

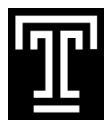
The Institute on Disabilities
Pennsylvania's University Center for Excellence in
Developmental Disabilities

Independent Monitoring for Quality (IM4Q)
State Centers
2018-2019

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

Submitted by: Sally Gould-Taylor, Mary Kay R. Cunningham,
James A. Lemanowicz, Guy Caruso, and Jenifer
Taylor Eaton
The Institute on Disabilities
Pennsylvania's University Center for Excellence in
Developmental Disabilities
Temple University
1755 North 13th Street
Student Center, Room 411S
Philadelphia, PA 19122

November, 2020



Institute on Disabilities
TEMPLE UNIVERSITY®

College of Education

Introduction

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

As a result of the IM4Q Program, ODP has developed and begun to implement quality improvement strategies to ensure the continued improvement of services and supports people receive through Pennsylvania's intellectual disability system. The IM4Q data are one source of information used to increase the quality of ODP's services and supports. The IM4Q Program is contracted through each of the 48 Administrative Entities (AEs). Each year, the AEs develop contracts with Local IM4Q Programs to independently conduct interviews and enter data regarding considerations into the Department of Human Services' (DHS) HCSIS web-based system. The remaining data emanating from the Essential Data Elements, Family/Friend/Guardian survey and the State center supplement are entered into ODESA (On-line Data Entry System) developed by the Human Services Research Institute (HSRI) NCI program for use by all NCI states. The IM4Q data are analyzed and reports are developed for dissemination to ODP staff, individuals, families, guardians, Administrative Entities (AEs), AE Mental Health/Intellectual Disabilities Advisory Boards, Local Programs, providers and other interested people.

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

Fiscal Year (FY)	Individuals Surveyed	Friends, Family, Guardians Surveyed
2000-2001	5298	2224
2001-2002	5659	2494
2002-2003	6487	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

A State Center sample was added in 2003-2004. The number of individuals receiving services in the five State Centers (Ebensburg, Hamburg, Polk, Selinsgrove and White Haven) and their family, friends and guardians who were sampled and who completed surveys in the following years is listed in the table below:

Fiscal Year (FY)	Individuals Surveyed	Friends, Family, Guardians Surveyed
2003-2004	181	92
2004-2005	387	198
2005-2006	198	59
2006-2007	225	60
2007-2008	218	80
2008-2009	177	71
2009-2010	184	68
2010-2011	183	85
2011-2012	178	80
2012-2013	172	85
2013-2014	117	58
2014-2015	190	85
2015-2016	185	62
2016-2017	149	38
2017-2018	148	61
2018-2019	148	44

Methodology

Instrument

The interview instruments for IM4Q include the Essential Data Elements (EDE) survey, a pre-survey form, and the Family/Friend/Guardian (F/F/G) survey. The IM4Q EDE has a total of 85 questions, 35 of which can only be answered by the individuals receiving supports and services.

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 in this section.
- **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.

Completed by the monitoring team at the time of the interview with someone who knows the individual the best:

- **State Center Addendum** – this section is only completed for individuals who are unable to communicate in traditional ways. The addendum provides surrogate information on the satisfaction and dignity, respect and rights questions from the Essential Data Elements.

Sample

Independent Monitoring focuses on the quality of life for children ages three and older, and to adults supported by the Intellectual Disability system. In FY 1999-2000, the sample for IM4Q was restricted to individuals living in licensed residential settings in 19 AE/County Programs, 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 county. Counties were instructed to draw a random sample of approximately one-third of the individuals living in licensed residential settings. AE/County programs 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.

In addition to the NCI and residential samples, during the 2003-04 year, each county was instructed to include 30 individuals who participate in the person and family directed supports waiver (PFDS).

In 2003-04, a decision was made to expand Independent Monitoring for Quality to the State Centers in a more intentional way. In prior years, the only way individuals from State Centers appeared in the sample was through random selection through an individual county's data for the National Core Indicators (NCI). The resulting number of individuals in the sample residing in State Centers has been quite small over the years.

Therefore, it has been impossible to look at a sample of individuals in each of the centers. In an effort to interview a number of individuals in each State Center, the Office of Developmental Programs decided to expand the number of individuals residing in State Centers to a random sample of 30 individuals in each of the state's six State Centers. The 2003-04 sample included 181 people, all of whom lived in the State's six publicly-funded ICFs/MR. – Polk, Ebensburg, White Haven, Selinsgrove, Hamburg and Altoona.

The sampling procedure for 2004-05 continued to be done through ODP's computerized database – the Home and Community Services Information System (HCSIS). The 2004-05 sample of people living in State Centers was expanded to include 387 individuals from the six State Centers. Data obtained from the 387 individuals in the State Center sample were not included in the Statewide Report. However, twenty-one individuals living in state centers were included in the statewide sample as part of the random sampling process for all people living in residential settings for the NCI. The data obtained from responses given by these individuals were not included in the State Center report.

The 2005-06 State Centers sample included 198 individuals from the five State Centers (Altoona had closed). Data obtained from the individuals in the State Center sample were not included in the Statewide Report, but were presented in a separate report.

The sample for the FY 2006-07 included 222 individuals from the five State Centers. Data obtained from the individuals in the State Center sample were not included in the Statewide Report. The 2007-2008 State Centers sample included 218 individuals from the five State Centers (Polk, Ebensburg, White Haven, Selinsgrove and Hamburg). A total of 177 interviews were conducted with individuals living in State Centers for FY 2008-2009. For FY 2009-2010, a total of 184 interviews were conducted with individuals living in State Centers. In FY 2010-2011 a total of 183 face-to-face interviews were conducted for individuals in the State Center sample. 178 interviews were conducted with individuals living in State Centers for FY 2011-2012. For FY 2012-

2013, a total of a 172 face-to-face interviews were conducted for individuals in the State Center sample. During FY 2013-2014 two state centers, Selinsgrove and Hamburg, did not have data collected in the method prescribed by the IM4Q program. Therefore, the sample size for FY 2013-2014 (N=117) is lower than prior fiscal years. For FY 2014-2015, a total of a 190 face-to-face interviews were conducted for individuals in the State Center sample. A total of 185 face-to-face interviews were conducted for individuals in the State Center sample for FY 2015-2016. For FY 2016-2017, a total of 149 face-to-face interviews were conducted for individuals in the State Center sample. For FY 2017-2018, a total of 148 face-to-face interviews were conducted for individuals in the four remaining State Centers in the State Center sample, Ebensburg, Polk, Selinsgrove and White Haven, after the closure of Hamburg during the previous fiscal year. For FY 2018-2019, 148 face-to-face interviews were conducted for the State Center sample from the Ebensburg, Polk, Selinsgrove and White Haven centers.

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 FFG Surveys. All potential IM4Q programs were screened by the State IM4Q Steering Committee. Selection criteria included: independence of the projects 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 newly formed entities. At the State Centers, to minimize having multiple local programs on each of the campuses, a

decision was made that all data collection in a center would be completed by the local IM4Q program in the county where that Center was located.

Training

Local IM4Q Programs received training on the EDE, F/F/G Survey and interviewing protocols from the three technical assistants from the Institute on Disabilities at Temple University. Trainings were held in each of the four regions for project staff and data collectors, wherever possible. Additional training was provided on a county-by-county basis for data collectors, as requested. Data entry instruction was provided by the Office of Developmental Programs.

Team Interview Process

Once the sample was drawn, a list of individuals to be monitored was forwarded to the Local Independent Monitoring for Quality Program by ODP. Data collection at the State Centers was done by the local IM4Q program where the State Center is located. As a result, data for residents of the White Haven Center are collected by the Luzerne/Wyoming local IM4Q program, Selinsgrove data are collected by the Columbia/Montour/Snyder/Union (CMSU) local IM4Q program, Ebensburg data are collected by the Cambria County local IM4Q program, Hamburg data are collected by the Berks County local IM4Q program and Polk Center data are collected by the Venango County local IM4Q program. Either the local program or the State Center itself completed the pre-survey forms. Once the pre-survey forms were completed, the local IM4Q Program assigned interviews to 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 also included other interested citizens who are not part of the intellectual disability system. Visits to the living units at the state center where the individuals lived were scheduled with the individual, or with the person designated on the pre-survey form.

Participation in the interview was voluntary; if an individual declined to participate, s/he was replaced in the sample with another individual. The interview was meant to take place at the living area of the individual, but if s/he preferred that the interview take place elsewhere, alternate arrangements were made. The interview was to be conducted in private whenever possible, unless the individual expressed a desire to have others present. Once the interview was completed, if the individual gave his/her permission, a survey was conducted with the family/friend/guardian, either face-to-face (at the time of the interview) or by phone. After the EDE was completed by the IM4Q team, the completed Essential Data Elements forms were returned to the local IM4Q Program and data were entered into the on-line data entry system.

Family/Friend/Guardian (F/F/G) data were collected either by the interview team or by staff of the local IM4Q program. EDE and F/F/G Survey data were entered directly 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 administrative entities (AEs), each local IM4Q Program has developed a process, referred to as “closing the loop”/follow-up activity with the administrative entity/state center to discuss issues related to individuals as well as systemic issues that may be specific to individual AEs/state centers. This process is an integral part of the quality improvement process and in a sense, determines the extent to which this process becomes more than just data collection – rather it creates a process that demonstrates change at the individual level, as well as at the AE and state levels.

RESULTS

This table displays the county of residence of each individual in the state center sample.

	People	Percent
Allegheny	0	0.0%
Armstrong/Indiana	0	0.0%
Beaver	0	0.0%
Bedford/Somerset	0	0.0%
Berks	0	0.0%
Blair	0	0.0%
Bradford/Sullivan	0	0.0%
Bucks	0	0.0%
Butler	0	0.0%
Cambria	36	24.3%
Cameron/Elk	0	0.0%
Carbon/Monroe/Pike	2	1.4%
Centre	0	0.0%
Chester	1	0.7%
Clarion	0	0.0%
Clearfield/Jefferson	0	0.0%
Columbia/Montour/Snyder/Union	45	30.4%
Crawford	0	0.0%
Cumberland/Perry	0	0.0%
Dauphin	0	0.0%
Delaware	1	0.7%
Erie	0	0.0%
Fayette	0	0.0%
Forest/Warren	1	0.7%
Franklin/Fulton	0	0.0%
Greene	0	0.0%
Huntington/Mifflin/Juniata	0	0.0%
Lackawanna/Susquehanna	4	2.7%
Lancaster	0	0.0%
Lawrence	0	0.0%
Lebanon	0	0.0%
Lehigh	0	0.0%
Luzerne/Wyoming	41	27.7%
Lycoming/Clinton	0	0.0%
McKean	0	0.0%
Mercer	0	0.0%
Montgomery	0	0.0%
Northampton	0	0.0%
Northumberland	0	0.0%
Philadelphia	0	0.0%
Potter	0	0.0%
Schuylkill	1	0.7%
Tioga	0	0.0%
Venango	16	10.8%
Washington	0	0.0%
Wayne	0	0.0%
Westmoreland	0	0.0%
York/Adams	0	0.0%
Wayne	0	0.0%
TOTAL	148	100%

The following table displays the state center where each individual in the sample lives.

