

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

Independent Monitoring for Quality (IM4Q)
Statewide Report
2022-2023

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 2022-2023 fiscal year. Following the Covid-19 Pandemic, data collection has shifted to a hybrid model, with some interviews taking place in person and others occurring remotely. Questions may be addressed to IM4Q@temple.edu.

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

Why We Do This

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

The IM4Q process also allows us to improve people’s lives in a direct way. When IM4Q monitors interview a person with a disability, they write down any concerns or requests the respondent(s) have. We call these “considerations.” Individual considerations are shared through the IM4Q system with someone who might be able to help, such as the supports coordinator (SC), a provider, or family members. The SC decides how the consideration will be handled and

reports back to the Administrative Entity (AE) or the Office of Developmental Programs (ODP) Bureau of Supports for Autism and Special Populations (BSASP). If the consideration is not addressed, the consideration process continues. When the person or family are satisfied with the action to address the consideration, we call this “Closing the Loop.”

Considerations may result in service changes or provide an opportunity to improve the quality of life of the individual who has been interviewed. For the 2022-2023 collection year, over 6,000 considerations were collected. Of these, nearly 70% have been closed.

Some qualitative data from the current 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, “Karl’s Consideration,” is provided below (NOTE: Name has been changed to protect the confidentiality of respondent.)

Story: Karl’s Consideration

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

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

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

For the 2022-2023 fiscal year, individuals had the option to participate in interviews held in person or remotely. This year, 75% of the interviews were conducted remotely using video conferencing and 25% were done in person. These methods, as well as some persistent hesitation about in person gatherings due to the pandemic, and a notable staffing shortage are likely to have affected the data. Throughout the report, notes have been added to point out where the data may have been influenced by social trends related to these issues.

Scale Scores

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

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

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

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

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

	Statewide
Mean	84.23
SD	19.82

Dignity, Respect and Rights – Scores range from 0 to 100. High scores mean people reported that others were nice to them, and they were treated with respect.

	Statewide
Mean	83.66
SD	15.47

Afraid – Scores range from 0 to 100. High scores mean people reported that they were NOT afraid at home, at their work or day activity, and in their neighborhood.

	Statewide
Mean	92.60
SD	15.73

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

	Statewide
Mean	60.93
SD	20.79

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

	Statewide
Mean	43.54
SD	17.87

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

	Statewide
Mean	7.56
SD	2.50

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

	Statewide
Mean	90.13
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](#), 3 out of 4 individuals reside in a relative's home or a community home. Nearly 80% are white, most are non-Hispanic/Latinx and about 60% are male.

[Satisfaction](#) rates remain high among individuals receiving services and their family members. As in recent years, 9 out of 10 individuals are satisfied with 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 research has shown that satisfaction rates for supports and services may be inflated for many reasons, such as a lack of alternative experiences from which to compare or because individuals who receive supports and services may appreciate receiving any services. Notably, 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](#). 9 out of 10 say their SC will help get what they need and more than half have discussed the possibility of employment with their SC.

The average scores for [Choice and Control](#) and [Inclusion](#) remain lower than for the previous categories. About half of individuals made choices about where to live and work and with whom. About 2 out of 5 respondents vote in political elections. Less than half say they had choice about their staff, though this may reflect the ongoing staff shortage. 90% say they chose their daily schedule without assistance and most report they have enough choice about their free time. More than half of individuals surveyed say they have access to cable (92%) and a computer with Internet (61%), while just over 40% have a cell phone, and about 1 in 4 have email access.

[IM4Q Monitor Impressions](#) were higher than in previous years, with nearly 1 in 3 monitors reporting they would "move in tomorrow" to the interviewees home. These results may have been affected by the interview format, as most interviews (3 in 4) were conducted remotely.

[Family, Friend and Guardian](#) perceptions of their relatives' supports and services remain highly positive. People in [Community Integrated Employment](#) and using [Self-Directed Services](#) increased slightly to 17% and 7% respectively. About a third use technology to support them in daily life. More than half talked to their SC using videoconferencing and 1 in 4 use teleconferencing to access other services.

Communication remains an issue for individuals who communicate other than verbally, for whom about a third have a system in place. For those with a system in place, 3 out of 4 report it is used across settings. Family members continue to report high satisfaction, with 4 out of 5 saying their relative has enough opportunity to participate outside of their home and to learn new things. Many remain unaware of the PA Family Network (71%). [Considerations](#) were largely closed, and the most common categories were: Service System; Personal Rights, Competence Enhancement and Growth; Community Presence and Participation.

Sample

i. Sample Data

i1. Total Surveyed

People with disabilities	4048	Family members	1532
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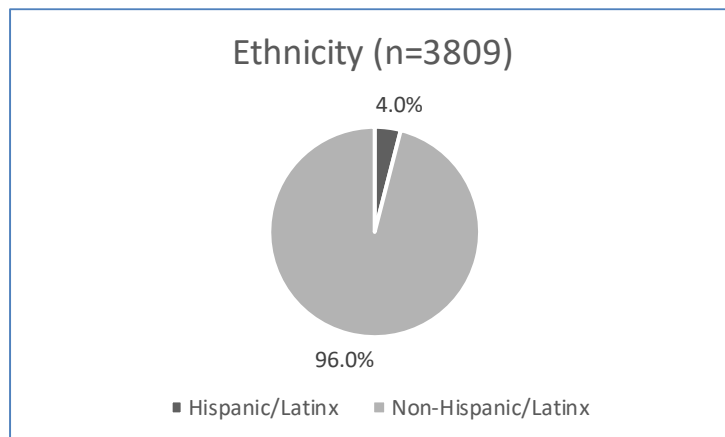
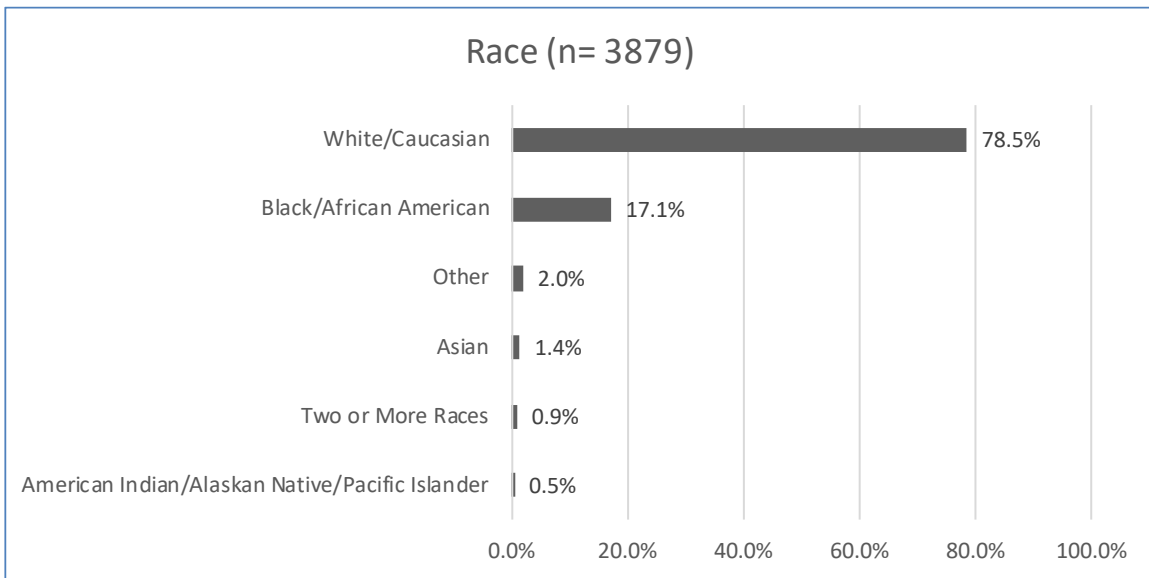
i2. Age

Range	6-88	Mean Age (SD)	41.7 (17.2)
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i3. Reported Gender

