

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

***Independent Monitoring for Quality (IM4Q)
A Statewide Summary
2007-2008***

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

**Submitted by: Celia S. Feinstein, James A. Lemanowicz,
and Mary Kay R. Cunningham
The Institute on Disabilities
Pennsylvania's University Center for Excellence in
Developmental Disabilities
Temple University
University Services Building, 6th Floor (004-00)
Philadelphia, PA 19122**

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**College of Education
Temple University
Philadelphia, Pennsylvania**

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).

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, 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. That year, 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, 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.

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 the 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 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 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. As the table shows, the majority of the people in the sample live in supervised living settings. Many people in the sample live at home with families, due in part to the sub-sample of people receiving supports through the PFDS waiver.

	N	Percent
State-Operated ICF/MR	11	0.2%
State MH Hospital	2	0.0%
Homeless	0	0.0%
Temporary Shelter	1	0.0%
Foster Care	9	0.1%
Incarceration	1	0.0%
Nursing Home/Facility	115	1.8%
Domiciliary Care	38	0.6%
Personal Care Home	243	3.7%

Family Living/Life sharing	389	6.0%
Unlicensed Family Living	23	0.4%
Own Residence	543	8.4%
Relative's Home	1566	24.1%
Children's Facility	2	0.0%
Approved Private School	2	0.0%
Private ICF/MR <4	54	.8%
Private ICF/MR 5-8	186	2.9%
Private ICF/MR 9-15	20	.3%
Private ICF/MR 16+	203	3.1%
Community Home 1	132	2.0%
Community Home 2-4	2532	38.9%
Community Home 5-6	226	3.5%
Community Home 7-8	68	1.0%
Community Home 9-15	21	0.3%
Community Home 16+	24	0.4%
Other	91	1.4%
Total	6512	100%

(*Residential setting type was missing for 10 people)

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 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 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 2007-08 survey cycle was to be collected by June 30, 2008 and entered into HCSIS by August 1, 2008. A usable data file was received by the Institute on Disabilities in October, 2008. This report presents data on the individuals surveyed by the IM4Q Local Programs, representing the 48 AEs across the state. In addition to this report,

each AE and local program will receive a report about the people monitored in their county. Separate reports will also be developed by HSRI for those individuals in the NCI sample and by the Institute on Disabilities for those individuals in the PFDS sample and those living in state centers.

Closing the Loop/Follow-up

In addition to this summary report and similar ones for each of the AEs, each local IM4Q Program has developed a process, referred to as “closing the loop” which ensures that follow-up activity with the AE is completed related to individual considerations for improvement. “Closing the loop” is an integral part of the quality improvement process, as it places quality improvement responsibilities with the AEs, supports coordinators, and other providers of service. “Closing the loop” is also facilitated by: provider level reporting in HCSIS, which enables providers of service and the AEs to review finalized aggregate IM4Q results. The IM4Q data warehouse in HCSIS also allows AE, regional and state personnel to review IM4Q aggregate data based on key demographic areas such as age, gender, race and type of living arrangement.

RESULTS

The following table displays the distribution of interviews conducted by each independent monitoring program by Administrative Entity.

	# of People	Percent
Allegheny	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

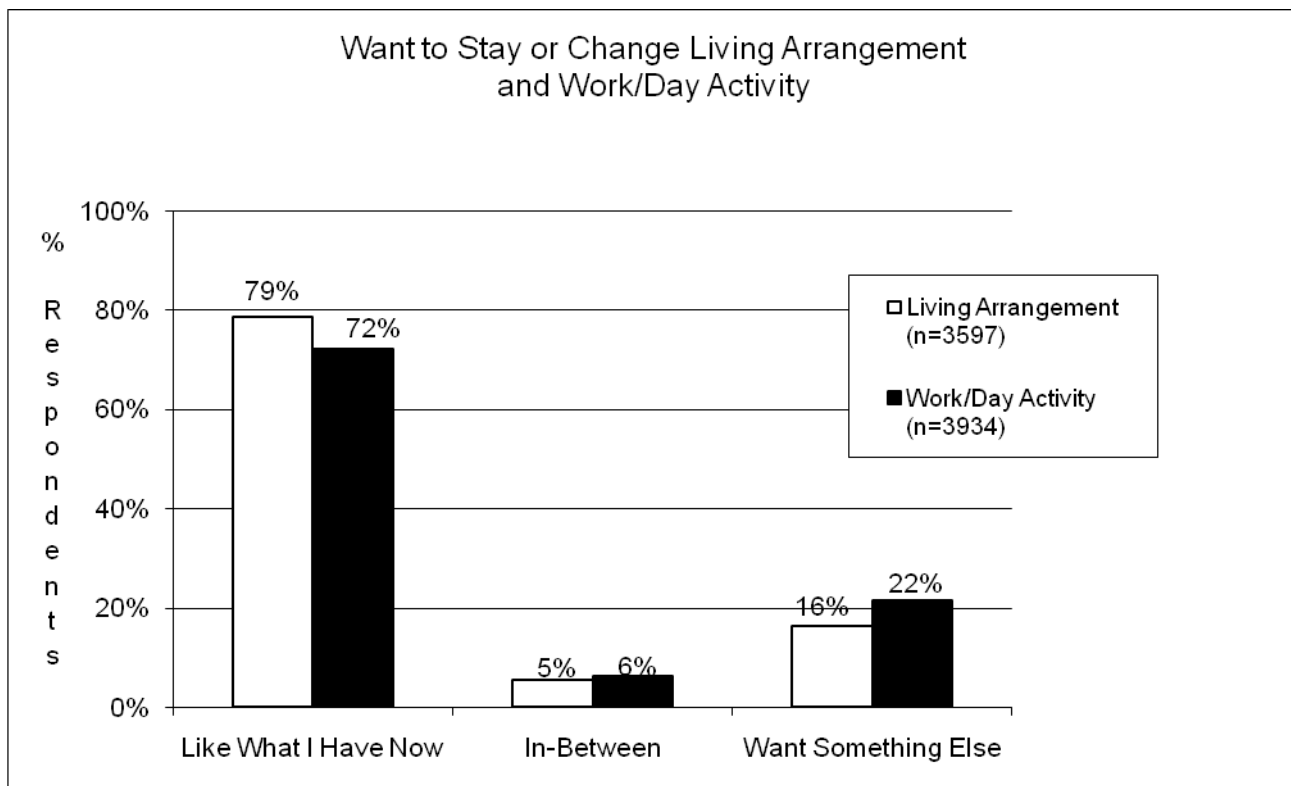
Respondents: Only the individual receiving services/supports could answer the questions on satisfaction. The percent of people who responded to questions in this section ranged from 41.6% to 65.7%.

Satisfaction with Living Arrangements

- 90% of individuals liked where they live
- 79% wanted to stay where they currently live

Satisfaction with Work/Day Activity

- 90% of individuals *with* a day activity/work liked what they did during the day
- 72% wanted to continue their current daytime activities/work, but 22% wanted to do something else



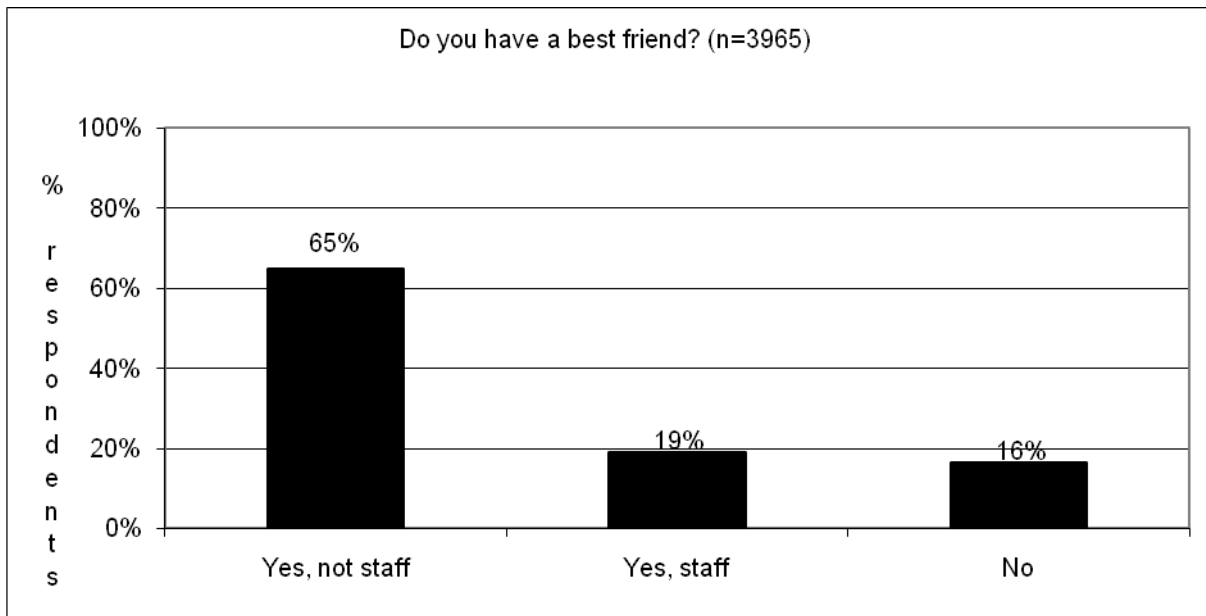
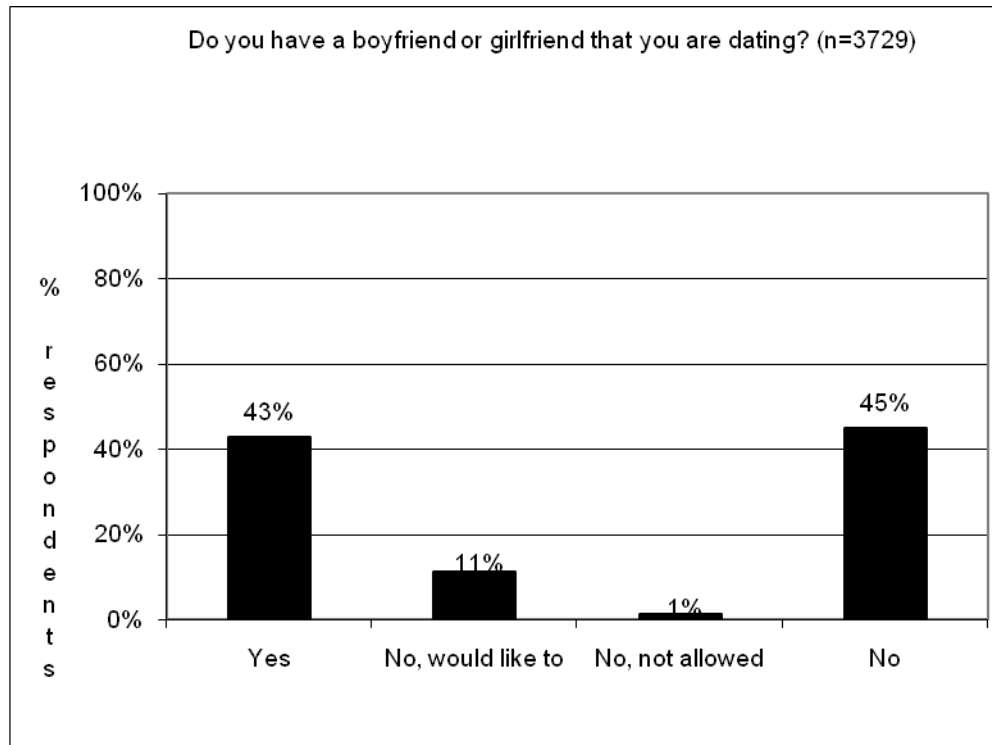
Daily Life

- 67% of the individuals interviewed always had opportunities to participate in household tasks like cooking and cleaning
- 80% of individuals get to do things in the community as often as they would like to (most of the time)
- 93% of the individuals get the services they need

	<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=4407)	67%	12%	13%	2%	7%

Happiness and Loneliness

- 85% reported feeling happy overall, 11% reported being in-between, and 4% reported feeling sad overall
- 58% of individuals reported never feeling lonely, 39% reported sometimes feeling lonely, and 3% reported always feeling lonely
- 84% of individuals reported that they have a best friend – for 65% of the people, their best friend is not a staff member
- 43% reported that they have a boyfriend or girlfriend that they are dating
- 68% reported having friends, that are not staff or family, they like to do things with



