

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

**Independent Monitoring  
A Statewide Summary  
1999-2000**

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

**Submitted by: Celia S. Feinstein, Robin M. Levine,  
James A. Lemanowicz and Allison C. Carey  
The Institute on Disabilities  
Pennsylvania's University Center for Excellence in  
Developmental Disabilities  
Temple University  
Ritter Hall Annex (004-00)  
Philadelphia, PA 19122**

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

## **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.

In January, 1999 OMR invited counties to participate in the Independent Monitoring Pilot Project. Counties were asked to describe what the independent monitoring projects would look like and how they would operate. To begin the pilot phase, counties were asked to submit a budget, assuming that one third of the individuals living in licensed residential settings would be visited each year.

The stated purposes of Independent Monitoring include:

1. Monitoring on an annual basis one third of the individuals in each county who are living in licensed residential settings including private intermediate care

facilities for people with mental retardation (ICFs/MR). The sample was meant to include both children and adults;

2. Providing information about life outcomes including the satisfaction of people receiving supports through Pennsylvania's Office of Mental Retardation;
3. Through the focus on consumer outcomes, providing families and consumers with information to assist in making informed choices about where and from whom services and supports are received;
4. Identifying best practices across the Commonwealth;
5. Eventually issuing performance profiles to providers, reporting strengths, and areas for improvement;
6. Continuously improving the quality of services and supports provided to people with mental retardation and their families in Pennsylvania, by focusing on a model of continuous quality improvement,
7. Creating a process to insure necessary change at the state, county and provider levels; and
8. Providing information through an entity that is independent of "hard" service delivery (residential, day, early intervention, etc.).

Of the forty-five county mental health/mental retardation programs (MH/MR) eligible to submit proposals, twenty applications were submitted. A ten-person review team chosen by OMR reviewed the 20 proposals. Thirteen proposals were approved to begin in Fiscal Year 1998-1999; the remaining seven counties were to begin during the first half of Fiscal Year 1999-2000. OMR sent letters to the remaining 25 counties (later a 26<sup>th</sup> county was added due to the split of a joiner in the western part of the state) requiring that they begin independent monitoring projects during the second half of Fiscal Year 1999-2000.

## **Literature Review**

Traditionally, quality in community residential programs for people with disabilities (specifically mental retardation) was measured through "compliance approaches" in which evaluators assessed programs' compliance with government-created rules concerning safety and well being (Lakin 2000). While there have been many criticisms of this type of approach, two related problems are central. First, compliance and quality are very different concepts, evidenced by the fact that most scandals and court cases concerning low quality care involved institutions that had met ICF/MR standards (Lakin, 2000). While standards for health and safety were very important, these measures did not tap

into the lived experience of consumers; measures of quality failed to consider how consumers were treated, if consumers had meaningful choices, and if consumers were satisfied. Second, the government assumed primary responsibility for compliance monitoring, relying on systems of provider reporting and inspections. Typically, consumers were not consulted throughout the monitoring process; they were not asked to assist in developing measures of quality or to provide their opinions concerning the quality of the programs in which they were involved. Monitoring was performed by professionals who had no experience as consumers of these types of services. According to Mochan et al (1996: II-1), “state licensure and county monitoring required no actual service recipients to be present or consulted during inspections. Often service providers received advanced notification of monitoring visits. Quite naturally, they sought to create problem-free environments and documents showing full compliance with all rules.” Thus, the compliance approach emphasized the creation of standards and the monitoring of compliance with these standards to be done by governmental and service professionals.

Recently, a significant shift has begun occurring in how we conceptualize and gather data concerning quality. Spurred on by the broader paradigm shift toward inclusion, empowerment, and equality, the meaning of quality has moved from compliance to a more complex conceptualization involving an examination of individual outcomes and the degree to which an individual is satisfied with those outcomes. Currently, quality is more likely to be understood as the extent to which a program or service assists a person to attain and maintain his/her “desired conditions of living related to home and community living, employment, and health functioning” (Schalock 1994). As such, what is defined as “quality” in part depends upon the needs, desires, and perceptions of individuals (Sundram 1994). Within this model, measures of quality take into account, for example, consumer satisfaction, consumer choice, and the degree to which consumers are treated with respect and dignity (Oregon Developmental Disabilities Council 1997).

As the experiences and perceptions of consumers became central to conceptualizing quality, the gathering of data also was called into question. On-site inspections and compliance forms no longer could adequately serve as a means by which to gather data, nor could government inspectors and human service professionals simply shift their focus and begin interviewing consumers rather than recording compliance. If consumers are to offer candid opinions concerning their quality of life, they must feel safe and comfortable confiding such information. Moreover, for consumers to invest their time, they need to be assured that the process is meaningful, both in terms of measuring what is important to them and of having the potential to create desired changes.

Citizen Monitoring (of which independent monitoring is one variation) “is a process for citizens who are not service providers, program staff, or human service bureaucrats to gather the experiences, outcomes, and candid opinions of citizens who are service recipients of the mental retardation (or developmental disabilities) service system” (Mochan 1996). Within this method, none of the people responsible for monitoring is a professional working in the systems being monitored. Moreover, consumers play a central role in all aspects of monitoring, from instrument design and data collection to interpretation, and they serve as the primary source of data concerning the quality of services.

There appears to be many advantages to this method. For service providers, they learn how consumers perceive their services and what consumers want from services and from life more generally. Because the measures reflect the priorities and goals of consumers, they offer service providers a valid indication of quality and provide concrete directions for future improvements. Thinking about benefits to consumers, they may be empowered through their involvement with monitoring, whether as interviewees, interviewers, or participants in focus groups concerning methods and measurements. Just being asked questions about choice, respect, and dignity can increase awareness about their rights and

what they ought to expect from their services. Ideally, the monitoring process works to benefit both consumers and providers such that service providers can improve their services to maximally meet the desires of their consumers (see Mochan 1996).

Oregon and Oklahoma developed similar projects, referred to as Advocates Involved in Monitoring (AIM) (Oklahoma's project was modeled after Oregon's project). Interviewers were volunteers, some of who had disabilities and others of whom were family members, friends, and advocates. No service professionals working for monitored systems could serve as interviewers. Two concepts central to their monitoring system were customer satisfaction and customer choice: "Customer satisfaction is the key to high quality services and customer choice encourages competition and quality" (Oregon Developmental Disabilities Council, 1997:1).

In Maryland, the "Ask Me!" project is unique for its commitment to hiring people with developmental disabilities as interviewers. The "Ask Me!" project hired forty persons with developmental disabilities, most of whom received state-funded services, to conduct quality of life interviews with consumers. Concerning the involvement of people with disabilities in the "Ask Me!" project, Bonham, et.al. (1999:1) Stated, "the project believes that people with developmental disabilities elicit and provide data on quality of life that is at least as valid and reliable as data collected from or by others, if not more valid and reliable."

Summarizing the experiences with consumer monitoring, Lakin (2000) found that the inclusion of people with disabilities in the monitoring process is still rare, but increasingly programs throughout the nation are making a concerted effort to include people with disabilities in their monitoring efforts and to allow people with disabilities to define the meaning(s) of quality. Moreover, he found that service providers and consumers found these monitoring efforts useful. Lakin also suggested several limitations of monitoring projects: (1) the findings of monitoring

projects had little official impact for licensing, certification, funding or program requirements; (2) the “add-on” status of monitoring projects reduced their ability to create change and gain access to programs, and increased the perception of monitoring as an extra burden; (3) projects were often limited by funding and reliance upon volunteers; and, (4) there was often a lack of clear purpose, agreed-upon outcomes, and well-defined reporting procedures, leading teams struggling to define the purpose and benefits of their project.

Given the concerns expressed by Lakin, the Pennsylvania Independent Monitoring Project has painstakingly developed guidelines for Independent Monitoring Projects. In an effort to streamline the number of visits to a person’s home, and hence reduce the perceived “burden” of monitoring, in the second year, the National Core Indicators Project has been folded into the Independent Monitoring Project. In addition, in July 2000 the projects came together to celebrate the first year’s data collection effort, and also to discuss and brainstorm systemic issues that had not yet been resolved. For example, projects continue to struggle with the notion of “closing the loop.” Once data are collected, how is the information reported, followed up on (by the county) and tracked by the Independent Monitoring Projects? As the projects mature, these issues are being resolved in a way that assures all parties that there is an agreed upon purpose, agreed upon outcomes and well developed and well defined reporting procedures.

At the current time the Office of Mental Retardation is involved in a significant information management initiative. As part of this initiative, the quality assurance and enhancement system is being developed (where necessary) and improved (where necessary) to produce a cohesive system that identifies issues through the provision of information in a way that people can respond, correct and improve on an ongoing basis. The independent monitoring data will be one source of information that will be used in this effort.

## **Methodology**

### **Instrument**

When the Planning Advisory Committee subcommittee on Independent Monitoring first began to meet, it was decided that in addition to developing a process for independent monitoring, there should be a core set of questions that would be asked of each individual surveyed. Projects were to be able to customize the survey instrument to meet their needs, but in order to create a statewide snapshot, it would be necessary to ask the same core set of questions of all individuals monitored.

One of the technical advisors to the project began the task of amassing the various instruments that had been developed around the country for similar efforts. It was decided by the subcommittee that Pennsylvania would develop its own instrument, rather than utilize any of the existing surveys in total. The instruments reviewed included the National Core Indicators Project Consumer Survey; Ask Me, AIM (Advocates Involved in Monitoring), 1990 National Consumer Survey, Consumer Survey from the National Home of Your Own Project, Vermont's Consumer Satisfaction Survey, and the Citizen Monitoring Instrument from ARC Allegheny. Other instruments were reviewed as well, but it was believed that the aforementioned instruments provided more than an adequate jumping off point from which to develop a Pennsylvania-specific instrument. An instrument was developed and revised several times to reflect the input of the PAC subcommittee. The resulting instrument, entitled, "Essential Data Elements" is comprised of the following sections:

- A pre-survey form which is completed prior to the scheduling of the appointment with the individual – this gives information about where the person lives, the name of the person to contact to schedule the appointment, whether the home is accessible, the case manager's name and phone number, and whether the individual has an unique communication style that might require the use of an interpreter (e.g., sign language, Spanish)
- Demographics – this includes questions about type of residential setting, BSU number, Social Security number, etc.



