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

Independent Monitoring for Quality (IM4Q)
Statewide Report
2020-2021

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

Submitted by: **James A. Lemanowicz, Jenifer Taylor Eaton, Mary Kay R. Cunningham, Guy Caruso and Sally Gould-Taylor**
The Institute on Disabilities
Pennsylvania's University Center for Excellence in Developmental Disabilities Education, Research and Service
Temple University
College of Education and Human Development
Institute on Disabilities at Temple University
Ritter Annex 4
1301 Cecil B. Moore Avenue
Philadelphia, PA 19122

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Temple University College of Education and Human Development | Institute on Disabilities

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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 Statewide Report

In this report, each section begins with a summary of the current year's data. If available, scale scores are provided and briefly explained. Progress Points highlight major changes in the data from the last published report. Improvements from the previous year are marked with a "Star" icon (★). Areas where there are Opportunities for Improvement are marked with a "Reaching" icon (𝟃). At the end of each summary, a hyperlink is provided that will take you to the summary for the next section of the report.

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 "95% of respondents reported that they were happy with their life."

Happy with life	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: Jerry's Considerations
Jerry was interviewed by his AE for the IM4Q project in 2018. When the IM4Q Monitors who were interviewing Jerry asked if he had unmet needs or requests, Jerry shared that he wanted a cell phone and help learning how to use it, a radio or CD player so he could listen to music, and a bus pass so he could travel in his community.

The considerations were shared with Jerry's SC, who planned a meeting with Jerry in his home. Here, Jerry had a chance to share his needs in more detail. Together, Jerry and the SC decided what kind of cell phone, radio, and bus pass would best fit Jerry's needs. They arranged payment details and planned training so Jerry could learn to use his new phone. Jerry also got to shop around and choose the radio he liked best.

Through these considerations, Jerry's life changed! He has better access to the community using his bus pass. He can have more communication and improved safety because of his cell phone. He can also have a higher quality of life with access to entertainment through his cd/radio player. His individuality was respected for what he wanted and valued in his life to improve the quality of his life.

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**.

Executive Summary

This report presents information collected through remote interviews with nearly 4,000 individuals and about 1,500 family members of individuals receiving supports in Pennsylvania. This was the first year the survey was conducted entirely in a remote format. This change, as well as the ongoing Covid-19 Pandemic, should be considered in the review of the data.

In this year's **sample**, most individuals reside in the home of a relative or a community home. Most are white, non-Hispanic/Latinx and about 60% are male.

Satisfaction rates are high among individuals receiving services and their family members. About 90% of individuals like where they live and work and say they are happy with their life. Although these percentages indicate high satisfaction, it is important to note that this type of research usually yields high satisfaction rates. Individuals who receive supports and services tend to appreciate getting such services and therefore see themselves as satisfied.

Perceptions of **Dignity, Respect and Rights** are also largely positive. Most indicate that they participate in their planning meeting, their supports coordinator (SC) listens to them, and their staff treats them with respect. People report good access to **Health Care** and satisfaction with their services and **Supports Coordination**.

People report lower scores for perceptions of **Choice and Control** and **Inclusion**. About half of individuals made choices about where to live and work, and more than half make their own decisions about what to buy with their money. 90% say they chose their daily schedule without assistance and most report they have enough choice about their free time.

Regarding community inclusion, less than half of people surveyed go out in the community frequently for shopping, eating, or entertainment. A quarter to nearly half of respondents reported that they would like to engage in these activities more. The ongoing Covid-19 Pandemic may be affecting access, however.

IM4Q Monitor Impressions reflect positive outcomes for individuals (nice home, respected by staff, opportunities for growth) in observed situations. **Family, Friend and Guardian** surveys are overwhelmingly optimistic about their relatives' living situation and services. Though people employed in **Community Integrated Employment** and using **Self-Directed Services** remain in the minority (17% and 7%), numbers are increasing despite the Covid-19 Pandemic.

As has been the trend for several reporting years, communication remains an issue for many individuals in the sample, particularly for those who communicate other than verbally. Responses indicate that individuals had trouble being understood by medical professionals (20%) and being understood by staff (11%). Of people who are non-verbal, only about 2 in 5 have a communication system in place. Of these, three-quarters use it across settings.

Though family members report high satisfaction, many family members lack information. 30% are unaware of the complaint and grievance procedure at any level, only a quarter are aware of the PA Family Network, and less than 1 in 5 had learned about Life Course Training and Tools.

Sample

i. Sample Data

i1. Total Surveyed

People with disabilities	3911	Family members	1569

i2. Age

Range	6-95	Mean Age (SD)	40.0 (17.1)

i3. Reported Gender

Female	41.0%	Male	58.8%	Other	0.1%

i4. Race and Ethnicity

Race (n=3624)

White/Caucasian	79.4%
Black/African American	16.2%
Other	2.0%
Pacific Islander	0.1%
Asian	1.3%
Two or More Races	1.1%
American Indian/Alaskan Native	0.2%

0.0% 10.0% 20.0% 30.0% 40.0% 50.0% 60.0% 70.0% 80.0%

Ethnicity (n=3413)

3.6%

96.4%

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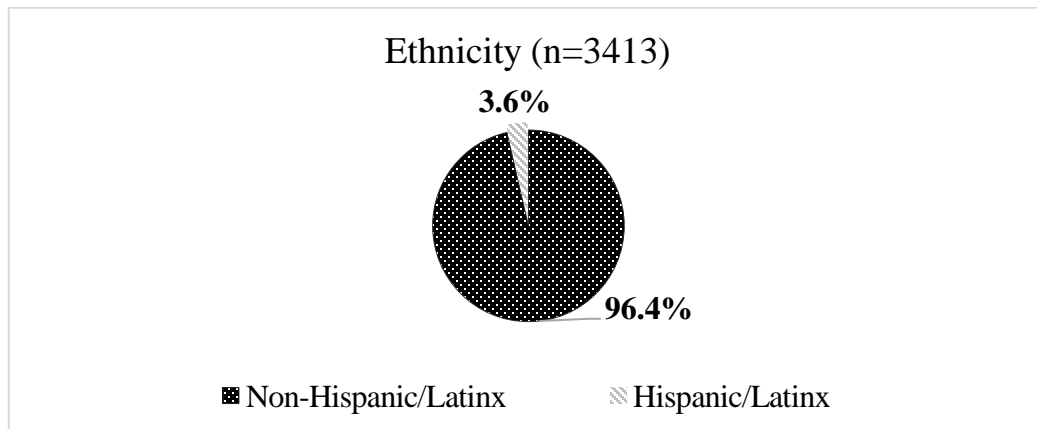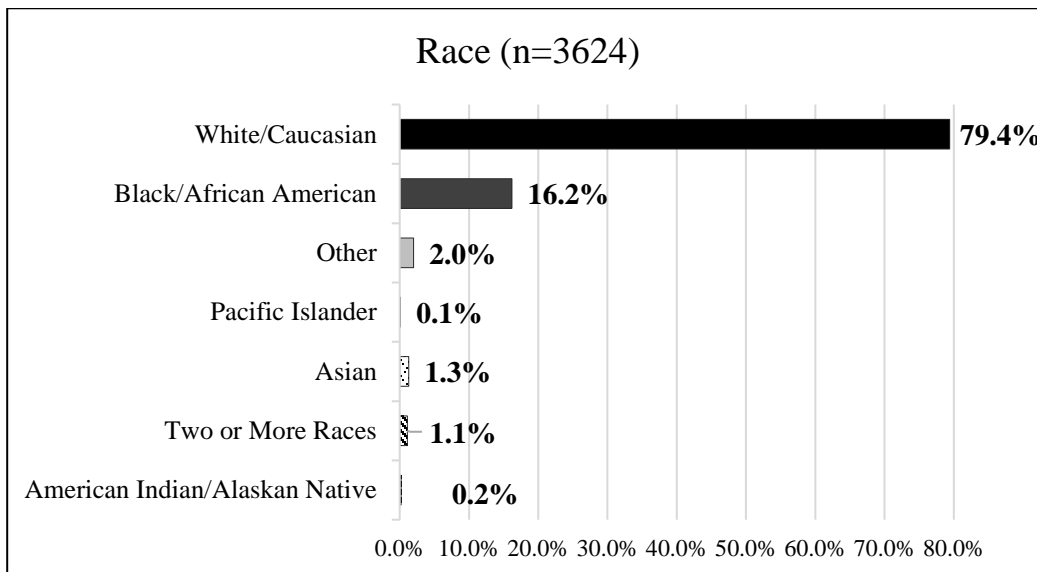
i5. Home Type Where Respondent Lives

