

Olmstead Quality of Life Survey

Second Follow-up – 2020
Final Report

April 2021



MINNESOTA

OLMSTEAD IMPLEMENTATION OFFICE

April 26, 2021

Olmstead Subcabinet

Dear Commissioner Ho and Members of the Olmstead Subcabinet:

The attached report shares findings from the newly released Olmstead Quality of Life Survey Second Follow-up – 2020.

As you know, the Olmstead Plan is a broad series of activities Minnesota must accomplish to ensure people live, learn, work, and enjoy life in the most integrated setting¹. The most integrated setting enables people who have disabilities to interact with non-disabled people to the fullest extent possible. The Olmstead Quality of Life Survey measures quality of life over time of people in potentially segregated settings, who have the most to gain from integration.

Much work remains. Both quality of life and decision-making power remain stagnant since 2017. Worse, people had fewer close relationships and less community engagement than in previous studies. This means that people in Minnesota continue to wait—for the freedom to make and keep friends; for the power to decide where they live and how they enjoy life; and for the ability to simply go to a park, a community event, or a movie when and how they want to.

How can we view these results as acceptable? We have an obligation to always be working towards meaningful progress.

In the survey, people shared areas where quality of life was low, including how COVID-19 has affected them. The pandemic's impacts have been deeply challenging:

- Participation in work, day programs, and school declined dramatically.
- It became even harder to find support staff (learn more in [this article about the pandemic's disruption to caregiving](#)).

¹The “most integrated setting” is defined as “a setting that enables individuals with disabilities to interact with non-disabled persons to the fullest extent possible.” Integrated settings are those that provide individuals with disabilities opportunities to live, work, and receive services in the greater community, like individuals without disabilities. Integrated settings are located in mainstream society; offer access to community activities and opportunities at times, frequencies and with persons of an individual's choosing; afford individuals choice in their daily life activities; and provide individuals with disabilities the opportunity to interact with non-disabled persons to the fullest extent possible. Evidence-based practices that provide scattered-site housing with supportive services are examples of integrated settings. 28 C.F.R. pt. 35 app. A (2010)

- Providers had to be creative to reach people (as described in [this article about how services have shifted](#)).

These insights and stories help us better understand these effects. Consider the man who lost some of his functioning ability after his day program closed due to the pandemic.

But COVID-19 is not the only cause. Minnesota was failing people with disabilities long before the pandemic. Take one example from the 2018 survey, when a woman shared frustration because she could not get the life coach she needed. When we spoke in 2020, she was still waiting.

People must have more control over decisions that affect them; be able to build and nurture meaningful relationships; and have the freedom to engage with their communities. The State must make changes to support this—centering people’s experiences, as represented in this report, in all its decisions.

This survey is meant to measure change over time, so people will answer these same questions again in a few years. As you read the attached report, consider: Where can we use our power to shift control and decision-making to people to improve their quality of life? What changes do we hope to see in the next round of survey findings as a result of actions taken today?

I welcome any opportunity to discuss this report with members of the Subcabinet, State employees, individuals with disabilities, families, professionals, and allies. I am very grateful to the Olmstead Subcabinet for supporting this longitudinal study.

Sincerely,

Shelley Madore

Director

Minnesota Olmstead Implementation Office

Table of Contents

About this report.....	1
Acknowledgements	1
A note on report language.....	2
Executive summary: Olmstead Quality of Life Second Follow-up – 2020	3
Background	6
Purpose.....	7
Methodology.....	8
Focus population	8
Survey administration.....	9
Analysis	11
Key findings and recommendations.....	12
Quality of life ratings	12
Social integration and engagement.....	16
Decision-making power	23
Closest relationships.....	27
Appendix A: Quality of life ratings.....	31
Appendix B: Decision-making control	32
Appendix C: Detailed methodology.....	34
Who responded to and administered the survey	34
What participants shared	40
How we administered the survey.....	42
How we analyzed the data.....	49
Appendix D: Survey tool	52

About this report

This report includes findings from the Olmstead Quality of Life Second Follow-up – 2020. Data collection took place from August 2020-February 2021. The Olmstead Quality of Life Survey Advisory Group developed this report in partnership with The Improve Group. The Improve Group is an evaluation, research, and strategic planning consulting firm based in St. Paul, Minnesota. The Improve Group has been the State of Minnesota’s Olmstead Quality of Life Survey research partner since 2014.

The survey is intended to help the State of Minnesota learn how it can better promote integration for people who have experienced segregation because they have a disability. The survey does not capture the wholeness of a person’s life. This is important to remember when considering the results, so the data is not harmfully misinterpreted.

Like everyone, participants in the survey lead complex, multifaceted lives. Participants told us about romantic relationships, careers, hobbies, and more. We know that what we heard through the survey is only a sliver of participants’ full lives and experiences. However, they experience systemic barriers to the quality of life they otherwise would have were it not for segregation. We heard consistently that segregation is still negatively affecting quality of life—despite many efforts by the State to improve the disability system.

Acknowledgements

The Improve Group thanks the following for their role in this report.

Survey participants. We appreciate the 561 people who chose to provide their time and energy to the survey during a challenging year. Without their participation, the survey could not exist.

Those who supported participants in completing the survey. This includes family members, guardians, setting staff, providers, case managers, and others who supported scheduling and survey completion.

A dedicated team of interviewers who are passionate about and skilled in person-centered data collection. Interviewers were:

- Mark Adzick
- Erika Herrmann
- Pamela Johnson
- Anne Flueckiger

- Julie Vogeler
- Steve Guberman
- Jenna Askevold
- KiloMarie Granda.

The Olmstead Quality of Life Survey Advisory Group, which provided expertise for the survey and this report. The Advisory Group included:

- Curtis Buhman, Minnesota Department of Human Services
- Diane Doolittle, Olmstead Implementation Office
- James Leibert, Minnesota Department of Human Services
- Shelley Madore, Olmstead Implementation Office
- Nagi Salem, Minnesota Department of Health
- Mike Tessneer, Olmstead Implementation Office.

James Conroy, president of the Center for Outcome Analysis (COA), also lent subject matter expertise as a member of the Advisory Group. COA has performed extensive work in the developmental disabilities field, including research and policy-relevant evaluation in all 57 states and territories. COA is a national leader in research on the impacts of self-determination initiatives, the effects of deinstitutionalization, and the cost-effectiveness of Medicaid waiver services.

A note on report language

Throughout the report, “people” and “person” refer to people with disabilities who live or work in potentially segregated settings. This is the only population with whom the survey was administered, which means it is the only population for whom results can be generalized. People were eligible for the survey if they accessed services in these settings as of 2016. “Participants” refers specifically to people in this population who took the Olmstead Quality of Life Survey.

Executive summary: Olmstead Quality of Life Second Follow-up – 2020

The Olmstead Quality of Life Survey measures quality of life over time for a specific population in Minnesota: people who access services in potentially segregated settings. This report summarizes findings from the Olmstead Quality of Life Second Follow-up – 2020 and compares these results to quality of life in 2017 and 2018. The findings are based on data from 561 surveys administered between August 2020 and February 2021. COVID-19's influence on the data is described below.

These findings can help the State of Minnesota assess what is working and where renewed efforts under Minnesota's Olmstead Plan are needed. This process is important because **the needle on quality of life has not moved since 2017**, despite millions of dollars in investments and well-intentioned initiatives. In many areas, this data indicates a continued decline in integration that the State must reverse. The below recommendations suggest key areas for improvement.

Focus on shifting decision-making power to people.

Overall, participants had the same amount of power over decisions that affect them as in previous years. On average, paid staff made big decisions. These could include choosing a participant's case manager, housemates, and the amount of time they spend at work or a day program. Participants with public guardians had less decision-making control and less integration on their outings than those with no guardian or a private (usually family) guardian. These findings show the State must **review policies that affect people's decision-making and set new or revised Olmstead Plan goals to increase people's control over decisions.**

Focus on increasing outings and relationships.

We cannot ignore COVID-19's effects on survey findings. At the same time, we know from the 2017 and 2018 surveys that the pandemic is not the only factor that has stalled progress. Previous surveys show that segregation was a problem before the pandemic disrupted day programs and social opportunities. For example, the 2018 survey showed declines in participants' outings and relationships long before COVID-19 started. The State should **strengthen policies affecting people's outings and relationships and set new or revised Olmstead Plan goals to increase people's outings and relationships.** The current Olmstead Plan goals do not reference relationships.

In some instances, participants shared how providers and staff enforcing COVID-19 restrictions lowered their quality of life. We must document these impacts because this may be the only statewide survey that captured the experiences of people with disabilities in Minnesota during the

pandemic. It can help to **restore the relationships, freedoms, and other aspects of quality of life that have eroded during the pandemic**. It can also document lessons for future pandemics.

Invest in expanding the menu of formal activities like work, day programs, and school.

The number of participants taking part in formal activities such as work, day programs, and school fell sharply. Imagine a rural community only has one day program. The fewer choices a person in that community has, the more COVID-19 shutdowns can disparately affect them. This reinforces the well-established need for a wide range of options for work and engagement. The pandemic just made that need clearer. The State should **focus efforts and investments on expanding the options available to people who choose to work, go to day programs, and attend school**.

Ensure access to technology.

Participants engaged with their communities far less during COVID-19. Only some could turn to the internet in place of in-person activities. This is partly because access to the technology required to join online events is not universal. The survey did not ask whether participants had access to the internet, but 84 percent took it by phone rather than video call. Note that the survey team could only use platforms approved by the Minnesota Department of Human Services (DHS) Institutional Review Board. It did not allow Zoom until December 2020. That also affected who used video because participants were hesitant about unfamiliar platforms. This is an example of how a State restriction, while grounded in data privacy concerns, had the unfortunate consequence of removing choice.

Interviewer observations also point to the need for better access to technology. In one case, a participant could not take the survey themselves because they could not use the setting's house phone while quarantined. In this way, the pandemic showed that while providers may comply with minimum technology access requirements, that access is restricted.

This points to the need to **improve enforcement of existing minimum technology requirements in potentially segregated settings**. For example, one state law requires that 245D-licensed settings ensure "daily, private access to and use of a non-coin-operated telephone for local calls and long-distance calls." Additionally, the State needs to **revise minimum technology access requirements to keep up with the times**. The right to freely access the internet, with reasonable limitations for safety concerns and resident-developed house rules, should be universal for people with disabilities. This includes people in potentially segregated settings, whose internet access may be at the mercy of staff where they live or work. The current Olmstead Plan lacks goals around this type of access to technology.

Expand the focus population of the Olmstead Quality of Life Survey.

This report provides helpful data on the experiences of a specific population in Minnesota—people who access services in potentially segregated settings. Specifically, participants in the survey were drawn from the population of people who accessed these services when data collection began in 2016. But many people who benefit from the Olmstead Plan are not included. As more people move to more integrated settings, different factors affect their quality of life. For example, shortages of Personal Care Attendants (PCAs) can affect people living independently. Survey data shows an increase in decision-making power when people move to integrated settings, but a lack of improvement in other measures of quality of life. This points to the need to **broaden the focus population of this survey to understand the experiences of people with disabilities in Minnesota at different stages of integration.**

Learn from adaptations.

In some cases, people and providers responded to COVID-19 with creativity and innovation. For one participant, Special Olympics, glee club, dance club, and equine therapy all changed formats for safety during the pandemic. The State should learn from and build on successful cases of adapting programming to online and other socially distant formats. Scaling up these types of solutions could increase quality of life in general, not just during a pandemic. The State should **invest in research to document these successes. It should also fund their expansion, such as through DHS innovation grants.**

Improve data-tracking systems.

