacement worker or family or friends to come in and help. Some members without family or friends nearby go without any type of help until a worker can get there. Even in instances when family members are available, people who

have a need for special assistance (such as help from a worker trained to a use mechanical lift) may go without help.

*“... if the helper doesn't come, I am alone for ten hours and there are so many things that I can't do. It is very hard. My son is gone for ten hours a day.”*

*“When (a worker) gets sick... it usually takes a lot of hustling to try to find someone and it can be expensive.”*

*“You are on the phone sometimes forever in hopes that you can find a former caregiver or someone that you met at the hospital or anybody that can get you out of bed.”*

## **2. Members that were interviewed have extensive medical needs.**

While it was not a direct question asked by the research team, every interviewee discussed his or her health history and medical needs during their interview, and how that related to the care they receive in their home. Self-reported health status was one of the most predominant themes in the interviews, second only to discussion of workers. Nine of the fourteen interviewees reported being admitted to a hospital within the past 24 months. Several interviewees receive skilled nursing care in their homes regularly, as well as for extended periods after a hospital stay.

*“I need two new knees; I am waiting on the surgery for two new knees. I am just recovering from a major abdominal surgery last February. The knee surgery is major as well.”*

*“I have a bleeding and clotting disorder and I am on Coumadin because I have some cardiac problems...”*

*“I had major (surgery)... they took out half of my colon and they took out my gallbladder.”*

*“... I have had some problems with pneumonia. It seems that every time I got a cold or anything it went into pneumonia and they have taken me (to the hospital).”*

## **3. Members are grateful for the services they receive and were eager to share what parts of the system work well.**

There were many conversations about what MaineCare members appreciate about their long term services and supports and what part of the programs work well for them. Overall, members were appreciative that MaineCare long term services and supports are available to them, as they described situations and emergencies where if they did not have the supports in place, their health would be in jeopardy.

*“The help that I am receiving allows me to maintain some sense of order in my life and in my home because there are things that I just can't do, but yet are necessary to run a household.”*

*“I am so very grateful for it. I couldn’t get along without it.”*

*“(What is going well?) Everything that I have had through (these services). In fact, I saw my doctor yesterday and he told me what a change the last year has been.”*

#### **4. Members want to stay independent in their homes.**

Members are aware that the long term services and supports they receive help them to remain independent in their homes. Most members expressed their desire to remain in their homes; in addition to acknowledging the services they receive as paramount to remaining independent, they also discussed the importance of home modifications that help.

*“...I had to go to a nursing home to get well enough to come home. I have been home more than a year now and I am so thankful to be here.”*

*“I want to be home. Home is where I heal.”*

*“I don’t want to end up in a nursing home because I would never come out of there.”*

*“What wouldn’t work for me is if I had to go back to a nursing home... (and) I know putting me in a nursing home costs a hundred times more than (the services) I am getting now.”*

#### **5. Many members had home modifications and assistive devices but others still needed additional modifications for living at home.**

Members were asked about home modifications and assistive devices that allow them to get around their homes and maintain independence; twelve of the members reported having home modifications in place such as door openers, a ramp, modified lighting, a hospital bed or grab bars in the shower.

*“I have grab bars and a ramp that the landlord installed.”*

*“It is a lifeline (on my wrist) so if I need help and I fall somebody can come get me... I press the button.”*

*“A friend of mine put this in for me, the accessibility to water. Another friend of mine, a couple of them took up the bath tub and put in a shower I could get into and put in a little permanent fiberglass ramp. They did most of that. The Housing Authority provided some of the materials, like the money for the countertop. The only way to get this in is to have mostly volunteer labor.”*

Ten members discussed home modifications or assistive devices that they don’t currently have that would help them. In those cases, the member either cannot afford the home modification or lives in a structure that would not allow for the type of modification they would like. One member has been homebound for a year because he needs a ramp but cannot afford to purchase and install one.

*“I at least need a handrail that isn’t broken... because I need assistance to get up and down, something I could really lean on... I just haven’t had any extra money.”*



*“There is not room to turn the wheelchair around into (the bathroom), even though they say that it is a handicapped bathroom. It is a bigger bathroom than the other apartments have, it is not a handicapped bathroom.”*

*“I have asked my landlord for a shower that I can walk into, a walk-in shower. That would make a big difference. He said that I would have to pay. It was approved but I would have to pay for it. I can't pay for that. But I need it.”*

## **6. The care transition from hospital or rehabilitation center back home is a fairly smooth process, with no interruption in long term services and supports.**

Nine of the fourteen interviewees reported at least one hospital stay within the past two years. Each member reporting a hospital stay was satisfied with the transition back home. There was no break in their services at home, and in cases where a member temporarily required extra care while they recuperated, these services were provided. That said, some members worry about getting the right services they need upon discharge. These members talked about their frustration with having to be re-assessed for extra services upon discharge and worrying about whether they would get assessed correctly to be able to come home and recuperate with the correct supports in place. So, while members have had smooth transitions back home, there is anxiety about whether their services will fall back into place.

Two members discussed trouble with transportation home from the hospital, which is discussed under Section 6 below.

