

Strengthening Medicaid

CHALLENGES STATES MUST ADDRESS AS
THE PUBLIC HEALTH EMERGENCY ENDS

MAY 2023



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Medicaid is an essential program that provides health services for millions of people who otherwise could not afford them. Medicaid improves health outcomes for recipients, improves their financial stability, provides access to potentially life-saving healthcare, creates thousands of jobs that bolster our local economies, and helps reduce economic and racial disparities in health insurance and healthcare access.¹

While Medicaid improves the health and lives of recipients and benefits the healthcare system and the US economy, Medicaid systems for enrollment, renewal/redetermination, and using Medicaid coverage need improvement. All people who meet Medicaid eligibility criteria are guaranteed coverage.² However, many who are eligible struggle to enroll in and maintain Medicaid coverage. Barriers to obtaining and renewing coverage and accessing services often make it challenging and time-consuming to navigate the system. Many who successfully enrolled face further dissatisfaction and stress as Medicaid leaves their needs unaddressed. Research shows that Medicaid recipients experience many barriers to accessing quality healthcare.³

The COVID-19 pandemic demonstrated even more clearly how vital access to affordable health care is for our communities. To meet the health care needs of low-income individuals during the COVID-19 pandemic, Congress passed legislation requiring Medicaid programs to keep people continuously enrolled through the end of the COVID-19 public health emergency (PHE) in exchange for enhanced federal funding. States suspended their Medicaid programs' renewal requirements ("continuous coverage") to comply. During this time, Medicaid enrollees did not face the too-typical barriers to renewing

coverage that caused many temporary or permanent disenrollments previously, leaving them without access to affordable care. As a result, Medicaid enrollment increased while uninsured rates decreased across the US.⁴

In December 2022, Congress terminated the continuous enrollment requirement (effective March 31, 2023) and scheduled a phased end to the enhanced federal Medicaid matching funds through December 2023.⁵ States have begun determining the eligibility of everyone enrolled in Medicaid, and recipients started losing coverage on April 1, 2023. Most states are unprepared to move all their recipients through the renewal process. Even before the pandemic, administrative barriers—such as burdensome documentation requirements and inadequate communication systems—caused many eligible people to lose coverage or fail to be enrolled.⁶ As many as 15 million people may lose their Medicaid coverage over the coming year, including millions still eligible.⁷ Many who lose coverage will not be able to afford other health insurance and will become uninsured, which puts them at severe health and financial risk.

Between September 2022 and February 2023, three national networks - the Center for Popular Democracy, Make the Road New York/States, and People's Action Institute - surveyed 2,937 Medicaid recipients primarily in 14 states⁸ to understand their experiences in applying for, renewing, and accessing services through Medicaid, as well as the impact that coverage has had on their lives (see the Technical Appendix for a detailed description of survey methods). The following report describes the results of this survey, providing insight into the massive reenrollment period that states have started.

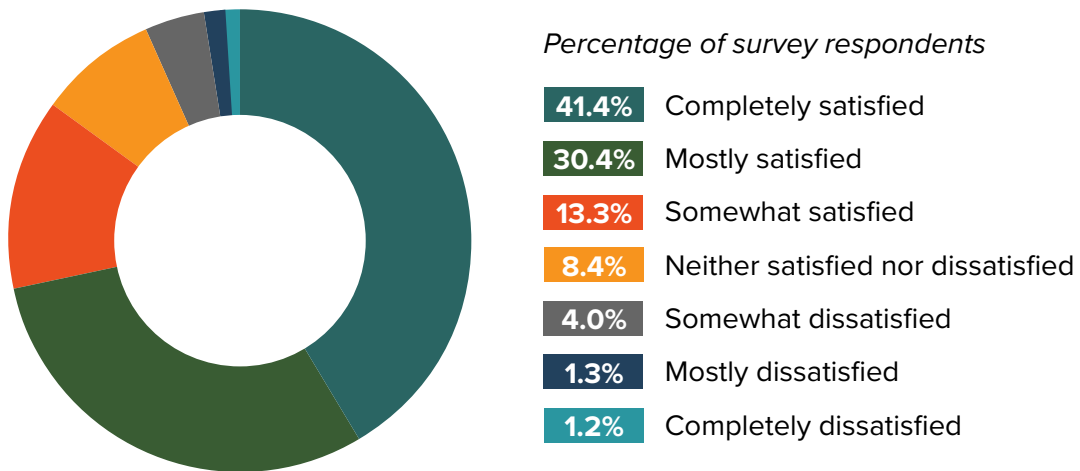
**Overall, we find that:**

- Most survey respondents were satisfied with the services they receive through Medicaid, and many shared personal stories of how critical these services have been for their health and the health of their families. More than two in three (71.8 percent) were either mostly or completely satisfied with the quality of care they receive, even as many survey respondents reported challenges enrolling, renewing, and accessing services through Medicaid.
- Nearly one in three survey respondents experienced challenges in applying for Medicaid, most frequently long waits on phone lines and difficulties with program websites. Individuals who received support in the application process were less likely to experience challenges.
- Approximately one in four survey respondents experienced challenges in renewing their Medicaid coverage. The most common challenges reported by respondents were the too-low income ceilings for program eligibility alongside confusing and burdensome paperwork.
- 44.3 percent of survey respondents were unaware of their need to go through a renewal process once the public health emergency ends, potentially putting them at risk of losing their Medicaid coverage.
- 38.9 percent of survey respondents reported challenges accessing health care services through Medicaid, including finding providers that accept Medicaid and have available appointments and accessing care from specialists. People were more likely to report challenges accessing health care services if they were Asian, trans, nonbinary, had a chronic illness or disability, or reported past discrimination based on a criminal conviction.
- One in three survey respondents (34.4 percent) reported needing medical treatment for themselves or their family and not receiving it over the past year.

IMPACT OF HAVING MEDICAID COVERAGE FOR ENROLLEES

Respondents expressed overall satisfaction with the services they receive through Medicaid and described the program's positive impact on them and their family's livelihoods. More than seven per ten (71.8 percent) were either mostly or completely satisfied with the quality of care they receive through Medicaid. Many on Medicaid said that if they lost it, they would not be able to get care, see doctors, or afford their treatment. Many said that they would have no insurance if they did not have Medicaid.

How would you rate the quality of care you receive through Medicaid?



Source: Medicaid Monitoring Survey 2022-2023



The support I receive from this health insurance is life changing. I would experience a drastic decline on my quality of life without this coverage. We need more funds and staff devoted to public health insurance so our luxury bones (teeth) and vision/hearing services are covered. It is bewildering that these are not considered essential health care."

- Respondent from Arkansas



Currently my physical and mental health is very stable and I owe that to Medicaid. It has allowed me to get diagnosed with ADHD, dramatically improving my quality of life."

- Respondent from Arkansas



Because of Medicaid I was able to access surgeries and care that I would not have been able to afford under a regular plan....I feel very grateful I am in a state with expanded coverage that is easy to access and has good education about Medicaid - been very helpful."

- Respondent from Connecticut

—“

Overall we have had positive experiences with Medicaid and are incredibly thankful for the coverage. We could not afford to keep my husband alive if we were not covered under Medicaid.”

- Respondent from Arkansas

—“

Overall I am definitely grateful for the program, because who can afford insurance for a family of four? You'd have to choose between health insurance and feeding your kids or rent.”

- Respondent from Connecticut

—“

I tried when I was younger and I got denied because I wasn't pregnant so I was surprised when I got it. And because I got it I have also been able to get a phone and with the phone I was able to get a job and I hope to be able to get out of the tent that I am living in.”

- Respondent from Missouri

—“

Thank you for Medicaid for me and my family it is necessary otherwise we would not receive quality healthcare. all people should receive Medicaid.”

- Respondent from DC

—“

Ella esta tranquila porque sabiendo que su hija tiene acceso a medicos y medicinas la hace sentir tranquila. Me gustaria que los ninos y adultos sin documentacion tambien puedan tener un seguro ya que es muy importante para nuestros hijos que los padres esten bien tambien”

She has peace of mind because knowing that her daughter has access to doctors and medicine makes her feel at ease. She would like undocumented children and adults to also be able to have insurance because it is very important for our children that their parents are well too.”

- Respondent from California

One notable exception to this overall trend was among trans and nonbinary respondents. Nearly four out of five trans and nonbinary respondents were somewhat, mostly, or completely dissatisfied with the care they received, compared to less than one in 10 of all survey respondents (6.5 percent). Respondents in DC (61.0 percent), Indiana (61.7 percent), and Missouri (65.9 percent) were also less likely to be mostly or completely satisfied with the quality of care they received.

CHALLENGES WITH APPLYING

A significant portion—more than one in four (28.6 percent)—of the survey respondents reported experiencing challenges in applying for Medicaid. Nearly one in ten respondents said they could not successfully enroll because either their application got rejected, they never received a response, or they gave up on submitting their application. Many respondents described the process as overly complicated, especially the documentation requirements.

Getting assistance with the application was very important for many respondents. Survey respondents who had support during the application process were less likely to report challenges (23.5 percent) than those who did not have support (33.1 percent). The most common source of application support came from either a community organization (20.1 percent) or a clinic or hospital (15.0 percent). Latinx individuals and immigrants were more likely to report having support in applying for Medicaid, while Black, trans, and nonbinary recipients were the least likely to report having received support.

