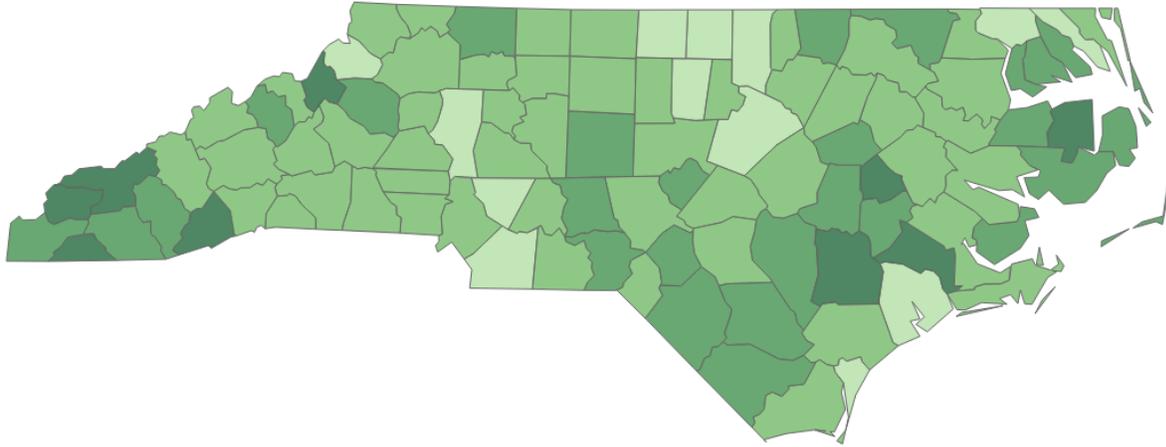


Violence Against the Poor: The Consequences of North Carolina's Failure to Expand Medicaid



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Percent uninsured, 19-64 years



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There was a sign at an event that a lady was holding that said, “no Medicaid expansion is violence against the working poor.” I saw that and I was like, “it is!” The sooner, the better [to expand Medicaid], because people are dying, and people are being hurt, and people are going without, and people’s lives are being shortened.”

- Dr. Stephen Luking

The human toll of North Carolina’s failure to expand Medicaid is immeasurable. In the first four years that expansion was available nationally, 1,400 North Carolinians between the ages of 55 and 64 died because of the state refusal to expand.¹ Going forward, over one thousand lives will be saved every year if Medicaid is expanded in North Carolina.² These numbers, grave as they are, only hint at the extent of individual suffering and loss. Nor do they begin to tally the larger harms to North Carolina’s healthcare system or its economy.

In 2016, the North Carolina Poverty Research Fund first examined the politically motivated and short-sighted decision by the GOP-led legislature to reject Medicaid expansion.³ Much has changed since then. Research on expansion has become extensive and robust. The political landscape is dramatically different at both the state and federal level. The debate over Medicaid expansion is at the heart of a longstanding state budget impasse. For these reasons, in the fall of 2019, we decided to revisit the topic. We wanted to hear from healthcare providers and uninsured people about what was at stake, on an individual, community and statewide level. Little did we know when we started that a global public health crisis—the coronavirus pandemic—would underscore and intensify the issue’s relevance.

In this report, we primarily focus on the healthcare consequences of North Carolina’s refusal to expand Medicaid. (Others, notably Leighton Ku of George Washington University, have documented the economic benefits of Medicaid expansion.)⁴ The status quo continues to inflict extensive harm on patients and their families, health care providers, and the healthcare system itself. All North Carolinians are paying the price. In this report, we describe the extensive literature on expansion and the experiences of other states. Most importantly, however, we offer the stories of our fellow Tar Heels who struggle to access to reliable healthcare in the richest nation on earth.

Overview of Medicaid and Medicaid Expansion

Established under the Social Security Act in 1965, Medicaid provides health insurance coverage to eligible low- and middle-income individuals across the United States. Funded jointly by federal and state governments, approximately 64 million Americans are currently enrolled in Medicaid.⁵ Since program costs are shared between the federal and state governments, states have the right, within federal

¹ Aron-Dine, “Medicaid Expansion Saves Lives.”

² West, “Expanding Medicaid in All States Would Save 14,000 Lives Per Year.”

³ Nichol, Norchi, and Hunt, *Putting A Face on Medicaid Expansion in North Carolina*.

⁴ Ku, Bruen, and Brantley, *The Economic and Employment Benefits of Expanding Medicaid in North Carolina: June 2019 Update*.

⁵ Centers for Medicare and Medicaid Services, “December 2019 Medicaid & CHIP Enrollment Data Highlights.”

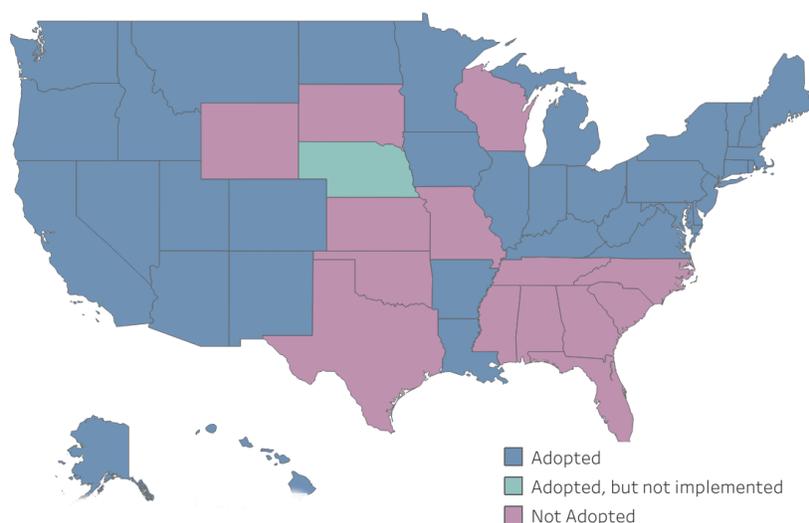
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guidelines, to determine eligibility criteria. They are required to insure certain populations (children, people with disabilities, seniors) but have some flexibility defining income limits, covered services and the like. However, under the traditional Medicaid model, most childless working-age adults are ineligible, no matter how poor.

The passage of the Affordable Care Act (ACA) in 2010 changed these eligibility rules. The ACA required states to expand Medicaid coverage to working-age adults earning up to 138% of the federal poverty level (FPL).⁶ This way, low-income individuals who could not afford private health insurance through the ACA Marketplace could obtain coverage. To sweeten the deal, the federal government underwrote 100% of the cost of expansion until the end of 2016, with the contribution stepping down to 90% in 2020. Barring a change in the law, the federal contribution will remain at this rate.

In 2012, the U.S. Supreme Court ruled that the ACA could not make Medicaid expansion mandatory, leaving the decision up to each state.⁷ To date, 36 states and the District of Columbia have opted to expand. North Carolina and 13 other states have not (Figure 1).⁸ Over 2.3 million people in non-expansion states fall into the “coverage gap.” Left in the lurch by their state’s refusal to expand, they are not eligible for either traditional Medicaid or the ACA’s private health insurance subsidies.⁹ An additional 2.1 million low-income individuals are eligible for ACA Marketplace subsidies but would be better served by Medicaid expansion.¹⁰

Figure 1. State Medicaid expansion decisions



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Source: Kaiser Family Foundation

⁶ Garfield, Orgera, and Damico, *The Coverage Gap: Uninsured Poor Adults in States That Do Not Expand Medicaid*.

⁷ *National Federation of Independent Business v. Sebelius*, 567 U.S. 519 (2012).

⁸ The Kansas legislature voted to expand Medicaid in 2017 but the bill was vetoed by then-Governor Brownback. A new bill was proposed in early 2020. A number of other states are creeping toward expansion, either through 1115 waivers or ballot initiatives. See Kaiser Family Foundation, “Status of State Medicaid Expansion Decisions.”

⁹ To receive a subsidy for the purchase of health insurance through the ACA Marketplace, an individual must make at least 100% and no more than 400% of the federal poverty line.

¹⁰ Garfield, Orgera, and Damico, *The Coverage Gap: Uninsured Poor Adults in States That Do Not Expand Medicaid*.

The split between pre- and post-expansion within states, and expansion and non-expansion between states, has created an opportunity to study and compare differences in outcomes. Employing a range of methods and approaches, a multitude of studies have found that Medicaid expansion leads to a host of positive effects.¹¹ Expansion increases healthcare coverage and reduces the number of the uninsured, especially among vulnerable, minority and rural populations.¹² It boosts access to care and utilization of services and prescriptions.¹³ It is associated with improved diagnosis, treatment and control of a range of diseases and conditions, including hypertension, diabetes, cancer and behavioral health issues.¹⁴ These improvements have saved lives. Between 2014 and 2017, roughly 19,200 people between the ages of 55 and 64 did not die thanks to expanded Medicaid programs in the states where they lived.¹⁵

Studies provide strong evidence that expansion supports hospitals, especially rural hospitals, and enhances provider capacity.¹⁶ Finally, expansion has been shown to lead to a range of downstream benefits such as greater personal financial stability, fewer bankruptcies and evictions, more jobs and stronger state budgets and economies.¹⁷

Pathways to Medicaid Expansion

In order to expand Medicaid, state Medicaid agencies must receive permission from the state. They have gained this authority through legislation, executive orders and ballot initiatives.¹⁸

¹¹ For a short overview of the research, see Center on Budget and Policy Priorities, *Chart Book: The Far-Reaching Benefits of the Affordable Care Act's Medicaid Expansion*. For a more exhaustive meta-analysis, see Guth, Garfield, and Rudowitz, *The Effects of Medicaid Expansion under the ACA*.

¹² Baumgartner et al., *How the ACA Has Narrowed Racial and Ethnic Disparities in Access to Health Care*; Buchmueller et al., “Medicaid Expansion and the Unemployed”; Foutz, Artiga, and Garfield, *The Role of Medicaid in Rural America*; Graves et al., “Medicaid Expansion Slowed Rates of Health Decline for Low-Income Adults In Southern States”; Mahal et al., “Early Impact of the Affordable Care Act and Medicaid Expansion on Racial and Socioeconomic Disparities in Cancer Care”; Wherry and Miller, “Early Coverage, Access, Utilization, and Health Effects Associated With the Affordable Care Act Medicaid Expansions.”

