

DEAD-END JOBS, LOW PAY

SCROLL

The state is segregating thousands of disabled adults in isolating jobs and homes. Many feel trapped, unable to lead independent lives.

Story by Chris Serres (<http://www.startribune.com/chris-serres/10645926/>) and Glenn Howatt (<http://www.startribune.com/glenn-howatt/10645091/>) • Photos by David Joles (<http://www.startribune.com/david-joles/10645151/>) • Star Tribune

NOVEMBER 8, 2015 — 12:00AM

WILLMAR, MINN.

In a field on the outskirts of town, a man with Down syndrome is spending another day picking up garbage.

He wears faded pants, heavy gloves, a bright yellow vest and a name tag that says "Scott Rhude."

His job is futile. Prairie winds blow debris from a landfill nearby faster than he and his co-workers can collect it. In the gray sky overhead, a turkey vulture circles in wide loops.

Rhude, 33, earns \$2 an hour. He longs for more rewarding work — maybe at Best Buy, he says, or a library. But that would require personalized training, a job counselor and other services that aren't available.

"He is stuck, stuck, stuck," said his mother, Mary Rhude. "Every day that he works at the landfill is a day that he goes backward."

NUMBING WORK

Scott Rhude picked up trash near a landfill in Willmar, Minn. He makes \$2 an hour and dreams of a better job.

Rhude is one of thousands of Minnesotans with disabilities who are employed by facilities known as sheltered workshops. They stuff envelopes, package candy or scrub toilets for just scraps of pay, with little hope of building better, more dignified lives.

Many states, inspired by a new civil rights movement to integrate the disabled into mainstream life, are shuttering places like this. Not Minnesota. It still subsidizes nearly 300 sheltered workshops and is now among the most segregated states in the nation for working people with intellectual disabilities.

The workshops are part of a larger patchwork of state policies that are stranding legions of disabled Minnesotans on grim margins of society. More than a decade after the U.S. Supreme Court ruled that Americans with disabilities have a right to live in the mainstream, many disabled Minnesotans and their families say they still feel forsaken — mired in profoundly isolating and sometimes dangerous environments they didn't choose and can't escape.

Records examined by the Star Tribune bear them out. Minnesota pours \$220 million annually into the sheltered workshop industry, consigning more than 12,000 adults to isolating and often mind-numbing work. It also relies more than any other state on group homes to house the disabled — often in remote locations where residents are far from their loved ones and vulnerable to abuse and neglect. And when Minnesotans with disabilities seek state assistance to lead more independent lives, many languish for months — even years — on a waiting list that is now one of the longest in the nation.

"We have entire communities of people with disabilities in this state who have zero choice," said Derek Nord, a University of Minnesota scholar who specializes in disability policy. "They live in closed systems with no obvious way out."

State officials defend Minnesota's record, saying it led the nation in closing large institutions for people with mental impairments and that it ranks high in the generosity of its disability benefits.

But in interviews with the Star Tribune, they acknowledged that people with disabilities deserve more control over their lives and said they are taking significant new steps to give them more choice in work and housing.

"Today, too many families believe their child, or their loved one, only has one option — a sheltered workshop," said Jennifer DeCubellis, assistant commissioner at the Department of Human Services. "So we have to undo that and make sure they understand there are other options. We have not done such a good job connecting people to those options."

Other states are far ahead of Minnesota. Vermont has abolished sheltered workshops and moved most of their employees into other jobs. States across New England place nearly three times as many disabled adults in integrated jobs as Minnesota. Washington offers disabled workers nine months of vocational training and career counselors.

"Nationally, the big river of change is flowing ... toward increased integration," said Pamela Hoopes, legal director of the Minnesota Disability Law Center. "Sometimes it appears that we [in Minnesota] are meandering along the bank and getting hung up on the weeds."

Safe, or trapped

The segregation starts early.

As a boy in special education classes, Scott Rhude showed talent with computers and photography. But once he graduated from high school, his mother says, he bounced from one segregated workplace to another, never quite escaping a system that has sometimes amounted to little more than what she calls "babysitting."

Away from his job, Rhude has built an independent life. He pays his own rent and shares a house with three friends in Willmar, a town of 19,600 west of the Twin Cities. He sings karaoke, goes on double dates and started his own book club. His bedroom is packed with trophies from Special Olympics events.

OUT OF THE MAINSTREAM

More than any other state, Minnesota relies on sheltered workshops to employ people with disabilities, rather than helping them find private-sector jobs in the community.

"I'm not afraid of anything," he joked recently, flexing his biceps under a poster of a professional wrestler in his bedroom.

But Rhude's pursuit of independence ends each morning when the city bus drops him off at West Central Industries, a sheltered workshop on the edge of town. From here, a van takes him to the Kandiyohi County landfill, where he spends the next five hours collecting trash on a hillside as big as two football fields.

Mary Rhude says she and her son hoped the roving work detail would broaden Scott Rhude's skills and give him exposure to other employers in Willmar. Instead, she says, it has become a "suffocating" experience that keeps her son isolated from the community.

Kristine Yost, a job placement specialist for people with disabilities, calls this system "the conveyor belt."

"It's heartbreaking," she said, "but time and again, young people get pigeonholed as destined for a sheltered workshop and then they can't get out."



Scott Rhude, 33, who has Down syndrome, and his mother, Mary, discuss their frustration in trying to find him a fulfilling job.

Civil rights revolution

In 1999, the U.S. Supreme Court issued a landmark ruling, known as Olmstead, that prohibits states from unnecessarily confining people with disabilities in special homes or workplaces. In a broad reading of the Americans with Disabilities Act, the court said that fairness demands not just access to buses and buildings, but to a life of dignity and respect. People with a wide range of disabilities — including Down syndrome, cerebral palsy and autism — call it their "Brown vs. Board of Education."

In the ruling's aftermath, many governors closed state institutions for the disabled and the U.S. Justice Department sued Oregon and Rhode Island to close sheltered workshops.

But, 16 years later, the movement has yet to take hold in Minnesota.

Under sustained pressure from a federal judge, Minnesota this fall became one of the last states in the country to adopt a blueprint — known as an Olmstead plan — to expand housing and work options for people with disabilities. County officials and social workers have begun consulting disabled clients about their goals and interests. By 2019, the state expects counties to complete detailed, individualized plans spelling out work and housing options for thousands of disabled adults.

Yet even if it is executed successfully, the state's plan calls for only modest increases in the number of disabled adults living and working in the community. It makes no mention of phasing out segregated workshops and group homes.

Its employment targets, Hoopes said, are "woefully inadequate" and a "lost opportunity."

Some families defend sheltered workshops, saying they provide a safe place and a sense of accomplishment for young adults who cannot hold competitive jobs. Minnesota has a high overall employment rate for adults with disabilities, in part because of its sheltered workshops.

Others say the state is clinging to an obsolete and paternalistic practice.

"We have this mind-set in [Minnesota] that says protection trumps everything else, and we have to keep people in these isolated bubbles to keep them safe," said Mary Fenske, a disability rights advocate from Maple Grove who advises employees of sheltered workshops.



(http://stmedia.stimg.co/forsaken1_cansBIG.jpg)
LOW-WAGE WORK DAVID JOLES

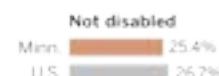
NEVER FINISHED Dustin Leibfried, 42, who has toiled for years at a sheltered workshop in Fairmont, Minn., stacked cans of chicken on a fast-moving conveyor belt known as the "T-Rex." "There are some days when you feel like you're just racing, racing, racing up," 1,232



POVERTY RATE



EARNINGS UNDER \$15K



Sources: Institute for Community Inclusion; U.S. Census Bureau

Sheltered workshops multiply

Sheltered workshops were designed after World War II to prepare people with disabilities for traditional employment. They caught on in Minnesota, and between 1970 and 1984 the sheltered workforce increased from 700 to 6,000 workers, including thousands of people who needed daily activities after the closing of state mental hospitals.

Today, state policy perpetuates the segregation.

Each year, Minnesota pays more than \$220 million in state and federal Medicaid funds to scores of sheltered workshops and training programs, which have become a large and self-sustaining industry. They operate fleets of vans, partner with local group homes, and use a federal loophole that exempts them from minimum-wage law.

Most of Minnesota's sheltered workshops are nonprofits, but many hold business contracts with companies such as 3M to assemble or package products, while others provide janitorial services to local businesses. Even though they pay, on average, just \$4.05 an hour, most could not survive without state subsidies to cover the cost of supervision and other services.

