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

Independent Monitoring for Quality (IM4Q)
Allegheny AE
2012-2013

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

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Introduction

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

As a result of the IM4Q Program, ODP has developed and begun to implement quality improvement strategies (QIS) 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. 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

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 85 questions, reduced from the 101 questions asked previously. Thirty-five of the questions can only be answered by the individuals receiving supports and services.

The EDE for fiscal year 2012-2013 includes all survey questions included in the FY 2012-2013 NCI Adult Consumer Survey. At the time of this report, approximately 1409 individuals included in this report are represented in the NCI sample for 2012-2013, based on a sampling methodology established by ODP and the Human Services Research Institute (HSRI). A copy of the NCI report for FY 2012-13 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.

The sampling procedure for this year continues to be drawn through the Home and Community Services Information System (HCSIS); ODP's computerized database continues to be used to enter IM4Q data as well. The following table shows the breakdown of the sample by type of residential setting. This year's sample included 599 people in Allegheny AE.

Type of Residential Setting for

Allegheny AE

Type of Residential Setting	Pennsylvania Overall		County/Joinder	
	N	Percent	N	Percent
State ICF/MR	48	0.8%	1	0.2%
State Mental Health Hospital	2	0.0%	0	0.0%
Homeless	0	0.0%	0	0.0%
Temporary Shelter	0	0.0%	0	0.0%
Foster Care	2	0.0%	0	0.0%
Incarceration	1	0.0%	0	0.0%
Nursing Home/Nursing Facility	68	1.2%	0	0.0%
Domiciliary Care	18	0.3%	1	0.2%
Personal Care Home (PCH)	96	1.7%	1	0.2%
Family living	290	5.1%	9	1.5%
Unlicensed Family Living	20	0.3%	1	0.2%
Own residence	426	7.4%	19	3.2%
Relative's home	1474	25.8%	27	4.5%
Children's Facility	6	0.1%	1	0.2%
Approved Private School	10	0.2%	0	0.0%
Private ICF/MR (4 or fewer persons)	96	1.7%	22	3.7%
Private ICF/MR (4 to 8 persons)	184	3.2%	27	4.5%
Private ICF/MR (9 to 15 persons)	19	0.3%	0	0.0%
Private ICF/MR (16 or more	432	7.5%	121	20.3%
Community Home (1 person)	100	1.7%	17	2.8%
Community Home (2 to 4 persons)	2093	36.6%	288	48.2%
Community Home (5 to 6 persons)	139	2.4%	20	3.4%
Community Home (7 to 8 persons)	63	1.1%	5	0.8%
Community Home (9 to 15 persons)	22	0.4%	0	0.0%
Community Home (16 or more	30	0.5%	0	0.0%
Other	84	1.5%	37	6.2%
Missing	135	-	2	-
Total	**5858**	**100%**	**599**	**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 State 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 newly formed entities.

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.

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 HCSIS website. Data for the 2012-13 survey cycle was collected by June 30, 2013 and entered into HCSIS by August 15, 2013. A data file was received by the Institute on Disabilities in January, 2014. 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 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	599	10.2%
Armstrong/Indiana	97	1.7%
Beaver	101	1.7%
Bedford/Somerset	77	1.3%
Berks	152	2.6%
Blair	99	1.7%
Bradford/Sullivan	45	0.8%
Bucks	215	3.7%
Butler	87	1.5%
Cambria	92	1.6%
Cameron/Elk	36	0.6%
Carbon/Monroe/Pike	100	1.7%
Centre	67	1.1%
Chester	151	2.6%
Clarion	45	0.8%
Clearfield/Jefferson	72	1.2%
Columbia/Montour/Snyder/Union	91	1.6%
Crawford	83	1.4%
Cumberland/Perry	91	1.6%
Dauphin	147	2.5%
Delaware	257	4.4%
Erie	226	3.9%
Fayette	80	1.4%
Forest/Warren	34	0.6%
Franklin/Fulton	70	1.2%
Greene	26	0.4%
Huntington/Mifflin/Juniata	47	0.8%
Lackawanna/Susquehanna	143	2.4%
Lancaster	147	2.5%
Lawrence	71	1.2%
Lebanon	67	1.1%
Lehigh	142	2.4%
Luzerne/Wyoming	132	2.3%
Lycoming/Clinton	98	1.7%
McKean	45	0.8%
Mercer	73	1.2%
Montgomery	281	4.8%
Northampton	113	1.9%
Northumberland	82	1.4%
Philadelphia	694	11.8%
Potter	0	0.0%
Schuylkill	84	1.4%
Tioga	39	0.7%
Venango	50	0.9%
Washington	94	1.6%
Wayne	34	0.6%
Westmoreland	143	2.4%
York/Adams	139	2.4%
TOTAL	**5858**	**100%**

Satisfaction

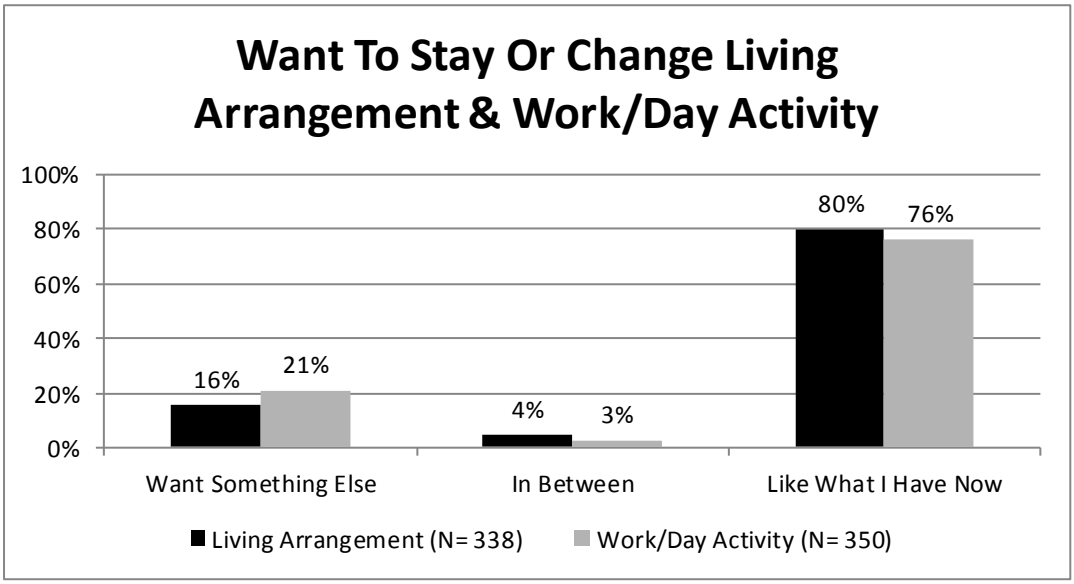
Respondents: Only the individual receiving services/supports could answer the questions on satisfaction. Statewide, the percent of people who responded to questions in this section ranged from 36% to 62%.

Satisfaction with Living Arrangements

- 88% of individuals liked where they live (state finding 90%, regional 90%).
- 80% wanted to stay where they currently live (state finding 79%, regional 80%).

Satisfaction with Work/Day Activity

- 93% of individuals with a day activity/work liked what they did during the day (state finding 92%, regional 93%).
- 76% wanted to continue their current daytime activities/work (state finding 73%, regional 73%), 21% wanted to do something else (state finding 20%, regional 21%).



Daily Life

- 97% of individuals reported getting the services and supports they need (state finding 89%, regional 93%).
- On most weekdays, 43% of individuals report they attend an adult training program (state finding 39%), 10% stay home, 4% go out and do things in the community, 35% are at a vocational facility, 11% work part time for pay, 2% work full time for pay, 0% help their neighbors and/or friends, 2% volunteer and 1% attend school; individuals report rarely attending college or trade school and rarely were retired.

Happiness and Loneliness

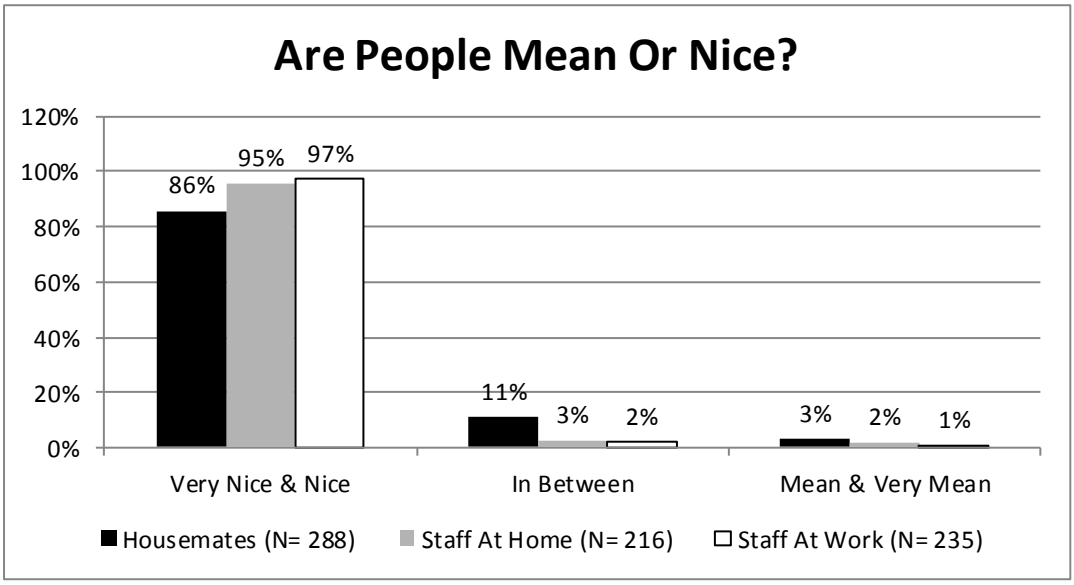
- 80% reported usually feeling happy (state finding 83%, regional 82%), 14% reported being in-between (state finding 13%, regional 14%), and 6% reported usually feeling sad (state finding 3%, regional 4%).
- 60% of individuals reported never feeling lonely (state finding 63%, regional 59%), 33% reported sometimes feeling lonely (state finding 32%, regional 35%), and 7% reported always feeling lonely (state finding 5%, regional 6%).
- 73% reported having friends, which are not staff or family, with whom they like to do things (state finding 72%, regional 76%).
- 96% reported that they can go on a date if they want to or are married (state finding 75%, regional 82%); 2% reported that they can go on a date if they want to but there are some restrictions and rules (state finding 13%, regional 9%), and 2% are not allowed to (state finding 13%, regional 9%).

