

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

***Independent Monitoring for Quality (IM4Q)
Philadelphia AE
2007-2008***

**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 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 is being developed to produce a cohesive system for assuring and improving the quality of services and supports people receive from the mental retardation system. The IM4Q data are one source of information that will be 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). The 2000-01 IM4Q statewide findings and recommendations of the IM4Q Steering Committee were also used as the foundation for the development of a 2003 Quality Action Plan that has been developed and is being implemented with all mental retardation system stakeholders through the ODP Planning Advisory Committee (PAC).

During fiscal year 2000-2001, all 46 AEs developed contracts with Local IM4Q Programs to independently conduct interviews and enter data onto the DPW's 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 IM4Q local 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).

Surveys were conducted from September, 2005 through June 30, 2006 using a standardized instrument and methodology developed in conjunction with the State IM4Q Steering Committee and ODP. Revisions to the instrument were made from previous years, based on feedback from the local programs, as well as from the statewide steering committee, counties, 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. There were no changes made to the data collection instrument.

This year, 2007-2008, a total of 6512 face-to-face interviews were conducted from September 2007 until June 2008. And, a total of 2731 Family/Friend/Guardian Surveys were completed. This year, there were a few changes to the instrument tool used to collect the data. There were three new items added to the Dignity, Respect and Rights section. In addition, there were 10 new items added to the instrument tool involving the frequency and intensity of physical activity.

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 EDE consists of 101 questions, 46 of which can only be answered by the individuals receiving supports and services.

The EDE for fiscal year 2007-2008 includes all survey questions included in the FY 2007-2008 NCI Consumer Survey. At the time of this report, approximately 1400 individuals included in this report are represented in the NCI sample for 2007-2008, based on a sampling methodology established by ODP and Human Services Research Institute (HSRI). A copy of the NCI report for FY 2007-08 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).
- 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 individual's 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 at the national level.
- **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 project 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 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 services and supports to children ages three and over, and to adults supported by the Office of Developmental Programs service system for individuals with mental retardation. 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. 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 continue to be included in the sample this 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 776 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	11	0.2%	1	0.1%
State Mental Health Hospital	2	0.0%	0	0.0%
Homeless	0	0.0%	0	0.0%
Temporary Shelter	1	0.0%	0	0.0%
Foster Care	9	0.1%	4	0.5%
Incarceration	1	0.0%	1	0.1%
Nursing Home/Nursing Facility	115	1.8%	3	0.4%
Domiciliary Care	38	0.6%	7	0.9%
Personal Care Home (PCH)	243	3.7%	15	1.9%
Family living	389	6.0%	48	6.2%
Unlicensed Family Living	23	0.4%	1	0.1%
Own residence	543	8.4%	12	1.5%
Relative's home	1566	24.1%	135	17.4%
Children's Facility	2	0.0%	0	0.0%
Approved Private School	2	0.0%	0	0.0%
Private ICF/MR (4 or fewer persons)	54	0.8%	0	0.0%
Private ICF/MR (4 to 8 persons)	186	2.9%	5	0.6%
Private ICF/MR (9 to 15 persons)	20	0.3%	2	0.3%
Private ICF/MR (16 or more persons)	203	3.1%	7	0.9%
Community Home (1 person)	132	2.0%	42	5.4%
Community Home (2 to 4 persons)	2532	38.9%	463	59.7%
Community Home (5 to 6 persons)	226	3.5%	13	1.7%
Community Home (7 to 8 persons)	68	1.0%	0	0.0%
Community Home (9 to 15 persons)	21	0.3%	3	0.4%
Community Home (16 or more persons)	24	0.4%	4	0.5%
Other	91	1.4%	9	1.2%
Missing	10	-	1	-
Total	6512	100%	776	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 FFG Survey. All potential IM4Q programs were screened by the State IM4Q Steering Committee. Selection criteria included: independence of the projects from service delivering entities, consumer and family involvement on governing boards, and involvement of individuals receiving supports and families in data collection activities. Local IM4Q Programs were selected by AEs from a variety of organizations, including non-service providing chapters of the Arc (formerly The Association for Retarded Citizens), 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 assistants from the Institute on Disabilities at Temple University. Trainings were held in each of the four regions for project staff and data collectors, wherever possible. Additional training was provided on a AEs-by-AEs basis for data collectors, 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 services 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 refused 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 preferred 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 2006-07 survey cycle was to be collected by June 30, 2007 and entered into HCSIS by August 1, 2007. A usable data file was received by the Institute on Disabilities in October, 2007. 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 AE program.

	# of People	Percent
Allegheny	657	10.1%
Armstrong/Indiana	108	1.7%
Beaver	96	1.5%
Bedford/Somerset	87	1.3%
Berks	172	2.6%
Blair	108	1.7%
Bradford/Sullivan	55	0.8%
Bucks	206	3.2%
Butler	95	1.5%
Cambria	94	1.4%
Cameron/Elk	38	0.6%
Carbon/Monroe/Pike	107	1.6%
Centre	73	1.1%
Chester	168	2.6%
Clarion	52	0.8%
Clearfield/Jefferson	83	1.3%
Columbia/Montour/Snyder/Union	100	1.5%
Crawford	93	1.4%
Cumberland/Perry	99	1.5%
Dauphin	164	2.5%
Delaware	280	4.3%
Erie	258	4.0%
Fayette	84	1.3%
Forest/Warren	48	0.7%
Franklin/Fulton	83	1.3%
Greene	38	0.6%
Huntington/Mifflin/Juniata	97	1.5%
Lackawanna/Susquehanna	148	2.3%
Lancaster	175	2.7%
Lawrence	87	1.3%
Lebanon	60	0.9%
Lehigh	158	2.4%
Luzerne/Wyoming	144	2.2%
Lycoming/Clinton	109	1.7%
McKean	45	0.7%
Mercer	75	1.2%
Montgomery	323	5.0%
Northampton	126	1.9%
Northumberland	81	1.2%
Philadelphia	776	11.9%
Potter	31	0.5%
Schuylkill	92	1.4%
Tioga	46	0.7%
Venango	51	0.8%
Washington	96	1.5%
Wayne	39	0.6%
Westmoreland	153	2.3%
York/Adams	154	2.4%
TOTAL	6512	100%

Satisfaction

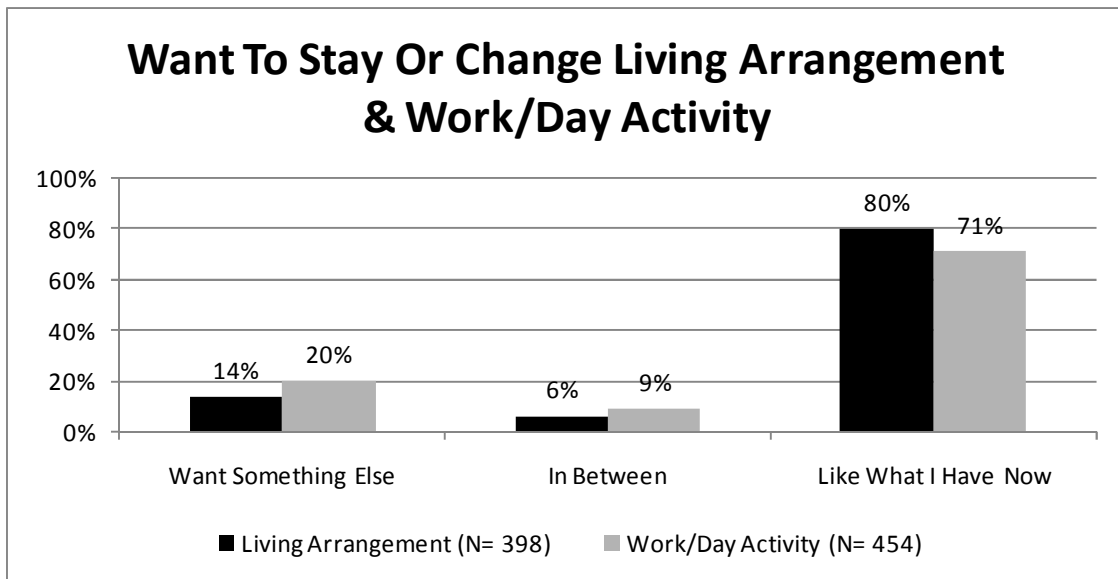
Respondents: Only the individual receiving services/supports could answer the questions on satisfaction. The percent of people who responded to questions in this section ranged from 41.6% to 65.7%.

Satisfaction with Living Arrangements

- 88% of individuals liked where they live (state finding 90%, regional 89%).
- 80% wanted to stay where they currently live (state finding 79%, regional 80%).

Satisfaction with Work/Day Activity

- 88% of individuals *with* a day activity/work liked what they did during the day (state finding 90%, regional 90%).
- 71% wanted to continue their current daytime activities/work (state finding 72%, regional 72%), 20% wanted to do something else (state finding 22%, regional 20%).



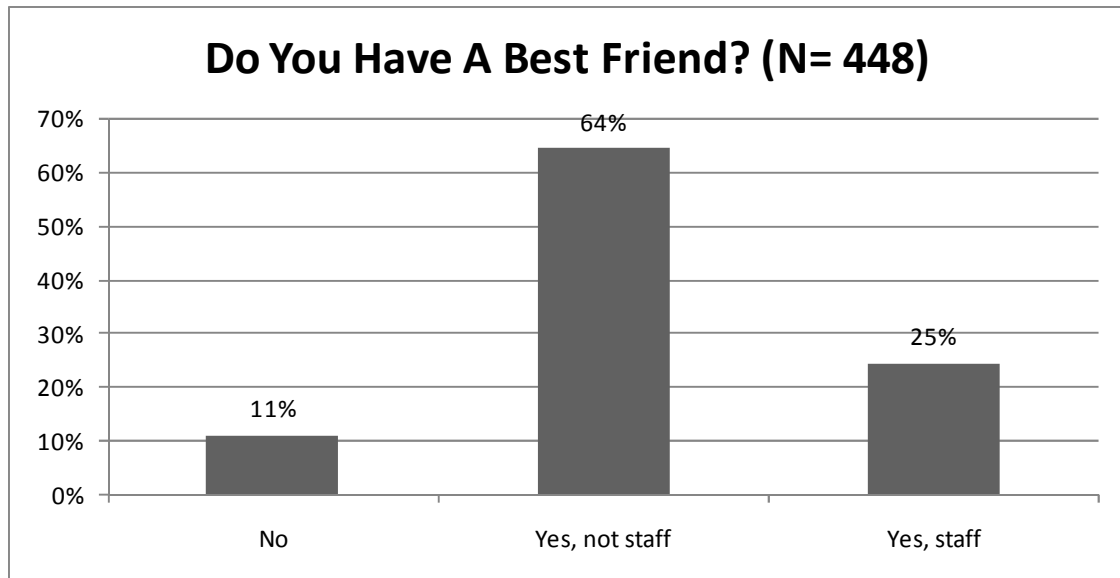
Daily Life

- 74% of the individuals always had opportunities to participate in household tasks like cooking and cleaning (state finding 67%, regional 65%).
- 79% of individuals get to do things in the community as often as they would like to (most of the time) (state finding 80%, regional 78%).
- 88% of individuals reported getting the services and supports they need (state finding 93%, regional 91%).

	<i>Always</i>	<i>Most of the Time</i>	<i>Sometimes</i>	<i>Rarely</i>	<i>Never</i>
Have opportunities to engage in household tasks (n=482)	74%	12%	10%	1%	3%

Happiness and Loneliness

- 84% reported usually feeling happy (state finding 85%, regional 87%), 12% reported being in-between (state finding 11%, regional 10%), and 4% reported usually feeling sad (state finding 4%, regional 4%).
- 56% of individuals reported never feeling lonely (state finding 58%, regional 58%), 42% reported sometimes feeling lonely (state finding 39%, regional 40%), and 2% reported always feeling lonely (state finding 3%, regional 2%).
- 89% of individuals reported that they have a best friend (state finding 84%, regional 88%) – for 64% of the people, their best friend is not a staff member (state finding 65%, regional 65%).
- 44% reported that they have a boyfriend or girlfriend that they are dating (state finding 43%, regional 45%).
- 75% reported having friends, which are not staff or family, with whom they like to do things (state finding 68%, regional 75%).

