

**The Institute on Disabilities**  
**Pennsylvania's University Center for Excellence in**  
**Developmental Disabilities**

***Independent Monitoring for Quality (IM4Q)***  
***Person and Family Directed Supports Waiver***  
***2018-2019***

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

**Submitted by: Sally Gould-Taylor, Mary Kay R. Cunningham,**  
**James A. Lemanowicz, Guy Caruso and Jenifer**  
**Taylor Eaton**

**The Institute on Disabilities**  
**Pennsylvania's University Center for Excellence in**  
**Developmental Disabilities**  
**Temple University**  
**1755 North 13<sup>th</sup> Street, Student Center 411S**  
**Philadelphia, PA 19122**

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**Institute on Disabilities**  
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## **Introduction**

In 1997, Pennsylvania's Office of Developmental Programs (ODP) developed a multi-year plan that represented a significant effort to convey its vision, values and goals for the coming years. As a result, recommendations were made to create a subcommittee of individuals, families, providers, advocates, administrative entity staff and ODP staff to create an independent monitoring program across the state of Pennsylvania. At the same time, a national project was developed to identify performance indicators that states could collect to determine the status of their system via the experiences of individuals, families, and providers delivering supports. Pennsylvania aligned the project created by ODP's subcommittee with the newly developed National Core Indicators (NCI) to create the Independent Monitoring for Quality (IM4Q) Program.

As a result of the IM4Q Program, ODP has developed and begun to implement quality improvement strategies (QIS) to ensure the continued improvement of services and supports people receive through Pennsylvania's intellectual disability system. The IM4Q data are one source of information used to increase the quality of ODP's services and supports. The IM4Q Program is contracted through each of the 48 Administrative Entities (AEs). Each year, the AEs develop contracts with Local IM4Q Programs to independently conduct interviews and enter data into the Department of Human Services (DHS) Home and Community Services Information System (HCSIS) web-based system. The IM4Q data are analyzed and reports are developed for dissemination to ODP staff, individuals, families, guardians, AEs, AE Mental Health and Intellectual Disabilities Advisory Boards, Local Programs, providers, and other interested people.

A list of the number of individuals receiving services and their family, friends and guardians who completed surveys in the following years is listed in the table below:

Fiscal Year	Individuals Surveyed	Friends, Family, Guardians Surveyed
2000-2001	5298	2224
2001-2002	5659	2494
2002-2003	4687	3163
2003-2004	6373	2975
2004-2005	6499	3010
2005-2006	6496	2851
2006-2007	6469	3028
2007-2008	6512	2731
2008-2009	6618	2896
2009-2010	6621	2590
2010-2011	6692	2510
2011-2012	6589	2517
2012-2013	5858	2160
2013-2014	5341	2187
2014-2015	5336	2002
2015-2016	5260	2047
2016-2017	5328	1608
2017-2018	5354	1980
2018-2019	5370	2240

The Home and Community–based Services Person and Family Directed Supports (P/FDS) Waiver provides home and community-based services for children and adults with intellectual disabilities as an alternative to care in an intermediate care facility for individuals with an intellectual disability (ICF/ID). Individuals live with their families,

friends, and other living arrangements and participate in community life through work, learning, and other community activities.

The Office of Developmental Programs (ODP) continues to be involved with the development of a significant quality management initiative. As part of this initiative, a quality framework is being developed to produce a cohesive system for assuring and improving the quality of services and supports people receive from the intellectual disabilities system. The IM4Q data are one source of information that are being used in this effort.

A list of the number of individuals receiving services in the PFDS Waiver and their family, friends and guardians who completed surveys in the following years is listed in the table below:

Fiscal Year	Individuals Surveyed	Friends, Family, Guardians Surveyed
2003-2004	1260	881
2004-2005	1319	884
2005-2006	1319	881
2006-2007	1339	894
2007-2008	1450	946
2008-2009	1454	992
2009-2010	1454	872
2010-2011	1462	873
2011-2012	1438	888
2012-2013	1256	695
2013-2014	1145	687
2014-2015	1231	768
2015-2016	1120	681
2016-2017	1125	648

2017-2018	1123	675
2018-2019	1639	923

## **Methodology**

### **Instrument**

The interview instruments for IM4Q include the Essential Data Elements (EDE) survey, which includes a pre-survey form, and the Family/Friend/Guardian (F/F/G) survey. As a result of the 2017-2018 revisions, the IM4Q Essential Data Elements (EDE) survey has a total of 148 questions. Seventy of the questions can only be answered by the individuals receiving supports and services.

The EDE for fiscal year 2017-2018 includes all survey questions included in the FY 2017-2018 National Core Indicators (NCI) Consumer Survey. A copy of the most recent NCI report is available on the Human Services Research Institute (HSRI) website at [www.hsri.org](http://www.hsri.org).

The **Essential Data Elements** (EDE) instrument is comprised of the following sections:

- A **pre-survey** which is completed by the County MH/MR Program designee prior to the scheduling of the appointment with the individual to give the local IM4Q Program information needed to schedule the interview with the individuals. Information includes: the person's address, contact people, supports coordinator information, accessibility and the individual's communication style (which may require the use of an interpreter, e.g. Sign Language or Spanish). The data are often provided by the Supports Coordination Organization (SCO).
- A **pre-survey addendum**, which is completed by the County MH/MR Program for only those individuals who were designated as part of the NCI sample. The addendum provides demographic information, along with information about the individual's degree and type of disability(ies), work and day activity routines.
- **Satisfaction** – this section was only to be completed based on the responses of the individual receiving supports. Questions were asked about satisfaction with where the individual works and lives, as well as with staff who support the individual.
- **Dignity, Respect and Rights** – this section was also only to be completed based on responses of the individual receiving supports. Questions were asked about

whether roommates and staff treated people with respect, whether people were afforded their rights, and whether they had fears at home, at work or in the community.

- **Choice and Control** – the questions in this section were answered by the individual, or by a family member, friend or staff person. Questions were asked about the extent to which individuals exerted choice and control over various aspects of their lives.
- **Relationships** – the questions in this section were answered by the individual, or by a family member, friend or staff person; questions were asked about friends, family and neighbors, and individuals' opportunity to visit and contact them.
- **Inclusion** – the questions in this section were answered by the individual, or by a family member, friend or staff person. Questions were asked about opportunities for community inclusion; a section of the Harris Poll was included for comparative purposes at the national level.
- **Monitor Impressions** – this section of the survey was completed by the Independent Monitoring team, after they had completed their visit. Questions were asked in the areas of physical setting, staff support and opportunities for growth and development.
- **Major Concerns** – this form was to be completed whenever there was an issue related to physical danger, significant sanitation problems, or evidence of physical or psychological abuse or neglect. Each local program was required to develop a mechanism for communicating this information. In the event of imminent danger, teams were instructed not to leave the home until resolution of some kind was achieved.
- **Family/Friend/Guardian Survey** – a survey was conducted with each family once the individual interviewed gave his/her approval. Questions related to the families' satisfaction with their relatives' living situation, as well as perceived satisfaction of their relatives. The survey was conducted either by phone or face-to-face at the time of the EDE interview.

## Sample

Sampling this year was done through HCSIS with a review of the sample performed by the ODP Regional IM4Q Coordinator and each of the Administrative Entity's (AE's) IM4Q coordinators in collaboration with the local program.

Each AE was instructed to include 30 individuals who participate in the Person and Family Directed Supports waiver (PFDS). The majority of the counties/joiners provided survey data for at least 20 individuals participating in the PFDS waiver. The data in this report reflect the responses of those individuals included in the PFDS sample. There were some individuals who were receiving PFDS Waiver supports at the time the sample was drawn but at the time of data collection were no longer receiving PFDS supports; we have removed them from the PFDS data analysis. They are, however, included in the overall statewide and AE/county analyses.

This year's PFDS sample included 1639 people. The following table shows the breakdown of the sample by type of residential setting. As the table shows, the majority of the people in the sample lived in their family's home, which is as one would expect for people receiving supports through the PFDS waiver.

	<b>N</b>	<b>Percent</b>
Temporary Shelter	1	0.1%
Domiciliary Care	17	1.0%
Nursing Facility	3	0.2%
Personal Care Home	21	1.3%
Family Living	9	0.5%
Own Residence	231	14.1%
Relative's Home	1297	79.1%
Community Home	4	0.3%
Approved Private School	1	0.1%

Other	3	0.2%
Missing	52	3.2%
<b>Total</b>	<b>1639</b>	<b>100%</b>

## **RESULTS**

The following table displays the distribution of interviews conducted by each independent monitoring program by AE.

	# of People	Percent
Allegheny	151	9.2%
Armstrong/Indiana	20	1.2%
Beaver	31	1.9%
Bedford/Somerset	26	1.6%
Berks	39	2.4%
Blair	15	0.9%
Bradford/Sullivan	7	0.4%
Bucks	73	4.5%
Butler	18	1.1%
Cambria	21	1.3%
Cameron/Elk	3	0.2%
Carbon/Monroe/Pike	17	1.0%
Centre	25	1.5%
Chester	61	3.7%
Clarion	5	0.3%
Clearfield/Jefferson	13	0.8%
Columbia/Montour/Snyder/Union	7	0.4%
Crawford	27	1.6%
Cumberland/Perry	25	1.5%
Dauphin	37	2.3%
Delaware	75	4.6%
Erie	52	3.2%
Fayette	24	1.5%
Forest/Warren	6	0.4%
Franklin/Fulton	29	1.8%
Greene	9	0.5%
Huntington/Mifflin/Juniata	22	1.3%
Lackawanna/Susquehanna	17	1.0%
Lancaster	41	2.5%
Lawrence	13	0.8%
Lebanon	7	0.4%
Lehigh	19	1.2%
Luzerne/Wyoming	33	2.0%
Lycoming/Clinton	17	1.0%
Mercer	16	1.0%
Montgomery	138	8.4%
Northampton	33	2.0%
Northumberland	19	1.2%
Philadelphia	259	15.8%
Potter	11	0.7%
Schuylkill	20	1.2%



Tioga	11	0.7%
Venango	7	0.4%
Washington	11	0.7%
Westmoreland	51	3.1%
York/Adams	30	1.8%
McKean	10	0.6%
Wayne	3	0.2%
Missing	35	2.1%
<b>TOTAL</b>	<b>1639</b>	<b>100%</b>

### **Demographic Characteristics of the Sample**

Data was collected on the gender, race and ethnicity, and age of the participants.

- Of those who reported gender in the sample (n=1568), 55.5% identified as male, 44.1% identified as female, and 0.3% identified as other.
- For those who reported their age (n=1576) the mean age in the sample was 36.81 (SD=13.17), with a range of 19 to 78 years
- Of those who reported on race in the sample (n=1405), 75.0% identified as white, 20.6% identified as black/African-American, 1.4% identified as Asian, 1.1% identified as mixed-race, 1.9% identified as other, and less than 1% identified as American Indian/Alaskan or Native/Pacific Islander.
- Of those who identified their ethnicity (n=1300), 4.5% identified as Hispanic/Latinx

### **Satisfaction**

**Respondents:** Only the individual receiving services/supports could answer the questions on satisfaction. The percent of people who responded to questions in this section ranged from 4% to 83%.

