

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

***Independent Monitoring for Quality (IM4Q)***  
***Allegheny AE***  
***2022-2023***

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

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**March 2024**

## Table of Contents

<b>Table of Contents .....</b>	<b>2</b>
<b>Introduction.....</b>	<b>3</b>
Guide to the AE Report.....	3
Why We Do This .....	3
Story: Karl’s Consideration .....	4
<i>A Note About This Year’s Report: The Ongoing Impact of the Covid-19 Pandemic .....</i>	<i>4</i>
<b>Scale Scores.....</b>	<b>5</b>
<b>Sample.....</b>	<b>7</b>
i. Sample Data .....	7
<b>Part I: Satisfaction .....</b>	<b>9</b>
A. Satisfaction Data .....	9
<b>Part II: Dignity, Respect and Rights .....</b>	<b>15</b>
B. Dignity Respect and Rights Data.....	15
Part II, Section A: Dignity, Respect and Rights .....	15
Part II, Section B: Supports Coordination .....	17
Part II, Section C: Emergency Preparation .....	19
<b>Part III: Choice and Control .....</b>	<b>20</b>
C. Choice and Control Data.....	20
Part III, Section A: Choice and Control.....	20
Part III, Section B: Health Questions.....	25
Part III, Section C: Employment and Community Participation Services.....	27
Part III, Section D: Self-Directed Supports .....	31
<b>Part IV: Relationships .....</b>	<b>32</b>
D. Relationships Data .....	32
<b>Part V: Inclusion .....</b>	<b>33</b>
E. Inclusion Data .....	33
<b>Section VI. Monitor Impressions of Competence, Personal Growth and Opportunities.....</b>	<b>38</b>
F. Competence, Personal Growth and Opportunities Data .....	38
G. Support for the Person Data.....	38
<b>Section VII. Family/Friend/Guardian Survey.....</b>	<b>39</b>
H. Family, Friend and Guardian Survey Data .....	39

## **Introduction**

This report includes data gathered through the Independent Monitoring for Quality (IM4Q) project in Pennsylvania during the 2022-2023 fiscal year. Following the Covid-19 Pandemic, data collection has shifted to a hybrid model, with some interviews taking place in person and others occurring remotely. 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 IM4Q interview questionnaire, 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. The number of responses to each item varies based on missing data. The number of responses for items are represented by the provided indication of n=\_. The percentage of respondents who provided the indicated response is then estimated to the nearest whole number.

## **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 Administrative Entity (AE) or the Bureau of Supports for Autism and Special Populations (BSASP). If the consideration is not addressed, the consideration process continues. When the person or family are satisfied with the action to address the consideration, 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 2022-2023 collection year, over 6,000 considerations were collected. Of these, nearly 70% have been closed. An analysis of this year’s considerations can be found at the end of the statewide report.

The IM4Q team also gathered several examples of completed considerations from the local IM4Q programs. These stories provide examples 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: Karl’s Consideration**

When we interviewed Karl this year, he told the team that he is in need of new clothes and shoes. Some questioning revealed that Karl felt he did not have enough money in his budget to afford new clothes. The team offered some places that give clothes away for free, but Karl shared that these places are too far for him to walk and that he did not have transportation to get there.

Karl’s SC talked to Karl, then the SC and SC supervisor met with Karl to discuss the best options. Karl indicated that he would prefer new clothes and shared what type of clothes and shoes he needed. The SC and SC coordinator reminded Karl that a request can be made to his Representative Payee at any time, should he need items, and supported him to request the funds he needed. Soon, Karl was able to go shopping, and purchased \$160 worth of new clothing (pants, shorts, shirts and socks) and a new pair of shoes. Karl was satisfied with the items he chose and looks great in his new wardrobe!

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

For the 2022-2023 fiscal year, individuals had the option to participate in interviews held in person or remotely. This year, 75% of the interviews were conducted remotely using video conferencing and 25% were done in person. These methods, as well as some persistent hesitation about in person 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 where the data may have been influenced by social trends related to these issues.

## **Scale Scores**

The scale scores in the tables below include a mean and a standard deviation (SD). 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	77.37	84.05	84.23
SD	22.39	19.49	19.82

**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	73.34	81.46	83.66
SD	14.78	16.15	15.47

**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	89.77	91.70	92.60
SD	18.42	17.00	15.73

**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	61.31	63.39	60.93
SD	19.71	19.86	20.79

**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	41.13	42.17	43.54
SD	17.25	17.60	17.87

**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	7.76	7.56
SD	N/A	2.60	2.50

**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	82.04	91.31	90.13
SD	22.03	14.03	14.07

## **Sample**

### **i. Sample Data**

#### ***i1. Total Surveyed***

People with disabilities	450	Family members	27
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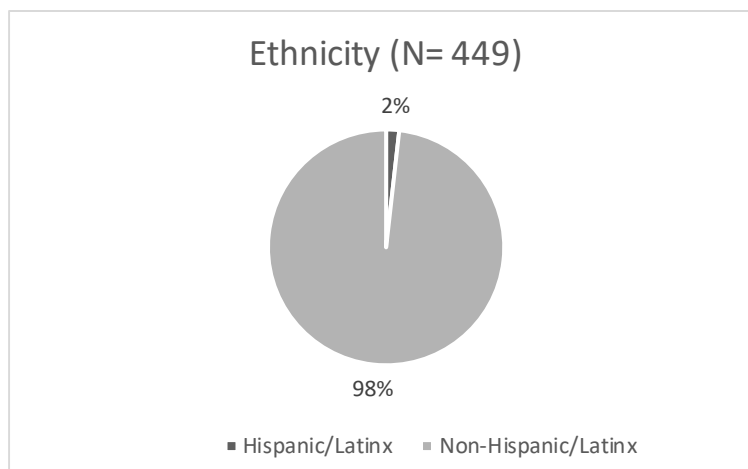
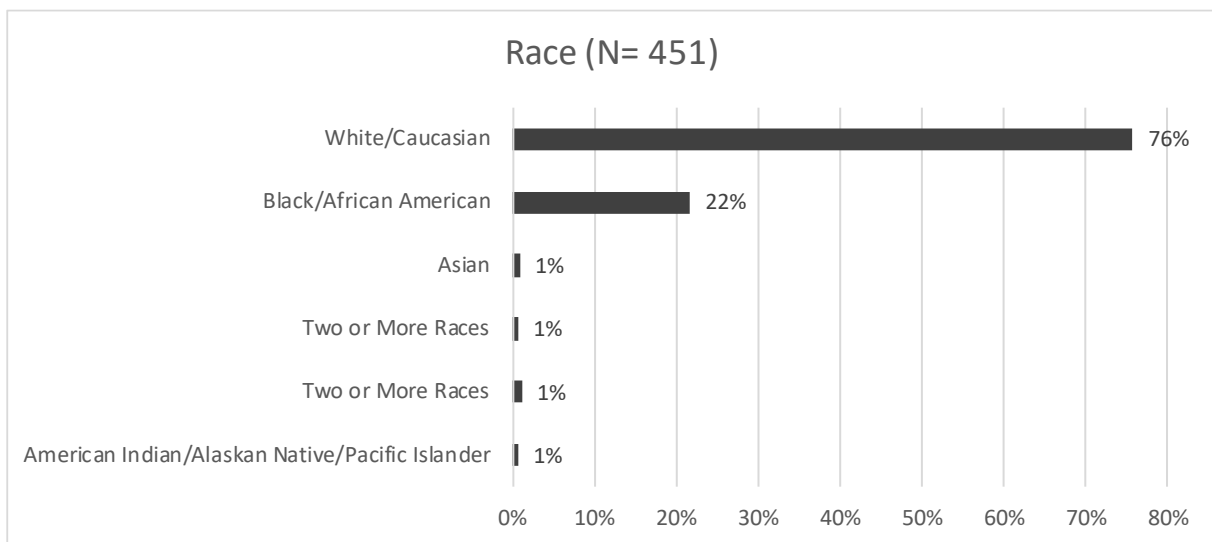
#### ***i2. Age***

Range	10-84	Mean Age (SD)	42.4 (17.4)
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#### ***i3. Reported Gender***

