

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

Independent Monitoring for Quality (IM4Q)
Delaware AE
2018-2019

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

Submitted by: Celia S. Feinstein, James A. Lemanowicz,
Mary Kay R. Cunningham, and Jenifer Taylor Eaton
The Institute on Disabilities
Pennsylvania's University Center for Excellence in Developmental
Disabilities
Temple University
1755 N 13th Street, Student Center, Room 411S (004-00)
Philadelphia, PA 19122

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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 data into the DPW 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 following years is listed in the table below:

Fiscal Year	Individuals Surveyed	Friends, Family, Guardians Surveyed
2000-2001	5298	2224
2001-2002	5659	2494
2002-2003	4687	3163
2003-2004	6373	2975

2004-2005	6499	3010
2005-2006	6496	2851
2006-2007	6469	3028
2007-2008	6512	2731
2008-2009	6618	2896
2009-2010	6621	2590
2010-2011	6692	2510
2011-2012	6589	2517
2012-2013	5858	2160
2013-2014	5341	2187
2014-2015	5336	2002
2015-2016	5260	2047
2016-2017	5328	1608
2017-2018	5354	1980
2018-2019	5326	2345

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, increased from the 118 questions asked previously. Seventy of the questions can only be answered by the individuals receiving supports and services.

The EDE for fiscal year 2018-2019 includes all survey questions included in the FY 2018-2019 NCI Adult In-Person Survey. At the time of this report, 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 2018-2019 is available on the HSRI website at www.nationalcoreindicators.org.

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

- A **pre-survey**, which was completed by the AE designee prior to the scheduling of the appointment with the individual to give the local IM4Q Program information needed to schedule the interview with the individuals. Information includes: the person's address, contact people, supports coordinator information, accessibility and the individual's communication style (which may require the use of an interpreter, e.g. Sign Language or Spanish). Often this information is provided by the supports coordination organization (SCO).
- A **pre-survey addendum**, which was completed by the AE for only those individuals who were designated as part of the NCI sample. The addendum provides demographic information, along with information about the individual's degree and type of disability(ies), work and day activity routines.
- **Satisfaction** – this section was only to be completed based on the responses of the individual receiving supports. Questions were asked about satisfaction with where the individual works and lives, as well as with staff who support the individual.
- **Dignity, Respect and Rights** – this section was also only to be completed based on responses of the individual receiving supports. Questions were asked about whether roommates and staff treated people with respect, whether people were afforded their rights, and whether they had fears at home, at work or in the community.
- **Choice and Control** – the questions in this section were answered by the individual, or by a family member, friend or staff person. Questions were asked about the extent to which individuals exerted choice and control over various aspects of their lives.
- **Relationships** – the questions in this section were answered by the individual, or by a family member, friend or staff person; questions were asked about friends, family and neighbors, and individuals' opportunity to visit and contact them.
- **Inclusion** – the questions in this section were answered by the individual, or by a family member, friend or staff person. Questions were asked about opportunities for community inclusion; a section of the Harris Poll was included for comparative purposes.
- **Monitor Impressions** – this section of the survey was completed by the Independent Monitoring team, after they had completed their visit. Questions were asked in the areas of physical setting, staff support and opportunities for growth and development.
- **Major Concerns** – this form was completed whenever there was an issue related to physical danger, significant sanitation problems, or evidence of physical or psychological abuse or neglect. Each program was required to develop a mechanism for communicating this information. In the event of imminent danger, teams were instructed not to leave the home until resolution of some kind was achieved.
- **Family/Friend/Guardian (F/F/G) Survey** – a survey was conducted with each family once the individual gave his/her approval. Questions related to the families' satisfaction with their relatives' living situation, as well as perceived satisfaction of their relatives. The survey was conducted either by phone or face-to-face at the time of the EDE interview.

Sample

Independent Monitoring focuses on the quality of life and services and supports to children ages three and over, and to adults supported by the Office of Developmental Programs service

system for individuals with intellectual disabilities. In Fiscal Year 1999-2000, the sample for IM4Q was restricted to individuals living in licensed residential settings in 19 AEs, including licensed community homes and apartments, family living arrangements, non-state operated private intermediate care facilities for people with mental retardation (ICFs/MR) and large community homes (formerly private licensed facilities).

In Fiscal Year 2000-01, the sample for IM4Q was expanded to include individuals not receiving residential supports. This resulting sample included 30 adults per county in the NCI subset and others living at home with families, in unlicensed living arrangements and independently. The proportion of individuals in non-residential settings for purposes of the NCI sample was to be proportional to the number of people receiving non-residential supports in the AE.

Administrative Entities were instructed to draw a random sample of approximately one-third of the individuals living in licensed residential settings. AEs were provided with written instructions for drawing the entire Fiscal Year 2001-02 sample; once the sample was selected, ODP staff checked the samples before individual names were given to the local IM4Q Program, to ensure consistency in the sample selection.

During fiscal year 2003-04, in addition to the NCI and residential samples, each AE was instructed to include 30 individuals who participate in the Person and Family Directed Supports (PFDS) Waiver. Individuals participating in the PFDS Waiver continued to be included in the sample in each subsequent year. Beginning in 2013-2014, we no longer sample 30 individuals per AE for the NCI sample; we have gone to a statewide simple random sample of approximately 700 individuals.

The sampling procedure for this year continues to be drawn through the Home and Community Services Information System (HCSIS). ODESA at HSRI is used to enter the IM4Q data. The following table shows the breakdown of the sample by type of residential setting. This year's sample included 240 people in Delaware AE.

**Type of Residential Setting for
Delaware AE**

Type of Residential Setting	Pennsylvania Overall		County/Joinder	
	N	Percent	N	Percent
State-Operated ICF/ID	3	0.1%	0	0.0%
State Mental Health Hospital	1	0.0%	0	0.0%
Homeless	0	0.0%	0	0.0%
Temporary Shelter	2	0.0%	0	0.0%
Foster Care	0	0.0%	0	0.0%
Incarceration	0	0.0%	0	0.0%
Nursing Home/Nursing Facility	156	2.9%	1	0.4%
Domiciliary Care	32	0.6%	0	0.0%
Personal Care Home (PCH)	144	2.7%	1	0.4%
Family living	202	3.8%	5	2.1%
Unlicensed Family Living	26	0.5%	3	1.3%
Own residence	623	11.7%	15	6.3%
Relative's home	2581	48.5%	177	73.8%
Children's Facility	9	0.2%	1	0.4%
Approved Private School	2	0.0%	0	0.0%
Private ICF/ID (4 or fewer)	15	0.3%	0	0.0%
Private ICF/ID (5 to 8)	7	0.1%	0	0.0%
Private ICF/ID (9 to 15)	2	0.0%	0	0.0%
Private ICF/ID (16 or more)	15	0.3%	1	0.4%
Community Home (1 person)	96	1.8%	0	0.0%
Community Home (2 to 4 persons)	1240	23.3%	30	12.5%
Community Home (5 to 6 persons)	51	1.0%	0	0.0%
Community Home (7 to 8 persons)	29	0.5%	4	1.7%
Community Home (9 to 15 persons)	11	0.2%	0	0.0%
Community Home (16 or more)	6	0.1%	0	0.0%
Other	21	0.4%	0	0.0%
Missing	52	-	2	-
Total	5326	100%	240	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 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 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. Individual programs provide training 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 directly onto the ODESA website managed by HSRI. Data for the 2018-2019 survey cycle were collected and entered into ODESA by June 30, 2019. A useable 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. Each AE and local program will receive a report about the people monitored in their 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. “Closing the loop” is also facilitated by provider level reporting in HCSIS, which enables providers of service and the AEs to review finalized aggregate IM4Q results. The IM4Q data warehouse in HCSIS

also allows AE, regional and state personnel to review IM4Q aggregate data based on key demographic areas such as age, gender, race and type of living arrangement.

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%

Demographics

- Of those who reported gender for this AE, 60% identified as male and 40% identified as female
- The average age is 40
- Of those who reported on race, 73% identified as white, 24% identified as black/African-American, 3% identified as Asian, 0% identified as mixed-race, 1% identified as other, and 0% identified as American Indian/Alaskan Native/Pacific Islander
- Of those who identified their ethnicity, 1% identified as Hispanic/Latinx

Satisfaction

Respondents: Only the individual receiving services/supports could answer the questions on satisfaction. Statewide, the percent of people who responded to questions in this section ranged from 27% to 65%.

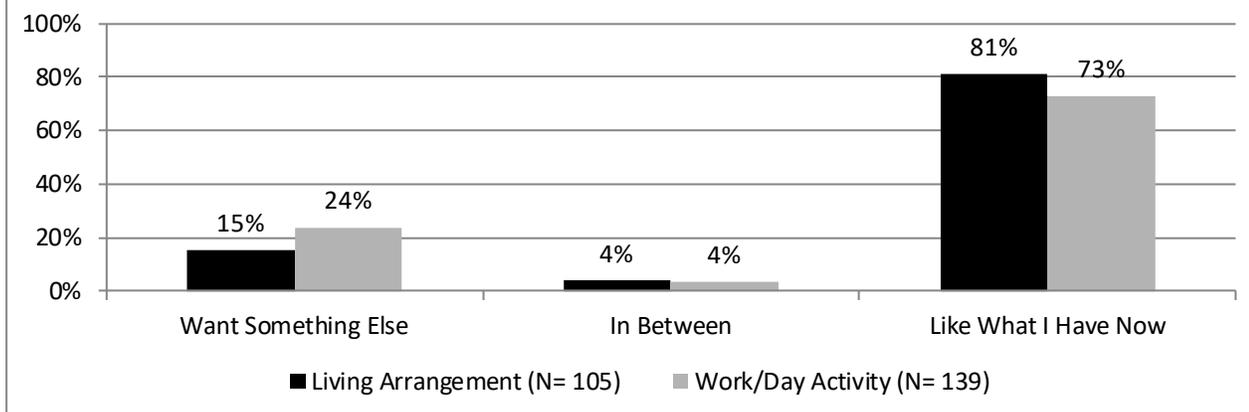
Satisfaction with Living Arrangements

- 88% of individuals liked where they live (state finding 89%, regional 87%).
- When asked what they don't like about where they live, 0% reported that it was because of a problem with housemates, 1% wanted to be closer to family and friends, 1% wanted more independence, 4% had some other reason they don't like where they live, 0% because of accessibility, 2% felt unsafe, 1% because their home needed repair, 0% had a problem with their staff, and 0% don't think it feels like home.
- 81% wanted to stay where they currently live (state finding 79%, regional 77%).

Satisfaction with Work/Day Activity

- 90% of individuals with a day activity/work liked the primary job/activity that they did during the day (state finding 91%, regional 91%). 94% of individuals liked the secondary job/activities they frequently do during the day (state finding 94%, regional 92%).
- 73% wanted to continue their current daytime activities/work (state finding 72%, regional 63%), 24% wanted to do something else (state finding 20%, regional 24%).