#### ***Satisfaction with Living Arrangements***

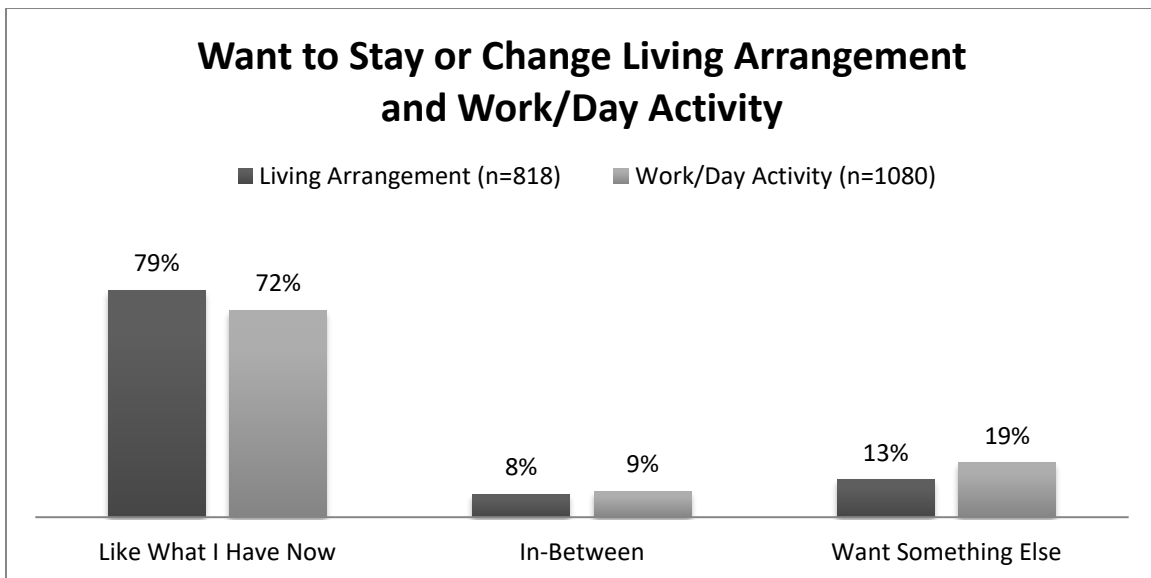
- 90% of individuals liked where they live. When asked what they don't like about where they live, 87% said nothing, 2% reported they feel unsafe, 2% indicated they want more independence, 1% indicated a problem with housemates, 1% indicated their home needs repair. Less than one percent of people reported that they did not like where they live because it is not accessible, it doesn't feel like

home or that they want to be closer to family and friends. 4% indicated there is another reason why they don't like where they live.

- 79% wanted to stay where they currently live but 13% wanted to move somewhere else.

### **Satisfaction with Work/Day Activity**

- 93% of individuals *with* a day activity/work liked what they did during the day. 94% of individuals liked the secondary job/activities they frequently do during the day.
- 72% wanted to continue their current daytime activities/work, but 19% wanted to do something else.



### **Daily Life**

- 81% of individuals reported always getting all the services and supports they need. 10% receive services but need more; 4% sometimes receive services.
- Of those who responded, on most weekdays 26% attended a vocational facility, 14% attended an adult training program, 11% worked in supported employment, 16% stayed home, 12% went out and did things in the community, 2% volunteered, 2% attended school (through high school), 12% worked with no

supports, less than 1% attended senior programs, 1% were retired, and 3% did something else.

- In addition to what individuals do on most weekdays, 30% also went out and did things in the community, 36% stayed home, 3% attended an adult training program, 3% attended a vocational facility, 10% volunteered, 3% worked in supported employment, 1% attended school, 3% worked with no supports, less than 1% attended senior programs, and 1% were retired.
- 58% of individuals that did not have a paid job in the community reported that they do not want a job; 35% reported they would like to have a job for pay.

### ***Happiness and Loneliness***

- 84% of individuals reported feeling happy overall, 13% reported being neither happy nor sad, and 2% reported feeling sad overall.
- 65% reported never feeling lonely, 32% reported sometimes feeling lonely, and 3% reported always feeling lonely.
- 85% reported having friends they like to do things with; for 74% of these people their friends are not staff or family.
- 69% reported they have a best friend who they are very close to.
- 79% reported that they can go on a date if they want to or they are married, 8% reported that they can go on a date if they want to but there are some restrictions and rules and 13% are not allowed to go on a date if they want.

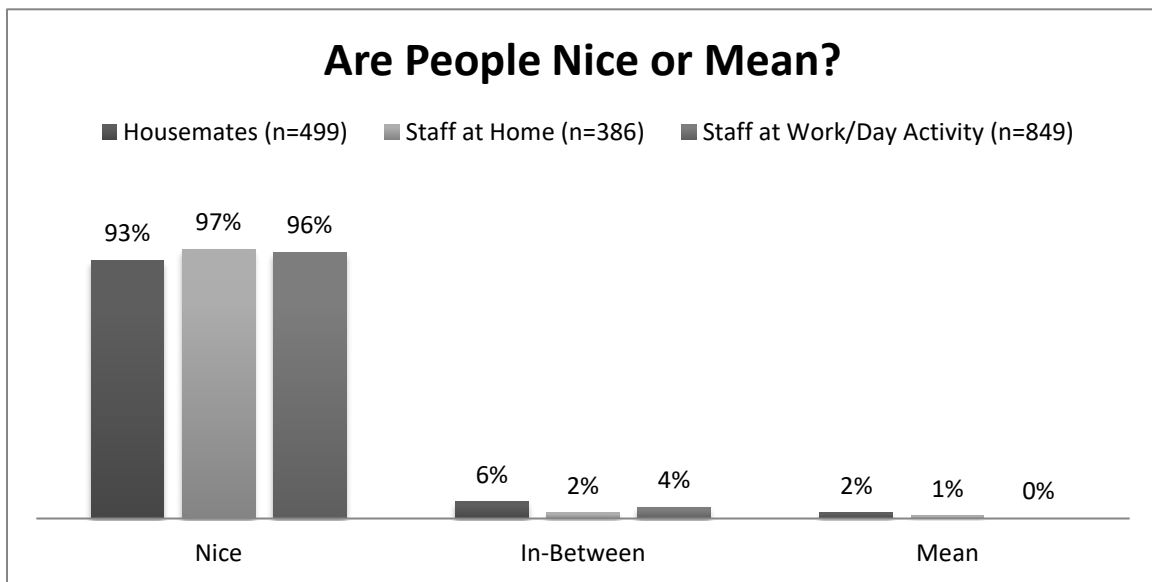
### ***Privacy***

- 97% of the individuals surveyed reported that they have enough privacy (a place to be alone) at home.
- 87% of individuals reported that they can be alone with friends at home.
- 93% reported that other people always let them know before coming into their home, 3% reported that sometimes other people let them know before coming into their home, and 4% reported that people never let them know before coming into their home.

- 82% reported that people always let them know before coming into their bedroom, 8% reported that sometimes other people let them know before coming into their bedroom and 9% reported that people never let them know before coming into their bedroom.

**Are People Nice or Mean?**

- 93% of respondents reported that their housemates are very nice or nice.
- 76% of people interviewed reported that they get along with the person they share a bedroom with most of the time.
- 97% of the people interviewed reported that their staff who work with them at home are very nice or nice.
- 96% reported staff who work with the respondents at work or day activity are nice or very nice.



**Satisfaction Scale:** Based on 6 individual items, a Satisfaction Scale was developed. Scores on the Satisfaction Scale could range from 0 to 100, with a higher score indicating greater satisfaction.

- The average (mean) score was 86.31 with a standard deviation of 18.48.
- The mode (the value that occurs the most frequently) was 100, indicating that many people (47%) were very satisfied on all measures of satisfaction.

## Note on Satisfaction Research

Although these percentages indicate fairly high levels of satisfaction, this type of research usually yields high satisfaction rates. Individuals who receive supports and services tend to appreciate getting such services and therefore see themselves as satisfied. Moreover, people with limited options may not have the experience to know that services could be better.

There were some differences regarding this year's data in this section when compared with data from 2017-2018:

- There was a 3% **increase** in those who report that they work during the day with no supports.
- There was a 3% **increase** in those that do not have a job who want a job for pay.
- There was a 5% **decrease** in the percentage of individuals that wanted to stay where they currently live.
- There was a 4% **decrease** in those who report they want to continue their current day activity.
- There was a 6% **decrease** in the percentage of people that reported that they are happy overall with their life.
- There was a 10% **decrease** in the percentage of individuals that reported getting along with the person with whom they share a bedroom.
- There was a 5% **decrease** in the percentage of individuals who reported that they have friends.
- There was a 5% **decrease** in the percentage of people who reported that people let them know before coming into their bedroom.
- There was a 3% **decrease** in the percentage of individuals who report their housemates are nice.
- There was a 3% **decrease** in those who report they can be alone with friends.

## **Dignity, Respect and Rights**

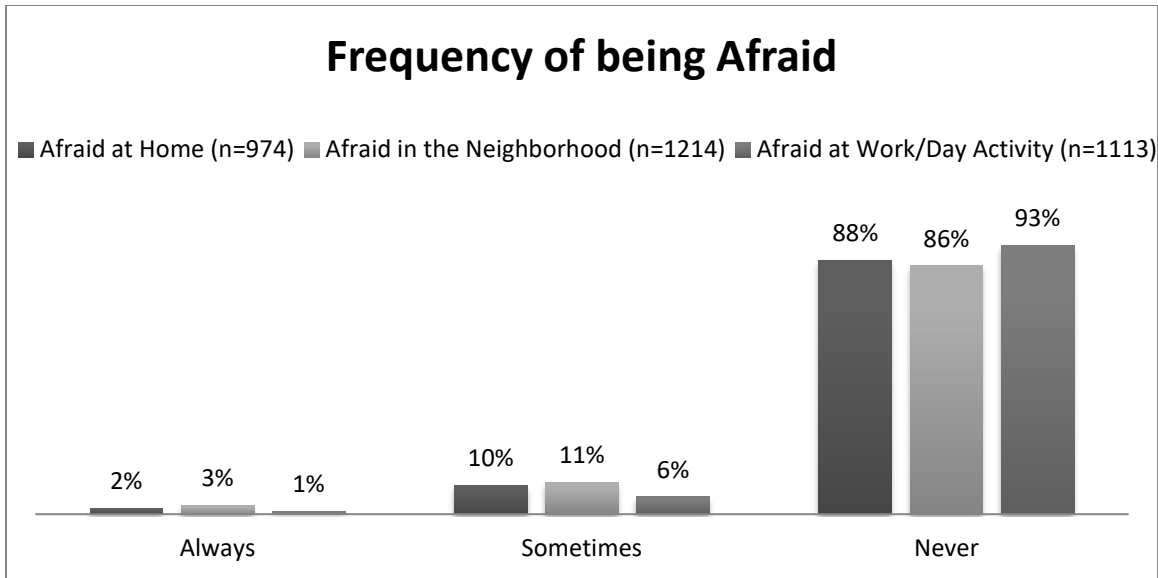
**Respondents:** Only the individual receiving services/supports could answer the questions on dignity, respect and rights. The percent of people who responded to questions in this section ranged from 44% to 77%.

### ***Support with Goals and Problems***

- 70% of people reported that they go to their family for help, 42% reported that they go to staff, 13% reported that they go to a friend, 11% go to their supports coordinator, and 9% reported that they go to someone else. 2% of individuals reported that they have no one to go to for help.
- 65% of individuals report that they get help to learn new things.
- 73% of individuals report that they get to help other people.
- 15% of individuals indicated that they have participated in a self-advocacy group meeting.
- 35% of people said someone had talked to them about self-advocacy.

### ***Being Afraid***

- 88% reported *never* being afraid at home; 10% reported sometimes being afraid at home.
- 86% reported *never* being afraid in the neighborhood; 11% reported sometimes being afraid in the neighborhood.
- 93% reported *never* being afraid at work, school or day activity; 6% reported sometimes being afraid at work, school or day activity.
- 94% reported never being afraid when using transportation; 6% reported sometimes being afraid when using transportation.
- 94% reported that they have someone they can talk to when they feel afraid.



