

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

Independent Monitoring for Quality (IM4Q)
Dauphin AE
2019-2020

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

Submitted by: James A. Lemanowicz, Mary Kay R. Cunningham
Guy Caruso and Jenifer Taylor Eaton
The Institute on Disabilities
Pennsylvania's University Center for Excellence in Developmental
Disabilities
Temple University
1755 N 13th Street, Student Center, Room 411S
Philadelphia, PA 19122

June, 2021



| Institute on Disabilities

Table of Contents

Introduction	2
Methodology	3
Results	7
Demographics.....	8
Satisfaction.....	8
Dignity, Respect, Rights	13
Choice	18
Employment.....	25
Self-Directed Supports.....	26
Community Participation	27
Relationships.....	28
Inclusion.....	30
Competence, Personal Growth.....	35
Staff Support of Person.....	35
Family/Friend/Guardian Survey.....	37
Summary	43

Introduction

Independent Monitoring for Quality (IM4Q) is a program designed to assess the overall quality of life for individuals with intellectual and developmental disabilities (I/DD) in Pennsylvania by surveying individuals and their families. IM4Q gathers important data about individuals' perceptions of their life that inform policy, family trainings, and quality management at the provider, administrative entity, and statewide levels.

The project originated in 1997, when 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 and families.

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 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 Department of Human Service (DHS) Home and Community Services Information System (HCSIS) web-based system. In 2013, we began to utilize ODESA, a web-based, secure data entry system developed by the Human Services Research Institute (HSRI) for National Core Indicators 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.

The number of survey respondents varies from year to year, but on average about 6000 individuals and 2500 family/friend/guardian representatives have responded to the survey over the last 20 years. This year there was a significant decrease in the number of respondents to both surveys due to the Covid pandemic, which limited the ability to conduct face-to-face interviews. Statewide, 2644 individuals and 1237 family members, friends or guardians completed the surveys prior to the early cessation of the project in March 2020.

Methodology

Instrument

The interview instruments for IM4Q include the Essential Data Elements (EDE) survey, the Consumer pre-survey form and the Family/Friend/Guardian (F/F/G) survey. The EDE survey has a total of 161 questions; 67 of the questions can only be answered by the individuals receiving supports and services.

The EDE for FY 2019-2020 includes all survey questions included in the FY 2019-2020 NCI Adult In-Person Survey. This year, 476 individuals included in this report are represented in the NCI sample for 2019-2020, based on a sampling methodology established by ODP and the Human Services Research Institute (HSRI). A copy of the NCI report for FY 2019-2020 is available on the HSRI website at www.nationalcoreindicators.org.

The EDE instrument is comprised of the following sections:

Completed by an AE designee:

- Consumer Pre-survey
- Background information (NCI)

Completed only based on responses of the individual receiving supports:

- Satisfaction
- Dignity, Respect and Rights
 - Supports Coordination
 - Emergency Preparation

Responses of the individual receiving supports, a family member, friend, or staff person:

- Choice and Control
 - Health

- Employment
- Self-Directed Supports
- Relationships
- Inclusion

Completed by the Independent Monitoring Team:

- Monitor Impressions
- Major Concerns

Completed by the family, with approval of the individual receiving supports:

- Family/Friend/Guardian survey

Sample

Independent Monitoring focuses on the quality of life and services and supports to children ages three and over, and adults supported by the Office of Developmental Programs' service system for individuals with intellectual disabilities. The sampling procedure for this year continues to be drawn through the Home and Community Services Information System (HCSIS) and attempts to more closely reflect the ODP service system. The following table shows the breakdown of the sample by type of residential setting. This year's sample included 118 people in Dauphin AE.

**Type of Residential Setting for
Dauphin AE**

Type of Residential Setting	Pennsylvania Overall		County/Joinder	
	N	Percent	N	Percent
State-Operated ICF/ID	25	1.0%	0	0.0%
State Mental Health Hospital	1	0.0%	0	0.0%
Homeless	0	0.0%	0	0.0%
Temporary Shelter	2	0.1%	0	0.0%
Foster Care	4	0.2%	0	0.0%
Incarceration	0	0.0%	0	0.0%
Nursing Home/Nursing Facility	42	1.6%	1	0.9%
Domiciliary Care	5	0.2%	2	1.7%
Personal Care Home (PCH)	35	1.3%	1	0.9%
Family living	87	3.3%	3	2.6%
Unlicensed Family Living	10	0.4%	2	1.7%
Own residence	258	9.8%	28	23.9%
Relative's home	1189	45.3%	68	58.1%
Children's Facility	8	0.3%	0	0.0%
Approved Private School	2	0.1%	0	0.0%
Private ICF/ID (4 or fewer)	10	0.4%	0	0.0%
Private ICF/ID (5 to 8)	7	0.3%	0	0.0%
Private ICF/ID (9 to 15)	1	0.0%	0	0.0%
Private ICF/ID (16 or more)	12	0.5%	0	0.0%
Community Home (1 person)	93	3.5%	1	0.9%
Community Home (2 to 4 persons)	767	29.2%	10	8.5%
Community Home (5 to 6 persons)	21	0.8%	0	0.0%
Community Home (7 to 8 persons)	13	0.5%	0	0.0%
Community Home (9 to 15 persons)	4	0.2%	0	0.0%
Community Home (16 or more)	3	0.1%	0	0.0%
Other	26	1.0%	1	0.9%
Missing	19	-	1	-
Total	2644	100%	118	100%

Procedure

AEs select and then contract with local IM4Q Programs to conduct interviews with individuals and families using the EDE and F/F/G Survey, using the following selection criteria: 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 received training on the EDE, F/F/G Survey, and interviewing protocols from technical advisors from the Institute on Disabilities (IOD) at Temple University. Data entry instruction was provided by ODP with support from the IOD.

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. Visits to individuals to be interviewed are scheduled with the individual, or with the person designated on the pre-survey form.

Participation in the interview is voluntary; if an individual refuses to participate, s/he is replaced in the sample with another individual. The 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 using the F/F/G Survey.

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. Data for the 2019-2020 survey cycle were collected and entered in ODESA by June 30, 2020. A usable data file was received by the Institute on

Disabilities in December 2020. This report presents data on the individuals surveyed by the IM4Q Local Programs, representing all 48 AEs across the state.

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	301	11.4%
Armstrong/Indiana	50	1.9%
Beaver	34	1.3%
Bedford/Somerset	29	1.1%
Berks	93	3.5%
Blair	29	1.1%
Bradford/Sullivan	7	0.3%
Bucks	102	3.9%
Butler	51	1.9%
Cambria	33	1.2%
Cameron/Elk	0	0.0%
Carbon/Monroe/Pike	18	0.7%
Centre	28	1.1%
Chester	89	3.4%
Clarion	20	0.8%
Clearfield/Jefferson	20	0.8%
Columbia/Montour/Snyder/Union	24	0.9%
Crawford	3	0.1%
Cumberland/Perry	37	1.4%
Dauphin	118	4.5%
Delaware	137	5.2%
Erie	185	7.0%
Fayette	45	1.7%
Forest/Warren	2	0.1%
Franklin/Fulton	18	0.7%
Greene	0	0.0%
Huntington/Mifflin/Juniata	45	1.7%
Lackawanna/Susquehanna	77	2.9%
Lancaster	62	2.3%
Lawrence	41	1.6%
Lebanon	20	0.8%

Lehigh	49	1.9%
Luzerne/Wyoming	50	1.9%
Lycoming/Clinton	15	0.6%
McKean	7	0.3%
Mercer	30	1.1%
Montgomery	144	5.4%
Northampton	39	1.5%
Northumberland	22	0.8%
Philadelphia	342	12.9%
Potter	10	0.4%
Schuylkill	1	0.0%
Tioga	14	0.5%
Venango	38	1.4%
Washington	12	0.5%
Wayne	29	1.1%
Westmoreland	74	2.8%
York/Adams	50	1.9%
Missing	0	0.0%
TOTAL	2644	100%

Demographics

- Of those who reported gender for this AE, 63% identified as male and 37% identified as female
- The average age is 35
- Of those who reported on race, 65% identified as white, 27% identified as black/African-American, 3% identified as Asian, 3% identified as mixed-race, 5% identified as other, and 0% identified as American Indian/Alaskan Native/Pacific Islander
- Of those who identified their ethnicity, 9% identified as Hispanic/Latinx

Satisfaction

Respondents: Only the individual receiving services/supports could answer the questions on satisfaction. Statewide, the percent of people who responded to questions in this section ranged from 26% to 71%.

Satisfaction with Living Arrangements

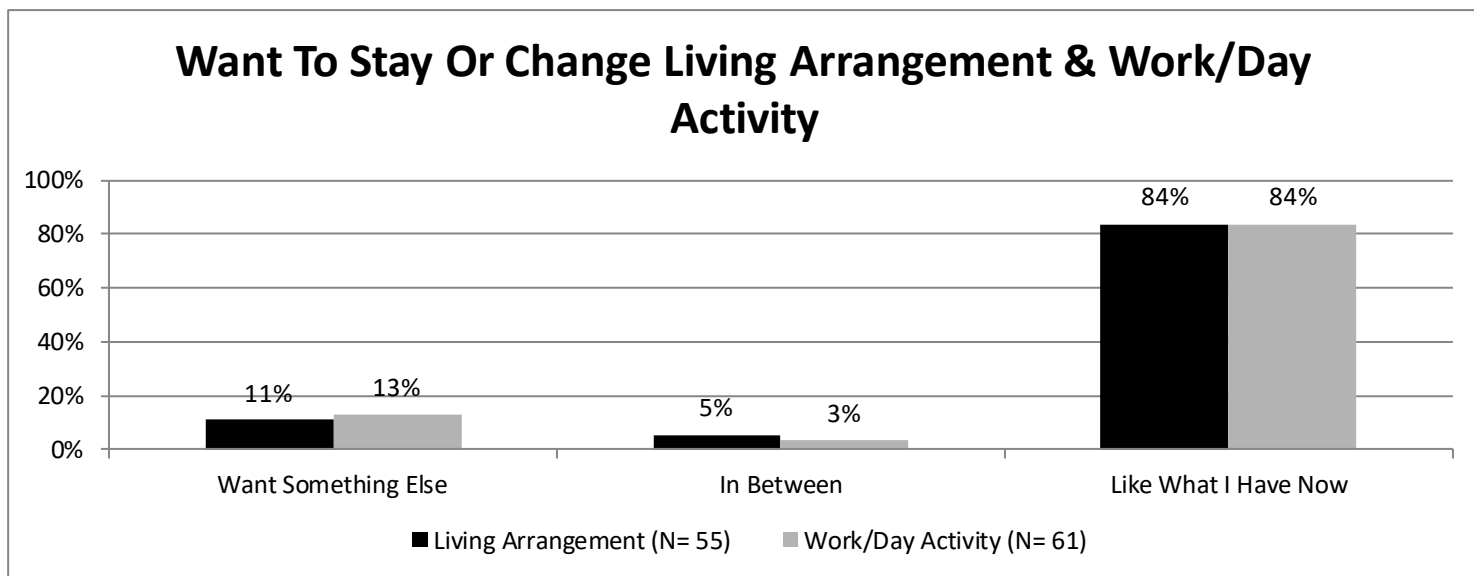
- 88% of individuals liked where they live (state finding 88%, regional 89%).
- When asked what they don't like about where they live, 2% reported that it was because of a problem with housemates, 0% wanted to be closer to family and friends, 0% wanted

more independence, 0% had some other reason they don't like where they live, 2% because of accessibility, 0% felt unsafe, 2% because their home needed repair, 0% had a problem with their staff, and 2% don't think it feels like home.

