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

Independent Monitoring for Quality (IM4Q)
Allegheny AE
2020-2021

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

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Introduction

This report includes data gathered through the Independent Monitoring for Quality (IM4Q) project in Pennsylvania during the 2020-2021 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%

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 the community over time.

The IM4Q process also allows us to improve the lives of individuals directly through personal considerations. 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, who either approves or disapproves the response. If the consideration is not addressed, the consideration process continues until the AE 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. The following closed (achieved) consideration is from 2018-2019 and provides an example of how IM4Q positively impacts the lives of people with disabilities who are receiving ODP supports. Each success story is 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: An Animal Lover Finds Her Calling

Lisa was interviewed by her AE for the IM4Q project in 2018. When the IM4Q Monitors who were interviewing Lisa asked if she was happy, Lisa shared that she really wanted to be a veterinarian.

The consideration was shared with Lisa's team. In talking to her about her desire to be a veterinarian, they found out that Lisa wasn't interested in going to school.. They started looking for opportunities for Lisa to have more time around animals.

Soon, the team found the perfect opportunity for Lisa. She now volunteers at a local rescue! She visits regularly and gets to play with the animals. When she shared her consideration, Lisa was barking up the right tree!

For more stories like this, follow this link to a collection of considerations stories across Pennsylvania, **Making a Difference in the Lives of People Supported by ODP**.

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. All interviews for this year were conducted remotely, using video conferencing, phone calls, or mailed surveys. These methods, as well as the social regulations in place due to the ongoing pandemic, are likely to affect the data. Throughout the report, notes have been added to point out trends in the data that are likely to have been influenced by the pandemic.

Questions about individual's experiences with the pandemic were added to the National Core Indicators (NCI) and Essential Data Elements (EDE) surveys. The responses to these specific questions are reported in a supplemental report. To review the responses, follow this link to the **IM4Q Covid Supplement Report**.

Scale Scores

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

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

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

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

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

	Administrative Entity	Region	Statewide
Mean	80.98	84.46	84.70
SD	20.48	20.14	19.47

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	74.07	82.61	83.33
SD	11.80	15.20	14.40

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	92.59	92.73	93.96
SD	19.52	17.49	15.32

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	60.79	62.09	60.44
SD	18.29	19.39	20.39

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	29.19	32.26	36.27
SD	20.03	20.02	21.32

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	8.05
SD	N/A	N/A	2.25

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	89.74	92.03	91.61
SD	13.40	11.19	12.17

Sample

i.   Sample Data

i1. Total Surveyed

People with disabilities	439	Family members	74

i2. Age

Range	10-87	Mean Age (SD)	40.4 (16.7)

i3. Reported Gender

Female	39.5%	Male	60.5%	Other	0%

i4. Race and Ethnicity
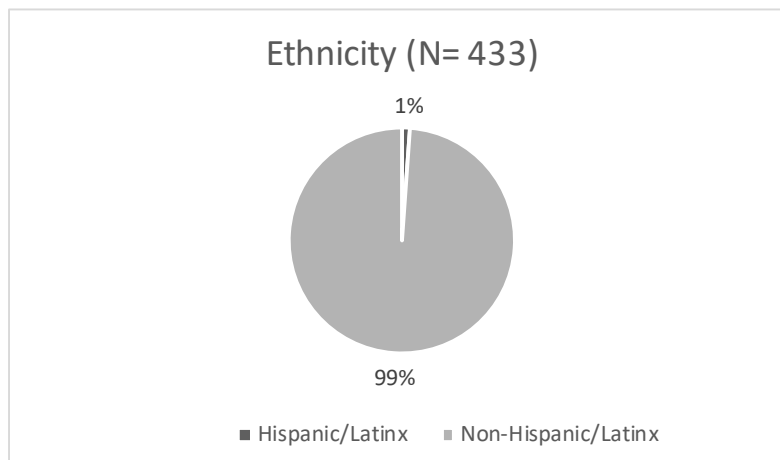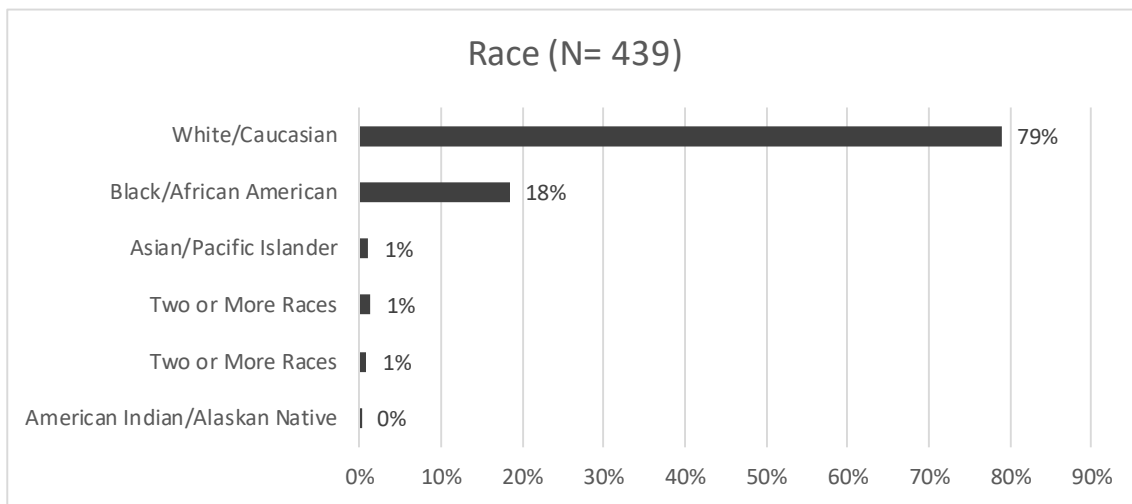
i5. Home Type Where Respondent Lives

Type of Residence	AE		Statewide	
	Number of Residents	Percent of the Sample	Number of Residents	Percent of the Sample
Relative's Home	149	34.1%	1734	44.9%
Community Home- All	242	55.4%	1418	36.7%
Community Home 1	*46*	*10.5%*	*196*	*5.1%*
Community Home 2-4	*185*	*42.3%*	*1174*	*30.4%*
Community Home 5-6	*5*	*1.1%*	*28*	*0.7%*
Community Home 7-8	*5*	*1.1%*	*12*	*0.3%*
Community Home 9-15	*0*	*0.0%*	*4*	*0.1%*
Community Home 16+	*1*	*0.2%*	*4*	*0.1%*
Own Residence	20	4.6%	317	8.2%
Family Living/Lifesharing	4	0.9%	161	4.2%
Private ICF/ID- All	8	1.8%	76	1.9%
Private ICF/ID 1-4	*2*	*0.5%*	*19*	*0.5%*
Private ICF/ID 5-8	*2*	*0.5%*	*27*	*0.7%*
Private ICF/ID 9-15	*1*	*0.2%*	*5*	*0.1%*
Private ICF/ID 16+	*3*	*0.7%*	*25*	*0.6%*
Personal Care Home	1	0.2%	37	1.0%
Nursing Home/Facility	2	0.5%	32	0.8%
Children's Facility	5	1.1%	18	0.5%
Unlicensed Family Living	0	0.0%	14	0.4%
Domiciliary Care	0	0.0%	5	0.1%
Foster Care	0	0.0%	4	0.1%
Approved Private School	0	0.0%	4	0.1%
State MH Hospital	0	0.0%	1	0.0%
Temporary Shelter	0	0.0%	1	0.0%
Other	0	0.0%	42	1.1%
Missing	2	-	47	-
Total	439	100%	3911	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	90%	89%	89%
Want to stay where they currently live	69%	73%	75%
Want to move somewhere else	19%	16%	17%
In between wanting to stay and wanting to move	12%	11%	8%

A2. Work/Day Activity

	AE	Region	Statewide
Like primary job or day activity	93%	91%	92%
Like other job or day activity	96%	93%	93%
Want to continue current job or day activity	52%	66%	66%
Want to do something else.	39%	26%	25%
In between wanting to continue and wanting to change jobs	9%	8%	10%

