

Wait For Community Placements Can Take Years For Those With IDD

by Olivia Olander, Jeremy Gorner, Chicago Tribune/TNS | April 11, 2025



Aaron Bass, 39, at the Kankakee Public Library in Kankakee, Ill. on Feb. 14, 2025. (Stacey Wescott/Chicago Tribune/TNS)

CHICAGO — Aaron Bass likes some things about Shapiro Developmental Center, a home he shares with some 500 others on a site along the Kankakee River that first housed Illinois residents with disabilities nearly 150 years ago.

He enjoys spending time outdoors, playing bingo and supervised outings to Burger King, the dollar store or local library to check out scary movies. But Bass, a 39-year-old who has a moderate intellectual disability, said he is seeking something greater.

“I want to see what it looks like ... freedom,” he said in an interview at the Kankakee Public Library, about a mile from the sprawling Shapiro campus.

Bass is one of hundreds of people living in state-operated developmental centers who have requested a move, typically to smaller group homes in community settings that offer greater independence.

While advocates credit Gov. JB Pritzker with putting a higher level of attention on the issue, the fights for placement in many cases underscore the state’s ongoing struggle to provide options for people with complex needs.

In January, a watchdog group found there were “concerning barriers” for people trying to transfer out of Choate Developmental Center in downstate Anna, almost two years after the Pritzker administration initiated plans to move out roughly half of Choate’s residents following years of reported resident abuse that led to more than a dozen criminal charges against employees.

But Choate isn’t the only state-operated developmental center that some residents are trying to exit.

Across Illinois’ seven state-operated developmental centers for people with developmental disabilities and medical or behavioral needs — known as SODCs — more than 200 residents were seeking placement elsewhere as of February, close to 15% of the total population in those centers, according to records from the Illinois Department of Human Services.

Of those, more than 125 had been on a waiting list for at least a year, records showed. That includes Bass, who has been awaiting placement for almost three years, according to his guardian.

Illinois has a troubled track record of transitioning residents to group homes, and supply remains low.

At the same time, many people living in large, state-run institutions have high needs and are accustomed to the setting after living there for decades. And the number living in those environments is far smaller than the population of residents in smaller settings across the state.

The state has an impetus to help those who want to leave its SODCs. In 2011, Illinois fell under a consent decree to ensure it establishes a process for people living in the state facilities to have the opportunity to move to a community-based group home. The consent decree was an offshoot of a 2005 lawsuit filed on behalf of people with developmental disabilities who sought placement in community-based facilities.

And Pritzker has shown a strong interest in getting the state in compliance, some advocates said.

“Every force in the universe wants these people to move,” said Kathy Carmody, CEO of the Institute on Public Policy for People with Disabilities and a member of the oversight committee for the 2011 consent decree on the issue. That they’re still not moving, she said, is “the best evidence that there are structural challenges.”

Among the 50 states, Illinois trailed only Texas in the number of people housed in state-run residential facilities for people with intellectual and developmental disabilities in fiscal 2020, according to a report from the University of Minnesota published last year that tracked such institutions serving more than 15 people.

Pritzker’s budget proposal, released in February, includes some sweeteners for community providers including a proposed wage increase for their workers. At the same time, it continues a pattern of allocating slightly more funding each year to SODCs, whose populations have stayed relatively flat.

While IDHS acknowledged there's more work to do in supporting individuals who want to live in less restrictive environments, department spokesperson Rachel Otwell said progress has made in the Pritzker administration.

"IDHS believes that people with intellectual and developmental disabilities deserve every opportunity to live full lives in the least restrictive setting of their choice," Otwell wrote in an email.

Some people with intellectual and development disabilities "have not had that experience due to systemic barriers, but in the last six years, IDHS has made historic investments to support an array of community options, and launched a transformational plan aimed at strengthening the entire system in Illinois," Otwell said.

Bass was placed in state custody in 2015, at age 30, according to the watchdog group Equip for Equality, which is advocating for his case and for others seeking placement outside of SODCs. Since then, he's lived at Choate and shuffled through several group homes that didn't work out for him before arriving at Shapiro, his state-appointed guardian said.

Bass says he would be comfortable moving anywhere in the state, as long as he has male roommates with a similar level of ability. His intellectual disability is considered moderate: He likes to chat with people around him and does piece work in a workshop for people with disabilities, earning minimum wage.

The main issue in finding placement outside of an SODC, his guardian believes, isn't his disability but that Bass has Type 1 diabetes. He needs to be in a facility with staff members who are qualified and comfortable administering insulin, which many providers don't have.

