Voices of the Newly Insured

The experiences of Arkansans in the first roll out of the Affordable Care Act

Arkansas Community Organizations

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“My life and any other uninsured person life are just as important as theirs. I worked all my life and aside from Medicaid during two pregnancies, I never received any type of governmental assistance or welfare. My income fell right in the middle of being too much for assistance, but just barely enough to cover my living expenses. I want them to know that real people are working hard every day giving their best. Our health care shouldn’t be used as toys in their political game.”

— An anonymous, retired African American woman living in Pine Bluff, Arkansas

The words above were shared with a student from the Fay W. Boozman College of Public Health at the University of Arkansas for Medical Sciences in April 2014. As part of a service learning course on racial and ethnic health disparities, 15 students and 3 instructors partnered with a local community based organization to learn about the experiences of individuals who signed up for health insurance in Arkansas through the Affordable Care Act. This report summarizes the main themes from 29 interviews and shares the stories of 11 Arkansans and their unique experiences. Above all else, the stories illustrate the genuine appreciation that these individuals share for the opportunity to have health insurance. Their stories explain challenges faced in accessing needed healthcare services while being uninsured and how their new insurance is likely to have both health and financial benefits. Many of those interviewed wanted to thank Arkansas policy makers for authorizing the Private Option throughout the state, and hope to see it continue in the future.
Acknowledgements

This project was planned and completed in partnership with Arkansas Community Organizations, a long standing community partner of the Fay W. Boozman College of Public Health. We extend our deepest thanks and appreciation to all the individuals who spoke with us and shared their personal stories so that others can learn about how the Affordable Care Act is unfolding in real communities in Arkansas.

This report was prepared by Ashley Bachelder, Creshelle Nash, Kate Stewart, and their students, listed below.

**Students:**

Ali Beebe
ReeShema Britt
Clare Brown
Jennifer Caldwell
Felisha Crosby
Alex Handfinger
Kimberly Hayman
LaQuisha Hervey
Angela Jimenez-Leon
Bianca Johnson
Patricia Minor
Jenna Rhodes
Ja’Qualane Scales
Donovan Shavers
“We need health insurance— I don’t mind paying a few dollars a month, I don’t have much, but I am willing pay a little to keep insurance. I’ve never even been given that option.”

—Whitney Abernathy, a 26-year-old mother of one
BACKGROUND

In March 2010, Congress passed the Affordable Care Act (ACA) with the aim of making health insurance more affordable for millions of Americans. At the time, about 48 million people across the country were uninsured, including more than 520,000 Arkansans.1 While 15% of the U.S. population was uninsured, 18% of residents in our state went without insurance. In a state where the median household income is just over $40,000,2 many Arkansans simply could not afford the average price of nearly $6,000 for single coverage or $16,000 for family coverage.3 Individuals without insurance were forced to pay out of pocket for preventive care or go without it. When they got sick, they delayed treatment or incurred expenses they often couldn’t afford to pay.

The Affordable Care Act created two ways of making health insurance accessible for low and middle income families who weren’t already insured. First, the law provides premium subsidies to help low and middle income individuals purchase private health insurance in a new online marketplace. The subsidies lower the cost of health insurance for individuals who don’t have access to employer-subsidized plans. With the subsidies, a single person earning $17,500, for example, may be able to purchase health insurance for no more than about $60 per month.4 The Act also gives states the option to expand Medicaid coverage to the working age adults with income less than 138% of the federal poverty level (people earning less than $16,105 for a single person or $32,913 for a family of four5). In the past in Arkansas, almost no adults without disabilities between the ages of 19-65, with very few exceptions, would have qualified for Medicaid. To expand Medicaid coverage in this state, Arkansas policymakers hit upon an innovative idea to use Medicaid dollars to purchase private health insurance for the expansion population. The Arkansas Legislature authorized the plan, known today as the Private Option, in 2013 and reauthorized it in 2014, securing the funding through at least mid-2015.

With these new opportunities for coverage, thousands of Arkansans have already signed up. By mid-April after the first deadline for the open enrollment period ended, over 200,000 Arkansans were shown to be enrolled in the new plans.6,7 This report reflects the voices of the newly insured in our state. It highlights the ways they managed their health without coverage, describes their experience signing up and offers insight about what the new coverage means for their physical health and mental well-being.