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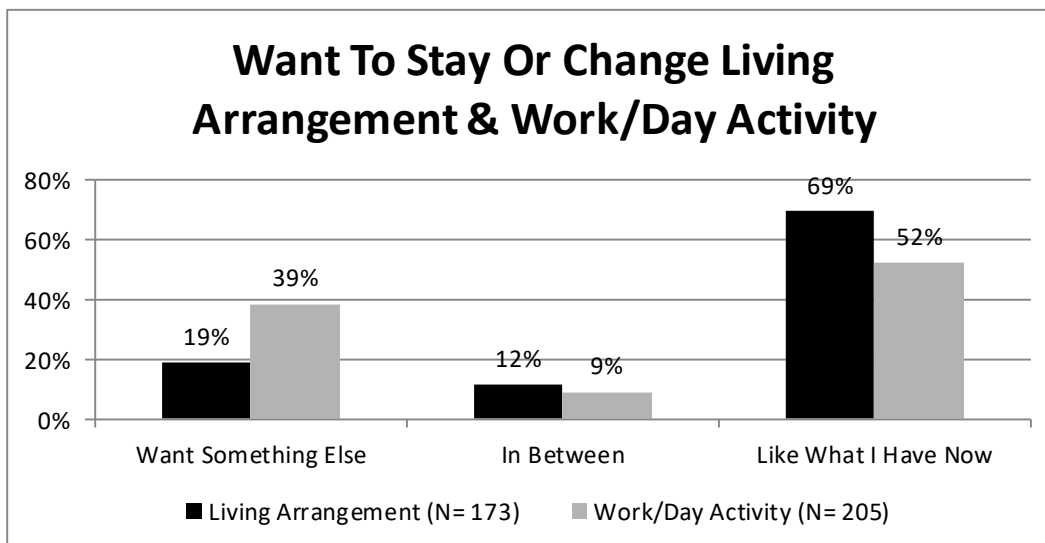
A3. Daily Activities

Primary Activity	AE	Region	Statewide
Stay home	50%	44%	38%
Work	15%	18%	21%
Work- no supports	*6%*	*11%*	*14%*
Work- with supports	*8%*	*7%*	*7%*
Attend school	5%	10%	10%
Attend a vocational facility	8%	7%	8%
Attend a day program or community center	9%	6%	7%
Go out in the community	4%	6%	7%
Retired	7%	5%	4%
Volunteer	1%	1%	2%
Something else	2%	3%	4%

Secondary Activity	AE	Region	Statewide
Stay home	56%	46%	45%
Work	6%	5%	5%
Work- no supports	*2%*	*3%*	*3%*
Work- with supports	*4%*	*2%*	*2%*
Attend school	0%	0%	<1%
Attend a vocational facility	2%	2%	1%
Attend a day program or community center	2%	4%	3%
Go out in the community	9%	15%	20%
Retired	4%	3%	2%
Volunteer	2%	4%	5%
Something else	19%	21%	19%

A3.1. Want to Work

	AE	Region	Statewide
Do not have or want a job	30%	49%	52%
If not, why?			
Like what I do now	8%	14%	13%
Retired	3%	3%	3%
Health limitations	0%	3%	2%
Benefits	0%	2%	1%
Would like a job for pay	66%	46%	43%

A4. Services

	AE	Region	Statewide
Always get services they need	94%	91%	88%
Sometimes get services they need	1%	2%	3%
Do not get services they need	2%	2%	4%
Need additional services	4%	5%	6%

A5. Happiness and Loneliness

	AE	Region	Statewide
Happy with life	81%	86%	87%
Neither happy nor sad with life	15%	11%	10%
Sad with life	4%	3%	3%
Never lonely	67%	67%	65%
Sometimes lonely	27%	29%	31%
Always lonely	6%	4%	4%
Have friends to do things with	91%	89%	87%
Friends are not staff or family	84%	79%	77%
Have a best friend	71%	71%	68%
Can date/marry, no restrictions	92%	83%	83%
Can date/marry, restrictions	2%	6%	6%
Cannot date/marry at all	6%	11%	12%

A6. Privacy

	AE	Region	Statewide
Have enough privacy (a place to be alone) at home	99%	98%	98%
Can be alone with friends at home	84%	85%	82%
No rules about friends or visitors	60%	62%	60%
People always let them know when coming into their home	86%	85%	89%
Sometimes people let them know when coming into their home	8%	8%	6%
People never let them know when coming into their home	6%	7%	5%
People always let them know when coming into their bedroom	92%	88%	89%
People sometimes let them know when coming into their bedroom	6%	6%	5%
People never let them know when coming into their bedroom	3%	6%	6%

A7. Are People Nice or Mean?

Are People Mean Or Nice?
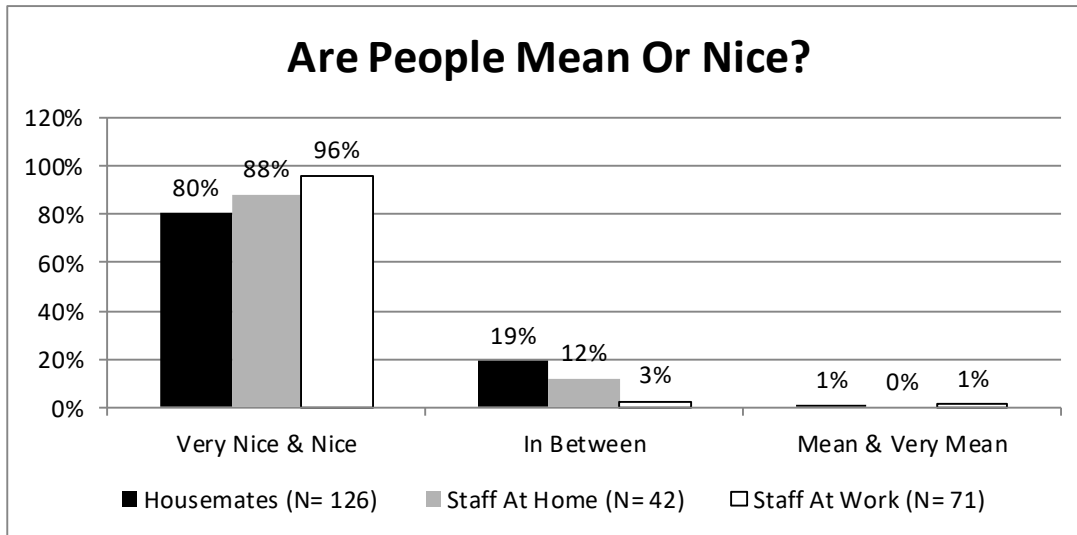
	AE	Region	Statewide
Staff at day or work activity are nice or very nice	96%	96%	97%
Staff at day or work activity are in between nice and mean	3%	2%	2%
Staff at day or work activity are mean or very mean	1%	1%	1%
Staff at home are nice or very nice	88%	95%	96%
Staff at home are in between nice and mean	12%	4%	4%
Staff at home are mean or very mean	0%	1%	0%
Housemates are nice or very nice	80%	85%	89%
Housemates are in between nice and mean	19%	13%	10%
Housemates are mean or very mean	1%	1%	1%
Get along well with the person they share a bedroom with*	67%	87%	82%
Get along OK with the person they share a bedroom with*	33%	7%	5%
Do not get along with the person they share a bedroom with*	0%	7%	14%

*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	79%	72%	69%
Do not get help	6%	8%	12%
Get to help other people	85%	79%	70%
Have participated in a self-advocacy group meeting	22%	19%	19%
Someone has talked to them about self-advocacy	63%	50%	46%
Have someone to talk to when afraid	97%	97%	96%

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

	AE	Region	Statewide
Staff	36%	34%	30%
Supports coordinator	4%	7%	6%
Other	8%	8%	6%
Family	22%	34%	33%
Friends	5%	6%	6%
Have no one	1%	1%	<1%

