

# Voices of Medicaid Enrollees

## The Importance of Consistent Coverage





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## About the Association for Community Affiliated Plans

The Association for Community Affiliated Plans (ACAP) is a national trade association which represents not-for-profit Safety Net Health Plans. Collectively, ACAP plans serve more than twenty-two million enrollees. For more information, visit [communityplans.net](https://communityplans.net).

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# Executive Summary

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More than 80 million people have relied on Medicaid or the Children's Health Insurance Program (CHIP) for health coverage in 2021.<sup>1</sup> But many are at risk of abruptly losing coverage, often for reasons unrelated to their underlying eligibility. This phenomenon, known as eligibility "churn," is unique to Medicaid and CHIP and has been shown to contribute to loss of coverage, foregone care,<sup>2</sup> and worse health outcomes.<sup>3</sup> At the start of the COVID-19 public health emergency (PHE), Congress authorized a "maintenance of effort" (MOE) provision that halted churn by prohibiting Medicaid disenrollment for the duration of the PHE. All 50 states adopted the provision.

To explore what this continuous eligibility protection means to Medicaid enrollees, ACAP and NORC at the University of Chicago conducted interviews with 15 Medicaid enrollees who would typically be at risk of churning but were protected during the PHE. The study sought to learn more about their experiences with the MOE provision and to hear, in people's own words, about the value of the Medicaid program to their lives.

The interviews showed that:

- Inconsistent coverage before the enactment of the MOE led to increased stress, canceled appointments, unexpected medical bills, and uncertainty about the effects of work hours on eligibility.
- Enrollees depend on Medicaid coverage; uncertainty about eligibility criteria and processes causes stress.
- Having health insurance coverage is a priority for most individuals, offering peace of mind related to managing the costs associated with health care-related expenses.
- Having Medicaid coverage and not having to worry about the costs associated with medical visits was the impetus behind enrollees accessing vital, and at times lifesaving, care.
- Medicaid promoted access to both prenatal and postpartum care while reducing costs associated with delivery.

Medicaid coverage is critical to ensure that individuals with low incomes can access care when they need it. However, the threat of disenrollment causes people to choose between other basic needs, such as increased income and seeking health care for themselves and their children. This research suggests that extending the protection from gaps in Medicaid coverage provided by the MOE requirement would vastly improve enrollees' health and well-being. A policy of 12-month continuous eligibility for all people on Medicaid, including children and their parents, people receiving treatment for substance use disorder or other chronic conditions, as well as other individuals, would benefit the people highlighted in this report and the tens of millions of people in the United States who rely on Medicaid.

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# Introduction

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Medicaid is the largest source of health coverage in the United States. In 2021, more than 80 million people relied on Medicaid or the Children’s Health Insurance Program (CHIP) for health coverage.<sup>4</sup> But many who rely on Medicaid are at risk of abruptly losing coverage for reasons unrelated to their underlying eligibility. This phenomenon, known as eligibility “churn,” is unique to Medicaid and CHIP and has been shown to contribute to loss of coverage, missed care,<sup>5</sup> and worse health outcomes.<sup>6</sup> Eligibility churn disrupts patients’ access to health services and raises administrative burdens for states, health care providers, and health plans.

At the beginning of the COVID-19 pandemic, Congress temporarily halted Medicaid churn by authorizing a 6.2 percentage point increase in federal Medicaid matching funds for states that met certain conditions, including a cessation of Medicaid disenrollment for the duration of the public health emergency (PHE). This provision, known as a “maintenance of effort” (MOE) requirement and adopted by all 50 states, assured that people who rely on Medicaid would not have it revoked in the middle of a historic pandemic.

Some states had previously offered protections against churn. Before the pandemic, about half of all states guaranteed 12-month continuous eligibility for all children who qualified for Medicaid or CHIP, and two states offered it for adults.

In some states, pregnant and postpartum women also benefit from continuous eligibility. Current policy requires Medicaid programs to cover people with low incomes (up to 138 percent of the Federal Poverty Level) through 60 days postpartum. Recently, Congress offered states a five-year option starting in 2022 to extend 12-month continuous eligibility for postpartum women.<sup>7</sup> Several states have also proposed demonstration projects to the Centers for Medicare & Medicaid Services to extend the postpartum Medicaid coverage period before the new law takes effect.<sup>8</sup>

This extension is intended to improve access to care for women who experience postpartum depression or chronic diseases such as cardiovascular disease and hypertension exacerbated by pregnancy. It also provides coverage for preventive services such as intrapartum care and contraception.

Medicaid continuous eligibility—protection from sudden disenrollment from Medicaid—would provide a powerful tool to improve enrollees’ health and sense of well-being. To explore what this protection means to people on Medicaid, ACAP and NORC at the University of Chicago conducted qualitative interviews to better understand the experiences of Medicaid enrollees who would typically be at risk of churning but who were protected during the PHE. The study sought to learn more about their experiences with the MOE provision and to hear, in people’s own words, about the value of the Medicaid program to their lives.

The study explores a series of research questions, which include:

- Did covered individuals experience any changes to the consistency of coverage during the PHE? Did they notice any differences compared to the period before the PHE?
- If disruptions to coverage were experienced, what was the reason for those disruptions?
- How well were Medicaid enrollees informed about the MOE, and how do they feel about the end of continuous eligibility when the PHE concludes?
- What is the value of Medicaid to enrollees?
- What role does Medicaid play in the physical and mental health, ability to work, finances, and well-being of enrollees?