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1 http://kff.org/other/state-indicator/total-population/?state=AR  
2 http://quickfacts.census.gov/qfd/states/05000.html  
4 http://kff.org/interactive/subsidy-calculator/?state=ar&zip=72211&income-type=dollars&income=17500&employer-coverage=0&people=1&alternate-plan-family=individual&adult-count=1&adults%5Bo%5D%5Bage%5D=21&adults%5Bo%5D%5Btobacco%5D=0&child-count=0&child-tobacco=0  
5 http://aspe.hhs.gov/poverty/14poverty.cfm  
6 Arkansas Blog, Enrollment in Arkansas Health Insurance Marketplace at 44,665, April 22, 2014  
7 Arkansas Blog, More than 150,000 have gained coverage under private option; DHS releases demographic information, April 21, 2014
During the spring of 2014, students at the University of Arkansas for Medical Sciences (UAMS) taking a course entitled “Racial and Ethnic Health Disparities: Theory, Experience and Elimination” at the Fay W. Boozman College of Public Health (COPH) were learning about the Affordable Care Act and its impact on Arkansans. Through a partnership with Arkansas Community Organizations (ACO), students completed a service learning project in which they conducted 29 qualitative interviews to learn about the experiences of individuals obtaining health insurance through the new Arkansas insurance Marketplace.

**Interview Guide.** The students worked with the instructors and the community partner to develop a qualitative interview guide. The guide included questions regarding the enrollment process, plan satisfaction, and health care access and use. They completed in-class training on in-depth interviewing skills, including several run-throughs using the interview guide. Students also collected demographic information from each participant. The project was reviewed by the UAMS Institutional Review Board and determined not to be human subjects research.

**Recruitment and Data Collection.** ACO provides free tax filing services to community members from January through October each year. A convenience sample of individuals at the tax site were given a simple screening questionnaire asking if they have enrolled or attempted to enroll in the new healthcare Marketplace and if they would be willing to participate in an interview with a student to talk about their experience. They were asked to provide their contact information and told that someone from the COPH would call them. A course instructor initiated phone calls to explain the purpose of the project, invite community members to participate and set up an interview time and location; then matched them with a student interviewer. Students were also given the option to recruit individuals from their personal networks for interviews. At the interview participants were again informed of the project’s purpose and given the opportunity to ask questions. They were then asked to sign a written consent form and whether or not they were willing to share their full name, a photograph, and if they would be interested in sharing their story with the media. Interviews of those consenting were also recorded. All participants were given a $10 Walmart gift card to compensate for their time. Interviews were conducted in the early months of the open enrollment period between February and April 2014.
Students interviewed 29 Arkansas residents who had either successfully signed up or attempted to sign up for insurance at the online Marketplace or through the Arkansas Private Option. Table 1 summarizes the demographics. Over half the respondents were between the ages of 25-44 years old. Both men and women were interviewed, although there were more than twice as many women as men (72% and 28% respectively). The overall sample comprised primarily low-income persons and families, with two-thirds of the participants’ combined family income totaling less than $14,999. Almost two-thirds self-identified as African American/Black (60%) and one-third as White/Caucasian (33%). More than half the individuals were employed (52%), and nearly one-quarter were students (24%). At least half the respondents were Private Option enrollees.

Table 1: Demographics of Sample Population

<table>
<thead>
<tr>
<th>N=29</th>
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<tbody>
<tr>
<td><strong>Age</strong></td>
<td>18-24</td>
<td>1 (3%)</td>
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<td></td>
<td>25-34</td>
<td>13 (45%)</td>
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<tr>
<td></td>
<td>35-44</td>
<td>4 (14%)</td>
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<td>45-54</td>
<td>5 (17%)</td>
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<td>55-64</td>
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<tr>
<td><em>Missing age for two participants</em></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td>Male</td>
<td>8 (28%)</td>
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<tr>
<td></td>
<td>Female</td>
<td>21 (72%)</td>
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<tr>
<td><strong>Race</strong></td>
<td>Black</td>
<td>18 (60%)</td>
</tr>
<tr>
<td></td>
<td>White</td>
<td>10 (33%)</td>
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<tr>
<td></td>
<td>Other</td>
<td>2 (7%)</td>
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<tr>
<td><strong>Combined family income</strong></td>
<td>Less than $14,999</td>
<td>19 (66%)</td>
</tr>
<tr>
<td></td>
<td>$15,000-$24,999</td>
<td>7 (24%)</td>
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<tr>
<td></td>
<td>$25,000-$34,999</td>
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<td>$35,000 or more</td>
<td>1 (3%)</td>
</tr>
<tr>
<td><strong>Employed</strong></td>
<td></td>
<td>15 (52%)</td>
</tr>
<tr>
<td><strong>Student</strong></td>
<td></td>
<td>7 (24%)</td>
</tr>
</tbody>
</table>
FINDINGS: The Themes

Each student typed a rough transcript of their interview and prepared a narrative version. All documents were reviewed by all students, instructors and the community partner for comments; first individually to detect patterns in responses, and then through class discussion to identify emergent themes and patterns. The following is a summary of those themes across the 29 interviews.

