Medicaid Unwinding Decried as Biased Against Disabled People

People are losing benefits with little or no notice and facing major disruptions in care.

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Jacqueline Saa has a genetic condition that leaves her unable to stand and walk on her own or hold a job. Every weekday for four years, Saa, 43, has relied on a home health aide to help her cook, bathe and dress, go to the doctor, pick up medications, and accomplish other daily tasks.

She received coverage through Florida's Medicaid program until it abruptly stopped at the end of March, she said.

"Every day the anxiety builds," said Saa, who lost her home health aide for 11 days, starting April 1, despite being eligible. The state has since restored Saa's home health aide service, but during the gap she leaned on her mother and her 23- and 15-year-old daughters, while struggling to regain her Medicaid benefits.

"It's just so much to worry about," she said. "This is a health care system that's supposed to help."

Medicaid's home and community-based services are designed to help people like Saa, who have disabilities and need help with everyday activities, stay out of a nursing facility. But people are losing benefits with little or no notice, getting bad advice when they call for information, and facing major disruptions in care while they wait for the issue to get sorted out, according to attorneys and advocates who are hearing from patients.

In Colorado, Texas, and Washington, D.C., the National Health Law Program, a nonprofit that advocates for low-income and underserved people, has filed civil rights complaints with two federal agencies alleging discrimination against people with disabilities. The group has not filed a lawsuit in Florida, though its attorneys say they've heard of many of the same problems there.

Attorneys nationwide say the special needs of disabled people were not prioritized as states began to review eligibility for Medicaid enrollees after a pandemic-era mandate for coverage expired in March 2023.

"Instead of monitoring and ensuring that people with disabilities could make their way through the process, they sort of treated them like everyone else with Medicaid," said Elizabeth Edwards, a

senior attorney for the National Health Law Program. Federal law puts an “obligation on states to make sure people with disabilities don’t get missed.”

At least 21 million people nationwide have been disenrolled from Medicaid since states began eligibility redeterminations in spring 2023, according to a KFF analysis.

The unwinding, as it’s known, is an immense undertaking, Edwards said, and some states did not take extra steps to set up a special telephone line for those with disabilities, for example, so people could renew their coverage or contact a case manager.

As states prepared for the unwinding, the Centers for Medicare & Medicaid Services, the federal agency that regulates Medicaid, advised states that they must give people with disabilities the help they need to benefit from the program, including specialized communications for people who are deaf or blind.

The Florida Department of Children and Families, which verifies eligibility for the state’s Medicaid program, has a specialized team that processes applications for home health services, said Mallory McManus, the department’s communications director.

People with disabilities disenrolled from Medicaid services were “properly noticed and either did not respond timely or no longer met financial eligibility requirements,” McManus said, noting that people “would have been contacted by us up to 13 times via phone, mail, email, and text before processing their disenrollment.”

Allison Pellegrin of Ormond Beach, Florida, who lives with her sister Rhea Whitaker, who is blind and cognitively disabled, said that never happened for her family.

“They just cut off the benefits without a call, without a letter or anything stating that the benefits would be terminating,” Pellegrin said. Her sister’s home health aide, whom she had used every day for nearly eight years, stopped service for 12 days. “If I’m getting everything else in the mail,” she said, “it seems weird that after 13 times I wouldn’t have received one of them.”

Pellegrin, 58, a sales manager who gets health insurance through her employer, took time off from work to care for Whitaker, 56, who was disabled by a severe brain injury in 2006.

Medicaid reviews have been complicated, in part, by the fact that eligibility works differently for home health services than for general coverage, based on federal regulations that give states more flexibility to determine financial eligibility. Income limits for home health services are higher, for instance, and assets are counted differently.

In Texas, a parent in a household of three would be limited to earning no more than $344 a month to qualify for Medicaid. And most adults with a disability can qualify without a dependent child and be eligible for Medicaid home health services with an income of up to $2,800 a month.

The state was not taking that into consideration, said Terry Anstee, a supervising attorney for community integration at Disability Rights Texas, a nonprofit advocacy group.