¹³ Eguia et al., “The Impact of the Affordable Care Act (ACA) Medicaid Expansion on Access to Minimally Invasive Surgical Care”; Eguia et al., “The Impact of the Affordable Care Act Medicaid Expansion on Vascular Surgery”; Goldman and Sommers, “Among Low-Income Adults Enrolled In Medicaid, Churning Decreased After The Affordable Care Act”; Margerison et al., “Impacts of Medicaid Expansion on Health Among Women of Reproductive Age.”

¹⁴ Cher, Morden, and Meara, “Medicaid Expansion and Prescription Trends”; Lee et al., “The Impact of Medicaid Expansion on Diabetes Management”; Mesquita-Neto et al., “Disparities in Access to Cancer Surgery After Medicaid Expansion”; Sommers, Gawande, and Baicker, “Health Insurance Coverage and Health — What the Recent Evidence Tells Us.”

¹⁵ Miller et al., *Medicaid and Mortality*.

¹⁶ Artiga et al., *Findings from the Field: Medicaid Delivery Systems and Access to Care in Four States in Year Three of the ACA*; Lindrooth et al., “Understanding the Relationship Between Medicaid Expansions and Hospital Closures”; Shin et al., *Health Center Patient Trends, Enrollment Activities, and Service Capacity: Recent Experience in Medicaid Expansion and Non-Expansion States*.

¹⁷ Caswell and Waidmann, “The Affordable Care Act Medicaid Expansions and Personal Finance”; Hayes et al., “The Fiscal Case for Medicaid Expansion”; Hu et al., *The Effect of the Patient Protection and Affordable Care Act Medicaid Expansions on Financial Wellbeing*; Ku, Bruen, and Brantley, *The Economic and Employment Benefits of Expanding Medicaid in North Carolina: June 2019 Update*; Zewde et al., “The Effects of the ACA Medicaid Expansion on Nationwide Home Evictions and Eviction-Court Initiations.”

¹⁸ Antonisse and Rudowitz, *An Overview of State Approaches to Adopting the Medicaid Expansion*.

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Legislative Measures

Many states, especially those in the first wave of expansion, have authorized Medicaid expansion legislatively, either through stand-alone bills or as part of the state budget. For example, in 2013, Colorado, Connecticut, California, New York and several other states all passed legislation to adopt expansion and appropriate state funds for it. This method is typical in states where both the legislative and executive branches of state government have reached consensus on expansion, although there are some exceptions.

Executive Action

Several states have expanded Medicaid using executive action without full approval from the state legislature. For example, the governors of West Virginia, Kentucky and Louisiana expanded their state's Medicaid program through executive orders. Former Governor John Kasich obtained approval from a bipartisan legislative panel to appropriate state funds for expansion in 2013 when the state's full legislature could not agree on a decision regarding expansion.¹⁹

Ballot Measures

A handful of states have expanded their Medicaid programs using ballot initiatives. Some states, such as Idaho, Nebraska and Utah, went this route after attempts to adopt expansion through the regular legislative process failed. For example, in 2017, after former Maine Governor Paul LePage vetoed Medicaid expansion five times, Mainers voted via referendum to expand.²³ Of the remaining non-expansion states, six allow public referendums on this issue. Ballot initiative campaigns are underway in Florida, Missouri and South Dakota.²⁰

Expansion with Section 1115 Waivers

In addition to authorization from the state, state Medicaid agencies need to seek permission from the federal Centers for Medicare and Medicaid Services (CMS) in order to expand Medicaid. CMS requires state Medicaid agencies to submit either a state plan amendment (SPA) or a Section 1115 waiver request, which allows states to make changes to the Medicaid program that are not otherwise allowed by law.

As of April 2020, ten states have expanded Medicaid with the use of a Section 1115 waiver (with several requests in the pipeline).²¹ The purpose of the waiver, which is authorized by Section 1115 of the Social Security Act, is to give states additional flexibility in the design of projects "promoting the objectives of the program."²² Waivers can stipulate terms that beneficiaries must meet, including work requirements, compulsory copayments and premiums, and behavioral health mandates. The work requirement in particular has been challenged in court, with a federal district judge invalidating it in Arkansas, Kentucky,

¹⁹ Higgs, "Controlling Board Gives OK to Use of Federal Money to Pay for Medicaid Expansion in Ohio."

²⁰ Kaiser Family Foundation, "Status of State Medicaid Expansion Decisions"; News Service of Florida, "Ballot Proposal to Expand Medicaid Pushed Back To 2022."

²¹ See Kaiser Family Foundation, "Status of State Medicaid Expansion Decisions."

²² Hinton et al., *Section 1115 Medicaid Demonstration Waivers: The Current Landscape of Approved and Pending Waivers*.

New Hampshire and Michigan. Upholding the Arkansas decision in February 2020, the D.C. Circuit Court of Appeals effectively suspended the work requirement for now.²³

Medicaid in North Carolina

North Carolina’s Medicaid program covers about 2.1 million individuals, or about 20% of the state’s population.²⁴ Eligibility is one of the most restrictive in the country.²⁵ Pregnant women and people who are elderly, blind or have a qualifying disability are eligible if they meet strict income guidelines. Non-elderly, non-disabled adults without dependent children are not eligible for Medicaid regardless of their income (Table 1).

Table 1. Income limits for Medicaid coverage in North Carolina as of April 2020

Eligibility category	Current monthly income limit	% of Federal Poverty Level
Elderly, blind or disabled adult	\$1,064 (Family size = 1)	100% of FPL
Non-disabled, non-elderly adult with dependent children	\$569 (Family size = 2)	≈40% of FPL
Pregnant woman (limited to treatment for conditions that affect pregnancy)	\$2,816 (Family size = 2)	196% of FPL
Non-disabled, non-elderly adult with no dependent children	Not eligible under current Medicaid criteria	N/A

Source: <https://files.nc.gov/ncdma/documents/files/Basic-Medicaid-Eligibility-Chart-2020.pdf>

North Carolina’s uninsured rate is higher than the national average, and considerably higher than neighboring expansion states, such as Kentucky and West Virginia.²⁶ Over one million North Carolinians are uninsured, most of whom are between the ages of 19 and 64. The statewide uninsured rate for these working age adults is 15.7%, though the rate is much higher—up to 29%—in some of the state’s rural counties. Certain racial/ethnic minorities, those with a high school diploma or less, and low-income North Carolinians experience much higher uninsured rates than the overall rate (Figures 2 and 3). Over 11% of people who work full-time year-round lack health insurance.

²³ Goodnough, “Appeals Court Rejects Trump Medicaid Work Requirements in Arkansas.”

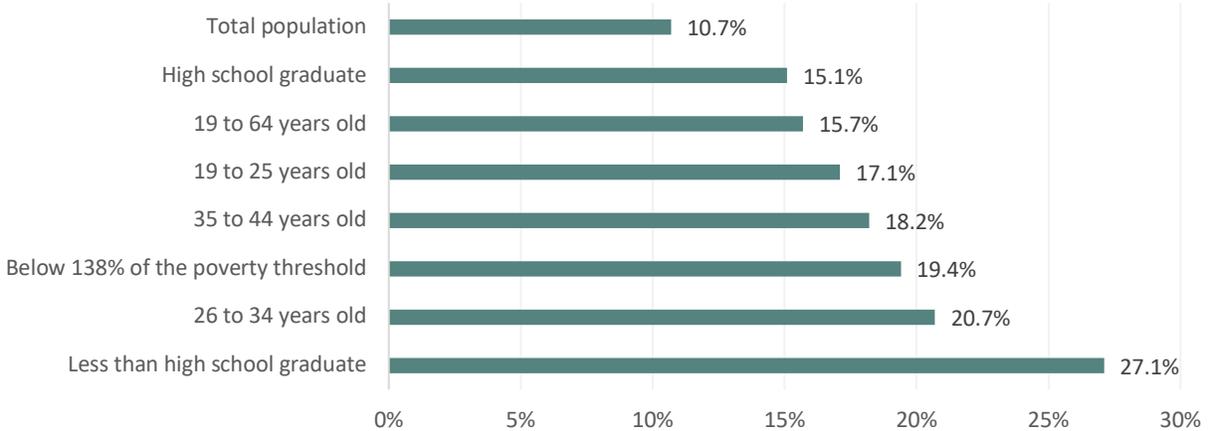
²⁴ N.C. Medicaid, Division of Health Benefits, “N.C. Medicaid: Dashboards”; U.S. Census Bureau, “U.S. Census Bureau QuickFacts.”

²⁵ Ku, Bruen, and Brantley, *The Economic and Employment Benefits of Expanding Medicaid in North Carolina: June 2019 Update*, 6.

²⁶ North Carolina’s uninsured rate is 10.7%, the national rate is 8.9%. Kentucky and West Virginia stand at 5.6% and 6.4% respectively. 2018 American Community Survey 1-Year Estimates.

