

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

Independent Monitoring for Quality (IM4Q)
Statewide Report
2021-2022

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 2021-2022 fiscal year. Data collection was different from prior years as all surveys were conducted remotely due to the ongoing Covid-19 Pandemic. Questions may be addressed to IM4Q@temple.edu.

Guide to the Statewide Report

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

Unless otherwise noted, tables throughout the document provide a statement and the percentage of individuals who reported that the statement applied to them. For instance, the following table would be read as “95% of respondents reported that they were happy with their life.”

Happy with life	95%
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The data points in the report correspond to questions on the Essential Data Elements (EDE) survey. Most questions are consistently included from year to year so that changes in the experiences of people with disabilities can be examined over time. However, occasionally questions are added, edited, or removed to address changing circumstances. If a data point from a previous report is not provided in the current report, it is likely the case that this question has been removed from the survey. New questions are marked by a “+” to indicate their new question status.

Why We Do This

The purpose of IM4Q is to understand how people feel about their lives and the services they receive. This allows decision makers at the state and county level and service providers to engage in quality improvement. 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 AE or the Bureau of Supports for Autism and Special Populations (BSASP), who either approves or disapproves the response. If the consideration is not addressed, the consideration process continues until the AE or BSASP and IM4Q program are satisfied with the

action to address the consideration. When the consideration is addressed, we call this “Closing the Loop.”

Considerations may result in service changes or provide an opportunity to improve the quality of life of the individual who has been interviewed. For the 2021-2022 collection year, over 5,000 considerations were collected. Of these, nearly 80% have been closed.

Some qualitative data from the current considerations are found in the [Considerations](#) section at the end of this report. Specific details about closed considerations are not yet available, but the following closed consideration, an excerpt from the 2020-2021 Considerations Storybook published by ODP, gives an example of how IM4Q positively impacts the lives of people with disabilities who are receiving ODP supports. Closed considerations are a result of the work, ingenuity, creativity, tenacity, and passion of SCs, providers, and others to make a positive difference in the daily lives of people with developmental disabilities in Pennsylvania. (NOTE: Name has been changed to protect the confidentiality of respondent.)

Story: Brittany’s Considerations

We interviewed Brittany, who lived on her own. She also had a boyfriend, Malcolm, and asked him to sit in on her survey. Brittany stated she wanted to be able to move into a community home with her boyfriend and he agreed that was also what he wanted. They both needed a little more assistance with managing their health, and they wanted to be able to live together.

One community home happened to be their provider of choice and had a bedroom licensed for two people. The couple was approved for Consolidated funding, and they were both able to move into the community home together and share a bedroom.

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

Early in 2020, a new virus was identified from an outbreak in Wuhan, China. Despite the efforts of international health officials, the virus spread quickly. SARS-COV-2, or Covid-19 as it came to be known, caused outbreaks across the world, leading to global shut-downs in an effort to slow the spread. By mid-March 2020, much of the United States, including Pennsylvania, was under quarantine and social distancing orders. These mandates affected many aspects of life, including how individuals work, engage with the community, and interact with others.

The pandemic halted IM4Q data collection for the 2019-2020 fiscal year several months early. Prior to the 2020-2021 collection year, IM4Q leaders came together to develop plans to continue to conduct surveys. This effort led to a remote interviewing initiative which has been underway for the last several collection years. For the 2021-2022 fiscal year, all interviews were conducted remotely. Interviews with people with disabilities used video conferencing. Family, friend, and guardian interviews were conducted with phone calls or mailed surveys. These methods, as well as some social regulations still in place, some persistent hesitation about large group gatherings due to the pandemic, and a notable staffing shortage are likely to affect the data. Throughout the report, notes have been added to point out trends in the data that may have been influenced by social trends related to these issues.

Scale Scores

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

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

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

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

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

	Statewide
Mean	84.87
SD	19.05

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

	Statewide
Mean	83.10
SD	16.30

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

	Statewide
Mean	93.09
SD	15.74

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

	Statewide
Mean	60.78
SD	21.12

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

	Statewide
Mean	40.30
SD	19.69

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

	Statewide
Mean	6.74
SD	2.18

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

	Statewide
Mean	90.97
SD	13.23

Executive Summary

This report presents information collected through remote interviews with close to 4,000 individuals and about 1,400 family members of individuals receiving supports in Pennsylvania. This was the second year the survey was conducted entirely in a remote format. This change, as well as the ongoing Covid-19 Pandemic, should be considered in the review of the data.

In this year's **sample**, most individuals reside in the home of a relative or a community home. Roughly 80% are white, most are non-Hispanic/Latinx and about 60% are male.

Satisfaction rates are high among individuals receiving services and their family members. Following a consistent trend, about 90% of 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 individuals who receive supports and services tend to appreciate getting services and therefore feel highly satisfied. Interestingly, about 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. Most say their supports coordinator listens to them, their staff treats them with respect, and people are respectful of their culture. People report good access to **Health Care** and satisfaction with **Support Coordination**.

The average scores for perceptions of **Choice and Control** and **Inclusion** are lower than for the previous categories. About half of individuals made choices about where to live and work, while less than half have a key to their home or choose their housemates. About 2 out of 5 respondents vote in political elections. Promisingly, 90% say they chose their daily schedule without assistance and most report they have enough choice about their free time.

Regarding community inclusion, less than half of people surveyed go out in the community frequently for shopping, eating, or entertainment. However, compared to last year, more people say they are satisfied with how much they go out in the community.

IM4Q Monitor Impressions reflect positive outcomes for individuals in that observed staff largely treat people with respect and support them in ways that promote independence. **Family, Friend and Guardian** perceptions of their relatives' supports and services are overwhelmingly positive. People employed in **Community Integrated Employment** and using **Self-Directed Services** remain in the minority (16% and 6% respectively), though this could be impacted by the Covid-19 Pandemic. About two-thirds of individuals used video conferencing to talk to their SC and about half used telehealth to communicate with a doctor or healthcare professional. Of these, about half of the people surveyed say they like using video conferencing or telehealth.

Although communication remains an issue for many individuals, there are some promising trends. People who communicate other than verbally are slightly more likely to have a system in place. Even with this increase, only about 2 in 5 have a communication system in place. Though family members report high satisfaction, 30% are unaware of the complaint and grievance procedure at any level, and only a third are aware of the PA Family Network. The most common **Considerations** dealt with service needs, personal rights, and community participation.

Sample

i. Sample Data

i1. Total Surveyed

People with disabilities	3817	Family members	1377
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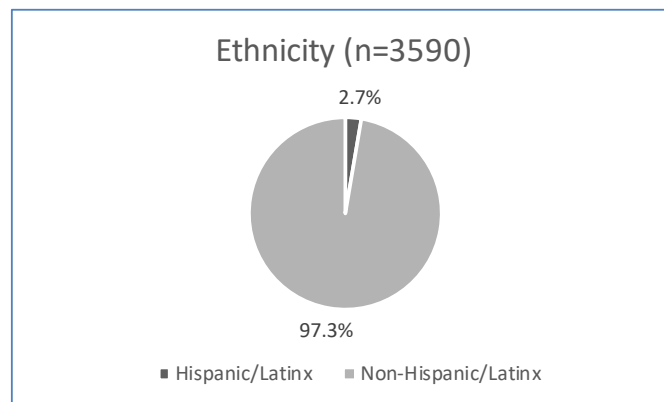
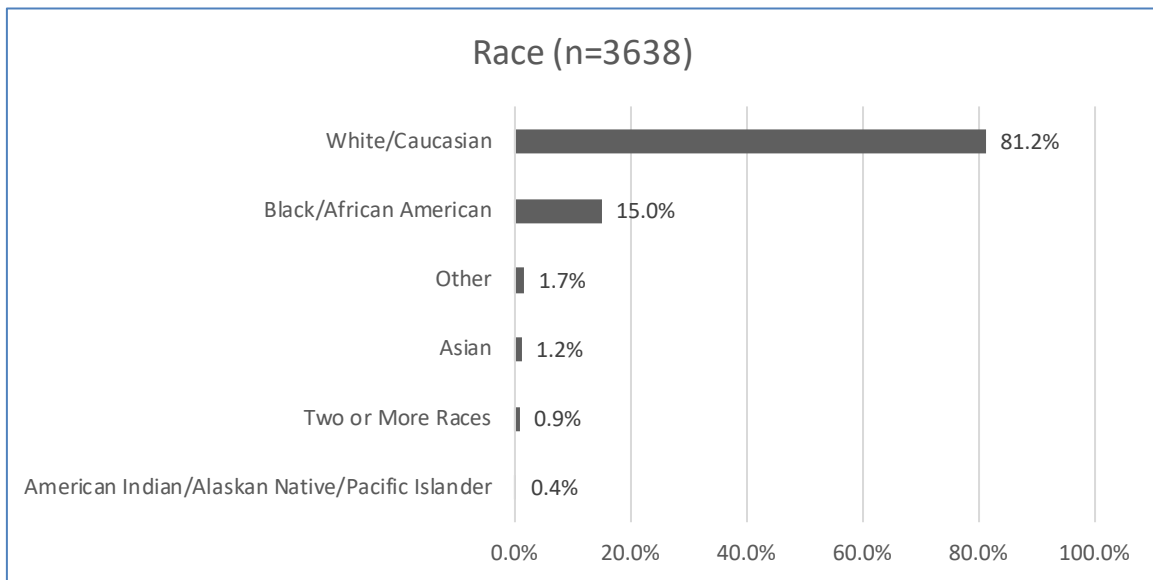
i2. Age

