

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

***Independent Monitoring for Quality (IM4Q)***  
***A Statewide Summary***  
***2019-2020***

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

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**April, 2021**

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## **Introduction**

Independent Monitoring for Quality (IM4Q) is a program designed to assess the overall quality of life for individuals with intellectual and developmental disabilities (I/DD) in Pennsylvania by surveying individuals and their families. IM4Q gathers important data about individuals' perceptions of their life that inform policy, family trainings, and quality management at the provider, administrative entity, and statewide levels.

The project originated in 1997, when 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 and families. Pennsylvania aligned the project created by ODP's subcommittee with the newly developed National Core Indicators® 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 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 consideration data into the Department of Human Service (DHS) Home and Community Services Information System (HCSIS) web-based system. In 2013, we began to utilize ODESA, a web-based, secure data entry system developed by the Human Services Research Institute (HSRI) for National Core Indicators to enter all data. The IM4Q data are analyzed, and reports are developed for dissemination to

ODP staff, individuals, families, guardians, AEs, local programs, providers, and other interested people.

The number of survey respondents varies from year to year, but on average about 6000 individuals and 2500 family/friend/guardian representatives have responded to the survey over the last 20 years. This year there was a significant decrease in the number of respondents to both surveys due to the Covid pandemic, which limited the ability to conduct face-to-face interviews. 2644 individuals and 1237 family members, friends or guardians completed the surveys prior to the early cessation of the project in March 2020.

## **Methodology**

### **Instrument**

The interview instruments for IM4Q include the Essential Data Elements (EDE) survey, the Consumer pre-survey form and the Family/Friend/Guardian (F/F/G) survey. The EDE survey has a total of 161 questions; 67 of the questions can only be answered by the individuals receiving supports and services.

The EDE for FY 2019-2020 includes all survey questions included in the FY 2019-2020 NCI Adult In-Person Survey. This year, 476 individuals included in this report are represented in the NCI sample for 2019-2020, based on a sampling methodology established by ODP and the Human Services Research Institute (HSRI). A copy of the NCI report for FY 2019-2020 is available on the HSRI website at [www.nationalcoreindicators.org](http://www.nationalcoreindicators.org).

The EDE instrument is comprised of the following sections:

#### **Completed by an AE designee:**

- Consumer Pre-survey
- Background information (NCI)

#### **Completed only based on responses of the individual receiving supports:**

- Satisfaction
- Dignity, Respect and Rights

- Supports Coordination
- Emergency Preparation

**Responses of the individual receiving supports, a family member, friend, or staff person:**

- Choice and Control
  - Health
  - Employment
  - Self-Directed Supports
- Relationships
- Inclusion

**Completed by the Independent Monitoring Team:**

- Monitor Impressions
- Major Concerns

**Completed by the family, with approval of the individual receiving supports:**

- Family/Friend/Guardian survey

**Sample**

Independent Monitoring focuses on the quality of life and services and supports to children ages three and over, and adults supported by the Office of Developmental Programs' service system for individuals with intellectual disabilities. The sampling procedure for this year continues to be drawn through the Home and Community Services Information System (HCSIS) and attempts to more closely reflect the ODP service system.

Type of Residence	Number	Valid Percent
State-Operated ICF/ID	25	1.0%
State MH Hospital	1	0.0%
Foster Care	4	0.2%
Nursing Home/Facility	42	1.6%
Domiciliary Care	5	0.2%
Personal Care Home	35	1.3%
Family Living/Life sharing	87	3.3%
Unlicensed Family Living	10	0.4%
Own Residence	258	9.8%
Relative's Home	1189	45.3%
Children's Facility	8	0.3%
Approved Private School	2	0.1%
Private ICF/ID 4 or fewer	10	0.4%
Private ICF/ID 5-8	7	0.3%
Private ICF/ID 9-15	1	0.0%
Private ICF/ID 16+	12	0.5%
Community Home 1	93	3.5%
Community Home 2-4	767	29.2%
Community Home 5-6	21	0.8%
Community Home 7-8	13	0.5%
Community Home 9-15	4	0.2%
Community Home 16+	3	0.1%
Other	28	1.1%
Missing	19	-
<b>Total</b>	<b>2644</b>	<b>100%</b>

## Procedure

AEs select and then contract with local IM4Q Programs to conduct interviews with individuals and families using the EDE and F/F/G Survey, using the following selection criteria: independence of the programs from service delivering entities, consumer and family involvement on governing boards, and involvement of individuals receiving supports and families in data collection activities. Local IM4Q Programs received training on the EDE, F/F/G Survey, and interviewing protocols from technical advisors

from the Institute on Disabilities (IOD) at Temple University. Data entry instruction was provided by ODP with support from the IOD.

Once an annual HCSIS-drawn random sample is sent to the AE from ODP, the AE establishes a final list of individuals to be monitored. This list is forwarded to the Local Independent Monitoring for Quality Program which assigns the IM4Q teams. IM4Q teams are comprised of a minimum of two people, one of whom must be an individual with a disability or a family member. Visits to individuals to be interviewed are scheduled with the individual, or with the person designated on the pre-survey form.

Participation in the interview is voluntary; if an individual refuses to participate, s/he is replaced in the sample with another individual. The interview takes place at the home of the individual, but if s/he prefers that the interview take place elsewhere, alternate arrangements are made. The interview is conducted in private whenever possible unless the individual expresses a desire to have others present. Once the interview is completed, if the individual gives his/her permission, a survey is conducted with the family/friend/guardian, either face-to-face (at the time of the interview) or by phone using the F/F/G Survey.

After the EDE is completed by the IM4Q team, the completed Essential Data Elements forms are returned to the local IM4Q Program for data entry. Family/Friend/Guardian data are collected either by the interview team or by staff of the local IM4Q program. EDE and F/F/G Survey data are entered into ODESA. Data for the 2019-2020 survey cycle were collected and entered in ODESA by June 30, 2020. A usable data file was received by the Institute on Disabilities in December 2020. This report presents data on the individuals surveyed by the IM4Q Local Programs, representing all 48 AEs across the state.

In addition to this summary report and similar ones for each of the AEs, each local IM4Q Program has developed a process, referred to as “closing the loop” which ensures that follow-up activity with the AE is completed related to individual considerations for

improvement. “Closing the loop” is an integral part of the quality improvement process, as it places quality improvement responsibilities with the AEs, supports coordinators, and other providers of service.



**RESULTS:** The following table displays the distribution of interviews conducted by each independent monitoring program by Administrative Entity.

	# of People	Percent
Allegheny	301	11.4%
Armstrong/Indiana	50	1.9%
Beaver	34	1.3%
Bedford/Somerset	29	1.1%
Berks	93	3.5%
Blair	29	1.1%
Bradford/Sullivan	7	0.3%
Bucks	102	3.9%
Butler	51	1.9%
Cambria	33	1.2%
Cameron/Elk	0	0.0%
Carbon/Monroe/Pike	18	0.7%
Centre	28	1.1%
Chester	89	3.4%
Clarion	20	0.8%
Clearfield/Jefferson	20	0.8%
Columbia/Montour/Snyder/Union	24	0.9%
Crawford	3	0.1%
Cumberland/Perry	37	1.4%
Dauphin	118	4.5%
Delaware	137	5.2%
Erie	185	7.0%
Fayette	45	1.7%
Forest/Warren	2	0.1%
Franklin/Fulton	18	0.7%
Greene	0	0.0%
Huntington/Mifflin/Juniata	45	1.7%
Lackawanna/Susquehanna	77	2.9%
Lancaster	62	2.3%
Lawrence	41	1.6%
Lebanon	20	0.8%
Lehigh	49	1.9%
Luzerne/Wyoming	50	1.9%
Lycoming/Clinton	15	0.6%
McKean	7	0.3%
Mercer	30	1.1%
Montgomery	144	5.4%
Northampton	39	1.5%
Northumberland	22	0.8%
Philadelphia	342	12.9%
Potter	10	0.4%
Schuylkill	1	0.0%
Tioga	14	0.5%
Venango	38	1.4%
Washington	12	0.5%
Wayne	29	1.1%
Westmoreland	74	2.8%
York/Adams	50	1.9%
Missing	0	0.0%
<b>TOTAL</b>	<b>2644</b>	<b>100%</b>

## **Demographic Characteristics of the Sample**

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

- Of those who reported gender in the sample (n=2616), 58% identified as male and 41% identified as female
- For those who reported their age (n=2593) the mean age in the sample was 40.34 (SD=17.59), with a range of 5 to 100 years
- Of those who reported race in the sample (n=2511), 78% identified as white, 18% identified as black/African American, 1% identified as Asian, 1% identified as mixed-race, 2% identified as other, and less than 1% identified as American Indian/Alaskan and Native/Pacific Islander
- Of those who identified their ethnicity (n=2362), 4% identified as Hispanic/Latinx

## **Satisfaction**

**Respondents:** Only the individual receiving services/supports could answer the EDE questions on satisfaction. A consistency check was performed, and 4 individuals' surveys were not included in the satisfaction section. The percent of people who responded to questions in this section ranged from 26% to 71%.

