

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

Independent Monitoring for Quality (IM4Q)
State Centers
2007-2008

Submitted to: Pennsylvania Office of Developmental Programs
Statewide Steering Committee on Independent
Monitoring

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Introduction

In 1997, Pennsylvania's Office of Mental Retardation (OMR) began to disseminate its Multi-Year Plan, which represented a significant effort by OMR to convey its vision, values and goals for the ensuing years. The Plan, developed by OMR's Planning Advisory Committee (PAC), included several recommendations. Recommendation #7 stated that the capacity for independent monitoring should be developed in Pennsylvania.

Through the PAC a subcommittee was formed to address recommendation #7. The charge to the subcommittee was to develop a process for the conduct of independent monitoring. The PAC subcommittee included consumers, families, providers, advocates, counties, direct care support professionals and OMR staff. The Developmental Disabilities Council, in collaboration with OMR, committed to fund the initial development and training work required to establish independent monitoring. Two technical advisors were contracted to assist in the subcommittee's deliberations.

The PAC subcommittee produced a document describing independent monitoring; the subcommittee recommended that the process include the collection of a minimal set of data by all counties in the Commonwealth. The document was accepted by the PAC, and reviewed and revised by OMR.

At about this time the National Association of State Directors of Developmental Disabilities Services (NASDDDS), in collaboration with the Human Services Research Institute (HSRI) developed a national project to identify performance indicators that states could collect to determine the status of their systems vis-à-vis the experiences of individuals supported, families supported and providers delivering supports. The Commonwealth of Pennsylvania joined this project, National Core Indicators 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 Developmental Programs is also involved in the development of a significant quality management initiative. As part of this initiative, a quality framework is being developed to produce a cohesive system for assuring and improving the quality of services and supports people receive from the mental retardation system. The IM4Q data are one source of information that is being used in this effort.

In Fiscal Year 1999-2000, twenty county MH/MR programs submitted proposals and were selected to participate in a pilot effort that resulted in the conducting of interviews with 2796 individuals. A final report of that effort was produced in early 2001 (Feinstein, Levine, Lemanowicz and Carey, 2001). A copy of this report can be accessed from the Department of Public Welfare's (DPW) Website at: www.dpw.state.pa.us/omr. This link does not work – please get an updated one. The 2000-01 report was used as the basis of a 2002 State Report of Independent Monitoring for Quality that is also available on the ODP web page. The 2000-01 IM4Q statewide findings and recommendations of the IM4Q Steering Committee were also used as the foundation for the development of a 2003 Quality Action Plan that was developed and implemented with all mental retardation system stakeholders through the OMR Planning Advisory Committee (PAC).

During fiscal year 2000-2001, all 46 County MH/MR programs developed contracts with Local IM4Q Programs to independently conduct interviews and enter data onto the OMR's IM4Q web-based system. A total of 5298 face-to-face interviews were conducted during that fiscal year, together with 2224 Family/Friend/Guardian surveys. The number of interviews completed increased during the 2001-2002 fiscal year. A total of 5659 face-to-face interviews were conducted along with 2494 Family/Friend/Guardian surveys during that year.

In fiscal year 2002-2003, all 46 County MH/MR programs contracted with local entities to assist them in fulfilling their obligation under IM4Q; most county programs continued to contract with the same local program as in the previous year. However, for a variety of reasons, a few counties entered into contracts with new IM4Q local programs. A total of 6487 face-to-face interviews were conducted in 2002-03. In addition to the interviews with individuals, 3163 interviews were conducted with families/friends and guardians.

In 2003-2004, 46 County MH/MR programs continued to contract with local entities to assist them in fulfilling their obligation under IM4Q; most county programs continued to contract with the same local program as in the previous year. 6373 face-to-face interviews were conducted. In addition to the interviews with individuals, 2975 interviews were conducted with families, friends and guardians.

In 2004-2005, 6499 face-to-face interviews were conducted and 3010 interviews were conducted with families, friends and guardians. The surveys were conducted from September 2004 until June 30, 2005 using a standardized instrument and methodology developed in conjunction with the State IM4Q Steering Committee and the Office of Mental Retardation. Revisions to the instrument were made from previous years, based on feedback from the local programs, as well as from the statewide steering committee, counties, regional office staff and the technical advisors.

For fiscal year 2005-2006, a total of 6496 face-to-face interviews were conducted. A total of 2851 interviews were conducted with family, friends and guardians, a decrease from the previous year.

Although individuals in State Centers have been included in the IM4Q survey process as part of the National Core Indicators sample for a number of years, the number of residents in the NCI sample did not create a large enough number of surveys for purposes of quality improvement. In FY 2003/04, the State decided to explore expanding IM4Q for people in State Centers as part of its Quality of Life initiative. In the

first year of that effort, data were collected from approximately 30 individuals living in each of the state's 6 mental retardation centers; Polk, Ebensburg, Altoona, Hamburg, Selinsgrove and Whitehaven.

For fiscal year 2006-2007, a total of 225 interviews were completed for individuals residing in the five State Centers (The Altoona Center had closed). In that year, there were no changes made to the data collection instrument. With the exception of questions focused on supports coordination, which were adjusted to reflect the ICF/MR qualified mental retardation professional (QMRP) role in State Centers, all questions were the same as those used in the statewide sample.

In December 2006, the PA Office of Mental Retardation changed its name to the Office of Developmental Programs.

State Center and local IM4Q Program staff were instructed to apply IM4Q Protocol and Guidelines to the project to the extent possible, and to adjust these practices as necessary. Administrative support was provided through Regional Offices of Developmental Programs and the Institute on Disabilities at Temple University.

In 2007-2008, a total of 218 interviews were completed for individuals residing in the five State Centers. This year, there were a few changes to the instrument used to collect the data. There were three new items added to the Dignity, Respect and Rights section. In addition, at the request of the Office of Developmental Programs, there were 10 new items added to the instrument involving the frequency and intensity of physical activity.

Additionally, a State Center Supplement has been created, to collect information for those individuals who do not communicate using words. The respondents are generally staff who know the individual well or family members. Because of the requirement to have the individual be the only respondent for the Satisfaction and Dignity, Respect and

Rights sections, these data will be analyzed separate from those of individuals who responded on their own behalf.

Methodology

Instrument

The interview instruments for IM4Q include the Essential Data Elements (EDE) survey, a pre-survey form, and the Family/Friend/Guardian (F/F/G) survey. The EDE consists of 99 questions, 40 of which can only be answered by the individuals receiving supports and services.

Modifications to the EDE and IM4Q pre-survey form were made based on feedback from the local IM4Q programs, AE/county IM4Q coordinators, ODP Regional IM4Q Coordinators 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 or the local IM4Q program prior to the scheduling of the appointment with the individual to give the local IM4Q Program information needed to schedule the interview with the individuals. Information includes: the person's address, contact people, supports coordinator information, accessibility and the individual's communication style (which may require the use of an interpreter, e.g. Sign Language or Spanish).
- A **pre-survey addendum**, which is completed by the County MH/MR Program for only those individuals who were designated as part of the NCI sample. The addendum provides demographic information, along with information about the individual's degree and type of disability(ies), work and day activity routines.
- **Satisfaction** – this section was only to be completed based on the responses of the individual receiving supports. Questions were asked about satisfaction with where the individual works and lives, as well as with staff who support the individual.
- **Dignity, Respect and Rights** – this section was also only to be completed based on responses of the individual receiving supports. Questions were asked about whether roommates and staff treated people with respect, whether people were afforded their rights, and whether individuals had fears at home, at work or in the community.
- **Choice and Control** – the questions in this section were answered by the individual, or by a family member, friend or staff person. Questions were asked about the

extent to which individuals exerted choice and control over various aspects of their lives.

- **Relationships** – the questions in this section were answered by the individual, or by a family member, friend or staff person; questions were asked about friends, family and neighbors, and individuals' opportunity to visit and contact them.
- **Inclusion** – the questions in this section were answered by the individual, or by a family member, friend or staff person. Questions were asked about opportunities for community inclusion; a section of the Harris Poll was included for comparative purposes at the national level.
- **Monitor Impressions** – this section of the survey was completed by the Independent Monitoring team, after they had completed their visit. Questions were asked in the areas of physical setting, staff support and opportunities for growth and development.
- **Major Concerns** – this form was to be completed whenever there was an issue related to physical danger, significant sanitation problems, or evidence of physical or psychological abuse or neglect. Each project was required to develop a mechanism for communicating this information. In the event of imminent danger, teams were instructed not to leave the home until resolution of some kind was achieved.
- **Family/Friend/Guardian Survey** – a survey was conducted with each family once the individual gave his/her approval. Questions related to the families' satisfaction with their relatives' living situation, as well as their perceived satisfaction of their relatives. The survey was conducted either by phone or face-to-face at the time of the EDE interview.

Sample

Independent Monitoring focuses on the quality of services and supports to children ages three and over, and to adults supported by the Mental Retardation system. In Fiscal Year 1999-2000, the sample for IM4Q was restricted to individuals living in licensed residential settings in 19 County MH/MR Programs, including licensed community homes and apartments, family living arrangements, non-state operated private intermediate care facilities for people with mental retardation (ICFs/MR) and large community homes (formerly private licensed facilities).

In Fiscal Year 2000-01, the sample for IM4Q was expanded to include individuals not receiving residential supports. This resulting sample included 30 adults per county in the NCI subset and others living at home with families, in unlicensed living arrangements and independently. The proportion of individuals in non-residential

settings for purposes of the NCI sample was to be proportional to the number of people receiving non-residential supports in the county. Counties were instructed to draw a random sample of approximately one-third of the individuals living in licensed residential settings. County MH/MR programs were provided with written instructions for drawing the entire Fiscal Year 2001-02 sample; once the sample was selected, OMR staff checked the samples before individual names were given to the local IM4Q Program, to ensure consistency in the sample selection.

In addition to the NCI and residential samples, during the 2003-04 year, each county was instructed to include 30 individuals who participate in the person and family directed supports waiver (PFDS).

In 2003-04, a decision was made to expand Independent Monitoring for Quality to the State Centers in a more intentional way. In prior years the only way individuals from State Centers appeared in the sample was through random selection through an individual county's data. The resulting number of individuals in the sample residing in State Centers has been quite small over the years. Therefore, it has been impossible to look at a sample of individuals in each of the centers. In an effort to interview a number of individuals in each State Center, the Office of Developmental Programs decided to expand the number of individuals residing in State Centers to a random sample of 30 individuals in each of the state's six State Centers. The 2003-04 sample included 181 people, all of whom lived in the State's six publicly-funded ICFs/MR. – Polk, Ebensburg, Whitehaven, Selinsgrove, Hamburg and Altoona.

The sampling procedure for 2004-05 continued to be done through ODP's computerized database – the Home and Community Services Information System (HCSIS). The 2004-05 sample of people living in State Centers was expanded to included 387 individuals from the six State Centers. Data obtained from the 387 individuals in State Center sample were not included in the Statewide Report. However, twenty-one individuals living in state centers were included in the statewide sample as part of the

random sampling process for all people living in residential settings. The data obtained from responses given by these individuals were not included in the State Center report.

The 2005-06 State Centers sample included 198 individuals from the five State Centers (Altoona had closed). Data obtained from the individuals in the State Center sample were not included in the Statewide Report.

The sample for the fiscal year 2006-07 included 222 individuals from the five State Centers. Data obtained from the individuals in the State Center sample were not included in the Statewide Report.

The 2007-2008 State Centers sample included 218 individuals from the five State Centers (Polk, Ebensburg, Whitehaven, Selinsgrove and Hamburg).

Procedure

Selection of Local IM4Q Programs

ODP requested that counties select local IM4Q Programs to conduct interviews with individuals and families using the EDE and FFG Survey. All potential IM4Q programs were screened by the State IM4Q Steering Committee. Selection criteria included: independence of the projects from service delivering entities, consumer and family involvement on governing boards, and involvement of individuals receiving supports and families in data collection activities. Local IM4Q Programs were selected by County MH/MR Programs from a variety of organizations, including non-service providing chapters of the Arc (formerly The Association for Retarded Citizens), Consumer Satisfaction Teams (in the mental health system), parent groups, universities and colleges, Centers for Independent Living and newly formed entities.

Training

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

collectors, wherever possible. Additional training was provided on a county-by-county basis for data collectors, as requested. Data entry instruction was provided by the Office of Developmental Programs. .

Team Interview Process

Once the sample was drawn, a list of individuals to be monitored was forwarded to the Local Independent Monitoring for Quality Program by ODP. For the State Centers effort, rather than have data collected by the local program from the county where the individual came, it was decided that it would be less intrusive to have one local program visit each State Center. Therefore, data collection was done by the local IM4Q program where the State Center is located. As a result, data for residents of the White Haven Center are collected by the Luzerne/Wyoming local IM4Q program, Selinsgrove data are collected by the C/M/S/U local IM4Q program, Ebensburg data are collected by the Cambria County local IM4Q program, Hamburg data are collected by the Berks County local IM4Q program and Polk Center data are collected by the Venango County local IM4Q program. Either the local program or the State Center itself completed the pre-survey forms. Once the pre-survey forms were completed, the local IM4Q Program assigned interviews to IM4Q teams. IM4Q teams are comprised of a minimum of two people, one of whom must be an individual with a disability or a family member. Teams also included other interested citizens who are not part of the mental retardation system. Visits to individuals' homes were scheduled with the individual, or with the person designated on the pre-survey form.