### **Legal Rights**

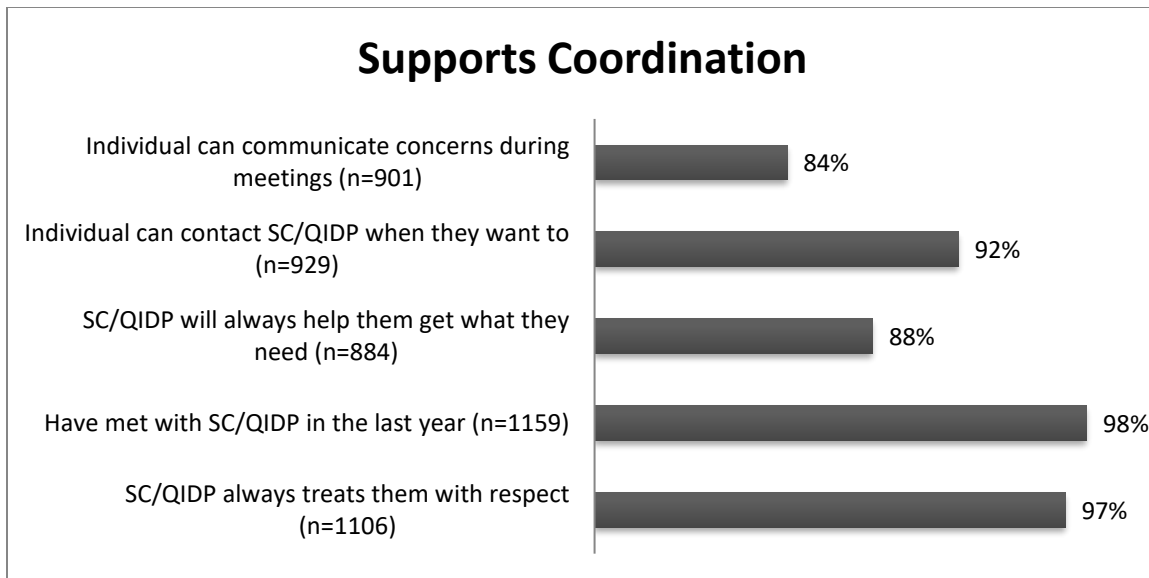
- For 80% of the individuals interviewed, their mail is never opened without permission; 12% say their mail is always opened without permission.

### **Qualified Intellectual Disability Professional (QIDP)/Supports Coordination**

- 98% said that they have met with their QIDP/support coordinator in the last year.
- 88% of individuals reported that if they ask their support coordinator will always help them get what they need; 9% said their support coordinator will sometimes help.
- 92% of individuals report that they can always contact their QIDP/support coordinator when they want to.
- 93% of individuals reported that their supports coordinator asks what their interests are.
- 83% of respondents said their supports coordinator asks them what they want their life to look like.
- 84% said the supports coordinator asks what they want in the future.
- 84% of people surveyed always have a chance during meetings to communicate their concerns.
- 97% of individuals reported that they took part in their last service planning meeting.

- 39% of individuals report that their supports coordinator has asked them about directing their own services.
- 97% of those surveyed talk with their supports coordinator about services to make sure everything is ok.
- 57% of those surveyed have been told how much money is in their annual budget.
- 63% of individuals reported that they know they have a choice of SC organizations.
- 95% reported that their ISP meeting included the people they wanted to be there.
- 81% of individuals indicated that they knew what was being talked about at their ISP meeting.
- 72% of individuals report that they talk about learning new things at their service planning meetings.
- 74% of individuals reported that they were able to choose the services they received as a part of their service plan; 18% had some input.
- 81% know who to ask if they want to change their services.
- 95% of individuals reported that their supports coordinator always listens to them; 4% said their supports coordinator sometimes listens, less than 1% said their supports coordinator never listens.
- 97% of individuals reported that the supports coordinator always treats them with respect. Less than 1% indicated that the supports coordinator never treats them with respect.





### **Staff**

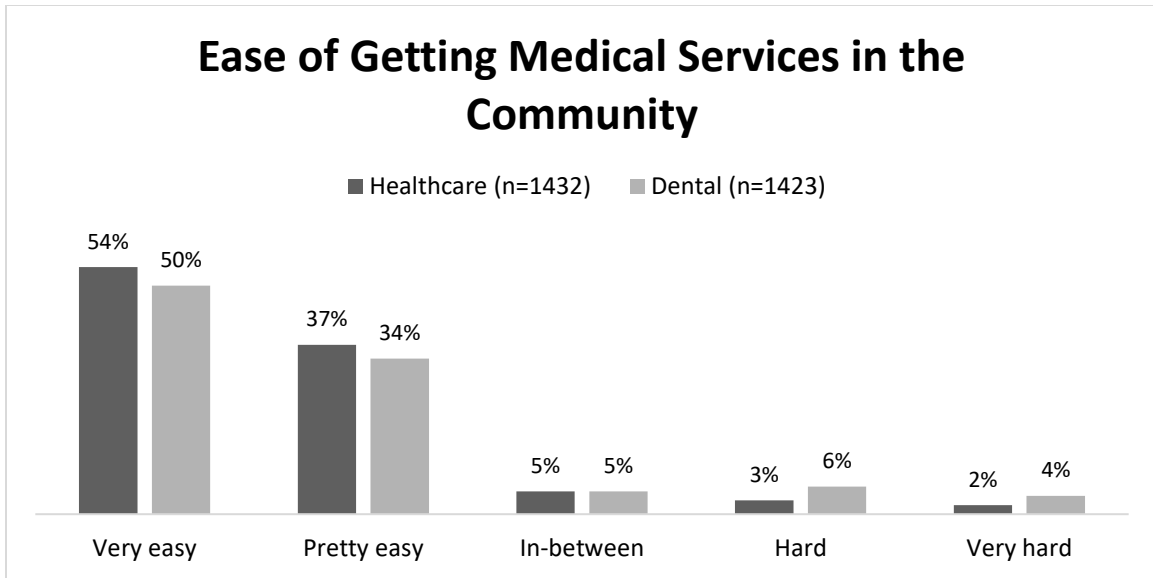
- 92% of individuals interviewed reported that their staff treats them with respect.
- 95% of individuals reported that they feel their staff has the right training to meet their needs.
- 88% of individuals report that all of their staff understand their communication; 7% say some staff understand them, 3% report that they are understood sometimes, and 1% indicated that their staff does not understand their communication.

### **Emergency Preparation Questions**

- 77% of individuals reported that someone has talked to them about what to do in an emergency.
- When asked who gave the individual information about what to do in an emergency, 65% received information from family, 34% received information from day program or employment staff, 11% from someone else, 11% from home staff, 11% from supports coordinator, 3% from police or fire department, 2% from friends, and less than 1% from the Red Cross.

### **Health Care Questions**

- When asked how many times per month they exercise at home, 48% of individuals said zero, and 27% said 10 or more times a month.
- 95% of individuals interviewed reported that they have the opportunity to discuss health with their primary care provider (PCP).
- 94% of individuals reported that they feel their doctor understands them.
- 88% of individuals say that they understood their doctors' instructions.
- 94% of respondents say if they needed help communicating at the doctor's office, it was available.
- 93% of respondents reported they were able to see if a medical specialist if they needed to, but 4% said they were not able to see a specialist due to barriers.
- 91% of individuals say they have not been prevented from receiving medical and dental services because of their disability; 9% said they had been prevented.
- When asked how hard it is to get health care services in their community, 91% of individuals reported that it was very easy or pretty easy, 5% reported that it was in-between, and 4% reported that it was very hard or hard.
- When asked how hard it is to get dental services in their community, 85% of individuals reported that it was very easy or easy, 5% reported that it was in-between, and 10% reported that it was very hard or hard.
- Of those who have a psychiatrist, 43% of individuals interviewed reported that they have the opportunity to discuss health concerns with a psychiatrist; 54% reported they do not have the opportunity to discuss their health concerns with a psychiatrist, and 3% reported they do not have a psychiatrist but want one.
- 93% of individuals reported that their doctor speaks directly to them during appointments.
- 67% of individuals reported that they are able to provide consent for medical treatment; of those able to provide consent, 87% said their doctor accepts their consent and 13% say their consent is not accepted.



Two distinct scales were created to represent this section of the survey.

**Dignity and Respect Scale:** The Dignity and Respect Scale included three measures that asked whether housemates/ roommates, staff at home, and staff at work/day activity are nice or mean. Scores on the Dignity and Respect Scale could range from 0 to 100, with a higher score indicating greater dignity and respect (people treating you as they would wish to be treated).

- The average (mean) score was 84.74 with a standard deviation of 14.63.
- The modal (most common) score was 75, reported by 45% of individuals.

**Safety Scale:** The scale included three measures that asked individuals if they feel afraid in their home, neighborhood, or at work/day activity. Scores on the Safety Scale could range from 0 to 100, with a higher score indicating less fear.

- The average (mean) score was 93.20 with a standard deviation of 15.15.
- The average is quite high, indicating there was not a great deal of fear reported among individuals receiving supports and services. The mode of 100 indicates that many individuals (78%) reported that they never feel afraid in their home, neighborhood or work/day activity site.

There were several differences regarding this year's data in the Dignity, Respect and Rights section when compared with data from 2017-2018:

- There was a 26% **increase** in the percentage of individuals who report that all of their staff understand their communication efforts.
- There was a 7% **decrease** in the percentage of individuals who report that they go to staff for support with goals and problems.
- There was a 3% **decrease** in the percentage of individuals who report that they go to family for support with goals and problems.
- There was a 4% **decrease** in the percentage of individuals who reported that they had participated in a self-advocacy meeting or that anyone had talked to them about self-advocacy.
- There was a 14% **decrease** in the percentage of individuals who said their supports coordinator had asked them about directing their own services.
- There was a 9% **decrease** in people surveyed who report that they are told their budget during service meetings.
- There was a 3% **decrease** in those who reported their supports coordinator asks what they want their life to look like.
- There was a 3% **decrease** in those who said they know they have a choice of supports coordinators.
- There was a 4% **decrease** in the percentage of individuals who report that they get to help other people.
- There was a 5% **decrease** in the percentage of the individuals interviewed who reported their mail is never opened without permission. (This follows a 3% decrease in last year's report).
- Regarding exercise habits, there was an 8% **increase** in those who reported that they never exercise at home and a 15% **decrease** in those who reported exercising 10 times per month or more at home.
- There was a 7% **decrease** in those who reported someone had talked to them about what to do in the case of an emergency.

## **Choice and Control**

**Respondents:** The questions in the choice and control section were answered by the individual receiving supports, a family member, a friend, advocate or paid staff. On the average,

- 40% of the questions were answered by the individual receiving supports.
- 4% of the questions were answered by paid staff.
- 5% of the questions were answered by the consumer and staff.
- 22% of the questions were answered by family/friend/advocate/guardian.
- 29% of the questions were answered by the consumer and family/friend/advocate/guardian.
- 1% of the questions were answered by staff and family/friend/advocate/guardian.
- A value of missing was assigned when individuals did not answer, gave an unclear answer, or responded, "Do not know."

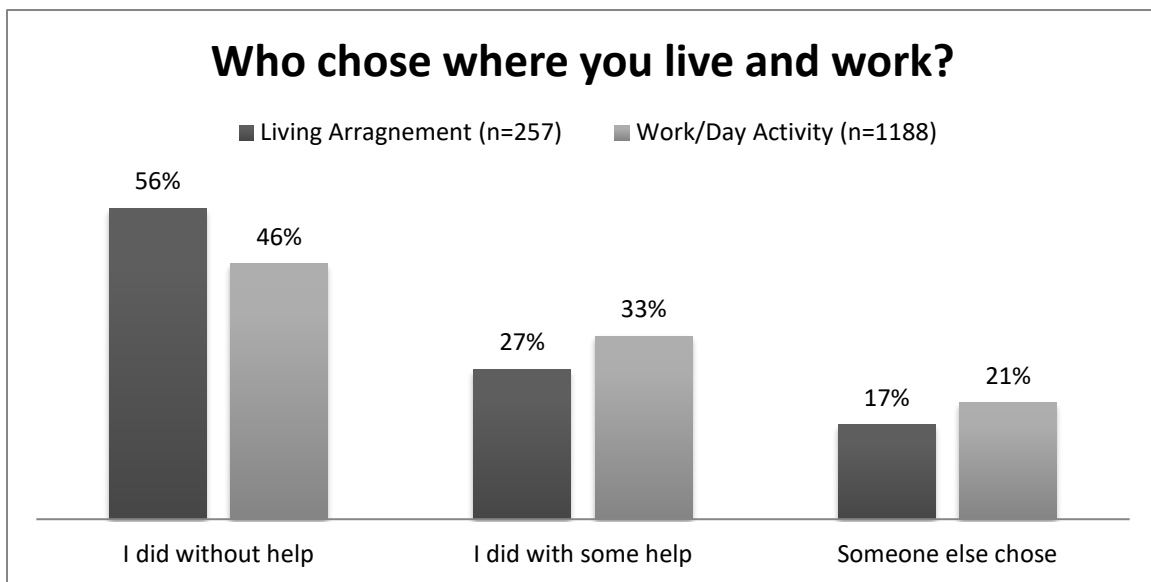
## ***Forms of Identification***

- 68% of individuals stated that they always carry a form of identification; 16% never do.

