

Emergency housing for NJ kids with disabilities is so scarce 'families often just give up'



Gene Myers

NorthJersey.com

Freehold's Lisa Fitton said she faced terror every day for years.

She hid in her car, behind neighbor's vehicles and in closets. Caring for her son, Andrew – whose severe autism led to violent outbursts – was almost impossibly hard for Fitton, who was on her own.

"I got to the point that I was afraid of my son," she recounted in an interview. "When he would go after me, I would run out of the house. It was impossible to do it alone and I just couldn't get the help I needed." New Jersey's Children's System of Care is supposed to offer a lifeline in such extreme cases. The program is tasked with providing emergency housing and treatment for children with severe disabilities whose behavior can pose a danger to loved ones – or themselves.

But families and disability advocates say the system is woefully underfunded, sometimes taking months or years to offer help to parents in crisis. And a labor shortage facing healthcare providers of all types since the COVID pandemic means temporary housing is even scarcer than before.



Lucas Tavarez, 16, is shown as his mother, Janet Tavarez brushes his teeth on Monday, June 11, in Clifton. Lucas' severe autism and other conditions can lead to violent outbursts. His mother says promised help from a state program was inadequate.

Kevin R. Wexler/NorthJersey.com

While an estimated 13,000 children and teens with disabilities take part in various CSOC programs, the state has just 353 emergency beds set aside for the population across New Jersey. Staffing shortages mean there are currently only 187 slots actually available, the state acknowledges.

"There is a tremendous, crisis-level shortfall of beds for individuals that are under 21 that are in need ... because of having severe and challenging, dangerous behaviors," said Lisa McCauley Parles, the mother of a child with a developmental disability and a Clark-based lawyer specializing in such cases. "The waits are very, very long, and the process is so complicated and cumbersome that families often just give up."

State promises changes to CSOC

The state is aware of the challenges and working to address them, said Jason Butkowski, a spokesperson for the Department of Children and Families, which oversees CSOC. Gov. Phil Murphy's proposed budget includes an additional \$7.3 million to expand respite services.

The administration is also looking to add to the lone behavioral health care company that administers the system, PerformCare Behavioral Health Solutions, in hopes that will ease the bottleneck, Butkowski said. PerformCare did not respond to requests for comment for this story.

"We have been working to identify and onboard new contracted service providers that can increase our capacity," Butkowski said.

With a more than \$800 million budget, the Children's System of Care is charged with providing behavioral health care for tens of thousands of young New Jerseyans with emotional and mental health needs, substance use challenges and intellectual or developmental disabilities.

Emergency and out-of-home care account for just a sliver of the services it provides but can be crucial in times of need, say advocates. CSOC provides counseling and temporary placements in group homes, foster care or psychiatric facilities, where kids are supposed to get treatment until it's safe to reunite them with their loved ones.

"It is the single most painful decision you will ever make, and you'll never get over it," said Parles. "You do everything you can to not ask for that help because the system, and particularly the Children's System of Care, makes you feel like a failure because the goal is that you raise your children."

'Every day was like a test of survival'

Fitton's son, Andrew, now 24, can be aggressive. He outsized his petite mom by the time he entered his teens. She has scars from multiple attacks when he took chunks of flesh out of her arms with his teeth.

She asked the state to intervene with a temporary placement but says she never got the help she was seeking. "We were on a waiting list for some kind of stabilization bed, residential treatment, whatever," she said. "We were on that for months, and yet every day was like a test of survival. His behaviors were off the wall."

While the family waited for a placement, things got worse. Fitton said her husband moved to California with their other child, leaving her to manage Andrew's care alone. When things got out of hand she called the police for help, she said. They would bring Andrew to a local emergency room, though that relief was only temporary. Fitton was eventually

approved for in-home help by CSOC, but a therapist either never showed up or canceled at the last minute, the mother said. Finally, about two years after her request, Andrew was placed in a group home for people with developmental disabilities.

New Jersey's disability ombudsman Paul Aronsohn, a Murphy appointee, has pointed to a number of concerns about the Department of Children and Families through the years.

Families often come to his office to complain about the agency, he has noted in annual reports. Though well-intentioned, the department often uses mental health tools for conditions that should be treated as a physical or developmental disability, he wrote.

The department offers a range of services for young people, but the complexity of some cases means it can take a while to provide the right care, Butkowski said. Children on the CSOC waiting list can receive interim services, including in-home care, until suitable treatment is available, he noted.



Paul Aronsohn, New Jersey's disability ombudsman, touring a group home in 2021. Aronsohn said Families often complain to him about a program that's supposed to offer emergency placements for children with sever conditions. Chris Pedota, NorthJersey.com-USA Today Network

Clifton mom says state therapist failed

Clifton resident Janet Tavarez also says the state fell short in her time of crisis. The 53-year-old divorced mom had problems similar to Fitton's.

She needed skilled assistance for her son, Lucas, now 16. He also has a severe form of autism that results in aggressive behaviors, including scratching, head-butting, choking, and pulling hair.

In 2021, his mother sought help from the state. She said she expected someone with expertise in autism to show up. But the therapist who appeared at her door a month after she reached out wasn't trained to handle her son's needs, Tavarez said.



Lucas Tavarez, 16, uses letters while doing an activity, Monday, June 11 2024, in Clifton, Lucas suffers from autism, obsessive-compulsive disorder and other issues that make it impossible for him to do everyday tasks independently
Kevin R. Wexler/NorthJersey.com

Instead of using typical therapeutic approaches to autism like applied behavior analysis, she said, the therapist spent the time trying to engage her son in games and play with him. The state authorized eight weeks of treatment, but Tavarez said Lucas received less because of the time needed to locate a therapist.

"At the end of the eight weeks, that was it," she said. "They were done and nothing had been resolved, my son was still aggressive," Tavarez said.

"Here it is 2024 and I am still waiting for the appropriate services to be delivered."

Butkowski didn't offer an average wait time but said the challenge of matching children to appropriate services often leads to longer wait times, especially for those needing specialized care.

"We don't maintain data on the reason a youth is on the waitlist, but we know, anecdotally, that sometimes the right program is not available at the time of application, despite there being available and clinically appropriate beds elsewhere within the System of Care" he said. "Age and gender also impact bed availability."

Severe autism can leave families with 'PTSD'

The lack of help often has a ripple effect. Advocates and families talk of the impact dealing with violent children can have on siblings, spouses and friends.

Loved ones develop "PTSD" and fear for their safety due to the challenging behaviors of their brothers or sisters, Aronsohn noted in his reports. Parents interviewed for this article concurred, saying their emotional stress is immense.

Feelings of helplessness and constant worry can affect the entire family, siblings feel neglected and marital conflicts can escalate. Aggressive behavior can put other family members at risk, which adds to the trauma and exhaustion. Economic strains to afford medical costs increase the pressure.

There's another hardship that may get overlooked: Watching out for others' safety means avoiding social situations, Tavarez said.



There's another hardship that may get overlooked: Watching out for others' safety means avoiding social situations, Tavarez said.

"Whether it's for the family's safety, the child's safety, or for the strangers' safety, there are things that we just cannot be a part of, and it is extremely depressing and frustrating," she said. "But you're looking out for public safety at the end of the day. I'm like, 'Thank you. I appreciate the invitation but I cannot go.' It is in the public's best interest for me to stay hidden."

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.](#)