

**The Institute on Disabilities**  
**Pennsylvania's University Center for Excellence in**  
**Developmental Disabilities Education, Research and Service**

***Independent Monitoring for Quality (IM4Q)***  
***Allegheny AE***  
***2021-2022***

**Submitted to:** **Pennsylvania Office of Developmental Programs &  
Statewide Steering Committee on Independent  
Monitoring for Quality**

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**February 2023**

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## **Introduction**

This report includes data gathered through the Independent Monitoring for Quality (IM4Q) project in Pennsylvania during the 2021-2022 fiscal year. Please note that the format of the report has changed from prior years to improve usefulness. Data collection was also different from prior years as all surveys were conducted remotely due to the ongoing Covid-19 Pandemic. Questions may be addressed to [IM4Q@temple.edu](mailto:IM4Q@temple.edu).

## **Guide to the AE Report**

Each section begins with an overall description of the kind of questions found in that part of the report and who can answer these questions. A breakdown of the respondents' roles is provided, if available.

Unless otherwise noted, tables throughout the document provide a statement and the percentage of individuals who reported that the statement applied to them. For instance, the following table would be read as "94% of respondents in this AE, 91% of respondents in this region, and 95% of respondents statewide reported that they are happy with their life."

	AE	Region	Statewide
Happy with life	94%	91%	95%

The data points in the report correspond to questions on the Essential Data Elements (EDE) survey. Most questions are consistently included from year to year so that changes in the experiences of people with disabilities can be examined over time. However, occasionally questions are added, edited, or removed to address changing circumstances. If a data point from a previous report is not provided in the current report, it is likely the case that this question has been removed from the survey. New questions are marked by a "+" to indicate their new question status.

## **Why We Do This**

The purpose of IM4Q is to understand how people feel about their lives and the services they receive. This allows decision makers at the state and county level and service providers to engage in quality improvement at the program level. The data provided in this report is intended to help with this goal by highlighting areas of strength and areas where improvement is possible. It also allows us to track changes in how people feel about their lives and the services they receive over time.

The IM4Q process also allows us to improve people's lives in a direct way. When IM4Q monitors interview a person with a disability, they write down any concerns or requests the respondent(s) may have. We call these considerations. Individual considerations are shared through the IM4Q system with someone who might be able to help, such as the supports coordinator (SC), a provider, or family members. The SC decides how the consideration will be handled and reports back to the AE or the Bureau of Supports for Autism and Special Populations (BSASP), who either approves or disapproves the response. If the consideration is

not addressed, the consideration process continues until the AE or BSASP and IM4Q program are satisfied with the action to address the consideration. When the consideration is addressed, we call this “Closing the Loop.”

Considerations may result in service changes or provide an opportunity to improve the quality of life of the individual who has been interviewed. For the 2021-2022 collection year, over 5,000 considerations were collected. Of these, nearly 80% have been closed. An analysis of this year’s considerations can be found at the end of the statewide report. T

The following closed consideration, an excerpt from the 2020-2021 Considerations Storybook published by ODP, gives an example of how IM4Q positively impacts the lives of people with disabilities who are receiving ODP supports. Closed considerations are a result of the work, ingenuity, creativity, tenacity, and passion of SCs, providers, and others to make a positive difference in the daily lives of people with developmental disabilities in Pennsylvania. (NOTE: Name has been changed to protect the confidentiality of respondent.)

### **Story: Brittany’s Considerations**

We interviewed Brittany, who lived on her own. She also had a boyfriend, Malcolm, and asked him to sit in on her survey. Brittany stated she wanted to be able to move into a community home with her boyfriend and he agreed that was also what he wanted. They both needed a little more assistance with managing their health, and they wanted to be able to live together.

One community home happened to be their provider of choice and had a bedroom licensed for two people. The couple was approved for Consolidated funding, and they were both able to move into the community home together and share a bedroom.

### **A Note About This Year’s Report: The Impact of the Covid-19 Pandemic**

Early in 2020, a new virus was identified from an outbreak in Wuhan, China. Despite the efforts of international health officials, the virus spread quickly. SARS-COV-2, or Covid-19 as it came to be known, caused outbreaks across the world, leading to global shut-downs in an effort to slow the spread. By mid-March 2020, much of the United States, including Pennsylvania, was under quarantine and social distancing orders. These mandates affected many aspects of life, including how individuals work, engage with the community, and interact with others.

The pandemic halted IM4Q data collection for the 2019-2020 fiscal year several months early. Prior to the 2020-2021 collection year, IM4Q leaders came together to develop plans to continue to conduct surveys. This effort led to a remote interviewing initiative which has been underway for the last several collection years. For the 2021-2022 fiscal year, all interviews were conducted remotely. Interviews with people with disabilities used video conferencing. Family, friend, and guardian interviews were conducted with phone calls or mailed surveys. These methods, as well as some social regulations still in place, some persistent hesitation about large group gatherings due to the pandemic, and a notable staffing shortage are likely to affect the data. Throughout the report, notes have been added to point out trends in the data that may have been influenced by social trends related to these issues.

## **Scale Scores**

The mean is the average. This is the number you get if you add all the scores provided by all the respondents and divide by the number of responses. The standard deviation (SD) tells us about how big of a difference there was between scores. A low SD means the scores were mostly grouped together. A large SD means there was a lot of variety, or variance, in the scores.

The mean are statistical numbers that can tell us about a set of scores. These numbers can be useful for comparing across scales or across locations. If the AE score is close to the score in the region and/or state, it means people in this AE answered questions in about the same way as other people. If the scale scores for the AE are a lot higher than the region or state, it means people in this AE responded to these questions a lot more favorably than people in other areas. If the AE score is a lot lower than the region and/or state score, people in this area answered questions less favorably than people in other areas.

If scores in one area, like Satisfaction, are higher than scores in another area, like Inclusion, this tells us that on average, people rated their satisfaction as higher than their community inclusion.

For each scale, we provide the score range and a description of what high scores mean. If you click the name of the scale, a link will take you to the corresponding section of the report.

**Satisfaction** – Scores range from 0 to 100. High scores mean people reported they were happy with their life and activities.

	Administrative Entity	Region	Statewide
Mean	80.60	85.03	84.87
SD	21.29	18.99	19.05

**Dignity, Respect and Rights** – Scores range from 0 to 100. High scores mean people reported that others were nice to them, and they were treated with respect.

	Administrative Entity	Region	Statewide
Mean	78.40	83.03	83.10
SD	16.01	17.19	16.30

**Afraid** – Scores range from 0 to 100. High scores mean people reported that they were NOT afraid at home, at their work or day activity, and in their neighborhood.

	Administrative Entity	Region	Statewide
Mean	90.24	92.34	93.09
SD	20.44	16.34	15.74

**Choice and Control** – Scores range from 0 to 100. High scores mean people reported having a lot of control and choice in their lives.

	Administrative Entity	Region	Statewide
Mean	67.86	66.16	60.78
SD	20.33	20.08	21.12

**Inclusion** – Scores range from 0 to 100. High scores mean people reported going out often to lots of places in the community.

	Administrative Entity	Region	Statewide
Mean	39.57	40.43	40.30
SD	18.61	18.90	19.69

**IM4Q Monitor Impressions** – Scores range from 1 to 10. High scores mean the Monitor would be happy to live in this home.

	Administrative Entity	Region	Statewide
Mean	N/A	N/A	6.74
SD	N/A	N/A	2.18

**Family Satisfaction** - Scores range from 0 to 100. High scores meant family members reported that they were satisfied with their relative's services and opportunities.

	Administrative Entity	Region	Statewide
Mean	86.00	91.00	90.97
SD	15.70	12.37	13.23

## Sample

### i. Sample Data

#### *i1. Total Surveyed*

People with disabilities	442	Family members	122
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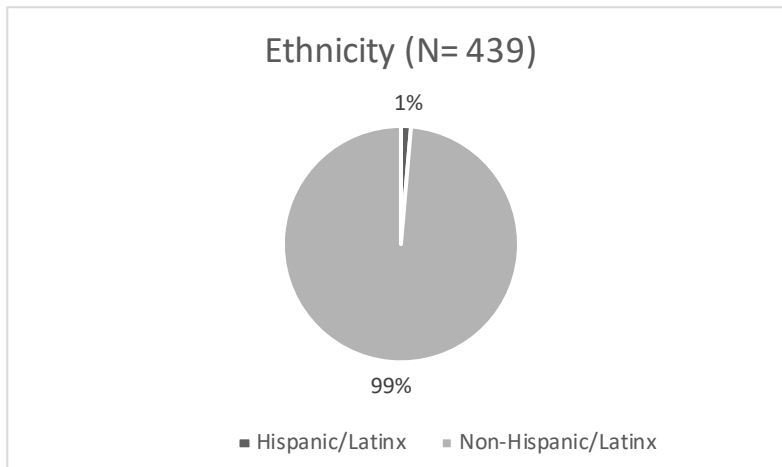
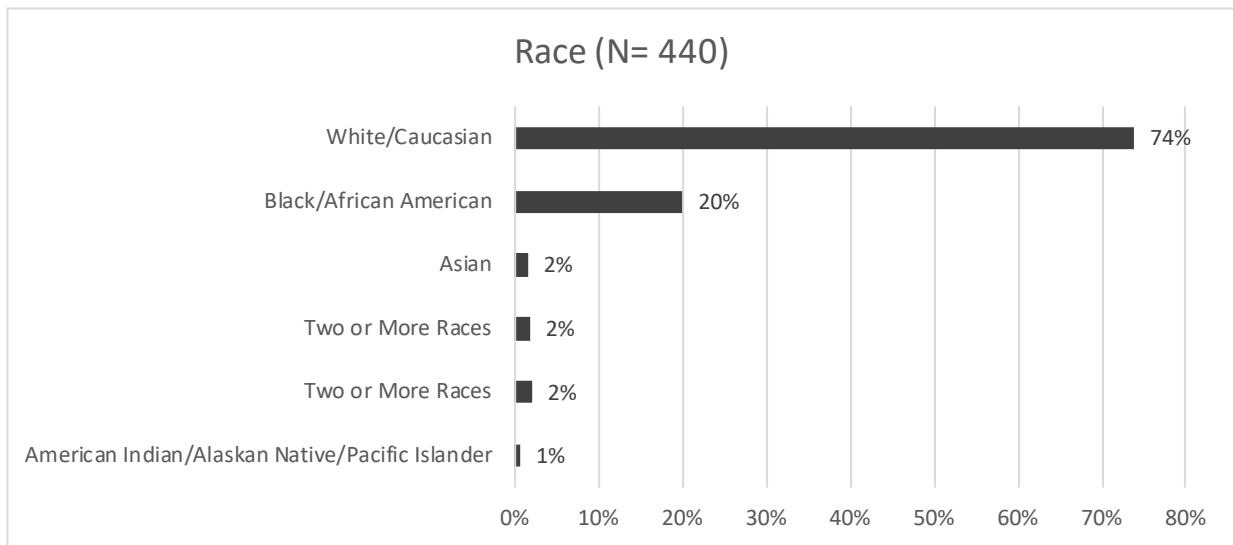
#### *i2. Age*

