

**Focus Group Research Report**

# **Hear Their Voices: The Experiences of Midlife Adults Who Gained Medicaid Coverage in Four Expansion States**

**Lynda Flowers, Senior Strategic Policy Advisor**  
AARP Public Policy Institute

**Edem Hado, Policy Research Senior Analyst**  
AARP Public Policy Institute



## **Acknowledgments**

The authors would like to thank their colleagues in the AARP Research Center—Indira Venkat, Terry Keenan, and Gerard Rainville—for supporting this project.

# Table of Contents

INTRODUCTION .....	1
UNINSURED MIDLIFE ADULTS EXPERIENCE A RANGE OF POTENTIALLY HARMFUL EMOTIONS.....	3
MEDICAID PROVIDES A SENSE OF SECURITY FOR NEWLY INSURED MIDLIFE ADULTS .....	4
MANY UNINSURED MIDLIFE ADULTS POSTPONE NEEDED MEDICAL CARE .....	5
MEDICAID IS A LIFELINE FOR LOW-INCOME MIDLIFE ADULTS .....	6
MEDICAID HELPS MIDLIFE ADULTS AFFORD NEEDED PRESCRIPTION DRUGS .....	7
MEDICAID PROVIDES ACCESS TO POTENTIALLY LIFESAVING PREVENTIVE SERVICES.....	8
MEDICAID PROVIDES CRITICAL SUPPORT FOR MIDLIFE FAMILY CAREGIVERS .....	9
MEDICAID HELPS SOME MIDLIFE ADULTS GET BACK INTO THE WORKFORCE.....	10
RECENT CHANGES IN MEDICAID POLICY ARE WORRISOME TO MIDLIFE ADULTS .....	11
MIDLIFE ADULTS HAD MESSAGES FOR POLICYMAKERS .....	13
SUMMARY OF FINDINGS .....	14
POLICY RECOMMENDATIONS .....	15
CONCLUSION.....	17
REFERENCES .....	17
APPENDIX A.....	19
Method .....	19
Data Collection.....	19
Data Analysis.....	19
Study Limitations.....	19
APPENDIX B.....	20
Participants.....	20

THIS PAGE INTENTIONALLY LEFT BLANK.

## Introduction

The importance and benefits of health insurance coverage for individuals of all ages, including midlife adults (ages 45–64), cannot be overstated. The advantages of coverage include access to preventive care as well as care and medications to manage chronic health conditions that often emerge among this age group<sup>1</sup> and that, if left unmanaged, can result in more serious health complications and even death. Access to health insurance coverage also relieves both the financial and emotional stress associated with being uninsured.

In recent years, the Affordable Care Act, signed into law in 2010, has increased access to health insurance coverage in part by creating a state option to expand Medicaid. To learn about the experiences of previously uninsured midlife adults without dependent children, before and after gaining access to health insurance through state Medicaid expansions, the AARP Public Policy Institute commissioned a series of focus groups in four states: Kentucky, New Mexico, Ohio, and Pennsylvania.

This report amplifies the voices of 32 midlife adults\* who graciously shared their stories (see appendix A for methodology and appendix B for participant characteristics). Their comments ranged from plaintive, as they described what it was like living without health insurance, to grateful to be living in a state that makes them eligible for Medicaid coverage. Their words can help policy makers gain a deeper understanding of what Medicaid means to low-income people who do not have other affordable coverage options. What follows is a description of what these adults told us, supplemented by additional topical background.

Medicaid is the nation's largest safety-net health insurance program, covering millions of Americans, including low-income adults, children, pregnant women, older adults, and people of all ages living with disabilities. Historically, Medicaid eligibility for adults was limited to adults with dependent children with a median annual income limit of 40 percent of the federal poverty level (FPL) or \$21,720 for a family of three in 2020. Before March 2010, childless adults were largely ineligible for Medicaid no matter how poor they were.

That changed when the Affordable Care Act<sup>1</sup> and a related US Supreme Court decision<sup>2</sup> created a state option to provide Medicaid coverage for all adults ages 19 to 64 with income at or below 138 percent of the FPL (\$17,236 for an individual in 2020). Since that time, as of July 2020, 37 states and the District of Columbia have adopted Medicaid expansions,<sup>3</sup> providing access to health care and needed medicines to millions of previously uninsured low-income adults.

- 1 Patient Protection and Affordable Care Act, Pub. L. No. 111-148, 124 Stat. 119 (2010), <https://www.congress.gov/111/plaws/publ148/PLAW-111publ148.pdf>.
- 2 National Federation of Independent Business et al. v. Sebelius, 567 U.S. 519 (2012), <https://www.supremecourt.gov/opinions/11pdf/11-393c3a2.pdf>.
- 3 “State Health Facts: Status of State Action on the Medicaid Expansion Decision,” Kaiser Family Foundation, last modified July 1, 2020, <https://www.kff.org/health-reform/state-indicator/state-activity-around-expanding-medicaid-under-the-affordable-care-act/?currentTimeframe=0&sortModel=%7B%22collid%22:%22Location%22,%22sort%22:%22asc%22%7D>.

\* The names of study participants have been changed to protect their privacy.

THIS PAGE INTENTIONALLY LEFT BLANK.

## Uninsured Midlife Adults Experience a Range of Potentially Harmful Emotions

Uninsured adults experience significantly more stress than those with health insurance coverage.<sup>2</sup> They are also more likely to have fears about not being able to get their health needs met. “It is like walking a tightrope,” said one participant. Before gaining Medicaid coverage, many midlife adults in the study experienced negative emotions related to being uninsured. Their emotions ranged from stress, worry, and fear, to depression, shame, and feelings of worthlessness. Such emotions have been associated with chronic illnesses like heart disease, diabetes, cancer, and substance abuse.<sup>3,4,5</sup>

### HERE'S WHAT THEY TOLD US:

- Being uninsured causes people significant stress, fear, worry, and depression.
- Being uninsured is associated with feelings of hopelessness, shame and worthlessness.

