

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

***Independent Monitoring for Quality (IM4Q)***  
***A Statewide Summary***  
***2016-2017***

**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

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.

In 2015-2016, one joinder (Huntingdon/Mifflin/Juniata) had a much lower number of individuals surveyed than was anticipated based on the sampling strategy.

## **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 118 questions; fifty-one of the questions can only be answered by the individuals receiving supports and services.

The EDE for fiscal year 2016-2017 includes all survey questions included in the FY 2016-2017 NCI Adult Consumer Survey. This year, approximately 708 individuals included in this report are represented in the NCI sample for 2016-2017, 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](http://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.

<b>N</b>	<b>Percent</b>	
State-Operated ICF/ID	42	0.8%
State MH Hospital	2	0.0%
Foster Care	2	0.0%
Nursing Home/Facility	33	0.6%
Domiciliary Care	14	0.3%
Personal Care Home	35	0.7%
Family Living/Life sharing	277	5.2%
Unlicensed Family Living	13	0.2%
Own Residence	240	4.5%
Relative's Home	1254	23.5%
Children's Facility	12	0.2%
Approved Private School	4	0.1%
Private ICF/ID 4 or fewer	73	1.4%
Private ICF/ID 5-8	144	2.7%
Private ICF/ID 9-15	32	0.6%
Private ICF/ID 16+	227	4.3%
Community Home 1	187	3.5%
Community Home 2-4	2466	46.3%
Community Home 5-6	118	2.2%
Community Home 7-8	55	1.0%
Community Home 9-15	3	0.1%
Community Home 16+	10	0.2%
Other	39	0.7%
Missing	46	0.9%
<b>Total</b>	<b>5328</b>	<b>100%</b>

## **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 2016-17 survey cycle were collected and entered into ODESA by June 30, 2017. A usable data file was received by the Institute on Disabilities in November, 2017. 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, those living in state centers and those involved in the transition pilot.

### 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	598	11.2%
Armstrong/Indiana	73	1.4%
Beaver	96	1.8%
Bedford/Somerset	51	1.0%
Berks	148	2.8%
Blair	74	1.4%
Bradford/Sullivan	31	0.6%
Bucks	209	3.9%
Butler	81	1.5%
Cambria	63	1.2%
Cameron/Elk	26	0.5%
Carbon/Monroe/Pike	77	1.4%
Centre	68	1.3%
Chester	151	2.8%
Clarion	30	0.6%
Clearfield/Jefferson	52	1.0%
Columbia/Montour/Snyder/Union	71	1.3%
Crawford	78	1.5%
Cumberland/Perry	67	1.3%

Dauphin	142	2.7%
Delaware	246	4.6%
Erie	235	4.4%
Fayette	57	1.1%
Forest/Warren	26	0.5%
Franklin/Fulton	75	1.4%
Greene	27	0.5%
Huntington/Mifflin/Juniata	52	1.0%
Lackawanna/Susquehanna	121	2.3%
Lancaster	150	2.8%
Lawrence	53	1.0%
Lebanon	40	0.8%
Lehigh	146	2.7%
Luzerne/Wyoming	136	2.6%
Lycoming/Clinton	74	1.4%
McKean	25	0.5%
Mercer	50	0.9%
Montgomery	275	5.2%
Northampton	92	1.7%
Northumberland	55	1.0%
Philadelphia	695	13.0%
Potter	23	0.4%
Schuylkill	58	1.1%
Tioga	39	0.7%
Venango	52	1.0%
Washington	66	1.2%
Wayne	33	0.6%
Westmoreland	122	2.3%
York/Adams	119	2.2%
Missing	0	0.0%
<b>TOTAL</b>	<b>5328</b>	<b>100%</b>

## **Satisfaction**

**Respondents:** Only the individual receiving services/supports could answer the questions on satisfaction. A consistency check was performed and 7 individuals' surveys were not included in the satisfaction section. The percent of people who responded to questions in this section ranged from 34% to 67%.

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

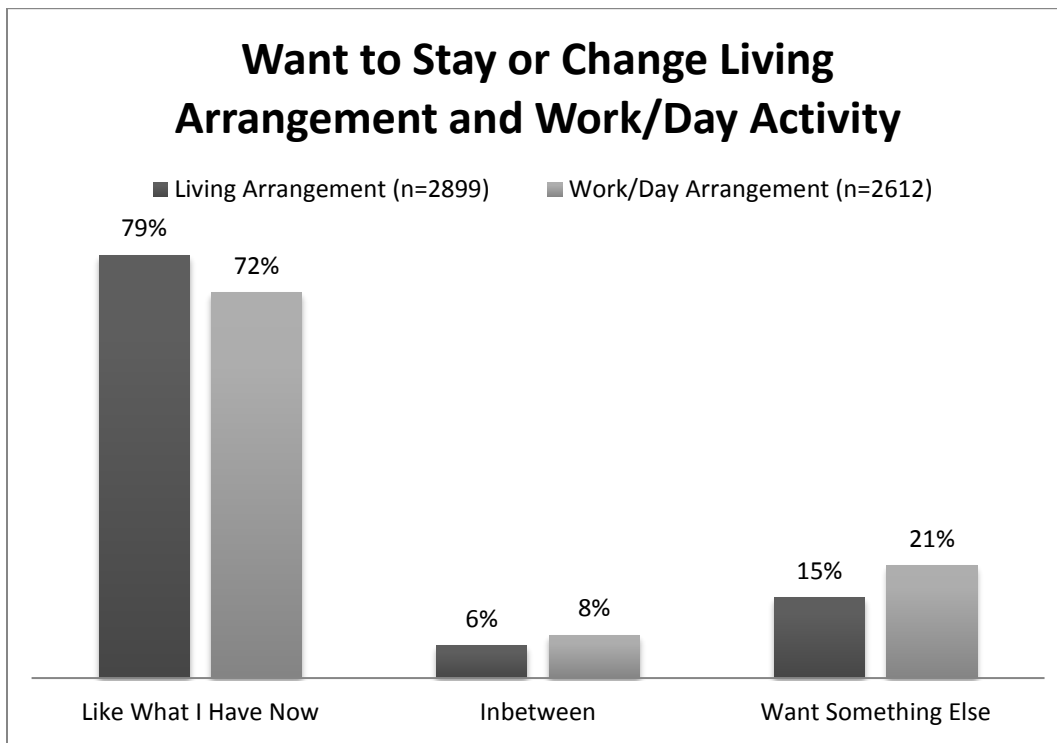
- 90% of individuals liked where they live. When asked what they don't like about where they live, 2% reported that it was because of a problem with housemates, 2% stated that they wanted more independence, 1% reported that they wanted to be closer to family and friends, 1% stated that it doesn't feel 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.

- 79% wanted to stay where they currently live but 15% 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.
- 72% wanted to continue their current daytime activities/work, but 21% wanted to do something else.



### **Daily Life**

- 92% of the individuals reported getting the services they needed to be able to live in their home, 5% 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, 35% of individuals attended an adult day program/community senior center, 22% attended a vocational facility, 10% stayed home, 11% went out and did things in the community, **10% worked part time for pay**, 3% volunteered, less than 1% helped neighbors and friends, 3% attended school, 3% are retired, **2% worked full time for pay**, and less than 1% attended college or a trade school.
- In addition to what individuals do on most weekdays, 45% also went out and did things in the community, 29% stayed home, 8% attended an adult training program, 2% attended a vocational facility, 7% volunteered, 4% worked part time for pay, 3% helped neighbors and friends, 2% are retired, 1% worked full time for pay, less than 1% attended school, and less than 1% attended college or a trade school.
- 63% of individuals that did not have a paid job in the community reported that they do not want a job; 33% reported they would like to have a job for pay.

