

Olmstead Quality of Life Survey

Third Follow-up Results Report

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Prepared by

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About this report

This report shows the Olmstead Quality of Life Third Follow-up Survey results. The survey asks questions that help the State of Minnesota learn how to better empower people with disabilities to be included in their communities. The purpose of the survey is to learn from Minnesotans with disabilities about what affects their quality of life and to track this over time.

The survey is part of Minnesota's Olmstead Plan, which we describe below. The survey is longitudinal, which means it measures how things change over the years by asking the same people questions each time. Doing so helps us see how people's lives change over time. People took the survey as a part of the Third Follow-up between June 2024 and October 2024. When possible, results are compared to what was found in previous rounds of the survey.

The Improve Group, working with the Olmstead Implementation Office and Quality of Life Survey Advisory Group, conducted the survey and wrote this report. The Improve Group is an evaluation consulting cooperative in St. Paul, Minnesota.

How to use this report

This report shows detailed survey results, which may be used to update the Olmstead Plan. Like everyone, the people who took the survey have many different parts to their lives. They told us about their families, friends, jobs, hobbies, and more. We know that what we learned from the survey is only a small part of their whole lives and experiences. It is important to remember this when looking at the results, so they are not used in overly general ways.

A certain population of people with disabilities in Minnesota took this survey. This survey was for people with disabilities who, at the time of the first survey (2017), were eligible to receive state-paid services in work or home settings that might keep them separate from others. These places are called "potentially segregated settings." In these settings, people might not be able to make many choices about their own lives. This means they might not get to choose where they live, who they live with, how often they see family and friends, and if they can go to work or school.

Important things to know about this report and survey:

- When we say "people" or "person" in this report, we mean people with disabilities who lived or worked in places that might keep them separate from others.
- Only people previously or currently eligible to live or work in potentially segregated settings took the survey. So, we can only show what we learned from them.
- We cannot use these results to talk about all people with disabilities in Minnesota.
- When we say "participants," we mean the people with disabilities who took the survey.

In the 2024 survey, 91% of respondents lived or worked in a segregated setting or received day services. Seventy-five percent had guardians. Just over half of respondents (51%) live in Community Residential Settings. The report shows results for different questions and for different groups of people. But it does not share additional context that was beyond the scope of the survey. Notably, the survey results tell us about relationships between factors, but they do not tell us why things are the way they are. Therefore, caution must be applied when drawing broad conclusions.

Thank you to everyone who made this survey possible, especially the 506 people who took the time to answer the survey. Without them, we could not have done this study.

Background

Many people with disabilities experience much of their lives segregated from the broader community. Some live or work in places that are potentially segregated. Potentially segregated settings are places where people live and work, identified in Minnesota's Olmstead Plan as having characteristics of institutions. This means people might not have control over where they live, who they live with, access to family and friends, and access to jobs or school. We say "potentially" because settings may be restrictive for one person but not for another.

People with disabilities have been demanding change for a long time. In 1999, there was an important legal case called [Olmstead v. L.C.](#) This case was about the rights of people with disabilities. The United States Supreme Court, the country's highest court, made an impactful decision. They said it is against the law for governments to keep people with disabilities separated from others if they choose to and can live in the community with support.

Lois Curtis and Elaine Wilson brought this case to court. They were people with disabilities who were living in an institution, even though health professionals said they could live in a community-based program. The Supreme Court decided that keeping people with disabilities unfairly separated from others went against a law called the [Americans with Disabilities Act](#). This decision meant that states had to offer services to people with disabilities in the most integrated setting. This included providing community-based services when possible. The Court also said it was important for governments to make plans to help more people with disabilities be part of their communities. This meant finding ways to include people with disabilities in everyday life, rather than keeping them separate.

Minnesota's Olmstead Plan

In 2009, plaintiffs who believed their family members were being maltreated at a program called Minnesota Extended Treatment Options filed a federal class action lawsuit named [Jensen et al v. Minnesota Department of Human Services](#). The lawsuit resulted in changes to the way people with disabilities are cared for and treated in

Minnesota. One part of the settlement, called the Jensen Settlement Agreement, required Minnesota to develop and implement an Olmstead Plan.

In 2013, Minnesota established the [Olmstead Subcabinet](#), which includes 12 state agencies and entities and the Metropolitan Council. The Olmstead Subcabinet works to make sure that the State of Minnesota follows the Minnesota Olmstead Plan. Developed by the Subcabinet and first approved in 2015, Minnesota's [Olmstead Plan](#) vision is that “people with disabilities are living, learning, working, and enjoying life in the most integrated setting.” The plan serves as a map to show how to reach this vision. Subcabinet members set goals to help make this happen. The plan is updated regularly, and a full update is planned for 2025 and 2026.

The Quality of Life Survey

Minnesota's Olmstead Plan says regular surveys should be done to better understand how people with disabilities are doing over time. The Olmstead Quality of Life Survey is the tool for this. Through the survey, participants share about how they engage with their communities, who makes decisions in their daily lives, how they perceive their quality of life in different areas, and about their closest relationships. The survey is longitudinal, meaning it tracks how responses change over time. This is the fourth time the survey has been done. The image below shows the four times the survey has been done.

Image 1. Olmstead Quality of Life (QoL) Survey timeline



The survey can be found in [Appendix A](#).

Brief methodology

This section briefly describes the survey methodology. The full methodology can be found in [Appendix B](#) for those who would like more information.

This report shares results from the fourth time we did the survey, the Olmstead Quality of Life Third Follow-up – 2024. The first survey in 2017 is called the Olmstead Quality of Life Baseline. It provided starting information about the quality of life for 2,005 people who took part. This starting information is called “Baseline data.” We did the survey

again in 2018, 2020, and 2024 with a smaller group of these people. These surveys are called the Olmstead Quality of Life First Follow-up – 2018, Olmstead Quality of Life Second Follow-up – 2020, and Olmstead Quality of Life Third Follow-up – 2024. In this report, we compare a smaller group's answers to their first answers from 2017. This helps us see if things have changed over time.

Designing the survey and process

This project follows the same group of people and asks the same set of questions over time. Because looking at change over time is a goal of this project, it is also important that we also keep consistent any practices that might influence results and who responds to the survey over time. That said, The Improve Group, along with the project Advisory Group, made two key changes to the Third Follow-up:

First, previous follow-up studies required guardians to sign a consent form on behalf of participants, when a guardian existed. Some guardians helped and supported respondents to be a part of the study. Other guardians prevented responses. The Third Follow-up is the first time that guardian consent was not required for participation. It has never been a legal requirement, and we wanted to provide an opportunity for all people to decide for themselves whether they wanted to participate. As is described below, The Improve Group did still communicate with many guardians, and many supported the Third Follow-up.

Second, previous follow-up studies had done outreach to a smaller group out of all Baseline participants. By the Third Follow-up, nearly one-quarter of Baseline participants were no longer eligible, because they had either passed away or moved out of Minnesota. Because of this, The Improve Group reached out to everyone who was still eligible for the study, rather than drawing a sample from remaining Baseline participants. We wanted to give as many people as possible a chance to participate, and to make sure enough people participated to be able to do meaningful analysis of groups.

Who could take the survey

To understand how to make Minnesota's Olmstead Plan better, people who might benefit most from changes took the survey. The answers from people with disabilities who have lived experience are very important. Their answers help us know if Minnesota's Olmstead Plan is working well.

The focus population for this survey is people in Minnesota with disabilities who were eligible to receive services in potentially segregated settings at the time of the first survey. A random sample of the focus population was selected to participate in the Baseline survey. This group includes people with all types of disabilities, including people with physical, cognitive, and intellectual disabilities. People can continue to participate in follow-up surveys if they still live in Minnesota.

How people took the survey

The Improve Group sent letters to all participants inviting them to take the survey. In addition, The Improve Group sent letters to people involved in the lives of participants, such as family, guardians, and providers. The letter notified them of the survey and encouraged them to support survey participants. The Improve Group made phone calls and sent emails to reach participants again after sending the letter.

Most surveys were taken in person where an interviewer asked the survey questions in a conversational way. A small number of participants chose to do the survey over the phone. No one took the survey without an interviewer.

Interviewers used a person-centered approach. This supported people to share their own experiences instead of having others answer for them. People who needed help taking the survey, such as people who do not use verbal or other expressive language, were able to get help from someone they know well to communicate their responses. Interviewers maintained a person-centered approach by confirming answers with participants after their support person's response. In some cases where a support person's answer differed from the participant's answer, interviewers recorded the participant's answers and continued directing questions to the participant.

In the survey, participants told us in their own words:

- What they do during the day
- Who their closest friends and family are
- How much they get to make decisions about their own lives
- How they feel about their life.

The survey did not explain what these things meant. This way, people could decide what these ideas meant to them. They could share their feelings about their life, even if others might disagree. The goal of the survey was for people with disabilities to lead the way in making decisions and shaping the systems that affect them.

Interviewers tried to make the survey easy for everyone to take. But it is important to know that some people experiencing the greatest oppression and segregation may not have been allowed to take the survey by people who had power over them. We made our best effort to connect with people directly, but there may have been gatekeepers – for example, some providers – who blocked access to people and decided for them that they could not take the survey. We know their views may be missing from the results.

Who completed the survey

Between June and October 2024, 506 people took the Third Follow-up – 2024 survey. Tables 1 through 12 below describe who participated. Some descriptions are demographic, such as how participants self-described their race and gender identities, their age groups, and location. Others describe factors related to participants' services, diagnoses, and program participation. In these tables, the columns labeled with "n"

share the number of participants in that subgroup. The columns labeled with “%” share the percentage, out of all participants for whom information about that topic is known, included in the subgroup.

The Improve Group used information in Tables 1 through 12 to explore similarities and differences across groups of people, and to learn more about which factors are related to a higher quality of life. Generally, demographic groups with fewer than 30 representatives have been excluded from subgroup analyses. This helps keep responses private and makes sure that a small number of people are not speaking for an entire subgroup inappropriately. We have also grouped some subgroups together, when meaningful and appropriate, to avoid small numbers. Descriptions of these groups are included below.

In Table 1, participants chose one or more racial or ethnic identities to describe themselves. Most participants are “white or Caucasian.” This is largely because the Baseline population was mostly white (86%), which was proportional to the eligible population at the time.

We did not have enough survey responses from participants of any race or ethnicity other than “white or Caucasian” to analyze the differences in survey responses for specific subgroups. Accordingly, for subgroup analyses, we combined participants who identified as “Black or African American,” “American Indian or Alaska Native,” “Asian,” “Native Hawaiian or Other Pacific Islander,” and/or “Hispanic or Latino,” into a “Black, Indigenous, or People of Color” group (BIPOC). We understand that there are sincere tradeoffs with this approach, especially as the BIPOC community is varied and diverse rather than monolithic. However, by combining participants who identified as non-“white or Caucasian,” we are still able to gather data on how participants of different racial identities may have different experiences in other areas of the survey.

Table 1. Participant race and ethnicity, as described by participants

Race and ethnicity	n	%
White or Caucasian	427	84%
American Indian or Alaska Native	29	6%
Black or African American	25	5%
Asian	10	2%
Hispanic or Latino	4	1%
Native Hawaiian or Other Pacific Islander	1	0%
Prefer to self-describe	10	2%
Prefer not to say	4	1%
Participant was unable to provide a response	12	2%

Table 2. Participant gender identity, as described by participants

Gender	n	%
Man	271	54%
Woman	219	43%
Non-binary	2	0%
Transgender	0	0%
Prefer to self-describe	2	0%
Prefer not to say	9	2%
Participant was unable to provide a response	3	1%

Table 3. Participant age, from Minnesota Department of Human Services (DHS) records

Age	n	%
34 and younger	81	16%
35 – 44	97	19%
45 – 54	101	20%
55 – 64	110	22%
65+	117	23%

As shown in Table 4, a high proportion of survey participants were never married. Because of this, we did not conduct subgroup analysis by marital status.

Table 4. Participant marital status, from DHS records

Marital status	n	%
Never married	459	91%
Divorced	35	7%
Married, living apart (separated)	8	2%
Legally separated	1	0%
Married, living with spouse	1	0%
Widowed	1	0%
Unknown	1	0%

Participant regions in Table 5 are based on DHS records for where participants live. The counties associated with each region are listed in [Appendix C](#).

Table 5. Participant region, from DHS records

Region	n	%
Metro	184	36%
Northwest	71	14%
Central	68	13%
Northeast	62	12%
Southwest	62	12%
Southeast	59	12%

DHS shared records about guardianship status from participants' most recent Developmental Disabilities (DD) Screening or Long-Term Care Screening. Guardianship is court appointed. Private guardians can be individuals, such as family members or friends, or non-profit or for-profit agencies. If an individual cannot access a private guardian, the courts appoint the DHS commissioner as the legal guardian, who then delegates day-to-day responsibilities to counties.

Table 6. Participant guardianship status, from DHS records

Guardianship status	n	%
Private guardianship	318	63%
No guardianship	91	18%
Public guardianship	56	11%
Other or unknown guardianship status	41	8%

Table 7. Participant home and community-based service waiver type, from DHS records

Waiver	n	%
Developmental Disability (DD)	307	61%
Community Access for Disability Inclusion (CADI)	121	24%
None	60	12%
Other	18	4%

Table 8. Participant home setting, as described by participants

Home setting	n	%
Community Residential Setting	255	51%
Family Foster Care	97	19%
Assisted Living	35	7%
Living with family, friends, or romantic partners	31	6%
Living independently (by self/alone)	23	5%
Intermediate care facility	13	3%
Supervised Living Facility	10	2%
Boarding Care	10	2%
Board and Lodging	9	2%
Nursing Home	9	2%
Transitional Housing	1	0%
Somewhere else	6	1%
Participant was unable to answer	3	1%

As a part of the survey, participants shared whether they are employed. For subgroup analyses, we combined anyone who said they were self-employed, in a job considered competitive employment, and/or in supportive employment (a community job with support staff) into “competitive, integrated employment.” Anyone who shared that they work in sheltered employment, a workshop, subminimum wage employment, work through a day habilitation program, and/or in an enclave or job crew had their responses combined into “sheltered or subminimum employment.”

Table 9. Participant employment type, as described by participants

Employment type	n	%
Sheltered employment, workshop employment, or subminimum wage employment	56	11%
Community job with support staff	44	9%
In an enclave or job crew	45	9%
Competitive employment	37	7%
Day Habilitation Program	20	4%
Pre-Vocational Program or Vocational Rehabilitation Program	5	1%
Self-Employed (has his or her own business)	7	1%
Other employment setting or vocational program	10	2%
No employment	290	57%

Table 10 shares whether participants receive day services, residential services, both, or neither. These service categories are informed by survey questions. In this context, residential services include everyone who shared that their home type is a family foster

care, assisted living, boarding and lodging, boarding care, community residential setting, intermediate care facility for a person with developmental disabilities, or nursing home. Day services include everyone who shared that they participate in an adult day program or non-vocational program, or work in a Day Habilitation Program (DT&H).

Table 10. Participant’s service type, by day and residential services, as described by participants

Service type	n	%
Residential services only	299	59%
Day and residential services	146	29%
Neither day nor residential services	44	9%
Day services only	17	3%

Table 11 shows the number of participants who have made a claim for a service related to substance use disorder, brain injury, autism, or dementia. DHS shared claim data from July 1, 2022 through June 30, 2024. Individual participants may have made claims related to none, one, or any combination of these four diagnoses.

Table 11. Participants with service claims related to specific diagnoses, from DHS records

Service claims	n	%
Dementia service claims	71	14%
Autism service claims	65	13%
Brain injury service claims	49	10%
Substance use disorder service claims	38	8%
None of the above	330	65%

Table 12 describes how many questions the participant answered during the interview. Survey interviewers tracked this information after completing each interview.

