

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

Independent Monitoring for Quality (IM4Q)
A Statewide Summary
2018-2019

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 (FY)	Individuals Surveyed	Friends, Family, Guardians Surveyed
2000-2001	5298	2224
2001-2002	5659	2494
2002-2003	4687	3163
2003-2004	6373	2975
2004-2005	6499	3010
2005-2006	6496	2851
2006-2007	6469	3028
2007-2008	6512	2731
2008-2009	6618	2896
2009-2010	6621	2590
2010-2011	6692	2510
2011-2012	6589	2517
2012-2013	5858	2160
2013-2014	5341	2187
2014-2015	5336	2002
2015-2016	5260	2047
2016-2017	5328	1608
2017-2018	5354	1980
2018-2019	5326	2345

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 FY 2017-2018, twelve questions regarding healthcare were added to the Dignity, Respect and Rights section. Questions on physical quality were removed as there was little to no variance in the scores.

The EDE for FY 2018-2019 includes all survey questions included in the FY 2018-2019 NCI Adult In-Person Survey. This year, 708 individuals included in this report are represented in the NCI sample for 2018-2019, based on a sampling methodology established by ODP and the Human Services Research Institute (HSRI). A copy of the NCI report for FY 2017-18 is available on the HSRI website at www.nationalcoreindicators.org.

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

Completed by an AE designee:

- A **pre-survey**, which was completed 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 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.

Completed only based on responses of the individual receiving supports:

- **Satisfaction** – this section included questions about satisfaction with where the individual works and lives, as well as with staff who support the individual.
- **Dignity, Respect and Rights** – this section included questions 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.

Completed based on responses of the individual receiving supports, or by a family member, friend or staff person:

- **Choice and Control** – the questions in this section were about the extent to which individuals exerted choice and control over various aspects of their lives. Additional sections on Health and Employment are included.
- **Relationships** – the questions in this section were about friends, family and neighbors, and individuals' opportunity to visit and contact them.
- **Inclusion** – the questions in this section were about opportunities for community inclusion; a section of the Harris Poll was included for comparative purposes.

Completed by the Independent Monitoring Team:

- **Monitor Impressions** – this section of the survey was completed after the visit. Questions were asked in the areas of staff support and opportunities for growth and development. Considerations are identified.
- **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.

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

- **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 FY 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 FY 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 FY 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 FY 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 major change that has occurred in FY 2015-16 was that we were no longer sampling 30 individuals per AE for the NCI sample; we moved to a statewide simple random sample of approximately 700 individuals for NCI.

The sampling procedure for this year continues to be drawn through the Home and Community Services Information System (HCSIS). The sampling procedure was changed for FY 2018-19 to more closely reflect the ODP service system. The following table shows the breakdown of the sample by type of residential setting. Some of the big shifts in residential setting from last year to this year were for Community homes (from 52% in 2018 to 27% in 2019), Relatives' homes (from 27% to 49%), Own homes (from 5% to 12%), and Private ICFs (from 7% to 1%).

	N	Valid %
State-Operated ICF/ID	3	0.1%
State MH Hospital	1	0.0%
Nursing Home/Facility	156	3.0%
Domiciliary Care	32	0.6%
Personal Care Home	144	2.7%
Family Living/Life sharing	202	3.8%
Unlicensed Family Living	26	0.5%
Own Residence	623	11.8%
Relative's Home	2581	48.9%
Children's Facility	9	0.2%
Approved Private School	2	0.0%
Private ICF/ID 4 or fewer	15	0.3%
Private ICF/ID 5-8	7	0.1%
Private ICF/ID 9-15	2	0.0%
Private ICF/ID 16+	15	0.3%
Community Home 1	96	1.8%
Community Home 2-4	1240	23.5%
Community Home 5-6	51	1.0%
Community Home 7-8	29	0.5%
Community Home 9-15	11	0.2%
Community Home 16+	6	0.1%
Other	23	0.4%
Missing	83	-
Total	5326	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 2018-2019 survey cycle were collected and entered into ODESA by June 30, 2019. A usable data file was received by the Institute on Disabilities in December 2019. 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	11.4%
Armstrong/Indiana	73	1.4%
Beaver	97	1.8%
Bedford/Somerset	50	0.9%
Berks	159	3.0%
Blair	70	1.3%
Bradford/Sullivan	28	0.5%
Bucks	210	3.9%
Butler	82	1.5%
Cambria	63	1.2%
Cameron/Elk	24	0.5%
Carbon/Monroe/Pike	79	1.5%
Centre	68	1.3%
Chester	152	2.9%
Clarion	31	0.6%
Clearfield/Jefferson	51	1.0%
Columbia/Montour/Snyder/Union	68	1.3%
Crawford	77	1.4%
Cumberland/Perry	69	1.3%
Dauphin	135	2.5%
Delaware	240	4.5%
Erie	235	4.4%
Fayette	56	1.1%
Forest/Warren	25	0.5%
Franklin/Fulton	73	1.4%
Greene	27	0.5%
Huntington/Mifflin/Juniata	57	1.1%
Lackawanna/Susquehanna	121	2.3%
Lancaster	152	2.9%
Lawrence	49	0.9%
Lebanon	41	0.8%
Lehigh	130	2.4%
Luzerne/Wyoming	136	2.6%
Lycoming/Clinton	76	1.4%
McKean	26	0.5%
Mercer	54	1.0%
Montgomery	282	5.3%
Northampton	93	1.7%
Northumberland	57	1.1%
Philadelphia	709	13.3%
Potter	20	0.4%
Schuylkill	59	1.1%
Tioga	32	0.6%
Venango	44	0.8%
Washington	63	1.2%
Wayne	34	0.6%
Westmoreland	123	2.3%
York/Adams	120	2.3%
Missing	0	0.0%
TOTAL	5326	100%

Demographic Characteristics of the Sample

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

- Of those who reported gender in the sample (n=5231), 57% identified as male and 43% identified as female
- For those who reported their age (n=5221) the mean age in the sample was 43.03 (SD=15.91), with a range of 18 to 94 years
- Of those who reported race in the sample (n=4697), 80% identified as white, 17% 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 and Native/Pacific Islander
- Of those who identified their ethnicity (n=4331), 4% identified as Hispanic/Latinx

Satisfaction

Respondents: Only the individual receiving services/supports could answer the questions on satisfaction. A consistency check was performed, and 6 individuals' surveys were not included in the satisfaction section. The percent of people who responded to questions in this section ranged from 27% to 65%.

Satisfaction with Living Arrangements

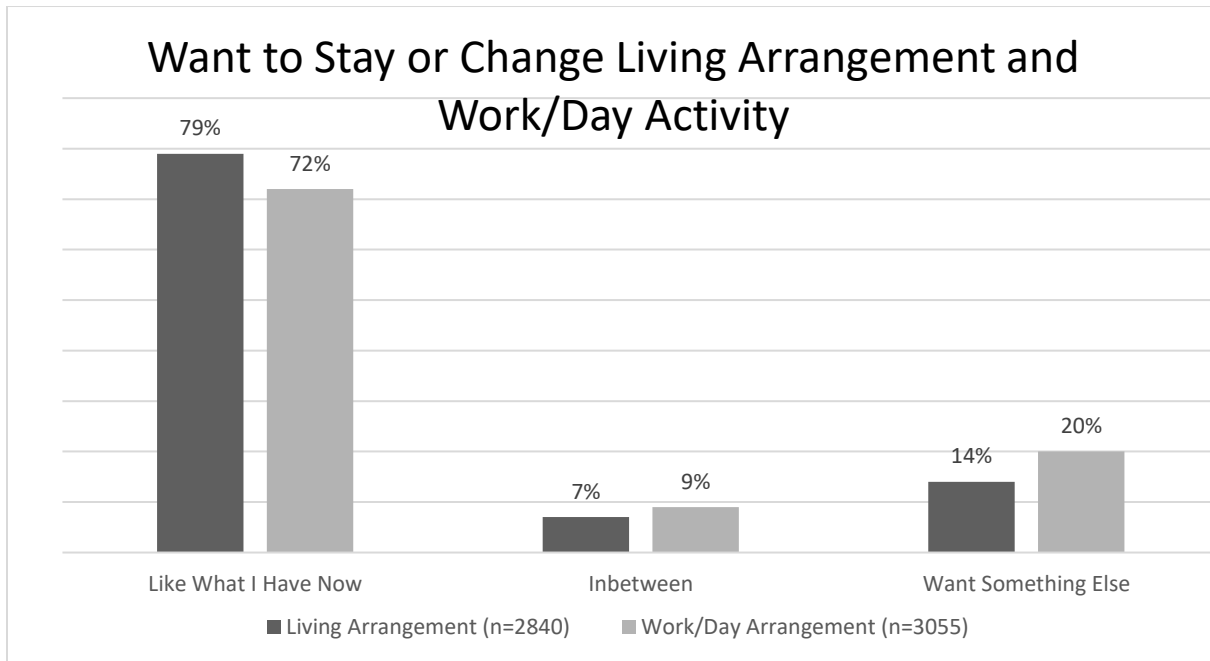
- 89% of individuals liked where they live.
 - When asked what they don't like about where they live, 1% reported that it was because of a problem with housemates, 2% stated that they wanted more independence, 1% reported that they wanted to be closer to family and friends, 1% stated it doesn't feel like a home, 1% reported they feel unsafe 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 have a problem with staff or their home needs repair.

- 79% wanted to stay where they currently live but 14% 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. 94% of individuals liked the secondary job/activities they frequently do during the day.
- 72% wanted to continue their current daytime activities/work, but 20% wanted to do something else.



Daily Life

- 83% of the individuals reported getting the services they needed to be able to live in their home, 12% said yes, sometimes and/or they need more, and 5% said they do not get the services they need to be able to live in their home.
- On most weekdays, 21% of individuals attended an adult day program/community senior center, 22% attended a vocational facility, 17% stayed home, 10% went out and did things in the community, 11% worked with

no supports, 8% worked in supported employment, 2% volunteered, 4% attended school, 3% are retired, and 3% did something else.

- In addition to what individuals do on most weekdays, 27% also went out and did things in the community, 40% stayed home, 3% attended an adult day program/community senior center, 3% attended a vocational facility, 9% volunteered, 3% worked with no supports, 2% worked in supported employment, 2% 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; 33% reported they would like to have a job for pay.

Happiness and Loneliness

- 83% reported feeling happy overall, 14% reported being neither happy nor sad, and 3% reported feeling sad overall.
- 63% of individuals reported never feeling lonely, 33% reported sometimes feeling lonely, and 4% reported always feeling lonely.
- 88% reported having friends they like to do things with – for 75% of these people their friends are not staff or family.
- 69% of respondents indicated they have a best friend.
- 82% reported that they can go on a date if they want to or are married; 6% 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.