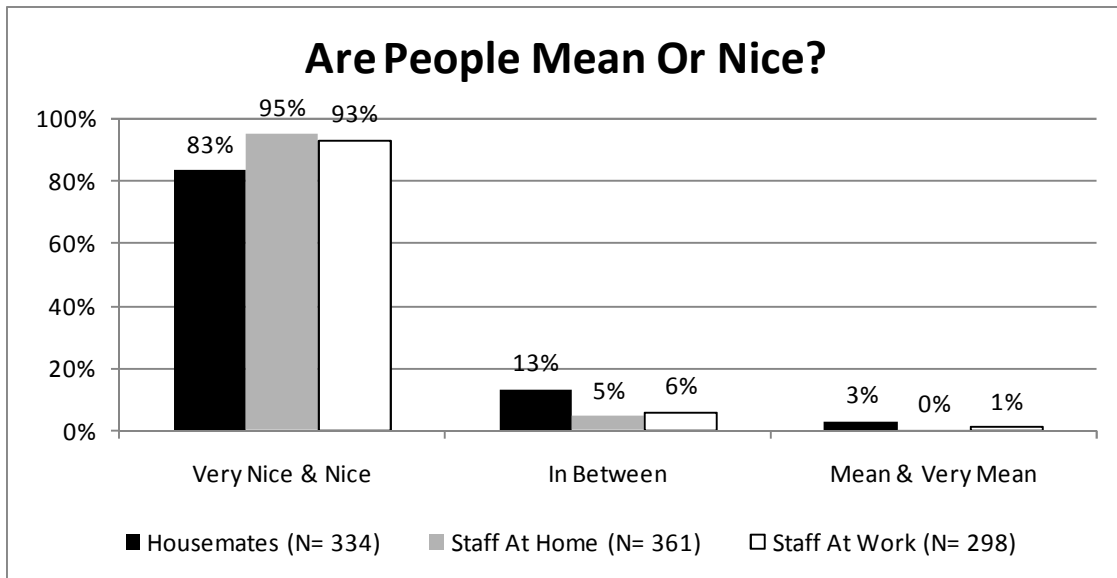


Privacy

- 90% of the individuals surveyed reported that they always have privacy (a place to be alone) when they want it (state finding 86%, regional 87%).
- At least most of the time 93% 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 87%).
- For 86% of the individuals, people always knock on the bedroom door and wait for a response before coming in (state finding 76%, regional 77%).

Are People Nice or Mean?

- 83% reported that their housemates are very nice or nice (state finding 86%, regional 86%).
- 95% of the people interviewed reported that their staff who work with them at home are very nice or nice (state finding 93%, regional 94%).
- 93% reported that staff who work with the respondents at work or day activity are nice or very nice (state finding 93%, regional 94%).



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 84.66 with a standard deviation of 19.08 (85.37 and 18.84 state finding; 85.96 and 18.69 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 15.9% to 63.2%.

Forms of Identification

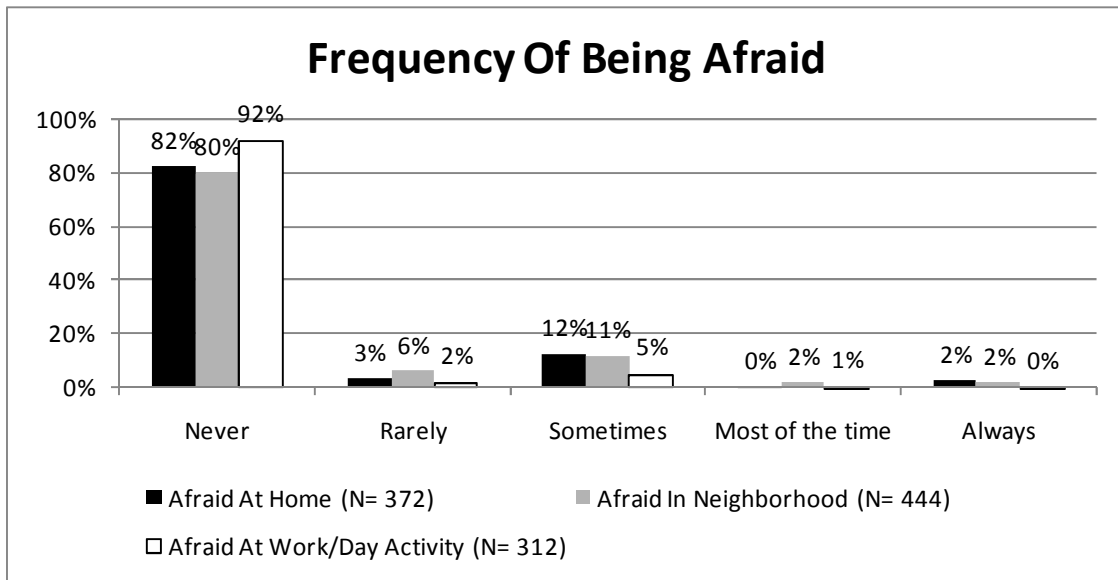
- 78% of individuals stated that they always carry a form of identification, such as a card with the individuals name, address and a person to call in case of emergency or a non-driver ID (state finding 60%, regional 66%); 12% never do (state finding 22%, regional 19%).

Support with Problems and Goals

- 92% of individuals always had someone in their life who will try to help make things better (state finding 89%, regional 90%).
- 54% of individuals go to staff at home for help most of the time (state finding 42%, regional 51%); 22% go to family (state finding 29%, regional 21%)
- 80% reported that people always help them learn/do new things (state finding 80%, regional 80%); 78% want help to learn new things (state finding 67%, regional 74%).

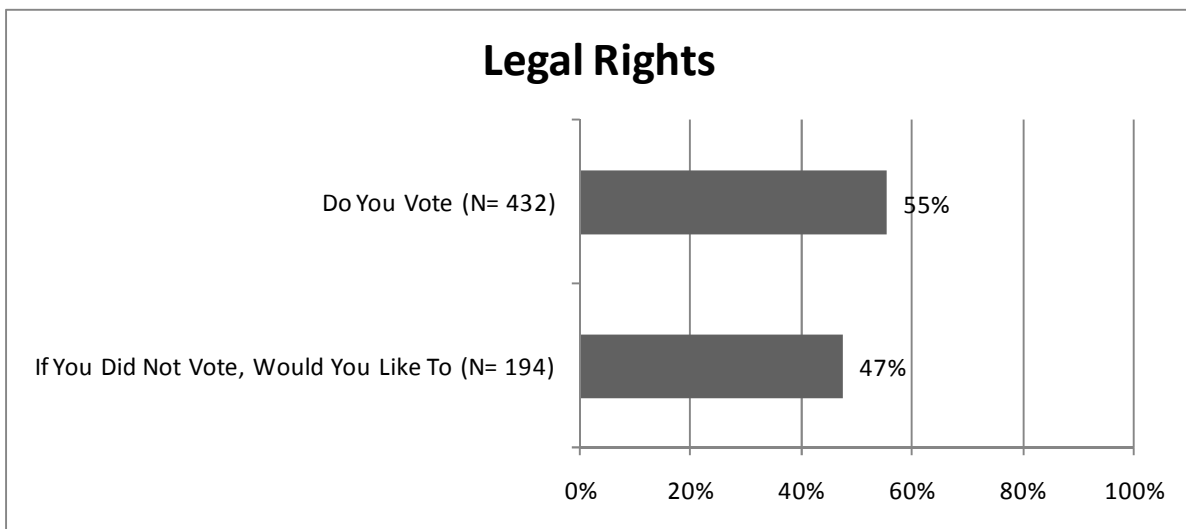
Being Afraid

- 82% reported never being afraid at home (state finding 77%, regional 76%).
- 80% reported never being afraid in the neighborhood (state finding 82%, regional 79%).
- 92% reported never being afraid at work, school or day activity (state finding 87%, regional 88%).



Legal Rights

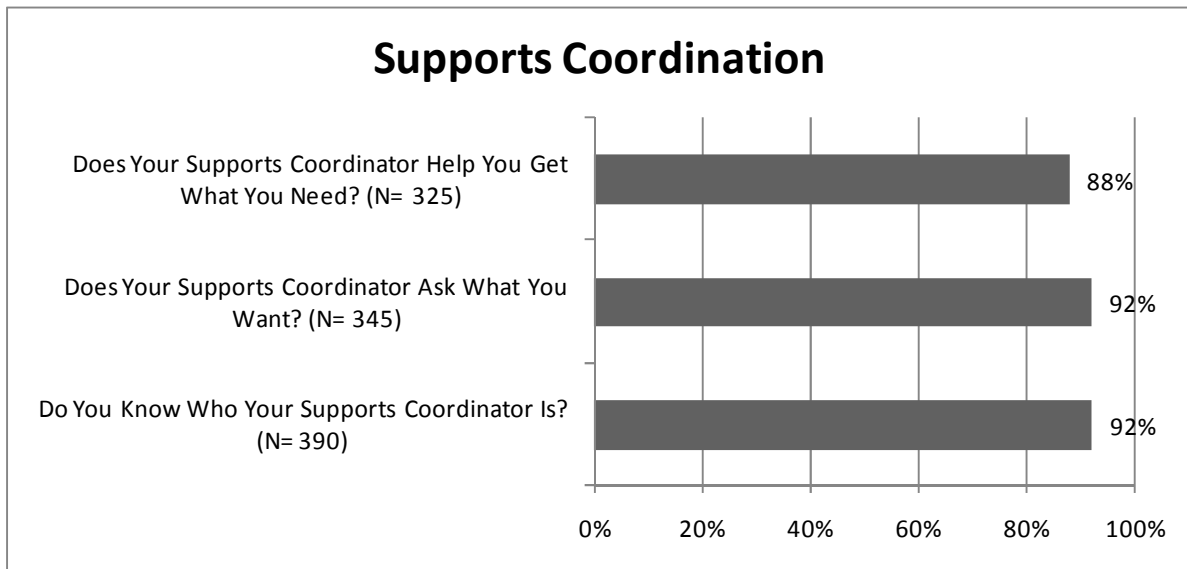
- 6% of those interviewed reported that someone has kept them from doing things they have the right to do (state finding 9%, regional 9%).
- 45% of people said that they do not vote (state finding 63%, regional 49%); 47% of these individuals would like to vote (state finding 33%, regional 45%)



Supports Coordination

- 92% of individuals know who their supports coordinator is (state finding 90%, regional 90%).

- 94% are happy with their supports coordinator (state finding 92%, regional 93%)
- 84% of individuals can always talk to their supports coordinator when they want (state finding 85%, regional 84%)
- 88% of the people surveyed reported that their supports coordinator helps them get what they need (state finding 86%, regional 86%).
- 92% of the people said that their supports coordinator asks them what they want (state finding 84%, regional 86%).



- 34% of individuals have had more than one supports coordinators in the past year (state finding 28%, regional 33%)
- When supports coordinators changed 7% got to choose the new one (state finding 24%, regional 11%)
- 99% of individuals reported that their supports coordinator always treats them with dignity and respect (state finding 97%, regional 98%)
- 98% reported that their supports coordinator talks to them and listens to them when visiting (state finding 95%, regional 95%)
- 80% of individuals reported that they were told how much money was in their annual budget (state finding 64%, regional 65%).

- 92% of individuals reported that they are getting all the services they expected based on the planning meetings with the supports coordinator and on the Individual Support Plan (ISP) (state finding 91%, regional 90%)
- 92% of individuals reported they are satisfied/happy with all the services they receive based on planning meeting with the supports coordinator and on the Individual Support Plan (ISP) (state finding 92%, regional 91%)
- 90% of individuals reported that their Individual Support Plan (ISP) included all of the things they needed (state finding 92%, regional 90%)

Three distinct scales were created to represent this section of the survey.

Dignity and Respect Scale: The Dignity and Respect Scale included three measures that asked whether housemates/ roommates, staff at home, and staff at work/day activity are nice or mean. Scores on the Dignity and Respect Scale could range from 0 to 100, with a higher score indicating greater dignity (people being nice to you).

- The average score was 80.68 with a standard deviation of 13.71 (82.45 and 15.10 state finding; 81.99 and 13.83 regional).

