Department of Health and Hospitals Office of Aging and Adult Services

2011 Consumer Survey

Elderly and Disabled Adults Waiver

1/30/2012

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Executive Summary

- The purpose of this report is to present the findings from an in-home survey of
 participants in the Elderly and Disabled Adult Waiver (EDA) Program. This waiver
 provides services to support elderly and disabled adults in the community.
- All EDA 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 2011 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

• Ninety-one percent (91.1%) received information from their support coordinator about the personal care agencies in their area.

Service Planning

- Ninety-two percent (91.9%) reported that they helped to plan their personal care services.
- Twenty-four percent (24.2%) reported that they would be interested in a consumer directed option.

Unmet Needs

- Almost five percent (4.7%) 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.
- Three percent (3.1%) 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

• Forty-nine percent (48.7%) 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-three percent report of those interviewed reported that workers treat them respectfully (96.4%) and listen carefully (93.8%) to what is asked of them.

Informal Supports

• Eighty-nine percent (88.8%) of those interviewed reported that they have family, friends or neighbors that help them.

Health

- Ninety-eight percent (98.3%) 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, only eight percent (8.5%) are not currently employed and would like assistance finding a job.

Purpose

The purpose of the 2011 Consumer Survey was to find out about the experiences of consumers receiving services through the Elderly and Disabled Adults (EDA) Waiver. EDA provides certain services in the home or community to elderly or persons with adult onset disabilities who qualify. Services include support coordination, transitional services (for those transitioning from an institutional setting into the community), personal assistance service (help with personal and household tasks such as bathing and meal preparation), environmental accessibility adaptations (home modifications), personal emergency response system (life alert pendant), and adult day health care services.

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 EDA 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 EDA recipient enrollment in the Spring\Summer of 2011 was 4,525 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 a telephone number on file were also excluded from the survey for scheduling and logistic reasons.

The final response rate was 40% with 358 completed interviews 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 EDA 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.

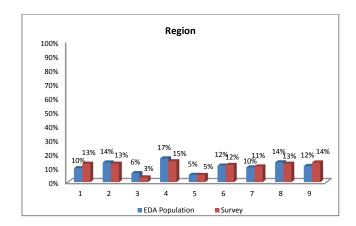
Benchmarks

In order to compare the results found in the EDA survey to population norms we used Louisiana's 2010 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 injury. The population is a random sample selected from any non-institutionalized adult (age 18 or over) with a household land line telephone.

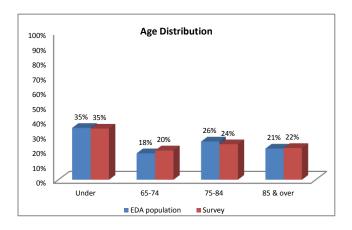
Though the BRFSS results are two years apart from the EDA results, it serves as a benchmark for the general population on a couple of survey questions. Comparison results are reported on body mass index as well as health screenings for men and women.

Characteristics of the sample

- Gender: Sixty-seven (67.7%) among the survey participants were female compared to 72 % of the total EDA population.
- Age: Mean age for the survey participants was 70.2 compared to the EDA population mean age of 69.8 years old.
 - Regions: Compared to the EDA population, the regional distribution of the sample was almost consistent with that of EDA population.



Age group: Age distribution of the sample was consistent with that of the entire EDA population. Almost thirty-five percent (34.6%) were under 65 years old while 63.4% were over 65. A larger portion of individuals under 65 and a smaller portion from the over 85 age group participated in the survey. This is most likely due to the pre-screening on cognition levels and the associated higher levels of cognitive impairment among the oldest age group.



Survey Results

Interviewer comments and observations

• The average time to complete the direct interview was thirty-two minutes. Seventy-nine percent (78.8%) among the participants completed the direct interview within thirty-five minutes.

- The interviewers reported that 77.1% of the participants appeared to understand most questions and 77.7% of the participants seemed to answer the questions in a consistent manner.
- The interviewers reported that 36.6% of the participants answered all the questions by themselves. When assistance was needed, the participant's child, home health care worker, parent, sibling or spouse helped with answering the survey questions.
- A service provider was present at 51.4% of the interviews.

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

Survey Question 1: (n=358)

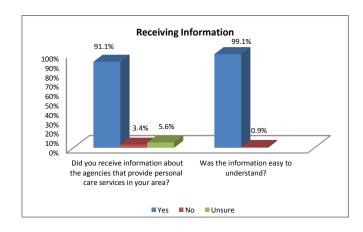
Did your support coordinator give you information about the agencies that provide services in your area?

