

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

***Independent Monitoring for Quality (IM4Q)***  
***A Statewide Summary***  
***2004-2005***

**Submitted to:** Pennsylvania Office of Mental Retardation  
Statewide Steering Committee on Independent  
Monitoring

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## **Introduction**

In 1997, Pennsylvania's Office of Mental Retardation (OMR) began to disseminate its Multi-Year Plan, which represented a significant effort by OMR to convey its vision, values and goals for the ensuing years. The Plan, developed by OMR'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 OMR staff. The Developmental Disabilities Council, in collaboration with OMR, 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 OMR.

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 the Office of Mental Retardation 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 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). A copy of this report can be accessed from the Department of Public Welfare's (DPW) Website at: [www.dpw.state.pa.us/omr](http://www.dpw.state.pa.us/omr). The 2000-01 report was used as the basis of a 2002 State Report of Independent Monitoring for Quality that is also available on the OMR web page. 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 OMR Planning Advisory Committee (PAC).

During fiscal year 2000-2001, all 46 County MH/MR programs 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 County MH/MR programs continued to contract with local entities to assist them in fulfilling their obligation under IM4Q; most county programs 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 County MH/MR programs 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.

This year, 2004-2005 the total of face-to-face interviews completed increased by slightly more than one hundred. A total of 6499 face-to-face interviews were conducted. A total of 3010 interviews were conducted with family, friends and guardians, also an increase from the previous year.

Surveys were conducted from September 2004 until June 30, 2005 using a standardized instrument and methodology developed in conjunction with the State IM4Q Steering Committee and the Office of Mental Retardation. Revisions to the instrument were made from previous years, based on feedback from the local programs, as well as from the statewide steering committee, counties, regional office staff and the technical advisors.

## **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 99 questions, 40 of which can only be answered by the individuals receiving supports and services.

The EDE for fiscal year 2004-2005 includes all survey questions included in the FY 2004-2005 NCI Consumer Survey. At the time of this report, approximately thirteen

hundred eighty (1380) individuals included in this report are represented in the NCI sample for 2004-2005, based on a sampling methodology established by the OMR and HSRI. A copy of the NCI report for FY 2004-05 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 County MH/MR Program 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 County MH/MR Program for only those individuals who were designated as part of the NCI sample. The addendum provides demographic information, along with information about the individual's degree and type of disability(ies), work and day activity routines.
- **Satisfaction** – this section was only to be completed based on the responses of the individual receiving supports. Questions were asked about satisfaction with where the individual works and lives, as well as with staff who support the individual.
- **Dignity, Respect and Rights** – this section was also only to be completed based on responses of the individual receiving supports. Questions were asked about whether roommates and staff treated people with respect, whether people were afforded their rights, and whether they had fears at home, at work or in the community.
- **Choice and Control** – the questions in this section were answered by the individual, or by a family member, friend or staff person. Questions were asked about the extent to which individuals exerted choice and control over various aspects of their lives.
- **Relationships** – the questions in this section were answered by the individual, or by a family member, friend or staff person; questions were asked about friends, family and neighbors, and individuals' opportunity to visit and contact them.
- **Inclusion** – the questions in this section were answered by the individual, or by a family member, friend or staff person. Questions were asked about opportunities for community inclusion; a section of the Harris Poll was included for comparative purposes at the national level.
- **Monitor Impressions** – this section of the survey was completed by the Independent Monitoring team, after they had completed their visit. Questions were asked in the areas of physical setting, staff support and opportunities for growth and development.
- **Major Concerns** – this form was to be completed whenever there was an issue related to physical danger, significant sanitation problems, or evidence of physical or

psychological abuse or neglect. Each project was required to develop a mechanism for communicating this information. In the event of imminent danger, teams were instructed not to leave the home until resolution of some kind was achieved.

- **Family/Friend/Guardian Survey** – a survey was conducted with each family once the individual gave his/her approval. Questions related to the families' satisfaction with their relatives' living situation, as well as perceived satisfaction of their relatives. The survey was conducted either by phone or face-to-face at the time of the EDE interview.

## **Sample**

Independent Monitoring focuses on the quality of services and supports to children ages three and over, and to adults supported by the Mental Retardation system. In Fiscal Year 1999-2000, the sample for IM4Q was restricted to individuals living in licensed residential settings in 19 County MH/MR Programs, 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 county. Counties were instructed to draw a random sample of approximately one-third of the individuals living in licensed residential settings. County MH/MR programs were provided with written instructions for drawing the entire Fiscal Year 2001-02 sample; once the sample was selected, OMR 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 county 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 Home and Community-based Services Information System (HCSIS), OMR's computerized database continues to be used to enter IM4Q data as well. This year's sample included 5180 people. 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 lived in supervised living settings. Many people in the sample live at home with families, due to the sub-sample of people receiving supports through the PFDS waiver.

	<b>N</b>	<b>Percent</b>
State-Operated ICF/MR	21	0.3%
State MH Hospital	4	0.1%
Homeless	0	0%
Temporary Shelter	5	0.1%
Foster Care	13	0.2%
Nursing Home/Facility	96	1.5%
Domiciliary Care	56	0.9%
Personal Care Home	213	3.3%
Family Living	403	6.2%
Unlicensed Family Living	24	0.4%
Own Residence	542	8.4%
Relatives Home	1792	27.7%
Children's Facility	7	0.1%
Approved Private School	7	0.1%
Private ICF/MR <4	54	0.8%
Private ICF/MR 5-8	158	2.4%
Private ICF/MR 9-15	30	0.5%
Private ICF/MR 16+	234	3.6%
Community Home 1	79	1.2%
Community Home 2-4	2275	35.1%
Community Home 5-6	249	3.8%
Community Home 7-8	71	1.1%
Community Home 9-15	32	0.5%
Community Home 16+	21	0.3%
Other	90	1.4%
<b>Total</b>	<b>6476</b>	<b>100%</b>

(\*Residential setting type was missing for 23 people)

## **Procedure**

### Selection of Local IM4Q Programs

OMR requested that counties 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 County MH/MR Programs from a variety of organizations, including non-service providing chapters of the Arc (formerly The Association for Retarded Citizens), Consumer Satisfaction Teams (in the mental health system), parent groups, universities and colleges, Centers for Independent Living and newly formed entities.

### Training

Local IM4Q Programs received training on the EDE, F/F/G Survey and interviewing protocols from technical assistants from the Institute on Disabilities at Temple University. Trainings were held in each of the four regions for project staff and data collectors, wherever possible. Additional training was provided on a county-by-county basis for data collectors, as requested. Data entry instruction was provided by the Office of Mental Retardation.

### Team Interview Process

Once the sample was drawn, a list of individuals to be monitored was forwarded to the Local Independent Monitoring for Quality Program by OMR. In some cases, the county completed the pre-survey forms. In other cases, the local program completed the pre-survey forms with family members, supports coordinators or directly with providers. Once the pre-survey forms were completed, the local IM4Q Program assigned interviews to 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 also included other interested citizens who are not part of the mental retardation system. Visits to individuals' homes were scheduled with the individual, or with the person designated on the pre-survey form.



Participation in the interview was voluntary; if an individual refused to participate, s/he was replaced in the sample with another individual. The interview was meant to take place at the home of the individual, but if s/he preferred that the interview take place elsewhere, alternate arrangements were made. The interview was to be conducted in private whenever possible, unless the individual expressed a desire to have others present. Once the interview was completed, if the individual gave his/her permission a survey was conducted with the family/friend/guardian, either face-to-face (at the time of the interview) or by phone.

After the EDE was completed by the IM4Q team, the completed Essential Data Elements forms were returned to the local IM4Q Program for data entry.

Family/Friend/Guardian data were collected either by the interview team or by staff of the local IM4Q program. EDE and F/F/G Survey data were entered directly onto the HCSIS website. Data were to be collected by June 30, 2005 and entered via HCSIS by August 1, 2005. A usable data file was received by the Institute on Disabilities in mid-August, 2005. This report presents data on the individuals surveyed by the IM4Q Local Programs, representing the 46 County MH/MR Programs across the state. In addition to this report, each county 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 counties, each local IM4Q Program has developed a process, referred to as “closing the loop”/follow-up activity with the county with whom they contract, to ensure that issues related to individuals, as well as systemic issues on the provider or county level are addressed. This process is an integral part of the quality improvement process since it places quality improvement responsibilities with the County MH/MR Programs and providers of service. “Closing the loop”/follow-up and quality improvement are also facilitated by: provider level reporting in HCSIS which enables providers of service and the counties to

review finalized aggregate IM4Q results and an IM4Q data warehouse in HCSIS which allows county, regional and state personnel to review IM4Q aggregate data based in 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 county/joiner program.

	# of People	Percent
Allegheny	665	10.2%
Armstrong/Indiana	108	1.7%
Beaver	112	1.7%
Bedford/Somerset	87	1.3%
Berks	172	2.6%
Blair	105	1.6%
Bradford/Sullivan	55	0.8%
Bucks	179	2.8%
Butler	104	1.6%
Cambria	99	1.5%
Cameron/Elk/McKean	90	1.4%
Carbon/Monroe/Pike	111	1.7%
Centre	59	0.9%
Chester	169	2.6%
Clarion	51	0.8%
Clearfield/Jefferson	83	1.6%
Columbia/Montour/Snyder/Union	105	1.5%
Crawford	92	1.4%
Cumberland/Perry	98	1.5%
Dauphin	156	2.4%
Delaware	277	4.3%
Erie	259	4.0%
Fayette	89	1.4%
Forest/Warren	43	0.7%
Franklin/Fulton	83	1.3%
Greene	40	0.6%
Huntington/Mifflin/Juniata	90	1.4%
Lackawanna/Susquehanna/Wayne	186	2.9%
Lancaster	164	2.5%
Lawrence	82	1.3%
Lebanon	47	0.7%
Lehigh	158	2.4%
Luzerne/Wyoming	145	2.2%
Lycoming/Clinton	111	1.7%
Mercer	77	1.2%
Montgomery	326	5.0%
Northampton	126	1.9%
Northumberland	90	1.4%
Philadelphia	787	12.1%
Potter	40	0.6%
Schuylkill	93	1.4%
Tioga	46	0.7%
Venango	58	0.9%
Washington	69	1.1%
Westmoreland	159	2.4%
York/Adams	154	2.4%
<b>TOTAL</b>	<b>6499</b>	<b>100%</b>