	People	Percent
Ebensburg	37	25.0%
Polk	17	11.4%
Selinsgrove	47	31.8%
White Haven	47	31.8%
TOTAL	148	100%

Demographic Characteristics of the Sample

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

- Of those who reported gender in the sample (n=147), 58% identified as male and 42% identified as female.
- For those who reported their age (n=147) the mean age in the sample was 62.71 (SD=9.67), with a range of 27 to 87 years.
- Of those who reported on race in the sample (n=142), 95% identified as white, 5% identified as black/African-American, 0% identified as Asian, 0% identified as mixed-race, 0% identified as other, and 0% identified as American Indian/Alaskan Native/Pacific Islander.
- Of those who identified their ethnicity (n=144), less than 1% identified as Hispanic or Latinx.

Satisfaction

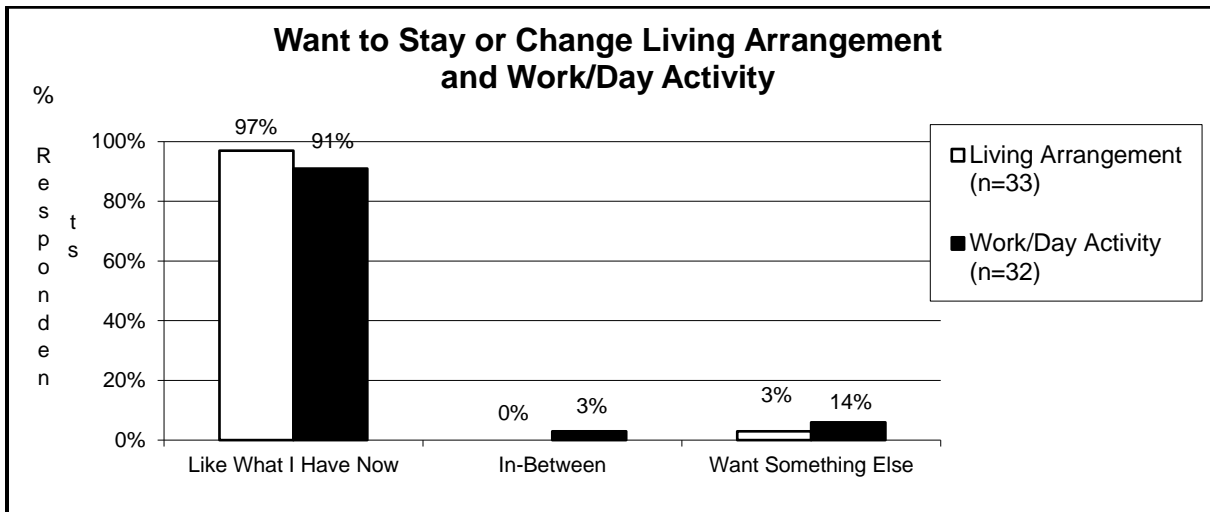
Respondents: Only the individual receiving services/supports could answer the questions on satisfaction. The percent of people who responded to questions in this section ranged from 4 to 26%. These data are consistent with last year's numbers (9% to 24%) and with prior years. Indeed, the response rate, which is slightly lower than the rate of responses in the statewide sample, is fitting considering that the questions in this section are designed to be answered only by the individual. Of the individuals interviewed in state centers, data indicates that nearly three-quarters do not communicate verbally (N=110), of which greater than 60% do not have a formal communication system in place.

Satisfaction with Living Arrangements

- 100% of individuals liked where they live (89% in Statewide Report which covers individuals living in the community, at home with families, on their own or in private ICFs/ID; **91% 2017-2018**).
 - When asked what they don't like about where they live, 100% reported there was no reason because they liked where they live.
- 97% wanted to stay where they currently live (79% Statewide; **90% 2017-2018**), but 3% wanted to move somewhere else (14% Statewide; **7% 2017-2018**).

Satisfaction with Work/Day Activity

- 100% of individuals with a day activity/work liked the primary job/activity that they did during the day (91% Statewide; **92% 2017-2018**). 100% of individuals liked the secondary job/activities they frequently do during the day (94% Statewide; **95% 2017-2018**).
- 91% wanted to continue in their current daytime activities/work (72% Statewide; **89% 2017-2018**), but 6% wanted to do something else (20% Statewide).



Daily Life

- 97% of respondents reported getting the services they needed to be able to live in their home (83% Statewide; **94% 2017-2018**).

- On most weekdays, 8% of individuals report they attend a non-vocational program (21% Statewide; **13% 2017-2018**), 47% attend vocational facility (22% Statewide; **31% 2017-2018**), 8% stay home (17% Statewide; **26% 2017-2018**), 11% work in supported employment (8% Statewide; **18% 2017-2018**), 5% are retired (3% Statewide; **0% 2017-2018**), 3% work with no supports (11% Statewide; **0% 2017-2018**) and 18% do something else (3% Statewide). 0% go out and do things in the community (10% Statewide; **5% 2017-2018**), attend school (4% Statewide; **3% 2017-2018**), or volunteer (2% Statewide).
- In addition to what individuals do on most weekdays, 20% also went out and did things in the community (27% Statewide; **68% 2017-2018**), 25% stayed home (40% Statewide; **4% 2017-2018**), 5% attended school (1% Statewide; **0% 2017-2018**), 5% worked in supported employment (2% Statewide; **8% 2017-2018**), 20% volunteered (9% Statewide; **0% 2017-2018**), 5% are retired (2% Statewide; **0% 2017-2018**), and 20% did something else. 0% reported that they attended a non-vocational facility (3% Statewide; **4% 2017-2018**), attended a vocational facility (3% Statewide; **4% 2017-2018**), or worked without supports (3% Statewide), or attended a senior program (3% Statewide; **4% 2017-2018**).
- 97% of individuals that did not have a paid job in the community reported that they do not want a job (61% Statewide; **90% 2017-2018**); 3% reported they would like to have a job for pay (33% Statewide; **7% 2017-2018**).

Happiness and Loneliness

- 94% of individuals reported feeling happy overall (83% Statewide; **97% 2017-2018**), and 0% reported feeling sad overall (3% Statewide).
- 81% reported never feeling lonely (63% Statewide), 16% reported sometimes feeling lonely (33% Statewide; **20% 2017-2018**).
- 100% reported having friends they like to do things with (88% Statewide; **97% 2017-2018**); for 63% of these people their friends are not staff or family (75% Statewide; **74% 2017-2018**).
- 52% of respondents indicated they have a best friend (69% Statewide).

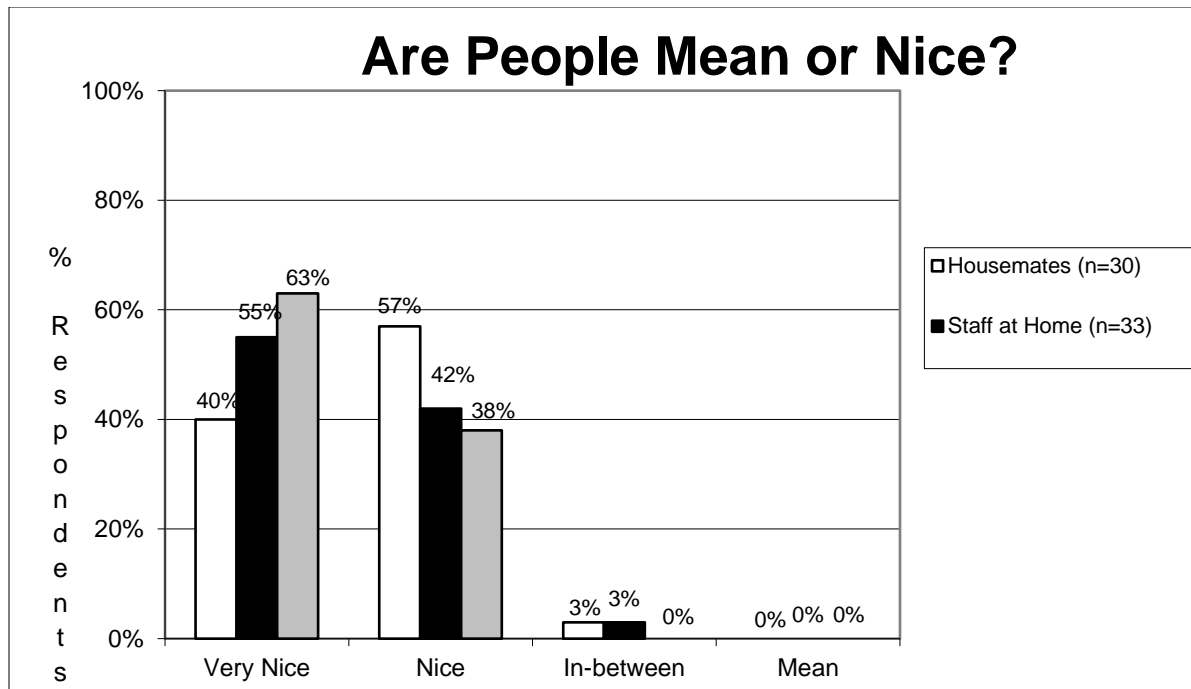
- 50% reported that they can go on a date if they want to or they are married (82% Statewide; **85% 2017-2018**), 17% reported that they can go on a date if they want to but there are some restrictions and rules (6% Statewide; **8% 2017-2018**) and 50% are not allowed to date (12% Statewide; **8% 2017-2018**).

Privacy

- 97% of the individuals surveyed, reported that they have enough privacy (a place to be alone) at home (95% Statewide).
- 90% of individuals reported that they can be alone with friends at home (86% Statewide; **80% 2017-2018**).
- 85% of individuals say there are no rules about having friends and visitors (72% Statewide), while 15% say there are some restrictions such as on visit times, certain friends, or rules about privacy (28% Statewide).
- 86% reported that other people always let them know before coming into their home (88% Statewide; **72% 2017-2018**).
- 93% reported that people let them know before coming into their bedroom (84% Statewide; **97% 2017-2018**).

Are People Nice or Mean?

- 97% of people reported that their housemates are very nice or nice (90% Statewide).
- 100% of people interviewed reported that they get along with the person they share a bedroom with most of the time (76% Statewide).
- 97% of the people interviewed reported that their staff who work with them at home are very nice or nice (94% Statewide; **100% 2017-2018**).
- 100% reported that the staff who work with the respondents at work or day activity are nice or very nice (96% Statewide).



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 equaled 96.05 (Statewide 85.44) with a standard deviation of 9.26 (Statewide 19.63).
- The mode (the value that occurs the most frequently) equaled 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.

- ⇒ It should also be noted that about a quarter of the individuals interviewed responded to this section. The individuals who responded are not necessarily representative of all individuals surveyed.

- ⇒ Comparison between the state centers was not done in this section due to the low response rate.

Dignity, Respect and Rights

Respondents: Only the individual receiving services/supports could answer the questions on dignity, respect and rights. The percent of people who responded to questions in this section ranged from 1% to 23%. This percentage is similar to that of last year's sample (2% to 24%) but continues to be much lower than the 2017-2018 statewide monitoring sample for which 36% to 68% of individuals responded to questions in this section. The low response rate can be attributed to data showing that of individuals in state centers interviewed, nearly three-quarters do not communicate verbally.