- Satisfaction – this section can only be completed by the individual receiving services/supports; questions are asked about satisfaction with where the person works and lives, as well as with staff who support the individual
- Dignity, Respect and Rights – this section can also only be completed by the individual receiving services/supports; questions are asked about whether roommates and staff treat people with respect, whether people are afforded their rights, and whether they have fears at home, at work or in the community
- Choice and Control – this section may be answered by the individual, or by a family member, friend or staff person; questions are asked about the extent to which individuals exert choice and control over various aspects of their lives
- Relationships – this section may be answered by the individual, or by a family member, friend or staff person; questions are asked about friends, family and neighbors, and individuals' opportunity to visit and see them
- Inclusion – this section may be answered by the individual, or by a family member, friend or staff person; questions are asked about opportunities for community inclusion; a section of the Harris Poll is included for comparative purposes
- Monitor Impressions – this section of the survey is completed by the Independent Monitoring team, after they have completed their visit; questions are asked in the areas of physical setting, staff support and opportunities for growth and development
- Major Concerns – this form is to be completed whenever there is an issue related to physical danger, significant sanitation problems, or evidence of physical or psychological abuse or neglect; each project is required to develop a mechanism for communicating this information; in the event of imminent danger, teams are instructed not to leave the home until resolution of some kind is achieved
- Family/Friend/Guardian Survey – a phone survey is conducted with each family once the individual gives his/her approval; questions relate to families' satisfaction with their relative's living situation, as well as their perceived satisfaction of their relative

## **Sample**

The focus of this Independent Monitoring effort is individuals served by the Mental Retardation service system. To begin with a known population that would be manageable, it was decided that Year 1 activities would be restricted to individuals living in licensed residential settings. This would include people living in community living arrangements, supervised apartments, family living programs, private intermediate care facilities for people with mental retardation (ICFs/MR) and large community homes (formerly private licensed facilities). The

intent is to expand the project over time to include people living in other types of settings (nursing homes, domiciliary care, etc.), people living at home with families, and people receiving other non-residential supports (vocational, etc.). Counties were asked to draw a random sample of one third of the individuals living in licensed residential settings. The budget for the project was based on the one-third sample, as determined by the Office of Mental Retardation.

The resulting sample includes 2,796 people. Reported ages range from 7 years to 95 years, with an average age of 44 (S.D. =13.8). The following table shows the breakdown of the sample by type of residential setting. As the table shows, the majority of the people in the sample live in supervised living settings.

	<b>N</b>	<b>Percent</b>
Own residence/family's home	15	0.5%
Supervised living	2017	72.0%
Supported living	109	3.9%
Family living	169	6.0%
Private licensed facility	65	2.3%
Private ICF/MR	397	14.2%
Other	24	0.8%

## **Procedure**

A request for proposals (RFP) was issued by OMR to the counties to develop Independent Monitoring Projects in their counties. The RFP included requirements of independence of the projects from service delivering entities and consumer and family involvement on governing boards as well as involvement in data collection activities. Seven projects were granted funds to begin work in January 1999; an additional 13 projects were to begin activity on July 1, 1999. The first several months of start-up involved developing project boards, recruiting and hiring data collectors and providing training to data collectors. Projects were selected by counties from a variety of organizations, including non-service providing ARCs, Consumer Satisfaction Teams (in the mental health system), parent groups and newly formed entities. Dr. Guy Caruso provided countless

hours of technical assistance to the projects to help with start up activities. Technical assistants from the Institute on Disabilities/UAP, Celia Feinstein and Robin Levine, developed training on the Essential Data Elements survey. 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.

Once the sample was drawn, a list of individuals to be monitored was forwarded to the Independent Monitoring Project (IMP) 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 projects assigned interviews to their independent monitoring teams (IMTs). At a minimum, IMTs are comprised of two people, one of whom is an individual with a disability or a family member. Teams also include other interested citizens who are not part of the mental retardation system. Visits to individuals' homes are scheduled with them, or with the person designated on the pre-survey form. Participation in the interview is voluntary; if an individual refuses to participate, s/he is replaced in the sample with another individual. The interviews are meant to take place at the home of the individual, but if s/he prefers that the interview take place elsewhere, alternate arrangements are made. The interview is to be conducted in private whenever possible, unless the individual expresses a desire to have others present.

After data collection, all Essential Data Elements forms are returned to the IMPs. The forms are edited for clarity and accuracy; then data entry occurs, performed by the local projects. This year's data were entered into an ACCESS database that was created by the Department of Public Welfare's Office of Information Systems (OIS), in collaboration with the staff of the Institute on Disabilities/UAP and the OMR. 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, 2000 and entered and mailed to both OMR and the Institute on Disabilities/UAP.

Data were to be sent by August 31, 2000. Due to some minor misunderstanding about where data were to be sent, the complete data were not received by the Institute on Disabilities/UAP until September 15<sup>th</sup>, 2000. This report presents data on the first 19 projects involved in the Independent Monitoring Project. 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.

	Frequency	Percent
Allegheny	674	24%
Armstrong/Indiana	75	3%
Beaver	32	1%
Berks	119	4%
Blair	33	1%
Bucks	179	6%
Butler	21	1%
Carbon/Monroe/Pike	86	3%
Crawford	51	2%
Delaware	274	10%
Fayette	66	2%
Lackawanna/Susquehanna/Wayne	50	2%
Lancaster	136	5%
Luzerne/Wyoming	64	2%
Montgomery	93	3%
Northampton	57	2%
Northumberland	47	2%
Philadelphia	709	25%
Schuylkill	30	1%
TOTAL	2796	100%

### Satisfaction

*Respondents:* The questions on satisfaction could only be answered by the individual receiving services/supports. A value of missing was assigned for those individuals unwilling or unable to respond. In addition, we checked for consistency by asking a similar question concerning satisfaction with where one lives in two different ways. One hundred sixty-two individuals gave different responses when asked these similar questions. Their responses were removed from analysis for all items concerning satisfaction.

*Measures:* The satisfaction section consisted of 7 questions:

- Do you like where you live now or would you rather live somewhere else?
- Do you like what you do during the day or would you rather do something else?

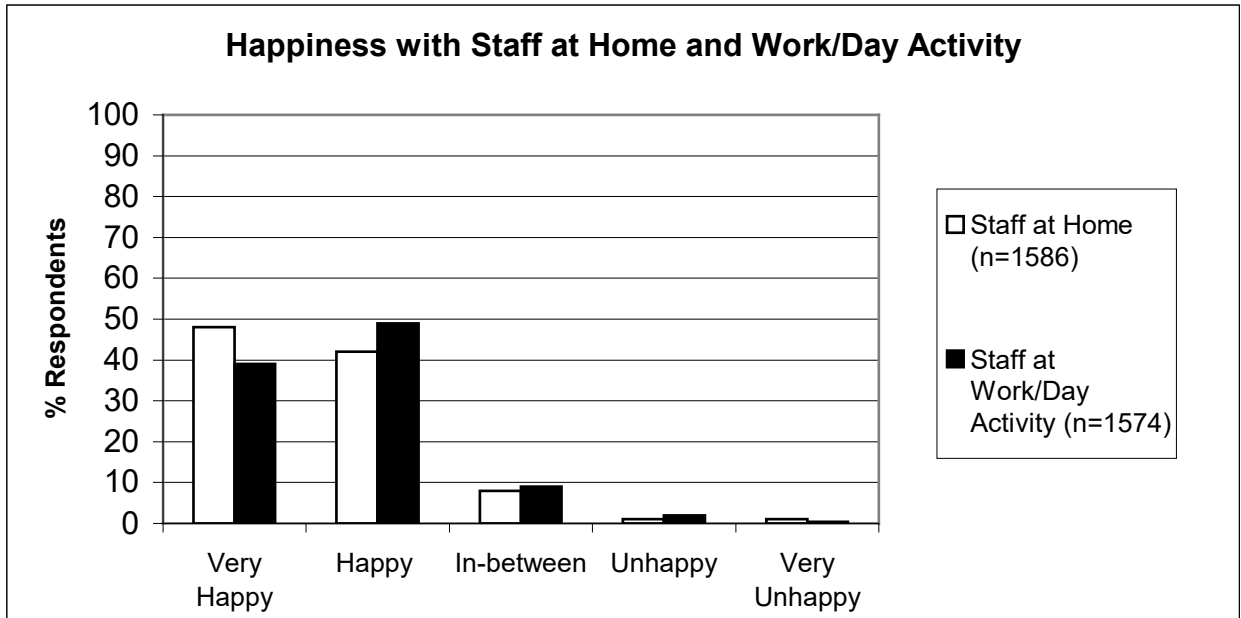
- Do you like what you do in your free time?
- How happy are you with the staff who work with you at home?
- How happy are you with the staff who work with you at work or other day activity outside of your home?
- Do you get a chance to be involved in household tasks like cooking and laundry?
- Do staff help you find new friends and keep friends you have made?

*Individual Items:* In general, satisfaction was high. Seventy-nine percent of individuals wanted to stay where they currently lived, and 85% liked their current work or day activity. These percentages are high, but it is important to note that satisfaction 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; rather than comparing their services to other services or an abstract ideal service, they draw only upon their limited experience and therefore perceive their service as satisfactory.



Looking at whether individuals are happy with their staff, 48% of individuals are very happy and 42% are happy with the staff who work with them at home.

Thirty-nine percent of individuals are very happy and 49% are happy with the staff who work with them at their work/day activity.



Sixty-three percent of individuals report always liking what they do in their free time, and an additional 26% report liking what they do in their free time most of the time. When asked if they had opportunities to participate in household tasks like cooking and cleaning, 69% report always or most of the time, but 31% report only having such opportunities sometimes, rarely or never. When asked if staff support you in making and keeping friends, 77 % report always or most of the time, but 23% report only having support sometimes, rarely, or never.

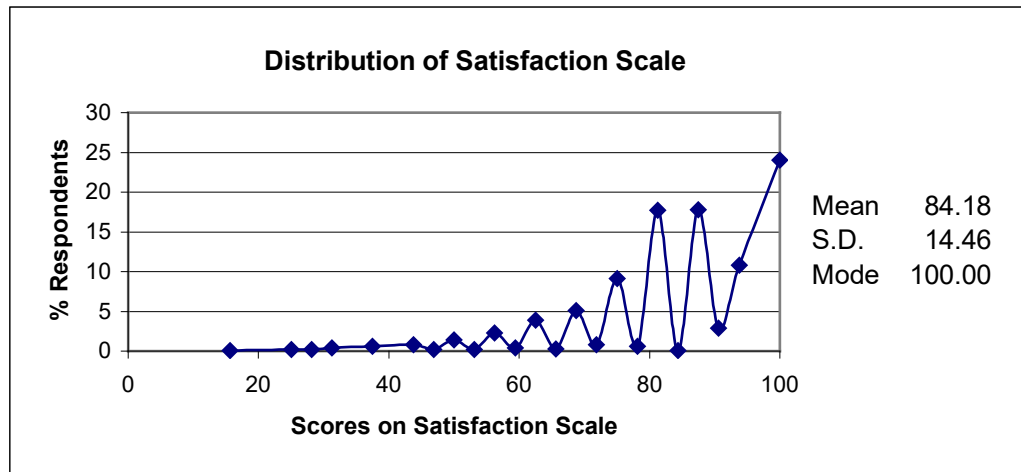
	<b><i>Always</i></b>	<b><i>Most of the Time</i></b>	<b><i>Sometimes</i></b>	<b><i>Rarely</i></b>	<b><i>Never</i></b>
<b>Like what you do in your free time (n=1637)</b>	63.3%	26.1%	9.2%	.6%	.8%
<b>Have opportunities to engage in household tasks (n=1669)</b>	47%	22.4%	21.4%	2.7%	6.5%
<b>Receive support from staff in making and keeping friends (n=1579)</b>	55.7%	21.2%	12.5%	4.1%	6.5%

*Scales:* Based on these individual items, we developed a Satisfaction Scale including the first 5 measures: satisfaction with where you live, satisfaction with day activities, satisfaction with what you do in your free time, happiness with staff at home, and happiness with staff at work/day activity. Scores on the Satisfaction Scale could range from 0 to 100, with a higher score indicating greater satisfaction. The average (mean) score equaled 84.18 with a standard deviation of 14.46. The mode equaled 100.