Table 12. Participant participation in the interview, as documented by survey interviewers

Participant interview participation	n	%
The participant was in the interview and answered all questions	260	51%
The participant was in the interview and answered most, but not all questions	95	19%
The participant was in the interview and answered about half of the questions	29	6%
The participant was in the interview and answered fewer than half of the questions	51	10%
The participant was in the interview but did not answer any questions	45	9%
The participant was not a part of the interview (the interview was conducted with a proxy)	26	6%

Survey interviewers also tracked how many people were present during the interview. Most often, the participant was alone with the interviewer (40%) or had one support person (44%). On average, 1.8 people were present (not including the interviewer). Support people played a variety of roles. Some actively listened in or participated in the interview conversations. Others left after getting participants and interviewers settled and making sure the conversation got off to a smooth start. Others were physically present but not actively participating. We understand that the presence of support people may influence how participants responded to some questions. However, this has been a factor for all Quality of Life Surveys and is not unique to the Third Follow-up. Interviewers did not notice any patterns in who or how the presence of others in the room influenced survey responses.

Survey results

The following includes the results from the Olmstead Quality of Life Third Follow-up Survey. We share results by major section within the survey and have included nearly all analysis conducted.

The Improve Group used different ways to understand the information participants shared to show:

- How people's lives changed over time
- What different groups of people experienced
- If things like race or age made a difference in experiences.

In most sections, we share the results of five types of analyses:

- Frequencies: This shares how many people selected a question's response option out of all people who responded to that question.

- Analysis of variance (ANOVA): This helps compare responses across different groups of people.
- T-test: This helps see how responses changed for people over time.
- Linear regression: This helps find out what things are connected to people's quality of life.
- Qualitative analysis: This looks at what people said in their own words on the survey. It helps find common ideas or feelings people shared.

How to read results

Consider the following when reading the results:

Many of the results we share are averages across groups. When we use the word “average,” that means we calculated the mean, or the mathematical average for the group.

Columns labeled “n” list the number of participants included in each group.

Sometimes we share frequencies, or the percentage of a group that selected a particular response. We rounded all percentages to the nearest whole percentage point. Because of this rounding, some totals may add up to slightly more or less than 100 percent. Columns with frequencies are labeled “%.”

To look at differences in groups, we did two analyses: analysis of variance (ANOVA) when comparing numeric results (participants’ average scores), and Pearson’s chi-squared when comparing how groups responded to a single question with categorical answers (like yes or no). These tests tell us if the differences in groups are real or due to chance. We ran these tests to look for differences across groups’ responses to the Third Follow-up Survey.

Running ANOVA and chi-squared tests result in p-values, which show the likelihood our results are due to chance. A smaller p-value means it is less likely that differences are due to chance. When our tests resulted in a p-value equal to or lower than 0.05, we included a sentence that says the test “found significant differences across 2024 averages by participant” above the results table.

We also did a test called a paired t-test. This test compares people’s responses over time. Like ANOVA, t-tests also give us p-values. This time, the p-value tells us if there is a significant difference in respondents’ average scores over time. We matched 2024 respondents to their 2017 responses and examined mean scores from both points in time.

Whenever we ran a t-test, we included columns with the “2017 average” and the “2024 average.” We then added a column labeled “significant,” where we wrote “no” for p-values higher than 0.05, and “yes” for p-values equal to or lower than 0.05. Only participants who had a score for both the Baseline and Third Follow-up are included in

these analyses. This is why the number in the “n” column will often be lower for paired t-tests than other results.

Lastly, we ran a regression analysis. We did this for each of the four survey sections: quality of life, social integration and engagement, decision-making power, and closest relationships. Participants answered a series of questions in each section, and their responses were translated into numeric scores. Regression analysis helps us understand which factors or characteristics affect these scores while accounting for other factors in the model. For example, regression analysis lets us test whether gender affects overall quality of life score, even for people living in different regions or with different types of jobs. We developed regression models with a number of potential factors to see which ones are important.

Each regression model includes several key pieces of information:

- Adjusted R squared: this number tells us how well the model fits our data. Fit means how close predicted values are to real observations. A higher number means the model is a better fit. Generally, an adjusted R squared of 0.5 means there is a good fit. A 0.2 means there is an OK fit. We shared all our results, even when the adjusted R squared was lower than 0.2.
- Terms: these are the factors or characteristics we input into the regression model. Some are numbers (for example, age) and others are categories (for example, gender).
- Estimate: this number tells us how much we think a factor might change the score. If it is positive, it means that as the value of the factor goes up, the score usually goes up, too. An estimate with a negative number suggests that as the factor increases, the score will tend to decrease. Not all terms have an estimate because one is used as a starting point for comparing to others.

Just like t-tests and ANOVA analyses, regression models give us p-values. Here we will have one p-value for each factor or characteristic (term) we looked at in the model. For tables with results of other tests, we wrote “yes” to p-values less than or equal to 0.05 to show when they pointed to significance. In the regression models tables, we included all p-values rather than “yes” or “no.” That is because the specific p-value may be more meaningful when reading a regression model (for example, if it is significant at the 0.05 level or 0.01).

While p-values and significance are an important piece to consider when thinking about the meaning of the results, they are just one piece. Just because one result is statistically significant does not necessarily mean that it is more important than another result. Similarly, if a test does not result in statistical significance, that does not mean it is meaningless. Accordingly, while we do share results from all analyses we ran, all results should be considered together when drawing meaning.

Quality of life

The Perceived Quality of Life Inventory was used to show how people feel about their lives. Participants answered questions about 15 parts of their lives, like their health, happiness, and comfort. They used a scale from "very bad" to "very good." Participants were not told what "bad" or "good" meant. Instead, people could use their own ideas and experiences to answer.

For comparison and data analysis, we turned all the answers into one score out of 100. This helped us understand the results better. Here is how it worked:

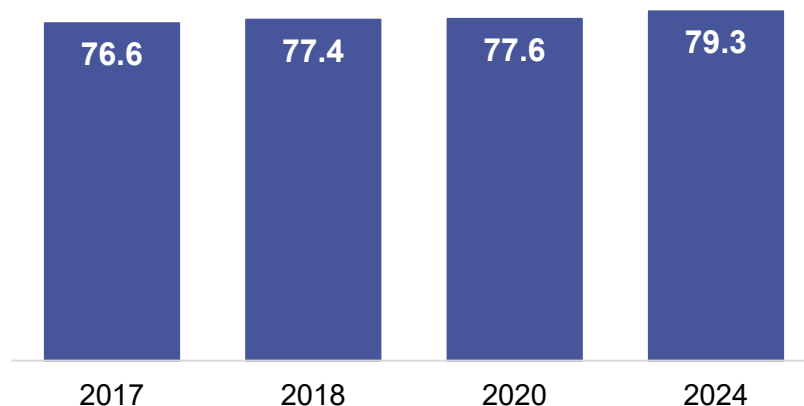
1. We looked at how each person rated the different parts of their life.
2. We took the average of those ratings.
3. Then we changed that average into a score out of 100.

We used 14 out of the 15 questions about perceived quality of life to calculate the score. People only got a score if they answered at least five of the 14 questions. If they answered fewer than five, we did not make a score for them. A higher score (closer to 100) means the person thought they had a better quality of life. A lower score (closer to 0) means they thought their quality of life was not as good.

Average overall quality of life scores for each year of the survey

Image 2 shows the average score for each year based on all participants' answers in that year. The score is out of 100.

Image 2. Participants' average quality of life score has increased slightly since the Baseline study.



Average overall quality of life scores from Baseline to Third Follow-up

We matched all participants in the Third Follow-up study to their Baseline Quality of Life score. If a participant had an average score for the Baseline and the Third Follow-up, we compared them. The 474 participants in this group had an average Baseline score of 77.8 and a Third Follow-up average score of 79.3. A t-test determined this increase was statistically significant.

Average quality of life ratings for all inventory items at Baseline and all Follow-ups

Table 13 lists the average rating for all Perceived Quality of Life Inventory items for each survey. Each average includes all participants from that year's survey. All averages are out of a possible maximum score of 5.

Table 13. Average quality of life ratings for all inventory items at Baseline and all Follow-ups

Inventory item	2017 average rating	2018 average rating	2020 average rating	2024 average rating
Safety	4.2	4.3	4.4	4.3
Treatment by staff/attendants	4.2	4.2	4.3	4.3
Privacy	4.2	4.2	4.3	4.3
Health care	4.3	4.3	4.4	4.3
Family relationships	4.1	4.1	4.2	4.2
Relationships with friends	4.1	4.1	4	4.2
Food	4.1	4.2	4.2	4.2
Happiness	4.1	4.1	4	4.2
Comfort	4.1	4.2	4.2	4.2
What I do all day	4	4	3.9	4.1
Getting out and getting around	3.9	3.9	3.5	4
Health	3.9	3.9	4	4
Running my own life, making choices	3.8	3.8	3.9	3.9
Overall quality of life	4.1	4.1	4.1	4.2
Overall inclusion in the broader community outside your home	Not asked	Not asked	Not asked	4

Average quality of life scores for demographic subgroups

Tables 14 through 21 share average quality of life scores by demographic subgroups. For each table, we only included subgroups which have 30 or more participants. This avoids having a small number of people's responses speak for an entire subgroup.

We did two types of analyses for demographic subgroups. First, we ran ANOVA tests to look for differences in average scores by group from the 2024 survey results. We included a sentence above each table about whether the ANOVA found significant differences across groups. When there are more than two subgroups, there are limits to what the ANOVA can tell us. The ANOVA can tell us whether there are significant differences between at least two groups, but not which specific groups they are. Further testing would be needed to find which specific groups are different.

Secondly, we ran t-tests to look for differences in responses over time by subgroup. To do this, we matched each participant to their Baseline score. We only include respondents who have a score at the Baseline and Third Follow-up in these analyses. The t-test looks for differences between Baseline (2017) scores and Third Follow-up (2024) scores. We wrote "yes" or "no" in the "significant" column depending on if the t-test found statistically significant differences in average scores between 2017 and 2024.

Refer to the "How to read results" section of this report on page 15 for more details about the tests we ran and how to read these tables.

Table 14. Average 2024 quality of life scores for white- and BIPOC-identified participants

The ANOVA test found a significant difference between 2024 average quality of life scores for white and BIPOC participants, finding white participants to have a better quality of life.

Race and ethnicity	n	2024 Average
White	406	80.1
BIPOC	69	75.3

Table 15. Comparison of 2017 Baseline average and 2024 Follow-up average quality of life score for white- and BIPOC-identified participants

Race and ethnicity	n	2017 Average	2024 Average	Significant
White	387	77.5	79.9	Yes
BIPOC	68	77.9	75.2	No

Table 16. Average quality of life score by gender

The ANOVA test did not find a significant difference between 2024 average quality of life scores by gender.

Gender	n	2024 Average
Male	265	80.0
Female	213	79.1

Table 17. Comparison of 2017 Baseline average and 2024 Follow-up average quality of life score by gender

Gender	n	2017 Average	2024 Average	Significant
Male	255	78.3	79.8	No
Female	203	77.0	79.0	No

Table 18. Average quality of life score by age

The ANOVA test found significant differences across 2024 average quality of life scores by age. This test does not tell us which age group(s) are significantly different from others.

Age	n	2024 Average
34 and younger	80	79.0
35 – 44	96	77.8
45 – 54	98	79.2
55 – 64	106	81.8
65+	114	78.4

Table 19. Comparison of 2017 Baseline average and 2024 Follow-up average quality of life score by age

Age	n	2017 Average	2024 Average	Significant
34 and younger	76	80.1	78.7	No
35 – 44	93	76.1	77.4	No
45 – 54	94	78.1	78.8	No
55 – 64	103	78.2	81.7	Yes
65+	108	76.6	78.6	No

Table 20. Average quality of life score by region

The ANOVA test found significant differences across 2024 average quality of life scores by region. This test does not tell us which region(s) are significantly different from others.

Region	n	2024 Average
Central	68	77.3
Metro	179	78.3
Northeast	61	83.1
Northwest	68	77.4
Southeast	57	82.3
Southwest	61	79.7

Table 21. Comparison of 2017 Baseline average and 2024 Follow-up average quality of life score by region

Region	n	2017 Average	2024 Average	Significant
Central	65	74.9	77.3	No
Metro	174	76.7	78.1	No
Northeast	60	78.3	83.1	Yes
Northwest	65	78.6	77.4	No
Southeast	50	80.5	81.7	No
Southwest	60	79.7	79.8	No

Subgroup average quality of life scores at Third Follow-up

We explored differences in average 2024 quality of life ratings by subgroups related to factors including guardianship status, home setting and services, employment, and the extent to which interview questions were answered by the participant or a proxy. We did not compare these groups to their Baseline averages, like we did for demographic subgroups shared above, because participants are more likely to have changed groups over time. Tables 22 through 31 show these results.

For each subgroup analysis, we ran an Analysis of Variance test (ANOVA), which is a statistical test that tells us whether there are significant differences in average responses across subgroups. We included a sentence above each table about whether the ANOVA test found significant differences across groups. When there are more than two subgroups, there are limits to what ANOVA tests can tell us. ANOVA tests can tell us whether there are significant differences between at least two groups, but not which specific groups. Further testing would be needed to find which specific groups are different.

Refer to the “How to read results” section of this report on page 15 for more details about ANOVA tests.

ANOVA testing found significant differences across subgroup average quality of life scores by waiver type, employment type, and whether participants had claims for services related to substance use disorders, brain injury, or dementia (Tables 22 through 26). ANOVA testing did not find significant differences across subgroups by guardianship status, home setting, service type, how the participant participated in the interview, or whether the participant had claims for services related to autism (Tables 27 through 31). All service claim data was for claims between July 1, 2022 and June 30, 2024. Individual participants may have made claims related to none, one, or any combination of the four diagnoses included in analysis.

Table 22. Average quality of life score by home and community-based service waiver type

The ANOVA test found significant differences across 2024 average quality of life scores by waiver type. This test does not tell us which waiver type(s) are significantly different from others.

Waiver	n	2024 Average
CADI	121	77.0
DD	298	81.2
None	57	75.2

Table 23. Average quality of life score by employment type

The ANOVA test found significant differences across 2024 average quality of life scores by employment type. This test does not tell us which employment type(s) are significantly different from others.

Employment type	n	2024 Average
No employment	281	77.8
Competitive, integrated employment	85	80.4
Sheltered or subminimum employment	107	82.1

Table 24. Average quality of life score of respondents with and without service claims related to substance use disorder

The ANOVA test found significant differences between 2024 average quality of life scores by substance use disorder service claims status, finding participants without substance use disorder service claims to have a better quality of life.

Substance use service claims status	n	2024 Average
With substance use disorder service claims	38	71.9
Without substance use disorder service claims	455	79.8

Table 25. Average quality of life score of respondents with and without service claims related to brain injury

The ANOVA test found significant differences between 2024 average quality of life scores by brain injury service claims status, finding participants without brain injury service claims to have a better quality of life.

Brain injury service claims status	n	2024 Average
With brain injury service claims	49	74.6
Without brain injury service claims	444	79.7

Table 26. Average quality of life score of respondents with and without service claims related to dementia

The ANOVA test found significant differences between 2024 average quality of life scores by dementia service claims status, finding participants without dementia service claims to have a better quality of life.

Dementia service claims status	n	2024 Average
With dementia service claims	69	75.3
Without dementia service claims	424	79.9

Table 27. Average quality of life score by guardianship status

The ANOVA test did not find significant differences across 2024 average quality of life scores by guardianship status.

Guardianship status	n	2024 Average
Private	309	80.4
Public	54	78.7
None	90	78.3

Table 28. Average quality of life score by home setting

The ANOVA test did not find significant differences across 2024 average quality of life scores by home setting.

Home setting	n	2024 Average
Family Foster Care	96	79.1
Assisted Living	34	74.7
Community Residential Setting	246	80.4
Living independently (by self/alone) or living with family, friends, or romantic partner	54	81.3

Table 29. Average quality of life score by service type

The ANOVA test did not find significant differences across 2024 average quality of life scores by service type.

Service type	n	2024 Average
Residential services only	290	78.2
Day and residential services	143	81.2
Neither day nor residential services	44	78.5

Table 30. Average quality of life score by participant interview participation

The ANOVA test did not find significant differences across 2024 average quality of life scores by whether the participant or a proxy answered most survey questions.

Participant's interview participation	n	2024 Average
The participant was in the interview and answered all or most questions	345	78.9
The participant was in the interview and answered half or fewer than half the questions	75	80.5
The participant was not a part of the interview (the interview was conducted with a proxy)	70	79.3

Table 31. Average quality of life score of respondents with and without service claims related to autism

The ANOVA test did not find significant differences between 2024 average quality of life scores by autism service claims status.

