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

Independent Monitoring for Quality
A Statewide Summary
2000-2001

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 attempt by OMR to disseminate 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, the National Core Indicators Project, (NCIP) as a pilot state. Ongoing efforts were set in place to ensure that Independent Monitoring for Quality (IM4Q) was consistent with the NCIP 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 Independent Monitoring for Quality (IM4Q) data is 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 conduct 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.

During this fiscal year (2000-2001), all forty-six 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 this fiscal year, together with 2224 Family/Friend/Guardian surveys.

Surveys were conducted from September, 2000 until June 30, 2001 using a standardized instrument and methodology developed in conjunction with the State IM4Q Steering Committee and the Office of Mental Retardation.

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 105 questions, 39 of which can only be answered by the individuals receiving supports and services.

The EDE for 2000-01 includes all survey questions included in the FY 2000-01 National Core Indicators Project (NCIP) Consumer Survey. Thirteen hundred thirty-five individuals included in this report are represented in the National Core Indicators Project sample for 2000-01, based on a sampling methodology established by the Office of Mental Retardation and the Human Services Research Institute (HSRI). A copy of the NCIP report for FY 2000-01 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 NCIP 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 National Core Indicators Project 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 NCIP sample were 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.

This year's sample included 5,298 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.

	N	Percent
Own residence	282	5.3%
Family's home	869	16.4%
Family living	299	5.6%
Apartment program	262	4.9%
Group home	2462	46.5%
Private ICF/MR	810	15.3%
State MR center	152	2.9%
Large community setting	97	1.8%
Nursing facility	38	0.7%
Other	152	2.9%

Procedure

<u>Selection Of Local IM4Q Programs</u>

OMR requested that counties select local IM4Q Programs to conduct interviews with individuals and families using the EDE and FFG Survey. All 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 and newly formed entities.

<u>Training</u>

Local IM4Q Programs received training on the EDE, F/F/G Survey and interviewing protocols from technical assistants from the Institute on Disabilities/University Center for Excellence. Trainings were held in each of the four regions for project staff. 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.

<u>Team Interview Process</u>

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 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 interviews were 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 was returned to the local IM4Q Program for data entry. EDE and F/F/G Survey data were entered directly onto the Worldwide Web, through a program developed by OMR in collaboration with the Department of Public Welfare's Office of Information Systems and Deloitte Consulting. Training in the use of the data entry program was provided in all four regions by OMR Central Office staff.

Data were to be collected by June 30, 2001 and entered via the Web by August 15, 2001. A usable data file was received by the Institute on Disabilities/UCE in mid-September, 2001. This report presents data on the programs involved in the IM4Q Program, representing the 46 County MH/MR Programs across the state. In addition to this report, each project 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	674	13%
Armstrong/Indiana	74	1%
Beaver	83	2%
Bedford/Somerset	50	<1%
Berks	143	3%
Blair	65	1%
Bradford/Sullivan	24	<1%
Bucks	214	4%
Butler	75	1%
Cambria	69	1%
Cameron/Elk/McKean	60	1%
Carbon/Monroe/Pike	82	1%
Centre	50	<1%
Chester	145	3%
Clarion	30	<1%
Clearfield/Jefferson	50	<1%
Columbia/Montour/Snyder/Union	68	1%
Crawford	49	<1%
Cumberland/Perry	70	1%
Dauphin	123	2%
Delaware	274	5%
Erie	219	4%
Fayette	67	1%
Forest/Warren	30	<1%
Franklin/Fulton	50	<1%
Greene	26	<1%
Huntington/Mifflin/Juniata	55	1%
Lackawanna/Susquehanna/Wayne	171	3%
Lancaster	136	3%
Lawrence	39	<1%
Lebanon	50	<1%
Lehigh	121	2%
Luzerne/Wyoming	117	2%
Lycoming/Clinton	66	1%
Mercer	33	<1%
Montgomery	303	6%
Northampton	88	2%
Northumberland	47	<1%
Philadelphia	745	14%
Potter	30	<1%
Schuylkill	60	1%
Tioga	30	<1%
Venango	30	<1%
Washington	65	1%
Westmoreland	131	2%
York/Adams	117	2%
TOTAL	**5298**	**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 42.8% to 64%.

Satisfaction with Living Arrangements

- 89% of individuals liked where they live
- 75% wanted to stay where they currently live

Satisfaction with Work/Day Activity

- 90% of individuals *with* a day activity/work liked what they did during the day
- 84% of those *without* 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 less
- 69% wanted to continue in their current daytime activities/work

Want to Stay or Change Living Arrangement and Work/Day Activity
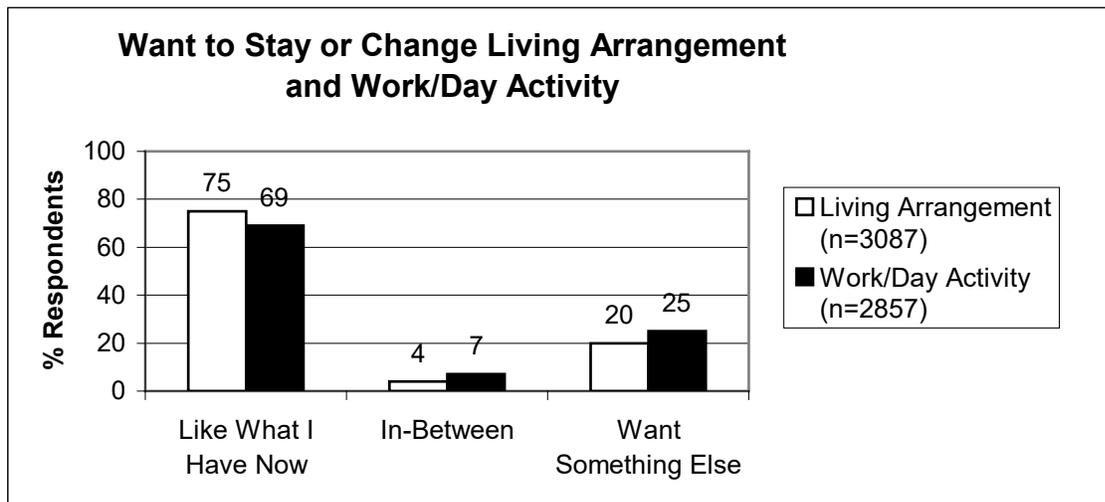
Happiness with Staff at Home

- 91% of individuals were either very happy or happy with the staff who worked with them at home
- 87% felt all staff at home cared about them

Happiness with Staff at Work/Day Activity

- 91% of individuals were either very happy or happy with the staff who worked with them at their work/day activity
- 70% of individuals reported receiving support from staff in making or keeping friends always or most of the time

Happiness with Staff at Home and Work/Day Activity

Staff at Home (n=2424)

Staff at Work/Day Activity (n=2452)

	Very Happy	Happy	In-between	Unhappy	Very Unhappy
Staff at Home	46	45	7	1	1
Staff at Work/Day Activity	42	49	6	2	1
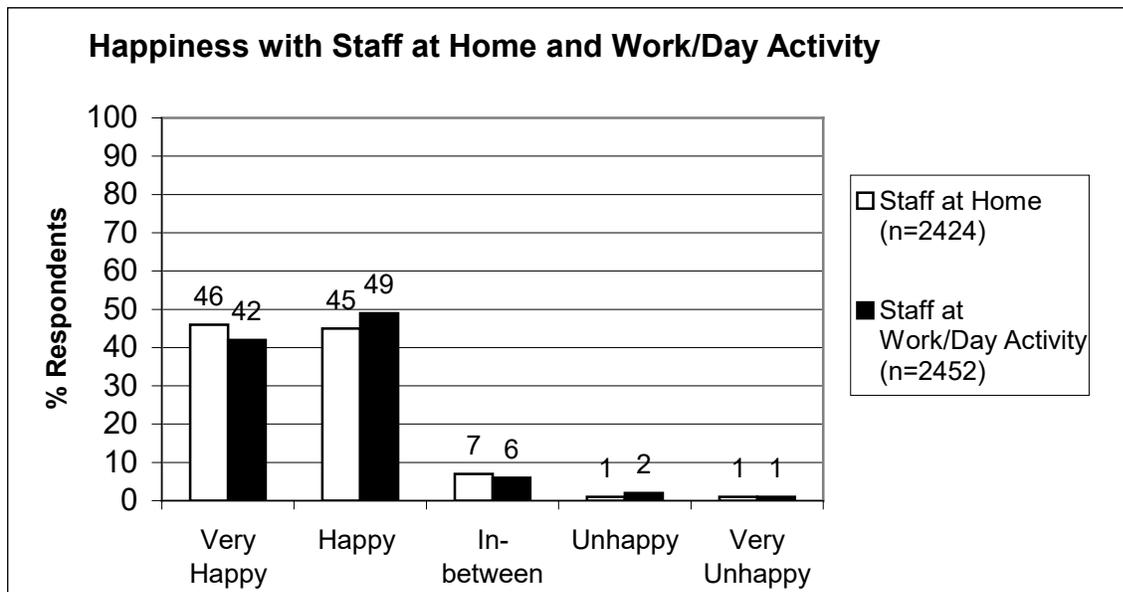
Daily Life

- The majority of individuals liked what they do in their free time

- Nearly half of individuals always had opportunities to participate in household tasks like cooking and cleaning

	Always	*Most of the Time*	*Sometimes*	*Rarely*	*Never*
Like what you do in your free time (n=3116)	64.8%	25.0%	7.9%	1.2%	1.1%
Have opportunities to engage in household tasks (n=3169)	47.5%	19.2%	20.8%	3.5%	8.9%

Happiness and Loneliness

- 74% reported usually feeling happy, 22% reported being in-between, and 5% reported usually feeling sad

- 57% of individuals reported never feeling lonely, 38% reported sometimes feeling lonely, and 5% reported always feeling lonely

Satisfaction Scale: Based on the 11 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 84.56 with a standard deviation of 14.26

- 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 43.5% to 63%.