Type of Residence	Number of Residents	Percent of the Sample
Relative's Home	1734	44.9%
Community Home- All	1418	36.7%
Community Home 1	*196*	*5.1%*
Community Home 2-4	*1174*	*30.4%*
Community Home 5-6	*28*	*0.7%*
Community Home 7-8	*12*	*0.3%*
Community Home 9-15	*4*	*0.1%*
Community Home 16+	*4*	*0.1%*
Own Residence	317	8.2%
Family Living/Lifesharing	161	4.2%
Private ICF/ID- All	76	1.9%
Private ICF/ID 4 or fewer	*19*	*0.5%*
Private ICF/ID 5-8	*27*	*0.7%*
Private ICF/ID 9-15	*5*	*0.1%*
Private ICF/ID 16+	*25*	*0.6%*
Personal Care Home	37	1.0%
Nursing Home/Facility	32	0.8%
Children's Facility	18	0.5%
Unlicensed Family Living	14	0.4%
Domiciliary Care	5	0.1%
Foster Care	4	0.1%
Approved Private School	4	0.1%
State MH Hospital	1	0.0%
Temporary Shelter	1	0.0%
Other	42	1.1%
Missing	47	-
Total	**3911**	**100%**

i6. Administrative Entity (AE) Where the Respondent Lives

AE	Number of Respondents	Percent of Sample
Allegheny	439	11.2%
Armstrong/Indiana	52	1.3%
Beaver	68	1.7%
Bedford/Somerset	35	0.9%
Berks	116	3.0%
Blair	50	1.3%
Bradford/Sullivan	22	0.6%
Bucks	159	4.1%
Butler	57	1.5%
Cambria	46	1.2%
Cameron/Elk	18	0.5%
Carbon/Monroe/Pike	64	1.6%
Centre	49	1.3%
Chester	110	2.8%
Clarion	20	0.5%
Clearfield/Jefferson	38	1.0%
Columbia/Montour/Snyder/Union	47	1.2%
Crawford	54	1.4%
Cumberland/Perry	56	1.4%
Dauphin	97	2.5%
Delaware	177	4.5%
Erie	165	4.2%
Fayette	38	1.0%
Forest/Warren	18	0.5%
Franklin/Fulton	0	0.0%
Greene	20	0.5%
Huntington/Mifflin/Juniata	38	1.0%
Lackawanna/Susquehanna	88	2.3%
Lancaster	87	2.2%
Lawrence	35	0.9%
Lebanon	31	0.8%
Lehigh	107	2.7%
Luzerne/Wyoming	106	2.7%
Lycoming/Clinton	54	1.4%
McKean	18	0.5%
Mercer	37	0.9%
Montgomery	216	5.5%
Northampton	70	1.8%
Northumberland	42	1.1%
Philadelphia	550	14.1%
Potter	19	0.5%
Schuylkill	45	1.2%
Tioga	31	0.8%
Venango	34	0.9%
Washington	48	1.2%
Wayne	27	0.7%
Westmoreland	96	2.5%
York/Adams	114	2.9%
Missing	3	-
TOTAL	**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.

Summary: People in this sample are mostly happy about where they live and work. Most people are happy and say that people in their lives are nice or very nice to them. Most people report high levels of privacy, and consistently report that they have friends, and can date and get married if they wish. Most individuals report that they get the services and supports they need to be able to live in their homes. (**Satisfaction Scale***: Mean: 84.7 (SD 19.5); Mode: 100)

Progress Points Compared to 2019-2020 Report:

★ Improvements

- There was a 3% increase in individuals who reported they always get the services they need (85% to 88%).

Opportunities for Improvement

- There was an 8% decrease in people who said they want to continue at their current job or daytime activity (74% to 66%) and a 7% increase in those who said they want to do something else (18% to 25%).
- There was an 8% increase in individuals who said if they do not have a job, they would like to have a job for pay (35% to 43%).

This link will skip data details and take you to the summary of the next Section **Dignity, Respect and Rights.**

A. Satisfaction Data

A1. Living Arrangements

Like where they live now	89%
Want to stay where they currently live	75%
Want to move somewhere else	17%

A2. Work/Day Activity

Like primary job or day activity	92%
Like other job or day activity	93%
Want to continue current job or day activity	66%
Want to do something else.	25%

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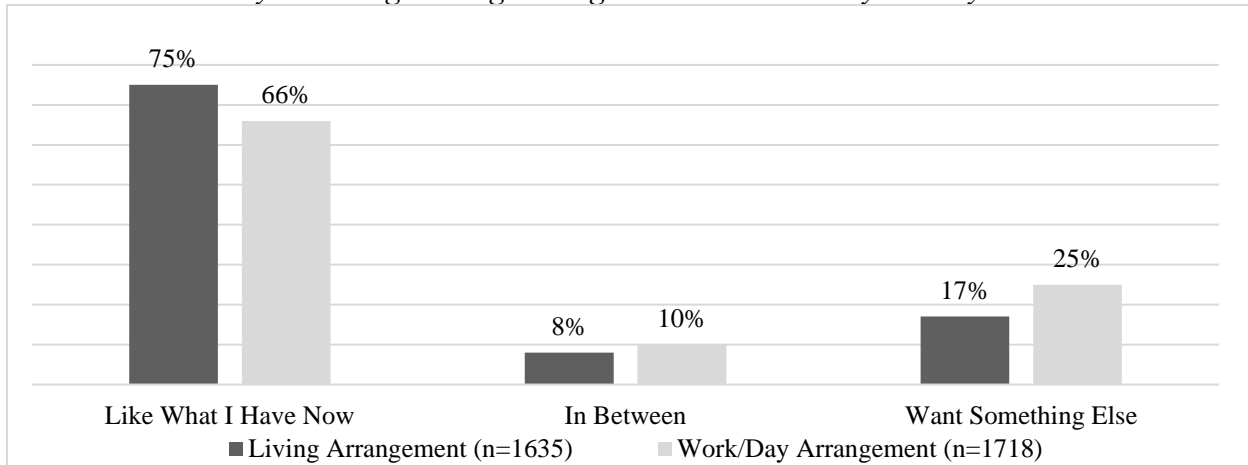
A3. Daily Activities

	Primary Activity	Secondary Activity
Stay home	38%	45%
Work	21%	5%
Work- no supports	*14%*	*3%*
Work- with supports	*7%*	*2%*
Attend school	10%	<1%
Attend a vocational facility	8%	1%
Attend a day program or community center	7%	3%
Go out in the community	7%	20%
Retired	4%	2%
Volunteer	2%	5%
Something else	4%	19%

A3.1. Want to Work

Do not have or want a job	52%
If not, why?	
Like what I do now	13%
Retired	3%
Health limitations	2%
Benefits	1%
Would like a job for pay	43%

A4. Services

|	
Always get services they need	88%
Sometimes get services they need	3%
Do not get services they need	4%
Need additional services	6%

A5. Happiness and Loneliness

Happy with life	87%
Neither happy nor sad with life	10%
Sad with life	3%
Never lonely	65%
Sometimes lonely	31%
Always lonely	4%
Have friends to do things with	87%
Friends are not staff or family	77%
Have a best friend	68%
Can date/marry, no restrictions	83%
Can date/marry, restrictions	6%
Cannot date/marry at all	12%

A6. Privacy

Have enough privacy (a place to be alone) at home	98%
Can be alone with friends at home	82%
No rules about friends or visitors	60%
People always let them know when coming into their home	89%
Sometimes people let them know when coming into their home	6%
People never let them know when coming into their home	5%
People always let them know when coming into their bedroom	89%
People sometimes let them know when coming into their bedroom	5%
People never let them know when coming into their bedroom	6%

A7. Are People Nice or Mean?
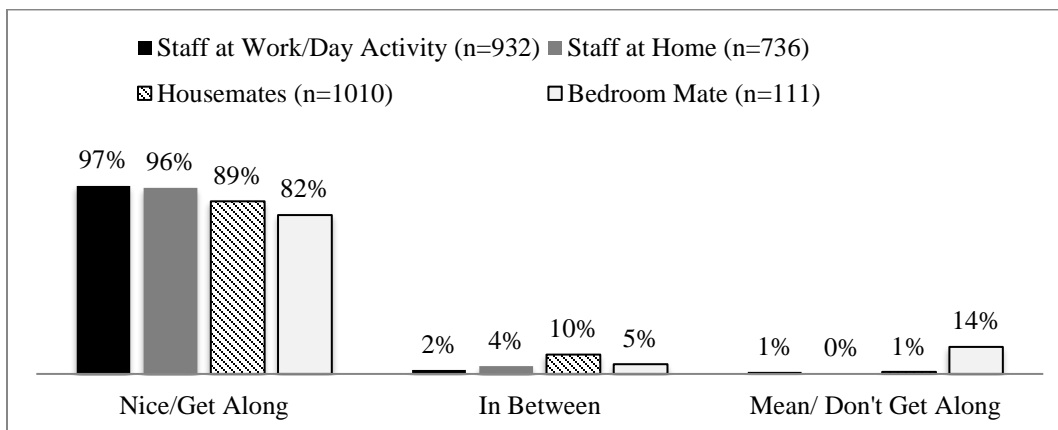
Part II: Dignity, Respect and Rights

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.

Summary: People in our sample report fairly high scores on Dignity, Respect and Rights. More than 4 in 5 report their mail is never opened without permission, while about 7 in 10 have the chance to learn new things and to help others. People are rarely afraid in their home, work, or neighborhood. About half of the individuals surveyed had talked to someone about self-advocacy. About 1 of 5 respondents had participated in a self-advocacy group meeting. Most people are highly satisfied with their SC and other staff members. Individuals report that staff members understand them, that they are listened to, and that they are treated with respect. Most had received information on preparation in case of emergency. (**Dignity Respect and Rights Scale***: Mean: 83.3 (SD 14.4); Mode: 75; **Afraid Scale***: Mean: 94.0 (SD 15.3); Mode: 100.)

