

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

***Independent Monitoring for Quality (IM4Q)  
A Statewide Summary  
2008-2009***

**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 has been 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 is being used in this effort.

In Fiscal Year 1999-2000, twenty Administrative Entities (AEs), previously called County MH/MR Programs, submitted proposals and were selected to participate in a pilot effort that resulted in the conducting of interviews with 2796 individuals. A final report of that effort was produced in early 2001 (Feinstein, Levine, Lemanowicz and Carey, 2001). 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 was developed and 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 local IM4Q programs. The number of face-to-face interviews continued to increase with a total of 6487 conducted during that fiscal year. The increase was a reflection of the addition of a sample of individuals receiving services through the Person and Family Directed Supports Waiver (PFDS). In addition

to the interviews with individuals, 3163 interviews were conducted with families, friends and guardians.

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

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

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

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

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

In 2007-2008, a total of 6512 face-to-face interviews were conducted from September 2007 until June 2008. A total of 2731 Family/Friend/Guardian Surveys were completed. 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. In addition, an additional technical advisor was added to the project.

In fiscal year 2008-2009, a total of 6618 face-to-face interviews were conducted. A total of 2896 interviews were conducted with family, friends and guardians. This year, there were major changes made to the data collection instrument. A stakeholder workgroup was developed to assist in the instrument revisions. The changes included the removal of a number of items to make the instrument less lengthy and redundant. In addition, the items that had been added at the request of ODP regarding physical activity were removed as they did not appear to yield meaningful data.

## **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. As a result of the 2008-2009 revisions, the IM4Q Essential Data Elements (EDE) survey has a total of 85 questions, instead of 101 questions. Thirty-five of the questions can only be answered by the individuals receiving supports and services.

The EDE for fiscal year 2008-2009 includes all survey questions included in the FY 2008-2009 NCI Consumer Survey. At the time of this report, approximately 1400 individuals included in this report are represented in the NCI sample for 2008-2009, based on a sampling methodology established by ODP and the Human Services Research Institute (HSRI). A copy of the NCI report for FY 2008-09 is available on the HSRI website at [www.hsri.org](http://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 program was required to develop a mechanism for communicating this information. In the event of imminent danger, teams were instructed not to leave the home until resolution of some kind was achieved.
- **Family/Friend/Guardian 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. Administrative Entities were instructed to draw a random sample of approximately one-third of the individuals living in licensed residential settings. AEs were provided with written instructions for drawing the entire Fiscal Year 2001-02 sample; once the sample was selected, ODP staff checked the samples before individual names were given to the local IM4Q Program, to ensure consistency in the sample selection.

During fiscal year 2003-04, in addition to the NCI and residential samples, each AE was instructed to include 30 individuals who participate in the Person and Family Directed Supports (PFDS) Waiver. Individuals participating in the PFDS Waiver continue to be included in the sample in each subsequent year.

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

	<b>N</b>	<b>Percent</b>
State-Operated ICF/MR	61	0.9%
State MH Hospital	4	.1%
Homeless	2	.0%
Temporary Shelter	0	0.0%
Foster Care	4	0.1%
Incarceration	0	0.0%
Nursing Home/Facility	113	1.7%
Domiciliary Care	35	0.5%
Personal Care Home	184	2.8%
Family Living/Life sharing	417	6.4%
Unlicensed Family Living	24	0.4%
Own Residence	525	8.0%
Relative's Home	1701	26.0%
Children's Facility	4	0.1%
Approved Private School	9	0.1%
Private ICF/MR <4	50	.8%
Private ICF/MR 5-8	125	1.9%
Private ICF/MR 9-15	23	.4%
Private ICF/MR 16+	215	3.3%
Community Home 1	130	2.0%
Community Home 2-4	2454	37.5%
Community Home 5-6	242	3.7%
Community Home 7-8	73	1.1%
Community Home 9-15	19	0.3%
Community Home 16+	32	0.5%
Other	90	1.4%
Missing	82	-
<b>Total</b>	<b>6618</b>	<b>100%</b>

## **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 programs from service delivering entities, consumer and family

involvement on governing boards, and involvement of individuals receiving supports and families in data collection activities. Local IM4Q Programs were selected by AEs from a variety of organizations, including non-service providing chapters of the Arc (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 2008-09 survey cycle was to be collected by June 30, 2009 and entered into HCSIS by August 1, 2009. A usable data file was received by the Institute on Disabilities in April, 2010. 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	659	10.0 %
Armstrong/Indiana	108	1.6%
Beaver	112	1.7%
Bedford/Somerset	87	1.3%
Berks	172	2.6%
Blair	108	1.6%
Bradford/Sullivan	49	0.7%
Bucks	199	3.0%
Butler	97	1.5%
Cambria	101	1.5%
Cameron/Elk	38	0.6%
Carbon/Monroe/Pike	107	1.6%
Centre	75	1.1%
Chester	168	2.5%
Clarion	49	0.7%
Clearfield/Jefferson	84	1.3%
Columbia/Montour/Snyder/Union	115	1.7%
Crawford	93	1.4%
Cumberland/Perry	104	1.6%
Dauphin	164	2.5%
Delaware	280	4.2%
Erie	261	3.9%
Fayette	89	1.3%
Forest/Warren	48	0.7%
Franklin/Fulton	84	1.3%
Greene	40	0.6%
Huntington/Mifflin/Juniata	88	1.3%
Lackawanna/Susquehanna	149	2.3%
Lancaster	176	2.7%
Lawrence	87	1.3%
Lebanon	69	1.0%
Lehigh	158	2.4%
Luzerne/Wyoming	135	2.0%
Lycoming/Clinton	111	1.7%
McKean	52	0.8%
Mercer	82	1.2%
Montgomery	323	4.9%
Northampton	126	1.9%
Northumberland	91	1.4%
Philadelphia	782	11.8%
Potter	48	0.7%
Schuylkill	94	1.4%
Tioga	46	0.7%
Venango	56	0.8%
Washington	102	1.5%
Wayne	39	0.6%
Westmoreland	157	2.4%
York/Adams	156	2.4%
<b>TOTAL</b>	<b>6618</b>	<b>100%</b>

## **Satisfaction**

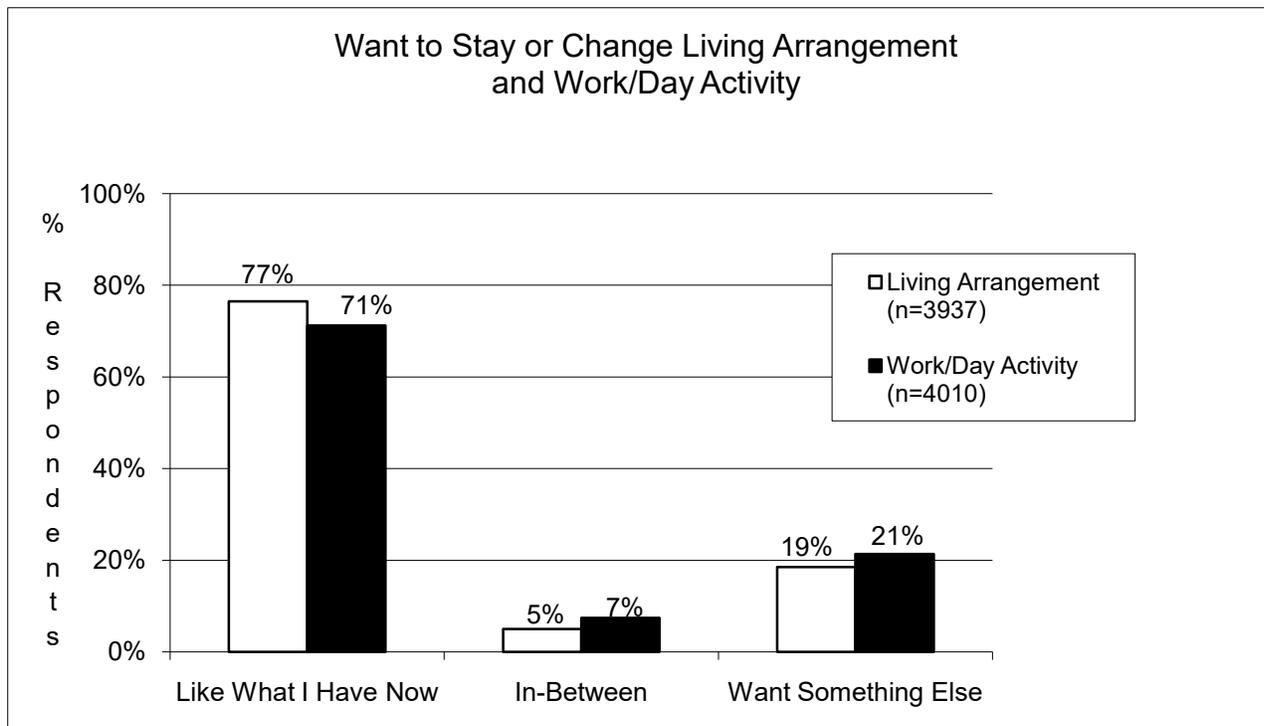
**Respondents:** Only the individual receiving services/supports could answer the questions on satisfaction. The percent of people who responded to questions in this section ranged from 37% to 70%.