Autism service claims status	n	2024 Average
With autism service claims	61	78.2
Without autism use disorder service claims	432	79.4

Regression analysis of quality of life scores

Regression analysis helps us understand which factors or characteristics might affect quality of life scores. We ran a regression model with the 29 factors (terms) listed in Table 32 to learn more about how each affects quality of life scores.

For each term that has categories (as opposed to a number, like age), we use one category as a reference group. A reference group is what we compare the other groups to. For example, in Table 32, “competitive employment” is the reference group for employment. We are comparing the scores for the categories “no employment” and “sheltered employment” to the score for “competitive employment.” Reference groups are those that do not have an estimate or p-value listed in Table 32.

We ran ANOVA tests for these same factors to explore significance across subgroups. ANOVA test results are in the previous section. The ANOVA tests consider each factor individually. The advantage of running them all in the same regression model is that the regression considers the factors together and helps to show which ones stand out while adjusting for the other factors in the model. Accordingly, some factors – including race and ethnicity, age, region, waiver type, and employment type – were found to be statistically significant in the ANOVA test but not in the regression. These differences are expected and do not mean that these factors are not important in quality of life scores.

Refer to the “How to read results” section of this report on page 15 for more details about regression models and reading results.

Regression analysis results in an adjusted R squared value, which tells us how well our data fits with what the model predicts. The regression model for quality of life resulted in an adjusted R squared of 0.21. This means the factors included in our model do help explain why someone rated their quality of life the way they did but that other meaningful factors are missing.

The model confirmed that there are several factors that have a significant impact on the quality of life score in the Third Follow-up. Most notably, a participant’s 2017 Baseline quality of life score will predict their score in 2024. Their 2024 activities interaction score and decision control index scores were also important in predicting their quality of life. As each of these scores increase for a person, we predict their quality of life score will increase, too.

Table 32. Regression analysis of characteristics associated with quality of life scores in the Third Follow-up

Adjusted R squared: 0.21

Term	Estimate	P-Value
(Intercept)	31.8	<0.001
Age	0.1	0.16
Sex (Female)	--	--
Sex (Male)	0.6	0.63
Race (BIPOC)	--	--
Race (White or Caucasian)	3.4	0.07
Region (Central)	--	--
Region (Metro)	1.2	0.57
Region (Northeast)	3.0	0.26
Region (Northwest)	-1.8	0.46
Region (Southeast)	-0.1	0.96
Region (Southwest)	-1.5	0.55
Waiver (CADI)	--	--
Waiver (DD)	0.6	0.75
Waiver (None)	-2.7	0.29
Waiver (Other)	-2.2	0.56
Home Type (Family Foster Care)	--	--
Home Type (Assisted Living)	-3.2	0.30
Home type (Community Residential Setting)	-1.2	0.49
Home type (Living independently)	-2.8	0.27
Home type (Other)	-5.7	0.02
Employment Type (Competitive)	--	--
Employment Type (No Employment)	-0.5	0.78
Employment Type (Sheltered)	1.3	0.52
Guardianship Status (No Guardian)	--	--
Guardianship Status (Has Guardian)	2.0	0.28
2024 Activities Interaction Score	0.1	0.004
2024 Decision Control Score	0.1	0.007
2024 Number of Close Relationships (up to 5)	0.3	0.53
2017 Baseline Quality of Life Score	0.4	<0.001

What would improve quality of life

Participants answered the question, “What three things would improve your quality of life?” The following are the themes from responses to this question. Themes are listed in order of frequency they were mentioned. The number in parentheses shows how many

participants gave that answer. When interpreting this data, it is important to keep in mind that more frequent themes do not necessarily mean something is more important for improving quality of life. These themes represent ideas for improvements directly from participants and describe how individuals may perceive their own quality of life.

More access to leisure activities (n=138)

Participants said that having more access to or being able to spend more time on activities they enjoy doing would improve their quality of life. For example, participants said they want to go to restaurants or the movies, play games, watch or play sports, collect items, do outdoor activities, or go on vacations. These activities varied based on individuals' interests and hobbies, and this theme describes how people wish to spend their free time or other resources.

Closer personal relationships (n=103)

Participants said that having better relationships with people they care about would improve their quality of life. Some participants named specific people in their life they wish to spend more time with. Other participants said they want to socialize more with other people in general. Some participants expressed desire for a romantic partner.

Changes to living situation (n=99)

Participants expressed that changes to their living situation would improve their quality of life. Some examples included moving to a different location to be closer to family, living independently, or moving in with a partner or friend. Some participants mentioned dissatisfaction with current housemates or lack of privacy.

Most participants who shared these responses have public or private guardians. However, the share of participants without guardians who said they want changes to their living situations is larger than the share of participants without guardians in the overall group of survey respondents. Most people who said a change in living situation would improve quality of life identified as male.

More opportunities to be out in communities (n=90)

Participants said they wanted more opportunities to be involved in and interact with other people in their communities. While some participant responses in this theme overlap with leisure activities, this theme is distinct in describing the need for community integration. Many participants generally asked for more opportunities to interact with others outside of their homes and be integrated into their communities. Some participants named specific community places they want to visit more, such as church, the library, and local stores. Others named specific community events they want to be part of, like going to the Minnesota State Fair. Some participants said they'd like to volunteer more or have jobs in the community. Some named barriers to spending more time in the community, like lack of transportation and inaccessible public spaces.

Better program staffing and capacity (n=84)

Participants said that changes to their program staff and/or capacity could improve their quality of life. Participants expressed dissatisfaction with staffing shortages and high staff turnover, which limits participants' freedom or ability to do activities. Some participants expressed desire for more funding and staff capacity to organize group activities.

More freedom to make decisions (n=69)

Participants said that having more freedom to make choices would improve their quality of life. Some participants expressed a desire to make more decisions about daily choices like types or amount of food, preparing their own meals, and when they would like to do certain activities. Some participants expressed a desire for more autonomy in general, like choosing to live independently or spend more time alone. Most participants who expressed a desire for more autonomy and freedom identified as male.

Better personal health and well-being (n=64)

Participants said improvements to their personal health status and well-being would improve their quality of life. Many participants stated personal health goals, like losing weight, exercising more, eating healthier, and sleeping better. Some participants expressed desire for changes that are specific to their disability, like being pain-free, being able to walk or see, and transitioning away from taking certain medications.

More access to transportation (n=60)

Participants said more accessible and flexible transportation would improve their quality of life. Many participants said their independence is limited by needing to rely on staff caregivers or other people for rides. Some asked for more frequent and accessible public transportation, while others expressed a desire to learn to drive themselves.

Better financial security (n=50)

Participants said more financial security would improve their quality of life. Many participants expressed desire for more money in general, while others said having more money would help them do more of the activities they enjoy. Some participants said the income and savings limits of disability benefits are barriers in their lives. Most responses about wanting better financial security come from participants who are not currently employed.

Improvements to healthcare, health insurance, and medical devices or assistive technology (n=49)

Participants said having better healthcare, benefits, and devices or technology to support their disability would improve their quality of life. Many participants asked for specialized therapies to support their disability, like physical therapy, speech therapy, or equine therapy. Some participants expressed the need for basic dental care, and others expressed a desire for more flexible use of their current health insurance. Some participants expressed a need for certain medical devices or assistive technology.

More opportunities to work (n=39)

Participants said that having more opportunities to work would improve their quality of life. Many participants who don't work said they wished they could have a job. Some participants who currently have a job expressed a desire to change jobs or have more options in the type of work they do.

More accessible public spaces (n=27)

Participants said more accessible public spaces would improve their quality of life. Many participants asked for more accessibility in public spaces, like accessible restrooms, guardrails, ramps, and safety pathways on roads or sidewalks.

Pet companions (n=25)

Participants expressed a desire to have pets or spend more time with animals.

More access to standard technology (n=14)

Participants said having more access to technology would improve their quality of life. Examples included having access to a cell phone, laptop, or internet.

More education opportunities (n=11)

Participants expressed a desire for more education opportunities, like learning to read, write, and do math. Some participants said they would like to go to college.

More access to culturally specific activities (n=6)

Participants expressed a desire to have more access to cultural events. In particular, participants who are members of Tribal Nations wanted to be able to attend powwows and other events in their Native communities.

Decision-making control

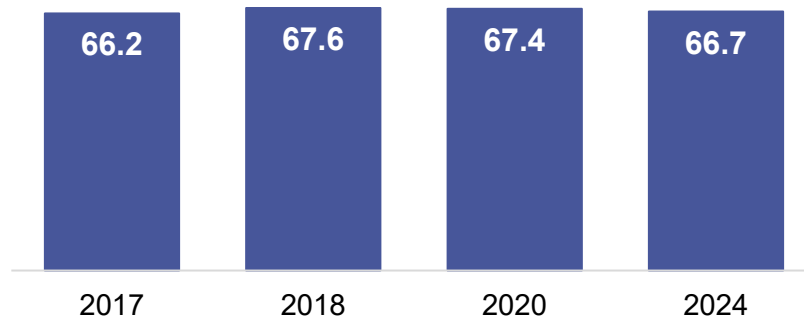
The Decision Control Inventory measured how much people get to choose what they do. Participants answered questions about who makes decisions in different areas of their lives. They had the options to say if the paid staff made the decision, if they and/or people they choose made the decision, or if it was somewhere in between.

The answers to these questions were turned into a decision control score in the form of a number out of 100. To get a score, a person had to answer at least 25 out of 34 questions. The answers were averaged to get one score. Then, this score was adjusted to fit on a 100-point scale to make it easier to understand. A higher score means that participants and/or the people they choose make more choices. A lower score means paid staff make more choices for the participants.

Average decision control scores for each year of the survey

The average for each year is based on all participants' answers in that year. All scores are out of 100.

Image 3. The average decision control score for participants has stayed about the same over time.



Average decision control scores from Baseline to Third Follow-up

We matched all participants in the Third Follow-up study to their Baseline decision control scores. We then compared average scores for only the participants who had scores in both the Baseline and at the Third Follow-up. The 484 participants in this group had an average Baseline score of 65 and a Third Follow-up average score of 66.7. A t-test determined this increase was not statistically significant.

Average Decision Control Inventory ratings for all items at the Third Follow-up

Table 33 includes all 35 index items in the Decision Control Inventory. The items are different decisions that participants encounter in their lives. Participants rated each item on a five-point scale. One meant that all decisions were made by paid staff, and five meant that the participant and/or chosen supporters made all the decisions. Items are listed in order from the lowest-rated on average to highest-rated on average, out of a possible total rating of five.

Table 33. Average Decision Control Inventory ratings for all items

Inventory items	n	2024 Average
Choice of support personnel: option to hire and fire support personnel	434	1.7
Choice of agency's support persons/staff	421	2.1
How to spend residential funds	402	2.2
Choice of people to live with	464	2.2
Who your case manager is	409	2.4
Type of transportation to and from day program or job	341	2.5
What foods to buy for the home when shopping	490	2.7
Whether to have pet(s) in the home	442	2.7
How to spend day activity funds	318	2.8
Who goes with you on trips, errands, outings	476	3.1
What to have for dinner	492	3.1
Choice of furnishings and decorations in the home	481	3.2
Amount of time spent working or at day program	332	3.4
Which service agency to work with	424	3.4
Choice of places to go	481	3.7
Type of work or day program	357	3.7
Choice of house or apartment	471	3.7
What to have for breakfast	484	3.8
When and how often bathe or shower	493	3.9
Choosing restaurants when eating out	465	4
What to do with personal funds	480	4.1
'Minor vices,' such as use of tobacco, alcohol, caffeine, explicit magazines, etc.	391	4.3
Who you hang out with in and out of the home	467	4.3
Visiting with friends who live outside of the person's residence	416	4.3
When to get up on weekends	493	4.4
Express affection, including sexual	434	4.4
What clothes to buy in store	491	4.4
When to go to bed on weekdays	494	4.4
When to go to bed on weekends	494	4.5
What clothes to wear on weekends	494	4.5
What clothes to wear on weekdays	494	4.5
When, where, and how to worship	451	4.6
Choosing to decline to take part in group activities	465	4.6
Taking naps in evenings and on weekends	474	4.7
What to do with relaxation time, such as choosing TV, music, hobbies, outings, etc.	493	4.7

Average decision control scores for demographic subgroups

Tables 34 through 41 share average decision control scores by demographic subgroups. For each table, we only included subgroups which had 30 or more participants. This helps avoid having a small number of people's responses speak for an entire subgroup.

We did two types of analyses for demographic subgroups. First, we ran ANOVA tests to look for differences in average scores by group in 2024 results. We included a sentence above each table about whether the ANOVA test found significant differences across groups. When there are more than two subgroups, there are limits to what ANOVA tests can tell us. ANOVA tests can tell us whether there are significant differences between at least two groups, but not which specific groups. Further testing would be needed to find which specific groups are different.

Secondly, we ran t-tests to look for differences in responses over time by subgroup. To do this, we matched each participant to their Baseline score. We only include respondents who have a score at the Baseline and Third Follow-up in these analyses. The t-test looks for differences between Baseline (2017) scores and Third Follow-up scores (2024). We wrote "yes" or "no" in the "significant" column depending on whether the t-test found statistically significant differences in average scores between 2017 and 2024.

Refer to the "How to read results" section of this report on page 15 for more details about the tests we ran and how to read these tables.

Table 34. Average 2024 decision control score for white- and BIPOC-identified participants

The ANOVA test did not find significant difference between 2024 average decision control scores for white and BIPOC participants.

Race and ethnicity	n	2024 Average
White	407	66.6
BIPOC	70	69.0

Table 35. Comparison of 2017 Baseline average and 2024 Follow-up average decision control score for white- and BIPOC-identified participants

Race and ethnicity	n	2017 Average	2024 Average	Significant
White	395	65.2	66.5	No
BIPOC	70	64.9	69.0	No

Table 36. Average decision control score by gender

The ANOVA test did not find significant differences between 2024 average decision control scores by gender.

Gender	n	2024 Average
Male	266	67.3
Female	215	66.2

Table 37. Comparison of 2017 Baseline average and 2024 Follow-up average decision control score by gender

Gender	n	2017 Average	2024 Average	Significant
Male	258	65.3	67.3	No
Female	211	64.6	66.1	No

Table 38. Average decision control score by age

The ANOVA test found significant differences across 2024 average decision control scores by age. This test does not tell us which age group(s) are significantly different from others.

Age	n	2024 Average
34 and younger	81	66.7
35 – 44	96	70.0
45 – 54	97	67.3
55 – 64	108	67.7
65+	114	62.3

Table 39. Comparison of 2017 Baseline average and 2024 Follow-up average decision control score by age

Age	n	2017 Average	2024 Average	Significant
34 and younger	78	65.1	66.7	No
35 – 44	94	65.8	70.1	Yes
45 – 54	94	64.8	66.7	No
55 – 64	107	65.4	67.8	No
65+	111	64.1	62.4	No

Table 40. Average decision control score by region

The ANOVA test found significant differences across 2024 average decision control scores by region. This test does not tell us which age region(s) are significantly different from others.

Region	n	2024 Average
Northwest	70	60.1
Northeast	60	69.7
Southeast	59	62.8
Southwest	62	68.0
Metro	177	68.7
Central	68	67.7

Table 41. Comparison of 2017 Baseline average and 2024 Follow-up average decision control score by region

Region	n	2017 Average	2024 Average	Significant
Northwest	69	61.0	60.4	No
Northeast	59	63.9	69.4	Yes
Southeast	54	63.9	62.6	No
Southwest	61	64.4	67.8	No
Metro	174	67.7	68.7	No
Central	67	64.3	67.3	No

Subgroup average decision control scores at Third Follow-up

We explored differences in average 2024 decision control scores by subgroups related to factors including guardianship status, home setting and services, employment, and the extent to which interview questions were answered by the participant or a proxy. We did not compare these groups to their Baseline averages like we did for demographic subgroups shared above because participants are more likely to have changed groups over time. Tables 42 through 51 show these results.