### **Happiness and Loneliness**

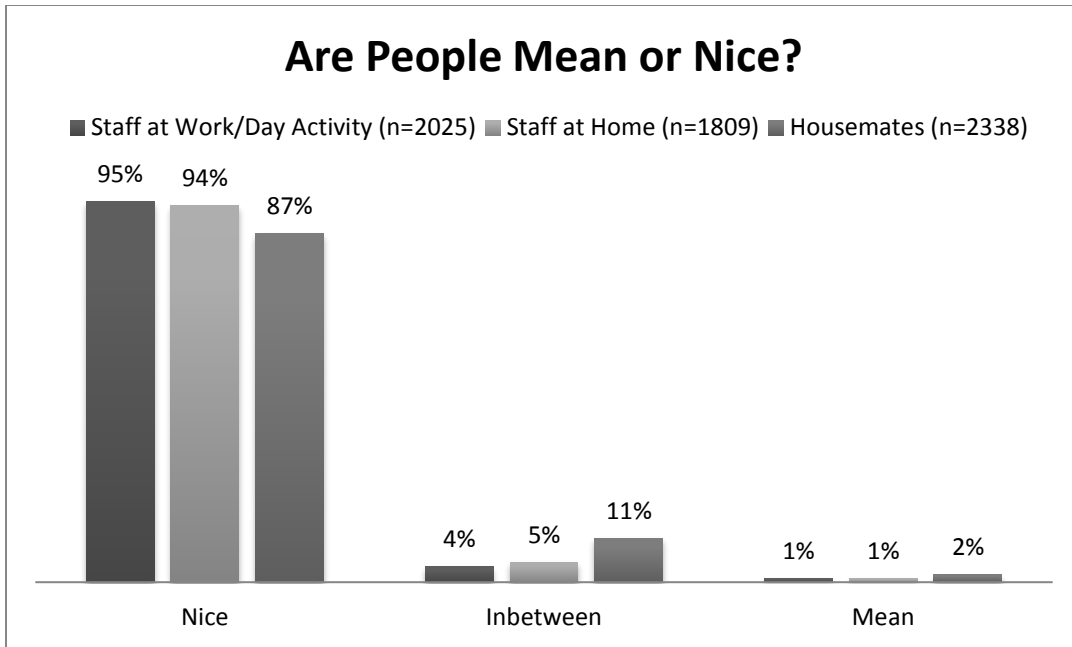
- 84% reported feeling happy overall, 14% reported being neither happy nor sad, and 2% reported feeling sad overall.
- 64% of individuals reported never feeling lonely, 32% reported sometimes feeling lonely, and 4% reported always feeling lonely.
- 90% reported having friends they like to do things with – for 72% of these people their friends are not staff or family.
- 76% reported that they can go on a date if they want to or are married; 15% reported that they can go on a date if they want to but there are some restrictions and rules and 9% are not allowed to date.

## ***Privacy***

- 98% of the individuals surveyed reported that they have enough privacy (a place to be alone) at home.
- 85% of individuals reported that they can be alone with friends at home.
- 89% reported that other people always let them know before coming into their home, 7% reported that sometimes other people let them know before coming into their home, and 4% 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?***

- Most people (87% of respondents) reported that their housemates are very nice or nice.
- 81% 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.
- 98% of people reported that their supports coordinator was always 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 85.87 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 2015-2016 report, there were several significant differences:

- There was a 4% **increase** in individuals that reported they could go on a date if they want to or are married.

- There was a 7% **decrease** in individuals that reported they get along with the person they share a bedroom with.
- There was a 3% decrease in individuals that reported they have friends they like to do things with that are not staff or family.

## **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 7 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 30% to 66%.

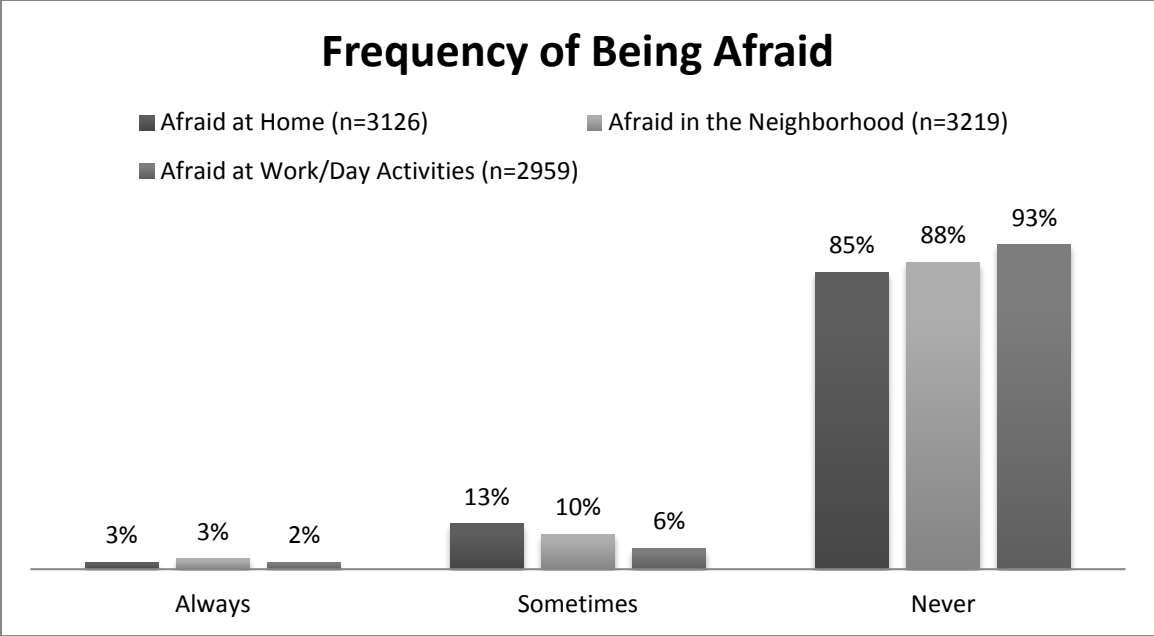
### ***Support with Goals and Problems***

- 50% of individuals want help to learn new things.
- 74% of individuals report that they get to help other people.
- 21% of individuals indicated that they have participated in a self-advocacy group meeting.
- 59% of people reported that they go to staff for help when they have a problem, 38% reported that they go to their family, 9% reported that they go to a friend, and 8% reported that they go to someone else. 1% of individuals reported that they have no one to go to for help.

### ***Being Afraid***

- 85% reported never being afraid at home; 13% 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.
- 93% 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.





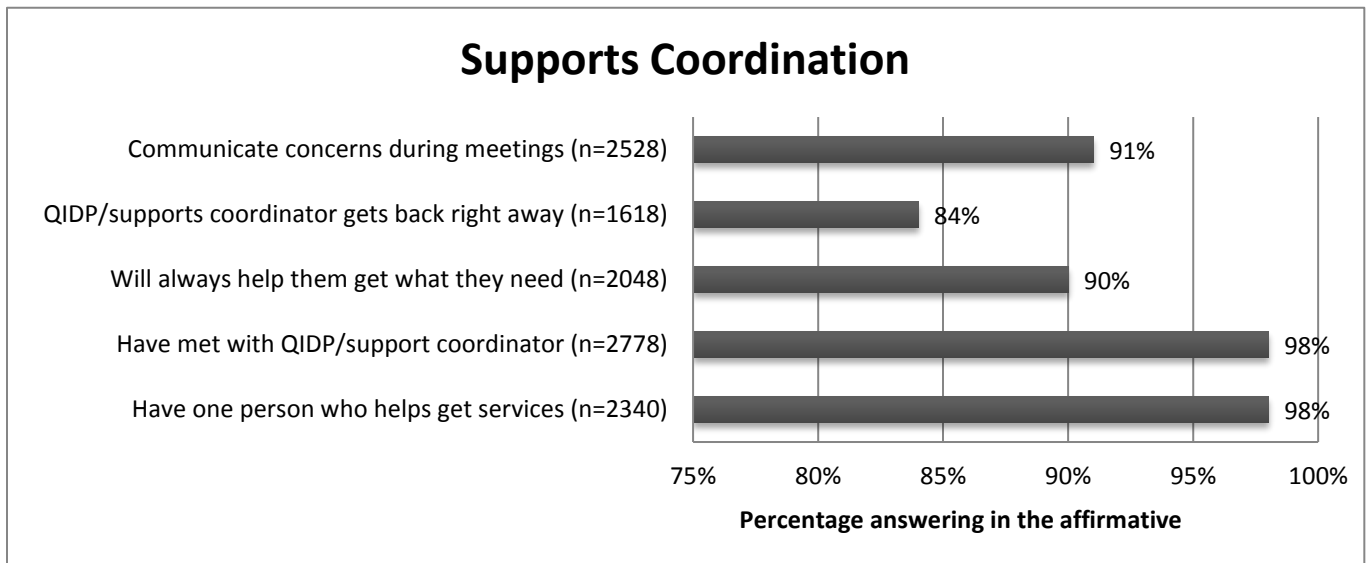
**Legal Rights**

- For 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)**

- 98% of individuals reported that they have one person (supports coordinator/QIDP) who helps them get the services they need.
- 98% reported that they have met with their supports coordinator/QIDP in the last year.
- 90% 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.
- 84% of individuals reported that when they call, their supports coordinator/QIDP always gets back to them right away.
- 91% of interviewees reported always being able to communicate their concerns during annual meetings; 7% reported that they are sometimes able to communicate their concerns.

- 99% of people surveyed reported that their supports coordinator talks with them about services to make sure everything is OK.
- 67% of those surveyed have been told at their planning meeting how much money is in their annual budget.
- 66% 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.



