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Personal Experiences With Long Term Care Services and **Supports**

Julie Fralich MBA

Muskie School of Public Service, University of Southern Maine

Mark Richards BA

University of Southern Maine, Muskie School of Public Service

Louise Olsen

University of Southern Maine, Muskie School of Public Service

Vanessa Bell

University of Southern Maine, Muskie School of Public Service

Jennifer Pratt

University of Southern Maine, Muskie School of Public Service

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With Long Term Care Services and Supports

■ Statewide Listening Sessions

Held across the state:

Bucksport Rumford
Lewiston Sanford
Machias Waldoboro
Presque Isle Waterville

Attended by:

Older Adults
Family Members
Advocates
Legislators
Voung Adults
Direct Care Workers
Long Term Care Providers
Community Members

■ Survey of Home Care Service Users

Home Based Care Homemaker Services Self-Directed Services

Prepared for:

Maine Long-Term Care Ombudsman Program

Prepared by:

Muskie School of Public Service

Funded by:

Maine Health Access Foundation and Bingham Foundation

January 2012

Personal Experiences

With Long Term Care Services and Supports

From Statewide listening sessions:

Held across the state: Attended by:

BucksportOlder AdultsLewistonYoung AdultsMachiasFamily MembersPresque isleDirect Care Workers

Rumford Long Term Care Providers

Sanford Advocates Waldoboro Legislators

Waterville Community Members

From a survey of people who use:

Home Based Care Homemaker Services

Consumer Directed Home Based Care

Prepared For:

Brenda Gallant

Maine Long Term Care Ombudsman Program

Prepared By:

Julie Fralich

Mark Richards

Louise Olsen

Vanessa Bell

Jennifer Pratt

Muskie School of Public Service University of Southern Maine

Funded by:

Listening Sessions Funded by Maine Health Access Foundation Home Care Survey Funded by Bingham Foundation

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FOREWORD

This report captures, in a direct way, the first hand experiences of older and disabled consumers of long term care services and supports. In addition, it includes the collective experiences of eight Maine communities regarding the long term care service delivery system in our state. While older and disabled people in need of services rely greatly on those services, they are often not at the table when policy decisions affecting long term care services are made. Clearly, consumers need and want to be heard. This is evidenced by the strong response we received to the lengthy survey we asked consumers of home based care and homemaker services to complete. You will find in the pages of this report data from the survey and descriptive comments about what matters most to people concerning the services they receive. From this information, we can learn much about the daily challenges they encounter and how we can do better in planning and providing services.

Fortunately, Maine communities have much to say about long term care services and supports. Two hundred and thirty eight (238) people across the state accepted our invitation to meet and talk in a local Listening Session about long term care. Consumers, family members, community leaders, providers and advocates were eager to come and share their experiences and ideas about services in all long term care settings. Each community has its own distinct personality. Some have a strong core group of citizens actively engaged in local activities that support older and disabled people. In all communities, we found people with energy, ideas and practical suggestions for improving service delivery.

We hope that the information in this report will help in shaping long term care service planning in Maine. This effort comes at a time when we are facing shrinking resources and a rapidly expanding aging population. As we go forward in meeting these challenges, it is critical that we develop a comprehensive statewide plan for long term care services and supports. The input of consumers, family members and Maine communities can make a significant contribution in this effort.

We would like to thank the legislators who attended the Listening Sessions. In particular, we would like to extend our appreciation to Senator Margaret Craven for requesting a Listening Session in Lewiston and to Representative Matthew Peterson for his willingness to serve as a facilitator at the Rumford Listening Session.

We would like to thank the Bingham Program and the Maine Health Access Foundation for their support in providing funding for the consumer survey and the Listening Sessions. Their faith in us is greatly appreciated.

Brenda Gallant Executive Director Maine Long Term Care Ombudsman Program

ACKNOWLEDGEMENTS

This report provides the results of two major initiatives that were undertaken to give people in Maine the opportunity to share their experiences and express their views on the needs of older adults and adults with disabilities in the State. In 2011, the Maine Long Term Care Ombudsman Program (LTCOP) received funding from the Maine Health Access Foundation and the Bingham Foundation to do the following:

- 1. Organize Statewide Listening Sessions in eight communities across the state where people could share their concerns, issues, and desires about the long term care service and support needs of older adults and people with disabilities in Maine. These sessions focused on access to long term care services, gaps in services, how services could be improved, support needed to remain living independently at home, quality of life concerns and physician care.
- 2. Conduct a survey of people using home and community based services to find out about their experience and satisfaction with their medical, in-home and transportation services.

Brenda Gallant, Director of the Maine Long Term Care Ombudsman Program (LTCOP), led this effort and provided the guidance, leadership and vision for the project. The overall goal of these initiatives was to make sure that the voice of older adults and others with disabilities in Maine was heard and to have that voice make a difference.

The Department of Health and Human Services was supportive in this effort to reach out to consumers, family members, providers, advocates, community leaders and stakeholders from across the state. The Maine Department of Health and Human Services (DHHS) Deputy Commissioner, Bonnie Smith and Ricker Hamilton, Director of the Office of Elder Services and Acting Director of the Office of Adults with Cognitive and Physical Disability Services attended the listening sessions welcoming participants and sitting in on group discussions. Their presence was helpful in assuring participants that the ideas and experiences shared during the sessions would be considered as DHHS goes forward in planning for long term care services and supports.

This report would not have been possible without many hundreds of hours of work to conceive of this project, design the survey instruments and organize and run the listening sessions across the state. Pam Allen, a consultant with LTCOP, worked closely with Brenda Gallant to organize and manage all aspects of this work.

Listening Sessions

The Maine Long Term Care Ombudsman Program organized a massive outreach and communication campaign to notify people of the listening sessions. In all, 238 people attended the listening sessions.

Many organizations and individuals worked to get the word out. The LTCOP posted the listening session on their website; sent out post cards to consumers and family members in each area; sent flyers to the Area Agencies on Aging, the Maine Association of Area Agencies on Aging, AARP, Alpha One, Maine Alzheimer's Association, Dementia Care Strategies, Catholic Charities, Home Care for Maine, EIM, Legal Services for the Elderly, the Maine Department of Health and Human

Services (DHHS) Office of Elder Services, DHHS Commissioner's Office, Home Care and Hospice Alliance of Maine, Congressional offices, city and town governments, Goold Health Systems, Maine Health Care Association, Senior College, Coastal Economic Enterprises, Kennebec Valley Organization; the Disability Rights Center and the Brain Injury Information Network. Veterans groups were notified by phone. Other outreach efforts included:

- Home Care for Maine sent out two hundred postcards to consumers
- Spectrum Generations sent brochures out to their centers for distribution
- Muskie Center in Waterville included information in their newsletter
- The Maine Alzheimer's Association created a link to LTCOP's web site and posted information in their office, on area bulletin boards, and on their social network outlets.
- Maine Health Care Association included information in their newsletter
- Volunteer Ombudsmen distributed flyers in their communities and in the long-term care facilities they visit
- Home Care and Hospice Alliance of Maine sent notices (both emails and brochures mailed) to their members
- Osher Life Long Learning Institute included information about the sessions in their newsletter
- Kennebec Valley Organization called their members encouraging attendance in Waterville
- Legislators in each area received emails and phone calls informing them about sessions in their area
- Churches received letters of invitation along with brochures (followed up by phone calls)
- Senior Centers were called, brochures were sent
- Long-Term Care facilities were called
- Legal Services for the Elderly notified their staff attorneys and sent out information
- Dementia Care Strategies sent a notice to their email contact list and other social network outlets
- Women's Business Center at Coastal Enterprises, Inc. sent out notices to several newsletters along with notices to over 100 people.