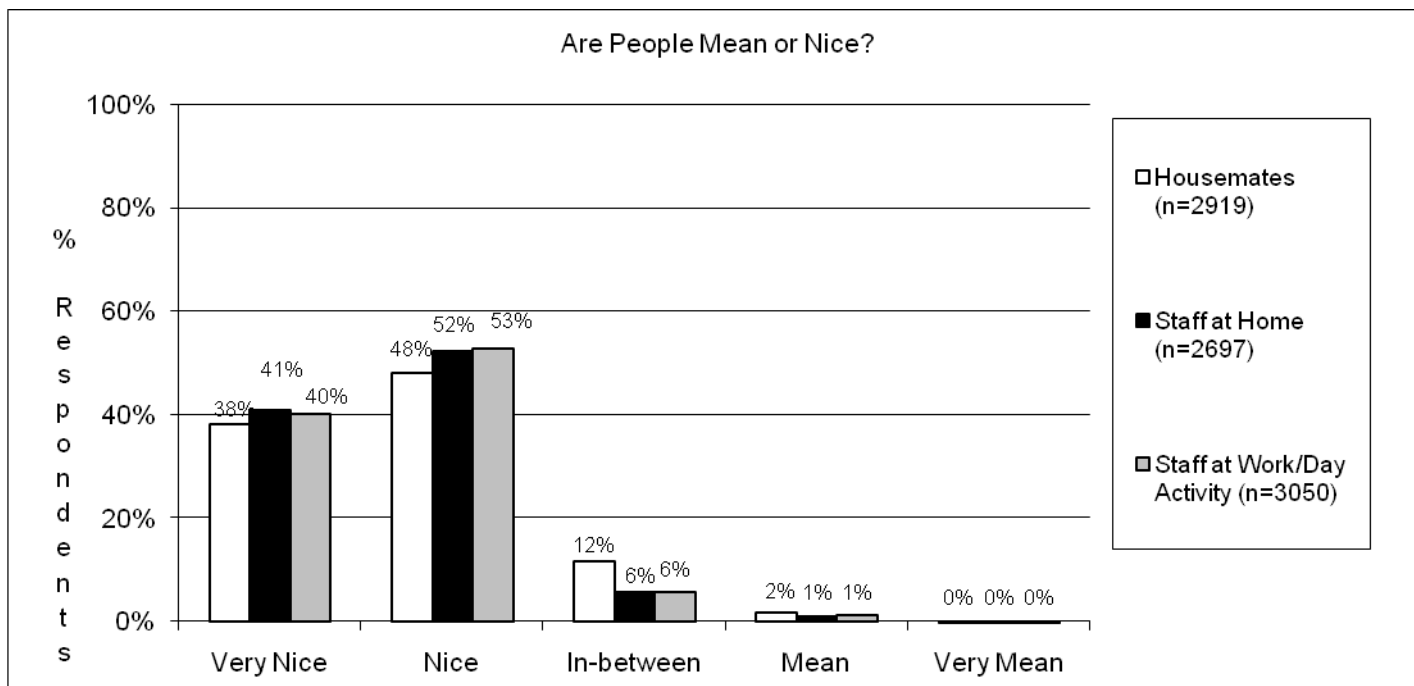
Privacy

- 86% of the individuals surveyed reported that they always have privacy (a place to be alone) when they want it

- For 83% of the individuals interviewed, other people always knock or ring the doorbell and wait for a response before coming in to people’s homes
- For 76% of the individuals, people always knock on the bedroom door and wait for a response before coming in

Are People Nice or Mean?

- 86% of respondents reported that their housemates are very nice or nice
- 93% of the people interviewed reported that their staff who work with them at home are very nice or nice
- 93% reported that staff who work with the respondents at work or day activity are nice or very nice



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

- The average (mean) score was 85.37 with a standard deviation of 18.84
- The mode (the value that occurs the most frequently) was 100, indicating that many people were very satisfied on all measures of satisfaction

This year's responses to the items in the satisfaction section of the survey yielded results similar to those reported in the 2006-2007 report.

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

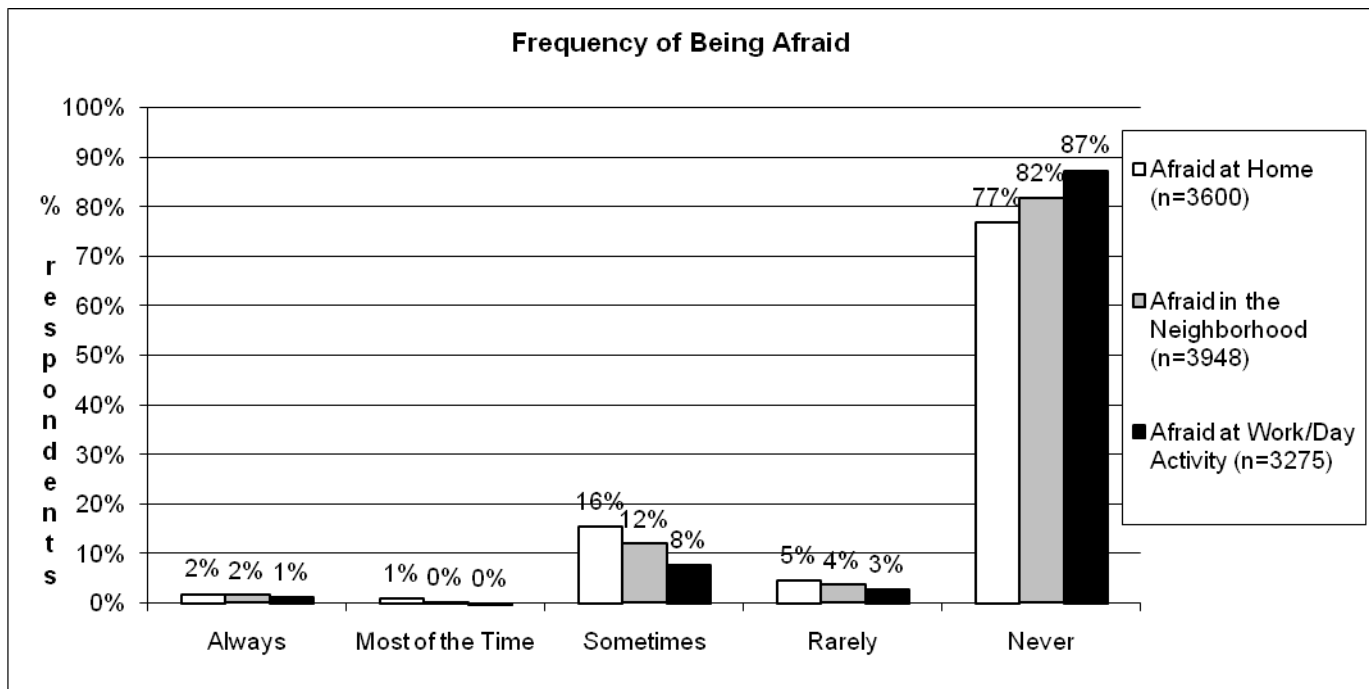
- 60% of individuals stated that they always carry a form of identification; 22% never do

Support with Problems and Goals

- 89% of individuals always had someone in their life who will try to help make things better
- 42% of individuals go to staff at home for help most of the time, 29% go to family
- 80% reported that people always help them to learn/do new things; 67% want help to learn new things

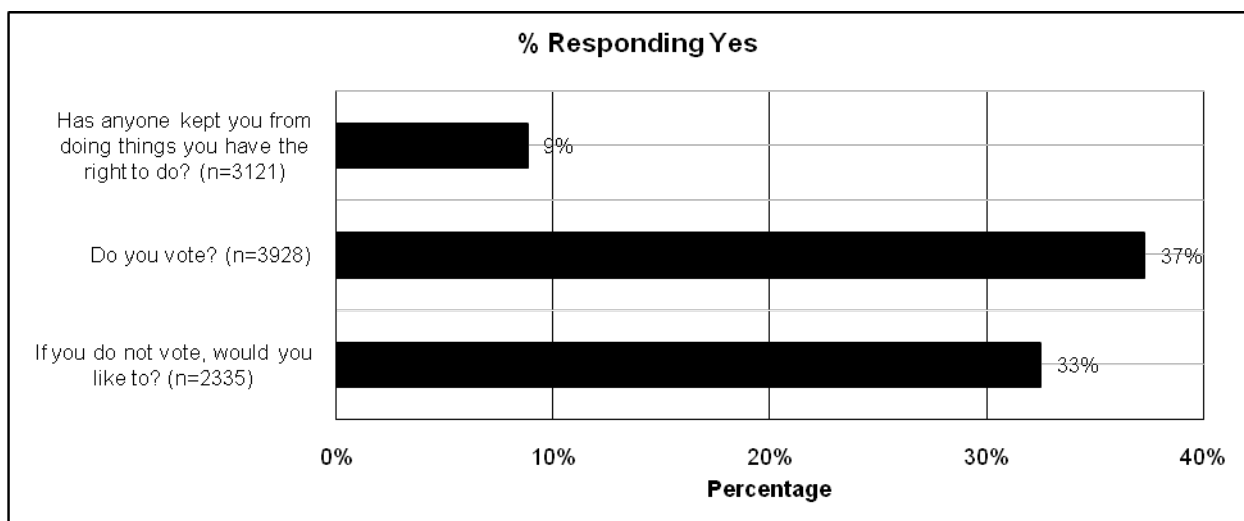
Being Afraid

- 77% reported never being afraid at home
- 82% reported never being afraid in the neighborhood
- 87% reported never being afraid at work, school or day activity



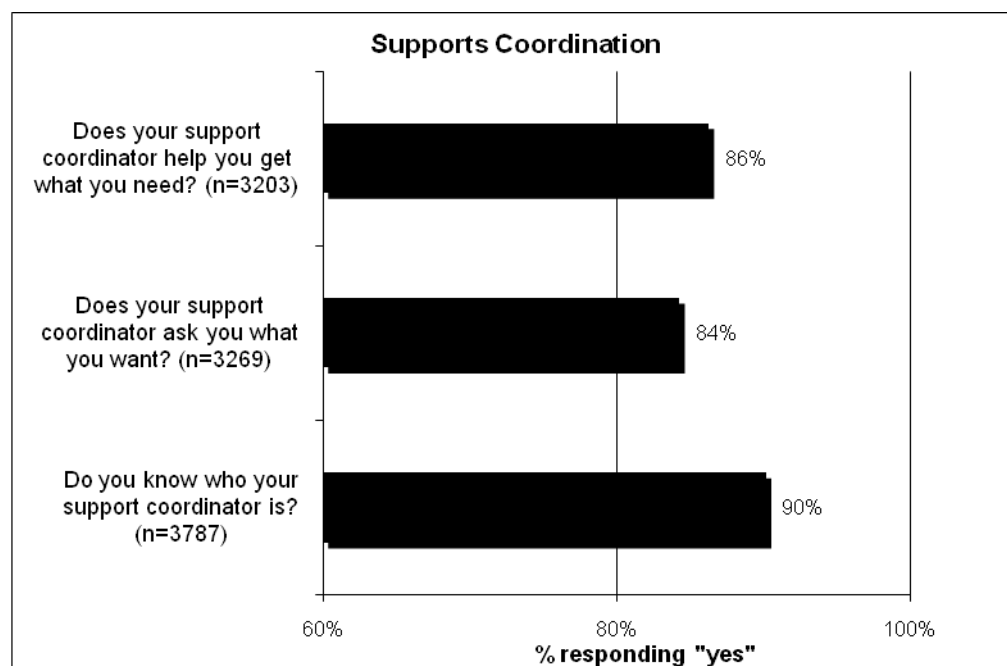
Legal Rights

- 9% of those interviewed reported that someone has kept them from doing things they have the right to do.
- 63% of people said that they do not vote; 33% of these individuals would like to



Supports Coordination

- 90% of individuals know who their supports coordinator is
- 92% are happy with their supports coordinator
- 85% of individuals can always talk to their supports coordinator when they want
- For 84% of individuals, their supports coordinator asks what they want; 86% reported that their supports coordinator helps them get what they need



- 28% of individuals have had more than one supports coordinator in the past year
- When supports coordinators changed, 24% got to choose the new one
- 97% of individuals reported that their supports coordinator always treats them with dignity and respect
- 95% reported that their supports coordinator talks to them and listens to them when visiting
- 64% of individuals reported that they were told how much money was in their annual budget
- 91% 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)

- 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)
- 92% on individuals reported that their Individual Support Plan (ISP) included all of the things they needed

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 and respect (people treating you as they would wish to be treated).

- The average score was 82.45 with a standard deviation of 15.10.
- The modal score was 75. Interestingly, the mode for the Dignity and Respect Scale was much lower than the Satisfaction Scale. This indicates that many individuals chose the most positive answer category (very satisfied) for all measures of the Satisfaction Scale, whereas for the Dignity and Respect Scale individuals were less likely to choose the most positive answer category for all measures.

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 90.49 with a standard deviation of 17.13
- The mode was 100
- The average here was quite high, and therefore there was not a great deal of fear reported among individuals receiving supports and services. The mode of 100 indicates that many individuals (67%) reported that they never feel afraid in their home, neighborhood or work/day activity site

Open-Ended Questions: In this section, individuals who reported being afraid at least sometimes were asked what made them afraid. We asked this question concerning being afraid in one's home, neighborhood and work / day activity site.