- 84% wanted to stay where they currently live (state finding 77%, regional 80%).

Satisfaction with Work/Day Activity

- 90% of individuals with a day activity/work liked the primary job/activity that they did during the day (state finding 93%, regional 93%). 96% of individuals liked the secondary job/activities they frequently do during the day (state finding 93%, regional 94%).
- 84% wanted to continue their current daytime activities/work (state finding 74%, regional 79%), 13% wanted to do something else (state finding 18%, regional 16%).



Daily Life

- 65% of individuals reported getting the services and supports they need (state finding 85%, regional 84%).
- On most weekdays, 15% of individuals report they attend an adult training program /community senior center (state finding 16%), 29% stay home, 5% go out and do things in the community, 0% are at a vocational facility (state finding 16%), 17% worked with no

supports, 6% worked in supported employment, 1% volunteer, 22% attend school, 3% were retired and 1% did something else.

- In addition to what individuals do on most weekdays, 9% also went out and did things in the community, 63% stayed home, 5% attended an adult training program/community senior center, 0% attended a vocational facility, 6% volunteered, 0% worked with no supports, 1% worked in supported employment, 1% were retired, 5% attended school, and 9% did something else.
- 76% of individuals that did not have a paid job in the community reported that they do not want a job (state finding 61%, regional 68%); 20% reported they would like to have a job for pay (state finding 35%, regional 28%). When those who do not want a job were asked why, 20% said they like what they do now and do not want to change, 7% said they were retired, 7% said it was due to health limitations, 1% said they did not want to affect their current benefits, 0% said it was due to transportation challenges, 0% accessibility, 0% lack of help/staffing/personal assistance, 0% feeling unwelcome, 0% feeling unsafe, 0% no jobs available, 0% lack of information, 0% financially secure, and 0% lack of equipment.

Happiness and Loneliness

- 88% reported usually feeling happy (state finding 86%, regional 90%), 11% reported being in-between (state finding 11%, regional 8%), and 1% reported usually feeling sad (state finding 3%, regional 2%).
- 57% of individuals reported never feeling lonely (state finding 64%, regional 64%), 37% reported sometimes feeling lonely (state finding 32%, regional 32%), and 6% reported always feeling lonely (state finding 5%, regional 4%).
- 82% reported having friends, which are not staff or family, with whom they like to do things (state finding 72%, regional 71%).
- 62% of respondents indicated they have a best friend (state finding 68%, regional 72%)
- 70% reported that they can go on a date if they want to or are married (state finding 81%, regional 74%); 3% reported that they can go on a date if they want to but there are some

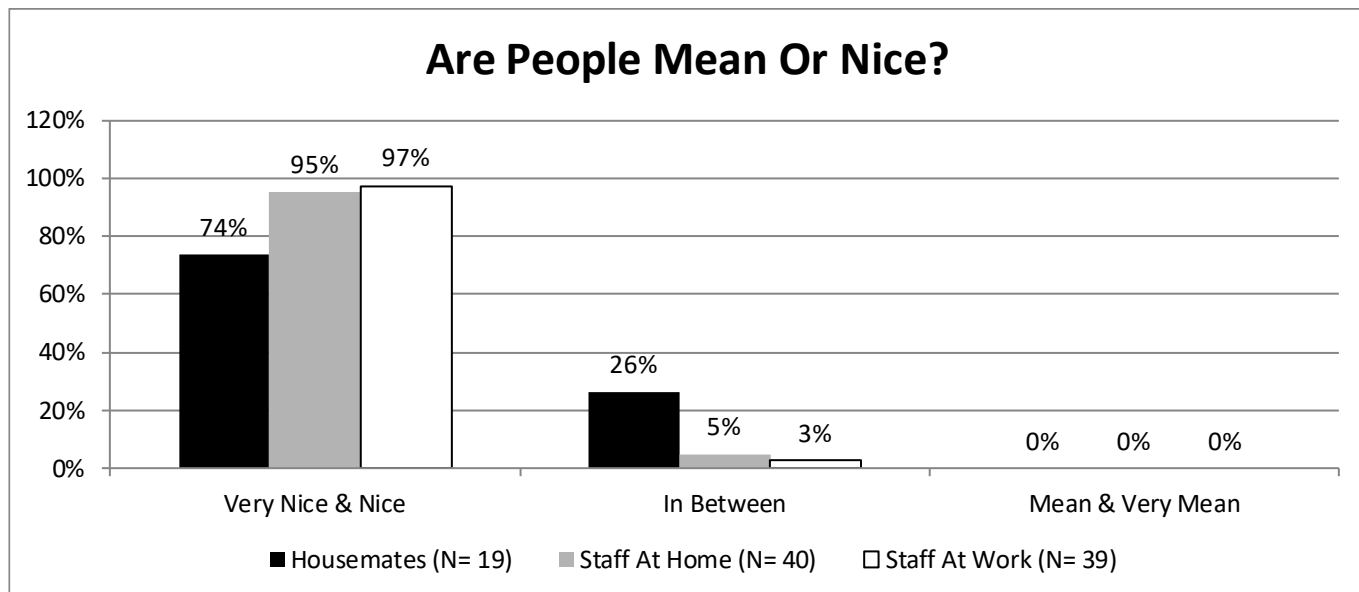
restrictions and rules (state finding 7%, regional 4%), and 27% are not allowed to date (state finding 12%, regional 23%).

Privacy

- 93% of the individuals surveyed reported that they always have privacy (a place to be alone) when they want it (state finding 96%, regional 93%).
- 86% of individuals reported that they can be alone with friends at home (state finding 82%, regional 82%).
- 65% of individuals say there are no rules about having friends and visitors (state finding 66%, regional 65%).
- 82% of the respondents reported that other people knock or ring the doorbell and wait for a response before coming in to their home (state finding 89%, regional 86%).
- For 77% of the individuals, people knock on the bedroom door and wait for a response before coming in (state finding 86%, regional 83%).

Are People Nice or Mean?

- 74% reported that their housemates are very nice or nice (state finding 88%, regional 89%).
- 40% of people interviewed reported that they get along with the person they share a bedroom with most of the time (state finding 80%, regional 75%).
- 95% of the people interviewed reported that their staff who work with them at home are very nice or nice (state finding 94%, regional 95%).
- 97% reported that staff who work with the respondents at work or day activity are nice or very nice (state finding 97%, regional 97%).



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 86.60 with a standard deviation of 18.45 (86.44 and 19.09 state finding; 87.89 and 18.74 regional).

Note on Satisfaction Research

⇒ Although these percentages indicate a high level of satisfaction, this type of research usually yields high satisfaction rates. Individuals who receive supports and services tend to appreciate getting such services and therefore see themselves as satisfied. Moreover, people with limited options may not have the experience to know that services could be better.

Dignity, Respect and Rights

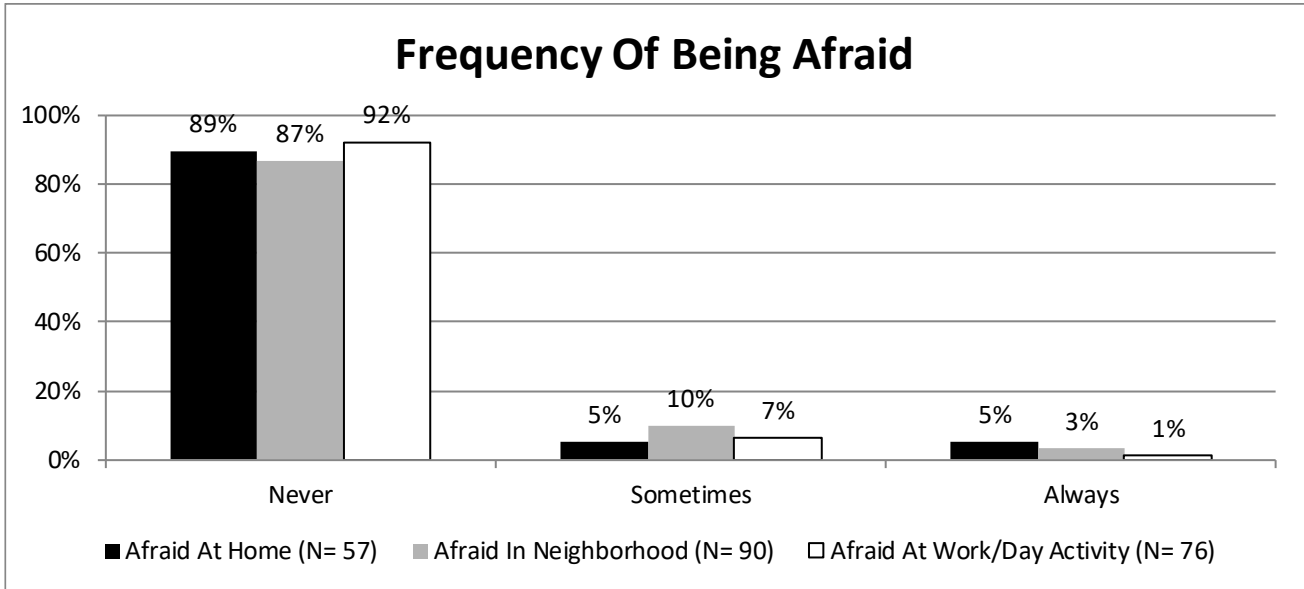
Respondents: Only the individual receiving services/supports could answer the questions on dignity, respect and rights. Statewide, the percent of people who responded to questions in this section ranged from 32% to 66%.

Support with Goals and Problems

- 22% of individuals reported that they go to staff for help when they have a problem (state finding 35%, regional 35%). 57% go to their family (state finding 35%, regional 48%), 20% go to a friend, and 8% go to someone else; 1% have no one to go to for help.
- 52% get help to learn new things (state finding 67%, regional 60%).
- 52% of individuals report that they get to help other people (state finding 72%, regional 61%).
- 27% of individuals indicated that they have participated in a self-advocacy group meeting (state finding 19%, regional 22%).
- 52% of individuals said that someone had talked to them about self-advocacy (state finding 44%, regional 43%)

Being Afraid

- 89% reported never being afraid at home (state finding 88%, regional 90%).
- 87% reported never being afraid in the neighborhood (state finding 88%, regional 89%).
- 92% reported never being afraid at work, school or day activity (state finding 93%, regional 93%).
- 90% reported never being afraid when using transportation (state finding 94%, regional 94%).
- 92% reported that they have someone they can talk to when they feel afraid (state finding 95%, regional 94%).