B2. Frequency of Being Afraid

Frequency Of Being Afraid

	Never	Sometimes	Always
Afraid At Home (N= 194)	90%	7%	4%
Afraid In Neighborhood (N= 255)	90%	7%	4%
Afraid At Work/Day Activity (N= 162)	90%	8%	2%
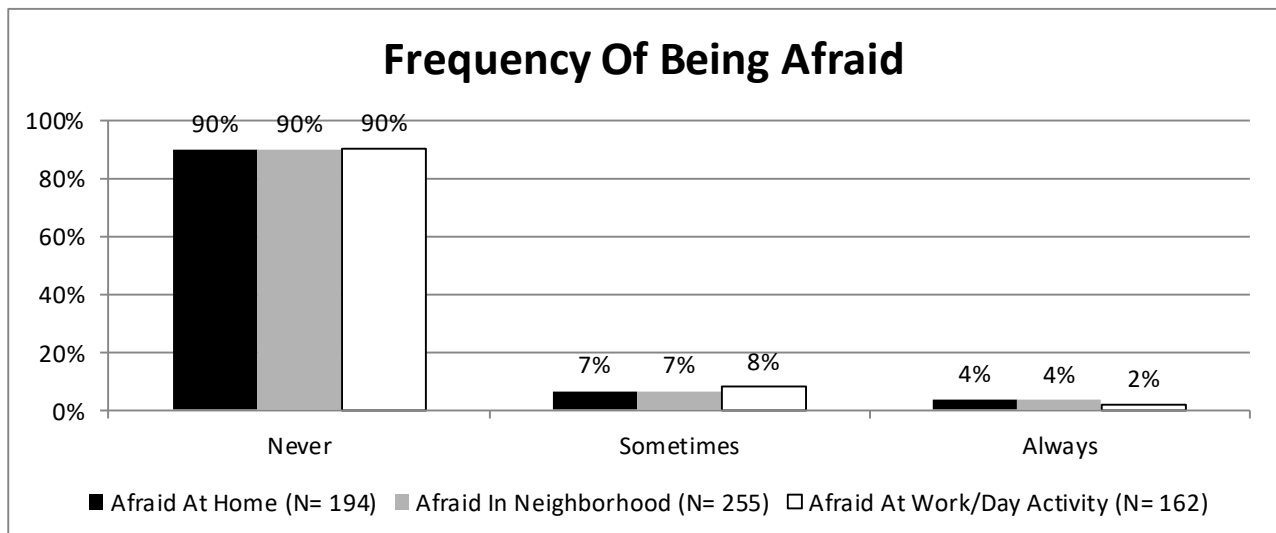
	AE	Region	Statewide
Never afraid at home	90%	87%	89%
Sometimes afraid at home	7%	9%	8%
Always afraid at home	4%	4%	3%
Never afraid in the neighborhood	90%	90%	90%
Sometimes afraid in the neighborhood	7%	7%	8%
Always afraid in the neighborhood	4%	3%	2%
Never afraid at work or day activities	90%	92%	94%
Sometimes afraid at work or day activities	8%	7%	5%
Always afraid at work or day activities	2%	1%	1%

B3. Legal Rights

	AE	Region	Statewide
Mail is never opened without permission	96%	90%	85%
Mail is sometimes opened without permission	0%	5%	7%
Mail is always opened without permission	4%	5%	8%

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)

Supports Coordination

Can communicate concerns during meetings (N= 160)	91%
QMRP/sup coord gets back right away (N= 176)	93%
Will always help them get what they need (N= 175)	95%
Have met with QMRP/support coordinator (N= 218)	91%
Support coordinator treats them with respect (N= 206)	97%
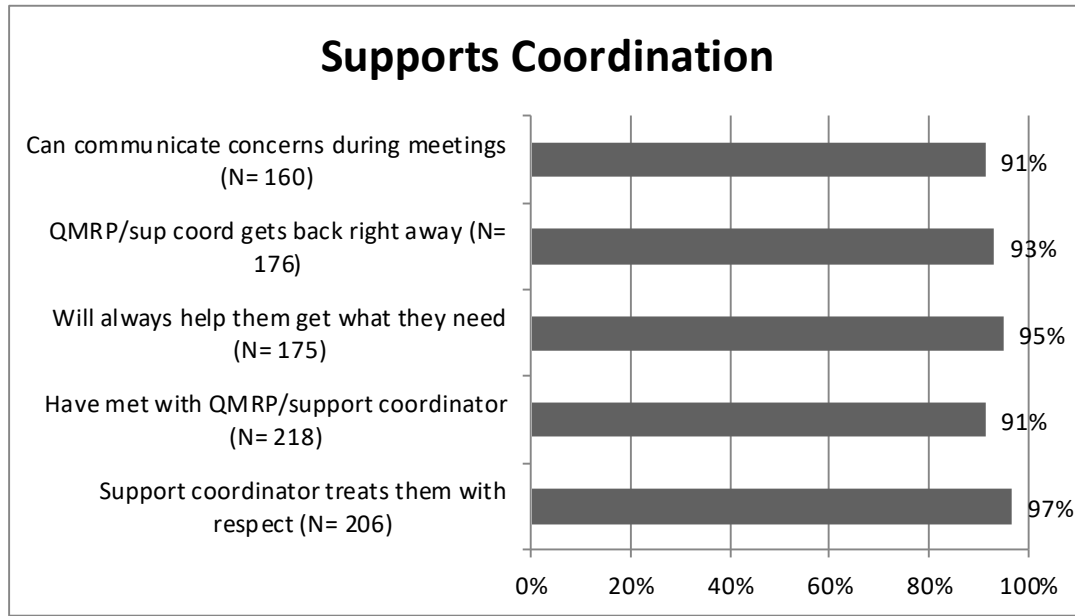
B4.1. SC Communication

	AE	Region	Statewide
SC asks what their interests are	93%	92%	94%
SC asks what they want their life to look like	85%	85%	89%
SC asks what they want in the future	87%	82%	87%
SC asks them about directing their own services	29%	43%	40%
SC asks if services are OK	98%	97%	98%
SC always listens to them	97%	95%	96%

B4.2. SC Interaction

	AE	Region	Statewide
Person knows they can choose SC	71%	67%	70%
SC always gets back to them right away	93%	92%	93%
SC will always help them get what they need	95%	92%	92%

	AE	Region	Statewide
Person has met with SC in the last year	91%	89%	91%
SC always treats the person with respect	97%	97%	98%

B5. Annual Planning Meeting

	AE	Region	Statewide
Participate in the meeting	96%	95%	95%
Know it is an option but choose not to participate in meeting	2%	2%	2%
Can communicate their concerns during the meeting	91%	87%	88%
Sometimes get to communicate concerns	6%	8%	8%
Told at the meeting how much money is in their budget	56%	58%	52%
Meeting includes the people they wanted to be there	96%	95%	95%
Know what is talked about at their ISP meeting	81%	80%	81%
Talk about learning new things at their planning meeting	78%	78%	77%
Maybe talk about learning new things	4%	8%	9%
Do not talk about learning new things	18%	14%	14%

B6. Services

	AE	Region	Statewide
Choose the services they get as a part of their service plan	93%	84%	82%
Have some input on services they get as a part of their service plan	5%	11%	14%
Know who to ask if they want to change their services	84%	82%	80%
Do not know who to ask to change services	15%	14%	13%

B7. Staff

	AE	Region	Statewide
Staff always treats them with respect	92%	94%	93%

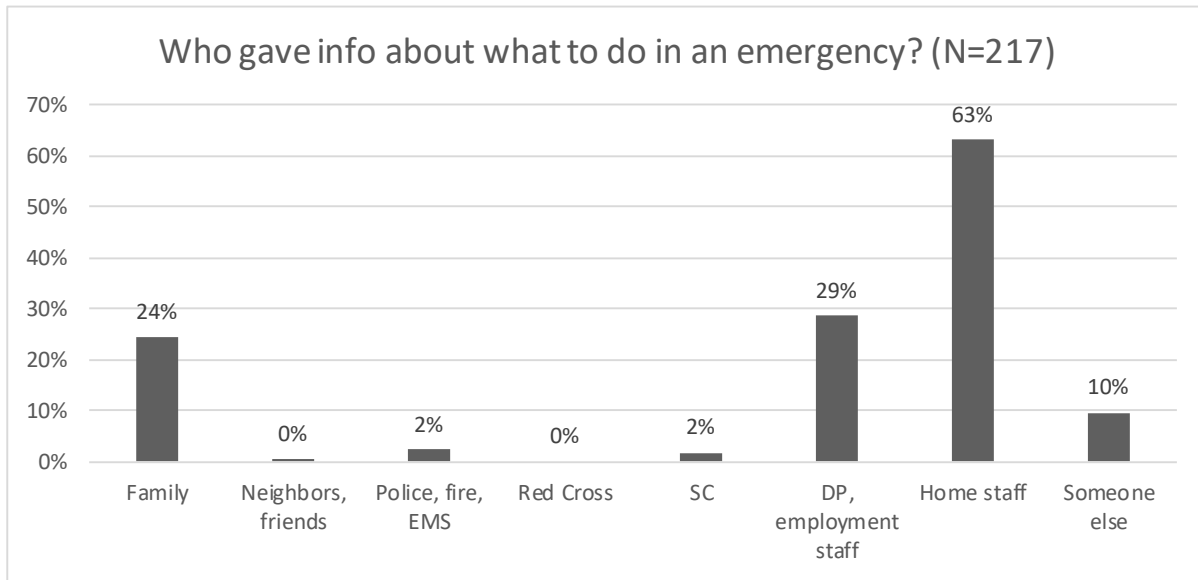|	AE	Region	Statewide
Staff have the right training to meet their needs	95%	94%	95%
All staff always understand their communication	91%	92%	89%
Some staff understand them	7%	5%	8%
Sometimes understood by staff	2%	2%	3%
Not understood by staff	1%	1%	1%