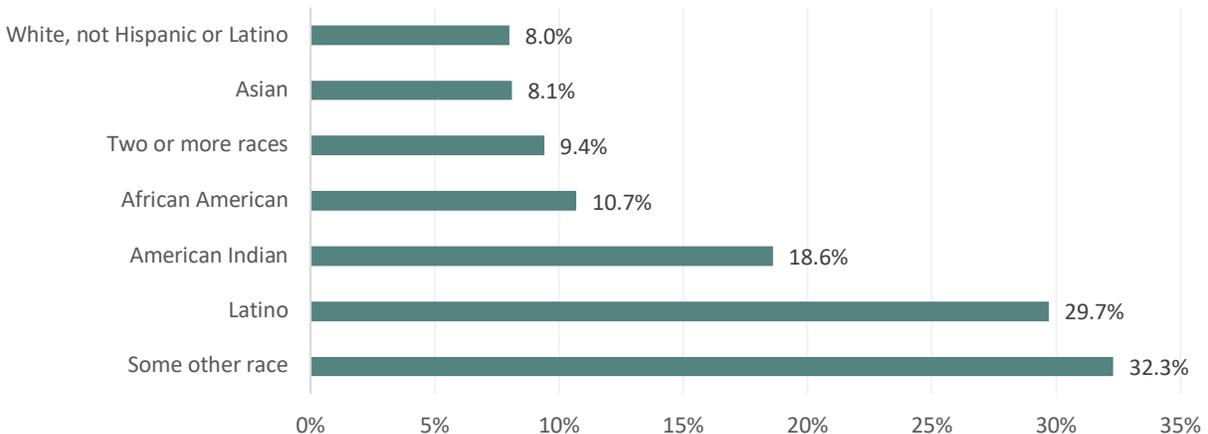
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Figure 2. Percent without health insurance by select age, education and income



Source: 2018 American Community Survey 1-Year Estimates

Figure 3. Percent without health insurance by racial/ethnic group, all ages



Source: 2018 American Community Survey 1-Year Estimates

Hundreds of thousands of uninsured adults fall into the insurance “coverage gap” in North Carolina.²⁷ They earn “too much” to receive Medicaid but less than 100% of the federal poverty line, which is what they need to qualify for the ACA’s health insurance subsidies. Other low-income adults who earn over 100% of FPL but still struggle to afford health insurance would also benefit from expansion.

Since the enactment of the ACA, North Carolina’s Republican-led legislature has taken a number of steps to block Medicaid expansion. In 2013, the General Assembly passed a bill that prohibits “any department, agency, or institution” from expanding Medicaid unless granted explicit permission by the legislature.²⁸

²⁷ Estimates vary from about 400,000 to 500,000. See, North Carolina Office of the Governor, “Healthcare: A Healthier North Carolina”; Garfield, Orgera, and Damico, *The Coverage Gap: Uninsured Poor Adults in States That Do Not Expand Medicaid*; Riley, “Profiling North Carolina’s Uninsured.”

²⁸ 2016 North Carolina Laws S.L. 2016-125, (S.B. 4), <https://www.ncleg.gov/EnactedLegislation/SessionLaws/PDF/2015-2016/SL2016-125.pdf>.

The same law also prevents the adoption of Medicaid expansion through a referendum. Shortly after taking office in early 2017, Governor Roy Cooper announced a plan to file an amendment to a pending Section 1115 waiver that would permit expansion. In response, legislative leaders filed a federal lawsuit in opposition, and on January 14, 2017—in the waning hours of the Obama administration—a federal district court judge issued a temporary order blocking CMS from approving the amendment.²⁹ Facing an incoming presidential administration intent on overturning the ACA, Cooper abandoned his plan.³⁰ In 2018, a proposal to study Medicaid expansion was stripped from the final version of the bill.³¹

Two bills have been introduced in the past year that would extend health insurance coverage to low-income North Carolinians. In April 2019, four Republican sponsors introduced House Bill 655, which would cover individuals up to 133% of the federal poverty level. House Bill 655 requires beneficiaries to pay an annual premium of 2% of household income plus co-payments. It also includes a work requirement.³² As of April 2020, the bill remains in committee. Spurred by the coronavirus pandemic, four Democrats introduced House Bill 1040 in late April 2020. If enacted, this bill would be a straight-up Medicaid expansion with no premiums or work requirement.³³

The debate over Medicaid expansion was the catalyst for an ongoing state budget showdown. In June 2019, Governor Cooper vetoed the budget passed by the General Assembly, in large part because it failed to include funding for Medicaid expansion.³⁴ On September 11, 2019, in a surprise, last-minute vote (many Democratic representatives were at a 9/11 memorial service), the House overrode Cooper's veto. To date, Republicans in the state Senate have not been able to summon the votes needed to override the veto. Ongoing budget negotiations have failed to resolve the conflict and the budget deadlock remains in place.

As this pitched political battle shows, much is at stake with Medicaid expansion. In the following sections, we will describe how the lack of Medicaid expansion in North Carolina has: 1) jeopardized the lives and wellbeing of Tar Heels across the state; 2) forced doctors and other healthcare providers to compromise the care they provide; and 3) hamstrung the state's healthcare system.

²⁹ Binker, "Court Blocks NC Medicaid Expansion Effort."

³⁰ Blythe, "NC Legislators Drop Lawsuit Challenging Cooper's Attempt to Expand Medicaid Under Obamacare."

³¹ See Improving N.C. Rural Health, H.B. 998, 3rd ed., 2017-2018 Session, <https://www.ncleg.gov/Sessions/2017/Bills/House/PDF/H998v3.pdf>. Enacted as 2018 North Carolina Laws S.L. 2018-88 (H.B. 998).

³² N.C. Health Care for Working Families, H.B. 655, 2019-2020 Session, <https://www.ncleg.gov/BillLookup/2019/H655>.

³³ Healthcare for Working North Carolinians, H.B.1040, 2019-2020 Session, <https://www.ncleg.gov/BillLookup/2019/HB1040>.

³⁴ Robertson, "Cooper Vetoes GOP Budget, Calling It 'Astonishing Failure'"; Thompson, "Medicaid Expansion Is at the Heart of the Budget Fight. Here's What It Means for NC."

Voices of the Uninsured

Suppose you're one of millions of North Carolinians who doesn't make enough to cover basic expenses.³⁵ You're not feeling well. Maybe your symptoms are a temporary problem. Maybe they're an indication of something more serious. Do you go to the doctor? What do you sacrifice if you do? Groceries, utilities, a child's school supplies? Is it worth it?

Low-income uninsured individuals must constantly prioritize between competing needs. They must choose between paying for a visit to the doctor and other pressing expenses. They weigh the severity of their symptoms, the seriousness of their condition, and how long they can postpone or do without treatment.

Concern about out-of-pocket costs means preventive care often falls by the wayside. Jackie Kiger, who serves low-income clients through Pisgah Legal Services in western North Carolina, reports she often hears something along these lines: "I couldn't afford to pay for medication this month because it's cold, and oil was expensive. Or I needed to buy presents for the children. There's only so much money, and there's no health insurance that I qualify for."

The uninsured individuals we interviewed talked about how they avoided medical care as much as possible due to concerns about cost. An uninsured gentleman in western North Carolina who receives care at his local health department's clinic explained that he consults the internet first. "I generally Google things, and if it sounds like it's serious then I say, 'Oh, I need to call the health department.'" Googling symptoms is common enough, but uninsured patients turn to Google to see if medical attention is absolutely necessary.

A healthcare provider at a community health center described that even when an income-based sliding scale fee system is in place for certain clinics, low-income patients may still have trouble paying the cost. "For very poor people," she said, "\$20 adds up and is its own obstacle." Dr. Evan Ashkin, a professor of family medicine and a physician at a local community health center, noted, "We see all the time that people are delaying care or not getting services. Especially a lot of preventive services are just unaffordable for folks."

In our hypothetical, let's say you're worried enough to think seriously about going to the doctor. How do you get there? The cost of transportation is another expense beyond the doctor's bill. Over 228,000 households in North Carolina have no access to a vehicle. Another 1.2 million have one vehicle shared by the entire household.³⁶ Even if a household owns a car, the costs associated with operating it—keeping it repaired, maintaining insurance, buying gas—might render it unavailable. Public transportation presents its own scheduling and cost challenges, if it exists at all.

For individuals who live in rural areas, fewer providers, greater distances and a scarcity of public transportation heighten transportation barriers. Dr. Ashkin cares for a low-income, uninsured patient with

³⁵ According to the U.S. Census Bureau, almost 3.4 million North Carolinians earn less than 200% of the poverty threshold. In 2019, this amount was \$35,244 for a family of one child and one adult. This is a common marker for earning enough for a household to maintain financial stability. It closely parallels the Living Income Standard (the amount required to afford basic necessities) for North Carolina, which in 2019, was \$38,488. Kennedy, *The 2019 Living Income Standard for 100 Counties*.

³⁶ 2018 American Community Survey 1-Year Estimates

multiple sclerosis who drives over an hour to attend his appointments. He described how this patient has to “save up for gas to see me” because he lives over 60 miles away.

The more often a person needs to see a health care professional, the more burdensome transportation becomes. We met a man with Type II diabetes and heart disease who used his mother’s car when possible to travel to his medical appointments. However, he often lacked gas money for the hour-and-twenty-minute round trip to the health department. His specialist appointments were even further away from home, requiring a two-hour round trip. He said, “I’m supposed to see another doctor for my diabetes, but I haven’t had the [gas] money to make the last two appointments. I didn’t have the money to make those.” At the time of the interview, he had an appointment in five weeks with his specialist that he wasn’t sure he could afford to get to. Lower healthcare costs would help this patient distribute more of his limited funds to transportation. In addition, eligible North Carolina Medicaid enrollees receive reimbursement for transportation expenses and free transportation.³⁷ With Medicaid expansion, both his healthcare costs and transportation expenses would be considerably reduced.

Making and attending medical appointments takes time. Are you willing to forgo income to see a doctor? As wages for low-income workers across the state stagnate and access to paid sick days in low-wage work remains scarce, you’re stuck with a dismal choice: work or doctor? Income or health?³⁸

Patients seeking reduced-cost care also face a time-consuming maze when they navigate the fragmented system that currently provides help for North Carolina’s uninsured. A care manager in a rural public health department that provides care on a sliding scale noted,

We make [patients] just fill out forms and jump through hoops to get assistance. It’s, “to get this, you have to fill out this form, and this one is 100% FPL and this one is 200% FPL. This is only open on Tuesdays; this is open on Wednesdays.” It’s a full-time job trying to get one appointment. Then we say, “Well, they’re non-compliant.” No, they’re not! They’re either physically or mentally unable to get it done. We ask a lot. It’s a full-time job to be uninsured and seek assistance.

With preventive care often beyond reach, conditions that could be caught or managed often deteriorate. As Dr. Ashkin observed, “health is low on the list until you get acutely ill.” We spoke to one man who went for six to eight months without treatment for his Type II diabetes after he lost his job and his employer-sponsored health insurance. He explained, “I wasn’t taking any medications. My sugar went up to 600, 660.” Normal blood sugar amounts should not exceed 140 mg/dL and he risked serious complications, including a heart attack or stroke, as a result.