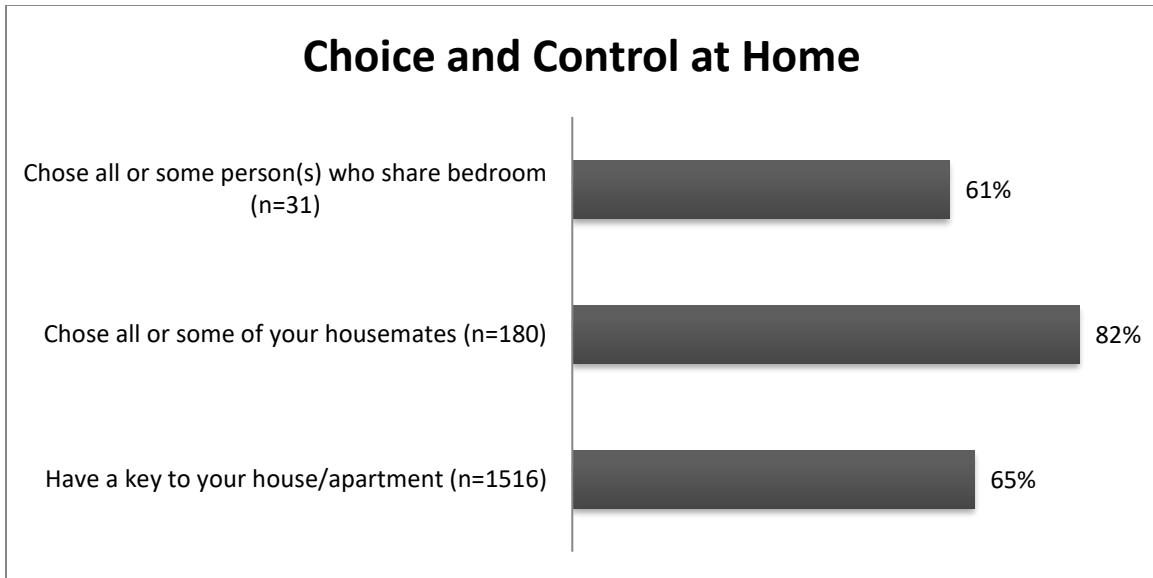
## ***Choice and Control at Home***

- 65% of the individuals surveyed had a key/way to get into to their house or apartment on their own. **According to data from the 2019-2020 statewide sample, only 49% had a key to their home. Because a large percentage of individuals in this sample live their family homes, it is not surprising that this percentage is higher in this report than in the statewide report.**
- 63% of respondents said that if other members of their house go out, they have the option to stay home; 11% sometimes have the option to stay home.
- 53% of respondents can lock their bedroom door if they want to.
- 4% of individuals reported that they own their own home.
- 22% of individuals report that their name is on the lease or rental agreement.

- For 17% of the individuals, someone else chose where they live; 56% of those interviewed chose without assistance. **The statewide data show that someone else chose living arrangements for 42% of the individuals and only 30% chose without assistance.**
- 87% of individuals said they were given a choice to live where people without disabilities live. **The statewide data show that 54% of the overall sample are given a choice to live where people without disabilities live.**
- 46% of individuals saw no other places before they moved into their residence.



- 18% of the individuals **did not** choose their housemates.
- For those who shared a bedroom, 58% chose who shares the room with them and 39% reported that someone else chose who shares their bedroom.

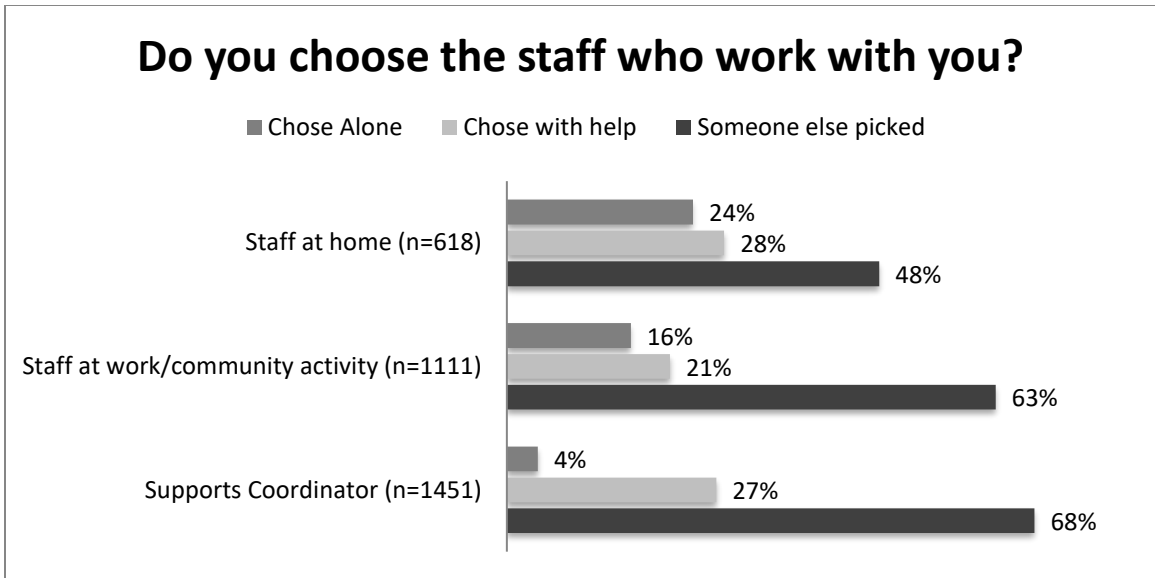


#### ***Choice and Control During the Day and for Leisure Time***

- 21% of the individuals interviewed reported that someone else chose what they do during the day.
- 58% of the people interviewed chose what they do during the day without assistance.
- 62% of individuals reported that when they chose their work or day activity, they had an option to go where people without disabilities go.
- 37% saw no other places when choosing what they do during the day.
- 91% of the individuals surveyed chose their daily schedules without assistance.
- 94% say they have enough choice about how they spend their free time.

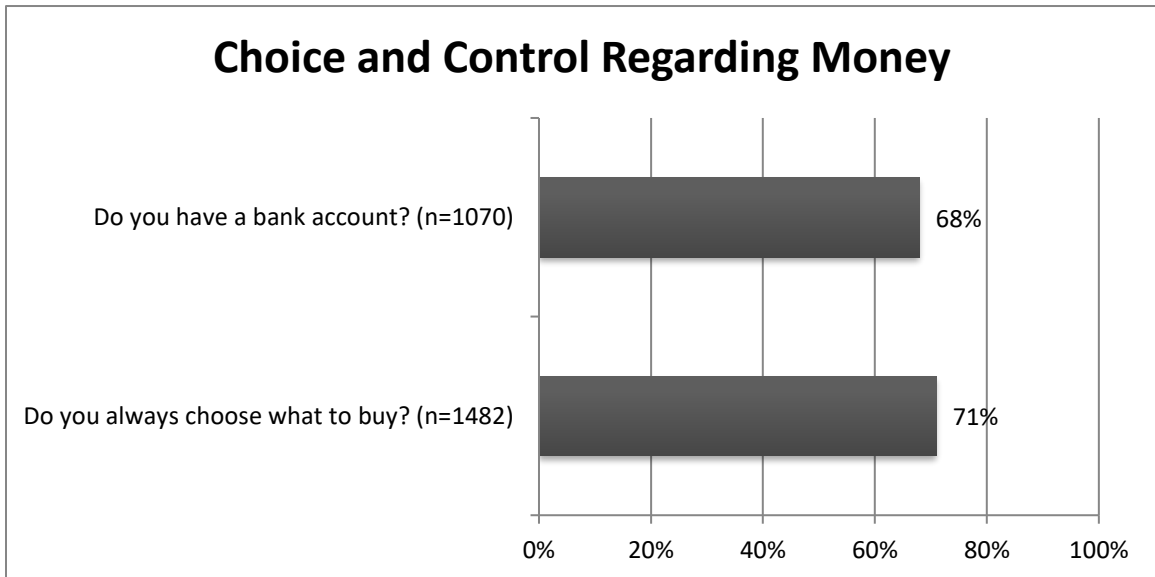
#### ***Choice and Control in Choosing Staff***

- 52% of the individuals interviewed chose at least some of the staff who help them at home (alone or with assistance). **According to data from the 2018-2019 statewide sample, 34% interviewed chose the staff who help them at home.**
- 37% of the individuals surveyed interviewed chose the staff who help them at work/day activity (alone or with assistance).
- 32% of individuals chose their supports coordinators (alone or with assistance).



### ***Choice and Control with Regard to Money***

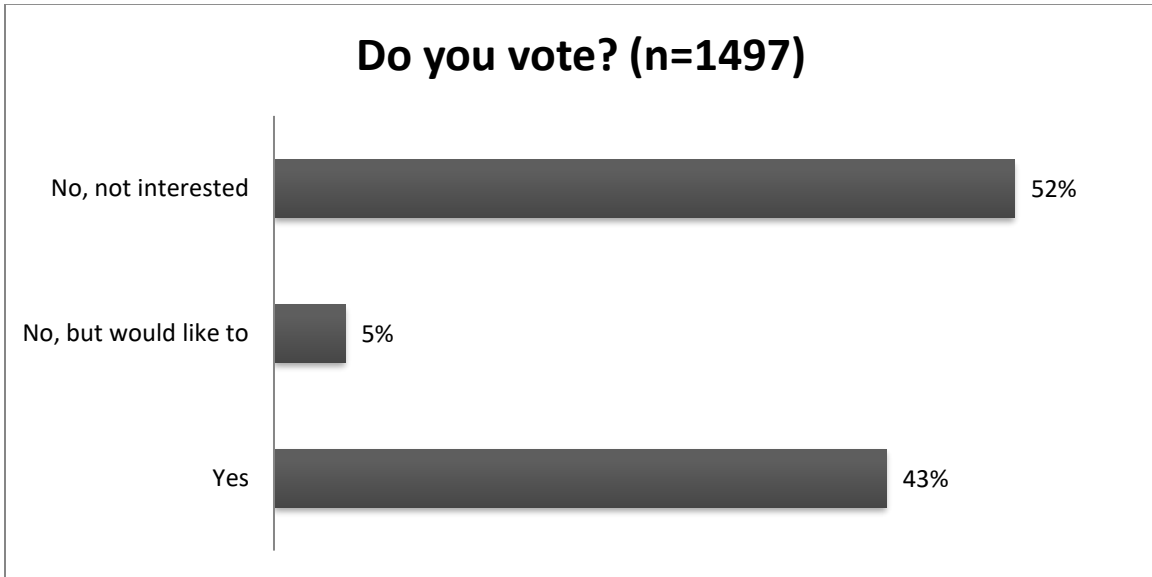
- 71% of the individuals reported that they always choose what to buy with their spending money, 23% report that they choose with help.
- 40% of the individuals reported that there is something they want to buy.
- 68% of the individuals reported they have a bank account that they can get to independently to withdraw money when they want it.