Privacy

- 95% of the individuals surveyed reported that they always have privacy (a place to be alone) when they want it (state finding 96%, regional 96%).
- At least most of the time 89% 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 90%, regional 90%).
- For 86% of the individuals, people always knock on the bedroom door and wait for a response before coming in (state finding 84%, regional 82%).

Are People Nice or Mean?

- 86% reported that their housemates are very nice or nice (state finding 89%, regional 89%).
- 95% of the people interviewed reported that their staff who work with them at home are very nice or nice (state finding 95%, regional 96%).
- 97% reported that staff who work with the respondents at work or day activity are nice or very nice (state finding 95%, regional 96%).



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

- The average (mean) score was 85.21 with a standard deviation of 19.90 (86.03 and 18.86 state finding; 85.41 and 19.08 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 34% to 63%.

Forms of Identification

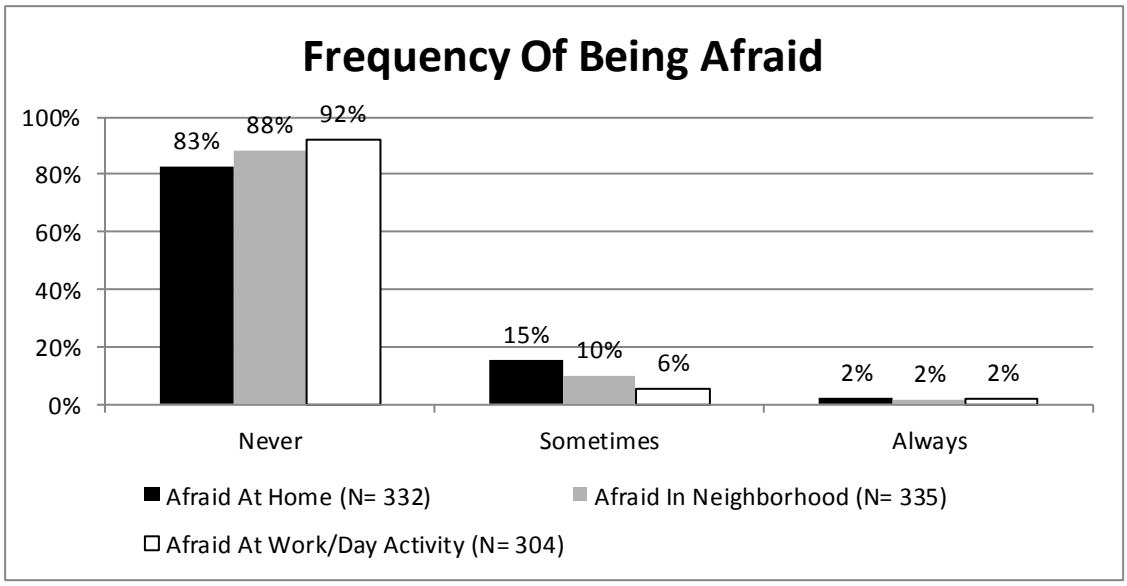
- 70% of individuals stated that they always carry a form of identification, such as a card with the individuals name, address and a person to call in case of emergency or a non-driver ID (state finding 61%, regional 61%); 14% never do (state finding 18%, regional 17%).

Support with Problems and Goals

- 94% of individuals always had someone to go to for help if they have a problem (state finding 93%, regional 93%).
- 57% want help to learn new things (state finding 55%, regional 54%).
- 79% of individuals report that they get to help other people (state finding 77%, regional 80%).

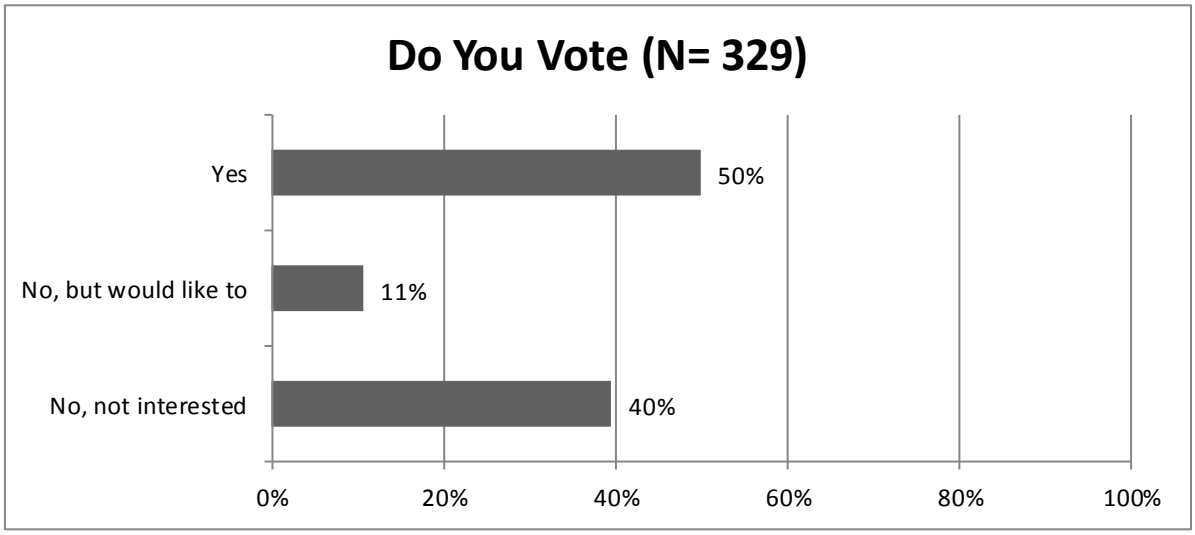
Being Afraid

- 83% reported never being afraid at home (state finding 84%, regional 83%).
- 88% reported never being afraid in the neighborhood (state finding 86%, regional 86%).
- 92% reported never being afraid at work, school or day activity (state finding 90%, regional 91%).



Legal Rights

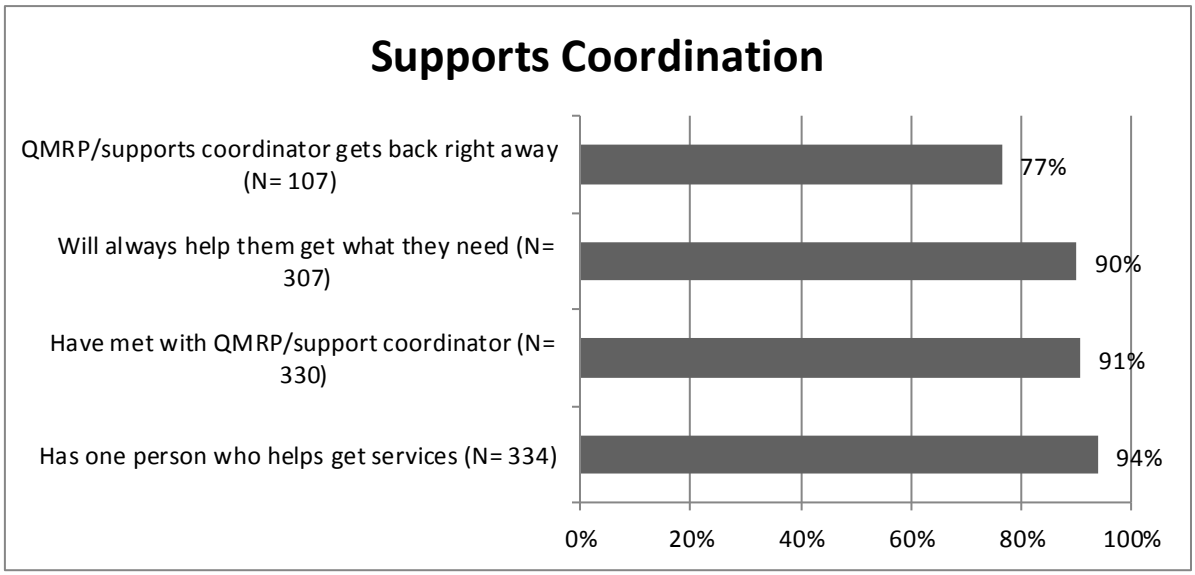
- 50% of people said that they do vote (state finding 42%, regional 38%); 11% do not vote but would like to (state finding 11%, regional 10%), and 40% do not vote and are not interested (state finding 47%, regional 52%).



Supports Coordination/Qualified Intellectual Disability Professional (QIDP)

- 94% of individuals reported that they have one person (supports coordinator/QIDP) who helps them get the services they need (state finding 97%, regional 97%).

- 91% reported that they have met with their supports coordinator/QIDP in the past year (state finding 95%, regional 95%).
- 90% of individuals reported that, if they ask, their supports coordinator will always help them get what they need (state finding 88%, regional 88%).
- 77% of the people reported that when they call, their supports coordinator/QIDP always gets back to them right away (state finding 82%, regional 82%).
- 76% of those surveyed have been told how much money was in their annual budget (state finding 70%, regional 75%).



Emergency Preparation Questions

- 95% of individuals have been given information about what to do in an emergency (state finding 78%, regional 73%).
- When asked who gave the individual information about what to do in an emergency, 78% received information from staff (state finding 52%), 31% from day program or employment staff, 6% from someone in their family, 3% from the police, fire department, or EMS, 1% from supports coordinator, 1% from neighbors or friends, and 1% from someone from red cross; 6% 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).