To briefly explain the terms used to describe the scales, the average (mean) is calculated by adding all the values together and dividing by the number of values. The average for the Satisfaction Scale is 84.18, indicating a high level of satisfaction. The standard deviation (S.D.) measures the degrees to which the values are clustered or dispersed around the mean. A standard deviation value of 14.46 (the S.D. for the Satisfaction Scale) means that, if we calculate for every value how many points it is from the mean, the average would be 14. With a mean of 84.18 and a S.D. of 14.46, we would expect that most of the values lie roughly between 70 and 98; hence, there is not enormous variation and most of the values are fairly high. The mode is the value that occurs the most frequently. Perhaps one of the most interesting things to notice for this scale is that the



mode is 100; in other words, the most frequent score indicated that people were very satisfied on all measures of satisfaction.



## Dignity, Respect and Rights

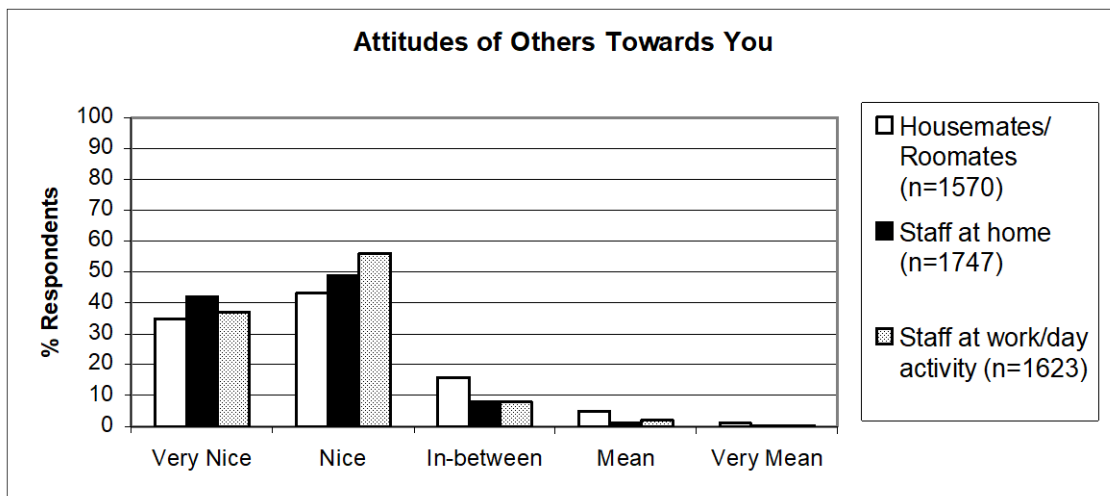
*Respondents:* The questions on dignity, respect and rights could only be answered by the individual receiving services/supports. A value of missing was assigned for those individuals unwilling or unable to respond. In addition, we checked for consistency by asking the same question concerning whether the staff are nice or mean in two different ways. Twenty-eight individuals gave different responses when asked these similar questions. Their responses were removed from analysis for all items concerning dignity, respect, and rights. (To note, in the “satisfaction” section, 162 individuals were removed from analysis due to inconsistency, so there is greater consistency in this section.)

*Measures:* The dignity, respect and rights section consisted of 11 questions.

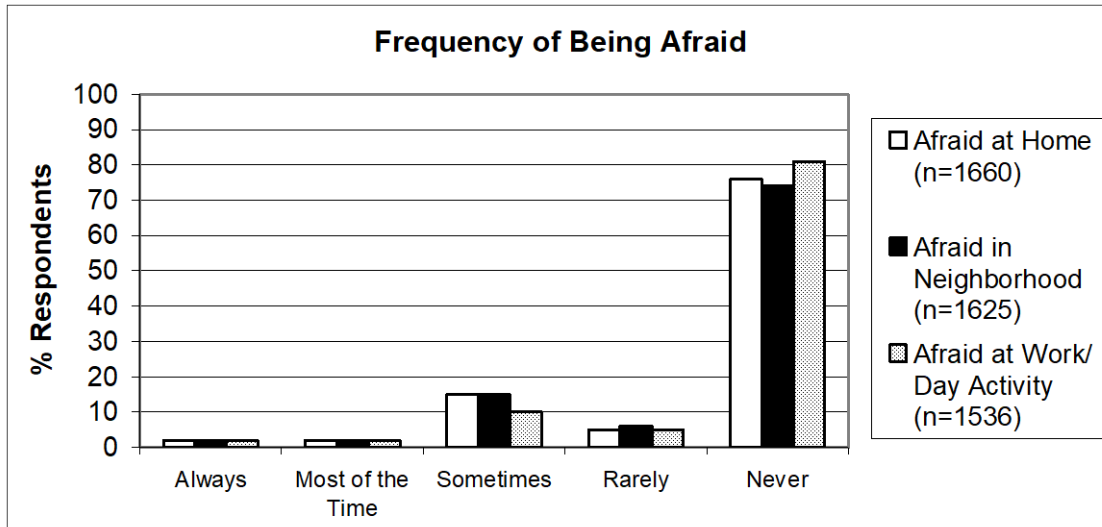
- Are your housemates/roommates nice or mean to you?
- Are the staff who work with you at your house nice or mean to you?
- Are the staff who work with you at work/day activity nice or mean to you?
- Are you ever afraid when you are home?
- Are you ever afraid when you are out in the neighborhood?
- Are you ever afraid when you are at work or your day activity?
- Do you know your legal rights?
- Have you voted in the past five years?
- Do you have a choice about how you spend your money?
- Do you know what to do if you have a complaint?

- Have you ever filed a complaint?

*Individual Items:* Most individuals report that those with whom they live and work are very nice or nice. Individuals are less likely to say that their housemates/roommates are very nice or nice as compared to staff, with a difference of slightly over ten percentage points. Seventy-eight percent of individuals report that their housemates/roommates are very nice or nice, 90% report that staff at work/day activity are very nice or nice, and 91% report that staff at home are very nice or nice.



Looking at the items on fear, most individuals report never being afraid, either in their home, work/day activity site or in their neighborhood. Individuals are less likely to be afraid at their work/day activity as compared to their homes or in their neighborhood. Seventy-four percent report never being afraid in the neighborhood, 76% percent report never being afraid at home, and 81% report never being afraid at work.

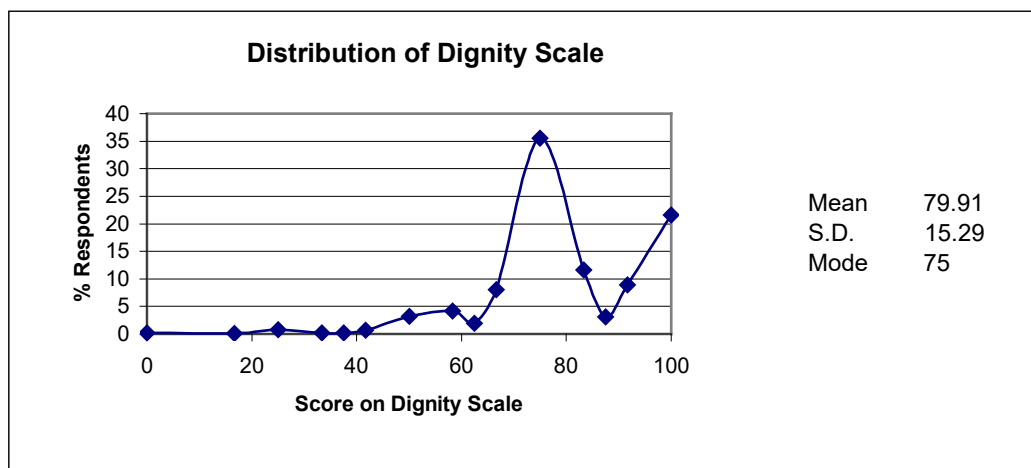


The section on legal rights is mixed in its messages. Eighty-three percent of respondents state that they know their legal rights, but only 35% had voted in the past 5 years. Seventy-five percent report that they always know what to do if they have a complaint, and 25% report having filed a complaint. Seventy-four percent of individuals state that they always have a choice in how to spend their money.

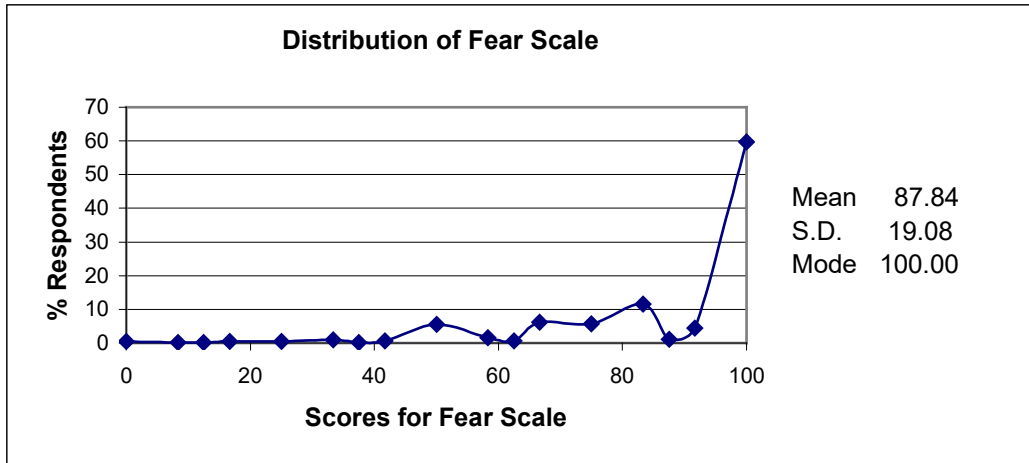
	<b>Yes</b>	<b>No</b>	
<b>Know Legal Rights (n=1460)</b>	83.2%	16.8%	
<b>Voted in Past Five Years (n=1559)</b>	35.3%	64.7%	
	<b>Always</b>	<b>Sometimes</b>	<b>Never</b>
<b>Know what to do if I have a complaint (n=1446)</b>	75%	15.6%	9.3%
	<b>Yes</b>	<b>No</b>	
<b>Have filed a complaint (n=1452)</b>	24.5%	75.5%	
	<b>Always</b>	<b>Sometimes</b>	<b>Never</b>
<b>Have a choice in how my money is spent (n=1677)</b>	73.6%	22.2%	4.2%

*Scales:* This section could be divided into two distinct scales: Dignity Scale and Fear Scale. The Dignity Scale included three measures that ask whether housemates/ roommates, staff at home, and staff at work/day activity are nice or mean to you. Scores on the Dignity Scale could range from 0 to 100, with a higher score indicating greater dignity (people being nice to you). The average score equals 79.91 with a standard deviation of 15.29. The modal score is 75.

