Nowhere to go: Young people with severe autism languish in hospitals

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Teenagers and young adults with severe autism are spending weeks or even months in emergency rooms and acute-care hospitals, sometimes sedated, restrained or confined to mesh-tented beds, a Kaiser Health News investigation shows.

These young people - who may shout for hours, bang their heads on walls or lash out violently at home - are taken to the hospital after community social services and programs fall short and families call 911 for help, according to more than two dozen interviews with parents, advocates and physicians in states from Maine to California.

There, they wait for beds in specialized programs that focus on treating people with autism and other developmental disabilities, or they return home once families recover from the crisis or find additional support.

Sixteen-year-old Ben Cohen spent 304 days in the ER of Erie County Medical Center in Buffalo. His room was retrofitted so the staff could view him through a windowpane and pass a tray of food through a slot in a locked door. His mother, who felt it wasn't safe to take him home, worried that staff "were all afraid of him ... (and) not trained on his type of aggressive behaviors."

The hospital "is the incredibly wrong place for these individuals to go in the beginning," said Michael Cummings, the Buffalo facility's associate medical director and a psychiatrist who worked on Ben's case. "It's a balancing act of trying to do the ... least harm in a setting that is not

meant for this situation."

Nationally, the number of people with an autism diagnosis who were seen in hospital ERs nearly doubled from 81,628 in 2009 to 159,517 five years later, according to the latest available data from the federal Agency for Healthcare Research and Quality. The number admitted also soared, from 13,903 in 2009 to 26,811 in 2014.

That same year, California's state health planning and development department recorded acute-care hospital stays of at least a month for 60 cases of patients with an autism diagnosis. The longest were 211 and 333 days.

Private-insurance data underscore the concerns. In a study published in February in the Journal of Autism and Developmental Disorders, researchers from Pennsylvania State University found that young people ages 12 to 21 with autism are four times more likely to go to the emergency room than peers without autism. Once there, they are 3 { times more likely to be admitted to a hospital floor - at which point they stay in the hospital nearly 30 percent longer.

The analysis, based on a sample of 87,000 insurance claims, also showed that older adolescents with autism are in the ER more than their younger counterparts. The percentage of their visits associated with a mental health crisis almost doubled from 2005 to 2013.

"You're looking at an increase in unmet need," said Nayfack, who with Stanford University colleagues documented a similar trend from 1999 to 2009 in hospital admissions for young Californians with autism. By contrast, they found, hospitalization rates held steady during that decade for children and teens with Down syndrome, cerebral palsy and other diagnoses.

Tyler Stolz, a 26-year-old woman with autism and a seizure disorder, was stabilized after a few weeks in a Sacramento hospital, yet she remained there 10 months, according to Disability Rights California, an advocacy group that described her case in its 2015 annual report.

Ultimately, Mercy San Juan Medical Center went to court to demand that Stolz's public guardian move her. The court filing noted that Stolz "previously harmed hospital staff" and that "a security officer is posted to the patient's room 24/7."

Although her conditions no longer required her hospitalization, they still "represent dangers to defendant and possibly to others if she were discharged to the community," the facility contended. "There is no safe place for the client to go."

The advocacy nonprofit helped place Stolz at a Northern California center that offered intensive behavioral therapy, recounted Katie Hornberger, its director of clients' rights. The medical center did not respond to a request for comment, but two years after an investigator found Stolz in a bed covered by a mesh tent, the case remains vivid in Hornberger's mind.

"I don't believe we put people in cages," she said.

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Some of the longest hospital stays in the nation, averaging 16.5 days, occur in New York state.

James Cordone, 11, spent seven weeks in a Buffalo, N.Y., children's hospital in a tent-like bed, with a hospital receptionist or instrument sterilization tech in his room at all times, his mother said. The difficulty families like hers face is "the dirty little secret no one wants to talk

about."

Debbie Cordone of Cheektowaga, N.Y., was a retired police dispatcher who had raised her own children when she and her husband adopted James as a toddler. Diagnosed with autism at 3, James was a boy with a bright smile who loved to cuddle, she said. At 8 {, James began to grow combative. To ward off injury, the Cordones locked up their knives and forks and put away glass picture frames.

But then their son started head-banging - a problem with some children who have a severe case of autism. The Cordones' house bears the scars of his pain, including holes in the drywall and a shattered window.

On his 9th birthday, in December 2014, James went into a rage, Cordone said. It took four adults to restrain him.

"He was trying to put his head through the window, sweating profusely," she said. "He was not there. It was a blank stare."

The family called 911. James was taken to the Women & Children's Hospital of Buffalo, where he was sedated on and off for 13 days. He went home, but a fit of rage a few months later landed the young boy in the same hospital for seven weeks in March 2015. "We couldn't ride out the storm any longer," Cordone said.

Cordone said her son lived out those weeks in a "Posey Bed," which resembles a child's playpen propped on top of a hospital bed. During that time, she joined her adult children in a social media campaign to pressure her insurer to pay for intensive behavioral therapy.

The family prevailed, and James went to a center in Baltimore where staff - three counselors for his case alone - focused on his communication skills and adjusted his medication. He now lives in a

group home near the Cordone family. He is "a success story," Cordone said, albeit a rare one among children with severe autism.

"This is a crisis," she said, "and no one is recognizing it."

Women & Children's Hospital of Buffalo did not return calls seeking comment.

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Mary Cohen, who also lives in the Buffalo area, has endured a similar struggle as a single mother. Ben's 6-foot-1, 240-pound presence dwarfed her petite frame.

She began locking herself in a basement room to escape his outbursts, while still monitoring him via cameras she'd installed throughout the house to make sure he was safe. As the lock-ins became more frequent, she realized, "I can't keep going like this." She found a nearby group home, covered by his disability and Medicaid payments, that could accommodate Ben.

On Aug. 1, 2016, it all imploded. Medication changes and an ear infection triggered a rage, Cohen said, and Ben hurt one of the staff members. Someone called 911, he was taken to the psychiatric emergency room at Erie County Medical Center, and a waiting room there is where he lived until early this summer.

"Staff was on the other side of the window watching him 24 hours around the clock," Cohen said.

Though a 304-day stay is a record there, cases like this have surged at the hospital, said Cummings, its executive director of behavioral health. They spurred him to launch a grant-funded home-visit program aimed at

keeping families with autistic children from reaching a breaking point. He and his clinical partner have counseled nearly 400 families to help manage their youngsters' medications and find services, and their ER visits have dropped by nearly 50 percent, he said.

"It's money best spent now, because you're going to spend it in the end," stressed Scott Badesch, president of the Autism Society. The organization, well aware of what Badesch calls hospital "warehousing," is pushing lawmakers nationally to spend more on behavioral counseling and in-home support for families.

A bed finally opened up for Ben at Baltimore's Kennedy Krieger Institute - a private, highly regarded facility that offers intensive therapy, psychiatry and family coaching. Cohen held out for a placement there, hoping the staff could turn Ben's behavior around. The teen and his mother made the 360-mile trip in June by ambulance and plane.

"I want to do the right thing for him," Cohen said. "Because one day I'm not going to be there for him."