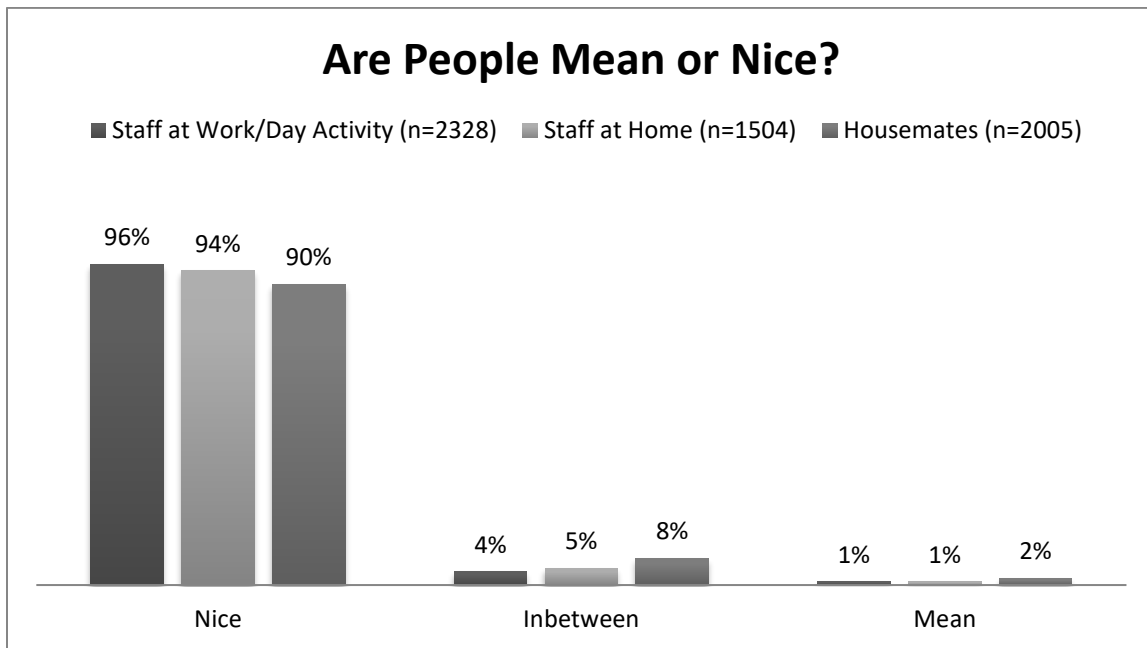
Privacy

- 95% of the individuals surveyed reported that they have enough privacy (a place to be alone) at home.
- 86% of individuals reported that they can be alone with friends at home.
- 72% of individuals say there are no rules about having friends and visitors, while 28% say there are some restrictions such as on visit times, certain friends, or rules about privacy.

- 88% reported that other people always let them know before coming into their home, 5% reported that sometimes other people let them know before coming into their home, and 7% said people never let them know before entering.
- 84% reported that people let them know before coming into their bedroom, 7% reported sometimes people let them know before coming into their room, and 8% never let them know.

Are People Nice or Mean?

- 90% of respondents reported that their housemates are very nice or nice.
- 76% of people interviewed reported that they get along with the person they share a bedroom with most of the time.
- 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 85.44 with a standard deviation of 19.63
- 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 2017-2018 report, there were several noteworthy differences:

- There was a 3% **decrease** in individuals who reported they have a place to be alone at home, and a 4% **decrease** in individuals who report people let them know before entering their bedroom.
 - This shift may be reflective of the change in the sampling procedure (described earlier in this report) which resulted in many more individuals in the sample living at home with families.
- There was a 3% **decrease** in individuals who reported they are getting the services they need to live at home, with a 2% **increase** in those who reported that they do not receive any of the services they need.
- There was a 2% **increase** in people who reported that they work
- There was a 2% **increase** in individuals who reported they could go on a date if they want to or that they are married.
- There was a 7% **decrease** in individuals reporting they get along with the person with whom they share a bedroom
- There was a 3% **decrease** in individuals who report they are happy overall

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 6 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 36% to 68%.

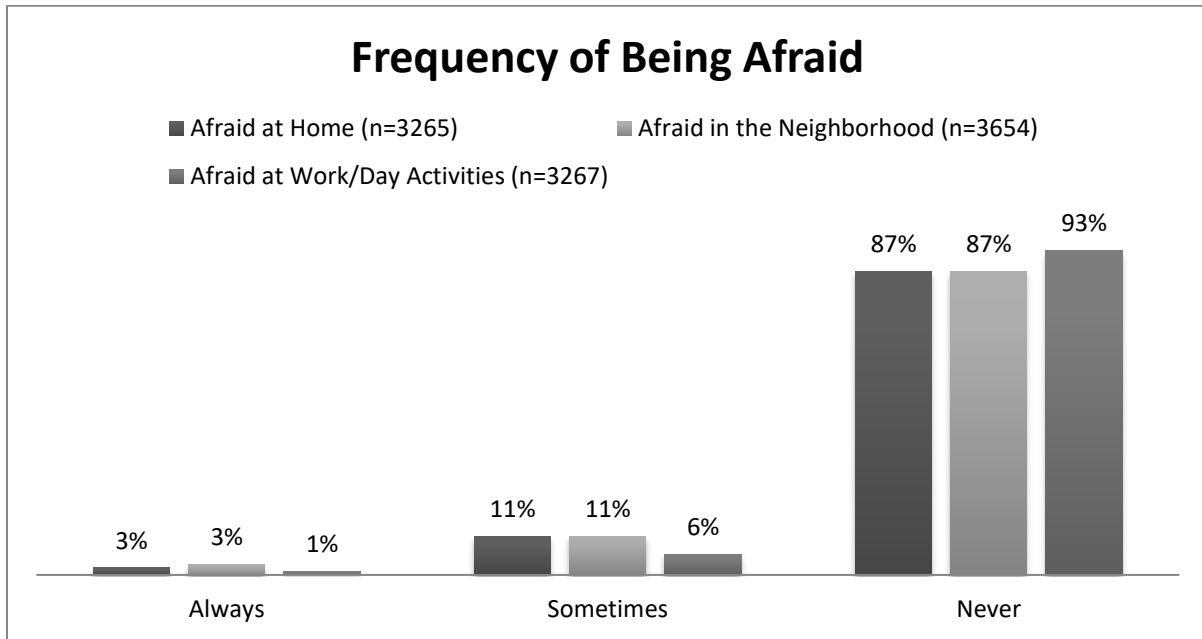
Support with Goals and Problems

- 64% of individuals get help to learn new things; 21% do not get help
- 72% of individuals report that they get to help other people.
- 16% of individuals indicated that they have participated in a self-advocacy group meeting.
- 38% of people said someone had talked to them about self-advocacy
- 50% of people reported that they go to staff for help when they have a problem, 53% reported that they go to their family, 11% reported that they go to their supports coordinator, 10% reported that they go to a friend, and 11% 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; 11% reported sometimes being afraid at home.
- 87% reported never being afraid in the neighborhood; 11% reported sometimes being afraid in the neighborhood.
- 93% reported never being afraid at work, school or day activity; 6% reported sometimes being afraid at work, school or day activity.
- 93% reported never being afraid when using transportation; 5% reported sometimes being afraid when using transportation.

- 94% reported that they have someone they can talk to when they feel afraid.



Legal Rights

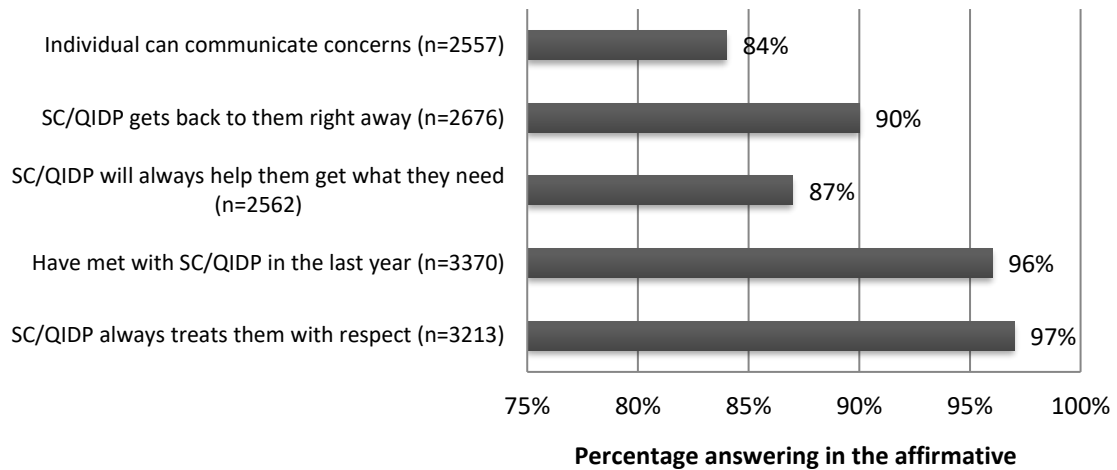
- For 83% of the individuals interviewed, their mail is never opened without permission; 10% say their mail is always opened without permission.

Supports Coordination/Qualified Intellectual Disability Professional (QIDP)

- 96% reported that they met with their supports coordinator/QIDP in the last year.
- 87% 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.
- 90% 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
- 84% of respondents said their supports coordinator asks them what they want their life to look like

- 84% said the supports coordinator asks what they want in the future
- 40% of individuals report that their supports coordinator has asked them about directing their own services
- 97% of people surveyed reported that their supports coordinator talks with them about services to make sure everything is OK.
- 65% of individuals reported that they know they have a choice of SC organizations.
- 95% of individuals reported that their supports coordinator always listens to them; 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.
- 96% of respondents said they took part in their annual planning meeting; 2% had the option but chose not to take part
- 84% of interviewees reported always being able to communicate their concerns during annual meetings; 11% reported that they are sometimes able to communicate their concerns.
- 57% of those surveyed have been told at their planning meeting how much money is in their annual budget.
- 95% reported that their ISP meeting included the people they wanted to be there.
- 80% of individuals indicated that they knew what was being talked about at their ISP meeting.
- 73% said they talked about learning new things at their planning meeting, 8% said maybe they talked about learning new things and 20% did not talk about learning new things.
- 74% of individuals reported that they chose the services they get as a part of their service plan, while 18% had some input.
- If they want to change something about their services, 81% know who to ask, but 14% do not know who to ask.

Supports Coordination



Staff

- 92% of individuals interviewed reported that their staff always treats them with respect.
- 95% of individuals reported that they feel their staff has the right training to meet their needs.
- 86% of individuals feel that all their staff understand their communication; 8% say some staff understand them, 4% feel they are understood sometimes, and 1% do not feel that their staff understand their communication.

Emergency Preparation Questions

- 81% 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, 36% received information from home staff, 34% from day program or employment staff, 44% from someone in their family, 4% from the police, fire department, or EMS, 12% from supports coordinator, 11% 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 84.15 with a standard deviation of 14.75.
- 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 92.86 with a standard deviation of 15.77.
- 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 2017-2018 report, there were several significant differences.