Perceptions of Other People

- 79% of individuals reported that their housemates/roommates are very nice or nice
- 90% reported that staff at work/day activity are very nice or nice
- 91% reported that staff at home are very nice or nice

Perceptions of Other People
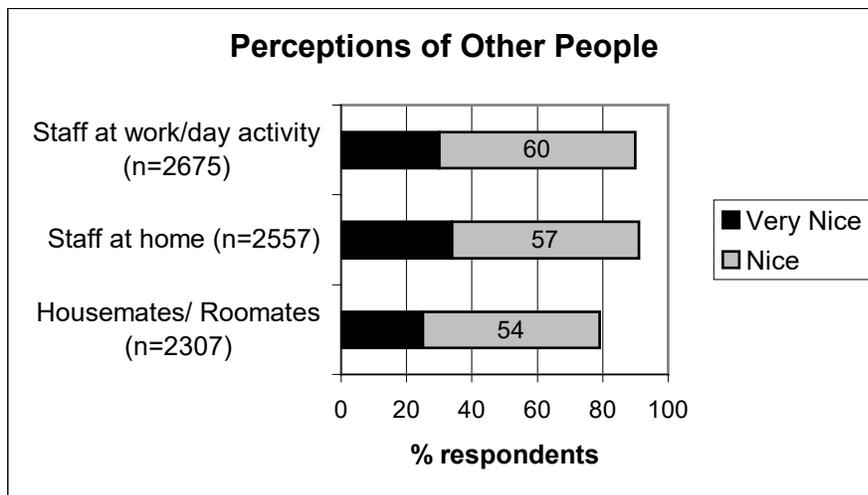
Being Afraid

- 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
- 76% reported never being afraid in the neighborhood
- 84% reported never being afraid at work
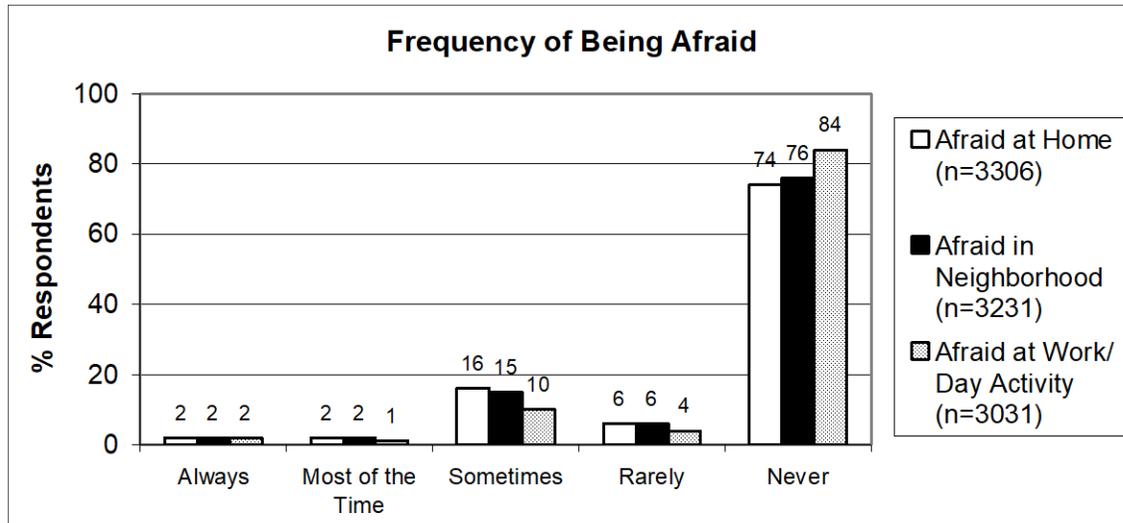
Legal Rights

- 93% of respondents stated that they know they have legal rights

- 42% of people said that they have not voted in the past five years but would like to vote

- Less than half of the people surveyed have been talked to about voting

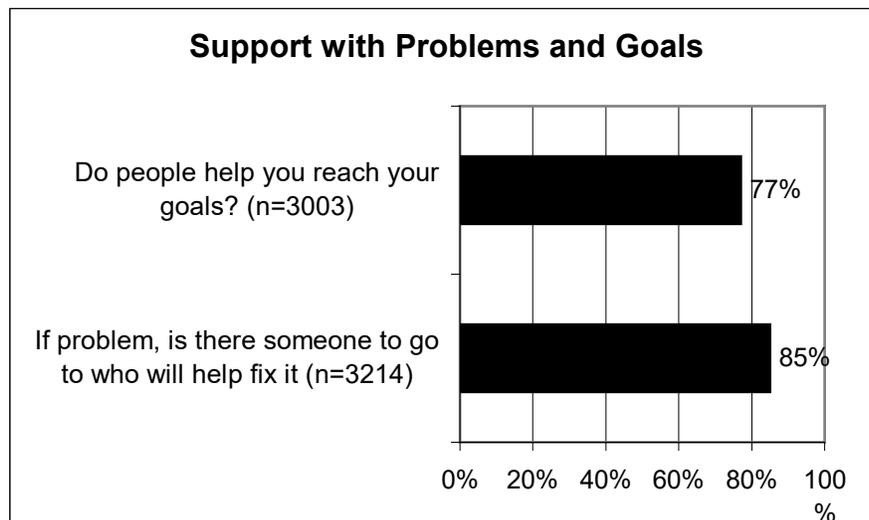- 76% of individuals stated that they always have a choice in how to spend their money

Legal Rights

Category	Percentage
Talked to you about voting (n=2641)	48%
If did not vote, would you like to (n=2524)	42%
Spoken to you about rights (n=2867)	62%
Know you have rights (n=3030)	93%

(0% – 20% – 40% – 60% – 80% – 100%)
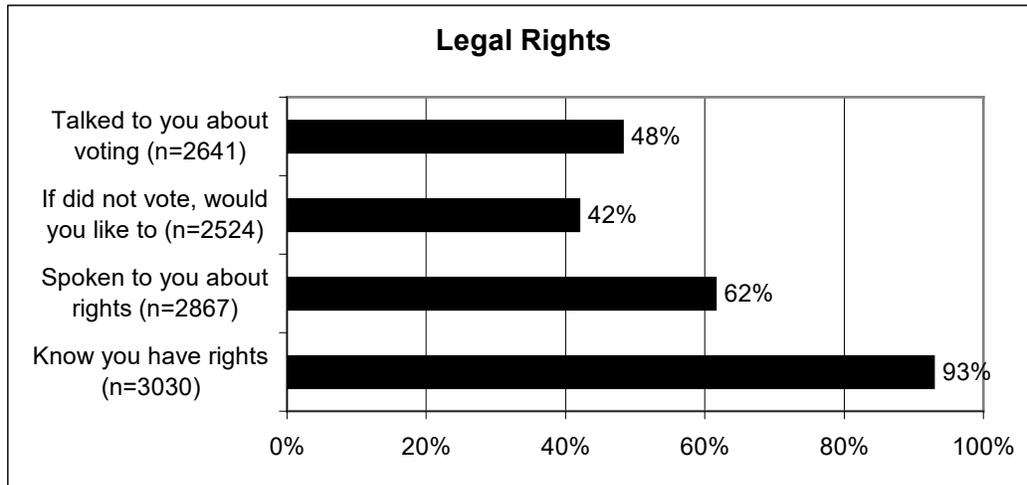
Service / Support Coordination

