

LOCAL

# Minnesotans with disabilities fight barriers to inclusion, unfilled promises

Nearly 3½ years after top state officials pledged to embrace integration, thousands are still living segregated and isolated lives.

By Chris Serres (<http://www.startribune.com/chris-serres/10645926/>) Star Tribune |

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Every so often, Tom Hodgson climbs behind the wheel of his Ford pickup truck, parked outside his parents' home in Eagan, cranks up the radio and imagines a different life for himself.

Hodgson, 26, who has autism and a mild intellectual disability, dreams of having an apartment of his own, working as a mechanic and one day getting married. For now, however, much of his life is circumscribed by his disability. He can't drive alone, has never dated, and spends hours alone in his room.

"I want to break out of my shell, but it's scary sometimes," Hodgson said.

Nearly 3½ years after top Minnesota state officials pledged to embrace integration for people with disabilities, thousands of individuals like Hodgson are still living segregated and isolated lives.

## A rare and in-depth survey

(<https://www.dhs.state.mn.us/main/groups/olmstead/documents/pub/dhs-307971.pdf>), examining the quality of life of Minnesotans with physical, intellectual and developmental disabilities, found that many of them still have limited freedom and little control over their daily lives. Everyday decisions that many people take for granted — such as where to live and the choice of pets — are often determined by others, including paid support staff whom they had no choice in hiring.

The survey, released in February, also found that people who live and work in cloistered settings, such as group homes, are more isolated socially and have far fewer interactions with the community than other Minnesotans.

The findings underscore the challenges ahead for the administration of Gov. Tim Walz, as it seeks to implement a state plan ([https://www.dhs.state.mn.us/main/idcplg?IdcService=GET\\_FILE&RevisionSelectionMethod=LatestReleased&Rendition=Primary&allowI299316](https://www.dhs.state.mn.us/main/idcplg?IdcService=GET_FILE&RevisionSelectionMethod=LatestReleased&Rendition=Primary&allowI299316)) to move people with disabilities out of segregated settings, help them live more independently and participate in community life.

Despite marked progress in some areas, such as helping people obtain jobs in the mainstream workforce, Minnesota has struggled to improve access to community services and to comply with a 1999 Supreme Court ruling, known as the Olmstead decision (<https://www.ada.gov/olmstead/>), which requires states to ensure that people live and work in the most integrated settings possible.

Members of Walz's Cabinet, including the commissioners overseeing human services and housing finance, have publicly pledged to continue a multiyear effort to eliminate obstacles to integration. Yet their efforts have been impeded by a severe shortage of support workers who help people with disabilities live on their own; as well as a recent, 7 percent cut to rates paid through a state "waiver" program, which helps 47,000 Minnesotans with disabilities pay for services such as transportation and personal caregiving that help them live and work in the community.

"A state needs to be pushed," Human Services Commissioner Tony Lourey said in an interview last week about the Olmstead plan. "We need to make really sure we are focused on ... ensuring that people with disabilities are integrated into the lifeblood of our communities."



DAVID JOLIS — STAR TRIBUNE



DAVID JOLIS, STAR TRIBUNE

Thomas Hodgson, 26, has autism and a mild intellectual disability. He lives with his parents, does not date or drive and spends a lot of time

## **'System is stuck'**

Until recently, state officials had little information about the daily lives of the people they were trying to help. To fill that gap, a subcabinet appointed by former Gov. Mark Dayton commissioned a first-of-its-kind study, interviewing 2,005 people statewide who live and work in potentially segregated settings. The study was repeated with a smaller group last year and tracked dozens of quality-of-life indicators, including levels of integration in the broader community and how much choice people with disabilities have in their daily decisions.

For two consecutive years, the survey found that "choice-making power" can be severely limited for people who live and work in segregated settings. Large and small life decisions — including where to live, how to spend funds and even what foods to buy — are mostly left to paid staff, including guardians. Respondents with disabilities had about 30 percent fewer monthly outings into the community last year than the general population as a whole.

The study also found that, among Minnesotans who live and work in segregated settings, poverty is pervasive.

