Voices of the Uninsured

Behind and Beyond the Numbers

Arkansas Community Organizations
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“Everybody needs health care; it should not be just for the rich or those that can afford it, [but for] everybody.”

This sentiment was voiced by a middle-aged, uninsured woman interviewed for a class project of the Fay W. Boozman College of Public Health, University of Arkansas for Medical Sciences in March/April 2013. In this service learning course on Racial Health Disparities, 17 students and 2 instructors partnered with a community based organization to learn how being uninsured affects peoples’ lives. This report summarizes the main themes that emerged from the in-depth, qualitative interviews they conducted with 34 uninsured Arkansans and presents highlights from 11 individuals’ stories about their experiences and feelings about being uninsured. Relayed herein, are examples of how one problem often cascades into another and another with the onset of sickness or disease. Health issues worsen with delays in seeking treatment, and for those who do end up finally seeking care, the emergency department is the place they most often go. Even then, medical debt is common and paychecks and tax refunds may be garnished to pay it off. Most of those interviewed knew very little about the Affordable Care Act other than what they had heard on the news.
The project described in this report was carried out in partnership with Neil Sealy of Arkansas Community Organizations and with all of the individuals who graciously shared their stories with us so that others might have a better understanding of some of the day to day experiences of the uninsured. We want to acknowledge their contribution here and express our gratitude for the time they spent talking with us.

This report was prepared by Creshelle Nash and Kate Stewart and their students, listed below, as part of a service learning project for their health disparities course at the UAMS Fay W. Boozman College of Public Health, University of Arkansas for Medical Sciences in March and April, 2013.

**Students:**

Katy Allison  
Allison Anthony  
Desiree BurroughsRay  
Renee Brink  
Jheanelle Dawkinsrichards  
Kaitlin Fitzpatrick  
Rebecca Groff  
Brad Houston  
Sherian Kwanisai  
Nicole Maddox  
MacKenzie Reynolds  
Marissa Roberts  
Rebecca Scissors  
Alice Story  
Ewelina Sulek  
Danielle Tchoungang  
Sharoda Williams
“Everybody needs health care; it should not be just for the rich or those that can afford it, [but for] everybody.”

-statement from middle-aged African American woman interviewed
Statistics show that being uninsured is bad for your health. Compared with insured individuals, adults without health insurance are more likely to delay seeking care. Such delays lead to a greater risk of advanced disease with worse treatment outcomes and higher cost to both the patient and the healthcare system as a whole. Studies of Medicaid expansions in other states have shown that these interventions save lives and lead to better population health. But lost behind these numbers are the voices of those most affected by policies dictating who will have access to affordable care.

In Arkansas, many of these voices are those that bear a disproportionate share of the burden of ill health and premature death that puts our state among the least healthy in the nation. Arkansas has some of the highest rates in the country for infant mortality, cancer, diabetes, hypertension, heart disease, stroke, and HIV. While healthcare and public health professionals work hard to address these and many other health issues facing Arkansans, the impact of such efforts is limited when so many lack affordable health care.

The Affordable Care Act (ACA) presents a unique opportunity to significantly invest in and improve the health of all Arkansans while addressing health care access, quality, and long term health care costs. To date, many of the changes in the health care system resulting from the ACA have not benefited those most in need, the working poor. The intense healthcare debate in the state and the nation has revolved largely around political, theoretical, and philosophical issues, but there is a key stakeholder missing at policy meetings and decision points. This stakeholder is critical to creating a health care system that cares for all people. The voice of this missing stakeholder is that of the uninsured.

METHODS

This project was done by students in a Service Learning Course entitled “Racial and Ethnic Health Disparities: Theory, Experience and Elimination.” The goal of the course is to examine health and health care disparities, the causes of disparities, and policy and programmatic strategies for reducing disparities. In addition to class sessions, the students participated in community service learning activities with a community based organization around the Affordable Care Act and the expansion of health insurance in Arkansas.

The project entitled “Health Care Coverage and the Affordable Care Act” was a qualitative interview project that had goals of learning: (1) how individuals feel about their health care access; (2) how health insurance affects their lives; and (3) how the community understands the health care law, the Medicaid expansion, and the health insurance exchange. The project was reviewed by UAMS’ IRB and was deemed not to be human subjects research requiring IRB oversight.

The project took place between February and April of 2013. Potential participants were recruited from Arkansas Community Organizations (ACO) while they were utilizing the organization’s project to educate the community about the Earned Income Tax Credit (EITC) and to help people receive the EITC without paying tax preparation fees. If they agreed to be interviewed, they were contacted by an interview coordinator and matched with a student for an individual interview at ACO. Additionally, some students recruited uninsured adults in their local communities for interviews.

All individuals interviewed were first informed of the purpose and scope of the interview and given a chance to have all questions answered before being asked to sign a written consent indicating their willingness to participate. Those willing to have their individual stories shared were also asked to indicate whether or not they were willing to share their name and/or their photograph with their personal narrative. After this formal consent process, each participant was asked a series of questions from an interview guide that broadly included questions about health care needs and their current level of health care access, if and how lack of health care access affects their lives and finally knowledge and perceptions of the Affordable Care Act. If the respondent agreed, the interview was recorded for accuracy. After the interview, each participant was offered a $10 Walmart gift card in appreciation for their time and contribution.
Participants

We interviewed 34 Arkansas residents who were more than 18 years old and who did not have health insurance. The demographics of the interviewees are found in Table 1. Almost two-thirds (63%) were in the 25-44 age group. Both men and women were interviewed (41% and 59%, respectively). A little over half were African American. We did not interview any persons of Hispanic ethnicity. The population was primarily low income with an average reported income of almost $15,000. The average number in the household was 2. There was a wide range with regard to parental status ranging from no children up to six. Significantly, 30% of the participants had coverage through ARkids for their children though they themselves were uninsured. Eighty-five percent of the participants were working full or multiple part-time jobs.

