Office of Aging and Adult Services

Long Term Personal Care Services

2009 Consumer Survey

1/24/2011

Table of Contents

Executive Summary	3
Key Findings from the Survey	3
Purpose	4
Methodology	4
Survey Instrument	5
Benchmarks	5
Characteristics of the sample	5
Survey Results	6
Interviewer comments and observations	6
Access	7
Service Planning and Delivery	9
Participation in Planning Services	9
Consumer Direction	10
Individual's needs are met: Medication	15
Services are responsive to the individual's changing needs	16
Qualified Providers	16
Health	19
Community & Social Connections	24
Employment/Day Supports	26
Housing	27
Rights, Responsibilities and Risk	29
Conclusion	30

Executive Summary

- The purpose of this report is to present the findings from an in-home survey of participants in the Long Term Personal Care Services (LTPCS) Program. This program provides services to support elderly and disabled adults in the community.
- All LTPCS recipients were considered for the initial sample population. However, those with high levels of cognitive impairment were excluded from the population from which the random sample was drawn.
- The survey was conducted in the summer of 2009 by an independent party on behalf of the Department of Health and Hospitals, Office of Aging and Adult Services.

Key Findings from the Survey

Access

• Seventy-six percent (76.1%) received information about the personal care agencies in their area.

Service Planning

- Almost seventy-nine (78.9%) reported that they helped to plan their personal care services.
- Twenty-seven percent (27.2%) reported that they would be interested in a consumer directed option.

Unmet Needs

- Nearly twenty percent (19.7%) of those interviewed reported that they were unable to complete a personal care task in the last 60 days because no one was there to help them. The tasks most often not performed were bathing and dressing.
- Fifteen percent (15.1%) of those interviewed reported that they were unable to complete a household task in the last 60 days because no one was there to help them. The task most often not performed was meal preparation.

Special Equipment

• Less than nineteen percent (18.7%) of those interviewed reported that that someone has discussed with them special equipment and\or home modifications that might make their life easier.

Workers

• Over ninety-seven percent of those interviewed reported that workers treat them respectfully (97.6%) and listen carefully (97.0%) to what is asked of them.

Informal Supports

 Seventy-five percent (75.0%) of those interviewed reported that they have family, friends or neighbors that help them.

Health

- Ninety-six percent (96%) of those interviewed reported that they have visited a doctor for a routine check-up within the past year.
- Only twenty-six percent (26%) of those interviewed reported that they have visited a dentist within the past year.

Employment

• Of those under age 65, thirteen percent (13.4%) are not currently employed and would like assistance finding a job.

Purpose

The purpose of the 2009 Consumer Survey was to find out about the experiences of consumers receiving services through the Long Term Personal Care Services (LTPCS) Program, a Medicaid State Plan Service. LTPCS program provides help with activities of daily living (ADL) and instrumental activities of daily living (IADL) to the elderly and persons with adult onset disabilities in their homes. LTPCS participants receive assistance with activities such as eating, bathing, dressing, grooming, transferring, walking or using a wheelchair, toileting, bed mobility, light housekeeping, food preparation and storage, shopping, laundry, medication reminders, help with medical appointments and help finding transportation to medical appointments.

The survey asks questions across multiple areas, including:

- Access to services
- Service planning and delivery
- Safety
- Health
- Qualified Providers
- Community and Social Connections
- Employment/Day Supports
- Housing
- Rights, Responsibilities and Risk

Methodology

The surveys were conducted by an independent contractor in the participant's home. All of the potential participants were mailed an announcement describing the purpose of the survey and inviting them to participate. Interviewers then called the LTPCS recipients to ask for permission to come into their home for the purpose of conducting the interview. The results of the survey were then entered into a data system by the interviewers for analysis by the Office of Aging and Adult Services (OAAS).

