

November 2012

**Faces of the Medicaid Expansion: Experiences of Uninsured Adults who Could Gain Coverage****EXECUTIVE SUMMARY**

The Affordable Care Act (ACA) provides for the expansion of Medicaid to a national eligibility floor of 138% FPL (\$15,415 for an individual or \$26,344 for family of three in 2012) in 2014, which would make millions of uninsured adults newly eligible for the program. The Supreme Court ruling on the ACA limits the Secretary's authority to enforce the Medicaid expansion, which may impact state decisions to implement it. If a state does not expand Medicaid, poor adults in that state will be without any new coverage options and will likely remain uninsured. To provide insight into the potential impact of expanding Medicaid, this report highlights the experiences of uninsured adults who could gain coverage under the expansion, based on focus groups conducted in Cincinnati, Houston, Las Vegas, and Tampa.

***Who Are Low-Income Uninsured Adults?***

**Uninsured adults who participated in the focus groups are a diverse group, ranging from young adults just entering the job market to retirees.** Participants vary in race and ethnicity as well as in family and living situations. They include single individuals, married individuals with and without children, and individuals living with extended family. Participants also are in varied stages of life, with some getting started on their careers and others having retired after many years in the workforce. Moreover, some have struggled financially for many years, while others are newly facing financial struggles.

**Most participants are working, but still struggle to make ends meet and cover their basic expenses.**

Most participants are employed, but tend to be in service, retail, or labor jobs that have low wages. They are grateful for their jobs, but many continue to search for better paying, more stable options. Other participants are unemployed—some have recently lost jobs while others have been out of work for longer periods of time. All participants describe the job market as extremely competitive, and several participants have gone back to school or entered training programs to expand their skills and improve their job prospects. Even those who are working say they are living paycheck to paycheck and juggling bills each month. Paying bills is even more difficult for individuals without a stable job, who rely on stringing together side jobs to pay for basic necessities. A number of participants described winnowing down their expenses to just the essentials. Nearly all participants lack any savings to fall back on, and, as such, feel very insecure.

**"I have a couple of jobs, which is good, but I would rather have a different job that takes care of everything and that I can enjoy more."**

Lindsey, Cincinnati

**"Actually, I have zero savings and yes, that worries me a lot because you know anything can happen, anything."**

Kelly, Las Vegas

***Health and Access to Health Coverage***

**Many participants have physical and mental health conditions.** While some participants are in good health, many others have physical and mental health conditions, which, in some cases, interfere with their daily lives and ability to work. These include chronic physical conditions such as high blood pressure, diabetes, asthma, high cholesterol, and arthritis as well as ongoing mental health conditions such as depression, anxiety, and bipolar disorder. Some participants also have experienced significant health problems, like a heart attack, brain aneurysm, and cancer.

**Participants want health insurance but do not have any affordable options.** All participants wish they had health insurance to access needed care and to provide financial protection from medical costs. However, they have been unable to find any affordable options. Most are not offered coverage by their employer and cannot afford private individual coverage.

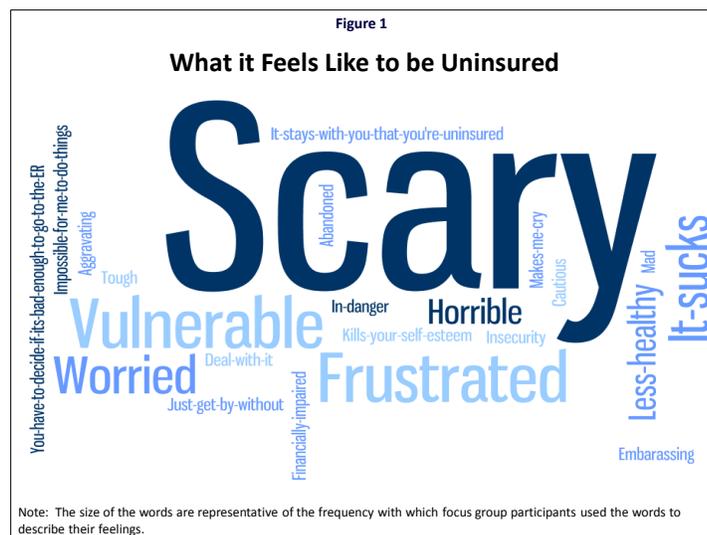
**“...After I had a heart attack eight years ago with no insurance, I checked around and it was like \$600-\$700 a month for insurance.”**

Cindy, Las Vegas

### **Being Uninsured**

**Being uninsured contributes to significant stress, worry, and anxiety in participants’ lives.**

They use words like “scary” and “horrible” to describe what it feels like to be uninsured (Figure 1). Many participants are anxious about their health because they have been unable to see a doctor. They worry about undiagnosed symptoms and untreated conditions and family histories of conditions like diabetes and cancer. They wish they could get care and screenings to prevent any health problems from getting worse and to catch any developing problems early. They also have significant anxiety about unexpected illnesses or accidents.