Fear 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 Fear Scale could range from 0 to 100, with a higher score indicating less fear.

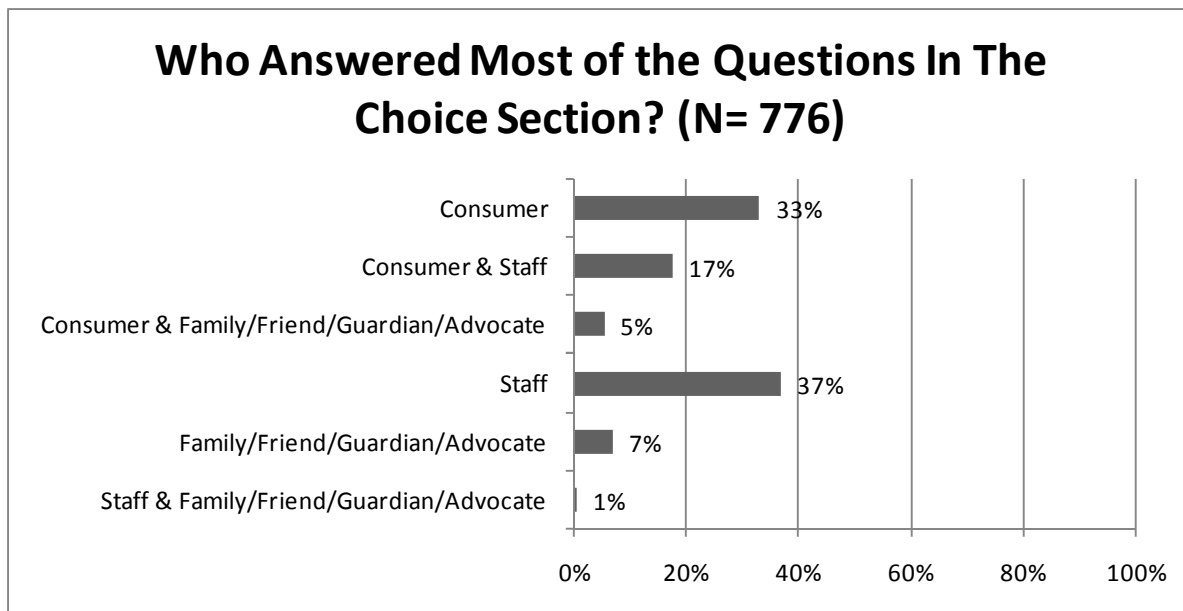
- The average (mean) score was 91.18 with a standard deviation of 16.67 (90.49 and 17.13 state finding; 90.09 and 17.43 regional).

Supports Coordinator Relationship Scale: This scale included four measures that asked individuals about their relationship with the case manager/supports coordinator. Scores on the Supports Coordinator Relationship Scale could range from 0 to 100, with a higher score indicating the perception of a more positive relationship with the case manager/supports coordinator.

- The average (mean) score was 87.66 with a standard deviation of 27.64 (84.38 and 30.15 state finding; 84.44 and 30.34 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.

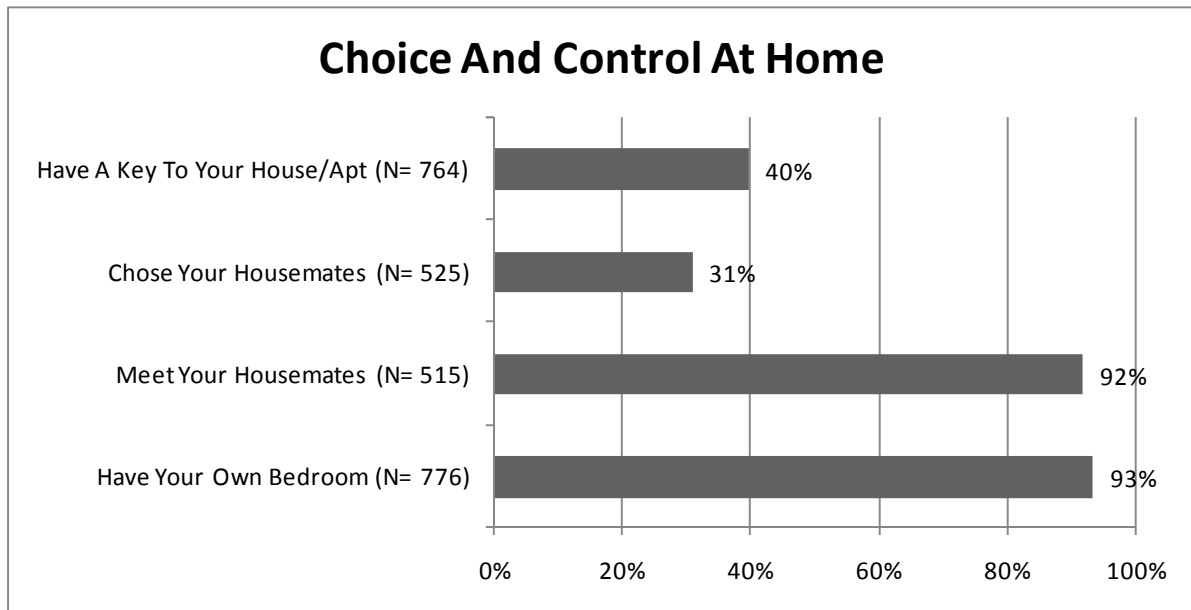


A value of missing was assigned when individuals did not answer, gave an unclear answer, or responded, “do not know.”

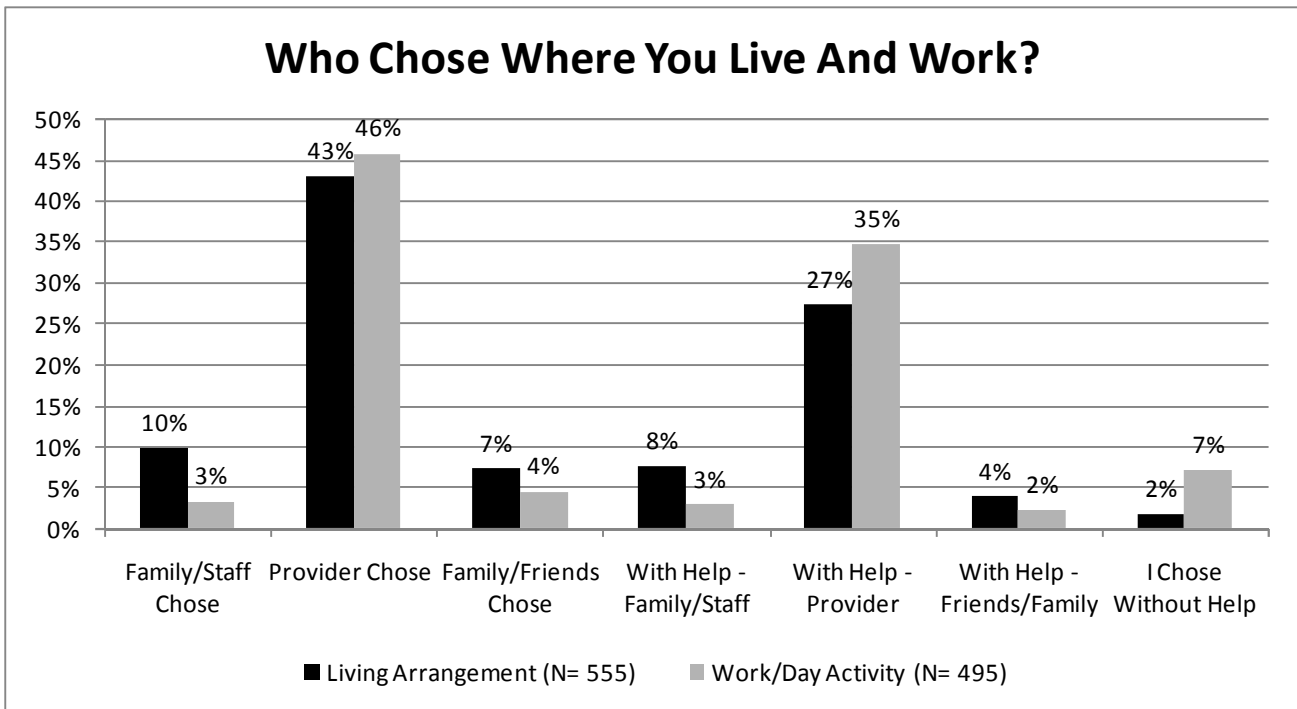
Choice and Control at Home

- 40% of the individuals surveyed had a key/way to get into their house or apartment on their own (state finding 38%, regional 35%).
- For 60% of the individuals, someone else choose where they live (state finding 53%, regional 59%); 2% of those interviewed chose without assistance (state finding 9%, regional 3%).
- For those individuals who had some control in choosing where they live, 25% saw more than one other place before moving in (state finding 25%, regional 28%); 55% saw no other places (state finding 53%, regional 52%).
- 69% of the individuals did not choose their housemates (state finding 73%, regional 68%).

- 92% of the individuals surveyed met some or all of their housemates before living together (state finding 84%, regional 87%)
- 93% of the individuals had their own bedroom (state finding 82%, regional 83%); for those who shared a bedroom, 30% chose some or all of their roommates (State finding 37%, regional 43%)



- For 85% of the individuals interviewed, their mail is never opened without permission (state finding 78%, regional 77%); 8% say their mail is always opened without permission (state finding 13%, regional 12%)
- 83% of the individuals reported that they can have privacy with visitors (state finding 86%, regional 84%).
- 95% are allowed to use the phone whenever they want (state finding 93%, regional 92%)

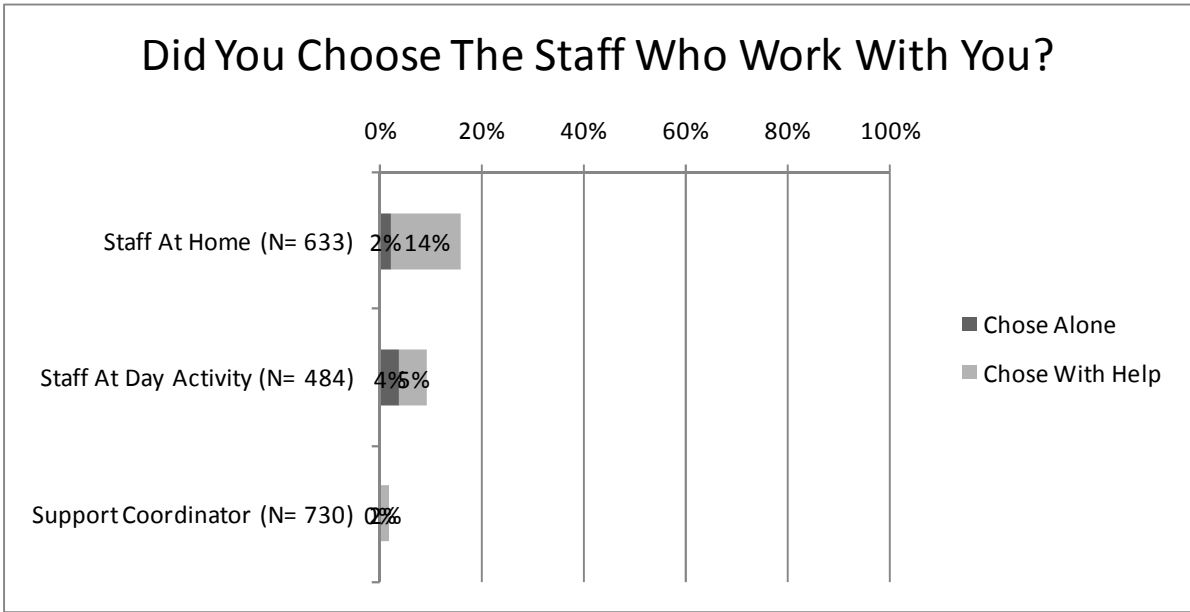


Choice and Control During the Day and for Leisure Time

- 53% of the individuals interviewed reported that someone else chose what they do during the day (state finding 38%, regional 49%).
- For 80% of the individuals interviewed, the provider either chose what the individual does during the day or helped the individual decide (state finding 54%, regional 64%).
- 7% of the people interviewed chose what they do during the day without assistance (state finding 18%, regional 10%).
- For those individuals who had some control in choosing what they do during the day, 17% saw more than one other place before deciding (state finding 20%, regional 22%); 61% saw no other places (state finding 58%, regional 56%).
- 60% of the individuals surveyed chose their daily schedules without assistance (state finding 61%, regional 54%).
- 71% chose how they spend their free time without assistance (state finding 71%, regional 66%).
- 84% chose at least some of the things they do outside their home at least some of the time (state finding 89%, regional 83%).