Given the importance of support for applicants, it is concerning that many applicants experienced significant challenges when they sought out help from a Medicaid office (40.2 percent of survey respondents reported at least one application challenge). The most common challenge cited in applying to Medicaid programs was long waits. Survey respondents who attempted to apply over the phone with a Medicaid office described being on hold for up to 11 hours, with up to 187 callers ahead of them in the queue. Many survey respondents described frustrating and time-consuming experiences attempting to apply over the phone—including very long wait times, unanswered phone calls, and having multiple calls dropped. Survey respondents in Missouri (54.5 percent), Vermont (56.9 percent), and Indiana (44.1 percent) were the most likely to report long wait times.

— “
When I initially applied, the process was overwhelming. The amount of paperwork you have to put together can be stressful.”

- Respondent from
New Hampshire

— “
Tuve que regresar a la oficina multiple veces porque cada vez que iba me dijeron de otro documento necesario y tenía que sacar más tiempo fuera del trabajo”

I had to go back to the office multiple times because every time I went I was told of another document that was needed and I had to take more time off work.”

- Respondent from California

—“

The biggest challenge I have found [is] getting information in a concise way... The other day I was on hold for 2 hours and I gave up. You need one small piece of information and it's hours to get it. I especially don't like it when I finally get through and they tell me to go to the web site - which means starting from the beginning! Also it is frustrating that every place you call has a callback feature to schedule a call back - but I have not experienced one of these with HUSKY [Connecticut's Medicaid program]."

- Respondent from Connecticut

—“

Al llamar para saber del Medicaid me decían que me pasarían con otra persona, esa persona me decía que me pasaría con otra persona porque no me podía ayudar. Así nos cancelaron Medicaid y nos dijeron que teníamos que aplicar nuevamente con todos los documentos. Cuando voy a la oficina en persona tengo que ir temprano en la mañana y me voy a las 4 de la tarde"

When I called to find out about Medicaid they told me that they would put me through to someone else, that person told me that they would put me through to someone else because they could not help me. So they canceled our Medicaid and told us that we had to reapply with all the documents. When I go to the office in person I have to go early in the morning and I leave at 4:00 pm."

- Respondent from Nevada



Even when respondents did talk to a representative from a Medicaid office, those representatives were not always helpful and occasionally were rude and disrespectful. Some respondents reported getting transferred between multiple representatives, getting different and sometimes contradictory information from each.



I was trying to enroll my son in disability Medicaid and the rest of our family in regular Medicaid. The representative told me that I would have to apply for these things separately which led to duplicate cases. This caused them to cancel one of our open cases and we were then instructed to re-apply for our family. The whole experience was extremely frustrating [because] I was told different things by each person I spoke with (i.e. from the local office and the 800 number I called). It also unnecessarily prolonged the process and ultimately prolonged the time interval we were without insurance. Re-submitting the application changed the 'date of application' so our retroactive benefits started later than they would have if the original application wasn't canceled."

- Respondent from Indiana



I went in person because I had many questions about the application. The lines were incredibly long and the staff was very rude and they made me feel scared to ask questions. They seemed annoyed to answer any questions and treated us like we were not humans. Then when I mailed sensitive documents they lost them. I spent hours trying to communicate via phone with them because I was afraid to go in person."

- Respondent from New Jersey

More than half (56.5 percent) of survey respondents who applied through a website reported those sites as either dysfunctional or challenging to navigate. Respondents in Missouri, Michigan, and Vermont reported the most challenges with applying through their state's website.



"The issue I primarily experienced was difficulty navigating the website, which would kick me out, refuse my attempts to access the application, go offline for maintenance at inopportune times, and once even deleted some of my information which I had to resubmit."

- Respondent from Arkansas

A smaller proportion of survey respondents reported challenges with language barriers, not only when their first language is not English but also for native English speakers who had difficulty understanding the technical language used in application materials. Since 2010, federal law has required agencies to use clear, understandable language in all public-facing documents.⁹

Had accessibility issues. ...As a neurodivergent person with autism and a learning disability, this is too complex of a system to navigate. It is not accessible. The language they use is not clear... Hard to understand the documents. Everyone's brain thinks differently. It is not a one size fits all system. I think the system is geared toward legislative officials instead of the average individual. This system has biases and inequality because the language is hard to understand....We need innovation and make it easier for people to understand the system."

- Respondent from Vermont

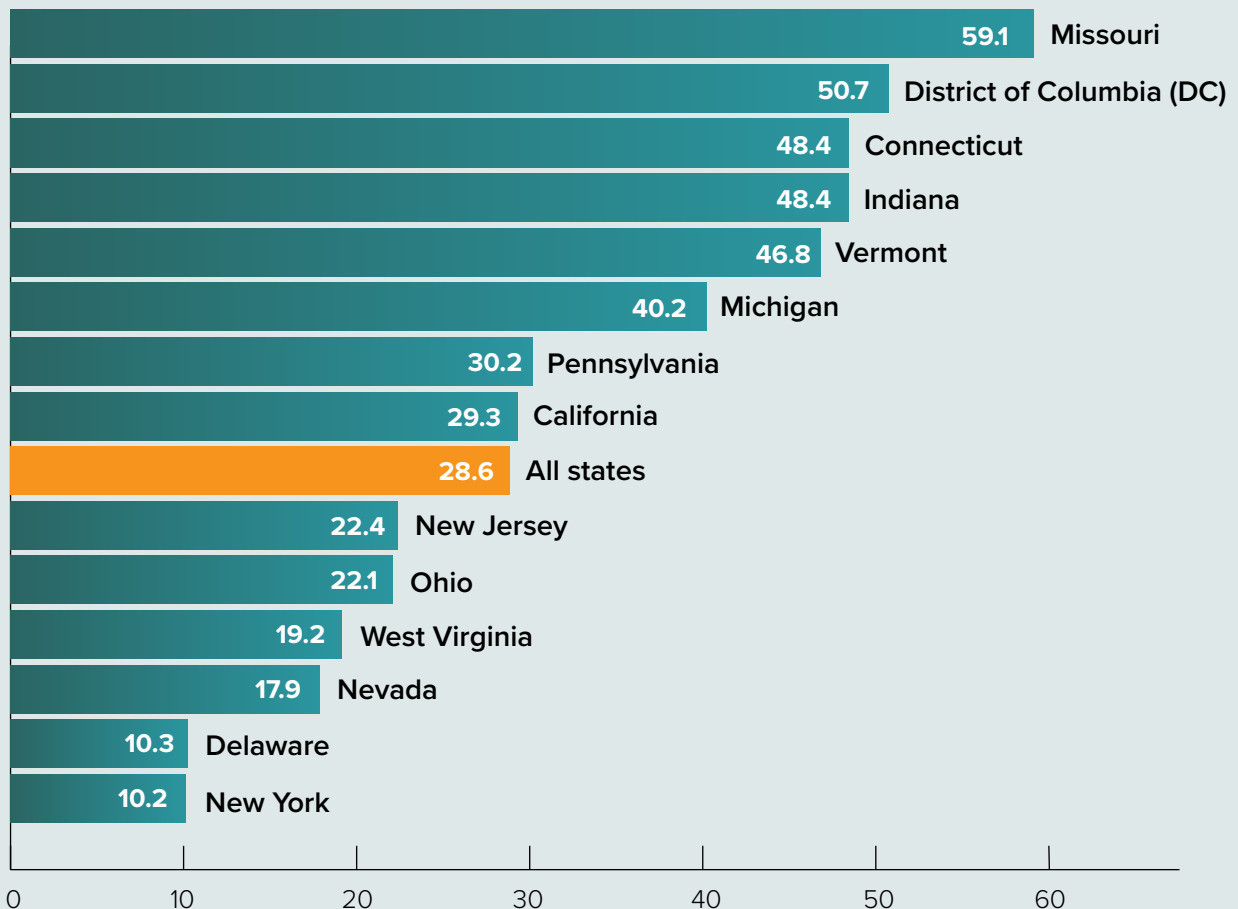
"Me fui caminando en el frío, no había nadie que hablara español, dijeron que el traductor regresaba en 2 semanas. Fueron muy malos educados."

"I went walking in the cold, there was no one who spoke Spanish, they said the interpreter would be back in 2 weeks. They were very rude."

- Respondent from New York

Did you face any challenges while applying for Medicaid coverage?