**Many participants are going without needed care and prescription drugs, including preventive care.**

Many cannot afford to pay for their prescriptions or to see a doctor regularly. Several participants described stretching out their medications by skipping doses or taking smaller than recommended doses to make them last longer. Almost all participants say they are going without regular preventive care and screenings. Some also are forgoing care for chronic conditions or follow-up treatments and care recommended by their doctors. Mental health needs, in particular, are going untreated. Most cannot afford to see a counselor or psychiatrist or to fill prescriptions for depression and anxiety.

**“I should be taking anxiety pills and I don’t because I’d have to buy them and they’re like \$120... so I do without them.”**

Steven, Cincinnati

**Participants put off getting care for as long as possible and have limited options when they finally seek care.** Participants try to avoid seeking care because they cannot afford the costs. Many say that they try to take care of themselves, for example, through diet and exercise; some also utilize home remedies and over-the-counter medications. However, many have health needs that require professional care, which continue to go unmet. Participants typically wait until they are in extreme pain or discomfort before seeking care. They note that affordable options for care, such as clinics, are limited and often have long waits. Further, they try to avoid going to the emergency room because they fear the resulting large medical bills that they will not be able to pay. Some obtain medications through pharmaceutical company and store discount programs, but say it is challenging to consistently get medications through these sources. As a result of the limited options for care, most participants do not have a regular doctor and receive episodic care without any follow-up or coordination to manage ongoing conditions.

**“I only can go to the doctor, when I’m extremely, extremely sick and I just can’t stand the pain anymore.”**

Lori, Houston

Being uninsured has significant negative impacts on individuals' physical and emotional health and finances and, in some cases, interferes with their ability to work and their daily lives. Several participants described suffering from significant pain as a result of going without care and prescription drugs. Some with mental health conditions say they have experienced unstable periods—even to the point of suicidal thoughts—because they cannot afford to see a counselor or a psychiatrist. Going without needed care also makes it difficult for participants to fully live their lives. Some described a cyclical challenge of their health problems interfering with their ability to work, but their lack of employment leading to their lack of health coverage and ability to get the care they need to be healthy enough to work. Some also say their health problems interfere with their daily lives and relationships. Moreover, many participants have large medical debt as a result of emergency room and inpatient hospital visits while they have been uninsured.

“...it just makes me cry, when I’m sitting on the side of the bed at 3:00 in the morning...[the prescription] says take two every six hours for pain, but I don’t have enough...I take one instead. It subsides the pain a little but, yet I’m in pain—severe pain. I’m crying and hurting, but I’m going to make it stretch until the next time.”  
Roosevelt, Houston

### Thoughts on Obtaining Health Coverage

Participants say they would feel “relief,” “security,” and “peace of mind,” if they obtained health insurance (Figure 2). They say obtaining coverage would remove a significant burden and anxiety from their lives. They would no longer have to worry about what may be wrong with them and could get the care and screenings they need. They also would no longer worry about the financial consequences of an unexpected accident or illness.

Participants say they would seek preventive care as well as care for ongoing conditions if they obtained coverage. Most say they would get a check-up and establish a relationship with a primary care doctor. Many want the peace of mind of knowing they are healthy or at least to know what is wrong with them if they have a problem. Those with ongoing physical and mental health conditions say they would finally be able to get the care they need. Many say they would see a primary care doctor and specialists on a regular basis, take their prescribed medications, and have all their recommended tests and blood work done. Those with mental health needs also would seek counseling and medications.



“I would want it because of the prevention factor...then I would definitely go and get my mammogram, my Pap smear, and exam.”

Valerie, Tampa

“[I would] definitely [get care for] my mental health because I know I need help in forgetting what has happened to me.... I used to feel real well when I used to go see my psychiatrist to talk about the situation, the abuse, the neglect and...other stuff that happened to me.”

Rafael, Tampa

### **Views on the ACA Medicaid Expansion**

After sharing their experiences being uninsured and thoughts on gaining coverage, participants were provided information on the ACA's Medicaid expansion and informed that they all are at an income level that would make them eligible for the expansion. They also were informed that states will be deciding whether to implement the expansion and told how this decision will impact the availability of coverage for people at different incomes as well as the reasons some states are considering not expanding Medicaid. They were then asked to share their views on the expansion, as summarized below.

**Nearly all participants said they would enroll in Medicaid if they became eligible.** Many felt this would be their foreseeable option to gain coverage. However, some were skeptical that any coverage offered to them would be affordable—they wanted details about what would be covered and how much it would cost. Similarly, some were skeptical that they could ever qualify for Medicaid since they have never been eligible in their adult lives. In addition, some participants expressed an internal conflict about obtaining Medicaid coverage—although they wish they were in better circumstances and had coverage through an employer, they would be grateful for Medicaid coverage and they feel as though they have earned it as hardworking, taxpayers.