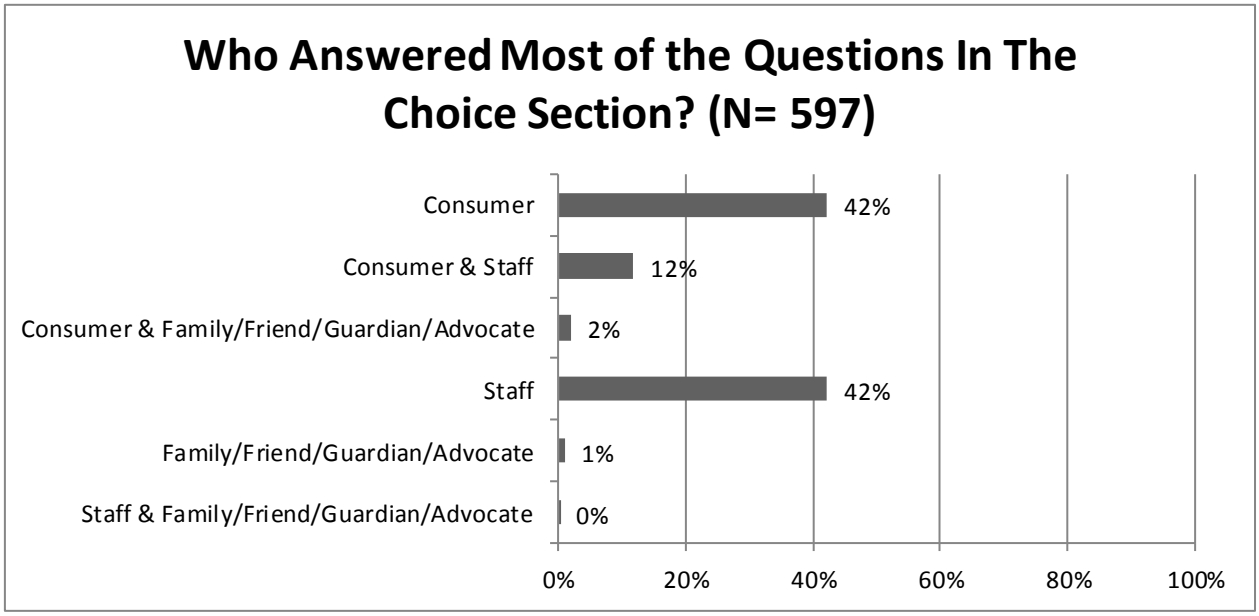
- The average score was 73.72 with a standard deviation of 8.97 (83.16 and 13.52 state finding; 80.84 and 12.48 regional).

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 92.17 with a standard deviation of 16.76 (91.79 and 16.99 state finding; 91.67 and 16.99 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.

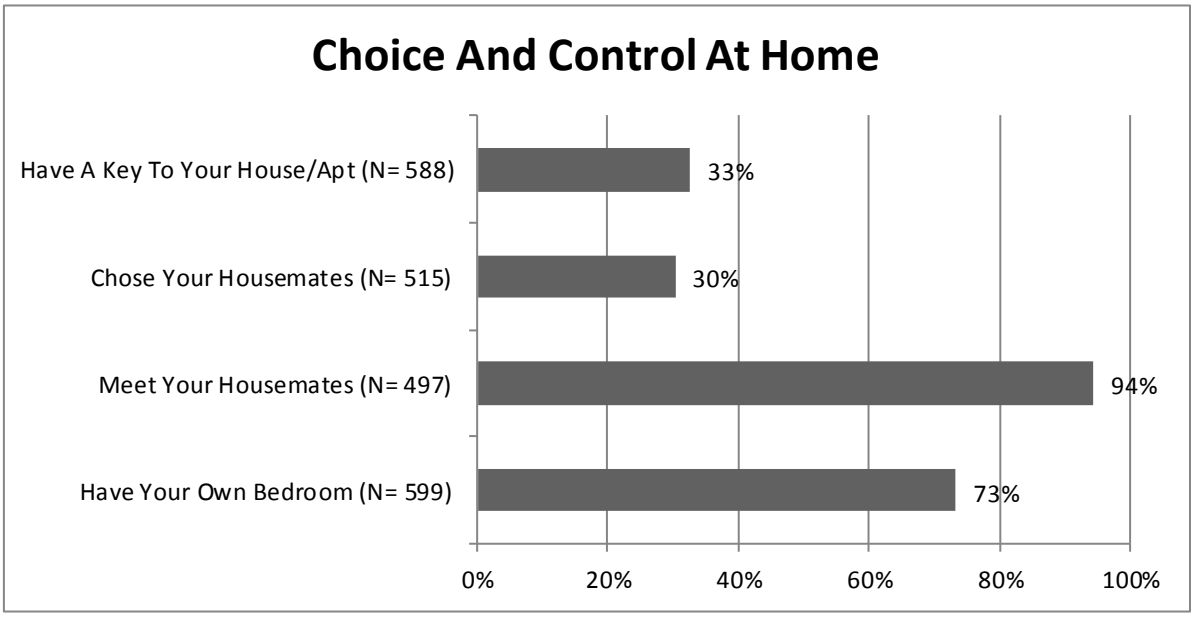


A value of missing was assigned when individuals did not answer, gave an unclear answer, or responded, “do not know.”

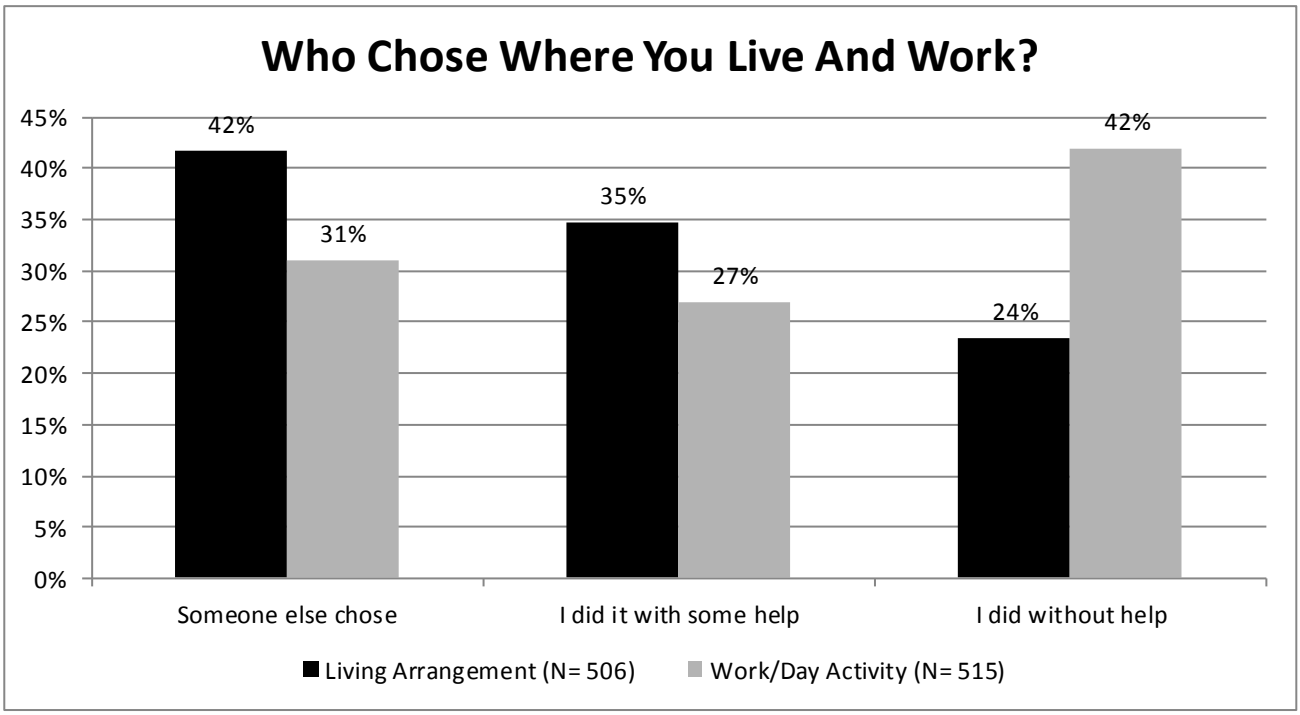
Choice and Control at Home

- 33% of the individuals surveyed had a key/way to get into their house or apartment on their own (state finding 34%, regional 35%).
- For 42% of the individuals, someone else choose where they live (state finding 52%, regional 47%); 24% of those interviewed chose without assistance (state finding 21%, regional 23%).
- For those individuals who had some control in choosing where they live, 49% saw more than one other place before moving in (state finding 44%, regional 44%); 5% saw no other places (state finding 13%, regional 13%).
- 70% of the individuals did not choose their housemates (state finding 67%, regional 69%).

- 94% of the individuals surveyed met some or all of their housemates before living together (state finding 84%, regional 87%)
- 73% of the individuals had their own bedroom (state finding 79%, regional 79%); for those who shared a bedroom, 31% chose some or all of their roommates (state finding 37%, regional 34%)



- For 96% of the individuals interviewed, their mail is never opened without permission (state finding 82%, regional 91%); 2% say their mail is always opened without permission (state finding 12%, regional 6%)



