

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

Independent Monitoring for Quality (IM4Q)
A Statewide Summary
2013-2014

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

Submitted by: Celia S. Feinstein, James A. Lemanowicz,
Mary Kay R. Cunningham and Ross Whiting
The Institute on Disabilities
Pennsylvania's University Center for Excellence in
Developmental Disabilities
Temple University
Student Center, 411S
1755 North 13th Street
Philadelphia, PA 19122

May, 2015



Institute on Disabilities

TEMPLE UNIVERSITY®

College of Education

Introduction

In 1997, Pennsylvania's Office of Developmental Programs (ODP) developed a multi-year plan that represented a significant effort to convey its vision, values and goals for the coming years. As a result, recommendations were made to create a subcommittee of individuals, families, providers, advocates, administrative entity staff and ODP staff to create an independent monitoring program across the state of Pennsylvania. At the same time, a national project was developed to identify performance indicators that states could collect to determine the status of their system via the experiences of individuals, families, and providers delivering supports. Pennsylvania aligned the project created by ODP's subcommittee with the newly developed National Core Indicators to create the Independent Monitoring for Quality (IM4Q) Program.

As a result of the IM4Q Program, ODP has developed and begun to implement quality improvement strategies (QIS) to ensure the continued improvement of services and supports people receive through Pennsylvania's intellectual disability system. The IM4Q data are one source of information used to increase the quality of ODP's services and supports. The IM4Q Program is contracted through each of the 48 Administrative Entities (AEs). Each year, the AEs develop contracts with Local IM4Q Programs to independently conduct interviews and enter consideration data into the DHS HCSIS web-based system. In 2013, we began to utilize ODESA, a web-based, secure data entry system developed for the National Core Indicators Project to enter all data. The IM4Q data are analyzed and reports are developed for dissemination to ODP staff, individuals, families, guardians, AEs, Local Programs, providers and other interested people.

A list of the number of individuals receiving services and their family, friends and guardians who completed surveys in the years of the project is listed in the table below:

| Fiscal Year | Individuals Surveyed | Friends, Family, Guardians Surveyed |
|-------------|----------------------|-------------------------------------|
| 2000-2001 | 5298 | 2224 |
| 2001-2002 | 5659 | 2494 |
| 2002-2003 | 4687 | 3163 |
| 2003-2004 | 6373 | 2975 |
| 2004-2005 | 6499 | 3010 |
| 2005-2006 | 6496 | 2851 |
| 2006-2007 | 6469 | 3028 |
| 2007-2008 | 6512 | 2731 |
| 2008-2009 | 6618 | 2896 |
| 2009-2010 | 6621 | 2590 |
| 2010-2011 | 6692 | 2510 |
| 2011-2012 | 6589 | 2517 |
| 2012-2013 | 5858 | 2160 |
| 2013-2014 | 5341 | 2187 |

The reduction in the number of individuals surveyed during 2012-2013 was due to the change in the sampling strategy for the National Core Indicators Survey.

Methodology

Instrument

The interview instruments for IM4Q include the Essential Data Elements (EDE) survey, which includes a pre-survey form, and the Family/Friend/Guardian (F/F/G) survey. The IM4Q Essential Data Elements (EDE) survey has a total of 85 questions; thirty-five of the questions can only be answered by the individuals receiving supports and services.

The EDE for fiscal year 2013-2014 includes all survey questions included in the FY 2013-2014 NCI Adult Consumer Survey. At the time of this report, approximately 699 individuals included in this report are represented in the NCI sample for 2013-2014, based on a sampling methodology established by ODP and the Human Services Research Institute (HSRI). A copy of the NCI report for FY 2013-14 is available on the HSRI website at www.nationalcoreindicators.org.

The **Essential Data Elements** (EDE) instrument is comprised of the following sections:

- A **pre-survey**, which was completed by the AE designee prior to the scheduling of the appointment with the individual to give the local IM4Q Program information needed to schedule the interview with the individuals. Information includes: the person's address, contact people, supports coordinator information, accessibility and the individual's communication style (which may require the use of an interpreter, e.g. Sign Language or Spanish). Often this information is provided by the supports coordination organization (SCO).
- A **background information section**, which was completed by the AE for only those individuals who were designated as part of the NCI sample. The section provides demographic information, along with information about the individual's degree and type of disability(ies), work and day activity routines.
- **Satisfaction** – this section was only to be completed based on the responses of the individual receiving supports. Questions were asked about satisfaction with where the individual works and lives, as well as with staff who support the individual.
- **Dignity, Respect and Rights** – this section was also only to be completed based on responses of the individual receiving supports. Questions were asked about whether roommates and staff treated people with respect, whether people were afforded their rights, and whether they had fears at home, at work or in the community.
- **Choice and Control** – the questions in this section were answered by the individual, or by a family member, friend or staff person. Questions were asked about the extent to which individuals exerted choice and control over various aspects of their lives.
- **Relationships** – the questions in this section were answered by the individual, or by a family member, friend or staff person; questions were asked about friends, family and neighbors, and individuals' opportunity to visit and contact them.
- **Inclusion** – the questions in this section were answered by the individual, or by a family member, friend or staff person. Questions were asked about opportunities for community inclusion; a section of the Harris Poll was included for comparative purposes.
- **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 completed whenever there was an issue related to physical danger, significant sanitation problems, or evidence of physical or psychological abuse or neglect. Each program 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 (F/F/G) Survey** – a survey was conducted with each family once the individual gave his/her approval. Questions related to the families' satisfaction with their relatives' living situation, as well as perceived satisfaction of their relatives. The survey was conducted either by phone or face-to-face at the time of the EDE interview.

Sample

Independent Monitoring focuses on the quality of life and services and supports to children ages three and over, and to adults supported by the Office of Developmental Programs' service system for individuals with intellectual disabilities. In Fiscal Year 1999-2000, the sample for IM4Q was restricted to individuals living in licensed residential settings in 19 AEs, including licensed community homes and apartments, family living arrangements, non-state operated private intermediate care facilities for people with intellectual disabilities (ICFs/ID) 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 AE. Administrative Entities were instructed to draw a random sample of approximately one-third of the individuals living in licensed residential settings. AEs were provided with written instructions for drawing the entire Fiscal Year 2001-02 sample; once the sample was selected, ODP staff checked the samples before individual names were given to the local IM4Q Program, to ensure consistency in the sample selection.

During fiscal year 2003-04, in addition to the NCI and residential samples, each AE was instructed to include 30 individuals who participate in the Person and Family Directed Supports (PFDS) Waiver. Individuals participating in the PFDS Waiver continued to be included in the sample in each subsequent year.

The sampling procedure for this year continues to be drawn through the Home and Community Services Information System (HCSIS). 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. Many people in the sample live at home with families, due in part to the sub-sample of people receiving supports through the PFDS waiver as well as for those who are a part of the NCI sample.

| | N | Percent |
|----------------------------|-------------|----------------|
| State-Operated ICF/MR | 34 | 0.6% |
| State MH Hospital | 2 | 0.0% |
| Homeless | 1 | 0.0% |
| Foster Care | 5 | 0.1% |
| Nursing Home/Facility | 46 | 0.9% |
| Domiciliary Care | 16 | 0.3% |
| Personal Care Home | 51 | 1.0% |
| Family Living/Life sharing | 315 | 5.9% |
| Unlicensed Family Living | 18 | 0.3% |
| Own Residence | 257 | 4.8% |
| Relative's Home | 1257 | 23.6% |
| Children's Facility | 7 | 0.1% |
| Approved Private School | 1 | 0.0% |
| Private ICF/MR 4 or fewer | 61 | 1.1% |
| Private ICF/MR 5-8 | 133 | 2.5% |
| Private ICF/MR 9-15 | 30 | 0.6% |
| Private ICF/MR 16+ | 156 | 2.9% |
| Community Home 1 | 137 | 2.6% |
| Community Home 2-4 | 2477 | 46.6% |
| Community Home 5-6 | 145 | 2.7% |
| Community Home 7-8 | 75 | 1.4% |
| Community Home 9-15 | 20 | 0.4% |
| Community Home 16+ | 15 | 0.3% |
| Other | 60 | 1.1% |
| Missing | 22 | 0.4% |
| Total | 5341 | 100% |

Procedure

Selection of Local IM4Q Programs

ODP requested that AEs select local IM4Q Programs to conduct interviews with individuals and families using the EDE and F/F/G Survey. All potential IM4Q programs were screened by the State IM4Q Steering Committee. Selection criteria included: independence of the programs 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 AEs from a variety of organizations, including non-service providing chapters of The Arc, Consumer Satisfaction Teams (in the mental health system), parent groups, universities and colleges, Centers for Independent Living, and entities formed specifically to implement IM4Q.

Training

Local IM4Q Programs received training on the EDE, F/F/G Survey and interviewing protocols from technical advisors from the Institute on Disabilities (IOD) at Temple University. Trainings were held in each of the four regions for project staff and monitors, wherever possible. Additional training was provided on an AE-by-AE basis for monitors, as requested. Data entry instruction was provided by ODP with support from the IOD. In addition to regional and statewide training, individual programs provide training to their monitoring teams based on need at the local level.

Sample and Team Interview Process

Once an annual HCSIS drawn random sample is sent to the AE from ODP, the AE establishes a final list of individuals to be monitored. This list is forwarded to the Local Independent Monitoring for Quality Program which assigns the 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 may also include other interested citizens who are not part of the ODP service system. Visits to individuals' homes are scheduled with the individual, or with the person designated on the pre-survey form that is completed prior to the visit.

Participation in the interview is voluntary; if an individual refuses to participate, s/he is replaced in the sample with another individual. The interview takes 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 conducted in private whenever possible, unless the individual expresses a desire to have others present. Once the interview is completed, if the individual gives his/her permission, a survey is conducted with the family/friend/guardian, either face-to-face (at the time of the interview) or by phone.

After the EDE is completed by the IM4Q team, the completed Essential Data Elements forms are returned to the local IM4Q Program for data entry. Family/Friend/Guardian data are collected either by the interview team or by staff of the local IM4Q program. EDE and F/F/G Survey data are entered into ODESA, a data entry system developed and maintained by HSRI, originally intended for NCI data, now expanded to include IM4Q data. Data for the 2013-14 survey cycle were collected by June 30, 2014 and entered into ODESA by June 30, 2014. A data file was received by the Institute on Disabilities in January, 2015. This report presents data on the individuals surveyed by the IM4Q Local Programs, representing the 48 AEs across the state. In addition to this report, each AE and local program will receive a report about the people monitored in their AE/county. Separate reports will also be developed by HSRI for those individuals in the NCI sample and by the Institute on Disabilities for those individuals in the PFDS sample and those living in state centers.

Closing the Loop/Follow-up

In addition to this summary report and similar ones for each of the AEs, each local IM4Q Program has developed a process, referred to as “closing the loop” which ensures that follow-up activity with the AE is completed related to individual considerations for improvement. “Closing the loop” is an integral part of the quality improvement process, as it places quality improvement responsibilities with the AEs, supports coordinators, and other providers of service.