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# Findings

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Fifteen people from across the United States who had at least 12 months of continuous Medicaid coverage during the public health emergency participated in semi-structured interviews to discuss their experiences with Medicaid and the MOE protection during the PHE. Of these, 12 had Medicaid-only coverage, two had dual Medicare-Medicaid coverage, and one had employer-sponsored insurance but had a child with Medicaid coverage.

Participants included residents from California, Georgia, Illinois, Kansas, Michigan, New Jersey, Pennsylvania, Texas, and Washington. One person was enrolled in Kansas's "Working Healthy" program, which provides Medicaid coverage for people with disabilities; one was enrolled in Georgia's "Transitional Medicaid" program, which provides coverage to parents and caregivers who have incomes too high to qualify for traditional Medicaid. Both programs include work requirements. Eleven of the 15 participants were female adults.

Though all people we interviewed reported having seasonal or hourly work during the recruitment process (a requirement for eligibility for the study), seven were no longer working at the time of the interview. They represented vocations such as instructor, tutor, barber, waitress, secretary or receptionist, nanny, package handler, editor, security guard, accountant, school administrator, and home health worker. Those who were no longer employed at the time of the interview reported that they were not working due to a recent health issue such as having open-heart surgery, the recent birth of a baby, or that they had lost their jobs due to the pandemic.

Three women had given birth between four and 12 months before the interview and discussed their prenatal, delivery, and postnatal experience with Medicaid. All three had Medicaid coverage since at least April 2020 and continued to be covered at the time of our discussion.

The appendix provides more information on the methods for this study.

## Characteristics of the 15 Participating Individuals

- Nine parents of at least one child covered by Medicaid
- Three individuals receiving treatment for substance use disorder (SUD)
- Four people currently seeking treatment for diabetes
- Four people who were diagnosed with and sought treatment for COVID
- Three people who had delivered a baby within the last four to 12 months

## Medicaid Enrollees' Experiences with Continuous Eligibility

Two-thirds of people reported prior loss of Medicaid coverage. About half lost coverage due to administrative reasons, and the other half due to income or work requirements. Two people who lost coverage were unsure why.<sup>9</sup>

## Inconsistent coverage leads to stress, uncertainty and unexpected bills

Most of the people we interviewed reported that losing coverage had lasting impacts on their lives, including:

- **Stress and fear related to redetermination and the re-enrollment process.** Some individuals expressed their anxiety about the redetermination outcome: "You can be cut off of Medicaid if the Medicaid office forgets to call you, if they call the wrong number, or if you don't answer the phone." A few discussed frustrating experiences trying to get their family re-enrolled in coverage after losing it for administrative reasons or because they had worked too many hours in a given week. For example, one person relayed an experience where his family lost



their Medicaid coverage because he had picked up a few extra shifts at work in one week. The Medicaid office considered his income only for those few weeks rather than his longer income history. He tried calling the Medicaid office several times to get his family re-enrolled, reporting that he waited for hours only to eventually be hung up on. Another person said of their re-enrollment experience, “You pray that you get a nice person to talk to.”

- **Canceled appointments and unexpected medical bills.** For example, two people reported an emergency room visit during the period when they had lost coverage. One was still paying for the visit at the time of our interview; the other was more fortunate: the hospital offered to write the visit off as uncompensated care, underscoring the negative impact that churning can have on hospitals and other providers when they decide against trying to obtain payment for services during periods where patients have lost their Medicaid coverage.
- **Fear of working both too many hours and too few hours,** and related experiences with loss of coverage due to both. People we interviewed reported that this fear held them back in their careers and kept them from taking higher-paying jobs: “When you have to make a certain amount to qualify, it kind of keeps you from reaching your other goals.”

## Maintenance of Effort: Most were unaware of continuous eligibility protection

One person reported receiving a letter from their Medicaid agency informing them that they would have continuous eligibility throughout the PHE. Another became knowledgeable about the MOE protection via a television commercial. The remaining people were unaware of the MOE before being interviewed. Some noticed that they had not recently been asked to go through the redetermination process but were unaware of what policy had caused the change. Some thought the additional flexibility resulted from a decision made by their caseworker or another employee from the Medicaid office. Others reported that they had continued to go through the redetermination process throughout the pandemic but, when prompted, noted that other benefits such as electric benefit transfer (EBT) or Supplemental Nutrition Assistance Program (SNAP) were included in the redetermination processes they described.

## Enrollees depend on Medicaid coverage, fear losing eligibility

**Upon learning about the MOE protection, many of the people we interviewed reported feeling “relieved” and “less stressed.”** One person noted: “[Not going through the redetermination process] saves me a huge headache...especially now that I have kids. I have to worry about insurance for my son, my daughter, and then me...and it’s hard to keep track of when I need to reapply.” She reported being particularly worried about maintaining health insurance coverage during the PHE because she wanted her children to have health care if they got sick.

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*Whenever it’s time to renew, I’m like man, we’ve got to pray that we get [Medicaid] and they will not [take it away] like they did last time. Especially the way things are going right now and my wife not being able to work...Knowing in fact that they can’t [kick you off Medicaid] right now, it’s a lot of stress off my back... When you’re a parent, you’re scared for whatever and you just go and just take [your children to the doctor]—we’re always very careful. Anything, a fever, anything, we’re ready to go to the doctor. —J.L.*

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**When asked how they felt about the MOE coming to an end, some individuals expressed fear of losing eligibility due to income requirements and stress about the process, along with feelings of uncertainty.** One person said, “You never know...income fluctuates, and you could get sick at any time.” Several noted how much they depend on Medicaid, with one person saying, “It would be heartache if I wasn’t provided (Medicaid).” Other people expressed confidence about their continued eligibility even if the MOE ends, but the reasons they cited for their confidence were misplaced. Some felt their ongoing eligibility would be based on chronic conditions, age, and prior history of Medicaid eligibility. However, Medicaid redetermination is not based on these criteria. Those who felt reassured of their continued eligibility had no prior experience of losing their Medicaid due to administrative requirements or income.