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

(at the time of the interview) or by phone. After the EDE was completed by the IM4Q team, the completed Essential Data Elements forms were returned to the local IM4Q Program and sent by the local program to the Institute on Disabilities at Temple University for data entry.

Family/Friend/Guardian data were collected either by the interview team or by staff of the local IM4Q program. EDE and F/F/G Survey data were entered directly onto the ODP website. Data were to be collected by June 30, 2008 and entered via the Web by August 1, 2008. A usable data file was received by the Institute on Disabilities in October, 2008; This report presents data on the individuals surveyed by the IM4Q Local Programs who live in State Centers. In addition to this report, each county and local program will receive a report about the people monitored in their county. Separate reports will also be developed by HSRI for those individuals in the NCI sample and by the Institute on Disabilities for those individuals in the PFDS sample.

Closing the Loop/Follow-up

In addition to this summary report and similar ones for each of the administrative entities (AEs) , each local IM4Q Program has developed a process, referred to as “closing the loop”/follow-up activity with the administrative entity/state center to discuss issues related to individuals as well as systemic issues that may be specific to individual AEs/state centers. This process is an integral part of the quality improvement process and in a sense, determines the extent to which this process becomes more than just data collection – rather it creates a process that demonstrates change at the individual level, as well as at the AE and state levels.

RESULTS

The following table displays the county of origin of each individual in the sample.

	# of People	Percent
Allegheny	21	9.6%
Armstrong/Indiana	1	0.5%
Beaver	3	1.4%
Bedford/Somerset	5	2.3%
Berks	8	3.7%
Blair	5	2.3%
Bradford/Sullivan	0	0%
Bucks	3	1.4%
Butler	4	1.8%
Cambria	10	4.6%
Cameron/Elk	3	1.4%
Carbon/Monroe/Pike	2	0.9%
Centre	1	0.5%
Chester	2	0.9%
Clarion	1	0.5%
Clearfield/Jefferson	3	1.4%
Columbia/Montour/Snyder/Union	1	0.5%
Crawford	4	1.8%
Cumberland/Perry	5	2.3%
Dauphin	2	0.9%
Delaware	12	5.5%
Erie	5	2.3%
Fayette	1	0.5%
Forest/Warren	5	2.3%
Franklin/Fulton	0	0.0%
Greene	1	0.5%
Huntington/Mifflin/Juniata	3	1.4%
Lackawanna/Susquehanna	1	0.5%
Lancaster	2	0.9%
Lawrence	1	0.5%
Lebanon	1	0.5%
Lehigh	9	4.1%
Luzerne/Wyoming	12	5.5%
Lycoming/Clinton	0	0.0%
McKean	4	1.8%
Mercer	4	1.8%
Montgomery	4	1.8%
Northampton	2	0.9%
Northumberland	2	0.9%
Philadelphia	31	14.2%
Potter	0	0.0%
Schuylkill	4	1.8%
Tioga	1	0.5%
Venango	11	5.0%
Washington	5	2.3%
Wayne	0	0%
Westmoreland	5	2.3%
York/Adams	8	3.7%
TOTAL	218	100%

Satisfaction

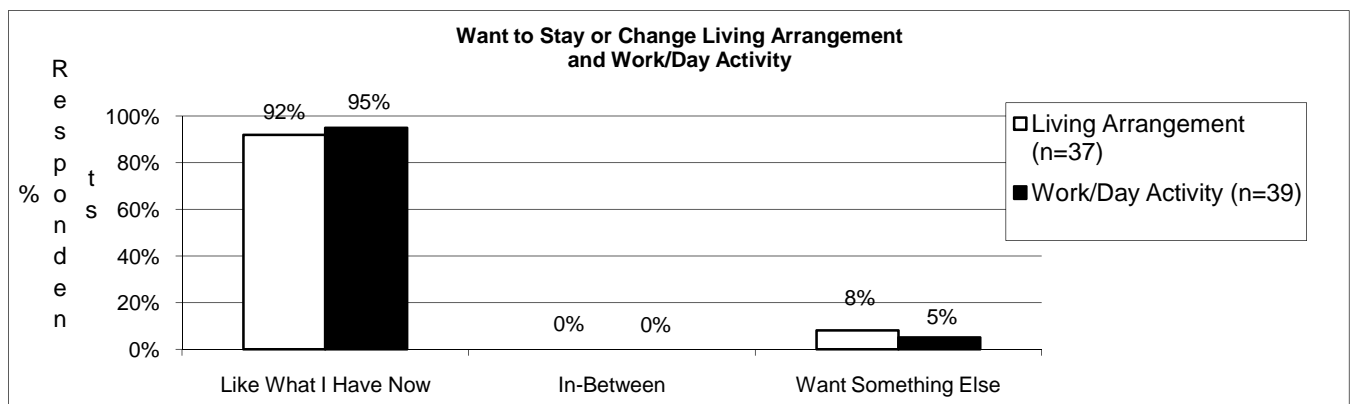
Respondents: Only the individual receiving services/supports could answer the questions on satisfaction. The percent of people who responded to questions in this section ranged from 11% to 18%. This percentage is similar to that of last year's state center sample (14% to 20%), but remains considerably lower than the 2007-08 statewide monitoring sample for which 42% to 66% of individuals responded. The low response rate can be attributed to data showing that of individuals interviewed in state centers, 73% do not communicate verbally.

Satisfaction with Living Arrangements

- 92% of individuals liked where they live.
- 66% wanted to stay where they currently live (79% in Statewide report that covers individuals living in the community and non-state ICFs/MR).

Satisfaction with Work/Day Activity

- 95% of individuals *with* a day activity/work liked what they did during the day.
- 70% wanted to continue in their current daytime activities/work (72% Statewide), but 18% wanted to do something else.



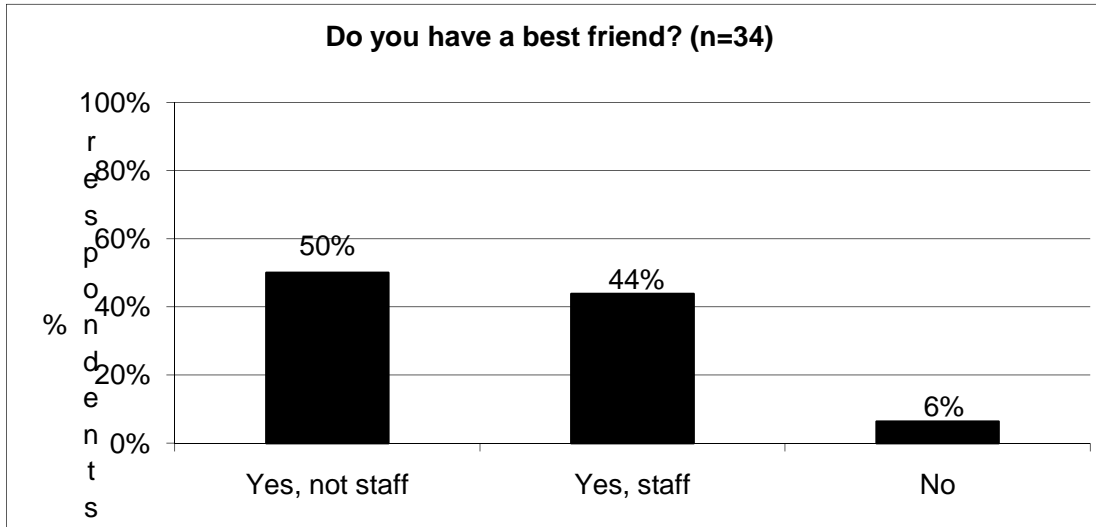
Daily Life

- 97% of respondents reported getting the services they needed.
- 77% of individuals get to do things in the community as often as they would like to (most of the time)
- 53% of individuals always had opportunities to participate in household tasks like cooking and cleaning.

	<i>Always</i>	<i>Most of the Time</i>	<i>Sometimes</i>	<i>Rarely</i>	<i>Never</i>
Have opportunities to engage in household tasks (n=34)	53%	18%	15%	3%	12%

Happiness and Loneliness

- 96% of individuals reported feeling happy overall, and 0% reported feeling sad overall.
- 58% reported never feeling lonely, 40% reported sometimes feeling lonely, and 3% reported always feeling lonely.
- 100% reported having friends they like to do things with – for 66% of these people their friends are not staff or family.
- 94% of individuals reported that they have a best friend – for 50% of the people, their best friend is not a staff member.
- 41% reported that they have a boyfriend or girlfriend that they are dating

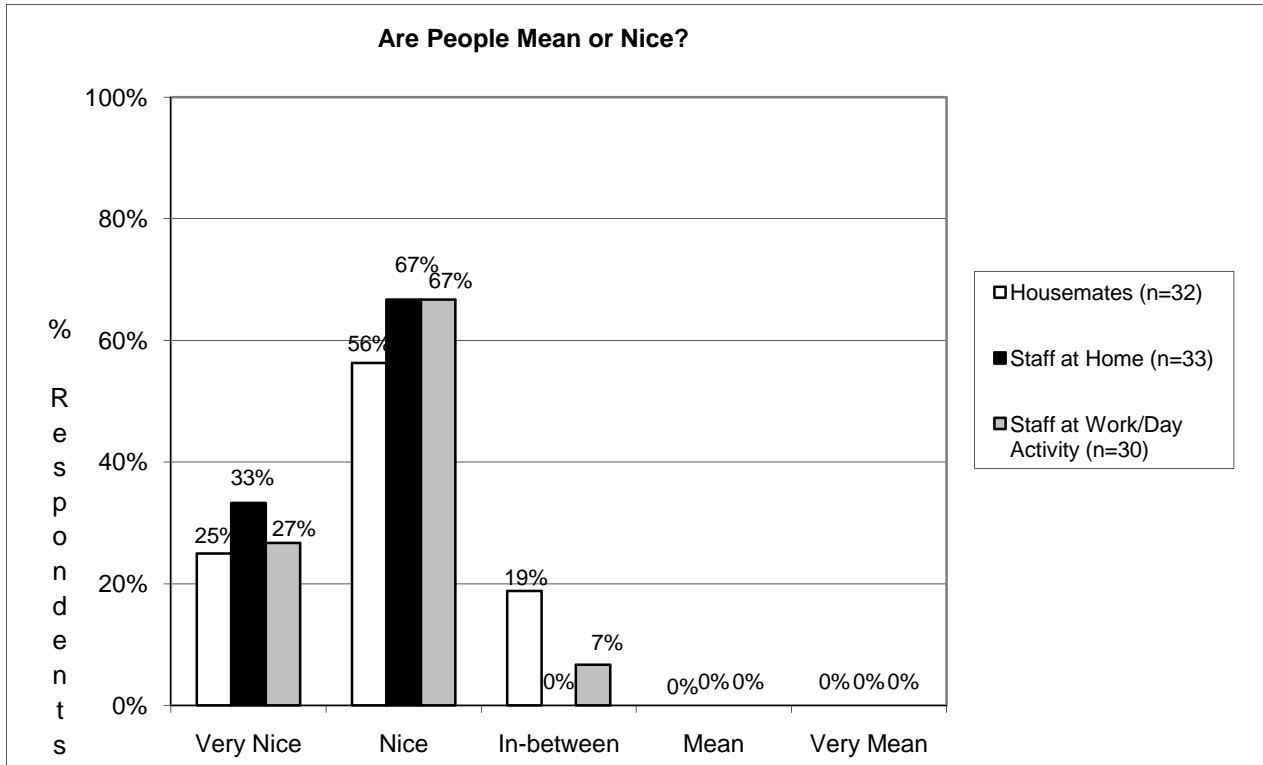


Privacy

- 81% of the individuals surveyed, reported that they always have privacy (a place to be alone) when they want it (86% Statewide).
- 50% reported that other people always knock or ring the doorbell and wait for a response before coming in to their homes (83% Statewide).
- 82% reported that people always knock on the bedroom door and wait for a response before coming in.

Are People Nice or Mean?

- Most people (81%) reported that their housemates are very nice or nice.
- 100% of the people interviewed reported that their staff who work with them at home are very nice or nice.
- 93% reported that the staff who work with the respondents at work or day activity are nice or very nice.



Satisfaction Scale: Based on 6 individual items, a Satisfaction Scale was developed. Scores on the Satisfaction Scale could range from 0 to 100, with a higher score indicating greater satisfaction.

- The average (mean) score equaled 84.70 (Statewide 85.37) with a standard deviation of 22.58.
- 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.

⇒ It should also be noted that less than one-fifth of the individuals interviewed responded to this section. The interviews who responded may not be representative of all individuals surveyed.

⇒ Comparison between the state centers was not done in this section due to the low response rate.

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 2% to 15%. This percentage is similar to that of last year's sample (3% to 17%), but continues to be lower than the 2007-08 statewide monitoring sample for which 16% to 63% of individuals responded. The low response rate, again, can be attributed to data showing that of individuals in state centers interviewed, 73% do not communicate verbally.

