

Trump's Cuts to Medicaid Threaten Services That Help Disabled People Live at Home

Disability rights advocates expect the pressure to intensify as states respond to reductions in federal Medicaid funding.

March 5, 2026 By Tony Leys and KFF Health News

OTTUMWA, Iowa — Leisa and Kent Walker recently received a disturbing notice: The private company managing their son's Medicaid coverage intends to cut nearly 40% of what it spends for caregivers who help him live at home instead of in a nursing home.

Sam Walker, 35, has severe autism and other disabilities. He is deaf and cannot speak. Sometimes when he's frustrated, he hits himself or others.

Medicaid provides about \$8,500 a month for health workers who visit his apartment in the basement of his parents' home. The staffers help him with everyday tasks, including dressing, bathing, and eating. They also take Walker on outings, such as dining at restaurants, volunteering at Goodwill, and exercising at a recreation center or on park trails. They stick to a strict routine, which soothes him.

His parents say that without the in-home services, their son would need to move to a specialized residential facility in another state. Sending him away would break their hearts and cost taxpayers much more money. They strive to keep him home because they know change makes him anxious.

"The last thing I want is to put him into some kind of care facility, where he'll just get kicked out," said his mother, Leisa. The Iowa Department of Health and Human Services did not respond to KFF Health News' questions about the Walkers' case.

Federal Cuts Raise Pressure

Patient advocates say state administrators in Iowa appear to be reining in Medicaid spending by cutting what are known as home and community-based services for people with disabilities, and they've heard of multiple families facing battles like the Walkers'.

Disability rights advocates expect the pressure to intensify as states respond to reductions in

federal Medicaid funding called for under the Trump administration's signature tax and spending law, which passed last year.

June Klein-Bacon, CEO of the Brain Injury Association of Iowa, said the cuts and proposed rule changes appear to be part of a quiet attempt to save money in response to the state's budget deficit and expected reductions in federal Medicaid funding.

Medicaid, jointly financed by the federal and state governments, covers people with low incomes or disabilities. Walker is one of [nearly 2 million people](#) served by "Medicaid waiver" programs, which pay for care that allows people with disabilities or who are at least 65 to live at home.

Unlike most parts of Medicaid, waiver programs are optional for states. Idaho's governor noted that fact in January, when he suggested legislators consider cutting them. Disability rights groups fear other states will do the same. Leaders in [Colorado](#), [Missouri](#), and [Nebraska](#) have considered such cuts this year.

Leisa Walker has heard Trump administration officials claim the national Medicaid cuts are intended to reduce waste, fraud, and abuse. That's not how it will play out, she said. "These are real people, real families, and this causes real suffering when you do this to people," she said. "It's a very scary time."

[Iowa Total Care](#), a private insurance company that manages Sam Walker's Medicaid benefits, intends to cut his in-home care coverage by about \$3,200 per month, his mother said. Company leaders told a judge they are following state officials' direction, but they did not dispute Leisa Walker's math.

Walker has been on the waiver program for three decades. It covers assistance from workers known as "direct service providers" — one of whom has been with him for 25 years. His parents receive no pay for the hours they spend caring for him when the aides aren't working.

On a February morning, Leisa and Kent Walker drove an hour and a half to Des Moines for an appeal hearing. An administrative law judge sat behind a wooden desk in a conference room as the Walkers and their lawyer faced off against three representatives from Iowa Total Care, a subsidiary of the national insurer Centene Corp.

Leisa testified that her son is 6 feet tall and weighs 230 pounds. Although he knows some sign language, he has trouble communicating, she said. When he becomes frustrated or his routine is interrupted, he sometimes wails and hits himself or other people. "It's devastating to watch," she testified.

He's not a bad person, she said. "He doesn't understand how strong he is."

She said her family would try to keep his main caregiver employed under the planned Medicaid reduction but would have to drop others who cover nights and weekends. She said no residential facility near their southern Iowa home could address her son's complicated needs. She said a case

manager told her that a Florida facility might be the closest one that could safely handle him.

Leisa Walker testified that the state's Medicaid program would pay about \$22,000 per month to put him in an institution, more than double what the program spends on his home care.