### ***Satisfaction with Living Arrangements***

- 91% of individuals liked where they live.
- 77% wanted to stay where they currently live but 19% wanted to move somewhere else.

### ***Satisfaction with Work/Day Activity***

- 91% of individuals *with* a day activity/work liked what they did during the day.
- 71% wanted to continue their current daytime activities/work, but 21% wanted to do something else.



### ***Daily Life***

- 92% of the individuals reported getting the services they needed to be able to live in their home.
- On most weekdays, 32% of individuals report they attend an adult training program, 25% stay home, 20% go out and do things in the community, 19% are at a vocational facility, 14% work part time for pay, 8% work full time for pay, 6% help their neighbors and/or friends, 6% volunteer and 5% attend school; individuals rarely report attending college or trade school and rarely were retired.

### ***Happiness and Loneliness***

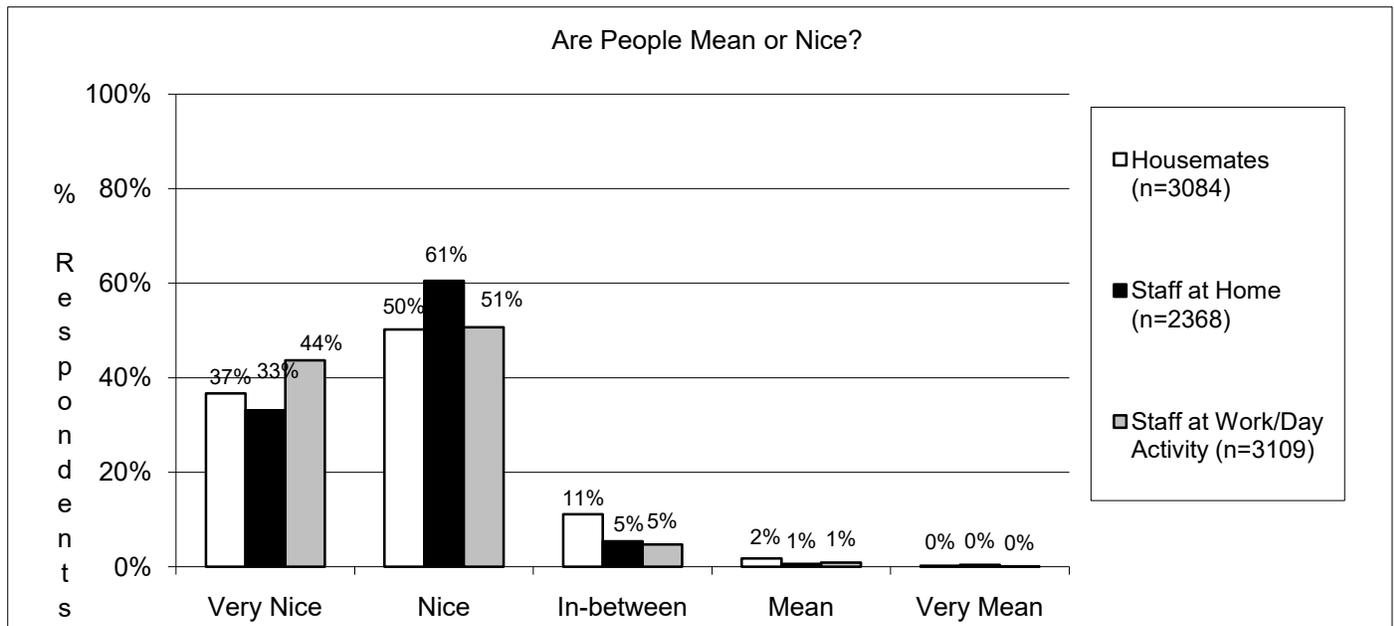
- 81% reported feeling happy overall, 15% reported being neither happy nor sad, and 4% reported feeling sad overall.
- 59% of individuals reported never feeling lonely, 36% reported sometimes feeling lonely, and 6% reported always feeling lonely.
- 91% reported having friends they like to do things with – for 71% of these people their friends are not staff or family.
- 74% reported that they can go on a date if they want to or are married; 12% reported that they can go on a date if they want to but there are some restrictions and rules and 14% are not allowed to date.

### ***Privacy***

- 95% of the individuals surveyed reported that they have enough privacy (a place to be alone) at home.
- 89% reported that other people always let them know before coming into their home, 5% reported that sometimes other people let them know before coming into their home, and 5% never let them know.
- 83% reported that people let them know before coming into their bedroom, 8% reported sometimes people let them know before coming into their room, and 9% never let them know.

### Are People Nice or Mean?

- Most people, 87% of respondents reported that their housemates are very nice or nice.
- 94% of the people interviewed reported that the staff who work with them at home are very nice or nice.
- 94% 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 84.34 with a standard deviation of 19.93
- The mode (the value that occurs the most frequently) was 100, indicating that many people were very satisfied on all measures of satisfaction

### **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.

Compared to the Satisfaction section of the 2007-2008 report, there were a few significant differences. The criteria established for noting comparable differences was based on a three-point range. Some differences included:

- There was a 4% **decrease** in the percentage of individuals who reported feeling happy overall and a 4% **increase** in the percentage of individuals who reported being neither happy nor sad.
- There was a 9% **increase** in the percentage of individuals who reported that they have enough privacy at home.
- There was a 6% **increase** in the percentage of individuals who reported that other people always let them know before coming into their home.
- There was 7% **increase** in the percentage of individuals who reported that people let them know before coming into their bedroom.

## **Dignity, Respect and Rights**

**Respondents:** Only the individual receiving services/supports could answer the questions on dignity, respect and rights. The percent of people who responded to questions in this section ranged from 35% to 67%.

### ***Forms of Identification***

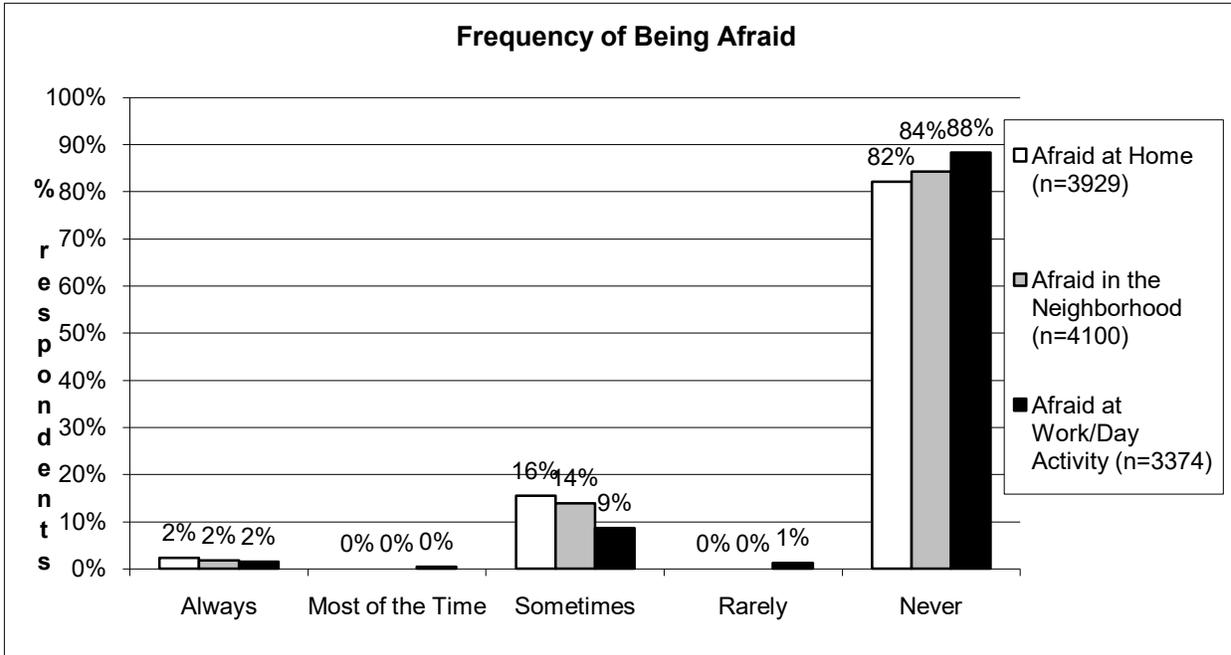
- 58% of individuals stated that they always carry a form of identification; 24% never do.

### ***Support with Problems and Goals***

- 92% always have someone to go to for help if they have a problem.
- 61% of individuals want help to learn new things.
- 74% of individuals report that they get to help other people.

