

# TRAPPED IN THE HEALTH CARE MAZE:

Struggling to Navigate Health Costs, Access, and Complexities in Rural North Carolina

**This project and report were a collaborative effort between United States of Care and the North Carolina Justice Center.**

United States of Care and the North Carolina Justice Center would like to thank the four community coordinators we worked with who used their deep relationships and dedication to their communities' health to recruit participants for this research. Further, special recognition should be given to the participants themselves in the four community conversations, as many shared their very courageous and, at times, heartbreaking stories with us, in hopes of change. This report would not have been possible without them.

to health care consolidation, experiencing depressed wages with little opportunity for economic advancement. In addition, people are seeing the names on their hometown doctors' doors change, experiencing long wait times, and facing limited access to critical services like mental health or maternity care. Those living in rural communities are often hit the hardest.

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North Carolina was also ranked the third worst state in the country for the percentage of people with significant medical debt (the largest contributor of personal debt nationally), further impacting their economic stability and mobility. While North Carolina recently launched an impressive first-of-its-kind initiative to provide medical debt relief and encourage hospitals to adopt better practices to protect patients, broader action is needed to bring down prices and ensure every person can access the care they need without fear of debt or financial hardship.

This report identifies ways that policymakers can build on recent momentum by continuing to honor the needs of patients, particularly in some of the state's most under-resourced communities.

## Introduction

North Carolina continues to be a leader in the South, forging a path forward to improve access to health care for residents. On December 1, 2023, more than 600,000 North Carolinians became eligible for health coverage as North Carolina became the 40th state to expand Medicaid, with hundreds of thousands now enrolled. More people than ever have the opportunity to access the coverage they need to stay healthier, treat sickness earlier, and have peace of mind knowing their health care is within their reach. Medicaid expansion marks a momentous milestone in achieving happier, healthier, and economically stronger communities through increased coverage.

However, affordability remains a major concern, with high and rising hospital prices contributing to premiums and out-of-pocket costs that many can't afford. In addition, provider shortages and the impacts of hospital consolidation mean people across the state are living in areas where they can't receive the services they need. These issues threaten the health and financial security of North Carolinians regardless of the type of coverage they have.

North Carolina leads the nation as the most expensive state for health care. Communities are facing lower wages due to increased health care spending on premiums and other out-of-pocket costs, and North Carolinians are struggling to pay for everyday living expenses. Many are unable to afford health care, with far too many delaying or forgoing care altogether.

Providers, like nurses, have fewer employment options due

**As Western North Carolina continues to grapple with Hurricane Helene's devastation, this report's findings and recommendations are more urgent than ever. As North Carolinians look ahead to the long-term impact climate disasters have on the health and economic well-being of their communities, their voices echo a resounding need for a transparent, accountable health care system to support them in times of crisis and prepare a thriving North Carolina for years to come.**

# Our Findings

We believe that sustainable improvement within the health care system starts by listening to people and including them in every step of the process. To better understand the experiences and opinions of North Carolinians on health care access and affordability, we completed four community conversations in August of 2024 across four counties representing rural communities around the state: Caldwell, Mitchell,<sup>1</sup> Rockingham, and Wayne. From these conversations, we learned a great deal about the health care issues most important to North Carolinians.

## HEALTH CARE IS *Unaffordable*

Health care costs are a significant concern for North Carolinians, with the high price of medications, surgeries, and emergency services driving financial strain. Prescription drug costs vary widely depending on insurance plans, and many people rely on discount services to be able to afford their medications, if they can afford them at all. Excessive premiums, high out-of-pocket costs, and insurance denials make health care unaffordable for many, with emergency services resulting in particularly devastating bills, especially around ambulance prices. Participants often accepted medical debt as the cost of staying healthy and shared devastating stories of bankruptcy, losing their homes, and having to use multiple credit cards to cover costs. Some reported seeing bills sent to collections quickly without the opportunity to understand the charges or work out realistic payment plans. Hospital prices were often the culprit—as participants expressed being unaware of the true cost of services due to complicated and unclear billing practices, which created a belief that providers arbitrarily inflate the actual cost of care.

When I told [the receptionist] I'd have to pay my bill using four cards, but I would be there, she said, "Oh, well, just go and run your hands through the couch, and find change in your couch." I said, "Ma'am, I don't even own a couch." She said, "Well, look in your car, in the cup holders, and get change." I said, "Ma'am, I just paid \$1,200 that I didn't have to have my car fixed. There's no change in the car."