A primary care provider described a patient who is living with two unaddressed and medically worrisome issues:

A fella I saw today [a house painter without insurance] had a heart attack five years ago. He has no insurance—I see him episodically. I have not been able to persuade him to get

³⁷ Division of Health Benefits, *Fact Sheet #4: Non-Emergency Medical Transportation (NEMT)*.

³⁸ Kennedy, *Health Coverage or Food on the Table?*; Gould, “Lack of Paid Sick Days and Large Numbers of Uninsured Increase Risks of Spreading the Coronavirus.”

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regular blood work. He should have had a colonoscopy seven or eight years ago. He hasn't had one, so therefore, according to the American Cancer Society, he has a higher risk of dying from colon cancer.

When patients can't get the preventive care they need and become ill as a result, they are at risk for more debilitating outcomes. Costs snowball as medical interventions become more complicated and intensive. One case manager from a rural county described her experience working with a patient with a heart condition that was exacerbated by lack of preventive care:

I could not get it under control and get him to the cardiologist before [he went into the hospital]. He ended up in the ICU for a month. He made it, and we spent a billion dollars on him. We can lessen the impact if we treat the client earlier. And some people don't make it, or they die way before they should die.

Another provider echoed how lack of basic preventive care leads to unnecessary suffering later:

I had [a patient] with a necrotic, infected toe and [she] hadn't done anything about it for a week. When she finally came to see me, I told her "You need to go to the hospital." And then she delayed going to the hospital again. I just got the hospital discharge summary. She lost a couple of toes and had to undergo a pretty invasive procedure. One of the reasons for the delay was knowing that the care would be very expensive.

Patients coping with ill health must also worry about a growing mountain of medical debt. One patient with multiple health issues described his outstanding hospital bills after being admitted without insurance. "With all the medicines that I'm on, it's just hard for me to pay . . . plus doctor bills, I mean I just got a bill from [the hospital] for \$19,000, and I think I owe [another hospital] probably \$25-30,000." When describing how he made decisions about whether to seek care, another person we interviewed said, "Cost is a major factor. Cause a lot of things you can't go for, I mean, if you don't have insurance this [the health department] is about the best effort you can do around here."

Not only are uninsured patients forced to pay out of pocket for their expenses when they seek care, they often pay more than other patients. Insurance companies are able to negotiate for lower rates and pick up the bulk of the bill for insured patients. Uninsured patients who have no negotiating power are billed at higher rates for the same procedure and have to pay the full amount, often before they receive services.³⁹ Additionally, uninsured patients who are seen in the emergency department are typically billed at double the rate charged by other parts of the hospital.⁴⁰

Dr. Pradeep Arumugham, a cardiologist from Kinston, described the impact of this system. "These people are drowning in medical bills. You go to the hospital, and when you come home you have bills from the ER physician, the lab, the pathologist, everything. And they're all the highest bill possible."

³⁹ Dusetzina, Basch, and Keating, "For Uninsured Cancer Patients, Outpatient Charges Can Be Costly, Putting Treatments Out of Reach"; Garfield, Orgera, and Damico, "The Uninsured and the ACA."

⁴⁰ Xu et al., "Variation in Emergency Department vs Internal Medicine Excess Charges in the United States."

Even if uninsured patients are able to see a provider once they become ill, they often cannot afford to follow through with necessary procedures or treatments, which further damages their health. As one primary care provider described,

I wouldn't be hard pressed to find an uninsured patient, if I took a look through his/her chart, where something that I thought was medically advisable either wasn't done or there was a delay in doing it because of a lack of insurance.

When asked about the health consequences of patients skipping tests, Dr. Stephen Luking, a physician in family medicine in Rockingham County, was blunt. "Potential for premature death would be one," was his reply.

The Uninsured and Chronic Health Conditions

Chronic conditions are a leading cause of death and disability in the U.S. They must be managed to maintain health and stave off debilitation and premature death. For example, without proper management, diabetes can lead to cardiovascular disease (the leading cause of early death among individuals with diabetes), kidney disease, blindness, and nerve damage resulting in lower-limb amputations.⁴⁵

Chronic conditions are defined broadly by the U.S. Centers for Disease Control and Prevention (CDC) as health conditions that last at least one year and require ongoing medical attention and/or limit a person's daily living activities. **In 2019, an estimated six in ten Americans lived with one chronic condition, and four in ten lived with two or more.**¹

Several chronic conditions, including heart disease, cancer, and diabetes, are the leading cause of preventable death and disability in the U.S. and become more common every year. **Ninety percent of the nation's average \$3.5 trillion spent annually on healthcare are for costs associated with chronic conditions and chronic disease management.**²

¹ Centers for Disease Control and Prevention, <https://www.cdc.gov/chronicdisease/about/index.htm>

² Centers for Disease Control and Prevention, <https://www.cdc.gov/chronicdisease/about/costs/index.htm>

Stark health disparities mark the diagnosis and progression of chronic conditions. Racial and ethnic minorities and people in poverty have a higher incidence of the most common chronic diseases, such as hypertension, diabetes, cancer, cardiovascular disease, and obesity, and they experience worse outcomes from these conditions.⁴¹ In addition to higher rates of chronic illness, lower wages and higher uninsured rates among racial and ethnic minority groups limit access to treatment for chronic conditions.⁴³ Other socioeconomic factors contribute to poor health as well. As one doctor commented, talking about diabetes,

It's a very difficult condition to control from a doctor's office because there are so many factors that go into the original development of diabetes and maintaining its strength and

⁴¹ Kurtzleben, "Americans in Poverty at Greater Risk for Chronic Health Problems"; Shaw et al., "Chronic Disease Disparities by County Economic Status and Metropolitan Classification, Behavioral Risk Factor Surveillance System, 2013"; Thorpe et al., "The United States Can Reduce Socioeconomic Disparities by Focusing on Chronic Diseases."

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damage to the body. So finances, transportation, life stress, time out of work, dozens of factors actually contribute to people being able to have healthy lifestyles.

For uninsured individuals grappling with chronic conditions, the penalty for going without healthcare is steep. Lack of preventive care can mean a delay in diagnosis—a missed opportunity to cut off disease progression before it becomes much more difficult to control. As Dr. Luking put it, “Uninsured women don’t just magically get more breast cancer. They get it diagnosed later in the ballgame when the horse is out of the barn. That’s a no-brainer.”

Once diagnosed, care of chronic conditions requires ongoing attention, regular check-ups and frequently, consultation with specialists. Although many uninsured patients receive catastrophic care in hospital emergency departments, the continuous care that is needed to manage chronic conditions over a lifetime isn’t available in an emergency department setting or in sporadic visits to free- or reduced-cost clinics. Chronic health problems often necessitate a range of treatments that uninsured patients can’t afford. During our visit, Dr. Luking mentioned a patient who, despite occasional visits to the doctor, couldn’t get comprehensive care for all his conditions.

[This patient] has a crapload of medical problems. He’s not taking care of himself, his asthma is out of control, diabetes, hypertension out of control, skipping his meds. I saw him, and was patching him together, but skipping all these things the experts say I should be giving him to keep him alive.

Uninsured patients have to make do with piecemeal, reactive services in lieu of comprehensive care. One primary care provider described an uninsured patient who delayed getting specialty care for her rheumatoid arthritis (RA) because of the high cost of the appointments. After nine months elapsed without accessing specialty care, she returned with significant joint damage. He commented,

With health insurance, she would have been able to have specialty care initially and not suffered from significant joint damage, which has a fair chance at affecting her ability to work or contribute financially to her family, and she has a high risk of applying for disability later on. And then not having Medicaid to keep her healthy, but having Medicaid because she’s disabled and not able to work, which is not the reason we want people to have Medicaid.

Prescription medication is often needed to manage chronic conditions effectively, which complicates treatment for the uninsured. Dr. Arumugham, the cardiologist, described how his low-income patients with chronic heart disease are often unable to take medications consistently. This limits his ability to treat and manage their condition to prevent future damage.

With high blood pressure, congestive heart failure, and all of that—you don’t really feel bad until you are in terrible shape. If you have a weak heart, you need to be on three or four medicines to strengthen your heart, at the least. You need to consistently take them for three to nine months before we can say for sure that your heart is not going to get any better. You have to consistently take them. The heart won't get better, if anything, it gets worse [if you don’t take medication consistently].

Because his uninsured patients can't reliably take their medications, he is ultimately unable to determine which medicines to continue prescribing and whether the medicines work effectively.

I don't even know for half these patients whether I can even make their heart better, because I cannot put them on the most appropriate medicines. But if they did have Medicaid, then I could put them on all of these appropriate medications. Right now, I am not even sure if it's the lack of health insurance that is preventing them from getting better, or if it's truly their heart that is not getting better.

Along with costs and other hurdles to accessing care, uninsured patients with chronic conditions have to navigate care coordination. Sporadic care, many interactions with multiple healthcare providers in different settings over time, an assortment of possibly contraindicated medications, conflicting diagnoses and medical advice, and other challenges related to care raise the risk of duplicate tests, hospitalization and unnecessary and possibly dangerous measures.⁴²

Dr. Peter Morris, the executive director of Urban Ministries Wake County, discussed the critical role that care coordination plays in patient treatment. Urban Ministries' Open Door Clinic serves uninsured, low-income patients with chronic conditions at no cost to the patient. Patient referrals come at all stages in disease progression, and it often receives patients who are "in crisis with disease management." Patients who receive chronic disease treatment and care coordination are better able to manage their conditions after attending several regular appointments at the clinic and receiving care coordination services:

It's not that we are affecting change, it's that they are affecting change for themselves. You know, if you're seeing someone four to seven times based on how difficult their chronic illness is to try to bring under control, it's really brought under control the other 361 days of the year you're not seeing them. So the plan of care you develop together is key. And it's not our work, it's their work.

Managing Chronic Conditions in Rural NC

Patients we spoke to who lived in rural counties described how provider turnover makes it harder for them to build relationships and receive consistent care. One patient talked about how he has to catch mistakes new providers make.