Female	38.9%	Male	61.0%	Other	0.1%
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i4. Race and Ethnicity



i5. Home Type Where Respondent Lives

Type of Residence	Number of Residents	Percent of the Sample
Relative's Home	1733	42.8%
Community Home- Subtotal	1458	36.0%
<i>Community Home 1</i>	123	3.0%
<i>Community Home 2-4</i>	1261	31.2%
<i>Community Home 5-6</i>	44	1.1%
<i>Community Home 7-8</i>	16	0.4%
<i>Community Home 9-15</i>	6	0.1%
<i>Community Home 16+</i>	8	0.2%
Own Residence	336	8.3%
Family Living/Lifesharing	141	3.5%
Private ICF/ID- Subtotal	197	4.9%
<i>Private ICF/ID 4 or fewer</i>	41	1.0%
<i>Private ICF/ID 5-8</i>	57	1.4%
<i>Private ICF/ID 9-15</i>	16	0.4%
<i>Private ICF/ID 16+</i>	83	2.1%
Personal Care Home	30	0.7%
Nursing Home/Facility	26	0.6%
Children's Facility	2	0.0%
Unlicensed Family Living	7	0.2%
Domiciliary Care	7	0.2%
Foster Care	1	0.0%
Approved Private School	2	0.0%
State Operated ICF/MR	8	0.2%
State MH Hospital	0	0.0%
Temporary Shelter	1	0.0%
Other	24	0.6%
<i>Data on Type of Residence Missing</i>	75	1.9%
Total	4048	100%

i6. Administrative Entity (AE) Where the Respondent Lives

AE	Number of Respondents	Percent of Sample
Allegheny	450	11.1%
Armstrong/Indiana	56	1.4%
Beaver	69	1.7%
Bedford/Somerset	37	0.9%
Berks	118	2.9%
Blair	48	1.2%
Bradford/Sullivan	9	0.2%
Bucks	159	3.9%
Butler	59	1.5%
Cambria	48	1.2%
Cameron/Elk	22	0.5%
Carbon/Monroe/Pike	64	1.6%
Centre	52	1.3%
Chester	109	2.7%
Clarion	26	0.6%
Clearfield/Jefferson	41	1.0%
Columbia/Montour/Snyder/Union	48	1.2%
Crawford	56	1.4%
Cumberland/Perry	59	1.5%
Dauphin	102	2.5%
Delaware	179	4.4%
Erie	166	4.1%
Fayette	38	0.9%
Forest/Warren	20	0.5%
Franklin/Fulton	55	1.4%
Greene	18	0.4%
Huntington/Mifflin/Juniata	37	0.9%
Lackawanna/Susquehanna	88	2.2%
Lancaster	105	2.6%
Lawrence	34	0.8%
Lebanon	31	0.8%
Lehigh	108	2.7%
Luzerne/Wyoming	106	2.6%
Lycoming/Clinton	58	1.4%
McKean	22	0.5%
Mercer	37	0.9%
Montgomery	217	5.4%
Northampton	70	1.7%
Northumberland	40	1.0%
Philadelphia	555	13.7%
Potter	16	0.4%
Schuylkill	45	1.1%
Tioga	32	0.8%
Venango	49	1.2%
Washington	48	1.2%
Wayne	26	0.6%
Westmoreland	97	2.4%
York/Adams	119	2.9%
TOTAL	4048	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: People in this sample are mostly happy about where they live and work. Most people say they are happy with their lives and report 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.

Progress Points Compared to 2021-2022 Report:



Improvements

- There was a 4% increase in those who said there are no rules about spending time with friends or visitors (75% to 79%) following a 15% increase last year (60% to 75%).
- There was a 2% increase in individuals who reported that their staff at their current job or day activity was nice or very nice (95% to 97%).



Opportunities for Improvement

- There was a 2% decrease in people who said they always get the services they need (85% to 83%), following a 3% decrease last year (88% to 85%).
- There was a 2% decrease in individuals who said that people always let them know when coming into their bedroom (88% to 86%).
- There was a 3% decrease in people who said that overall they are happy with their life (86% to 83%)

This link will skip data details and take you to the summary of the next Section [Dignity, Respect and Rights.](#)

A. Satisfaction Data

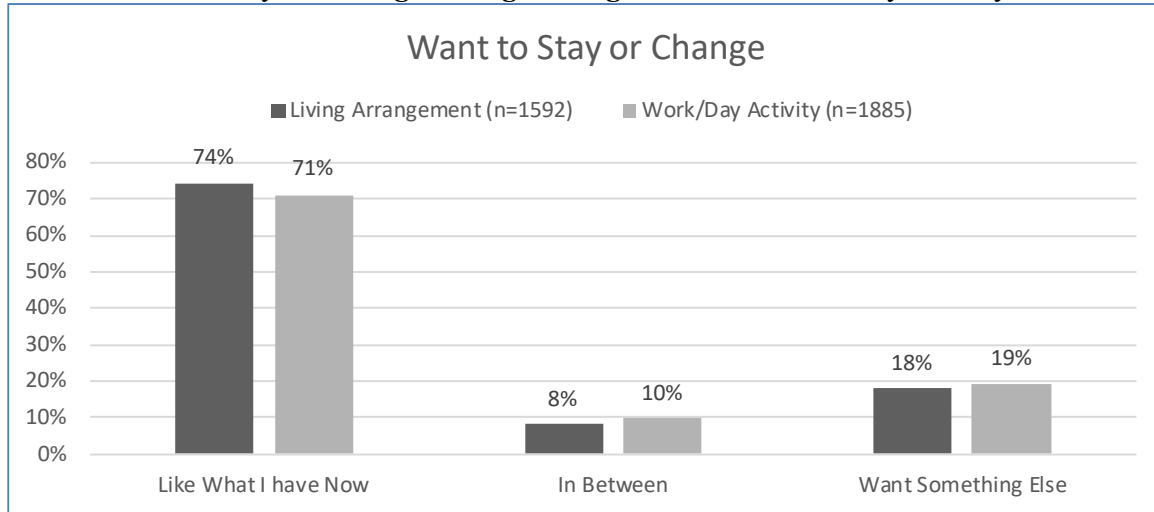
A1. Living Arrangements

Like where they live now	88%
Want to stay where they currently live	74%
Want to move somewhere else	18%

A2. Work/Day Activity

Like primary job or day activity	90%
Like other job or day activity	93%
Want to continue current job or day activity	71%
Want to do something else	19%

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



A3. Daily Activities

What do people do on most days?	Primary activity	Secondary activity
Stay home	25%	40%
Work	25%	4%
<i>Work- no supports</i>	15%	2%
<i>Work- with supports</i>	10%	1%
Attend school	6%	1%
Attend a vocational facility	12%	2%
Attend a day program or community center	10%	2%
Go out in the community	14%	28%
Retired	2%	1%
Volunteer	2%	6%
Something else	5%	17%

A3.1. Want to Work

Do not have or want a job	55%
Would like a job for pay	40%
Uses special technology to help do work	14%

A4. Services

Always get services they need	83%
Sometimes get services they need	2%
Do not get services they need	7%
Need additional services	8%

A5. Happiness and Loneliness

A5.1 Happy with Life

Happy with life	83%
Neither happy nor sad with life	14%
Sad with life	3%

A5.2 Loneliness

Never lonely	64%
Sometimes lonely	31%
Always lonely	5%

A5.3 Friendship

Have friends to do things with	83%
Friends are not staff or family	70%
Have a best friend	69%

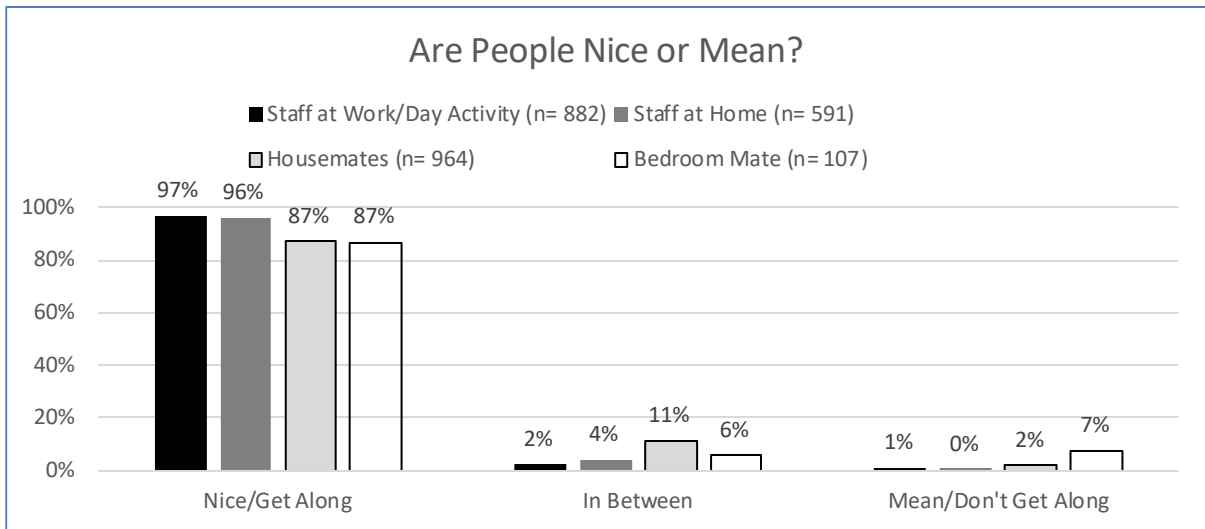
A5.4 Dating and Marriage

Can date/marry, no restrictions	84%
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	79%
People always let them know when coming into their home	88%
Sometimes people let them know when coming into their home	7%
People never let them know when coming into their home	5%
People always let them know when coming into their bedroom	86%
People sometimes let them know when coming into their bedroom	6%
People never let them know when coming into their bedroom	8%

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: Most people in the sample report high scores on Dignity, Respect and Rights. Nearly 9 in 10 report their mail is never opened without permission and that they get help to learn new things. People are rarely afraid in their home, work, or neighborhood. More than 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.

