

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

***Independent Monitoring for Quality (IM4Q)
A Statewide Summary
2001-2002***

**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 a significant transformation initiative. As part of this initiative, the 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. 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 is currently being developed and 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.

In this fiscal year, 2001-2002, 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. This year 5659 face-to-face interviews were conducted; this increase is a reflection of the increase in the size of OMR's residential program. In addition to the

interviews with individuals, 2494 interviews were conducted with families/friends and guardians.

Surveys were conducted from September, 2001 until June 30, 2002 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 94 questions, 35 of which can only be answered by the individuals receiving supports and services.

The EDE for fiscal year 2001-2002 includes all survey questions included in the FY 2001-02 NCI Consumer Survey. Twelve hundred eighty (1280) individuals included in this report are represented in the NCI sample for 2001-02, based on a sampling methodology established by the OMR and HSRI. A copy of the NCI report for FY 2001-02 is available on the HSRI website at www.hsri.org.

Modifications to the EDE and IM4Q pre-survey form were made based on feedback from the local IM4Q programs and recommendations from the State IM4Q Steering Committee. 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, support 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 see them.
- **Inclusion** – the questions in this section were answered by the individual, or by a family member, friend or staff person. Questions were asked about opportunities for community inclusion; a section of the Harris Poll was included for comparative purposes.
- **Monitor Impressions** – this section of the survey was completed by the Independent Monitoring team, after they had completed their visit. Questions were asked in the areas of physical setting, staff support and opportunities for growth and development.
- **Major Concerns** – this form was to be completed whenever there was an issue related to physical danger, significant sanitation problems, or evidence of physical or psychological abuse or neglect. Each 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 phone survey was conducted with each family once the individual gave his/her approval. Questions related to families' satisfaction with their relative's living situation, as well as perceived satisfaction of their relative.

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.

The sampling procedure for this year was similar. As part of the OMR Transformation Project a computerized, database has been developed – the Home and Community-based Services Information System (HCSIS). It is anticipated that sampling for IM4Q will be done through HCSIS in the future.

This year's sample included 5,659 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. An increasing number of people in the sample live at home with families.

	N	Percent
Own residence	388	6.9%
Family's home	990	17.5%
Family living	389	6.9%
Apartment program	232	4.1%
Group home	2638	46.7%
Private ICF/MR	611	10.8%
State MR center	18	<1%
Large community setting	159	2.8%
Nursing facility	60	1.1%
Other	164	2.9%
Total	5649	

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 ARCs (formerly The Association for Retarded Citizens), Consumer Satisfaction Teams (in the mental health system), parent groups, universities and colleges, consumer satisfaction teams (created in the mental health community) 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 Project by the county. In some cases, the county completed the pre-survey forms. In other cases, the projects completed the pre-survey forms with case managers/support 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 should 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.

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. EDE and F/F/G Survey data were entered directly onto the OMR website. Data were to be collected by June 30, 2002 and entered via the Web by August 15, 2002. A usable data file was received by the Institute on Disabilities in mid-September, 2002. 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.

RESULTS

The following table displays the distribution of interviews conducted by each independent monitoring project by county program.

	# of People	Percent
Allegheny	723	13%
Armstrong/Indiana	80	1%
Beaver	82	1%
Bedford/Somerset	52	<1%
Berks	158	3%
Blair	69	1%
Bradford/Sullivan	30	<1%
Bucks	230	4%
Butler	85	1%
Cambria	76	1%
Cameron/Elk/McKean	65	1%
Carbon/Monroe/Pike	88	2%
Centre	42	<1%
Chester	153	3%
Clarion	31	<1%
Clearfield/Jefferson	57	1%
Columbia/Montour/Snyder/Union	67	1%
Crawford	53	<1%
Cumberland/Perry	75	1%
Dauphin	138	2%
Delaware	282	5%
Erie	237	4%
Fayette	71	1%
Forest/Warren	32	<1%
Franklin/Fulton	54	1%
Greene	37	<1%
Huntington/Mifflin/Juniata	56	1%
Lackawanna/Susquehanna/Wayne	177	3%
Lancaster	150	3%
Lawrence	41	<1%
Lebanon	51	<1%
Lehigh	132	2%
Luzerne/Wyoming	127	2%
Lycoming/Clinton	69	1%
Mercer	55	1%
Montgomery	333	6%
Northampton	93	2%
Northumberland	50	<1%
Philadelphia	767	14%
Potter	27	<1%
Schuylkill	66	<1%
Tioga	32	<1%
Venango	31	<1%
Washington	63	1%
Westmoreland	143	2%
York/Adams	129	2%
TOTAL	5659	100%

Satisfaction

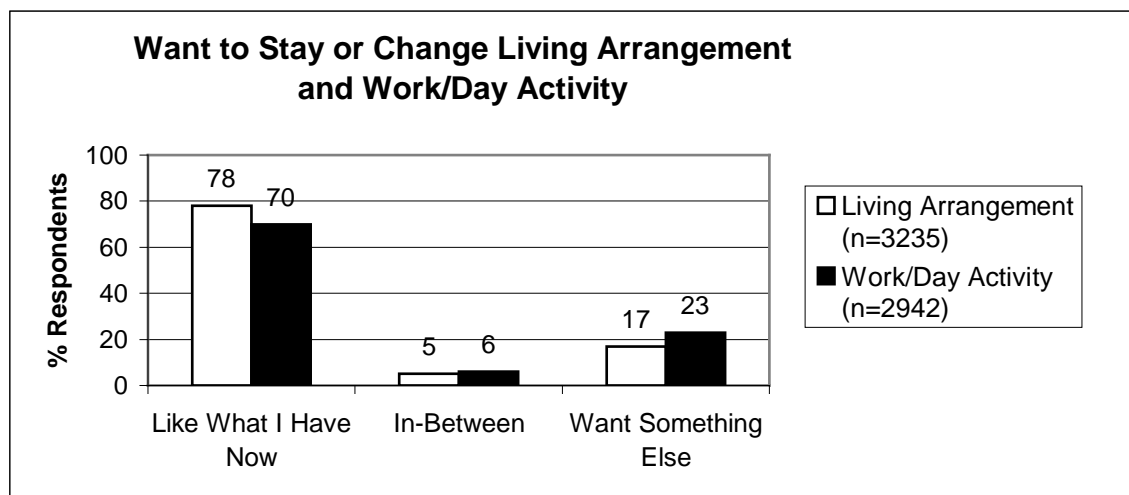
Respondents: Only the individual receiving services/supports could answer the questions on satisfaction. The percent of people who responded to questions in this section ranged from 43.3% to 65.6%.

Satisfaction with Living Arrangements

- 90% of individuals liked where they live
- 78% 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
- 84% of those who work felt they worked sufficient hours, 13% wanted to work more, and 3% wanted to work fewer hours
- 70% wanted to continue in their current daytime activities/work



Daily Life

- Half of the individuals 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>
Have opportunities to engage in household tasks (n=3435)	51.0%	17.6%	18.5%	3.2%	9.7%