### ***Voting***

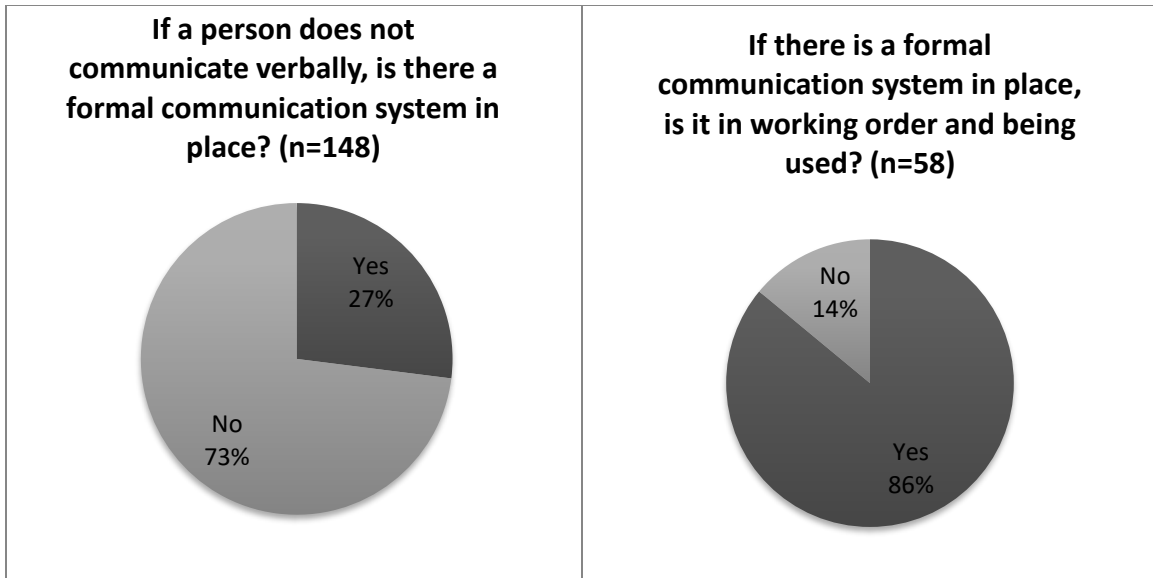


- 43% of people said that they vote; 52% of individuals do not vote and are not interested in voting, and 5% do not vote but would like to. It is our hope that individuals have the opportunity to learn the importance of voting.



### ***Access to Communication***

- For those individuals who do not communicate using words, there is a formal communication system in place for 27% of the people interviewed.
- For those people with formal communication systems in place, 94% reported that the systems are in working order; if the communication system was in place and working, it was being used regularly for 86% of the people interviewed.
- 68% of individuals with a formal communication system reported using it across all settings.
- 65% of individuals with a formal communication system are supported by a parent or caregiver, 40% are supported by their staff or a program coordinator, 31% are supported by a speech and language clinician, and 8% are supported by someone else.



With regard to other forms of communication:

- 47% have and use a cell phone; there are restrictions for 7% of these people.
- 23% have and use e-mail; there are restrictions for 2% of these people.
- 41% have and use internet; there are restrictions for 9% of these people.
- 32% have and use text-messaging; there are restrictions for 3% of these people.
- 78% have and use cable television; there are restrictions for 6% of these people.
- 47% have and use a computer; there are restrictions for 8% of these people.

**Choice and Control Scale:** The scale included eight measures that asked individuals about the extent to which individuals have choice and control in their lives. Scores on the Choice and Control Scale could range from 0 to 100, with a higher score indicating more opportunities to exert choice and control.

- The average (mean) score was 63.60 with a standard deviation of 19.87.
- The modal score was 76.32, indicating the most frequent score.

There were many differences regarding this year's data in the Choice and Control section when compared with data from 2017-2018:

- There was a 4% **increase** in the percentage of the individuals surveyed who had a key/way to get into to their house or apartment on their own.

- There was a 6% **increase** in the percentage of individuals who said they always carry identification.
- There was a 7% **increase** in the percentage of individuals surveyed who reported that they vote in elections.
- There was an 9% **increase** in the percentage of people interviewed who reported that they chose where they live where they live without assistance.
- There was an 5% **decrease** in the percentage of the individuals surveyed who reported that they did not choose their housemates.
- There was a 10% **increase** in the percentage of people who reported that if they share a bedroom, they chose some or all of their roommates.
- There was a 6% **increase** in the percentage of the people interviewed who chose what they do during the day without assistance.
- There was a 12% **decrease** in the percentage of individuals who chose their supports coordinators alone or with assistance.
- There was a 4% **decrease** in the percentage of individuals surveyed who reported that they chose those who helped them at their work or day activity.
- There was a 3% **decrease** in the percentage of individuals surveyed who reported that they chose those who helped them at home.
- There was a 26% **increase** in the percentage of individuals who reported they chose their daily schedule without assistance.
- There was a 4% **increase** in individuals with a formal communication system in place who report the system is being used regularly.
- There was an 9% **increase** in the percentage of people with formal communication systems who are supported by speech and language clinicians, an 8% **decrease** in people supported by a parent/caregiver, and a 3% **decrease** in individuals who are supported by staff or program coordinator.
- In terms of people's access to other forms of communication, this year's responses indicate **increases** in those who have and use a cell phone (8%), email (4%), Internet (5%), and text messaging (7%).

## **Employment**

**Respondents:** Of the 1458 individuals surveyed as part of the PFDS sample, 24% (n=344) answered that they are employed in a community integrated setting.

### ***Community Integrated Employment***

- 24% (n=344) of individuals work in a community integrated setting while 82% do not work at all.
- The majority of individuals have been employed for 1 to 3 years (32%). 20% of individuals have been employed for less than one year, 17% have been employed for 4-6 years, 12% have been employed for 7-10 years, and 18% have been employed for more than 11 years.

### ***Types of Work***

- Of those who report that they work, 27% of individuals work in cleaning services, 19% work in retail, 26% work in food services, 2% do office work, 8% work in a stock room or stock shelves, 3% work in maintenance, 4% work in assembly or factories, 2% work as care-workers or aides, 1% work in animal care, less than 1% work in landscaping or outdoors, and 8% work in some other occupation.

### ***Supports Getting into the Workplace***

- 12% of individuals take classes or training to help you get a job in the community, get a better job, or do better at their current job.
- 63% of individuals surveyed reported that someone had talked to them about employment in their planning meeting.
- When asked who had talked to them about employment, 38% indicated no one, 56% said their supports coordinator, 10% said their service provider, 19% said their family, less than 1% said their housemates, and 6% said someone else.

***Note: individuals answering this question had the option to indicate more than one response.***

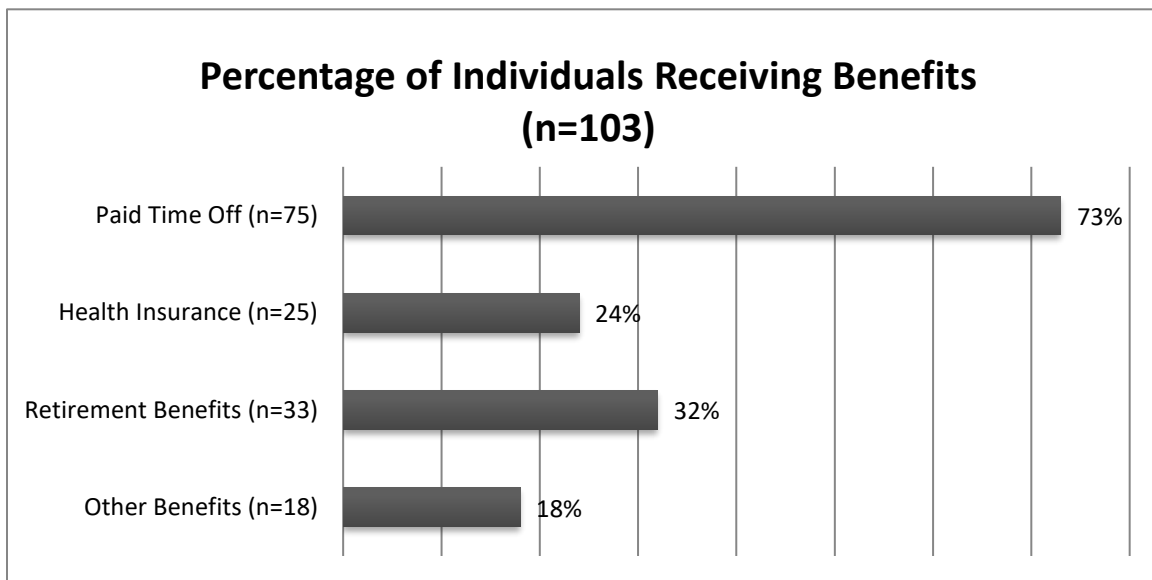
### ***Compensation, Advancement and Type of Work***

- 103 individuals reported receiving some kind of benefits package in addition to their pay. 73% received paid time off, 32% received retirement benefits, 24%

received health insurance, and 18% received some other kind of benefit.

Individuals answering this question had the option to indicate more than one response.

- 53% of individuals have been promoted and/or received an increase in pay.
- The mean number of hours worked per week was 16.25. Hours worked per week ranged from 1 to 40; the most common responses were 12 (N=33), 20 (N=48), and 25 (N=27) hours per week.
- 85% of individuals reported that they know how much they earn and are willing to share it.
- Individuals reported hourly wages ranging from \$7.25 to \$15.00.
- The most common hourly wage, reported by 41% of individuals, was \$9.01 - \$12.00. 23% of individuals earned \$7.25, 28% of individuals reported earning \$7.26 to \$9.00 an hour, and 8% earned more than \$12.01 per hour.



**Self-employment:**

- Of the 322 individuals who have community integrated employment, 2% (n=19) of individuals are self-employed.

There were several differences regarding this year's data in the Employment section when compared with data from 2017-2018:

- Among the types of jobs supported, there was a 9% **increase** in people who reported that they worked in cleaning professions, and there was a 6% **decrease** in those who worked in assembly professions.
- There was a 13% **increase** in individuals reporting they have been promoted and/or received a pay increase.
- Of those who received benefits, there was an 7% **decrease** in people who reported receiving paid time off as a benefit and a 20% **increase** in people that received health insurance as a benefit, there was a 12% **increase** in people who received retirement benefits and there was a 7% increase in people who reported receiving some other kind of benefit.

## **Self-Directed Supports**

**Respondents:** Of the 1502 individuals surveyed as part of the PFDS sample, 98 people indicated they use self-directed supports.

- 6% of respondents report that they use self-directed supports while 94% do not.

Among those individuals using self-directed supports,

- 10% make most of the decisions about how their budget for services is used on their own; 42% have input but family and friends help, 40% say a family member or friend makes decisions, and 8% report that a case manager or another state professional makes the decision.
- 70% participate in decisions about budget, staff, and managing services.
- 78% hire and manage their own staff.
- 88% can make changes to their budget or services if they need to.
- 93% say they have enough help deciding how to use their budget/services, while 4% want more help.
- 83% receive information about the money left in their budget.
  - Of these, 86% say the information is easy to understand.
  - 64% receive this information at least every three months, 14% report they receive the information about twice a year, and 21% receive information once a year or less.