– BLACK WOMAN, WAYNE COUNTY

**TAKEAWAY:** Rural North Carolinians largely experienced increased stress, anxiety, and deteriorating mental health, and at times chose to delay necessary care due to uncertainty around cost and their experiences with medical debt. The unaffordability of health care services, medical debt, and high inflation continue to put intense strain on already stretched family budgets and economic opportunities.

I had some medical debt that was coming up and I got an abscess on my hand and I waited. I thought it's going to clear up, it's going to clear up, it's going to clear up. I wound up getting septic because I originally didn't want to go for care because I was worried about the expense. You work a few days hanging out, waiting, just it's going to get better, it's going to get better, [but] it costs me.

– WHITE WOMAN, CALDWELL COUNTY

<sup>1</sup> This research took place just prior to Hurricane Helene causing severe damage to Mitchell County and further restricting access to health care services.



*When they get big, we get small.*

– WHITE WOMAN, CALDWELL COUNTY

## HEALTH CARE IS *Unpredictable*

Over the past decade, North Carolina’s hospitals, including those in rural areas, have increasingly consolidated—acquired by other hospitals or larger hospital systems, such as UNC and HCA.

This consolidation has created an unpredictable and overly complicated health care system. While some participants spoke of expanded access to providers and services in the consolidated systems, most expressed concerns over providers being unavailable or no longer “in-network,” the closure of birthing centers and loss of maternal health services, increased costs, and a growing culture of medical debt.

From 2016 to 2021, there were *27 changes in ownership* involving hospitals in North Carolina due to mergers, acquisitions, or other changes of ownership. Among patients surveyed, *45%* reported that they *delayed or avoided visiting the doctor or undergoing procedures because of consolidation.*

My son went through that [confusion around hospital consolidation and its impact on health insurance claims/costs] when they changed everything. It was very chaotic because you got to figure it out. It’s a frightening feeling because you feel like you’re just being tossed whatever way they want to toss you for the whole money racket. Whatever works for them, that’s what they’re going to do, never mind the smaller person. – BLACK WOMAN, WAYNE COUNTY

“When they [HCA] consolidated with Mission, services started getting cut. HCA cut services. This hospital here, 25 years ago, very seldom did anything ever get shipped out. It was handled here. We had surgeons. We had everything here. Now you can't even get an appendix taken out at this hospital. You can't have a baby at this hospital.” – WHITE MAN, MITCHELL COUNTY

As hospitals consolidate and buy up practices, they are often able to charge patients new “*facility fees*” due to how they bill for providing those otherwise routine services and care. Facility fees often come at a surprise to patients, like our participant in Rockingham County after a visit to her ankle specialist, and leave them paying *hundreds or thousands of dollars* in addition to other charges for the services or care itself.

Confusing hospital billing practices, lack of transparency around pricing, and an inability to negotiate payment arrangements with the hospitals themselves also contributed to the unpredictability of health care. One participant shared a story about being charged a \$500 facility fee—or fee in addition to her doctor's fee—for ankle therapy just because the clinic where she received care was associated with a hospital, while others reported receiving multiple confusing bills after seeing providers associated with certain hospitals.

Participants felt confusion and disorientation navigating new health care networks following consolidations. One person needed to engage legal representation to address recurring continuity of care issues like lost medical records and misdiagnoses. Participants also expressed high levels of concern that continued consolidation will result in fewer affordable options for quality care.

“When I started my process for disability, some of our records couldn't be found [because of the merger]. At one point in my chart system, they had me off medication, they had me on some old medications. I said, “Well, I don't take that no more.” – HISPANIC WOMAN, WAYNE COUNTY

## TAKEAWAY:

Participants in rural North Carolina feel like they receive lower-quality care after consolidation. They have seen increased patient load on remaining local providers who often seem rushed and unable to deliver the same level of care, and many keenly feel the absence of the relationships and personal connections they once had. They have seen prices increase and available services decrease resulting in longer appointment wait times and travel times.

Despite sharing these largely negative experiences with hospital consolidation, the viewpoint of most was that continued hospital consolidation appeared inevitable due to the financial instability of small hospitals and clinics in rural areas.

“If you can’t get in to see your doctor now for a doctor’s appointment, [they say] “We’ll see you in October.” Do you wait till October, do you go up here to the ER and get a \$300/\$500 bill to walk in the door, plus whatever the doctor wants to charge you, plus whatever the labs are? You say, “Well, if I’m alive in three months, I’ll see the doctor.” – WHITE MAN, MITCHELL COUNTY

## HEALTH CARE IS *Inaccessible*

High health care costs are not the only concern for North Carolinians. People also identified significant barriers to accessing crucial health care services when they need them most.