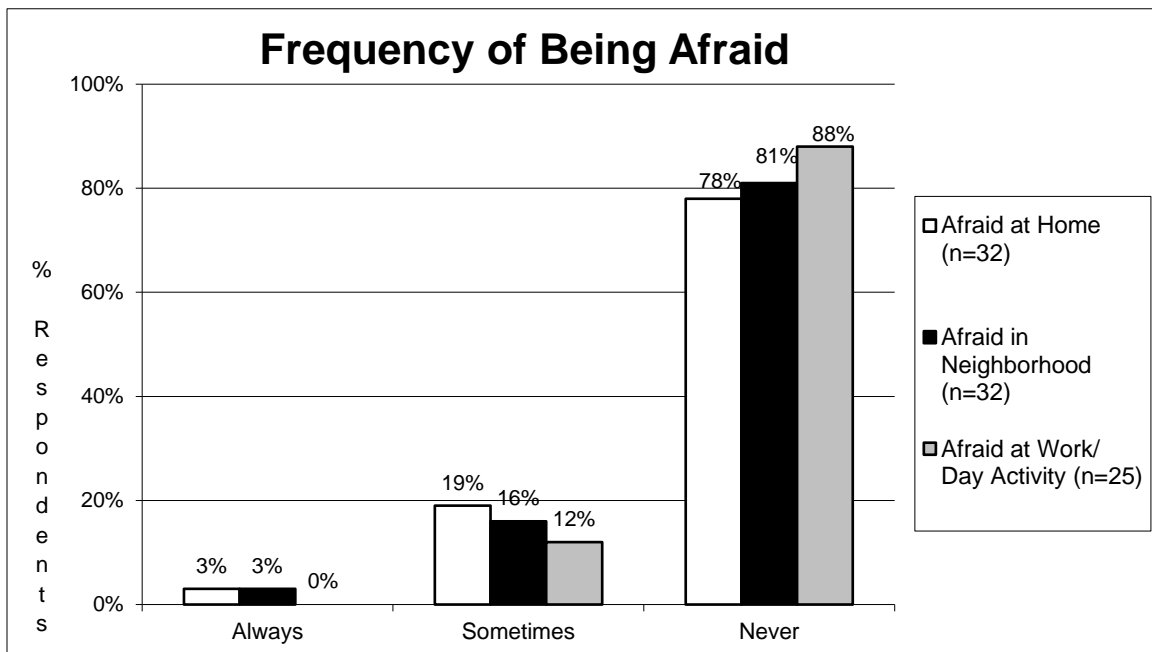
Support with Goals and Problems

- 89% of individuals get help to learn new things (64% Statewide).
- 97% if individuals report that they get to help other people (72% Statewide; **90% 2017-2018**).
- 59% of individuals indicated that they have participated in a self-advocacy group meeting (16% Statewide; **65% 2017-2018**).
- 100% of people said someone had talked to them about self-advocacy (38% Statewide; **79% 2017-2018**).
- 80% of people reported that they go to staff for help when they have a problem (50% Statewide; **40% 2017-2018**), and 8% reported that they go to someone else (11% Statewide; **12% 2017-2018**). 0% of people reported that they go to family (53% Statewide), friends (10% Statewide), or their supports coordinator (11% Statewide). 0% of individuals reported that they have no one to go to for help (1% Statewide).

Being Afraid

- 78% reported never being afraid at home (87% Statewide; **97% 2017-2018**); 19% reported sometimes being afraid at home (11% Statewide; **3% 2017-2018**).

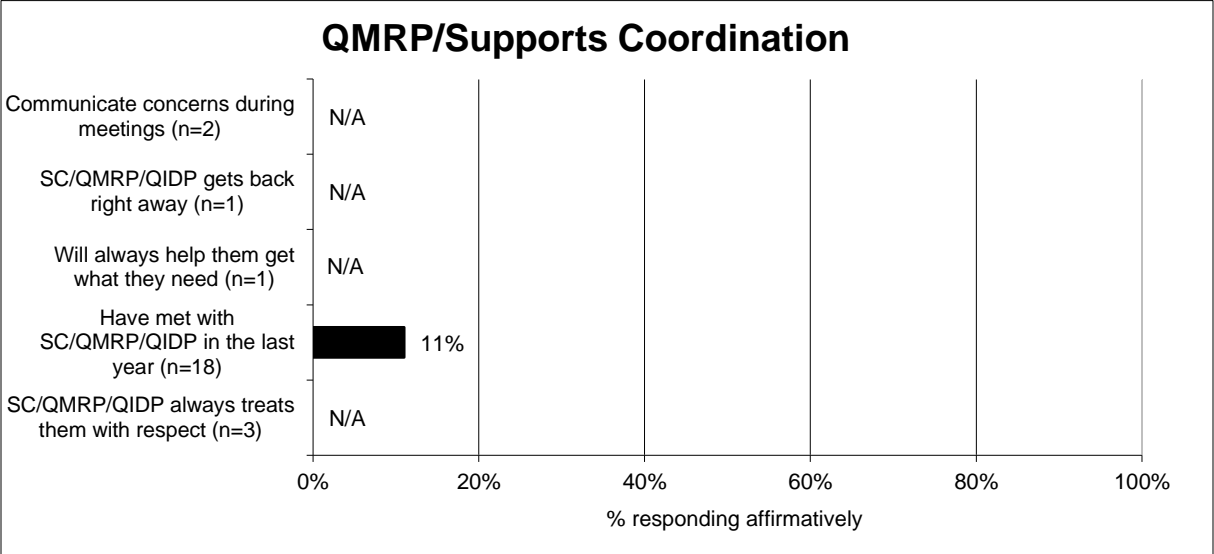
- 81% reported never being afraid in the neighborhood (87% Statewide; **83% 2017-2018**); 16% reported sometimes being afraid in the neighborhood (11% Statewide; **13% 2017-2018**).
- 88% reported never being afraid at work, school or day activity (93% Statewide; **96% 2017-2018**); 12% reported sometimes being afraid at work, school or day activity (6% Statewide).
- 84% reported never being afraid when using transportation (93% Statewide; **89% 2017-2018**); 3% reported always being afraid when using transportation (2% Statewide; **11% 2017-2018**).
- 94% reported that they have someone they can talk to when they feel afraid (94% Statewide; **100% 2017-2018**).



Legal Rights

- For 89% of the individuals interviewed, their mail is never opened without permission (83% Statewide; **96% 2017-2018**); 4% reported their mail is sometimes opened without permission (6% Statewide).

Qualified Intellectual Disability Professional (QIDP)/Supports Coordination



- 11% of respondents (n=18) reported that they have met with their QIDP/supports coordinator in the last year (96% Statewide; **56% 2017-2018**).
- 100% of respondents (n=20) said they took part in their annual planning meeting (96% Statewide); 0% had the option but chose not to take part (2% Statewide).
- 29% of those surveyed (n=14) have been told how much money is in their annual budget (57% Statewide; **57% 2017-2018**).
- 100% of people (n=20) reported that their ISP meeting included the people they wanted to be there (95% Statewide; **70% 2017-2018**).
- 74% of individuals (n=19) indicated that they knew what was being talked about at their ISP meeting (80% Statewide).
- 100% of respondents (n=20) said they talked about learning new things at their planning meeting (73% Statewide).
- 27% of individuals (n=22) reported that they chose the services they get as a part of their service plan (74% Statewide), while 68% had some input (18% Statewide).
- If they want to change something about their services, 97% of individuals (n=18) know whom to ask (81% Statewide), but 3% do not know whom to ask (14% Statewide).

Based on the limited responses to several questions in this section, further analysis could not be completed.

Staff

- 97% of individuals interviewed reported that their staff always treats them with respect (92% Statewide; **90% 2017-2018**).
- 100% of individuals reported that they feel their staff has the right training to meet their needs (95% Statewide).
- 97% of individuals feel that all of their staff understand their communication (86% Statewide; **59% 2017-2018**); 0% say only some staff understand them (8% Statewide; **34% 2017-2018**), 3% feel they are understood sometimes (4% Statewide; **6% 2017-2018**), and 0% do not feel that their staff understand their communication (1% Statewide).

Emergency Preparation Questions

- 100% of individuals reported have had someone talk to them about what to do in an emergency (81% Statewide).
- When asked who gave the individual information about what to do in an emergency, 89% of respondents said they got information from home staff (36% Statewide), 11% from day or employment staff (34% Statewide; **33% 2017-2018**), 4% from someone in their family (44% Statewide), 4% from police or EMS workers (4% Statewide), 0% received information about emergency preparation from friends (2% Statewide), the Red Cross (1% Statewide), their Supports Coordinator (12% Statewide) or someone else (11% Statewide). ***It is important to note that in state centers the Qualified Intellectual Disabilities Professional (QIDP) is an employee of the state center, which could affect the results in this section.***

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 (people being nice to you).

- The average score was 86.49 (Statewide 84.15) with a standard deviation of 11.60 (Statewide 14.75).
- The modal score was 75.

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 89.14 (Statewide 92.86) with a standard deviation of 22.49 (Statewide 15.77).
- The mode was 100.
- The average on this scale is very high indicating that individuals receiving supports and services do not report high amounts of fear. The mode of 100 indicates that many individuals (87%) reported that they never feel afraid in their home, neighborhood or work/day activity site.
- One caveat to this finding is the low response rate; less than a quarter of those individuals interviewed responded to this section of the survey, and some questions received responses from as few as 1% of those surveyed.

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,

- 1% of the questions were answered by the individual receiving supports.
- 82% of the questions were answered by paid staff.
- 14% of the questions were answered by the individual and staff.
- 2% of the questions were answered by staff and family.
- 1% of the questions were answered by family/friend/advocate/guardian.
- A value of missing was assigned when individuals did not answer, gave an unclear answer, or responded, “Do not know.”

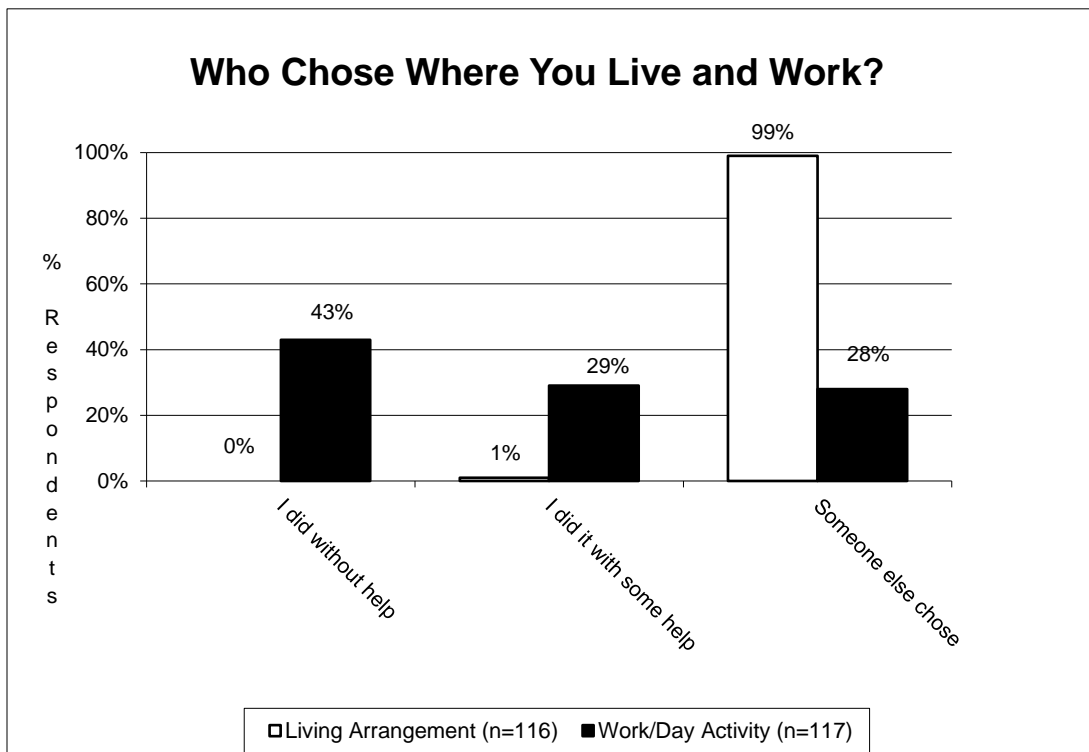
Forms of Identification

- 18% of individuals stated that they always carry a form of identification (61% Statewide; **51% 2017-2018**); 40% never do (23% Statewide; **20% 2017-2018**).