For each subgroup analysis, we ran an Analysis of Variance test (ANOVA), which is a statistical test that tells us whether there are significant differences in average responses across subgroups. We included a sentence above each table about whether the ANOVA test found significant differences across groups. When there are more than two subgroups, there are limits to what ANOVA tests can tell us. ANOVA tests can tell us whether there are significant differences between at least two groups, but not which specific groups. Further testing would be needed to find which specific groups are different.

Refer to the “How to read results” section of this report on page 15 for more details about ANOVA tests.

ANOVA testing found significant differences across subgroup average decision control scores by guardianship status, waiver type, home setting, employment type, service type, how the participant participated in the interview, and whether participants had claims for services related to dementia (Tables 42 through 48). ANOVA testing did not find significant differences across subgroups by whether the participant had service claims for services related to substance use disorders, brain injury, or autism (Tables 49 through 51). All service claim data was for claims between July 1, 2022 and June 30, 2024. Individual participants may have made claims related to none, one, or any combination of the four diagnoses included in analysis.

Table 42. Average decision control score by guardianship status

The ANOVA test found significant differences across 2024 decision control scores by guardianship status. This test does not tell us which guardianship group(s) are significantly different from others.

Guardianship status	n	2024 Average
Private	311	65.2
Public	56	59.5
None	90	73.8

Table 43. Average decision control score by home and community-based service waiver type

The ANOVA test found significant differences across 2024 decision control scores by waiver type. This test does not tell us which waiver type(s) are significantly different from others.

Waiver	n	2024 Average
CADI	119	71.7
DD	300	64.9
None	60	66.1

Table 44. Average decision control score by home setting

The ANOVA test found significant differences across 2024 decision control scores by home setting. This test does not tell us which setting type(s) are significantly different from others.

Home setting	n	2024 Average
Family Foster Care	97	65.0
Assisted Living	33	72.9
Community Residential Setting	249	62.9
Living independently (by self/alone) or living with family, friends, or romantic partner	53	84.1

Table 45. Average decision control score by employment type

The ANOVA test found significant differences across 2024 decision control scores by employment type. This test does not tell us which employment type(s) are significantly different from others.

Employment type	n	2024 Average
No employment	284	65.2
Competitive, integrated employment	85	73.2
Sheltered or subminimum employment	108	65.9

Table 46. Average decision control score by service type

The ANOVA test found significant differences across 2024 decision control scores by service type. This test does not tell us which service type(s) are significantly different from others.

Service type	n	2024 Average
Residential services only	292	65.6
Day and residential services	144	62.5
Neither day nor residential services	43	83.2

Table 47. Average decision control score by participant interview participation

The ANOVA test found significant differences across 2024 decision control scores by whether the participant or a proxy answered most survey questions. This test does not tell us which respondent group(s) are significantly different from others.

Participant's interview participation	n	2024 Average
The participant was in the interview and answered all or most questions	344	69.4
The participant was in the interview and answered half or fewer than half the questions	75	62.8
The participant was not a part of the interview (the interview was conducted with a proxy)	73	57.0

Table 48. Average decision control score of respondents with and without service claims related to dementia

The ANOVA test found significant differences between 2024 decision control scores by dementia service claims status, finding participants without dementia services claims to have higher scores.

Dementia service claims status	n	2024 Average
With dementia service claims	68	61.9
Without dementia service claims	447	67.4

Table 49. Average decision control score of respondents with and without service claims related to substance use disorder

The ANOVA test did not find significant differences between 2024 decision control scores by substance use disorder service claims status.

Substance use service claims status	n	2024 Average
With substance use disorder service claims	38	68.1
Without substance use disorder service claims	457	66.5

Table 50. Average decision control score of respondents with and without service claims related to brain injury

The ANOVA test did not find significant differences between 2024 decision control scores by brain injury service claims status.

Brain injury service claims status	n	2024 Average
With brain injury service claims	48	66.4
Without brain injury service claims	447	66.7

Table 51. Average decision control score of respondents with and without service claims related to autism

The ANOVA test did not find significant differences between 2024 decision control scores by autism service claims status.

Autism service claims status	n	2024 Average
With autism service claims	65	67.1
Without autism use disorder service claims	430	66.6

Regression analysis of decision control scores

Regression analysis helps us understand which factors or characteristics might affect decision control scores. We ran a regression model with the 29 factors (terms) listed in Table 52, to learn more about how each affects decision control scores.

For each term that has categories (as opposed to a number, like age), we use one category as a reference group. A reference group is what we compare the other groups to. For example, in Table 52, “competitive employment” is the reference group for employment. We are comparing the scores for the categories “no employment” and “sheltered employment” to the score for “competitive employment.” Reference groups are those that do not have an estimate or p-value listed in Table 52.

We ran ANOVA tests for these same factors to explore significance across subgroups. ANOVA test results are in the previous section. The ANOVA tests consider each factor individually. The advantage of running them all in the same regression model is that the regression considers the factors together and helps to show which ones stand out while adjusting for the other factors in the model. Accordingly, some factors, including age, region, waiver type, and employment type, were found to be statistically significant in the ANOVA test but not in the regression. These differences are expected and do not mean that these are not important factors in decision control scores.

Refer to the “How to read results” section of this report on page 15 for more details about regression models and reading results.

Regression analysis results in an adjusted R squared value, which tells us how well our data fits with what the model predicts. This model resulted in an adjusted R squared value of 0.27. This means the factors included in our model do help explain why someone rated their decision-making control the way they did but that other meaningful factors are missing.

Our model found several factors to have a significant impact on decision control scores. Notably, a participant’s 2017 Baseline decision control score, as well as their 2024 Follow-up quality of life score, activities interaction score, and the number of close relationships are all associated with their 2024 decision control score.

Guardianship status and home type also influence 2024 decision control score. We see that having a guardian will result in a decrease of 5 in their decision control score compared to not having a guardian. Living independently is very strongly associated with a higher decision control score, as is assisted living (compared to adult foster care).

Table 52. Regression analysis of characteristics associated with respondent decision control scores in the Third Follow-up

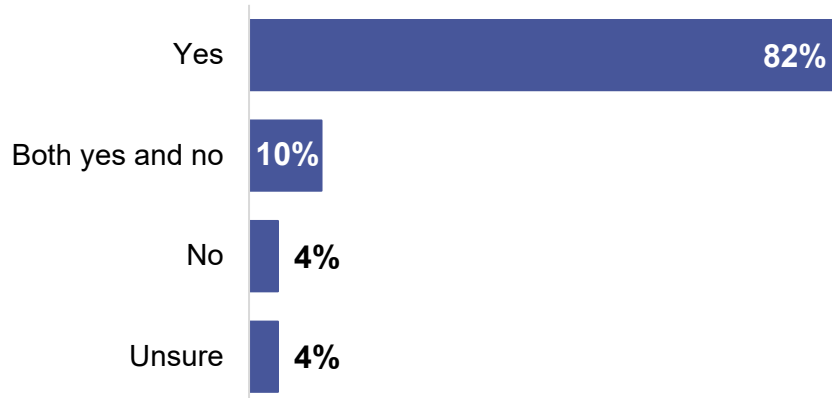
Adjusted R squared: 0.27

Term	Estimate	P-Value
(Intercept)	52.1	<0.001
Age	-0.1	0.16
Sex (Female)	--	--
Sex (Male)	-0.1	0.93
Race (BIPOC)	--	--
Race (White or Caucasian)	-2.1	0.33
Region (Central)	--	--
Region (Metro)	1.3	0.60
Region (Northeast)	3.1	0.30
Region (Northwest)	-5.5	0.049
Region (Southeast)	-0.9	0.77
Region (Southwest)	2.9	0.31
Waiver (CAD)	--	--
Waiver (DD)	-2.6	0.23
Waiver (None)	-4.2	0.15
Waiver (Other)	-5.1	0.25
Home Type (Family Foster Care)	--	--
Home Type (Assisted Living)	9.0	0.01
Home type (Community Residential Setting)	1.0	0.59
Home type (Living independently)	13.7	<0.001
Home type (Other)	3.4	0.21
Employment Type (Competitive)	--	--
Employment Type (No Employment)	-3.7	0.07
Employment Type (Sheltered)	-2.2	0.34
Guardianship Status (No Guardian)	--	--
Guardianship Status (Has Guardian)	-5.0	0.02
2024 Activities Interaction Score	0.1	0.07
2024 Quality of Life Score	0.1	0.053
2024 Number of Close Relationships (up to 5)	1.1	0.02
2017 Baseline Decision Control Score	0.2	<0.001

Satisfaction with decision-making

Participants shared whether they are happy with who makes decisions for them, overall. Most participants responded “yes.”

Image 4. Most respondents responded “yes” when asked whether they are happy with who makes decisions for them.



While many participants responded that they are happy with who makes decisions for them, responses may have been influenced by who was in the room with them during the interview. About half of the time, participants had at least one person with them. Often, these may be the people who made decisions for them (for example, parents, guardians, or staff members). This is the first year that the Quality of Life Survey included this question, so we do not have previous years’ data to compare responses to. It is also important to note that the question asked whether people are happy with who makes decisions for them, not whether they are happy with the decisions that are available to them.

Percentage of participants who are happy with who makes decisions for them

To give a sense of who is more or less happy with who makes decisions in their lives, we looked at the percentage of respondents who said “yes” they are happy by subgroup. Tables 53 through 66 share these results.

We ran a Pearson’s chi-squared test for each subgroup. This test tells us whether the differences in the amount of people who answered “yes” to this question are statistically significant across subgroups. The chi-squared test found significant differences across subgroups by age and whether participants had claims for services related to substance use disorders or autism (Tables 53 through 55). The chi-squared test did not find significant differences across subgroups by race and ethnicity, gender, region, guardianship status, waiver type, home setting, employment type, service type, how the participant participated in the interview, or whether the participant had claims for services related to brain injury or dementia (Tables 56 through 66). All service claim data was for claims between July 1, 2022 and June 30, 2024. Individual participants

may have made claims related to none, one, or any combination of the four diagnoses included in analysis.

We included a sentence about whether the chi-squared test found significant differences in groups before each table with these results. This tells us if there is a difference in the amount of people who said “yes” or not, but when there are more than two groups, it does not tell us where there is difference.

Refer to the “How to read results” section of this report on page 15 for more details about the tests we ran and how to read these tables.

Table 53. Percentage of respondents who are happy with who makes their decisions, by age

The chi-squared test found significant differences in who is happy with who makes their decisions by age. This test does not tell us which age group(s) are significantly different from others.

Age	n	%
34 and younger	56	69%
35 – 44	76	78%
45 – 54	84	86%
55 - 64	97	90%
65 – 74	97	84%

Table 54. Percentage of respondents with and without service claims related to substance use disorder who are happy with who makes their decisions

The chi-squared test found significant differences in who is happy with who makes their decisions by substance use disorder service claims status, finding those without claims to be happier.

Substance use service claims status	n	2024 Average
With substance use disorder service claims	24	63%
Without substance use disorder service claims	385	84%

Table 55. Percentage of respondents with and without service claims related to autism who are happy with who makes their decisions

The chi-squared test found significant differences in who is happy with who makes their decisions by substance use disorder service claims status, finding those without claims to be happier.

Autism service claims status	n	2024 Average
With autism service claims	42	66%
Without autism use disorder service claims	367	85%

Table 56. Percentage of white- and BIPOC-identified participants who are happy with who makes their decisions

The chi-squared test did not find significant differences in who is happy with who makes their decisions between white and BIPOC participants.

Race and ethnicity	n	%
White	339	83%
BIPOC	53	76%

Table 57. Percentage of respondents who are happy with who makes their decisions, by gender

The chi-squared test did not find significant differences in who is happy with who makes their decisions by gender.

Gender	n	%
Male	218	81%
Female	179	83%

Table 58. Percentage of respondents who are happy with who makes their decisions, by region

The chi-squared test did not find significant differences in who is happy with who makes their decisions by region.

Region	n	%
Northwest	50	71%
Northeast	49	82%
Southeast	48	81%
Southwest	54	87%
Metro	156	86%
Central	53	79%

Table 59. Percentage of respondents who are happy with who makes their decisions, by guardianship status

The chi-squared test did not find significant differences in who is happy with who makes their decisions by guardianship status.

Guardianship status	n	%
Private	258	82%
Public	43	78%
None	80	88%

Table 60. Percentage of respondents who are happy with who makes their decisions, by home and community-based service waiver type

The chi-squared test did not find significant differences in who is happy with who makes their decisions by waiver type.

Waiver	n	%
CADI	94	78%
DD	255	85%
Other	12	67%
None	49	82%

Table 61. Percentage of respondents who are happy with who makes their decisions, by home setting

The chi-squared test did not find significant differences in who is happy with who makes their decisions by home setting.

Home setting	n	%
Family Foster Care	75	78%
Assisted Living	28	82%
Community Residential Setting	207	83%
Living independently (by self/alone) or living with family, friends, or romantic partner	47	87%

Table 62. Percentage of respondents who are happy with who makes their decisions, by employment type

The chi-squared test did not find significant differences in who is happy with who makes their decisions by employment type.

Employment type	n	%
No employment	230	80%
Competitive, integrated employment	68	80%
Sheltered or subminimum employment	96	89%

Table 63. Percentage of respondents who are happy with who makes their decisions, by service type

The chi-squared test did not find significant differences in who is happy with who makes their decisions by service type.

Service type	n	%
Residential services only	234	80%
Day and residential services	123	85%
Neither day nor residential services	39	89%

Table 64. Percentage of respondents who are happy with who makes their decisions, by participant interview participation

The chi-squared test did not find significant differences in who is happy with who makes their decisions by whether the participant or a proxy answered most survey questions.

Participant's interview participation	n	%
The participant was in the interview and answered all or most questions	284	82%
The participant was in the interview and answered half or fewer than half the questions	64	83%
The participant was not a part of the interview (the interview was conducted with a proxy)	59	81%

Table 65. Percentage of respondents with and without service claims related to brain injury who are happy with who makes their decisions

The chi-squared test did not find significant differences in who is happy with who makes their decisions by brain injury service claims status.

Brain injury service claims status	n	2024 Average
With brain injury service claims	37	76%
Without brain injury service claims	372	83%

Table 66. Percentage of respondents with and without service claims related to dementia who are happy with who makes their decisions

The chi-squared test did not find significant differences in who is happy with who makes their decisions by dementia service claims status.

Dementia service claims status	n	2024 Average
With dementia service claims	56	80%
Without dementia service claims	353	82%

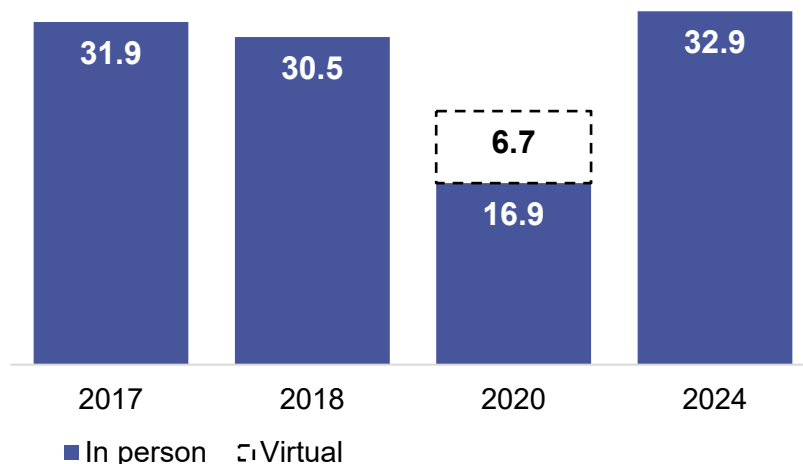
Community integration and engagement

Participants answered questions about what they do in their free time. They thought about the four weeks before they took the survey and answered if they did activities outside of their homes, like visiting friends, going to the store, or attending events. Participants also answered how many times they did each activity, who they did it with, and how often they interacted with people in the community during these activities.

Average total number of activities in the last four weeks

Participants shared the number of times they did different activities outside of their homes in the four weeks before they took the survey. The survey asked about 13 specific activities, and participants were able to add others to the list. Because of the COVID-19 pandemic, the 2020 Follow-up survey asked how often participants did activities virtually or in-person. Other surveys (including the Third Follow-up) did not ask about virtual activities specifically. Image 5 shares the average total number of activities participants did in the past month. These averages include all participants in that year's survey.