Happiness and Loneliness

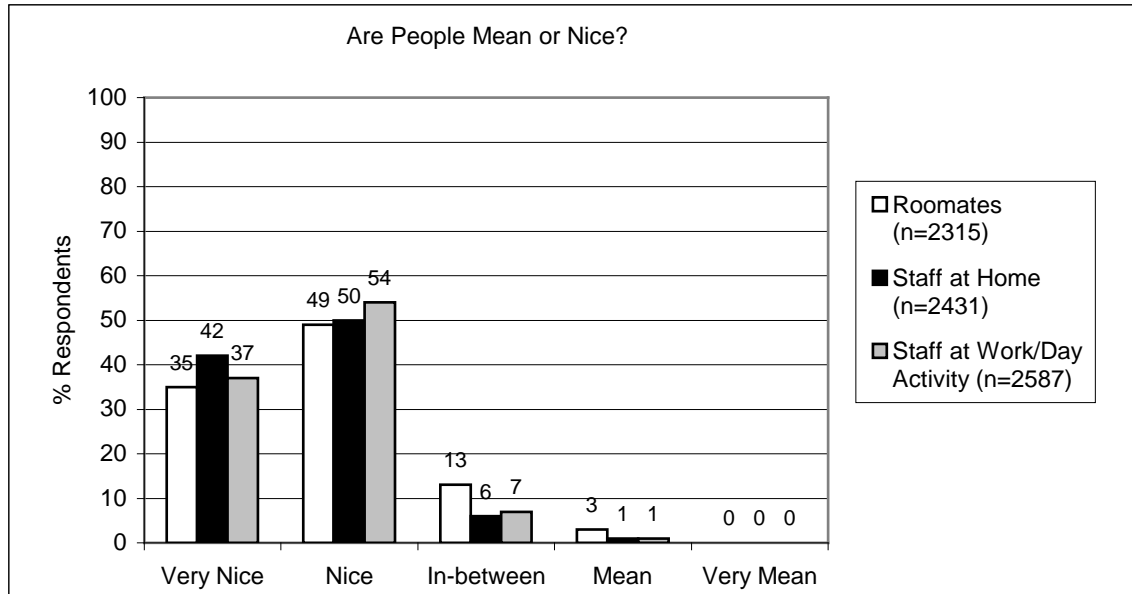
- 77% reported usually feeling happy, 19% reported being in-between, and 5% reported usually feeling sad
- 59% of individuals reported never feeling lonely, 37% reported sometimes feeling lonely, and 3% reported always feeling lonely

Privacy

- 80% of the individuals surveyed, reported that they always have privacy (a place to be alone) when they want it
- Most of the time (76%), people knock or ring the doorbell and wait for a response, before coming in to people's homes
- 70% of the time, people knock on the bedroom door and wait for a response before coming in

Are People Nice or Mean?

- Most people (84%) reported that their housemates are very nice or nice
- 92% of the people interviewed reported that their staff who work with them at home are very nice or nice
- 92% reported that staff who work with the respondents at work or day activity are nice or very nice



Satisfaction Scale: Based on 7 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 equaled 84.79 with a standard deviation of 19.23
- The mode (the value that occurs the most frequently) equaled 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.

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 46.5% to 62.2%.

Identification Cards

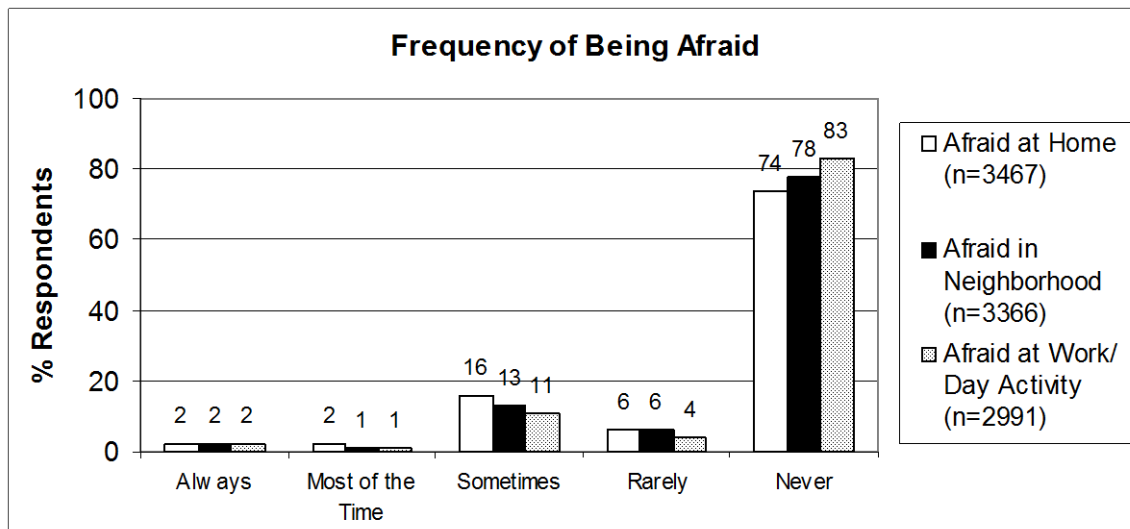
- 60% of individuals stated that they always carry an identification card.

Support with Problems and Goals

- 88% of individuals always had someone in their life who helped try to fix a problem

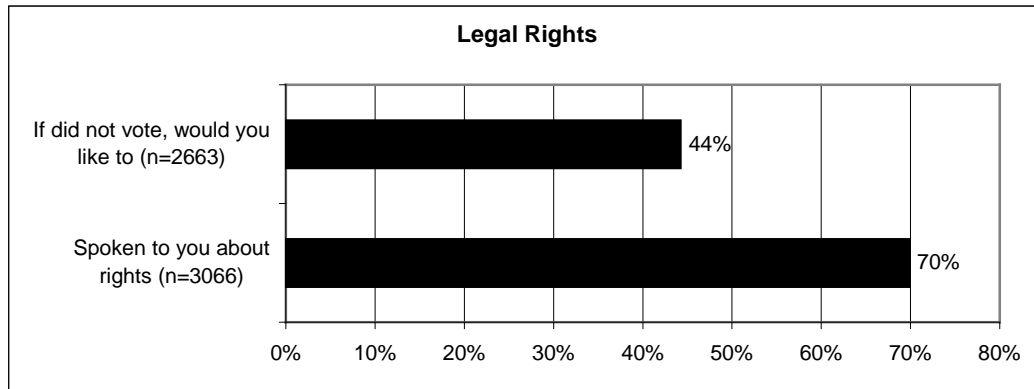
Being Afraid

- Many individuals reported never being afraid, either in their home, work/day activity site or in their neighborhood
- 74% reported never being afraid at home
- 78% reported never being afraid in the neighborhood
- 83% reported never being afraid at work



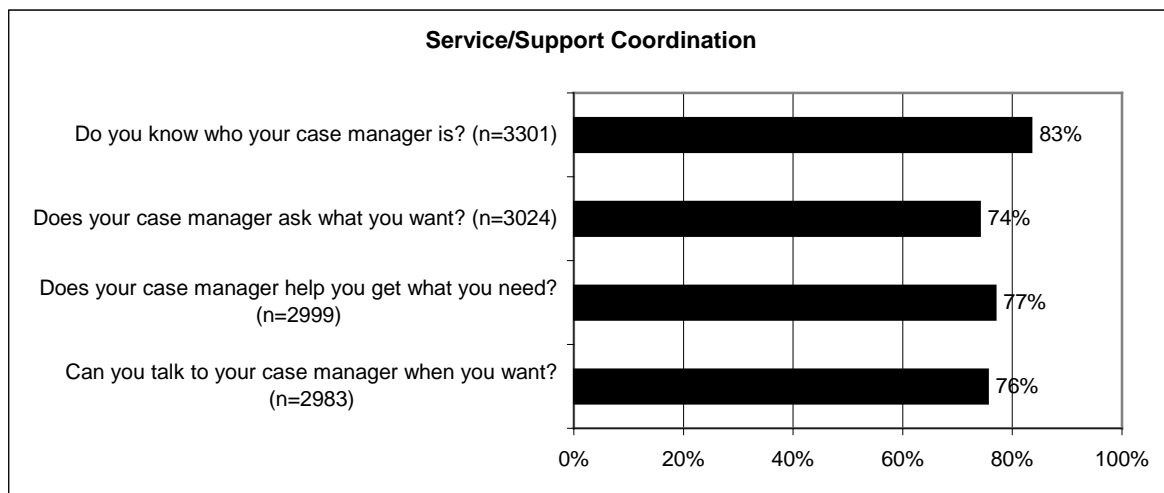
Legal Rights

- 70% of the people surveyed have had discussions about their rights in the past year
- 44% of people said that they have not voted in the past five years but would like to vote



Service / Support Coordination

- The majority of people interviewed responded “yes” or “always” to questions about services/supports coordination indicating a positive experience



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

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

- The average score equaled 81.36 with a standard deviation of 14.99.
- 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 (very nice) for all measures.

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

- The average (mean) score equaled 88.64 with a standard deviation of 18.70
- The mode was 100
- Here again we see that the average 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 (61%) 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 workplace/ day activity program.

- At home, individuals were most afraid of the weather and darkness/sleep
- In the neighborhood, individuals were most afraid of animals / insects
- At work, the largest definable category of what individuals were afraid of was staff / consumers.