Range	8-93	Mean Age (SD)	31.5 (19.2)
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#### *i3. Reported Gender*

Female	42.2%	Male	57.4%	Other	0%
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#### *i4. Race and Ethnicity*



*i5. Home Type Where Respondent Lives*

Type of Residence	AE		Statewide	
	Number of Residents	Percent of the Sample	Number of Residents	Percent of the Sample
Relative's Home	297	67.2%	1604	42.0%
Community Home- All	72	16.3%	1472	38.6%
<i>Community Home 1</i>	5	1.1%	135	3.5%
<i>Community Home 2-4</i>	61	13.8%	1272	33.3%
<i>Community Home 5-6</i>	4	0.9%	40	1.0%
<i>Community Home 7-8</i>	2	0.5%	21	0.6%
<i>Community Home 9-15</i>	0	0.0%	2	0.1%
<i>Community Home 16+</i>	0	0.0%	2	0.1%
Own Residence	17	3.8%	254	6.7%
Family Living/Lifesharing	3	0.7%	127	3.3%
Private ICF/ID- All	13	2.9%	133	3.5%
<i>Private ICF/ID 1-4</i>	1	0.2%	29	0.8%
<i>Private ICF/ID 5-8</i>	8	1.8%	48	1.3%
<i>Private ICF/ID 9-15</i>	1	0.2%	13	0.3%
<i>Private ICF/ID 16+</i>	3	0.7%	43	1.1%
Personal Care Home	9	2.0%	42	1.1%
Nursing Home/Facility	20	4.5%	40	1.0%
Children's Facility	2	0.5%	8	0.2%
Unlicensed Family Living	0	0.0%	10	0.3%
Domiciliary Care	0	0.0%	8	0.2%
Foster Care	1	0.2%	2	0.1%
Approved Private School	0	0.0%	0	0.0%
State Operated ICF/MR	1	0.2%	11	0.3%
State MH Hospital	0	0.0%	0	0.0%
Temporary Shelter	0	0.0%	0	0.0%
Other	7	1.6%	21	0.6%
Missing	0	-	85	-
<b>Total</b>	<b>442</b>	<b>100%</b>	<b>3817</b>	<b>100%</b>



## **Part I: Satisfaction**

Satisfaction questions ask how individuals feel about their life. These questions can only be answered by the individual receiving supports.

### **A. Satisfaction Data**

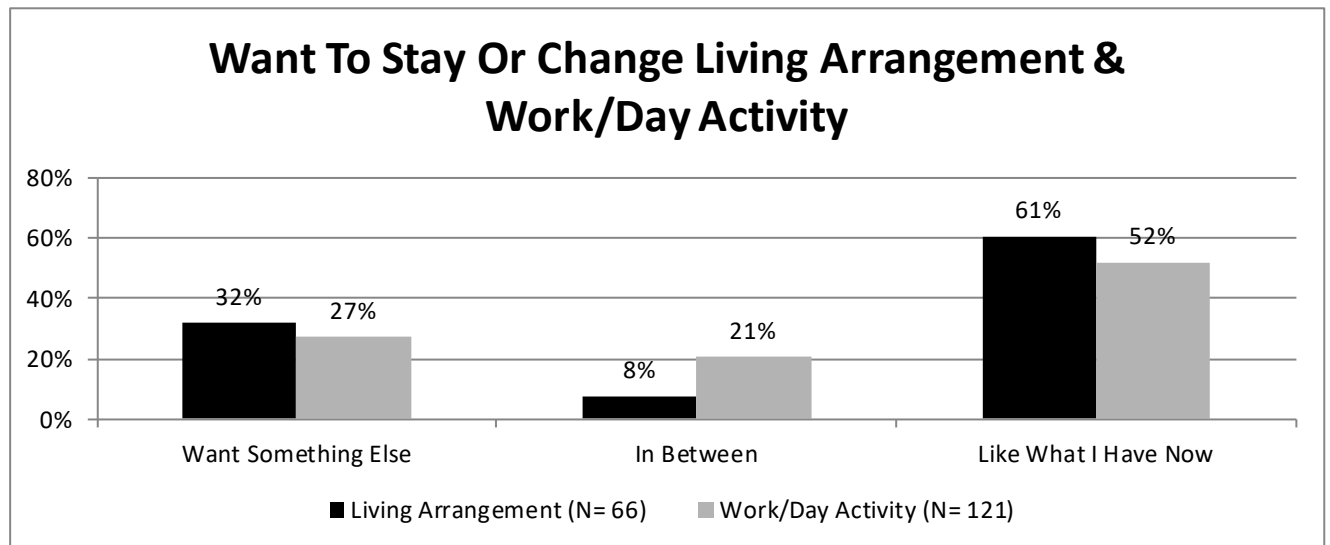
#### ***A1. Living Arrangements***

	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
Like where they live now	86%	88%	89%
Want to stay where they currently live	61%	72%	74%
Want to move somewhere else	32%	20%	18%
In between wanting to stay and wanting to move	8%	8%	8%

#### ***A2. Work/Day Activity***

	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
Like primary job or day activity	89%	91%	91%
Like other job or day activity	92%	95%	94%
Want to continue current job or day activity	52%	73%	73%
Want to do something else.	27%	17%	19%
In between wanting to continue and wanting to change jobs	21%	10%	9%

#### ***A1-2.1. Want to Stay or Change Living Arrangement and Work/Day Activity***



#### ***A3. Daily Activities***

<b>Primary Activity</b>	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
Stay home	22%	30%	27%
Work	18%	23%	23%

<b>Primary Activity</b>	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
<i>Work- no supports</i>	12%	16%	14%
<i>Work- with supports</i>	5%	7%	9%
Attend school	31%	15%	8%
Attend a vocational facility	3%	7%	9%
Attend a day program or community center	4%	7%	9%
Go out in the community	3%	10%	12%
Retired	5%	2%	2%
Volunteer	0%	1%	2%
Something else	13%	6%	6%

<b>Secondary Activity</b>	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
Stay home	32%	38%	40%
Work	8%	5%	4%
<i>Work- no supports</i>	5%	2%	2%
<i>Work- with supports</i>	3%	2%	2%
Attend school	1%	1%	1%
Attend a vocational facility	1%	2%	2%
Attend a day program or community center	3%	2%	2%
Go out in the community	13%	22%	25%
Retired	1%	1%	2%
Volunteer	7%	6%	6%
Something else	35%	22%	19%

### *A3.1. Want to Work*

	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
Do not have or want a job	31%	50%	56%
Would like a job for pay	66%	45%	40%
Uses special technology to help do work <sup>+</sup>	13%	13%	13%

#### ***A4. Services***

	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
Always get services they need	69%	86%	85%
Sometimes get services they need	5%	3%	3%
Do not get services they need	11%	4%	5%
Need additional services	15%	6%	7%