### **Staff**

- 94% 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.

### **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, 58% received information from home staff, 37% from day program or employment staff, 28% from someone in their family, 4% from the police, fire department, or EMS, 6% from supports coordinator, 9% from someone else, 2% from friends, and less than 1% 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 82.28 with a standard deviation of 15.07.
- The modal score was 75. Interestingly, 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 92.54 with a standard deviation of 16.21.
- The mode was 100.
- The average here was quite high, and therefore there was not a great deal of fear reported among individuals receiving supports and services. The mode of 100 indicates that many individuals (85-93%) reported that they never feel afraid in their home, neighborhood or work/day activity site.

Compared to the Dignity, Respect and Rights section of the 2015-2016 report, there were several significant differences.

- There was a 3% **decrease** in individuals that reported that they know they have a choice of SC organizations.
- There was a 3% **increase** in individuals that reported that they have participated in a self-advocacy group meeting.

## **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,

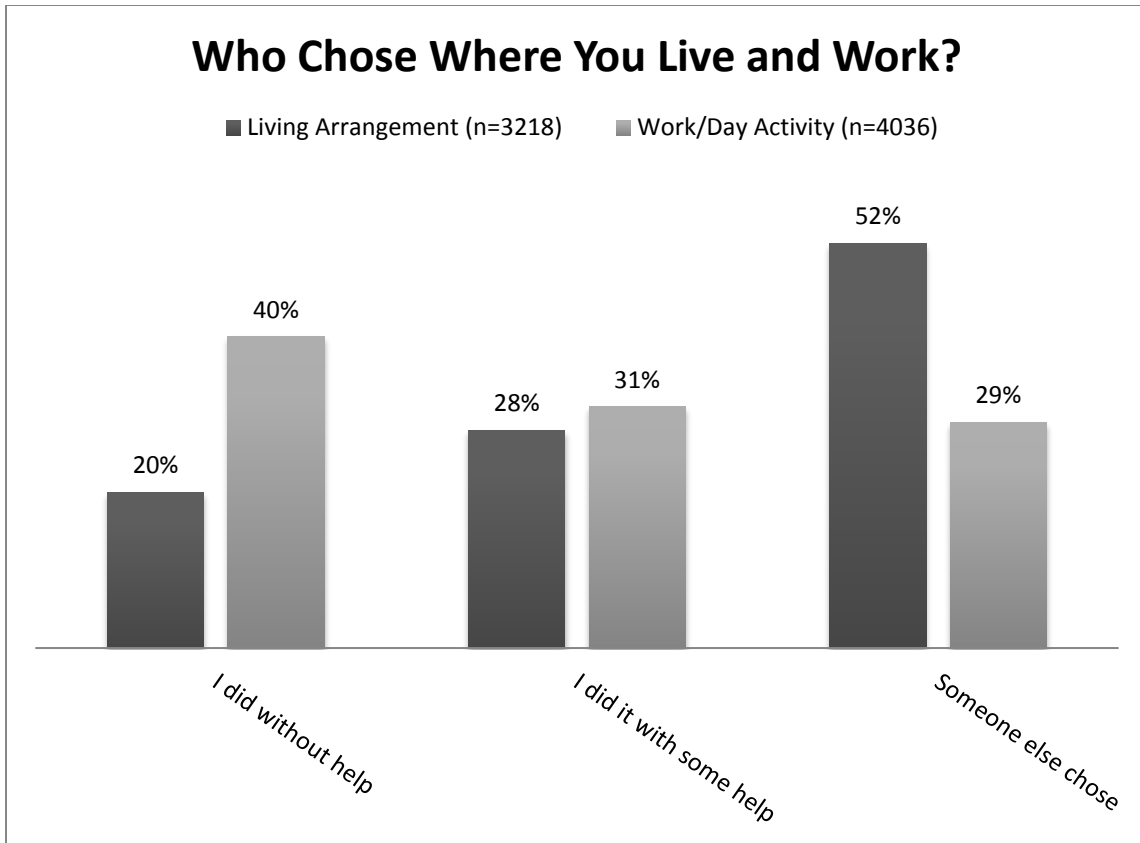
- 35% of the questions were answered by the individual receiving supports
- 35% of the questions were answered by paid staff
- 15% of the questions were answered by the individual and staff
- 7% of the questions were answered by family/friend/advocate/guardian
- 7% of the questions were answered by the individual and family
- 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.”

### ***Forms of Identification***

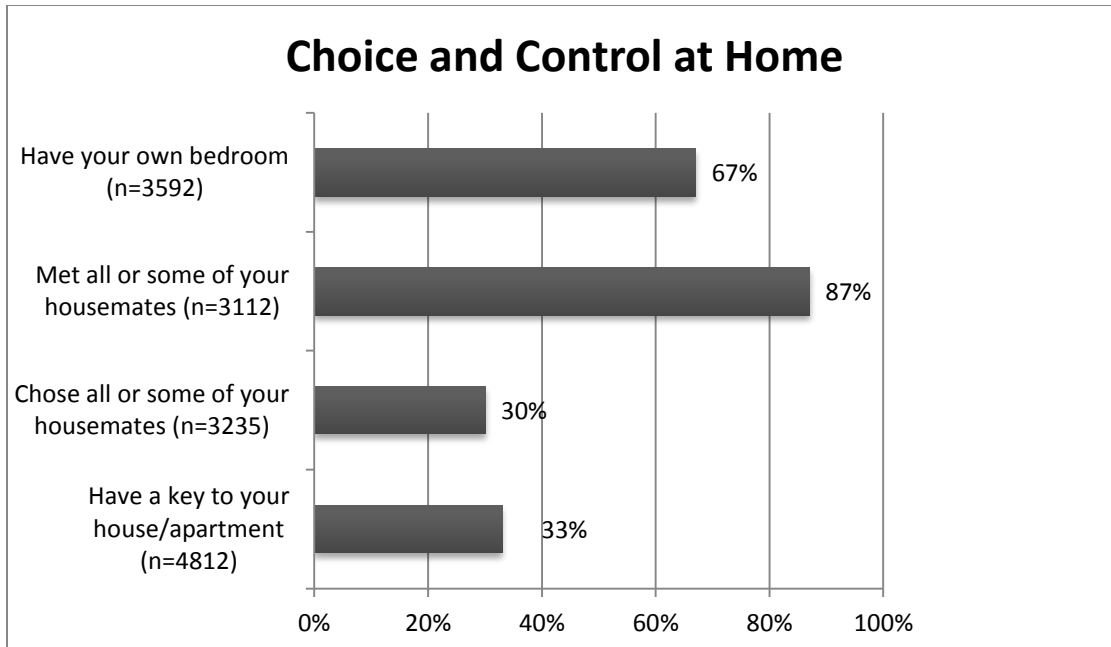
- 52% of individuals stated that they always carry a form of identification; 27% never do.

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

- Only 33% of the individuals surveyed had a key/way to get into to their house or apartment on their own.
- For 52% of the individuals, someone else chose where they live; 20% of those interviewed chose without assistance.
- For those individuals who had some control in choosing where they live, 10% saw no other places, 43% saw one other place, and 47% saw more than one other place before moving in.



- 71% of the individuals **did not** choose their housemates.
- 87% of the individuals surveyed met some or all of their roommates before living together.
- 67% of the individuals had their own bedroom; however, for those who shared a bedroom, only 42% chose some or all of their roommates.