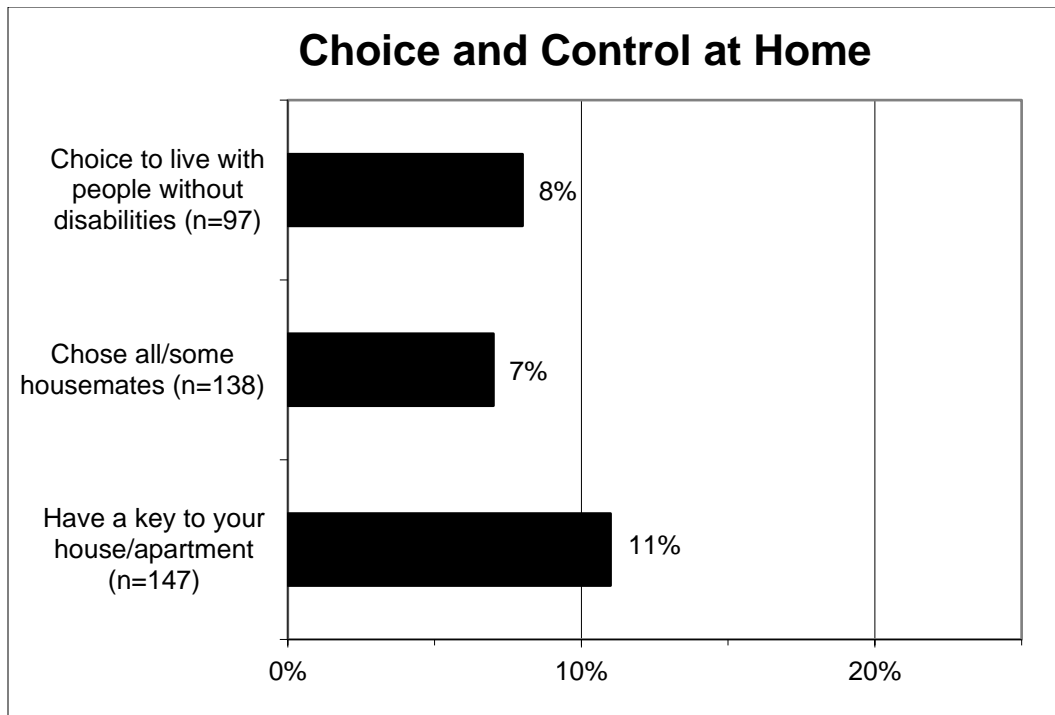
Choice and Control at Home

- 11% of the individuals surveyed had a key to their home or living area. (49% Statewide; 0% Ebensburg, 0% Polk, 13% Selinsgrove, 21% White Haven; **3% 2017-2018**).
- 92% of respondents said that if other members of their house go out, they have the option to stay home; 3% sometimes have the option to stay home. (58% Statewide).
- 11% of respondents can lock their bedroom door if they want to. (44% Statewide).
- 0% of individuals reported that they own their own home (3% Statewide).
- 0% of individuals report that their name is on the lease or rental agreement (25% Statewide).

- For 99% of the individuals, someone else chose where they live (42% Statewide); 0% of those interviewed chose without assistance (30% Statewide).
- 8% of individuals said they were given a choice to live where people without disabilities live (54% Statewide; **20% 2017-2018**).
- 51% of individuals surveyed saw no other places before they moved into their residence (50% Statewide; **61% 2017-2018**).



- 94% of the individuals **did not** choose their housemates (60% Statewide; **96% 2017-2018**).
- For those who shared a bedroom, 16% chose some or all of their roommates (37% Statewide; **19% 2017-2018**).



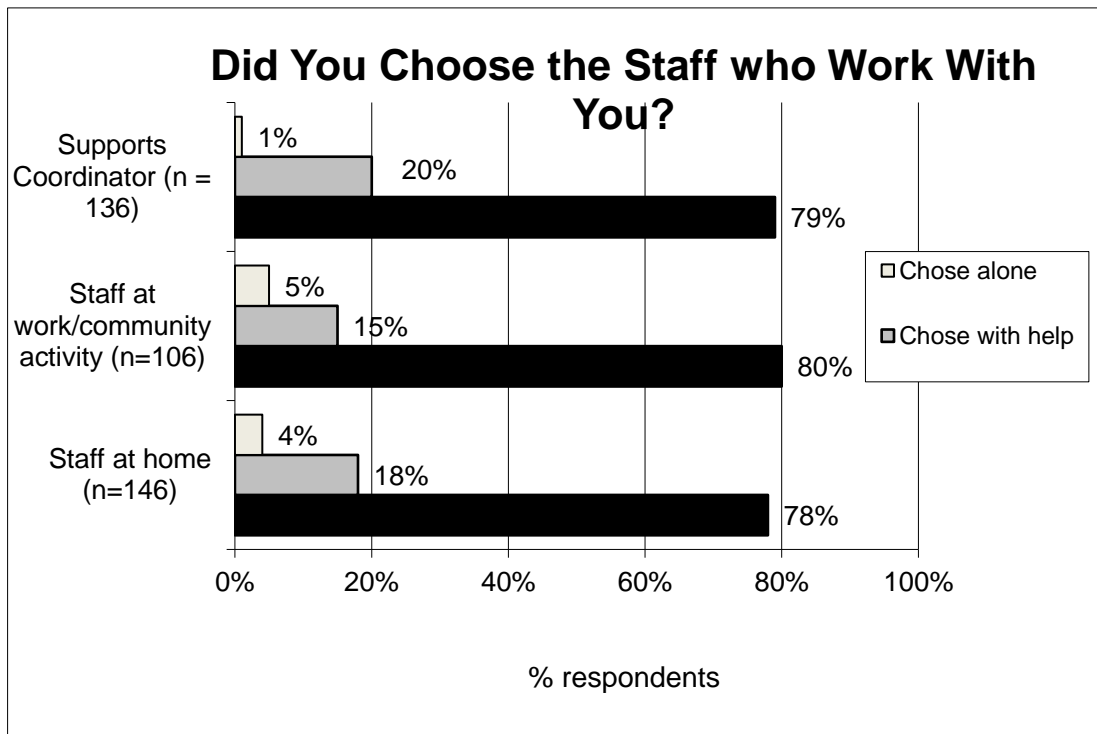
Choice and Control During the Day and for Leisure Time

- 28% of the individuals interviewed reported that someone else chose what they do during the day (24% Statewide; 68% Ebensburg, 14% Polk, 6% Selinsgrove, 16% White Haven; **15% 2017-2018**).
- 43% of the people interviewed chose what they do during the day without assistance (45% Statewide; 0% Ebensburg, 36% Polk, 62% Selinsgrove, 84% White Haven).
- 16% of individuals reported that when they chose their work or day activity they had an option to go where people without disabilities go (57% Statewide; **10% 2017-2018**).
- For those individuals who participated in choosing what they do during the day, 74% saw no other places (41% Statewide; **56% 2017-2018**).
- 80% of the individuals surveyed report that they choose their daily schedules without assistance (89% Statewide; 83% Ebensburg, 43% Polk, 83% Selinsgrove, 87% White Haven; **32% 2017-2018**).

- 80% choose how they spend their free time without assistance (93% Statewide; 75% Ebensburg, 71% Polk, 98% Selinsgrove, 94% White Haven; **57% 2017-2018**).
- 88% of the individuals surveyed say they have enough choice about what they do in their free time (93% Statewide).

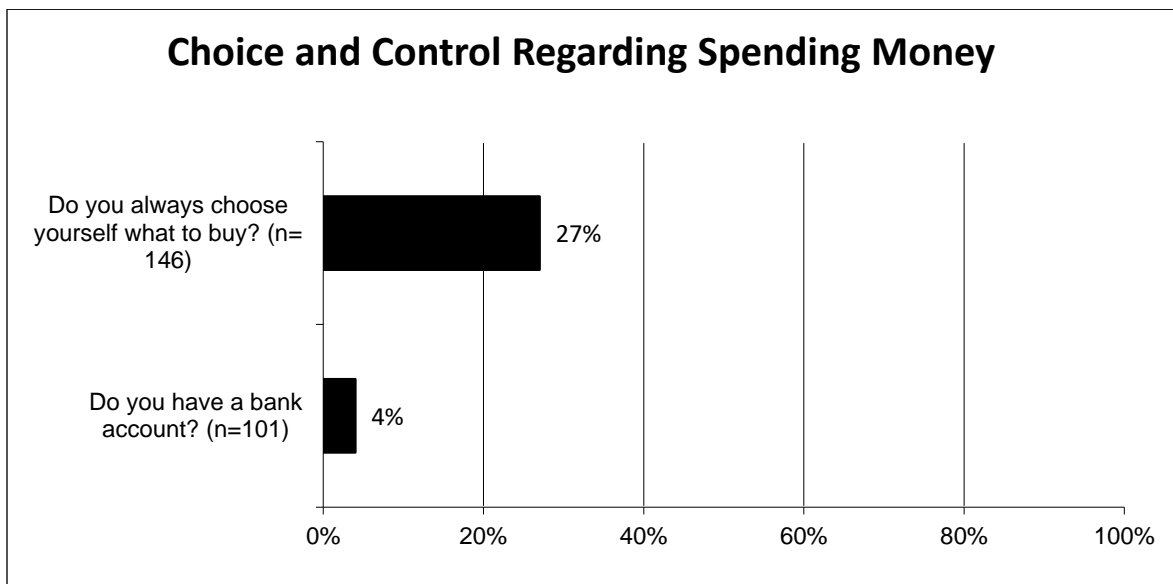
Choice and Control in Choosing Staff

- 22% of the individuals interviewed/chose at least some of the staff who help them at home (alone or with assistance from family or provider); (44% Statewide; 6% Ebensburg, 6% Polk, 62% Selinsgrove, 0% White Haven; **38% 2017-2018**).
- 20% of the individuals surveyed chose (alone or with assistance) at least some of the staff that help them at work/community activity (36% Statewide, 20% Ebensburg, 0% Polk, 30% Selinsgrove, 0% White Haven; **27% 2017-2018**).
- 21% of the individuals reported that they chose their QIDP/supports coordinator (alone or with assistance from family or provider) (33% Statewide; 3% Ebensburg, 0% Polk, 65% Selinsgrove, 0% White Haven; **17% 2017-2018**).