Want To Stay Or Change Living Arrangement & Work/Day Activity



Daily Life

- 72% of individuals reported getting the services and supports they need (state finding 83%, regional 74%).
- On most weekdays, 23% of individuals report they attend an adult training program /community senior center (state finding 21%), 21% stay home, 3% go out and do things in the community, 14% are at a vocational facility (state finding 22%), 17% worked with no supports, 7% worked in supported employment, 4% volunteer, 7% attend school, 2% were retired and 3% did something else.
- In addition to what individuals do on most weekdays, 12% also went out and did things in the community, 50% stayed home, 1% attended an adult training program/community senior center, 1% attended a vocational facility, 7% volunteered, 4% worked with no supports, 4% worked in supported employment, 2% were retired, 3% attended school, and 17% did something else.
- 58% of individuals that did not have a paid job in the community reported that they do not want a job (state finding 61%, regional 55%); 37% reported they would like to have a job for pay (state finding 33%, regional 40%).

Happiness and Loneliness

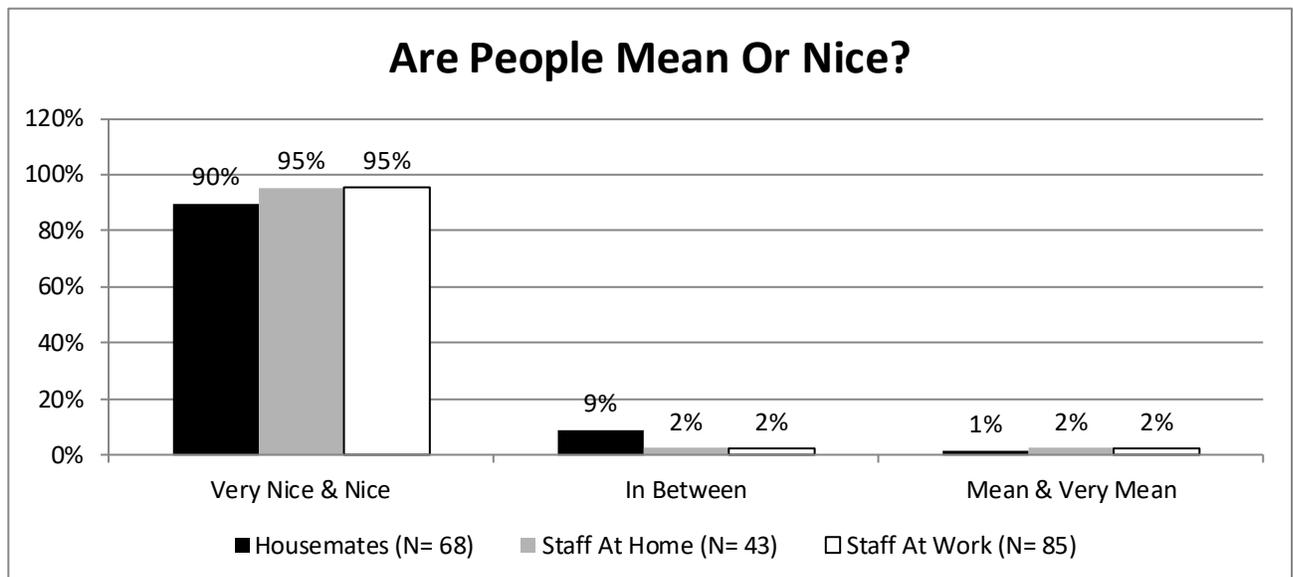
- 89% reported usually feeling happy (state finding 83%, regional 80%), 10% reported being in-between (state finding 14%, regional 16%), and 1% reported usually feeling sad (state finding 3%, regional 4%).
- 66% of individuals reported never feeling lonely (state finding 63%, regional 63%), 32% reported sometimes feeling lonely (state finding 33%, regional 33%), and 2% reported always feeling lonely (state finding 4%, regional 4%).
- 81% reported having friends, which are not staff or family, with whom they like to do things (state finding 75%, regional 72%).
- 59% of respondents indicated they have a best friend (state finding 69%, regional 62%)
- 85% reported that they can go on a date if they want to or are married (state finding 82%, regional 81%); 5% reported that they can go on a date if they want to but there are some restrictions and rules (state finding 6%, regional 7%), and 11% are not allowed to date (state finding 12%, regional 12%).

Privacy

- 98% of the individuals surveyed reported that they always have privacy (a place to be alone) when they want it (state finding 95%, regional 95%).
- 84% of individuals reported that they can be alone with friends at home (state finding 86%, regional 80%).
- 58% of individuals say there are no rules about having friends and visitors (state finding 72%, regional 64%).
- 88% of the respondents reported that other people knock or ring the doorbell and wait for a response before coming in to their home (state finding 88%, regional 90%).
- For 79% of the individuals, people knock on the bedroom door and wait for a response before coming in (state finding 84%, regional 86%).

Are People Nice or Mean?

- 90% reported that their housemates are very nice or nice (state finding 90%, regional 91%).
- 33% of people interviewed reported that they get along with the person they share a bedroom with most of the time (state finding 76%, regional 73%).
- 95% of the people interviewed reported that their staff who work with them at home are very nice or nice (state finding 94%, regional 95%).
- 95% reported that staff who work with the respondents at work or day activity are nice or very nice (state finding 96%, regional 95%).



Satisfaction Scale: Based on 6 individual items, a Satisfaction Scale was developed. Scores on the Satisfaction Scale could range from 0 to 100, with a higher score indicating greater satisfaction.

- The average (mean) score was 86.56 with a standard deviation of 19.41 (85.44 and 19.63 state finding; 83.20 and 21.30 regional).

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.

Dignity, Respect and Rights

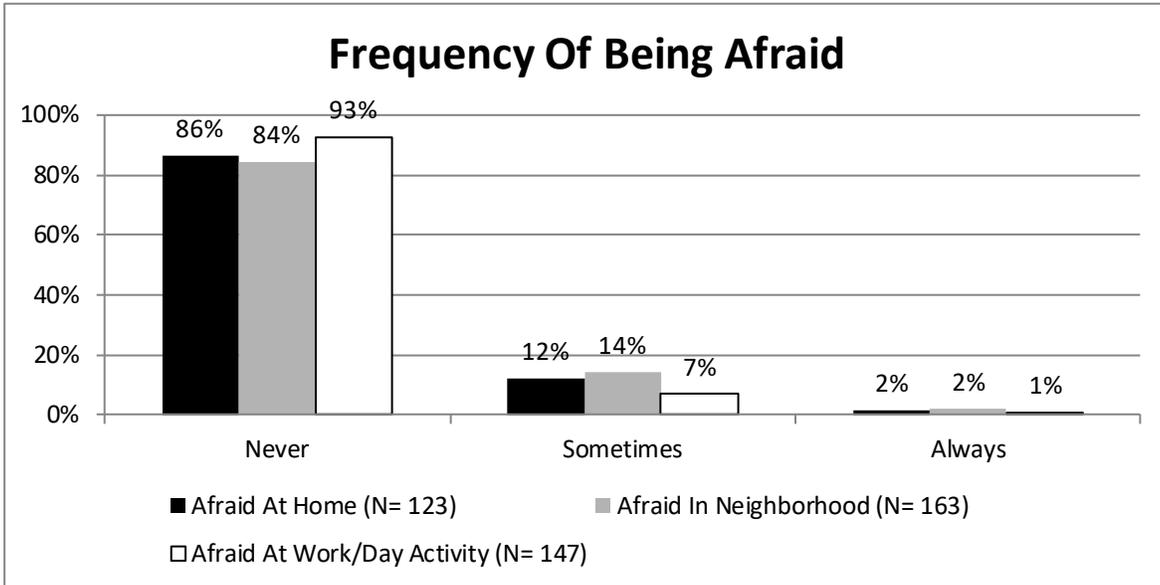
Respondents: Only the individual receiving services/supports could answer the questions on dignity, respect and rights. Statewide, the percent of people who responded to questions in this section ranged from 36% to 68%.

Support with Goals and Problems

- 28% of individuals reported that they go to staff for help when they have a problem (state finding 50%, regional 40%). 60% go to their family (state finding 53%, regional 62%), 12% go to a friend, and 6% go to someone else; 3% have no one to go to for help.
- 57% get help to learn new things (state finding 64%, regional 62%).
- 50% of individuals report that they get to help other people (state finding 72%, regional 64%).
- 17% of individuals indicated that they have participated in a self-advocacy group meeting (state finding 16%, regional 11%).
- 23% of individuals said that someone had talked to them about self-advocacy (state finding 38%, regional 27%)

Being Afraid

- 86% reported never being afraid at home (state finding 87%, regional 87%).
- 84% reported never being afraid in the neighborhood (state finding 87%, regional 86%).
- 93% reported never being afraid at work, school or day activity (state finding 93%, regional 92%).
- 90% reported never being afraid when using transportation (state finding 93%, regional 92%).
- 95% reported that they have someone they can talk to when they feel afraid (state finding 94%, regional 94%).



Legal Rights

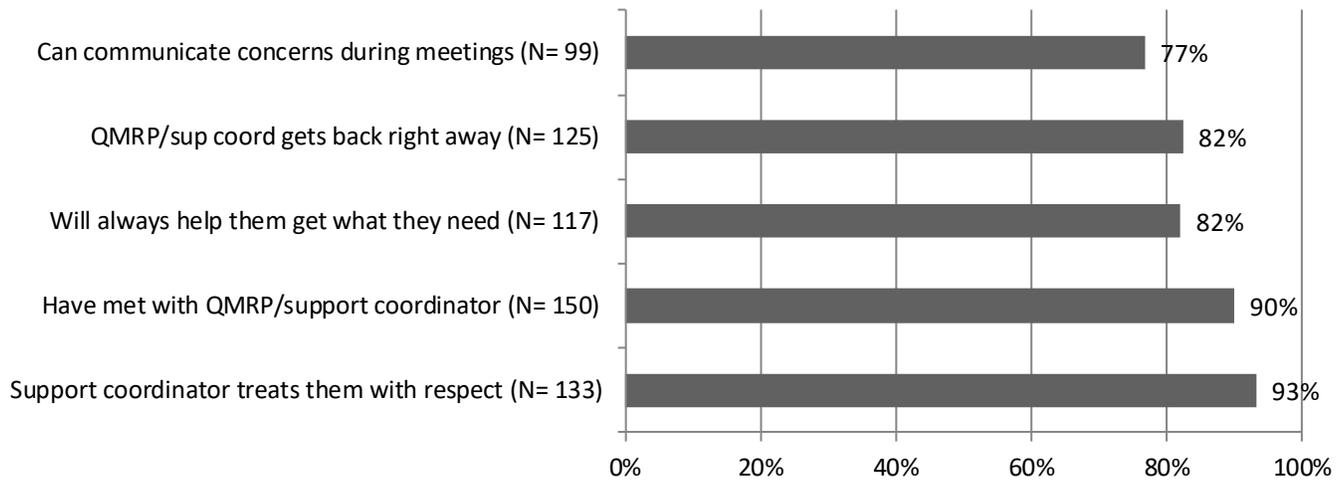
- For 53% of the individuals interviewed, their mail is never opened without permission (state finding 83%, regional 76%); 20% say their mail is always opened without permission (state finding 10%, regional 13%)

Supports Coordination/Qualified Intellectual Disability Professional (QIDP)

- 90% reported that they have met with their supports coordinator/QIDP in the past year (state finding 96%, regional 95%).
- 82% of individuals reported that, if they ask, their supports coordinator will always help them get what they need (state finding 87%, regional 82%).
- 82% of the people reported that when they call, their supports coordinator/QIDP always gets back to them right away (state finding 90%, regional 86%).
- 91% of individuals reported that their supports coordinator asks what their interests are (state finding 92%, regional 92%).
- 81% of respondents said their supports coordinator asks them what they want their life to look like (state finding 84%, regional 76%).
- 78% said the supports coordinator asks what they want in the future (state finding 84%, regional 79%).