1: Problems accessing healthcare services before the ACA

Nearly all of the interviewees reported challenges accessing healthcare before the implementation of the Affordable Care Act. The most common problem was a lack of health insurance due to prohibitive costs or pre-existing conditions. Since health insurance in this country has traditionally been employer-based, many participants, like Mr. Don Bankers spoke of instances of losing coverage with a change in job status: “I was laid off and am now unemployed and my unemployment is not enough to pay for insurance out of pocket.” About accessing healthcare, he “would just go to the doctor and they would set me up with a bill plan and those bills used to be high too, especially going to the emergency room.”

Others reported an inability to obtain health insurance because of pre-existing conditions the stress of trying to live with those diseases while uninsured. Ms. Kaitlin Lott’s story about being uninsured and living with Type-1 diabetes illustrates this problem. She needs regular insulin supplies that costs over $700 a month; she explained, “with Type-1 diabetes, 24 hours without my medicine and I die. So if the money isn’t in my account it’s horrifying. It is absolutely horrifying.”

Mr. and Mrs. Thompson spoke of the combination of issues when they shared, “We’ve been trying for years to get insurance—we just couldn’t ever afford it. She had cancer, so we couldn’t ever get insurance on her. No one wanted to insure her because of the cancer.” Nearly all of the interviewees with pre-existing conditions expressed similar sentiments of not being able to obtain health insurance prior to the implementation of the ACA.

Without health insurance regular care is often forfeited and individuals are left with few options—often free or discounted clinics which may not have the capacity to address complex needs; or the emergency room where they may incur high medical bills. Ms. Regina Tims shared, “since I lost my job I have not been able to go to the doctor or seek other services. I remember one night I was hurting extremely bad and needing to go to the emergency room, but I didn’t go because I didn’t have $150 to give them.” Another woman shared the financial repercussion she is facing after suffering from acute respiratory problems from mold in a house she was renting: “I racked up about $3,000 in ER bills that I don’t know if I’ll ever be able to pay.”

“With Type-1 Diabetes, 24 hours without my medicine and I die. So if the money isn’t in my account it’s horrifying...absolutely horrifying.”
2: Experiences with the enrollment process

The enrollment process varied with electronic, paper, and over-the-phone applications. Many people tried to enroll online but encountered malfunctions in the system and had to do a paper application or complete it over the phone, which for some was a tedious process with long wait times and uncertainties about the process. A few individuals reported waiting several weeks or even months not knowing if their applications had been approved or not. One woman said, “I was so worried wondering if I had got approved or not... And you never get anyone to say if you did get approved or you didn’t get approved, you just stay on the phone waiting or on hold but you never get through to anybody and I was so afraid to be penalized!”

A number of individuals who reported difficulties signing up sought assistance from an in-person assister, health navigator or insurance agent. Problems enrolling were not universal, though, as more than half did not report difficulties and as Ms. Rosie Jones, who was helped by an In-Person Assister guide explained, “it took me about 15 minutes to enroll. The in-person assister was quite accurate. She was really fast. Everything she gave me was precise. That’s the only thing I can say. She was really good and really fast. Within the next 3 or 4 weeks I had my insurance card and I’ve already used it. I had no problem enrolling. No problems at all.”

Despite challenges in the process, everyone who has received the details of their insurance plan is pleased with having health insurance. One woman explained, “It’s a wonderful feeling. I’m over 50 now and I’m not getting any younger. It is a great feeling knowing that if I get seriously sick, I am now covered and my sons don’t have to worry about if they will be afford to pay for me.”

Theme 3: Understanding of plan details and scope of benefits

About one-third of the participants admitted not fully understanding all the details of their health insurance plans. Half of those individuals had not yet received the information regarding the plan’s scope of benefits; they only knew that they had been told their applications were received and approved. Others who did have that information were still unsure about some of their plan details. “I don’t know anything about the different plans, my plan was just picked for me,” explained one respondent.