The following newspapers and radio stations were contacted:

Radio Stations
WOXO Rumford
WQSS/WBFB Waldoboro
WQDY Machias
WBACH Sanford
WXCU Presque Isle

At the listening sessions, many people volunteered their time to facilitate the discussions and take notes. Many thanks to these individuals and organizations.

Facilitator Note Taker	Organization	Facilitator Note Taker	Organization
Brenda Gallant	LTCOP	Dr. Meghan Duff	University of Maine Machias
Patricia Thorsen	LTCOP	Joseph Ferrier	University of Maine Machias
Maria Woodard	LTCOP	Elisabeth Kay Beal	University of Maine Machias
Pamela Marshall	LTCOP	Abigail Propp	USM intern at AARP
Pam Allen	LTCOP	Megan Ford	University of Maine PI
Betsy Sawyer-Manter	EIM	Kathryn Pears	Dementia Care Strategies
Rep. Mathew Peterson	Maine Legislature	Julie Fralich	Muskie School
Mollie Baldwin	Home Care for Maine	Mark Richards	Muskie School
Don Harden	Catholic Charities	Danny Westcott	Muskie School
Carmen Carney	SeniorsPlus	Larry Ullian	Muskie School

Consumer Surveys

Many people provided input and guidance into the design and administration of the survey instruments. Elizabeth Gattine and Romaine Turyn from the Office of Elder Services; Michelle Probert from the Office of MaineCare Services; Brenda Gallant and Pam Allen from the Long Term Care Ombudsman Program; Morgan Floyd from MEHAF provided advice and consultation on the questions for the survey instruments.

Others helped with the mailing of the survey. Staff from LTCOP assembled the surveys. EIM mailed the surveys to people on the Home Based Care Program; Catholic Charities of Maine mailed the surveys to people using Homemaker services; and Alpha One mailed the surveys to people using Consumer Directed Home Based Care Services.

Staff from the Long Term Care Ombudsman Program collated and organized the surveys that were returned; Mark Richards and Bobbi Lops collected the surveys at the Muskie School; and Jen Pratt scanned the surveys into the computer and cleaned the data.

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INTRODUCTION

This report provides the results of two major initiatives that were undertaken in Maine to learn more about the needs and service experience of older adults and adults with disabilities.

- 1. Listening Sessions were held in eight communities across the state.
- 2. A survey was conducted of people using state funded home care services including home based care services, homemaker services, and services for people who self direct their care.

These two methods were chosen to provide multiple ways for people to express their views on the current long term care system, the services that they are receiving and how well things are working.

It is not always easy for older adults or people with disabilities to give voice to their concerns, have a forum to express their opinions and provide input into policy discussions.

Many people who are receiving services in their home, by definition, cannot easily attend public meetings, go to legislative hearings, or participate in listening sessions. Home care consumers have few opportunities to voice their opinions, share their experiences or express their satisfaction or dissatisfaction in a way that will be publicly reported. The mailed survey was used to capture the experience of people who are currently getting services in their home and to summarize those experiences in a way that will inform policy makers, legislators, and other stakeholders.

The listening sessions provided an opportunity to expand stakeholder input into the process and hear from a broad cross section of people including consumers, family members, friends, providers, advocates, legislators, community members and other stakeholders. The listening sessions provided a more open ended way to get input from the public and to hear directly from Maine citizens about what was working well, what was not working well and what would be a preferred system of long term care services and supports. The listening sessions were not limited to people who were getting home care services. People who attended these sessions shared their views on a wide range of topics including home care services, long term care services, housing, transportation, food and other issues.

The following two sections provide a review of the purpose, methods and results from the listening sessions and mailed surveys.

LISTENING SESSIONS

Purpose

In September and October 2011, the Maine Long Term Care Ombudsman Program held listening sessions across the state and invited Maine consumers, family members, friends, providers, advocates, legislators, community members and other stakeholders to hear about their experiences and ideas concerning:

- Access to long term care services
- Gaps in services
- How services could be improved
- What is needed to support their independence in living at home
- Their top quality of life concerns
- What their physicians can do to better support their health and care

A copy of the Listening Session Brochure is included as Appendix A.

Methodology

The listening sessions were held at community buildings in Waterville, Rumford, Waldoboro, Machias, Sanford, Presque Isle, Lewiston and Bucksport. In all, 238 people attended these sessions. The following is a summary of the number of people who attended at each session.

Town	Date	Location	Number Attending
Waterville	September 19	Muskie Center	40
Rumford	September 26	American Legion Hall	26
Waldoboro	September 27	VFW Hall	24
Machias	September 28	U Maine Machias	22
Sanford	October 3	Elks Club	31
Presque Isle	October 5	Presque Isle Inn	27
Lewiston	October 17	Seniors Plus	32
Bucksport	October 7	Bucksport Senior Center	36
Total			238

The listening sessions were conducted as open ended meetings where participants were divided into smaller groups. A facilitator and note taker was assigned to each group. The facilitator asked each group to address the following questions:

- What has been your experience when you have needed to access long term care services?
- What services have you been able to get?
- If you had a magic wand and could change one thing in long term care what would it be?

• Are there things that you would like to preserve in the services you have received?

The facilitator recorded the responses of the group on a flip chart. In addition, each participant was given a note card and asked to write down one issue or idea that was most important to them. We received a total of 124 comments on index cards from the participants in the listening sessions. Each comment was recorded and categorized into a major theme or category. The themes from the discussions at the listening sessions were analyzed in combination with the themes from the index cards. The quotes that are included throughout this section are illustrative of the themes that emerged from the listening sessions and the index cards.

RESULTS

The following is a summary of the themes that emerged on the flip charts or on the individual index cards. It was difficult to rank the themes and comments. Many comments related to more than one theme. Below are comments organized into eight general categories and are ranked from one to eight based on the frequency with which they were mentioned.

	Theme	
1.	Access to Affordable Services at Home	
2.	Easy to Understand Information	
3.	Transportation	
4.	Qualified Workers	
5.	Navigation Assistance	
6.	Family Support	
7.	Housing and Food	
8.	Assessment Process	

1. Access to Services

Access to services in the home was by far the largest and most prominent theme of the listening sessions. Access concerns focused on

- Sustainability of future funding for services
- The affordability of services
- The availability of services
- Need for more home care services for people to remain at home

"We need affordable services to keep rural elderly in their own homes."