RESULTS: The following table displays the distribution of interviews conducted by each independent monitoring program by Administrative Entity.

| | # of People | Percent |
|-------------------------------|-------------|---------|
| Allegheny | 600 | 11.3% |
| Armstrong/Indiana | 73 | 1.4 |
| Beaver | 70 | 1.3% |
| Bedford/Somerset | 50 | 0.9 % |
| Berks | 156 | 2.9% |
| Blair | 72 | 1.4% |
| Bradford/Sullivan | 33 | 0.6% |
| Bucks | 209 | 3.9% |
| Butler | 79 | 1.5% |
| Cambria | 63 | 1.2% |
| Cameron/Elk | 25 | 0.5% |
| Carbon/Monroe/Pike | 78 | 1.5% |
| Centre | 68 | 1.3% |
| Chester | 151 | 2.8% |
| Clarion | 29 | 0.5% |
| Clearfield/Jefferson | 51 | 1.0% |
| Columbia/Montour/Snyder/Union | 67 | 1.3% |
| Crawford | 78 | 1.5% |
| Cumberland/Perry | 67 | 1.3% |
| Dauphin | 147 | 2.8% |
| Delaware | 248 | 4.7% |
| Erie | 235 | 4.4% |
| Fayette | 54 | 1.0% |
| Forest/Warren | 25 | 0.5% |
| Franklin/Fulton | 70 | 1.3% |
| Greene | 27 | 0.5% |
| Huntington/Mifflin/Juniata | 38 | 0.7% |
| Lackawanna/Susquehanna | 122 | 2.3% |
| Lancaster | 149 | 2.8% |
| Lawrence | 54 | 1.0% |
| Lebanon | 40 | 0.8% |
| Lehigh | 142 | 2.7% |
| Luzerne/Wyoming | 128 | 2.4% |
| Lycoming/Clinton | 76 | 1.4% |
| McKean | 26 | 0.5% |

| | | |
|----------------|-------------|-------------|
| Mercer | 49 | 0.9% |
| Montgomery | 278 | 5.2% |
| Northampton | 90 | 1.7% |
| Northumberland | 64 | 1.2% |
| Philadelphia | 738 | 13.9% |
| Potter | 8 | 0.2% |
| Schuylkill | 59 | 1.1% |
| Tioga | 42 | 0.8% |
| Venango | 48 | 0.9% |
| Washington | 63 | 1.2% |
| Wayne | 35 | 0.7% |
| Westmoreland | 124 | 2.3% |
| York/Adams | 119 | 2.2% |
| Missing | 24 | 0.4% |
| TOTAL | 5341 | 100% |

Satisfaction

Respondents: Only the individual receiving services/supports could answer the questions on satisfaction. A consistency check was performed and 13 individuals' surveys were not included in the satisfaction section. The percent of people who responded to questions in this section ranged from 35% to 60%.

Satisfaction with Living Arrangements

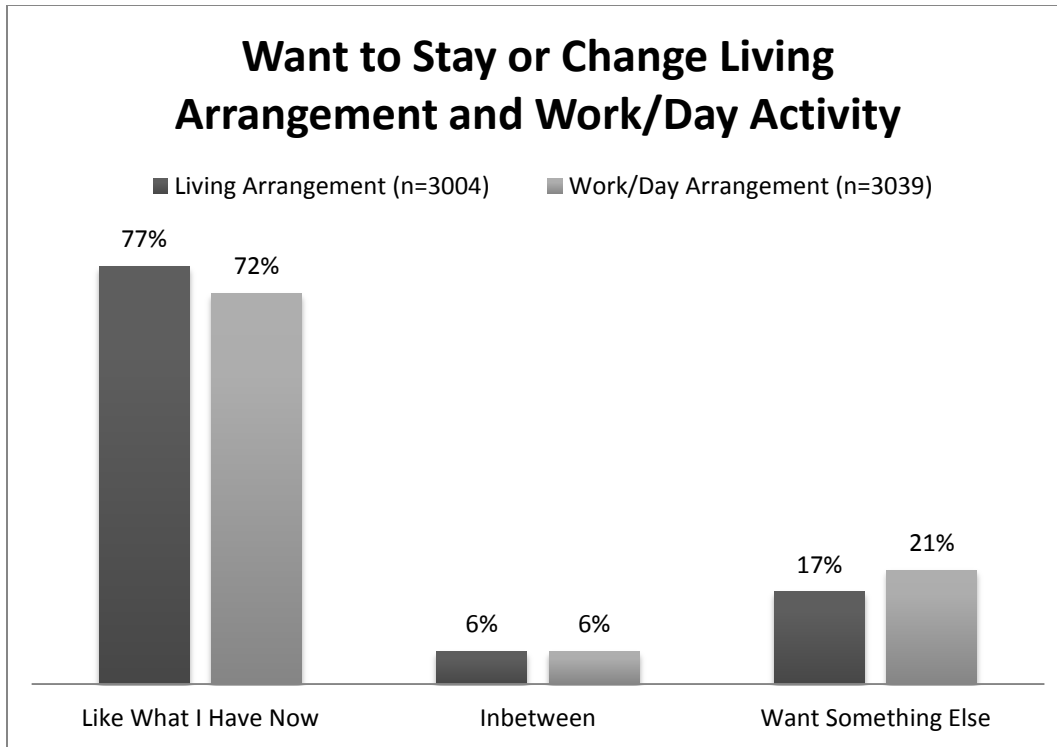
- 90% of individuals liked where they live.
- 77% wanted to stay where they currently live but 17% wanted to move somewhere else.

Satisfaction with Work/Day Activity

- 91% of individuals *with* a day activity/work liked what they did during the day.
- 72% wanted to continue their current daytime activities/work, but 21% wanted to do something else.

Satisfaction with Supports Coordination Organization

- 90% of individuals reported being satisfied with their supports coordination organization.



Daily Life

- 89% of the individuals reported getting the services they needed to be able to live in their home, 6% said yes, but they sometimes need more, and 4% said they do not get the services they need to be able to live in their home.
- On most weekdays, 27% of individuals attended an adult training program, 22% attended a vocational facility, 15% stayed home, 15% went out and did things in the community, **7% worked part time for pay**, 4% volunteered, 4% helped neighbors and friends, 3% attended school, 2% are retired, **1% worked full time for pay**, and less than 1% attended college or a trade school.

Happiness and Loneliness

- 82% reported feeling happy overall, 14% reported being neither happy nor sad, and 4% reported feeling sad overall.
- 62% of individuals reported never feeling lonely, 33% reported sometimes feeling lonely, and 5% reported always feeling lonely.

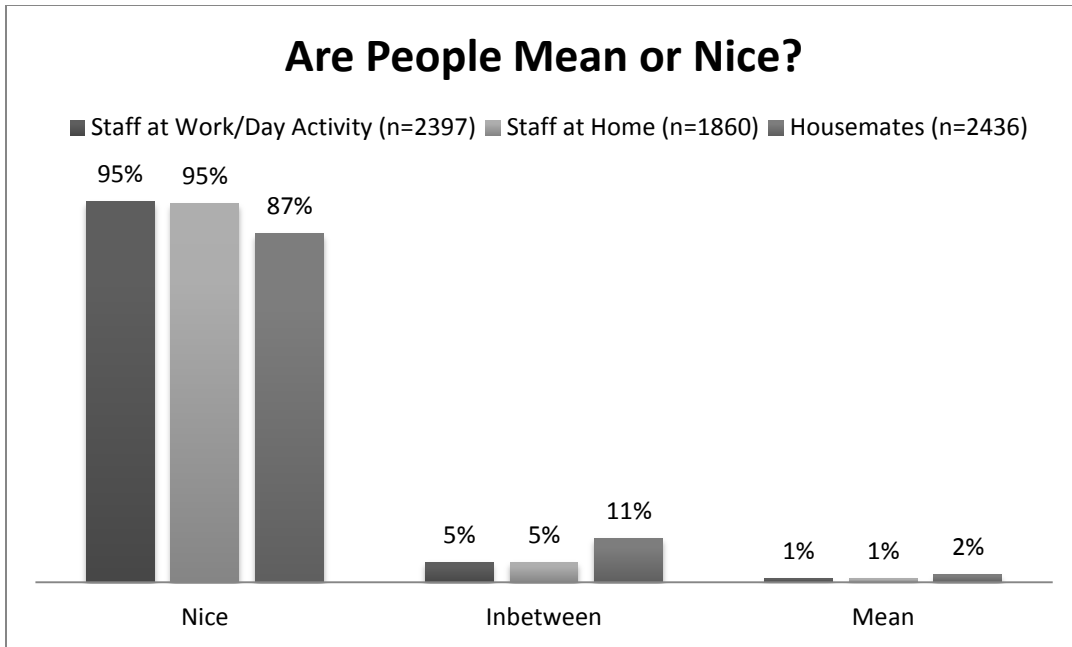
- 90% reported having friends they like to do things with – for 73% of these people their friends are not staff or family.
- 75% reported that they can go on a date if they want to or are married; 14% reported that they can go on a date if they want to but there are some restrictions and rules and 11% are not allowed to date.

Privacy

- 95% of the individuals surveyed reported that they have enough privacy (a place to be alone) at home.
- 91% reported that other people always let them know before coming into their home, 5% reported that sometimes other people let them know before coming into their home, and 5% never let them know.
- 86% reported that people let them know before coming into their bedroom, 7% reported sometimes people let them know before coming into their room, and 7% never let them know.

Are People Nice or Mean?

- Most people, 87% of respondents, reported that their housemates are very nice or nice.
- 95% of the people interviewed reported that the staff who work with them at home are very nice or nice.
- 95% reported that staff who work with the respondents at work or day activity are nice or very nice.
- 98% of people reported that their supports coordinator was always 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 was 85.05 with a standard deviation of 19.63.
- The mode (the value that occurs the most frequently) was 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.

Compared to the Satisfaction section of the 2012-2013 report, there were several significant differences:

- There was a 3% **decrease** in the percentage of individuals who worked part time for pay.

- There was a 12% **decrease** in the percentage of individuals who attended an adult day training program.
- There was a 6% **decrease** in the percentage of individuals who attended a vocational facility.
- There was a 3% **decrease** in the percentage of individuals who did things in the community during the day.
- There was a 7% **decrease** in the percentage of individuals who stayed home during the day.

Dignity, Respect and Rights

Respondents: Only the individual receiving services/supports could answer the questions on dignity, respect and rights. A consistency check was performed and 13 individuals' surveys were not included in the Dignity, Respect and Rights section. The percent of people who responded to questions in this section ranged from 31% to 60%.