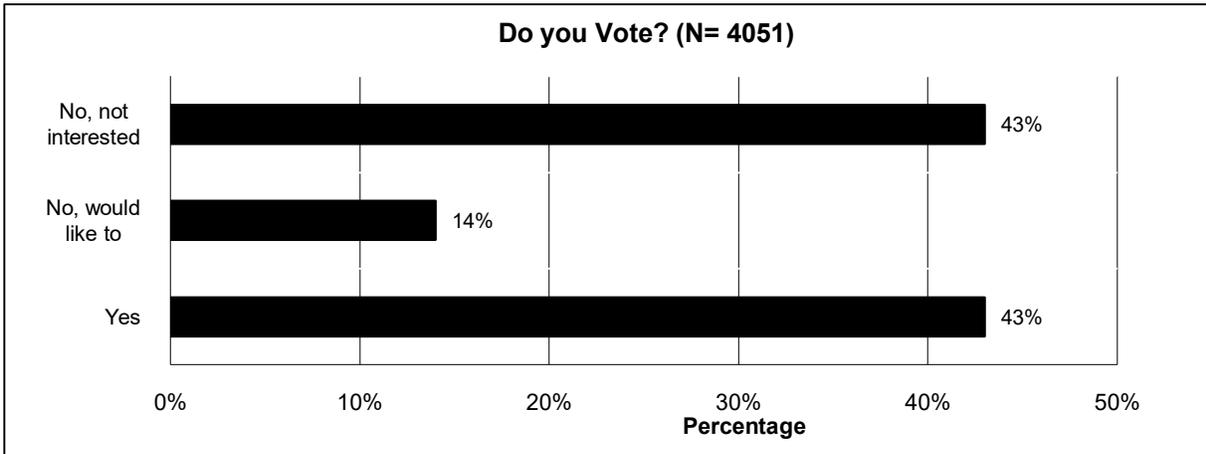
### ***Being Afraid***

- 82% reported never being afraid at home; 16% reported sometimes being afraid at home.
- 84% reported never being afraid in the neighborhood; 14% reported sometimes being afraid in the neighborhood.
- 88% reported never being afraid at work, school or day activity.

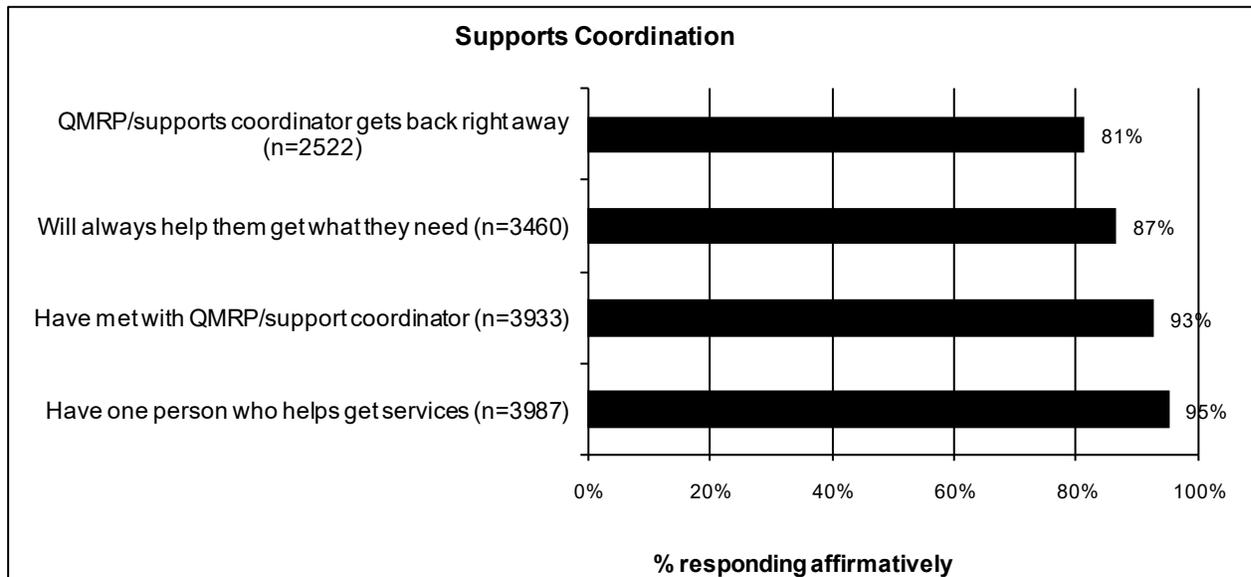


### Legal Rights

- 43% of the people said they vote, 43% of the people said they do not vote and are not interested in voting, and 14% do not vote but would like to.



## **Supports Coordination/ Qualified Mental Retardation Professional (QMRP)**



- 95% of individuals reported that they have one person (supports coordinator/QMRP) who helps them get the services they need.
- 93% reported that they have met with their supports coordinator/QMRP in the last year.
- 87% of individuals reported that if they ask, their support coordinator will always help them get what they need; 10% said their support coordinator will sometimes help.
- 81% of individuals reported that when they call, their supports coordinator/QMRP always gets back to them right away.
- 64% of those surveyed have been told how much money is in their annual budget.

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

**Dignity and Respect Scale:** The Dignity and Respect Scale included three measures that asked whether housemates/ roommates, staff at home, and staff at work/day

activity are nice or mean. Scores on the Dignity and Respect Scale could range from 0 to 100, with a higher score indicating greater dignity and respect (people treating you as they would wish to be treated).

- The average score was 82.77 with a standard deviation of 14.53.
- 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.

***Afraid Scale:*** The scale included three measures that asked individuals if they feel afraid in their home, neighborhood, or at work/day activity. Scores on the Afraid Scale could range from 0 to 100, with a higher score indicating less fear.

- The average (mean) score was 91.00 with a standard deviation of 17.05
- 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 (71%) 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 the staff, consumers and co-workers

	At Home #	In Neighborhood #	At Work #
Alone	22	11	3
Animals / Insects	28	69	6
Being Scolded / Fear of Being Hurt / People Yelling / Fear of the Unknown	20	13	20
Darkness / Sleep / Nightmares / Night	45	39	4
Emergency Situations / Fire / Fire Alarms	21	5	12
Falling / Sickness / Seizures/ Death	10	4	8
Neighbors / Local kids	1	15	3
Work/school related-Lose job/ New things on job/ Making mistakes	2	0	26
Noises	32	14	20
Staff / Consumers / Co-Workers	58	11	44
Strangers / Crime	14	37	2
Transportation/ Traffic/ Emergency vehicles	4	19	4
Weather	71	32	6
Houses/ Locked Rooms/ Office/ Stairs/ Elevator/ Escalator	6	3	2
Mythical & Fictional Creatures	8	1	0
Scary Movies/ Halloween / TV	11	3	1
Other people/ People in general/ Crowds	10	38	19
Fighting/ Violence/ Teasing/ Behavioral Outbursts	6	8	7
Neighborhood/ Getting lost/ Being outside	3	27	3
Other	40	35	30
TOTAL	412	384	285

Compared to the Dignity, Respect and Rights section of the 2007-2008 report, there were a few significant differences. Some differences included:

- There was a 6% **decrease** in the percentage of individuals who want help to learn new things.
- There was a 5% **increase** in the percentage of individuals who reported never being afraid at home.
- There was a 6% **decrease** in the percentage of individuals who reported that they do not vote.

- There was an 8% **decrease** in the percentage of individuals who would like to vote.
- This year, individuals are most afraid of staff, consumers and co-workers while at work, compared to last year's report where individuals were most afraid of people, and crowds while at work.