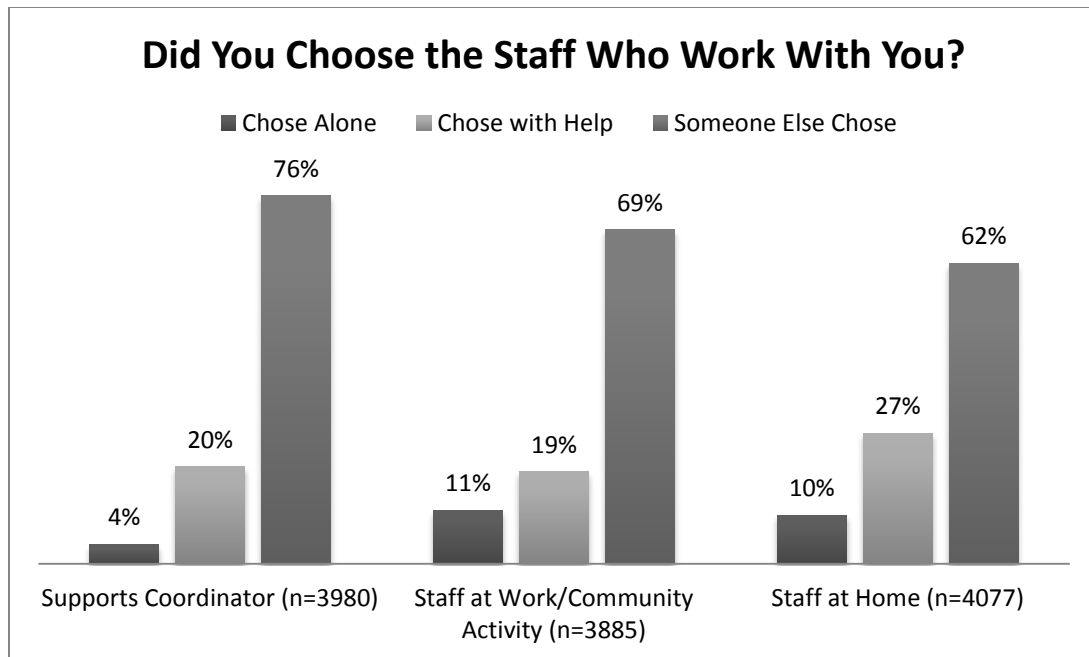


#### ***Choice and Control During the Day and for Leisure Time***

- 29% of the individuals interviewed reported that someone else chose what they do during the day.
- 40% of the people interviewed chose what they do during the day without assistance.
- For those individuals who participated in choosing what they do during the day, 9% saw no other places, 45% saw one other place, and 46% saw more than one other place before deciding.
- 51% of the individuals surveyed chose their daily schedules without assistance.
- 65% chose how they spend their free time without assistance.

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

- 38% of the individuals interviewed/chose at least some of the staff who help them at home (alone or with assistance from family or provider).
- 31% 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).
- 24% of individuals chose their supports coordinators (alone or with assistance from family or provider).

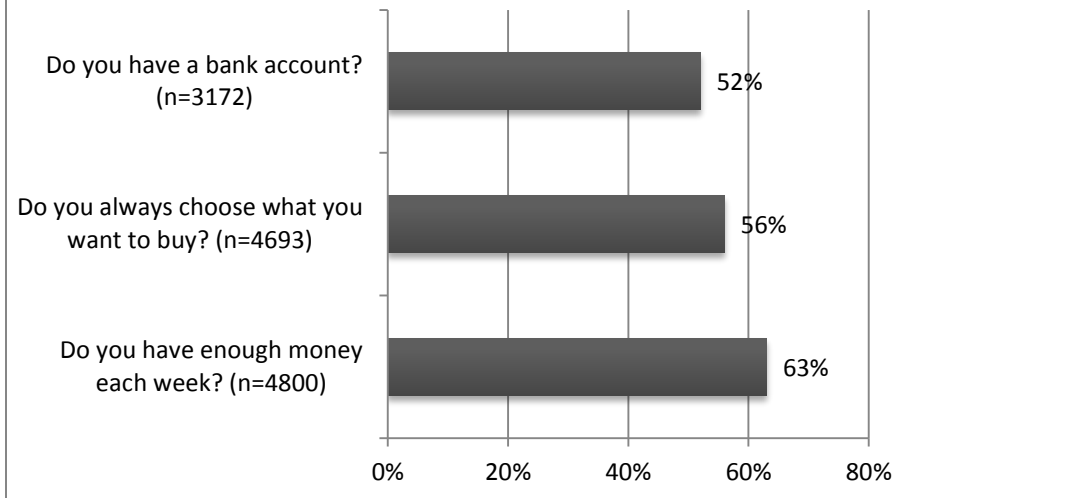


#### ***Choice and Control with Regard to Money***

- 93% of the individuals have enough money to do many of the things they want to do each week.
- 56% of the individuals reported that they always choose what to buy with their spending money.
- 38% of the individuals reported that there is something they want to buy.
- 52% of the individuals reported they have a bank account that they can get to independently to withdraw money when they want it.

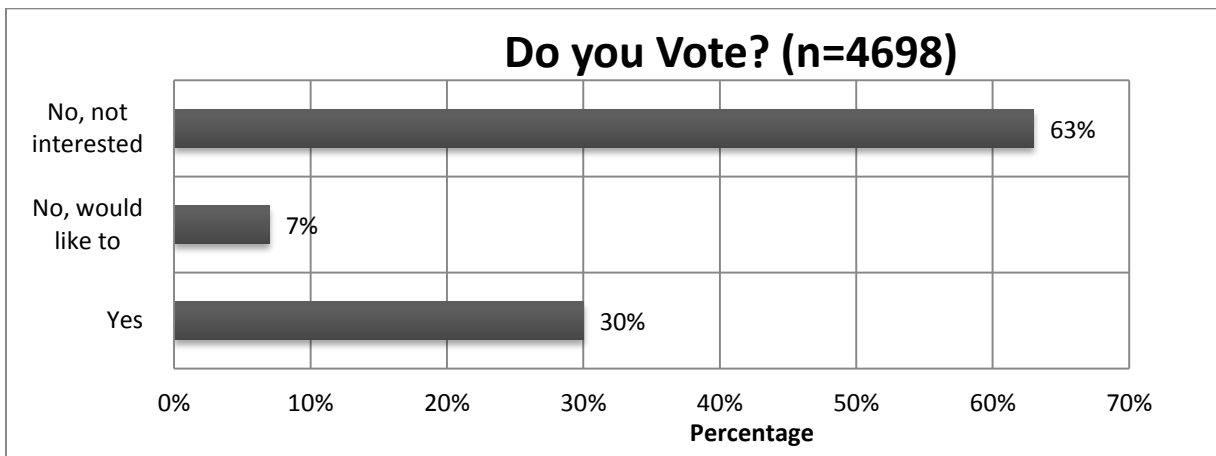


## Choice and Control Regarding Spending Money



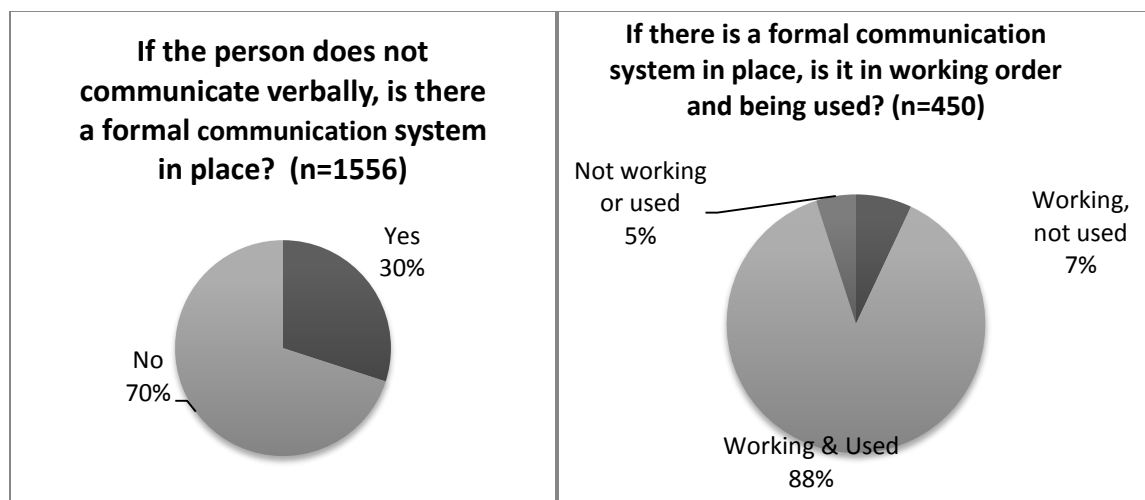
### Voting

- 30% of the people said they vote, 63% of the people said they do not vote and are not interested in voting, and 7% 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, the systems are in working order and utilized for 88% of the people interviewed.
- 79% of individuals with a formal communication system reported using it across all settings.
- 74% of individuals with a formal communication system are supported by staff or a program coordinator, 28% are supported by a parent or caregiver, 35% are supported by their speech language clinician, and 9% are supported by someone else.



With regard to other forms of communication:

- 25% have and use a cell phone; there are restrictions for 10% of these people
- 13% have and use e-mail; there are restrictions for 4% of these people
- 29% have and use internet; there are restrictions for 12% of these people
- 15% have and use text-messaging; there are restrictions for 5% of these people
- 91% have and use cable television; there are restrictions for 7% of these people
- 34% have and use a computer; there are restrictions for 11% 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 46.90 with a standard deviation of 23.15.
- The modal score was 47.37, indicating the most frequent score.

There were two significant differences regarding this year's data in this section when compared with the data from 2015-2016:

- There was a 5% **decrease** in individuals that chose their supports coordinator.
- There was a 4% increases in individuals with a formal communication system that reported the system was being used across all settings.

## **Employment**

**Respondents:** Of the 5328 individuals surveyed for the 2015-2016 Statewide IM4Q sample, 523 people indicated they are employed.

