

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

Independent Monitoring for Quality (IM4Q)
A Statewide Summary
2017-2018

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

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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 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 DHS HCSIS web-based system. In 2013, we began to utilize ODESA, a web-based, secure data entry system developed 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.

A list of the number of individuals receiving services and their family, friends and guardians who completed surveys in the years of the project 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

The reduction in the number of individuals surveyed during 2012-2013 was due to the change in the sampling strategy for the National Core Indicators Survey.

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. 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. For fiscal year 2017-2018, twelve questions regarding healthcare were added to the Dignity, Respect and Rights section.

The EDE for fiscal year 2017-2018 includes all survey questions included in the FY 2017-2018 NCI Adult In-Person Survey. This year, 708 individuals included in this report are represented in the NCI sample for 2017-2018, based on a sampling methodology established by ODP and the Human Services Research Institute (HSRI). A copy of the NCI report for FY 2016-17 is available on the HSRI website at www.nationalcoreindicators.org.

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

- A **pre-survey**, which was completed by the AE 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). Often this information is provided by the supports coordination organization (SCO).
- A **background information section**, which was completed by the AE for only those individuals who were designated as part of the NCI sample. The section 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.
- **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 completed whenever there was an issue related to physical danger, significant sanitation problems, or evidence of physical or psychological abuse or neglect. Each 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 (F/F/G) Survey** – a survey was conducted with each family once the individual 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

Independent Monitoring focuses on the quality of life and services and supports to children ages three and over, and to adults supported by the Office of Developmental Programs' service system for individuals with intellectual disabilities. In Fiscal Year 1999-2000, the sample for IM4Q was restricted to individuals living in licensed residential settings in 19 AEs, including licensed community homes and apartments, family living arrangements, non-state operated private intermediate care facilities for people with intellectual disabilities (ICFs/ID) and large community homes (formerly private licensed facilities).

In Fiscal Year 2000-01, the sample for IM4Q was expanded to include individuals not receiving residential supports. This resulting sample included 30 adults per county in the NCI subset and others living at home with families, in unlicensed living arrangements and independently. The proportion of individuals in non-residential settings for purposes of the NCI sample was to be proportional to the number of people receiving non-residential supports in the AE. Administrative Entities were instructed to draw a random sample of approximately one-third of the individuals living in licensed residential settings. AEs were provided with written instructions for drawing the entire Fiscal Year 2001-02 sample; once the sample was selected, ODP staff checked the samples before individual names were given to the local IM4Q Program, to ensure consistency in the sample selection.

During fiscal year 2003-04, in addition to the NCI and residential samples, each AE was instructed to include 30 individuals who participate in the Person and Family Directed Supports (PFDS) Waiver. Individuals participating in the PFDS Waiver continued to be included in the sample in each subsequent year.

The sampling procedure for this year continues to be drawn through the Home and Community Services Information System (HCSIS). The major change that has occurred over the past three years is that we are no longer sampling 30 individuals per AE for the NCI sample; we have gone to a statewide simple random sample of approximately 700 individuals. 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 live in supervised living settings. Many people in the sample live at home with families, due in part to the sub-sample of people receiving supports through the PFDS waiver as well as for those who are a part of the NCI sample.

	N	Percent
State-Operated ICF/ID	6	0.1%
State MH Hospital	3	0.1%
Foster Care	1	0.0%
Nursing Home/Facility	41	0.8%
Domiciliary Care	7	0.1%
Personal Care Home	56	1.1%
Family Living/Life sharing	235	4.5%
Unlicensed Family Living	26	0.5%
Own Residence	282	5.4%
Relative's Home	1438	27.3%
Children's Facility	5	0.1%
Approved Private School	1	0.0%
Private ICF/ID 4 or fewer	44	0.8%
Private ICF/ID 5-8	126	2.4%
Private ICF/ID 9-15	26	0.5%
Private ICF/ID 16+	172	3.3%
Community Home 1	175	3.3%
Community Home 2-4	2383	45.3%
Community Home 5-6	110	2.1%
Community Home 7-8	70	1.3%
Community Home 9-15	6	0.1%
Community Home 16+	22	0.4%
Other	26	0.5%
Missing	93	1.7%
Total	5354	100%

Procedure

Selection of Local IM4Q Programs

ODP requested that AEs select local IM4Q Programs to conduct interviews with individuals and families using the EDE and F/F/G Survey. All potential IM4Q programs were screened by the Statewide IM4Q Steering Committee. Selection criteria included: 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 were selected by AEs from a variety of organizations, including non-service providing chapters of The Arc, Consumer Satisfaction Teams (in the mental health system), parent groups, universities and colleges, Centers for Independent Living, and entities formed specifically to implement IM4Q.

Training

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. Trainings were held in each of the four regions for project staff and monitors, wherever possible. Additional training was provided on an AE-by-AE basis for monitors, as requested. Data entry instruction was provided by ODP with support from the IOD. In addition to regional and statewide training, individual programs provide training to their monitoring teams based on need at the local level.

Sample and Team Interview Process

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. Teams may also include other interested citizens who are not part of the ODP service system. Visits to individuals' homes are scheduled with the individual, or with the person designated on the pre-survey form that is completed prior to the visit.

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.

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, a data entry system developed

and maintained by HSRI, originally intended for NCI data, now expanded to include IM4Q data. Data for the 2017-2018 survey cycle were collected and entered into ODESA by June 30, 2018. A usable data file was received by the Institute on Disabilities in December, 2018. This report presents data on the individuals surveyed by the IM4Q Local Programs, representing the 48 AEs across the state. In addition to this report, each AE and local program will receive a report about the people monitored in their AE/county. Separate reports will also be developed by HSRI for those individuals in the NCI sample and by the Institute on Disabilities for those individuals in the PFDS sample, and those living in state centers.

Closing the Loop/Follow-up

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	606	11.3%
Armstrong/Indiana	73	1.4%
Beaver	99	1.8%
Bedford/Somerset	50	0.9%
Berks	151	2.8%
Blair	73	1.4%
Bradford/Sullivan	34	0.6%
Bucks	209	3.9%
Butler	82	1.5%
Cambria	63	1.2%
Cameron/Elk	25	0.5%
Carbon/Monroe/Pike	82	1.5%
Centre	68	1.3%
Chester	152	2.8%
Clarion	27	0.5%
Clearfield/Jefferson	51	1.0%
Columbia/Montour/Snyder/Union	67	1.3%
Crawford	79	1.5%
Cumberland/Perry	68	1.3%
Dauphin	146	2.7%
Delaware	249	4.7%

Erie	238	4.4%
Fayette	57	1.1%
Forest/Warren	25	0.5%
Franklin/Fulton	73	1.4%
Greene	29	0.5%
Huntington/Mifflin/Juniata	54	1.0%
Lackawanna/Susquehanna	125	2.3%
Lancaster	148	2.8%
Lawrence	53	1.0%
Lebanon	40	0.7%
Lehigh	148	2.8%
Luzerne/Wyoming	129	2.4%
Lycoming/Clinton	77	1.4%
McKean	25	0.5%
Mercer	49	0.9%
Montgomery	276	5.2%
Northampton	91	1.7%
Northumberland	55	1.0%
Philadelphia	693	12.9%
Potter	14	0.3%
Schuylkill	59	1.1%
Tioga	38	0.7%
Venango	50	0.9%
Washington	68	1.3%
Wayne	39	0.7%
Westmoreland	122	2.3%
York/Adams	125	2.3%
Missing	0	0.0%
TOTAL	5354	100%

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=5227), 56% identified as male and 44% identified as female
- For those who reported their age (n=5227) the mean age in the sample was 45.45 (SD=16.64), with a range of 7 to 97 years
- Of those who reported on race in the sample (n=4416), 81% identified as white, 16% identified as black/African-American, 1% identified as Asian, 1% identified as mixed-race, 1% identified as other, and less than 1% identified as American Indian/Alaskan Native/Pacific Islander
- Of those who identified their ethnicity (n=4032), 3% identified as Hispanic/Latinx

Satisfaction

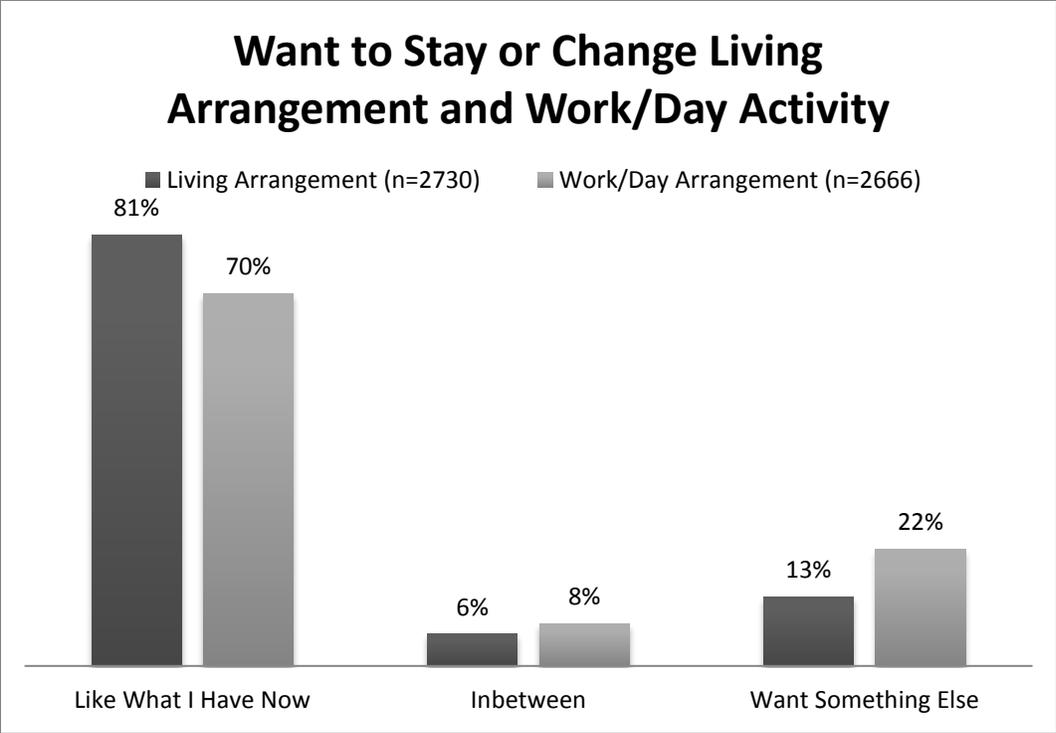
Respondents: Only the individual receiving services/supports could answer the questions on satisfaction. A consistency check was performed and 3 individuals' surveys were not included in the satisfaction section. The percent of people who responded to questions in this section ranged from 32% to 60%.