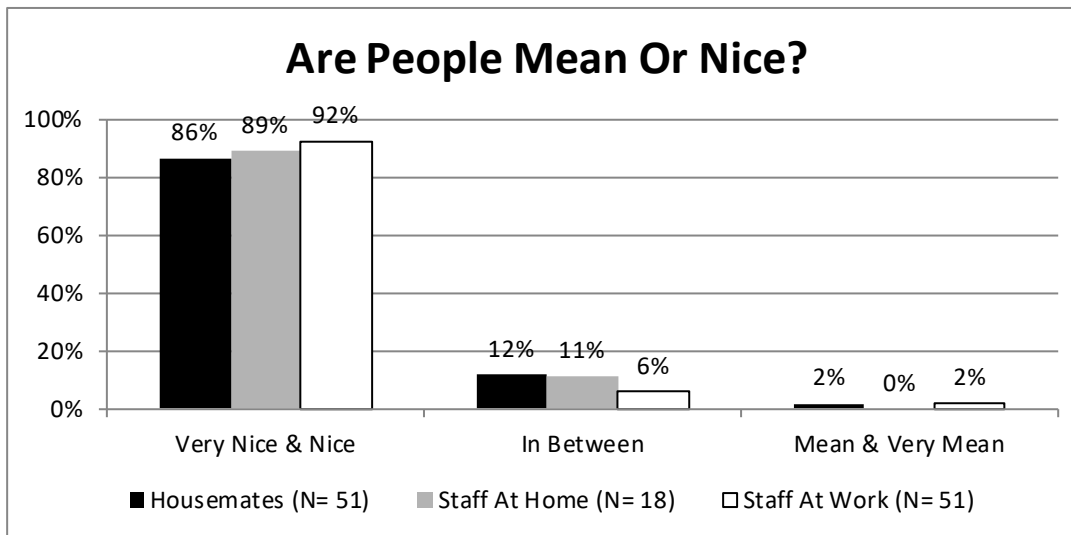
#### ***A5. Happiness and Loneliness***

	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
Happy with life	84%	85%	86%
Neither happy nor sad with life	14%	12%	12%
Sad with life	3%	3%	2%
Never lonely	57%	63%	63%
Sometimes lonely	38%	32%	32%
Always lonely	5%	5%	5%
Have friends to do things with	90%	89%	84%
Friends are not staff or family	78%	79%	72%
Have a best friend	76%	75%	71%
Can date/marry, no restrictions	83%	86%	85%
Can date/marry, restrictions	6%	3%	4%
Cannot date/marry at all	12%	11%	12%

#### ***A6. Privacy***

	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
Have enough privacy (a place to be alone) at home	94%	95%	97%
No rules about friends or visitors	73%	78%	75%
People always let them know when coming into their home	86%	90%	91%
Sometimes people let them know when coming into their home	10%	4%	3%
People never let them know when coming into their home	4%	6%	6%
People always let them know when coming into their bedroom	87%	86%	88%
People sometimes let them know when coming into their bedroom	10%	6%	4%
People never let them know when coming into their bedroom	3%	8%	8%

**A7. Are People Nice or Mean?**



	AE	Region	Statewide
Staff at day or work activity are nice or very nice	92%	94%	95%
Staff at day or work activity are in between nice and mean	6%	5%	4%
Staff at day or work activity are mean or very mean	2%	1%	1%
Staff at home are nice or very nice	89%	94%	95%
Staff at home are in between nice and mean	11%	6%	4%
Staff at home are mean or very mean	0%	0%	0%
Housemates are nice or very nice	86%	84%	87%
Housemates are in between nice and mean	12%	14%	10%
Housemates are mean or very mean	2%	2%	2%
Get along well with the person they share a bedroom with*	79%	86%	80%
Get along OK with the person they share a bedroom with*	7%	7%	12%
Do not get along with the person they share a bedroom with*	14%	7%	8%

\*This question was only asked if people shared a bedroom and do not live with relatives.

## **Part II: Dignity, Respect and Rights**

**Dignity, Respect and Rights questions ask how individuals feel they are treated. They explore issues of basic rights such as learning new things and carrying identification. There are subsections about supports coordination and emergency preparedness. These questions can only be answered by the individual receiving supports.**

### **B. Dignity Respect and Rights Data**

#### **Part II, Section A: Dignity, Respect and Rights**

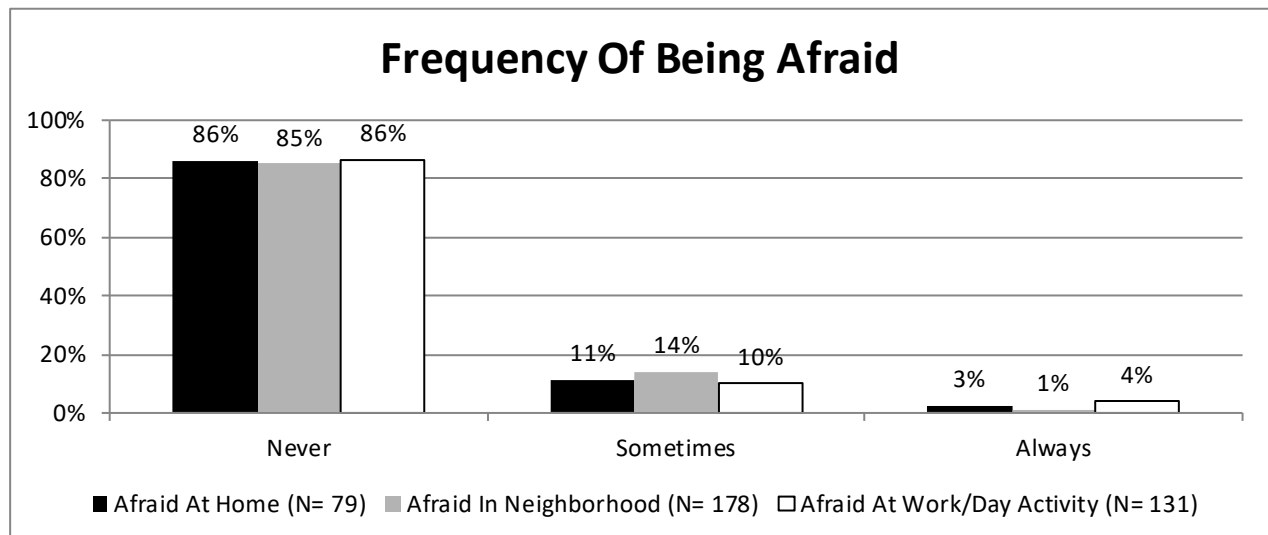
##### ***B1. Support with Goals and Problems***

	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
Get help to learn new things	82%	86%	82%
Do not get help	9%	9%	12%
Get to help other people	82%	76%	69%
Have participated in a self-advocacy group meeting	33%	20%	19%
Someone has talked to them about self-advocacy	80%	61%	53%
Have someone to talk to when afraid	92%	95%	94%

##### ***B1.1. Who do you go to for help?***

	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
Staff	25%	44%	47%
Supports coordinator	5%	8%	9%
Other	26%	14%	9%
Family	58%	50%	47%
Friends	5%	7%	7%
Have no one	2%	1%	1%

##### ***B2. Frequency of Being Afraid***



	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
Never afraid at home	86%	87%	87%
Sometimes afraid at home	11%	11%	11%
Always afraid at home	3%	2%	2%
Never afraid in the neighborhood	85%	87%	89%
Sometimes afraid in the neighborhood	14%	12%	9%
Always afraid in the neighborhood	1%	1%	2%
Never afraid at work or day activities	86%	90%	91%
Sometimes afraid at work or day activities	10%	8%	6%
Always afraid at work or day activities	4%	2%	2%

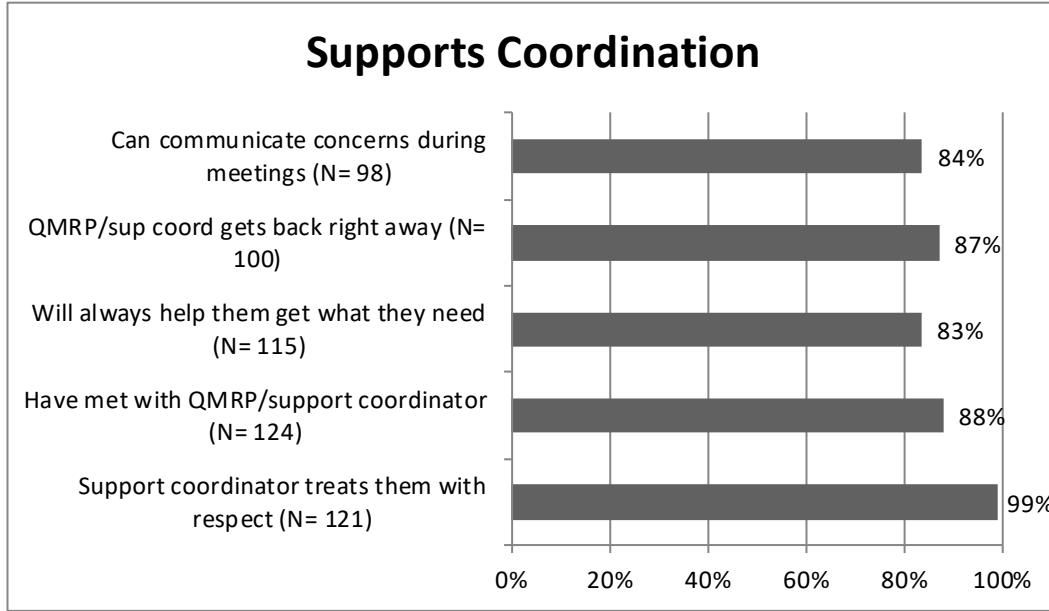
### ***B3. Legal Rights***

	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
Mail is never opened without permission	86%	86%	85%
Mail is sometimes opened without permission	7%	7%	6%
Mail is always opened without permission	7%	7%	9%

**Part II, Section B: Supports Coordination**

This section asks questions related to supports coordination. Questions cover the supports coordinator (SC), services, and other staff members. These questions can only be answered by the individual receiving services.