## **Satisfaction**

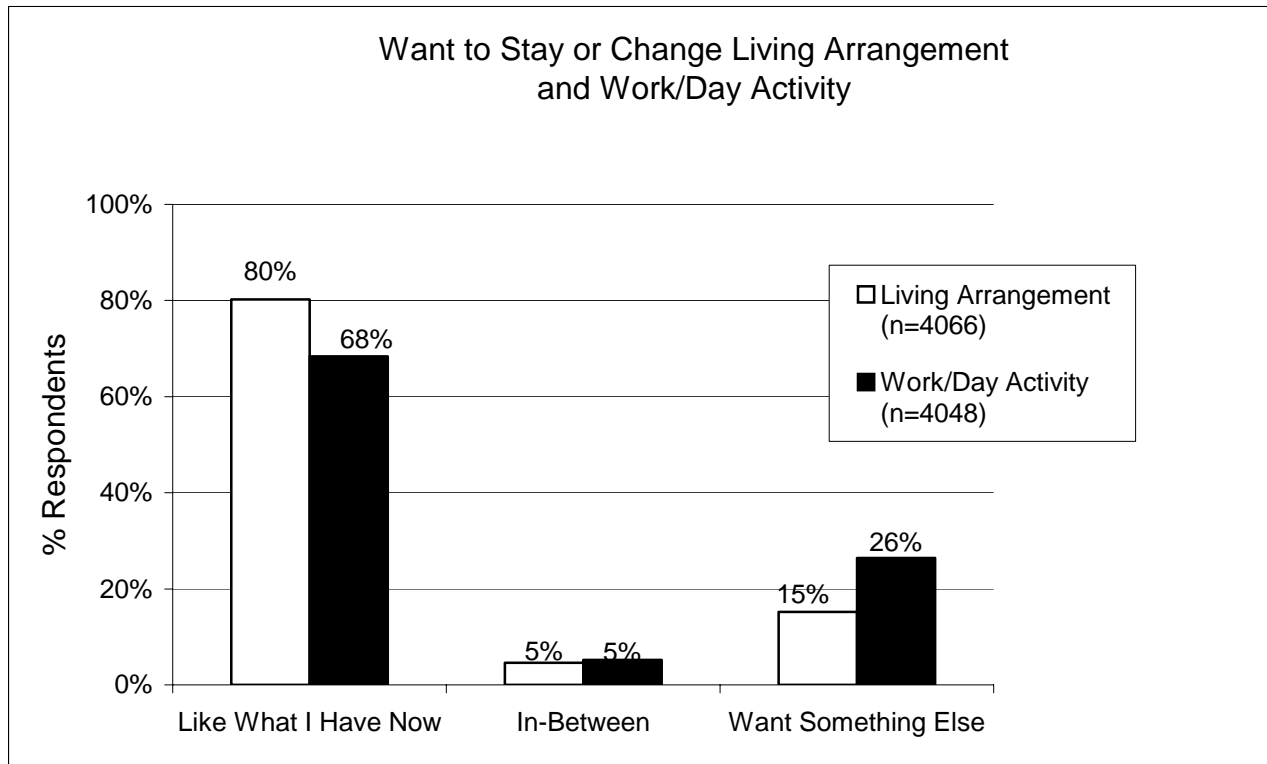
**Respondents:** Only the individual receiving services/supports could answer the questions on satisfaction. The percent of people who responded to questions in this section ranged from 41.7% to 69.4%.

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

- 89% of individuals liked where they live
- 80% wanted to stay where they currently live

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

- 91% of individuals *with* a day activity/work liked what they did during the day
- 68% wanted to continue their current daytime activities/work, but 26% wanted to do something else



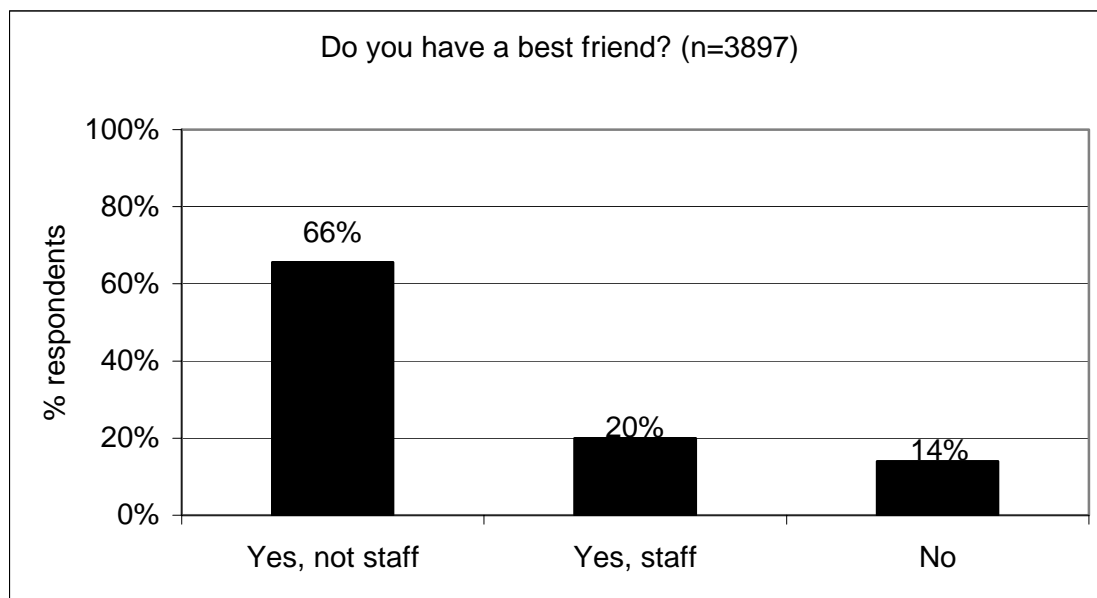
### Daily Life

- 61% of the individuals interviewed always had opportunities to participate in household tasks like cooking and cleaning

	<i>Always</i>	<i>Most of the Time</i>	<i>Sometimes</i>	<i>Rarely</i>	<i>Never</i>
<b>Have opportunities to engage in household tasks (n=4296)</b>	61%	12%	15%	3%	9%

### Happiness and Loneliness

- 74% reported usually feeling happy, 20% reported being in-between, and 6% reported usually feeling sad
- 57% of individuals reported never feeling lonely, 37% reported sometimes feeling lonely, and 6% reported always feeling lonely
- 86% of individuals reported that they have a best friend – for 66% of the people, their best friend is not a staff member
- 59% reported having friends, that are not staff or family, they like to do things with

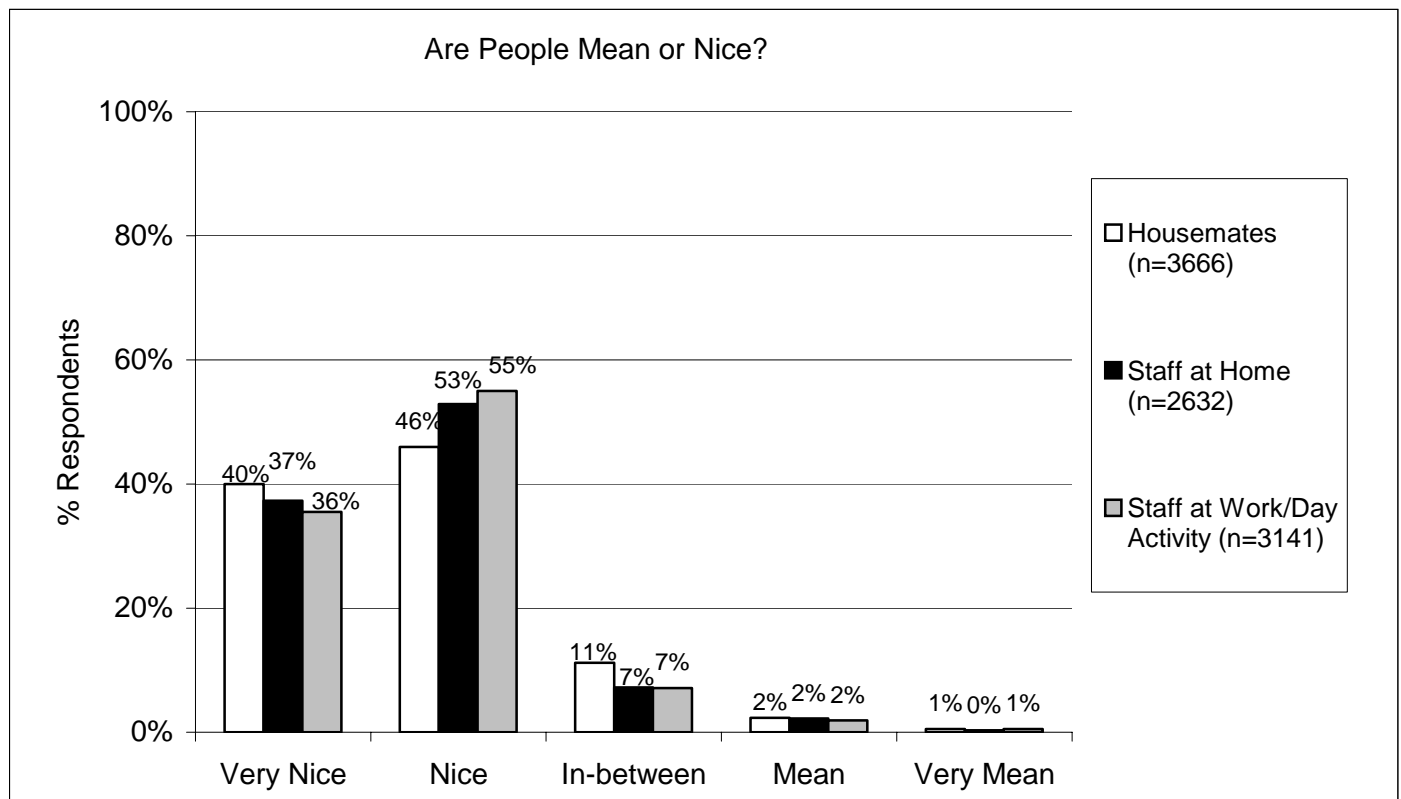


## Privacy

- 85% of the individuals surveyed, reported that they always have privacy (a place to be alone) when they want it
- For 82% 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 73% 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
- 90% of the people interviewed reported that their staff who work with them at home are very nice or nice
- 91% 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. One question previously used in the satisfaction scale was eliminated from the EDE this year; therefore only 6 items were included in the scale.

- The average (mean) score was 83.05 with a standard deviation of 20.58
- 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 2003-2004 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 34.8% to 64.6%.

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

- 55% of individuals stated that they always carry a form of identification; 28% never do

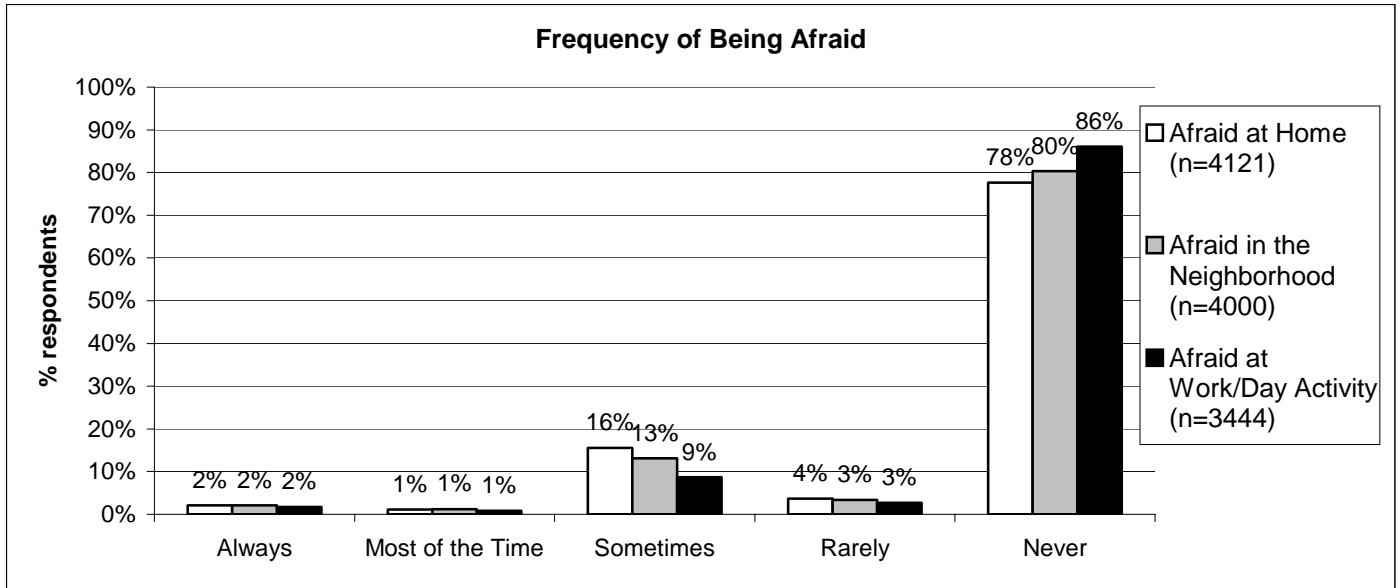
### ***Support with Problems and Goals***