- The mode for the Dignity and Respect Scale was much lower than the Satisfaction Scale. This indicates that many individuals chose the most positive answer category (very satisfied) for all measures of the Satisfaction Scale, whereas for the Dignity and Respect Scale individuals were less likely to choose the most positive answer category for all measures. The mode of 100 on the Afraid scale indicates that the majority of individuals surveyed (82%) report that they never feel afraid in their home, neighborhood or work/day activity site.

Progress Points Compared to 2019-2020 Report:

Improvements

- There was a 2% increase in individuals who reported that someone had talked to them about self-advocacy (44% to 46%)
- There was a 6% increase in people who said they chose the services they get as a part of their service plan (76% to 82%).

Opportunities for Improvement

- There was a 4% decrease in individuals reporting they are told at their planning meeting how much money is in their budget (56% to 52%).

This link will skip data details and take you to the summary of the next Section **Supports Coordination.**

B. Dignity Respect and Rights Data
### Part II, Section A: Dignity, Respect and Rights

B1. Support with Goals and Problems

Get help to learn new things	69%
Do not get help	12%
Get to help other people	70%
Have participated in a self-advocacy group meeting	19%
Someone has talked to them about self-advocacy	46%
Have someone to talk to when afraid	96%

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

Staff	30%	Family	33%
Supports coordinator	6%	Friends	6%
Other	6%	Have no one	<1%

B2. Frequency of Being Afraid
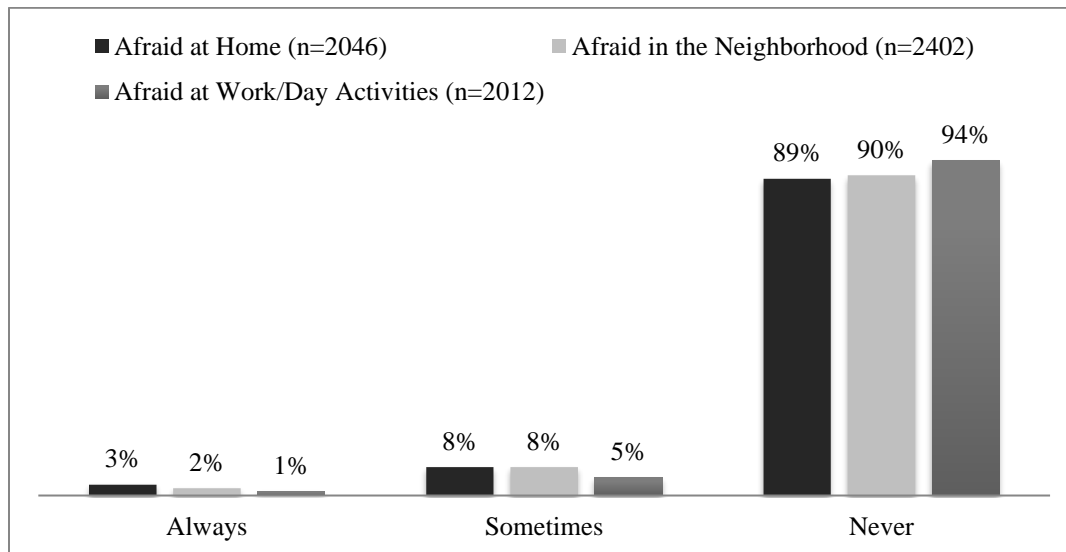
B3. Legal Rights

	Never	Sometimes	Always
Mail opened without permission	85%	7%	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.

Summary: Overall, people said they were highly satisfied with their supports coordination. At least 9 in 10 consistently reported positive interactions and communication with their SC and felt that staff have the right training and treated them with respect. About 4 in 5 were happy with their services and report getting all the services they need. About half know how much money is in their budget and slightly less than half were asked about directing their own services.

Progress Points Compared to 2019-2020 Report:

★ **Improvements**
- There was a 7% increase in respondents who reported they know they have a choice of supports coordinator organizations (63% to 70%).
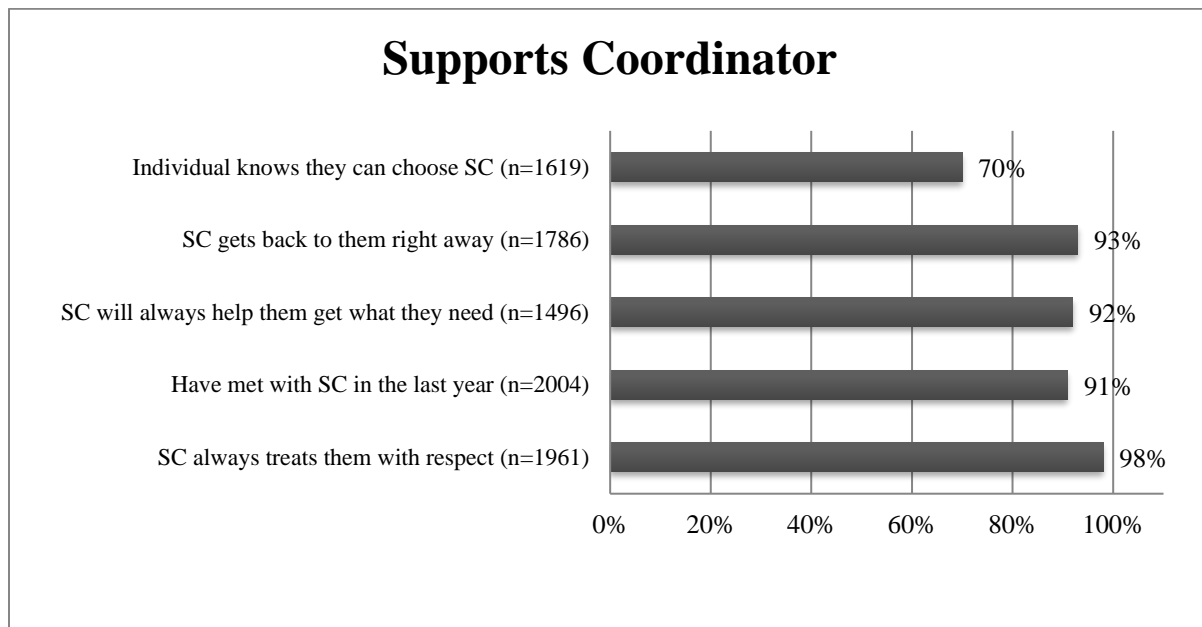
Opportunities for Improvement
- There was a 6% decrease in people who reported they had met with their SC in the last year (97% to 91%).

This link will skip data details and take you to the summary of the next Section **Emergency Preparation.**

B4. Supports Coordinator (SC)

Supports Coordinator

Individual knows they can choose SC (n=1619)	70%
SC gets back to them right away (n=1786)	93%
SC will always help them get what they need (n=1496)	92%
Have met with SC in the last year (n=2004)	91%
SC always treats them with respect (n=1961)	98%

0%   20%   40%   60%   80%   100%

B4.1. SC Communication

SC asks what their interests are	94%
SC asks what they want their life to look like	89%
SC asks what they want in the future	87%
SC asks them about directing their own services	40%
SC asks if services are OK	98%
SC always listens to them	96%

B5. Annual Planning Meeting

Have participated in the meeting	95%
Know it is an option but choose not to participate in meeting	2%
Can communicate their concerns during the meeting	88%
Sometimes get to communicate concerns	8%
Told at the meeting how much money is in their budget	52%
Meeting includes the people they wanted to be there	95%
Know what is talked about at their ISP meeting	81%
Talk about learning new things at their planning meeting	77%
Maybe talk about learning new things	9%
Do not talk about learning new things	14%

B6. Services

Choose the services they get as a part of their service plan	82%
Have some input on services they get as a part of their service plan	14%
Know who to ask if they want to change their services	80%
Do not know who to ask to change services	13%

B7. Staff

Staff always treats them with respect	93%
Staff have the right training to meet their needs	95%
All staff always understand their communication	89%
Some staff understand them	8%
Sometimes understood by staff	3%
Not understood by staff	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.

Summary:
The vast majority of people, nearly 9 in 10, have been given information about what to do in cases of emergency. Nearly half of people received information from their family members. More than a third received information from their staff at home. Day staff and SCs were also good sources of information, while few received emergency preparedness information from police, fire, or Emergency Medical Service (EMS) workers and none reported receiving information from the Red Cross.