Progress Points Compared to 2021-2022 Report:



Improvements

- There was a 2% increase in individuals who reported their mail is never opened without their permission (85% to 87%)



Opportunities for Improvement

- There was a 3% decrease in people who reported that they get to learn new things (82% to 79%).
- There was a 3% decrease in those who reported that they get the chance to help others (69% to 66%).

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

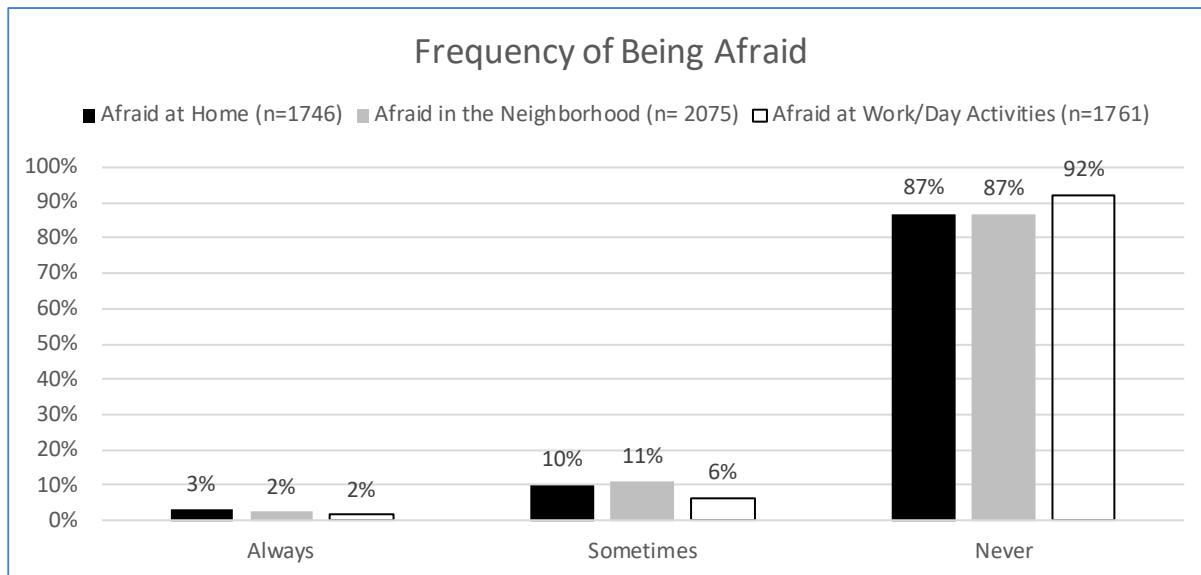
B1. Support with Goals and Problems

Get help to learn new things	79%
Do not get help	12%
Get to help other people	66%
Have participated in a self-advocacy group meeting	19%
Someone has talked to them about self-advocacy	53%
Have someone to talk to when afraid	95%

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

Staff	49%	Family	49%
Supports coordinator	10%	Friends	8%
Other	9%	Have no one	1%

B2. Frequency of Being Afraid



B3. Legal Rights

	Never	Sometimes	Always
Mail opened without permission	87%	7%	7%

Part II, Section B: Supports Coordination

This section asks questions related to supports coordination. Questions cover the supports coordinator (SC), services, and other staff members. These questions can only be answered by the individual receiving services.

Summary: Overall, people in this year's sample were satisfied with their support 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. Most participate in their annual planning meeting.

Progress Points Compared to 2021-2022 Report:



Improvements

- There was a 2% increase in respondents who reported their SC always treats them with respect (92% to 94%).

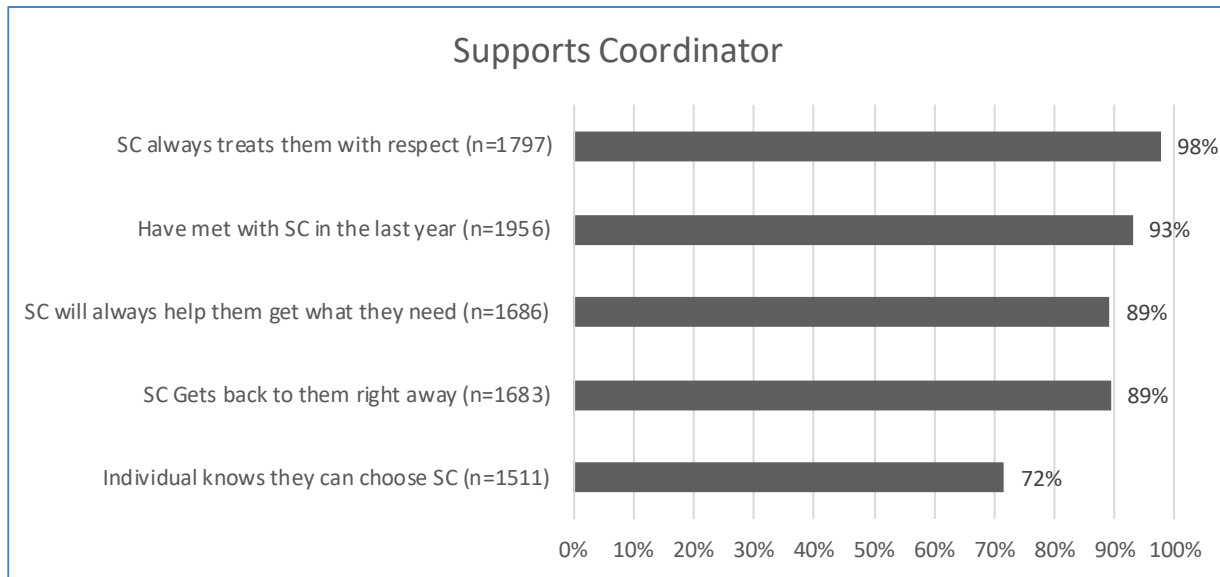


Opportunities for Improvement

- There was a 6% decrease in respondents who reported their SC asks them about directing their own services (46% to 40%).
- There was a 3% decrease in respondents who reported their SC gets back to them right away (92% to 89%).
- There was a 3% decrease in respondents who reported that they know who to ask if they want to change their services (83% to 80%).
- There was a 3% decrease in respondents who reported that they know how much money is in their budget (57% to 54%).

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	89%
SC asks them about directing their own services	40%
SC asks if community employment is a possibility ⁺	62%
SC asks if services are OK	96%
SC always listens to them	96%

B5. Annual Planning Meeting

Have participated in the meeting	96%
Know it is an option but choose not to participate in meeting	1%
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	54%
Meeting includes the people they wanted to be there	95%
Know what is talked about at their ISP meeting	81%

B6. Services

Know who to ask if they want to change their services	80%
Do not know who to ask to change services	14%

B7. Staff

Staff always treats them with respect	94%
Staff are respectful of their culture	98%
Have staff that help them	77%
Staff have the right training to meet their needs	94%
Staff do things the way they want them done	89%
All staff always understand their communication	90%
Some staff understand them	6%
Sometimes understood by staff	3%
Not understood by staff	0%

Part II, Section C: Emergency Preparation

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

Summary:

The vast majority of people, more than 8 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 frequent 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 2021-2022 Report:



Improvements

- The number of people who reported family had given them information about what to do in an emergency increased by 6% (40% to 46%).