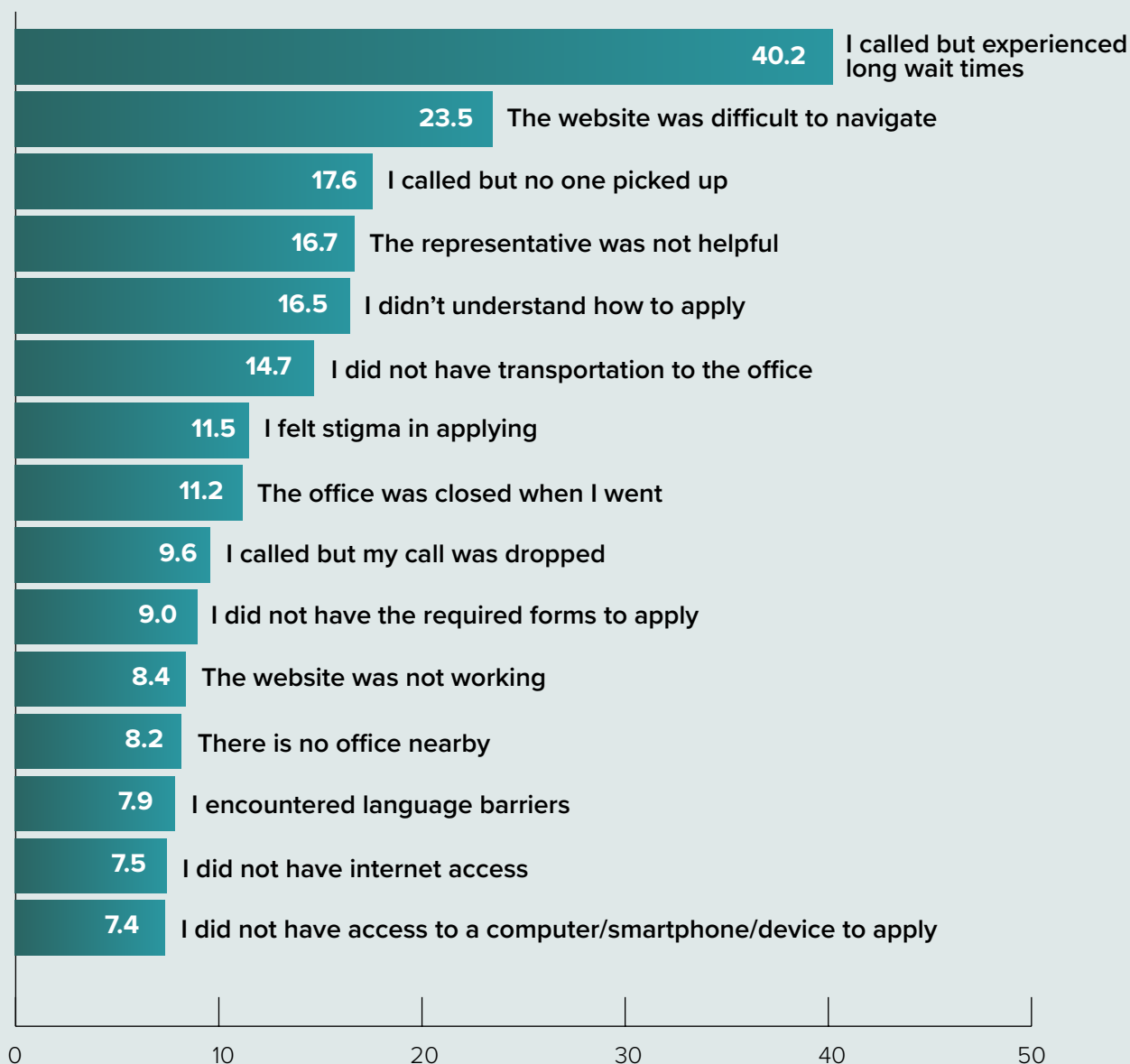
(Proportion of survey respondents that reported any challenge applying to Medicaid, by state)



Percentage of survey respondents reporting at least one challenge applying for Medicaid coverage

Source: Medicaid Monitoring Survey 2022-2023

For those survey respondents that reported any challenge while applying for Medicaid coverage, what specific challenges did they face?



Percentage of survey respondents (only includes respondents who reported at least one challenge)

Source: Medicaid Monitoring Survey 2022-2023

Note: This was a "select all that apply" question and respondents may have selected more than one application entry point. Because of this, row percentages do not sum to 100.

CHALLENGES WITH RENEWING

One in four survey respondents (23.4 percent) reported challenges with renewing their Medicaid coverage. The most commonly cited challenge with renewals was low-income limits—earning just a few dollars more can make someone ineligible. Low-income workers are more likely than those with higher incomes to experience fluctuations in income, especially if they work part-time, perform gig or seasonal work, or are employed in an industry with unpredictable schedules, like retail or restaurants.¹⁰ Self-employed people reported having a tough time meeting income documentation requirements.



My income level has fluctuated over the past few years while I've been on Medicaid and it's always stressful trying to renew my coverage. It's also a dehumanizing process because now they require not just bank statements, but Venmo and PayPal statements, and I always feel like I'm under a huge amount of financial surveillance, when my average annual income is about \$10,000 a year."

- Respondent from New Hampshire



Told to apply for unemployment -only got a small amount but with my SSDI it put me slightly over the income limit for regular Medicaid. Lost attendant care services for 6 months until unemployment ran out."

- Respondent from Vermont



I am self-employed, so it is always a nightmare to renew. Multiple forms, I have to print out my huge tax returns, take them to the FSSA office, wait for them to stamp them, fax them to the document center. Then the document center takes too long to review them, so it is always denied and then reversed when they finally review the forms. Centralizing the documents hasn't worked."

- Respondent from Indiana

One in four survey respondents (23.4 percent) reported challenges with renewing their Medicaid coverage.

Overall, survey respondents described renewal requirements as confusing and burdensome. Many respondents said they often receive inaccurate or incomplete information about the renewal process from Medicaid representatives. Some also mentioned difficulties getting doctors to do the required paperwork for renewals. People disenrolled due to an unsuccessful renewal process described having to delay care because they could not afford to see doctors or pay for their medications.

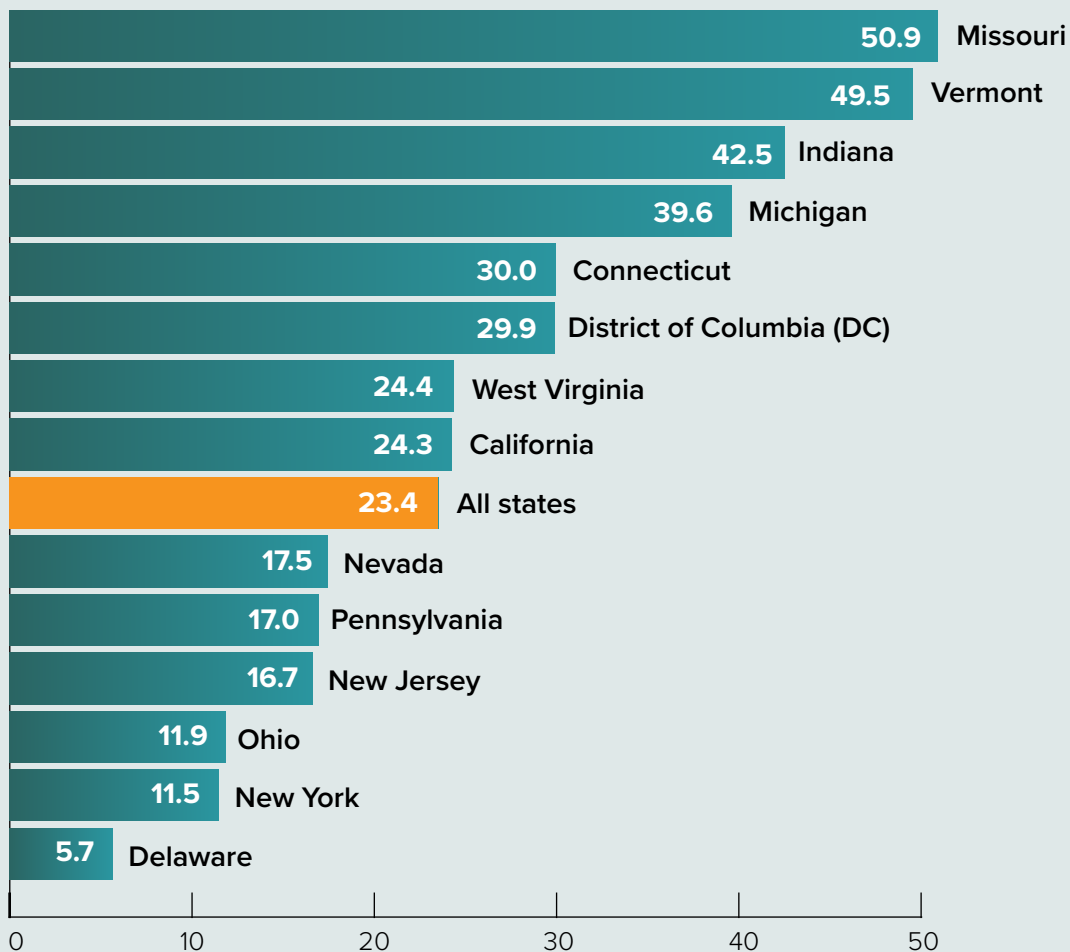


I would apply online then get mailings via USPS asking for more information or the same information in different ways, specifically the questions regarding income were different/confusing compared to the website application questions. I filled it all out as best as possible. Then you have to call to follow up with an interview and if you miss completing any of this during a very restrictive time limit you have to start over in some cases. Their mailings often arrive late which affect deadlines to get them the information - i.e. I often would only have a few days to gather the info and get it in the mail to them and sometimes it would not be delivered by deadline.”

- Respondent from Vermont

Did you face any challenges while renewing Medicaid coverage?

(Proportion of survey respondents that reported any challenge renewing Medicaid, by state)



Percentage of survey respondents reporting at least one challenge renewing Medicaid coverage

Source: Medicaid Monitoring Survey 2022-2023

For those survey respondents that reported any challenge while renewing Medicaid coverage, what specific challenges did they face?