---

*When I didn't have health insurance, I was terrified.*

— Eric, 46, New Mexico

---

*Without health insurance, you feel stressed. The little things are fine, but if something big happens, like a heart attack, you're screwed.*

—Eric, 46, New Mexico

*Being uninsured was very stressful because my family comes from [has a history of] cancer.*

—Vincent, 54, Ohio

*It was messing with my mind. I'm like, oh God, if something happens, I can't even go to the hospital. I think it was depressing me.*

—Cindy, 63, Pennsylvania



---

*You kind of feel worthless and useless because you don't have the money to pay for your prescriptions. You're like, I'm just worthless. I can't even take care of myself the way I need to.*

—Michelle, 46, Kentucky

---

*I think a lot of the shame comes from [knowing] we're in the greatest economy ever [in 2019], but I can't find a job that can give me health insurance.*

—Peter, 53, Kentucky

*Before I had Medicaid, I was uninsured, and I really felt ashamed. I don't know where that came from. . . . [I thought] why is this happening to me? I'm a good person. Why shouldn't I be able to go to the doctor? And I really felt ashamed about it.*

—Robert, 53, Kentucky

*When I didn't have health insurance, I felt hopeless.*

—Juana, 59, New Mexico

## Medicaid Provides a Sense of Security for Newly Insured Midlife Adults

In 2017, adults without health insurance reported significantly higher average stress levels compared with those with insurance. The average stress level among insured adults was 4.7 (on a 10-point scale, where 1 is little or no stress and 10 is a great deal of stress), while uninsured adults reported a significantly higher average stress level of 5.6.<sup>6</sup> It's not surprising that access to health insurance can be a major stress reliever and improve one's sense of well-being.<sup>7</sup> Almost all study participants expressed feelings of relief and security when they gained access to Medicaid expansion coverage. As one participant said, "so here Medicaid comes along and you've got all this support, and that's very, very beautiful."

### HERE'S WHAT THEY TOLD US:

- People are grateful because Medicaid gives them peace of mind and less worry.

---

*Medicaid gives you the opportunity to take needed medical tests, so it gives you a peace of mind and makes me feel so blessed that Medicaid is in my life.*

—Marc, 63, Ohio

---

*The key thing is peace of mind, knowing that I can go and get that FibroScan [test for liver disease] or I can go get that colonoscopy, because cancer is all about early detection.*

—Bruce, 56, Pennsylvania

*It's just a wonderful thing because you don't have to worry about your health. And then Medicaid coverage can just kind of take a weight off you where you're not going to be as stressed.*

—Kelly, 64, New Mexico

*Having Medicaid is peace of mind. It really boils down to peace of mind.*

—Bruce, 56, Pennsylvania

*Having Medicaid means mental stability for me.*

—Isabella, 51, New Mexico

*I sleep better at night because of Medicaid. I am able to breathe knowing I can get my health care taken care of.*

—Diana, 45, Ohio

- Medicaid provides a sense of hope and relief.

---

*To me it was a sense of relief to get Medicaid, like if you get cancer or have a heart attack or any of those major things, you know you're going to be covered. So you don't have to worry.*

—Lauren, 52, Kentucky

---

*It's like having this huge backstop . . . it's so much less nerve-racking because you can actually go get medical care and not come out of there with some massive bill.*

—Chris, 51, Kentucky

*It was less stressful. I didn't have to worry about when you get sick, do you have to go to the emergency room instead of just going to see a doctor.*

—Sonya, 53, Kentucky

## Many Uninsured Midlife Adults Postpone Needed Medical Care

Having health insurance is a critical determinant of access to health care.<sup>8</sup> Uninsured people are more likely to go without needed health care than their insured counterparts. One participant told us, “I was uninsured, so there were times when I didn’t go to the doctor, even though I really needed to go.” This person was not alone. In 2018, one in five uninsured adults went without needed medical care due to cost.<sup>9</sup> Avoiding needed health care can exacerbate underlying health conditions, worsen health outcomes, and negatively affect one’s sense of well-being.<sup>10</sup> Our discussions with midlife adults in this study drove the point home.

### HERE’S WHAT THEY TOLD US:

- Many people are uninsured for years before they gain Medicaid coverage.
- Many people live with pain and unaddressed health conditions for years due to lack of health insurance.

---

*Before Medicaid, I never really had any kind of insurance in my life.*

— Martín, 46, New Mexico

---

*I went without health insurance from age 30 to about age 52.*

—Jennifer, 57, Kentucky

*Before Medicaid I went without health insurance for 11 years.*

—Roger, 58, Pennsylvania

*For about nine years [before I got Medicaid], I had no coverage. For maybe a year in there, I had coverage through an employer, but I couldn’t afford to use it, because I got a low wage and you’ve got a high deductible and co-insurance so you just don’t use it.*

—Matthew, 58, New Mexico

*For decades, I had gold-level insurance. I mean, I was so fortunate. Then the economy turned, and I lost my six-figure job and didn’t work, so I went without insurance for about six years and didn’t go to the doctor. I got lucky and had a doctor friend who got me medication for depression and high blood pressure.*

—Robert, 53, Kentucky

---

*Without health insurance, you just white-knuckle it. When [you’ve] got nothing, you just do what you can.*

—Eric, 46, New Mexico

---

*I had diverticulitis, and I just lived with it for years. I had pain, and I wouldn’t go to the doctor because I didn’t have a health insurance plan.*

—Bruce, 56, Pennsylvania

*After I got Medicaid, I got an actual diagnosis of diabetes. Before that, I kind of figured I had it, but just never took care of it because I didn’t have insurance. But now I have an actual diagnosis, [have] actually been put on medication, and [have] a plan, and now everything’s changed.*

—Eric, 46, New Mexico

*My manager called me into the office. He’s like, how do you come to work with a bad hip, and I can’t get guys to come in with a nosebleed or paper cuts? I said I’m old school, I just do it. You know, I just try to block the pain out.*

—Vincent, 54, Ohio

*I was working, but I had no insurance, and I tried really hard not to have anything to do with the medical world, because I had no money, and then I crashed out in the emergency room.*

—Chris, 51, Kentucky



Photo Credit: Getty Images

## Medicaid Is a Lifeline for Low-Income Midlife Adults

Medicaid provides access to insurance coverage for people who lack other affordable coverage options. A large and growing body of research demonstrates that access to health insurance coverage generally, and Medicaid specifically, saves lives. For example, a 2019 study conducted by the National Bureau of Economic Research found that, between 2014 and 2017, almost 16,000 deaths could have been avoided if all states had expanded Medicaid.<sup>11</sup> “Medicaid was absolutely lifesaving,” said one participant. Many other participants expressed similar sentiment.

### HERE’S WHAT THEY TOLD US:

- Many people get lifesaving care through Medicaid.