The survey team experienced challenges with the State’s data systems that people with disabilities who access public services likely share. The survey team frequently observed outdated data that did not reflect someone’s death or change in services. In other cases, guardianship information was not updated or contact information for settings was wrong. The State has a responsibility to keep people who access services safe and provide services in the most integrated setting. Yet, the survey team noticed several discrepancies in the data on where people access services. Without knowing where people are, the State will have difficulty ensuring people’s safety. The State should **strengthen systems that track where people access services and how to contact them and the people who support them.**

Background

Many people experience much of their lives segregated from the broader community, simply because of a disability. This begins early—in school, or before—and compounds over the course of a lifetime. It includes **potentially segregated settings, which are the focus of this report**. In these settings, people can have a lack of control over their lives.

Potentially segregated settings are residential and day settings identified in Minnesota’s Olmstead Plan as having characteristics of institutions. This includes a lack of control over where people live, with whom they live, access to family and friends, and access to work or school. The term “potentially” is used to indicate these settings may be restrictive for one person but not for another.

This report shares the urgency of people with disabilities who have been demanding change for decades. The plan and survey get their name from “Olmstead v. L.C.,” a 1999 U.S. Supreme Court case. Two women with developmental disabilities brought the case. As Justice Ruth Bader Ginsburg explained in [the court’s landmark opinion](#), one of the women pursued legal action after officials failed to move her from an institution to a community-based program. This happened even though professionals determined the move was appropriate for her. As the Court stated, this segregation violated the **Americans with Disabilities Act (ADA)**. It “perpetuates unwarranted assumptions that such persons are unfit for or unworthy of participating in community life.”

The **Americans with Disabilities Act**, passed in 1990, prohibits discrimination against people with disabilities in all areas of public life.

The Court went on to explain how this segregation affects quality of life:

If unnecessary institutionalization is the price that a person with mental disabilities must pay to receive needed medical services, then that person is forced to forego the pleasure of the less restrictive living that person could enjoy given reasonable accommodations.

[Minnesota’s Olmstead Plan](#) is named for this Supreme Court ruling. It originated as a settlement to a federal lawsuit called “Jensen v. DHS.” In this case, people with developmental disabilities who had been residents of a Minnesota Department of Human Services (DHS) facility sued the agency. As part of the settlement, the State of Minnesota agreed to develop an Olmstead Plan. Minnesota’s Olmstead Plan envisions people enjoying

their lives in the **most integrated setting**. It charges each Minnesota State agency with measurable goals to achieve this vision.

Minnesota's Olmstead Plan is a broad series of key activities Minnesota must accomplish to ensure people live, learn, work, and enjoy life in the most integrated setting. The plan defines the **most integrated setting** as one that enables people with disabilities to interact with non-disabled people to the fullest extent possible.

The plan defines employment and living settings for people with disabilities as potentially segregated if they are:

(1) congregate settings populated exclusively or primarily with people with disabilities; (2) congregate settings characterized by regimentation in daily activities, lack of privacy or autonomy, policies limiting visitors, or limits on individuals' ability to engage freely in community activities and to manage their own activities of daily living; or (3) settings that provide for daytime activities primarily with other people with disabilities.

Person-centered planning is a core element of Minnesota's Olmstead Plan. This approach to providing services enables people to share what is important to them and to create lives they personally value.

Person-centered planning is an organized process of discovery and action meant to improve a person's quality of life. Person-centered plans identify what is important to and for a person.

Minnesota's Olmstead Plan assumes that when people have more control over their own lives, their quality of life improves.

Purpose

Minnesota's Olmstead Plan requires that a **longitudinal** survey—one that follows the same group of people over time—measure quality of life. That is the purpose of the Olmstead Quality of Life Survey. People who were receiving services in potentially segregated settings as of 2016 are re-surveyed periodically to detect change.

The Olmstead Quality of Life Survey is **longitudinal**, meaning it measures change over multiple years by following the same people over time.

Survey findings, which are only generalizable to people in potentially segregated settings, can inform where the State needs to continue making changes. This report is a resource for the Olmstead Subcabinet to listen to people with disabilities to improve systems, practices, and policies.

Methodology

This report includes findings from the third round of the survey. The first survey in 2017 provided **baseline data** about quality of life for the 2,005 people who participated.

Baseline data, in this case from 2017, is data against which follow-up survey data is compared to detect change.

Focus population

To best understand how to improve Minnesota’s Olmstead Plan, people who could most benefit from changes participated in the survey.

The focus population for this survey is people in Minnesota with disabilities who were authorized to receive services in potentially segregated settings at the time they were invited to join the study. A sample of people from the focus population was selected to participate in the study. The sample includes people of all disability types, including people with multiple disabilities, people with physical disabilities, and people with cognitive and intellectual disabilities. Participants are eligible to remain in the study as long as they live in Minnesota.

Survey responses from people with lived experience is invaluable to knowing whether Minnesota’s Olmstead Plan is having the desired effects.

Purposive sample of people who are Black, Indigenous, and People of Color

The 2020 survey included additional surveys with people who are Black, Indigenous, and People of Color (BIPOC).

Black, Indigenous, and People of Color (BIPOC) is used to highlight the unique history and experiences of Black and Indigenous communities in relationship to the United States. By using this term, we are working toward recognizing many experiences, nuances, and communities.

It is important to note that BIPOC communities encompass vast differences in identity, experiences, and perspectives—not only across Black, Indigenous, and People of Color groups but within each of these.

Table 1: One in five survey participants is Black, Indigenous, and/or a Person of Color.

Race/ethnicity	Number of participants	Percent
American Indian/Alaska Native	23	4.1%
Asian	15	2.7%
Black/African American	39	6.9%
Hispanic/Latino	9	1.6%
Multiracial/mixed race	16	2.8%
Native Hawaiian/Pacific Islander (not reported in findings by race/ethnicity)	1	0.2%
White	451	80.2%
Race not provided (not reported in findings by race/ethnicity)	7	1.2%

Participants included one Native Hawaiian/Pacific Islander person. This person’s data is not reported in findings disaggregated by race/ethnicity to honor our commitment to confidentiality. This person’s results are included in the full data.

This data can help illuminate the different ways the disability system serves white and BIPOC people and the experiences they have as a result. The topic of BIPOC people’s experiences with public services is complex, layered, and well-documented, such as in the [2001 report from the Transnational Racial Justice Initiative \(PDF\)](#) and Minnesota’s own [Advancing Health Equity in Minnesota report \(PDF\)](#). As these reports and many others show, policies that benefit white people while disadvantaging people who are BIPOC are embedded throughout U.S. public institutions. As the U.S. Department of Health and Human Services acknowledged in a [2011 report on assuring health equity \(PDF\)](#):

Aside from the public health issues that most racial/ethnic minorities face, minorities with disabilities experience additional disparities in health, prejudice, discrimination, economic barriers, and difficulties accessing care as a result of their disability—in effect, they face a “double burden.”

Survey administration

The Improve Group leveraged multiple contact methods to invite people to participate in the survey, including mail, phone calls, text messages, and email. By being flexible with the contact method, we built efficiencies into the project while prioritizing individual preferences.

In 2018, the survey team conducted the First Follow-up with 511 people who had taken the 2017 survey. The Second Follow-up – 2020 engaged 561 people. This included 509 who participated in the baseline survey and 52 people who were added to the sample to allow a more nuanced understanding of BIPOC experiences.

In the survey, people who access services in potentially segregated settings shared in their own words:

- How they spend their days
- With whom they hold their closest relationships
- How involved they are in decisions affecting them
- Their general outlook on their life.

The survey did not define the concepts referenced, which allowed participants to self-define them and share how they perceive their quality of life—even if that contradicted what medical professionals or others would say. **The point is for people with disabilities to continue to lead the way in making the decisions and shaping the systems that are most important to them.**

The survey team intentionally designed the survey to **affirm people’s realities as the truth and as the most important data for informing policymakers.** This fills a gap in research informing policymaking. Studies have shown that people with disabilities are frequently left out of mainstream research. This can be because research criteria are designed in a way that excludes their participation, or because the research is not designed to be accessible (more information in this [journal article on conducting accessible research](#)). While the survey team made efforts to make the survey accessible, it is important to note that people experiencing the greatest oppression and segregation may have been restricted by people with power over them from taking the survey. We recognize these perspectives may be missing from the survey results.

A team of **highly qualified, dedicated interviewers conducted the interviews using a person-centered approach.** This allowed people to share their own experiences rather than having others answer for them. Participants who needed support to complete the survey, such as people who do not use verbal or other expressive language, had the option to get assistance from someone they know well. When possible, participants met with an interviewer they knew from previous surveys.

See the detailed methodology and survey tool in the Appendices C and D of this report for more information.

Challenges

In past years, the survey was conducted in person, typically at the participant's home or day setting. The move to conducting all surveys virtually due to the pandemic presented multiple layers of difficulty, such as if participants required additional support for using technology.

In addition, once a survey was scheduled, virtual interviews presented technology challenges for many participants. This led to an increased use of proxies; in some cases, interviewers could not determine the extent to which the participant drove responses. While most technology glitches were solved in the moment, video and sound delays could impact the participant experience in some cases.

The survey team also experienced challenges with the State's data systems that people with disabilities who access public services likely share. The survey team frequently observed outdated data that did not reflect someone's death or change in services. In other cases, guardianship information was not updated or contact information for settings was wrong.

Recommendation: Improve data-tracking systems.

The State has a responsibility to keep people who access services safe and provide services in the most integrated setting. Yet, the survey team noticed several discrepancies in the data on where people access services. Without knowing where people are, the State will have difficulty ensuring people's safety. The State should **strengthen systems that track where people access services and how to contact them and the people who support them.**

Analysis

The survey team used multiple types of analysis to come to the findings included below. Findings are meaningful if they are big enough that people would notice the changes in their lives. Changes over time or relationships between factors (e.g., that race makes a meaningful difference for some parts of life) are also meaningful if they are likely not due to chance. The analysis methods included:

- Analysis of variance, aka ANOVA, to compare difference across groups.
- T-tests, to compare differences in groups over time. Each participant is identified by a confidential number in the data, allowing the team to connect their most recent responses to past responses.
- **Linear regression** to identify factors or characteristics associated with quality of life and changes in quality of life. Regression informs where the State may have opportunities to drive real and significant change in these outcomes.

- Qualitative **analysis** to determine themes from interviewer debrief forms and open-ended survey questions.

The survey team brought the results of analysis to the survey Advisory Group for co-interpretation and to inform recommendations.

Key findings and recommendations

Overall, **the needle on quality of life has not moved since 2017**. In many areas, this data indicates a continued decline in integration that the State must reverse. The Olmstead Subcabinet can use these findings and recommendations to improve the disability system and people’s quality of life.

The findings below include some comparisons by race and ethnicity. In interpreting these findings, it is important to note that many factors affect an individual person’s quality of life. At the same time, societal factors like racism can impact life more for certain groups. For example, different experiences within the system could lead white participants to rate treatment by staff more positively than Black/African American or multiracial/mixed race participants. Or, inequities in how health care systems serve Black participants could contribute to how someone rates their health (more information in this [National Academies of Sciences, Engineering, and Medicine resource on health inequities](#)). The compounding of these factors may explain some of the differences described below.

Quality of life ratings

Participants rated 14 areas of their quality of life, from food, to relationships, to their health. The scale ranged from “very bad” to “very good.” The survey did not define “bad” or “good.” It allowed participants to draw on their own beliefs and experiences in their responses. The 14 areas covered in the survey were the most common responses in studies asking over 1 million people¹ worldwide what is important to them and gives value to their lives.

