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Even with a court order, families struggle to find services for developmentally disabled adults: ‘We have great programs, you just can’t get into them.’

By Marie Fazio
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Charlene Synoga and her son Jason in their Chicago home on Dec. 19, 2019. (Zbigniew Bzdak / Chicago Tribune)

Charlene Synoga has spent the past year searching in vain for someone to help her 23-year-old son Jason.

Nonverbal and on the severe end of the autism spectrum, Jason needs to be bathed, dressed, fed and constantly supervised. But Synoga wants more for her son. She wants him to learn “everyday skills” — washing the dishes, grooming himself, crossing the street, going to the grocery store — and is hoping to find a day program that will teach him.

So far, she said she has been rejected by 12 programs. After she thought she finally

found one, she said she then realized the provider was woefully understaffed: Two staff members working with 11 young adults with severe disabilities confined to a classroom.

“I want my son to be able to get back to his routine,” Synoga said. “His whole life has changed so much, he’s miserable. ... It’s so hard because this isn’t fair to him. He could still be learning things.”

Some of his medical conditions, including thyroid disease and severe psoriasis, have worsened recently, and she blames the stress he has been under since he finished school last year. Frustrated at being cooped up, he often hands her his coat over and over until she takes him for a drive around the neighborhood. Sometimes he hits himself on the head repeatedly or tries to run away. He has gained a lot of weight.

“You can see the boredom in his eyes,” she said.

Nearly 20,000 people with disabilities in Illinois are on a waiting list to receive state aid after they age out of the state’s public education system, [the Tribune reported](#) last month. Most wait years before they are selected.

While the state is working to reduce the wait time by making funding more readily available, many people are still being left in limbo. Once they are off the list, some like Jason, are being turned away by programs that don’t have enough room or staff to handle their needs.

A single mother, Synoga works full time at home. She uses the state aid she receives from the Department of Human Services to pay someone to watch Jason while she keeps searching for a program.

“It’s really, really hard,” she said. “Every day is a rough day. They’re our kids, we want what’s best for them. ... What is out there for the low-functioning?”

She said she’s considering moving to another state — a decision others in her situation have made.

Illinois ranks among the worst states in the country for how it cares for people with developmental disabilities, according to Ancor, a national association of more than 1,600 private providers of services to people with disabilities. Since 2011, the state

has been under a federal court order to do better. The question is, how much better can the state afford to be?

The state spends at least \$400 million a year on services and aid for the developmentally disabled, according to Allison Stark, director of the Human Services Department's division of developmental disabilities. She estimates Illinois would have to double that amount to eliminate the wait for services.

There aren't enough community programs and group homes, said Stark, who served as CEO of a community provider before being hired by the state. Some providers, strapped for resources, are unwilling to accept people who need highly skilled care.

"There has been a significant lack of investment in our community capacity for service providers, so that is a huge component to this problem," Stark told the Tribune. "We want to fund more families and individuals to services, but we need to have services that they can go into that they want."

Advances in medical care are helping people with disabilities live longer, further straining resources, she noted. "I wish I had an easy answer for why Illinois is in the state that we're in," Stark said. "Part of it is that we're now in the process of investing more than we probably have in the past, and there has been a renewed commitment to trying to address the wait list."

'Reasonable pace'

There are roughly 19,500 people on a waiting list the state keeps of those who want state aid and services. About 8,200 of them are actively seeking services and about 11,300 anticipate needing services sometime in the future. Generally, no one under 18 is selected unless there is a "crisis situation" such as homelessness or abuse or neglect, according to Stark.

Under a "reasonable pace" provision in the court order, the state has promised that by 2025, no person will wait more than five years after their 18th birthday to receive state aid to pay for home care, job coaches or other services. The current wait is as long as seven years. Stark said the department is on track to reach its target.