Female	40.3%	Male	59.7%	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	153	34.0%	1733	42.8%
Community Home-Subtotal	229	50.9%	1458	36.0%
<i>Community Home 1</i>	20	4.4%	123	3.0%
<i>Community Home 2-4</i>	197	43.8%	1261	31.2%
<i>Community Home 5-6</i>	5	1.1%	44	1.1%
<i>Community Home 7-8</i>	1	0.2%	16	0.4%
<i>Community Home 9-15</i>	4	0.9%	6	0.1%
<i>Community Home 16+</i>	2	0.4%	8	0.2%
Own Residence	24	5.3%	336	8.3%
Family Living/Lifesharing	2	0.4%	141	3.5%
Private ICF/ID - Subtotal	39	8.7%	197	4.9%
<i>Private ICF/ID 1-4</i>	12	2.7%	41	1.0%
<i>Private ICF/ID 5-8</i>	12	2.7%	57	1.4%
<i>Private ICF/ID 9-15</i>	0	0.0%	16	0.4%
<i>Private ICF/ID 16+</i>	15	3.3%	83	2.1%
Personal Care Home	0	0.0%	30	0.7%
Nursing Home/Facility	2	0.4%	26	0.6%
Children's Facility	0	0.0%	2	0.0%
Unlicensed Family Living	0	0.0%	7	0.2%
Domiciliary Care	0	0.0%	7	0.2%
Foster Care	0	0.0%	1	0.0%
Approved Private School	0	0.0%	2	0.0%
State Operated ICF/MR	0	0.0%	8	0.2%
State MH Hospital	0	0.0%	0	0.0%
Temporary Shelter	0	0.0%	1	0.0%
Other	1	0.2%	24	0.6%
<i>Data on Type of Residence Missing</i>	0	-	75	-
<b>Total</b>	450	100%	4048	100%



## **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**

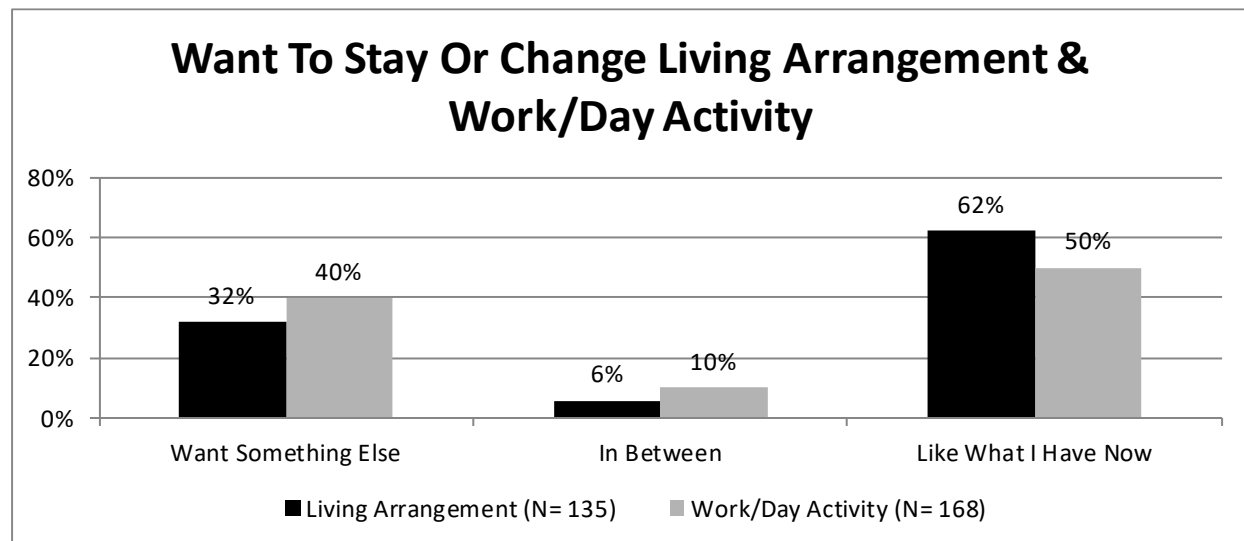
#### ***A1. Living Arrangements***

	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
Like where they live now	84%	87%	88%
Want to stay where they currently live	62%	74%	74%
Want to move somewhere else	32%	20%	18%
In between wanting to stay and wanting to move	6%	6%	8%

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

	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
Like primary job or day activity	88%	89%	90%
Like other job or day activity	94%	95%	93%
Want to continue current job or day activity	50%	71%	71%
Want to do something else.	40%	20%	19%
In between wanting to continue and wanting to change jobs	10%	9%	10%

#### ***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	25%	27%	25%
Work	31%	27%	25%
<i>Work- no supports</i>	<i>18%</i>	<i>17%</i>	<i>15%</i>
<i>Work- with supports</i>	<i>13%</i>	<i>10%</i>	<i>10%</i>

<b>Primary Activity</b>	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
Attend school	3%	6%	6%
Attend a vocational facility	10%	11%	12%
Attend a day program or community center	8%	9%	10%
Go out in the community	11%	11%	14%
Retired	3%	2%	2%
Volunteer	1%	2%	2%
Something else	8%	5%	5%

<b>Secondary Activity</b>	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
Stay home	37%	40%	40%
Work	2%	4%	4%
<i>Work- no supports</i>	2%	2%	2%
<i>Work- with supports</i>	0%	1%	1%
Attend school	1%	1%	1%
Attend a vocational facility	4%	4%	2%
Attend a day program or community center	3%	3%	2%
Go out in the community	17%	23%	28%
Retired	2%	1%	1%
Volunteer	3%	3%	6%
Something else	32%	21%	17%

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

	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
Do not have or want a job	35%	53%	55%
Would like a job for pay	64%	41%	40%
Uses special technology to help do work	3%	12%	14%

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

	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
Always get services they need	79%	85%	83%
Sometimes get services they need	3%	2%	2%
Do not get services they need	9%	6%	7%
Need additional services	9%	7%	8%

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

##### ***A5.1. Happy with Life***

	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
Happy with life	81%	84%	83%
Neither happy nor sad with life	14%	13%	14%
Sad with life	5%	3%	3%

##### ***A5.2. Loneliness***

	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
Never lonely	62%	64%	64%
Sometimes lonely	31%	31%	31%
Always lonely	7%	5%	5%

##### ***A5.3. Friendship***

	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
Have friends to do things with	87%	87%	83%
Friends are not staff or family	70%	75%	70%
Have a best friend	74%	74%	69%

##### ***A5.4. Dating and Marriage***

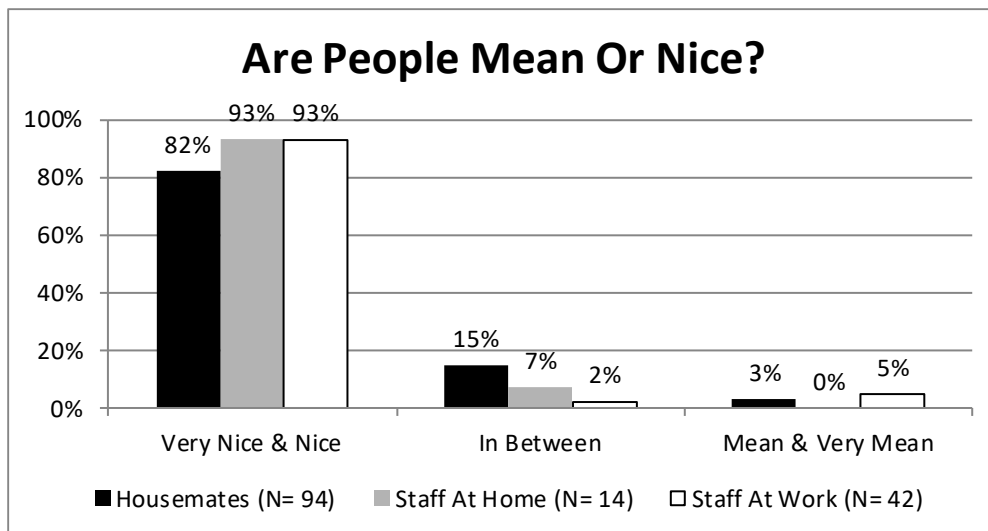
	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
Can date/marry, no restrictions	84%	85%	84%
Can date/marry, restrictions	2%	2%	5%
Cannot date/marry at all	14%	12%	11%

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

	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
Have enough privacy (a place to be alone) at home	96%	96%	97%
No rules about friends or visitors	72%	77%	79%
People always let them know when coming into their home	81%	86%	88%
Sometimes people let them know when coming into their home	8%	8%	7%

	AE	Region	Statewide
People never let them know when coming into their home	10%	6%	5%
People always let them know when coming into their bedroom	75%	82%	86%
People sometimes let them know when coming into their bedroom	9%	7%	6%
People never let them know when coming into their bedroom	16%	11%	8%