Answer	Percentage
Yes	91.1%
No	3.4%
Unsure	5.6%

Survey Question 2: (n=324)

If yes, was the information easy to understand?

Answer	Percentage
Yes	99.1%
No	0.9%



Survey Question 27: (n=357)

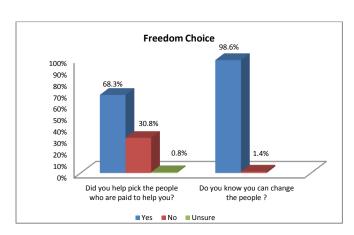
Do you help pick the people who are paid to help you?

Answer	Percentage
Yes	68.3%
No	30.9%
Unsure	0.8%

Survey Question 28: (n=356)

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

Answer	Percentage
Yes	98.6%
No	1.4%



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=357)

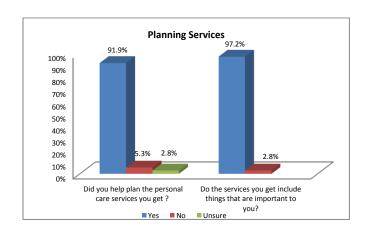
Did you help plan the services you get and when you get them?

Answer	Percentage
Yes	91.9%
No	5.3%
Unsure	2.8%

Survey Question 4: (n=353)

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

Answer	Percentage
Yes	97.2%
No	2.8%



Consumer Direction

Survey Question 53a: (n=356)

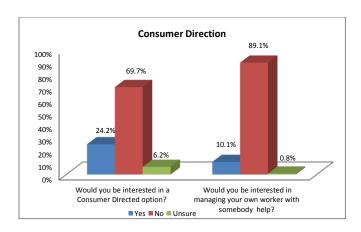
There are programs that allow people to choose their own worker, who could be a friend or family member. You would train that person, set the hours he or she works, and manage that worker, rather than have an agency send someone to your home. Would you be interested in this option?

Answer	Percentage
Yes	24.2%
No	69.7%
Unsure	6.1%

Survey Question 53b: (n=248)

If not, would you be interested in managing your own worker if someone helped you with it?

Answer	Percentage
Yes	10.1%
No	89.1%
Unsure	0.8%



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

Survey Question 5: (n=358)

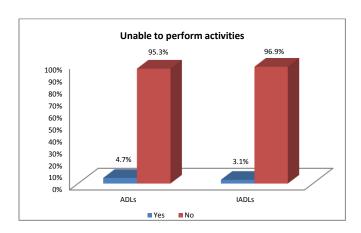
In the last 60 days, have you ever been unable to complete a personal care task such as bathing or dressing, because there was no one there to help?

Answer	Percentage
Yes	4.7%
No	95.3%

Survey Question 9: (n=358)

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?

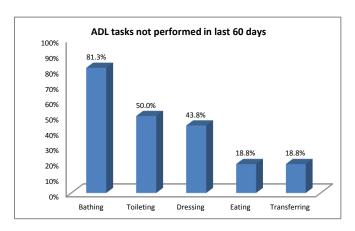
Answer	Percentage
Yes	3.1%
No	96.9%



Survey Question 6: (ADLs n= 17)

What personal care tasks were you unable to do because there was no one to help? (The total percentage is larger than 100%, because of multiple answers.)

ADL(n=16)	Count	Percentage
Bathing	13	81.3%
Toileting	8	50.0%
Dressing	7	43.8%
Eating	3	18.8%
Transferring	3	18.8%



Survey Question 7: (n=17)

Why was there no one there to help you?

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

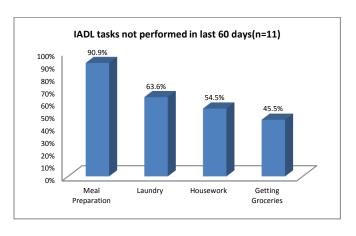
Answer	Count	Percentage
Worker didn't show up and no replacement was sent	3	17.6%
Worker called in sick	1	5.9%
Worker was late	1	5.9%
No family or friends available	4	23.5%
Other	10	58.8%

Of the 17 respondents, fifty-nine(59%) percent answered 'Other'. The most frequent responses reported in the 'Other' category were "worker gone for the day", "no worker on Sunday", and "needed help between assigned shifts".

