

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

Independent Monitoring for Quality (IM4Q)
Philadelphia AE
2009-2010

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), known as the Office of Mental Retardation (OMR) at the time, began to disseminate its Multi-Year Plan, which represented a significant effort by ODP to convey its vision, values and goals for the ensuing years. The Plan, developed by ODP's Planning Advisory Committee (PAC), included several recommendations. Recommendation #7 stated that the capacity for independent monitoring should be developed in Pennsylvania.

Through the PAC, a subcommittee was formed to address recommendation #7. The charge to the subcommittee was to develop a process for the conduct of independent monitoring. The PAC subcommittee included consumers, families, providers, advocates, counties, direct care staff and ODP staff. The Developmental Disabilities Council, in collaboration with ODP, committed to fund the initial development and training work required to establish independent monitoring. Two technical advisors were contracted to assist in the subcommittee's deliberations.

The PAC subcommittee produced a document describing independent monitoring; the subcommittee recommended that the process include the collection of a minimal set of data by all counties in the Commonwealth. The document was accepted by the PAC, and reviewed and revised by ODP.

At about this time the National Association of State Directors of Developmental Disabilities Services (NASDDDS), in collaboration with the Human Services Research Institute (HSRI) developed a national project to identify performance indicators that states could collect to determine the status of their systems vis-à-vis the experiences of individuals supported, families supported and providers delivering supports. The Commonwealth of Pennsylvania joined this project, National Core Indicators (NCI), as a pilot state. Ongoing efforts were set in place to ensure that Independent Monitoring for Quality (IM4Q) was consistent with the NCI and that neither of the projects caused an undue burden for individuals receiving supports, families and providers.

At the current time, ODP is also involved in the development of a significant quality management initiative. As part of this initiative, a quality framework has been developed to produce a cohesive system for assuring and improving the quality of services and supports people receive from the intellectual disability system. The IM4Q data are one source of information that is being used in this effort.

In Fiscal Year 1999-2000, twenty Administrative Entities (AEs), previously called County MH/MR Programs, submitted proposals and were selected to participate in a pilot effort that resulted in the conducting of interviews with 2796 individuals. A final report of that effort was produced in early 2001 (Feinstein, Levine, Lemanowicz and Carey, 2001).

During fiscal year 2000-2001, all 46 AEs developed contracts with Local IM4Q Programs to independently conduct interviews and enter data into the DPW IM4Q web-based system. A total of 5298 face-to-face interviews were conducted during that fiscal year, together with 2224 Family/Friend/Guardian surveys. The number of interviews completed increased during the 2001-2002 fiscal year. A total of 5659 face-to-face interviews were conducted along with 2494 Family/Friend/Guardian surveys during that year.

In fiscal year, 2002-2003, all 46 AEs continued to contract with local entities to assist them in fulfilling their obligation under IM4Q; most AEs continued to contract with the same local program as in the previous year. However, for a variety of reasons, a few counties entered into contracts with new local IM4Q programs. The number of face-to-face interviews continued to increase with a total of 6487 conducted during that fiscal year. The increase was a reflection of the addition of a sample of individuals receiving services through the Person and Family Directed Supports Waiver (PFDS). In addition to the interviews with individuals, 3163 interviews were conducted with families, friends and guardians.

Forty-six AEs continued to contract with local entities to assist them in implementing IM4Q during fiscal year 2003-2004. A total of 6373 face-to-face interviews were conducted. A total of 2975 interviews were conducted with family, friends and guardians.

In fiscal year 2004-2005, a total of 6499 face-to-face interviews were conducted from September 2004 until June 30, 2005. A total of 3010 interviews were conducted with family, friends and guardians.

In 2005-2006, a total of 6496 face-to-face interviews were conducted. A total of 2851 interviews were conducted with family, friends and guardians. In 2005-2006, the number of AEs increased to 48, due to two AEs that split from their previous joinders (McKean split from the Cameron/Elk joinder and Wayne split from the Lackawanna/Susquehanna joinder).

Revisions to the Essential Data Elements instrument were made from previous years, based on feedback from the local programs, as well as from the statewide steering committee, AEs, regional office staff and the technical advisors.

In 2006-2007, a total of 6469 face-to-face interviews were conducted. A total of 3028 interviews were conducted with family, friends and guardians. That year, there were no changes made to the data collection instrument.

In 2007-2008, a total of 6512 face-to-face interviews were conducted. A total of 2731 Family/Friend/Guardian Surveys were completed. There were a few changes to the instrument used to collect the data. There were three new items added to the Dignity, Respect and Rights section. In addition, at the request of the Office of Developmental Programs, there were 10 new items added to the instrument involving the frequency and intensity of physical activity. In addition, an additional technical advisor was added to the project.

In fiscal year 2008-2009, a total of 6618 face-to-face interviews were conducted. A total of 2896 interviews were conducted with family, friends and guardians. In preparation for the 2008-2009 year, there were major changes made to the data collection instrument. A stakeholder workgroup was developed to assist in the instrument revisions. The changes included the removal of a number of items to make the instrument less lengthy and redundant. In addition,

the items that had been added at the request of ODP regarding physical activity were removed as they did not appear to yield meaningful data.

A total of 6621 face-to-face interviews were conducted in fiscal year 2009-2010. A total of 2590 interviews were conducted with family, friends and guardians. There were no significant changes made to the data collection instrument for this year.

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 2009-2010 includes all survey questions included in the FY 2009-2010 NCI Adult Consumer Survey. At the time of this report, approximately 1400 individuals included in this report are represented in the NCI sample for 2009-2010, based on a sampling methodology established by ODP and the Human Services Research Institute (HSRI). A copy of the NCI report for FY 2009-10 is available on the HSRI website at www.hsri.org.

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

- A **pre-survey**, which is 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 is 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 to be 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 780 people in Philadelphia AE.

**Type of Residential Setting for
Philadelphia AE**

Type of Residential Setting	Pennsylvania Overall		County/Joinder	
	N	Percent	N	Percent
State ICF/MR	59	0.9%	2	0.3%
State Mental Health Hospital	5	0.1%	0	0.0%
Homeless	1	0.0%	0	0.0%
Temporary Shelter	2	0.0%	1	0.1%
Foster Care	15	0.2%	3	0.4%
Incarceration	1	0.0%	0	0.0%
Nursing Home/Nursing Facility	120	1.8%	9	1.2%
Domiciliary Care	50	0.8%	11	1.4%
Personal Care Home (PCH)	209	3.2%	37	4.7%
Family living	353	5.4%	40	5.1%
Unlicensed Family Living	14	0.2%	1	0.1%
Own residence	632	9.7%	58	7.4%
Relative's home	1728	26.6%	175	22.4%
Children's Facility	22	0.3%	15	1.9%
Approved Private School	7	0.1%	3	0.4%
Private ICF/MR (4 or fewer persons)	59	0.9%	6	0.8%
Private ICF/MR (4 to 8 persons)	191	2.9%	28	3.6%
Private ICF/MR (9 to 15 persons)	16	0.2%	3	0.4%
Private ICF/MR (16 or more	419	6.5%	110	14.1%
Community Home (1 person)	124	1.9%	39	5.0%
Community Home (2 to 4 persons)	2045	31.5%	213	27.3%
Community Home (5 to 6 persons)	203	3.1%	4	0.5%
Community Home (7 to 8 persons)	94	1.4%	1	0.1%
Community Home (9 to 15 persons)	17	0.3%	0	0.0%
Community Home (16 or more	35	0.5%	12	1.5%
Other	70	1.1%	9	1.2%
Missing	130	-	0	-
Total	6621	100%	780	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 prepared 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 2009-10 survey cycle was collected by June 30, 2010 and entered into HCSIS by August 15, 2010. A data file was received by the Institute on Disabilities in October, 2010. A report presents data on the individuals surveyed by the IM4Q Local Programs, representing the 48 AEs across the state. In addition, 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 AE program.

	# of People	Percent
Allegheny	670	10.1%
Armstrong/Indiana	103	1.6%
Beaver	112	1.7%
Bedford/Somerset	88	1.3%
Berks	172	2.6%
Blair	108	1.6%
Bradford/Sullivan	49	0.7%
Bucks	214	3.2%
Butler	97	1.5%
Cambria	101	1.5%
Cameron/Elk	40	0.6%
Carbon/Monroe/Pike	107	1.6%
Centre	75	1.1%
Chester	169	2.6%
Clarion	52	0.8%
Clearfield/Jefferson	85	1.3%
Columbia/Montour/Snyder/Union	109	1.6%
Crawford	93	1.4%
Cumberland/Perry	101	1.5%
Dauphin	165	2.5%
Delaware	280	4.2%
Erie	259	3.9%
Fayette	89	1.3%
Forest/Warren	50	0.8%
Franklin/Fulton	83	1.3%
Greene	42	0.6%
Huntington/Mifflin/Juniata	84	1.3%
Lackawanna/Susquehanna	149	2.3%
Lancaster	175	2.6%
Lawrence	88	1.3%
Lebanon	71	1.1%
Lehigh	158	2.4%
Luzerne/Wyoming	145	2.2%
Lycoming/Clinton	110	1.7%
McKean	49	0.7%
Mercer	82	1.2%
Montgomery	323	4.9%
Northampton	126	1.9%
Northumberland	84	1.3%
Philadelphia	780	11.8%
Potter	34	0.5%
Schuylkill	93	1.4%
Tioga	46	0.7%
Venango	55	0.8%
Washington	102	1.5%
Wayne	39	0.6%
Westmoreland	159	2.4%
York/Adams	156	2.4%
TOTAL	6621	100%