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

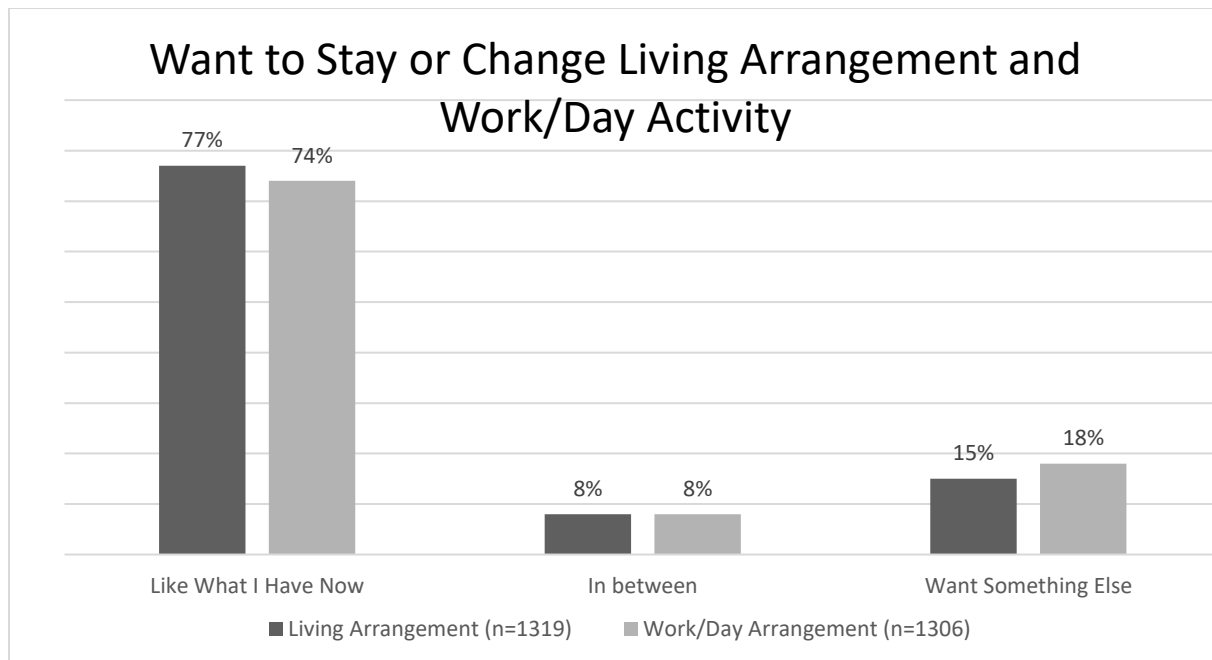
- 88% of individuals liked where they live.
  - When asked what they don't like about where they live, 2% reported that it was because of a problem with housemates, 2% stated that they wanted more independence, 1% reported that they wanted to be closer to family and friends, 1% stated it doesn't feel like a home, 1% reported they feel unsafe, 1% stated their home needs repair, 1% reported they have a problem with staff, and 4% reported there is some other reason they don't like where they live. Less than 1% of

people reported that they did not like where they live because of accessibility.

- 77% wanted to stay where they currently live but 15% wanted to move somewhere else.

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

- 93% of individuals *with* a day activity/work liked the primary job/activity that they did during the day. 93% of individuals liked the secondary job/activities they frequently do during the day.
- 74% wanted to continue their current daytime activities/work, but 18% wanted to do something else.



### **Daily Life**

- 85% of the individuals reported always getting the services they needed to be able to live in their home, 9% said yes, sometimes and/or they need more, and 6% said they do not get the services they need to be able to live in their home.
- On most weekdays, 16% of individuals attended an adult day program/community senior center, 16% attended a vocational facility, 20% stayed home, 11% went out and did things in the community, 10% worked with

no supports, 9% worked in supported employment, 2% volunteered, 10% attended school, 4% are retired, and 3% did something else.

- In addition to what individuals do on most weekdays, 28% also went out and did things in the community, 36% stayed home, 4% attended an adult day program/community senior center, 2% attended a vocational facility, 9% volunteered, 2% worked with no supports, 4% worked in supported employment, 3% are retired, and 3% attended school.
- 61% 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. When those who do not want a job were asked why, 17% said they like what they do now and do not want to change, 4% said they were retired, 3% said it was due to health limitations, and 1% said they did not want to affect their current benefits. Less than 1% said it was due to transportation challenges, accessibility, lack of help/staffing/personal assistance, feeling unwelcome, feeling unsafe, no jobs available, lack of information, financially secure, and lack of equipment.

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

- 86% reported feeling happy overall, 11% reported being neither happy nor sad, and 3% reported feeling sad overall.
- 64% of individuals reported never feeling lonely, 32% reported sometimes feeling lonely, and 5% reported always feeling lonely.
- 85% reported having friends they like to do things with – for 72% of these people their friends are not staff or family.
- 68% of respondents indicated they have a best friend.
- 81% reported that they can go on a date if they want to or are married; 7% reported that they can go on a date if they want to but there are some restrictions and rules and 12% are not allowed to date.

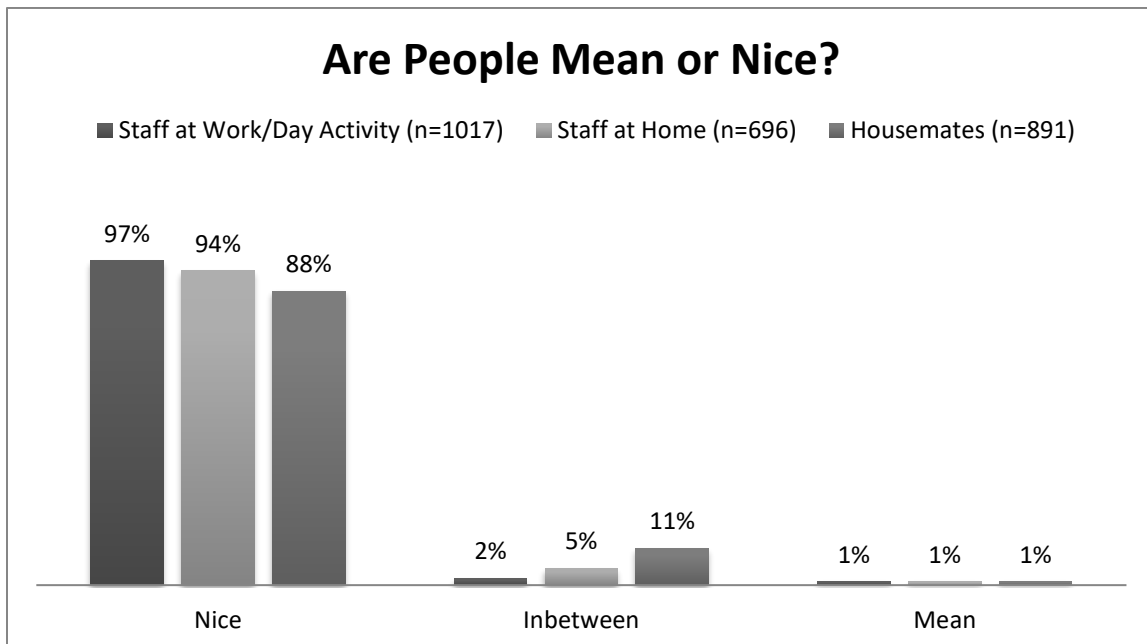
### ***Privacy***

- 96% of the individuals surveyed reported that they have enough privacy (a place to be alone) at home.

- 82% of individuals reported that they can be alone with friends at home.
- 66% of individuals say there are no rules about having friends and visitors, while 34% say there are some restrictions such as on visit times, certain friends, or rules about privacy.
- 89% reported that other people always let them know before coming into their **home**, 6% reported that sometimes other people let them know before coming into their home, and 5% said people never let them know before entering.
- 86% reported that people let them know before coming into their **bedroom**, 7% reported sometimes people let them know before coming into their room, and 7% never let them know.

***Are People Nice or Mean?***

- 88% of respondents reported that their housemates are very nice or nice.
- 80% of people interviewed reported that they get along with the person they share a bedroom with most of the time.
- 94% of the people interviewed reported that the staff who work with them at home are very nice or nice.
- 97% reported that 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 86.44 with a standard deviation of 19.09.
- The mode (the value that occurs the most frequently) was 100, indicating that many people were very satisfied on all measures of satisfaction.

### **Note on Satisfaction Research**

⇒ Although these percentages indicate a high level 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.

Compared to the Satisfaction section of the 2018-2019 report, there were several noteworthy differences:

- There was a 9% **increase** in individuals who reported they could go on a date if they want to or that they are married.
- There was a 6% **decrease** in individuals reporting there are no rules about having friends and visitors

## **Dignity, Respect and Rights**

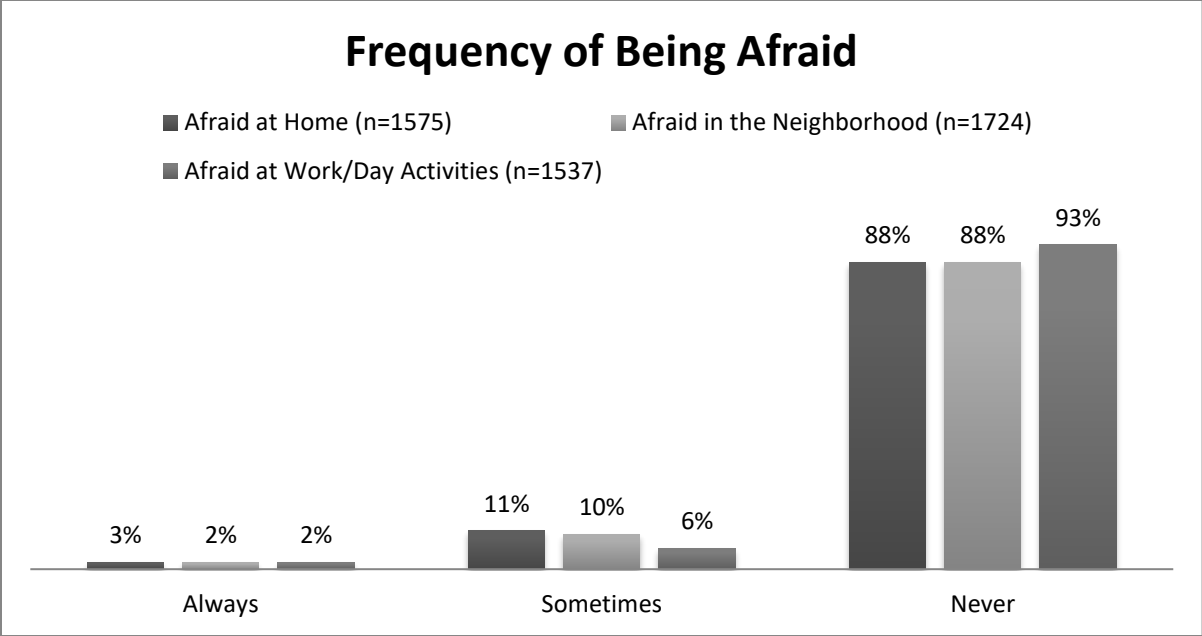
**Respondents:** Only the individual receiving services/supports could answer the EDE questions on dignity, respect, and rights. A consistency check was performed, and 4 individuals' surveys were not included in the Dignity, Respect and Rights section. The percent of people who responded to questions in this section ranged from 32% to 66%.

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

- 67% of individuals get help to learn new things; 15% do not get help.
- 72% of individuals report that they get to help other people.
- 19% of individuals indicated that they have participated in a self-advocacy group meeting.
- 44% of people said someone had talked to them about self-advocacy.
- 35% of people reported that they go to staff for help when they have a problem, 35% reported that they go to their family, 8% reported that they go to their supports coordinator, 7% reported that they go to a friend, and 4% reported that they go to someone else. 1% of individuals reported that they have no one to go to for help.