Image 5. The average number of monthly activities has returned to, and even slightly exceeded, pre-pandemic levels.



In 2024, participants on average did 5.8 different types of activities in the four weeks before they took the survey. The average group size for all out of home activities was 3.4 people.

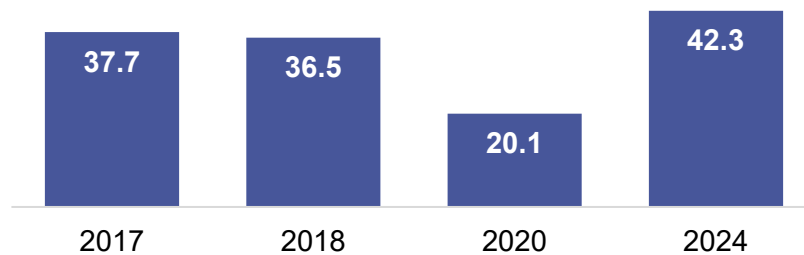
Average activities interaction scores for each year of the survey

Participants' answers about the activities they did in the past month were used to create an activities interaction score. The score included how much they interacted with others in the community when doing activities. Participants rated each of the activities they participate in an average month on a five-point scale for how much interaction they have with community members during each activity. A one on this scale means that they had

“no” interaction with community members, and a five means they had “very much” interaction.

Average ratings were then changed to a score. The score fits a 100-point scale to make it easier to understand. A higher score means participants had more interactions with the community during activities, not that they necessarily participated in more activities. The average score for each year includes all participants’ answers in that year.

Image 6. The 2024 average activities interaction score exceeds pre-pandemic levels.



Average activities interaction scores from Baseline to Third Follow-up

We also matched all participants in the Third Follow-up study to their Baseline average activities interaction scores. We then compared average scores for only the participants who had scores in both the Baseline and at the Third Follow-up. The 483 participants in this group had an average Baseline score of 39.1 and a Third Follow-up average score of 42.3. A t-test determined this increase was significant.

Average Activities Interaction Index item ratings for all inventory items at the Third Follow-up

Table 67 includes the 13 items in the Activities Interaction Index. Participants rated each item only if they participated in it during the past four weeks before they took the survey. All average scores are out of a possible rating of five.

Table 67. Average Activities Interaction Index ratings for all items

Index items	n	2024 Average
Go to a place of worship	186	3.4
Visit with close friends, relatives, or neighbors who live outside the home	401	3.2
Go to a sports event	118	3.1
Go to bars, taverns, nightclubs, etc.	46	3.0
Go to a theater or cultural event (including local school & club events)	129	2.8
Go to a health or exercise club, spa, or center	123	2.8
Go to a grocery store	334	2.7
Go to a restaurant	399	2.7
Go to a shopping center, mall, or other retail store to shop	348	2.7
Go to a library	142	2.7
Use public transportation	148	2.7
Go to a park or playground	277	2.5
Go to a movie	174	2.4

Average activities interaction scores for demographic subgroups

Tables 68 through 75 share average activities interaction scores by demographic subgroups. For each table, we only included subgroups which had 30 or more participants who responded to these survey questions. This helps avoid having a small number of people speak for an entire subgroup.

We did two types of analyses for demographic subgroups. First, we ran ANOVA tests to look for differences in average scores by group in 2024 results. We included a sentence above each table about whether the ANOVA test found significant differences across groups. When there are more than two subgroups, there are limits to what ANOVA tests can tell us. ANOVA tests can tell us whether there are significant differences between at least two groups, but not which specific groups. Further testing would be needed to find which specific groups are different.

Secondly, we ran t-tests to look for differences in responses over time by subgroup. To do this, we matched each participant to their Baseline score. We only include respondents who have a score at the Baseline and Third Follow-up in these analyses. The t-test looks for differences between Baseline (2017) scores and Third Follow-up

(2024) scores. We wrote “yes” or “no” in the “significant” column depending on if the t-test found statistically significant differences in average scores between 2017 and 2024.

Refer to the “How to read results” section of this report on page 15 for more details about the tests we ran and how to read these tables.

Table 68. Average 2024 activities interaction score for white- and BIPOC-identified participants

The ANOVA test found a significant difference between 2024 average activities interaction scores for white and BIPOC participants, finding white participants to have a higher average score.

Race and ethnicity	n	2024 Average
White	408	43.2
BIPOC	68	39.2

Table 69. Comparison of 2017 Baseline average and 2024 Follow-up average activities interaction score for white- and BIPOC-identified participants

Race and ethnicity	n	2017 Average	2024 Average	Significant
White	399	39	43.3	No
BIPOC	65	40.6	38.3	Yes

Table 70. Average activities interaction score by gender

The ANOVA test did not find significant differences between 2024 average activities interaction scores by gender.

Gender	n	2024 Average
Male	265	42.4
Female	215	43.3

Table 71. Comparison of 2017 Baseline average and 2024 Follow-up average activities interaction score by gender

Gender	n	2017 Average	2024 Average	Significant
Male	257	38.7	42.4	No
Female	211	39	43.4	Yes

Table 72. Average activities interaction score by age

The ANOVA test did not find significant differences across 2024 average activities interaction scores by age.

Age	n	2024 Average
34 and younger	81	43.1
35 – 44	97	41.9
45 – 54	96	43.6
55 – 64	106	42.2
65 +	115	41.2

Table 73. Comparison of 2017 Baseline average and 2024 Follow-up average activities interaction score by age

Age	n	2017 Average	2024 Average	Significant
34 and younger	80	42.7	42.7	No
35 – 44	93	41.3	43.2	No
45 – 54	93	38.5	42.7	No
55 – 64	105	36.7	42.2	No
65 +	112	35.8	41.1	No

Table 74. Average activities interaction score by region

The ANOVA test found significant differences across 2024 average activities interaction scores by region. This test does not tell us which region(s) are significantly different from others.

Region	n	2024 Average
Northwest	69	44.1
Northeast	61	42.9
Southeast	57	43.9
Southwest	62	55.6
Metro	181	36.4
Central	65	42.3

Table 75. Comparison of 2017 Baseline average and 2024 Follow-up average activities interaction score by region

Region	n	2017 Average	2024 Average	Significant
Northwest	68	46.0	43.2	No
Northeast	60	33.9	43.0	Yes
Southeast	56	46.5	44.7	No
Southwest	61	40.2	56.1	Yes
Metro	175	33.9	36.8	No
Central	63	40.5	40.7	No

Subgroup average activities interaction score at Third Follow-up

We explored differences in average activities interaction scores by subgroups related to factors including guardianship status, home setting and services, employment, and the extent to which interview questions were answered by the participant or a proxy. We did not compare these groups to their Baseline averages like we did for demographic subgroups shared above because participants are more likely to have changed groups over time. Tables 76 through 85 show these results.

For each subgroup analysis, we ran an Analysis of Variance test (ANOVA), which is a statistical test that tells us whether there are significant differences in average responses across subgroups. We included a sentence above each table about whether the ANOVA test found significant differences across groups. When there are more than two subgroups, there are limits to what ANOVA tests can tell us. ANOVA tests can tell us whether there are significant differences between at least two groups, but not which specific groups. Further testing would be needed to find which specific groups are different.

Refer to the “How to read results” section of this report on page 15 for more details about ANOVA tests.

ANOVA testing found significant differences across subgroup average activities interaction score how the participant participated in the interview and whether participants had claims for services related to dementia (Tables 76 through 77). ANOVA testing did not find significant differences across subgroups by guardianship status, waiver type, home setting, employment type, service type, or whether the participant had claims for services related to substance use disorders, brain injury, or autism (Tables 78 through 85). All service claim data was for claims between July 1, 2022 and June 30, 2024. Individual participants may have made claims related to none, one, or any combination of the four diagnoses included in analysis.

Table 76. Average activities interaction score by participant interview participation

The ANOVA test found significant differences across 2024 average activities interaction scores by whether the participant or a proxy answered most survey questions. This test does not tell us which participant group(s) are significantly different from others.

Participant's interview participation	n	2024 Average
The participant was in the interview and answered all or most questions	342	44.4
The participant was in the interview and answered half or fewer than half the questions	77	42.0
The participant was not a part of the interview (the interview was conducted with a proxy)	72	30.8

Table 77. Average activities interaction score of respondents with and without service claims related to dementia

The ANOVA test found significant differences between 2024 average activities interaction scores by dementia service claims.

Dementia service claims status	n	2024 Average
With dementia service claims	66	36.1
Without dementia service claims	428	43.2

Table 78. Average activities interaction score by guardianship status

The ANOVA test did not find significant differences across 2024 average activities interaction scores by guardianship status.

Guardianship status	n	2024 Average
Private	311	43.0
Public	54	41.0
None	90	43.1

Table 79. Average activities interaction score by home and community-based service waiver type

The ANOVA test did not find significant differences across 2024 average activities interaction scores by waiver type.

Waiver	n	2024 Average
CADI	119	40.9
DD	300	42.4
None	59	43.2

Table 80. Average activities interaction score by home setting

The ANOVA test did not find significant differences across 2024 average activities interaction scores by home setting.

Home setting	n	2024 Average
Family Foster Care	97	40.9
Assisted Living	33	42.5
Community Residential Setting	250	43.8
Living independently (by self/alone) or living with family, friends, or romantic partner	54	44.4

Table 81. Average activities interaction score by employment type

The ANOVA test did not find significant differences across 2024 average activities interaction scores by employment type.

Employment type	n	2024 Average
No employment	283	41.4
Competitive, integrated employment	86	46.7
Sheltered or subminimum employment	107	42.4

Table 82. Average activities interaction score by participant service type

The ANOVA test did not find significant differences across 2024 average activities interaction scores by service type.

Service type	n	2024 Average
Residential services only	292	40.4
Day and residential services	143	45.8
Neither day nor residential services	43	41.1

Table 83. Average activities interaction score of respondents with and without service claims related to substance use disorder

The ANOVA test did not find significant differences between 2024 average activities interaction scores by substance use disorder service claims.

Substance use service claims status	n	2024 Average
With substance use disorder service claims	38	34.8
Without substance use disorder service claims	456	42.8

Table 84. Average activities interaction score of respondents with and without service claims related to brain injury

The ANOVA test did not find significant differences between 2024 average activities interaction scores by brain injury service claims.

Brain injury service claims status	n	2024 Average
With brain injury service claims	48	40.6
Without brain injury service claims	446	42.4

Table 85. Average activities interaction score of respondents with and without service claims related to autism

The ANOVA test did not find significant differences between 2024 average activities interaction scores by autism service claims.

Autism service claims status	n	2024 Average
With autism service claims	64	38.7
Without autism use disorder service claims	430	42.7

Regression analysis of activities interaction scores

Regression analysis helps us understand which factors or characteristics might affect activities interaction scores. We ran a regression model with the 29 factors (terms) listed in Table 86, to learn more about how each affects activities interaction scores.

For each term that has categories (as opposed to a number, like age), we use one category as a reference group. A reference group is what we compare the other groups to. For example, in Table 86, “competitive employment” is the reference group for employment. We are comparing the scores for the categories “no employment” and “sheltered employment” to the score for “competitive employment.” Reference groups are those that do not have an estimate or p-value listed in Table 86.

We ran ANOVA tests for these same factors to explore significance across subgroups. ANOVA test results are in the previous section. The ANOVA tests consider each factor individually. The advantage of running them all in the same regression model is that the regression considers the factors together and helps to show which ones stand out while adjusting for the other factors in the model. Accordingly, some factors – including race and ethnicity and region – were found to be statistically significant in the ANOVA test but not in the regression. These differences are expected and do not mean that these factors are not important in activities interaction scores.

Refer to the “How to read results” section of this report on page 15 for more details about regression models and reading results.

Regression analysis results in an adjusted R squared value, which tells us how well our data fits with what the model predicts. The regression model for activities interaction score has an adjusted R squared value of 0.16, which is low. This means that we are missing key characteristics associated with higher activities interaction scores.

Even with our low adjusted R squared, we can still see some influence. Our model confirms that Baseline activities interaction scores and 2024 quality of life scores are both important for predicting 2024 activities interaction scores. Higher 2024 quality of life scores and Baseline activities interaction scores predict higher 2024 activities interaction scores.

Table 86. Regression analysis of characteristics associated with respondent activities interaction scores in the Third Follow-up

Adjusted R squared: 0.16

Term	Estimate	P-Value
(Intercept)	-13.4	0.27
Age	0.0	0.71
Sex (Female)	--	--
Sex (Male)	-1.0	0.69
Race (BIPOC)	--	--
Race (White or Caucasian)	5.3	0.17
Region (Central)	--	--
Region (Metro)	-4.3	0.32
Region (Northeast)	4.4	0.40
Region (Northwest)	1.2	0.80
Region (Southeast)	2.4	0.64
Region (Southwest)	14.9	0.003
Waiver (CADI)	--	--
Waiver (DD)	1.9	0.61
Waiver (None)	8.1	0.11
Waiver (Other)	12.7	0.10
Home Type (Family Foster Care)	--	--
Home Type (Assisted Living)	1.7	0.78
Home type (Community Residential Setting)	4.5	0.19
Home type (Living independently)	-0.6	0.90
Home type (Other)	1.1	0.81
Employment Type (Competitive)	--	--
Employment Type (No Employment)	-0.6	0.86
Employment Type (Sheltered)	-4.8	0.23
Guardianship Status (No Guardian)	--	--
Guardianship Status (Has Guardian)	-1.5	0.69
2024 Quality of Life Score	0.4	<0.001
2024 Decision Control Score	0.1	0.18
2024 Number of Close Relationships (up to 5)	0.8	0.31
2017 Baseline Activities Interaction Score	0.3	<0.001

Time and integration during the day

Participants answered questions about what they do during the day. This included things like work, school, and other activities in the community. If someone had a job, they were asked what kind of job it was, how many hours they worked, and how much money they made. If someone went to school, they were asked what type of school they went to and how many hours they spent there. If someone did other activities in the community, they were asked what those activities were and how many hours they spent doing them.

For each activity, participants were asked if they did these with people with disabilities, people without disabilities, or a mix. This is known as the level of integration. Participant answers to this question were scored from one (completely segregated) to five (completely integrated).

Jobs and Vocational Programs

The survey asked participants to share whether they go to a job or vocational program in a typical week. Of the people who took the 2024 Follow-up, 42%, or 242 people, said yes. The most common job sites for participants were sheltered employment, workshops, subminimum wage employment, enclaves or job crews, and supported employment (Table 87).

Table 87. Types of jobs for participants who work or attend vocational programs

Job types	n	%
Sheltered employment, workshop employment, or subminimum wage employment	56	27%
In an enclave or job crew	45	22%
Community job with support staff	44	21%
Competitive employment	37	18%
Day Habilitation Program (DT&H)	20	10%
Other employment setting or vocational program	10	5%
Self-Employed (has his or her own business)	7	3%
Pre-Vocational Program or Vocational Rehabilitation Program	5	2%

For each job or vocational program, participants rated the extent to which they are integrated with people without disabilities. Participants rated each setting on a five-point scale, from completely segregated (one) to completely integrated (five). Table 88 includes the average score for each job setting with more than 30 participants, out of a possible five. Only people who work in each setting are included in the average.

Table 88. Average integration rating by job setting

The ANOVA test found significant differences across 2024 average integration ratings scores by job setting. This test does not tell us which setting(s) are significantly different from others.

Job settings	n	2024 Average
Competitive employment	37	4.4
Community job with support staff	44	3.9
In an enclave or job crew	43	2.5
Sheltered employment, workshop employment, or subminimum wage employment	56	1.9

Across all job and vocational programs listed in the Third Follow-up, the average integration rating from all participants was three out of five. In 2017, the Baseline survey year, the average was 2.2 out of five.

School and educational settings

The survey asked participants whether they participate in school or attend classes regularly. Of the 490 respondents who answered the question, 10 (or 2%) said yes. Because this number is such a small amount of the entire respondent pool for the Third Follow-up, we did not analyze community integration of school programs.