- 88% of individuals always had someone in their life who will try to help make things better
- 40% of individuals go to staff at home for help most of the time, 31% go to family
- 74% reported that people always help them to learn/do new things; 73% want help to learn new things

### ***Being Afraid***

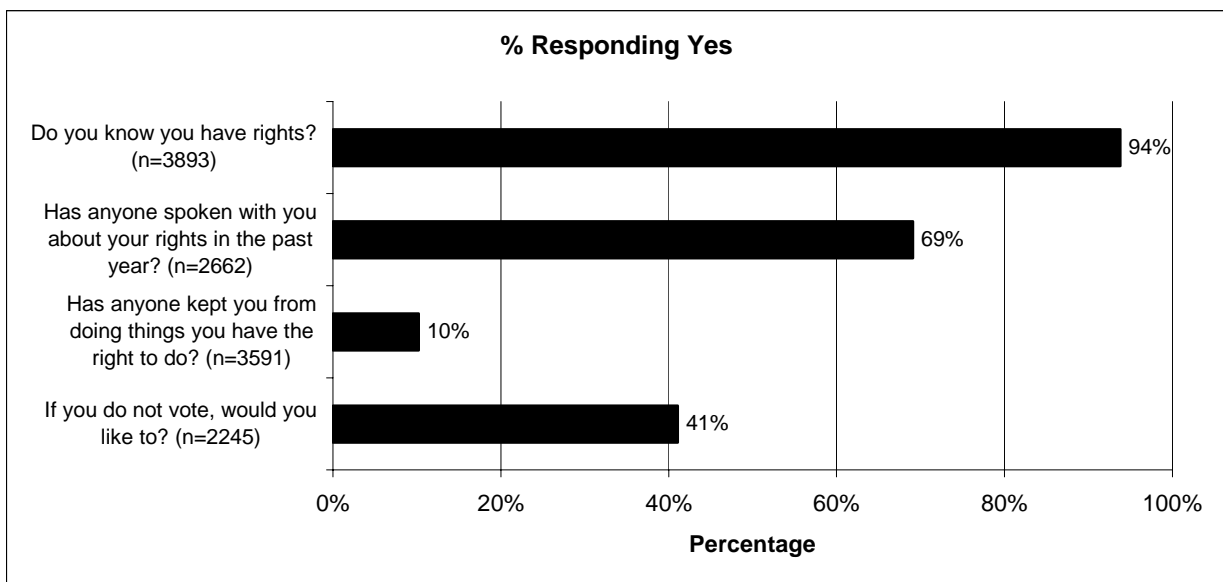
- 78% reported never being afraid at home
- 80% reported never being afraid in the neighborhood
- 86% reported never being afraid at work, school or day activity





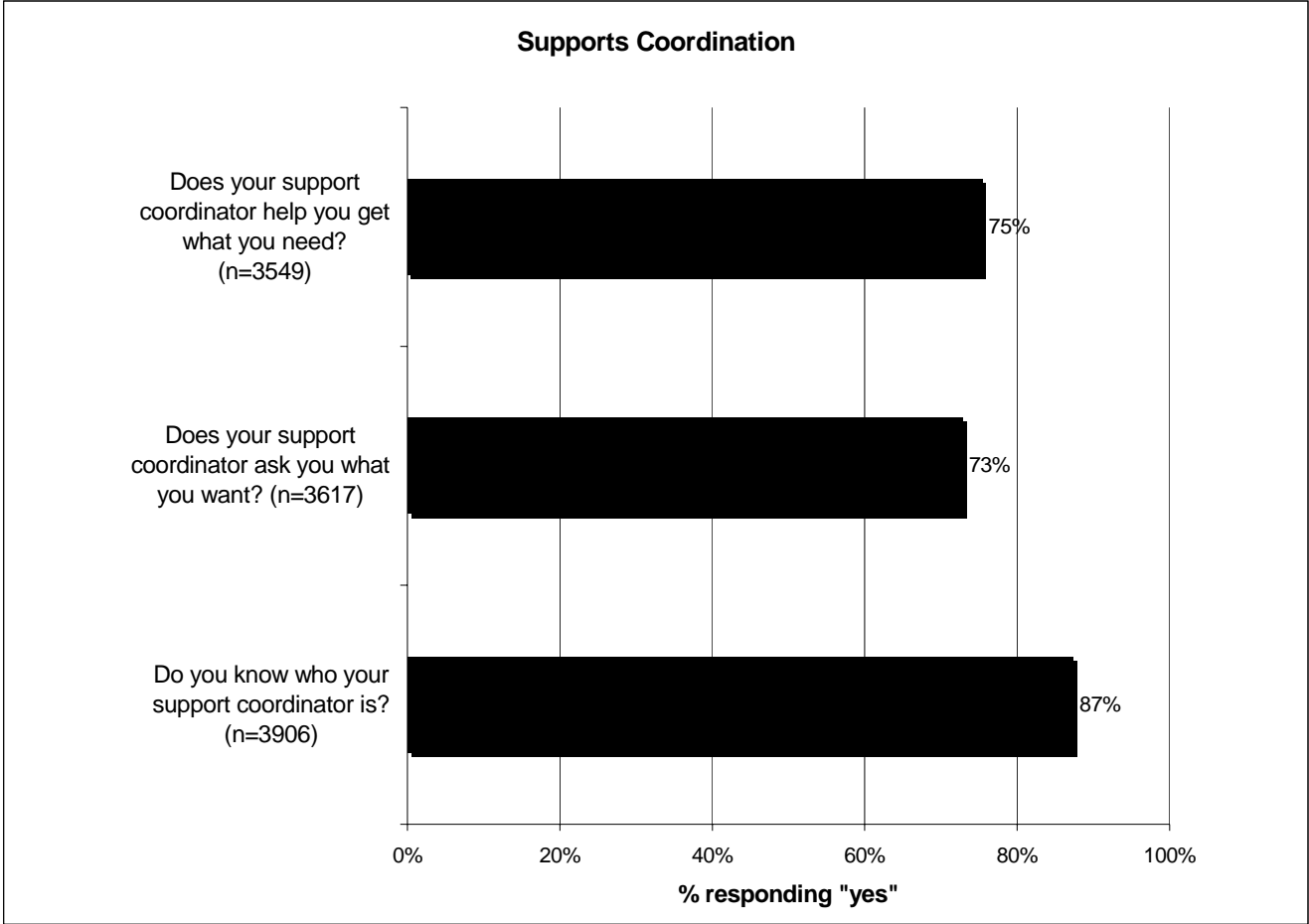
### Legal Rights

- 69% of the people surveyed have had discussions about their rights in the past year
- 94% of individuals know that they have rights regarding religion, friendships, and citizenship.
- 10% of those interviewed reported that someone has kept them from doing things they have the right to do.
- 61% of people said that they do not vote; 41% of these individuals would like to



**Service / Support Coordination**

- 87% of individuals know who their supports coordinator is
- 76% of individuals can always talk to their supports coordinator when they want
- For 73% of individuals, their supports coordinator asks what they want; 75% reported that their supports coordinator helps them get what they need



- 85% of individuals reported getting the services and supports they need.
- 59% of individuals reported that they were told how much money was in their annual budget.

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 81.50 with a standard deviation of 15.92.
- 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.

Compared to the Dignity, Respect and Rights section of the 2003-2004 report, there was one significant difference. The percentage of individuals reporting that they do not vote decreased from 71% to 61%.

It is important to note that 15% of individuals did not get all the services and supports they needed. 41% of individuals report not being told how much money is in their budget.

**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 89.51 with a standard deviation of 18.21
- 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 (65%) 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 staff/consumers

	At Home #	In Neighborhood #	At Work #
Alone	49	18	1
Animals / Insects	39	109	5
Being Scolded / Fear of Being Hurt / People Yelling / Fear of the Unknown	33	26	39
Darkness / Sleep / Nightmares / Night	58	67	6
Emergency Situations / Fire / Fire Alarms	32	7	19
Falling / Sickness / Seizures/ Death	38	23	15
Neighbors / Local kids	7	32	8
Work/school related-Lose job/ New things on job/ Making mistakes	2	2	29
Noises	31	29	18
Staff / Consumers / co-workers	52	4	64
Strangers / Crime	53	75	5
Transportation/ Traffic/ Emergency vehicles	2	42	4
Weather	157	46	16
Houses/ Locked Rooms/ Office/ Stairs/ Elevator/ Escalator	3	0	5
Mythical & Fictional Creatures	18	7	4
Scary Movies/ Halloween / TV /	17	3	1
Other people/ People in general/ Crowds	30	27	38
Fighting/ Violence/ Teasing/ Behavioral Outbursts	7	20	35
Neighborhood/ Getting lost/ Being outside	4	23	2
Other	64	38	10
TOTAL	696	595	324

**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 79.90 with a standard deviation of 31.72
- The mode was 100, indicating that was the most frequently selected response. More than half of the individuals (57%) scored at the top of the scale regarding their relationship with their supports coordinator.