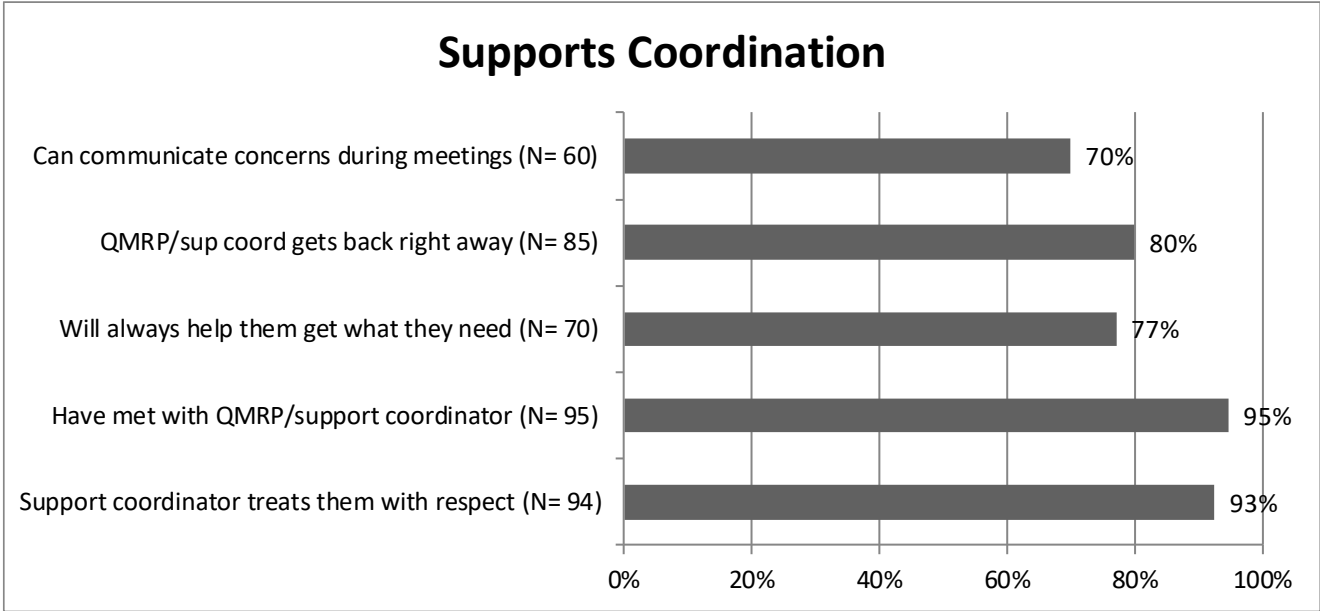
Legal Rights

- For 57% of the individuals interviewed, their mail is never opened without permission (state finding 83%, regional 72%); 26% say their mail is always opened without permission (state finding 8%, regional 14%)

Supports Coordination/Qualified Intellectual Disability Professional (QIDP)

- 95% reported that they have met with their supports coordinator/QIDP in the past year (state finding 97%, regional 96%).
- 77% of individuals reported that, if they ask, their supports coordinator will always help them get what they need (state finding 88%, regional 85%).
- 80% of the people reported that when they call, their supports coordinator/QIDP always gets back to them right away (state finding 91%, regional 89%).
- 90% of individuals reported that their supports coordinator asks what their interests are (state finding 93%, regional 93%).
- 72% of respondents said their supports coordinator asks them what they want their life to look like (state finding 87%, regional 86%).
- 72% said the supports coordinator asks what they want in the future (state finding 86%, regional 83%).

- 70% of individuals reported always being able to communicate their concerns during annual meetings (state finding 88%, regional 83%).
- 43% of individuals report that their supports coordinator has asked them about directing their own services (state finding 40%, regional 40%).
- 82% of people surveyed reported that their supports coordinator talks with them about services to make sure everything is OK (state finding 96%, regional 93%).
- 31% of those surveyed have been told how much money was in their annual budget (state finding 56%, regional 44%).
- 35% of individuals reported that they know they have a choice of SC organizations (state finding 63%, regional 47%).
- 89% reported that their ISP meeting included the people they wanted to be there (state finding 96%, regional 95%).
- 58% of individuals indicated that they knew what was being talked about at their ISP meeting (state finding 77%, regional 66%).
- 91% of individuals reported that their supports coordinator always listens to them (state finding 95%, regional 92%)
- 93% of individuals reported that the supports coordinator always treats them with respect (state finding 97%, regional 94%)
- 90% of respondents said they took part in their annual planning meeting (state finding 96%, regional 94%)
 - 63% said they talked about learning new things at their planning meeting (state finding 74%, regional 72%)
 - 65% of individuals reported that they chose the services they get as a part of their service plan (state finding 76%, regional 70%)
 - If they want to change something about their services, 74% know who to ask (state finding 79%, regional 76%)



Staff

- 86% of individuals interviewed reported that their staff treats them with respect (state finding 93%, regional 91%).
- 73% of individuals reported that they feel their staff has the right training to meet their needs (state finding 93%, regional 89%).
- 80% of individuals feel that all of their staff understood their communication (state finding 88%, regional 84%)

Emergency Preparation Questions

- 80% of individuals have been given information about what to do in an emergency (state finding 85%, regional 80%).
- When asked who gave the individual information about what to do in an emergency, 30% received information from staff (state finding 41%), 16% from day program or employment staff, 54% from someone in their family, 3% from the police, fire department, or EMS, 22% from supports coordinator, 6% from neighbors or friends, and 0% from someone from red cross; 26% of individuals responding to this survey received information from someone else.

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).

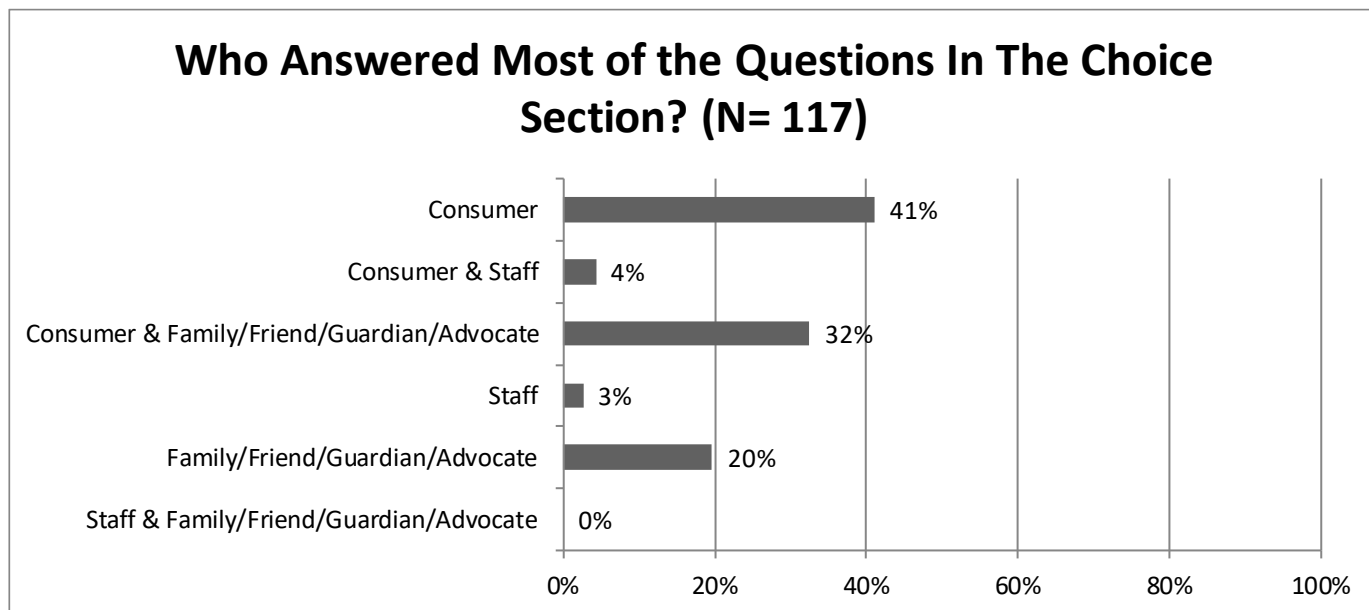
- The average score was 84.26 with a standard deviation of 14.15 (82.86 and 14.38 state finding; 85.93 and 14.02 regional).

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 being afraid less frequently.

- The average (mean) score was 93.17 with a standard deviation of 18.45 (93.28 and 15.40 state finding; 93.80 and 15.73 regional).

Choice and Control

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



A value of missing was assigned when individuals did not answer, gave an unclear answer, or responded “do not know.”

