The Trump Administration Cracked Down on Medicaid. Kids Lost Insurance.

Weeks before 4-year-old Paul Petersen's surgery to close a hole in his stomach, he lost coverage. The administration's latest enforcement of the Affordable Care Act burdened many Idaho Medicaid recipients, as a million kids nationwide lost coverage.

by Lexi Churchill, Oct. 31, 2019, 5:09 p.m. EDT

ProPublica is a nonprofit newsroom that investigates abuses of power. Sign up for ProPublica's <u>Big Story</u> newsletter to receive stories like this one in your inbox as soon as they are published.

In early August, Elizabeth Petersen was home-schooling her children in the kitchen of their northern Idaho home when she got a call from Providence Sacred Heart Medical Center, where her 4-year-old son, Paul, was set to have surgery a few weeks later.

Since having a stroke around his first birthday, Paul had been under treatment to restore use of the right side of his body. He had recently graduated from a feeding tube and needed surgery to close a hole in his stomach.

The hospital's surgery department reached out to alert the family that Paul was no longer covered by Medicaid. Petersen broke down in tears, knowing she could not afford the surgery without the government health insurance.

"I was shocked to hear it," Petersen said.

Petersen's anxiety grew after she called the state Medicaid agency to find out why Paul was abruptly cut from coverage before her son was due for his reevaluation. The agency employee insisted Petersen had failed to meet an annual deadline for reporting detailed financial information — which Petersen contends she knew nothing about.

Families like the Petersens are wrestling with administrative burdens that are one reason more than <u>1 million children across the country</u> are no longer covered by Medicaid and the Children's Health Insurance Program, two government-run programs for low-income children. It is the <u>first</u> enrollment decline in a decade.

States across the country have implemented updated paperwork requirements, but Idaho is the first to attribute its new administrative

burdens to direct instructions from the Centers for Medicare and Medicaid Services under the Trump administration.

CMS said in a statement it determined Idaho was not complying with verification rules established under the Obama administration's Affordable Care Act. "CMS provided Idaho technical assistance on the issue, and the state plans to revise their process." the statement said.

CMS has promoted safeguards to help catch improper payments to ineligible recipients. In Idaho, this meant a major change to procedures that it established in the Obama years. Idaho led the nation in allowing Medicaid recipients to renew coverage automatically, without requiring additional documentation, but CMS has deemed some of the state's procedures inadequate.

Idaho's changed requirements have ensnared in red tape many recipients who have no income or are self-employed. They have also pulled in some residents who receive Katie Beckett coverage, a type of Medicaid for families that have special-needs children but that have too high an income to qualify for traditional Medicaid. Parents were accustomed to reevaluating their child's diagnosis every three years to keep Katie Beckett coverage, but their annual financial information was usually reviewed by the state internally.



Paul Petersen was cut from Katie Beckett coverage in Idaho weeks before a surgery to close a hole in his stomach. His family spent weeks trying to get his coverage back before he was able to undergo the procedure. (Courtesy of Elizabeth Petersen)

As of January 2019, Idaho's Katie Beckett program covers about 2700 children, who are among the nation's most vulnerable, with complex medical needs or long-term disabilities. They typically need more costly care and more frequent treatment than the average child on Medicaid.

ProPublica spoke with six Katie Beckett families in Idaho that lost coverage and interviewed providers, advocates and Department of Health and Welfare employees who worked with a few dozen additional recipients. Some Katie Beckett families waited weeks before their coverage was restored, leaving parents to gamble their finances and their children's health. In severe cases like Petersen's, she skipped her son's routine therapy sessions and pushed back his surgery several weeks until the department restored Katie Beckett coverage.

The Affordable Care Act, the Obama administration's landmark health care policy overhaul, required states to modernize eligibility procedures, and state Medicaid agencies began developing IT systems that could automatically verify recipients' income. New technology allowed states to avoid asking recipients for new annual paperwork by comparing their reported incomes with state and federal income data.

If the eligibility system found contradictions, the state could then ask for more information. When the data confirmed that recipients' income fell below the cut off, the systems could automatically renew their coverage without paperwork hassles. This is also called an "ex parte" renewal.

Jennifer Wagner, a senior policy analyst at the Center on Budget and Policy Priorities in Washington, said the shift to verifying income electronically removes many bureaucratic hoops that can penalize qualified recipients unfairly if "they didn't receive a document, they didn't send in the right information or the state is overwhelmed and failed to process that renewal timely."