- There was a 23% **increase** in individuals who reported that their staff can always understand them.

- There was an 8% **increase** in individuals who reported they can always contact their supports coordinator when they want to.
- There was a 5% **decrease** in individuals who reported that they have been told at their planning meeting how much money is in their annual budget.
- There was a 6% **decrease** in individuals who reported their supports coordinator asks about directing their own services.
- There was a 5% **decrease** in individuals who reported that they had attended a self-advocacy meeting.
- There was a 4% **decrease** in individuals who reported their mail was never opened without their permission.
- There was a 6% **decrease** in those who reported someone had talked to them about what to do in an emergency.
- There was also a substantial shift in whom individuals report going to when they need help; the majority now go to family, a 15% **increase** from last year's report, while about half report going to staff, a 10% **decrease** from last year.
 - This shift may be reflective of the change in the sampling procedure (described earlier in this report) which resulted in many more individuals in the sample living at home with families.

There were also several differences in the 2017-2018 report with regard to health care:

- Exercise habits at home changed significantly, with a 9% **increase** in individuals who report they never exercise at home, and a 6% **decrease** in those who report exercising at home 10 times per month or more.
- There was a 4% **decrease** in individuals who reported they have an opportunity to discuss their health concerns with their PCP.
- There was a 6% **decrease** in people who reported their doctor understands their communication.
- There was a 10% **decrease** in those who reported understanding their doctors' instructions.
- There was a 33% **increase** in those who said they were able to see a medical specialist if they needed to.

- Of those who have a psychiatrist, there was a 20% **decrease** in individuals who reported they have the opportunity to discuss health concerns with the psychiatrist if they wanted.
- There was a 20% **decrease** in people who reported they are able to provide consent for their medical treatment.

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,

- 38% of the questions were answered by the individual receiving supports
- 18% of the questions were answered by paid staff
- 11% of the questions were answered by the individual and staff
- 16% of the questions were answered by family/friend/advocate/guardian
- 17% 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.”

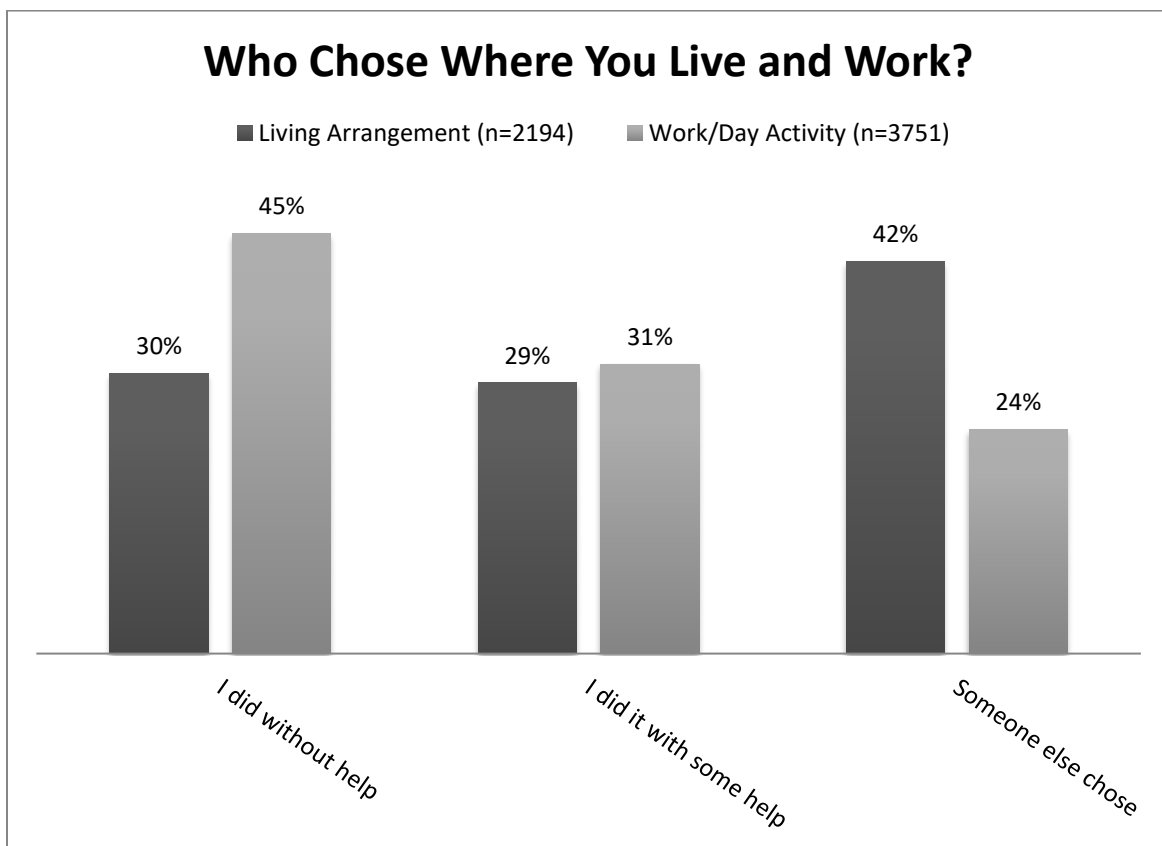
Forms of Identification

- 61% of individuals stated that they always carry a form of identification; 23% never do.

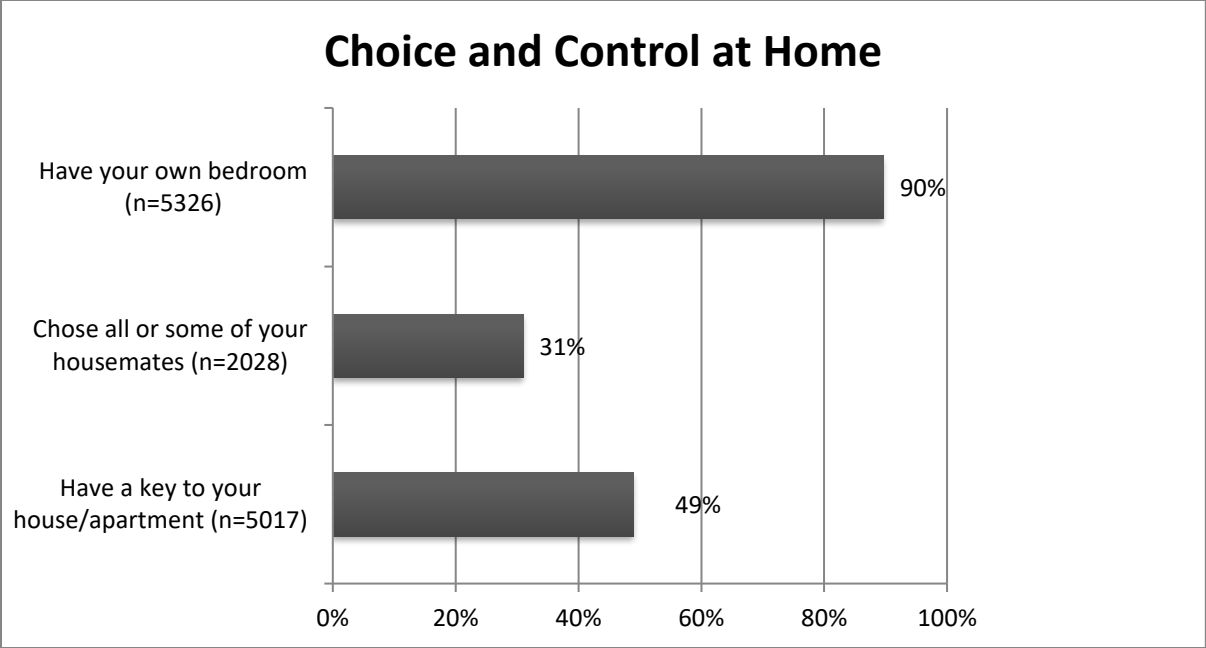
Choice and Control at Home

- 49% of the individuals surveyed had a key/way to get into to their house or apartment on their own.
- 58% of respondents said that if other members of their house go out, they have the option to stay home;10% sometimes have the option to stay home.
- 44% of respondents can lock their bedroom door if they want to.

- 3% of individuals reported that they own their own home
- 25% of individuals report that their name is on the lease or rental agreement
- For 42% of the individuals, someone else chose where they live; 30% of those interviewed chose on their own.
- 54% of individuals said they were given a choice to live where people without disabilities live
- 50% of individuals surveyed saw no other places before they moved into their residence.



- 60% of the individuals **did not** choose their housemates.
- For those who shared a bedroom, 37% chose some or all of their roommates.



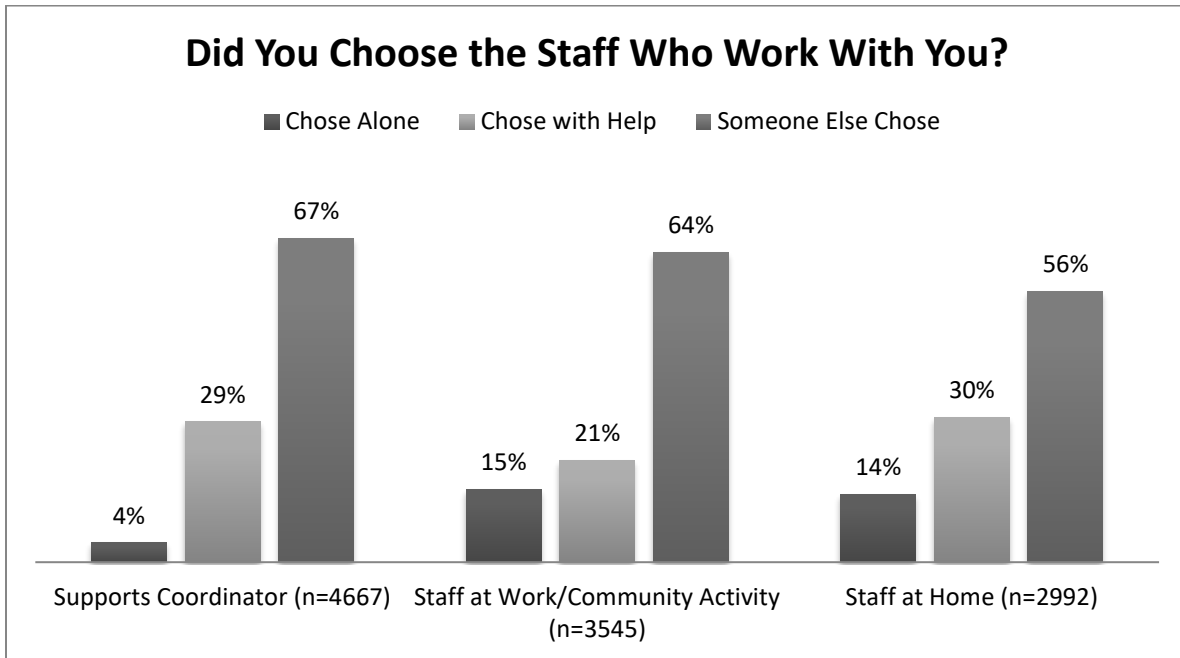
Choice and Control During the Day and for Leisure Time

- 24% of the individuals interviewed reported that someone else chose what they do during the day.
- 45% of the people interviewed chose what they do during the day without assistance.
- 57% of individuals reported that when they chose their work or day activity, they had an option to go where people without disabilities go
- 41% of individuals saw no other places when choosing what they do during the day.
- 89% of the individuals surveyed chose their daily schedules without assistance.
- 93% say they have enough choice about how they spend their free time.