Forms of Identification

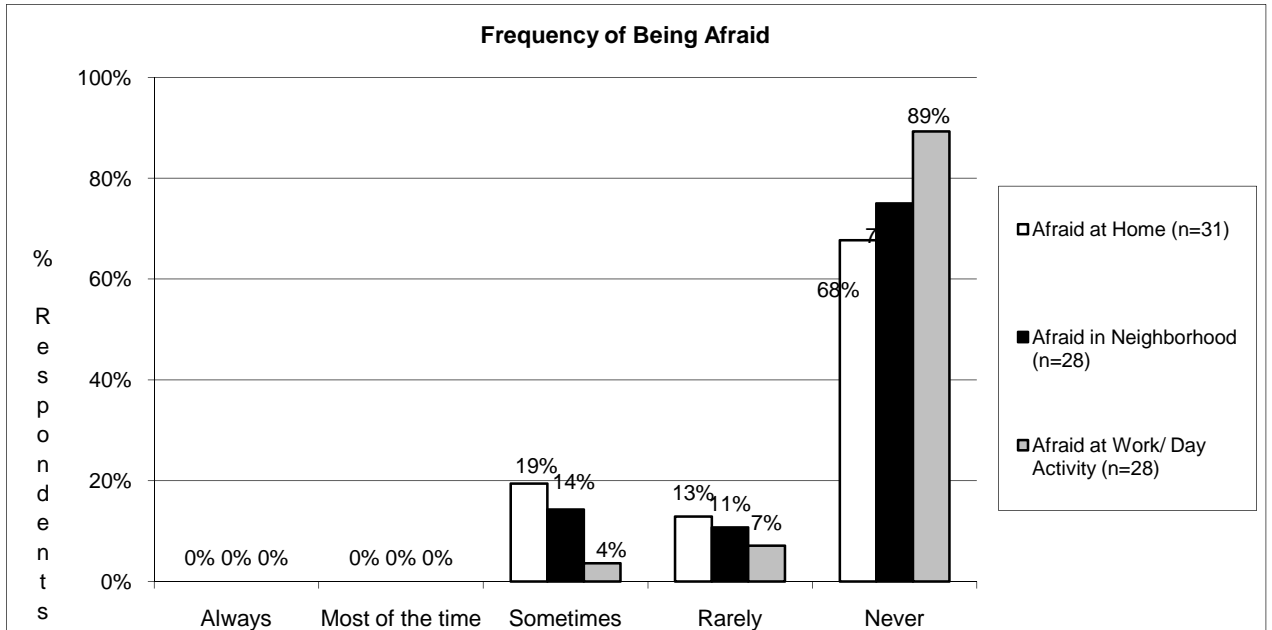
- 24% of individuals stated that they always carry a form of identification; 21% never do.

Support with Problems and Goals

- 90% of individuals always had someone in their life who will try to make things better
- 77% go to staff at home for help most of the time (42% Statewide)
- 85% of individuals say people always help them to learn new things (80% Statewide).
- 62% of individuals want help to learn new things.

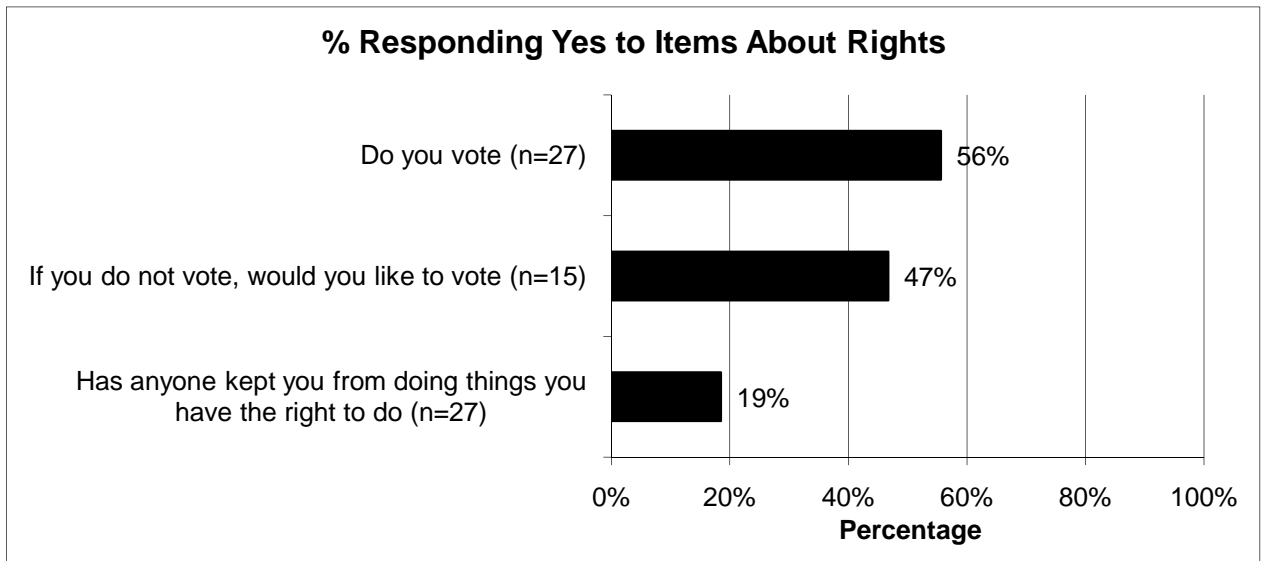
Being Afraid

- 68% reported never being afraid at home; 0% reported always being afraid at home
- 75% reported never being afraid in the neighborhood; 0% reported always being afraid in the neighborhood
- 89% reported never being afraid at work, school or day activity.



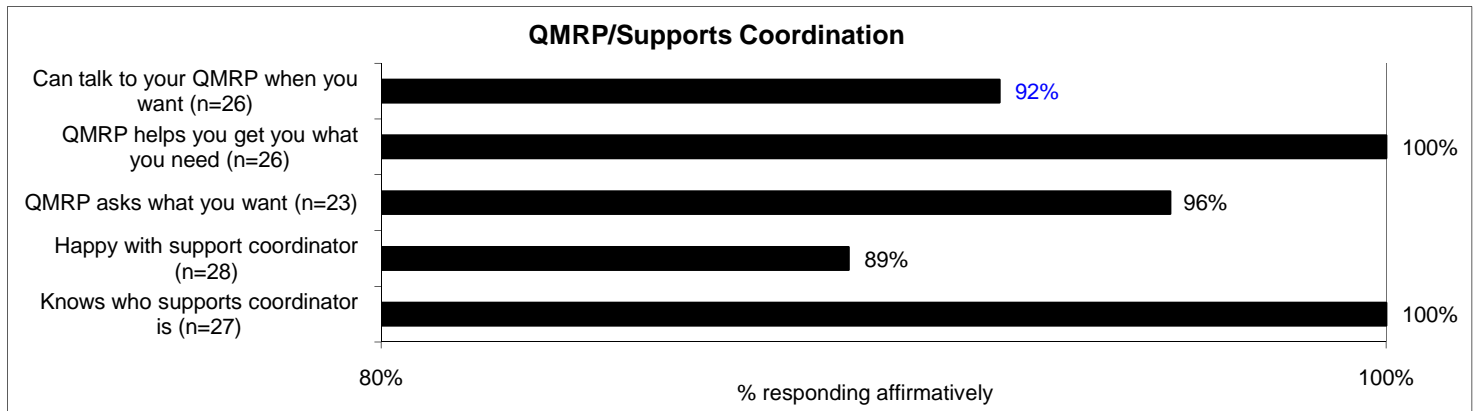
Legal Rights

- 19% of the individuals reported that someone has kept them from doing things they have the right to do.
- 44% of people said that they do not vote; of these individuals 47% would like to vote.



Qualified Mental Retardation Professional (QMRP)/Supports Coordination

- The majority of people interviewed answered “yes” to questions about qualified mental retardation professional/supports coordinator indicating a positive experience.



- 8% of individuals have had more than one QMRP/supports coordinators in the past year
- When QMRP/supports coordinators changed, 20% got to choose the new one (24% Statewide)
- 96% of individuals reported that their QMRP/supports coordinator always treats them with dignity and respect
- 100% reported that their QMRP/supports coordinator talks to them and listens to them when visiting
- 59% of those surveyed have been told how much money is in their budget
- 96% of individuals reported that they are getting all the services they expected based on the planning meetings with the supports coordinator and on the Individual Support Plan (ISP)
- 89% of individuals reported they are satisfied/happy with all the services they receive based on planning meeting with the supports coordinator and on the Individual Support Plan (ISP)
- 96% on individuals reported that their Individual Support Plan (ISP) included all of the things they needed

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 was 80.00 (Statewide 82.45) with a standard deviation of 11.99
- The modal score was 75. Interestingly, the mode for the Dignity and Respect Scale was much lower than the Satisfaction Scale. This indicates that many individuals chose the most positive answer category (very satisfied) for all measures of the Satisfaction Scale, whereas for the Dignity and Respect Scale individuals were less likely to choose the most positive answer category (very nice) for all measures.

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

- The average (mean) score was 90.10 (Statewide 90.49) with a standard deviation of 15.03.
- The mode was 100.
- The average here was quite high, and therefore there was not a great deal of fear reported among individuals receiving supports and services. The mode of 100 indicates that many individuals (59%) reported that they never feel afraid in their home, neighborhood or work/day activity site.

Qualified Mental Retardation Professional (QMRP)/Supports Coordinator

Relationship Scale: This scale included four measures that asked individuals about their relationship with the QMRP and/or supports coordinator. The first three questions focused on supports coordination were adjusted to reflect the ICF/MR qualified mental retardation professional (QMRP) role in State Centers. Scores on the QMRP/Supports Coordinator Relationship Scale could range from 0 to 100, with a higher score indicating the perception of a more positive relationship with the QMRP/supports coordinator.

- The average (mean) score equaled 98.66 (Statewide 84.38) with a standard deviation of 3.93.
- The mode was 100, indicating that was the most frequently selected response. Many of the individuals (89%) scored at the top of the scale regarding their relationship with their QMRP/supports coordinator.

⇒ It should be noted that less than a fifth of the individuals interviewed responded to this section. The interviews who responded may not be representative of all individuals surveyed.

⇒ Comparison between the state centers was not done in this section due to the low response rate.

