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

Independent Monitoring for Quality (IM4Q)
Philadelphia AE
2021-2022

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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.**

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	82.36	82.29	84.87
SD	21.93	20.18	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	76.79	82.23	83.10
SD	16.20	15.61	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	96.14	93.65	93.09
SD	10.81	14.58	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	52.69	53.64	60.78
SD	16.14	21.64	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	41.40	37.82	40.30
SD	18.47	19.15	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	92.48	89.93	90.97
SD	12.70	14.13	13.23

Sample

i.   Sample Data

i1. Total Surveyed

People with disabilities	552	Family members	149

i2. Age

Range	21-95	Mean Age (SD)	54.5 (15.6)

i3. Reported Gender

Female	42.9%	Male	57.1%	Other	0%

i4. Race and Ethnicity

Race (N= 548)

White/Caucasian	45%
Black/African American	51%
Asian	1%
Two or More Races	0%
Two or More Races	3%
American Indian/Alaskan Native/Pacific Islander	1%

Ethnicity (N= 549)

5%

95%

■ Hispanic/Latinx   ■ Non-Hispanic/Latinx
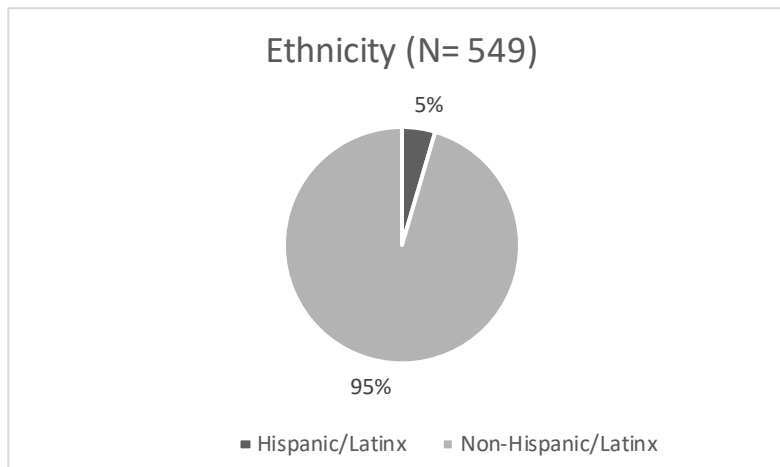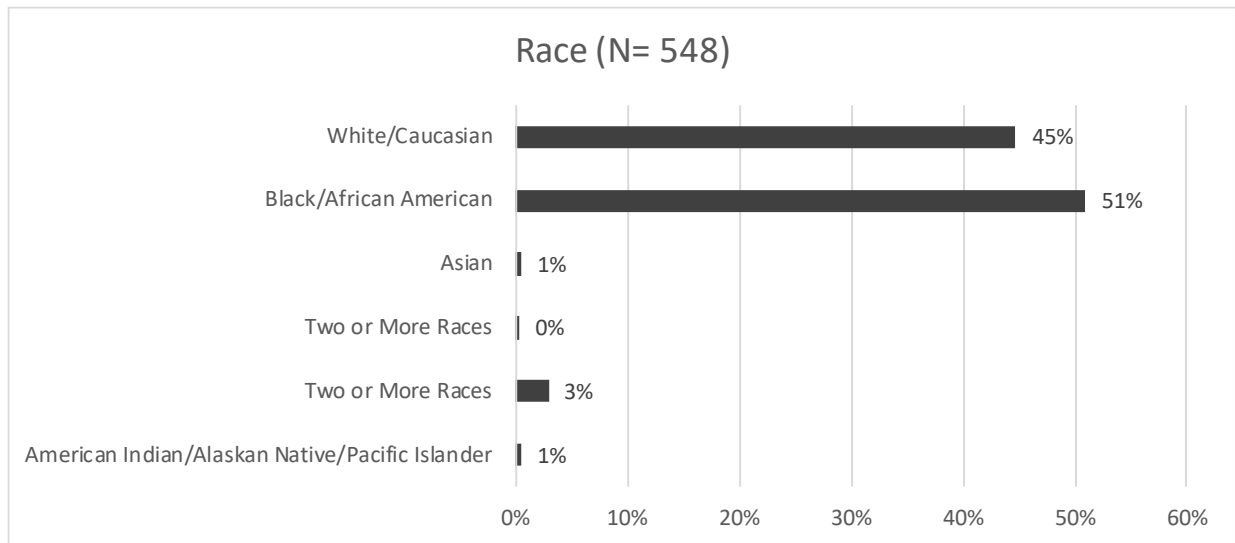
i5. Home Type Where Respondent Lives

Type of Residence	_ AE		Statewide	
	Number of Residents	Percent of the Sample	Number of Residents	Percent of the Sample
Relative's Home	70	12.7%	1604	42.0%
Community Home- All	455	82.4%	1472	38.6%
Community Home 1	*48*	*8.7%*	135	3.5%
Community Home 2-4	*395*	*71.6%*	1272	33.3%
Community Home 5-6	*8*	*1.4%*	40	1.0%
Community Home 7-8	*2*	*0.4%*	21	0.6%
Community Home 9-15	*1*	*0.2%*	2	0.1%
Community Home 16+	*1*	*0.2%*	2	0.1%
Own Residence	1	0.2%	254	6.7%
Family Living/Lifesharing	16	2.9%	127	3.3%
Private ICF/ID- All	9	1.6%	133	3.5%
Private ICF/ID 1-4	*5*	*0.9%*	29	0.8%
Private ICF/ID 5-8	*2*	*0.4%*	48	1.3%
Private ICF/ID 9-15	*0*	*0.0%*	13	0.3%
Private ICF/ID 16+	*2*	*0.4%*	43	1.1%
Personal Care Home	0	0.0%	42	1.1%
Nursing Home/Facility	0	0.0%	40	1.0%
Children's Facility	0	0.0%	8	0.2%
Unlicensed Family Living	0	0.0%	10	0.3%
Domiciliary Care	0	0.0%	8	0.2%
Foster Care	0	0.0%	2	0.1%
Approved Private School	0	0.0%	0	0.0%
State Operated ICF/MR	0	0.0%	11	0.3%
State MH Hospital	0	0.0%	0	0.0%
Temporary Shelter	0	0.0%	0	0.0%
Other	0	0.0%	21	0.6%
Missing	1	-	85	-
Total	552	100%	3817	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

	AE	Region	Statewide
Like where they live now	86%	88%	89%
Want to stay where they currently live	73%	73%	74%
Want to move somewhere else	19%	19%	18%
In between wanting to stay and wanting to move	7%	8%	8%

A2. Work/Day Activity

	AE	Region	Statewide
Like primary job or day activity	88%	90%	91%
Like other job or day activity	89%	92%	94%
Want to continue current job or day activity	71%	64%	73%
Want to do something else.	23%	27%	19%
In between wanting to continue and wanting to change jobs	6%	9%	9%

A1-2.1. Want to Stay or Change Living Arrangement and Work/Day Activity
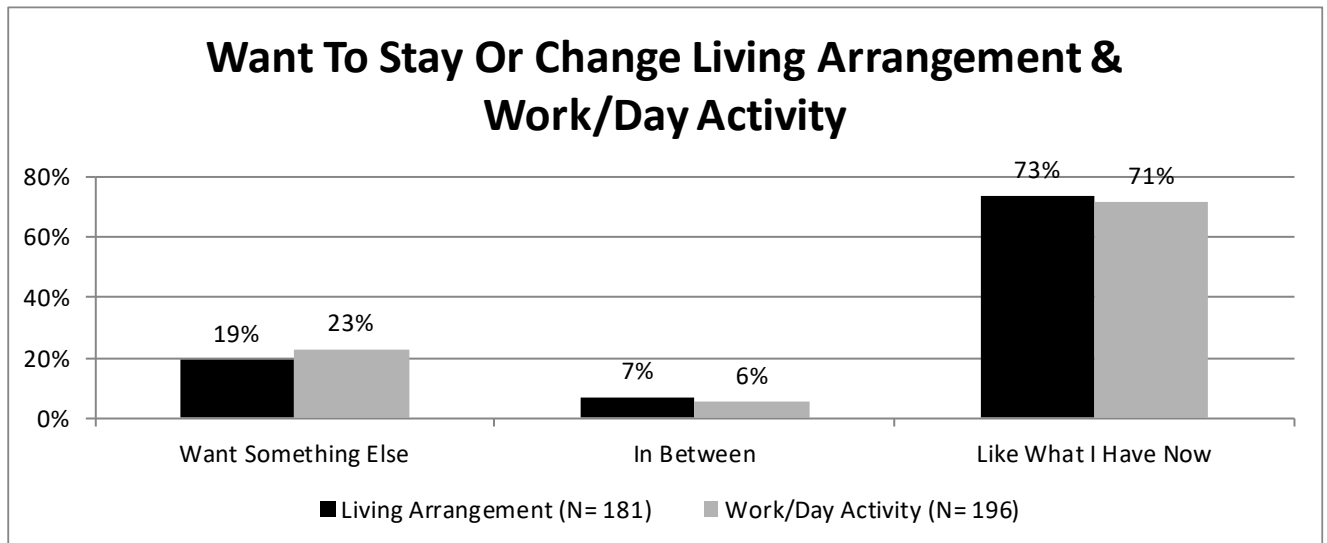
A3. Daily Activities