---

*For me, Medicaid had a profound impact on my life. It’s given me my life back.*

—Peter, 53, Kentucky

---

*Medicaid was absolutely lifesaving.*

—Peter, 53, Kentucky

*Medicaid did save my life. Well, you know when you’re not healthy you get depressed, because you feel kind of hopeless, so the suicide bullshit comes in. Sorry I cursed, but those bad thoughts stay with you because everything seems so hopeless. Like, why even bother, you know?*

—Juana, 59, New Mexico

*I came down with blood in my urine, and I had a bad case of kidney stones, and I was in a lot of pain. If I didn’t have Medicaid insurance, I’d be dead.*

—Roger, 58, Pennsylvania

*Medicaid saved my life because it allowed me to have the mammograms done. . . . I was really worried about that because cancer runs in our family.*

—Cindy, 63, Pennsylvania

*When I weighed 375 pounds, it was impossible to move. When I got Medicaid, my doctor sent me to have a gastric bypass and I lost 125 pounds. Before my surgery, I took maybe 7 to 10 pills a day; now I take 1. I’m so happy for everything because my life started again.*

—Rosalia, 57, New Mexico

## Medicaid Helps Midlife Adults Afford Needed Prescription Drugs

Many uninsured, low-income adults are unable to afford their prescribed medications, so they use strategies to try to reduce their costs. Strategies range from going without needed medicines altogether, to reducing recommended dosages and frequency, to getting cheaper medication outside the country.<sup>12</sup> Some of these cost-saving strategies can lead to poorer health status, increased emergency room use, and avoidable hospitalizations.<sup>13</sup> Our conversations with midlife adults in this study confirmed that many did go without needed medications or engaged in sometimes risky mitigation strategies before they became eligible for Medicaid.

### HERE'S WHAT THEY TOLD US:

- Some people go without needed medications because of cost, and some even travel across the border to get affordable medicines.
- Medicaid helped people gain access to affordable drugs.

---

*I went without my high blood pressure medicine and my depression medicine for the longest time because I couldn't afford it.*

—Michelle, 46, Kentucky

---

*When I didn't have insurance, I remember my doctor switching one of my medications just because he had samples that he could give me. So I did have to switch from one that worked well to a different one.*

—Lauren, 52, Kentucky

---

*Before Medicaid, I risked getting arrested to get my drugs from Mexico. I would go to Juarez and buy my medicine over the counter. So yeah, it's a risk, . . . but I had to do it because of blood pressure. It's awesome now because I don't have to worry about not having my medication.*

—Isabella, 51, New Mexico

---

*I had just lost my job, so my medication I was taking hit and miss, because I couldn't afford it. So that was a true blessing and a relief when they did put me on Medicaid.*

—Tonya, 56, Ohio

---

*Medicaid saved my life. I probably would have stroked out by now without that blood pressure medicine.*

—Michelle, 46, Kentucky

---

*This is the first time I've had medication for a long time.*

—Martín, 46, New Mexico

---

*It's awesome now [that I have Medicaid], because I don't have to worry about not having my medication and going through all that drama again.*

—Isabella, 51, New Mexico

---

*The Medicaid prescription drug plan is pretty good. I mean, without the medication, I wouldn't be here.*

—Alan, 55, Pennsylvania

---

*Now I get my Protonix [acid reflux medicine] for a dollar. It's a wonderful thing. I was grateful because Medicaid saved me a fair amount of money on prescriptions.*

—Bruce, 56, Pennsylvania

*Now I'm taking my high blood pressure medicine. . . . I guess if I wasn't taking it, I could have a stroke. I feel better having Medicaid. You know that's a big relief.*

—Cindy, 63, Pennsylvania

*I was on at least 10 prescriptions at one point in time. If I hadn't had Medicaid so I could get those medicines, I would have killed myself from the pain.*

—Alan, 55, Pennsylvania

## Medicaid Provides Access to Potentially Lifesaving Preventive Services

Many chronic illnesses are preventable or responsive to treatment if detected early. Despite this, clinical preventive services are underused. For example, in 2015, only 8 percent of US adults ages 35 and older received all recommended clinical preventive services, and nearly 5 percent received none.<sup>14</sup> While many factors contribute to low utilization of preventive care, access to health insurance removes a significant barrier.<sup>15</sup> Study participants were well aware of the value of prevention and were eager to get needed preventive services once they gained Medicaid coverage.

### HERE'S WHAT THEY TOLD US:

- Medicaid helps people get potentially lifesaving tests.
- Medicaid provides people with access to other routine preventive services.

---

*I had a colonoscopy recently. They found six polyps. That could have turned into colon cancer.*

—Bruce, 56, Pennsylvania

---

*Medicaid, it allowed me to have the mammograms done.*

—Cindy, 63, Pennsylvania

---

*I finally had a doctor [who] I could talk to and I could get everything done, and get . . . my colonoscopy and all my tests done.*

—Wayne, 62, Ohio

---

*I just got the shingles shot, and I'll go back in two more months for the other shot, and I got the flu shot. Before I got Medicaid, I never got preventive services.*

—Cindy, 63, Pennsylvania

*Once I got Medicaid, I had my doctor do a complete run-through and check me for everything—colonoscopy and everything.*

—Juana, 59, New Mexico

---

*Since I got Medicaid, I put my body in the shop every fall.*

—Vanessa, 58, Pennsylvania

*My last pap smear came back abnormal a couple of times, so we're doing this consistent testing.*

—Regina, 62, Pennsylvania



## Medicaid Provides Critical Support for Midlife Family Caregivers

Family caregivers play a vital role in this country's long-term care system, providing \$470 billion in unpaid care every year. The range of activities they perform is stunning, ranging from performing hands-on medical or nursing tasks to arranging doctor's appointments and managing provider payments.<sup>16</sup> Some of the midlife adults in this study were family caregivers, and Medicaid covered the care they needed to stay healthy so they could support their aging loved ones.

### HERE'S WHAT THEY TOLD US:

- Medicaid keeps people healthy so they can fulfill their family caregiving responsibilities.
- Some people are the sole caregiver for a family member.