Forms of Identification

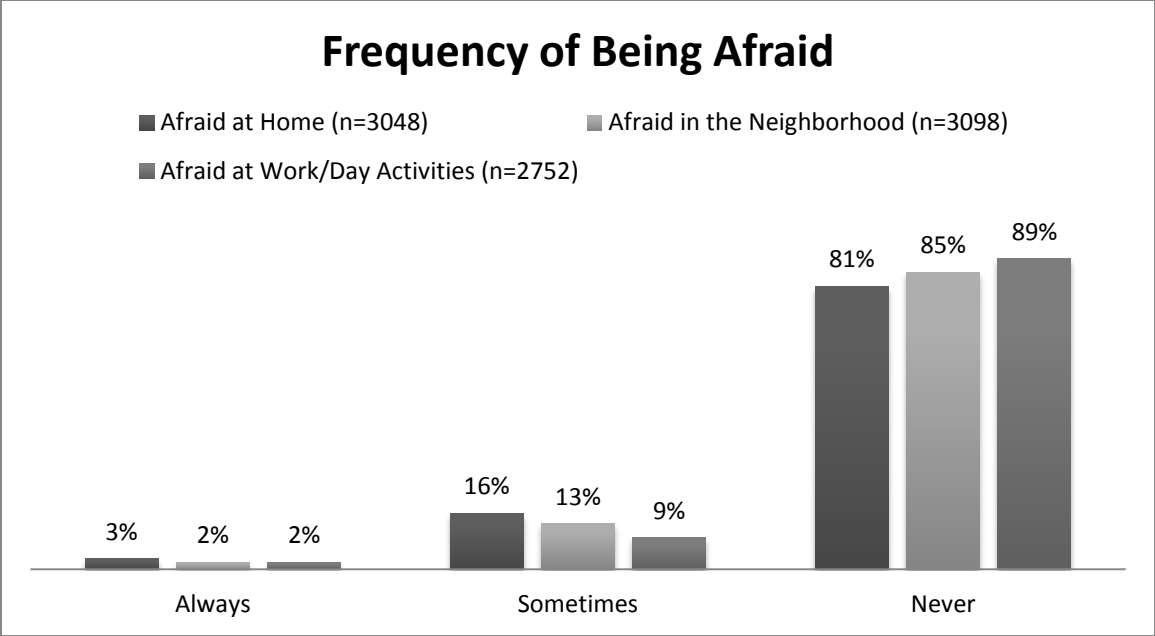
- 58% of individuals stated that they always carry a form of identification; 18% never do.

Support with Problems and Goals

- 91% always have someone to go to for help if they have a problem.
- 58% of individuals want help to learn new things.
- 75% of individuals report that they get to help other people.

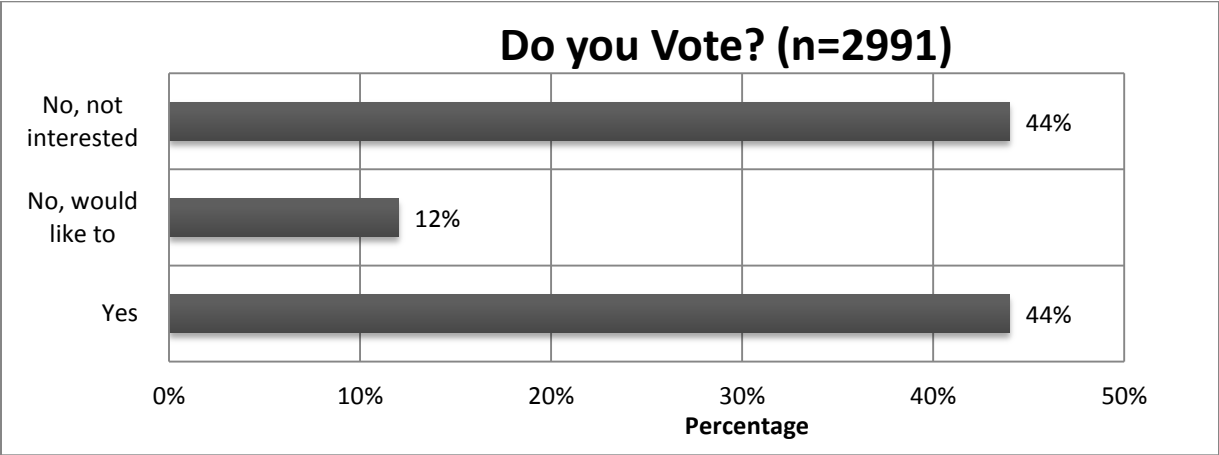
Being Afraid

- 81% reported never being afraid at home; 16% reported sometimes being afraid at home.
- 85% reported never being afraid in the neighborhood; 13% reported sometimes being afraid in the neighborhood.
- 89% reported never being afraid at work, school or day activity.



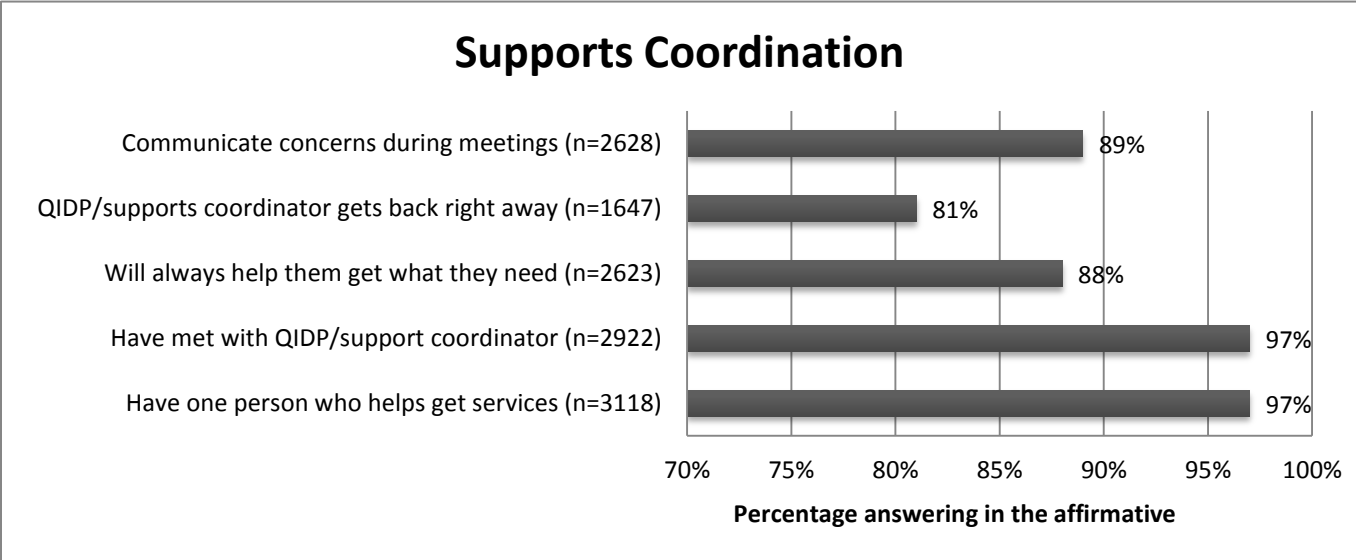
Legal Rights

- 44% of the people said they vote, 44% of the people said they do not vote and are not interested in voting, and 12% do not vote but would like to. It is our hope that for those individuals expressing a desire to vote, a consideration has been written to assist the individuals in registering to vote and in voting.



Supports Coordination/Qualified Intellectual Disability Professional (QIDP)

- 97% of individuals reported that they have one person (supports coordinator/QIDP) who helps them get the services they need.
- 97% reported that they have met with their supports coordinator/QIDP in the last year.
- 88% of individuals reported that if they ask, their supports coordinator will always help them get what they need; 9% said their supports coordinator will sometimes help.
- 81% of individuals reported that when they call, their supports coordinator/QIDP always gets back to them right away.
- 89% of interviewees reported always being able to communicate their concerns during annual meetings; 8% reported that they are sometimes able to communicate their concerns.
- 98% of people surveyed reported that their supports coordinator talks with them about services to make sure everything is OK.
- 93% of people report that their supports coordinator helps them find services that are comfortable for them.
- 69% of those surveyed have been told how much money is in their annual budget.



Emergency Preparation Questions

- 79% of individuals have been given information about what to do in an emergency.
- When asked who gave the individual information about what to do in an emergency, 58% received information from staff, 43% from day program or employment staff, 26% from someone in their family, 5% from the police, fire department, or EMS, 7% from supports coordinator, 11% from someone else, 2% from neighbors or friends, and less than 1% from someone from Red Cross.

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

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

- The average score was 82.57 with a standard deviation of 14.03.
- The modal score was 75. Interestingly, the mode for the Dignity and Respect Scale was much lower than the Satisfaction Scale. This indicates that many individuals chose the most positive answer category (very satisfied) for all measures of the Satisfaction Scale, whereas for the Dignity and Respect Scale individuals were less likely to choose the most positive answer category for all measures.

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 Afraid Scale could range from 0 to 100, with a higher score indicating less fear.

- The average (mean) score was 90.84 with a standard deviation of 17.33.
- 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 (71%) reported that they never feel afraid in their home, neighborhood or work/day activity site.

Open-Ended Questions: In this section, individuals who reported being afraid at least sometimes were asked what made them afraid. We asked this question concerning being afraid in one's home, neighborhood and work / day activity site.

- At home, individuals were most afraid of the weather, followed by darkness, then being alone.
- In the neighborhood, individuals were most afraid of strangers or crime.
- At work, individuals were most afraid of being scolded, hurt, yelling, or of the unknown; they were also afraid of work or school related issues including losing their job, learning new things, or making mistakes.

| | At Home # | In Neighborhood # | At Work # |
|--|--------------|----------------------|--------------|
| Alone | 28 | 8 | 0 |
| Animals / Insects | 14 | 39 | 3 |
| Being Scolded / Fear of Being Hurt / People Yelling / Fear of the Unknown | 21 | 4 | 12 |
| Darkness / Sleep / Nightmares / Night | 47 | 22 | 4 |
| Emergency Situations / Fire / Fire Alarms | 14 | 7 | 8 |
| Falling / Sickness / Seizures/ Death | 21 | 24 | 10 |
| Neighbors / Local kids | 1 | 17 | 1 |
| Work/school related-Lose job/ New things on job/ Making mistakes | 0 | 0 | 2 |
| Noises | 9 | 8 | 8 |
| Staff / Consumers / Co-Workers | 39 | 4 | 19 |
| Strangers / Crime | 25 | 52 | 9 |
| Transportation/ Traffic/ Emergency vehicles | 0 | 16 | 3 |
| Weather | 57 | 23 | 3 |
| Houses/ Locked Rooms/ Office/ Stairs/ Elevator/ Escalator | 0 | 0 | 0 |
| Mythical & Fictional Creatures | 16 | 7 | 5 |
| Scary Movies/ Halloween / TV | 10 | 2 | 0 |
| Other people/ People in general/ Crowds | 1 | 3 | 9 |

| | | | |
|--|-----|-----|-----|
| Fighting/ Violence/ Teasing/ Behavioral Outbursts | 2 | 9 | 24 |
| Neighborhood/ Getting lost/ Being outside | 1 | 8 | 1 |
| Other | 6 | 9 | 12 |
| TOTAL | 313 | 262 | 128 |

Compared to the Dignity, Respect and Rights section of the 2012-2013 report, there were several significant differences.