Participants across communities spoke of the importance of building a trusting relationship with their providers, yet struggled to access care locally. A shortage of providers, particularly mental health providers and other specialists, causes patients to seek costly out-of-network care and travel—at times over an hour one way—to a neighboring town. Lack of public transportation further impedes access. Participants expressed frustratingly long wait times—some over six months—to see their primary care providers, resulting in delayed care or seeking care in costly emergency departments.

Some participants were reluctant to seek care due to existing social stigma around mental health conditions. Others experienced discrimination from medical providers with whom they did not share similar cultural backgrounds or were unable to build strong relationships due to high provider turnover.

“I like the fact that they do take time with you and also there’s always a backup. In the event that they can’t really figure out what’s going on, then they’ll consult with the doctor. If you have a good nurse practitioner who does intake very well, that listens to what your issues are, your symptoms, that kind of thing, and he or she makes recommendations, that’s great. Then if they don’t know, they’ll say, ‘Let me consult with Doctor so-and-so and then from a team approach, we’ll come up with some recommendations.’ – BLACK WOMAN, ROCKINGHAM COUNTY

“My PA’s involved in the community. His office is downtown over the coffee shop. He’s in the coffee shop. He knows the community. He greets people. If he sees you out, he speaks to you, so it’s almost a family feel, with him is my comfort.

– WHITE WOMAN, MITCHELL COUNTY

### BRIGHT SPOTS:

Participant experiences with mid-level providers like nurse practitioners and physician assistants were overwhelmingly positive. Participants voiced satisfaction around longer consultations, personalized care, and open communication styles resulting in stronger, more productive relationships than with the doctors supervising them.

## TAKEAWAY:

North Carolinians face many barriers to accessing the care they need, including inadequate health care networks, shortage of primary and specialist care providers, and bias and discrimination within the health care system.

# Policy Recommendations

Policymakers should consider the following policy solutions to address these concerns.

## MAKE HEALTH CARE *More Affordable*

As North Carolinians continue to struggle with high health care costs, policymakers should enact policies to:

- **Protect patients from medical debt:** As noted [in side bar], policymakers recently took action to relieve and protect patients with low incomes from existing and future medical debt. The provisions in this program should be made permanent and codified into statute, including implementing presumptive eligibility for financial assistance, capping interest rates at 3%, and banning extraordinary debt collection practices. Additionally, legislators should relieve medical debt for those who were not eligible for the recent program, expand the financial and consumer protections for those with incomes beyond 300% of the Federal Poverty Level, and ensure agencies have the tools and resources they need to enforce these requirements.
- **Address premium and out-of-pocket costs:** Policymakers should provide increased authority to the Department of Insurance to review rates and out-of-pocket costs as well as consider policies that limit copays and deductibles. In addition, the rate review process should include more transparency, with more opportunity provided for stakeholder input so plans that are offered better meet the needs of North Carolinians.
- **Lower prescription drug costs:** Policymakers should take action to address the impact Pharmacy Benefit Managers (PBMs) have on people's prescription drug costs. Policymakers should limit PBMs' use of manufacturer rebates and "spread pricing," where PBMs increase the cost of prescriptions to increase their profits.
- **Lower ambulance costs and limit unfair collection practices:** Policymakers should enact policies to make ambulance bills more affordable, such as requiring ambulance companies to offer financial assistance and capping the length and amounts of payment plans. Additionally, these companies should be prohibited from garnishing wages or tax returns.