Range	5-95	Mean Age (SD)	41.3 (18.1)
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i3. Reported Gender

Female	41.4%	Male	58.6%	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	1604	42.0%
Community Home- Subtotal	1472	38.6%
<i>Community Home 1</i>	135	3.5%
<i>Community Home 2-4</i>	1272	33.3%
<i>Community Home 5-6</i>	40	1.0%
<i>Community Home 7-8</i>	21	0.6%
<i>Community Home 9-15</i>	2	0.1%
<i>Community Home 16+</i>	2	0.1%
Own Residence	254	6.7%
Family Living/Lifesharing	127	3.3%
Private ICF/ID- Subtotal	133	3.5%
<i>Private ICF/ID 4 or fewer</i>	29	0.8%
<i>Private ICF/ID 5-8</i>	48	1.3%
<i>Private ICF/ID 9-15</i>	13	0.3%
<i>Private ICF/ID 16+</i>	43	1.1%
Personal Care Home	42	1.1%
Nursing Home/Facility	40	1.0%
Children's Facility	8	0.2%
Unlicensed Family Living	10	0.3%
Domiciliary Care	8	0.2%
Foster Care	2	0.1%
Approved Private School	0	0.0%
State Operated ICF/MR	11	0.3%
State MH Hospital	0	0.0%
Temporary Shelter	0	0.0%
Other	21	0.6%
<i>Missing</i>	85	-
Total	3817	100%

i6. Administrative Entity (AE) Where the Respondent Lives

AE	Number of Respondents	Percent of Sample
Allegheny	442	11.6%
Armstrong/Indiana	53	1.4%
Beaver	69	1.8%
Bedford/Somerset	35	0.9%
Berks	118	3.1%
Blair	47	1.2%
Bradford/Sullivan	23	0.6%
Bucks	159	4.2%
Butler	59	1.5%
Cambria	48	1.3%
Cameron/Elk	19	0.5%
Carbon/Monroe/Pike	66	1.7%
Centre	48	1.3%
Chester	109	2.9%
Clarion	21	0.6%
Clearfield/Jefferson	37	1.0%
Columbia/Montour/Snyder/Union	39	1.0%
Crawford	58	1.5%
Cumberland/Perry	13*	0.3%
Dauphin	28*	0.7%
Delaware	179	4.7%
Erie	166	4.3%
Fayette	38	1.0%
Forest/Warren	19	0.5%
Franklin/Fulton	51	1.3%
Greene	18	0.5%
Huntington/Mifflin/Juniata	37	1.0%
Lackawanna/Susquehanna	88	2.3%
Lancaster	104	2.7%
Lawrence	34	0.9%
Lebanon	31	0.8%
Lehigh	107	2.8%
Luzerne/Wyoming	105	2.8%
Lycoming/Clinton	58	1.5%
McKean	9	0.2%
Mercer	37	1.0%
Montgomery	217	5.7%
Northampton	70	1.8%
Northumberland	43	1.1%
Philadelphia	552	14.5%
Potter	4	0.1%
Schuylkill	0*	0.0%
Tioga	32	0.8%
Venango	36	0.9%
Washington	48	1.3%
Wayne	27	0.7%
Westmoreland	97	2.5%
York/Adams	119	3.1%
TOTAL	3817*	100%

**The number of respondents is lower than in past reporting years*

Part I: Satisfaction

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

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

Progress Points Compared to 2020-2021 Report:



Improvements

- There was a 3% increase in people who said they have a best friend (68% to 71%).
- There was a 15% increase in those who said there are no rules about spending time with friends or visitors (60% to 75%).
- There was a 7% increase in individuals who reported they want to stay at their current job or day activity (66% to 73%).
- There was a 6% decrease in people who reported that they did not get along with their bedroom mate (14% to 8%).



Opportunities for Improvement

- There was a 3% decrease in people who said they always get the services they need (88% to 85%).
- There was a 4% increase in individuals who said that they do not have or want a job for pay (52% to 56%).

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

A. Satisfaction Data

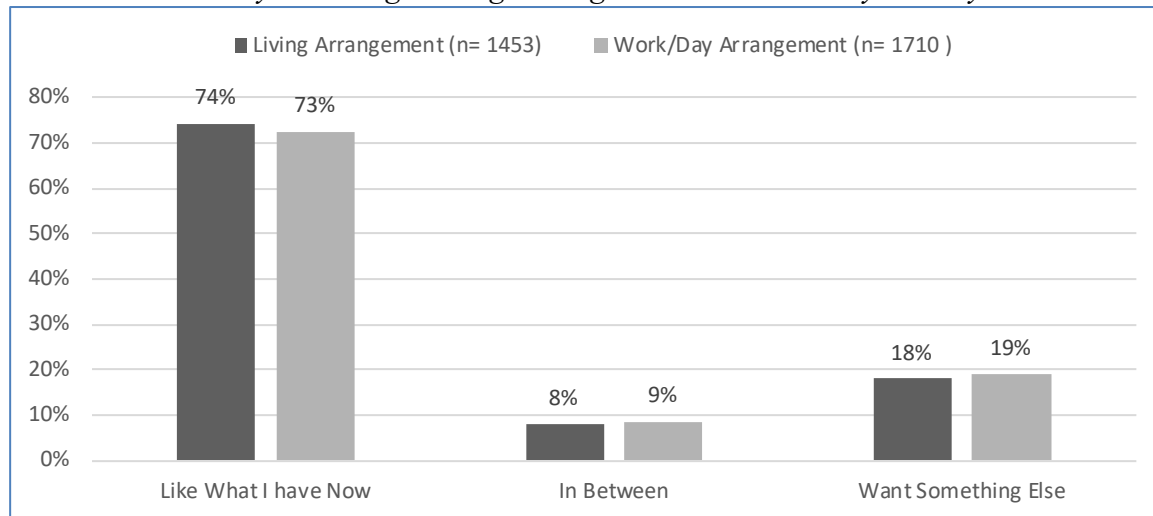
A1. Living Arrangements

Like where they live now	89%
Want to stay where they currently live	74%
Want to move somewhere else	18%

A2. Work/Day Activity

Like primary job or day activity	91%
Like other job or day activity	94%
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 and Work/Day Activity



A3. Daily Activities

What do people do on most days?	Primary activity	Secondary activity
Stay home	27%	40%
Work	23%	4%
<i>Work- no supports</i>	14%	2%
<i>Work- with supports</i>	9%	2%
Attend school	8%	1%
Attend a vocational facility	9%	2%
Attend a day program or community center	9%	2%
Go out in the community	12%	25%
Retired	2%	2%
Volunteer	2%	6%
Something else	6%	19%

A3.1. Want to Work

Do not have or want a job	56%
Would like a job for pay	40%
Uses special technology to help do work ⁺	13%

A4. Services

Always get services they need	85%
Sometimes get services they need	3%
Do not get services they need	5%
Need additional services	7%

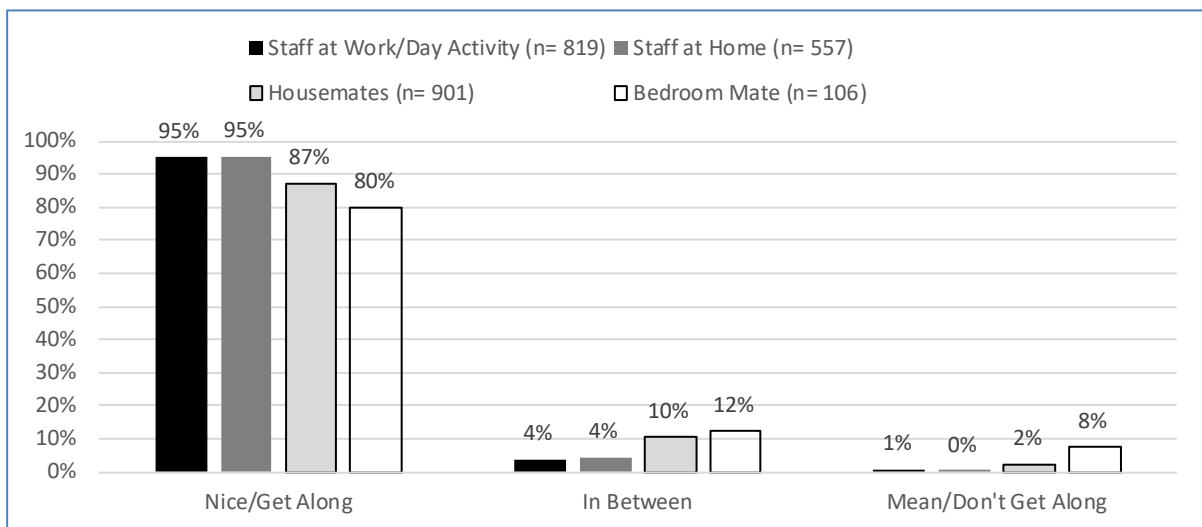
A5. Happiness and Loneliness

Happy with life	86%
Neither happy nor sad with life	12%
Sad with life	2%
Never lonely	63%
Sometimes lonely	32%
Always lonely	5%
Have friends to do things with	84%
Friends are not staff or family	72%
Have a best friend	71%
Can date/marry, no restrictions	85%
Can date/marry, restrictions	4%
Cannot date/marry at all	12%

A6. Privacy

Have enough privacy (a place to be alone) at home	97%
No rules about friends or visitors	75%
People always let them know when coming into their home	91%
Sometimes people let them know when coming into their home	3%
People never let them know when coming into their home	6%
People always let them know when coming into their bedroom	88%
People sometimes let them know when coming into their bedroom	4%
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: People in our sample report fairly high scores on Dignity, Respect and Rights. More than 4 in 5 report their mail is never opened without permission 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 2020-2021 Report:



Improvements

- There was a 7% increase in individuals who reported that someone had talked to them about self-advocacy (46% to 53%)
- There was a 13% increase in people who said they get help to learn new things (69% to 82%).