Table 1: Demographics of Sample Population

<table>
<thead>
<tr>
<th>N=34</th>
<th>N(%)</th>
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<tbody>
<tr>
<td>Age</td>
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<tr>
<td>18-24</td>
<td>2 (6%)</td>
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<tr>
<td>Male</td>
<td>14 (41%)</td>
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<tr>
<td>Female</td>
<td>20 (50%)</td>
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<tr>
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<td>18 (53%)</td>
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<tr>
<td>White</td>
<td>15 (44%)</td>
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<tr>
<td>Average Income per year</td>
<td>$14,646 (Range-0-$100,000)</td>
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<tr>
<td>Average Number in Household</td>
<td>2 (Range-1-16)</td>
</tr>
<tr>
<td>Average Number of Children</td>
<td>1 (Range-0-4)</td>
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<tr>
<td>Adults with Children Coverage by AR Kids</td>
<td>10</td>
</tr>
<tr>
<td>Employed</td>
<td>29 (85%)</td>
</tr>
</tbody>
</table>

*one participant did not answer

In keeping with the goal of magnifying the voices of the uninsured in the context of impersonal statistics and national studies, this project used qualitative methods to explore the real life experiences of uninsured individuals living in Arkansas. These methods allow for a more comprehensive picture of the realities that lie behind and beyond the numbers.
FINDINGS: THE THEMES

All interviews were individually reviewed and analyzed in a group session with all the students and instructors and subsequently, with the community based partner. Multiple recurrent themes were identified through a group process and discussion. Finally, interviews were then reexamined for illustrative quotes and stories. The following is a summary of the main themes that emerged in common across the 34 interviews.

1. Cascade of Problems

Many respondents described how quickly one problem led to another, making it difficult to stay healthy and to keep on top of their financial and family responsibilities. Working in low income jobs without paid sick leave or health insurance and living from paycheck to paycheck creates difficult choices when they become sick.

Emerald Garrett’s story illustrates this dilemma:
Ms. Garrett can very rarely afford the medication that is prescribed. She is often forced to go without paying utility bills to make ends meet when she gets sick. In early 2012, Ms. Garrett was having severe back pain. After suffering for over a month, Ms. Garrett had to leave her shift one night to go to the emergency room. After expensive testing, it was determined that she had pulled a lower back muscle. Four medications were prescribed, totaling $275. This was over a week’s worth of wages for Ms. Garrett, and something that she could not afford. As a result of not being able to afford the medication, Ms. Garrett was unable to treat her back injury and ended up losing her job. From the emergency room visit to treat her back injury over a year ago, Ms. Garrett still has over $1,000 in medical debt. She is unable to afford the bills, so for the past two years she has not received a state refund with her tax return as this money is held to pay off that debt. Ms. Garrett said that her state refund should be around $300, which would be enough to get her ahead on her utility bills. By not receiving this refund, Ms. Garrett is unable to get ahead and remains in the same poverty cycle year after year.

2. Barriers to needed care

Most (85%) of the respondents we talked to are working though a number were unable to get full-time work and none were obtaining health insurance through their jobs. While many worked in situations where insurance was not an option, those whose employers did offer insurance were either not eligible or could not afford the cost. Almost none of those interviewed had paid sick leave and could not afford to take off when they were sick.
As one respondent, who has no sick leave explained: “I’m 53 years old and if I get hurt I won’t heal as soon as I used to. That’s why I know it’s (health insurance) important. I got to work when I’m sick, because I can’t afford to stay home.”

3. Health Issues

Health issues reported included chronic health problems such as hypertension, diabetes, asthma, and chronic lung disease; acute conditions such as influenza and pneumonia; injuries; reproductive health problems; and in a few cases, cancer. The most consistent complaint across all respondents, however, was a plethora of oral health problems resulting from a lack of dental care.

As one respondent said, “money keeps me from getting the care I need. Bills come before medicine and dental work, pull your own teeth out I guess…It’s just a sad thing. If you sick, you just sick.”

4. Medical debt and hard choices

The financial impact of being uninsured was also a common theme. Most of those interviewed avoid seeking care until their illness or injury is critical since for many, the emergency room is the only place they are able to receive care. The high cost of medications was also a persistent issue which is dealt with by either doing without, self-medicating, taking others’ medications, and/or adjusting medications to make them last longer. Those having to rely on emergency care found it extremely expensive and less than ideal and likely to force them into significant medical debt. Many spoke of having to choose between healthcare and medications on the one hand, and food, rent, lights, and heat on the other.

One respondent described having incurred medical debt at three major hospitals in town, totaling close to $20,000. “I have debt at every hospital. I’m being sued by [...] hospital for $15,000. I owe [another hospital] $3,000. I went in to [a third hospital] for an anxiety attack because I couldn’t catch my breath, and they charged me $4,000. You gonna charge me $4,000? That’s going to make me lose my breath again.”

Comments from other respondents illustrate similar struggles.

