TuSalud

The Future of Medicaid is “Really Scary” for People With Long COVID

Medicaid is the bare minimum for people with long COVID, but instead of improving it, the Trump administration is making it worse.

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Key points you should know:

- Cuts to Medicaid and the Affordable Care Act in President Trump’s spending bill total almost $1 trillion and will lead to some 10 million people losing their insurance in the next decade.
- The bill will require Medicaid recipients to work in order to maintain their insurance, despite such measures being ineffective and discriminatory.
- Though there are technically exemptions to the work requirements for people with disabilities, patients and advocates worry they will not be applied correctly.
- The bill also increases bureaucratic red tape and confines eligibility, which will result in many losing insurance and access to care. For those with energy-limiting diseases like long COVID, it will be even harder — and more harmful — to keep up.
- Medicaid is the bare minimum for people with long COVID and other complex conditions. But instead of improving it, amid skyrocketing disability claims, the Trump administration is making it worse.

Jessie Boyd, who lives in Michigan, has had long COVID since 2021. For their first year of symptoms, Boyd tried to keep up with their remote administrative job, but after a while was unable to continue.

“I think I pushed myself a little too hard,” they said, explaining that they went straight back to work without adequate recovery time, which can increase the odds of contracting long COVID. Once Boyd left their job, Medicaid was their only health insurance option. Now the health benefits they rely on are at risk.

The deep cuts to Medicaid funding in the Trump administration's spending bill of almost $1 trillion — as well as new requirements making Medicaid more difficult to obtain and maintain — will hit disadvantaged groups hard. Over the next decade, some 7.5 million people are estimated to lose their Medicaid, an insurance program that helps cover medical costs for about 70 million low-income people.

For people like Boyd, Medicaid is the bare minimum of healthcare — but rather than improving care, the cuts instead put their lives and well-being at risk.

Tens of millions of Americans have long COVID, a number we can only expect to grow as people become reinfected multiple times. Long COVID has contributed to a rapid increase in disability rates in the U.S. and is also now the most common chronic condition in children, with an estimated six million affected.

Yet despite this increased need for healthcare, the government is slashing Medicaid.

These cuts add more red tape, which will wind up getting people kicked off the program, often erroneously. Yet adding work requirements to qualify for Medicaid will have the biggest impact. Though people with disabilities are technically exempted from these requirements, in practice, they will add burdensome layers of bureaucracy. As doctors, advocates, and patients shared with The Sick Times, the end result will be that the people who need healthcare most will lose access to it.

Disabled people over 65 who qualify for Medicare and Medicaid might also find their care cut, even though they are at higher risk for developing severe and persistent symptoms after SARS-CoV-2 infections. Medicare patients' access to telehealth is under threat as well, causing further challenges for disabled and older Americans; while this coverage returned with the end of the government shutdown, it was extended only through January 2026.

"This country is not prepared, hasn't been prepared for five years for this massive increase in disabled people," said Dom Kelly, CEO of New Disabled South, an advocacy organization.

Work requirements are ableist and ineffective

Among the most concerning changes to Medicaid, set to go into effect January 1, 2027, is the introduction of national work requirements. Under those requirements, in order to qualify for health insurance, Medicaid recipients will need to prove that they are employed at least 80 hours per month. This can include formal employment, volunteering, or community service.

While the vast majority of Medicaid recipients do work, according to KFF, research has repeatedly shown that these requirements are ineffective and discriminatory.

Technically, the new national requirements would exempt people with disabilities. But there is widespread worry among advocates and patients that these exemptions will not be applied fairly or correctly, and that any barrier to healthcare will have deleterious impacts on disabled

communities, especially those with ignored diseases like long COVID.

It may be difficult for people with long COVID to prove they should be exempt from work requirements, as many do not have an official diagnosis. In addition, for people with more severe symptoms, it may be difficult or impossible to go to a physical Medicaid office — and doing so could expose them to the threat of reinfection. The requirements set up a dynamic that frames some people as deserving of healthcare over others.

The new rules also restrict most immigrants — communities who have been hit hardest by COVID-19 — from qualifying for Medicaid, and penalize states that offer coverage to these groups.

For some people with long COVID, "the Medicaid cuts make an already bad situation much worse. I worry that this will mean that many who rely on this coverage to get basic healthcare will now be living without it," said Ziyad Al-Aly, a clinical epidemiologist at Washington University in St. Louis, in an emailed statement.

"Due to their illness, they may not be able to navigate the bureaucratic red tape. The broader funding cuts threaten access to doctors and therapies long COVID patients need."

Boyd also expressed concern about losing their access to Medicaid due to the work requirements. "It's definitely been really scary for me because I know that I can't work consistently," they said. If the standards of qualifying for state disability are any indication, it could be difficult. That's especially the case with an underfunded, stigmatized disease like long COVID.

"To put such a strict boundary around work discounts how dynamic disability is," said Kelly, of New Disabled South.

Miranda DeNovo agreed. DeNovo is a Medicaid recipient in New York who left her job in 2024, and the founder of the grassroots patient advocacy group Long COVID Safety Net. She explained: "Could I sit at a desk for eight hours for one day? Maybe. Could I do it five days a week forever? Absolutely not. But if they're only looking at one time, it's just not gonna capture that." She also doubted that a Medicaid administrator would understand facets of long COVID like post-exertional malaise.

Accessibility and bureaucracy issues

Overall, Boyd has had a positive experience with Medicaid in Michigan, which they credit to finding a supportive and helpful primary care doctor. Still, Boyd did note they've faced "roadblocks" and other bureaucratic obstacles while on the program.