### ***Being Afraid***

- 88% reported never being afraid at home; 11% reported sometimes being afraid at home.
- 88% reported never being afraid in the neighborhood; 10% 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; 5% reported sometimes being afraid when using transportation.
- 95% reported that they have someone they can talk to when they feel afraid.



**Legal Rights**

- For 83% of the individuals interviewed, their mail is never opened without permission; 8% say their mail is always opened without permission.

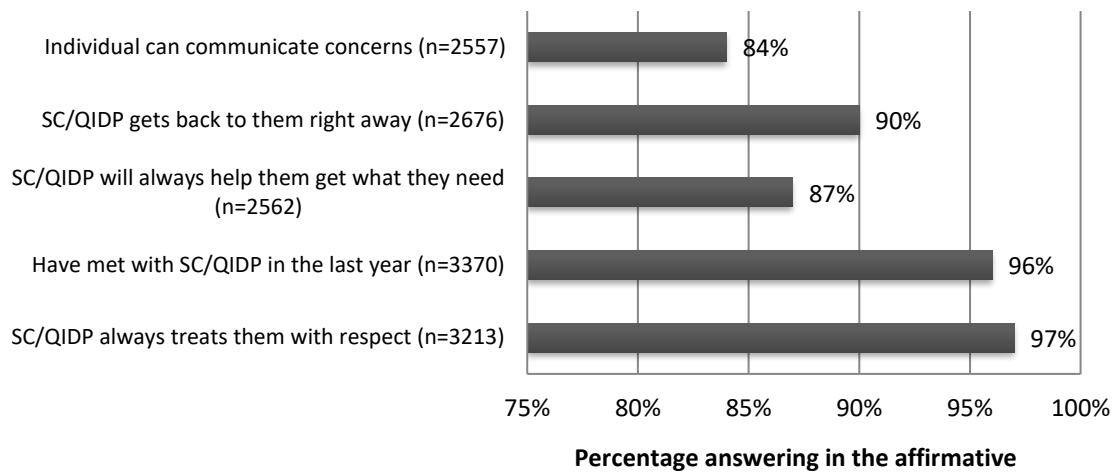
**Supports Coordination/Qualified Developmental Disability Professional (QDDP)**

- 97% reported that they met with their supports coordinator/QDDP in the last year.
- 88% of individuals reported that if they ask, their supports coordinator will always help them get what they need; 9% said their supports coordinator will sometimes help.
- 91% of individuals reported that when they call, their supports coordinator/QDDP always gets back to them right away.
- 93% of individuals reported that their supports coordinator asks what their interests are.
- 87% of respondents said their supports coordinator asks them what they want their life to look like.
- 86% said the supports coordinator asks what they want in the future.
- 40% of individuals report that their supports coordinator has asked them about directing their own services.



- 96% of people surveyed reported that their supports coordinator talks with them about services to make sure everything is OK.
- 63% of individuals reported that they know they have a choice of SC organizations.
- 95% of individuals reported that their supports coordinator always listens to them; 5% said their supports coordinator sometimes listens, and 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.
- 96% of respondents said they took part in their annual planning meeting; 1% had the option but chose not to take part.
- 88% of interviewees reported always being able to communicate their concerns during annual meetings; 8% reported that they are sometimes able to communicate their concerns.
- 56% of those surveyed have been told at their planning meeting how much money is in their annual budget.
- 96% reported that their ISP meeting included the people they wanted to be there.
- 77% of individuals indicated that they knew what was being talked about at their ISP meeting.
- 74% said they talked about learning new things at their planning meeting, 6% said maybe they talked about learning new things and 20% did not talk about learning new things.
- 76% of individuals reported that they chose the services they get as a part of their service plan, while 15% had some input.
- If they want to change something about their services, 79% know who to ask, but 15% do not know who to ask.

## Supports Coordination



### Staff

- 93% of individuals interviewed reported that their staff always treats them with respect.
- 93% of individuals reported that they feel their staff has the right training to meet their needs.
- 88% of individuals feel that all their staff understand their communication; 8% say some staff understand them, 3% feel they are understood sometimes, and 1% do not feel that their staff understand their communication.

### Emergency Preparation Questions

- 85% of individuals have been given information about what to do in an emergency.
- When asked who gave the individual information about what to do in an emergency, 41% received information from home staff, 30% from day program or employment staff, 42% from someone in their family, 3% from the police, fire department, or EMS, 12% from supports coordinator, 11% from someone else, 3% from friends, and 0% from the Red Cross.

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 score was 82.86 with a standard deviation of 14.38.
- The modal score was 75. As was the trend in last year's data, the mode for the Dignity and Respect Scale was much lower than the Satisfaction Scale. This indicates that many individuals chose the most positive answer category (very satisfied) for all measures of the Satisfaction Scale, whereas for the Dignity and Respect Scale individuals were less likely to choose the most positive answer category for all measures.

***Afraid 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 Afraid Scale could range from 0 to 100, with a higher score indicating less fear.

- The average (mean) score was 93.28 with a standard deviation of 15.40.
- The mode was 100.
- The average on this scale was high, indicating that there was not a great deal of fear reported among individuals receiving supports and services. The mode of 100 indicates that the majority of individuals surveyed (88-93%) report that they never feel afraid in their home, neighborhood or work/day activity site.

Compared to the Dignity, Respect and Rights section of the 2018-2019 report, there were significant differences.

- There was a 6% **increase** in individuals who reported that someone had talked to them about self-advocacy.

## **Choice and Control**

**Respondents:** The EDE 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,

- 31% of the questions were answered by the individual receiving supports.
- 21% of the questions were answered by paid staff.
- 13% of the questions were answered by the individual and staff.
- 19% of the questions were answered by family/friend/advocate/guardian.
- 15% of the questions were answered by the individual 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.”

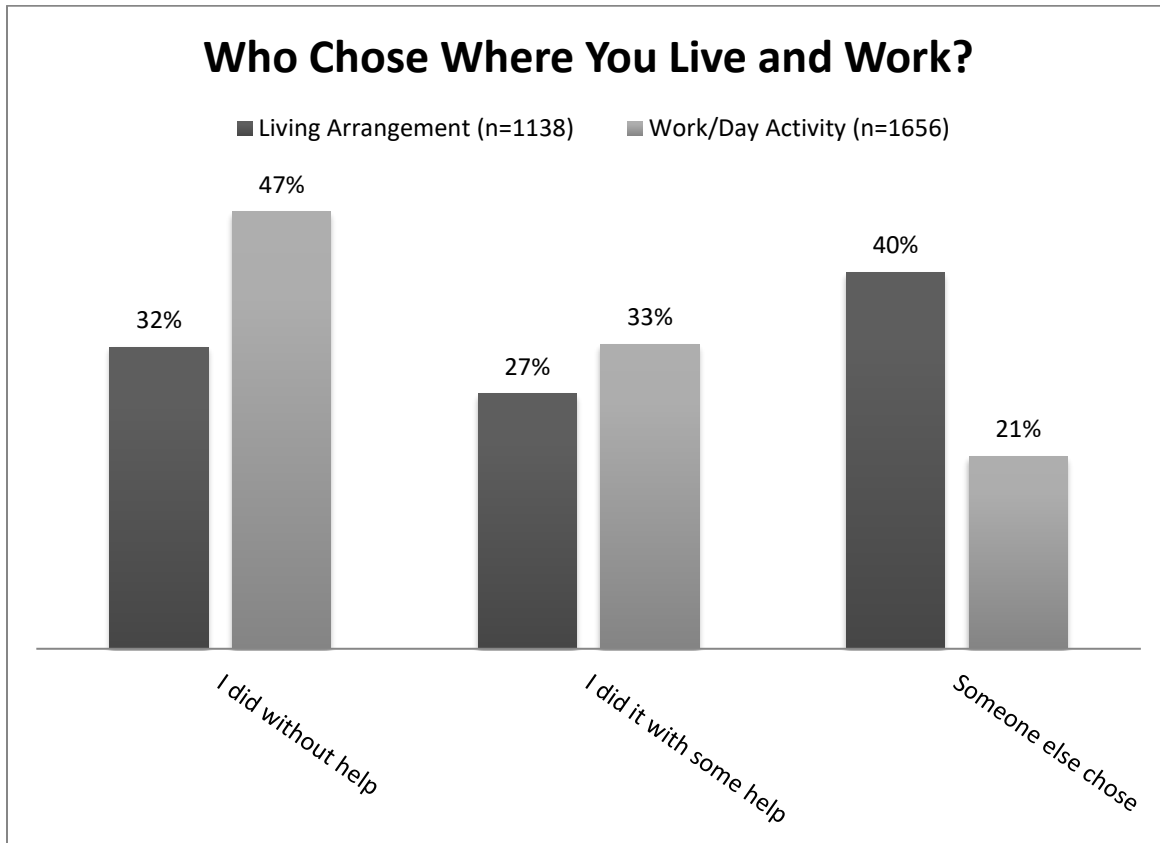
## ***Forms of Identification***

- 60% of individuals stated that they always carry a form of identification; 24% never do.