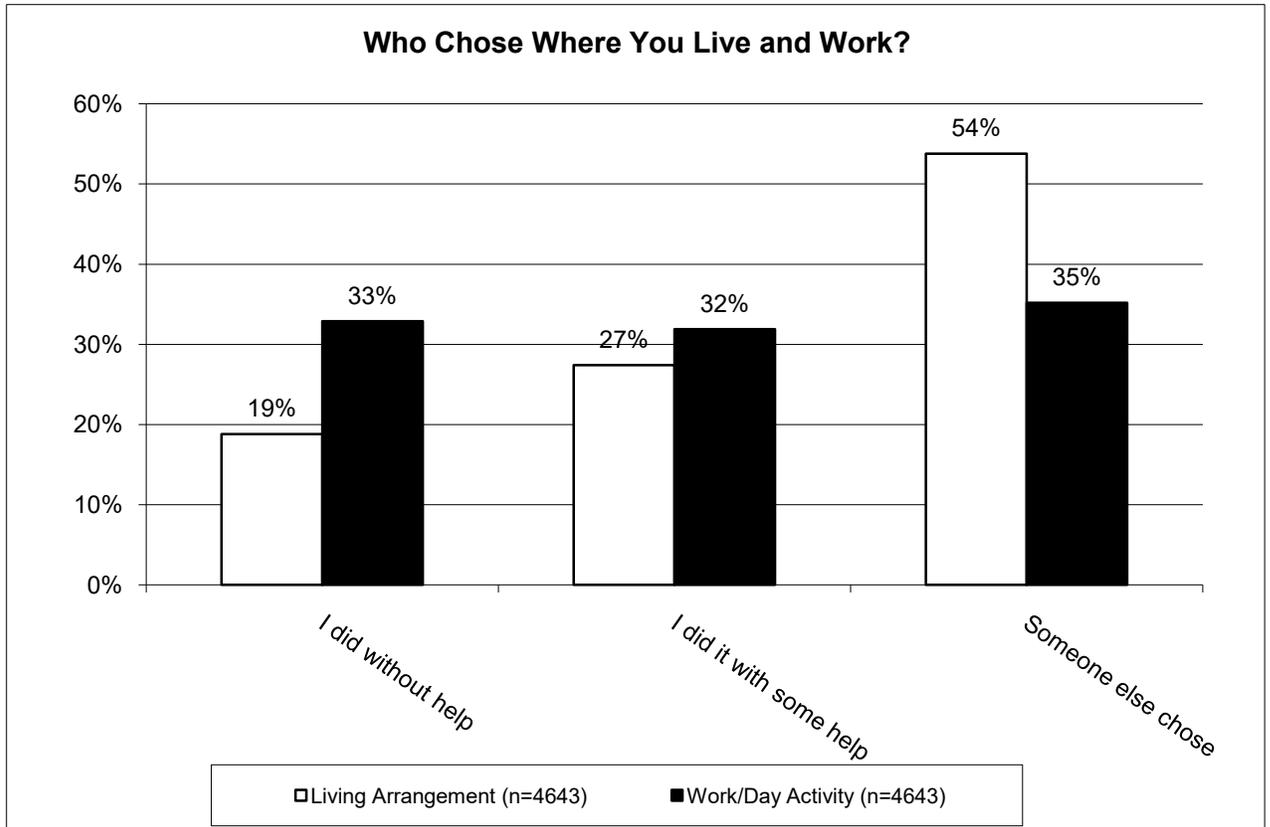
### **Choice and Control**

**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,

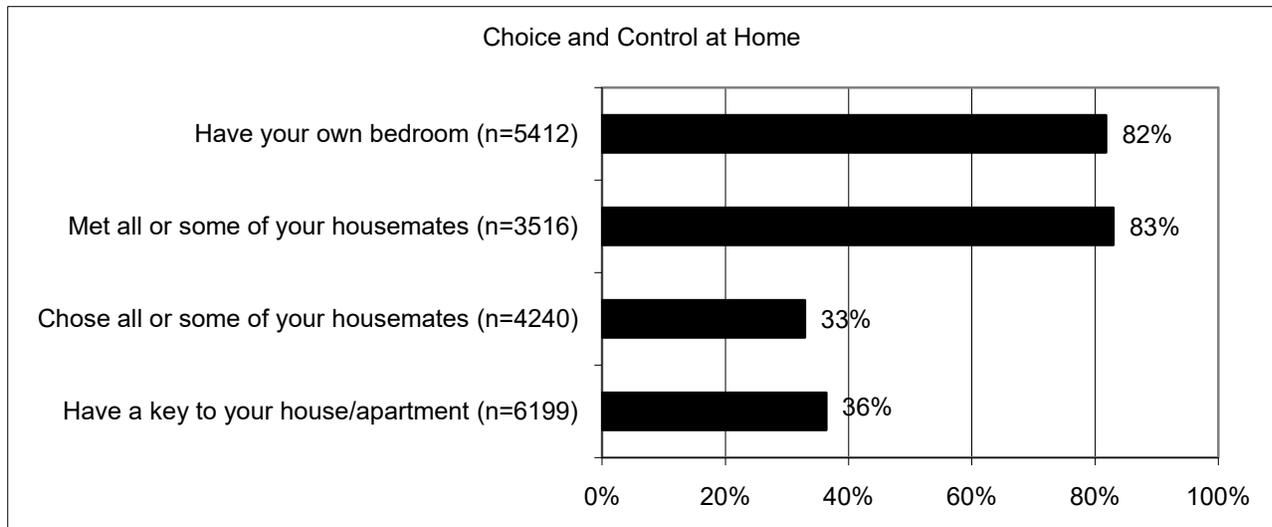
- 45% of the questions were answered by the individual receiving supports
- 29% of the questions were answered by paid staff
- 11% of the questions were answered by the individual and staff
- 9% of the questions were answered by family/friend/advocate/guardian
- 5% of the questions were answered by the individual 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**

- 36% of the individuals surveyed had a key/way to get into to their house or apartment on their own.
- For 54% of the individuals, someone else chose where they live; 19% of those interviewed chose without assistance.
- For those individuals who had some control in choosing where they live, 20% saw no other places, 41% saw one other place, and 39% saw more than one other place before moving in.



- 67% of the individuals **did not** choose their housemates.
- 83% 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, 41% chose some or all of their roommates.
- For 81% of the individuals interviewed, their mail is never opened without permission; 12% say their mail is always opened without permission.

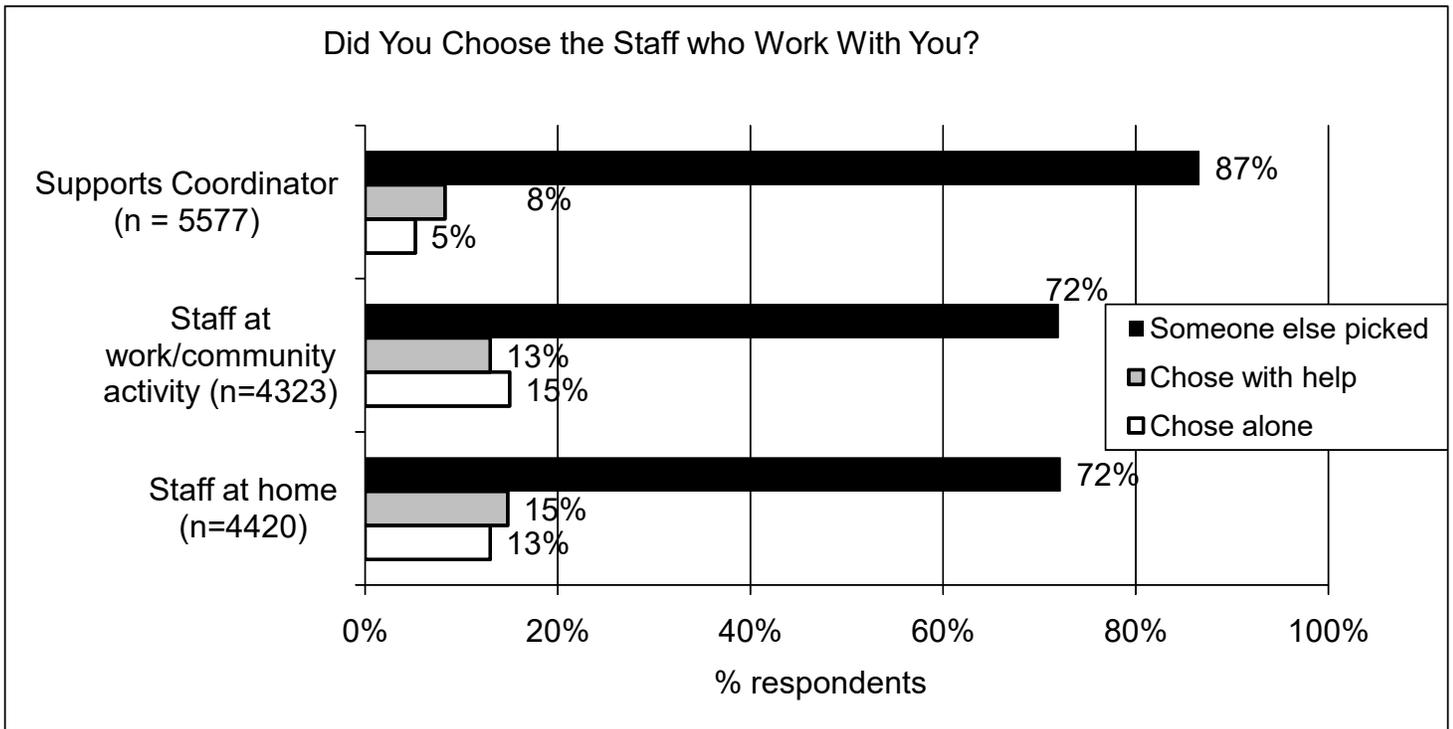


### ***Choice and Control During the Day and for Leisure Time***

- 35% of the individuals interviewed reported that someone else chose what they do during the day
- 33% 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, 15% saw no other places, 45% saw one other place, and 40% saw more than one other place before deciding
- 58% of the individuals surveyed chose their daily schedules without assistance
- 69% chose how they spend their free time without assistance