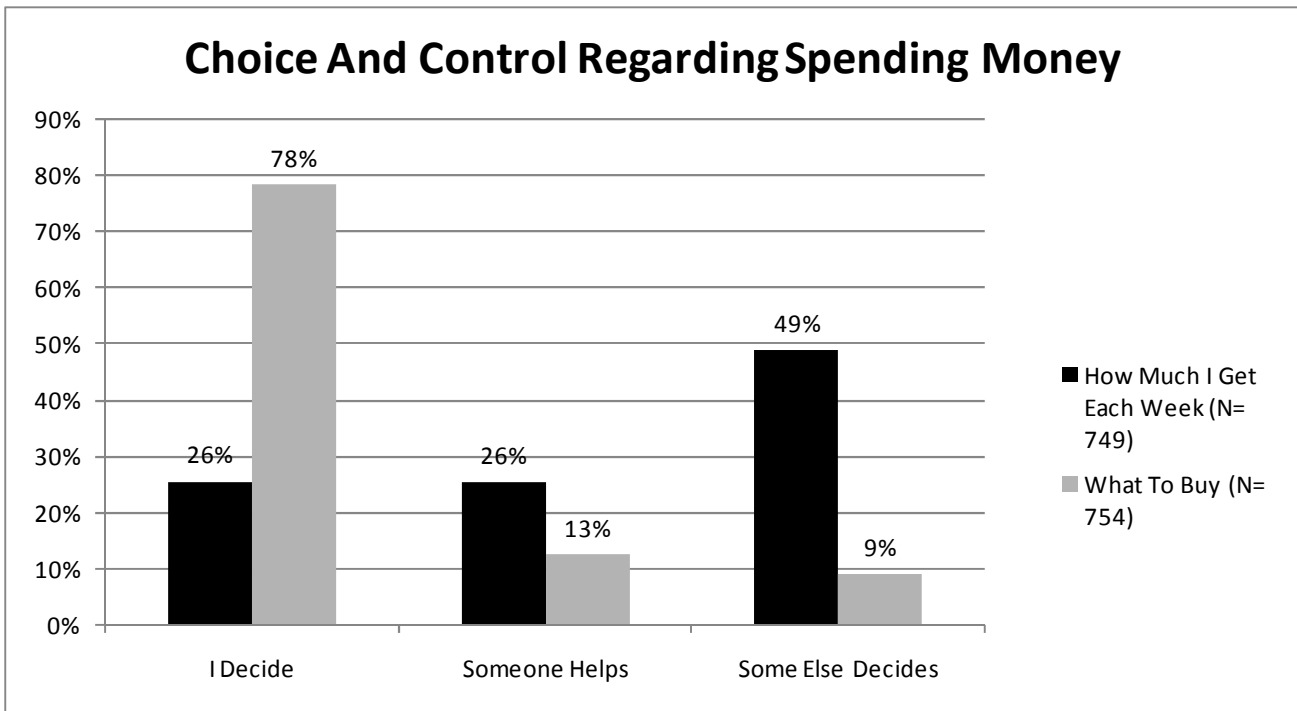
Choice and Control in Choosing Staff

- 16% of the individuals interviewed chose the staff who help them at home (alone or with assistance from family or provider) (state finding 25%, regional 23%).
- 9% 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 31%, regional 21%).
- 2% of the individuals reported that they chose their supports coordinator (alone or with assistance from family or provider) (state finding 5%, regional 2%).



Choice and Control with Regard to Money

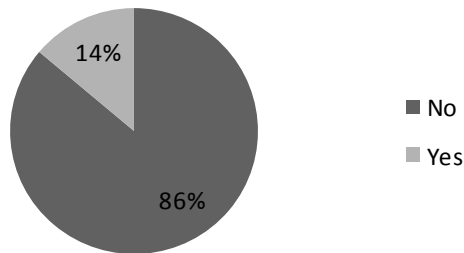
- 26% of the individuals interviewed reported that they choose how much spending money they have each week (state finding 27%, regional 23%).
- 78% of the individuals reported that they always choose what to buy with their spending money (state finding 76%, regional 68%).



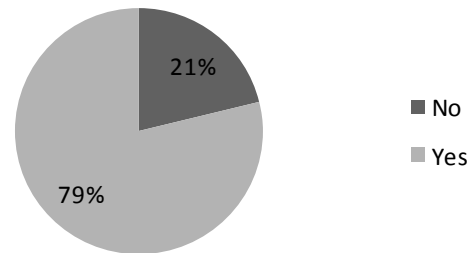
Access to Communication

- For those individuals who do not communicate using words (n=244), there is a formal communication system in place for 14% of the people interviewed (state finding 33%, regional 26%).
- For those people with formal communication systems in place (n=33), the systems are in working order and utilized for 79% of the people interviewed (state finding 83%, regional 81%).

If Nonverbal, Is There A Formal Communication System In Place (N= 244)



If There Is A Formal Communication System In Place, Is It Working And Being Used (N= 33)

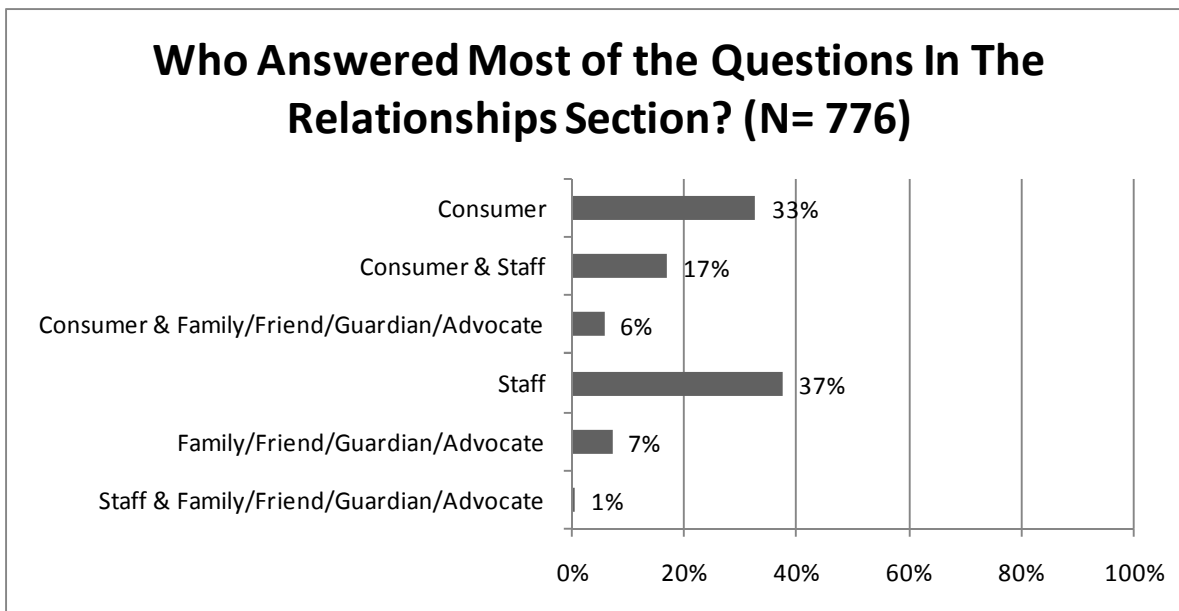


Choice and Control Scale: The scale included eight measures that asked individuals about the extent to which individuals have choice and control in their lives. Scores on the Choice and Control Scale could range from 0 to 100, with a higher score indicating more opportunities to exert choice and control.

- The average (mean) score was 43.21 with a standard deviation of 19.65 (48.22 and 20.21 state finding, 42.42 and 19.90 regional).

Relationships

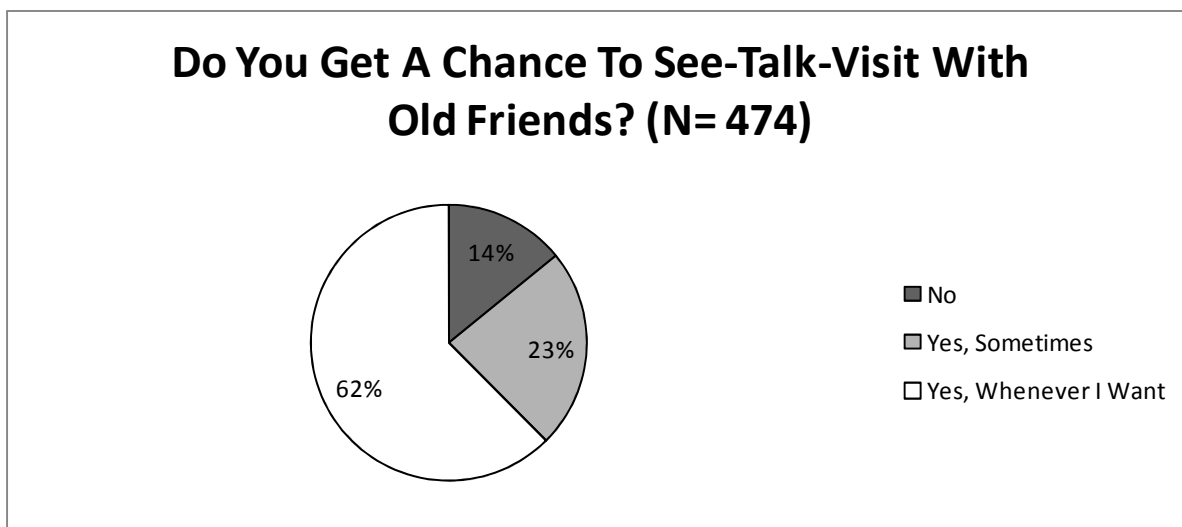
Respondents: The questions on relationships could be answered by the individual receiving services/supports, a family member, a friend, or paid staff.



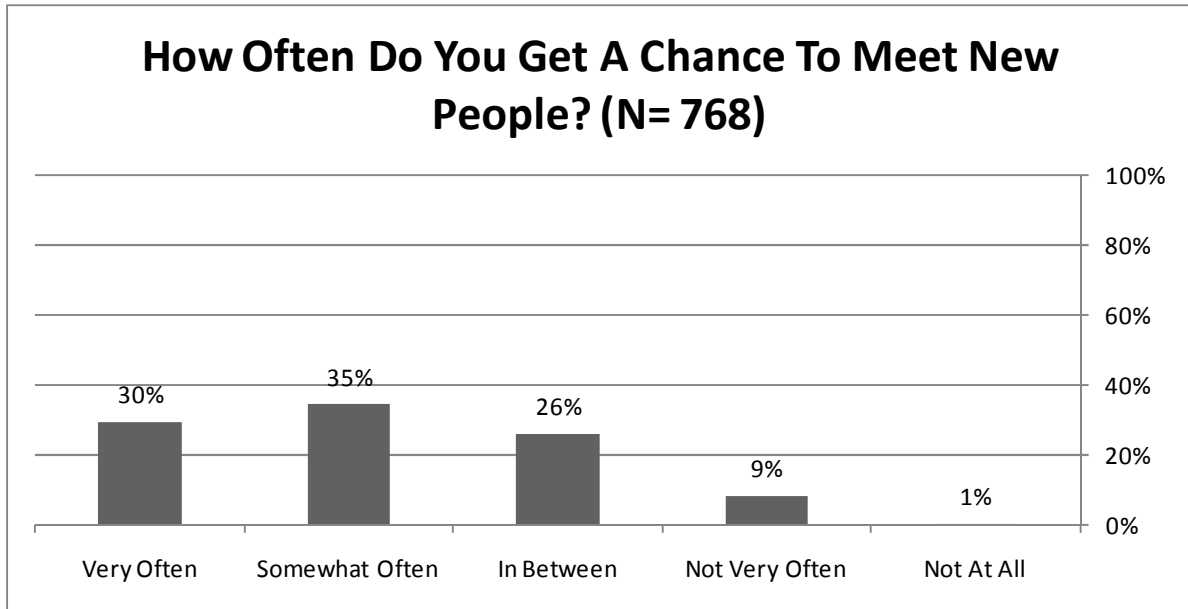
A value of missing was assigned when individuals did not answer, gave an unclear answer, or responded, “do not know.”