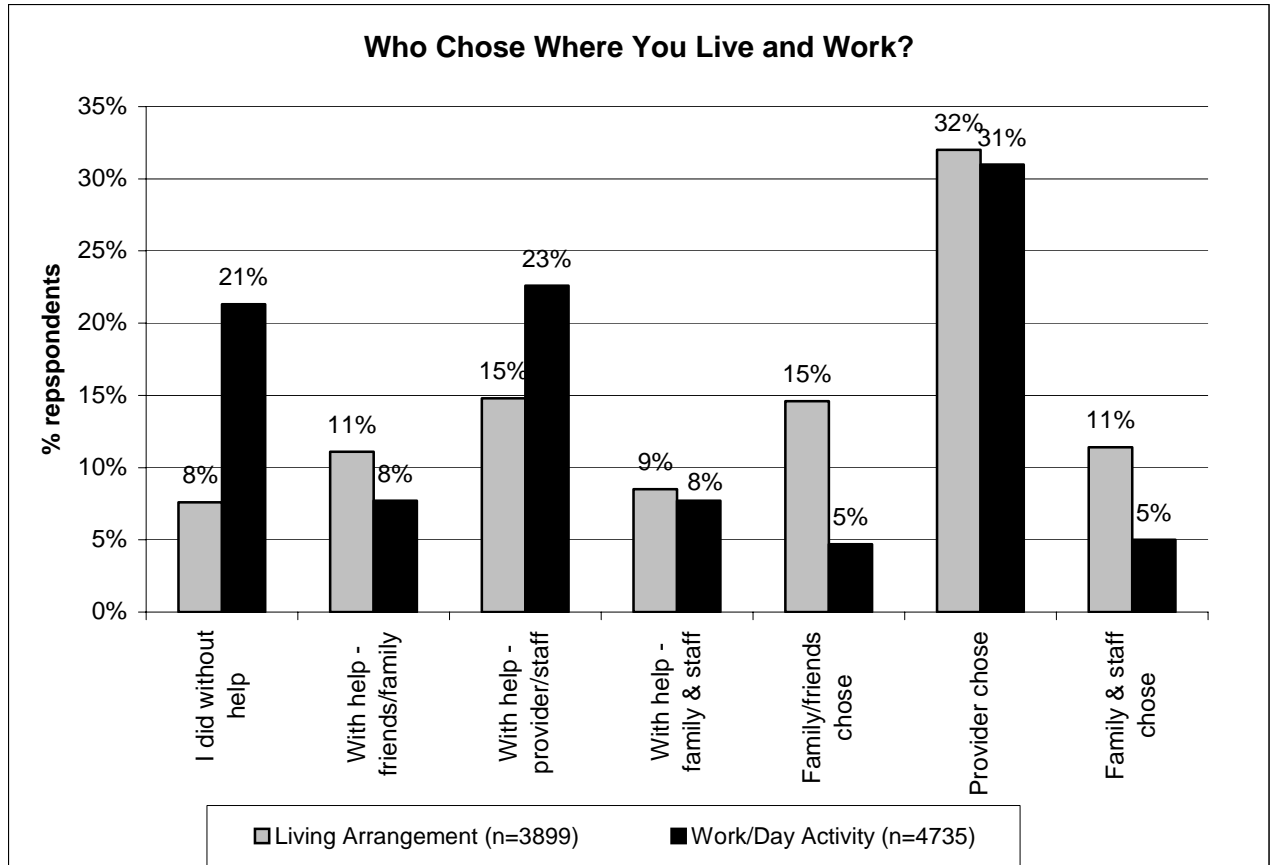
## ***Choice and Control***

**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,

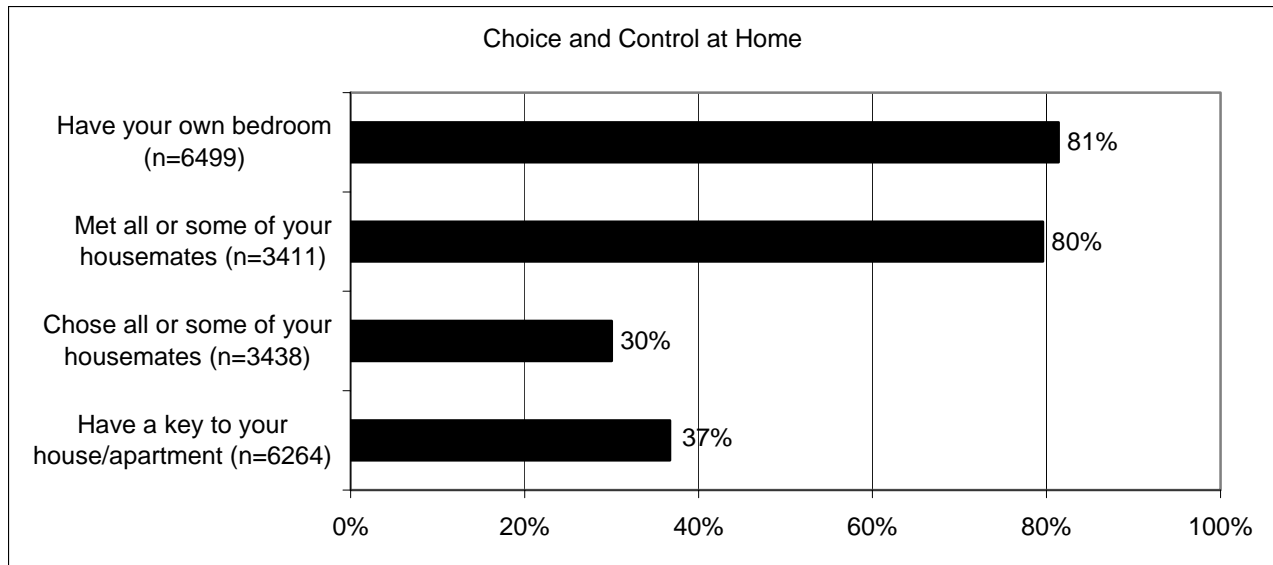
- 42% of the questions were answered by the individual receiving supports
- 28% of the questions were answered by paid staff
- 13% of the questions were answered by the consumer and staff
- 10% of the questions were answered by family/friend/advocate/guardian
- 7% of the questions were answered by the 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***

- 37% of the individuals surveyed had a key/way to get into to their house or apartment on their own
- For 58% of the individuals, someone else chose where they live; 8% of those interviewed chose without assistance
- For those individuals who had some control in choosing where they live, people visited a range of 0 to 9 or more different places before choosing their home, with an average of 1 place visited (67% saw no other places)



- 70% of the individuals did not choose their housemates
- 80% of the individuals surveyed met some or all of their roommates before living together
- 81% of the individuals had their own bedroom; however for those who shared a bedroom, 44% 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
- 91% are allowed to use the phone whenever they want



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

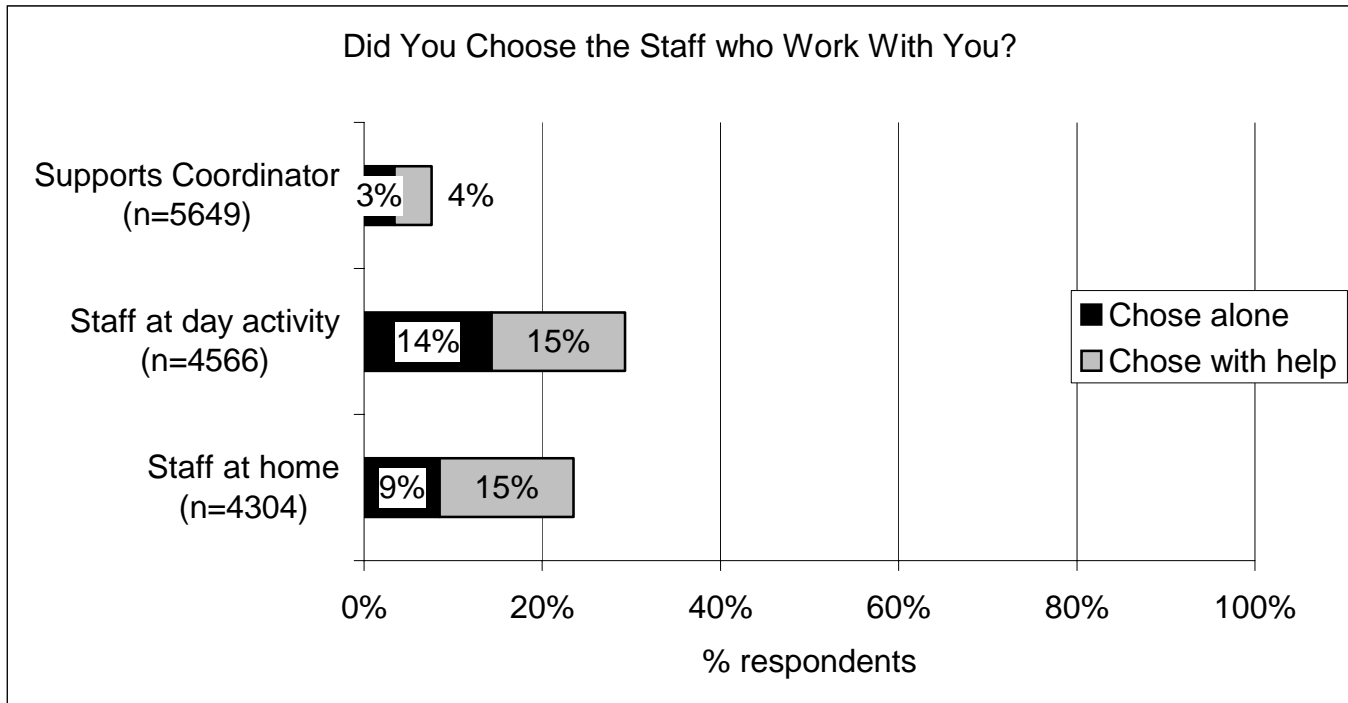
- 41% of the individuals interviewed reported that someone else chose what they do during the day
- For 54% of people, the provider either chose what the individual does during the day or helped the individual decide
- 21% of the people interviewed chose what they do during the day without assistance
- For those individuals who participated in choosing what they do during the day, people visited a range of 0 to 9 other places (9 = 9 or more), with an average of 1 other place visited (66% saw no other places)
- 53% of the individuals surveyed chose their daily schedules without assistance
- 70% chose how they spend their free time without assistance
- 84% 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***

- 24% of the individuals interviewed/chose at least some of the staff who help them at home (alone or with assistance from family or provider)

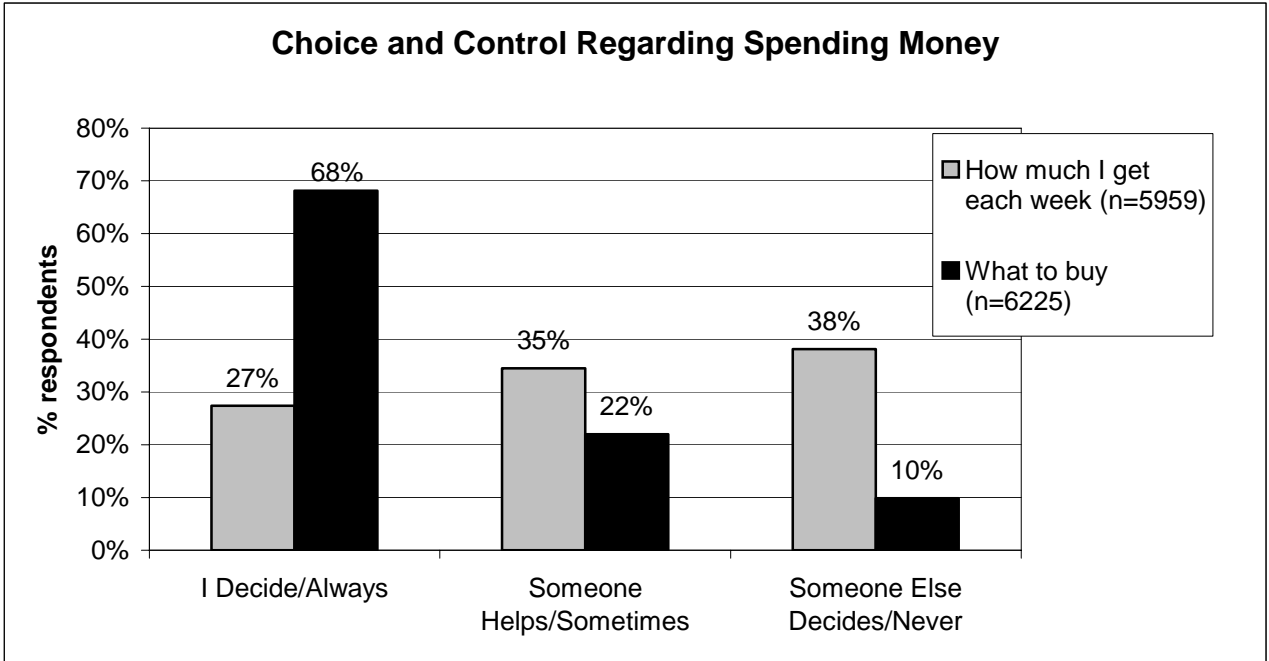


- 30% of the individuals surveyed interviewed/chose the staff who help them at work/day activity (alone or with assistance from family or provider)
- 8% of individuals chose their supports coordinators (alone or with assistance from family or provider)



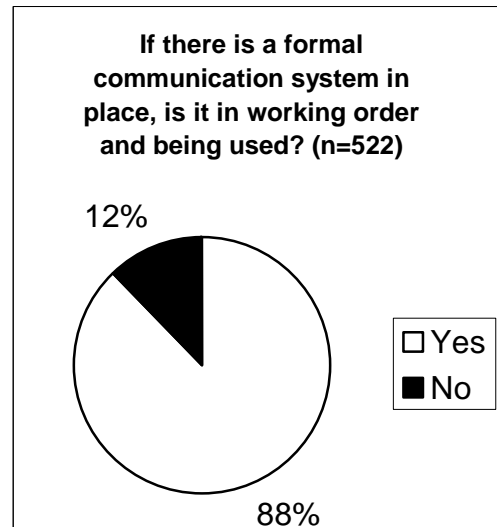
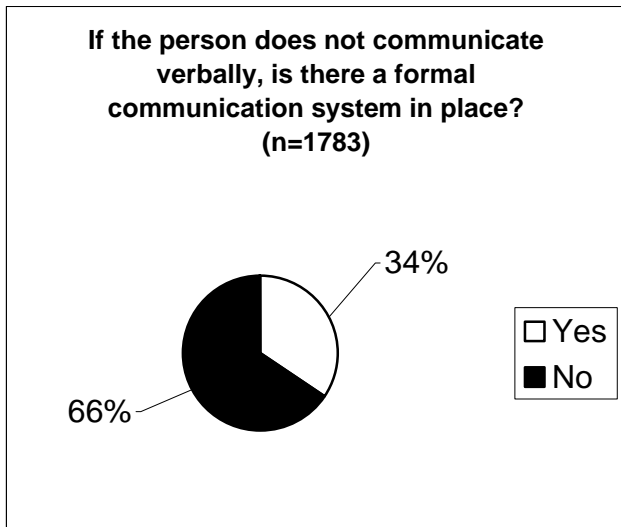
***Choice and Control with Regard to Money***

- 27% of the individuals interviewed reported that they choose how much spending money they have each week
- 68% 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 34% of the people interviewed
- For those people with formal communication systems in place, the systems are in working order and utilized for 88% of the people interviewed



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

- The average (mean) score was 46.93 with a standard deviation of 21.25
- The modal score was 56.52, indicating the most frequent score

There were some significant differences regarding this year's data in this section when compared with the data from 2002-03.