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



	AE	Region	Statewide
Staff at day or work activity are nice or very nice	93%	96%	97%
Staff at day or work activity are in between nice and mean	2%	2%	2%
Staff at day or work activity are mean or very mean	5%	2%	1%
Staff at home are nice or very nice	93%	94%	96%
Staff at home are in between nice and mean	7%	6%	4%
Staff at home are mean or very mean	0%	0%	0%
Housemates are nice or very nice	82%	85%	87%
Housemates are in between nice and mean	15%	12%	11%
Housemates are mean or very mean	3%	3%	2%
Get along well with the person they share a bedroom with*	100%	95%	87%

	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
Get along OK with the person they share a bedroom with*	0%	3%	6%
Do not get along with the person they share a bedroom with*	0%	3%	7%

\*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**

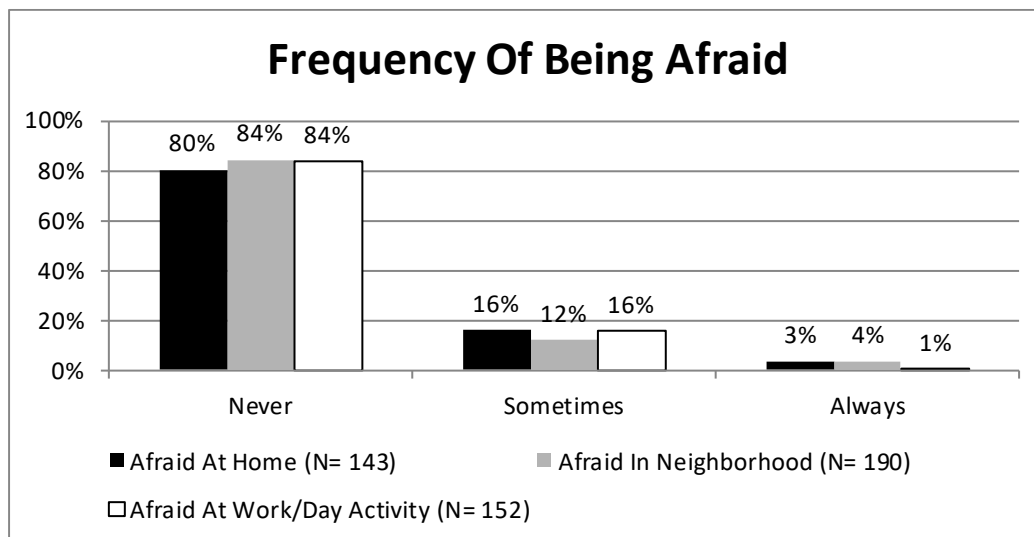
##### ***B1. Support with Goals and Problems***

	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
Get help to learn new things	78%	83%	79%
Do not get help	12%	9%	12%
Get to help other people	61%	72%	66%
Have participated in a self-advocacy group meeting	28%	23%	19%
Someone has talked to them about self-advocacy	73%	63%	53%
Have someone to talk to when afraid	94%	94%	95%

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

	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
Staff	58%	53%	49%
Supports coordinator	2%	10%	10%
Other	23%	14%	9%
Family	34%	44%	49%
Friends	5%	10%	8%
Have no one	0%	2%	1%

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



	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
Never afraid at home	80%	85%	87%
Sometimes afraid at home	16%	12%	10%
Always afraid at home	3%	3%	3%
Never afraid in the neighborhood	84%	85%	87%
Sometimes afraid in the neighborhood	12%	12%	11%
Always afraid in the neighborhood	4%	3%	2%
Never afraid at work or day activities	84%	91%	92%
Sometimes afraid at work or day activities	16%	8%	6%
Always afraid at work or day activities	1%	2%	2%

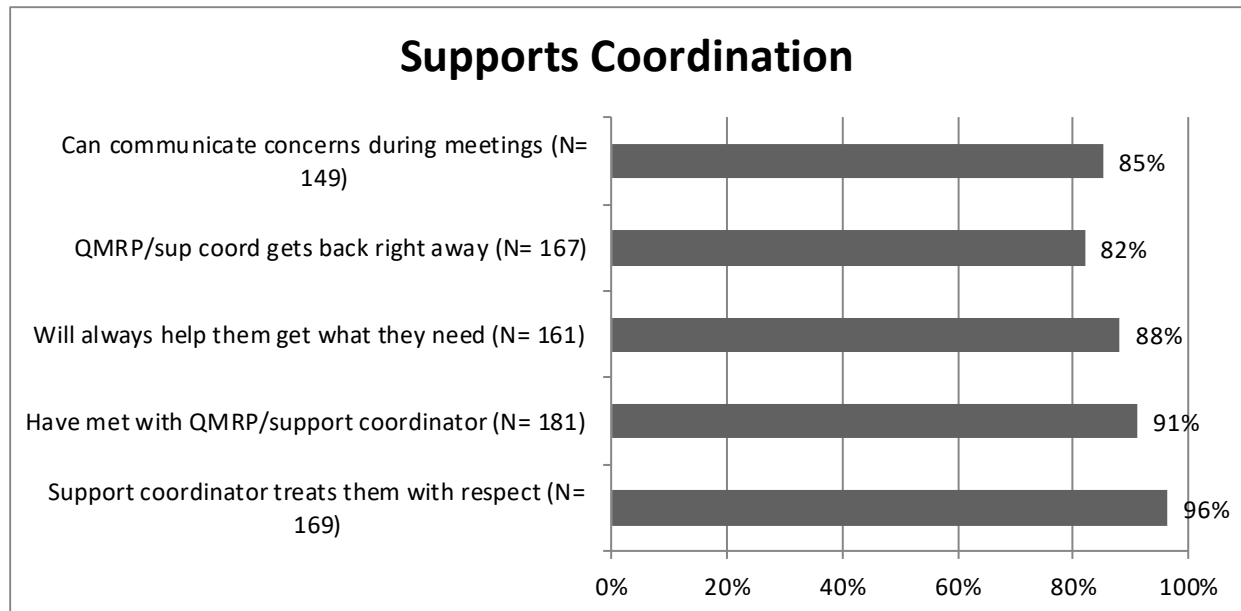
### ***B3. Legal Rights***

	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
Mail is never opened without permission	84%	86%	87%
Mail is sometimes opened without permission	7%	8%	7%
Mail is always opened without permission	9%	6%	7%

## 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

	AE	Region	Statewide
SC asks what their interests are	91%	92%	92%
SC asks what they want their life to look like	81%	83%	86%
SC knows what is important to them	91%	91%	89%
SC asks them about directing their own services	41%	48%	40%
SC asks if community employment is a possibility <sup>+</sup>	72%	64%	62%
SC asks if services are OK	98%	97%	96%
SC always listens to them	98%	96%	96%

#### B4.2. SC Interaction

	AE	Region	Statewide
Person knows they can choose SC	72%	75%	72%
SC always gets back to them right away	82%	88%	89%
SC will always help them get what they need	88%	90%	89%



	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
Person has met with SC in the last year	91%	92%	93%
SC always treats the person with respect	96%	97%	98%

#### ***B5. Annual Planning Meeting***

	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
Participated in the meeting	96%	96%	96%
Know it is an option but choose not to participate in meeting	2%	1%	1%
Can communicate their concerns during the meeting	85%	88%	88%
Sometimes get to communicate concerns	7%	7%	8%
Told at the meeting how much money is in their budget	42%	59%	54%
Meeting includes the people they wanted to be there	94%	94%	95%
Know what is talked about at their ISP meeting	81%	79%	81%

#### ***B6. Services***

	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
Know who to ask if they want to change their services	77%	81%	80%
Do not know who to ask to change services	21%	15%	14%

#### ***B7. Staff***

	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
Staff always treat them with respect	91%	92%	94%
Staff are respectful of culture	95%	98%	98%
Have staff who help them	83%	76%	77%
Staff do things the way the individual wants them done	85%	87%	89%
Staff have the right training to meet their needs	95%	96%	94%
All staff always understand their communication	88%	89%	90%
Some staff understand them	4%	7%	6%
Sometimes understood by staff	7%	3%	3%
Not understood by staff	1%	1%	0%