Opportunities for Improvement

- There was a 3% decrease in those who reported that they are never afraid at home (94% to 91%).

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

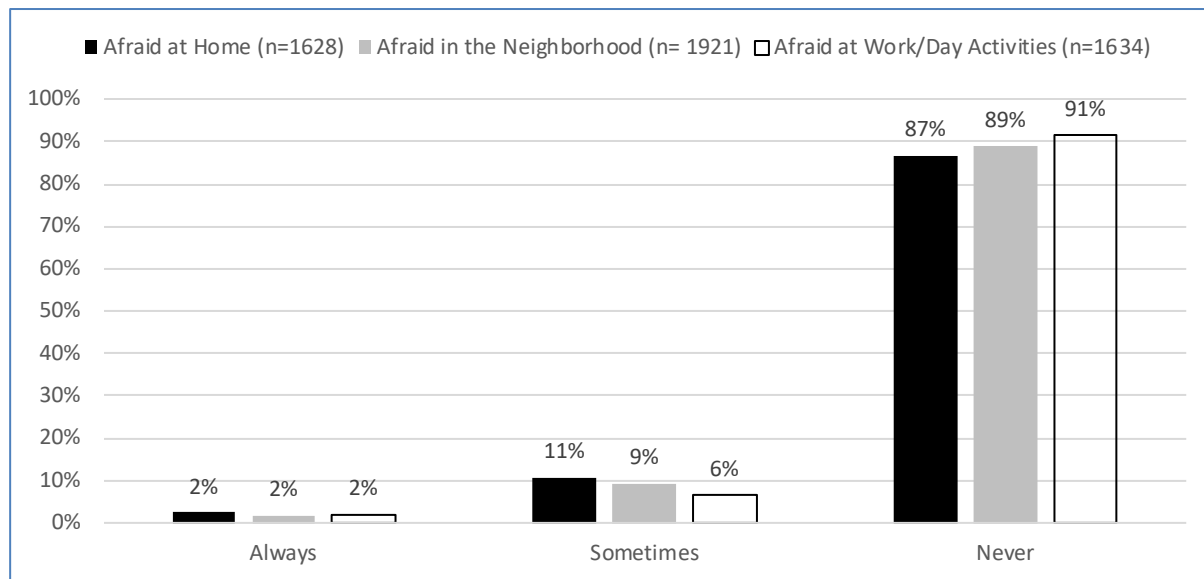
B1. Support with Goals and Problems

Get help to learn new things	82%
Do not get help	12%
Get to help other people	69%
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	94%

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

Staff	47%	Family	47%
Supports coordinator	9%	Friends	7%
Other	9%	Have no one	1%

B2. Frequency of Being Afraid



B3. Legal Rights

	Never	Sometimes	Always
Mail opened without permission	85%	6%	9%

Part II, Section B: Supports Coordination

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

Summary: Overall, people said they were highly 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. More than half know how much money is in their budget and about half were asked about directing their own services.

Progress Points Compared to 2020-2021 Report:



Improvements

- There was a 6% increase in respondents who reported their SC asks them about directing their own services (40% to 46%).
- There was a 5% increase in respondents who reported they are told how much money is in their annual budget (52% to 57%).

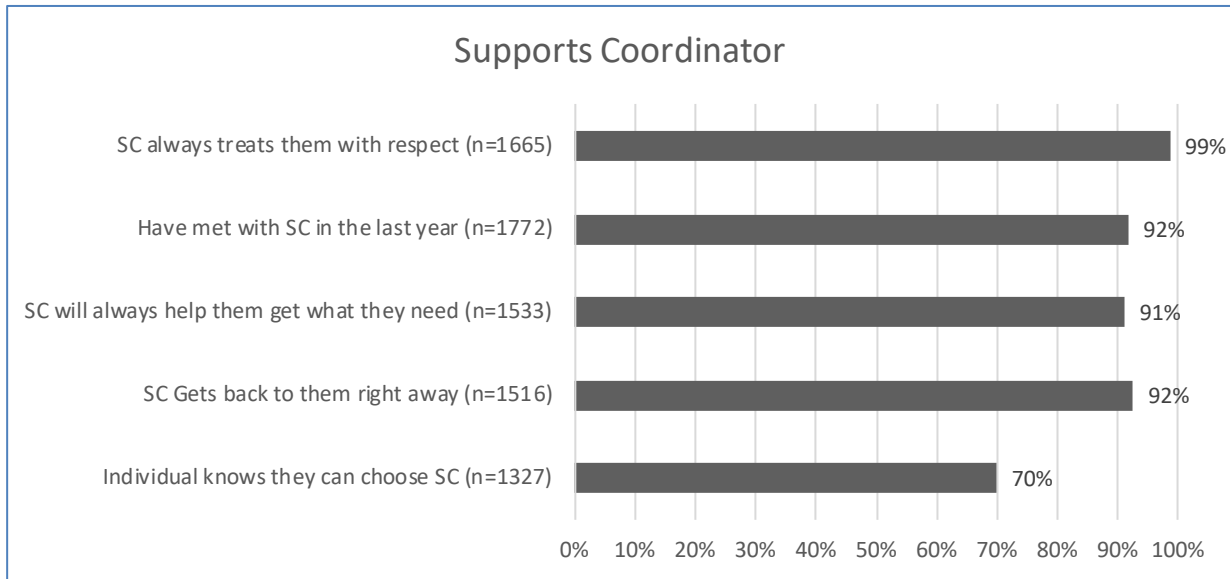


Opportunities for Improvement

- None identified.

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	88%
SC knows what is important to them ⁺	91%
SC asks them about directing their own services	46%
SC asks if services are OK	97%
SC always listens to them	96%

B5. Annual Planning Meeting

Have participated in the meeting	97%
Know it is an option but choose not to participate in meeting	1%
Can communicate their concerns during the meeting	90%
Sometimes get to communicate concerns	7%
Told at the meeting how much money is in their budget	57%
Meeting includes the people they wanted to be there	97%
Know what is talked about at their ISP meeting	82%

B6. Services

Know who to ask if they want to change their services	83%
Do not know who to ask to change services	11%

B7. Staff

Staff always treats them with respect	92%
Staff are respectful of their culture ⁺	98%
Have staff that help them ⁺	77%
Staff have the right training to meet their needs	93%
Staff do things the way they want them done ⁺	90%
All staff always understand their communication	89%
Some staff understand them	7%
Sometimes understood by staff	3%
Not understood by staff	1%

Part II, Section C: Emergency Preparation

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

Summary:

The vast majority of people, 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 2020-2021 Report:



Improvements

- None identified



Opportunities for Improvement

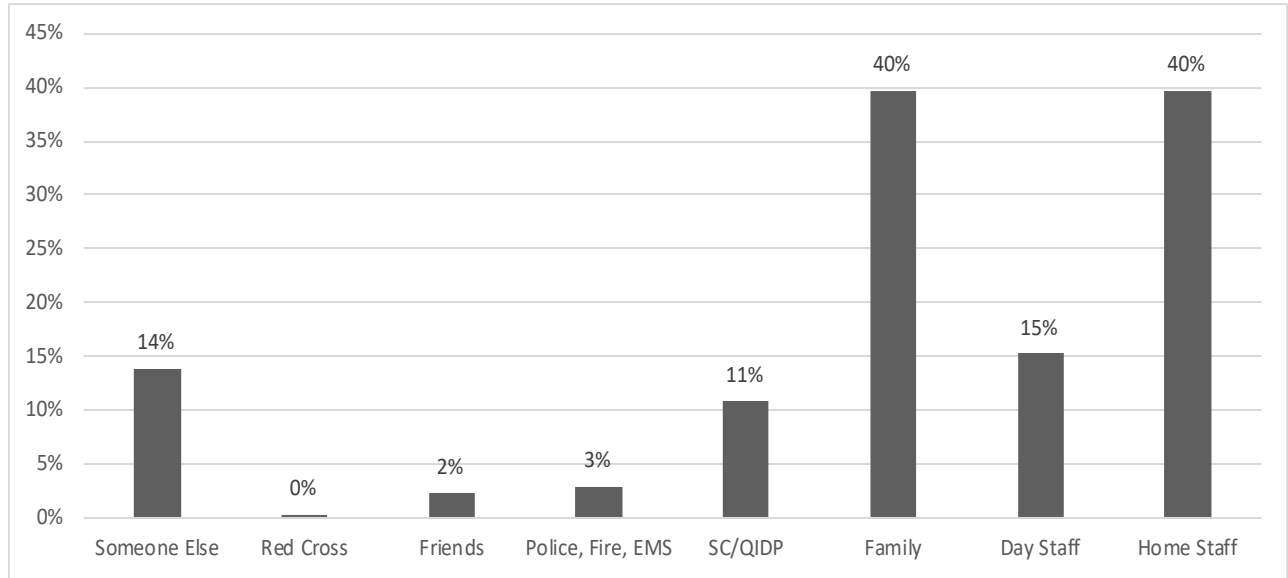
- The number of people for whom someone had talked to them about what to do in case of emergency decreased by 3% (87% to 84%).

