

Center for New York City Affairs



In Covid-Era New York, Suicidal Kids Spend Days Waiting for Hospital Beds

By Abigail Kramer January, 2021 t happened in November, the thing that Christina Hauptman had dreaded for years: She went to wake up her 13-year-old son, Cody, and found a paper folded on his pillow, the words "PLEASE READ" scrawled across the front. "I just couldn't deal with the drama and the things that are and have been happening in my life," he'd written. "This is a suicide note from Cody. I LOVE U MOM!"

Cody was alive. He'd written the note the night before, after Hauptman went to bed. Then he hunted the house for pills, planning to swallow as many as he could find. There weren't any – Hauptman had locked them up weeks earlier, when she saw Cody's mood start to spiral downward.

His next plan was to cut his wrists and throat, but the knives and razors were locked away too. He resorted to the sharpest thing he could find in the house, a shark's tooth necklace Hauptman had bought him on his 11th birthday. Exhausted, he scratched jagged red lines across his arms and neck until he fell asleep.

When Hauptman woke him up in the morning, he was glassy-eyed and disoriented – furious that she had thwarted his plan. Hauptman looked at the angry scabs forming on his throat, bundled him into her car, and drove the 40 minutes from their home on central Long Island to Stony Brook University Hospital – the only facility in the area with a dedicated psychiatric emergency room for children. There, a doctor determined that Cody was a danger to himself and needed to be admitted to an inpatient unit for kids in mental health crisis.

That's when Cody and Hauptman ran into a new problem – one that's facing children and adolescents across New York State: The unit was already full, not just at Stony Brook but at every hospital with an inpatient psychiatric program for kids in the entire region. Not a single bed on Long Island was free.

AN INFLUX OF KIDS IN CRISIS

Even before the coronavirus arrived, New York State – like much of the country – had seen a long and steep increase in mental health emergencies among young people. From 2009 to 2017, reported suicide attempts by New York high school students <u>climbed by close to a third</u>. For several years, suicide has been the <u>second-leading cause of death</u> among youth aged 15 to 19 across the state, and the third-leading cause among kids aged 9 to 14.

Then last March, young people saw their lives turned upside down. Millions were were cut off from friends, teachers, and routines. Within three months, more than 4,000 New York kids had lost a parent to Covid-19, while 325,000 were pushed up to or over the edge of poverty. Videos went viral of police killing unarmed Black citizens, while protests erupted on the streets and the president flirted openly with white supremacists.

For young people, the psychological fallout was significant and inevitable, says Dr. Wanda Fremont, the vice chair of child psychiatry at SUNY Upstate Medical University, in Syracuse. "Kids with preexisting anxiety or depression, it's getting worse. Then for other kids, the school variability and the family stressors, they're taking a toll."

At hospitals, the consequences became evident in phases. In the spring of 2020, when schools first shut down and life was, in some ways, frozen into place, emergency rooms were all but empty, according to psychiatrists who see kids around the state. In New York City and on Long Island, many

hospitals converted kids' psychiatric beds, or even their entire psychiatric units, to treat Covid-positive and quarantining patients.

But then in the summer and fall, as the pandemic ground on, kids' mental health care providers saw a spike in demand at every level. Outpatient clinics filled up, holding most of their appointments by phone or video. Wait times for therapists – which can drag on for months under the best of circumstances – got even longer. Nationally, emergency room visits by kids in mental health crisis climbed steadily from June through October, even as visits for injuries and medical illnesses plummeted, according to the U.S. Centers for Disease Control.

Suicide attempts and other psychiatric emergencies are up, inpatient units are full, and very sick kids regularly spend days in loud and crowded emergency rooms, waiting for beds to open up.

New York State does not publish real-time data on emergency room visits or psychiatric hospitalizations, so the only way to understand statewide trends is to piece together information from individual hospitals. Through the fall and winter, doctors in every region of the state – from Western and Central New York to the Hudson Valley, New York City, and Long Island – reported the same phenomenon: Suicide attempts and other psychiatric emergencies are up, inpatient units are full, and very sick kids regularly spend days in loud and crowded emergency rooms, waiting for beds to open up.

"It's a sin, the way we treat kids in psychiatric crisis," says Dr. Jennifer Havens, the vice chair of child and adolescent psychiatry at NYU Langone Health. "We would never tolerate this, if kids couldn't get treatment for some kind of medical condition."

In Syracuse, Dr. Fremont oversees an eight-bed inpatient unit for adolescents at Upstate University Hospital. The unit has been full since summer, Fremont says, with as many as 18 kids at a time "boarding" in medical beds because there was no space in the psychiatric unit.

