The Institute on Disabilities

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

Independent Monitoring for Quality (IM4Q) Statewide Report 2023-2024

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 2023-2024 fiscal year. Following the Covid-19 Pandemic, data collection has shifted to a hybrid model, with some interviews taking place in person and others occurring remotely. Questions may be addressed to **IM4Q@temple.edu**.

Guide to the Statewide Report

In this report, each section begins with a summary of the current year's data. Progress Points highlight major changes in the data from the last published report and some trends over time. Improvements 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%

The data points in the report correspond to questions on the IM4Q interview questionnaire, the Essential Data Elements (EDE) survey. Most questions are consistently included from year to year so that changes in the experiences of people with disabilities can be examined over time. However, occasionally questions are added, edited, or removed to address changing circumstances. If a data point from a previous report is not provided in the current report, it is likely that this question has been removed from the survey. New questions are marked by a "+" to indicate their new question status. The number of responses to each item varies because not all respondents answer all interview questions. The number of responses for each item is represented by "n=_". The percentage of respondents who provided each response is estimated to the nearest whole number.

Why We Do This

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

The IM4Q process also allows us to improve people's lives in a direct way. When IM4Q monitors interview a person with a disability, they write down any concerns or requests the respondent has. We call these "considerations." Individual considerations are shared through the IM4Q system with someone who might be able to help, such as the supports coordinator (SC), a

provider, or family members. The SC decides how the consideration will be handled and reports back to the Administrative Entity (AE) or the Office of Developmental Programs (ODP) Bureau of Supports for Autism and Special Populations (BSASP). If the consideration is not addressed, the consideration process will continue. When the person or family are satisfied with the action to address the consideration, we call this "Closing the Loop."

Considerations may result in service changes or provide an opportunity to improve the quality of life of the individual who has been interviewed. For the 2023-2024 collection year, over 6,000 considerations were collected. Of these, more than 70% have been closed.

Some qualitative data from recent considerations are found in the **Considerations** section at the end of this report. The local IM4Q programs have also provided several examples of completed considerations. These stories provide examples of how IM4Q positively impacts the lives of people with disabilities who are receiving ODP supports. Closed considerations are a result of the work, ingenuity, creativity, tenacity, and passion of SCs, providers, and others to make a positive difference in the daily lives of people with developmental disabilities in Pennsylvania. An example, "Ken's Consideration," is provided below (NOTE: Name has been changed to protect the confidentiality of the respondent.)

Story: Ken's Consideration- Exploring Your Passion!

When the IM4Q team interviewed Ken a few years ago, he indicated that he would like assistance in finding avenues to pursue a unique passion. Ken has an interest in drawing prehistoric animals, also known as paleoart. This was shared with Ken's Supports Coordinator, who spoke with Ken, his mother, and the Program Specialist about his interest and how to best support Ken. They decided to expand Ken's community participation days to include a day that would focus on paleontology. Now, Ken visits a local paleontology museum and research center every Friday to explore. He has since started to volunteer there. He even has drawings displayed in the building! Thanks to IM4Q, Ken gets the chance to live his passion and share his gifts with others.

A Note About Data Collection: The Ongoing Impact of the Covid-19 Pandemic

Since the 2019-2020 fiscal year, individuals have had the option to participate in interviews held in person or remotely. This shift in methods to include remote interviews may affect some of the data and should be acknowledged when performing comparisons to data reported prior to 2020.

Scale Scores

The scale scores in the tables below include a mean and a standard deviation (SD). The mean is the average. This is the number you get if you add all the scores provided by all the respondents and divide by the number of responses. The standard deviation (SD) tells us 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 means 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 served by 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 served by 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 AE area answered questions less favorably than people in other areas.

If scores in one topical 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.

	Statewide
Mean	84.21
SD	19.43

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.

	Statewide
Mean	83.63
SD	15.68

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.

	Statewide
Mean	92.01
SD	17.79

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

	Statewide
Mean	68.83
SD	19.55

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

	Statewide
Mean	40.63
SD	17.17

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

	Statewide
Mean	6.96
SD	2.59

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

	Statewide
Mean	91.18
SD	14.07

Executive Summary

This year's statewide IM4Q report provides information collected through in person and remote interviews with just over 4,000 individuals and about 1,500 family members of individuals receiving supports services through the Office of Developmental Programs in Pennsylvania.

In this year's **sample**, more than 3 out of 4 individuals reside in a relative's home or a community home. Nearly 8 in 10 are white, most are non-Hispanic/Latinx, and 6 in 10 are male.

Satisfaction rates remain high among respondents receiving services and their family members. As in recent years, about 9 out of 10 individuals like where they live and work and say they are happy with their life. 3 out of 4 want to stay where they currently live. Although these percentages indicate high satisfaction, it is important to note that research has shown that satisfaction rates for supports and services may be inflated for many reasons, such as a lack of experience or because individuals who receive supports and services may appreciate receiving any services. Nearly 1 in 5 people interviewed indicated they would like to change their living and/or work arrangement.

Overall, people's **Dignity, Respect and Rights** perceptions are also favorable. Most people get help to learn new things and participate in their planning meeting. People report good access to **Health Care** and satisfaction with **Support Coordination**. About half had been asked about self-advocacy and 1 in 5 have attended a self-advocacy meeting.

As has been the case consistently over the last several reporting years, the average scores for **Choice and Control** and **Inclusion** are lower than for the previous categories. About half of individuals report that they made the choice about where to live and work and with whom, with significant increases this year in people who saw more than one place before moving into their home and who had a choice about their housemates. Less than half say they had choice about their staff. About a third reported that they vote in political elections. Nearly half have a cell phone and about 2 in 3 have a computer and Internet. 90% say they chose their daily schedule and most report they have enough choice about their free time.

IM4Q Monitor Impressions of participants' homes were high again this year, an average of nearly 7 on a 10-point scale. It is worth noting that more interviews continue to be conducted remotely, which may limit opportunities for monitors to observe the residences.

Family, Friend and Guardian perceptions of their relatives' supports and services remain highly positive. About 1 in 5 reports working in **Competitive Integrated Employment.** About 1 in 10 use **Self-Directed Services**. About a third use technology to support them in daily life.

Despite continued focus on issues around communication, the needle has not moved much in recent years, remaining at about a third of non-verbal individuals who report having a communication system in place. For those with a system in place, 3 out of 4 report it is used across settings.

Considerations were largely closed, and the most common categories were Service System; Personal Rights, Competence Enhancement and Growth; and Community Presence and Participation.

Sample

i. Sample Data

i1. Total Surveyed

People with disabilities	4,110	Family members	1,466

i2. Age

Range	5-96	Mean Age (SD)	40.9 (17.2)

i3. Reported Gender

Female	40.4%	Male	59.5%	Other	0.1%

i4. Race and Ethnicity

Race (n=3953)

White/Caucasian	79.7%
Black/African American	15.9%
Other	1.7%
Asian	1.7%
Two or More Races	1.0%
American Indian/Alaskan Native/Pacific Islander	0.5%

Ethnicity (n=3727)

4.3%

95.7%

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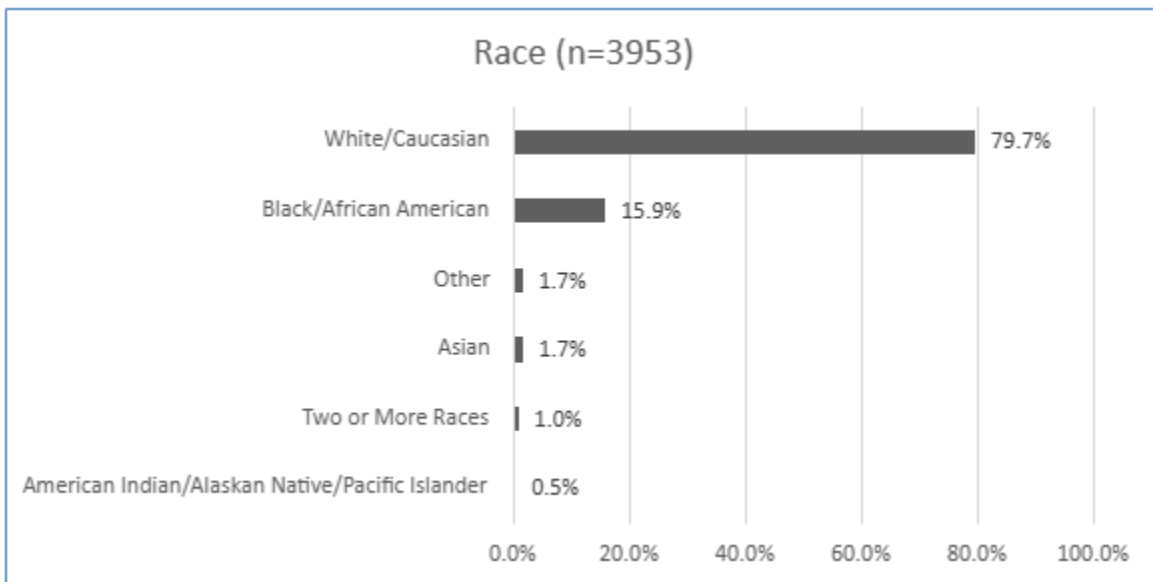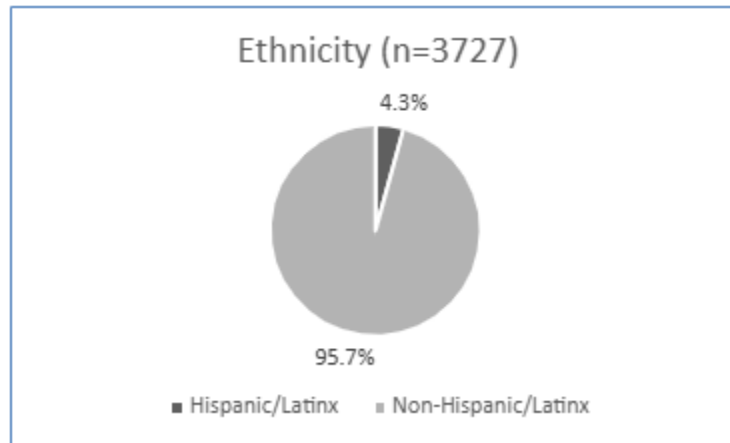
i5. Home Type Where Respondent Lives