	Percentage of survey respondents (only includes respondents who reported at least one challenge)
My income level changed	33.6
I didn't know about or understand the renewal requirements	21.7
My age changed	11.3
I did not have the required forms to renew	10.7
I did not have the required documentation to renew	9.1
I experienced barriers because of state-mandated work requirements	7.4
I didn't have enough time to complete the renewal process	6.8
I was no longer qualified for another reason, such as no longer being pregnant	5.6
I encountered language barriers	5.4
I don't have a permanent address	5.0

Source: Medicaid Monitoring Survey 2022-2023

Note: This was a "select all that apply" question and respondents may have selected more than one application entry point. Because of this, row percentages do not sum to 100.



CONSEQUENCES OF APPLICATION/RENEWAL CHALLENGES

Delays in getting Medicaid coverage, being denied, or losing coverage can have serious health, financial, and other consequences. For many people, Medicaid is the only health insurance that is financially accessible to them. For most respondents, if they could not get Medicaid coverage, they would not be able to afford health insurance and would remain uninsured.

Those who were either disenrolled or never enrolled often described delaying care or stopping treatments and not being able to afford to see doctors or get their medications. Other respondents who were still enrolled expressed fear about what would happen if they lost coverage, including no longer being able to afford to go to doctors or get needed medication or treatment. Several survey respondents described keeping coverage as a life-or-death situation.

— “

I took a long time to get approved for Medicaid. In that time my daughter got very sick and I couldn't take her to the doctor.”

- Respondent from New Jersey

— “

I tried multiple times. I would apply and wouldn't get denied or hear nothing. I would try again and then get denied. Eventually I got on Medicaid for women but it didn't cover much and then I heard that I could go to ER and get billed but could get some kind of care. I then just got discharged and two weeks later I had to call the fire dept and they had to break down my door to get me because I couldn't get up and my legs wouldn't work. I got put in the hospital and that is when I found out that I had been approved for Medicaid Expansion and then I was put in a home to get help and I was there for two months. Just last night I was dropped off at a homeless shelter because while I was in the hospital I lost my house and my job and now I have nowhere to go and now I have no place to live and Medicaid doesn't cover the long term care that I need.”

- Respondent from Missouri

— “

When my MediCal was stopped, I had to suddenly stop taking my medications. I take meds for both chronic depression and ADHD. When I am not on them, it does greatly affect my life. The real issue was that I am a gig worker, and while I am working, I also have to save up money for the periods of time when I am not working. So even though my monthly income may seem high, my yearly income remains low. But this disqualified me for MediCal. It doesn't make any sense to me. I also think the income limits are way WAY too low for LA City. The cost of living here is exorbitant and the only way you can qualify is if you have a homeless wage - literally...I was unbelievably sad. My mood swings resumed. I could not focus. I was tired all the time. It felt overall horrible. It took me YEARS to muster up the courage to start taking meds for my mental health and losing it all so suddenly after I was doing so well was very difficult for me.”

- Respondent from California

CHALLENGES ACCESSING HEALTH CARE WITH MEDICAID

Over 34 percent of survey respondents reported challenges accessing health care services through Medicaid. Individuals were more likely to report challenges accessing health care services if they were Asian, trans, nonbinary, had a chronic illness or disability, or reported past discrimination based on a criminal conviction.¹¹ Respondents in Indiana (64.1 percent), DC (63.2 percent), and Missouri (62.8 percent) were much more likely to report challenges than respondents from other states.

The most common challenges reported by survey respondents were finding medical providers that would accept Medicaid and had available appointments. For many survey respondents, this meant traveling long distances to see doctors, waiting extended periods to receive care as time passed between appointments far into the future, or not going to the doctor at all. Survey respondents described spending hours finding a doctor who would accept Medicaid and take new patients. Some survey respondents also said that the only doctors that accepted Medicaid patients were not good-quality doctors. The small number of doctors taking Medicaid also meant that survey respondents usually had little to no choice of doctor; even if they did not like their doctor or they made them feel uncomfortable, they had no other options.

— “

Waiting to see a doctor for near a year to get a operation done that I really need”

- Respondent from DC

— “

[Where] I live...there isn't many doctors who accept Medicaid there, so I had to find a clinic 45 minutes away that doesn't necessarily give quality care, where we see a different doctor every visit because of how it's set up. Seeing a different doctor means the doctor doesn't really know my child or their health therefore it doesn't feel like quality medical care but I have to settle because my kids need their yearly check ups and or if they get sick.”

- Respondent from Michigan

— “

I moved and finding a new doctor who takes my insurance is difficult. I have to drive 1.5 hours away and it's hard to work that around my schedule. My daughter needs mental health care and it's nearly impossible to find a doctor to help with mental health for kids.”

- Respondent from Indiana

— “

I am diabetic and I need insulin but [it] takes time to refill. The insulin is only for 10 days and I run out by those 10 days but refilling [the] prescription takes 20-22 days. This is a huge issue as it's dangerous.”

- Respondent from New Jersey

— “

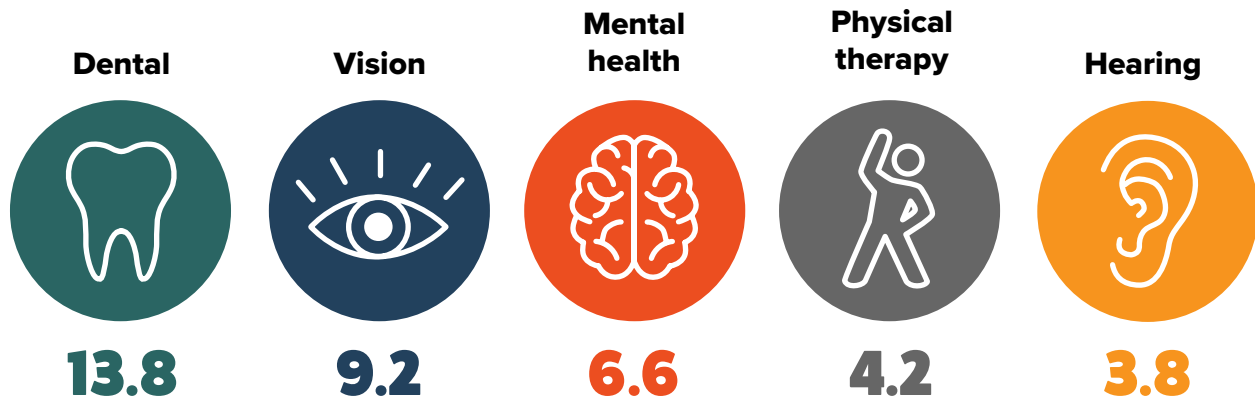
“Well I can't find a dentist who will take Medicaid nearby besides a dentist I stopped going to because he was misogynist and too aggressive. I haven't been to the dentist in 3 years even though my crown fell off and my teeth hurt because no other dentist nearby takes Medicaid.”

- Respondent from Vermont

About one in ten survey respondents described challenges accessing referrals to and services from specialist providers.

Medicaid did not cover some services that survey respondents needed, especially dental services. While federal law requires states to cover at least some dental, vision, and mental health services for children,¹² these services and physical therapy are optional for adults. Many states choose to either not cover them, only cover emergencies, or severely limit coverage in other ways.¹³

Which services do you want Medicaid to cover?



Percentage of survey respondents

Source: Medicaid Monitoring Survey 2022-2023

Note: This was a “select all that apply” question and respondents may have selected more than one service they’d like covered. Because of this, row percentages do not sum to 100.



— “

I have literally had doctors tell me I need a treatment but it doesn't matter because your insurance won't cover it."

- Respondent from Indiana

— “

On a waitlist for speech therapy for over a year. Extremely frustrating."

- Respondent from Nevada

— “

No renové mi cobertura porque el seguro no me cubría los especialistas, tratamientos, y medicaciones que yo necesito para mi accidente entonces no quise pasar por todo el proceso de nuevo si no lo voy a poder usar para lo que necesito."

I did not renew my coverage because the insurance did not cover the specialists, treatments, and medications that I need after my accident so I did not want to go through the whole process again if I am not going to be able to use it for what I need."

- Respondent from New York

— “

Very hard to find dentists that accept Medicaid. I have to go to the other end of town from where I live to my dentist when there are at least 50 where I live but they won't accept my insurance."

- Respondent from New Jersey

— “

The majority of the time my card does not cover outpatient medical treatment and I have to pay out of pocket for them. Unfortunately I cannot afford that and that means I have to not go to the doctor for things"

- Respondent from Indiana

— “

My daughter needed glasses and it was required by the school. Due to the insurance issues she was not able to get the help she needed immediately. I had to save money to pay about \$300 for a requirement by the school to have an exam and glasses. She also needed dental care that had to be put off until I finally got the health care she needed. I could not afford it without insurance."

- Respondent from Arkansas

— “

I have been off of the medications I need for almost a year, and because of difficulty accessing the specialist I cannot get what I need for my chronic pain and mental health needs. and because of the primary care provider I have, I cannot get the correct treatment I need."

- Respondent from Alaska

Some survey respondents said that experiences with stigma and discrimination made accessing the care they needed challenging. Respondents described discrimination based not only on their status as Medicaid recipients but also on homelessness, race, disability, LGBTQ status, fatphobia, and actual or perceived history of addiction. A number of respondents said that their pain was not taken seriously or treated, with many mentioning that this was likely due to perceived or actual history of drug use. Individuals who were Asian, had a chronic illness or disability, or reported past discrimination based on a criminal conviction were all more likely to report being mistreated by medical providers. These experiences of discrimination and disrespect led some respondents to avoid or delay seeking care.