**Nearly all participants say their state should implement the Medicaid expansion.** Some noted that, in addition to enabling them to obtain coverage, the expansion would have economic benefits, such as more productive citizens and lower health care costs. However, some expressed concerns about how the expansion would be paid for and recognized that states face competing priorities with limited resources. Even so, for most, the needs of uninsured individuals outweigh these concerns.

**Participants want multiple options to enroll in Medicaid and are particularly interested in an online enrollment option.** The majority has access to the internet at home or at the library and say their preferred Medicaid enrollment method would be online. However, some still want to meet with someone face-to-face to ask questions and ensure they are enrolling properly. Some also would like to have phone or online chat assistance available.

**“How could you not want the best for your state and everybody in it—not just the rich, but the poor and just the middle...that are still struggling? They may have jobs, they may have...an income, but they're still struggling you know.”**

Christine, Cincinnati

**“I think he should take the funding because in the bigger scheme of things, if he takes the funding now that helps people. In the long-term, there'll be less health issues, and I think medical costs, in general, for the state will go down.”**

Shirley, Houston

### **CONCLUSION**

This study reveals that uninsured adults who could benefit from the Medicaid expansion are a hardworking, diverse group facing challenging times. Many have unmet physical and mental health care needs and face significant health and financial consequences as a result of being uninsured. These adults say that gaining coverage would provide them a huge sense of relief and feeling of security as well as access to needed care, which they believe would improve the management of their health conditions, enable them to obtain preventive care, and reduce their use of the emergency room. Individuals want coverage and most would enroll in Medicaid if they were eligible. They largely support their states expanding Medicaid and feel the expansion provides an important opportunity for them to gain coverage and for their state to help those most in need.

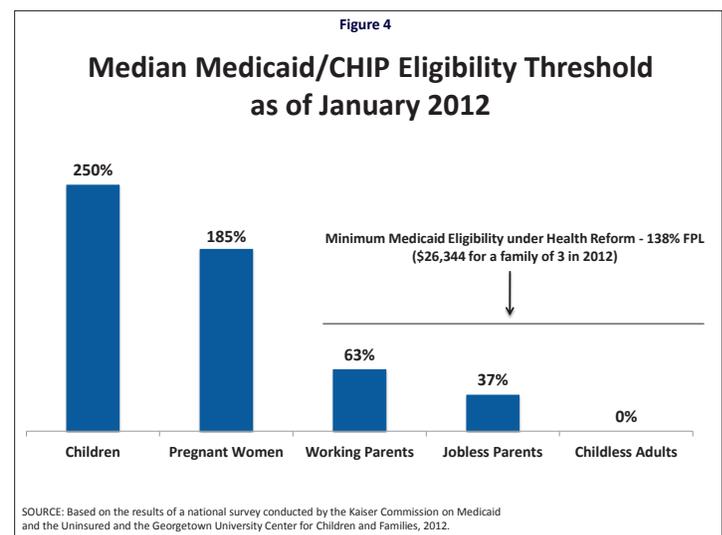
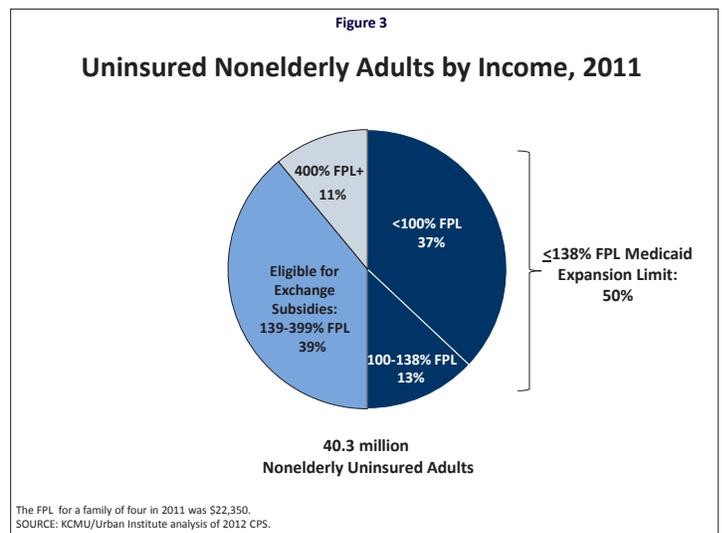
## INTRODUCTION

Beginning in 2014, the Affordable Care Act (ACA) provides for the expansion of Medicaid to a national eligibility floor of 138% FPL (\$15,415 for an individual or \$26,344 for family of three in 2012), which would make millions of uninsured adults newly eligible for the program. The Supreme Court ruling on the ACA maintains the Medicaid expansion, but limits the Secretary’s authority to enforce it, which may impact state decisions to implement it. If a state does not expand Medicaid, poor adults in that state will not have any new coverage options and likely remain uninsured. To provide insight into the potential impact of expanding Medicaid, this report highlights the experiences of currently uninsured adults who could gain coverage under the Medicaid expansion. It is based on eight focus groups with uninsured adults who could be eligible for the Medicaid expansion in Cincinnati, Houston, Las Vegas, and Tampa, conducted during August and September 2012. A companion report, “Faces of the Medicaid Expansion: Profiles of Uninsured Adults Who Could Gain Coverage,” provides individual profiles of selected focus group participants and is available at <http://www.kff.org/medicaid/8385.cfm>.