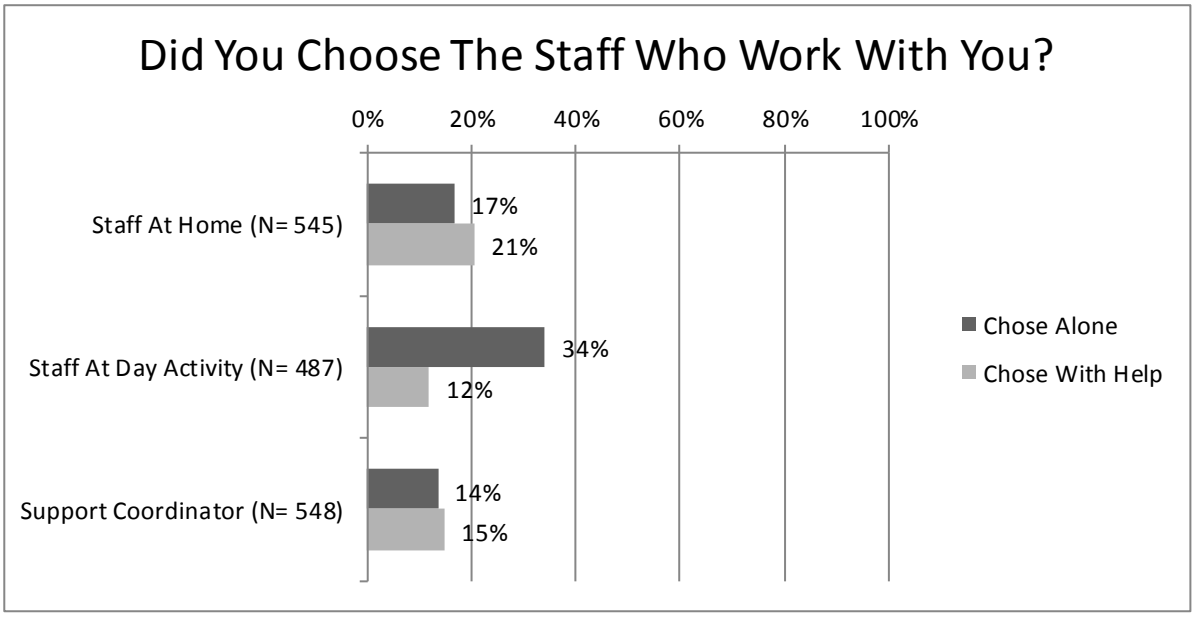
Choice and Control During the Day and for Leisure Time

- 31% of the individuals interviewed reported that someone else chose what they do during the day (state finding 34%, regional 34%).
- 42% of the people interviewed chose what they do during the day without assistance (state finding 35%, regional 39%).
- For those individuals who participated in choosing what they do during the day, 50% saw more than one other place before deciding (state finding 42%, regional 40%); 5% saw no other places (state finding 12%, regional 13%).
- 48% of the individuals surveyed chose their daily schedules without assistance (state finding 51%, regional 50%).
- 82% chose how they spend their free time without assistance (state finding 68%, regional 76%).

Choice and Control in Choosing Staff

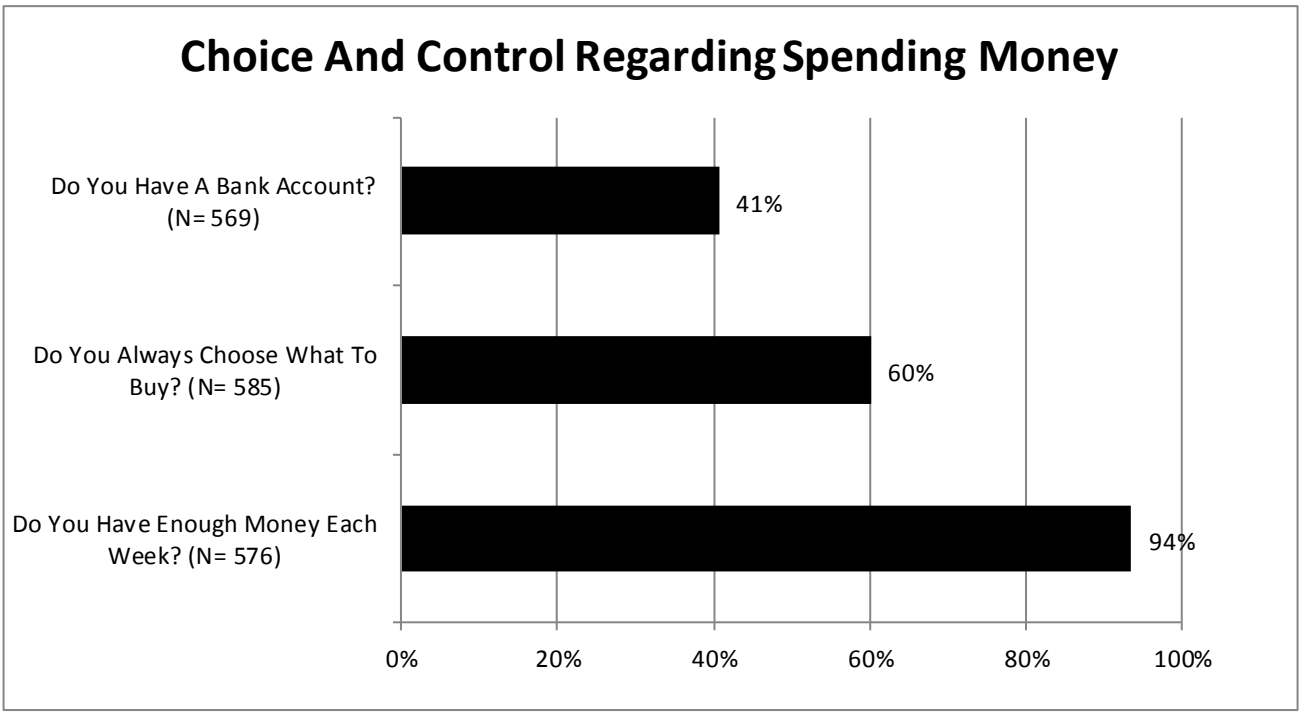
- 37% of the individuals interviewed chose the staff that helps them at home, alone or with assistance from family or provider (state finding 41%, regional 37%).

- 46% 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 38%, regional 40%).
- 28% of the individuals reported that they chose their supports coordinator (alone or with assistance from family or provider) (state finding 32%, regional 34%).



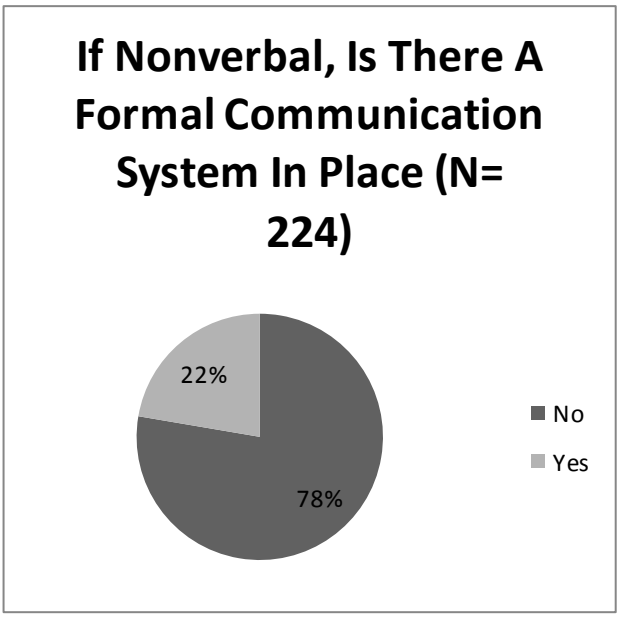
Choice and Control with Regard to Money

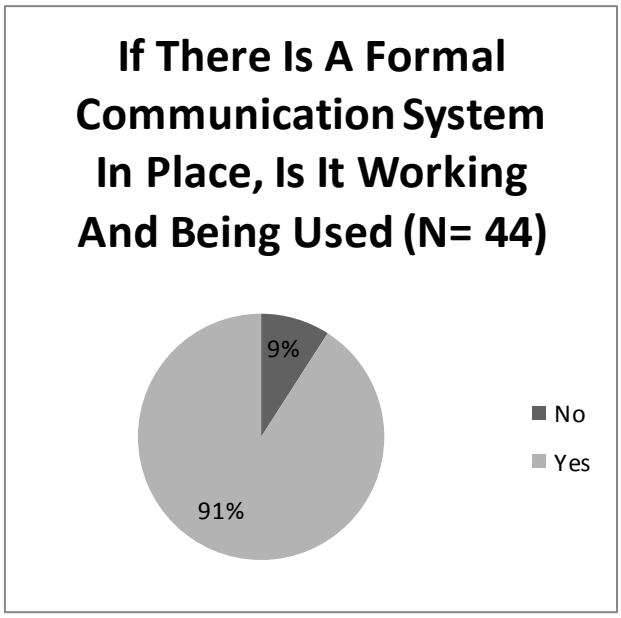
- 94% of the individuals have enough money to do many of the things they want to do each week (state finding 92%, regional 92%).
- 60% of the individuals reported that they always choose what to buy with their spending money (state finding 57%, regional 61%).
- 41% of the individuals reported that they have a bank account that they can get to independently to withdraw money when they want it (state finding 45%, regional 43%).



Access to Communication

- For those individuals who do not communicate using words (n=224), there is a formal communication system in place for 22% of the people interviewed (state finding 32%, regional 34%).
- For those people with formal communication systems in place (n=44), the systems are in working order and utilized for 91% of the people interviewed (state finding 90%, regional 93%).
- 87% of individuals with a formal communication system reported using it across all settings (state finding 77%, regional 86%).





- In regards to forms of communication individuals have and use, 94% have and use cable television (state finding 83%, regional 88%), 18% cell phones, 12% internet, 8% email, and 7% text messaging.

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 48.72 with a standard deviation of 23.14 (48.72 and 23.39 state finding, 49.73 and 23.02 regional).

Employment

Respondents: Of the 594 individuals surveyed for the Allegheny AE, 44 respondents indicated they are employed.

Community Integrated Employment

- 7% of individuals work in a community integrated setting (8% state finding, 8% regional).

Types of Work

- Statewide, 37% of individuals work in food services; 24% work in cleaning; 4% work in the stock room; 6% work in assembly; 6% work in office work and 5% in maintenance.

Supports in the Workplace

- 80% of individuals had job coach supports.
- 69% of individuals had transportation other than public transportation provided.
- 26% of those surveyed received counseling.
- 11% of individuals received some other kind of supports.