## A few extra shifts led to a loss of coverage and medical debt

J.L. is a husband and father of three kids ages 2, 12, and 13. He has been a security guard for about seven years. Two of his three children have had consistent Medicaid coverage since May 2020. Though his family had previously had Medicaid coverage on and off over the years, they became eligible for Medicaid again when his wife lost her job during the COVID-19 pandemic, which has made life a little harder. J.L. describes living paycheck to paycheck and having to be very mindful of expenses to ensure bills are paid. Sometimes, he relies on family to borrow money to make ends meet and on food stamps to feed his family. Despite the financial difficulty, he notes he is grateful to have food and shelter for his family.

*It's hard but, like I tell my wife, as long as we've got a roof over our head and food on the table, man we've just got to be thankful we've got that.*

J.L. describes a prior experience where he lost Medicaid coverage after he worked overtime for a few weeks. During this uninsured period, his son—a baby at the time—got an earache that caused him to spike a fever. J.L. accrued a \$1,600 emergency room bill along with other out-of-pocket costs. Because of this experience of losing Medicaid coverage and the costs incurred by the family during their uninsured period, J.L. notes he no longer works overtime, despite needing the extra money, because his family needs the coverage and he is afraid to lose Medicaid. He also notes having prior medical debt from when his daughter got sick, and he had to take her to the emergency room when they did not have health coverage.

*It was frustrating because, for those three months that we didn't have [Medicaid], we weren't able to go to the doctor, or we would have to go to the emergency room...I think one time or two times during that time, my little boy got sick, so I had to take him to the doctor, and we had to pay regular, out of pocket. That was very frustrating and hard, because I mean we're already struggling as it is, and you take my Medicaid away, now I've got to pay out of my pocket for a doctor and then the medicine too, we had to pay for that, and that's not cheap.*

Having health insurance coverage is one of J.L.'s top priorities for his family. He notes his medical expenses are low, with little to no out-of-pocket costs with Medicaid. He notes that, as a parent, he is always concerned for his kids' health and well-being. He wants to ensure that they are taken care of and receive all their preventive visits, regular check-ups, and dental care. Medicaid coverage reduces his stress and worry about medical costs.

*Now I know whenever my kids get sick, I can just take them to the doctor, and I don't have to be worrying about...how am I going to pay for this medicine? You don't know how much that's going to cost...I want my kids to have—especially when they're sick—I want them to have good medicine...I try to give my kids everything I can give them.*

J.L. notes that knowing that MOE protection is currently in place reduces his stress. He is worried all the time about finances, losing Medicaid coverage, and the well-being of his family.



# The Value of Medicaid Coverage for Enrollees

## Medicaid lowers out of pocket costs, allows access to lifesaving medication

**Individuals participating in interviews described Medicaid as critical in reducing medical debt or unaffordable health care costs.** Some people said that having Medicaid reduced their medical expenses, noting that without coverage they likely would have had unaffordable medical bills, leading to medical debt. Some reported being burdened by prior medical debt from periods when they lacked or lost Medicaid coverage; others incurred debt from high out-of-pocket costs associated with previous employer-based coverage.

*For those...months that I didn't have [Medicaid, hospitals] were sending me bills all the time, and calling me every day. But I can't make payments because I barely can afford what I'm doing right now. So you know, it goes towards my credit probably...There was another time our other daughter got sick and we had to take her [to the emergency room] and that cost us money too. So I think I had [a medical bill of] \$4,000-\$5,000 for the emergency room, total. —J.L.*

**For some, health insurance coverage allowed people to afford medications to treat serious health conditions.** Most people reported minimal out-of-pocket costs due to no copays, deductibles, and no or minimal costs for prescription medications. For those with chronic conditions like diabetes, Medicaid facilitated access to lifesaving medications, such as insulin, allowing them to control their chronic conditions. For example, people with chronic conditions reported paying only \$1-\$4 for their prescription medications. Individuals described how copays, deductibles, medications, and other costs were unaffordable on top of monthly premium payments under their employer-based insurance coverage. One person explained that having lost their job due to the COVID-19 pandemic, without Medicaid they would have had unaffordable COBRA costs for coverage: “If I had to pay for medical expenses like COBRA, you know \$600-\$700 a month if I didn't have Medicaid, because I have to keep my health if I want to continue to live, then no I wouldn't [be able to afford it].” Another noted that she would not have been able to afford adding her children to her employer-based insurance coverage.

**Most people reported that Medicaid coverage reduced their stress and worry about finances.** They described being grateful for Medicaid coverage and how not having to worry about medical bills gave them “peace of mind” and helped them have “a few extra dollars” to cover other areas of need. They spoke of the stress associated with not knowing how much doctors' visits would cost them or if they would be able to afford the copays or other medical fees. Many described having Medicaid coverage as a “privilege” and a “blessing” and noted they did not know how they would be able to afford health care otherwise.

## Medicaid saved her life by covering insulin and major procedures she needed

R.F. is a 72-year-old woman living in Kansas City. She is retired but works part-time as an editor. She has dual Medicare and Medicaid coverage. Though she notes being able to meet her monthly expenses, it can be challenging when extra costs come up. For example, when her computer, which she needed for her editing job, broke down, finding the money to replace it was difficult.

R.F. was diagnosed with diabetes 25 years ago. She describes her diabetes as “difficult to control,” noting she has progressed from needing an oral medication once a day to being on two kinds of insulin. Her out-of-pocket costs for maintaining her chronic condition are low; for example, a vial of insulin only costs her \$3.