But families will still likely have problems finding programs near them or staffed well enough. A monitor appointed by the federal court has found the department out of compliance several times over the availability and quality of group homes

and day programs in some parts of the state. The monitor also found services lacking for people with intense medical, behavioral or physical needs, and inadequate monitoring of services.

Ronnie Cohn, the court monitor, said a study on the quality and availability of community services is underway, with results expected in February. She acknowledged that whittling down the wait list “really is not that meaningful if you have nowhere to go.”

Sherri Schneider runs Family Benefit Solutions, an organization that helps families navigate the complex benefit system and find services. Selection from the waiting list can feel like “winning the lotto,” but the thrill is short-lived for families who struggle to find programs that match their needs.

“They may say they’re taking people off the list, but there’s not enough services for all these people,” Schneider said. “Even though the state is selecting people, they’re not creating enough community capacity. ... We have great programs, you just can’t get into them or there are not enough programs.”

One of Schneider’s clients was selected from the waiting list to move her son into a group home. She cares for him alone, and she occasionally is injured by his aggressive behavior. Sometimes he needs to go to the emergency room to be calmed down. The client has spent the last four years contacting and visiting agencies throughout the state, but no one will take him, Schneider said.

‘Scrambling for nothing’

There are more than 300 providers of adult services, but the availability and scope differ across the state and even across Chicago.

Nancy Hughes’ son Zachary made it off the list months ago when his behavioral problems grew worse. He was physically harming himself and losing skills he had learned in school.

But Hughes said her son hasn’t received state funding yet because services must first be in place. “The program options for people on the South Side of Chicago are limited and don’t have the capacity to do individual services that many adults with autism need,” Hughes complained.

Gary Hake, director of an agency that covers 31 counties in southern Illinois, said service providers there face the same issues. “They’re underfunded and having a hard time recruiting staff,” he said.

Ellen Garber Bronfeld said it took a year to set up funding for her son to work at Perk Center Cafe in Glenview, a not-for-profit coffee shop that provides employment and vocational training to people with developmental disabilities. It has taken other families she knows two to four years to find agencies that will take them.

Some parents have quit their jobs and sought better services out of state once their children aged out of public education, according to Garber Bronfeld, co-founder of IPADDUnite, a networking and advocacy group.

“Those with higher needs are often left scrambling for nothing,” she said. “All of a sudden, you’re 22 and there’s nothing.”

To help people while they are still on the list, the state Department of Rehabilitation Services offers job training and employment support. The state also funds grants, including the Illinois Lifespan program, which provides information, resources and family support.

But again, the funding, availability and geographic reach are limited, according to Meg Cooch, CEO of Arc of Illinois, another advocacy group.

She said the state has improved the process in the past year. Families are notified six months before a person is expected to make it off the list so they can at least begin looking and planning.

However, schools differ in how much guidance and preparation they offer to parents as people transition from public education to adult services. In rural areas, especially, there can be a lack of communication between the state, schools and families.

“It’s a fragmented system,” Cooch said. “The disability services and schools don’t always communicate.”

June Oosterhoff-Hoops works with the families of 14- to 21-year-old students at the Elim School in Palos Heights to ensure they’re on the wait list for services. When they’re selected, she helps them choose adult programs in the community.

Since the court order, more of her students are getting access to funding. But a lot of them are being turned away from programs.

“What we’re finding is that many of our students get denied based on the fact that programs are saying we just don’t have support based on our current funding stream,” she said. “It’s frustrating for our families to have funding and get denied from multiple placements and they don’t know what to do.”

‘Not a minimum wage job’

Experts in the field say a key problem is the low reimbursement rates the state pays providers.

Caretakers in group homes and staff at day programs are barely paid minimum wage, which creates a revolving door of staff as administrators struggle to find qualified people.

“This is not a minimum wage job and yet they’re getting paid, sometimes, less than minimum wage,” said Schneider, of Family Benefit Solutions. “If I can make more at Taco Bell, why would I want to change someone’s diaper and help them out? ... It’s a very hard job, and people quit.”