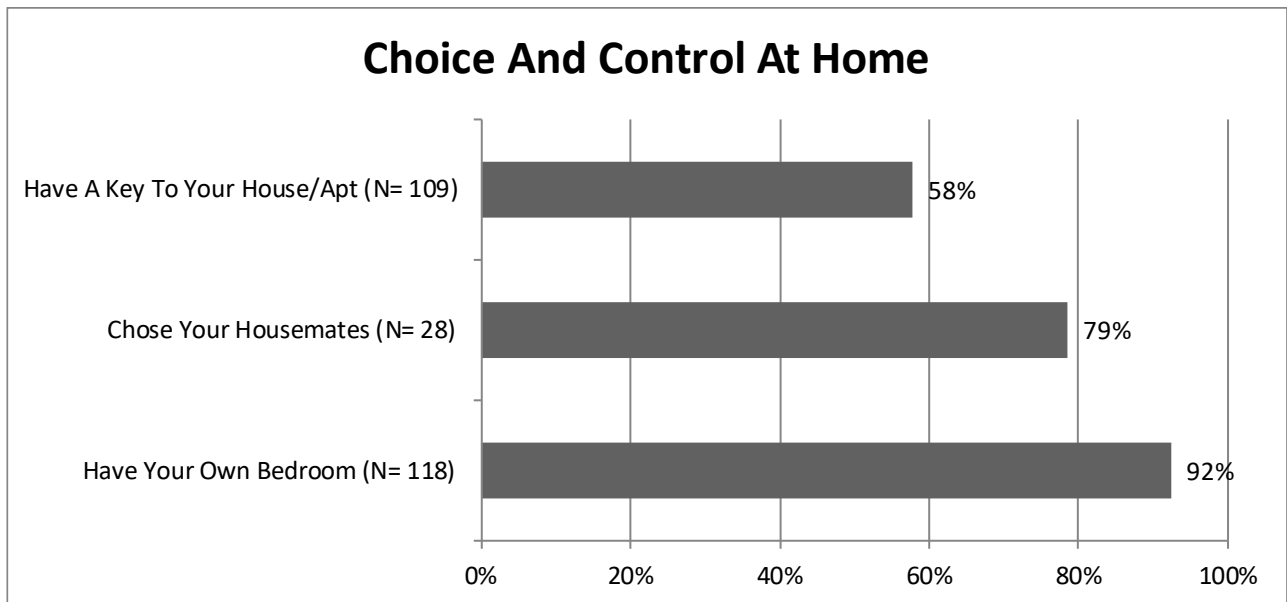
Forms of Identification

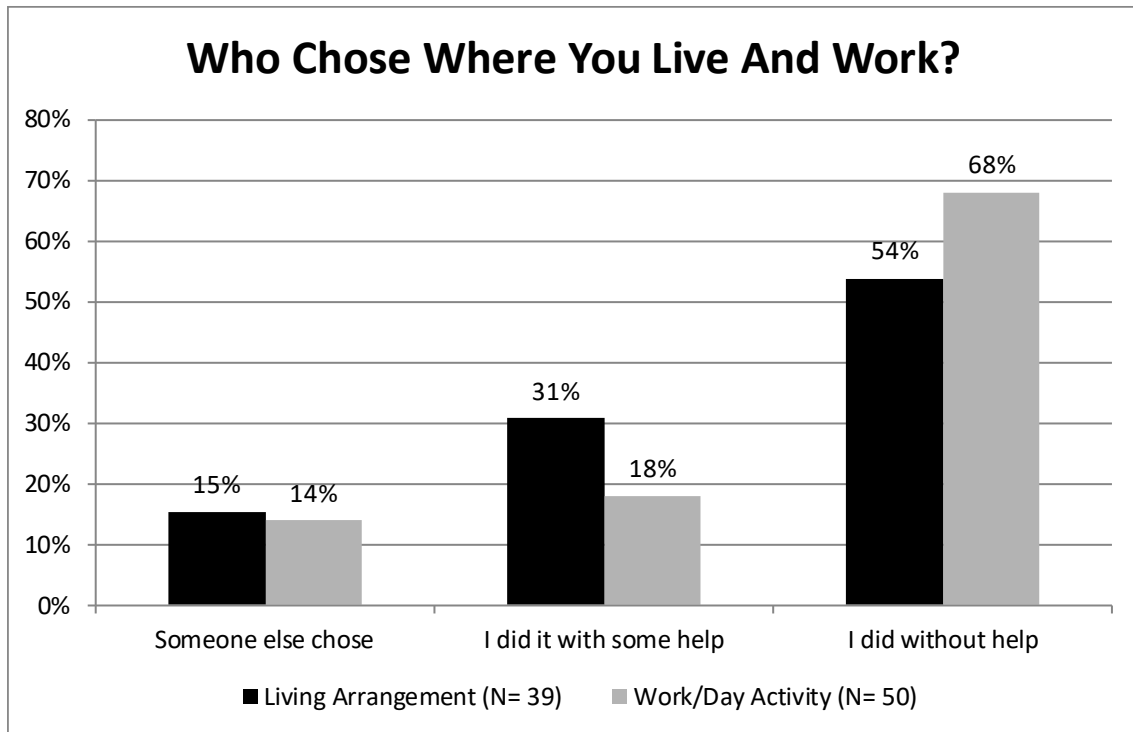
- 71% of individuals stated that they always carry a form of identification, such as a card with the individuals name, address and a person to call in case of emergency or a non-driver ID (state finding 60%, regional 58%); 10% never do (state finding 24%, regional 17%).

Choice and Control at Home

- 58% of the individuals surveyed had a key/way to get into their house or apartment on their own (state finding 47%, regional 50%).
- 46% of respondents said that if other members of their house go out, they have the option to stay home (state finding 52%, regional 51%).

- 71% of respondents can lock their bedroom door if they want to (state finding 41%, regional 49%).
- 12% of individuals reported that they own their own home (state finding 3%, regional 6%)
- 41% of individuals reported that their name is on the lease or rental agreement (state finding 26%, regional 30%)
- For 15% of the individuals, someone else choose where they live (state finding 40%, regional 41%); 54% of those interviewed chose without assistance (state finding 32%, regional 34%).
- 68% of individuals said they were given a choice to live where people without disabilities live (state finding 58%, regional 54%).
- For those individuals who had some control in choosing where they live, 62% saw more than one other place before moving in (state finding 57%, regional 53%); 38% saw no other places (state finding 43%, regional 47%).
- 21% of the individuals did not choose their housemates (state finding 57%, regional 57%).
- 92% of the individuals had their own bedroom (state finding 90%, regional 89%); for those who shared a bedroom, 0% chose some or all of their roommates (state finding 33%, regional 21%)



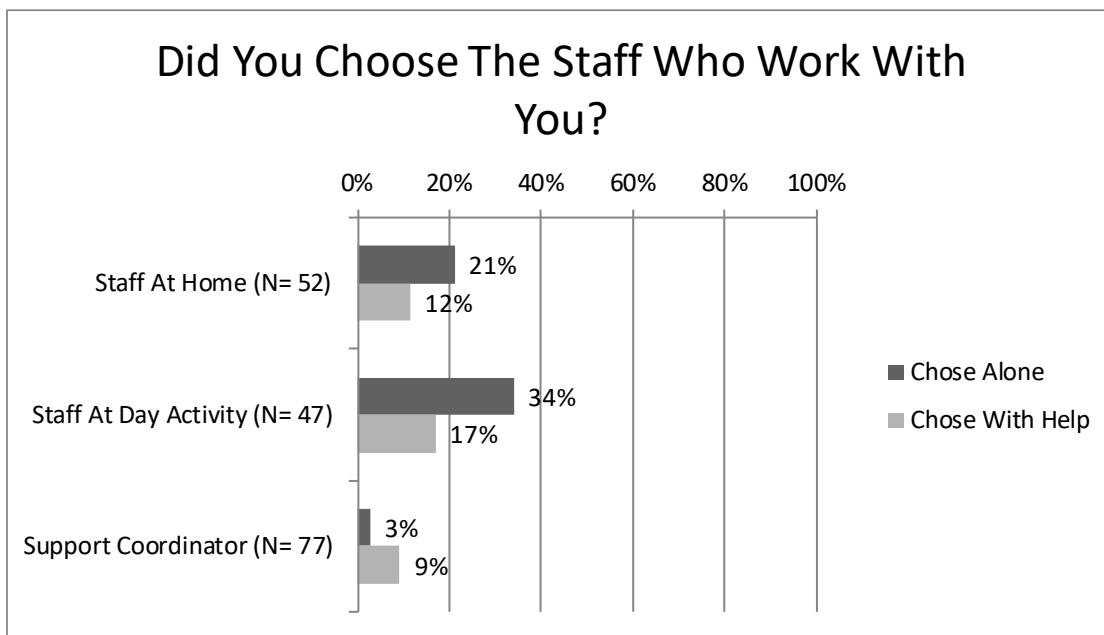


Choice and Control During the Day and for Leisure Time

- 14% of the individuals interviewed reported that someone else chose what they do during the day (state finding 21%, regional 16%).
- 68% of the people interviewed chose what they do during the day without assistance (state finding 47%, regional 56%).
- 74% of individuals reported that when they chose their work or day activity they had an option to go where people without disabilities go (state finding 55%, regional 61%)
- For those individuals who participated in choosing what they do during the day, 65% saw other places before deciding (state finding 62%, regional 52%); 35% saw no other places (state finding 38%, regional 48%).
- 87% of the individuals surveyed chose their daily schedules without assistance (state finding 89%, regional 90%).
- 85% chose how they spend their free time without assistance (state finding 93%, regional 91%).

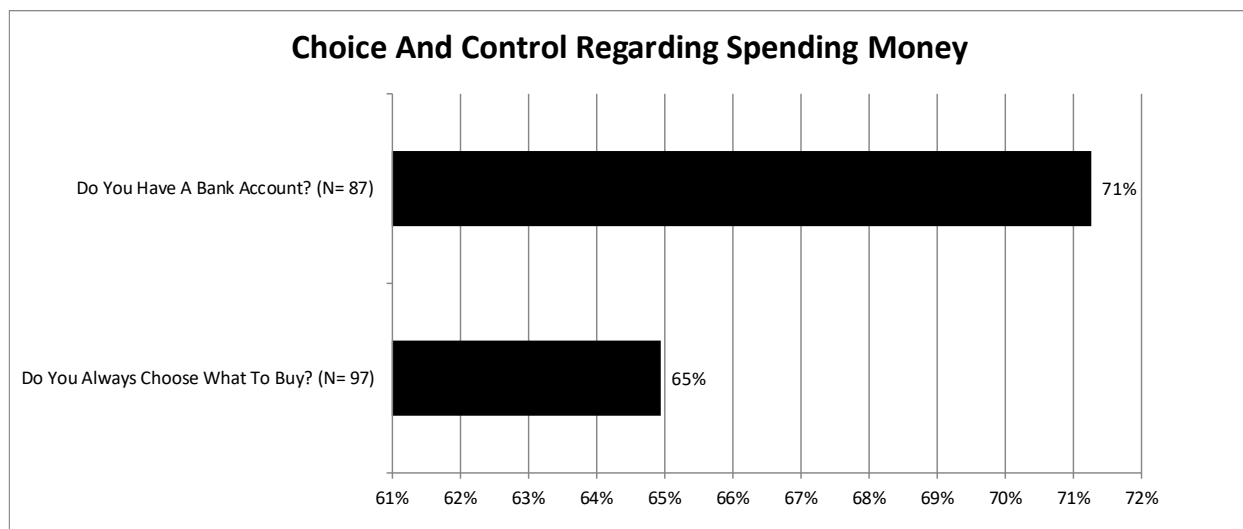
Choice and Control in Choosing Staff

- 33% of the individuals interviewed/chose the staff that helps them at home, alone or with assistance from family or provider (state finding 43%, regional 35%).
- 51% of the individuals interviewed/chose the staff that helps them at their work/day activity, alone or with assistance from family or provider (state finding 35%, regional 34%).
- 12% of the individuals reported that they chose their supports coordinator, alone or with assistance from family or provider (state finding 31%, regional 22%).



Choice and Control with Regard to Money

- 65% of the individuals reported that they always choose what to buy with their spending money (state finding 60%, regional 65%).
- 51% of the individuals reported that there is something they want to buy (state finding 43%, regional 48%).
- 71% of the individuals reported that they have a bank account that they can get to independently to withdraw money when they want it (state finding 64%, regional 72%).

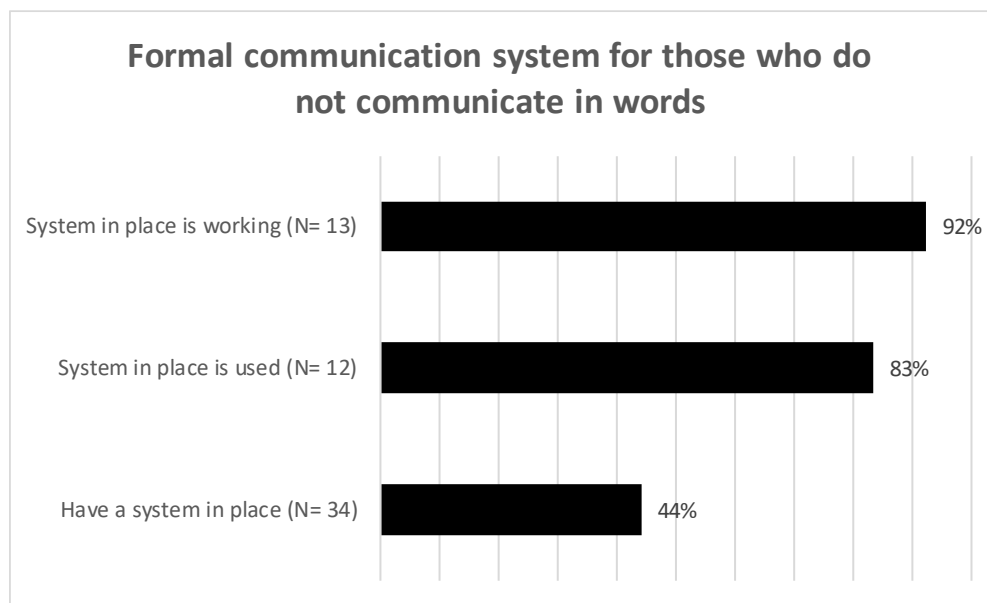


Voting

- 23% of people said that they do vote (state finding 32%, regional 21%); 9% do not vote but would like to (state finding 6%, regional 6%), and 68% do not vote and are not interested (state finding 63%, regional 73%).