Thus, the average score was fairly high, although lower than on the satisfaction scale. Interestingly, the mode was much lower. Whereas on the Satisfaction Scale, the mode (the most frequent score) was 100, here it was 75. This shows that for the Satisfaction Scale, many individuals choose the most positive answer category (very satisfied) for all measures, whereas for the Dignity Scale individuals are less likely to choose the most positive answer category (very nice) for all measures. Most often individuals respond with some combination of nice and very nice, bringing the mean and the mode down.



The Fear Scale includes three measures that ask 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 equals 87.84 with a standard deviation of 19.08. The mode is 100. Here again we see that the average is quite high, and therefore there is not a great deal of fear reported among individuals receiving supports and services. The mode of 100 indicates that many individuals (60%) report 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. When listing things that they were afraid of at home, staff and other residents (48 responses) were the most frequently mentioned item followed by the weather (such as storms and lightening) (42 responses). To note, we were unable to distinguish between staff and other residents for the purposes of coding, so they are coded together. In the community, individuals were most afraid of strangers/ crime (58 responses) followed by animals/ insects, especially stray dogs (47 responses). At work/ day activity, by far the most common response concerned staff and/or other consumers at the site.

	At Home	In Community	At Work
Alone	19	8	2
Animals / Insects	12	<b>47</b>	1
Being Scolded	5	2	10
Darkness / Sleep	28	26	3
Emergency Situations	7	5	7
Falling/Sickness	13	14	18
Neighbors / Local kids	7	13	5
New/ Unfamiliar Things	8	12	1
Noises	11	9	13
Staff / Consumers	<b>48</b>	22	<b>56</b>
Strangers / Crime	33	<b>58</b>	15
Traffic / Transportation	2	19	4
Weather	<b>42</b>	26	1
Other	24	16	17
TOTAL	259	277	153

### **Choice and Control**

*Respondents:* The questions on choice and control were asked first of the person receiving services/supports. If the person was unable to answer or did not want to continue with the survey after answering the first two sections of the survey; his/her wishes were respected and the interview with the individual ended at that point. In this case, a surrogate respondent who knows the individual well was identified and asked to complete this section. Each question in this section noted whether the respondent was the person receiving service/supports, family, staff or friend. As in previous sections, a value of missing was assigned for those individuals unwilling or unable to respond. However, the amount of missing data was lower because of the ability to utilize other respondents.

In this section, *Choice and Control*, the person receiving services answered questions 41% of the time; staff answered 57%; family answered 2% and friends answered less than 1% of the time.

*Measures:* The choice and control section consists of 19 questions:

- Do you own your own home/apartment, rent your home/apartment or pay rent to a provider for your home?
- Do you have a key to your house or apt?
- Who chose (picked) the place where you live?
- Did you choose (pick) your roommates (the other people you live with)?
- Did you meet your roommates (the other people you live with) before you moved into your house or apartment?
- Do you have your own bedroom?
- If you share a bedroom, did you choose (pick) who shares the room with you?
- How many other people live with you who are not family or paid staff?
- Of those people, how many have disabilities?
- Did you choose (pick) what you do during the day (work, day activity, school, retirement)?
- How many places did you visit before deciding what you wanted to do during the day?
- In general what do you do during the day (number of hours per week in a variety of settings)?
- Did you choose the staff that work with you at home?
- Did you choose how to spend your free time?
- Do you have privacy?
- Do people knock or ring the doorbell and wait for a response or let you know they are entering your house or apartment before coming in?
- Do people knock on your bedroom door and wait for a response before entering?
- Do people read your mail without permission?

*Individual Items:* The majority of people receiving services are paying rent to a provider for their home or apartment. Eight percent of people pay rent to a community landlord for their home or apartment, 1% own their own home or apartment while 91% pay rent to a service provider. Twenty-eight percent of people have a key to their home or apartment and 72% do not have a key. It appears that while most people are living in a provider agency home, some people are experiencing greater control by having a key to their homes.

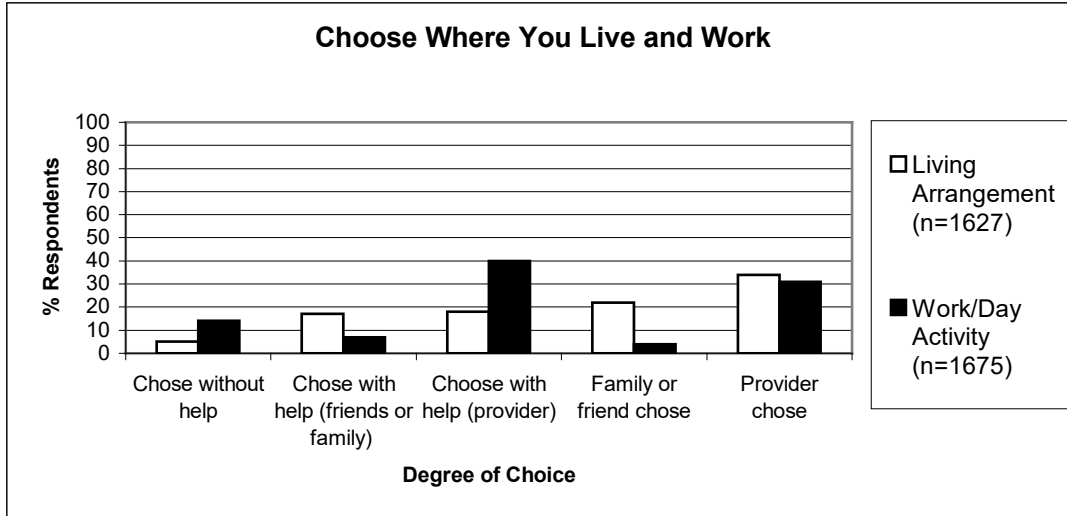
<b><i>Own or Rent (n=2282)</i></b>	<b><i>% Respondents</i></b>
<b><i>Own home or apartment</i></b>	1.3%
<b><i>Rent home or apartment</i></b>	8.1%
<b><i>Pay rent to a provider</i></b>	90.7%

	<b><i>Yes</i></b>	<b><i>No</i></b>
<b><i>Do you have a key to your house or apartment? (n=2747)</i></b>	28.3%	71.7%

The following graph represents the degree to which people choose where they live and work or attend day activity. Five percent of people chose where they live without help; 16% chose where they work or attend day activity without help. Providers chose the living arrangement for 34% of the people in the survey and helped with the choice for an additional 20%. Families or friends chose where 22% of the people live and helped an additional 18%.

Providers chose work or day activity for 34% of the individuals and helped make the choice for an additional 39% of the people. Family and friends helped choose the work or day activity for 8% of the people and chose for the remaining 4% of individuals. The data show that Providers have the greatest role in choosing both the living arrangement and work or day activity for the individual.





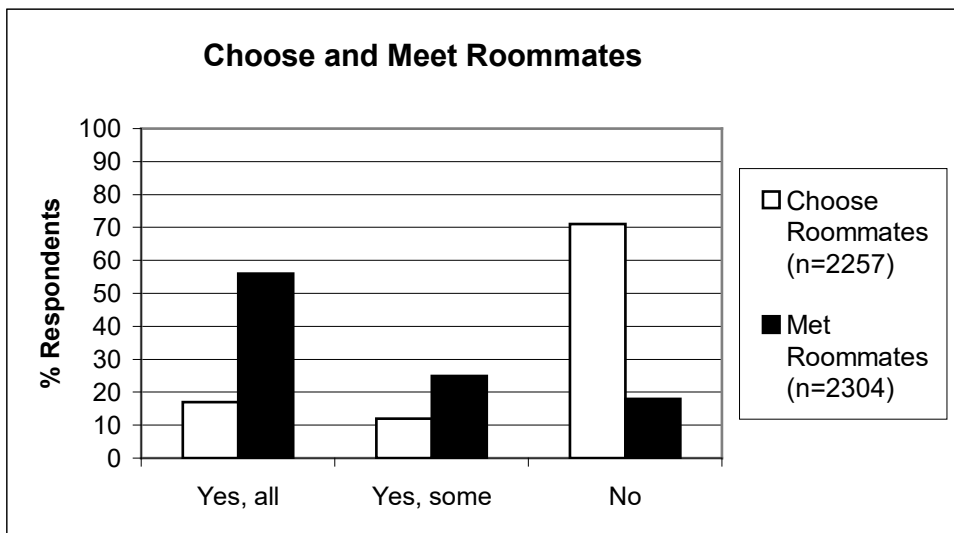
For people who chose where to live, a follow-up question was asked to determine how many other places were visited before making this choice. The intent of this question was to determine the degree of informed choice. The range of responses is from 0 to 30. Less than half (39%) of the people reported seeing one or more other homes before choosing where they live.

<b># other homes seen</b>	<b>% respondents (n=1060)</b>
<b>0</b>	61%
<b>1</b>	16%
<b>2</b>	11%
<b>3</b>	5%
<b>4</b>	3%
<b>5</b>	2%
<b>6 or more</b>	2%

People were also asked how many day activities were visited before deciding what to do during the day. Thirty-six percent of the people chose what to do during the day after visiting other possible programs or activities.

<b># other day activities seen</b>	<b>% respondents (n=1516)</b>
<b>0</b>	64%
<b>1</b>	14%
<b>2</b>	10%
<b>3</b>	6%
<b>4 or more</b>	5%

People were asked whether they chose and met their roommates before moving into their home. The majority of people (71%) did not choose their roommates; 12% chose some of their roommates; 17% chose all of their roommates. People did have greater opportunity to meet their roommates. Fifty-six percent met all of the roommates; 25% met some and 18% met none before moving into their homes.



The following table depicts how many other people (not including family or paid staff) live with the person receiving services and how many of the roommates/housemates have disabilities. Almost half (48%) of the people interviewed live with one or two other people. Twenty-seven percent of people receiving services live with 3 to 5 other people and 17% of the people live with 6 or more people. Additionally, it appears that almost all of the housemates are people with disabilities.

	<b># of housemates n=2788</b>
<b>No housemates</b>	7%
<b>1 or 2 housemates</b>	48.5%
<b>3 –5 housemates</b>	27.9%
<b>6-10 housemates</b>	8.3%
<b>11 – 20 housemates</b>	4.9%
<b>20 + housemates</b>	3.3%

In addition to choosing your own home, having a private bedroom and choosing with whom you share your bedroom are of increasing interest. The data suggest that most people have their own bedroom. However, few people have the opportunity to select with whom they share their bedroom. Seventy-four percent of the people receiving services have a private bedroom and 66% did not choose the person with whom they share a bedroom.