Type of Residence	Number of Residents	Percent of the Sample
Relative's Home	1,777	43.2%
Community Home- Subtotal	1,400	34.1%
Community Home 1	181	4.4%
Community Home 2-4	1,176	28.6%
Community Home 5-6	23	0.6%
Community Home 7-8	13	0.3%
Community Home 9-15	4	0.1%
Community Home 16+	3	0.1%
Own Residence	345	8.4%
Family Living/Lifesharing	120	2.9%
Private ICF/ID- Subtotal	189	4.6%
Private ICF/ID 4 or fewer	31	0.8%
Private ICF/ID 5-8	50	1.2%
Private ICF/ID 9-15	26	0.6%
Private ICF/ID 16+	82	2.0%
Personal Care Home	35	0.9%
Nursing Home/Facility	32	0.8%
Children's Facility	8	0.2%
Unlicensed Family Living	20	0.5%
Domiciliary Care	5	0.1%
Foster Care	1	0.0%
Approved Private School	0	0.0%
State Operated ICF/MR	79	1.9%
State MH Hospital	1	0.0%
Temporary Shelter	1	0.0%
Other	29	0.7%

Data on Type of Residence Missing	*68*	*1.7%*
Total	4,110	100%

i6. Administrative Entity (AE) Where the Respondent Lives

AE	Number of Respondents	Percent of Sample
Allegheny	462	11.2%
Armstrong/Indiana	58	1.4%
Beaver	70	1.7%
Bedford/Somerset	39	0.9%
Berks	118	2.9%
Blair	50	1.2%
Bradford/Sullivan	20	0.5%
Bucks	160	3.9%
Butler	59	1.4%
Cambria	50	1.2%
Cameron/Elk	19	0.5%
Carbon/Monroe/Pike	64	1.6%
Centre	53	1.3%
Chester	114	2.8%
Clarion	22	0.5%
Clearfield/Jefferson	42	1.0%
Columbia/Montour/Snyder/Union	50	1.2%
Crawford	62	1.5%
Cumberland/Perry	60	1.5%
Dauphin	103	2.5%
Delaware	182	4.4%
Erie	166	4.0%
Fayette	40	1.0%
Forest/Warren	22	0.5%
Franklin/Fulton	52	1.3%
Greene	18	0.4%
Huntington/Mifflin/Juniata	38	0.9%
Lackawanna/Susquehanna	89	2.2%
Lancaster	108	2.6%
Lawrence	35	0.9%
Lebanon	31	0.8%
Lehigh	108	2.6%
Luzerne/Wyoming	108	2.6%
Lycoming/Clinton	59	1.4%
McKean	19	0.5%
Mercer	36	0.9%

AE	Number of Respondents	Percent of Sample
Montgomery	216	5.3%
Northampton	70	1.7%
Northumberland	42	1.0%
Philadelphia	565	13.7%
Potter	15	0.4%
Schuylkill	47	1.1%
Tioga	34	0.8%
Venango	38	0.9%
Washington	48	1.2%
Wayne	26	0.6%
Westmoreland	100	2.4%
York/Adams	123	3.0%
TOTAL	4,110	100.0%

Part I: Satisfaction

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

Summary: Most respondents are satisfied with their lives and report getting the services they need. Overall, they feel their privacy is respected by others. More than 8 out of 10 respondents said that they have friends to do things with, can date or marry whomever they wish, and are happy with their life. Less than half of respondents indicate they are lonely with more than two thirds reporting that they have a best friend.

Progress Points Compared to 2022-2023 Report:

★ **Improvements**

- There was a 2% increase in respondents who said they always get the services they need (83% to 85%).
- There was a 3% increase in respondents who said they like their primary job or day activity (90% to 93%).
- There was a 2% increase in respondents who said they want to continue their current job or day activity (71% to 73%).

Opportunities for Improvement

- None identified.

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	88%
Want to stay where they currently live	75%
Want to move somewhere else	17%

A2. Work/Day Activity

Like primary job or day activity	93%
Like other job or day activity	95%
Want to continue current job or day activity	73%
Want to do something else	19%

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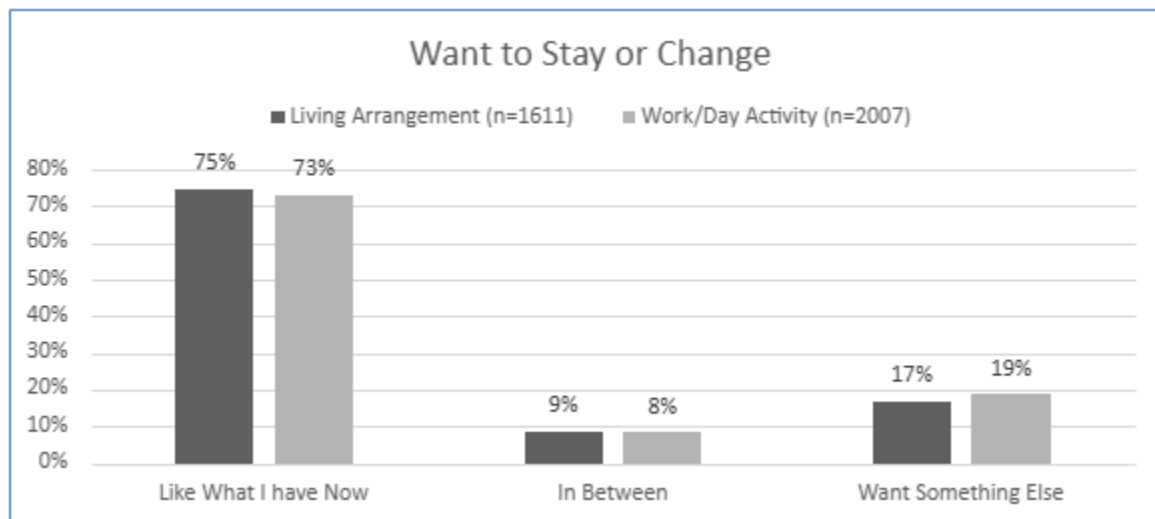
A3. Daily Activities

What do people do on most days?	Primary activity	Secondary activity
Stay home	24%	37%
Work	25%	5%
Work - no supports	15%	3%
Work - with supports	10%	2%
Attend school	6%	1%
Attend a vocational facility	10%	2%
Attend a day program or community center	10%	3%
Go out in the community	16%	31%
Retired	2%	1%
Volunteer	3%	7%
Something else	5%	14%

A3.1. Want to Work

Do not have or want a job	54%
Would like a job for pay	39%
Uses special technology to help do work	12%

A4. Services

Always get services they need	85%
Sometimes get services they need	4%
Do not get services they need	5%
Need additional services	7%

A5. Happiness and Loneliness

A5.1 Happy with Life

Happy with life	82%
Neither happy nor sad with life	15%
Sad with life	2%

A5.2 Loneliness

Never lonely	63%
Sometimes lonely	28%
Always lonely	9%

A5.3 Friendship

Have friends to do things with	85%
Friends are not staff or family	73%
Have a best friend	70%

A5.4 Dating and Marriage

Can date/marry, no restrictions	85%
Can date/marry, restrictions	5%
Cannot date/marry at all	11%

A6. Privacy

Have enough privacy (a place to be alone) at home	97%
No rules about friends or visitors	80%
People always let them know when coming into their home	91%
Sometimes people let them know when coming into their home	6%
People never let them know when coming into their home	3%
People always let them know when coming into their bedroom	82%
People sometimes let them know when coming into their bedroom	8%