Funding for services – People expressed concerns about continued funding of home care services, the potential for federal and state cuts in funding, and the cost effectiveness of home care services compared to long term care services. Examples of comments include:

- Need for more Medicaid funds specifically for home care
- Fear of continued federal reimbursement cuts to long term care

"The fear of the loss of MaineCare funding for the elderly and those who cannot provide for their own care needs."

Affordability of care - Others commented on the affordability of care, and the need for services for people above the federal poverty guidelines. Comments on the flip charts included:

- Need for affordable services to keep rural elderly in their own homes
- Need for available and affordable assisted living for middle class population.
- Need lower rates for private pay customers
- Long term care needs to be more affordable and part of our social benefits

"We need funding for services for individuals who live above the federal poverty guidelines but are not able to afford the services."

Availability of services – Many commented on the need for certain services/lack of services in certain areas. Notes from the listening sessions suggested that people were concerned about:

- Lack of doctors, dentists and service providers in rural areas
- Need for assistance with dentures, hearing aids, and vision
- Need more housing with services for younger adults with mental illness
- Lack of adult day care and facilities for younger people
- Need for more heating assistance
- Length of waitlists for services

More home care services – People commented on the need for a more balanced long term care system with more funds allocated to home care services. In general, people wanted to be able to live at home as long as possible.

- We should be looking to communities for support and creative ideas to help elder and disabled people remain at home.
- Need more money for home health care and less for nursing facilities
- More funds allocated to home health care, reversing to some extent the formula that gives most of the funding to nursing homes
- Need funding to support care (the whole continuum of care from basic support to the more complex) at home for as long as possible

 "Higher percentage of MaineCare."
- Need funding for elderly to stay at home with adequate staffing
- Want to be able to stay in home as long as possible comfortably
- Provide enough money to continue to live in my home and maintain it. (e.g., repairs, upgrades, energy efficiency, etc.) and access to competent people to do assist with maintenance and repairs.

"Higher percentage of MaineCare funding should go to HCBS rather than facility care. This would save money and allow people to stay in their own home."

2. Easy to Understand Information

A second major theme was the need for easy to read information on services available. This includes information for the general public as well as materials geared towards seniors; information explaining to doctors what services are available; and information that is presented in plain language and not full of jargon and hard to understand.

Some themes that arose during the listening sessions included:

Available information

- Lack of information/awareness/communication about local services
- Need for more information on dementia
- Better dissemination of information to the senior population
- Need for public education for all ages
- No central clearinghouse for information
- Need to educate doctors about services available for people to live at home
- Lack of communication and knowledge sharing between hospital and facilities makes preplanning, discharge and rehab difficult
- More information about future planning (living wills, legal documents needed, LTC insurance, retirement, financial planning, Medicaid 5 year look-back and asset transfer)

"There needs to be more community education regarding long term care (families, physicians and communities."

"Lack of collaborative information between hospitals and agencies."

Hard to understand information

- Generally cannot understand the system
- Applications are long and difficult
- Lack of cultural awareness
- DHHS website is too difficult

"Terminology is difficult to understand – alphabet soup."

3. Transportation

Transportation continues to be a major issue for people in Maine and especially for people in rural areas who need help with care. Listening session comments include:

- Few public options approved for medical transport
- Lack of general transport to get to social and family activities
- Need for more affordable transportation! Increased, affordable public transportation with a flexible route for by-appointment pick-ups. Benefits to local businesses by increasing customer flow and the mental health of seniors/people with a disability.
- Need for more transportation options and opportunities especially in rural areas to and from non-medical services.
- Need more public transportation
- Need vehicles that can transport people with physical disabilities

"Lack of transport forces people into care/prevents people from living at home."

4. Qualified Workers

People are very satisfied with their direct care workers but stress the importance of good training, the difficulties created by high turnover rates, the lack of staff in certain areas, and the need for good wages for home care workers. The themes related to workers can be grouped into: worker performance, training, funding/wages and other.

"Need public recognition for worker."

Performance

- Need to publicly recognize workers
- High rate of no shows for nursing staff
- Home care companies should be accountable for providing staff and consistent coverage

Training

- Staffing needs to get better in nursing homes
- Offer more technical and vocational training for home care students
- Create volunteer programs for visitors and running errands.
- Need more trained volunteers who are trustworthy and affordable

Funding/Wages

- Have the resources and staff connected to the ongoing needs of the community
- Help more elderly with better paid aides at the nursing homes
- Need more funding for elderly to stay at home with adequate staffing

Other

- No over-night coverage for in-home care
- Need peer assistance
- Need a registry
- Need background checks

"Need more training for home care provider."

5. Navigation Assistance

Many people commented on the need for help with care management, help transitioning people from hospitals and nursing homes, and help navigating the system.

Care Management

- Need more care managers to navigate the system
- Centralized care planning for elderly to connect with any and all needs
- Lack of continuity in long term care programs
- More expectation for consumer to self-advocate and little guidance to do so

"Need better follow-up with families/patients after serious illness."

Care Transition

- Need transition assistance (between services/facilities)
- Assistance needed with private pay when gap in coverage
- Assistance with pet care issues; people afraid they will lose pets
- Improved discharge planning would more appropriately place people
- Child to adult system difficult to move between and needs attention

Navigation

- Remove the 3 overnight hospital stay requirement to access short term in-patient rehab. The sooner people come to nursing homes the sooner they can get home.
- Improve access to long term care after a health issue (hospitalization for stroke, heart attack, accident)
- What kinds of options are available and can be planned for prior to major health issues?
- Recognize the need for counseling for families trying to cope with transitions from independence to dependence
- Practical application navigator
- Needs not met before leaving LTC facility
- Need navigators for private pay

"There is little to no help with discharge planning."

"Need navigator right after discharge for support and planning."

6. Family Support

Families and informal caregivers taking care of family members are stressed and need information and training on how to care for a family member; they also need support in their role as a caregiver.

Education/Training

- Need caregiver education and support
- Lack of training for current family care providers
- Need for information about financial considerations when caring for family members, Medicaid rules (asset transfer and 5 year look back)
- Need for more information on how family members can proactively plan for an aging loved one's future so people can have critical conversations before they are needed

Support

- No support for family caregivers
- No money to pay family caregivers
- Families should be paid for providing care
- "For elders at home who are being cared for - their caregiver needs respite."
- Problem of family caregiver burnout without more support in the consumer's home.
- Caregivers caring for people at home need respite.
- Caregivers who are sick need help with transportation to places such as day programming

7. Housing and Food

Affordable housing for seniors was a recurrent theme. In general, people wanted more kinds of housing options, and more affordable housing. The trade-off between food and other services was also mentioned.