**B4. Supports Coordinator (SC)**



**B4.1. SC Communication**

	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
SC asks what their interests are	94%	94%	92%
SC asks what they want their life to look like	85%	89%	88%
SC knows what is important to them <sup>+</sup>	86%	91%	91%
SC asks them about directing their own services	36%	48%	46%
SC asks if services are OK	94%	98%	97%
SC always listens to them	95%	96%	96%

**B4.2. SC Interaction**

	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
Person knows they can choose SC	67%	69%	70%
SC always gets back to them right away	87%	92%	92%
SC will always help them get what they need	83%	90%	91%

	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
Person has met with SC in the last year	88%	92%	92%
SC always treats the person with respect	99%	99%	99%

***B5. Annual Planning Meeting***

	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
Participate in the meeting	95%	95%	97%
Know it is an option but choose not to participate in meeting	2%	1%	1%
Can communicate their concerns during the meeting	84%	90%	90%
Sometimes get to communicate concerns	10%	7%	7%
Told at the meeting how much money is in their budget	47%	66%	57%
Meeting includes the people they wanted to be there	91%	96%	97%
Know what is talked about at their ISP meeting	86%	81%	82%

***B6. Services***

	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
Know who to ask if they want to change their services	79%	83%	83%
Do not know who to ask to change services	15%	11%	11%

***B7. Staff***

	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
Staff always treats them with respect	95%	92%	92%
Staff always respectful of their culture <sup>+</sup>	100%	99%	98%
Have staff who help them <sup>+</sup>	55%	69%	77%
Staff do things the way the individual wants them done <sup>+</sup>	86%	89%	90%
Staff have the right training to meet their needs	93%	94%	93%
All staff always understand their communication	86%	91%	89%



	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
Some staff understand them	6%	3%	7%
Sometimes understood by staff	8%	5%	3%
Not understood by staff	0%	1%	1%

**Part II, Section C: Emergency Preparation**

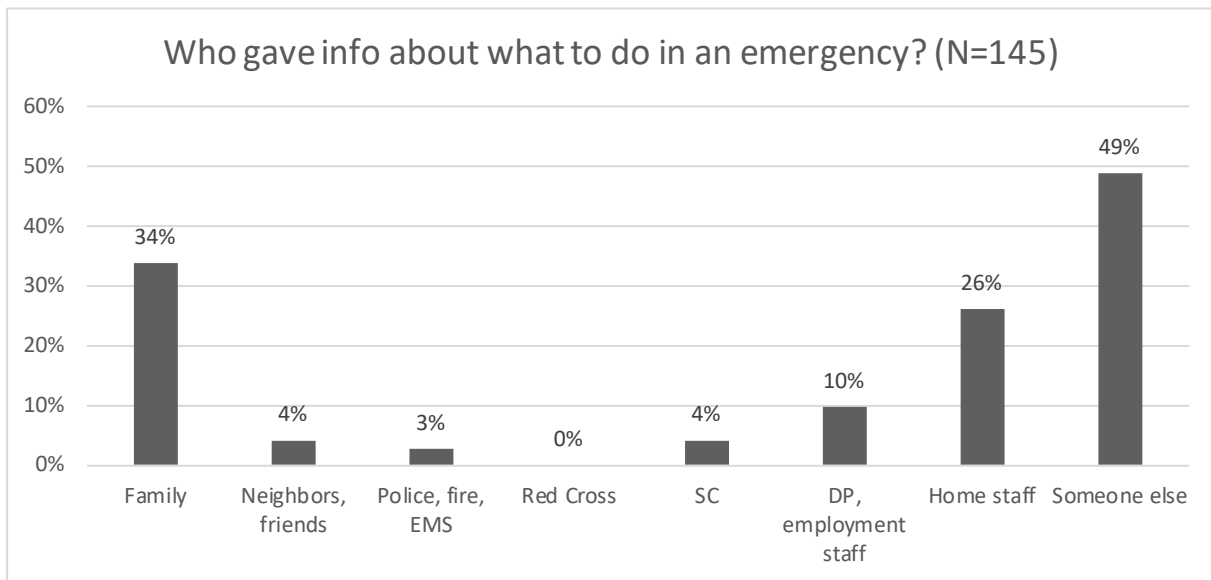
This section asks questions related to emergency preparation. These questions can only be answered by the individual receiving services.

**B8. Emergency Preparation Questions**

	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
Have been given information about what to do in an emergency	92%	87%	84%

**B8.1. Who Provided Emergency Information**

	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
Home staff	26%	33%	40%
Day staff	10%	16%	15%
Family	34%	34%	40%
SC	4%	17%	11%
Police, Fire, or EMS Workers	3%	3%	3%
Friends	4%	3%	2%
Red Cross	0%	0%	0%
Someone Else	49%	23%	14%



### **Part III: Choice and Control**

**Choice and control questions ask about options people have control over in their lives. These questions can be answered by the individual, paid staff, a family member, friend or advocate, or a combination of these.**

#### **Respondents (AE):**

Individual	15%	Individual and Paid staff	8%
Paid staff	14%	Individual and Family/friend/guardian/advocate	17%
Family/friend/guardian/advocate	45%	Staff and Family/friend/guardian/advocate	0%

### **C. Choice and Control Data**

#### **Part III, Section A: Choice and Control**

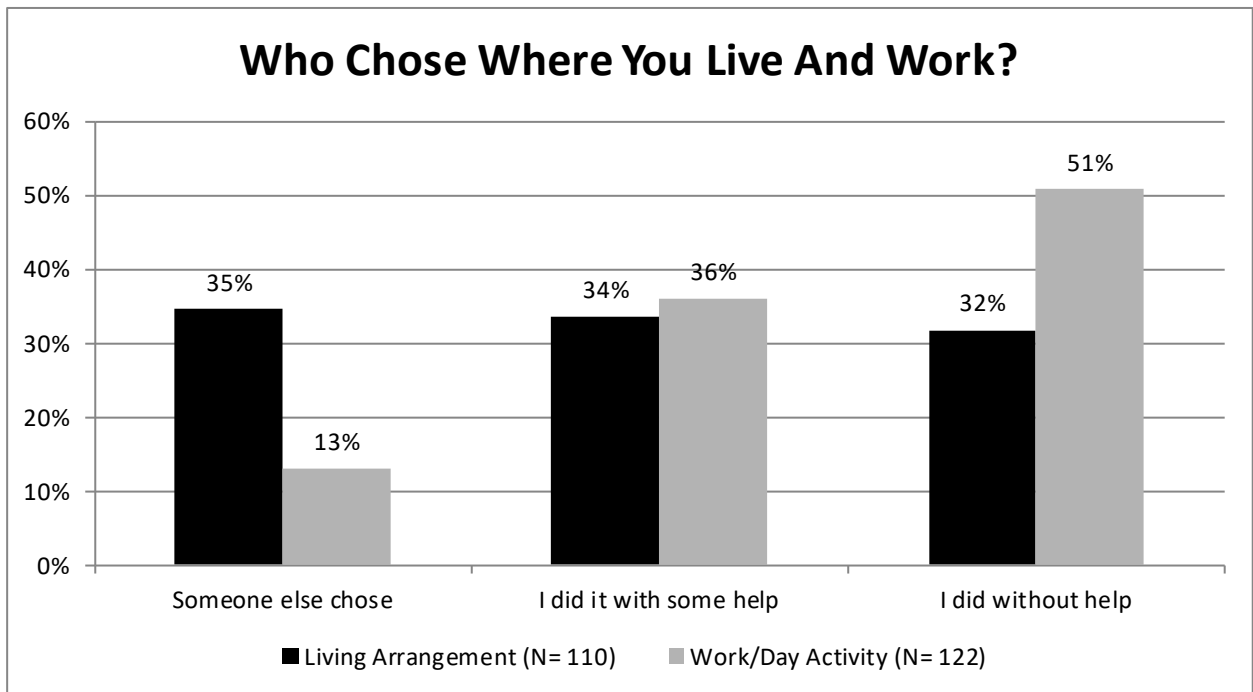
##### ***C1. Identification***

	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
Always carry ID	44%	59%	65%
Never carry ID	40%	26%	20%

##### ***C2. Choice and Control at Home***

	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
Have a key or way to get into their home	43%	48%	47%
If other household members go out, they have the option to stay home	37%	44%	46%
If other household members go out, they sometimes can stay home	17%	14%	14%
Can lock bedroom door	44%	50%	49%
Own their home	1%	2%	2%
Name is on the lease or rental agreement	25%	30%	34%
Have a choice to live where people without disabilities live	64%	51%	46%
Saw no other places before they moved into their home	31%	45%	50%
Did not choose housemates	60%	61%	63%
If individual shares a bedroom, chose some or all roommates	36%	35%	37%

*C2.1. Who Chooses Where the Person Lives and Works?*

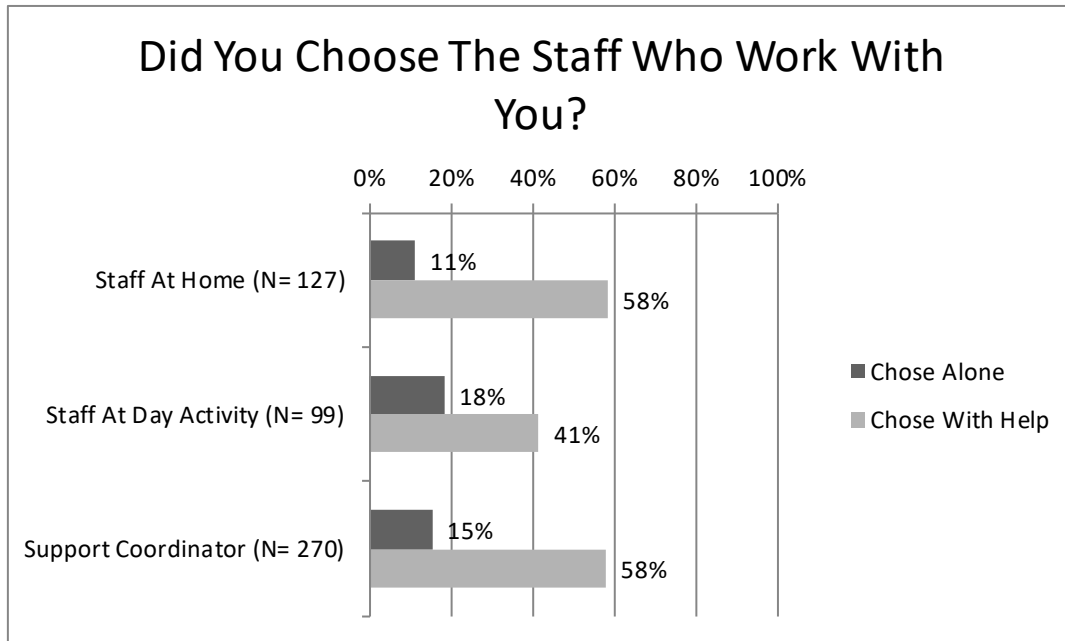


	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
Chose living arrangement without help	32%	32%	27%
Chose living arrangement with some help	34%	26%	27%
Someone else chose living arrangement	35%	43%	46%
Chose work or day activity without help	51%	58%	51%
Chose work or day activity with some help	36%	24%	31%
Someone else chose work or day activity	13%	18%	18%