- At home, individuals were most afraid of the weather
- In the neighborhood, individuals were most afraid of animals/insects
- At work, individuals were most afraid of other people/people in general/crowds

	At Home #	In Neighborhood #	At Work #
Alone	38	11	0
Animals / Insects	34	105	7
Being Scolded / Fear of Being Hurt / People Yelling / Fear of the Unknown	25	29	16
Darkness / Sleep / Nightmares / Night	68	58	9
Emergency Situations / Fire / Fire Alarms	15	3	21
Falling / Sickness / Seizures/ Death	35	25	10
Neighbors / Local kids	14	22	1
Work/school related-Lose job/ New things on job/ Making mistakes	0	0	17
Noises	33	19	18
Staff / Consumers / co-workers	42	4	13
Strangers / Crime	49	55	10
Transportation/ Traffic/ Emergency vehicles	3	26	4
Weather	147	66	21
Houses/ Locked Rooms/ Office/ Stairs/ Elevator/ Escalator	0	0	0
Mythical & Fictional Creatures	15	4	4
Scary Movies/ Halloween / TV	15	2	3
Other people/ People in general/ Crowds	29	40	60
Fighting/ Violence/ Teasing/ Behavioral Outbursts	28	12	40
Neighborhood/ Getting lost/ Being outside	0	28	2
Other	63	25	29
TOTAL	653	534	285

Supports Coordinator Relationship Scale: This scale included four measures that asked individuals about their relationship with the 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 supports coordinator.

- The average (mean) score was 84.38 with a standard deviation of 30.15.
- The mode was 100, indicating that was the most frequently selected response. More than half of the individuals (67%) scored at the top of the scale regarding their relationship with their supports coordinator.

In this section, there were three new items added to the survey for this 2007-2008 fiscal year. The three new items were included in the Supports Coordination Relationship scale. The items included:

- Are you getting all the services you expected based on the planning meetings with the supports coordinator and on the Individual Support Plan (ISP)?
- Are you satisfied/happy with all the services you receive based on planning meeting with the supports coordinator and on the Individual Support Plan (ISP)?
- Does your Individual Support Plan (ISP) include all of the things you need?

Compared to the Dignity, Respect and Rights section of the 2006-2007 report, there were a few significant differences. Some differences included:

- There was a 4% increase in the percentage of individuals who go to staff at home for help most of the time
- There was a 5% decrease in the percentage of individuals who go to their family for help most of the time
- There was a 4% increase in the percentage of individuals whose supports coordinator ask what they want
- There was a 4% increase in the percentage of individuals whose supports coordinator helps them get what they need
- The percentage of individuals who reported that they were told how much money was in their annual budget increased from 57% to 64%.

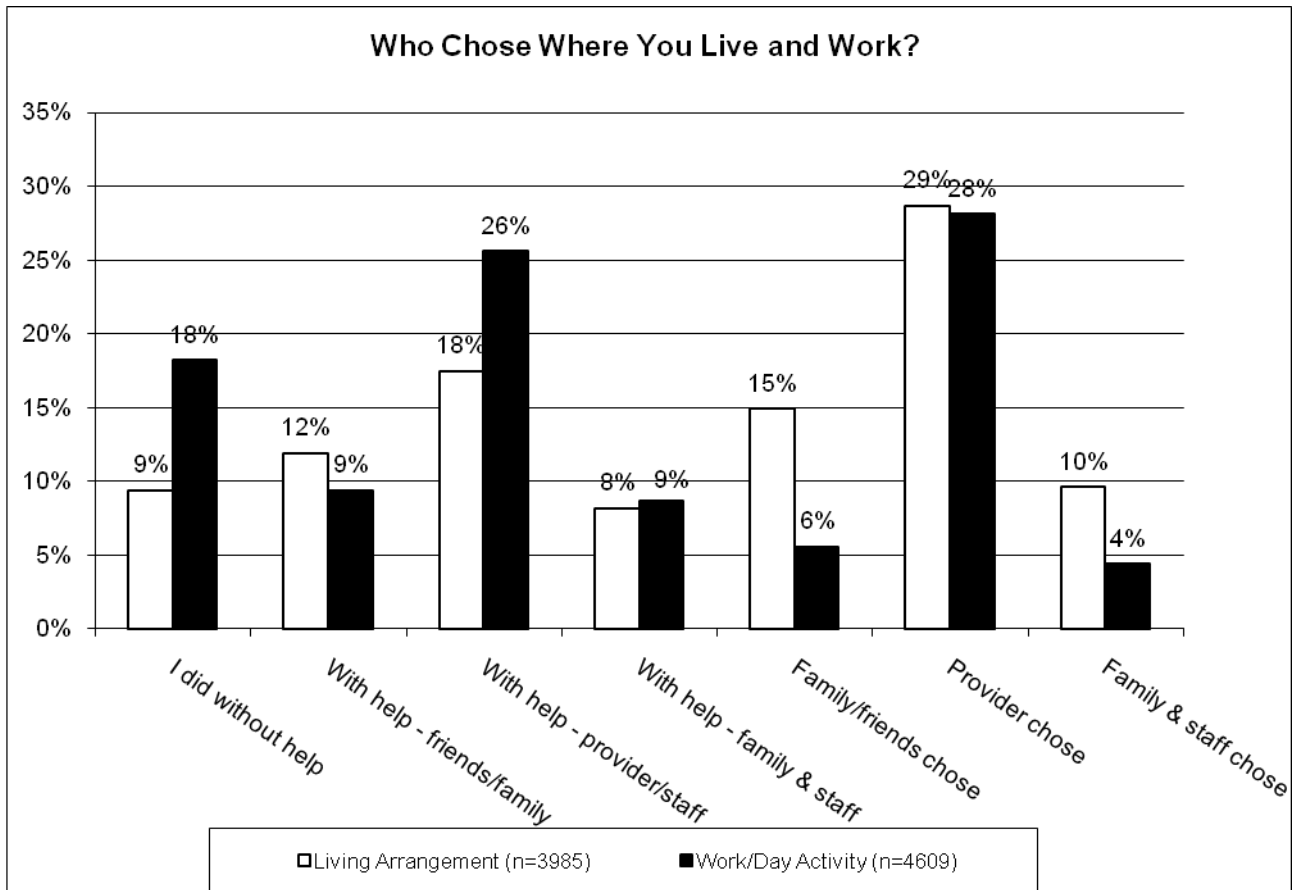
Choice and Control

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

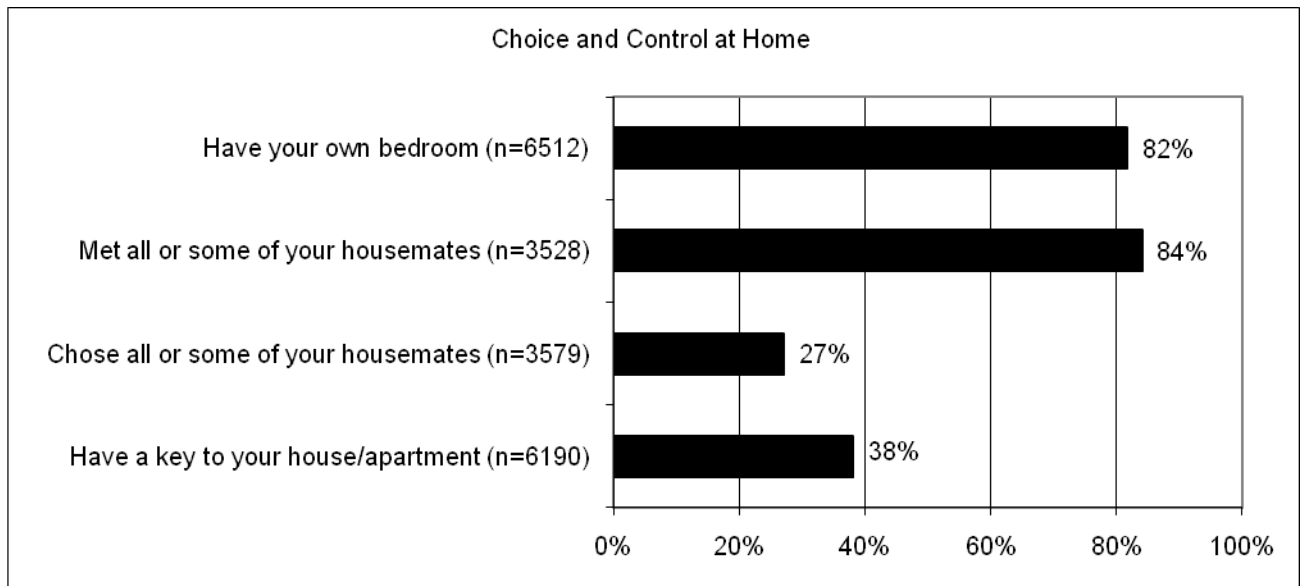
- 44% of the questions were answered by the individual receiving supports
- 30% of the questions were answered by paid staff
- 11% of the questions were answered by the consumer and staff
- 7% of the questions were answered by family/friend/advocate/guardian
- 6% of the questions were answered by the consumer and family
- 1% of the questions were answered by staff and family
- A value of missing was assigned when individuals did not answer, gave an unclear answer, or responded, “do not know.”

Choice and Control at Home

- 38% of the individuals surveyed had a key/way to get into to their house or apartment on their own
- For 53% of the individuals, someone else chose where they live; 9% of those interviewed chose without assistance
- For those individuals who had some control in choosing where they live, 53% saw no other places, 22% saw one other place, and 25% saw more than one other place before moving in; this raises question with regard to whether the choice individuals made was informed



- 73% of the individuals **did not** choose their housemates
- 84% of the individuals surveyed met some or all of their roommates before living together
- 82% of the individuals had their own bedroom; however, for those who shared a bedroom, 37% chose some or all of their roommates
- For 78% of the individuals interviewed, their mail is never opened without permission; 13% say their mail is always opened without permission
- 86% of the individuals reported that they can have privacy with visitors
- 93% are allowed to use the phone whenever they want



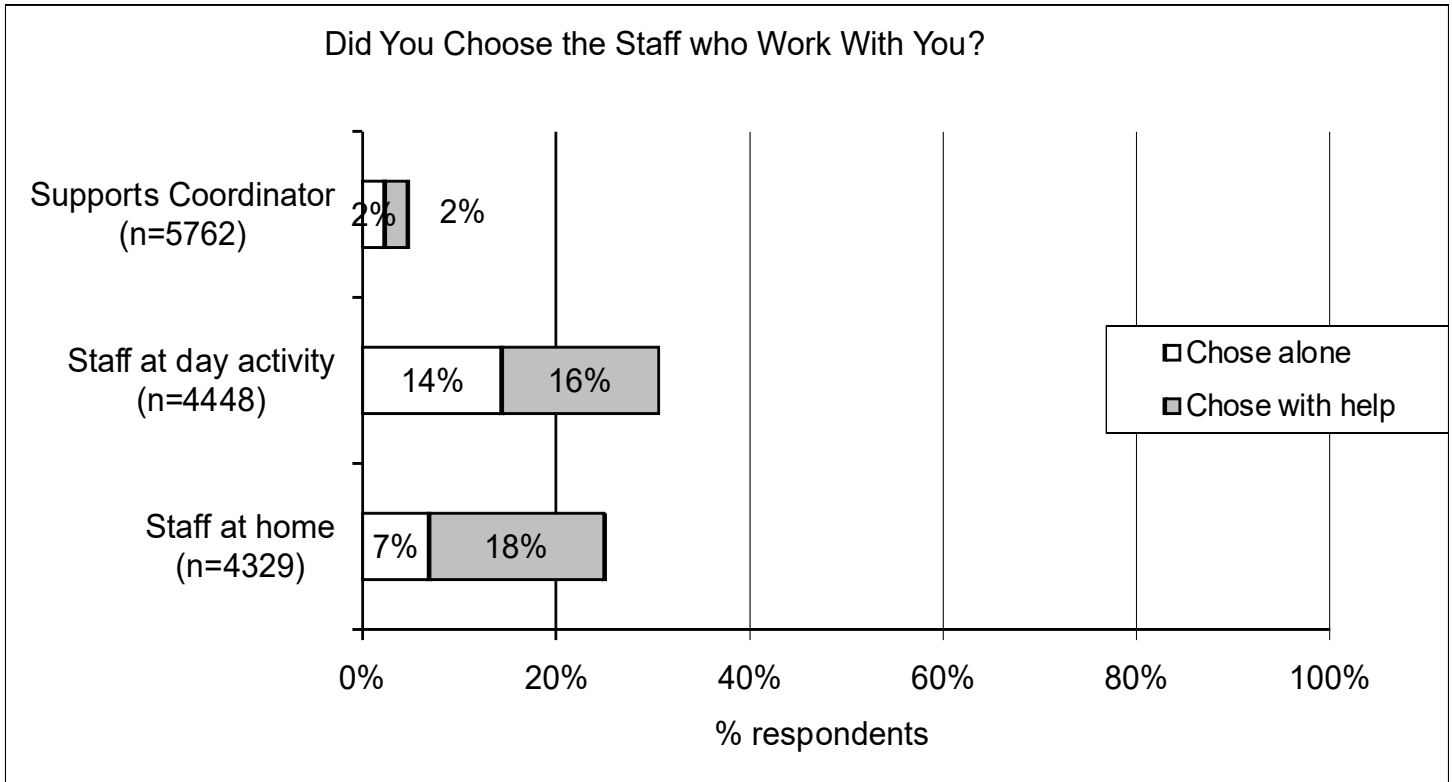
Choice and Control During the Day and for Leisure Time