Of the young people who come into the emergency department, a much higher percentage than usual are too unsafe to send home. "Normally, you'd see kids who might have made a suicidal gesture, but you evaluate them and there are good supports in place and you can send them home safely with follow-up care," Fremont says. "The kids we're seeing now, they have acute suicidal thoughts or they've made serious attempts. These kids are really sick."

At Stony Brook, on Long Island, where Cody spent three days in the psychiatric ER, the hospital's 10 inpatient beds for kids in mental health crisis have been full since the beginning of October, according to Dr. Judith Crowell, who directs the division of child and adolescent psychiatry. The hospital hired several new clinicians to treat young people in its outpatient clinic, but wait times are long and growing longer, Crowell wrote in an email.

In Queens, at Cohen Children's Medical Center, Dr. Vera Feuer directs a psychiatric urgent care and an inpatient unit with capacity for 22 adolescents, though some beds have been converted to treat Covid patients at various times since the spring. Emergency mental health visits plummeted in March and remained low for about three months, Feuer says, but they've been climbing since early June.

"This morning, we had five kids waiting for beds in the ER," Feuer said on a Thursday in late December. "Hopefully we'll get them all going today, but that also means there won't be anything available for the kids who come in tonight."

Nearly 350 miles northwest of New York City, in Rochester, Dr. Michael Scharf directs a 27-bed inpatient unit for children and teens at the University of Rochester Medical Center. Emergency department and inpatient volumes shot up in October, he says, after kids received their first grades of the new school year. "They were seeing the concrete consequences of remote school, or of not logging in and failing classes." By November, he had to send young people out of the region to find inpatient beds.

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The Rochester numbers dipped after the Thanksgiving holidays, at least in part because families were avoiding hospitals out of increased fear of coronavirus, Scharf says. But the kids who came in were acutely ill. Typically, about 20 percent of kids who come to the emergency department with mental health problems are so unsafe they need to be admitted. In December, that number was up to 50 percent.

"People seem to be waiting longer to get care," Scharf says. "We see more kids coming in after a suicide attempt, rather than before."

'IT'S EMBARRASSING AND SCARY.'

Christina Hauptman suspected that something was terribly wrong when Cody was just a toddler. She was a single parent and, since her older daughter was grown, Cody was, effectively, an only child. Most of the time, he was sweet and affectionate, even clingy. But his tantrums were violent and frightening, Hauptman says. "He would bite chunks out of you, or go after me with scissors."

By the time he was in preschool, Cody had been diagnosed with a "serious emotional disturbance" – the childhood equivalent of a serious mental illness – and placed in a special classroom for kids with behavioral problems, He tried to electrocute himself when he was just four years old – an event that resulted in the first of many stays in a hospital psychiatric unit. Over the next five years, Cody and Hauptman became familiar with the inside of every emergency room on Long Island.

If you have a question about the efficiency, regulations, staffing patterns, or relative physical comforts of a region's hospitals (including the likelihood that the TVs will be working) you would do well to ask the parent of a child with serious mental health problems. Those who have cars, flexibility, and the dubious benefit of experience learn to take their kids straight to a hospital with a dedicated psychiatric ER for children and adolescents, or even to call around to see where a bed is available, in case their child is admitted.

If a young person is violent, however, or determined to run away or hurt themselves, families often have little choice but to call 911, which, depending on the county, will dispatch either an ambulance or a police car to transport the child – probably restrained, possibly sedated – to whichever emergency room is closest.

What happens next can vary widely. A very small number of hospitals have separate spaces for children and teens with psychiatric emergencies. More typically, kids sit in medical ERs, where there may or may not be a mental health specialist on duty. If they are lucky, they wait in an exam room for a few hours. If they're unlucky, they might sit in a hallway all night.

At some hospitals, kids are mixed in with adults in the midst of their own psychiatric crises. "Maybe you're behind a curtain, next to someone moaning and screaming," says Vera Feuer, the doctor from Queens. "It's not the most therapeutic environment."

Once a child makes it to the point of a psychiatric evaluation, they are typically buzzed into a locked area. "The door closes behind you with this loud clang," says one mother of an 11-year-old with a long history of psychiatric hospitalizations. "They take your purse and keys or whatever you have." Where other pediatric rooms might be decorated for the holidays or in bright colors, "there's nothing on the walls, nothing in the rooms. The bathroom has these foam doors that Velcro on. Anyone can hear you."

"It makes you feel, not like you're a bad person exactly, but a lot of people frown on mental illness and this doesn't make it any better," the mother says. "It's embarrassing and scary."

Typically, an adult is required to stay in the emergency room as long as their child is there, which can become an emergency in its own right for parents with other kids who've been left with a neighbor, or who need to be met at a school bus stop.