Satisfaction

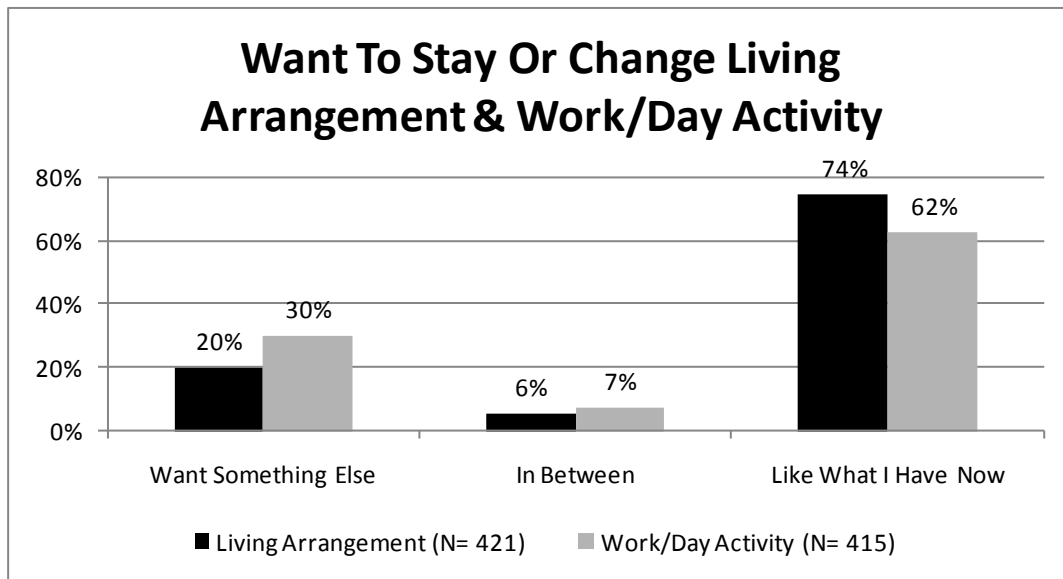
Respondents: Only the individual receiving services/supports could answer the questions on satisfaction. The percent of people who responded to questions in this section ranged from 35% to 68%.

Satisfaction with Living Arrangements

- 84% of individuals liked where they live (state finding 89%, regional 87%).
- 74% wanted to stay where they currently live (state finding 76%, regional 75%).

Satisfaction with Work/Day Activity

- 87% of individuals with a day activity/work liked what they did during the day (state finding 92%, regional 90%).
- 62% wanted to continue their current daytime activities/work (state finding 71%, regional 67%), 30% wanted to do something else (state finding 22%, regional 26%).



Daily Life

- 69% of individuals reported getting the services and supports they need (state finding 89%, regional 81%).
- On most weekdays, 19% of individuals report they attend an adult training program (state finding 32%), 29% stay home, 20% go out and do things in the community, 25% are at a vocational facility, 15% work part time for pay, 2% work full time for pay, 2% help their neighbors and/or friends, 4% volunteer and 14% attend school; individuals report rarely attending college or trade school and rarely were retired.

Happiness and Loneliness

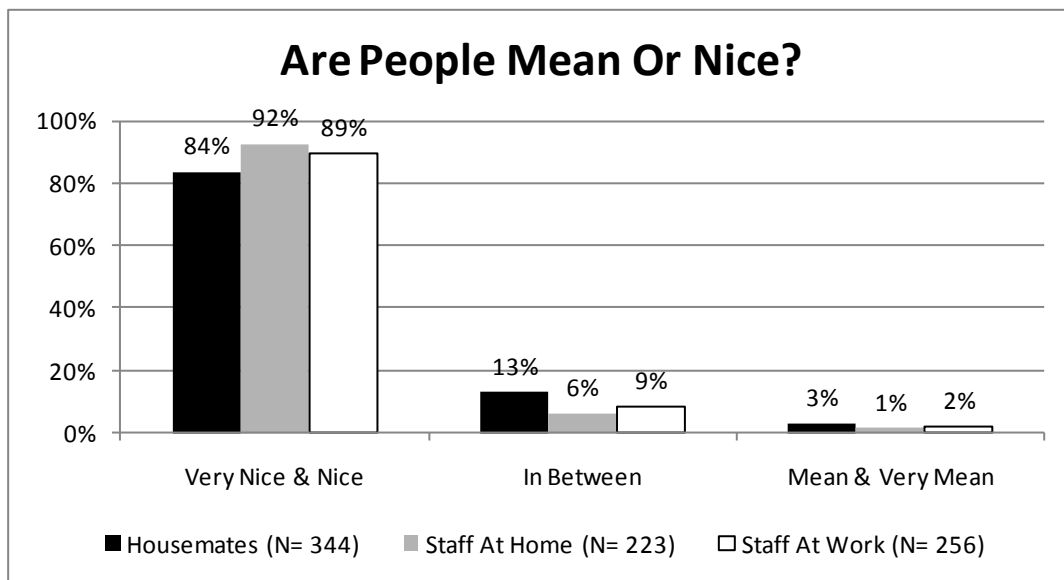
- 80% reported usually feeling happy (state finding 82%, regional 82%), 16% reported being in-between (state finding 14%, regional 14%), and 4% reported usually feeling sad (state finding 4%, regional 4%).
- 58% of individuals reported never feeling lonely (state finding 60%, regional 60%), 38% reported sometimes feeling lonely (state finding 35%, regional 36%), and 4% reported always feeling lonely (state finding 5%, regional 5%).
- 76% reported having friends, which are not staff or family, with whom they like to do things (state finding 75%, regional 74%).
- 77% reported that they can go on a date if they want to or are married (state finding 74%, regional 74%); 8% reported that they can go on a date if they want to but there are some restrictions and rules (state finding 11%, regional 10%), and 15% are not allowed to (state finding 15%, regional 16%).

Privacy

- 92% of the individuals surveyed reported that they always have privacy (a place to be alone) when they want it (state finding 95%, regional 92%).
- At least most of the time 87% 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 89%, regional 83%).
- For 79% of the individuals, people always knock on the bedroom door and wait for a response before coming in (state finding 83%, regional 80%).

Are People Nice or Mean?

- 84% reported that their housemates are very nice or nice (state finding 88%, regional 85%).
- 92% of the people interviewed reported that their staff who work with them at home are very nice or nice (state finding 94%, regional 91%).
- 89% reported that staff who work with the respondents at work or day activity are nice or very nice (state finding 94%, regional 92%).



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 81.75 with a standard deviation of 21.68 (84.76 and 19.62 state finding; 83.73 and 20.75 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. The percent of people who responded to questions in this section ranged from 35% to 64%.

Forms of Identification

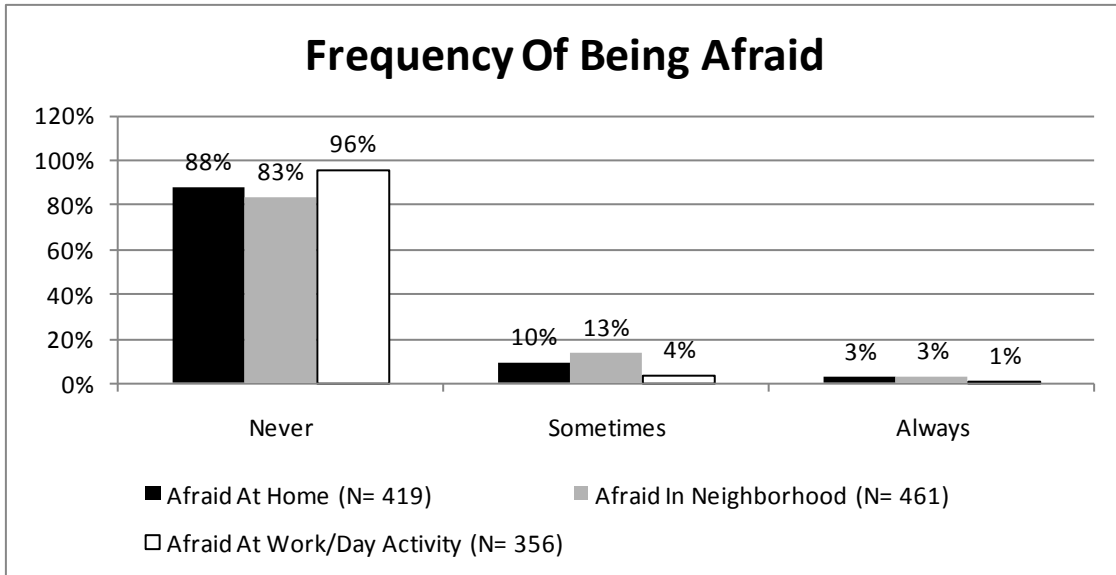
- 66% of individuals stated that they always carry a form of identification, such as a card with the individuals name, address and a person to call in case of emergency or a non-driver ID (state finding 61%, regional 60%); 20% never do (state finding 22%, regional 23%).

Support with Problems and Goals

- 90% of individuals always had someone to go to for help if they have a problem (state finding 91%, regional 90%).
- 73% want help to learn new things (state finding 59%, regional 69%).
- 65% of individuals report that they get to help other people (state finding 73%, regional 63%).

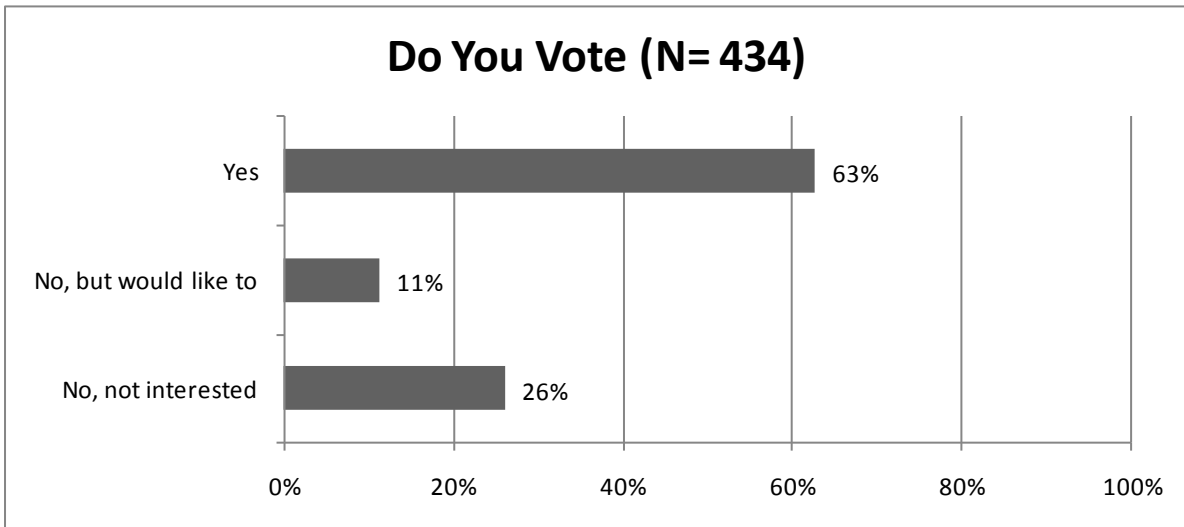
Being Afraid

- 88% reported never being afraid at home (state finding 81%, regional 83%).
- 83% reported never being afraid in the neighborhood (state finding 84%, regional 85%).
- 96% reported never being afraid at work, school or day activity (state finding 90%, regional 91%).