Sam Walker's longtime psychiatrist, Christopher Okiishi, testified that Walker's family and their support staff spent years developing a "fragile" but stable existence for him.

Lori Palm, a senior manager for Iowa Total Care, testified that Sam Walker gets about 16 hours of daily assistance financed by Medicaid. Palm said much of that time amounts to "supervision." She said state officials recently advised her company that the program should pay mainly for "skill-building" time, not supervision.

The Walkers showed the judge a 2018 document in which a previous Iowa Medicaid director stipulated that supervision of people with disabilities is an allowable service for workers paid under the program.

Judge Rachel Morgan asked the Iowa Total Care representatives if the recent policy change was made in writing by the state Department of Health and Human Services. They said it was not and that they couldn't specify who at the department had given them the new guidance.

The judge suggested during the hearing that for someone like Sam Walker, learning to regulate emotions could be an important form of skill-building. Three days later, the judge ruled in the Walkers' favor, writing that the insurer's attempt to cut care hours was improper. The insurer appealed the decision to the director of the Iowa Department of Health Human Services, who could overrule it. The dispute could eventually wind up in district court.

Iowa Total Care and the state Department of Health and Human Services did not respond to questions about the reports that many other Iowans with disabilities face reductions in care hours covered by Medicaid. Department spokesperson Danielle Sample said in an email that the agency supports home and community-based services, which, she noted, help "states save money by avoiding expensive long-term facility care."

Spokespeople for the federal Department of Health and Human Services, which oversees Medicaid nationally, did not respond to a request for comment on the issue.

Medicaid waiver programs started in the 1980s, after President Ronald Reagan heard about an Iowa girl with a disability who was forced to live in a hospital for months because Medicaid wouldn't pay for home care. The Republican president thought it was outrageous that the girl, [Katie Beckett](#), had to live that way, even though home care would have been cheaper.

Members of Congress approved allowing states to use their Medicaid programs to pay for in-home care. But they made the change optional, to offer states flexibility and encourage innovation.

Designating such spending as optional "waiver programs" also made the change more politically palatable, said Kim Musheno, senior director of Medicaid policy for [The Arc of the United States](#),

which represents people with intellectual and developmental disabilities.

Prospects were much different for babies born with serious disabilities before the change, Musheno said. “Doctors instructed families to forget they existed, and to put them in an institution.”

Waivers Have Been Cut Before

All states have Medicaid waiver programs, but benefits and the number of people covered vary significantly. Applicants often wait months or years to get into the programs because of limited funding. More than 600,000 Americans were on waiting lists or “interest lists” for waiver services in 2025, [according to KFF](#), a health information nonprofit that includes KFF Health News.

Disability rights advocates and care providers have fought for decades to maintain funding for the programs, but a national leader said the threat feels especially severe now.

“When Medicaid is cut, people with disabilities are at the center of the impact,” said Barbara Merrill, CEO of the American Network of Community Outcomes and Resources, which represents agencies that care for people with intellectual disabilities or autism.

That’s what happened after Congress reduced Medicaid funding in 2011, according to a recent paper published by [Health Affairs](#).

States could again rein in waiver programs by limiting enrollment, reducing covered services, or cutting pay for caregivers, who already are in short supply.

However, states that try to cut the in-home care programs could face legal challenges, Musheno said. The U.S. Supreme Court declared in 1999 that people with disabilities have a right to live outside of institutions if possible. The decision, in the case of [Olmstead v. L.C.](#), has been cited in lawsuits against states that fail to provide care options apart from nursing homes and similar facilities.

Several Iowans who belong to a Facebook group for Medicaid participants have posted in recent weeks that their families were notified of impending cuts in coverage of home care services for people with disabilities.

Sam Walker’s main caregiver, Andy Koettel, has worked with him since Walker was in fourth grade. Koettel, who works full-time, knows how to keep Walker calm in most situations and soothe him during a blowup. Their relationship took years to build, and it is a key reason Walker can continue to live at home with his parents, Koettel said.

“If I was not there, it would be incredibly difficult for all of them,” he said.

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