- 38% of the individuals interviewed reported that someone else chose what they do during the day
- For 54% of people, the provider either chose what the individual does during the day or helped the individual decide
- 18% of the people interviewed chose what they do during the day without assistance
- For those individuals who participated in choosing what they do during the day, 58% saw no other places, 22% saw one other place, and 20% saw more than one other place before deciding
- 61% of the individuals surveyed chose their daily schedules without assistance
- 71% chose how they spend their free time without assistance
- 89% of those interviewed chose at least some of the things they do outside their home at least some of the time

Choice and Control in Choosing Staff

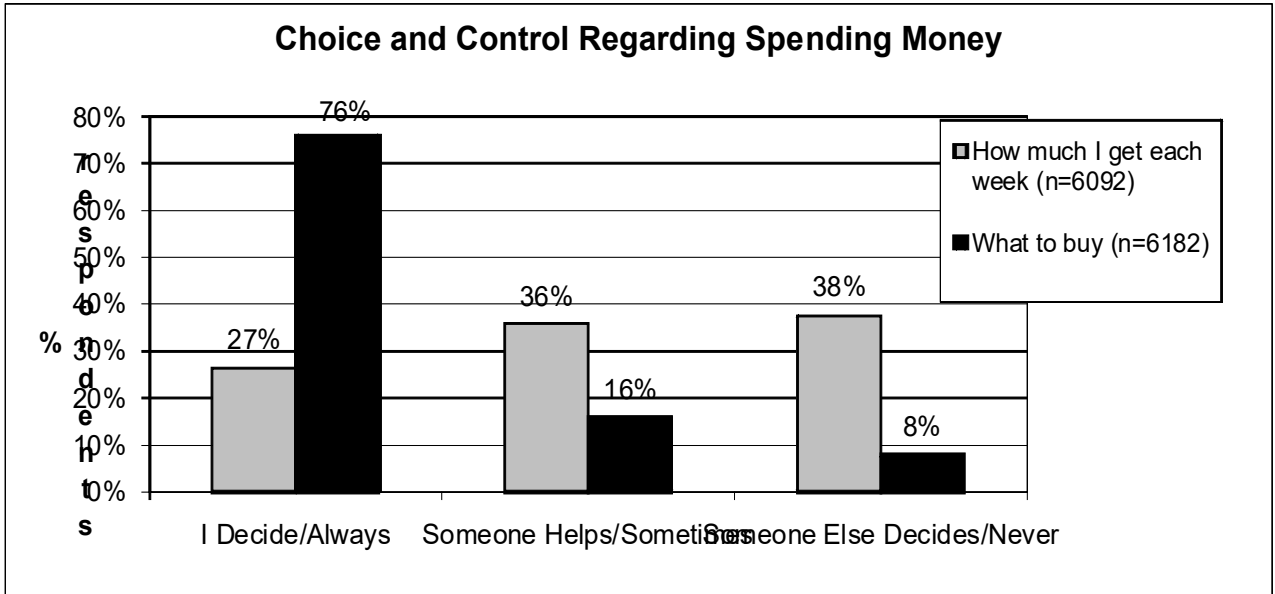
- 25% of the individuals interviewed/chose at least some of the staff who help them at home (alone or with assistance from family or provider)

- 31% of the individuals surveyed interviewed/chose the staff who help them at work/day activity (alone or with assistance from family or provider)
- Only 5% of individuals chose their supports coordinators (alone or with assistance from family or provider)



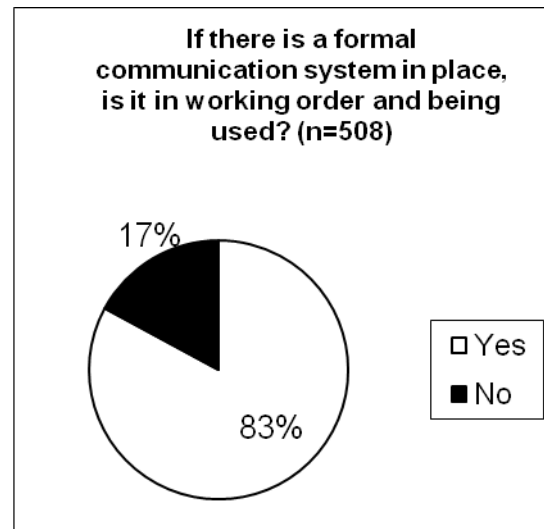
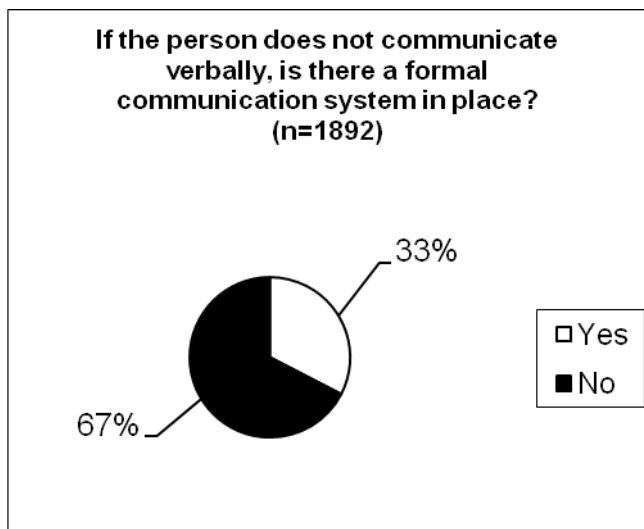
Choice and Control with Regard to Money

- 27% of the individuals interviewed reported that they choose how much spending money they have each week
- 76% of the individuals reported that they always choose what to buy with their spending money



Access to Communication

- For those individuals who do not communicate using words, there is a formal communication system in place for 33% of the people interviewed
- For those people with formal communication systems in place, the systems are in working order and utilized for 83% of the people interviewed



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

- The average (mean) score was 48.22 with a standard deviation of 20.21
- The modal score was 52.17, indicating the most frequent score

There were some significant differences regarding this year's data in this section when compared with the data from 2006-07.

- There was a 3% decrease in the percentage of individuals who had someone else chose where they live
- There was a 3% decrease in the percentage of individuals who did not choose their housemates
- There was a 3% increase in the percentage of individuals who met some or all of their roommates before living together
- There was a 4% increase in the percentage of individuals who had their own bedroom
- There was a 3% decrease in the percentage of individuals who chose some or all of their roommates
- There was a 3% increase in the percentage of individuals who chose their daily schedules without assistance
- There was 4% increase in the percentage of individuals who chose at least some of the things they do outside their home at least some of the time
- There was a 4% increase in the percentage of individuals who always choose what to buy with their money
- There was a 4% decrease in the percentage of individuals for whom a communication system is in working order and utilized.

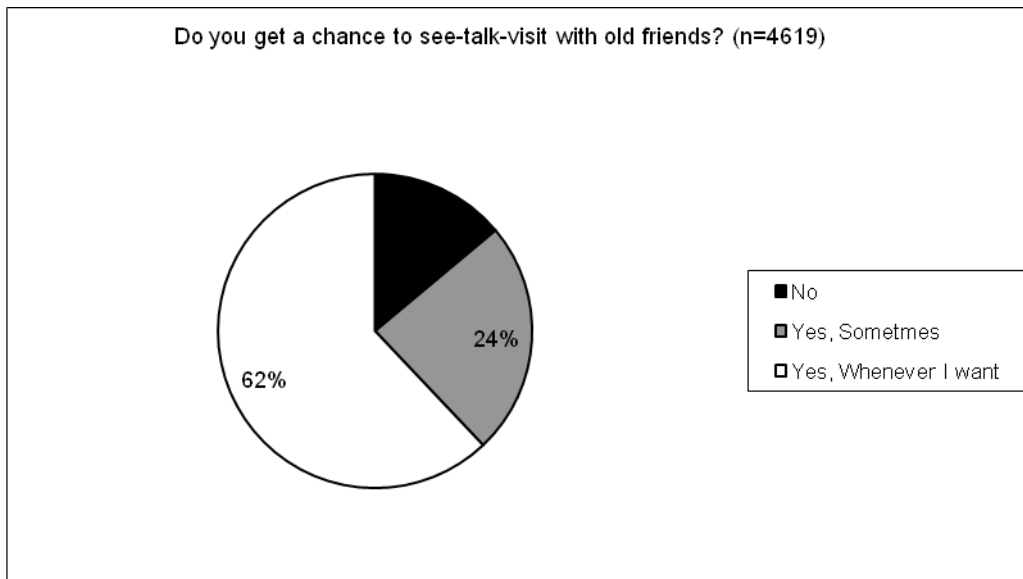
Relationships

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

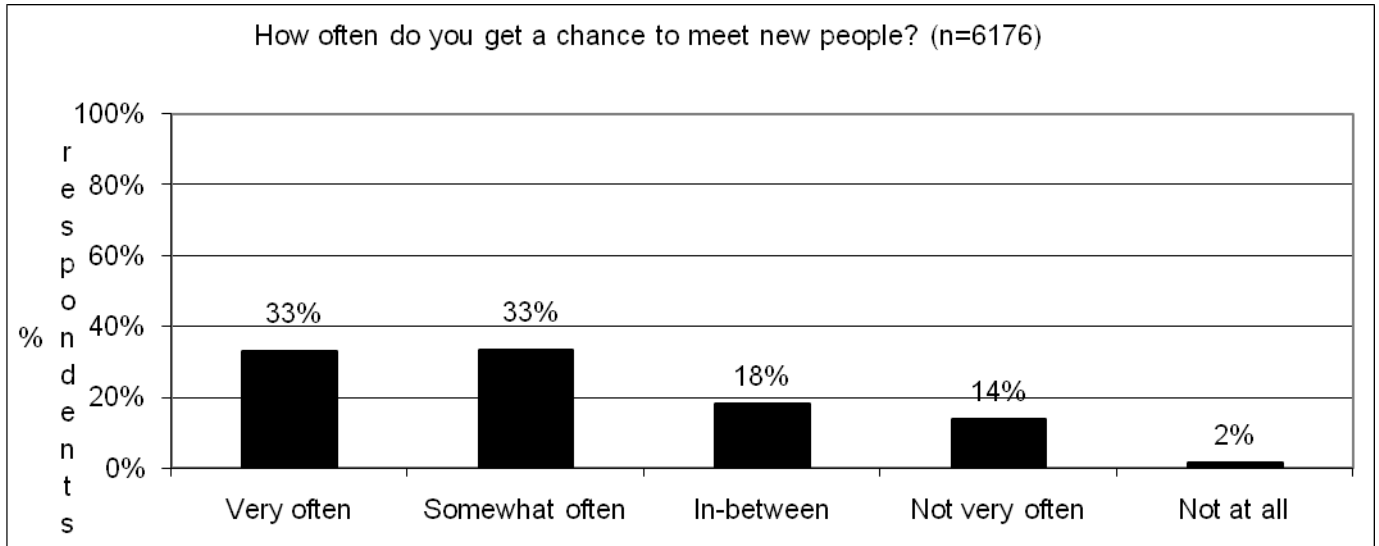
- 46% of the questions were answered by individuals receiving supports
- 31% were answered by paid staff
- 10% were answered by individuals receiving support and staff
- 7% were answered by family
- 6% of the questions were answered by individuals receiving support and a family/friend/guardian/advocate
- 1% of the questions were answered by staff and family
- A value of missing was assigned when individuals did not answer, gave an unclear answer, or responded, “do not know.”