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

Service/Support Coordination

Question	Percentage
Do you know who your case manager is? (n=3137)	78%
Does your case manager ask what is important to you? (n=2831)	71%
Does your case manager help you get what you need? (n=2834)	73%
Can you talk to your case manager when you want? (n=2426)	73%
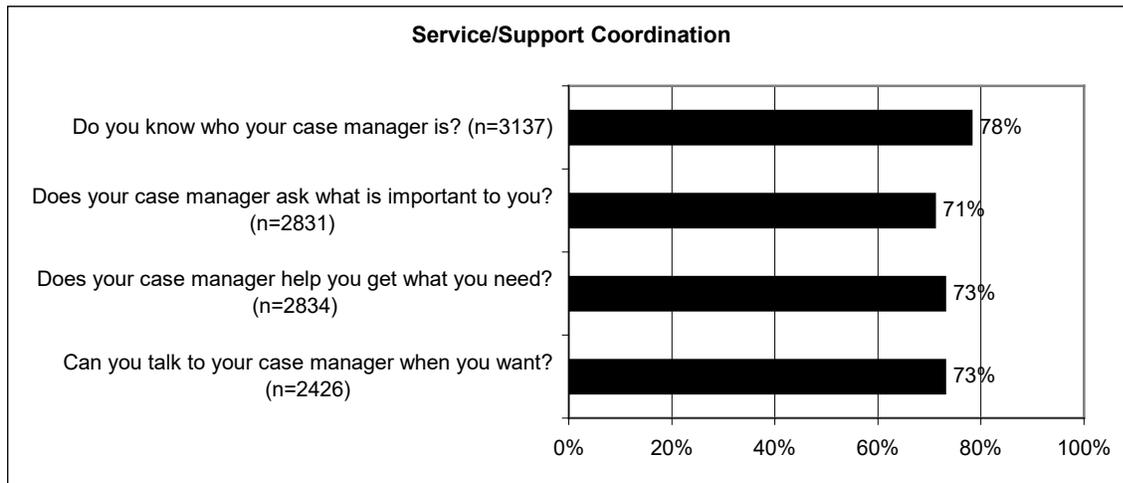
Support with Problems and Goals

- Most people had someone in their life that provided support in fixing problems and reaching goals (indicated on chart by % who responded "always")

Support with Problems and Goals

Question	Percentage
Do people help you reach your goals? (n=3003)	77%
If problem, is there someone to go to who will help fix it (n=3214)	85%

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 78.54 with a standard deviation of 15.45.
- 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 88.35 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 staff /consumers
- In the neighborhood, individuals were most afraid of animals / insects and crime
- At work, the largest definable category of what individuals were afraid of was staff / consumers

	At Home #	In Neighborhood #	At Work #
Alone	26	10	1
Staff / Consumers	77	1	63
Other people/ People in general/ Crowds	46	39	24
Strangers / Crime	28	79	9
Mythical Creatures	16	8	2
Neighbors / Local kids	5	28	3
Darkness / Sleep	69	62	6
Falling / Sickness / Death	31	16	15
Hallucinations/ Delusions	5	2	2
Fighting, violence, teasing	4	2	15
Being Scolded/ Fear of Being Hurt/ Other Feelings	18	19	22
Emergency Situations / Fire / Fire alarms	32	3	4
Weather	123	37	10
Traffic/ Emergency Vehicles/ Transportation	7	30	11
Walking	1	6	0
Noises	35	14	14
Animals / Insects	30	88	6
Houses/ Locked rooms/ Offices/ Stairs	9	2	2
Scary Movies/ Halloween	5	12	0
Work-related mistakes/ Losing Job/ New things on the job	0	0	13
Other	49	31	54
TOTAL	610	496	280

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

- The average (mean) score equaled 76.14 with a standard deviation of 33.37
- The mode was 100. Half of the individuals (50%) scored at the top of the scale regarding their relationship with their case manager.

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,

- 44% of the questions were answered by the individual receiving supports
- 5% of the questions were answered by family
- 51% of the questions were answered by paid staff
- <1% of the questions were answered by friends
- 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 29% of the individuals surveyed had a key to their house or apartment
- For 66.5% 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 15 different places before choosing their home, with an average of 1.17 places (47% saw no other places)
- 78% of the individuals did not choose their housemates
- 74% 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, 35.3% chose some or all of their roommates

Who Chose Where You Live and Work?

% Respondents

Legend: □ Living Arrangement (n=3888)   ■ Work/Day Activity (n=4605)

	Chose without help	Chose with help (friends or family)	Chose with help (provider)	Family or friend chose	Provider chose
Living Arrangement	6	13	14	26	40
Work/Day Activity	17	10	27	6	40

Choice and Control at Home

Have your own bedroom (n=5266)	73%
Meet your housemates (n=3583)	74%
Choose your housemates (n=3650)	24%
Have a key to your house/apartment (n=5233)	29%

(Axis: 0% 20% 40% 60% 80% 100%)

Choice and Control During the Day and for Leisure Time

- 46% of the individuals interviewed reported that someone else chose what they do during the day

- 17% 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 15 other places, with an average of 1.15 other places visited (44% saw no other places)

- 40% of the individuals surveyed chose their daily schedules without assistance

- 58% chose how they spend their free time without assistance

How People Spend Their Day

Type of Activity	Average # of Hours Per Week	N
Workshop	28.18	2385
Work with a job coach	18.05	427
Work independently	19.05	561
Community-based activities	9.05	1621
Adult training/adult day care	26.5	1287
School	23.2	274
Post-secondary education program	6.9	38
Vocational or technical education	15.12	95
Volunteer	5.5	455
Hours spent in transportation	4.97	4141

Note on How People Spend Their Day

> Of the 5298 people interviewed, 6.6% (or 350 people) were not involved in any of the aforementioned activities.

Choosing Staff

- 21% of the individuals interviewed chose at least some of the staff who help them at home (alone or with assistance from family or provider)
- 32% of the individuals surveyed chose the staff who help them at work (alone or with assistance from family or provider)
- 10% of the individuals reported that they chose their case managers/support coordinators (alone or with assistance from family or provider)

Did You Choose the Staff who Work With You?

Category	%
Case manager (n=4742)	5.9
Staff at day activity (n=3628)	20
Staff at home (n=4183)	12.7

Legend: ■ Chose alone □ Chose with help

% respondents
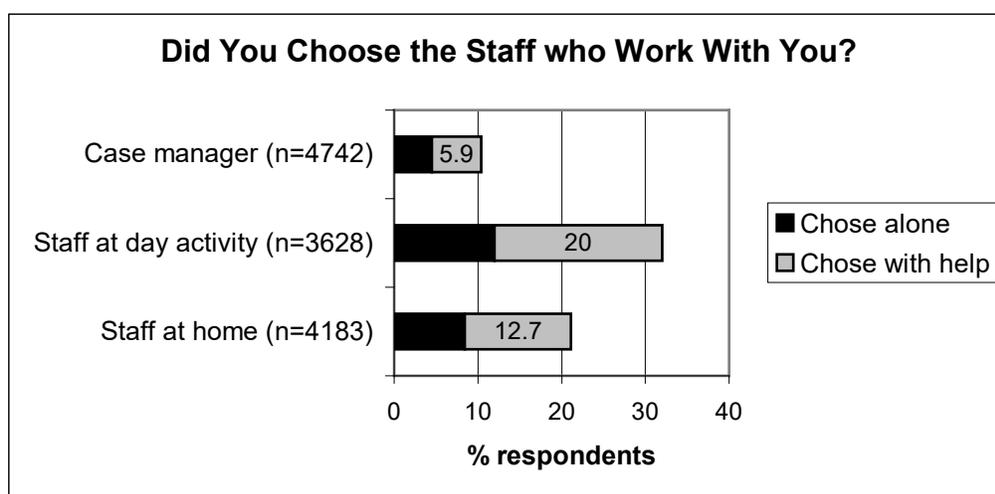
Money

- 62% of the individuals interviewed reported that they always have their spending money whenever they want it
- 53% of the individuals reported that they can always have as much of their spending money as they want

Access to Spending Money
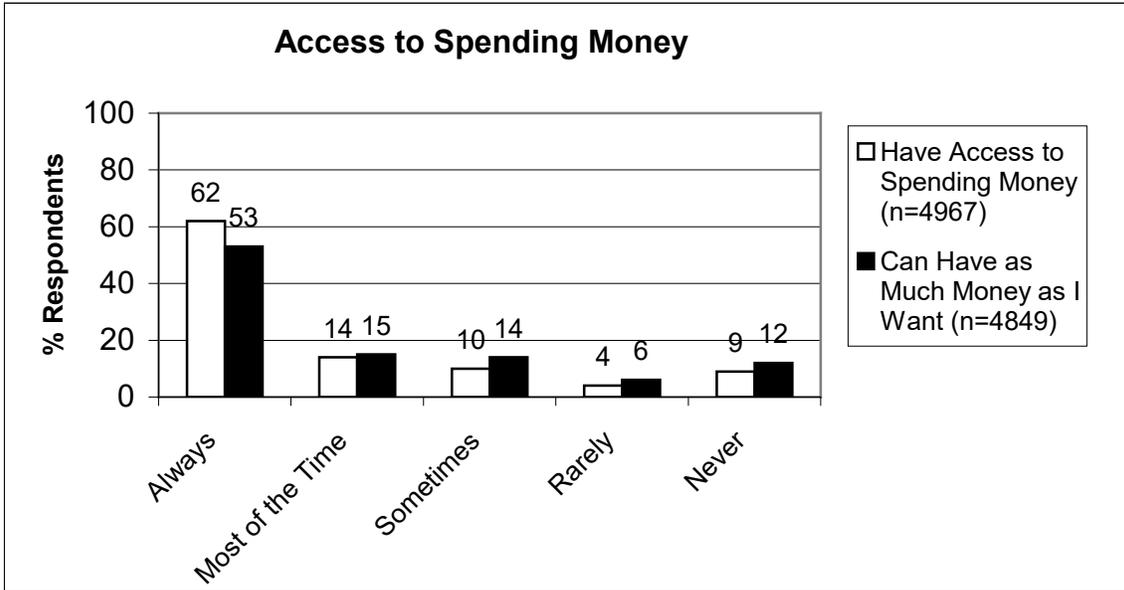
Privacy

- 72% of the individuals always had privacy to make phone calls
- 70% of individuals reported that people always knock and wait for an answer before coming into peoples' homes
- 66% of individuals reported that people always knock and wait for an answer before entering peoples' bedrooms
- For 68% of the individuals interviewed, their mail is never opened without permission; however, 16% say their mail is always opened without permission
- 90% of the individuals reported that they can have privacy with visitors