"If not for the government money, a lot of these [sheltered workshops] would be starved out of existence," said Jim Clapper, board chairman of Midwest Special Services, Inc., a sheltered workshop and day training provider in St. Paul. Clapper's son works at a sheltered workshop.

From a taxpayer's perspective, the workshop model is highly inefficient. It costs roughly \$52,000 to create a sheltered workshop job that pays at least minimum wage, state records show. That's nearly 10 times the \$5,300 it costs to help a disabled worker get a job in the community, according to a 2010 survey by the Department of Human Services.

"This all comes down to funding," said John Butterworth, director of the Institute for Community Inclusion, a research and training center at the University of Massachusetts. "If Minnesota spent this money on competitive employment, you would see more people working in typical workplaces earning typical wages."

If sheltered workshops prepared their clients for better jobs, they might justify the huge investment. But academic research and state reviews suggest they do not. When Minnesota's legislative auditor studied the industry in the 1980s, he found that only 83 of 3,000 sheltered workers graduated to competitive jobs. Today, research places the share at about 5 percent.

In fact, sheltered workshops can actually impede clients' progress by training them to be compliant and settle for mundane tasks, said Bryan Dague, a University of Vermont researcher who advises states on disability employment.

"All too often, a job in a sheltered workshop is a dead end," Dague said.

Factory work

Early one morning last spring, at a warehouse set amid cornfields near Fairmont, Minn., more than 30 workers with varying disabilities stood quietly in line, clutching their white time cards. A few checked their watches nervously.

At 8:15, a clipboard-wielding supervisor shouted, "It's time to get rollin'! Time to get rollin'!"

With its clockwork precision, this workshop operated by MRCI Inc. of Mankato shows how the industry has developed a keenly efficient model — but also why many of its employees find it suffocating.

Over the next eight hours, employees filled 3,600 plastic tubes with patriotic red, white and blue gumballs for Memorial Day sales at big-box retailers. They also arranged more than 50,000 cans of chicken into tidy piles as they tumbled down a fast-moving conveyor belt known as the "T-Rex."

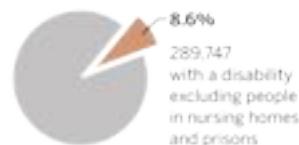
Apart from managers occasionally yelling orders, the sprawling room was quiet but for the steady rat-a-tat of gumballs pouring into 12-inch tubes and the hum of a machine wrapping plastic around cans of chicken.

"Our workers are very well-behaved and task-focused," said Ramona Harper, the workshop's manager, as she walked the plant floor. "This is the best-kept secret in Martin County."

MINNESOTANS WITH DISABILITIES

Just under 9 percent of working-age Minnesotans have disabilities, as counted by the U.S. Census. Many have multiple disabilities.

WORKING-AGE MINNESOTANS
2014 (ages 18 to 64)



TYPES OF DISABILITIES

4.1% Cognitive	Including autism, developmental disabilities and mental illness
3.5% Ambulatory	Can't get around independently
3% Independent-living	Unable to live alone
2% Hearing	Deaf or have very poor hearing
1.4% Self-care	Need help caring for self
1.2% Vision	Blind or near blind

Sources: Institute for Community Inclusion, StateData.info, U.S. Census Bureau, American Community Survey



(http://stmedia.stimg.co/forsaken1_gumballsCROPPED2.jpg
DAVID JOLES)

ASSEMBLY LINE: Employees filled tubes with colored gumballs at a sheltered workshop in Fairmont, Minn., where their pay is based on speed and productivity. Workers at state-subsidized sheltered workshops in Minnesota made an average of \$4.05 an hour last year.

Next to many workers were small white sheets to track their productivity. Every so often, a manager stopped by and jotted down how many tubes each employee had filled with gumballs. Pay is calculated using the prevailing wage for similar work: A disabled worker who pours gumballs half as fast as a non-disabled person makes half the prevailing wage for light manufacturing, or about \$5 an hour.

At noon, workers rushed into the cafeteria for plastic-wrapped sandwiches waiting under a heat lamp. On this day, the room buzzed with talk of two colleagues who “made it to the outside.” One landed a job at Wal-Mart and the other was bagging groceries at a local supermarket for \$9 per hour.

“It’s the success stories that give us hope that someday we can make it out of here,” said Dustin Leibfried, 42. “Because there are some days when you feel like you’re just racing, racing to catch up. Most of us want out.”



Closer look

DIFFERENT WORLDS

Suzanne Sukalski is a breakfast hostess at a hotel in Fairmont, and Erin Ebert works in a sheltered workshop on a cleaning crew. They both have Down syndrome, but have very different job outlooks.

Read full story

(<http://www.startribune.com/331070182/>)

A closed system

John Wayne Barker was working his way through the brightly lit lunchroom of Merrick Inc., where he has been executive director for the past 17 years. Every few steps, a worker stopped him for a high five or a hug.

Barker is a vocal defender of sheltered workshops, and his expansive facility is considered a model for the industry. It operates an assembly line where about 100 workers perform tasks like inserting greeting cards into envelopes for sale at grocery stores. But it also offers an array of “life enrichment” services, from music and pet therapy to yoga and gardening, for people who may be unable to work.

If the workshop closed, many of its employees would be “at home, staring at the wall,” deprived of their sole source of wages and social interaction, Barker said.

“Without our program, virtually nine out of 10 people we’re serving would have no consistent daytime activity,” he said. “Nobody [here] is trapped or unhappy.”

Some parents agree. Ivan Levy said his 26-year-old son, Jason, who has autism and a developmental disability, has improved his social skills and self-confidence since coming to work at Merrick five years ago. After years of job coaching, he earns minimum wage in Merrick’s recycling center.

“If you closed the workshop, Jason would go from being in an environment with a lot of support and a lot of interaction to one with zero support and zero interaction,” said Levy, an attorney in St. Paul. “He’d be sitting at home, watching television or playing video games all day.”

But for a large share of Minnesota’s disabled workers, that’s simply not true. At sheltered workshops subsidized by Minnesota’s state workforce agency, as many as 45 percent of employees simultaneously hold other jobs in the community for at least

Video



Director John Wayne Barker explains the opportunities at Merrick Inc., a large sheltered workshop.

minimum wage, according to an internal analysis. When Vermont closed its last sheltered workshop in 2002, social workers found jobs for 80 percent of the workers.

"The numbers show that a lot of people [in workshops] can do real work for real wages if given the opportunity," said Jon Alexander, a supported employment provider in Little Canada.

That includes people like Larry Lubbers, 61, who made \$15 an hour moving shopping carts at a Rainbow Foods until he suffered a back injury. Unable to find other work, Lubbers, who has an intellectual disability, said he didn't object when the county suggested a sheltered workshop.

Yet Lubbers says he remains shocked by his low pay. He now makes less than \$30 a week doing menial tasks such as inserting straws into plastic bags.

"It's out of sight, out of mind," Lubbers said one day as he waited for a van to work from his home in Inver Grove Heights. "Once you walk into a sheltered workshop, you become invisible."

Breaking out of the system can be extremely difficult. Because their wages are so low, many sheltered workshop employees can't afford their own apartments or transportation. A 2010 state survey found that nearly 80 percent rely on their employer as their primary source of transit. In fact, a half-dozen sheltered workshops also run their own group homes; at least one, Functional Industries in Buffalo, Minn., shuttles people to its sheltered workshops from its group homes in its own vans.

"It's a closed system," said Mary Kay Kennedy, executive director of Advocating Change Together, a disability rights group in St. Paul. "It's so safe and predictable that a lot of people never get to explore other options and realize their true potential."



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Handing out résumés

Kenisha Conditt, 27, who has a developmental disability, went straight to work at Midwest Special Services in St. Paul after graduating from youth vocational training. For the past five years, she has been assigned to a cleaning crew that collects trash, mops floors and cleans toilets at area businesses.

On a recent morning, Conditt's team marched in a line through the parking lot of an industrial park in Minneapolis, carrying large plastic jugs in one hand and long-handled pincers in the other. With a supervisor watching, they plucked plastic bags, cigarette butts and shattered glass from the blacktop.

"You missed one, Kenisha!" the supervisor called, pointing to a rusty nail.

After dumping her last bucket of trash and mopping the entryway of a bus terminal, Conditt returned to Midwest's gated campus in St. Paul, where she spent the next several hours killing time before a Metro Mobility bus arrived to take her home. Sitting with a group of co-workers on a row of plastic chairs, she stared ahead stoically as a woman with an accordion played "Goodnight Irene" and then the workshop's special song, "Midwest Special Services is where I like to be ..."

