

Medicaid in the Mountain State: The Unwinding through the Voices of Program Participants

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Overview and Key Findings

Medicaid is one of the most important health care programs in West Virginia. During the COVID-19 public health emergency (PHE), it served up to 655,000 people—or one in three West Virginians.¹ It helped folks across the state stay afloat and connected to their health care during an unprecedented time. Between April 2023 and April 2024, the state embarked on reviewing every single case, a process referred to as the Medicaid unwinding.² The program returned to pre-pandemic enrollment levels after the unwind and covers 508,000 West Virginians as of November 2024.³

Throughout the pandemic and the subsequent unwinding, the WVCBP has worked in partnership with West Virginians for Affordable Health Care (WVAHC) on a series of listening projects to better understand how folks navigated their health care via Medicaid during an unprecedented period for the program. Through these conversations, we hoped to highlight the value of the program to enrollees and to identify opportunities to enhance the user experience. This year, we focused on hearing from populations we repeatedly received feedback from and about via external partners: families with children and folks who were in recovery from a substance use disorder (SUD). Members within these groups had unique experiences that helped us determine specific strengths and gaps in the Medicaid user experience.

Key Themes:

- Once people are able to access the Medicaid program, they love being connected to their care
- Communication barriers between individuals and agency make the program more difficult to access
- Participants cannot complete an application in one setting, making it more difficult than necessary to complete their paperwork
- Gaps in benefits, such as dental and eye care, limit the program's efficacy

¹ Bureau for Family Assistance, “BFA Monthly Reports to the Secretary,” Department of Health Services, (January 2023 to October 2024).

² Bureau for Medicaid Services, “West Virginia Medicaid, Public Health Emergency and Unwinding the Continuous Eligibility,” Department of Health Services, (February 2023).

³ Bureau for Medicaid Services, “West Virginia Medicaid Managed Care and Fee for Service Monthly Report 2024,” Department of Health Services, (November 2024).

We aimed to understand how West Virginians accessed and utilized Medicaid during and after the COVID-19 PHE. In addition to quantitative data, the majority of the information that shaped this project came from conversations with direct service providers, advocates, and people with lived experiences.

The WVCBP hosted biweekly stakeholders' meetings throughout and after the PHE. These meetings provided clarity about federal and state rule changes, as well as connected advocates' efforts to help folks stay updated and connected to their health care. Importantly, it was during these meetings that the WVCBP and WVAHC began to hear anecdotes from providers about how enrollees were accessing (or not accessing) health care during this unprecedented period. Significantly, different populations had unique experiences, with some navigating changes more easily than others.

There is a misconception that the PHE created a host of problems within Medicaid programs across the United States, including funding and budgetary issues. While this period introduced challenges, including disconnection from health care during the lockdown period, our findings indicate that, while the PHE exacerbated some patterns, it primarily uncovered longstanding issues that participants had experienced prior to the pandemic. Furthermore, the federal government sent states additional funds in exchange for keeping folks enrolled in the program, temporarily delaying an impending budget crisis in the Mountain State. In other words, the pandemic provided an opportunity for advocates to closely examine barriers facing Medicaid programs across the country, while flexibilities at the federal level created a roadmap to mitigating these difficulties until states could address them permanently.

Methods

The WVCBP and WVAHC utilized two primary methods to better understand folks' health care experiences within the West Virginia Medicaid program. The first method utilized a tool called Vocal Video. This platform prompts participants to answer a set of questions via video or audio recording, which they can complete on their own time. In the past, this project has relied on online surveys, which were multiple choice or open-ended questions that people could type their answers into. While such tools are useful in many instances, recorded answers prompted deeper, more diverse, and more nuanced answers than those from traditional survey tools. We also narrowed our focus to specific populations, including families with children and people in recovery from a substance use disorder (SUD). Combined, the recording platform and narrowed scope contributed to the success of the project while reducing recruitment efforts on the backend.

The second method was a traditional interview. Based on their recordings, several participants were invited to participate in a one-hour phone or video call. They spoke more to the answers they had initially shared and answered several additional questions. These conversations offered a holistic understanding of their health care experiences.

In all, the project garnered video and audio recordings from 20 Medicaid enrollees across the state, with follow up, in-depth conversations with three people.