Survey Question 10: (IADLS n=11)

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

IADLs(n=11)	Count	Percentage
Meal Preparation	10	90.9%
Laundry	7	63.6%
Housework	6	54.5%
Getting Groceries	5	45.5%



Survey Question 11 (n=11)

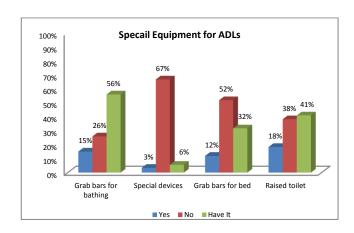
Why was there no one to help you?

Of the 11 respondents, about twenty-seven percent (27%) answered 'Worker didn't show up and no replacement was sent 'and sixty-seven percent (73%) answered 'Other'. The most frequent responses mentioned in the 'Other' category were "worker left for the day", "only has two hours services in evenings", and "worker often takes breaks".

Survey Question 8: (n=358)

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

ADL Special Equipment	Yes	No	Have It
Grab bars for bathing	15%	26%	56%
Special devices	3%	67%	6%
Grab bars for bed	12%	52%	32%
Raised toilet	18%	38%	41%



Survey Question 12 (n=15)

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 and only 15 responded; the most frequent responses mentioned were "shower chair", "walk-in shower", "rolling tray", "larger bathroom"," emergency button", "lift" and "grab bar".

Individual's needs are met: Medication

Survey Question 14: (n=357)

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

Answer	Percentage
Yes	73.7%
No	26.3%

Survey Question 15: (n=261)

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

Answer	Percentage
Yes	4.2%
No	95.8%

Individual's needs are met: Special equipment

Survey Question 21: (n=343)

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

Answer	Percentage
Yes	48.7%
No	51.3%

Survey Question 22(n= 167)

What equipment or changes did you talk about? This was an open ended question; the responses included things like bathroom equipment and modifications, handicapped bathroom, shower chair, wheelchair, walker, ramps, lift chair, walk-in tub, grab bars and personal emergency response system.

Survey Question 23a: (n=161)

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

Answer		Percentage
Yes		63.4%
No		34.2%
Unsure		2.5%

Survey Question 23b: (n=105)

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

changes?

Answer	Percentage
Yes	93.3%
No	6.7%

Services are responsive to the individual's changing needs

Survey Question 24: (n=357)

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

Answer	Percentage	
Yes	19.6%	
No	80.4%	

Survey Question 25: (n= 70)

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

Answer	Percentage
Yes	24.3%
No	75.7%

Survey Question 26: (n=17)

Were you satisfied with the change in services?

Answer	Percentage
Yes	82.4%
No	17.6%

Qualified Providers: the workforce is consistent, stable and competent

Survey Question 17: (n=357)

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	94.4%
No	5.6%

Survey Question 18a: (n=357)

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

Answer	Percentage
Yes	7.8%
No	81.2%
Sometimes	10.9%

Survey Question 18b: (n=59)

Please tell me more about this?

This was an open ended question. Some complained worker absence, while others felt lonely, anxious or scared. A lot of participants were afraid of falling.

Survey Question 29: (n=358)

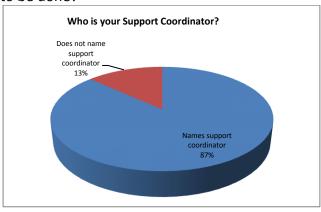
Thinking again about the people who are paid to help you, do you tell them what to help you with?

Answer	Percentage
Yes	91%
No	2%
Sometimes	6%

Survey Question 31: (n=358)

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

Answer	Percentage
Yes	93.6%
No	1.7%
Sometimes	4.7%



Survey Question 34: (n=355)

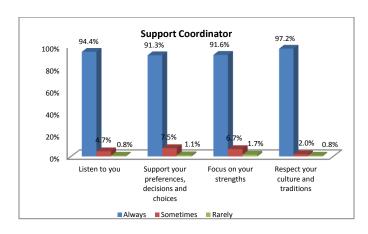
Who is your support coordinator?

Answer	Percentage
Names support coordinator	86.8%
Does not name support coordinator	13.2%

Survey Question 34a: (n=358)

Thinking about the meetings with your Support Coordinator, and the people who support you, dose your Support Coordinator:

Support Coordinator's attitude	Always	Sometimes	Rarely
Listen to you	94.4%	4.7%	0.8%
Support your preferences, decisions and choices	91.3%	7.5%	1.1%
Focus on your strengths	91.6%	6.7%	1.7%
Respect your culture and traditions	97.2%	2.0%	0.8%



Survey Question 35: (n= 357)

Can you talk your Support Coordinator when you need to?