When the song ended, Conditt and the others filed quietly back to a row of desks full of puzzles and games.



(<http://stm>)

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"Five years of this, and I'm ready to move on," she said. "I don't want to spend the rest of my life cleaning toilets."

A few days later, Conditt seemed transformed. On Sundays she helps teach children at Christ Temple Apostolic Church in Roseville. She laughed, sang and read children's books as toddlers crawled over her lap and shoulders.

"Kenisha has gifts that people at the workshop never see," said her mother, Antoinette Conditt.

On the drive home from church, they spotted an Old Country Buffet with a "Help Wanted" sign in the window. Her mother pulled over. Conditt darted across the parking lot.

Stepping into the restaurant's lobby, she smoothed her blue skirt, smiled broadly, and asked if she could speak with the manager. In one of her hands Conditt held tightly to a folder filled with copies of her résumé.

She takes them everywhere she goes.

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ALONE AND AT RISK

SCROLL

Set up to be safe havens, some group homes for the disabled have become remote "prisons," where residents are vulnerable to violence and neglect.

Story by Chris Serres (<http://www.startribune.com/chris-serres/10645926/>) and Glenn Howatt (<http://www.startribune.com/glenn-howatt/10645091/>) • Photos by David Joles (<http://www.startribune.com/david-joles/10645151/>) • Star Tribune

NOVEMBER 9, 2015 — 12:00AM

L ate one night this summer, George Daly woke abruptly to the sound of the fax machine humming from the den of his tidy home near Minneapolis.

It brought tragic news: Just hours earlier, on a desolate stretch of highway in northern Minnesota, Daly's granddaughter, Ashley, had slashed her wrist with a piece of glass and thrown herself in front of a speeding car.

It was the seventh suicide attempt since Ashley, who has bipolar disorder and a cognitive impairment, was sent to live in a group home three hours away, on the wooded outskirts of Hermantown, Minn.

"Ashley feels lost and abandoned," said Daly, who settled on the facility only after several others closer to the Twin Cities turned them down. "She has no place to call home in this world and this is her way of crying out for help."

'I BECAME LOST'

Ashley Daly, who has bipolar disorder and is cognitively impaired, has attempted suicide seven times since she moved hours away from her grandparents.



Video (05:29): Ashley Daly's grandparents grew too frail to handle her bipolar disorder

Each year, hundreds of Minnesotans with developmental disabilities and mental illnesses are uprooted from their families and sent to live in secluded group homes in remote parts of the state. Cut off from the communities they know, housed with strangers, they often fall deeper into anger and despair. Many, like Ashley, see violence and self-injury as their only means of escape.

Minnesota's far-flung network of group homes is another sign of how it has fallen behind other states in the movement to integrate people with disabilities into mainstream life. Though designed as safe havens for people too vulnerable to care for themselves, group homes now leave thousands of adults isolated and vulnerable to neglect and abuse.

A Star Tribune review of hundreds of public documents has found:

- Minnesota relies more than any other state on group homes to house adults with disabilities, spending \$1 billion annually for about 19,000 people in more than 4,500 facilities.
- While many group homes are safe and orderly, others are understaffed and chaotic. Each year, state regulators receive more than 700 reports of abuse, neglect, exploitation and serious injury at Minnesota group homes. In 2013, a federal judge became so alarmed at conditions facing group home residents that he appointed a special monitor to review their care.
- Scores of Minnesota's group homes lie in remote rural settings, placing residents hours away from relatives who might assist with their care and check on their well-being. The Star Tribune analyzed records for more than 5,000 individuals and found that one-third were placed in group homes outside their home counties. Of these, hundreds live more than 100 miles from their home counties, often in small towns such as Hermantown in rural St. Louis County.
- In dozens of interviews, people with intellectual and developmental disabilities said they were sent to group homes against their will, even when they were capable of taking care of themselves.

"This feels like a prison," said Joshua Burt, 28, standing outside the Rochester group home where he was placed, against his wishes, six years ago. "This is not the place for me, but it feels like my life is outside of my hands."

Erin Metzger, director of outpatient mental health at St. Luke's Hospital in Duluth, said she has seen dozens of patients cycle through local psychiatric wards and clinics after they ran away from group homes.

"My heart breaks for these people," she said. "They're hundreds of miles away from their families and support systems, and that makes them sicker."

In September, under pressure from U.S. District Judge Donovan Frank, Minnesota completed a plan that would give people with disabilities more say in where they live and raise the number living independently. But the increases are modest, and the plan does not call for closing group homes or reducing their state payments.

'Woods and swamps'

Remote settings such as Hermantown not only place group home residents far from family and friends, they can contribute to neglect and violence.

In 2010, a 44-year-old man with schizophrenia went missing after wandering away from his group home north of Duluth. A group of deer hunters discovered his bones two years later, decomposing inside his clothing in the woods.

"People like to say these homes are in the 'community,'" said St. Louis County undersheriff David Phillips, as he drove by the woods where the man's remains were found. "But about the only community out here is woods and swamps."

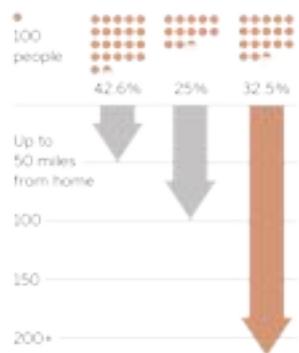
In Lewiston, a man with schizophrenia and a degenerative brain disease died after falling seven times in the kitchen of his group home. Despite sustained bruising and four cuts on his head, staff members said the 58-year-old man fell "for attention" and did not call for medical help, state investigators found.

and violent mood swings. so they moved her to

LIVING FAR FROM HOME

The Star Tribune analyzed records for 5,100 Minnesota group home residents. More than one-third were placed in counties other than their county of residence, and hundreds live more than three hours from their home address.

Distance group home residents live from their communities by percent



Sources: County records, Star Tribune reporting



(http://stmedia.stimg.co/forsaken2_roomCROPPED.jpg)
DAVID JOLES

FAR FROM HOME: Ashley Daly woke up to another day at her group home in Hermantown, Minn., three hours from her childhood home.

In a case last year, a 26-year-old man living at a group home in Princeton, Minn., was found dead on his bedroom floor after staff had lost contact with him for more than 44 hours.

In some cases, residents simply run away, hoping that someone will move them if police take notice. VaLinda Henry suspects that's what drove her son, Troy Henry, 41, who was cognitively disabled and had schizophrenia, to wander off into the forest near Stillwater with a plastic bucket full of his personal belongings. Later that night, his body was found floating down the St. Croix River, with the bucket attached to his waist. Sheriff's deputies found what appeared to be the words "MY WILL" scrawled in the sand nearby.

Just days earlier, Henry had called his mother, saying the group home wouldn't let him leave for a weekend with his two children, ages 13 and 15. "They treated my son like a prisoner," his mother said, sobbing.

In far northern Minnesota, the consequences of isolation have reached crisis levels. Stuck for months or years, often among housemates with severe mental illnesses, many residents lash out at each other, turning these homes into small battlegrounds, according to county health officials and group home workers.

"It's not right for human beings to live this way," said Cody Jakowski, a crisis responder at Stepping Stones for Living, a company that operates group homes near Duluth. "People aren't meant to be isolated like this."

In St. Louis County, more than one out of every three 911 calls involve incidents at group homes, the sheriff's office estimates.

"What is happening up here is brutal beyond belief," Phillips said. "It's like hundreds of little train wrecks dotting our landscape."

Remote clusters

Minnesota's reliance on group homes dates to the late 1970s, when it led the nation in shutting down large state hospitals that housed people with mental illnesses and developmental disabilities. The state encouraged small, private group homes as a more humane and cost-effective alternative, and subsidized them through Medicaid and other programs.

Many of these early group homes sprouted up near the shuttered state hospitals, in outstate cities such as Faribault and Rochester. Soon, large for-profit operators began clustering group homes nearby, in rural areas where land was cheap and local resistance was minimal. Today, 62 percent of Minnesota's group homes are outside the Twin Cities metro area, state data show.

The biggest cluster is in St. Louis County, where half the group home residents come from other parts of the state. Some local officials now refer to their county as the "State Hospital of Duluth."

The result, some advocates say, is a system with the same misguided paternalism that "separate but equal" embodied during the civil rights movement a half century ago.