People never let them know when coming into their bedroom	10%

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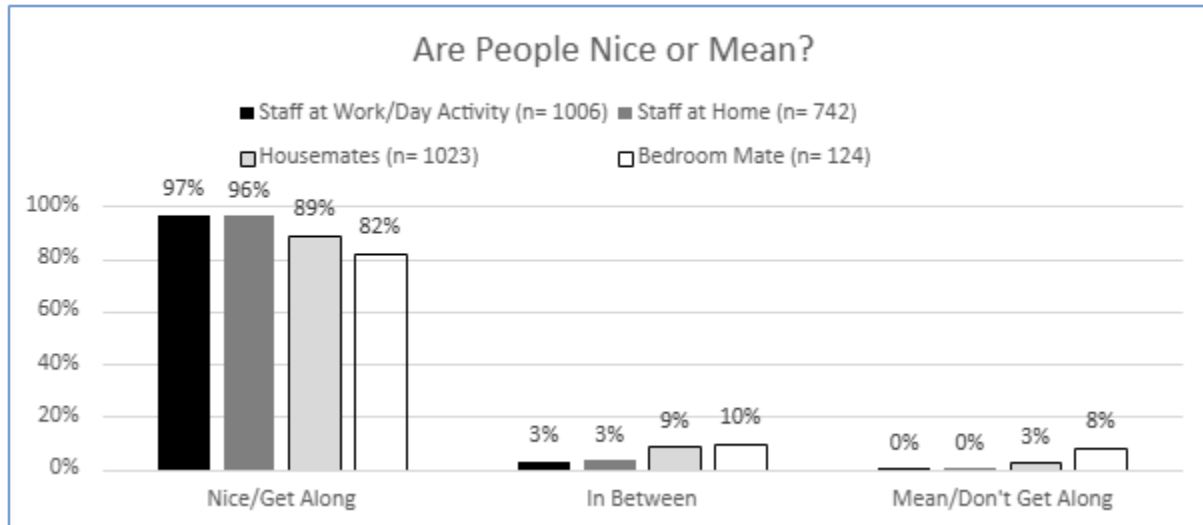
Part II: Dignity, Respect, and Rights

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: Overall, most respondents interviewed indicated high scores on Dignity, Respect, and Rights. In terms of fear, more than 8 out of 10 respondents stated that they never feel scared in their home, neighborhood, or workplace setting. Further, more than 7 out of 10 respondents said that they get help from other people if they request it, and two-thirds say that they have the opportunity to help others. In terms of privacy, over 8 out of 10 of surveyed respondents said that they never have to worry about their mail being opened without permission.

Progress Points Compared to 2022-2023 Report:

 Improvements

- No changes of note.

 Opportunities for Improvement

- No changes of note.

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	78%
Do not get help	13%
Get to help other people	66%
Have participated in a self-advocacy group meeting	20%
Someone has talked to them about self-advocacy	54%
Have someone to talk to when afraid	93%

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

Staff	47%	Family	50%
Supports coordinator	9%	Friends	9%
Other	8%	Have no one	1%

B2. Frequency of Being Afraid
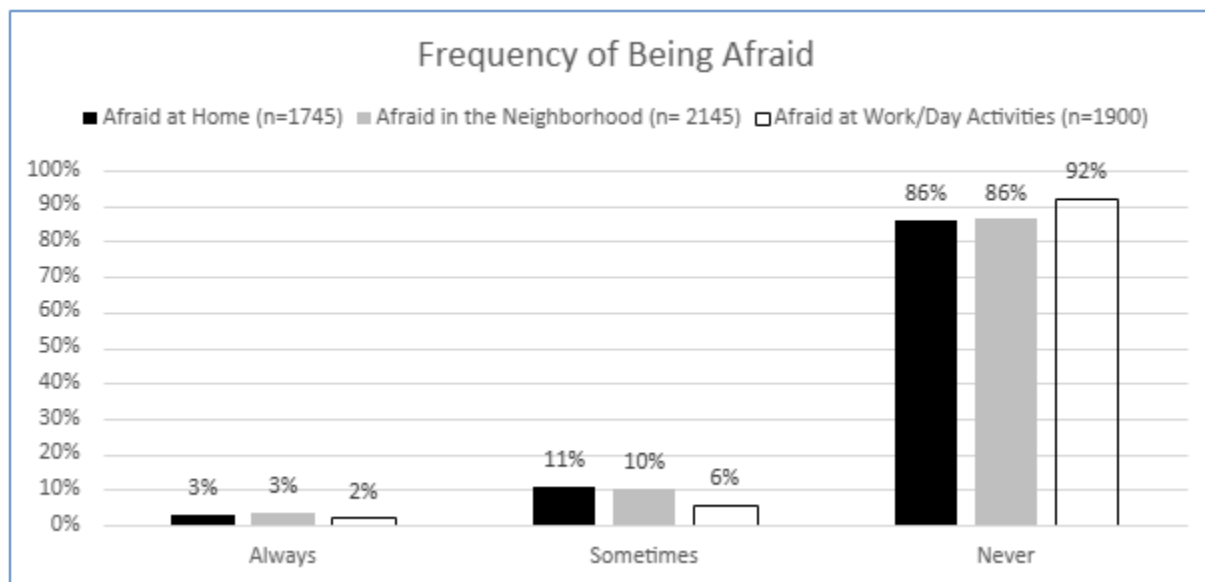
B3. Legal Rights

	Never	Sometimes	Always
Mail opened without permission	88%	7%	6%

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: The relationship between respondents and their SC seems overall to be positive and respectful. Almost 9 out of 10 respondents indicate that their SC knows what is important to them and asks if their services are okay. While there was an increase in respondents claiming that their SC asks them about directing their own services (40% to 47%) there is still room for improvement. Only 2 out of 3 respondents know they can choose their own SC.

Progress Points Compared to 2022-2023 Report:

★ Improvements

- There was a 7% increase in respondents who reported their SC asks them about directing their own services (40% to 47%).

- There was a 2% increase in respondents who reported their SC asks them what they want out of their life (86% to 88%).

- There was a 3% increase in respondents who said they met with their SC in the last year (93% to 96%).
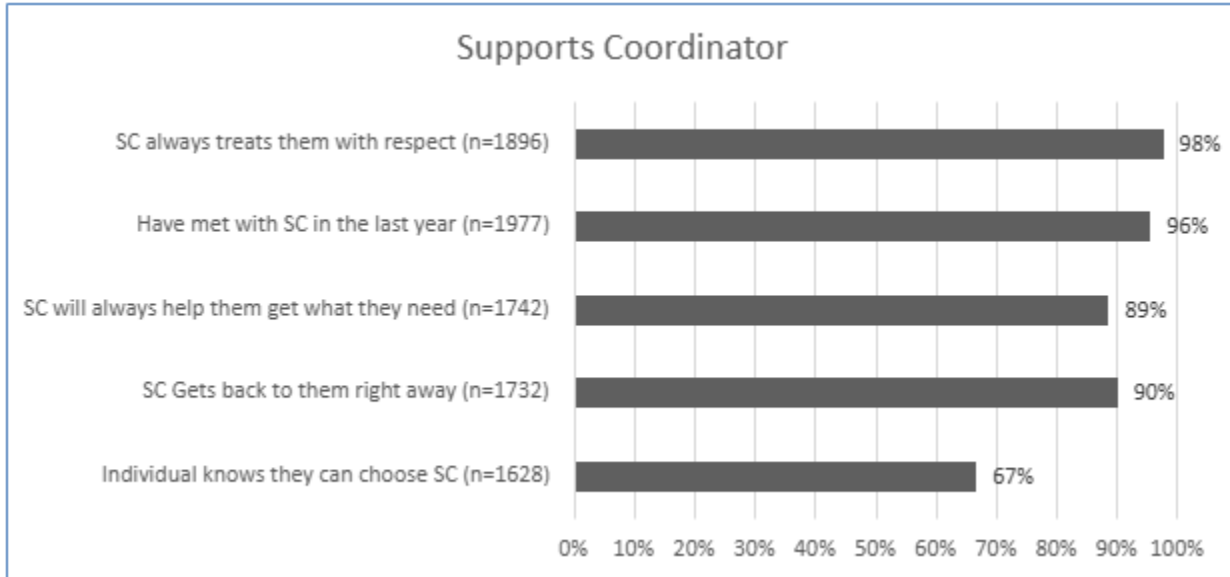
Opportunities for Improvement

- There was a 5% decrease in respondents knowing they can choose their SC (72% to 67%).

- There was a 2% decrease in respondents saying their SC always listens to them (96% to 94%).

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

B4. Supports Coordinator (SC)

B4.1. SC Communication

SC asks what their interests are	92%
SC asks what they want their life to look like	86%
SC knows what is important to them	88%
SC asks them about directing their own services	47%
SC asks if community employment is a possibility[+]	63%
SC asks if services are OK	96%
SC always listens to them	94%

B5. Annual Planning Meeting

Attended last service planning meeting[+]	96%
Know it is an option but choose not to attend meeting	1%
Told at the meeting how much money is in their budget	52%
Meeting includes the people they wanted to be there	96%
Know what is talked about at their ISP meeting	83%
Helped make their service plan or set their own goals[+]	86%
Their service plan includes things that are important to them[+]	92%

B6. Services

Know who to ask if they want to change their services	81%
Do not know who to ask to change services	13%

B7. Staff

Staff always treats them with respect	93%
Staff are respectful of their culture	98%
Have staff that help them	75%
Staff have the right training to meet their needs	94%
Staff do things the way they want them done	91%
All staff always understand their communication	90%
Some staff understand them	5%
Sometimes understood by staff	4%
Not understood by staff	1%
Staff come and leave when they are supposed to	94%

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: In the case of emergency preparation, more than 8 in 10 respondents have reported being given information about what to do. While almost half of surveyed respondents (47%) indicate that their family was responsible for giving them this information, about a third (34%) reported being given the information by home-based staff, while a little over 1 in 10 (13%) received information from their day staff. The least likely providers of this information were the American Red Cross (1%) and friends (2%), respectively.

Progress Points Compared to 2022-2023 Report:

★ **Improvements**

- No changes of note

Opportunities for Improvement

- In the previous year, 36% of respondents indicated that home staff provided them with emergency preparation. This year 34% reported this, indicating a 2% decrease.