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

- 10% (n=523) of individuals work in a community integrated setting while 90% do not work at all.
- The majority of individuals have been employed for 1 to 3 years (30%). 20% of individuals have been employed for less than one year, 20% have been employed for 4-6 years, 11% have been employed for 7-10 years, and 19% have been employed for more than 11 years.

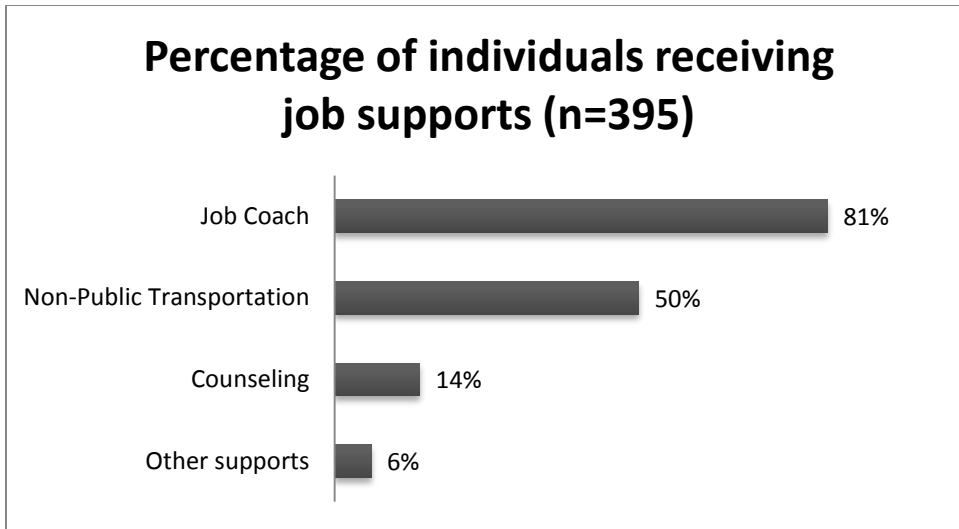
### ***Types of Work***

- 36% of individuals work in janitorial (including laundry), 19% work in retail (including grocery stores), 13% work in food services, 8% work in office work, 7% work in the stock room, 4% in maintenance, 4% work in assembly, 4% work as a care-worker or aide, 1% in work in landscaping or outdoors, and 5% work in some other occupation.

### ***Supports in the Workplace***

- 81% of individuals had job coach supports.
- 50% of individuals had transportation other than public transportation provided.
- 14% of those surveyed received counseling.
- 6% of individuals received some other kind of supports.

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

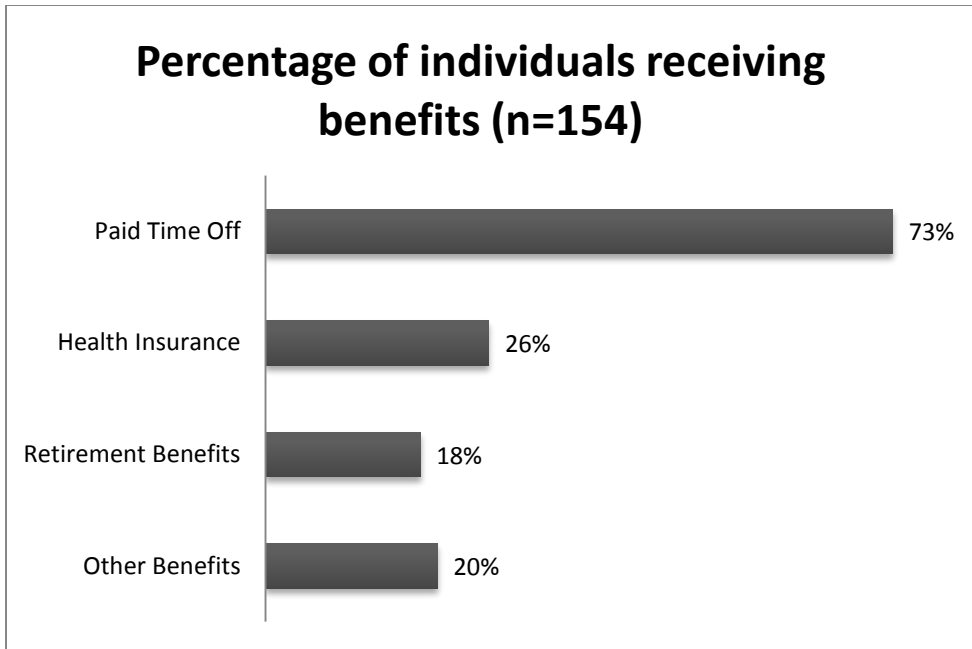


### ***Compensation and Advancement***

- 73% of individuals received paid time off, 26% received health insurance, 18% received retirement benefits, and 20% received some other kind of benefit.

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

- 43% of individuals who work have been promoted and/or received an increase in pay.
- The mean number of hours worked per week was 16.48 hours. Hours worked per week ranged from 1 to 51 hours; the most common response was 20 hours per week.
- 77% of individuals reported that they know how much they earn and are willing to share it.
- The mean hourly wage was \$8.50. Hourly wage ranged from \$7.15 to \$21.00.



**Self-employment and Supports:** Of the 523 individuals who have community integrated employment, less than 1% (n=4) of individuals are self-employed.

- To maintain their self-employment, 2 people received funding and 1 person received job coaching.

There were some significant differences regarding this year's data in this section when compared with the data from 2015-2016:

- Of employed individuals, there was a 5% **increase** in individuals that have been employed for less than one year, a 3% **decrease** in individuals that have been employed for 1-3 years, a 3% **increase** in individuals that have been employed for 4-6 years, and a 4% **decrease** in individuals that have been employed for more than 11 years.
- There was a 5% **decrease** in employed individuals that received paid time off.
- There was a 4% **decrease** in employed individuals that received health insurance.
- There was an 11% **decrease** in employed individuals that received retirement benefits.

- There was an 8% **increase** in employed individuals that received some other type of benefit.

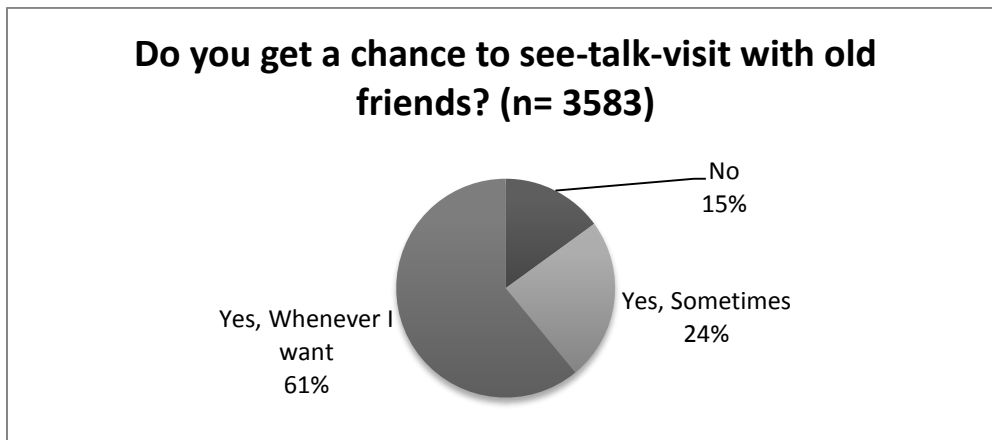
## **Relationships**

**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
- 35% were answered by paid staff
- 14% were answered by individuals receiving support and staff
- 8% 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.”

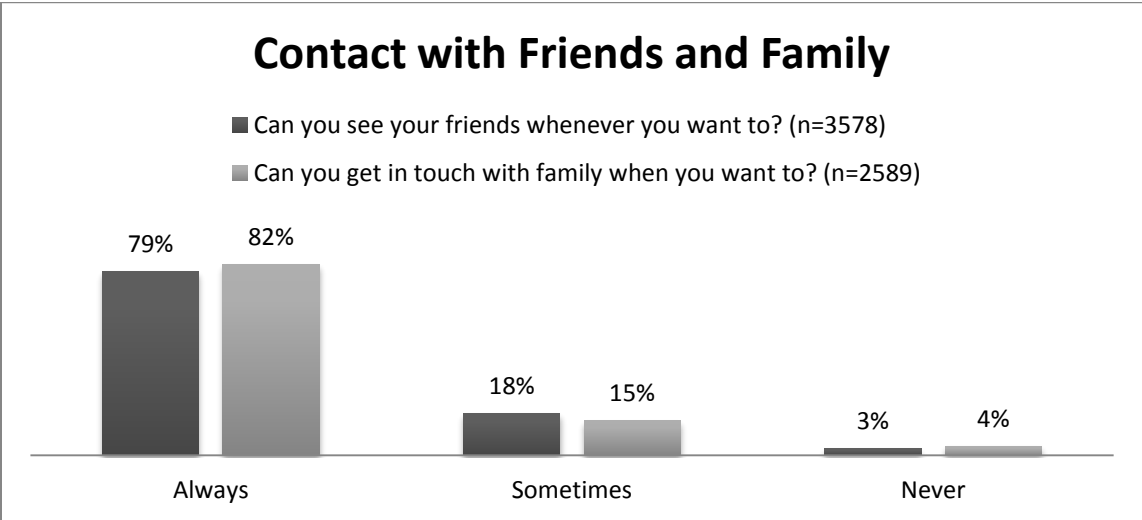
## **Friendships**

- 61% of people answered that they can see-talk-visit with old friends whenever they want, 24% only sometimes and 15% not at all.