A few had questions about whether or not dental and vision benefits were offered in their plan, or if they could get dental coverage if their plan did not already include it. A few had questions about how changes in income will affect their plan. Two participants shared that their prescription coverage benefits are not adequate for their medication needs. Ms. Tims said she would “have liked to talk to someone face to face to ask questions,” that she had while enrolling and about the plan she ultimately selected. Still, the majority, including those with some limitations, were happy with the details of their plan and even surprised, as Dani Folks stated, “I was kind of expecting to give up access to healthcare by getting on that plan, and I’m not. It’s still pretty flexible in terms of where I can go and what I’m covered for.”
4: Healthcare benefits of having insurance

All individuals who were interviewed and had received confirmation of their insurance described feelings of relief knowing they had coverage. Interviewees felt that now they will be able to get healthcare services to address their needs that they mostly did not have access to prior to being insured. Three-quarters said they are now more likely to see a primary care physician to get routine check-ups and other preventive care services to proactively manage their health instead of only getting care when they have a crisis or acute problems. With insurance, almost half of those interviewed indicated they would be less likely to use the emergency room less than before.

Mr. Bankers does not have any immediate health concerns, but looks forward to getting routine care. He shared: “I’m gonna start going in to see the doctor and have my check-ups and getting back healthy. People over 40 years old need to go to the doctor on a regular basis.”

For others, health insurance will allow them to get specialty care they need but have been putting off or were previously unable to afford. “It’s a big relief,” Mrs. Thompson explained. “The last CAT scan I had was right after my son was born, and he’s eight today. So it’s been 8 years. And they found live cancer cells in my neck, my stomach, and my intestines…it terrifies me. Knowing that I have those live cancer cells and they can become active at any time and I can be sick and not know it and not be here for my kids.”

5: Financial benefits of having insurance

Almost half individuals expressed gratitude that their insurance plans had no cost-sharing components and that they did not have any monthly premiums, co-pays, deductibles or other out of pocket costs. This feature of some Private Option plans was very valued by many, as Ms. Jones giddily exclaimed, “There is no monthly payment. No deductions. Zero! Zero! Thank God! I wouldn’t be able to afford it right now if I did have one.”

The ability to schedule an appointment in advance and avoid the burden of months of medical bills provides them with the sense of security that they will receive the care they need to live healthier lives; or if an emergency happens it will not have severe health-related or financial implications. Ms. Valorie King explained the feeling of “Not worry[ing] about running up a bill. It takes a lot of stress off of you knowing you can go to doctor, knowing you don’t have money to pay for it but now knowing it’s covered... it’s relief... it felt good to walk in there and hand them my card.”

“It takes a lot of stress off of you knowing you can go to the doctor, knowing you don’t have money to pay for it but now knowing it’s covered... it’s relief.”
FINDINGS: The Stories

With the implementation of the Affordable Care Act and the expansion of Medicaid in Arkansas through the Private Option, the healthcare landscape is rapidly changing and evolving to meet the requirements of these new laws. While many of the evaluations of the Marketplace and the Private Option are quantitative in nature and look at the hard numbers, the individual voices and can sometimes be overlooked. This report was created in an effort to fill that gap through introducing you to the individuals most directly affected by these changes—real Arkansans living and working in our communities.

“There is no greater burden than carrying an untold story.”

- Maya Angelou
Ms. Dawn Spears is in her early 40s and has one son. In need of health insurance, Ms. Spears discussed options with a co-worker who connected her to an insurance representative. Ms. Spears called the insurance representative in December and provided her personal information to obtain health insurance over the phone. She also provided the representative with the necessary information to get insurance for her son. “I thought it was a pretty good experience when I was enrolling, but I haven’t heard anything from them so now I don’t know,” she said in March.

At the time of her interview in March, Ms. Spears had not yet received any information or confirmation of her application which was disheartening. Fortunately, she learned through this process that her son qualifies for coverage through ARKids and he is now insured.

Though Ms. Spears expresses appreciation for her son having insurance, she is still very concerned about the status of her own insurance application and coverage. She compares the experience to a time she lived in Memphis, Tennessee, and had coverage through TennCare—the state’s health insurance program. She has never qualified for assistance in obtaining insurance since moving to Arkansas. “Why is it so hard for a person to get healthcare in this state,” she asks. “I just think that it’s really sad that we have to go through all of this just to get health insurance that we have to pay for!”