### ***Choice and Control in Choosing Staff***

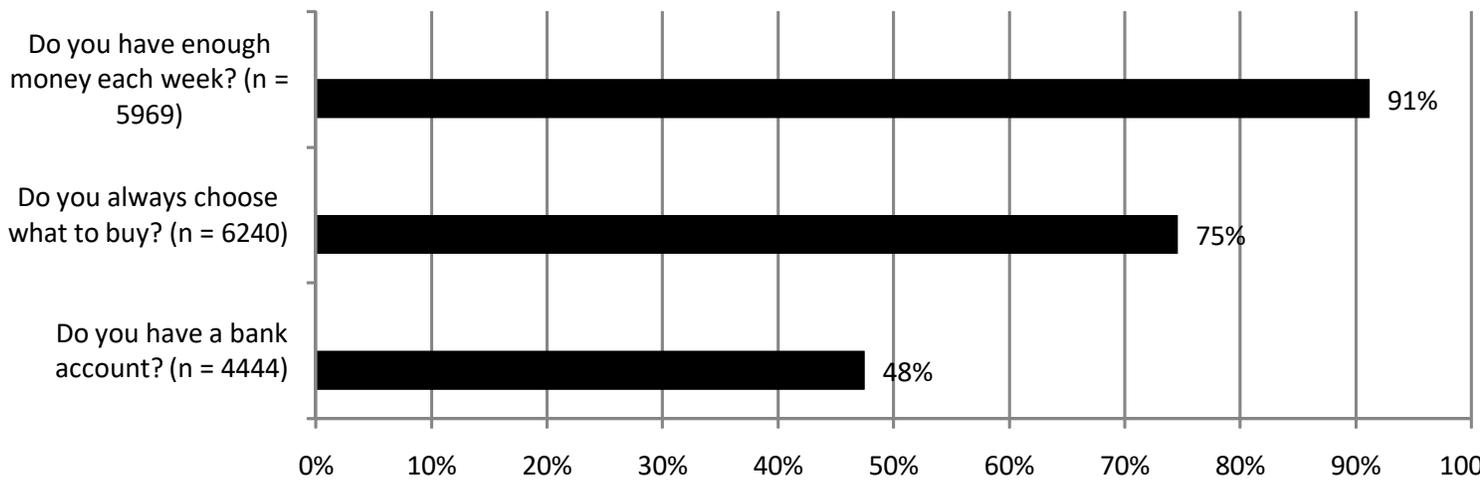
- 28% of the individuals interviewed/chose at least some of the staff who help them at home (alone or with assistance from family or provider).
- 28% of the individuals surveyed interviewed/chose the staff who help them at work/day activity (alone or with assistance from family or provider).
- Only 14% of individuals chose their supports coordinators (alone or with assistance from family or provider).



***Choice and Control with Regard to Money***

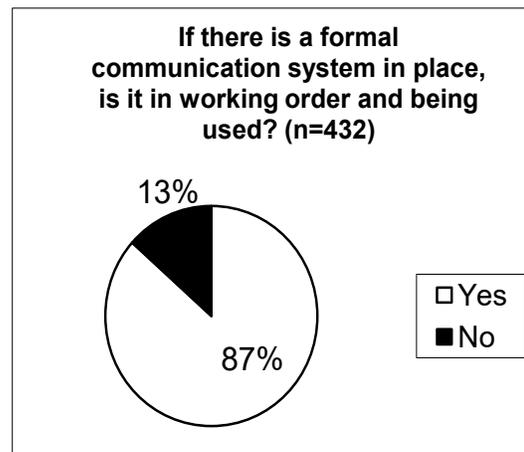
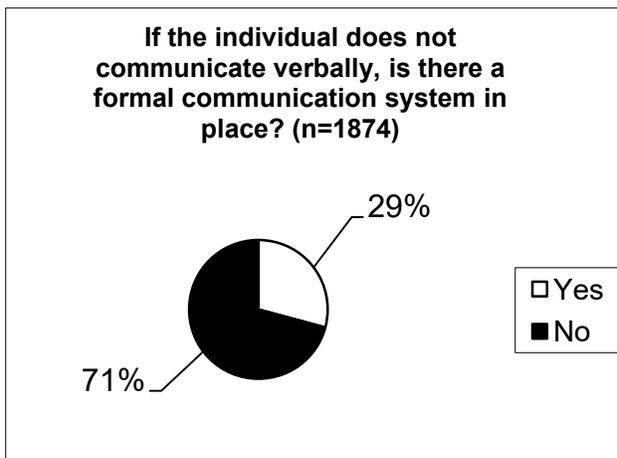
- 91% of the individuals have enough money to do many of the things they want to do each week
- 75% of the individuals reported that they always choose what to buy with their spending money
- 48% of the individuals reported they have a bank account that they can get to independently to withdraw money when they want it.

## Choice and Control Regarding Spending Money



### Access to Communication

- For those individuals who do not communicate using words, there is a formal communication system in place for 29% of the people interviewed
- For those people with formal communication systems in place, the systems are in working order and utilized for 87% of the people interviewed
- 73% of individuals with a formal communication system reported using it across all settings



- With regard to forms of communication individuals have and use, 81% have and use cable television, 17% cell phones, 15% internet, 11% email, and 8% text messaging.

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

- The average (mean) score was 48.19 with a standard deviation of 21.54
- The modal score was 52.63, indicating the most frequent score

There were some significant differences regarding this year's data in this section when compared with the data from 2007-08.

- There was a 10% **increase** in the percentage of individuals who chose where they live without assistance.
- There was a 6% **increase** in the percentage of individuals who chose their housemates.
- There was a 4% **increase** in the percentage of individuals who chose some or all of their roommates.
- There was a 3% **increase** in the percentage of individuals whose mail is never opened without permission.
- There was a 3% **decrease** in the percentage of individuals who had someone else choose what they do during the day.
- There was a 15% **increase** in the percentage of individuals who chose what they do during the day without assistance.
- There was a 3% **decrease** in the percentage of individuals who chose their daily schedules without assistance.
- There was a 3% **increase** in the percentage of individuals who chose at least some of the staff who help them at home.

- There was a 3% **decrease** in the percentage of individuals who chose at least some of the staff who help them at their work/day activity.
- There was a 9% **increase** in the percentage of individuals who chose their supports coordinators.
- There was a 4% **decrease** in the percentage of individuals who have a formal communication system in place if they do not communicate using words.
- There was a 4% **increase** in the percentage of individuals with a formal communication system in place which is in working order and is utilized.

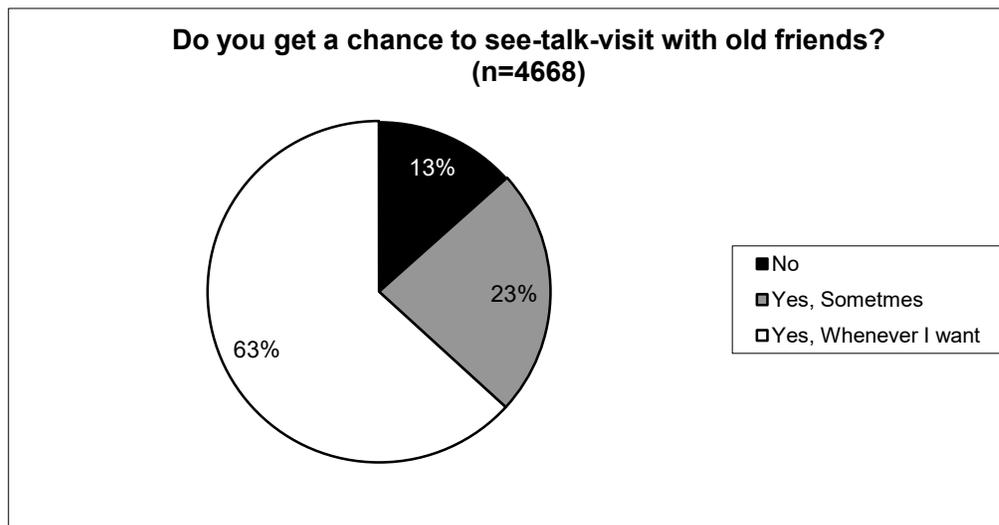
## Relationships

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

- 43% of the questions were answered by individuals receiving supports
- 32% were answered by paid staff
- 11% were answered by individuals receiving support and staff
- 8% were answered by family/friend/guardian/advocate
- 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.”

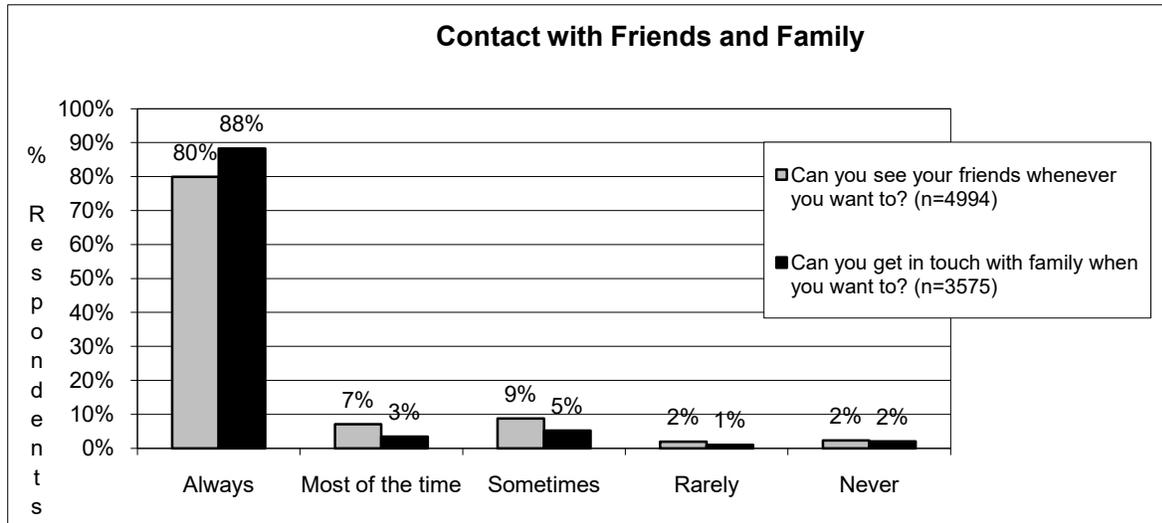
## **Friendships**

- 63% of people answered that they can see-talk-visit with old friends whenever they want.