Housing

- Need more affordable housing
- Need more affordable assisted living
- Need more affordable senior housing
- Need more subsidized housing
- Need more specialized beds

Food

- Hungry seniors
- Seniors will give up medications or stretch them to pay for food.
- Food security in general is a concern.
- Participants mentioned longer lines at food banks

8. Assessment Process

The long term care assessment process was confusing to many. People reference the "Goold assessment" which is the long term care assessment that determines the medical and functional eligibility for publicly funded long term care programs. This assessment is currently conducted by Goold Health Systems, the state's Assessing Services Agency. Some wanted more information; some wanted the assessment to look at additional conditions or diagnosis; some did not like the assessment process.

Assessment was confusing

- The system is confusing to access;
- Not sure what the assessment process is or does
- People too proud to admit what they need help with
- Assessment process is focused on determining program eligibility; but does not look at real needs agencies still do their own assessment to determine need.

Areas included in the assessment

- Assessment misses family support, independent needs
- Doesn't necessarily capture behavior and cognitive difficulties
- Conditions that fluctuate not captured

Assessment process satisfaction/dissatisfaction with assessment process

- Long wait time for assessment- holds up process especially when immediate person presents an immediate need
- Some have lost a bed waiting for assessment
- No information about Goold in general
- Eliminate the use of the Goold assessment. This is a rationing tool for health care services that does not adequately measure need
- Don't like the Goold assessment
- Poor access to Goold assessment

SURVEY OF STATE FUNDED HOME CARE USERS

Purpose

The purpose of the survey was to learn more about the experiences of people who were receiving services from Maine's three state funded home and community based care programs. These programs are available to low-income people who are not eligible for services under the MaineCare program but who have needs that require some level of assistance. Each program requires a co-pay. Home Based Care participants are more likely to use workers from personal care and home health agencies. A small number of people direct their own personal support services through a self-directed option within the program. All Consumer-directed Home Based Care participants hire and manage their workers directly. Homemaker participants are served by homemakers working through an agency. The three programs and the services they provide are:

Program ¹	Services	Medical Eligibility
Home Based Care	Personal Support, Skilled Services, Emergency Response	Four levels of eligibility that require assistance with a combination of Activities of Daily Living (ADLs)* and Instrumental Activities of Daily Living (IADLs)** Highest level is nursing facility level of care
Homemaker Services	Laundry, Housekeeping, Grocery Shopping, Meal Preparation	Need assistance and physical support in 3 of the 4 IADLs**
Consumer Directed Home Based Care (HBC) Services	Personal Support	Assistance with two ADLs. People hire and manage their own workers.

^{*}ADLS include bed mobility, transfer, locomotion, eating, toilet use, dressing, and bathing.

The survey was designed to capture the experience of people using services along a number of domains. These domains included satisfaction with the home care services they were receiving, as well as their experience with the medical system; their satisfaction with care management services; the use and need for assistive technology; and their use of transportation services.

^{**}IADLs include: main meal preparation, routine housework, grocery shopping or laundry.

¹ Home Based Care (HBC) is Home Based Care Program (OES Policy Section 63) Homemaker Services formal name is Independent Support Services (OES Policy Section 69) Consumer Directed Home Based Care is Consumer Directed Personal Assistance Services (OACPDS Section 11)

Methodology

The survey was mailed in August 2011 to all people using any of the above programs. In order to protect the confidentiality of people completing the survey, the survey was mailed by the agency that administers the program and the completed surveys were returned to the Long Term Care Ombudsman Program. EIM, the agency that manages the Home Based Care program sent out the survey to people on that program. Catholic Charities of Maine, the agency that administers the Homemaker program, sent the survey to its consumers. Alpha One, the Independent Living Center that manages the Consumer Directed Home Based Care program, sent out the surveys to its consumers.

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 survey instruments that had been tested or used by others. In a few instances, the evaluation team developed new survey questions. One of the challenges of the survey was to identify questions that captured the full array of domains that were of interest. Most commonly used instruments (e.g. the Medicare CAHPS² survey or the HCBS Participant Experience Survey) focus on the 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.

Surveys were sent to all participants on the three programs. The following table provides a summary of the surveys that were sent, received and the response rate.

Table 1: Survey Response Rates

Program	Surveys Mailed	Completed Surveys	Response Rate
Home Based Care	990	351	35%
Homemaker	1000	354	35%
Consumer Directed (HBC)	105	50	48%
Total	2095	755	36%

Given the length of the survey and the impairments of people surveyed, this is a very strong response rate.

² CAHPS is the Consumer Assessment of HealthCare Providers and Systems Survey that asks consumers and patient to report on and evaluate their experiences with health care.

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

Table 2: Age Range of Respondents

Age Range	Home Based Care (n = 340)	Homemaker (n = 346)	Consumer Directed HBC (n = 48)
	Percent	Percent	Percent
25 to 44	1%	5%	6%
45 to 64	13%	30%	35%
65 to 74	18%	25%	42%
75 to 84	33%	22%	10%
85 or older	35%	17%	6%
Total	100%	99%	99%

As indicated in Table 2, approximately 86% of the Home Based Care respondents were over the age of 65 and more than a third are 85 years old or older. In comparison, 64% of the Homemaker program were 65 years or older. Thirty percent of the people on the homemaker program are 45 to 65 years old. The Consumer Directed Home Based Care Program serves a younger population with approximately 41% of respondents being under the age of 65. It is worth noting that 42% (20 out of 48) were between 65 and 74 years old.

The following table provides information on the living arrangement of the respondents.

Table 3: Living Arrangement

Living Arrangement	Home Based Care (n = 340)	Homemaker (n = 339)	Consumer Directed HBC (n = 48)
	Percent	Percent	Percent
Live Alone	56%	76%	35%

As evident in the above table, 76% of respondents who use the Homemaker Program live alone; while a little more than half of the Home Based Care respondents live alone. Approximately one third of the people using the Consumer Directed Home Based Care Program who responded to the survey live alone.

For those who were not living alone, the people using the Consumer Directed Home Based Care Program were most likely to be living with a spouse or companion (78%); while 57% of those using the Homemaker program and only 39% of those on the Home Based Care Program, lived with a spouse/companion.

Table 4: For those not living alone:

Person lives with:	Home Based Care (n = 156)	Homemaker (n = 76)	Consumer Directed HBC (n = 27)
	Percent	Percent	Percent
Spouse/Companion	39%	57%	78%
Family	41%	30%	15%
Friend	3%	5%	4%
Other	17%	8%	4%
Total	100%	100%	101%

The following table shows how people rated their own health.

Table 5: Consumer Self Rated Health

	Home Based Care (n = 338)	Homemaker $(n = 339)$	Consumer Directed HBC (n = 48)
	Percent	Percent	Percent
Excellent	.6%	2%	4%
Very Good	8%	9%	21%
Good	32%	28%	35%
Fair	43%	43%	31%
Poor	17%	18%	8%
Total	100.6%	100%	99%

People on the Home Based Care Program and the Homemaker Program had very similar ratings of health status. Approximately 40% of the people in each of these programs rated their health as excellent/very good/ or good; and about 60% rated their health as fair or poor.