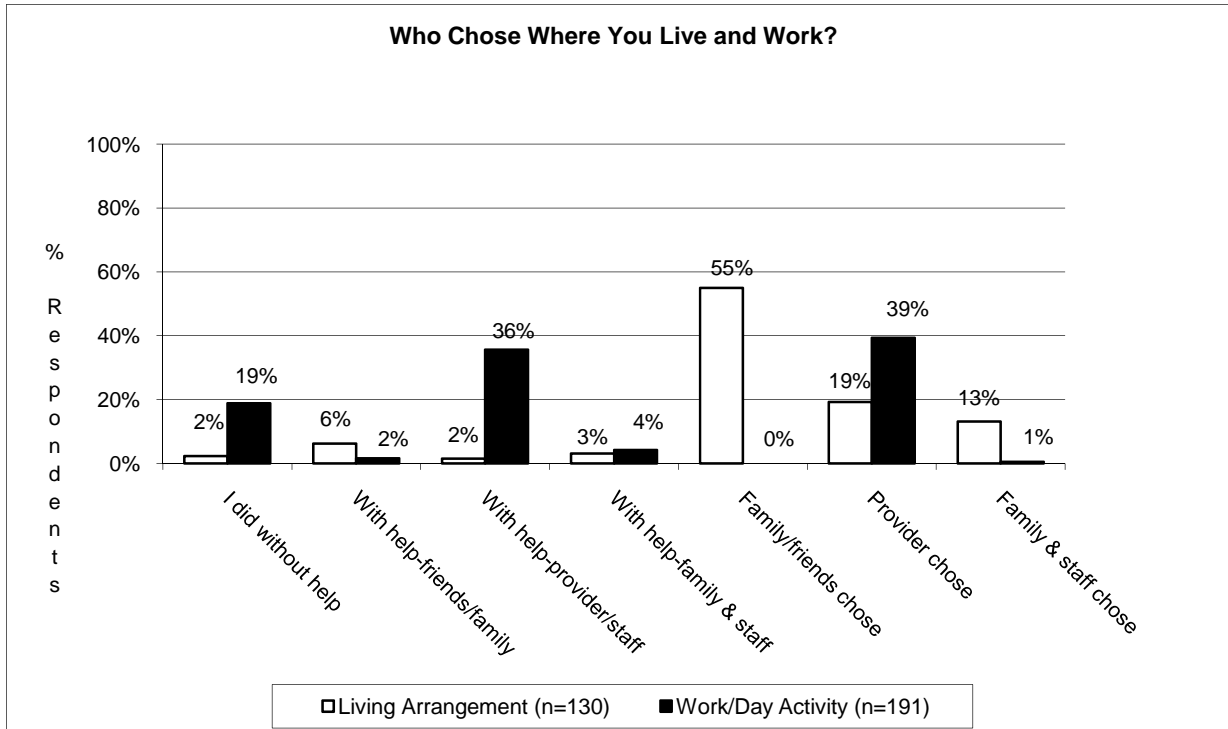
Choice and Control

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

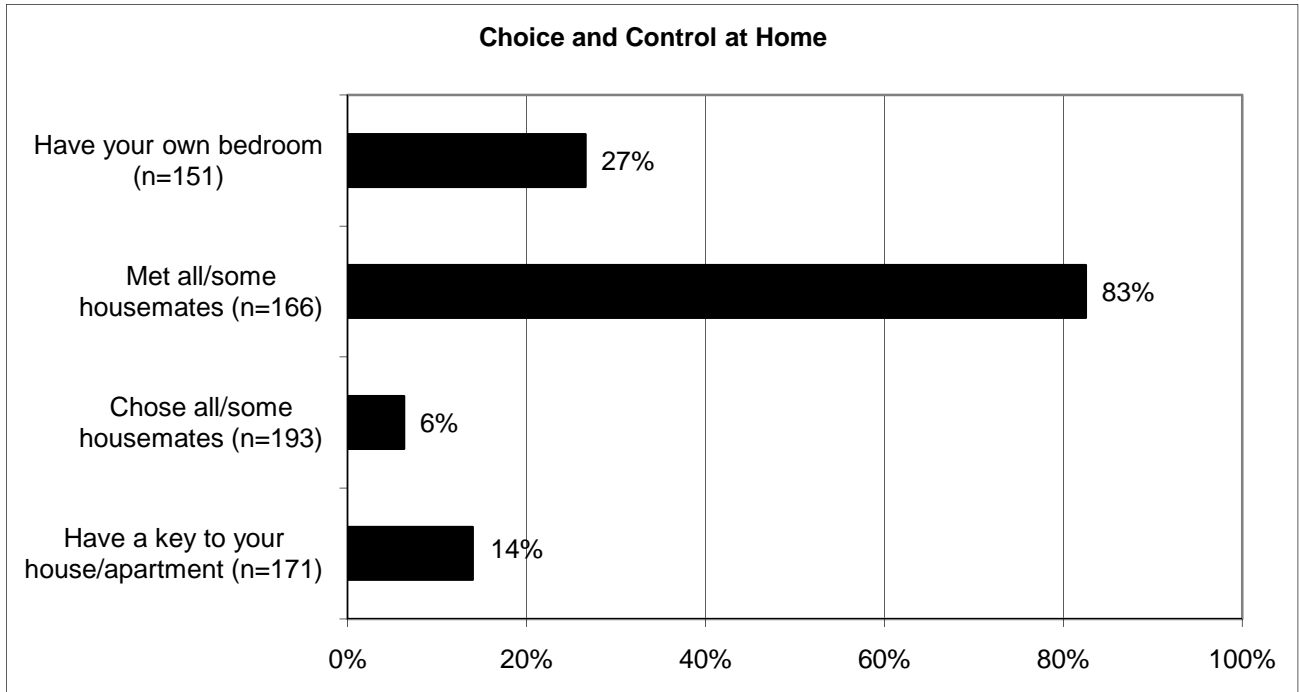
- 7% of the questions were answered by the individual receiving supports.
- 85% of the questions were answered by paid staff.
- 6% of the questions were answered by the consumer and staff.
- 1% of the questions were answered by family/friend/advocate/guardian.
- 0% of the questions were answered by the consumer and family.
- 0% of the questions were answered by staff and family.
- A value of missing was assigned when individuals did not answer, gave an unclear answer, or responded, “do not know.”

Choice and Control at Home

- 14% of the individuals surveyed had a key to their home or living area (38% Statewide).
- For 87% of the individuals, someone else chose where they live (53% Statewide); 2% of those interviewed chose without assistance.
- For those individuals who had some control in choosing where they live, 56% saw no other places, 22% saw one other place, and 22% saw more than one other place before moving in; this raises a question with regard to whether the choice individuals made was informed



- 94% of the individuals **did not** choose their housemates (73% Statewide).
- 83% of the individuals surveyed met some or all of their housemates before living together. (88% Ebensburg, 97% Hamburg, 73% Polk, 97% Selinsgrove, 42% Whitehaven) – 84% Statewide
- 27% of the individuals had their own bedroom (82% Statewide); however for those who shared a bedroom, only 16% chose some or all of their roommates.
- For 84% of the individuals interviewed, their mail is never opened without permission (92% Ebensburg, 94% Hamburg, 74% Polk, 97% Selinsgrove, 70% Whitehaven); 10% say their mail is always opened without permission.
- 94% of the individuals reported that they can have privacy with visitors.
- 96% are allowed to use the phone whenever they want.



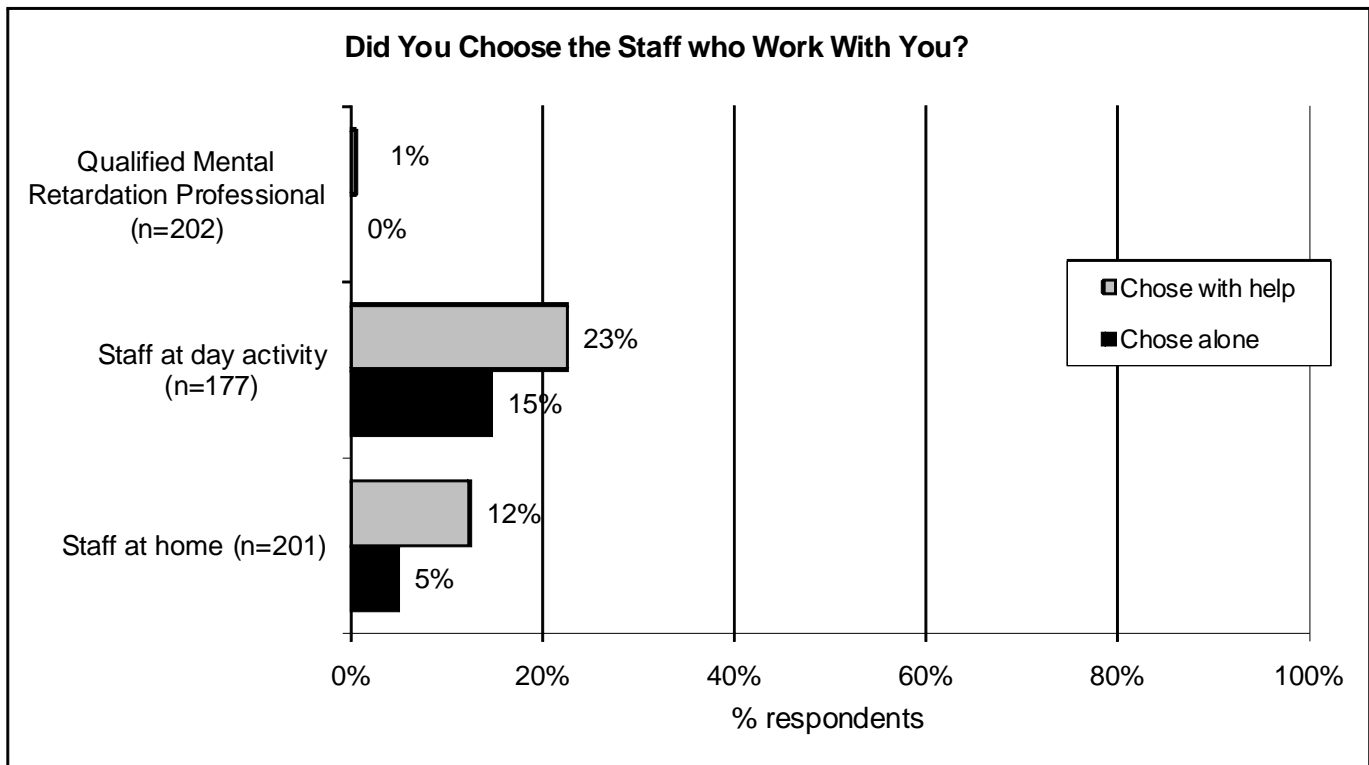
Choice and Control During the Day and for Leisure Time

- 40% of the individuals interviewed reported that someone else chose what they do during the day. (46% Ebensburg, 34% Hamburg, 43% Polk, 31% Selinsgrove, 45% Whitehaven)
- For a significant number of people (75%), the provider either chose what the individual does during the day or helped the individual decide (54% Statewide).
- 19% of the people interviewed chose what they do during the day without assistance. (16% Ebensburg, 11% Hamburg, 17% Polk, 26% Selinsgrove, 24% Whitehaven)
- For those individuals who participated in choosing what they do during the day, 50% saw no other places, 24% saw one other place, and 26% saw more than one other place before choosing where to attend day program.
- 26% of the individuals surveyed choose their daily schedules without assistance. (17% Ebensburg, 14% Hamburg, 7% Polk, 62% Selinsgrove, 43% Whitehaven) – 61% Statewide
- 54% choose how they spend their free time without assistance (54% Ebensburg, 36% Hamburg, 37% Polk, 89% Selinsgrove, 57% Whitehaven)– 71% Statewide

- 55% choose at least some of the things they do outside their home at least some of the time (89% Statewide).

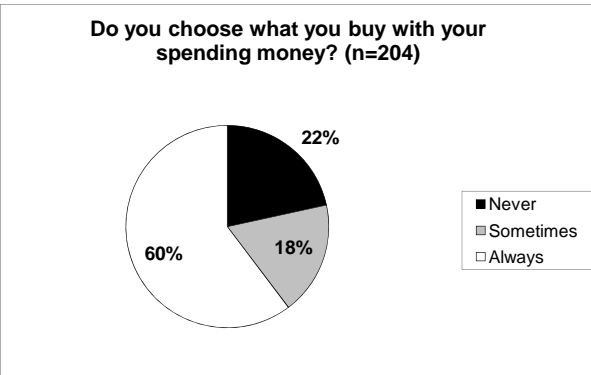
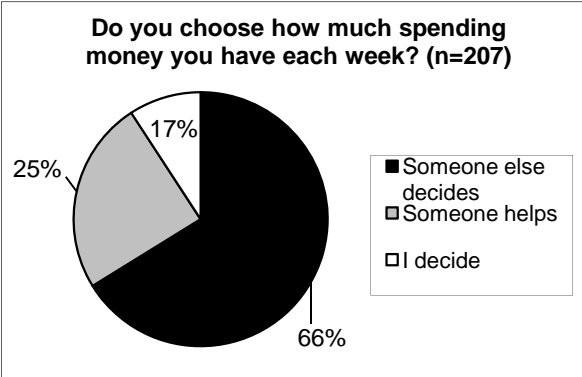
Choice and Control in Choosing Staff

- 17% of the individuals interviewed/chose at least some of the staff who help them at home (alone or with assistance from family or provider). (48% Ebensburg, 11% Hamburg, 15% Polk, 3% Selinsgrove, 7% Whitehaven)
- 37% of the individuals surveyed chose the staff that help them at work/day activity (alone or with assistance from family or provider). (53% Ebensburg, 46% Hamburg, 19% Polk, 35% Selinsgrove, 32% Whitehaven)
- 1% of the individuals reported that they chose their QMRP (alone or with assistance from family or provider).



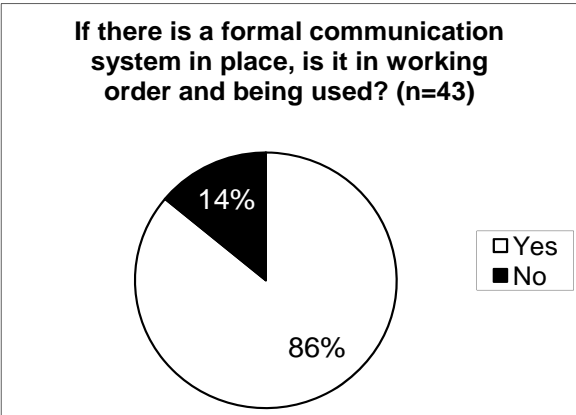
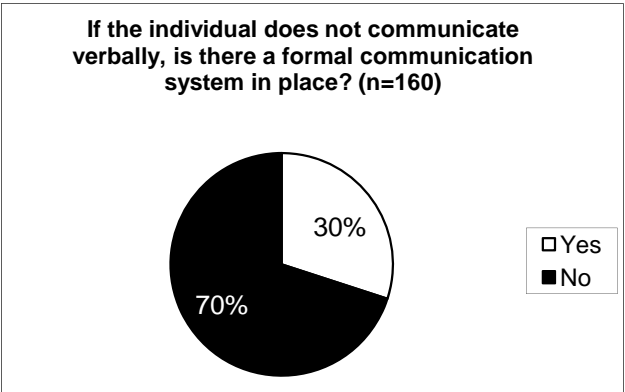
Choice and Control with Regard to Money

- 9% of the individuals interviewed reported that they choose how much spending money they have each week (27% Statewide).
- 60% of the individuals reported that they always choose what to buy with their spending money. (62% Ebensburg, 51% Hamburg, 56% Polk, 77% Selinsgrove, 57% Whitehaven) – 76% Statewide



Access to Communication

- For those individuals who do not communicate using words, there is a formal communication system in place for 30% of the people interviewed. (48% Ebensburg, 19% Hamburg, 18% Polk, 39% Selinsgrove, 15% Whitehaven)
- For those people with formal communication systems in place, the systems are in working order and utilized for 86% of the people interviewed.



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

- The average (mean) score equaled 30.88 (Statewide 48.22) with a standard deviation of 18.24.

The modal score was 43.48, indicating the most frequent score.

⇒ Comparison between the state centers was done in this section based on 2 conditions: at least 25 people in each of the state centers responded to the item and at least one of the state center's data varied by at least ten percent from the total state center result.