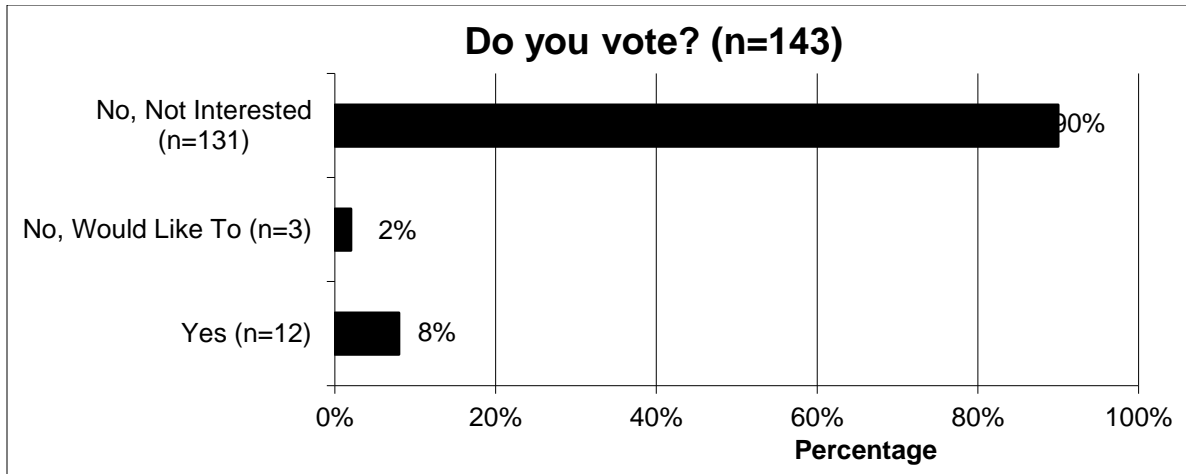
Choice and Control with Regard to Money

- 27% of the individuals reported that they always choose alone what to buy with their spending money. (65% Statewide; 11% Ebensburg, 20% Polk, 28% Selinsgrove, 43% White Haven; **35% 2017-2018**).
- 28% of the individuals reported that there is something they want to buy (40% Statewide; **32% 2017-2018**).
- 4% of the individuals reported they have a bank account that they can get to independently to withdraw money when they want it (63% Statewide; 0% Ebensburg, 0% Polk, 14% Selinsgrove, 0% White Haven; **22% 2017-2018**).



Voting

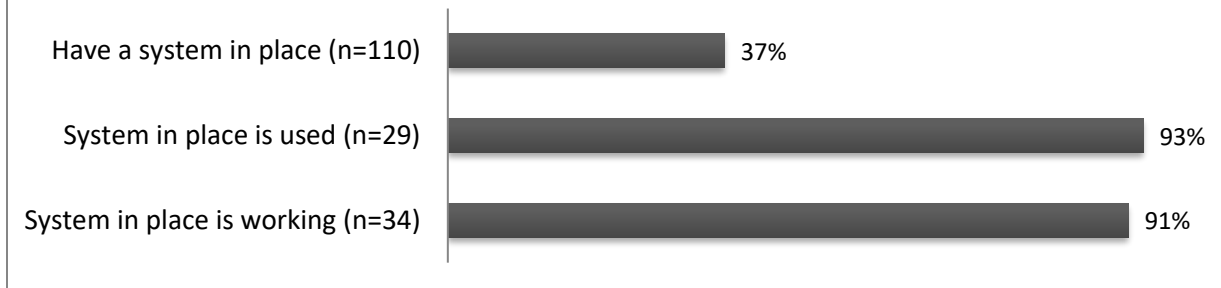
- 8% of people said they vote (34% Statewide); and 90% of people said they do not vote and are not interested in voting (59% Statewide). 2% said they do not vote but would like to (6% Statewide).



Access to Communication

- For those individuals who do not communicate using words, there is a formal communication system in place for 37% of the people interviewed (27% Statewide; **28% 2017-2018**).
- For those people with formal communication systems in place, the systems are in working order for 91% of respondents (90% Statewide; **71% 2017-2018**); if the communication system was in place and working, it was used regularly for 93% of the people interviewed (86% Statewide; **100% 2017-2018**).
- 58% of individuals with a formal communication system reported using it across all settings (73% Statewide; **29% 2017-2018**).
- 89% of individuals with a formal communication system are supported by staff or a program coordinator (58% Statewide; **21% 2017-2018**), 23% are supported by their speech language clinician (30% Statewide; **89% 2017-2018**), and 0% are supported by a parent or caregiver (44% Statewide) or someone else (11% Statewide).

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



Other Forms of Communication:

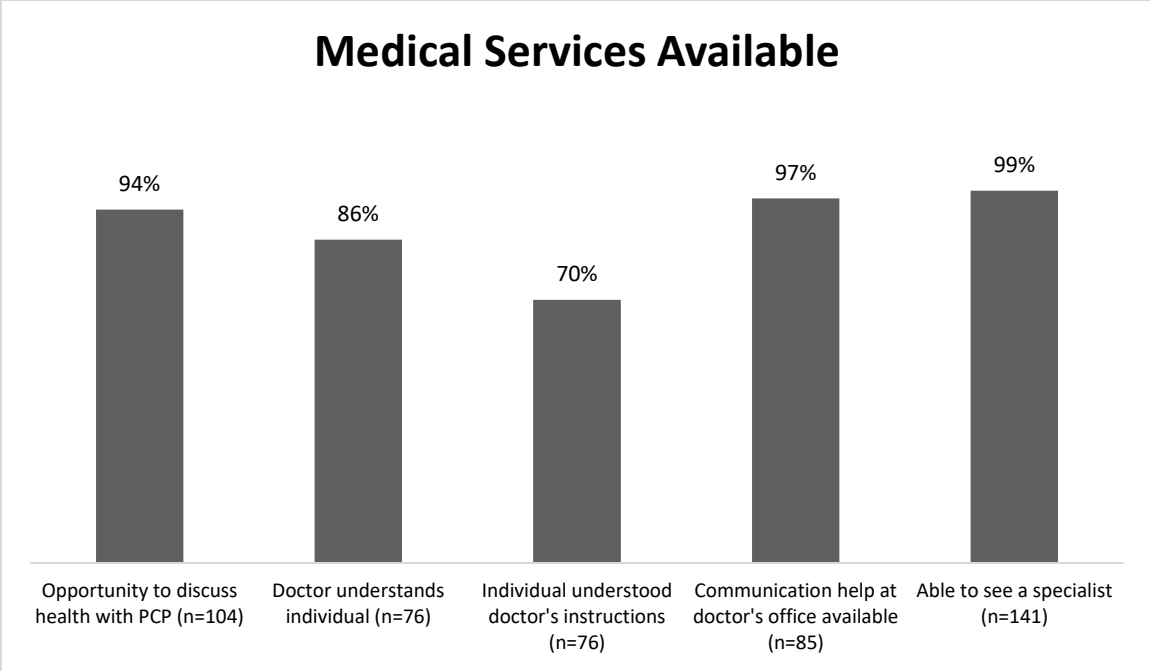
- 0% have and use a cell phone (34% Statewide).
- 0% have and use e-mail (16% Statewide).
- 1% have and use Internet (30% Statewide); there are restrictions for 100% of those people (10% Statewide).
- 0% have and use text-messaging (22% Statewide).
- 93% have and use cable television (78% Statewide; **96% 2017-2018**); there are restrictions for 0% of these people (5% Statewide).
- 6% have and use a computer (37% Statewide); there are restrictions for 11% of these people (9% Statewide; **0% 2017-2018**).

Health Care Questions

- When asked how many times per month they exercise at home, 41% of individuals said zero (54% Statewide; **36% 2017-2018**), and 56% said 10 or more times a month (31% Statewide).
- 94% of individuals interviewed reported that they have the opportunity to discuss health with their primary care provider (PCP) (93% Statewide; **83% 2017-2018**).
- 86% of individuals reported that they feel their doctor understands them (91% Statewide; **73% 2017-2018**).
- 67% of individuals feel that they understood their doctors' instructions (84% Statewide; **70% 2017-2018**).

- 97% of respondents say if they needed help communicating at the doctor's office, it was available (94% Statewide; **46% 2017-2018**).
- 99% of respondents reported they were able to see if a medical specialist if they needed to (94% Statewide; **57% 2017-2018**); 0% said they were not able to see a specialist due to barriers (8% Statewide; **44% 2017-2018**).
- 98% of individuals say they have not been prevented from receiving medical and dental services because of their disability (92% Statewide).
- When asked how hard it is to get health care services in their community, 97% of individuals reported that it was very easy or pretty easy (92% Statewide; **100% 2017-2018**).
- When asked how hard it is to get dental services in their community, 97% of individuals reported that it was very easy or easy (86% Statewide; **100% 2017-2018**).
- Of those who have a psychiatrist, 85% of individuals interviewed reported that they have the opportunity to discuss health concerns with a psychiatrist (57% Statewide; **91% 2017-2018**); 12% reported they do not have the opportunity to discuss their health concerns with a psychiatrist (3% Statewide; **9% 2017-2018**).
- 97% of individuals reported that their doctor speaks directly to them during appointments (93% Statewide; **75% 2017-2018**).
- 17% of individuals reported that they are able to provide consent for medical treatment (65% Statewide; **46% 2017-2018**); of those able to provide consent, 90% said their doctor accepts their consent (88% Statewide) and 10% say their consent is not accepted (12% Statewide).

Note: The number of respondents in this section changed drastically this year, affecting the results. This is due, in part, to a shift of the health care questions to the choice and control section of the questionnaire. This means questions could be answered by the individual receiving supports, or by a family member, friend or staff person.



Choice and Control Scale: The scale included eight measures that asked 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 equaled 37.14 (Statewide 58.50; **2017-2018 33.96**) with a standard deviation of 15.70 (Statewide 21.57). The modal score was 47.37, indicating the most frequent score.

Employment

Respondents: Of the 139 individuals who responded to questions about employment, 2.1% (n=3) answered that they are employed in a community integrated setting (Statewide 12%). 0.7% (n=1) reported being self-employed. 97% (n=135) of individuals reported that they do not work.

Supports Getting Into the Workplace

- 1% of individuals take classes or training to help you get a job in the community, get a better job, or do better at their current job (10% Statewide).

- 35% of individuals surveyed reported that someone had talked to them about employment in their planning meeting (57% Statewide).
- 2% of individuals report that community employment is a goal in their plan (32% Statewide).
- When individuals were asked who had talked to them about employment, 66% said no one (44% Statewide), 4% said their supports coordinator (51% Statewide), 31% said their service provider (10% Statewide), 0% said their family (11% Statewide), 0% said their housemates (less than 1% Statewide), and 7% said someone else (6% Statewide).

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

Based on the limited number of individuals employed in an integrated setting, further analysis of the employment data was not completed.

Self-Directed Supports

Respondents: Of the 134 individuals surveyed who responded to questions about self-directed supports, 0 people indicated they use self-directed supports.

Based on the absence of data on individuals using self-directed services in this sample, further analysis of this section could not be completed.

Relationships

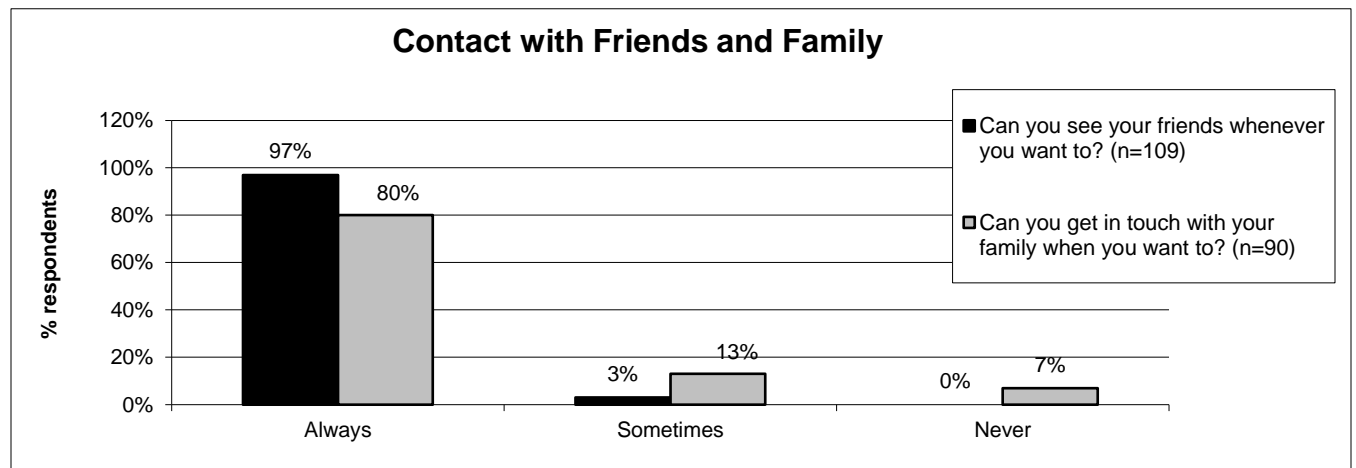
Respondents: The questions on relationships could be answered by the individual receiving services/supports, a family member, a friend, or paid staff.