- There was a 3% **increase** in the percentage of individuals who want help to learn new things.
- There was a 6% **increase** in the percentage of people who received emergency information from staff, and a 5% **increase** in the percentage of people who received emergency information from day program staff.
- There was a 3% **decrease** in the percentage of individuals who reported always carrying a form of identification
- There was a 3% **decrease** in the percentage of individuals who reported never being afraid at home.
- There was a 3% **decrease** in the percentage of people who reported that they do not vote and are not interested in voting.

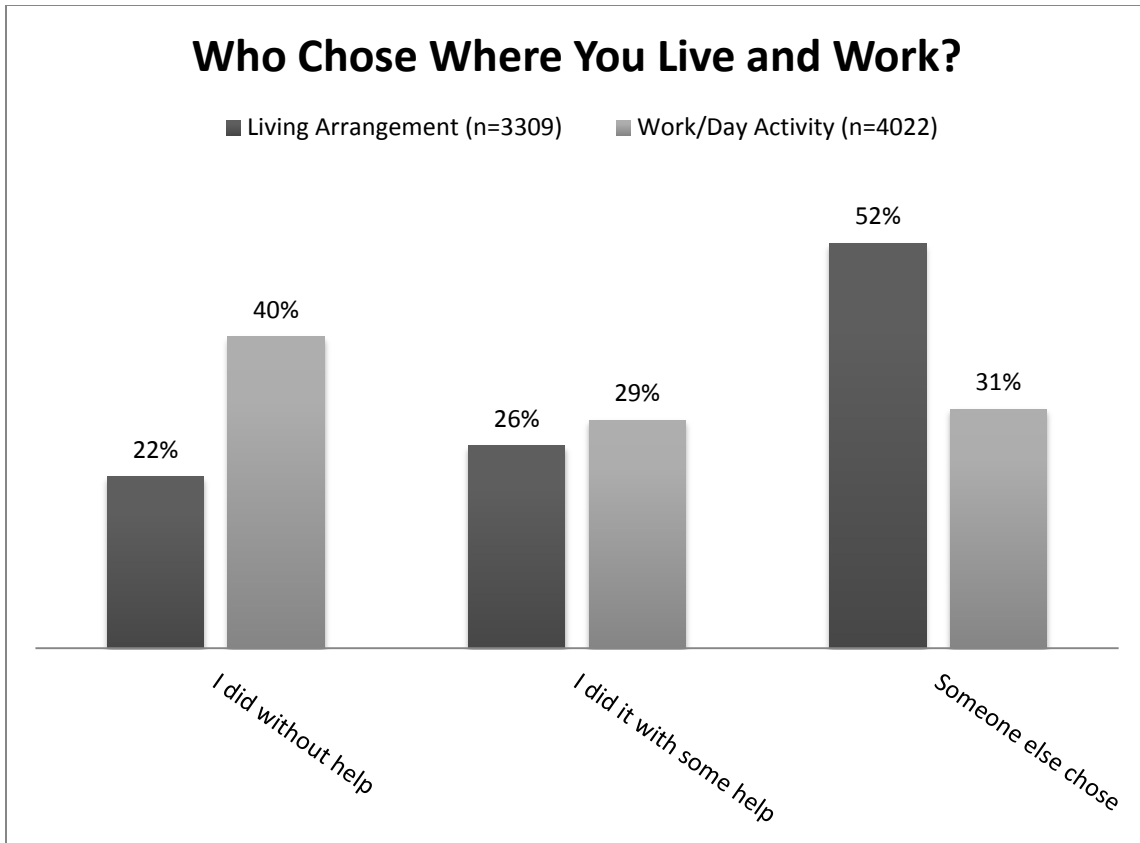
Choice and Control

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,

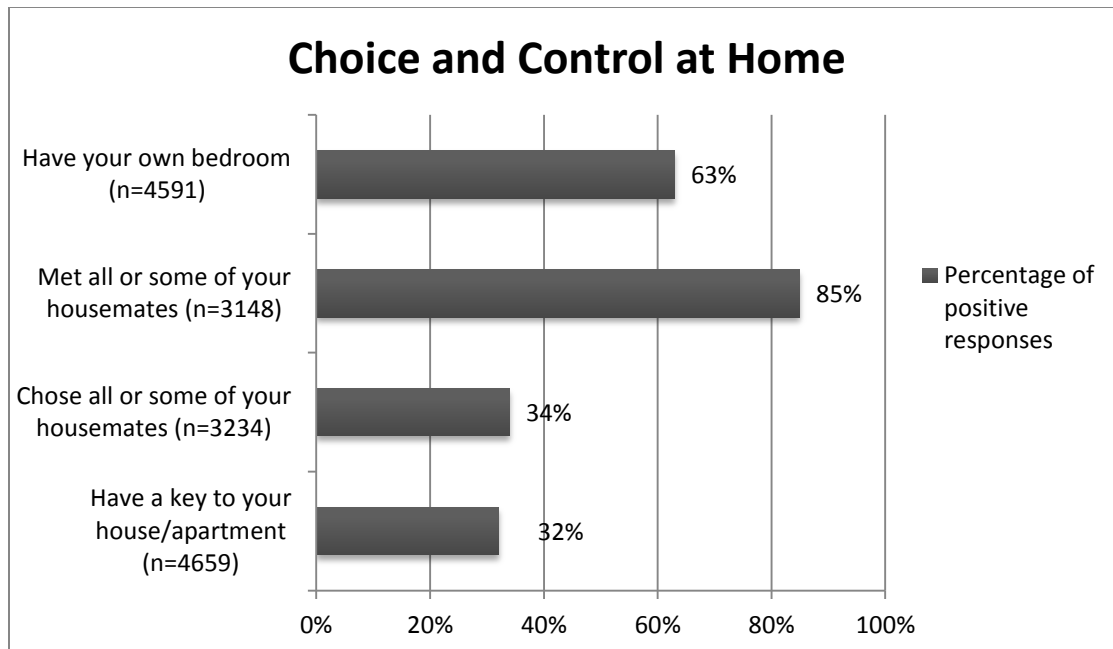
- 39% of the questions were answered by the individual receiving supports
- 33% of the questions were answered by paid staff
- 14% of the questions were answered by the individual and staff
- 7% of the questions were answered by family/friend/advocate/guardian
- 7% of the questions were answered by the individual and family
- 1% of the questions were answered by staff and family
- A value of missing was assigned when individuals did not answer, gave an unclear answer, or responded, “do not know.”

Choice and Control at Home

- 32% of the individuals surveyed had a key/way to get into to their house or apartment on their own.
- For 52% of the individuals, someone else chose where they live; 22% of those interviewed chose without assistance.
- For those individuals who had some control in choosing where they live, 13% saw no other places, 44% saw one other place, and 43% saw more than one other place before moving in.



- 66% of the individuals **did not** choose their housemates.
- 85% of the individuals surveyed met some or all of their roommates before living together.
- 63% of the individuals had their own bedroom; however, for those who shared a bedroom, only 46% chose some or all of their roommates.
- For 80% of the individuals interviewed, their mail is never opened without permission; 13% say their mail is always opened without permission.

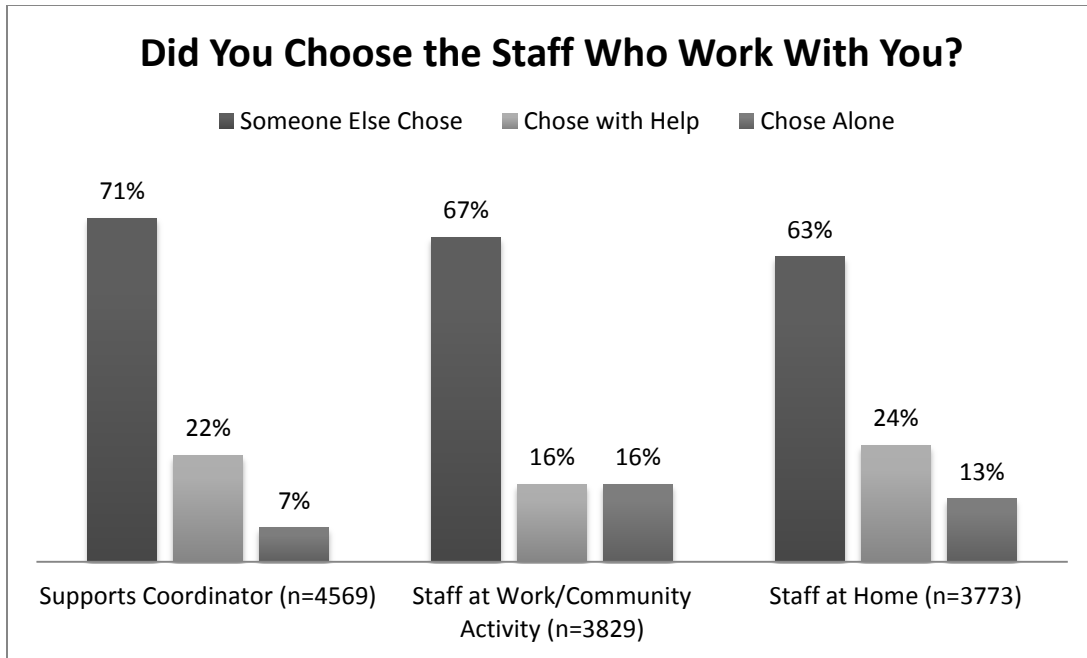


Choice and Control During the Day and for Leisure Time

- 31% of the individuals interviewed reported that someone else chose what they do during the day.
- 40% of the people interviewed chose what they do during the day without assistance.
- For those individuals who participated in choosing what they do during the day, 13% saw no other places, 44% saw one other place, and 43% saw more than one other place before deciding.
- 53% of the individuals surveyed chose their daily schedules without assistance.
- 69% chose how they spend their free time without assistance.

Choice and Control in Choosing Staff

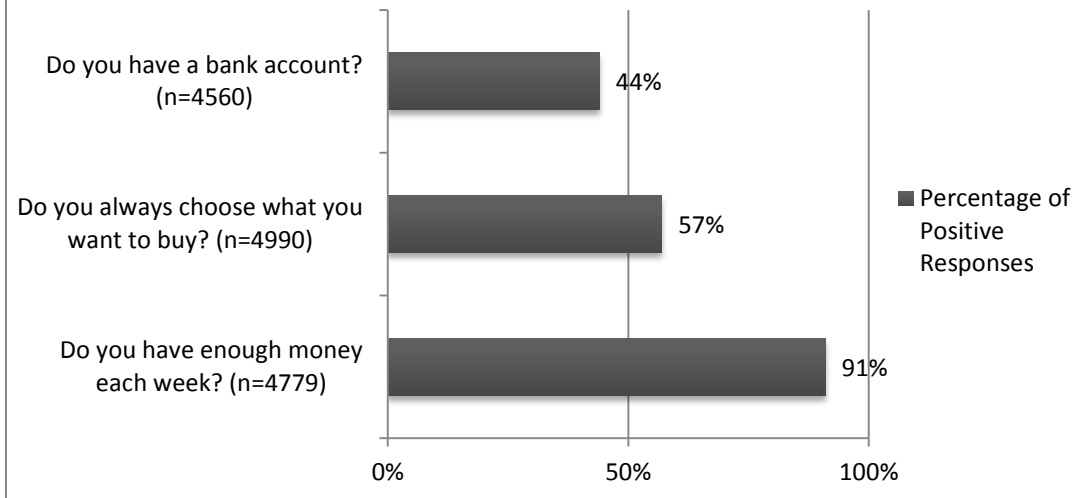
- 37% of the individuals interviewed/chose at least some of the staff who help them at home (alone or with assistance from family or provider).
- 33% of the individuals surveyed interviewed/chose the staff who help them at work/day activity (alone or with assistance from family or provider).
- 29% of individuals chose their supports coordinators (alone or with assistance from family or provider).