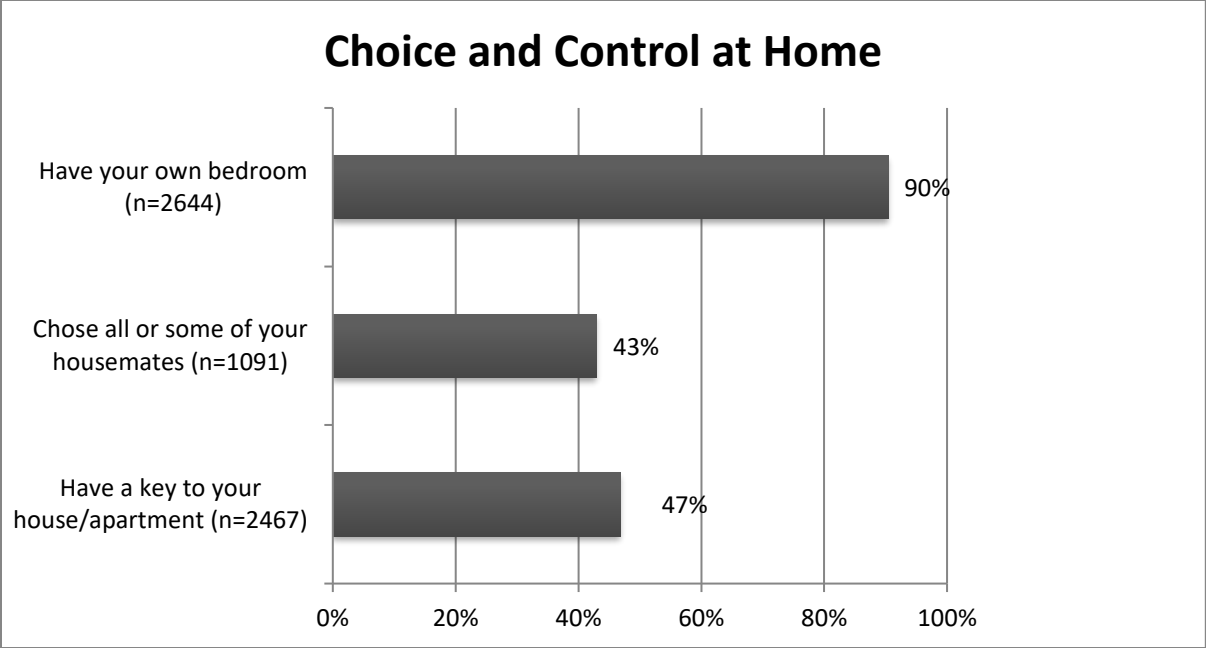
## ***Choice and Control at Home***

- 47% of the individuals surveyed had a key/way to get into to their house or apartment on their own.
- 52% of respondents said that if other members of their house go out, they have the option to stay home;10% sometimes have the option to stay home.
- 41% of respondents can lock their bedroom door if they want to.
- 3% of individuals reported that they own their own home.
- 26% of individuals report that their name is on the lease or rental agreement.
- For 40% of the individuals, someone else chose where they live; 32% of those interviewed chose on their own.
- 58% of individuals said they were given a choice to live where people without disabilities live.

- 43% of individuals surveyed saw no other places before they moved into their residence.



- 57% of the individuals **did not** choose their housemates.
- For those who shared a bedroom, 33% chose some or all their roommates.



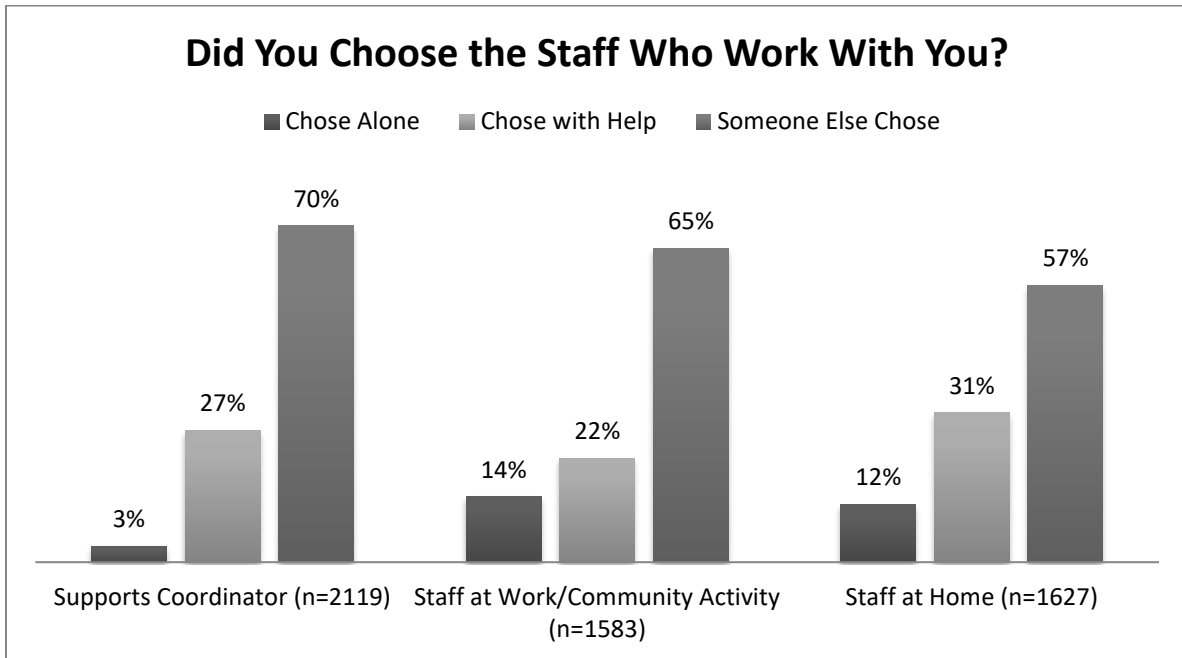
***Choice and Control During the Day and for Leisure Time***

- 21% of the individuals interviewed reported that someone else chose what they do during the day.
- 47% of the people interviewed chose what they do during the day without assistance.
- 55% of individuals reported that when they chose their work or day activity, they had an option to go where people without disabilities go.
- 38% of individuals saw no other places when choosing what they do during the day.
- 89% of the individuals surveyed chose their daily schedules without assistance.
- 93% say they have enough choice about how they spend their free time.

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

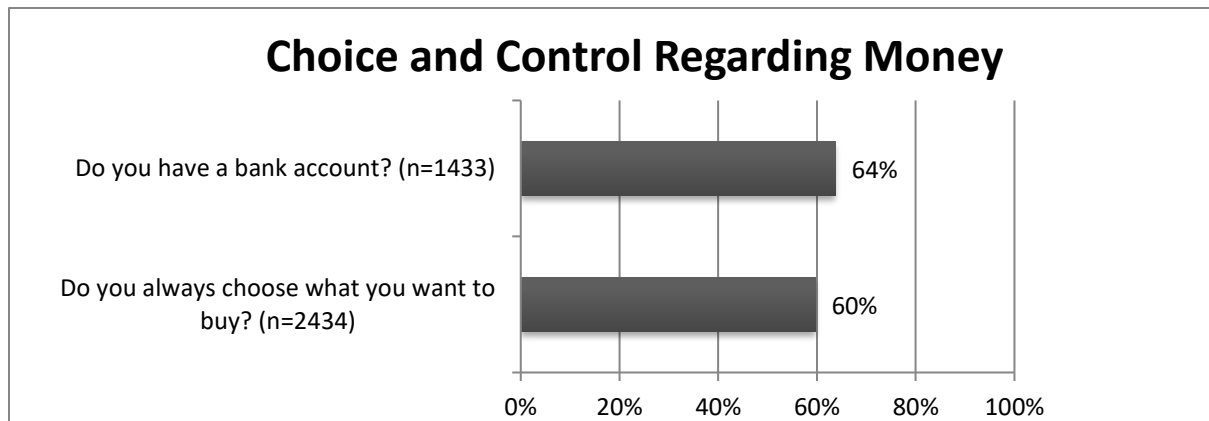
- 43% of the individuals interviewed/chose at least some of the staff who help them at home (alone or with assistance from family or provider).
- 35% of the individuals surveyed interviewed/chose at least some of the staff who help them at work/day activity (alone or with assistance from family or provider).

- 31% of individuals chose their supports coordinators (alone or with assistance from family or provider).



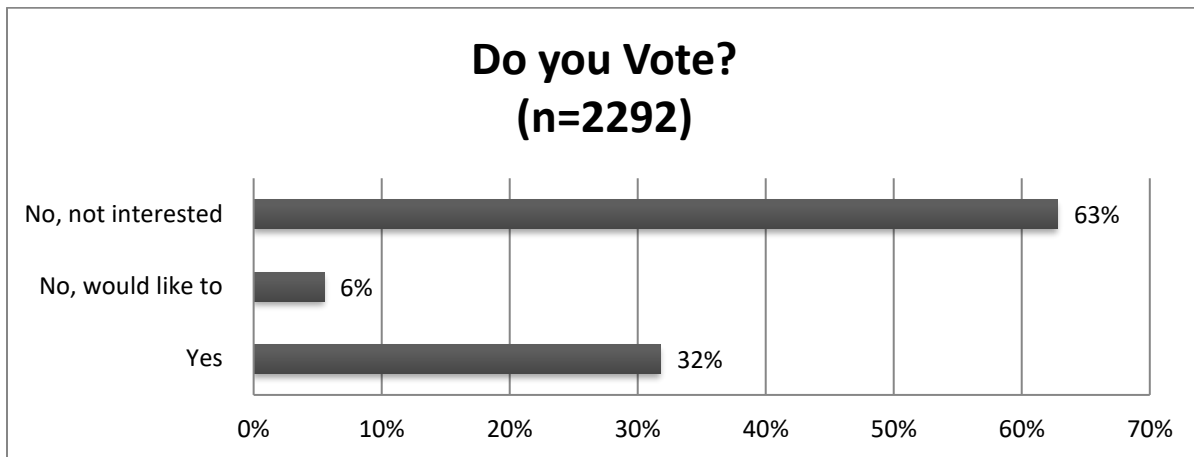
### **Choice and Control Regarding Money**

- 60% of the individuals reported that they always choose what to buy with their spending money, 32% report that they choose with help.
- 43% of the individuals reported that there is something they want to buy.
- 64% of the individuals reported they have a bank account that they can get to independently to withdraw money when they want it.



## **Voting**

- 32% of the people said they vote, 63% of the people said they do not vote and are not interested in voting, and 6% do not vote but would like to.

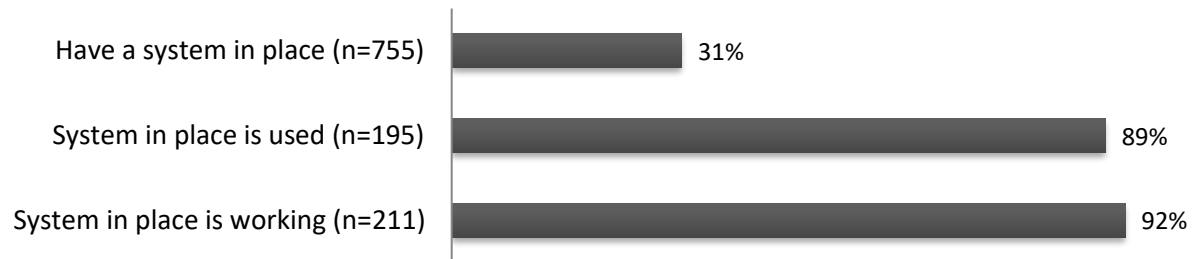


## **Access to Communication**

- For those individuals who do not communicate using words, there is a formal communication system in place for 31% of the people interviewed.
- For those people with formal communication systems in place, 92% reported that the systems are in working order; if the communication system was in place and working, it was being used regularly for 89% of the people interviewed.
- 76% of individuals with a formal communication system reported using it across all settings.
- 60% of individuals with a formal communication system are supported by staff or a program coordinator, 42% are supported by a parent or caregiver, 37% are supported by their speech language clinician, and 5% are supported by someone else.