Primary Activity	AE	Region	Statewide
Stay home	23%	25%	27%
Work	17%	22%	23%

Primary Activity	AE	Region	Statewide
Work- no supports	*14%*	*14%*	14%
Work- with supports	*3%*	*8%*	9%
Attend school	0%	4%	8%
Attend a vocational facility	7%	11%	9%
Attend a day program or community center	8%	9%	9%
Go out in the community	19%	14%	12%
Retired	1%	2%	2%
Volunteer	2%	2%	2%
Something else	23%	10%	6%

Secondary Activity	AE	Region	Statewide
Stay home	36%	36%	40%
Work	4%	5%	4%
Work- no supports	3%	3%	2%
Work- with supports	2%	2%	2%
Attend school	1%	0%	1%
Attend a vocational facility	1%	0%	2%
Attend a day program or community center	2%	1%	2%
Go out in the community	15%	27%	25%
Retired	5%	2%	2%
Volunteer	2%	5%	6%
Something else	36%	23%	19%

A3.1. Want to Work

	AE	Region	Statewide
Do not have or want a job	61%	55%	56%
Would like a job for pay	37%	41%	40%
Uses special technology to help do work[+]	13%	7%	13%

A4. Services

	AE	Region	Statewide
Always get services they need	85%	80%	85%
Sometimes get services they need	5%	4%	3%
Do not get services they need	3%	7%	5%
Need additional services	7%	8%	7%

A5. Happiness and Loneliness

	AE	Region	Statewide
Happy with life	83%	83%	86%
Neither happy nor sad with life	14%	15%	12%
Sad with life	3%	2%	2%
Never lonely	63%	59%	63%
Sometimes lonely	33%	36%	32%
Always lonely	4%	4%	5%
Have friends to do things with	84%	76%	84%
Friends are not staff or family	61%	65%	72%
Have a best friend	59%	65%	71%
Can date/marry, no restrictions	84%	81%	85%
Can date/marry, restrictions	2%	5%	4%
Cannot date/marry at all	14%	14%	12%

A6. Privacy

	AE	Region	Statewide
Have enough privacy (a place to be alone) at home	99%	98%	97%
No rules about friends or visitors	71%	67%	75%
People always let them know when coming into their home	94%	91%	91%
Sometimes people let them know when coming into their home	2%	3%	3%
People never let them know when coming into their home	4%	5%	6%
People always let them know when coming into their bedroom	90%	88%	88%
People sometimes let them know when coming into their bedroom	4%	5%	4%
People never let them know when coming into their bedroom	6%	8%	8%

A7. Are People Nice or Mean?

Are People Mean Or Nice?
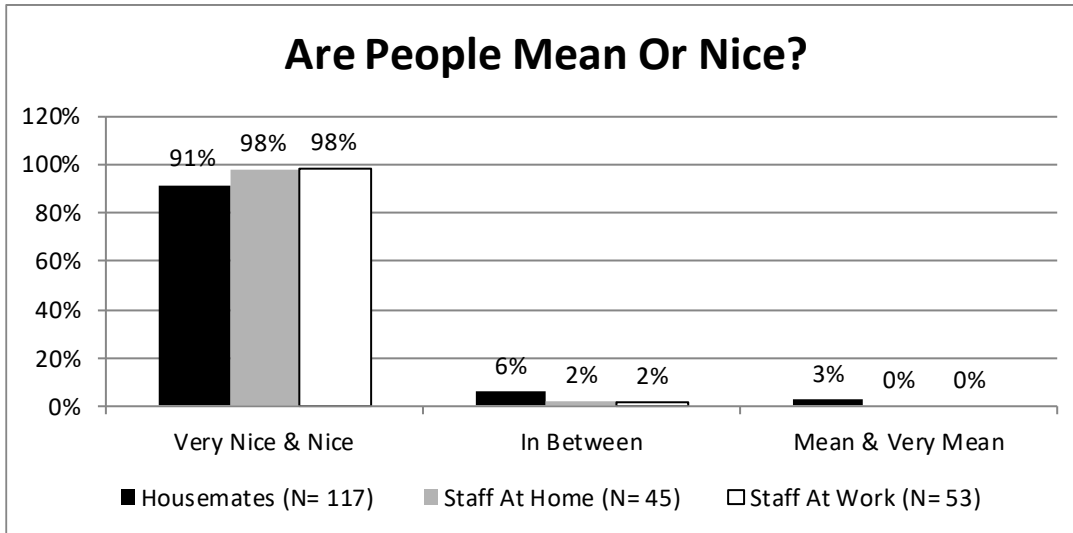
	AE	Region	Statewide
Staff at day or work activity are nice or very nice	98%	97%	95%
Staff at day or work activity are in between nice and mean	2%	3%	4%
Staff at day or work activity are mean or very mean	0%	0%	1%
Staff at home are nice or very nice	98%	97%	95%
Staff at home are in between nice and mean	2%	3%	4%
Staff at home are mean or very mean	0%	0%	0%
Housemates are nice or very nice	91%	88%	87%
Housemates are in between nice and mean	6%	10%	10%
Housemates are mean or very mean	3%	2%	2%
Get along well with the person they share a bedroom with*	33%	61%	80%
Get along OK with the person they share a bedroom with*	33%	22%	12%
Do not get along with the person they share a bedroom with*	33%	17%	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

	AE	Region	Statewide
Get help to learn new things	85%	77%	82%
Do not get help	10%	17%	12%
Get to help other people	66%	60%	69%
Have participated in a self-advocacy group meeting	19%	15%	19%
Someone has talked to them about self-advocacy	36%	43%	53%
Have someone to talk to when afraid	89%	93%	94%

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

	AE	Region	Statewide
Staff	60%	53%	47%
Supports coordinator	16%	11%	9%
Other	8%	9%	9%
Family	24%	43%	47%
Friends	3%	4%	7%
Have no one	1%	2%	1%

B2. Frequency of Being Afraid

Frequency Of Being Afraid

	Never	Sometimes	Always
Afraid At Home (N= 180)	92%	7%	1%
Afraid In Neighborhood (N= 200)	92%	7%	2%
Afraid At Work/Day Activity (N= 163)	98%	1%	1%
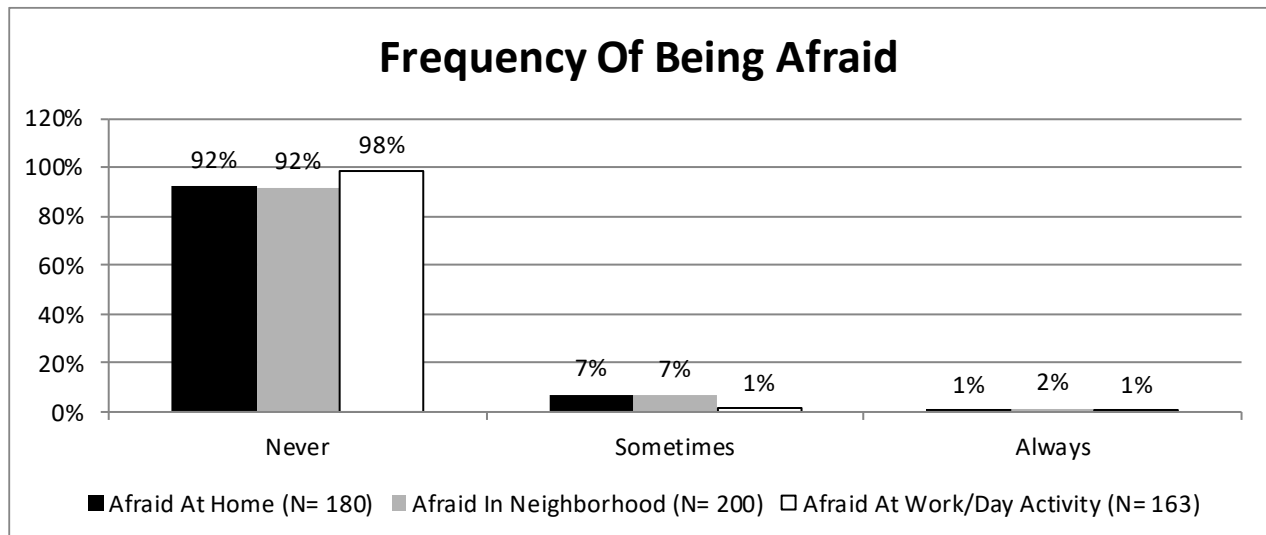
	AE	Region	Statewide
Never afraid at home	92%	86%	87%
Sometimes afraid at home	7%	12%	11%
Always afraid at home	1%	2%	2%
Never afraid in the neighborhood	92%	89%	89%
Sometimes afraid in the neighborhood	7%	9%	9%
Always afraid in the neighborhood	2%	2%	2%
Never afraid at work or day activities	98%	94%	91%
Sometimes afraid at work or day activities	1%	4%	6%
Always afraid at work or day activities	1%	1%	2%