Access to Communication

- For those individuals who do not communicate using words (n=34), there is a formal communication system in place for 44% of the people interviewed (state finding 31%, regional 35%).
- For those people with formal communication systems in place (n=13), the systems are in working order for 92% of the people interviewed (state finding 92%, regional 87%).
- If the communication system was in place and working, it was being used regularly for 83% of the people interviewed (state finding 89%, regional 88%).
- 60% of individuals with a formal communication system reported using it across all settings (state finding 76%, regional 65%).
- 46% of individuals with a formal communication system are supported by staff or a program coordinator (state finding 60%, regional 61%), 54% are supported by a parent or caregiver, 85% are supported by their speech language clinician, and 0% are supported by someone else.

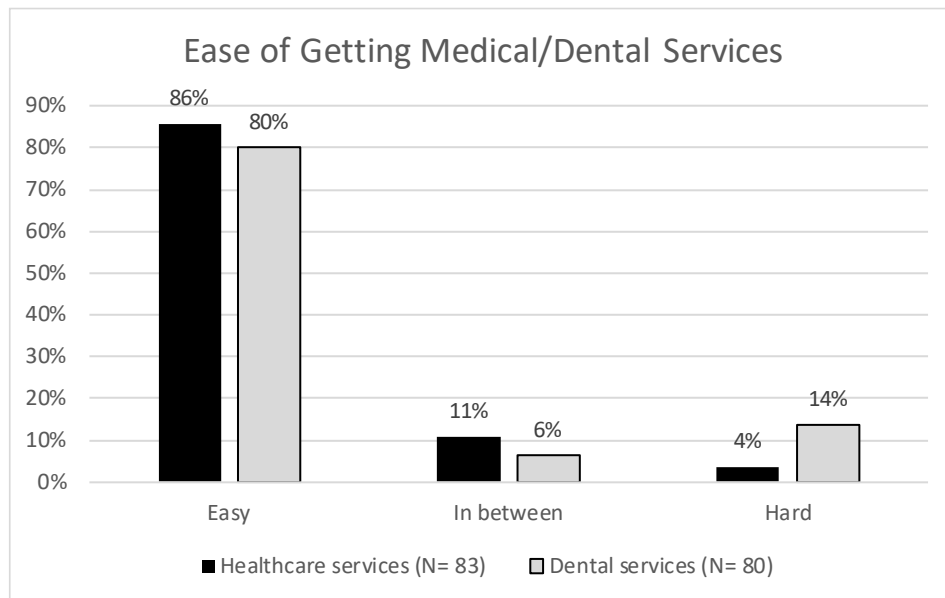


- In regards to forms of communication individuals have and use, 95% have and use cable television (state finding 92%, regional 86%), 39% computer, 30% cell phones, 33% internet, 15% email, and 20% text messaging.

Health Care Questions

- When asked how many times per month they exercise at home, 35% of individuals said zero (state finding 53%, regional 48%), and 43% said 10 or more times a month (state finding 32%, regional 38%).
- 74% of individuals interviewed reported that they have the opportunity to discuss health with their primary care provider (state finding 86%, regional 84%)
- 69% of individuals reported that they feel their doctor understands them (state finding 80%, regional 79%)
- 53% of individuals feel that they understood their doctors' instructions (state finding 67%, regional 66%)
- 70% of respondents say if they needed help communicating at the doctor's office, it was available (state finding 93%, regional 83%)
- 97% of respondents reported they were able to see a medical specialist if they needed to (state finding 96%, regional 97%)

- 90% of individuals say they have been prevented from receiving medical and dental services because of their disability (state finding 90%, regional 91%)
- When asked how hard it is to get health care services in their community, 86% of individuals reported that it was very easy or pretty easy (state finding 91%, regional 88%)
- When asked how hard it is to get dental services in their community, 80% of individuals reported that it was very easy or easy (state finding 84%, regional 79%)
- Of those who have a psychiatrist, 84% of individuals interviewed reported that they have the opportunity to discuss health concerns with a psychiatrist (state finding 62%, regional 71%)
- 78% of individuals reported that their doctor speaks directly to them during appointments (state finding 92%, regional 92%)
- 56% of individuals reported that they are able to provide consent for medical treatment (state finding 60%, regional 63%); of those able to provide consent, 72% said their doctor accepts their consent (state finding 82%, regional 70%)



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 65.04 with a standard deviation of 22.32 (58.57 and 21.04 state finding, 61.98 and 22.33 regional).

Employment

Respondents: Of the 106 individuals who responded for the Dauphin AE, 20 respondents indicated they are employed.

Community Integrated Employment

- 19% of individuals work in a community integrated setting (17% state finding, 16% regional).
- 35% of individuals have been employed for 1 to 3 years (state finding 29%). 12% of individuals have been employed for less than one year, 29% have been employed for 4-6 years, 12% have been employed for 7-10 years, and 12% have been employed for more than 11 years (state finding 18%).

Types of Work

- 57% of individuals work in cleaning services, 7% work in retail (including grocery stores), 0% work in food services, 7% work in office work, 0% work in the stock room, 7% in maintenance, 7% work in assembly, 0% work as a care-worker or aide, 0% work in animal care, 0% in work in landscaping or outdoors, and 7% work in some other occupation.

Supports Getting Into the Workplace

- 41% of individuals surveyed reported that someone had talked to them about employment in their planning meeting (state finding 57%, regional 44%)
- 33% of individuals report that community employment is a goal in their plan (state finding 31%, regional 31%)
- When individuals were asked who had talked to them about employment, 59% said no one (state finding 44%), 36% said their supports coordinator, 11% said their service provider, 16% said their family, 0% said their housemates, and 4% said someone else

- 13% of individuals take classes or training to help them get a job in the community, get a better job, or do better at their current job (state finding 10%, regional 12%).

Compensation and Advancement

- 88% of individuals received paid time off, 0% received health insurance, 0% received retirement benefits, and 13% received some other kind of benefit. Note: individuals answering this question had the option to indicate more than one response.
- 79% of individuals who work have been promoted (50% state finding, 56% regional).
- The mean number of hours worked per week was 20 hours (16 hours state finding, 19 hours regional).
- 16% of individuals reported that they know how much they earn and are willing to share it (state finding 79%, regional 60%).
- Regarding hourly wage, 0% earned \$7.25 (state finding 16%, regional 17%); 0% earned \$7.26 to \$9.00 (state finding 33%, regional 17%); 67% earned \$9.00 to \$12.00; 33% earned more than \$12.00.

Self-Employment and Supports

- Of the 20 individuals who have community integrated employment, 0 individuals are self-employed (29 individuals state finding, 1 individuals regional).

Self-Directed Supports

Respondents: Of the 114 individuals surveyed, 12 indicated they use self-directed supports.

- 11% of respondents report that they use self-directed supports (state finding 6%, regional 8%)

Among those individuals using self-directed supports,

- 11% make most of the decisions about how their budget for services is used on their own; 10% have input but family and friends help (state finding 33%, regional 45%), 40%

say a family member or friend makes decisions (state finding 49%, regional 36%), and 10% report that a case manager or another state professional makes the decision

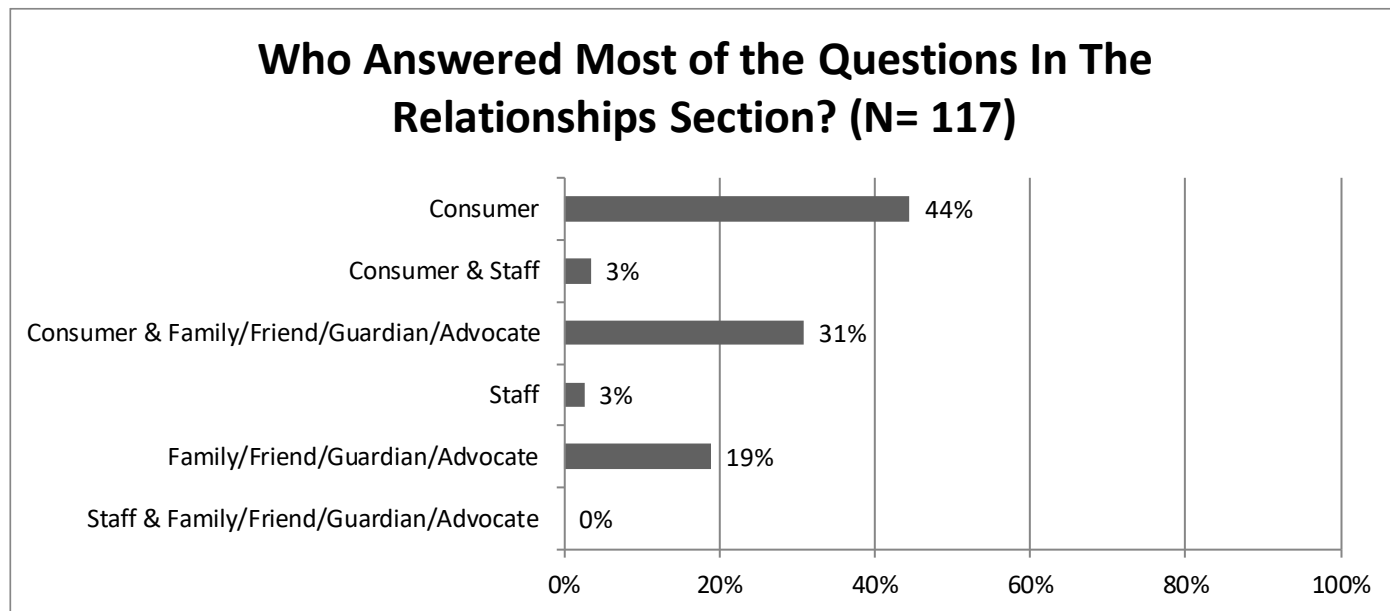
- 82% participate in decisions about budget, staff, and managing services (state finding 63%, regional 66%)
- 89% hire and manage their own staff (state finding 77%, regional 89%)
- 63% can make changes to their budget or services if they need to (state finding 87%, regional 75%)
- 100% say they have enough help deciding how to use their budget/services (state finding 92%, regional 90%)
- 100% receive information about the money left in their budget (state finding 79%, regional 85%)
- Of these, 75% say the information is easy to understand (state finding 87%, regional 84%)
- 57% receive this information at least every three months (state finding 70%, regional 73%)

Community Participation

- 17% of individuals reported that they use Community Participation Services (state finding 34%, regional 25%).
- Community Participation Services being used were: developing skills and competencies necessary for employment 33%, fine/gross motor development and mobility 28%, participating in community activities to develop social networks 44% (state finding 63%), participating in opportunities to develop interests or promote health/wellness 83% (state finding 77%), training/education for self-determination 44%, community adult learning opportunities 44%, volunteer opportunities 78%, and learning to navigate the local community 17%.

