

Lower-income Americans are being shut out of life-saving treatments for anorexia

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The pandemic exacerbated many mental health problems, and eating disorders are no exception: Emergency room visits for girls suffering

from anorexia and bulimia were twice as high in January of this year as they were three years earlier.

What hasn't kept up is how government-funded insurance programs have responded to the crisis. Families are struggling to obtain adequate care on the plans designed to help the very people who can't afford the costly treatments that higher-income Americans turn to.

The Covens family, who live just outside Raleigh, North Carolina, found themselves trapped in a loop as a result of the barriers to care. Their daughter Penny, who dropped from 90 pounds to 63 pounds over just three months when she was 12 years old, first got admitted to the hospital in June of 2021 when her parents realized just how thin she had become. Penny was so gaunt that [hospital staff](#) notified the state's child protective services that she was malnourished, prompting an investigation. Even so, the hospital sent Penny home the next day, saying there was little they could do for her.

At the time, Penny was one of the more than 38 million children in the U.S. whose families are on health insurance plans that are funded by federal and state dollars. The Covens didn't earn enough to pay for [private insurance](#), but their state-funded CHIP plan—a program for families who make too much money for Medicaid—limited their options when it came to Penny's care.

Penny was suffering from severe anorexia. The hospital told her mother, Robin Sinton, that it was already "overrun" with kids in its psychiatric unit. Instead, Penny was put on a waiting list and told that it would be months before she could hope to get any therapy that was covered by her insurance plan. Nor did her plan cover a dietician, a critical component of anorexia treatment. Inpatient eating-disorder programs in her insurance network had no openings.

Illnesses like anorexia and bulimia have the second-highest mortality rate of any mental health condition, behind only overdose deaths. They're also complex conditions that typically require both a medical and psychological approach to care. But even with the Biden administration's efforts to expand mental health services for the young, government-funded insurance plans aren't required to cover treatment beyond what's deemed "medically necessary" in a hospital. And that's a highly subjective call.

Bloomberg contacted all 50 state health systems, requesting information on types of treatment that state-funded programs cover for eating disorders. Of the 18 states that responded, including Penny's home state of North Carolina, all said they are required to cover inpatient treatment and most outpatient services. But then the details become murky. Because coverage is dependent on medical necessity, a third-party organization is typically contracted to weigh in. Several states that don't have in-state residential centers also don't cover out-of-state care.

Gregg Montalto, a pediatric eating-disorder specialist at Lurie Children's Hospital in Chicago, said more than half of his patients are on government insurance plans, which is a problem because many residential eating disorder facilities don't take that kind of insurance. "There are just gross inequities in access to care," he said.

As her condition got worse, Penny cycled in and out of various hospitals while her parents struggled to find a therapist or residential facility that insurance would cover.

This isn't uncommon. Sara Buckelew, director of the University of California San Francisco's eating disorder program, said her hospital has seen some of the same [young patients](#) readmitted upwards of 15 times. Hospitals are supposed to be a safety net, they aren't adequate places to receive treatment for months, added Jillian Lampert, chief strategy

officer for Accanto Health, which runs eating disorder treatment centers and acts as an advocacy group.

With nearly 2 million young people expected to have an eating disorder before they turn 20, the cost to the U.S. health care system is high, said Bryn Austin, founding director of the Strategic Training Initiative for the Prevention of Eating Disorders at the Harvard Chan School of Public Health and Boston Children's Hospital. According to a study Austin co-authored, published in Deloitte Access Economics, eating disorders cost the U.S. health-care system around \$4.6 billion per year.

But the true financial burden extends beyond the health-care system, with families bearing the brunt. Almost a quarter of those with eating disorders sought care from a family member or close friend, the study found. Penny's mom, for example, would like to get a job to help pay the family's medical bills, but when her daughter was home from the hospital, she needed to sit with Penny at mealtimes, ensuring she ate six times a day and wasn't purging. The total financial costs borne by people living with eating disorders and their loved ones were \$23.5 billion from 2018 to 2019—including \$363.5 million in out-of-pocket payments for health care.

From the beginning, Robin was fighting for more care than Medicaid would provide for her daughter. "The hospital is sending my daughter home this week. She eats zero food, is on a tube, nowhere near recovered and there is no place that will take the insurance. I do not understand the point of even having the 'residential' piece of the insurance if no one will accept it," Robin wrote to North Carolina's Medicaid Ombudsman last October.

The Covens tried everything they could while Penny was at home, but caring for a child with an eating disorder is often a losing proposition.

"We literally just sat and watched our daughter deteriorate while we waited for the year to run out," at which point they could try to switch insurance plans to get onto a plan that covered things like residential care, Robin said.

In the end, to get Penny into a facility that Robin felt she could trust, the Covens uprooted their life even further. By taking one of their other daughters, then 21 years old, off their insurance plan and asking her to move out, they had one less dependent and would qualify for an exchange-based plan based on their income. Developed under the Affordable Care Act, these types of plans allow families to "shop" for subsidized options available through state partnerships with private insurers. The Covens were able to get on a Cigna plan, which was still low-cost, but gave them more options for Penny's treatment.

More than a year after she was first admitted to the hospital, Penny finally got a place at a residential facility in Texas—more than 1,000 miles from home. At the center, Penny had the care she needed: Around-the-clock support, one-on-one therapy, and individualized nutrition counseling. She's now back home with her family and attending a day program about a 50-minute drive away, which is covered by the Covens' new [insurance](#) plan.

Still, rare family visits to the Texas facility required airfare and hotels, further straining the budget. And the center also asked for \$7,000 up front, the full amount of the Covens' deductible.

"I'm sitting there going, 'oh, my God, it's August. What if she isn't better? What if we're still in this loop next year, and I'm paying seven grand every January?" Robin said. "We're going to go bankrupt. It's insanity."

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