B3. Legal Rights

	AE	Region	Statewide
Mail is never opened without permission	86%	84%	85%
Mail is sometimes opened without permission	2%	5%	6%
Mail is always opened without permission	11%	12%	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)
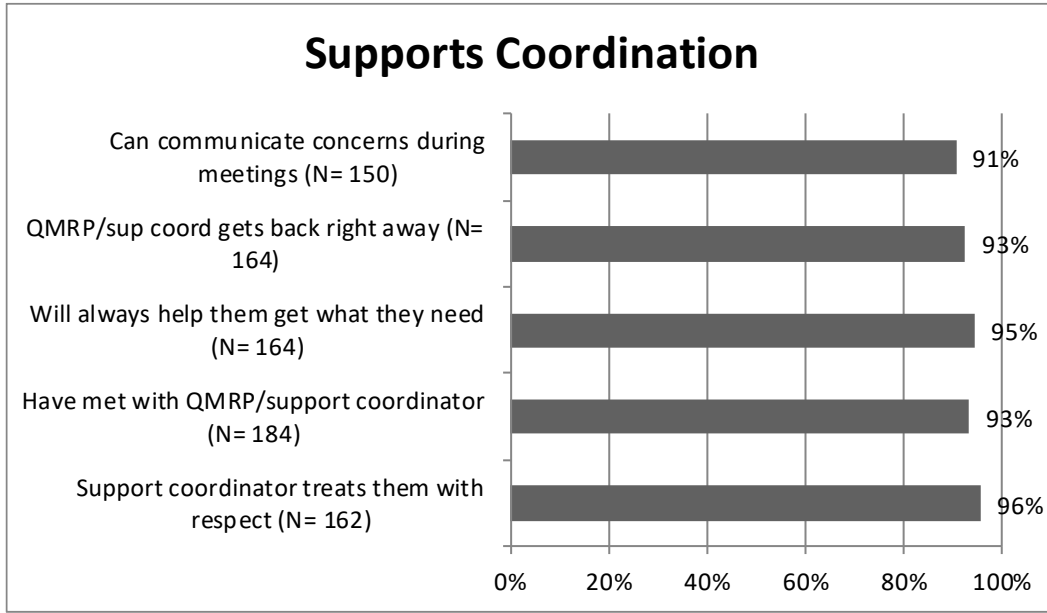
B4.1. SC Communication

	AE	Region	Statewide
SC asks what their interests are	97%	92%	92%
SC asks what they want their life to look like	96%	85%	88%
SC knows what is important to them$^+$	95%	91%	91%
SC asks them about directing their own services	37%	31%	46%
SC asks if services are OK	99%	96%	97%
SC always listens to them	95%	96%	96%

B4.2. SC Interaction

	AE	Region	Statewide
Person knows they can choose SC	79%	69%	70%
SC always gets back to them right away	93%	91%	92%
SC will always help them get what they need	95%	92%	91%

	AE	Region	Statewide
Person has met with SC in the last year	93%	92%	92%
SC always treats the person with respect	96%	98%	99%

B5. Annual Planning Meeting

	AE	Region	Statewide
Participate in the meeting	97%	96%	97%
Know it is an option but choose not to participate in meeting	1%	1%	1%
Can communicate their concerns during the meeting	91%	87%	90%
Sometimes get to communicate concerns	5%	8%	7%
Told at the meeting how much money is in their budget	65%	51%	57%
Meeting includes the people they wanted to be there	99%	98%	97%
Know what is talked about at their ISP meeting	91%	84%	82%

B6. Services

	AE	Region	Statewide
Know who to ask if they want to change their services	89%	79%	83%
Do not know who to ask to change services	7%	15%	11%

B7. Staff

	AE	Region	Statewide
Staff always treats them with respect	93%	91%	92%
Staff always respectful of their culture[+]	96%	97%	98%
Have staff who help them[+]	88%	84%	77%
Staff do things the way the individual wants them done[+]	90%	89%	90%
Staff have the right training to meet their needs	94%	96%	93%
All staff always understand their communication	85%	86%	89%

	AE	Region	Statewide
Some staff understand them	11%	11%	7%
Sometimes understood by staff	1%	1%	3%
Not understood by staff	3%	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

	AE	Region	Statewide
Have been given information about what to do in an emergency	95%	76%	84%

B8.1. Who Provided Emergency Information

	AE	Region	Statewide
Home staff	77%	55%	40%
Day staff	6%	7%	15%
Family	21%	34%	40%
SC	4%	5%	11%
Police, Fire, or EMS Workers	1%	2%	3%
Friends	0%	1%	2%
Red Cross	0%	0%	0%
Someone Else	3%	9%	14%

Who gave info about what to do in an emergency? (N=156)

Family	Neighbors, friends	Police, fire, EMS	Red Cross	SC	DP, employment staff	Home staff	Someone else
21%	0%	1%	0%	4%	6%	77%	3%
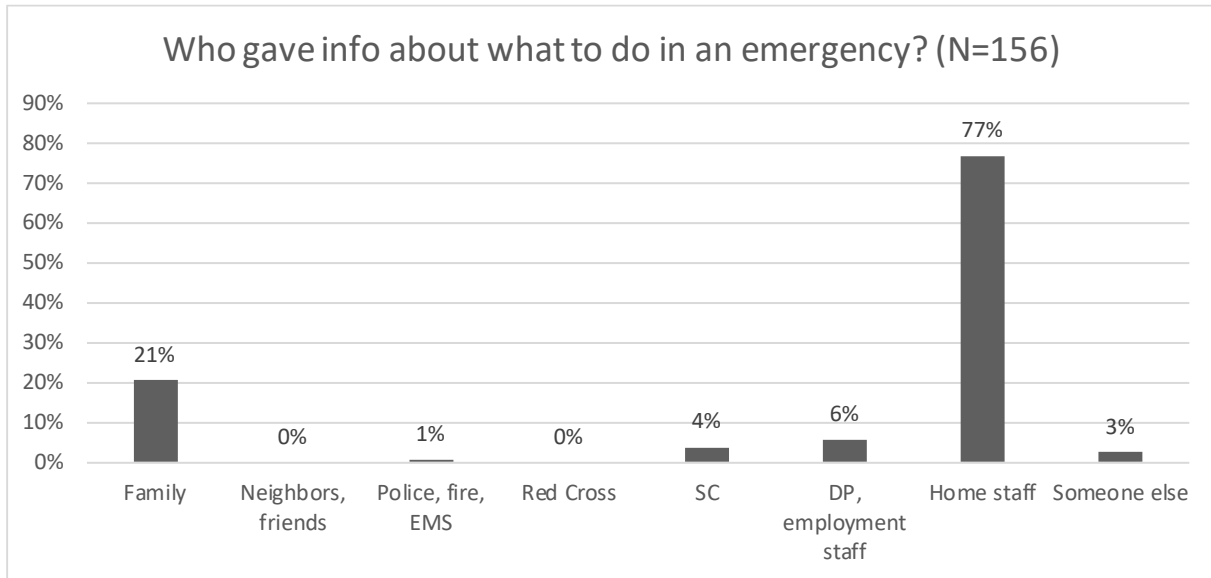
Part III: Choice and Control