“If I have to have that medicine just to live, that’s eighty something dollars for one and
that’s missing out on my gas, water, light bill, one of them. So one of my bills has to be skipped. Or I’ll have to borrow money from people and I hate having to borrow money from anybody. I could work more hours but there’s no sense in that because I’ll have to pay for daycare for my son. The way I work, I take him to school and pick him up and that’s what I can afford. Plenty of medical debt and the hospital that sued me is the hospital that’s garnishing the $10 from my check. My job even told them I’m not working that many hours so they can’t get more than that. That $10 can be going in my gas tank. I deal with medical bills that best I can. Just like I said, if I can afford to get it, I get it. If not, I don’t. That’s how you deal with it, keep praying and going to church.”

“I called for an appointment w/ my PCP when I told the receptionist that I no longer had insurance she stated that I would have to pay $150 – I knew that I could not pay that and googled home remedies to my assumed problem.”

“There has been a time that I needed healthcare but could not get it. I have gall bladder disease and the doctor suggested that I get corrective surgery- but I cannot afford it so I don’t think about it.”

“I got one [bill] that says ‘you are delinquent’. No, I’m not delinquent! They send you a bill right after you get out of the hospital, about a week or so after you get out of the hospital, half the time you’re on medicine, and I’m by myself, I’m single, so, I’m taking care of [name]. Nobody else is writing my bills out for me, I’m depending on my own income. They don’t care.”

5. Insurance would be valued

Almost all respondents said they would value having health insurance and talked about how it would give them peace of mind, helping them to worry less about how they will manage when they get sick. Interestingly, when asked what they would do if they had insurance, most talked about how they would seek preventive care and annual check-ups. While several talked about how they would be less likely to delay treatment, many were quick to say they would “only go if I need it.” Additionally, a common sentiment expressed was that healthcare is a right to which all should have access.

As Greg Deckelman said, “There is no more important issue than someone’s own health. The state should view it’s vital to have healthy citizens to drive a good economy and community health. A healthy population will be beneficial for everyone. This is an important issue.”

“I CALLED FOR AN APPOINTMENT W/ MY PCP WHEN I TOLD THE RECEPTIONIST THAT I NO LONGER HAD INSURANCE SHE STATED THAT I WOULD HAVE TO PAY $150...”
6) Knowledge of the Affordable Care Act

Most did not recognize the name of the Affordable Care Act but rather knew of it as “ObamaCare”. Many had heard of the mandate to purchase insurance and several were concerned about having to pay a penalty if they couldn’t afford to do so. Few knew much more than this.

“The only thing I heard is it depends on your money. You make half a penny more, you can’t get Medicaid or they’ll let you get in summer while you’re not working. Then you go back to work, they cut it off so what’s the use? That’s a bunch of crap to me; if you give it to me, give it me, don’t give it to me then take it from me. So maybe with this new law Obama got going on it’ll work out better, I just don’t know, time will tell. But it will surely help a lot of people out!

“The tax thing shocks me, the tax penalty. But it’s an action step that I think is needed because if that’s what will force people to get health insurance, so that they have it and don’t accrue so much debt, fantastic, but it’s just a Band-Aid. It’s not a permanent fix because, obviously, the healthcare problem in America is much larger than that, and there needs to be more taxation on drug companies, and doctors, and facilities…”

“This is in place to help those that cannot afford medical insurance based upon their need”

“I don’t really know a whole lot of about it. I know it’s supposed to make it easier for people to get insurance even with preexisting conditions, which was one of the problems I had.”

“I DON’T REALLY KNOW A WHOLE LOT OF ABOUT IT. I KNOW IT’S SUPPOSED TO MAKE IT EASIER FOR PEOPLE TO GET INSURANCE EVEN WITH PREEXISTING CONDITIONS...”
FINDINGS: THE STORIES

The discussions with people about their health, health care and concerns were very revealing and bring a real life perspective to the high level policy issues of the state and the nation. The students were in a unique position to personally see and have their assumptions challenged about the impact that lack of health insurance and access to health care has on the individual and the community. While the themes present an overall view, which echoes findings from larger surveys that have less depth, the following individual stories illustrate the complexity and real world issues that people face daily as represented in all of the stories we heard.

‘WHAT IS TRUER THAN TRUTH?’
THE ANSWER IS: ‘THE STORY’.
Jewish Proverb
Dawn Spears works part time at a fast food restaurant. She is currently uninsured because her employer doesn’t offer health insurance for its part time employees and she cannot afford to purchase it on her own. She also has no paid sick leave so if she gets sick the stress of deciding whether to go to work or seek treatment is a heavy burden.

She states she currently has terrible chronic back pain, which at this current time she is worried may require surgery. Ms. Spears is worried that if she seeks care the physician would recommend treatment that would not allow her to work for a significant amount of time. She can’t afford to miss any work and not receive an income.

When she needs health care she can go to River City Ministries for affordable dental care, but the long waiting times pose a significant barrier. She at one time went to a free health clinic for her chronic back pain, and the clinic advised her to go to UAMS. She states UAMS discharged her from the Emergency Room (ER) with a prescription to help with the pain in her back. She could not afford the medication, and a few weeks later she received an ER bill she could not afford to pay. She states she will only seek care now if it’s a life or death situation. She does not have a primary care provider (PCP) at this time due to lack of health insurance and can’t afford the medical bills. Ms. Spears currently reports her health status as poor. She has severe chronic back problems. She describes her back pain as severe and the pain limits her in daily activities. The client reports trying to receive care from the health department, but she states the health department offers only health screenings such as pap smears. Shehas difficulties with her vision, and she knows she needs to have an eye exam. She has never been screened for diabetes or hypertension. She has several dental problems that have gone untreated due to an inability to afford a dentist.