- 77% of individuals reported always being able to communicate their concerns during annual meetings (state finding 84%, regional 81%).
- 34% of individuals report that their supports coordinator has asked them about directing their own services (state finding 40%, regional 24%).
- 98% of people surveyed reported that their supports coordinator talks with them about services to make sure everything is OK (state finding 97%, regional 95%).
- 51% of those surveyed have been told how much money was in their annual budget (state finding 57%, regional 45%).
- 49% of individuals reported that they know they have a choice of SC organizations (state finding 65%, regional 60%).
- 93% reported that their ISP meeting included the people they wanted to be there (state finding 95%, regional 94%).
- 65% of individuals indicated that they knew what was being talked about at their ISP meeting (state finding 80%, regional 78%).
- 94% of individuals reported that their supports coordinator always listens to them (state finding 95%, regional 94%)
- 93% of individuals reported that the supports coordinator always treats them with respect (state finding 97%, regional 96%)
- 95% of respondents said they took part in their annual planning meeting (state finding 96%, regional 95%)
 - 59% said they talked about learning new things at their planning meeting (state finding 73%, regional 64%)
 - 78% of individuals reported that they chose the services they get as a part of their service plan (state finding 74%, regional 70%)
 - If they want to change something about their services, 77% know who to ask (state finding 81%, regional 73%)

Supports Coordination



Staff

- 92% of individuals interviewed reported that their staff treats them with respect (state finding 92%, regional 90%).
- 91% of individuals reported that they feel their staff has the right training to meet their needs (state finding 95%, regional 94%).
- 82% of individuals feel that all of their staff understood their communication (state finding 86%, regional 86%)

Emergency Preparation Questions

- 76% of individuals have been given information about what to do in an emergency (state finding 81%, regional 74%).
- When asked who gave the individual information about what to do in an emergency, 25% received information from staff (state finding 36%), 16% from day program or employment staff, 64% from someone in their family, 7% from the police, fire department, or EMS, 3% from supports coordinator, 0% from neighbors or friends, and 0% from someone from red cross; 7% of individuals responding to this survey received information from someone else.

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).

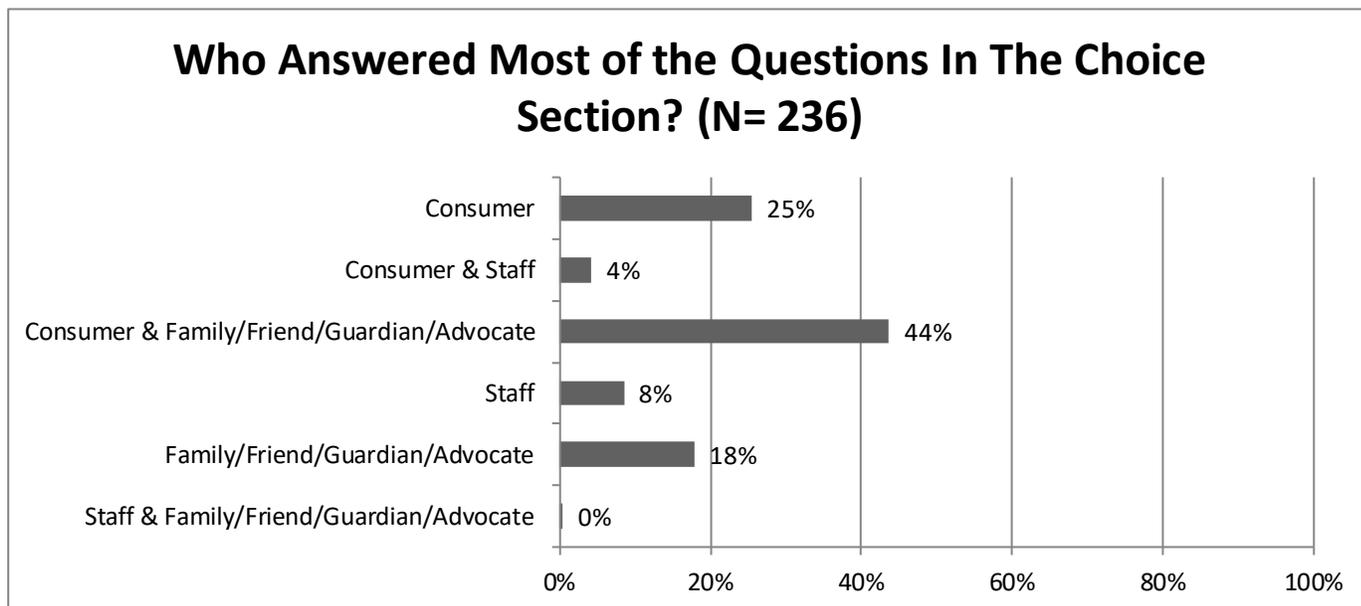
- The average score was 90.82 with a standard deviation of 15.17 (84.15 and 14.75 state finding; 82.44 and 14.45 regional).

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 being afraid less frequently.

- The average (mean) score was 93.13 with a standard deviation of 13.90 (92.86 and 15.77 state finding; 92.76 and 15.60 regional).

Choice and Control

Respondents: The questions in the choice and control section were answered by the individual receiving supports, a family member, a friend or advocate, or paid staff.



A value of missing was assigned when individuals did not answer, gave an unclear answer, or responded “do not know.”

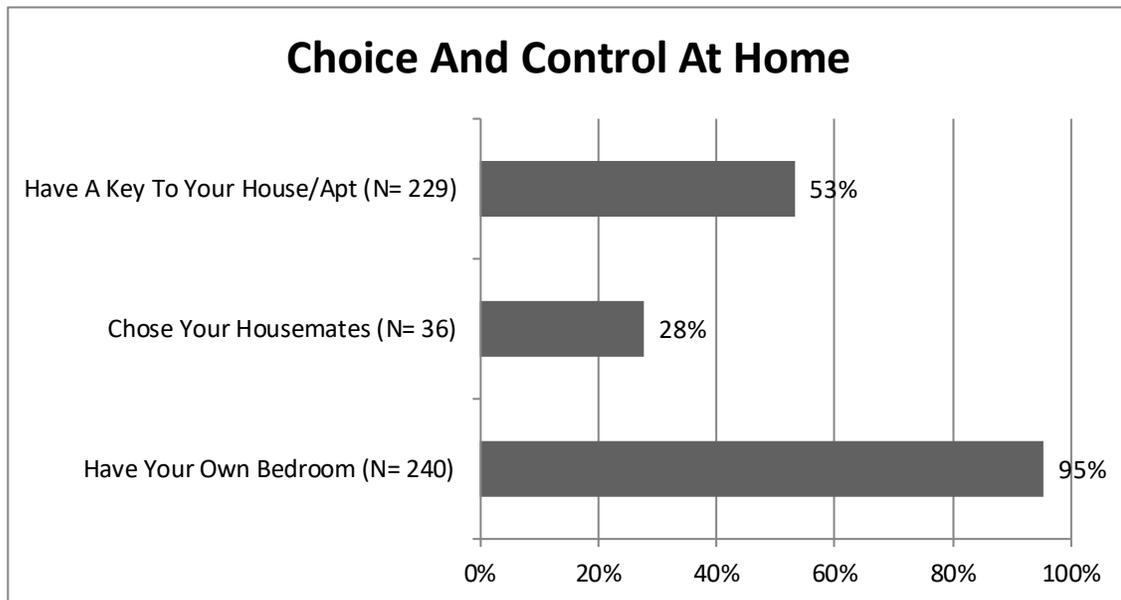
Forms of Identification

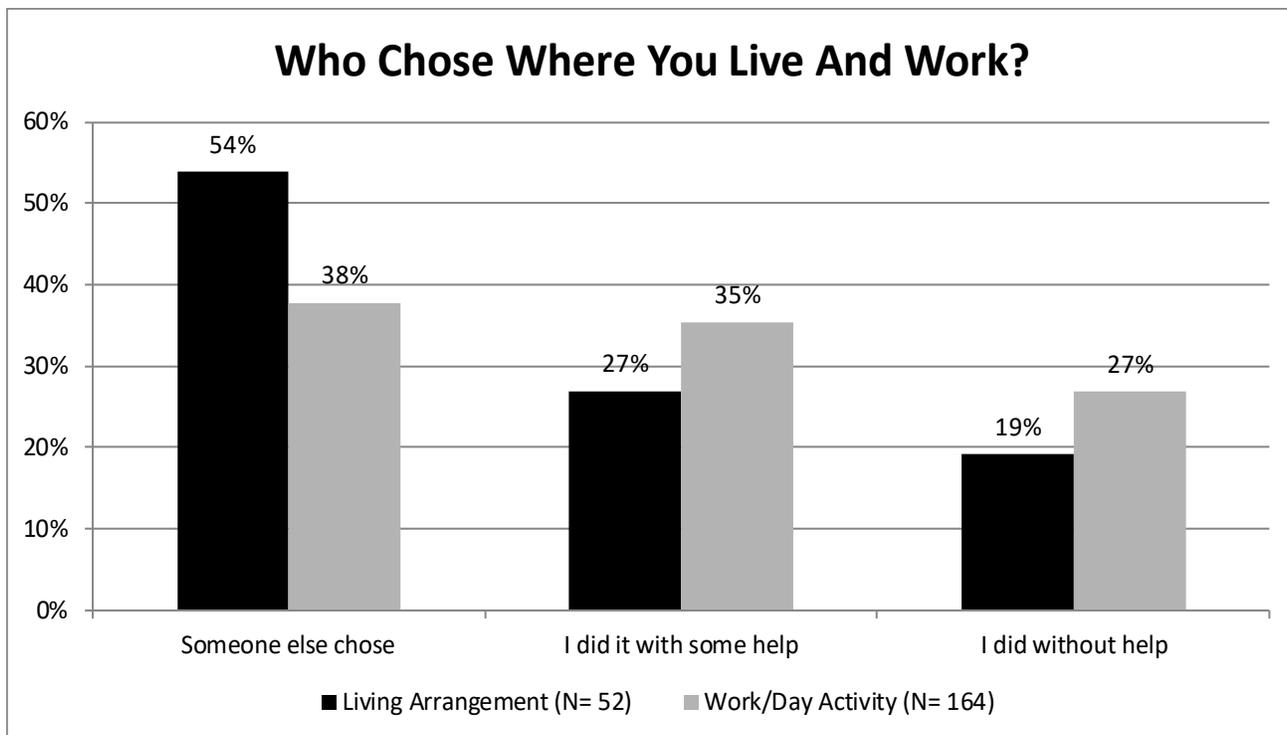
- 69% of individuals stated that they always carry a form of identification, such as a card with the individuals name, address and a person to call in case of emergency or a non-driver ID (state finding 61%, regional 69%); 12% never do (state finding 23%, regional 19%).