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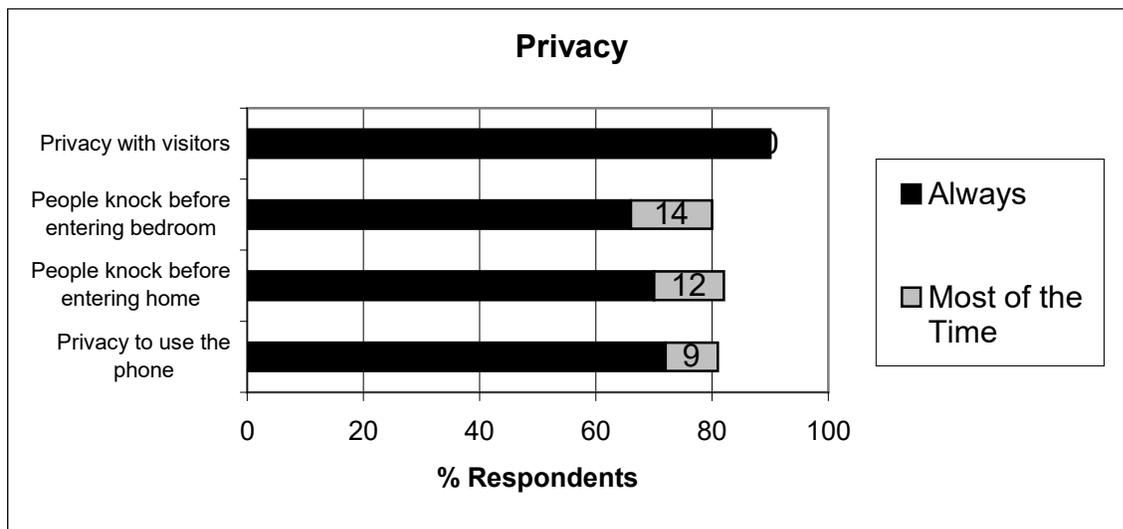
Choice and Control Scale: The scale included nine measures that asked individuals about the extent to which individuals have choice and control in their lives. Scores on the Choice and Control Scale could range from 0 to 100, with a higher score indicating more opportunities to exert choice and control.

- The average (mean) score equaled 59.07 with a standard deviation of 19.26
- The modal score was 65

Relationships

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

- 46% of the questions were answered by individuals receiving supports
- 6% were answered by family
- 48% were answered by paid staff
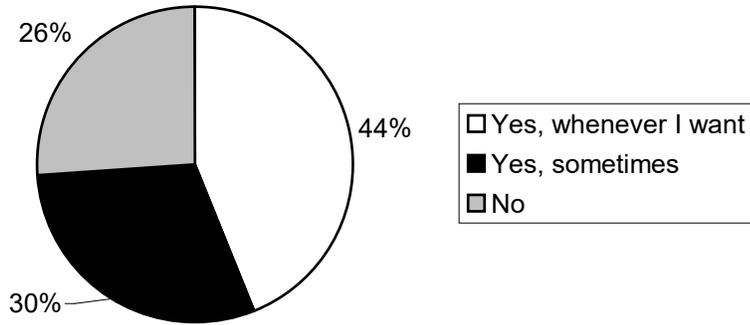- A value of missing was assigned when individuals did not answer, gave an unclear answer, or responded, "do not know."
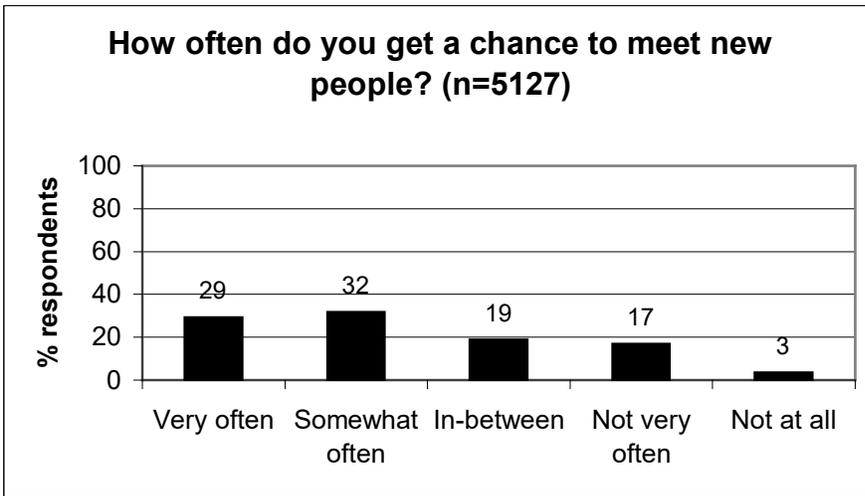
Friendships

- Slightly more than half of the individuals had friends that they like to do things with who are not staff or family
- 15% of individuals reported that they had no friends with whom they like to do things

Do you have friends you like to do things with? (n=4944)
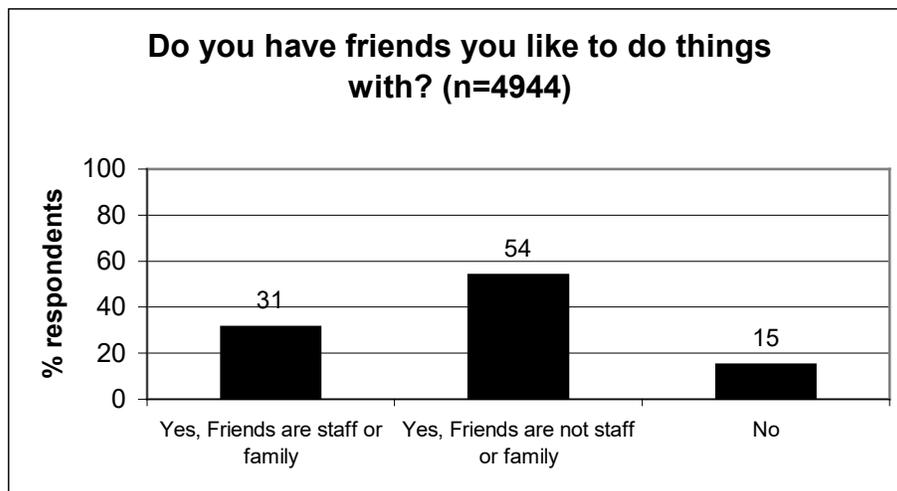
- 44% of people answered that they can see-talk-visit with old friends whenever they want
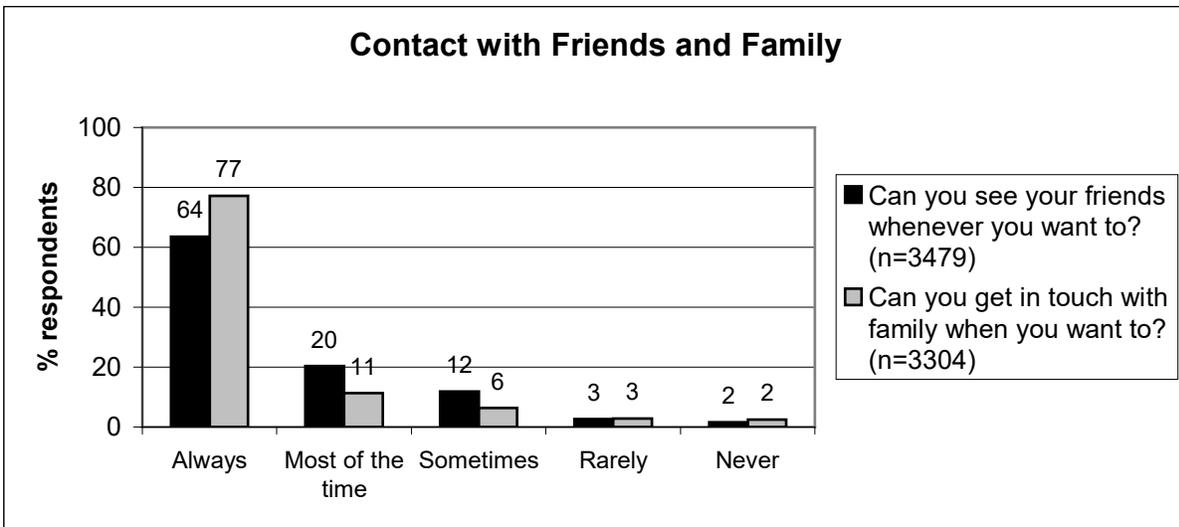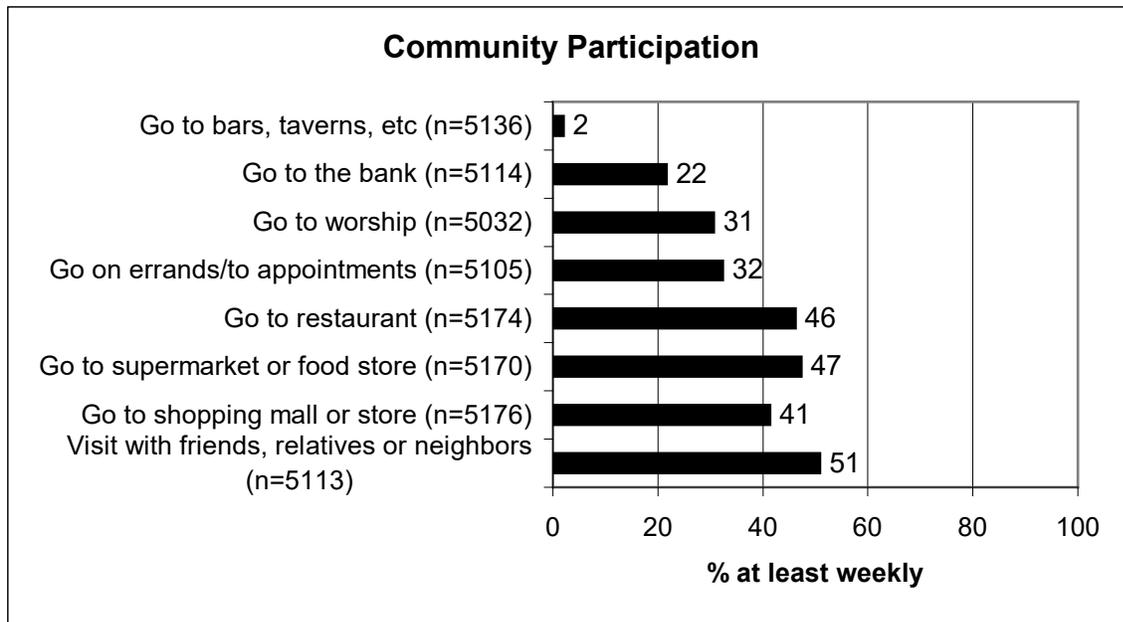- 77% of individuals reported that they have a best friend