**Contact with Friends and Family**

- 79% 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, 32% reported that it was difficult to find time to see friends, 17% reported that they couldn't see friends because of a transportation issue, 5% reported a lack of staff, 5% reported that there were rules/restrictions, and 41% reported that there was another reason why they couldn't see friends.
- 82% of respondents were always able get in touch with family when they wanted to.



There were several significant differences regarding this year's data in this section when compared with the data from 2015-2016.

- There was a 3% **decrease** in individuals who reported that they can get in touch with their family whenever they want to.
- There was a 3% **decrease** in individuals who reported that they can see friends whenever they want to.



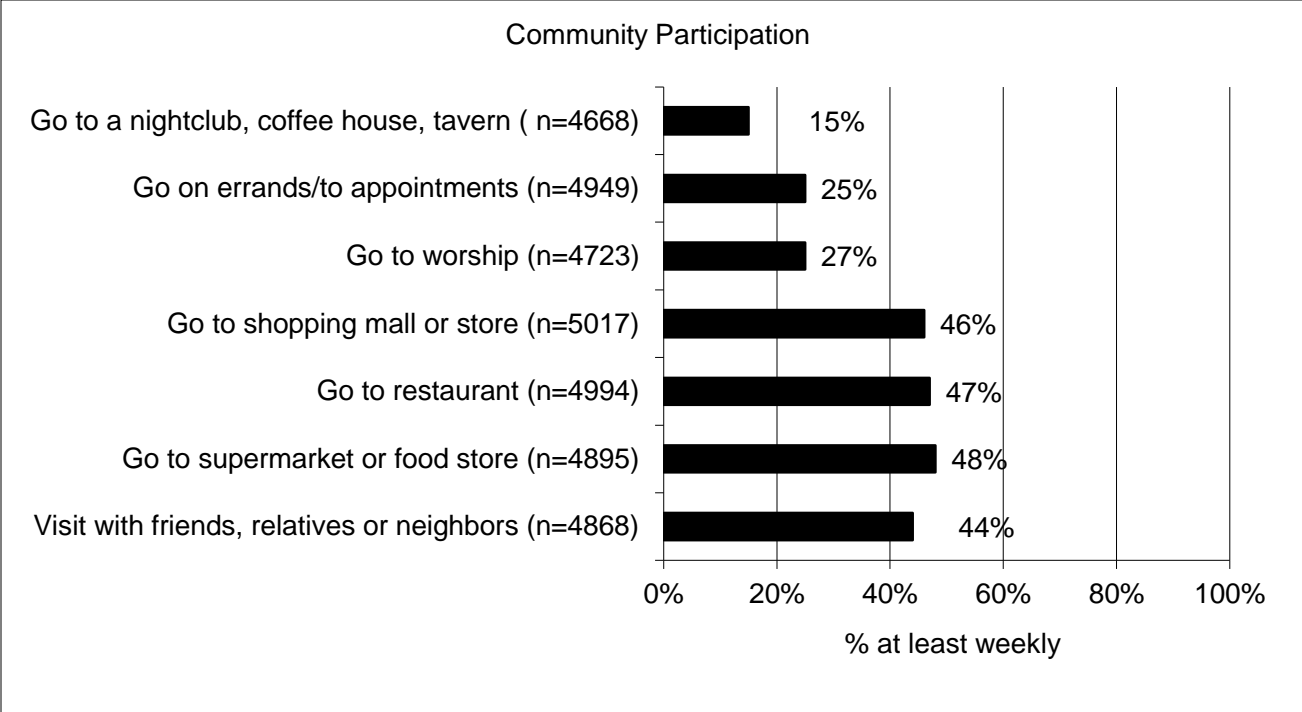
## **Inclusion**

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

- 31% of the questions were answered by individuals receiving supports
- 36% were answered by paid staff
- 17% were answered by individuals receiving support and staff
- 8% were answered by family/friend/guardian/advocate
- 8% 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***

- 44% of the people visited with friends, relatives and neighbors at least weekly.
- 48% of those surveyed went to a supermarket at least weekly.
- 47% of respondents went to restaurants at least weekly.
- 46% of individuals went to a shopping center or mall at least weekly.
- 25% of respondents went to places of worship at least weekly
- 25% of those surveyed went out on errands or appointments at least weekly
- 15% of individuals go to a night club, coffee house, or tavern to meet people at least weekly.



**Harris Poll**

In May and June 2010, the National Organization on Disability commissioned Harris Interactive, Inc. to conduct a national phone survey to examine and compare the quality of life and standard of living for people with and people without disabilities. We compared the frequency of weekly community participation reported by individuals in our Independent Monitoring for Quality (IM4Q) sample to this national sample. The Harris Poll depends on self-report in determining whether a person has a disability and defines someone with a disability as someone who:

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

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

- Pennsylvanians with disabilities in IM4Q are less likely than individuals with disabilities to visit with friends, relatives, and neighbors. People without disabilities are 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.

<b>Weekly Participation in Community Activities</b>			
	<b>Harris 2010: People without Disabilities</b>	<b>Harris 2010: People with Disabilities</b>	<b>Independent Monitoring 2016</b>
<b>Visit with friends, relatives, and neighbors</b>	65%	54%	44%
<b>Go to restaurant</b>	41%	20%	47%
<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 43.71 with a standard deviation of 16.36
- 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 was 50.00, which is the most frequent score.

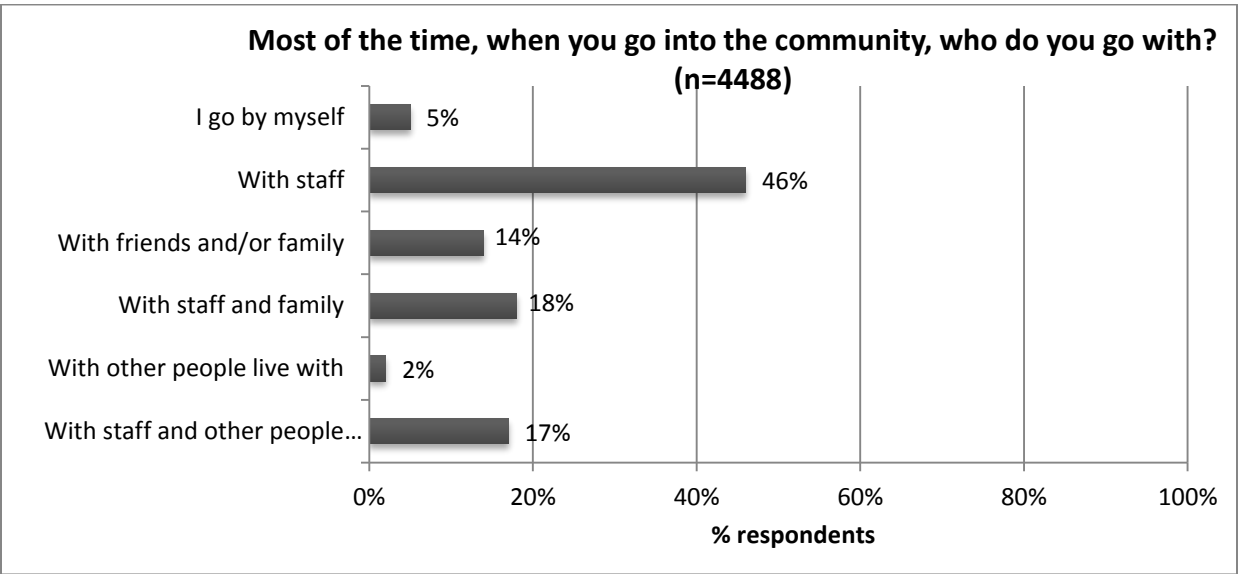
**Community Activities**

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

- 60% of individuals go frequently into the community for entertainment and 31% go occasionally.
- 42% 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.
- 43% of individuals went on a vacation in the past year.
- Regarding monthly exercise, 30% of individuals reported never going out for exercise, 6% exercise less than weekly, 12% exercise once a week and 53% exercise more than once a week.