*C3. Choice and Control During the Day and for Leisure Time*

	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
Have the choice to go where people without disabilities go	84%	67%	66%
See no other places when choosing day activity	23%	41%	41%
Choose daily schedule without assistance	82%	88%	89%
Have enough choice about free time	84%	91%	94%

**C4. Choice and Control in Choosing Staff**

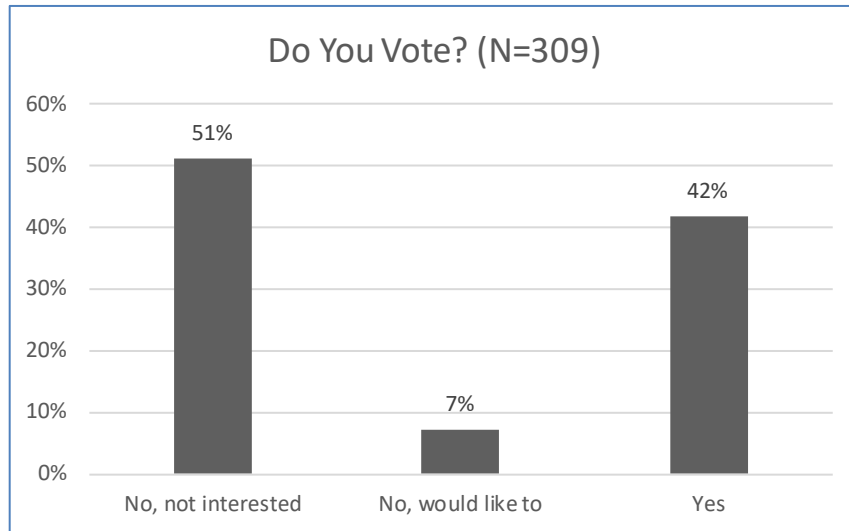


	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
Chose SC without help	15%	22%	18%
Chose SC with some help	58%	32%	24%
Someone else chose SC	27%	46%	58%
Chose staff at work or day activity without help	18%	22%	18%
Chose staff at work or day activity with some help	41%	26%	21%
Someone else chose staff at work or day activity	40%	51%	60%
Chose staff at home without help	11%	14%	13%
Chose staff at home with some help	58%	34%	29%
Someone else chose staff at home	31%	52%	58%

**C5. Choice and Control Regarding Money**

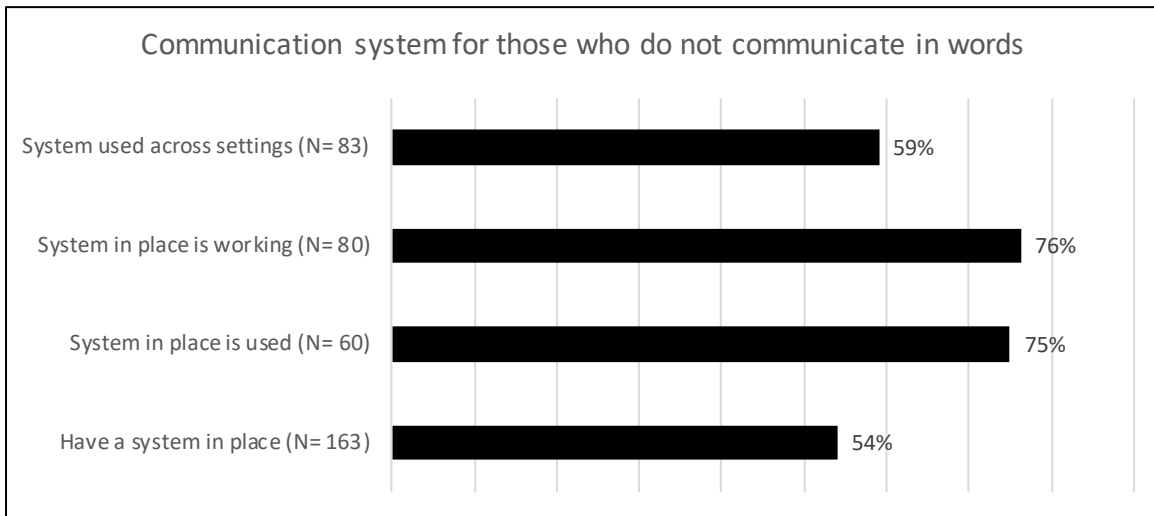
	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
Always choose alone what to buy with spending money	52%	63%	58%
Choose what to buy with help	39%	30%	34%
There is something they want to buy	54%	42%	48%
They have a bank account and withdrawal money when they want	75%	73%	67%

**C6. Voting**



	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
Votes	42%	33%	39%
Chooses not to vote	51%	63%	57%
Does not vote but would like to	7%	4%	4%

**C7. Status of Formal Communication System**



	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
Have a communication system in place*	54%	45%	41%
System is being used**	75%	84%	88%
System is working**	76%	81%	87%
System is used across settings**	59%	68%	74%

\* Question was only asked for people who do not communicate using words.

\*\*Question was only asked for people who have a system in place.

***C8. Who Supports Communication System?***

	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
Staff or Program Coordinator	28%	47%	44%
Speech Language Clinician	78%	53%	41%
Parent or Caregiver	56%	45%	43%
Someone Else	21%	18%	16%

***C9. Other Forms of Communication***

*C9.1. Forms the Person Has Access to and Uses*

	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
Cell phone	49%	47%	41%
E-mail	24%	30%	26%
Internet	74%	71%	62%
Text-messaging	35%	34%	28%
Cable TV	88%	89%	91%
Computer	73%	69%	63%

*C9.2. Restrictions in Place for Communication*

	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
Cell phone	20%	14%	9%
E-mail	9%	7%	6%
Internet	29%	18%	11%
Text-messaging	14%	10%	6%
Cable TV	23%	13%	7%
Computer	31%	18%	11%

**Part III, Section B: Health Questions**

This section asks questions related to health and healthcare. Questions cover general medical care, dental care, and mental health care topics.

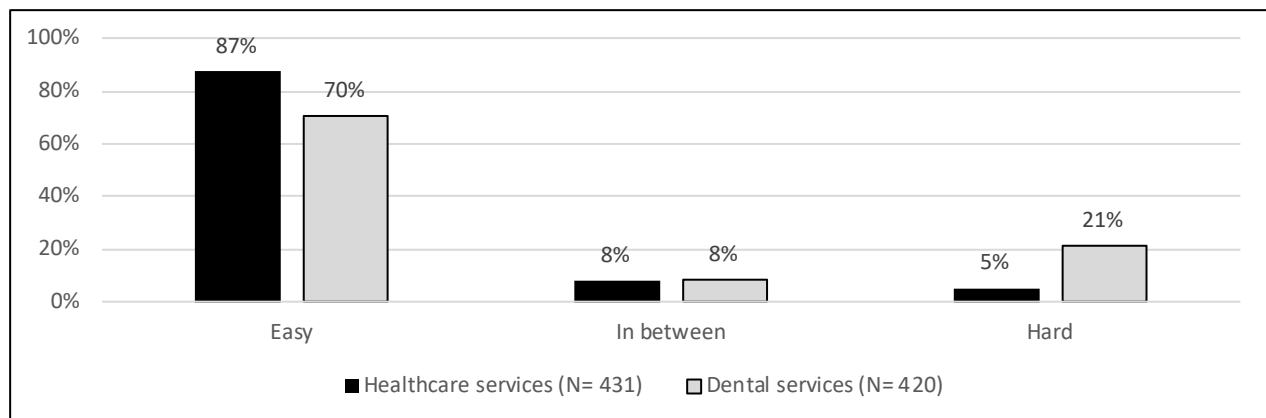
***C10. Exercise at Home***

	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
Exercises at home 10+ times per month	37%	40%	42%
Exercises at home <1 time per month	39%	41%	43%

***C11. Medical & Dental Care***

	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
Overall health excellent or very good <sup>+</sup>	49%	47%	48%
Opportunity to discuss health with primary care provider (PCP)	93%	92%	86%
Talked with health care provider using telehealth <sup>+</sup>	59%	54%	56%
Liked talking to health care provider using telehealth <sup>+</sup>	45%	50%	56%
Able to see a medical specialist if needed	88%	94%	96%
Have not been prevented from receiving medical or dental care due to disability	83%	89%	90%

***C11.1. How Hard is it to Access Care?***





	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
Accessing medical care is very/pretty easy	87%	88%	91%
Accessing medical care is between easy & hard	8%	8%	6%
Accessing medical care is hard or very hard	5%	4%	3%
Accessing dental care is very/pretty easy	70%	77%	83%
Accessing dental care is in between easy and hard	8%	9%	6%
Accessing dental care is hard or very hard	21%	14%	11%