## BACKGROUND

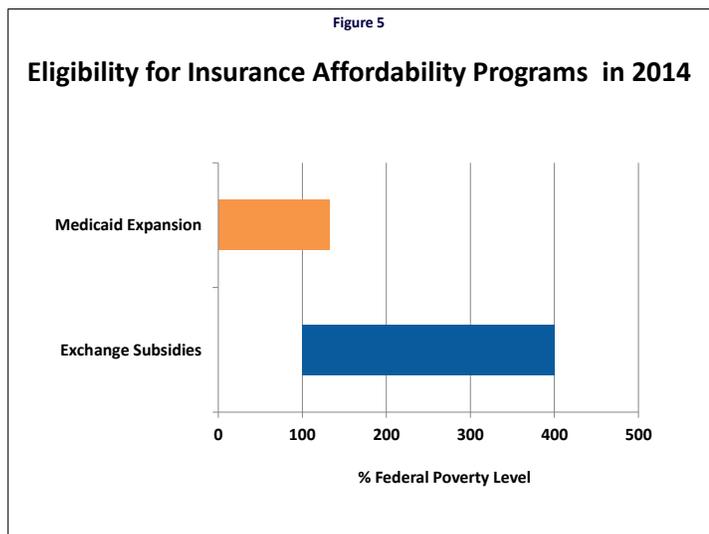
As of 2011, there were 48 million nonelderly uninsured individuals in the United States, including over 40 million adults. One key goal of the ACA is to reduce the number of uninsured by creating a new continuum of coverage options beginning in 2014. These options include a Medicaid expansion to a national eligibility floor of 138% FPL (\$15,415 for an individual or \$26,344 for family of three in 2012) and the creation of Health Benefit Exchanges with tax credits for individuals up to 400% FPL to help purchase Exchange coverage. In 2011, half of uninsured adults had incomes below the Medicaid expansion limit of 138% FPL and nearly nine in ten had incomes below 400% FPL (Figure 3).

One key reason for the large number of uninsured low-income adults is their limited eligibility for Medicaid today. While states have expanded Medicaid and CHIP eligibility for children and pregnant women, Medicaid eligibility levels for parents remain low in most states. In addition, other “childless adults,” who do not have a child in the home or qualify as having a disability, historically have been excluded from Medicaid no matter how low their income. As such, the ACA Medicaid expansion will significantly increase eligibility for low-income adults (Figure 4). The ACA also requires states to vastly streamline Medicaid enrollment processes for all enrollees and to offer multiple options to enroll, including online, via the telephone, and in person.



The Supreme Court ruling on the ACA maintains the Medicaid expansion, but limits the Secretary’s authority to enforce it, which may impact state decisions to implement the expansion. If a state does not expand Medicaid, poor uninsured adults in that state would be left without any new coverage options since those with incomes below 100% FPL would not be eligible for tax credits to help purchase coverage through the new Exchanges. Those with incomes between 100%-400%, FPL, however, would be eligible for these subsidies (Figure 5).

As such, state decisions to implement the Medicaid expansion will have a significant impact on uninsured adults. If a state does not expand Medicaid, many poor uninsured adults would not have any new coverage options and likely remain uninsured. To provide greater insight into these consequences, this report examines the impacts of being uninsured and uninsured adults’ perspectives on potentially gaining Medicaid coverage based on focus groups conducted with uninsured adults who would be newly eligible for Medicaid under the expansion.



## METHODOLOGY

The Kaiser Commission on Medicaid and the Uninsured (KCMU) and Lake Research Partners (LRP) conducted focus group discussions with uninsured adults to gain a greater understanding of the impact being uninsured has on their lives and perspectives on how their lives might change if they became eligible for Medicaid. A total of 61 individuals participated in 8 focus groups held in Las Vegas, NV; Houston, TX; Tampa, FL; and Cincinnati, OH between August 28 and September 6, 2012.

The four states selected for the focus groups – Florida, Nevada, Ohio, and Texas– currently have very limited Medicaid eligibility for parents and do not extend Medicaid coverage to non-disabled childless adults, regardless of their income. They also have high numbers of uninsured adults with incomes below the Medicaid expansion limit.<sup>1</sup> Two focus groups were held in each city and participants in each group represented a mix of gender, age, race, income, education, employment status, history of medical debt and chronic illnesses. One of the two focus groups in Houston was conducted in Spanish. Participants in all groups were uninsured and had incomes below 138% FPL. The focus groups were conducted using a structured guide that addressed their employment and financial situation, health care needs, impacts of being uninsured, and perspectives on obtaining health coverage and the ACA Medicaid expansion.