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	84%

B8.1. Who Provided Emergency Information
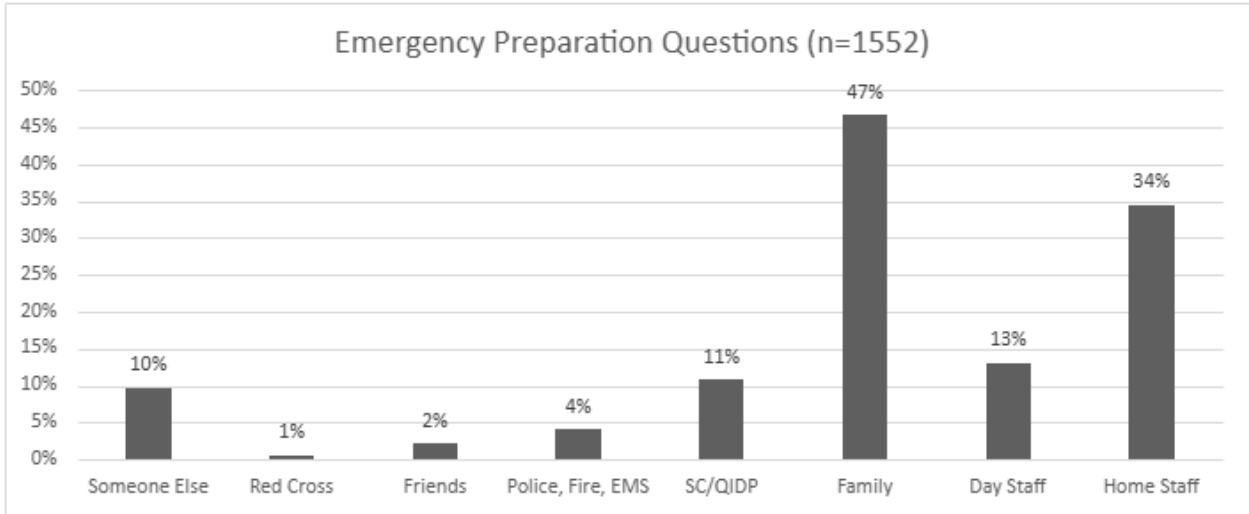
Note: Qualified Intellectual Disability Professional (QIDP)

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	29%	Individual and Paid staff	12%
Paid staff	25%	Individual and Family/friend/guardian/advocate	14%
Family/friend/guardian/advocate	19%	Staff and Family/friend/guardian/advocate	1%

Summary: Regarding choice and control, nearly 9 out of 10 participants indicate that they have a choice about their daily schedule, and slightly more say that they have enough choice of what they can do in their free time. More than 2 out of 3 participants have the opportunity to interact with people who don't identify as having a disability. Less than half of participants indicate that they have a choice to stay home if other household members go out or have their name on their lease or rental agreement. More than half of participants reported sharing a home with someone with a disability.

Progress Points Compared to 2022-2023 Report:

★ Improvements

- There was a 2% increase in the number of respondents who have a key or way to get into their home (50% to 52%).

- There was an 8% decrease in the respondents who did not choose their housemates (63% to 55%).

- There was a 9% decrease in the respondents who reported that they saw no other places before they moved into their home (54% to 45%).

Opportunities for Improvement

- There was a 2% decrease in the respondents whose name is on the lease or rental agreement (37% to 35%).

- There was a 2% decrease in the respondents who said they see no other places before choosing a day activity (39% to 37%).

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	66%
Never carry ID	18%

C2. Choice and Control at Home

Have a key or way to get into their home	52%
If other household members go out, they have the option to stay home	44%
If other household members go out, they sometimes can stay home	14%
Can lock bedroom door	53%
Own their home	3%
Name is on the lease or rental agreement	35%
Have a choice to live where people without disabilities live	45%
Saw no other places before they moved into their home	47%
Did not choose housemates	55%
If individual shares a bedroom, chose some or all roommates	40%

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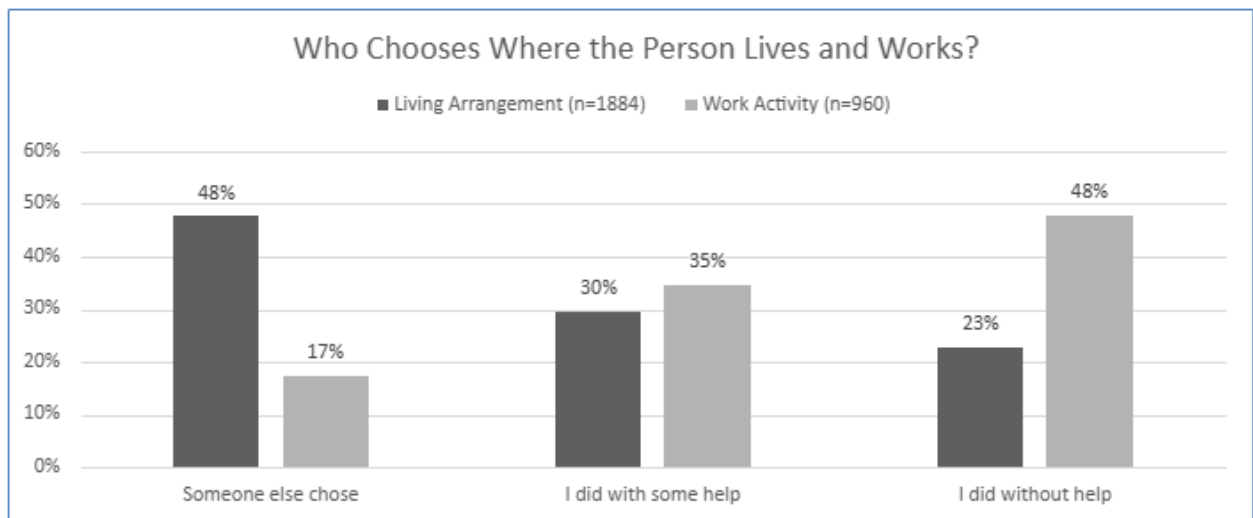
C3. Choice and Control During the Day and for Leisure Time

Have the choice to go where people without disabilities go	68%
Saw no other places when choosing day activity	41%
Choose daily schedule without assistance	89%
Have enough choice about free time	94%

Chose day program or workshop without assistance	31%
Chose other activities without assistance	28%

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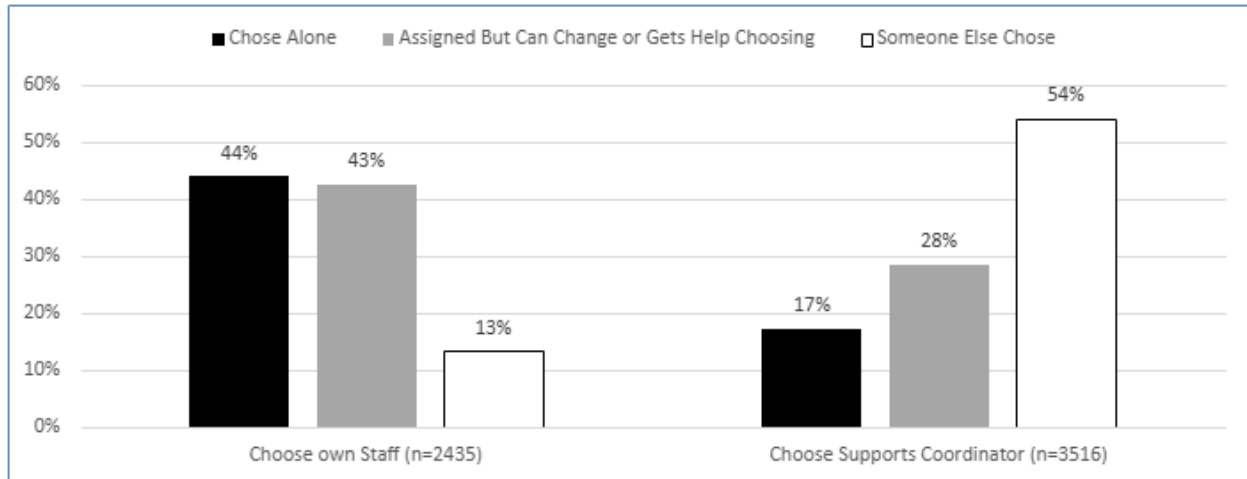
C5. Choice and Control Regarding Money

Always choose alone what to buy with spending money	57%
Choose what to buy with help	34%
There is something they want to buy	46%
They have a bank account and withdrawal money when they want	72%