Choice and Control at Home

- 53% of the individuals surveyed had a key/way to get into their house or apartment on their own (state finding 49%, regional 52%).
- 43% of respondents said that if other members of their house go out, they have the option to stay home (state finding 58%, regional 57%).

- 38% of respondents can lock their bedroom door if they want to (state finding 44%, regional 41%).
- 4% of individuals reported that they own their own home (state finding 3%, regional 2%)
- 11% of individuals reported that their name is on the lease or rental agreement (state finding 25%, regional 21%)
- For 54% of the individuals, someone else choose where they live (state finding 42%, regional 41%); 19% of those interviewed chose without assistance (state finding 30%, regional 23%).
- 66% of individuals said they were given a choice to live where people without disabilities live (state finding 54%, regional 57%).
- For those individuals who had some control in choosing where they live, 71% saw more than one other place before moving in (state finding 50%, regional 58%); 29% saw no other places (state finding 50%, regional 42%).
- 72% of the individuals did not choose their housemates (state finding 60%, regional 54%).
- 95% of the individuals had their own bedroom (state finding 90%, regional 94%); for those who shared a bedroom, 50% chose some or all of their roommates (state finding 37%, regional 39%)



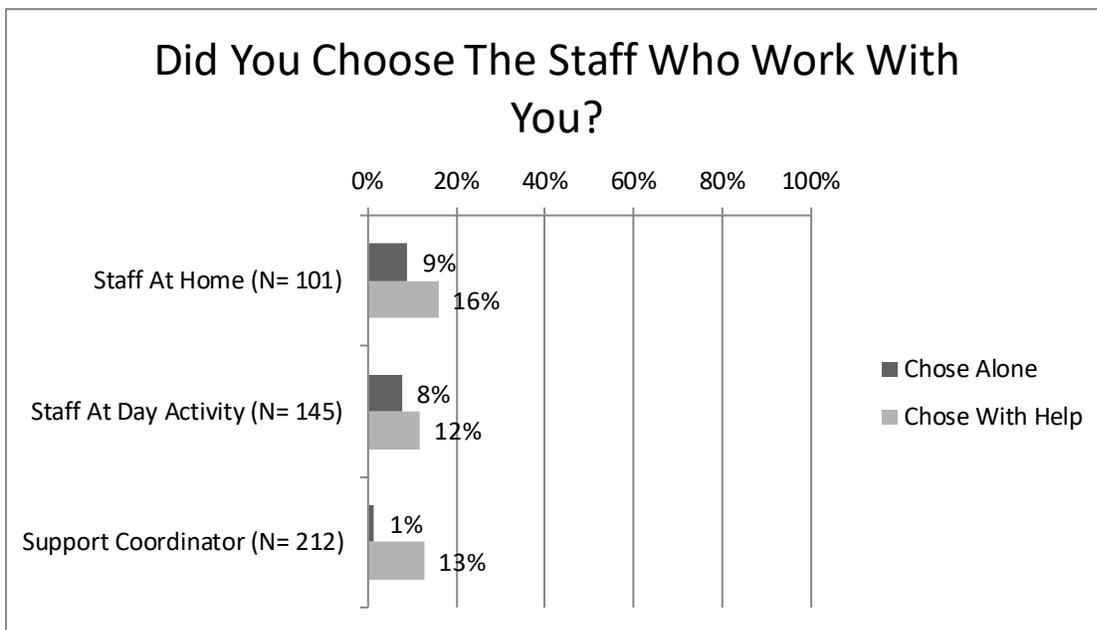


Choice and Control During the Day and for Leisure Time

- 38% of the individuals interviewed reported that someone else chose what they do during the day (state finding 24%, regional 30%).
- 27% of the people interviewed chose what they do during the day without assistance (state finding 45%, regional 37%).
- 55% of individuals reported that when they chose their work or day activity they had an option to go where people without disabilities go (state finding 57%, regional 58%)
- For those individuals who participated in choosing what they do during the day, 69% saw other places before deciding (state finding 59%, regional 63%); 31% saw no other places (state finding 41%, regional 37%).
- 80% of the individuals surveyed chose their daily schedules without assistance (state finding 89%, regional 84%).
- 92% chose how they spend their free time without assistance (state finding 93%, regional 90%).

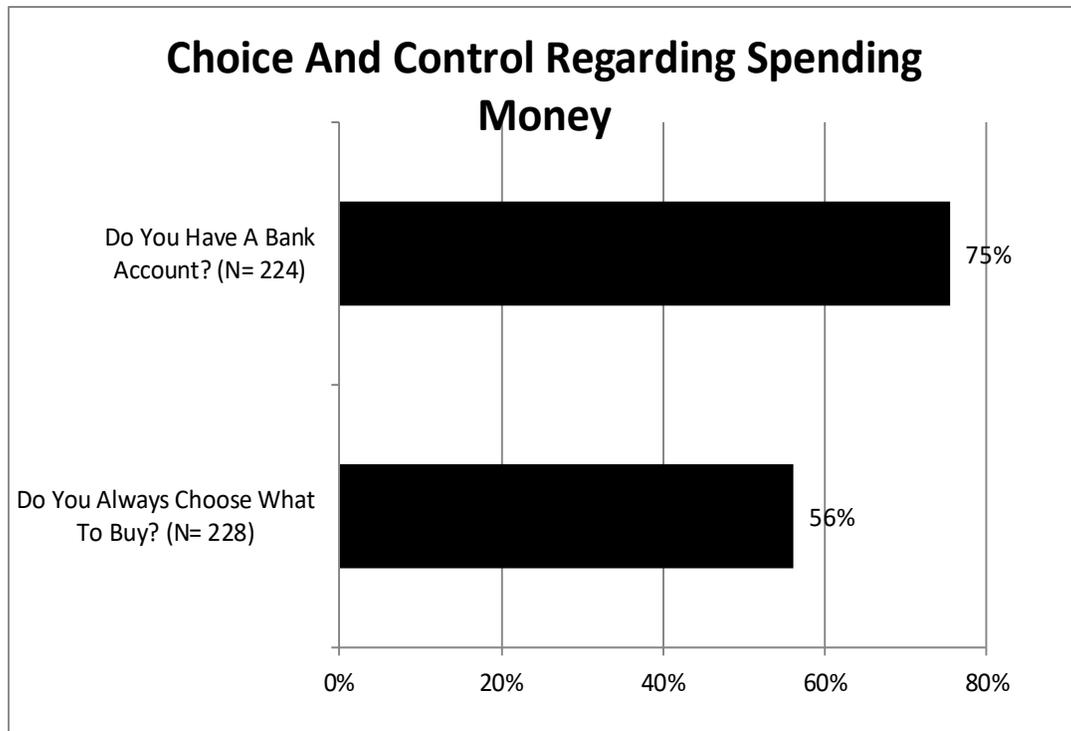
Choice and Control in Choosing Staff

- 25% of the individuals interviewed/chose the staff that helps them at home, alone or with assistance from family or provider (state finding 44%, regional 43%).
- 19% of the individuals interviewed/chose the staff that helps them at their work/day activity, alone or with assistance from family or provider (state finding 36%, regional 31%).
- 14% of the individuals reported that they chose their supports coordinator, alone or with assistance from family or provider (state finding 33%, regional 22%).



Choice and Control with Regard to Money

- 56% of the individuals reported that they always choose what to buy with their spending money (state finding 65%, regional 59%).
- 29% of the individuals reported that there is something they want to buy (state finding 40%, regional 47%).
- 75% of the individuals reported that they have a bank account that they can get to independently to withdraw money when they want it (state finding 63%, regional 56%).



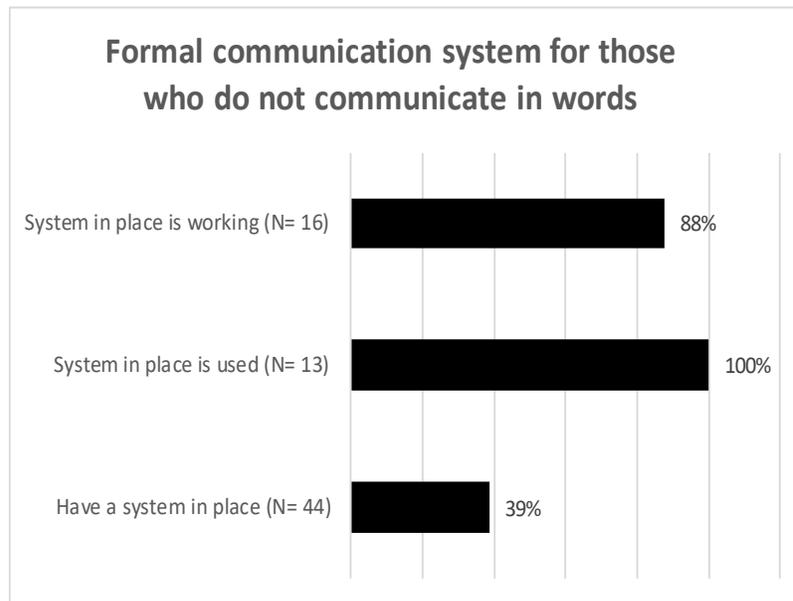
Voting

- 45% of people said that they do vote (state finding 34%, regional 52%); 5% do not vote but would like to (state finding 6%, regional 5%), and 51% do not vote and are not interested (state finding 59%, regional 43%).

Access to Communication

- For those individuals who do not communicate using words (n=44), there is a formal communication system in place for 39% of the people interviewed (state finding 27%, regional 25%).
- For those people with formal communication systems in place (n=16), the systems are in working order for 88% of the people interviewed (state finding 90%, regional 92%).
- If the communication system was in place and working, it was being used regularly for 100% of the people interviewed (state finding 86%, regional 86%).
- 81% of individuals with a formal communication system reported using it across all settings (state finding 73%, regional 70%).
- 40% of individuals with a formal communication system are supported by staff or a program coordinator (state finding 58%, regional 50%), 40% are supported by a parent or

caregiver, 47% are supported by their speech language clinician, and 13% are supported by someone else.