<sup>1</sup> Statehealthfacts.org, “Health Insurance Coverage of the Nonelderly (0-64) with Incomes up to 139% Federal Poverty Level (FPL), states (2010-2011),” <http://www.statehealthfacts.org/comparetable.jsp?typ=1&ind=849&cat=3&sub=177>

## FINDINGS

### *Who Are Low-Income Uninsured Adults?*

**Uninsured adults who participated in the focus groups are a diverse group, ranging from young adults just entering the job market to retirees.** Participants vary in race and ethnicity as well as in family and living situations. They include single individuals living on their own or with roommates, married individuals with and without children, and individuals living with extended family. Some are caring for family members with special health care needs. For example, Vincent, in Las Vegas, recently moved back to the area to help care for his mother, a stroke survivor, and his stepfather, who had stomach cancer, and Lisa, in Houston, is raising her nephew, who has special needs, in addition to her two children. Participants also are in varied stages of life, with some just getting started on their careers and others having retired after many years in the workforce. Moreover, some have struggled financially for many years, while others are newly facing financial struggles as a result of the recent recession.

**Participants are eager to work and frustrated with the challenging job market.** Most participants are employed, but tend to be in low-wage jobs or positions, so they still have difficulty covering their expenses. Some cobble together multiple part-time jobs to pay their bills. While they are grateful for their jobs, many are looking for better paying, more stable jobs, but finding limited options available. Other participants are unemployed—some have recently lost jobs while others have been out of work for longer periods of time. Most of those who received unemployment insurance have exhausted these benefits. All participants describe the job market as extremely competitive and challenging. They say that there are hundreds of applicants for each open position and that it is rare to get calls back for interviews after submitting a resume or application. Some also feel they are at a disadvantage in the job market because of their age. Several participants have gone back to school or entered training programs to expand their skills and improve their job prospects, and a few are hoping to start up their own small businesses. For example, Denise, in Las Vegas, is in the process of obtaining her cosmetology license and Christine, in Cincinnati, is completing nursing school. Those who have gone back to school say it is difficult balance the demands of school while still working to pay their bills.

**Participants are struggling to make ends meet and cover their basic expenses.** Even those who are working say they are living paycheck to paycheck and juggling bills each month. Paying bills is even more difficult for individuals without a stable job, who rely on stringing together side jobs to pay for basic necessities. A number of participants described winnowing down their expenses to just the essentials like food and transportation, and some have made changes to reduce expenses, such as moving in with family members or roommates and selling items. Nearly all participants lack any savings to fall back on, and, as such, feel

**“It just seems like you put in...a bunch of applications and a bunch of resumes and you’re still not getting calls back...”**

Eric, Las Vegas

**“...after my mom had a stroke, I took off work to try and rehab her. She was 63, she didn’t have...insurance, so it was all on us, all of her rehab and everything... that kind of just really set me back and then trying to find work after that...places are like—well you’ve been out of work so long we can’t hire you....”**

Vincent, Las Vegas

**“...that’s another reason that I can’t get a job, because of my experience and of my age....because I’m in that experience, no one wants to hire me. They want somebody right out of school for ten bucks an hour.”**

Valerie, Tampa

**“Unfortunately, since I’ve been having difficulty paying for my rent, I’m being evicted next Wednesday.”**

Rita, Cincinnati

**“Actually, I have zero savings and yes, that worries me a lot because you know anything can happen, anything.”**

Kelly, Las Vegas

**“If it wasn’t for my friends...and going to the churches and...food banks, I wouldn’t have been able to eat.”**

Cynthia, Tampa

very insecure—many believe they are one accident or unexpected expense away from disaster. A few have already lost cars and their homes due to missed payments. Some borrow from family and friends or rely on churches or food pantries for help. In addition, about half of participants are receiving assistance from the Supplemental Nutrition Assistance Program (SNAP, formerly food stamps). While they are grateful for help, many feel guilty about relying on assistance. They want to be independent and to make their own way without help but continue to have difficulty getting ahead, despite trying to find more work and limiting their expenses. Even with these challenges, many participants are optimistic about the future and hopeful that life will become easier and that they will be able to secure a good-paying job.

### ***Health and Access to Health Coverage***

**Many participants have physical and mental health conditions.** While some participants are in good health without any known health care problems, many others have physical and mental health conditions, which, in some cases, interfere with their daily lives and ability to work. These include chronic physical conditions such as high blood pressure, diabetes, asthma, high cholesterol, and arthritis as well as ongoing mental health conditions such as depression, anxiety, and bipolar disorder. Some participants also have experienced significant health problems, like a heart attack, brain aneurysm, and cancer.