The LTPCS recipient count in the summer of 2009 was 9,038 individuals. Because of the length of the survey and the amount of recall expected from the clients, OAAS was concerned about

the recipients' ability to participate. For this reason, the recipients' most recent assessment (MDS-HC) was used to limit the sample. To be included in the potential survey population, memory, decision making, delirium, hearing, expression, and comprehension were all considered in excluding recipients with high levels of cognitive impairment. Those participants without any telephone numbers on file were also excluded from the survey for scheduling and logistic reasons.

Three hundred eighty (380) completed interviews were obtained; which provided the necessary statistical power to achieve a 95% confidence level with a 5% confidence interval.

Survey Instrument

The Participant Experience Survey (PES), developed by The MEDSTAT Group, Inc. for Centers for Medicare and Medicaid Services (CMS), was the core of the survey. In August 2003, CMS released the PES as a way to solicit feedback from HCBS waiver participants about the services that they receive. Louisiana contracted with the Muskie School to develop a set of questions relevant for the Louisiana LTPCS population. Additional questions were added to the PES survey in order to capture information about all of the following areas: access to services, service planning and delivery, qualified providers, safety, health, community and social connection, housing, employment\day supports, rights, responsibilities and risk.

Benchmarks

In order to compare the results found in the LTPCS survey to population norms we used Louisiana's 2008 Behavioral Risk Factor Surveillance System (BRFSS) Report. The BRFSS is a state-based system of health surveys that collect information on health risk behaviors, preventive health practices and health care access primarily related to chronic disease and injury¹. The population is a random sample selected from any non-institutionalized adult (age 18 or over) with a household land line telephone.

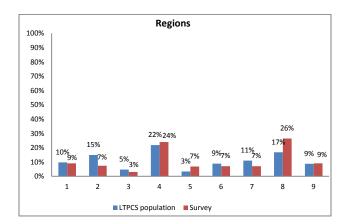
Though the BRFSS results are a year apart from the LTPCS results, it serves as a benchmark for the general population on a couple of survey questions. Comparison results are reported on body mass index as well as health screenings for men and women.

Characteristics of the sample

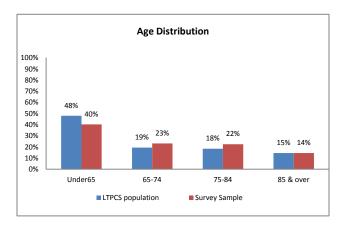
• Gender: Three-in-four (76.3%) among the survey participants were female compared to 73.9% of the total LTPCS population.

¹ http://www.dhh.louisiana.gov/offices/publications/pubs-245/BRFSS2008FINAL.pdf

- Age: Mean age for the survey participants was 67.7 compared to the LTPCS population mean age of 65.6 years old.
- Regions: Compared to the LTPCS population, the regional distribution of the sample was almost consistent with that of LTPCS population except for Region 2 and Region 8.



• Age group: Age distribution of the sample was consistent with that of the entire LTPCS population. Forty percent (40%) were under 65 years old while 60% were over 65.



Survey Results

Interviewer comments and observations

- The average time to complete the direct interview was thirty-two minutes. Eight-in-ten (80.3%) among the participants completed the direct interview within thirty-five minutes.
- The interviewers reported that, in their opinion, 86.8% of the participants appeared to understand most questions and 87.4% of the participants seemed to answer the questions in a consistent manner.

- The interviewers reported that 62.9% of the participants answered all the questions by themselves. The participant's child, home health care worker, parent, or spouse helped with answering the survey questions.
- A service provider was present at 21.8% of the interviews.

Access: Individuals have information about how to access the service system and what services are available

Survey Question 1: (n=380)

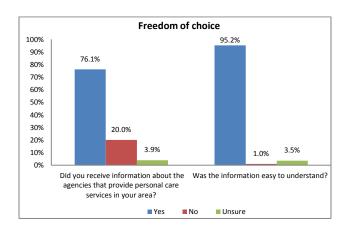
Did you receive information about the agencies that provide personal care services in your area?

Answer	Percentage
Yes	76.1%
No	20.0%
Unsure	3.9%

Survey Question 2: (n=288)

If yes, was the information easy to understand?