Even a brief lapse in Medicaid home health services can fracture relationships that took years to build.

“It may be very difficult for that person who lost that attendant to find another attendant,” Anstee said, because of workforce shortages for attendants and nurses and high demand.

Nearly all states have a waiting list for home health services. About 700,000 people were on waiting lists in 2023, most of them with intellectual and developmental disabilities, according to KFF data.

Daniel Tsai, a deputy administrator at CMS, said the agency is committed to ensuring that people with disabilities receiving home health services “can renew their Medicaid coverage with as little red tape as possible.”

CMS finalized a rule this year for states to monitor Medicaid home health services. For example, CMS will now track how long it takes for people who need home health care to receive the services and will require states to track how long people are on waitlists.

Staff turnover and vacancies at local Medicaid agencies have contributed to backlogs, according to complaints filed with two federal agencies focused on civil rights.

The District of Columbia’s Medicaid agency requires that case managers help people with disabilities complete renewals. However, a complaint says, case managers are the only ones who can help enrollees complete eligibility reviews and, sometimes, they don’t do their jobs.

Advocates for Medicaid enrollees have also complained to the Federal Trade Commission about faulty eligibility systems developed by Deloitte, a global consulting firm that contracts with about two dozen states to design, implement, or operate automated benefits systems.

KFF Health News found that multiple audits of Colorado’s eligibility system, managed by Deloitte, uncovered errors in notices sent to enrollees. A 2023 review by the Colorado Office of the State Auditor found that 90% of sampled notices contained problems, some of which violate the state’s Medicaid rules. The audit blamed “flaws in system design” for populating notices with incorrect dates.

Deloitte declined to comment on specific state issues.

In March, Colorado officials paused disenrollment for people on Medicaid who received home health services, which includes people with disabilities, after a “system update” led to wrongful terminations in February.

Another common problem is people being told to reapply, which immediately cuts off their benefits, instead of appealing the cancellation, which would ensure their coverage while the claim is investigated, said attorney Miriam Harmatz, founder of the Florida Health Justice Project.

“What they’re being advised to do is not appropriate. The best way to protect their legal rights,” Harmatz said, “is to file an appeal.”

But some disabled people are worried about having to repay the cost of their care.

Saa, who lives in Davie, Florida, received a letter shortly before her benefits were cut that said she “may be responsible to repay any benefits” if she lost her appeal.

The state should presume such people are still eligible and preserve their coverage, Harmatz said, because income and assets for most beneficiaries are not going to increase significantly and their conditions are not likely to improve.

The Florida Department of Children and Families would not say how many people with disabilities had lost Medicaid home health services.

But in Miami-Dade, Florida’s most populous county, the Alliance for Aging, a nonprofit that helps older and disabled people apply for Medicaid, saw requests for help jump from 58 in March to 146 in April, said Lisa Mele, the organization’s director of its Aging and Disability Resources Center.

“So many people are calling us,” she said.

States are not tracking the numbers, so “the impact is not clear,” Edwards said. “It’s a really complicated struggle.”

Saa filed an appeal March 29 after learning from her social worker that her benefits would expire at the end of the month. She went to the agency but couldn’t stand in a line that was 100 people deep. Calls to the state’s Medicaid eligibility review agency were fruitless, she said.

“When they finally connected me to a customer service representative, she was literally just reading the same explanation letter that I’ve read,” Saa said. “I did everything in my power.”

Saa canceled her home health aide. She lives on limited Social Security disability income and said she could not afford to pay for the care.

On April 10, she received a letter from the state saying her Medicaid had been reinstated, but she later learned that her plan did not cover home health care.

The following day, Saa said, advocates put her in touch with a point person at Florida’s Medicaid agency who restored her benefits. A home health aide showed up April 12. Saa said she’s thankful but feels anxious about the future.

“The toughest part of that period is knowing that that can happen at any time,” she said, “and not because of anything I did wrong.”

Have you or someone you know with disabilities unexpectedly lost Medicaid benefits since April 2023? Tell KFF Health News about it here.

KFF Health News correspondents Samantha Liss and Rachana Pradhan contributed to this report.

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