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	25%	Individual and Paid staff	15%
Paid staff	25%	Individual and Family/friend/guardian/advocate	13%
Family/friend/guardian/advocate	21%	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 in words, 2 in 5 have a communication system in place. More than 9 in 10 reported they had enough choice about their free time and 9 in 10 made their own schedule. More than 9 in 10 have access to cable television, while 3 in 5 have Internet and a computer and slightly less than half have a cell phone.

Progress Points Compared to 2020-2021 Report:



Improvements

- There was a 6% decrease in those who reported that someone else chose their SC (64% to 58%); further, there was a 14% increase in individuals who reported that they chose their SC alone (4% to 18%).
- There was a 4% increase in people who do not communicate in words reporting they have a system in place (37% to 41%).
- There was a 7% increase in people who reported that a speech/language clinician supported their communication system (34% to 41%).



Opportunities for Improvement

- There was a 3% decrease in individuals who reported that they choose alone what to do with their spending money (61% to 58%).
- There was a 7% decrease in people who said they chose some or all of the roommates they share a bedroom with (44% to 37%).
- There was an 8% decrease in individuals who reported they had the option to live where people without disabilities would live (54% to 46%). This decrease follows a 4% decrease reported last year, for a total of a 12% decrease in the last 2 years.

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

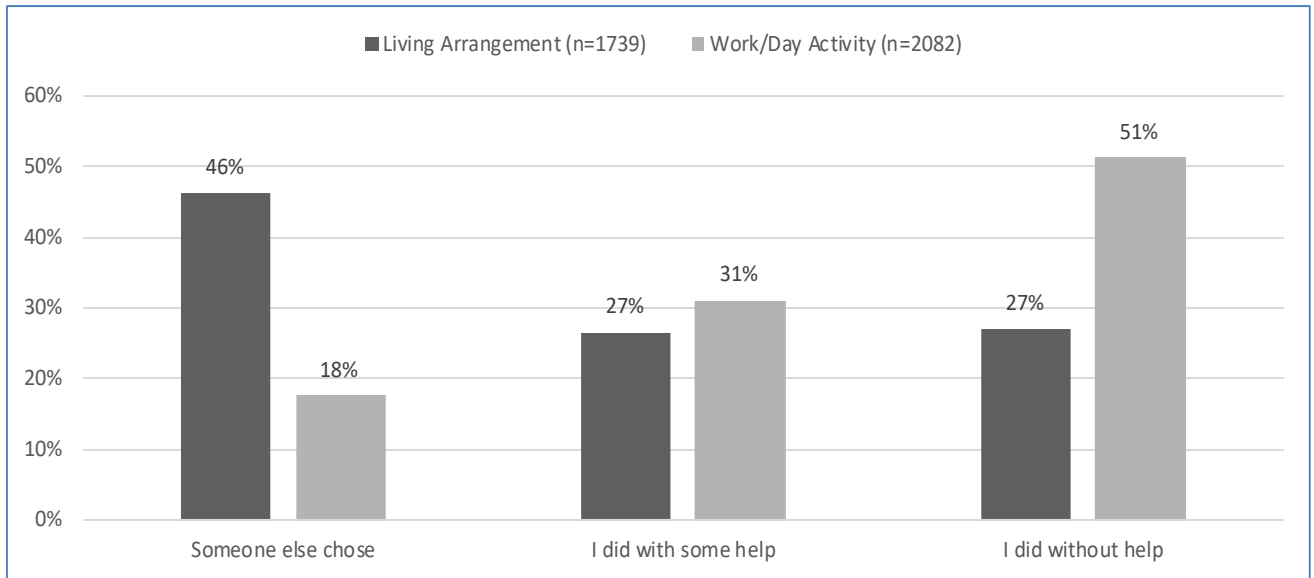
C1. Identification

Always carry ID	65%
Never carry ID	20%

C2. Choice and Control at Home

Have a key or way to get into their home	47%
If other household members go out, they have the option to stay home	46%
If other household members go out, they sometimes can stay home	14%
Can lock bedroom door	49%
Own their home	2%
Name is on the lease or rental agreement	34%
Have a choice to live where people without disabilities live	46%
Saw no other places before they moved into their home	50%
Did not choose housemates	63%
If individual shares a bedroom, chose some or all roommates	37%

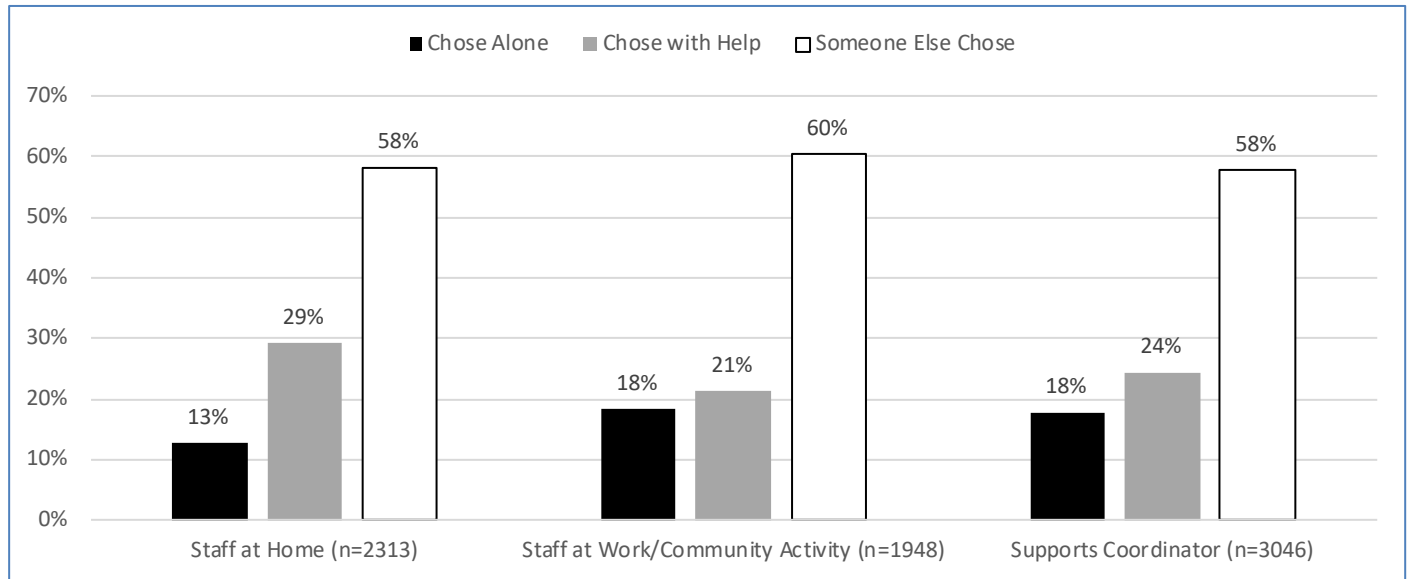
C2.1. Who Chooses Where the Person Lives and Works?