Opportunities for Improvement

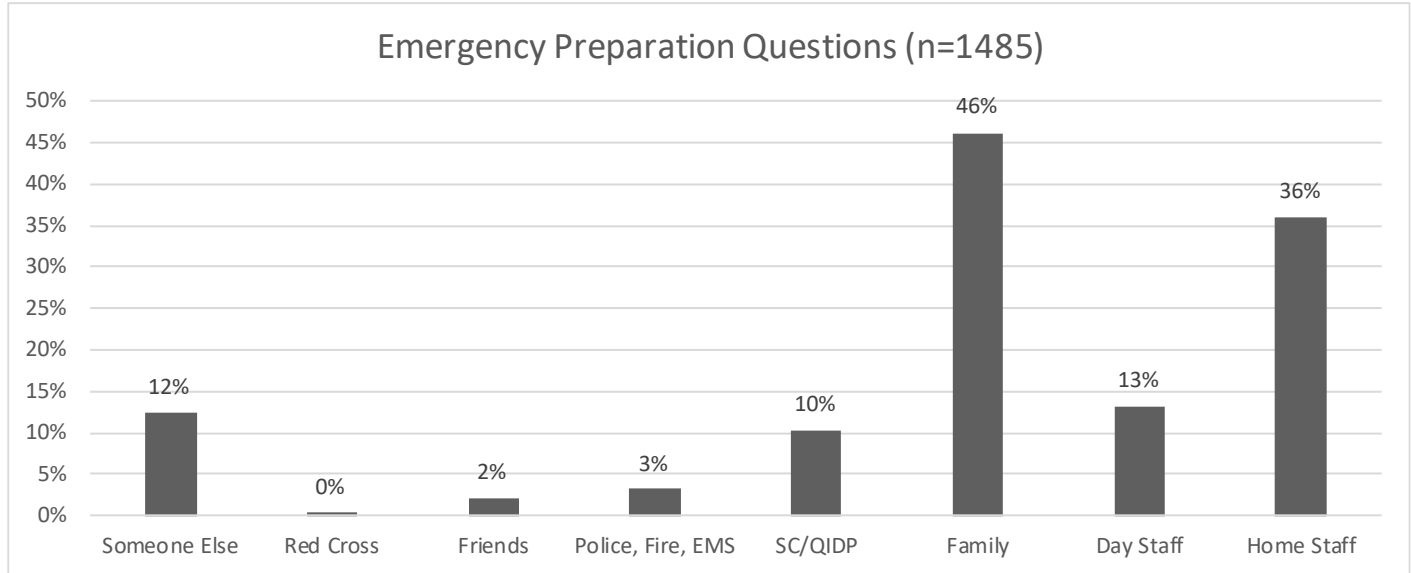
- The number of people who reported staff had given them information about what to do in an emergency decreased by 2% (day staff, 15% to 13%) to 4% (home staff, 40% to 36%).

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%
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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	26%	Individual and Paid staff	14%
Paid staff	24%	Individual and Family/friend/guardian/advocate	14%
Family/friend/guardian/advocate	20%	Staff and Family/friend/guardian/advocate	1%

Summary: About 2 of 3 people 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 using words, 1 in 3 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 slightly less than half have a cell phone.

Progress Points Compared to 2020-2021 Report:



Improvements

- There was a 5% increase in those who reported that they have a bank account they can access when they want something (67% to 72%).
- There was a 3% increase in people who report that they have a key to their home (47% to 50%), and that they can lock their bedroom door (49% to 52%).
- There was a 3% increase in people who said that their name is on the lease or rental agreement (34% to 37%).
- There was a 3% increase in people who reported that they had the choice to go where people without disabilities go during the day (66% to 69%). This is promising following a 12% decrease in the last two years.



Opportunities for Improvement

- There was a 4% increase in individuals who reported that they saw no other places when selecting their home (50% to 54%).
- There was an 8% decrease in people who do not communicate in words reporting they have a system in place (41% to 33%).

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

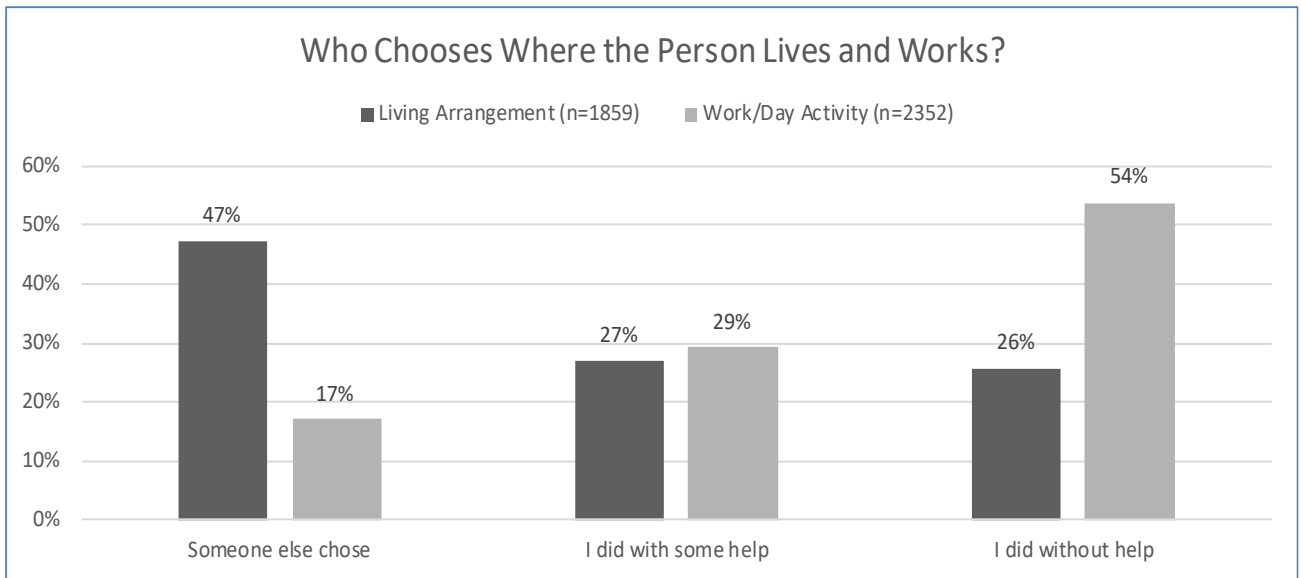
C1. Identification

Always carry ID	67%
Never carry ID	18%

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	45%
If other household members go out, they sometimes can stay home	13%
Can lock bedroom door	52%
Own their home	3%
Name is on the lease or rental agreement	37%
Have a choice to live where people without disabilities live	46%
Saw no other places before they moved into their home	54%
Did not choose housemates	63%
If individual shares a bedroom, chose some or all roommates	41%

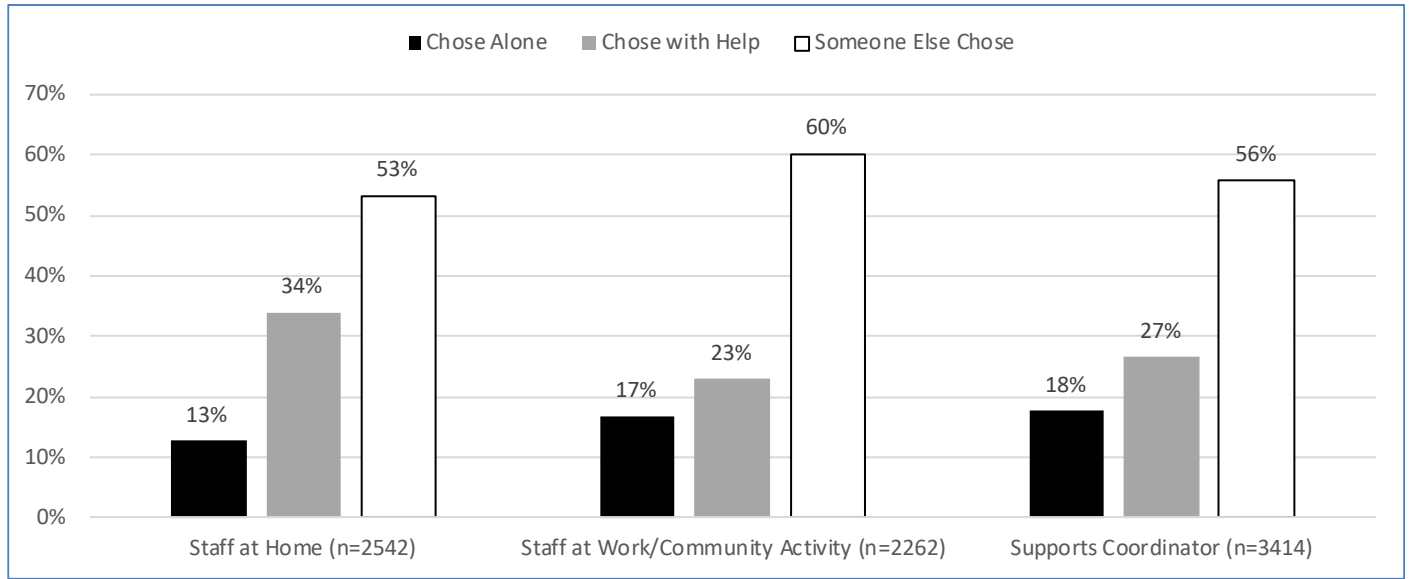
C2.1. Who Chooses Where the Person Lives and Works?