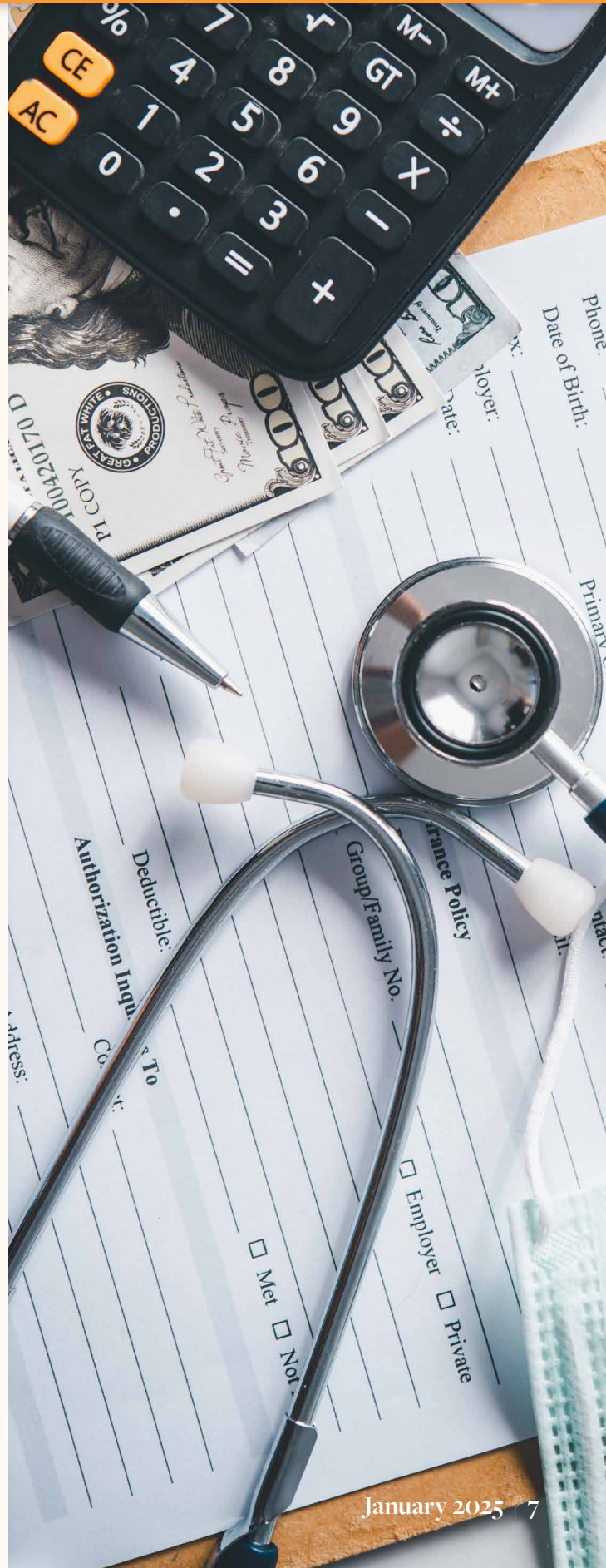
**All 99 acute care hospitals opted into a new program that the state recently created to relieve existing medical debt for two million North Carolinians with low incomes by the end of 2026. Starting January 2025, this program requires hospitals to create plain language debt mitigation policies that expand financial assistance eligibility for patients with low incomes. Other protections will be phased in over time, including capping interest rates at 3% for hospital-owned debt, creating income-based payments that are capped at 36 months, and curbing problematic debt collection practices.**



# MAKE HEALTH CARE *More Predictable*

As North Carolinians continue to struggle with high health care costs, policymakers should enact policies to:

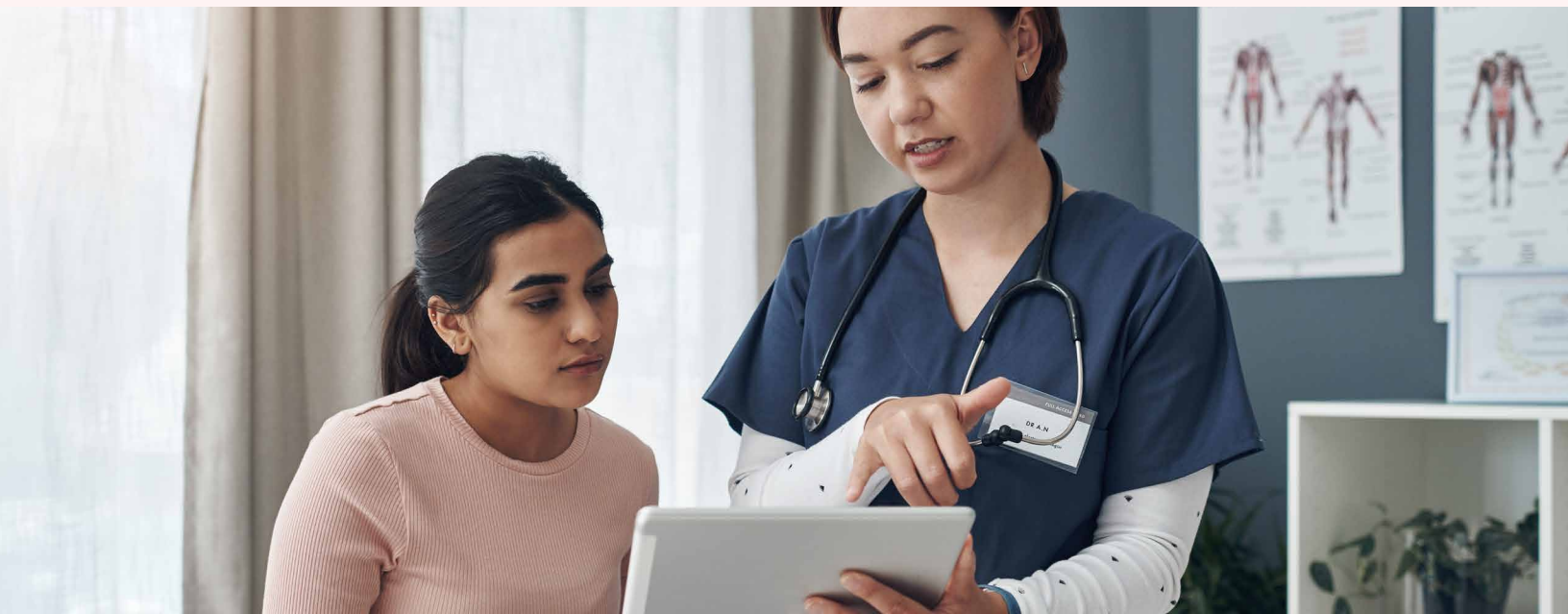
- **Protect patients from unjust prices and facility fees:** Policymakers should enact policies to make hospital prices more fair and consistent, including limiting when hospitals can charge facility fees. States across the country are passing policies to limit facility fee charges and to require hospitals to notify patients about facility charges if they do occur. Texas and Ohio, for example, prohibit facility fees being charged for telehealth and drive-thru services at free-standing emergency departments, and Indiana limits the types of hospitals and types of locations allowed to bill for these fees. In addition, policymakers should explore policies that establish “site neutral” payment for services so people are charged the same price for the same service regardless of location.
- **Ensure patients receive understandable and straightforward bills:** Policymakers should require hospitals to provide good faith estimates of a patient’s charges at the time of their appointment and provide them with clear, comprehensive, itemized bills in a timely manner following a hospital visit or stay.
- **Increase ownership transparency and transaction oversight resulting from consolidation:** Policymakers should expand oversight and review authority for future health care transactions, allow conditions to be placed on new mergers and acquisitions, create clear criteria and standards for review, increase oversight and transparency of ownership of hospitals and other related entities, and provide agencies with the needed tools and resources to enforce antitrust laws. North Carolina can look to lessons learned from states like Arizona and Louisiana that are increasing health care market oversight authority for state agencies.
- **Reduce anti-competitive practices:** Policymakers should enact policies to ban anti-competitive contract terms, such as all-or-nothing contracting, anti-tiering/steering clauses, gag clauses, and physician non-compete clauses that give large hospitals and hospital systems too much power to determine prices at the expense of patients. This would put North Carolina in line with states like Tennessee that have enacted similar policies.



## MAKE HEALTH CARE *More Accessible*

As North Carolinians continue to face barriers finding and receiving the health care they need, legislators should enact policies to:

- **Grant full practice authority to more providers:** Streamlining regulations to allow for Advanced Practice Registered Nurses (APRNs) to fully utilize their training can lessen the impact of physician shortages in rural areas without compromising quality of health care. Legislators should pass policies, such as The SAVE Act, so providers can exercise the full scope of their training while saving the state billions of dollars. Nurse practitioners, certified nurse midwives, and other non-physician providers are widely popular with patients and serve to increase access for people currently living in areas with limited numbers of physicians. Legislation related to increasing the scope of practice for non-physicians has been pursued in dozens of states.
- **Ensure adequate provider networks and accurate provider directories:** Many North Carolinians struggle to find in-network providers. While federal protections are in place, North Carolina lawmakers also have a role to play in ensuring provider networks are meeting the needs of patients and that provider directories are up-to-date. Legislators should establish and enforce time and distance standards, limit wait times, and increase access to essential community providers. In addition, policymakers should explore ways to build a more robust pipeline of diverse providers to better reflect the communities they serve.



## Conclusion

Our listening sessions in four rural North Carolina counties showed that hardworking people feel like their health and the health of their communities don't matter—they are tired of feeling small. Rural North Carolinians are looking to policymakers on both sides of the aisle to prioritize investing in their communities and passing policies that ensure access to *affordable, dependable, and quality care*. As health care prices continue to rise nationally, policymakers have an opportunity to elevate North Carolina as a strong leader in health care by considering the recommendations in this report. Enacting these policies will ensure North Carolinians can access the health care services they need with providers they trust at prices they can afford.