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

Have the choice to go where people without disabilities go	66%
See no other places when choosing day activity	41%
Choose daily schedule without assistance	89%
Have enough choice about free time	94%

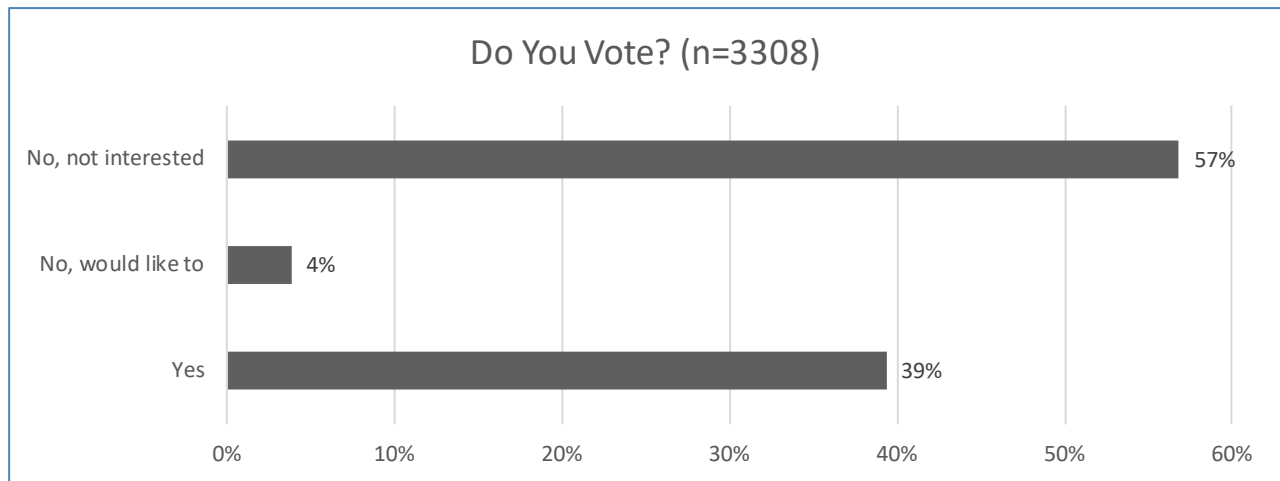
C4. Choice and Control in Choosing Staff



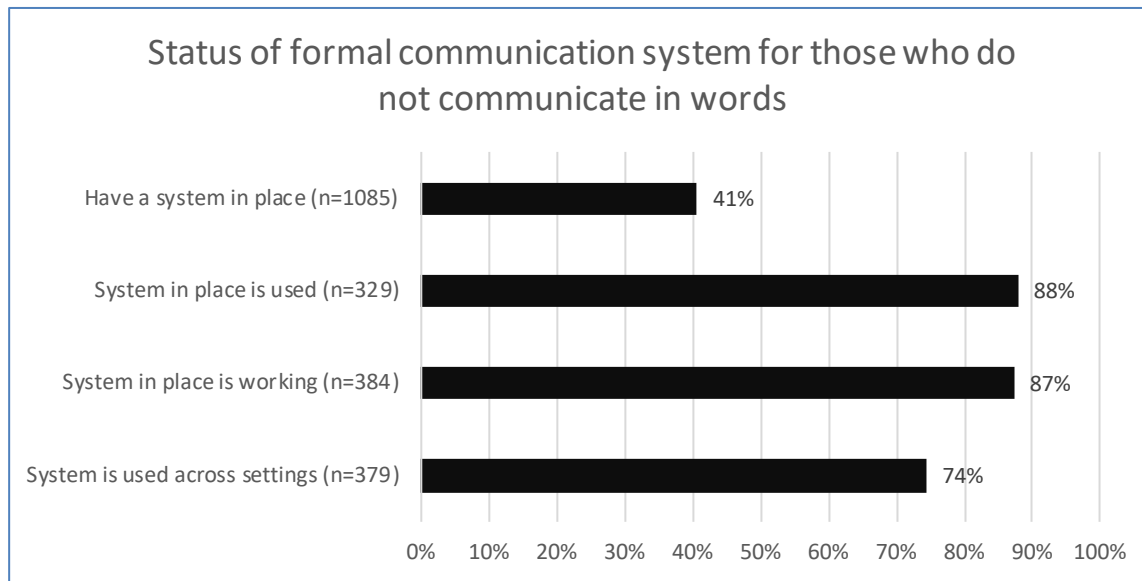
C5. Choice and Control Regarding Money

Always choose alone what to buy with spending money	58%
Choose what to buy with help	34%
There is something they want to buy	48%
They have a bank account and withdrawal money when they want	67%

C6. Voting



C7. Status of Formal Communication System



C8. Who Supports the Communication System?

Staff or Program Coordinator	44%	Parent or Caregiver	43%
Speech Language Clinician	41%	Someone Else	16%

People had the option to select more than one response.

C9. Other Forms of Communication

	Have and Use	Restrictions
Cell phone	41%	9%
E-mail	26%	6%
Internet	62%	11%
Text-messaging	28%	6%
Cable TV	91%	7%
Computer	63%	11%

Part III, Section B: Health Questions

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

Summary: Healthcare is an important issue in our sample, as less than half of those surveyed would describe their general health as “good” or “excellent.” Most people surveyed report that they have high levels of access to general healthcare, dental care, and medical specialists. 4 out of 5 of the individuals surveyed felt that their doctor understood them, and most reported that if they needed help communicating it was available. Slightly more than half say they have talked to their doctor using telehealth, and that they like using telehealth. 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 2020 - 2021 Report:



Improvements

- There was a 3% increase in respondents who reported that they have an opportunity to discuss their health concerns with a psychiatrist (62% to 65%).



Opportunities for Improvement

- There was a 5% decrease in people who reported that they understood their doctor’s instructions (66% to 61%).

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

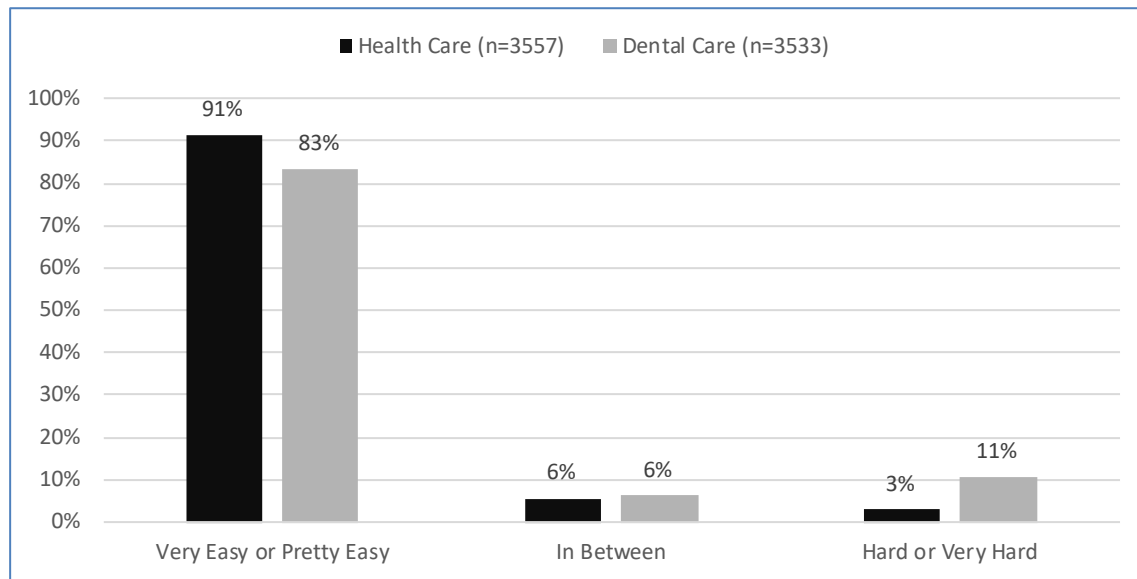
C10. Exercise at Home

	10+ Times	<1 Time
How many times they exercise at home per month	42%	43%

C11. Medical & Dental Care

Describes health as very good or excellent ⁺	48%
Opportunity to discuss health with primary care provider (PCP)	86%
Able to see a medical specialist if needed	96%
Has talked with health care provider using telehealth ⁺	56%
Like talking with health care provider using telehealth ⁺	56%
Have not been prevented from receiving medical or dental care due to disability	90%

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



C12. Mental Health

Have an opportunity to discuss health concerns with psychiatrist	65%
Do not have psychiatrist, but want one	2%

C13. Communicating Health Needs

Their doctor understands them	78%
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	93%
Able to provide consent for medical treatment	60%
If they provide consent, is it accepted	85%

Part III, Section C: Employment and Community Participation Services

Employment in this survey refers to Community Integrated Employment (CIE). CIE is work that is paid directly to the employee, provides at least minimum wage, and occurs in a typical work setting where a person with a disability interacts with coworkers with and without disabilities. The survey also asks about Community Participation Services (CPS), or services that give people with intellectual and developmental disabilities opportunities and support for community inclusion and skill development. Questions about employment benefits, hours, salary, and field of work are only addressed to people who indicated they are employed in CIE. Questions regarding support getting into the workplace, employment planning, and CPS are asked of all respondents.

Summary: Nearly 1 in 6 individuals report that they work in CIE. The most common occupations reported are in cleaning services, food service, and retail. Most frequently, individuals who are employed reported working 20 hours a week. The most common salary range reported was \$12.01 or more per hour, and 68% 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. Of those who are not employed, about half say that someone talked about employment in their planning meeting and more than a third say employment is a goal in their plan. About 1 in 10 take classes or training to obtain a job or get a better job. About 1 out of 4 respondents use CPS. The most common services used are developing social networks and developing interests or promoting health/wellness. There are 77 people in the sample who report that they are self-employed, nearly double the number of people in this category last year.

- Hours worked: Mean: 18.08 hours. Range: 1 to 67 hours. Mode: 20 hours.
- Hourly wages: Range from \$7.25 to greater than \$15.00.

Progress Points Compared to 2020-2021 Report:



Improvements

- There was a 3% increase in respondents who reported that they used CPS Services (21% to 24%).
- There was a 4% increase in people who received paid time off as a benefit of employment (76% to 80%).