	<b>Yes, all</b>	<b>Yes, some</b>	<b>No</b>
<b>Choose with whom to share bedroom (n=731)</b>	23%	11%	66%

The majority (75%) of people receiving services in this survey do not choose the staff that work in their home. Ten percent of people chose all staff with or without help from family or friends and 15% chose some staff with or without help.

	<b>No input</b>	<b>Yes, all (without help)</b>	<b>Yes, all (with help)</b>	<b>Yes, some (without help)</b>	<b>Yes, some (with help)</b>
<b>Choose staff (n=2658)</b>	75%	6%	4%	2%	13%

The last question regarding choice asked the person receiving services the extent to which he/she chooses how to spend free time. More than half of the people choose how they spend their free time without help; 40% choose with help and 8% do not choose.

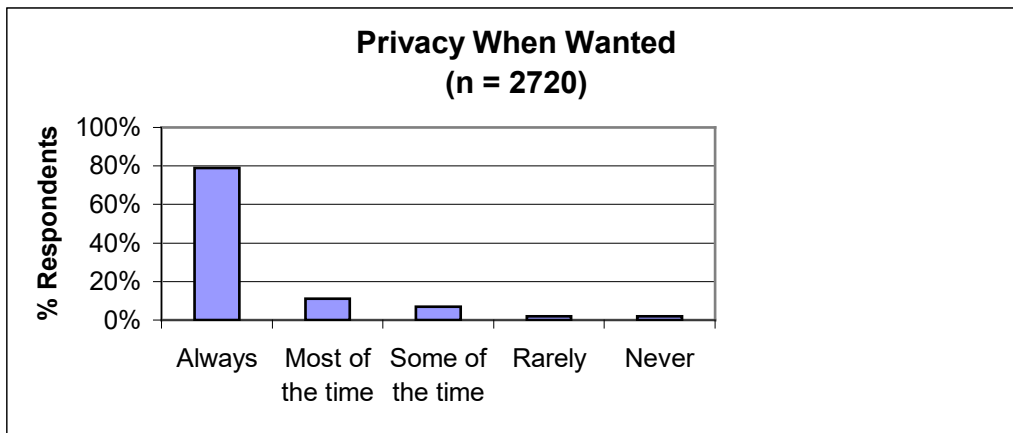
The following table shows how people spend their day. We report the average number of hours per week spent by people in the various settings. On average, people spend the most amount of time in a workshop (28 hours) and at home (17 hours). Five hours a week is spent on transportation, on the average.

<b>Type of Activity (n=2796)</b>	<b>% participating</b>	<b>Avg. hrs./week</b>
<b>Stay at home</b>	66%	16.7
<b>Workshop</b>	61%	27.8
<b>Work at job w/job coach</b>	9%	16.8
<b>Work indep.</b>	11%	16.3
<b>Comm-based activity</b>	43%	10.6
<b>Post-sec. Educ. Prog.</b>	4%	13.7
<b>Voc-Tech Educ. Prog.</b>	4%	17.5
<b>Volunteer</b>	8%	5.1
<b>Transportation</b>	81%	5.4

Further analysis displays the distribution of the percent of people who have no involvement, some involvement or a great deal of involvement in a specific work or day activity. We include the category of “stay at home” for those individuals who do that as part of their average day.

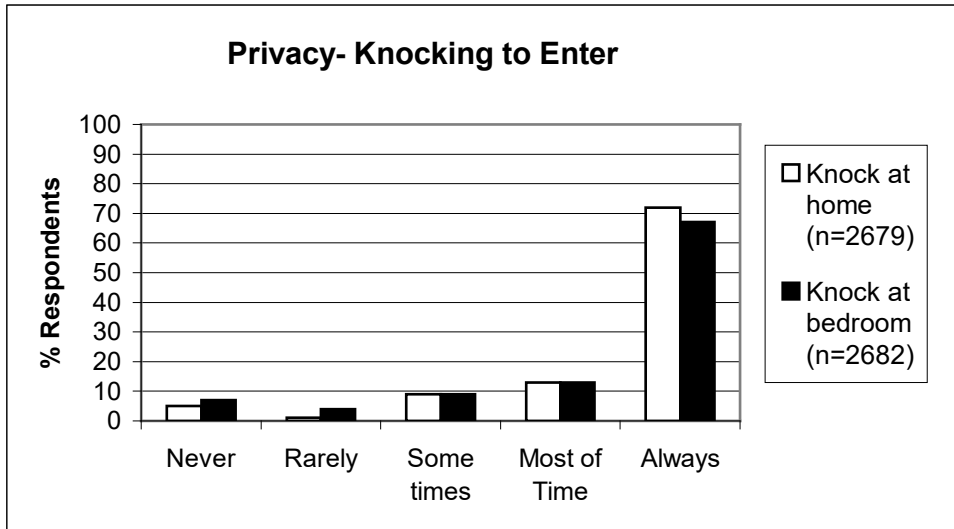
<b>Type of Activity (n=2796)</b>	<b>% with 0 hrs/week</b>	<b>% with 1-19 hrs/week</b>	<b>% with 20+ hrs/week</b>
<b>Stay at home</b>	34%	43%	23%
<b>Workshop</b>	39%	8%	53%
<b>Work at job w/job coach</b>	91%	5%	4%
<b>Work indep.</b>	89%	7%	4%
<b>Comm-based activity</b>	57%	34%	9%
<b>Post-sec. Educ. Prog.</b>	96%	2%	2%
<b>Voc-Tech Educ. Prog.</b>	96%	2%	2%
<b>Volunteer</b>	92%	7%	1%
<b>Transportation</b>	19%	80%	1%

Four questions in the survey related to privacy as a part of the dimension we refer to as control. People were asked about an overall respect for wanted privacy. Ninety percent of the people receiving services report that they always or mostly have privacy (a place to be alone) when they want it. In contrast, only four percent of people rarely or never have privacy when wanted.



Most of the people (85%) responded that privacy is respected by knocking on the door of the home and waiting for a response before entering all or most of the time. Six percent of people reported that other people rarely or never knocked; 9% said that people knocked some of the time. Eighty percent of people said that other people knocked and wait for a response before entering their bedroom

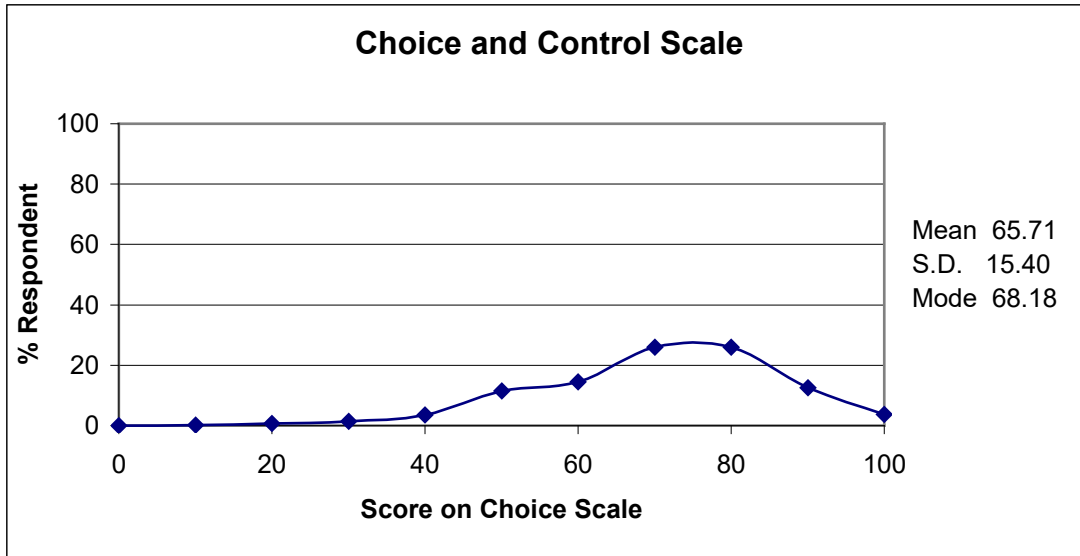
door; 9% reported other people knocked some of the time and 11% rarely or never knocked before entering.



Lastly regarding privacy, people were asked if their mail was read without permission. The majority of people (69%) rarely or never have their mail opened without their permission. However, for 23% of the people receiving services, mail is always or most of the time opened without permission.

	<b>Never</b>	<b>Rarely</b>	<b>Sometimes</b>	<b>Most of the time</b>	<b>Always</b>
<b>Read Mail without permission (n=2633)</b>	64%	5%	8%	4%	19%

**Scales:** The Choice and Control scale included nine items from the survey. The possible scores ranged from 0 to 100, with a higher score indicating greater choice and control. The average score in this scale equals 65.71 with a standard deviation of 15.40. The mode (most frequent score) is 68.18. The Choice and Control Scale will be used in the future to measure change over time.



## Relationships

*Respondents:* The questions on relationships could be answered by the individual receiving services/supports, a family member, a friend, or paid staff. On average, 44% of the questions were answered by individuals receiving services/supports, 54% were answered by paid staff, and 2% by family. A value of missing was assigned when individuals did not answer, gave an unclear answer, or responded “do not know.”

*Measures:* The relationship section consisted of 7 questions:

- Do you have friends you like to do things with, such as see movies, go out for a meal with or play sports with?
- Do you get a chance to see, talk or visit with old friends?
- Do you feel extra close to someone? Do you have a special friend?
- How often do you have a chance to meet new people?
- Can you see your friends whenever you want to see them?
- Can you get in touch with your family when you want to?
- How often do you spend time with your neighbors?

*Individual Items:* A very high percentage (93.2%) of individuals reported having friends. For this question, friends could include family and paid staff, and unfortunately we cannot tell if individuals had friends other than family and paid

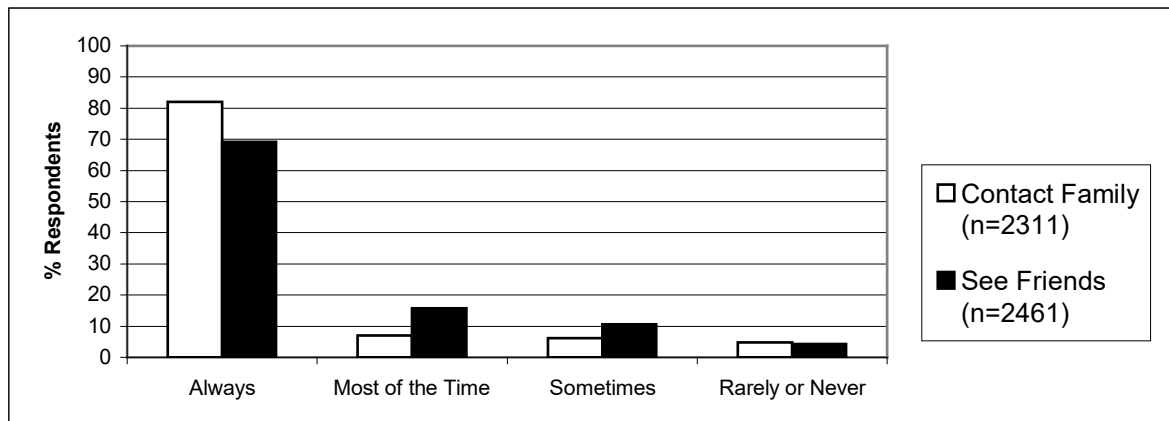
staff. Most individuals (84.1%) reported feeling extra close to someone. When asked if they see old friends, 45% said yes, whenever they want. Thirty-three percent said that they sometimes see old friends and 22% said they do not see old friends. Thus, less than half of the individuals had old friends whom they could see whenever they wanted.