	At Home #	In Neighborhood #	At Work #
Alone	45	13	3
Animals / Insects	35	89	10
Being Scolded/ Fear of Being Hurt/ Other Feelings	23	30	21
Darkness / Sleep	72	59	7
Emergency Situations/ Fire/ Fire Alarms	35	7	21
Falling / Sickness / Death	38	16	17
Neighbors / Local kids	9	21	0
Work related-Lose job/ New things on job	4	8	4
Noises	33	18	12
Staff / Consumers	42	6	66
Strangers / Crime	41	48	5
Transportation/ traffic/ emergency vehicles	3	12	0
Weather	109	41	17
Houses/ Locked Rooms/ Office/ Stairs	2	2	4
Mythical Creatures	14	12	4
Scary Movies	9	0	3
Other people/ People in general/ Crowds	41	46	35
Other	63	63	39
TOTAL	618	491	268

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

- The average (mean) score equaled 80.46 with a standard deviation of 33.37
- The mode was 100. More than half of the individuals (57%) scored at the top of the scale regarding their relationship with their case manager/support coordinator.

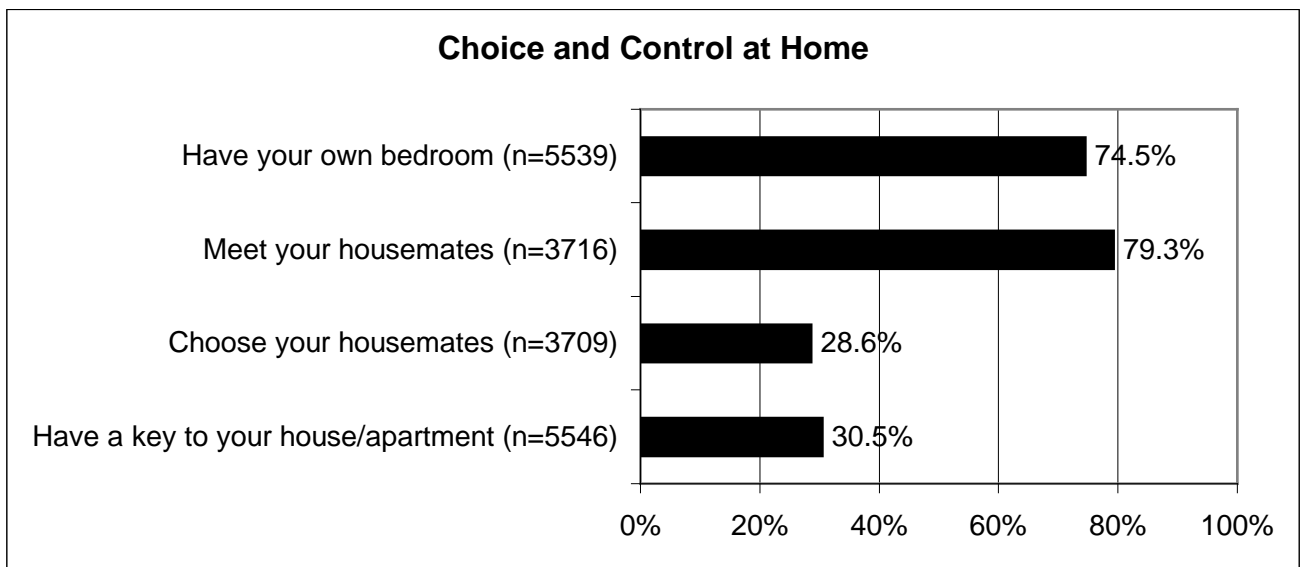
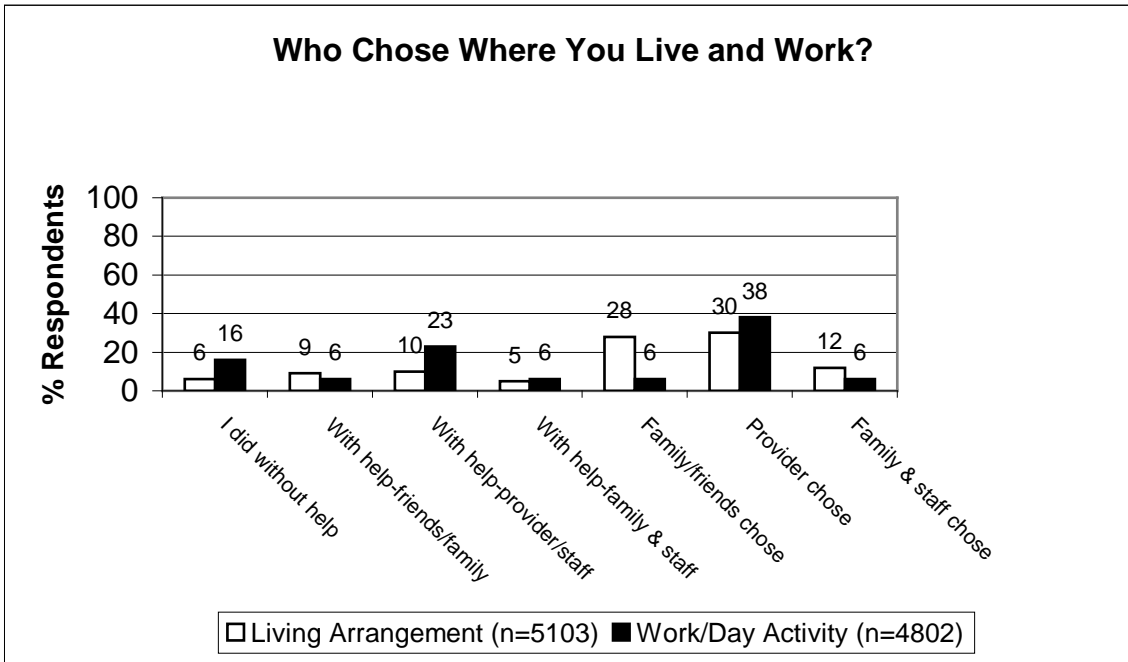
Choice and Control

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

- 39% of the questions were answered by the individual receiving supports
- 37% of the questions were answered by paid staff
- 12% of the questions were answered by the consumer and staff
- 7% of the questions were answered by family/friend/advocate/guardian
- 5% 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

- Only 30.5% of the individuals surveyed had a key to their house or apartment
- For 69.5% of the individuals, someone else chose where they live (only 6% 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 1.22 places (55% saw no other places)
- 71% of the individuals did not choose their housemates
- 79% of the individuals surveyed met some or all of their roommates before living together
- 73% of the individuals had their own bedroom; however for those who shared a bedroom, 36.2% chose some or all of their roommates
- For 70% of the individuals interviewed, their mail is never opened without permission; however, 16% say their mail is always opened without permission
- 89% of the individuals reported that they can have privacy with visitors
- 92% are allowed to use the phone whenever they want



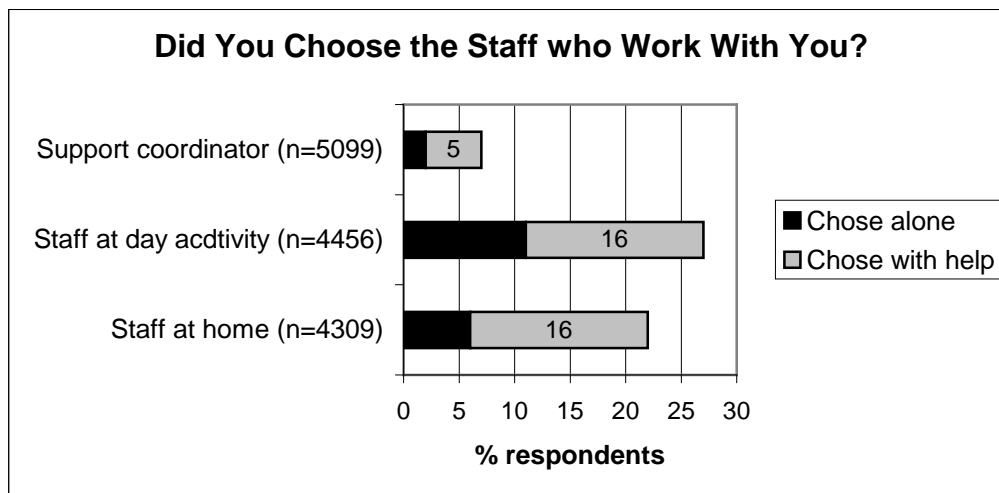
Choice and Control During the Day and for Leisure Time