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	94%	92%	87%

B8.1. Who Provided Emergency Information

	AE	Region	Statewide
Home staff	63%	43%	38%
Day staff	29%	20%	17%
Family	24%	39%	46%
SC	2%	15%	9%
Police, Fire, or EMS Workers	2%	3%	3%
Friends	0%	2%	2%
Red Cross	0%	0%	0%
Someone Else	10%	13%	12%

Who gave info about what to do in an emergency? (N=217)

Family 24%, Neighbors, friends 0%, Police, fire, EMS 2%, Red Cross 0%, SC 2%, DP, employment staff 29%, Home staff 63%, Someone else 10%

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	28%	Individual and Paid staff	15%
Paid staff	27%	Individual and Family/friend/guardian/advocate	7%
Family/friend/guardian/advocate	20%	Staff and Family/friend/guardian/advocate	3%

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

C1. Identification

	AE	Region	Statewide
Always carry ID	65%	62%	64%
Never carry ID	25%	27%	20%

C2. Choice and Control at Home

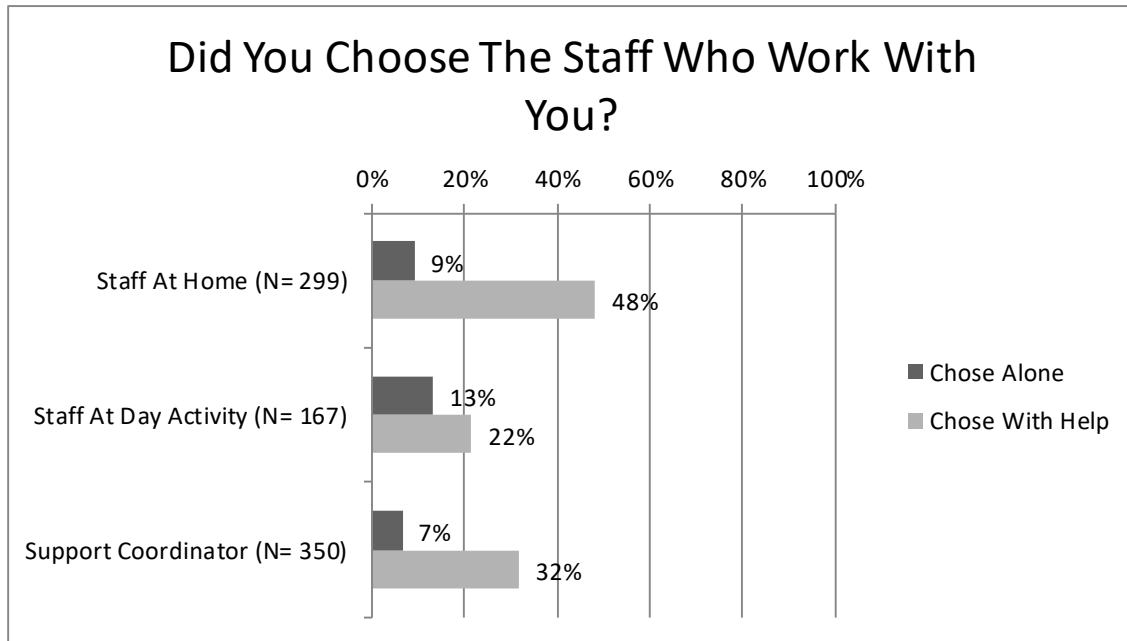|	AE	Region	Statewide
Have a key or way to get into their home	50%	49%	50%
If other household members go out, they have the option to stay home	68%	53%	49%
If other household members go out, they sometimes can stay home	7%	12%	13%
Can lock bedroom door	54%	53%	51%
Own their home	4%	3%	3%
Name is on the lease or rental agreement	14%	28%	33%
Have a choice to live where people without disabilities live	71%	65%	54%
Saw no other places before they moved into their home	49%	46%	48%
Did not choose housemates	61%	57%	59%
If individual shares a bedroom, chose some or all roommates	62%	47%	44%

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

Who Chose Where You Live And Work?
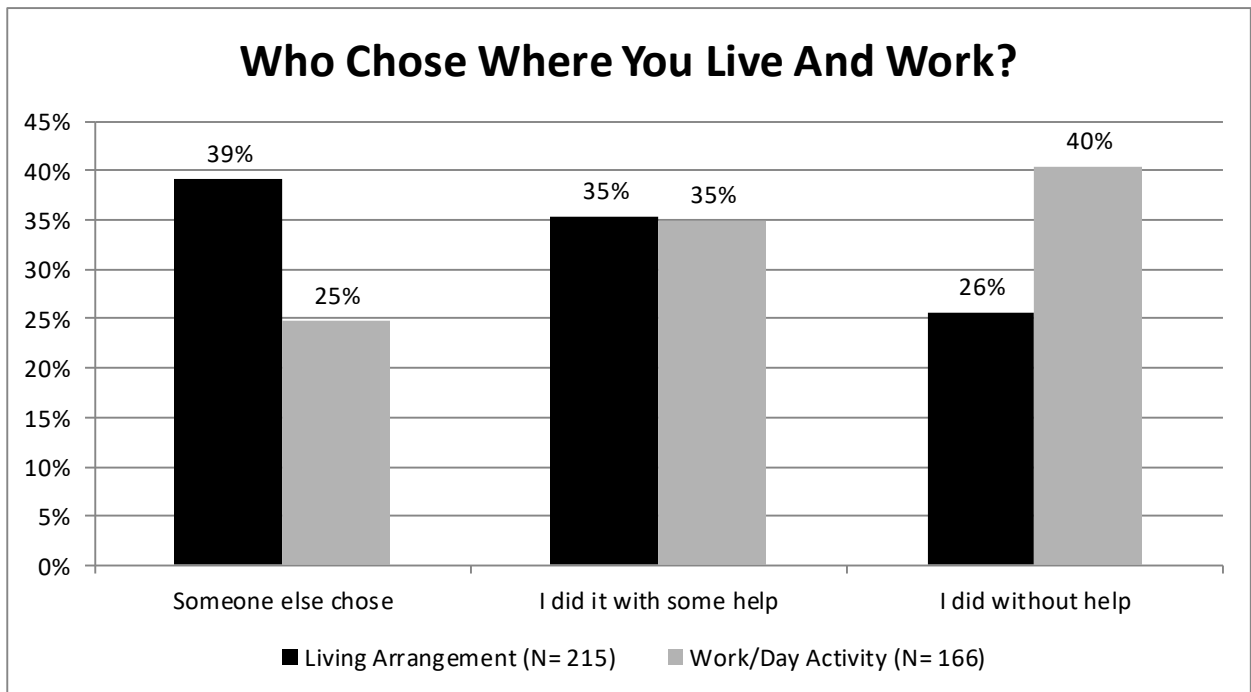
	AE	Region	Statewide
Chose living arrangement without help	26%	29%	26%
Chose living arrangement with some help	35%	31%	31%
Someone else chose living arrangement	39%	41%	44%
Chose work or day activity without help	40%	51%	54%
Chose work or day activity with some help	35%	31%	30%
Someone else chose work or day activity	25%	18%	16%

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

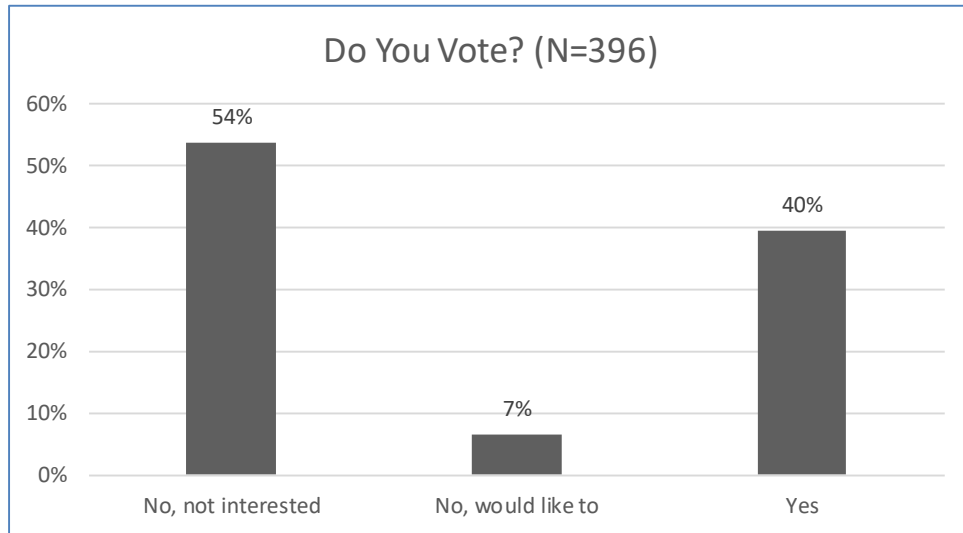|	AE	Region	Statewide
Have the choice to go where people without disabilities go	60%	67%	64%
See no other places when choosing day activity	34%	35%	38%
Choose daily schedule without assistance	94%	90%	89%
Have enough choice about free time	93%	94%	94%

C4. *Choice and Control in Choosing Staff*

Did You Choose The Staff Who Work With You?