Participants’ overall quality of life has essentially remained flat since 2017.

Ratings of specific parts of life generally increased. However, these small increases did not lead to a meaningful increase in overall scores. The 2020 survey overall **average quality of life score of 77.6 out of 100 is only slightly higher than the 2017 score of 76.6**.

¹ These studies were conducted by the Center for Outcome Analysis, the founder of which sits on the Advisory Group for the survey.

Average quality of life scores were essentially unchanged.



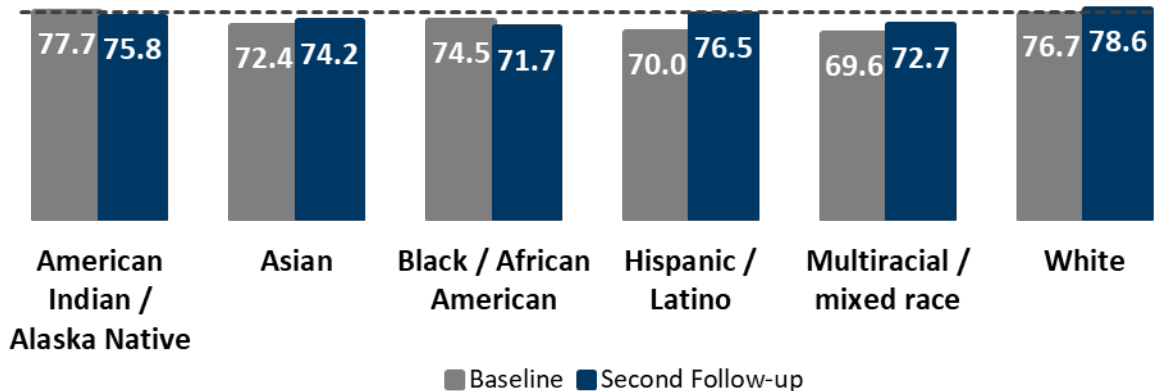
See average ratings for all 14 scores for each year in Appendix A.

Inequities exist in quality of life.

Responses to this item show that the system is resulting in inequitable quality of life for participants of different races and ethnicities.

White participants reported the highest quality of life (78.6 out of 100). Black participants do not have the same opportunities for quality of life as their white counterparts, reporting a lower score (71.7).

Black/African American and multiracial/mixed race participants reported the lowest quality of life scores. The state average score of 77.6 is represented by the dotted line.



Regression analysis confirms that **differences by race persist** in survey findings related to quality of life, decision-making, and outing interactions, even when other factors, such as whether someone lives in the Twin Cities or greater Minnesota, are the same.

Participants who live in residential settings reported lower quality of life than participants who do not access residential services.

Quality of life was highest for participants receiving only day services, at 82.5. Participants only receiving residential services reported an average quality of life score of 75.5. This means that **people who live in potentially segregated settings have a meaningfully lower quality of life than people who do not**. Looking at specific settings, quality of life was highest (80.2) for day training and habilitation and lowest (72.5) for nursing facilities and customized living services, aka assisted living.

Recommendation: Expand the focus population of the Quality of Life Survey.

This report provides useful data on the experiences of a specific population in Minnesota—people who access services in potentially segregated settings. Specifically, participants in the survey were drawn from the population of people who accessed these services when data collection began in 2016. But many who are affected by the Olmstead Plan are not included. As more people move to more integrated settings, different factors affect their quality of life. For example, shortages of Personal Care Attendants (PCAs) can affect people living independently. Survey data shows an increase in decision-control power when people move to integrated settings, but a lack of improvement in other measures of quality of life. The State should broaden the focus population of this survey **to understand the experiences of people with disabilities in Minnesota at different stages of integration.**

When asked specifically about COVID-19, most participants said their life got worse during the pandemic.

Participants shared how life during the pandemic compared to before it started.

Table 2: Most participants said their quality of life was worse during COVID-19 than before.

Response	Percent of responses
Much better	1.1%
Better	6.2%
About the same	35.6%
Worse	42.4%
Much worse	11.8%

Participants also shared why life was worse. Reasons included lost income, fewer opportunities to be social, and a loss of a sense of community.

Participants shared missing activities they experienced pre-pandemic. As one person said,

I was very independent, I could meet with my friends from church, I could be part of the community inclusion, even though I'm disabled I could make a difference. I could go to my groups and they could help me. I used to go to the Capitol each year and advocate. I volunteered for the zoo. I miss this stuff a lot.

In some cases, options for how to live life may have gone from few to zero. People in potentially segregated settings already had fewer choices about how to spend their time and less power to make those choices than people not in potentially segregated settings. Restrictions on visitors, day program closures, and other pandemic limitations cut people off from opportunities for integration and social activities. This means that while COVID-19 has affected everybody, it can have greater impacts on those who live in a place where other people make decisions about daily life.

Participants shared:

I couldn't go anywhere or do anything, people couldn't come in the house, I get depressed when I can't visit friends or go places.

I'm not making money, not working every day, I don't like to stay home.

I feel like a shut-in, in quarantine, and now I have a lot more hip and shoulder pain from not moving around as much.

As another participant's mother said,

He's not going to his day program or going anywhere; he's not getting stimulation. When he does not get stimulation, he tends to want to sleep more and he loses some of his functioning ability. He doesn't see as many different people and they are having troubles staffing, so he misses out on services and people coming to work with him.

Some participants shared that their quality of life improved during the pandemic.

Roughly 7 percent of participants said life was better or much better. One reason they shared was **reduced stress from not having to participate in day activities and outings**. This shows that people's quality of life could be better if they could make these decisions for themselves. Regression analysis shows that increased decision-making control is associated with increased quality of life. As the following two participants said:

I get to stay home and not go to my day program and can sleep later in the morning. I can sleep when I want. I don't have to get dressed.

I get to sleep, now I don't have to get up and go to my support group. Now we meet by phone.

As one family member, who serves as the participant's guardian, shared:

Even though she hasn't been able to get out, she's handling [it] better than others including her family. When she was going to her day program, she would come [home] unhappy and had issues with people, so she would complain a lot, but this seems to [be] more stable for her mood and every day is the same. She seems much more relaxed and less anxious having the same events day to day.

Some participants said the pandemic made them feel more connected and equal to other people. For example, one participant said:

We have a mutual emergency to deal with. It's brought everyone into the same boat, common ground. It makes me feel more equal.

Meanwhile, 36 percent of participants said their quality of life stayed the same during the pandemic.

Most participants said their activities had changed to some degree. However, some said their routine had not changed much since the pandemic started.

Participants shared some ways providers or setting staff have supported their quality of life amid pandemic restrictions. This may explain why some participants said life was the same as before the pandemic. As one participant's private guardian noted,

His group home has done a good job of doing things to keep busy despite having some isolation when they could not leave the house.

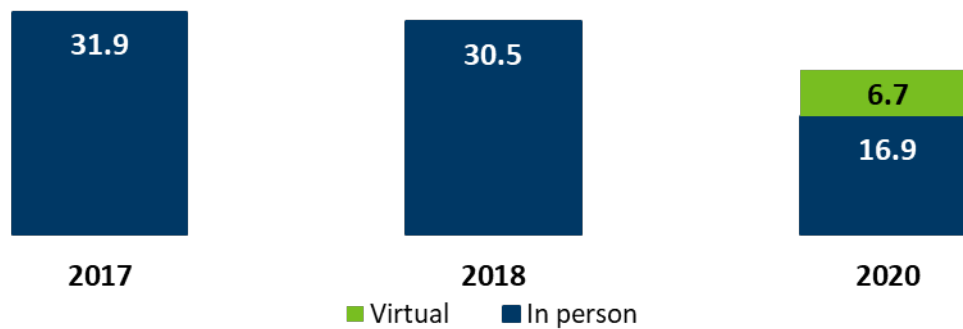
Social integration and engagement

Integration, membership, social inclusion, and community engagement are central to quality of life. The survey asked participants about their daily activities and opportunities for engagement in the previous four weeks. Participants shared how many hours they worked, how much time they spent volunteering, how often they visited with friends and family, and how often they participated in community events.

Participants engaged with their communities far less.

Social activities outside the home decreased sharply, partially replaced by virtual experiences.

On average, participants had far fewer outings per month. The virtual and in-person outings in 2020 add to an overall average of 23.6 outings.



In September 2020, the survey team also asked comparable questions of 125 people who live in Minnesota who do not access services in potentially segregated settings. They provided information about their daily activities before and during COVID-19. It is important to note this is one measure of how people in potentially segregated settings may have experienced COVID-19 differently than people not in these settings. It does not account for the many factors that shape someone's quality of life.

In 2019, people in the comparison survey averaged 32.7 outings per month. In 2020, the average dropped to 16.5, including virtual opportunities. While the comparison survey respondents reported fewer outings during COVID-19 than the study participants, it is likely that fewer comparison survey respondents lost their other outlets for social engagement, such as work, school, or other activities.

Only some participants could turn to the internet for social activities.

Participants engaged with their communities far less during COVID-19. However, only some could turn to the internet in place of in-person activities. This is partly because **access to the technology required to join online events is not universal**. The survey did not ask whether participants had access to the internet, but 84 percent took it by phone rather than video call. Note that the survey team could only use platforms approved by the DHS Institutional Review Board. It did not allow Zoom until December 2020. That also affected who used video because participants were hesitant about unfamiliar platforms. This is an example of

how a State restriction, while grounded in data privacy concerns, had the unfortunate consequence of removing choice.

Interviewer observations also point to the need for better access to technology. In one case, a participant could not take the survey themselves because they could not use the setting's house phone while quarantined. In this way, the pandemic showed that while providers may comply with minimum technology access requirements, that access is restricted.

Recommendation: Ensure access to technology.

This points to the need to **improve enforcement of existing minimum technology requirements in potentially segregated settings**. For example, one state law requires that 245D-licensed settings ensure “daily, private access to and use of a non-coin-operated telephone for local calls and long-distance calls.” Additionally, the State needs to **revise minimum technology access requirements to keep up with the times**. The right to freely access the internet, with reasonable limitations for safety concerns and resident-developed house rules, should be universal for people with disabilities. This includes people in potentially segregated settings, whose internet access may be at the mercy of staff where they live or work. The current Olmstead Plan lacks goals around this type of access to technology.

BIPOC participants had more virtual outings than white participants.

BIPOC and white participants had similar numbers of in-person outings. But when it came to virtual outings, each group of BIPOC participants had more than white participants. BIPOC participants also visited with friends and family an average of 11 times per month, compared to eight times a month for white participants.

In outings, participants had less interaction with people outside the disability system than in previous years.

The survey asked participants how often they interact with community members during outings. This helped measure how integrated their lives are. These responses were calculated into an outing interactions score out of 100. The closer to 100, the more interaction participants had with community members.

In addition to going on fewer outings, participants reported a **meaningful decline from previous years in interaction with people outside the disability system**.

Participants engaged with people in the community far less.



Certain factors are associated with higher outing interactions scores.

Regression analysis shows that certain factors and activities are associated with higher outing interactions. The following increase the likelihood participants interacted more with community members in their outings:

- Having any type of job. However, some types of sheltered or supportive employment were associated with a big decrease in outing interactions in the 2020 survey.
- Partaking in a wider variety of outings (e.g., seeing friends, going to bars, and going to the park, as compared to only seeing friends).
- Having more close relationships.