Choice and Control in Choosing Staff

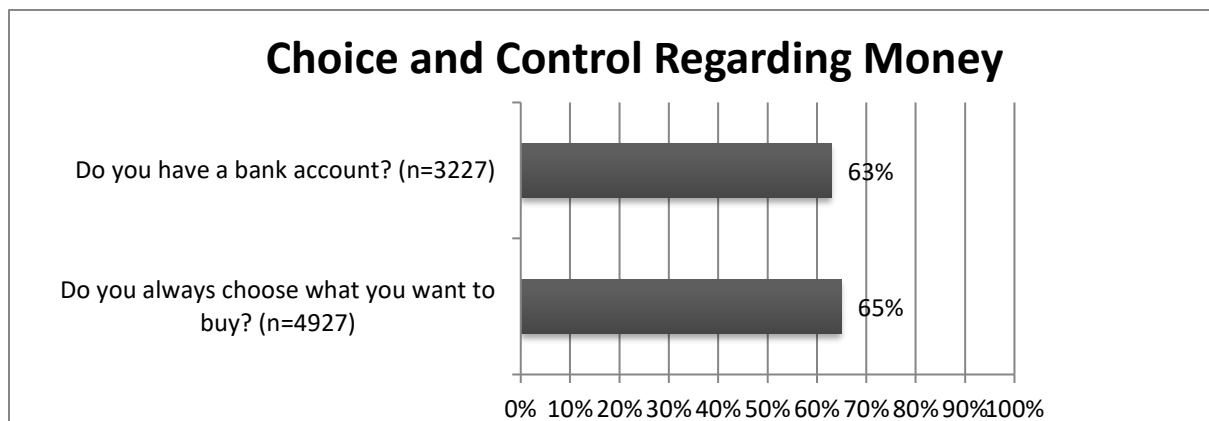
- 44% of the individuals interviewed/chose at least some of the staff who help them at home (alone or with assistance from family or provider).
- 36% of the individuals surveyed interviewed/chose at least some of the staff who help them at work/day activity (alone or with assistance from family or provider).

- 33% of individuals chose their supports coordinators (alone or with assistance from family or provider).



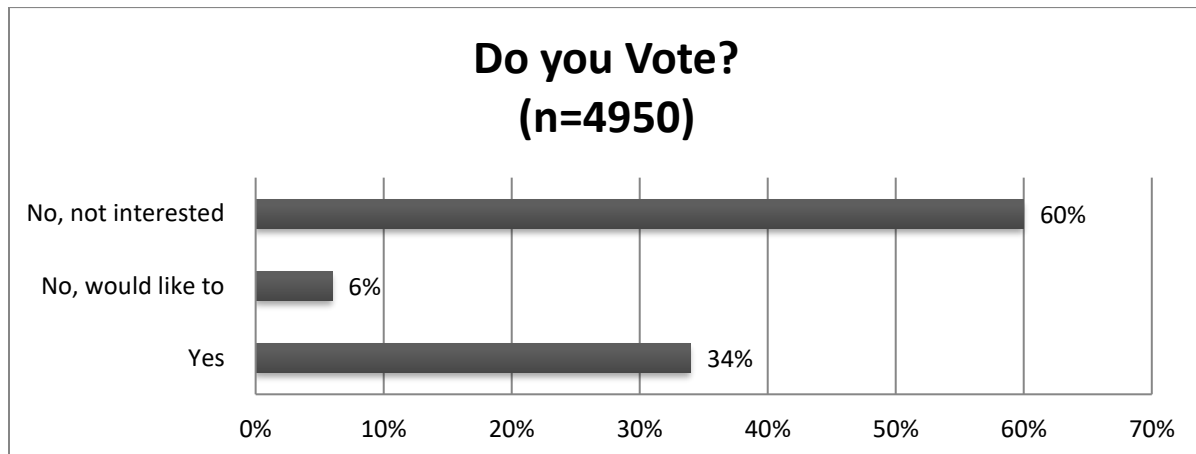
Choice and Control with Regard to Money

- 65% of the individuals reported that they always choose what to buy with their spending money, 28% report that they choose with help.
- 40% of the individuals reported that there is something they want to buy.
- 63% of the individuals reported they have a bank account that they can get to independently to withdraw money when they want it.



Voting

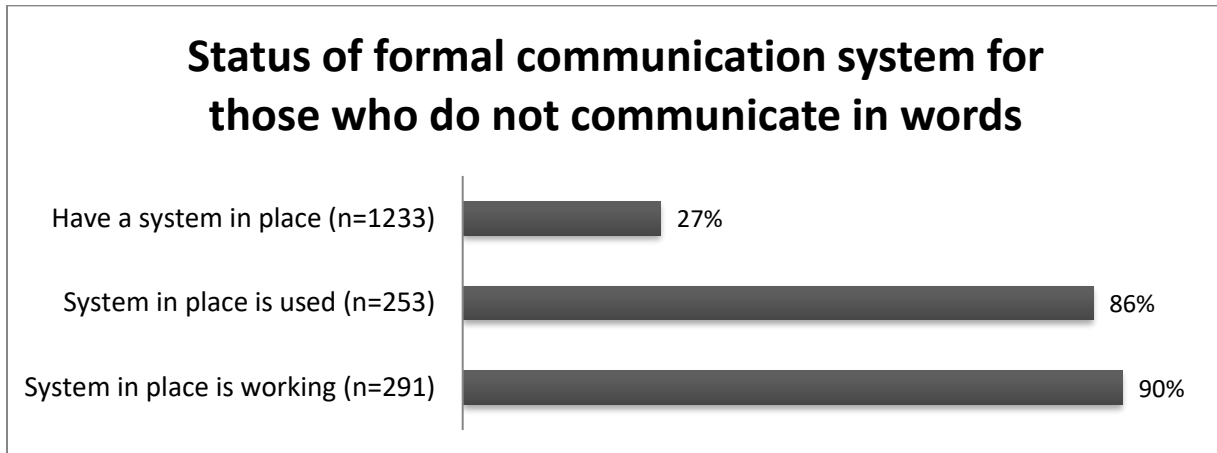
- 34% of the people said they vote, 59% of the people said they do not vote and are not interested in voting, and 6% do not vote but would like to. ***It is our hope that for those individuals expressing a desire to vote, a consideration has been written to assist the individuals in registering to vote and in voting. Additionally, it is our hope that individuals have the opportunity to learn the importance of voting. For those who are not interested in voting, perhaps efforts could be devoted to determining why they are not interested in voting.***



Access to Communication

- For those individuals who do not communicate using words, there is a formal communication system in place for 27% of the people interviewed.
- For those people with formal communication systems in place, 90% reported that the systems are in working order; if the communication system was in place and working, it was being used regularly for 86% of the people interviewed
- 73% of individuals with a formal communication system reported using it across all settings.
- 58% of individuals with a formal communication system are supported by staff or a program coordinator, 44% are supported by a parent or caregiver, 30% are

supported by their speech language clinician, and 11% are supported by someone else.



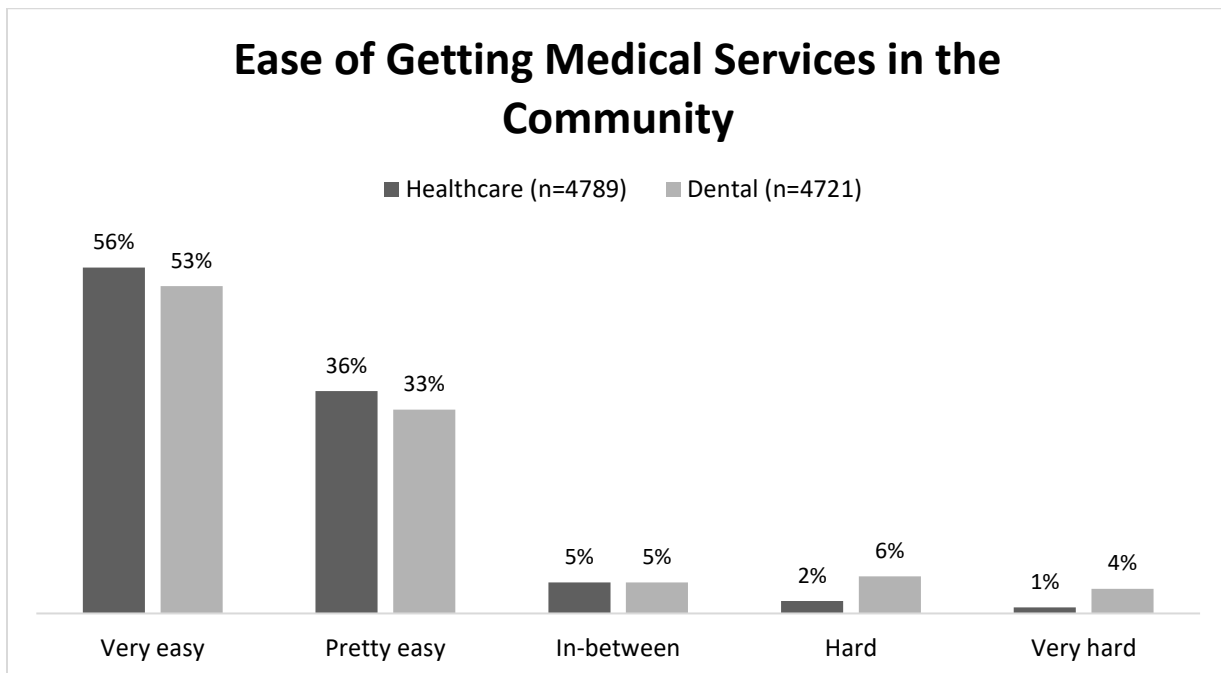
Other Forms of Communication:

- 34% have and use a cell phone; there are restrictions for 7% of these people
- 16% have and use e-mail; there are restrictions for 2% of these people
- 30% have and use internet; there are restrictions for 10% of these people
- 22% have and use text-messaging; there are restrictions for 3% of these people
- 78% have and use cable television; there are restrictions for 5% of these people
- 37% have and use a computer; there are restrictions for 9% of these people

Health Care Questions

- When asked how many times per month they exercise at home, 54% of individuals said zero, and 31% said 10 or more times a month.
- 93% of individuals interviewed reported that they have the opportunity to discuss health with their primary care provider (PCP)
- 91% of individuals reported that they feel their doctor understands them
- 84% of individuals feel that they understood their doctors' instructions
- 94% of respondents say if they needed help communicating at the doctor's office, it was available
- 94% of respondents reported they were able to see a medical specialist if they needed to

- 92% of individuals say they have not been prevented from receiving medical and dental services because of their disability
- When asked how hard it is to get health care services in their community, 92% of individuals reported that it was very easy or pretty easy, 5% reported that it was in-between, and 4% reported that it was very hard or hard
- When asked how hard it is to get dental services in their community, 86% of individuals reported that it was very easy or easy, 5% reported that it was in-between, and 9% reported that it was very hard or hard
- 57% of individuals interviewed reported that they have the opportunity to discuss health concerns with a psychiatrist; 3% reported they do not have a psychiatrist but want one
- 93% of individuals reported that their doctor speaks directly to them during appointments
- 65% of individuals reported that they are able to provide consent for medical treatment; of those able to provide consent, 88% said their doctor accepts their consent and 12% say their consent is not accepted



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

- The average (mean) score was 58.50 with a standard deviation of 21.57.
- The modal score was 47.37, indicating the most frequent score.