Friendships

- 62% of people answered that they can see-talk-visit with old friends whenever they want

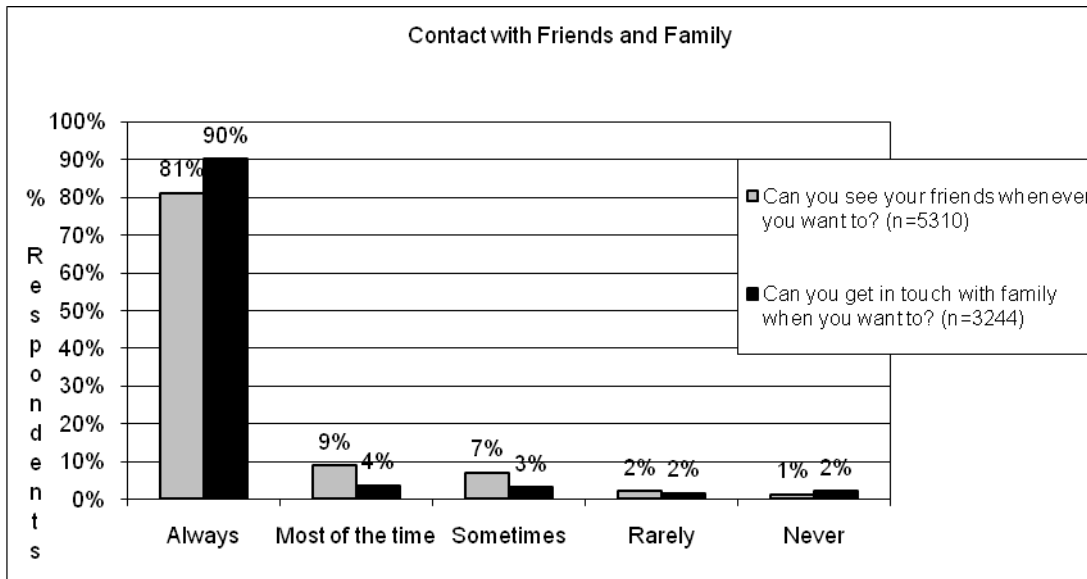


- 67% of individuals reported that they get a chance to meet new people at least somewhat often.



Contact with Friends and Family

- 81% of individuals were always able to see friends whenever they wanted
- 90% of respondents were always able get in touch with family whenever they wanted



There was one significant difference regarding responses to the items in the relationships section of the survey when compared with the data from 2006-2007.

- The percentage of individuals who said they get a chance to meet new people at least somewhat often increased from 64% to 67%.

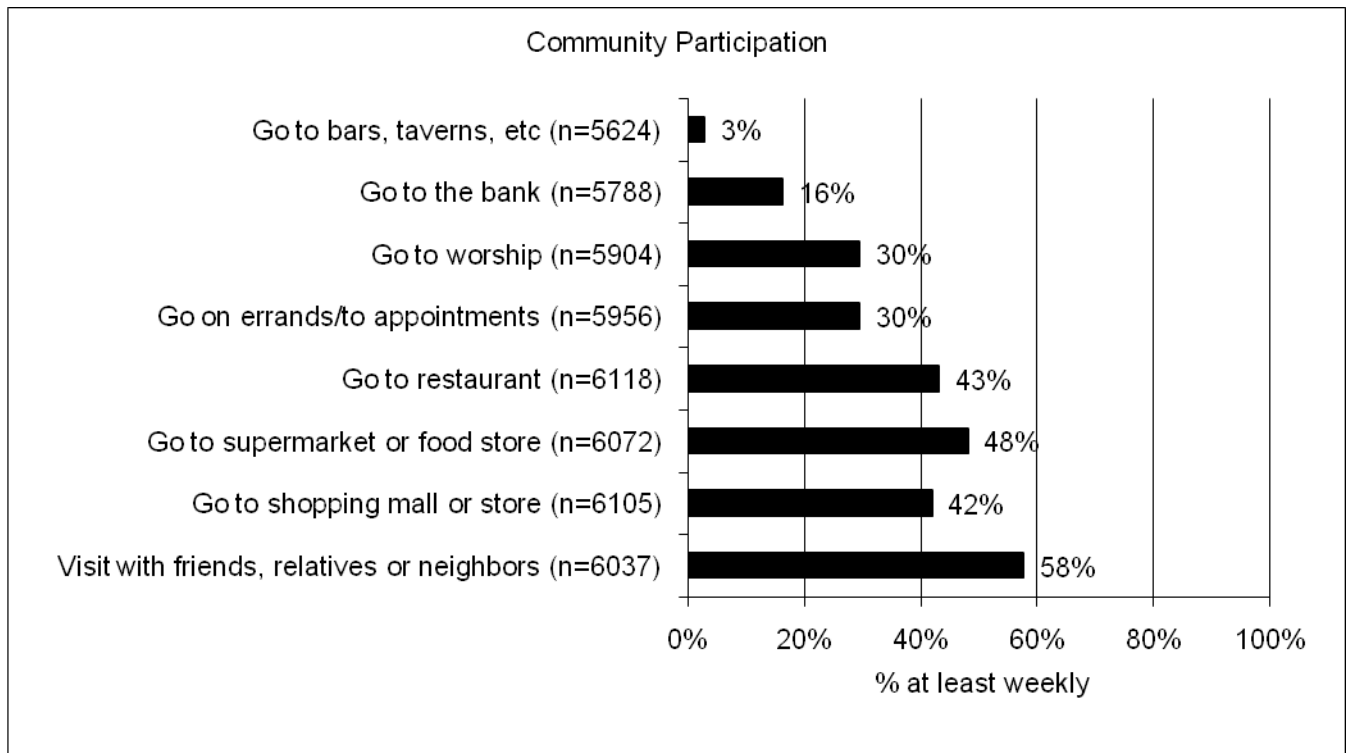
Inclusion

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

- 41% of the questions were answered by individuals receiving supports
- 32% were answered by paid staff
- 13% were answered by individuals receiving support and staff
- 8% were answered by family/friend/guardian/advocate
- 7% of the questions were answered by individuals receiving support and a family/friend/guardian/advocate
- 1% of the questions were answered by staff and family
- A value of missing was assigned when individuals did not answer, gave an unclear answer, or responded, “do not know.”

Community Participation

- 58% of the people visited with friends, relatives and neighbors at least weekly
- 48% of those surveyed went to a supermarket at least weekly
- 43% of respondents went to restaurants at least weekly
- 42% of individuals went to a shopping center or mall at least weekly
- 30% of respondents went to places of worship at least weekly
- 30% of those surveyed went out on errands or appointments at least weekly
- Individuals did not go out as frequently to banks and to bars/taverns



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 people without disabilities. We compared the frequency of community participation reported by individuals in our sample to this national sample. The Harris Poll depends on self-report in determining whether a person has a disability. The definition used is that a person has a disability if they have a disability or health problem that prevents them from participating fully in work, school or other activities, if they have a physical disability, seeing, hearing or speech impairment (sic), an emotional or mental disability or a learning disability (Harris, 2000).

- 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 as likely to go to 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 people with disabilities or people without disabilities in the Harris Poll.

Weekly Participation in Community Activities

	Harris: People without Disabilities	Harris: People with Disabilities	Independent Monitoring
Visit with friends, relatives, and neighbors	85%	70%	58%
Go to supermarket	83%	55%	48%
Go to restaurant	59%	40%	43%
Go to worship	47%	30%	30%
Go to shopping mall or store	41%	23%	42%

Inclusion Scale

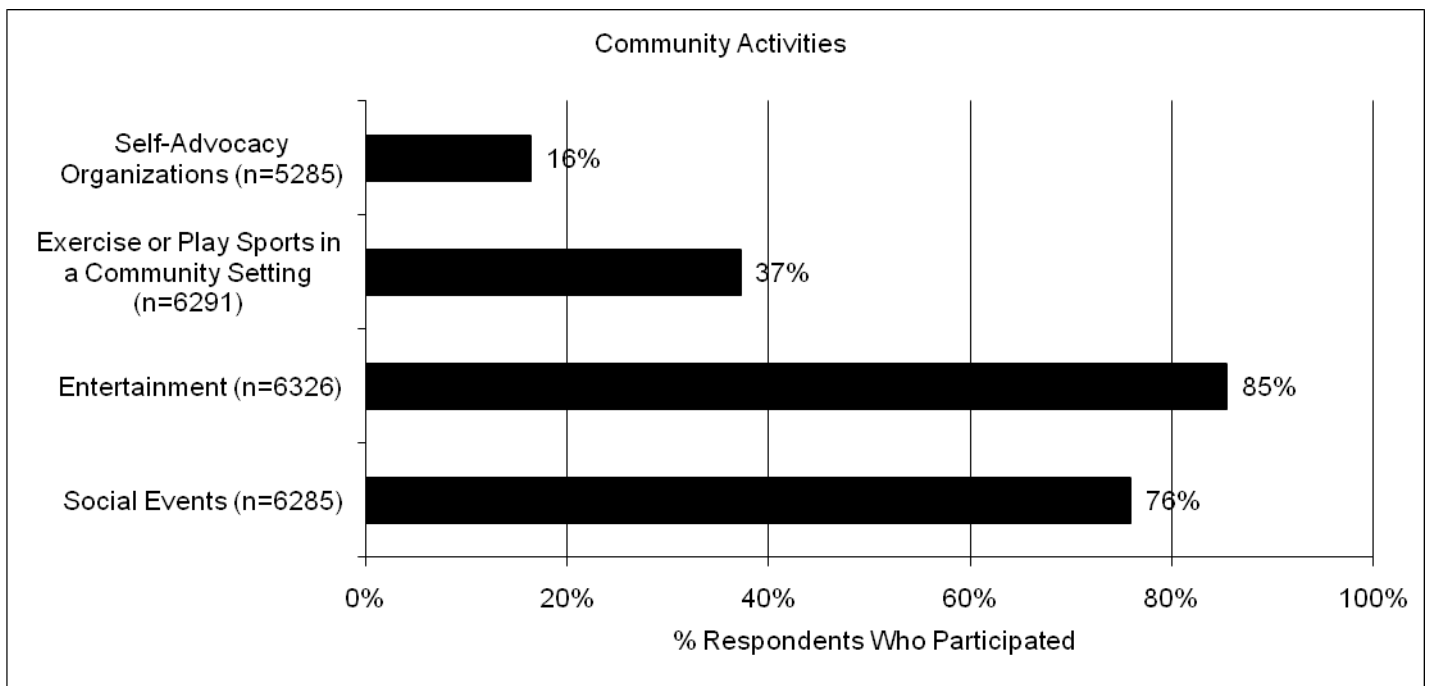
Scores on the Inclusion Scale could range from 0 to 100, with a higher score indicating greater inclusion (going more frequently to places in the community). The scale includes 8 items measuring frequency of participation in community activities. These items include visiting with friends, going to the 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 42.09 with a standard deviation of 14.79
- The average score was less than half of the possible scale score, indicating that individuals do not go to community places with great frequency.
- The mode was 50, which is the most frequent score.

Community Activities

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

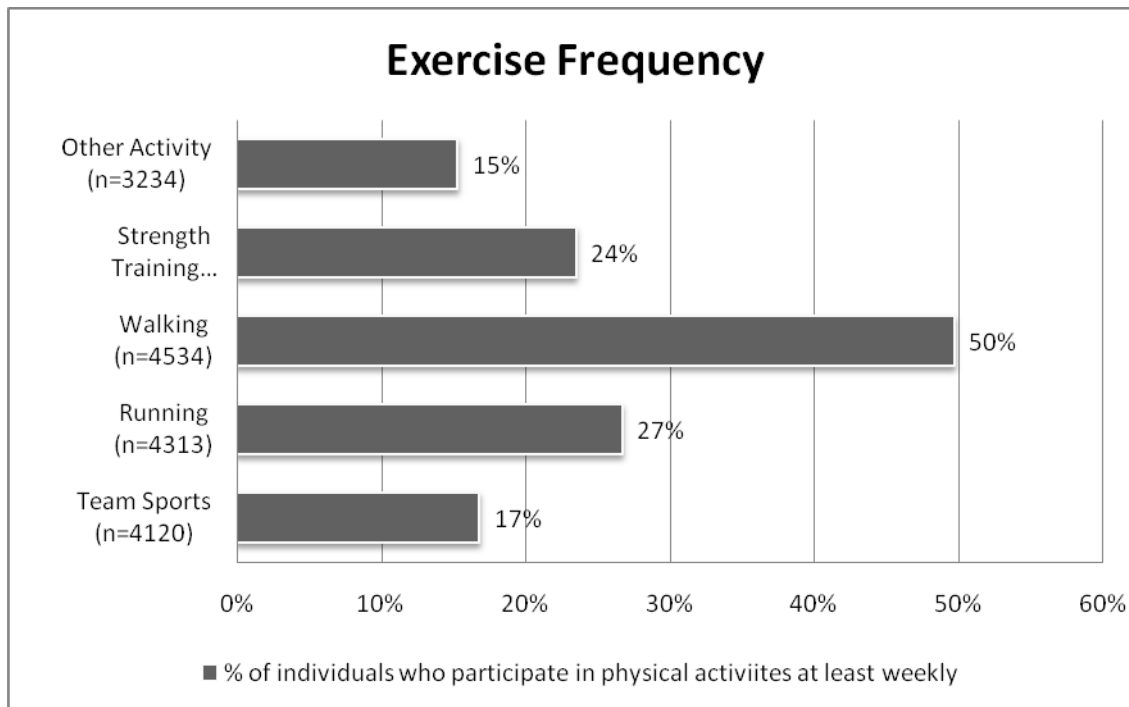
- 85% of individuals go into the community for entertainment
- 16% respondents attend or have attended a meeting/event of a self-advocacy group
- 76% of individuals reported that they go to social events in the community that are attended by people with and without disabilities
- 37% of individuals reported that they exercise or play sports in a community setting; 20% exercise or play sports in a non-integrated setting
- 43% of those interviewed do not exercise or play sports