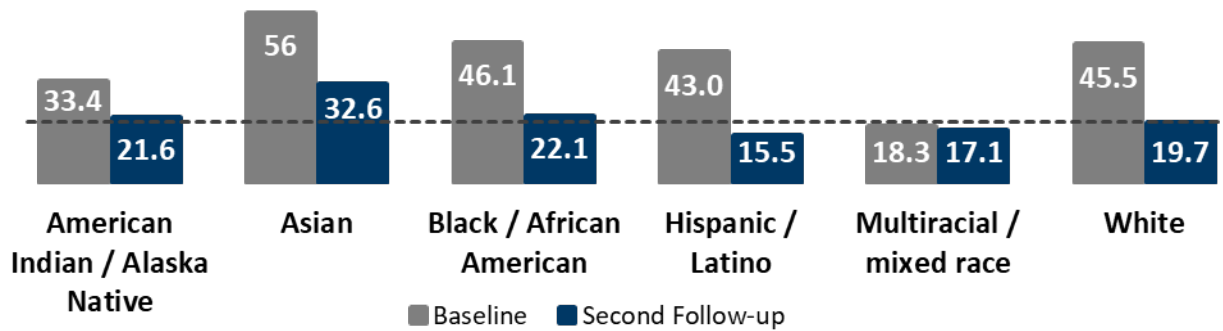
On the flip side, partaking in any school activity is associated with a decrease in outing interactions.

Older participants, participants with public guardians, and Hispanic/Latino participants reported lower outing interactions scores.

Some differences emerged in levels of outing interactions.

- Participants ages 40-49 had the highest outing interactions scores (24.4), while participants ages 70 and over had the lowest (12.8).
- Participants with private guardians had the highest outing interactions at 21.4. Meanwhile, participants with public guardians had the lowest outing interactions, at 13.9.
- Asian participants reported the highest average level, at 32.6. Hispanic/Latino participants reported the lowest at 15.5.

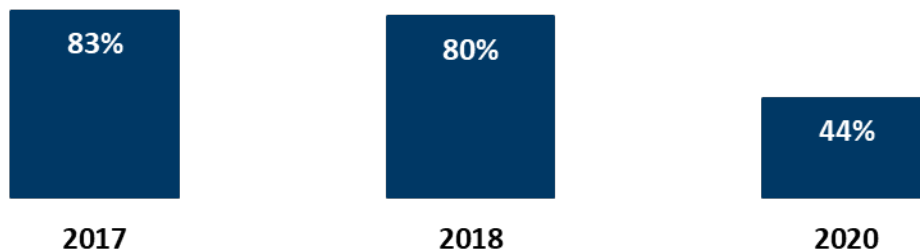
Outing interactions scores varied widely by race and ethnicity. Asian, Black/African American, and American Indian/Alaska Native participants had higher outing interactions scores than the state average of 20.1, which is represented by the dotted line.



Participation in work, day programs, and school declined dramatically.

Only 44 percent of participants went to any day activity in the four weeks before the survey. This is compared to 82.8 percent of participants in 2018 and 80.3 percent of participants in 2017.

Fewer than half of participants went to work, day programs, or school.



This decrease was similar across work, school, and other types of day activities.

Programming changes due to the pandemic partially explain the decrease. While day programs were open during the survey, **adaptations limited who could access the programming.** These included reduced capacity, limits on the number of daily hours, restrictions due to COVID-19 exposure, and limitations for high-risk individuals (see more at [this DHS webpage on adult day services during the pandemic](#)). For example, one amendment to an executive order limited capacity at adult day centers to 50 percent even after they could reopen. People may have also felt unsafe attending programs. However, this cannot entirely explain the big drop in participation across formal activities.

Participants who did take part in formal activities reported half as many hours there (17.1 per week) as in previous years.

Closures negatively affected participants' lives. The effects included lost income, fewer opportunities to be social, and loss of a sense of community. As one participant shared:

I don't get out and do as much as I used to because of COVID. I can't do sports because of COVID. I lost a job that I got hired to do dishes, and got promoted, then lost [it] because of COVID. I was set to get married and be moving in with my fiancé, and this stupid virus shot everything ... pushed me off that pedestal. There have been positives, but it's been hard.

Some participants shared that the restrictions made them feel more isolated or trapped. A few shared that they felt their provider used the pandemic to limit their choices. For example, one participant said:

They [staff] want to take your decisions away from you, instill fear in you about COVID. You don't live here—you exist.

The interviewer also noted that the participant referred to her living setting as a "prison." This participant was not allowed to leave the building to go down the street to a park, a decision staff attributed to COVID-19 risks.

Participants in more integrated day settings, like competitive employment, were often able to continue working, in some cases making more money. As one participant making \$13 per hour in a maintenance position said:

[I] wasn't laid off, so still working and keeping essentially the same schedule. Only issue is mask wearing is a bummer.

More segregated settings were more affected by COVID-19.

The survey also measured integration by day activity. This showed that in 2020, fewer participants spent time in the following types of day activity/employment—all of which had integration levels below 4—than in previous surveys:

- Supported employment
- Enclave or job crew
- Sheltered employment or workshop
- Day training and habilitation
- Adult day program
- Volunteer work.

This is an example of how COVID-19 restrictions more disparately hindered access to segregated settings than integrated settings.

Recommendation: Invest in expanding the menu of formal activities like work, day programs, and school.

The number of participants taking part in formal activities such as work, day programs, and school fell sharply. Imagine a rural community only has one day program. The fewer choices a person in that community has, the more COVID-19 shutdowns can disparately affect them. This reinforces the well-established need for a wide range of options for work and engagement. The pandemic just made that need clearer. The State should **focus efforts and investments on expanding the options available to people who choose to work, go to day programs, and attend school.**

Participants had limited choice in how to make money and how much money they earn.

One participant said she enjoys her work at a thrift store. The participant's mother commented that job programs and other supports in the participant's small, rural town are limited. Despite this, they are both happy with the participant's job situation.

Meanwhile, multiple participants shared that they are not satisfied with their job or income situation:

- One participant has reported in all three surveys frustration that he cannot find a better job.
- Another participant worked for the local YMCA before COVID-19 cost them their job. They mentioned difficulty managing restrictions on how much money they can have. If they have more than \$2,000, they must spend it down to qualify for supplemental security income. This impacts their quality of life because they cannot save for vacations or other big costs without it impacting other income sources.
- Another participant worked at a day program before COVID-19. The participant's wife said he cannot retire because they could not otherwise afford his care.

The pandemic forced providers to engage in creative person-centered planning.

As COVID-19 limited regular programming, **some employers and providers supported participants to join online or socially distant options.** For example, some put exercise classes, adaptive recreational services, and worship services online. In other cases, staff

adapted to new ways of operating during the pandemic. For example, staff at one setting have taken a participant to get craft materials through curbside pickup.

One participant's mother, who serves as his guardian, explained how his activities transitioned online. The participant's busy schedule pre-COVID-19 included Special Olympics, glee club, dance club, and equine therapy. Each program adapted to either virtual or other pandemic-safe formats. For example, the equine therapy program resumed with a parent or household member serving as the spotter who is one-on-one with the rider (typically staff's role).

In these promising cases, the State can learn from providers' and other organizations' creative solutions.

Recommendation: Learn from adaptations.

In some cases, people and providers responded to COVID-19 with creativity and innovation. The State should learn from and build on successful cases of adapting programming to online and other socially distant formats. Scaling up these types of solutions could increase quality of life in general, not just during a pandemic. The State should **invest in research to document these successes. It should also fund their expansion, such as through DHS innovation grants.**

Decision-making power

To understand a participant's **decision-making power**, interviewers asked if the participant, paid staff, or unpaid allies make different types of decisions. The answers from these questions were calculated into an overall decision-making score out of 100. Higher decision-making scores indicate participants and **unpaid allies** have more decision-making power than **paid staff**. This is important because paid staff are inherently in a position of power over people. While participants may develop real, loving relationships with paid staff, it is still inherently a transactional relationship. Meanwhile, unpaid allies are family members or friends who support the person because of a personal relationship.

Decision-making power is the extent to which people make decisions for themselves. These decisions may include input from **unpaid allies** who know and love the person and whose primary motivator is their loving relationship. In other cases, decisions are made by **paid staff** who work where people live or access services. Paid staff can also include case managers and other professionals who are hired to provide services to people.

Regression analysis shows that as the number of participants' close staff relationships increases, decision-control scores decrease. This means that **when people are closer with staff than with unpaid allies like friends and family, they have less control over decisions affecting them.**

Overall, participants had the same amount of power about decisions affecting them as in previous years.

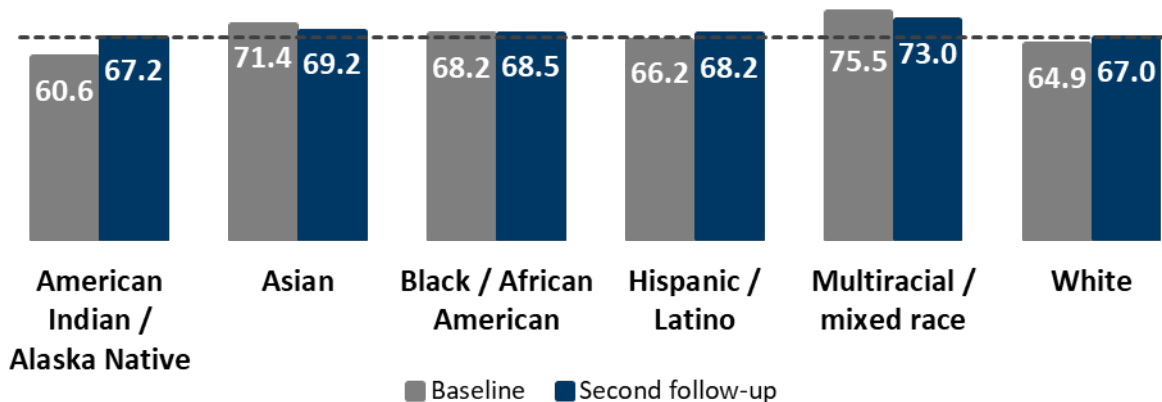
An overall decision-making score was calculated to compare results to previous years. This score—**67.4 out of 100**—has essentially not moved since 2017.

Participants' decision-making power has not substantially increased since 2017.



The level of decision-making power was similar across participants of different races and ethnicities.

Decision-making scores were similar across race and ethnicity, with American Indian/Alaska Native participants reporting a meaningful increase in decision-making power. The dotted line represents the 2020 state average of 67.4.



Participants had more control over day-to-day choices.

When looking at specific types of decisions, on average participants said that paid staff had the most control, and participants the least, in decisions that impact how and when participants engage with their community. Participants reported lower decision-making control over choices about:

- Support personnel, including the choice to hire and fire staff
- How to spend residential funds
- Agency's support person/staff
- Type of transportation to and from a day program or job.

This contrasts with more day-to-day decisions. On average, participants said they themselves and unpaid allies made decisions like when to nap on evenings and weekends, what to have for breakfast, and when and how often to bathe.

Different stories shared by participants illustrate how decision-making control affects quality of life. Often, participants lacked the decision-making control to change parts of their life that did not satisfy them. For example:

- One participant, who lives in a group home, criticized several aspects of his living situation—staffing of the home, his ability to go shopping and have alone time, and how the living room was furnished.
- Another participant, who lives in adult foster care, told the interviewer that her foster mom does not take her to church, even though the participant is a “full-faith Christian.”
- A participant said she does not like living in a group home because her boyfriends cannot visit overnight. When visiting, they must give identification and sign in with the home staff, which she finds restrictive. She wishes she could live on her own and has expressed this to her case manager.
- A participant shared frustration that she could not hire a life coach. She said this type of support is not covered or offered.