- 50% of the individuals interviewed reported that someone else chose what they do during the day

- for a significant number of people (at least 61%), the provider either chose what the individual does during the day or helped the individual decide
- 16% 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 .90 other places visited (61% saw no other places)
- 43% of the individuals surveyed chose their daily schedules without assistance
- 59% chose how they spend their free time without assistance

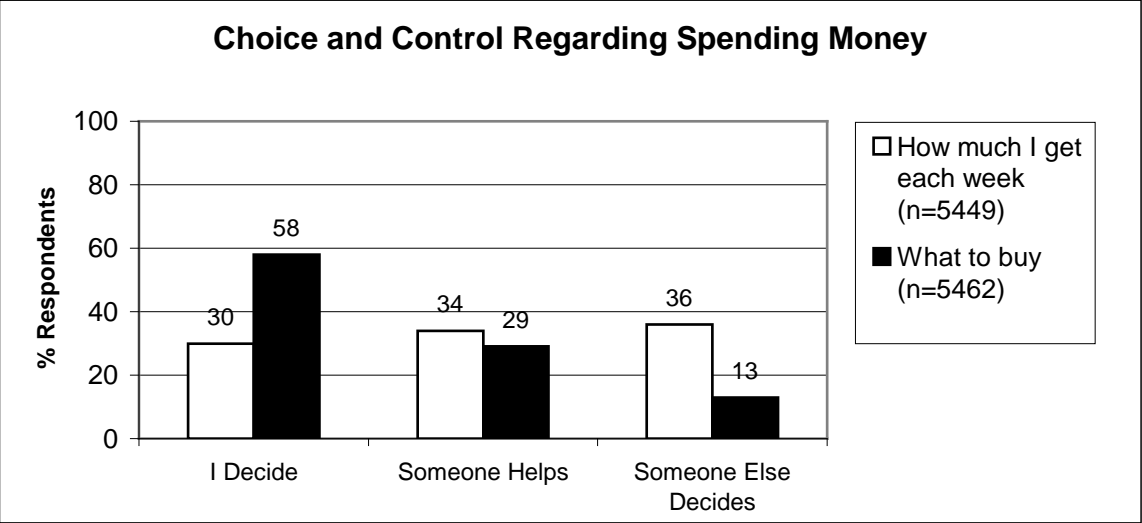
Choice and Control in Choosing Staff

- 22% of the individuals interviewed chose at least some of the staff who help them at home (alone or with assistance from family or provider)
- 27% of the individuals surveyed chose the staff who help them at work (alone or with assistance from family or provider)
- 7% of the individuals reported that they chose their case managers/support coordinators (alone or with assistance from family or provider)



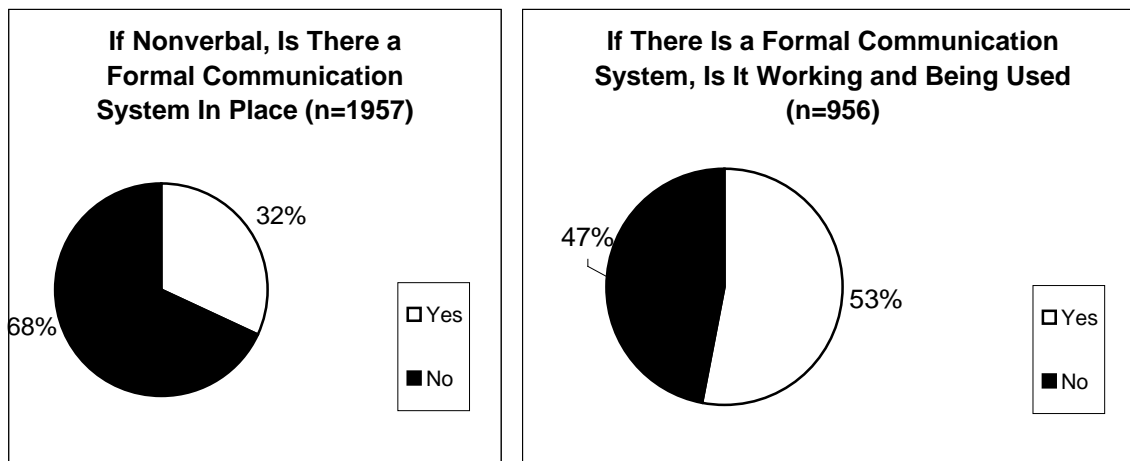
Choice and Control with Regard to Money

- only 30% of the individuals interviewed reported that they choose how much spending money they have each week
- 58% 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 32% of the people interviewed
- For those people with formal communication systems in place, the systems are in working order and utilized for 53% 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 equaled 40.2 with a standard deviation of 20.94
- The modal score was 30.43

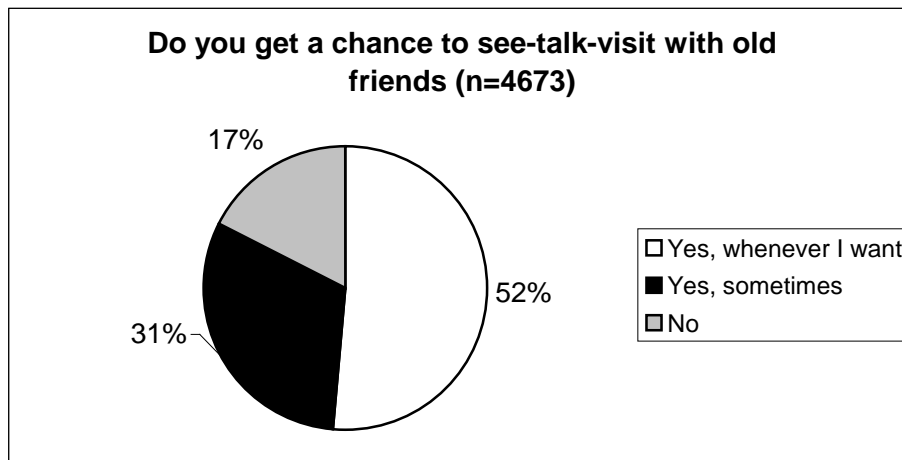
Relationships

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

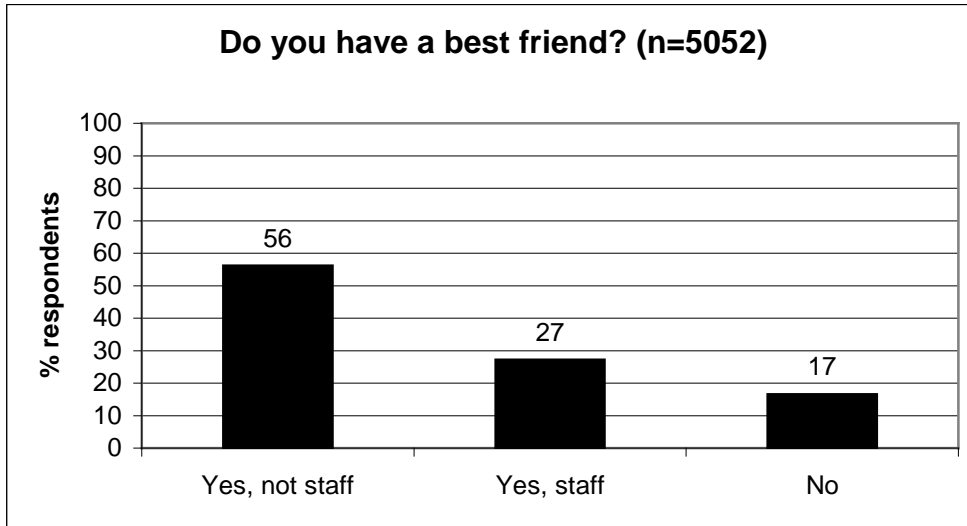
- 39% of the questions were answered by individuals receiving supports
- 38% were answered by paid staff
- 11% were answered by individuals receiving support and staff
- 7% were answered by family
- 4% of the questions were answered by individuals receiving support and a family/friend/guardian/advocate
- Less than one percent 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