If you were going to a regular doctor, they would know your patient history pretty well. When you're getting switched around like that, not so much. And then you get sort of like, "well, I'm not sure that they're gonna catch..." I've had them try to prescribe this one medicine and I'm allergic to it. They've tried to do that several times to me. And I say "whoa whoa whoa, haven't you looked at my file? It says I'm allergic," and then they'll say, "oh yeah, I see now." And if you ain't proactive here the more prone you are to hurt yourself, so you have to be proactive.

This frequent provider turnover hinders patient trust, which can lead to increased stress about going to the doctor and reluctance to divulge important health information.

⁴² Anderson, *Chronic Care: Making the Case for Ongoing Care*.

Harm to Families and Communities

Uninsured people don't generally experience poor health in isolation: it affects their families and communities. Poor health can lay a breadwinner low or incapacitate a caregiver. The financial drain of healthcare is felt by the whole household. One uninsured person we spoke to discussed at some length how his healthcare costs wore on his mother:

My dad passed away last year and I'm with my mother, and it's hard to make ends meet. It's hard for her. She's helping me as much as she can, but it takes away from her paying her way, and I don't know, it's just . . . it's just rough.

When asked how Medicaid expansion would affect his life, he explained "Well, it would probably help my mother save a little money without having to pay for everything, without having to pay somebody to take me somewhere, or pay for my medicines, because I have no income."

In addition to the financial implications, lack of care can cut to the heart of what family means. One rural provider described a crisis he is seeing in his clinic with uninsured pregnant women with diabetes. Because of the diabetes, they lose their pregnancies—an outcome that is entirely preventable with reliable care.

We've had eight patients with very poorly controlled diabetes just before the onset of pregnancy, and seven of the eight have lost their pregnancies. The way that we're able to work through Type II diabetes during pregnancy typically is by seeing a patient before they become pregnant and have their diabetes under excellent control and then have them be seen by OB/GYN specialists in maternal-fetal medicine, which are only available in the main population hubs—they're not available in rural North Carolina. That's impossible outside of pregnancy, generally because of cost.

When patients are pregnant, we have a swifter system to get patients to OB/GYN specialty care, but for pre-pregnancy planning, ahead of time, there's not any kind of swift system and there's no method for taking care of these very high-risk mothers.

The preventable loss of a family member due to lack of care affects survivors too. Dr. Arumugham described how one patient who might have received a necessary defibrillator refused it. Her uninsured daughter died of heart disease at 23 and the mother's remorse has influenced the course of her treatment. As Dr. Arumugham recalled, "The mother said, 'My child would have been alive if she had had health insurance. How is it fair that I should be alive just because I do?'"

Lack of Health Insurance Keeps People Out of Work

Health shapes the ability to work. Access to affordable care helps people get and keep a job.⁴³ Poor health is associated with greater difficulty finding a job.⁴⁴ Workers who say they experience poor health are more

⁴³ Ohio Department of Medicaid, *Ohio Medicaid Group VIII Assessment: A Report to the Ohio General Assembly*; Institute for Healthcare Policy & Innovation, "Jump in Employment Seen Among Medicaid Expansion Enrollees, Especially the Most Vulnerable."

⁴⁴ Antonisse and Garfield, *The Relationship Between Work and Health*.

likely to perceive that their jobs are insecure and are more likely to lose their jobs.⁴⁵ Job loss and unemployment can also harm health, deepening the connection between employment and wellbeing.⁴⁶

For uninsured low-wage workers, maintaining employment while coping with poor health is a struggle. Forty percent of workers in North Carolina are not entitled to paid sick days.⁴⁷ In low-wage industries like food preparation, personal care, and cleaning services, the share of workers without paid sick days is much higher.⁴⁸ Low-wage employers are more likely to assign unpredictable and erratic schedules and are less likely to provide employer-sponsored benefits.⁴⁹

We met a primary care provider in central North Carolina who watched his patients struggle to maintain both health and employment. Describing a patient, he referred to the catch-22 that traps people in unemployment and ill health.

Medical care is the reason she can work, and she cannot work without it. If she has a flare and then can't work and loses her job, the only way for her to get back into work is to have health insurance to pay for medicine.

Jackie Kiger, of Pisgah Legal Services, summarized it this way:

It's not uncommon to hear that [clients] weren't able to work because they didn't feel well. And they don't have health insurance, and they couldn't afford going to the doctor for insulin or anti-depressants or whatever else. We hear that a lot.

Jobs and Health Insurance

Although North Carolina is expected to add an additional 550,000 jobs by 2024, the majority will be low-wage jobs and 90% will be in the service sectors like hospitality, retail, and restaurants.¹ These jobs offer fewer supports for workers with health challenges. In addition, job growth is primarily occurring in major metropolitan areas, leaving rural areas behind. Forty-nine rural counties across the state had more jobs before the 2008 crash than they have today. Rural North Carolinians are more likely to be unemployed, and if they do find employment, they are more likely to work in low-wage jobs. Racial disparities amplify differences in access to jobs: rural African American workers have almost twice the unemployment rate of rural white workers.²

¹ North Carolina Department of Commerce, <https://www.nccommerce.com/blog/2016/10/04/north-carolina%E2%80%99s-statewide-employment-projections-released-2014-2024>.

² Advancing Employment Equity in Rural North Carolina, https://www.policylink.org/sites/default/files/Employment_Equity_North-Carolina_06_19_18_0.pdf.

⁴⁵ Antonisse and Garfield; Khubchandani and Price, "Association of Job Insecurity with Health Risk Factors and Poorer Health in American Workers."

⁴⁶ Brand, "The Far-Reaching Impact of Job Loss and Unemployment"; Strully, "Job Loss and Health in the U.S. Labor Market."

⁴⁷ North Carolina Justice Center, *Work, Interrupted: How the Recession and a Changed Labor Market Will Affect Millennials in North Carolina for Years to Come*. Racial and ethnic minorities in North Carolina are less likely to have paid days, and sixty percent of Hispanic workers do not have paid sick days.

⁴⁸ Institute for Women's Policy Research, *Access to Paid Sick Days in North Carolina*.

⁴⁹ Boushey and Ansel, *Working by the Hour: The Economic Consequences of Unpredictable Scheduling Practices*.

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Work isn't optional for most people in poor health, in part because programs like Social Security Insurance (SSI) and Social Security Disability Insurance (SSDI)⁵⁰ impose very strict eligibility standards.⁵¹ Only 35% of applications for SSDI are ultimately accepted for benefits, 12% of whom gain benefits only after appeal.⁵² Appeals can take years. In 2017, over 10,000 Americans died while waiting for disability determinations.⁵³

Dr. Ashkin recalled watching a patient with progressive multiple sclerosis (MS) try to obtain SSDI assistance:

[He] applied for disability three times and got turned down, so his MS continued to progress with continuous disability. Finally, he actually did qualify for disability. So that's this perverse win: now he's disabled enough that he has Medicaid.

States that have expanded Medicaid have seen a rise not only in overall workforce participation, but specifically in workforce participation among people with disabilities.⁵⁴ Expansion states have also seen a decrease in SSI participation by an average of 3%.⁵⁵ As Dr. Peter Morris, of Urban Ministries in Raleigh, observed, "When people are feeling better, they are able to return to the workforce. They are able to support their families, and they are able to improve their quality of life."

Getting pushed out of the workforce can be financially and psychologically ruinous. It also saps communities and the economy generally. As a primary care doctor told us,

My patients are sick in their 30s. They're not contributing 30 years of financial benefit to the U.S., if we think of it from an economic perspective. I have people having strokes from diabetes at 38 and getting charcot [a disease that causes progressive deformation of the foot] from diabetes and not being able to walk at 38.

The Medicaid Work Requirement

N.C. Health Care for Working Families, or House Bill 655, would require able-bodied adults to report 80-hours per month of work or volunteer activities through an online portal or lose their coverage. If HB 655 becomes law, an estimated 23% percent of individuals who would otherwise benefit from coverage—88,000 people—would not be eligible as a result of the work requirement.¹ A work requirement would disproportionately impact already disadvantaged communities that face barriers to work, including rural residents, minorities, people with disabilities, veterans and the homeless.

⁵⁰ Social Security Insurance (SSI) provides financial assistance to very low-income, low-asset people who are aged, blind, and/or have serious disabilities. Social Security Disability Insurance (SSDI) provides financial assistance to people who have worked outside of the home for a certain period of time who have disabilities who meet a high level of impairment.

⁵¹ For example, applicants for SSDI must show sufficient work history, prove they have a severe ongoing impairment, and demonstrate that their impairment prevents them from being hired for any job, regardless of whether that job is available where they live, whether vacant positions exist or whether they'd be hired. Center on Budget and Policy Priorities, "Chart Book: Social Security Disability Insurance."

⁵² Center on Budget and Policy Priorities.

⁵³ McCoy, "597 Days. And Still Waiting."

⁵⁴ Hall et al., "Effect of Medicaid Expansion on Workforce Participation for People with Disabilities"; Tipirneni et al.,

"Association of Medicaid Expansion with Enrollee Employment and Student Status in Michigan."

⁵⁵ Soni et al., "Medicaid Expansion and State Trends in Supplemental Security Income Program Participation."

Most people on Medicaid who can work, do work. Six in ten nonelderly adults enrolled in Medicaid work outside of the home. For those who don't work full-time, the main reasons include not being able to find work, attending school, or taking care of family members.

While Medicaid work requirements exempt some people with disabilities, many Medicaid beneficiaries suffer from disabilities that limit their ability to work but don't rise to the level necessary to receive federal benefits.² Workers whose hours fluctuate or who work seasonally also risk losing coverage. (As Dr. Luking asked, "my outdoor painters, from November through May, what are they supposed to do, suspend their coronary artery disease?")