Ms. Spears does not seek care because of the fear of possible expensive medical bills. She states, “What is the purpose of seeking treatment if I can’t afford it?” She will only go to the doctor if she thinks it is a life or death situation. The money she possesses goes towards paying the bills at her house. An interesting side note she reports during the interview is that 3 years ago she was covered under TENNCARE, which is Tennessee’s Medicaid program, but after moving to Little Rock she can no longer be covered under Arkansas’ Medicaid program due to her annual income of $17,000 with 2 dependents. She has a history of medical debt due to seeking care for her back problems. However, Ms. Spears at this time does not have an outstanding medical debt because the state took her income tax return to pay for her past medical bills.

If Ms. Spears were able to obtain health insurance, she would no longer have to worry about her health. She would know if she currently has chronic health problems, such as diabetes or hypertension. Obtaining health insurance would bring a huge relief of stress in her life. She would be able to go to the doctor’s office. If she had health insurance she would go to her PCP on a regular basis. In addition, she would seek an eye exam from the optometrist.

She has not heard anything about the current debate on the Medicaid expansion. She states, “I think it should be expanded... for the ones who can’t have insurance...why should people have to suffer just because we can’t afford it...Medicaid is not like public assistance, rather this is something different and important that people need.” She thinks the government should pass the Medicaid expansion. She states more health coverage would in return save more lives in our state. She states the expansion would prevent people from waiting to the last minute to seek medical care. She states, “Everyone acts like we are one big happy family living in the USA, when really there are two different communities, the big fish vs. the little fish.”

Ms. Spears would like her local representatives to know, “I am in a lot of pain and I wish they would give an option to help me, just to help me, because I need to go to the doctor, and if I have to pay a little for it that’s okay with me as long as I can afford it.” She states, “Health insurance is a necessity just like you need water and food. At least make health insurance affordable where I can pay for it.”
Ms. Garrett is an uninsured single mother who works full time to support her two young boys. Ms. Garrett was inspiring, to say the least. When asked how she felt about not having health insurance, she summed up her entire experience in one word, “devastated”. This word shaped the remainder of her interview, and as she shared more of her experiences, I understood why she felt this way.

Ms. Garrett, like most other uninsured Arkansans, is forced to go without primary care. She can’t afford regular visits to the doctor and has not had any dental care since childhood. As a result, Ms. Garrett battles sickness as long as possible before being forced to go to the emergency room. After going to the emergency room, there still is no guarantee of relief. Without insurance, Ms. Garrett can very rarely afford the medication that is prescribed. She is often forced to go without paying utility bills to make ends meet when she gets sick.

One story that Ms. Garrett revealed demonstrates the real impact that not having health insurance can have. In early 2012, Ms. Garrett was having severe back pain. She was working a minimum wage janitorial job and the physical labor was very tiring. After suffering for over a month, Ms. Garrett had to leave her shift one night to go to the emergency room. After expensive treatment, it was determined that she had pulled a lower back muscle. Four medications were prescribed, totaling $275. This was over a week’s worth of wages for Ms. Garrett, and something that she could not afford. As a result of not being able to afford the medication, Ms. Garrett was unable to treat her back injury and ended up losing her job.

From the emergency room visit to treat her back injury over a year ago, Ms. Garrett still has over $1,000 in medical debt. She is unable to afford the bills, so for the past two years she has not received a state refund with her tax return as this money is held to pay off that debt. Ms. Garrett said that her state refund should be around $300, which would be enough to get her ahead on her utility bills. By not receiving this refund, Ms. Garrett is unable to get ahead and remains in the same poverty cycle year after year.

The one thing that Ms. Garrett knew about the Affordable Care Act was that the government was going to start mandating health insurance. This was of great concern to her, as there would be no way for her to make ends meet if another bill was added to her monthly expenses. Ms. Garrett supports herself, a 7 year old, and a 2 year old off of an income of $12,000 per year. There is no such thing as a “savings account” in her vocabulary, and paying a monthly insurance fee is out of the question.

In Ms. Garrett’s case, expanding Medicaid would be the only way she can foresee having health insurance in her immediate future. She continually stressed the belief that Medicaid expansion would be a “blessing” for single parents. She expressed that it is difficult to have healthy children, even when they are covered by ARKids, without having healthy parents. Referencing her back injury again, Ms. Garrett spoke about how the quality of care for her children decreased greatly when she was injured. She had trouble getting them ready for school and caring for them. When she lost her job due to the back injury, it became increasingly more difficult when she didn’t have a regular paycheck.
If you are ever craving soul food, Sweet Soul, is sure to please your appetite. Andrea Sanders, owner and operator of Sweet Soul, has six employees in approximately 300 square feet of space in the River Market Food Court. The restaurant is in its third year of operation and despite the need for a more lucrative means; Andrea loves cooking and the benefits of self-employment. When I asked Andrea if she had health insurance, she delightfully responded, “No, I am waiting for this Obamacare.” The optimism in her voice sincerely conveyed hope for accessing health insurance.