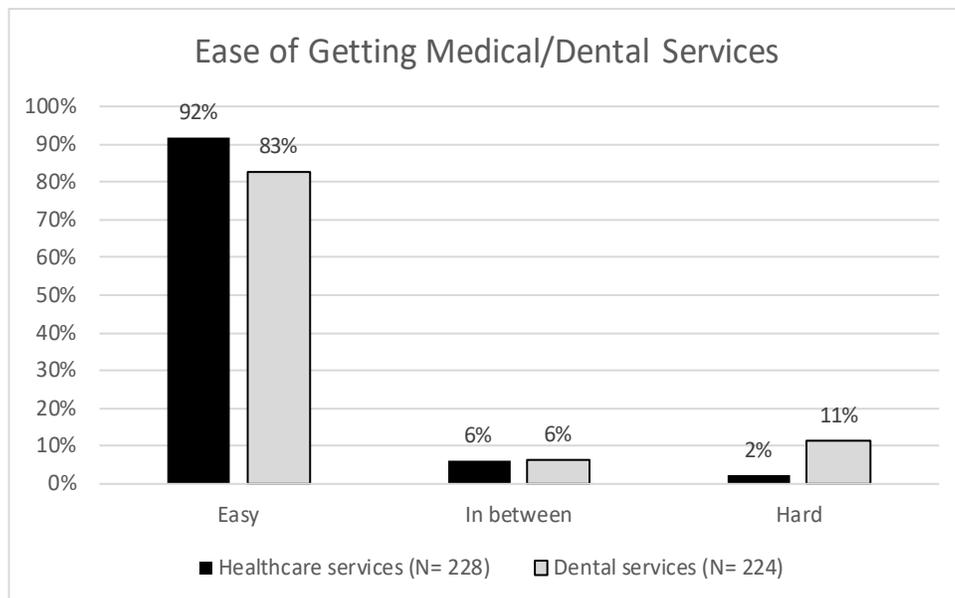


- In regards to forms of communication individuals have and use, 78% have and use cable television (state finding 78%, regional 80%), 48% computer, 43% cell phones, 39% internet, 27% email, and 29% text messaging.

Health Care Questions

- When asked how many times per month they exercise at home, 61% of individuals said zero (state finding 54%, regional 59%), and 22% said 10 or more times a month (state finding 31%, regional 22%).
- 90% of individuals interviewed reported that they have the opportunity to discuss health with their primary care provider (state finding 93%, regional 91%)
- 84% of individuals reported that they feel their doctor understands them (state finding 91%, regional 91%)
- 74% of individuals feel that they understood their doctors' instructions (state finding 84%, regional 83%)
- 91% of respondents say if they needed help communicating at the doctor's office, it was available (state finding 94%, regional 92%)

- 91% of respondents reported they were able to see a medical specialist if they needed to (state finding 94%, regional 91%)
- 86% of individuals say they have been prevented from receiving medical and dental services because of their disability (state finding 92%, regional 91%)
- 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 (state finding 92%, regional 93%)
- When asked how hard it is to get dental services in their community, 83% of individuals reported that it was very easy or easy (state finding 86%, regional 87%)
- Of those who have a psychiatrist, 42% of individuals interviewed reported that they have the opportunity to discuss health concerns with a psychiatrist (state finding 57%, regional 51%)
- 82% of individuals reported that their doctor speaks directly to them during appointments (state finding 93%, regional 89%)
- 52% of individuals reported that they are able to provide consent for medical treatment (state finding 65%, regional 61%); of those able to provide consent, 90% said their doctor accepts their consent (state finding 88%, regional 90%)



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 52.79 with a standard deviation of 21.73 (58.50 and 21.57 state finding, 54.60 and 23.48 regional).

Employment

Respondents: Of the 219 individuals who responded for the Delaware AE, 53 respondents indicated they are employed.

Community Integrated Employment

- 24% of individuals work in a community integrated setting (17% state finding, 19% regional).
- 24% of individuals have been employed for 1 to 3 years (state finding 30%). 16% of individuals have been employed for less than one year, 24% have been employed for 4-6 years, 8% have been employed for 7-10 years, and 28% have been employed for more than 11 years (state finding 25%).

Types of Work

- 17% of individuals work in cleaning services, 37% work in retail (including grocery stores), 19% work in food services, 6% work in office work, 8% work in the stock room, 2% in maintenance, 4% work in assembly, 6% work as a care-worker or aide, 0% work in animal care, 0% in work in landscaping or outdoors, and 2% work in some other occupation.

Supports Getting Into the Workplace

- 47% of individuals surveyed reported that someone had talked to them about employment in their planning meeting (state finding 57%, regional 54%)
- 34% of individuals report that community employment is a goal in their plan (state finding 32%, regional 39%)
- When individuals were asked who had talked to them about employment, 53% said no one (state finding 44%), 41% said their supports coordinator, 9% said their service provider, 19% said their family, 0% said their housemates, and 6% said someone else

Compensation and Advancement

- 76% of individuals received paid time off, 18% received health insurance, 29% received retirement benefits, and 47% received some other kind of benefit. Note: individuals answering this question had the option to indicate more than one response.
- 72% of individuals who work have been promoted (53% state finding, 61% regional).
- The mean number of hours worked per week was 17 hours (18 hours state finding, 17 hours regional).
- 74% of individuals reported that they know how much they earn and are willing to share it (state finding 84%, regional 83%).
- Regarding hourly wage, 9% earned \$7.25 (state finding 24%, regional 17%); 48% earned \$7.26 to \$9.00 (state finding 29%, regional 27%); 36% earned \$9.00 to \$12.00; 6% earned more than \$12.00.

Self-Employment and Supports

- Of the 53 individuals who have community integrated employment, 4 individuals are self-employed (49 individuals state finding, 19 individuals regional).

Self-Directed Supports

Respondents: Of the 227 individuals surveyed, 19 people indicated they use self-directed supports.

- 8% of respondents report that they use self-directed supports (state finding 5%, regional 3%)

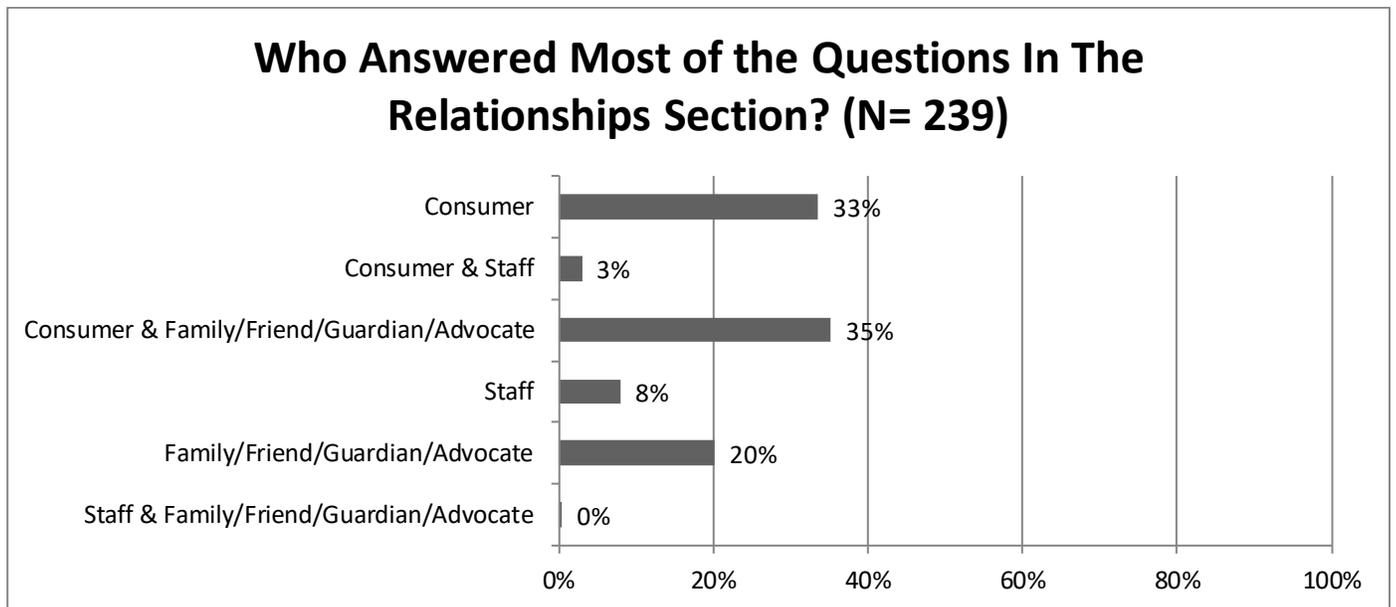
Among those individuals using self-directed supports,

- 8% make most of the decisions about how their budget for services is used on their own; 0% have input but family and friends help (state finding 37%, regional 35%), 73% say a family member or friend makes decisions (state finding 40%, regional 55%), and 0% report that a case manager or another state professional makes the decision

- 69% participate in decisions about budget, staff, and managing services (state finding 74%, regional 73%)
- 91% hire and manage their own staff (state finding 71%, regional 88%)
- 90% can make changes to their budget or services if they need to (state finding 86%, regional 92%)
- 91% say they have enough help deciding how to use their budget/services (state finding 93%, regional 96%)
- 55% receive information about the money left in their budget (state finding 79%, regional 69%)
- Of these, 63% say the information is easy to understand (state finding 84%, regional 75%)
- 40% receive this information at least every three months (state finding 63%, regional 56%)

Relationships

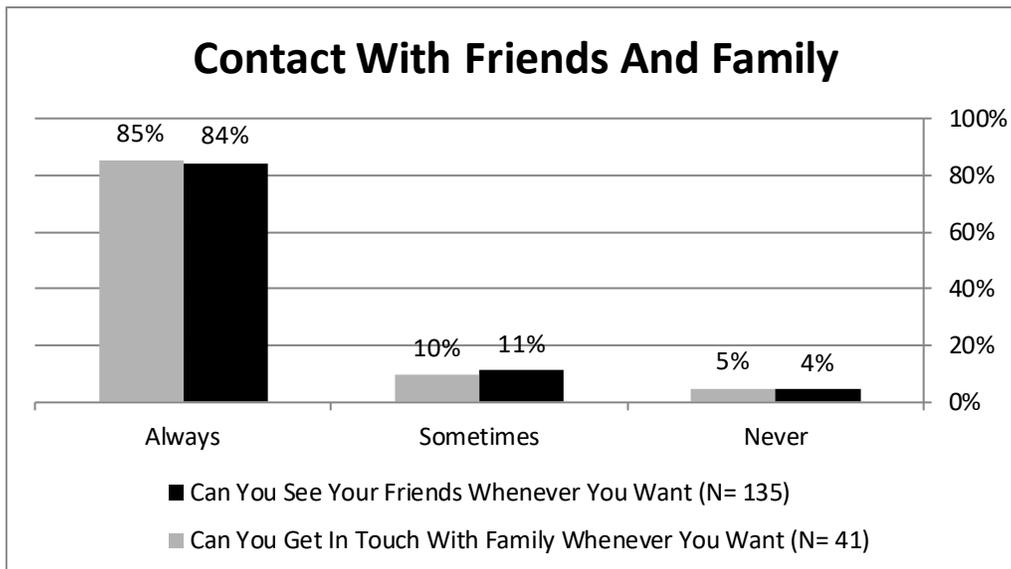
Respondents: The questions on relationships could be answered by the individual receiving services/supports, a family member, a friend, or paid staff.



A value of missing was assigned when individuals did not answer, gave an unclear answer, or responded, “do not know.”