Legal Rights

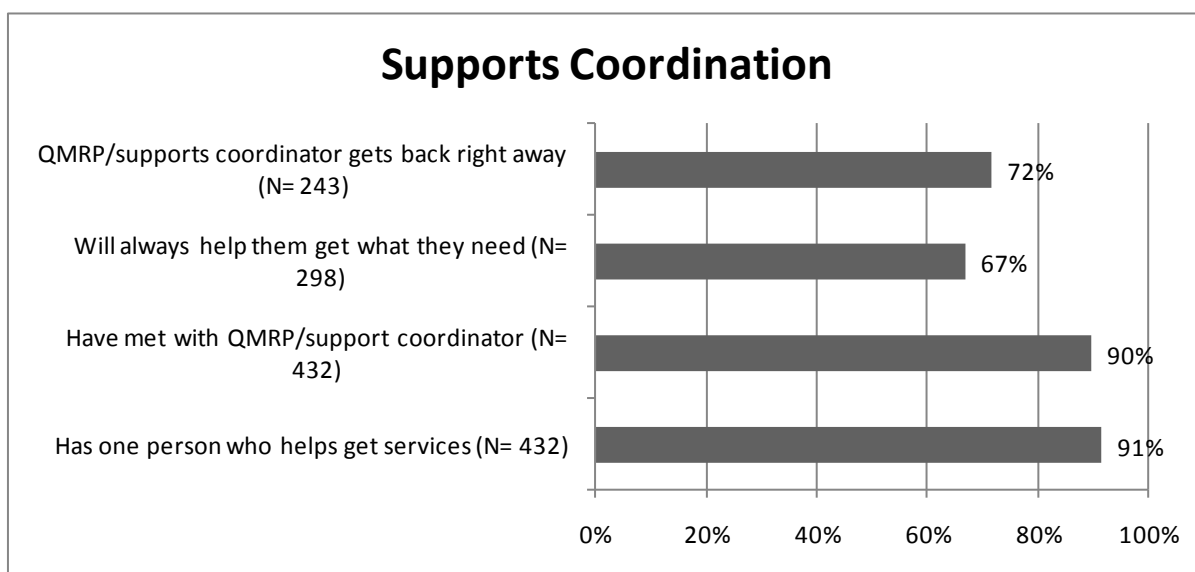
- 63% of people said that they do vote (state finding 41%, regional 56%); 11% do not vote but would like to (state finding 13%, regional 15%), and 26% do not vote and are not interested (state finding 46%, regional 30%).



Supports Coordination

- 91% of individuals reported that they have one person (QMRP/supports coordinator) who helps them get the services they need (state finding 95%, regional 93%).

- 90% reported that they have met with their QMRP/supports coordinator in the past year (state finding 91%, regional 89%).
- 67% of individuals reported that if they ask their supports coordinator will always helps them get what they need (state finding 85%, regional 75%).
- 72% of the people reported that when they call, their QMRP/supports coordinator always gets back to them right away (state finding 81%, regional 74%).
- 66% of those surveyed have been told how much money was in their annual budget (state finding 67%, regional 62%).



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).

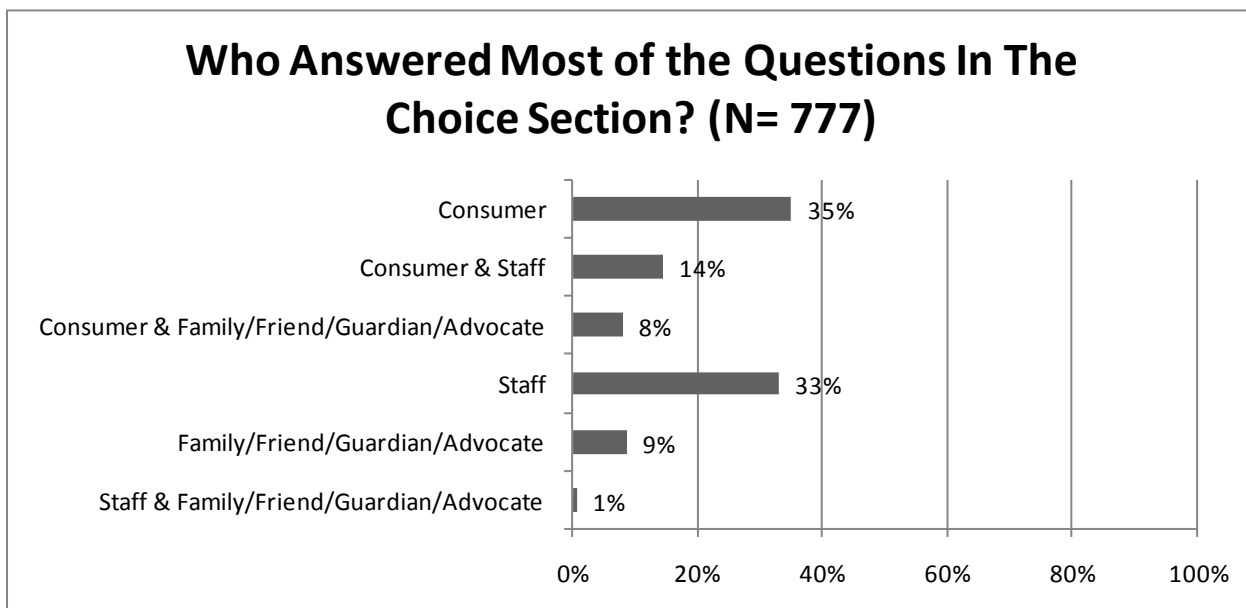
- The average score was 81.04 with a standard deviation of 17.32 (83.14 and 14.77 state finding; 81.24 and 15.69 regional).

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 92.18 with a standard deviation of 17.00 (90.90 and 17.20 state finding; 91.39 and 16.94 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.

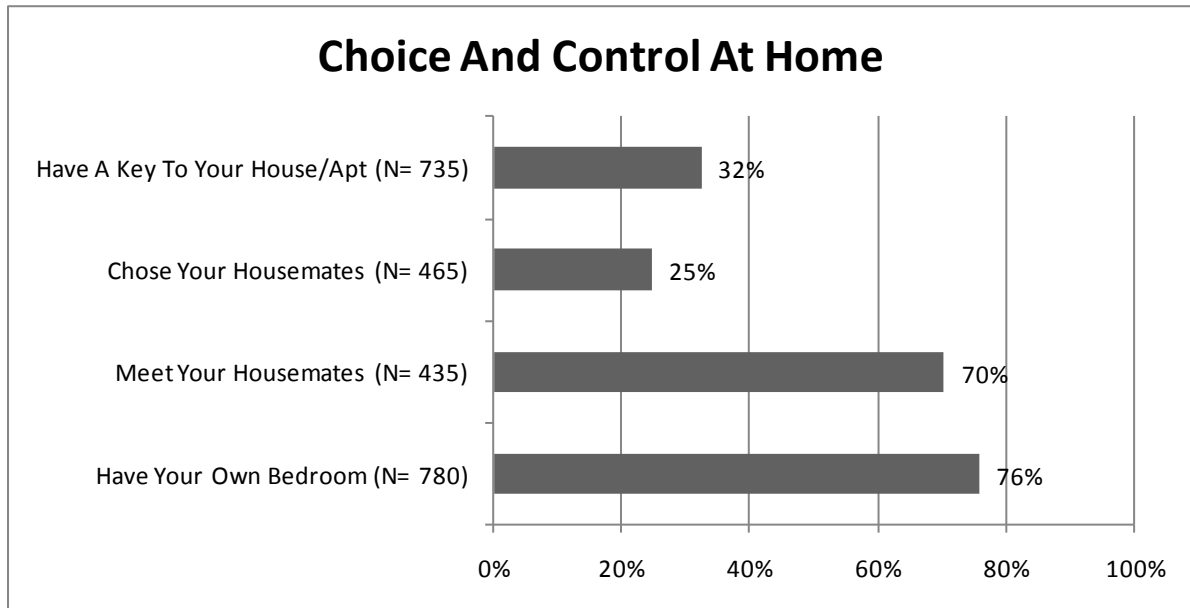


A value of missing was assigned when individuals did not answer, gave an unclear answer, or responded, “do not know.”