### ***C12. Mental Health***

	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
Have an opportunity to discuss health concerns with psychiatrist	65%	70%	65%
Do not have psychiatrist, but want one	4%	2%	2%

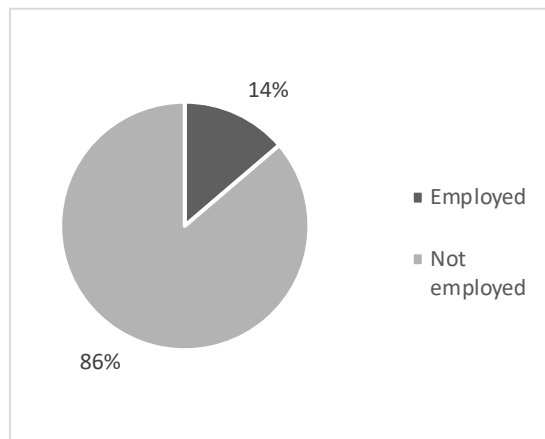
### ***C13. Communicating Health Needs***

	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
Their doctor understands them	75%	81%	78%
They understand their doctor's instructions	50%	64%	61%
If they need help communicating at doctor's office, it is available	96%	95%	95%
Doctor speaks directly to them during appointments	95%	94%	93%
Able to provide consent for medical treatment	56%	65%	60%
If they provide consent, is it accepted	86%	88%	85%

**Part III, Section C: Employment and Community Participation Services**

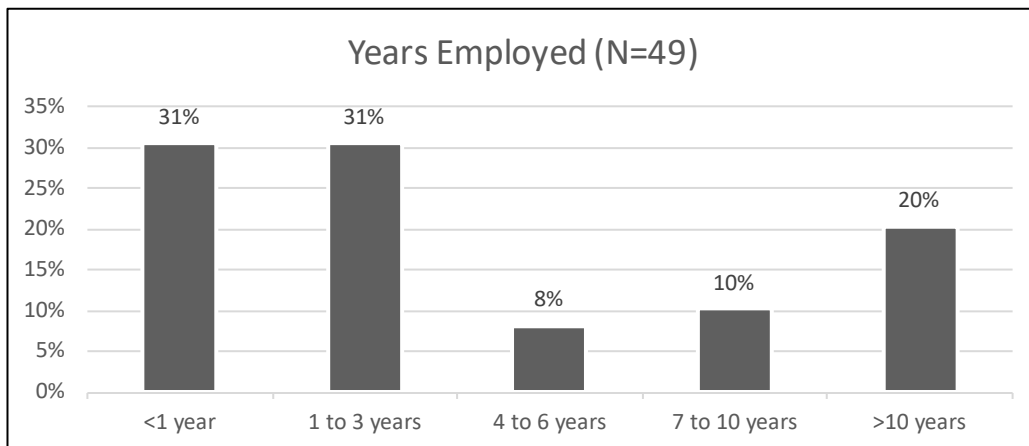
**Employment in this survey refers to Community Integrated Employment (CIE). CIE is work that is paid directly to the employee, provides at least minimum wage, and occurs in a typical work setting where a person with a disability interacts with coworkers with and without disabilities. The survey also asks about Community Participation Services (CPS), or services that give people with intellectual and developmental disabilities opportunities and support for community inclusion and skill development. Questions about employment benefits, hours, salary, and field of work are only addressed to the people who indicated they are employed in CIE. Questions regarding support getting into the workplace, employment planning, and CPS are asked of all respondents.**

***C14. Employment in CIE***



	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
Employed in CIE	14%	17%	16%

***C15. Length of Employment***



	AE	Region	Statewide
Employed <1 Year	31%	27%	24%
Employed 1 to 3 Years	31%	26%	30%
Employed 4 to 6 Years	8%	15%	15%
Employed 7 to 10 Years	10%	13%	11%
Employed 11+ Years	20%	20%	19%

### ***C16. Types of Work***

Cleaning Services	22%	Assembly/Factory Work	6%
Food Services	22%	Care Workers/Aides	4%
Retail Services	11%	Recycling	0%
Office Work	2%	Outdoor Work	0%
Stock Room	7%	Animal Care	0%
Maintenance	2%	Other	24%

### ***C17. Supports Getting into the Workplace***

	AE	Region	Statewide
Take classes/training for employment purposes	28%	15%	11%
Talked about employment in their planning meeting	56%	57%	51%
Community employment is a goal in their plan	59%	44%	37%

#### ***C17.1. Who Talked to the Person about Employment?***

No one	45%	SC	48%
Service Provider	3%	Family	21%
Housemates	0%	Someone Else	10%

*Note: individuals had the option to indicate more than one response for C17.1.*

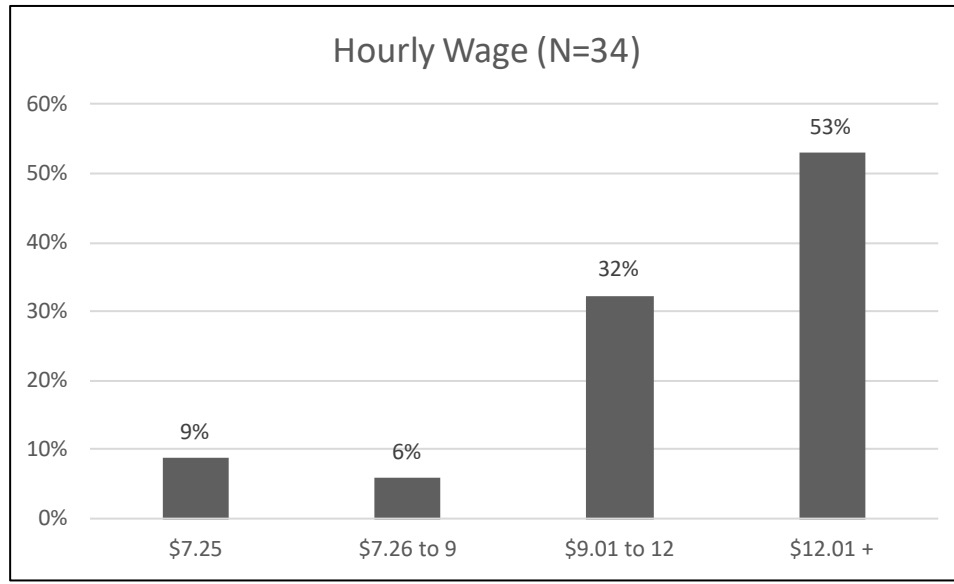
### ***C18. Self-Employment***

	AE	Region	Statewide
Person reports that they are self-employed	0%	4%	2%

### ***C19. Compensation and Advancement***

	AE	Region	Statewide
Have been promoted or received an increase in pay	67%	49%	52%
Receive paid time off from work as a benefit of employment	83%	80%	80%
Receive health insurance benefits from employer	22%	30%	26%
Receive retirement benefits from their employer	44%	39%	31%
Receive other work benefits from their employment	6%	7%	12%
Know how much they earn and willing to share	80%	77%	76%

*C19.1. Hourly Wage*



	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
\$7.25 per hour (Minimum wage)	9%	17%	14%
\$7.26 - \$9.00 per hour	6%	19%	18%
\$9.01 - \$12.00 per hour	32%	35%	33%
\$12.01 or more per hour	53%	29%	35%

**C20. Community Participation**

	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
Use Community Participation Services (CPS)	9%	24%	24%

*C20.1. If yes, What CPS Services Are Used?*

	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
Developing skills and competencies necessary for employment	10%	11%	14%
Fine/gross motor skill development and mobility	17%	16%	19%
Participating in community activities to develop social networks	59%	60%	58%
Participating in opportunities to develop interests or promote health/wellness	72%	60%	66%
Training/education for self-determination and self-advocacy	21%	11%	13%
Community adult learning opportunities	17%	18%	15%

	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
Volunteering opportunities	48%	29%	24%
Learning to navigate the local community	21%	14%	12%

***C21. Technology use<sup>+</sup>***

	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
Internet at home always works <sup>+</sup>	84%	80%	84%
Uses technology in their everyday life to do things on their own <sup>+</sup>	48%	44%	36%
Has enough help to use technology in everyday life <sup>+</sup>	86%	89%	91%
Has talked to SC using videoconference <sup>+</sup>	59%	55%	67%
Likes talking to SC using videoconference <sup>+</sup>	53%	61%	66%
Has used videoconference for other services <sup>+</sup>	65%	46%	44%
Likes using videoconference for other services <sup>+</sup>	37%	49%	61%

### Part III, Section D: Self-Directed Supports

Use of Self-Directed Supports is a model of service delivery that allows the person receiving support to have increased control over their services. For instance, the person can decide, alone or with help from friends or family, how, when, and from whom their services will be delivered. Only the people who indicated they use self-directed supports were asked questions about these supports.