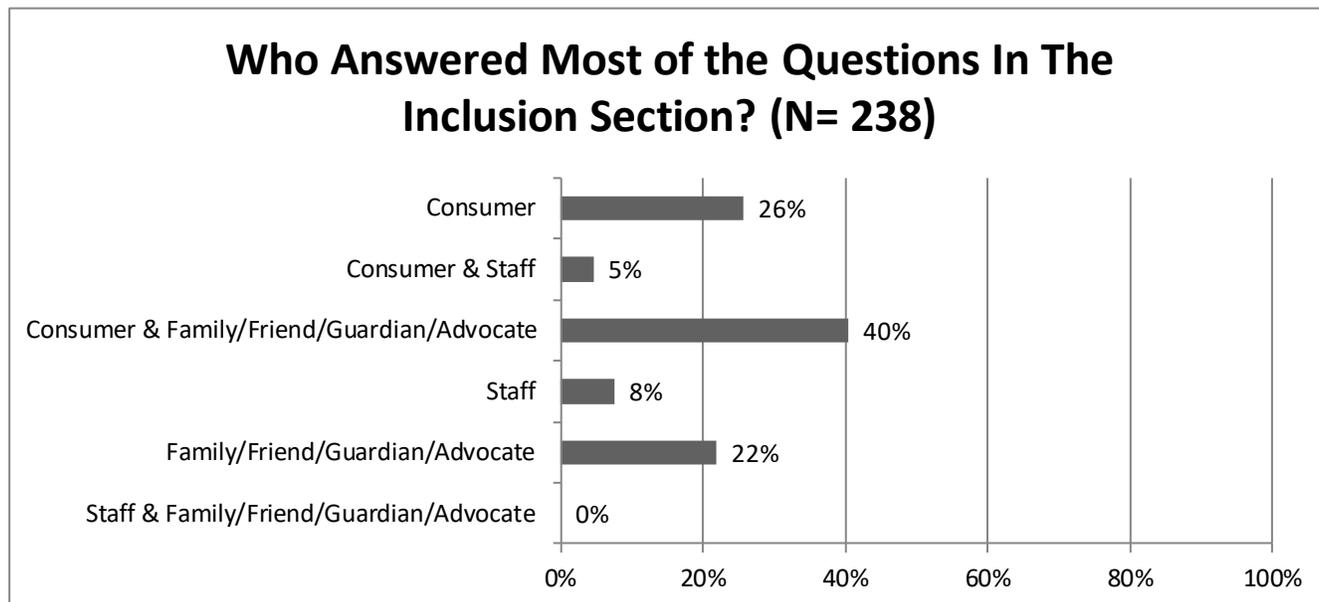
Contact with Friends and Family

- 84% of individuals were always able to see friends whenever they wanted (state finding 86%, regional 81%)
- Of individuals that reported that they were unable to see their friends whenever they wanted, 36% reported that it was difficult to find time to see friends, 21% reported that they couldn't see friends because of a transportation issue, 7% reported a lack of staff, 0% reported that there were rules/restrictions, 7% reported difficulty with money/cost, and 29% reported that there was another reason why they couldn't see friends.
- 85% of respondents were always able to get in touch with family whenever they wanted (state finding 84%, regional 79%).



Inclusion

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

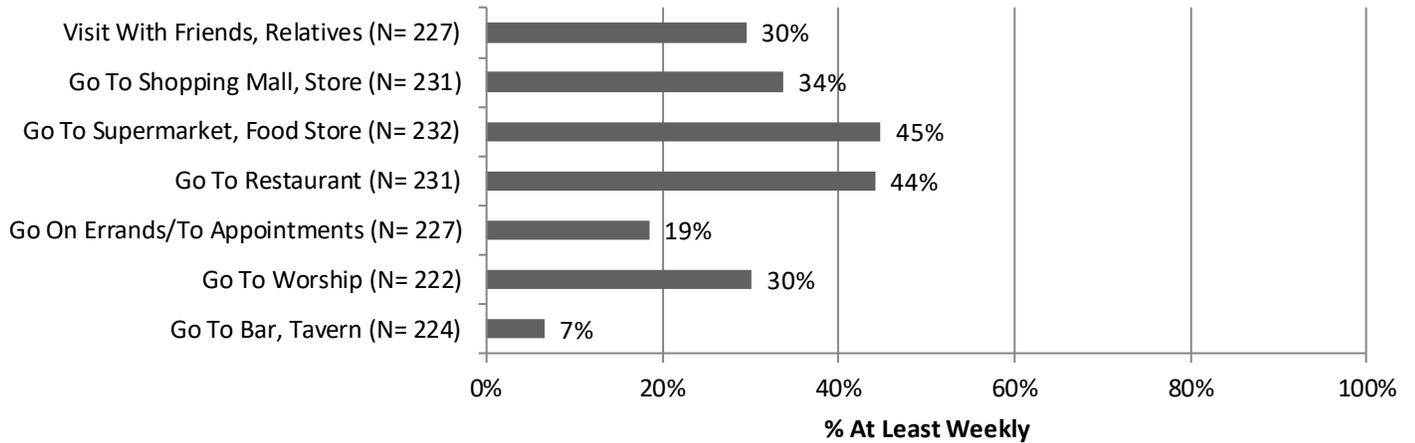


A value of missing was assigned when individuals did not answer, gave an unclear answer, or responded “do not know.”

Community Participation

- 30% of the people visited with friends, relatives and neighbors at least weekly (state finding 51%, regional 48%)
- 45% of individuals went to a supermarket, 44% went to a restaurant, and 34% went to a shopping mall at least weekly (state finding 51%, 51%, and 44%; regional 51%, 44% and 39% respectively)
- At least weekly, individuals went out for errands and appointments (19%), to places of worship (30%), and to bars/taverns (7%). State findings were 29%, 31%, and 19%; regional 23%, 33%, and 18% respectively.
- 19% of individuals go out for entertainment at least weekly (state finding 27%, regional 26%).

Community Participation



For each area of community participation, respondents reported who the individual usually goes with.

WITH WHOM	Alone	Friends	Family	Housemates, coworkers	Staff	Other
Visit friends, relatives, neighbors	10%	19%	56%	1%	13%	1%
Went to a shopping mall	3%	3%	66%	4%	24%	0%
Went to a supermarket	7%	2%	69%	1%	22%	0%
Went to a restaurant	1%	11%	65%	4%	18%	0%
Went out for errands/appointments	8%	2%	69%	4%	18%	0%
Went to worship	5%	3%	78%	3%	10%	0%
Went out for entertainment	1%	12%	64%	2%	20%	1%
Went to bars/taverns	6%	10%	68%	0%	11%	5%

For each area of community participation, respondents reported if the amount was enough (wanted more, wanted less, wanted current amount).

WITH WHOM	More	Less	Right amount
Visit friends, relatives, neighbors	22%	3%	75%
Went to a shopping mall	12%	4%	83%
Went to a supermarket	10%	5%	85%
Went to a restaurant	18%	2%	79%
<i>Went out for errands/appointments</i>	7%	3%	90%
<i>Went to worship</i>	8%	1%	91%
<i>Went out for entertainment</i>	23%	1%	76%
<i>Went to bars/taverns</i>	7%	1%	92%

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, while people without disabilities are about 10% more likely to visit with friends, relatives, and neighbors than people with disabilities.
- Pennsylvanians with disabilities in IM4Q were slightly more than twice as likely to go to a restaurant weekly as people with disabilities in the Harris Poll, and also slightly more likely than people without disabilities in the Harris Poll.
- Pennsylvanians with disabilities in IM4Q are a little more likely to go to places of worship weekly than people with disabilities in the Harris Poll.

County comparisons are as follows:

Weekly Participation in Community Activities for Delaware AE

	Harris 2010: People without Disabilities	Harris 2010: People with Disabilities	IM4Q State	IM4Q County/ Joinder
Visit with friends, relatives, and neighbors	65%	54%	51%	30%
Go to restaurant	41%	20%	51%	44%
Go to worship	28%	24%	31%	30%

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 average score was 39.47 with a standard deviation of 16.84 (state finding 45.62 and 17.52; regional 44.24 and 17.33)

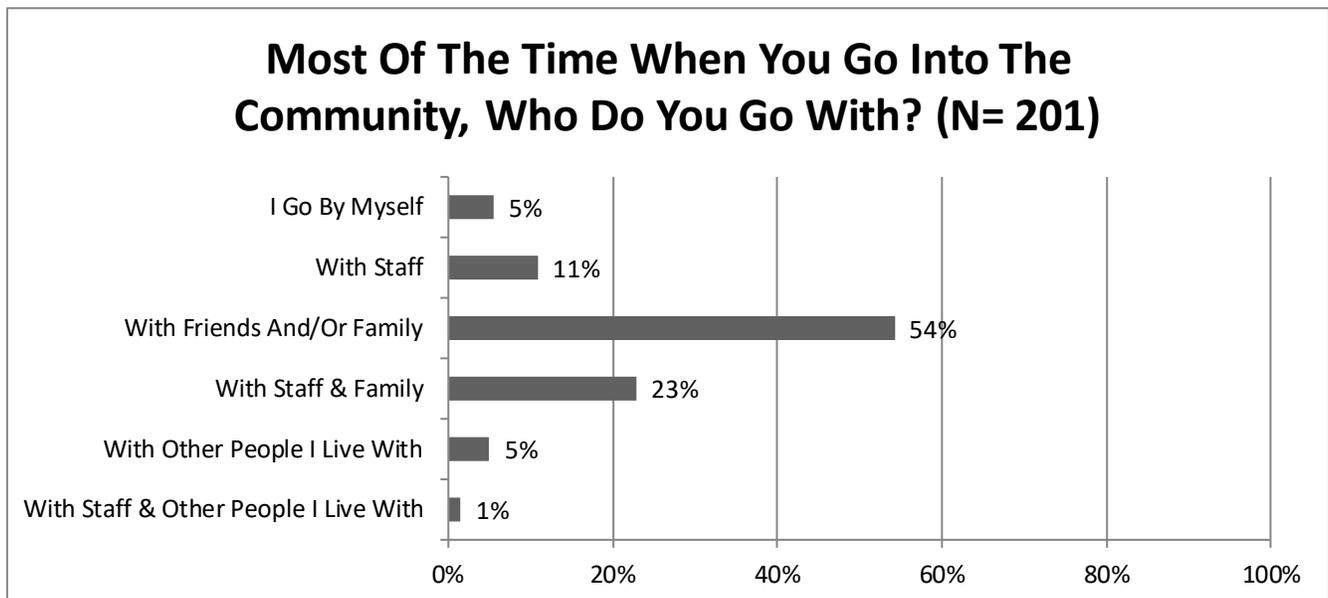
Community Activities

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

- 47% of the individuals go frequently into the community for entertainment (state finding 55%, regional 54%)
- 28% of individuals reported that they frequently go to social events in the community that are attended by people with and without disabilities (state finding 42%, regional 39%)
- 39% of individuals would like to be a part of more groups in their community (state finding 31%, regional 40%).
- 55% of individuals went on a vacation in the past year (state finding 48%, regional 55%)
- Regarding monthly exercise, 43% of individuals reported never going out for exercise (state finding 39%, regional 39%), 3% exercise less than weekly, 11% exercise once a week, and 43% exercise more than once a week (state finding 46%, regional 47%).