Bass more than six years ago entered a guilty plea on a misdemeanor charge of resisting or obstructing authorities, Winnebago County records show. Details on the case weren't immediately available. But that has never been cited as a reason for a community provider turning him away, and his dependence on insulin seems to be his only barrier, according to Equip for Equality.

He hasn't had any behavioral problems recorded since being on the list for a community placement, according to his guardian, Isha Ward.

Ward, along with a service provider, has made 58 attempts to place Bass with community providers throughout the state, she said, emphasizing that he's sociable and relatively independent. But he has not been accepted by any of those providers. Of Ward's 90 clients, 19 are awaiting community placement.

Bass' trouble finding placement outside of a state institution speaks to some of the larger issues in the system, his attorney Lauren Schrero said.

Guardians looking to place people at community homes confront an archaic, paper-based system, and if their request is rejected, they typically are not told why.

Community providers are private organizations that receive state funds. They argue they need additional funding for staffing and more support from the state when they take in people with complex needs, said Joshua Evans, CEO of the Illinois Association of Rehabilitation Facilities, which represents providers.

Pritzker's newly proposed budget includes \$3 billion for the developmental disabilities division at the Department of Human Services, which would mark an increase of \$1.3 billion across his time in office. The division is "maximizing efforts" to transition at least 100 people out of institutions in fiscal 2026.

that have requested other placements “to appropriate, and significantly less costly, community-based settings,” according to a budget document.

“This initiative is focused on residents who (with their guardians) have affirmatively indicated a desire to exit institutional care,” the document says. The budget, which is subject to approval from the General Assembly, would also include a \$5 million program incentivizing community providers to accept residents from SODCs.

In total, there were about 160 transitions from state-operated developmental centers to community integrated living arrangements (or CILAs) from July 2016 through June 2022, according to researchers at the University of Illinois Chicago Institute on Disability and Human Development in a state-funded analysis published in 2023.

As advocates and IDHS have pushed for some people in SODCs to explore community based options, the number of people who are awaiting community placement has grown in recent years, from 91 at the beginning of 2018 to more than 200 this year, according to IDHS records.

Pritzker’s proposal also budgets for raising wages for direct service providers in community living arrangements by fifty cents an hour, which Evans said was a “pleasant surprise” for his members in a tight budget year.

The proposal would increase the budget of the seven SODCs by about \$28 million, or almost 5%. For advocates who believe the prominence of SODCs in Illinois could be downsized and the funds reallocated to smaller settings, that increase is disappointing, said Amie Lulinski, former executive director of The Arc of Illinois, an advocacy group that pushes for transitions to community arrangements.

Research has found that transitions out of institutions and into the community can lead to positive outcomes for people with intellectual and developmental disabilities, but “inadequate community capacity” can limit those transitions, “particularly in Illinois,” the UIC analysis said.

At the same time, groups that support SODCs argue the state needs a continuum of options including institutions for people who have a high level of needs.

The population of SODCs is a little over 1,500, a decline of only about 70 from three years ago, according to budget documents from the governor’s office. There were about 10,000 people living in CILAs statewide across more than 200 providers in the fiscal year that ended in June 2024, according to IDHS data.

It costs considerably more to house people in state-operated institutions than community living arrangements, according to the same IDHS data: more than \$250,000 annually for SODCs and about \$100,000 per person in CILAs.

“You can do a lot for a lot more people for less money when you are serving them in the community. And that is what we will continue to insist that the state continue to do,” said Heidi Dalenberg, a lawyer for the American Civil Liberties Union of Illinois who pushes for people with developmental disabilities to be able to live in community settings. “But we are going to work in a partnership with the state to try to get that accomplished.”

Otwell from IDHS said helping individuals “pursue the least restrictive setting of their choice” is the right legal, moral and financial thing to do. But there are many factors that can slow or stop an individual who wants to leave an SODC from moving.

IDHS in part blamed budget cuts from the previous administration that “hollowed out state services” as weakening “the entire human service infrastructure in Illinois.” Home availability, willingness of community providers to serve people with certain behavioral or medical needs, and a lack of support from guardians can be issues both in Illinois and nationwide, Otwell said.

Bass, the Shapiro resident, is reliant on the advocacy of his public guardian and others in the system. Still, families who advocate for relatives constantly also say the system can be prohibitively difficult to navigate.