C6. Voting

C7. Status of Formal Communication System

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

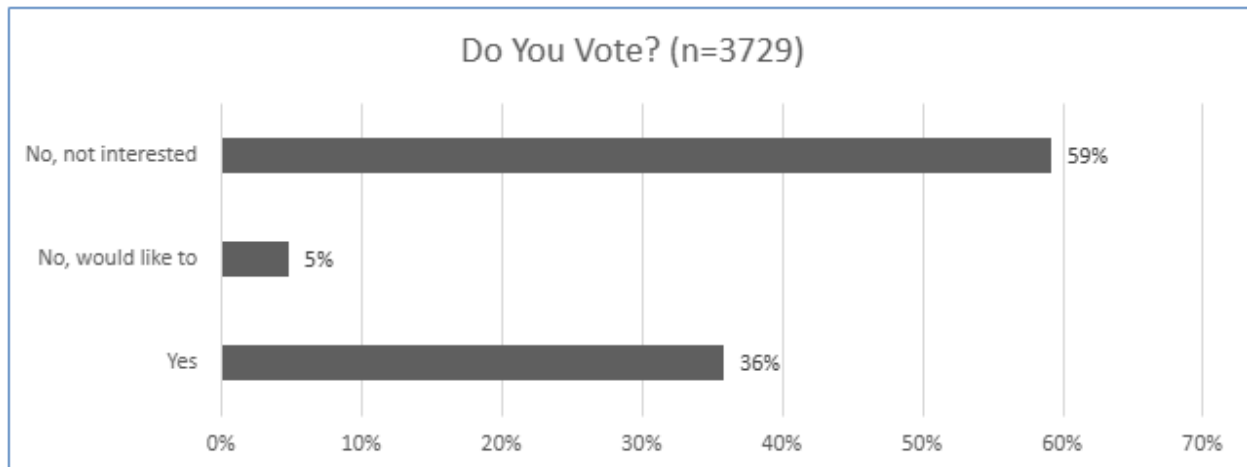|	
Have a system in place (n=1125)	36%
System in place is used (n=315)	86%
System in place is working (n=355)	91%
System is used across settings (n=340)	79%
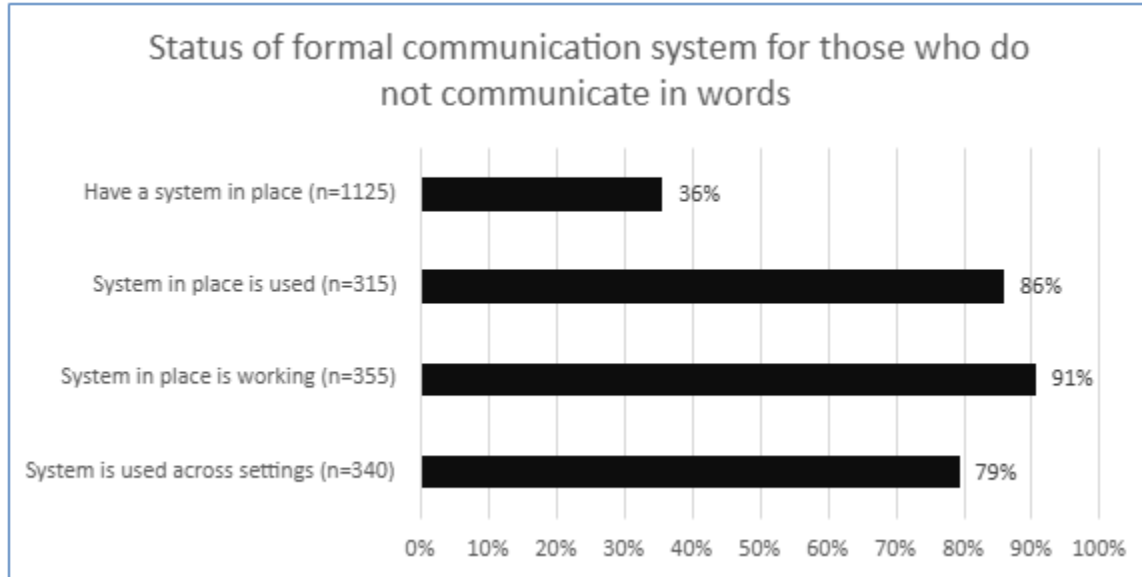
C8. Who Supports the Communication System?

Staff or Program Coordinator	52%	Parent or Caregiver	45%
Speech Language Clinician	23%	Someone Else	12%

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

C9. Other Forms of Communication

	Have and Use	Restrictions
Cell phone	44%	6%
E-mail	27%	4%
Internet	62%	8%
Text-messaging	32%	4%
Cable TV	90%	5%
Computer	61%	8%

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

Part III, Section B: Health Questions

This section asks questions related to health and healthcare. Questions cover general medical care, dental care, and mental health care topics. These questions can be answered by the individual and/or their paid staff, family/friend/guardian/advocate, or some combination of these.

Summary: Of the participants surveyed, about half reported that their health was very good or excellent. Regarding healthcare, most people surveyed report that they have high levels of access to general healthcare, dental care, and medical specialists. Most say they have not been prevented from receiving healthcare services due to a disability. Of surveyed individuals, 4 out of 5 felt that their doctor understood them, and 3 in 5 say they understood their doctor's instructions and can provide consent for treatment. Less than half of surveyed participants say that they exercise more than 10 times per month. Most say their doctor speaks directly to them during their appointments.

Progress Points Compared to 2022 - 2023 Report:

★ Improvements

- There was a 4% increase in respondents who reported that when they give consent for medical treatment, it is accepted (81% to 85%).

Opportunities for Improvement

- There was a 2% decrease in respondents who described their health as being very good or excellent (50% to 48%).

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	36%	45%

C11. Medical & Dental Care

Describes health as very good or excellent	48%
Opportunity to discuss health with primary care provider (PCP)	87%
Able to see a medical specialist if needed	97%
Has talked with health care provider using telehealth	47%
Like talking with health care provider using telehealth	50%
Have not been prevented from receiving medical or dental care due to disability	89%

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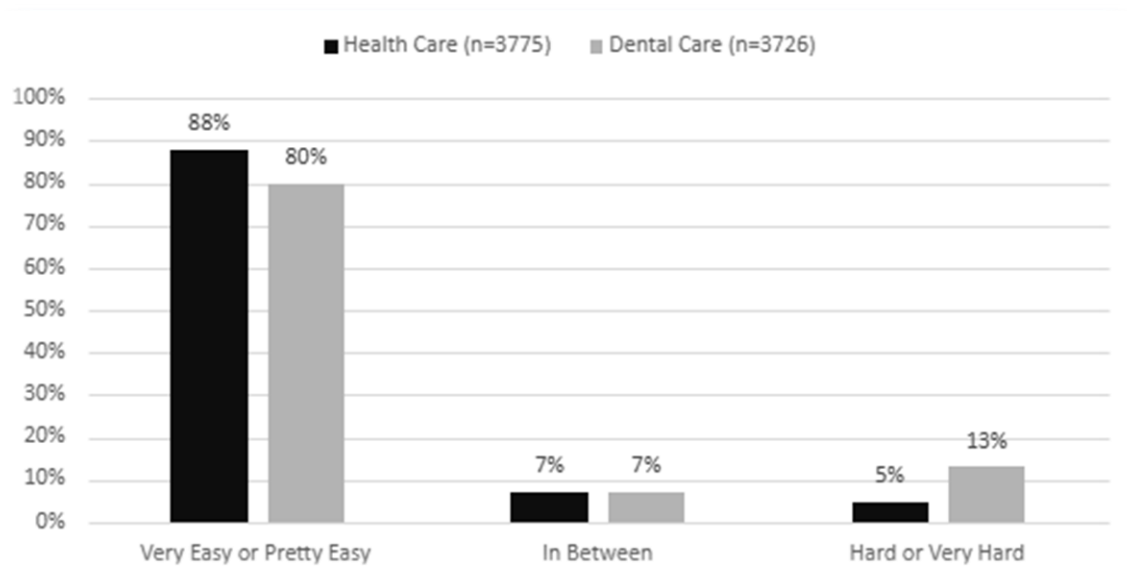
C12. Mental Health

Have an opportunity to discuss health concerns with psychiatrist	63%
Do not have psychiatrist, but want one	3%

C13. Communicating Health Needs

Their doctor understands them	80%
They understand their doctor's instructions	62%
If they need help communicating at doctor's office, it is available	95%
Doctor speaks directly to them during appointments	93%

Able to provide consent for medical treatment	62%
If they provide consent, is it accepted	85%

Part III, Section C: Employment and Community Participation Services

Employment in this survey refers to Competitive Integrated Employment (CIE). CIE is work that is paid directly to the employee, provides at least minimum wage, and occurs in a typical work setting where a person with a disability interacts with coworkers with and without disabilities. Questions about employment benefits, hours, salary, and field of work are only addressed to people who indicated they are employed in CIE.

The survey also asks about Community Participation Support (CPS), or services that give people with intellectual and developmental disabilities opportunities and support for community inclusion and skill development. Questions regarding support getting into the workplace, employment planning, and CPS are asked of all respondents.

Summary: Nearly 1 in 5 respondents report that they work in CIE. Less than 50% of people who reported their wages earned $12.01 or more per hour. The most common benefit reported by workers was receiving paid time off, followed by retirement benefits and health insurance. 2% are self-employed. A little less than a third have been employed for 1 to 3 years, while almost 1 in 5 has been employed for 11 or more years. Of those who are not employed, about half say that someone talked with them about employment in their planning meeting and about a third say employment is a goal in their plan. A little more than 1 out of 4 respondents use CPS. The most common services used are developing interests (71%) and developing social networks (54%).

Progress Points Compared to 2022-2023 Report:

⭐ **Improvements**

- There was a 3% increase in respondents reporting an hourly wage of $12.01 or greater (46% to 49%).

- There was a 3% increase in respondents who reported they talked about employment in their meeting (50% to 53%).

- In terms of compensation and advancement, there was a 5% increase in respondents who receive health insurance benefits from their employer (20% to 25%).

- There was a 3% increase in respondents who reported they receive retirement benefits as part of their compensation (23% to 26%).

🏃 **Opportunities for Improvement**

- Regarding benefits, there was a 4% decrease in respondents who received paid time off (80% to 76%), and a 5% decrease in those who know how much they earn and are willing to share the information with the interviewer (75% to 70%).

