

As States Purge Medicaid Rolls, Legal Aid Groups Step Up

By Alison Knezevich | July 7, 2023, 7:03 PM EDT · [Listen to article](#)



Gillian Sapia is shown with her 5-year-old daughter, Penelope, who has a rare metabolic disorder called classic galactosemia. Penelope lost Medicaid coverage for several weeks in May as states have started renewing eligibility reviews following the end of the federal COVID-19 pandemic emergency. After connecting with the Florida Health Justice Project, which she turned to for help, Sapia's coverage was ultimately restored. (Courtesy of Gillian Sapia)

North Carolina resident Anthony Brooks spent the last few weeks rushing to schedule doctor's appointments and procedures to treat his chronic heart problems.

The 57-year-old is set to lose his health care coverage through Medicaid at the end of the month, so he is racing to set up surgery to implant a defibrillator his doctors said Brooks needs.

"I can't afford insurance," said Brooks, who worked as a traveling home health aide for the elderly until he suffered a heart attack last September. "This is devastating to me."

Meanwhile, in Florida, Gillian Sapia was shocked when her 5-year-old daughter Penelope's occupational therapist texted her the day before a scheduled session in May to tell her

Penelope was no longer covered by Medicaid.

Penelope, who has been on Medicaid her whole life, has a rare metabolic disorder called classic galactosemia, as well as other health conditions. After the message from her daughter's therapist, Sapia began a frustrating pursuit to get answers from the state's Department of Children and Families.

"I spent like a week trying to get somebody, and it was just hours and hours of phone calls," Sapia said, only to eventually receive conflicting information.

Brooks and Penelope are among the millions of Americans who have recently faced losing their coverage as states have started to review eligibility for the first time since 2020.

During the COVID-19 pandemic, the federal government prohibited states from kicking people off Medicaid because of a "continuous coverage requirement" linked to the federal health emergency. But that requirement ended March 31, allowing states to once again start cutting Medicaid rolls.

Both Brooks and Gillian Sapia turned to legal aid organizations for help.

Across the country, nonprofit legal groups are working to raise awareness about the changes, help people appeal coverage terminations and educate beneficiaries about their rights.

Attorneys report that as states undertake the massive review, beneficiaries are experiencing confusion, difficulty getting answers and processing errors.

"This is a very complex process that states have to implement," said Cassidy Estes-Rogers, an attorney and program director with the Charlotte Center for Legal Advocacy, the North Carolina organization Brooks went to for guidance. As renewal paperwork has started to go out, "at the beginning of the month, we see a huge volume of calls with just absolutely confused people."

Medicaid rolls skyrocketed during the pandemic, with nationwide enrollment growing by 21.2 million people, a 30% increase, from February 2020 to December 2022, according to the health policy nonprofit KFF.

During the public health emergency, Medicaid recipients did not need to renew their eligibility. And many newer enrollees are not familiar with the renewal process, Estes-Rogers said. People generally need to renew coverage yearly and may have to fill out forms with information about their income and other criteria.

Brooks became eligible for Medicaid during the public health emergency. But when his eligibility was recently reviewed, he learned that his monthly Social Security disability income put him \$12 over the income limit.

"I was ... astonished," Brooks said.

Under a Medicaid expansion law that was approved in North Carolina earlier this year, but [has yet to take effect](#), Brooks would be eligible to remain covered. In the meantime, however, Brooks said the Charlotte Center for Legal Advocacy has been helping him navigate the system and look for alternative coverage.

States are approaching the Medicaid redeterminations differently, with varying timelines and processes.

In Florida, the state has said it will delay determinations for vulnerable groups — such as those under age 21 diagnosed with medically complex conditions — until the end of the review process.

Despite that, "we're hearing from parents of children with very complex, serious medical conditions — the kinds of conditions that cannot go a day without coverage," said Miriam Hartz, advocacy director and founder of the Florida Health Justice Project.

Florida resident Sapia said Penelope's medical needs include anti-seizure medications, regular lab work, and occupational and speech therapy. When her Medicaid was terminated, Penelope was undergoing assessment for new seizure activity and kidney dysfunction.

Sapia, a nurse who is now Penelope's full-time caregiver, said she is very organized about her daughter's care and knew about the redetermination process months ago. Despite her best efforts, however, Sapia said she never got notice from the state that Penelope's coverage was being terminated.

After attorneys with the Florida Health Justice Project got involved with her case, she said she received a call informing her that Penelope's coverage was back in place. But in the three weeks her daughter went without coverage, Sapia said she paid roughly \$2,000 in medical expenses out of her own pocket.

Sapia said she never received a straight answer from the state about why her daughter's coverage initially ended.