See Appendix B for the full results of the decision-making control scores.

Older participants and participants in certain settings had less decision-making control.

Participants ages 30-39 had the highest amount of decision-making control, at 72.7. Those ages 70 and older had the least, at 59.7.

Participants in center-based employment averaged a decision-making score of 86.6. Participants in intermediate care facilities for people with developmental disabilities, which are residential, had far less control. They averaged a decision-making score of 54.5. Regression analysis further supports this. It shows that **living independently or with friends or family is associated with higher decision-making control** (an average of 12 to 24 points more than participants in adult foster care). This illustrates the ways different settings can impact people’s lives.

Participants with public guardians had less choice and took part in fewer activities.

People who live and work in potentially segregated settings often have public guardians. Typically, a public guardian assumes the role that a family member or friend would play, acting on behalf of the person in decisions about food, health care, housing, and other parts of life. The State or county pays the guardian to provide this service.

Because of the important role these guardians can play in people’s lives, we analyzed the survey results using the guardianship status from participant’s most recent assessment. This can uncover where participants’ guardianship status could be affecting quality of life.

Table 3: Participants with public guardians had less control over decisions that affect them.

Guardianship status	Average decision-making score in 2017	Average decision-making score in 2018	Average decision-making score in 2020
No guardian	71.6	72.5	69.9
Private guardian	64.2	65.8	66.8
Public guardian	54.8	56.2	60.2
Statewide	66.2	67.6	67.4

Recommendation: Focus on shifting decision-making power to people.

Overall, participants had the same amount of power over decisions that affect them as in previous years. On average, paid staff made big decisions. These could include choosing a participant’s case manager, housemates, and the amount of time they spend at work or a day program. Participants with public guardians had less decision-making control and less integration on their outings than those with no guardian or a private (usually family) guardian. These findings show the State must **review policies that affect people’s decision-making and set new or revised Olmstead Plan goals to increase people’s control over decisions.**

This could build on current Olmstead Plan goals around informed choice, as measured by the National Core Indicators survey, and around people’s participation in public commissions and input opportunities.

Closest relationships

Close relationships are central to quality of life. For people who live and work in potentially segregated settings, friendships—especially with people outside the disability system—can be rare. Loneliness among people with disabilities is a well-documented issue (learn more from this [policy brief on loneliness and isolation \(PDF\)](#)).

Our current residential and employment systems can limit people’s opportunities to build and nurture these relationships. Both the lack of choices and the limited chances to participate in employment and education reduce these opportunities.

This can mean people’s closest relationships are with paid staff. This can be problematic since staff can come and go from people’s lives. For example, many parents said participants used to have long-term relationships with case managers who knew them and their needs very well. After these long-term case managers retired, they were replaced with a revolving door of case managers, who moved on after one or two meetings. The parents noted that these “pass-through” case managers offered little value and required extra effort to get up to speed. Several factors—including the job market and how positions are structured—seem to be driving this turnover.

Regression analysis for this survey confirms that the more relationships someone has, the higher their quality of life is. Participants told interviewers about their closest family members and friends. Participants shared how long they have known each person and how often they connect in person, by phone, over email, or in other ways.

The number of close relationships participants reported continues to decline.

Interviewers asked participants to describe their five closest relationships. Thirty-nine percent shared five, while the rest of participants reported between zero and four close relationships.

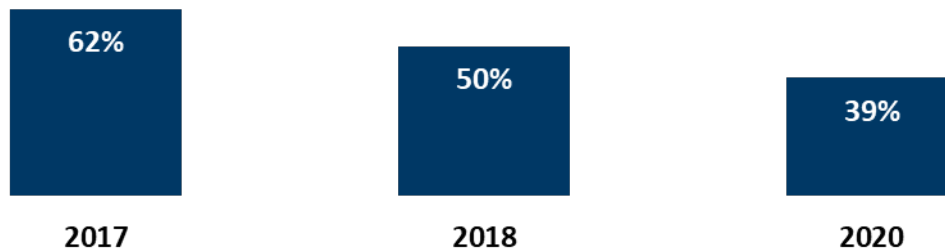
Six percent of participants reported no close relationships at all, compared to 8 percent in 2018 and 2 percent in 2017.

Participants' average number of close relationships has decreased since 2017.



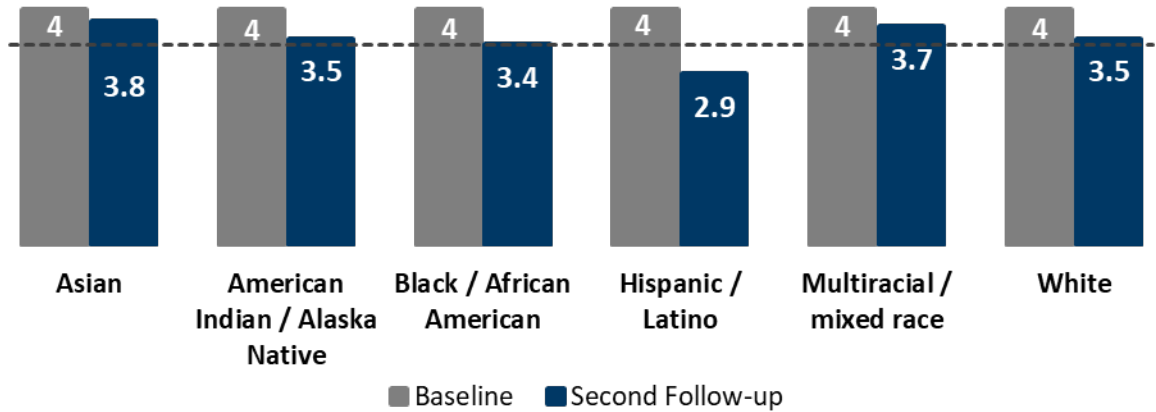
Note that interviewers have observed survey fatigue can influence this data, as this topic is covered late in the survey. Restrictions on activities outside the home have limited opportunities to connect with partners, family, friends, and others. But it is unlikely COVID-19 was the only cause of the decline. The rate of participants reporting five or more close relationships has declined since 2017.

The percent of participants who said they had at least five close relationships has declined dramatically since 2017.



Participants shared that they miss getting out of the house and being social. Many miss seeing family and friends. Several participants said they could not see their romantic partner during the pandemic.

All participants reported fewer close relationships, with Hispanic/Latino participants reporting fewer than 3 close relationships in 2020. The dotted line represents the 2020 state average of 3.4 close relationships.



Participants had fewer close relationships with staff outside the home but more close relationships with housemates and staff where they live.

This could reflect people being more confined to living settings due to COVID-19.

Table 4: Participants reported more relationships with the staff of their home and with housemates.

Relationship type	Percent of close relationships in 2017	Percent of close relationships in 2018	Percent of close relationships in 2020
Other paid staff (case manager, nurse, etc.)	3.2%	3.6%	0.7%
Staff of day program, school, or job	4.5%	4.0%	2.7%
Housemate (not family or significant other)	4.9%	4.2%	5.7%
Staff of home	18.2%	20.4%	25.8%

Recommendation: Focus on increasing outings and relationships.

We cannot ignore COVID-19’s effects on survey findings. At the same time, we know from the 2017 and 2018 surveys that the pandemic is not the only factor that has stalled progress. Previous surveys show that segregation was a problem before the pandemic disrupted day

programs and social opportunities. For example, the 2018 survey showed declines in participants' outings and relationships long before COVID-19 started. The State should **strengthen policies affecting people's outings and relationships and set new or revised Olmstead Plan goals to increase people's outings and relationships**. The current Olmstead Plan goals do not reference relationships.

In some instances, participants shared how providers and staff enforcing COVID-19 restrictions lowered their quality of life. We must document these impacts because this may be the only survey that captured the experiences of people with disabilities in Minnesota during the pandemic. It can help to **restore the relationships, freedoms, and other aspects of quality of life that have eroded during the pandemic. It can also document lessons for future pandemics.**

Appendix A: Quality of life ratings

Quality of life item rated (out of 5)	Average 2017 rating	Average 2018 rating	Average 2020 rating
Running my own life, making choices	3.8	3.8	3.9
Getting out and getting around	3.9	3.9	3.5
Health	3.9	3.9	4.0
What I do all day	4.0	4.0	3.9
Family relationships	4.1	4.1	4.2
Relationships with friends	4.1	4.1	4.0
Food	4.1	4.2	4.2
Happiness	4.1	4.1	4.0
Comfort	4.1	4.2	4.2
Safety	4.2	4.3	4.4
Treatment by staff/attendants	4.2	4.2	4.3
Privacy	4.2	4.2	4.3
Health care	4.3	4.3	4.4
Overall quality of life	4.1	4.1	4.1

Appendix B: Decision-making control

In the below table, common types of decisions are organized by the level of decision-making control participants reported having.

<p>People make most of these decisions on their own</p>	<ul style="list-style-type: none"> • Naps on evenings and weekends • When, where, and how to worship. • Choice of places to go • Choice of house or apartment • Choice of furnishings and decorations in the home • Choice of restaurants when eating out • What to have for breakfast • What to do with personal funds • Time and frequency of bathing or showering • Visits with friends outside the person's residence • Who the person hangs out with in and out of the home • What clothes to buy at the store • "Minor vices" – use of tobacco, alcohol, caffeine, explicit magazines, et cetera • When to go to bed on weekdays • What clothes to wear on weekdays • What clothes to wear on weekends • When to go to bed on weekends • When to get up on weekends • Choice of declining to take part in group activities • Whether to express affection, including sexual • What to do with relaxation time, such as choosing TV, music, hobbies, outings, etc.
<p>People and paid staff share these decisions</p>	<ul style="list-style-type: none"> • Which service agency to work with • What to have for dinner • Who goes with a person on trips, errands, and outings. • Type of work or day program • What foods to buy for the home when shopping • How to spend day activity funds • Whether to have pet(s) in the home

Paid staff make most of these decisions on behalf of the person

- Amount of time spent working or at a day program
- Choice of people to live with.
- Choice of case manager
- Type of transportation to and from a day program or job
- Choice of agency's support persons/staff (N/A if family)
- How to spend residential funds
- Choice of support personnel: option to hire and fire support personnel

Appendix C: Detailed methodology

This section explains the methodology of the Olmstead Quality of Life Survey – Second Follow-up – 2020. This section is written from the perspective of The Improve Group, the St. Paul-based research and evaluation firm that has partnered with the State of Minnesota Olmstead Implementation Office on the survey since 2014. We explain who administered and responded to the survey; what participants shared; how the survey was administered; and how data was analyzed.

Who responded to and administered the survey

The **focus population** for this survey is people in Minnesota with disabilities who receive services in potentially segregated settings. These are residential and day settings identified in the Olmstead Plan as having the potential to be segregated. These settings have characteristics of institutions, including a lack of control over where people live, with whom they live, access to family and friends, and attending a job or school they choose. The term “potentially” is used to indicate these settings may be restrictive for one person but not for another.

Because the survey is **longitudinal**, a subset of the same group of participants takes the survey periodically so we can detect change over time among the same people.

Focus population

The focus population for the Olmstead Quality of Life Survey is people in Minnesota with disabilities who receive services in potentially segregated settings. The survey’s focus population includes people of all ages and disability types in the eight service settings described in Table 1.

Note: Community Residential Services, Supervised Living Facilities, and Intermediate Care Facilities for Persons with Developmental Disabilities are colloquially referred to as group homes.