Answer	Percentage
Yes	83.2%
No	0.8%
Sometimes	2.0%
Unsure	1.4%
Not applicable - have not tried	12.6%

Survey Question 35a: (n=357)

When you call your Support Coordinator, they respond within-

Answer	Percentage
Less than a day	58.0%
Less than a week	3.4%
Less than a month	1.1%
Unsure	1.7%
Not applicable - have not tried	35.9%

Survey Question 36: (n=357)

Does your support coordinator help you when you ask for something?

Answer	Percentage
Yes	73.4%
No	1.1%
Sometimes	6.7%
Unsure	1.4%
Not applicable - have not asked	17.4%

Survey Question 36a: (n=355)

Does your Support Coordinator respond to your health or safety needs?

Answer	Percentage
Yes	84.2%
No	1.4%
Sometimes	2.8%
Unsure	1.4%
Not applicable - have not asked	10.1%

Survey Question 37: (n=355)

Does your support coordinator treat you with respect?

Answer	Percentage
Yes	98.0%
No	1.4%
Sometimes	0.3%
Unsure	0.3%

Survey Question 37a: (n=356)

How satisfied are you with your Support coordinator?

Answer	Percentage
Very satisfied	77.0%
Satisfied	19.9%
Dissatisfied	1.7%
Unsure	1.4%

Survey Question 38: (n=357)

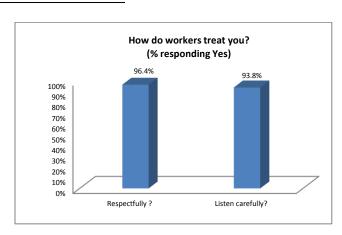
Do the people paid to help you treat you respectfully in your home?

Answer	Percentage
Yes	96.4%
No	1.1%
Sometimes	2.5%

Survey Question 39: (n= 357)

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	93.8%
No	1.7%
Sometimes	4.5%



Survey Question 29: (n=358)

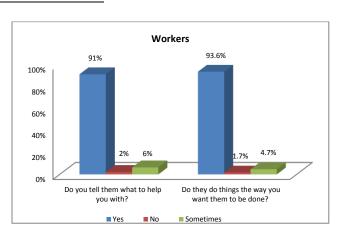
Thinking again about the people who are paid to help you, do you tell them what to help you with?

Answer	Percentage
Yes	91%
No	2%
Sometimes	6%

Survey Question 31: (n=358)

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

Answer	Percentage
Yes	93.6%
No	1.7%
Sometimes	4.7%

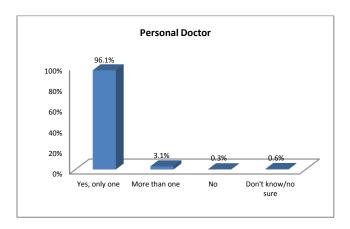


Health: Individuals have the best possible health

Survey Question 63: (n=358)

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

Answer	Percentage
Yes, only one	96.1%
More than one	3.1%
No	0.3%
Don't know/no sure	0.6%



Survey Question 67& 68: (n=301)

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.

Answer	Percentage
Under weight	4.7%
Normal	22.9%
Over weight	28.6%
Obese	43.9%

Louisiana's 2010 BRFSS results for the population of obese overall was 31.7% compared to that of the EDA survey at 43.9%. This appears to be a major problem among waiver participants and is important due to potentially higher risks obesity can increase the likelihood of various diseases, particularly heart disease, type 2 diabetes, obstructive sleep apnea, certain types of cancer, and osteoarthritis. The results showed some disparity among gender, seventy-seven percent of female EDA participants reported they are obese compared to twenty-three percent of male participants.

Survey Question 64: (n=358)

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.

Answer	Percentage
Within past year	98.3%
Within past 2 years	1.4%
Don't know / not sure	0.3%

Survey Question 65: (n=358)

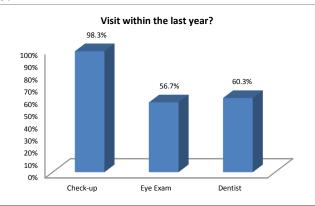
When was the last time you had your eyes examined by any doctor or eye care provider?