---

*Medicaid pretty much saved my life, so I am able to help my mom, who has macular degeneration. She's just starting to deal with not being able to drive or do her shopping.*

—Tracey, 45, Ohio

---

*I'm my 91-year-old mom's primary caregiver. I spend two-thirds of every day with her. Yeah, I think [Medicaid helps me to be a caregiver] because I can use that to maintain my own health, to take care of her. Yeah, that would be totally different if I didn't have any insurance.*

—Chris, 51, Kentucky



---

*I take care of my dad, so that's a big thing. There's nobody else to help him.*

—Diana, 45, Ohio

---

*Medicaid helps me to stay healthy enough to take care of that other person. Because I have the insurance if something's wrong with me, I can go get it done and take care of my mother. It's a big issue for a lot of people in that age group of 55 on up. They can't work because [they have to] take care of another.*

—Wayne, 62, Ohio

*Taking care of my dad is my biggest challenge. He is in a place where he just [can't take care of himself]. I didn't want to put him [in] any facility or anything like that. I can't really secure a permanent job right now because he's almost burned down my house twice.*

—Eric, 46, New Mexico

## Medicaid Helps Some Midlife Adults Get Back into the Workforce

Health status is a strong predictor of whether a Medicaid adult is employed. People who report having excellent or very good health are more likely to be working than those who report fair or poor health.<sup>17</sup> In 2017, 11 percent of adults on Medicaid were unable to work because of an illness or disability.<sup>18</sup> Several of our midlife study participants who were unable to work because of disabling health conditions credited Medicaid with helping them address their health concerns, get back on their feet, and start working again.

### HERE'S WHAT THEY TOLD US:

- Medicaid helps people get back on their feet.

---

*Before Medicaid, I had no hope of being able to afford a neurosurgeon. Now I'm able to work again.*  
—Peter, 53, Kentucky

---

*Medicaid paid for surgery and now I'm able to work. I will make enough money that I probably won't need Medicaid anymore. But Medicaid got me through a bad time in my life. Absolutely, yes, Medicaid got me back to work.*

—Bruce, 56, Pennsylvania

*I ended up with an aneurysm, you know. So that was a true blessing and a relief when they did put me on Medicaid. Then I got off [Medicaid] and I was able to go back to work.*

—Tonya, 56, Ohio



Photo Credit: Getty Images

## Recent Changes in Medicaid Policy are Worrisome to Midlife Adults

In recent years, some states have sought federal approval to implement a broad range of new Medicaid policies, many of which, if imposed, could create significant barriers for enrollees or result in coverage losses.<sup>19</sup> Examples of these emerging waiver policies include conditioning eligibility for Medicaid on compliance with work requirements and requiring increased cost sharing. Another emerging policy is to allow states to use the section 1115 waiver process<sup>20</sup> to seek capped federal Medicaid funding through block grants, which are fixed amounts of money the federal government gives to states to operate their Medicaid programs. If states run into problems providing coverage and services within their fixed allotments, they would be forced to cut optional eligibility, optional services, provider payments, or all three.<sup>21,22</sup> Many midlife adults were apprehensive about these new policies, but a few expressed support for some of them under certain conditions.

### HERE'S WHAT THEY TOLD US:

- People feel that work requirements could be difficult to comply with, and want to see exemptions from the policy, especially for older workers.
- People bemoan the administrative burden associated with work requirements.

---

*There's [a need for Medicaid] because there are some places that don't want to hire older people.*

—Cindy, 63, Pennsylvania

---

*For me, it's okay because I'm working. I plan on working for a long time, but other people . . . are unable to work. I think that it's not a good thing. If someone doesn't have a skilled trade, there are less and less opportunities to find work, and there is already age discrimination out there.*

—Regina, 62, Pennsylvania

*As long as you can be exempt for certain reasons, as long as they're not trying to make people work [who] are not able [then a work requirement might be ok].*

—Lauren, 52, Kentucky

---

*[Discussing proof of compliance with verification of work requirements] You can fax it, you can take it, they can scan it in, they could plaster it all over the walls, but it won't be found when it's time to prove you did the hours..*

—Lisa, 46, Kentucky

---

*All of a sudden you have more paperwork or things like that to go through, if you miss a deadline, . . . you lose it, I think that's wrong. It shouldn't be so prohibitive . . . people . . . need it, and they don't need extra stress to keep it. If you're helping someone stay healthy, but you're giving them all this stress of deadlines and making sure they have their pay stub and whatever, I think that's wrong. [They] want to penalize people [who] need it the most, and you are already down, you don't need to be kicked again and again.*

—Kelly, 64, New Mexico

- People have mixed feelings about increased cost sharing in Medicaid.

---

*I think cost-sharing requirements are totally fair, if it is with a sliding income scale. Like, if I'm making 20 grand a year and somebody else is only able to make 12 grand a year, I would hope that their fees are lower.*

—Craig, 49, Ohio

---

*I was out of work, and I couldn't pay any money for coverage.*

—Roger, 58, Pennsylvania

*If you're getting a stable job or if it's like 30 hours a week, copays and premiums don't seem too bad, but it's not a bad idea. So if that's . . . a means to keep your Medicaid, that's okay.*

—Isabella, 51, New Mexico

*If you are making money, then it wouldn't hurt to pay the premium or the copay. But not everybody has consistent work. So I wouldn't mind paying a monthly premium as long as I have income coming in.*

—Juana, 59, New Mexico

*It appears to me is what they're trying to do with cost sharing is trying to entice people not to go to the doctor.*

—Peter, 53, Kentucky

- Many people feel that capped Medicaid funding poses serious risks for consumers.

---

*That's not what Medicaid is set up for. Medicaid is set up for people [who] need help so they can go get it. Don't put up barriers like the block grant thing. . . . You think about that in some of these states; oh my God it would be . . . a travesty in particular in Kentucky.*

—Peter, 53, Kentucky

---

*I could see how they [block grants] could definitely be abused or taken advantage of by whoever is running the legislature and controlling state government.*

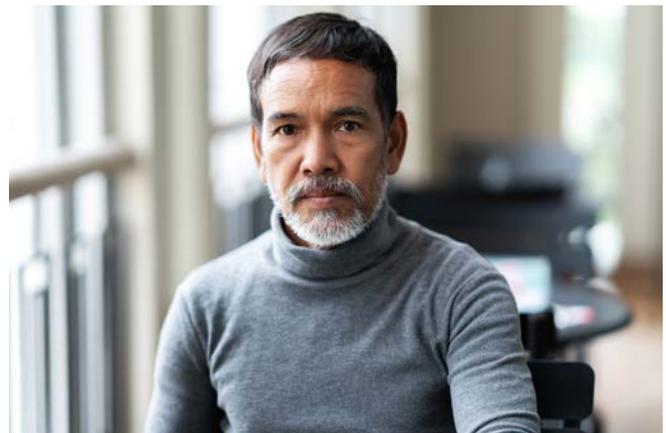
—Craig, 49, Ohio

*You can't forecast. You can kind of estimate the future. But it's not going to be precise, so if it [the amount of money needed to cover Medicaid costs] goes over what they're predicting, then the state is only going to have so much money to deal with this [making Medicaid available for those who need it].*

—Marc, 63, Ohio

*The politicians need to look at universal health care and eliminate all this.*

—Juana, 59, New Mexico



- Some people feel that the new Medicaid policies are an indication that politicians look down on them or are using the policies to make them ineligible for the program.