"It's a segregated system," said Mark Nelson, division director of adult services in St. Louis County. "If you concentrated this many people of color in one area, there would be accusations of discrimination."

Once this far-flung network emerged, it became self-perpetuating. County social workers typically recommended group homes as the only option, even for people with moderate cognitive problems, even in communities with services to support independent living.

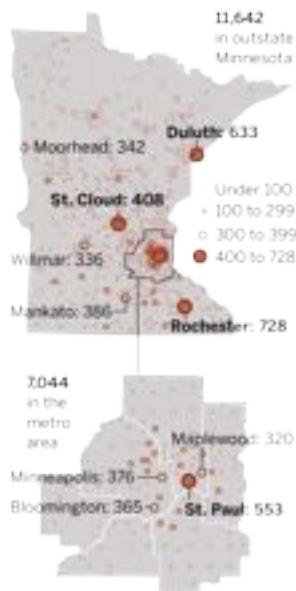
And though group homes were meant for people needing 24-hour care, such as patients with severe mental illnesses, many accept just about anyone with an intellectual or developmental disability. Records show that even clients who need just basic assistance with daily activities — like cooking meals or catching the bus — can wind up in group homes that cost up to \$80,000 per person per year.

"We are spending hundreds of millions of dollars a year for 24/7 care for people who don't want it and don't need it," said Nancy Fitzsimons, a professor of social work at Minnesota State University in Mankato. "Minnesota fell in love with the four-bedroom

REMOTE SETTINGS

Minnesota relies heavily on small, private group homes for people with disabilities, and the homes have formed clusters that are often remote from the Twin Cities. Duluth, for example, has more group home beds than either Minneapolis or St. Paul, even though it is much smaller.

GROUP HOME BEDS, BY CITY



Sources: County records, Star Tribune reporting

group home model, and we got stuck."

Top state administrators and group home industry leaders acknowledged that many people who could be living independently are instead steered toward group homes. Clients are now being asked where they want to live, a process the state plans to complete by the end of 2016.

"There are people living in group homes who probably could live in other settings, but either don't know the options or don't trust the options," said Alex Bartolic, disability services director at the state Department of Human Services. "Everything has to change — our context and our way of coming at this."

Closer look

'SET UP TO FAIL'

Tony peered nervously from behind the plastic blinds of his one-room apartment. He could hear a police siren in the distance, then some loud shouting, then a heavy silence.

"I wish I lived far, far away from this ..." he paused, searching for the right word, "sewer."

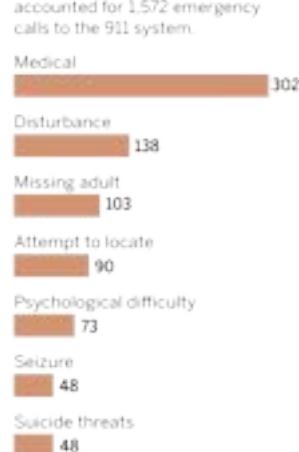
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BOARDS
The hundreds
a year.
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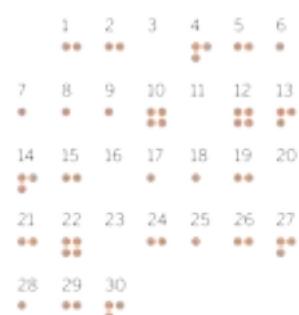
One month of 911 calls in Duluth,

June 2015 (latest data available)

During a typical month this year, Duluth's 911 dispatchers received emergency calls from group homes nearly every day.

June 2015

* = 1 group home related call



Sources: Star Tribune reporting,
Duluth Police Department

'Most people get to choose'

Every so often, Joshua Burt stares out the basement window of his Rochester group home and imagines an elaborate escape. Burt sees himself packing a suitcase and then waiting for a rare moment, usually a Sunday afternoon, when shift changes sometimes leave him unsupervised. He imagines running to a nearby bus stop, using the neighborhood trees and bushes as cover.

"I think about escaping two or three times a day," said Burt. "But where would I go?"

Burt, who has a mild developmental disability, was never asked whether he wanted to live in a group home. The decision came, he said, on the day he and his siblings learned that their mother had lung cancer.

"My brother came up to me and said, 'Mom wanted you in a group home,' and that was it," he recalled. Weeks later, Burt was told to pack his belongings from his mother's trailer in a mobile home park outside Rochester, then was taken to a group home he had never seen, to live with three strangers.

"It seemed unfair," said Burt. "Most people at least get to visit the places where they live and choose who they get to live with."

Burt works two part-time jobs — at a Wal-Mart and a Culver's restaurant — and aspires to get his own apartment. Then he wouldn't have to ask permission to have visitors or go on fishing trips with co-workers. But Burt gets just one chance a year to make his case, at a meeting that includes his county case worker, group home provider, and his older sister, who is also his guardian.

At this year's meeting, Burt said, he was told he still lacked adequate "financial management skills."

"I keep saying, 'I want out,' but no one listens," Burt said, after wrapping up a shift at Culver's. "How is it possible that I can work two jobs and take the bus here every day, but can't live on my own?"

A pattern of scars

No one ever asked Ashley Daly either.

When her grandparents, who adopted her as an infant, decided they had grown too frail to handle Ashley's violent mood swings, they asked for help from the county. A social worker gave them a long printout of group homes, most located far away, that might accept Ashley.

With little more than Google to guide them, George and Ruth Daly worked their way through the list. George asked each provider a series of 10 questions — "Do you have locked doors?" and "Do you involve them in the community?" — and jotted down plus or minus signs next to each one.

The group homes with the most plus signs were typically in remote places, like Saginaw and Thief River Falls. Many had wait times of a year or more for a bed.

When a provider from northern Minnesota finally called them with an opening, the Dalys were elated. Though it was a long way away, the couple hoped the remote location would keep their granddaughter safe. "You wouldn't run away, because you wouldn't know what direction to run," George said.

A year later, the Dalys admit they underestimated Ashley's attachment to her family and childhood home. It was only after arriving in Hermantown that she began her suicide attempts, each one prompting a faxed report to her grandparents. More than a dozen deep, zigzagging scars line her forearms, marking the many times she has cut herself since arriving up north.

On a recent morning, she staggered from her bedroom at the group home, spread out on a couch, and described how much she misses her grandparents' house and her pet terrier, Holly, who stayed behind.

"I had a dream last night that I finally got to see Holly," she said. "Why has everyone abandoned me?"

On long distance calls home, Ashley would ask her grandparents, "Why did you adopt me if you couldn't even finish the job?"

The question hangs heavy over the Dalys, who now wonder whether they made a mistake by sending her so far away. They even considered shipping all her bedroom furniture up north to make her feel more at home. But, like thousands of other Minnesota families, they were beginners in a baffling system that seemed to offer no middle ground between keeping Ashley at home and sending her far away.

"We did our very best with the options we had," Ruth Daly said, "and no one to help us."



(http://stmedia.stimg.co/forsaken2_JoshuaBurtCROP1.jpg
DAVID JOLES)

ESCAPE PLAN: Joshua Burt, who has a mild developmental disability, lives in a group home outside Rochester and often imagines running away.



http://stmedia.stimg.co/forsaken2_dogGreet2.jpg



http://stmedia.stimg.co/forsaken2_petCROP1.jpg

LEADING 'HOME': Ashley Daly was excited about a weekend with her grandparents and her terrier, Holly. When she got up, where she was cared for by Amber Johnson, above right, she felt abandoned.



(http://stmedia.stimg.co/forsaken2_holdingHands.jpg)

'I became lost'

On the long drive back from the North Woods, Ashley Daly hummed the words to her favorite song, "Put Your Records On," from the back seat of her grandparents' sport-utility vehicle. Ashley's voice got louder and more animated as the family neared the suburban landscape of her youth — the day care center and the playground where she once walked her dog now spread out asleep on her lap.

After a long, cold winter in Hermantown, in a group home that allowed her only 20 minutes of "alone time" each day, Ashley was brimming with excitement at spending Easter weekend with her grandparents in Minnetrista. George and Ruth have kept Ashley's bedroom exactly as she left it — walls painted with pink butterflies and windowsills lined with teddy bears. On the living room couch is the extra-thick security blanket that George and Ruth would gently wrap around Ashley when she would fly into one of her "rages" and needed to calm down.

"Grandpa!" Ashley called out from the back seat. "Tonight, after we get home, can we watch the stars? Like we did when I was little?"

"Honey, we told you this before," George Daly said, as he pulled into his neighborhood. "This is NOT your home. Your home is in Duluth."