## Part II, Section C: Emergency Preparation

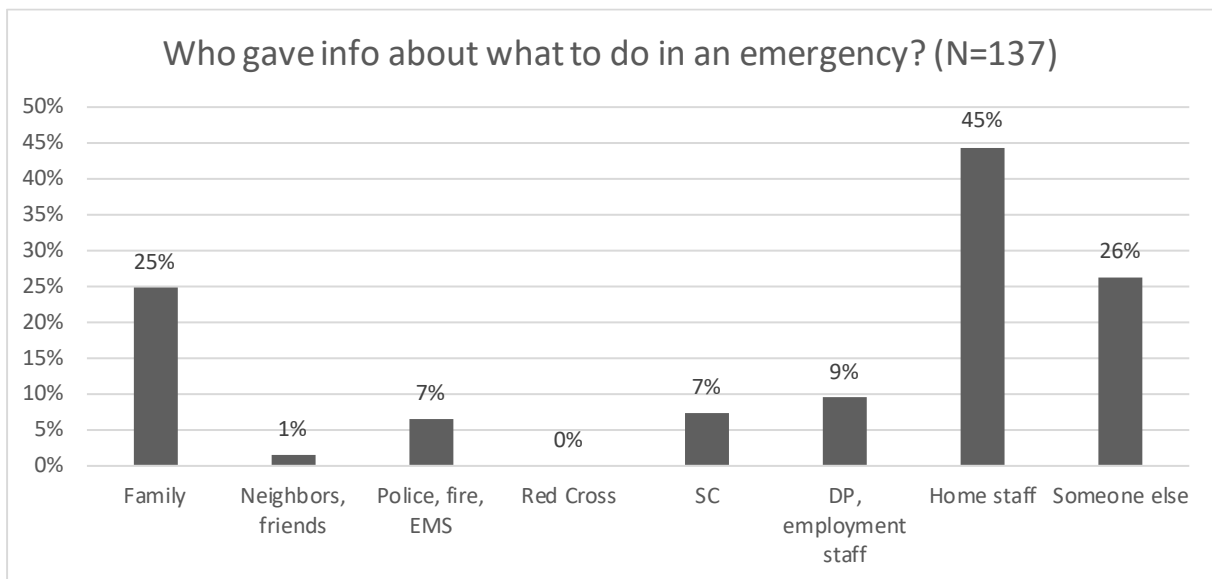
This section asks questions related to emergency preparation. These questions can only be answered by the individual receiving services.

### B8. Emergency Preparation Questions

	AE	Region	Statewide
Have been given information about what to do in an emergency	86%	88%	84%

#### B8.1. Who Provided Emergency Information

	AE	Region	Statewide
Home staff	45%	36%	36%
Day staff	9%	13%	13%
Family	25%	35%	46%
SC	7%	16%	10%
Police, Fire, or EMS Workers	7%	5%	3%
Friends	1%	3%	2%
Red Cross	0%	1%	0%
Someone Else	26%	17%	12%



### **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	21%	Individual and Paid staff	22%
Paid staff	27%	Individual and Family/friend/guardian/advocate	11%
Family/friend/guardian/advocate	19%	Staff and Family/friend/guardian/advocate	0%

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

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

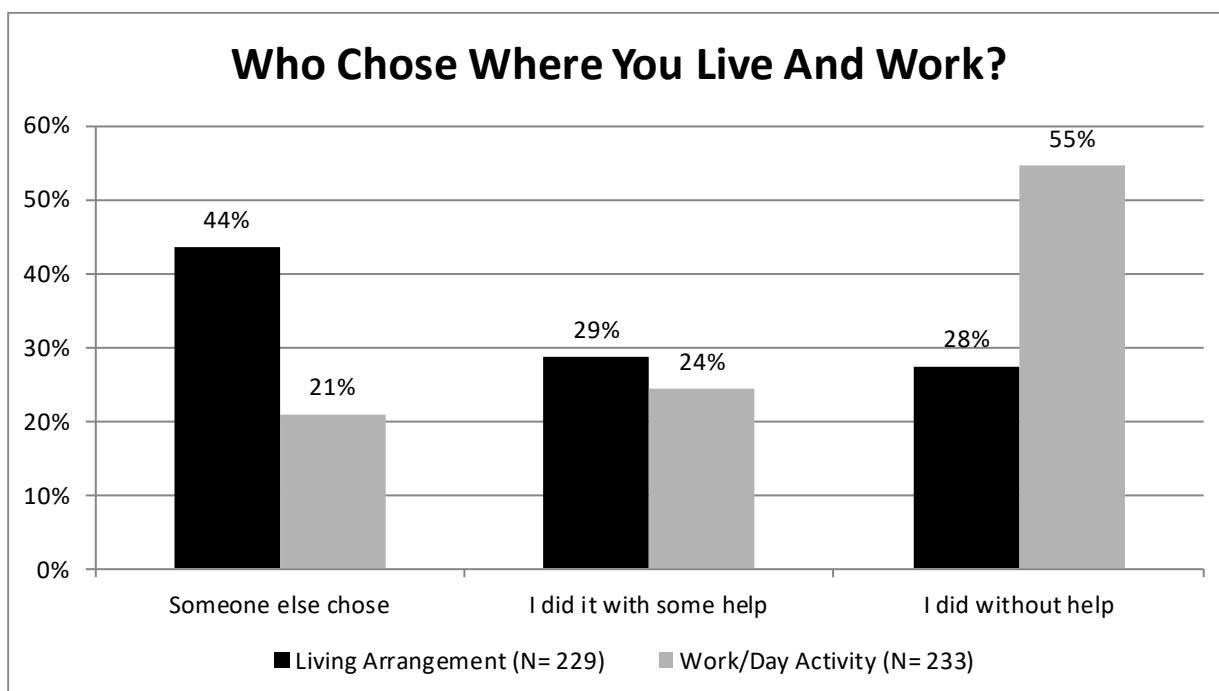
##### ***C1. Identification***

	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
Always carry ID	60%	62%	67%
Never carry ID	24%	23%	18%

##### ***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	56%	51%	50%
If other household members go out, they have the option to stay home	42%	44%	45%
If other household members go out, they sometimes can stay home	13%	12%	13%
Can lock bedroom door	61%	54%	52%
Own their home	2%	2%	3%
Name is on the lease or rental agreement	52%	44%	37%
Have a choice to live where people without disabilities live	53%	46%	46%
Saw no other places before they moved into their home	41%	43%	46%
Did not choose housemates	64%	66%	63%
If individual shares a bedroom, chose some or all roommates	39%	36%	41%

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

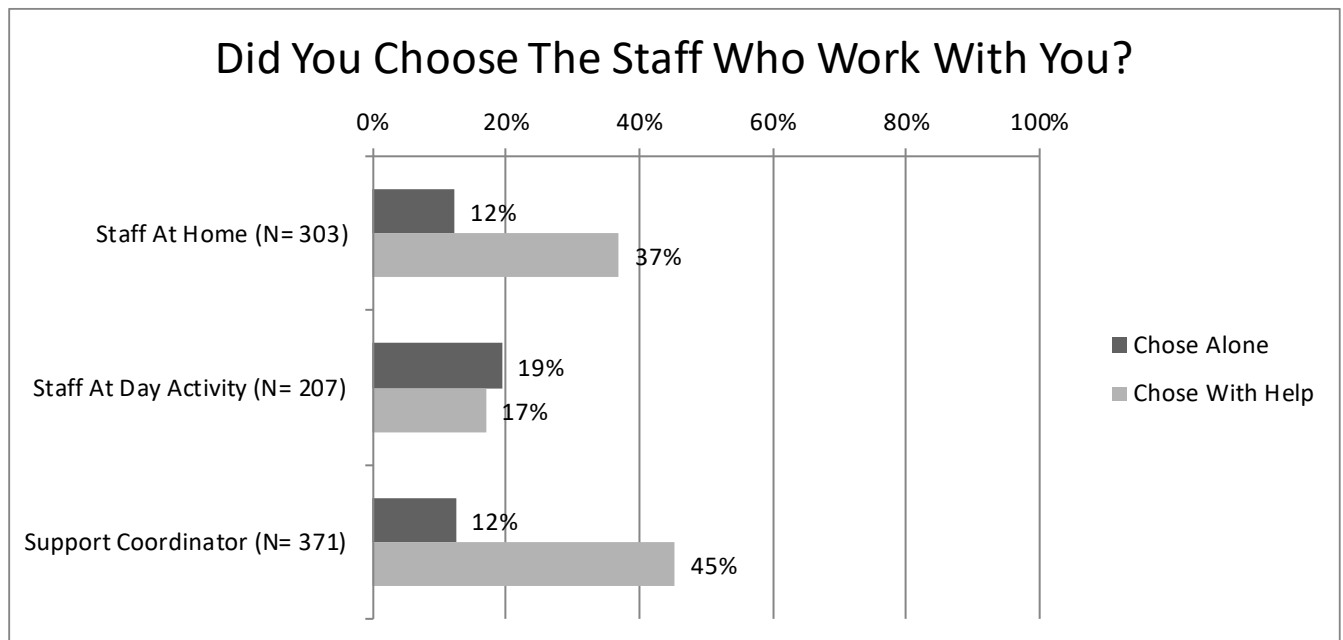


	AE	Region	Statewide
Chose living arrangement without help	28%	28%	26%
Chose living arrangement with some help	29%	25%	27%
Someone else chose living arrangement	44%	47%	47%
Chose work or day activity without help	55%	57%	54%
Chose work or day activity with some help	24%	23%	29%
Someone else chose work or day activity	21%	20%	17%