Themes

Medicaid Has an Overwhelmingly Positive Impact on West Virginians' Lives

“Medicaid saved my life.” – Anonymous participant, Cabell County

The overwhelming response from participants highlighted the importance of the Medicaid program to themselves and their families. Despite some difficulty in obtaining and retaining coverage, enrollees found the process worth going through to receive health care they otherwise could not access. Lisa from Kanawha County reflected, “when you don't have insurance, you can't see anyone. [Before Medicaid] I had to travel hours to free

clinics to try and solve medical issues. It took years of me being in pain to finally start getting answers.” Another participant, who is in recovery from a substance use disorder, put it simply: “Medicaid saved my life.”

Each person who participated talked about how the program played a critical role in their health care. Several people indicated that, before enrolling, it had been many years since they had seen a doctor. For others, having Medicaid was the first time they had the opportunity to address their health care needs.

Primary care, mental health services, dental care, and access to substance use treatment programs were the most common services that participants highlighted as crucial for themselves and their families. A participant with two young children said, “health insurance has allowed my family to get regular checkups, dental cleanings, [kept us] up to date on vaccines, and [allowed us to] see a doctor when sick.” Quantitative data shows those experiences are not unique: in West Virginia, Medicaid covers roughly half of births and over 50 percent of children in the state. Further, the state sits at the heart of the opioid crisis—and Medicaid has played a significant role in combatting it. It is the primary means of addressing substance use disorders, connecting nearly 25,000 people with treatment programs across the state in 2024.⁴

Chukwudi from Cabell County recounts, “I was once addicted to drugs. I was having some terrible health issues that were taking a huge toll on me. What really helped me improve was Medicaid... I got the chance to meet with a doctor and he told me my seizures were because of my drug use. They got me the medication I needed and counseling. They actually communicated with me. The care meant so much. Medicaid helped me pass through this phase of my life and I’m so much happier now.”

Barriers to Accessing Health Care

Though most participants described their overall experiences as positive, they also indicated several barriers that impacted their ability to seek care for themselves and their families in a consistent, timely manner. Many of the themes were also observed in past listening projects, such as difficulty reaching the agency by phone and stigma.

Communication Breakdowns

Many participants indicated that somewhere in the process of completing their application, renewal, or otherwise interacting with the agency, information got lost, misconstrued, or was otherwise unclear. Examples include submitting paperwork, hearing back about their application or renewal, and difficulty getting clear answers about their health care online and over the phone. Many expressed frustration, disappointment, and even eventual apathy, opting to forego health care and other services they qualified for because it was too hard to navigate administrative red tape. This narrative aligns with findings from our last iteration of this project, which cited being accustomed to hardship as a barrier to accessing health care.⁵

Difficulty Submitting Paperwork

Several participants reported that submitting supporting documents for their application or renewal made obtaining Medicaid challenging. While the application requires much paperwork, participants indicated that verifying changes in the renewal period was difficult, too. One person surveyed said, “it doesn’t matter if it’s online or in the mail. You still have to mail stuff anyway.”

⁴ Substance use disorder data requests acquired by the WVCPB from the Bureau for Medicaid Services within the West Virginia Department of Health Services, October 2024.

⁵ Rogombe, Rhonda, “Simplifying Medicaid Processes Can Increase Efficiency and Improve the User Experience,” West Virginia Center on Budget and Policy, (May 2022).

The online portal, known as WV PATH, is a tool that allows people who utilize Medicaid and other state-run safety net programs to access their accounts online, including applications and renewals. However, as the participant above indicated, the final step of the process may include providing physical documentation. West Virginia is just one of three states that has an online system that does not currently allow users to upload documents online.⁶

If a person needs to verify income, household size, or other requested information, they must mail it or deliver it to their local health department. Delivering paperwork to the office could be logistically challenging, from creating the time to get to the office to having reliable transportation to get there. Mailing it could result in delays in eligibility as individuals wait for confirmation that their paperwork got to the right person in time. Improving the online system will make the process easier for enrollees and caseworkers alike.