"They danced around it," she said.

Mallory McManus, deputy chief of staff for the Florida Department of Children and Families told Law360 the agency could not comment on a specific case, but that recipients are notified of ineligibility either through email or mail, depending on how they have chosen to be contacted.

McManus said "safeguards are in place" during the appeals process if someone believes their coverage was terminated in error.

"Coverage is reinstated during this review if the hearing is requested before coverage ends, or retroactively applied if the appeal concludes with a reinstatement of benefits," the deputy chief said, adding that some children with medically complex conditions are having their eligibility reviewed now if "a parent initiated a review early."

While most states are planning to take at least a year with what's known as the Medicaid unwinding, Arkansas lawmakers in 2021 decided the state would complete the process within six months. The state started sending renewal letters in February, and so far, more than 110,000 people have lost their coverage, according to state data.

"The beginning of March, we were already inundated with calls," said attorney Trevor Hawkins, leader of the economic justice workgroup at Legal Aid of Arkansas.

By the time someone contacts Legal Aid, he said they are often "frantic or about to give up."

"We really have to hit the ground running as soon as we talk to someone," Hawkins said, adding that people have had their coverage ended without receiving notice.

Conflicting information is a big issue in the process, said Trevor Townsend, a managing attorney in the public benefits section at the Center for Arkansas Legal Services. He pointed to one client who reported receiving two Medicaid coverage notices within a week, each with different income findings for the family.

Arkansas has among the nation's highest rates of "procedural terminations" — where someone is cut from Medicaid for something like not returning a form — with more than 80% of disenrollments being procedural.

"Some of those folks may have made the decision not to return the [paperwork] just because they knew that they weren't eligible, but I suspect a large portion of those just got tripped up in this process," Townsend said.

Nationally, more than 70% of terminations are for procedural reasons, according to KFF. That has raised alarms among federal officials.

In a letter to governors last month, [U.S. Department of Health and Human Services Secretary Xavier Becerra](#) wrote he was "deeply concerned with the number of people unnecessarily losing coverage, especially those who appear to have lost coverage for avoidable reasons that state Medicaid offices have the power to prevent or mitigate."

A spokesman for the Arkansas Department of Human Services said many people "simply will not return their packet because they are aware that they no longer qualify because of their change in circumstances."

"A closure for procedural reasons does not mean that the packet was not received or that the beneficiary was unaware of this need to renew," said spokesman Gavin Lesnick. "Extensive efforts have been made — and are continuing to be made — to ensure that Medicaid recipients know what to expect."

The state mails renewal notices 90 or 120 days before they are due, depending on the coverage type, as well as reminder notices about 45 days before renewals are due, he said. The state also issues text messages and emails when notices go out.

Lesnick said that whenever possible, "eligible beneficiaries have their coverage renewed through an automated process" rather than requiring them to submit new information. He added that the state prepared for the end of the public health emergency for more than a year, including running a campaign to ensure people's contact information was updated.

Legal Groups Work To Spread Word, Keep Eyes on States

Around the nation, legal organizations are working to connect people with help through social media, advertising and community outreach efforts. [Maryland Legal Aid](#), for instance, started a series of social media posts called "Medicaid Mondays," said Jennifer Lavella, the organization's director of marketing and communications. It also ran an advertising campaign on Facebook and [Instagram](#) that reached at least 30,000 people.

Groups are also monitoring states' compliance with legal requirements and providing feedback to Medicaid agencies.

Legal Aid Services of Oklahoma has worked to keep the lines of communication open with the state Medicaid director, said staff attorney Dianna Berry. About 300,000 Oklahomans are expected to lose their coverage during the unwinding.

"We're monitoring everything that the state is doing because we know that this is going to have a significant impact on a lot of individuals, and we want to try to minimize that," and ensure that people who are still eligible remain covered, Berry said.

It's vital for people to understand their rights in the process, said Majesta-Doré Legnini, an Equal Justice Works health justice fellow with the [Legal Aid Justice Center](#) in Charlottesville, Virginia.

Legnini has a medical-legal partnership with [VCU Health System](#)'s emergency department in which she counsels patients on legal issues. She's encountered many people who mistakenly believe that they're automatically losing their coverage.

"It's really important that people know that they are not without options when dealing with Medicaid," Legnini said.

Sapia said she felt "like a horrible mom" when her daughter lost coverage. Before the Florida Health Justice Project attorneys looked at the case, she thought she must have made some kind of mistake.

The relief Sapia felt when she got the legal help she needed, she said, was almost beyond words.

"I can't even describe how grateful I felt," Sapia said.

--Editing by Lakshna Mehta.