In contrast, approximately 60% of those on the Consumer Directed HBC Program rated their health as excellent/very good/good and 40% rated their health as fair or poor.

The following table provides the distribution of responses by county.

Table 6: Respondents by County

	Home Based Care		Homemaker		Consumer Directed Home Based Care	
	n	Percent	n	Percent	n	Percent
Androscoggin	11	3.4%	42	12.4%	3	6.4%
Aroostook	100	30.7%	42	12.4%	2	4.3%
Cumberland	31	9.5%	48	14.2%	6	12.8%
Franklin	8	2.5%	11	3.2%	1	2.1%
Hancock	6	1.8%	7	2.1%	1	2.1%
Kennebec	35	10.7%	49	14.5%	4	8.5%
Knox	4	1.2%	3	.9%	4	8.5%
Lincoln	9	2.8%	7	2.1%	0	0
Oxford	13	4.0%	10	2.9%	1	2.1%
Penobscot	27	8.3%	31	9.1%	8	17.0%
Piscataquis	7	2.1%	8	2.4%	0	0
Sagadahoc	4	1.2%	3	.9%	0	0
Somerset	23	7.1%	14	4.1%	3	6.4%
Waldo	5	1.5%	13	3.8%	0	0
Washington	7	2.1%	20	5.9%	5	10.6%
York	34	10.4%	30	8.8%	9	19.1%
Not Sure Don't know	2	.6%	1	.3%	0	0
Total	326	100.0%	339	100.0%	47	100.0%

Thirty-one percent of the Home Based Care respondents were from Aroostook County. The high number of respondents from Aroostook County is due to the fact that a high number of people in the county use the service (264 out of 1378 in Dec. 2011) and people from Aroostook had a response rate (38%) that was higher than most of the other counties. In comparison, 191 people in Cumberland County were using home based care services in Dec. 2011 and the users in Cumberland County had a response rate of approximately 16%.

The distribution of respondents on the Homemaker and Consumer Directed Programs is consistent with the distribution of people who use those programs in those counties.

The following table shows information on who completed the surveys.

Table 7: Survey Respondents

	Home Based Care	Homemaker	Consumer Directed Home Based Care
	Percent	Percent	Percent
Filled out myself	40%	73%	52%
I answered, someone else filled out	33%	19%	39%
Someone else answered and filled out	27%	7%	9%
Total	100%	100%	100%

People on the Home Based Care Program required the most assistance in completing the survey. Twenty-seven percent of surveys were answered by someone other than the consumer. Although this was a fairly high percentage, we decided to report on all the answers, whether the survey was completed by the individual or by someone else. We felt it was important to capture the view of consumers and others who may be caring for the consumer and include all responses.

Over 90% of the surveys by those on the Homemaker Program and the Consumer Directed HBC Program were answered by the individual on the program.

RESULTS

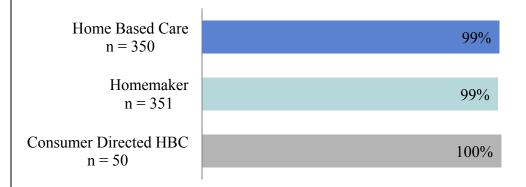
The following graphs provide the results of the three surveys that were administered to the people using the Home Based Care Program, the Homemaker Program and the Consumer Directed Home Based Care (HBC) Program.

ACCESS TO MEDICAL SERVICES

"Dr. X is among the very top caring knowledgeable compassionate medical providers. I trust him implicitly and would recommend him to anyone."

"I now have a great PCP! It takes a while to find a good doctor especially for your illness."

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

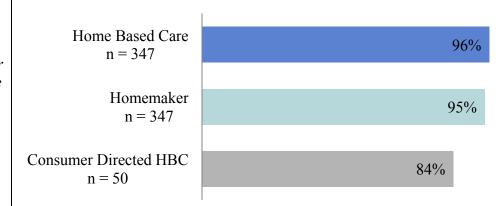


Across all three programs, virtually all respondents indicated they had a primary care doctor. Of the 751 people who responded to all three surveys, only 6 indicated that they did not have a primary care doctor.

ACCESS TO MEDICAL SERVICES

In the last 6 months, did you visit your primary care doctor to get care for yourself? (Yes Responses)

"My primary care doctor is very familiar with my needs and the services I receive."



Those on the Home Based Care Program and the Homemaker Program were more likely to have visited their doctor in the prior six months. Approximately 95% of respondents in those programs had seen their primary care doctor in the last six months compared with 84% (42 out of 50 people) on the Consumer Directed HBC program.

ACCESS TO MEDICAL SERVICES

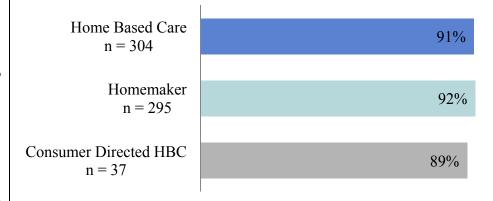
"Phone system terrible. Never get to doctor. Wait at times for response. Don't care to explain my problems to receptionist. I need the doctor, not receptionist."

"Would like help getting in and out of the office. Make home visits".

"Would like to have a doctor who knows about what is wrong and come to see you 24/7."

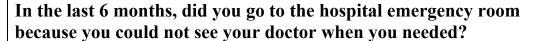
"Would like doctor to have more time allowed for them to be with a patient."

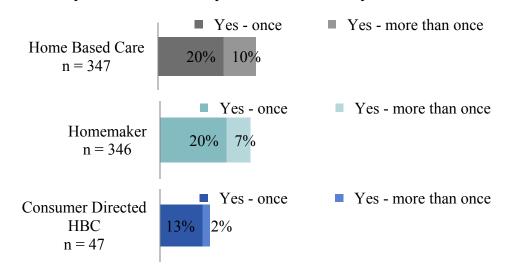
In the last 6 months, when you needed medical care right away, did you get an appointment as quickly as you needed it? (Yes Responses)



Nine out of 10 respondents indicated that when they needed medical care right away, they could get an appointment. This was very consistent across programs.

Some of the open ended responses provide examples of the challenges some people experienced when trying to see their doctor. A few respondents commented on the difficulty of getting out of the house and expressed their desire to have home visits.





Approximately 30% of Home Based Care and Homemaker respondents went to the emergency room (ER) at least once in the prior six months because they could not see a doctor when they needed. Twenty percent of these respondents had gone the ER once and 7-10% had gone more than once.

Of the Consumer Directed HBC consumers, 15% went to the ER because they could not see their doctor when they needed. Only two percent had gone more than once to the ER.