**Going Out Alone or With Other People**

- 5% of individuals go out alone; 14% go out with friends and family.
- 63% of individuals go out with staff or staff and other people they live with most of the time.

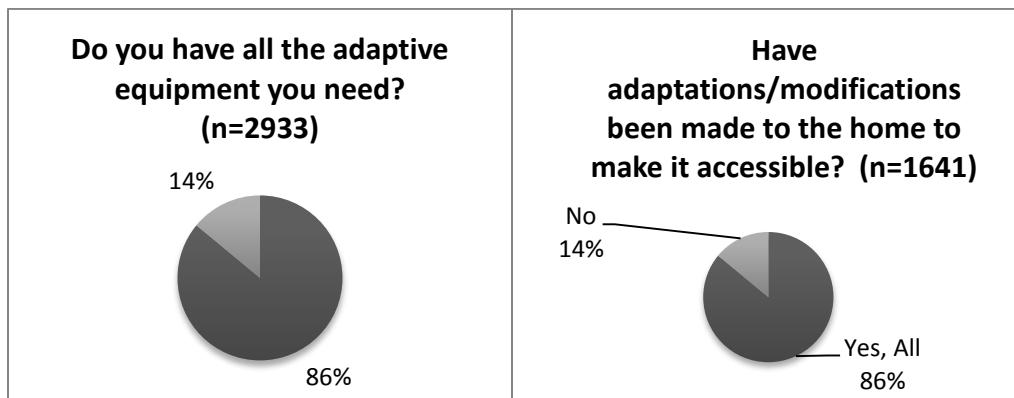


## Transportation

- 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 (58%). 21% 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.
- 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.

## Home Adaptive Equipment

- 86% of individuals reported having all the adaptive equipment they needed.
- 86% 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 2015-2016:

### Inclusion

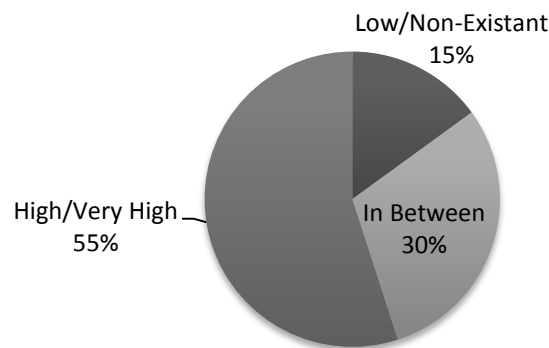
- There was a 4% **increase** in individuals who went to a shopping center, mall, or other store to shop at least weekly.
- There was a 4% **increase** in people who reported going outside their home with staff and other people they live with.

- There was a 3% **increase** in people getting a ride from staff in the provider ran to get to places that they need to go.
- 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.

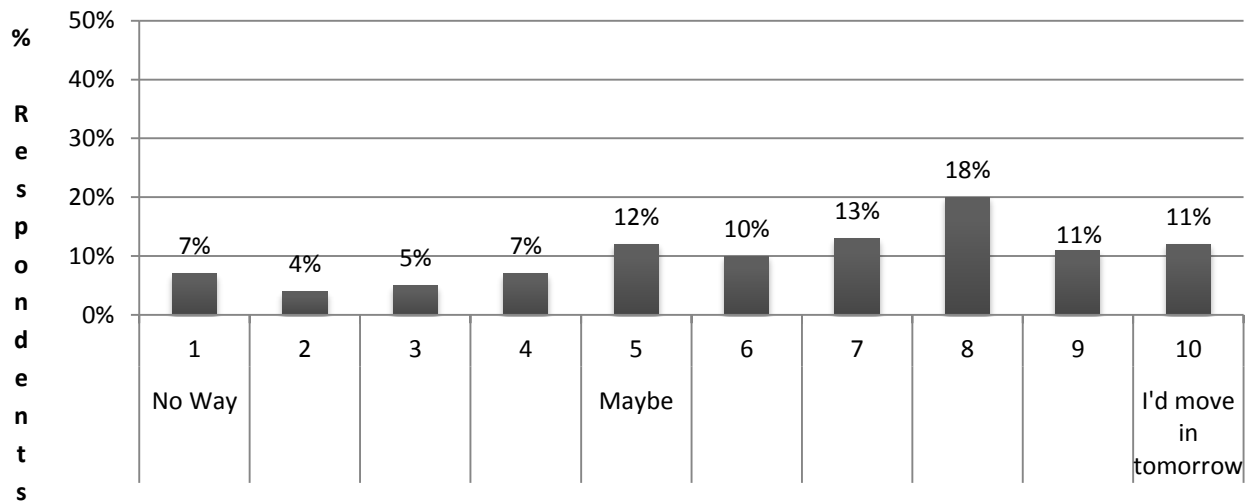
### **What are the caregiver's expectations regarding learning/growth for this individual? (n=3795)**



According to the IM4Q teams,

- Caregiver expectations regarding growth were reported as being high or very high for 55% of the individuals.
- 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 6.44.

## Would You (The Monitor) Want to Live in This Home? (n=3861) Mean = 6.44



Compared to the Competence, Personal Growth and Opportunities to Grow and Learn section of the 2015-2016 report, there was one significant difference.

- There was a 4% **decrease** in the percentage of people who had high or very high expectations for growth in the individuals they care for.



## **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 87% of observed situations.
- 85% of staff observed recognized the individuals in ways that promote independence.

Compared to the Staff Support for the Person section of the 2015-2016 report, there were no significant differences.

## **Physical Setting**

**Respondents:** The IM4Q Team answered the following questions regarding the physical setting, which referred to the place where the individual lives or where they go for work/day activity. Most interviews took place in the individual's home (73%), although some took place at work/day activity (23%).

### ***Home/Work/Day Activity Repair***

- Monitors observed that individuals lived in homes or went to work/day activities which were in good repair on the outside (95%) and on the inside (94%).

### ***Neighborhood***

According to IM4Q teams,

- Individuals lived in homes or went to work/day activities which were in a safe neighborhood (94%)
- Individuals lived in homes that “fit in” with the neighborhood in which they were located (91%)

### ***Personal Belongings and Personalities***

According to IM4Q teams,

- Most individuals (99%) lived in homes which had sufficient space for personal belongings
- Individuals (62%) lived in homes which reflected the hobbies, interests and personalities of the people who live there; for 35% of people only their bedroom reflected their personalities and interests.

**Physical Setting Scale:** Based on the three individual items, a Physical Setting Scale (based on the place where the individual lives) was developed. Scores on the Physical Setting Scale could range from 0 to 100, with a higher score indicating a nicer setting.

- The average (mean) score was 96.92 with a standard deviation of 10.25.

- The mode (the value that occurs the most frequently) was 100, indicating that many people (89%) lived in homes which were at the top of the scale on all measures of the physical setting

Compared to the Physical Setting section of the 2015-2016 report, there was one significant difference.

- There was a 4% **decrease** in individuals who lived in homes that “fit in” with the neighborhood in which the home was located.

## **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 1608 family members, friends, and guardians.

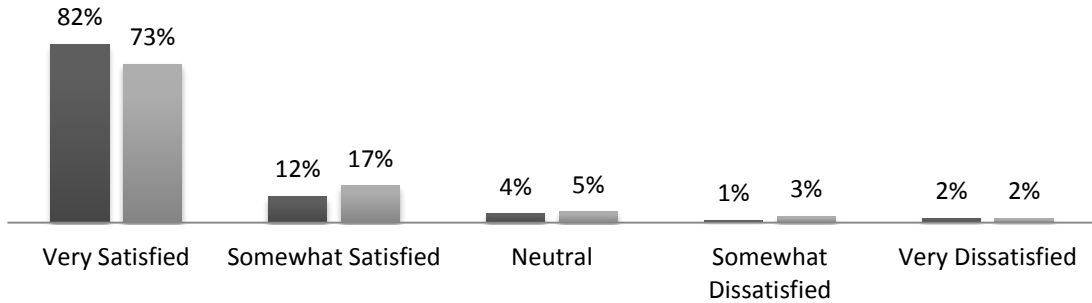
- 70% of the surveys were answered by parents
- 18% were answered by siblings
- 3% were answered by the guardian
- 5% were answered by another relative (spouse, aunt, uncle, cousin, grandparent)
- 4% were answered by persons with other relationships to the individual receiving supports.
- Less than one percent of surveys were answered by friends.