Satisfaction with Living Arrangements

- 89% 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, 1% stated that they wanted more independence, 1% reported that they wanted to be closer to family and friends, 1% stated that it doesn't feel like home, 1% stated they have a problem with staff, and 4% reported there is some other reason they don't like where they live. Less than one percent of people reported that they did not like where they live because of accessibility, they feel unsafe, or their home needs repair.
- 81% wanted to stay where they currently live but 13% wanted to move somewhere else.

Satisfaction with Work/Day Activity

- 91% 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.
- 70% wanted to continue their current daytime activities/work, but 22% wanted to do something else.



Daily Life

- 86% of the individuals reported getting the services they needed to be able to live in their home, 11% said yes, but they sometimes need more, and 3% said they do not get the services they need to be able to live in their home.
- On most weekdays, 27% of individuals attended an adult day program/community senior center, 24% attended a vocational facility, 13% stayed home, 9% went out and did things in the community, 7% worked with no supports, 8% worked in supported employment, 2% volunteered, 3% attended school, 4% are retired, and 3% did something else.
- In addition to what individuals do on most weekdays, 29% also went out and did things in the community, 33% stayed home, 5% attended an adult day program/community senior center, 3% attended a vocational facility, 9% volunteered, 2% worked with no supports, 3% worked in supported employment, 4% are retired, and 1% 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.

Happiness and Loneliness

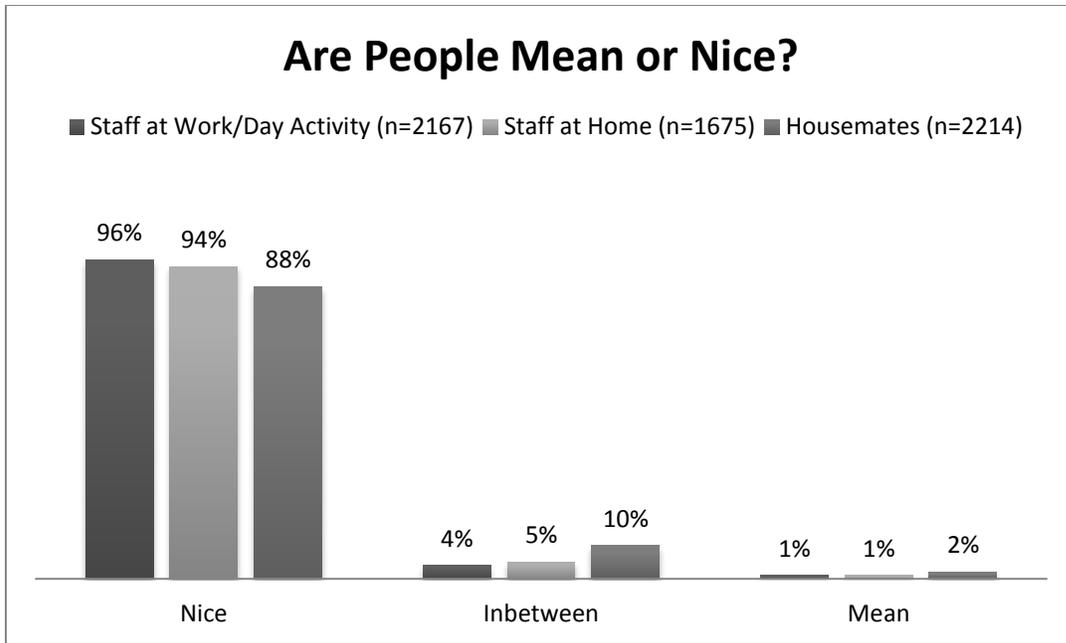
- 86% reported feeling happy overall, 12% reported being neither happy nor sad, and 2% reported feeling sad overall.
- 64% of individuals reported never feeling lonely, 32% reported sometimes feeling lonely, and 3% reported always feeling lonely.
- 89% reported having friends they like to do things with – for 71% of these people their friends are not staff or family.
- 80% reported that they can go on a date if they want to or are married; 9% 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

- 98% 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.
- 88% 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 6% never let them know before entering.
- 88% reported that people let them know before coming into their bedroom, 6% reported sometimes people let them know before coming into their room, and 6% never let them know.

Are People Nice or Mean?

- 88% of respondents reported that their housemates are very nice or nice.
- 83% 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.
- 96% 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 85.91 with a standard deviation of 19.10
- 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 2016-2017 report, there were several noteworthy differences:

- There was a 6% **decrease** in individuals who reported they like where they live

- There was a 6% **decrease** in individuals who reported they are getting the services they need to live at home, with a 6% **increase** in those who reported that they receive some services but need more.
- There was a 3% **increase** in people who reported that they work
- There was a 4% **increase** in individuals who reported they could go on a date if they want to or that they are married.

Dignity, Respect and Rights

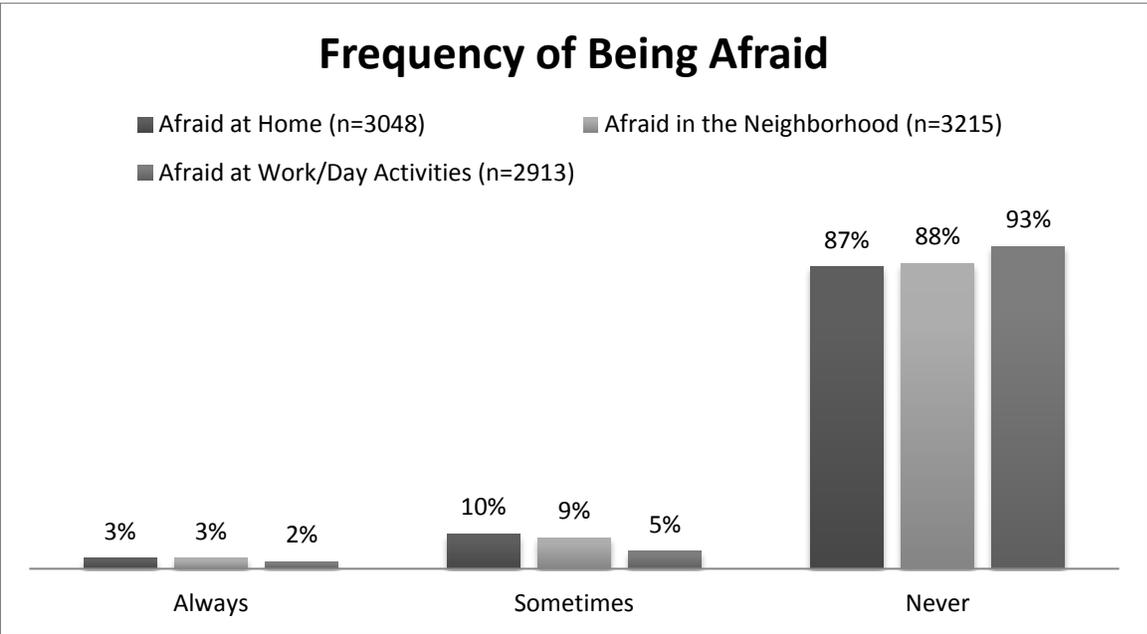
Respondents: Only the individual receiving services/supports could answer the questions on dignity, respect and rights. A consistency check was performed and 3 individuals' surveys were not included in the Dignity, Respect and Rights section. The percent of people who responded to questions in this section ranged from 32% to 61%.

Support with Goals and Problems

- 50% of individuals want help to learn new things.
- 72% of individuals report that they get to help other people.
- 21% of individuals indicated that they have participated in a self-advocacy group meeting.
- 40% of people said someone had talked to them about self-advocacy
- 60% of people reported that they go to staff for help when they have a problem, 38% reported that they go to their family, 11% reported that they go to their supports coordinator, 9% reported that they go to a friend, and 10% reported that they go to someone else. 1% of individuals reported that they have no one to go to for help.

Being Afraid

- 87% reported never being afraid at home; 10% reported sometimes being afraid at home.
- 88% reported never being afraid in the neighborhood; 9% reported sometimes being afraid in the neighborhood.
- 93% reported never being afraid at work, school or day activity; 5% reported sometimes being afraid at work, school or day activity.
- 93% reported never being afraid when using transportation; 5% reported sometimes being afraid when using transportation.
- 96% reported that they have someone they can talk to when they feel afraid.