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

- There was a 13% **increase** in individuals who reported that they had a key/way to get into to their house or apartment on their own.
- There was a 5% **increase** in individuals who reported that their name is on the lease or rental agreement.
- There was a 7% **increase** in those who report they always carry ID.
- There was a 9% **increase** in those who report that they chose where they wanted to live.
- There was a 15% **increase** in those who reported they had a choice to live where people without disabilities live, and a 6% **increase** in those who say they had the option to work in a place where people without disabilities work.
- There was a 35% **increase** in those who reported they chose what they do during the day without assistance.
- There was a 9% **increase** in those who reported having a bank account, and an 8% **increase** in those who report choosing what to spend their money on.
- There was a 9% **decrease** in individuals who reported that they interviewed/chose at least some of the staff who help them at home.
- Regarding forms of communication, there was an **increase** in respondents' reports that they have and use a cell phone (13%), have and use email (5%) have and use the Internet (7%) and have and use text messaging (9%) and have and use a computer (5%).

- There was also a 7% **increase** in individuals who chose some or all of their roommates.
- NOTE: Several large shifts in the responses to the questions in this section could be related to the change in sampling procedure.

Employment

Respondents: Of the 5326 individuals surveyed for the 2018-2019 Statewide IM4Q sample, 820 people indicated they are employed.

Community Integrated Employment

- 17% (n=820) of individuals surveyed report that they work in a community integrated setting while 83% do not.
- The majority of individuals have been employed for 1 to 3 years (30%). 19% of individuals have been employed for less than one year, 17% have been employed for 4-6 years, 9% have been employed for 7-10 years, and 25% have been employed for more than 11 years.

Types of Work

- Of those who report that they work, 28% of individuals work in cleaning services, 14% work in retail, 25% work in food services, 4% do office work, 6% work in a stock room or stock shelves, 3% work in maintenance, 7% work in assembly or factories, 3% work as care-workers or aides, 1% work in recycling, and less than 1% work in animal care or landscaping/outdoors. 11% work in some other occupation.

Supports Getting Into the Workplace

- 10% of individuals take classes or training to help them get a job in the community, get a better job, or do better at their current job.
- 57% of individuals surveyed reported that someone had talked to them about employment in their planning meeting.
- 32% of individuals report that community employment is a goal in their plan.

- When individuals were asked who had talked to them about employment, 44% said no one, 51% said their supports coordinator, 10% said their service provider, 11% said their family, less than 1% said their housemates, and 6% said someone else.

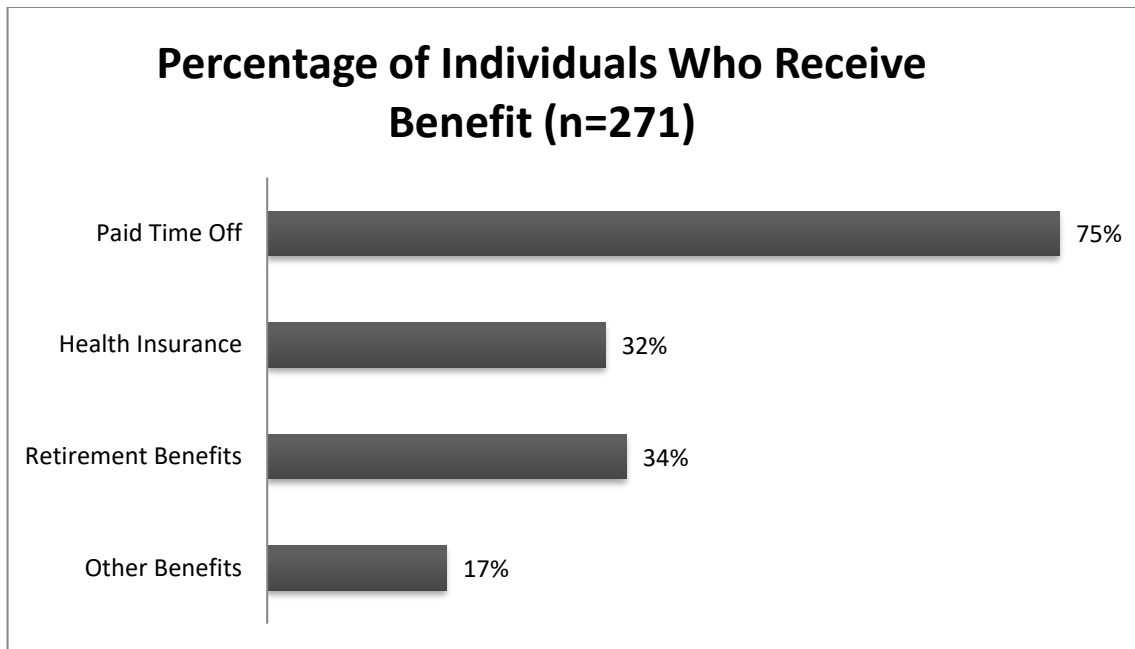
Note: individuals answering this question had the option to indicate more than one response.

Compensation and Advancement

- 75% of individuals received paid time off, 32% received health insurance, 34% received retirement benefits, and 17% received some other kind of benefit.

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

- 53% of individuals who work have been promoted and/or received an increase in pay.
- The mean number of hours worked per week was 18.18 hours. Hours worked per week ranged from 1 to 60 hours; the most common response was 20 hours per week.
- 84% of individuals reported that they know how much they earn and are willing to share it.
- Individuals reported hourly wages ranging from \$7.25 to more than \$15.00.
- The most common hourly wage range, reported by 36% of individuals, was \$9.01 to \$12.00. 24% of individuals reported earning \$7.25 per hour. 29% of individuals reported earning \$7.26 to \$9.00 an hour, and 11% earned more than \$12.01 per hour.



Self-employment: 1% (n=49) 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 2017-2018:

- There was a 5% **increase** in individuals who reported talking about employment in their planning meeting.
- There was also a 5% **increase** in people who reported that employment is a goal in their plan.
- There was a 5% **increase** in those who report working in a community integrated setting.
- For employed individuals, there was an **increase** in mean hours worked per week (+2.21 hours).
- The most common salary reported **increased** from \$7.25 per hour to \$9.01-\$12.00 per hour (36%).
 - Additionally, people who reported earning \$12.01 or more per hour **increased** by 5%.

- There was a 13% **increase** in individuals that have peer promoted or received an increase in pay.
- There was a 17% **increase** in employed individuals that received health insurance.
- There was an 13% **increase** in employed individuals that received retirement benefits.

Self-Directed Supports

Respondents: Of the 5326 individuals surveyed for the 2018-2019 Statewide IM4Q sample, 233 people indicated they use self-directed supports.

- 5% of respondents report that they use self-directed supports while 95% do not.

Among those individuals using self-directed supports,

- 12% make most of the decisions about how their budget for services is used on their own; 37% have input but family and friends help, 40% say a family member or friend makes decisions, and 11% report that a case manager or another state professional makes the decision.
- 74% participate in decisions about budget, staff, and managing services.
- 71% hire and manage their own staff.
- 86% can make changes to their budget or services if they need to.
- 93% say they have enough help deciding how to use their budget/services, while 4% want more help.
- 79% receive information about the money left in their budget.
 - Of these, 84% say the information is easy to understand.
 - 63% receive this information at least every three months, 14% report they receive the information about twice a year, and 23% receive information once a year or less.

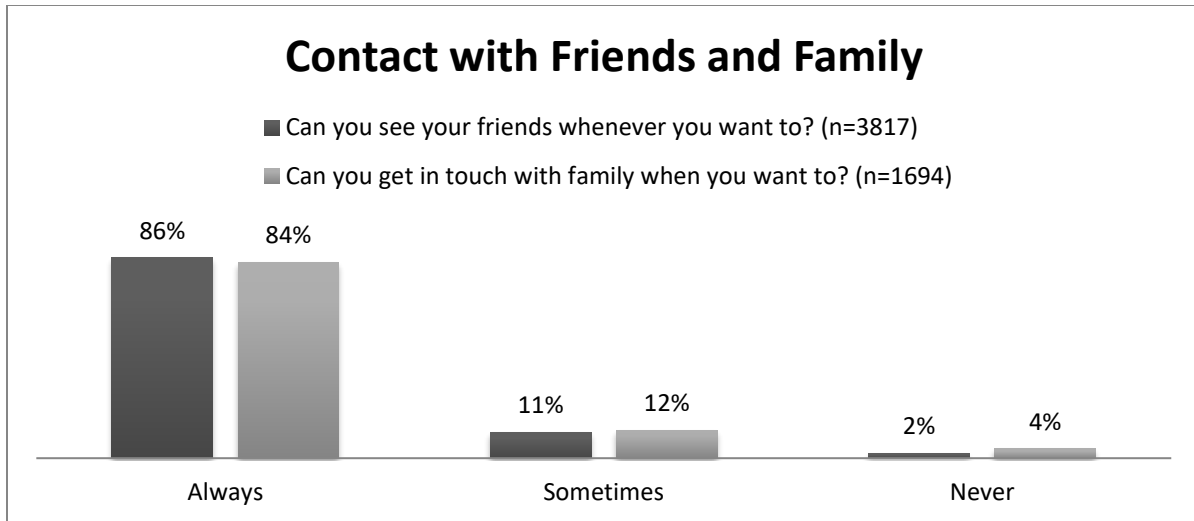
Relationships

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

- 44% of the questions were answered by individuals receiving supports.
- 18% were answered by paid staff.
- 8% were answered by individuals receiving support and staff.
- 16% were answered by family/friend/guardian/advocate.
- 13% 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

- 86% 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, 25% reported that it was difficult to find time to see friends, 25% reported that they couldn't see friends because of a transportation issue, 5% reported a lack of staff, 7% reported that there were rules/restrictions, 2% reported money/cost, and 36% reported that there was another reason why they couldn't see friends.
- 84% 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 2017-2018.