Going Out Alone or With Other People

- 5% of individuals go out alone (state finding 8%, regional 9%)
- 12% of individuals go out with staff (or staff and other people they live with) most of the time (state finding 34%, regional 24%)

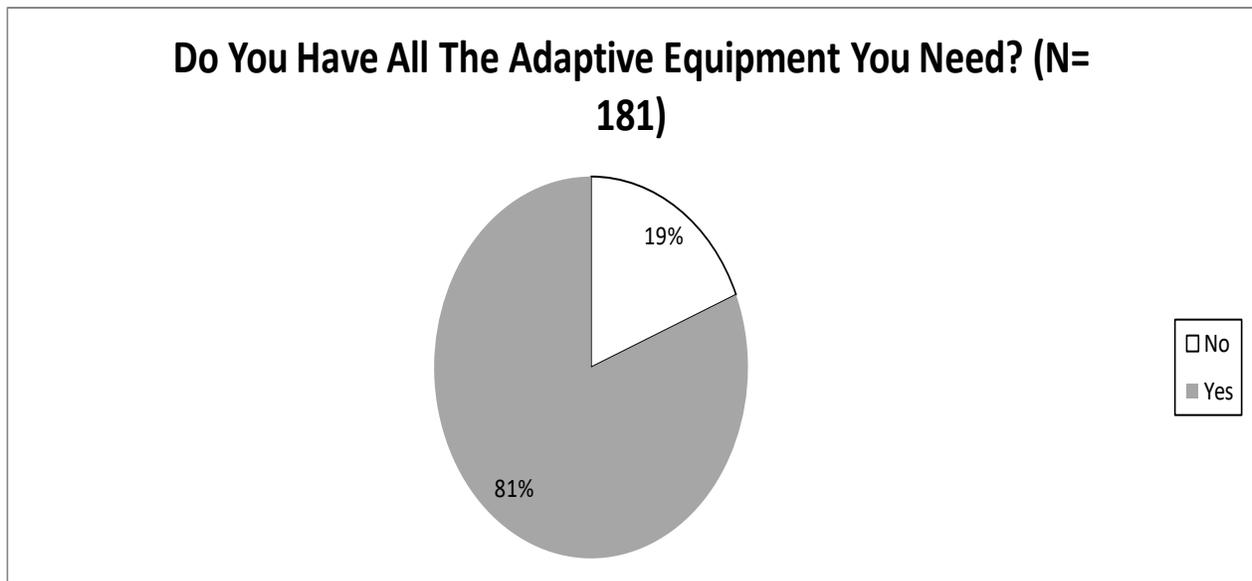


Transportation

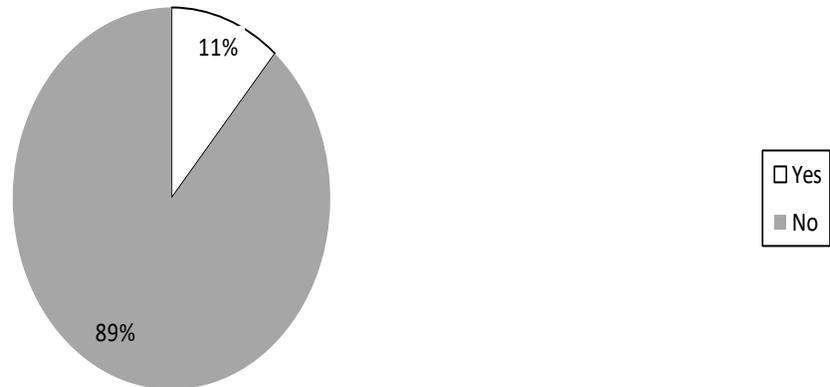
- 87% of people always had a way to get where they wanted to go (90% state finding, 89% regional)
- In order to get to places they needed to go, individuals reported getting a ride from staff in the provider van (15%). 61% reported getting a ride from family or friends, 8% reported getting a ride in a staff member's car, 5% transport themselves, 4% ride public transportation, 6% ride paratransit, and 0% take a taxi, Uber or Lyft.
- Of those who cannot always get where they want to go, 15% cannot get where they want to go because there is not enough staff (16% state finding, 12% regional)

Home Adaptive Equipment

- 81% of individuals reported having all the adaptive equipment they needed (state finding 85%, regional 77%)
- 89% of people said that they do not need any changes to their home to make it accessible (state finding 92%, regional 93%)



**Do you need changes to make your home more accessible?
(N= 230)**

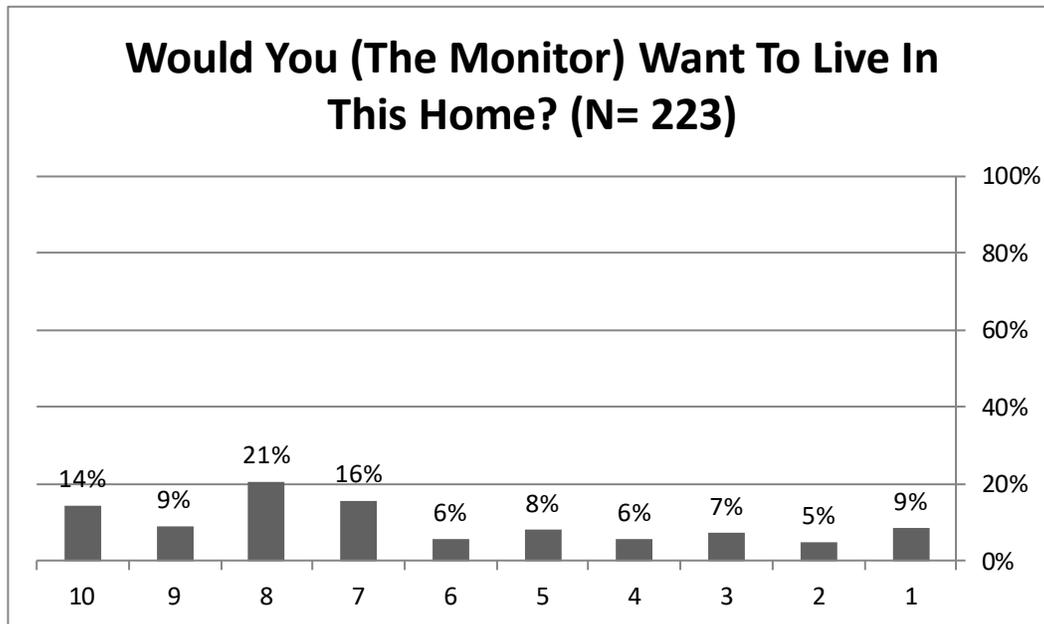


Competence, Personal Growth and Opportunities to Grow and Learn

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 5 (maybe) to 10 (I'd move in tomorrow), the average score was 6.4 (state finding 6.6, regional 6.5)



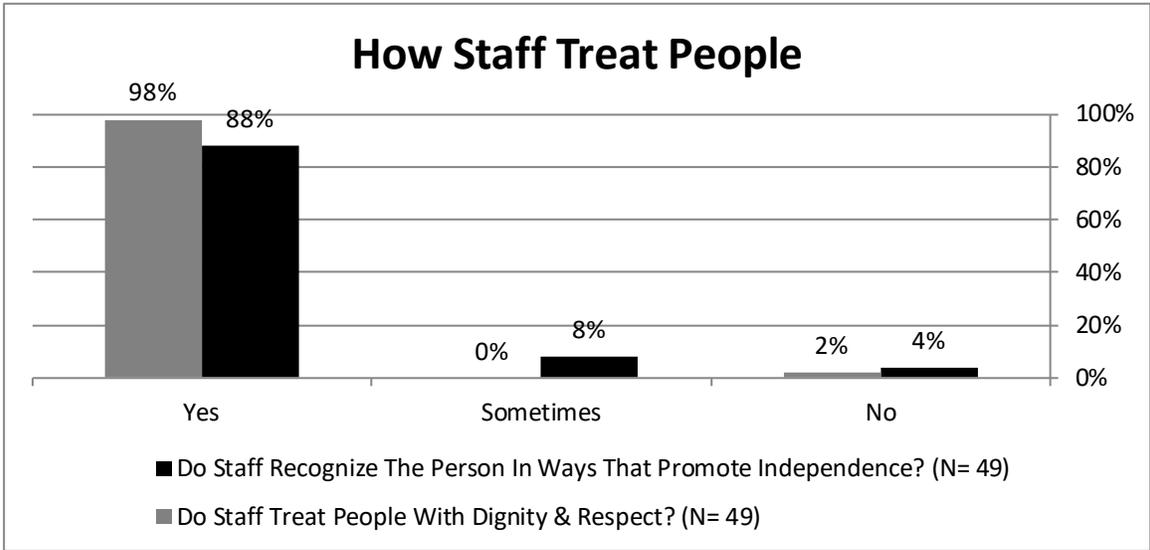
Staff Support for the Person

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 IM4Q teams,

- 88% of staff observed recognized the individuals in ways that promote independence (state finding 91%, regional 81%)
- 98% of the monitoring teams observed that the staff treated individuals with dignity and respect (state finding 92%, regional 83%)
- 94% of staff observed that support individuals at home and/or work appeared to have the skills they needed to support the person (state finding 91%, regional 82%).