Friendships

- 62% of people answered that they can see-talk-visit with old friends whenever they want (state finding 62%, regional 57%).



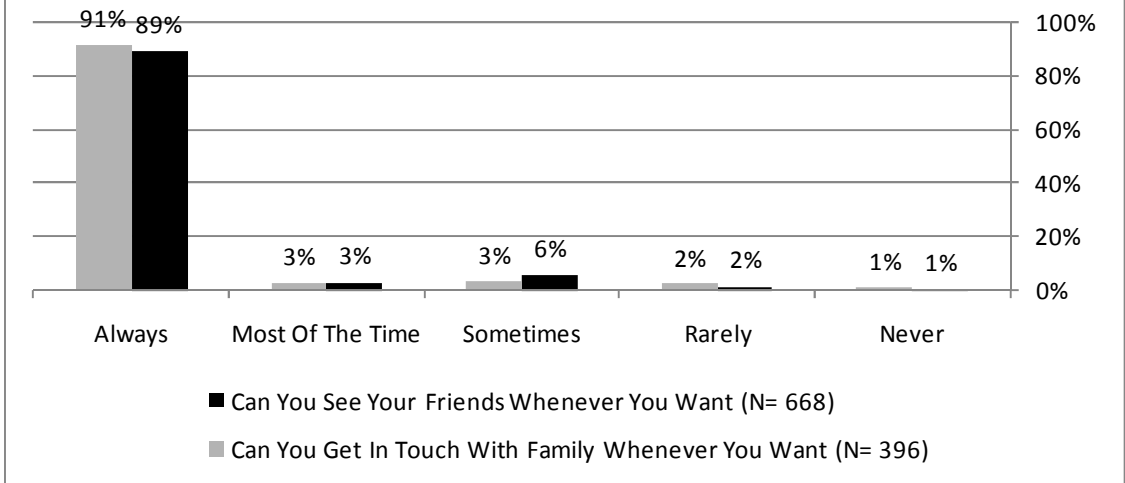
- 64% of individuals reported that they get a chance to meet new people at least somewhat often (state finding 67%, regional 62%).



Contact with Friends and Family

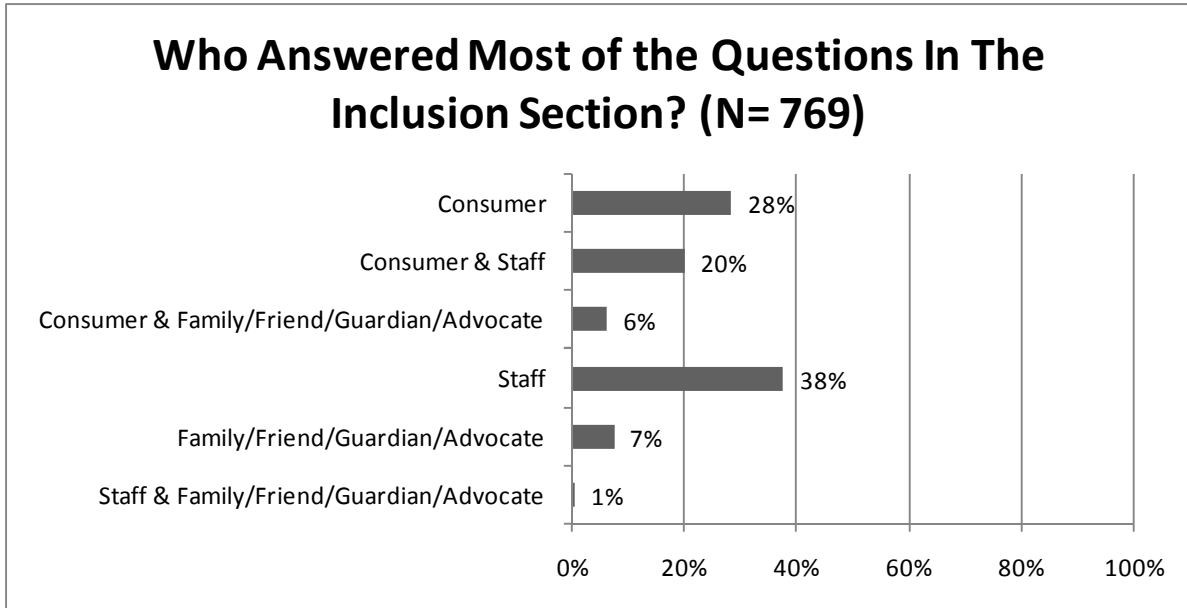
- 89% of individuals were always able to see friends whenever they wanted (state finding 81%, regional 79%)
- 91% of respondents were always able to get in touch with family whenever they wanted (state finding 90%, regional 87%).

Contact With Friends And Family



Inclusion

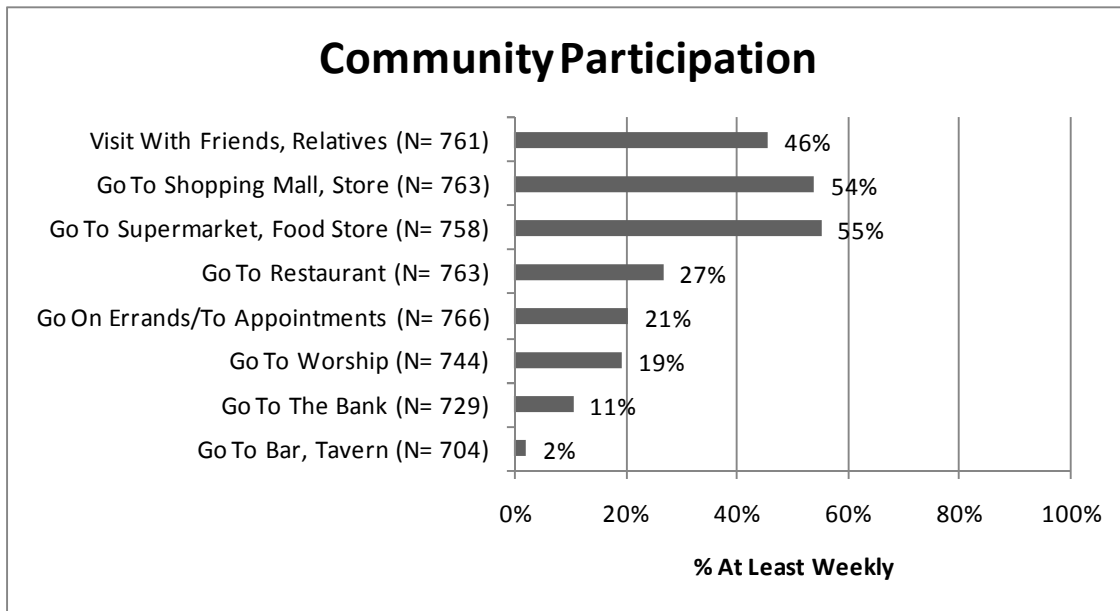
Respondents: The questions on inclusion could be answered by the individual receiving services/supports, a family member, a friend, or paid staff.



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

Community Participation

- 46% of the people visited with friends, relatives and neighbors at least weekly (state finding 58%, regional 48%)
- 55% of individuals went to a supermarket, 27% went to a restaurant, and 54% went to a shopping mall at least weekly (state finding 48%, 43%, and 42%; regional 48%, 36% and 47% respectively)
- At least weekly, individuals went out for errands and appointments (21%), to places of worship (19%), to banks (11%), and to bars/taverns (2%). State findings were 30%, 30%, 16%, and 3%; regional 27%, 23%, 15%, and 2% 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%	58%	46%
Go to supermarket	83%	55%	48%	55%
Go to restaurant	59%	40%	43%	27%
Go to worship	47%	30%	30%	19%
Go to shopping mall or store	41%	23%	42%	54%

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.

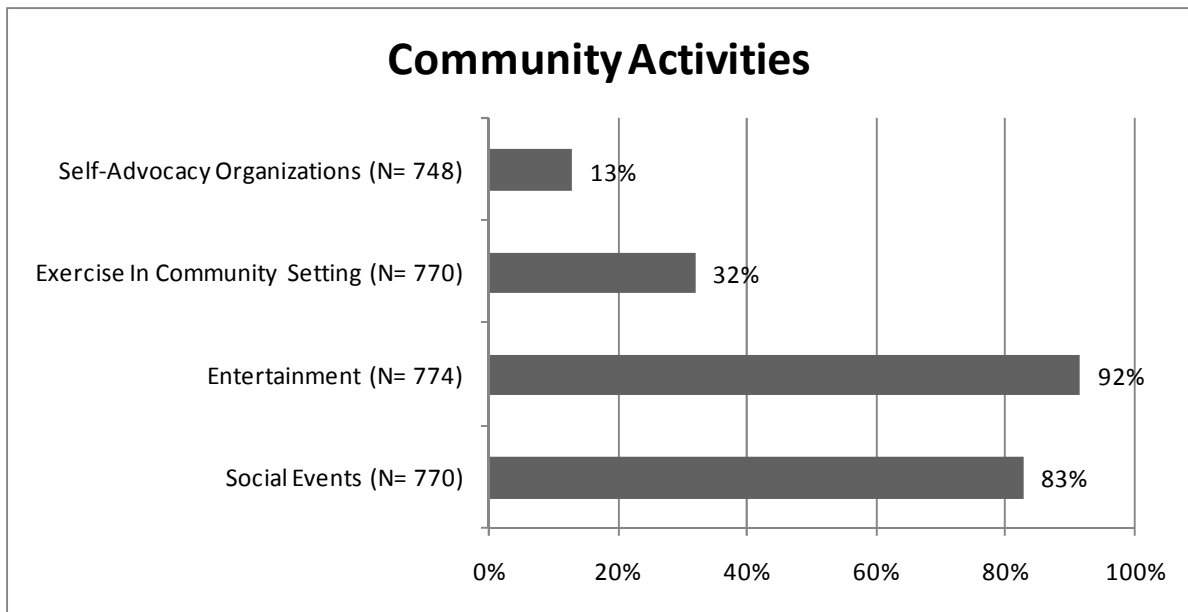
- The average score was 40.84 with a standard deviation of 12.44 (state finding 42.09 and 14.79; regional 40.31 and 13.65)

Community Activities

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

- 92% of the individuals went into the community for entertainment (state finding 85%, regional 90%)
- 13% of people have been to a meeting/event of an advocacy group (state finding 16%, regional 17%)
- 83% of individuals reported that they go to social events in the community that are attended by people with and without disabilities (state finding 76%, regional 77%)

- 32% of individuals reported that they exercise or play sports in a community setting (state finding 37%, regional 34%); 13% exercise or play sports in a non-integrated setting (state finding 20%, regional 19%).
- 55% of respondents do not exercise or play sports (state finding 43%, regional 47%).

