

Vulnerable Florida patients scramble after abrupt Medicaid termination

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Esther JeanBart leaned over her son's wheelchair, caressing his face and trying to make him giggle. Gianni JeanBart was under the weather, but still his eyes rolled toward her and his mouth widened, cracking a smile.

Esther JeanBart said she has missed the sound of Gianni's voice the most. In 2017, the U.S. Marine was in a motorcycle accident on his way

to work, about a month shy of his 20th birthday.

Since then, Gianni has undergone more than a dozen surgeries. Now quadriplegic and prone to seizures due to a [traumatic brain injury](#), he requires around-the-clock care from licensed [health professionals](#). For the past seven years, he's lived with Esther in their home in Valrico with his medical care covered by Medicaid.

"He is still here," she said. "He fights every day."

But on April 1, Gianni's Medicaid coverage was abruptly terminated without notice from the Florida Department of Children and Families, the agency that determines eligibility.

Gianni is one of several patients—the full number is unknown—to lose access this month to Medicaid's Home and Community Based Services, which is geared toward patients who are disabled or have extensive long-term-care needs. The program allows beneficiaries to receive services in the home, rather than in an isolated institution or long-term care facility.

Since the beginning of April, Miriam Harmatz, advocacy director and founder of the Florida Health Justice Center, said the organization has received panicked calls from caregivers and patients. Most said they learned their coverage was terminated only after nurses and other providers began canceling services.

In a statement, a spokesperson from the Florida Department of Children and Families said the agency was not aware of any HCBS participant who inappropriately lost Medicaid coverage without receiving proper notification.

"The examples you have provided the Department from so called 'advocates' show that each individual was properly noticed and either did

not respond timely or no longer met financial eligibility requirements," said Mallory McManus, the spokesperson. "As we have shared previously, those who were disenrolled because they did not respond to our requests would have been contacted by us up to 13 times via phone, mail, email, and text before processing their disenrollment."

Harmatz said this is not the reality for a number of home care recipients who contacted her organization. She said her organization reviewed several patients' Medicaid access portals, and saw no notifications from the agency warning them of termination.

These patients are the latest Medicaid recipients to find their coverage threatened amid the state's redetermination process, which began in April 2023. Florida's Medicaid rolls swelled by 1.7 million people during the pandemic, when the [federal government](#) gave states additional funding to keep people covered even if they were no longer eligible. Once the funding ended, the Department of Children and Families began conducting its first eligibility checks in years.

The state agency is meant to send notice at least 10 days prior to when a patient loses Medicaid coverage. This notice should include the reason for coverage being terminated.

But most long-term home care patients would have no reason to lose eligibility, Harmatz said.

"Think about who they are, what they're dealing with," she said. "They're so disabled that they could go right into a nursing home or institution, and suddenly, their home health aid didn't show up. How do they get out of their wheelchair? How do they clean themselves? ... The level of concern with any interruption is heightened."

Harmatz and her organization are pushing for all home care patients who

were removed from the rolls to be immediately reinstated while the state assesses what happened. In an email she sent to general counsels at the Department of Children and Families and the Florida Agency for Health Care Administration, she said it was "the only logical and humane solution."

"We're at the panic point now," Harmatz said. "We should not have to unpack every single reason why a person lost coverage."

JeanBart began worrying about her son's medical coverage in mid-March, when providers already began canceling appointments. They told her their computer systems showed Gianni's coverage ending April 1.

She had been trying to order medical braces to help Gianni stretch the muscles in his arms and hands, but the braces take three to four weeks to create. In emails JeanBart shared with the Tampa Bay Times, employees of the brace company wrote they were concerned Medicaid would not pay. The retrofitted van service that Gianni uses to attend physical therapy and other outings also canceled.

This made little sense to JeanBart, who said her son was previously set for Medicaid renewal in July 2024. She called and emailed his health plan provider, Sunshine Health, as well as state agencies.

JeanBart said representatives at all three groups told her Gianni's coverage was safe. A Sunshine Health case manager told her the April 1 expiration date could be a "ghost term date," and that coverage would automatically renew once it passed.

"If Medicaid is going to give me something in writing, showing me he's qualified, why would I question that?" she said.

But she called Sunshine Health once more on April 1—just to be sure.

This time, the representative told her Gianni's coverage had been terminated.

JeanBart said she never received written notice or an explanation from the state.

Some of Gianni's regular nurses continued to work without pay, but not always for the 24 hours a day he required. The rest of the time, JeanBart was on her own, caring for him through the night.

As his mother, JeanBart said it's an honor to care for Gianni. But she has no medical training, and with three other children between the ages of 11 and 15, as well as her own home health care business to run, she knew she wasn't equipped.

"He's not able to go out; I don't have a car to accommodate him," she said. "He can't go out and see the sun, get his braces, get therapy to move his muscles. ... I can't put him on a chair, so he's stuck on a bed. That's deterioration, that's detrimental to his health and his emotional well-being."

It felt like the health care system was erasing her son, JeanBart said.

"As long as I'm breathing, I'm going to fight," she said. "This is not OK."

After 10 days, she received a voicemail from an Agency for Health Care Administration employee, who told her Gianni's coverage would be reinstated by the following morning. But when she called to confirm around 11 a.m. Thursday, he still wasn't in the system.

Even if the issue gets fixed, she said, "It's not over. Tell me what happened, so I can be sure it won't happen again."

Harmatz said it's difficult to determine how many patients like Gianni have been affected or what caused so many ostensibly eligible recipients to lose their coverage. It's part of a larger pattern, she said, in Florida's bumpy redetermination process.

"To DCF's credit, the plan was to put the most vulnerable people last," she said. "But we don't have a dedicated phone line at the relevant agencies ... as far as we know, there is no special team or unit set up (to assist). ... Florida didn't do that."

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