

# After losing Medicaid, parents of Florida's sickest kids are in limbo

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Osceola resident Oscar Hernandez is scrambling to ensure his 16-year-old terminally ill son, Llarell, will continue to receive medical care.

Llarell is paralyzed and relies on three life support machines and specialized nursing care for 16 hours per day. Hernandez thought his son would receive Medicaid coverage for the rest of his life, until late

March, when he got a call from his son's Medicaid plan telling him his coverage would soon be terminated.

"It's been 16 years of taking care of a kid with a terminal disease. By the grace of God, he's still with us. But we shouldn't be dealing with situations like this. It is just wrong," Hernandez said.

His son's coverage was set to end March 31, Easter Sunday, but the state extended it to the end of April. He's spent over a dozen hours on the phone trying to understand what he can do next.

"I don't know what to do. I don't know which way to go. I call Medicaid, and they have no answers for me," Hernandez said. "I haven't received any letters or anything. ... So I don't know what's happening. I really have no clue."

## **1.3 million dropped**

Over the last year, Florida has dropped over 1.3 million people, including 460,000 children, from its state Medicaid program after the end of a pandemic-era policy that banned states from removing participants who became ineligible. In March, the state began redetermining eligibility for kids with chronic complex conditions, like Llarell. Reviews for these children were delayed until now.

The state says cases where the family didn't find out about termination until it was already happening are an anomaly. Yet advocates point out that during the past month, when the state's sickest kids had eligibility reviews, some Florida families found out their kids lost coverage with just days of notice and struggled to get answers from the state about what to next.

"It's very troubling. It seems like there are a lot of very sick children who

are now left out in the cold," said Joan Alker, executive director of Georgetown University Center for Children and Families.

The Florida Department of Children and Families informed families throughout the eligibility review process through letters, emails, texts and calls, said spokeswoman Mallory McManus. She said the department called recipients two months before their redeterminations, successfully speaking with 93% of those affected.

If the department doesn't get a response, it conducts additional outreach for those who might normally be terminated for being non-responsive, she said.

"This level of outreach goes above and beyond the requirements of the federal government and is further evidence of our commitment to supporting recipients through the process," she wrote, adding that people no longer eligible are automatically referred to KidCare, a state health insurance option for families who make too much money for Medicaid.

Yet dozens of people have told the nonprofit Florida Health Justice Project they didn't get advance warning and didn't find out their coverage was up for review until they were already losing it, said Florida Health Justice Project founder Miriam Harmatz.

In some cases, the children were terminated not because they were ineligible but because their parents didn't receive instructions from DCF on how to keep coverage, Harmatz said. Those families then faced high call center wait times and are not always given information about their right to appeal the termination, she added.

"A significant number appear to have fallen through the cracks," Harmatz said. "We received a tremendous number of requests for advice and help from parents who only learned their child's loss of Medicaid

from their medical providers in late March. They tried to reach out to DCF and either could not get through or got incorrect information."

## **Easter Sunday cutoff**

On Easter Sunday, coverage for most children with complex chronic conditions was set to expire. Some, but not all, ended up getting an extension until the end of April, Harmatz said. But even those who got an extension are stumped on what to do or why they lost coverage, she added.

The Orlando Sentinel shared the story last month of Kaitlin Maron, who found out her son was set to lose Medicaid coverage by chance at a routine doctor's appointment. She, too, said she never saw any warnings despite thoroughly checking her inbox, mailbox, phone and MyACCESS state account. She didn't realize she could appeal the decision until she talked to the Florida Health Justice Project.

Her son's Medicaid was also originally set to end March 31 but was extended through the end of April. He didn't experience a coverage gap and she has been told he will continue to qualify as long as he remains eligible for Supplemental Security Income, a program that provides cash payments to low-income and disabled people.

Yet after significant time devoted to addressing the situation, she still has "no explanation" as to why he was set to lose Medicaid in the first place.

"I spoke with both Medicaid and Social Security and there wasn't any sort of notes. They were both stumped as to why he was canceled," she said via text.

Harmatz said that some clients who appealed before their termination date still haven't had all their coverage restored. She's also heard about

several severely disabled adults whose coverage was terminated on Easter Sunday without notice, leaving them without home health services that they depend on for their daily health and safety.

## Seeking assurances

The Florida Health Justice Project has asked the state to ensure there's no gap in coverage for people who never received notice they were up for redetermination or for medically complex kids. They are also pushing the state to post Florida's plan for these kids on its website so advocates have somewhere to refer parents.

Right now, FHJP is referring families to the personal email of a KidCare staff member who said they could send parents directly to her for assistance. FHJP has also created a Q&A for parents of kids with complex medical conditions.

"We're a small nonprofit. We're struggling to keep up with responding to the people who email us, and we can't deal with these cases one by one," Harmatz said. "There needs to be a sustainable system fix."

Hernandez is at a loss about what to do next for his son.

The family now makes too much for traditional Medicaid. Llarell is still eligible for Florida's medically needy "share of cost" program, which will allow him to receive Medicaid coverage each month after his medical bills exceed a certain amount based on income, \$7,000 a month in this case. But many providers are unable or unwilling to provide care without guaranteed reimbursement.

"I told them that's impossible because the only way that I can get \$7,000 in invoices is if the nurses show up, and they won't show up because they don't have proof of payment," Hernandez said.

Without nurses, Hernandez would have to quit two of his three jobs and work from home full-time to care for Llarell.

In the meantime, he has enrolled his son in Florida Healthy Kids, part of the state's Children's Health Insurance Program. He has two daughters on Healthy Kids, and it's better than nothing, he said, but he worries it won't come close to meeting all his son's care needs.

Healthy Kids does not provide as much coverage for medically complex kids as Medicaid does, Alker said.

"A child with serious health conditions is going to be much better served by the Medicaid benefits package," she said.

## **DeSantis defends KidCare**

During an April 1 press conference on toll relief, a reporter asked Gov. Ron DeSantis about the thousands of kids set to lose Medicaid coverage, and he defended KidCare.

"Well, but our KidCare has been very effective," DeSantis said. "I mean, I think if you look at what the Legislature has done over the years, you know, they've really focused on helping working families make sure that their kids have access to health coverage."

In 2023, the Legislature voted unanimously to expand KidCare to higher-income families, which was predicted to help 42,000 uninsured kids.

The expansion was supposed to take effect Jan. 1 but was delayed by paperwork snafus. It has now been postponed indefinitely while the state sues the federal government over a new rule that would require states to keep children on KidCare for 12 months even if their families miss a premium payment.

A hearing on that suit is scheduled for April 18 in federal court in Tampa.

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