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

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

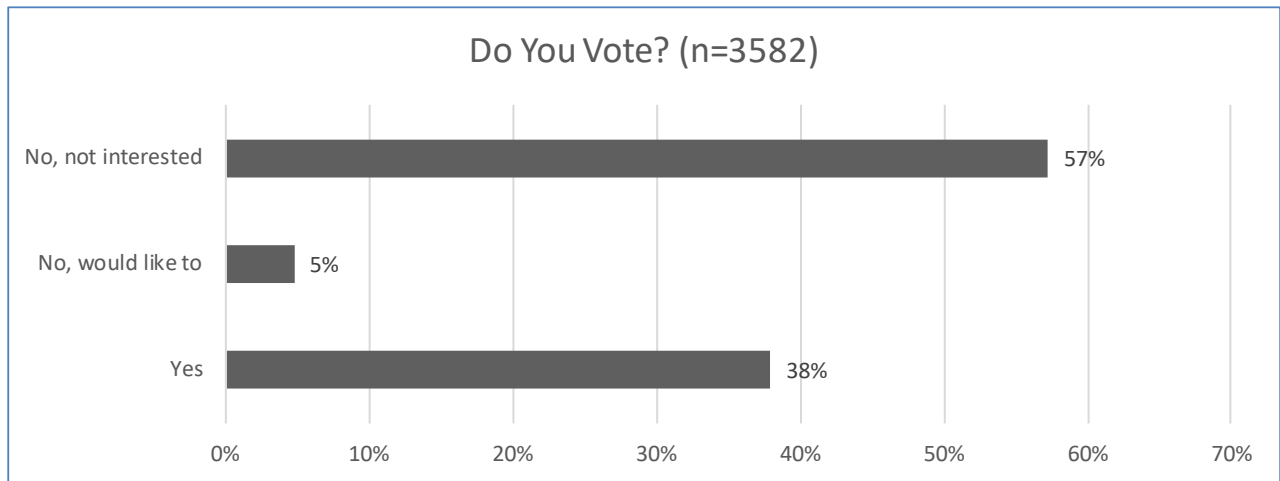
C4. Choice and Control in Choosing Staff



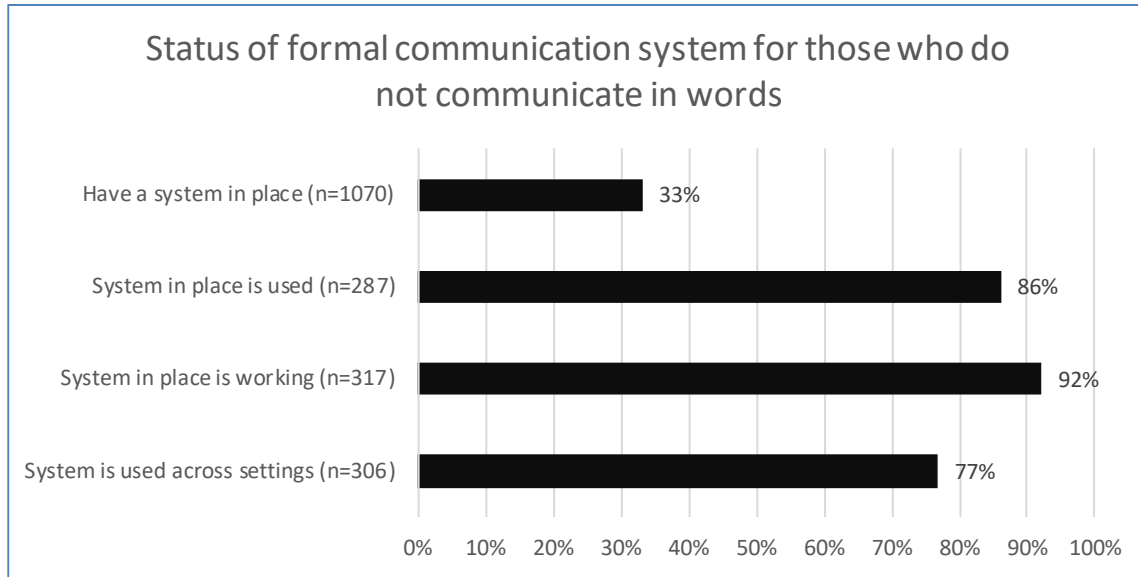
C5. Choice and Control Regarding Money

Always choose alone what to buy with spending money	58%
Choose what to buy with help	36%
There is something they want to buy	52%
They have a bank account and withdrawal money when they want	72%

C6. Voting



C7. Status of Formal Communication System



C8. Who Supports the Communication System?

Staff or Program Coordinator	57%	Parent or Caregiver	40%
Speech Language Clinician	28%	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	42%	8%
E-mail	26%	5%
Internet	61%	8%
Text-messaging	30%	5%
Cable TV	92%	6%
Computer	61%	9%

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

Part III, Section B: Health Questions

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

Summary: 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. Reports of telehealth use dropped 4% this year, which may be the result of coming out of the pandemic and returning to in-person healthcare visits. 4 out of 5 of the individuals surveyed felt that their doctor understood them, but only slightly more than half say they understood their doctor's instructions. About half say that they can provide consent for their medical treatment, and it is accepted. Most say their doctor speaks directly to them during their appointments.

Progress Points Compared to 2021 - 2022 Report:



Improvements

- There was a 3% increase in respondents who reported that their doctor understands them (78% to 81%).
- There was a 4% increase in respondents who reported that they can give consent for medical treatment (60% to 64%).



Opportunities for Improvement

- There was a 5% increase in people who reported that they exercise at home less than once a month (43% to 48%).
- There was a 4% decrease in respondents who reported that when they give consent for medical treatment, it is accepted (85% to 81%).

This link will skip data details and take you to the summary of the next Section [Employment.](#)

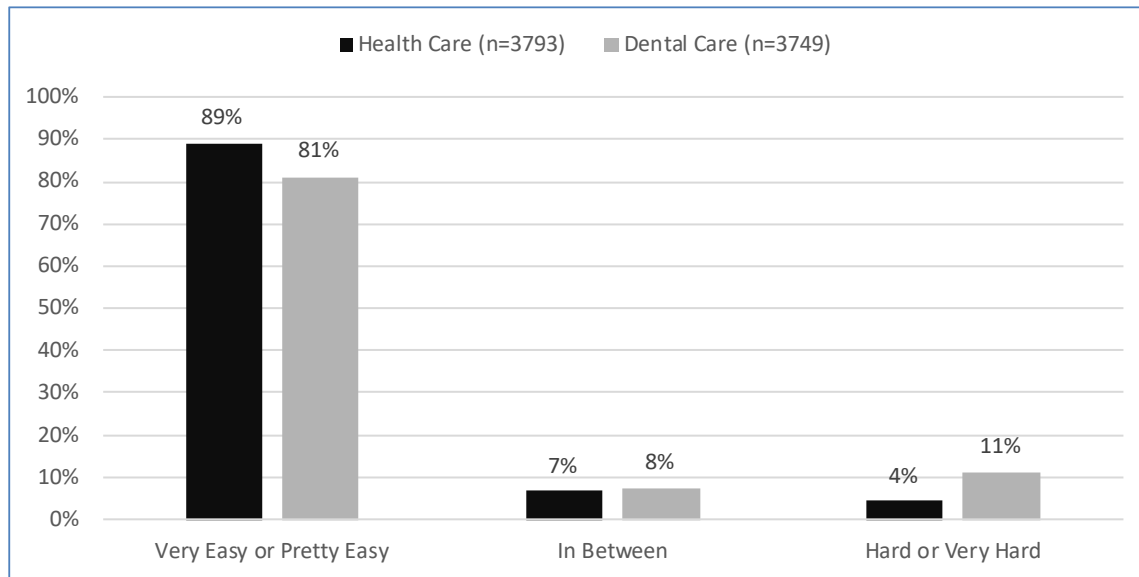
C10. Exercise at Home

	10+ Times	<1 Time
How many times they exercise at home per month	37%	48%

C11. Medical & Dental Care

Describes health as very good or excellent	50%
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	52%
Like talking with health care provider using telehealth	53%
Have not been prevented from receiving medical or dental care due to disability	88%

C11.1. How Hard is it to Access Care?



C12. Mental Health

Have an opportunity to discuss health concerns with psychiatrist	64%
Do not have psychiatrist, but want one	3%

C13. Communicating Health Needs

Their doctor understands them	81%
They understand their doctor's instructions	61%
If they need help communicating at doctor's office, it is available	95%
Doctor speaks directly to them during appointments	94%
Able to provide consent for medical treatment	64%
If they provide consent, is it accepted	81%

Part III, Section C: Employment and Community Participation Services

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

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

Summary: Nearly 1 in 6 individuals report that they work in CIE. The most common occupations reported are in cleaning services, food service, and retail. Most people who reported their wages earned \$12.01 or more per hour, and 77% of the sample make at least \$9.01 per hour. The most common benefit reported by workers was receiving paid time off, followed by retirement benefits and health insurance. 1% are self-employed. About a third have been employed for 1 to 3 years, while 1 in 5 has been employed for 11 or more years. Of those who are not employed, about half say that someone talked about employment in their planning meeting and about a third say employment is a goal in their plan. About 1 out of 4 respondents use CPS. The most common services used are developing interests (73%) and developing social networks (56%).

