Christina Hauptman knows that if her son, Cody, doesn’t get help soon, he’ll end up back in the hospital—or worse.

When he’s well, Hauptman says, Cody’s a sweet 12-year-old. He likes to take care of rescue animals, and he fantasizes about winning the lottery and opening a center for young children with mental health problems. But when he’s sick, he suffers from episodes of psychosis, which often turn violent. His first visit to a psychiatric emergency room happened when he was 4 years old. By the time he was 9, he’d been hospitalized 17 times.

One of the worst moments of Hauptman’s life, she says, was when Cody begged her to let him kill himself after he had flown into a rage and attacked her.

Two years ago, Cody ended up in a residential program in upstate New York that seemed to help him. He worked with animals, got stable on medication, and graduated with a plan to come back to Hauptman’s home, on Long Island, and receive specialized mental health services in his community.

Three months later, those services haven’t materialized and are nowhere in sight.

“I’ve called every provider on Long Island,” Hauptman said. “They tell me Cody’s at the top of the waitlist because he’s such a high-risk child, but no one has room for him.”

Across New York State, children and adolescents regularly wait weeks—or even months—to get treatment for serious mental health problems. In the coming year, mental health providers and advocates warn that the situation may get worse.

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Despite an increase in teen suicide attempts, State officials plan to cut payments for several mental health programs that serve young people in their homes and communities, aiming to keep them out of hospitals.

And there may be other cuts to come: In November, the State Division of Budget announced that it will make across-the-board reductions to Medicaid reimbursements, in order to plug a $4 billion hole in the
program’s budget. Medicaid provides health insurance coverage to roughly one-third of the state’s entire population; that includes more than 200,000 children and adolescents with mental health or substance abuse problems.

It wasn’t supposed to be like this. Early in 2019, New York State launched a reform that was intended to bring mental health and substance abuse services to hundreds of thousands of young people on Medicaid, from birth to age 21.

Under a slate of new, Medicaid-funded services, providers would be able to work with kids in their homes and schools, rather than waiting for them to show up at clinics or emergency rooms. And they would use strategies designed to identify mental health problems early and prevent them from becoming more serious. In addition to reaching a young person like Cody, who needs intensive help to stay safe at home, a therapist could work, for example, in the new foster home of a 5-year-old who’d just been separated from her mother, or practice social skills at school with a tween who’d begun to struggle with anxiety and depression.

While the expansion of services would require investment in the short-term, mental health experts believed that it would ultimately save taxpayers many millions of dollars, preventing expensive—and traumatic—events like emergency room visits, foster care placements, and juvenile arrests, not to mention treatment for adult mental illness.

“&#8220;We had a plan that was fantastic,” says Trish Luchnick, the Director of Family Driven Care at Astor Services for Children & Families in Poughkeepsie, NY, which offers mental health care across Dutchess County. “The system had always treated kids like little adults. Finally, we were saying children are different. We need flexibility, we need to think out of the box.”

However, a year since the reform launched, services are reaching a tiny fraction of the kids who need them, and many of the nonprofits that deliver the new programs are struggling just to keep their doors open.

After promising to make care available for any child on Medicaid, the State set reimbursement rates so low for most of the new programs, providers say, that agencies can’t cover basic costs or hire staff—many of whom are paid just above minimum wage.

“Everybody’s asking, what the hell happened to the beautiful plan we just had?” Luchnick says. “I was in Hobby Lobby the other day. They’re paying the same as I am, with better hours and a Christmas bonus.”

In many parts of the state, mental health care is provided by small community organizations that can’t afford to offer services that cost more than they are reimbursed. The new programs allow providers to bill Medicaid for face-to-face time with kids, but rates don’t cover the time they spend traveling to a family’s home or writing case notes—much less supervisors, laptops, electronic health record systems, or the back-
office staff it takes to manage billing to multiple insurance companies with different rules and requirements.

“For smaller agencies, it’s really destroying us,” says Tori Barnes, who directs youth and family services at Family of Woodstock, which serves much of Ulster County. “It really does feel like they want to drive the services into the ground.”

Unsurprisingly, many staff positions go unfilled, turnover is high, and care has not reached anywhere near the number of children that the State promised to serve.

The reform included two packages of new services: A slate of 18 Home and Community Based Services (HCBS) were designed to provide intensive wraparound support to kids at very high risk of ending up in hospitals or residential programs, while six new Children and Family Treatment and Support Services (CFTSS) were intended for young people with somewhat less intensive needs.

In a 2017 report, the NYS Office of Mental Health estimated that some 200,000 children and adolescents in the State Medicaid program have a medical need for services in the CFTSS package. As of early November, only 7,900 children were receiving CFTSS—less than five percent of eligible kids. (OMH provided data for this story but did not offer comment.)

Similarly, the State estimated that 65,000 children would need the more intensive HCBS programs. As of October, fewer than one-tenth of that number—just 6,400 young people—were receiving them.

These numbers could soon drop even lower.