Do you get a chance to see-talk-visit with old friends (n=4517)

26%

44%

30%

- ☐ Yes, whenever I want
- ■ Yes, sometimes
- ☐ No

How often do you get a chance to meet new people? (n=5127)

Category	% respondents
Very often	29
Somewhat often	32
In-between	19
Not very often	17
Not at all	3

Contact with Friends and Family

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

Contact with Friends and Family

Category	Can you see your friends whenever you want to? (n=3479)	Can you get in touch with family when you want to? (n=3304)
Always	64	77
Most of the time	20	11
Sometimes	12	6
Rarely	3	3
Never	2	2

Inclusion

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

- 41% of the questions were answered by individuals receiving services/supports
- 8% were answered by family
- 51% were answered by paid staff
- A value of missing was assigned when individuals did not answer, gave an unclear answer, or responded, "do not know."

Community Participation

- About 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

Community Participation

Category	% at least weekly
Go to bars, taverns, etc (n=5136)	2
Go to the bank (n=5114)	22
Go to worship (n=5032)	31
Go on errands/to appointments (n=5105)	32
Go to restaurant (n=5174)	46
Go to supermarket or food store (n=5170)	47
Go to shopping mall or store (n=5176)	41
Visit with friends, relatives or neighbors (n=5113)	51

% at least weekly

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 as compared to the Harris Poll
- Pennsylvanians with disabilities in this study were more likely to go to a restaurant, to worship or to a shopping mall as compared to the national sample of people with disabilities (although still less likely than the national sample of people 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%	51%
Go to supermarket	83%	55%	47%
Go to restaurant	59%	40%	46%
Go to worship	47%	30%	31%
Go to shopping mall or store	41%	23%	41%

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 average score equaled 40.21 with a standard deviation of 15.43.
- The average score was not very high, indicating that individuals do not go to community places with great frequency.
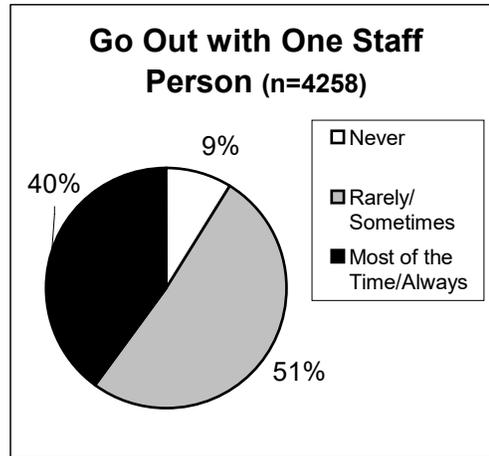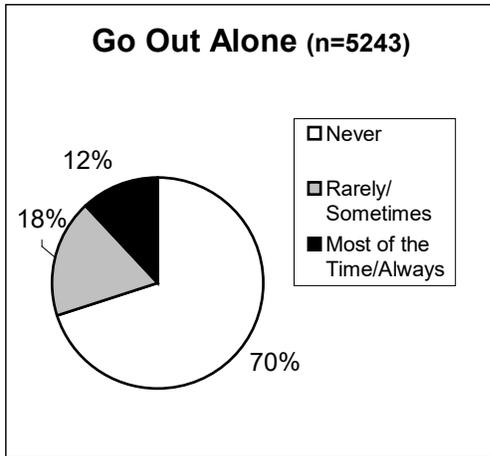- The mode was 50.00

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 to a social event (81.5%) and least likely to have been to a meeting/event of an advocacy group (18.9%).

- 22% of individuals reported that they always or most of the time attend community events that are only for people with disabilities

- 42% of respondents never carry an ID card and 40% always carry an ID card

Community Activities

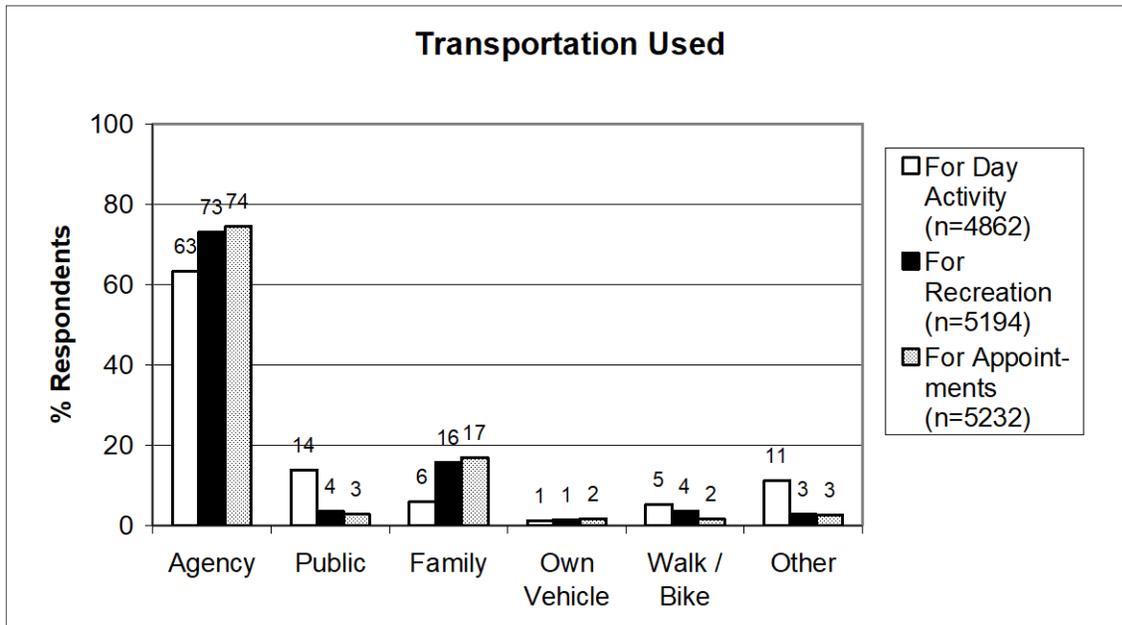| Category	% Respondents Who Participated
Self-Advocacy Organizations (n=4894)	19
Clubs/Community Organizations (n=5147)	41
Exercise (n=5211)	77
Entertainment (n=79.6)	80
Social Events (n=5236)	82