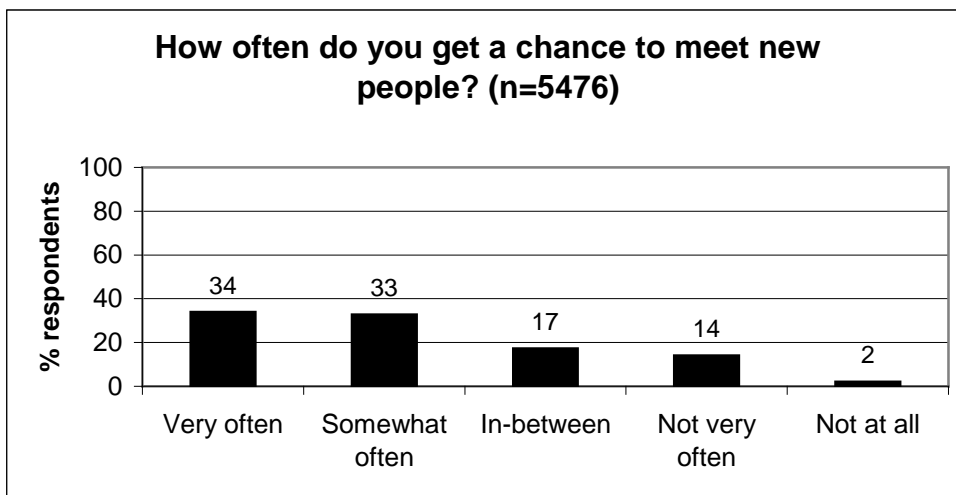
- 52% of people answered that they can see-talk-visit with old friends whenever they want



- 83% of individuals reported that they have a best friend

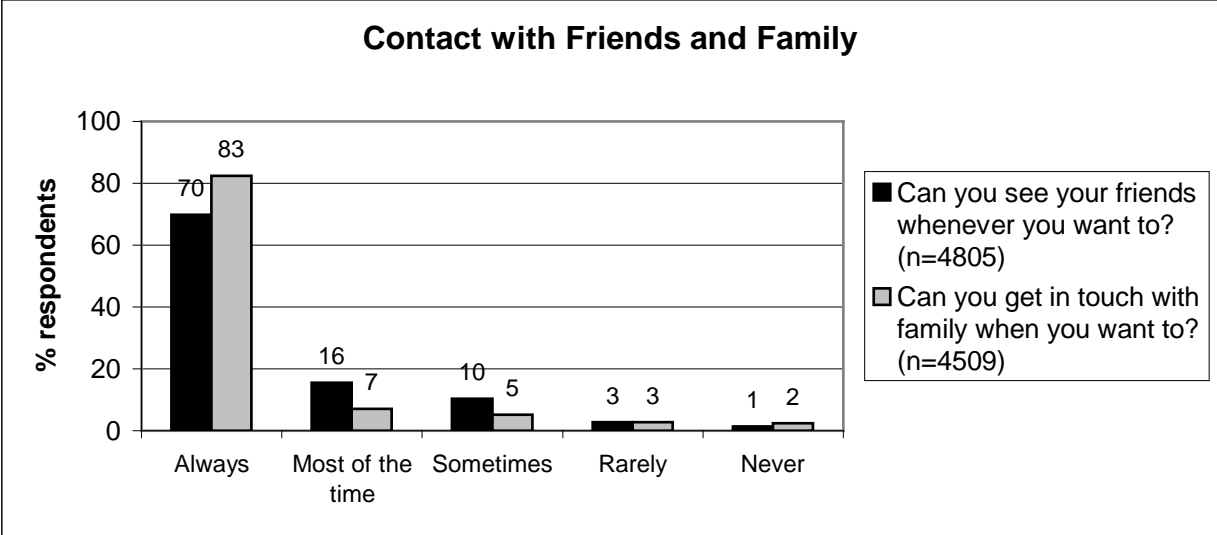


- 67% of individuals reported that they get a chance to meet new people at least somewhat often



Contact with Friends and Family

- The majority of individuals were always able to see friends and get in touch with family whenever they wanted



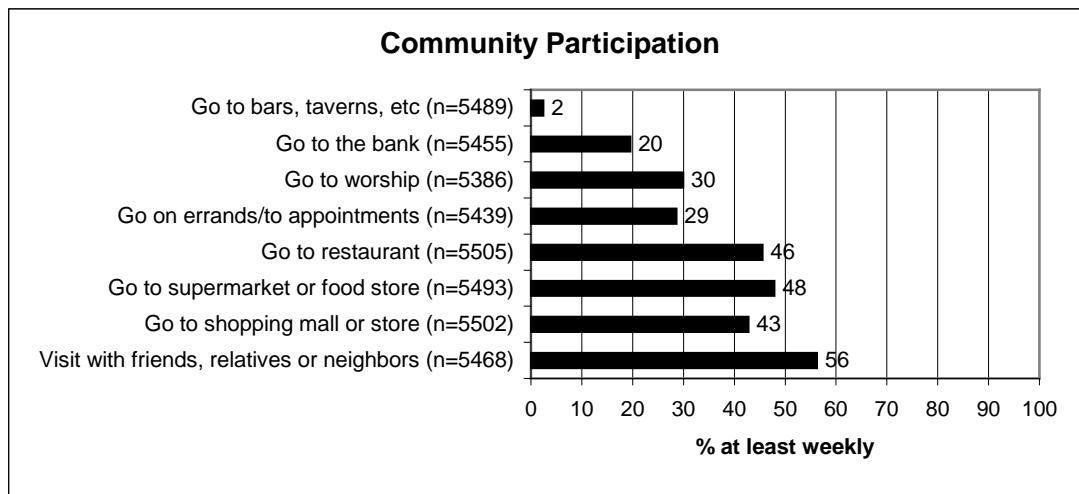
Inclusion

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

- 36% of the questions were answered by individuals receiving supports
- 39% were answered by paid staff
- 13% were answered by individuals receiving support and staff
- 7% were answered by family
- 5% of the questions were answered by individuals receiving support and a family/friend/guardian/advocate
- Less than one percent 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

- More than half of the people visited with friends, relatives and neighbors at least weekly
- Almost half of the individuals surveyed went to a supermarket, a restaurant, or to a shopping mall at least weekly
- Individuals did not go out as frequently for errands and appointments, to places of worship, 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.

- 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 by the Harris Poll
- Pennsylvanians with disabilities in this study were more likely to go to a restaurant than people with disabilities in the Harris Poll, but less likely than people without disabilities in the Harris Poll
- People with disabilities in this survey were about as likely to go to worship as people with disabilities in the Harris Poll, yet less likely than people without disabilities in the Harris Poll
- People in this study were more likely to visit a shopping mall compared to the national sample of people with and without disabilities

Weekly Participation in Community Activities

	Harris: People without Disabilities	Harris: People with Disabilities	Independent Monitoring
Visit with friends, relatives, and neighbors	85%	70%	56%
Go to supermarket	83%	55%	48%
Go to restaurant	59%	40%	46%
Go to worship	47%	30%	30%
Go to shopping mall or store	41%	23%	43%

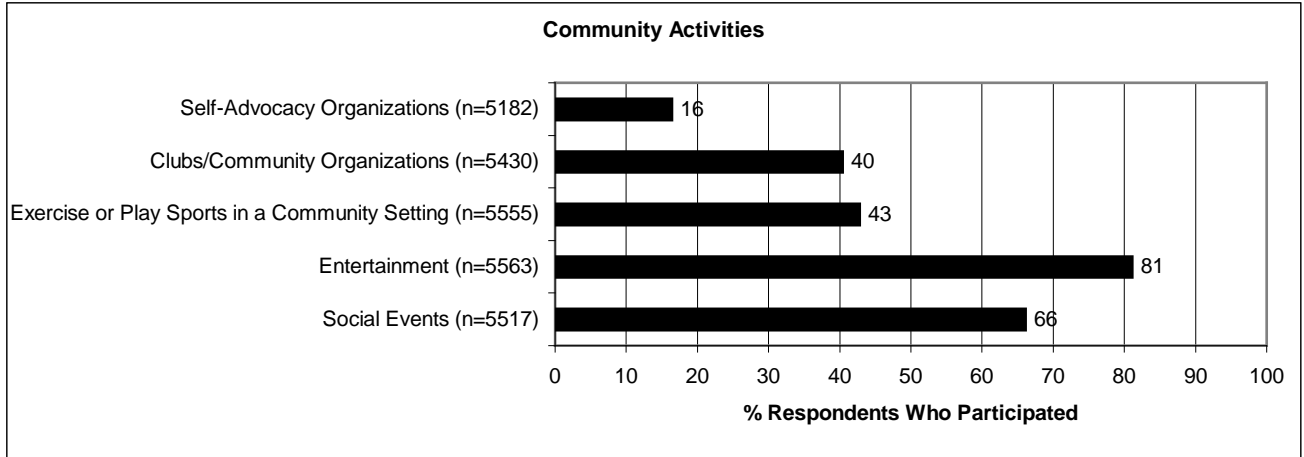
Inclusion Scale

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 equaled 40.84 with a standard deviation of 14.77
- 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.