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Answer	Percentage	
Within past year	56.7%	
Within past 2 years	14.5%	
More than 2 years	27.9%	
Never/not sure	0.8%	

Survey Question 66: (n=358)

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	26.0%
Within past 2 years	10.6%
More than 2 years	60.3%
Never/not sure	3.1%



Survey Question 69 (only for women): (n=80)

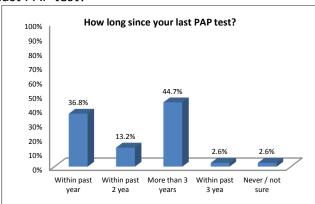
A Pap test is a test for cancer of the cervix. Have you ever had a Pap test?

Answer	Percentage
Yes	95.0%
No	5.0%

Survey Question 70: (n=76)

How long has it been since your last PAP test?

Answer	Percentage
Within past year	36.8%
Within past 2 years	13.2%
More than 3 years	44.7%
Within past 3 years	2.6%
Never / not sure	2.6%



Almost forty-five (44.59%) percent EDA women 21 to 64 of age reported having a PAP test within the last three years. This result was lower than that of the clinical guidelines from HEDIS measures (67.2%).

Survey Question 71 (only for men aged 40 and older): (n=100)

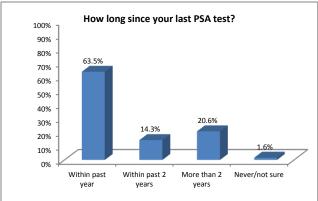
A Prostate-specific Antigen test, also called PSA test, is a blood test used to check men for prostate cancer. Have you ever had a PSA test?

Answer	Percentage
Yes	63.0%
No	21.0%
Unsure	16.0%

Survey Question 72: (n=63)

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

Answer	Percentage
Within past year	63.5%
Within past 2 years	14.3%
More than 2 years	20.6%
Never/not sure	1.6%



Seventy-seven (77%) percent of EDA men ages 40 and above reported having a PSA test within the last 2 years. This was higher than the results from the 2010 BRFSS (54.3%)

Safety: Exploitation and Abuse by Direct Service Providers

Survey Question 40: (n=356)

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	99.7%

Survey Question 42: (n=357)

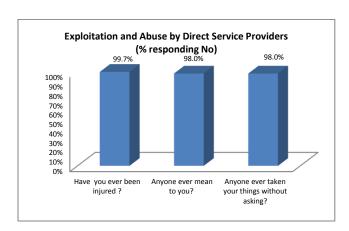
Are any of the people paid to help you now mean to you, or do they yell at you?

•		, ,
Answer		Percentage
Yes		1.4%
No		98.0%
Sometimes		0.6%

Survey Question 44: (n=356)

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

Answer	Percentage
Yes	2.0%
No	98.0%



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

Survey Question 13: (n=358)

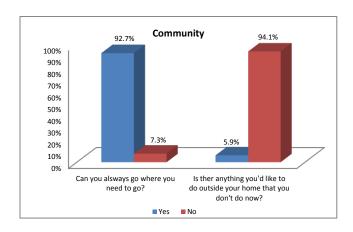
Can you always get to the places you need to go, like work, shopping, the doctor's office, or a friend's house?

Answer	Percentage
Yes	92.7%
No	7.3%

Survey Question 46: (n=356)

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
No	94.1%
Yes	5.9%



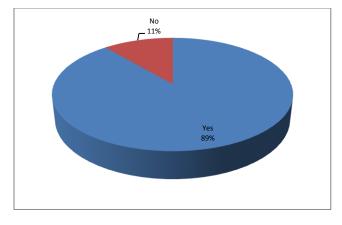
Survey Question 47: (n=20)

What would you like to do? What do you need to make this happen? Some respondents wanted to travel or social outings, others were concerned about going to church, library 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=358)

Do you have family, friends or neighbors who help you e.g. with shopping, transportation, or meals?

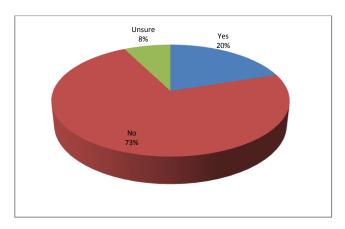
Answer	Percentage
Yes	88.8%
No	11.2%



Survey Question 20: (n=40)

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

Answer	Percentage
Yes	20.0%
No	72.5%
Unsure	7.5%



Employment/Day Supports: Individuals have a choice of employment

Survey Question 48: (n=134)

Are you working right now (under 65 only)?

