

Politics

# Waitlists for people with intellectual disabilities grew again. Here's what Maine could do about it.



Caitlin Andrews | BDN

Dan, left, and Kim Humphrey pose on the deck of Dan's home in Lewiston on Friday, Dec. 13, 2019. Dan, who is autistic, receives Section 21 services that allow him to live in a group home setting.

By **Caitlin Andrews**, BDN Staff  
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AUGUSTA, Maine — Maine is again trying to reduce waitlists for services to people with intellectual disabilities or autism that have grown to some of the highest levels ever.

The state has long struggled to give everyone on those waitlists the services they need. Part of the problem has been not enough funding to keep up with growing demand, and even if slots are open, low wages for direct care staff have made attracting workers a challenge.

The two services — Section 21 and Section 29 — provide different levels of support for these people. Section 21 provides the highest level of support to adults who need near-constant supervision to keep them safe and some work assistance. Section 29 offers in-home services and work support.

Both are provided as Medicaid waivers, and two-thirds of the money is provided by the federal government. The programs are expensive — the state allocated **\$317 million** in this two-year budget cycle. More than 1,900 people were waiting for one service or the other as of Oct. 1.

Waitlists are **nothing new** in Maine. Solutions being floated by officials are in line with previous efforts. The state says funding waitlists could cost as much as \$80 million more per year. Advocates and parents say the current system is flawed and traditional fixes may not work.



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Waitlists for the services came more than a decade ago. Their roots stretch back decades. The country began **moving away from institutionalization** in the 1960s and 1970s as concerns of how people with mental illnesses and disabilities were treated in state institutions gained traction. Section 21 and 29 waivers arose from the closure of the Pineland Center, which was the largest residential facility for people with intellectual disabilities.

Pineland closed after federal lawsuits from residents — first in **1975** and again in **1991** — who argued the state had violated rights to acceptable living standards, and then were not being adequately protected from abuse and were not receiving help in transitioning out of the facility.

**A 1994 agreement** outlined how the state would provide enough support to allow Pineland residents to leave the center until none remained after the state announced plans to close it. That led to the waiver services, and Pineland closed two years later.

Waitlists for the services came around 2008. Richard Estabrook, the chief advocate in the Maine Department of Health and Human Services' advocacy office from 1985 to 2012, who now is the vice chair of the **Independence Association's** board of directors, said the state routinely underestimated how

much money the program needed, while the amount of people who needed Section 21 services continued to grow.

Waitlists have been increasing for years. Health officials say numbers don't tell the whole story. As of Oct. 1, nearly 3,200 people were receiving Section 21 services with more than 1,600 waiting for services as of Oct. 1, with 68 percent of waitlisted individuals receiving other services. That's the second-highest that waitlist has been since it was created.



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At the same time, 2,286 people were receiving Section 29 services with 323 people on the waitlist and 41 percent receiving other services. That waitlist sprung up last October after having no one on it for three years, according to state data, and peaked at 512 in late 2014.

DHHS Commissioner Jeanne Lambrew told the Legislature's budget committee in November the number of people who are receiving other services indicates many may be putting their children on waitlists with hope that they won't have to wait for services when they come up.

Rep. Drew Gattine, D-Westbrook, the budget committee's co-chair, said many parents put their children receiving less intensive care on the Section 21 waitlist preemptively, fearing their child will have no services when they die.

"It doesn't give you a great sense of the need," Gattine said of the waitlist numbers.

Waitlists are also exacerbated by the state's twin workforce struggles of low reimbursement rates for direct care staff and attracting qualified workers, Lambrew has said.

Parents and advocates say typical solutions won't solve the problem. The state has prioritized funding Section 29 waitlists as well as the top tier of the Section 21 waitlists — those with the greatest need. For years, the Legislature has tried to either increase direct care staff wages or fund spots on the waitlist to keep numbers down.

Both options may be on the table next year. Lambrew has said addressing the Section 29 waitlist will be a priority if there is a supplemental budget. The Long-Term Care Workforce Shortage Commission also has drafted **recommendations** that DHHS increase starting wages for direct care workers to at least 125 percent of the minimum wage.

Lambrew has also said she is looking at combining the two waivers into a lifespan waiver that would allow a person's services to fluctuate based on their needs, like **Delaware** and **Connecticut**. But Estabrook said the way the services work and are funded is flawed — and traditional short-term fixes won't fix the problem.

“What the department is asking for is logical and rational,” he said. “... It just doesn't solve the problem that is staff shortages and Section 21 in general.”

While the waitlists continue, parents who take care of their children with intellectual disabilities and autism say their children suffer. Cullen Ryan, who chairs the Maine Coalition for Housing and Quality Services, said parents have seen their children backslide after aging out of special education services. Some quit their jobs to be full-time caretakers if they can't get services.

Kim Humphrey of Auburn said she had to send her son, Dan, out of state when he was 11 because the state did not have appropriate services for him. While he currently lives in a group home, she said anytime his services were disrupted, his condition would deteriorate.

“It was this big unknown about what was going to happen when he came back,” Humphrey said. “It was hard to focus on other things. There was a lot of angst involved.”

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