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	12%	Individual and Paid staff	25%
Paid staff	52%	Individual and Family/friend/guardian/advocate	5%
Family/friend/guardian/advocate	6%	Staff and Family/friend/guardian/advocate	0%

C. Choice and Control Data
Part III, Section A: Choice and Control

C1. Identification

	AE	Region	Statewide
Always carry ID	77%	70%	65%
Never carry ID	10%	17%	20%

C2. Choice and Control at Home

	AE	Region	Statewide
Have a key or way to get into their home	36%	40%	47%
If other household members go out, they have the option to stay home	59%	50%	46%
If other household members go out, they sometimes can stay home	13%	14%	14%
Can lock bedroom door	42%	43%	49%
Own their home	2%	1%	2%
Name is on the lease or rental agreement	80%	50%	34%
Have a choice to live where people without disabilities live	65%	51%	46%
Saw no other places before they moved into their home	38%	37%	50%
Did not choose housemates	46%	55%	63%
If individual shares a bedroom, chose some or all roommates	70%	48%	37%

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

Who Chose Where You Live And Work?
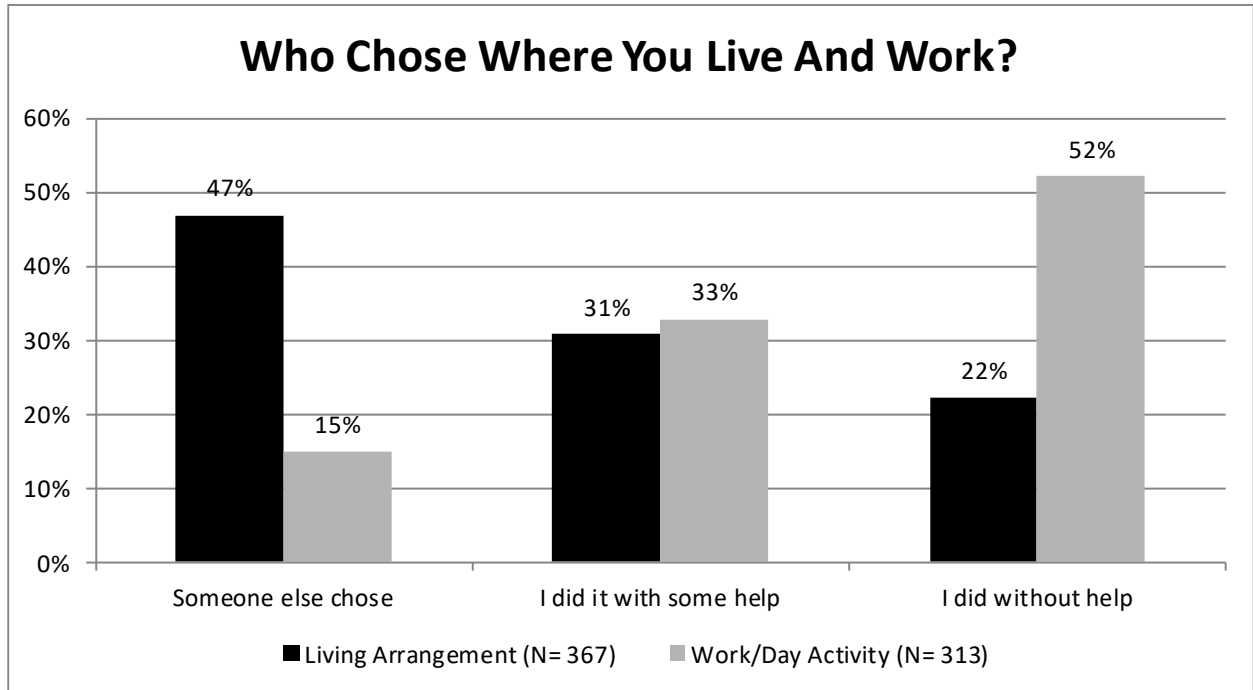
	AE	Region	Statewide
Chose living arrangement without help	22%	21%	27%
Chose living arrangement with some help	31%	28%	27%
Someone else chose living arrangement	47%	51%	46%
Chose work or day activity without help	52%	43%	51%
Chose work or day activity with some help	33%	36%	31%
Someone else chose work or day activity	15%	21%	18%

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

	AE	Region	Statewide
Have the choice to go where people without disabilities go	85%	70%	66%
See no other places when choosing day activity	23%	29%	41%
Choose daily schedule without assistance	92%	89%	89%
Have enough choice about free time	96%	94%	94%

C4. Choice and Control in Choosing Staff

Did You Choose The Staff Who Work With You?

Staff At Home (N= 494)
- Chose Alone: 4%
- Chose With Help: 31%

Staff At Day Activity (N= 363)
- Chose Alone: 10%
- Chose With Help: 13%

Support Coordinator (N= 502)
- Chose Alone: 8%
- Chose With Help: 4%

Legend: ■ Chose Alone ■ Chose With Help
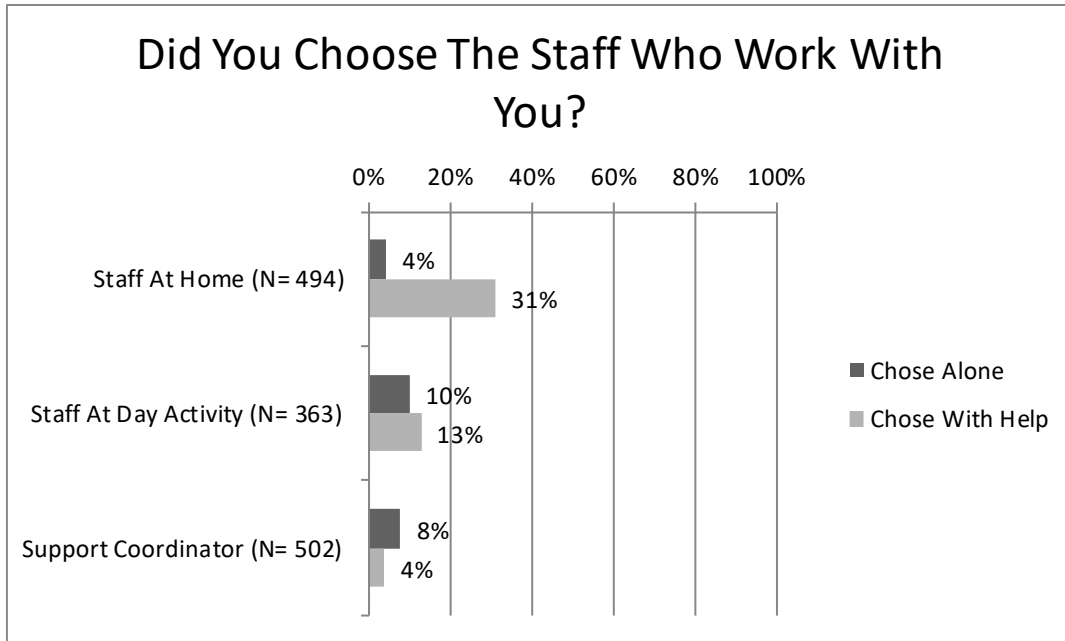
	AE	Region	Statewide
Chose SC without help	8%	11%	18%
Chose SC with some help	4%	15%	24%
Someone else chose SC	88%	75%	58%
Chose staff at work or day activity without help	10%	14%	18%
Chose staff at work or day activity with some help	13%	16%	21%
Someone else chose staff at work or day activity	77%	70%	60%
Chose staff at home without help	4%	10%	13%
Chose staff at home with some help	31%	29%	29%
Someone else chose staff at home	65%	60%	58%