Legend: ■ Chose Alone ■ Chose With Help

- Staff At Home (N= 299): Chose Alone 9%, Chose With Help 48%
- Staff At Day Activity (N= 167): Chose Alone 13%, Chose With Help 22%
- Support Coordinator (N= 350): Chose Alone 7%, Chose With Help 32%

	AE	Region	Statewide
Chose SC without help	7%	5%	4%
Chose SC with some help	32%	35%	32%
Someone else chose SC	62%	60%	64%
Chose staff at work or day activity without help	13%	16%	17%
Chose staff at work or day activity with some help	22%	23%	20%
Someone else chose staff at work or day activity	65%	61%	63%
Chose staff at home without help	9%	13%	13%
Chose staff at home with some help	48%	35%	31%
Someone else chose staff at home	42%	51%	57%

C5. *Choice and Control Regarding Money*

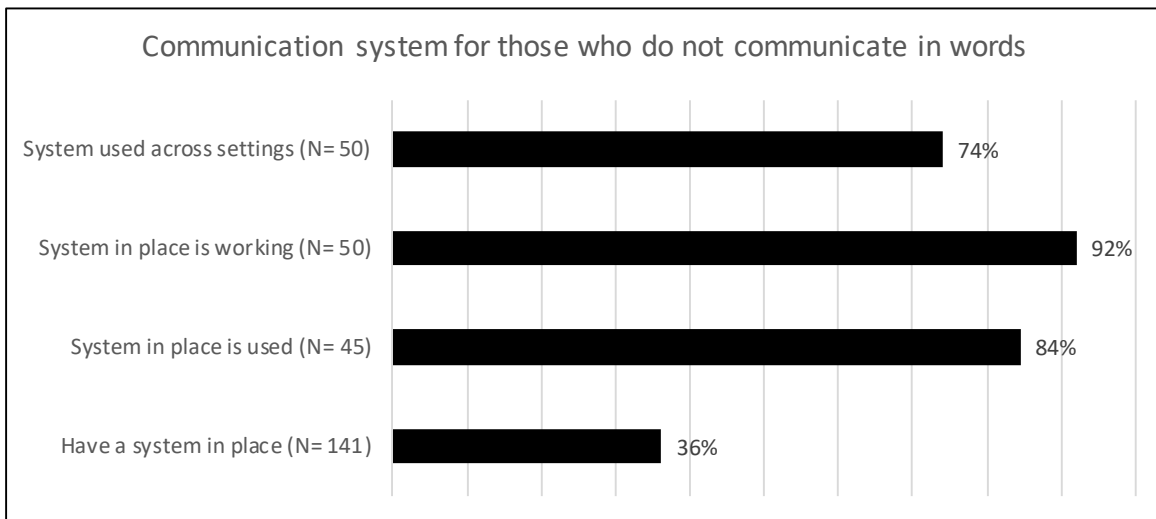|	AE	Region	Statewide
Always choose alone what to buy with spending money	61%	62%	61%
Choose what to buy with help	32%	30%	31%
There is something they want to buy	27%	35%	41%
They have a bank account and withdrawal money when they want	87%	71%	67%

C6. Voting

Do You Vote? (N=396)

	AE	Region	Statewide
Votes	40%	34%	39%
Chooses not to vote	54%	61%	57%
Does not vote but would like to	7%	5%	4%

C7. Status of Formal Communication System

Communication system for those who do not communicate in words

	AE	Region	Statewide
Have a communication system in place*	36%	38%	37%
System is being used**	84%	87%	87%
System is working**	92%	88%	91%
System is used across settings**	74%	71%	75%

* 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	57%	58%	53%
Speech Language Clinician	50%	42%	34%
Parent or Caregiver	45%	51%	49%
Someone Else	14%	17%	16%

C9. Other Forms of Communication

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

	AE	Region	Statewide
Cell phone	35%	43%	43%
E-mail	21%	28%	28%
Internet	70%	70%	64%
Text-messaging	26%	31%	30%
Cable TV	97%	95%	94%
Computer	65%	66%	65%

C9.2. Restrictions in Place for Communication

	AE	Region	Statewide
Cell phone	6%	10%	10%
E-mail	4%	7%	7%
Internet	9%	15%	11%
Text-messaging	2%	8%	6%
Cable TV	8%	11%	7%
Computer	8%	14%	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%	40%
Exercises at home <1 time per month	50%	51%	42%

C11. Medical & Dental Care

	AE	Region	Statewide
Opportunity to discuss health with primary care provider (PCP)	98%	92%	88%
Able to see a medical specialist if needed	96%	97%	96%
Have not been prevented from receiving medical or dental care due to disability	89%	89%	90%

C11.1. How Hard is it to Access Care?
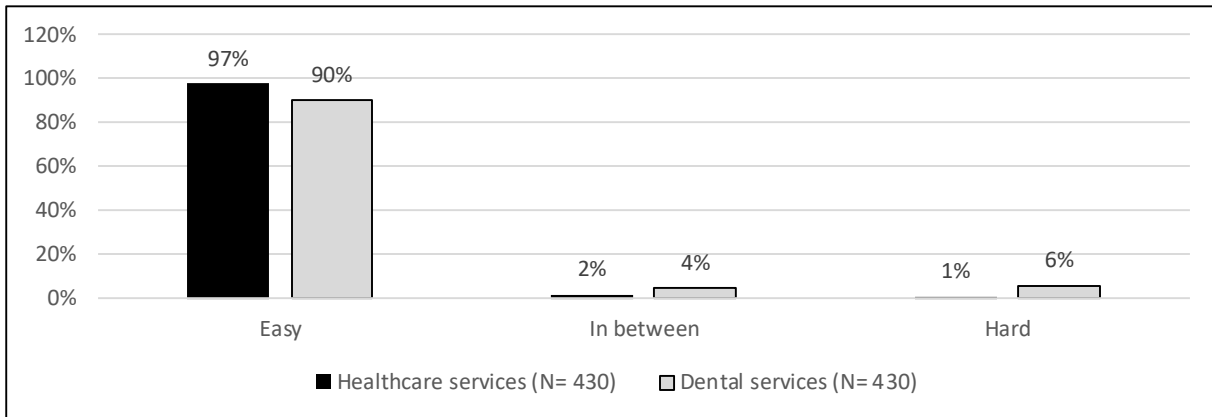
	AE	Region	Statewide
Accessing medical care is very/pretty easy	97%	93%	93%
Accessing medical care is between easy & hard	2%	5%	5%
Accessing medical care is hard or very hard	1%	2%	3%
Accessing dental care is very/pretty easy	90%	85%	85%
Accessing dental care is in between easy and hard	4%	7%	6%
Accessing dental care is hard or very hard	6%	8%	9%

C12. Mental Health

	AE	Region	Statewide
Have an opportunity to discuss health concerns with psychiatrist	84%	74%	62%
Do not have psychiatrist, but want one	0%	1%	2%

C13. Communicating Health Needs

	AE	Region	Statewide
Their doctor understands them	86%	84%	80%
They understand their doctor's instructions	66%	68%	66%
If they need help communicating at doctor's office, it is available	98%	96%	94%
Doctor speaks directly to them during appointments	99%	96%	93%
Able to provide consent for medical treatment	71%	67%	61%
If they provide consent, is it accepted	81%	82%	83%