After a busy lunch hour on Friday, one of the more crowded days of the week, Andrea agreed to an interview. Andrea is a 29-year-old native Arkansan, married without children, and currently dealing with two health conditions: a recent miscarriage and another woman’s health issue. She is one of four children in a military family. Growing up living the army lifestyle, having health insurance was a given; now it is a luxury. She is currently uninsured and unable to afford a private plan. She has been uninsured since being on her own, approximately three years now. When she had health insurance, nothing went wrong and now everything is an issue. An unfortunate miscarriage in December left her with a $5,000 hospital bill. Andrea was unaware of the pregnancy and now has to deal with both loss and debt—a financial and emotional toll—without supportive services. She added that “a lot of people are struggling and it’s unfair for hospitals to send people into debt.” Some people in the community are unaware of the Affordable Care Act and she thinks both the radio and the community should do a better job with informing people and helping people to get the services they need.

When asked how she felt about not having health insurance, she plainly said, “it sucks.” She does not have access to an employer-based plan even though the city of Little Rock manages the space. The vendors pay rent to the city of Little Rock, which pays the cleaning staff in the Food Court. Members of the cleaning staff are city employees with benefits. City employees have both assurance and insurance to miss work when necessary and to access healthcare, respectively. The city supports only one half of the business operation. Without the vendors, the cleaning staff is not required; yet, this independent-dependent relationship carries monetary significance but no perquisites toward a quality lifestyle. Andrea relies on free health clinics, mainly St. Vincent’s in the east end, to access care when necessary. She avoids the emergency room for fear of accumulating an insurmountable bill. Just last week, she had to undergo emergency surgery on her teeth leaving her with another unexpected expense. She has learned to request at least three months of medication when she does see a doctor because getting a refill requires another doctor’s visit, one that she cannot afford. Andrea believes that health care should be free or paid for by a tax.

In conclusion, Andrea would like lawmakers to know that people like her deserve basic human rights. She wants to add her story to the pool of educated, working class people who work hard every day despite low pay and unequal access to health insurance. She is anticipating the opportunity to access health insurance once the ACA goes into full effect in January 2014. She looks forward to being able to seek preventive care options to support a healthier life. Having health insurance would mean having “security” for this extraordinary chef.
Ms. Sheila Hall does not currently work, but she was trained and employed as a Certified Nursing Assistant (CNA). She would take care of elderly people; but she is not able to do this anymore because of physical and mental ailments. She has no income. Ms. Hall is among Arkansas’ aging population, not yet old enough to be eligible for Medicare. Ms. Hall has two grown daughters, one of whom has been her primary caregiver. Her daughter has a $7.40/hour job and pays for Ms. Hall’s living expenses at a senior residential center. Ms. Hall says that she used to live with her daughter, but that everyone deserves some independence, even the poor.

Ms. Hall worries about her health all the time and because of this, she only gets a few hours of sleep each night, which makes her physical health deteriorate along with her mental health. She cannot afford to go to a primary care physician so she uses Harmony Health Clinic in Little Rock for any and every service they offer from which she could benefit. Although they offer services for her ailments, they are many and it is difficult for her to make all of her appointments for various reasons.

One of the main difficulties for Ms. Hall is her Chronic Obstructive Lung Disease (COPD). She uses a nebulizer that she carries with her because she is scared of what might happen when she cannot breathe. This has caused her to go to the Emergency Department on two separate occasions. Her total of two weeks in the hospital have drowned her in $30,000 of medical debt and without a job, she has no way of paying it back. She talked about how the hospital called and asked her to give up her state income tax return and she said “Sure. The way I see it, nothing from nothing leaves nothing.” With all of this debt, her dream of owning her own home one day is long forgotten.

One of the more worrisome things that Ms. Hall told me about her health was that when she is unable to get the free inhalers from Harmony Health, she uses whatever inhaler or COPD medication friends of hers might give her. Her hope is that other people in her situation are as “lucky” as she is to have friends who can afford to give her some medical help when she is in need.

While medical insurance would give her some of the answers she is desperately seeking, she also has a history of lack of dental care. When I asked her what she does for dental care, she blankly said, “nothing.” She had all of her teeth removed except for three on top and three on bottom. Finding some humor in the situation, she laughed that she eats like a rabbit. After a moment she said she had them removed last year because she clenched them all the time with worry.

When I asked her how it makes her feel to not have health insurance, she said that she feels “terrible” and it is “very important”. She did not know much about the Affordable Care Act (ACA), but she is very resourceful and made sure to tell me that she wanted to research it. What she did know was that the ACA should help those with pre-existing conditions get affordable care and not be denied. This was especially important to her because she had been offered insurance at one point for $159/month, but when she told them she had preexisting conditions, it jumped to $300.

She feels she would really benefit from the Medicaid expansion. Even though it would not relieve all of her worries and medical debt, she feels it would give her peace of mind to know she had a regular doctor she could trust to properly diagnose her ailments and follow her through her entire plan of care. Her final note to legislators was to, “please do what is right. I need coverage and cannot afford it.”
Gregory Deckelman is a self-employed musician who plays with local bands. He is currently without health insurance because he can’t afford it on his income and he receives no paid sick leave due to his self-employment. Obtaining health insurance is very important to Mr. Deckelman. He believes the people in our society are ostracized. He states, “People are made to feel bad that they don’t have health insurance, and then they become a burden to society when things go wrong.” Mr. Deckelman states if he were covered under Medicaid, he would utilize prevention services and annual check-ups at the doctor’s office. Mr. Deckelman seeks medical care depending on the situation. He states, “Depends on what the problem is. The last resort is going to the Emergency Department.” In addition, he has several dental care needs, but he has not sought treatment due to cost. He reports no significant history of needing health care, but he thinks he has several chronic issues, such as hypertension, that have gone untreated due to lack of access to a primary care physician.