	<b>Yes</b>	<b>No</b>
<b>Have Friends? (n=2670)</b>	93.2%	6.8%
<b>Feel Extra Close to Someone? (n=2562)</b>	84.1%	15.9%

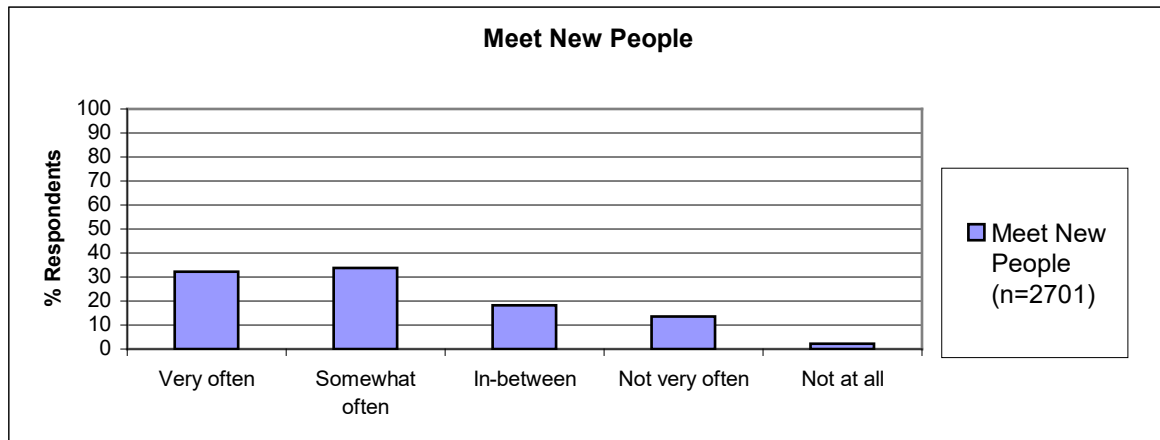
	<b>Yes, Whenever I want to</b>	<b>Yes, Sometimes</b>	<b>No</b>
<b>See Old Friends (n=2429)</b>	44.5%	33.1%	22.4%

We also asked if individuals could get in touch with their family and see friends whenever they wanted. Most respondents said that they could always get in touch with family and see friends whenever they wanted. However, while 82% of individuals said they could always get in touch with family when they wanted, only 69% said they could always see friends when they wanted, a difference of 13 percentage points. We do not know if this difference is due to service providers encouraging contact with family more so than contact with friends, or rather if it is a result of friends being busier or less available than family. The difference may also be due to different question wording; we asked if individuals could *get in contact* with family and if individuals could see friends. It may just be easier to get in contact with someone than to see someone.





We were also interested in how often individuals met new people. Almost sixteen percent said not at all or not very often, and 18% said in-between. Thirty-four percent reported meeting new people somewhat often and 32% said very often.



## Inclusion

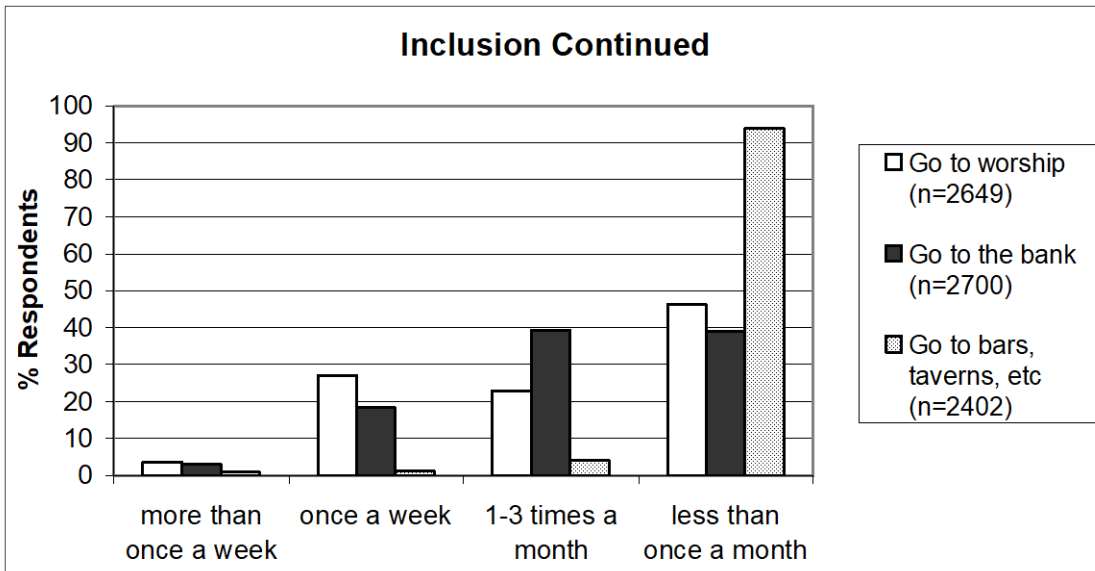
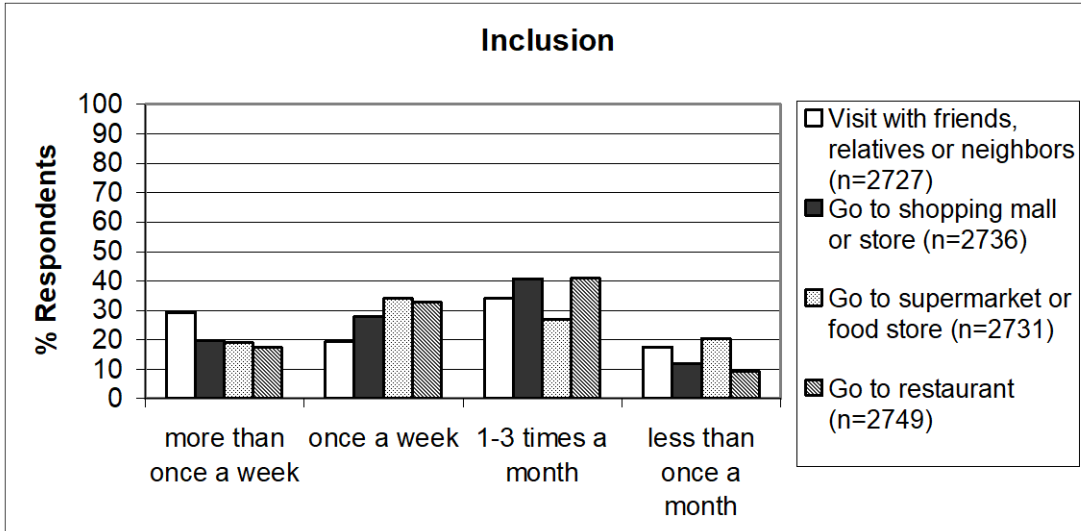
*Respondents:* The questions on inclusion could be answered by the individual receiving services/supports, a family member, a friend, or paid staff. On average, 35% of the questions were answered by individuals receiving services/supports, 63% were answered by paid staff and 2% by family. To compare this section on inclusion with the section on relationships, the section on inclusion has a lower percentage of responses by individuals receiving services/supports (35% for the inclusion section compared to 44% for the relationship section). A value of missing was assigned when individuals did not answer, gave an unclear answer, or responded “do not know.”

*Measures:* The inclusion section consisted of 18 questions.

- About how often do you visit with close friends, relatives, or neighbors?
- About how often do you visit a supermarket or food store?
- About how often do you go to a restaurant?
- About how often do you go to a church, synagogue or other place of worship?
- About how often do you go to a shopping center, mall or other store to shop?
- About how often do you go to bars, taverns, etc.?
- About how often do you go to the bank?
- When you go out, do you go by yourself or with just one staff person?

- In the last month, have you gone into the community for sports or exercise?
- In the last month, have you gone out for entertainment?
- In the last month, have you gone to a social event?
- In the last month, have you gone to a club, social group, community organization, church, synagogue, or other religious event?
- Most of the time, what transportation do you use to get to work?
- How reliable/dependable is your transportation to work/day activity?
- Most of the time, what transportation do you use to go out for recreation?
- How reliable/dependable is your transportation for recreation?
- Most of the time, what transportation do you use to get to medical and business appointments?
- How reliable/dependable is your transportation to medical and business appointments?

*Individual Items:* The first set of questions listed a series of places in the community and asked individuals how often they went to such places. The following two charts summarize the results for these questions. The first chart shows places where individuals go fairly frequently: to visit with friends, family or neighbors, to shopping malls, to supermarkets, and to restaurants. About half of the individuals surveyed went to these places at least weekly (52.7% go to a supermarket, 49.9% go to a restaurant, 48.6% visit with friends, family and neighbors, and 47.3% go to a shopping mall). On the other hand, the second chart shows places where individuals do not go frequently: to places of worship, to banks, and to bars/taverns. Again looking at the percentages of individuals who go to these places at least once a week, almost 30.6% go to a place of worship once a week or more, 21.6% go to banks, and 2% go to bar/taverns.