Hearing Back from Agency About Application or Renewal

“You just cancel your appointments until you get covered again.” – Melinda, Cabell County

Once a person got through the first part of the process, many indicated that the next challenge they faced was hearing back from the agency about whether they had been approved. Melinda from Cabell County said it took three months to hear back about her renewal. Another person from Berkeley County recounted a similar experience, adding, “I was stressed out waiting to hear back. I felt hopeless but was embarrassed to keep coming back [to the office]. So, I waited.”

Eventually, he got approved. In the meantime, he and Melinda noted, they did not see doctors or go to the pharmacy. Others chose to continue engaging with their health care, paying out of pocket for critical medications. Being unable to afford medications or otherwise having difficulty accessing them can have serious health consequences for people with substance use disorders or other chronic conditions, which can cost the state even more in emergency hospital visits and treatment for more serious ailments.

Statewide, about four percent of applications take more than 45 days, though it is unclear what the average wait time between application or renewal and approval is.⁷ Clear communication about the timeline and process can help keep people connected to their care without worrying about how they will make ends meet.

Reaching Agency Via Phone

Feedback from participants was mixed when discussing their experiences with calling the agency. Of those who had called, several indicated that they had a positive experience. Joey from Jefferson County said that “the service was phenomenal. They went above and beyond to answer my questions.” Participants recalled that they generally preferred to fill out paperwork online or mail it, but sought additional information about their case or the program over the phone when they could not find it online.

However, long wait times and getting clear, consistent answers were themes that came up repeatedly. On average, people wait 17 minutes to connect with the agency, though the 25 percent call abandonment rate indicates that there is a wide variation.⁸ Timothy added, “depending on the time of day or week, you can be on hold for a long time... sometimes you have to call more than once. But the person on the phone is always very respectful and gives me the answers I need.” Being able to readily get necessary information made enrollees feel more empowered about their health and shaped the services they sought.

⁶ Brooks, Tricia, et. al, “A Look at Medicaid and CHIP Eligibility, Enrollment, and Renewal Policies During the Unwinding of Continuous Enrollment and Beyond,” Kaiser Family Foundation, (June 2024).

⁷ Centers for Medicare and Medicaid, “Medicaid and CHIP Unwinding Operations Snapshot – July 2024 Data,” CMS, (October 2024).

⁸ Ibid.

Stigma

“I’ve felt embarrassed about having Medicaid, especially when people comment on me living off the government. But I’ve learned to prioritize my health and see seeking help as a sign of strength.” – Berkeley County resi

Many participants spent time discussing how stigma and discrimination impacted how they viewed themselves and experienced care. While these experiences did not prevent them from engaging with their health care, about half of participants had a story about how they or another person made them feel embarrassed, ashamed, or otherwise less-than. One respondent said of their interactions at the doctors’ office, “once people know that you’re actually on it, they can guess your social status and judge you based on that. I could feel a shift in the air, in the way I was being treated. I had to reflect about whether I was projecting [because] I was insecure. But I know I wasn’t making it up. It’s like, the government says that taxpayers are doing this for you. So, you don’t deserve the best we can do.”

Others indicated that they had felt ashamed when they first got Medicaid, but once they started to receive care and become healthier, those feelings changed. It was connecting with health care, perhaps for the first time, that changed their attitudes toward the program. Ashley said, “I can’t say I’m embarrassed. I’m proud to say that I receive assistance from the state because not everyone is able. I’m happy.” Addressing stigma can improve health care experiences and outcomes.

Recommendations

There are several opportunities that can mitigate the challenges that participants shared. Though not exhaustive, these recommendations can help simplify the process, making enrollment and renewal easier on both enrollees and Medicaid staff. The COVID-19 public health emergency illuminated many of these issues as the state renewed each person in the program over the course of a year. These recommendations seek to apply the lessons learned during this period to improve the program for both enrollees and Medicaid staff.

Maximizing *Ex Parte* Renewals

Ex parte renewals utilize data sources that the state agency has access to—including existing income, payroll, unemployment, and more—to confirm Medicaid eligibility for an individual or household up for renewal. If a person has adequate financial information available via these data sources, they can be re-enrolled in Medicaid without additional paperwork, saving both the enrollee and the Medicaid agency time. If not, the individual will still receive renewal paperwork to complete online or via mail to verify their eligibility.