Braxton Farr’s parents drive 360 miles round trip every weekend from their home in suburban Elmhurst to Mabley Developmental Center in Dixon, where he lives most of the time. His mother, Rachel Hellenga, said they have been looking to get him in a smaller community placement closer to home for about two years.

Farr is minimally verbal and is diagnosed with autism and a genetic disorder that causes intellectual disability. His mother is open that he has at times struggled with maladaptive behaviors, but she has spent years trying to remove language from his “packet” — the profile sent to potential community placements — that she said doesn’t reflect his current needs or habits.

In one example, Hellenga said, Farr’s toenails grew too long as his sensory issues made it hard for him to get them cut. His nails tore a hole in his socks, leading him to rip them up. That behavior was recorded by the state as destruction of property in documents sent to prospective community facilities, she said.

Hellenga believes her son can be in a Chicago-area setting that facilitates more activities during the day and that he would thrive in a home with fewer people, as he struggles to be around large groups.

During a visit to his Elmhurst home, Farr was affectionate to his mother and to his caregiver and companion, Kareem Stevenson. With his mom and Stevenson, he counted down the days to his favorite activity: staying at the Hilton at O’Hare International Airport to see planes take off up close. He watched, excitedly, as Stevenson filled in X’s on a countdown wall calendar.

Hellenga said she likes Mabley’s campus and appreciated that they seemed to lessen her son’s issues with running away. Her issue, she said, was with the distance to Mabley and the bureaucracy of the large setting.

“It’s not like some diabolical scheme to keep him in Dixon,” Hellenga said. “They just aren’t being proactive about helping him to transition to a group home.”

The family recently scheduled a screening with a possible provider in early March, Hellenga said — a location that would be an hour drive away, instead of 90 minutes.

A placement at a community provider doesn’t turn out to be a solution in all cases, and some families have concluded that their loved ones are better off in an SODC.

“People like my son can’t be supported with the current structure of CILAs as we know them today in the state of Illinois,” said Joan Janzon, president of the group Friends of Shapiro, which advocates for the center and its residents. “So, people like my son end up at the SODCs.”

Cheryl Rogers, a mother of a 38-year-old with a developmental disability who has been seeking another placement from Shapiro for five years, said her son was previously at a CILA that didn’t meet his needs.

Her son, Joseph Rogers, is 7 feet, 1 inch tall, with mobility issues and had “intermittently explosive behaviors,” leading him to be removed from the community provider and placed at Shapiro.

Still, she said, it’s “aggravating” that she can’t find a placement for him outside an SODC, even with complex needs.

“He’s not an easy (person to) place,” she said. “The problem I have with all of these placements is that it’s definitely a cookie cutter model.”

People transitioning out of SODCs frequently have “specific, significant, and sometimes increasing support needs,” the UIC report on movement from those facilities said. In fiscal 2022, more than two thirds of people leaving state operated developmental centers had a psychiatric diagnosis, up significantly from six years prior, the report said.

Of 160 transitions from an SODC to a CILA during the period researchers studied, about three quarters “remained at the same home” at the time of the study. About 1 in 5 individuals across that timeframe went back to a state operated facility from a CILA — all for behavioral reasons.

IDHS itself has come under criticism for how it monitors CILAs.

According to an August 2024 report from Illinois Auditor General Frank Mautino’s office, IDHS failed, in certain situations, to consistently apply rules governing CILAs to all its providers and hold CILAs accountable if they didn’t properly report “critical incidents” involving people with developmental disabilities.

The auditor general’s office found 22 instances in which one particular provider violated state law or rule by not cooperating with internal investigations, the audit indicated. IDHS is implementing a plan to correct the issues in the audit including timely reporting of incidents, Otwell said.

State Rep. Charlie Meier, a Republican from Okawville, has been critical of CILAs that might not be able to provide suitable care for certain residents and while he noted they’re subject to inspection by the state every two years, he’d like to see them inspected quarterly.

“I can say that I’ve known many residents who have had problems happening and I’ve tried to get them out of a bad CILA and it’s not happened in time,” Meier said.

Some people, though, are still seeking every opportunity to at least get a foot in the door of a community provider and experience something other than a state-operated facility.

“So many states have managed to figure this out,” Lulinski, the former Arc of Illinois executive director, said. “I don’t feel like we’re doing the best that we can.”

For Bass, that’s meant feeling stuck at Shapiro despite years of trying to be placed elsewhere.

“I’ve been waiting, and waiting, and it’s like, it’s too much patience,” Bass said, sitting across a library table from his guardian. “I’m just trying to get out of here quicker.”