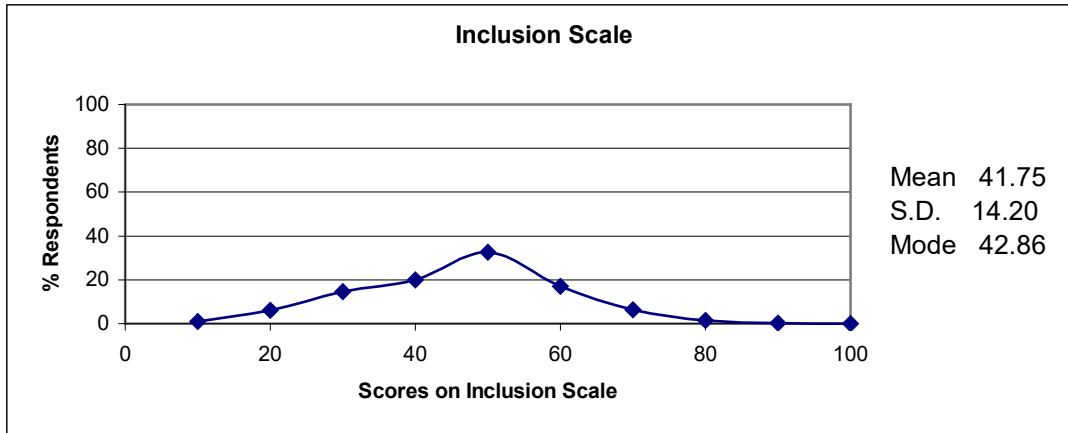
In May and June, 2000, the National Organization on Disability commissioned Harris Interactive, Inc. to conduct a national phone survey to examine and compare the quality of life and standard of living for people with and people without disabilities. Harris Interactive surveyed 997 people with disabilities and 953 people without disabilities throughout the nation. Several of the items already discussed in this section were asked also by Harris Interactive, Inc.. Therefore, we are able to compare the frequency of community activity reported by individuals in our sample to a national sample including people with many

different kinds of disabilities as well as a national sample of persons without disabilities. The following table lays out this comparison.

The results are very mixed. Of all three groups, individuals receiving supports/services in Pennsylvania were the *most likely* group to go to a shopping mall. Looking at going to a restaurant, individuals receiving supports/services in Pennsylvania were 9 percentage points more likely to go to a restaurant compared to a national sample of people with disabilities, but 10 percentage points less likely compared to a national sample of people without disabilities. For going to a supermarket and going to worship, our sample was very similar to the national sample of people with disabilities, but people without disabilities were far more likely to engage in these activities. Lastly, individuals receiving supports/services in Pennsylvania were the *least likely* group to socialize; our survey showed individuals receiving supports/services in Pennsylvania were 21 percentage points less likely to socialize as compared to the national sample of people with disabilities and 35 percentage points less likely to socialize as compared to the national sample of people without disabilities. Thus, compared to people with disabilities, individuals receiving supports/services in Pennsylvania are somewhat similar in their frequency of activity, getting to the mall more often and socializing less often. Compared to people without disabilities, they lag quite a bit behind, especially for socializing.

	<b>At Least Once a Week</b>	<b>Less Than Once a Week</b>
<b>Socialize with friends, relatives, and neighbors</b>		
Harris: People w/o disabilities	85%	15%
Harris: People w/ disabilities	70%	29%
Independent Monitoring	49%	51%
<b>Go to shopping mall or store</b>		
Harris: People w/o disabilities	41%	58%
Harris: People w/ disabilities	23%	76%
Independent Monitoring	47%	53%
<b>Go to supermarket or food store</b>		
Harris: People w/o disabilities	83%	17%
Harris: People w/ disabilities	55%	45%
Independent Monitoring	53%	47%
<b>Go to restaurant</b>		
Harris: People w/o disabilities	59%	41%
Harris: People w/ disabilities	40%	60%
Independent Monitoring	50%	50%
<b>Go to worship</b>		
Harris: People w/o disabilities	47%	53%
Harris: People w/ disabilities	30%	70%
Independent Monitoring	31%	69%

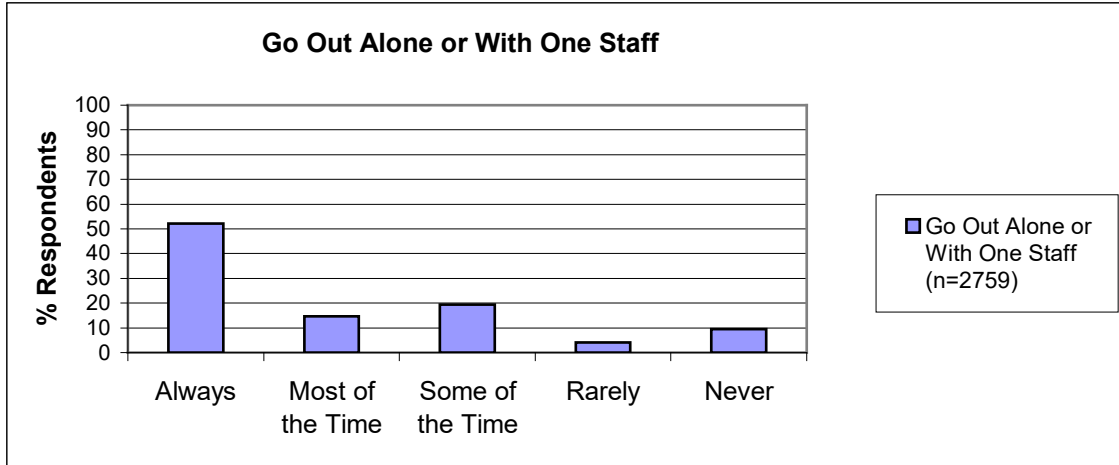
*Scales:* This section has two scales, the first of which -the Inclusion Scale- includes all 7 of the above inclusion items. Scores on the Inclusion Scale could range from 0 to 100, with a higher score indicating greater inclusion (going more frequently to places in the community). The average score equaled 41.75 with a standard deviation of 14.20. The modal score was 42.86. Thus, the average score was not very high, indicating that individuals do not go to community places with great frequency. As we saw above, we know that the infrequency of going out to places of worship, banks, and especially bars/taverns brought down the average. The mode (most frequent score) was very close to the average and therefore does not provide additional information.



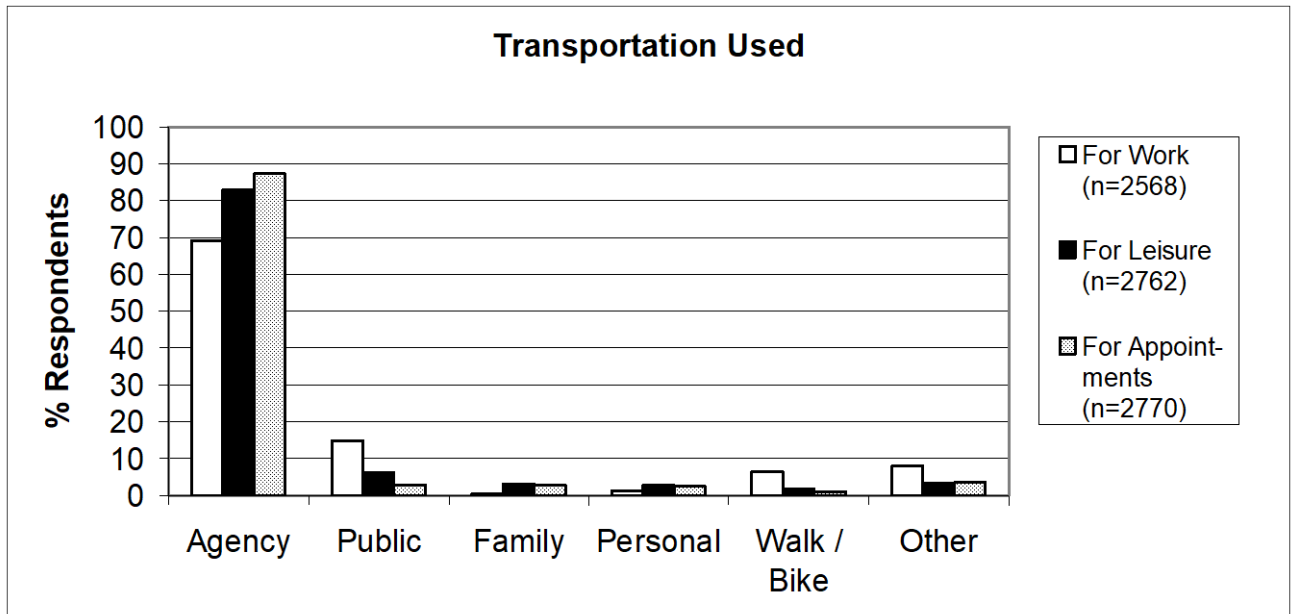
The next set of questions asked individuals to think about their activities in the past month and if they had done particular activities in the community, including sports/ exercise, entertainment events (movie, play, museum, library, etc), social events (party, dance, date, etc.), and meetings/events of clubs/ organizations/ religious groups. Individuals were asked to answer yes or no to whether they had been to such an event in the community in the past month. The majority of individuals had been to each kind of event within the past month. Individuals were most likely to have been to a social event (87.6%) and least likely to have been to a meeting/event of a community club/organization/religious group (60.8%).

	<b>Yes</b>	<b>No</b>
<b>Social Event (n=2747)</b>	87.6%	12.4%
<b>Sports/Exercise (n=2740)</b>	77.2%	22.8%
<b>Entertainment (n=2739)</b>	74.3%	25.7%
<b>Clubs/Organizations (n=2725)</b>	60.8%	39.2%

We also asked individuals, when they go out, do they go out alone or with one staff person. Just over 50% (52.2%) reported that they always went out alone or with one staff person. Thirty-four percent reported that most or some of the time they go out alone or with one staff person, and 24% reported they rarely or never go out alone or with one staff person.



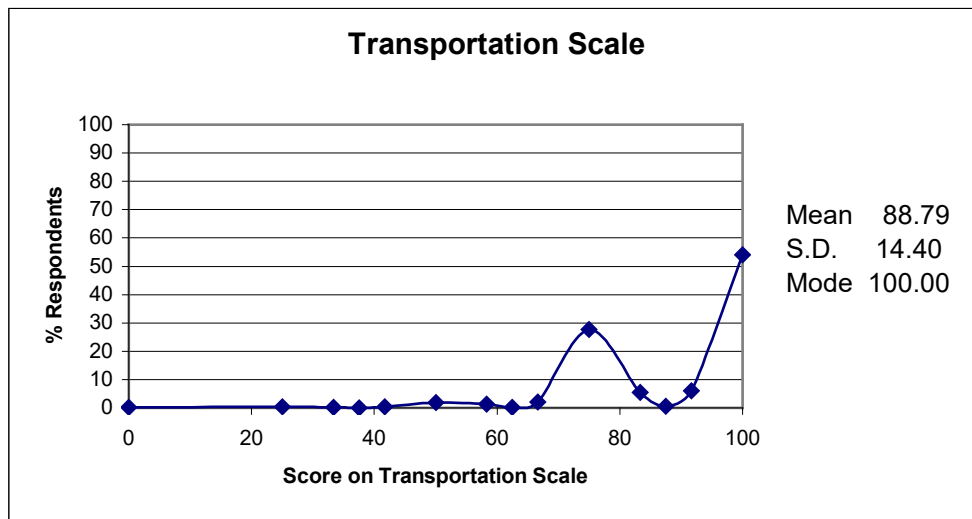
Finally in this section we asked about transportation. Overwhelmingly, individuals rely on agency transportation, especially for medical and business appointments (87.2%). The next most common method of transportation is public, but only 15% use public transportation for work, 6% for leisure, and 3% for appointments.



Most individuals feel that their transportation is reliable, with only between 3-6% of individuals reporting that their transportation is somewhat reliable, unreliable or very unreliable.