Wagner, who tracks Medicaid eligibility policies and procedures, considered Idaho as the gold standard of streamlined renewals. The state approved at least three of every four recipients without requiring updated documentation in the last few years, according to the Kaiser Family Foundation's annual 50-state surveys.

Idaho's long-standing procedures were questioned after a CMS audit flagged possible payment errors that, if not corrected, could imperil federal funding. After further review, CMS instructed the state for the first time to change its automatic renewal process that looked for discrepancies. The federal agency said the state needed additional documentation.

"CMS said, no, that is not right," said Lori Wolff, Idaho's deputy director of health, welfare and family services. "What you have to do is go check those interfaces and prove that what those interfaces have matched the information that the client has told you."

The Division of Welfare's administrator, Julie Hammon, created a list of Medicaid recipients in different financial circumstances, some of whom would now likely be required to go through the manual renewal process as a result of the change. This included those who report having no income

and those who are self-employed, circumstances that could not be verified through available databases.

"Anytime some people have to complete a reevaluation instead of being auto reviewed, I worry about the impact, and I did share that with CMS," Hammon said.

Another Idaho resident affected by the abrupt change was Casey McNabb, who walked out of her son's biweekly occupational and speech therapy appointments at Synergy Healthcare in northern Idaho as a front desk worker was taping a sign to the check-in window. The notice urged families with Katie Beckett coverage to call the state health and welfare agency to verify coverage.

McNabb wasn't expecting a medical reevaluation for another year. Her 5-year-old son, Trayden, who has autism, had been approved for Katie Beckett coverage two years earlier after a lengthy application process that included financial information and medical evaluation.

Once approved, the health agency said Trayden's diagnosis would need reevaluation every three years. Until then, McNabb only received a notice asking if her family's financial circumstances had changed. If not, the notice said there was no need to return the form.

When McNabb called the agency, she was told she, too, had been dropped for failing to return financial paperwork. McNabb appealed to department officials, saying that it wasn't time for her son's reevaluation and that she didn't receive any updated notices.

"I am having to fight for something I shouldn't have to fight for and something I'm clearly already qualified for," McNabb said.

Many parents learned from their child's medical provider that they had been dropped from coverage. Others received a final notice informing them they'd been dropped, though they said they never received the initial paperwork.

Many who did receive notices were confused, since the new forms did not clearly explain the changed requirements.

Even advocates who help families navigate Idaho's complex health care system, like leaders in a Boise-based organization called Idaho Parents Unlimited, struggled to make this distinction. Two parents who work for the group lost their own Katie Beckett coverage.

State administrators did not flag the procedural change to their own staff members who work directly with Medicaid recipients, according to three department staff members. Case managers could only instruct clients to check with "Self Reliance," the agency department that handles eligibility for Idaho's public programs.

Hammon said she saw no need to inform department employees who work directly with recipients.

"Our staff out in the field don't have a need to know why somebody has to do a manual reevaluation," Hammon said. "Our system automatically determines that and sends the notices out. We don't make them worry about things like this. They just do their job."

Parents grew frustrated with unclear agency answers and turned to outside advocates. Liz Woodruff, the assistant director of Idaho Voices for Children, a statewide organization that advocates for families, was already tracking the decline in Idaho's Medicaid enrollment when she learned about the Katie Beckett complications. The uptick in calls was unusual for the organization, which usually has to reach out to community members.

"There was a real sense of frustration that something had changed in the process that they had become so expert in, that they had not been aware of it and the consequences could be so severe for them," Woodruff explained.

Idaho's Katie Beckett challenges illustrate one small example of how administrative burdens can keep eligible recipients from coverage. New paperwork requirements are only one factor driving more extentensive enrollment declines within the state and nationwide.

About 8% of Idaho's Medicaid and CHIP population, mostly children, has disappeared from the state-run programs since the decline began in December of 2017.

Many state and federal administrators chalked up the trend to an improved economy, which may have helped boost residents' income so they no longer qualified for Medicaid or led them to jobs with private insurance.

However, the latest census insurance data released in September made clear that a healthier economy was not a blanket reason for declines. As the number of recipients enrolled in Medicaid and CHIP dipped, the number of uninsured residents rose. Meanwhile, those with private insurance coverage remained virtually the same.