Relationships

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

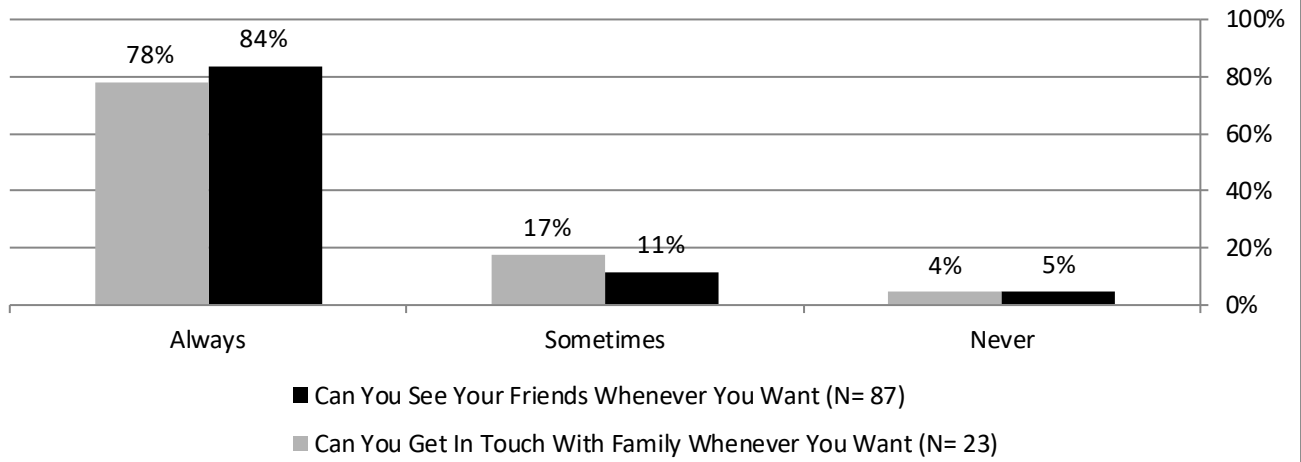


A value of missing was assigned when individuals did not answer, gave an unclear answer, or responded, “do not know.”

Contact with Friends and Family

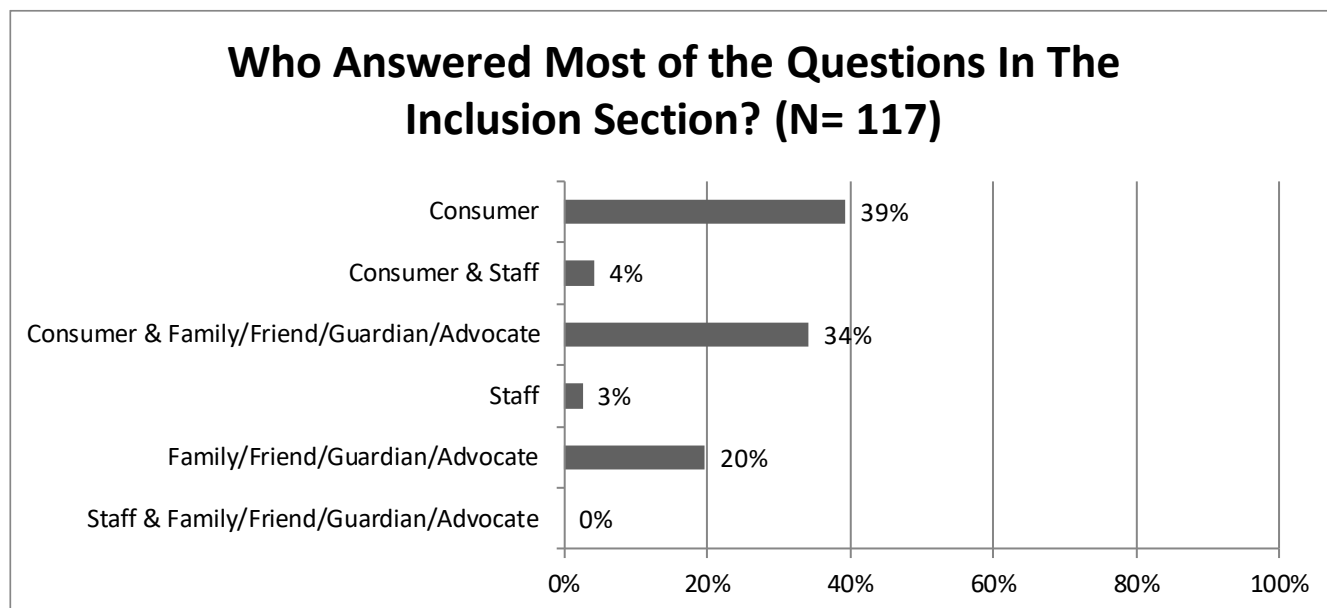
- 84% of individuals were always able to see friends whenever they wanted (state finding 85%, regional 86%)
- Of individuals that reported that they were unable to see their friends whenever they wanted, 57% reported that it was difficult to find time to see friends, 14% reported that they couldn't see friends because of a transportation issue, 0% reported a lack of staff, 0% reported that there were rules/restrictions, 0% reported difficulty with money/cost, and 29% reported that there was another reason why they couldn't see friends.
- 78% of respondents were always able to get in touch with family whenever they wanted (state finding 87%, regional 85%).

Contact With Friends And Family



Inclusion

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

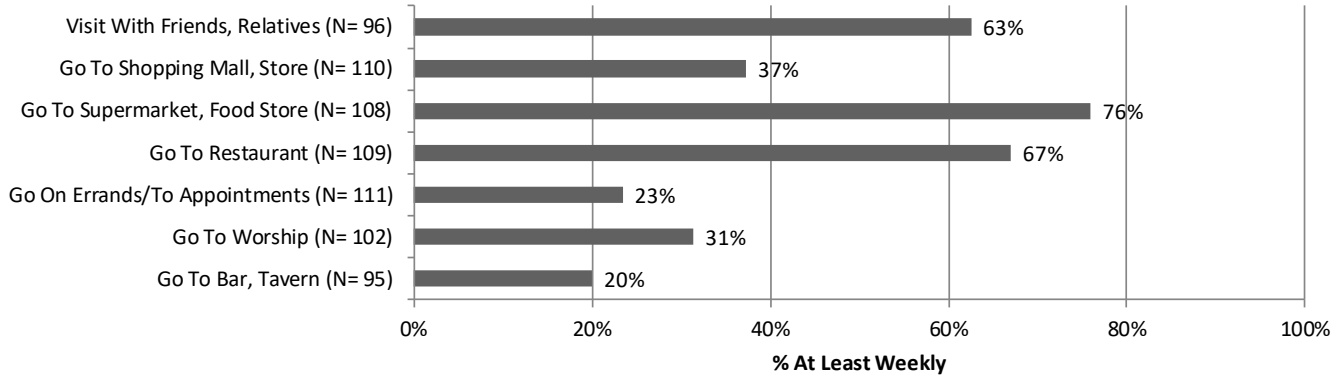


A value of missing was assigned when individuals did not answer, gave an unclear answer, or responded “do not know.”

Community Participation

- 63% of the people visited with friends, relatives and neighbors at least weekly (state finding 48%, regional 61%)
- 76% of individuals went to a supermarket, 67% went to a restaurant, and 37% went to a shopping mall at least weekly (state finding 51%, 51%, and 45%; regional 60%, 55% and 43% respectively)
- At least weekly, individuals went out for errands and appointments (23%), to places of worship (31%), and to bars/taverns (20%). State findings were 32%, 27%, and 22%; regional 30%, 31%, and 18% respectively.
- 15% of individuals go out for entertainment at least weekly (state finding 28%, regional 22%).

Community Participation



For each area of community participation, respondents reported who the individual usually goes with.

WITH WHOM	Alone	Friends	Family	Housemates, coworkers	Staff	Other
Visit friends, relatives, neighbors	32%	11%	44%	0%	11%	2%
Went to a shopping mall	9%	8%	61%	1%	22%	0%
Went to a supermarket	16%	4%	64%	2%	14%	0%
Went to a restaurant	12%	13%	58%	2%	14%	1%
Went out for errands/appointments	7%	4%	69%	3%	16%	2%
Went to worship	7%	7%	82%	2%	2%	0%
Went out for entertainment	4%	24%	56%	1%	15%	0%
Went to bars/taverns	18%	26%	33%	0%	23%	0%

For each area of community participation, respondents reported if the amount was enough (wanted more, wanted less, wanted current amount).

WITH WHOM	More	Less	Right amount
Visit friends, relatives, neighbors	12%	1%	87%
Went to a shopping mall	10%	3%	87%
Went to a supermarket	8%	2%	90%
Went to a restaurant	13%	3%	84%
<i>Went out for errands/appointments</i>	1%	1%	98%
<i>Went to worship</i>	7%	3%	90%
<i>Went out for entertainment</i>	14%	0%	86%
<i>Went to bars/taverns</i>	4%	1%	95%

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 50.35 with a standard deviation of 18.05 (state finding 45.62 and 17.70; regional 48.13 and 18.58)

Community Activities

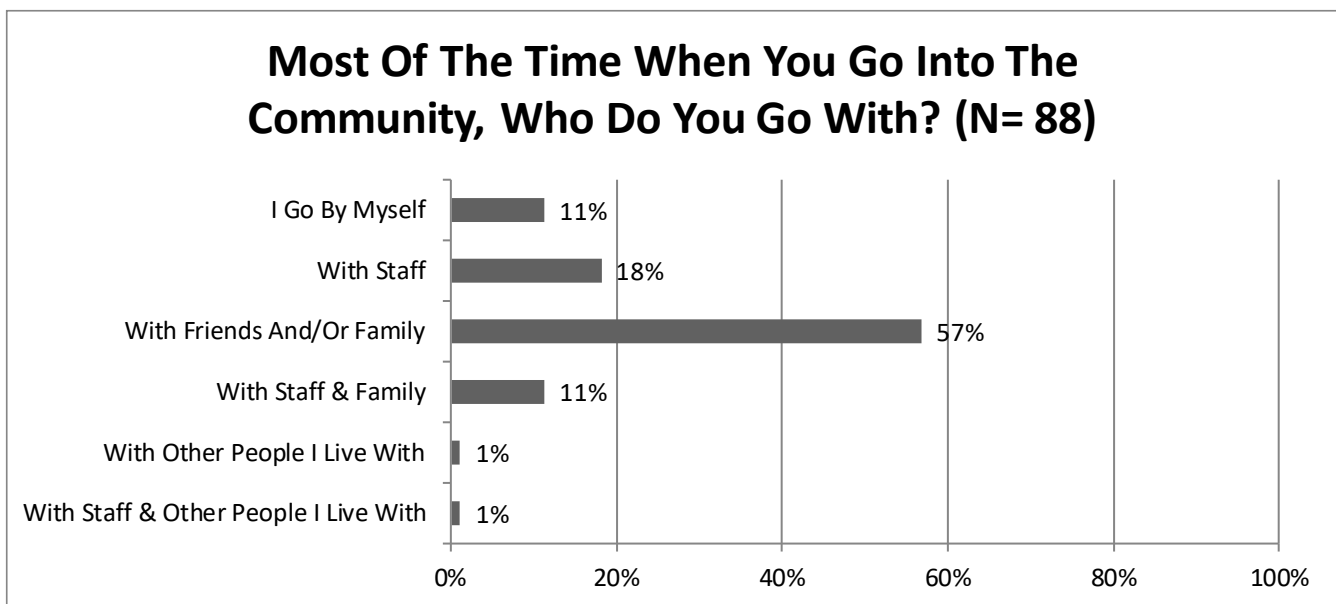
We asked individuals about several other types of community activities including attending social events and recreational events.