Choice and Control with Regard to Money

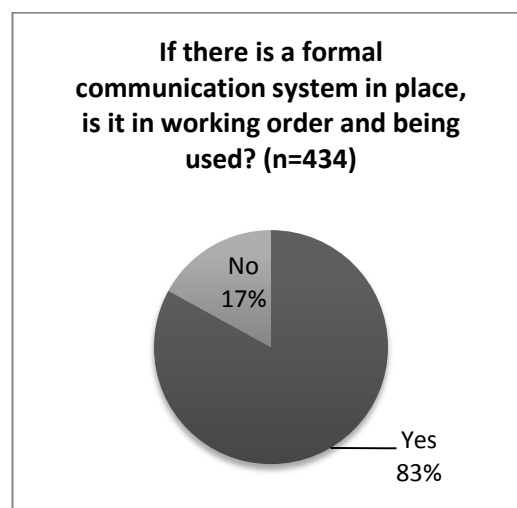
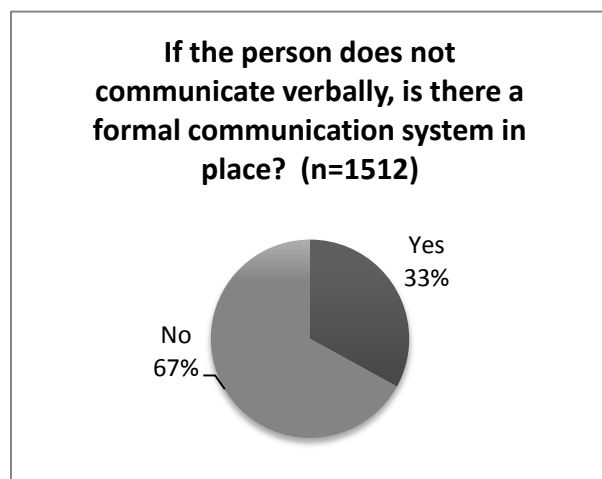
- 91% of the individuals have enough money to do many of the things they want to do each week.
- 57% of the individuals reported that they always choose what to buy with their spending money.
- 44% of the individuals reported they have a bank account that they can get to independently to withdraw money when they want it.

Choice and Control Regarding Spending Money



Access to Communication

- For those individuals who do not communicate using words, there is a formal communication system in place for 33% of the people interviewed.
- For those people with formal communication systems in place, the systems are in working order and utilized for 83% of the people interviewed.
- 76% of individuals with a formal communication system reported using it across all settings.



With regard to other forms of communication:

- 21% have and use a cell phone; there are restrictions for 11% of these people
- 12% have and use e-mail; there are restrictions for 5% of these people
- 21% have and use internet; there are restrictions for 14% of these people
- 11% have and use text-messaging; there are restrictions for 6% of these people
- 89% have and use cable television; there are restrictions for 6% of these people

(Reporting note: The way communicative device usage is calculated has become more accurate, and percentages may have changed significantly compared to last year as a result.)

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

- The average (mean) score was 47.89 with a standard deviation of 22.50.
- The modal score was 47.37, indicating the most frequent score.

There were some significant differences regarding this year's data in this section when compared with the data from 2012-2013:

- There was a 5% **increase** in the percentage of people who chose what they do during the day without assistance.
- There was a 23% **increase** in the percentage of individuals who chose their supports coordinator.
- There was a 16% **decrease** in the percentage of individuals who reported having their own bedroom, and a 9% **decrease** in the percentage of people who chose all or some of their roommates.
- There was a 3% **decrease** in the percentage of people who reported that someone else chose what they do during the day.
- There was a 3% **decrease** in the percentage of people who saw only one other place before choosing what they do during they do during the day.

- There was a 4% **decrease** in the percentage of individuals who interviewed/chose at least some of the staff who help them at home.
- There was a 5% **decrease** in the percentage of people who interviewed/chose staff who help them at work/day activity.
- There was a 7% **decrease** in the number of individuals who have a communication system in working order.

Employment

Respondents: Of the 5341 individuals surveyed for the 2013-2014 Statewide IM4Q sample, 420 people indicated they are employed.

Community Integrated Employment

- 8% (n=420) of individuals work in a community integrated setting while 92% do not work at all.
- The mean number of years individuals reported being competitively employed was 6.94 years.

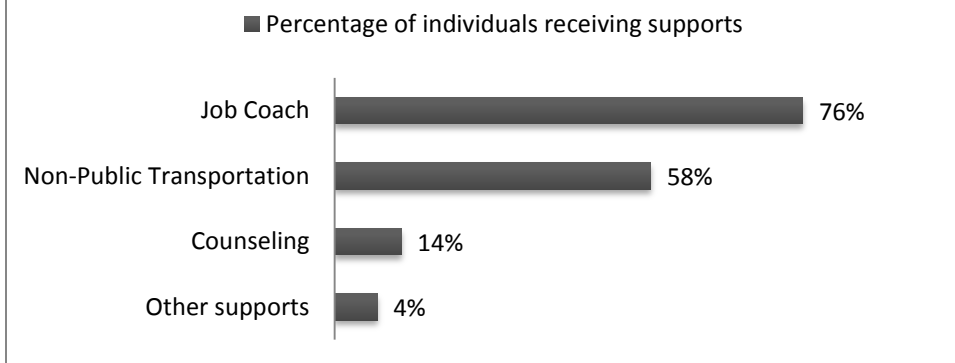
Types of Work

- 24% of individuals work in retail (including grocery stores), 23% work in cleaning, 22% work in food services, 8% work in office work, 5% work in assembly, 5% in maintenance, 5% in work in landscaping or outdoors, 4% work in the stock room, 3% work as a care-worker or aide, 2% work in some other occupation. (Reporting note: three categories were added to this year's report to reduce the number of responses in the "other" category, and more accurately capture where people are working. Percentages have changed significantly from last year as a result of this change.)

Supports in the Workplace

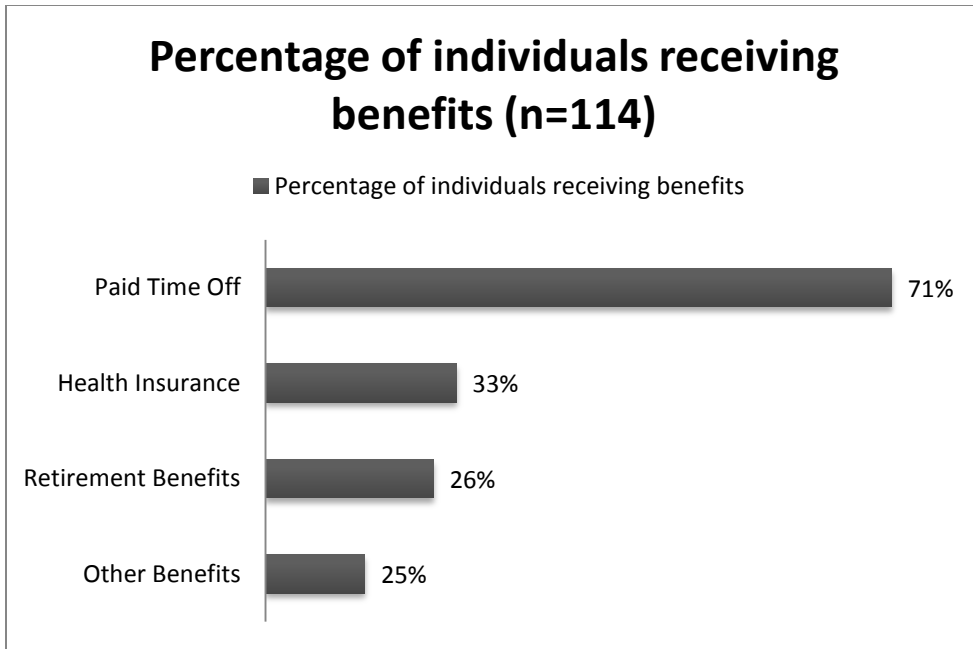
- 76% of individuals had job coach supports.
- 58% of individuals had transportation other than public transportation provided.
- 14% of those surveyed received counseling.
- 4% of individuals received some other kind of supports.

Percentage of individuals receiving job supports (n=335)



Compensation and Advancement

- 71% of individuals received paid time off, 33% received health insurance, 26% received retirement benefits, and 25% received some other kind of benefit. Note: individuals answering this question had the option to indicate more than one response.
- 13% of individuals who work have been promoted.
- The mean number of hours worked per week was 16.04 hours. Hours worked per week ranged from .5 to 40 hours; the most common response was 20 hours per week.
- The mean hourly wage was \$8.30. Hourly wage ranged from \$7.25 to \$15.00.



Self-employment and Supports: Of the 420 individuals who have community integrated employment, 3% (n=12) of individuals are self-employed.

- 88% receive job coaching, 2% receive counseling, 5% receive funding, and 5% received some other kind of support.

There were some significant differences regarding this year's data in this section when compared with the data from 2021-2013:

- There was a 6% **increase** in the number of people who reported having transportation other than public transportation provided as a support in the workplace, a 3% **increase** in the number of individuals who reported receiving counseling as a support in the workplace, and a 3% **decrease** in the percentage of people who received some other kind of support in the workplace.
- There was a 13% **decrease** in the percentage of people who received paid time off, an 8% **increase** in the percentage of people who received health insurance, a 3% **increase** in the percentage of people who received a retirement benefit, and a 11% **increase** in the percentage of people who reported having some other kind of benefit in the workplace.