Other day programs, volunteering, and other programming

Participants shared whether they go to other scheduled activities in the day, like volunteer activities, a senior program, or other activities in the community. Of the 497 respondents who answered this question, 228 (46%) said yes.

Table 89. Types of programs and day activities for survey respondents who participate

Activity types	n	%
Adult Day Program or non-vocational program	173	76%
Other activities	36	16%
Community experiences	28	12%
Volunteer work	21	9%

Participants shared the extent to which their activities are integrated with people without disabilities. They used the same five-point integration rating scale as with work and vocational programs, where a rating of one is equal to “completely segregated” and five is equal to “completely integrated.” Table 90 lists the average interaction ratings score for each type of day activity, on a scale from one to five.

Table 90. Average integration ratings by activity type

The ANOVA test found significant differences across 2024 average integration ratings scores by activity type. This test does not tell us which activity type(s) are significantly different from others.

Activity types	n	2024 Average
Volunteer work	21	4.2
Other activities	36	3.1
Community experience	28	2.8
Adult Day Program or Non-Vocational Program	173	2.2

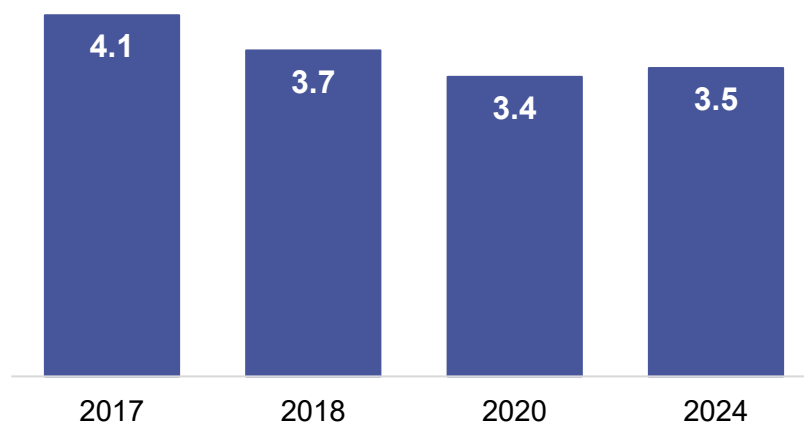
Close relationships

Participants answered questions about the people who are closest to them. They could list up to five people. Participants were not told what a “close relationship” meant. Instead, they could decide what a close relationship meant to them. For each person they listed, they answered questions about who that person is, how long they have known each other, and how much they see each other.

Average number of close relationships, up to five, for each year of the survey

The survey counted how many close relationships, up to five, participants chose to describe. Each average includes all participants’ answers in that year.

Image 7. The average number of close relationships, up to five, has decreased since the Baseline survey but stayed fairly level since the last survey.



Average number of close relationships, up to five, from Baseline to Third Follow-up

We matched all participants in the Third Follow-up study to their Baseline number of close relationships. We then compared the average number of relationships for only the participants who shared in both the Baseline and at the Third Follow-up. The 469 participants in this group had an average of 4.2 relationships at Baseline and 3.5 at the Third Follow-up. A t-test determined that this is a significant decrease.

Number of relationships, up to five, types and contacts

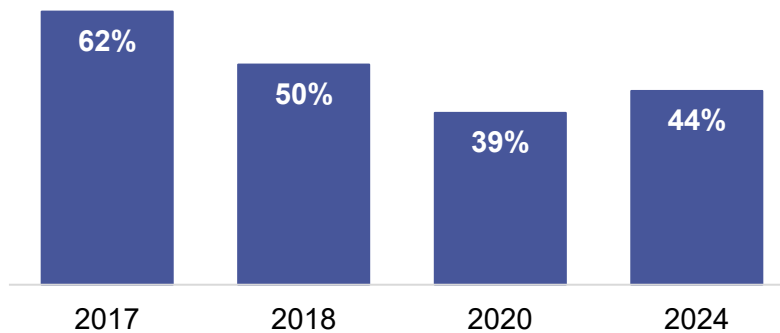
Most frequently, when asked to list up to five close relationships, survey respondents listed five (Table 91).

Table 91. The number of relationships respondents listed in 2024, up to five

Number of close relationships listed	n	%
0	39	8%
1	35	7%
2	62	13%
3	74	15%
4	64	13%
5	215	44%

Image 8 shows the percentage of participants who said they have at least five close relationships in each year of the survey. Each year includes all respondents from that year's survey.

Image 8. Fewer participants list five close relationships since the 2017 Baseline.



Just as the number of participants who can list up to five relationships has generally decreased over time, the number of participants who list no close relationships has generally increased. In the 2020 Follow-up Survey, 3% of respondents said they did not have any close relationships. This increased to 8% in 2024.

Survey respondents named the relationship type for each close relationship they listed. Some relationships are paid (including staff of homes, day programs, school, or job, or other paid relationships like case managers or nurses). Other relationships are unpaid (including relatives, housemates, coworkers or schoolmates, neighbors, or other unpaid friends or nonrelatives). Table 92 shows the frequency for whether participants shared paid relationships, unpaid relationships, or a combination.

Table 92. How many participants listed paid, unpaid, or a combination of relationships among their closest five

Relationship types among closest five	n	%
Listed all unpaid relationships	246	50%
Listed some paid and some unpaid relationships	172	35%
No close relationships listed	39	8%
Listed all paid relationships	32	7%

The survey asked respondents approximately how many times in the past month they had contact with each of their five closest relations. Across all 2024 survey respondents, Table 93 shows the total number of times each relationship was named, and the average number of contacts participants had with that type of relationship over the past month.

Table 93. Average number of contacts in the past month, by relationship type

Relationship type	n	Average number of contacts
Housemate	48	26.9
Staff of home	166	20.8
Co-worker or schoolmate	11	19.0
Neighbor	16	18.0
Staff of day program, school, or job	39	16.2
Other unpaid friend or non-relative	164	12.3
Relative	356	10.3
Other paid relationships (case manager, nurse, etc.)	47	7.1

Average number of close relationships, up to five, for demographic subgroups

Tables 94 through 101 share the average number of close relationships, up to five, shared by demographic subgroups. For each table, we only included subgroups which had thirty or more participants who responded to these survey questions. This avoided having a small number of people's responses speak for an entire subgroup.

We did two types of analyses for demographic subgroups. First, we ran ANOVA tests to look for differences in averages by group in 2024 results. We included a sentence above each table about whether the ANOVA test found significant differences across groups. When there are more than two subgroups, there are limits to what ANOVA tests can tell us. ANOVA tests can tell us whether there are significant differences between at least two groups, but not which specific groups. Further testing would be needed to find which specific groups are different.

Secondly, we ran t-tests to look for differences in responses over time by subgroup. To do this, we matched each participant to their Baseline number of close relationships. We only include respondents who have a number at the Baseline and Third Follow-up in these analyses. The t-test looks for differences between Baseline (2017) number of relationships and Third Follow-up (2024) number of relationships. We wrote "yes" or "no" in the "significant" column depending on if the t-test found statistically significant differences in average scores between 2017 and 2024.

Refer to the "How to read results" section of this report on page 15 for more details about the statistical tests we ran and how to read these tables.

Table 94. Average number of close relationships, up to five, for white- and BIPOC-identified participants

The ANOVA test did not find a significant difference between 2024 average number of close relationships for white and BIPOC participants

Race and ethnicity	n	2024 Average
White	400	3.5
BIPOC	70	3.7

Table 95. Comparison of 2017 Baseline average and 2024 Follow-up average number of close relationships, up to five, for white- and BIPOC-identified participants

Race and ethnicity	n	2017 Average	2024 Average	Significant
White	383	4.2	3.5	Yes
BIPOC	68	3.9	3.7	No

Table 96. Average number of close relationships, up to five, by gender

The ANOVA test did not find a significant difference between 2024 average number of close relationships by gender.

Gender	n	2024 Average
Male	264	3.4
Female	209	3.7

Table 97. Comparison of 2017 Baseline average and 2024 Follow-up average number of close relationships, up to five, by gender

Gender	n	2017 Average	2024 Average	Significant
Male	252	4.1	3.4	Yes
Female	202	4.3	3.7	Yes

Table 98. Average number of close relationships, up to five, by age

The ANOVA test found significant differences across 2024 average number of close relationships by age. This test does not tell us which age group(s) are significantly different from others

Age	n	2024 Average
34 and younger	81	4.0
35 – 44	95	3.7
45 – 54	97	3.5
55 – 64	106	3.1
65+	110	3.3

Table 99. Comparison of 2017 Baseline average and 2024 Follow-up average number of close relationships, up to five, by age

Age	n	2017 Average	2024 Average	Significant
34 and younger	79	4.6	3.9	Yes
35 – 44	91	4.4	3.7	Yes
45 – 54	90	4.3	3.6	Yes
55 – 64	104	3.9	3.1	Yes
65+	105	3.8	3.3	Yes

Table 100. Average number of close relationships, up to five, by region

The ANOVA test did not find significant differences across 2024 average number of close relationships by region.

Region	n	2024 Average
Central	68	3.7
Metro	176	3.6
Northeast	59	3.6
Northwest	68	3.6
Southeast	58	3.4
Southwest	60	2.9

Table 101. Comparison of 2017 Baseline average and 2024 Follow-up average number of close relationships, up to five, by region

Region	n	2017 Average	2024 Average	Significant
Central	66	4.1	3.7	No
Metro	169	4.2	3.7	Yes
Northeast	58	3.7	3.6	No
Northwest	65	4.1	3.6	Yes
Southeast	52	4.4	3.3	Yes
Southwest	59	4.6	2.9	Yes

Subgroup average number of close relationships, up to five, at Third Follow-up

We explored differences in the number of close relationships, up to five, by subgroups related to factors including guardianship status, home setting and services, employment, and the extent to which interview questions were answered by the participant or a proxy. We did not compare these groups to their Baseline averages like we did for demographic subgroups shared above because participants are more likely to have changed groups over time. Tables 102 through 111 show these results.

For each subgroup analysis, we ran an Analysis of Variance test (ANOVA), which is a statistical test that tells us whether there are significant differences in average responses across subgroups. We included a sentence above each table about whether the ANOVA test found significant differences across groups. When there are more than two subgroups, there are limits to what ANOVA tests can tell us. ANOVA tests can tell us whether there are significant differences between at least two groups, but not which specific groups. Further testing would be needed to find which specific groups are different.

Refer to the “How to read results” section of this report on page 15 for more details about ANOVA tests.

ANOVA testing found significant differences across subgroup average number of close relationships (up to five) by home setting, employment type, service type, and whether participants had claims for services related to substance use disorders (Tables 102 through 105). ANOVA testing did not find significant differences across subgroups by guardianship status, waiver type, how the participant participated in the interview, or whether the participant had claims for services related to autism, brain injury, or dementia (Tables 106 through 11). All service claim data was for claims between July 1, 2022 and June 30, 2024. Individual participants may have made claims related to none, one, or any combination of the four diagnoses included in analysis.

Table 102. Average number of close relationships, up to five, by home setting

The ANOVA test found significant differences across 2024 average number of close relationships by home setting. This test does not tell us which home setting(s) are significantly different from others.

Home setting	n	2024 Average
Family Foster Care	96	3.2
Assisted Living	32	3.1
Community Residential Setting	245	3.5
Living independently (by self/alone) or living with family, friends, or romantic partner	54	4.3

Table 103. Average number of close relationships, up to five, by employment type

The ANOVA test found significant differences across 2024 average number of close relationships by employment type. This test does not tell us which employment type(s) are significantly different from others.

Employment type	n	2024 Average
No employment	280	3.2
Competitive, integrated employment	84	3.8
Sheltered or subminimum employment	105	4.0

Table 104. Average number of close relationships, up to five, by participant service type

The ANOVA test found significant differences across 2024 average number of close relationships by service type. This test does not tell us which service type(s) are significantly different from others.

Service type	n	2024 Average
Residential services only	287	3.3
Day and residential services	141	3.6
Neither day nor residential services	44	4.0

Table 105. Average number of close relationships, up to five, for respondents with and without service claims related to substance use disorder

The ANOVA test found significant differences between 2024 average number of close relationships by substance use disorder service claims, finding participants without substance use disorder service claims to have more relationships.

Substance use service claims status	n	2024 Average
With substance use disorder service claims	37	2.7
Without substance use disorder service claims	451	3.6

Table 106. Average number of close relationships, up to five, by guardianship status

The ANOVA test did not find significant differences across 2024 average number of close relationships by guardianship status.

Guardianship status	n	2024 Average
Private	306	3.6
Public	53	3.3
None	91	3.3

Table 107. Average number of close relationships, up to five, by home and community-based service waiver type

The ANOVA test did not find significant differences across 2024 average number of close relationships by waiver type.

Waiver	n	2024 Average
CADI	119	3.3
DD	295	3.6
None	57	3.4

Table 108. Average number of close relationships, up to five, by participant interview participation

The ANOVA test did not find significant differences across 2024 average number of close relationships by whether the participant or a proxy answered most survey questions.

Participant's interview participation	n	2024 Average
The participant was in the interview and answered all or most questions	340	3.4
The participant was in the interview and answered half or fewer than half the questions	74	3.4
The participant was not a part of the interview (the interview was conducted with a proxy)	71	3.8

Table 109. Average number of close relationships, up to five, for respondents with and without service claims related to brain injury

The ANOVA test did not find significant differences between 2024 average number of close relationships by brain injury service claims.

Brain injury service claims status	n	2024 Average
With brain injury service claims	47	3.3
Without brain injury service claims	441	3.5

Table 110. Average number of close relationships, up to five, for respondents with and without service claims related to autism

The ANOVA test did not find significant differences between 2024 average number of close relationships by autism service claims.

Autism service claims status	n	2024 Average
With autism service claims	62	3.6
Without autism use disorder service claims	426	3.5

Table 111. Average number of close relationships, up to five, for respondents with and without service claims related to dementia

The ANOVA test did not find significant differences between 2024 average number of close relationships by dementia service claims.

Dementia service claims status	n	2024 Average
With dementia service claims	68	3.4
Without dementia service claims	420	3.5

Regression analysis for the average number of close relationships, up to five

Regression analysis helps us understand which factors or characteristics might affect the number of close relationships, up to five. We ran a regression model with the 29 factors (terms) listed in Table 112, to learn more about how each affects the number of close relationships.

For each term that has categories (as opposed to a number, like age), we use one category as a reference group. A reference group is what we compare the other groups to. For example, in Table 112, “competitive employment” is the reference group for employment. We are comparing the scores for the categories “no employment” and “sheltered employment” to the score for “competitive employment.” Reference groups are those that do not have an estimate or p-value listed in Table 112.

We ran ANOVA tests for these same factors to explore significance across subgroups. ANOVA test results are in the previous section. The ANOVA tests consider each factor

individually. The advantage of running them all in the same regression model is that the regression considers the factors together and helps to show which ones stand out while adjusting for the other factors in the model.

Regression analysis results in an adjusted R squared value, which tells us how well our data fits with what the model predicts. Our regression model for close relationships has an adjusted R squared value of 0.11. This is the lowest value, or worst fit, of all the regression models we ran.

Accordingly, the model did not perform well enough to draw conclusions about what influences the average number of close relationships. This could be because important factors are missing. It could also be because there is not much spread in the outcome data (number of close relationships). The other outcomes in the regression models had scores up to 100, and close relationships were capped at five, limiting possible outcomes. There also was a small amount of variation in the responses; most participants named five relationships.

While we are not able to draw conclusions about which factors help predict a higher number of close relationships, we did still include the results of the model, for reference, below. Also, just because our regression model did not perform well enough to draw conclusions does not mean that these are not important factors for predicting the number of close relationships. Notably, age, home setting, employment type, and service type emerged as being particularly meaningful in our ANOVA test analysis above.