*“It was all set up and the workers were hired and the hours are honored.”*

(Member is discussing a future planned surgery): *“So I was hoping... they'll give me two hours a day times seven days, if they gave me 14 hours a week for a couple of weeks until I am, you know, I am able to do things myself or I am not requiring that machine and stuff like that. There is some planning, but there is no guarantee.”*

*“You let them know that you are going in (to the hospital). But they can't do it (set up services) that fast, you have to go through the whole assessment thing. It has to be done through the hospital... (they) expect that you have family and friends that (will) take care of you. That is not the way it is when you live alone.”*

## **7. Members that use MaineCare transportation are appreciative of the service, though express some frustration with aspects of the system.**

Members report using a variety of transportation options to get to medical appointments; some drive themselves or have family and friends take them, while others depend on their workers or regional transportation services provided through MaineCare. Most members using regional transportation services talked about the long advance notice needed for these types of rides, which is not a problem for appointments made in advance, but can be problematic for short-notice, non-emergency needs. That said, other members reported only



needing to give 24 hours notice, so there may be variations by region on how this works. Members using MaineCare regional transportation had mixed reviews; some reported on an efficient system that worked well for them, while others said that they were never able to get a ride at the times they needed.

Two members reported problems getting any type of transportation back home after a hospital stay, i.e. transportation was not in place for them and they were calling people from the hospital trying to find a ride home.

*“I let them know when I am going, where I have to be and what time I have to be there... You have to let them know at least two or three days ahead of time.”*

*“Like if you want a next day service you would have to call before ten o’clock that day and you get your appointment.”*

*“That is the other thing, the state will send you out of state, like often times a surgery like the one that I had, my doctors all prefer that I go to Boston for it. So I get down there, but then I have no way to get home.”*

*When they (regional transportation) say they will be here, they will be here (to pick up at home)... sometimes I have to wait an hour for them to get me after (at the doctors), but it is better than me not being able to get there at all.”*

*“We tried (regional transportation) a couple of times, it just didn’t seem to work out that they would be here when we needed them here. We just try and schedule appointments for when (the worker) is going to be here... she will take me.”*

## **8. Members would like easy to understand information from the Department of Health and Human Services and Elder Independence of Maine.**

Some members described feeling confused by the paperwork and letters they receive. Members would also like to see more user-friendly communication; often the materials they receive in the mail are vague and difficult to understand. They believe that a more efficient and streamlined system could help improve communication while saving MaineCare money by reducing unnecessary mailings.

Additionally, there is great frustration with the lack of communication from agencies around worker absences, as described in Section 1 above.

*“I have never sort of been given by anyone exactly what MaineCare covers and what they don’t cover. I guess there isn’t such a booklet or list or anything?”*

*“They (DHHS) have come in the last three years to writing the most vague letters requesting something or telling you that they are going to do something. You cannot understand.”*

*“I think if people were aware that they do have... different openings they can access, that perhaps is the major problem is that most people are not aware of the different avenues that they have for help.”*

## CONCLUSION

The MaineCare members that we spoke with were very experienced with and passionate about the services and benefits they receive. The majority felt fortunate to have access to long term services and supports. Many have had extremely positive experiences with their workers, their agencies, and the health care system. At the same time, there were members that believe there is room for improvement, particularly around communications with DHHS and the provider agencies they deal with, worker no-shows and some worker performance issues, transportation and home modifications. Members believe that improvement in these areas would in turn improve their quality of life.

## APPENDIX A: INTERVIEW PROTOCOL

### MaineCare Long Term Services and Supports Interview Questions (In person and phone)

#### Interviewer, after completing consent process:

*Do you have any questions for me before we begin? Okay, let's get started.*

*(Begin tape recorder, if not started already.)*

*Just to remind you, we want to better understand the needs of older adults and persons with disabilities who receive services in their home. When answering these questions, keep in mind the services and supports you receive in your home.*

- Q1.** What is working well for you?  
*Probe: Can you tell me what types of services you receive?*
- Q2.** What is not working well for you?
- Q3.** I want to ask about the people who come in your home to help you. Are you happy with the person who comes to help you in your home? With how well they do their job?  
*Probes: Do they come on time? If NO: what do you do if they show up late or don't come at all?  
Do they come at times that are convenient for you?  
Do they do things the way you want them done?  
Are they courteous and professional?*
- Q4.** There are ways to make changes in your home to make it easier for you to get around, and do things for yourself. For example some people have grab bars in their showers, special faucets, lights that go on automatically or change in their home such as a ramp for a wheelchair. Are there changes in your home that would make things easier for you?  
*Probes: Have you discussed these with anyone? What happened?*
- Q5.** Now I'd like to ask about your doctor, or your primary care physician. When you visit your doctor, does your doctor talk to you about the services you are getting at home?  
*Probes: Does he or she ask how the services are going and if they are right for you?  
Would you like to talk with your doctor more about your situation at home?*
- Q6.** Have you recently been in a hospital or nursing home or rehabilitation center?  
*If yes: When it was time for you to return home, did anyone help you coordinate your services at home? Did you think it was an easy transition back home, why or why not? What would make it work better?*
- Q7.** How do you get to your medical appointments? Do you ever call the regional transportation provider in your area?

*If yes/ person uses MaineCare transportation: Do they pick you up and get you to your appointments on time? Do you find them a reliable way to get to your medical appointments, why or why not?*

- Q8.** How do you get to the grocery store, or to social engagements or recreational activities?
- Q9.** Is there anything else you'd like to share with me about the services you receive in your home that we have not talked about yet?