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R.F. is grateful for her dual coverage, which she credits for her ability to afford her medications and for keeping her alive. Specifically, she credits Medicaid for taking care of the cost of medications that Medicare would not cover.

*Anytime I need anything, it's there. It's right there. I've never been turned down for medicine...it's all covered...I'm very grateful to live in a country where all of that is taken care of. If I lived in a country where that couldn't be taken care of, I'd be dead by now, for sure.*

R.F. also has other ongoing health issues. She is grateful to have minimal out-of-pocket payment for the various procedures she has had over the last couple of years. Last July, she had a procedure to remove abnormal tissue growth. She was out of work due to the COVID-19 pandemic at the time, so she is grateful that her dual coverage resulted in only \$80 in out-of-pocket costs for the procedure. She also had a heart procedure a few years ago where she needed to receive an angioplasty and a stent, and her insurance fully covered her procedure.

*I'm doing better now financially but, at that time, I was out of work and had no savings so I would not have been able to afford to pay those medical bills that I incurred at that time...So I'm very grateful that Medicaid stepped in and took care of it during the time...Medicaid is a lifesaver for people with no money... otherwise you just sit home and are sick.*

R.F. credits her dual Medicare and Medicaid health care coverage with her being alive right now because she does not have to choose between eating and taking needed, lifesaving medications.

*Getting old can be very hard because things start to fall apart. Everybody has some organ system that falls apart in some way. I'm a diabetic, which affects several organ systems, and then I also had these [other] problems and being low income and sometimes without income, I've been very grateful for the coverage that I've had, that I don't have to pay for out of pocket for, for some of the expensive stuff—especially the cost of insulin.*

## Most are willing to make financial sacrifices to keep Medicaid coverage

### **Most people we interviewed are meeting their monthly expenses, but many are just getting by.**

Although some individuals noted they do not have to go without anything they need, the majority described forgoing eating out, leisure activities like going to the movies or taking trips, or purchases like clothes, cars, or even hair and house products to ensure their expenses are minimal and they can meet their monthly bills.

One person described not buying all his prescribed medications, purchasing those he deemed critical and forgoing others to keep expenses down. Most people said they prioritized rent, food, and utilities, considering them necessities they cannot live without.

*You really only need shelter and water and food...But if I had to classify something [as] a want, there are certain times where I have to cut back in order to make sure that the necessities are taken care of...I have all the bills being on me. It can, at times, get difficult because [income] fluctuates. You get one bill paid and then the next bill comes and, sometimes, you got to rob this area to get this area and, so, it can be frustrating at times. —B.W.*

To meet monthly expenses and payments, many people noted they:

- Develop and stick to strict budgets and live frugally
- Seek financial support from family
- Take on extra work or participate in research studies and focus groups for extra money
- Find lower-cost or free substitutes, such as taking public transportation in lieu of owning a car or creating free entertainment activities for families (like outdoor picnics in the summer)

For a few who lost their jobs due to COVID-19, unemployment payments and SNAP help bridge the gap to meet monthly expenses.

**Most individuals reported that keeping their health insurance coverage is a high priority, even if they must make financial sacrifices to afford coverage.**

- Almost all people who were asked whether they could pay \$50 per month for Medicaid coverage stated that they would reallocate their budget to keep their health insurance. Many who said they would keep their insurance reported that financial sacrifices would be necessary to afford the \$50 health insurance fee, such as reducing eating out, cutting phone or cable bills, or budgeting very carefully. One person reported that they would risk being uninsured.
- When asked if they could pay \$150 per month for coverage, half of the people said they would pay the monthly fee; the other half either said they would go uninsured or that they were unsure. Those who reported they would pay for the insurance characterized health coverage as an absolute necessity for which they would make sacrifices. One participant said, “I don’t know what I would do, probably try to sell things on eBay.” Those who stated that they would go uninsured noted that \$150 was simply unaffordable even if they would prefer to maintain health coverage.

Many parents placed a far higher priority on their children’s health care than their own, noting that they would make sure their children received the care they needed even in the absence of Medicaid and even if it was unaffordable for them.

## \$50 per month

*I would dig it out of something else, and I’m already down to a place where I can’t dig it out for very much...any extra money has got to be carefully budgeted. —R.F.*

*[I would forgo] the phone bill...or cable... Health insurance would be definitely more important than the cable. —B.W.*

## \$150 per month

*I mean with my situation right now, financially that would be much, much harder to figure out. I mean, then we’d be talking about a change in insurance coverage on our car or something or making a higher deductible there, that type of switching finances around, I think would be a lot more difficult, but we utilize it enough to where I would have to make it work. —B.J.*

**Throughout the interviews, people underscored the value of health insurance in enabling access to critical care.** Several reported that having Medicaid coverage and not having to worry about the costs associated with medical visits was the impetus behind them accessing vital, and at times lifesaving, care. For people with critical conditions, Medicaid coverage helped them decide to access support services and treatment they needed. For example, one person reported that he would not have gone to the hospital for COVID-19 treatment if he had not had Medicaid. Another reported that she would not have received needed open-heart surgery. A few people with diabetes said they would not have received their diagnoses or necessary treatment without Medicaid. Parents reported that Medicaid coverage offered protection for their children and peace of mind that they could receive treatment in the case of an emergency.

