Even as Governor Andrew Cuomo promises to defend New Yorkers' health care from federal funding cuts, his proposed budget threatens to kill a long-planned fix to the state's underfunded, overburdened system of mental health services for children.

Back in 2011, when the governor launched his signature project to overhaul Medicaid (the shared federal-state health insurance program for low-income children and adults), the central premise was that New York could rein in costs by investing in better, more creative, preventive health care strategies for its most vulnerable residents. It saves both money and needless suffering, the logic goes, to pay an outreach worker to monitor a homeless patient's blood sugar rather than a hospital to manage the crisis caused by that patient's uncontrolled diabetes.

For children—who don’t rack up hospital bills of nearly the same magnitude as adults—the Medicaid redesign plan focused primarily on mental health, approving a package of new services designed to catch problems early and intervene before kids devolve into crisis.

Slated to begin in July 2018, the new services would allow providers to treat kids up to age 21 with evidence-based interventions, designed specifically for children and delivered in their homes and communities. A social worker could bill Medicaid, for example, for meeting with a child’s teacher to help her manage behavior problems in the classroom—potentially stopping that child from getting kicked out of school. The parents of a child with a severe emotional disturbance could get respite care in their home, reducing the risk that they resort to an institution.

Like other aspects of Medicaid redesign, the children’s reform plan has run into obstacles and delays. But late last year, the state Department of Health began designating providers to offer the new services. “Everyone was changing what they were doing in preparation for an expansion,” says Andrea Smyth, the executive director of the New York State Coalition for Children’s Behavioral Health and a member of the state subcommittee that designed the children’s reform plan.
When Cuomo released his executive budget on January 16th, he pledged to protect New Yorkers from “unprecedented and repeated assaults from Washington aimed at crippling the State’s health care system.”

However, children’s health care providers—along with advocates and members of the state’s Medicaid Redesign Team—were surprised to find no indication of money allocated to the new services, Smyth says.

It’s impossible to know exactly what the services would have cost in the coming year, since spending would depend on how many children used them. But supplemental budget documents project a $30 million savings from delaying implementation of the children’s reform, half of which would have been covered by federal funds. In the longer term, if the federal government were to turn Medicaid into a limited block grant, being on the hook for the new services could make it more difficult for the state to control spending.

State officials did not respond to requests for comment about the budget or future plans for the children’s reform.

However, Gail Nayowith, a widely respected policy expert who served as co-chair of the state subcommittee that designed the children’s reform, describes the budget as a betrayal of the state’s commitment to vulnerable children.

“We’ve been working for seven years in a state-led process that has misrepresented its intentions to the public, providers, parents and children,” Nayowith says. “Instead of the stronger system for medically fragile and seriously ill children we were promised, we have a depleted system with no services to offer them and a governor’s budget that leaves these children holding the bag. It’s inconceivable that even after the federal government approved the state’s request to move ahead [with the children’s reform], the Medicaid director and governor’s office choked and made the decision to do nothing.”

Under current conditions, advocates and providers say the Medicaid-funded mental health system sits on the brink of fiscal crisis, with nowhere near the capacity to serve the number of children who need care. Of the two million children enrolled in New York’s Medicaid program, approximately 220,000 receive mental health or substance abuse services, according to a report by the Medicaid Institute at the United Hospital Fund. Many more sit on waitlists for overwhelmed, underfunded clinics and treatment facilities. 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 pediatric psychiatrist.

The capacity crisis has only grown worse as providers have shut down existing programs in anticipation of offering the new services, Smyth says. “Lack of capacity was the reason for the expansion in the first place. Instead, we are ending up with a contraction to already insufficient services.”

It’s difficult to measure the gap between need and capacity, since many children with mental health problems never even make it onto waitlists, but the Department of Health published estimates during its reform planning that indicate a severe shortage of care. For example, a limited number of children receive home- and community-based services through the state’s longstanding, capped
and waitlisted waiver programs for special Medicaid populations. According to data presented last year, fewer than 8,000 children received the waiver services in 2014. Health Department officials predicted that after the reform, with eligibility opened up to all Medicaid children with medical need, that number would more than quadruple, to 33,000.

In planning for a related initiative, Health Department officials estimated that more than 100,000 children, statewide, have mental health or substance abuse problems serious enough to warrant the kind of special care-management services that are currently only available to children in the waiver programs.

One kid waiting in line is Troy (not his real name), a talkative 10-year-old with a quick sense of humor and a dual diagnosis of ADHD and oppositional defiant disorder—precisely the kinds of conditions, experts say, that can either be resolved with care and attention, or can lead to a lifetime of problems.

Last year, after his dad lost first his job and then the family’s apartment, Troy moved from Brooklyn to Staten Island—far from the doctor who’d been prescribing his medication. His mother, who was seven months pregnant and caring for three kids under school age, couldn’t find him an appointment closer to the family’s new home.

Out of treatment, Troy started getting in trouble at school and home until, one afternoon, he stabbed a younger brother in the ribs with a pencil, ran away, and ended up in a psychiatric hospital.

Since returning home, he’s been working with Carissa Molinary, a care manager with the Jewish Board for Children and Family Services on Staten Island, who helps make sure he receives therapy and medication management appointments. But he needs far more intensive supports, Molinary says. She put him on a waiting list for a waiver program that would not only manage his health care but offer twice-a-week respite services, sending someone to give him breaks from the chaos of his home and the responsibility of taking care of his younger siblings.

“He has so much potential,” Molinary says. “He’s just neglected and very overwhelmed. With the right interventions now, it could make a huge difference in what happens to his life.”

But that kind of long-term thinking isn’t what guides budget-making, says Alan Mucatel, the executive director of the social service organization Leake & Watts. “We know that if we don’t address kids’ problems, it’s going to cost us, whether it’s homelessness or behavioral health issues or medical needs. These issues will manifest in 15 or 20 years.”

Unfortunately, prioritizing children doesn’t fix budget problems now, Mucatel says. “Kids don’t lend themselves to short-term dollar savings.”