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



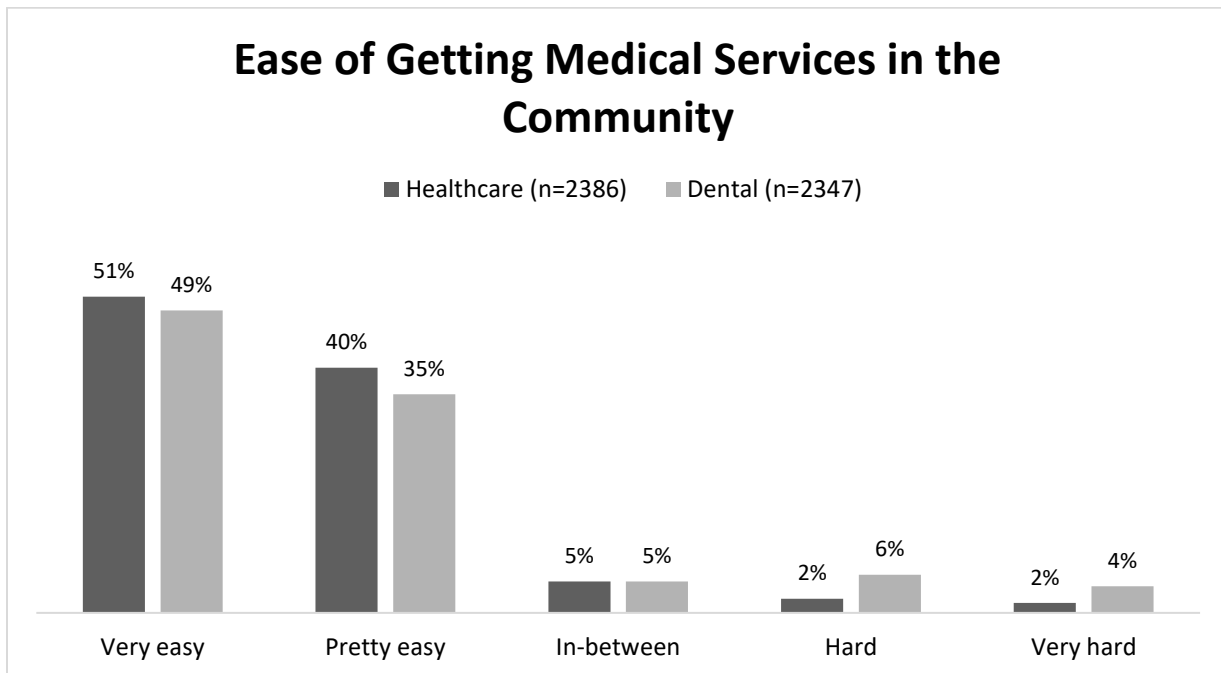
### ***Other Forms of Communication:***

- 37% have and use a cell phone; there are restrictions for 7% of these people.
- 20% have and use e-mail; there are restrictions for 2% of these people.
- 39% have and use internet; there are restrictions for 10% of these people.
- 25% have and use text-messaging; there are restrictions for 3% of these people.
- 92% have and use cable television; there are restrictions for 5% of these people.
- 46% have and use a computer; there are restrictions for 9% of these people.

### ***Health Care Questions***

- When asked how many times per month they exercise at home, 53% of individuals said zero, and 32% said 10 or more times a month.
- 86% of individuals interviewed reported that they have the opportunity to discuss health with their primary care provider (PCP).
- 80% of individuals reported that they feel their doctor understands them.
- 67% of individuals feel that they understood their doctors' instructions.
- 93% of respondents say if they needed help communicating at the doctor's office, it was available.
- 96% of respondents reported they were able to see a medical specialist if they needed to.
- 90% of individuals say they have not been prevented from receiving medical and dental services because of their disability.

- 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, 84% of individuals reported that it was very easy or easy, 5% reported that it was in-between, and 11% reported that it was very hard or hard.
- 62% of individuals interviewed reported that they have the opportunity to discuss health concerns with a psychiatrist; 2% reported they do not have a psychiatrist but want one.
- 92% of individuals reported that their doctor speaks directly to them during appointments.
- 60% of individuals reported that they are able to provide consent for medical treatment; of those able to provide consent, 82% said their doctor accepts their consent and 18% say their consent is not accepted.



**Choice and Control Scale:** The scale included twelve 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 58.57 with a standard deviation of 21.04.
- The modal score was 47.37, indicating the most frequent score.

There were several significant differences regarding this year's data in the Choice and Control section when compared with the data from 2018-2019:

- There was a 6% decrease in individuals who reported that they had the option to stay home when other members of their house go out.
- There was a 7% decrease in individuals who reported that they saw no other places before they moved into their residence.
- Regarding forms of communication, there was an **increase** in respondents' reports that they have and use the Internet (9%), have and use cable TV (14%) and have and use a computer (9%).

There were also several differences compared to the 2018-2019 report regarding health care:

- There was a 7% **decrease** in individuals who reported they have an opportunity to discuss their health concerns with their PCP.
- There was an 11% **decrease** in people who reported their doctor understands their communication.
- There was a 17% **decrease** in those who reported understanding their doctors' instructions.

## **Employment**

### ***Supports Getting into the Workplace (All respondents)***

- 10% of individuals take classes or training to help them get a job in the community, get a better job, or do better at their current job.
- 57% of individuals surveyed reported that someone had talked to them about employment in their planning meeting.
- 31% of individuals report that community employment is a goal in their plan.
- When individuals were asked who had talked to them about employment, 44% said no one, 51% said their supports coordinator, 12% said their service provider, 12% 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.

***Respondents:*** Of the 2644 individuals surveyed for the 2019-2020 Statewide IM4Q sample, 384 people indicated they are employed.

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

- 17% (n=384) of individuals surveyed report that they work in a community integrated setting while 83% do not.
- Of those working, most individuals have been employed for 1 to 3 years (29%). 20% of individuals have been employed for less than one year, 20% have been employed for 4-6 years, 13% 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, 32% of individuals work in cleaning services, 17% work in retail, 23% work in food services, 4% do office work, 4% work in a stock room or stock shelves, 1% work in maintenance, 6% work in assembly or factories, 2% work as care-workers or aides, 1% work in recycling, and less than 1% work in animal care or landscaping/outdoors. 9% work in some other occupation.

### ***Compensation and Advancement***

- 77% of individuals received paid time off, 15% received health insurance, 19% received retirement benefits, and 14% received some other kind of benefit. Note: individuals answering this question had the option to indicate more than one response.
- 50% of individuals who work have been promoted and/or received an increase in pay.
- The mean number of hours worked per week was 16.46 hours. Hours worked per week ranged from 1 to 40 hours; the most common response was 20 hours per week.
- 79% 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 more than \$15.00.
- The most common hourly wage range, reported by 42% of individuals, was \$9.01 to \$12.00. 16% of individuals reported earning \$7.25 per hour. 33% of individuals reported earning \$7.26 to \$9.00 an hour, and 10% earned more than \$12.01 per hour.

***Self-employment:*** 1% (n=29) of individuals surveyed report that they are self-employed.

There were some significant differences regarding this year's data in this section when compared with the data from 2018-2019:

- There was a 17% **decrease** in employed individuals that received health insurance.
- There was an 15% **decrease** in employed individuals that received retirement benefits.

## **Self-Directed Supports**

**Respondents:** Of the 2644 individuals surveyed for the 2019-2020 Statewide IM4Q sample, 151 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,

- 11% make most of the decisions about how their budget for services is used on their own; 33% have input but family and friends help, 49% say a family member or friend makes decisions, and 7% report that a case manager or another professional employed by the state makes the decision.
- 63% participate in decisions about budget, staff, and managing services.
- 77% hire and manage their own staff.
- 87% can make changes to their budget or services if they need to.
- 92% say they have enough help deciding how to use their budget/services, while 4% want more help.
- 79% receive information about the money left in their budget.
  - Of these, 87% say the information is easy to understand.
  - 70% receive this information at least every three months, 17% report they receive the information about twice a year, and 13% receive information once a year or less.

## **Community Participation**

- 34% of individuals reported that they use Community Participation Services.
- Community Participation Services being used were: developing skills and competencies necessary for employment (20%), fine/gross motor development and mobility (29%), participating in community activities to develop social networks (63%), participating in opportunities to develop interests or promote health/wellness (77%), training/education for self-determination (13%),

community adult learning opportunities (20%), volunteer opportunities (39%), and learning to navigate the local community (15%).