"I remember once we were there for four days, waiting for a bed," says the mother of a daughter, now 18, who was hospitalized multiple times for depression and psychosis. "I'm sleeping on an armchair, the TV doesn't work, you don't have a phone. It's hell. I said, 'I can't do this anymore. What happens if I walk out?' And the nurse says, 'She'll be handed over to social services and put in foster care.'"

Eventually, kids are evaluated by a psychologist or clinical social worker to determine whether they are a danger to themselves or others, or simply too ill to be safe in the community – a descriptor most often applied to very young children who are flipping desks in classrooms or out of control at home. If the evaluator decides that a child needs to be admitted to a hospital, the process of finding a bed begins.

How long that takes depends on several factors, but the biggest is the season. Doctors say that in summer, when schools are out, inpatient units often have available beds. In the fall and especially in the spring, when marking periods end and students get stressed over grades, the units fill up. And in moments of near-universal crisis – like the one we're in now – it is no surprise that emergency rooms overflow with kids who can't find an inpatient spot.

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A CHRONIC SHORTAGE OF CARE

The shortage of mental health care for kids isn't new, though it's been magnified by the coronavirus pandemic. Rather, doctors, parents, and advocates say that it is a crisis decades in the making. And like many things that determine access to health care, it has a lot to do with money.

Under state and federal parity laws, insurance companies are required to offer mental health coverage to their plan members that is equal to their medical coverage. An insurance plan can't, for example, charge a higher copay for psychotherapy to treat anxiety than for physical therapy to treat a bum knee.

The same standard, however, does not apply to the payments made to providers. When a hospital provides a patient with cardiac care, it can charge anywhere from \$28,000 to \$86,000, according to an analysis by the New York Nurses Association. The inpatient rate for treating depressive neuroses, by contrast, is less than \$4,500. The reimbursement rate for a hip replacement is more than \$9,000 per bed, per day; for acute inpatient treatment of psychosis, it's less than \$1,400.

"Parity is an illusion," says Dr. Feuer from Cohen Children's Medical Center. "Insurance companies don't pay for the work we do. My attending doctor can spend 90 minutes to two hours with a patient, working with the family, talking to the child. We might get reimbursed \$75 or \$100. Or we can get more, it's really a crapshoot."

"Reimbursement is poor in outpatient, it's poor in inpatient, it doesn't cover the actual cost of care," Feuer continues. "A lot of people, even if they get the training, they end up doing private practice and not taking any insurance."

The result is a chronic and longstanding scarcity of mental health care. In New York – which actually ranks better than most states on this measure – there are just <u>five psychiatrists</u> for every 10,000 children under age 18. In many parts of the state, young people wait six months to see a therapist, and even longer for a psychiatrist who can manage medication.

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For young people who need something more intensive than therapy once a week, treatment is even harder to find. Doctors say that many of the kids who end up in hospital beds would never have gotten so sick in the first place if they'd had access to intensive outpatient care. For example, "partial hospitalization" or "day treatment" programs are designed to provide short-term, daily mental health care to kids in crisis, without the disruption and upheaval – or the astronomical costs – of a hospital stay.

Intensive outpatient programs, however, are among the hardest to find. In 2017, the New York State Office of Mental Health (OMH) <u>estimated</u> that approximately 264,000 children and youth, ages 9 to 17, have a diagnosable mental disorder or impairment that substantially limits their ability to function. And yet, in December 2018 (the most recent month for which <u>this data</u> is publicly available) there were just over 3,100 slots in intensive outpatient programs, statewide.

"At the busiest times of year, we've routinely had 90 kids on the waitlist for partial hospitalization, all on the brink of going into the hospital," says Dr. Scharf from the University of Rochester, where he is currently using an infusion of philanthropic funds to expand the Medical Center's partial hospitalization program from 22 to 33 slots.

Part of the larger problem, Scharf says, is that the State, which licenses and regulates private mental health providers as well as operating some services directly, does not count or track the number of young people who seek care but don't find it. "You can't get data about how many days people waited in hospitals for beds. We don't have measurable wait lists for outpatient clinics," he says. "If no one really knows how big the system should be, how can we set targets for what should be available?"

The trouble, Scharf points out, is that measuring the gap would amplify the obligation to fill it. "If you start counting, then you have to do the work. Sometimes people want to fund the cheaper stuff and not pay attention to the serious things."

'I COULD GO WORK AT MCDONALD'S.'

Nearly seven years ago, New York State promised to expand and improve its pediatric mental health system, at least for the approximately two million young people enrolled in the state's Medicaid program. The effort was part of Governor Andrew Cuomo's Medicaid reform plan – a massive, multi-year overhaul premised on the ambitious idea that New York can improve health care and get better outcomes for patients, while also saving money.