*I feel like the word Medicaid with politicians is almost demonized, like “those bums getting Medicaid.” Unfortunately, I’m in a spot right now where I need Medicaid, it’s definitely not where I wanted to be, but we’re here. And when they [politicians] hear Medicaid, it’s like, oh well, screw them guys, they’re not paying for it anyway. They take what they get.*

—Eric, 46, New Mexico

---

*I’m convinced they want to make those changes to save bucks, and save the really big bucks. That’s what all these different changes and tweaks are all about. It’s all about not covering people. Tricks.*

—Jennifer, 57, Kentucky

---

*Yeah, it’s just like voter ID. They’re exactly the same thing man. Make sure people don’t vote and absolutely, it works.*

—Peter, 53, Kentucky

## Midlife Adults Have Messages for Policymakers

Looking ahead, midlife adults in this study urge lawmakers to protect Medicaid for the vulnerable populations who rely on the program to maintain their health and well-being. Rather than imposing restrictive conditions on eligibility and coverage, midlife adults want federal and state lawmakers to make it easier for those who qualify for the program to receive needed care and services.

### HERE’S WHAT THEY TOLD US:

- Study participants want policy makers to see them as people, putting themselves in the shoes of someone living without health insurance.
- Study participants value Medicaid and don’t want to see it go away.

---

*I think we’ve seen what Medicaid is, how it’s helped our lives; it’s important right now, it’s very important.*

—Peter, 53, Kentucky

---

*Losing Medicaid would be more stress again, because then I’d be worried I would go back to not going to the doctor when I needed to.*

—Lauren, 52, Kentucky

---

*Come on, this is people’s lives. We’re blessed to have Medicaid.*

—Robert, 53, Kentucky

---

*Just tell them to leave it alone.*

—Bruce, 56, Pennsylvania

---

*Live your life without insurance for two years.*

—Bruce, 56, Pennsylvania

---

*Keep the program going and, and everybody that qualifies for it, make sure that they are able to get it.*

—Wayne, 62, Ohio

## Summary of Findings

Study participants represented a range of political party affiliations as well as different races and ethnicities. The group also included significant variations in age as well as employment status. Despite their differences, participants' responses to focus group discussion topics were remarkably consistent, demonstrating that the value of Medicaid in the lives of these low-income midlife adults cut across politics, race/ethnicity, age, and employment status.

Study findings show that lack of health insurance had harmful effects on the mental and physical health of study participants, and provide key insights into how Medicaid coverage helped improve these individuals' health status and quality of life. All participants experienced some level of emotional distress as a result of being uninsured, and most had unaddressed chronic health conditions as well. Access to Medicaid alleviated stress associated with lack of insurance and allowed participants to manage their chronic health conditions through acute medical interventions, regular checkups, and maintenance prescription drug therapy. Many credited the program with saving their lives.

In addition to being able to have their immediate health concerns addressed because they were enrolled in Medicaid, most study participants clearly understood the value of preventive services in maintaining and improving their health, and were relieved to have access to these services. Those with family histories of cancer were especially grateful that Medicaid covered routine cancer screenings like mammograms and colonoscopies. Others were grateful to be able to access recommended immunizations.

The majority (56 percent) of study participants were working. Those who were not had disabling health conditions that prevented them from working, or were full-time family caregivers for an aging parent. A few participants who were not working when they gained access to Medicaid expansion coverage credited the program with helping them get the care they needed to become healthy enough to rejoin the



workforce. Those who were family caregivers were grateful that the program helped them stay healthy so they could provide the needed care for their loved one.

Most study participants either opposed or expressed concern about state or federal policies that create insurmountable barriers to continued access to Medicaid expansion coverage. For example, many said that imposing work requirements on midlife adults creates a high bar in a society where older workers are not valued, making it difficult, if not impossible, for them to find jobs. Others worried that caring for an older relative might not count as an exception to a work requirement. Many felt that premium requirements are acceptable policy as long as they are crafted to reflect what people can reasonably be expected to pay, given their individual circumstances. Many study participants felt that capping Medicaid funding would pose serious challenges for beneficiaries, including coverage losses. Finally, some study participants expressed concerns that people, including some policy makers, stigmatize state Medicaid expansion programs and look down on enrollees, instead of seeing them as people who are down on their luck and need help to get by.

## Policy Recommendations

### STATES THAT HAVE NOT ENACTED MEDICAID EXPANSIONS SHOULD DO SO AS SOON AS POSSIBLE.

As of November 2020, 12 states have not taken up Medicaid expansion,<sup>23</sup> leaving millions of low-income uninsured adults, including midlife adults, without needed access to care. Study findings demonstrate a pent-up demand for lifesaving services and treatments, as well as preventive services. Although this study is limited to four expansion states, it is likely that midlife adults in nonexpansion states have similar health care needs and experience similar stresses because they are uninsured at a point in their lives in which the onset of health conditions is a serious concern. As the nation continues to battle the coronavirus pandemic,<sup>24</sup> access to care is even more important for adults of any age, including midlife adults, who may have untreated health conditions—like type 2 diabetes, chronic kidney disease, or obesity—that increase their risk for serious illness and death from the virus.<sup>25</sup> In addition to providing access to lifesaving care, Medicaid expansions—in which the federal government pays 90 percent of the costs—are a cost-effective way for states

to improve and maintain the health of their populations during the current pandemic and after its eventual end.

### STATES SHOULD NOT SEEK OR ENFORCE WAIVER POLICIES THAT PRESENT BARRIERS TO NEW COVERAGE OR CONTINUED COVERAGE FOR MIDLIFE ADULTS.

States have been using section 1115 waivers<sup>26</sup> to seek federal permission to condition Medicaid eligibility on compliance with work and/or increased cost-sharing requirements. They also have the ability to seek waivers to cap federal Medicaid funding in return for increased program flexibility.<sup>27</sup> During the current coronavirus pandemic, Congress passed legislation that allows states to receive extra federal Medicaid funds during the declared public health emergency<sup>28</sup> if they, among other things, keep people continuously eligible for Medicaid until the emergency ends.<sup>29</sup> This means that states cannot deny people coverage if they do not comply with work or increased cost-sharing requirements. When the pandemic ends, state and federal policy makers should remember the devastating impact COVID-19 had on hundreds of thousands of individuals and families. They



Photo Credit: Getty Images

should also consider the number of lives that could have been saved or chronic COVID-19-related morbidities avoided had every midlife low-income adult had adequate access to needed care heading into the pandemic.