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

C14. Employment in CIE
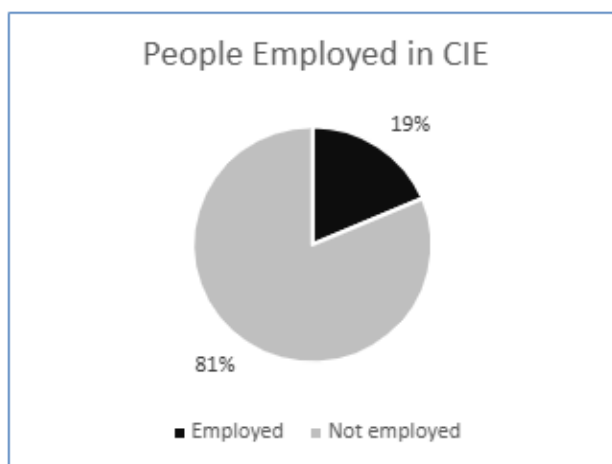
C15. Length of Employment
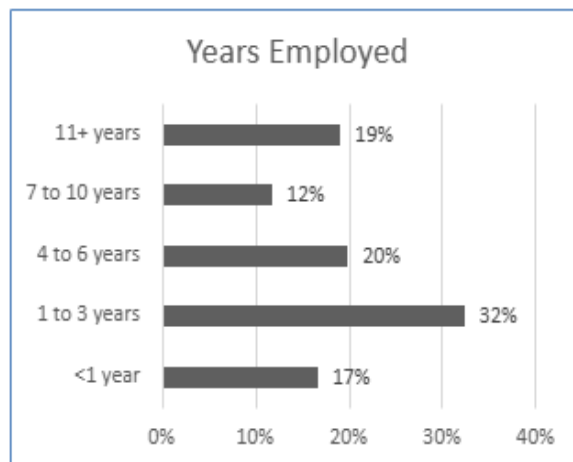
C16. Types of Work

Cleaning Services	20%	Assembly/Factory Work	5%
Food Services	24%	Care Workers/Aides	3%
Retail Services	22%	Recycling	0%
Office Work	3%	Outdoor Work	0%
Stock Room	6%	Animal Care	0%
Maintenance	2%	Other	13%

C17. Supports Getting into the Workplace

Take classes/training for employment purposes	8%
Talked about employment in their planning meeting	53%
Community employment is a goal in their plan	32%

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

No one	48%	SC	44%
Service Provider	7%	Family	10%
Housemates	0%	Someone Else	5%

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

C18. Self-Employment

Person reports that they are self-employed	2%	n=61

C19. Compensation and Advancement

Have been promoted or received an increase in pay	53%
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	26%
Receive other work benefits from their employment	16%
Know how much they earn and willing to share	70%

Hourly Wage

$12.01+	49%
$9.01 to $12.00	27%
$7.26 to $9.00	10%
$7.25	13%
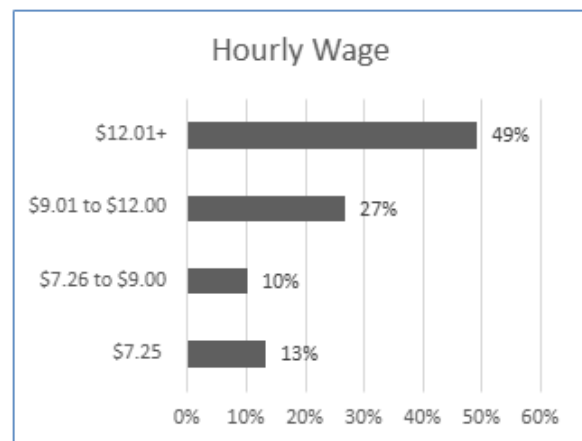
C20. Community Participation

Use Community Participation Support (CPS)	27%

C20.1. If yes, CPS Services Used

Developing skills and competencies necessary for employment	12%
Fine/gross motor skill development and mobility	19%
Participating in community activities to develop social networks	54%
Participating in opportunities to develop interests or promote health/wellness	71%
Training/education for self-determination and self-advocacy	12%
Community adult learning opportunities	16%
Volunteering opportunities	25%
Learning to navigate the local community	11%

C21. Technology use

Internet at home always works	85%
Uses technology in their everyday life to do things on their own	36%
Has enough help to use technology in everyday life	93%
Has talked to SC using videoconference	42%
Likes talking to SC using videoconference	*58%*
Has used videoconference for other services	29%

Likes using videoconference for other services	*59%*

Part III, Section D: Self-Directed Supports

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

Summary: Less than 1 out of 10 respondents report using self-directed supports. In relation to their budget, less than 1 out of 5 people indicate making decisions on their own. Most respondents indicate that they receive information about the money in their budget and that it is easy for them to understand. More than 6 out of 10 respondents receive this information at least every 3 months.

Progress Points Compared to 2022-2023 Report:

★ **Improvements**

- There was a 4% increase in respondents who say they make decisions on their own about their budget (15% to 19%) and also in who receives information about the money left in their budget (68% to 72%).
- There was a 2% increase in individuals who use self-directed services (7% to 9%).

🏃 **Opportunities for Improvement**

- There was a 2% decrease in respondents saying they receive information at least every 3 months about their budget (65% to 63%).

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

C22. Self-Directed Services

Use self-directed services	9%

C23. Who Makes Choices About Budget?

Individual makes decisions on their own	19%
Individual has input, family and friends help	36%
A family member or friend makes decisions	42%
A case manager or state professional makes the decision	2%

C24. Making Decisions

Can make changes to their budget or services if they need to	93%
Have enough help deciding how to use their budget/services	90%
Want more help deciding how to use their budget/services	3%

C25. Money Left in Budget

Receive information about the money left in their budget	72%
Information they receive is easy to understand	83%
They receive information at least every 3 months	63%
They receive information about twice a year	23%
They receive information once a year or less	14%

Part IV: Relationships

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

Respondents:

Individual	34%	Individual and Paid staff	10%
Paid staff	25%	Individual and Family/friend/guardian/advocate	11%
Family/friend/guardian/advocate	19%	Staff and Family/friend/guardian/advocate	1%

Summary: In the previous year, more than three-quarters of this sample reported they were able to see family and friends whenever they wanted, and less than 1 in 10 reported that they were never able to see family and friends. For this cycle, the results were the same.

Progress Points Compared to 2022-2023 Report:

★ **Improvements**

- None identified.

🏃 **Opportunities for Improvement**

- None identified.

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

Chart: Bar chart comparing "Can you see your friends when you want? (n=2816)" (black) and "Can you see your family when you want? (n=1560)" (gray).

- Always: 82% (friends), 84% (family)
- Sometimes: 14% (friends), 11% (family)
- Never: 4% (friends), 5% (family)

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.

Respondents:

Individual	34%	Individual and Paid staff	10%
Paid staff	25%	Individual and Family/friend/guardian/advocate	11%
Family/friend/guardian/advocate	19%	Staff and Family/friend/guardian/advocate	1%

Summary: In terms of inclusion, less than half of respondents reported that they have weekly participation in community activities. However, more than 3 out of 4 respondents stated they have enough opportunity to engage in these same activities. Less than half of respondents report going out into the community often to participate in entertainment activities, and less than half also report wanting to be part of more groups in the community.

Progress Points Compared to 2022-2023 Report:

⭐ **Improvements**

- There were 2% increases, respectively, in people who reported that they went out into the community <u>weekly</u> to run errands and have appointments (27% to 29%) and can go out for entertainment (25% to 27%).
- In terms of community engagement there was an increase in the following areas for surveyed respondents who reported they went out <u>enough</u>:
  - Going to a supermarket (+2%; 85% to 87%)
  - Going out to a bar or social club (+8%; 86% to 94%)
  - For entertainment (+2%; 78% to 80%).
- There was a 3% increase in respondents who reported frequently attending social events by people with and without disabilities in their community (29% to 32%).

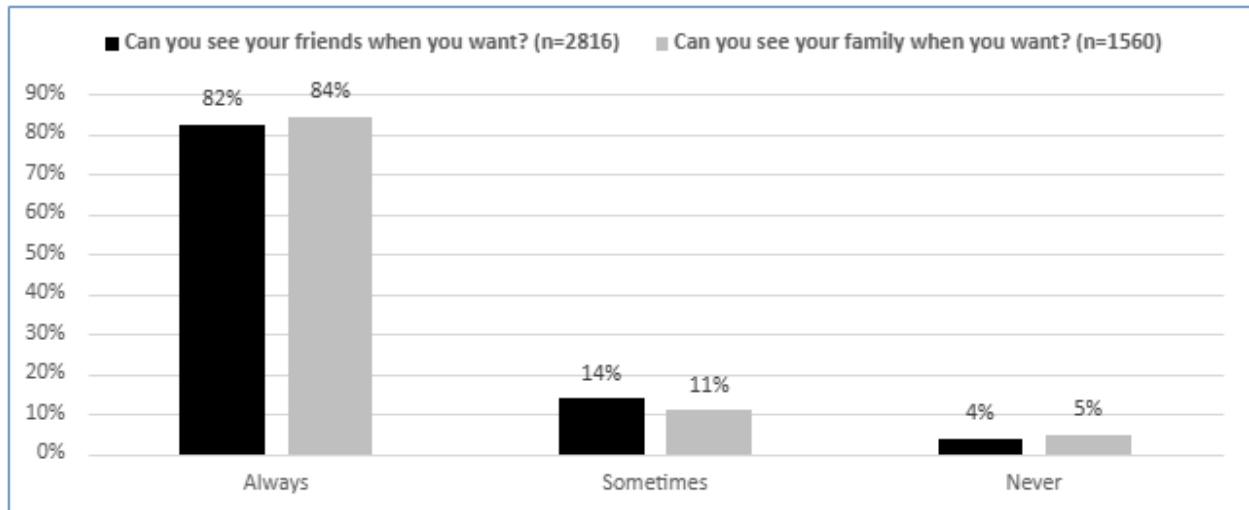🏃 **Opportunities for Improvement**

- None identified.

