

Olmstead Quality of Life Survey

October 2020 brief: Quality of life ratings

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 survey participants themselves tell us about their quality of life and what that suggests for areas of improvement.

In the quality of life ratings module, we ask participants to rate 14 areas of their quality of life on a scale from 'very bad' to 'very good.'

The survey does not define what "good" or "bad" is but rather allows the participant to draw on their own beliefs and experiences in their response. This direct input from participants supplements other parts of the survey, which quantify aspects of life—such as social integration—that are known to impact a person's quality of life. This input is important because people's own feelings are the best gauge of their quality of life—who knows better?

The 14 areas asked about in the survey come from the most common responses in studies asking over a million people across cultures, countries, abilities, and ages what is important to them and gives value to their lives. Participants rate the quality of their health, family relationships, food, and other areas. Because these factors are so personal, it is important participants answer as many questions as possible themselves. In some cases, a support person may assist in answering some or all of the questions, and interviewers note the number of questions the participant answers themselves.

Minnesota's Olmstead Plan envisions people enjoying their lives in the most integrated setting.

Person-centered planning, a core element of the Olmstead Plan, can support this because it enables people to share what is important to them and to create a life they personally value.

For example, "Elena" has significant medical needs and gets a lot of care from a medical professional. The condition is manageable and a normal part of her life. In fact, when asked, she says she rates her

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 third 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.

overall health as very good. However, her family members and caregivers are likely to fixate on her chronic condition and define her by how the condition affects her life, rather than by asking her how she sees herself. This leads people with control over her life—such as staff at settings where Elena receives services—to limit her activities.

By taking someone else’s opinion about Elena as truth and not asking her what she thinks, these staff dehumanize Elena and keep her from participating in activities that she enjoys and chooses. This paternalism limits Elena as much as or more than her medical condition.

Quality of life ratings are related to other modules in the survey—we know that when other parts of life improve, so do these measures of quality of life.

For example, when people have less [decision-making power](#), it means staff, guardians, and program administrators have control over their lives. Providers then make decisions without taking into account people’s hopes, dreams, and goals. This lack of power over one’s own life compounds day after day and can drastically impact quality of life. Other survey modules dig deeper into the factors that contribute to quality of life and provide nuance to some of these areas and interrelations.

Higher scores would demonstrate improvements in people charting their own course toward a better quality of life. The effect of COVID-19 is uncertain and deserves attention.

This year, participants are also asked to rate their overall quality of life during the pandemic, as compared to before. However, as with the rest of the survey, COVID-19 will have an unpredictable effect on scores, and it will be hard to know what is caused by the pandemic and what is caused by experiences outside the pandemic. Plus, impacts of COVID-19 and of living in potentially segregated settings are inherently related—people in these settings already have limited decision-making power and therefore are more affected by pandemic restrictions like Stay At Home orders.

This is the third of four briefs on the survey.

The [project briefs](#) and survey findings are available on the [Olmstead Quality of Life website](#), the [Olmstead Implementation Office website](#), and the Olmstead Implementation Office’s social media pages. The next brief will discuss the presence of close and valued relationships. In partnership with the survey Advisory Group, [The Improve Group](#) created this brief, drawing on the [Minnesota’s Olmstead Plan](#) and related [demographic data](#).

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.

Quality of life ratings: How people rate different areas of their own lives based on what is important to them, regardless of what others (e.g., guardians or providers) may say.

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