- The respondent profile was different from last year. This year's respondent was more likely to have been the individual receiving services (9% increase), the individual with a family member, friend or advocate (6% increase), or a family member, friend or advocate alone (5% increase). There was a decrease in respondents who identified as a staff member (15%) or individual along with staff (5%).
- When they could not see their friends, there was a 14% **increase** in those who reported transportation reasons, but a 5% **decrease** in those who found it difficult to find the time, a 2% **decrease** in those who said rules and restrictions were to blame, and an 8% **decrease** in those who cited some other reason.

Inclusion

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

- 36% of the questions were answered by individuals receiving supports

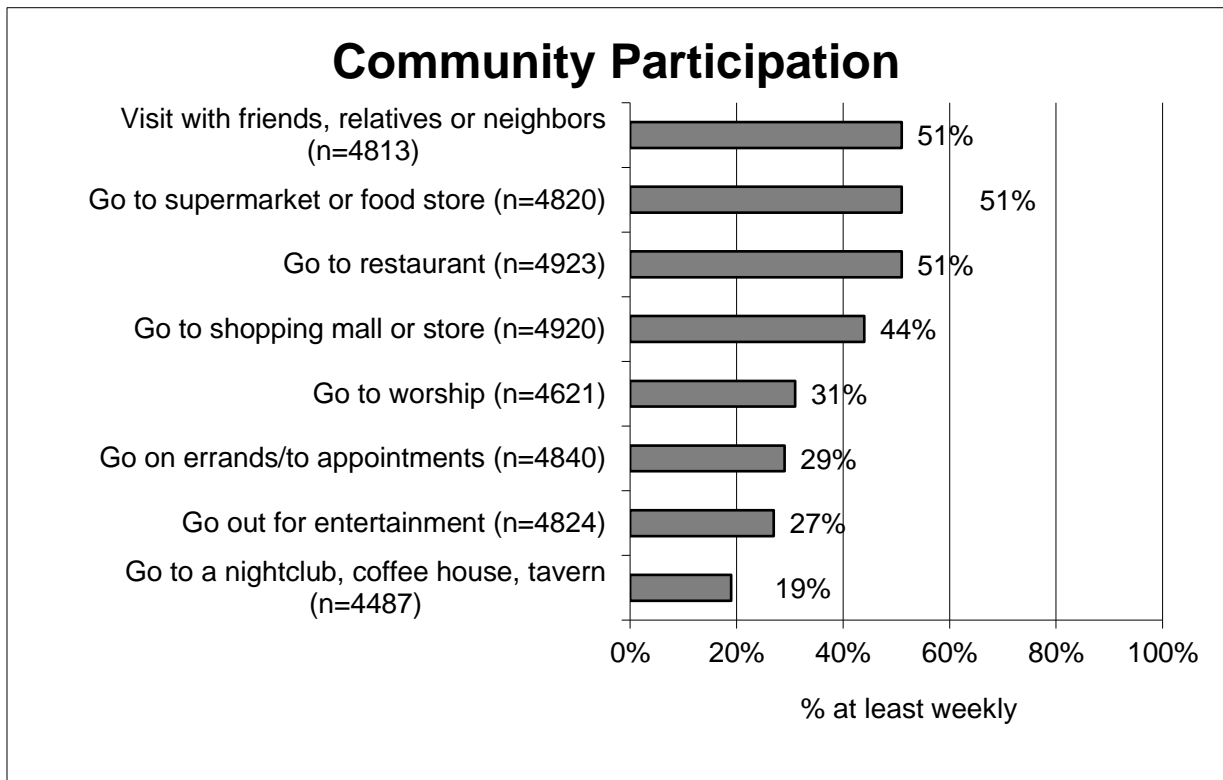
- 18% were answered by paid staff
- 11% were answered by individuals receiving support and staff
- 16% were answered by family/friend/guardian/advocate
- 18% of the questions were answered by individuals receiving support and a family/friend/guardian/advocate
- 1% of the questions were answered by staff and family
- A value of missing was assigned when individuals did not answer, gave an unclear answer, or responded, “do not know.”

Community Participation

- 51% of the people visited with friends, relatives and neighbors at least weekly.
 - When they visited friends, relatives and neighbors, individuals reported they went alone 16% of the time, with family 47% of the time, with staff 23% of the time, with friends 13% of the time, with housemates or coworkers 1% of the time, and with someone else less than 1% of the time.
 - 82% of individuals said this was enough time to visit friends, 17% wanted more, but 1% wanted less.
- 51% of those surveyed went to a supermarket at least weekly.
 - When they went to the supermarket, individuals reported they went alone 7% of the time, with family 48% of the time, with staff 40% of the time, with friends 3% of the time, with housemates or coworkers 1% of the time, and with someone else less than 1% of the time.
 - 88% of individuals said this was enough time to go to the supermarket, 9% wanted more, but 3% wanted less.
- 51% of respondents went to restaurants at least weekly.
 - When they went to a restaurant, individuals reported they went alone 5% of the time, with family 46% of the time, with staff 39% of the time, with friends 8% of the time, with housemates or coworkers 3% of the time, and with someone else less than 1% of the time.

- 81% of individuals said that they visited restaurants just enough, 17% wanted more and 2% wanted less.
- 44% 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 6% of the time, with family 42% of the time, with staff 45% of the time, with friends 5% of the time, with housemates or coworkers 2% of the time, and with someone else less than 1% of the time.
 - 85% of individuals said they went to shopping centers or malls often enough, 13% wanted more and 3% wanted less.
- 31% of respondents went to places of worship at least weekly.
 - When they went to a place of worship, individuals reported they went alone 8% of the time, with family 58% of the time, with staff 24% of the time, with friends 7% of the time, with housemates or coworkers 2% of the time, and with someone else 1% of the time.
 - 89% of individuals report they go to worship often enough, while 10% wanted more and 1% wanted less.
- 29% of those surveyed went out on errands or appointments at least weekly.
 - When they went of errands or appointments, individuals reported they went alone 9% of the time, with family 47% of the time, with staff 41% of the time, with friends 3% of the time, with housemates or coworkers 1% of the time, and with someone else less than 1% of the time.
 - 92% of individuals said this was enough time for errands and appointments, 6% wanted more and 2% wanted less.
- 19% 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 9% of the time, with family 36% of the time, with staff 44% of the time, with friends 8% of the time, with housemates or coworkers 2% of the time, and with someone else 1% of the time.
 - 89% of individuals reported that they had enough time to visit night clubs, coffee houses or taverns but 10% wanted more and 1% wanted less.

- 27% of individuals go out for entertainment at least weekly.
 - When they went out for entertainment, individuals reported they went alone 4% of the time, with family 40% of the time, with staff 43% of the time, with friends 10% of the time, with housemates or coworkers 3% of the time, and with someone else less than 1% of the time.
 - 81% of individuals said they went out for entertainment enough, 18% wanted more and 1% wanted less.



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 slightly less likely than individuals with disabilities in the Harris Poll to visit with friends, relatives, and neighbors. People without disabilities are about 15% 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 more likely to go out to eat 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 or without disabilities in the Harris Poll.

Weekly Participation in Community Activities			
	Harris 2010: People without Disabilities	Harris 2010: People with Disabilities	Independent Monitoring 2018-2019
Visit with friends, relatives, and neighbors	65%	54%	51%
Go to restaurant	41%	20%	51%
Go to worship	28%	24%	31%

Inclusion Scale

Scores on the Inclusion Scale could range from 0 to 100, with a higher score indicating greater inclusion (going more frequently to places in the community). The scale includes 7 items measuring frequency of participation in community activities. These

items include visiting with friends, going to the supermarket, going to a restaurant, going to worship, going to a shopping mall, going to a bar, and going on errands.

- The average score was 45.61 with a standard deviation of 17.52
- The average score was less than half of the possible scale score, indicating that individuals do not go to community places with great frequency.
- The mode, or most frequent score, was 50.00.

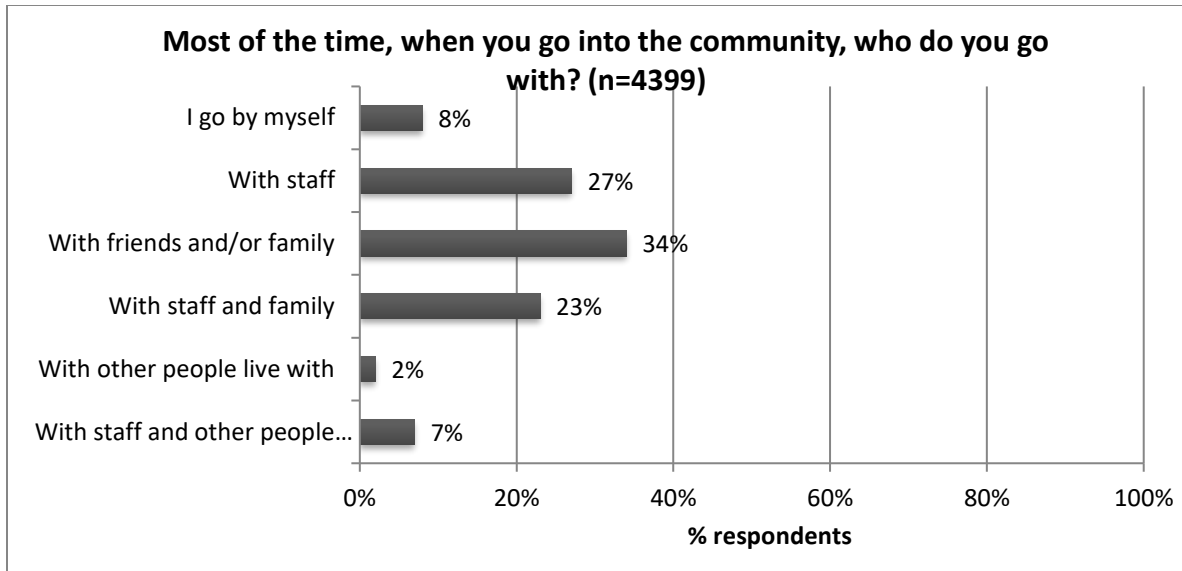
Community Activities

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

- 55% of individuals go frequently into the community for entertainment and 32% 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 41% go occasionally.
- 31% of individuals would like to be a part of more groups in their community.
- 48% of individuals went on a vacation in the past year.
- Regarding monthly exercise, 39% of individuals reported never going out for exercise, 4% exercise less than weekly, 11% exercise once a week and 46% exercise more than once a week.