— “

I have been to hospitals...and they have judged me and made me feel unworthy of the services that I deserve. They always try to make me feel like I'm pill-seeking and gaslighting me and they just make me feel bad to where I don't want to go to the hospital and get any treatment here."

- Respondent from Ohio

— “

There was a time I needed back surgery and the doctor wouldn't take me/my pain seriously. I needed imaging done and because he said it was just a mental health issue (the pain was all in my head - due to depression and anxiety) so treatment was not provided and it led to me having emergency back surgery."

- Respondent from Vermont

— “

I was told by a doctor that I was 'less of a priority as a patient' because other insurances paid more."

- Respondent from Indiana

— “

felt like concerns were just dismissed in the E.R. because I had Medicaid - didn't answer my questions, had a serious complication that ended up with losing my leg - two days later had to have leg amputated"

- Respondent from Missouri

— “

People on the phone in the dentist office will start asking us our issue in a nice and pleasant way but change their tone when they discover we have Medicaid. As a family we feel insulted, poor and sometimes angry."

- Respondent from New Jersey

— “

Just a judgment and a stigma when you go to the main hospital for emergency room visits and how they treat and how they talk to me it's so disrespectful like they have no empathy and no compassion and they judge me because of my lifestyle and I feel like they should have consequences for that"

- Respondent from Ohio

— “ —

I feel like because I have Medicaid medical staff have assumptions already about me. I also feel like because I have Medicaid they don't prioritize certain things and treat me differently than people with private insurance.”

- Respondent from California

— “ —

Being on Medicaid and homeless, people take me less seriously, especially with history of drug abuse, my concerns are dismissed and my quality of health care is not as good as it should be.”

- Respondent from Missouri

— “ —

Dental professionals are extremely rude and judgmental if you have Medicaid. I realized that when I got private insurance -- their attitude is astoundingly and shockingly different between a private insurance holder and Medicaid holder.”

- Respondent from New Jersey

— “ —

I have been able to get the medical needs I needed. However, I always felt a little discriminated against. When entering the office I feel like they are nicer with other nationalities than hispanics and blacks.”

- Respondent from Connecticut

— “ —

I would say being discriminated against by healthcare providers was due to being gay, and not necessarily because I was on Medicaid. That said, the discrimination at times has been horrific. Lots of inappropriate behavior and things said, sometimes not directly to me but in vicinity. I've had to change my primary care doctor three times because of it. I'm running out of Medicaid options. I guess I'm lucky to have a primary care doctor at all, but it is extremely stressful getting care because of these issues.”

- Respondent from Indiana

— “ —

Not as good of care because they thought that we weren't as good because we were poor. We received the bare minimum treatment.”

- Respondent from West Virginia

Numerous survey respondents mentioned issues with billing, such as being charged for services they did not receive or incurring out-of-pocket fees for services and medications that Medicaid should cover.

— “
I’m constantly getting bills
and asking them to refile to
Medicaid.”

- Respondent from Arkansas

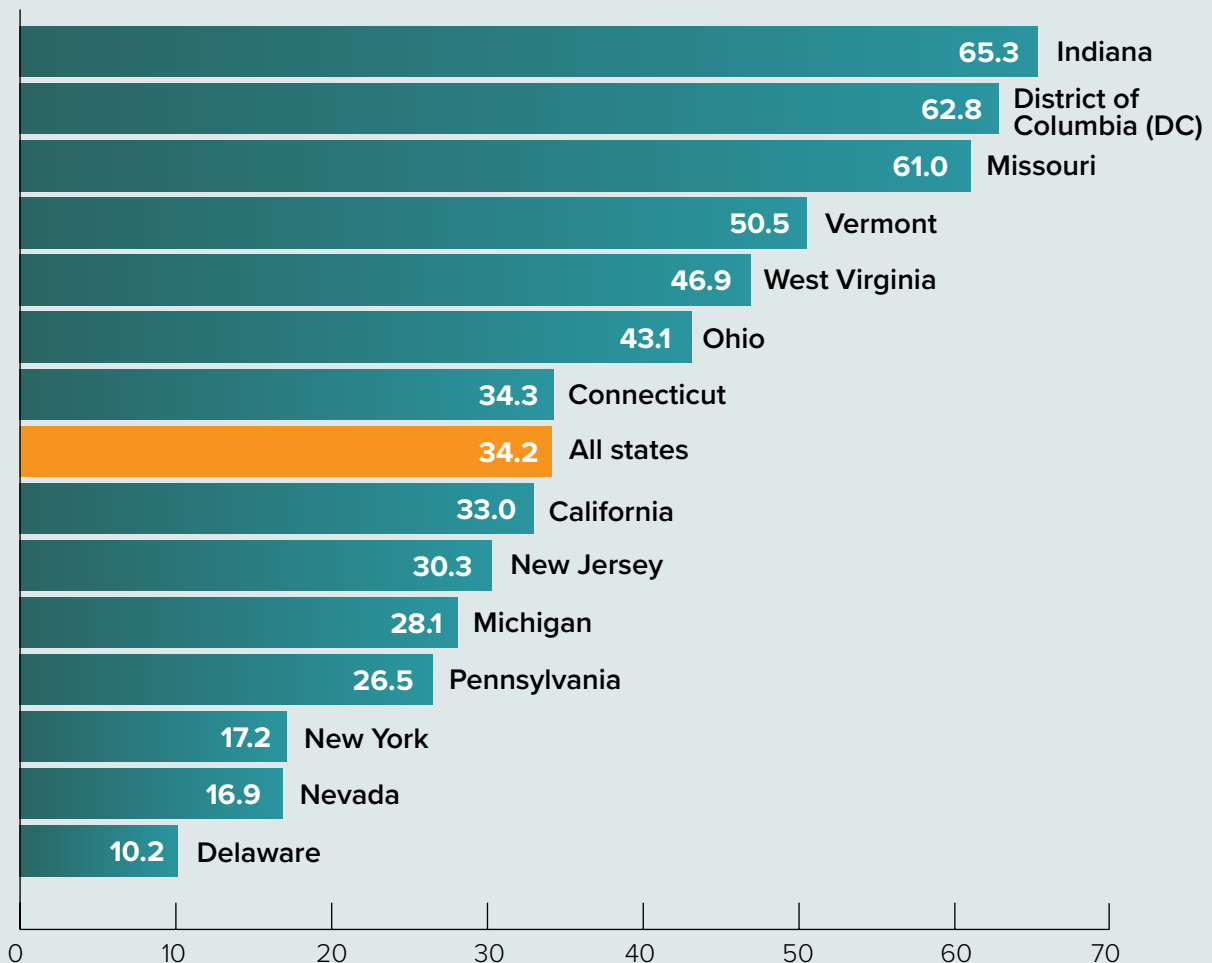
— “
*Fui aprobada pero me está mandando cartas
de una factura del doctor.”*
**I was approved but I’m getting letters about a
medical bill.”**

- Respondent from New York

A few individuals mentioned that it was difficult to access care because they lived close to a state border, and the closest providers were out of state (where they could not use their Medicaid coverage).

Did you face any challenges while accessing care?

(Proportion of survey respondents that reported any challenge accessing services through Medicaid, by state)



Source: Medicaid Monitoring Survey 2022-2023

For those survey respondents that reported any challenges while accessing care, what specific challenges did they face?

	Percentage of survey respondents (only includes respondents who reported at least one challenge)
Unable to find a clinic/provider that will accept Medicaid	41.3
Healthcare provider not available to see you within a reasonable timeframe	35.5
Difficulty getting referred or approved to see a specialist	29.1
Other difficulties making an appointment with a specialist (i.e. there were none in network, within a reasonable distance, who could see you within a reasonable timeframe, etc.)	25.3
Difficulty accessing specific medications	24.4
Difficulty accessing care because it was located far away	23.9
Difficulty making the appointment (i.e. language barriers, office not answering the phone or returning phone calls, unable to provide documentation requested by office staff)	20.2
Difficulty accessing personal or public transportation or Medicaid travel	20.7
Were treated poorly or discriminated against by those who work at the clinic (can include the administrative staff, nurses, and doctors)	14.4
Place of care (clinic, doctor's office, etc.) refused to treat you because you did not have proof of insurance/Medicaid coverage	10.4
Was disenrolled from Medicaid without knowing it	5.1

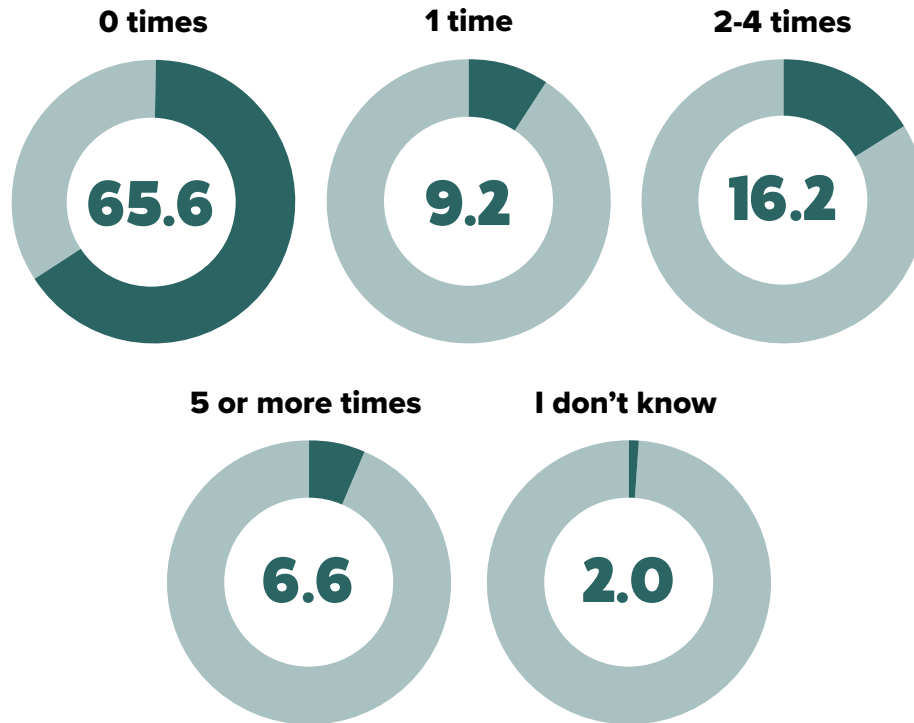
Source: Medicaid Monitoring Survey 2022-2023

Note: This was a "select all that apply" question and respondents may have selected more than one challenge. Because of this, row percentages do not sum to the total number that experienced any challenge.