But attempts to make Ashley feel at home up north have not worked. In late July, she moved to a new group home in Duluth after the one in Hermantown determined it lacked adequate staffing to keep her safe. The new home is in a residential neighborhood, but Ashley said she's still lonely — she still misses Holly and staying up late watching episodes of "CSI" with her grandpa.

Beneath Ashley's bed is a box full of the poems and essays she has written since middle school. Many reflect her sense of abandonment, including self-portraits showing her lying in a pool of blood or hanging from a noose. Among the assorted letters is one she wrote to herself on the October night her grandparents first dropped her off up north.

"I became lost once I learned I was moving to Duluth," Ashley said, reading the letter. "I lost everything. Trust. Hope. Relationships. Friends. Family. ... I felt this was the end."

Ashley leaned her forehead on the dining room table, exasperated, and added, "I just want to go home."

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EPIC WAIT FOR UNSPENT AID

SCROLL

Thousands of disabled Minnesotans languish on waiting lists for crucial services even as millions of dollars remain unspent.

Story by Chris Serres (<http://www.startribune.com/chris-serres/10645926/>) and Glenn Howatt (<http://www.startribune.com/glenn-howatt/10645091/>) • Photos by David Joles (<http://www.startribune.com/david-joles/10645151/>) • Star Tribune

NOVEMBER 10, 2015 — 12:00AM

Thousands of Minnesota families are being forced to wait months — even years — when they seek state financial assistance that helps people with disabilities build more independent lives.

Minnesota's waiting list for this form of aid, relative to its population, is now among the largest in the nation.

And yet tens of millions of dollars intended for these families is going unspent in Minnesota every year, records show.

Carrie Peterson-Edberg, whose 12-year-old son Garrett has severe autism, recalls shouting with joy when a county social worker called to say he qualified for aid to cover behavioral therapy and personal caregiving at home.

That was seven years ago. They are still waiting.

DIFFERENT FATES

Brianna Hoover and her twin brother, Cory, in background, both have fetal alcohol syndrome, but Cory jumped to the front of the aid line when he gashed his arm.

Jeff and Ellen Pearson moved to Minnesota from Indiana in the hope of obtaining a better life for their daughter, Abby, who has been cognitively impaired since birth. Abby was immediately placed on the waiting list.

That was 14 years ago. They are still waiting.

Families say the long waits needlessly isolate people with disabilities from mainstream work and more fulfilling lives. Adults who could be living in their own apartments or working in middle-class jobs are instead stuck in their parents' basements, awaiting approval they may never get.

The chronic delays do not occur because Minnesota is a stingy state. It consistently ranks among the top states nationally on a key measure of disability spending. For those who do receive the coveted assistance, known as a Medicaid "waiver," Minnesota's package of benefits is the most generous in the nation. And, state officials point out, most families on the waiting list still receive other subsidized services, such as personal care aides and county case managers.

Still, families say, in distributing a form of aid that can open the door to mainstream life, Minnesota remains wedded to a process that is opaque and infuriatingly slow. Since 1995, more than \$1 billion allocated to counties for this assistance by the Legislature has gone unspent, records show. For someone with a developmental disability, the median wait is now five-and-a-half years.

Abby Pearson, now 26, said she "feels trapped" in her parent's home as she waits for a waiver that would cover the cost of independent housing and in-home care.

"Every year that goes by, I wonder, 'Why am I still on this list?'" said Abby. "I want to live on my own, have my own friends, and not have to spend the rest of my life dependent on my mom and dad."

'All hands on deck'

Jennifer DeCubellis, assistant commissioner of the Minnesota Department of Human Services, which oversees the state Medicaid program, acknowledged that the state "clearly needs to manage these dollars better."

Under pressure from a federal judge and state lawmakers, her agency has begun to pool the funds, so that counties with long waiting lists can get help from counties with large reserves. And, after noting that many counties had large unspent accounts, the Legislature last year directed them to spend at least 97 percent of the money allocated to them.

"We need to very assertively make sure that those dollars are getting out the door ... " DeCubellis said. "It's all hands on deck."

State officials have made similar efforts in the past. Yet the waiting list continues to grow: It now exceeds 5,000 applicants and, adjusted for state population, is the nation's ninth-largest. A number of counties have underspent their funds by 10 percent or more, and have still not been ordered to change course, state records show. And while the new law requires counties to submit "corrective action plans" if they fail to spend enough of their money, those plans vary widely from county to county and are not subject to any automatic penalties for falling short.

"The system has no teeth," said Shamus O'Meara, the lead attorney for a group of disabled families who sued the state in August over the issue. "We can throw more money at the problem, but without structural change, we would still have these waiting lists 10 years from now."

The problem stems, in part, from a long Minnesota history of relying on counties to administer social services such as welfare and disability aid. One result is a patchwork system in which a family's odds of getting this form of aid depend largely on where they live. Faribault County, for instance, held back 21 percent, or \$1.3 million, of its allocated funds for a key waiver in 2014. Meanwhile, Olmsted County spent nearly 99 percent of its funds.

Closer look



Abigail Pearson:
14 years on wait list

(<http://www.startribune.com/331058632>)



Simon Heil:
7 months on wait list

(<http://www.startribune.com/331060792>)



(<http://stm>)

ON HOLD: C
been waiting
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autism.

Worse, the state has sometimes sent mixed signals to county officials. About 15 years ago, the Legislature approved a temporary expansion of the program, with more money, that briefly eliminated the waiting list. Then, in 2005, it passed a law requiring counties to reimburse the state if they overspent their allocations. Many counties became extremely cautious in spending waiver money, and waiting lists swelled back to pre-2001 levels.

Perverse competition

Across Minnesota, the wait-list ordeal pits parents of disabled children against each other in a fierce competition to prove who is most deserving. Those with a high priority can move up the list and get approval within weeks. Others will wait a decade or more.

Steve and Maureen Hayes, who are in their 60s, said they felt like they had “won the lottery” after their developmentally disabled son, Brett, finally received approval this spring after a 10-year wait. For Brett, who is 24, it was a ticket to independence. The waiver covered the cost of a personal caregiver and, for the first time, enabled Brett to move out of his parents’ home in Plymouth.

“The waiver makes the difference between having a life and not having a life,” Steve Hayes said.

But like many successful applicants, the Hayes said they feel a sense of guilt seeing their son get tens of thousands of dollars in services, while friends with disabled children find themselves waiting indefinitely.

“It’s like this perverse competition,” Steve Hayes said. “You’re forcing me to tell you, year after year, how much I’m not able to take care of my own child. ... Emotionally, it’s a draining experience.”

Some parents say that approval seems arbitrary, reflecting decisions by county administrators who never actually meet or speak to them.

WAITING FOR WAIVERS

More than 5,000 Minnesotans with disabilities wait months, even years, to receive a coveted form of assistance known as a Medicaid waiver that can help them lead independent lives.

UNSPENT FUNDS, STATEWIDE
Millions in state Medicaid money allocated for waivers goes unspent each year.



Sources: Truven Health Analytics; Minn. Dept. of Human Services



http://stmedia.stimg.co/forsaken3_shave2.jpg



[\(http://stmedia.stimg.co/forsaken3_briannaHoover.jpg\)](http://stmedia.stimg.co/forsaken3_briannaHoover.jpg)



[\(http://stmedia.stimg.co/forsaken3_briannaGame2.jpg\)](http://stmedia.stimg.co/forsaken3_briannaGame2.jpg)

EDING HELP: Brianna Hoover, 19, and her twin brother, Cory, shown at right with sister Jarelyn, 7, both need help with basic tasks. While Cory gets money to pay for therapy and outings that improve his social skills, Brianna – stuck on a waiting list – has been unable to live more independently.

Candy Hoover of Cambridge applied for waiver assistance for the twins she adopted years ago, Brianna and Cory, both now 19. Cory, who suffers from fetal alcohol syndrome, was approved for financial assistance in 2010, within weeks after he went into

a violent rage, punching his fist through the window of their kitchen door, deeply gashing his arm.

Because of the meltdown, Cory was deemed to be in “immediate need” of in-home therapy to help him control his behavior. Today, Cory gets money to pay for outings that improve his social skills and therapy to control his temper.

Yet Brianna, who also was born with fetal alcohol syndrome and has the intellectual capacity of a 6-year-old, was stuck on the waiting list for five years. Brianna was finally approved for a waiver in October but has yet to receive any services.