Compensation and Advancement

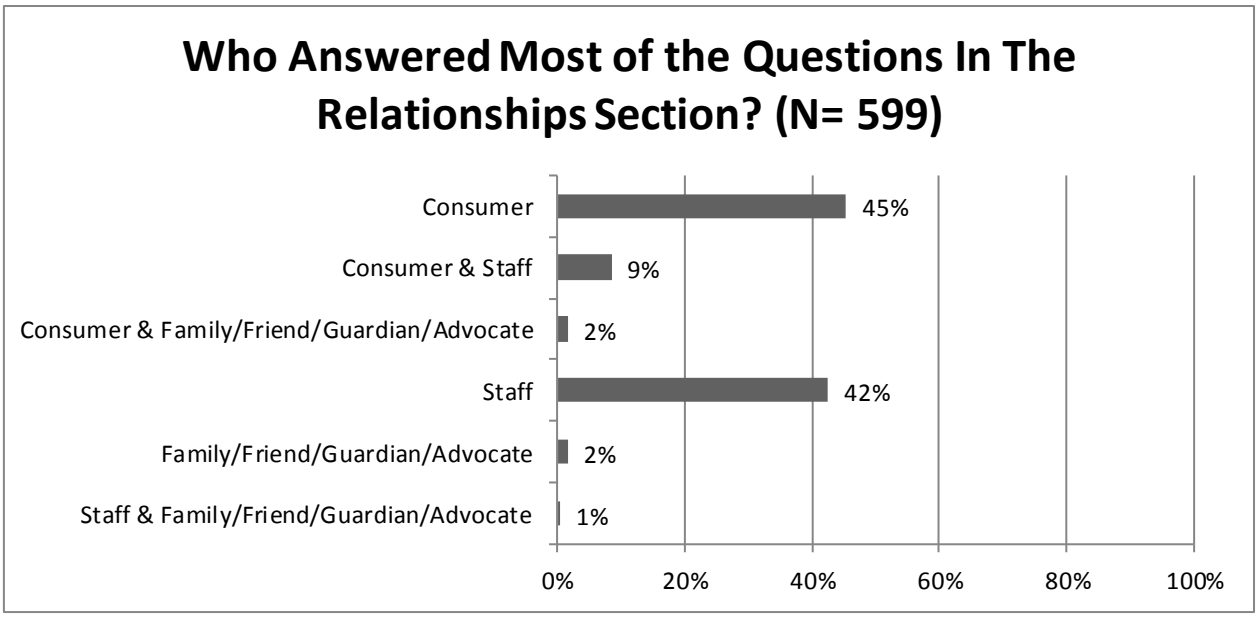
- 96% of individuals received paid time off, 30% received health insurance, 17% received retirement benefits, and 0% received some other kind of benefit. Note: individuals answering this question had the option to indicate more than one response.
- 24% of individuals who work have been promoted (11% state finding, 12% regional).
- The mean number of hours worked per week was 22 hours (18 hours state finding, 17 hours regional).
- The mean hourly wage was $9.05 ($8.34 state finding, $8.09 regional).
- The mean yearly wage was $1,700.00 ($3,864.29 state finding, $3,147.81 regional).

Self-Employment and Supports

- Of the 44 individuals who have community integrated employment, 0 individuals are self-employed (6 individuals state finding, 2 individuals regional).

Relationships

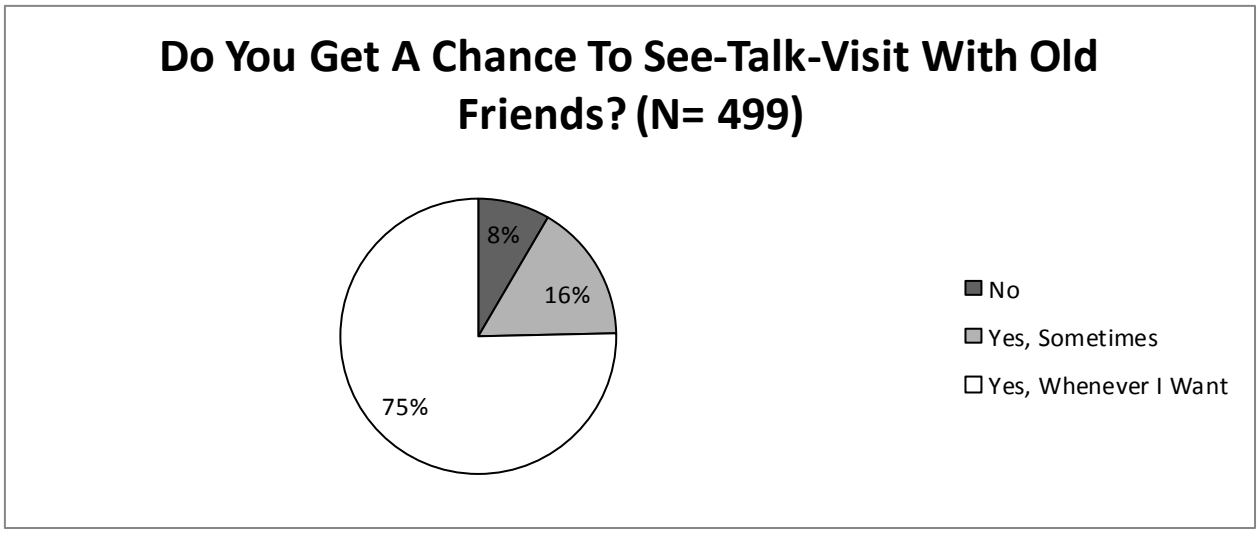
Respondents: The questions on relationships could be answered by the individual receiving services/supports, a family member, a friend, or paid staff.



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

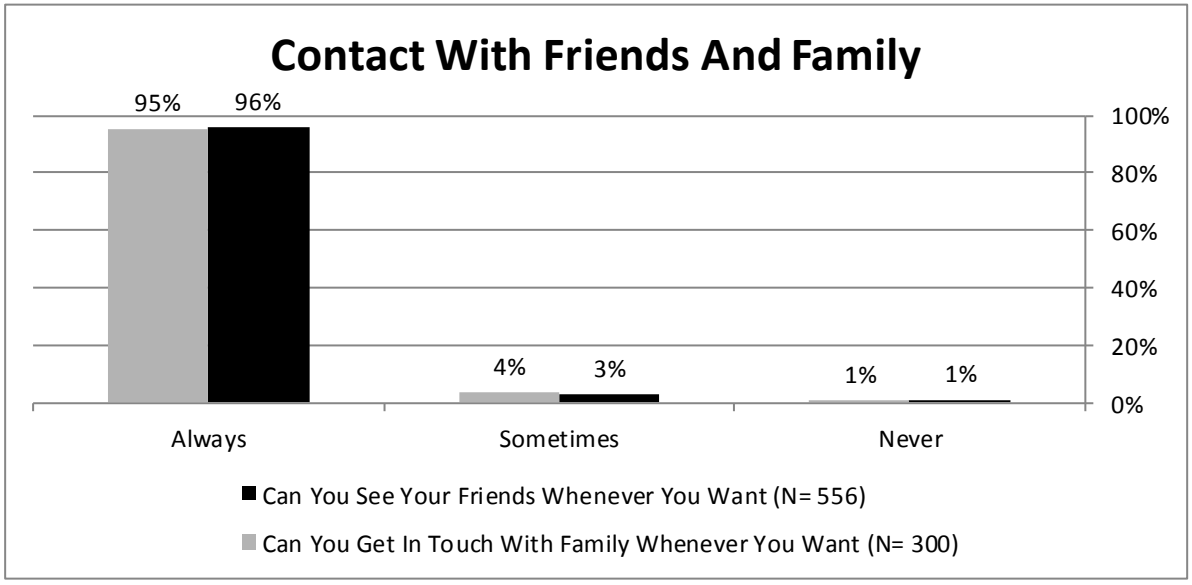
Friendships

- 75% of people answered that they can see-talk-visit with old friends whenever they want (state finding 61%, regional 67%).



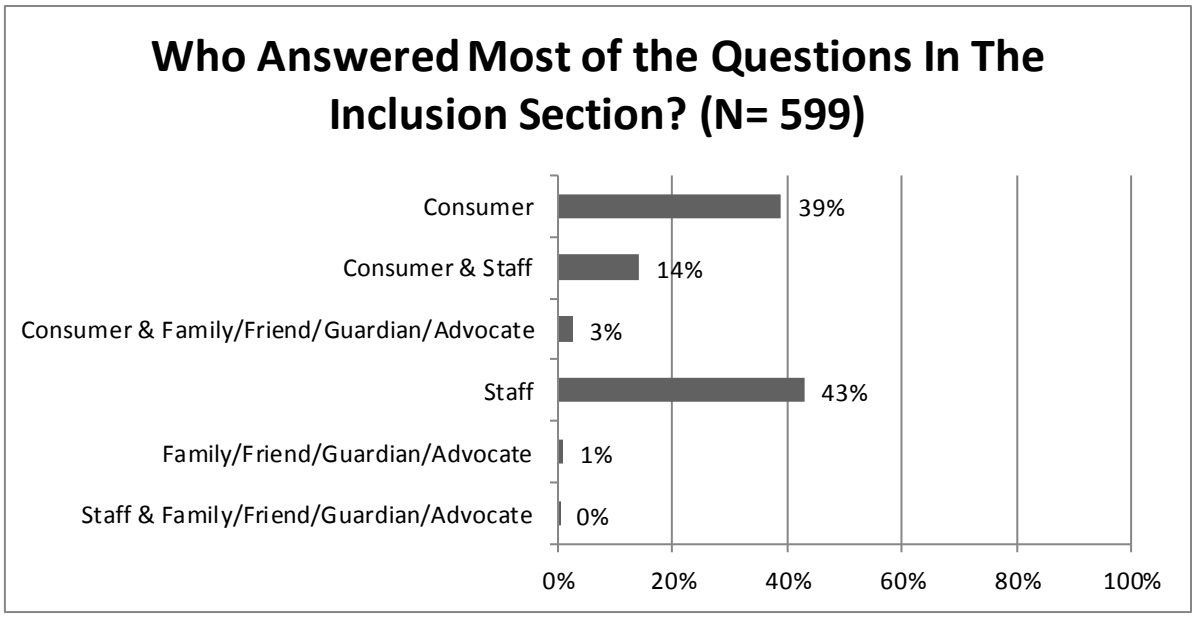
Contact with Friends and Family

- 96% of individuals were always able to see friends whenever they wanted (state finding 82%, regional 89%)
- 95% of respondents were always able to get in touch with family whenever they wanted (state finding 90%, regional 93%).