Progress Points Compared to 2019-2020 Report:

Improvements

- There was a 2% increase in people reporting someone had given them information about what to do in case of emergency (85% to 87%).
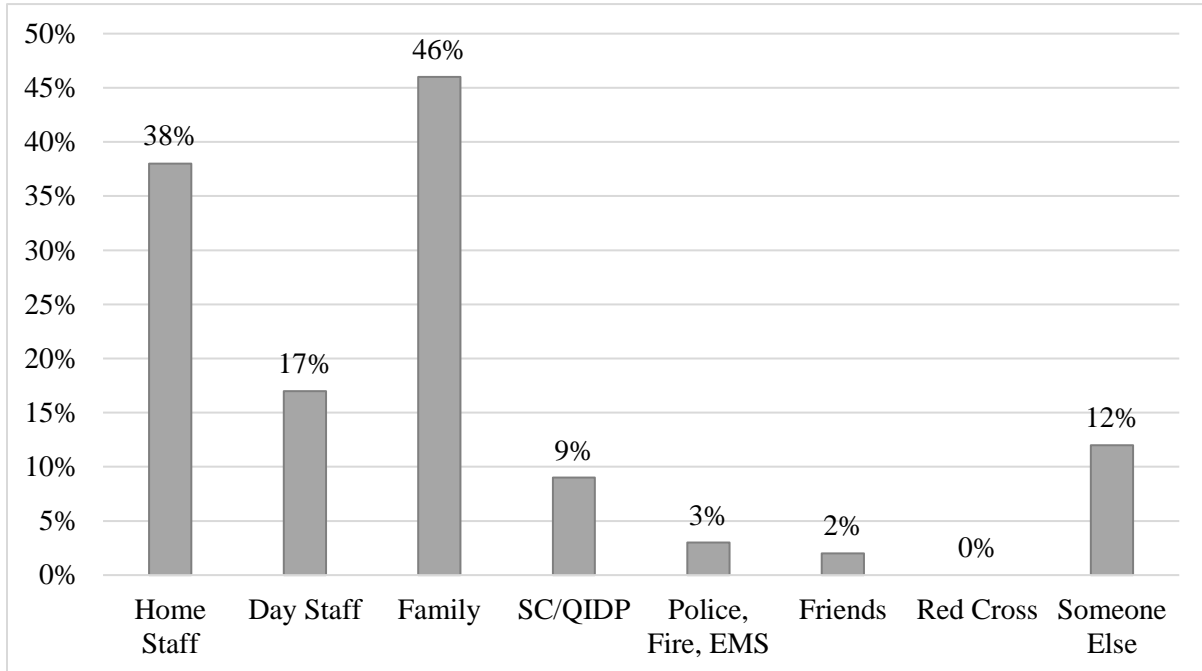
Opportunities for Improvement

- None identified.

This link will skip data details and take you to the summary of the next Section **Choice and Control.**

B8. Emergency Preparation Questions

Have been given information about what to do in an emergency	87%

B8.1. Who Provided Emergency Information

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:

Individual	30%	Individual and Paid staff	11%
Paid staff	23%	Individual and Family/friend/guardian/advocate	15%
Family/friend/guardian/advocate	20%	Staff and Family/friend/guardian/advocate	1%

Summary: About 3 in 5 individuals surveyed always carry identification (ID), while 1 in 5 never do. Nearly 2 in 5 choose to vote in elections. About half of respondents have a key to their home, an option to stay home when others go out, and the ability to lock their bedroom door. Less than half chose their housemates, roommates, staff or where they live on their own. If they do not communicate in words, 2 in 5 have a communication system in place. More than 9 in 10 reported they had enough choice about their free time and 9 in 10 made their own schedule. More than 9 in 10 have access to cable television, while 3 in 5 have Internet and a computer and less than half have a cell phone. (***Choice and Control Scale****: Mean: 60.4 (SD: 20.4). Mode: 47.4).*

- The mode for the Choice and Control Scale was much lower than the Satisfaction or Dignity Respect and Rights Scales. This indicates that many individuals do not report many opportunities to exert choice and control.

Progress Points Compared to 2019-2020 Report:

★ Improvements

- There was a 7% increase in people who reported that they vote (32% to 39%).
- There was a 4% increase in those who said they carry ID all the time (60% to 64%).
- There was an 11% increase in those who share a bedroom reporting that they chose some or all of their roommates (33% to 44%).
- There was a 9% increase in people reporting they had the choice to go where people without disabilities go during the day for leisure time (55% to 64%).

Opportunities for Improvement

- There was a 3% decrease in individuals who reported that they had the option to stay home when other members of their house go out (52% to 49%).
- There was a 4% decrease in individuals who reported they had the option to live where people without disabilities would live (58% to 54%).

This link will skip data details and take you to the summary of the next Section **Health Questions.**

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

C1. Identification

Always carry ID	64%
Never carry ID	20%

C2. Choice and Control at Home

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

C2.1. Who Chooses Where the Person Lives and Works?
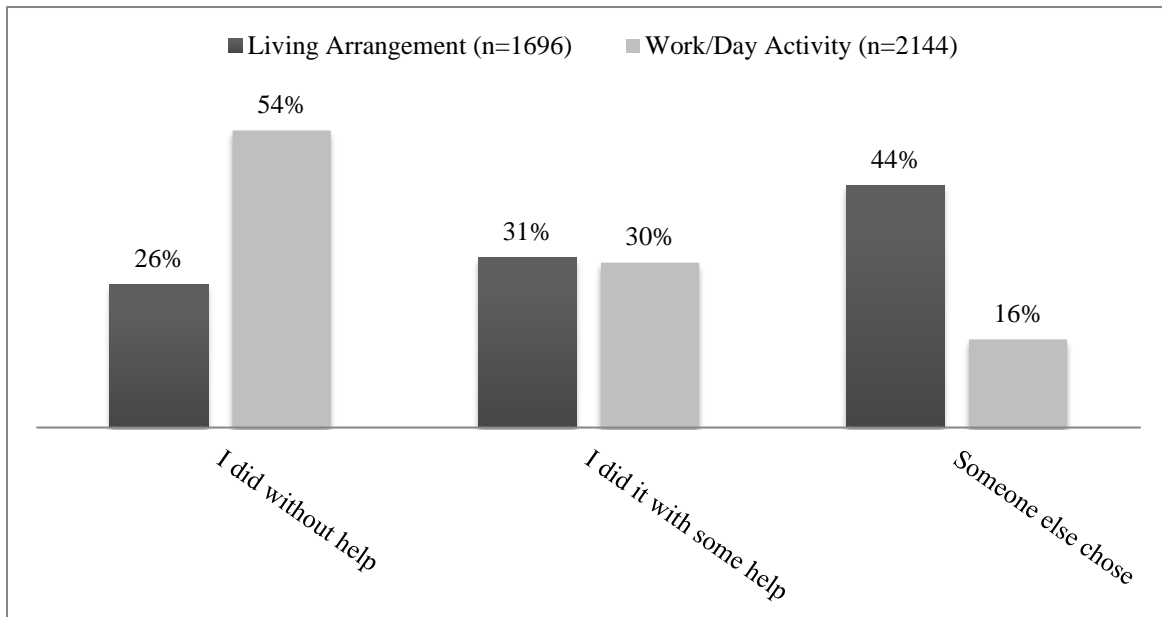
C3. Choice and Control During the Day and for Leisure Time

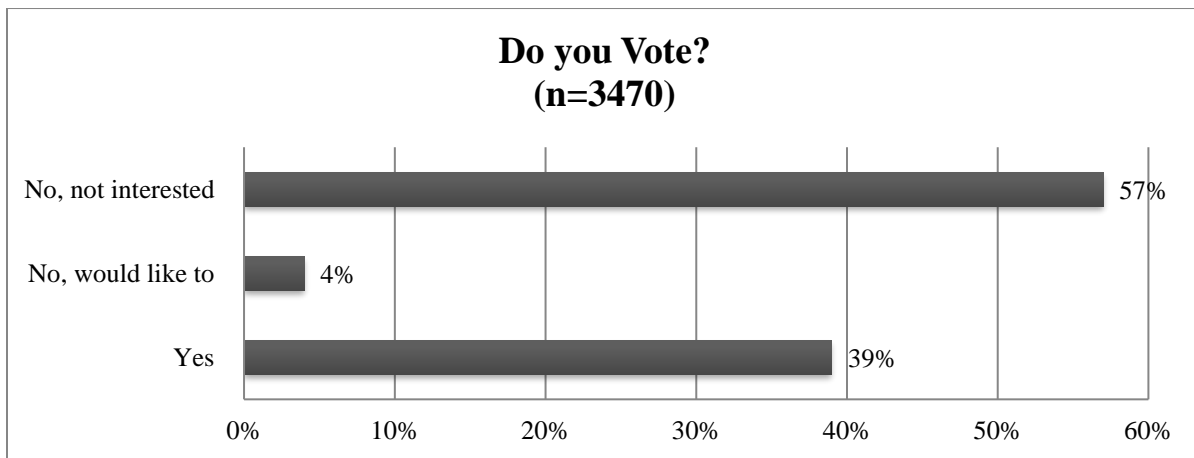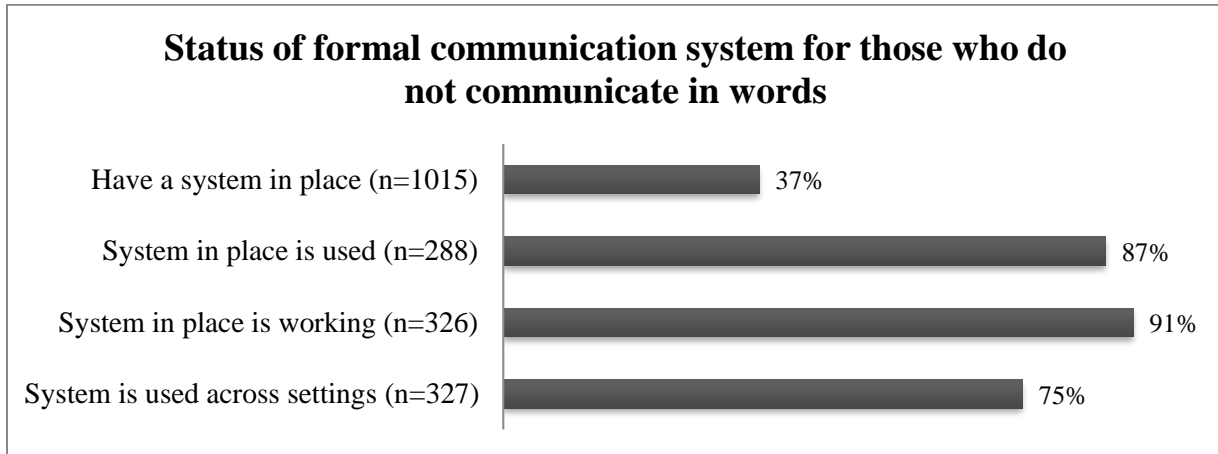|	
Have the choice to go where people without disabilities go	64%
See no other places when choosing day activity	38%
Choose daily schedule without assistance	89%
Have enough choice about free time	94%