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
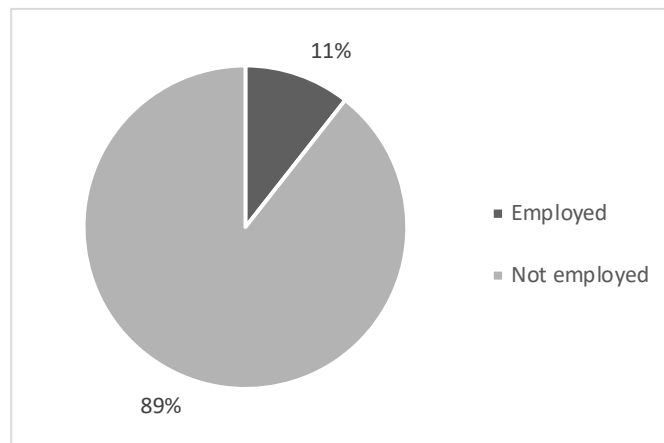
	AE	Region	Statewide
Employed in CIE	11%	15%	17%

C15. Length of Employment
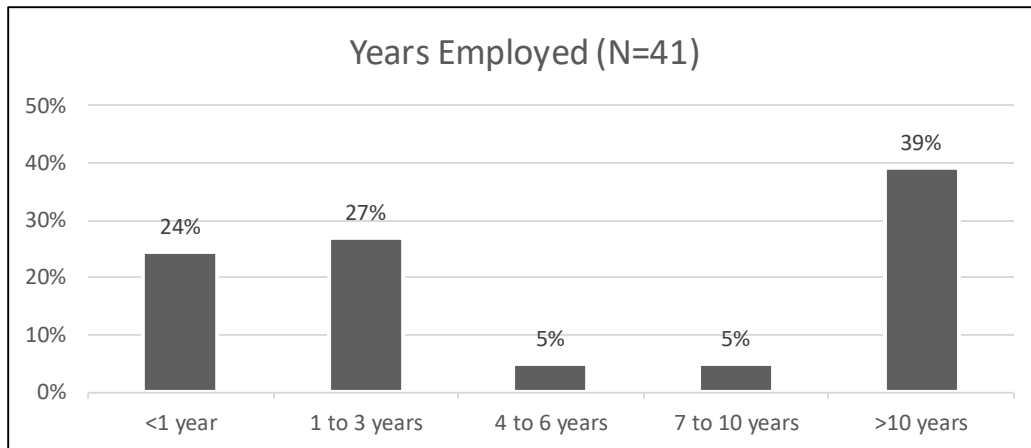
	AE	Region	Statewide
Employed <1 Year	24%	21%	17%
Employed 1 to 3 Years	27%	31%	32%

Employed 4 to 6 Years	5%	14%	19%
Employed 7 to 10 Years	5%	7%	9%
Employed 11+ Years	39%	26%	23%

C16. Types of Work

Cleaning Services	33%	Assembly/Factory Work	2%
Food Services	19%	Care Workers/Aides	5%
Retail Services	21%	Recycling	0%
Office Work	5%	Outdoor Work	2%
Stock Room	7%	Animal Care	0%
Maintenance	0%	Other	5%

C17. Supports Getting into the Workplace

	AE	Region	Statewide
Take classes/training for employment purposes	5%	8%	9%
Talked about employment in their planning meeting	59%	57%	54%
Community employment is a goal in their plan	33%	32%	35%

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

No one	43%	SC	49%
Service Provider	14%	Family	10%
Housemates	0%	Someone Else	13%

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

C18. Self-Employment

	AE	Region	Statewide
Person reports that they are self-employed	0%	1%	1%

C19. Compensation and Advancement

	AE	Region	Statewide
Have been promoted or received an increase in pay	54%	51%	52%
Receive paid time off from work as a benefit of employment	67%	75%	76%
Receive health insurance benefits from employer	39%	36%	25%
Receive retirement benefits from their employer	44%	31%	31%

	AE	Region	Statewide
Receive other work benefits from their employment	17%	20%	14%
Know how much they earn and willing to share	86%	91%	79%

C19.1. Hourly Wage

Hourly Wage (N=29)
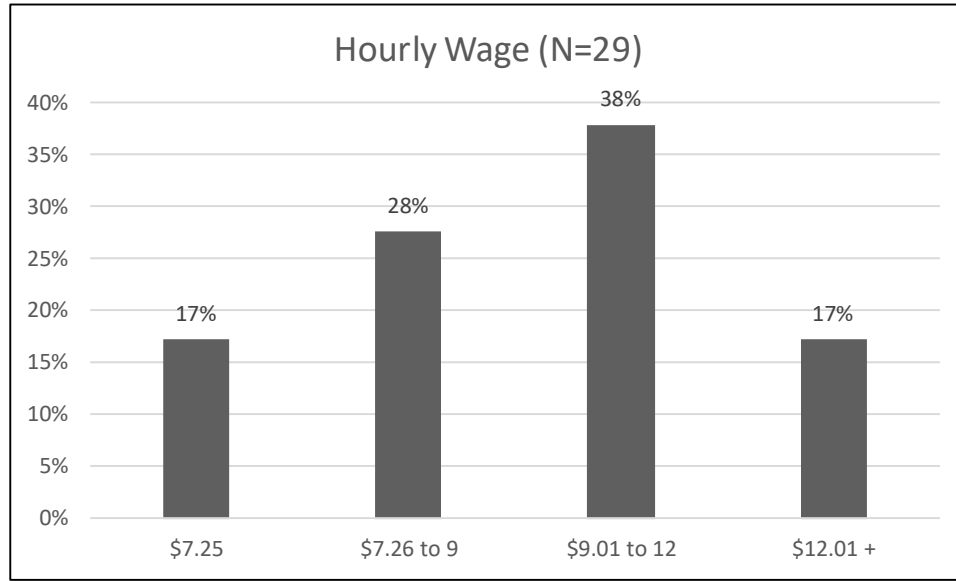
	AE	Region	Statewide
$7.25 per hour (Minimum wage)	17%	23%	17%
$7.26 - $9.00 per hour	28%	28%	25%
$9.01 - $12.00 per hour	38%	37%	45%
$12.01 or more per hour	17%	12%	14%

C20. Community Participation

	AE	Region	Statewide
Use Community Participation Services (CPS)	18%	21%	21%

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

	AE	Region	Statewide
Developing skills and competencies necessary for employment	19%	20%	18%
Fine/gross motor skill development and mobility	10%	15%	17%
Participating in community activities to develop social networks	60%	62%	59%

	AE	Region	Statewide
Participating in opportunities to develop interests or promote health/wellness	70%	62%	65%
Training/education for self-determination and self-advocacy	10%	11%	14%
Community adult learning opportunities	12%	16%	18%
Volunteering opportunities	34%	35%	30%
Learning to navigate the local community	7%	14%	12%

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%	4%	7%

C22. Who Makes Choices About Budget?

	AE	Region	Statewide
Individual makes decisions on their own	20%	35%	14%
Individual has input, family and friends help	40%	20%	30%
A family member or friend makes decisions	0%	38%	46%
A case manager or state professional makes the decision	40%	8%	10%

C23. Making Decisions

	AE	Region	Statewide
Individual participates in decisions about budget, staff, and managing services	80%	73%	70%
Hire and manage their own staff	67%	67%	62%

	AE	Region	Statewide
Can make changes to their budget or services if they need to	100%	81%	87%
Have enough help deciding how to use their budget/services	75%	96%	94%
Want more help deciding how to use their budget/services	0%	0%	1%