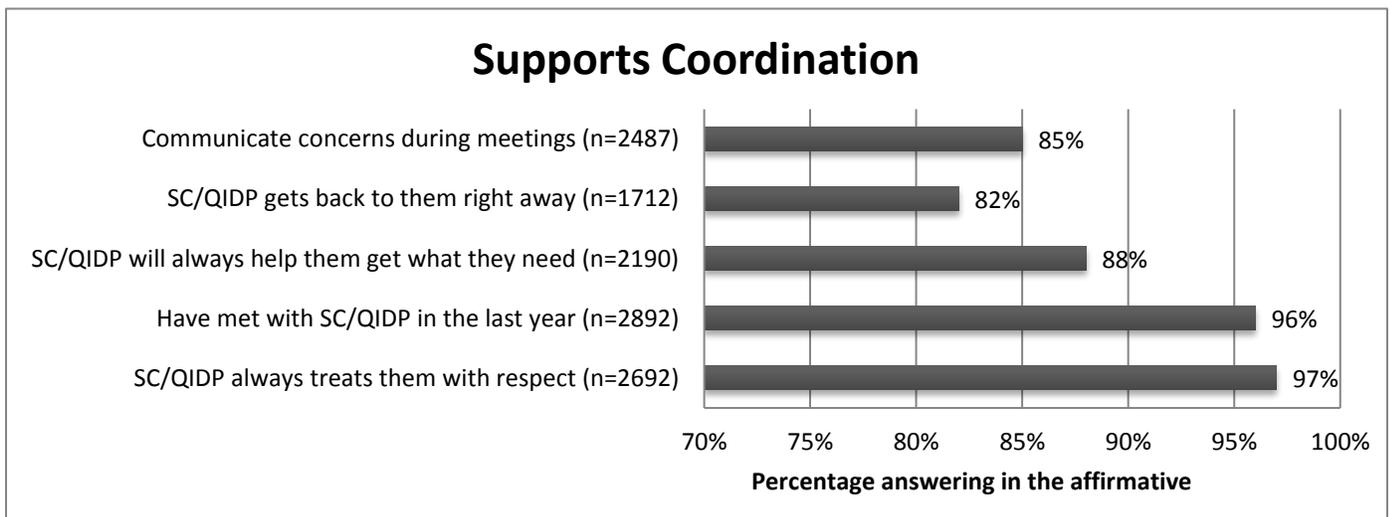
Legal Rights

- For 87% of the individuals interviewed, their mail is never opened without permission; 7% say their mail is always opened without permission.

Supports Coordination/Qualified Intellectual Disability Professional (QIDP)

- 96% reported that they met with their supports coordinator/QIDP 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.
- 82% of individuals reported that when they call, their supports coordinator/QIDP always gets back to them right away.
- 92% 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
- 82% said the supports coordinator asks what they want in the future

- 85% of interviewees reported always being able to communicate their concerns during annual meetings; 11% reported that they are sometimes able to communicate their concerns.
- 46% of individuals report that their supports coordinator has asked them about directing their own services
- 98% of people surveyed reported that their supports coordinator talks with them about services to make sure everything is OK.
- 62% of those surveyed have been told at their planning meeting how much money is in their annual budget.
- 68% of individuals reported that they know they have a choice of SC organizations.
- 94% 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.
- 95% of individuals reported that their supports coordinator always listens to them; 4% 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.



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.
- 63% of individuals feel that all of their staff understand their communication; 30% say some staff understand them, 6% feel they are understood sometimes, and 2% do not feel that their staff understand their communication.

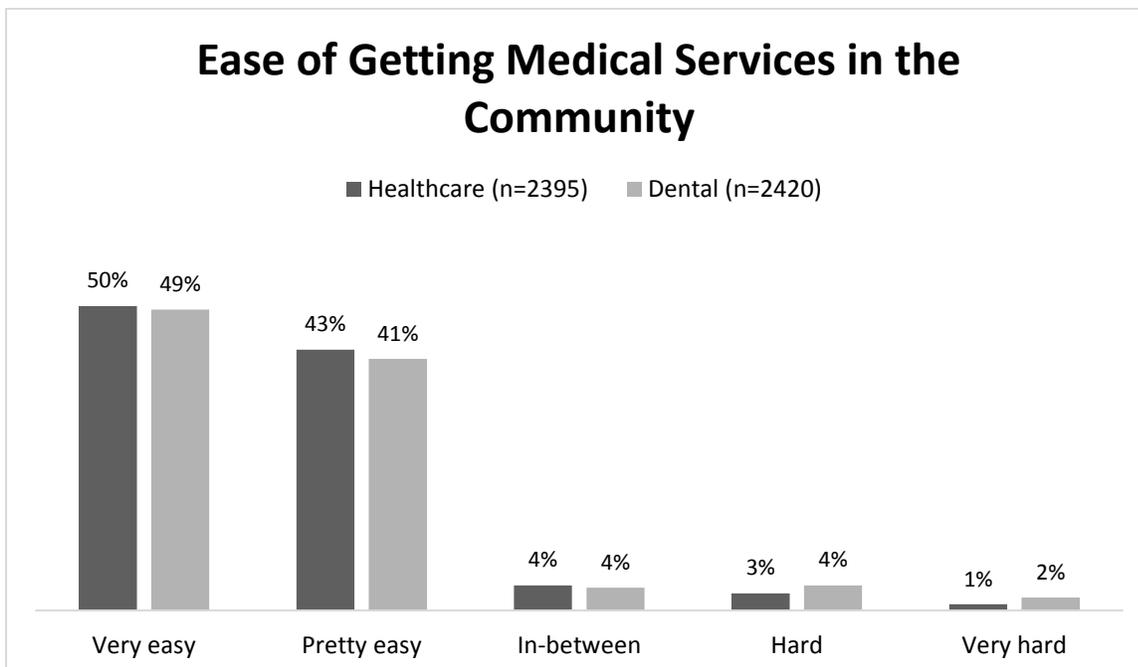
Emergency Preparation Questions

- 87% 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, 56% received information from home staff, 37% from day program or employment staff, 29% from someone in their family, 5% from the police, fire department, or EMS, 8% from supports coordinator, 9% from someone else, 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, 45% of individuals said zero, and 39% said 10 or more times a month.
- 97% of individuals interviewed reported that they have the opportunity to discuss health with their primary care provider (PCP)
- 97% of individuals reported that they feel their doctor understands them
- 94% of individuals feel that they understood their doctors' instructions
- 91% of respondents say if they needed help communicating at the doctor's office, it was available
- 61% of respondents reported they were able to see if a medical specialist if they needed to, but 39% said they were not able to see a specialist due to barriers
- 89% of individuals say they have not been prevented from receiving medical and dental services because of their disability; 11% said they had been prevented

- When asked how hard it is to get health care services in their community, 92% of individuals reported that it was very easy or pretty easy, 4% 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, 90% of individuals reported that it was very easy or easy, 4% reported that it was in-between, and 6% reported that it was very hard or hard
- Of those who have a psychiatrist, 77% of individuals interviewed reported that they have the opportunity to discuss health concerns with a psychiatrist; 21% 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
- 97% of individuals reported that their doctor speaks directly to them during appointments
- 85% of individuals reported that they are able to provide consent for medical treatment; of those able to provide consent, 90% said their doctor accepts their consent and 10% 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 score was 82.70 with a standard deviation of 14.44.
- 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 92.59 with a standard deviation of 17.64.
- 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 (87-93%) 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 2016-2017 report, there were several significant differences.

- There was a 6% **decrease** in individuals who reported that they can always voice their concerns during their annual meetings.
- There was a 6% **decrease** in individuals who reported that they have been told at their planning meeting how much money is in their annual budget.

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,

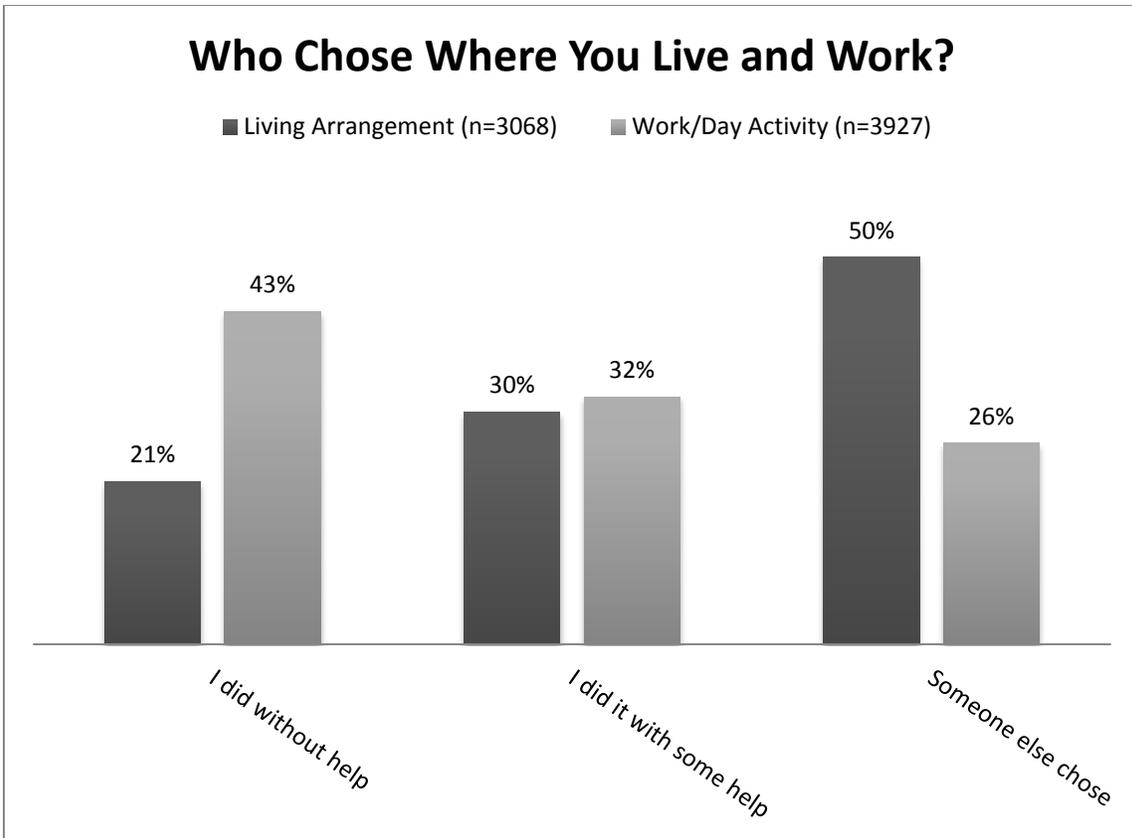
- 33% of the questions were answered by the individual receiving supports
- 33% of the questions were answered by paid staff
- 15% of the questions were answered by the individual and staff
- 10% of the questions were answered by family/friend/advocate/guardian
- 8% of the questions were answered by 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