- There was a 9% increase in the percentage of individuals who chose or helped choose where they live.
- There was a 6% increase in the percentage of individuals who chose at least some of their housemates
- There was a 5% increase in the percentage of people who chose what they did during the day without assistance.
- There was a 7% increase in the percentage of individuals who interviewed/chose the staff who help them at work/day activity (alone or with assistance from family or provider) and a 5% increase in the percentage of people who interviewed/chose the staff that help them at home (alone or with assistance)

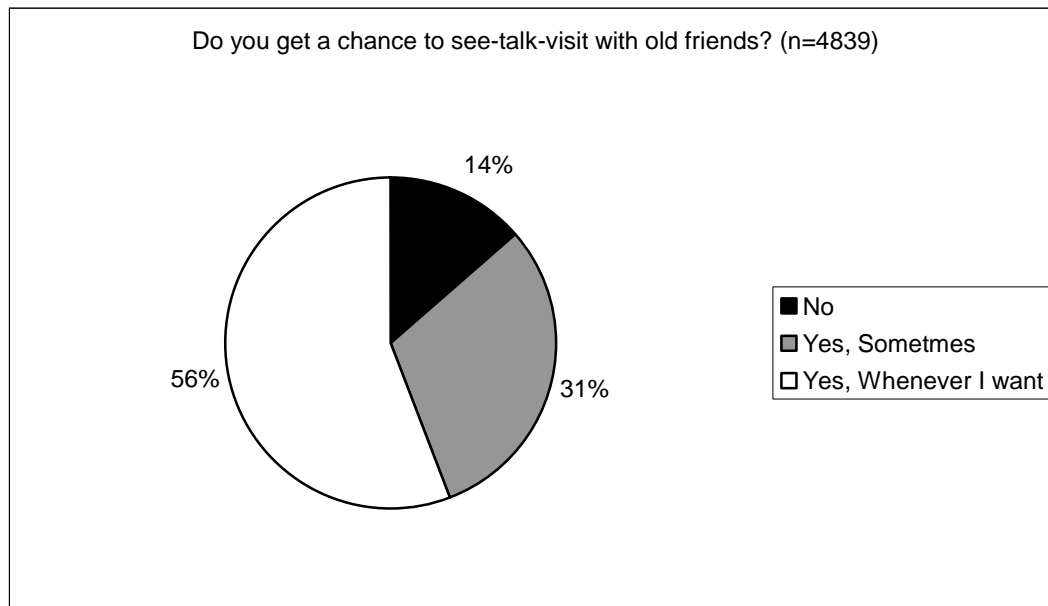
## **Relationships**

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

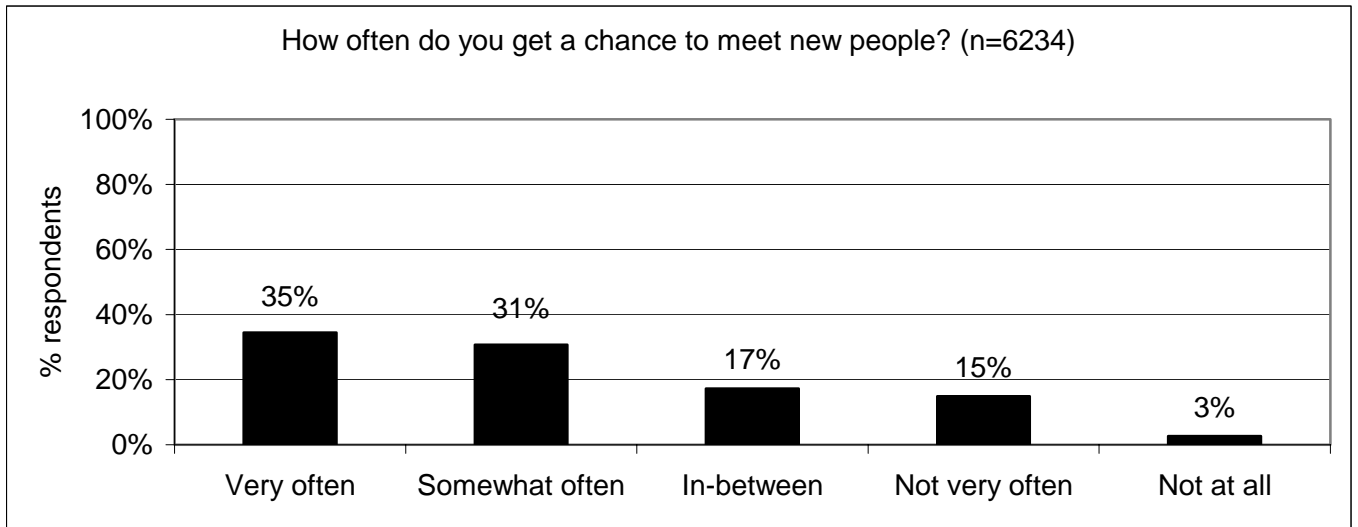
- 44% of the questions were answered by individuals receiving supports
- 29% were answered by paid staff
- 11% were answered by individuals receiving support and staff
- 10% were answered by family
- 7% of the questions were answered by individuals receiving support and a family/friend/guardian/advocate
- <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.”

## **Friendships**

- 56% of people answered that they can see-talk-visit with old friends whenever they want

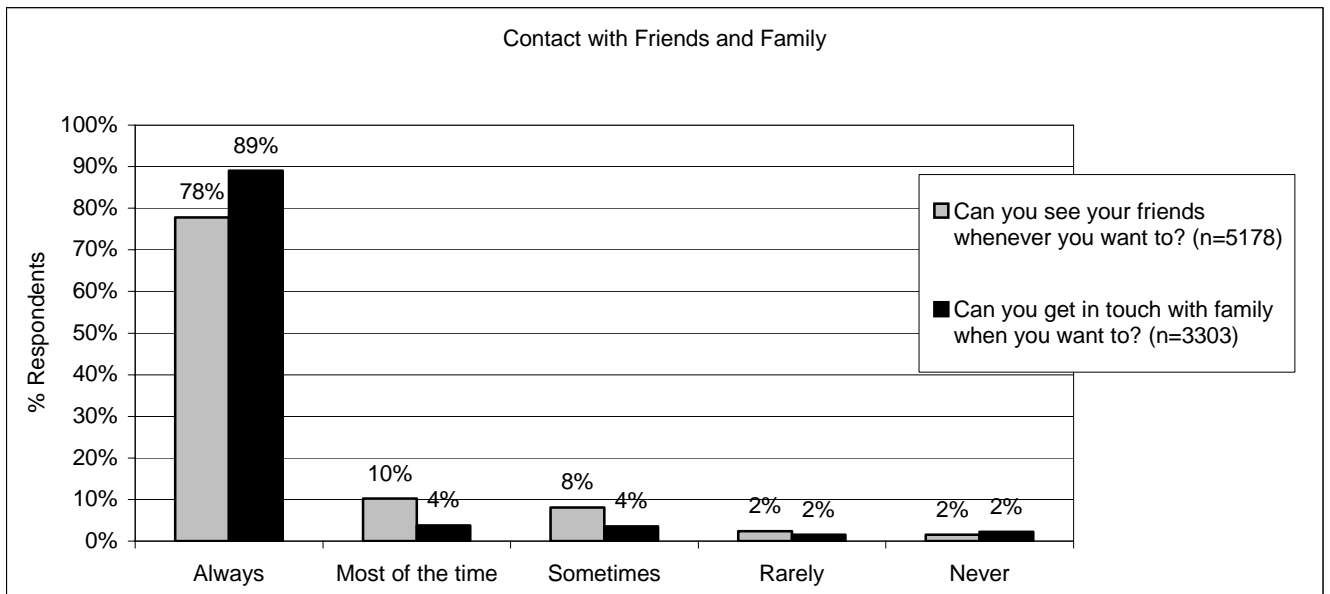


- 65% of individuals reported that they get a chance to meet new people at least somewhat often



**Contact with Friends and Family**

- 78% of individuals were always able to see friends whenever they wanted
- 89% of respondents were always able get in touch with family whenever they wanted



This year's responses to the items in the relationships section of the survey yielded results similar to those reported in the 2003-2004 report.

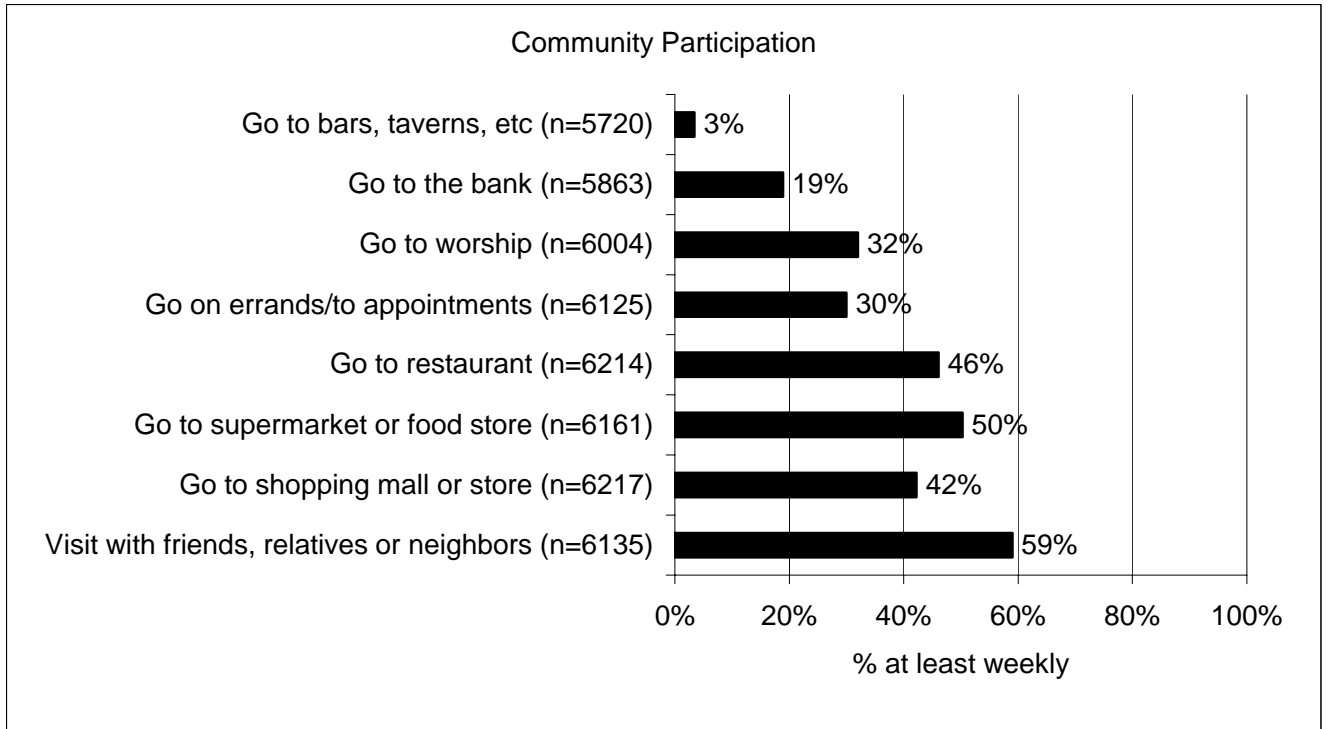
## **Inclusion**

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

- 39% of the questions were answered by individuals receiving supports
- 29% were answered by paid staff
- 13% were answered by individuals receiving support and staff
- 10% were answered by family/friend/guardian/advocate
- 8% 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***

- 59% of the people visited with friends, relatives and neighbors at least weekly
- 50% of those surveyed went to a supermarket at least weekly
- 46% of respondents went to restaurants at least weekly
- 42% of individuals went to a shopping center or mall at least weekly
- 32% 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 places of worship than people with disabilities in the Harris Poll, but less likely than people without disabilities in the Harris Poll

- Pennsylvanians with disabilities were more likely to go to shopping centers or malls than either of the two groups (people with and without disabilities) as compared with the Harris Poll.