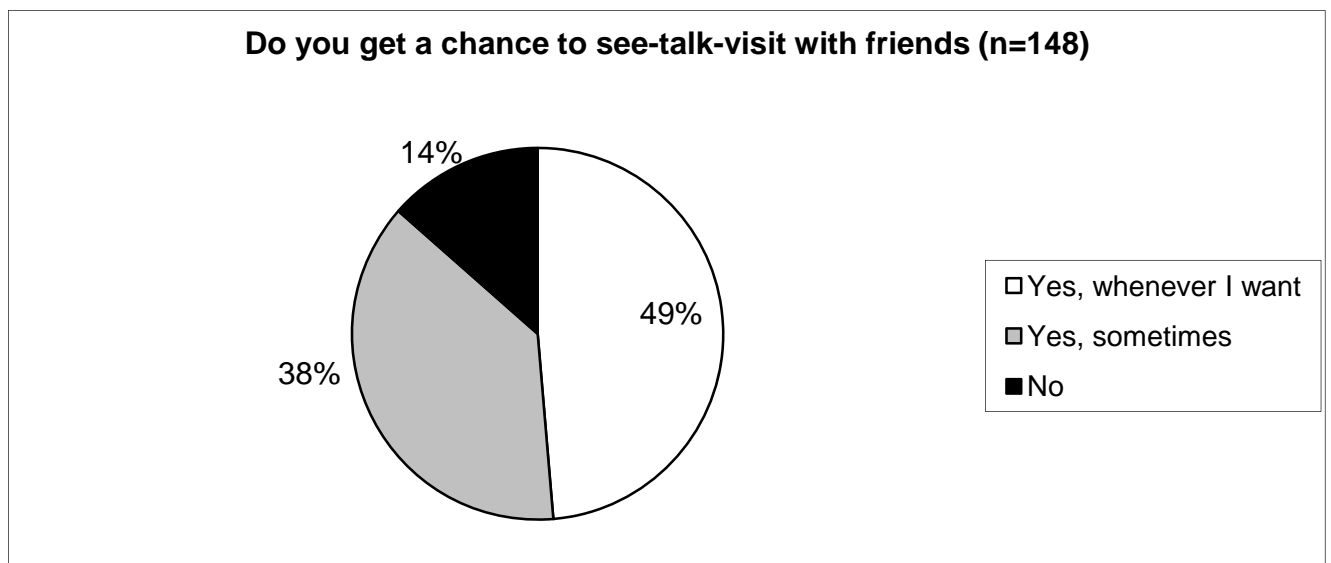
Relationships

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

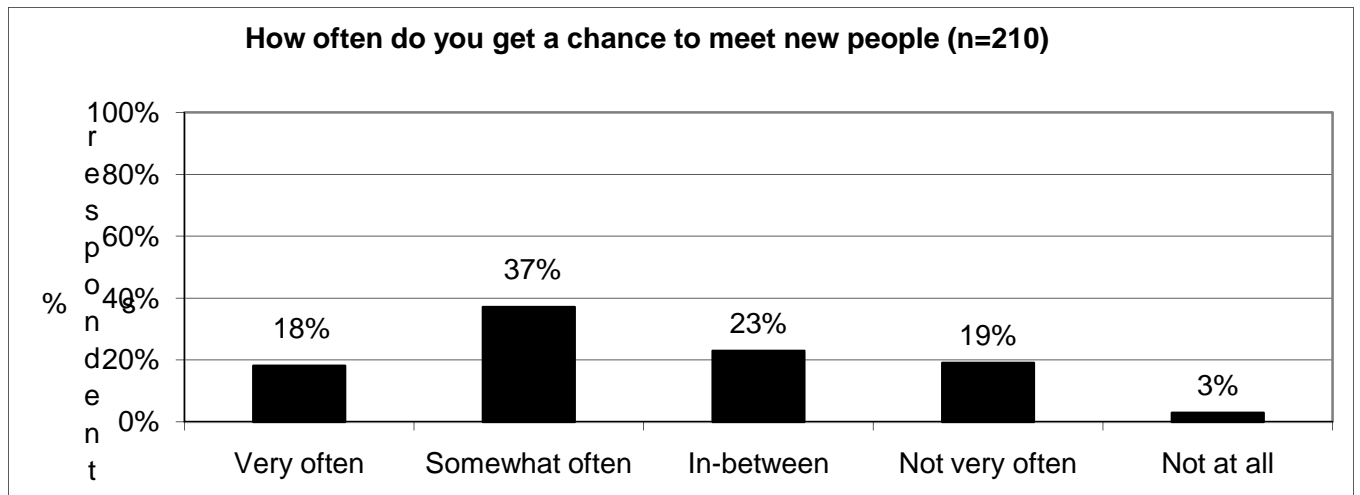
- 8% of the questions were answered by individuals receiving supports.
- 84% were answered by paid staff.
- 5% were answered by individuals receiving supports and staff.
- 1% were answered by family.
- 1% of the questions were answered by individuals receiving support and a family/friend/guardian/advocate.
- 1% of the questions were answered by staff and family.
- A value of missing was assigned when individuals did not answer, gave an unclear answer, or responded, “do not know.”

Friendships

- 49% of the people answered that they can see-talk-visit with friends whenever they want. (59% Ebensburg, 42% Hamburg, 23% Polk, 69% Selinsgrove, 55% Whitehaven)

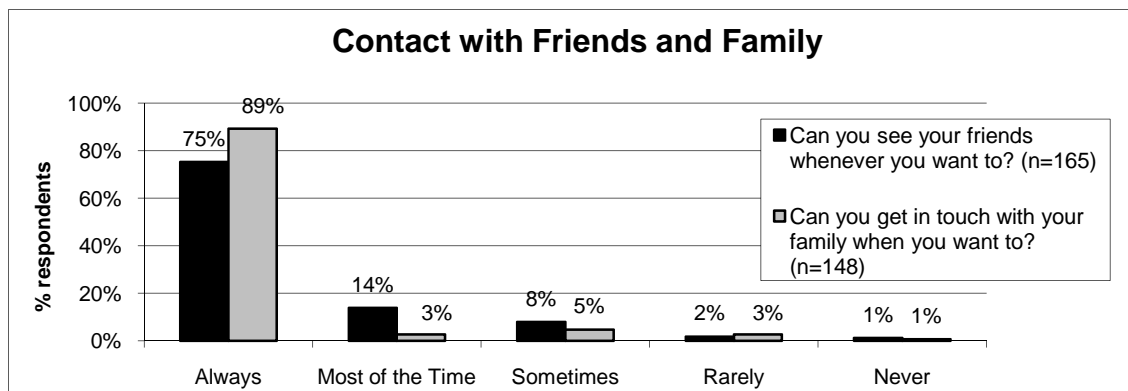


- 55% of individuals reported that they get a chance to meet new people at least somewhat often. (52% Ebensburg, 26% Hamburg, 23% Polk, 57% Selinsgrove, 32% Whitehaven)



Contact with Friends and Family

- 75% of individuals were always able to see friends whenever they wanted. (80% Ebensburg, 87% Hamburg, 55% Polk, 69% Selinsgrove, 88% Whitehaven)
- 89% of individuals were always able to get in touch with family (90% Statewide).



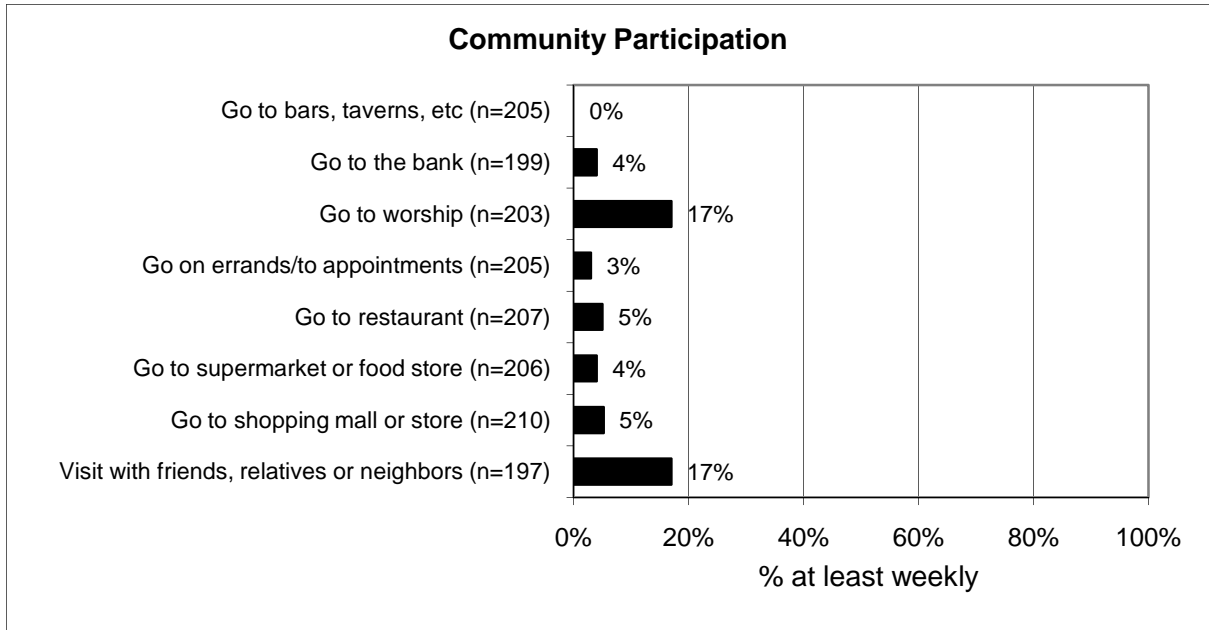
Inclusion

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

- 8% of the questions were answered by individuals receiving supports.
- 86% were answered by paid staff.
- 4% were answered by individuals receiving support and staff.
- 1% were answered by family/friend/guardian/advocate.
- 0% of the questions were answered by individuals receiving support and a family/friend/guardian/advocate.
- 0% of the questions were answered by staff and family.
- A value of missing was assigned when individuals did not answer, gave an unclear answer, or responded, “do not know.”

Community Participation

- 17% of the people visited with friends, relatives and neighbors at least weekly (58% Statewide).
- 17% of the individuals went to a place of worship at least weekly.
- 4% of the individuals surveyed went to supermarkets (48% Statewide) and 5% went to restaurants at least weekly (43% Statewide).
- Individuals rarely went out for errands and appointments, to banks, shopping malls/stores or to bars/taverns.



Harris Poll

In May and June 2000, the National Organization on Disability commissioned Harris Interactive, Inc. to conduct a national phone survey to examine and compare the quality of life and standard of living for people with and people without disabilities. We compared the frequency of community participation reported by individuals in our sample to this national sample. The Harris Poll depends on self-report in determining whether a person has a disability. The definition used is that a person has a disability if they have a disability or health problem that prevents them from participating fully in work, school or other activities, if they have a physical disability, seeing, hearing or speech impairment (sic), an emotional or mental disability or a learning disability (Harris, 2000).

- Pennsylvanians with disabilities living in state centers, according to this study were less likely to visit with friends, relatives and neighbors, go to supermarkets, restaurants, places of worship, and shopping malls/stores than either of the two Harris Poll groups (people with and without disabilities) and those in the 2007-08 Independent Monitoring Sample.

Weekly Participation in Community Activities

	Harris: People without Disabilities	Harris: People with Disabilities	Pennsylvania: 2007-2008 Monitoring Sample	Pennsylvania: State Centers
Visit with friends, relatives and neighbors	85%	70%	58%	17%
Go to a supermarket	83%	55%	48%	4%
Go to a restaurant	59%	40%	43%	5%
Go to worship	47%	30%	30%	17%
Go to a shopping mall or store	41%	23%	42%	5%

Inclusion Scale

Scores on the Inclusion Scale could range from 0 to 100, with a higher score indicating greater inclusion (going more frequently to places in the community). The scale includes 8 items measuring frequency of participation in community activities. These items include visiting with friends, going to the supermarket, going to a restaurant, going to worship, going to a shopping mall, going to a bar, going to the bank, and going on errands.

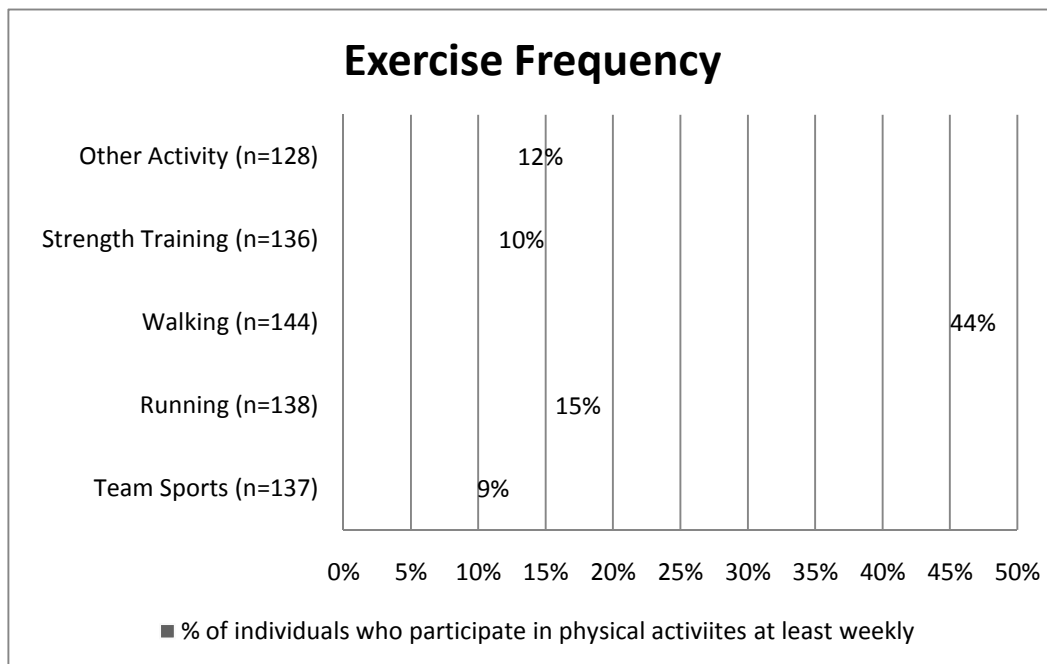
- The mean was 18.37 (18.84 Ebensburg, 12.21 Hamburg, 13.81 Polk, 27.50 Selinsgrove, 20.60 Whitehaven – 42.09 Statewide) with a standard deviation of 11.53.
- The mode was 10.42, indicating the most frequent score and that few individuals participate in community activities.