Progress Points Compared to 2021-2022 Report:



Improvements

- There was a 3% increase in respondents who reported that they used CPS Services for the second consecutive year (24% to 27%).
- There was an 11% increase in respondents reporting an hourly wage of \$12.01 or greater (35% to 46%) and a 2% increase in respondents reporting they had been promoted or received an increase in pay.
- Regarding benefits, there was a 3% increase in those who reported that they received other work benefits from their employment (12% to 15%).



Opportunities for Improvement

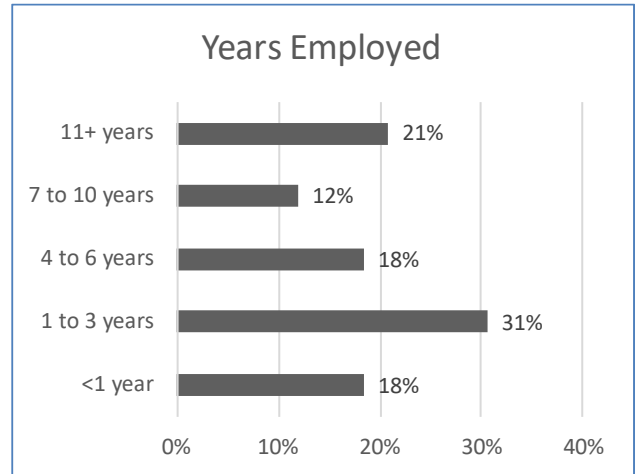
- There was a 5% decrease of people who are not employed who say employment is a goal in their plan (37% to 32%).
- Regarding benefits, there was a 6% decrease in people who received healthcare (26% to 20%), and an 8% decrease in people who received retirement benefits (31% to 23%).

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	26%	Assembly/Factory Work	7%
Food Services	23%	Care Workers/Aides	2%
Retail Services	19%	Recycling	0%
Office Work	2%	Outdoor Work	1%
Stock Room	6%	Animal Care	0%
Maintenance	2%	Other	12%

C17. Supports Getting into the Workplace

Take classes/training for employment purposes	8%
Talked about employment in their planning meeting	50%
Community employment is a goal in their plan	32%

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

No one	51%	SC	42%
Service Provider	8%	Family	10%
Housemates	0%	Someone Else	6%

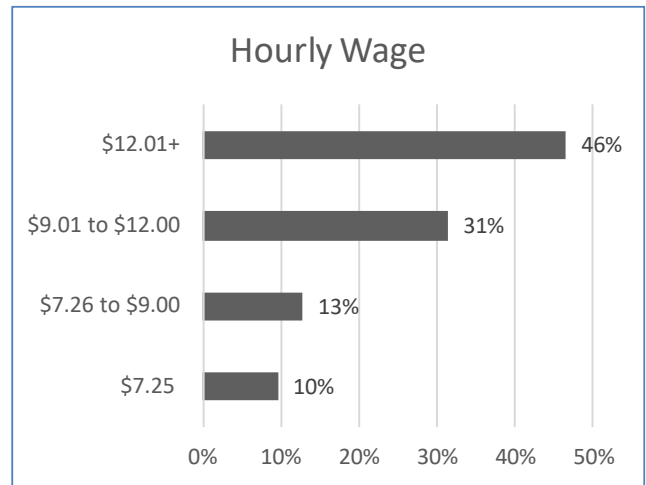
Note: Individuals had the option to indicate more than one response for C17.1.

C18. Self-Employment

Person reports that they are self-employed	1%	n=50
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C19. Compensation and Advancement

Have been promoted or received an increase in pay	54%
Receive paid time off from work as a benefit of employment	80%
Receive health insurance benefits from employer	20%
Receive retirement benefits from their employer	23%
Receive other work benefits from their employment	15%
Know how much they earn and willing to share	75%



C20. Community Participation

Use Community Participation Services (CPS)	27%
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C20.1. If yes, CPS Services Used

Developing skills and competencies necessary for employment	11%
Fine/gross motor skill development and mobility	18%
Participating in community activities to develop social networks	56%
Participating in opportunities to develop interests or promote health/wellness	73%
Training/education for self-determination and self-advocacy	11%
Community adult learning opportunities	12%
Volunteering opportunities	27%
Learning to navigate the local community	9%

C21. Technology use

Internet at home always works	84%
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	57%
<i>Likes talking to SC using videoconference</i>	59%
Has used videoconference for other services	33%
<i>Likes using videoconference for other services</i>	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: About 1 out of every 15 respondents report using self-directed services. Of these, about half made budget decisions alone or with family and friends. 7 in 10 respondents reported that they receive information about how much money is left in their budget, a drop from last year. About 9 out of 10 say they can make changes to their budget and services when they need to and that they have enough help to make decisions about their budget and services.

Progress Points Compared to 2021-2022 Report:



Improvements

- There was a 10% increase in individuals who say the information they receive about their budget is easy to understand (72% to 82%).



Opportunities for Improvement

- There was a 6% increase in people who report that a case manager or state professional makes decisions about their budget (2% to 8%).
- There was a 4% decrease in people who report that they can make changes to their budget when they need to (96% to 92%).
- There was a 10% decrease in individuals who say they receive information about how much money is left in their budget (78% to 68%).

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%
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C22. Who Makes Choices About Budget?

Individual makes decisions on their own	15%
Individual has input, family and friends help	37%
A family member or friend makes decisions	39%
A case manager or state professional makes the decision	8%

C23. Making Decisions

Can make changes to their budget or services if they need to	92%
Have enough help deciding how to use their budget/services	91%
Want more help deciding how to use their budget/services	5%

C24. Money Left in Budget

Receive information about the money left in their budget	68%
Information they receive is easy to understand	82%
They receive information at least every 3 months	65%
They receive information about twice a year	18%
They receive information once a year or less	18%

Part IV: Relationships

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

Respondents:

Individual	31%	Individual and Paid staff	12%
Paid staff	24%	Individual and Family/friend/guardian/advocate	12%
Family/friend/guardian/advocate	20%	Staff and Family/friend/guardian/advocate	0%

Summary: More than three-quarters of this sample reported they were able to see family and friends whenever they wanted. Less than 1 in 10 reported that they were never able to see family and friends.

Progress Points Compared to 2021-2022 Report:



Improvements

- There was a 5% increase in people who said they could see their friends whenever they wanted to (76% to 81%).
- There was a 5% increase in people who said they could get in touch with their family members whenever they wanted to (79% to 84%).



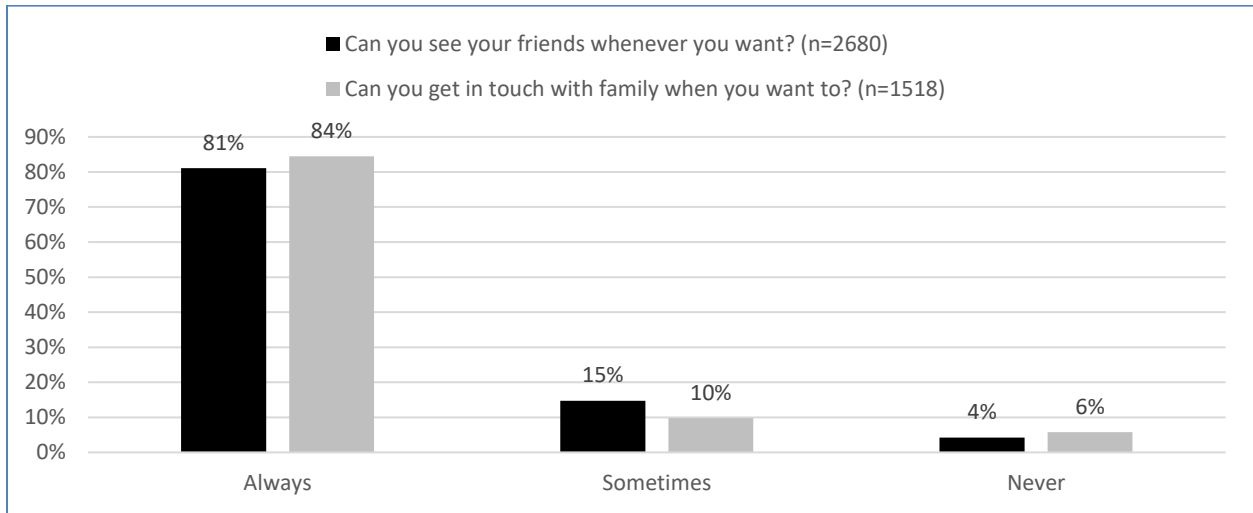
Opportunities for Improvement

- 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



Part V: Inclusion

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

Respondents:

Individual	25%	Individual and Paid staff	15%
Paid staff	25%	Individual and Family/friend/guardian/advocate	15%
Family/friend/guardian/advocate	20%	Staff and Family/friend/guardian/advocate	1%

Summary: Though people still report limited time going out in their communities, inclusion scores have continued to increase over the last year. Less than half of the sample participated in any community activity on at least a weekly basis, but people were more likely to report that they engaged in community activities “enough” for their preferences. When they do go out, people most frequently go to shopping malls, supermarkets, go out to restaurants to eat, and go visit friends and neighbors. When people engage in community activities, they most often go with family or staff.