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

	AE	Region	Statewide
Have the choice to go where people without disabilities go	77%	69%	69%
See no other places when choosing day activity	41%	41%	39%
Choose daily schedule without assistance	85%	89%	89%
Have enough choice about free time	94%	95%	94%

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

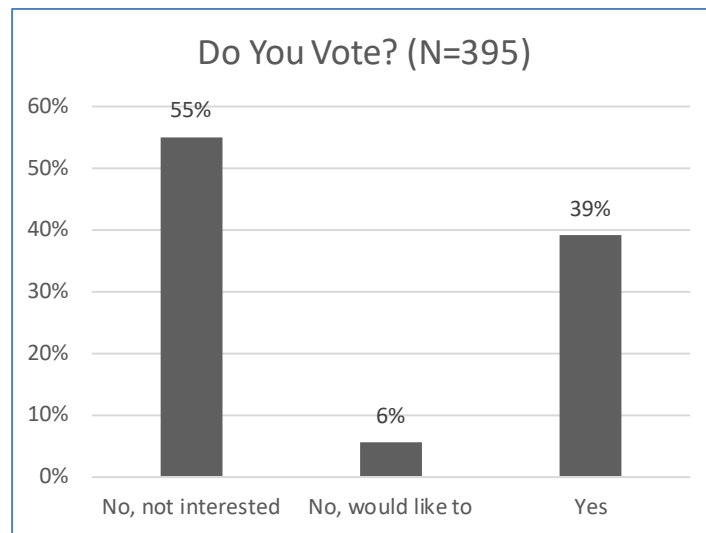


	AE	Region	Statewide
Chose SC without help	12%	22%	18%
Chose SC with some help	45%	31%	27%
Someone else chose SC	42%	48%	56%
Chose staff at work or day activity without help	19%	21%	17%
Chose staff at work or day activity with some help	17%	21%	23%
Someone else chose staff at work or day activity	64%	58%	60%
Chose staff at home without help	12%	14%	13%
Chose staff at home with some help	37%	34%	34%
Someone else chose staff at home	51%	53%	53%

#### C5. Choice and Control Regarding Money

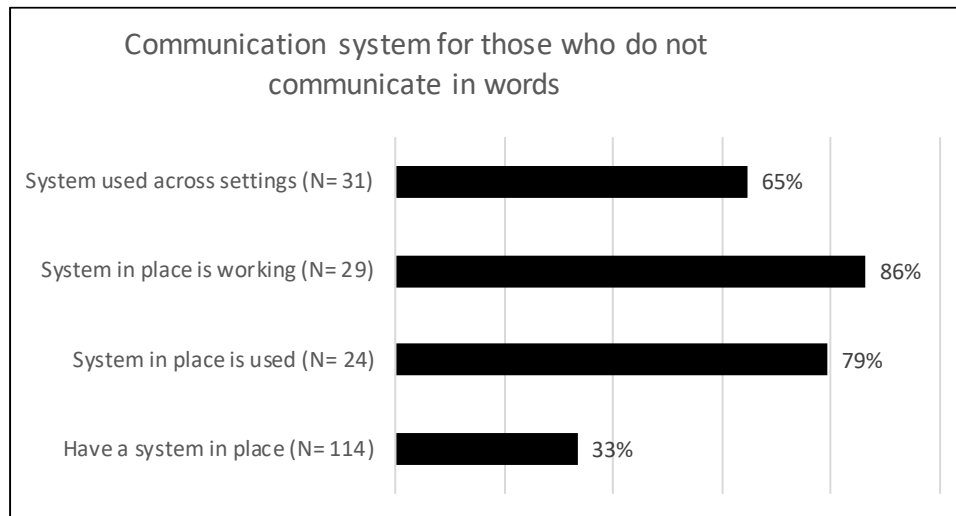
	AE	Region	Statewide
Always choose alone what to buy with spending money	60%	62%	58%
Choose what to buy with help	37%	32%	36%
There is something they want to buy	72%	51%	52%
They have a bank account and withdrawal money when they want	77%	74%	72%

## C6. Voting



	AE	Region	Statewide
Votes	39%	33%	38%
Chooses not to vote	55%	63%	57%
Does not vote but would like to	6%	5%	5%

## C7. Status of Formal Communication System



	AE	Region	Statewide
Have a communication system in place*	33%	31%	33%
System is being used**	79%	86%	86%
System is working**	86%	90%	92%
System is used across settings**	65%	71%	77%

\* 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	50%	52%	57%
Speech Language Clinician	36%	28%	28%
Parent or Caregiver	36%	53%	40%
Someone Else	7%	17%	12%

*Note: People had the option to select more than one response for C8.*

***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	44%	43%	42%
E-mail	22%	30%	26%
Internet	71%	67%	61%
Text-messaging	33%	33%	30%
Cable TV	95%	91%	92%
Computer	66%	63%	61%

***C9.2. Restrictions in Place for Communication***

	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
Cell phone	12%	10%	8%
E-mail	5%	5%	5%
Internet	5%	8%	8%
Text-messaging	3%	4%	5%
Cable TV	7%	7%	6%
Computer	10%	10%	9%

*Note: People had the option to select more than one response for C9.*

### 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. These questions can be answered by the individual and/or their paid staff, family/friend/guardian/advocate, or some combination of these.

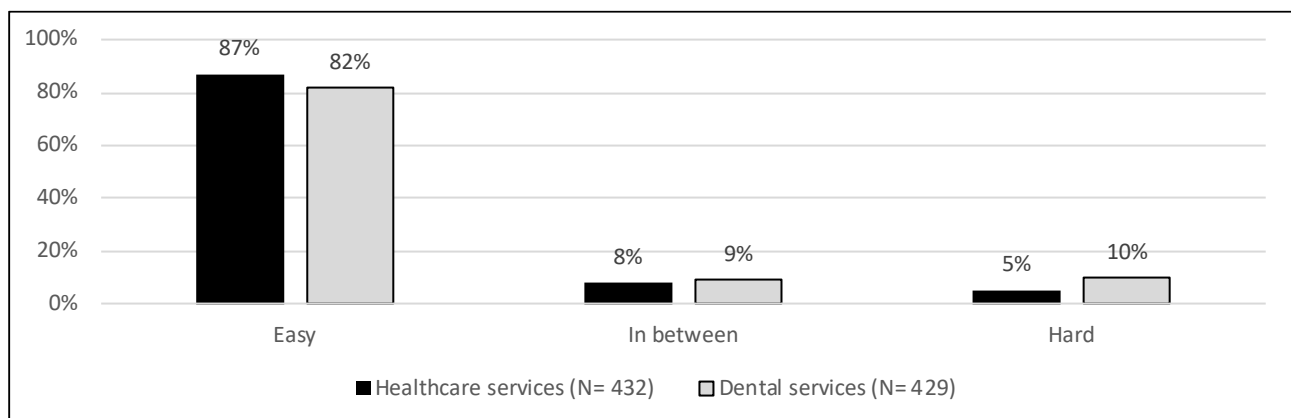
#### *C10. Exercise at Home*

	AE	Region	Statewide
Exercises at home 10+ times per month	20%	33%	37%
Exercises at home <1 time per month	66%	52%	48%

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

	AE	Region	Statewide
Describes health as very good or excellent	49%	49%	50%
Opportunity to discuss health with primary care provider (PCP)	90%	91%	87%
Has talked with health care provider using telehealth	65%	57%	52%
Like talking to health care provider using telehealth	52%	54%	53%
Able to see a medical specialist if needed	97%	98%	97%
Have not been prevented from receiving medical or dental care due to disability	91%	90%	88%