Table 112. Regression analysis of characteristics associated with number of close relationships, up to five, at the Third Follow-up

Adjusted R squared: 0.11

Term	Estimate	P-Value
(Intercept)	2.1	0.007
Age	0.0	0.07
Sex (Female)	--	--
Sex (Male)	-0.3	0.06
Race (BIPOC)	--	--
Race (White or Caucasian)	-0.1	0.68
Region (Central)	--	--
Region (Metro)	0.0	0.94
Region (Northeast)	-0.2	0.51
Region (Northwest)	0.2	0.49
Region (Southeast)	-0.3	0.29
Region (Southwest)	-1.0	<0.001
Waiver (CADI)	--	--
Waiver (DD)	-0.1	0.78
Waiver (None)	-0.1	0.78
Waiver (Other)	0.1	0.82
Home Type (Family Foster Care)	--	--
Home Type (Assisted Living)	0.2	0.70
Home type (Community Residential Setting)	0.2	0.38
Home type (Living independently)	0.4	0.15
Home type (Other)	0.1	0.76
Employment Type (Competitive)	--	--
Employment Type (No Employment)	-0.2	0.34
Employment Type (Sheltered)	0.3	0.28
Guardianship Status (No Guardian)	--	--
Guardianship Status (Has Guardian)	0.3	0.22
2024 Quality of Life Score	0.0	0.28
2024 Decision Control Score	0.0	0.009
2024 Activities Interaction Score	0.0	0.29
2017 Baseline Number of Close Relationships, up to five	0.1	0.04

Assistive technology

Participants answered questions about the tools they use to help them do daily activities on their own. These tools are called assistive technology. These tools can help people speak, walk, remember, see, hear, learn, and more. The survey asked participants about the tools they use.

As seen in Table 113, most participants shared that they use assistive technology.

Table 113. Participant responses to whether they use or have used assistive technology

Technology use status	n	%
Yes, I use it now	298	60%
Yes, I have used it in the past	6	1%
No, but I need help doing certain tasks and would like to use it	10	2%
No	180	36%

The survey asked participants to describe the types of assistive technology they use. Table 114 includes a summary of the most common types of technology mentioned, with examples.

Table 114. Common types and examples of assistive technology described by participants

Types of Assistive technology	Examples
Mobility aids	Wheelchair; walker; cane; chair lift
Visions aids	Glasses; cane for blindness/low vision
Standard technology	Computer; cell phone; digital calendar; digital reminders; GPS maps
Hearing aids	Hearing aids
Medical devices	Heart monitor; CPAP machine; blood sugar monitor; life alert safety monitor
Specialized communication technology	Speech-to-text; text-to-speech; eye-tracking device; communication/picture board

Participants who answered “Yes, I have used it in the past” or “No, but I need help doing certain tasks and would like to use it” were asked why they do not currently use assistive technology. Most participants said they choose not to use assistive technology because they feel it is not necessary or find it uncomfortable to use (e.g., hearing aids). Some participants choose to use assistive technology on a conditional basis (e.g., using a wheelchair only after a seizure). Four participants said they have requested assistive technology and are waiting for these requests to be approved and received.

The survey asked participants to describe the impact of assistive technology on their lives. Most commonly, participants shared that technology has made “a lot” of difference in their independence (Table 115).

Table 115. The difference assistive technology has made in increasing independence for the participants who use it

How much difference has assistive technology made in increasing your...	A lot	Some	A little	None
...independence such as your ability to do things with less help from others or on your own?	62%	21%	10%	7%
...productivity such as your ability to do more in the same amount of time?	52%	20%	15%	14%
...community integration such as doing things in your community outside of your home?	59%	20%	10%	11%

The survey also asked participants to share, overall, how much their use of assistive technology has decreased their need for help from another person. Forty-five percent of respondents said “a lot,” twenty-four percent said “some,” 15% said “a little” and 16% said “none.”

Percentage of participants who are currently using assistive technology

To give a sense of who is currently using assistive technology, we looked at the percentage of respondents who said “yes, I use it now” when asked about their use. Tables 116 through 125 share these results.

We ran a Pearson’s chi-squared test for each subgroup. This test tells us whether the differences in the amount of people who answered “yes, I use it now” to this question are statistically significant across subgroups. The chi-squared test found significant differences across subgroups by region and home setting (Tables 116 and 117). The chi-squared test did not find significant differences across subgroups by race and ethnicity, gender, age, guardianship status, waiver type, home setting, employment type, service type, or how the participant participated in the interview (Tables 118 through 125).

We included a sentence about whether the chi-squared test found significant differences in groups before each table with these results. This tells us if there is a difference in the amount of people who said “yes, I use it now” or not, but when there are more than two groups, it does not tell us where there is difference.

Refer to the “How to read results” section of this report on page 15 for more details about the tests we ran and how to read these tables.

Table 116. Percentage of respondents who use assistive technology, by region

The chi-squared test found significant differences in who uses assistive technology by region. This test does not tell us which region(s) are significantly different from others.

Region	n	%
Northwest	59	86%
Northeast	32	52%
Southeast	29	49%
Southwest	39	64%
Metro	98	56%
Central	41	60%

Table 117. Percentage of respondents who use assistive technology, by home setting

The chi-squared test found significant differences in who uses assistive technology by home setting. This test does not tell us which setting(s) are significantly different from others.

Home setting	n	%
Family Foster Care	50	52%
Assisted Living	25	74%
Community Residential Setting	151	61%
Living independently (by self/alone) or living with family, friends, or romantic partner	30	56%

Table 118. Percentage of white- and BIPOC-identified participants who use assistive technology

The chi-squared test did not find significant differences in who uses assistive technology between white and BIPOC participants.

Race and ethnicity	n	%
White	244	60%
BIPOC	44	63%

Table 119. Percentage of respondents who use assistive technology, by gender

The chi-squared test did not find significant differences in who uses assistive technology by gender.

Gender	n	%
Male	157	59%
Female	133	63%

Table 120. Percentage of respondents who use assistive technology, by age

The chi-squared test did not find significant differences in who uses assistive technology by age.

Age	n	%
34 and younger	43	53%
35 – 44	59	61%
45 – 54	58	59%
55 – 64	64	59%
65+	74	67%

Table 121. Percentage of respondents who use assistive technology, by guardianship status

The chi-squared test did not find significant differences in who uses assistive technology by guardianship status.

Guardianship status	n	%
Private	177	57%
Public	32	60%
None	61	67%

Table 122. Percentage of respondents who use assistive technology, by home and community-based service waiver type

The chi-squared test did not find significant differences in who uses assistive technology by waiver type.

Waiver	n	%
CADI	75	62%
DD	170	57%
Other	11	61%
None	42	74%

Table 123. Percentage of respondents who use assistive technology, by employment type

The chi-squared test did not find significant differences in who uses assistive technology by employment type.

Employment type	n	%
No employment	185	66%
Competitive, integrated employment	53	62%
Sheltered or subminimum employment	50	47%

Table 124. Percentage of respondents who use assistive technology, by service type

The chi-squared test did not find significant differences in who uses assistive technology by service type.

Service type	n	%
Day services only	10	59%
Residential services only	174	60%
Day and residential services	90	63%
Neither day nor residential services	24	55%

Table 125. Percentage of respondents who use assistive technology, by participant interview participation

The chi-squared test did not find significant differences in who uses assistive technology by whether the participant or a proxy answered most survey questions.

Participant's interview participation	n	%
The participant was in the interview and answered all or most questions	201	59%
The participant was in the interview and answered half or fewer than half the questions	48	62%
The participant was not a part of the interview (the interview was conducted with a proxy)	47	66%

Appendix A. Olmstead Quality of Life Survey

Demographic and Housing Questions

What is your gender identity? (select all that apply)

- Woman
- Man
- Transgender
- Non-binary
- Prefer to self-describe, please describe: _____
- Prefer not to say
- Participant was unable to provide a response

What is your race/ethnicity?

- White or Caucasian
- Black or African American
- American Indian or Alaska Native
- Asian
- Native Hawaiian or Other Pacific Islander
- Hispanic or Latino
- Prefer to self-describe
- Prefer not to say
- Participant was unable to provide a response

What type of home are you living in now?

- Living with family, friends, or romantic partners
- Board and Lodging
- Supervised Living Facilities
- Boarding Care
- Shelter
- Transitional Housing
- Nursing Home
- Assisted Living
- Family Foster Care
- Community Residential Setting
- ICF/DD
- Living independently, please describe: _____
- Somewhere else, please describe: _____
- Participant was unable to provide a response

How many people live in your home right now?

- Total number of people who live in your home (cottage, living unit, etc.)

- People with disabilities (including friends, family, romantic partners, or other unpaid roommates with a disability, and/or others who receive services)
- People without disabilities (including friends, family, romantic partners, or other unpaid roommates who do not have a disability)
- Staff who live here (paid cohabitants)

With how many people do you share a bedroom?

Community Integration and Engagement

Part 1: Time, Money, & Integration – During the Day

Please describe your (the person's) past week – if last week wasn't usual, please describe a usual week.

HOURS: Estimate how many hours per week you worked, on average, in each kind of work setting

EARNINGS: Estimate how much money per week you earned from each kind of activity on average

INTEGRATION SCALE

#	Scale	Description
1	Completely segregated	Never in the presence of people without disabilities
2	Mostly segregated	Some or a little of the time in the presence of people without disabilities
3	In between	In between
4	Mostly integrated	Often in a situation where people without disabilities are, or might be, present
5	Completely integrated	Nearly always in a situation where people without disabilities might be present

Type of Day Activity	# Hours Work / Week	\$ Earned / Week	Integration Level
Self-Employed	#	\$	1 2 3 4 5
Competitive, integrated employment	#	\$	1 2 3 4 5
Community job with support staff	#	\$	1 2 3 4 5
In an enclave or job crew	#	\$	1 2 3 4 5
Sheltered employment, workshop employment, or subminimum wage employment	#	\$	1 2 3 4 5
Pre-Vocational Program or Vocational Rehabilitation Program	#	\$	1 2 3 4 5
Day Habilitation Program	#	\$	1 2 3 4 5

Type of Day Activity	# Hours Work / Week	\$ Earned / Week	Integration Level
Adult day program or non-vocational program	#	\$	1 2 3 4 5
Volunteer Work	#	\$	1 2 3 4 5
Public School (K-12)	#	\$	1 2 3 4 5
Private School (K-12)	#	\$	1 2 3 4 5
Adult Education (GED, Adult Ed, Trade School, etc.)	#	\$	1 2 3 4 5
Community Experience	#	\$	1 2 3 4 5
Other	#	\$	1 2 3 4 5

Part 2: Integrative Activities Scale – In the Past Four Weeks

About how many times did you do each of the following in the past four weeks?

Next, what is the average group size for each kind of experience?

Finally, do you normally have ANY interaction with community members when out?

Activity	None	Little	Some	Much	Very Much
Visit with close friends, relatives, romantic partners, or neighbors	1	2	3	4	5
Go to a grocery store	1	2	3	4	5
Go to a restaurant	1	2	3	4	5
Go to a place of worship	1	2	3	4	5
Go to a shopping center, mall or other retail store to shop	1	2	3	4	5
Go to bars, taverns, night clubs, etc.	1	2	3	4	5
Go to a movie	1	2	3	4	5
Go to a park or playground	1	2	3	4	5
Go to a theater or cultural event (including local school & club events)	1	2	3	4	5
Go to a library	1	2	3	4	5
Go to a sports event	1	2	3	4	5
Go to a health or exercise club, spa, or center	1	2	3	4	5
Use public transportation (May be marked "N/A")	1	2	3	4	5
Other:	1	2	3	4	5

Autonomy over Daily Life: Decision Control Inventory

Who makes decisions?

#	Scale
1	All or Nearly All Decisions Made by Paid Folks
2	Mostly Made by Paid Folks
3	Equally Shared Decisions
4	Mostly Made by Person and/or Freely Chosen Allies
5	All or Nearly All Made by Person and/or Freely Chosen Allies – relatives, friends, advocates
99	D/K, N/A

FOOD	All Paid	Mostly Paid	Equal	Mostly Unpaid	All Unpaid	D/K
What foods to buy for home when shopping	1	2	3	4	5	99
What to have for breakfast	1	2	3	4	5	99
What to have for dinner	1	2	3	4	5	99
Choosing restaurants when eating out	1	2	3	4	5	99

CLOTHES AND GROOMING	All Paid	Mostly Paid	Equal	Mostly Unpaid	All Unpaid	D/K
What clothes to buy in store	1	2	3	4	5	99
What clothes to wear on weekdays	1	2	3	4	5	99
What clothes to wear on weekends	1	2	3	4	5	99
Time and frequency of bathing or showering	1	2	3	4	5	99

SLEEP AND WAKING	All Paid	Mostly Paid	Equal	Mostly Unpaid	All Unpaid	D/K
When to go to bed on weekdays	1	2	3	4	5	99
When to go to bed on weekends	1	2	3	4	5	99
When to get up on weekends	1	2	3	4	5	99

SLEEP AND WAKING	All Paid	Mostly Paid	Equal	Mostly Unpaid	All Unpaid	D/K
Taking naps in evenings and on weekends	1	2	3	4	5	99

RECREATION	All Paid	Mostly Paid	Equal	Mostly Unpaid	All Unpaid	D/K
Choice of places to go	1	2	3	4	5	99
What to do with relaxation time, such as choosing TV, music, hobbies, going out, etc.	1	2	3	4	5	99
Visiting with friends who live outside of the person's residence	1	2	3	4	5	99
Choosing to <u>decline</u> to take part in group activities	1	2	3	4	5	99
Who goes with you on trips, errands, going out	1	2	3	4	5	99
Who you hang out with in and out of the home	1	2	3	4	5	99

SUPPORT AGENCIES AND STAFF	All Paid	Mostly Paid	Equal	Mostly Unpaid	All Unpaid	D/K
Choice of which service agency works with person	1	2	3	4	5	99
Choice of Case Manager	1	2	3	4	5	99
Choice of agency's support persons/staff (N/A if family)	1	2	3	4	5	99
Choice of support personnel: option to hire and fire support personnel	1	2	3	4	5	99

ECONOMIC RESOURCES	All Paid	Mostly Paid	Equal	Mostly Unpaid	All Unpaid	D/K
What to do with personal funds	1	2	3	4	5	99
How to spend residential funds	1	2	3	4	5	99

ECONOMIC RESOURCES	All Paid	Mostly Paid	Equal	Mostly Unpaid	All Unpaid	D/K
How to spend day activity funds	1	2	3	4	5	99

HOME	All Paid	Mostly Paid	Equal	Mostly Unpaid	All Unpaid	D/K
Choice of house or apartment	1	2	3	4	5	99
Choice of people to live with	1	2	3	4	5	99
Choice of furnishings and decorations in the home	1	2	3	4	5	99

WORK OR OTHER DAY ACTIVITIES	All Paid	Mostly Paid	Equal	Mostly Unpaid	All Unpaid	D/K
Type of work or day program	1	2	3	4	5	99
Amount of time spent working or at day program	1	2	3	4	5	99
Type of transportation to and from day program or job	1	2	3	4	5	99

OTHER	All Paid	Mostly Paid	Equal	Mostly Unpaid	All Unpaid	D/K
Express affection, including sexual	1	2	3	4	5	99
"Minor vices" - use of tobacco, alcohol, caffeine, explicit magazines, etc.	1	2	3	4	5	99
Whether to have pet(s) in the home	1	2	3	4	5	99
When, where, and how to worship	1	2	3	4	5	99

[If option 4 or 5 is selected above] You indicated, at times, that you or freely chosen allies make the decisions most to all of the time. Can you describe who usually makes the decisions?

- The person

- Their freely chosen ally
- Both the person and their freely chosen ally together
- Both the person and their freely chosen ally, but different decisions
- Other, please specify: _____

Overall, are you happy with who makes decisions for you?

- Yes
- Both yes and no
- No
- Unsure

Perceived Qualities of Life

#	Scale
1	Very Bad
2	Bad
3	In Between
4	Good
5	Very Good
99	D/K, N/A

Area	Very Bad	Bad	In Between	Good	Very Good	Don't know N/A
Health	1	2	3	4	5	99
Running my own life, making choices	1	2	3	4	5	99
Family relationships	1	2	3	4	5	99
Relationships with friends	1	2	3	4	5	99
Getting out and getting around	1	2	3	4	5	99
What I do all day	1	2	3	4	5	99
Food	1	2	3	4	5	99
Happiness	1	2	3	4	5	99
Comfort	1	2	3	4	5	99
Safety	1	2	3	4	5	99
Treatment by staff/attendants	1	2	3	4	5	99
Health care	1	2	3	4	5	99
Privacy	1	2	3	4	5	99
Overall quality of life	1	2	3	4	5	99
Overall inclusion in the broader community outside your home	1	2	3	4	5	99

Closest Relationships Inventory

A “close relationship” or friend is anyone the person (or whoever knows the person best) defines that way. If there are fewer than 5 close relationships, just describe however many there are.