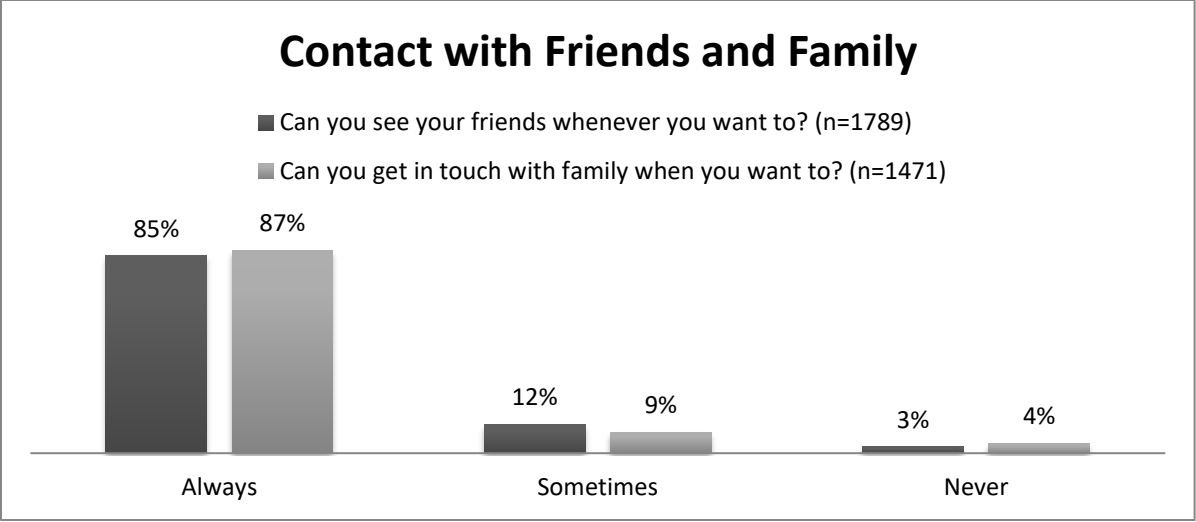
## **Relationships**

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

- 35% of the questions were answered by individuals receiving supports.
- 22% were answered by paid staff.
- 10% were answered by individuals receiving support and staff.
- 20% were answered by family/friend/guardian/advocate.
- 13% of the questions were answered by individuals receiving support and a family/friend/guardian/advocate.
- 2% 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***

- 85% of individuals were always able to see friends whenever they wanted.
- Of individuals that reported that they were unable to see their friends whenever they wanted, 31% reported that it was difficult to find time to see friends, 16% reported that they could not see friends because of a transportation issue, 3% reported a lack of staff, 9% reported that there were rules/restrictions, 2% reported money/cost, and 40% reported that there was another reason why they could not see friends.
- 87% of respondents were always able get in touch with family when they wanted to.



There were some significant differences regarding this year's data in this section when compared with the data from 2018-2019.

- The respondent profile was different from last year. This year's respondent was more likely to have been the individual receiving services (9% increase).



## **Inclusion**

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

- 29% of the questions were answered by individuals receiving supports.
- 21% were answered by paid staff.
- 13% were answered by individuals receiving support and staff.
- 20% were answered by family/friend/guardian/advocate.
- 16% of the questions were answered by individuals receiving support and a family/friend/guardian/advocate.
- 2% 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.”

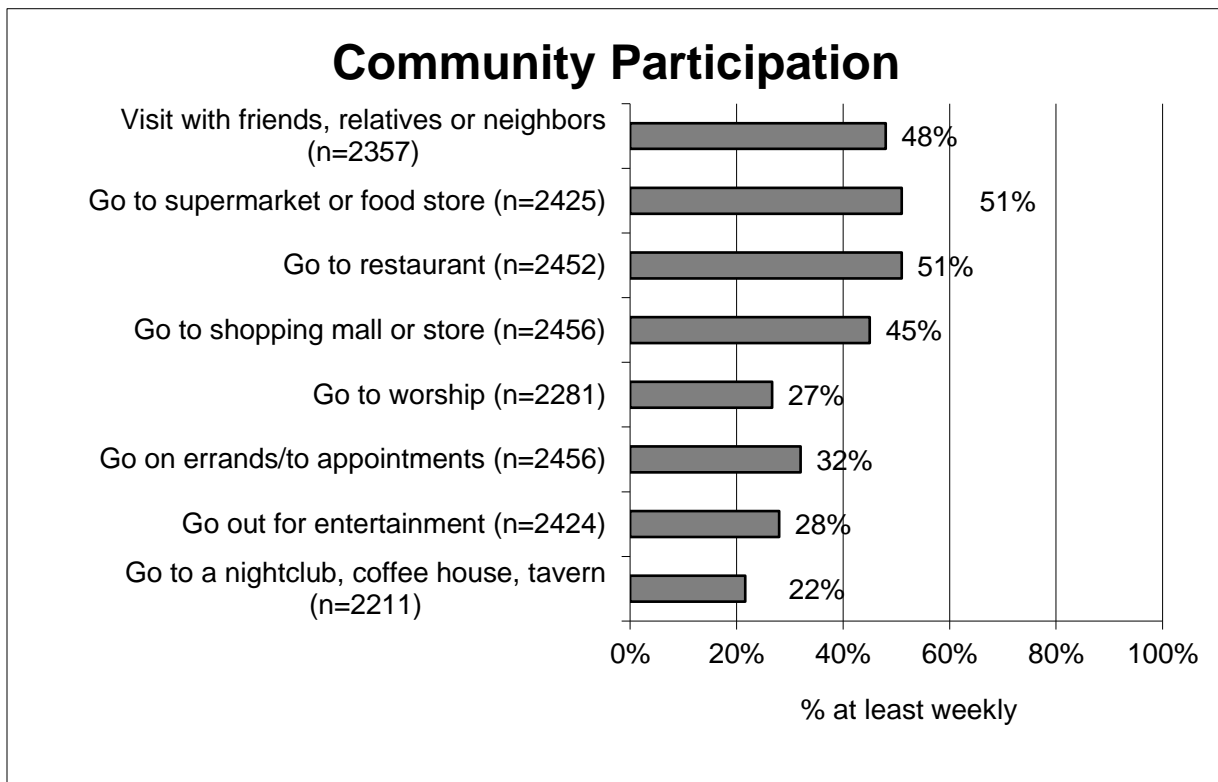
## ***Community Participation***

- 48% of the people visited with friends, relatives, and neighbors at least weekly.
  - When they visited friends, relatives and neighbors, individuals reported they went alone 13% of the time, with family 49% of the time, with staff 26% 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.
  - 80% of individuals said this was enough time to visit friends, 19% wanted more, but 1% wanted less.
- 51% of those surveyed went to a supermarket at least weekly.
  - When they went to the supermarket, individuals reported they went alone 7% of the time, with family 46% of the time, with staff 44% of the time, with friends 2% of the time, with housemates or coworkers less than 1% of the time, and with someone else less than 1% of the time.
  - 87% of individuals said this was enough time to go to the supermarket, 10% wanted more, but 3% wanted less.
- 51% of respondents went to restaurants at least weekly.

- When they went to a restaurant, individuals reported they went alone 4% of the time, with family 43% of the time, with staff 43% of the time, with friends 7% of the time, with housemates or coworkers 3% of the time, and with someone else less than 1% of the time.
- 79% of individuals said that they visited restaurants just enough, 19% wanted more and 2% wanted less.
- 45% of individuals went to a shopping center or mall at least weekly.
  - When they went to a shopping center or mall, individuals reported they went alone 5% of the time, with family 40% of the time, with staff 50% of the time, with friends 4% of the time, with housemates or coworkers 2% of the time, and with someone else less than 1% of the time.
  - 82% of individuals said they went to shopping centers or malls often enough, 16% wanted more and 3% wanted less.
- 27% of respondents went to places of worship at least weekly.
  - When they went to a place of worship, individuals reported they went alone 7% of the time, with family 59% of the time, with staff 25% of the time, with friends 5% of the time, with housemates or coworkers 3% of the time, and with someone else 1% of the time.
  - 88% of individuals report they go to worship often enough, while 11% wanted more and 1% wanted less.
- 32% of those surveyed went out on errands or appointments at least weekly.
  - When they went of errands or appointments, individuals reported they went alone 7% of the time, with family 45% of the time, with staff 46% of the time, with friends 2% of the time, with housemates or coworkers 1% of the time, and with someone else less than 1% of the time.
  - 91% of individuals said this was enough time for errands and appointments, 6% wanted more and 4% wanted less.
- 22% of individuals go to a night club, coffee house, or tavern to meet people at least weekly.
  - When they went to a night club, coffee house or tavern, individuals reported they went alone 8% of the time, with family 30% of the time, with

staff 53% of the time, with friends 7% of the time, with housemates or coworkers 1% of the time, and with someone else less than 1% of the time.

- 90% of individuals reported that they had enough time to visit night clubs, coffee houses or taverns but 10% wanted more and 1% wanted less.
- 28% of individuals go out for entertainment at least weekly.
  - When they went out for entertainment, individuals reported they went alone 3% of the time, with family 38% of the time, with staff 46% of the time, with friends 9% of the time, with housemates or coworkers 3% of the time, and with someone else 1% of the time.
  - 80% of individuals said they went out for entertainment enough, 19% wanted more and 1% wanted less.



### **Harris Poll**

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

- Pennsylvanians with disabilities in IM4Q were slightly less likely than individuals with disabilities in the Harris Poll to visit with friends, relatives, and neighbors. People without disabilities were much more likely than individuals in IM4Q to visit with friends, relatives, and neighbors.
- Pennsylvanians with disabilities in IM4Q were more than twice as likely to go to a restaurant weekly as people with disabilities in the Harris Poll, and more likely to go out to eat than people without disabilities in the Harris Poll.
- Pennsylvanians with disabilities in IM4Q were as likely to go to places of worship weekly as people with or 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 2019-2020</b>
<b>Visit with friends, relatives, and neighbors</b>	65%	54%	48%
<b>Go to restaurant</b>	41%	20%	51%
<b>Go to worship</b>	28%	24%	27%

### ***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 45.62 with a standard deviation of 17.70.

- 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, or most frequent score, was 50.00.

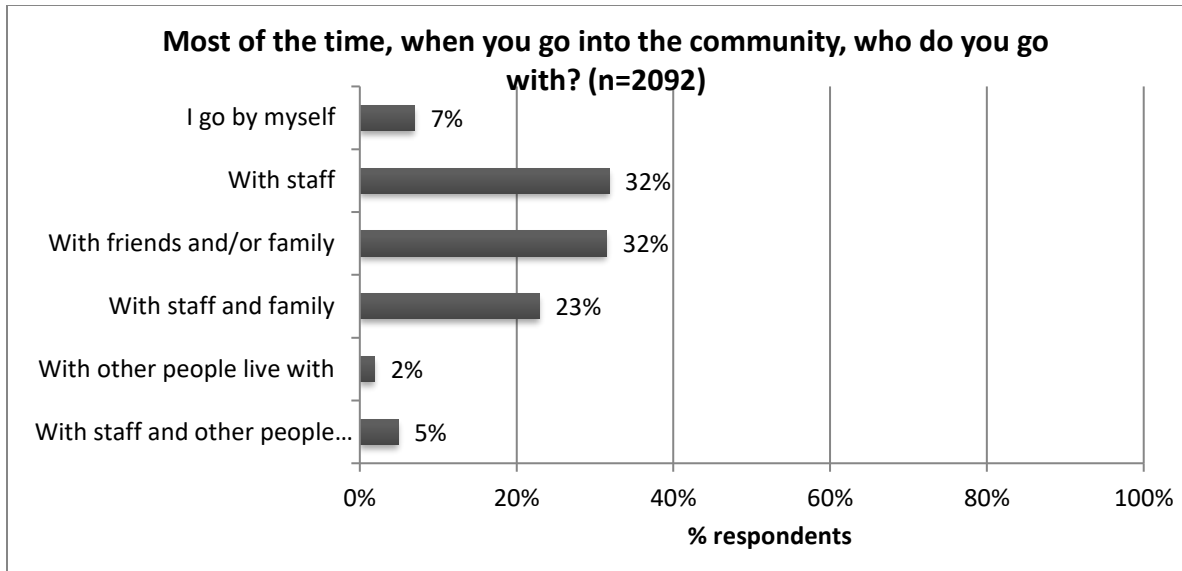
### ***Community Activities***

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

- 55% of individuals go frequently into the community for entertainment and 31% go occasionally.
- 36% of individuals reported that they frequently go to social events in the community that are attended by people with and without disabilities and 44% go occasionally.
- 31% of individuals would like to be a part of more groups in their community.
- 48% of individuals went on a vacation in the past year.
- Regarding monthly exercise, 36% of individuals reported never going out for exercise, 4% exercise less than weekly, 13% exercise once a week and 47% exercise more than once a week.