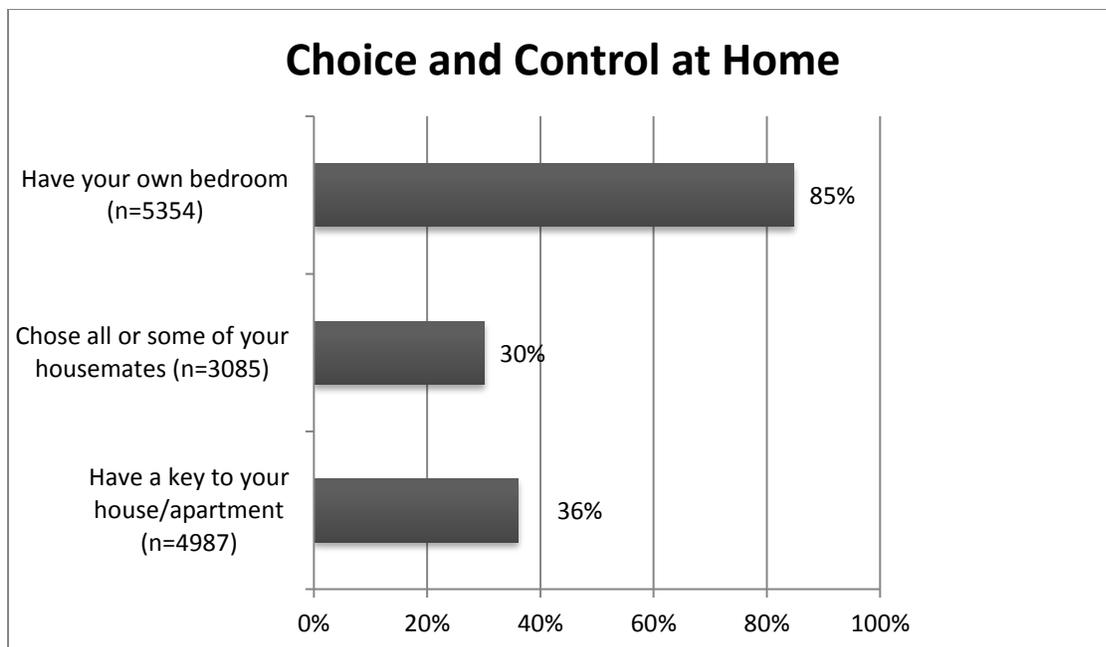
- 54% of individuals stated that they always carry a form of identification; 25% never do.

Choice and Control at Home

- 36% of the individuals surveyed had a key/way to get into to their house or apartment on their own.
- 3% of individuals reported that they own their own home
- 20% of individuals report that their name is on the lease or rental agreement
- For 50% of the individuals, someone else chose where they live; 21% of those interviewed chose on their own.
- 39% of individuals said they were given a choice to live where people without disabilities live
- 49% of individuals surveyed saw no other places before they moved into their residence.



- 70% of the individuals **did not** choose their housemates.
- For those who shared a bedroom, only 30% chose some or all of their roommates.



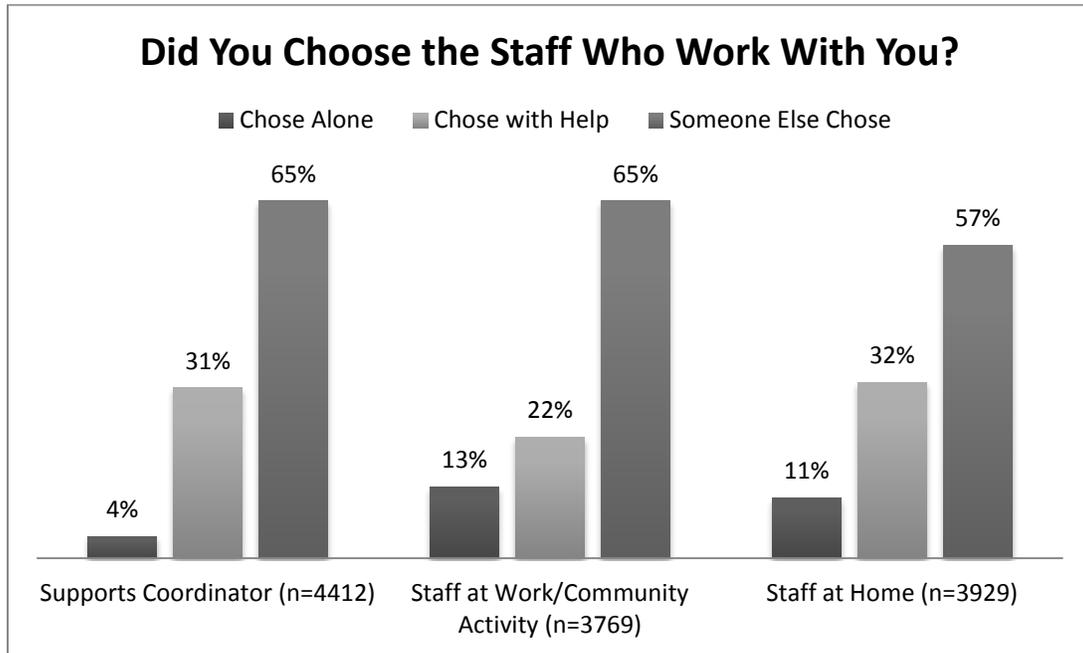
Choice and Control During the Day and for Leisure Time

- 26% of the individuals interviewed reported that someone else chose what they do during the day.
- 43% of the people interviewed chose what they do during the day without assistance.
- 51% of individuals reported that when they chose their work or day activity they had an option to go where people without disabilities go
- 46% of individuals saw no other places when choosing what they do during the day.
- 54% of the individuals surveyed chose their daily schedules without assistance.
- 69% chose how they spend their free time without assistance.

Choice and Control in Choosing Staff

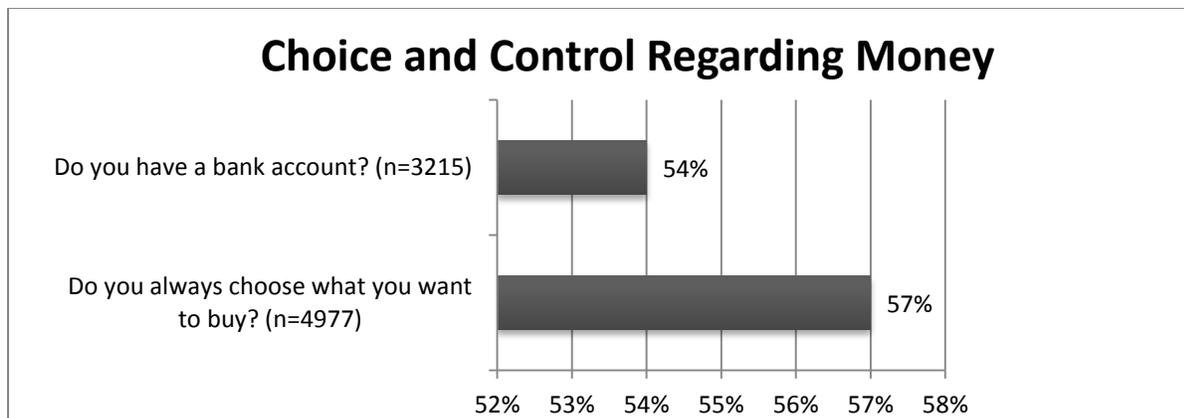
- 43% of the individuals interviewed/chose at least some of the staff who help them at home (alone or with assistance from family or provider).
- 35% of the individuals surveyed interviewed/chose at least some of the staff who help them at work/day activity (alone or with assistance from family or provider).

- 35% of individuals chose their supports coordinators (alone or with assistance from family or provider).



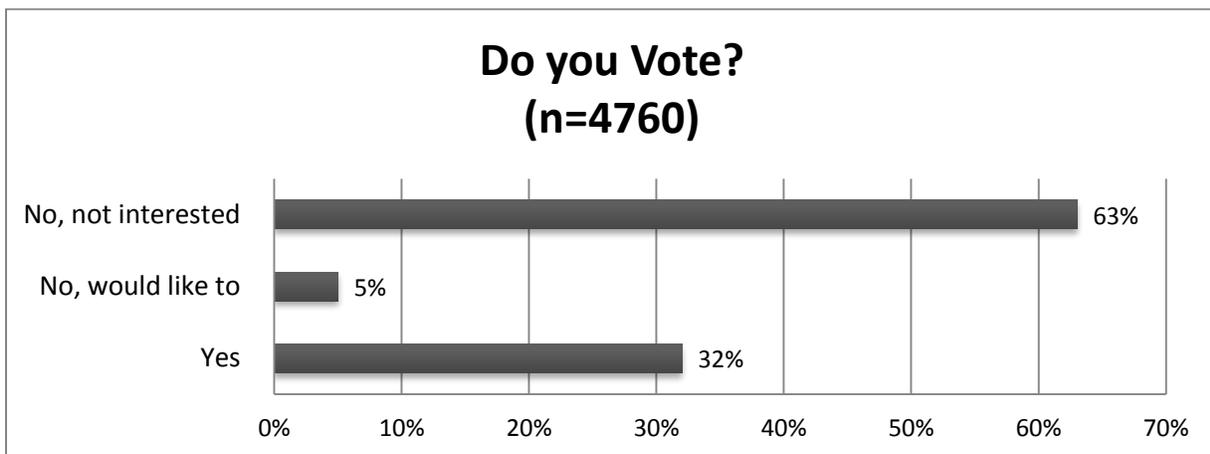
Choice and Control with Regard to Money

- 57% of the individuals reported that they always choose what to buy with their spending money, 33% report that they choose with help.
- 40% of the individuals reported that there is something they want to buy.
- 54% of the individuals reported they have a bank account that they can get to independently to withdraw money when they want it.