ACCESS TO MEDICAL SERVICES

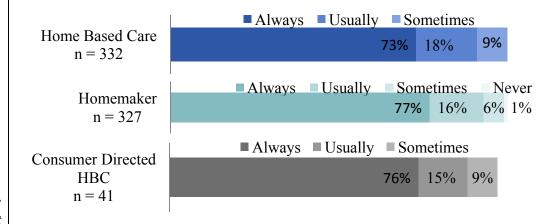
"He could take more time to listen to me and explain the tests at the hospital that he orders for me."

"My doctor continues to be kind and pleasant and accommodating with my French language."

"My new PCP is distant and doesn't have time to listen to problems".

"It bothers me that my primary doctor doesn't listen to me. The attitude he has sometimes that he's always right and my feeling or thoughts don't matter really upsets me."

In the last 6 months, how often did this doctor listen carefully to you?



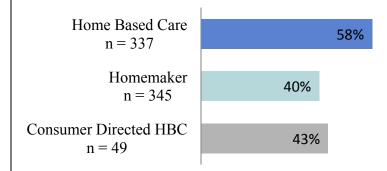
Approximately three quarters of the respondents from all three programs indicated that their primary care doctor **always** listened to them. Fifteen to 18% of respondents indicated that their doctor usually listened carefully to them.

A number of the open ended comments from survey respondents were from people who felt that their doctor was not listening to them.

SERVICE COORDINATION

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

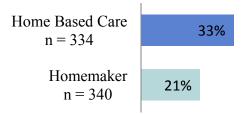
I would like my doctor to "formulate a care plan communicate and with all my specialists regularly and follow my problems. I feel as if I am managing my own care."



About four out of ten respondents on the Homemaker and Consumer Directed HBC programs said their doctors asked them about any services they need or were getting at home. A somewhat higher percentage of respondents on the Home Based Care Program (58%) said their doctors asked them about services they need or were getting at home.

In the last 6 months, did your primary care doctor or someone in the doctor's office make a referral for you for services in your home? (Yes Responses)

I would like my doctor to "help my family who is struggling to care for me and doing everything possible to keep me in my home as long as possible. A social worker in the office would be great."



Doctors are not a major source of referral for services in the home. Doctors made a referral for services in the home to about a third of the people on the Home Based Care Program and only about one fifth of the people receiving Homemaker services.

INFORMATION ABOUT HOME CARE SERVICES

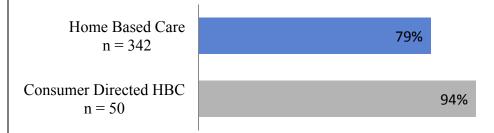
Table 8: How did you first hear about the services you receive?

	Home Based Care (n = 324)	Homemaker (n = 331)	Consumer Directed Home Based Care (n = 49)
	Percent	Percent	Percent
Family/Friend	20%	19%	20%
Goold	23%	11%	2%
EIM	6%	2%	0%
Alpha One	0%	1%	49%
Catholic Charities	1%	9%	0%
At the hospital	10%	7%	6%
Area Agency on Aging AAA ADRC	8%	7%	0%
DHHS	3%	2%	0%
Primary care doctor	10%	5%	2%
I can't remember	13%	20%	10%
Other	6%	18%	10%
Total	100%	100%	100%

Family and friends remain a strong source of referral to services. For people on the Home Based Care Program, Goold, the Assessing Services Agency, is the primary source of referral. For people using the Consumer Directed Home Based Care Program, Alpha One, the Center for Independent Living and a service coordination agency, is the major source of information/referral.

CARE MANAGMENT

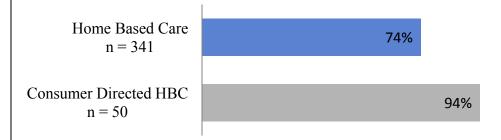
"I don't know who my case worker is. I called and left an automated message a couple of times but never got a call back." Do you know the name of your care manager or Independent Living Specialist? (Yes Responses)



About 80% of the people using the Home Based Care Services knew the name of their care manager. This compares with 94% of the people on the Consumer Directed HBC Program.

People receiving Homemaker services do not have care managers and thus are not reported here.

Can you talk to your care manager/Independent Living Specialist when you need to? (Yes Responses)



Three quarters of the people using Home Based Care reported they could talk with their care manager when they needed to compared with 94% of those using consumer directed home based care services.

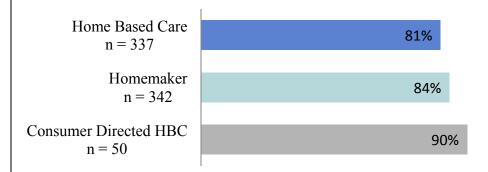
"I am having a hard time contacting my case worker."

NEEDS THAT ARE MET

"Extremely satisfied with Alpha One, would be devastated without their program."

"My care exceeds the number of allowable paid hours. My husband, and when needed my friends, provide the additional care that I need."

Do the services you receive at home meet your needs? (Yes Responses)



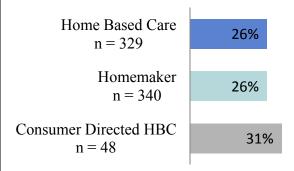
Approximately 8 out of 10 people receiving services on the Home Based Care and Homemaker programs felt the programs met their needs.

People using the Consumer Directed HBC program were more likely to feel that their needs were met (90%).

"Getting more hours a week. Not enough to do everything I need."

"As her sister I would like to have someone check on her at night time."

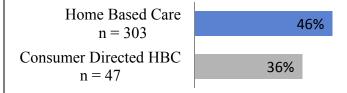
Do you have additional needs not being met by the program? (Yes Responses)



Approximately one out of four people on the Home Based Care and Homemaker Programs felt that they had needs that were not being met.

Almost a third of the people using the Consumer Directed HBC program indicated that they had additional needs that were not being met.

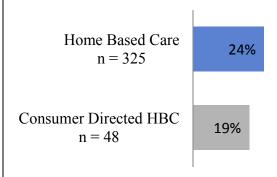
In the last 6 months, have you talked with your care manager about these needs? (Yes Responses)



Slightly less than half of the Home Based Care respondents and one-third of the Consumer Directed HBC respondents talked with their care managers about their unmet needs.

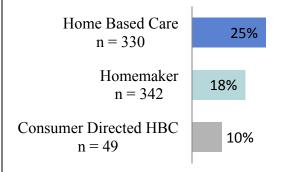
OTHER RESOURCES

In the last 6 months, has your care manager referred you to the Area Agency on Aging to learn about other services in your area? (Yes Responses)



The Area Agencies on Aging provide information and referral, options counseling, Meals on Wheels, Medicare Part D education, and caregiver support. Only 20-25% of the respondents had been referred by their care manager to anyone at their Area Agency on Aging in the last 6 months.

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



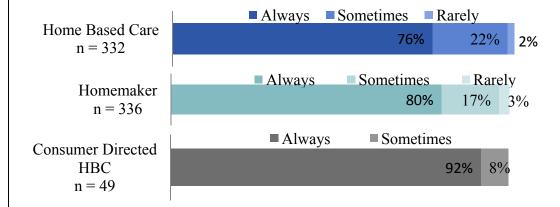
Similarly, only 20-25% of the people on the Homemaker Program and 10% of the people on the Consumer Directed HBC Program had contacted the Area Agency Aging.