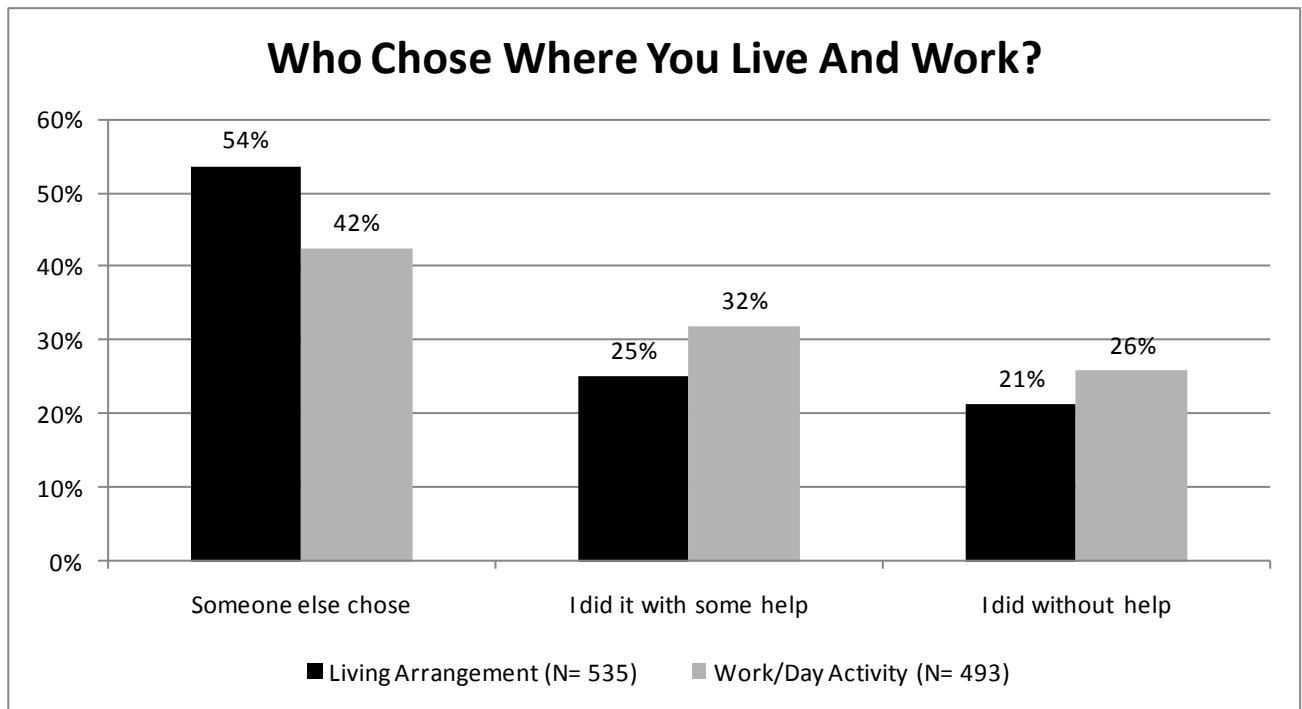
Choice and Control at Home

- 32% of the individuals surveyed had a key/way to get into their house or apartment on their own (state finding 36%, regional 32%).
- For 54% of the individuals, someone else choose where they live (state finding 54%, regional 58%); 21% of those interviewed chose without assistance (state finding 22%, regional 18%).
- For those individuals who had some control in choosing where they live, 33% saw more than one other place before moving in (state finding 39%, regional 38%); 19% saw no other places (state finding 18%, regional 19%).
- 75% of the individuals did not choose their housemates (state finding 70%, regional 71%).

- 70% of the individuals surveyed met some or all of their housemates before living together (state finding 80%, regional 78%)
- 76% of the individuals had their own bedroom (state finding 77%, regional 74%); for those who shared a bedroom, 19% chose some or all of their roommates (state finding 35%, regional 32%)



- For 70% of the individuals interviewed, their mail is never opened without permission (state finding 81%, regional 72%); 17% say their mail is always opened without permission (state finding 12%, regional 16%)



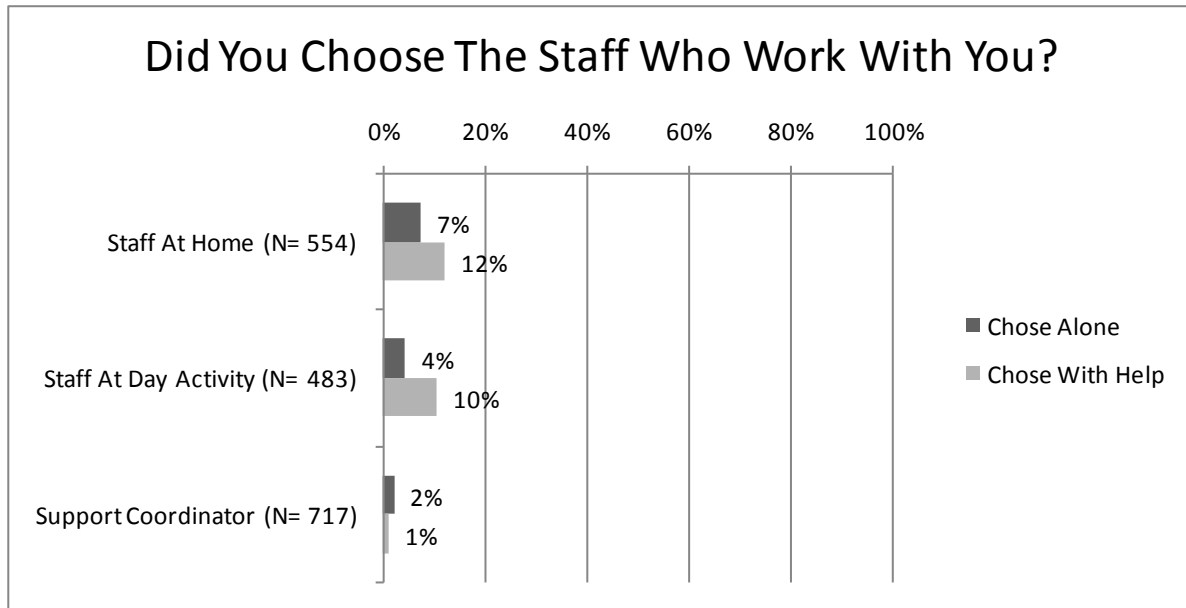
Choice and Control During the Day and for Leisure Time

- 42% of the individuals interviewed reported that someone else chose what they do during the day (state finding 36%, regional 42%).
- 26% of the people interviewed chose what they do during the day without assistance (state finding 34%, regional 27%).
- For those individuals who participated in choosing what they do during the day, 29% saw more than one other place before deciding (state finding 39%, regional 36%); 22% saw no other places (state finding 14%, regional 19%).
- 55% of the individuals surveyed chose their daily schedules without assistance (state finding 56%, regional 48%).
- 65% chose how they spend their free time without assistance (state finding 69%, regional 61%).

Choice and Control in Choosing Staff

- 19% of the individuals interviewed chose the staff that helps them at home, alone or with assistance from family or provider (state finding 28%, regional 25%).

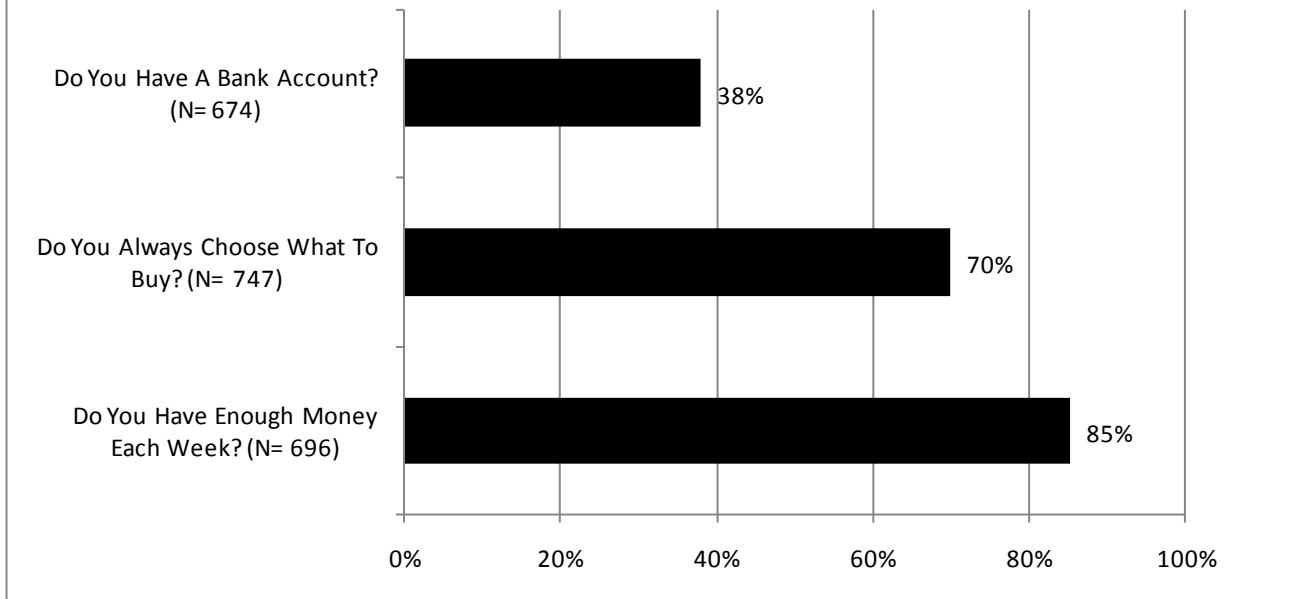
- 15% of the individuals interviewed chose the staff that helps them at their work/day activity, alone or with assistance from family or provider (state finding 30%, regional 24%).
- 3% of the individuals reported that they chose their supports coordinator (alone or with assistance from family or provider) (state finding 12%, regional 7%).



Choice and Control with Regard to Money

- 85% of the individuals have enough money to do many of the things they want to do each week (state finding 91%, regional 88%).
- 70% of the individuals reported that they always choose what to buy with their spending money (state finding 72%, regional 64%).
- 38% 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 47%, regional 51%).