Utilizing this process is required by federal Medicaid rules, but states have a lot of flexibility around how they implement it.⁹ West Virginia has improved significantly over the past several years, going from a rate of less than one percent in 2020 to ten percent in April 2023, as the unwinding began, to nearly 60 percent in September 2024.¹⁰ While West Virginia is finally on par with other states, others improved, too; staying on or above average requires the state to continue to explore means of improving this rate.¹¹

⁹ Medicaid and CHIP Payment and Access Commission, “Increasing the Rate of Ex Parte Renewals,” MACPAC, (September 2023).

¹⁰ West Virginia Bureau for Medicaid Services, “Monthly Unwinding Reports,” (April 2023 to September 2024).

¹¹ Brooks, Tricia, et. al, “Most States Show Improvement in Automated (Ex Parte) Medicaid Renewal Rates,” Georgetown University Center for Children and Families, (January 2024).

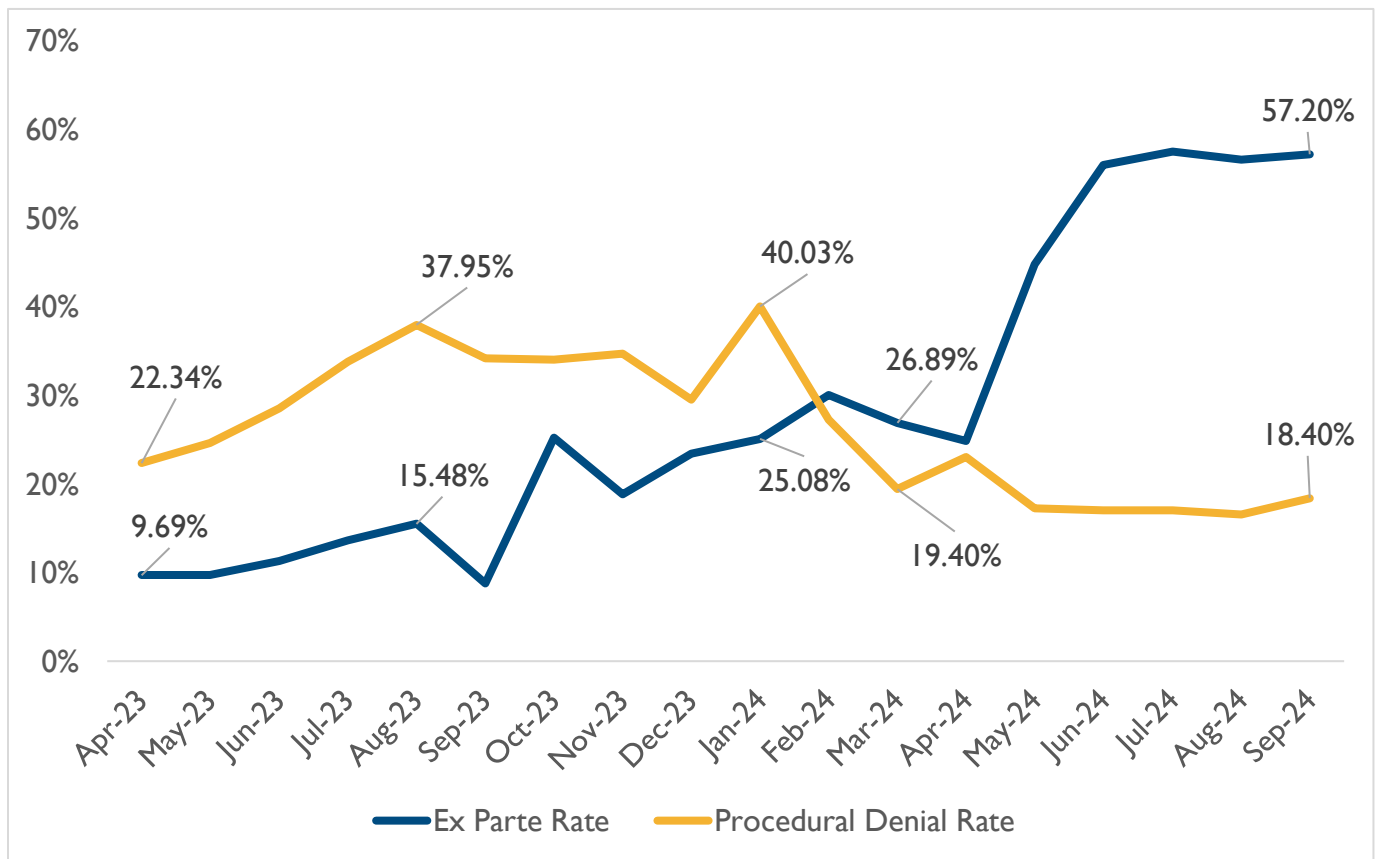
The *ex parte* process is important not only for reducing enrollee and staff time spent on a renewal, but also preventing otherwise qualified enrollees from losing their coverage because they did not correctly and completely fill out their paperwork on time (known as a procedural denial). By eliminating the need for enrollees to manually submit information, it can make the renewal process easier while preventing things like lost paperwork and delayed mail from interfering with services. It can also reduce the need for phone calls to the agency. It may speed the process up as well, meaning the likelihood of coverage lapsing may decrease.