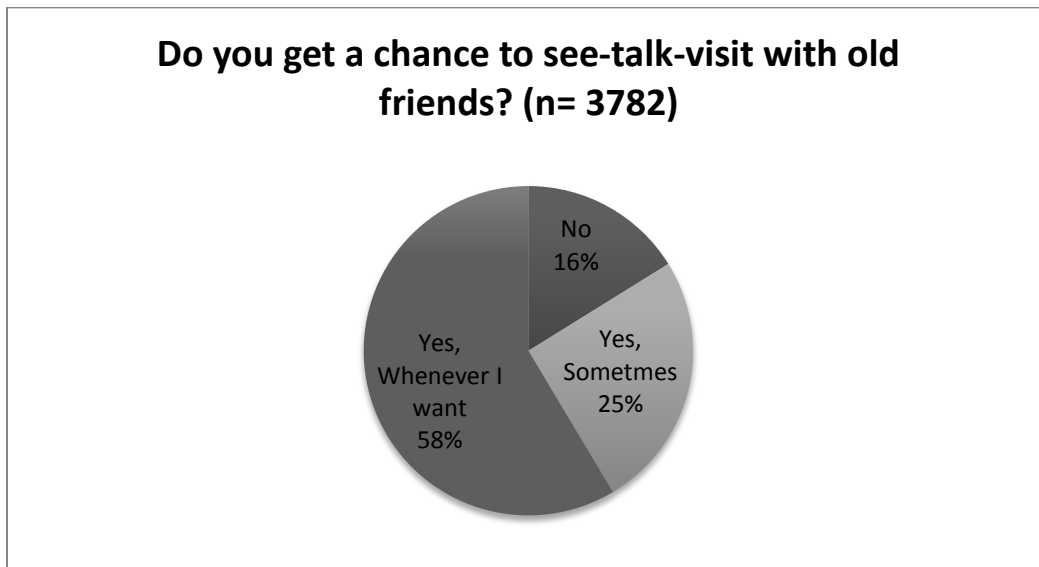
Relationships

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

- 41% of the questions were answered by individuals receiving supports
- 34% were answered by paid staff
- 12% were answered by individuals receiving support and staff
- 7% were answered by family/friend/guardian/advocate
- 7% of the questions were answered by individuals receiving support and a family/friend/guardian/advocate
- 1% of the questions were answered by staff and family
- A value of missing was assigned when individuals did not answer, gave an unclear answer, or responded, “do not know.”

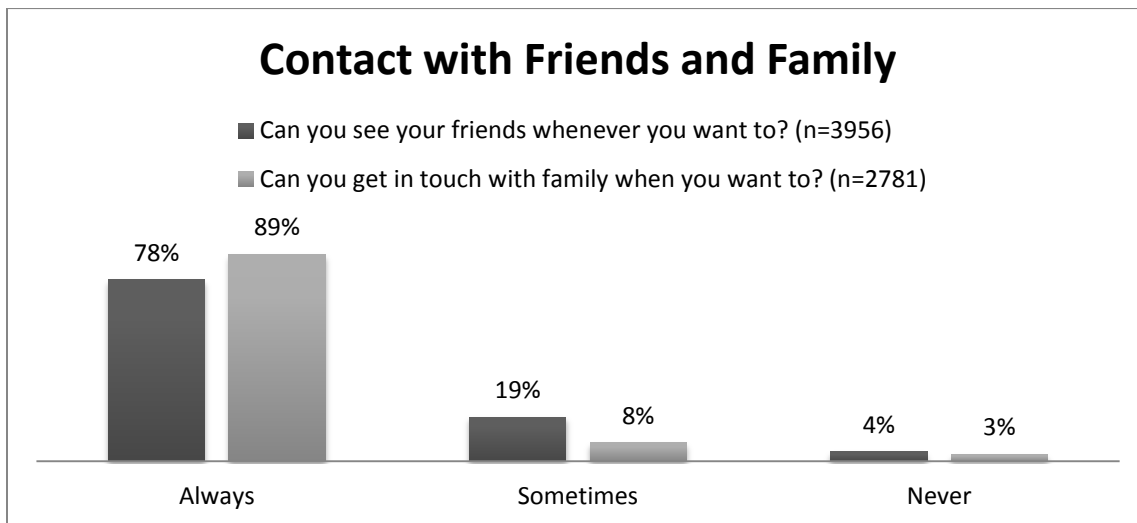
Friendships

- 58% of people answered that they can see-talk-visit with old friends whenever they want, 25% only sometimes and 16% not at all.



Contact with Friends and Family

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



There were some significant differences regarding this year's data in this section when compared with the data from 2012-2013:

- There was a 3% **decrease** in the percentage of people who answered that they can see-talk-visit with old friends whenever they want.
- There was a 4% **decrease** in the number of people who were always able to see friends whenever they wanted.

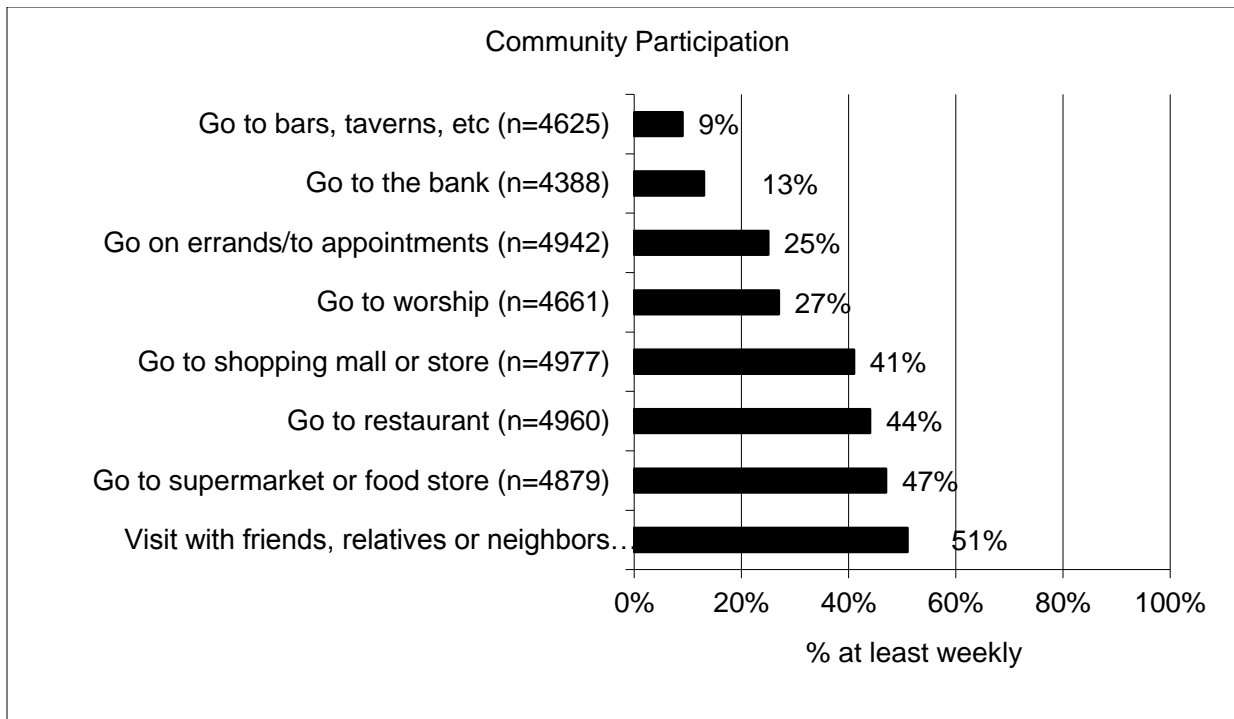
Inclusion

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

- 34% of the questions were answered by individuals receiving supports
- 34% were answered by paid staff
- 16% were answered by individuals receiving support and staff
- 7% were answered by family/friend/guardian/advocate
- 8% of the questions were answered by individuals receiving support and a family/friend/guardian/advocate
- 1% of the questions were answered by staff and family
- A value of missing was assigned when individuals did not answer, gave an unclear answer, or responded, “do not know.”

Community Participation

- 51% of the people visited with friends, relatives and neighbors at least weekly.
- 47% of those surveyed went to a supermarket at least weekly.
- 44% of respondents went to restaurants at least weekly.
- 41% of individuals went to a shopping center or mall at least weekly.
- 27% of respondents went to places of worship at least weekly
- 25% of those surveyed went out on errands or appointments at least weekly
- 13% of people went to the bank at least weekly.
- 9% of individuals go to a night club, coffee house, or tavern to meet people at least weekly.



Harris Poll

In May and June 2010, 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 weekly community participation reported by individuals in our Independent Monitoring for Quality (IM4Q) sample to this national sample. The Harris Poll depends on self-report in determining whether a person has a disability and defines someone with a disability as someone who:

“has a health problem or disability that prevents him or her from fully participating in work, school, housework or other activities; or reports having a physical disability of any kind; a seeing, hearing, or speech impairment; an emotional or mental disability; or a learning disability; or considers himself or herself a person with a disability” (Harris, 2010, p. 33).

A summary of results that were comparable on IM4Q and the Harris Poll are provided below:

- Pennsylvanians with disabilities in IM4Q and individuals with disabilities are nearly equally likely to visit with friends, relatives, and neighbors, while people without disabilities are about 10% more likely to visit with friends, relatives, and neighbors.
- Pennsylvanians with disabilities in IM4Q were slightly more than twice as likely to go to a restaurant weekly as people with disabilities in the Harris Poll, and also slightly more likely than people without disabilities in the Harris Poll.
- Pennsylvanians with disabilities in IM4Q are more likely to go to places of worship weekly than people with disabilities in the Harris Poll.

| Weekly Participation in Community Activities | | | |
|---|---|--|--|
| | Harris 2010: People without Disabilities | Harris 2010: People with Disabilities | Independent Monitoring 2014 |
| Visit with friends, relatives, and neighbors | 65% | 54% | 51% |
| Go to restaurant | 41% | 20% | 44% |
| Go to worship | 28% | 24% | 27% |

Inclusion Scale

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

- The average score was 41.39 with a standard deviation of 15.12
- The average score was less than half of the possible scale score, indicating that individuals do not go to community places with great frequency.
- The mode was 33.33, which is the most frequent score.

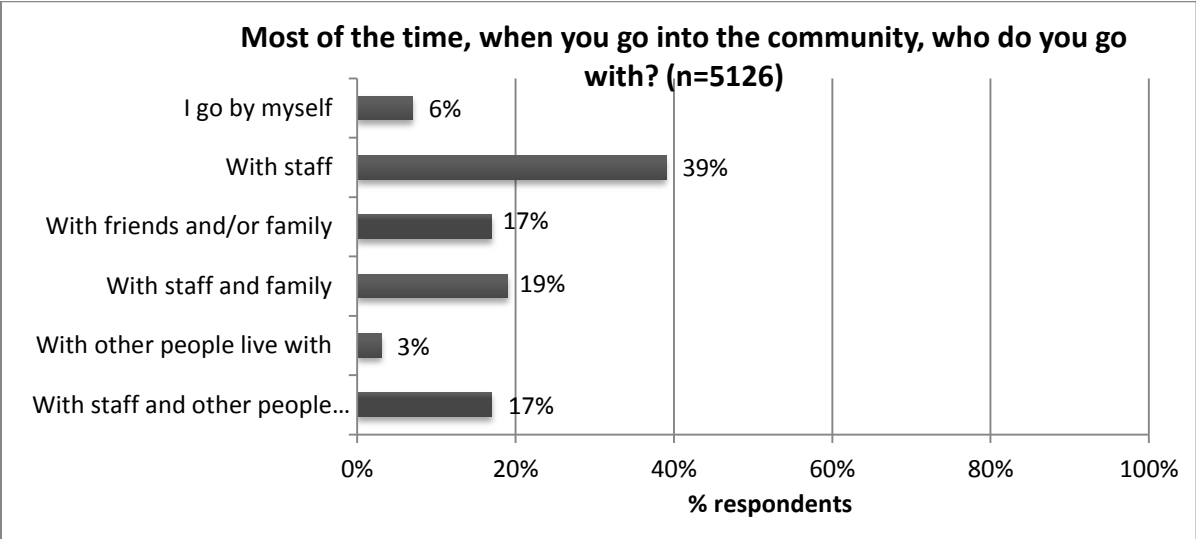
Community Activities

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

- 57% of individuals go frequently into the community for entertainment and 30% go occasionally.
- 33% of individuals reported that they frequently go to social events in the community that are attended by people with and without disabilities and 45% go occasionally.
- 45% of individuals went on a vacation in the past year.
- Regarding monthly exercise, 33% of individuals reported never going out for exercise, 8% exercise less than weekly, 11% exercise once a week and 48% exercise more than once a week.