Challenges in accessing care can lead to individuals delaying or never receiving needed care. One in three survey respondents (34.4 percent) reported needing medical treatment for themselves or their family and not receiving it over the past year. Respondents who were trans, nonbinary, Asian, had a chronic illness or disability, or reported past discrimination based on a criminal conviction were more likely to have gone without needed medical care.

In the last year, how many times did you and/or your child/ family member need medical treatment but NOT receive it?

Percentage of survey respondents



Source: Medicaid Monitoring Survey 2022-2023



— “

Consequences are that there are medications I need that I cannot get, and services I really need in order to better my health and quality of life that are not deemed ‘necessary’ by Medicaid. A yearly eye exam and dental exam are not luxuries that should only be awarded to people with a certain income, they are important to your overall health AS WELL as can solve problems that will only compound and cost more money if left untreated.”

- Respondent from New Hampshire

— “

We are all in pain. As I speak to you, I am in pain. My wife is in pain and my children are in pain. We are suffering. But we don’t have the money to pay thousands of dollars for dental treatment. I am thinking I may have to take out a bank loan soon to at least get my daughter treated for her dental issues.”

- Respondent from New Jersey

— “

We just are not receiving the services we need in order to live an independent and self-sufficient life. It has turned me into a shut-in.”

- Respondent from Arkansas

— “

Because it took a long time to see me, my surgery was postponed so much and I ended up with a lot of pain, stuck on bed rest for about a year, and I developed a staph infection.”

- Respondent from California

— “

My teeth are rotting in my mouth. I’m tired and exhausted. The more that they get bad the worse my health gets and it doesn’t seem to matter. When I go to the ER they can’t really help me and they aren’t interested in actually helping all of me, the teeth problems or other things.”

- Respondent from Missouri

— “

Made me uncomfortable in seeking healthcare and have let things get bad.”

- Respondent from West Virginia

— “

You feel like you don’t matter.”

- Respondent from New York

— “

You’re left feeling like you’d rather not choose to get treatment for your conditions because of the fear of being stigmatized. You’re also left wondering how adequate the care truly is and if the provider’s own bias ends up playing a role in your treatment, diagnosis, or care in general.”

- Respondent from Ohio

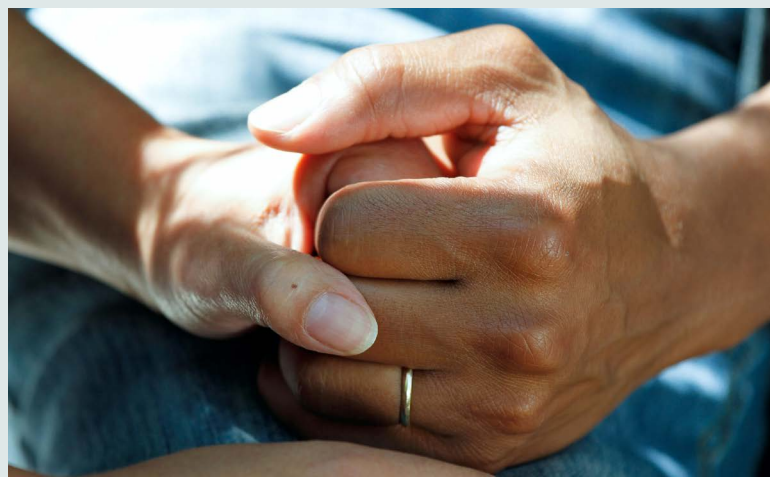
END OF PUBLIC HEALTH EMERGENCY

When the federal government declared the COVID-19 public health emergency in early 2020, it temporarily suspended requirements that Medicaid recipients regularly renew their coverage by providing evidence that they are still eligible. During this time, the number of individuals enrolled in Medicaid increased, and the proportion of uninsured people dropped to eight percent.¹⁴ However, the Biden administration recently declared that the public health emergency would end on May 11, 2023. (The continuous coverage provision ended on March 31, 2023.) With the end of the public health emergency, all Medicaid recipients will face redetermination (checking their eligibility). States began to disenroll people on April 1 -- jumpstarting the process for over 92 million Medicaid recipients¹⁵ who will be required to prove their eligibility once again and will be at risk of losing their coverage if they fail to do so. Kaiser Family Foundation estimates that between 5 million and 14 million people will be disenrolled, potentially including millions who are still eligible.¹⁶

Most survey respondents were unaware that the public health emergency protected their Medicaid coverage against disenrollment. **44.3 percent did not know they would need to renew their coverage once the public health emergency ended.** Respondents in California (51.3 percent) and Nevada (73.9 percent) were much more likely to be aware of the need to renew when the public health emergency ends, while respondents living in Delaware (23.0 percent), Missouri (27.4 percent), and West Virginia (25.2 percent) were the least likely. Of those respondents who knew that they would need to renew their coverage, four out of five (78.0 percent) found out via letter.

Even before the pandemic, the Medicaid renewal process in most states was burdensome, confusing, and inadequate, often resulting in individuals losing coverage even if they were still eligible. Because Medicaid recipients have low incomes, many have communication limitations, which makes the renewal process more challenging, especially after no one has had to renew for two years.¹⁷ For example, sending

letters to people with unstable housing, notices distributed without translations into languages other than English, and emails to rural populations with limited internet access are ineffective, yet this is often how Medicaid programs communicate with recipients. Many state Medicaid offices are chronically understaffed, already have a backlog of enrollment applications, and are ill-prepared to review the eligibility of hundreds of thousands to millions of Medicaid recipients.¹⁸



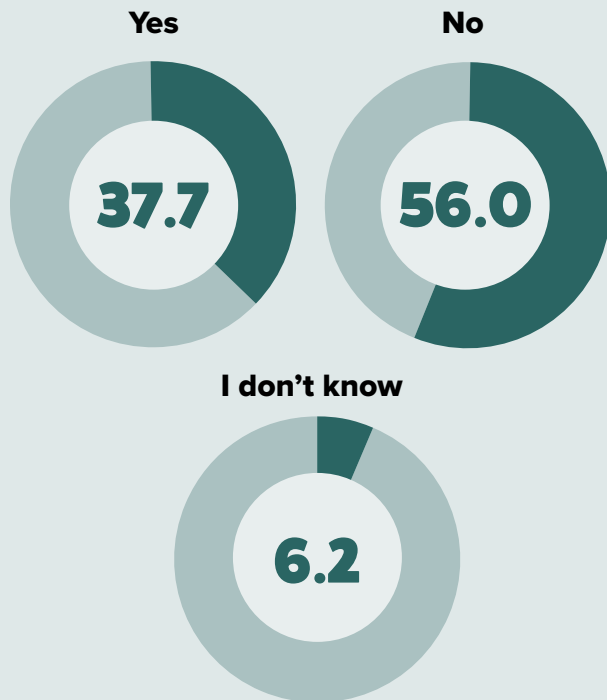
Source: Unsplash, National Cancer Institute

The many challenges survey respondents described in the section above suggest that recipients will experience similar problems with the redetermination process once the public health emergency ends. These include burdensome or confusing documentation requirements; long wait times to talk to representatives on the phone or in person; and receiving incorrect, confusing, or contradictory information from representatives.

In 2018, 10.3 percent of individuals disenrolled from Medicaid successfully re-enrolled within a year.¹⁹ Having to reapply means that recipients must spend additional time preparing and submitting paperwork and may have to delay or go without needed care while their coverage remains suspended. Forcing recipients to disenroll and re-enroll also increases the administrative costs of Medicaid programs.

Are you aware that since the start of the COVID-19 pandemic, people can not lose their Medicaid coverage?