**Participants want health insurance but do not have any affordable options.** All participants wish they had health insurance to be able to access needed health care and to provide financial protection from medical bills and emergencies. However, they have been unable to find any affordable options. Some lost employer-sponsored coverage when they lost their jobs. The few that were offered COBRA in these cases say it was unaffordable. Among those employed, many work in low-wage jobs or part-time positions that do not offer health insurance benefits. In the few cases in which employer coverage is offered, participants say their share of the premium cost is unaffordable given their low incomes. Some participants have searched for private coverage on the individual market but found it difficult to sort out information on plans and too expensive. Several participants have tried to apply for Medicaid but were denied. Others have not attempted to apply because they were not aware of the program or did not believe they would be eligible. Given these experiences, many participants have given up looking for affordable health insurance and most view a better job as the only way they will be able to obtain health coverage

**“...After I had a heart attack eight years ago with no insurance, I checked around and it was like \$600-\$700 a month for insurance.”**

Cindy, Las Vegas

**“When I lost my job and they told me how much COBRA was...that [amount] was like almost like a whole unemployment check...”**

Shirley, Cincinnati

**“And Medicaid, you can’t get on unless you have kids.”**

Maya, Tampa

### ***Being Uninsured***

**Being uninsured contributes to significant stress, worry, and anxiety in participants’ lives.** They use words like “scary” and “horrible” to describe what it feels like to be uninsured (Figure 6, next page). Others describe it as a constant pressure, a weight on their shoulders, and a “dangerous” way to live. Many participants are anxious about their overall health because they have not been able to see a doctor. They worry about undiagnosed symptoms and untreated conditions and family histories of conditions like diabetes and cancer. They wish they could get care and screenings to prevent any health

problems from getting worse and to catch any developing problems early. They also have significant anxiety about unexpected illnesses or accidents, particularly the large bills that would be associated with an emergency room or hospital visit.



**Many participants are going without needed care and prescription drugs, including preventive care and screenings.** Because they lack health insurance, many cannot afford to pay for their prescriptions or to see a doctor regularly. Several participants described stretching out their medications by skipping doses or taking smaller than recommended doses to make them last longer. Few can afford to see a specialist. Almost all participants say they are going without regular preventive care and screenings, including dental check-ups. Several noted that they only see a dentist when they can no longer endure ongoing pain and typically the visit results in an extraction. Some also are forgoing care for chronic conditions or follow-up treatments their doctors ordered after surgery. For example, Christine from Cincinnati has multiple sclerosis but cannot afford the recommended regular visits with her neurologist, spinal taps, or MRI. Similarly, Martha, in Houston, was advised by her doctor to obtain an MRI of her thyroid to screen for cancer, but has been unable to obtain one. Mental health needs, in particular, are going untreated. Most cannot afford to see a counselor or psychiatrist or to fill prescriptions for depression and anxiety.

**“I should be taking anxiety pills and I don’t because I’d have to buy them and they’re like \$120... so I do without them.”**

Steven, Cincinnati

**“I’ve been pretty much saving, using less of my asthma medication, only as really needed when I feel like it’s gonna come....I’m supposed to take a treatment like once before I go to bed....but I can’t because...I got to worry about when it runs out...”**

Rafael, Tampa

**“Last week I had to go for some [tests] and I didn’t go because I didn’t have the money.”**

Maria, Houston

**Participants put off getting care for as long as possible and have limited options when they finally seek care.** Participants try to avoid seeking care because they cannot afford the costs. Many say that they try to take care of themselves, for example, through diet and exercise, by taking vitamins, and by avoiding certain activities. Some also utilize home remedies and over-the-counter medications. However, many have health needs requiring professional care, which continue to go unmet. Participants typically wait until they are in extreme pain or discomfort before seeking care. They note that affordable options for care, such as clinics, are limited and often have long waits. Further, they try to avoid going to the emergency room because they fear the resulting large medical bills that they will not be able to pay. Some obtain medications through pharmaceutical company and store discount programs, but say it is challenging to consistently get medications through these sources. Few participants have a regular doctor; those who do have infrequent visits, only when they have the cash in hand to pay for the visit. Finally, very few of those with chronic health conditions receive any kind of help from a health care professional to coordinate their care. Rather, they are in charge of their own care, which tends to be episodic and based on when they can afford it. This infrequent care and inability to monitor conditions makes participants feel like “ticking bombs” heading toward a crisis they cannot seem to avoid.