C4. *Choice and Control in Choosing Staff*
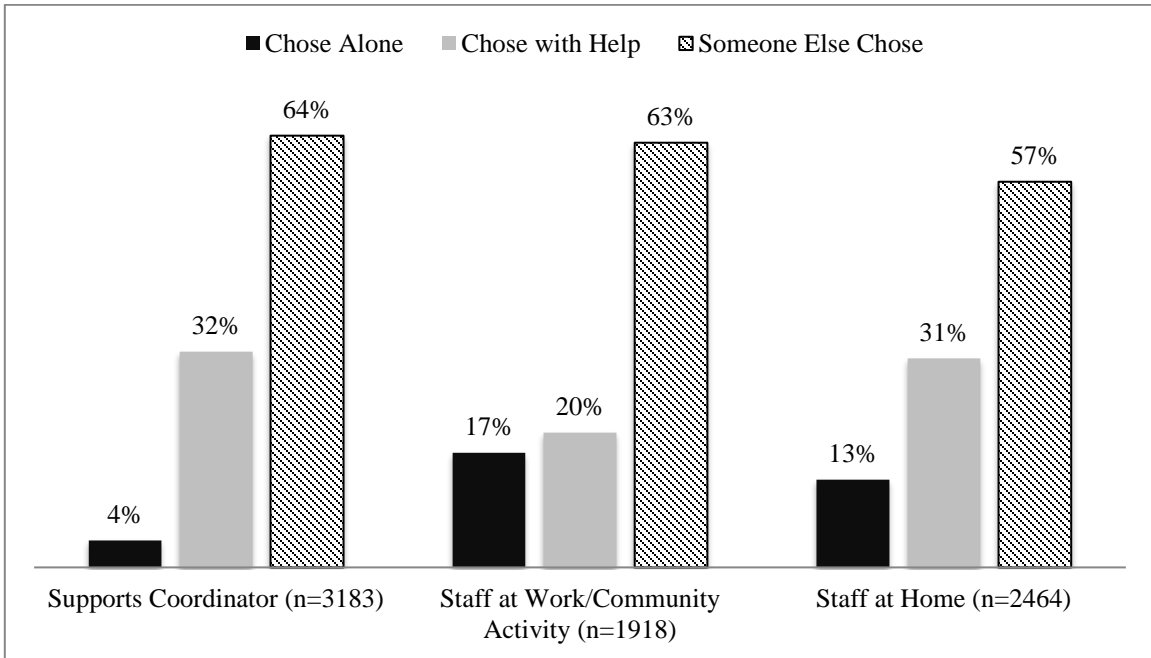
C5. *Choice and Control Regarding Money*

Always choose alone what to buy with spending money	61%
Choose what to buy with help	31%
There is something they want to buy	41%
They have a bank account and withdrawal money when they want	67%

C6. *Voting*

C7. *Status of Formal Communication System*

Status of formal communication system for those who do not communicate in words

Have a system in place (n=1015)	37%
System in place is used (n=288)	87%
System in place is working (n=326)	91%
System is used across settings (n=327)	75%

C8. *Who Supports Communication System?*

Staff or Program Coordinator	53%	Parent or Caregiver	49%
Speech Language Clinician	34%	Someone Else	16%

C9. *Other Forms of Communication*

	Have and Use	**Restrictions**
Cell phone	43%	10%
E-mail	28%	7%
Internet	64%	11%
Text-messaging	30%	6%
Cable TV	94%	7%
Computer	65%	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. These questions can be answered by the individual and/or their paid staff, family/friend/guardian/advocate, or some combination of these.

Summary: Most people surveyed reported high levels of access to general healthcare, dental care, and medical specialists. 4 in 5 individuals in this sample felt that their doctor understood them, while about 3 in 5 reported that they understood their doctor's instructions. More than 4 out of 5 people reported that if they provide consent, it is accepted. In terms of exercise, the sample was about split, with nearly half exercising regularly and the other half exercising rarely or not at all.

Progress Points Compared to 2019-2020 Report:

★ Improvements

- There was an 11% decrease in people who reported that they never exercise at home (53% to 42%).
- There was a 2% increase in respondents who reported they have the opportunity to discuss their health with a PCP (86% to 88%).

Opportunities for Improvement

- None identified.

This link will skip data details and take you to the summary of the next Section **Employment.**

C10. Exercise at Home

	10+ Times	<1 Time
How many times they exercise at home per month	40%	42%

C11. Medical & Dental Care

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

C11.1. How Hard is it to Access Care?
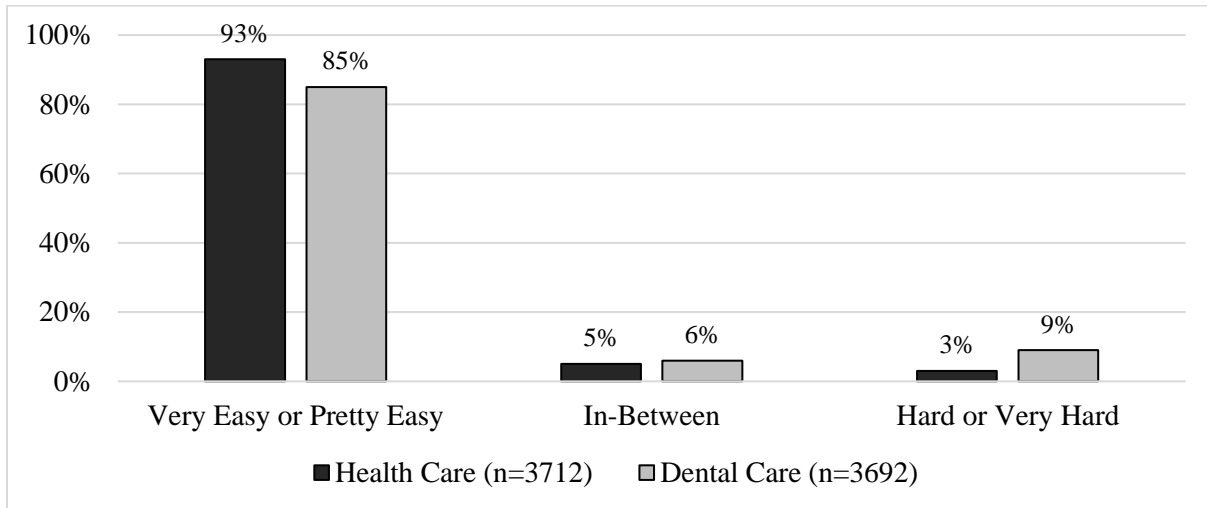
C12. Mental Health

Have an opportunity to discuss health concerns with psychiatrist	62%
Do not have psychiatrist, but want one	2%

C13. Communicating Health Needs

Their doctor understands them	80%
They understand their doctor's instructions	66%
If they need help communicating at doctor's office, it is available	94%
Doctor speaks directly to them during appointments	93%
Able to provide consent for medical treatment	61%
If they provide consent, is it accepted	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 570 people who indicated they are employed in CIE. Questions regarding support getting into the workplace, employment planning, and CPS are asked of all respondents.

Summary: Nearly 1 in 5 individuals report that they work in CIE. The most common occupations reported are in cleaning services, food service, and retail. Most frequently, individuals who are employed reported working 20 hours a week. The most common salary range reported was between $9.01 - $12.00 per hour. The most common benefit reported by workers was receiving paid time off, followed by retirement benefits and health insurance. Of those who are not employed, more than half say that someone talked about employment in their planning meeting and more than a third say employment is a goal in their plan. About 1 in 10 take classes or training to obtain a job or get a better job. About 1 out of 5 respondents use CPS. The most common services used are developing social networks and developing interests or promoting health/wellness. There are 40 people in the sample who report that they are self-employed.

- Hours worked: Mean: 18.5 hours. Range: 1 to 47 hours. Mode: 20 hours.
- Hourly wages: Range from $7.25 to greater than $15.00.

