Many People With Disabilities Risk Losing Their Medicaid if They Work Too Much

Disability rights advocates say income and asset caps for Medicaid buy-in programs can prevent participants from working full time or accepting promotions.

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Zach Mecham has heard politicians demand that Medicaid recipients work or lose their benefits. He also has run into a jumble of Medicaid rules that effectively prevent many people with disabilities from holding full-time jobs.

“Which is it? Do you want us to work or not?” he said.

Mecham, 31, relies on the public insurance program to pay for services that help him live on his own despite a disability caused by muscular dystrophy. He uses a wheelchair to get around and a portable ventilator to breathe.

A paid assistant stays with Mecham at night. Then a home health aide comes in the morning to help him get out of bed, go to the bathroom, shower, and get dressed for work at his online marketing business. Without the assistance, he would have to shutter his company and move into a nursing home, he said.

Private health insurance plans generally do not cover such support services, so he relies on Medicaid, which is jointly financed by federal and state governments and covers millions of Americans who have low incomes or disabilities.

Like most other states, Iowa has a Medicaid “buy-in program,” which allows people with disabilities to join Medicaid even if their incomes are a bit higher than would typically be permitted. About two-thirds of such programs charge premiums, and most have caps on how much money participants can earn and save.

Some states have raised or eliminated such financial caps for people with disabilities. Mecham has repeatedly traveled to the Iowa Capitol to lobby legislators to follow those states’ lead. The “Work Without Worry” bill would remove income and asset caps and instead require Iowans with disabilities to pay 6% of their incomes as premiums to remain in Medicaid. Those fees would be

waived if participants pay premiums for employer-based health insurance, which would help cover standard medical care.

Disability rights advocates say income and asset caps for Medicaid buy-in programs can prevent participants from working full time or accepting promotions. “It’s a trap — a poverty trap,” said Stephen Lieberman, a policy director for the United Spinal Association, which supports the changes.

Lawmakers in Florida, Hawaii, Indiana, Iowa, Maine, Mississippi, and New Jersey have introduced bills to address the issue this year, according to the National Conference of State Legislatures.

Several other states have raised or eliminated their program’s income and asset caps. Iowa’s proposal is modeled on a Tennessee law passed last year, said Josh Turek, a Democratic state representative from Council Bluffs. Turek, who is promoting the Iowa bill, uses a wheelchair and earned two gold medals as a member of the U.S. Paralympics basketball team.

Proponents say allowing people with disabilities to earn more money and still qualify for Medicaid would help ease persistent worker shortages, including in rural areas where the working-age population is shrinking.

Turek believes now is a good time to seek expanded employment rights for people with disabilities, since Republicans who control the state and federal governments have been touting the value of holding a job. “That’s the trumpet I’ve been blowing,” he said with a smile.

The Iowa Legislature has been moving to require many nondisabled Medicaid recipients to work or to document why they can’t. Opponents say most Medicaid recipients who can work already do so, and the critics say work requirements add red tape that is expensive to administer and could lead Medicaid recipients to lose their coverage over paperwork issues.

Iowa Gov. Kim Reynolds has made Medicaid work requirements a priority this year. “If you can work, you should. It’s common sense and good policy,” the Republican governor told legislators in January in her “Condition of the State Address.” “Getting back to work can be a lifeline to stability and self-sufficiency.”

Her office did not respond to KFF Health News’ queries about whether Reynolds supports eliminating income and asset caps for Iowa’s buy-in program, known as Medicaid for Employed People with Disabilities.

National disability rights activists say income and asset caps on Medicaid buy-in programs discourage couples from marrying or even pressure them to split up if one or both partners have disabilities. That’s because in many states a spouse’s income and assets are counted when determining eligibility.

In Iowa, for example, the monthly net income cap is $3,138 for a single person and $4,259 for a couple.

Iowa's current asset cap for a single person in the Medicaid buy-in plan is $12,000. For a couple, that cap rises only to $13,000. Countable assets include investments, bank accounts, and other things that could be easily converted to cash, but not a primary home, vehicle, or household furnishings.

"You have couples who have been married for decades who have to go through what we call a 'Medicaid divorce,' just to get access to these supports and services that cannot be covered in any other way," said Maria Town, president of the American Association of People with Disabilities.

Town said some states, including Massachusetts, have removed income caps for people with disabilities who want to join Medicaid. She said the cost of adding such people to the program is at least partially offset by the premiums they pay for coverage and the increased taxes they contribute because they are allowed to work more hours. "I don't think it has to be expensive" for the state and federal governments, she said.

Congress has considered a similar proposal to allow people with disabilities to work more hours without losing their Social Security disability benefits, but that bill has not advanced.

Although most states have Medicaid buy-in programs, enrollment is relatively low, said Alice Burns, a Medicaid analyst at KFF, a health information nonprofit that includes KFF Health News.

Fewer than 200,000 people nationwide are covered under the options, Burns said. "Awareness of these programs is really limited," she said, and the income limits and paperwork can dissuade potential participants.

In states that charge premiums for Medicaid buy-in programs, monthly fees can range from $10 to 10% of a person's income, according to a KFF analysis of 2022 data.

The Iowa proposal to remove income and asset caps has drawn bipartisan backing from legislators, including a 20-0 vote of approval from the House Health and Human Services Committee. "This aligns with things both parties are aiming to do," said state Rep. Carter Nordman, a Republican who chaired a subcommittee meeting on the bill. Nordman said he supports the idea but wants to see an official estimate of how much it would cost the state to let more people with disabilities participate in the Medicaid buy-in program.

Mecham, the citizen activist lobbying for the Iowa bill, said he hopes it allows him to expand his online marketing and graphic design business, "Zach of All Trades."

On a recent morning, health aide Courtnie Imler visited Mecham's modest house in Pleasantville, a town of about 1,700 people in an agricultural region of central Iowa. Imler chatted with Mecham while she used a hoist to lift him out of his wheelchair and onto the toilet. Then she cleaned him up, brushed his hair, and helped him put on jeans and a John Deere T-shirt. She poured him a cup of coffee and put a straw in it so he could drink it on his own, swept the kitchen floor, and wiped the counters. After about an hour, she said goodbye.

After getting cleaned up and dressed, Mecham rolled his motorized wheelchair over to his plain wooden desk, fired up his computer, and began working on a social media video for a client promoting a book. He scrolled back and forth through footage of an interview she'd done, so he could pick the best clip to post online. He also shoots video, takes photos, and writes advertising copy.

Mecham loves feeling productive, and he figures he could work at least twice as many hours if not for the risk of losing Medicaid coverage. He said he's allowed to make a bit more money than Iowa Medicaid's standard limit because he signed up for a federal option under which he eventually expects to work his way off Social Security disability payments.

There are several such options for people with disabilities, but they all involve complicated paperwork and frequent reports, he said. "This is such a convoluted system that I have to navigate to build any kind of life for myself," he said. Many people with disabilities are intimidated by the rules, so they don't apply, he said. "If you get it wrong, you lose the health care your life depends on."

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