The results are stark: On afternoons after school when Cory gets to go on community outings with a caregiver funded through his waiver, Brianna is stuck at home playing in her room. Though her adolescence is nearly over, her mother said, she still plays with dolls she had as a toddler. “It’s a game of roulette,” Candy Hoover said. “You shouldn’t have to gash up your arm on glass to get a waiver.”

Tough trade-off

Medicaid waivers first appeared nationally in the early 1980s as an innovative way to control spending while encouraging integration of adults with disabilities. The benefits were called “waivers” because they waived certain federal rules and allowed states to send Medicaid money directly to families, rather than spend the money on institutional settings, such as nursing homes and hospitals.

By 2008, waivers had become the largest single funding source for social services for people with disabilities. Last year, they covered home and community services for nearly 36,000 Minnesotans and cost \$2 billion.

The strategy has lived up to its promise of efficiency. In Minnesota, the average annual cost of services for a developmentally disabled client on a waiver is \$64,272, compared with \$104,194 for those who receive care in an institution.

“Eliminating the waiting list is not just humane — it’s also the fiscally responsible thing to do,” said Steve Larson, senior policy director at the Arc Minnesota, a disability rights group in St. Paul.

Minnesota could reduce the waiting list if it simply spent less money on each successful recipient and spread the money around — as some other states have done, DeCubellis said. The risk is hurting one client while helping another, she added.

“We could easily go to no wait-list,” DeCubellis said. “But it would mean we would have to skinny down what people are offered. We do not think that’s the quality system we want in Minnesota.”

That means leaving in place a system that many families find mysterious and frustrating. Among the states, Minnesota’s process for approving waivers stands out for its lack of transparency. Applicants typically remain in the dark about why they are initially placed on a waiting list and when they can expect to get off.

“If I go to Disney World, I get my ticket and I can see who is in line,” said Bud Rosenfield, supervising attorney with Mid-Minnesota Legal Aid’s Disability Law Center. “But with the waiver, folks get their tickets, get in line and never move, and they are invisible to everyone else in line. It’s disheartening.”

As they wait, many parents of disabled children say they can practically hear the clock ticking. More than two-thirds of the developmentally disabled people on Minnesota’s waiting list are younger than 18. And for parents with grown children who still depend on them, the suspense is excruciating, said Pamela Hoopes, legal director of the Disability Law Center.

“Parents,” she said, “feel they are getting closer and closer to the edge of that cliff.”

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A STATEWIDE PATCHWORK

Some counties spend much more of their state waiver funds than others, so a family’s odds of getting help can be an accident of where they live.

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INCLUSION PAYS OFF

SCROLL

Today many disabled Vermont residents are thriving in the community – and the state is saving money.

Story by Chris Serres (<http://www.startribune.com/chris-serres/10645926/>) • Photos by David Joles (<http://www.startribune.com/david-joles/10645151/>) • Star Tribune

NOVEMBER 11, 2015 – 12:00AM

MIDDLEBURY, VT.

In the basement kitchen of a stone church nestled in the Green Mountains, Rachel Wollum studied her reflection in an oven window, adjusting her auburn hair and orange polka-dot dress until they were just right.

Satisfied with her appearance, Wollum, who is 26 and has Down syndrome, carefully poured four trays of freshly baked chocolate chip cookies into bags bearing her name. Then, with the intensity of a drama student, she rehearsed lines familiar to almost every store clerk in Middlebury, where “Rachel’s Cookies” are now a household name.

“Hi, my name is Rachel, any cookies today?” she said. “Great, thank you so much for serving my cookies. Have a beautiful day! You’re welcome!”

With her zest and ambition, Wollum personifies the remarkable strategy that has made Vermont a leader in the civil rights movement for adults with disabilities. If she lived in Minnesota, Wollum might have been steered into a sheltered workshop or mobile

ENTREPRENEUR

Rachel Wollum, 26, who has Down syndrome, runs a thriving cookie business in Middlebury, Vt.

cleaning crew, where thousands of disabled adults perform mundane tasks and have little or no contact with the broader community.

But here, in this state of hardscrabble hillside farms and country roads lined with sugar maples, sheltered workshops are a thing of the past. Disabled adults are expected to take their place each day alongside other working people. In the 16 years since the U.S. Supreme Court ordered states to end the segregation of people with disabilities, few states have carried the flag as boldly as Vermont.

"The days of hiding people away in closeted boxes where you could no longer see them or think about them — those days are over here," said Pauline O'Brien, 80, whose cognitively impaired son, Sean, worked at a sheltered workshop for 23 years. "And we're never going back."

In 2002, Vermont became the first state to stop funding sheltered workshops. The state also ended the practice, still common in other states, of using Medicaid to subsidize group homes for people with disabilities.

Instead, the state sends money directly to disabled clients for services of their choosing, such as job coaching and transportation.

Today, Vermont leads the nation in almost every measure of workplace inclusion. Vermonters with intellectual disabilities are twice as likely to find jobs in the community as their counterparts in other states. Nearly 40 percent work in the community alongside people without disabilities, compared with 13 percent in Minnesota.

"In Vermont, they imagined a system focused on the empowerment of individuals, rather than institutions, and they achieved it," said John Butterworth, director of the Institute for Community Inclusion at the University of Massachusetts, a research center on developmental disabilities. "They proved it can be done."

A shameful history

When Bill Villemaire looks back on the 36 years he spent toiling in a sheltered workshop in the town of Colchester, he remembers the daily ringing of the cowbell.

Each morning it signaled the huddled crowd of developmentally disabled workers that it was time to march downstairs to the assembly line. There, Villemaire would spend hours in a windowless basement, performing rote tasks such as inserting wires into air ducts, until the cowbell rang to mark the end of his shift. He made as little as \$2 a day.

"I wanted to destroy that cowbell," said Villemaire, 59, who now makes \$10 an hour stocking shelves in a neighborhood grocery store. "They treated us like animals. ... It was soul-draining."

Though famous for maple syrup, Ben & Jerry's and picturesque ski resorts, Vermont has a long, dark history of segregation and abuse of people with disabilities. Memories of that era still hang like a shadow over those who experienced it.

As recently as the late 1980s, Vermont housed more than 500 people with disabilities at a sprawling west Vermont campus once known as the Brandon Training School. Here, in brick buildings where weeds now curl out of shattered windows, so-called "mentally deficient" adults were often beaten and tied down with restraints.

A lawsuit filed by one of the residents, Robert Brace, coupled with public outrage, led to the facility's closure in 1993 and marked the beginning of Vermont's revolution.

More than two decades later, Brace, now 55, struggles to contain his anxiety as he recalls his 17 years at Brandon Training School. His fingers twitched and his eyes glanced nervously at the ceiling as he recounted being placed in a straitjacket and given shots of psychotropic drugs when he "acted out." To ease his anxieties, a therapist gently touched Brace on his hands, arms and face — a therapy known as "tapping" — while speaking soothing words.

"Robert, you're OK now, you're safe," said his therapist, Al Vecchione. "Don't worry. You're never going back to that horrible place."

Video



Vermont's dark history finds redemption in the stories of entrepreneur Rachel Wollum, "shining star" Kate Daley and scarred survivors.



(http://stmedia.stimg.co/forsaken4_bill.jpg)
DAVID JOLES

VALUED EMPLOYEE: Bill Villemaire stocks shelves at a grocery store, making \$10 an hour and, like many disabled Vermonters, working in the community. He spent 36 years toiling in a sheltered workshop in Colchester, Vt., earning about \$2 a day. "It was soul-draining."

New alternatives

The effort to close sheltered workshops met stiff resistance, largely from parents who feared their children would be stuck at home, idle and bored. That group included Dottie Fullem, 89, who was among a handful of parents who founded a workshop known as Champlain Industries with the best of intentions.

As a working mother in the 1960s, Fullem had no place to send her daughter, Ann Marie, who has a developmental disability, after she graduated from high school. At the time, the workshop seemed like a safer, more humane alternative to a state institution.

"It was a dull and dreary place," recalled Fullem of the workshop. "They treated my daughter like a fixture on the wall." Still, she said, the workshop was "a safe place to go, a place where she could stay busy and make friends."

But parents like Fullem discovered that Vermont could do better. Starting in 2001, the state redirected its money, from workshops to individuals. Hundreds of people who once labored in workshops for as little as \$1 an hour now make at least minimum wage and receive stipends to pay for their own job training and transportation, among other services.

Vermont also centralized job services, rather than farming them out to counties as Minnesota does, and hired "community inclusion facilitators," who carve out jobs for clients by making visits to local employers.