Going Out Alone or With Other People

- 8% of individuals go out alone; 34% go out with friends and family.
- 34% of individuals go out with staff or staff and other people they live with most of the time.

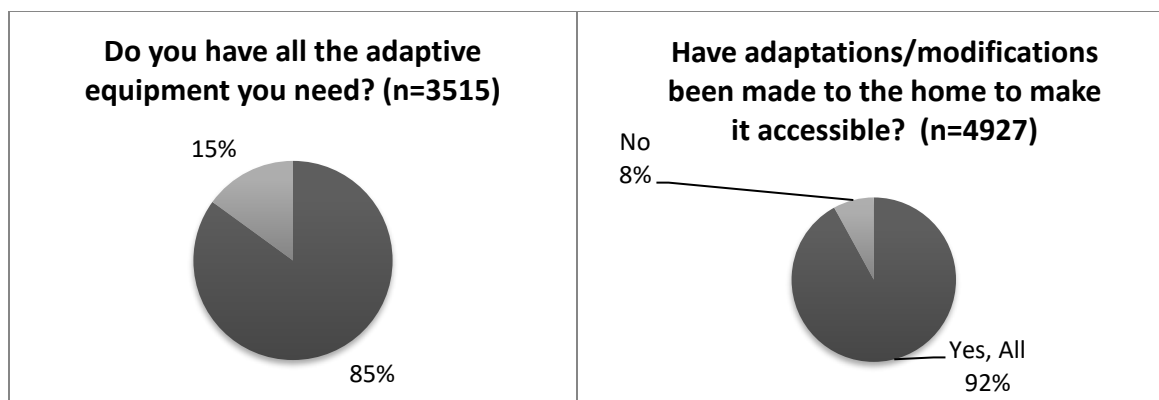


Transportation

- 90% of individuals always had a way to get where they wanted to go.
- In order to get to places they needed to go, the majority of individuals reported getting a ride from family or friends (40%). 32% reported getting a ride from staff in the provider van, 12% reported getting a ride in a staff member’s car, 7% transport themselves, 5% ride public transportation, 4% ride paratransit, and less than one percent take a taxi, Uber or Lyft.
- Of those who cannot always get where they want to go, 16% cannot get where they want to go because there is not enough staff. 11% said para transit is unreliable, 5% have transportation for work/school only, 3% report that no one who lives or works at their home can drive, and 65% said there was some other reason they cannot get where they want to go.

Home Adaptive Equipment

- 85% of individuals reported having all the adaptive equipment they needed.
- 92% of people said that all necessary modifications have been made to their home to make it accessible.



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

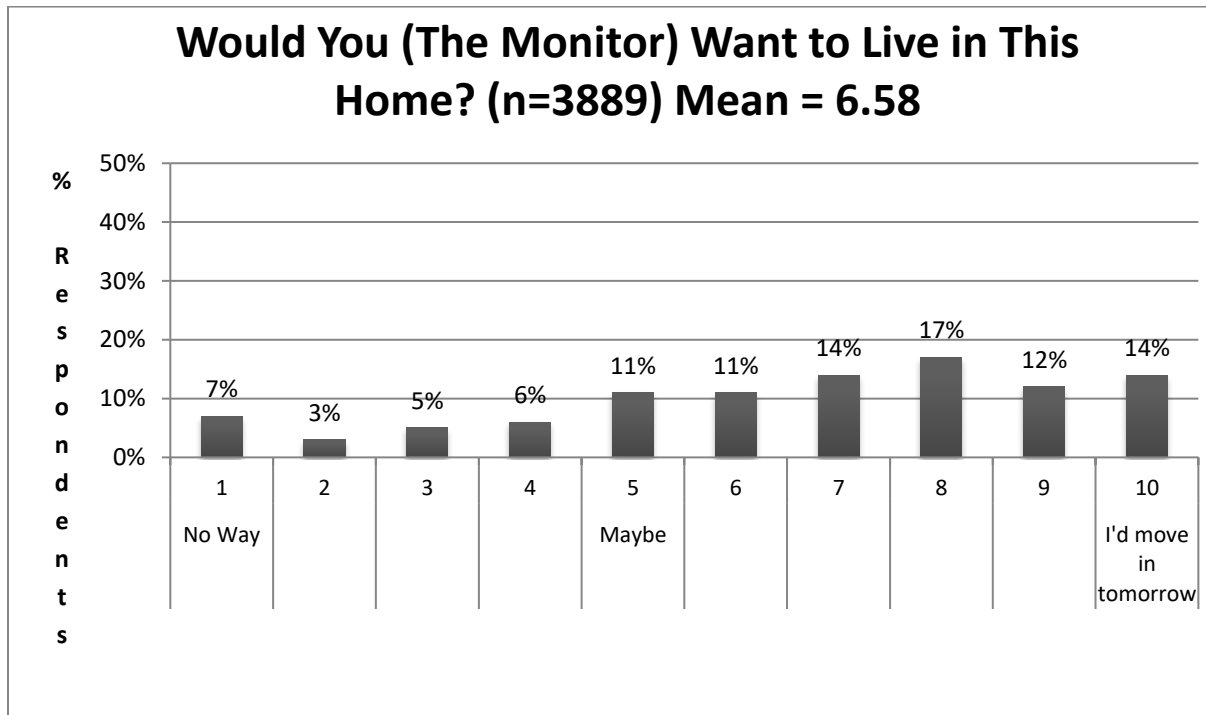
- There was a 5% **increase** in individuals who visit friends, relatives, and neighbors at least weekly.
- There was a 4% **increase** in people who go out to eat at least weekly.
- There was a 4% **increase** in people who go to worship services at least weekly.
- There was a 5% **increase** in people who went on vacation in the last year.
- There was also a significant change in the trends of whom people went with when they went out into the community to visit others, shop, and seek entertainment.
 - 2-8% **increase** in people who reported going alone.
 - 7-22% **increase** in people who reported going with family members.
 - 18-27% **decrease** in people who reported going with staff members.
- Finally, when they cannot visit friends, there was a 14% **increase** in those who cited transportation issues as the reason.

Competence, Personal Growth and Opportunities to Grow and Learn

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

According to the IM4Q teams,

- When asked whether team members would want to live in the individual's home on a scale of 1 ("No way") to 10 ("I'd move in tomorrow"), the average score was 6.58.



Compared to the Competence, Personal Growth and Opportunities to Grow and Learn section of the 2017-2018 report, there was a 2% **increase** in monitors who reported they would move in tomorrow.

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 92% of observed situations.

- 91% of respondents observed that all staff recognized the individuals in ways that promote independence.
- 91% of staff observed that all 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 2017-2018 report, there were two significant differences.

- There was a 2% **increase** in the observed situations in which IM4Q teams perceived that individuals were treated with dignity and respect.
- There was a 2% **increase** in the perception of IM4Q teams that all staff recognized the individuals in ways that promote independence.

Family/Friend/Guardian Survey

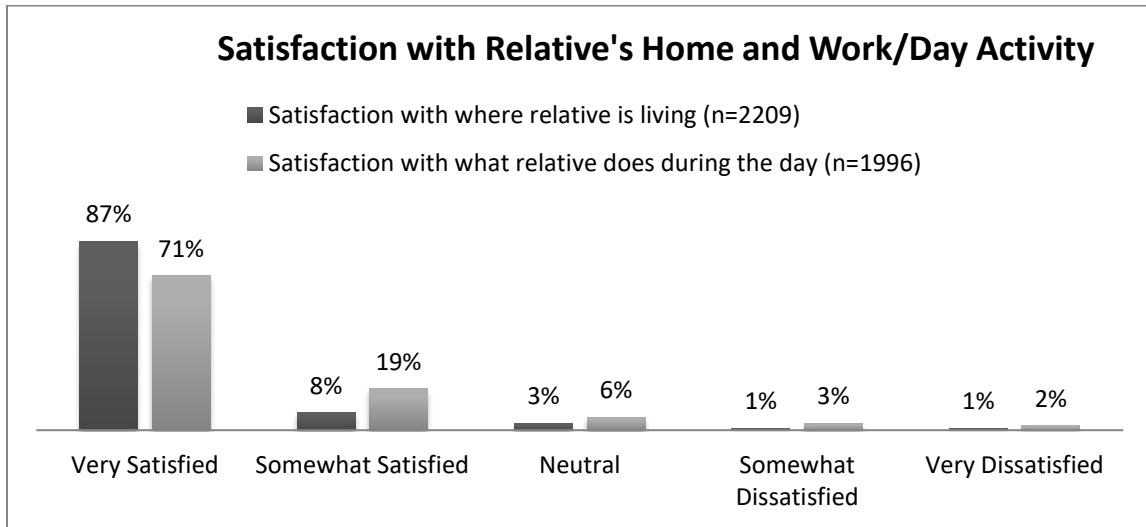
Respondents: This survey was completed by telephone or face-to-face with a family member, guardian, or friend who was identified through the Essential Data Elements Pre-Survey. In the event that a phone or face-to-face survey could not be completed, surveys were completed by mail. Surveys were completed for 2238 family members, friends, and guardians.

- 74% of the surveys were answered by parents
- 16% were answered by siblings
- 2% were answered by the guardian
- 5% were answered by another relative (spouse, aunt, uncle, cousin, grandparent)
- 3% were answered by persons with other relationships to the individual receiving supports.
- Less than one percent of surveys were answered by friends.

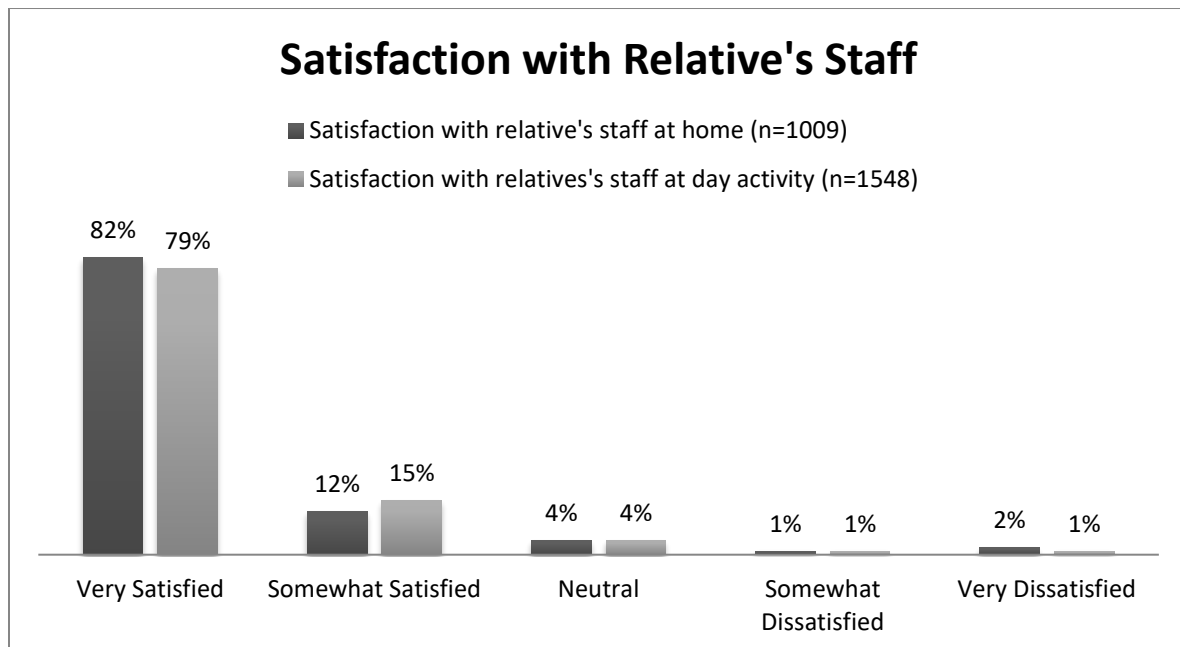
Satisfaction

- 95% of the families surveyed were either somewhat satisfied or very satisfied with where their relative lives.