## Without Medicaid, he “probably would have been another statistic”

S.H. is a single male adult living in Detroit, Michigan. He has been unemployed since October 2018. While unemployed and lacking health care coverage, he was taken to the hospital with high blood sugar and diagnosed with diabetes. At the hospital, he learned about and was enrolled in Medicaid. S.H. is currently searching for a job, but a recent open-heart surgery eliminates jobs requiring physical exertion. He meets his monthly expenses through unemployment benefits, Medicaid coverage for medical expenses, and SNAP for food. S.H. says that Medicaid coverage reduces stress and worry associated with financial expenses.

*[Medicaid] enabled me to be more proactive [with my health rather] than reactive...I think it's definitely become [less] stressful because... it's a tool that you know we're blessed here in the United States to have.*

After suffering a heart attack, S.H. had open-heart surgery in February 2021. He contracted COVID-19 about a month later. Because of his Medicaid coverage, he was able to go to the hospital when he could not breathe and got access to antibiotics and Remdesivir. S.H. notes that without Medicaid coverage he would not have sought treatment for COVID-19 at a hospital out of fear of incurring a large bill. S.H. is grateful that Medicaid has covered the costs of his heart attack hospitalization, open-heart surgery, COVID-19 hospitalization, follow-up doctor visits, and medications.

*If I didn't have the medication coverage, I would have been stuck in whatever and just kind of like deal[t] with it, and I probably would have been one of the 580,000 plus people that have died so far in America [from COVID]...I was so thankful [to have Medicaid] because I wouldn't have went [to the hospital] because I was like okay, well, that's another \$100,000, that's the bill for just being there for five days. I wouldn't have went and probably would have been another statistic.*

S.H. reports that Medicaid has empowered him to take care of himself and his health. He notes that he was a caregiver for his father before he passed away and often put his father's health before his own. Heart disease runs in his family, and he has lost his mother, father, and brother. Medicaid coverage has provided him with access to services related to depression and anxiety, including therapy and psychiatry services. It also covers the management of his diabetes, including medications and insulin. Other Medicaid benefits S.H. has used recently include reading glasses, bifocals, and dentures. He is grateful to have Medicaid to support his health and well-being.

*Since October of 2018, it was like \$300,000 that Medicaid has paid out. So, I mean you do the math. That's almost three years, 36 months, that's 10 grand a month, almost eight grand a month that I was saved, which would have been more of a financial burden. Obviously, you can't declare bankruptcy on medical bills. I mean, it's basically something I'd be living with the rest of my life at 49 years old.*

## Without Medicaid, many would have skipped needed care

Many of the people we interviewed noted that, without Medicaid coverage, the potential cost of services would have dissuaded them from seeking necessary health care services such as consistent primary care. All people reported that Medicaid coverage made it easier to access primary and

preventive care. One person noted, “I’ve been going to the doctor pretty frequently, and that might not be the case if I didn’t have [Medicaid].” Almost all parents noted Medicaid allowed their children to receive their well-child and preventive care visits. Still, most noted they would be inclined to skip these visits for themselves in the absence of insurance coverage. One parent said, “With [the kids], that’s different. I would always make sure they had what they needed.”

## Medicaid helps keep his diabetes and high blood pressure under control

A.B. is a 44-year-old man from Philadelphia, Pennsylvania. He has been unemployed for the last four to five years and has had Medicaid coverage for seven or eight years. He was diagnosed with diabetes about 12 years ago. A.B. credits Medicaid with helping him develop a plan to manage his diabetes and high blood pressure: “Before Medicaid, there was no consistent plan for handling my illnesses.”

A.B. notes that Medicaid coverage has kept his out-of-pocket costs to a minimum. He pays only around \$1 each month for his diabetes medication, which he takes twice a day. He notes that it would be very difficult for him to access his diabetes medication and pain medication without health coverage. He notes that, when he did not have health coverage, he did not take his medication.

*I’m able to get more sleep. My [A1C] levels are going in the direction that they’re supposed to be going in. I’m able to get the help and the treatment that I need, when I need it for the most part, so yeah, definitely more of a benefit to have it than to not have it.*

A.B. notes that Medicaid also makes it easier to access health care, see a specialist, and obtain a referral. Since having Medicaid, he has obtained regular care for the maintenance of his diabetes, including seeing a foot doctor, eye doctor, dentist, and cardiologist.

The few people who reported a need for vision or dental care were grateful to have coverage for these services under Medicaid. The majority of people noted they had received dental care in the past year, and all who received it said that Medicaid covered it and their co-payment was minimal. One person reported, “[My children and I] see the dentist for cleanings every six months. Cavities, fillings, all that...if it weren’t for [Medicaid], I don’t think I would keep up with all of that. It would just be ‘brush my teeth and do my best.’” People who took advantage of Medicaid vision benefits used it for yearly vision exams and glasses or contacts. One parent of a child with esotropia, a condition where one or both eyes are turned inward, said, “If I didn’t have [Medicaid], it would be a huge obstacle because my child has esotropia, and it requires appointments with specialists. If I had to pay out of pocket, it would cost me thousands of dollars that I couldn’t have afforded, and it would have been a tough, tough decision.”

*Having [Medicaid has] helped a lot. I don’t have to worry when I call and set up an appointment for the doctor. I know it will be taken care of... [Because of Medicaid,] we’ve got a permanent doctor we can always call, we’ve got a permanent dentist we can always call, so it’s very helpful. I don’t have to worry about who is cheaper or who has payment plans, you know stuff like that. —J.L.*

**Medicaid also facilitated access to mental health and substance use services.** Half of the people we interviewed accessed counseling through Medicaid for depression, to process trauma, or to manage anxiety.

Most reported they were satisfied with the mental health care they received through Medicaid, although a few reported that they would have liked to have a broader choice of providers.