The lack of health insurance has affected Mr. Deckelman in a number of ways. If he went to the doctor for high blood pressure issues he would not be able to afford the bill. He would have to pay for his medical care out of pocket. He would have to make a choice as to whether to pay for his medication or pay for his utility bill. He reports a history of medical debt for the treatment of a fractured arm. However, he has not been sued by a hospital collections agency though he did have bad experiences trying to set up a payment plan for medical bills. Medical bills have brought a lot of stress in his life. If he had health insurance it would mean, “The worries about whether you can afford a doctor are swept away. It would mean the ability to catch preventable diseases earlier rather than later.” If he were covered under a health insurance plan Mr. Deckelman would seek medical services such as regular check-ups and be proactive about his health.

Mr. Deckelman knew quite a bit about the ACA. He understands the law well. He does have concerns about the possible financial ramifications in the near future that will come with the new act. Mr. Deckelman has been aware of the Medicaid expansion issues in our local state government. On this issue he questions if the proposed Medicaid expansion will provide enough coverage for the lower income citizens of Arkansas. He believes the amount of people in need of Medicaid expansion is greater than what the government has proposed. He states, “The government’s best interest is to have a healthy workforce.” Mr. Deckelman believes the expansion will benefit the community. He states, “This law will help save lives in the future that would have otherwise been lost. Public health needs to be a priority for a future healthy population. If we create a healthy workforce we will create a healthy country.”

I asked Mr. Deckelman if there were one thing he would like the decision makers to hear from him. He stated, “There is no more important issue than someone’s own health. The state should view it’s vital to have healthy citizens to drive a good economy and community health. A healthy population will be beneficial for everyone. This is an important issue.” In addition, he stated, “The money is out there for legislators to create mechanisms to back the Medicaid expansion. The government needs to reorder their priorities. In 20 years if we have done this program correctly everyone will be better off. Don’t be selfish. Think of the greater good.”
Ms. Burks is not currently working and won’t be able to work because of her health (nerve damage in her foot), although she does not qualify for Social Security Disability Insurance or SSDI. Ms. Burks does not currently have health insurance and therefore, cannot afford the $400-500 monthly premium required to buy coverage on her own. Though among the aging, Ms. Burks is not yet eligible for Medicare. She previously had a job that offered health insurance, but after an extensive illness that lasted over three months she was not able to continue working and lost her coverage. She currently pays all of her medical bills and medication out of pocket. Ms. Burks feels that having health insurance is very important, especially at her age. One of the first things she did when she became a full-time employee was get health insurance. If she qualified for Medicaid, she would use it to cover medicines and primary care visits. She considers those “everyday things that she needs.”

The out of pocket cost of medical care keeps Ms. Burks from getting the care that she needs. In December, she applied for public assistance through DHS but was denied. Ms. Burks currently has high blood pressure, but it is being controlled. She also has an injured leg, and she describes herself as “crippled”. To help her walk she uses a brace or cane. Her pain pills cost $300 a month. She also has to pay for follow-up services and for her blood pressure medication and lab work, which are very expensive. She owes money for these and other health care services, including her previous hospital bills. Medical debt from previous orthopedic care is still with her. Ms. Burks has been proactive in coming to an agreement with the hospital regarding a payment plan that is appropriate for her. She is able to see a primary care provider through a community clinic in Pine Bluff and pays for this care using their sliding scale payment system. Before she goes to see the doctor again she will call to see how much they will charge for her visit. If they need to run lab tests, she won’t be able to have those done because she cannot afford it. She also needs to have a dental cleaning and maybe a few fillings, but can’t afford that either.

Because she does not have health insurance, Ms. Burks is afraid of getting sick. She worries about what medical care she might need as a result and how much that would cost. In general she avoids getting medical care if she can because of the cost. If she had insurance, she would get blood work done, visit the OB/GYN, and have yearly preventive procedures done.

Ms. Burks was familiar with some of the elements of the Affordable Care Act, but noted that because there were so many parts to the Act, she was confused as to what all was in it. Regarding the expansion of Medicaid, Ms. Burks said that she had heard about the discussion in Arkansas, but wasn’t sure what all of the terms mean. In her opinion, the ACA might bring some good because everyone needs health insurance, and it may encourage people to take care of themselves. Health care/insurance is so important to people that they will leave America to get it. She thinks that people will appreciate the expanded coverage, especially regarding preventive care. The ACA could be helpful for establishing a medical home and setting up more hospitals.

She would like decision makers to simplify what the ACA means for individuals, so that they understand and don’t complain. Currently decision makers, she said, talk in complicated and elevated terminology. Breaking the law/changes down into steps would be helpful. She wishes that the ACA was fully enacted now so that she wouldn’t have to pay full price for her medical care. She hopes that the legislation that is left (Medicaid expansion) passes.
This respondent works part time. She used to have Medicaid when she was unemployed, but she said, when she got her job “they took it away. The state claimed I make too much money on my job, which is not much at all in my eyes.” She only works a couple of hours a day and does not know how she is making too much to get Medicaid.