For young people, the governor's Medicaid Redesign Team proposed two slates of new mental health services designed to catch and address mental health problems earlier, and to help the highest-risk kids stay safe at home. A package of 18 HOBS) would provide intensive wraparound support to young people at very high risk of ending up in hospitals or residential programs, while six new CETSS) were intended for children and adolescents with somewhat less intensive needs.

Cumulatively, the services were intended to inject flexibility into a mental health system primarily designed for adults. Social workers would see kids in their homes and schools. Coaches would work with young people on life and social skills. Peer advocates who'd struggled with their own mental health problems would be paid to offer advice and support.

After many years of delay, the new programs launched in January of 2019. According to mental health providers and advocates, however, the State set such low reimbursement rates for the services that they lose money for the nonprofit organizations designated to run them. Provider organizations struggle to hire and retain staff, many of whom work for minimum wage.

"Frankly, I could go work at McDonald's and make more money," says one longtime case worker who transitioned into one of the new programs at Astor Services in Poughkeepsie. "The girl at Stewart's who brings my coffee makes 50 cents [an hour] less than me."

Advocates for kids with mental health problems describe the programs as a typical example of the State's failure to invest in care. "As a State, we need to fulfill the promise made to families when we began Medicaid redesign by creating a system that doesn't leave children on waitlists or parents desperately searching for services," says Alice Bufkin, a director of policy at New York City's Citizens'

Committee for Children, which spearheads a mental health advocacy campaign called Healthy Minds, Health Kids.

"We need to hold insurers accountable, including by increasing reimbursement rates. Covid-19 has made even clearer the fact that we have to invest in the full continuum of care, from prevention and early intervention to intensive clinical services."

As of November 2020, dozens of nonprofit agencies had asked to be released from their contracts, according to documents from OMH. Many others are understaffed, or running just one or two of the multiple programs they were originally designated to provide.

The result is that the programs have reached just a tiny fraction of the kids who were supposed to receive them. In 2017, <u>OMH estimated</u> that approximately 200,000 children would be eligible for the six new children and family treatment services. As of June 2020 (the most recent month for which reliable data is available) less than four percent of that number – just 7,300 children – were receiving services under the program, according to OMH documents.

Similarly, the State estimated that 65,000 children would meet criteria for the more intensive slate of home- and community-based programs, designed to support the highest-risk kids. As of June 2020, fewer than 7,000 children were enrolled in HCBS programs, and only 570 of those kids actually received any services during the month.

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'I FEEL LIKE THIS IS GOING TO END WITH MY SON DYING.'

For nearly a year and a half, Cody has been one of those kids.

Between the ages of 6 and 9, Cody was hospitalized for psychiatric crises 16 times. As he got bigger, his episodes became more frightening, Hauptman says. Once, he set the kitchen on fire, trying to burn the spiders he believed were attacking him.

Eventually, he was admitted to a residential program for kids with very serious mental health problems. It was the first thing that really helped him, Hauptman says. The program was located on a farm, where Cody discovered that he loved animals – something he could be gentle and nurturing toward. He came off of several medications, and he learned skills to cope with his intense thoughts and feelings. For the first time in his life, he made a friend.

After two years, he had made enough progress that it was decided he could live safely in the community, with support from the new Medicaid programs. But when he came home, no one had staff available to work with him. He was assigned a care manager, who was supposed to coordinate all the other services, but it took 13 months before he received respite care or a coach to work on social skills, Hauptman says. And he was never assigned a therapist to work with him at home.

"I called every program on Long Island," Hauptman says. "I got numbers for all their supervisors. They told me he should be at the top of the list because he's so high-risk, but no one could take him."

Meanwhile, Cody lost much of the progress he'd made, Hauptman says. His psychosis became more frequent, and so did his violent attacks. Hauptman often had no choice but to call the police, who would handcuff Cody and drive him to the hospital in the back of a squad car. Once, when she was being treated for a head injury he'd given her, he was released from the hospital and taken to a juvenile detention center, where he was strip-searched, fingerprinted, and held overnight.

"He never should have gone through that," Hauptman says. "He's not a bad kid; he has a mental illness. He doesn't 'learn a lesson' from that."

Increasingly, Cody became distraught and depressed after his episodes. He and Hauptman were both scared that he would hurt her badly, and he started talking about wanting to die. Then, in November, he reached a breaking point. "This is the first time he really sat down and was like, 'That's it. I'm done. I'm gonna kill myself,'" Hauptman says. "This has been my biggest fear this whole time. Now it's just a reality."

After the suicide note, Hauptman applied to get Cody back into a residential program. "I absolutely think if he had gotten his services when he was supposed to, we wouldn't be here," she says. "But I can't do this by myself. I've been fighting this fight since he was 3. I feel like I failed him as a parent. I've been crying for a month because I feel like this is going to end with my son dying."

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