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Answer	Percentage
Yes	95.5%
No	1.0%
Unsure	3.5%



Survey Question 27: (n=372)

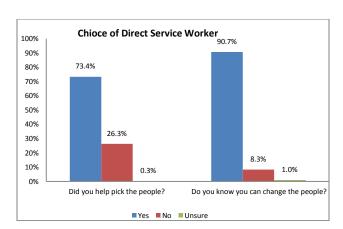
Did you help pick the people who are paid to help you?

Answer	Percentage
Yes	73.4%
No	26.3%
Unsure	0.3%

Survey Question 28: (n=97)

Do you know you can change the people who are paid to help you if you want to?

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Answer	Percentage)
Yes	90.7%	
No	8.3%	
Unsure	1.0%	



Service Planning and Delivery: Individuals have a choice of services, which are responsive to the individual's changing needs. The individuals are supported to learn to be independent and to participate in planning their services. Individuals' needs are met.

Participation in Planning Services

Survey Question 3: (n=380)

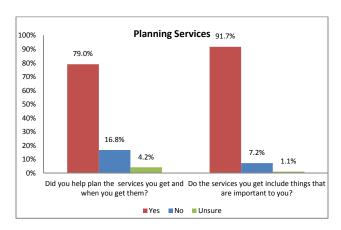
Did you help plan the personal care services you get and when you get them?

Answer	Percentage
Yes	79.0%
No	16.8%
Unsure	4.2%

Survey Question 4: (n=375)

Given your current situation and health status, do the services you get include things that are important to you?

Answer	Percentage
Yes	91.7%
No	7.2%
Unsure	1.1%



Consumer Direction

Survey Question 49a: (n=364)

There are programs that allow people to choose their own worker, who could be a friend or family member. You would train that person, set the hours he or she works, and manage that worker, rather than have an agency send someone to your home. Would you be interested in this option?

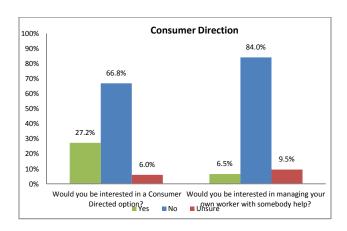
Answer	Percentage
Yes	27.2%
No	66.8%
Unsure	6.0%

Survey Question 49b: (n=232)

If not, would you be interested in managing your own worker if someone, maybe a friend or

family member, helped you with it?

Answer	Percentage
Yes	6.5%
No	84.0%
Unsure	9.5%



Individual's needs are met: Personal Tasks (ADL) & Household Tasks (IADL)

Survey Question 5: (n=380)

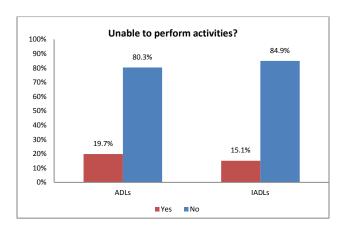
In the last 60 days, have you ever been unable to complete a personal care task such as bathing or dressing, because there was no one there to help?

Answer	Percentage
Yes	19.7%
No	80.3%

Survey Question 9: (n=377)

In the last 60 days, have you ever been unable to complete a household task, such as laundry or preparing food, because you didn't' have someone to help?

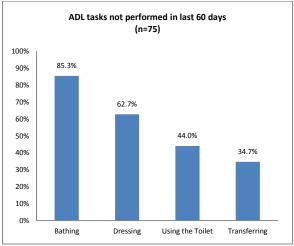
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Answer	Percentage
Yes	15.1%
No	84.9%



Survey Question 6: (ADLs n=75)

What tasks were you unable to do because there was no one to help?

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ADL(n=188)	Count	Percentage
Bathing	64	85.3%
Dressing	47	62.7%
Using the Toilet	33	44.0%
Transferring	26	34.7%
Eating	18	24.0%



Survey Question 7: (n=67)

Why was there no one there to help you?

(The total percentage is larger than 100%, because of multiple answers.)