C5. Choice and Control Regarding Money

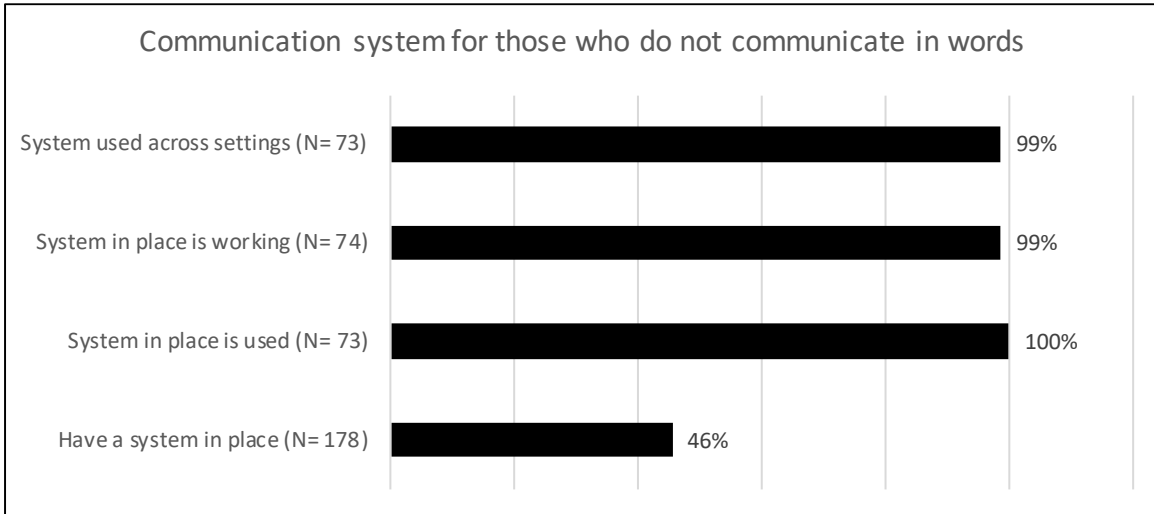|	AE	Region	Statewide
Always choose alone what to buy with spending money	51%	52%	58%
Choose what to buy with help	40%	38%	34%
There is something they want to buy	45%	50%	48%
They have a bank account and withdrawal money when they want	52%	63%	67%

C6. Voting

Do You Vote? (N=506)

- No, not interested: 39%
- No, would like to: 2%
- Yes: 58%
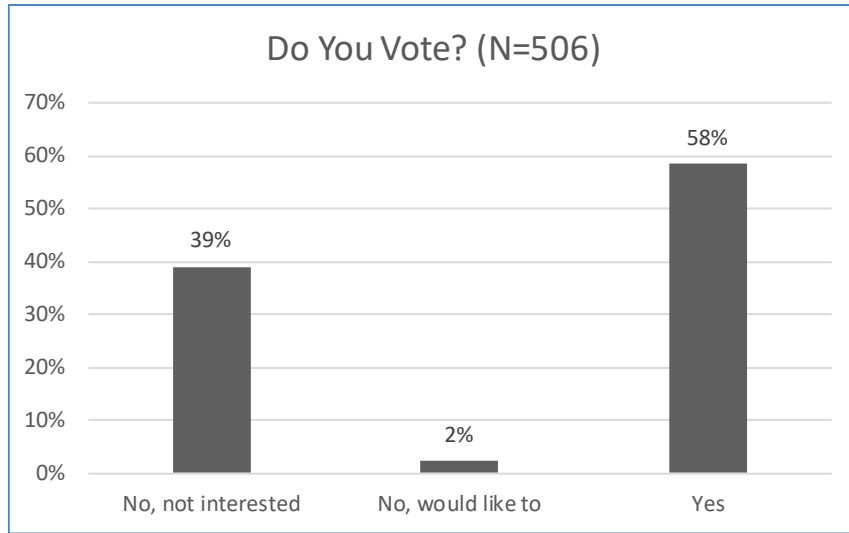
	AE	Region	Statewide
Votes	58%	52%	39%
Chooses not to vote	39%	45%	57%
Does not vote but would like to	2%	3%	4%

C7. *Status of Formal Communication System*

Communication system for those who do not communicate in words

- System used across settings (N= 73): 99%
- System in place is working (N= 74): 99%
- System in place is used (N= 73): 100%
- Have a system in place (N= 178): 46%

	AE	Region	Statewide
Have a communication system in place*	46%	38%	41%
System is being used**	100%	91%	88%
System is working**	99%	96%	87%
System is used across settings**	99%	81%	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?

	AE	Region	Statewide
Staff or Program Coordinator	71%	42%	44%
Speech Language Clinician	14%	42%	41%
Parent or Caregiver	29%	33%	43%
Someone Else	14%	12%	16%

C9. Other Forms of Communication

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

	AE	Region	Statewide
Cell phone	28%	35%	41%
E-mail	13%	21%	26%
Internet	52%	53%	62%
Text-messaging	14%	23%	28%
Cable TV	97%	96%	91%
Computer	51%	59%	63%

C9.2. Restrictions in Place for Communication

	AE	Region	Statewide
Cell phone	7%	6%	9%
E-mail	4%	3%	6%
Internet	4%	7%	11%
Text-messaging	2%	2%	6%
Cable TV	1%	3%	7%
Computer	2%	6%	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

	AE	Region	Statewide
Exercises at home 10+ times per month	30%	31%	42%
Exercises at home <1 time per month	51%	51%	43%

C11. Medical & Dental Care

	AE	Region	Statewide
Overall health excellent or very good[+]	41%	48%	48%
Opportunity to discuss health with primary care provider (PCP)	72%	75%	86%
Talked with health care provider using telehealth[+]	77%	66%	56%
Liked talking to health care provider using telehealth[+]	56%	61%	56%
Able to see a medical specialist if needed	97%	97%	96%
Have not been prevented from receiving medical or dental care due to disability	95%	92%	90%

C11.1. How Hard is it to Access Care?
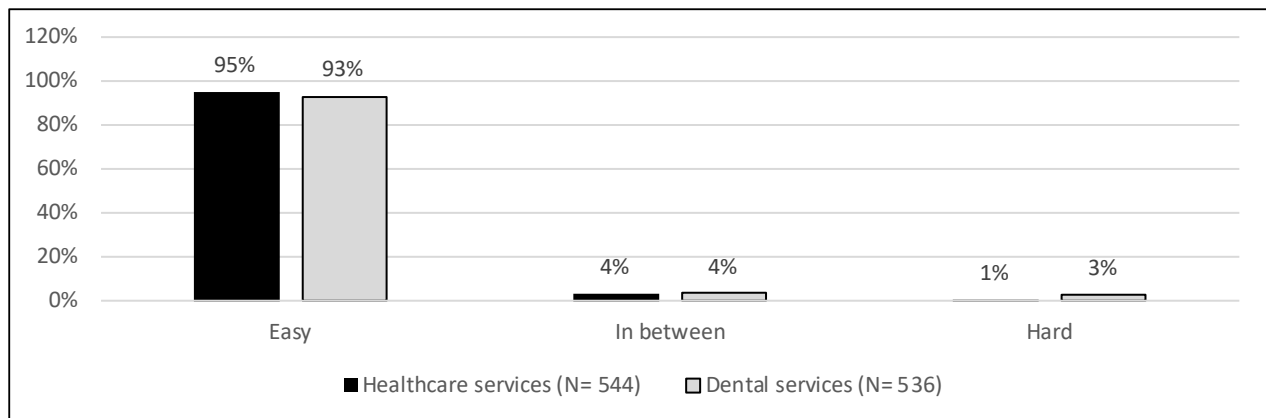
	AE	Region	Statewide
Accessing medical care is very/pretty easy	95%	94%	91%
Accessing medical care is between easy & hard	4%	5%	6%
Accessing medical care is hard or very hard	1%	2%	3%
Accessing dental care is very/pretty easy	93%	91%	83%
Accessing dental care is in between easy and hard	4%	4%	6%
Accessing dental care is hard or very hard	3%	5%	11%

C12. Mental Health

	AE	Region	Statewide
Have an opportunity to discuss health concerns with psychiatrist	63%	60%	65%
Do not have psychiatrist, but want one	2%	1%	2%

C13. Communicating Health Needs

	AE	Region	Statewide
Their doctor understands them	71%	75%	78%
They understand their doctor's instructions	53%	57%	61%
If they need help communicating at doctor's office, it is available	90%	94%	95%
Doctor speaks directly to them during appointments	94%	89%	93%
Able to provide consent for medical treatment	52%	50%	60%
If they provide consent, is it accepted	86%	83%	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
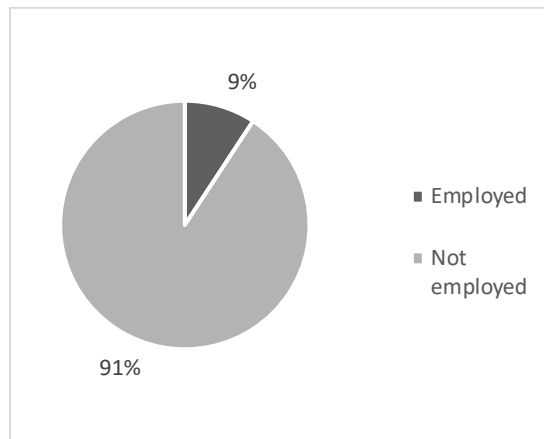
	AE	**Region**	**Statewide**
Employed in CIE	9%	15%	16%