"If someone can work in a sheltered workshop, then they can work somewhere else," said Ric Wheeler, a manager at the Counseling Service of Addison County in Middlebury. "What's so special about a sheltered workshop? They're doing tasks. They're showing up." Laughing, he added, "That's what you do at work, right?"

The push for inclusion starts early. College students with developmental disabilities can receive mentoring from fellow students, who attend classes with them and connect them with campus activities. Nearly 90 percent of students who participate in the program find jobs in the community upon graduation.

Kate Daly, 29, who has Down syndrome, is among them. In high school, Daly found herself stuck in a part-time job bagging groceries at a supermarket in her hometown of Rutland. But with help from a state-funded mentor, she earned a certificate in business and now works as front desk manager at a health and wellness studio in Rutland, where she greets customers and leads dance classes.

"I told my mom, 'I am absolutely not going to spend my entire life bagging groceries,'" Daly said. "Now, I have my dream job."

In Middlebury, Wollum runs her cookie business with support from a state-funded job coach. She buys ingredients at a local grocery store, bakes and delivers the cookies, and deposits her daily receipts at a bank near her apartment. Wollum, who converted to Catholicism after high school, donates most of her profits to St. Mary's Catholic Elementary School, which lets her use its kitchen.

"I do all this!" she said proudly, as she rolled cookie dough. "I am the baker and the operator."

The "Vermont model" of supported employment has thrived. Within three years, 80 percent of the employees at the state's last sheltered workshop had found paying jobs. It has the highest rate of community job placements for clients with developmental disabilities; in 2013, its rate was nearly six times the national average.

Few places embody Vermont's transition like Champlain Community Services, a bustling job center near Burlington. On a bright morning in June, people who 15 years ago would have worked at a sheltered workshop here poured in for advice on everything from opening a bank account to asking for better pay.

Among the visitors was Jay Lafayette, 42, who announced that he had just gotten a \$2-an-hour raise cooking and serving food at the local baseball stadium. He clutched a packet of John Hancock 401(k) retirement pamphlets, asking about where to invest. It was a dramatic about-face for a man who remembers being dragged and beaten at Brandon Training School when he was a youth.



RobertBrace.jpg)

(http://stmedia.stimg.co/forsaken4_dance1.jpg)

SCARS RUN DEEP: Robert Brace's

DAVID JOLES

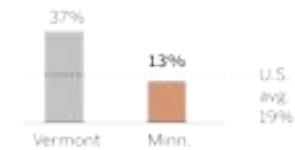
lawsuit against the infamous Brandon

DREAM JOB: Kate Daly helped her Down syndrome sister find a job at a Vermont wellness studio after deciding that ~~disabled people~~ spend her life bagging groceries at a local supermarket. She earned an associate degree in business with the help of a state-funded mentor.

TWO STATES, TWO PATHS

Vermont stopped funding sheltered workshops more than a decade ago. Today, it's a leader in mainstream employment and income for people with cognitive disabilities.

Developmentally disabled adults receiving state support to work in the community



Cognitively disabled adults finding jobs in the community within a year after applying for state services



Median annual income of non-institutionalized people with cognitive disabilities, aged 21 to 64



Sources: Institute for Community Inclusion, Univ. of Massachusetts, Boston; Coleman Institute, University of Colorado; American Community Survey (ACS).

"I never imagined in my wildest dreams that I would have a future like this," Lafayette said later as he served fries at a Vermont Lake Monsters baseball game in Burlington.



http://stmedia.stimg.co/forsaken4_tiffany.jpg



http://stmedia.stimg.co/forsaken4_tiffanyPlamondon1.jpg

ACCESS STORY: Tiffany Plamondon, 26, who has cerebral palsy and limited use of her limbs, runs her own greeting card company with the help of a social worker. At right, she left a Bradford, Vt., gallery where her cards are sold with her caregiver Katie Upham.

The benefits of 'hard work'

It was late morning when Tiffany Plamondon, 26, rolled her wheelchair, laden with art supplies, into a gift shop on Main Street in Bradford, a sleepy town on Vermont's eastern border.

Outside, the air was foggy and cold. But the store was warm, and Plamondon, who has cerebral palsy and limited use of her limbs, was already working up a sweat. With the help of a social worker, Plamondon strained to communicate which of her colorful greeting cards would be sold in Vermont stores ahead of the July 4th weekend. A wide grin or a grunt signaled a "yes." Silence or a roll of the eyes usually meant "no."

By pressing her head against a mechanical lever, Plamondon can trigger a series of prerecorded sales messages through a voice synthesizer attached to her wheelchair. Even now, two years after launching her card business, she struggles a bit to make the device work.

"I don't want anyone to get the impression, for a single second, that this is easy," said Lisa Culbertson, manager at Upper Valley Services in Bradford, as she helped Plamondon adjust the voice synthesizer. "Figuring out what works for Tiffany is hard work."

Nonetheless, the payoff for taxpayers is sizable. Since 2005, Vermonters like Plamondon have paid \$11.9 million in payroll taxes and, by working, have reduced outlays on Social Security disability and other entitlements by \$5.5 million, according to state figures. The public funding is also highly efficient: In Vermont, 61 percent of people with disabilities find work in the community within a year after receiving state employment supports, more than double the rate in Minnesota and the rest of the country.

The fiscal benefits have been a crucial selling point in this small but politically complicated state.

"This issue is a bit like Switzerland — it's neutral territory," said Elizabeth Sightler, executive director of Champlain Community Services in Colchester. "The notion of inclusion ... appeals to just about everyone, regardless of their political stripes."

Warm cookies all around

Back at St. Mary's Church in Middlebury, Rachel Wollum was performing a victory dance. With her hands outstretched, she hopped around the church kitchen with her father, Joel Wollum. "Woo-hoo! Hooray!" she yelled, circling the room.

The cause for celebration was a handwritten note from the church secretary, now clutched in Wollum's sweaty palm, announcing that nearby Middlebury College had called to say it would sell her chocolate-chip cookies in the college bookstore. The order might double her cookie business, and meant she might have to hire someone to keep up with demand.

There was, however, little time to celebrate. Across Middlebury, small businesses, from a local tire store to the Ford dealership, awaited Wollum's daily delivery.

"OK, we're ready to roll," yelled her delivery driver from an SUV idling in the church parking lot.

"Let's make some money!" Wollum yelled back, darting out the door with a wicker basket full of still-warm cookies.

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(http://stmedia.stimg.co/forsaken4_kitchen.jpg)

DAVID JOLES

BIG PLANS: In the church school basement in Middlebury, Vt., where she makes her famous cookies, Wollum got excited as she told her dad, Joel, of her weekend plans with friends. Her dad's response: "Yes you can," and Rachel replied: "Yes I can!"

INTIMACY DENIED

SCROLL

Adults with disabilities must overcome constant barriers to pursue a fundamental human right – loving relationships.

Story by Chris Serres (<http://www.startribune.com/chris-serres/10645926/>) • Photos by David Joles (<http://www.startribune.com/david-joles/10645151/>) • Star Tribune

NOVEMBER 12, 2015 — 12:00AM

Near sunset, Rachel Larson grabbed Nicholas Hamilton by the hand and pulled him down a steep embankment below a graffiti-covered bridge.

With late-summer mosquitoes buzzing around them, the two giggled and caressed each other, their voices muffled by the rush of a nearby stream and the traffic above.

"It's our secret hideaway," said Rachel, 21, who has Down syndrome, as she snuggled with Nicholas, 24, who has a developmental disability. "Here, no one can see us and we are free to do whatever we want."

For people with disabilities like Rachel and Nicholas, such freedom to be intimate is rare. Across Minnesota, disabled adults complain of having to overcome constant hurdles to engage in romantic activity and sustain loving relationships. The obstacles

HIDEAWAY

Rachel Larson and her boyfriend, Nicholas Hamilton, sometimes slip away to a spot near her house to enjoy something most couples take for granted — privacy.

include arbitrary curfews, lack of transportation, and segregated housing that cuts them off from mainstream social life and opportunities to date. Often, the barriers are imposed by group home operators that place safety above intimacy.

In the isolating confines of Minnesota's more than 4,500 group homes, true intimacy can be impossible. To go on a date, adult residents generally have to obtain permission in advance, then go out under the watchful eyes of paid staff. More ambitious requests — such as spending the night in bed with a partner — can trigger a long sequence of meetings and consultations.

The physical and legal barriers are sometimes reinforced by the widely held perception that people with disabilities are "asexual," or are too helpless to consent to intimacy, advocates say.