### Contact with Friends and Family

- 80% of individuals were always able to see friends whenever they wanted
- 88% of respondents were always able get in touch with family whenever they wanted



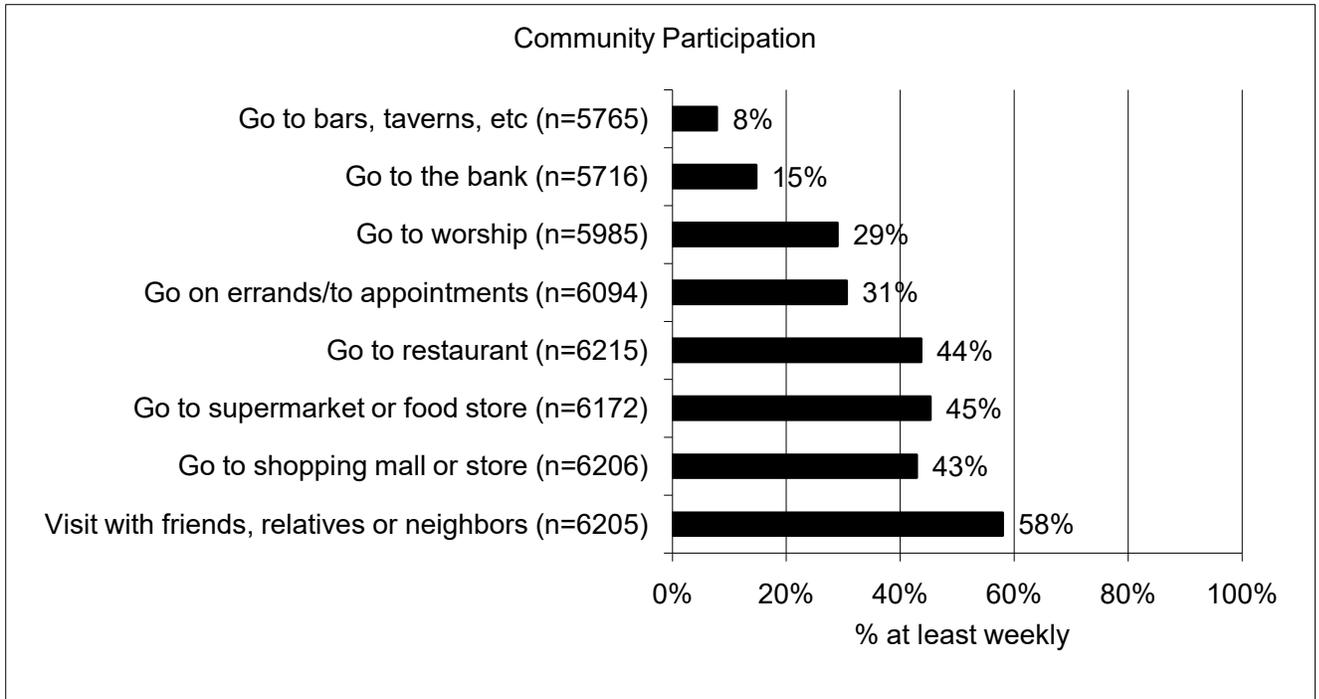
## **Inclusion**

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

- 42% of the questions were answered by individuals receiving supports
- 30% were answered by paid staff
- 12% were answered by individuals receiving support and staff
- 9% were answered by family/friend/guardian/advocate
- 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.”

## ***Community Participation***

- 58% of the people visited with friends, relatives and neighbors at least weekly
- 45% of those surveyed went to a supermarket at least weekly
- 44% of respondents went to restaurants at least weekly
- 43% of individuals went to a shopping center or mall at least weekly
- 29% of respondents went to places of worship at least weekly
- 31% 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 IM4Q 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) in the Harris Poll
- Pennsylvanians with disabilities in the IM4Q sample 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**

	<b>Harris: People without Disabilities</b>	<b>Harris: People with Disabilities</b>	<b>Independent Monitoring</b>
<b>Visit with friends, relatives, and neighbors</b>	85%	70%	58%
<b>Go to supermarket</b>	83%	55%	45%
<b>Go to restaurant</b>	59%	40%	44%
<b>Go to worship</b>	47%	30%	29%
<b>Go to shopping mall or store</b>	41%	23%	43%

***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 42.26 with a standard deviation of 15.63
- 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.

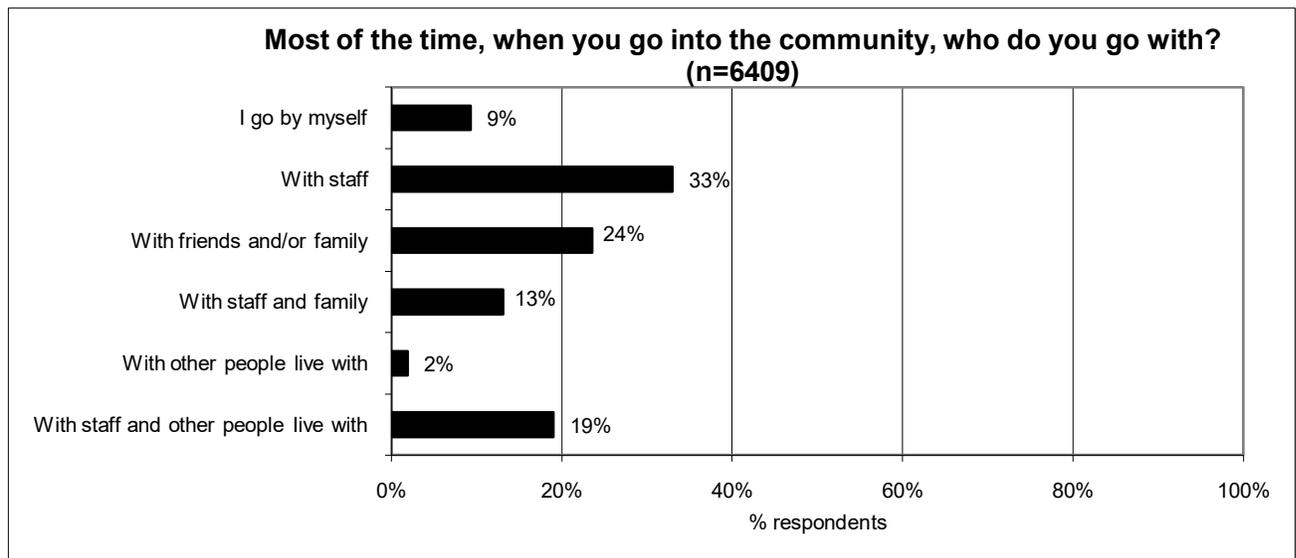
## **Community Activities**

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

- 56% of individuals go frequently into the community for entertainment and 28% go occasionally.
- 39% of individuals reported that they frequently go to social events in the community that are attended by people with and without disabilities and 36% go occasionally.
- 51% of individuals went on a vacation in the past year.
- Regarding monthly exercise, 41% of individuals reported never going out for exercise, 9% exercise less than weekly, 11% exercise once a week and 39% exercise more than once a week.

## **Going Out Alone or With Other People**

- 9% of individuals go out alone; 24% go out with friends and family.
- 52% of individuals go out with staff or staff and other people they live with most of the time.



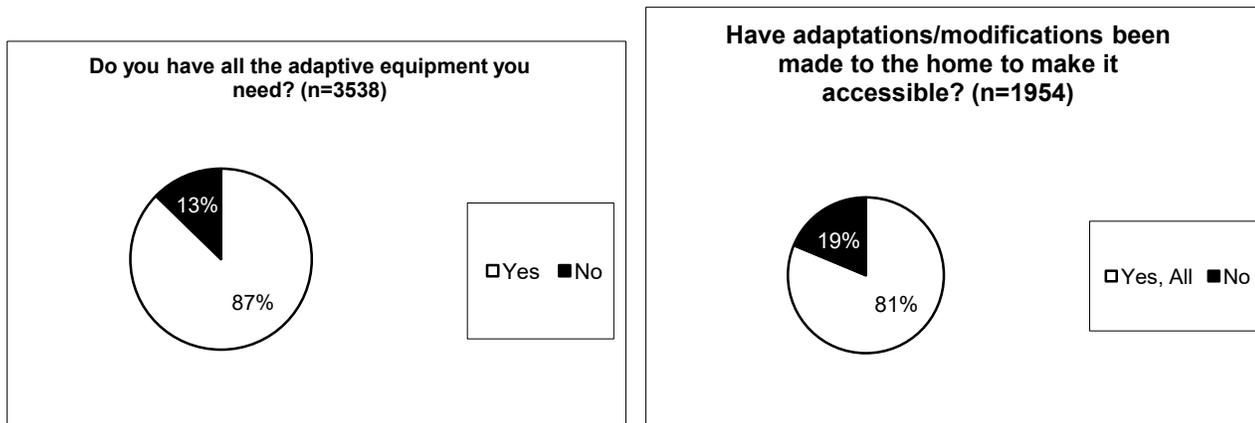
## **Transportation**

- 68% of individuals always had a way to get where they wanted to go.