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

- 7% of individuals go out alone; 32% go out with friends and family.
- 37% of individuals go out with staff or staff and other people they live with most of the time.

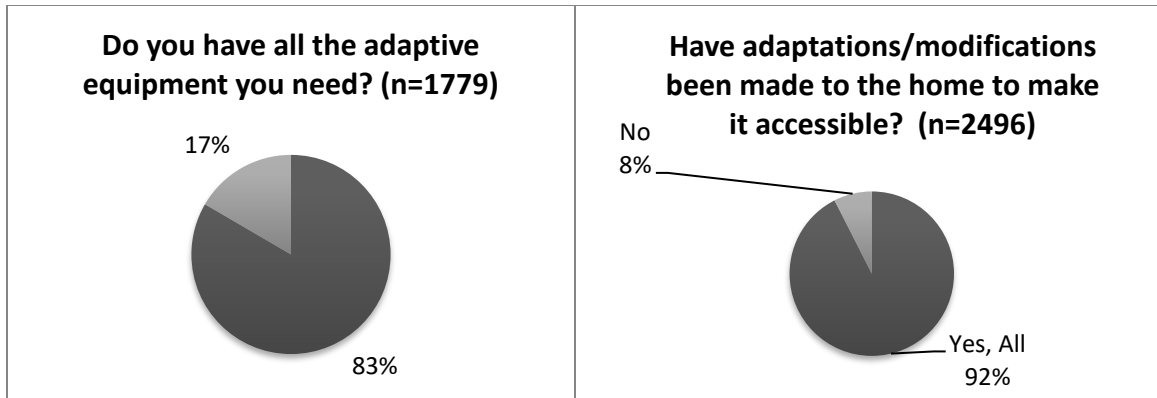


### ***Transportation***

- 92% of individuals always had a way to get where they wanted to go.
- To get to where they needed to go, the majority of individuals reported getting a ride from family or friends (37%). 38% reported getting a ride from staff in the provider van, 11% reported getting a ride in a staff member's car, 6% transport themselves, 4% ride public transportation, 4% ride paratransit, and 1% take a taxi, Uber, or Lyft.
- Of those who cannot always get where they want to go, 22% cannot get where they want to go because there is not enough staff. 13% said para transit is unreliable, 6% have transportation for work/school only, 4% report that no one who lives or works at their home can drive, and 54% said there was some other reason they cannot get where they want to go.

### ***Home Adaptive Equipment***

- 83% of individuals reported having all the adaptive equipment they needed.
- 93% of people said that all necessary modifications have been made to their home to make it accessible.



There were some significant differences regarding this year’s data in this section when compared with the data from 2018-2019:

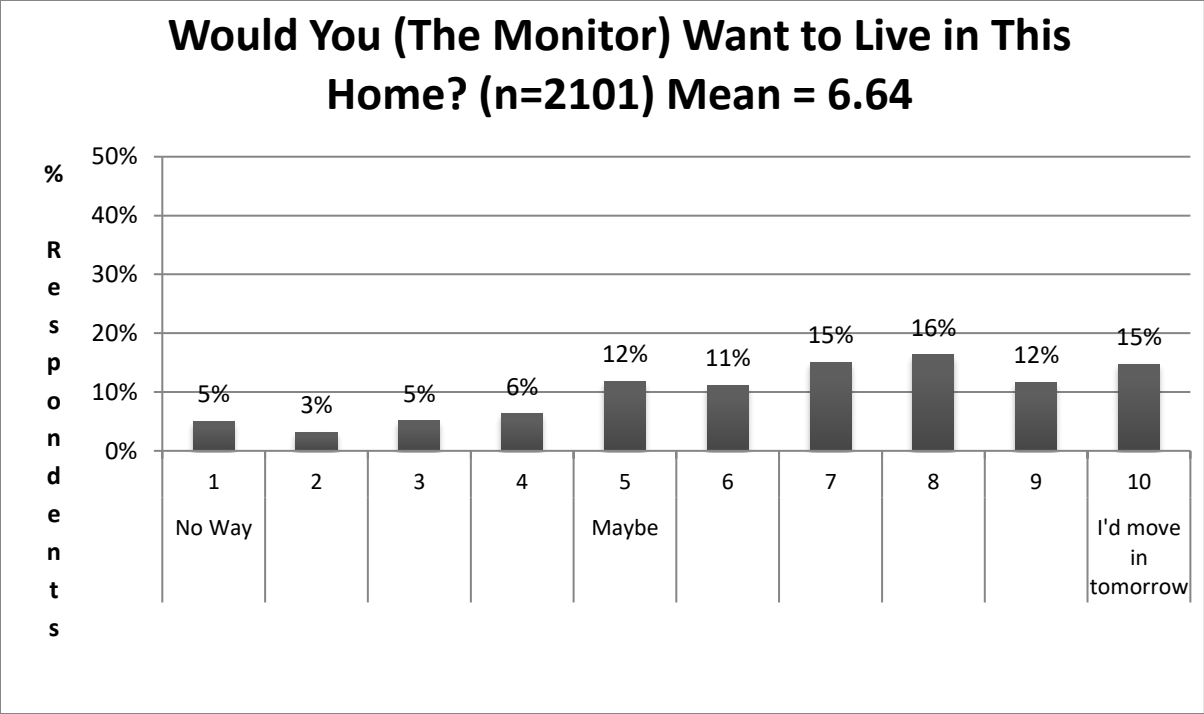
- There was a 6% **decrease** in individuals who reported that they frequently go to social events in the community that are attended by people with and without disabilities.

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

**Respondents:** The Independent Monitoring Team answered the EDE 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 6.64.



**Staff Support for the Person**

**Respondents:** The Independent Monitoring Team answered the EDE 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 92% of observed situations.
- 92% of respondents observed that all staff recognized the individuals in ways that promote independence.
- 92% of staff observed that all support individuals at home and/or work appeared to have the skills they needed to support the person.



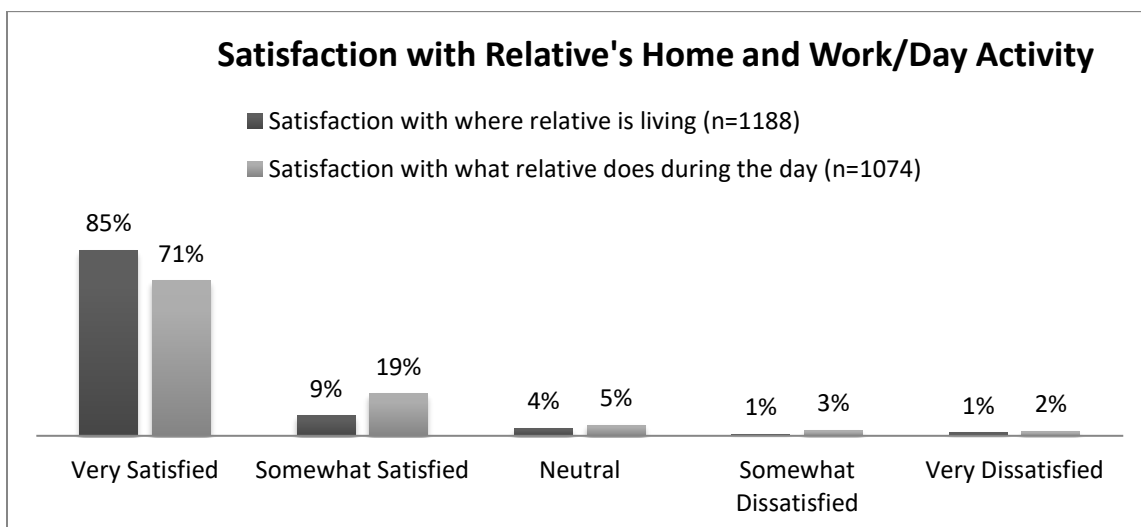
## **Family/Friend/Guardian Survey**

**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. If a phone or face-to-face survey could not be completed, surveys were completed by mail. Surveys were completed for 1237 family members, friends, and guardians.