"We are denying people [with disabilities] a fundamental part of being human — the right to have intimacy and connectedness," said Nancy Fitzsimons, a professor of social work at Minnesota State University, Mankato. "We do this because it makes us uncomfortable, without ever asking what's right for them."

Building trust

Ninety minutes.

That's all Bradley Duncan is permitted for "alone time" with the woman he fell in love with nearly a year ago.

Ninety minutes to talk, cuddle and get intimate in bed. Ninety minutes to watch their favorite wrestler, John Cena, on television.

The clock starts to tick the moment Duncan shuts the bedroom door of his room at a Fergus Falls group home.

"They set their watches and say, 'Your time starts now,'" said Duncan, who is 46 and has a cognitive disability. "Now, if it's 11:30 [a.m.], that means I've got until 5 minutes to 1 p.m., before they start knocking on the door, saying my time is up. It's not much time."

Duncan said he met his sweetheart, who is 41 and developmentally disabled, while they were sitting at opposite computer terminals at the local library. Captivated by her long blonde hair and dark eyes, Duncan introduced himself. "I said, 'Hi, I'm Brad and I'm single,'" he said. The woman, whom he declined to identify, first insisted that she was engaged, then reluctantly agreed to go out with him, Duncan said.

Their first date was a visit to the Minnesota Twins winter caravan in Fergus Falls. Over hamburgers and fries, they discussed their mutual fondness for baseball, professional wrestling and books.

"She seemed really high-strung at first," Duncan said, pointing to a framed photo of the couple on his dresser. "But she has this great personality. We're a wonderful match."

But as their relationship grew, so did the rules.

To be taken on a date, Duncan had to notify his group home staff at least 24 hours ahead of time. Gradually, he built enough trust with his girlfriend's legal guardian, who oversees her care, so the couple could visit each other at their group homes. Most days, however, Duncan's group home lacked the staff to drive him to her house; so he would walk the winding, 1 ½-mile route on his own.

Now, after nearly a year of supervised visits, Duncan said he is building up courage to ask permission for an overnight stay alone with his friend. But that will require another complicated round of negotiations. He suspects the answer will be "No." Fear of rejection has kept him from making the formal request.

"I love her," Duncan said. "But if I ask for an overnight, I'm worried that I'm going to come off as some creep, as some guy who just thinks with his pants. What are they going to think?"



(http://stmedia.stimg.co/forsaken5_kiss2.jpg)
DAVID JOLES

Video
SWEETHEARTS: Rachel Larson, 21, and Nicholas Hamilton, 24, who have developmental disabilities, have been dating for a year. Both have the same condition, which sometimes sets them apart from others with disabilities.



Rachel's mom talks about her daughter's growing relationship.

Asked why a night alone with his friend is so important, Duncan shot back: "You have someone, right? Right? Well, I want that. I want to wake up in the morning and have someone there by my side and feel happy — just like everyone else."



http://stmedia.stimg.co/forsaken5_hands.jpg



[\(http://stmedia.stimg.co/forsaken5_iceCream2.jpg\)](http://stmedia.stimg.co/forsaken5_iceCream2.jpg)



[\(http://stmedia.stimg.co/forsaken5_momCROPPED2.jpg\)](http://stmedia.stimg.co/forsaken5_momCROPPED2.jpg)

NITE NIGHT: Rachel Larson and Nicholas Hamilton had an evening out at Rosedale Center. They have support from their parents, including Larson's mother, Janet, who said people with disabilities deserve the chance to "make the sort of mistakes we made when we were young."

Striking a balance

Many restrictions reflect a well-intentioned effort to keep group home residents safe. Some are subject to violent mood swings; others have problems with impulse control.

Although Minnesota law gives group home residents the right to have visitors and associate with people of their choosing, their legal guardians must nonetheless balance respect for their rights with the need for safety. One in five residents of state-licensed group homes has a severe and persistent mental illness, and most have cognitive disabilities, which can limit their capacity to consent to sex.

In some cases, disabled adults arrive at group homes having been sexually abused as children or adolescents, heightening the need for supervision.

Even so, there are practical ways to strike a balance between freedom and safety, said Roberta Opheim, Minnesota's ombudsman for mental health and developmental disabilities. She has long argued that sexual health and vulnerability should be among the factors assessed when a disabled person moves into a group home. If the resident has a history of being abused, or has difficulty giving consent, then the home, the guardian and the resident should devise a "plan of care" to prevent abuse while still permitting loving relationships, she said.

The key, Opheim said, is for each person to be assessed individually, rather than permitting group homes to create rules that arbitrarily apply to all residents. "There are very good reasons to be cautious, but we shouldn't allow blanket restrictions that exist solely for the protection of the group home provider," Opheim said. "All too often, we err on the side of overprotection."

In the meantime, sex remains a taboo subject in many residential settings for disabled people, which makes them more vulnerable to abuse because they are unsure about setting boundaries, said Fitzsimons of Minnesota State, Mankato.

"We think we're protecting people with disabilities by not talking to them about sex, when in fact we're only making them easier targets for abuse," she said. "You can't put a bubble around people."

Closer look

[\(http://www.startribune.com/340341182\)](http://www.startribune.com/340341182)

Guardians' decisions sometimes test civil rights.

[\(http://www.startribune.com/340341182\)](http://www.startribune.com/340341182)

Paris Gatlin, a senior advocate with Arc Greater Twin Cities, a disability rights organization, said the barriers can be so great that people with disabilities sometimes give up on pursuing relationships. Recently, Gatlin said she represented a woman who wanted help requesting a night with her boyfriend, who lived in a group home. The request was initially turned down, prompting the woman to demand a meeting with the group home staff. Though visibly nervous at the meeting, the woman prevailed, Gatlin said.

"How do you go to a committee of people and say, 'I want some alone time with my significant other,' or, 'I want to have sex,'" said Gatlin, who leads community forums on healthy relationships among people with disabilities. "It saddens my heart that so many people still have to fight for what most of us take for granted."

Facebook friends

Rachel and Nicholas are among the lucky ones.

Both have parents who encouraged them to talk openly about sex and about setting their own boundaries. Rachel is a freshman at Bethel University, a conservative Christian school, where she signed a pledge to remain abstinent until marriage. After some hesitation, Nicholas agreed with her decision.

"It's really been a dream come true," said LouAnn Larson, Rachel's mother.

But their relationship has not been without adversity. After their first encounter, at the Anoka County library, Rachel and Nicholas immediately became friends on Facebook. The next day, Nicholas sent a message suggesting they meet at a McDonald's. Rachel, whose disability makes her prone to impulsive behavior, darted out of the house without telling anyone, setting her mother and sister off on a frantic search through the neighborhood. A few hours later, LouAnn Larson got a cellphone call from Nicholas saying they were safe.

"I just wanted to scream, 'What were you thinking!'" Larson said. "But it was a real breakthrough moment. I told her that you don't have to run from me if you want to have a relationship. I will help you, and she understood that."

A social worker, Larson said her philosophy stems in part from a decade working in group homes for people with disabilities. Starved for intimacy, residents would occasionally approach her and ask for help in finding someone to date, she said. The experience haunted Larson, who resolved to help her daughter's search for a loving partner.

"Sometimes, we just have to relax," she said, "and be willing to let people with disabilities make the sort of mistakes we made when we were young."

Nearly a year into their relationship, Rachel and Nicholas are still approaching sex cautiously. When they snuggle on Rachel's bed at her mother's home in Andover, they keep the bedroom door open as a precaution. And they've limited their daily phone conversations to an hour each night, so that Rachel can focus on her studies at Bethel.

"If he goes too far, I push him back, like this!" said Rachel, slapping Nicholas' hand. "He can get overly excited."

On date nights, however, the young couple isn't shy about expressing affection. On a recent evening at the Rosedale Center, they drew odd looks from older shoppers as they behaved like teenage lovers, licking vanilla ice cream off each other's lips outside Dairy Queen and purring at each other.

When a mother with a baby stroller walked by, Rachel grabbed Nicholas by the arm and declared, "I want to have kids some day! They are so adorable!"

Later that evening, tired after their date, the couple cuddled in the back seat of LouAnn Larson's car as she drove Rachel back to Bethel. When they arrived, at dusk, Nicholas walked Rachel to the front door of the dormitory and they held each other in a long embrace.



(http://stmedia.stimg.co/forsaken5_hug.jpg)
DAVID JOLES

ROMANCE: Rachel Larson and Nicholas Hamilton hugged as they said goodbye after a date.