**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%	59%
<b>Go to supermarket</b>	83%	55%	50%
<b>Go to restaurant</b>	59%	40%	46%
<b>Go to worship</b>	47%	30%	32%
<b>Go to shopping mall or store</b>	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.

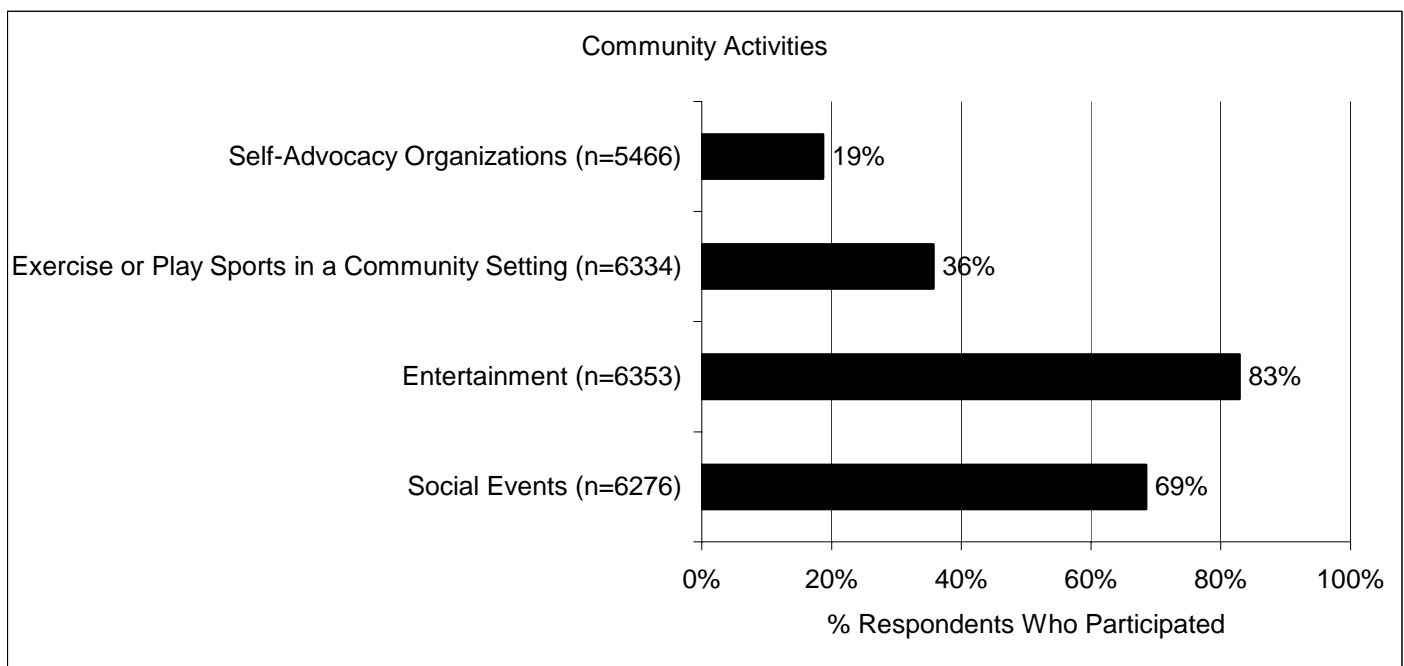
- The average score was 42.36 with a standard deviation of 15.11
- The average score was less than half of the possible scale score, indicating that individuals do not go to community places with great frequency.
- The mode was 50 which is the most frequent score.



## **Community Activities**

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

- 83% of individuals go into the community for entertainment
- 19% respondents attend or have attended a meeting/event of a self-advocacy group
- 69% of individuals reported that they go to social events in the community that are attended by people with and without disabilities
- 36% of individuals reported that they exercise or play sports in a community setting; 28% exercise or play sports in a non-integrated setting
- 36% of those interviewed do not exercise or play sports

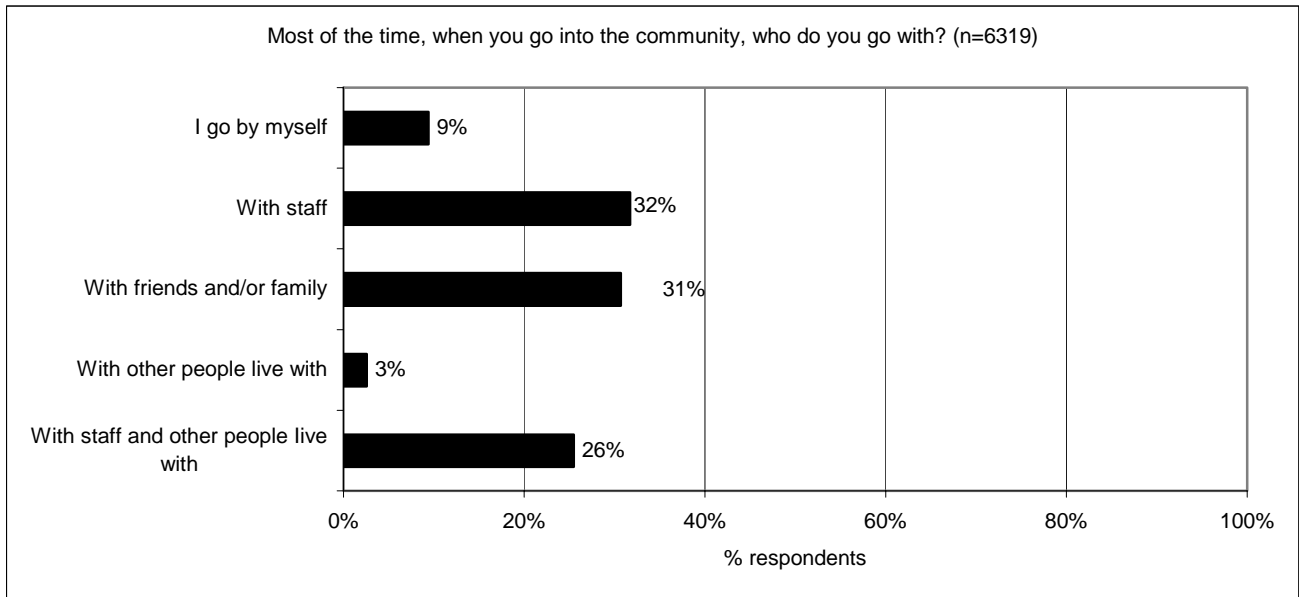


- 77% of individuals get to do things in the community as often as they would like to (most of the time)

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

- 9% of individuals go out alone

- 57% of individuals go out with staff or staff and other people they live with most of the time



### **Transportation**

- 90% of individuals always or almost always had a way to get where they wanted to go
- 27% cannot always 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=6236)**

Yes, always or almost always – 90%

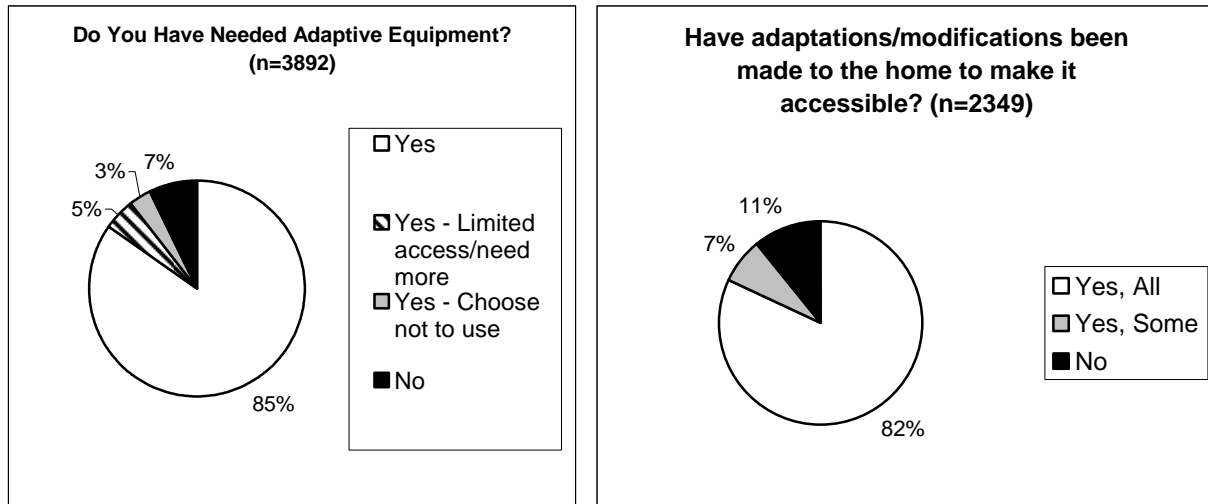
Sometimes – 8%

Never, almost never – 2%

- 35% of respondents use public transportation at least sometimes
- Of individuals not using public transportation, 60% do not use it because it does not exist where they live.

## Home Adaptive Equipment

- 85% 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

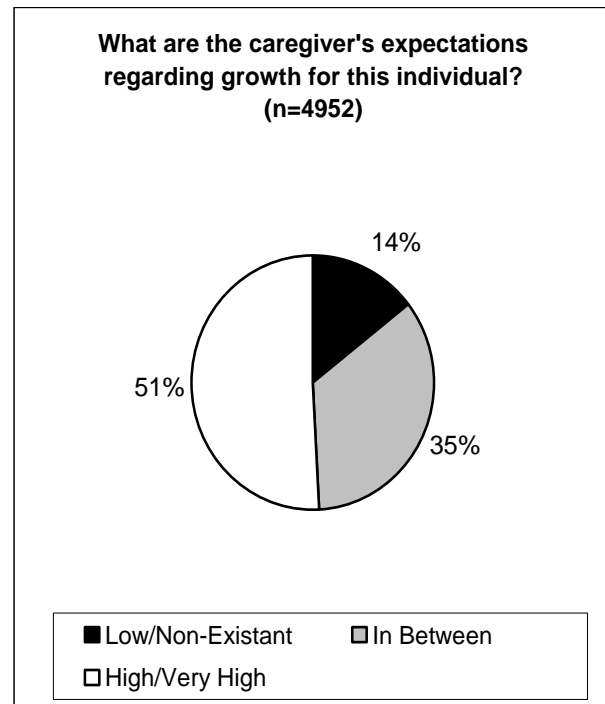
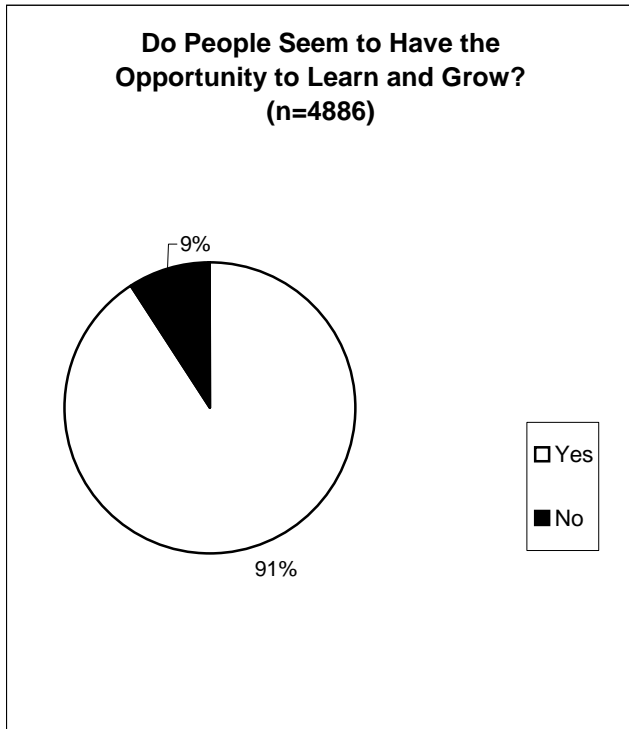


This year's responses to the items in the inclusion section of the survey yielded results similar to those reported in the 2003-2004 report. Below are data that could be useful to the closing the loop process.