This respondent is a middle-aged woman with chronic medical problems that she has to manage along with child care, bills, and working. Having pre-existing illnesses makes it hard to find affordable insurance. All of this creates many challenges for her. “I’m on two blood pressure medicines, two cholesterol medicines and an aspirin a day. I can’t afford it on the hours I make.” She does not have money to get her medications most of the time. When asked how she deals with this she said “What I do is I just take me a teaspoon of vinegar …….. But the old remedy is the vinegar which helps make your blood pressure go down. Sometimes it do, sometimes it don’t……and say a lot of prayers…..I keep on rolling.”

She has considered many options for her situation that show what she has to balance. “If I have to have that medicine just to live, that’s eighty something dollars for one and that’s missing out on my gas, water, light bill, one of them. So one of my bills have to be skipped. Or I’ll have to borrow money from people and I hate having to borrow money from anybody. I could work more hours but there’s no sense in that because I’ll have to pay for daycare for my son. The way I work, I take him to school and pick him up and that’s what I can afford.”

Despite this delicate balance on a day to day basis, there have been many times when she has needed health care. She remembers one time when her blood pressure “jumped up so high that I was at stroke level”. And somebody told her about a free place where she ended up going to get some help. But she must be “really bad sick to miss work to go to the doctor” since she does not have paid sick leave. “You don’t go to work, you don’t get paid! I can’t afford it. I have to just go to the hospital and make a bill.”

She has significant medical debt where her already small check is being garnished $10 every pay period. She constantly worries about groceries, bills and gas for her tank. She knew that the ACA was a law for people to get health insurance in 2014. She thinks that it will help a lot of people. “I think it’s a good idea if they can come up with it because it’s a lot of people that need help out here. When it comes to a choice between eating and medicine or your bills and medicine, that’s horrible. No one should have to make a decision like that.”
Story #8
Cindy Hott
Working two part time jobs but can’t afford insurance

Ms. Hott has two part-time jobs working for two different companies. She doesn’t have health insurance because she can’t afford it. As a part-time employee, her cost to purchase insurance is higher than it is for those with full-time positions who, she says, “get a better rate.” She feels “awful” about not having insurance. In addition, she can’t really afford to miss work when she’s sick because she doesn’t get paid when she doesn’t work. Unfortunately, she has been sick for the past six months and had to go to the Emergency Room three times:

“This year has been different for me, I am usually pretty healthy. I can’t get well because I’m not getting the rest I need to get during my illness; because I cannot afford to miss work. Since I don’t have sick time or any benefits far as vacation or anything, I have to go to work. Even if I’m not feeling the best in the world, I still have to go to either one of my jobs, sometimes I work one job, and sometimes I work both jobs in one day, so it’s not a choice.”

Having to use the ER during this sickness has resulted in her having over $3,000 in medical bills that she is now trying to pay. She hasn’t been sued for her medical debt, she says, because “I try to make some type of payment arrangements to pay them, even if it’s over the next 10 years, but I try to pay them.”

Ms. Hott believes there may be something else keeping her from getting well and that having insurance would allow her to have lab work and other tests done to find out what is wrong.

“When I go to the doctor, they are only treating the illness that I come there for; but they are not doing an overall view on my health to see if there is any other medical problem that’s going on (that may be keeping me sick)...I have had pneumonia at least 4 months. [When I go to the ER] I have a breathing treatment because I have asthma. They usually do a steroid shot. The last time I went I was dehydrated so they did an IV with antibiotics in it, then they sent me home with a prescription that I have to pay for out of pocket to get filled. Some medicines I was not able to get filled because I can’t afford to.... If I had health care, even if it was Medicaid, I would go to the doctor as soon as I get sick. I would set up my regular routine checkups ...have my pap smear, breast exam, maybe every 6 months have my doctor do an over view of my health or physical on me.”
Matt Marshall is one of those guys anyone could get along with, the type of guy you root for to do well. That may be why he is working as a bartender right now in northwest Arkansas. He is the second person I interviewed who does not have health insurance. A former student who is looking to go back to school after paying off some debts to the U of A, he is “scared every single day” about the fact that he does not have insurance. He is a 30-year old white male from a middle class family who never expected to be in the position to be without insurance and says medical or dental insurance would be the first thing he would purchase if he could afford it.

Although Matt does not seem to have a problem getting shifts covered when he is sick, he does have issues getting the medical care he needs. Most of the time, he uses home remedies and rest to make himself feel better; however, this takes more time away from his job than it would if he could get the professional medical care he needs. If he absolutely has to, he goes to “cash” clinics in his town where he has to pay up front to see a doctor. He could really use a specialist for his annual sinus infections, but the cash clinics do not provide these services.

Matt is cautiously optimistic that he is relatively healthy and does not have any major medical issues or bills; but he does say that a trip to the Emergency Department would probably bankrupt him. When asked about what having health insurance would mean to him, he somberly says that it would “…mean a lot. I would be less concerned about what I would do if I were hurt. It would ease my mind quite a bit.” He would use the insurance to receive regular checkups and get his sinus infections under control so he could stop missing work.

Since Matt is in a great occupation to hear people’s thoughts about the ACA, he has heard a vast range of opinions across the board, mainly divided along party lines. However, he is all for it. Matt actually stated one of the theories we learn in class about healthy populations, “increase access and you increase health.” If you increase the health of the community, then you increase the health of the workforce, thus increasing the health of the economy. Matt leaves us with this final thought, “Think about it as a human issue and not as a financial issue.”
Halie Qualls is a young woman who owns a home with her fiancé, who works full time to support her and their three-year-old son, Tommy. Halie has been job searching without much luck for the past year. For her family, the price of day care is a barrier to her finding a job. With a high school education, Halie has only been able to work minimum wage jobs that barely cover the cost of putting her son in day care. As a result, they rely on her fiancé’s income to support their family.