Community Activities

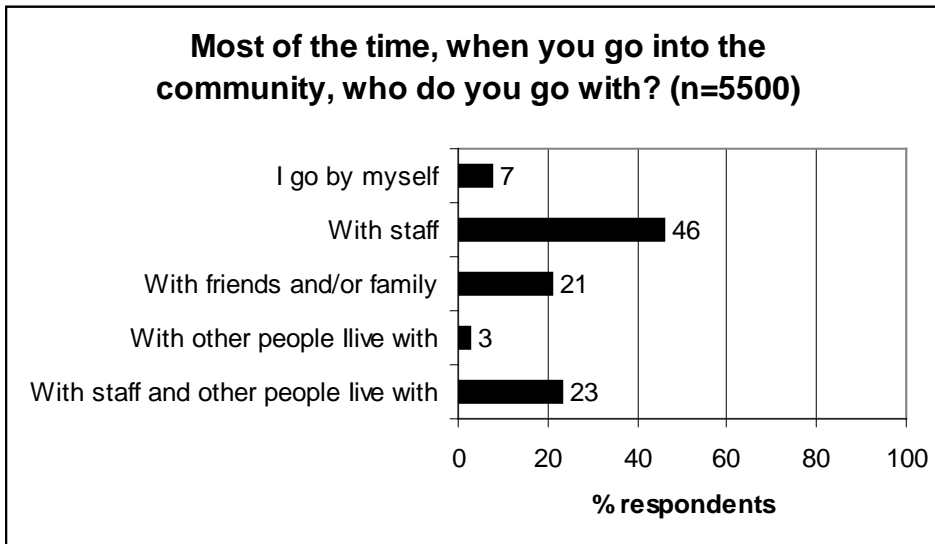
- We asked individuals about several other types of community activities including attending social events and recreational events.
- Individuals were most likely to have been in the community for entertainment (81.1%) and least likely to have been to a meeting/event of an advocacy group (16.4%).
- 21% of individuals reported that they always or most of the time attend community events that are only for people with disabilities
- 43% of individuals reported that they exercise or play sports in a community setting; 30% exercise or play sports in a non-integrated setting



- 71% 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

- Only 7% of individuals go out alone
- 46% of individuals go out with staff most of the time



Transportation

- People always or almost always had a way to get where they wanted to go

Do you always have a way to get where you want to go? (n=5546)

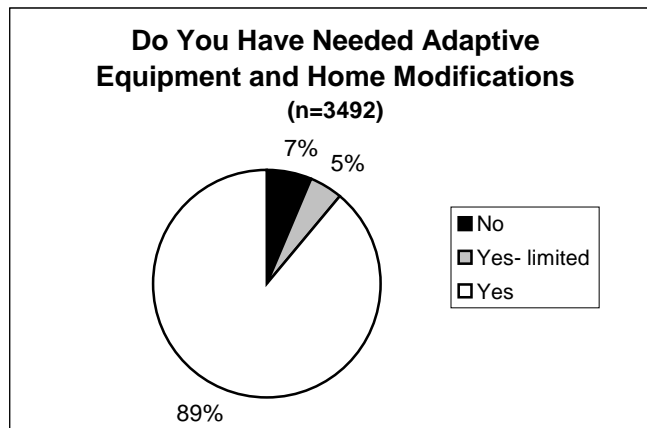
Yes, always or almost always – 90%

Sometimes – 8 %

Never, almost never – 2%

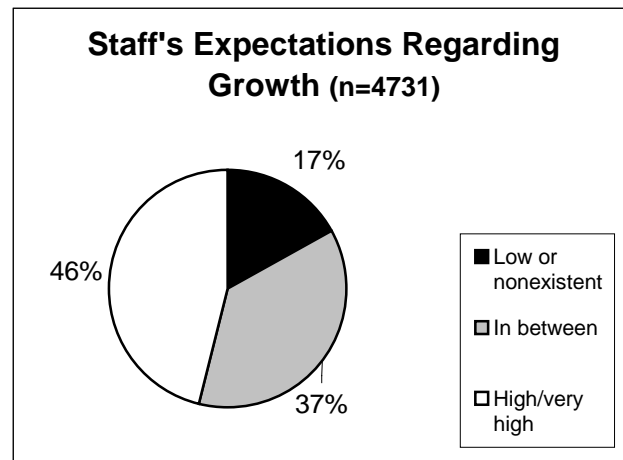
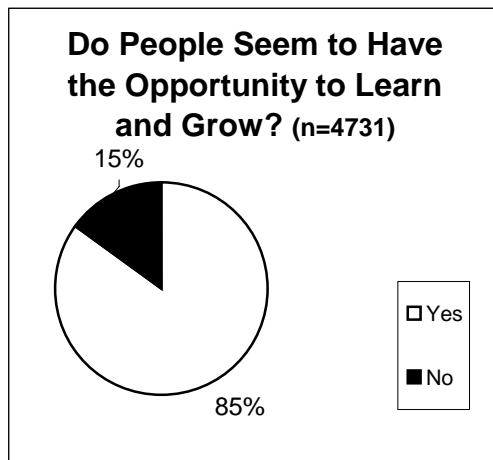
Home Adaptive Equipment

- 89% of individuals reported having all the adaptive equipment and home modifications they needed
- 88% of people said that all necessary adaptations have been made to their home to make it accessible



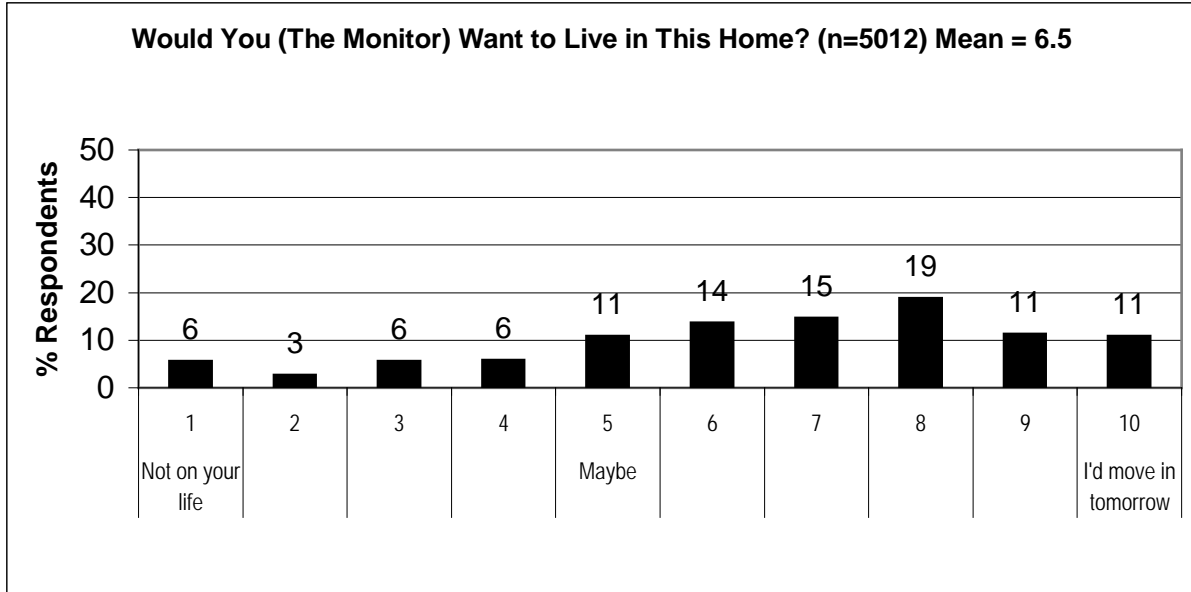
Competence, Personal Growth and Opportunities to Grow and Learn

