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Public Facing Advocacy Writing

By Abigail Kramer, THE CITY

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New York state has failed to provide children on Medicaid with the mental health care they are entitled to by law, according to a lawsuit filed in federal court Thursday by two adolescents acting on behalf of hundreds of thousands of Medicaid-eligible kids.

As a result, the lawsuit alleges, young people with serious mental health conditions suffer unnecessarily, ending up in hospitals and residential treatment programs because they dont have access to services that would keep them safe at home.

New Yorks mental health system for children is languishing in a state of dysfunction, providing inadequate, inaccessible, and woefully underfunded mental health services, according to the complaint, filed in U.S. District Court in Central Islip, Long Island, by attorneys from the advocacy groups Disability Rights New York, Childrens Rights and the National Health Law Program, as well as the law firm Proskauer Rose LLP.

THE CITY and ProPublica reported Monday how New Yorks vow to transform mental health care for children has left young people with <u>inadequate access to outpatient treatment</u> and hospital care. Under a plan launched in 2014 by then-Gov. Andrew Cuomo, New York cut the number of state-run childrens psychiatric hospital beds by nearly a third. While the plan shifted savings into outpatient and community-based services, it did not reduce demand for hospitalization in the first five years, and it increased the wait time for hospital beds for children with mental health emergencies.

For kids with serious mental health conditions, the stakes are life and death, said the mother of a plaintiff in the case, who lives on Long Island. If I left it up to the system, my son would be gone already, the mother, who is identified by the initials P.K. in the complaint, told THE CITY and ProPublica.

Her son, who is now 15 years old, first showed signs of mental health problems when he was still a toddler. He was hospitalized for a psychiatric emergency when he was 4 years old, then cycled in and out of hospitals approximately 16 times before he was 10 often as the result of violent episodes in which he hallucinated and tried to hurt himself or his mother, P.K. said. His symptoms grew frightening enough that he spent two years, from ages 10 to 12, in a residential treatment program for kids with very serious mental health conditions.

At the residential program, he learned skills to cope with his symptoms and was taken off of several psychiatric medications, his mother said. Eventually, he was discharged with a plan to receive intensive mental health services that were supposed to help him stay well at home.

But when the mother contacted the mental health agencies in her area, she was told that all the programs were full. Im calling everyone, and theres nothing, she told THE CITY and ProPublica. Her son went months without getting any home-based mental health services at all, according to the lawsuit. When providers were finally assigned to his case, they disappeared after a session or two, moving on to other jobs, the mother said. Its just: Boom, theyre gone. They never even really got started.

While she struggled to find help for her son, she watched him become dangerously ill. He started cutting himself, she said, and ended up in emergency rooms and hospital beds after multiple suicide attempts. I worry every day that Im going to go home and not find my son alive, she said. I check on him at night like hes a newborn. Is he breathing? Is he OK? Its heartbreaking. I still cry every day.

I honestly feel if he had those services when he came home, hed be in a whole different place today, she continued. I know hes been failed by the system. Ive been fighting and fighting. But my heart also says, if something happens, its my fault. Ultimately, Im his mother. Thats my child.

New York has long known that its mental health system fails to meet kids needs, according to the lawsuit, which names as defendants the commissioner of New Yorks Department of Health, Mary Bassett, and the commissioner of the states Office of Mental Health, Ann Sullivan.

Both DOH and OMH declined to comment on pending litigation.

Under federal rules, the state is required to provide intensive mental health services to any child with a medical need who is enrolled in

Medicaid, the federal-state health insurance program that covers more than 2.2 million people under age 21 in New York. The services are supposed to be delivered in kids homes, schools and other places a child would naturally be a model that mental health care providers say works better for many kids with serious challenges than requiring them to sit in clinicians offices like small adults.

In 2011, a Medicaid Redesign Team established by Cuomo acknowledged that the states mental health system was underfunded and inadequate, with little accountability for the provision of quality care and for improved outcomes for patients/consumers. As a result, the work group found, harmful and costly developmental trajectories continue to be formed early in life.

In response, the state created two new sets of services that were supposed to become available to hundreds of thousands of children. The first, called Children and Family Treatment and Support Services, would provide clinical help to any child on Medicaid who had a medical need. Kids would have access not only to in-home therapy, but also to providers who would take them out into the community so they could work on coping skills in public and to mental health professionals who could respond to a crisis, making it less likely that a family would have to call the police for help with a violent or suicidal child.

The second package, called Home and Community Based Services, would offer intensive support to kids at imminent risk of ending up in a hospital or residential program.

But, the lawsuit alleges, while the state purports to make these services available, they arent intensive enough to meet the requirements of federal law. And even if they were, the programs arent available to anywhere near the number of kids who are entitled to them.

The state does not track the number of kids who sit on waitlists for mental health care, but data from OMH shows that community-based services reach a tiny fraction of the kids who are supposed to receive them.

In 2017, OMH projected that more than 200,000 children and adolescents in the state Medicaid program have a medical need for Children and Family Treatment and Support Services. In 2020, fewer than 16,000 children received those services. Thats less than 8% of eligible kids, according to OMH data cited in the complaint.

Similarly, the state estimated that 65,000 children and adolescents would need its more intensive Home and Community Based Services. As of July 2020, approximately one-tenth of that number was enrolled in the programs, according to the complaint.

Without the care they are entitled to, young peoples mental health conditions continue to deteriorate, causing disruption and harm to the children, their education, their families and relationships, their future adulthood, and their very lives, the lawsuit charges. The plaintiffs are asking that a judge require the state to provide kids with the mental health services mandated by federal law.

The mother of the 15-year-old plaintiff said she thinks her son may have missed his chance to benefit from the kinds of services he was supposed to receive when he came home from the residential treatment program three years ago. Those were prime years for him, she said. He missed all those years of developing, when he should have been learning social skills and how to cope.

I just hope this lawsuit gets up there and makes a difference, she said. Its a little too late for us, but hopefully its not too late for others.

This story was originally published by ProPublica.

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