Inclusion

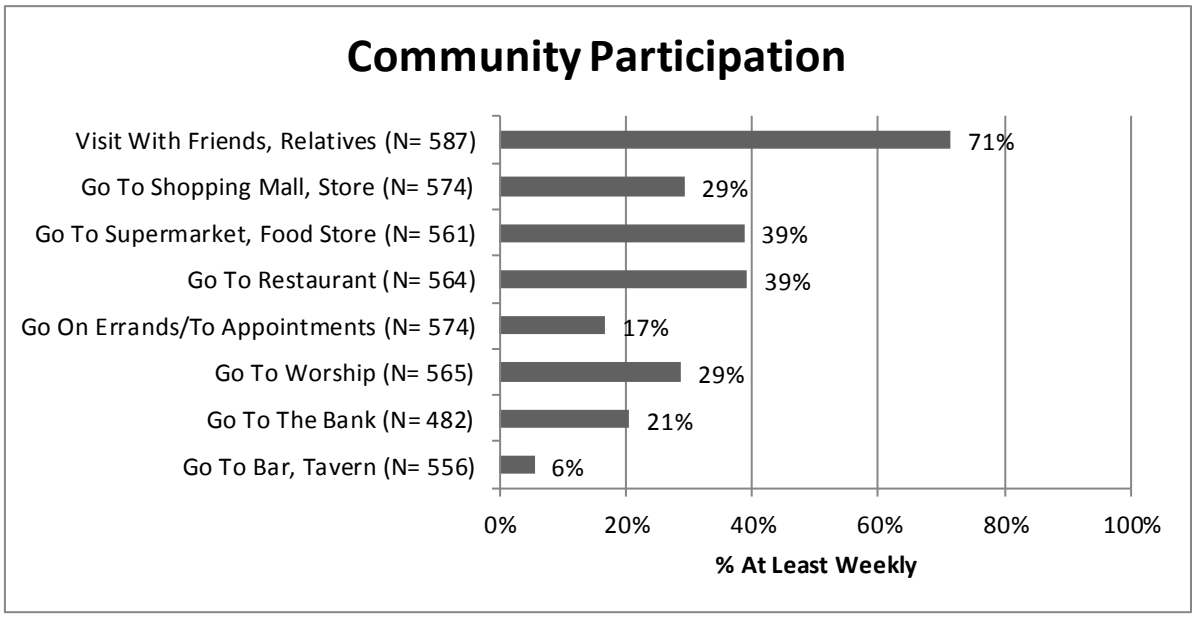
Respondents: The questions on inclusion could be answered by the individual receiving services/supports, a family member, a friend, or paid staff.



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

Community Participation

- 71% of the people visited with friends, relatives and neighbors at least weekly (state finding 54%, regional 64%)
- 39% of individuals went to a supermarket, 39% went to a restaurant, and 29% went to a shopping mall at least weekly (state finding 43%, 43%, and 41%; regional 42%, 41% and 39% respectively)
- At least weekly, individuals went out for errands and appointments (17%), to places of worship (29%), to banks (21%), and to bars/taverns (6%). State findings were 24%, 27%, 13%, and 7%; regional 21%, 26%, 15%, and 7% respectively.



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 and individuals with disabilities are nearly equally likely to visit with friends, relatives, and neighbors, while people without disabilities are about 10% more likely to visit with friends, relatives, and neighbors.
- 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 more likely to go to places of worship weekly than people with disabilities in the Harris Poll, and slightly more likely than people without disabilities in the Harris Poll.

County comparisons are as follows:

Weekly Participation in Community Activities for Allegheny AE

	Harris 2010: People without Disabilities	Harris 2010: People with Disabilities	IM4Q State	IM4Q County/ Joinder
Visit with friends, relatives, and neighbors	65%	54%	54%	71%
Go to restaurant	41%	20%	43%	39%
Go to worship	28%	24%	27%	29%

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 40.85 with a standard deviation of 13.36 (state finding 40.28 and 15.74; regional 40.45 and 14.99)

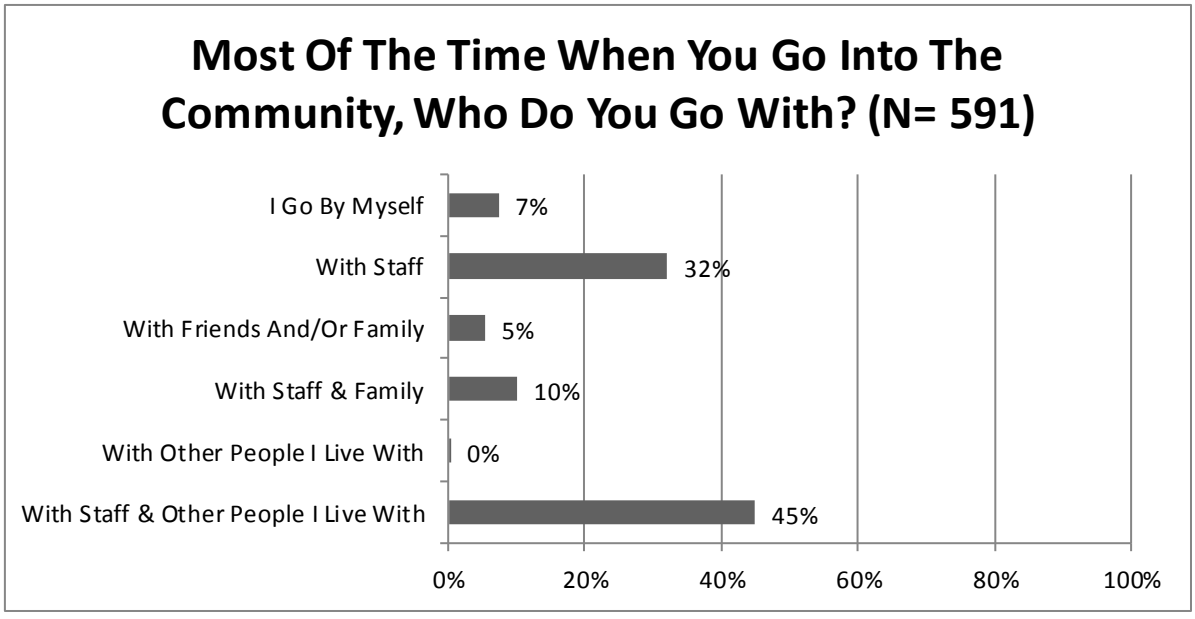
Community Activities

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

- 58% of the individuals go frequently into the community for entertainment (state finding 55%, regional 49%)
- 47% of individuals reported that they frequently go to social events in the community that are attended by people with and without disabilities (state finding 29%, regional 33%)
- 38% of individuals went on a vacation in the past year (state finding 44%, regional 39%)
- Regarding monthly exercise, 19% of individuals reported never going out for exercise (state finding 38%, regional 38%), 8% exercise less than weekly, 13% exercise once a week, and 60% exercise more than once a week (state finding 44%, regional 42%).

Going Out Alone or With Other People

- 7% of individuals go out alone (state finding 7%, regional 7%)
- 77% of individuals go out with staff (or staff and other people they live with) most of the time (state finding 53%, regional 57%)