- 3% of the questions were answered by individuals receiving supports.
- 85% were answered by paid staff.
- 9% were answered by individuals receiving support and staff.
- 2% of the questions were answered by staff and family.
- 1% were answered by family/friend/guardian/advocate.

- 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

- 97% of individuals were always able to see friends whenever they wanted (86% Statewide).
- Of individuals that reported that they were unable to see their friends whenever they wanted (n=2), 50% reported that it was difficult to find the time (25% Statewide), and 50% reported there is another reason that prevents them from seeing their friends (36% Statewide). 0% said they could not see friends because of a transportation issue (25% Statewide), a lack of staff (5% Statewide), rules/restrictions (7% Statewide), or money/cost (2% Statewide).
- 80% of individuals were always able to get in touch with family (84% Statewide; **74% 2017-2018**).



Inclusion

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

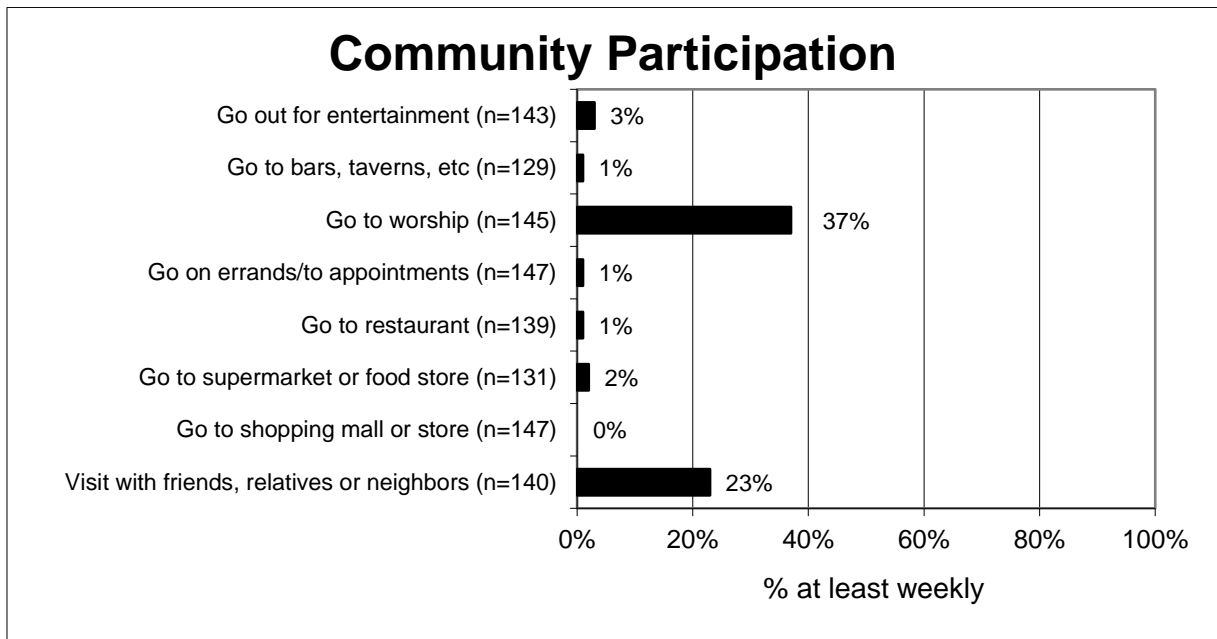
- 2% of the questions were answered by individuals receiving supports.
- 85% were answered by paid staff.
- 12% were answered by individuals receiving support and staff.
- 1% were answered by family/friend/guardian/advocate.
- 1% of the questions were answered by staff and family.
- A value of missing was assigned when individuals did not answer, gave an unclear answer, or responded, “do not know.”

Community Participation

- 23% of the people visited with friends, relatives and neighbors at least weekly (51% Statewide; 14% Ebensburg, 12% Polk, 59% Selinsgrove, 4% White Haven; **15% 2017-2018**).
 - When they visited friends, relatives and neighbors, individuals reported they went alone 9% of the time, with family 14% of the time, with staff 31% of the time, with friends 19% of the time, and with housemates or coworkers 26% of the time, and with someone else 1% of the time.
 - 92% of respondents thought this was enough time to visit friends; 7% wanted more time visiting friends and 2% wanted less.
- 2% of those surveyed went to a supermarket at least weekly (51% Statewide; 0% Ebensburg, 0% Polk, 3% Selinsgrove, 4% White Haven).
 - When they went to the supermarket, individuals reported they went with family 2% of the time, with staff 84% of the time, with housemates or coworkers 14% of the time, and with friends or someone else 0% of the time.
 - 97% of respondents thought this was enough time to go to the supermarket; 3% wanted to go more often.

- 1% of respondents went to restaurants at least weekly (51% Statewide; 3% Ebensburg, 6% Polk, 0% Selinsgrove, 0% White Haven; **11% 2017-2018**).
 - When they went to a restaurant, individuals reported they went with family 2% of the time, with staff 66% of the time, and with housemates or coworkers 32% of the time.
 - 94% of respondents said they went out to eat enough; 5% wanted to go out to eat more often and 1% wanted to go less.
- 0% of individuals went to a shopping center or mall at least weekly (44% Statewide; 0% Ebensburg, 0% Polk, 0% Selinsgrove, 0% White Haven; **5% 2017-2018**).
 - When they went to a shopping center or mall, individuals reported they went with family 1% of the time, with staff 72% of the time, with friends 0% of the time, and with housemates or coworkers 27% of the time.
 - 95% of respondents said they went to shopping malls enough; 4% wanted to go more often and 1% wanted to go less.
- 37% of respondents went to places of worship at least weekly (31% Statewide; 14% Ebensburg, 0% Polk, 69% Selinsgrove, 34% White Haven; **26% 2017-2018**).
 - When they went to a place of worship, individuals reported they went alone 4% of the time, with family 1% of the time, with staff 74% of the time, with friends 1% of the time, and with housemates or coworkers 20% of the time.
 - 99% of respondents thought this was enough time to worship; 1% wanted more.
- 1% of those surveyed went out on errands or appointments at least weekly (29% Statewide; 0% Ebensburg, 0% Polk, 0% Selinsgrove, 2% White Haven).
 - When they went on errands or appointments, individuals reported they went with staff 100% of the time (41% Statewide).
 - 98% of respondents said they went to errands and appointments just enough; 1% wanted to go more often and 1% wanted to go less.

- 1% of individuals go to a night club, coffee house, or tavern to meet people at least weekly (19% Statewide; 0% Ebensburg, 0% Polk, 3% Selinsgrove, 0% White Haven).
 - When they went to a night club, coffee house or tavern, individuals reported they went with staff 53% of the time, with friends 4% of the time, and with housemates or coworkers 44% of the time.
 - 97% of respondents said they went to a night club, coffee house or tavern often enough; 3% wanted to go more often and 1% wanted to go less.
- 3% of those surveyed went out for entertainment at least weekly (27% Statewide; 0% Ebensburg, 6% Polk, 7% Selinsgrove, 0% White Haven).
 - When they went out for entertainment, individuals reported they went with staff 71% of the time, with family 2% of the time, and with housemates and coworkers 28% of the time.
 - 98% of respondents said they went to errands and appointments just enough; 1% wanted to go more often and 1% wanted to go 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 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.
- People in State Centers are significantly less likely to visit with friends, relatives, and neighbors or go to a restaurant than people in the Statewide monitoring sample or people in the Harris Poll.

Weekly Participation in Community Activities

	Harris 2010: People without Disabilities	Harris 2010: People with Disabilities	Pennsylvania: 2018-2019 Monitoring Sample	Pennsylvania: 2018-2019 State Centers Sample
Visit with friends, relatives and neighbors	65%	54%	51%	23%
Go to a restaurant	41%	20%	51%	1%
Go to worship	28%	24%	31%	37%

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 8 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, going to the bank, and going on errands.

- The mean was 26.58 (45.61 Statewide) with a standard deviation of 15.21 (Statewide 17.52).
- The mode or most frequent score was 14.29 (50.00 Statewide; **16.67 2017-2018**), far less than half of the total possible score for the scale.
- It remains consistently the case that, according to the data, few individuals in this sample have the opportunity to engage in community activities despite ongoing initiatives at the State Centers to address community participation and inclusion.

Community Activities

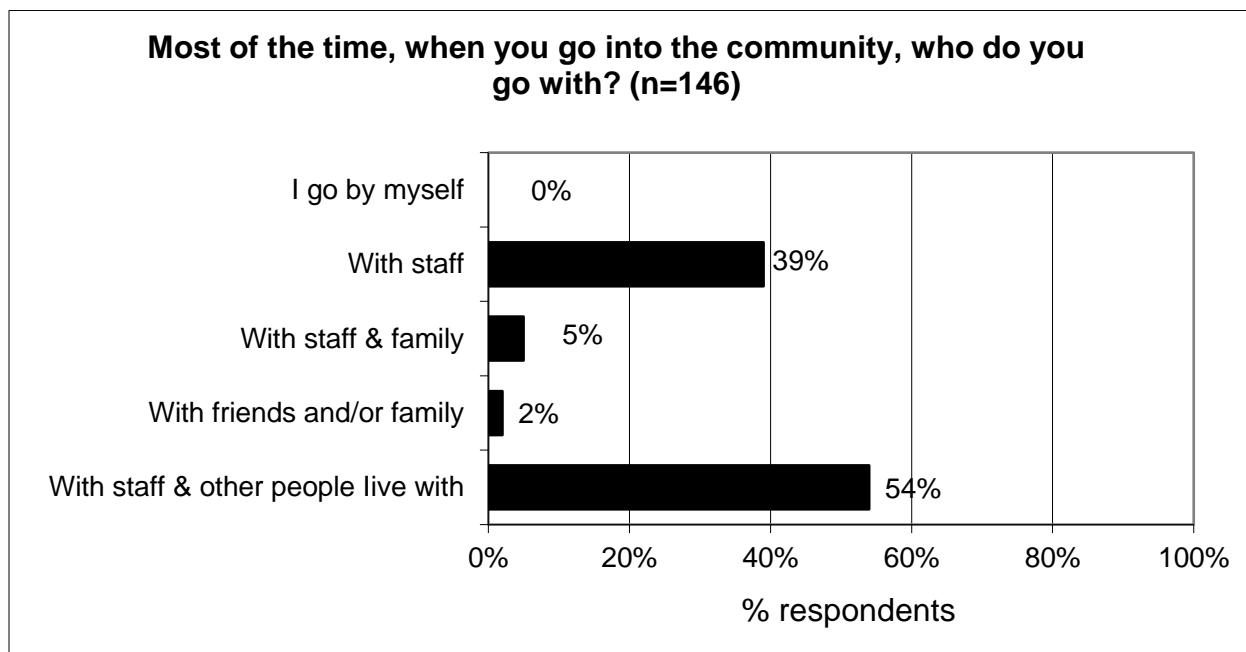
We asked individuals about several other types of community activities including attending social events and recreational events.