## **Relationships**

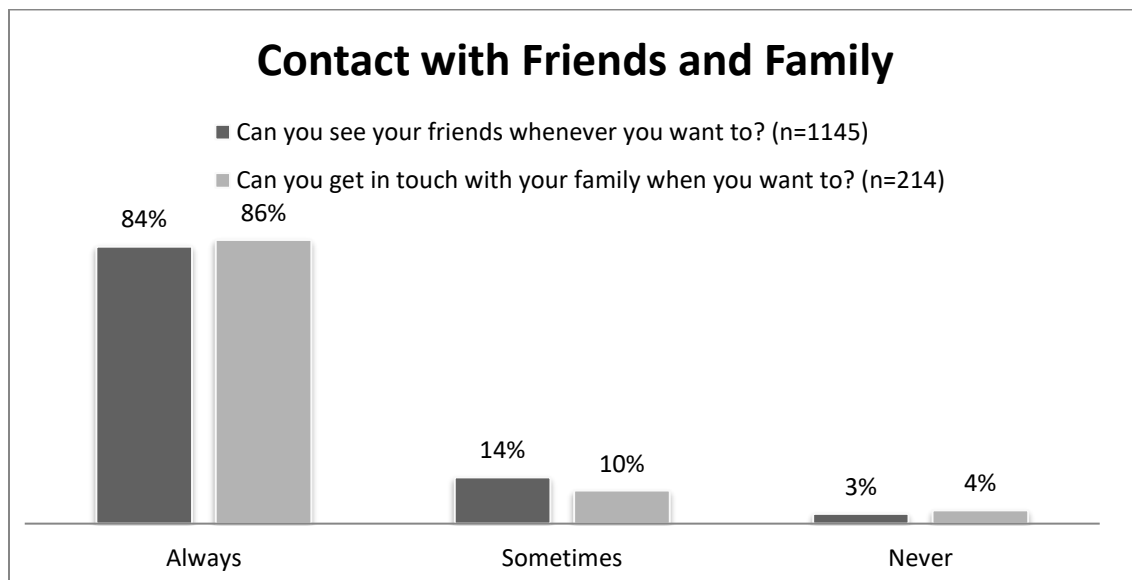
**Respondents:** The questions on relationships could be answered by the individual receiving services/supports, a family member, a friend, or paid staff.

- 48% of the questions were answered by individuals receiving supports.
- 4% were answered by paid staff.
- 4% were answered by individuals receiving support and staff.
- 22% were answered by family/friend/guardian/advocate.
- 21% of the questions were answered by individuals receiving support and a family/friend/guardian/advocate.

- Less than 1% of the questions were answered by staff and family.
- A value of missing was assigned when individuals did not answer, gave an unclear answer, or responded, “Do not know.”

### **Contact with Friends and Family**

- 84% of individuals were always able to see friends whenever they wanted.
- 71% reported there are no rules against having friends or visitors in their home.
- Of individuals that reported that they were unable to see their friends whenever they wanted, 21% reported that they couldn’t see their friends because it was difficult to find time, 32% reported that there was of a transportation issue, 7% reported that there were rules/restrictions, 2% reported a lack of staff, and 35% reported that there was another reason why they couldn’t see friends.
- 86% of respondents were always able get in touch with family whenever they wanted.



There was one substantial difference regarding this year’s data in the Relationship section when compared with data from 2017-2018.

- There is an 3% **decrease** in people that can see friends whenever they want to.



## **Inclusion**

**Respondents:** The questions on inclusion could be answered by the individual receiving services/supports, a family member, a friend, or paid staff.

- 39% of the questions were answered by individuals receiving supports.
- 3% were answered by paid staff.
- 6% were answered by individuals receiving support and staff
- 22% were answered by family/friend/guardian/advocate.
- 30% of the questions were answered by individuals receiving support and a family/friend/guardian/advocate.
- 1% of the questions were answered by staff and family.
- A value of missing was assigned when individuals did not answer, gave an unclear answer, or responded, "Do not know."

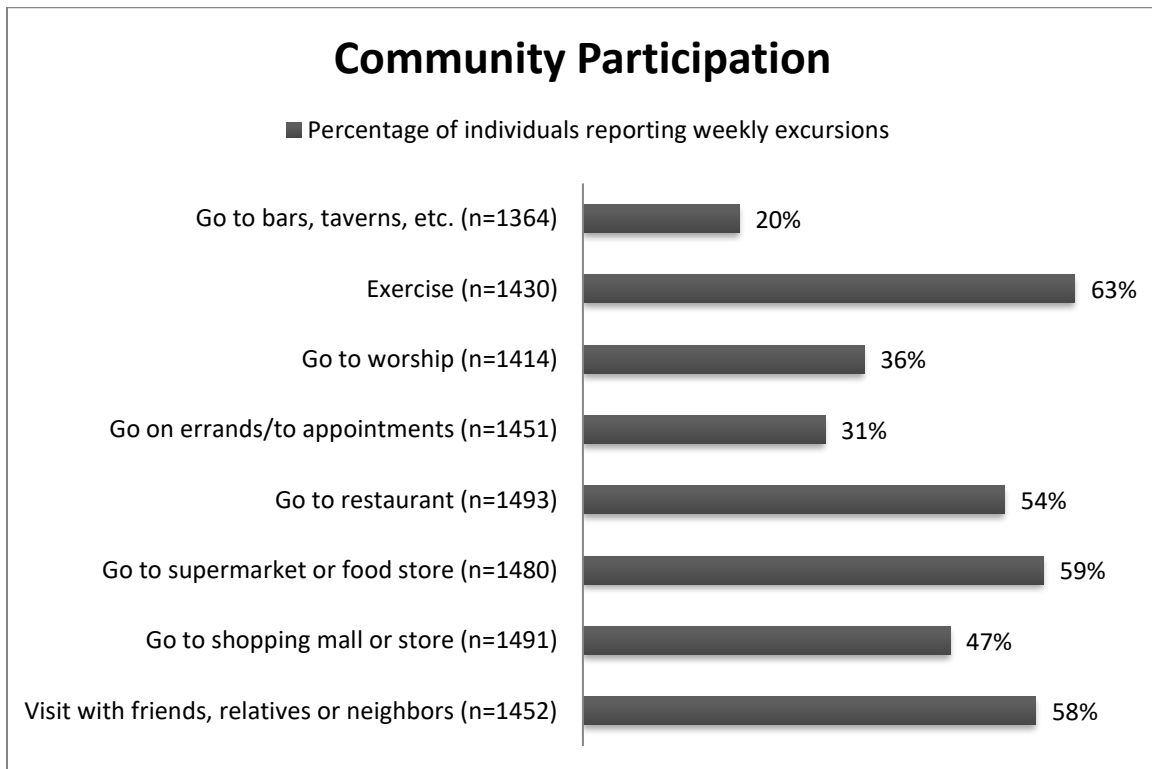
## ***Community Participation***

- 58% of the people visited with friends, relatives and neighbors at least weekly.
  - When they visited friends, relatives and neighbors, individuals reported they went alone 19% of the time, with family 61% of the time, with staff 6% of the time, with friends 14% of the time, with someone else or with housemates or coworkers less than 1% of the time.
  - 81% of individuals said this was enough time to visit friends, 18% wanted more, but 1% wanted less.
- 59% of those surveyed went to a supermarket at least weekly.
  - When they went to the supermarket, individuals reported they went alone 8% of the time, with family 71% of the time, with staff 16% of the time, with friends 4% of the time, with someone else or with housemates or coworkers less than 1% of the time.
  - 88% of individuals said this was enough time to go to the supermarket, 9% wanted more, but 3% wanted less.
- 54% of respondents went to restaurants at least weekly.
  - When they went to a restaurant, individuals reported they went alone 5% of the time, with family 68% of the time, with staff 17% of the time, with

friends 9% of the time, and with housemates, coworkers, or someone else 1% of the time.

- 80% of individuals said that they visited restaurants just enough, 17% wanted more and 3% wanted less.
- 47% of individuals went to a shopping center or mall at least weekly.
  - When they went shopping, individuals reported they went alone 6% of the time, with family 62% of the time, with staff 25% of the time, with friends 7% of the time, and with housemates, coworkers, or someone else 1% of the time.
  - 84% of individuals said they went to shopping centers or malls often enough, 13% wanted more and 3% wanted less.
- 36% of respondents went to places of worship at least weekly.
  - When they went to worship, individuals reported they went alone 7% of the time, with family 81% of the time, with staff 5% of the time, with friends 6% of the time, with someone else 1% of the time, and with housemates or coworkers 1% of the time.
  - 90% of individuals report they go to worship often enough, while 1% wanted more and 1% wanted less.
- 31% of people run errands or go to appointments at least weekly.
  - When they went on errands or to appointments, individuals reported they went alone 10% of the time, with family 72% of the time, with staff 14% of the time, with friends 3% of the time, with someone else or with housemates or coworkers less than 1% of the time.
  - 91% of individuals said this was enough time for errands and appointments, 6% wanted more and 3% wanted less.
- 20% of individuals go to bars, taverns, nightclubs, or coffee houses to meet and be with people at least weekly.
  - When they went to a bar, coffee shop, etc., individuals reported they went alone 11% of the time, with family 55% of the time, with staff 22% of the time, with friends 11% of the time, with housemates or coworkers 1% of the time, and with someone else less than 1% of the time.

- 86% of individuals reported that they had enough time to visit night clubs, coffee houses or taverns but 12% wanted more and 1% wanted less.
- 29% of individuals go out for entertainment at least weekly.
  - When they went out for entertainment, individuals reported they went alone 5% of the time, with family 61% of the time, with staff 20% of the time, with friends 13% of the time, with housemates or coworkers 1% of the time, and with someone else less than 1% of the time.
  - 79% of individuals said they went out for entertainment enough, 20% wanted more and 1% wanted less.
- 63% of respondents go out to exercise at least weekly.



### **Harris Poll**

In May and June 2010, the National Organization on Disability commissioned Harris Interactive, Inc. to conduct a national phone survey to examine and compare the quality of life and standard of living for people with and people without disabilities. We compared the frequency of weekly community participation reported by individuals in our Independent Monitoring for Quality (IM4Q) sample to this national sample. The

Harris Poll depends on self-report in determining whether a person has a disability and defines someone with a disability as someone who

“has a health problem or disability that prevents him or her from fully participating in work, school, housework or other activities; *or* reports having a physical disability of any kind; a seeing, hearing, or speech impairment; an emotional or mental disability; or a learning disability; *or* considers himself or herself a person with a disability” (Harris, 2010, p. 33).

A summary of results that were comparable on IM4Q and the Harris Poll are provided below:

- Pennsylvanians with disabilities receiving supports through the PFDS waiver were more likely to visit with friends, relatives and neighbors, go to a restaurant, and go to a place of worship, than people with disabilities in the Harris Poll and in the Statewide Independent Monitoring sample.
- Pennsylvanians with disabilities receiving supports through the PFDS waiver were more likely to go to a restaurant and go to a place of worship than people without disabilities in the Harris Poll.

<b>Weekly Participation in Community Activities</b>				
	<b>Harris 2010: People without Disabilities</b>	<b>Harris 2010: People with Disabilities</b>	<b>Independent Monitoring (Statewide)</b>	<b>Independent Monitoring (PFDS)</b>
<b>Visit with friends, relatives and neighbors</b>	65%	54%	51%	58%
<b>Go to a restaurant</b>	41%	20%	51%	54%
<b>Go to worship</b>	28%	24%	31%	36%

### ***Inclusion Scale***

Scores on the Inclusion Scale could range from 0 to 100, with a higher score indicating greater inclusion (going more frequently to places in the community). The scale includes 7 items measuring frequency of participation in community activities. These items include visiting with friends, going to the supermarket, going to a restaurant, going to worship, going to a shopping mall, going to a bar, and going on errands.

- The average score was 48.59 with a standard deviation of 16.48.
- The average score was less than half of the possible scale score, indicating that individuals do not go to community places with great frequency.
- The mode, which is the most frequent score, was 50.00.

### ***Community Activities***

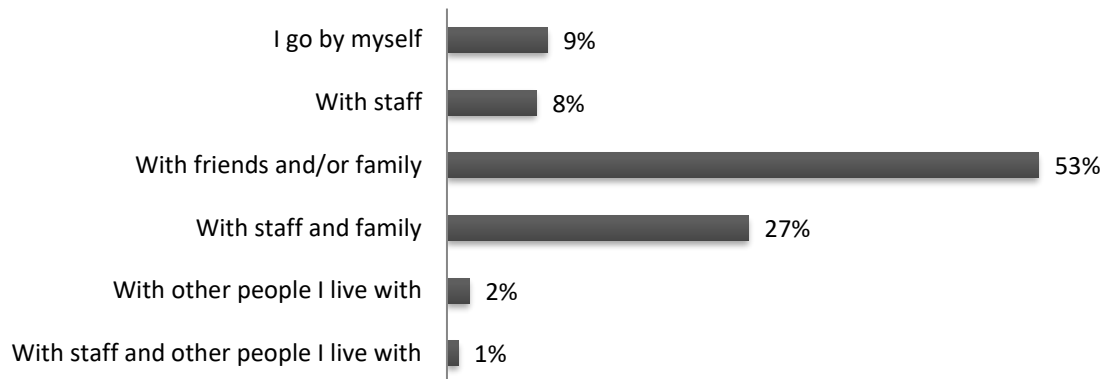
We asked individuals about several other types of community activities including attending social events and recreational events.