Exercise Frequency and Intensity

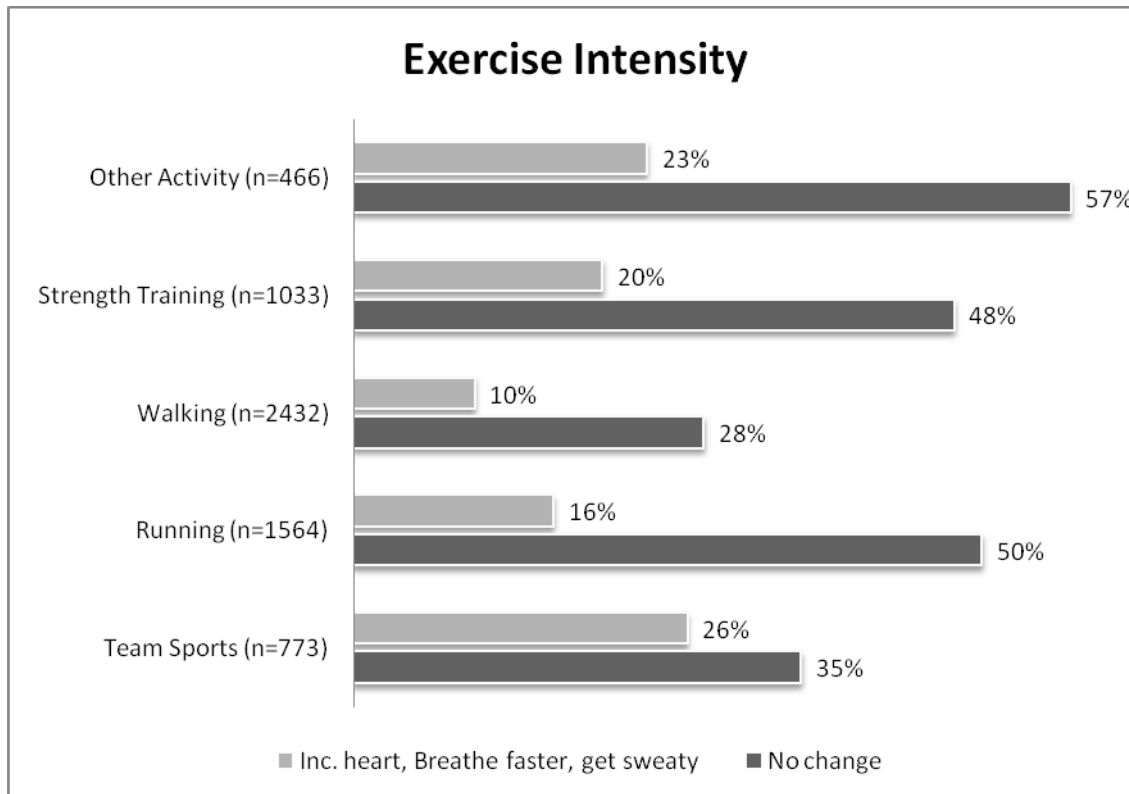
We asked individuals about how often (20 minutes or more per day) do they participate in exercise, playing sports and/or other physical activities. In addition, we also asked individuals, if they do exercise in team sports, running, walking, strength training, and other physical activities, to what intensity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

- 77% of individuals interviewed reported they never participated in team sports; 17% of individuals reported participating in team sports at least weekly
- 55% of individuals interviewed reported they never participated in activities like running; 27% of individuals reported participating in activities like running at least weekly
- 37% of individuals interviewed reported they never participated in activities like walking; 50% of individuals reported participating in activities like walking at least weekly
- 69% of individuals interviewed reported they never participated in activities like strength training; 24% of individuals reported participating in activities like strength training at least weekly
- 81% of individuals interviewed reported they never participated in other physical activities; 15% of individuals reported participating in other physical activities at least weekly



- 26% 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; 35% of individuals reported no change when participating in activities like team sports
- 16% 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; 50% of individuals reported no change when participating in activities like running
- 10% 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; 58% of individuals reported no change when participating in activities like walking
- 20% 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; 48% of individuals reported no change when participating in activities like strength training

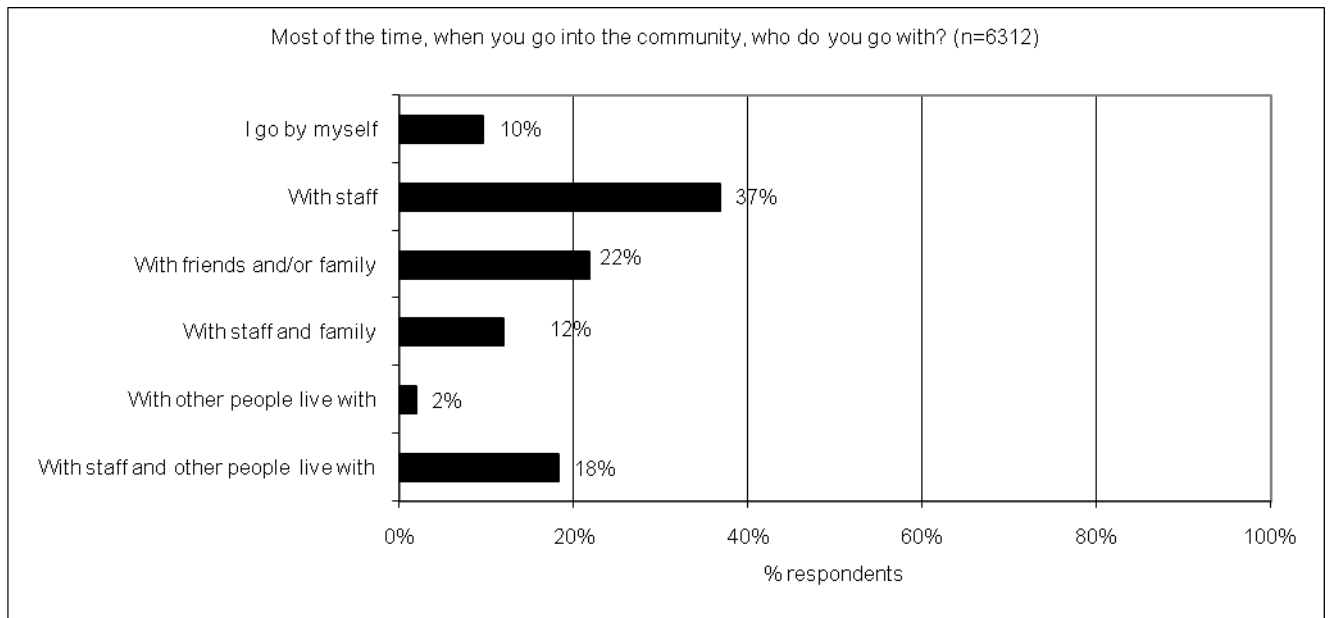
- 23% of individuals interviewed reported they participate in other physical activities to the extent that their heart rate increased, they breathed faster and they got sweaty; 57% of individuals reported no change when participating in other physical activities



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

- 10% of individuals go out alone; 22% go out with friends and family
- 55% of individuals go out with staff or staff and other people they live with most of the time



Transportation

- 92% of individuals always or almost always had a way to get where they wanted to go
- Of those who cannot always get where they want to go, 29% cannot get where they want to go because there is not enough staff

**When you want to go somewhere, do you always have a way to get there?
(n=6148)**

Yes, always or almost always – 92%

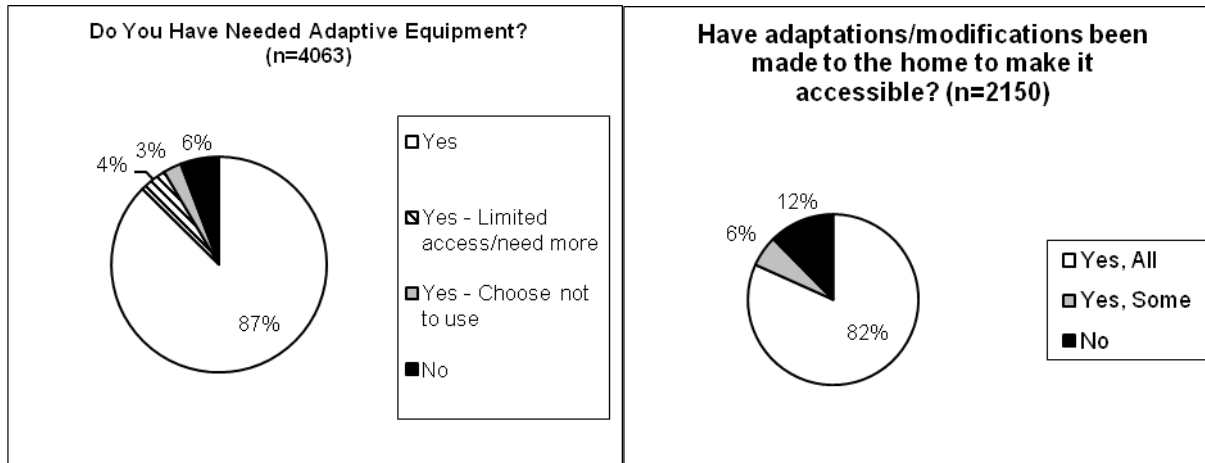
Sometimes – 6%

Never, almost never – 2%

- Of individuals not using public transportation, 50% do not use it because it does not exist where they live.

Home Adaptive Equipment

- 87% of individuals reported having all the adaptive equipment they needed
- 82% of people said that all necessary modifications have been made to their home to make it accessible



This year's responses to the items in the inclusion section of the survey yielded some significant differences compared with the data from 2006-07. Some differences were noted:

- There was a 3% increase in the percentage of individuals who go to social events in the community that are attended by people with and without disabilities
- There was a 4% decrease in the percentage of individuals who exercise or play sports in a community setting, also there was a 4% decrease in the percentage of individuals who exercise and play sports in a non-integrated setting
- Overall, there was a 9% increase in the percentage of individuals who do not exercise or play sports
- There was a 5% decrease in the percentage of individuals who go out with friends and family
- There was a 7% increase in the percentage of individuals who go out with staff or staff and other people they live with most of the time

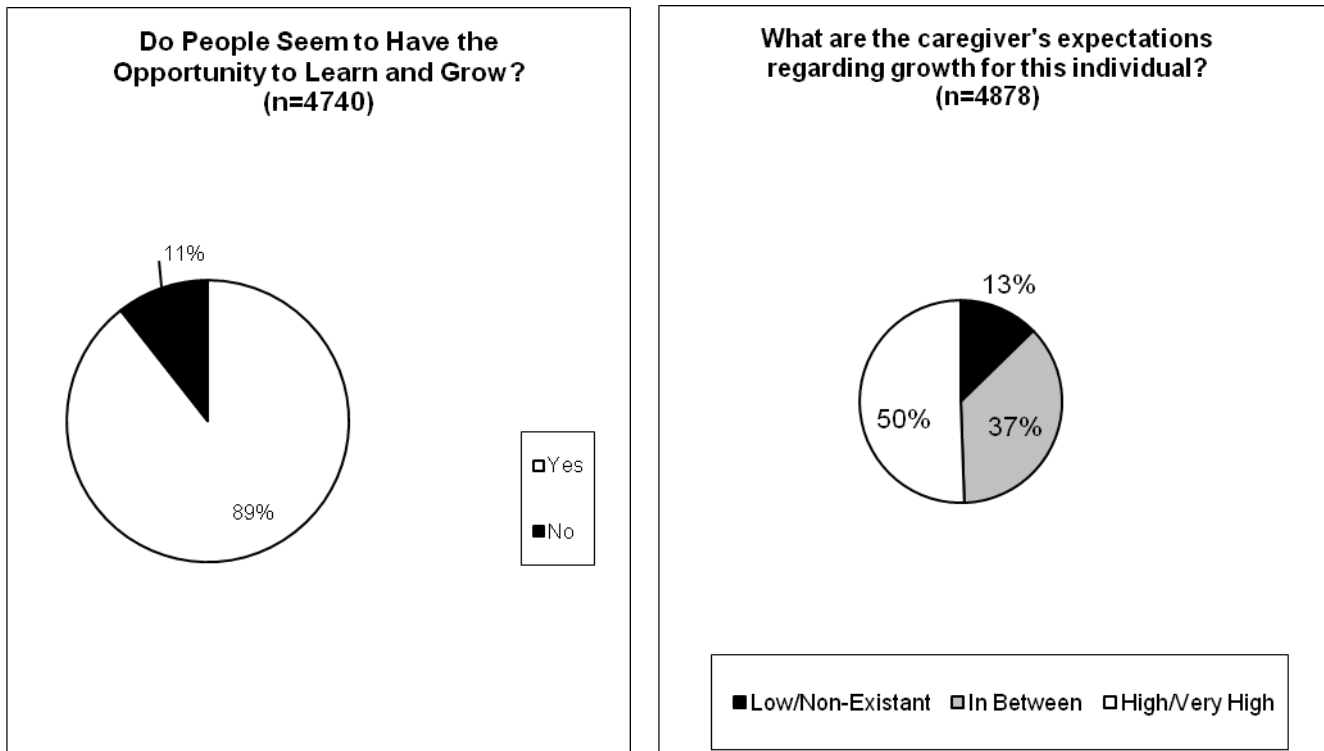
- There was a 7% increase in the percentage of individuals whom always or almost always had a way to get where they wanted to go
- There was a 5% increase in the percentage of individuals who cannot get where they want to go because there is not enough staff

Below are data that could be useful to the closing the loop process, as explained on page nine of the report.