## Medicaid helped her to access substance use disorder medication, counseling services for her children

B.J. is a single mother of two teenagers, ages 15 and 16. In 2020, she lost her full-time job as an office manager due to the COVID-19 pandemic, and her children's father passed from COVID-19. B.J. started delivering food for DoorDash to help make ends meet. She describes being able to pay her monthly expenses as long as she keeps working for DoorDash, though she notes it is not always easy to buy necessities like shoes and clothes. She is also currently going to school for software development.

B.J. has had Medicaid coverage for close to 10 years; both of her children are also covered by Medicaid. Medicaid coverage has been instrumental in helping her manage her finances, and she notes she would not be able to afford coverage and health care services without this coverage.

*I mean I don't know what I would do if I had to pay copays and deductibles and stuff like that. I know I've been on the borderline of being able to qualify to get it, worrying that maybe this year I made too much and I'm not going to get it or something, and I don't know how I'd be able to afford my health care.*

In addition, Medicaid has helped B.J. manage her health and SUD. Medicaid pays for Naltrexone, a medication-assisted treatment used to support recovery from SUD. Since she started taking Naltrexone in February, her cravings for methamphetamine have diminished. However, she is still attempting to access outpatient counseling services, which she noted she would like to receive to further help manage her SUD.

Medicaid coverage has also helped B.J. manage her ongoing health conditions, including her continuous positive airway pressure (CPAP) therapy machine and visits to respiratory specialists. Medicaid coverage also assures that her two children have access to needed services, including mental health services and therapists. Overall, Medicaid coverage lessens B.J.'s financial stress and contributes to her overall happiness and emotional well-being.

*If I didn't have the coverage I have, then I feel like I couldn't, you know? I mean, there's been situations where I feel like I probably could have even died if I didn't have the coverage I had. So, yeah, [Medicaid] definitely affected my life as a whole, and then also my emotional or mental health has been way better knowing that I have the coverage, and you know I can be proactive in taking care of health care stuff for me and my kids.*

## Medicaid promoted access to both prenatal and postpartum care while reducing costs associated with delivery

**All three women who had recently given birth reported they would not have attended all the recommended prenatal appointments without Medicaid coverage, citing concerns about affordability.**

Despite having high-risk pregnancies, two women noted that they would not have attended all prenatal

appointments without Medicaid coverage. One person stated, "If I didn't have health insurance, I probably would have just gone bare minimum...I mean, I would have skipped a lot of [prenatal] appointments, which would have affected my well-being." Another reported she had transportation issues. Medicaid made it possible for her to attend all her prenatal appointments, offering her both transportation to appointments and a service that provides prenatal care at home. Another said, "Every pregnancy is different, and you need a lot



of care. So just having the peace of mind, knowing that you're taken care of, and there are good quality health care professionals who are willing to help you and take care of you, it's a huge, huge benefit."

**As delivery approached, Medicaid alleviated concerns about the cost of the delivery.** People reported that Medicaid coverage was critical to relieving stress associated with the delivery. One person who had a previous delivery while uninsured reported that she had "a little bit of [post-traumatic stress disorder] PTSD...I wasn't even scared about giving birth. I was more scared about the big bill that was going to come afterwards." Another who had delivered her previous child while under employer-based coverage noted substantial differences in costs, noting she was grateful that she did not have to worry about the out-of-pocket costs associated with delivery.

**All three women said that they attended postpartum visits, which were critical to identifying postpartum depression and providing needed mental health services.** Two received a screening for postpartum depression at their postpartum visit, one requiring treatment. One person was referred to specialty counseling eight weeks postpartum and received follow-up care one year following her birth to address additional concerns.

**All three received additional supports from Medicaid that helped them recover from delivery and adjust to life with a newborn.** All three women reported receiving postnatal supports, including equipment such as breast pumps, car seats, and strollers; breastfeeding support; and social services. One reported that she had

*It would have been very stressful not knowing how much the cost is going to be because I don't know if I can ever pay it back. The fees are so high, it's in thousands. It's very, very stressful, just not knowing what you're going to get into, what to expect. There are too many unknowns. Yes, I had an easy delivery, everything worked out well, I was very fortunate. But you just don't know what to expect. Too many unknowns and it's very stressful because you're thinking about all of those things and the costs associated. —G.P.*

had two babies by C-section in less than 15 months. She was offered 30 days of postpartum support to help ease her transition back home following the birth of the second child, in recognition of the difficulties of having two babies during the pandemic. She was also offered continuous support: "They had seen me the first two weeks postpartum, and I had a mild case of postpartum [depression] with my son. It was just so overwhelming. So my doctor...she was really good and attentive and always made sure...Did I have food? Did I need anything? Was I running out of resources for the two babies?"

## **She lost her job during the pandemic—Medicaid provided affordable access to the care she needed during a high-risk pregnancy**

D.M., a mother of two, lives in California. She and her husband lost their jobs due to the COVID-19 pandemic. When the organizations they worked for shut down, they lost their health benefits. D.M. found a new job a few months later, but the new company also shut down due to the Delta strain. She can pay her monthly bills, but there is no extra money for savings or other purchases. She prioritizes her bills and making sure her children have enough food.

D.M. received Medicaid coverage in April 2020. She had had Medicaid coverage while employed at a prior job where she was making minimum wage but notes that she had employer-based insurance through her last job until it ended. She notes she had her first child while on employer-based insurance. In addition to monthly premiums, she was charged nearly \$6,000 in delivery and NICU costs and copays for prenatal appointments and bloodwork. She noted that the out-of-pocket copays and medication costs were adding

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up; these costs came at a time when she was out of work due to doctor-recommended bed rest during her pregnancy, which meant the family had to rely only on the income of her husband, causing them to deplete their savings.