Advocates have pointed to a number of Trump administration policies that have driven former recipients away from Medicaid and CHIP. One of the most commonly discussed proposals is the "public charge" rule, which would count immigrants' reliance on public programs against them if they apply for a green card.

State-driven processes have also contributed. Minnesota's Medicaid agency recently sent recipients a new form asking for permission to verify their assets, giving them a few weeks to respond before coverage was suspended. The majority of the 70,000 recipients who lost coverage in

Missouri in 2018 were removed after <u>failing to return the mailed renewal</u> form.

The Affordable Care Act instructs states to officially renew recipients once a year unless there is a change in circumstances. Under the Trump administration, CMS has encouraged Medicaid agencies to look for those changes more frequently.

Tricia Brooks, a research professor at Georgetown University's Center for Children and Families, has tracked children's enrollment and eligibility policies for a decade. After working with CMS under both the Obama and Trump administrations, Brooks sees shifting priorities.

"It comes down to the philosophical approach," Brooks said. "With the ACA, we really were wanting to embrace coverage for everyone and to find a way to fit them into the options that match their circumstances, but still with the goal of reducing the number of uninsured eligible people. I don't know that we have that goal any longer."

Regaining Katie Beckett coverage after disqualification depended on each families' circumstances, according to Wolff.

Some recipients were reinstated the same day they provided the requested financial information. Others had to completely reapply, forcing families to wait up to a month without coverage.

Petersen was an unlucky one. She reached out to the state agency the day after her coverage was cut off. Petersen spoke with an agency employee who insisted she reapply, starting with submitting her updated financial information then later reevaluating Paul's diagnosis.

Petersen panicked. She didn't know how long it would take to regain insurance, if she did at all. She canceled Paul's surgery, hoping he would have no complications.

"I was worried about the long term, not being able to get him on insurance again and not being able to pay for his weekly therapy," Petersen said.

Over the next three weeks, Petersen called Paul's therapy provider every Monday to see if coverage had been restored. Each time there was bad news. She canceled Paul's speech, occupational and physical therapy sessions during those weeks to save money.

"Without these medications, without those therapeutic services, without being able to see specialists that sometimes are booked up for months, that can result in major lapses in children's progress towards having that higher quality of life that is so important," Woodruff said.

Petersen was finally informed she had regained coverage and was able to reschedule Paul's surgery for early September. The procedure was

successful.

Meanwhile, the Department of Health and Welfare appealed to CMS to reconsider its new requirements after Woodruff, with help from the governor's office and a state senator, made the case.

CMS officials took another look at the list of those affected by the change and told Idaho officials if it was "reasonable" to believe income remained the same, they could still be automatically renewed.

"Well, what's reasonable?" Hammon said. "That was difficult for them to clearly define."

Early this month, Idaho shifted the eligibility system from checking parental income to the child's income, which should allow a higher percentage of families to be renewed without sending in additional paperwork.

For the remaining recipients affected by the change, often the state's poorest residents who report having no income and the self-employed, CMS does not yet see any reasonable way to confirm their eligibility without requiring additional paperwork.

Hannah Fresques contributed to this report.

Filed under: Trump Administration, Health Care

Protect Independent Journalism

ProPublica is a nonprofit newsroom that produces nonpartisan, evidence-based journalism to expose injustice, corruption and wrongdoing. We were founded ten years ago to fill a growing hole in journalism: newsrooms were (and still are) shrinking, and legacy funding models failing. Deep-dive reporting like ours is slow and expensive, and investigative journalism is a luxury in many newsrooms today — but it remains as critical as ever to democracy and our civic life. A decade (and five Pulitzer Prizes) later, ProPublica has built the largest investigative newsroom in the country. Our work has spurred reform through legislation, at the voting booth, and inside our nation's most important institutions.

This story you've just finished was funded by our readers and we hope it inspires you to make a gift to ProPublica so that we can publish more investigations like this one that holds people in power to account and produces real change.

Your donation will help us ensure that we can continue this critical work. From the Trump Administration, criminal justice, health care, immigration and so much more, we are busier than ever covering

stories you won't see anywhere else. Make your gift of any amount today and join the tens of thousands of ProPublicans across the country, standing up for the power of independent journalism to produce real, lasting change. Thank you.

DONATE NOW

Lexi Churchill

Lexi Churchill is a Scripps Howard research reporting fellow at ProPublica.