- 59% of individuals go into the community for entertainment frequently (55% Statewide; 49% Ebensburg, 6% Polk, 52% Selinsgrove, 92% White Haven; **62% 2017-2018**).

- 48% of individuals reported that they frequently go to social events that are attended by anyone in the community (42% Statewide; 14% Ebensburg, 6% Polk, 46% Selinsgrove, 92% White Haven; **29% 2017-2018**) and 48% go occasionally (32% Statewide; 78% Ebensburg, 88% Polk, 54% Selinsgrove, 4% White Haven; **65% 2017-2018**).
- 5% of individuals would like to be a part of more groups in their community (31% Statewide).
- 20% of individuals went on a vacation in the past year. (48% Statewide; 0% Ebensburg, 0% Polk, 17% Selinsgrove, 45% White Haven; **27% 2017-2018**).
- Regarding monthly exercise, 77% of individuals reported never going out for exercise (39% Statewide; **49% 2017-2018**), 2% exercise less than weekly (4% Statewide), 2% exercise once a week (11% Statewide) and 20% exercise more than once a week (46% Statewide; **36% 2017-2018**).

Going Out Alone or With Other People

- 0% of individuals reported that they go out alone (8% Statewide).
- 54% of individuals go out with staff and other people they live with most of the time (34% Statewide; **48% 2017-2018**).



Transportation

- 91% of individuals always or almost always had a way to get where they wanted to go (90% Statewide).
- In order to get to places they needed to go, the majority of individuals reported getting a ride from staff in the provider van (97%; 32% Statewide). 2% ride paratransit (4% Statewide) and 1% reported getting a ride in a staff member's car (12% Statewide). No one reported getting a ride from family or friends (40% Statewide), transporting themselves (7% Statewide), riding public transportation (5% Statewide), or taking a taxi, Uber or Lyft (<1% Statewide).
- Of those who cannot always get where they want to go, 54% cannot get there due to there not being enough staff (16% Statewide; **44% 2017-2018**) and 46% say there is another reason they can't get where they want to go (65% Statewide).

Home Adaptive Equipment

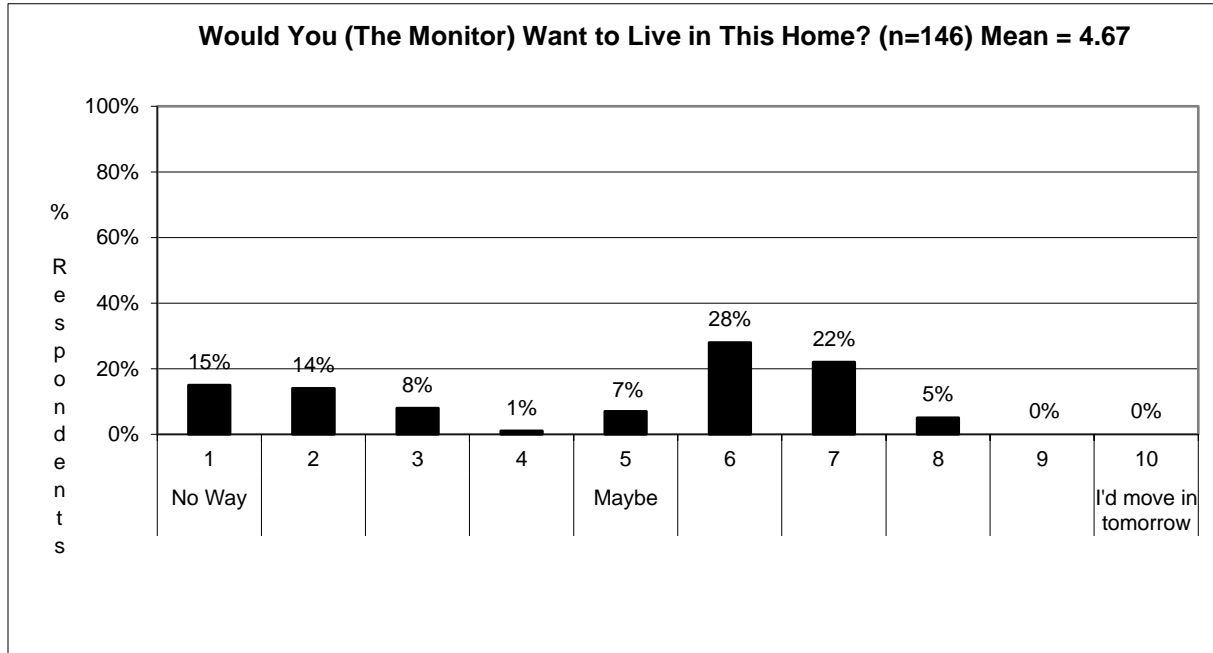
- 89% of individuals have all the adaptive equipment they needed (85% Statewide; **94% 2017-2018**).
- 99% of respondents reported that all necessary modifications have been made to their home to make it accessible (92% Statewide).

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 4.67 (Statewide 6.58).



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 98% of observed cases (92% Statewide).
- 99% of staff observed recognized the individuals in ways that promote independence (91% Statewide).
- 99% of staff observed that support individuals at home and/or work appeared to have the skills they needed to support the person (91% Statewide).

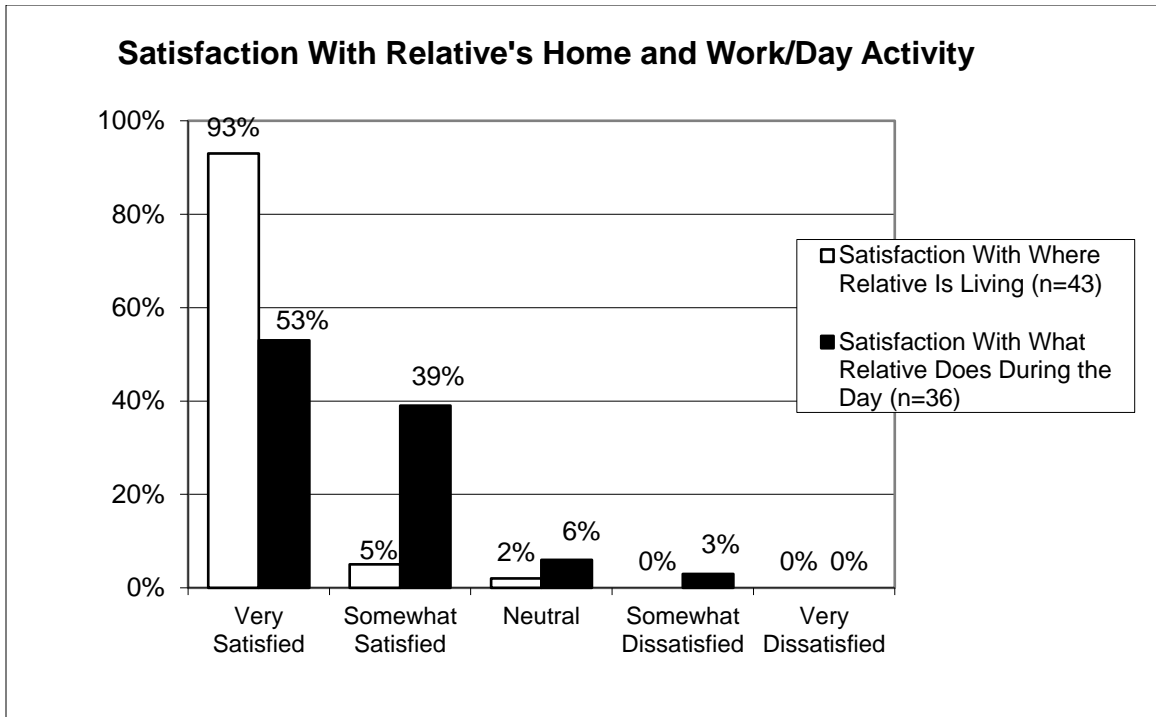
Family/Friend/Guardian Survey

Respondents: This survey was completed by telephone with a family member, guardian, or friend who was identified through the Essential Data Elements Pre-Survey. In the event that a phone survey could not be completed, surveys were completed by mail. Thirty percent of the individuals (n=44) had a family/friend/guardian that responded to this portion of the survey.

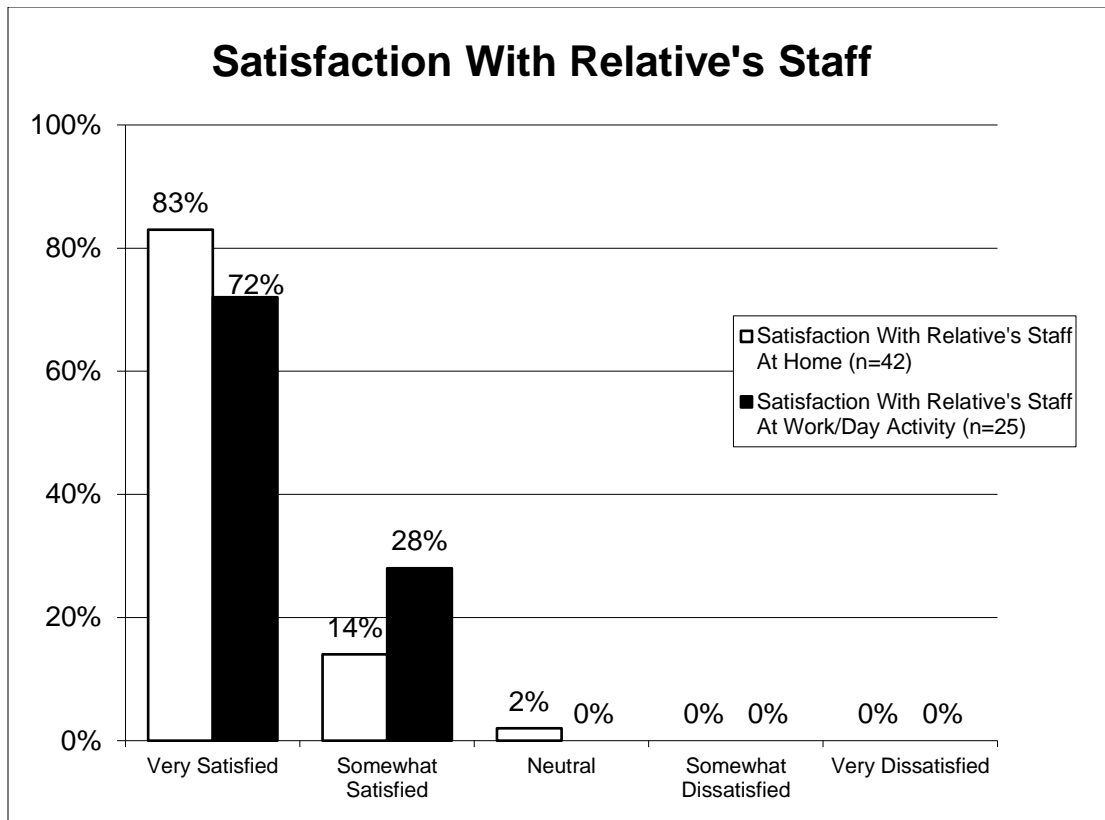
- 25% of the surveys were answered by parents.
- 57% were answered by siblings.
- 9% were answered by another relative.
- 5% were answered by a guardian.
- 5% were answered by persons with other relationships to the individual receiving supports.