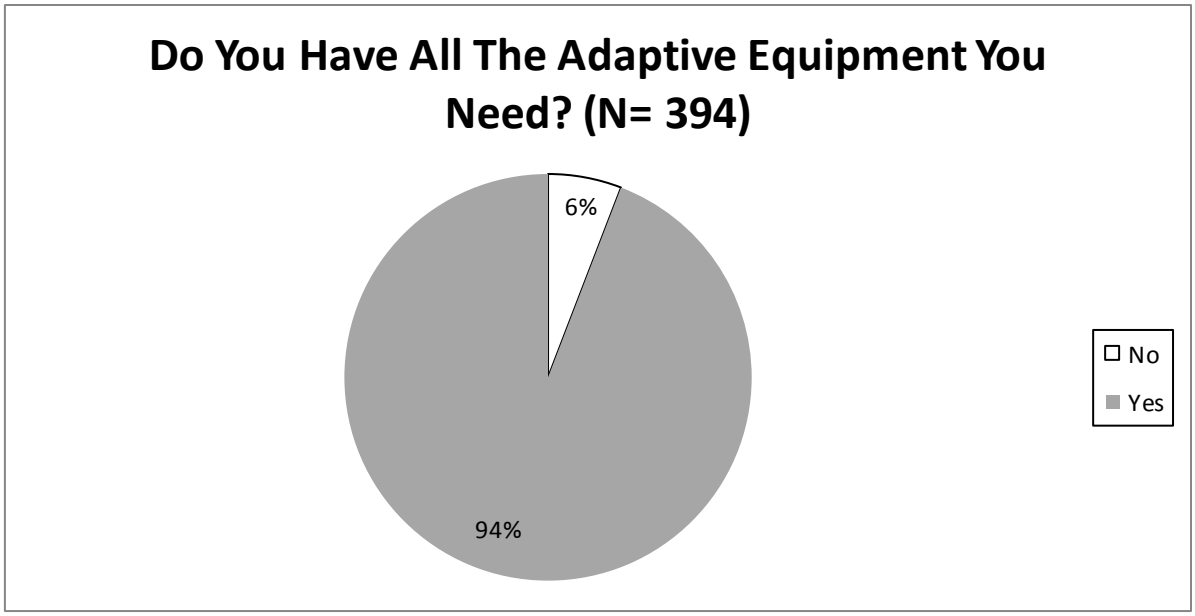


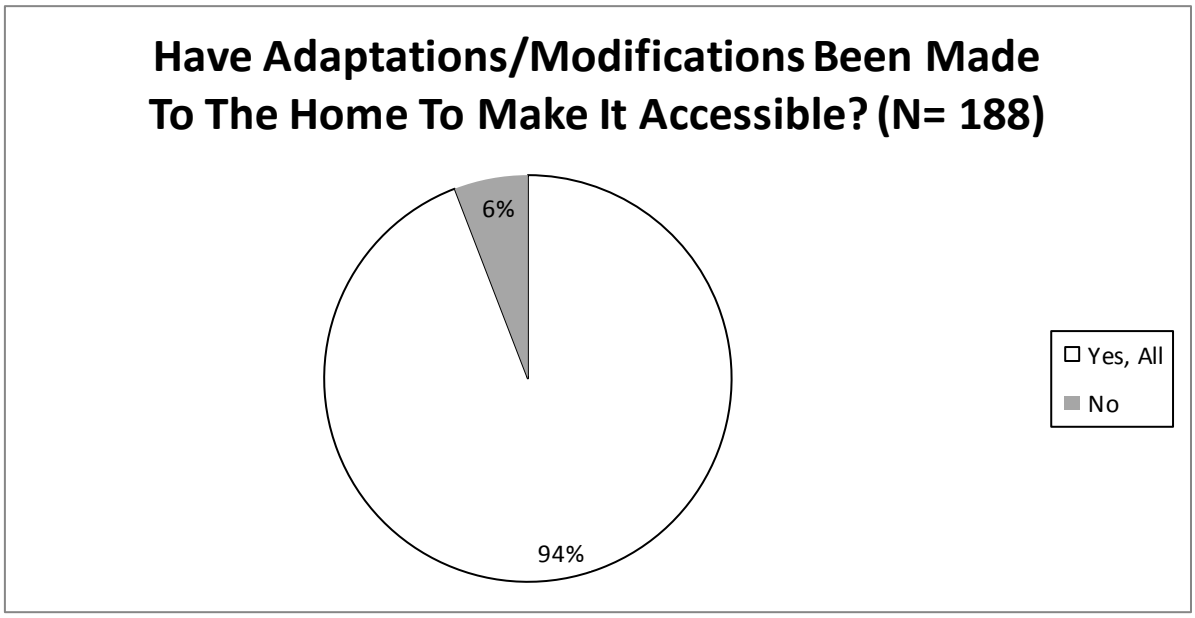
Transportation

- 94% of people always had a way to get where they wanted to go (80% state finding, 83% regional)
- Of those who cannot always get where they want to go, 42% cannot get where they want to go because there is not enough staff (37% state finding, 30% regional)

Home Adaptive Equipment

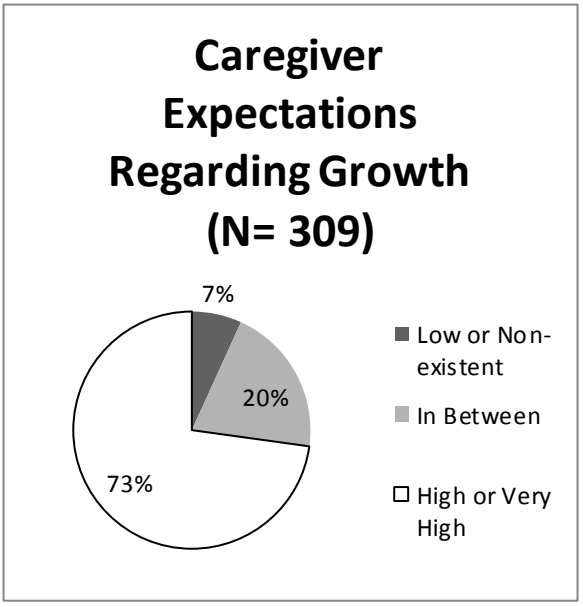
- 94% of individuals reported having all the adaptive equipment they needed (state finding 89%, regional 92%)
- 94% of people said that all necessary adaptations have been made to their home to make it accessible (state finding 84%, regional 86%)





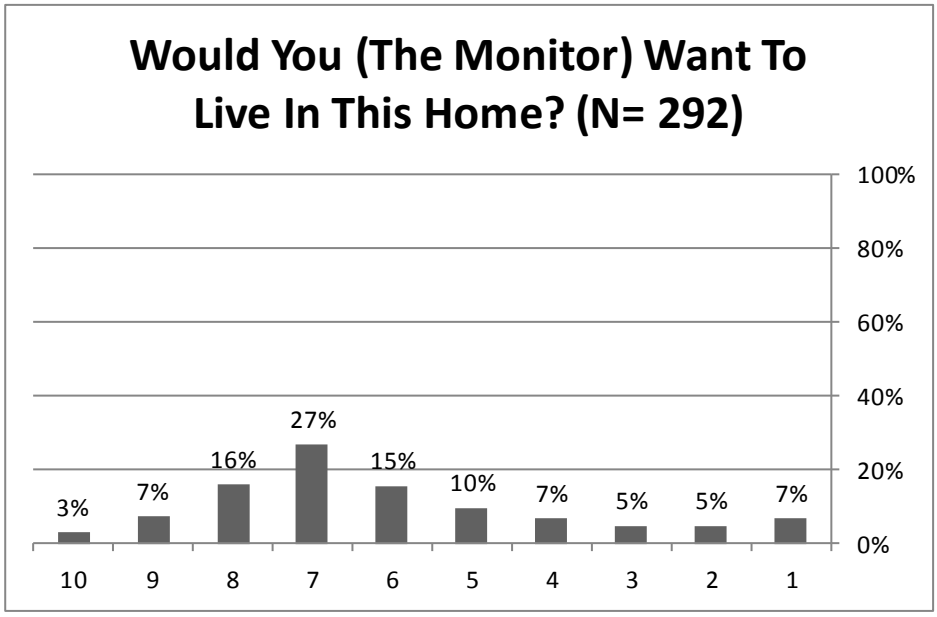
Competence, Personal Growth and Opportunities to Grow and Learn

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,

- For 73% of the individuals, caregiver expectations regarding growth was reported as high or very high (state finding 57%, regional 58%)
- 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 6.0 (state finding 6.4, regional 5.9)



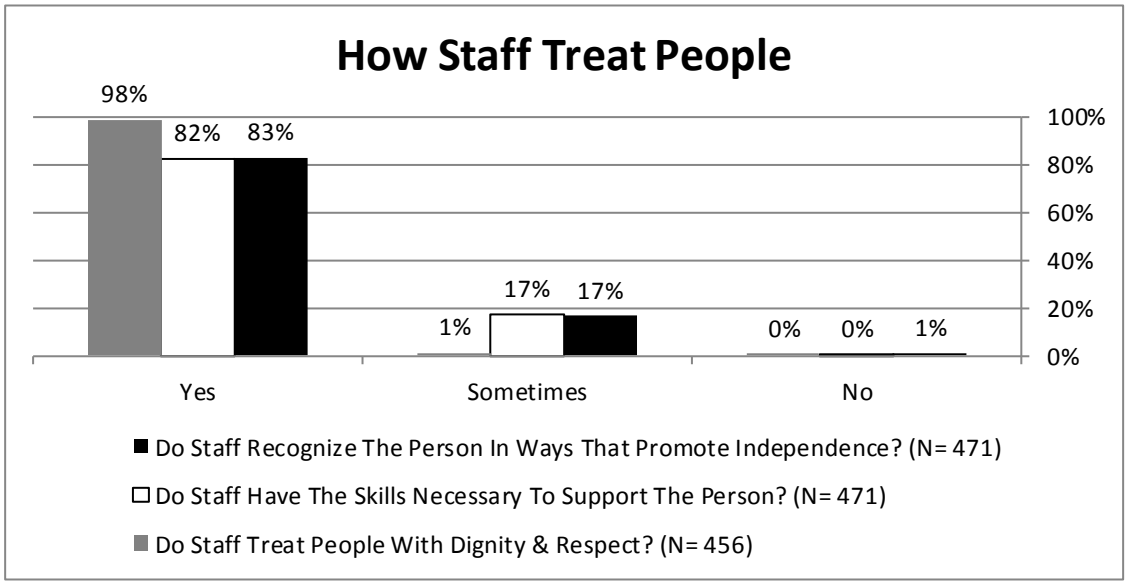
Staff Support for the Person

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,

- 83% of staff observed recognized the individuals in ways that promote independence (state finding 85%, regional 85%)
- Individuals had either all staff (82%) or some staff (17%) with the skill needed to support them (state finding 87% and 13% respectively; regional 87% and 13% respectively).
- 98% of the monitoring teams observed that the staff treated individuals with dignity and respect (state finding 96%, regional 96%)



Physical Setting

Respondents: The IM4Q Team answered the following questions regarding the physical setting, which referred to the place where the individual lives or where they go for work/day activity. 48% of the interviews took place in the individual's home (state finding 69% regional 63%), although 51% took place at work/day activity (state finding 27%, regional 33%).

Repair at Home or Work/Day Activity

- Monitors observed that 95% of individuals lived in homes (or went to work/day activities) which were in good repair on the outside and 96% lived in homes (or went to work/day

activities) which were in good repair on the inside (state finding 95% and 95% respectively; regional finding 95% and 94% respectively).

Neighborhood

According to IM4Q teams,

- 95% of individuals lived in homes which were in a safe neighborhood (state finding 93%, regional 93%).
- 98% of individuals lived in homes that "fit in" with the neighborhood in which they were located (state finding 88%, regional 92%).

Personal Belongings and Personalities

According to IM4Q teams,

- 98% of individuals lived in homes which had sufficient space for personal belongings (state finding 97%, regional 97%).
- 82% of individuals lived in homes which reflected the hobbies, interests and personalities of the people who live there (state finding 61%, regional 69%); for 11% of the people only their bedroom reflected their personalities and interests (state finding 34%, regional 25%).