Progress Points Compared to 2019-2020 Report:

★ Improvements

- There was a 4% increase in respondents who reported that CIE is a goal in their plan (31% to 35%).
- There was a 10% increase in people who received health insurance benefits (15% to 25% and a 12% increase in those who received retirement benefits (19% to 31%).
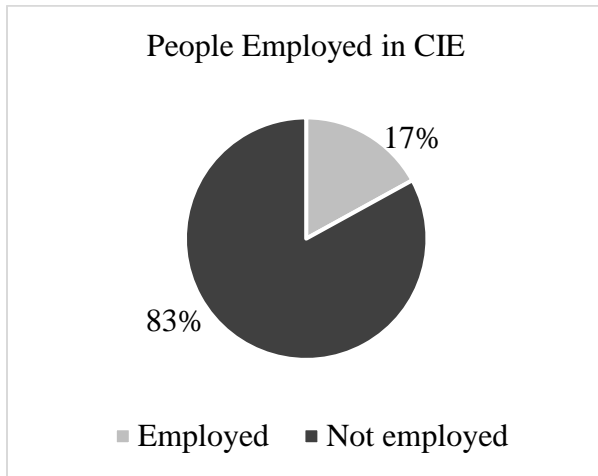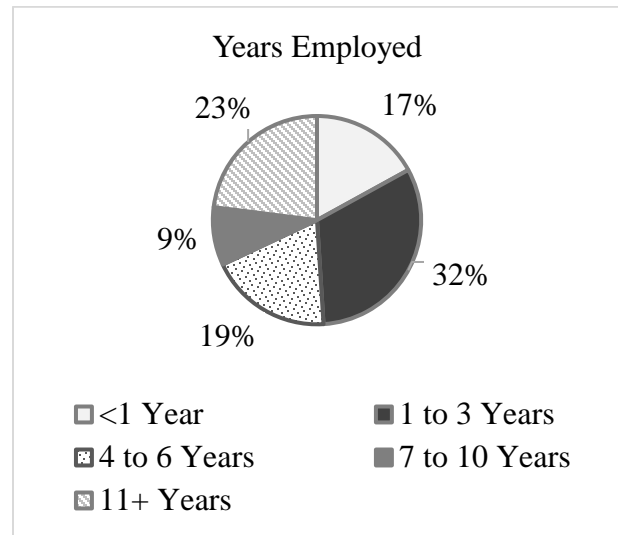
🏃 Opportunities for Improvement

- There was a 3% decrease of people who are not employed who say they discussed employment in their planning meeting (57% to 54%).
- There was a 13% decrease in individuals who report they use CPS (34% to 21%).

This link will skip data details and take you to the summary of the next Section **Self-Directed Supports.**

C14. Employment in CIE

People Employed in CIE

- 17% Employed
- 83% Not employed

C15. Length of Employment

Years Employed

- <1 Year: 17%
- 1 to 3 Years: 32%
- 4 to 6 Years: 19%
- 7 to 10 Years: 9%
- 11+ Years: 23%

C16. Types of Work

Cleaning Services	24%	Assembly/Factory Work	5%
Food Services	25%	Care Workers/Aides	2%
Retail Services	17%	Recycling	<1%
Office Work	3%	Outdoor Work	1%
Stock Room	6%	Animal Care	<1%
Maintenance	3%	Other	13%

C17. Supports Getting Into the Workplace

Take classes/training for employment purposes	9%
Talked about employment in their planning meeting	54%
Community employment is a goal in their plan	35%

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

No one	47%	SC	47%
Service Provider	10%	Family	12%
Housemates	1%	Someone Else	6%

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

C18. Self-Employment

Person reports that they are self-employed	1%	n=40

C19. Compensation and Advancement

Have been promoted or received an increase in pay	52%
Receive paid time off from work as a benefit of employment	76%
Receive health insurance benefits from employer	25%
Receive retirement benefits from their employer	31%
Receive other work benefits from their employment	14%
Know how much they earn and willing to share	79%

Hourly Wage

- $7.25 — 17%
- $7.26 to $9.00 — 25%
- $9.01 to $12.00 — 45%
- 12.01+ — 14%
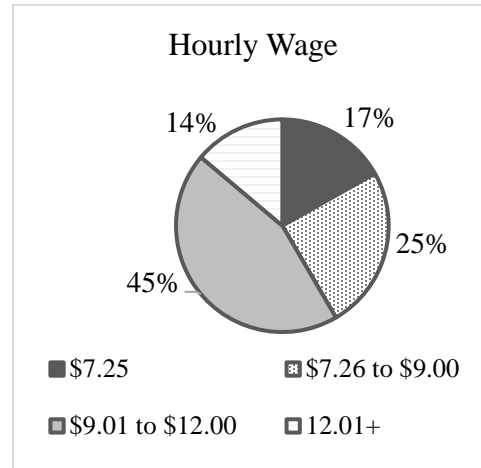
C20. Community Participation

Use Community Participation Services (CPS)	21%

C20.1. If yes, CPS Services Used

Developing skills and competencies necessary for employment	18%
Fine/gross motor skill development and mobility	17%
Participating in community activities to develop social networks	59%
Participating in opportunities to develop interests or promote health/wellness	65%
Training/education for self-determination and self-advocacy	14%
Community adult learning opportunities	18%
Volunteering opportunities	30%
Learning to navigate the local community	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 240 people who indicated they use self-directed supports were asked questions about these supports.

Summary: About 1 out of every 15 respondents report using self-directed services. Of these, nearly half made budget decisions alone or with family and friends. 7 in 10 respondents reported that they participate in service decisions and receive information about how much money is left in their budget, and the vast majority of these say the information they receive is easy to understand. More than 9 out of 10 say they have enough help to make decisions about their budget and services.

Progress Points Compared to 2019-2020 Report:

★ Improvements

- There was a 7% increase in people who report they participate in decisions about their budget, staff, and managing their services (63% to 70%).

Opportunities for Improvement

- There was a 15% decrease in individuals who hire and manage their own staff (77% to 62%).
- There was an 6% decrease in individuals who receive information about how much money is left in their budget (79% to 73%).

This link will skip data details and take you to the summary of the next Section **Relationships.**

C21. Self-Directed Services

Use self-directed services	7%

C22. Who Makes Choices About Budget?

Individual makes decisions on their own	14%
Individual has input, family and friends help	30%
A family member or friend makes decisions	46%
A case manager or state professional makes the decision	10%

C23. Making Decisions

Individual participates in decisions about budget, staff, and managing services	70%
Hire and manage their own staff	62%
Can make changes to their budget or services if they need to	87%
Have enough help deciding how to use their budget/services	94%
Want more help deciding how to use their budget/services	1%

C24. Money Left in Budget

Receive information about the money left in their budget	73%
Information they receive is easy to understand	79%
They receive information at least every 3 months	63%
They receive information about twice a year	17%
They receive information once a year or less	20%

Part IV: Relationships

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

Respondents:

Individual	33%	Individual and Paid staff	10%
Paid staff	23%	Individual and Family/friend/guardian/advocate	13%
Family/friend/guardian/advocate	20%	Staff and Family/friend/guardian/advocate	1%

Summary: About three-quarters of this sample reported they were able to see family and friends whenever they wanted. About 1 in 10 reported that they were never able to see family and friends. It is worthy of note that the Covid-19 pandemic continues to restrict travel and socialization for many people. These numbers may shift as pandemic restrictions are lifted.

Progress Points Compared to 2019-2020 Report:

★ Improvements

- There was a 12% decrease in people who said transportation issues kept them from seeing friends (16% to 4%).
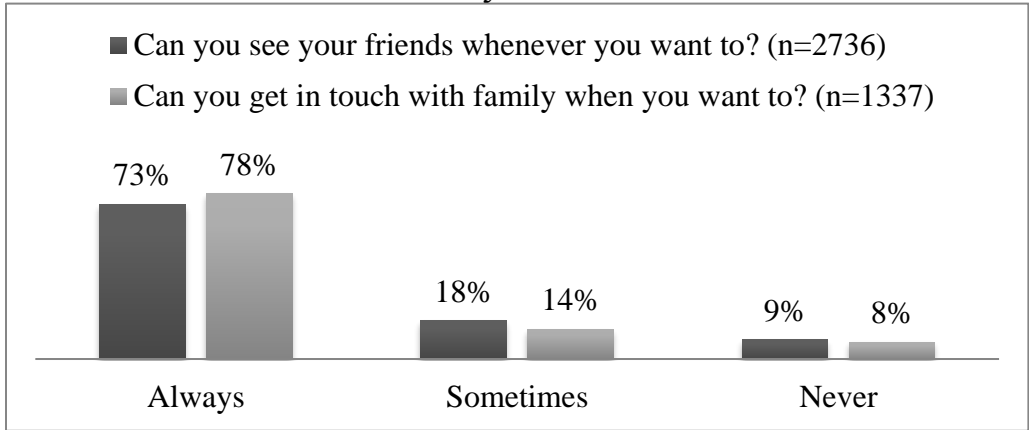
🏃 Opportunities for Improvement

- There was a 9% decrease in those who reported they could get in touch with family whenever they wanted (87% to 78%).
- There was a 12% decrease in people who reported they could see friends whenever they wanted (85% to 73%).