Who are the people who are closest to you? We can talk about up to 5 people.

What kind of relationship do you have with each person?

- Relative
- Staff of home
- Staff of day program, school, or job
- Other paid (Case manager, nurse, etc.)
- Housemate
- Co-worker or schoolmate
- Neighbor
- Merchant
- Other (unpaid friend, non relative), please describe: _____

About how long have you known this person? (in years)

About how many times have you had ANY contact with this person, in the past four weeks (28 days)? Describe contact types in notes.

Initials or code:	<u>Relationship</u> (Present or Former) <ul style="list-style-type: none"> • Relative • Staff of home • Staff of day program, school, or job • Other paid • Housemate • Co-worker or schoolmate • Neighbor • Merchant • Other 	<u>Duration</u> About how long have you known this friend?	<u>Frequency</u> About how many times have you had ANY contact with this friend, in the past four weeks (28 days)?
1	1 2 3 4 5 6 7 8 9	Years	Times in Past 28 Days
2	1 2 3 4 5 6 7 8 9	Years	Times in Past 28 Days
3	1 2 3 4 5 6 7 8 9	Years	Times in Past 28 Days
4	1 2 3 4 5 6 7 8 9	Years	Times in Past 28 Days
5	1 2 3 4 5 6 7 8 9	Years	Times in Past 28 Days

Assistive Technology

The next questions are about assistive technology. Assistive technology includes anything you use to help you do things that might be difficult or impossible to do on your own. Assistive Technology can help you speak, walk, talk, remember, see, hear, learn, and more.

Do you use any assistive technology in your life?

- Yes, I use it now (ask 4-8)
- Yes, I have used it in the past (ask 3-8)
- No, but I need help doing certain tasks and would like to use it (ask 2)
- No (skip to last question)

Why don't you use assistive technology?

Why don't you use assistive technology anymore?

What assistive technology have you used or are you using?

How much difference has assistive technology made in increasing your independence such as your ability to do things with less help from others or on your own?

- A lot
- Some
- A little
- None

How much difference has assistive technology made in increasing your productivity such as your ability to do more in the same amount of time?

- A lot
- Some
- A little
- None

How much difference has assistive technology made in increasing your community integration such as doing things in your community outside of your home?

- A lot
- Some
- A little
- None

Overall, how much has your use of assistive technology decreased your need for help from another person?

- A lot
- Some
- A little
- None

The last question is:

- What three things would improve your quality of life?

Appendix B. Expanded methodology

The following section describes the process for the Olmstead Quality of Life Third Follow-up - 2024. This section is written from the perspective of The Improve Group, the evaluation firm that has partnered with the State of Minnesota Olmstead Implementation Office on this survey since 2024. We describe the project design, how we collected survey responses, and how we prepared the results for sharing.

In appreciation

Many people helped make this study possible. Some have been part of the project since it started in 2017. Others joined for this latest follow-up. The input and support from all contributors made the 2024 survey possible.

In particular, we want to thank the following people who helped in this work:

The 506 people who took the time to answer the survey. Without them, we could not have done this project.

The family members, guardians, staff, providers, case managers, and others who helped people take the survey.

The team of skilled interviewers who carefully collected information in a way that focused on each person.

The Olmstead Quality of Life Survey Advisory Group for advising on the survey and this report.

The Center for Outcome Analysis (COA) for their knowledge and tools.

Planning and collaboration

The State of Minnesota Olmstead Implementation Office partnered with The Improve Group to do this project. We also convened experts into an Advisory Group to offer guidance and recommendations at key points. The Advisory Group offered input into the project purpose and design, updates to the survey instrument, the plan for analysis, and making meaning and understanding results. The Advisory Group included:

Erica Alley, Ph.D., Minnesota Department of Health

Curtis Buhman, Minnesota Department of Human Services

James Conroy, Ph.D., Consultant

Steven Devlin, Ph.D., Consultant

Diane Doolittle, Olmstead Implementation Office

Aisha Elmquist, Olmstead Implementation Office

Rachel Garaghty, Minnesota Department of Health

Lisa Harrison-Hadler, Ombudsman for Mental Health and Developmental Disabilities

James Leibert, Ph.D., Minnesota Department of Human Services

Kody Olson, Minnesota Department of Health

John Patterson, Minnesota Housing

Scott Spreat, Ed.D. Consultant

Holly Sunderman, Minnesota Department of Employment and Economic Development

Mike Tessneer, Olmstead Implementation Office

Colleen Wieck, Ph.D., Minnesota Governor's Council on Developmental Disabilities

Study design

The Olmstead Quality of Life study is longitudinal, meaning it measures changes over time for the same group of people. In 2017, 2,005 people took part in the Baseline survey. For each follow-up survey, including the Third Follow-up in 2024, a subset of the same group of people were interviewed again using mostly the same protocol (see the following section for a description of the survey). The goal is to learn about their quality of life and how things have changed over time.

The Baseline survey engaged a randomly selected group of Minnesotans with disabilities who were eligible to receive services in potentially segregated settings. The survey's focus population includes people of all ages and disability types in eight service settings. These settings are listed and defined in [Appendix D](#).

Survey instrument

Olmstead Quality of Life projects have used an adapted version of the [Center for Outcome Analysis' Quality of Life Tool](#). This survey has a series of questions in four modules:

- Quality of life
- Social integration and engagement
- Decision-making power
- Closest relationships

It also asks participants questions to describe themselves and their current living situations, and about their use of assistive technology.

Advantages of this instrument are that it has been tested, used, and validated with a variety of populations over time. It explores important concepts, and results in scores

which can be measured over time. The instrument has been studied, and results from using it have been published. However, one note from the authors is that it has still never been used to study the general public broadly, or to determine what a “good” score is. Making statements about whether scores are “good” or not is outside of the purpose of this study, in favor of tracking change over time for the specific population involved in this project.

The Improve Group worked with the Advisory Group to update the survey instrument for 2024. Updates included removing questions that had been added to specifically ask about the impacts of the COVID-19 pandemic during the Second Follow-up. The Second Follow-up project happened at the height of the COVID-19 pandemic, when many activities were regularly done virtually. We also added questions to help fill in gaps in information identified during previous survey rounds.

Representatives from the Center for Outcome Analysis who developed this survey instrument participated in the Advisory Group’s conversations about updates. They verified that all updates were appropriate for the purpose of the project.

Sampling

A key goal for the Third Follow-up study was to have 500 people from the Baseline study participate again. This number matches the number of people who participated in earlier follow-up studies. Having 500 people take the Third Follow-up survey also provides enough responses to conduct meaningful subgroup analysis.

Two Minnesota State agencies hold program data and contact information about the 2,005 Baseline participants: the Minnesota Department of Human Services (DHS) and the Minnesota Department of Employment and Economic Development (DEED). DEED holds data associated with the 96 Baseline participants whose participation in Center Based Employment made them eligible for the survey. However, The Improve Group was not able to obtain a data sharing agreement with DEED. This meant we were not able to get individual-level data for these participants and were not able to do the same tiered, direct outreach as we did for others (described below). DEED sent a letter directly to these participants on behalf of The Improve Group inviting them to schedule an interview. However, no DEED participants reached out to participate. Therefore, these Baseline participants were not included in the Third Follow-up survey.

The Improve Group obtained individual-level data from the Minnesota Department of Human Services on the remaining 1,909 Baseline participants. Of those, 404 could no longer participate because they had passed away or moved out of state. Accordingly, 1,505 individuals from the 2,005 in the Baseline survey remained eligible for the Third Follow-up.

All previous follow-up surveys have reached out to a sample of Baseline participants. However, because so many fewer people remained eligible for the Third Follow-up than previously, we invited all 1,505 Baseline participants to take the survey in 2024. We

made this decision to give as many people as possible the chance to take the survey and give us the best chance of surveying 500 people.

Guardian consent

Previous surveys have always required guardians to sign a consent form on behalf of participants, when a guardian existed. Some guardians helped and supported respondents to be a part of the study. Others prevented responses. The Third Follow-up is the first time that guardian consent was not required for participation. It has never been a legal requirement, and we wanted to provide an opportunity for all people to decide for themselves whether they wanted to participate. As is described below, we did still communicate with many guardians. We sent letters to all guardians for whom we had contact information and reached out to guardians when we were not able to contact participants directly. Many guardians supported this project by helping to schedule, coordinate, and facilitate surveys.

Outreach and data collection

The Improve Group convened, trained, and supported a team of interviewers to reach out to people and support them to take the survey. Many interviewers came back to help with this follow-up survey after working on previous ones. While not a requirement, many interviewers also identified as either having a disability or a deep connection to the disability community in general. This natural connection contributed to participants feeling at ease and comfortable during the process.

To start data collection, we sent letters to all participants and their guardians. The letters explained the survey and how it would work. The letter included a written consent form for participants to use to share whether they wanted to participate or would choose not to. Within a few days of the first mailing, interviewers then began calling and emailing participants, their guardians, residential service providers, and other contacts. Contact information for participants and guardians largely came from the Minnesota Department of Human Services, previous surveys, and returned consent forms.

Surveys were administered like conversations, using a protocol. This allowed interviewers to provide support and explanations about questions, as needed. While a small number of interviews were conducted by phone due to participant preferences, almost all were conducted in person. No participants shared responses to the survey in an unsupported way (for example, by completing the survey alone, without an interviewer).

Interviewers arranged for additional support to be available during interviews when requested by participants. This included interpretation, technology, a space that is comfortable for the participant, or other supportive individuals. Following each interview, interviewers completed a debrief form where they documented other details of the interview, like where it took place, how many people were present, how many questions the participant answered compared to a proxy, and whether any follow-up was needed.

Interviewers also noted on the debrief form if any concerns about abuse or neglect were raised during the survey.

Analysis

The Improve Group used different ways to understand the information collected. The goal of the data analysis was to show:

- How people's lives changed over time
- What different groups of people experienced
- If things like race or age made a difference in experiences

The Improve Group used five types of analysis:

- Frequencies: This shares how many people selected a question's response option out of all people who responded to that question.
- Analysis of variance (ANOVA): This helps compare responses across different groups of people.
- T-test: This helps see how responses changed for people over time.
- Linear regression: This helps find out what things are connected to people's quality of life.
- Qualitative analysis: This looks at what people said in their own words on the survey. It helps find common ideas or feelings people shared.

The survey has four sets of questions, called modules. These modules are quality of life ratings, social integration and engagement, decision-making power, and closest relationships. Based on each respondent's answers to the questions, we calculated a score for each module. Then we compared average scores of different subgroups to help determine where there were differences between groups.

We also matched people's scores on the 2024 follow up to their scores on the 2017 survey. This matching allowed us to learn about change over time.

We also created a regression model. Regression helps to identify characteristics associated with an outcome. Our regression model helped to explore how things like participant demographics, services, and Baseline scores related to 2024 scores.

Appendix C. Minnesota counties, by region

We included some analysis by participant region. This was based on where participants lived, from DHS address records. Table 1 lists the counties included in each region for this analysis.

Table 1. Minnesota counties, by region

Region	Counties
Central	<ul style="list-style-type: none">• Benton• Chisago• Isanti• Kanabec• Kandiyohi• McLeod• Meeker• Mille Lacs• Pine• Renville• Sherburne• Stearns• Wright
Metro	<ul style="list-style-type: none">• Anoka• Carver• Dakota• Hennepin• Ramsey• Scott• Washington
Northeast	<ul style="list-style-type: none">• Aitkin• Carlton• Cook• Itasca• Koochiching• Lake• St. Louis

Region	Counties
Northwest	<ul style="list-style-type: none"> • Becker • Beltrami • Cass • Clay • Clearwater • Crow Wing • Douglas • Grant • Hubbard • Kittson • Lake of the Woods • Mahnommen • Marshall • Morrison • Norman • Otter Tail • Pennington • Polk • Pope • Red Lake • Roseau • Stevens • Todd • Traverse • Wadena • Wilkin
Southeast	<ul style="list-style-type: none"> • Mower • Dodge • Fillmore • Freeborn • Goodhue • Houston • Olmsted • Rice • Steele • Wabasha • Winona

Region	Counties
Southwest	<ul style="list-style-type: none">• Big Stone• Blue Earth• Brown• Chippewa• Cottonwood• Faribault• Jackson• Lac qui Parle• Le Sueur• Lincoln• Lyon• Martin• Murray• Nicollet• Nobles• Pipestone• Redwood• Rock• Sibley• Swift• Waseca• Watonwan• Yellow Medicine

Appendix D. Focus population settings

In 2017, the Baseline Quality of Life Survey drew a random sample of people who were eligible to receive services in the potentially segregated settings listed in Table 1. That year, 2,005 people responded to the survey. Each follow-up survey has reached out to a group of those original 2,005, regardless of their service eligibility at the time of the follow-up.

Table 1 lists the settings included in the 2017 baseline sample and a description of how those settings were defined in 2017. Since then, some setting definitions have changed, either in name or by statutory requirement. We share the historical definitions, which have been edited only for clarity, in Table 1 to maintain the record of the definitions used by researchers when drawing the original baseline sample.

Table 1. Description of focus population settings

Setting	Description
Center Based Employment	Center Based Employment programs help people with disabilities learn and practice work skills in a separate and supported environment. People may be involved in the program for a short or long amount of time. People who do work in these programs are paid based on the amount of goods or services they produce, instead of being paid by hour. The kind of work and the types of disabilities people experience can vary widely by program and by the area where the organization is located.
Day Training and Habilitation (DT&H)	DT&H programs are located in a separate place from where people live. The programs help people develop and maintain life skills, participate in community life, and engage in proactive and satisfying activities of their own choosing. These programs have health and social services to increase and maintain the physical, intellectual, emotional, and social functioning of people with developmental disabilities.
Board and Lodging	Board and Lodging facilities are licensed by the Minnesota Department of Health (or local health department). They provide sleeping accommodations and meals to five or more adults for a period of one week or more. They offer private or shared rooms with a private or attached bathroom. There are common areas for dining and other activities. Many offer a variety of supportive services (housekeeping or laundry) or home care services (assistance with bathing or medication administration) to residents. Board and Lodging facilities vary greatly in size—some resemble small homes and others are more like apartment buildings.

Setting	Description
Supervised Living Facilities (SLF)	Supervised Living Facilities have a Minnesota Department of Health license to operate. They provide supervision, lodging, meals, counseling, developmental habilitation, or rehabilitation services. These facilities support five or more adults who have intellectual disabilities, chemical dependencies, mental illness, or physical disabilities.
Boarding Care	Boarding Care homes are licensed by the Minnesota Department of Health and are homes for people who need minimal nursing care. They provide personal or custodial care and related services for five or more older adults or people with disabilities. They have private or shared rooms with a private or attached bathroom. There are common areas for dining and for other activities.
Nursing Facilities and Customized Living Services	Nursing facilities are inpatient health care facilities that provide nursing and personal care over an extended period of time (usually more than 30 days) for people who require convalescent care at a level less than that provided in an acute facility, people who are chronically ill or frail elderly, or people with disabilities. Customized living is a package of regularly scheduled individualized health-related and supportive services provided to a person residing in a residential center (apartment buildings) or housing with services establishment.
Adult Foster Care with Supported Living Services (Community Residential Setting and Family Foster Care)	Adult foster care includes individual waiver services provided to people living in a home licensed as foster care. Foster care and Supported Living Services are individualized and based on the individual needs of the person, and service rates must be determined accordingly.
Intermediate Care Facilities for Persons with Developmental Disabilities (ICF/DD)	IFC/DD are residential facilities that are licensed as health care institutions. They are certified by the Minnesota Department of Health. They provide health or rehabilitative services for people with developmental disabilities or related conditions who require active treatment.