- Of those who cannot always get where they want to go, 31% cannot get where they want to go because there is not enough staff.

### **Home Adaptive Equipment**

- 87% of individuals reported having all the adaptive equipment they needed
- 81% of people said that all necessary modifications have been made to their home to make it accessible

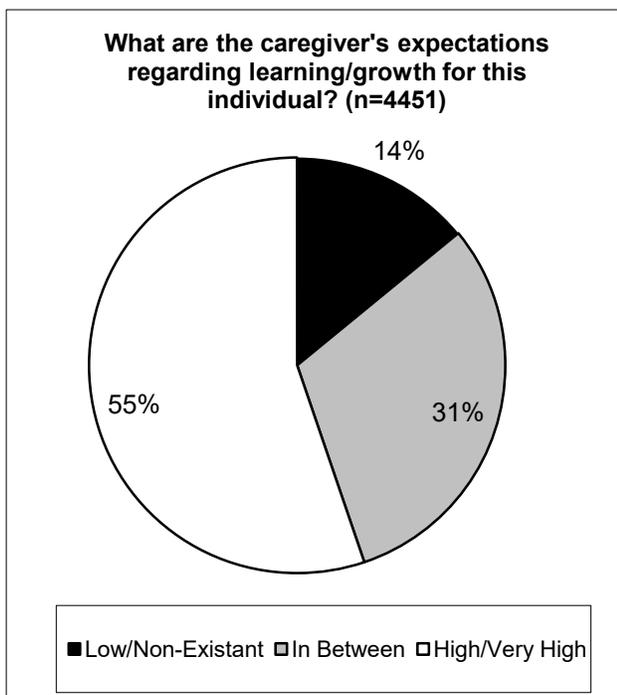


This year's responses to the items in the inclusion section of the survey yielded some significant differences compared with the data from 2007-08. Some differences were noted:

- There was a 3% **decrease** in the percentage of individuals who went to a supermarket at least weekly.
- There was a 3% **decrease** in the percentage of individuals who go out with staff or staff and other people they live with most of the time.

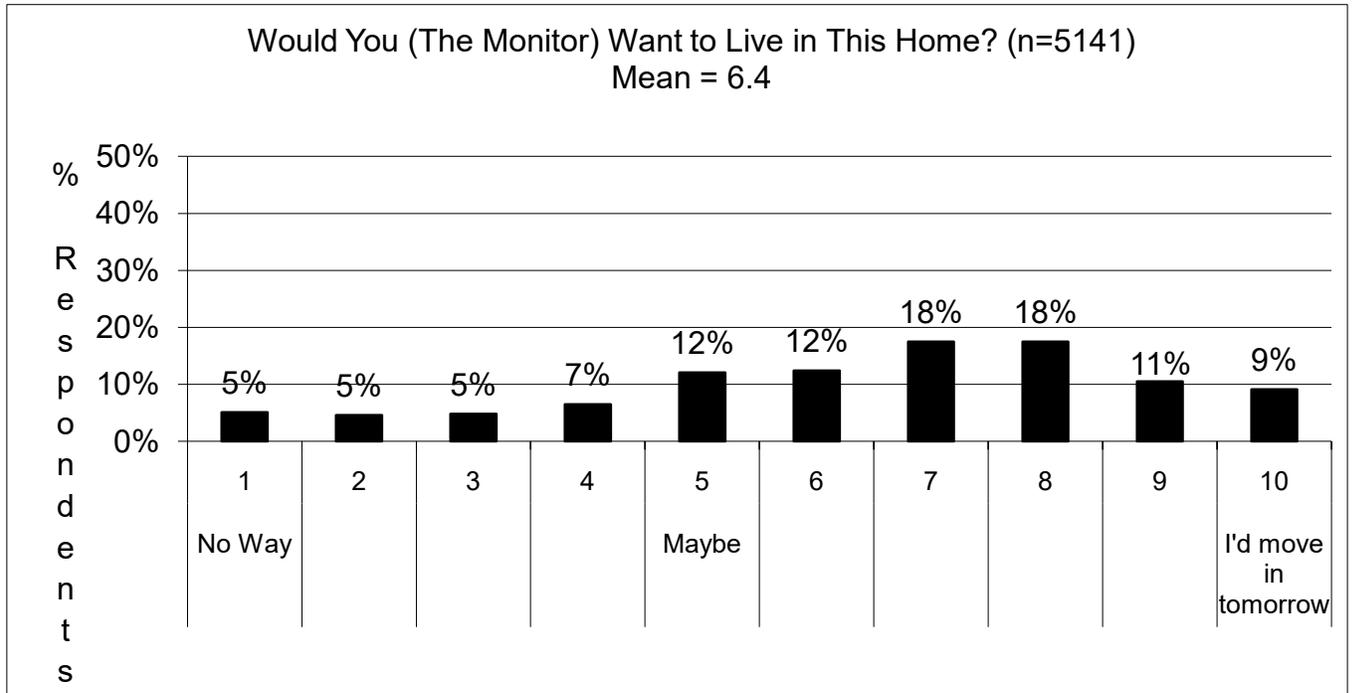
## **Competence, Personal Growth and Opportunities to Grow and Learn**

**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,

- Caregiver expectations regarding growth were reported as being high or very high for 55% of the individuals
- When asked whether team members would want to live in the individual's home on a scale of 1 ("No way") to 10 ("I'd move in tomorrow"), the average score was 6.4



There was one significant difference regarding responses to the items in the Competence, Personal Growth, and Opportunities to Grow and Learn section of the 2007-2008 report:

- Caregiver expectations regarding growth were reported as being high or very high for 55% of the individuals this year compared to last year's result of 51%. This yields a 4% **increase**.

### **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 the IM4Q teams,

- The majority of individuals had either all staff (87%) or some staff (13%) with the skill needed to support them.
- Staff treated individuals with dignity and respect in 96% of observed cases.
- 84% of staff observed recognized the individuals in ways that promote independence

Compared to the Staff Support for the Person section of the 2007-2008 report, there was one significant difference:

- There was a 3% **increase** in the percentage of individuals who had all staff with the skill needed to support them and a 4% **increase** in the percentage of individuals who had some staff with the skill needed to support them.

### **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 (76%), although some took place at work/day activity (20%).

#### ***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 (90%)

#### ***Personal Belongings and Personalities***

According to IM4Q teams,

- Most individuals (96%) 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 96.14 with a standard deviation of 11.93
- 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 2007-2008 report, there was no significant difference.

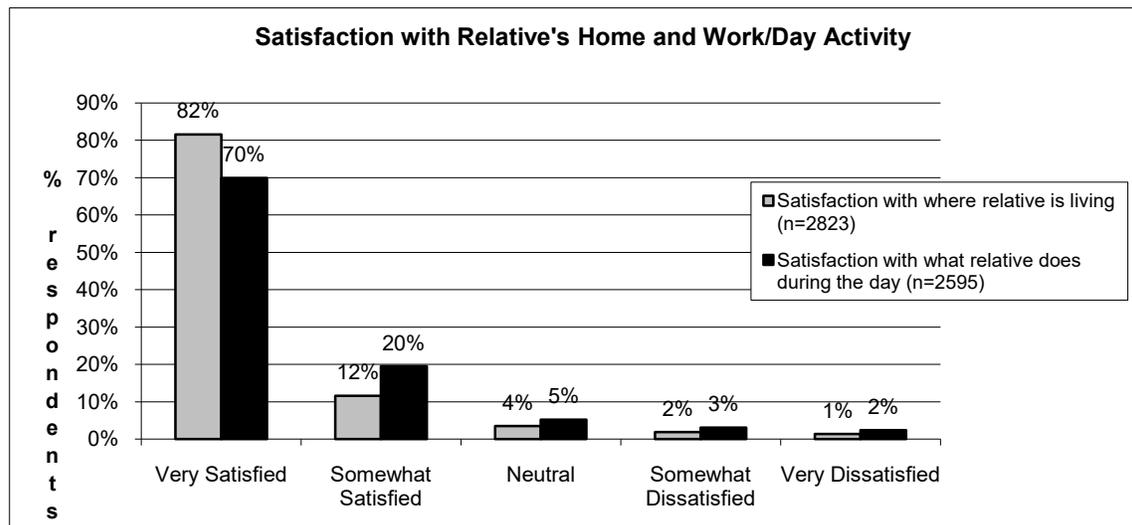
## **Family/Friend/Guardian Survey**

**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. 2896 family members, friends, and guardians participated in the survey.