Exercise Frequency and Intensity

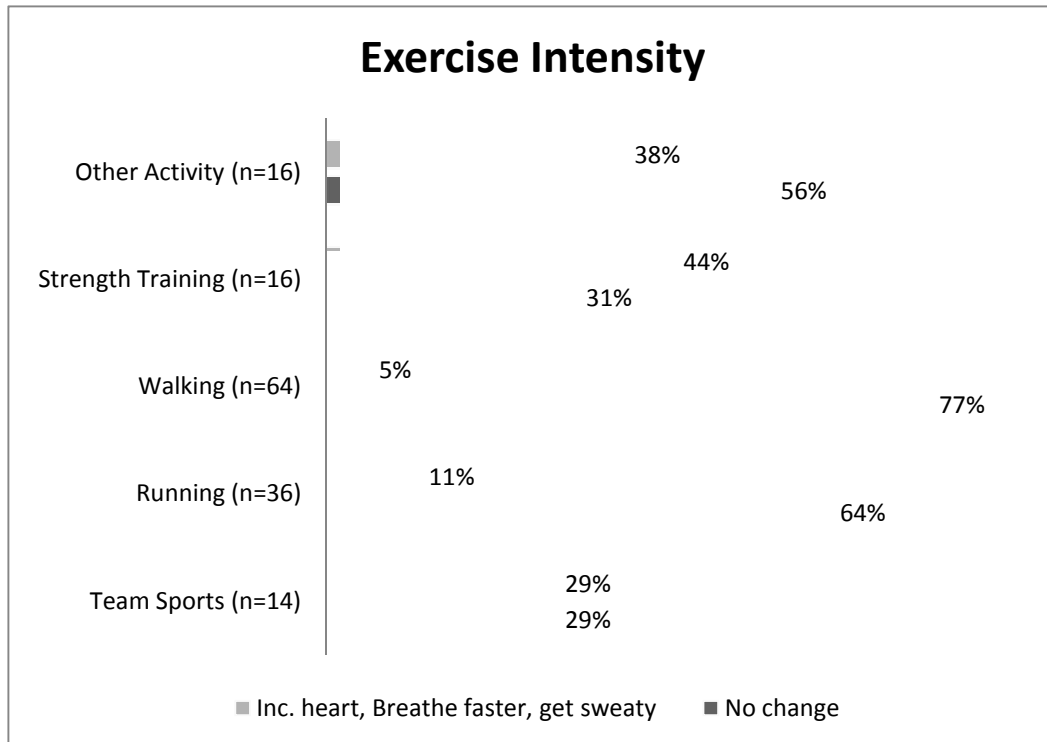
We asked individuals about how often (20 minutes or more per day) they participate in exercise, playing sports and/or other physical activities. In addition, we also asked

individuals, if they do exercise in team sports, running, walking, strength training, and other physical activities, to what intensity to they participate in these activities.

- 91% of individuals interviewed reported they never participated in team sports; 9% of individuals reported participating in team sports at least weekly
- 67% of individuals interviewed reported they never participated in activities like running; 15% of individuals reported participating in activities like running at least weekly
- 48% of individuals interviewed reported they never participated in activities like walking; 44% of individuals reported participating in activities like walking at least weekly
- 87% of individuals interviewed reported they never participated in activities like strength training; 10% of individuals reported participating in activities like strength training at least weekly
- 87% of individuals interviewed reported they never participated in other physical activities; 12% of individuals reported participating in other physical activities at least weekly



- 27% of individuals interviewed reported they participate in activities like team sports to the extent that their heart rate increased, they breathed faster and they got sweaty; 29% of individuals reported no change when participating in activities like team sports
- 11% of individuals interviewed reported they participate in activities like running to the extent that their heart rate increased, they breathed faster and they got sweaty; 64% of individuals reported no change when participating in activities like running
- 5% of individuals interviewed reported they participate in activities like walking to the extent that their heart rate increased, they breathed faster and they got sweaty; 77% of individuals reported no change when participating in activities like walking
- 44% of individuals interviewed reported they participate in activities like strength training to the extent that their heart rate increased, they breathed faster and they got sweaty; 31% of individuals reported no change when participating in activities like strength training
- 38% of individuals interviewed reported they participate in other physical activities to the extent that their heart rate increased, they breathed faster and they got sweaty; 56% of individuals reported no change when participating in other physical activities



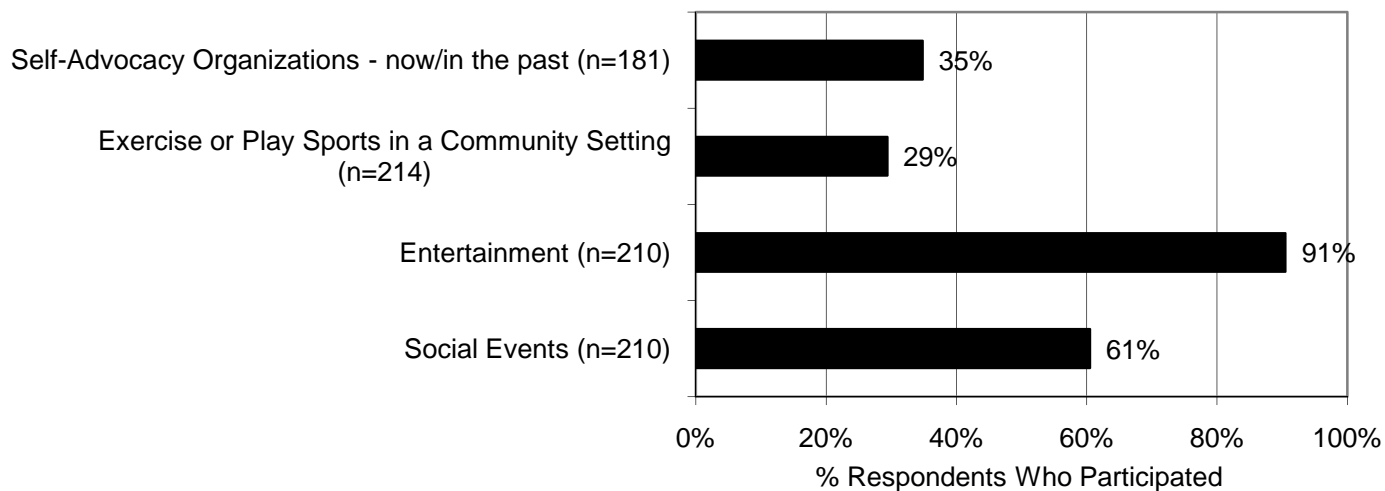
Due to the great difficulty reported in responding to the aforementioned group of questions, these questions will be removed when the EDE is revised for 2008-2009

Community Activities

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

- 91% of individuals go into the community for entertainment.
- 35% of individuals currently participate in a self-advocacy group or have participated in a similar event in the past (16% Statewide).
- 61% of individuals reported that they attend community events that are attended by anyone in the community (69% Ebensburg, 47% Hamburg, 35% Polk, 78% Selinsgrove, 78% Whitehaven).
- 29% of individuals reported that they exercise or play sports in a community setting (37% Statewide); 26% exercise or play sports in a non-inclusive setting.

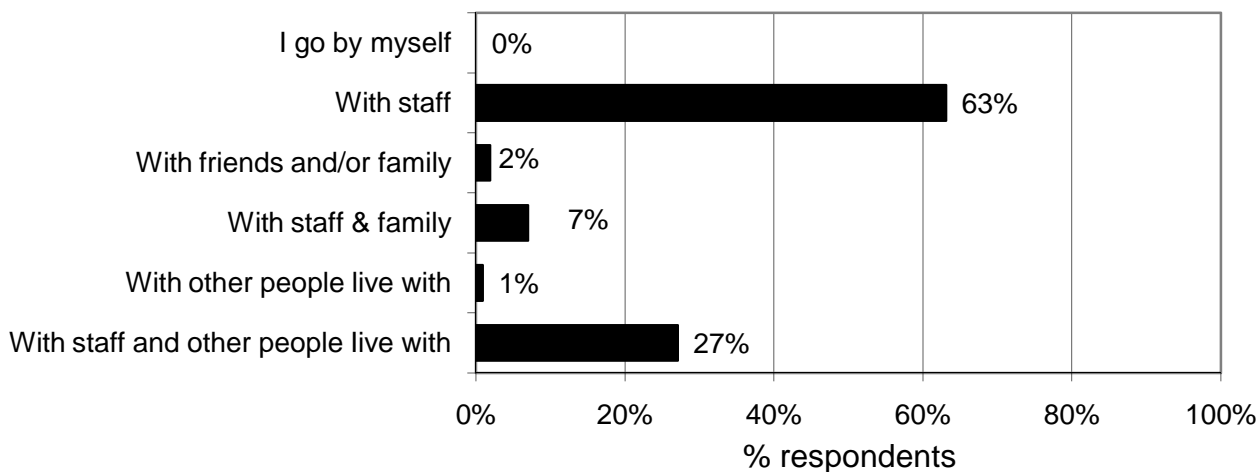
Community Activities



Going Out Alone or With Other People

- 0% of individuals go out alone.
- 63% of individuals go out with staff most of the time (37% Statewide).

Most of the time, when you go into the community, who do you go with? (n=214)



Transportation

- 87% of individuals always or almost always had a way to get where they wanted to go (100% Ebersburg, 92% Hamburg, 53% Polk, 100% Selinsgrove, 100% Whitehaven); of those who cannot always get where they want to go, 78% cannot get there due to there not being enough staff (29% Statewide).
- Of individuals not using public transportation, 69% do not use it because it does not exist where they live (50% Statewide).

Do you always have a way to get where you want to go? (n=207)

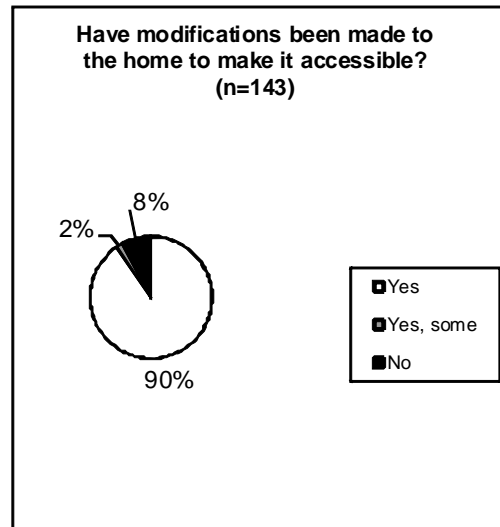
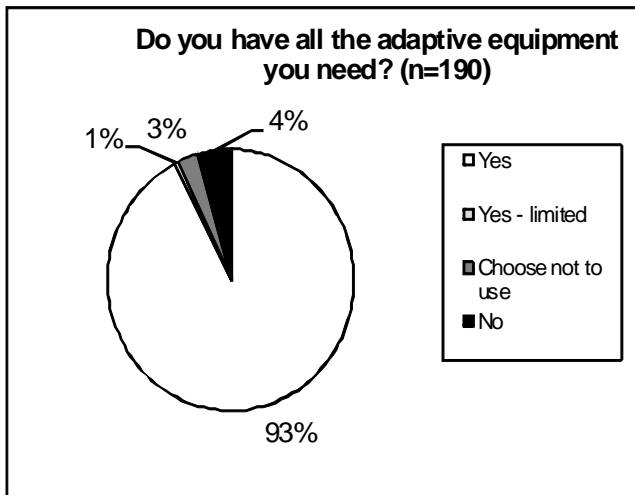
Yes, always or almost always – 87%

Sometimes – 12%

Never, almost never – 1%

Home Adaptive Equipment

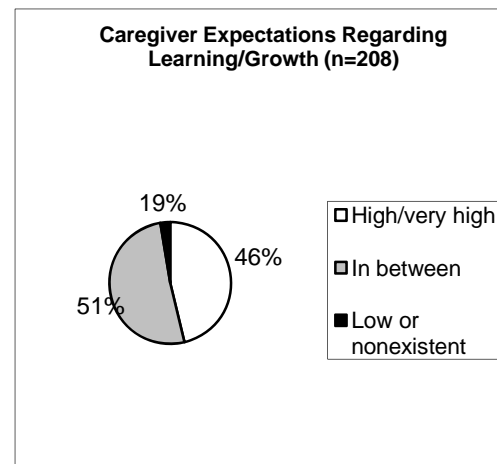
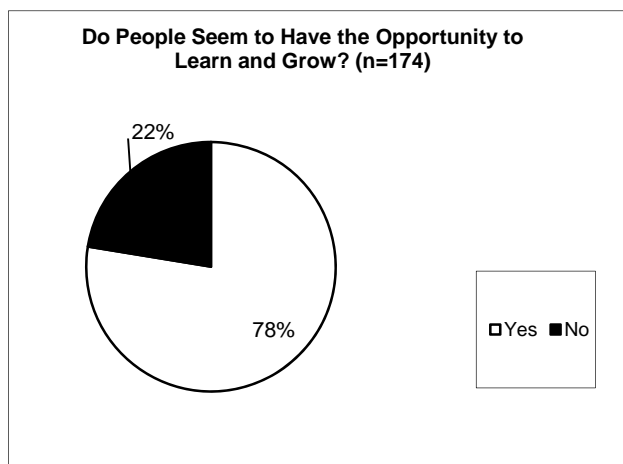
- 93% of individuals have all the adaptive equipment they needed. (100% Ebersburg, 97% Hamburg, 79% Polk, 96% Selinsgrove, 93% Whitehaven)
- 90% of respondents reported that all necessary modifications have been made to their home to make it accessible (82% Statewide).