This link will skip data details and take you to the summary of the next Section **Inclusion.**

D. Relationships Data

D1. Contact with Friends and Family

■ Can you see your friends whenever you want to? (n=2736)

■ Can you get in touch with family when you want to? (n=1337)

	Always	Sometimes	Never
Can you see your friends whenever you want to?	73%	18%	9%
Can you get in touch with family when you want to?	78%	14%	8%

D1.1. Why Person is Unable to See Friends

Difficult to find time	6%	Transportation Issue	4%
Lack of staff	2%	Rules or restrictions	4%
Money or cost	<1%	Something else	84%

Part V: Inclusion

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

Respondents:

Individual	27%	Individual and Paid staff	12%
Paid staff	23%	Individual and Family/friend/guardian/advocate	17%
Family/friend/guardian/advocate	20%	Staff and Family/friend/guardian/advocate	1%

Summary: Most people report limited time going out in their communities. When they do go out, people most frequently go to supermarkets, go out to restaurants to eat, and go shopping. As has been the trend in recent years, people report wanting to participate in community events more frequently, though people very rarely report they want to go out into the community less frequently. The proportion of people wanting to go out more increased significantly this year, possibly influenced by the Covid-19 Pandemic. When people engage in community activities, they most often go with family or staff. In terms of transportation, 9 out of 10 people report that they can get where they want to go. People also largely report that they have all the adaptive equipment they need in their home. (**Inclusion Scale***: Mean: 36.3 (SD: 21.3). Mode: 0.0.)

- The average score for the Inclusion Scale was about one-third of the possible scale score, indicating that individuals do not go to community places often. The scale score and mode are substantially lower than in recent years prior to the Covid-19 Pandemic.

Progress Points Compared to 2019-2020 Report:

 Improvements

- People who reported they went out for exercise increased by 7% (47% to 54%).

 Opportunities for Improvement

- There were significant decreases in all weekly activities measured for community participation, including visiting friends (-8%), shopping (-11%), going out to eat (-14%), and going out for entertainment (-11%). There were also decreases in people who report they do these activities enough. People overwhelmingly want to participate in the community more, with reports of wanting more engagement rising across the board for visiting friends (+19%), eating out (+23%), attending worship (+12%), shopping (+18%), and wanting to go out for entertainment (+29%).

This link will skip data details and take you to the summary of the next Section **Monitor Impressions**.

E. Inclusion Data

E1. Community Participation

E1.1. How Much People Engage in Community Activities & Whether it is Enough

Activity	% of people who say they do this weekly	% of people who say they do this enough	% of people who want to do this more	% of people who want to do this less
Visit friends, relatives, neighbors	40%	61%	38%	1%
Go to a supermarket	44%	72%	25%	3%
Go out to eat/restaurants	37%	56%	42%	2%
Go to a shopping center or mall	34%	64%	34%	2%
Go out to a worship service	20%	76%	23%	1%
Run errands and appointments	26%	80%	16%	3%
Meeting people at coffee house/tavern	15%	75%	24%	1%
Go out for entertainment	17%	52%	47%	<1%

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

Activity	Staff	Family	Friends	Roommates Coworkers	Go Alone	Other
Visit friends, relatives, neighbors	27%	48%	9%	<1%	15%	<1%
Go to a supermarket	40%	49%	2%	<1%	8%	<1%
Go out to eat/restaurants	40%	48%	6%	1%	5%	<1%
Go to a shopping center or mall	44%	45%	3%	<1%	6%	<1%
Go out to a worship service	25%	59%	4%	1%	9%	<1%
Run errands and appointments	46%	44%	2%	<1%	7%	<1%
Meeting people at coffee house/tavern	46%	37%	7%	1%	9%	<1%
Go out for entertainment	42%	43%	8%	1%	5%	<1%

E2. Extra-Curricular Activities

Would like to be a part of more groups in the community	37%
Went on a vacation in the past year	27%

E2.1. How Often Do You Go into the Community?
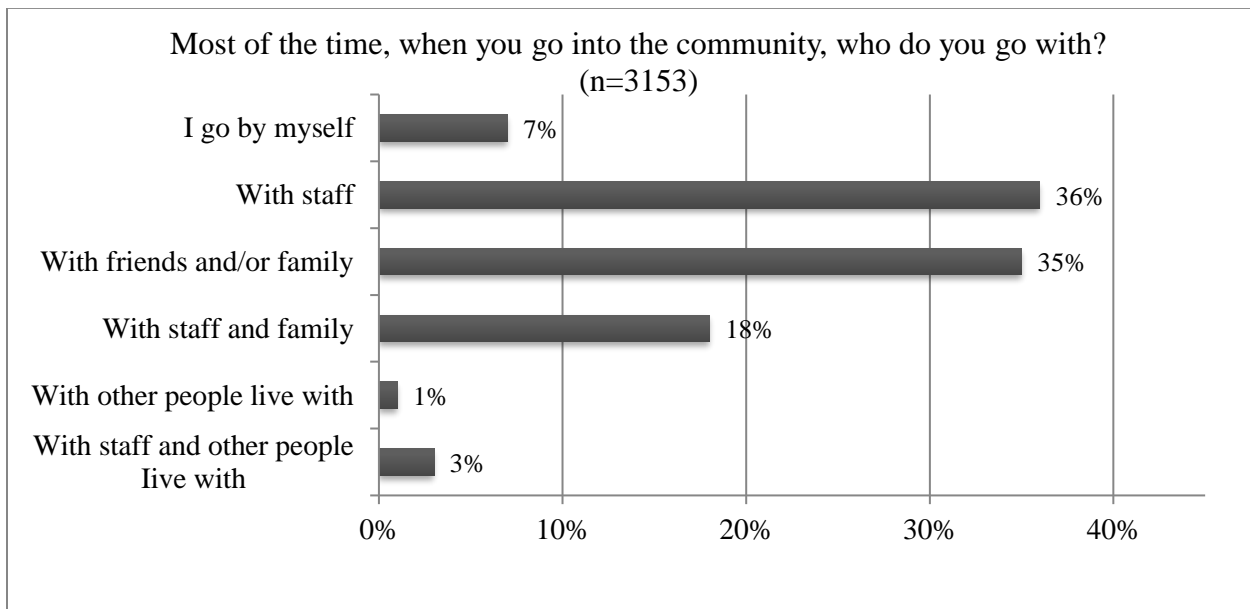
	Frequently	Occasionally
Go out into the community for entertainment	26%	33%
Go to social events attended by people with and without disabilities	18%	39%

E2.2. Exercise in the Community

	Never	<Weekly	Weekly	>Weekly
How often the person exercises	33%	3%	11%	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=3153)

- I go by myself: 7%
- With staff: 36%
- With friends and/or family: 35%
- With staff and family: 18%
- With other people live with: 1%
- With staff and other people live with: 3%

E4. Transportation

Always have a way to get where they wanted to go	93%

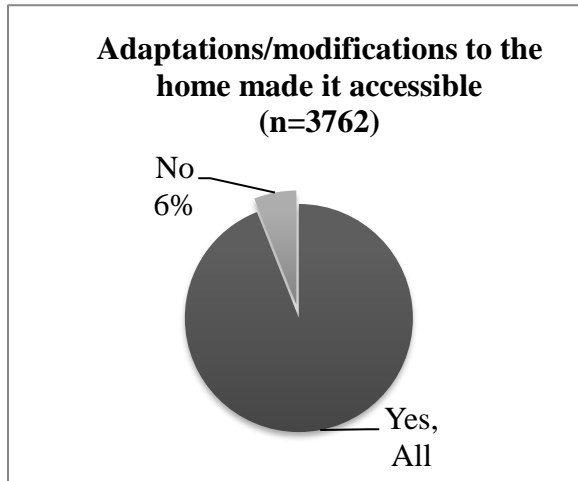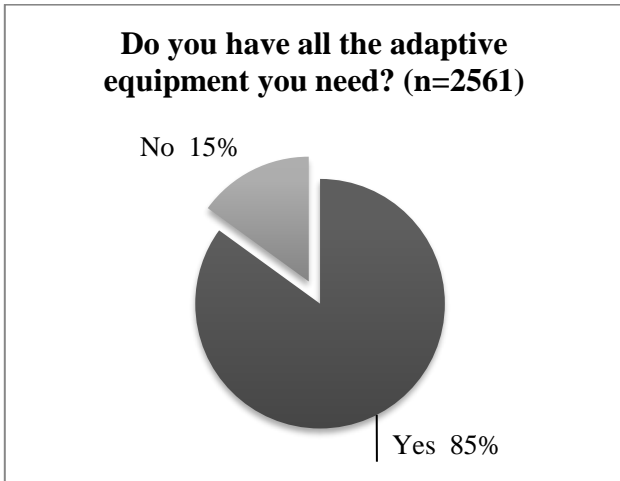### E4.1. Transportation Methods Used Most Frequently

Get a ride from family or friends	42%
Get a ride from staff in provider van	37%
Get a ride in staff member's car	11%
Transport themselves	5%
Ride public transportation	3%
Ride paratransit	1%
Take a taxi, Uber or Lyft	<1%

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

Not enough staff	13%
Paratransit is unreliable	9%
Transportation for work/school only	5%
No one at home can drive	2%
Some other reason	72%

E5. Home Adaptive Equipment

Do you have all the adaptive equipment you need? (n=2561)

No 15%

Yes 85%

Adaptations/modifications to the home made it accessible (n=3762)

No 6%

Yes, All

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. The number of IM4Q Monitors who responded to these questions this year decreased dramatically, from about 2,000 responses last year to less than 100 this year. It is likely the case that because all interviews were conducted remotely this year, most monitors did not have enough information to respond to these questions.