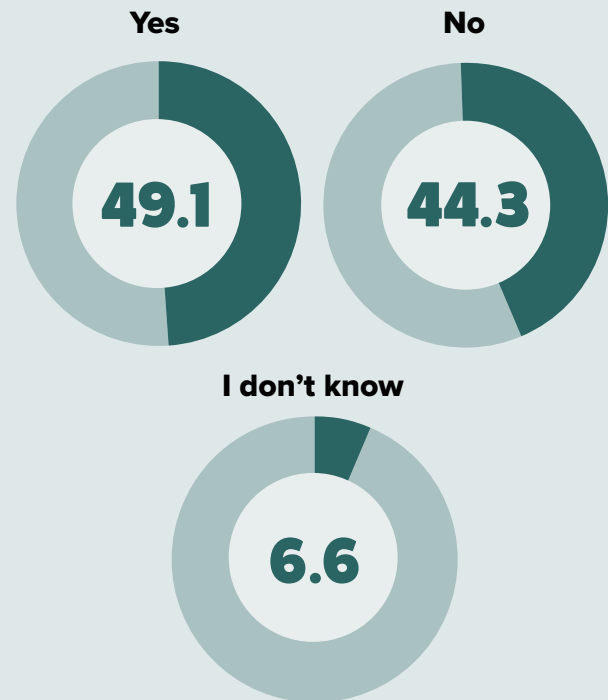
Percentage of survey respondents



Source: Medicaid Monitoring Survey 2022-2023

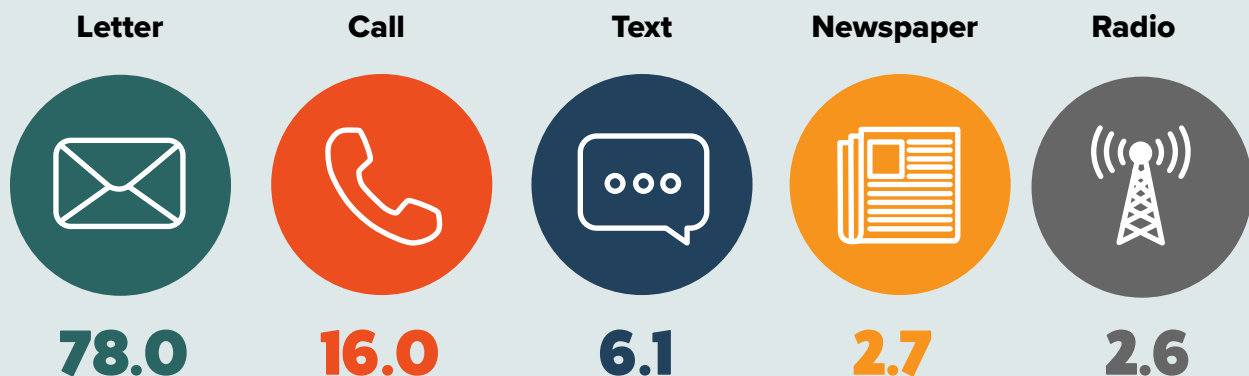
Are you aware that you'll need to renew your Medicaid coverage within 12 months once the Public Health Emergency is declared over?

Percentage of survey respondents



Source: Medicaid Monitoring Survey 2022-2023

How did you find out that you will need to renew your Medicaid coverage once the Public Health Emergency is declared over?



Percentage of survey respondents who were aware

Source: Medicaid Monitoring Survey 2022-2023

EMERGENCY MEDICAID

Medicaid restricts eligibility to citizens and certain qualified immigrants (many legal permanent residents, refugees, and asylees). However, immigrants—including undocumented immigrants—who do not qualify for regular Medicaid because of their immigration status but meet all other eligibility criteria can receive Emergency Medicaid coverage. Emergency Medicaid covers only emergency services, with states having broad discretion about what services qualify as an “emergency.” Most Emergency Medicaid costs are for prenatal care.²⁰

About 37.7 percent of our survey respondents reported being on Emergency Medicaid. Many of these respondents called the emergency coverage critical and were grateful for it, but some also said they needed non-emergency health care covered, too.

Emergency Medicaid is an indispensable program for low-income immigrants, but all immigrants need the comprehensive coverage full Medicaid provides. Only covering emergency medicine comes at a cost to recipients’ health and finances and to the entire healthcare system.²¹

— “

Helped me tremendously. I lost my job and insurance and needed something to help me and my children and this emergency Medicaid did. ...Emergency Medicaid...was a life saver.”

- Respondent from Connecticut

— “

Siento más segura que si tengo alguna emergencia estoy cubierta.”

“I feel more confident that if I have an emergency, I am covered.”

- Respondent from New York

— “

Me ayudo para los exámenes de covid, tengo tranquilidad de saber que si me enfermo puedo ir al hospital por urgencias pero si me gustaria obtener seguro médico regular.”

“It helped me with the covid exams, I have peace of mind knowing that if I get sick I can go to the hospital for emergency care but I would like to get regular health insurance.”

- Respondent from New York

— “

Es una ayuda buena porque en caso de emergencia me cubre por otro lado no estan bueno ya que no ofrece cobertura completa y hay muchos servicios que necesito y no me cubre como por ejemplo unos lentes los cuales necesito y no me cubre.”

“It is good in case of an emergency because it covers me. On the other hand it is not good because it does not offer complete coverage and there are many services that I need, for example, glasses, and the insurance does not cover it.”

- Respondent from New York

— “

Because when a medical need isn’t considered ‘emergency’ I rather ‘wait it out’ or even if it may be an emergency I still won’t go into the emergency room for fear of being billed for medical care.”

- Respondent from Michigan

RECOMMENDATIONS

FEDERAL RECOMMENDATIONS

Public health emergency unwinding

- **Provide emergency healthcare coverage for people who will lose Medicaid** due to changes in eligibility, work requirements (if states implement them), or other policy changes. This coverage should be made available to everyone currently eligible for Medicaid, regardless of whether they meet the new requirements.
- **Fund navigator and outreach programs, primarily through community-based organizations**, to inform people about the Medicaid unwinding and to help them connect to the Marketplace and other healthcare options. Beyond the unwinding, navigator and outreach programs through community-based organizations that engage and educate their communities and assist people with enrollment and renewals should continue to receive funding. Navigators and outreach workers in community-based organizations can solve many of the issues with communication from Medicaid programs throughout the US, mainly because they are located within and trusted by the communities they serve. They know how to reach and communicate best with their community members.

Additional federal recommendations

- **Protect Medicaid from budget cuts and do not shift more costs to states.** Cutting the Medicaid budget would result in many people losing their healthcare coverage with potentially devastating health and financial results.
- **Create a system for Medicaid recipients to notify the Centers for Medicare and Medicaid Services** when states fail to comply with federal requirements.
- **Promote ex parte renewals and expand requirements for ex parte renewals.** Federal regulations require states to conduct *ex parte* renewals for seniors and people with disabilities. This requirement should expand to cover all Medicaid recipients. Further, CMS should provide support to help states that conduct no or few *ex parte* renewals improve their processes and use enforcement mechanisms when necessary.²² CMS should also create guidelines for states to ensure they do not use *ex parte* renewals to automatically disenroll individuals without allowing sufficient time for enrollees to prove eligibility.
- Create a standard for **annual renewals in all states for Medicaid recipients** rather than monthly.
- **Incentivize states to develop targeted outreach and continuous coverage for recipients who have substance use disorder or are in recovery** and provide them with continuous coverage. About 12% of Medicaid recipients over 18 have a substance use disorder, and they are at increased risk of both health complications and may need additional assistance to meet renewal requirements.²³
- Create a standard for all state Medicaid programs to **provide comprehensive dental and vision coverage**.

Cutting the Medicaid budget would result in many people losing their healthcare coverage with potentially devastating health and financial results.

- **Expand access to health insurance for all immigrants**, regardless of immigration status, by taking the following steps:
 - » Lift Affordable Care Act restrictions and expand Medicaid eligibility for Deferred Action for Childhood Arrivals (DACA) recipients, thus expanding their access to health insurance.
 - » Pass the LIFT the BAR Act (H.R.5227/S.4311) to remove the five-year bar (waiting period) and other barriers that deny critical care and aid to people who are lawfully present -- including people with “green cards,” Deferred Action for Childhood Arrivals, crime victims, COFA migrants, child maltreatment victims and orphans who hold Special Immigrant Juvenile Status (SIJS), and other non-citizens residing lawfully in the United States.
 - » Lift all immigration status restrictions for health insurance programs to ensure that all immigrants have equitable access to comprehensive, affordable care and do not need to only rely on emergency Medicaid coverage in dire situations.
- **Mandate and provide funding for states to increase reimbursements to Medicaid providers.** This action will help prevent the loss of current Medicaid providers and encourage more providers to accept Medicaid-enrolled patients.
- **Congress must pass Medicare for All.** The US healthcare system is broken. Passing Improved Medicare for All will create a universal healthcare system that can provide equitable health care for everyone in the US.

Source: Unsplash, Jhon David



STATE RECOMMENDATIONS

We recommend that all states take the following actions if they have not already done so:

Public health emergency unwinding

- **Outreach to current enrollees** about the public health emergency unwinding to ensure they know they will need to re-enroll and connect them to the supports to help them do so. Outreach efforts should happen in consultation with community-based organizations.
 - » Many survey respondents reported confusing communication from their Medicaid programs and recommended that Medicaid offices improve and clarify their communication practices. Make sure that communication on renewals and the steps enrollees need to take is easy to understand by people with limited literacy and translated into other languages that enrollees speak. Make sure the communication clearly states the specific actions enrollees must take and by what date.
 - » Contact enrollees through multiple modes of communication, including sending text messages (instead of just letters in the mail).
 - » Do a better job of maintaining accurate contact information for enrollees:
 - Create simple tools like online forms and dedicated phone lines for enrollees to be able to update their contact information.
 - Use data from USPS and other programs to update mailing addresses.
 - Collect email addresses and cell phone numbers from enrollees to be able to contact them through email, phone calls, and mail.
 - » Send reminders and follow-up communications to enrollees.
 - » Allow extra time for enrollees to submit renewal documentation.
 - » Provide navigators, assisters, community health centers, and community-based organizations with additional funds for outreach and renewal support





- All states are required to report data on the unwinding to the federal government. However, they should also ***make data on the unwinding publicly available*** and update it as regularly as possible, as several states have done by creating public dashboards. Dashboards should include a visual display of information AND downloadable data updated at least monthly.
- Designate an unwinding czar, as some states have already implemented, to oversee unwinding plans and coordinate communication with stakeholders on the ground, including meeting regularly with a variety of stakeholders (including community groups, navigators, and providers) to provide regular updates, respond to information on the ground, and collaborate to ensure no one still eligible loses their Medicaid coverage.