**STATES THAT IMPLEMENT WORK REQUIREMENTS AFTER THE PUBLIC HEALTH EMERGENCY IS OVER SHOULD CLEARLY EXEMPT FAMILY CAREGIVERS TO ENSURE THAT THEY DO NOT LOSE MEDICAID COVERAGE.**

Among states that have an approved work requirement or have plans to seek federal approval for one, states should either exempt caregivers from the requirement or count caregiving hours toward the work requirement. However, in many cases the qualifying criteria are narrow and many provisions are unclear and subject to multiple interpretations, which could lead to loss of coverage for caregivers.<sup>30</sup> Results from this study demonstrate how Medicaid keeps caregivers healthy so they can support individuals who depend on them. In addition, the coronavirus pandemic has taught us how valuable it is to be able to provide care for older adults in their homes and communities, as opposed to care in nursing homes; 40 percent of COVID-19-related deaths in the United States have occurred in long-term care facilities, including nursing homes, as of November 13, 2020.<sup>31</sup> In addition to requiring clear waiver language that ensures that no caretaker loses Medicaid coverage, the federal government and states should recognize that caregiving responsibilities often preclude people from being able to work and also provide exemptions from increased cost-sharing requirements.

**STATES SHOULD REJECT THE FEDERAL GOVERNMENT'S OFFER TO SEEK SECTION 1115 WAIVERS TO CAP FEDERAL MEDICAID FUNDING.**

The Medicaid funding structure does not have pre-set federal funding limits.<sup>32</sup> This means that the federal government pays a share of each state's expenses for qualifying services provided to eligible enrollees (based on a formula). This approach to funding protects states by enabling them to provide coverage and pay for services for all eligible enrollees, including in times like the current coronavirus public health emergency, during which Medicaid enrollment has significantly increased.

Any policy aimed at capping federal Medicaid funding has the potential to have harmful effects<sup>33</sup> as states seek to operate their programs with limited federal funds. State Medicaid programs that are unable to function within their capped federal allotments would likely have to limit enrollment, cut or limit optional services (like home- and community-based long-term care), cut provider reimbursement, or undertake some combination of each approach. When the public health emergency ends, states will no longer receive extra federal funds to support their Medicaid programs, however, the long-term disruption to state economies is likely to continue,<sup>34</sup> making states less able to take on greater financial risk by seeking capped federal funding in return for increased program flexibilities.<sup>35</sup> Current Medicaid rules already give states significant flexibility to tailor their programs. As states strategize on ways to manage their budgets and rebuild their economies, maintaining the current Medicaid funding structure will be instrumental in ensuring that low-income enrollees continue to have access to needed health care and long-term services and supports.

**ALL LEVELS OF GOVERNMENT AND THE PROVIDER COMMUNITY SHOULD CONDUCT ROBUST CAMPAIGNS TO PROMOTE ENROLLMENT IN MEDICAID EXPANSIONS.**

Medicaid expansions can eliminate a significant access barrier to health care. However, negative attitudes toward Medicaid and negative perceptions of the low-income people who use the program can also pose a significant barrier to enrollment and use of needed services. Such attitudes can stigmatize the program and diminish public support for it. Stigma can also result from patient perceptions of demeaning encounters with providers.<sup>36</sup> The vast racial and ethnic disparities in health care brought into clear focus during the COVID-19 pandemic<sup>37</sup> create an imperative for policymakers, in partnership with the provider community, to work toward eliminating systemic barriers to Medicaid enrollment and service use—including stigma—to ensure that people of all races and ethnicities, especially Black and Latino individuals, who suffer a disproportionate disease burden, access care in a nonjudgmental environment.

## Conclusion

Study results demonstrate that Medicaid coverage makes a lifesaving difference in the lives of low-income, midlife adults in the four study states, but can also make them feel ashamed and stigmatized when they perceive that people, including policy makers, view the program and those who use it with disdain. Policy makers should keep Medicaid beneficiaries' experiences at the forefront of their minds when weighing whether to expand coverage in their states and considering policies that create enrollment barriers. Policy makers and providers should also work together to develop and disseminate positive public messages that encourage Medicaid enrollment.