Indeed, data shows a relationship between *ex parte* renewals and procedural denials (Figure 1). In the first several months of the unwinding, about one in three enrollees were losing coverage due to procedural reasons, while the *ex parte* rate hovered around 14 percent. Just after the unwinding in May 2024, the *ex parte* rate was about 45 percent, with procedural denials down to fewer than one in five people. Improving the *ex parte* rate was a major success that eased the burden of renewals for both enrollees and case workers. By continuing to enhance the process, West Virginia can stay on par with other states and make Medicaid more accessible.

Figure 1

Increasing Automatic Renewals Associated with Fewer Procedural Denials in West Virginia

Ex parte rate and procedural denial rate in West Virginia Medicaid program, April 2023 to September 2024.



Alt-text: Line graph comparing the WV Medicaid *ex parte* and procedural denial rates, where an increase in *ex parte* renewals is related to a decrease in procedural denials.

Source: West Virginia for Medicaid Services Monthly Unwinding Report

Note: R²=0.39

Improving the Online System

Improving the online system can make a significant difference in how people interact with their health care. Participants indicated that being able to upload support documents online would make it easier for them to apply and renew. They also said it would decrease the instances of them visiting their local office or calling the agency via phone to follow up. West Virginia is one of three states where participants cannot upload documents on their computers or phones.¹² Survey participants also indicated that being able to save their progress as they go and having prompts consolidated would improve their ability to submit paperwork. Being able to complete paperwork from beginning to end, even in cases where the state may need additional information, can impact how enrollees and caseworkers experience the program.

Data Sharing

Throughout the pandemic and in the period following, the Medicaid agency was transparent with stakeholders about policies, processes, and data. They even created a landing page that shared their plans, monthly data, member communications, and additional resources about how to renew and reach the agency. All these resources helped stakeholders understand how the state was experiencing the unwinding, prepared advocates to inform their communities, and mitigated the overall stress deriving from the unprecedented undertaking.

Participants who knew about these tools indicated that they were useful. However, they would like a clearer way to understand their benefits and available options, specifically online so that they would not need to call the agency. Understanding their health care options would enhance their ability to access it.

Supporting Medicaid

Of course, none of the work that Medicaid does would be possible without adequate, robust funding. Years of flat budgets and deceptive narratives have harmed the program's ability to provide necessary services. It has also made it impossible to fully staff the program with the necessary number of caseworkers and phone operators to fully optimize Medicaid. Federal funds during the PHE mitigated the crisis, but this moment is a critical one for West Virginia Medicaid. Decisionmakers must prioritize funding the program and making it accessible to improve health outcomes in the Mountain State.

A Note of Gratitude

This project would not be possible without the participation of enrollees, who shared intimate details about their lives and health care experiences. We would like to extend our sincerest gratitude to our participants for sharing their expertise—it is critical to uplift lived experience as much as it is to collect data. Thank you!

¹² Brooks, Tricia, et. al, "A Look at Medicaid and CHIP Eligibility, Enrollment, and Renewal Policies," KFF, (June 2024).

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