Improving application and renewal processes

- ***Expand Medicaid eligibility*** to cover more uninsured people by increasing the income eligibility ceiling and asset limits.
- ***Expand health insurance to all residents regardless of immigration status.*** Millions of low-income immigrants across the United States are ineligible for health insurance due to federal and state laws prohibiting them from obtaining public insurance. Many states have begun to expand access to non-citizens, and recently the federal government announced plans to include DACA recipients in Medicaid. States should take active steps to expand coverage to immigrants, regardless of status.
- ***Implement 12-month continuous eligibility regardless of changes in income,*** as some states have already done. This move would significantly reduce the administrative burden of enrollees needing continual eligibility documentation and prevent the “churn” caused by frequent wrongful disenrollment.
- ***Reduce wait times by hiring and training sufficient staff*** to process new applications and renewals in an efficient and timely manner and provide assistance to enrollees as they call in or arrive at offices. (Most states’

Medicaid programs are currently extremely understaffed.) This measure will also reduce the number of individuals wrongly disenrolled, reducing the overall workload for state agencies. An estimated 45 percent of those who lose coverage through the renewal process during the PHE unwinding will still be eligible and can apply again.²⁴ Reducing wait times and giving enrollees the support they need in re-enrolling will also reduce the time enrollees spend re-enrolling. Many respondents recommended that Medicaid staff receive training on how to exercise patience and better treatment toward Medicaid recipients and those trying to enroll. They emphasized the importance of compassion for people in need.

- » If staff recruitment is a problem, **raise wages for call center and other agency workers.**
- » **Hire call center workers that speak other languages** for non-English speakers.
- **Make it easier to apply for Medicaid by implementing an “easy enrollment”** program, as some states have already done, that allows households to enroll in Medicaid by checking off a box on their state tax return.
- **Make it easier to renew Medicaid by automating renewal systems, allowing self-attestation of some basic information about enrollees, and aligning renewals with SNAP**, as some states have already done.
 - » **Build more robust automatic ex parte renewal systems using existing administrative data when possible** instead of requiring all enrollees to complete forms and submit documentation manually.
 - » However, **periodic administrative data checks should not be used to automatically disenroll individuals** without allowing sufficient time for enrollees to prove eligibility. Some states use automatic systems that regularly check administrative records; if the system finds that income has increased, it will automatically send a notice in the mail giving an enrollee only days to prove eligibility or become disenrolled.²⁵ This systemic flaw leads many enrollees to lose coverage even though they are eligible for coverage, as low-income workers are more likely to have monthly fluctuations in their income.
- **Improve online enrollment/re-enrollment software** to make it functional and easy for enrollees to use. If websites for enrollment work well, more enrollees can apply/re-enroll online, reducing the number that will need to apply/re-enroll over the phone, thus reducing the burden on call centers and wait times. Ensure websites work well on mobile devices, as low-income individuals are more likely to use a mobile device than a laptop or desktop computer.

Many respondents recommended that Medicaid staff receive training on how to **exercise patience** and **better treatment** toward Medicaid recipients and those trying to enroll.

Removing barriers to accessing health services through Medicaid

- **Cover telehealth appointments** to make it easier for enrollees to access services even when transportation is unavailable, or providers are not nearby.
- **Increase reimbursement rates for Medicaid providers** to prevent the loss of current Medicaid providers and encourage more providers to accept Medicaid-enrolled patients.
- **Require providers to accept Medicaid as a condition of receiving state operating licenses** to expand the network of providers that accept Medicaid.
- **Maintain an up-to-date and easily accessible list of providers who accept Medicaid.**
- **Establish monitoring and enforcement mechanisms to make sure Medicaid providers do not discriminate against enrollees with disabilities, LGBTQ enrollees, non-citizen enrollees, and undocumented enrollees.**
- **Institute quality metrics and increase oversight of Medicaid sub-contractors** like Maximus that provide eligibility, enrollment, helpline, and other administrative services to ensure the services support the public interest, not just private profit.²⁶
- **Provide comprehensive coverage for dental, vision, mental and behavioral health, and physical therapy.**

Medicaid must be protected and strengthened, including simplifying enrollment and renewal requirements so everyone eligible can get coverage. Healthcare is a public good, and it is vitally important to fix our broken healthcare system so that all people have access to low-cost, quality, and easily accessible health care.



TECHNICAL APPENDIX

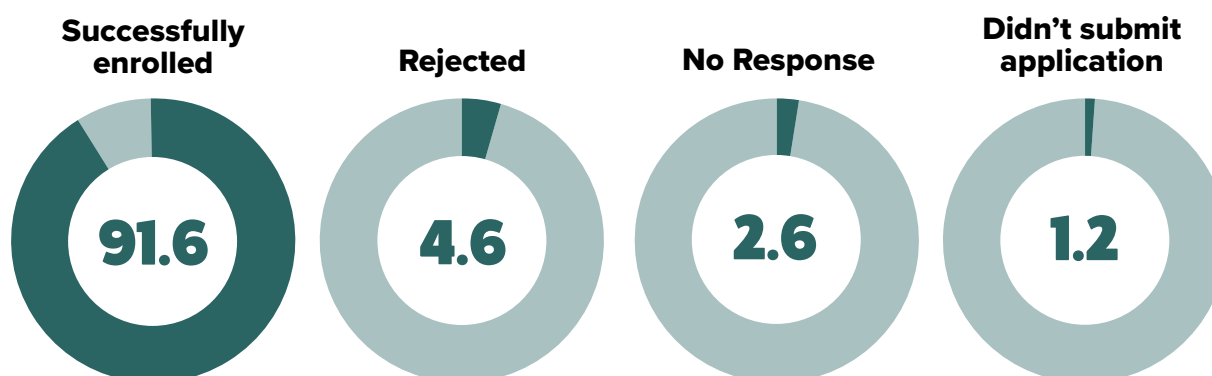
Between September 2022 and February 2023, a total of 2,937 individuals from 27 states completed the survey. Our outreach focused on 14 states where the participating networks have affiliate organizations; 2,821 surveys, or 96.1 percent of our overall sample, came from these states. Only individuals who had applied for or been enrolled in Medicaid since January 2020 were eligible to complete the survey. Surveys were collected through Survey Monkey; two versions of the survey were provided, in English and Spanish. Survey participants were recruited by affiliate organizations of the three networks (Center for Popular Democracy, Make the Road, and People's Action Institute) through in-person outreach, phone banking, organization websites, and social media. Most affiliate organizations provided stipends for participation to survey respondents in their state.

Characteristics of survey respondents

	Percentage of survey respondents
Latinx	52.1
White	25.4
Black	17.8
Native American	1.7
Asian	1.7
Pacific Islander	0.4
Middle Eastern	0.6
Prefer to self-describe	1.0
Female	63.7
Male	33.7
Nonbinary	1.1
Trans	0.8
Prefer to self describe	0.3
Immigrant	21.9
Have a chronic illness or disability	27.6
Has experienced discrimination based on a prior criminal conviction	23.9
Enrolled in emergency Medicaid	16.4
Completed the survey in Spanish	40.1
Applied during the pandemic	48.6

What was the outcome of the applicant's attempt to enroll in Medicaid?

Percentage of survey respondents



	Number of surveys collected	Percentage of survey respondents
New Jersey	501	17.1
New York	415	14.1
Nevada	393	13.4
Connecticut	337	11.5
West Virginia	179	6.1
Ohio	145	4.9
Indiana	129	4.4
California	120	4.1
Pennsylvania	120	4.1
Vermont	110	3.7
Michigan	103	3.5
Missouri	102	3.5
Delaware	88	3.0
District of Columbia (DC)	79	2.7
All other states*	116	3.9
All states	2,937	100.0

* Other states included Arkansas, Alaska, Maryland, New Hampshire, Colorado, Florida, Alabama, Hawaii, North Carolina, Texas, Maine, Massachusetts, and Wisconsin

ACKNOWLEDGMENTS

This report was written by Sarah Thomason of Movement Economics working with People's Action and Eli Vitulli of Center for Popular Democracy. This project was a collaboration between the Center for Popular Democracy, Make the Road New York/States, and People's Action Institute networks, including:

Alaskans Take a Stand

Arkansas Community Organizations

Connecticut Citizen Research Group

Hoosier Action

Make the Road Connecticut

Make the Road New Jersey

Make the Road Nevada

Make the Road New York

Make the Road Pennsylvania

Michigan United

Missouri Jobs with Justice

New Jersey Citizen Action Education Fund

POWER Los Angeles

Opportunity Knocks Delaware

Our Future West Virginia

Rights and Democracy Institute

River Valley Organizing

SPACES in Action

Texas Organizing Project

This project was funded by the Robert Wood Johnson Foundation.



ENDNOTES

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