

HEALTH

In NJ, people with disabilities face ‘excruciatingly long’ wait for group home funding

4-minute read



Gene Myers

NorthJersey.com

Published 4:30 a.m. ET Feb. 29, 2024 | Updated 4:51 p.m. ET Feb. 29, 2024

Even after a big boost in funding in recent years, thousands of New Jerseyans with disabilities are waiting seven to 10 years to access critical funding for group homes and other support.

New Jersey's Community Care Program was designed to help disabled adults who require “institutional-level care” to live as independently as possible.

Run by the state's Division of Developmental Disabilities, it taps state and federal money to fund essentials like caretakers, therapy and transportation to assist adults with developmental disabilities, either in their family homes or in group facilities.

But despite \$1.4 billion pumped into the system by Gov. Phil Murphy over the last two years, demand for the help still far outstrips its resources. Almost 4,400 people with developmental disabilities are on New Jersey's waiting list for the Community Care Program, according to the latest figures.

For 10 years, that was the reality for the Mullery family in Millstone, Monmouth County. Their 27-year-old son, Chris, has Down syndrome. He can dress and shower himself, brush his teeth and shave – but not without prompting, said his mom, Kathy Mullery, 68.

Chris wouldn't be able to live alone, she said recently. It's hard for him to communicate and his room would be “chaos” without her help, she said. Knowing she and her 71-year-old husband Harry were getting older, the couple put Chris on the state's waiting list so he could get a spot in a group home, a residential setting where he could live with professional care. It

took a decade until he finally reached the top of the list late last year – “an excruciatingly long wait,” according to his mom.

Hundreds with disabilities kept in nursing homes

A report issued by the advocacy group Disability Rights New Jersey last fall highlighted one result of that lack of capacity: hundreds of people with developmental disabilities are placed in nursing homes without the proper care because they have no better options. The Murphy administration recently announced \$6 million to build and upgrade more group home slots, but the money is expected to cover only about 100 more people.

"When a mom or dad who are getting older, who've been caring for their son or daughter their whole life, find out that there's a seven to 10 year waiting list, it is a problem," said Thomas Baffuto, executive director of The Arc of New Jersey, a nonprofit whose group homes and programs serve about 15,000 people in the state.

Currently, there are 2,589 people like Mullery on a state "priority list" to get CCP funding. The list includes people whose parents are 55 or over and may have trouble caring for adult children with disabilities, according to the Department of Human Services, which oversees the DDD.

As of September 2023, there were an additional 1,803 people on a general waiting list, according to The Arc of New Jersey, whose chapters house more people with disabilities than any other organization in the state.

Still The Arc's Baffuto gives New Jersey credit. While he calls the wait "a crisis," he notes other services, like therapy and daytime activities, are available to relieve some of the burden.

NJ ahead of other states

The “vast majority, about 95%,” of people who are waiting are already enrolled in these services by the time a group home becomes available, Human Services spokesperson Tom Hester said in an email.

Baffuto said that's not the case in some states, where people waiting for homes often spend their days sitting around with no support.

"New Jersey is a great place because everybody who is eligible (for Division of Developmental Disabilities programs) gets some services," Baffuto said. "But the problem lies in accessing

residential services like group homes."

More than 3,000 people have been moved off the waiting list since Murphy took office in 2018, Hester said, adding that the administration is aiming to do more.

Its initial goal was to remove 200 people from the waiting list each year. That number has doubled to 400 in the past two fiscal years, Hester said.

More: ALS silenced him. But AI and voice banking gave this NJ man a new way to communicate

"In response to the crisis, Gov. Murphy has allocated historic levels of funding toward DHS and DDD, with the Community Services budget seeing an increase of more than \$1.4 billion, or 88%," he wrote. About 12,000 people are enrolled in the CCP, with another 13,000 in a Supports Program that funds day programs and other activities, Hester said.

Aging caregivers wait and worry

Still, advocates and families say it's simply not enough.

The Mullerys spent 10 years waiting and worrying. They faced a fear common among parents of children with more severe disabilities: What if they grow too old or ill to care for their child properly? Would time run out before they could find Chris a home set up for his needs?

Their son made it to the front of the waiting list in the end of 2023. They are now looking for a location that's a good fit.

"The funding is now available for Chris to live in a supervised setting, like a group home. If one of us had a tragedy tomorrow, we know that he could be eligible to be in a group home," said Kathy Mullery. "There's a huge amount of relief for us."

About 200 people were added to the state priority list annually between 2015 and 2023. But that number has been steadily increasing since the COVID pandemic started, Hester said. Another 296 were added in 2021, followed by 422 in 2022 and 624 last year.

Hester attributed the sharp rise to increased efforts to inform families about the services available in New Jersey.

Half-million waiting for access in U.S.

Nationwide, there were more than 480,000 people with developmental disabilities on such waiting lists by the end of 2021, according to "The Case for Inclusion 2023," a report by United Cerebral Palsy and the American Network of Community Options and Resources Foundation, a group that studies services for people with developmental disabilities.

The wait "significantly" impacts people's quality of life, the report said, hindering the ability to participate in communities, maintain employment and live independently.

It called for increasing federal funding for Medicaid home- and community-based services, regularly reviewing Medicaid reimbursement rates, collecting and reporting better data and expanding eligibility and access to needed support.

In New Jersey, Baffuto said The Arc is about to start a lobbying campaign seeking to get the number of people moved off the wait list to 600 a year, at a cost of \$78 million for the state and federal government. Mercedes Witowsky, executive director of the New Jersey Council on Developmental Disabilities, agreed that the state should be doing more.

"The state is not doing enough to identify these individuals or ensure their proper care and placement," she said.

Gene Myers covers disability and mental health for NorthJersey.com and the USA TODAY Network. For unlimited access to the most important news from your local community, please subscribe or activate your digital account today.

Email: myers@northjersey.com Twitter: @myersgene