Progress Points Compared to 2021-2021 Report:



Improvements

- There were increases in people who reported that they went out into the community weekly to the supermarket (+3%, 46% to 49%), visit friends (+6%, 40% to 46%), to restaurants (+5%, 40% to 45%), to go shopping (+5%, 35% to 40%) and for entertainment (+4%; 21% to 25%).
- People who reported they went out enough continued to increase again this year after previous gains last year for several activities across the sample, including:
 - Visiting friends and neighbors (+8%; 69% to 77%), following an 8% increase;
 - Going to a supermarket (+6%; 79% to 85%), following a 7% increase;
 - Going out to restaurants (+8%; 69% to 77%), following a 13% increase
 - Going shopping (+8%; 73% to 81%), following a 9% increase; and
 - For entertainment (+10%, 68% to 78%).



Opportunities for Improvement

- There was an 10% increase in the percentage of people who reported that if they could not get where they needed to go it was because of a lack of staff (24% to 34%).

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	46%	77%	21%	1%
Go to a supermarket	49%	85%	13%	3%
Go out to eat/restaurants	45%	77%	21%	1%
Go to a shopping center or mall	40%	81%	17%	2%
Go out to a worship service	23%	87%	13%	1%
Run errands and appointments	27%	89%	7%	4%
Meeting people at coffee house/tavern	18%	86%	13%	1%
Go out for entertainment	25%	78%	21%	1%

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

Activity	Staff	Family	Friends	Roommates Coworkers	Go Alone	Other
Visit friends, relatives, neighbors	34%	46%	7%	1%	12%	0%
Go to a supermarket	48%	43%	1%	1%	6%	0%
Go out to eat/restaurants	49%	41%	4%	2%	3%	0%
Go to a shopping center or mall	55%	37%	2%	1%	5%	0%
Go out to a worship service	34%	56%	4%	1%	6%	0%
Run errands and appointments	52%	40%	1%	1%	6%	0%
Meeting people at coffee house/tavern	54%	33%	4%	1%	6%	1%
Go out for entertainment	52%	38%	5%	2%	3%	0%

E2. Extra-Curricular Activities

Would like to be a part of more groups in the community	36%
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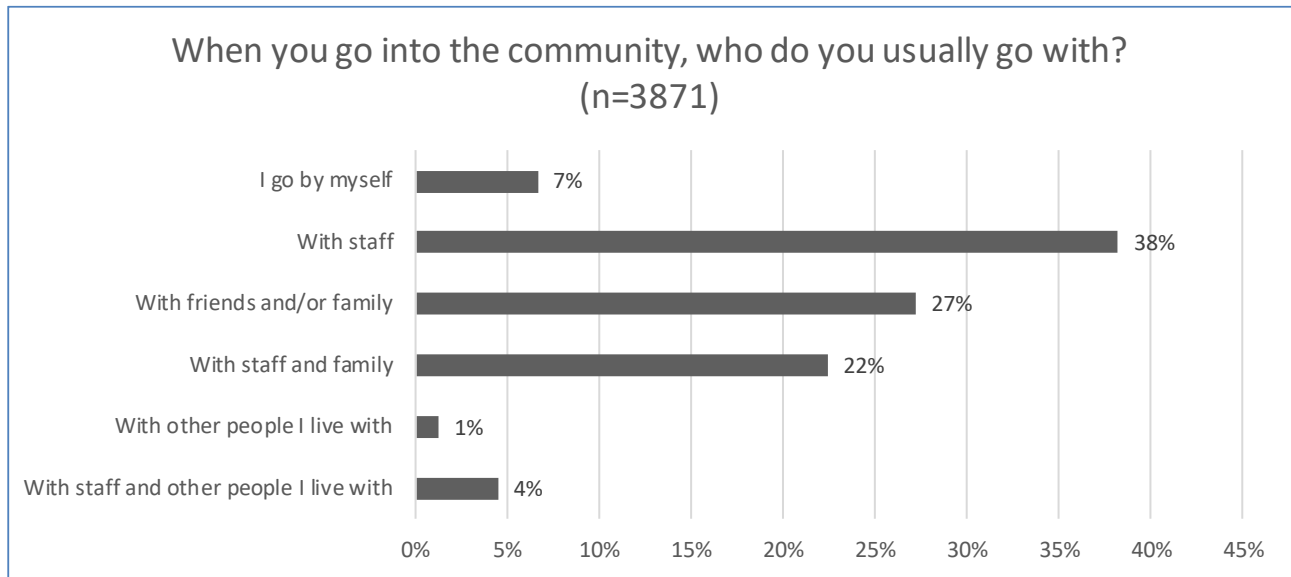
E2.1. How Often Do You Go into the Community?

	Frequently	Occasionally
Go out into the community for entertainment	45%	38%
Go to social events attended by people with and without disabilities	29%	46%

E2.2. Exercise in the Community

	Never	Less than Weekly	Weekly	More than Weekly
How often the person exercises	40%	3%	8%	49%

E3. Going Out Alone or with Other People



E4. Transportation

Always have a way to get where they wanted to go	92%
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E4.1. Transportation Methods Used Most Frequently

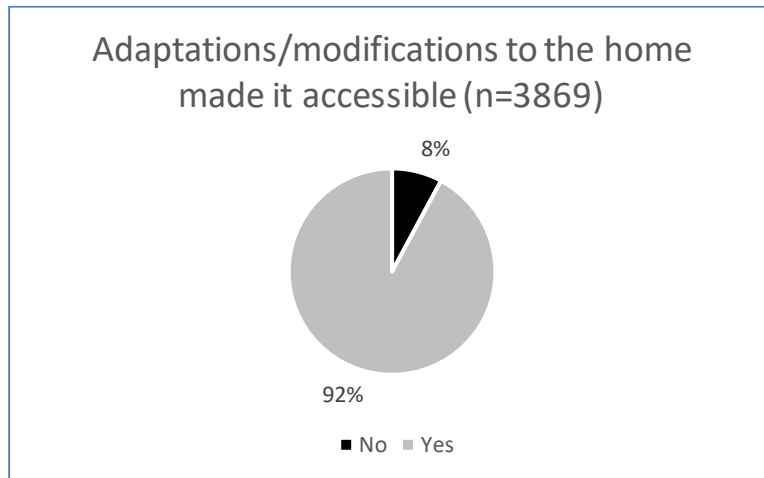
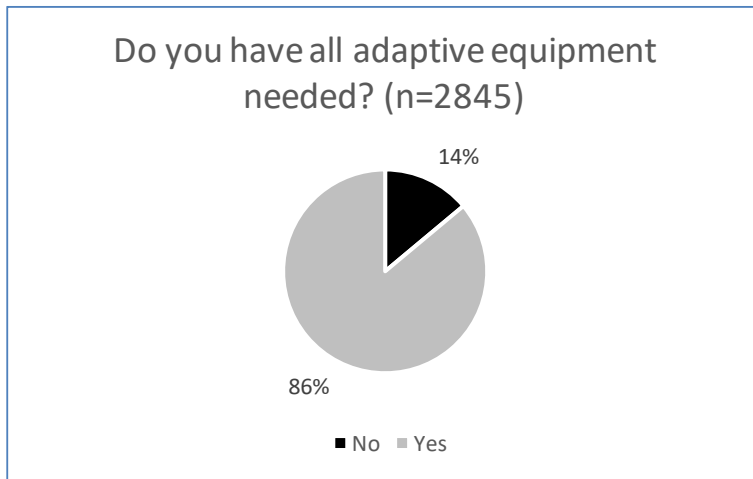
Get a ride from family or friends	37%
Get a ride from staff in provider van	39%
Get a ride in staff member's car	12%
Transport themselves	5%
Ride public transportation	4%
Ride paratransit	1%
Take a taxi, Uber or Lyft	1%

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

Not enough staff	34%
Paratransit is unreliable	9%
Transportation for work/school only	3%
No one at home can drive	1%
Some other reason	53%

- It is probable that the current staffing crisis affected these numbers.

E5. Home Adaptive Equipment



Section VI. Monitor Impressions of Competence, Personal Growth and Opportunities

The questions in this section are answered by IM4Q Monitors after they have spent time with the individual in his/her home or other place of his/her choosing. The first several questions address issues of competence, personal growth, and opportunities to grow and learn. The next series of questions ask about support for the person. It is likely the case that because all interviews were conducted remotely this year, many monitors did not have enough information to respond to these questions.