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,

- 85% of the individuals appeared to have the opportunity to learn new things
- For 46% of the individuals, staff expectations regarding growth was reported as high or very high
- 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 6.5

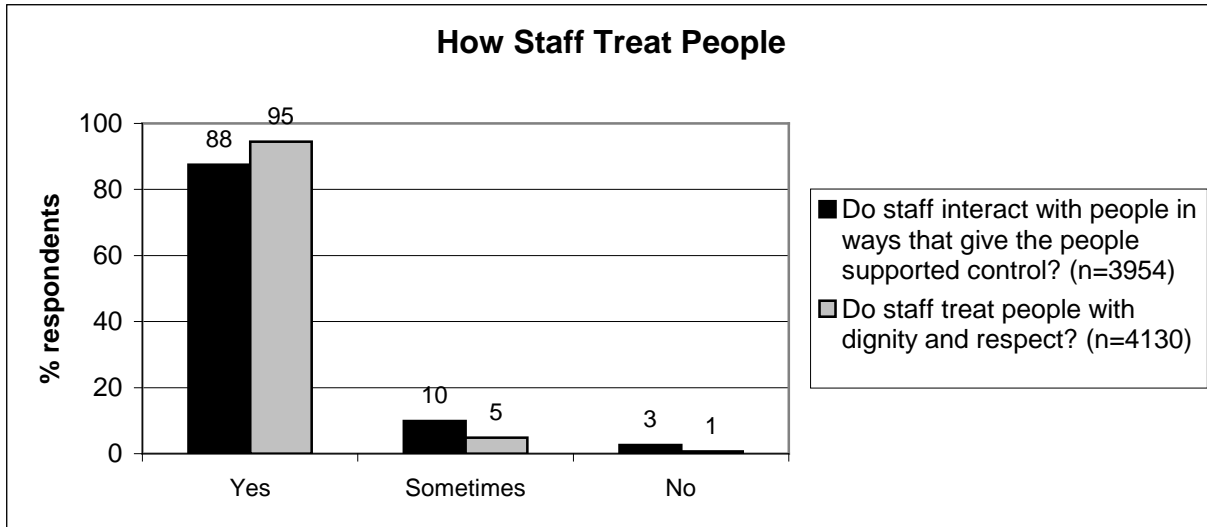


Staff Support for the Person

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

- The majority of staff observed interacted with individuals in ways that gave control to the people supported (87%)
- The majority of individuals had either all staff (68%) or some staff (30%) with the skill needed to support them
- A majority of the staff treated individuals with dignity and respect (94%)



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

- The majority of individuals lived in homes which were in good repair on the outside (93%) and on the inside (91%)

Neighborhood

- The majority of individuals lived in homes which were in a safe neighborhood (94%)
- The majority of individuals lived in homes that “fit in” with the neighborhood in which they were located (90%)

Personal Belongings and Personalities

- The vast majority of individuals (95%) lived in homes which had sufficient space for personal belongings
- Many individuals (63%) lived in homes which reflected the hobbies, interests and personalities of the people who live there

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.

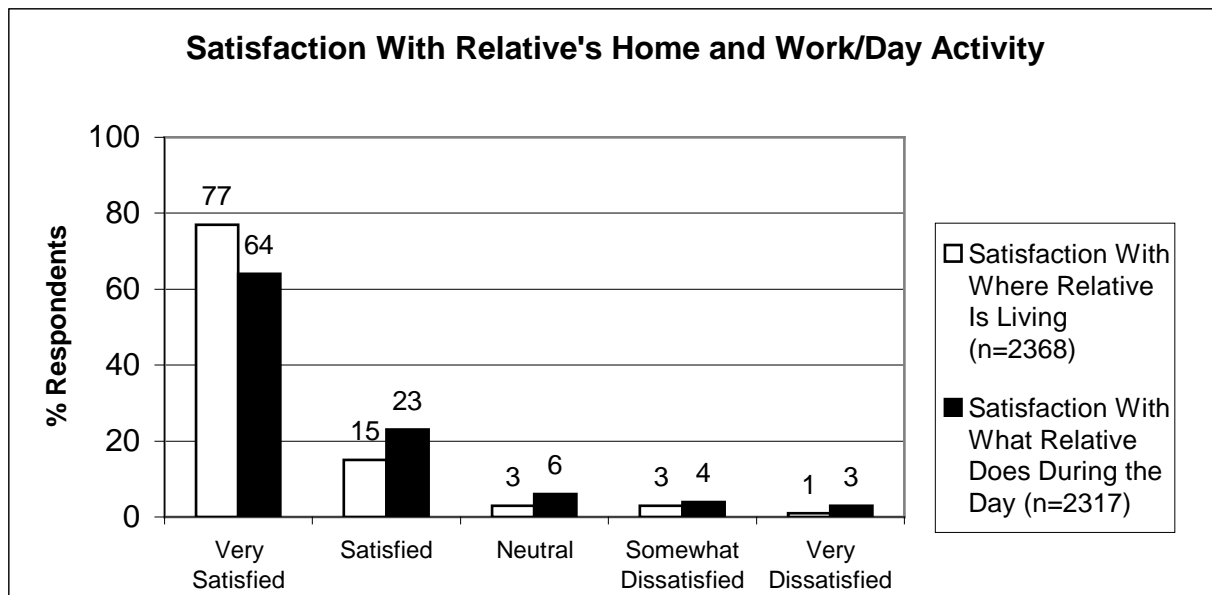
- The average (mean) score equaled 95.64 with a standard deviation of 12.58
- The mode (the value that occurs the most frequently) equaled 100, indicating that many people lived in homes which were at the top of the scale on all measures of the physical setting

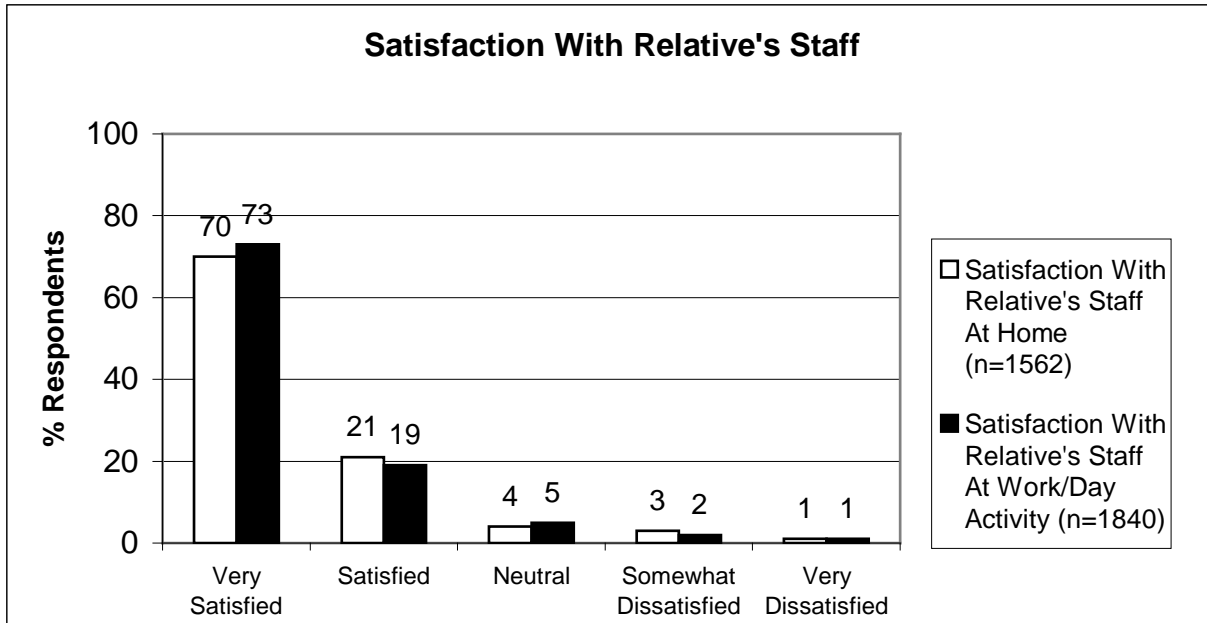
Family/Friend/Guardian Survey

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

- 60% of the surveys were answered by parents
- 25% were answered by siblings
- 1% were answered by the guardian
- <1% were answered by a friend
- 13% were answered by persons with other relationships to the individual receiving supports