⇒ Comparison between the state centers was done in this section based on 2 conditions: at least 25 people in each of the state centers responded to the item and at least one of the state center's data varied by at least ten percent from the total state center result.

Competence, Personal Growth and Opportunities to Grow and Learn

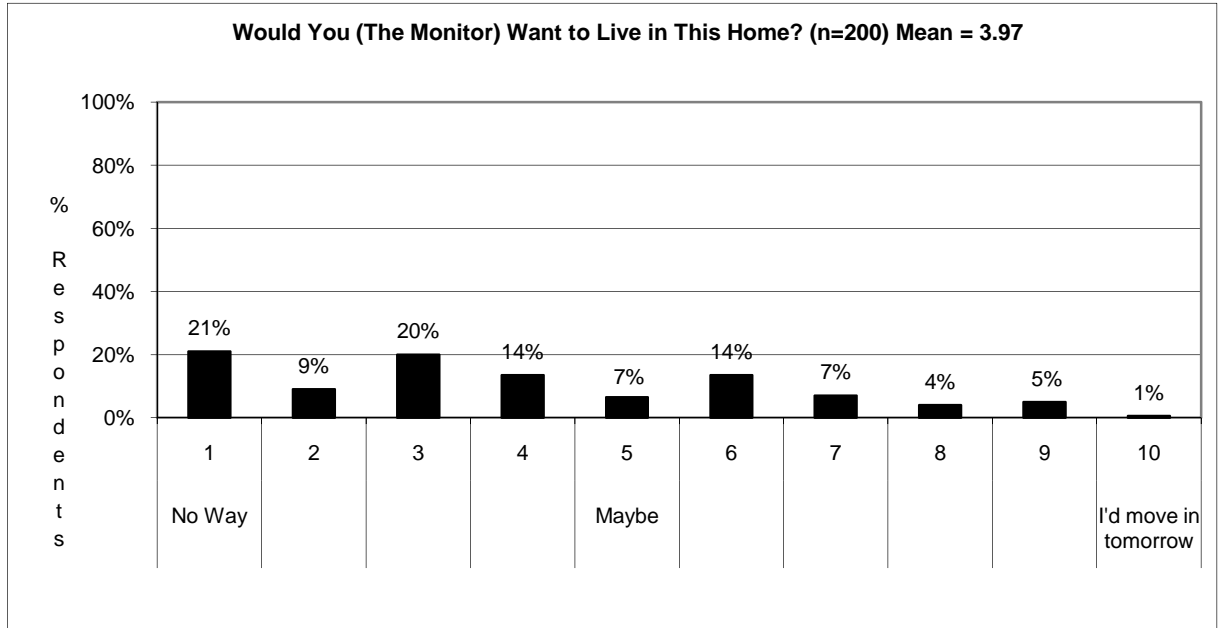
Respondents: The Independent Monitoring Team answered the questions on competence, personal growth, and opportunities to grow and learn after they spent time with the individual in his/her home or other place of his/her choosing.



According to the IM4Q teams,

- 78% of the individuals appeared to have the opportunity to learn new things. (83% Ebensburg, 94% Hamburg, 54% Polk, 70% Selinsgrove, 97% Whitehaven)
- Caregiver expectations regarding growth were reported as being high or very high for 37% of the individuals. (55% Ebensburg, 22% Hamburg, 34% Polk, 36% Selinsgrove, 35% Whitehaven – 51% Statewide))

- When asked whether team members would want to live in the individual's home on a scale of 1 ("No way") to 10 ("I'd move in tomorrow"), the average score was 3.9 (Statewide 6.8)



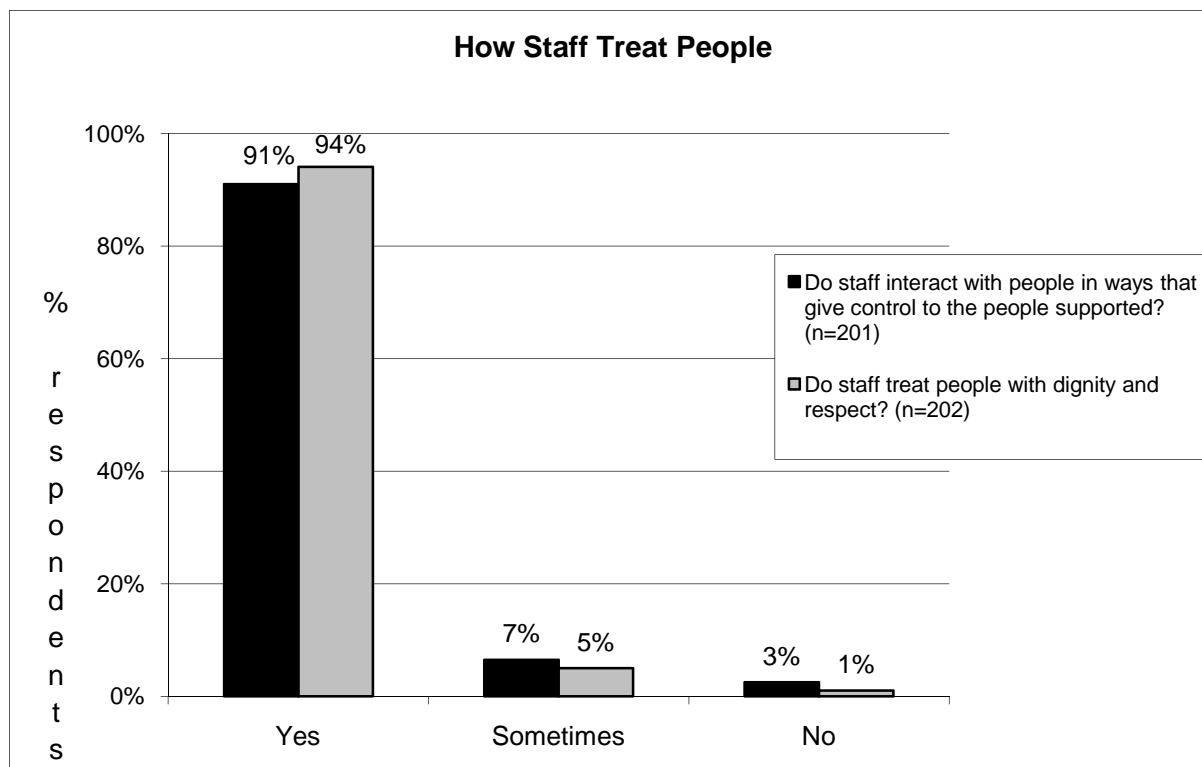
Staff Support for the Person

Respondents: The Independent Monitoring Team answered the questions on staff support for the person, after having spent time with the person and the staff who support them.

Number of Staff and Staff Skill

According to the IM4Q teams,

- 91% of staff observed interacted with individuals in ways that gave control to the people supported. (98% Ebensburg, 100% Hamburg, 72% Polk, 97% Selinsgrove, 97% Whitehaven)
- The majority of individuals had either; all staff (91%) (86% Ebensburg, 100% Hamburg, 79% Polk, 97% Selinsgrove, 100% Whitehaven) or some staff (6%) with the skill needed to support them. (14% Ebensburg, 0% Hamburg, 11% Polk, 3% Selinsgrove, 0% Whitehaven)
- Staff treated individuals with dignity and respect in 94% of observed cases. (100% Ebensburg, 97% Hamburg, 79% Polk, 100%, Selinsgrove, 100% Whitehaven)



Physical Setting

Respondents: The IM4Q Team answered the following questions regarding the physical setting, which referred to the place where the individual lives. Most interviews took place in the individual's home (74%), or at work/day activity (6%).

Home Repair

- According to the IM4Q teams, the majority of individuals lived in homes/living areas which were in good repair on the outside (100%) and on the inside (99%).

Neighborhood

According to the IM4Q teams,

- 100% of individuals lived in homes/living areas which were in a safe neighborhood.
- 30% of individuals lived in homes/living areas that "fit in" with the neighborhood in which they were located (98% Ebensburg, 6% Hamburg, 16% Polk, 24% Selinsgrove, 11% Whitehaven – 92% Statewide).

Personal Belongings and Personalities

- 92% of individuals lived in homes which had sufficient space for personal belongings.
- 12% lived in homes which reflected the hobbies, interests and personalities of the people who live there (50% Ebensburg, 6% Hamburg, 21% Polk, 0% Selinsgrove, 0% Whitehaven – 65% Statewide); for 74% of individuals only their bedroom reflected their interests (50% Ebensburg, 91% Hamburg, 49% Polk, 80% Selinsgrove, 88% Whitehaven).

Physical Setting Scale: Based on the three individual items, a Physical Setting Scale (based on the place where the individual lives) was developed. Scores on the Physical Setting Scale could range from 0 to 100, with a higher score indicating a nicer setting.

- The average (mean) score was 99.53 (Statewide 96.25) with a standard deviation of 4.81.
- The mode (the value that occurs the most frequently) equaled 100, indicating that most people lived in homes which were at the top of the scale on all measures of the physical setting.

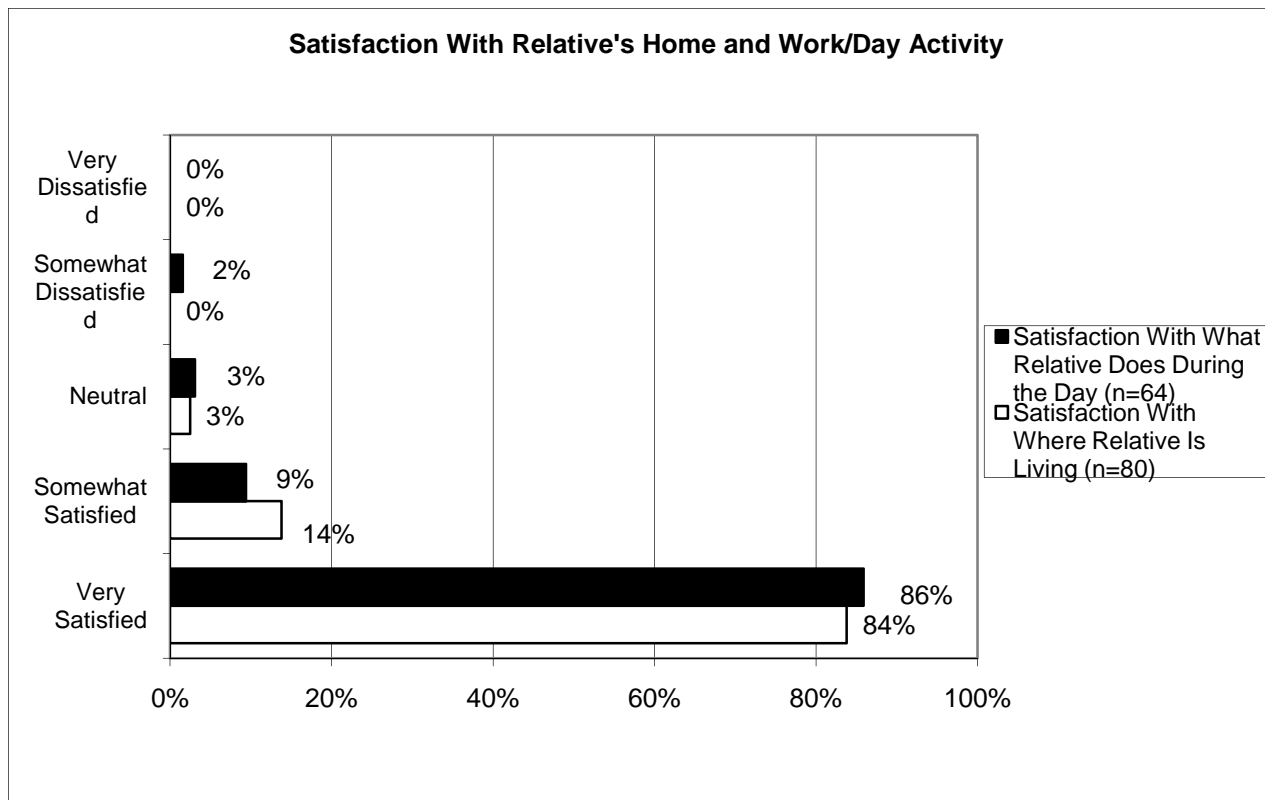
⇒ Comparison between the state centers was done in this section based on 2 conditions: at least 25 people in each of the state centers responded to the item and at least one of the state center's data varied by at least ten percent from the total state center result.

