Olmstead Quality of Life Survey

September 2020 brief: Decision-making

Minnesota's **Olmstead Plan** serves as the roadmap for state agencies in improving quality of life and increasing integration for all Minnesotans. To meet the Plan's goal of enabling people with disabilities to live, learn, work, and enjoy life in the **most integrated setting**, we measure quality of life over time through the Olmstead Quality of Life Survey. Using thoughtful and inclusive research methods, we gather input from **Minnesotans with disabilities** who receive services in the **potentially segregated settings** defined in the Olmstead Plan. This brief focuses on what the survey tells us about the decisions people make, the choices they have, and how policies can better support individual choice.

Participants share how decisions affecting their lives are made about their basic daily needs and the services they receive. This would include the food they eat, when they sleep, where they work and live, and their recreational opportunities.

Because of how they are structured, potentially segregated settings inherently allow people less **decision-making power**. This is why explicitly asking people who live and work in these settings about decision-making helps us understand where to improve. In the survey, people tell us who makes decisions in their lives and what choices they have. To understand the level of decision-making power, we ask if the person, **paid staff**, or **unpaid allies** make decisions ranging from where people live or work to what they do with their relaxation time. To understand where choice exists in the first place, we document whether people know who makes decisions on their behalf.

We know there is work to be done to shift decision-making power to individuals. For example, in the baseline survey, 31 percent of people who responded said it is mostly or all paid staff, not they themselves, who decided what type of work or day program they participate in. Twenty-seven percent of people, meanwhile, said they did not know who made this decision, indicating 1 in 4 participants did not know this was a choice that could be made in their lives.

We calculate the responses to all these questions into a statewide score. At the baseline survey, Minnesota's score was 66.2 out of 100, which means people have a moderate amount of decision-making power, but do not have full control over the decisions affecting their lives. The Center for Outcome Analysis has conducted similar surveys at the state and national level for over 30 years. The Center's studies

Olmstead Plan: A broad series of key activities Minnesota must accomplish to ensure people with disabilities are living, learning, working, and enjoying life in the most integrated setting.

Most integrated setting: A setting that enables individuals with disabilities to interact with non-disabled persons to the fullest extent possible.

Minnesotans with disabilities:

The focus population for this survey is Minnesotans with disabilities who receive services in potentially segregated settings, referred to in this brief as "Minnesotans with disabilities."

Potentially segregated settings: 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

This is the second of four briefs about the Olmstead Quality of Life Survey. These briefs, along with survey results, can inform efforts to improve quality of life for Minnesotans with disabilities.

have shown that decision-making power can increase when interventions aim to shift power.

Minnesota's Olmstead Plan is working to shift decision-making power to people with disabilities by emphasizing person-centered planning.

With **person-centered planning** processes that include individuals and their partners in care, people get to make decisions about the things that are important for them. This means they can focus on the things they want for themselves instead of what others want for them. For example, imagine a man with cerebral palsy, "Tom," who refused to do the exercises his physical therapist gave him. As it turned out, Tom really liked golf. He shared this with his planning team and added twice-weekly golf outings to his plan. A year later, his health and level of <u>social engagement</u> had improved significantly.

Increased decision-making power would mean the Olmstead Plan is working.

Higher scores from this survey would indicate a shift in decision-making power from paid staff to individuals and unpaid allies. For example, Minnesota has developed plans to give people more choice and voice in how public dollars are used to support them. If this has been successful, we should see an uptick in results from the survey currently being administered. However, consequences of COVID-19 will likely undermine some, if not all, recent progress—specifically on gains in increasing the choices people have. Simple daily choices that arise during the pandemic, such as calling a family member or joining a virtual hangout with friends, may be even more limited in potentially segregated settings. Such a choice is affected by access to technology, provider control of shared technology or even the person's own technology, and availability of staff to support people in using technology.

This is the second of four briefs on the survey.

The <u>first project brief</u> and survey findings are available on the <u>Olmstead Quality of Life website</u>, the <u>Olmstead Implementation Office website</u>, and the Olmstead Implementation Office's social media pages. The next two briefs will discuss perceived qualities of life and presence of close and valued relationships. <u>The Improve Group</u> created this brief, drawing on the <u>Minnesota's Olmstead Plan</u> and related <u>demographic data</u>.

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.

Decision-making power: The extent to which a person makes decisions for themselves. These decisions may include input from people who know and love them.

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

Paid staff: People who work for the place where people with disabilities live or receive services. Paid staff can also include case managers or other professionals who are hired to provide services to people with disabilities.

Unpaid allies: Friends, family, or anyone a person wants to help them make the decision. What characterizes unpaid allies is that they are trusted and known to the person, and that their primary motivator is their loving relationship with the person.

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