Difficulty reporting or misunderstandings regarding the requirement cause some recipients to lose coverage. Many Medicaid recipients lack computers or internet access. Nationally, three out of ten adults enrolled in Medicaid don't use a computer, 28% don't use the internet and 41% don't use email.²

A study of the work requirement in Arkansas reported that about a third of Medicaid recipients who failed to report lacked internet access. Additionally, implementation of the work requirement was "plagued by confusion." Large proportions of the target population had not heard about the requirement or were unsure if it applied to them.³ The same study found that while about 17,000 adults were removed from Medicaid over a three-month period, there was no corresponding uptick in actual employment.³

¹ Sirota, *People Trying to Access High Quality, Affordable Health Insurance Should Not be Met with Work Reporting Barriers.*

² Garfield et al., *Implications of Work Requirements in Medicaid: What Does the Data Say?*

³ Sommers et al., "Medicaid Work Requirements — Results from the First Year in Arkansas."

The Burden on Healthcare Providers

While uninsured individuals experience hardship up close, healthcare providers who treat uninsured patients are professionally and personally affected as well. One of the primary goals of healthcare professionals is to serve as a patient advocate and deliver the best care possible. The failure to expand Medicaid undermines these goals and makes providers complicit in a two-tier system of care. Dr. Ashkin described the feeling of helplessness this situation engenders:

I went into medicine to fix things, right, not to just sit there and wring my hands. But that's literally one of the skills, actually, that I've had to develop. To just let people tell me the challenges they have and just sort of be witness to that. Even if I can't do much about stuff.

Provider options are constrained when patients are uninsured. Just as their patients have to weigh competing priorities—groceries or medications, going to work or going to the doctor—providers also have to weigh factors like patient concerns about cost, household income, and the overall best interest of the patient and their family when deciding on a course of action. If a provider knows that ordering an important but expensive test or medication will be a burden, financially or emotionally, she may decide against it even though it's medically advised. Several providers we interviewed reflected on this dilemma.

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It happens every week, if not every day, that I have to, for example, change which medication to give based upon how much money they have. We only refer to specialists if we feel like they really need them.

A part of it is that you stretch, you do more than you would, and you try to go without whenever you can. I order a lot fewer labs and tests and things than a lot of people in better resourced situations, because I have to really need it for it to be worth it. I'm aware that, you know, is this test worth a fourth of the month of rent? Is this test worth a missed day of work? What is the cost of this happening? Is it worth it? Because I know that the families don't have extra. Anything that I'm asking them to do has to be really necessary. We [providers] know what the cheap medicines are, we know what the cheaper places are, we develop a lot of friendships with people in the community that do different things, so you try to do the best you can with connections, but there are lots of times that it would be a whole lot easier if they had coverage.

Providers are further circumscribed in the provision of care by irregular and inconsistent patient visits. When providers have to tend to multiple exacerbated health conditions within the limited amount of time of an appointment, quality of care can suffer. A primary care provider described the pressure of addressing all of an uninsured patient's needs in a short time due to his infrequent visits.

He still cannot reach his feet, which is a dangerous thing when you have diabetes because diabetes affects the nerves in your feet, and you cannot feel if you have a foot ulcer developing. It's important to catch early if you have a foot ulcer. He can't afford to go to a podiatrist and has very significant nail abnormalities, so I perform his foot care and toenail care when he comes for visits. That said, I get 20 minutes and I'm supposed to cover hypertension, diabetes, sleep apnea, depression, and toenail care. It's impossible to do a good job in that time span. So I do my best.

Similarly, a pediatrician reflected on the free medical advice and care she provides to the parents of her patients who are often uninsured and lack consistent access to care.

We have a lot of people, a lot of the parents who have serious health conditions that don't have medical care, they'll ask me, you know at least can I look at something on their skin, their arms, their ears, you know this and that, can I give them free medical advice? Can I cover them with a prescription? That kind of thing, because you know they don't have a source of medical care. So I worry about the kids, too, because the parents aren't able to parent as effectively when they're sick and they don't have access to care.

I have a lot of parents with mental illness, and maybe they had medicine for a little while and then it ran out and they don't have insurance. Well, they have a really hard time taking care of their kids when they're not able to access their medications... Yes, I have written prescriptions for my parents for serious mental illnesses, when I know that they've been stable, and they were fine except they just lost access to their medicines, because I don't want the parent hospitalized, it's not good for anybody.

The quandary providers face in caring for uninsured patients—balancing affordability against optimal care—is not only corrosive, it raises liability questions.⁵⁶ One provider discussed the way he handles the legal risk:

I don't send people to specialists or get imaging, advanced imaging, on a routine basis when I would with patients otherwise, because of health insurance status, and I accept the legal risk to myself for not doing that. Not doing the [specialty] steps because that's not an option for those patients. I make clear in my clinic notes that ideally, I would refer patients to rheumatology for RA [rheumatoid arthritis] management. Ideally, I'd obtain a follow up chest CT scan based on recommendations from a prior CT scan, but it's most likely benign so we will forgo follow-up imaging because a patient can't pay for it, because they already have a thousand dollar bill and have already attempted applying for charity care without success.

Primary care providers also find themselves acting as de facto specialists for uninsured patients who cannot afford to see a real specialist. Dr. Luking, the physician in family medicine, discussed one of many instances when he took on the role of specialist for one of his uninsured patients:

He does not see a heart doc yearly, though he should. I'm his de facto cardiologist because I charge a lot less than a cardiologist would charge. We maintain him with his meds. He usually comes in for very disaster-oriented visits. No dental care and horrible teeth. Horrible teeth also increase the risk for further coronary heart disease. He'll come in, I'll patch him up, give him his meds. I'll clarify once again that he needs all of these things that I could order, but it's kind of, he can't pay for them.

There are those folks who need that radiologist or cardiologist, but they're used to going into those offices and walking out with a \$800 bill, so they tell their families "I can't go there."

Providers who take on specialist care shoulder added stress as the care they provide is largely out of their focus and scope of work. That stress is compounded by the extra demands placed on providers by a complex and fragmented healthcare system. Providers dedicate their lives and careers to improving the health of individuals, their families and communities. To advocate for uninsured patients means going beyond the already demanding, routine administrative tasks they perform. They find sources of charity care and help patients apply. They fundraise for local clinics, bargain with pharmaceutical companies, aid patients as they navigate the healthcare system, and build partnerships with community organizations. Noted one pediatrician:

Sometimes we have fundraisers to try to just get some cash available to us for those scary situations when we have a child that, for example, has a serious infection and doesn't have money, or we'll just sort of reach into our own pockets to try to get that covered.

⁵⁶ Weiner, "I Can't Afford That!"

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The demands of the current dysfunctional healthcare system have contributed to high levels of physician burnout.⁵⁷ One reason for burnout is the “challenge of simultaneously knowing what care patients need but being unable to provide it due to constraints” that are beyond physician control.⁵⁸ Forced to provide circumscribed care, providers can become cynical and disillusioned about their practice. A physician described the rude awakening new doctors experience when they encounter these constraints:

I see most residents go through a transition where they have in their mind the way things should be and then they learn the way things work. And occasionally those who...you know, don't learn to bend with, or accept those realities and learn to work with them, occasionally folks do decide this is just not worth it, it's too much of a headache.... A couple of residents who have gone into private practice, I saw in them just a lot of frustration. You know, people go into medicine because you want to practice medicine, not deal with the hurdles of getting someone care.

Providers who care for the uninsured often witness physical deterioration or death that is completely avoidable. Forced to stand by without satisfying answers or solutions, providers must grapple with the inequities inflicted by the healthcare system that they are part of. Several providers shared painful assessments of the current system. “A lot of my patients are dying without health insurance,” said Dr. Arumugham. A pediatrician noted bluntly, “We have had children who have died as a result of not accessing medication.” Caring for patients who experience preventable suffering and death leaves an indelible mark. As Dr. Luking recounted:

For more than 30 years I have watched my patients with no insurance pay a terrible price.

I've seen women die of invasive breast cancer and cervical cancer when they couldn't afford mammograms and preventive checkups.

I've hospitalized patients who stopped their medicines so they could pay other bills.

I've spoken to the next of kin in funeral homes about symptoms regrettably ignored by those afraid of the cost of evaluation.

You name just about any cancer or serious disease, and I can tell you about uninsured patients who delayed coming to see me, often with disastrous results.

The slow death by invasive colon cancer in the patient who could not afford a colonoscopy, the diabetic who could not pay for insulin and the resultant dialysis, the families left bankrupt and depressed after a serious illness, and on and on.⁵⁹

⁵⁷ A recent survey of 15,000 physicians around the country reported that 42% are burned out, 15-18% (depending on age) are experiencing some form of depression, and approximately 23% have had thoughts of suicide. Kane, “Medscape National Physician Burnout & Suicide Report 2020.”

⁵⁸ Dean, Talbot, and Dean, “Reframing Clinician Distress.”

⁵⁹ Luking, “Please Expand Medicaid.”

The Toll on the Healthcare System

The decision to forego Medicaid expansion dampens the effectiveness of a state’s health delivery systems. Community health centers and public health departments struggle to meet the needs of their patients. Rural hospitals face closure. The decision to not expand Medicaid creates wide-reaching challenges in the form of constricted capacity, pressure on safety net programs, uncompensated care, hospital closures, and, ultimately, increased costs for everyone, straining North Carolina’s entire healthcare system.

Hobbled Community Health Centers

Community health centers, one type of federally qualified health center (or FQHC), are community-based outpatient clinics that receive federal funding to provide primary care services in underserved areas. In order to maintain their eligibility, community health centers must meet specific administrative, clinical, and financial operation requirements.⁶⁰ Many community health centers also provide integrated services, such as pharmacies, dental care, mental health services, or nutrition services. Nationally, community health centers serve more than 29 million people, including one in three people in poverty and one in five people living in rural areas.⁶¹

In North Carolina, community health centers served over 570,000 patients in 2018.⁶² Despite the large—and growing—number of people who rely on them for care, community health centers have limited capacity and funding, forcing them to limit the number of uninsured patients they can see. One provider at a community health center in a rural county discussed the challenge of maintaining a balanced patient population mix of insured and uninsured patients at his clinic:

A reality of any health center that treats uninsured folks is that the payments we receive for insured folks help subsidize the care of uninsured folks. Although we get some funding from the government and recoup some money from the sliding scale fees, we depend to a significant extent on reimbursement from insured folks to pay for those uninsured folks. Margins are razor thin.