Satisfaction

- 98% of the families surveyed, were either somewhat satisfied or very satisfied with where their relative lives (95% Statewide; **100% 2017-2018**).
- 92% were either somewhat satisfied or very satisfied with what their relative does during the day (89% Statewide; **94% 2017-2018**).



- 98% of the families surveyed were either somewhat satisfied or very satisfied with their relatives' staff at home (95% Statewide; **100% 2017-2018**).
- 100% of the families surveyed were either somewhat satisfied or very satisfied with the staff at their relatives' day activity (96% Statewide; **94% 2017-2018**).



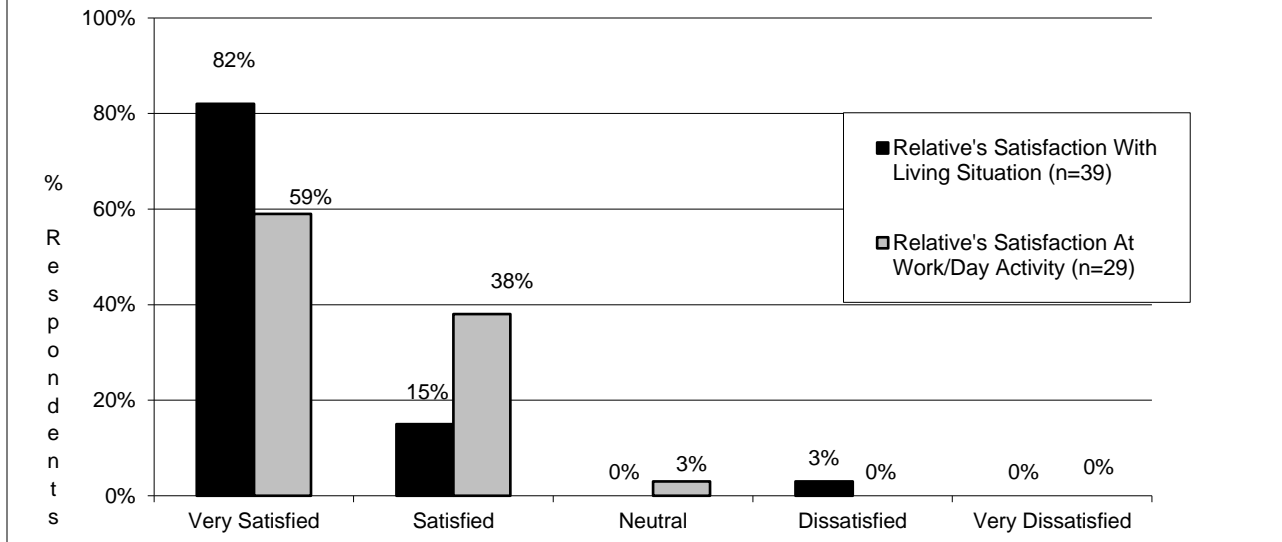
How Often Do You Contact/See Your Relative?

- 58% of the family/friend/guardians contacted their relative at least monthly (87% Statewide; **47% 2017-2018**); 25% have not contacted their relative in the past year (5% Statewide; **12% 2017-2018**).
- 37% 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 (81% Statewide); 11% did not get to see their relative in the past year (3% Statewide; **5% 2017-2018**).

Your Relative's Satisfaction

- 97% of respondents felt their relative was either very satisfied or satisfied with his/her living situation (95% Statewide); 97% felt their relative was either very satisfied or satisfied with what they do during the day (91% Statewide; **94% 2017-2018**).

Relative's Satisfaction At Home and At Work



- 98% of respondents felt their relative was either very satisfied or satisfied with the staff who support them at home (95% Statewide).
- 100% of respondents felt their relative was either very satisfied or satisfied with the staff who support them at work (or during the day) (96% Statewide; **94% 2017-2018**).

Your Relative's Safety

- 90% of respondents said they think their relative felt safe in their community/home/neighborhood always (86% Statewide; **86% 2017-2018**) while 5% said their relative felt safe most of the time (12% Statewide; **13% 2017-2018**).

Your Relative's Opportunities

- 100% of the respondents said that their relative got enough opportunities to participate in activities outside the home (85% Statewide; **98% 2017-2018**).
- 87% of the respondents said that their relative seemed to have the opportunity to learn new things (86% Statewide; **92% 2017-2018**).

Your Relative's Staff

- 95% of the respondents said that their relative's home appeared to have an adequate number of paid staff (85% Statewide; **89% 2017-2018**).

- 100% of the respondents said that staff in their relative's home always treats people with dignity and respect (96% Statewide; **98% 2017-2018**).
- 95% of the respondents said that all staff in the relative's home appear to have the skills they need to support their relative (89% Statewide; **91% 2017-2018**); 5% felt that way about only some staff (9% Statewide; **9% 2017-2018**).
- 100% of the respondents said that their relative's place of work appears to have an adequate number of paid staff (95% Statewide; **96% 2017-2018**).
- 95% of respondents said that staff in their relative's place of work always treat people with dignity and respect (97% Statewide; **100% 2017-2018**).
- 90% of respondents reported that staff in their relative's place of work appear to have the skills they need to support their relative (91% Statewide; **97% 2017-2018**).
- If their relative did not communicate verbally, 50% of the respondents said that there is a formal communication system in place for their relative and they use it (36% Statewide; **32% 2017-2018**). For 67%, the communication system is used across all settings (78% Statewide; **75% 2017-2018**).

Relative's Supports

- 75% of relatives were satisfied with the QIDP/supports coordination their relative receives (84% Statewide; **92% 2017-2018**).
- 43% of relatives reported that they were always told how much money is in their relative's annual budget (63% Statewide; **46% 2017-2018**).
- 0% of relatives report that their relative self-directs their own services (8% Statewide).
- 93% said that their relative always received the supports they needed (69% Statewide).
- 97% said that the services and supports their relative receives change when their relative's needs change (85% Statewide).
- 92% of relatives always felt that the staff who assisted them with planning respected their choices and opinions (91% Statewide; **100% 2017-2018**).

- 33% of relatives never felt that there were frequent changes in support staff at their family member's home, work or day program (57% Statewide; **49% 2017-2018**); 10% felt that there were always frequent changes (13% Statewide; **15% 2017-2018**).
- 88% of relatives always got to choose the agency/provider who worked with their relative (42% Statewide; **56% 2017-2018**); 0% said their relative chose (6% Statewide); 0% chose with their relative (20% Statewide), 13% said someone else chose (32% Statewide; **42% 2017-2018**).
- 60% of relatives were familiar with the way complaints and grievances are handled at the provider level (59% Statewide), 41% of relatives were familiar with the way complaints and grievances are handled at the county/AE level (58% Statewide; **17% 2017-2018**), and 48% of relatives were familiar with the way complaints and grievances are handled at the state level (52% Statewide; **17% 2017-2018**). 33% were not familiar of the grievance and complaint process on any level (34% Statewide; **41% 2017-2018**).

Family Resources

- 95% of relatives felt that the information they received about their relative's services was easy to understand (90% Statewide; **98% 2017-2018**).
- 0% of respondents had learned about the Life Course Framework and Tools (12% Statewide; **6% 2017-2018**).
- 63% of relatives have an opportunity to connect and network with other families with relatives at similar life stages (46% Statewide).
- 15% of relatives said they were aware of the PA Family Network (22% Statewide); of those who were aware, 25% had attended a workshop led by the Network of Family Advisors (32% Statewide; **29% 2017-2018**).
- 85% of relatives said that they have enough information about services for which their family is eligible (78% Statewide; **88% 2017-2018**).
- 20% of respondents whose family member transitioned from school to adult services in the past year were happy with the process (32% Statewide; **0% 2017-2018**).

- 14% of relatives report that the services coordinator asks about their vision for an everyday life for their family member (71% Statewide; **24% 2017-2018**).

Emergency Preparation Questions

- 65% of relatives have been given information about an emergency plan for their family member in case of an emergency (55% Statewide; **20% 2017-2018**).

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 equaled 92.23 (Statewide 91.48; **96.50 2017-2018**) with a standard deviation of 10.08 (Statewide 13.14).
- The mode (the value that occurs the most frequently) was 100, indicating that many of the families' satisfaction levels were at the top of the scale on all measures of family satisfaction.

Summary

This report contains information collected through face-to-face interviews with 148 individuals living in state centers and receiving supports through the Office of Developmental Programs.

The report shows that people in the State Center sample are predominantly happy and satisfied with their living situation. A higher percentage of individuals responded to the questions in the satisfaction and dignity, respect and rights sections of the survey than in previous years, with respondents overwhelmingly reporting high levels of satisfaction with where they live and what they do during the day.

Individuals continue to report that they receive the services they need. The vast majority report that they rarely feel lonely, have friends, and have enough privacy. About half of respondents report that they have a best friend and can date if they want to.

In contrast, people in this sample report relatively low ratings for choice and control. The majority of respondents say that others are responsible for deciding where and with whom they live and work. In a substantial decrease from last year's report, only about 1 in 5 people report carrying identification all the time. About 1 in 10 have a key to their home/living area, while less than one-third choose what they buy or know how much money is in their annual budget. 9 out of 10 do not vote and are not interested in voting, a notable statistic during a contentious election year. Interestingly, 80% of respondents report that they chose their daily schedules without assistance, an increase of 23% from last year.

It remains true that few individuals participate in community activities such as shopping, going to restaurants or running errands on a weekly basis, with the exception of engaging in regular religious activities. Further, few individuals go into the community with people other than individuals they live with or staff. Despite a multi-year focus on this area in the State Centers' quality improvement activities, the needle hasn't moved

substantially in this area, and it may be time to rethink these efforts.

Communication remains an important issue in this sample. About three-quarters of individuals do not communicate verbally, of which greater than 60% do not have a formal communication system in place. For these individuals, about one-third have a formal communication system in place. Promisingly, when a system has been implemented, most say it is in working order and used regularly, with half of individuals reporting that it is being used across settings. While most respondents have access to a cable TV with few restrictions, very few have a computer or access to the Internet, and no respondents report having access to cell phone, text-messaging, or email.

The data on health outcomes continues to be mostly positive, with most individuals reporting that it is very easy or easy to obtain medical or dental care, that they were not prevented from obtaining health services due to a disability, and that if they needed help communicating at the doctor's office, it was available. However, only two-thirds understood their doctor and about 1 in 5 were able to provide consent for medical care.

For the first time this year, individuals and families were asked about self-directed supports. In this sample, both individuals and families reported that 0% of the sample directs their own services, and individuals unanimously reported that supports coordinators did not suggest self-directed services as an option.

IM4Q Teams reported that staff members consistently treat individuals with high levels of dignity and respect and interact in ways that give control to the people they support. Further, team members report that all staff appear to have the skills they need to support those being interviewed.

Family, Friends, and Guardians indicate high levels of satisfaction with their relative's living and working arrangements and staff. More than half of the individuals surveyed indicated they visit their family members on a monthly basis. 1 in 4 family members had not contacted their relatives in the past year, a 10% increase from last year's report.

The data shows that none of the family members surveyed are familiar with Life Course Framework and Tools or the PA Family Network, but more than half had the opportunity to connect with families at similar life stages.