*It was mostly just copays on my private insurance that were adding up because \$25 to \$30 a couple times a week adds up very fast. And then, getting meds also was adding up because a couple prescriptions weren't covered by my private insurance. I was having to pay out-of-pocket.*

D.M. experienced preeclampsia, which caused her to have regular prenatal visits, do bi-weekly stress tests, and take medications to keep her blood pressure down. She noted that having Medi-Cal, California's Medicaid program, ensured she did not have to worry about costs associated with the delivery.

*When I had my son, I was still on my private insurance. And I noticed that they don't really tell you—well, obviously because you're in childbirth—but they don't tell you, 'To do this procedure or to do this is going to cost you this much deductible.' I never understood it because it was my first kid. So, when I had Medi-Cal it kind of made it like you don't have to worry about having a baby. You kind of just come, have your baby, and then there's no bill. And they also enrolled my daughter—before we left the hospital she had her insurance, which was a blessing because I had her early also as a preemie because of my preeclampsia. So, I wasn't worried about, 'Oh, my God, I don't have her coverage.'*

Her providers got her enrolled in WIC, which she did not even know was a resource at the time, and offered her various options like breast pumps, car seats, strollers, and childcare. D.M. was also screened for depression and offered access to counseling and other mental health services, given she had experienced postpartum depression with the birth of her son, and providers were also worried about the effects of the pandemic on her mental health. Medicaid has also helped her manage the weight she gained from her two kids, offering access to a nutritionist.

*My prenatal care was amazing, and they helped me so much. Even afterwards just with my postpartum care, they were still going above and beyond and asking me, 'Are you okay because of the pandemic and two babies under two? Do you want to go talk to someone?' So, they were on it. It was really good, actually.*

D.M. notes that her stress levels have decreased now that she knows about the MOE provisions, giving her confidence that her children are covered for any accidents or regular check-ups. She noted that when she first had Medicaid many years ago, her Medicaid was canceled because she did not know there was a redetermination process. She had to go to the emergency room and did not know that her Medicaid coverage had lapsed the previous month, resulting in a large medical bill. Luckily, the hospital was able to write off the cost and helped her reapply for Medicaid.

*Not having to worry about the insurance lapsing and not being able to be seen, especially with COVID because a little cough will make us go in just to make sure they don't have COVID, has been a huge help.*

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# Conclusions

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## **Most people expressed that their Medicaid coverage was very important to them. Some said that Medicaid saved their lives.**

Conversations with the 15 people who participated in this project underscore the critical—even “lifesaving,” in the words of several—importance of Medicaid coverage. Medicaid coverage ensured that individuals who routinely experienced financial uncertainty and stress related to paying bills could access care when they needed it. Many described how, in light of tenuous financial situations, they might have had to forgo even lifesaving health care for themselves in the absence of Medicaid coverage. Participants in this project described the ways in which Medicaid ensured they could receive the care they and their children needed, including primary and preventive care, as well as critical measures such as open-heart surgery, hospitalization for COVID-19 treatment, and ongoing care to manage diabetes.

People who had recently given birth universally reported they would have skipped prenatal check-ups had they lacked coverage; going without prenatal care can have dire consequences for both the child and the mother. Participating women also reported high levels of need for counseling and other forms of mental health treatment postpartum. These findings are consistent with existing literature, which has shown that Medicaid coverage significantly increases the use of health care services, raises the probability of diabetes detection and management, and lowers rates of clinical depression while reducing financial strain.<sup>10</sup>

Parents of children reported a different decision calculus. Parents were more willing to take on medical debt to get care for a sick child. However, the medical debt incurred by obtaining this care could have long-term implications for family finances and further contribute to their financial stress.

## **Because Medicaid coverage was so impactful, the idea of losing this coverage caused personal distress, and temporary increases in income that could lead to disenrollment were a source of stress.**

Eligibility churn leading to loss of coverage and care caused significant financial stress. Many people indicated they knew they could lose Medicaid at any time, while describing the anguish they would feel if they were to lose coverage. Some told personal stories about how working overtime or missing phone calls led to the loss of their Medicaid coverage. In some cases, such as the parent who was disenrolled from Medicaid after working a few days of overtime, people had the impression that the eligibility office had not followed proper procedures. Ironically, the financial consequences associated with losing coverage are in some cases directly linked to temporary increases in income. Getting a raise, temporary or permanent, should be helpful, not harmful, to individuals and families with low incomes.

## **Most people we interviewed were unaware of the current Medicaid eligibility MOE protection and lacked certainty regarding the process of redetermination and criteria that would impact their eligibility.**

People revealed anxiety at the idea of losing Medicaid eligibility during the redetermination process. Still, few understood how the process worked. Most people lacked certainty regarding how frequently eligibility was redetermined and which criteria would impact it. People who lost coverage during the redetermination process expressed frustration with cumbersome processes for re-enrollment following a loss of coverage, and many worried about working too many hours to maintain their Medicaid coverage.

Most people were also unaware of the current Medicaid eligibility maintenance of effort. Not knowing that this protection existed left them concerned about losing Medicaid coverage and, in turn, access to needed medical care.

**Medicaid is unlike other coverage because the threat of disenrollment hangs over the people it serves.**

Other coverage, such as Medicare and employer-sponsored insurance, does not penalize enrollees for mid-year increases in income, missed phone calls, or lost mail. The threat of disenrollment in Medicaid causes people to choose between other basic needs, such as increased income and seeking health care for themselves and their children.