Voting

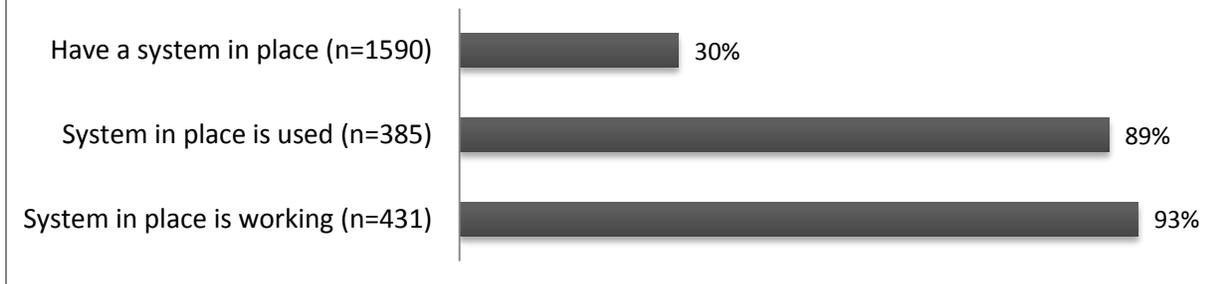
- 32% of the people said they vote, 63% of the people said they do not vote and are not interested in voting, and 5% do not vote but would like to. ***It is our hope that for those individuals expressing a desire to vote, a consideration has been written to assist the individuals in registering to vote and in voting. Additionally, 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 30% of the people interviewed.
- For those people with formal communication systems in place, 93% 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
- 79% of individuals with a formal communication system reported using it across all settings.
- 70% of individuals with a formal communication system are supported by staff or a program coordinator, 29% are supported by a parent or caregiver, 28% are supported by their speech language clinician, and 10% are supported by someone else.

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



Other Forms of Communication:

- 21% have and use a cell phone; there are restrictions for 9% of these people
- 11% have and use e-mail; there are restrictions for 5% of these people
- 23% have and use internet; there are restrictions for 11% of these people
- 13% have and use text-messaging; there are restrictions for 4% of these people
- 79% have and use cable television; there are restrictions for 5% of these people
- 32% have and use a computer; there are restrictions for 10% of these people

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 49.69 with a standard deviation of 23.05.
- The modal score was 47.37, indicating the most frequent score.

There were several significant differences regarding this year's data in this section when compared with the data from 2016-2017:

- There was a 3% **increase** in individuals who reported that they had a key/way to get into to their house or apartment on their own.
- There was an 11% **increase** in individuals who reported they chose their supports coordinators (alone or with assistance from family or provider).

- There was a 4% **increase** in those who reported they chose what they do during the day without assistance.
- There was an **increase** in individuals who reported that they interviewed/chose at least some of the staff who help them at home (5%) and at their work/day activity (4%).
- Regarding forms of communication, there was a **decrease** in respondents' reports that they have and use a cell phone (4%), have and use internet (6%) and have and use cable television (12%)
- There was also a substantial **decrease** in individuals who chose some or all of their roommates (12%)
- Finally, there was a substantial **increase** in individuals who reported they saw no other options prior to moving into their residence (39%)
 - This large increase could be partially explained by a rewording of the question from last year

Employment

Respondents: Of the 5354 individuals surveyed for the 2016-2017 Statewide IM4Q sample, 500 people indicated they are employed.

Community Integrated Employment

- 12% (n=500) of individuals report that they work in a community integrated setting while 88% do not.
- The majority of individuals have been employed for 1 to 3 years (32%). 19% 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 21% 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, 14% work in retail, 24% work in food services, 2% do office work, 5% work in a stock room or stock shelves, 3% work in maintenance, 8% work in assembly or factories, 2% work as care-workers or aides, 1% work in animal care, 1% work in landscaping or outdoors, and 11% work in some other occupation

Supports Getting Into the Workplace

- 52% of individuals surveyed reported that someone had talked to them about employment in their planning meeting
- 27% of individuals report that community employment is a goal in their plan
- When individuals were asked who had talked to them about employment, 50% said no one, 43% said their supports coordinator, 12% said their service provider, 8% said their family, less than 1% said their housemates, and 6% said someone else

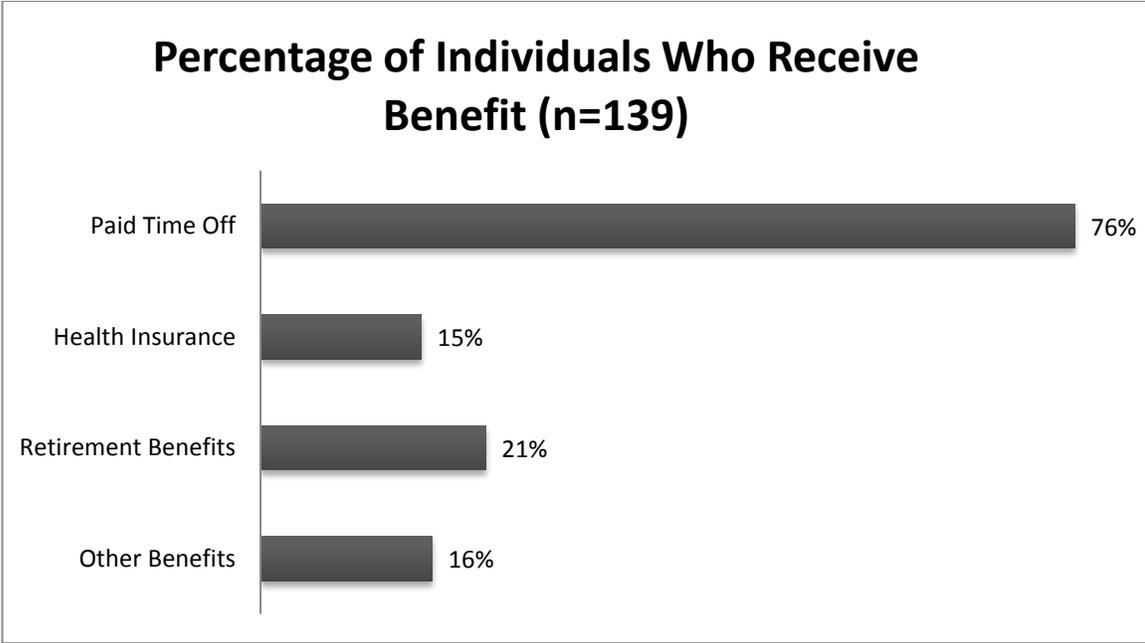
Note: individuals answering this question had the option to indicate more than one response.

Compensation and Advancement

- 76% of individuals received paid time off, 15% received health insurance, 21% received retirement benefits, and 16% received some other kind of benefit.

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

- 40% of individuals who work have been promoted and/or received an increase in pay.
- The mean number of hours worked per week was 15.97 hours. Hours worked per week ranged from 1 to 55 hours; the most common response was 20 hours per week.
- 81% 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, reported by 39% of individuals, was \$7.25. 32% of individuals reported earning \$7.26 to \$9.00 an hour, 23% earned \$9.01 to \$12.00 per hour, and 6% earned more than \$12.01 per hour.



Self-employment: 1% (n=48) 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 2016-2017:

- Of employed individuals, there was a 3% **increase** in individuals that have been employed for 4-6 years.
- There was a 3% **increase** in employed individuals that received paid time off.
- There was an 11% **decrease** in employed individuals that received health insurance.
- There was a 3% **increase** in employed individuals that received retirement benefits.
- There was a 4% **increase** in employed individuals that received some other type of benefit.

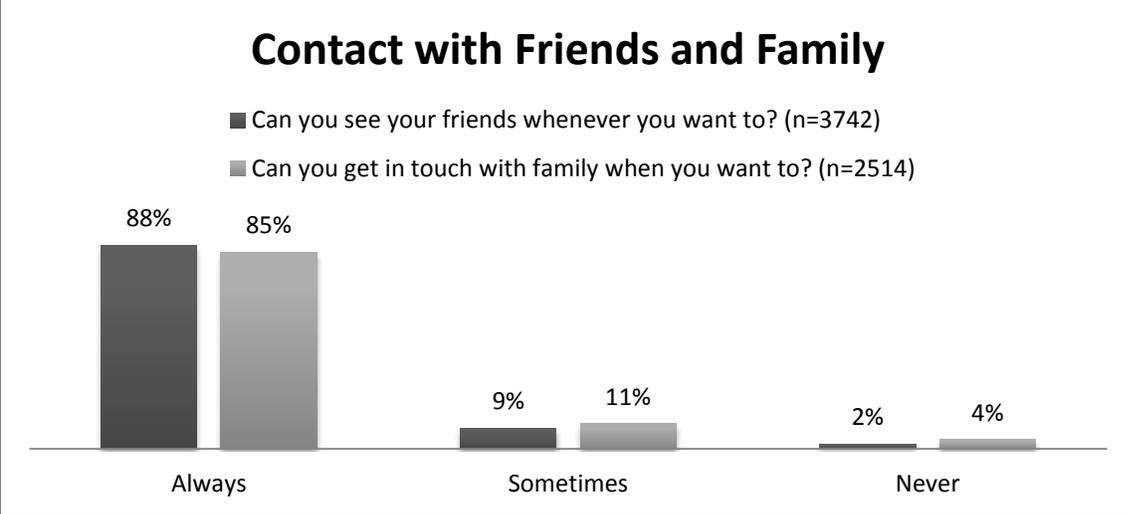
Relationships

Respondents: The 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
- 33% were answered by paid staff
- 13% were answered by individuals receiving support and staff
- 10% were answered by family/friend/guardian/advocate
- 7% 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."