Table 1: Potentially segregated settings

Setting	Description
Center Based Employment	Center Based Employment programs provide opportunities for people with disabilities to learn and practice work skills in a separate and supported environment. Participants may be

	involved in the program on a transitional or ongoing basis and are paid for their work, generally under a piecework arrangement. The nature of the work and the types of disabilities represented in the workforce vary widely by program and by the area in which the organization is located.
Day Training and Habilitation (DT&H)	DT&H programs provide licensed supports in a day setting to help people develop and maintain life skills, participate in community life, and engage in proactive and satisfying activities of their own choosing. Health and social services are directed toward increasing and maintaining 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) and 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.
Supervised Living Facilities (SLF)	Supervised Living Facilities provide supervision, lodging, meals, counseling, developmental habilitation, or rehabilitation services under a Minnesota Department of Health license to 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 needing 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 (Assisted Living)	<p>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.</p> <p>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.</p>
Community Residential Setting (Adult Foster Care and Supported Living Services)	Adult foster care includes individual waiver services provided to people living in a home licensed as foster care. Foster care services are individualized and based on the individual needs of the person, and service rates must be determined accordingly. People who receive supported living services are receiving additional supports within adult foster care.
Intermediate Care Facilities for Persons with Developmental Disabilities (ICF/DD)	Intermediate Care Facilities for Persons with Developmental Disabilities are residential facilities licensed as health care institutions and certified by the Minnesota Department of Health to provide health or rehabilitative services for people with developmental disabilities or related conditions who require active treatment.

The survey focuses on these settings because they are potentially segregated, meaning they have the most room for improvement under the Olmstead Plan. This also means that the people receiving services in these settings would be most affected by Olmstead Plan efforts. They are the best people to speak to progress—or lack thereof.

Selecting the survey sample

The survey uses **simple random sampling** to generate survey samples. This technique randomly selects a sample from a larger sample or population, with each person having an equal chance of being selected. Simple random sampling is generally easier to understand and reproduce compared to other sampling techniques. Simple random sampling also allows for more flexibility to accommodate changes in setting definitions.

For the 2017 **Baseline Survey**, a representative random sample was generated from the focus population (people receiving services in the eight settings above), with 2,005 participants completing the survey. A representative sample means we can generalize the results to the focus population—while each individual experience is unique, we can apply the conclusions from the study to the population overall. A random and representative sample of those 2,005 participants was selected for the First Follow-up Survey in 2018 and for the Second Follow-up Survey in 2020. In 2020, a second sample of people identifying as Black, Indigenous, and People of Color (BIPOC) was selected. The 2,005 Baseline Survey participants will continue to be the sample from which future follow-up survey participants will be drawn at random. We will add new people to the sample in future years to account for attrition.

The sample includes people of all disability types, including people with multiple disabilities. Disability types include:

- People with physical disabilities
- People with intellectual/developmental disabilities
- People with mental health needs/dual diagnosis (mental health diagnosis and chemical dependency)
- People who are deaf or hard of hearing
- People who are blind or visually impaired
- People with brain injury.

Intentional additional sample of people who are Black, Indigenous, and People of Color

The Baseline and First Follow-up surveys did not survey enough people who are **Black, Indigenous, and People of Color (BIPOC)**² to allow for meaningful subgroup analysis. To learn more about this population in order to advance the State’s equity goals, the Second Follow-up Survey engaged a strategic additional sample of 50 people who are BIPOC.

Our sampling approach for the Baseline Survey meant that the demographics of the people invited to participate reflected those of the eligible population. As a result, people who are BIPOC made up a small, but proportional, number of Baseline Survey participants. Because this is the population from which the follow-up samples are drawn, we need to select an additional sample of people who are BIPOC in order to ethically and confidently report results by race. Additional Baseline Survey-specific challenges contributed to the limited number of people who are BIPOC who are eligible for the Second Follow-up.³ The resulting small group sizes in the follow-up surveys means traditional quantitative analysis with a sample of 500 people would not yield meaningful subgroup analysis of the survey results by race or ethnicity over time.

Yet, it is critical to understand the experiences of people who are BIPOC receiving services in potentially segregated settings. Therefore, in 2020, we adapted our approaches to meaningfully engage people who are BIPOC and to conduct strategic additional sampling. This helped us reach people in numbers that allow for subgroup analysis and assisted us in gathering qualitative insights that can deepen our understanding of their experiences.

A random sample of 200 people was selected for the BIPOC sample. To be eligible for the BIPOC sample, a person must:

- Be currently authorized for services in one of the eight potentially segregated settings included in the Baseline Survey

² The term “BIPOC” is used to highlight the unique history and experiences of Black and Indigenous communities in relationship to the United States. We recognize “People of Color” is not a homogenous group and is a broad term that encompasses many nuances, experiences, and communities as well.

³ While we do not know all of the reasons for the lower response rates among people who are Black (11 percent compared to 17 percent overall), we believe that it is partly related to the overall lower response rates in Hennepin County due to an outreach challenge. One of the baseline outreach strategies was to coordinate with lead agencies to contact guardians. While most lead agencies were able to support the work, a few—including Hennepin County, where nearly half of Minnesotans who are Black or African American live⁴ per census data—did not have the capacity to support requests for updated guardian contact information or facilitate consent requests.

- Be listed in State data as a race or ethnicity other than white only. People who are two or more races are eligible for the BIPOC sample. People for whom race is unknown will be included in the sample; however, these people will be screened for eligibility during outreach.
- Not have participated in the Baseline Survey.

Outreach to the BIPOC sample was similar to outreach to the rest of the sample, with several changes, including:

- Adding more information in the survey invitation letter for this group about the study, why they are being asked to participate, and the importance of their participation
- Working with disability advocacy groups and other organizations that have relationships with BIPOC people with disabilities to inform outreach strategies
- Tailoring phone outreach to people and designated contacts regarding the value of the work
- Engaging a BIPOC interviewer in developing and implementing outreach to the group.

Populations not included in the survey

The goal of this survey is to be as inclusive as possible; however, the survey methodology and eligibility criteria does not include all people in Minnesota with disabilities. The eligible population from which the original Baseline Survey sample was drawn does not include:

- People who are incarcerated
- Youth living with their parents
- People living in their own home or family home who do not access day services in selected settings
- People who are currently experiencing homelessness
- People who access services in settings other than the eight settings identified above.

For these reasons, the survey results can only be generalized for the people receiving services in these eight settings and are not representative of the experiences of all people in Minnesota with disabilities.

Project team

The Improve Group led the administration of the survey. As part of this role, The Improve Group hired and supervised a team of skilled interviewers. Interviewers and The Improve Group have been involved in the Olmstead Quality of Life Survey since its inception.

Interview team

A team of experienced interviewers conducted outreach and interviews. They have been with the project since the Baseline Survey. The eight interviewers had already completed 40 hours of project training from the Baseline Survey and 12 hours of refresher training for the First Follow-up. Before beginning outreach, interviewers completed an additional 10 hours of refresher training, which included both Improve Group-led and self-guided trainings. Refresher training topics included:

- Project overview
- Review of survey modules and survey updates
- Interviewing skills and reducing bias
- Person-centered planning and practices
- Human subjects and data security
- Abuse and neglect
- Interview logistics
- COVID-19-specific updates, including administration and data privacy procedures
- Self-guided trainings on survey outreach and administration tools.

The interview team is listed above in the “Acknowledgements.”

Advisory Group

Throughout the survey, an expert Advisory Group provided strategic guidance to the study and identified recommendations based on the data. While the Olmstead Subcabinet provides oversight of the entire Olmstead Plan, the survey-specific Advisory Group provided stakeholder insight to help finalize survey decisions. Through regular meetings, advisers informed outreach, analysis, COVID-19 mitigation, emerging research questions, and recommendations. Because many factors affect quality of life, it was critical to provide this space and facilitation to explore new possibilities as they came up in the data. Advisory Group members are listed above in the “Acknowledgements.”

What participants shared

The survey was intended to hear from people with disabilities, in their own words, about different factors affecting quality of life.

Survey tool selection

This survey adapted the Center for Outcome Analysis’ (COA) Quality of Life tool for the needs of Minnesota’s Olmstead Plan. Before the Baseline Survey, the Olmstead Implementation Office reviewed seven possible tools for consideration and presented them

to the Subcabinet. The office used the following criteria, provided by the Subcabinet, to judge the tools:

- Applicability across multiple disability groups and ages
- Validity and reliability
- Ability to measure changes over time
- Whether integration is included as an indicator in the survey
- Low cost.

The Subcabinet voted to use the field-tested COA Quality of Life survey tool developed by James Conroy, Ph.D., with the COA. The tool was tailored to meet the needs of Minnesota's Olmstead Plan and selected because it best met the selection criteria above. The tool meets the selection criteria because it can be used with participants with any disability type, is designed to be used in longitudinal studies, measures change over time, and includes reliability and validity data.

Survey structure and modules

The Olmstead Quality of Life Survey includes four modules and a series of questions about assistive technology. The sections of the survey are:

- Quality of life ratings
- Social integration and engagement
- Decision-making power
- Closest relationships inventory
- Use of assistive technology.

Although the survey was administered as a package, each module is designed to stand on its own. Surveys were considered complete if 75 percent of any module was finished.

Changes for the 2020 survey

In 2020, we made some survey tool changes, including alterations to understand the effects of COVID-19. We were careful to make sure the changes captured important effects of this new situation without jeopardizing the ability to compare results over time. Changes to understand the impacts of COVID-19 included:

- Distinguishing between in-person and virtual community engagement events
- Asking if people's lives are better or worse during COVID-19
- Asking an open-ended question about how the pandemic has affected people's lives.

Additionally, we added demographic questions allowing people to self-identify (previous studies used State data only).

Later in this section we explain in more detail how COVID-19-related challenges were mitigated.

How we administered the survey

To abide by the spirit of the Olmstead Plan and its goals, the survey was administered in a person-centered way that aimed to remove barriers that have traditionally prevented people from sharing their lived experiences. This meant making the survey as comfortable and accessible as possible for all participants in terms of scheduling and administration.

Data sources

Four main sources of data were used in the survey: Minnesota Department of Human Services (DHS) data, Minnesota Department of Employment and Economic Development (DEED) data, outreach tracking data, and data gathered through the Quality of Life Survey itself. DHS and DEED provided individual demographic data for the survey sample.

DHS holds data for people who receive services in seven of the settings included in this survey. DEED holds data for people receiving services through Center Based Employment.

Outreach tracking data includes details about contact made with the person and/or their guardian to participate in the survey, as well as any contact made with other allies, providers, or others.

For the Second Follow-up Survey, The Improve Group requested updated service and screening data from DHS and DEED for the 2,005 people who participated in the Baseline Survey. The Improve Group used this data to identify people who were no longer authorized to receive services in potentially segregated settings. People who are no longer living in Minnesota are not eligible for the survey. In 2020, 10 percent of participants from the DHS baseline sample did not have cost data for services. During outreach, the survey team learned that 3 percent of baseline participants were now deceased.

Outreach to invite participants to take the survey

The Improve Group leveraged multiple contact methods to invite people to participate in the survey, including mail, phone calls, text messages, and email. By being flexible with the contact method, we built efficiencies into the project while prioritizing individual preferences.

Mail

Notification of the study was sent to service providers authorized to provide services to people selected to participate in the Second Follow-up Survey. The notification included instructions for confirming a person's status with the provider, contact information, and for supporting the person in deciding whether to participate in the survey. The Improve Group sent this notification using our printing vendor.

Then, The Improve Group sent notification of selection to the person, guardians, and other associated contacts (if appropriate). The notification included study information, a timeline for interviews, consent information, and instructions for opting out of the study. The notification also included instructions for submitting consent via an online portal. The Improve Group sent this notification and monthly reminder notices.