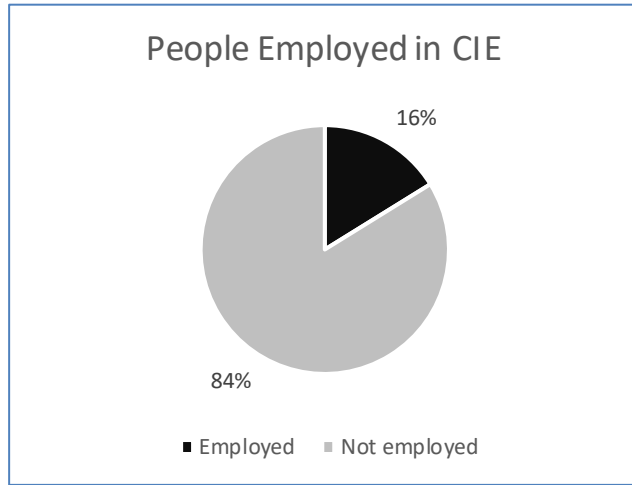


Opportunities for Improvement

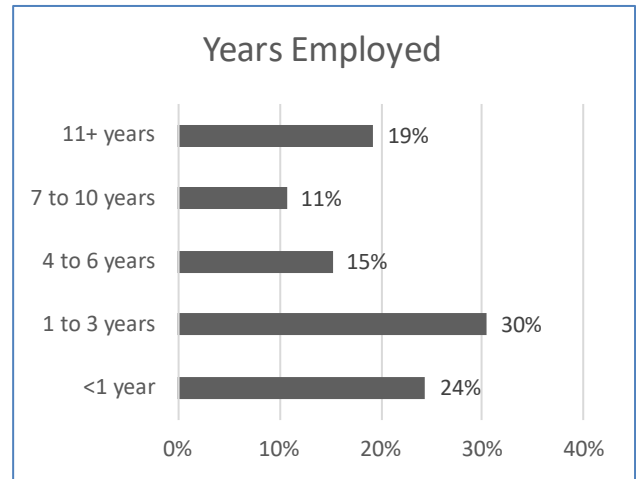
- There was a 3% decrease of people who are not employed who say they discussed employment in their planning meeting (54% to 51%). This decrease follows a 3% decrease reported in last year's report, for a total of a 6% decrease in the last 2 years.

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	24%	Assembly/Factory Work	8%
Food Services	24%	Care Workers/Aides	4%
Retail Services	17%	Recycling	0%
Office Work	4%	Outdoor Work	0%
Stock Room	5%	Animal Care	0%
Maintenance	3%	Other	13%

C17. Supports Getting Into the Workplace

Take classes/training for employment purposes	11%
Talked about employment in their planning meeting	51%
Community employment is a goal in their plan	37%

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

No one	50%	SC	45%
Service Provider	10%	Family	11%
Housemates	0%	Someone Else	6%

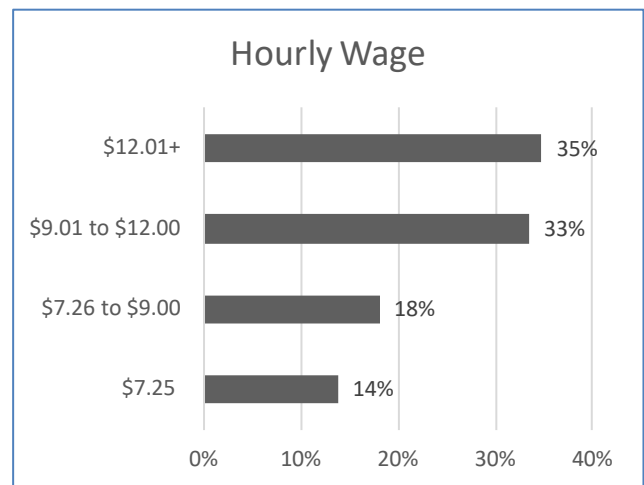
Note: individuals had the option to indicate more than one response for C17.1.

C18. Self-Employment

Person reports that they are self-employed	2%	n=77
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C19. Compensation and Advancement

Have been promoted or received an increase in pay	52%
Receive paid time off from work as a benefit of employment	80%
Receive health insurance benefits from employer	26%
Receive retirement benefits from their employer	31%
Receive other work benefits from their employment	12%
Know how much they earn and willing to share	76%



C20. Community Participation

Use Community Participation Services (CPS)	24%
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C20.1. If yes, CPS Services Used

Developing skills and competencies necessary for employment	14%
Fine/gross motor skill development and mobility	19%
Participating in community activities to develop social networks	58%
Participating in opportunities to develop interests or promote health/wellness	66%
Training/education for self-determination and self-advocacy	13%
Community adult learning opportunities	15%
Volunteering opportunities	24%
Learning to navigate the local community	12%

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 ⁺	91%
Has talked to SC using videoconference ⁺	67%
Likes talking to SC using videoconference ⁺	66%
Has used videoconference for other services ⁺	44%
Likes using videoconference for other services ⁺	61%

Part III, Section D: Self-Directed Supports

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

Summary: About 1 out of every 20 respondents report using self-directed services. Of these, about half made budget decisions alone or with family and friends. 8 in 10 respondents reported that they receive information about how much money is left in their budget. More than 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 2020-2021 Report:



Improvements

- There was an 5% increase in individuals who receive information about how much money is left in their budget (73% to 78%).
- There was an 8% decrease in people who report that a case manager or state professional makes decisions about their budget (10% to 2%).



Opportunities for Improvement

- There was a 7% decrease in individuals who say the information they receive is easy to understand (79% to 72%).

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	6%
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C22. Who Makes Choices About Budget?

Individual makes decisions on their own	14%
Individual has input, family and friends help	38%
A family member or friend makes decisions	46%
A case manager or state professional makes the decision	2%

C23. Making Decisions

Can make changes to their budget or services if they need to	96%
Have enough help deciding how to use their budget/services	92%
Want more help deciding how to use their budget/services	1%

C24. Money Left in Budget

Receive information about the money left in their budget	78%
Information they receive is easy to understand	72%
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. The ongoing Covid-19 Pandemic may have affected these ratings since socialization restrictions were in place in many areas.

Respondents:

Individual	30%	Individual and Paid staff	12%
Paid staff	26%	Individual and Family/friend/guardian/advocate	10%
Family/friend/guardian/advocate	22%	Staff and Family/friend/guardian/advocate	1%

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. It is worthy of note that the Covid-19 pandemic continues to restrict travel and socialization for some people.

Progress Points Compared to 2020-2021 Report:



Improvements

- There was a 3% increase in people who said they could see their friends whenever they wanted to (73% to 76%).



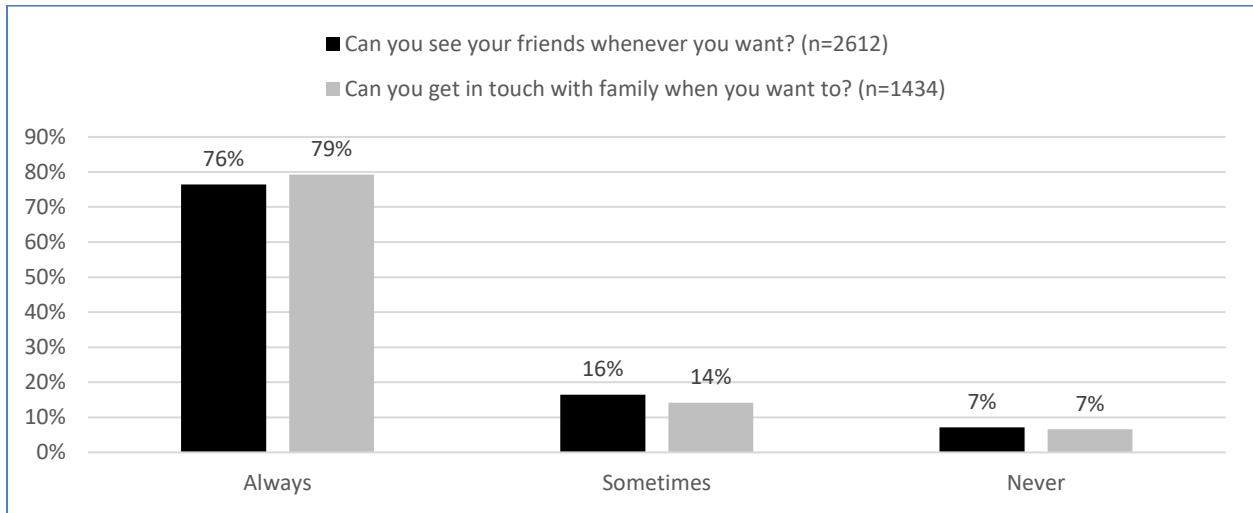
Opportunities for Improvement

- 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 probable that restrictions on socialization in the community due to the ongoing Covid-19 Pandemic affected these numbers.