Going Out Alone or With Other People

- 6% of individuals go out alone; 17% go out with friends and family.
- 56% of individuals go out with staff or staff and other people they live with most of the time.



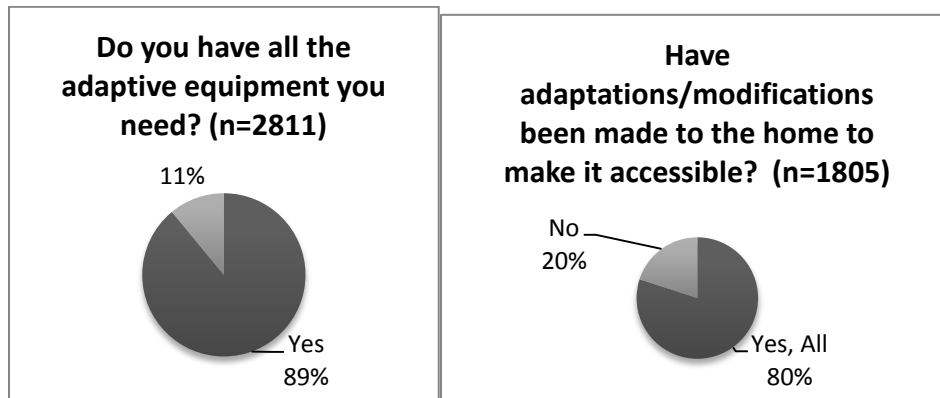
Transportation

- 81% of individuals always had a way to get where they wanted to go.

- Of those who cannot always get where they want to go, 32% cannot get where they want to go because there is not enough staff.

Home Adaptive Equipment

- 89% of individuals reported having all the adaptive equipment they needed.
- 80% of people said that all necessary modifications have been made to their home to make it accessible.



There were some significant differences regarding this year's data in this section when compared with the data from 2012-2013:

Inclusion

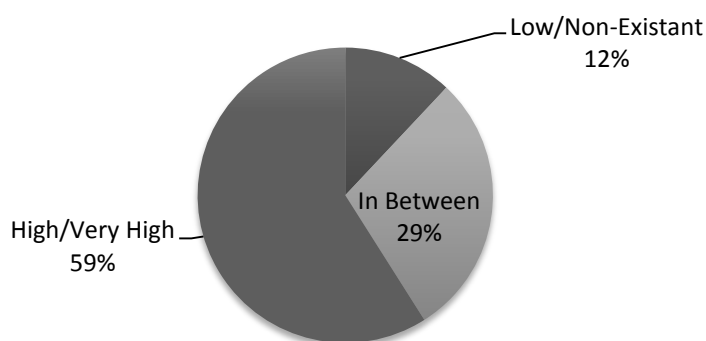
- There was a 4% **increase** in the percentage of people who reported frequently going to social events in the community that are attended by people with and without disabilities.
- There was a 3% **increase** in the number of people who reported going to a supermarket weekly.
- There was a 4% **decrease** in the percentage of people who reported visiting with friends, relatives, and neighbors at least weekly.
- There was a 5% **decrease** in the percentage of people who report never going out for exercise, and a 4% **increase** in the percentage of people who exercise more than once a week.

- There was a 5% **decrease** in the number of people who cannot get where they want to go because there is not enough staff.
- There was a 4% **decrease** in the percentage of people who report that all necessary modifications have been made to their home to make it accessible.

Competence, Personal Growth and Opportunities to Grow and Learn

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

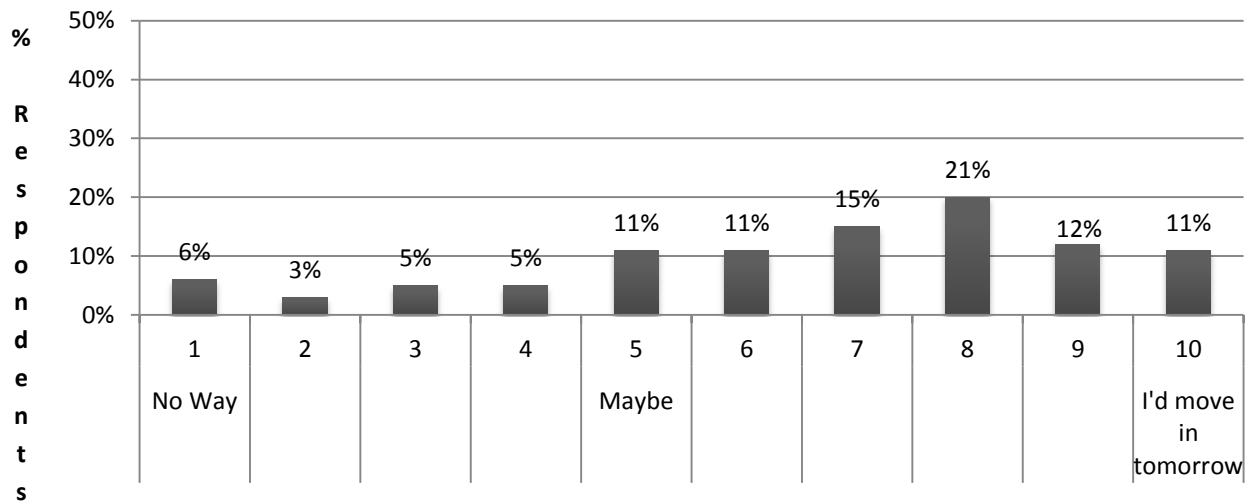
What are the caregiver's expectations regarding learning/growth for this individual? (n=3789)



According to the IM4Q teams,

- Caregiver expectations regarding growth were reported as being high or very high for 59% of the individuals.
- 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 6.58.

Would You (The Monitor) Want to Live in This Home? (n=4098) Mean = 6.39



Compared to the Competence, Personal Growth and Opportunities to Grow and Learn section of the 2012-2013 report, there were no significant differences.

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,

- The majority of individuals had either all staff (88%) or some staff (11%) with the skill needed to support them.
- Staff treated individuals with dignity and respect in 95% of observed situations.
- 88% of staff observed recognized the individuals in ways that promote independence.

Compared to the Staff Support for the Person section of the 2012-2013 report, there was one significant difference:

- There was a 3% **increase** in the percentage of people who reported that staff recognized individuals in ways that promote independence.

Physical Setting

Respondents: The IM4Q Team answered the following questions regarding the physical setting, which referred to the place where the individual lives or where they go for work/day activity. Most interviews took place in the individual's home (70%), although some took place at work/day activity (26%).

Home/Work/Day Activity Repair

- Monitors observed that individuals lived in homes or went to work/day activities which were in good repair on the outside (95%) and on the inside (95%).

Neighborhood

According to IM4Q teams,

- Individuals lived in homes or went to work/day activities which were in a safe neighborhood (94%)
- Individuals lived in homes that “fit in” with the neighborhood in which they were located (94%)

Personal Belongings and Personalities

According to IM4Q teams,

- Most individuals (98%) lived in homes which had sufficient space for personal belongings
- Individuals (61%) lived in homes which reflected the hobbies, interests and personalities of the people who live there; for 34% of people only their bedroom reflected their personalities and interests.

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

- The average (mean) score was 96.94 with a standard deviation of 10.28.

- The mode (the value that occurs the most frequently) was 100, indicating that many people (89%) lived in homes which were at the top of the scale on all measures of the physical setting

Compared to the Physical Setting section of the 2012-2013 report, there was a significant difference.

- There was a 6% **increase** in the number of people who reported that homes “fit in” with the neighborhood in which they were located.

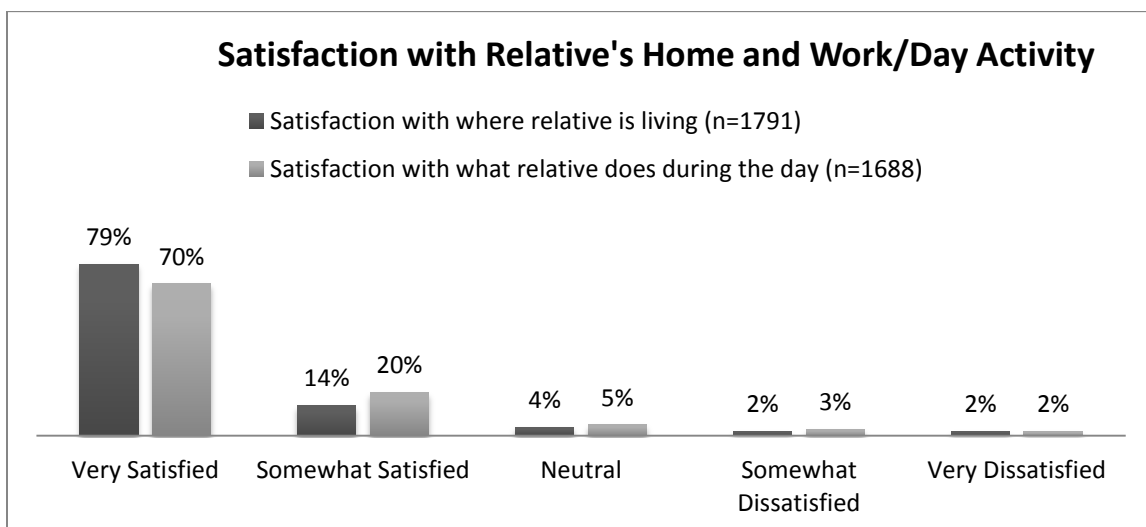
Family/Friend/Guardian Survey

Respondents: This survey was completed by telephone or face-to-face with a family member, guardian, or friend who was identified through the Essential Data Elements Pre-Survey. In the event that a phone or face-to-face survey could not be completed, surveys were completed by mail. Surveys were completed for 2187 family members, friends, and guardians.