Overall, researchers found that the more segregated the setting, the lower the earnings. Minnesota still has nearly 12,000 adults with disabilities working in more than 100 segregated workshops and other settings that pay subminimum wages, state data show. Those who reported earnings from these workshops make a mere \$63 a week, compared to \$150 for those who held competitive jobs in the community.

Those who work in sheltered workshops, where people do menial jobs like packing boxes or picking up garbage, also reported low levels of participation within the broader community.

"The system is stuck," said Teresa Williams, chief executive of Mains'1 Services, a Brooklyn Park-based firm that provides services for people with disabilities. "We have raised an entire generation of people who view individuals with disabilities as fragile... and our system does not allow them to take natural risks in their lives. We need to rethink that."

This poverty and isolation threaten to overshadow other significant gains toward meeting the goals of Olmstead.

Hundreds of people who live in state-licensed facilities are no longer subjected to restraints and seclusion, as the state has moved to phase out the practice except in extreme cases. And after families complained, the Department of Human Services (DHS) eliminated long-standing waiting lists for services under Medicaid waivers, and these services are being approved at a much faster pace. The state's workforce agency is also putting hundreds more young people with disabilities on the path to competitive employment, through more targeted job training and rigorous evaluations of their skills and interests.

In the 2018 fiscal year, 16 percent of Minnesotans with disabilities who received state services worked in the community alongside people without disabilities. Though still below the national average, that's up significantly from 2012, when only 12 percent were part of the mainstream workforce, state data show. "We are recognizing that people with disabilities are a real treasure and add tremendously to our quality of life," Lourey said.

## **Caregiver shortage**

Hodgson is among those who has benefited. Last summer, he landed a job at a car wash in St. Paul after going through a "personal empowerment class" paid for through his Medicaid waiver. The class helped Hodgson, who has worked on repairing cars since he was in elementary school, identify his strengths and match him with an employer.

"His confidence in himself has really taken off," said his mother, Louise Hodgson.

Still, disability advocates and some legislators argue that the severe workforce shortage and the chronic underfunding of the state-funded personal care assistance (PCA) program are blocking progress.

The PCA program was created four decades ago to help people with disabilities live independently and today serves more than 40,000 people. But reimbursement rates have lagged behind the overall growth of the economy and the caregiving needs of an aging population, state officials say. State data show more than 8,000 unfilled home care jobs in Minnesota — and a need for an additional 60,000 workers during the coming years.

A proposal making its way through the Legislature would increase the minimum wage for personal care attendants from \$12 to \$13.25 an hour, but many advocates say that's still too low to compete for workers.

As a result, across the state, young people with mild disabilities who could live on their own are being forced to move into sterile and restrictive facilities, and pass up work opportunities, because they cannot find and retain caregivers who can help them with basic activities like eating, dressing and bathing, say disability advocates.

In many cases, people with disabilities are just one crisis away from losing home care supports and ending up in an institution.

In January, Jerry Parson, 60, was forced to move into a senior home in Eden Prairie after his primary caregiver, his wife, Joyce, suffered a sudden stroke at the elementary school where she works. Jerry, who has multiple sclerosis and no motion in his limbs, now spends most of his days alone in a hospital bed, flipping television channels with a voice-activated device. Joyce said she has been unable to find a replacement caregiver so Jerry could return home.

"It's hard seeing Jerry suffer like this," Joyce said during one of her visits to her husband. "He misses his cat. He misses his room. He misses me. He just wants to come home."

The workforce shortage isolates people in other ways.

David "Butch" Karcher, whose company owns seven group homes in north-central Minnesota, said he has been unable to fill about one-third of his available work shifts, which means he often cannot provide certain services that help residents feel more integrated in society. This includes community outings and fun events like fishing trips, holiday meals and community dances, which have traditionally been provided by his agency.

Even when outings do occur, he said, they tend to be less individualized: Without adequate staff, residents of group homes often have to go shopping or even to medical appointments in groups, which some consider stigmatizing.

"Most providers are doing everything they can to make people's lives happy," Karcher said. "But it's really hard to be person-centric in an environment like this."

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