

Why adults with developmental disabilities are waiting seven years, or longer, for programs they need to live on their own

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Susie Redfern and her son, Nick, who has autism, at their Aurora home on Nov. 13, 2019. The Redferns have been on the Prioritization for Urgency of Need for Services list, a waitlist for disabilities services in Illinois for years. (Antonio Perez / Chicago Tribune)

Nick Redfern, diagnosed with autism, filled his school days with lessons and field trips that taught him skills he needs for a life on his own.

But that all changed when he turned 22.

Aging out of the state's public special education system, Nick now stays at home, where his mother worries he is becoming more and more isolated and losing what he has learned. She wants to get him into adult programs funded by the state that would continue his training and maybe even set him up in a group home.

Susie Redfern has been waiting for a spot to open for three years. Her son is now 25.

“I’m hoping he’ll have activities and work every day and get the support he needs to basically have a life that’s more than just me and my husband,” Redfern said. “Because we’re not going to be here forever.”

Nick is among nearly 20,000 people with developmental disabilities in Illinois who are on a waiting list to get into adult programs. Many of them come from families who don’t have a way to pay for home care, job coaches or other services.

Most wait an average of seven years before they are selected, despite a court order in 2011 that Illinois shrink the list and do other things to improve how it serves developmentally disabled adults.

One family told the Tribune they signed up their child when he was just 5 and he still did not get a spot when he turned 22 this year.



Nick Redfern, 25, at home in Aurora on Nov. 13, 2019. He has been on a waitlist for disabilities services in Illinois for several years. (Antonio Perez / Chicago Tribune)

At a hearing in October, U.S. District Judge Sharon Johnson Coleman said the state was still not complying with the order. As a result, she said people have “suffered substantially” and called the current situation “for lack of a better phrase, messed up.”

Experts in the field say parents are quitting jobs to take care of their children and even moving to other states.

“The truth of the matter is, we’re in the midst of a crisis,” said Rebecca Clark, CEO of the Anixter Center, which provides day programming, residential group homes and other services for people with disabilities. “Keeping people engaged in programs is so critical because it allows them to continue to move forward toward their independence and meaningful lives and potentially job experiences.”

A gap in services can cause “magnificently terrible” setbacks, she added.

‘Paying lip service’

The Illinois Department of Human Services provides funding for a variety of services for people with disabilities, from small group housing to larger facilities with nine or more residents, sometimes hundreds. It also offers home-based services that include day programs in the community, adaptive equipment and job training.

Fifteen years ago, a federal lawsuit accused the department of failing to provide community and home-based services to those who wanted them. It said the agency used an “antiquated system of

serving people with developmental disabilities that relies heavily on large public and private institutions."

The lawsuit estimated that 6,250 people lived in these larger institutions, which it described as "segregated and isolated from the rest of society," where the residents are denied "experiencing the dignity and freedom of living in the community as normally as possible."

"While paying lip service to the value of community-based programs, defendants have made paltry efforts to reduce the state's reliance on large institutions or to expand Illinois' community-based programs," the lawsuit added.

A federal judge agreed, and in 2011 issued a consent decree requiring the state to provide such programs to those who requested them. It gave the state six years to provide individuals living in large institutions with community based living arrangements, if they wanted them, and give community services to an additional 3,000 people who were waiting at home. After that, the state agreed to move people off the list "at a reasonable pace."

The list is a statewide database known as Prioritization for Urgency of Need for Services. The department uses this data to select people as funding becomes available. The agency says its selection is based on length of time on the list, urgency of need and where the person lives, but confusion about the process is common among those who are waiting.

As of Nov. 15, the Human Services Department said 19,474 people were currently on the list. Ronnie Cohn, a monitor appointed by the court, told the Tribune the state has met numerical benchmarks for the first six years of the consent decree, but it's too soon to tell whether people are being served at a reasonable pace. She said there is definite room for improvement both in terms of the number of people served and the quality of resources available.



Nick Redfern, who has autism, with his mother Susie Redfern at their Aurora home on Nov. 13, 2019. (Antonio Perez / Chicago Tribune)

‘Perpetual motion machine’

Nick has been on the waiting list for seven years. The last time his mother checked with the department, she was told he may be selected in the spring but there was no guarantee. Redfern isn't too hopeful. She's met families whose children are in their 30s or 40s and have been on the list for more than 10 years.

“It's difficult unless you have the resources yourself,” Redfern said. “It may take a while but right now ... because we've not been picked, we don't have any support from anybody on trying to figure this out and getting him moving forward.”