C15. Length of Employment
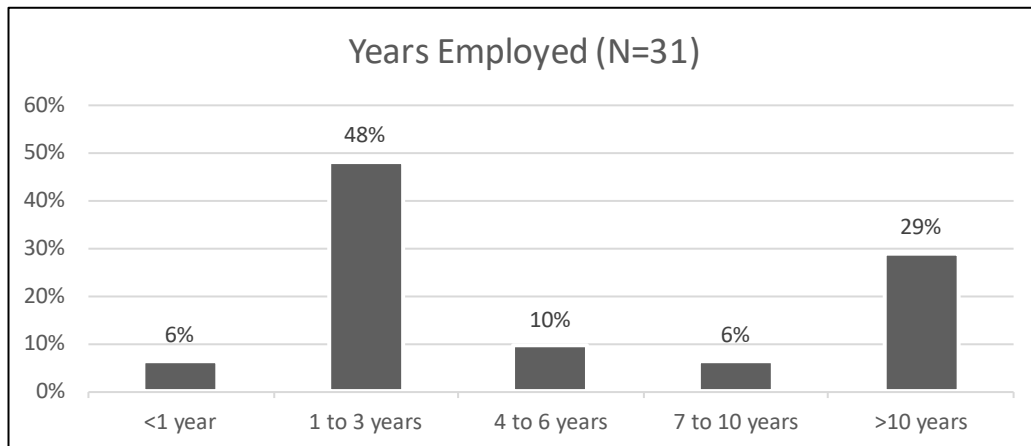
	AE	Region	Statewide
Employed <1 Year	6%	16%	24%
Employed 1 to 3 Years	48%	35%	30%
Employed 4 to 6 Years	10%	14%	15%
Employed 7 to 10 Years	6%	9%	11%
Employed 11+ Years	29%	27%	19%

C16. Types of Work

Cleaning Services	26%	Assembly/Factory Work	3%
Food Services	39%	Care Workers/Aides	3%
Retail Services	16%	Recycling	0%
Office Work	3%	Outdoor Work	0%
Stock Room	3%	Animal Care	0%
Maintenance	3%	Other	3%

C17. Supports Getting into the Workplace

	AE	Region	Statewide
Take classes/training for employment purposes	6%	9%	11%
Talked about employment in their planning meeting	56%	51%	51%
Community employment is a goal in their plan	32%	34%	37%

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

No one	48%	SC	47%
Service Provider	34%	Family	13%
Housemates	0%	Someone Else	6%

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	1%	1%	2%

C19. Compensation and Advancement

	AE	Region	Statewide
Have been promoted or received an increase in pay	46%	64%	52%
Receive paid time off from work as a benefit of employment	73%	82%	80%
Receive health insurance benefits from employer	27%	25%	26%
Receive retirement benefits from their employer	27%	20%	31%
Receive other work benefits from their employment	18%	16%	12%
Know how much they earn and willing to share	71%	87%	76%

C19.1. Hourly Wage

Hourly Wage (N=15)
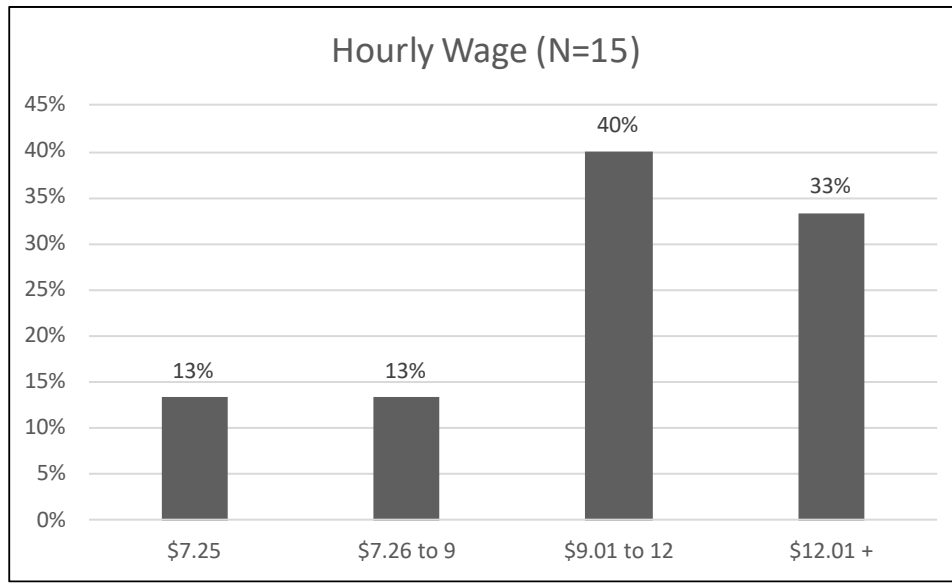
	AE	Region	Statewide
$7.25 per hour (Minimum wage)	13%	7%	14%
$7.26 - $9.00 per hour	13%	13%	18%
$9.01 - $12.00 per hour	40%	38%	33%
$12.01 or more per hour	33%	42%	35%

C20. Community Participation

	AE	Region	Statewide
Use Community Participation Services (CPS)	19%	16%	24%

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

	AE	Region	Statewide
Developing skills and competencies necessary for employment	11%	13%	14%
Fine/gross motor skill development and mobility	18%	24%	19%
Participating in community activities to develop social networks	63%	59%	58%
Participating in opportunities to develop interests or promote health/wellness	72%	69%	66%
Training/education for self-determination and self-advocacy	13%	13%	13%
Community adult learning opportunities	11%	11%	15%

	AE	Region	Statewide
Volunteering opportunities	14%	18%	24%
Learning to navigate the local community	15%	9%	12%

C21. Technology use[+]

	AE	Region	Statewide
Internet at home always works[+]	95%	92%	84%
Uses technology in their everyday life to do things on their own[+]	27%	31%	36%
Has enough help to use technology in everyday life[+]	89%	94%	91%
Has talked to SC using videoconference[+]	91%	84%	67%
Likes talking to SC using videoconference[+]	67%	69%	66%
Has used videoconference for other services[+]	45%	44%	44%
Likes using videoconference for other services[+]	74%	69%	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

	AE	Region	Statewide
Use self-directed services	2%	6%	6%

C22. Who Makes Choices About Budget?

	AE	Region	Statewide
Individual makes decisions on their own	40%	8%	14%
Individual has input, family and friends help	60%	43%	38%
A family member or friend makes decisions	0%	49%	46%
A case manager or state professional makes the decision	0%	0%	2%

C23. Making Decisions

	AE	Region	Statewide
Can make changes to their budget or services if they need to	75%	95%	96%
Have enough help deciding how to use their budget/services	100%	88%	92%
Want more help deciding how to use their budget/services	0%	3%	1%