Ms. Spears’ concerns about access to healthcare services are beyond just having insurance. After discussing her concerns about the status of her application, Ms. Spears expressed her worries about the possible implications of not having had access to healthcare services in the past. Though she has received annual women’s health exams, she has had no access to a primary care physician. She ultimately fears that because she does not have a primary care doctor she will have to go to the emergency room if something happens to her where she will discover that something is seriously wrong with her. “Here you can’t even go to the doctor? I want to be able to go and make sure I don’t have cancer or I don’t have diabetes without something going wrong and having to go to the emergency room to find that out.”

Overall, Ms. Spears remained frustrated with the lack of answers about the status of her insurance. As a moderate income person, her insurance should be partially subsidized and she will have a monthly premium. In closing she re-emphasized “I just think that it’s really sad that we have to go through all of this just to get health insurance that we have to pay for!”

UPDATE: Dawn Spears finally received her insurance confirmation and plan details in April. It took approximately 4 months.
Mrs. Montague is a 47-year-old bar tender who was able to get health care insurance again because of the Affordable Care Act. It has been almost 20 years since she was last able to afford coverage. With the help of a private insurance agent in Batesville, she had no trouble signing up for a Silver plan under the Private Option.

Mrs. Montague has been eagerly waiting an opportunity to have health insurance because she recently discovered that her pancreas is not functioning properly. Living in a small town in Northeast Arkansas, there are no specialists that can evaluate the medical condition that is causing her pancreas to improperly produce enzymes. Without insurance, Mrs. Montague has not been able to schedule an appointment with a specialist. Now that she has insurance, she is scheduled to see a specialist in Little Rock after her insurance coverage begins in February.

In addition to being able to see a specialist to treat her pancreatic issues, Mrs. Montague is pleased that she will now have a much lower copayment ($25) than she had before her new insurance. She knows that she will now be able to go to the doctor when she needs to, rather than trying to decide if she is really sick enough to pay “the $70 [she] used to have to pay every time [she] walked in the door!” Mrs. Montague is also eager to be able to just pay cash upfront at her visit “instead of saying ‘just bill us.’” She will be able to pay for her doctor’s visits rather than finding ways to access to healthcare “by the Grace of God.” She shared that she has $10,000 in medical debts because of trips to the emergency room for care she and her husband have needed to get in the past while being uninsured.

Despite her excitement for her new insurance, Mrs. Montague was also troubled with some questions and concerns about how the subsidies are applied both for herself and others. Having always worked and often at multiple jobs—sometimes up to four or five—Mrs. Montague has never had subsidized healthcare before. She “feels bad for having it... [because] somebody else has to pick up the tab where I’m being paid for”—even though she cannot afford insurance or the costs of healthcare without it. She wonders if others who are also working multiple jobs to support their families will qualify for subsidies and have affordable insurance rates. She expressed that people should be able to work as much as they need to adequately support themselves while also being able to get affordable insurance through the government.

Mrs. Montague is encouraging her colleagues and other individuals from Batesville to go see the private insurer that she used because she has spoken with many individuals who do not know how to sign up for health care insurance and who are unaware of the available options for their coverage.
Story #3
Jennifer and David Thompson

Mr. and Mrs. Thompson are a married couple who recently received health insurance because of the Affordable Care Act. Although their four children were previously covered under ARKids, this is the first time for Mrs. Thompson to have insurance. Mr. Thompson has not had insurance for about six years. With a combined family income of $20,000 for themselves and their four children, before their new insurance doctor's visits and medications (for the parents) were just not options. Now with their new insurance coverage, Mr. and Mrs. Thompson no longer have to stress about the financial struggle to manage their life-threatening health conditions.

When Mrs. Thompson was pregnant with her first child twelve years ago, she received some medical care through DHS’s family planning Medicaid waiver. During one of her check-ups, the doctors found that she had thyroid cancer and her thyroid was removed. During her pregnancy with her second child, who was celebrating his 8th birthday the day of this interview, other doctors found live cancer cells in Mrs. Thompson’s neck, stomach, and intestines. Luckily these newly discovered cancer cells were not active yet. Because she no longer had Medicaid coverage after her pregnancy, she could not receive any treatments or scans to assure the cancer cells did not become active. Living these past eight years without a scan “terrifie[d]” her “knowing that [she has] those live cancer cells and they can become active at any time and [she could] be sick and not known it and not be here for her kids.”

Mrs. Thompson is not alone with her terrifying medical condition. Mr. Thompson has had high blood pressure for 5 or 6 years. Because of the inability to pay for doctor’s visits, he has not been to a doctor regularly in over three years. During his first check-up after receiving his insurance, his blood pressure was an alarmingly high 236/138. Now that he has insurance, Mr. Thompson is working with his doctors to try to identify the cause of his high blood pressure.