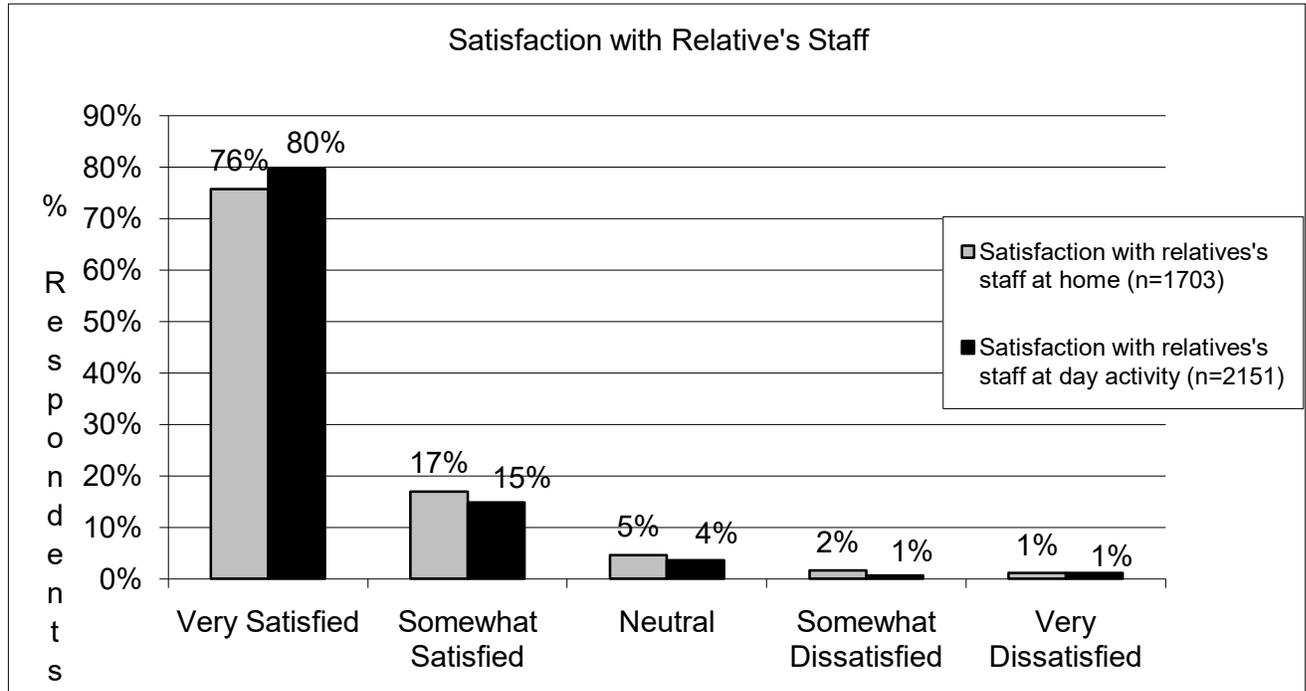
- 67% of the surveys were answered by parents
- 20% were answered by siblings
- 2% were answered by the guardian
- 1% were answered by a friend
- 5% were answered by another relative (spouse, aunt, uncle, cousin, grandparent)
- 5% were answered by persons with other relationships to the individual receiving supports.

### **Satisfaction**

- 93% of the families surveyed were either somewhat satisfied or very satisfied with where their relative lives.
- 89% were either somewhat 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
- 95% of the families surveyed were either somewhat satisfied or very satisfied with the staff at their relatives' day activity

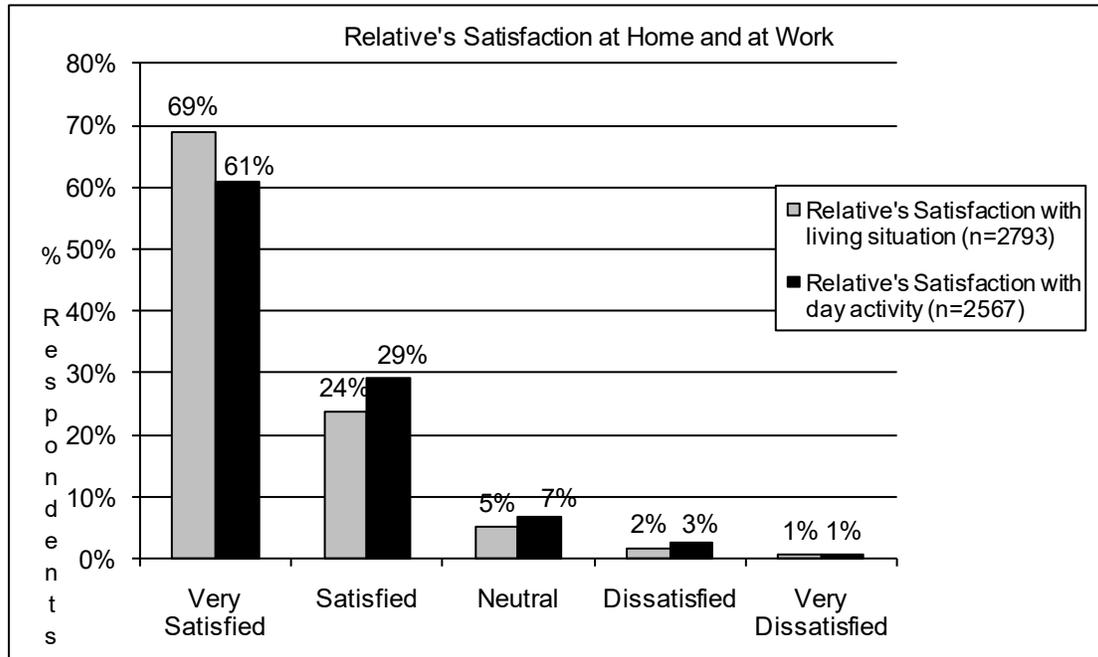


### ***How Often Do You Contact/See Your Relative?***

- 88% of the family/friend/guardians contacted their relative at least monthly; 3% have not contacted their relative in the past year.
- 76% 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; 3% did not get to see their relative in the past year.

### ***Your Relative's Satisfaction***

- 93% of respondents felt their relative was either very satisfied or satisfied with his/her living situation; 90% felt their relative was either very satisfied or satisfied with what they do during the day



- 95% of relatives felt their relative was either very satisfied or satisfied with the staff who support them at home; 1% believed their relative was either dissatisfied or very dissatisfied.
- 95% of respondents felt their relative was either very satisfied or satisfied with the staff who support them at work (or during the day); 1% believed their relative was either dissatisfied or very dissatisfied.

### ***Your Relative's Safety***

- Respondents said that their relative felt safe in their community/home/neighborhood always (86%) or most of the time (12%).

### ***Your Relative's Opportunities***

- 84% of the respondents said that their relative had enough opportunities to participate in activities in the community.
- 86% of the respondents said that their relative seemed to have the opportunity to learn new things.

### ***Your Relative's Staff***

- If their relative did not communicate verbally, 34% of the respondents said that there is a formal communication system in place for their relative and they use it and for 52% the communication system is used across all settings.
- 89% of the respondents said that their relative's home appeared to have an adequate number of paid staff.
- 94% of the respondents said that staff in their relative's home always treat people with dignity and respect.
- 85% of the respondents said that all staff appear to have the skills they need to support their relative; 13% felt that way about only some staff.

### ***Relative's Supports***

- 85% of relatives interviewed said that their supports coordinator/QMRP is always available to assist them if there is a crisis.
- 84% 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.
- 86% of relatives always felt that the staff who assisted them with planning respected their choices and opinions.
- 62% of relatives *never* felt that frequent changes in support staff were a problem for their family member.
- 28% of relatives always got to choose the agency/provider who worked with their relative; 6% had their relative choose; 50% never got to choose.
- 63% of relatives were familiar with the way complaints and grievances are handled; 37% were not familiar.

***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 89.73 with a standard deviation of 13.95
- The mode (the value that occurs the most frequently) was 100, indicating that many of the families' (40%) satisfaction levels were at the top of the scale on all measures of family satisfaction

Compared to the Family/Friend/Guardian section of the 2007-2008 report, there were several significant differences.

- There was a 3% **increase** in the percentage of individuals who reported that all staff appear to have the skills needed to support their relatives and a 3% **decrease** in the percentage of individuals who reported that only some staff appear to have the skill needed to support their relatives.
- There was a 4% **decrease** in the percentage of individuals who *never* felt that frequent changes in support staff was a problem for their family member.
- There was a 14% **decrease** in the percentage of relatives who always got to choose the agency/provider who worked with their relative.

## **Summary**

This report presents information collected through face-to-face interviews with 6618 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. However, the percentage of individuals who reported feeling happy overall decreased from the previous year. There was a significant decrease in the percentage of individuals who reported that they do not vote. A quarter of individuals interviewed who do not vote, would like to vote. Individuals report high levels of privacy.

The majority of individuals report that they get the services and supports they need to be able to live in their homes. More than half of all individuals and families report that they were told how much money is in their annual budget. The monitoring teams observed that staff treat 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.

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 system in place. When it has been explored and people have acquired systems including devices, for some people the devices are not in working order or being used across all settings.

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

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.