C24. Money Left in Budget

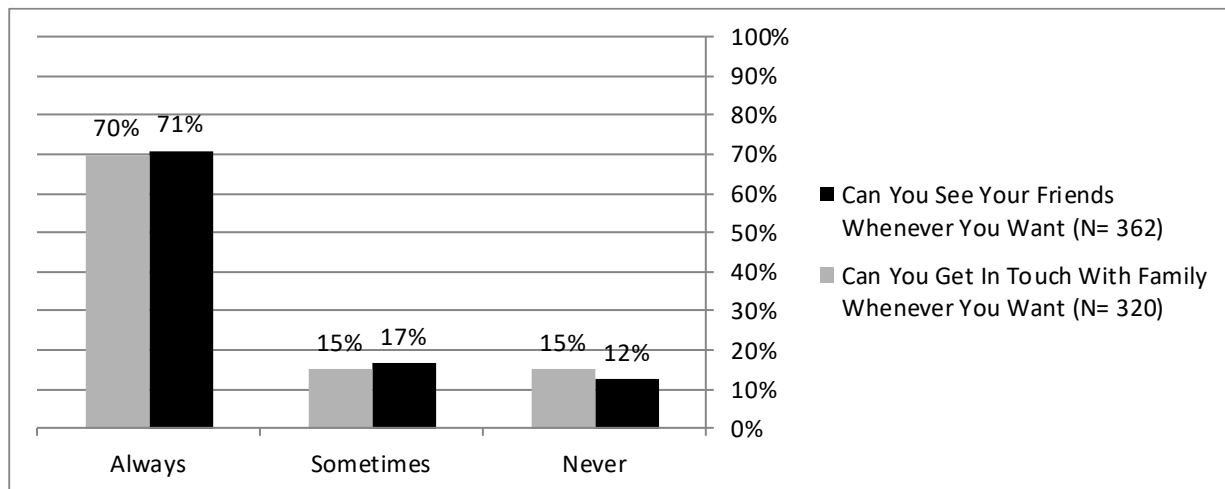|	AE	Region	Statewide
Receive information about the money left in their budget	80%	71%	78%
Information they receive is easy to understand	25%	63%	72%
They receive information at least every 3 months	50%	65%	63%
They receive information about twice a year	0%	16%	23%
They receive information once a year or less	50%	19%	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	12%	Individual and Paid staff	24%
Paid staff	52%	Individual and Family/friend/guardian/advocate	5%
Family/friend/guardian/advocate	6%	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	71%	71%	76%
Sometimes see friends when they want to	17%	17%	16%
Never get to see friends when they want to	12%	12%	7%
Always can get in touch with family when they want to	70%	75%	79%
Sometimes can get in touch with family when they want to	15%	15%	14%
Never can get in touch with family when they want to	15%	10%	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	12%	Individual and Paid staff	24%
Paid staff	53%	Individual and Family/friend/guardian/advocate	5%
Family/friend/guardian/advocate	7%	Staff and Family/friend/guardian/advocate	1%

E. Inclusion Data

E1. Community Participation

Activity	% of people who do this at least weekly- AE	% of people who do this at least weekly- Region	% of people who do this at least weekly- Statewide
Visit friends, relatives, neighbors	31%	32%	40%
Go to a supermarket	43%	42%	46%
Go out to eat/restaurants	33%	33%	40%
Go to a shopping center or mall	35%	32%	35%
Go out to a worship service	16%	19%	22%
Run errands and appointments	13%	16%	25%
Meeting people at coffee house/tavern	27%	20%	17%
Go out for entertainment	24%	21%	21%

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

Activity	% of people in this AE who say they do this enough	% of people in this AE who want to do this more	% of people in this AE who want to do this less
Visit friends, relatives, neighbors	91%	9%	0%
Go to a supermarket	94%	4%	1%
Go out to eat/restaurants	91%	9%	0%
Go to a shopping center or mall	92%	7%	0%
Go out to a worship service	86%	11%	3%

Activity	% of people in this AE who say they do this enough	% of people in this AE who want to do this more	% of people in this AE who want to do this less
Run errands and appointments	95%	4%	1%
Meeting people at coffee house/tavern	86%	12%	2%
Go out for entertainment	91%	9%	0%

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

Activity	Staff	Family	Friends	Roommates Coworkers	Go Alone	Other
Visit friends, relatives, neighbors	67%	23%	2%	0%	8%	0%
Go to a supermarket	85%	10%	1%	1%	4%	0%
Go out to eat/restaurants	82%	12%	1%	1%	4%	0%
Go to a shopping center or mall	87%	9%	1%	0%	3%	0%
Go out to a worship service	67%	22%	2%	3%	5%	1%
Run errands and appointments	84%	11%	0%	1%	3%	0%
Meeting people at coffee house/tavern	83%	10%	2%	0%	5%	0%
Go out for entertainment	81%	12%	2%	1%	3%	0%

E2. Extra-Curricular Activities

	AE	Region	Statewide
Would like to be a part of more groups in the community	22%	30%	37%

E2.1. How Often Do You Go into the Community?
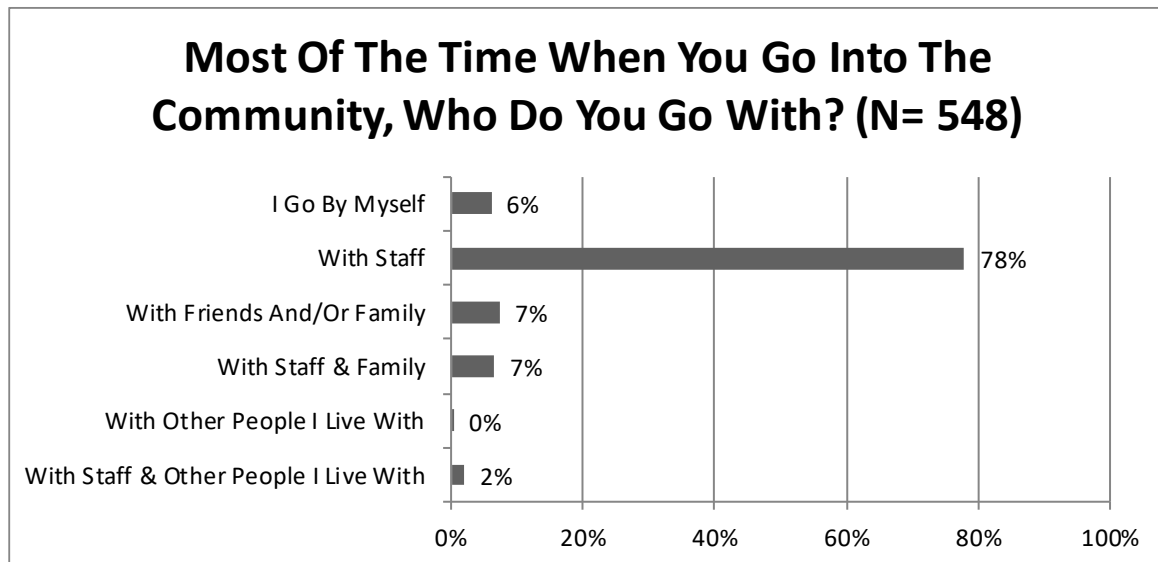
	AE	Region	Statewide
Go out into the community for entertainment frequently	27%	29%	35%
Go out into the community for entertainment occasionally	31%	35%	38%

	AE	Region	Statewide
Go to social events attended by people with and without disabilities frequently	13%	15%	20%
Go to social events attended by people with and without disabilities occasionally	40%	38%	46%

E2.2. Exercise in the Community

	AE	Region	Statewide
Person never exercises	41%	39%	38%
Person exercises less than once a week	3%	3%	3%
Person exercises about once a week	6%	8%	7%
Person exercises more than once a week	50%	51%	52%

E3. Going Out Alone or with Other People

Most Of The Time When You Go Into The Community, Who Do You Go With? (N= 548)

I Go By Myself — 6%
With Staff — 78%
With Friends And/Or Family — 7%
With Staff & Family — 7%
With Other People I Live With — 0%
With Staff & Other People I Live With — 2%

	AE	Region	Statewide
Myself	6%	6%	6%
With Staff	78%	52%	40%
With Friends and/or Family	7%	22%	32%
With Housemates	0%	1%	1%
With Staff and Housemates	2%	5%	4%
With Staff and Family	7%	15%	17%

E4. Transportation

	AE	Region	Statewide
Always have a way to get where they wanted to go	97%	93%	93%

E4.1. Transportation Methods Used Most Frequently

	AE	Region	Statewide
Get a ride from family or friends	8%	27%	39%
Get a ride from staff in provider van	75%	54%	41%
Get a ride in staff member's car	9%	11%	12%
Transport themselves	1%	2%	4%
Ride public transportation	5%	4%	2%
Ride paratransit	2%	2%	2%
Take a taxi, Uber or Lyft	0%	0%	0%

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

	AE	Region	Statewide
Not enough staff	17%	15%	24%
Paratransit is unreliable	22%	10%	11%
Transportation for work/school only	6%	1%	3%
No one at home can drive	0%	2%	3%
Some other reason	56%	71%	59%

E5. Home Adaptive Equipment

Do You Have All The Adaptive Equipment You Need? (N= 359)

- No 16%
- Yes 84%

Do you need changes to make your home more accessible?