#### *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%	87%	89%
Accessing medical care is between easy & hard	8%	8%	7%
Accessing medical care is hard or very hard	5%	5%	4%
Accessing dental care is very/pretty easy	82%	78%	81%
Accessing dental care is in between easy and hard	9%	9%	8%
Accessing dental care is hard or very hard	10%	13%	11%

***C12. Mental Health***

	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
Have an opportunity to discuss health concerns with psychiatrist	87%	74%	64%
Do not have psychiatrist, but want one	4%	3%	3%

***C13. Communicating Health Needs***

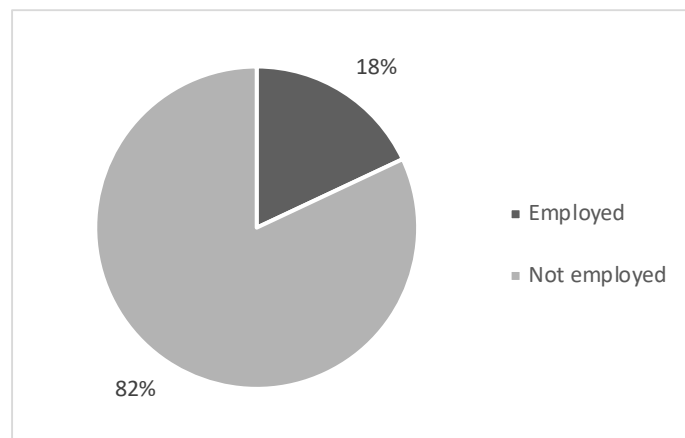
	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
Their doctor understands them	84%	83%	81%
They understand their doctor's instructions	54%	61%	61%
If they need help communicating at doctor's office, it is available	99%	97%	95%
Doctor speaks directly to them during appointments	94%	95%	94%
Able to provide consent for medical treatment	79%	72%	64%
If they provide consent, is it accepted	78%	79%	81%

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

Employment in this survey refers to **Competitive 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. Questions about employment benefits, hours, salary, and field of work are only addressed to people who indicated they are employed in CIE.

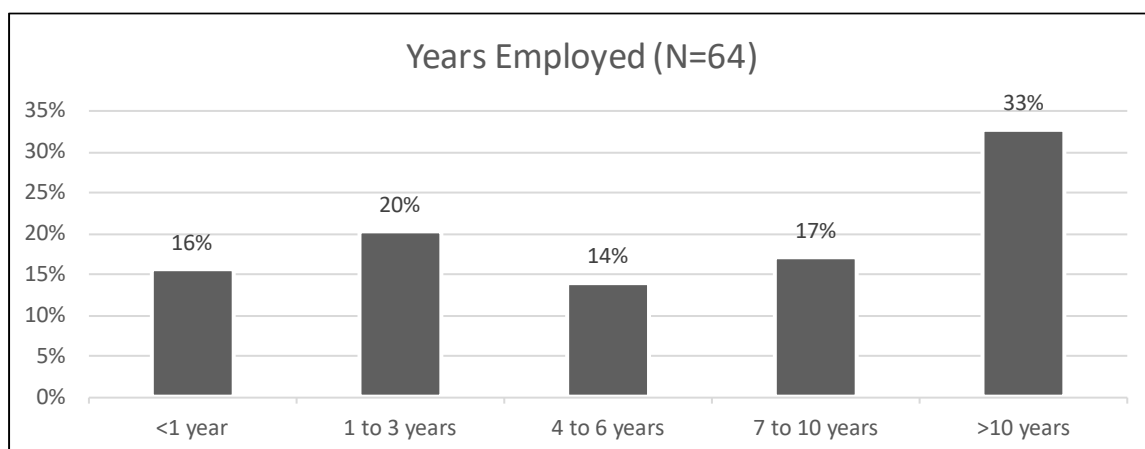
The survey also asks about **Community Participation Services (CPS)**, or services that give people with intellectual and developmental disabilities opportunities and support for community inclusion and skill development. Questions about employment benefits, hours, salary, and field of work are only 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*



	AE	Region	Statewide
Employed in CIE	18%	17%	17%

#### *C15. Length of Employment*



	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
Employed <1 Year	16%	17%	18%
Employed 1 to 3 Years	20%	30%	31%
Employed 4 to 6 Years	14%	15%	18%
Employed 7 to 10 Years	17%	13%	12%
Employed 11+ Years	33%	25%	21%

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

Cleaning Services	30%	Assembly/Factory Work	4%
Food Services	19%	Care Workers/Aides	1%
Retail Services	19%	Recycling	0%
Office Work	3%	Outdoor Work	0%
Stock Room	3%	Animal Care	N/A
Maintenance	0%	Other	20%

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

	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
Take classes/training for employment purposes	9%	8%	8%
Talked about employment in their planning meeting	53%	52%	50%
Community employment is a goal in their plan	46%	34%	32%

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

No one	49%	SC	46%
Service Provider	3%	Family	7%
Housemates	0%	Someone Else	8%

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

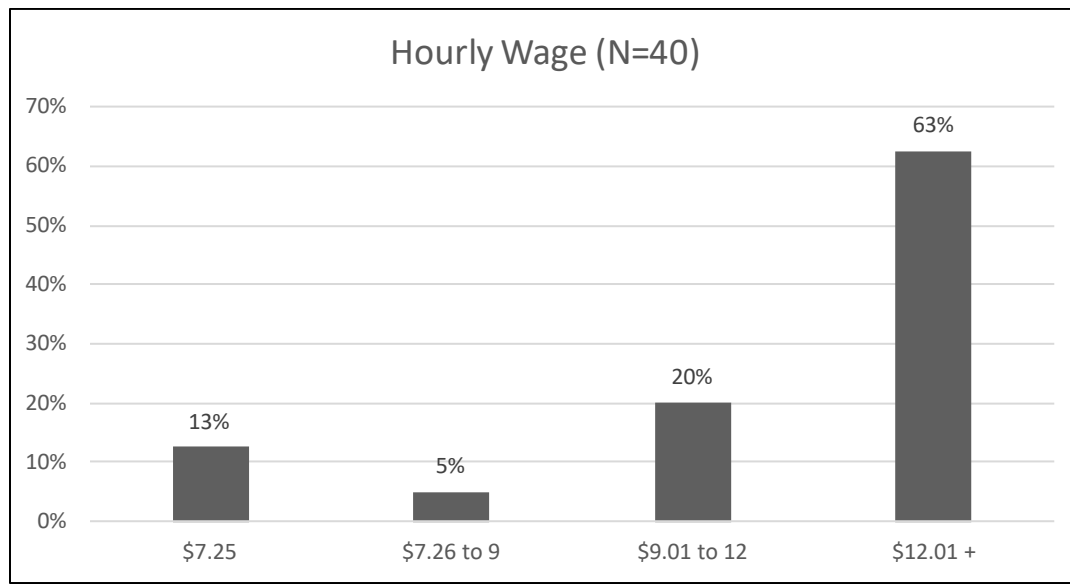
#### ***C18. Self-Employment***

	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
Person reports that they are self-employed	1%	1%	1%

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

	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
Have been promoted or received an increase in pay	62%	53%	54%
Receive paid time off from work as a benefit of employment	92%	72%	80%
Receive health insurance benefits from employer	13%	14%	20%
Receive retirement benefits from their employer	13%	18%	23%
Receive other work benefits from their employment	4%	18%	15%
Know how much they earn and willing to share	89%	81%	75%

### ***C19.1. Hourly Wage***



	AE	Region	Statewide
\$7.25 per hour (Minimum wage)	13%	17%	10%
\$7.26 - \$9.00 per hour	5%	13%	13%
\$9.01 - \$12.00 per hour	20%	27%	31%
\$12.01 or more per hour	63%	44%	46%

### ***C20. Community Participation***

	AE	Region	Statewide
Use Community Participation Services (CPS)	30%	32%	27%

#### ***C20.1. If yes, CPS Services Used***

	AE	Region	Statewide
Developing skills and competencies necessary for employment	6%	9%	11%
Fine/gross motor skill development and mobility	15%	15%	18%
Participating in community activities to develop social networks	54%	54%	56%
Participating in opportunities to develop interests or promote health/wellness	77%	78%	73%
Training/education for self-determination and self-advocacy	6%	10%	11%
Community adult learning opportunities	10%	12%	12%

	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
Volunteering opportunities	15%	22%	27%
Learning to navigate the local community	10%	11%	9%