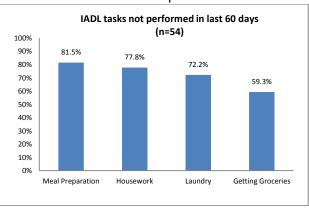
Answer	Percentage
Worker did not show up and no replacement was sent	3.0%
No family or friends available	16.4%
Worker was late	1.5%
Other	82.1%

Of the 67 respondents, eighty-two percent answered 'Other' to this question. When asked further to explain they responded with details such as 'limited hours for worker' or 'worker off' and some simply answered 'need more help or assistance'.

Survey Question10: (IADLS n=54)

What tasks were you unable to do because there was no one to help?

IADLs(n=54)	Percentage
Meal Preparation	81.5%
Housework	77.8%
Laundry	72.2%
Getting Groceries	59.3%



Survey Question 11 (n=48)

Why was there no one to help you?

(The total percentage is larger than 100%, because of multiple answers.)

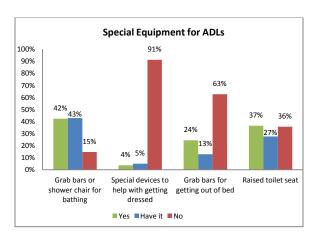
Answer	Percentage
Worker did not show up and no replacement was sent	8.3%
No family or friends available	12.5%
Other	81.3%

Of the 48 respondents, eighty-one percent answered 'Other' to this question. When asked further to explain they responded with details such as 'limited hours for worker' and 'help needed at night'.

Survey Question 8: (n=380)

Would any of the following special equipment make it easier for you to complete personal care tasks?

Special Equipment for ADLs	Yes	Have it	No
Grab bars or shower chair for bathing	42.4%	42.9%	14.7%
Special devices to help with getting dressed	3.7%	5.0%	91.3%
Grab bars for getting out of bed	24.5%	12.9%	62.6%
Raised toilet seat	36.6%	27.6%	35.8%



Survey Question 12 (n=43)

Is there any special equipment or other things that would make it easier to complete household tasks when there is no one there to help? This was an opened question; the most frequent responses mentioned were "Wheelchair", "lift chair", "Walker".

Individual's needs are met: Medication

Survey Question 14: (n=373)

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

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Answer	Percentage
Yes	66.5%
No	33.5%

Survey Question 15: (n=238)

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

Answer	Percentage
Yes	11.3%
No	84.7%

Survey Question 16: (n=25)

Is this because there is no one there to help you?

Answer	Percentage
Yes	68%
No	32%

Individual's needs are met: Special equipment

Survey Question 21: (n=374)

Has anyone ever talked to you about any special equipment, or changes to your home that might make your life easier?

Answer	Percentage
Yes	18.7%
No	78.6%
Unsure	2.7%

Survey Question 22(n=70)

What equipment or changes did you talk about? This was an open ended question; the responses included things like bathroom equipment and modifications, hospital bed, wheelchair, walker, ramps, shower chair, and grab bars.

Survey Question 23a: (n=66)

Did you get the equipment or make the changes you needed?

Answer	Percentage
Yes	44.0%
No	54.5%
Unsure	1.5%

Survey Question 23b: (n=16)

If yes, did someone explain to you how to use the equipment or make the changes?

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Answer	Percentage
Yes	87.5%
No	12.5%

Services are responsive to the individual's changing needs

Survey Question 24: (n=374)

In the past 6 months has the type of help you need changed?

Answer	Percentage
Yes	28.3%
No	70.6%
Unsure	1.1%

Survey Question 25: (n=98)

If your needs changed, did the number of hours of service or the type of service change?

Answer	Percentage
Yes	28.6%
No	68.4%
Unsure	3.0%

Survey Question 26: (n=39)

Were you satisfied with the change in services?