% Respondents Who Participated
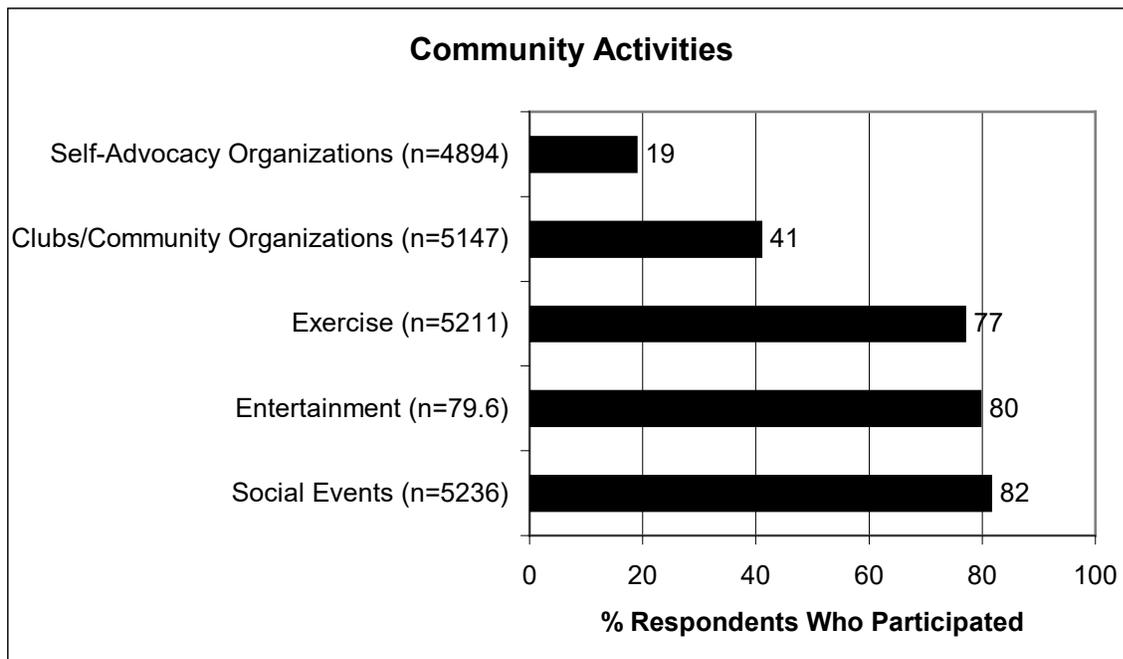
Going Out Alone or With Just One Staff

- 71% of individuals never go out alone

- 40% of individuals go out with just one staff most of the time or always
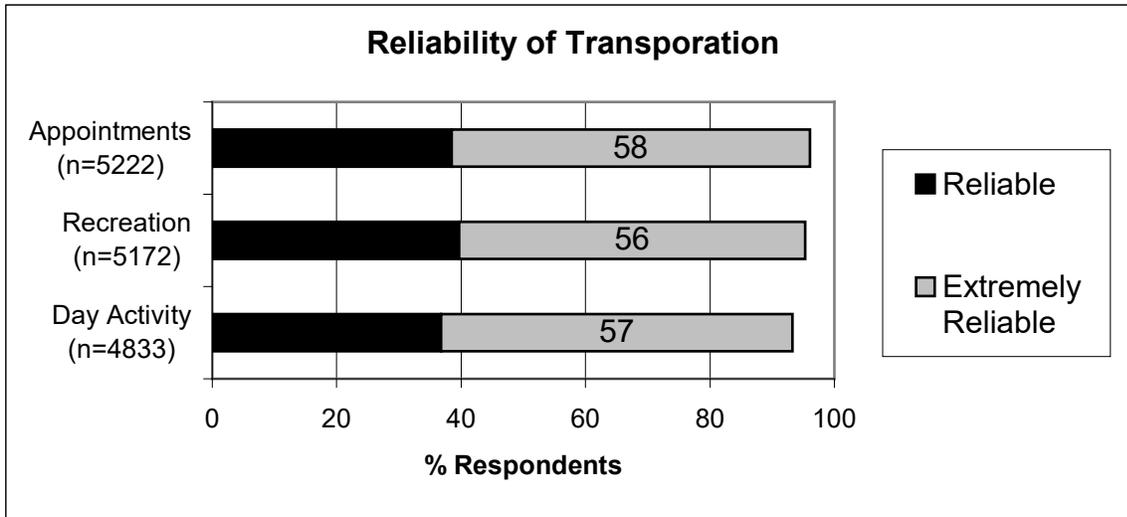
Go Out Alone (n=5243)

12%

18%

70%

Never

Rarely/ Sometimes

Most of the Time/Always

Go Out with One Staff Person (n=4258)

9%

40%

51%

Never

Rarely/ Sometimes

Most of the Time/Always

Transportation

- Overwhelmingly, individuals relied on agency transportation, especially for medical and business appointments

Transportation Used

% Respondents

100

80

60

40

20

0

| Agency | Public | Family | Own Vehicle | Walk / Bike | Other |

63 73 74

14 4 3

6 16 17

1 1 2

5 4 2

11 3 3

For Day Activity (n=4862)

For Recreation (n=5194)

For Appoint- ments (n=5232)

- Most individuals felt that their transportation was reliable or extremely reliable

Reliability of Transporation

Transportation Scale: Scores could range from 0 to 100, with a higher score indicating greater reliability.

- The average (mean) score equaled 87.43 with a standard deviation of 14.35
- The mode was 100
- Individuals perceived their transportation to be very reliable, with the greatest number of individuals reporting that their transportation for work, leisure and appointments are all extremely reliable
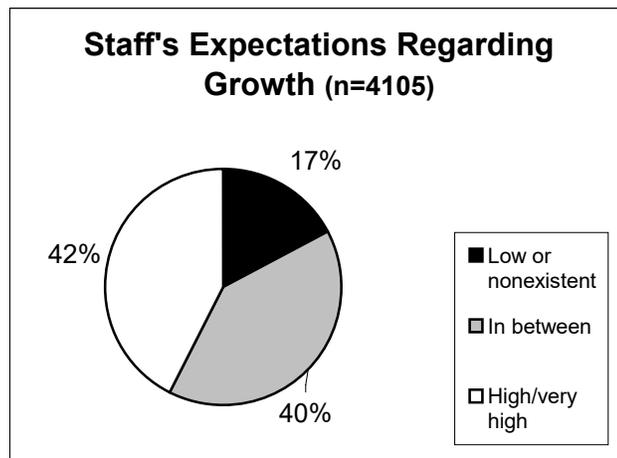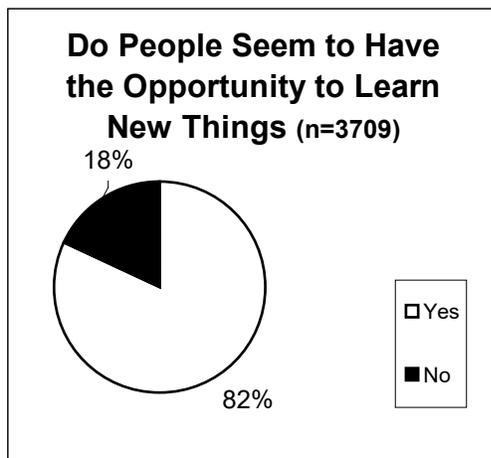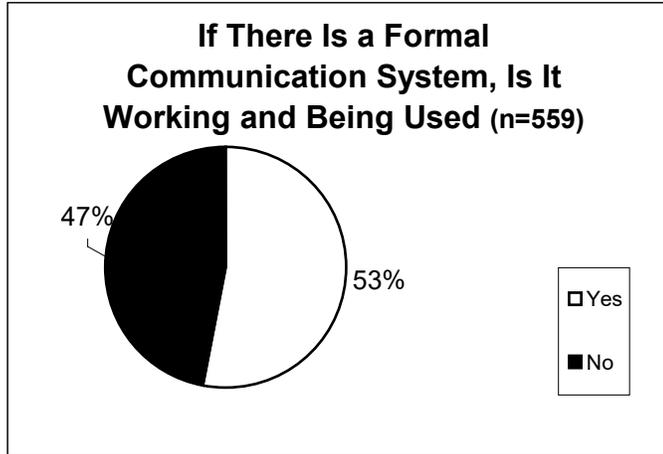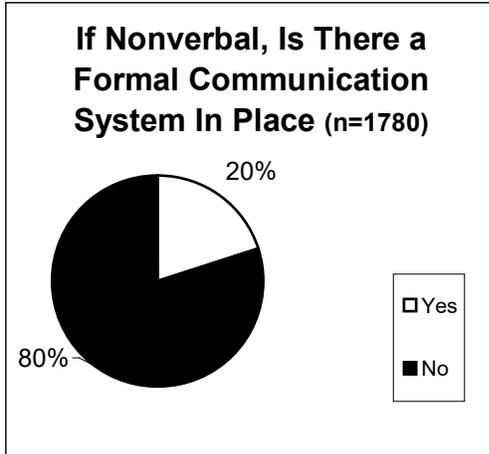
Home Adaptive Equipment

- 85% of individuals reported having all the adaptive equipment and home modifications they needed.