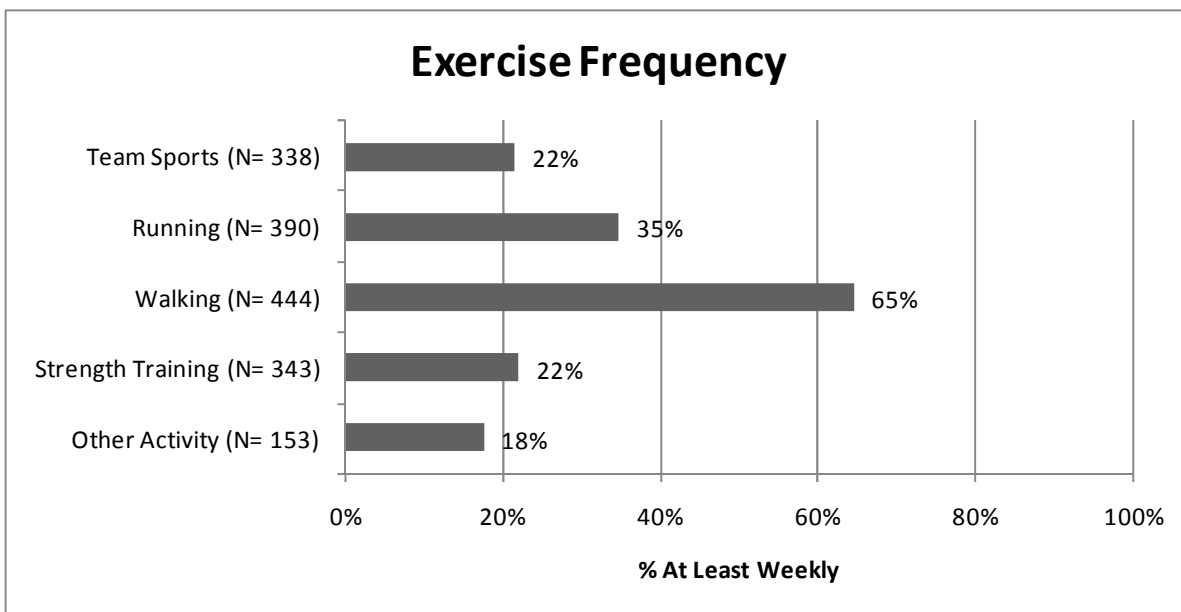


Exercise Frequency and Intensity

We asked individuals about how often (20 minutes or more per day) do they participate in exercise, playing sports and/or other physical activities. In addition, we also asked individuals, if they do exercise in team sports, running, walking, strength training, and other physical activities, to what intensity to they participate in these activities.

- 70% of individuals interviewed reported they never participated in team sports (state finding 77%, regional 78%); 22% of individuals reported participating in team sports at least weekly (state finding 17%, regional 18%)
- 35% of individuals interviewed reported they never participated in activities like running (state finding 55%, regional 57%); 35% of individuals reported participating in activities like running at least weekly (state finding 27%, regional 28%)

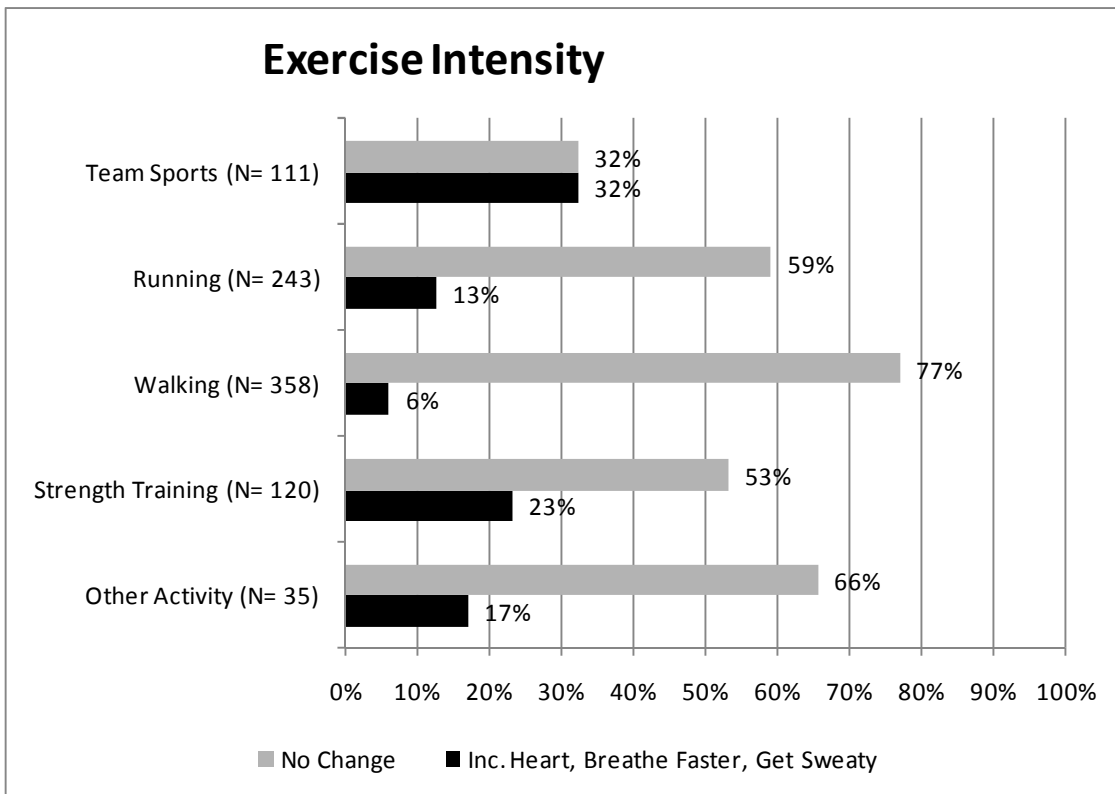
- 15% of individuals interviewed reported they never participated in activities like walking (state finding 37%, regional 40%); 65% of individuals reported participating in activities like walking at least weekly (state finding 50%, regional 46%)
- 66% of individuals interviewed reported they never participated in activities like strength training (state finding 69%, regional 68%); 22% of individuals reported participating in activities like strength training at least weekly (state finding 24%, regional 25%)
- 75% of individuals interviewed reported they never participated in other physical activities (state finding 81%, regional 83%); 18% of individuals reported participating in other physical activities at least weekly (state finding 15%, regional 14%)



- 32% of individuals interviewed reported they participate in activities like team sports to the extent that their heart rate increased, they breathed faster and they got sweaty (state finding 26%, regional 26%); 32% of individuals reported no change when participating in activities like team sports (state finding 35%, regional 39%)
- 13% of individuals interviewed reported they participate in activities like running to the extent that their heart rate increased, they breathed faster and they got sweaty (state finding 16%, regional 17%); 59% of individuals reported no change when participating in activities like running (state finding 50%, regional 46%)
- 6% of individuals interviewed reported they participate in activities like walking to the extent that their heart rate increased, they breathed faster and they got sweaty (state

finding 10%, regional 12%); 77% of individuals reported no change when participating in activities like walking (state finding 58%, regional 56%)

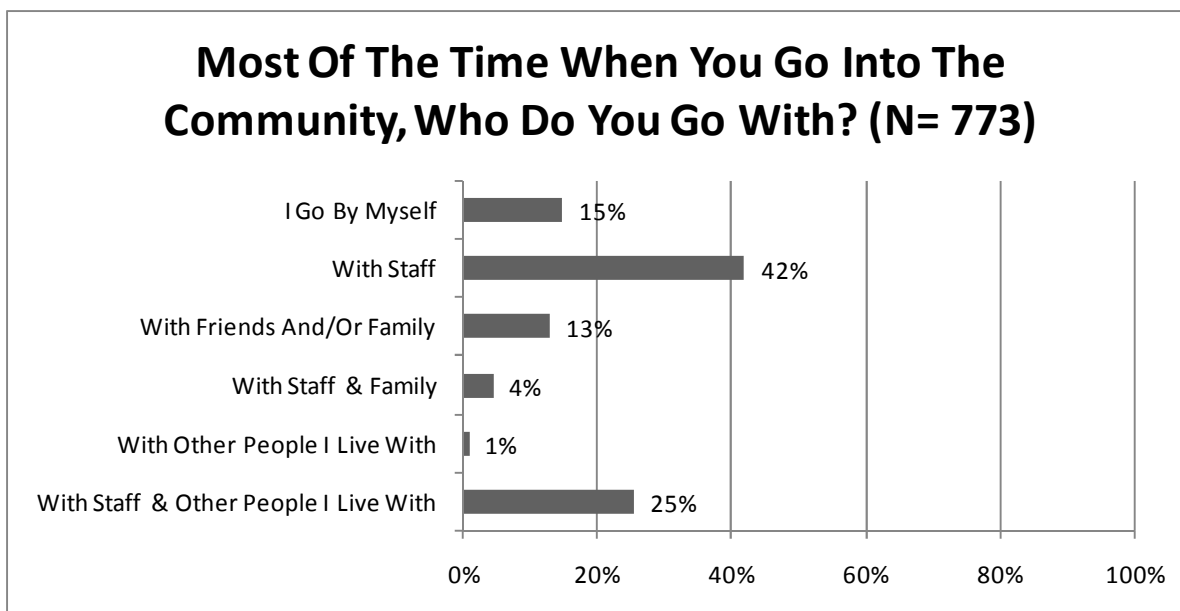
- 23% of individuals interviewed reported they participate in activities like strength training to the extent that their heart rate increased, they breathed faster and they got sweaty (state finding 20%, regional 22%); 53% of individuals reported no change when participating in activities like strength training (state finding 48%, regional 49%)
- 17% of individuals interviewed reported they participate in other physical activities to the extent that their heart rate increased, they breathed faster and they got sweaty (state finding 23%, regional 27%); 66% of individuals reported no change when participating in other physical activities (state finding 57%, regional 55%)



Due to the great difficulty reported in responding to the aforementioned group of questions, these questions will be removed when the EDE is revised for 2008-2009.

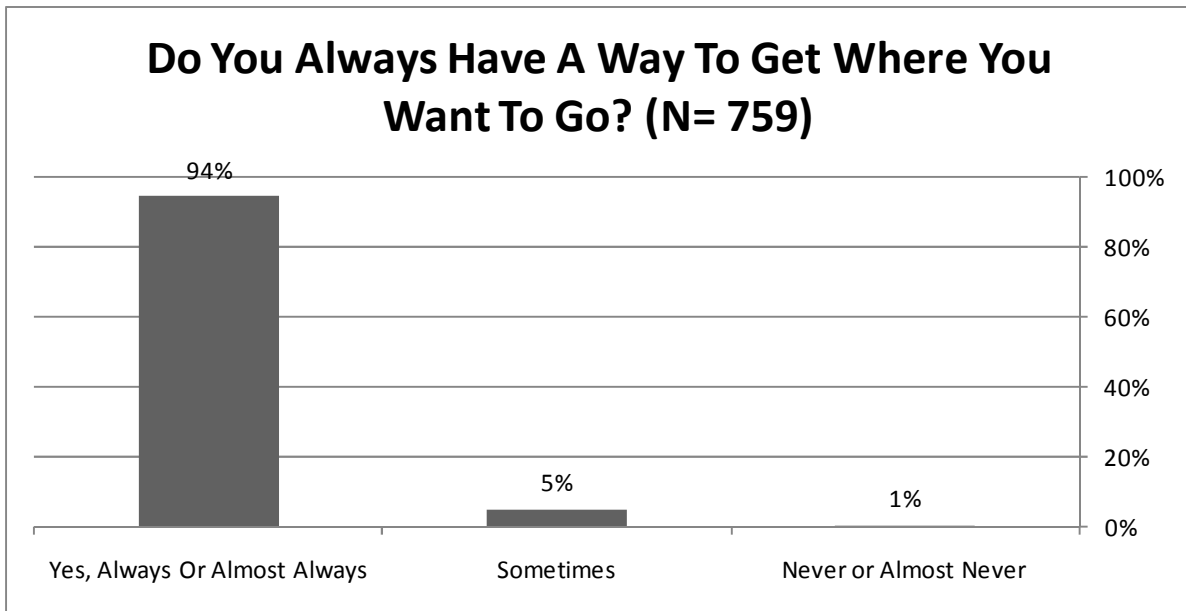
Going Out Alone or With Other People

- 15% of individuals go out alone (state finding 10%, regional 9%)
- 42% of individuals go out with staff most of the time (state finding 37%, regional 41%)



Transportation

- 94% of people always or almost always had a way to get where they wanted to go (92% state finding, 93% regional)

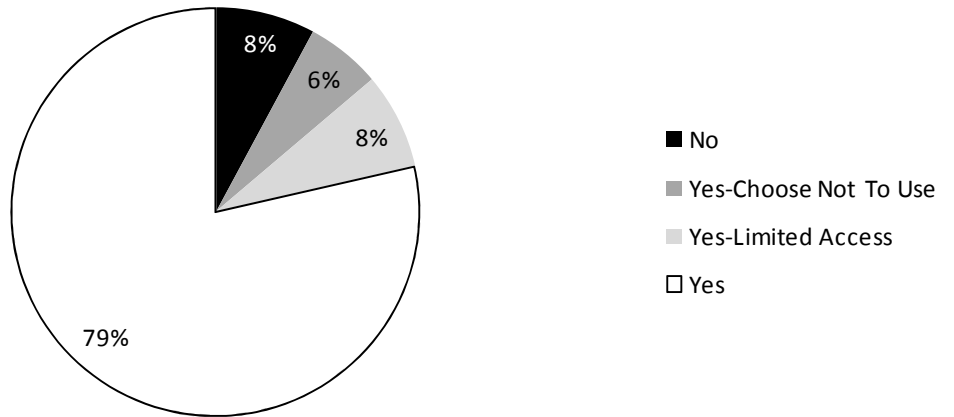


- 21% cannot always get where they want to go because there is not enough staff (state finding 29%, regional 28%).
- Of individuals not using public transportation, 23% do not use it because it does not exist where they live (state finding 50%, regional 24%).