Answer	Percentage
Yes	38.5%
No	61.5%

Qualified Providers: the workforce is consistent, stable and competent

Survey Question 17: (n=373)

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

Answer	Percentage
Yes	94.9%
No	5.1%

Survey Question 18a: (n=375)

In the past 3 months, have you felt unsafe because you did not have a worker present?

Answer	Percentage
Yes	16.0%
Sometimes	7.5%
No	76.5%

Survey Question 18b: (n=53)

Please tell me more about this?

There was much variation thus it was hard to categorize. Some complained that workers hours were limited, while others needed the life alert pendant. A lot of participants were afraid to be alone and afraid of falling.

Survey Question 29: (n=372)

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

Answer	Percentage
Yes	90.0%
Sometimes	5.1%
No	4.6%
Unsure	0.3%

Survey Question 30: (n=14)

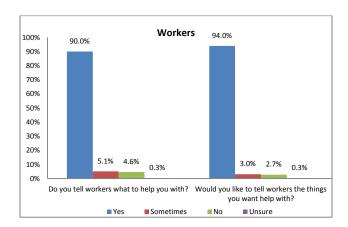
Would you like to tell them the things you want help with?

Answer	Percentage
Yes	35.7%
Sometimes	14.3%
No	42.9%
Unsure	7.1%

Survey Question 31: (n=372)

Do they do things the way you want them to be done?

Percentage
94.0%
3.0%
2.7%
0.3%



Survey Question 34: (n=371)

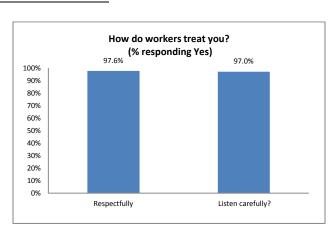
Do the people paid to help you treat you respectfully in your home?

Answer	Percentage
Yes	97.6%
Sometimes	1.3%
No	1.1%

Survey Question 35: (n=367)

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

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Answer	Percentage
Yes	97.0%
No	1.9%
Unsure	1.1%

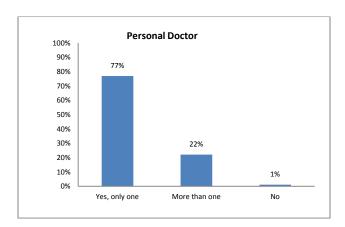


Health: Individuals have the best possible health

Survey Question 59: (n=376)

Do you have one person you think of as your personal doctor or health care provider?

Answer	Percentage
Yes, only one	77%
More than one	22%
No	1%



Survey Question 63& 64: (n=334)

How much do you weigh without shoes? How tall are you without shoes? Body Mass Index (BMI) is a way to estimate an individual's relative body fat. It measures the relationship between weight and height. The BMI is grouped into Underweight, Normal, Overweight and Obese categories. If your BMI is too high, you are at an increasing risk for many health problems.

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Result	Percentage
Underweight	4.5%
Normal	20.4%
Overweight	24.9%
Obese	50.2%

Louisiana's 2008 BRFSS results for the population overall was at 27.6% compared to that of the LTPCS population at 50.2%. This appears to be a major problem in this program. It is important to remember that there are differences in the two populations, those served by the LTPCS program are either elderly or have an adult onset physical disability which limits their ability to perform daily activities at a level equal to that of Nursing Facility admission requirements. Even with the differences among populations, the high results on BMI are of concern. Higher BMI increases your risk of for many chronic health conditions.

Survey Question 60: (n=60)

How long has it been since you last visited a doctor for a routine checkup? A routine check-up is a general physical exam, not an exam for a specific injury, illness or condition.

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Answer	Percentage
Within past year	96%
Within past 2 years	2%
Over 2 years\not sure	2%

Survey Question 61: (n=380)

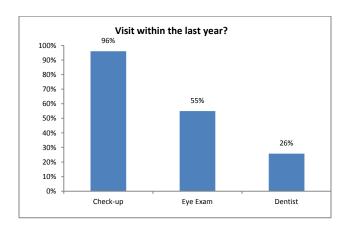
When was the last time you had your eyes examined by any doctor or eye care provider?