- Many individuals (36%) report that they do not exercise or play sports.
- 27% of individuals cannot always get where they want to go due to lack of staffing.
- 60% of individuals do not use public transportation because it does not exist where they live.

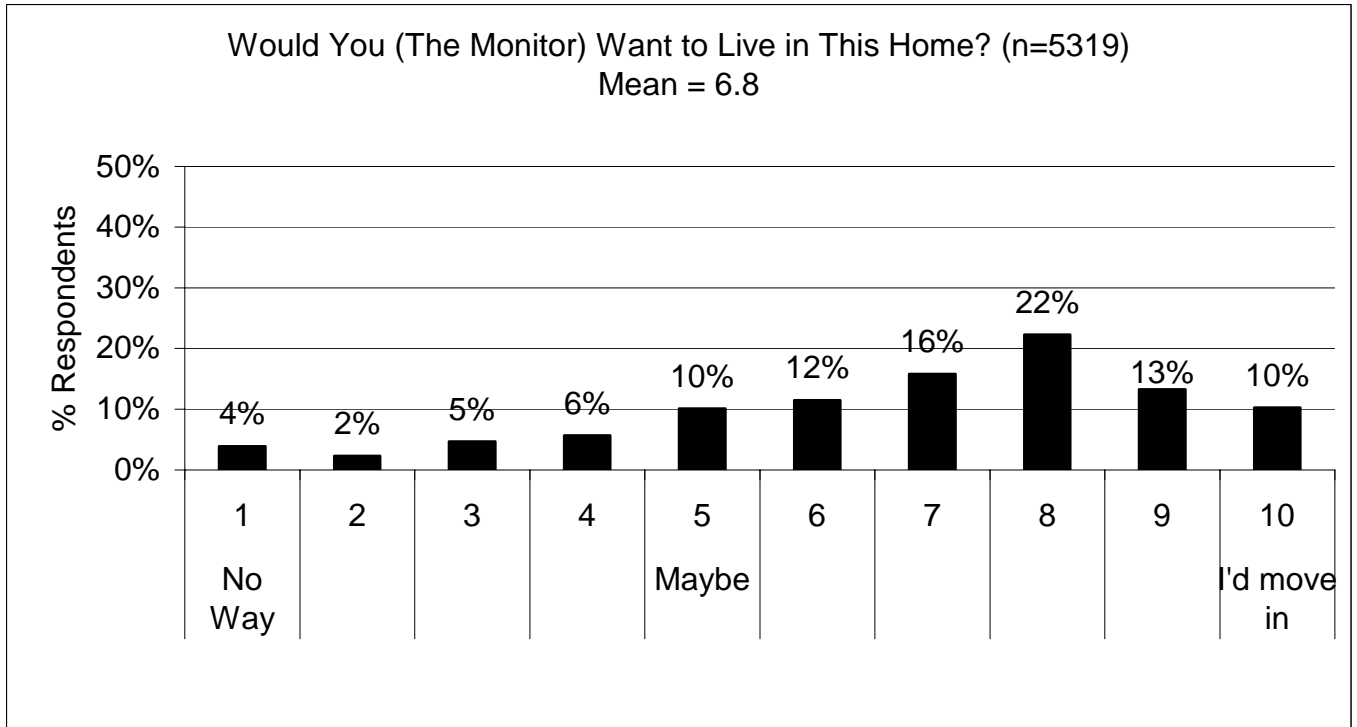
## **Competence, Personal Growth and Opportunities to Grow and Learn**

**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,

- 91% 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



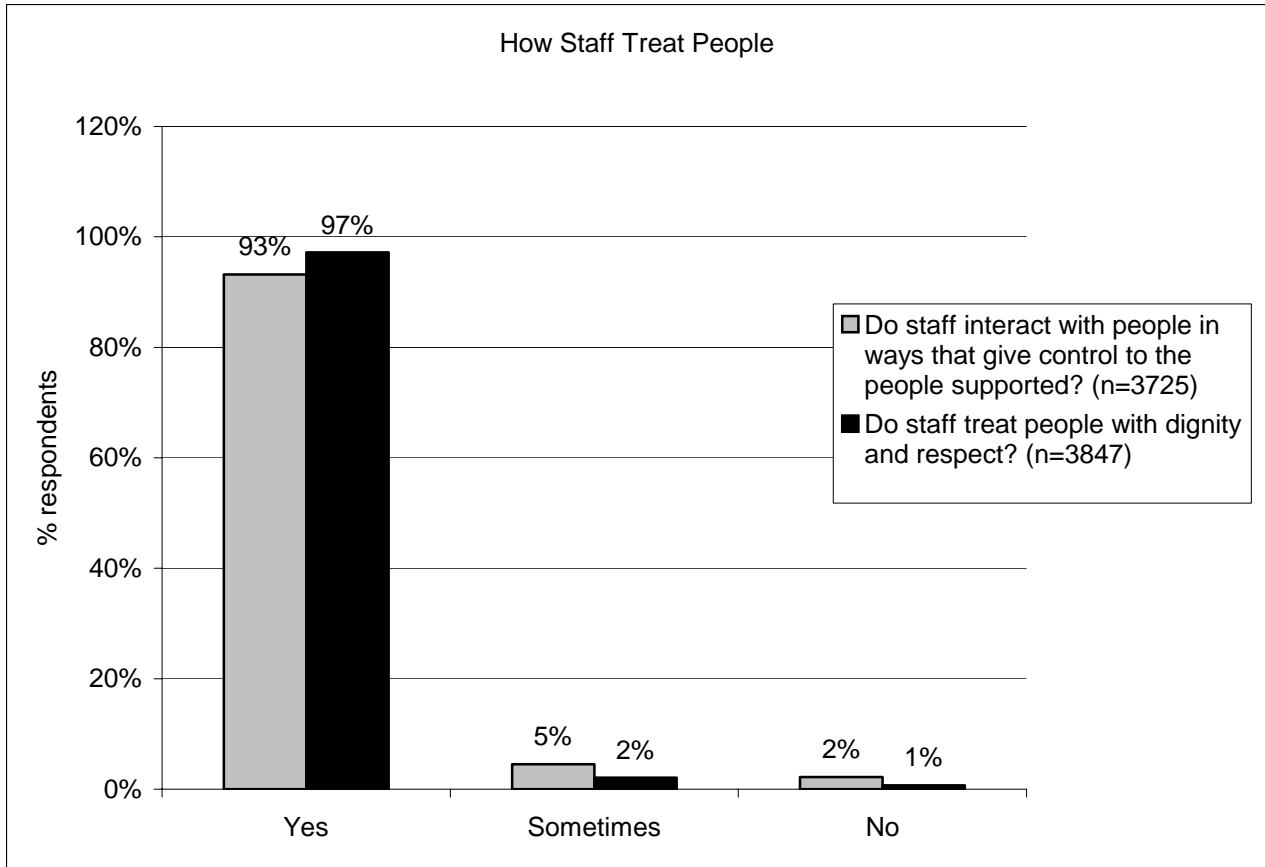
### **Staff Support for the Person**

**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,

- 93% of staff observed, interacted with individuals in ways that gave control to the people supported
- Individuals had either all staff (89%) or some staff (10%) with the skill needed to support them
- 97% of staff treated individuals with dignity and respect



## **Physical Setting**

**Respondents:** The IM4Q Team answered the following questions regarding the physical setting, which referred to the place where the individual lives. These questions were answered for interviews that took place in the individual's home.

### **Home Repair**

- Monitors observed that individuals lived in homes which were in good repair on the outside (92%) and on the inside (92%)

## ***Neighborhood***

According to IM4Q teams,

- Individuals lived in homes which were in a safe neighborhood (93%)
- Individuals lived in homes that “fit in” with the neighborhood in which they were located (91%)

## ***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 29% 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 95.47 with a standard deviation of 13.21
- The mode (the value that occurs the most frequently) was 100, indicating that many people (86%) lived in homes which were at the top of the scale on all measures of the physical setting

Compared to the Competence, Personal Growth and Opportunities to Grow and Learn section of the 2003-2004 report, there was one significant difference. The percentage of monitors reporting that all observed staff had the skills necessary to support the person increased from 79% to 89%.

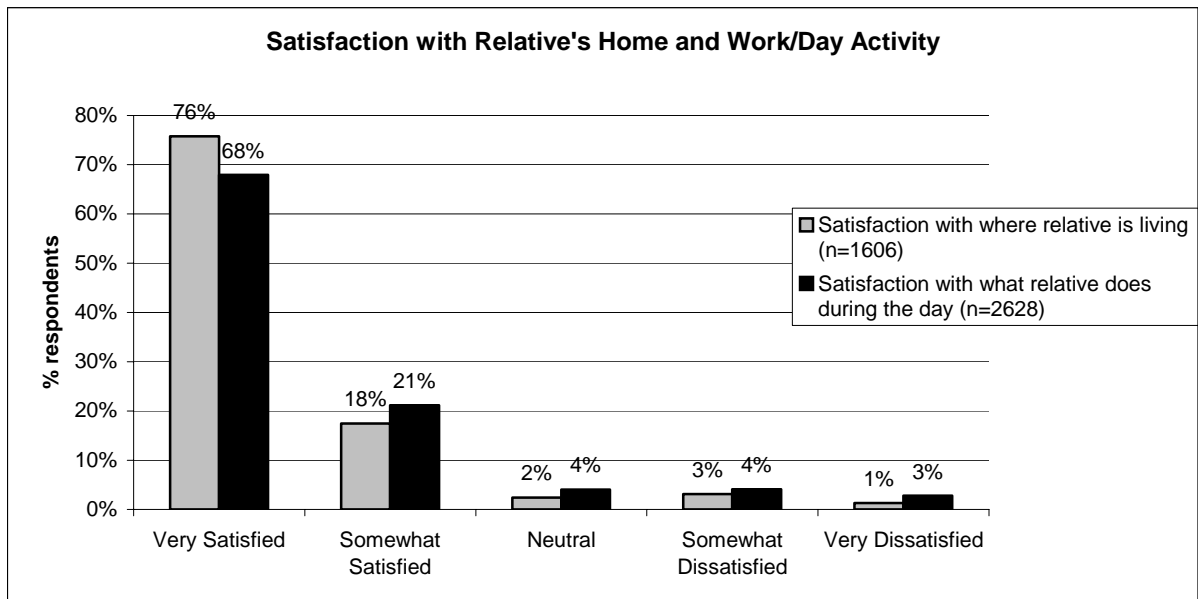
## **Family/Friend/Guardian Survey**

**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. 3010 family members, friends, and guardians participated in the survey.