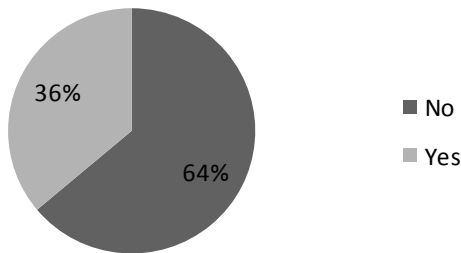
Choice And Control Regarding Spending Money



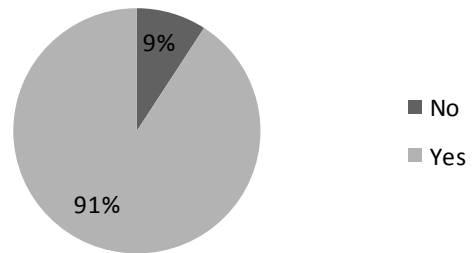
Access to Communication

- For those individuals who do not communicate using words (n=269), there is a formal communication system in place for 36% of the people interviewed (state finding 32%, regional 36%).
- For those people with formal communication systems in place (n=76), the systems are in working order and utilized for 91% of the people interviewed (state finding 88%, regional 88%).
- 69% of individuals with a formal communication system reported using it across all settings (state finding 73%, regional 70%).

If Nonverbal, Is There A Formal Communication System In Place (N= 269)



If There Is A Formal Communication System In Place, Is It Working And Being Used (N= 76)



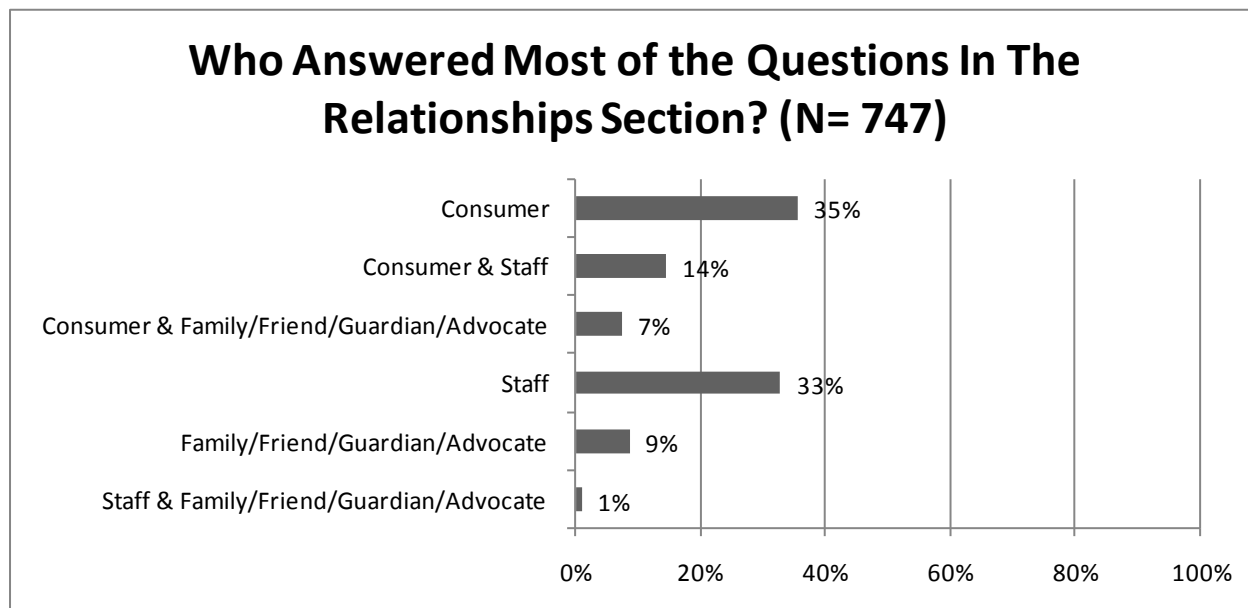
- In regards to forms of communication individuals have and use, 84% have and use cable television (state finding 82%, regional 87%), 22% cell phones, 16% internet, 11% email, and 10% text messaging.

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 43.94 with a standard deviation of 23.66 (47.79 and 22.37 state finding, 43.68 and 23.32 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

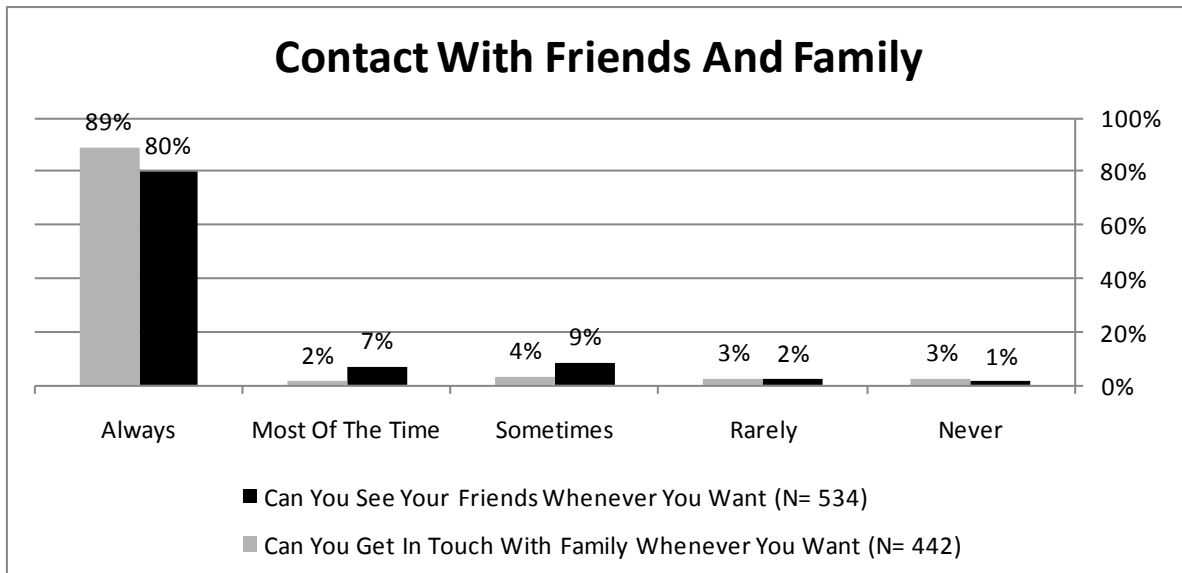
- 67% of people answered that they can see-talk-visit with old friends whenever they want (state finding 62%, regional 56%).

Do You Get A Chance To See-Talk-Visit With Old Friends? (N= 467)



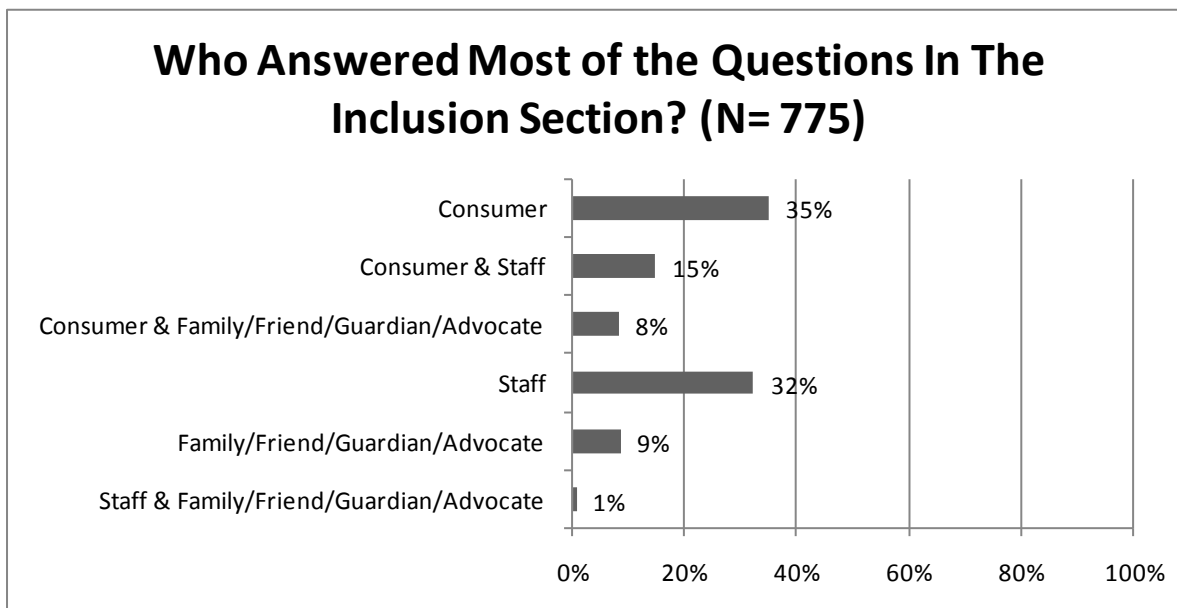
Contact with Friends and Family

- 80% of individuals were always able to see friends whenever they wanted (state finding 78%, regional 72%)
- 89% of respondents were always able to get in touch with family whenever they wanted (state finding 87%, regional 84%).



Inclusion

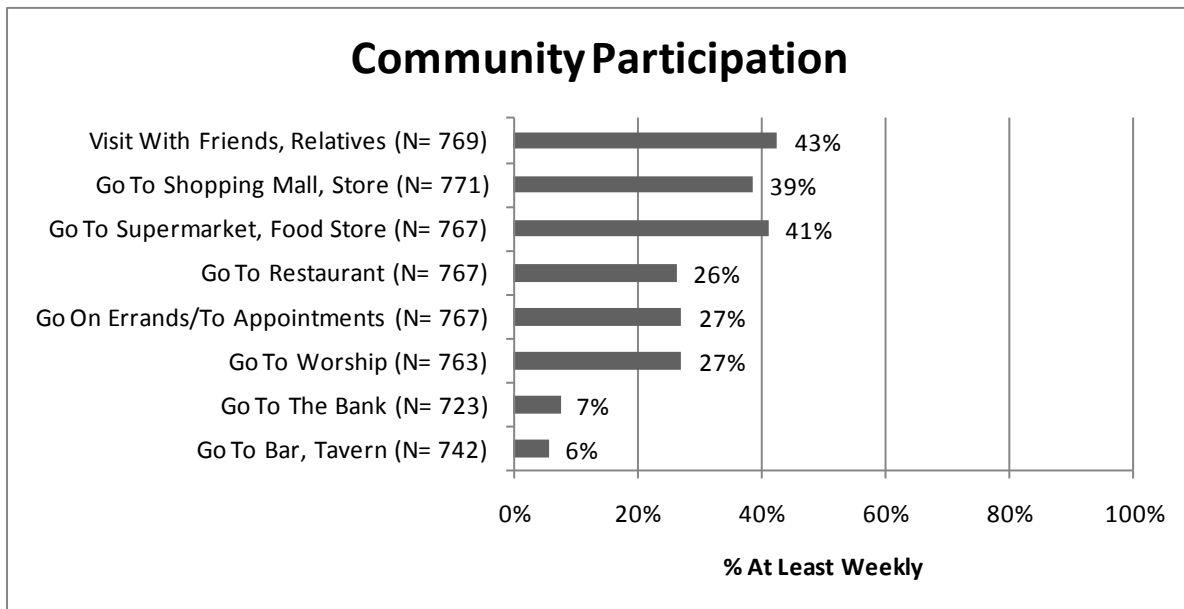
Respondents: The questions on inclusion could be answered by the individual receiving services/supports, a family member, a friend, or paid staff.