### **Satisfaction**

- 94% of the families surveyed were either somewhat satisfied or very satisfied with where their relative lives.
- 90% were either somewhat satisfied or very satisfied with what their relative does during the day.

### Satisfaction with Relative's Home and Work/Day Activity

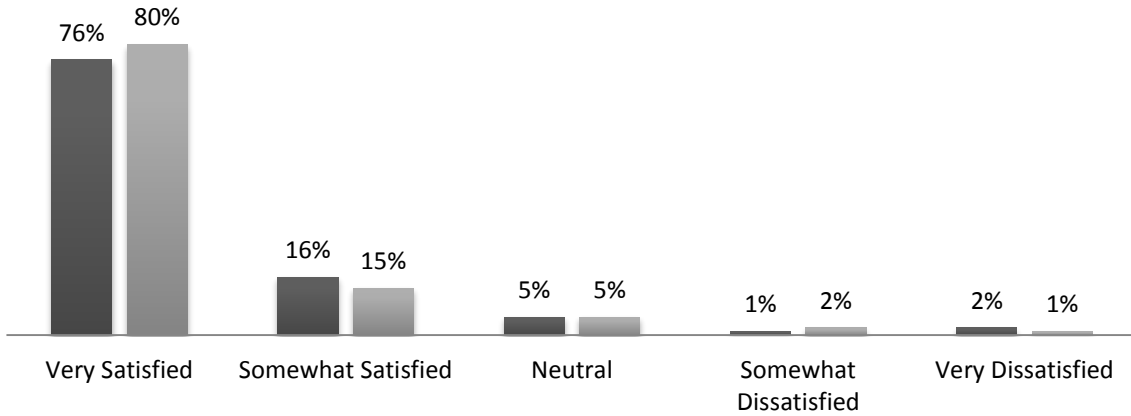
■ Satisfaction with where relative is living (n=1580)  
 ■ Satisfaction with what relative does during the day (n=1470)



- 90% of the families surveyed were either somewhat satisfied or very satisfied with their relatives' staff at home.
- 92% of the families surveyed were either somewhat satisfied or very satisfied with the staff at their relatives' day activity.

### Satisfaction with Relative's Staff

■ Satisfaction with relatives's staff at home (n=1008)  
 ■ Satisfaction with relatives's staff at day activity (n=1276)

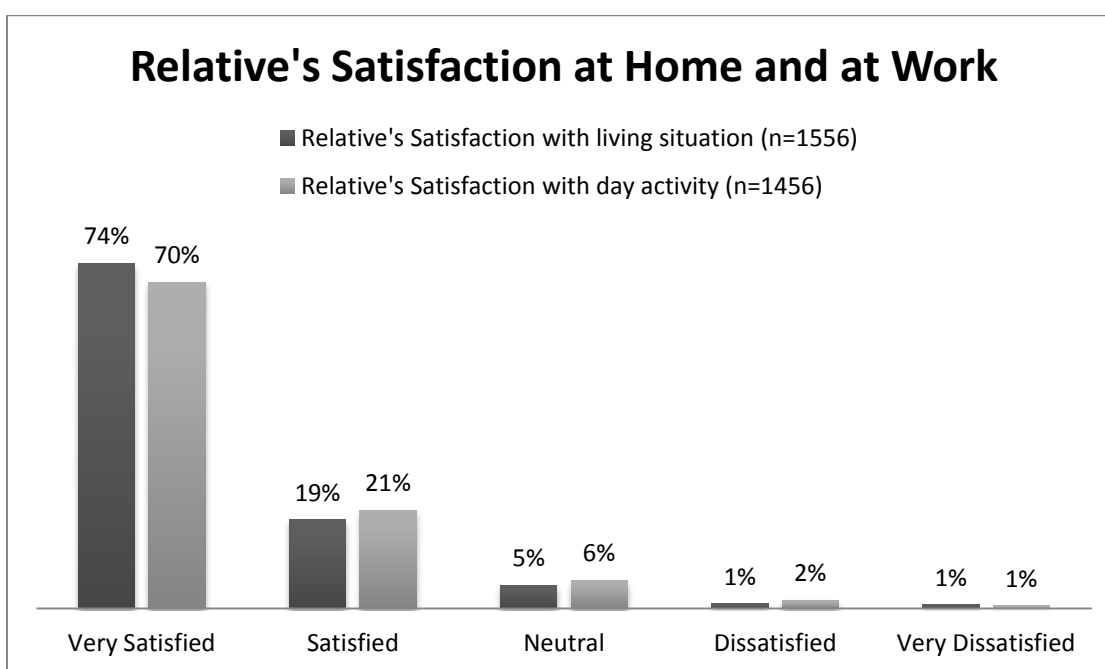


### **How Often Do You Contact/See Your Relative?**

- 88% of the family/friend/guardians contacted their relative at least monthly; 4% have never contacted their relative.
- 77% 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; 3% have never visited with their relative.

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

- 93% 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.



- 93% 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.
- 94% 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/neighborhood always (85%) or most of the time (13%).

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

- 89% of the respondents said that their relative had enough opportunities to participate in activities in the community.
- 88% of the respondents said that their relative seemed to have the opportunity to learn new things.

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

- 88% of the respondents said that their relative's home appeared to have an adequate number of paid staff.
- 92% 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; 14% felt that way about only some staff.
- 95% of the respondents said that their relative's place of work appears to have an adequate number of paid staff.
- 95% 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.
- If their relative did not communicate verbally, 37% of the respondents said that there is a formal communication system in place for their relative and they use it and for 78% the communication system is used across all settings.

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

- 87% 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.

- 76% said that their relative always received the supports they needed.
- 90% of relatives always felt that the staff who assisted them with planning respected their choices and opinions.
- 58% of relatives *never* felt that frequent changes in support staff were a problem for their family member.
- 42% of relatives always got to choose the agency/provider who worked with their relative; 6% had their relative choose; 20% chose with their relative; 32% never got to choose.
- 70% of relatives were familiar with the way complaints and grievances are handled; 30% were not familiar.

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

- 54% 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 90.54 with a standard deviation of 14.59.
- The mode (the value that occurs the most frequently) was 100, indicating that many of the families' (46%) satisfaction levels were at the top of the scale on all measures of family satisfaction.

Compared to the Family/Friend/Guardian section of the 2015-2016 report, there were several significant differences.

- There was a 3% **decrease** in family members who were either satisfied or very satisfied with the program staff who support their relative during the day.
- There was a 3% **decrease** in family members who were either satisfied or very satisfied with the paid staff who support their relative where they live.
- There was a 3% decrease in family members who believe the paid staff in their relative's home treat the people who live there with dignity and respect.



- There was a 3% **decrease** in family members who indicated that their relative is receiving the supports and services that he/she needs.
- There was a 4% **increase** in family members who are able to contact their relative at least once per month.

## **Summary**

This report presents information collected through face-to-face interviews with 5328 individuals receiving supports through the Office of Developmental Programs.

Overall, individuals report high levels of satisfaction with where they live, where they work, and with who provides supports to them at home and during the day. The majority of individuals report having friends and have high levels of privacy.

The majority of individuals report that they get the services and supports they need to be able to live in their homes. The monitoring teams observed that staff treat individuals with dignity and respect in most situations.

The data continue to indicate that few individuals make choices without assistance with regard to where they live and with whom they live. Additionally, two thirds of the individuals interviewed still do not have a key or a way to get into their homes.

For those individuals who do not communicate using words, there continues to be issues around lack of exploration of alternative strategies. Over two-thirds of individuals that do not communicate using words do not have a communication system in place. For people with a formal communication system in place, the system is in working order and being used for almost 90% of individuals; about 5% of those with a working formal communication system are not using it. There was a 3% increase in the percentage of people who report using a formal communication system across all settings. About one-fifth of people surveyed do not use their communication system across all settings.

One in ten individuals surveyed are employed. Individuals who are employed commonly work in janitorial including laundry, retail including grocery stores, food services, office work, assembly, or maintenance. Most individuals who are employed reported working about 16 hours a week. There were several significant changes from the previous year. There was a 5% decrease in individuals who receive paid time off, a 4% decrease in

people who receive health insurance, and an 11% decrease in people who receive retirement benefits.

Less than half of the people interviewed participate in community activities (i.e. going shopping) on a weekly basis. The percentage of individuals with disabilities participating in community events continues to be lower than the comparison group of people without disabilities, with the exception of going to a restaurant. In comparison to last year's results, there was a 4% increase in individuals who went to a shopping center, mall or other stores to shop at least weekly.

The majority of individuals (92%) can always get where they want to go. In order to get to places, the majority of people (58%) reported getting a ride from staff in the provider van, which is a 3% increase from last year. Of those who could not get where they wanted to go, nearly one-third of people could not get there because there was not enough staff.