Answer	Percentage
Within past year	55%
Within past 2 years	18%
Over 2 years	25%
Never\not sure	2%

Survey Question 62: (n=380)

How long has it been since you visited a dentist or dental clinic for any reason? Include visits to dental specialists or orthodontists?

Answer	Percentage
Within past year	26%
Within past 2 years	10%
Over 2 years	60%
Never\not sure	4%



Survey Question 65 (Only for women): (n=290)

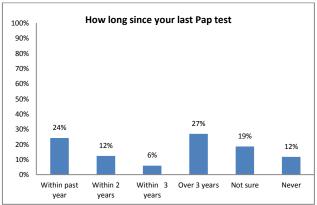
A Pap test is a test for cancer of the cervix. Have you ever had a Pap test?

Answer	Percentage
Yes	85%
No	11%
Not Sure	4%

Survey Question 66 (n=290)

How long has it been since your last PAP test?

Answer	Percentage
Within past year	24%
Within 2 years	12%
Within 3 years	6%
Over 3 years	27%
Not sure	19%
Never	12%



Forty-two percent (42%) of LTPCS women reported having a PAP test within the last 3 years. This result was lower than that of the 2008 BRFSS (74.4%). When limiting the results to only those women 65 and over there was again disparity in the results. BRFSS indicated that 57.2% of Louisiana women age 65 and over have had a PAP screening in the previous 3 years, while only thirty percent (30%) of LTPCS women 65 and over reported having one.

Survey Question 67(Only for men aged 40 years and older): (n=72)

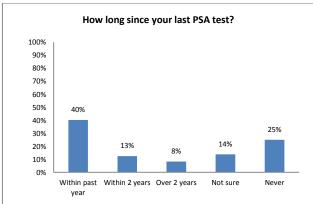
A Prostate-specific Antigen test, also called PSA test, is a blood test used to check men for prostate cancer. Have you ever had a PSA test?

Answer	Percentage
Yes	67%
No	25%
Not sure	8%

Survey Question 68: (n=72)

How long has it been since you had your last PSA test

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Answer	Percentage
Within past year	40%
Within 2 years	13%
Over 2 years	8%
Not sure	14%
Never	25%



Fifty-three percent of LTPCS men ages 40 and above reported having a PSA test within the last 2 years. This result was roughly the same as that of the 2008 (46.9%) which is reported on men age 35 and over.

Safety: Exploitation and Abuse by Direct Service Providers

Survey Question 36: (n=372)

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

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Answer	Percentage
Yes	0.3%
No	99.2%
Unsure	0.5%

Survey Question 38: (n=321)

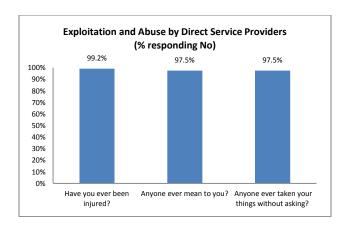
Are any of the people paid to help you now mean to you, or do they yell at you?

Answer	Percentage
Yes	1.3%
Sometimes	0.9%
No	97.5%
Unsure	0.3%

Survey Question 40: (n=324)

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

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Answer				Percentage
Yes				1.9%
No				97.5%
Unsure				0.6%



Community & Social Connections: Individuals have meaningful relationships and have access to the community

Survey Question 13: (n=378)

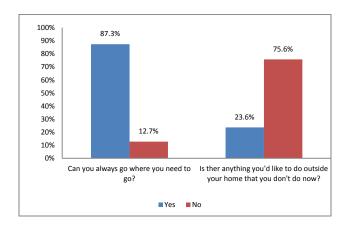
Can you always get to the places you need to go, like work, shopping, the doctor's office, or a friend's house?

Answer	Percentage
Yes	87.3%
No	12.7%

Survey Question 42: (n=365)

Given your current situation and health status, is there anything you want to do outside your home that you don't do now?