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

Community Participation

- 43% of the people visited with friends, relatives and neighbors at least weekly (state finding 57%, regional 41%)
- 41% of individuals went to a supermarket, 26% went to a restaurant, and 39% went to a shopping mall at least weekly (state finding 45%, 41%, and 41%; regional 41%, 35% and 38% respectively)
- At least weekly, individuals went out for errands and appointments (27%), to places of worship (27%), to banks (7%), and to bars/taverns (6%). State findings were 28%, 33%, 13%, and 7%; regional 28%, 29%, 11%, and 5% respectively.



Harris Poll

In May and June 2000, 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 without disabilities. We compared the frequency of community participation reported by individuals in our sample to this national sample.

- Pennsylvanians with disabilities in this study were less likely to visit with friends, relatives and neighbors and to go to a supermarket than either of the other two groups (people with and without disabilities) as compared with the Harris Poll
- Pennsylvanians with disabilities in this study were more likely to go to restaurants and places of worship than people with disabilities in the Harris Poll, but less likely than people without disabilities in the Harris Poll
- Pennsylvanians with disabilities were more likely to go to shopping centers or malls than either of the two groups (people with and without disabilities) as compared with the Harris Poll.

County comparisons are as follows:

Weekly Participation in Community Activities for Philadelphia AE

	Harris: People without Disabilities	Harris: People with Disabilities	IM4Q State	IM4Q County/ Joinder
Visit with friends, relatives, and neighbors	85%	70%	57%	43%
Go to supermarket	83%	55%	45%	41%
Go to restaurant	59%	40%	41%	26%
Go to worship	47%	30%	33%	27%
Go to shopping mall or store	41%	23%	41%	39%

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 36.64 with a standard deviation of 15.48 (state finding 41.34 and 15.83; regional 37.54 and 15.65)

Community Activities

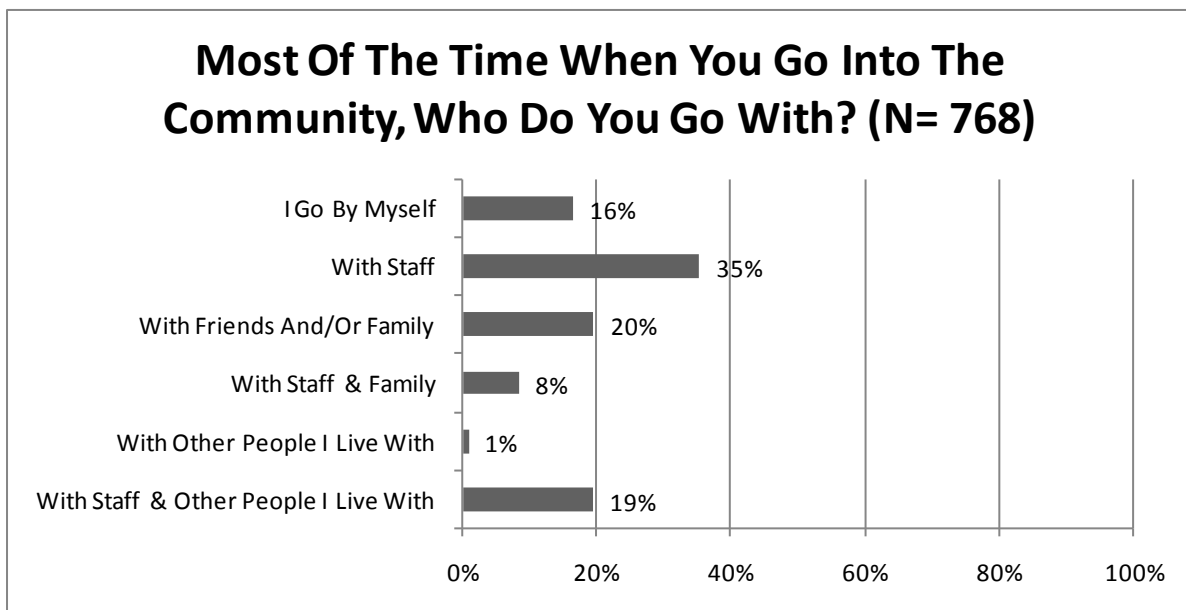
We asked individuals about several other types of community activities including attending social events and recreational events.

- 56% of the individuals go frequently into the community for entertainment (state finding 56%, regional 55%)
- 30% of individuals reported that they frequently go to social events in the community that are attended by people with and without disabilities (state finding 39%, regional 28%)
- 49% of individuals went on a vacation in the past year (state finding 48%, regional 55%)

- Regarding monthly exercise, 58% of individuals reported never going out for exercise (state finding 38%, regional 47%), 7% exercise less than weekly, 8% exercise once a week, and 27% exercise more than once a week (state finding 43%, regional 34%).

Going Out Alone or With Other People

- 16% of individuals go out alone (state finding 10%, regional 12%)
- 55% of individuals go out with staff (or staff and other people they live with) most of the time (state finding 53%, regional 59%)



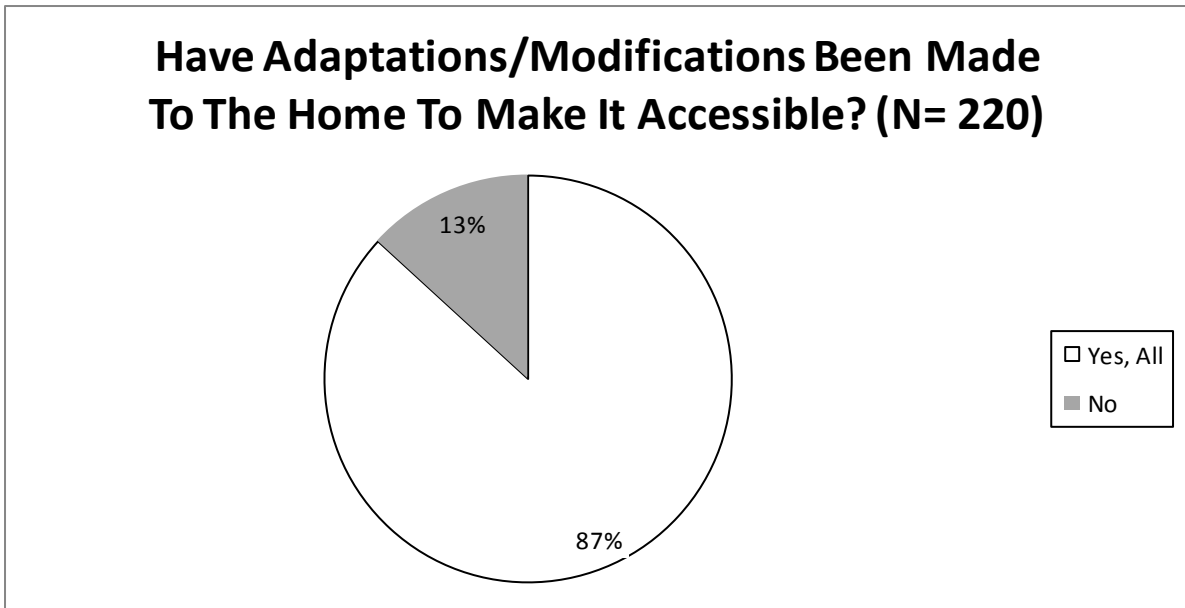
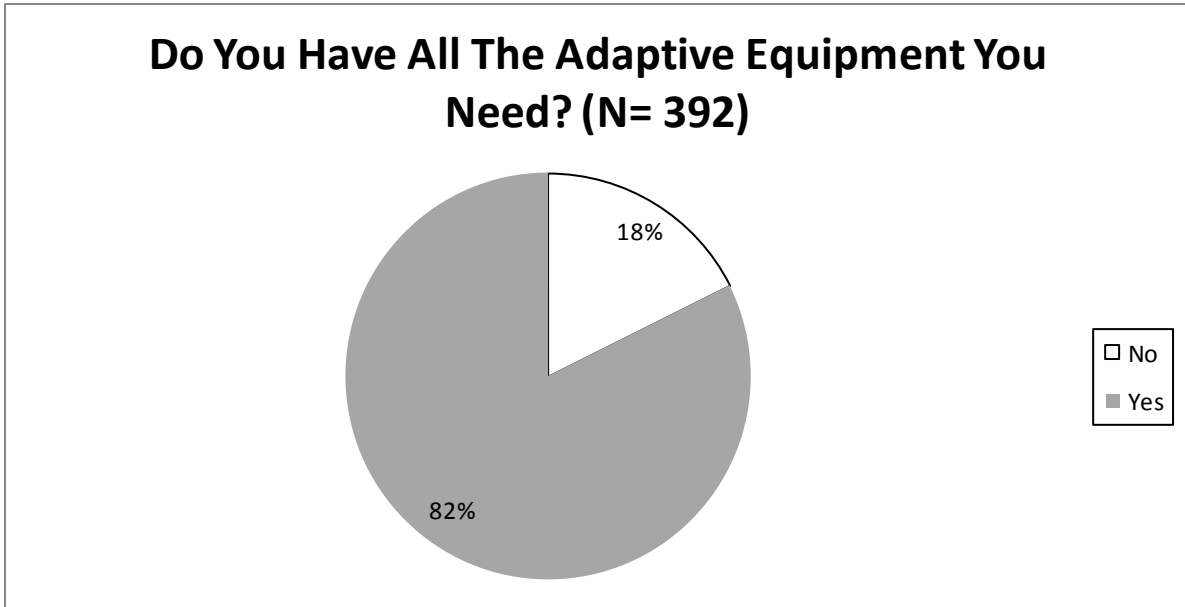
Transportation