**“\$60 may not be a lot of money to somebody. That’s probably pretty cheap for a doctor’s visit. But, for me, \$60 dollars is \$60 dollars, plus my medication, and for five or ten minutes of his time. I only can go to the doctor when I’m extremely, extremely sick and I just can’t stand the pain anymore.”**

Lori, Houston

**“I can’t afford to go to a personal physician, but I would go to a free clinic or go to the emergency room.... There’s one free clinic, but they stay so packed, you have to make an appointment...like a month or two months ahead of time. You can try to walk in, but they tell you don’t come after a certain time because they couldn’t give everybody care.”**

Maya, Tampa

**“A lot of doctors won’t accept you if you don’t have insurance you know.....So it’s like you almost have...to go through the emergency room....“**

Christine, Cincinnati

**Going without care causes physical and emotional pain for many participants and, in some cases, has broader negative impacts on their ability to work and their daily lives.** Several participants described suffering from significant pain as a result of going without care and prescription drugs. In particular, many say they have ongoing dental pain and cope by eating on one side of their mouth and taking aspirin. Moreover, some of those with mental health conditions say they have experienced unstable periods—even to the point of suicidal thoughts—because they cannot afford to see a counselor or a psychiatrist. Going without needed care also makes it difficult for participants to fully live their lives. Some described a cyclical challenge of their health problems interfering with their ability to work, but their lack of employment leading to their lack of health coverage and ability to get the care they need to be healthy enough to work. Some also say their health problems interfere with their daily lives and relationships and a few commented that being uninsured affects their confidence and self-worth. They feel that, as uninsured patients, they do not get treated as well as they did when they were insured.

“I know for myself, it’s like there’s days that I...can’t get out of bed, because I’m not taking my medication and I can’t, I just can’t get up.”

Kelly, Las Vegas

“...it just makes me cry, when I’m sitting on the side of the bed at 3:00 in the morning...[the prescription] says take two every six hours for pain, but I don’t have enough...I take one instead. It subsides the pain a little but, yet I’m in pain—severe pain. I’m crying and hurting, but I’m going to make it stretch until the next time.”

Roosevelt, Houston

“Now I’m using a cane...I can barely walk, so getting a job [is] really limited. So, I also applied for social security disability to hopefully get the medical coverage to get my knees fixed so I can work again....”

Cindy, Las Vegas

**Many participants have large medical debt as a result of emergency room and inpatient hospital visits while they have been uninsured.** In some cases, the debt is into the tens of thousands of dollars. Many have tried to negotiate payment amounts with the hospitals, but a number have given up on being able to pay this debt down since they have nothing left in their monthly budgets after paying their basic expenses. As a result, most of these bills have been sent to collection agencies and participants note that they often receive calls from collection agencies and that their credit is ruined.

### **Thoughts on Obtaining Health Coverage**

Participants say they would feel “relief,” “security,” and “peace of mind,” if they obtained health insurance (Figure 7). They say obtaining coverage would remove a significant burden and anxiety from their lives. They would no longer have to worry about what may be wrong with them and could get the care and screenings they need. They also would no longer worry about the financial consequences of an unexpected accident or illness.

Figure 7

### **What it Would Feel Like to Obtain Health Coverage**



Note: The size of the words are representative of the frequency with which focus group participants used the words to describe their feelings.

**Participants say they would seek preventive care as well as care for ongoing conditions if they obtained coverage.** Most say they would get a check-up and establish a relationship with a primary care doctor if they obtained health coverage; many also would like to receive dental care. Many want the peace of mind of knowing they are healthy or at least to know what is wrong with them if they have a problem. Many miss having their own doctor, and establishing a doctor-patient relationship is a priority. Those with ongoing physical and mental health needs say they would finally be able to get the care they need. Many say that if they had health coverage, they would see a primary care doctor and specialists on a regular basis, take their prescribed medications, and have their recommended tests and blood work done. Those with mental health needs also would like to seek counseling and medications. They feel they would no longer need to rely on the emergency room for care.

**“I would want it because of the prevention factor...then I would definitely go and get my mammogram, my Pap smear, and exam.”**

Valerie, Tampa

**“I have diabetes on one side of my family and cancer on the other side of my family, and so I would really...feel comfortable being able to go in and say—I’m okay, right?”**

Eric, Las Vegas

**“[I would] definitely [get care for] my mental health because I know I need help in forgetting what has happened to me.... I used to feel real well when I used to go see my psychiatrist to talk about the situation, the abuse, the neglect and...other stuff that happened to me.”**

Rafael, Tampa

**“...it would be nice to be able to ...keep track of what’s going on right now...and to know...that I can actually get my medicine....I don’t have to...go without it.”**

Gary, Cincinnati

### ***Views on the ACA Medicaid Expansion***

After sharing their experiences being uninsured and thoughts on gaining coverage, participants were provided information on the ACA’s Medicaid expansion and informed that they all are at an income level that would make them eligible for the expansion. They also were informed that states will be deciding whether to implement the expansion and told how this decision will impact the availability of coverage for people at different incomes as well as the reasons some states are considering not expanding Medicaid. They were then asked to share their views on the ACA and the Medicaid expansion, as summarized below.