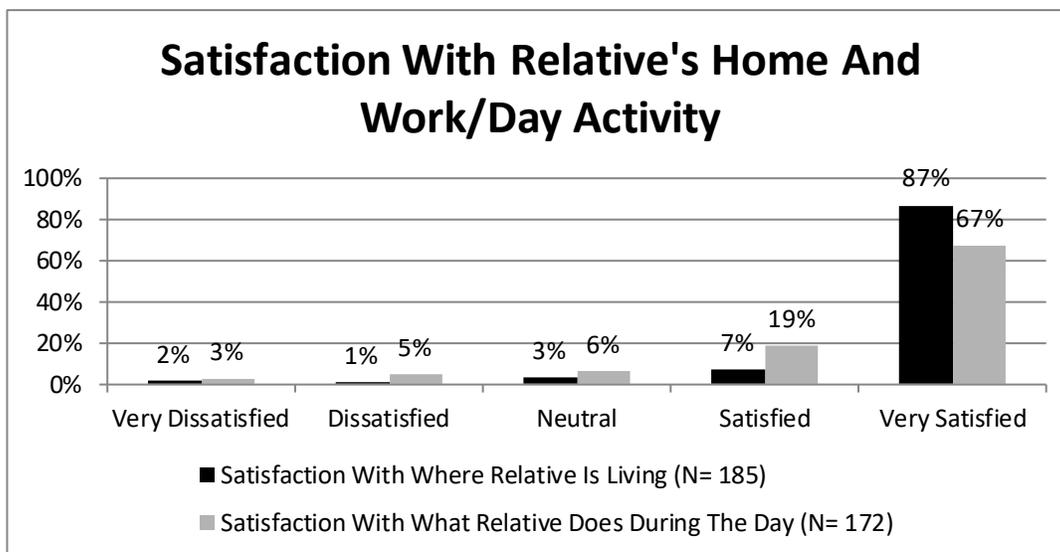


Family/Friend/Guardian Survey

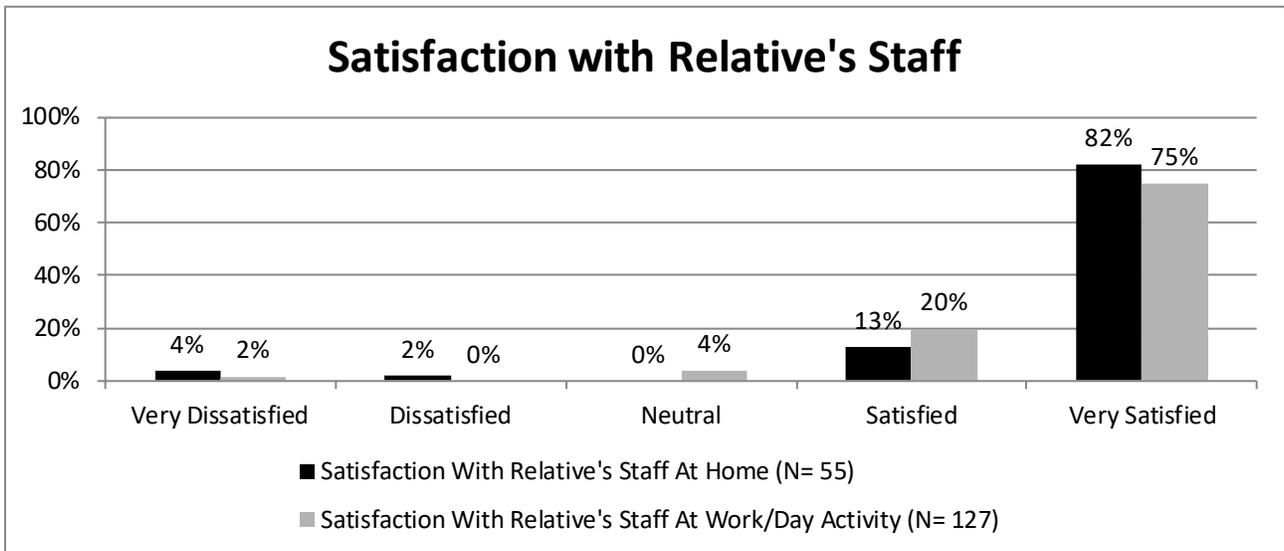
Respondents: This survey was completed by telephone with a family member, guardian, or friend who was identified through the Essential Data Elements Pre-Survey. In the event that a phone survey could not be completed, surveys were completed by mail. A total of 185 family members, friends, and guardians from the Delaware AE participated in the survey.

- 81% of the surveys were answered by parents
- 11% were answered by siblings
- 2% were answered by the guardian
- 1% were answered by a friend
- 2% were answered by another relative (spouse, aunt, uncle, cousin, grandparent)
- 4% were answered by persons with other relationships to the individual receiving supports

Satisfaction



- 94% of the families surveyed were either somewhat satisfied or very satisfied with where their relative lives (state finding 95%, regional 94%).
- 86% were either somewhat satisfied or very satisfied with what their relative does during the day (state finding 89%, regional 87%).



- 95% of the families surveyed were either somewhat satisfied or very satisfied with their relative's staff at home (state finding 94%, regional 92%).
- 94% of the families surveyed were either somewhat satisfied or very satisfied with the staff at their relative's day activity (state finding 95%, regional 94%).

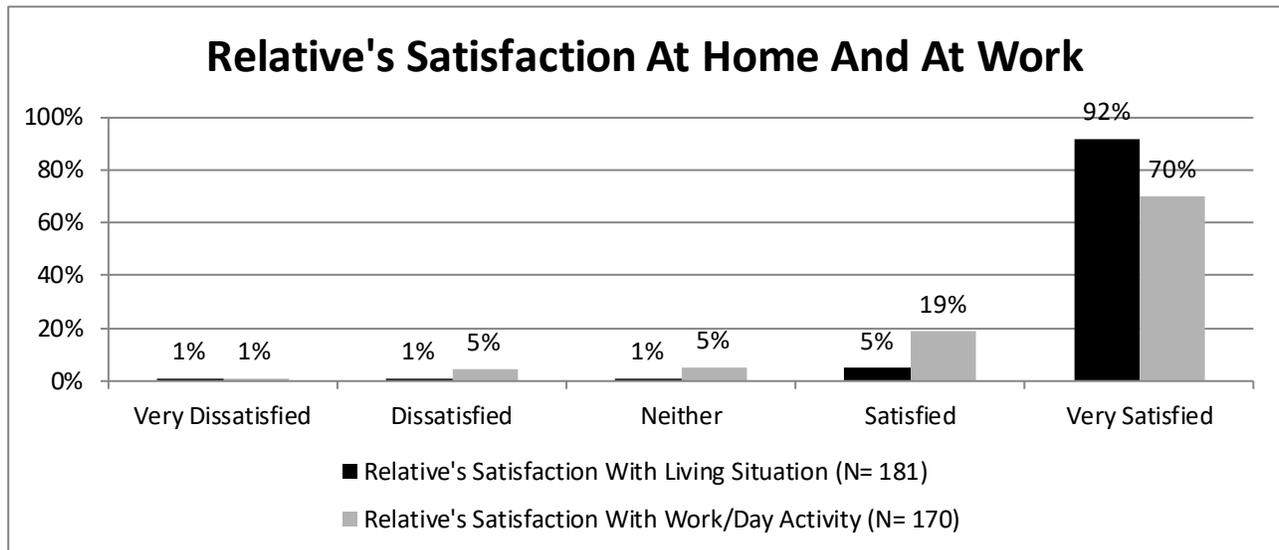
How Often Do You Contact/See Your Relative?

- 100% of the family/friend/guardians contacted their relative at least monthly (state finding 87%, regional 89%); 0% have not contacted their relative in the past year (state finding 5%, regional 4%).
- 100% 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 (state finding 81%, regional 87%); 0% did not get to see their relative in the past year (state finding 3%, regional 3%)

Your Relative's Satisfaction

- 97% of respondents felt their relative was either very satisfied or satisfied with his/her living situation (state finding 95%, regional 95%)
- 89% felt their relative was either very satisfied or satisfied with what they do during the day (state finding 91%, regional 87%)

- 96% of respondents felt their relative was either very satisfied or satisfied with the staff who support them at home (state finding 95%, regional 94%); 2% felt their relative was either dissatisfied or very dissatisfied (state finding 2%, regional 3%)
- 97% of respondents felt their relative was either very satisfied or satisfied with the staff who support them at work or during the day (state finding 96%, regional 94%); 1% felt their relative was either dissatisfied or very dissatisfied (state finding 1%, regional 2%)



Your Relative's Safety

- Respondents said that their relative felt safe in their community / home / neighborhood always (82%) or most of the time (16%). State findings were 86% and 12% respectively; 83% and 14% regional.

Your Relative's Opportunities

- 75% of the respondents said that their relative got enough opportunities to participate in activities in the community (state finding 85%, regional 78%)
- 73% of the respondents said that their relative seemed to have the opportunity to learn new things (state finding 86%, regional 81%)

Your Relative's Staff

- If their relative did not communicate verbally, 35% of the respondents said that there is a formal communication system in place for their relative and they use it (state finding 36%, regional 29%); for 83%, the communication system is used across all settings (state finding 78%, regional 73%).
- 66% of the respondents said that their relative's home appeared to have enough paid staff (state finding 85%, regional 80%)
- 97% of the respondents said that staff in their relative's home treat people with dignity and respect (state finding 96%, regional 95%)
- 89% of the respondents said that all staff appear to have the skills they need to support their relative, and 3% felt that way about only some staff (state finding 89% and 9% respectively; 89% and 8% regional)
- 89% of the respondents said that their relative's place of work appears to have an adequate number of paid staff (state finding 95%, regional 93%).
- 98% of respondents said that staff in their relative's place of work always treat people with dignity and respect (state finding 97%, regional 97%).
- 92% of respondents reported that staff in their relative's place of work appear to have the skills they need to support their relative (state finding 91%, regional 91%).

Your Relative's Supports

- 74% of relatives were satisfied with the supports coordination their relative receives (state finding 84%, regional 77%)
- 60% of relatives reported that they were told how much money is in their relative's annual budget (state finding 63%, regional 60%)
- 10% of relatives report that their relative self-directs their own services (state finding 8%, regional 7%).
- 66% said that their relative always received the supports they needed (state finding 69%, regional 61%)
- 81% said that the services and supports their relative receives change when their relative's needs change (state finding 85%, regional 78%)

- 87% of relatives always felt that the staff who assisted them with planning respected their choices and opinions (state finding 91%, regional 90%)
- 53% of relatives never felt that there were frequent changes in support staff at their family member's home, work or day program (state finding 57%, regional 55%)
- 36% of relatives always got to choose the agency/provider who worked with their relative (state finding 42%, regional 46%); 4% had their relative choose (state finding 6%, regional 7%); 12% chose with their relative (state finding 20%, regional 15%); 48% never got to choose (state finding 32%, regional 32%)
- 36% of relatives were familiar with the way complaints and grievances are handled at the provider level (state finding 59%, regional 53%). 36% of relatives were familiar with the way complaints and grievances are handled at the county/AE level (state finding 58%, regional 51%). 30% of relatives were familiar with the way complaints and grievances are handled at the state level (state finding 52%, regional 46%). 59% were not familiar of the grievance and complaint process on any level (state finding 34%, regional 42%)

Family Resources

- 80% of relatives felt that the information they received about their relative's services was easy to understand (state finding 90%, regional 87%)
- 11% of respondents had learned about the Life Course Framework and Tools (state finding 12%, regional 10%)
- 34% of relatives have an opportunity to connect and network with other families with relatives at similar life stages (state finding 46%, regional 41%)
- 16% of relatives said they were aware of the PA Family Network (state finding 22%, regional 17%); of those who were aware, 38% had attended a workshop led by the Network of Family Advisors (state finding 32%, regional 42%).
- 78% of relatives said that they have enough information about services for which their family is eligible (state finding 78%, regional 73%)
- 5% of respondents whose family member transitioned from school to adult services in the past year were happy with the process (state finding 32%, regional 24%)

- 62% of relatives report that the services coordinator asks about their vision for an everyday life for their family member (state finding 71%, regional 66%)

Emergency Preparation Questions

- 49% of relatives had someone talk to them about an emergency plan for their family member, in case of emergencies (state finding 55%, regional 53%)

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

- The average (mean) score was 90.62 with a standard deviation of 14.42 (state finding 91.48 and 13.14 respectively, 90.24 and 11.57 regional)

Summary

For a summary of the information collected through face-to-face interviews with the 240 individuals in Delaware AE receiving supports through the Office of Developmental Programs, please refer to the two user-friendly reports produced for the AE. One version presents key data for both the AE and statewide in chart format. The other presents an abbreviated number of items using a more easily understandable icon format. Each AE receives each of these reports, along with the statewide report and two statewide user-friendly reports (one with charts, one with icons).