***C21. Technology use***

	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
Internet at home always works	89%	82%	84%
Uses technology in their everyday life to do things on their own	35%	36%	36%
Has enough help to use technology in everyday life	92%	91%	93%
Has talked to SC using videoconference	67%	53%	57%
<i>Likes talking to SC using videoconference</i>	52%	57%	59%
Has used videoconference for other services	41%	36%	33%
<i>Likes using videoconference for other services</i>	47%	54%	59%

### **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.**

#### ***C22. Self-Directed Services***

	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
Use self-directed services	1%	4%	7%

#### ***C23. Who Makes Choices About Budget?***

	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
Individual makes decisions on their own	0%	38%	15%
Individual has input, family and friends help	100%	35%	37%
A family member or friend makes decisions	0%	15%	39%
A case manager or state professional makes the decision	0%	12%	8%

#### ***C24. Making Decisions***

	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
Can make changes to their budget or services if they need to	75%	93%	92%
Have enough help deciding how to use their budget/services	100%	93%	91%
Want more help deciding how to use their budget/services	0%	7%	5%

#### ***C25. Money Left in Budget***

	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
Receive information about the money left in their budget	33%	76%	68%
Information they receive is easy to understand	0%	83%	82%
They receive information at least every 3 months	100%	71%	65%
They receive information about twice a year	0%	14%	18%
They receive information once a year or less	0%	14%	18%

## Part IV: Relationships

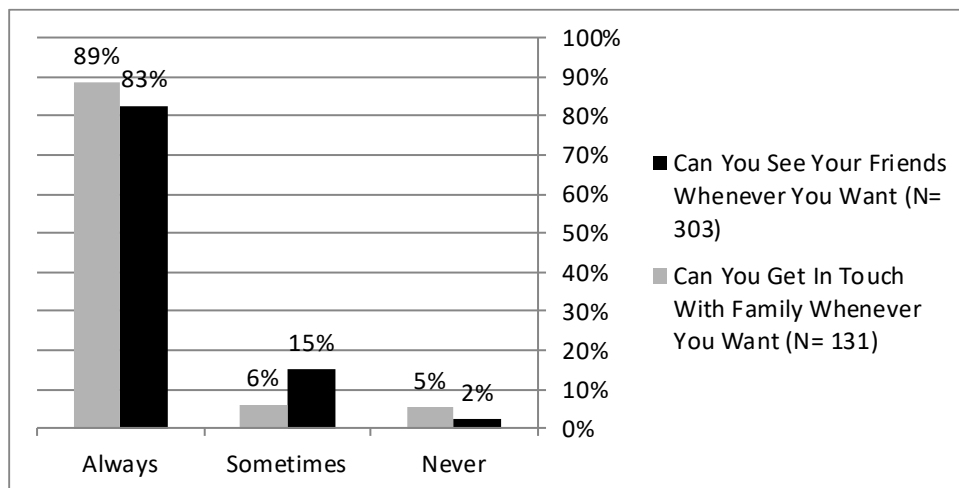
Relationships questions ask about individuals' interactions with others in their lives. These questions can be answered by the individual, paid staff, a family member, friend or advocate, or a combination of these.

### Respondents:

Individual	32%	Individual and Paid staff	13%
Paid staff	30%	Individual and Family/friend/guardian/advocate	6%
Family/friend/guardian/advocate	19%	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	83%	83%	81%
Sometimes see friends when they want to	15%	14%	15%
Never get to see friends when they want to	2%	3%	4%
Always can get in touch with family when they want to	89%	89%	84%
Sometimes can get in touch with family when they want to	6%	7%	10%
Never can get in touch with family when they want to	5%	4%	6%

## **Part V: Inclusion**

These questions explore how much time individuals spend in the community. Questions can be answered by the individual, paid staff, a family member, friend or advocate, or a combination of these. It is possible that persistent hesitation about socialization following the Covid-19 Pandemic and the ongoing staff shortage affected these numbers.

### **Respondents:**

Individual	18%	Individual and Paid staff	21%
Paid staff	31%	Individual and Family/friend/guardian/advocate	12%
Family/friend/guardian/advocate	18%	Staff and Family/friend/guardian/advocate	0%

## **E. Inclusion Data**

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

#### ***E1.1. How Much People Engage in Community Activities***

<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	54%	50%	46%
Go to a supermarket	43%	48%	49%
Go out to eat/restaurants	46%	46%	45%
Go to a shopping center or mall	38%	37%	40%
Go out to a worship service	17%	22%	23%
Run errands and appointments	30%	30%	27%
Meeting people at coffee house/tavern	16%	15%	18%
Go out for entertainment	32%	29%	25%

#### ***E1.2. 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	52%	45%	3%
Go to a supermarket	65%	29%	6%
Go out to eat/restaurants	52%	44%	3%
Go to a shopping center or mall	55%	39%	6%



<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>
Go out to a worship service	66%	31%	3%
Run errands and appointments	66%	17%	17%
Meeting people at coffee house/tavern	62%	36%	2%
Go out for entertainment	55%	43%	2%

### ***E1.3. 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	35%	39%	9%	3%	13%	0%
Go to a supermarket	54%	33%	0%	6%	7%	0%
Go out to eat/restaurants	50%	33%	6%	8%	3%	0%
Go to a shopping center or mall	59%	30%	1%	6%	4%	0%
Go out to a worship service	29%	57%	3%	4%	7%	0%
Run errands and appointments	59%	31%	0%	3%	7%	0%
Meeting people at coffee house/tavern	57%	26%	5%	4%	7%	1%
Go out for entertainment	50%	31%	6%	8%	4%	1%

### ***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	50%	36%	36%

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

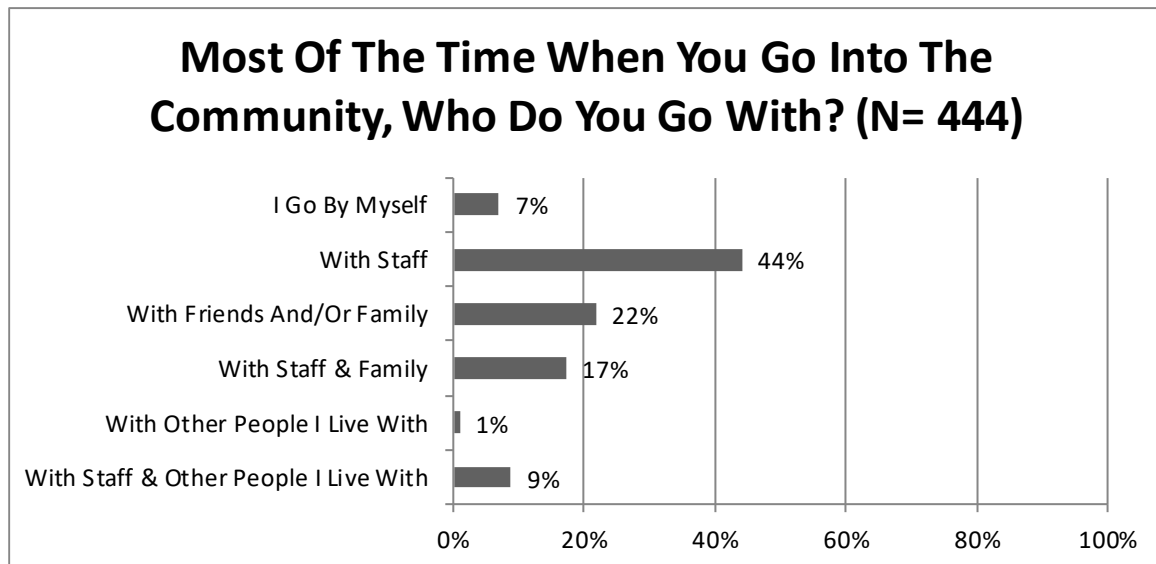
	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
Go out into the community for entertainment frequently	49%	50%	45%
Go out into the community for entertainment occasionally	32%	33%	38%

	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
Go to social events attended by people with and without disabilities frequently	35%	34%	29%
Go to social events attended by people with and without disabilities occasionally	47%	45%	46%

### ***E2.2. Exercise in the Community***

	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
Person never exercises	54%	45%	40%
Person exercises less than once a week	4%	4%	3%
Person exercises about once a week	10%	8%	8%
Person exercises more than once a week	32%	43%	49%

### ***E3. Going Out Alone or with Other People***



	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
Myself	7%	7%	7%
With Staff	44%	37%	38%
With Friends and/or Family	22%	26%	27%
With Housemates	1%	2%	1%
With Staff and Housemates	9%	6%	4%
With Staff and Family	17%	22%	22%