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

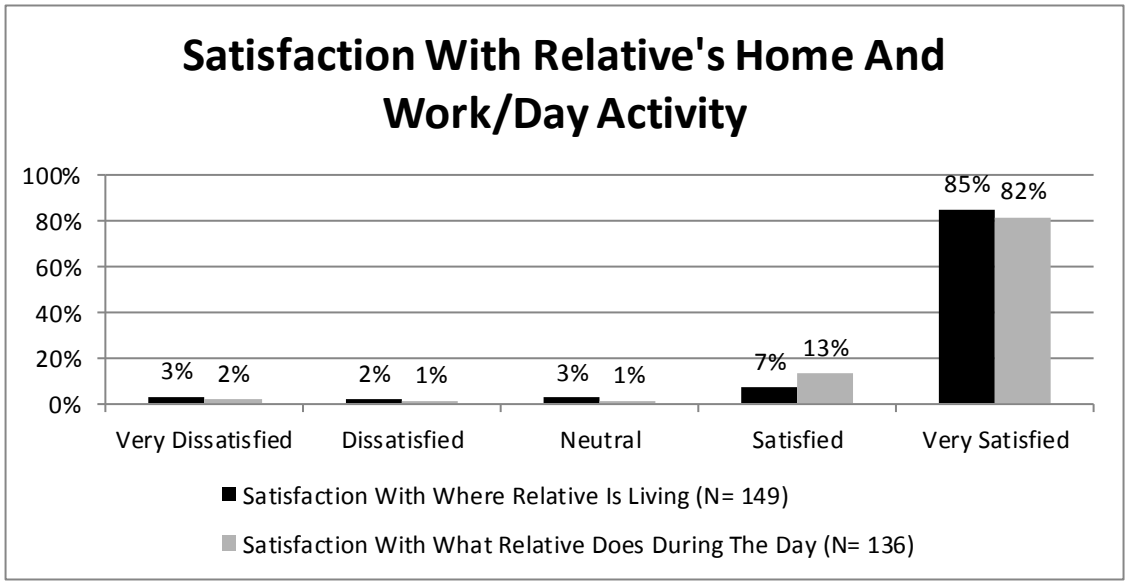
- The average (mean) score was 97.42 with a standard deviation of 9.18 (state finding 96.76 and 10.55 respectively, 96.62 and 11.27 regional)

Family/Friend/Guardian Survey

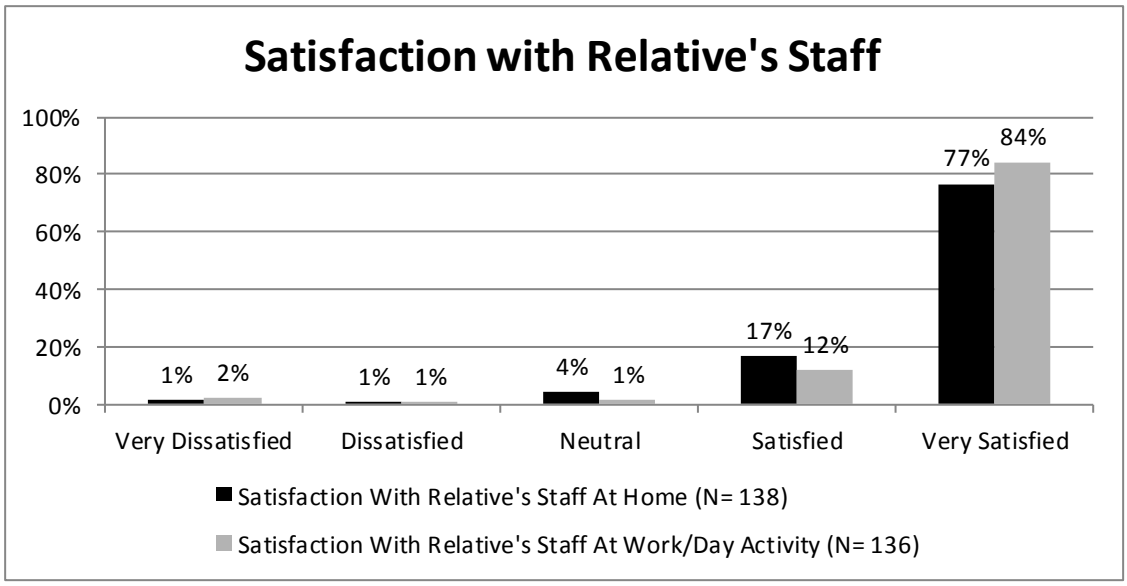
Respondents: This survey was completed by telephone with a family member, guardian, or friend who was identified through the Essential Data Elements Pre-Survey. In the event that a phone survey could not be completed, surveys were completed by mail. A total of 149 family members, friends, and guardians from the Allegheny AE participated in the survey.

- 60% of the surveys were answered by parents
- 34% were answered by siblings
- 2% were answered by the guardian
- 0% were answered by a friend
- 3% were answered by another relative (spouse, aunt, uncle, cousin, grandparent)
- 1% were answered by persons with other relationships to the individual receiving supports

Satisfaction



- 92% of the families surveyed were either somewhat satisfied or very satisfied with where their relative lives (state finding 95%, regional 96%).
- 95% were either somewhat satisfied or very satisfied with what their relative does during the day (state finding 92%, regional 93%).



- 93% of the families surveyed were either somewhat satisfied or very satisfied with their relative's staff at home (state finding 94%, regional 95%).
- 96% of the families surveyed were either somewhat satisfied or very satisfied with the staff at their relative's day activity (state finding 95%, regional 96%).

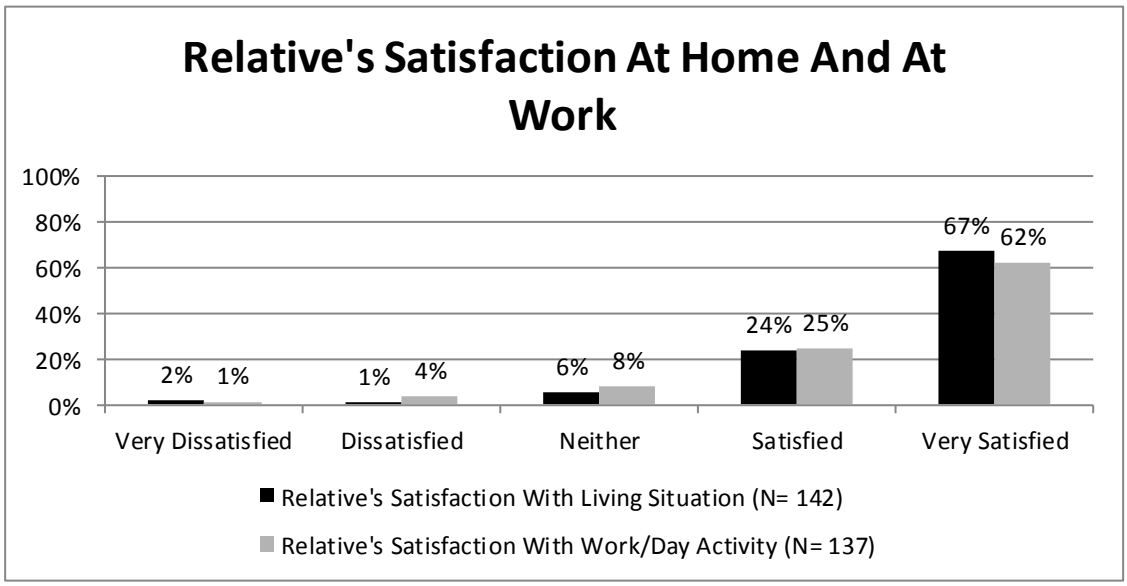
How Often Do You Contact/See Your Relative?

- 81% of the family/friend/guardians contacted their relative at least monthly (state finding 84%, regional 81%); 3% have not contacted their relative in the past year (state finding 4%, regional 6%).
- 71% 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 74%, regional 70%); 3% did not get to see their relative in the past year (state finding 4%, regional 6%)

Your Relative's Satisfaction

- 91% of respondents felt their relative was either very satisfied or satisfied with his/her living situation (state finding 95%, regional 95%)
- 87% felt their relative was either very satisfied or satisfied with what they do during the day (state finding 91%, regional 93%)

- 91% of respondents felt their relative was either very satisfied or satisfied with the staff who support them at home (state finding 95%, regional 96%); 1% felt their relative was either dissatisfied or very dissatisfied (state finding 1%, regional 0%)
- 89% 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 95%); 2% felt their relative was either dissatisfied or very dissatisfied (state finding 1%, regional 1%)



Your Relative's Safety

- Respondents said that their relative felt safe in their community / home / neighborhood always (78%) or most of the time (20%). State findings were 84% and 14% respectively; 86% and 12% regional.

Your Relative's Opportunities

- 95% of the respondents said that their relative got enough opportunities to participate in activities in the community (state finding 88%, regional 91%)
- 92% of the respondents said that their relative seemed to have the opportunity to learn new things (state finding 90%, regional 92%)

Your Relative's Staff

- If their relative did not communicate verbally, 38% of the respondents said that there is a formal communication system in place for their relative and they use it (state finding 32%, regional 41%); for 38%, the communication system is used across all settings (state finding 51%, regional 54%).
- 88% of the respondents said that their relative's home appeared to have enough paid staff (state finding 90%, regional 91%)
- 91% of the respondents said that staff in their relative's home treat people with dignity and respect (state finding 95%, regional 94%)
- 84% of the respondents said that all staff appear to have the skills they need to support their relative, and 16% felt that way about only some staff (state finding 87% and 11% respectively; 89% and 11% regional)

Your Relative's Supports

- If something changed in their relative's life, 43% reported they would contact a relative; 57% would contact the supports coordinator; and 67% would contact agency staff; 15% would contact someone else.
- 87% of relatives were satisfied with the supports coordination their relative receives (state finding 88%, regional 91%)
- 38% of relatives reported that they were told how much money is in their relative's annual budget (state finding 62%, regional 63%)
- 86% said that their relative always received the supports they needed (state finding 79%, regional 83%)
- 84% of relatives always felt that the staff who assisted them with planning respected their choices and opinions (state finding 90%, regional 92%)
- 47% of relatives never felt that frequent changes in support staff was a problem for their family member (state finding 64%, regional 63%)
- 31% of relatives always got to choose the agency/provider who worked with their relative (state finding 33%, regional 34%); 4% had their relative choose (state

finding 7%, regional 5%); 52% never got to choose (state finding 42%, regional 46%)

- 53% of relatives were familiar with the way complaints and grievances are handled (state finding 71%, regional 70%); 47% were not familiar (state finding 29%, regional 30%)
- 24% of relatives had someone talk to them about an emergency plan for their family member, in case of emergencies (state finding 49%, regional 44%)

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 90.42 with a standard deviation of 16.08 (state finding 91.38 and 12.65 respectively, 92.75 and 11.19 regional)

Summary

For a summary of the information collected through face-to-face interviews with the 599 individuals in Allegheny 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).