- 37% of the individuals go frequently into the community for entertainment (state finding 55%, regional 49%)
- 25% of individuals reported that they frequently go to social events in the community that are attended by people with and without disabilities (state finding 36%, regional 35%)
- 39% of individuals would like to be a part of more groups in their community (state finding 31%, regional 33%).
- 48% of individuals went on a vacation in the past year (state finding 48%, regional 48%)

- Regarding monthly exercise, 19% of individuals reported never going out for exercise (state finding 36%, regional 39%), 4% exercise less than weekly, 17% exercise once a week, and 60% exercise more than once a week (state finding 47%, regional 46%).

Going Out Alone or With Other People

- 11% of individuals go out alone (state finding 7%, regional 8%)
- 19% of individuals go out with staff (or staff and other people they live with) most of the time (state finding 37%, regional 31%)



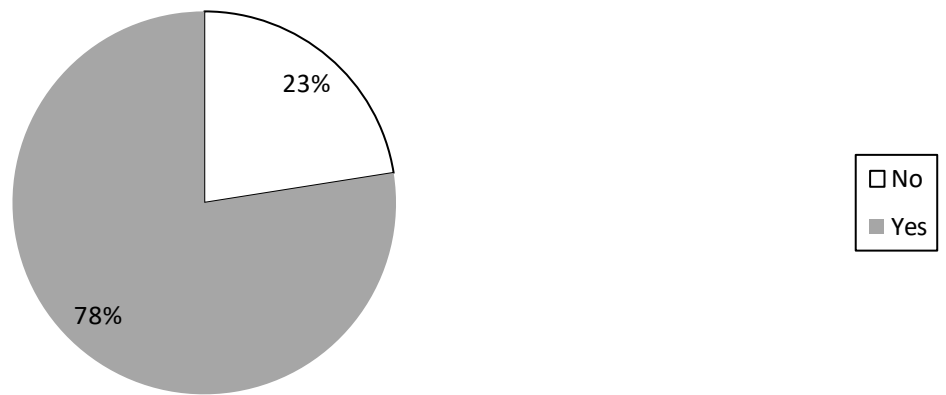
Transportation

- 86% of people always had a way to get where they wanted to go (92% state finding, 88% regional)
- In order to get to places they needed to go, individuals reported getting a ride from staff in the provider van (10%). 63% reported getting a ride from family or friends, 12% reported getting a ride in a staff member’s car, 15% transport themselves, 0% ride public transportation, 0% ride paratransit, and 1% take a taxi, Uber or Lyft.
- Of those who cannot always get where they want to go, 0% cannot get where they want to go because there is not enough staff (22% state finding, 17% regional)

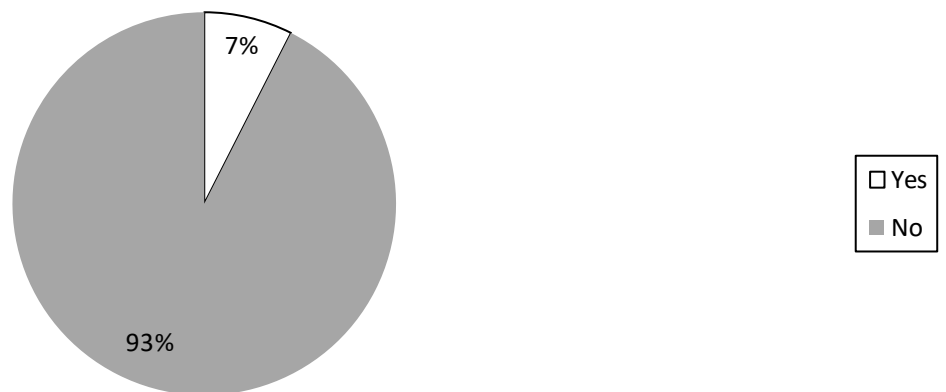
Home Adaptive Equipment

- 78% of individuals reported having all the adaptive equipment they needed (state finding 83%, regional 83%)
- 93% of people said that they do not need any changes to their home to make it accessible (state finding 93%, regional 94%)

Do You Have All The Adaptive Equipment You Need? (N= 80)



Do you need changes to make your home more accessible? (N= 107)

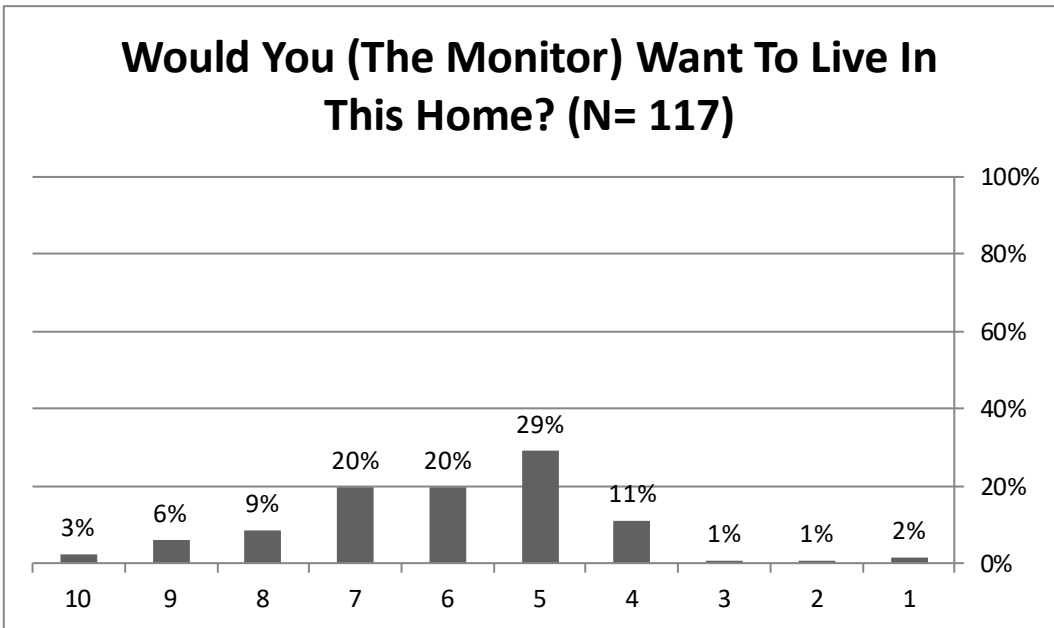


Competence, Personal Growth and Opportunities to Grow and Learn

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,

- When asked whether team members would want to live in the individual’s home on a scale of 1 (no way) to 5 (maybe) to 10 (I’d move in tomorrow), the average score was 6.0 (state finding 6.6, regional 6.7)



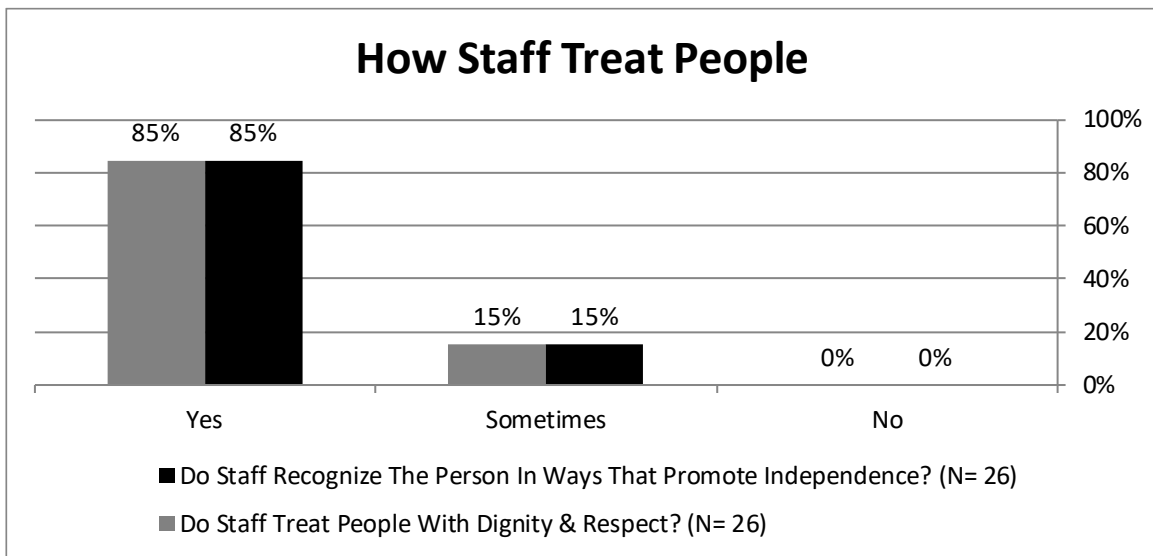
Staff Support for the Person

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 IM4Q teams,

- 85% of staff observed recognized the individuals in ways that promote independence (state finding 92%, regional 97%)
- 85% of the monitoring teams observed that the staff treated individuals with dignity and respect (state finding 92%, regional 96%)
- 85% of staff observed that support individuals at home and/or work appeared to have the skills they needed to support the person (state finding 92%, regional 96%).