Another provider described how nutrition services, a vital diabetes management tool, was not available to all uninsured patients:

We have a nutrition counselor who can see patients, and does see a good number of uninsured patients still. But in order to make that work financially, she has to see at least 50% insured patients. Most of the patients that are coming to us as new patients who need care are uninsured, and so in order to make ends meet, we have . . . You know we’re lucky in being able to see uninsured patients, but the challenge is that we can’t see too, too many uninsured patients otherwise the system doesn’t work.

⁶⁰ Health Center Program, “What Is a Health Center?”

⁶¹ National Association of Community Health Centers, “About Health Centers”; Health Center Program, “Health Center Program: Impact and Growth.”

⁶² National Association of Community Health Centers, *Health Centers in North Carolina, 2018*.

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North Carolina's community health centers serve significantly more uninsured patients than health centers nationally. In 2018, over 42% of community health center patients in North Carolina were uninsured, compared to 23% of patients in health centers in the U.S.⁶³

The providers at community health centers who we interviewed believed that Medicaid expansion would allow them to provide better care to more patients. As Dr. Ashkin pointed out, with expansion, a patient “can see a behavioral health specialist, nutritionist, all these services which we want to provide, we’ll be able to afford to provide in so much more of a robust fashion.” Another provider mentioned that with more people insured under Medicaid, their clinic could then reach more uninsured patients:

So one thing Medicaid expansion would allow us to do, in addition to just providing more care, better care for those who now have insurance, is more of a cushion to pay for and expand our care of uninsured folks. I think it would have dividends for even those who aren't covered, in addition to just helping clinics like our own to continue.

The other benefit would be, we'd just see more folks. I think there's a good percentage of folks who don't come in because they know or think it would just be too expensive. I think there's a good percentage of working poor folks who we don't see who we are missing and who we would see.

Expanded Medicaid offers health centers the potential to better engage with their community and address preventive health and wellness holistically and comprehensively. Dr. Luking stated,

If you are a community-based organization whose role is to improve the wellness of your community, and people have health insurance, you are then able to use other grant funding and other resources to understand why people are coming in sick in the first place. Eighty percent of health does not happen inside the clinic, right? It's a small part. But then you're able to partner much more effectively with community-based organizations to improve wellness.

Research investigating post-expansion effects on community health centers found that health centers in expansion states had higher total patient volume, larger shares of Medicaid patients, smaller shares of uninsured patients, increases in total visits and mental health visits, and improved quality of care for conditions such as asthma, obesity, high blood pressure, and women's health.⁶⁴ Additionally, health centers in expansion states are more likely to be financially secure and better able to provide affordable care to their patients.⁶⁵

⁶³ National Association of Community Health Centers; National Association of Community Health Centers, *United States Health Center Fact Sheet*.

⁶⁴ Cole et al., “At Federally Funded Health Centers, Medicaid Expansion Was Associated with Improved Quality Of Care”; Han, Luo, and Ku, “Medicaid Expansion and Grant Funding Increases Helped Improve Community Health Center Capacity.”

⁶⁵ Lewis et al., *The Role of Medicaid Expansion in Care Delivery at Community Health Centers*.

Granville Vance Public Health: A Case Study

Granville Vance Public Health (GVPH) is a district health department serving two rural counties on North Carolina's northern border. Lisa Harrison, GVPH's Health Director, described the limitations that many rural counties face. "We all have a short bench. None of us have the mountain of resources we need, either financial or human or infrastructure, to do what needs to be done in a high need, low resources area."

The limitations of having a "short bench" have considerable implications for those without health insurance. Harrison explains,

I mean it's painful, it's terrible. I wish we had more resources. I think people assume that because we're a health department we can and have to see everyone. And that's just not the case. I wish we could, I wish we were funded well enough to see everyone but we're not. We are not funded to see the uninsured.

Similar to community health centers, public health departments struggle with balancing the priorities of entire communities while maintaining an even distribution of insured and uninsured patients for clinical services. Noted Harrison, "None of us, the health department included, can see only uninsured populations. More than 50% of patients cannot be uninsured or else we can't take people and keep the doors open or keep the lights on either."

Public health departments also manage federally funded programs such as Title IX and Children's Health Insurance Program, that provide services to specific groups. This requires balancing the demands of these programs against services overall.

So, for those programs, anybody who comes to us and wants a child health wellness visit, anyone who comes to us and wants family planning, we absolutely see everyone who walks through the door. As a result, probably 90% of those two services [Title IX and CHIP] are uninsured populations.

The health department is stretched trying to meet its multiple mandates, forcing it to make difficult decisions about financing and access. Harrison stated,

We have to make up the difference somewhere else. So, for example our primary care clinic does not accept any federal or state dollars. We run that independent from any other dollars in the system. We had some grant funds that helped get us started, helped us buy equipment, helped us pay for our physician and then it was her responsibility to find a way to make the revenues higher than the expenses over a three-year period. So, we absolutely have uninsured populations who would like to come to us for care, but we have to keep our revenues over expenses right now because there are too many other programs we don't have control over.

This juggling act gets trickier when new public health crises, such as opioid addiction, arise. Mental health and substance use disorders are priority concerns for Granville and Vance, which have seen high overdose death rates.¹ Comprehensive treatment of substance use disorder requires clinical care, prescription medication, and continuous behavioral health services, making it extremely difficult for those without insurance to afford or sustain treatment plans.

Some of our biggest challenges come in simply not having a lot of solution options for people who can't afford care. You know, it's just a really dark and painful reality to see that people have to choose not to get the care they need when there are no resources. I wish there was more that we could do to connect them better.

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States that have expanded Medicaid have seen substantial increases in insurance coverage for people with opioid use disorders and gains in access to treatment for substance abuse. The number of uninsured patients who are hospitalized for opioid-related reasons has fallen dramatically in expansion states, as have opioid-related deaths.² Fears that expansion would lead to an increase in opioid prescriptions have proven unfounded.³

Under Medicaid expansion, newly insured individuals would free up health department resources to address other community health needs. Harrison discussed her hope for change if expansion were to pass.

I would hope that Medicaid expansion would be a wonderful boon for individuals who need to have access to care, especially opioid treatment, which is a dire crisis right now. It feels very unethical to me that we are denying people treatment based on their inability to pay for that treatment.

¹ Haffajee et al., "Characteristics of US Counties with High Opioid Overdose Mortality and Low Capacity to Deliver Medications for Opioid Use Disorder."

² Broaddus, Bailey and Aron-Dine, "Medicaid Expansion Dramatically Increased Coverage for People with Opioid-Use Disorders, Latest Data Show"; Kravitz et al., "Association of Medicaid Expansion with Opioid Overdose Mortality in the United States"; Snider et al., "Association Between State Medicaid Eligibility Thresholds and Deaths Due to Substance Use Disorders."

³ Broaddus, Bailey and Aron-Dine, "Medicaid Expansion Dramatically Increased Coverage for People with Opioid-Use Disorders."

Hospitals at Risk

Hospitals are required to treat people regardless of insurance status. As a result, they absorb the costs of care when they're not paid by an insurance company or the patient. This unpaid sum, known as "uncompensated care," is a drag on hospitals' bottom line.⁶⁶ The cost of uncompensated care forces hospitals to forfeit other investments, such as new equipment, technology or facilities, or to pull back from community engagement and outreach. Uncompensated care and the opportunity cost it exacts make it difficult for hospitals to remain financially viable. Hospitals that serve a larger share of low-income or uninsured individuals, like those in rural areas, are on shakier ground.⁶⁷ One study found that each additional uninsured person costs a local hospital \$900 per year.⁶⁸

In North Carolina, 11 rural hospitals closed between 2006 and 2017⁶⁹ and another 13 have a mid-high or high risk of closing.⁷⁰ Because rural residents are poorer, older and sicker, hospital closures represent a devastating blow to the wellbeing of these communities.⁷¹ Jackie Kiger, of Pisgah Legal Services, sees rural hospital closures as a growing challenge in the communities she serves:

Rural hospitals across North Carolina are closing because they're just simply not able to fiscally survive. Having more insured people is an impact that Medicaid expansion would immediately have on some of our communities who haven't yet lost rural hospitals but are still potentially looking at that.

⁶⁶ Uncompensated care includes charity care that the hospital knowingly provides at a free or reduced rate and bad debt, in which arises when the hospital expects but does not receive payment.

⁶⁷ Wishner et al., *A Look at Rural Hospital Closures and Implications for Access to Care*.

⁶⁸ Calvert, "Who Bears the Cost of the Uninsured? Nonprofit Hospitals."

⁶⁹ N.C. Rural Health Research Program, "170 Rural Hospital Closures."

⁷⁰ Thomas, Pink, and Reiter, *Geographic Variation in the 2019 Risk of Financial Distress among Rural Hospitals*.

⁷¹ Wishner et al., *A Look at Rural Hospital Closures and Implications for Access to Care*.

Dr. Luking reflected on the loss that hospital closure inflicted on his community:

We have two hospitals in our county, and one hospital went bankrupt several years ago. Community hospitals are linchpins to keep capable providers in the community. These are your OB/GYNs, your cardiologists, oncologists, radiologists, all the important “ologists” that deliver the goods and keep people going. They are much more likely to come to a community if you have a hospital. And hospitals are much more likely to come to a community if you have Medicaid expansion, particularly in rural communities.

Medicaid expansion is linked to an increase in Medicaid revenue, a decrease in uncompensated care and an overall boost in hospitals’ operating margins. Rural and public hospitals have seen the largest effects.⁷² By one estimate, uncompensated care costs dropped by roughly half in expansion states.⁷³ Since hospitals’ operating margins are paper-thin, a decline in uncompensated care can make all the difference in terms of survival. One study found that hospitals in expansion states are six times less likely to close than hospitals in non-expansion states.⁷⁴

In addition to providing essential health services, hospitals are mainstays of rural economies. Not only are they typically one of the largest employers, hospitals offer reliable and steady employment. They attract related enterprises such as labs and clinics, stimulate economic growth through the purchase of goods and services, and, as dollars ripple through the economy, generate indirect benefits. Without hospitals, rural regions have a tough time attracting new businesses or residents, making it difficult to boost their economies.⁷⁵

What’s good for hospitals is also good for patients, as people with Medicaid, unlike the uninsured, enjoy greater access to healthcare services in a range of settings and don’t rely on the emergency department as their primary source of care.⁷⁶ As Dr. Ashkin pointed out, with Medicaid expansion,

We’ll be able to keep people well and have them actually have better health outcomes and reduce unnecessary ER utilization and preventable hospitalizations. This has been shown over and over again so this is not pie in the sky. I mean this is what happens when people have access to healthcare.