## References

- 1 Lydia Saad, "Chronic Illness Rates Swell in Middle Age, Taper Off after 75," *Gallup News*, April 29, 2011, <https://news.gallup.com/poll/147317/chronic-illness-rates-swell-middle-age-taper-off.aspx>.
- 2 American Psychological Association (APA), "Stress in America: Uncertainty about Healthcare," APA, Washington, DC, January 2018, <https://www.apa.org/news/press/releases/stress/2017/uncertainty-health-care.pdf>.
- 3 National Institute of Mental Health, *5 Things You Should Know about Stress* (Bethesda, MD: National Institute of Mental Health), <https://www.nimh.nih.gov/health/publications/stress/index.shtml>.
- 4 Katie A. McLaughlin, "The Public Health Impact of Major Depression: A Call for Interdisciplinary Prevention Efforts," National Institutes of Health, National Library of Medicine, Washington, DC, December 2011, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3219837/>.
- 5 Luna Dolezal and Barry Lyons, "Health-Related Shame: An Affective Determinant of Health?," *British Medical Journal* 43, no. 4 (2017) 257-263, <https://mh.bmj.com/content/medhum/43/4/257.full.pdf>.
- 6 APA, "Stress in America."
- 7 Marlene C. Baca, "Health Insurance Protects Financial and Physical Health, Offers Peace of Mind," *The Valley Daily Post*, <https://valleydailypost.com/blog/health-insurance-protects-financial-and-physical-health-offers-peace-of-mind/>.
- 8 National Center for Health Statistics, "Health Insurance Coverage and Access to Care," National Center for Health Statistics, Hyattsville, MD, February 2017, [https://www.cdc.gov/nchs/data/factsheets/factsheet\\_hiac.pdf](https://www.cdc.gov/nchs/data/factsheets/factsheet_hiac.pdf).
- 9 Jennifer Tolbert et al., "Key Facts about the Uninsured Population," the Henry J. Kaiser Family Foundation, San Francisco, CA, December 2019, <https://www.kff.org/uninsured/issue-brief/key-facts-about-the-uninsured-population/>.
- 10 Ibid.
- 11 Shanoor Seervai and David Blumenthal, "Insurance Coverage Saves Lives" (blog), August 2019, <https://www.commonwealthfund.org/blog/2019/insurance-coverage-saves-lives>.
- 12 Robin A. Cohen and Maria A. Villarreal, "Strategies Used by Adults to Reduce Their Prescription Drug Costs: United States, 2013," Data Brief No. 184, National Center for Health Statistics, Hyattsville, MD, January 2015, <https://www.cdc.gov/nchs/data/databriefs/db184.pdf>.
- 13 Howard LeWine, "Millions of Adults Skip Medications Due to Their High Cost," *Harvard Health Blog*, posted January 30, 2015, updated June 15, 2020, <https://www.health.harvard.edu/blog/millions-skip-medications-due-to-their-high-cost-201501307673>.
- 14 Susan Levine et al., "Health Care Industry Insights: Why the Use of Preventive Services Is Still Low," *Preventing Chronic Disease* 16 (2019), [https://www.cdc.gov/pcd/issues/2019/18\\_0625.htm](https://www.cdc.gov/pcd/issues/2019/18_0625.htm).
- 15 "Access to Health Services," Office of Disease Prevention and Health Promotion, Healthy People.gov, <https://www.healthypeople.gov/2020/topics-objectives/topic/Access-to-Health-Services>.
- 16 Susan C. Reinhard et al., *Valuing the Invaluable: 2019 Update Charting a Path Forward* (Washington, DC: AARP Public Policy Institute, November 2019), <https://www.aarp.org/content/dam/aarp/ppi/2019/11/valuing-the-invaluable-2019-update-charting-a-path-forward.doi.10.26419-2Fppi.00082.001.pdf>.
- 17 Medicaid adults are those ages 19 to 64 who do not receive Supplemental Security Income and are dually eligible for Medicare and Medicaid. Rachel Garfield et al., "Understanding the Intersection of Medicaid and Work: What Does the Data Say?," Kaiser Family Foundation, San Francisco, CA, 2019, <https://www.kff.org/medicaid/issue-brief/understanding-the-intersection-of-medicaid-and-work-what-does-the-data-say/>.
- 18 Ibid.
- 19 Lynda Flowers and Jean Accius, *The New Medicaid Waivers: Coverage Losses for Beneficiaries, Higher Costs for States* (Washington, DC: AARP Public Policy Institute, June 2019), <https://www.aarp.org/content/dam/aarp/ppi/2019/06/the-new-medicaid-waivers-coverage-losses-for-beneficiaries-higher-costs-for-states.doi.10.26419-2Fppi.00066.001.pdf>.
- 20 Robin Rudowitz et al., "Implications of CMS's New 'Healthy Adult Opportunity' Demonstrations for Medicaid," Kaiser Family Foundation, Washington, DC, February 2020, <https://www.kff.org/medicaid/issue-brief/implications-of-cmss-new-healthy-adult-opportunity-demonstrations-for-medicaid/>.
- 21 Cindy Mann et al., "The Fiscal Impact of the Trump Administration's Medicaid Block Grant Initiative," The Commonwealth Fund, New York, NY, March 2020, <https://www.commonwealthfund.org/publications/issue-briefs/2020/mar/fiscal-impact-trump-administration-medicaid-block-grant-initiative>.

- 22 For a full discussion of capped Medicaid funding and its implications, see Lynda Flowers, *Block Grants and Per Capita Caps Pose Risk for Consumers and for States* (Washington, DC: AARP Public Policy Institute, February 2017), <https://www.aarp.org/content/dam/aarp/ppi/2017-01/Block%20Grants.pdf>.
- 23 “Status of State Medicaid Expansion Decisions: Interactive Map,” Kaiser Family Foundation, August 2020, <https://www.kff.org/medicaid/issue-brief/status-of-state-medicaid-expansion-decisions-interactive-map/>.
- 24 “Coronavirus, Overview,” World Health Organization, [https://www.who.int/health-topics/coronavirus#tab=tab\\_1](https://www.who.int/health-topics/coronavirus#tab=tab_1).
- 25 Centers for Disease Control and Prevention (CDC), “Coronavirus Disease 2019 (COVID-19), People with Certain Medical Conditions,” Centers for Disease Control and Prevention, updated August 14, 2020, <https://www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/people-with-medical-conditions.html>.
- 26 “About Section 1115 Demonstrations,” Centers for Medicare & Medicaid Services, Medicaid.gov, <https://www.medicaid.gov/medicaid/section-1115-demonstrations/about-section-1115-demonstrations/index.html>.
- 27 US Department of Health and Human Services, Centers for Medicare & Medicaid Services (CMS), “Dear State Medicaid Director Letter, re: Healthy Adult Opportunity,” CMS, Baltimore, MD, January 30, 2020, <https://www.medicaid.gov/sites/default/files/Federal-Policy-Guidance/Downloads/smd20001.pdf>.
- 28 Emergency declarations typically last for 90 days. The most recent declaration was made on July 23, 2020. “Renewal of Determination that a Public Health Emergency Exists,” US Department of Health and Human Services, June 23, 2020, <https://www.phe.gov/emergency/news/healthactions/phe/Pages/covid19-23June2020.aspx>.
- 29 MaryBeth Musumeci, “Key Questions about the New Increase in Federal Medicaid Matching Funds for COVID-19,” Kaiser Family Foundation, Washington, DC, May 4, 2020, <https://www.kff.org/coronavirus-covid-19/issue-brief/key-questions-about-the-new-increase-in-federal-medicaid-matching-funds-for-covid-19/>.
- 30 Natalie Kean, “Medicaid Work Requirements: The Impact on Family Caregivers and Older Adults,” Justice in Aging, Washington, DC, November 2018, <http://www.justiceinaging.org/wp-content/uploads/2018/11/JusticeInAging-Medicaid-IssueBrief-November19-11am-2018.pdf>.
- 31 Kaiser Family Foundation, “State Data and Policy Actions to Address Coronavirus,” Kaiser Family Foundation, Washington, DC, September 25, 2020, <https://www.kff.org/health-costs/issue-brief/state-data-and-policy-actions-to-address-coronavirus/#long-term-care-cases-deaths>.
- 32 US Department of Health and Human Services, “Federal Financial Participation in State Assistance Expenditures,” Federal Register, Vol. 84, No. 232 (2019) 66204-66206, <https://www.govinfo.gov/content/pkg/FR-2019-12-03/pdf/2019-26207.pdf>.
- 33 Lynda Flowers, “New Waiver Guidance Giving States Authority to Cap Medicaid Funding Could Put All Medicaid Enrollees at Risk,” (blog), February 5, 2020, <https://blog.aarp.org/thinking-policy/new-waiver-guidance-could-put-all-medicaid-enrollees-at-risk>.
- 34 Elizabeth McNichol and Michael Leachman, *States Continue to Face Large Shortfalls Due to COVID-19 Effects* (Washington, DC: Center on Budget and Policy Priorities, July 7, 2020), <https://www.cbpp.org/sites/default/files/atoms/files/6-15-20sfp.pdf>.
- 35 CMS, “Dear State Medicaid Director Letter.”
- 36 Heidi Allen et al., “The Role of Stigma in Access to Health Care for the Poor,” *Milbank Quarterly* 92, no. 2 (2014): 289-318, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4089373/>.
- 37 Monica Webb Hooper, Anna María Nápoles, and Eliseo J. Pérez-Stable, “COVID-19 and Racial/Ethnic Disparities,” *Journal of the American Medical Association* 323, no. 24 (2020): 2466-67, <https://jamanetwork.com/journals/jama/article-abstract/2766098>.