- Yes 3%
- No 97%
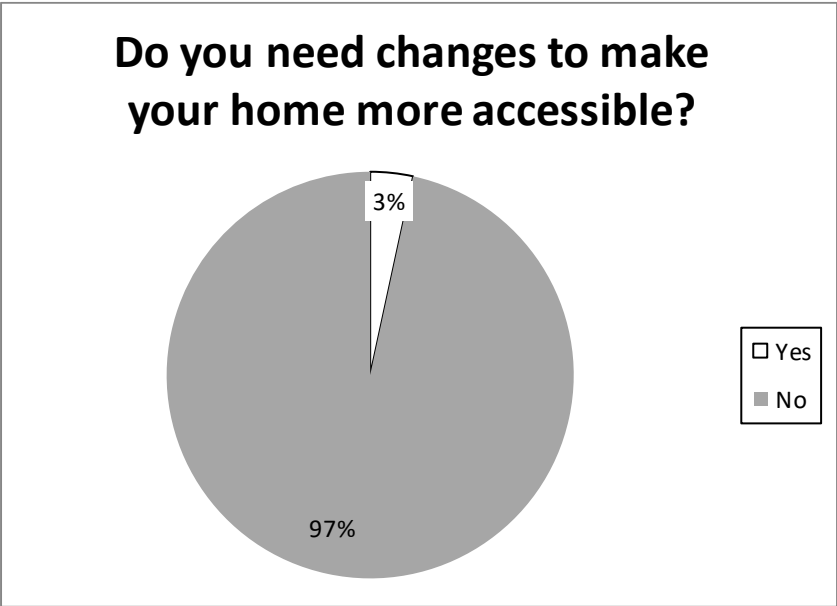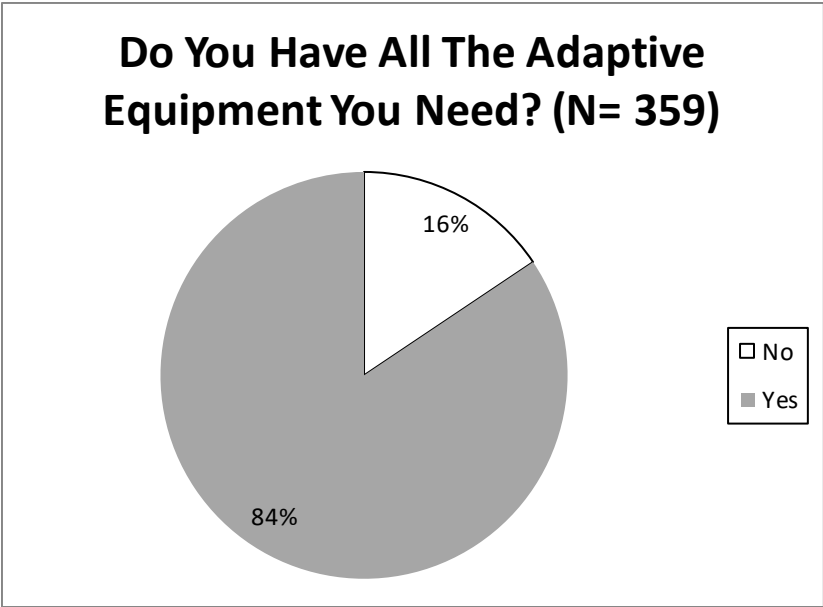
	AE	Region	Statewide
Have all the adaptive equipment needed at home	84%	84%	86%
Any adaptations or modifications needed to make the home accessible have been made	97%	96%	94%

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

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

G. Support for the Person Data

G1. Monitor Observations

	AE	Region	Statewide
Staff treat individuals with dignity and respect	73%	75%	85%
Staff recognize the individual in ways that promote independence	73%	74%	85%
Staff who support individuals have the skills they needed	73%	74%	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 149 family members, friends, and guardians.

Respondents:

Parent(s)	48%	Another Relative	7%
Sibling(s)	40%	Friend	0%
Guardian	1%	Other	3%

H. Family, Friend and Guardian Survey Data

H1. Daily Life

	AE	Region	Statewide
Somewhat satisfied or very satisfied with where their relative lives	95%	95%	95%
Somewhat satisfied or very satisfied with what relative does during the day	88%	82%	87%
Somewhat satisfied or very satisfied with relative's staff at home	94%	92%	94%
Somewhat satisfied or very satisfied with staff at relative's day activity	97%	93%	95%

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

	AE	Region	Statewide
Contacted their relative at least monthly	91%	89%	91%
Never contacted their relative	0%	0%	1%
See their relative at least monthly	65%	66%	74%
Never visited their relative	6%	9%	5%

H3. Your Relative's Satisfaction

	AE	Region	Statewide
Relative is satisfied or very satisfied with his/her living situation	95%	95%	95%
Relative is satisfied or very satisfied with what they do during the day	90%	85%	89%

	AE	Region	Statewide
Relative is satisfied or very satisfied with the staff who support them at home	95%	95%	95%
Relative is dissatisfied or very dissatisfied with the staff who support them at home	2%	2%	2%
Relative is satisfied or very satisfied with the staff who support them during the day	98%	96%	96%
Relative is dissatisfied or very dissatisfied with the staff who support them during the day	0%	1%	1%

H4. Your Relative's Safety

	AE	Region	Statewide
Relative always feels safe in their community, home, and neighborhood	95%	86%	89%
Relative feels safe in their community, home, and neighborhood most of the time	2%	12%	8%

H5. Your Relative's Opportunities

	AE	Region	Statewide
Relative has enough opportunities to participate in activities in the community	77%	69%	76%
Relative has the opportunity to learn new things	72%	78%	86%

H6. Your Relative's Staff

	AE	Region	Statewide
Relative's home appears to have an adequate number of paid staff	77%	76%	81%
Staff in relative's home always treat people with dignity and respect	97%	95%	95%
All staff in their relative's home have the skills they need to support their relative	90%	88%	89%
Some of the staff in their relatives home have the skills they need to support their relative	8%	11%	10%

	AE	Region	Statewide
Relative's place of work appears to have an adequate number of paid staff	92%	92%	92%
Staff at relative's place of work always treat people with dignity and respect	98%	96%	97%
All staff in their relative's workplace have the skills needed to support their relative	95%	92%	93%
Some staff at their relative's workplace have the skills they need to support their relative	4%	7%	6%
The staff who assist their relative with planning always respects their choices and opinions	87%	88%	91%

H7. Relative's Communication System

	AE	Region	Statewide
If their relative does not communicate verbally, there is a formal system in place, and they use it	70%	48%	47%
If there is a communication system in place, it is used across settings	100%	73%	77%

H8. Relative's Supports

	AE	Region	Statewide
Satisfied with the support coordination their relative receives	72%	77%	81%
Told how much money is in their relative's budget	62%	53%	61%
Their relative directs their own services	13%	13%	12%
Their relative always receives the supports they needed	65%	55%	67%
The supports and services their relative receive change when their needs change	83%	81%	86%
There are never or rarely changes in support staff at their family member's home, work, or day program	60%	45%	55%

	AE	Region	Statewide
There are always frequent changes in support staff at their family member's home, work or day program	24%	22%	17%
They chose the agency/provider who worked with their relative	72%	54%	46%
Their relative chose the agency or provider who worked with their relative, alone or with their help	15%	21%	27%
Someone else chose the agency/provider who worked with their relative	13%	25%	27%

H9. Complaints and Grievances

	AE	Region	Statewide
Relative was familiar with the complaint and grievance process on some level	56%	65%	70%

H9.1. At what level?

	AE	Region	Statewide
At the provider level	55%	62%	65%
At the county/AE level	48%	61%	64%
At the state level	47%	58%	60%

H10. Family Resources

	AE	Region	Statewide
The information they receive about their relative's services is easy to understand	90%	88%	89%
They had learned about the Life Course Framework and Tools	11%	14%	19%
They had an opportunity to connect and network with other families with relatives at similar life stages	28%	39%	47%
They are aware of the PA Family Network (PAFN)	19%	25%	32%
Of those who were aware of the PAFN, who had attended a workshop led by the Network of Family Advisors	55%	34%	31%
Have enough information about services for which the family is eligible	85%	81%	83%

	AE	Region	Statewide
If family member transitioned from school to adult services, were happy with the process	27%	21%	28%
SC asks about their vision for an everyday life for their family member	78%	68%	78%

H11. Emergency Preparation Questions

	AE	Region	Statewide
Given information about an emergency plan for their family member in case of emergency	72%	48%	55%

This link will take you back to the **Beginning of the Report**