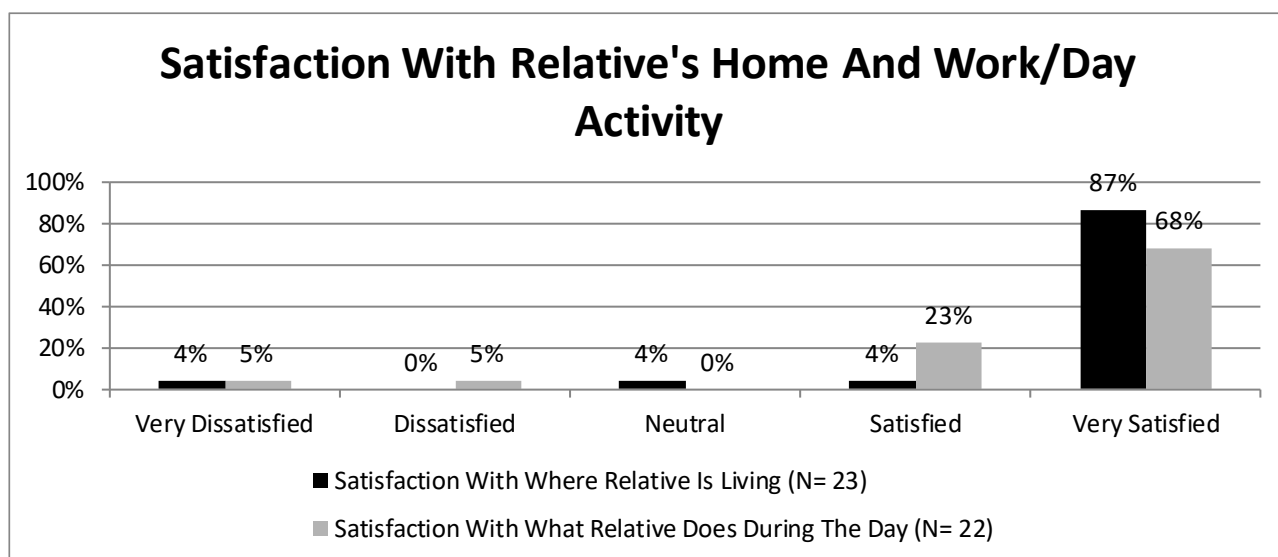


Family/Friend/Guardian Survey

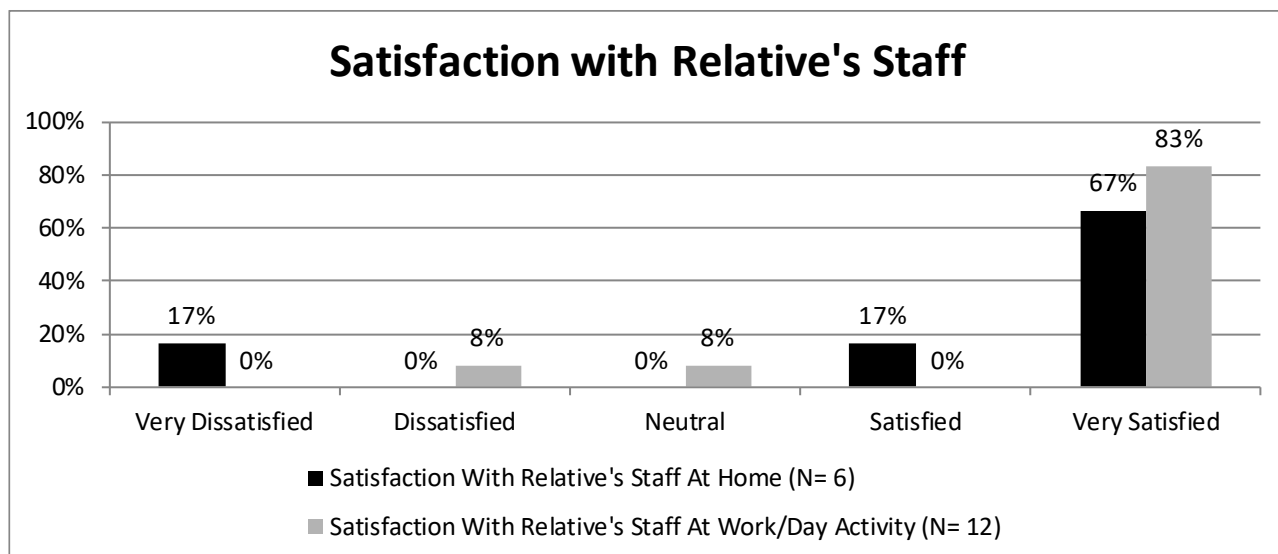
Respondents: This survey was completed by telephone with a family member, guardian, or friend who was identified through the Essential Data Elements Pre-Survey. In the event that a phone survey could not be completed, surveys were completed by mail. A total of 24 family members, friends, and guardians from the Dauphin AE participated in the survey.

- 88% of the surveys were answered by parents
- 8% were answered by siblings
- 4% were answered by the guardian
- 0% were answered by a friend
- 0% were answered by another relative (spouse, aunt, uncle, cousin, grandparent)
- 0% were answered by persons with other relationships to the individual receiving supports

Satisfaction



- 91% of the families surveyed were either somewhat satisfied or very satisfied with where their relative lives (state finding 95%, regional 93%).
- 91% were either somewhat satisfied or very satisfied with what their relative does during the day (state finding 91%, regional 93%).



- 83% of the families surveyed were either somewhat satisfied or very satisfied with their relative's staff at home (state finding 94%, regional 92%).
- 83% of the families surveyed were either somewhat satisfied or very satisfied with the staff at their relative's day activity (state finding 95%, regional 93%).

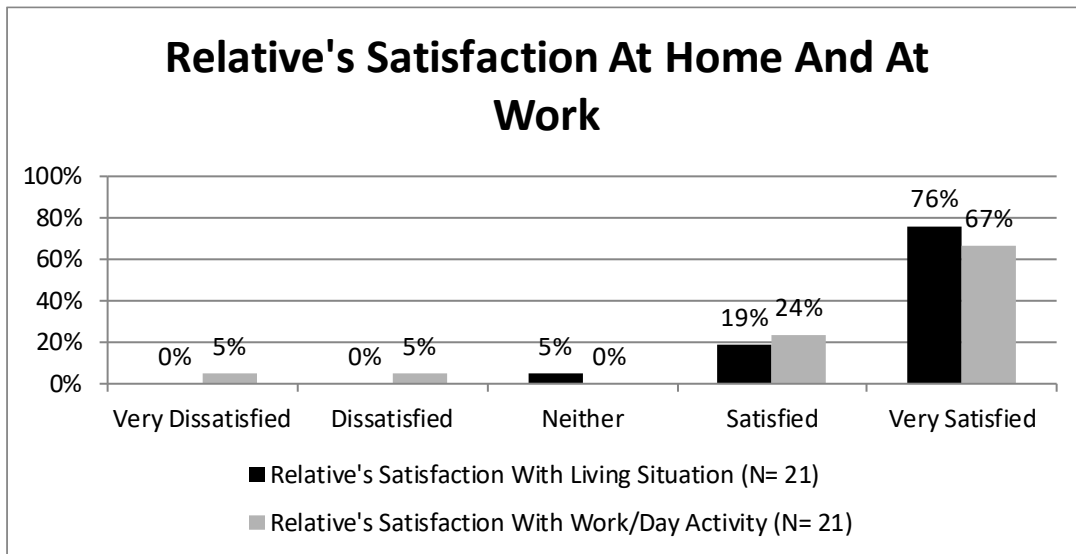
How Often Do You Contact/See Your Relative?

- 100% of the family/friend/guardians contacted their relative at least monthly (state finding 90%, regional 96%); 0% have not contacted their relative in the past year (state finding 3%, regional 0%).
- 100% 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 (state finding 83%, regional 87%); 0% did not get to see their relative in the past year (state finding 2%, regional 5%)

Your Relative's Satisfaction

- 95% of respondents felt their relative was either very satisfied or satisfied with his/her living situation (state finding 95%, regional 94%)
- 90% felt their relative was either very satisfied or satisfied with what they do during the day (state finding 91%, regional 90%)

- 100% of respondents felt their relative was either very satisfied or satisfied with the staff who support them at home (state finding 94%, regional 89%); 0% felt their relative was either dissatisfied or very dissatisfied (state finding 2%, regional 4%)
- 92% of respondents felt their relative was either very satisfied or satisfied with the staff who support them at work or during the day (state finding 96%, regional 95%); 0% felt their relative was either dissatisfied or very dissatisfied (state finding 2%, regional 3%)



Your Relative's Safety

- Respondents said that their relative felt safe in their community / home / neighborhood always (70%) or most of the time (25%). State findings were 85% and 12% respectively; 82% and 15% regional.

Your Relative's Opportunities

- 92% of the respondents said that their relative got enough opportunities to participate in activities in the community (state finding 84%, regional 88%)
- 91% of the respondents said that their relative seemed to have the opportunity to learn new things (state finding 89%, regional 86%)

Your Relative's Staff

- If their relative did not communicate verbally, 11% of the respondents said that there is a formal communication system in place for their relative and they use it (state finding 37%, regional 49%); for 100%, the communication system is used across all settings (state finding 82%, regional 85%).
- 50% of the respondents said that their relative's home appeared to have enough paid staff (state finding 85%, regional 87%)
- 100% of the respondents said that staff in their relative's home treat people with dignity and respect (state finding 96%, regional 96%)
- 75% of the respondents said that all staff appear to have the skills they need to support their relative, and 25% felt that way about only some staff (state finding 89% and 10% respectively; 89% and 11% regional)
- 100% of the respondents said that their relative's place of work appears to have an adequate number of paid staff (state finding 95%, regional 98%).
- 100% of respondents said that staff in their relative's place of work always treat people with dignity and respect (state finding 97%, regional 96%).
- 83% of respondents reported that staff in their relative's place of work appear to have the skills they need to support their relative (state finding 91%, regional 90%).

Your Relative's Supports

- 75% of relatives were satisfied with the supports coordination their relative receives (state finding 83%, regional 84%)
- 70% of relatives reported that they were told how much money is in their relative's annual budget (state finding 59%, regional 67%)
- 14% of relatives report that their relative self-directs their own services (state finding 7%, regional 10%).
- 50% said that their relative always received the supports they needed (state finding 68%, regional 68%)
- 65% said that the services and supports their relative receives change when their relative's needs change (state finding 84%, regional 84%)

- 94% of relatives always felt that the staff who assisted them with planning respected their choices and opinions (state finding 90%, regional 92%)
- 50% of relatives never felt that there were frequent changes in support staff at their family member's home, work or day program (state finding 52%, regional 53%)
- 11% of relatives always got to choose the agency/provider who worked with their relative (state finding 47%, regional 41%); 11% had their relative choose (state finding 7%, regional 4%); 56% chose with their relative (state finding 18%, regional 24%); 22% never got to choose (state finding 27%, regional 31%)
- 41% of relatives were familiar with the way complaints and grievances are handled at the provider level (state finding 59%, regional 57%). 41% of relatives were familiar with the way complaints and grievances are handled at the county/AE level (state finding 58%, regional 54%). 27% of relatives were familiar with the way complaints and grievances are handled at the state level (state finding 53%, regional 47%). 50% were not familiar of the grievance and complaint process on any level (state finding 36%, regional 38%)

Family Resources

- 89% of relatives felt that the information they received about their relative's services was easy to understand (state finding 91%, regional 88%)
- 17% of respondents had learned about the Life Course Framework and Tools (state finding 13%, regional 12%)
- 52% of relatives have an opportunity to connect and network with other families with relatives at similar life stages (state finding 48%, regional 47%)
- 29% of relatives said they were aware of the PA Family Network (state finding 22%, regional 26%); of those who were aware, 17% had attended a workshop led by the Network of Family Advisors (state finding 24%, regional 30%).
- 65% of relatives said that they have enough information about services for which their family is eligible (state finding 78%, regional 79%)
- 25% of respondents whose family member transitioned from school to adult services in the past year were happy with the process (state finding 28%, regional 22%)

- 61% of relatives report that the services coordinator asks about their vision for an everyday life for their family member (state finding 72%, regional 75%)

Emergency Preparation Questions

- 43% of relatives had someone talk to them about an emergency plan for their family member, in case of emergencies (state finding 57%, regional 52%)

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 90.67 with a standard deviation of 15.92 (state finding 91.32 and 13.60 respectively, 90.34 and 13.95 regional)

Summary

For a summary of the information collected through face-to-face interviews with the 118 individuals in Dauphin AE receiving supports through the Office of Developmental Programs, please refer to the two user-friendly reports produced for the AE. One version presents key data for both the AE and statewide in chart format. The other presents an abbreviated number of items using a more easily understandable icon format. Each AE receives each of these reports, along with the statewide report and two statewide user-friendly reports (one with charts, one with icons).