Do You Have Needed Adaptive Equipment and Home Modifications (n=3822)

8%

6%

85%

- No
- Yes- limited
- Yes
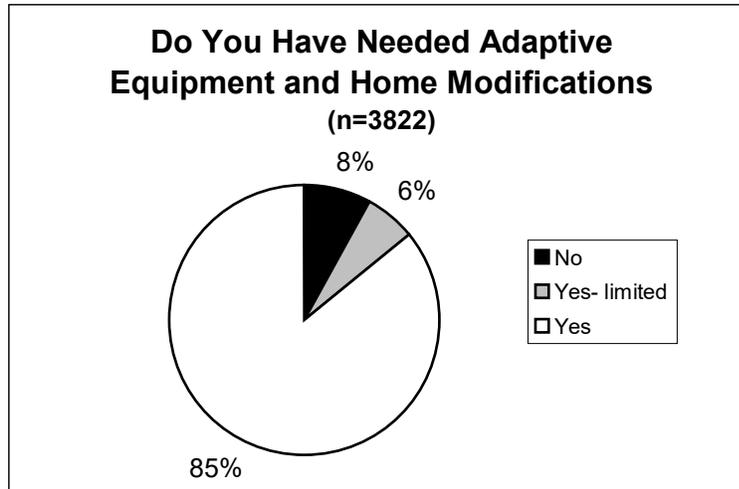
## *Competence, Personal Growth and Opportunities to Grow and Learn*

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.

Do People Seem to Have the Opportunity to Learn New Things (n=3709)

18%

82%

- Yes
- No

Staff's Expectations Regarding Growth (n=4105)

17%

42%

40%

- Low or nonexistent
- In between
- High/very high

If Nonverbal, Is There a Formal Communication System In Place (n=1780)

20%

80%

□ Yes
■ No

If There Is a Formal Communication System, Is It Working and Being Used (n=559)

47%

53%

□ Yes
■ No

According to the IM4Q teams,

- 82% of the individuals appeared to have the opportunity to learn new things

- for 42% of the individuals, staff expectations regarding growth was reported as high or very high

- for those individuals who do not communicate using speech, only 20% had a formal communication system in place

- for those people with a communication system in place, the system was working and being used for 53% of the individuals

- when asked how interesting is this home on a scale of 1 to 10, the average score was 6.7


How interesting is this home, from 1 to 10? (n=5243) Mean = 6.7

% respondents

1	2	3	4	5	6	7	8	9	10
2	2	4	6	13	15	19	21	11	8
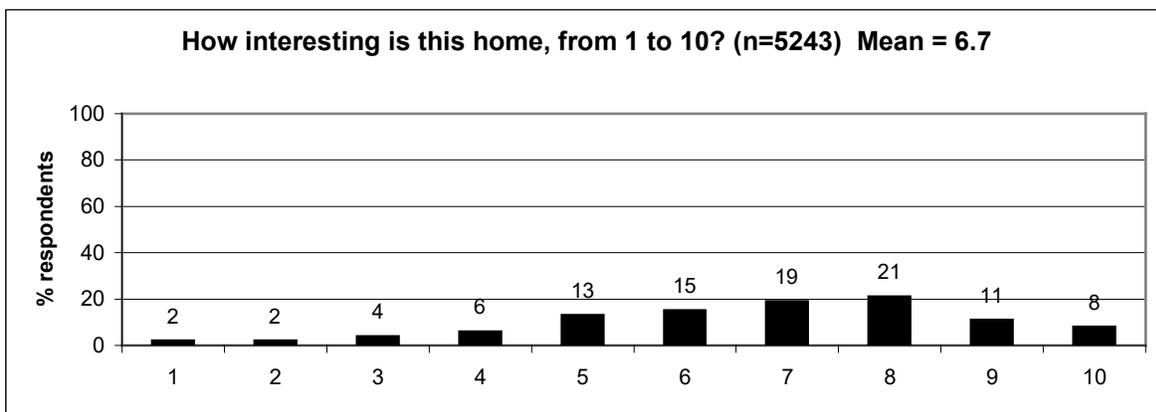
Staff Support for the Person

**Respondents:** The Independent Monitoring Team answered the questions on staff support for the person.

Number of Staff and Staff Skill

- The majority of individuals had an adequate number of staff to support them (83%)
- The majority of individuals had either all staff (71%) or some staff (26%) with the skill needed to support them
- Many individuals were observed making choices or decisions (55%)

How Staff Treat People
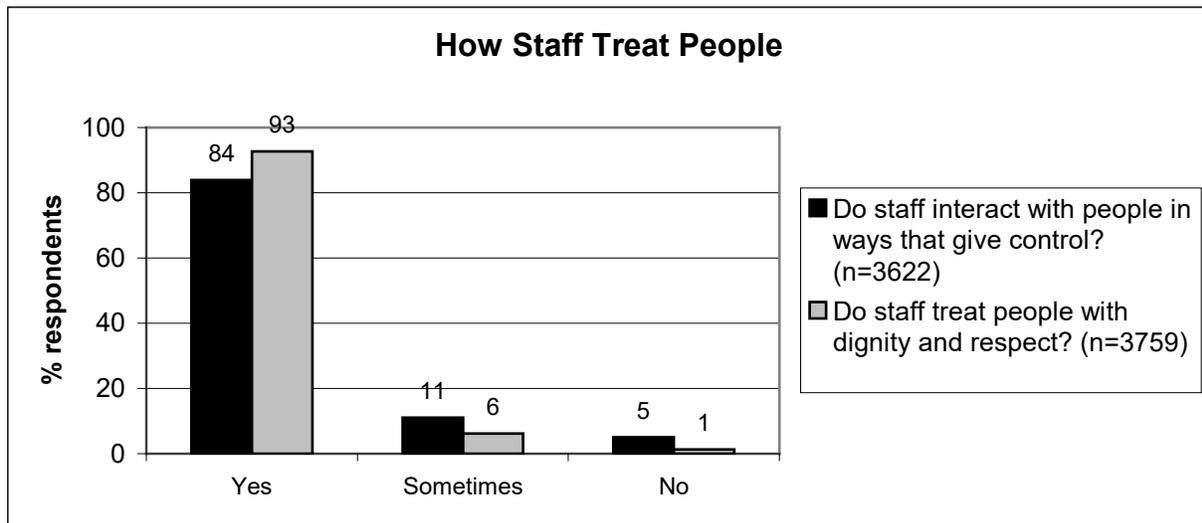
Physical Setting

**Respondents:** The IM4Q Team answered the following questions regarding the physical setting.

Home Repair

- The majority of individuals lived in homes which were in good repair on the outside (89%) and on the inside (87%)

Neighborhood

- The majority of individuals lived in homes which were in a safe neighborhood (89%)
- The majority of individuals lived in homes which looked harmonious with the neighborhood in which they were located (84%)

Home Adaptations

- The majority of individuals (80%) lived in homes in which all necessary adaptations have been made to make the house accessible to the people who live there (n=2823)
- The majority of individuals (87%) lived in homes in which all necessary environmental adaptations have been made for the people who live there (n=2517)

Personal Belongings and Personalities

- The vast majority of individuals (93%) lived in homes which had sufficient space for personal belongings
- Many individuals (66%) 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 was developed. Scores on the Physical Setting Scale could range from 0 to 100, with a higher score indicating a nicer setting.
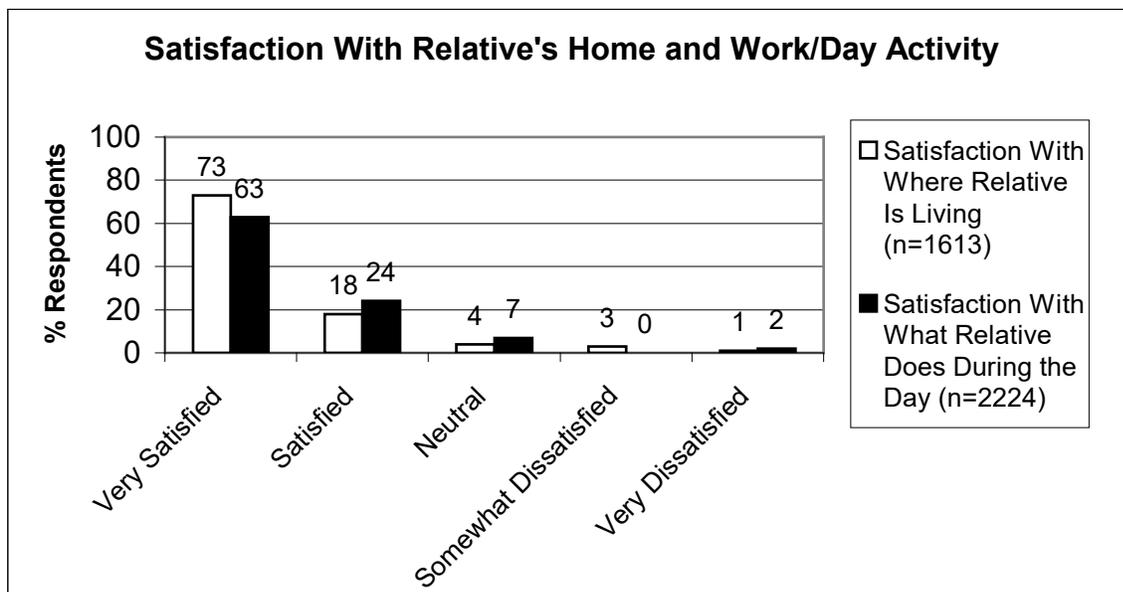
- The average (mean) score equaled 92.84 with a standard deviation of 17.15
- The mode (the value that occurs the most frequently) equaled 100, indicating that many people lived in homes which were at the top of the scale on all measures of the physical setting

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.