# Appendix A

## METHOD

The purpose of this study was to learn about low-income midlife adults' experiences with being uninsured versus having access to Medicaid coverage. Focus group methodology was used because this semi structured group interview process allows for an in-depth gathering of information and opinions from a group of people through facilitated discussions.

## DATA COLLECTION

The AARP Public Policy Institute (PPI) commissioned Perry Udem Research and Communications to conduct focus groups with midlife adults (ages 45–64) in four states—Kentucky, New Mexico, Ohio, and Pennsylvania—that expanded Medicaid to cover, among other groups, midlife adults with income at or below 138 percent of the FPL (\$17,609 for a single-person household in 2020). Study states had to have implemented Medicaid expansions at least one year before this study was conducted, and participants had to have been uninsured for at least one year before gaining Medicaid coverage. In addition to these criteria, study states were also selected to ensure racial and geographic diversity.

Perry Udem and PPI developed an interview guide (available upon request) to facilitate the discussions. Each participant signed a written consent to join the study and received a small stipend to compensate for time and travel. Focus group interviews were conducted between October 9 and October 28, 2019. They ranged in size from 6 to 9 participants and lasted approximately 1 hour and 45 minutes.

## DATA ANALYSIS

Each focus group session was videotaped and transcribed. Based on PPI's analysis of the transcribed data and video recordings, we identified several themes that provided insight into the value of Medicaid coverage among midlife adults in this study. For purposes of this report, the names of participants have been changed to protect their privacy.

## STUDY LIMITATIONS

This study has several limitations. First, participants may influence the responses of others, especially if one or more participants tend to dominate discussions. Second, given the group nature of the methodology, some participants may not be forthcoming on sensitive topics. Third, moderator bias (intended or unintended) may have influenced responses. Finally, and most importantly, our findings reflect the experiences and feelings of study participants and are not generalizable to the entire midlife population gaining access to Medicaid coverage. With this caveat, findings do provide a rich source of data that can serve as a reliable basis for further exploration using other methods.

## Appendix B

### PARTICIPANTS

The focus group study comprised 32 participants. Participants were between ages 45 and 64, had no dependent children, and had been uninsured for at least one year before gaining access to Medicaid. We also sought to have racial and ethnic diversity among the four groups. Of the 32 participants, more than half (56 percent) said that they were employed.

Participant Demographics				
Category	Participant Count by State	Total Count	Total Percentage	
Age	45 - 48	KY - 3 NM - 2 OH - 2 PA - 0	7	22%
	49 - 52	KY - 2 NM - 1 OH - 1 PA - 0	4	13%
	53 - 56	KY - 3 NM - 1 OH - 2 PA - 2	8	25%
	57 - 60	KY - 1 NM - 3 OH - 1 PA - 3	8	25%
	61 - 64	KY - 0 NM - 1 OH - 2 PA - 2	5	16%
Sex	Female	KY - 5 NM - 4 OH - 4 PA - 3	16	50%
	Male	KY - 4 NM - 4 OH - 4 PA - 4	16	50%
Race/Ethnicity	White	KY - 6 NM - 3 OH - 4 PA - 3	16	50%
	Black	KY - 2 NM - 0 OH - 3 PA - 3	8	25%
	Hispanic/Latino	KY - 0 NM - 5 OH - 1 PA - 1	7	22%
	Mixed Race	KY - 1 NM - 0 OH - 0 PA - 0	1	3%

Participant Demographics				
Category		Participant Count by State	Total Count	Total Percentage
Employment Status	Employed	KY - 4 NM - 5 OH - 6 PA - 3	18	56%
	Unemployed	KY - 5 NM - 3 OH - 2 PA - 4	14	44%
Chronic Conditions*	Specified	KY - 7 NM - 6 OH - 5 PA - 6	24	75%
	Unspecified	KY - 2 NM - 2 OH - 3 PA - 1	8	25%
Top Six Chronic Conditions*	Chronic Pain	KY - 3 NM - 1 OH - 1 PA - 2	7	21%
	High Blood Pressure	KY - 1 NM - 2 OH - 0 PA - 3	6	19%
	Diabetes	KY - 1 NM - 3 OH - 0 PA - 1	5	16%
	Behavioral Health Conditions	KY - 3 NM - 1 OH - 0 PA - 1	5	16%
	Thyroid Conditions	KY - 2 NM - 1 OH - 0 PA - 0	3	10%
	Weight (overweight, obesity, morbid obesity)	KY - 0 NM - 1 OH - 2 PA - 0	3	10%

*\*This category does not sum to 100 percent of participants. Total percentage represents the share of total participants (32) who reported having the chronic condition. The results may not reflect the true range of chronic conditions among the groups, as some participants may have felt uncomfortable disclosing that information in a focus group setting.*

Research Report 2020-25, November 2020

© **AARP PUBLIC POLICY INSTITUTE**

601 E Street, NW  
Washington DC 20049

Follow us on Twitter @AARPolicy  
on facebook.com/AARPolicy  
[www.aarp.org/ppi](http://www.aarp.org/ppi)

For more reports from the Public Policy  
Institute, visit <http://www.aarp.org/ppi/>.

<https://doi.org/10.26419/ppi.00118.001>