“Cody will end up back in the hospital before he gets off the waiting list.”

Since the CFTSS programs were new, the State added a 25 percent rate enhancement, intended to help providers cover startup costs. After six months, the enhancement was cut in half, and on December 31st, for most services, it will go away altogether. Advocates fear that many programs will disappear along with it—and that as a result, even more families will be left on their own, watching their children get worse.

On Long Island, Christina Hauptman has given up hoping for help. “Cody will end up back in the hospital before he gets off the waiting list,” she says.

The struggle to find mental health care is not new. Under Federal law, insurance companies and State Medicaid programs are required to offer coverage for mental health and substance use services that is equal to what they provide for other medical care. In other words, it should be just as easy to find and pay for treatment for a child’s depression as for her broken leg.

But compliance with parity laws is scarce, and enforcement is even scarcer. In New York, as in most places,
low pay and stingy insurance coverage have led to chronic shortages of pediatric mental health and substance abuse programs across the state. Depending on where a child lives, it can take half a school year to get into a therapy program that serves kids, and even longer to see a child psychiatrist. More than half of New York kids with a mental health condition do not receive treatment, including 55 percent of young people with major depression.

Counter-intuitively, New York’s Medicaid program has historically offered higher reimbursement rates and a wider range of mental health and substance abuse treatment than commercial insurance providers. But the system has been hit hard by successive reimbursement cuts over the past decade.

Experts say that the consequences for kids are severe. “If we don’t take care of people who are at risk when they’re young, they end up being sick adults,” says Jennifer Havens, who directs behavioral health services for children and adolescents at New York City’s Health and Hospitals Corporation, which operates public hospitals and clinics.

As in much of the country, suicide attempts among teenagers in New York have risen dramatically in the past decades. Statewide, suicide is the 2nd leading cause of death for kids age 15-19, with 17 percent of high schoolers reporting that they had seriously considered an attempt in the previous year.

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When New York State set out to redesign its Medicaid program, the Cuomo administration announced that it would attempt to rein in spending by moving all Medicaid-funded services to private, managed-care insurance companies—including mental health and substance abuse treatment for very vulnerable kids, which has traditionally been reimbursed directly by the State at set rates.

It was a move that worried many advocates for children, but it came with the promise of new services, increased flexibility, and the potential to bring mental health and substance abuse treatment to a vastly expanded number of kids.

Providers say that, where the State’s new services are in fact reaching young people, they’re working. “Families get the help they need, when they need it. They feel supported,” says Marleen Litt, who directs several programs at JCCA, a multi-service agency in New York City and Westchester County.

“And it’s pennies,” Litt says. “One kid in the emergency room for two or three hours for a psychotic episode, or because mom doesn’t know what else to do, is way more expensive than sending [a mental health provider] to the family’s house for an hour or two a week, throughout the year.”

Community-based services are often more effective than programs that require kids to come into a clinic, mental health experts say. If a child loves to draw but is aggressive with other kids, a behavioral specialist might take her to a neighborhood art class, where she can practice her social skills while doing something she feels good about. For other kids, it might be an animal shelter or a job fair, says Dr. Melinda Konigsberg, who oversees medical and mental health services at Little Flower Children and Families, which operates in New York City and on Long Island.

“We can incorporate things like art into therapy in an office,” Konigsberg says, “but we can’t replicate the experience of being in a child’s environment with her peers.”
The new services also allow Little Flower staff to work in new and effective ways with young people who have very intensive needs, in the agency’s residential treatment facility, Konigsberg says. If a child, for example, has a history of going AWOL from the residence when he’s upset, a behavioral health specialist can meet with him a few times a week—in addition to his other mental health services—to talk through an alternate plan: What can he do instead of running away? Who can he talk to when he gets mad?

Or for a child with thoughts of suicide, a specialist can role play strategies from the safety plan she’s made with her therapist.

Overall, Little Flower has seen a remarkable drop in hospitalizations among the children they serve since starting the new services, Konigsberg says. “When I started as clinical director, we had 24 hospitalizations in a year. Since we implemented CFTSS, we’ve only had one.”

In the face of the State’s gaping Medicaid deficit, mental health advocates are calling for a moratorium on cuts to mental health care and substance abuse treatment for kids.

Budget documents show that the State planned to spend $52 million to implement reforms to children’s behavioral health care in the current fiscal year, which concludes at the end of March 2020. That money would be doubled by federal Medicaid funds, bringing the total above $100 million.

However, advocates say that actual spending hasn’t come close to the amount that was promised, and should not be targeted for cuts.

“After years of planning, countless implementation delays, and repeated failure to meet the most basic parity requirements, New York State once again turns its back on children by walking away from its promise to fund core services,” says Gail Nayowith, who served as co-chair of the committee that developed the reform plan for children, as part of Governor Cuomo’s Medicaid Redesign Team.

“The time has come for New York State to call a moratorium on cuts to children’s mental health services,” Nayowith says. •

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