- 88% of people always had a way to get where they wanted to go (80% state finding, 81% regional)
- Of those who cannot always get where they want to go, 9% cannot get where they want to go because there is not enough staff (31% state finding, 29% regional)

Home Adaptive Equipment

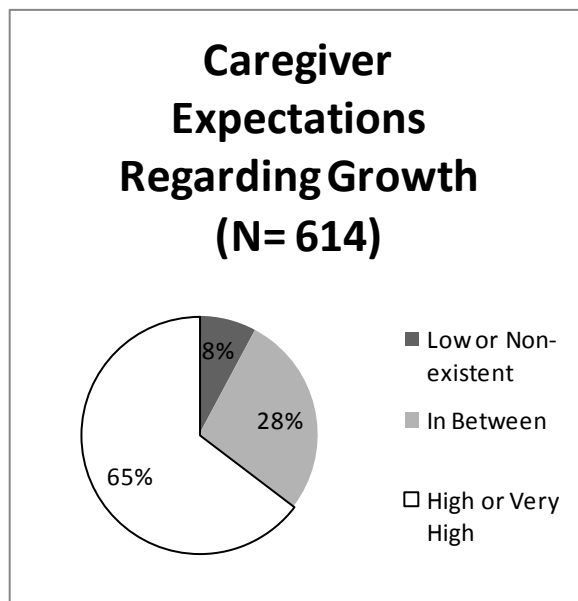
- 82% of individuals reported having all the adaptive equipment they needed (state finding 89%, regional 87%)

- 87% of people said that all necessary adaptations have been made to their home to make it accessible (state finding 82%, regional 83%)



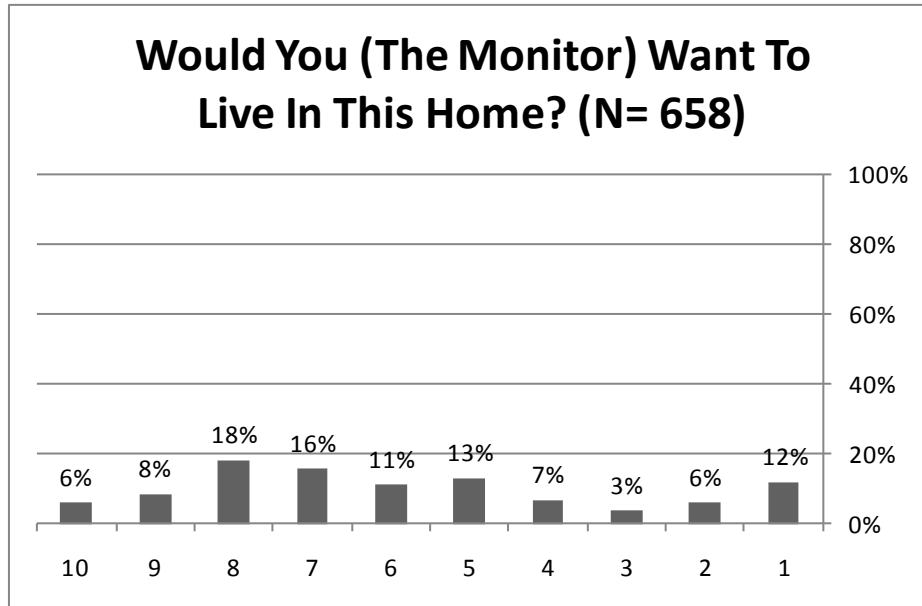
Competence, Personal Growth and Opportunities to Grow and Learn

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 65% of the individuals, caregiver expectations regarding growth was reported as high or very high (state finding 56%, regional 55%)
- 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 5.8 (state finding 6.3, regional 6.1)



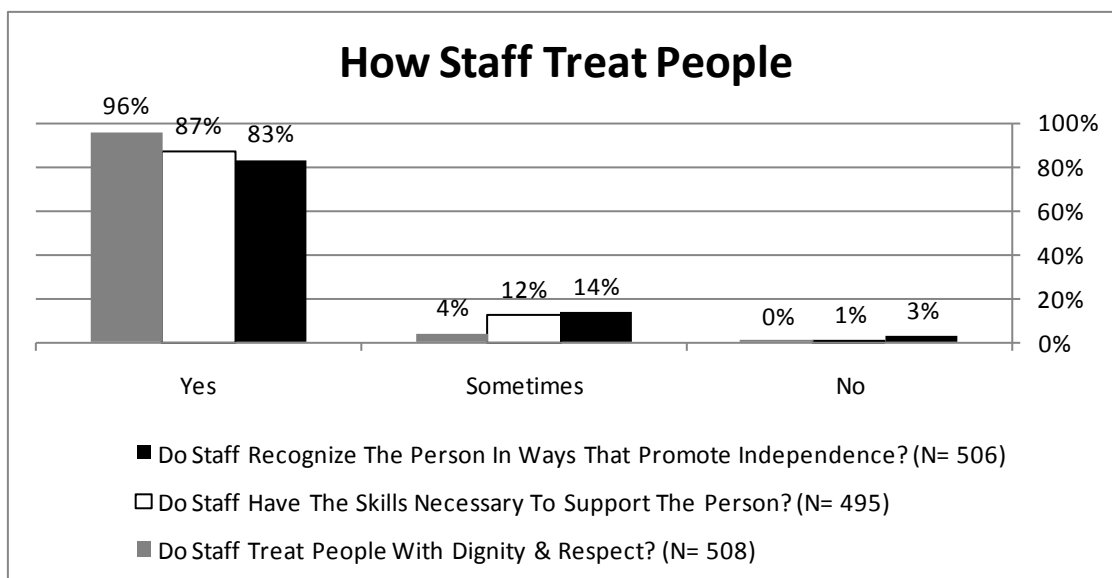
Staff Support for the Person

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 86%, regional 79%)
- Individuals had either all staff (87%) or some staff (12%) with the skill needed to support them (state finding 88% and 12% respectively; regional 82% and 16% respectively).
- 96% of the monitoring teams observed that the staff treated individuals with dignity and respect (state finding 96%, regional 95%)



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. 82% of the interviews took place in the individual’s home (state finding 72% regional 75%), although 15% took place at work/day activity (state finding 23%, regional 21%).

Repair at Home or Work/Day Activity

- Monitors observed that 92% of individuals lived in homes (or went to work/day activities) which were in good repair on the outside and 87% lived in homes (or went to work/day activities) which were in good repair on the inside (state finding 94% and 93% respectively; regional finding 93% and 91% respectively).

Neighborhood

According to IM4Q teams,

- 86% of individuals lived in homes which were in a safe neighborhood (state finding 93%, regional 92%).
- 90% of individuals lived in homes that “fit in” with the neighborhood in which they were located (state finding 90%, regional 89%).

Personal Belongings and Personalities

According to IM4Q teams,

- 97% of individuals lived in homes which had sufficient space for personal belongings (state finding 97%, regional 98%).
- 62% of individuals lived in homes or had bedrooms which reflected the hobbies, interests and personalities of the people who live there (state finding 64%, regional 55%); for 30% of the people only their bedroom reflected their personalities and interests (state finding 30%, regional 38%).

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.

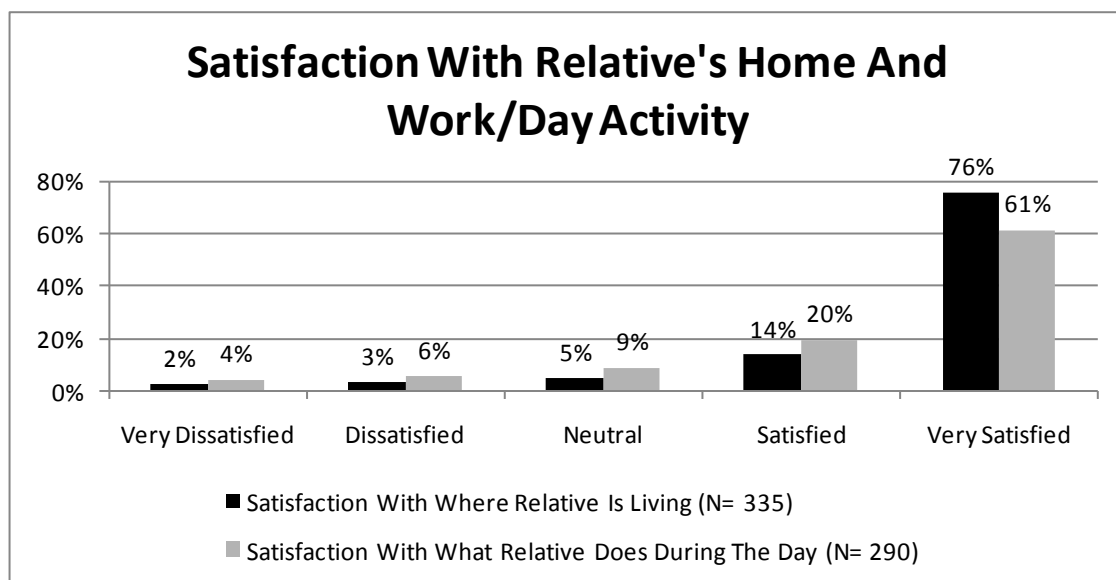
- The average (mean) score was 93.05 with a standard deviation of 15.00 (state finding 96.00 and 12.15 respectively, 95.50 and 12.16 regional)