C24. Money Left in Budget

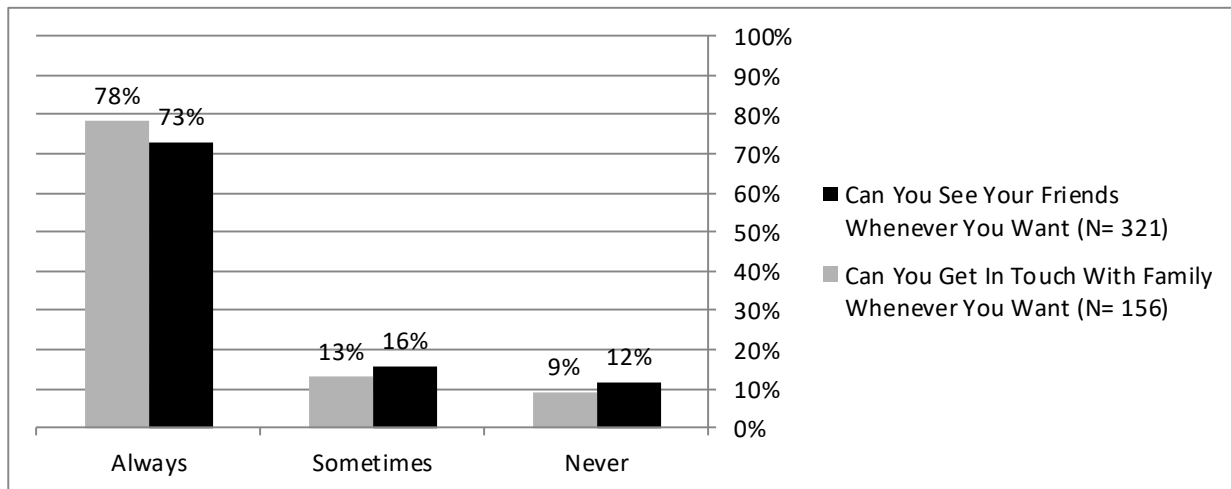|	AE	Region	Statewide
Receive information about the money left in their budget	100%	88%	73%
Information they receive is easy to understand	67%	85%	79%
They receive information at least every 3 months	67%	85%	63%
They receive information about twice a year	0%	5%	17%
They receive information once a year or less	33%	10%	20%

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	34%	Individual and Paid staff	10%
Paid staff	28%	Individual and Family/friend/guardian/advocate	4%
Family/friend/guardian/advocate	21%	Staff and Family/friend/guardian/advocate	3%

D. Relationships Data

D1. Contact with Friends and Family

	AE	Region	Statewide
Always see friends whenever they want to	73%	70%	73%
Sometimes see friends when they want to	16%	19%	18%
Never get to see friends when they want to	12%	11%	9%
Always can get in touch with family when they want to	78%	80%	78%
Sometimes can get in touch with family when they want to	13%	13%	14%
Never can get in touch with family when they want to	9%	7%	8%

D1.1. Why Person is Unable to See Friends

Difficult to find time	6%	Transportation Issue	0%
Lack of staff	0%	Rules or restrictions	5%
Money or cost	0%	Something else	89%

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	24%	Individual and Paid staff	15%
Paid staff	28%	Individual and Family/friend/guardian/advocate	10%
Family/friend/guardian/advocate	21%	Staff and Family/friend/guardian/advocate	3%

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	35%	38%	40%
Go to a supermarket	36%	39%	44%
Go out to eat/restaurants	26%	29%	37%
Go to a shopping center or mall	30%	30%	34%
Go out to a worship service	12%	16%	20%
Run errands and appointments	32%	29%	26%
Meeting people at coffee house/tavern	9%	9%	15%
Go out for entertainment	14%	14%	17%

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	42%	56%	2%
Go to a supermarket	68%	28%	4%
Go out to eat/restaurants	44%	55%	1%
Go to a shopping center or mall	58%	40%	1%
Go out to a worship service	66%	34%	1%

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	77%	18%	5%
Meeting people at coffee house/tavern	69%	30%	1%
Go out for entertainment	39%	61%	0%

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

Activity	Staff	Family	Friends	Roommates Coworkers	Go Alone	Other
Visit friends, relatives, neighbors	30%	52%	8%	0%	10%	0%
Go to a supermarket	45%	46%	0%	0%	7%	0%
Go out to eat/restaurants	45%	43%	3%	3%	6%	0%
Go to a shopping center or mall	53%	39%	1%	0%	7%	0%
Go out to a worship service	26%	60%	3%	1%	9%	0%
Run errands and appointments	57%	36%	1%	1%	5%	0%
Meeting people at coffee house/tavern	51%	34%	0%	0%	14%	1%
Go out for entertainment	57%	38%	2%	1%	2%	0%

E2. Extra-Curricular Activities

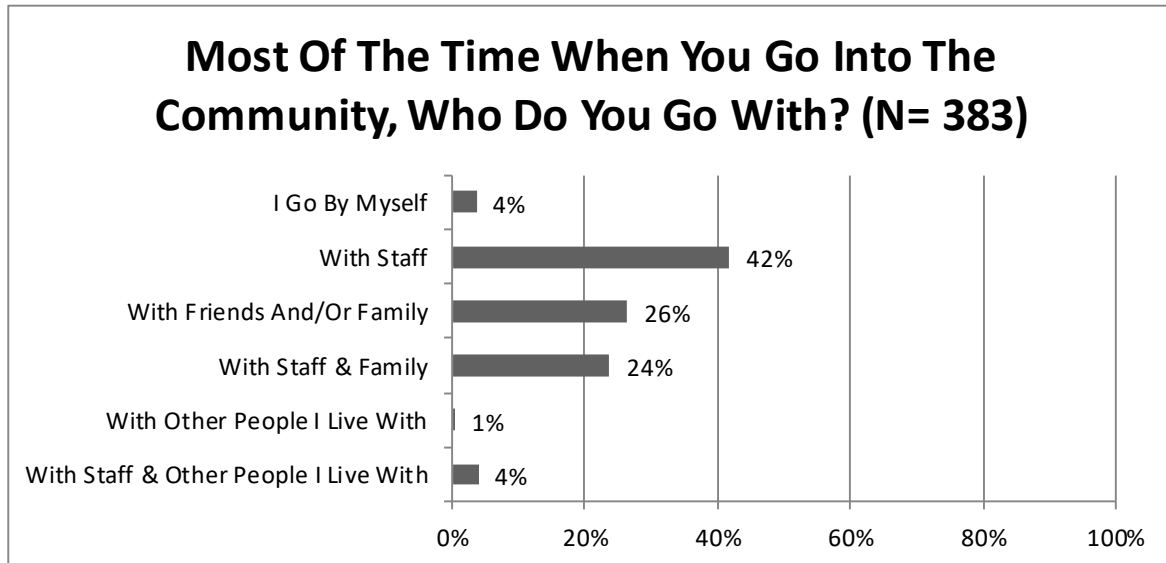|	AE	Region	Statewide
Would like to be a part of more groups in the community	49%	41%	37%
Went on a vacation in the past year	23%	24%	27%

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

	AE	Region	Statewide
Go out into the community for entertainment frequently	22%	23%	26%

	AE	Region	Statewide
Go out into the community for entertainment occasionally	16%	27%	33%
Go to social events attended by people with and without disabilities frequently	17%	18%	18%
Go to social events attended by people with and without disabilities occasionally	18%	32%	39%

E2.2. Exercise in the Community

	AE	Region	Statewide
Person never exercises	41%	40%	33%
Person exercises less than once a week	4%	4%	3%
Person exercises about once a week	10%	11%	11%
Person exercises more than once a week	45%	45%	54%

E3. Going Out Alone or with Other People

Most Of The Time When You Go Into The Community, Who Do You Go With? (N= 383)

- I Go By Myself — 4%
- With Staff — 42%
- With Friends And/Or Family — 26%
- With Staff & Family — 24%
- With Other People I Live With — 1%
- With Staff & Other People I Live With — 4%

	AE	Region	Statewide
Myself	4%	6%	7%
With Staff	42%	33%	36%
With Friends and/or Family	26%	34%	35%
With Housemates	1%	2%	1%
With Staff and Housemates	4%	3%	3%
With Staff and Family	24%	22%	18%

E4. Transportation

	AE	Region	Statewide
Always have a way to get where they wanted to go	99%	96%	93%

E4.1. Transportation Methods Used Most Frequently

	AE	Region	Statewide
Get a ride from family or friends	32%	42%	42%
Get a ride from staff in provider van	55%	38%	37%
Get a ride in staff member's car	5%	10%	11%
Transport themselves	2%	5%	5%
Ride public transportation	4%	3%	3%
Ride paratransit	2%	2%	1%
Take a taxi, Uber or Lyft	0%	0%	<1%

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

	AE	Region	Statewide
Not enough staff	20%	20%	13%
Paratransit is unreliable	20%	22%	9%
Transportation for work/school only	0%	2%	5%
No one at home can drive	0%	4%	2%
Some other reason	60%	53%	72%

E5. Home Adaptive Equipment

Do You Have All The Adaptive Equipment You Need? (N= 320)

No
Yes

10%

90%

Do you need changes to make your home more accessible? (N= 431)