**Most are unaware about changes occurring in health care due to the ACA other than the requirement to obtain health coverage.** All participants have heard of “Obamacare” but few know what the law means for them. Many have heard that they will be required to have health insurance in the future. Some have heard that insurance companies will not be able to turn them down because of pre-existing conditions. A few young women had heard that birth control must now be covered by health plans. Some have heard their governors speak negatively about Obamacare and about “turning down money.” However, beyond these topics, participants’ understanding of health reform is very limited, and they are unaware that the law will provide new health coverage options.

**Nearly all participants said they would enroll in Medicaid if they became eligible.** Participants would be eager to enroll in a new affordable coverage option if it became available to them, including Medicaid. Those with previous experience with Medicaid—for themselves or their children—have positive perceptions of the program and appreciate its broad coverage of services and medications, although some said the enrollment process is complicated and that it can be difficult to obtain certain specialty care. Some were skeptical any coverage offered to them would be affordable—they wanted details about what would be covered and how much it would cost. Similarly, some were skeptical that they could ever qualify for Medicaid since they have never been eligible in their adult lives. Some participants expressed an internal conflict about obtaining Medicaid coverage—although they wish they were in better circumstances and had an employer who offered coverage, they would be grateful for the Medicaid coverage and they feel as though they have earned it as hardworking, taxpayers.

**Participants support their state expanding Medicaid.** After hearing that states will decide whether or not to expand their Medicaid program, nearly all participants say their state should expand. Many see the expansion as their only opportunity to obtain health coverage. They also suggest broader economic reasons to expand Medicaid, such as more productive and healthier citizens and lower health care costs. Some participants did express concerns about where the money would come from for the expansion—they are worried they will face increased costs somewhere else in their lives or some sort of “catch.” They also identify with state budget concerns and recognize that states have competing priorities and limited resources. However, most feel the urgent needs of uninsured individuals outweigh these concerns.

**“I would think...that you would want to help more of your citizens. If the state opts out of it, that takes away that right for some of the actual citizens to have [health coverage]. Why would you opt out of something like that?”**  
Maya, Tampa

**“How could you not want the best for your state and everybody in it—not just the rich, but the poor and just the middle...that are still struggling? They may have jobs, they may have...an income, but they’re still struggling you know.”**  
Christine, Cincinnati

**“Because for a lot of people who don’t have insurance and they need that insurance, they have no other way to get it. If this can help them get it, then I think they should definitely do that,”**  
Eric, Las Vegas

**“I think he should take the funding because in the bigger scheme of things, if he takes the funding now that helps people. In the long-term, there’ll be less health issues, and I think medical costs, in general, for the state will go down.”**  
Shirley, Houston

**Participants want multiple options to enroll in Medicaid and are particularly interested in online enrollment.** When told that the Medicaid enrollment process will be simplified in the future and that states will have an online enrollment option, most participants find this to be appealing. Many say they want to avoid the long waits and inconvenience of going to social services offices to apply. The majority has access to the internet at home or at the library would prefer to enroll online. However, some participants still want to meet with someone face-to-face to ask questions and ensure they are enrolling properly. Some also would like to have phone or online chat assistance available.

**Participants want their state to widely advertise if they decide to expand Medicaid.** Health coverage is important to these individuals and they want opportunities to learn if new affordable health coverage options are available to them. The top preference is for TV advertising explaining that rules have changed and they may now be eligible for Medicaid. They also want radio ads, banner ads on Facebook, and to hear about this through other government programs like SNAP/food stamps. They also say doctors' offices, clinics, libraries, and unemployment offices are other good places to get the word out.

## CONCLUSION

This study highlights the voice of individuals who will be directly impacted by state decisions to expand their Medicaid programs. In sum, these focus groups reveal that uninsured adults who would benefit from the expansion are a diverse group facing challenging times. Although most are working, meeting their basic expenses remains a struggle. Moreover, many have unmet physical and mental health care needs and face significant health and financial consequences as a result of being uninsured, which sometimes impact their ability to work and their daily lives and relationships.

These adults say that gaining coverage would provide them a huge sense of relief and feeling of security as well as access to needed care, which they believe would improve the management of their ongoing health conditions, enable them to obtain preventive care and screenings, and reduce use of the emergency room. They also expressed interest in establishing a relationship with a primary care provider to help manage and coordinate their care.

These adults have limited knowledge about the coverage expansions included in the ACA, including the Medicaid expansion. Individuals want coverage and most say they would enroll in Medicaid if they were eligible. After learning about the Medicaid expansion, they feel it provides an important opportunity for their state to help those most in need and largely support their states moving forward with the expansion, although some recognize that states need to balance competing priorities amid limited resources. Most say they would feel confused and disappointed if their state does not implement the expansion, particularly since those with slightly higher incomes would still receive assistance through the new Exchanges. Many are hard-working individuals who have struggled without coverage for a long time, and they feel if their state does not implement the expansion, it will be a significant missed opportunity to improve their lives and the lives of many others in similar situations.

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