- Many individuals (43%) report that they do not exercise or play sports.
- 29% of individuals cannot always get where they want to go due to lack of staffing.
- 50% of individuals do not use public transportation because it does not exist where they live.

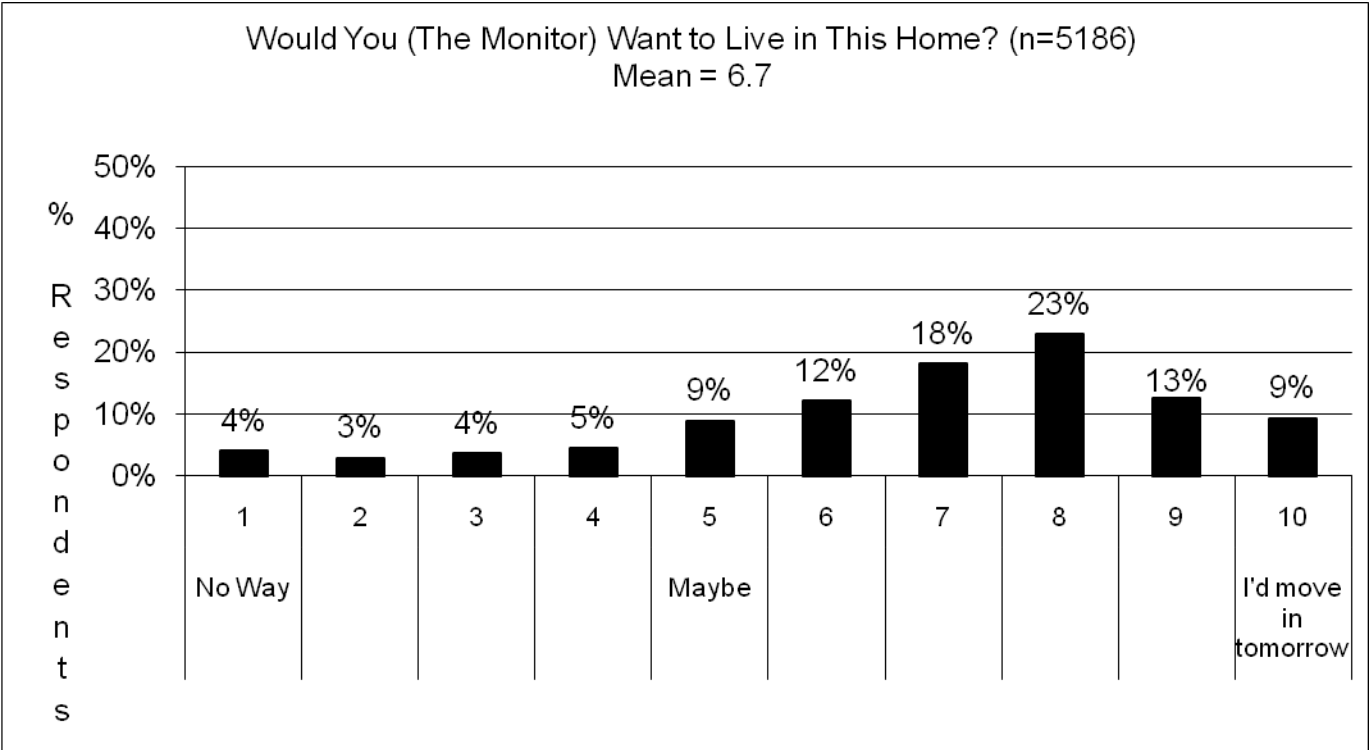
Competence, Personal Growth and Opportunities to Grow and Learn

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,

- 89% of the individuals appeared to have the opportunity to learn new things
- Caregiver expectations regarding growth were reported as being high or very high for 51% of the individuals
- When asked whether team members would want to live in the individual's home on a scale of 1 to 10, the average score was 6.8



Compared to the Competence, Personal Growth and Opportunities to Grow and Learn section of the 2006-2007 report, there was no difference.

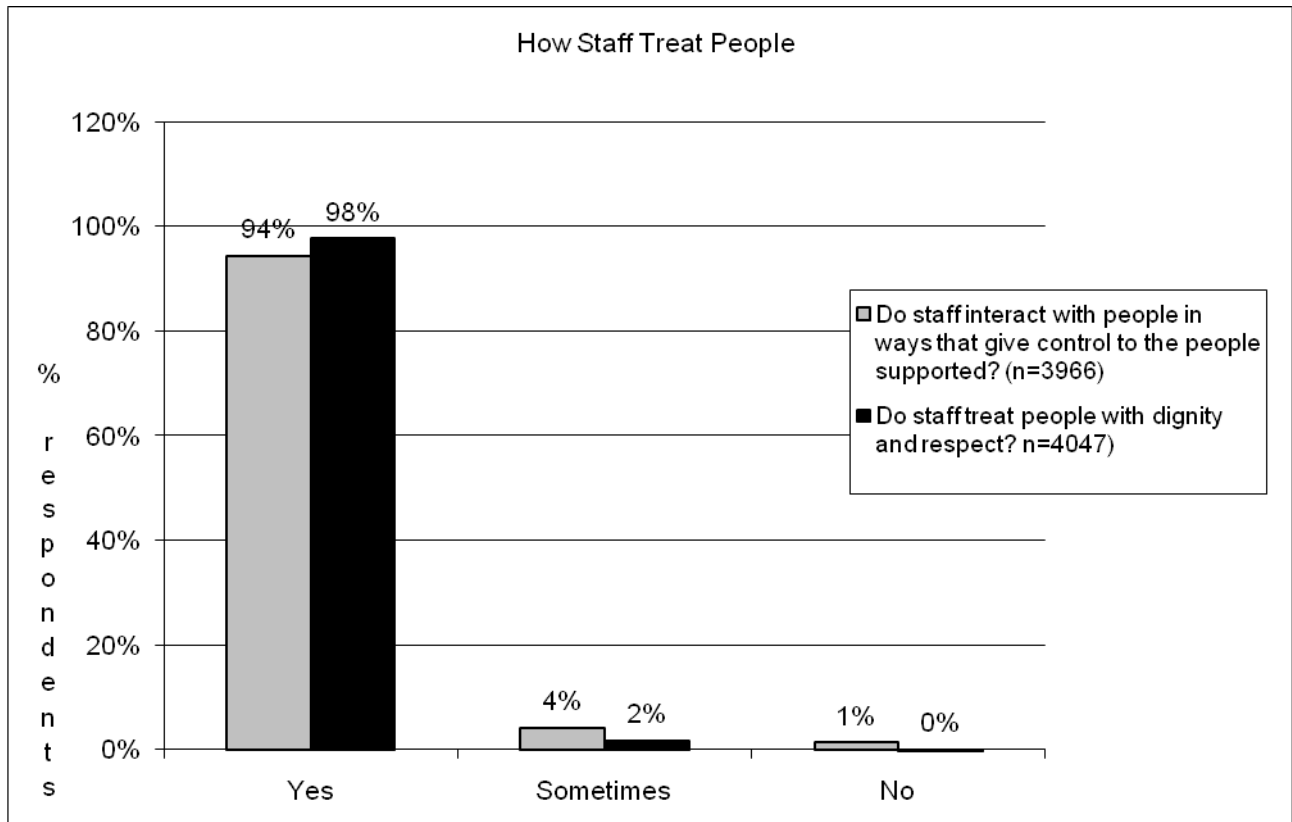
Staff Support for the Person

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.

Staff Skill, Staff Giving Control to People Supported

According to the IM4Q teams,

- 94% of staff observed interacted with individuals in ways that gave control to the people supported
- Individuals had either all staff (90%) or some staff (9%) with the skill needed to support them
- 98% of staff treated individuals with dignity and respect



Compared to the Staff Support for the Person section of the 2006-2007 report, there was no significant difference.

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. Most interviews took place in the individual's home (78%), although some took place at work/day activity (19%).

Home/Work/Day Activity Repair

- Monitors observed that individuals lived in homes or went to work/day activities which were in good repair on the outside (94%) and on the inside (93%)

Neighborhood

According to IM4Q teams,

- Individuals lived in homes or went to work/day activities which were in a safe neighborhood (93%)
- Individuals lived in homes that "fit in" with the neighborhood in which they were located (92%)

Personal Belongings and Personalities

According to IM4Q teams,

- Most individuals (97%) lived in homes which had sufficient space for personal belongings
- Individuals (65%) lived in homes which reflected the hobbies, interests and personalities of the people who live there; for 30% of people only their bedroom reflected their personalities and interests.

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 96.25 with a standard deviation of 11.38

- The mode (the value that occurs the most frequently) was 100, indicating that many people (87%) lived in homes which were at the top of the scale on all measures of the physical setting

Compared to the Physical Setting section of the 2006-2007 report, there was no difference.

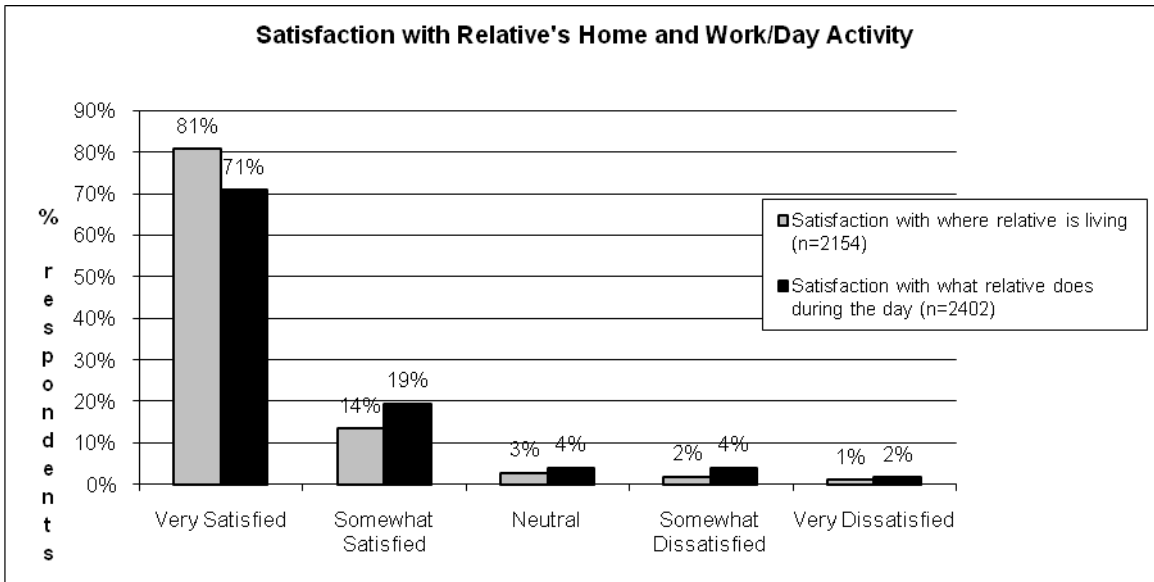
Family/Friend/Guardian Survey

Respondents: This survey was completed by telephone or face-to-face with a family member, guardian, or friend who was identified through the Essential Data Elements Pre-Survey. In the event that a phone or face-to-face survey could not be completed, surveys were completed by mail. 2731 family members, friends, and guardians participated in the survey.