Respondents:

Individual	25%	Individual and Paid staff	14%
Paid staff	26%	Individual and Family/friend/guardian/advocate	13%
Family/friend/guardian/advocate	21%	Staff and Family/friend/guardian/advocate	1%

Summary: Most people report limited time going out in their communities. Less than half of the sample participated in any community activity on at least a weekly basis. When they do go out, people most frequently go to supermarkets, go out to restaurants to eat, and go visit friends and neighbors. As has been the trend in recent years, people report wanting to participate in community events more frequently, though people very rarely report they want to go out into the community less frequently. However, the percentage of people who reported they were doing enough social activity was significantly higher than in last year’s report. When people engage in community activities, they most often go with family or staff.

- Community inclusion numbers are lower than they had been prior to the pandemic. This may be due to regulations put in place during the pandemic that are slowly changing. There may be changing attitudes about socialization influenced by the pandemic. It is also possible that people have less of an opportunity to engage in community activities because of the ongoing staff shortage issues (“staffing crisis”).

Progress Points Compared to 2020-2021 Report:



Improvements

- There were increases in people who reported that they went out into the community for entertainment frequently (+9%; 26% to 35%) and occasionally (+5%; 33% to 38%).
- People who reported they went out “enough” increased for several activities across the sample, including visiting friends and neighbors (+8%; 61% to 69%), going to a supermarket (+7%; 72% to 79%), going out to restaurants (+13%; 56% to 69%) and going shopping (+9%; 64% to 73%).



Opportunities for Improvement

- There was an 11% 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 (13% to 24%).

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

E. Inclusion Data

E1. Community Participation

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

Activity	% of people who say they do this weekly	% of people who say they do this enough	% of people who want to do this more	% of people who want to do this less
Visit friends, relatives, neighbors	40%	69%	30%	1%
Go to a supermarket	46%	79%	18%	3%
Go out to eat/restaurants	40%	69%	29%	2%
Go to a shopping center or mall	35%	73%	25%	2%
Go out to a worship service	22%	82%	16%	1%
Run errands and appointments	25%	85%	12%	3%
Meeting people at coffee house/tavern	17%	81%	18%	1%
Go out for entertainment	21%	68%	32%	0%

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

Activity	Staff	Family	Friends	Roommates Coworkers	Go Alone	Other
Visit friends, relatives, neighbors	31%	46%	8%	1%	13%	0%
Go to a supermarket	48%	44%	1%	1%	5%	1%
Go out to eat/restaurants	47%	45%	4%	1%	3%	1%
Go to a shopping center or mall	52%	40%	3%	1%	4%	0%
Go out to a worship service	32%	57%	3%	1%	6%	1%
Run errands and appointments	50%	43%	1%	0%	5%	1%
Meeting people at coffee house/tavern	52%	36%	5%	1%	5%	1%
Go out for entertainment	49%	41%	6%	1%	3%	1%

E2. Extra-Curricular Activities

Would like to be a part of more groups in the community	37%
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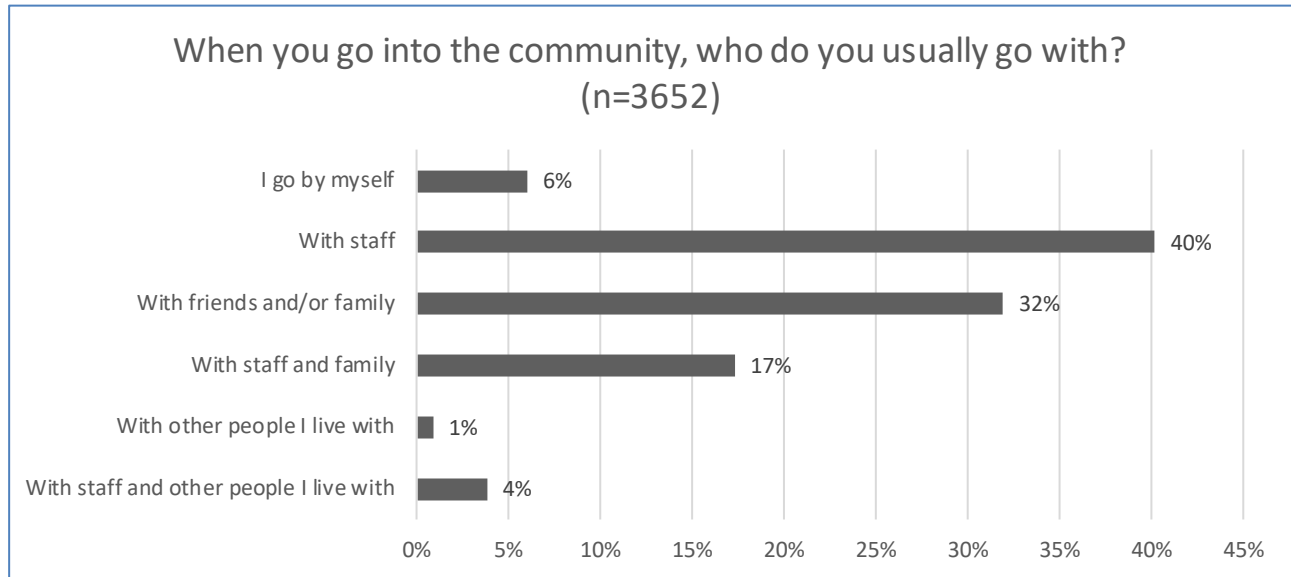
E2.1. How Often Do You Go into the Community?

	Frequently	Occasionally
Go out into the community for entertainment	35%	38%
Go to social events attended by people with and without disabilities	20%	46%

E2.2. Exercise in the Community

	Never	Less than Weekly	Weekly	More than Weekly
How often the person exercises	38%	3%	7%	52%

E3. Going Out Alone or with Other People



E4. Transportation

Always have a way to get where they wanted to go	93%
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E4.1. Transportation Methods Used Most Frequently

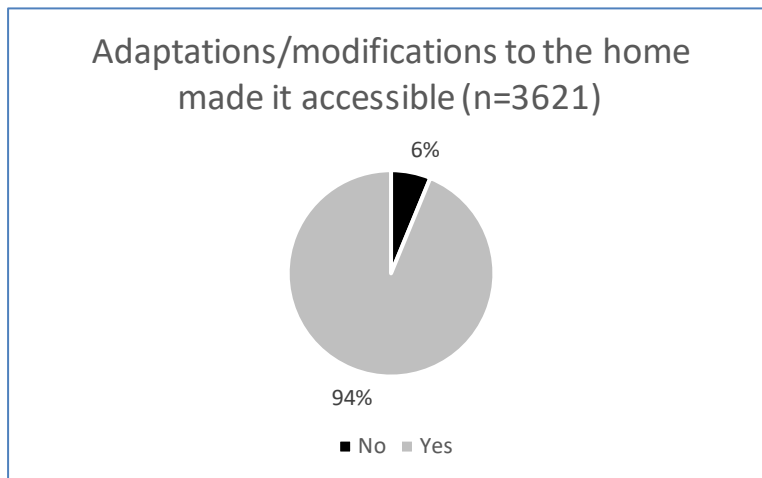
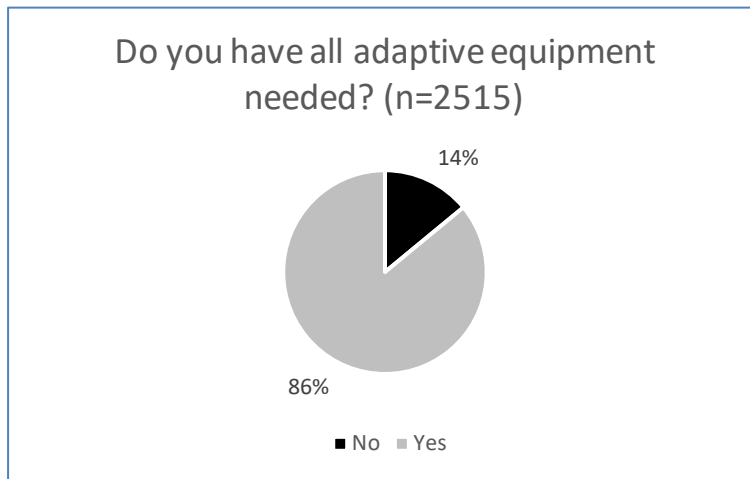
Get a ride from family or friends	39%
Get a ride from staff in provider van	41%
Get a ride in staff member’s car	12%
Transport themselves	4%
Ride public transportation	2%
Ride paratransit	2%
Take a taxi, Uber or Lyft	0%

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

Not enough staff	24%
Paratransit is unreliable	11%
Transportation for work/school only	3%
No one at home can drive	3%
Some other reason	59%

- It is probable that restrictions on socialization in the community due to the ongoing Covid-19 pandemic as well as 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 favorable in their reports of respondents' home environments. Most monitors rated homes as a 6 or 7 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.

Progress Points Compared to 2020-2021 Report:



Improvements

- None identified.