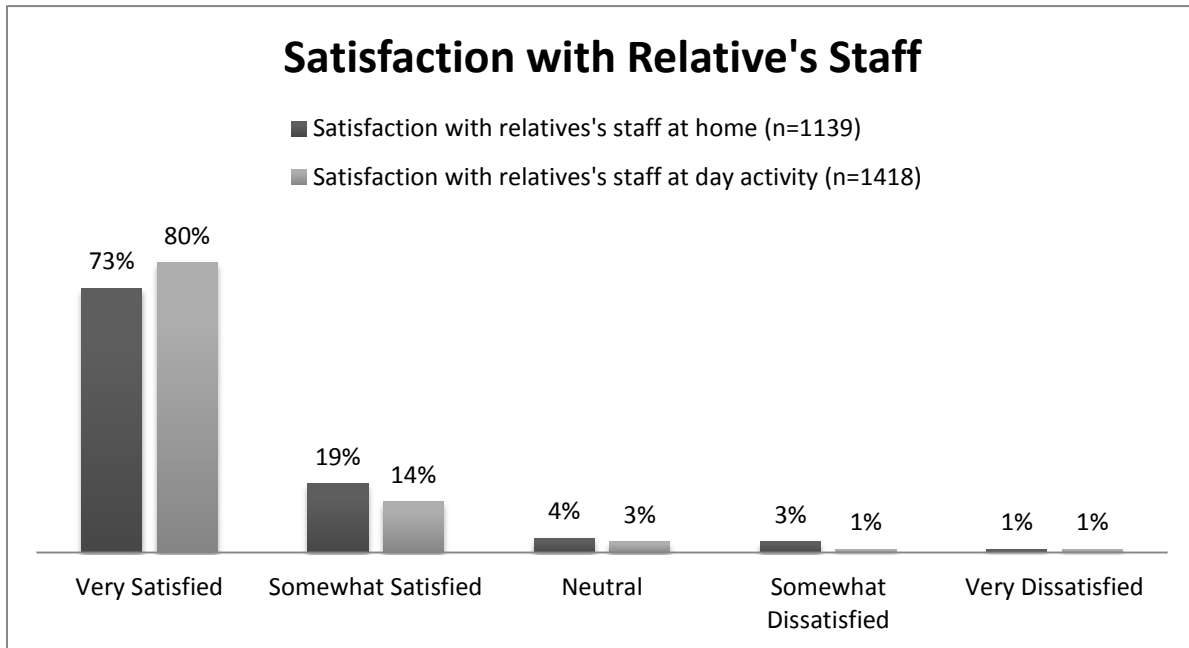
- 67% of the surveys were answered by parents
- 19% were answered by siblings
- 2% were answered by the guardian
- 5% were answered by another relative (spouse, aunt, uncle, cousin, grandparent)
- 7% were answered by persons with other relationships to the individual receiving supports.
- Less than one percent of surveys were answered by friends.

Satisfaction

- 93% of the families surveyed were either somewhat satisfied or very satisfied with where their relative lives.
- 90% were either somewhat satisfied or very satisfied with what their relative does during the day.



- 92% of the families surveyed were either somewhat satisfied or very satisfied with their relatives' staff at home.
- 95% of the families surveyed were either somewhat satisfied or very satisfied with the staff at their relatives' day activity.

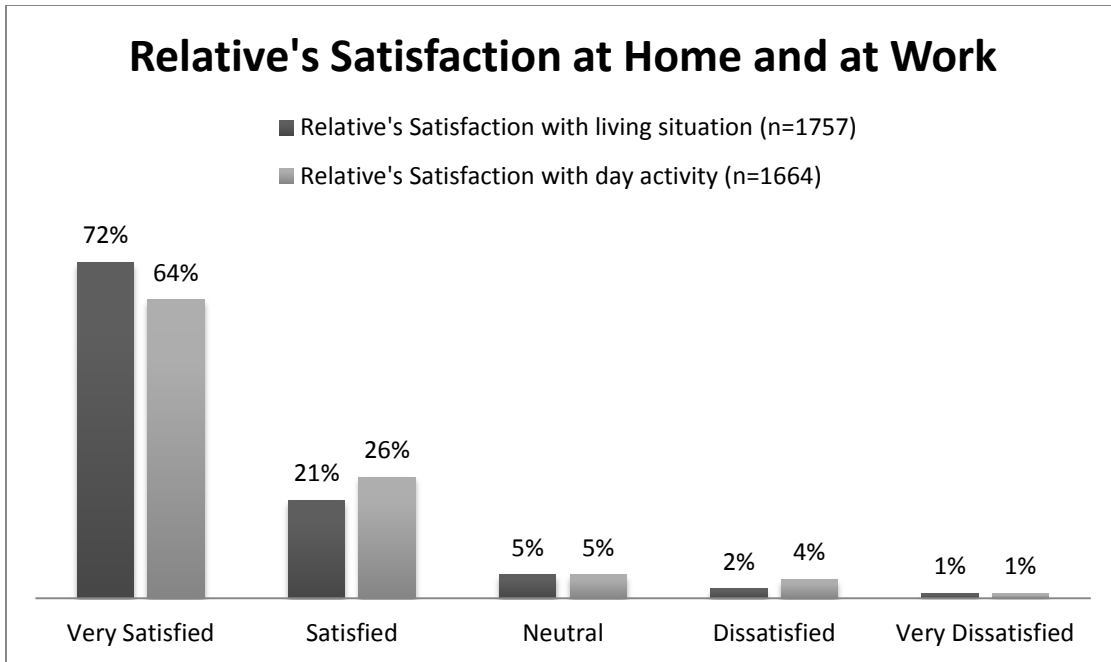


How Often Do You Contact/See Your Relative?

- 84% of the family/friend/guardians contacted their relative at least monthly; 5% have not contacted their relative in the past year.
- 74% 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; 3% did not get to see their relative in the past year.

Your Relative's Satisfaction

- 93% of respondents felt their relative was either very satisfied or satisfied with his/her living situation; 90% felt their relative was either very satisfied or satisfied with what they do during the day.



- 94% of relatives felt their relative was either very satisfied or satisfied with the staff who support them at home; 2% believed their relative was either dissatisfied or very dissatisfied.
- 95% of respondents felt their relative was either very satisfied or satisfied with the staff who support them at work (or during the day); 2% believed their relative was either dissatisfied or very dissatisfied.

Your Relative's Safety

- Respondents said that their relative felt safe in their community/home/neighborhood always (82%) or most of the time (14%).

Your Relative's Opportunities

- 87% of the respondents said that their relative had enough opportunities to participate in activities in the community.
- 88% of the respondents said that their relative seemed to have the opportunity to learn new things.

Your Relative's Staff

- If their relative did not communicate verbally, 40% of the respondents said that there is a formal communication system in place for their relative and they use it and for 70% the communication system is used across all settings.
- If something changed in their relative's life, 54% reported they would contact a relative; 41% would contact the supports coordinator; and 44% would contact agency staff; 9% would contact someone else.
- 89% of the respondents said that their relative's home appeared to have an adequate number of paid staff.
- 93% of the respondents said that staff in their relative's home always treat people with dignity and respect.
- 84% of the respondents said that all staff appear to have the skills they need to support their relative; 14% felt that way about only some staff.

Relative's Supports

- 86% of relatives were satisfied with the supports coordination their relative receives.
- 61% of relatives reported that they were told how much money is in their relative's annual budget.
- 74% said that their relative always received the supports they needed.
- 87% of relatives always felt that the staff who assisted them with planning respected their choices and opinions.
- 61% of relatives *never* felt that frequent changes in support staff were a problem for their family member.
- 33% of relatives always got to choose the agency/provider who worked with their relative; 6% had their relative choose; 20% chose with their relative; 41% never got to choose.
- 70% of relatives were familiar with the way complaints and grievances are handled; 30% were not familiar.

Emergency Preparation Questions

- 52% of relatives have been given information about an emergency plan for their family member in case of an emergency.

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

- The average (mean) score was 89.61 with a standard deviation of 14.65.
- The mode (the value that occurs the most frequently) was 100, indicating that many of the families' (39%) satisfaction levels were at the top of the scale on all measures of family satisfaction.

Compared to the Family/Friend/Guardian section of the 2012-2013 report, there were several significant differences.

- There was a 7% **increase** in the percentage of individuals who reported that staff have the skills they need to support their relative, and a 6% **decrease** in the percentage who felt that only some staff have the skills they need to support their relative.
- There was a 4% **decrease** in the percentage of individuals who contacted their relative at least monthly; there was also a 4% **increase** in the percentage of individuals who have not contacted their relatives in the past year.
- There was a 4% **decrease** in the percentage of individuals who were able to see their relative at least once a month.
- There was a 5% **decrease** in the percentage of individuals who reported that their relative had enough opportunities to participate in activities in the community.
- There was a 3% **decrease** in the percentage of respondents who reported that there is a formal communication system in place for their relative and a 20% **increase** in the percentage of those individuals who report that it is used across all settings.

- There was a 7% **decrease** in the percentage of individuals who reported they would contact a relative if something changed in their relative's life, a 10% **decrease** in the percentage of individuals who reported they would contact their supports coordinator, and a 3% **increase** in the percentage of individuals who reported they would contact someone else.
- There was a 4% **decrease** in the percentage of individuals who reported that their relative always received the supports they needed.
- There was a 3% **decrease** in the percentage of individuals who reported a 100 rating on the satisfaction scale.

Summary

This report presents information collected through face-to-face interviews with 5341 individuals receiving supports through the Office of Developmental Programs.

Overall, individuals report high levels of satisfaction with where they live, where they work, and with who provides supports to them at home and during the day. The majority of individuals report having friends and have high levels of privacy.

The majority of individuals report that they get the services and supports they need to be able to live in their homes. The monitoring teams observed that staff treat individuals with dignity and respect in nearly all situations.

The data continue to indicate that few individuals make choices without assistance with regard to where they live and with whom they live. There were several notable changes related to choice and control from the prior year, there was a 16% decrease in the percentage of people who reported having their own bedroom, and a 9% decrease in the percentage of people who chose all or some of their roommates. Additionally, more than two thirds of the individuals interviewed do not have a key or a way to get into their homes. However, there was a 23% increase in the percentage of people who chose their supports coordinator, and a 5% increase in the percentage of people who chose what they do during the day without assistance.

For those individuals who do not communicate using words, there continues to be issues around lack of exploration of alternative strategies. Over two-thirds of individuals that do not communicate using words do not have a communication system in place. A formal communication system is in working order for 83% of individuals, yet 17% of those who use a formal communication system are unable to use it. Importantly, there was a 7% increase in the percentage of people who have a communication system but are unable to use it because it is not in working order.

Less than one in ten individuals surveyed are employed. Individuals who are employed commonly work in retail including grocery stores, cleaning, food services, office work, assembly, or maintenance. Most individuals who are employed reported working about 16 hours a week, four fewer hours than was reported last year, and make slightly more than federal minimum wage. Noticeably, there was a 13% decrease in the percentage of people who report receiving paid time off, but an 8% increase in the percentage of people who report receiving health insurance as a work benefit.

Far less than half of the people interviewed participate in community activities (i.e. going shopping) on a weekly basis. The percentage of individuals with disabilities participating in community events continues to be lower than the comparison group of people without disabilities, with the exception of going to the shopping mall.

Four-fifths of individuals can always get where they want to go; however, one third of people could not get where they want to go because there is not enough staff. Of those individuals who do not use public transportation, the main reason is because it does not exist where they live.