Family/Friend/Guardian Survey

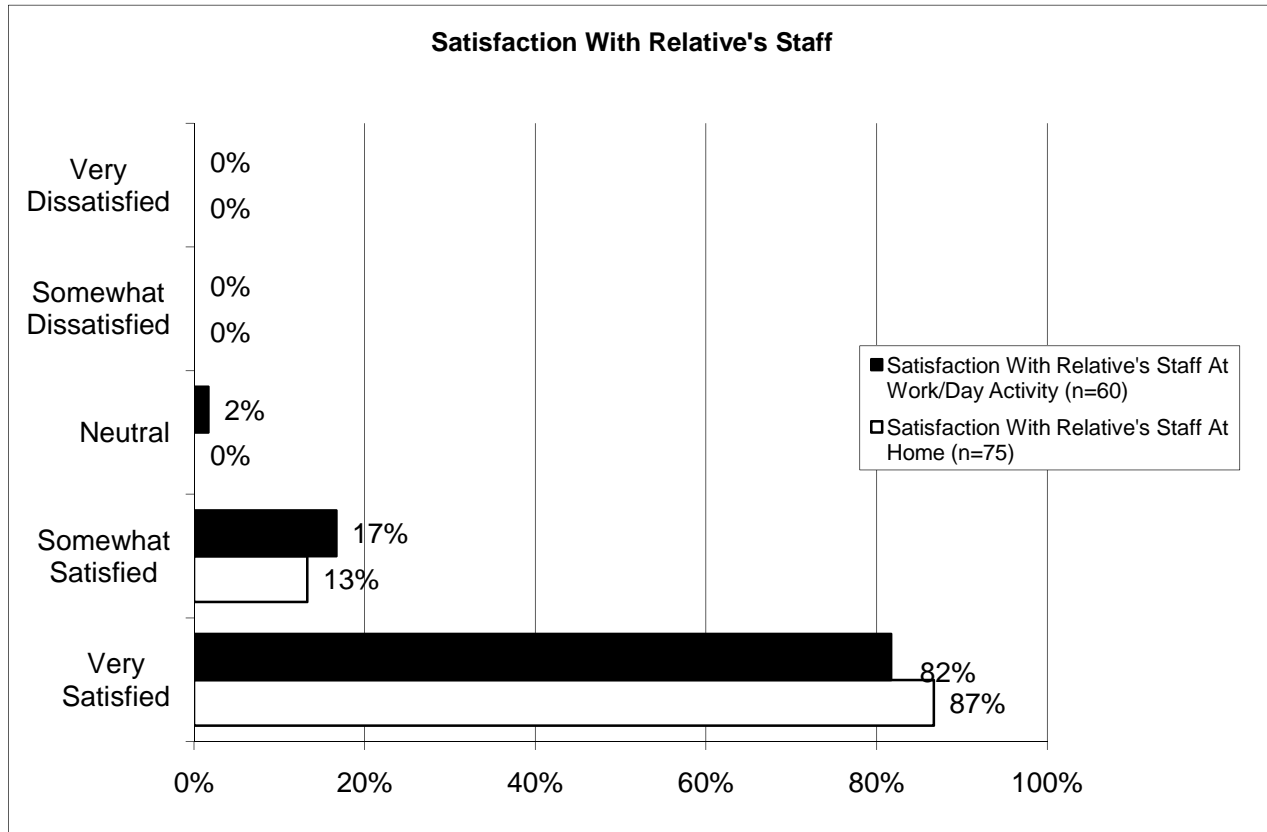
Respondents: This survey was completed by telephone with a family member, guardian, or friend who was identified through the Essential Data Elements Pre-Survey. In the event that a phone survey could not be completed, surveys were completed by mail. Thirty-seven percent of the individuals had a family/friend/guardian that responded to this portion of the survey.

- 49% of the surveys were answered by parents.
- 44% were answered by siblings.
- 0% were answered by the guardian.
- 1% were answered by persons with other relationships to the individual receiving supports.

Satisfaction



- 98% of the families surveyed, were either somewhat satisfied or very satisfied with where their relative lives.
- 95% were either satisfied or very satisfied with what their relative does during the day (90% Statewide).



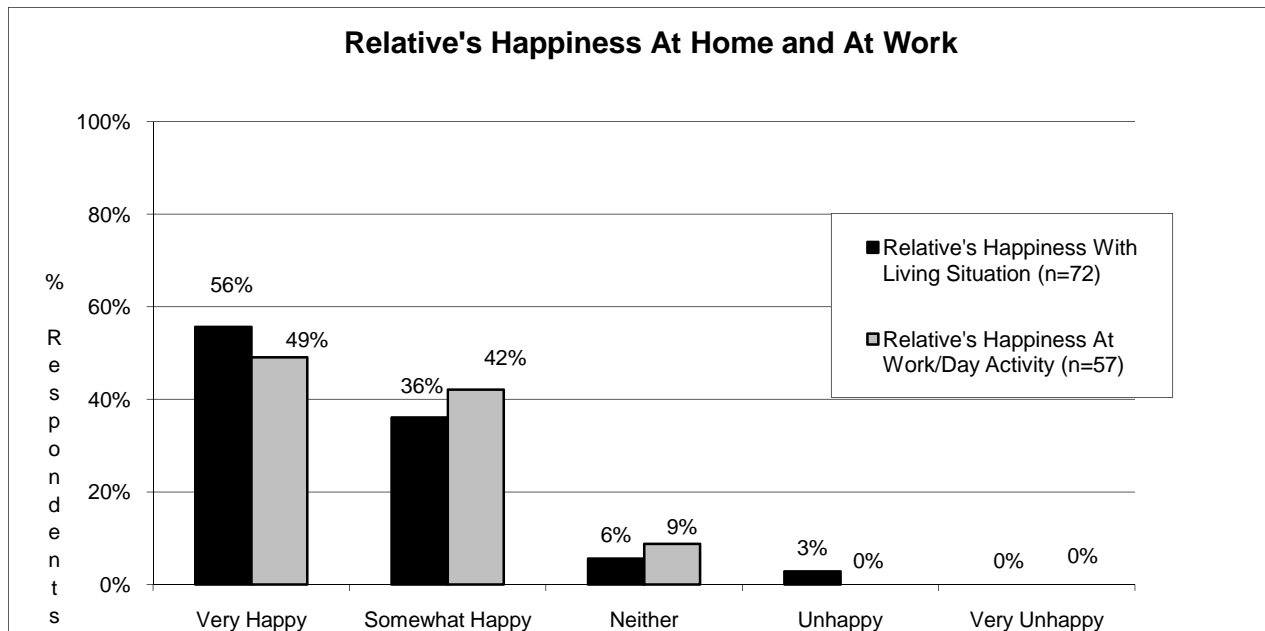
- 100% of the families surveyed were either somewhat satisfied or very satisfied with their relatives' staff at home.
- 98% of the families surveyed were either somewhat satisfied or very satisfied with the staff at their relatives' day activity.

How Often Do You Contact/See Your Relative?

- 40% of the family/friend/guardians contacted their relative at least monthly (86% Statewide); 13% have not contacted their relative in the past year.
- 26% of the family/friend/guardians were able to see their relative (family's home, individual's home, or on an outing) at least once a month (74% Statewide); 30% did not get to see their relative in the past year.

Your Relative's Happiness

- 92% of respondents felt their relative was either very happy or somewhat happy with his/her living situation; 91% felt their relative was either very happy or somewhat happy with what they do during the day.



- 96% of respondents felt their relative was either very happy or somewhat happy with the staff who support them at home;
- 95% of respondents felt their relative was either very happy or somewhat happy with the staff who support them at work (or during the day).

Your Relative's Safety

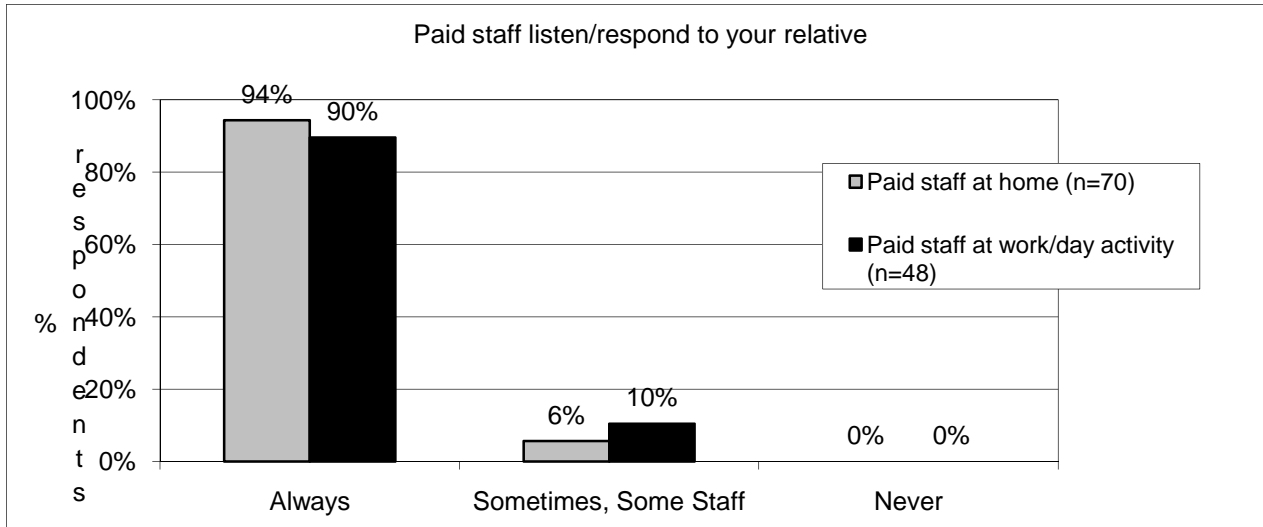
- Respondents said that their relative felt safe at home always (74%).
- Respondents said they think their relative felt safe in their neighborhood always (82%) or most of the time (15%).
- 86% of respondents said they think their relative always felt safe at his/her day activity.

Your Relative's Opportunities

- 86% of the respondents said that their relative got enough opportunities to participate in activities outside the home (85% Statewide).
- 78% of the respondents said that their relative seemed to have the opportunity to learn new things.

Your Relative's Staff

- 60% of the respondents said that their relative's staff at home had high or very high expectations regarding growth for their relative; 64% felt that their relative's staff at work/day activity had high or very high expectations regarding growth for their relative (62% Statewide)
- If their relative did not communicate verbally, 18% of the respondents said that there is a formal communication system in place for their relative and they use it
- 94% of the respondents said that their relative's home appeared to have enough paid staff (88% Statewide).
- 94% of the respondents said that staff in their relative's home interact with people in ways that give control to the people being supported (87% Statewide).
- 97% of the respondents said that staff in their relative's home treat people with dignity and respect.
- 94% of the respondents said that all staff appear to have the skills they need to support their relative (82% Statewide); 6% felt that way about only some staff (16% Statewide).



- In terms of relative-staff interactions, families believe that staff at home listen/respond to their relative's communication (94% always); for staff at work/day activity, 90% always listen and respond to their relative's communication

Relative's Supports

- 88% of relatives interviewed said that the QMRP/supports coordinator is always available to assist them if there is a crisis (86% Statewide).
- 100% of relatives were satisfied with the QMRP/supports coordination their relative receives (83% Statewide).
- 38% of relatives reported that they were told how much money is in their relative's annual budget (56% Statewide)
- 93% said that their relative always received the supports they needed (74% Statewide)
- 92% of relatives reported that they always got enough information to help them participate in planning services for their family member (76% Statewide)
- 98% of relatives always felt that the staff who assisted them with planning respected their choices and opinions (87% Statewide)

- 93% of relatives felt that when they asked the QMRP/supports coordinator for help the QMRP/supports coordinator always helped them get what they needed (80% Statewide)
- 61% of relatives never felt that frequent changes in support staff was a problem for their family member
- 39% of relatives always got to choose the agency/provider who worked with their relative; 54% never got to choose
- 73% of relatives were always satisfied with the way complaints and grievances are handled (50% Statewide); 21% were never satisfied
- 10% of relatives report that there is other information they would like to have (26% Statewide).

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 91.06 (Statewide 88.65) with a standard deviation of 10.12.
- The mode (the value that occurs the most frequently) was 100, indicating that many of the families' satisfaction levels were at the top of the scale on all measures of family satisfaction.

⇒ Comparison between the state centers was not done in this section due to the low response rate.

Summary

This report presents information collected through face-to-face interviews with 218 individuals living in state centers and receiving supports through the Office of Developmental Programs.

A small percentage of individuals were able to respond to the questions being presented in the satisfaction and dignity, respect and rights sections of the survey. Those responding reported relatively high levels of satisfaction with where they live and where they work, **however, approximately a third of the individuals reported that they would rather live somewhere else.**

More than three-fourths of individuals reported having privacy when they want it and reported that people knock on their bedroom doors before entering. **Approximately a quarter of individuals interviewed reported always carry a form of identification.**

Data indicate that individuals living in state centers have little choice with regard to where they live and with whom they live. Prior to moving into their home, more than half of the people interviewed did not visit other places for comparison. In choosing day activities or work, providers, either alone or with the person, made the decision most frequently.

A small percentage of individuals chose how much spending money they have each week. More than half of those interviewed always chose what they buy with their money; approximately a quarter of the people never chose.

Data show that individuals living in state centers have some control over their free time. Half of those interviewed chose how to spend their leisure time alone or with help from others. Few individuals participated in community activities such as shopping, going to restaurants or running errands; however, when participating in community activities less than two-thirds of the people participate in inclusive activities, rather than activities

designed only for people with disabilities. Few individuals go into the community with people other than individuals they live with or staff. More than half of individuals always have the opportunity to participate in household tasks.

Approximately three-fourths of individuals surveyed do not communicate using words. **For these individuals, there are issues around lack of exploration of alternative strategies.** When it has been explored and people have acquired devices, less than a quarter say they are not in working order and being used.

Data show positive results with regard to the individuals' living environments. A majority of staff have the skills they need to support those being interviewed. They treat individuals with dignity and respect and interact in ways that give control to the people they support. Although the state centers do not typically "fit in" with the neighborhood, they were found to be in good repair on both the outside and inside.

The results of the Family/Friend/Guardian Survey found high levels of satisfaction similar to the responses given by the individual. However, less than half of the individuals contact or visit their family members on a monthly basis; nearly a tenth of the family members had not visited or contacted their relatives in the past year.