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	45%	77%	22%	2%
Go to a supermarket	49%	83%	12%	5%
Go out to a restaurant or a coffee shop	44%	77%	21%	2%
Go to a shopping center or mall	39%	81%	15%	3%
Go out to a worship service	24%	88%	11%	1%
Run errands and appointments	29%	89%	6%	5%
Go to a bar/pub or social club	4%	94%	6%	1%
Go out for entertainment	27%	80%	19%	1%

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

Activity	Staff	Family	Friends	Roommates Coworkers	Go Alone	Other
Visit friends, relatives, neighbors	33%	47%	8%	1%	12%	0%
Go to a supermarket	48%	43%	1%	1%	6%	0%
Go out to a restaurant or a coffee shop	49%	42%	4%	1%	3%	0%
Go to a shopping center or mall	55%	37%	3%	1%	4%	0%

Go out to a worship service	32%	57%	3%	1%	7%	1%
Run errands and appointments	52%	41%	1%	0%	5%	0%
Go to a bar/pub or social club	34%	46%	12%	1%	6%	1%
Go out for entertainment	53%	37%	7%	1%	2%	0%

E2. Extra-Curricular Activities

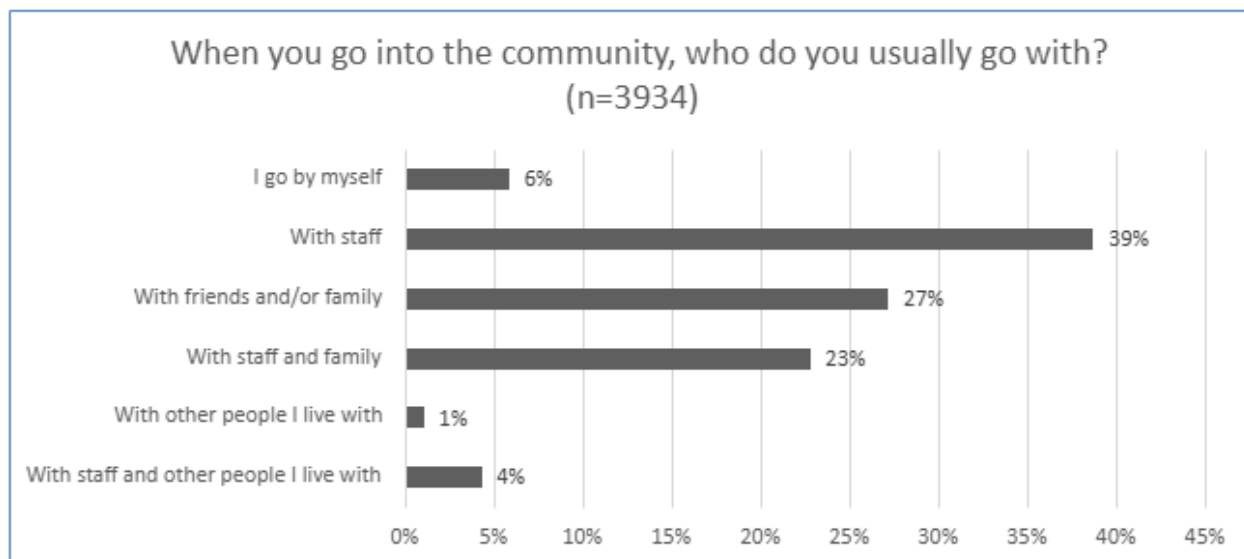| Would like to be a part of more groups in the community	35%

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

	Frequently	Occasionally
Go out into the community for entertainment	45%	38%
Go to social events attended by people with and without disabilities	32%	47%

E2.2. Exercise in the Community

	Never	Less than Weekly	Weekly	More than Weekly
How often the person exercises	38%	4%	9%	49%

E3. Going Out Alone or with Other People

When you go into the community, who do you usually go with? (n=3934)

- I go by myself — 6%
- With staff — 39%
- With friends and/or family — 27%
- With staff and family — 23%
- With other people I live with — 1%
- With staff and other people I live with — 4%

E4. Transportation

Always have a way to get where they **need** to go[+]	95%
Can always get to where they **want** to go[+]	94%

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

Not enough staff	23%
Paratransit is unreliable	14%
Transportation for work/school only	4%
No one at home can drive	4%
Some other reason	54%

E5. Home Adaptive Equipment

Do you have all adaptive equipment needed? (n=2795)

11% No
89% Yes

Adaptations/modifications to the home made it accessible (n=3927)

6% No
94% Yes
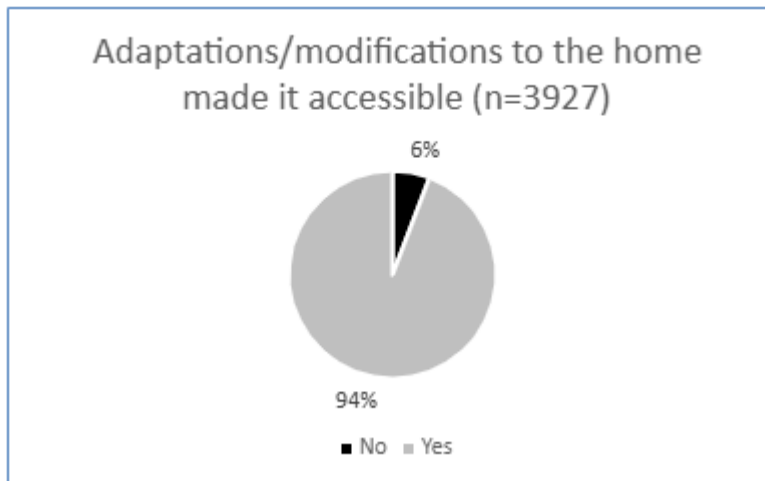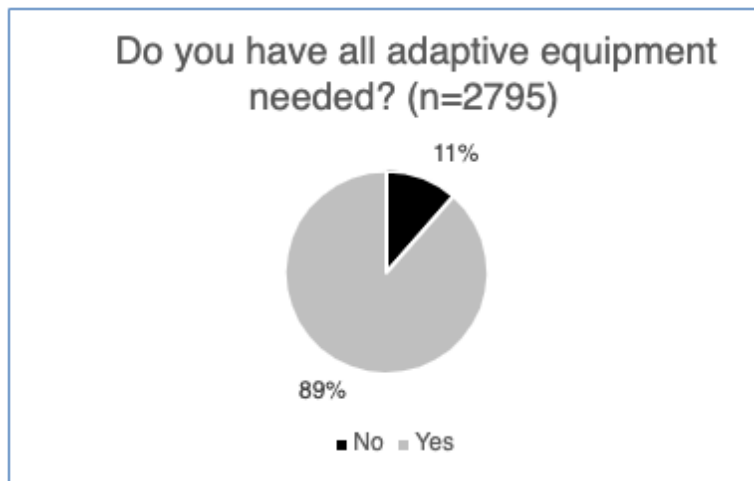
Part VI. Monitor Impressions of Competence, Personal Growth and Opportunities

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 Monitors' perceptions of staff competence and whether they provide opportunities to grow and learn for the individual. The next series of questions ask about support for the person. It should be noted that because all interviews were conducted remotely this year, many Monitors did not have enough information to effectively respond to these questions.

Summary: When accounting for IM4Q Monitors reporting on the home environment, more than half indicated they would either "maybe" want to move into the home or "move in tomorrow." More than 9 out of 10 Monitors indicated that staff treat individuals with respect, recognize them in ways that promote independence, and have the necessary skills to support the individual. For all 3 of these areas, there was a 2% increase.

Progress Points Compared to 2022-2023 Report:

★ Improvements

- There was a 2% increase in Monitors observations that staff treat individuals with dignity and respect (90% to 92%).

- There was a 2% increase in Monitors observations that staff recognize the individual in a way that promotes independence (89% to 91%).

- There was a 2% increase in Monitors observations that staff who support individuals have the skills they need (90% to 92%).
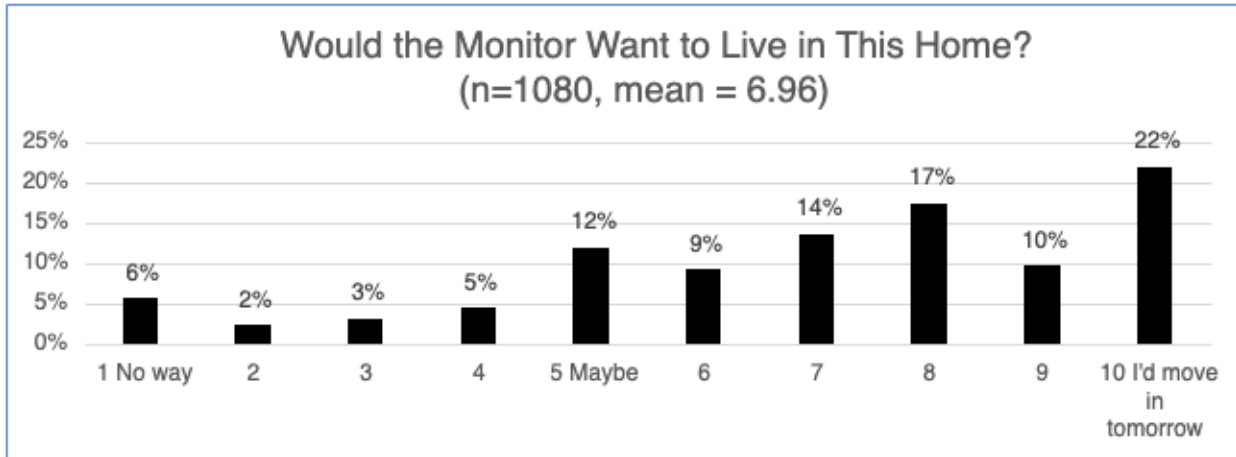
Opportunities for Improvement

- None identified.