Home Adaptive Equipment

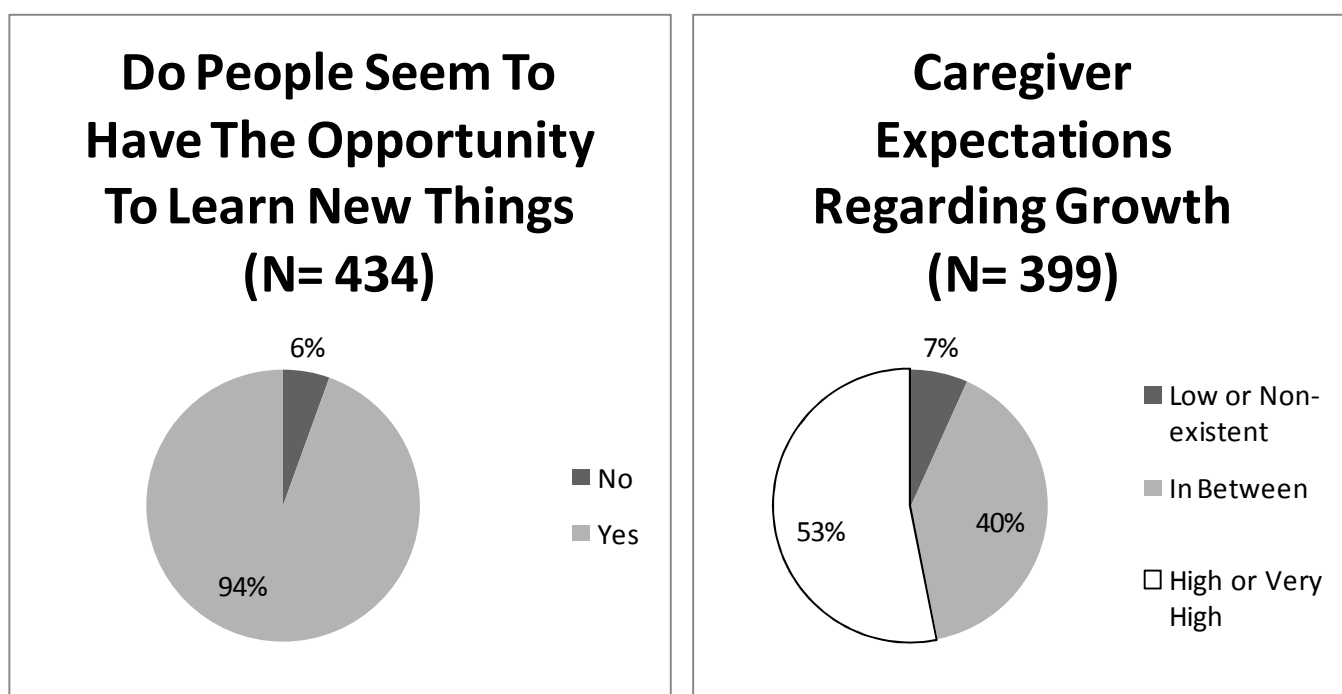
- 79% of individuals reported having and using all the adaptive equipment they needed (state finding 87%, regional 82%)
- 77% of people said that all necessary adaptations have been made to their home to make it accessible (state finding 82%, regional 80%)

Do You Have Needed Adaptive Equipment? (N= 420)



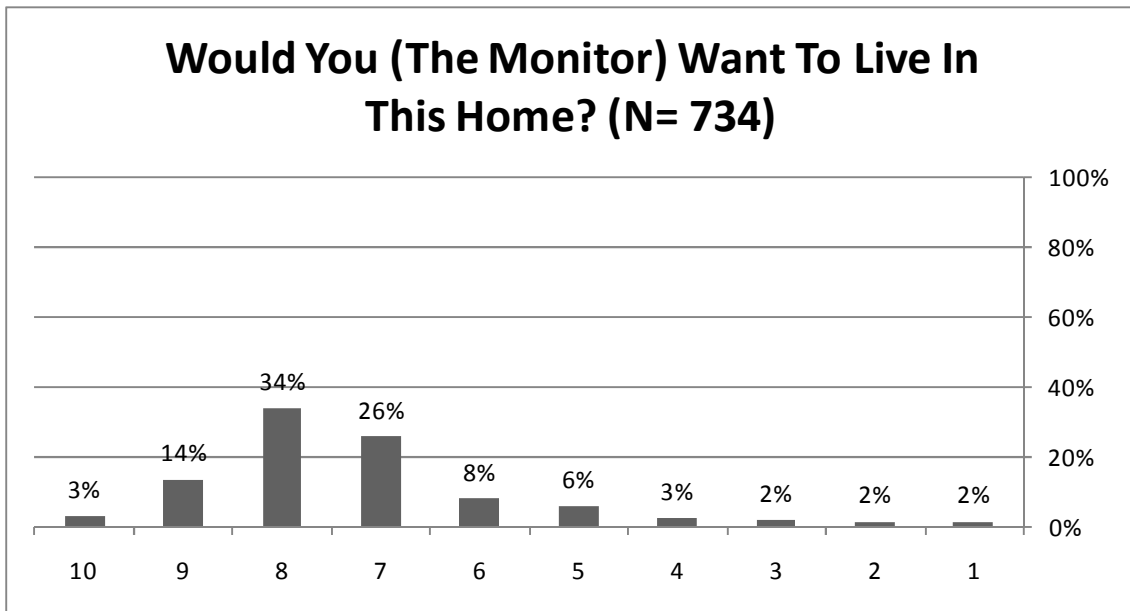
Competence, Personal Growth and Opportunities to Grow and Learn

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,

- 92% of the individuals appeared to have the opportunity to learn new things (state finding 89%, regional 88%)
- For 55% of the individuals, caregiver expectations regarding growth was reported as high or very high (state finding 51%, regional 48%)
- 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 7.1 (state finding 6.8, regional 6.9)



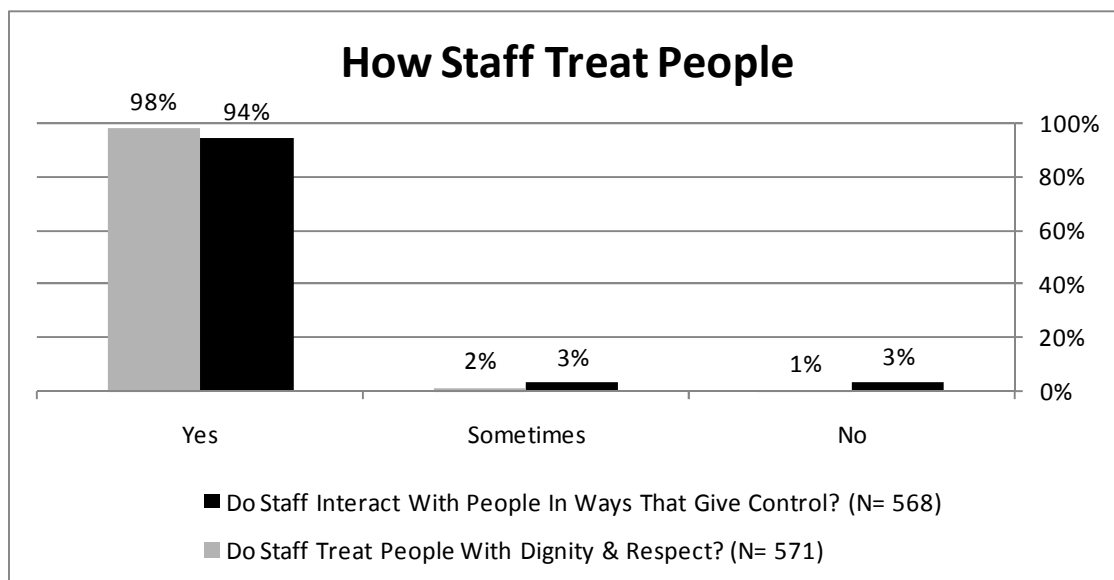
Staff Support for the Person

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,

- 94% of the monitoring teams observed that staff interacted with individuals in ways that gave control to the people supported (state finding 94%, regional 93%)
- Individuals had either all staff (95%) or some staff (4%) with the skill needed to support them (state finding 90% and 9% respectively; regional 88% and 10% respectively).
- 98% of the monitoring teams observed that the staff treated individuals with dignity and respect (state finding 98%, regional 98%)



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. 95% of the interviews took place in the individual’s home (state finding 78% regional 91%), although 4% took place at work/day activity (state finding 19%, regional 7%).

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 90% 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 95% and 91% respectively).

Neighborhood

According to IM4Q teams,

- 87% of individuals lived in homes which were in a safe neighborhood (state finding 93%, regional 93%).
- 97% of individuals lived in homes that “fit in” with the neighborhood in which they were located (state finding 92%, regional 95%).

Personal Belongings and Personalities

According to IM4Q teams,

- 99% of individuals lived in homes which had sufficient space for personal belongings (state finding 97%, regional 98%).
- 95% of individuals lived in homes or had bedrooms which reflected the hobbies, interests and personalities of the people who live there (state finding 95%, regional 95%).

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.

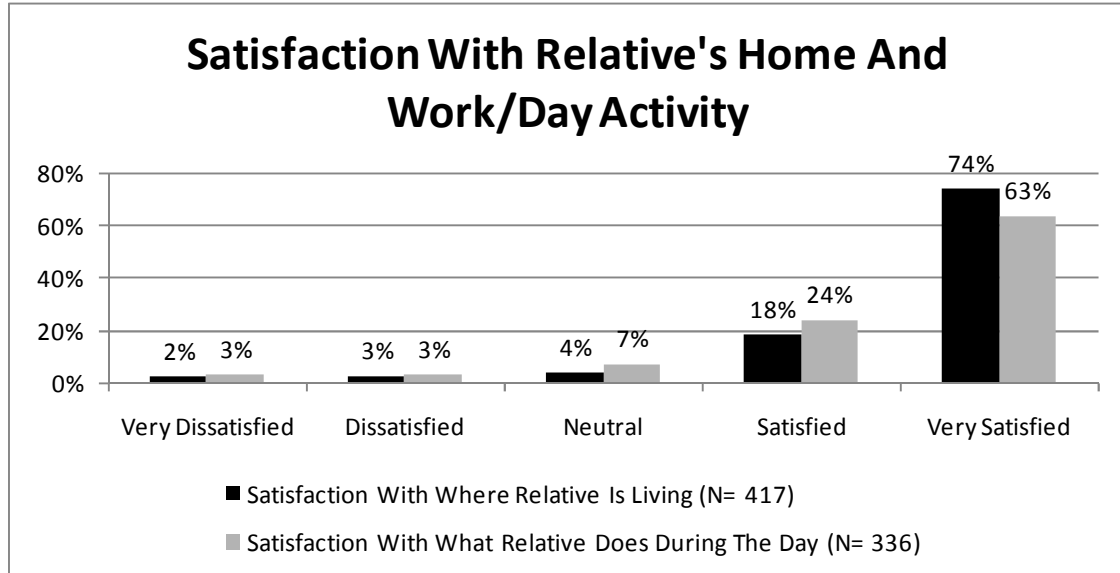
- The average (mean) score was 94.53 with a standard deviation of 12.86 (state finding 96.25 and 11.38 respectively, 95.93 and 11.32 regional)