Answer	Percentage
Yes	0.7%
No	99.3%

Survey Question 52a: (n=120)

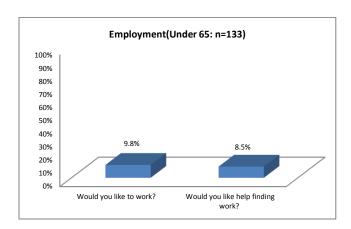
Given your current situation and health status, do you want to work?

Answer	Percentage
Yes	10.8%
No	88.3%
Unsure	0.8%

Survey Question 52b: (n=13)

Would you like help finding work?

Answer		Percentage
Yes	•	69.2%
No		30.8%



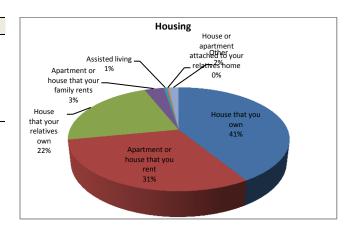
From this series of employment-related questions, 8.5% of those participants under 65 years old would like help finding work.

Housing: Individuals choose where they live

Survey Question 54: (n=358)

What kind of housing do you live in?

Answer	Percentage
House that you own	41.3%
Apartment or house that you rent	30.7%
House that your relatives own	22.1%
Apartment or house that your family rents	3.4%
Assisted living	0.6%
House or apartment attached to your relatives home	0.3%
Other	1.7%



Survey Question 55: (n=358)

Are you living in your preferred housing arrangement?

Answer	Percentage
Yes	96.6%
No	3.4%

Survey Question Q56: (n=12)

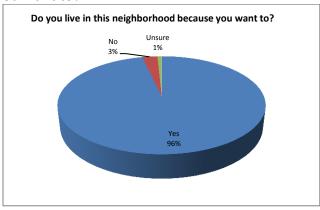
If not, what kind of housing would you prefer?

Answer	Count	Percentage
House that you own	6	50.0%
Apartment or house that your family rent Assisted living	3 1	25.0% 8.3%
House or apartment attached to your relatives home Other	1 1	8.3% 8.3%

Survey Question 62: (n=354)

Do you live in this neighborhood because you want to?

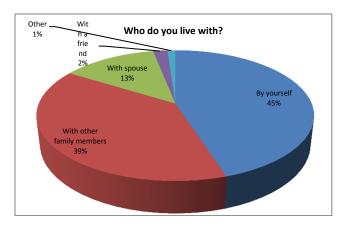
Answer	Percentage
Yes	96.3%
No	2.8%
Unsure	0.8%



Survey Question 57a: (n=358)

Who do you live with now?

Answer	Percentage
By yourself	45.0%
With other family members	38.8%
With spouse	13.1%
With a friend	2.0%
Other	1.1%



Survey Question 57b: (n=161)

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

Percentage
90.1%
9.9%

Survey Question 58: (n=197)

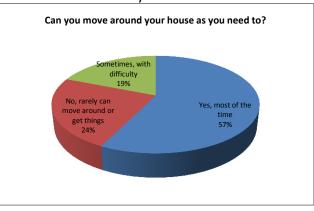
If living with others, do you live with people you prefer to live with?

Answer	Percentage
Yes	97.0%
No	2.5%
Unsure	0.5%

Survey Question 60: (n=358)

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

Answer	Percentage
Yes, most of the time	57.3%
No, rarely can move around or get things	23.7%
Sometimes, with difficulty	19.0%



Survey Question 61: (n=358)

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.)

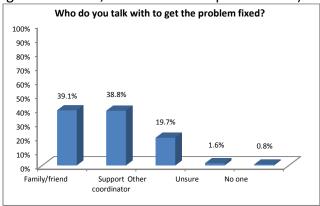
Answer	Percentage
None of the above	76.3%
Other	11.5%
Wider doorways	4.7%
Chairlift, ramp, or elevator	3.9%
An entrance with no stairs	1.4%
Different bed	1.4%
Walker/cane	1.4%
Stair rails on both sides of stairways or steps	0.8%
Better handles on doors and faucets	0.3%
Better lighting	0.3%

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

Survey Question 32: (n=358)

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.)

Answer	Percentage
Family/friend	41.6%
Support coordinator/other staff	41.3%
Other	20.9%
Unsure	1.7%
No one	0.8%



Survey Question 33: (n=356)

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

Answer	Percentage
Yes	62.9%
No	25.3%
Unsure	11.8%

If yes, who? Participants often responded with the Support Coordinator, the agency or provider supervisor.

Conclusion