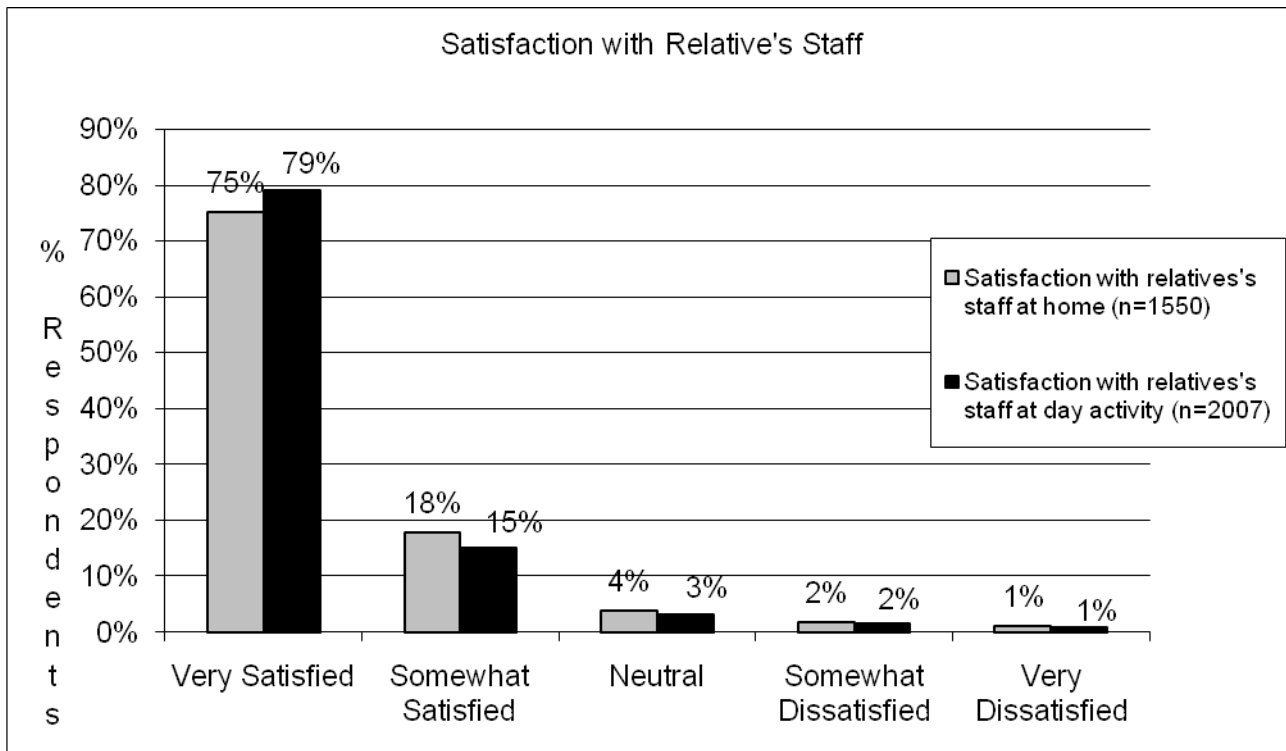
- 61% of the surveys were answered by parents
- 21% were answered by siblings
- 2% were answered by the guardian
- 1% were answered by a friend
- 5% were answered by another relative (spouse, aunt, uncle, cousin, grandparent)
- 4% were answered by persons with other relationships to the individual receiving supports

Satisfaction

- 94% of the families surveyed were either somewhat satisfied or very satisfied with where their relative lives
- 90% were either satisfied or very satisfied with what their relative does during the day



- 93% of the families surveyed were either somewhat satisfied or very satisfied with their relatives' staff at home
- 94% of the families surveyed were either somewhat satisfied or very satisfied with the staff at their relatives' day activity

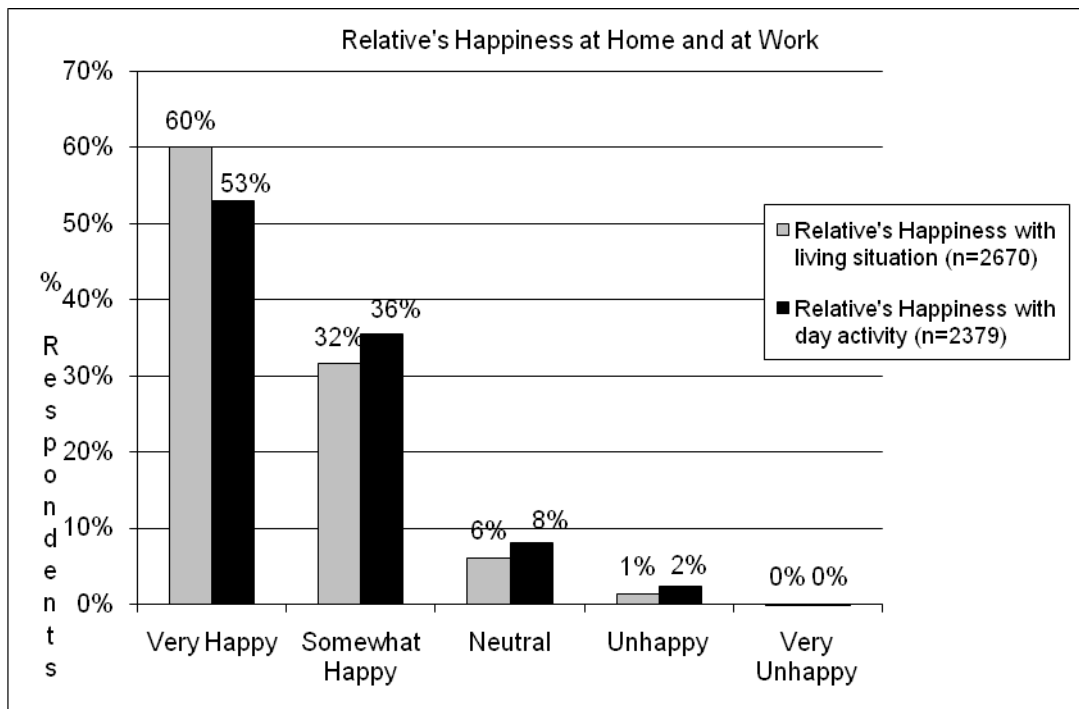


How Often Do You Contact/See Your Relative?

- 86% of the family/friend/guardians contacted their relative at least monthly; 3% have not contacted their relative in the past year
- 74% 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; 5% did not get to see their relative in the past year

Your Relative's Happiness

- 92% of respondents felt their relative was either very happy or somewhat happy with his/her living situation; 89% felt their relative was happy with what they do during the day



- 93% of relatives felt their relative was either very happy or somewhat happy with the staff who support them at home; 1% believed their relative was either unhappy or very unhappy
- 94% of respondents felt their relative was either very happy or somewhat happy with the staff who support them at work (or during the day); 1% believed their relative was either unhappy or very unhappy

Your Relative's Safety

- Respondents said that their relative felt safe at home always (84%) or most of the time (14%)
- Respondents said they think their relative felt safe in his/her neighborhood always (84%) or most of the time (13%)
- Respondents said that their relative felt safe at his/her day activity always (86%) or most of the time (12%)

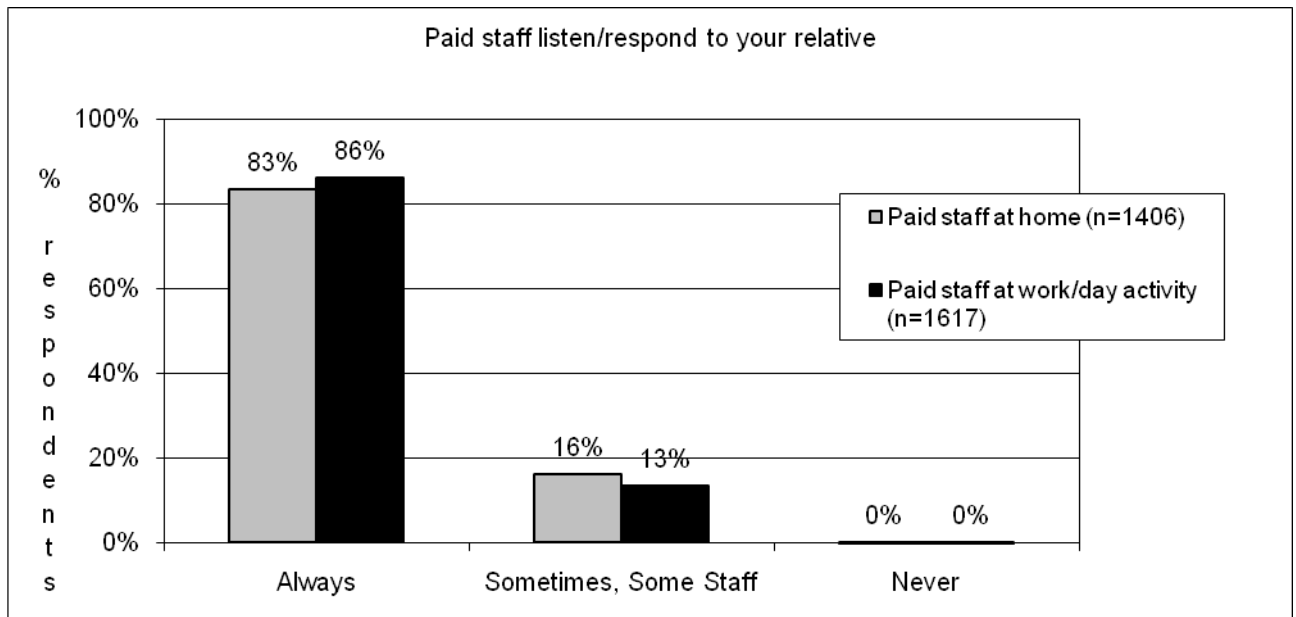
Your Relative's Opportunities

- 85% of the respondents said that their relative had enough opportunities to participate in activities in the community
- 88% of the respondents said that their relative seemed to have the opportunity to learn new things

Your Relative's Staff

- 57% of the respondents said that their relative's staff at home had high or very high expectations regarding growth for their relative; 62% felt that their relative's staff at work/day activity had high or very high expectations regarding growth for their relative
- If their relative did not communicate verbally, 32% of the respondents said that there is a formal communication system in place for their relative and they use it
- 88% of the respondents said that their relative's home appeared to have enough paid staff

- 87% of the relatives said that staff in their relative's home interact with people in ways that give control to the people being supported
- 94% of the respondents said that staff in their relative's home treat people with dignity and respect
- 82% of the respondents said that all staff appear to have the skills they need to support their relative (16% felt that way about only some staff)
- In terms of relative-staff interactions, families believe that staff at home listen/respond to their relative's communication (83% always); for staff at work/day activity, 86% always listen and respond to their relative's communication



Relative's Supports

- 86% of relatives interviewed said that the supports coordinator is always available to assist them if there is a crisis
- 83% of relatives were satisfied with the supports coordination their relative receives
- 56% of relatives reported that they were told how much money is in their relative's annual budget
- 74% said that their relative always received the supports they needed

- 76% of relatives reported that they always got enough information to help them participate in planning services for their family member
- 87% of relatives always felt that the staff who assisted them with planning respected their choices and opinions
- 80% of relatives felt that when they asked the supports coordinator for help, the supports coordinator always helped them get what they needed
- 66% of relatives never felt that frequent changes in support staff was a problem for their family member
- 42% of relatives always got to choose the agency/provider who worked with their relative; 41% never got to choose
- 50% of relatives were always satisfied with the way complaints and grievances are handled; 28% were never satisfied
- 26% of relatives report that there is other information they would like to have.

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 88.65 with a standard deviation of 13.77
- The mode (the value that occurs the most frequently) was 100, indicating that many of the families' (34%) satisfaction levels were at the top of the scale on all measures of family satisfaction

Compared to the Family/Friend/Guardian section of the 2006-2007 report, there were several significant differences.

- The percentage of individuals who said that there is a formal communication system in place for their relative and they use it decreased from 36% to 32%.
- The percentage of individuals who said that their relative's supports coordinator is always available to assist them if there is a crisis increased from 81% to 86%.
- The percentage of relatives who felt that their relative always received the supports they needed increased from 66% to 74%.

- The percentage of relatives who felt that they always got enough information to help them participate in planning services for their family member increased from 71% to 76%.
- The percentage of relatives who felt that when they asked the supports coordinator for help the supports coordinator always helped them get what they needed increased from 74% to 80%.
- The percentage of relatives who were never satisfied with the way complaints and grievance are handled decreased from 35% to 28%.
- And, the percentage of relatives who reported that there is other information they would like to have decreased from 32% to 26%.

For purposes of “closing the loop,” it is important to note that only 56% of relatives report being told how much money is in their relative’s budget. 26% report needing/wanting additional information.

Summary

This report presents information collected through face-to-face interviews with 6512 individuals 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, more than a third 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 half of all individuals and families report that they were not 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, 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.

Less than half of the people interviewed participate in community activities (i.e. going shopping) on a weekly basis. 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. Of those individuals who do not use public transportation, the main reason is because it does not exist where they live.

Those responding to the Family/Friend/Guardian Survey reported high levels of satisfaction similar to the responses given by the individual. One area of concern is a decrease in satisfaction by families with how complaints or grievances are handled.