⁷² Rhodes et al., “Heterogeneous Effects of the Aca Medicaid Expansion on Hospital Financial Outcomes.” See also Schubel and Broaddus, *Uncompensated Care Costs Fell in Nearly Every State as ACA’s Major Coverage Provisions Took Effect: Medicaid Waivers That Create Barriers to Coverage Jeopardize Gains*.

⁷³ Schubel and Broaddus, *Uncompensated Care Costs Fell in Nearly Every State as ACA’s Major Coverage Provisions Took Effect: Medicaid Waivers That Create Barriers to Coverage Jeopardize Gains*.

⁷⁴ Lindrooth et al., “Understanding the Relationship Between Medicaid Expansions and Hospital Closures.”

⁷⁵ See Farmer, “Economic Ripples”; Frakt, “A Sense of Alarm as Rural Hospitals Keep Closing”; Holmes et al., “The Effect of Rural Hospital Closures on Community Economic Health.”

⁷⁶ Scholars debate the effect of the ACA and Medicaid expansion on emergency departments. Some studies find increased ED use; others report decreased use. See Elani, Kawachi, and Sommers, “Changes in Emergency Department Dental Visits After Medicaid Expansion”; Finkelstein et al., “Effect of Medicaid Coverage on ED Use — Further Evidence from Oregon’s Experiment”; Kliff, “Study: Expanding Medicaid Doesn’t Reduce ER Trips. It Increases Them.”; Pines et al., “Medicaid Expansion In 2014 Did Not Increase Emergency Department Use but Did Change Insurance Payer Mix”; Zhou et al., “The Uninsured Do Not Use the Emergency Department More—They Use Other Care Less.” The evidence overwhelmingly suggests that Medicaid recipients access care in a wider range of healthcare settings, including primary care, than the uninsured. See Finkelstein et al., “Effect of Medicaid Coverage on ED Use — Further Evidence from Oregon’s Experiment”; Paradise, “Data Note: Three Findings about Access to Care and Health Outcomes in Medicaid.”

Dr. Luking envisioned similar benefits:

Let's have less folks filling up the ER and getting mega workups, and maybe fund a CHC [community health center] with three more PCPs [primary care providers] at the same cost of those mega workups, delivering much more good for the community rather than these ER visits that my uninsured patients don't need.

People with Insurance Are Hurt Too

Even the insured are penalized by North Carolina's current Medicaid system. A 2015 study by the U.S. Department of Health and Human Services found that ACA Marketplace premiums were 7% lower in expansion states.⁷⁷ Researchers have continued to find even more dramatic reductions in price.⁷⁸ Because poorer people tend to have worse health, moving them from the private insurance pool to Medicaid reduces costs for everyone else. Lisa Harrison, of Granville Vance Public Health, stated,

It's not like the money goes directly to the people who have Medicaid. It goes into a system and makes the system cheap for everyone who has private insurance. The reason we're paying so much for private insurance in North Carolina is because we haven't expanded Medicaid.

There are also future implications for *Medicare* spending. Those who aren't getting preventive, life-saving care now will eventually enter Medicare in poorer health. A provider in a rural community health center is currently witnessing these effects in his clinic:

I see a lot of middle-aged patients who don't have insurance. That's kind of our gap with insurance, and so the ones [other clinic doctors] who are real heavy on pediatrics and have a lot of patients with Medicaid or see a lot of prenatal care who have Medicaid, they give a lot more money to the clinic operations, and then Medicare as well. But there's this in-between huge group of adults who either came from one of those groups or is eventually going to fall into those groups that are just receiving bodily harm regularly and will cost those other insurance programs more money.

Right now, the cost of non-expansion is built into the healthcare system in North Carolina. By defraying a portion of this cost, expanded Medicaid would produce far-reaching financial benefits. These translate into better care for a greater number of people and more stable rural hospitals and local economies. Reducing costs also benefits individuals through lowered premiums and reduced taxes.

⁷⁷ Sen and DeLeire, *The Effect of Medicaid Expansion on Marketplace Premiums*.

⁷⁸ Peng, "How Does Medicaid Expansion Affect Premiums in the Health Insurance Marketplaces? New Evidence from Late Adoption in Pennsylvania and Indiana"; Sen and DeLeire, "How Does Expansion of Public Health Insurance Affect Risk Pools and Premiums in the Market for Private Health Insurance? Evidence from Medicaid and the Affordable Care Act Marketplaces"; Sen and DeLeire, "Medicaid Expansion In Wisconsin Would Lower Premiums For Those With Private Insurance | Health Affairs."

Conclusion

We were finishing the first draft of this report when Covid-19 was declared a pandemic by the World Health Organization. In what is surely an undercount, more than 1.6 million total cases and almost 100,000 deaths have been identified in the U.S. to date, with many more predicted in the coming months.⁷⁹ The disease has upended lives with terrifying speed and revealed with brutal precision the failures of our healthcare system. Poverty and systemic inequalities contribute to the unimaginable damage exacted by the virus.⁸⁰ An overwhelming percentage of coronavirus patients who have been hospitalized suffered from at least one chronic health condition; African Americans have borne the disproportionate brunt of the disease, falling ill and dying at rates greater than their share of the population.⁸¹

Covid-19's staggering economic blow has emphasized the financial fragility of many American households. Although widespread, the pain has fallen disproportionately on vulnerable populations.⁸² Workers such as grocery store clerks, transportation workers, meatpackers and others who provide "essential services" don't have the luxury of working from home.⁸³ These jobs, which are often low wage with few or no benefits, are held disproportionately by women and people of color.⁸⁴ Even as they are exposed to the coronavirus, they are excluded from the recently enacted federal law that guarantees 80 hours of paid time off for people who are unable to work because of quarantine or illness.⁸⁵

Other service sector jobs have simply vanished.⁸⁶ To say that unemployment claims have skyrocketed is to understate wildly. Over 38 million Americans have filed for unemployment insurance since mid-March; economists reckon that the unemployment rate is between 15% and 20%.⁸⁷ For a number of reasons, this count is undoubtedly too low.

As people lose employment, they lose their employer-sponsored health insurance. The Urban Institute estimates that between 25 million and 43 million Americans will lose their employer-sponsored health coverage as a result of coronavirus-related layoffs. In the states that have refused to expand Medicaid, a large share—about 40%—of the newly unemployed will become uninsured. In North Carolina that means an additional 193,000 to 359,000 people without health insurance.⁸⁸

⁷⁹ New York Times, "Coronavirus in the U.S.: Latest Map and Case Count."

⁸⁰ North, "Every Aspect of the Coronavirus Pandemic Exposes America's Devastating Inequalities"; Pinsker, "The Pandemic Will Cleave America in Two."

⁸¹ Rabin, "Nearly All Patients Hospitalized with Covid-19 Had Chronic Health Issues, Study Finds"; N.C. Department of Health and Human Services, "COVID-19 North Carolina Dashboard"; Scott, "4 Reasons Coronavirus Is Hitting Black Communities So Hard."

⁸² Smialek, "Poor Americans Hit Hardest by Job Losses Amid Lockdowns, Fed Says."

⁸³ For many, "home" is not safe or is nonexistent. For people who are incarcerated, detained or living in a shelter, "home" increases the chance of exposure to the coronavirus.

⁸⁴ Ross and Bateman, *Meet the Low-Wage Workforce*.

⁸⁵ Fowers and Tan, "The New Sick Leave Law Doesn't Help the Workers That Need It Most."

⁸⁶ Hart, "The Coronavirus Pandemic Threatens Low Wage Jobs."

⁸⁷ Rugaber, "April Jobs Data to Show Epic Losses and Soaring Unemployment"; Siegel and Van Dam, "3.8 Million Americans Sought Jobless Benefits Last Week, Extending Pandemic's Grip on the National Workforce."

⁸⁸ Garrett and Gangopadhyaya, *How the COVID-19 Recession Could Affect Health Insurance Coverage*.

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Even before the coronavirus struck, the American healthcare system was deeply unequal. As author Zadie Smith memorably put it, “Death comes to all—but in America it has long been considered reasonable to offer the best chance of delay to the highest bidder.”⁸⁹ The punishment for those who can’t place a bid is harsh: circumstances diminished by poor health and lives cut short.⁹⁰

Medicaid expansion takes a significant step toward addressing these systemic inequities. It is, quite literally, a life saver. Thousands of North Carolinians have died for want of health insurance. Medicaid expansion would spare thousands more from premature and unnecessary loss of life. Across the state, residents would gain access to reliable care, improved health, and all the benefits that greater mental and physical wellbeing entail—longer periods of employment, more secure families, the opportunity to live a full life. Medicaid expansion would enable healthcare providers to better serve their patients and reach a larger number of underserved individuals. It would bolster critically important yet fragile rural hospitals. To say nothing of the larger savings and economic benefits to be gained. The failure to enact Medicaid expansion is a self-inflicted wound on the state, its healthcare system and its people.

⁸⁹ Smith, “The American Exception.”

⁹⁰ Miller et al., *Medicaid and Mortality*.

Methodology

Between October 2019 and January 2020, the authors engaged in in-depth interviews with patients, providers, and other public health officials from across the state about the impacts of Medicaid non-expansion in North Carolina. Interviews were conducted in person and over the phone and were audio-recorded. Participants were recruited based on their experience with Medicaid expansion, through their local public health departments, and through snowball sampling. Participants were recruited with attention to geographic diversity. Authors combined analysis of interviews with a literature review and secondary data analysis of existing work on Medicaid and expansion.

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