Her fiancé’s job does not offer health insurance, so while Tommy is covered by ARKids, Halie and her fiancé go without any type of health insurance. The word to describe Halie’s interview would have to be “worry”. She spoke often about how she is in a constant state of worry that something serious will happen to one of them that will require medical care that they can’t afford. Their current plan of action is to rough out any sickness unless it becomes serious, at which point they go to the emergency room. Like many Arkansans, this is not ideal, but it is the reality of the situation.

Halie’s fiancé does landscaping and a few months ago he got something in his eye. After dealing with it for several days, he eventually had to go to the emergency room. There was a scratch on his cornea that required expensive medications. Halie spoke about having to turn off their cell phones for two months to pay for the prescriptions. This is a big deal when you consider that they were living alone in a home with a three year old without any type of phone in case of an emergency. This is just one example of the sacrifices they have had to make for health care.

Her fiancé also has very bad dental problems. Halie spoke about the choices they have had to make in order to get him the dental care that he needs. He has needed several root canals that they couldn’t afford, so their only option was to save the money and have his teeth pulled. As a result, he is going to eventually need bridges and implants put in later in life. This inevitable expense worries Halie greatly. Additionally, he has had an abscessed tooth that required a trip to the emergency room. Between this and a few other necessary emergency room visits, they are in over $3,000 worth of medical debt.

Like many others, they have no way of paying this debt. As a result, their state tax refunds are held every year. Halie still has debt stemming from Tommy’s birth that is unpaid. She said that their debt is a result of making decisions. They have decided it is more important to have electricity, water, and a roof over their heads than being debt free. When you can’t afford to pay medical bills and a mortgage in the same month, you pay the mortgage. The fact that they have been sent to collections is not something Halie is proud of, but it is a choice she has made to better the circumstances of her family.

Halie expressed that to her, having health insurance would mean she wouldn’t have to worry anymore. She wouldn’t have to feel anxious at the first sign of a cough or a toothache. One thing that truly bothered Halie was that since she was unable to treat sicknesses as they came on, she oftentimes passed them onto Tommy. Halie admitted to being so sick at times that she would actually take some of Tommy’s medication since he had health insurance. She feels it is not possible to be the best parent you can possibly be without health insurance. She worries she will get sick and be too sick to give her child the best care she can possibly give him.
This respondent is a contract employee for the Arkansas Department of Health working as a Personal Care Aide. Insurance or other benefits are not offered and she receives no paid sick leave. She states that she cannot afford private insurance, as she is considered low income, and her husband is disabled and collects Supplemental Security Income or SSI. She works part-time, 25 hours per week, because if she works more hours her husband’s SSI is adjusted and decreased. This respondent says “not having insurance is scary when you are older. I am 59 years old and I don’t have health insurance. Obama is pushing for everyone to have health insurance and I do not know where the money is going to come from. How am I going to pay for it? Right now, I use the Breast Care Program for my check-ups, but that only includes women’s health. I think I have chronic obstructive pulmonary disease and would like to get a regular doctor to go to for follow up. I have quit smoking, as I know that I have asthma. Also, I would really like to get my teeth fixed, I recently had to have a tooth pulled and it cost $60.00. I do not go to the doctor because I cannot afford it; I treat myself at home, so I do not have a regular doctor. So far, I have been lucky and have not had any serious health issues. I have had jobs before where I did have insurance and that was great.”

“Recently my husband had to have lab work and his insurance (Medicaid) did not pay for it all, and I had 3 bills that had to be paid and the lab was one of them. You just have to prioritize on what you are going to pay. Also, I didn’t know that there are only 6 slots for medicine on his Medicaid Card so if he needs something else we use the $4.00 medicine at Wal-Mart. If they quit that I don’t know what we will do.” She shared that she has medical debt and makes monthly payments, so this extra lab bill was an additional medical payment for the month. She also shared that if she had insurance she would utilize preventive care with regular check-ups, and routine screenings like a colonoscopy. She would go and have her lungs checked and get her teeth fixed and begin regular dental check-ups. When asked how she thought the Medicaid Expansion would affect the health of the community she said, “Oh, it will help a lot of people, there is nowhere to work that offers health insurance.”

Individual health is important to the community and economic development. We also know that health care and therefore health insurance is critical in that process. Currently, there are over 500,000 uninsured Arkansans. The implementation of the Affordable Care Act can directly affect this population in January of 2014. To date policy makers have not heard from those most in need. As the political debate goes on, the voice of the uninsured and underserved must be heard as we seek to improve the health of all Arkansans.

This service learning project revealed that health insurance is valued by people. There are currently many chronic unmet health needs. In our sample of poor, working individuals, not having affordable health insurance and health care access set up a cycle of financial distress, poverty, and other problems. It is a cycle that many have been unable to escape. People live on the edge daily, choosing between necessities for their family (food, utilities, child care, and transportation), and health care.

There are additional barriers to accessing care such as no paid sick leave. Additionally, health insurance and access to care can be a life and death issue for many uninsured people and their families. While there is a lack of knowledge about the ACA, there is support for expanding health insurance to low-income people so they can have healthy families and communities.

While we continue to debate whether or not and how to implement health care reform and expand access in the state of Arkansas, we must hear, understand and consider the voices of the uninsured. As one of our participants succinctly put it:

“Think about it as a human issue and not as a financial issue.”
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