Family/Friend/Guardian Survey

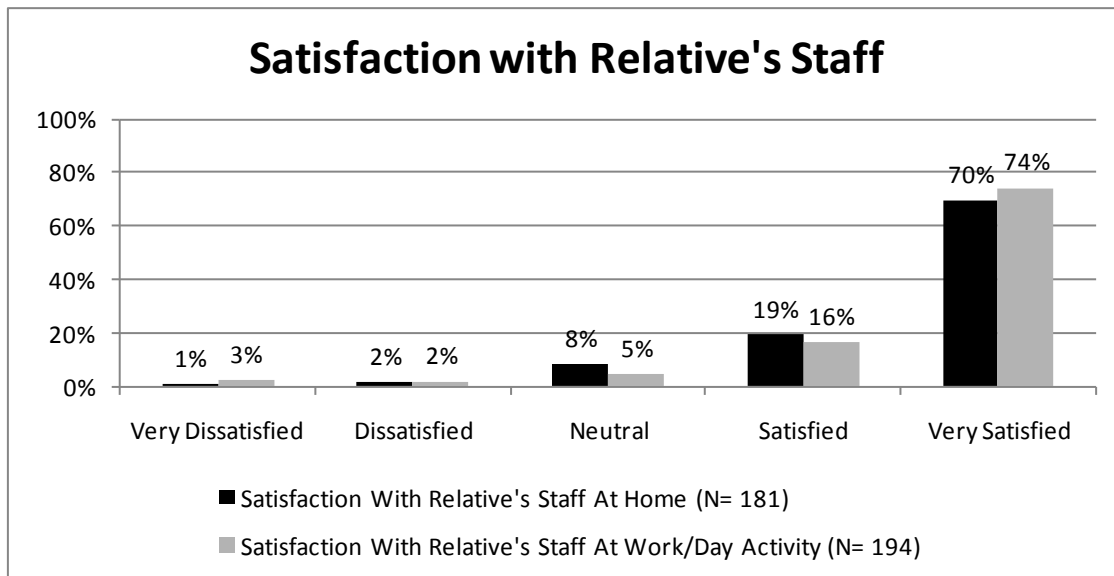
Respondents: This survey was completed by telephone with a family member, guardian, or friend who was identified through the Essential Data Elements Pre-Survey. In the event that a phone survey could not be completed, surveys were completed by mail. A total of 336 family members, friends, and guardians from the Philadelphia AE participated in the survey.

- 62% of the surveys were answered by parents
- 23% were answered by siblings
- 2% were answered by the guardian
- 1% were answered by a friend
- 9% were answered by another relative (spouse, aunt, uncle, cousin, grandparent)
- 3% were answered by persons with other relationships to the individual receiving supports

Satisfaction



- 90% of the families surveyed were either somewhat satisfied or very satisfied with where their relative lives (state finding 94%, regional 91%).
- 81% were either somewhat satisfied or very satisfied with what their relative does during the day (state finding 90%, regional 87%).



- 89% of the families surveyed were either somewhat satisfied or very satisfied with their relative's staff at home (state finding 93%, regional 91%).
- 91% of the families surveyed were either somewhat satisfied or very satisfied with the staff at their relative's day activity (state finding 95%, regional 93%).

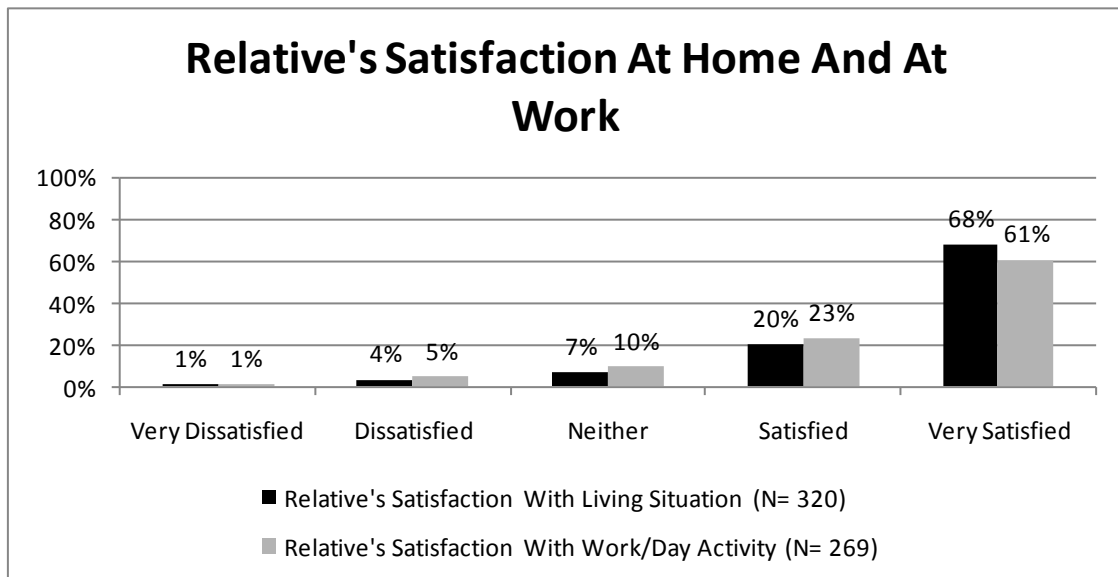
How Often Do You Contact/See Your Relative?

- 90% of the family/friend/guardians contacted their relative at least monthly (state finding 86%, regional 84%); 3% have not contacted their relative in the past year (state finding 3%, regional 4%).
- 75% 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 77%, regional 76%); 5% did not get to see their relative in the past year (state finding 3%, regional 3%)

Your Relative's Satisfaction

- 88% of respondents felt their relative was either very satisfied or satisfied with his/her living situation (state finding 93%, regional 91%)
- 84% felt their relative was either very satisfied or satisfied with what they do during the day (state finding 90%, regional 89%)

- 93% of respondents felt their relative was either very satisfied or satisfied with the staff who support them at home (state finding 94%, regional 93%); 2% felt their relative was either dissatisfied or very dissatisfied (state finding 1%, regional 2%)
- 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 95%, regional 92%); 3% 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 (84%) or most of the time (11%). State findings were 85% and 12% respectively; 83% and 13% 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 86%, regional 80%)
- 79% of the respondents said that their relative seemed to have the opportunity to learn new things (state finding 88%, regional 83%)

Your Relative's Staff

- If their relative did not communicate verbally, 31% of the respondents said that there is a formal communication system in place for their relative and they use it (state finding 34%, regional 32%); for 49%, the communication system is used across all settings (state finding 52%, regional 51%).
- 94% of the respondents said that their relative's home appeared to have enough paid staff (state finding 90%, regional 91%)
- 92% of the respondents said that staff in their relative's home treat people with dignity and respect (state finding 93%, regional 92%)
- 84% of the respondents said that all staff appear to have the skills they need to support their relative, and 14% felt that way about only some staff (state finding 85% and 13% respectively; 79% and 19% regional)

Your Relative's Supports

- 73% of relatives interviewed said that the supports coordinator is always available to assist them if there is a crisis (state finding 85%, regional 77%)
- 68% of relatives were satisfied with the supports coordination their relative receives (state finding 83%, regional 76%)
- 63% of relatives reported that they were told how much money is in their relative's annual budget (state finding 59%, regional 52%)
- 56% said that their relative always received the supports they needed (state finding 74%, regional 66%)
- 81% of relatives always felt that the staff who assisted them with planning respected their choices and opinions (state finding 87%, regional 84%)
- 70% of relatives never felt that frequent changes in support staff was a problem for their family member (state finding 64%, regional 60%)
- 26% of relatives always got to choose the agency/provider who worked with their relative (state finding 29%, regional 31%); 5% had their relative choose (state finding 7%, regional 6%); 58% never got to choose (state finding 48%, regional 50%)

- 53% of relatives were familiar with the way complaints and grievances are handled (state finding 66%, regional 57%); 47% were not familiar (state finding 34%, regional 43%)

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 85.82 with a standard deviation of 18.04 (state finding 90.22 and 14.38 respectively, 87.87 and 15.95 regional)

Summary

This report presents information collected through face-to-face interviews with 780 individuals in Philadelphia AE receiving supports through the Office of Developmental Programs.

Overall, individuals report high levels of satisfaction with where they live, where they work, and with who provides supports to them at home and during the day. Some of the individuals interviewed do not vote but would like to. Individuals report high levels of privacy. Most individuals have enough money each week, and choose what they buy with their spending money. Less than half have a bank account that they can get to independently.

The majority of individuals report that they get the services and supports they need. Two-thirds of all individuals report that they were told how much money is in their annual budget; less than two-thirds of all families report that they were told how much money is in their relative's annual budget. The monitoring teams observed that staff treats individuals with dignity and respect in nearly all situations.

The data continue to indicate that few individuals make choices without assistance with regard to where they live and with whom they live. Prior to moving into their home, less than half of the people interviewed visited multiple places for comparison. In choosing day activities or work, most frequently the individual had some input in the decision.

For those individuals who do not communicate using words, there continues to be issues around lack of exploration of alternative strategies. Most individuals that do not communicate using words do not have a communication device in place. Even when it has been explored and people have acquired devices, for some people the devices are not in working order or being used across all settings.

Less than half of the people interviewed participate in community activities (i.e. going shopping or out to eat) on a weekly basis. Statewide, the percentage of individuals with disabilities participating in community events continues to be lower than the comparison group of people without disabilities, with the exception of going to the shopping mall. Less than one-third of the

people interviewed participate in inclusive social activities that can be attended by people with and without disabilities.

The majority of individuals can always get where they want to go; however, some individuals cannot always get where they want to go due to there not being enough staff.

Those responding to the Family/Friend/Guardian Survey reported high levels of satisfaction similar to the responses given by the individual.