#### ***E4. Transportation***

	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
Always have a way to get where they wanted to go	92%	92%	92%

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

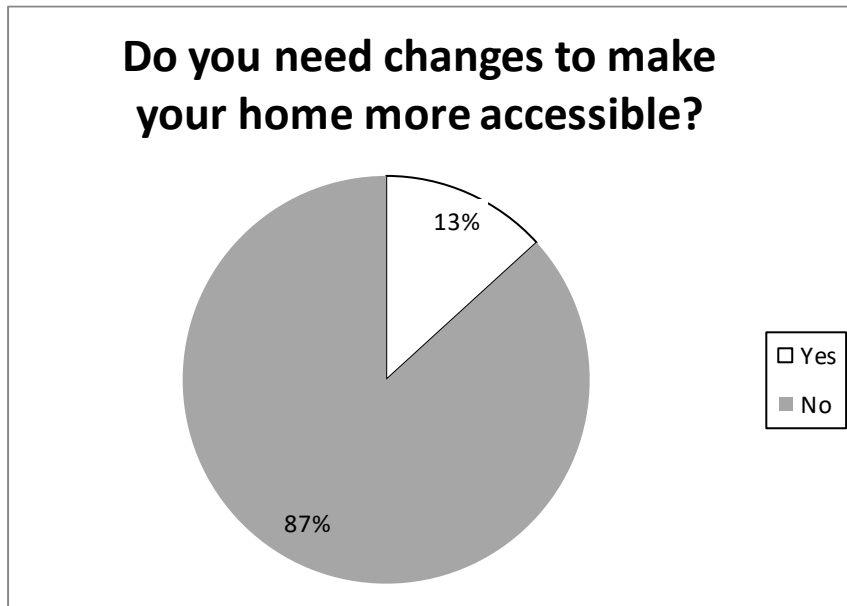
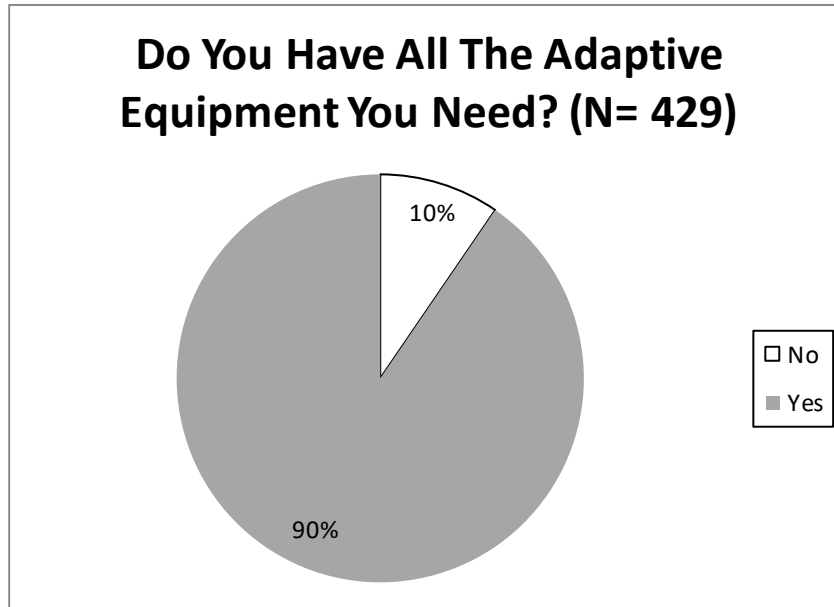
	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
Get a ride from family or friends	32%	38%	37%
Get a ride from staff in provider van	53%	40%	39%
Get a ride in staff member's car	8%	12%	12%
Transport themselves	3%	6%	5%
Ride public transportation	3%	3%	4%
Ride paratransit	1%	1%	1%
Take a taxi, Uber or Lyft	0%	0%	1%

##### ***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	33%	36%	34%
Paratransit is unreliable	5%	11%	9%
Transportation for work/school only	0%	1%	3%
No one at home can drive	0%	0%	1%
Some other reason	62%	52%	53%

***Note:*** It is probable that the current staffing crisis affected these numbers.

### E5. Home Adaptive Equipment



	AE	Region	Statewide
Have all the adaptive equipment needed at home	90%	90%	86%
Any adaptations or modifications needed to make the home accessible have been made	87%	90%	92%

## **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. It is likely the case that because most interviews were conducted remotely this year, many 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 Standard Deviation of Monitor Ratings*

	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
Mean	N/A	7.76	7.56
Standard Deviation	N/A	2.60	2.50

### **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	90%	94%	90%
Staff recognize the individual in ways that promote independence	82%	93%	89%
Staff who support individuals have the skills they needed	85%	94%	90%

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

This survey was completed remotely by telephone or videoconference this year with a family member, guardian, or friend who was identified through the Essential Data Elements (EDE) Pre-Survey. Surveys were completed for 27 family members, friends, and guardians.

### **Respondents:**

Parent(s)	93%	Another Relative	0%
Sibling(s)	0%	Friend	0%
Guardian	0%	Other	7%

## **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	81%	96%	94%
Somewhat satisfied or very satisfied with what relative does during the day	73%	87%	84%
Somewhat satisfied or very satisfied with relative's staff at home	75%	95%	94%
Somewhat satisfied or very satisfied with staff at relative's day activity	86%	96%	94%

### ***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%	98%	92%
Never contacted their relative	0%	0%	2%
See their relative at least monthly	100%	83%	79%
Never visited their relative	0%	2%	3%

### ***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	85%	93%	93%
Relative is satisfied or very satisfied with what they do during the day	71%	92%	89%

	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
Relative is satisfied or very satisfied with the staff who support them at home	89%	96%	96%
Relative is dissatisfied or very dissatisfied with the staff who support them at home	11%	1%	2%
Relative is satisfied or very satisfied with the staff who support them during the day	93%	98%	96%
Relative is dissatisfied or very dissatisfied with the staff who support them during the day	7%	1%	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	81%	89%	86%
Relative feels safe in their community, home, and neighborhood most of the time	19%	8%	11%

#### ***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	67%	82%	78%
Relative has the opportunity to learn new things	71%	91%	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	50%	86%	80%
Staff in relative's home always treat people with dignity and respect	75%	97%	96%
All staff in their relative's home have the skills they need to support their relative	40%	92%	89%
Some of the staff in their relatives home have the skills they need to support their relative	20%	6%	9%

	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
Relative's place of work appears to have an adequate number of paid staff	80%	95%	95%
Staff at relative's place of work always treat people with dignity and respect	100%	99%	99%
All staff in their relative's workplace have the skills needed to support their relative	73%	93%	94%
Some staff at their relative's workplace have the skills they need to support their relative	18%	6%	5%
The staff who assist their relative with planning always respects their choices and opinions	89%	94%	89%

#### ***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	40%	41%	40%
If there is a communication system in place, it is used across settings	75%	77%	72%

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

	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
Satisfied with the support coordination their relative receives	70%	85%	80%
Told how much money is in their relative's budget	60%	68%	61%
Their relative directs their own services	14%	9%	13%
Their relative always receives the supports they needed	32%	72%	61%
The supports and services their relative receive change when their needs change	81%	88%	81%
There are never or rarely changes in support staff at their family member's home, work, or day program	24%	56%	58%



	<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	6%	10%	13%
They chose the agency/provider who worked with their relative	71%	37%	42%
Their relative chose the agency or provider who worked with their relative, alone or with their help	8%	25%	26%
Someone else chose the agency/provider who worked with their relative	21%	38%	31%

### ***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	50%	69%	65%

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

	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
At the provider level	42%	67%	61%
At the county/AE level	35%	65%	61%
At the state level	27%	64%	56%

### ***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	76%	89%	87%
They had learned about the Life Course Framework and Tools	14%	19%	18%
They had an opportunity to connect and network with other families with relatives at similar life stages	40%	48%	43%
They are aware of the PA Family Network (PAFN)	4%	30%	29%
Of those who were aware of the PAFN, who had attended a workshop led by the Network of Family Advisors	100%	28%	31%
Have enough information about services for which the family is eligible	65%	75%	76%

	<b>AE</b>	<b>Region</b>	<b>Statewide</b>
If family member transitioned from school to adult services, were happy with the process	33%	23%	23%
SC asks about their vision for an everyday life for their family member	75%	80%	72%

***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	43%	63%	55%

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