In Illinois, the average number of people living in a group home is up to the federal maximum of eight, compared with the national average of two to three, Schneider said. The quality of life can suffer in larger group homes because there aren’t enough staff to accommodate everyone.

“If there are six people living in a group home and four wish to go bowling, due to low staffing levels it is common for everyone to have to go bowling even if they do not wish to,” she said.

One family has tried to move their son from a state-operated developmental center into a community group home three times, Schneider said. Each time he was moved back to the center because he didn’t have enough support. One of the times, there was funding for a staff professional to help their son but no funding for a rapid response team in case of a crisis.

“Many organizations are hesitant to serve more difficult cases due to the low rates and the inflexibility of the services that are vital to meet their needs but are not available,” Schneider said. “He didn’t fail, the system failed him. I believe

everyone should be able to live where you want to live and eat when you want to eat and turn the lights on when you want to turn the lights on.”

One provider, who asked not to be identified, said the lack of resources forces agencies to make difficult decisions, including the closing of group homes. One of the homes was in Cook County and cared for eight people, several of them with intensive needs who required around-the-clock support.

With only one staff member working in the home at a time, the agency asked administrators to step in and lend a hand to support shifts.

To begin to remedy the issue, the state increased the reimbursement rate by 3.5%, retroactive to July, and initiated a study on rate structure, according to Barry Taylor with Equip for Equality, a major advocate for people with disabilities that’s been involved in the legal action. It has also hired an outside consultant make recommendations.

“The state to its credit is now, I think, looking very seriously at an issue that needed looking at for decades,” Taylor said. “Obviously the ideal would be that people would receive services as soon as they turn 18, and I wish we were at that point and hopefully we will be that down the road, but what we’re trying to do is ensure that this is done responsibly with the capacity.”

The governor’s office released a statement saying, “it took years to get to where we are today” and that Gov. J.B. Pritzker was “working every day to ensure our government is working for those who need it most.” He gave no details.

Crossing state lines

Anne Higley’s son was diagnosed with autism when he was 3. For years the family lived in southern Illinois and traveled to St. Louis for his medical care. When he was in seventh grade, they moved to Bloomington, Indiana, in search of a more inclusive school system, better transition services, future employment opportunities and support for their son.

“We pretty much knew we would not receive those things in Illinois,” Higley said. “It’s a painful lack of services for families.”

Finding better options in Indiana, they decided to stay. Higley’s son, now 25, attends college where he’s studying criminal justice. He has access to tutors and will start receiving waiver services in January, which Higley said will allow him to

receive behavioral support services and have someone to help him as a personal assistant.

According to the Department of Human Services, more than 1,353 people were removed from the wait list last year because they moved out of state. It's not known how many of them left in search of better services, but Illinois ranked 44th in a recent report on how well states' Medicaid programs serve people with developmental disabilities and their families.

"We are behind in Illinois comparatively," said Josh Evans, president and CEO of Illinois Association of Rehabilitation Facilities. "But the benefit of being behind is we can look at what other states have done. ... You can't make these changes overnight."

In Michigan, ranked 13th, there is no wait list for community-based services. Special education laws allow people to stay in school until 25. Services are supposed to begin within 14 days of a diagnosis, said Lynn Sutfin with the Michigan Department of Human and Health Services.

Wisconsin coordinates its home and community-based programs for people with developmental disabilities with the physically disabled and the elderly. This creates "a larger pool of funds to generate savings to support the continued expansion of home and community-based services and elimination of the wait list," said Curtis Cunningham, assistant administrator for the state's long-term care benefits and programs.

Wisconsin plans to eliminate the wait list by July 2021, he added.

After the Tribune reported on the length of the wait list, Taylor expressed concern that it would discourage people from signing up. He said those caring for adults with disabilities have more reason to be hopeful than they have in the past.