Medicaid serves as a lifeline to more than 80 million people across the nation. The interviews conducted for this project consistently demonstrate the value this coverage provides in terms of access to care and diminished financial and personal stress. While the interviews show the degree to which people on Medicaid are profoundly grateful for this coverage, the lack of continuity built into the existing Medicaid eligibility policy often negatively impacts the people the program is designed to serve.

This research suggests that the protection from gaps in Medicaid coverage provided during the PHE by the maintenance of effort requirement has helped people on Medicaid. It also clearly illustrates how extending such protection beyond the PHE would vastly improve enrollees' health and well-being. A policy of 12-month continuous eligibility for all people on Medicaid, including children and their parents, people receiving treatment for SUD or other chronic conditions, would benefit the people highlighted in this report and the tens of millions of people in the United States who rely on Medicaid.

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# Appendix: Methods

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## Outreach and Screening

NORC conducted 15 interviews with Medicaid enrollees to discuss the value of their Medicaid coverage during the PHE. NORC identified Medicaid members who had at least 12 months of continuous Medicaid coverage during the PHE. Parents of individuals who were covered by CHIP were not interviewed, as CHIP recipients were not subject to the continuous eligibility MOE during the pandemic. The team sought to recruit at least three people from each of the following groups:

- People receiving treatment for SUD
- People who had recently delivered a baby or were expecting to do so
- People with chronic condition(s) and those currently seeking treatment for diabetes
- People who were diagnosed with and sought treatment for COVID-19
- Parents with children from states without continuous eligibility for children in Medicaid

Ultimately, those recruited to the study often fell into more than one of the above categories. For example, all postpartum women were also parents, and many people suffered from more than one condition.

People were recruited from a Medicaid panel held by Murray Hill National, a leading data collection and recruitment organization. To be eligible for the study, a person needed to:

1. Live in a state that did not have continuous eligibility in place before the PHE. (Adults from Montana and New York were not eligible to participate, and parents of children from any state with an existing child continuous eligibility policy were not eligible to participate.<sup>11</sup>)
2. Have current Medicaid coverage.
3. Fall into one of the five populations of interest.
4. Be a seasonal or hourly worker.

NORC recruited seasonal and hourly workers for interviews due to the likelihood they would experience income fluctuations. Income volatility is a predictor of Medicaid eligibility churn.<sup>12</sup>

## Interview and Analysis Process

NORC conducted interviews with recruited individuals using a semi-structured interview guide. The interviews were recorded with the participants' permission. Each lasted 30 to 60 minutes. People received \$100 cash as compensation for their participation. Tape recordings were sent to a professional transcription service, and transcripts were uploaded into the NVIVO qualitative analysis software package and coded. Codes were developed using the semi-structured interview protocol as a guide and analyzed to identify themes across interview participants.

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# Endnotes

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- 1 HHS. (2021, June 21). *New Medicaid and chip enrollment snapshot shows almost 10 million Americans enrolled in coverage during the COVID-19 public health emergency*. HHS.gov. Retrieved October 11, 2021, from <https://www.hhs.gov/about/news/2021/06/21/new-medicaid-and-chip-enrollment-snapshot-shows-almost-10-million-americans-enrolled.html>.
- 2 Sugar, S., Peters, C., De Lew, N., & Sommers, B. D. (2021, April 12). *Medicaid Churning and Continuity of Care: Evidence and Policy Considerations Before After the COVID-19 Pandemic*. ASPE. Retrieved October 11, 2021, from <https://aspe.hhs.gov/sites/default/files/private/pdf/265366/medicaid-churning-ib.pdf>.
- 3 Ku, L., & Steinmetz, E. (2013, September 10). *Bridging the Gap: Continuity and Quality of Coverage in Medicaid*. Community Plans. Retrieved October 11, 2021, from <http://www.communityplans.net/Portals/0/Policy/Medicaid/GW%20Continuity%20Report%20%209-10-13.pdf>.
- 4 HHS. (2021, June 21). *New Medicaid and chip enrollment snapshot shows almost 10 million Americans enrolled in coverage during the COVID-19 public health emergency*. HHS.gov. Retrieved October 11, 2021, from <https://www.hhs.gov/about/news/2021/06/21/new-medicaid-and-chip-enrollment-snapshot-shows-almost-10-million-americans-enrolled.html>.
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- 7 This option, passed as part of the American Rescue Plan Act, is set to expire in five years.
- 8 *Medicaid Postpartum Coverage Tracker*. Published October 15, 2021, from <https://www.kff.org/medicaid/issue-brief/medicaid-postpartum-coverage-extension-tracker/>.
- 9 One of these two individuals reported that the reason was unclear; the other reported lost coverage for a very short period due to work requirements, but the state had no documented work requirements for Medicaid eligibility.
- 10 Baicker, K., Taubman, S. L., Allen, H. L., Bernsetin, M., et. al. (2013, May 2). The Oregon Experiment—Effects of Medicaid on Clinical Outcomes. *N Engl J Med*; 368:1713-1722.
- 11 Parents of children were eligible to participate if they lived in one of these states: Arizona, Arkansas, Connecticut, Delaware, District of Columbia, Florida, Georgia, Hawaii, Kentucky, Maryland, Massachusetts, Minnesota, Missouri, Nebraska, Nevada, New Hampshire, Oklahoma, Pennsylvania, Rhode Island, South Dakota, Tennessee, Texas, Vermont, Wisconsin, and Utah.
- 12 Sugar, S., Peters, C., De Lew, N., & Sommers, B. D. (2021, April 12). *Medicaid Churning and Continuity of Care: Evidence and Policy Considerations Before After the COVID-19 Pandemic*. ASPE. Retrieved October 11, 2021, from <https://aspe.hhs.gov/sites/default/files/private/pdf/265366/medicaid-churning-ib.pdf>.











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