- 62% of the surveys were answered by parents

- 23% were answered by siblings

- 1% were answered by the guardian

- 2% were answered by a friend

- 11% were answered by persons with other relationships to the individual receiving supports

Satisfaction

Satisfaction With Relative's Home and Work/Day Activity

Legend:
- □ Satisfaction With Where Relative Is Living (n=1613)
- ■ Satisfaction With What Relative Does During the Day (n=2224)

	Very Satisfied	Satisfied	Neutral	Somewhat Dissatisfied	Very Dissatisfied
Where Relative Is Living	73	18	4	3	1
What Relative Does During the Day	63	24	7	0	2

**Satisfaction With Relative's Staff**

How Often Do You See Your Relative

- Most family/friend/guardians visited their relative at least monthly (61%), although 10% have not visited their relative in the past year

- Less than half of the family/friend/guardians had a visit from their relative (or went on outings with them) at least once a month (49%); 24% 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 (89%) 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 (89%) also felt their relative was either happy or very happy with the staff who support them at work (or during the day)

Relative's Happiness At Home and At Work
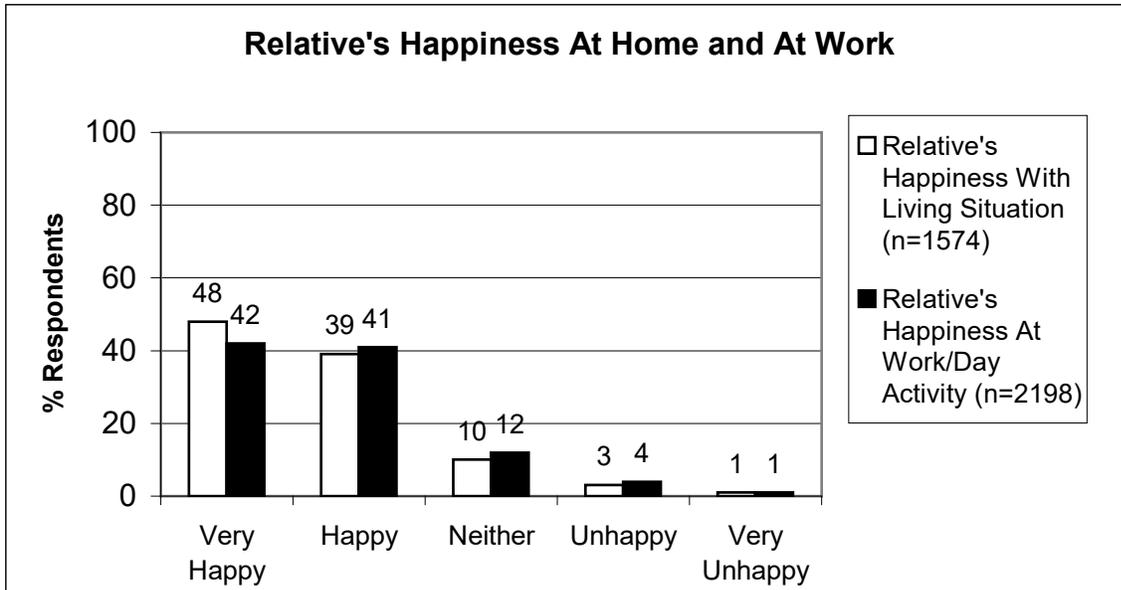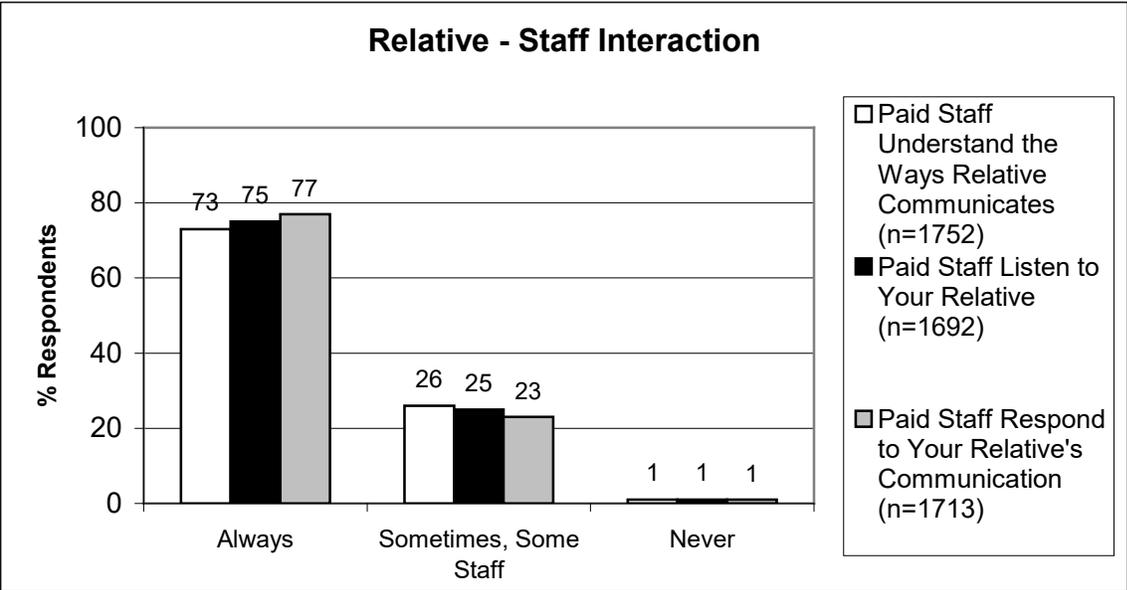

Your Relative's Safety

- Respondents said that their relative felt safe at home always (74%), or most of the time (22%)

- Respondents said they think their relative felt safe in their neighborhood always (74%), or most of the time (21%)

Your Relative's Opportunities

- 84% of the respondents said that their relative got 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
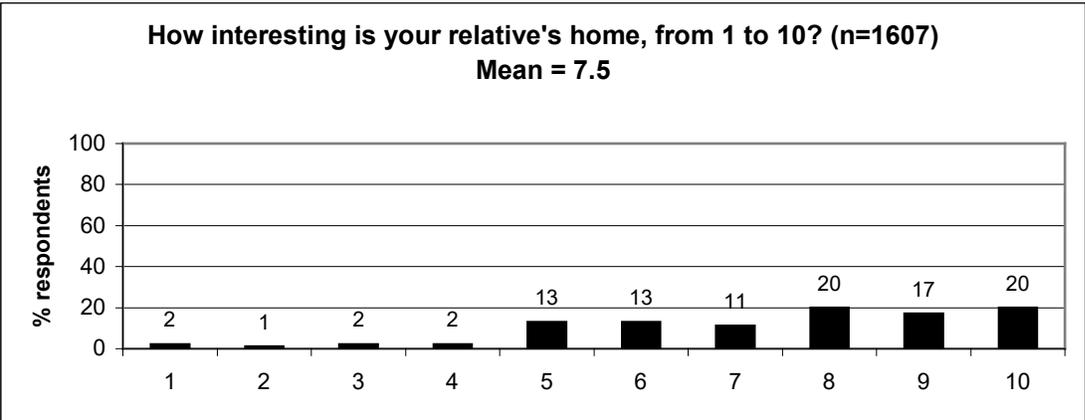
Your Relative's Staff

- More than half of the respondents (55%) said that their relative's staff had either high or very high expectations regarding growth for their relative
- If their relative was non-verbal, 38% 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, 66% 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
- 83% of the respondents said that staff in their relative's home interact with people in ways that give control to the people being supported
- 92% of the respondents said that staff in their relative's home treat people with dignity and respect
- 72% of the respondents said that all staff appear to have the skills they need to support their relative (26% felt that way about only some staff)

Relative - Staff Interaction

Legend:
- ☐ Paid Staff Understand the Ways Relative Communicates (n=1752)
- ■ Paid Staff Listen to Your Relative (n=1692)
- ☐ Paid Staff Respond to Your Relative's Communication (n=1713)

Always: 73, 75, 77
Sometimes, Some Staff: 26, 25, 23
Never: 1, 1, 1

Your Relative's Home Is Interesting

- When asked how interesting is your relative's home on a scale of 1 to 10, the average score was 7.5

How interesting is your relative's home, from 1 to 10? (n=1607)
Mean = 7.5

Score	1	2	3	4	5	6	7	8	9	10
% respondents	2	1	2	2	13	13	11	20	17	20

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 83.95 with a standard deviation of 17.24
- 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 86.67 with a standard deviation of 20.54
- 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 5298 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, 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 are few examples where augmentative communication has been explored. 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 communication loop 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, known as "closing the loop" 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.