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").

F1.1. Mean and Mode of Monitor Ratings

Mean	6.96
Mode	10

Note: The __Mean__ is the average. The __Mode__ is the number that is reported most frequently.

G. Support for the Person Data

G1. Monitor Observations

Staff treat individuals with dignity and respect	92%
Staff recognize the individual in ways that promote independence	91%
Staff who support individuals have the skills they needed	92%

Part VII. Family/Friend/Guardian Survey

This survey was completed remotely by telephone or mail this year with a family member, guardian, or friend who was identified through the Essential Data Elements (EDE) Pre-Survey. Surveys were completed for 1,466 family members, friends, and guardians.

Respondents:

Parent(s)	77%	Another Relative	4%
Sibling(s)	13%	Friend	1%
Guardian	2%	Other	3%

Summary: Generally, respondents reported high levels of satisfaction with where their relatives are staying. High satisfaction was also indicated with the staff they interact with. Respondents reported positive feelings towards their ability to contact their loved ones. Of surveyed respondents, 8 out of 10 reported their relative is able to interact and participate in community events and activities. More than 8 out of 10 indicated that their relative has an adequate number of paid staff. The majority of respondents indicated staff always treat their loved ones with dignity and respect. More than 80% of respondents were satisfied with the supports their loved one receives. Only 2 of 3 respondents believed their relatives were familiar with how to file a complaint or grievance. 61% of respondents indicated they have been given information about an emergency plan in case their relative is involved in an emergency situation.

Progress Points Compared to 2022-2023 Report:

★ **Improvements**

- There was a 5% increase in family members who reported that there is an adequate number of paid staff in their relative's home (80% to 85%) and that their relative has enough opportunities to participate in community activities (78% to 83%).
- There was a 2% increase in family members who reported that their family member was satisfied or very satisfied with what they do during the day (89% to 91%) and that they think their relative feels safe in their community, home, or neighborhood most of the time (86% to 88%).
- There was a 3% increase in family members who reported that their loved one has the opportunity to learn new things (86% to 89%).
- There was a 4 % increase in family members who reported that their loved one directs their own services (13% to 17%)

- There was a 7% increase in family members who reported they had learned about the Life Course Framework and Tools (18% to 25%).

⩗ Opportunities for Improvement

- There was a 3% decrease in respondents who reported that there was a communication system in place for their relative and that it was being used (40% to 37%).

This link will skip data details and take you to the next Section, **Considerations**.

H. Family, Friend and Guardian Survey Data

H1. Daily Life

Somewhat satisfied or very satisfied with where their relative lives	94%
Somewhat satisfied or very satisfied with what relative does during the day	88%
Somewhat satisfied or very satisfied with relative's staff at home	93%
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	94%
Never contacted their relative	1%
See their relative at least monthly	82%
Never visited their relative	3%

H3. Your Relative's Satisfaction

Relative is satisfied or very satisfied with his/her living situation	94%
Relative is satisfied or very satisfied with what they do during the day	91%
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	2%
Relative is satisfied or very satisfied with the staff who support them during the day	97%
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	88%
Relative feels safe in their community, home, and neighborhood most of the time	9%

H5. Your Relative's Opportunities

Relative has enough opportunities to participate in activities in the community	83%
Relative has the opportunity to learn new things	89%

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	94%
All staff in their relative's home have the skills they need to support their relative	88%
Some of the staff in their relative's home have the skills they need to support their relative	10%
Relative's place of work appears to have an adequate number of paid staff	94%
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	91%

H7. Relative's Communication System

If their relative does not communicate verbally, there is a formal system in place, and they use it	37%
If there is a communication system in place, it is used across settings	81%

H8. Relative's Supports

Satisfied with the support coordination their relative receives	81%
Told how much money is in their relative's budget	62%
Their relative directs their own services	17%
Their relative always receives the supports they needed	67%
The supports and services their relative receive change when their needs change	84%
There are never or rarely changes in support staff at their family member's home, work, or day program	64%
There are always frequent changes in support staff at their family member's home, work or day program	13%
They chose the agency/provider who worked with their relative	45%
Their relative chose the agency or provider who worked with their relative, alone or with their help	26%
Someone else chose the agency/provider who worked with their relative	29%

H9. Complaints and Grievances

Relative was familiar with the complaint and grievance process on some level	66%

H9.1. At what level?

At the provider level	63%
At the county/AE level	62%
At the state level	60%

H10. Family Resources

The information they receive about their relative's services is easy to understand	89%
They had learned about the Life Course Framework and Tools	25%
They had an opportunity to connect and network with other families with relatives at similar life stages	47%
They are aware of the PA Family Network (PAFN)	33%
Of those who were aware of the PAFN, who had attended a workshop led by the Network of Family Advisors	36%
Have enough information about services for which the family is eligible	81%
If family member transitioned from school to adult services, were happy with the process	37%

SC asks about their vision for an everyday life for their family member	77%

H11. Emergency Preparation Questions

Given information about an emergency plan for their family member in case of emergency	61%

Part VIII. Considerations

Considerations consist of concerns or requests identified during the IM4Q process. There were 6,143 total considerations in the 2023-2024 collection year. The greatest number of Considerations came from Allegheny (32.28%), Philadelphia (11.85%), and Berks (5.97%) counties.

Summary: The topic of each consideration was analyzed, resulting in 15 categories, or primary themes. The primary themes of greatest significance were Service System (18.62%); Personal Rights, Competence Enhancement and Growth (18.15%); Community Presence and Participation (15.29%), and Work/Employment/Meaningful and Purposeful Activity (11.23%). For each primary theme, the percentage of total considerations and resolved considerations are provided. Within each primary theme, considerations were analyzed to determine whether significant secondary themes were evident. When identified, 2-3 secondary themes are listed in the tables below the primary themes in order of significance. A secondary theme of "Other" was not included in the analysis.

Service System: 18.62% of total (80.59% resolved)

Secondary theme 1	Request for information
Secondary theme 2	Request for additional services
Secondary theme 3	General support issues

Personal Rights, Competence Enhancement and Growth: 18.15% of total (81% resolved)

Secondary theme 1	Learning a skill
Secondary theme 2	Independence / choice / control

Community Presence and Participation: 15.29% of total (85.41% resolved)

Secondary theme 1	Individual needs increased opportunities
Secondary theme 2	Funding needed to attend/join/participate in events

Work/Employment/Meaningful and Purposeful Activity: 11.23% of total (81.01% resolved)

Secondary theme 1	Job opportunity request
Secondary theme 2	Individual needs meaningful day activity

Health and Well Being: 9.52% of total (80.85% resolved)

Secondary theme 1	Medical, behavioral, health concern

Secondary theme 2	Difficulty accessing medical professional/specialist

Relationships/Friendships: 6.58% of total (80.69% resolved)

Secondary theme 1	Individual needs increased opportunities
Secondary theme 2	Family contact
Secondary theme 3	Social skill building

Residential/Living Situation Personal Change: 4.80% of total (76.27% resolved)

Secondary theme 1	Request to live elsewhere
Secondary theme 2	Request regarding roommate/housemate

Communication Needs/Devices/Services: 3.24% of total (81.91% resolved)

Secondary theme 1	Individual needs communication device
Secondary theme 2	Training needed to use device

Adaptive Equipment: 2.65% of total (72.39% resolved)

Secondary theme 1	Individual needs personal adaptive equipment (82.35%)
Secondary theme 2	Funding needed to obtain equipment
Secondary theme 3	Equipment needs repair

Residential Build Adaptation/Modifications: 1.97% of total (74.38% resolved)

Secondary theme 1	Structural adaptation/modification in/outside of residence needed
Secondary theme 2	Repairs/maintenance needed
Secondary theme 3	Funding needed

Transportation: 1.68% of total (76.70% resolved)

Secondary theme 1	Request for transport to/from activities/programs
Secondary theme 2	Request for accessible transportation

Safety: 2.47% of total (86.18% resolved)

Secondary theme 1	Concern regarding location
Secondary theme 2	Personal safety awareness

Major Concerns: 0.24% of total (93.33% resolved)

Secondary theme 1	Evidence of physical abuse or neglect
Secondary theme 2	Physical danger within a residential site/home or place of day activity
Secondary theme 3	Evidence of a human rights violation

Spiritual Life: 1.12% of total (86.96% resolved)

Secondary theme 1	Individual needs increased opportunities
Secondary theme 2	Education requested

No Primary Theme: Miscellaneous or Loop Not Closed: 2.43 % of total (79.73% resolved)

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