WORKER PERFORMANCE

"I have an excellent worker. She does everything I need and anything reasonable that I ask her to do. She is always pleasant and very easy to talk to, I would recommend her to anybody and everybody."

"Excellent worker makes my life so much easier thank you for caring about Maine's Senior Citizens."

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



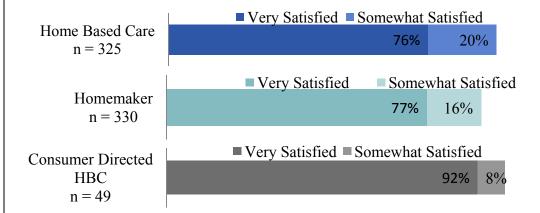
People using Consumer Directed HBC services report high levels of satisfaction with worker performance. Ninety-two percent (45 out of 49) people responded that the worker does things the way they want them done. This is compared with 76% and 80%, respectively, of people on the Home Based Care or Homemaker Programs who report that the worker always does things the way the consumer wants them done.

WORKER PERFORMANCE

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

"Worker who comes to help me is excellent."

"Absolutely Love the Alpha One Home-based care program, especially the fact that it allows the spouse to be the PCA when chosen."

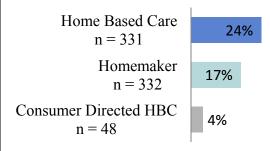


People on all three programs are generally satisfied with the workers who provide care. About three quarters of the people on the Home Based Care Program and the Homemaker Program report that they are very satisfied with their worker compared with 92% of the people on the Consumer Directed HBC Program.

The possible answers to the question were very satisfied, somewhat satisfied, neither satisfied or dissatisfied, somewhat dissatisfied and very dissatisfied. Less than 3% of the respondents on the Home Based Care Program and 2% of the respondents on the Homemaker Program indicated they were either somewhat dissatisfied or very dissatisfied with their worker.

WORKER PERFORMANCE

During the past 30 days, did the worker paid to help you not show up?



Almost a quarter of the respondents on Home Based Care reported that a worker did not show up at least once during the past 30 days. People using Consumer Directed Home Based Care reported that workers did not show up only 4% of the time in the last 30 days.

Table 9: If the worker did not show up, what did you do?

	Home Based Care (n = 224)	Homemaker (n = 354)	Consumer Directed Home Based Care (n = 23)
	Percent	Percent	Percent
Called family member	10%	4%	17%
Called neighbor or friend	4%	3%	9%
Called agency	19%	7%	13%
Went without help	25%	14%	9%
Other	9%	9%	4%

Among those getting home based care or homemaker services, the most common response was to go without help when a worker didn't show up. People using the Consumer Directed HBC program were more likely to call a family member or friend when a worker did not show up.

Surprisingly, less than 20% of the respondents called the agency when a worker did not show up.

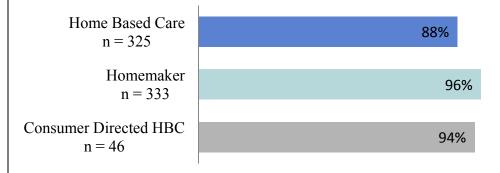
IN HOME MOBILITY AND ASSISTIVE DEVICES

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

"A handle on bathroom wall to help me in and out of shower".

"It is difficult for me to stretch enough to reach things high up in my cupboard & to bend over Info about getting aids to help with these problems would be very helpful."

"Hard to get out of house without ramp for my electric wheelchair".



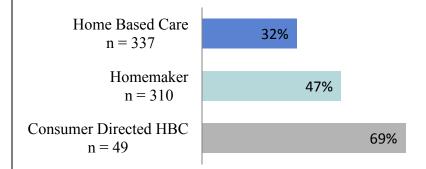
Although a high percentage of people indicated they could get around the house and get to the rooms and items they needed, there were a number of simple changes to the home that many mentioned would be helpful. These included lights that go on automatically when you enter the room, temperature controls and large numbers on the phone and TV. (See Table 10 on next page).

IN HOME MOBILITY AND ASSISTIVE DEVICES

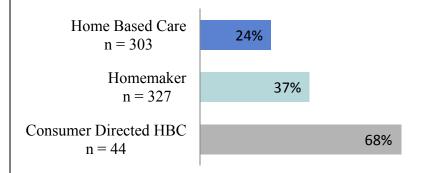
Table 10: Devices that were mentioned as Top 10			
Do not have device but think it would be helpful	Home Based Care	Homemaker	Consumer Directed HBC
Lights that go on automatically when you enter a room	✓	✓	✓
Temperature controls that change when it gets hotter or colder	✓	✓	✓
Large numbers on the telephone/easy to read TV controls	✓	✓	✓
Grab bars for getting out of bed /for shower/bathing	✓	✓	
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	✓		
An entrance ramp with no stairs	✓	✓	
Motorized wheelchair		✓	✓
Medication reminders/dispensers		✓	
Stair lift			✓
Video telephone computer/touch screen computer			✓
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 Homemaker and Consumer-directed Home Based Care both mention Emergency Response system which is not a covered service under these programs while it is covered, and not mentioned, under Home Based Care. All types of respondents mentioned 'lights that go on automatically when you enter a room'.

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)



People on the Consumer Directed HBC Program and Homemaker Programs, who tend to be younger, are much more likely to have and use a computer. People on the Home Based Care Program, who tend to be older and have greater needs, are less likely to have or use a computer.

Table 11: In the last 6 months, could you always get to the doctor's office when you needed to?

	Home Based Care (n = 327)	Homemaker (n = 338)	Consumer Directed HBC (n = 49)
	Percent	Percent	Percent
Never	1%	1%	2%
Usually	21%	25%	18%
Sometimes	11%	7%	4%
Always	66%	65%	63%
Did not go to the doctor's office	2%	3%	12%
Total	101%	101%	99%

Difficulty getting to the doctor's office was a frequent challenge reported by respondents. Approximately two-thirds of the respondents could always get to the doctor's office. About one-third of the respondents could usually/sometimes get to the doctor's office.

"I could use some help to get me to my doctors' appointments".

[&]quot;Need help with transportation to and from appointments and tests."

TRANSPORTATION

Table 12: How do you usually get to the doctor's office?

	Home Based Care (n = 300)	Homemaker (n = 289)	Consumer Directed Home Based Care (n = 46)
	Percent	Percent	Percent
Drive myself	10%	30%	17%
Family drives	60%	31%	30%
Friend drives	8%	8%	2%
Direct care worker drives	12%	6%	37%
Ride public transportation	2%	3%	0%
Use my regional transportation agency	1%	14%	2%
Other	6%	8%	11%
Total	100%	100%	100%

People on the Home Based Care Program have higher care needs and must rely more heavily on family members or their direct care workers to take them to doctors' appointments. About a third of people using the Homemaker Program can drive themselves to their doctors' appointments. People on the Consumer Directed Home Based Care Program rely heavily on their direct care workers for transportation.