For example, they said that Medicaid didn't want to pay for a tilt table test, which is used to diagnose dysautonomia, common for people with long COVID; and some doctors who take Medicaid have been hesitant to give them specific diagnoses. They also said they've had to jump through some hoops to get insurance to cover trans healthcare, like hormone replacement therapy.

But rather than streamlining and improving care, the new spending bill may increase these challenges. In addition to work requirements, accessibility issues will increase the burden for people with long COVID and other disabilities to keep their health insurance, DeNovo explained.

It is common for people to get kicked off their healthcare due to access issues, she said. DeNovo described advocating for a friend with severe long COVID who lost her Medicaid coverage because she was a wheelchair user and couldn't physically get to her mailbox to open the letters.

"I am most worried for the people who don't have the resources to navigate the system," DeNovo said.

In addition to having to prove they are too disabled to work, under the new rules, recipients will be required to recertify their eligibility for Medicaid twice a year rather than annually, leading to disruptions in care.

Medicaid is "designed to kick people off," said DeNovo. Without coverage and access to basic preventive care, people will be more likely to wind up having urgent health emergencies and end up in the emergency room, or facing major medical debt.

Keeping up with even more bureaucratic red tape will be especially harmful for those with energy-limiting diseases like long COVID and myalgic encephalomyelitis (ME). As Boyd put it, sometimes they don't feel well enough to stay on top of paperwork. With limited energy, it's difficult to "jump through all these hoops," Boyd said. "I'm in bed. I can't."

People of color and those immigrants who will still be eligible for Medicaid will face additional stigma going up against this bureaucracy, getting diagnosed, and getting the care they need, according to Karla Monterroso, founder of Brava Leaders, a consultancy firm for multiracial and multicultural institutions. In the current climate, there is more fear than ever around interacting with government officials, due to the threat of arrest and deportation.

"There are low-income, low-information people of color who currently have long COVID, so they're exhausted," Monterroso said. And now, "they have to navigate the stress of the state — whether they are citizens or not — coming to get them."

Monterroso also spoke to the health risks that may come with reasserting Medicaid eligibility more often. For those with moderate and severe ME, the energy required to keep up with the red tape, especially when required to physically go to the Medicaid office, could send people into more frequent symptom flares.

Cuts to home care and critical programs endanger people with long COVID

DeNovo and other disability advocates are concerned that Trump's budget bill could also mean less funding for Home and Community Based Services (HCBS), waivers that allow disabled people to hire at-home caregivers rather than being forced into an institution, as I wrote recently in Prism Reports.

DeNovo's fledgling Long COVID Safety Net project and other efforts, such as #MEAction's Minnesota Home Help Navigation Program, seek to assist people with long COVID and ME to access these services. People with severe long COVID need more care, not less, DeNovo said, and that includes assistance with daily living tasks.

But with no healthcare and no income, many people with long COVID are vulnerable to becoming homeless, or worse, she said. Qualifying for state disability payments is such an uphill battle that it often takes multiple denials — not to mention exorbitant lawyers' fees — to get approval, and it's even harder for people with long COVID. This system "systemically consigns people into poverty," said Monterroso.

DeNovo's own experience on Medicaid has been mixed. "In New York City, it's pretty difficult to actually get care on Medicaid if you have any kind of complex medical needs," she said.

Switching from employer-based insurance to Medicaid meant losing access to many of her specialist providers, many of whom do not take Medicaid. In addition, Medicaid plans are health maintenance organization plans (commonly called HMOs), which require a referral from a primary care doctor to see specialists. That can be a major barrier to care for patients with complex medical needs.

Soon, fewer people will be eligible for Medicaid in the first place because the Trump administration's bill targets states that expanded the income cap to qualify for Medicaid under the Affordable Care Act (ACA). For those who make over the income cap, however, switching over to ACA marketplace plans will also be difficult because subsidies that helped people pay for the plans are set to expire at the end of the year. While this expiration was a key issue leading to the government shutdown, it remains unresolved with the government back open. An estimated 5.4 million people are at risk of losing health insurance over the next decade if subsidies are not extended.

"I think people are starting to feel real stress at the grocery store and are going to start making choices between their families' ability to eat and the ability to get insured," said Monterroso, who relies on an ACA plan. Another 2.5 million people are estimated to lose their ACA plans over the next decade under the spending bill's new restrictions.

For families that include people with chronic illnesses like long COVID, accessing healthcare and support "is going to be really tough because they're going to be choosing between two different survival needs," said Monterroso.

It is also unclear what the cuts might mean for those eligible for Medicaid buy-in programs in many states, which allow disabled people who make over the income cap to pay a nominal fee to access Medicaid.

Medicaid funding should be the bare minimum, DeNovo said, but people with long COVID need far more. She underscored that while she wants to "fight for the preservation of Medicaid," she's also had challenges with accessing the care she needs in that system. "Medicaid is the best thing

we've got, but there's a lot of issues with it, too."

Advocacy opportunities:

- With the federal budget bill already passed, you can call on your representatives at the state level not to cut their Medicaid programs and to continue to fund and support Home and Community Based Services.
- Sign this letter advocating for states to preserve their Medicaid programs.
- Mutual aid and community-based organizing are more important than ever. Look to this map for a non-comprehensive list of mutual aid groups across the country, as well as your local mask bloc for ways to plug in.
- Some states are pushing for better healthcare options for all, such as the New York Health Act. Look to organizations like the Physicians for a National Health Program for more information.
- You can support patient advocacy–led options like #MEAction's Minnesota Home Help Navigation Program. DeNovo's Long COVID Safety Net has a list of resources for patients in New York. Other organizations like New York's Center for Independence of the Disabled can also provide assistance.

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