- 89% were either somewhat satisfied or very satisfied with what their relative does during the day.



- 94% of the families surveyed were either somewhat satisfied or very satisfied with their relatives' staff at home.
- 95% of the families surveyed were either somewhat satisfied or very satisfied with the staff at their relatives' day activity.

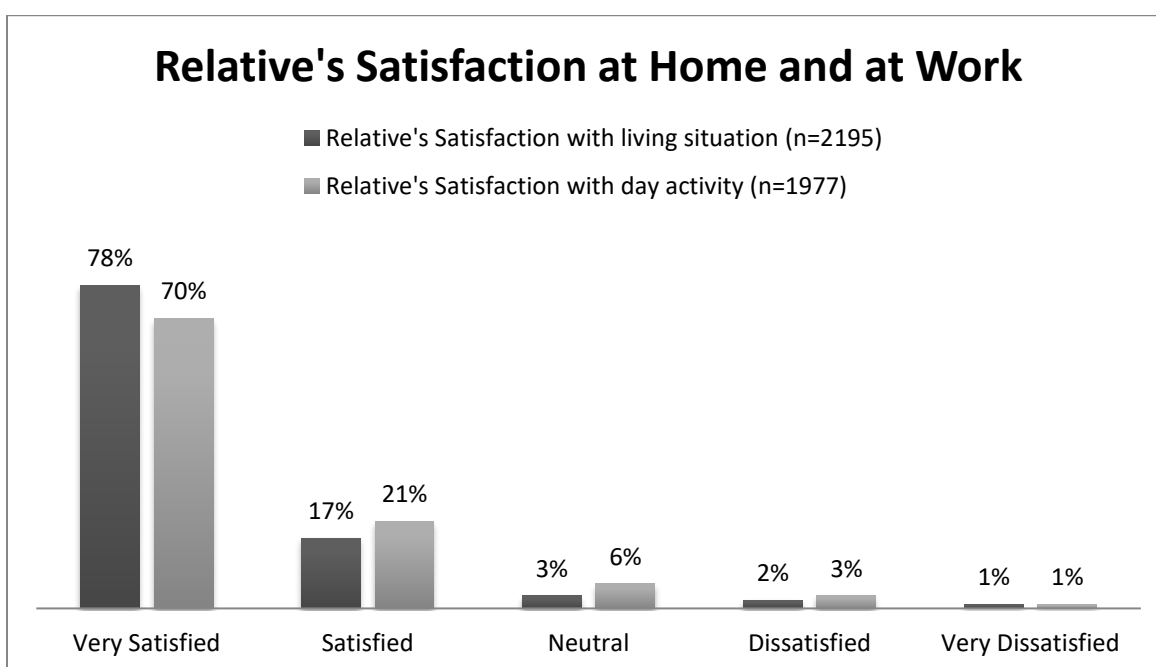


How Often Do You Contact/See Your Relative?

- 87% of the family/friend/guardians contacted their relative at least monthly; 5% have never contacted their relative.
- 81% 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% never visited with their relative.

Your Relative's Satisfaction

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



- 95% of relatives felt their relative was either very satisfied or satisfied with the staff who support them at home; 2% believed their relative was either dissatisfied or very dissatisfied.
- 96% of respondents felt their relative was either very satisfied or satisfied with the staff who support them at work (or during the day); 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, and neighborhood always (86%) or most of the time (12%).

Your Relative's Opportunities

- 85% of the respondents said that their relative had enough opportunities to participate in activities in the community.
- 86% of the respondents said that their relative seemed to have the opportunity to learn new things.

Your Relative's Staff

- 85% of the respondents said that their relative's home appeared to have an adequate number of paid staff.
- 96% of the respondents said that staff in their relative's home always treat people with dignity and respect.
- 89% of the respondents said that all staff appear to have the skills they need to support their relative in the home; 9% felt that only some staff have these skills.
- 95% of the respondents said that their relative's place of work appears to have an adequate number of paid staff.
- 97% of respondents said that staff in their relative's place of work always treat people with dignity and respect.
- 91% of respondents reported that staff in their relative's place of work appear to have the skills they need to support their relative; 8% felt only some staff do.
- If their relative did not communicate verbally, 36% of the respondents said that there is a formal communication system in place for their relative and they use it. For 78%, the communication system is used across all settings.

Relative's Supports

- 84% 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.

- 8% of relatives report that their relative self-directs their own services.
- 69% said that their relative always received the supports they needed.
- 85% said that the services and supports their relative receives change when their relative's needs change
- 91% of relatives always felt that the staff who assisted them with planning respected their choices and opinions.
- 57% of relatives never felt that there were frequent changes in support staff at their family member's home, work or day program; 13% felt that there were always frequent changes
- 42% of relatives choose the agency/provider who worked with their relative; 6% said their relative chose; 20% chose with their relative; 32% said someone else chose.
- 59% of relatives were familiar with the way complaints and grievances are handled at the provider level, 58% of relatives were familiar with the way complaints and grievances are handled at the county/AE level, and 52% of relatives were familiar with the way complaints and grievances are handled at the state level. 34% were not familiar of the grievance and complaint process on any level.

Family Resources

- 90% of relatives felt that the information they received about their relative's services was easy to understand
- 12% of respondents had learned about the Life Course Framework and Tools
- 46% of relatives have an opportunity to connect and network with other families with relatives at similar life stages
- 22% of relatives said they were aware of the PA Family Network; of those who were aware, 32% had attended a workshop led by the Network of Family Advisors.
- 78% of relatives said that they have enough information about services for which their family is eligible

- 32% of respondents whose family member transitioned from school to adult services in the past year were happy with the process
- 71% of relatives report that the supports coordinator asks about their vision for an everyday life for their family member

Emergency Preparation Questions

- 55% of relatives have been given information about an emergency plan for their family member in case of an emergency.

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

- The average (mean) score was 91.48 with a standard deviation of 13.14.
- The mode (the value that occurs the most frequently) was 100, indicating that many of the families' (49%) satisfaction levels were at the top of the scale on all measures of family satisfaction.

Compared to the Family/Friend/Guardian section of the 2017-2018 report, there were several significant differences.

- In terms of who responded to the survey, there was an 8% **increase** in parent responses and a 5% decrease in sibling responses.
- There was a 5% **decrease** 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 5% **increase** in family members who had attended PAFN workshops.
- There were **increases** of 2-5% in family members who reported awareness of complaint and grievance procedures across settings
- There was a 6% **increase** in family members who report their supports coordinators ask about their vision for an Everyday Life for their family member.

Summary

This report presents information collected through face-to-face interviews with 5370 individuals receiving supports through the Office of Developmental Programs. In this year's sample, these individuals increasingly reside in their own home or the home of a relative and were less likely than in past years to reside in community homes.

Many trends from past years remain consistent. Individuals surveyed continued to report high levels of satisfaction overall. 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, though it remains the case that 1 in 5 say that they would prefer to do something else during the day, and about 1 in 7 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 2% increase in people who said they need more services at home.

Most people report high levels of privacy, and consistently report that they have friends, including friends who are not paid staff, and can date and get married if they wish. Access to communication tools such as cell phones, e-mail, text-messaging services and the Internet increased across the board. There were also modest increases in the number of people who regularly go out in the community to visit friends, dine-out, and attend worship services. This year's trends demonstrated that people are more likely to engage in these activities with family and friends as opposed to staff members, a shift from prior years. Additionally, more people are going out independently. Though the number is rising, only about half of participants go out into the community on a weekly basis. We hope to see this number continue to rise.

In the area of self-advocacy and self-directed services, it remains the case that less than half of the respondents had spoken to someone about self-advocacy or self-directed services, and the number of respondents who reported that they had participated in a self-advocacy group meeting dropped by 5% from last year to 1 in 7.

Questions were added to this year's survey specifically targeting those who self-direct their own services. We found that 5% of respondents choose to self-direct their services. Of these, about half make decisions about their budget, alone or with the input of friends and family, and 7 out of 10 hire their own staff. Further, most participants receive information about how much money is left in their budget, and report that information is easy to understand.

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

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

The data on choice and control indicated some positive trends, though overall people in the sample report limited choices. For instance, the individuals reporting they chose where to live on their own increased by nearly 10 percent; it is now almost 1 in 3. People increasingly chose some or all of the roommates with whom they share a bedroom, but more than 50% did not choose. There was a 13% increase in individuals who have a key or a way to get into their homes, but more than half do not have a key. 3 out of 5 always carry identification with them, but 1 in 5 never do. Some trends are even more promising; the number of individuals who report that they have a bank account and decide what they want to buy increased to nearly two-thirds, and 9 out of 10 report that they chose their daily schedule without assistance. .

In terms of employment, nearly 1 in 5 individuals report that they work in a community integrated setting. Of those who are not employed, more than half say that someone

talked about employment in their planning meeting and nearly a third say employment is a goal in their plan. 10% take classes or training to obtain a job or get a better job. Among those who work, the most common occupations are cleaning services, food services, retail, assembly, or stock room work, though 1 in 10 work in an unlisted job type. Most individuals who are employed reported working about 18 hours a week. Regarding pay benefits, there were several increases this year; the most common salary increased from \$7.25 to between \$9.01 - \$12.00 per hour. Benefits reported by workers also increased, including a 17% increase in people who receive health insurance benefits and a 13% increase in people who received retirement benefits.

As has been the trend for several reporting years, communication remains an issue for many individuals in the sample, particularly for those who communicate other than verbally. People had trouble understanding their doctor (16%), being understood by their doctor (9%), and being understood by staff (14%). Of people who are non-verbal, only about 1 in 4 have a communication system in place. For those who do have a system in place, there were declines in those who report it is in working order (90%, 3% decrease), used regularly (86%, 3% decrease), and used across settings (73%, 6% decrease).