Satisfaction



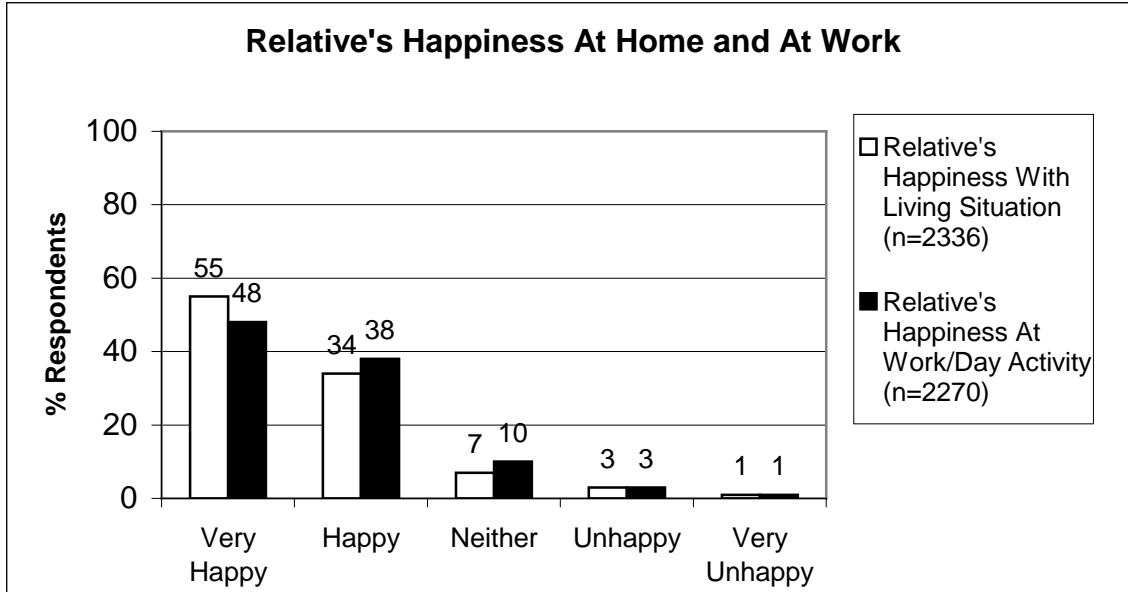


How Often Do You See Your Relative

- Most family/friend/guardians visited their relative at least monthly (70%), although 7% have not visited their relative in the past year
- Sixty percent of the family/friend/guardians had a visit from their relative (or went on outings with them) at least once a month; 17% did not get a visit at all from their relative (or go on an outing) in the past year

Your Relative's Happiness

- The majority of respondents (90%) felt their relative was either very happy or somewhat happy with his/her living situation; 86% felt their relative was happy with what they do during the day
- The majority of respondents (92%) felt their relative was either happy or very happy with the staff who support them at home; only 2% felt their relative was either unhappy or very unhappy
- The majority of respondents (91%) also felt their relative was either happy or very happy with the staff who support them at work (or during the day)



Your Relative's Safety

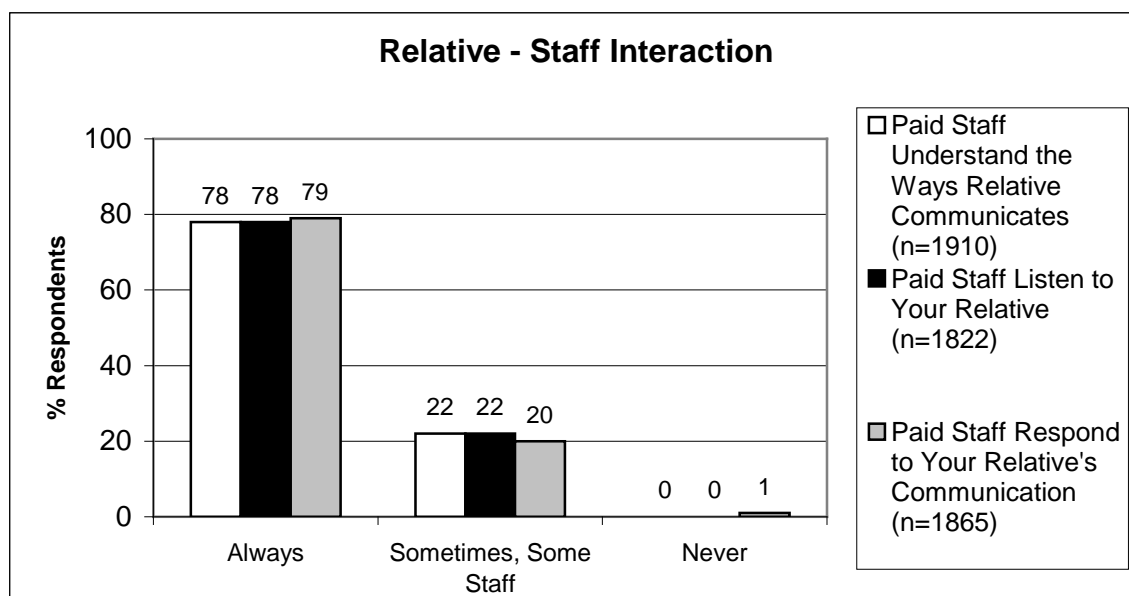
- Respondents said that their relative felt safe at home always (83%), or most of the time (14%)
- Respondents said they think their relative felt safe in their neighborhood always (81%), or most of the time (15%)

Your Relative's Opportunities

- 82% of the respondents said that their relative got enough opportunities to participate in activities in the community
- 87% of the respondents said that their relative seemed to have the opportunity to learn new things

Your Relative's Staff

- More than half of the respondents (51%) said that their relative's staff had either high or very high expectations regarding growth for their relative
- If their relative was non-verbal, 41% 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, 71% of the respondents said that the system was in working order and was being used
- 87% of the respondents said that their relative's home appeared to have enough paid staff
- 85% of the respondents 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
- 73% of the respondents said that all staff appear to have the skills they need to support their relative (25% felt that way about only some staff)



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 equaled 86.23 with a standard deviation of 14.99
- The mode (the value that occurs the most frequently) equaled 100, indicating that many of the families' satisfaction levels were at the top of the scale on all measures of family satisfaction

Family Staff-Relative Communication Scale: Based on the three individual items, a Family Staff-Relative Communication Scale was developed. Scores on this scale could range from 0 to 100, with a higher score indicating greater staff-relative communication.

- The average (mean) score equaled 88.43 with a standard deviation of 18.95
- The mode (the value that occurs the most frequently) equaled 100, indicating that many of the families' staff-relative communication levels were at the top of the scale

Summary

This report presents information collected through face-to-face interviews with 5659 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.

However, the data continue to indicate that individuals have little choice in where they live, with whom they live and with whom they share a bedroom. Individuals report high levels of privacy and respect and significant control over and access to their personal spending money. In addition, for those individuals who do not communicate using words, there continues to be issues around lack of exploration of alternative strategies. Even when it has been explored and people have acquired devices, half the time the devices are not in working order.

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 discuss issues related to individuals as well as systemic issues that may be specific to individual counties. This process is an integral part of the quality improvement process and in a sense, determines the extent to which this process becomes more than just data collection – rather it creates a process that demonstrates change at the individual level, as well as at the county and state levels.