- 58% of individuals go into the community for entertainment frequently and 32% go occasionally.
- 42% of individuals reported that they frequently go to social events that are attended by anyone in the community and 40% go occasionally.
- 35% of individuals would like to be a part of more groups in their community.
- 58% of individuals went on a vacation in the past year.
- Regarding monthly exercise, 33% of individuals reported never going out for exercise, 4% exercise less than weekly, 13% exercise once a week and 50% of individuals exercise more than once a week.

### ***Going Out Alone or With Other People***

- 9% of individuals go out alone; 53% of individuals go out with friends and/or family most of the time.
- 35% of individuals go out with staff or staff and family most of the time.

## Most of the time, when you go into the community who do you go with? (n=1365)

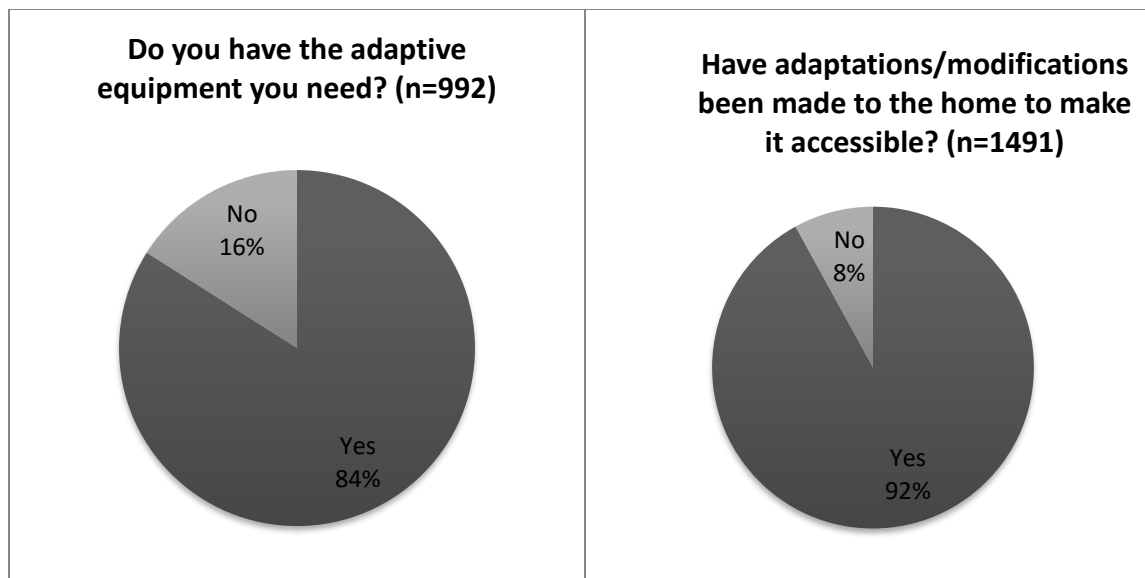


### **Transportation**

- 90% of individuals always had a way to get where they wanted to go.
- In order to get to places they needed to go, 64% of individuals reported getting a ride from family or friends, 11% get a ride from staff in a staff member's car, 6% transport themselves, 6% get a ride from staff in the provider van, 5% ride paratransit, 8% take public transportation, and less than one percent take a taxi, Uber or Lyft.
- Of those who cannot always get where they want to go, 3% reported that they cannot get where they want to go because they only have transportation for work/school, 9% reported that there is not enough staff to take them, 16% reported that para-transit or public transportation is unreliable, and 4% reported that no one who works at their home can drive them. 68% indicated there is another reason why they cannot get where they want to go.

### **Home Adaptive Equipment**

- 84% of individuals reported having all the adaptive equipment they needed.
- 92% of people said that all necessary modifications have been made to their home to make it accessible.



There were several differences regarding this year's data in the Inclusion section when compared with data from 2017-2018:

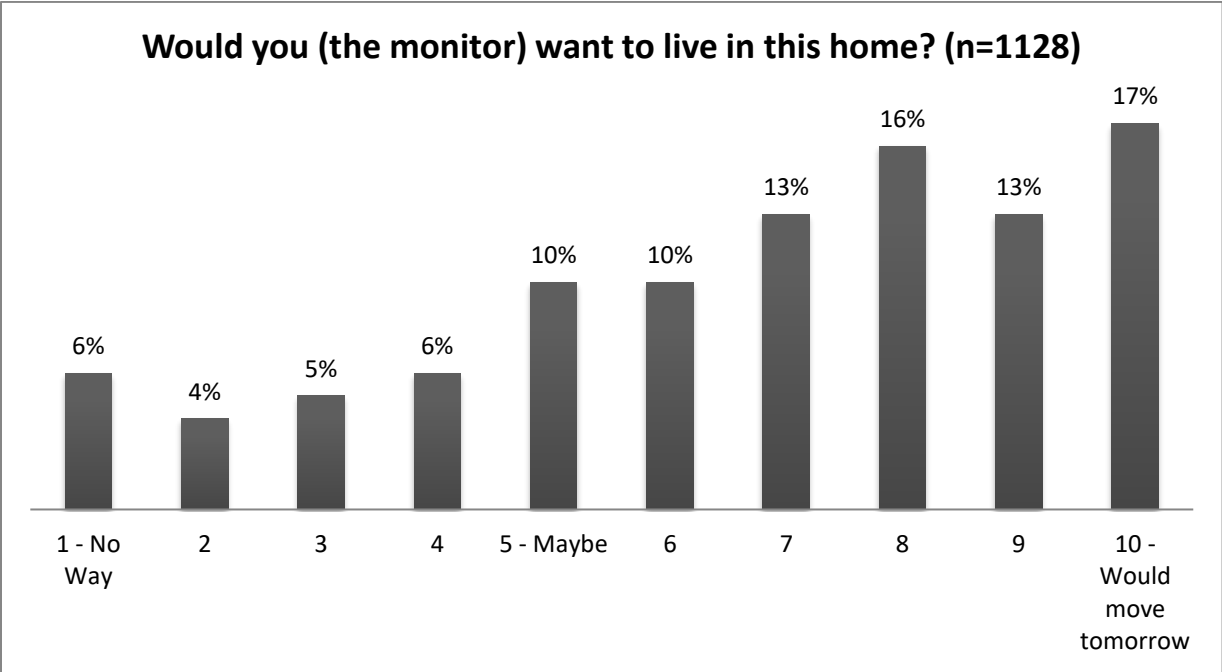
- There is a 5% **decrease** in people who report that they visit friends, relatives and neighbors at least weekly.
- There is a 4% **decrease** in people who report that they go to a supermarket at least weekly.
- There is a 3% **decrease** in people who report that they go out to eat at least weekly.
- There is a 3% **increase** in people who report that they often go out alone.
- There is a 10% **increase** in people that report they go out with friends and/or family most of the time.
- There is a 11% **decrease** in people that report they go out with staff or staff and family most of the time.
- There is a 4% **increase** in people who report that they use public transportation to get where they need to go.
- When asked why they sometimes cannot get where they need to go, there was a 4% **decrease** of people who said that transportation is for work or school only, a 5% **decrease** of people who said there is not enough staff, and an 8% **increase** of people who said there was another reason.

**Competence, Personal Growth and Opportunities to Grow and Learn**

**Respondents:** The Independent Monitoring Team answered the questions on competence, personal growth, and opportunities to grow and learn after they spent time with the individual in his/her home or other place of his/her choosing.

According to the IM4Q teams,

- When asked whether team members would want to live in the individual’s home on a scale of 1 (“No way”) to 10 (“I’d move in tomorrow”), the average score was 6.72.



There were some major differences regarding this year’s data when compared with data from 2017-2018.

- There was a 5% **increase** in the number of IM4Q teams who provided a score of 3-5 when asked if they would want to live in the individual’s home.
- There was a 5% **decrease** in the number of IM4Q teams who provided a score of 8-10 when asked if they would want to live in the individual’s home.



## **Staff Support for the Person**

**Respondents:** The Independent Monitoring Team answered the questions on staff support for the person, after having spent time with the person and the staff who support them.

### ***Number of Staff and Staff Skill***

According to the IM4Q teams,

- Staff treated individuals with dignity and respect in 93% of observed situations.
- 92% felt all staff observed recognized the individuals in ways that promote independence.
- 92% of respondents reported that support individuals at home and/or work appeared to have the skills they needed to support the person.

There were no major changes regarding this year's data in the Staff Support for the Person section when compared with data from 2017-2018.

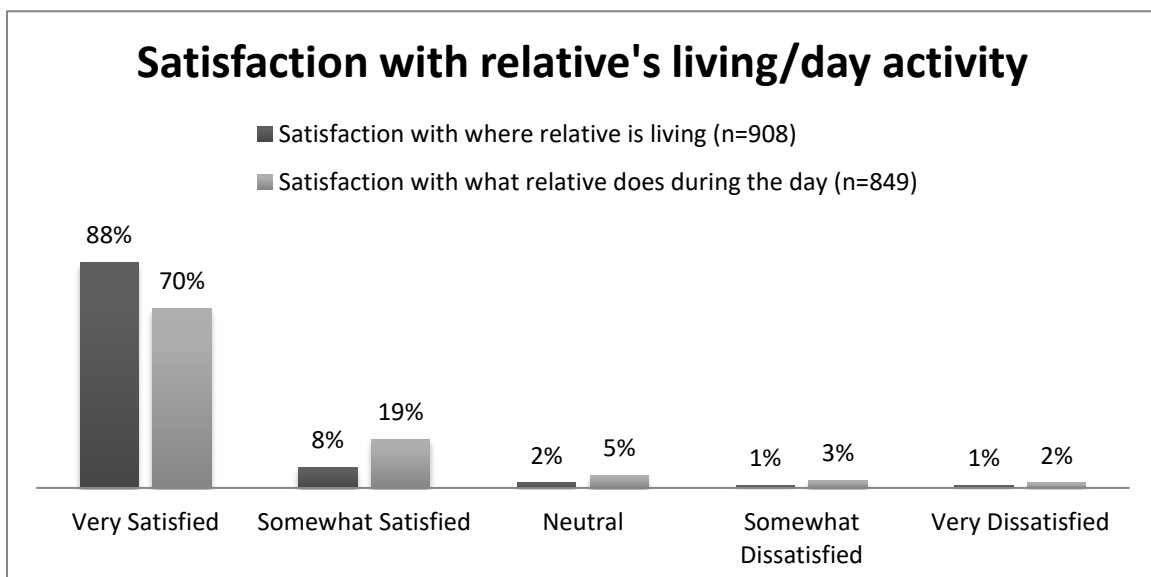
## **Family/Friend/Guardian Survey**

**Respondents:** This survey was completed by telephone or face-to-face with a family member, guardian, or friend who was identified through the Essential Data Elements Pre-Survey. In the event that a phone or face-to-face survey could not be completed, surveys were completed by mail. Nine hundred twenty-three family members, friends, and guardians participated in the survey.

- 83% of the surveys were answered by parents.
- 11% were answered by siblings.
- 1% were answered by the guardian.
- 6% were answered by persons with other relationships to the individual receiving supports.