Contact with Friends and Family

- 88% 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, 30% reported that it was difficult to find time to see friends, 11% reported that they couldn't see friends because of a transportation issue, 5% reported a lack of staff, 9% reported that there were rules/restrictions, and 44% reported that there was another reason why they couldn't see friends.
- 85% 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 2016-2017.

- There was a 9% **increase** in individuals who reported that they can see their friends whenever they want to.
- When they could not see their friends, there was a 6% **decrease** in those who reported transportation reasons, but a 4% **increase** in those who said rules and restrictions were to blame
- There was a 3% **increase** in individuals who reported that they can get in touch with their family whenever they want to.

Inclusion

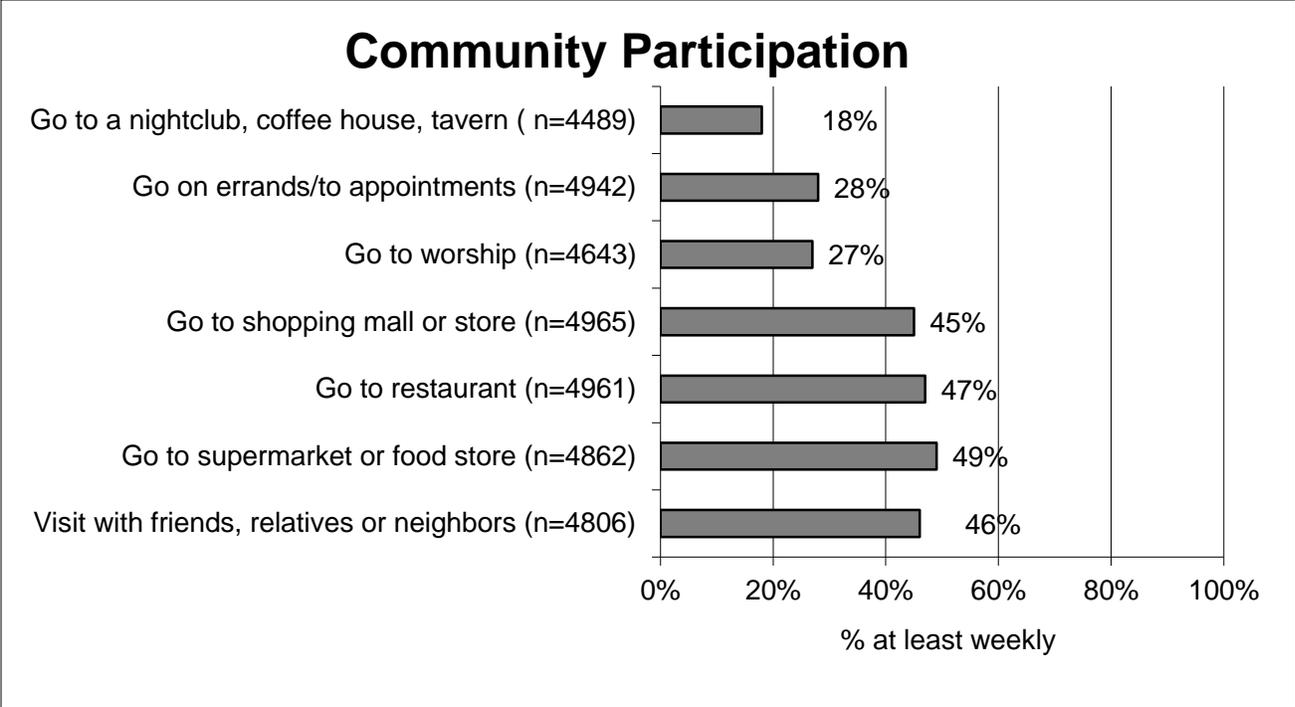
Respondents: The questions on inclusion could be answered by the individual receiving services/supports, a family member, a friend, or paid staff.

- 30% of the questions were answered by individuals receiving supports
- 34% were answered by paid staff
- 17% were answered by individuals receiving support and staff
- 10% were answered by family/friend/guardian/advocate
- 9% 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

- 46% of the people visited with friends, relatives and neighbors at least weekly
 - When they visited friends, relatives and neighbors, individuals reported they went alone 8% of the time, with family 40% of the time, with staff 41% of the time, with friends 9% of the time, with housemates or coworkers 2% of the time, and with someone else less than 1% of the time
- 49% of those surveyed went to a supermarket at least weekly
 - When they went to the supermarket, individuals reported they went alone 4% of the time, with family 26% of the time, with staff 67% of the time, with friends 1% of the time, with housemates or coworkers 2% of the time, and with someone else less than 1% of the time
- 47% of respondents went to restaurants at least weekly.
 - When they went to a restaurant, individuals reported they went alone 2% of the time, with family 27% of the time, with staff 61% of the time, with friends 4% of the time, with housemates or coworkers 5% of the time, and with someone else less than 1% of the time
- 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 4% of the time, with family 24% of the time, with staff 66% of the time, with friends 3% of the time, with housemates or coworkers 4% of the time, and with someone else less than 1% of the time
- 27% of respondents went to places of worship at least weekly
 - When they went to a place of worship, individuals reported they went alone 5% of the time, with family 38% of the time, with staff 46% of the time, with friends 5% of the time, with housemates or coworkers 4% of the time, and with someone else 2% of the time
- 28% of those surveyed went out on errands or appointments at least weekly
 - When they went of errands or appointments, individuals reported they went alone 4% of the time, with family 26% of the time, with staff 67% of the time, with friends 1% of the time, with housemates or coworkers 2% of the time, and with someone else less than 1% of the time
- 18% 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 6% of the time, with family 22% of the time, with staff 63% of the time, with friends 5% of the time, with housemates or coworkers 3% of the time, and with someone else 3% of the time



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 in IM4Q are less likely than individuals with disabilities in the Harris Poll to visit with friends, relatives, and neighbors. People without disabilities are still about 20% 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 also slightly more likely than people without disabilities in the Harris Poll.
- Pennsylvanians with disabilities in IM4Q are a little more likely to go to places of worship weekly than people with disabilities in the Harris Poll.

Weekly Participation in Community Activities			
	Harris 2010: People without Disabilities	Harris 2010: People with Disabilities	Independent Monitoring 2017-2018
Visit with friends, relatives, and neighbors	65%	54%	46%
Go to restaurant	41%	20%	47%
Go to worship	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 44.79 with a standard deviation of 17.01
- 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.

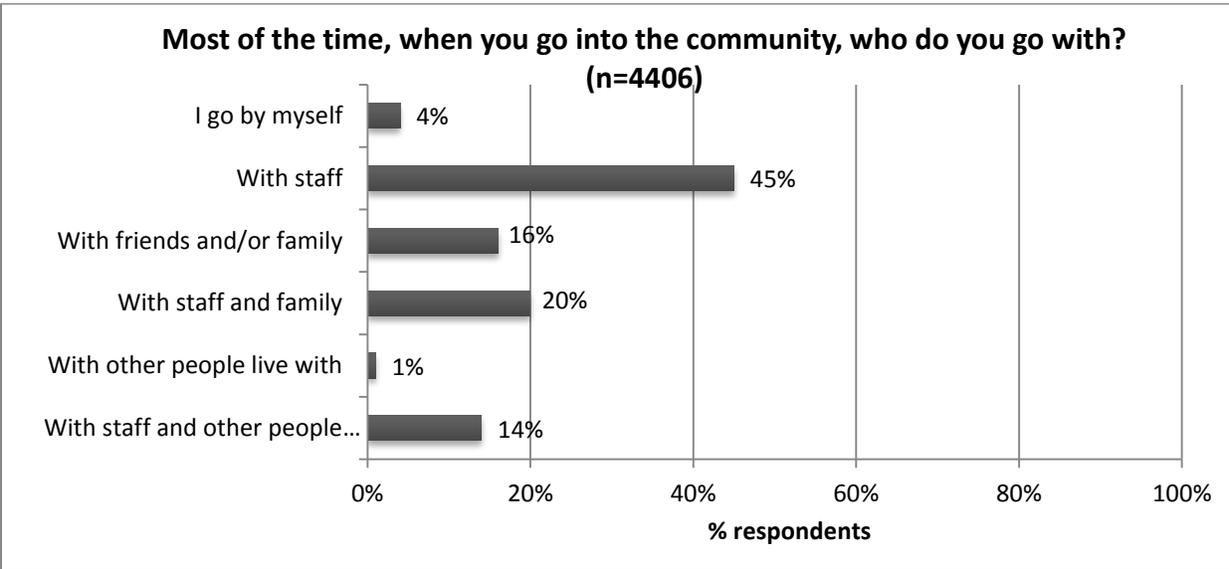
Community Activities

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

- 58% of individuals go frequently into the community for entertainment and 30% go occasionally.
- 41% of individuals reported that they frequently go to social events in the community that are attended by people with and without disabilities and 42% go occasionally.
- 43% of individuals went on a vacation in the past year.
- Regarding monthly exercise, 36% of individuals reported never going out for exercise, 6% exercise less than weekly, 13% exercise once a week and 45% exercise more than once a week.