Table 13: In the last 6 months, could you always get to the grocery store when you needed to?

	Home Based Care (n = 323)	Homemaker (n = 331)	Consumer Directed HBC (n = 48)
	Percent	Percent	Percent
Never	5%	2%	0%
Usually	15%	30%	19%
Sometimes	13%	18%	6%
Always	29%	42%	50%
Did not go to the grocery store	39%	9%	25%
Total	101%	101%	100%

Many people (40%) on the Home Based Care Program did not go to the grocery store in the prior six months. Instead they relied on family, friends or workers to go for them. About one quarter of the people on the Consumer Directed HBC program did not go to the grocery store.

"I have had a conversation with everyone (in the apartment where I live) and most agree our hardest thing is to get to the doctors or grocery store (without our own car."

"I have a hard time getting transportation. I have a hard time to just get to the grocery store."

TRANSPORTATION

Table 14: How do you usually get to the grocery store?

	Home Based Care (n = 300) Percent	Homemaker (n = 289) Percent	Consumer Directed Home Based Care (n = 46) Percent
Drive myself	8%	30%	15%
Family drives	43%	28%	26%
Friend drives	5%	11%	0%
Direct care worker PCA PSS drives	15%	13%	46%
Ride public transportation	2%	5%	0%
Use my regional transportation agency	1%	2%	0%
Other	26%	12%	13%
Total	100%	100%	100%

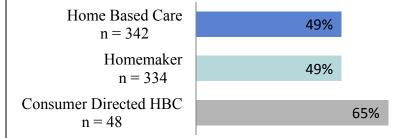
Family members and friends are the major sources of help with transportation to the grocery store. Almost half of the respondents on the Consumer Directed HBC Program rely on their direct care workers to take them to the grocery store.

In the last 30 days, did you participate in some type of social activity outside your home? (Yes Responses)

"I rarely leave my apartment except when I have to go to the doctor."

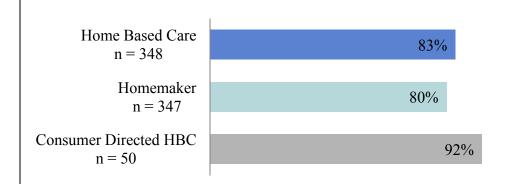
"Social activities are very rare."

"I get lonely at times and would love to socialize more."



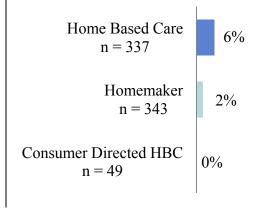
Almost half the people receiving Home Based Care services and Homemaker services did not participate in some type of social activity outside their house in the last 30 days.

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



Eight out of 10 people on the Home Based Care and Homemaker programs know who to call if they have a complaint. Nine out of 10 people on the Consumer Directed HBC program know who to call if they need to make a complaint.

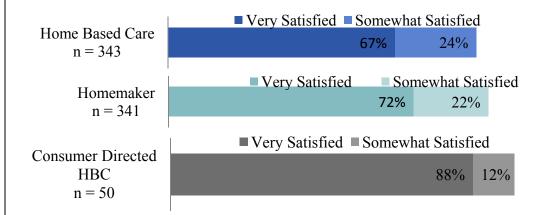
In the last 6 months, have you contacted anyone at the Long Term Care Ombudsman Program (LTCOP)? (Yes Responses)



"If we didn't have this service my wife, caregiver, would have had to give up by now and I would be in a nursing home. It has saved our marriage and everyday life at home."

"The services I receive in my home enable me to live independently. Don't know what I'd do without them!"

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



People are generally satisfied with the services they are receiving. Sixty-seven percent of people on the Home Based Care Program and 72% of the people on the Homemaker Program are very satisfied with their services. Over 90% of the respondents on these programs were either very satisfied or somewhat satisfied with their services

People on the Consumer Directed HBC Program report higher rates of satisfaction. Almost 90% report being very satisfied and 100% are either very satisfied or somewhat satisfied.

The possible responses to these questions were very satisfied, somewhat satisfied, neither satisfied or dissatisfied, somewhat dissatisfied and very dissatisfied. In the Home Based Care Program, less than 4% of respondents were either somewhat or very dissatisfied with services. In the Homemaker program, 2.6% of respondents were either somewhat or very dissatisfied with services

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

- I'm so thankful for this survey. I know someone will listen now!
- Thank you for the survey. I know that it is very helpful for you folks. I pray that you will be able to help others with their needs. I live independently in a senior citizen center so there are many things to do for fun.
- Thank you for all the assistance provided to me to allow me to remain in my home.
- Excellent worker makes my life so much easier. Thank you for caring about Maine's senior citizens
- Thank you so much. I am grateful you have such a program to offer us to be able to stay at home.
- I would not be able to live alone as I have for the past 2 years. I am moving into disability housing a week from now and there are grab bars in bathroom space to use my walker and eventually my wheelchair. This housing will make some areas of my life easier. Thank you for caring. May God bless you!
- Thank the Lord for the help I'm getting now. I am starting to breathe now that (name) is doing the dusting everyday along with all the other jobs she does. She takes care of my feet and legs.
- It's hard to live at home and see things we used to do and need to be done and we can't do but we are happy and thankful for everything that is being done.
- I am so very thankful for all the help I have received and very grateful for those willing to help people with needs like mine or worse. Sincerely!!

APPENDIX A: LISTENING SESSION BROCHURE

Community Listening Sessions

The Maine Long-Term Care Ombudsman Program will be holding community listening sessions with Maine seniors, family caregivers and consumers of long-term care services to hear from them about their experiences and ideas concerning:

- access to long-term care services
- gaps in services
- how services could be improved
- what is needed to support their independence in remaining at home
- their top quality of life concerns
- what their physicians can do to better support their health and care





Please join us at a community forum to discuss the issues that are so important to older and disabled citizens in Maine. Small discussion groups and refreshments will be available.

Meeting Dates, Locations, and Times

September 19 1:30-3:30 pm Muskie Center 38 Gold Street, Waterville

September 26 10 am-noon American Legion Hall 184 Congress Street, Rumford

September 27 10:00 am-noon VFW Hall 50 Mills Street, Waldoboro

September 28 10 am-noon University of Maine at Machias Kimball Hall, Portside Room 116 O'Brian Avenue, Machias October 3 1:30-3:30 pm Elks Club 13 Elm Street, Sanford

October 5 1:30-3:30 pm Presque Isle Inn Main Street, Presque Isle

October 7 9:15–11:15 am Bucksport Senior Center 125 Broadway, Bucksport

The Maine Long-Term Care Program is an advocacy program for long-term care consumers

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Together We Can Make A Difference!