Phone, text, and email

After the initial outreach letters were sent, The Improve Group began direct outreach to people and/or their designated contact person using contact information provided by the State and providers, as well as from updated consent forms. The direct outreach was an opportunity to explain the survey, invite people to participate, gather consent, and schedule the interview. The interviewers used the person's preferred contact method, if known. Text messaging was not used without a contact person's prior consent.

Website

The third mode of outreach was The Improve Group's Olmstead Quality of Life Survey website, where we posted updated information about the survey.

Obtaining participant and guardian consent

For all survey participants, The Improve Group obtained guardian and/or participant consent before scheduling or administering the survey. If a person had a guardian, but guardian contact information was unavailable or outdated, The Improve Group contacted providers or case managers to request help in obtaining guardian contact information or collecting guardian consent forms. Because all surveys were conducted virtually, interviewers documented verbal or visual confirmation of consent at the time of the interview. Written consent was obtained before conducting the interview.

If the participant had a guardian, the interview was scheduled upon obtaining verbal consent from the guardian. Interviews were not conducted until we had obtained written consent.

All participants could opt out of the survey at any time during the outreach and scheduling process. Participants were also asked to consent at the time of the interview. The consent form included a notice of the person's right to decline or stop the survey at any time. If a

participant declined to consent or did not understand the consent form, they were not interviewed. The informed consent process was designed to allow participants time to formulate their response about taking the survey. This recognized that some people may not feel comfortable declining to participate in the survey when first approached, especially when speaking to someone in a perceived position of authority.

Scheduling interviews

Interviews were scheduled over the phone or via email. Participants, their guardians, and/or their providers could have been involved in scheduling interviews.

The person scheduling the interview completed an interview scheduling form that included the participant name, contact information, time, accommodations to participate, and the name(s) of anyone who may assist the participant during the interview. Participants were also given the option to name a support person at the time of the interview. The support person could help the participant complete the survey or answer questions for the person. Interviewers noted on the survey when a support person was present or, in the case of the quality of life ratings module, when the support person helped complete the survey.

Survey administration

Interviewers administered the survey in an interview format via phone, video call, or other COVID 19-compliant mode identified by the participant. They conducted interviews from their homes and/or other private spaces they could safely access. They complied with all study privacy practices, including but not limited to conducting interviews in a private space where they could not be overheard by others; using over-the-ear headsets with attached microphones; and ensuring no one could see the screen they used to enter the survey responses. Responses were directly entered into our survey software, Snap Webhost.

Accommodations

The Improve Group provided reasonable accommodations to complete the survey as requested by the participant or the support person. If a case manager, provider, or guardian was involved in scheduling interviews, The Improve Group asked if accommodations were needed for the person to participate in the survey. The Improve Group was able to honor all requests for accommodations during the Baseline and follow-up surveys.

We offered the following accommodations:

- Advance copies of survey materials, including consent forms and the survey tool, were provided.
- American Sign Language (ASL) interpreters were provided upon request.

- People who were blind or visually impaired could access a large print text version of the survey.
- Screen reader-compatible surveys were provided.
- People who were nonverbal or had limited expressive communication were able to use any communication supports needed to respond to the survey. Examples include personal sign language, technology, or cards to communicate. If needed, The Improve Group worked with the person’s staff or another support person to assist with participation in the survey.
- The Improve Group worked with specialized interpreters to accommodate deafblind participants. If possible, The Improve Group arranged for the participant to be able to work with a qualified interpreter who was knowledgeable about that person’s communication preferences.
- For non-English-speaking participants, The Improve Group provided interpretation services in the participant’s language.
- The Improve Group worked with multiple translation and interpretation providers to minimize barriers to scheduling the interviews.

Challenges

The Improve Group implemented the Second Follow-up Survey amid the COVID-19 pandemic. This led to challenges and the need for several course corrections.

In past years, the survey was conducted in person, typically at the participant’s home or day setting. The move to conducting all surveys virtually presented multiple layers of difficulty to scheduling surveys:

- Many participants required additional support or had limited access to technology for video or conference calls.
- Mail, our primary method of contact with guardians and for obtaining consents, was affected by post office delays. This made it difficult to obtain guardian consent to reach out to participants or obtain participant consent. These delays impacted both outgoing and incoming mail.
- High volumes of phone calls during the leadup to the 2020 presidential election affected some people’s willingness to answer phone calls.
- After we obtained consent, scheduling contacts (often staff at the participant’s home) were less likely than in previous surveys to answer the phone and slower to return messages to coordinate interviews. Staffing shortages and the additional level of support participants needed to take part in virtual interviews made it more challenging to schedule interviews. Although most providers were willing to work toward a solution, finding the right solution for each participant could take days of negotiation. This also related to a challenge we have experienced in the past:

outdated contact information. Providers, staff, and guardians were integral to obtaining consent and administering the survey. Sometimes, inaccurate or outdated contact information made survey outreach challenging. At times, The Improve Group was unable to obtain updated provider or guardian contact information for potential participants. If updated contact information was not available, the person was removed from outreach for the Second Follow-up Survey. These people remain eligible for subsequent follow-up surveys.

- Conducting the survey remotely made it difficult to build relationships with staff at service settings; these relationships were critical in past surveys to scheduling interviews at settings with multiple participants.

In addition, once a survey was scheduled, virtual interviews presented technology challenges for many participants. This led to an increased use of proxies; in some cases, interviewers could not determine the extent to which the participant drove responses. While most technology glitches were solved in the moment, video and sound delays could impact the participant experience in some cases.

While 91.6 percent the 561 participants completed the survey, 47 surveys ended early. Most people gave a combination of reasons for ending early. These included survey length, survey content, external distractions, and technical challenges. Several interviewers noted that survey length was more of a challenge for 2020 survey participants because the survey was conducted virtually.

Part of a broader challenge

These factors, along with the emotional effect of the pandemic, affected the pace of outreach and slowed scheduling significantly.

These challenges—though unique in how they appeared in the Olmstead Quality of Life Survey—were part of general challenges researchers experienced during the pandemic. Researchers at the local, national, and international levels experienced decreased response rates. Because this was an evolving, emergent challenge during survey administration, it was difficult to find one single solution to conducting surveys with populations that are considered “hard-to-reach.” These populations include low-income households, people who are BIPOC, and people with disabilities. Solutions ranged from extending data collection, to accepting a smaller sample size, to not publishing certain results, as the National Core Indicators (NCI) announced it would do (read more in this [NCI brief about the decision \(PDF\)](#)).

The most visible case of this was the U.S. Census, which relied heavily on in-person work to reach people who are BIPOC and low-income families. Hand delivery and door-knocking are key to reaching these households, and these methods were paused because of COVID-19.

During Census data collection, the American Statistical Association and the American Association for Public Opinion Research (AAPOR) issued a joint statement raising concerns about a likely undercount. The U.S. Census Bureau and The Bureau of Labor Statistics (BLS) both raised concerns about the impact of COVID-19 on response rates for national surveys, especially among households that typically complete in-person surveys. This exemplifies how COVID-19 presented a challenge to data collection broadly during the time of survey data collection.

We knew COVID-19 would have a measurable effect on quality of life for many participants. People with disabilities who live in congregate settings are at greater risk of acquiring COVID-19 and of developing serious complications from the disease. Most critically to the survey, the integration module assumed participants had the option to safely engage in activities outside the home. Integrative activities were limited throughout the administration period.

While the impact of COVID-19 on quality of life is important to measure, we also wanted to be attentive to the primary question driving the study: Are people better off because of Minnesota's Olmstead Plan? To this end, we worked with the Advisory Group to incorporate the implications of COVID-19 into our analysis strategy to account for how the pandemic could affect survey results, while keeping focus on the overall survey goal. Strategies included:

- Adding questions to the survey (see above) to account for individual experiences related to COVID-19, such as a question about pre-COVID-19 integrative activities
- Adding new response options to account for changing behavior patterns and decision-making
- Including variables in the regression model to account for temporary changes to service or care delivery. These changes may have included federal waivers to certain Medicare and Medicaid programs or the increased use of telemedicine.
- Re-examining the general population data we compared against. For example, we compared survey participants' outings per month to the general population's; we knew COVID-19 would impact both these figures.

Abuse and neglect reporting

Procedures were in place for documenting and reporting any incidents in which people threatened to hurt themselves or others or for incidents of reported or suggested abuse or neglect. These procedures required that all incidents of self-reported, observed, or suspected abuse or neglect be reported to the Minnesota Adult Abuse Reporting Center or Common Entry Point within 24 hours of the interview. All incidents, including incidents that

did not require a report, were documented internally and reported to the Olmstead Implementation Office (OIO).

Due to the vulnerability of the focus population, interviewers erred on the side of reporting possible abuse or neglect. That means some cases reported by The Improve Group had already been investigated or resolved. In the Baseline Survey, interviewers reported 15 cases of possible abuse or neglect. For the First Follow-up Survey, interviewers reported one case of possible abuse or neglect. For the Second Follow-up Survey, interviewers reported three cases of possible abuse or neglect.

All study team members were required to report suspected cases of abuse and neglect to the State as soon as possible. This was a core topic of interview training and ongoing monitoring. Throughout implementation, The Improve Group supported interviewers to report incidents of abuse and neglect, including following up as needed. The abuse and neglect documentation and reporting protocol is outlined below.

At the time of the incident:

- Call 911 to report serious or immediate danger
- Report the incident to the provider or a staff person (if appropriate)
- Complete the Documentation of Suspected Abuse or Neglect Form
- Report the incident to the supervisor on duty.

Within 24 hours of the incident:

- Submit the completed Suspected Abuse or Neglect Form
- Report the incident to the MN Adult Abuse Reporting Center or Common Entry Point (if required)
- Notify OIO about the incident and next steps.

Within 72 hours of the incident:

- Submit a written report to the MN Adult Abuse Reporting Center or Common Entry Point (if required)
- Notify OIO about the incident and next steps.

Quality assurance

A quality assurance plan outlined steps The Improve Group took to administer, monitor, and evaluate the project to ensure data quality and research integrity. The plan also included corrective action procedures.

Interviewer oversight

During survey administration, The Improve Group provided responsive daily coordination and interviewer support to assure data quality, maintain progress, and proactively troubleshoot challenges. We also monitored the project phone number and email address for questions and managed documentation of consent. Interview oversight included:

- Weekly check-ins with each interviewer for the first two months of survey administration, then as needed
- Weekly team meetings for troubleshooting and sharing successes
- An interview team lead who served as interviewers' first point of contact and observed themes and shared challenges/solutions across the team
- An escalation plan⁴ for challenges
- A shared calendar for scheduling interviews
- Support for abuse and neglect reporting
- Daily survey monitoring, weekly quality assurance checks, and twice-weekly sample tracking to track how well participant characteristics match the sample.

These quality assurance activities allowed us to proactively identify the need for targeted outreach in certain communities or settings and make other course corrections as needed.

Managing data and evaluating its quality

As we collected survey results, we maintained raw data in a secure database that combined data from all survey modes. The database also maintained information about what mode was used, when the survey was completed, and if a support person participated. It also maintained relevant notes to assist in following up with participants as needed. The Improve Group reviewed survey data and supporting documentation for completeness and accuracy throughout the data collection period. This allowed us to identify and address threats to data quality as they arose. In addition, we visually checked the final data and ran statistical tests to check for data quality concerns such as patterns in missing data, non-response patterns, and data entry errors.

How we analyzed the data

Researchers designed analysis to answer the following research questions:

⁴ The interviewer started with the daily coordinator, who engaged the project lead if needed, who turned to additional contingency/grievance plans and fellow leadership team members if needed.