#### *C21. Self-Directed Services*

	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
Use self-directed services	0%	5%	6%

#### *C22. Who Makes Choices About Budget?*

	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
Individual makes decisions on their own	N/A	38%	14%
Individual has input, family and friends help	N/A	30%	38%
A family member or friend makes decisions	N/A	28%	46%
A case manager or state professional makes the decision	N/A	4%	2%

#### *C23. Making Decisions*

	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
Can make changes to their budget or services if they need to	N/A	95%	96%
Have enough help deciding how to use their budget/services	N/A	93%	92%
Want more help deciding how to use their budget/services	N/A	0%	1%

#### *C24. Money Left in Budget*

	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
Receive information about the money left in their budget	N/A	88%	78%
Information they receive is easy to understand	N/A	80%	72%
They receive information at least every 3 months	N/A	81%	63%
They receive information about twice a year	N/A	16%	23%
They receive information once a year or less	N/A	3%	14%

## Part IV: Relationships

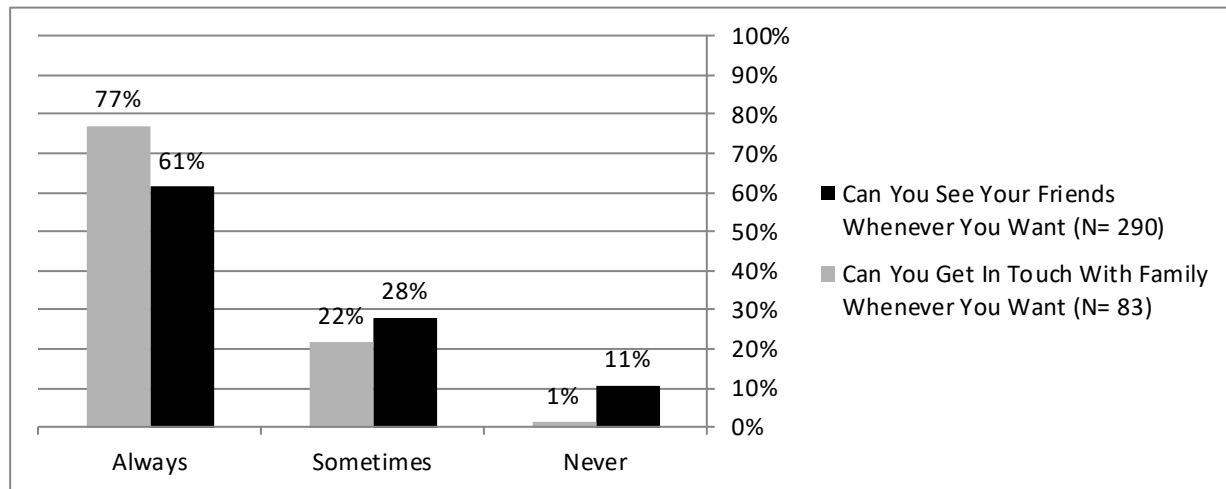
Relationships questions ask about individuals' interactions with others in their lives. The ongoing Covid-19 Pandemic may have affected these ratings since socialization restrictions were in place in many areas. These questions can be answered by the individual, paid staff, a family member, friend or advocate, or a combination of these.

### Respondents:

Individual	21%	Individual and Paid staff	7%
Paid staff	15%	Individual and Family/friend/guardian/advocate	12%
Family/friend/guardian/advocate	45%	Staff and Family/friend/guardian/advocate	0%

## D. Relationships Data

### D1. Contact with Friends and Family



	AE	Region	Statewide
Always see friends whenever they want to	61%	75%	76%
Sometimes see friends when they want to	28%	19%	16%
Never get to see friends when they want to	11%	6%	7%
Always can get in touch with family when they want to	77%	80%	79%
Sometimes can get in touch with family when they want to	22%	15%	14%
Never can get in touch with family when they want to	1%	5%	7%

## **Part V: Inclusion**

**These questions explore how much time individuals spend in the community. It is probable that restrictions on socialization in the community due to the ongoing Covid-19 Pandemic affected these numbers. Questions can be answered by the individual, paid staff, a family member, friend or advocate, or a combination of these.**

### **Respondents:**

Individual	15%	Individual and Paid staff	8%
Paid staff	15%	Individual and Family/friend/guardian/advocate	18%
Family/friend/guardian/advocate	43%	Staff and Family/friend/guardian/advocate	1%

## **E. Inclusion Data**

### ***E1. Community Participation***

<b>Activity</b>	<b>% of people who do this at least weekly- AE</b>	<b>% of people who do this at least weekly- Region</b>	<b>% of people who do this at least weekly- Statewide</b>
Visit friends, relatives, neighbors	46%	45%	40%
Go to a supermarket	47%	47%	46%
Go out to eat/restaurants	35%	39%	40%
Go to a shopping center or mall	28%	32%	35%
Go out to a worship service	23%	23%	22%
Run errands and appointments	32%	28%	25%
Meeting people at coffee house/tavern	13%	14%	17%
Go out for entertainment	24%	19%	21%

### ***E1.1. Do People Engage in Community Activities Enough?***

<b>Activity</b>	<b>% of people in this AE who say they do this enough</b>	<b>% of people in this AE who want to do this more</b>	<b>% of people in this AE who want to do this less</b>
Visit friends, relatives, neighbors	41%	57%	2%
Go to a supermarket	55%	39%	6%
Go out to eat/restaurants	38%	58%	4%
Go to a shopping center or mall	47%	50%	4%
Go out to a worship service	64%	32%	5%



<b>Activity</b>	<b>% of people in this AE who say they do this enough</b>	<b>% of people in this AE who want to do this more</b>	<b>% of people in this AE who want to do this less</b>
Run errands and appointments	68%	22%	9%
Meeting people at coffee house/tavern	56%	42%	2%
Go out for entertainment	33%	67%	0%

*E1.2. With Whom Do People Engage in Community Activities*

<b>Activity</b>	<b>Staff</b>	<b>Family</b>	<b>Friends</b>	<b>Roommates Coworkers</b>	<b>Go Alone</b>	<b>Other</b>
Visit friends, relatives, neighbors	10%	62%	8%	0%	19%	1%
Go to a supermarket	19%	70%	1%	0%	7%	3%
Go out to eat/restaurants	19%	71%	4%	0%	3%	2%
Go to a shopping center or mall	24%	65%	5%	0%	5%	2%
Go out to a worship service	14%	74%	2%	1%	8%	1%
Run errands and appointments	24%	66%	1%	0%	8%	1%
Meeting people at coffee house/tavern	25%	58%	8%	1%	6%	3%
Go out for entertainment	26%	61%	9%	0%	2%	2%

*E2. Extra-Curricular Activities*

	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
Would like to be a part of more groups in the community	64%	43%	37%

*E2.1. How Often Do You Go into the Community?*

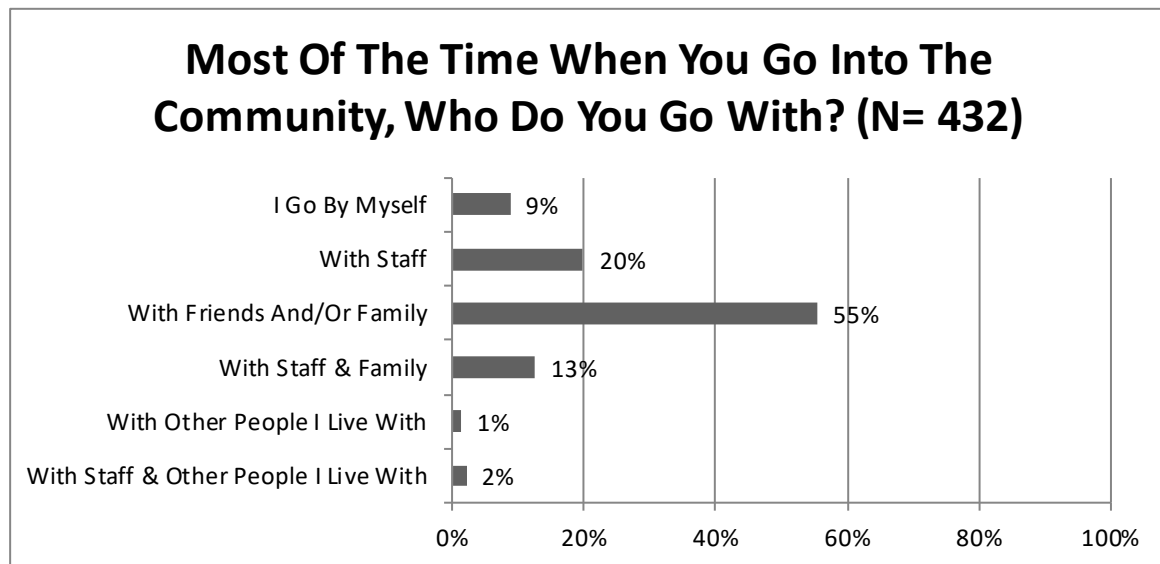
	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
Go out into the community for entertainment frequently	44%	41%	35%
Go out into the community for entertainment occasionally	35%	37%	38%

	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
Go to social events attended by people with and without disabilities frequently	28%	26%	20%
Go to social events attended by people with and without disabilities occasionally	46%	49%	46%

*E2.2. Exercise in the Community*

	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
Person never exercises	29%	36%	38%
Person exercises less than once a week	2%	4%	3%
Person exercises about once a week	9%	9%	7%
Person exercises more than once a week	60%	51%	52%

*E3. Going Out Alone or with Other People*



	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
Myself	9%	7%	6%
With Staff	20%	32%	40%
With Friends and/or Family	55%	40%	32%
With Housemates	1%	1%	1%
With Staff and Housemates	2%	3%	4%
With Staff and Family	13%	16%	17%

***E4. Transportation***

	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
Always have a way to get where they wanted to go	87%	90%	93%