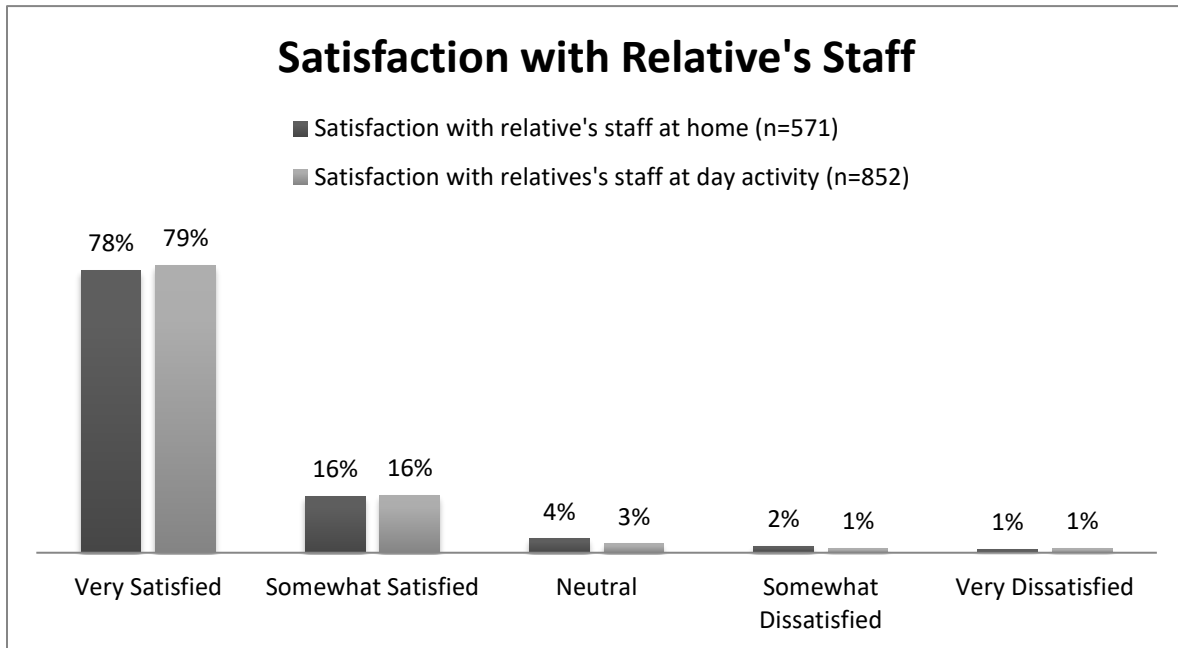
- 75% of the surveys were answered by parents.
- 15% were answered by siblings.
- 2% were answered by the guardian.
- 4% were answered by another relative (spouse, aunt, uncle, cousin, grandparent).
- 4% were answered by persons with other relationships to the individual receiving supports.
- Less than one percent of surveys were answered by friends.

### **Satisfaction**

- 95% of the families surveyed were either somewhat satisfied or very satisfied with where their relative lives.
- 91% were either somewhat 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.
- 95% of the families surveyed were either somewhat satisfied or very satisfied with the staff at their relatives' day activity.



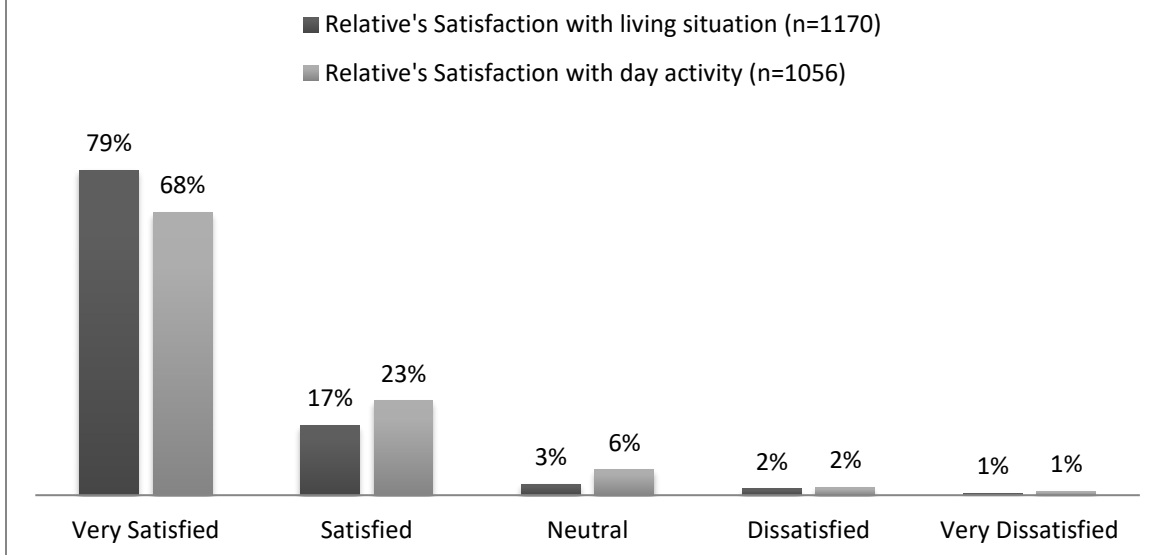
#### ***How Often Do You Contact/See Your Relative?***

- 90% of the family/friend/guardians contacted their relative at least monthly; 3% have never contacted their relative.
- 83% of the family/friend/guardians were able to see their relative (family's home, individual's home, or on an outing) at least once a month; 2% never visited with their relative.

#### **Your Relative's Satisfaction**

- 95% of respondents felt their relative was either very satisfied or satisfied with his/her living situation; 91% felt their relative was either very satisfied or satisfied with what they do during the day.

## Relative's Satisfaction at Home and at Work



- 94% of relatives felt their relative was either very satisfied or satisfied with the staff who support them at home; 2% believed their relative was either dissatisfied or very dissatisfied.
- 96% of respondents felt their relative was either very satisfied or satisfied with the staff who support them at work (or during the day); 2% believed their relative was either dissatisfied or very dissatisfied.

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

- Respondents said that their relative felt safe in their community, home, and neighborhood always (85%) 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 in the community.
- 89% of the respondents said that their relative seemed to have the opportunity to learn new things.

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

- 85% of the respondents said that their relative's home appeared to have an adequate number of paid staff.
- 96% of the respondents said that staff in their relative's home always treat people with dignity and respect.
- 89% of the respondents said that all staff appear to have the skills they need to support their relative in the home; 10% felt that only some staff have these skills.
- 95% 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.
- 91% of respondents reported that staff in their relative's place of work appear to have the skills they need to support their relative; 8% felt only some staff do.
- 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. For 82%, the communication system is used across all settings.

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

- 83% of relatives were satisfied with the supports coordination the individual receives.
- 59% of relatives reported that they were told how much money is in the individual annual budget.
- 7% of relatives report that the individual self-directs their own services.
- 68% said that the individual always received the supports they needed.
- 84% said that the services and supports the individual receives change when the individual's needs change.
- 90% of relatives always felt that the staff who assisted them with planning respected their choices and opinions.
- 52% of relatives never felt that there were frequent changes in support staff at the individual's home, work, or day program; 12% felt that there were always frequent changes.

- 47% of relatives choose the agency/provider who worked with the individual; 7% said the individual chose; 18% chose with the individual; 27% said someone else chose.
- 59% of relatives were familiar with the way complaints and grievances are handled at the provider level, 58% of relatives were familiar with the way complaints and grievances are handled at the county/AE level, and 53% of relatives were familiar with the way complaints and grievances are handled at the state level. 36% were not familiar with the grievance and complaint process on any level.

### ***Family Resources***

- 91% of relatives felt that the information they received about the individual's services was easy to understand.
- 13% of respondents had learned about the Life Course Framework and Tools.
- 48% of relatives have an opportunity to connect and network with other families with relatives at similar life stages.
- 22% of relatives said they were aware of the PA Family Network; of those who were aware, 24% had attended a workshop led by the Network of Family Advisors.
- 78% of relatives said that they have enough information about services for which their family is eligible.
- 28% of respondents whose family member transitioned from school to adult services in the past year were happy with the process.
- 72% of relatives report that the supports coordinator asks about their vision for an everyday life for their family member.

### ***Emergency Preparation Questions***

- 57% of relatives have been given information about an emergency plan for their family member in case of an 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 91.32 with a standard deviation of 13.60.
- The mode (the value that occurs the most frequently) was 100, indicating that many of the families' (47%) satisfaction levels were at the top of the scale on all measures of family satisfaction.

Compared to the Family/Friend/Guardian section of the 2018-2019 report, there were several significant differences.

- There was a 5% decrease in family members who reported that they never felt there were frequent changes in support staff at their relative's home.
- There was a 5% increase in family members who said that they chose the agency/provider who worked with their relative.

## **Summary**

This report presents information collected through face-to-face interviews with 2644 individuals receiving supports through the Office of Developmental Programs. In this year's sample, most individuals resided in the home of a relative.

Many trends from past years remain consistent. Individuals surveyed continued to report high levels of satisfaction overall. Most people were happy and said that people in their lives are nice or very nice to them. Many people also reported that they like where they live and work, though it remains the case that 1 in 6 said that they would prefer to do something else during the day, and about 1 in 7 would prefer to live somewhere else. Most individuals reported that they get the services and supports they need to be able to live in their homes.

Most people reported high levels of privacy, and consistently reported that they have friends, and can date and get married if they wish. Access to communication tools such as cable TV, computers, and the Internet increased. About half of the people regularly went out in the community to visit friends, dine-out, and shop at the supermarket and shopping center. A smaller portion regularly attended worship services, ran errands, and went out to coffee houses or taverns.

In the area of self-advocacy and self-directed services, it remains the case that less than half of the respondents had spoken to someone about self-advocacy or self-directed services. About 1 out of 5 respondents had participated in a self-advocacy group meeting, and about 1 out of 20 respondents used self-directed services. About 1 out of 3 respondents used Community Participation Services.

Although most people reported high levels of access to general healthcare, dental care, and medical specialists, over a third of individuals reported that they cannot consent for their own health services.

Most individuals were highly satisfied with their supports coordinator and other staff members. Individuals reported that staff members understand them, that they are listened to, and that they are treated with respect. This was supported by IM4Q teams, who largely reported that individuals were treated with respect in observed situations.

Overall people in the sample reported limited choices. About 1 in 3 individuals reported that they chose where to live on their own, and about 1 in 2 individuals chose what they do during the day on their own. However, more than half of the respondents did not choose their housemates or their roommates. More than half did not have a key to get into their house. 3 out of 5 always carried identification with them, but 1 in 4 never did. Two-thirds of individuals reported that they have a bank account and decided what they want to buy, and 9 out of 10 reported that they chose their daily schedule without assistance.

In terms of employment, nearly 1 in 6 individuals reported that they work in a community integrated setting. Of those who were not employed, more than half said that someone talked about employment in their planning meeting and nearly a third said employment is a goal in their plan. One in 10 took classes or training to obtain a job or get a better job. Among those who work, the most common occupations were cleaning services, food services, and retail. Most frequently, individuals who were employed reported working 20 hours a week. Regarding pay, the most common salary reported was between \$9.01 - \$12.00 per hour. The most common benefit reported by workers was receiving retirement benefits.

As has been the trend for several reporting years, communication remained an issue for many individuals in the sample, particularly for those who communicated other than verbally. People had trouble understanding their doctor (33%), being understood by their doctor (20%), and being understood by staff (12%). Of people who are non-verbal, only about 1 in 3 had a communication system in place.