1. To what extent did integration, decision-making, quality of life, and number of relationships change from the Baseline Survey to the Second Follow-up Survey?
2. What factors are related to integration, decision-making, quality of life, and number of relationships at the Baseline Survey?
3. What factors are related to changes in integration, decision-making, quality of life, and number of relationships at the time of the Second Follow-up Survey?

Three main types of analysis were used to come to key findings:

1. Linear regression, a method of quantitative analysis that identifies what characteristics (e.g., region of residence) or items (e.g., number of close relationships) are associated with an outcome (e.g., quality of life)
2. Calculations of differences over time and between population subgroups, to detect any changes among the participant population
3. Qualitative analysis of open-ended questions.

As survey administration neared completion, researchers facilitated an “emerging findings” workshop with the survey Advisory Group. The emerging findings workshop is a technique to engage key stakeholders in interpreting the results and contributing to recommendations. These conversations helped validate our interpretation of the data and ensured recommendations included in the report meet the needs of the Olmstead Plan.

Linear regression quantitative analysis

Linear regression is useful in identifying characteristics associated with a specified outcome. For example, a real estate agent could select houses to represent by using linear regression to identify which housing characteristics are strongly associated with a higher home-selling price. In relation to the Olmstead Quality of Life Survey, linear regression helps determine how participant demographics, setting characteristics, and other important characteristics were related to each of the four module scores: outing interactions, decision control (choice-making), perceived quality of life, and closest relationships.

Because the survey offers hundreds of variables, we drew on the knowledge of the Advisory Group and theories from the field to build our regression models with the variables that were most likely to be related to the module scores.

Differences between subgroups and points in time

We will also calculate individual scores for the four survey modules: quality of life ratings, social integration and engagement, decision-making power, and closest relationships. We

will then compare the average scores for each module by year and subgroups, testing for differences between groups using ANOVA, or analysis of variance.

We will use “paired T-tests” to detect change over time. “Paired” means a participant’s responses in the Baseline Survey were tied to their responses in the Second Follow-up Survey. Each participant is identified by a confidential number in the data, allowing us to connect their most recent responses to past responses. Using “T-tests” simply means looking at data from one point in time (e.g., the Baseline Survey) in comparison to the same data at another point in time (e.g., the Second Follow-up Survey).

Qualitative analysis

Researchers also used qualitative analysis to determine themes from interviewer debrief forms and open-ended survey questions.

In addition to reviewing interviewer debrief forms throughout administration to identify any immediate actions needed, researchers analyzed all debrief data. Researchers also facilitated a debrief meeting with the interviewer team to reflect on the administration process, themes from conversations with participants and providers, and results.

Appendix D: Survey tool

Olmstead Quality of Life Survey

Part 1: Demographic and Housing Questions

1. What is your gender identity? (select all that apply)
 - Female
 - Male
 - Transgender
 - Non-binary/ third gender
 - Prefer to self-describe _____
 - Prefer not to say
 - Participant was unable to provide a response

2. 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

3. What type of home are you living in now?
 - Living with family or friends
 - Board and Lodging
 - Housing with Services
 - Supervised Living Facilities
 - Boarding Care
 - Shelter
 - Transitional Housing
 - Nursing Homes, Assisted Living
 - Adult Foster Care
 - ICF/DD
 - Living independently
 - No response

4. How many people live in your home right now? (“HOME” can usually be interpreted as a unique MAILING ADDRESS - - a group dwelling or individual home or apartment. If this is a congregate care facility, use cottage or living unit or building or wing or other meaningful sub-unit. If there are vacancies, only count how many people live here RIGHT NOW. Note if the individual lives with a family member or other caregiver who is paid to provide services through CDCS or similar programs)

	2A. Total number of people who live in your home (cottage, living unit, etc.)
	2B. People with disabilities (including friends, family, or other unpaid roommates with a disability/label and/or others who receive services)
	2C. People without disabilities (including friends, family, or other unpaid roommates who do not have a disability/label)
	2D. Paid staff who <u>live</u> here (paid cohabitants)

5. WITH HOW MANY PEOPLE DO YOU [PERSON] SHARE A BEDROOM? _____
 People

COMMUNITY INTEGRATION AND ENGAGEMENT

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

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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

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 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 Per Week	\$ Earned Per Week	Integration Level
Self-Employed			
Regular Job (Competitive Employment)			
Regular community job with support staff			
In an enclave or job crew			
Sheltered employment or workshop employment			
Pre-Vocational Program or Vocational Rehabilitation Program (Voc Rehab)			
Day Habilitation Program (DT&H)			
Adult day program or non-vocational program			
Volunteer Work			
Public School			
Private School			
Adult Education (GED, Adult Ed, Trade School, etc)			
Community Experience			
Other _____			
TOTAL HOURS			xxx

COMMUNITY INTEGRATION AND ENGAGEMENT

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

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ABOUT HOW MANY TIMES did this you do each of the following in the past four weeks?

(Rough estimates are fine. If the past month was not typical, ask about the average month during the past year. Write DK if "Don't Know.")

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

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

	Number of in person outings	Number of virtual outings	Average group size (in person)	Average group size (virtual)	None	Little	Some	Much	Very Much
Visit with close friends, relatives 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:									

AUTONOMY OVER DAILY LIFE: Decision Control Inventory

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Ask the person and/or the person's chosen ally to say who actually makes decisions in each area.

WHO MAKES DECISIONS?

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

	All Paid	Mostly Paid	Equal	Mostly Unpaid	All Unpaid	D/K
FOOD						
1 What foods to buy for the home when shopping	1	2	3	4	5	99
2 What to have for breakfast	1	2	3	4	5	99
3 What to have for dinner	1	2	3	4	5	99
4 Choosing restaurants when eating out	1	2	3	4	5	99
CLOTHES AND GROOMING						
5 What clothes to buy in store	1	2	3	4	5	99
6 What clothes to wear on weekdays	1	2	3	4	5	99
7 What clothes to wear on weekends	1	2	3	4	5	99
8 Time and frequency of bathing or showering	1	2	3	4	5	99
SLEEP AND WAKING						
9 When to go to bed on weekdays	1	2	3	4	5	99
10 When to go to bed on weekends	1	2	3	4	5	99
11 When to get up on weekends	1	2	3	4	5	99
12 Taking naps in evenings and on weekends	1	2	3	4	5	99
RECREATION						
13 Choice of places to go	1	2	3	4	5	99
14 What to do with relaxation time, such as choosing TV, music, hobbies, outings, etc.	1	2	3	4	5	99

	All Paid	Mostly Paid	Equal	Mostly Unpaid	All Unpaid	D/K
15 Visiting with friends who live outside of the person's residence	1	2	3	4	5	99
16 Choosing to <u>decline</u> to take part in group activities	1	2	3	4	5	99
17 Who goes with you on trips, errands, outings	1	2	3	4	5	99
18 Who you hang out with in and out of the home	1	2	3	4	5	99
SUPPORT AGENCIES AND STAFF						
19 Choice of which service agency works with person	1	2	3	4	5	99
20 Choice of Case Manager	1	2	3	4	5	99
21 Choice of agency's support persons/staff (N/A if family)	1	2	3	4	5	99
22 Choice of support personnel: option to hire and fire support personnel	1	2	3	4	5	99
ECONOMIC RESOURCES						
23 What to do with personal funds	1	2	3	4	5	99
24 How to spend residential funds	1	2	3	4	5	99
25 How to spend day activity funds	1	2	3	4	5	99
HOME						
26 Choice of house or apartment	1	2	3	4	5	99
27 Choice of people to live with	1	2	3	4	5	99
28 Choice of furnishings and decorations in the home	1	2	3	4	5	99
WORK OR OTHER DAY ACTIVITIES						
29 Type of work or day program	1	2	3	4	5	99
30 Amount of time spent working or at day program	1	2	3	4	5	99
31 Type of transportation to and from day program or job	1	2	3	4	5	99
OTHER						
32 Express affection, including sexual	1	2	3	4	5	99
33 "Minor vices" - use of tobacco, alcohol, caffeine, explicit magazines, etc.	1	2	3	4	5	99
34 Whether to have pet(s) in the home	1	2	3	4	5	99
35 When, where, and how to worship	1	2	3	4	5	99

PERCEIVED QUALITIES OF LIFE

(To Be Answered by the Person or Whoever Knows the Person Best)

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Rate the qualities of your own life. **If the you can't answer, accept answers from whoever knows the person best.**

1	2	3	4	5	99
Very Bad	Bad	In Between	Good	Very Good	Don't know, N/A

Area	Very Bad	Bad	In Between	Good	Very Good	Don't know N/A
1. Health	1	2	3	4	5	99
2. Running my own life, making choices	1	2	3	4	5	99
3. Family relationships	1	2	3	4	5	99
4. Relationships with friends	1	2	3	4	5	99
5. Getting out and getting around	1	2	3	4	5	99
6. What I do all day	1	2	3	4	5	99
7. Food	1	2	3	4	5	99
8. Happiness	1	2	3	4	5	99
9. Comfort	1	2	3	4	5	99
10. Safety	1	2	3	4	5	99
11. Treatment by staff/attendants	1	2	3	4	5	99
12. Health care	1	2	3	4	5	99
13. Privacy	1	2	3	4	5	99
14. Overall quality of life	1	2	3	4	5	99

15. How would you rate your overall quality of life during the COVID-19 pandemic compared to your quality of life before?

- Much worse
- Worse
- About the same
- Better
- Much better

16. What are some of the reasons your life is [response] now?

Closest Relationships Inventory

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This module is intended to get at the types and characteristics of a few of the person's closest relationships.

- 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.
 - If there are close relationships with more than 5 people, please try to count only the closest 5.
 - This scale may be left empty, if the person has no close friends; please indicate this with a large “X.”
 - “Contact” can include phone, letter, computer, or even just waving or saying hello.
1. Who are the people who are closest to you? We can talk about up to 5 people.
 2. 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
 3. About how long have you known this friend? (in years)
 4. About how many times have you had ANY contact with this friend, in the past four weeks (28 days)? Describe contact types in notes.

Initials or code:	Relationship (Present or Former) 1. Relative 2. Staff of home 3. Staff of day program, school, or job 4. Other paid (Case manager, nurse, etc.) 5. Housemate 6. Co-worker or schoolmate 7. Neighbor 8. Merchant 9. Other	Duration About how long have you known this friend? (Years - use fractions and decimals if needed, as in 2.5 years, or 2 ½ years) (99 = D/K)	Frequency About how many times have you had ANY contact with this friend, in the past four weeks (28 days)? (For people seen several times every day, such as staff of the home, just enter 28.) (99 = D/K)
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

1. Do you use any assistive technology in your life?
 - Yes, I use it now (Go to 4)
 - Yes, I have used it in the past (Go to 2)
 - No, but I need help doing certain tasks and would like to use it (Go to 3)
 - No
2. If you have used it in the past, why don't you use assistive technology anymore?
3. If you don't use it but would like to, why don't you use assistive technology?
4. If you currently use or have used it, what assistive technology have you used or are you using?
5. If yes, how much difference has assistive technology made in increasing your independence?
 - A lot
 - Some
 - A little
 - None
6. How much difference has assistive technology made in increasing your productivity?
 - A lot
 - Some
 - A little
 - None
7. How much difference has assistive technology made in increasing your community integration?
 - A lot
 - Some
 - A little
 - None
8. Overall, how much has your use of assistive technology decreased your need for help from another person?
 - A lot
 - Some
 - A little
 - None