Answer	Percentage
Yes	23.6%
No	75.6%
Unsure	0.8%



Survey Question 43: (n=86)

What would you like to do? What do you need to make this happen?

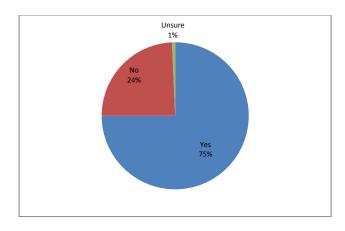
Some respondents wanted to work in the yard or go outside, others were concerned about going to church or going shopping, while others liked to visit friends or family. Transportation and wheelchair were often responses for how to make this happen.

Survey Question 19: (n=294)

Do you have family, friends or neighbors who help you? For example, with things such as

shopping, transportation, or meals?

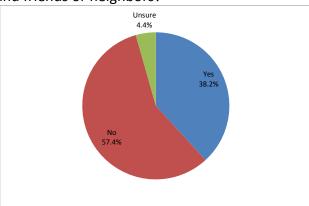
Answer	Percentage
Yes	74.8%
No	24.5%
Unsure	0.7%



Survey Question 20: (n=68)

If not, would you like help from family and friends or neighbors?

Answer	Percentage
Yes	38.2%
No	57.4%
Unsure	4.4%



Employment/Day Supports: Individuals have a choice of employment

Survey Question 44: (n=149)

Are you working right now (under 65 only)?

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Answer	Percentage	
Yes	0.7%	
No	99.3%	

Survey Question 48a: (n=131)

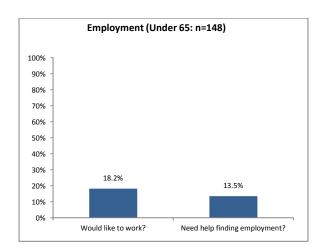
Given your current situation and health status, do you want to work?

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Answer	Percentage
Yes	19.9%
No	78.6%
Unsure	1.5%

Survey Question 48b: (n=25)

Would you like help finding work?

Answer	Percentage
Yes	80.0%
NO	8.0%
Unsure	12.0%



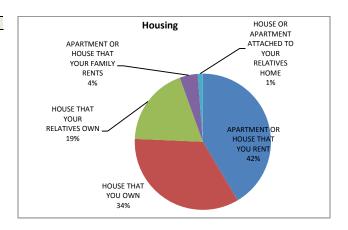
From this series of employment-related questions, 13.5% of those participants under 65 years old would like help finding work.

Housing: Individuals choose where they live

Survey Question 50: (n=345)

What kind of housing do you live in?

Answer	Percentage
Apartment or house that you rent	41.5%
House that you own	34.2%
House that your relatives own	18.8%
House that your family rents	4.3%
House attached to your relatives home	1.2%



Survey Question 51: (n=369)

Are you living in your preferred housing arrangement?

Answer		Percentage
Yes		90.2%
No		9.5%
Unsure		0.3%

Survey Question Q52: (n=35)

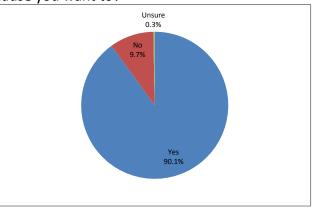
If not, what kind of housing would you prefer?

Answer	Percentage
House that you own	34%
Apartment or house that you rent	25%
Assisted living	9%
House or apartment attached to your relatives home	9%
House that your relatives own	3%
Unsure	3%
Other	17%

Survey Question 58: (n=362)

Do you live in this neighborhood because you want to?

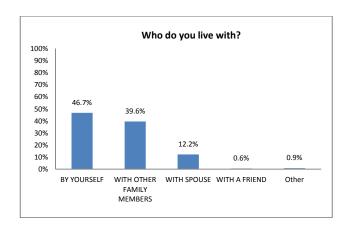
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Answer	Percentage
Yes	90.0%
No	9.7%
Unsure	0.3%



Survey Question 53a: (n=336)

Who do you	live with now?	
Anguer		ב

Answer	Percentage
By yourself	46.7%
With other family members	39.6%
With spouse	12.2%
With a friend	0.6%
Other	0.9%



Survey Question 53b: (n=157)

If living by yourself, do you prefer to live by yourself?