Going Out Alone or With Other People

- 4% of individuals go out alone; 16% go out with friends and family.
- 59% of individuals go out with staff or staff and other people they live with most of the time.

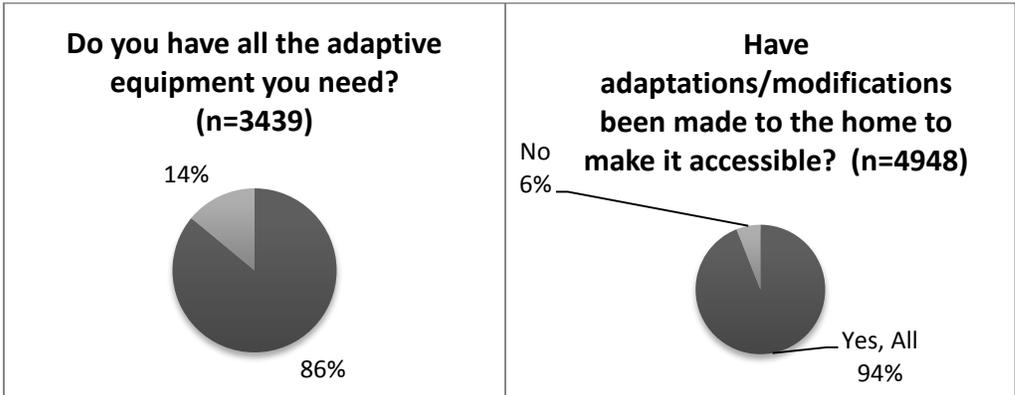


Transportation

- 92% of individuals always had a way to get where they wanted to go.
- In order to get to places they needed to go, the majority of individuals reported getting a ride from staff in the provider van (56%). 23% reported getting a ride from family or friends, 12% reported getting a ride in a staff member’s car, 3% transport themselves, 3% ride public transportation, 3% ride paratransit, and less than one percent take a taxi, Uber or Lyft.
- Of those who cannot always get where they want to go, 31% cannot get where they want to go because there is not enough staff. 10% said para transit is unreliable, 4% have transportation for work/school only, 2% 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

- 86% of individuals reported having all the adaptive equipment they needed.
- 94% 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 2016-2017:

- There was a 4% **increase** in individuals who went out on errands or appointments at least weekly.

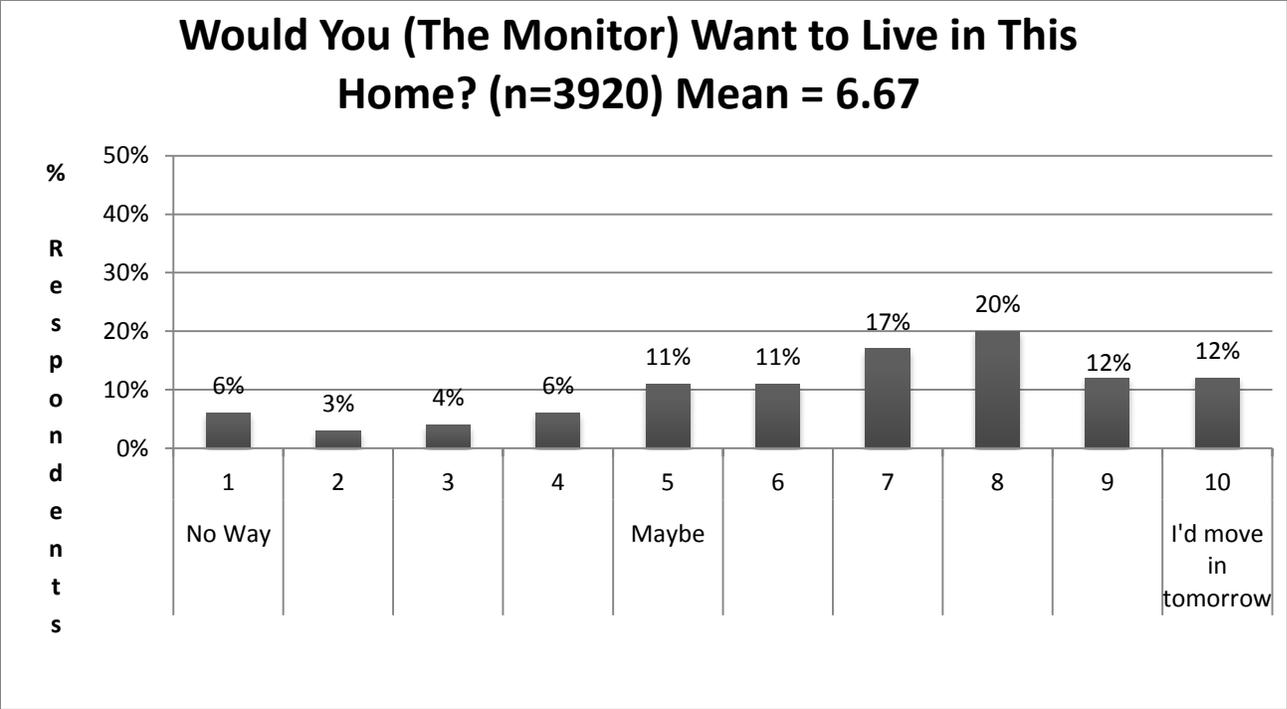
- There was a 3% **increase** in people who go to a night club, coffee house, or tavern to meet people at least weekly
- There was a 6% **increase** in individuals who reported never going out for exercise
- There was an 8% **decrease** in individuals who reported that they exercise more than once a week
- There was an 8% **increase** in people who reported that all necessary modifications have been made to their home to make it accessible.

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 6.67.



Compared to the Competence, Personal Growth and Opportunities to Grow and Learn section of the 2016-2017 report, there were no significant differences.

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 90% of observed situations.
- 89% of staff observed recognized the individuals in ways that promote independence.
- 90% of staff observed that support individuals at home and/or work appeared to have the skills they needed to support the person.

Compared to the Staff Support for the Person section of the 2016-2017 report, there were two significant differences.

- There was a 3% **increase** in the observed situations in which IM4Q teams perceived that individuals were treated with dignity and respect
- There was a 4% **increase** in the perception of IM4Q teams that staff in the individual's home and/or work had the skills necessary to help the person

Family/Friend/Guardian Survey

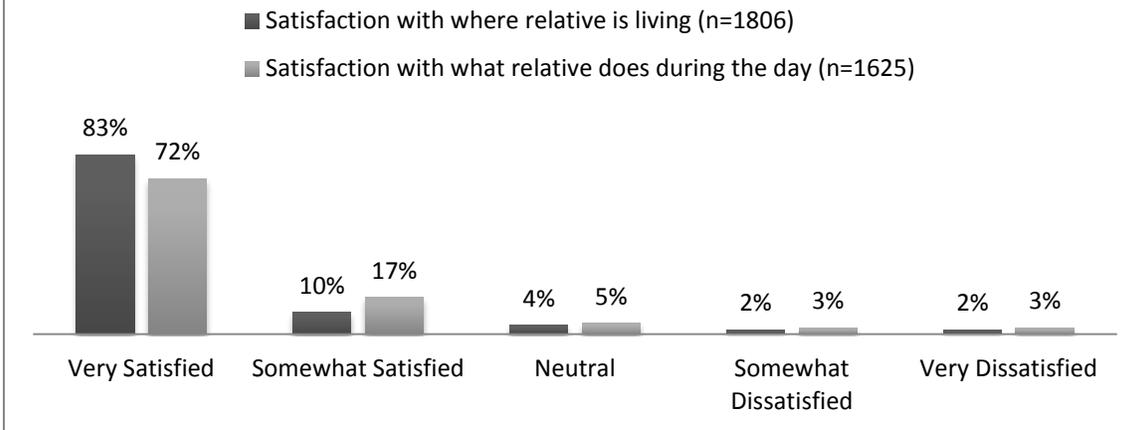
Respondents: This survey was completed by telephone or face-to-face with a family member, guardian, or friend who was identified through the Essential Data Elements Pre-Survey. In the event that a phone or face-to-face survey could not be completed, surveys were completed by mail. Surveys were completed for 1980 family members, friends, and guardians.

- 66% of the surveys were answered by parents
- 21% were answered by siblings
- 3% were answered by the guardian
- 5% were answered by another relative (spouse, aunt, uncle, cousin, grandparent)
- 5% were answered by persons with other relationships to the individual receiving supports.
- Less than one percent of surveys were answered by friends.