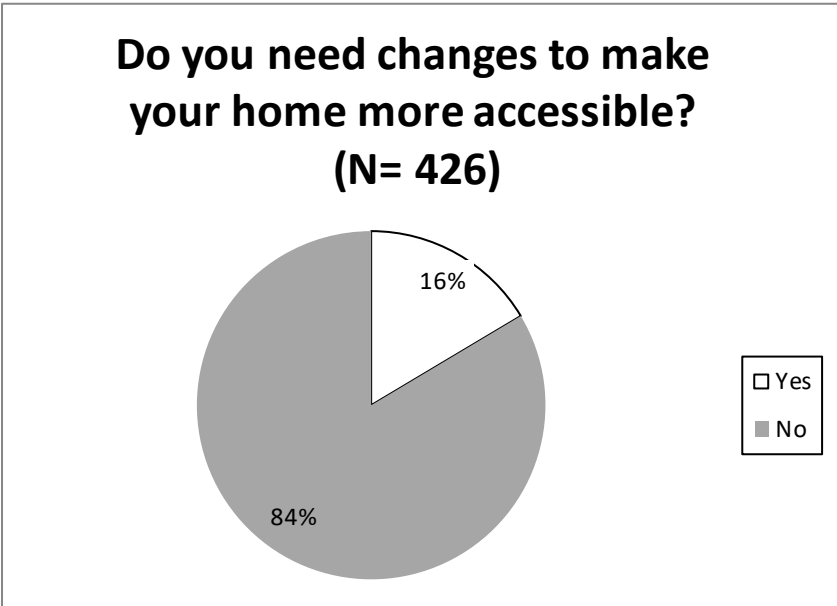
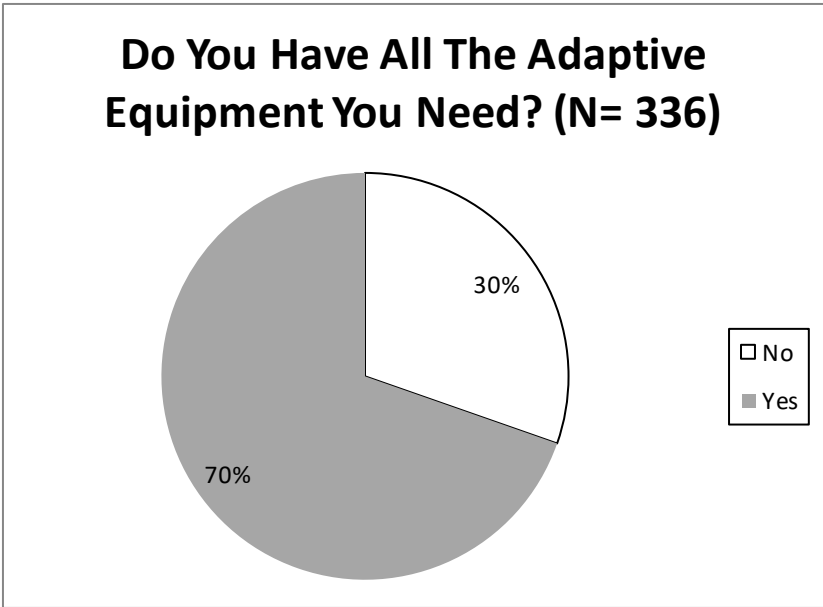
***E4.1. Transportation Methods Used Most Frequently***

	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
Get a ride from family or friends	60%	47%	39%
Get a ride from staff in provider van	20%	31%	41%
Get a ride in staff member's car	6%	12%	12%
Transport themselves	5%	6%	4%
Ride public transportation	3%	2%	2%
Ride paratransit	6%	3%	2%
Take a taxi, Uber or Lyft	1%	0%	0%

***E4.2. If You Cannot Get Where You Need to Go, Why Not?***

	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
Not enough staff	6%	21%	24%
Paratransit is unreliable	4%	8%	11%
Transportation for work/school only	6%	3%	3%
No one at home can drive	2%	1%	3%
Some other reason	82%	67%	59%

**E5. Home Adaptive Equipment**



	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
Have all the adaptive equipment needed at home	70%	86%	86%
Any adaptations or modifications needed to make the home accessible have been made	84%	90%	94%

**Section VI. Monitor Impressions of Competence, Personal Growth and Opportunities**

The questions in this section are answered by IM4Q Monitors after they have spent time with the individual in his/her home or other place of his/her choosing. The first several questions address issues of competence, personal growth, and opportunities to grow and learn. The next series of questions ask about support for the person. Since all interviews were conducted remotely this year, most monitors did not have enough information to respond to these questions.

**F. Competence, Personal Growth and Opportunities Data**

*F1. Would you (the monitor) want to live in this home, on a scale of 1 (“No way”) to 10 (“I’d move in tomorrow”)*

*F1.1. Mean and Mode of Monitor Ratings*

	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
Mean	N/A	N/A	6.74
Mode	N/A	N/A	6, 7

**G. Support for the Person Data**

*G1. Monitor Observations*

	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
Staff treat individuals with dignity and respect	100%	94%	85%
Staff recognize the individual in ways that promote independence	100%	94%	85%
Staff who support individuals have the skills they needed	100%	94%	85%

## **Section VII. Family/Friend/Guardian Survey**

This survey was completed by telephone or remotely this year with a family member, guardian, or friend who was identified through the Essential Data Elements (EDE) Pre-Survey. When a phone or remote survey could not be completed, surveys were completed by mail. Surveys were completed for 122 family members, friends, and guardians.

### **Respondents:**

Parent(s)	89%	Another Relative	3%
Sibling(s)	3%	Friend	0%
Guardian	2%	Other	2%

## **H. Family, Friend and Guardian Survey Data**

### ***H1. Daily Life***

	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
Somewhat satisfied or very satisfied with where their relative lives	88%	94%	95%
Somewhat satisfied or very satisfied with what relative does during the day	83%	89%	87%
Somewhat satisfied or very satisfied with relative's staff at home	89%	95%	94%
Somewhat satisfied or very satisfied with staff at relative's day activity	88%	94%	95%

### ***H2. How Often Do You Contact/See Your Relative?***

	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
Contacted their relative at least monthly	100%	93%	91%
Never contacted their relative	0%	1%	1%
See their relative at least monthly	100%	85%	74%
Never visited their relative	0%	2%	5%

### ***H3. Your Relative's Satisfaction***

	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
Relative is satisfied or very satisfied with his/her living situation	93%	95%	95%
Relative is satisfied or very satisfied with what they do during the day	85%	91%	89%

	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
Relative is satisfied or very satisfied with the staff who support them at home	82%	96%	95%
Relative is dissatisfied or very dissatisfied with the staff who support them at home	6%	1%	2%
Relative is satisfied or very satisfied with the staff who support them during the day	90%	94%	96%
Relative is dissatisfied or very dissatisfied with the staff who support them during the day	0%	2%	1%

#### ***H4. Your Relative's Safety***

	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
Relative always feels safe in their community, home, and neighborhood	90%	92%	89%
Relative feels safe in their community, home, and neighborhood most of the time	7%	6%	8%

#### ***H5. Your Relative's Opportunities***

	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
Relative has enough opportunities to participate in activities in the community	58%	80%	76%
Relative has the opportunity to learn new things	82%	90%	86%

#### ***H6. Your Relative's Staff***

	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
Relative's home appears to have an adequate number of paid staff	59%	84%	81%
Staff in relative's home always treat people with dignity and respect	94%	95%	95%
All staff in their relative's home have the skills they need to support their relative	88%	91%	89%
Some of the staff in their relatives home have the skills they need to support their relative	13%	9%	10%

	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
Relative's place of work appears to have an adequate number of paid staff	85%	91%	92%
Staff at relative's place of work always treat people with dignity and respect	98%	99%	97%
All staff in their relative's workplace have the skills needed to support their relative	91%	93%	93%
Some staff at their relative's workplace have the skills they need to support their relative	9%	5%	6%
The staff who assist their relative with planning always respects their choices and opinions	88%	93%	91%

### ***H7. Relative's Communication System***

	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
If their relative does not communicate verbally, there is a formal system in place, and they use it	54%	46%	47%
If there is a communication system in place, it is used across settings	70%	79%	77%

### ***H8. Relative's Supports***

	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
Satisfied with the support coordination their relative receives	57%	83%	81%
Told how much money is in their relative's budget	39%	62%	61%
Their relative directs their own services	2%	8%	12%
Their relative always receives the supports they needed	47%	74%	67%
The supports and services their relative receive change when their needs change	69%	88%	86%
There are never or rarely changes in support staff at their family member's home, work, or day program	53%	61%	55%



	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
There are always frequent changes in support staff at their family member's home, work or day program	24%	14%	17%
They chose the agency/provider who worked with their relative	60%	42%	46%
Their relative chose the agency or provider who worked with their relative, alone or with their help	14%	27%	27%
Someone else chose the agency/provider who worked with their relative	26%	31%	27%

### ***H9. Complaints and Grievances***

	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
Relative was familiar with the complaint and grievance process on some level	56%	75%	70%

#### *H9.1. At what level?*

	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
At the provider level	48%	70%	65%
At the county/AE level	44%	69%	64%
At the state level	39%	64%	60%

### ***H10. Family Resources***

	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
The information they receive about their relative's services is easy to understand	79%	89%	89%
They had learned about the Life Course Framework and Tools	15%	22%	19%
They had an opportunity to connect and network with other families with relatives at similar life stages	62%	58%	47%
They are aware of the PA Family Network (PAFN)	32%	39%	32%
Of those who were aware of the PAFN, who had attended a workshop led by the Network of Family Advisors	22%	31%	31%
Have enough information about services for which the family is eligible	70%	85%	83%

	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
If family member transitioned from school to adult services, were happy with the process	22%	26%	28%
SC asks about their vision for an everyday life for their family member	77%	84%	78%

***H11. Emergency Preparation Questions***

	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
Given information about an emergency plan for their family member in case of emergency	41%	59%	55%

This link will take you back to the [Beginning of the Report](#)