Yes
No

6%

94%
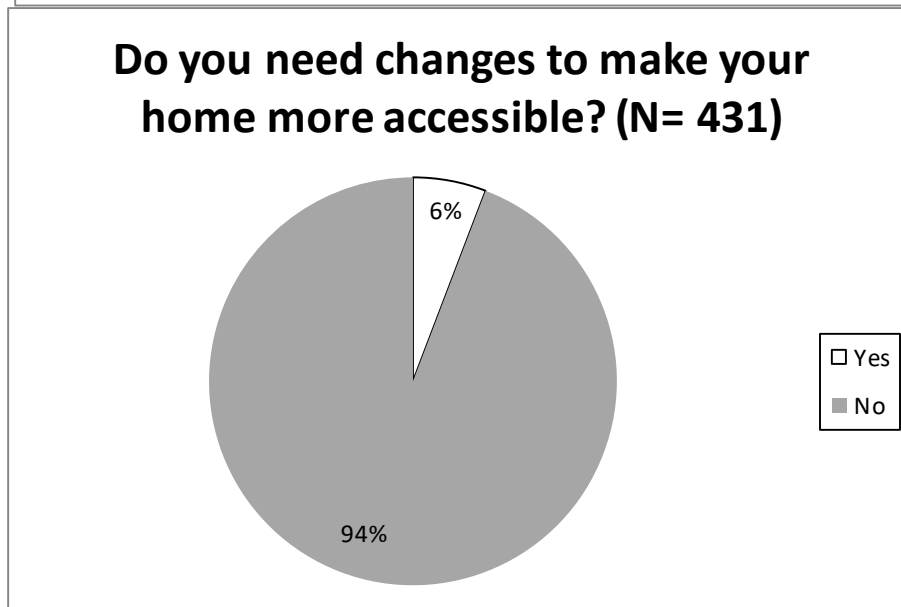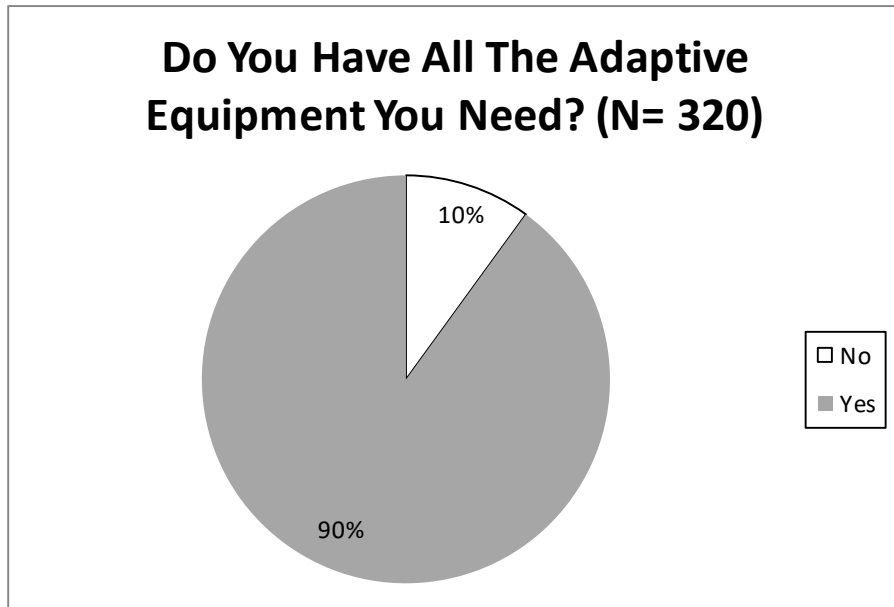
	AE	Region	Statewide
Have all the adaptive equipment needed at home	90%	88%	85%
Any adaptations or modifications needed to make the home accessible have been made	94%	92%	94%

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	8.1
Mode	N/A	N/A	9.0

G. Support for the Person Data

G1. Monitor Observations

	AE	Region	Statewide
Staff treat individuals with dignity and respect	97%	96%	89%
Staff recognize the individual in ways that promote independence	97%	97%	89%
Staff who support individuals have the skills they needed	97%	97%	89%

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 74 family members, friends, and guardians.

Respondents:

Parent(s)	79%	Another Relative	3%
Sibling(s)	11%	Friend	0%
Guardian	3%	Other	4%

H. Family, Friend and Guardian Survey Data

H1. Daily Life

	AE	Region	Statewide
Somewhat satisfied or very satisfied with where their relative lives	96%	97%	97%
Somewhat satisfied or very satisfied with what relative does during the day	81%	88%	87%
Somewhat satisfied or very satisfied with relative's staff at home	97%	97%	96%
Somewhat satisfied or very satisfied with staff at relative's day activity	95%	94%	94%

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

	AE	Region	Statewide
Contacted their relative at least monthly	97%	95%	93%
Never contacted their relative	0%	2%	1%
See their relative at least monthly	69%	70%	63%
Never visited their relative	19%	11%	13%

H3. Your Relative's Satisfaction

	AE	Region	Statewide
Relative is satisfied or very satisfied with his/her living situation	96%	95%	95%
Relative is satisfied or very satisfied with what they do during the day	83%	90%	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	0%	1%	<1%
Relative is satisfied or very satisfied with the staff who support them during the day	91%	96%	95%
Relative is dissatisfied or very dissatisfied with the staff who support them during the day	2%	1%	<1%

H4. Your Relative's Safety

	AE	Region	Statewide
Relative always feels safe in their community, home, and neighborhood	90%	92%	89%
Relative feels safe in their community, home, and neighborhood most of the time	10%	6%	10%

H5. Your Relative's Opportunities

	AE	Region	Statewide
Relative has enough opportunities to participate in activities in the community	70%	74%	77%
Relative has the opportunity to learn new things	84%	89%	88%

H6. Your Relative's Staff

	AE	Region	Statewide
Relative's home appears to have an adequate number of paid staff	87%	82%	85%
Staff in relative's home always treat people with dignity and respect	94%	96%	95%
All staff in their relative's home have the skills they need to support their relative	77%	89%	89%
Some of the staff in their relatives home have the skills they need to support their relative	23%	11%	9%

	AE	Region	Statewide
Relative's place of work appears to have an adequate number of paid staff	97%	96%	96%
Staff at relative's place of work always treat people with dignity and respect	97%	97%	98%
All staff in their relative's workplace have the skills needed to support their relative	85%	92%	93%
Some staff at their relative's workplace have the skills they need to support their relative	12%	6%	5%
The staff who assist their relative with planning always respects their choices and opinions	84%	91%	93%

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	40%	46%	47%
If there is a communication system in place, it is used across settings	67%	76%	82%

H8. Relative's Supports

	AE	Region	Statewide
Satisfied with the support coordination their relative receives	78%	88%	86%
Told how much money is in their relative's budget	51%	55%	60%
Their relative directs their own services	4%	8%	10%
Their relative always receives the supports they needed	75%	77%	76%
The supports and services their relative receive change when their needs change	90%	91%	90%
There are never or rarely changes in support staff at their family member's home, work, or day program	39%	65%	62%

	AE	Region	Statewide
There are always frequent changes in support staff at their family member's home, work or day program	19%	11%	10%
They chose the agency/provider who worked with their relative	36%	38%	42%
Their relative chose the agency or provider who worked with their relative, alone or with their help	38%	29%	30%
Someone else chose the agency/provider who worked with their relative	26%	33%	28%

H9. Complaints and Grievances

	AE	Region	Statewide
Relative was familiar with the complaint and grievance process on some level	63%	71%	71%

H9.1. At what level?

	AE	Region	Statewide
At the provider level	53%	67%	63%
At the county/AE level	48%	65%	66%
At the state level	44%	63%	60%

H10. Family Resources

	AE	Region	Statewide
The information they receive about their relative's services is easy to understand	92%	90%	91%
They had learned about the Life Course Framework and Tools	6%	17%	18%
They had an opportunity to connect and network with other families with relatives at similar life stages	51%	44%	44%
They are aware of the PA Family Network (PAFN)	22%	26%	26%
Of those who were aware of the PAFN, who had attended a workshop led by the Network of Family Advisors	14%	19%	26%
Have enough information about services for which the family is eligible	73%	81%	83%

If family member transitioned from school to adult services, were happy with the process	78%	20%	27%
SC asks about their vision for an everyday life for their family member	65%	77%	80%

H11. Emergency Preparation Questions

	AE	Region	Statewide
Given information about an emergency plan for their family member in case of emergency	51%	62%	62%

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