Answer	Percentage
Yes	85.4%
No	14.6%

Survey Question 54: (n=163)

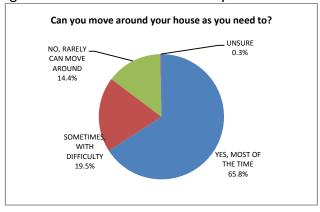
If living with others, do you live with people you prefer to live with?

Answer	Percentage
Yes	97.5%
No	2.5%

Survey Question 56: (n=319)

Can you move around your house and get to the rooms and items that you need?

Answer	Percentage
Yes, most of the time	65.8%
Sometimes, with difficulty	19.5%
No, rarely can move around	14.4%
Unsure	0.3%



Survey Question 57: (n=373)

What do you not have that would help you (either in terms of equipment or home modifications) move around your house more easily or get items that you need? (The total percentage is larger than 100%, because of multiple answers.)

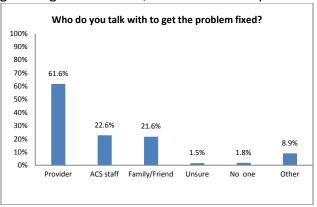
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Answer	Percentage
Chairlift, ramp or elevator	17%
An entrance with no stairs	10%
Wider doorways	9%
Better handles on doors and faucets	5%
Different bed	4%
Stair rails on both sides of stairway or steps	6%
Walker/Cane	5%
None of the above	62%
Other	8%

Rights, Responsibilities and Risk: Individuals have and exercise their rights

Survey Question 32: (n=380)

If there is something wrong with the help you are getting, who do you talk with to get the problem fixed? (The total percentage is larger than 100%, because of multiple answers.)

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Answer	Percentage
Provider	61.6%
ACS staff	22.6%
Family/Friend	21.6%
Unsure	1.6%
No one	1.8%
Other	6.3%



Survey Question 33: (n=352)

Do you know who to call to make a formal complaint?

Answer	Percentage
Yes	73.3%
No	22.7%
Unsure	4.0%

If yes, who? Participants often responded with the agency or director. Some simply named a family member or their provider.

Conclusion

The Office of Aging and Adult Services (OAAS) would like to thank all of the recipients that participated in this survey. It is the goal of OAAS to develop and provide services that offer meaningful choices for persons in need of long term care. We are committed to developing a system that provides choice, ensures quality, and meets the needs of consumers and caregivers. The findings from the survey are vital to meeting these goals. This report can inform administrators of the areas that are working well and of those that need improvements.

The survey results showed that 91.7% reported that these services include things that are important to them. Ninety-four percent (94%) reported that the LTPCS worker does things the way they want them done and 97.6% report that the worker treats them respectfully.

Some areas for improvement are visible as well. Almost 20% have experienced times where they could not perform a personal task because no one was there to help them. Less than 19% report that someone has discussed special equipment or home modifications with them. Although LTPCS does not provide funding for home modifications, there are other possible community resources that could be discussed or durable medical equipment through the Medicaid State Plan. This is an area for improvement on the part of OAAS to make referrals to community resources when appropriate. In the area of health, only 26% of those interviewed reported that they have seen a dentist in the past year. Finally, only 73.3% reported that they knew who to call to make a formal complaint.

One interesting finding from the survey was that 27% of participants indicated an interest in a consumer directed option. Consumer direction is a program that allows the participant to choose their own worker; this could be a family member or a friend. The participant would interview and train the worker, agree on a payment rate and set the hours for them to come into their home. This is in contrast to a typical agency model where the provider agency hires someone and sends them to the participant's home.

The purpose of this survey was to find out about the experiences of those receiving services through the LTPCS program. This is the first consumer survey for this program and has provided a wealth of information to the OAAS.