Summary:

- Monitors were very favorable in their reports of respondents' home environments this year. Almost a third of monitors rated homes as 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, with the majority reporting that staff were respectful and supported individuals in ways that promote independence. There may be selection bias in these numbers, as people chose whether to have their interviews remotely (75%) or in person (25%).

Progress Points Compared to 2021-2022 Report:



Improvements

- The monitors' average ratings of individuals' homes increased substantially, indicating highly favorable reports from monitors who conducted interviews in-person in individuals' homes.
- Monitors who reported that all staff appear to recognize individuals in ways that promote independence increased by 4% (85% to 89%).
- Monitors who reported that staff treat individuals with dignity and respect, and appear to have all the skills necessary to do their work, increased by 5%, respectively (85% to 90%). This increase is a promising shift following a 7% decrease over the previous 2 years.



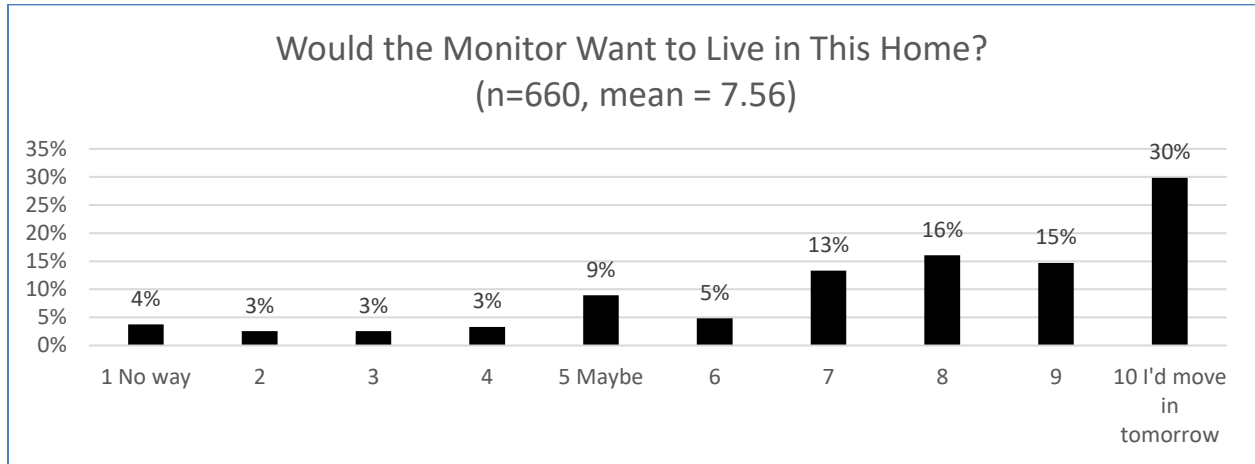
Opportunities for Improvement

- 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	7.56
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	90%
Staff recognize the individual in ways that promote independence	89%
Staff who support individuals have the skills they needed	90%

Section 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 1532 family members, friends, and guardians.

Respondents:

Parent(s)	77%	Another Relative	4%
Sibling(s)	13%	Friend	0%
Guardian	2%	Other	3%

Summary: Family members report high levels of satisfaction overall, though there appear to be some gaps in knowledge and services, as revealed by the data. People are satisfied with where their relative lives, what they do during the day, and their relative's staff. 3 out of 5 are satisfied that the relatives services change when their needs change. Less than half reported that if their relative did not communicate using 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 3 are familiar with the PA Family Network. 2 in 5 felt they had enough opportunities to connect with other families at similar life stages.

Progress Points Compared to 2021-2022 Report:



Improvements

- There was a 5% increase in family members who reported that they see their relative at least monthly (74% to 79%).
- There was a 2% increase in family members who reported that their family member had enough opportunity to participate in activities in the community (76% to 78%).



Opportunities for Improvement

- There was a 7% decrease in those who reported that there was a communication system in place for their relative and that it was being used (47% to 40%) and a 5% decrease in those who reported that if there was a system, it was used across settings (77% to 72%).
- There was a 5% decrease in family members who reported that their relatives' services change when their needs change (86% to 81%).
- People who felt their relative received all the supports they needed decreased by 6% (67% to 61%), following a 9% decrease last year, for a 15% decrease in the last 2 years.
- Regarding family resources, there was a 7% decrease in family members who reported that they have enough information about services for which the family is eligible (83% to 76%), a 5% decrease in family members who reported that if their family member transitioned from school to adult services, they were happy with the process (28% to 23%), and a 6% decrease in family members who reported that the SC asks about their vision for an everyday life for their family member (78% to 72%).

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	84%
Somewhat satisfied or very satisfied with relative's staff at home	94%
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	92%
Never contacted their relative	2%
See their relative at least monthly	79%
Never visited their relative	3%

H3. Your Relative's Satisfaction

Relative is satisfied or very satisfied with his/her living situation	93%
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	96%
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	96%
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	86%
Relative feels safe in their community, home, and neighborhood most of the time	11%

H5. Your Relative's Opportunities

Relative has enough opportunities to participate in activities in the community	78%
Relative has the opportunity to learn new things	86%

H6. Your Relative's Staff

Relative's home appears to have an adequate number of paid staff	80%
Staff in relative's home always treat people with dignity and respect	96%
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	95%
Staff at relative's place of work always treat people with dignity and respect	99%
All staff in their relative's workplace have the skills needed to support their relative	94%
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	89%

H7. Relative's Communication System

If their relative does not communicate verbally, there is a formal system in place, and they use it	40%
If there is a communication system in place, it is used across settings	72%

H8. Relative's Supports

Satisfied with the support coordination their relative receives	80%
Told how much money is in their relative's budget	61%
Their relative directs their own services	13%
Their relative always receives the supports they needed	61%
The supports and services their relative receive change when their needs change	81%
There are never or rarely changes in support staff at their family member's home, work, or day program	58%
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	42%
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	31%

H9. Complaints and Grievances

Relative was familiar with the complaint and grievance process on some level	65%
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H9.1. At what level?

At the provider level	61%
At the county/AE level	61%
At the state level	56%

H10. Family Resources

The information they receive about their relative's services is easy to understand	87%
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	43%
They are aware of the PA Family Network (PAFN)	29%
Of those who were aware of the PAFN, who had attended a workshop led by the Network of Family Advisors	31%
Have enough information about services for which the family is eligible	76%
If family member transitioned from school to adult services, were happy with the process	23%
SC asks about their vision for an everyday life for their family member	72%

H11. Emergency Preparation Questions

Given information about an emergency plan for their family member in case of emergency	55%
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Section VIII. Considerations

There were 6,460 total considerations in the 2022-2023 collection year. The greatest number of Considerations came from Allegheny (28.51%), Philadelphia (17.43%), and Berks (6.73%) counties.

The topic of each consideration was analyzed, resulting in 15 categories, or primary themes. The primary themes of greatest significance were Service System (20.29%); Personal Rights, Competence, Enhancement, and Growth (16.78%); and Community Presence and Participation (15.28). For each primary theme, the percentage of the total considerations and the percentage of resolved considerations are provided. Within each primary theme, considerations were analyzed to determine whether significant secondary themes were evident. When identified, secondary themes are listed in the tables below the primary themes in order of significance.

Primary Theme: Service System: 20.29% of total (66.13% resolved)

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

Primary Theme: Personal Rights, Competence Enhancement and Growth: 16.78% of total (68.08% resolved)

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

Primary Theme: Community Presence and Participation: 15.28% of total (72.95% resolved)

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

Primary Theme: Work/Employment/Meaningful and Purposeful Activity: 11.36% of total (66.76% resolved)

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

Primary Theme: Health and Well Being: 9.54% of total (65.58% resolved)

Secondary theme 1	Medical, behavioral, health concern
Secondary theme 2	Difficulty accessing medical professional/specialist

Primary Theme: Relationships/Friendships: 5.36% of total (75.43% resolved)

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

Primary Theme: Residential/Living Situation Personal Change: 4.09% of total (64.39% resolved)

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

Primary Theme: Communication Needs/Devices/Services: 3.48% of total (70.67% resolved)

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

Primary Theme: Adaptive Equipment: 3.14% of total (57.64% resolved)

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

Primary Theme: Residential Build Adaptation/Modifications: 2.60% of total (62.5% resolved)

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

Primary Theme: Transportation: 1.92% of total (60.48% resolved)

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

Primary Theme: Safety: 1.61% of total (73.08% resolved)

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

Primary Theme: Spiritual Life: 1.24% of total (75% resolved)

Secondary theme 1	Individual needs increased opportunities
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Primary Theme: Major Concerns: 0.28% of total (83.33% 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	Significant sanitation problems
Secondary theme 4	Evidence of a human rights violation

No Primary Theme: Miscellaneous or Loop Not Closed: 3.03% of total (78.57% resolved)

This link will take you to back to the beginning of the [Statewide Report](#).