Redfern said Nick has increasingly been displaying behavioral issues and anxiety because he lacks regular interaction with peers and ways to build skills. She calls her son a “perpetual motion machine.”

In her Aurora home recently, an eclectic collection of pop music drifted down the stairs from Nick's room as a lunch of cheddar cheese, marinara sauce and toast sat waiting at the kitchen table. He thrives on routine, so she prepares this meal almost every day.

Nick sat down at the table and asked his mother for water and more cheese using his limited vocabulary. These days, Nick's activities include working occasionally at a greenhouse in West Chicago, swim lessons once a week or trips to the doctor. Nick and his mother sometimes walk in the neighborhood or drive to the mall.

“The more you go without structured activities on a daily basis, the more you can have behaviors, partly out of boredom,” Redfern said. “His whole mindset is different now after three and a half years.”

Nick has been deemed unsuitable for several job programs, so Redfern said she's hoping to create a customized employment program, like lining up special jobs for him.

But the family can't pay for the one-on-one attention Nick needs. “He wants to be helpful, do things and be productive,” Redfern said. “There just isn't that much that I can get going for him and it's frustrating for me and I think it is for him too.”

‘Completely heartbreaking’

Josh Long, principal of Southside Occupational Academy, said fewer than 5% of his students have been selected from the list after they age out of his school.

“People lose all the skills they've established over the years,” he said. “It's completely heartbreaking. We're very powerless in this situation.”

Southside Occupational specializes in preparing people with developmental disabilities for the transition into the adult world. When students begin at the school, Long makes sure they're on

the state list. He estimated that 40% of students' families were unaware of its existence, which likely means the number of people in need of adult services far exceeds 20,000.

"We should walk you hand in hand to adult services, but what happens is we're pushing you off a cliff," Long said. "We don't do this to any other group of people."

When his students leave school, some move into group community homes or receive job offers through internships. But others go from an active lifestyle filled with social interaction to "sitting on the couch, waiting for funding," he said.

"It's absolutely essential," he said of getting into adult programs. "(It's) the gateway to opportunity in terms of being an adult with disabilities. It's an all or nothing thing."

Tonia Stigger's son, Pierre, has been diagnosed as being on the autism spectrum. He attended Southside Occupational until his 22nd birthday this summer. Stigger placed her son on the list when he was 5, meticulously keeping his application up to date each year. He still has not been selected.

"Everything I can do for Pierre to continue to grow and continue to live and be happy, I will," Stigger said. "And I'm not waiting on (the list) to make sure I can do that."

Even when Pierre does get chosen, Stigger worries that there won't be programs that match his needs.

Minimum pay

Many providers have a hard time finding and keeping skilled staff for group homes and other programs, according to filings in the case. The state reimburses providers less than the minimum wage for workers, forcing organizations to skimp on staffing or make up the difference in wages themselves.

During a four month period in 2019, one Chicago-based agency turned away 46 referrals for services, citing safety concerns due to a lack of adequate staff, according to court documents. The same agency reported a 41% turnover rate for employees in its community group homes, which contributed to the agency operating at a \$2 million deficit in 2019.

At Anixter, the difference between state reimbursement and what the organization pays employees creates a deficit of about \$580,000 in wages, Clark said.

The Illinois attorney general's office, in a recent filing, said the staffing problems have resulted in "restrictions in community integration opportunities, overworked staff and significant overtime being paid."

The office specifically criticized the Human Services Department for being late in implementing a 3.5% rate increase for community-based providers. The raise is not scheduled to go into effect until January and will be retroactive to July of this year.

But even if the increase is entirely applied to workers' pay, as recommended, it will barely equal the minimum wage in Chicago.

“We are asking minimum wage workers to be highly skilled and to understand behavior and disability and we can't pay them for that expertise,” Clark said. “If they think \$13 an hour will solve the problem, I'm worried the system will collapse on itself.”

Kathy Carmody, CEO of the Institute on Public Policy for People with Disabilities, traces the problems to years of political decisions by both parties. “This is an Illinois issue,” she said. “There is a decades-long history of decay and neglect, but we have to start righting the ship to ensure that the community services remain an option for people.”

For Redfern, that option means setting up her son to live a fulfilling life. “What plan do we create, and how do we make that happen, so at some point for the rest of his life he's interacting with peers, he's doing stuff, he's working, he's starting to get a life?”

Until then, she waits.

An earlier version of this story referred to those on the waiting list as adults. The list includes both minors and adults.

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