	<i>Extremely Reliable</i>	<i>Reliable</i>	<i>Somewhat Reliable</i>	<i>Unreliable</i>	<i>Extremely Unreliable</i>
<b>For Work (n=2633)</b>	60.4%	33.5%	4.6%	.9%	.6%
<b>For Leisure (n=2767)</b>	61.3%	34.0%	3.7%	.5%	.5%
<b>For Appts. (n=2770)</b>	63.0%	34.1%	2.1%	.5%	.5%

The three measures of reliability for transportation (for work, leisure, and appointments) were placed together in a scale: the Transportation Scale. Scores could range from 0 to 100, with a higher score indicating greater reliability. The average (mean) score equaled 88.79 with a standard deviation of 14.4. The mode (most frequent score) was 100. Thus, 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.



### **Independent Monitoring Team Impressions**

Once the IMT has completed the Essential Data Elements survey, there are several other questions that the teams must answer. These questions include the areas of opportunities for personal growth and development, staff support and physical setting. The teams are asked to respond to these questions once



they have spent time with the individual and the staff or family. These responses are the subjective responses of the team members based on their observations, interviews and perceptions, given the time spent with the person.

The first question asks whether individuals have the opportunity to learn new things (n=2796). The responses are as follows:

No	8.5%
Sometimes	23.6%
Yes	67.8%

The next questions asks what the staff's expectations are regarding growth for this individual (n=2620). The responses are as follows:

Virtually non-existent	2.5%
Low	12.2%
In-between	35.5%
High	31.9%
Very High	17.9%

The next three questions relate to the need for and use of assistive technology, including augmentative communication. First, we ask, "for those individuals who do not communicate verbally, is there a formal communication system in place for them (e.g., a picture board, communication device, sign language)? This is an area of significant concern. Of the 987 individuals who do not communicate verbally, only 176 (17.8%) have a formal communication system in place. The next question asks, "for those individuals with a formal communication system, is it in working order and being used?" For about half of the people, the communication system is in working order and being used. However, for the other half it is not. The last of the three questions asks if the person has all of the adaptive equipment and home modifications needed, such as glasses, hearing aids, ramps, braces, etc. (n=1435). The responses were as follows:

Has all equipment, it works and person knows how to use	78%
Has limited access, needs more or needs to better understand use	8.2%
Does not have needed equipment	13.8%

The next series of questions ask the teams to make somewhat subjective judgments about the staff in the home. Due to limited time in the home, their assessments are based on a slice of time that may be anywhere from one to three hours. The first question asks whether there appear to be an adequate number of staff to support the individuals in the home (n=2549). The teams responded in the following way:

Adequate staff	91.6%
Too many staff	0.6%
Not enough staff	7.8%

The next question asks whether staff interact with people in ways that give the people supported control (n=2503). The responses were favorable as the table illustrates.

Yes	86.9%
Sometimes	10.5%
No	2.6%

In terms of whether staff treat people with dignity and respect, the following responses (n=2534) were given:

Yes	86.9%
Sometimes	4.8%
No	1.3%

Last in this section, the teams were asked whether they believed that the staff have the necessary skills to support the person (n=2487). As the table shows, there was a bit more variation for this question.

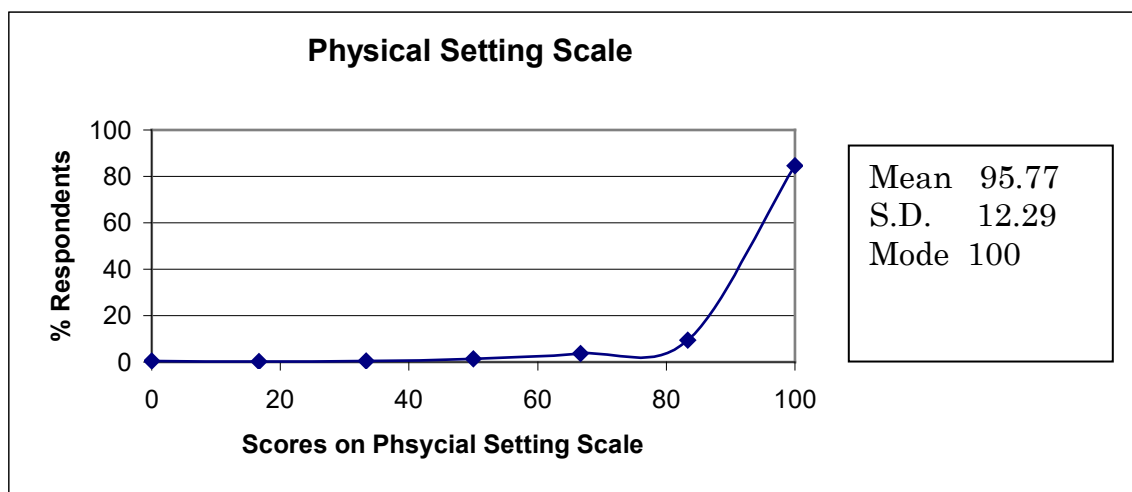
Yes, all staff	78.2%
Yes, some staff	17.4%
No	4.4%

The last section of the survey asks for the team’s perceptions of physical quality.

The questions asked include the following:

- Is the home in a safe neighborhood?
- Is the home in good repair outside?
- Is the home in good repair inside?
- Does the home’s exterior look harmonious with the neighborhood in which it is located?
- If necessary, have adaptations been made to the home to make it accessible to the people who live there?
- If necessary, have environmental adaptations been made for the people who live here?
- Do people have sufficient space for personal belongings?
- Does the home reflect the hobbies, interests and personalities of the people who live there?

The responses to the questions were summed to form a physical setting scale. Responses range from 0 to 100, with 100 indicating a physically more pleasant setting. The average score for the physical setting scale is 95.7, with a standard deviation of 12.2, indicating that most team members feel that the settings in which people live are very pleasant, in safe neighborhoods with necessary adaptations made.



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

*Respondents:* This part of the Essential Data Elements Survey was completed by telephone with a family member, guardian or friend who was identified through the pre-survey. In total, 1093 family members completed the telephone interview. For some people, there were no family contacts; for others, three attempts were made to contact the family, but after three attempts the data collection effort was abandoned. On average, 57% of questions were answered by parents, 28.9% were answered by siblings, 1.5% by guardians, and 12.6% by persons with other relationships to the individual receiving supports and services. A value of missing was assigned for when individuals did not answer, gave an unclear answer, or responded “do not know.”

*Measures:* The family/ friend/ guardian section consisted of 11 questions:

- Overall, how satisfied are you with the place where your relative is living?
- Overall, how satisfied are you with what your relative does during the day?
- How often were you able to visit your relative in the past year?
- How often did your relative come to visit you or go on outings with you in the past year?
- How happy do you think your relative is with his/her living situation?
- How happy do you think your relative is with what s/he does during the day?
- Overall, how satisfied are you with the staff who support your relative at home?
- Overall, how satisfied are you with the staff who support your relative during the day?
- Do the staff who work with your relative understand the ways in which your relative communicates?
- Do the staff who work with your relative listen to him/her?
- Do the staff who work with your relative respond to your relative’s communication (needs and wants)?

*Individual Items:* A high percentage (88.4%) of family, friends, and guardians report being very satisfied or somewhat satisfied with the place where their relative lives. Eighty percent of family, friends, and guardians are very satisfied or somewhat satisfied with what their relative does during the day. Looking at satisfaction with staff, 86% of family, friends and guardians are very satisfied or

somewhat satisfied with the staff who support their relative at home. Seventy-six percent are satisfied with the staff who support their relative during the day. Thus, while satisfaction is high overall, it is a bit lower for day activity and the staff at day activity staff as compared to home and the staff at home.

	Very Satisfied	Somewhat Satisfied	Neutral	Somewhat Dissatisfied	Very Dissatisfied
Relative's home (n=1088)	68.8%	19.6%	6.2%	6.5%	3.1%
Relative's day/ work activity (n=1088)	58.0%	22.2%	13.1%	5.0%	1.8%
Staff at home (n=1083)	63.6%	22.1%	9.1%	3.6%	1.6%
Staff at day/ work (n=1073)	56.9%	18.7%	21.8%	2.2%	0.3%

We also asked family, friends, and guardians to consider how happy they think their relative is with where s/he lives and what s/he does during the day. The numbers are similar to the relative's own satisfaction levels. Eighty-four percent believe that their relative is very happy or happy with their living situation, and 78% believe their relative is happy with what s/he does during the day.

	Very Happy	Happy	Neutral	Unhappy	Very Unhappy
Relative's home (n=1085)	45.4%	39.0%	11.6%	3.1%	0.8%
Relative's day/ work activity (n=1081)	36.1%	41.9%	17.9%	3.4%	0.7%

Family, friends, and guardians have mixed levels of face-to-face interaction with their relatives. Over half (59.9%) saw their relative once a month or more, with 10.4% not seeing their relative at all in the past year. Similarly, 53% of families, friends, and guardians have had their relative visit them or go out on an outing

with them once a month or more, but almost 18% did not have their relative visit or accompany them on an outing within the past year.

	Once a week or more	Once a month	About every three months	Once or twice this past year	Not in past year
Visit relative (n=1091)	30.3%	29.6%	16.8%	12.9%	10.4%
Relative visit you (n=1086)	24.0%	29.0%	17.1%	12.0%	17.9%

Last, we asked family, friends, and guardians about the communication between staff and their relative. We asked, do staff understand the ways in which your relative communicates, do staff listen to him/her, and do staff respond to his/her communication? Roughly 70% of family, friends and guardians say that staff always do each of these three things. No more than 1% report that staff never do any of these three things.

	Always	Sometimes/Some Staff	Never
Understand communication (n=1082)	71.3%	28.1%	0.6%
Listen to relative (n=1069)	70.6%	28.4%	0.9%
Respond to communication (n=1064)	72.7%	26.5%	0.8%

## **Summary**

This report presents information that came from face-to-face interviews with 2796 individuals with mental retardation who receive residential supports through OMR. This project is the first statewide effort of its kind in this Commonwealth, where individuals with mental retardation are interviewed by teams of people (some of whom are people with disabilities, others of whom are family members or interested citizens) to determine their quality of life. In general, people report high levels of satisfaction with where they live, where they work, and what they do in their free time. However, there is considerable room for improvement in the areas of choice and control. People have little choice in deciding where they live, with whom they live, and with whom they share a bedroom. In the area of inclusion, a comparison to the general population showed that people in the sample participated less often in the social fabric of daily life. In addition, for those individuals who do not communicate verbally, there is little in the way of formal programs or systems available to enhance their communication. Through the data collection efforts of the Independent Monitoring Teams, these issues are being brought to the attention of OMR for the discussion of future policy initiatives in these areas.

In the next several weeks and months, the Institute on Disabilities at Temple University will continue to analyze these data to examine several areas such as the impact of residential setting type, the impact of the number of people with whom an individual lives, etc.

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