- 69% of the surveys were answered by parents
- 20% were answered by siblings
- 2% were answered by the guardian
- <1% were answered by a friend
- 10% were answered by persons with other relationships to the individual receiving supports

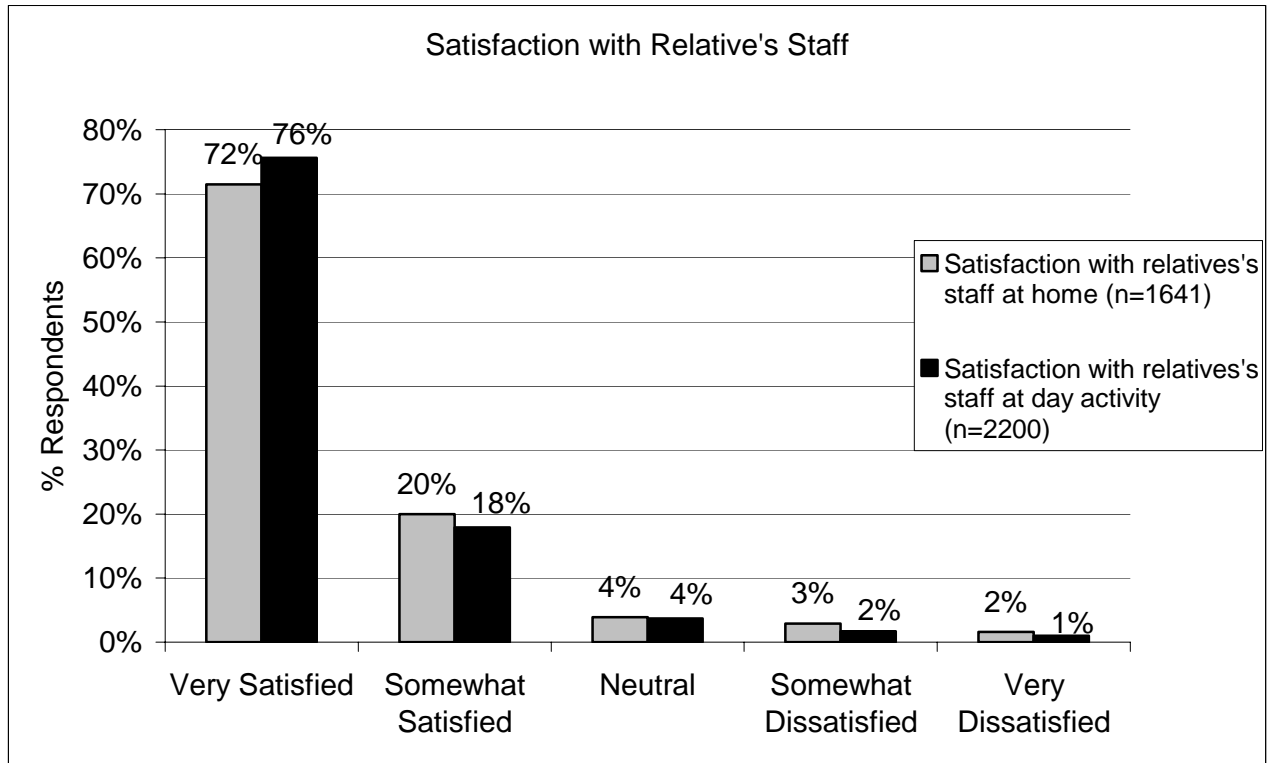
### **Satisfaction**

- 93% of the families surveyed, were either somewhat satisfied or very satisfied with where their relative lives
- 89% were either satisfied or very satisfied with what their relative does during the day





- 92% 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

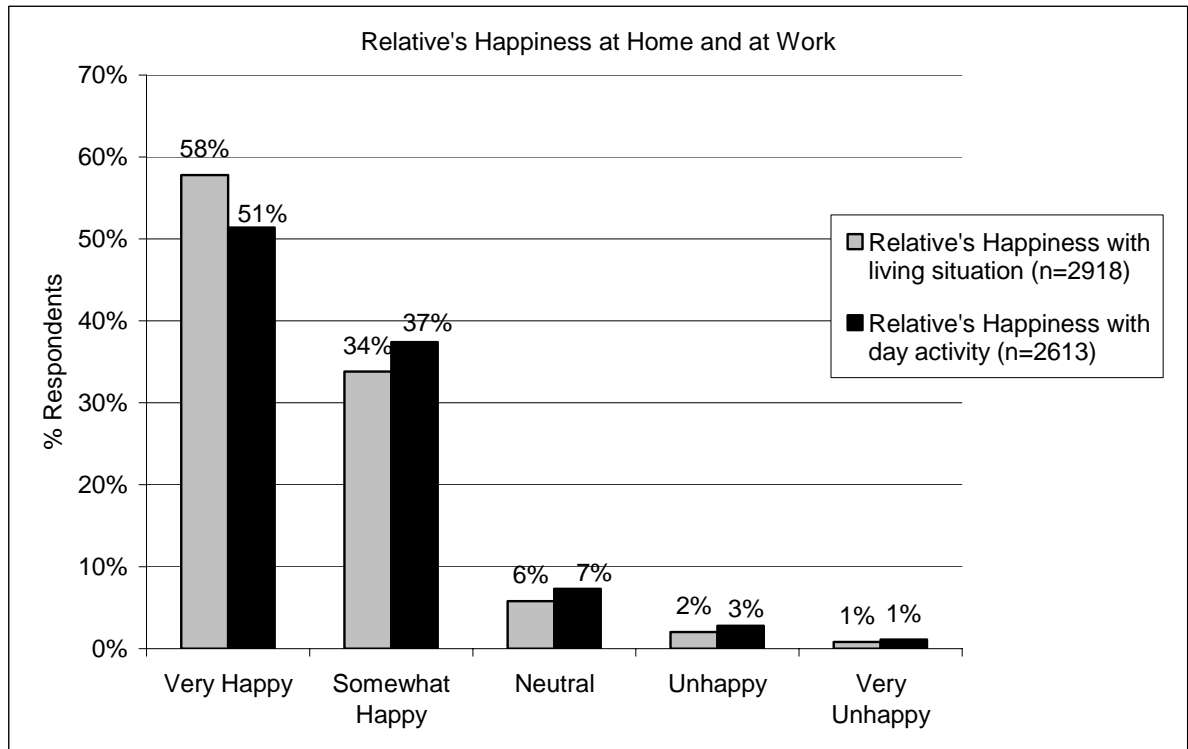


***How Often Do You See Your Relative***

- 66% Family/friend/guardians visited their relative at least monthly; 7% have not visited their relative in the past year
- 55% of the family/friend/guardians had a visit from their relative (or went on outings with them) at least once a month; 18% did not get a visit at all from their relative (or go on an outing) 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



- 92% of relatives felt their relative was either very happy or somewhat happy with the staff who support them at home; 2% 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 (83%) 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 (85%) or most of the time (13%)

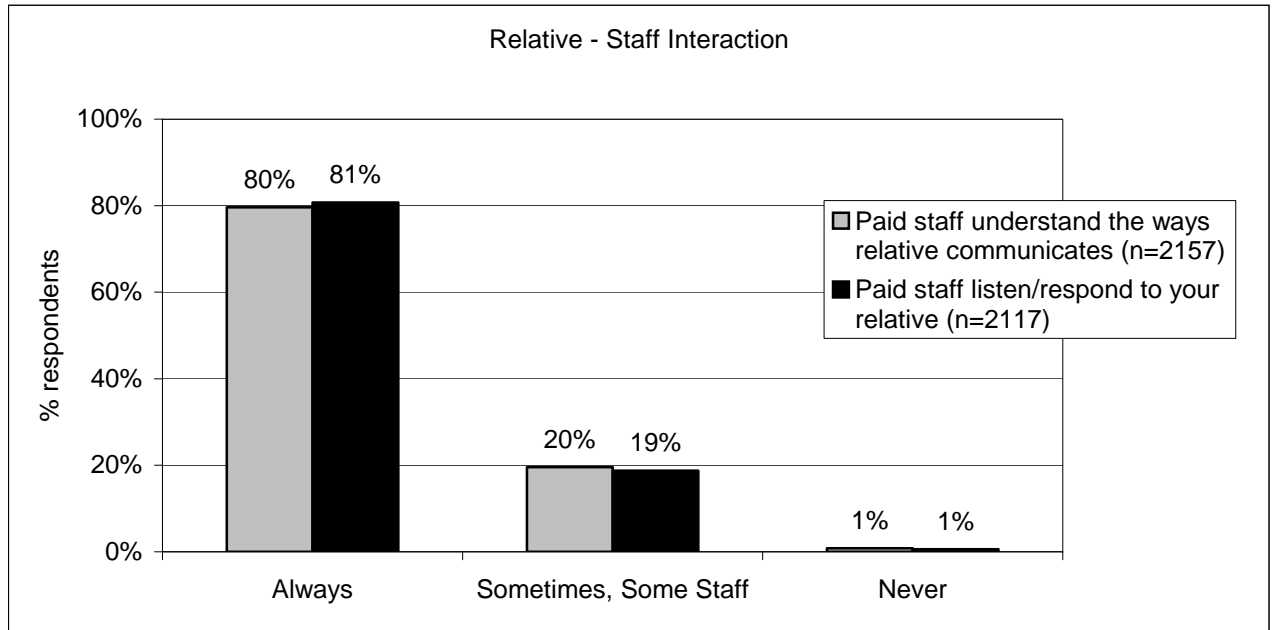
### ***Your Relative's Opportunities***

- 83% 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***

- 58% of the respondents said that their relative's staff had either high or very high expectations regarding growth for their relative.
- If their relative did not communicate verbally, 44% of the respondents said that there is a formal communication system in place for their relative
- If there is a formal communication system in place for their relative, 88% of the respondents said that the system was in working order and was being used
- 85% of the respondents said that their relative's home appeared to have enough paid staff
- 84% 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
- 78% of the respondents said that all staff appear to have the skills they need to support their relative (20% felt that way about only some staff)

- In terms of relative-staff interactions, families believe that staff understand the ways in which their relatives communicate (80% always), staff listen/respond to their relatives (81% always)



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

- 91% of relatives interviewed know who to call with regard to their relative if their life situation changes
- 87% of relatives were satisfied with the supports coordination their relative receives
- 46% of relatives reported that they were told how much money is in their relative's annual budget.
- 35% 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 87.00 with a standard deviation of 15.09

- The mode (the value that occurs the most frequently) was 100, indicating that many of the families' (31%) satisfaction levels were at the top of the scale on all measures of family satisfaction

Compared to the Family/Friend/Guardian section of the 2003-2004 report, there was one significant difference. The percentage of individuals reporting that they did not get a visit from or go on an outing with their relative decreased from 25% to 18%.

For purposes of "closing the loop," it is important to note that only 46% of relatives report being told how much money is in their relative's budget. 35% report needing/wanting additional information.

## **Summary**

This report presents information collected through face-to-face interviews with 6499 individuals receiving supports through the Office of Mental Retardation.

Overall individuals report high levels of satisfaction with where they live, where they work, with what they do in their leisure time and with who provides supports to them at home and during the day. The monitoring teams observed that staff treats individuals with dignity and respect in most cases.

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 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 day activities or work, providers continue to make the decision most frequently.

Although, most individuals report that they get the services and supports they need, there continue to be individuals that have not received all the services and supports they need. In addition, many individuals and families report that they were not told how much money is in their annual budget.

For those individuals who do not communicate using words, there continues to be issues around lack of exploration of alternative strategies. Most of 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 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 a shopping mall or store. Most of the people interviewed participate in inclusive social activities, rather than those designed only for people with disabilities.

Some individuals cannot always get where they want to go due to there not being enough staff. Transportation continues to be an issue for people with disabilities in Pennsylvania. The majority of individuals do not use public transportation, primarily 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.