Summary:
- Monitors were overwhelmingly favorable in their reports of respondents' home environments. More than half of monitors rated homes as a 9 or a 10 on a scale of 1 to 10 in which 10 was "I'd move in tomorrow." Most monitors also had positive impressions of staff. 9 out of 10 said that staff were respectful and supported individuals in ways that promote independence.

Progress Points Compared to 2019-2020 Report:

Improvements
- The average score assigned by IM4Q Monitors to individuals' home environments increased significantly, from 6.6 to 8.1.

Opportunities for Improvement
- Monitors who reported that all staff appear to recognize individuals in ways that promote independence, treat individuals with dignity and respect, and appear to have all the skills necessary to do their work decreased by 3% (92% to 89%).

This link will skip data details and take you to the summary of the next Section **Family, Friend and Guardian (FFG) Responses.**

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")

Would You (The Monitor) Want to Live in This Home? (n=92) Mean = 8.1
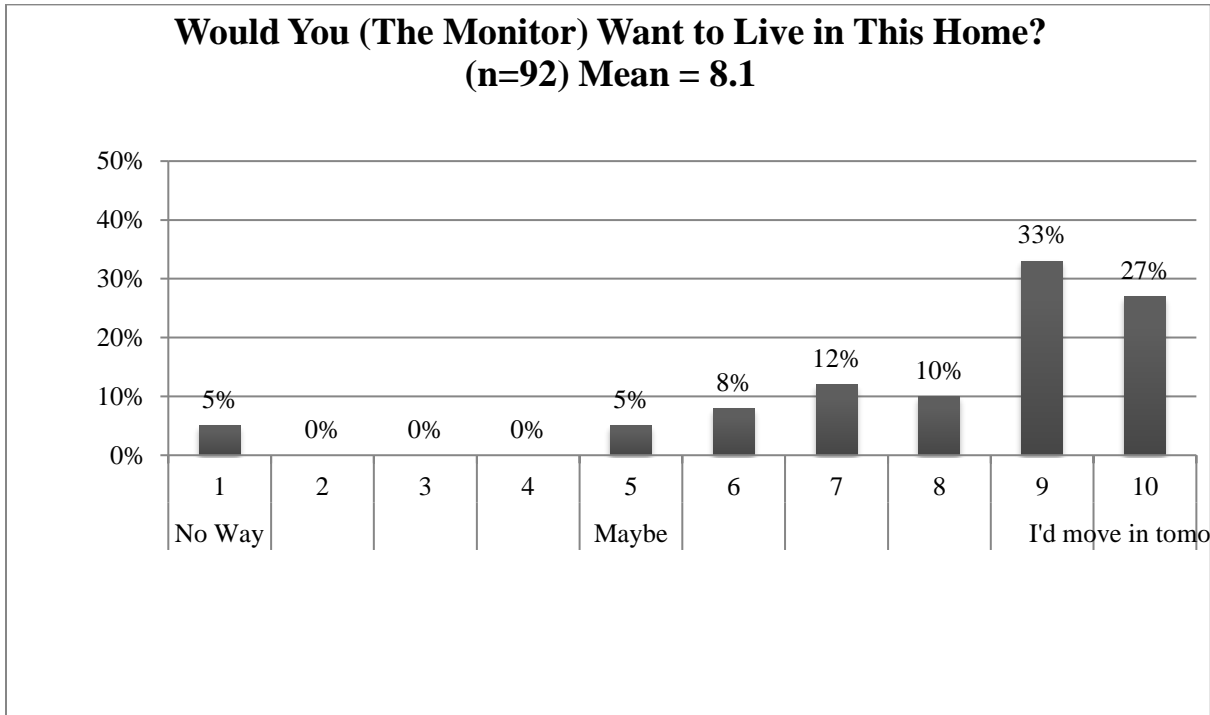
F1.1. Mean and Mode of Monitor Ratings

Mean	8.1
Mode	9.0

G.   Support for the Person Data

G1. Monitor Observations

Staff treat individuals with dignity and respect	89%
Staff recognize the individual in ways that promote independence	89%
Staff who support individuals have the skills they needed	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 1569 family members, friends, and guardians.

Respondents:

Parent(s)	77%	Another Relative	4%
Sibling(s)	13%	Friend	<1%
Guardian	2%	Other	4%

Summary: Family members continue to report high levels of satisfaction overall. Most people are satisfied with where their relative lives, what they do during the day, their relative's staff, and their relative's services. About half reported that if their relative did not communicate in words, a communication system was in place. About one-third were not familiar with the complaint and grievance process, about 1 in 5 are familiar with Life Course Framework and Tools, and 1 in 4 are familiar with the PA Family Network. 9 out of 10 respondents report that they contact their relative at least monthly. 1 in 10 indicated that they had not seen their relative in the past year. (**Family Satisfaction Scale:** Mean 91.6 (SD: 12.2); Mode: 100)

- The high mean and mode indicate that many (47%) of the families' satisfaction levels were at the top of the scale on all measures of family satisfaction.

★ Improvements

- There was a 10% increase in family members who reported that if their relative did not communicate in words, a communication system was in place (37% to 47%).
- There was an 8% increase in family members who reported that their SC asked about their vision for an Everyday Life for their family member (72% to 80%).
- There was a 5% increase in family members who said that they had learned about the Life Course Framework and Tools (13% to 18%) and a 4% increase in those who were aware of the PA Family Network (22% to 26%). Of these, an increase of 2% had attended a workshop (24% to 26%).

Opportunities for Improvement

- The percentage of respondents who reported they had not visited their relative in the past year increased by 11% (2% to 13%).
- People who felt their relative had enough opportunity to engage in the community fell by 7% (84% to 77%).
- About a quarter of respondents (27%) who had a family member transition from school to adult services were happy with the process.

This link will take you to back to the beginning of the **Statewide Report.**

H. Family, Friend and Guardian Survey Data

H1. Daily Life

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

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

Contacted their relative at least monthly	93%
Never contacted their relative	1%
See their relative at least monthly	63%
Never visited their relative	13%

H3. Your Relative's Satisfaction

Relative is satisfied or very satisfied with his/her living situation	95%
Relative is satisfied or very satisfied with what they do during the day	89%
Relative is satisfied or very satisfied with the staff who support them at home	95%
Relative is dissatisfied or very dissatisfied with the staff who support them at home	<1%
Relative is satisfied or very satisfied with the staff who support them during the day	95%
Relative is dissatisfied or very dissatisfied with the staff who support them during the day	<1%

H4. Your Relative's Safety

Relative always feels safe in their community, home, and neighborhood	89%
Relative feels safe in their community, home, and neighborhood most of the time	10%

H5. Your Relative's Opportunities

Relative has enough opportunities to participate in activities in the community	77%
Relative has the opportunity to learn new things	88%

H6. Your Relative's Staff

Relative's home appears to have an adequate number of paid staff	85%
Staff in relative's home always treat people with dignity and respect	95%
All staff in their relative's home have the skills they need to support their relative	89%
Some of the staff in their relatives home have the skills they need to support their relative	9%
Relative's place of work appears to have an adequate number of paid staff	96%
Staff at relative's place of work always treat people with dignity and respect	98%
All staff in their relative's workplace have the skills needed to support their relative	93%
Some staff at their relative's workplace have the skills they need to support their relative	5%
The staff who assist their relative with planning always respects their choices and opinions	93%

H7. Relative's Communication System

If their relative does not communicate verbally, there is a formal system in place, and they use it	47%
If there is a communication system in place, it is used across settings	82%

H8. Relative's Supports

Satisfied with the support coordination their relative receives	86%
Told how much money is in their relative's budget	60%
Their relative directs their own services	10%
Their relative always receives the supports they needed	76%
The supports and services their relative receive change when their needs change	90%
There are never or rarely changes in support staff at their family member's home, work, or day program	62%
There are always frequent changes in support staff at their family member's home, work or day program	10%
They chose the agency/provider who worked with their relative	42%
Their relative chose the agency or provider who worked with their relative, alone or with their help	30%
Someone else chose the agency/provider who worked with their relative	28%

H9. Complaints and Grievances

Relative was familiar with the complaint and grievance process on some level	71%

H9.1. At what level?

At the provider level	63%
At the county/AE level	66%
At the state level	60%

H10. Family Resources

The information they receive about their relative's services is easy to understand	91%
They had learned about the Life Course Framework and Tools	18%
They had an opportunity to connect and network with other families with relatives at similar life stages	44%
They are aware of the PA Family Network (PAFN)	26%
Of those who were aware of the PAFN, who had attended a workshop led by the Network of Family Advisors	26%
Have enough information about services for which the family is eligible	83%
If family member transitioned from school to adult services, were happy with the process	27%
SC asks about their vision for an everyday life for their family member	80%

H11. Emergency Preparation Questions

Given information about an emergency plan for their family member in case of emergency	62%