Family/Friend/Guardian Survey

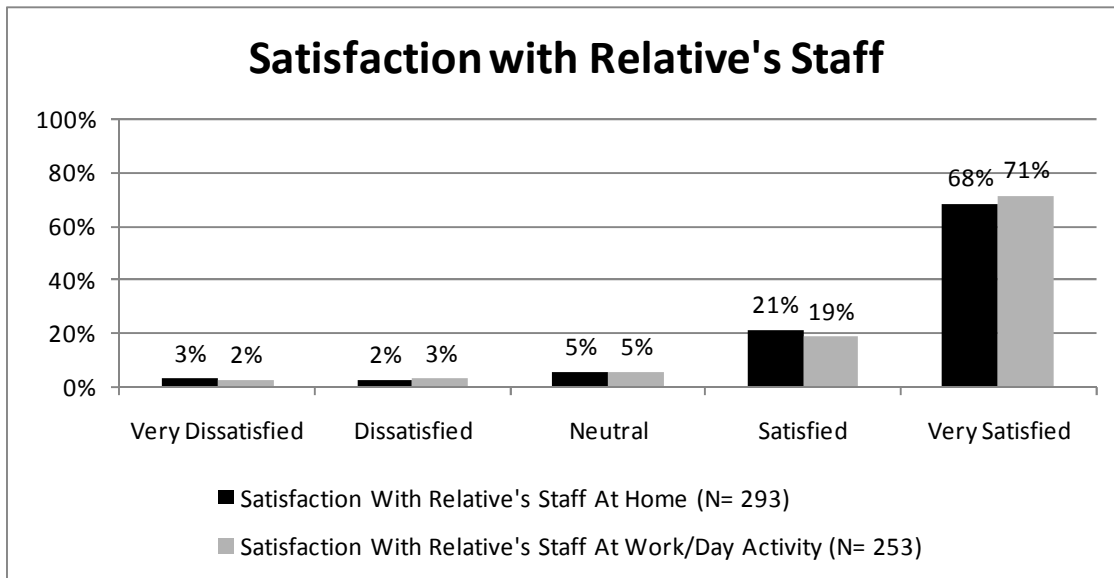
Respondents: This survey was completed by telephone with a family member, guardian, or friend who was identified through the Essential Data Elements Pre-Survey. In the event that a phone survey could not be completed, surveys were completed by mail. A total of 427 family members, friends, and guardians from the Philadelphia AE participated in the survey.

- 57% of the surveys were answered by parents
- 29% were answered by siblings
- 2% were answered by the guardian
- 0% 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



- 92% of the families surveyed were either somewhat satisfied or very satisfied with where their relative lives (state finding 94%, regional 93%).
- 87% were either somewhat satisfied or very satisfied with what their relative does during the day (state finding 90%, regional 90%).



- 89% of the families surveyed were either somewhat satisfied or very satisfied with their relative's staff at home (state finding 93%, regional 92%).
- 90% of the families surveyed were either somewhat satisfied or very satisfied with the staff at their relative's day activity (state finding 94%, regional 93%).

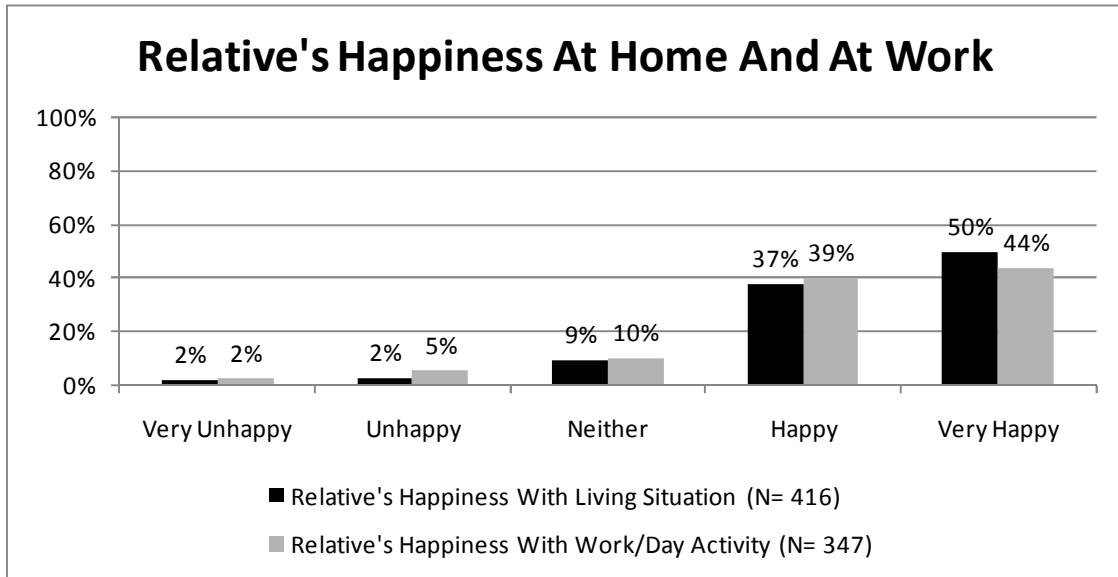
How Often Do You Contact/See Your Relative?

- 84% of the family/friend/guardians contacted their relative at least monthly (state finding 86%, regional 85%); 5% have not contacted their relative in the past year (state finding 3%, regional 4%).
- 63% 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%); 9% did not get to see their relative in the past year (state finding 5%, regional 6%)

Your Relative's Happiness

- 87% of respondents felt their relative was either very happy or somewhat happy with his/her living situation (state finding 92%, regional 90%)
- 83% felt their relative was either very happy or somewhat happy with what they do during the day (state finding 89%, regional 87%)

- 89% of respondents felt their relative was either very happy or somewhat happy with the staff who support them at home (state finding 93%, regional 92%); 2% felt their relative was either unhappy or very unhappy (state finding 1%, regional 1%)
- 91% of respondents felt their relative was either very happy or somewhat happy with the staff who support them at work or during the day (state finding 94%, regional 94%); 2% felt their relative was either unhappy or very unhappy (state finding 1%, regional 1%)



Your Relative's Safety

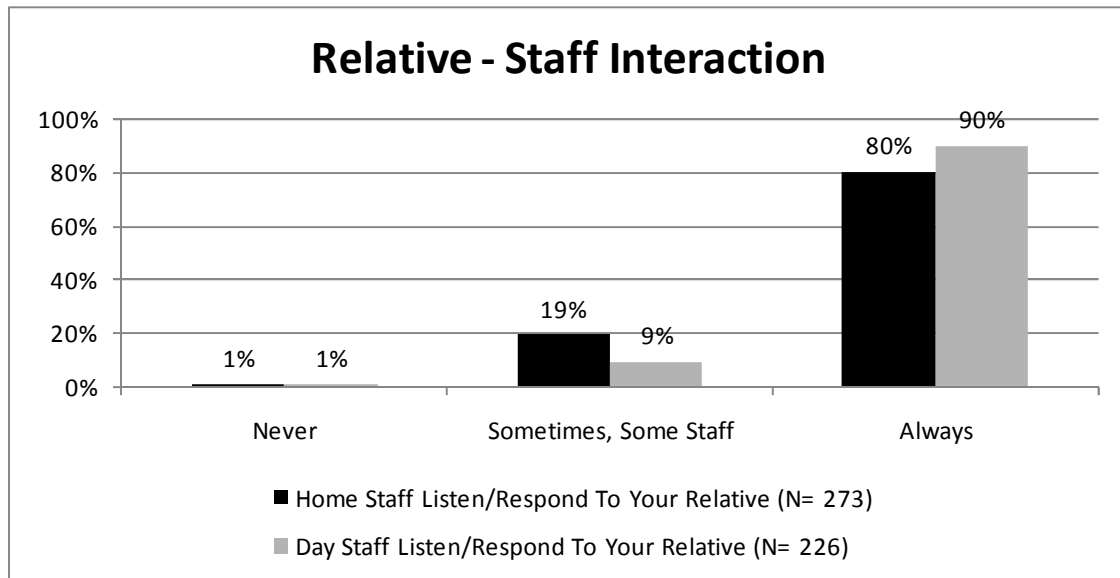
- Respondents said that their relative felt safe at home always (80%) or most of the time (16%). State findings were 84% and 14% respectively; 82% and 16% regional.
- Respondents said they think their relative felt safe in their neighborhood always (75%), or most of the time (21%). State findings were 84% and 13% respectively; 80% and 17% regional.
- Respondents said they think their relative felt safe at their day activity always (81%) or most of the time (16%). State findings were 86% and 12% respectively, 83% and 15% regional.

Your Relative's Opportunities

- 81% of the respondents said that their relative got enough opportunities to participate in activities in the community (state finding 85%, regional 83%)
- 86% of the respondents said that their relative seemed to have the opportunity to learn new things (state finding 88%, regional 86%)

Your Relative's Staff

- 55% of the respondents said that their relative's staff at home had high or very high expectations regarding growth for their relative (state finding 57%, regional 52%); 63% felt that their relative's staff at work/day activity had high or very high expectations regarding growth for their relative (state finding 62%, regional 59%)
- If their relative did not communicate verbally, 16% of the respondents said that there is a formal communication system in place for their relative and they use it (state finding 32%, regional 28%)
- 90% of the respondents said that their relative's home appeared to have enough paid staff (state finding 88%, regional 88%)
- 84% of the respondents said that staff in their relative's home interact with people in ways that give control to the people being supported (state finding 87%, regional 84%)
- 91% of the respondents said that staff in their relative's home treat people with dignity and respect (state finding 94%, regional 93%)
- 81% of the respondents said that all staff appear to have the skills they need to support their relative, and 17% felt that way about only some staff (state finding 82% and 16% respectively; 78% and 20% regional)



- In terms of relative-staff interactions, families believe that staff at home listen/respond to their relative’s communication (80% always, state finding 83%, regional 80%); for staff at work/day activity, 90% always listen and respond to their relative’s communication (state finding 86%, regional 85%)

Your Relative’s Supports

- 79% of relatives interviewed said that the supports coordinator is always available to assist them if there is a crisis (state finding 86%, regional 81%)
- 78% of relatives were satisfied with the supports coordination their relative receives (state finding 83%, regional 81%)
- 55% of relatives reported that they were told how much money is in their relative’s annual budget (state finding 56%, regional 49%)
- 65% said that their relative always received the supports they needed (state finding 74%, regional 70%)
- 65% of relatives reported that they always got enough information to help them participate in planning services for their family member (state finding 76%, regional 71%)
- 82% of relatives always felt that the staff who assisted them with planning respected their choices and opinions (state finding 87%, regional 84%)
- 71% of relatives felt that when they asked the supports coordinator for help the supports coordinator always helped them get what they needed (state finding 80%, regional 73%)

- 59% of relatives never felt that frequent changes in support staff was a problem for their family member (state finding 66%, regional 56%)
- 35% of relatives always got to choose the agency/provider who worked with their relative (state finding 42%, regional 43%); 52% never got to choose (state finding 41%, regional 42%)
- 38% of relatives were always satisfied with the way complaints and grievances are handled (state finding 50%, regional 47%); 48% were never satisfied (state finding 28%, regional 30%)
- 38% of relatives report that there is other information they would like to have (state finding 26%, regional 32%).

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 85.07 with a standard deviation of 16.56 (state finding 88.65 and 13.77 respectively, 87.33 and 14.74 regional)

Summary

This report presents information collected through face-to-face interviews with 776 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. Less than a tenth of the people interviewed reported someone has kept them from doing things they have the right to do. And, nearly half of individuals interviewed who do not vote, would like to vote. Individuals report high levels of privacy. Although those interviewed have little control over how much spending money they have each week, many have significant control over what they buy with their spending money.

The majority of individuals report that they get the services and supports they need. More than three-fourths of all individuals and families report that they were told how much money is in their annual budget. The monitoring teams observed that staff treats individuals with dignity and respect in nearly all cases.

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, a little less than half of the people interviewed visited other homes for comparison. In choosing where to live, day activities or work, providers continue to make the decision most frequently.

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.

More than half of the people interviewed participate in community activities (i.e. going shopping) 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. Most 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.