Satisfaction

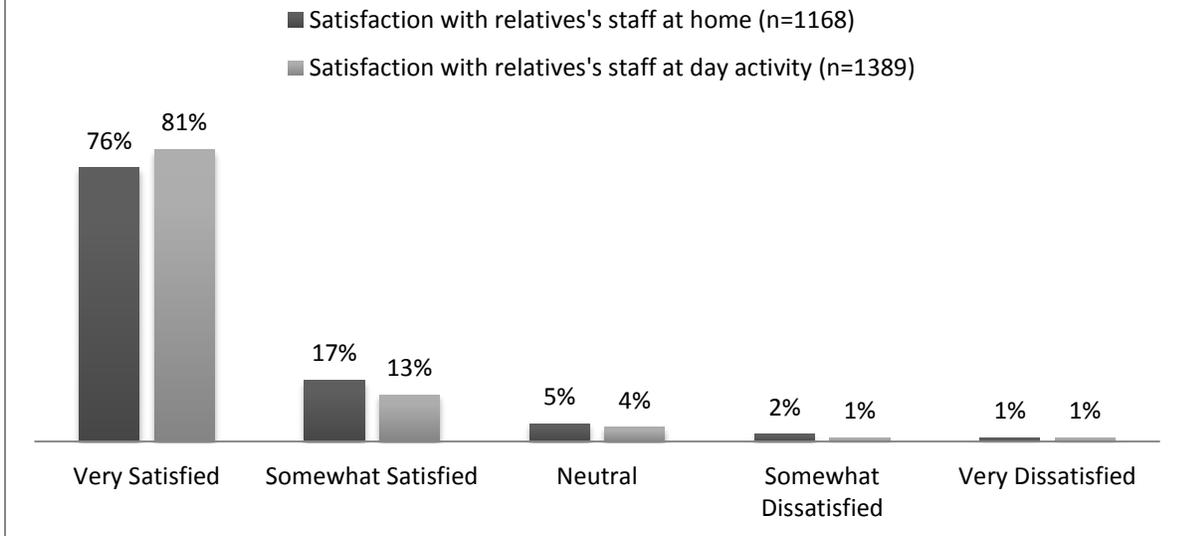
- 93% of the families surveyed were either somewhat satisfied or very satisfied with where their relative lives.
- 89% were either somewhat satisfied or very satisfied with what their relative does during the day.

Satisfaction with Relative's Home and Work/Day Activity



- 92% of the families surveyed were either somewhat satisfied or very satisfied with their relatives' staff at home.
- 94% of the families surveyed were either somewhat satisfied or very satisfied with the staff at their relatives' day activity.

Satisfaction with Relative's Staff

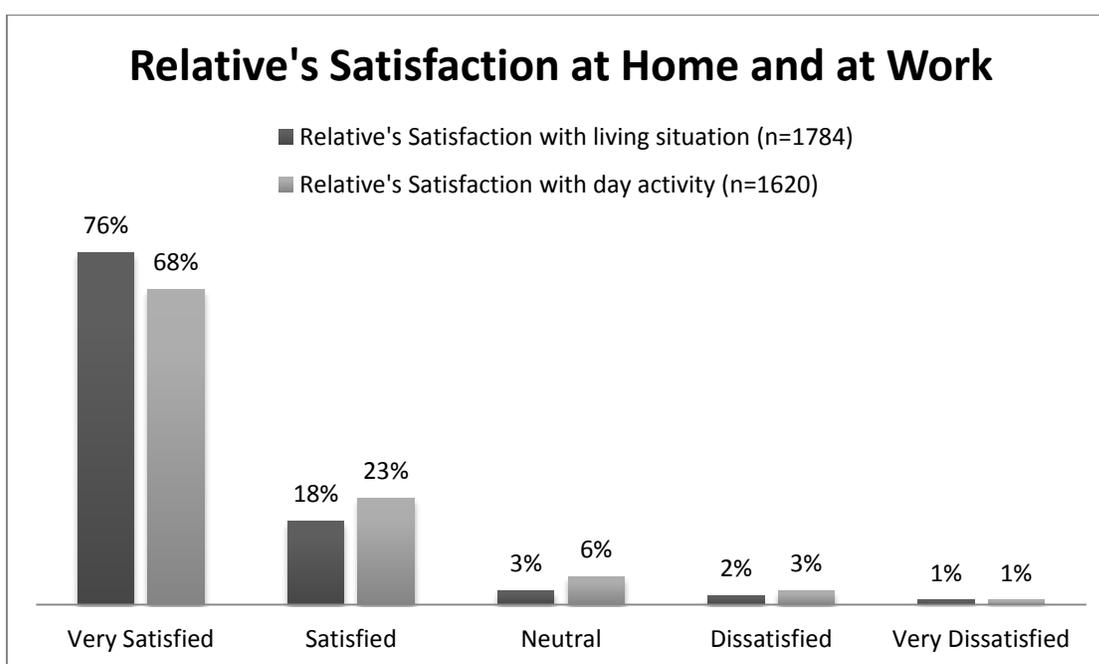


How Often Do You Contact/See Your Relative?

- 87% of the family/friend/guardians contacted their relative at least monthly; 3% have never contacted their relative.
- 76% 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% have never visited with their relative.

Your Relative's Satisfaction

- 94% of respondents felt their relative was either very satisfied or satisfied with his/her living situation; 90% felt their relative was either very satisfied or satisfied with what they do during the day.



- 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.
- 95% of respondents felt their relative was either very satisfied or satisfied with the staff who support them at work (or during the day); 1% believed their relative was either dissatisfied or very dissatisfied.

Your Relative's Safety

- Respondents said that their relative felt safe in their community/home/neighborhood always (84%) or most of the time (13%).

Your Relative's Opportunities

- 87% of the respondents said that their relative had enough opportunities to participate in activities in the community.
- 87% of the respondents said that their relative seemed to have the opportunity to learn new things.

Your Relative's Staff

- 87% of the respondents said that their relative's home appeared to have an adequate number of paid staff.
- 93% of the respondents said that staff in their relative's home always treat people with dignity and respect.
- 84% of the respondents said that all staff appear to have the skills they need to support their relative in the home; 14% 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.
- 96% 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; 7% felt only some staff do.
- If their relative did not communicate verbally, 35% of the respondents said that there is a formal communication system in place for their relative and they use it. For 83%, the communication system is used across all settings.

Relative's Supports

- 86% of relatives were satisfied with the supports coordination their relative receives.
- 63% of relatives reported that they were told how much money is in their relative's annual budget.

- 10% of relatives report that their relative self-directs their own services.
- 73% said that their relative always received the supports they needed.
- 86% said that the services and supports their relative receives change when their relative's needs change
- 88% of relatives always felt that the staff who assisted them with planning respected their choices and opinions.
- 50% of relatives never felt that there were frequent changes in support staff at their family member's home, work or day program; 15% felt that there were always frequent changes
- 43% of relatives always choose the agency/provider who worked with their relative; 4% had their relative choose; 22% chose with their relative; 32% never got to choose.
- 57% of relatives were familiar with the way complaints and grievances are handled at the provider level, 55% of relatives were familiar with the way complaints and grievances are handled at the county/AE level, and 46% of relatives were familiar with the way complaints and grievances are handled at the state level. 36% 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
- 11% of respondents had learned about the Life Course Framework and Tools
- 46% of relatives have an opportunity to connect and network with other families with relatives at similar life stages
- 21% of relatives said they were aware of the PA Family Network; of those who were aware, 27% had attended a workshop led by the Network of Family Advisors.
- 77% of relatives said that they have enough information about services for which their family is eligible

- 31% of respondents whose family member transitioned from school to adult services in the past year were happy with the process
- 65% of relatives report that the services 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 90.72 with a standard deviation of 14.24.
- 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 2016-2017 report, there were several significant differences.

- In terms of who responded to the survey, there was a 4% decrease in parent responses and a 3% increase in sibling responses.
- There was a 5% **increase** in family members who reported that their relative's communication system is used across all settings.
- There was a 3% **decrease** in family members who said that their relative always received the supports they needed.
- There was a 6% **increase** in family members who were not familiar of the grievance and complaint process on any level.
- There was a 3% **increase** in family members who have been given information about an emergency plan for their family member in case of an emergency.

Summary

This report presents information collected through face-to-face interviews with 5354 individuals receiving supports through the Office of Developmental Programs.

Overall, the individuals surveyed reported high levels of satisfaction. Most people are happy and say that people in their lives are nice or very nice to them. Many people also report that they like where they live and work, while about 1 in 5 say that they would prefer to do something else during the day, and 1 in 10 would prefer to live somewhere else. The majority of individuals report that they get the services and supports they need to be able to live in their homes, but there was a 5% increase in people who said they need more services at home.

Most people report high levels of privacy, and increasingly report that they can see friends, date, and get married if they want to. The number of people who regularly go out in the community increased slightly this year, and the number of people who say they can visit friends when they want increased by nearly 10% from last year. However, it remains the case that less than half of participants go out into the community on a weekly basis. The data demonstrate that when they do go out in the community, most individuals go with their staff or family most of the time. More than a third of people say that they are lonely at least some of the time.

This year's survey added several questions about self-advocacy and self-directed services. Less than half of the respondents had spoken to someone about self-advocacy or self-directed services, and only about 1 in 5 indicated that they had participated in a self-advocacy group meeting.

There were also questions added to this year's survey about healthcare access. The results show that most people report high levels of access to general healthcare as well as dental care. 39% said that there were barriers if they wanted to see a medical specialist.

The vast majority of individuals are highly satisfied with their supports coordinator, reporting that they are listened to and treated with respect. This was supported by IM4Q teams, who largely reported that individuals were treated with respect in observed situations.

The data on choice and control continue to indicate that few individuals make choices without assistance with regard to where and with whom they live and work. Nearly half of people surveyed saw no other places before they moved into their residence or decided what they do during the day. 70% did not choose their housemates. About 1 in 3 individuals were given a choice to live where people without disabilities live, and slightly more than half had an option to participate in a day activity where people without disabilities go. There was a 3% increase in individuals who have a key or a way to get into their homes, but 64% do not have a key.

Although there was a modest increase compared to last year's data, it remains the case that only about 1 in 10 individuals are employed. Further, 1 in 3 individuals who do not have a job say that they would like one. The most common occupations are cleaning services, food services, retail, assembly, or stock room work. Most individuals who are employed reported working about 16 hours a week. Regarding benefits, there were slight increases this year in the number of people who received paid time off, retirement benefits, and some other benefit, and an 11% decrease in people who receive health insurance benefits.

Communication continues to be an issue for many people in the sample. More than a third (37%) of the individuals surveyed do not feel that all of their staff understand their communication attempts. Of people who are non-verbal, 30% have a communication system in place. For those who do have a system in place, most report that it is in working order (93%) and used regularly (89%).