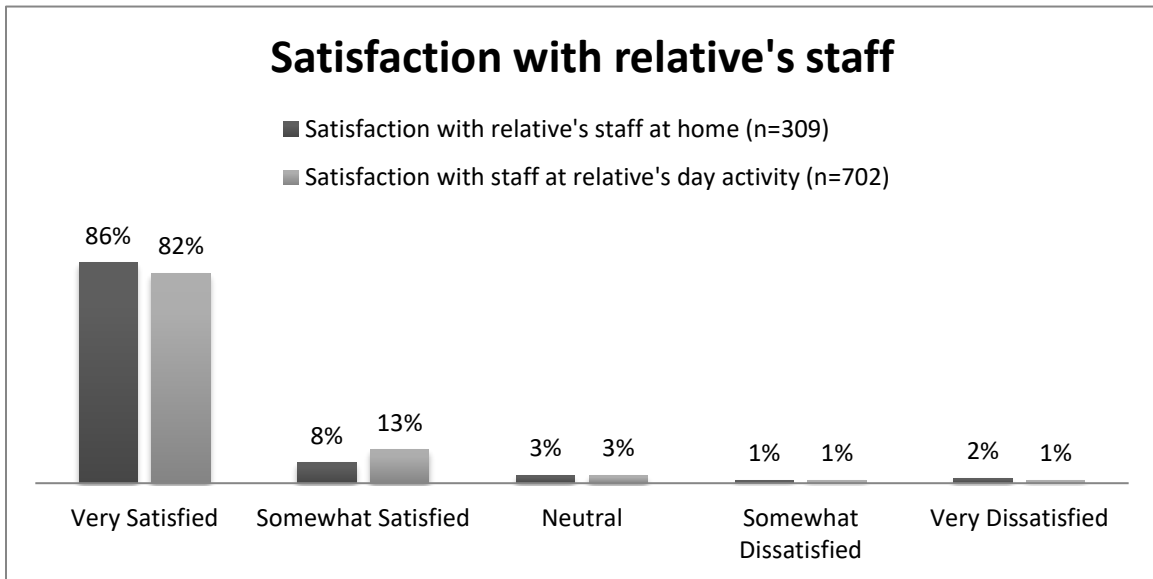
### **Satisfaction**

- 96% of the families surveyed, were either somewhat satisfied or very satisfied with where their relative lives.
- 89% were either satisfied or very satisfied with what their relative does during the day.



- 94% of the families surveyed were either somewhat satisfied or very satisfied with their relatives' staff at home.

- 96% of the families surveyed were either somewhat satisfied or very satisfied with the staff at their relatives' day activity.

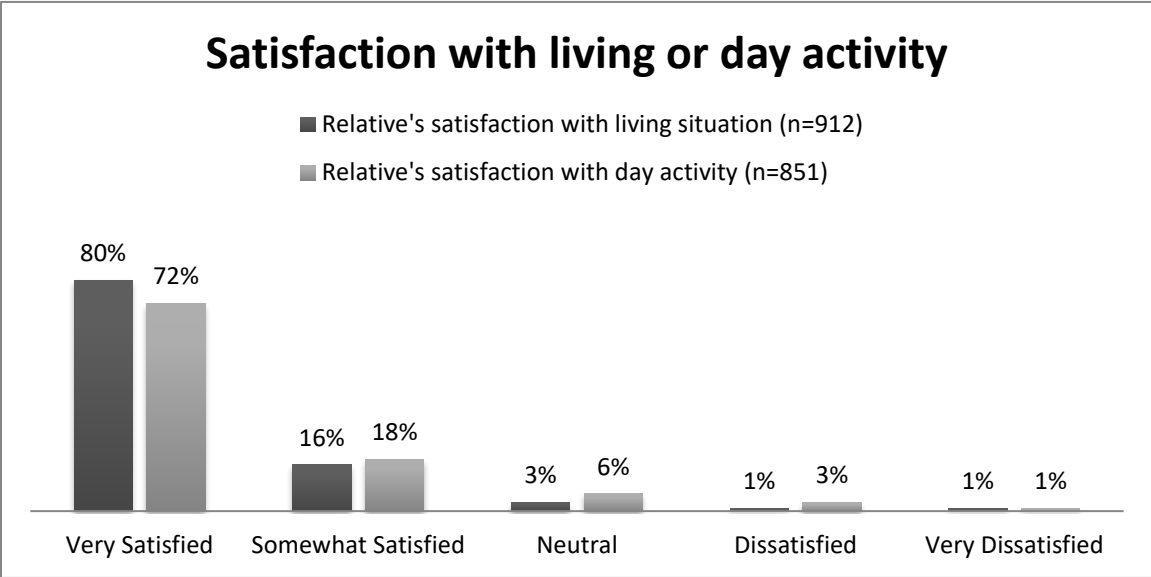


#### ***How Often Do You Contact/See Your Relative***

- 88% of respondents reported contacting their relative once per week or more, and 97% reported that they contacted their relative at least monthly. **According to data from the 2018-2019 statewide sample, 87% of family/friend/guardians contacted their relative at least monthly and 5% have never contacted their relative.**
- 94% of the family/friend/guardians reported that they were able to see their relative (family's home, individual's home, or on an outing) at least once a month; 0% have never visited with their relative. **According to data from the 2018-2019 statewide sample, 81% had at least a monthly visit from their relative and 3% never visited. Differences in these data points reflect the large percentage of individuals who live at home with their families in the current sample.**

**Your Relative's Happiness**

- 95% of respondents felt their relative was either very satisfied or satisfied with his/her living situation; 90% felt their relative was very satisfied or satisfied with what they do during the day.



- 97% of families felt their relative was either very satisfied or somewhat satisfied with the staff who support them at home.
- 96% of respondents felt their relative was either very satisfied or somewhat satisfied with the staff who support them at work (or during the day).

### ***Your Relative's Safety***

- Respondents said they think their relative felt safe in their community/home/neighborhood always (86%) or most of the time (12%).

### ***Your Relative's Opportunities***

- 84% of the respondents said that their relative had enough opportunities to participate in activities outside the home.
- 88% of the respondents said that their relative seemed to have the opportunity to learn new things.

### ***Your Relative's Staff***

- 79% of the respondents said that their relative's home appeared to have an adequate number of paid staff.
- 98% of the respondents said that staff in their relative's home always treat people with dignity and respect.
- 95% of the respondents said that all staff in their relative's home appear to have the skills they need to support their relative; 4% felt that way about only some staff.
- 94% of the respondents said that their relative's place of work appears to have an adequate number of paid staff.
- 97% of respondents said that staff in their relative's place of work always treat people with dignity and respect.
- 93% of respondents reported that staff in their relative's place of work appear to have the skills they need to support their relative; 6% felt that way about only some staff.

- If their relative did not communicate verbally, 37% of the respondents said that there is a formal communication system in place for their relative and they use it and for 82% the communication system is used across all settings.

### ***Your Relative's Supports***

- 83% of relatives were satisfied with the supports coordination their relative receives.
- 71% of relatives reported that they were told how much money is in their relative's annual budget.
- 9% of relatives report that their relative self-directs their own services.
- 68% said that their relative always received the supports they needed.
- 85% said that the services and supports their relative receives change when their relative's needs change.
- 93% of relatives always felt that the staff who assisted them with planning respected their choices and opinions.
- 60% of relatives indicated that there were never frequent changes in support staff at their family member's home, work or day program; 13% indicated that there were always frequent changes.
- 40% of relatives always chose the agency/provider who worked with their relative; 7% reported that their relative chose; 23% chose with their relative; 30% reported that someone else chose.
- 63% of relatives were familiar with the way complaints and grievances are handled at the provider level, 60% of relatives were familiar with the way complaints and grievances are handled at the county/AE level, and 54% of relatives were familiar with the way complaints and grievances are handled at the state level. 32% were not familiar of the grievance and complaint process on any level.

### ***Family Resources***

- 90% of relatives felt that the information they received about their relative's services was easy to understand.
- 12% of respondents had learned about the Life Course Framework and Tools.

- 49% of relatives have an opportunity to connect and network with other families with relatives at similar life stages.
- 24% of relatives said they were aware of the PA Family Network; of those who were aware, 37% had attended a workshop led by the Network of Family Advisors.
- 80% of relatives said that they have enough information about services for which their family is eligible.
- 34% of respondents whose family member transitioned from school to adult services in the past year were happy with the process.
- 74% of relatives report that the services coordinator asks about their vision for an everyday life for their family member.

### ***Emergency Preparation***

- 53% of relatives had someone talk to them about an emergency plan for their family in case of emergency.

***Family Satisfaction Scale:*** Based on the eight individual items, a Family Satisfaction Scale was developed. Scores on the Family Satisfaction Scale could range from 0 to 100, with a higher score indicating greater family satisfaction.

- The average (mean) score was 91.86 with a standard deviation of 12.94.
- The mode (the value that occurs the most frequently) was 100, indicating that many of the families' (50%) satisfaction levels were at the top of the scale on all measures of family satisfaction.

There were several major differences regarding this year's data in the Family/Friend/Guardian section when compared with data from 2017-2018:

- There was a 4% **increase** in the percentage of the families surveyed who were either somewhat satisfied or very satisfied with what their relatives does during the day.
- There was a 3% **increase** in families who were able to see their relative at least once a week.

- There was a 4% **increase** in family members who said that all staff appear to have the skills they need to support their relative.
- There was a 5% **decrease** in the percentage of the respondents said that their relative's home appeared to have an adequate number of paid staff.
- There was a 3% **decrease** in relatives who said that their relative always received the supports they needed.
- There was a 5% **decrease** in relatives who reported they are satisfied with the supports their relative receives.
- There was a 7% **increase** in the percentage of family members who report that if there relative does not communicate in words there is a formal communication system in place and they use it and a 12% **increase** in those who report the system is used across all settings.
- There was a 6% **decrease** in the percentage of relatives who reported that they were told how much money is in their relative's annual budget.
- There was a 6% **decrease** in relatives who report that their relative self-directs their own services.
- There was a 6% **increase** in family members who reported they were not familiar of the grievance and complaint process on any level.
- There was a 6% **decrease** in relatives who reported they have an opportunity to connect and network with other families with relatives at similar life stages.
- There was a 3% **decrease** in the percentage of relatives who said they were aware of the PA Family Network; of those who were aware, there was an 11% **increase** in those who had attended a workshop led by the Network of Family Advisors.
- There was a 7% **decrease** in family members who reported they chose a provider with their relative, and a 5% **increase** in family members who reported that someone other than their relative or the family member chose the provider.
- There was a 8% **decrease** in the percentage of relatives who had someone talk to them about an emergency plan for their family in case of emergency.



## **Summary**

This report presents information collected through face-to-face interviews with 1639 individuals receiving supports through the PFDS waiver through the Office of Developmental Programs.

As was the case in past years, individuals who participated in the IM4Q survey who receive supports through the PFDS waiver report high levels of satisfaction with where they live and what they do during the day. Responses continue to indicate that most people are satisfied with their lives, feel they have enough privacy, and feel that people are nice to them and treat them with respect. Family members' surveys and the feedback of IM4Q monitors support the finding that most people are happy and treated with respect in most situations.

The individuals who participated in this year's survey also report high levels of community involvement. Many individuals go out in the community at least weekly to shop, visit friends and family, and dine out. Increasingly, individuals are going out into the community with friends and family members as opposed to staff members.

In terms of choice, the data indicate that about half of individuals surveyed have a high level of choice regarding what they do during the day, where they live, and how to spend their money. Many individuals are able to make choices on their own, while others make choices with the support of their family/friend/guardian and/or staff members.

Many individuals are receiving the supports they need, but it remains true that a significant number of respondents feel that more supports are needed. Although communication remains an issue for many, there are some promising trends in the data, indicating that individuals are more likely to report that they have a communication system in place and that it is used across settings. There were also substantial increases in the number of respondents who report that their staff understand them. There were also some substantial increases in the percentage of people who reported that they have and use cell phones, email, Internet, a computer, and text-messaging.

While many individuals participate in decisions about their budget, hiring staff members, and managing services, only a very small percentage of individuals are self-directing services. There was also a substantial decrease in individuals who reported their Supports Coordinator asked them about directing their own services.

Although overall, friends and relatives responding to the Family Friend and Guardian Survey report high levels of satisfaction with their relative's care, it remains the case that many family members are not aware of available services and supports, such as the Life Course Framework and Tools and the PA Family Network. Only a third of family members whose relative transitioned from school to adult services in the last year were satisfied with the process.