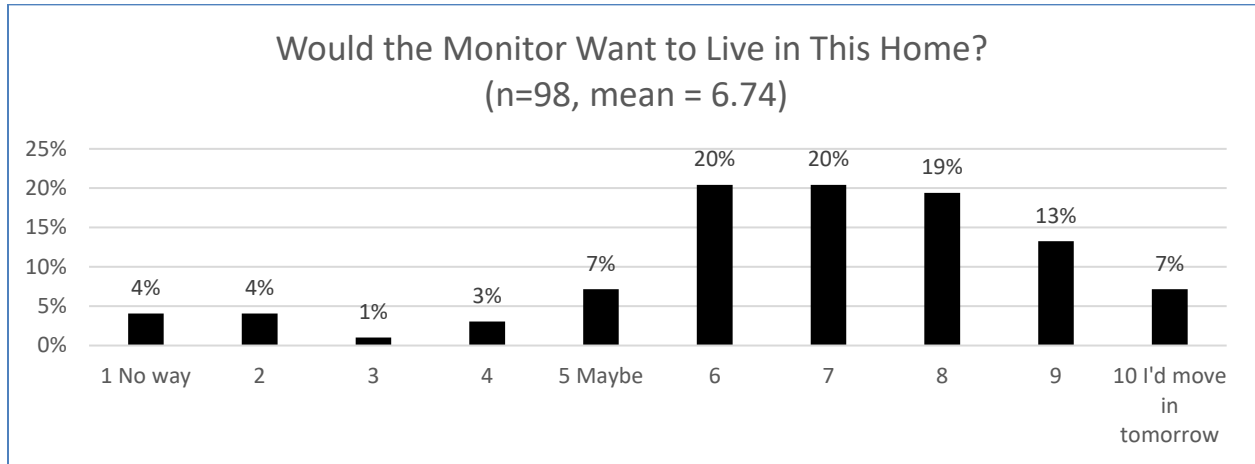
Opportunities for Improvement

- Monitors who reported that all staff appear to recognize individuals in ways that promote independence, treat individuals with dignity and respect, and appear to have all the skills necessary to do their work decreased by 4% (89% to 85%). This decrease follows a 3% decrease reported in last year's report, for a total of a 7% decrease in the last 2 years.

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”)



NOTE: Out of almost 4,000 interviews conducted for the 2021-2022 reporting year, less than 100 monitors included a rating of the individuals’ home environment. Interviews were conducted remotely with limited opportunity for monitors to observe respondents’ home environments. This data is likely not reflective of the sample and should be considered with caution.

F1.1. Mean and Mode of Monitor Ratings

Mean	6.74
Mode	6 & 7

G. Support for the Person Data

G1. Monitor Observations

Staff treat individuals with dignity and respect	85%
Staff recognize the individual in ways that promote independence	85%
Staff who support individuals have the skills they needed	85%

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 1377 family members, friends, and guardians.

Respondents:

Parent(s)	76%	Another Relative	4%
Sibling(s)	15%	Friend	0%
Guardian	2%	Other	3%

Summary: Family members continue to report high levels of satisfaction overall. Most people are satisfied with where their relative lives, what they do during the day, their relative’s staff, and their relative’s services. About half reported that if their relative did not communicate in words, a communication system was in place. About one-third were not familiar with the complaint and grievance process, about 1 in 5 are familiar with Life Course Framework and Tools, and 1 in 3 are familiar with the PA Family Network. 9 out of 10 respondents report that they contact their relative at least monthly. 1 in 20 indicated that they had not seen their relative in the past year.



Improvements

- There was an 11% increase in family members who reported that they see their relative at least monthly (63% to 74%).
- There was a 6% increase in family members who reported that they are familiar with the PA Family Network (26% to 32%).
- There was an 5% increase in family members who reported that they had attended a workshop led by the Network of Family Advisors (26% to 31%).



Opportunities for Improvement

- There was a 5% decrease in those who reported that if there was a communication in place for their relative, it was used across settings (82% to 77%).
- There was a 5% decrease in family members who reported that they are satisfied with the supports coordination their relative receives (86% to 81%).
- People who felt their relative received all the supports they needed decreased by 9% (76% to 67%).
- Family members who reported that their relative’s home and place of work seemed to have an adequate number of paid staff each decreased by 4% (85% to 81% and 96% to 92%, respectfully).
- There was a 7% increase in family members who reported that there are always or frequently changes in their relative’s support staff across settings (10% to 17%).

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	95%
Somewhat satisfied or very satisfied with what relative does during the day	87%
Somewhat satisfied or very satisfied with relative's staff at home	94%
Somewhat satisfied or very satisfied with staff at relative's day activity	95%

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

Contacted their relative at least monthly	91%
Never contacted their relative	1%
See their relative at least monthly	74%
Never visited their relative	5%

H3. Your Relative's Satisfaction

Relative is satisfied or very satisfied with his/her living situation	95%
Relative is satisfied or very satisfied with what they do during the day	89%
Relative is satisfied or very satisfied with the staff who support them at home	95%
Relative is dissatisfied or very dissatisfied with the staff who support them at home	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	89%
Relative feels safe in their community, home, and neighborhood most of the time	8%

H5. Your Relative's Opportunities

Relative has enough opportunities to participate in activities in the community	76%
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	81%
Staff in relative's home always treat people with dignity and respect	95%
All staff in their relative's home have the skills they need to support their relative	89%
Some of the staff in their relatives home have the skills they need to support their relative	10%
Relative's place of work appears to have an adequate number of paid staff	92%
Staff at relative's place of work always treat people with dignity and respect	97%
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	6%
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	47%
If there is a communication system in place, it is used across settings	77%

H8. Relative's Supports

Satisfied with the support coordination their relative receives	81%
Told how much money is in their relative's budget	61%
Their relative directs their own services	12%
Their relative always receives the supports they needed	67%
The supports and services their relative receive change when their needs change	86%
There are never or rarely changes in support staff at their family member's home, work, or day program	55%
There are always frequent changes in support staff at their family member's home, work or day program	17%
They chose the agency/provider who worked with their relative	46%
Their relative chose the agency or provider who worked with their relative, alone or with their help	27%
Someone else chose the agency/provider who worked with their relative	27%

H9. Complaints and Grievances

Relative was familiar with the complaint and grievance process on some level	70%
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H9.1. At what level?

At the provider level	65%
At the county/AE level	64%
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	19%
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)	32%
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	83%
If family member transitioned from school to adult services, were happy with the process	28%
SC asks about their vision for an everyday life for their family member	78%

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

5,129 Considerations were collected during this year's surveys. The greatest number of Considerations came from Allegheny (33.26%), Philadelphia (12.88%), and Delaware (8.46%) counties. Qualitative analysis was conducted to determine the major themes, or topics, of considerations. The most common themes were Service System (22.50%); Personal Rights, Competence Enhancement and Growth (17.66%); Community Presence and Participation (12.86%); and Work/Employment/Meaningful and Purposeful Activity (12.43%). For each primary theme, the percentage of resolved considerations was determined. Within each primary theme, the three most significant secondary themes were calculated. Primary and secondary themes are defined below in order of significance.

Service System: 22.50% of total (85.55% 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: 17.66% of total (73.17% resolved)

Secondary theme 1	Independence/choice/control
Secondary theme 2	Having an ID
Secondary theme 3	Learning a skill

Community Presence and Participation: 12.86% of total (80.90% resolved)

Secondary theme 1	Individual needs more opportunities
Secondary theme 2	Funding needed to attend/join/participate in events
Secondary theme 3	Other

Work/Employment/Meaningful and Purposeful Activity: 12.43% of total (78.05% resolved)

Secondary theme 1	Job opportunity request
Secondary theme 2	Individual needs meaningful day activity
Secondary theme 3	Work/vocational support

Health and Well Being: 7.44% of total (77.22% resolved)

Secondary theme 1	Difficulty accessing medical professional/specialist
Secondary theme 2	Medical, behavioral, health concern
Secondary theme 3	Difficulty scheduling/needs appointment

Relationships/Friendships: 5.55% of total (78.24% resolved)

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

Residential/Living Situation Personal Change: 4.91% of total (70.63% resolved)

Secondary theme 1	Request to live elsewhere
Secondary theme 2	Request regarding roommate/housemate
Secondary theme 3	Respite Request

Communication Needs/Devices/Services: 3.54% of total (79.67% resolved)

Secondary theme 1	Individual needs communication device
Secondary theme 2	Training needed to use device
Secondary theme 3	Funding needed to obtain equipment

Miscellaneous: 3.11% of total (73.75% resolved)

Secondary theme	Other
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Adaptive Equipment: 2.98% of total (76.47% 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: 2.33% of total (81.66% resolved)

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

Transportation: 1.79% of total (73.91% resolved)

Secondary theme 1	Request for transport to/from activities/programs
Secondary theme 2	Request for accessible funding
Secondary theme 3	Funding needed

Safety: 1.01% of total (75.00% resolved)

Secondary theme 1	Personal safety
Secondary theme 2	Concern regarding location
Secondary theme 3	Other

Major Concerns: 0.91% of total (82.79% resolved)

Secondary theme 1	Evidence of human rights violation
Secondary theme 2	Physical danger within a residential site/home or place of day activity
Secondary theme 3	Significant sanitation problems

Spiritual Life: 0.81% of total (83.33% resolved)

Secondary theme 1	Individual needs more opportunities
Secondary theme 2	Other

Loop Not Closed: 0.03% of total (100% resolved)

Secondary theme 1	Not applicable
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This link will take you to back to the beginning of the [Statewide Report](#).