The Thompsons have been trying for years to get insurance, but they could never receive coverage because of Mrs. Thompson’s preexisting cancer condition. The couple was previously denied Medicaid coverage because they were not deemed disabled. Mr. Thompson said, “Everyone was like ‘they have the Christian centers… go there and they will help you,’ but they don’t deal with cancer.” Mr. Thompson would occasionally have such high blood pressure that he would have to go to the emergency department, and he would have medicine for “a month… you know here and there… but not like [he] should.”

The couple was notified about their insurance eligibility and assisted with sign-up by DHS. They now have a silver plan from the Private Option with no copayments, monthly premium, or deductible. Mrs. Thompson says that with this plan they are “pretty much covered on everything like dental and vision.” They indicated that although the signup process was quick and not difficult, some of the paperwork they have since received is very confusing. Primarily, they are concerned about whether their children will be staying on ARKids or if they will be switched to their new plan.

With their new insurance the couple was surprised at how easy it was to receive care. They have both had a wellness visit, received medications, and Mrs. Thompson is scheduled to see a specialist in Jonesboro for her thyroid. Mr. Thompson has received testing to determine if he has a kidney problem that is causing his blood pressure issues, and he is currently waiting on test results. He hopes to learn if he will need to have a stint put in. He is very relieved to have insurance, but knows that his kidney condition could have been detected much earlier with proper and regular access to care. He said as he shook his head in disbelief, “I could have had a stroke or heart attack at any time… without the health care that we are provided I probably wouldn’t be around much longer.”
Ms. Laverne Hollinger is a middle age female who sought new health insurance in search of something more affordable than the insurance she had prior to the Affordable Care Act. Ms. Hollinger lives with many ailments which impact her quality of life and cause pain; including gout, kidney disease, heart problems, arthritis, bone spurs, neuropathy, acid reflex and a weak bladder. She also has hip problems and uses an assistive walker. She is not yet eligible for social security benefits, so Ms. Hollinger works as a part-time early education teacher.

Ms. Hollinger was paying about $500 a month for her previous health insurance package through BlueCross BlueShield. Since she already had insurance, the hopes of obtaining a less expensive plan was the reason she chose to enroll on the Marketplace. She called a 1-800 number and spoke with a representative over the phone and chose a plan. She chose a plan that included dental and vision coverage. She is now saving about $350 a month in premiums and about $200 a month in her prescription drugs costs.

Ms. Hollinger stated that although she is glad that she has switched plans to a much more affordable one, the new plan does not meet all her needs. She explained feeling overwhelmed and confused with all the plan options while signing up with the telephone representative. She feels that she was not given enough information to determine what plan would be her best choice. Ms. Hollinger thinks that the Marketplace representatives need to be more knowledgeable in how they explain the various plans and information so that people will understand what they are purchasing.

She shared that she had gone to a specialist for her rheumatoid arthritis the day of this interview and was told that her insurance was not accepted. Due to her many ailments, the provider network, including specialists, is of great concern. Ms. Hollinger wanted to know when she selected a plan what physicians would accept it. She also has some medications that are not covered.

Still, Ms. Hollinger is pleased that her copayments, deductible, some office visits and prescription drugs that are now more affordable because of the ACA. She intends to look into her options for changing her insurance plan to one that will meet more of her needs. Ms. Hollinger “applaud[s] the effort to make sure everyone is insured.”
The participant is a 45 year old homemaker living in Southwest Little Rock. Eleven years ago she lost her job as a head start teacher and became a housewife. Her husband worked to provide for their five member family while she took care of things in the home. Over the course of those 11 years, she was uninsured and developed a medical condition that required surgery and treatment.

“I've been without insurance all that time,” she said. “We decided we were going to add me to his [her husband’s] insurance, but his provider refused to carry me. By that time, I had a pre-existing illness which they weren't going to cover.” With the implementation of the Affordable Care Act, the respondent saw this as the opportunity to finally get the surgery that she so long needed, but she again ran into barriers.

She first called the number listed on the website because she wanted to ask questions about the costs of getting a health insurance plan on the Marketplace. She was informed that she would qualify for assistance through the Private Option. She was instructed to use the Access Arkansas website to enroll, but she decided to visit the DHS office for assistance in person.

The respondent was not satisfied with the help that she received at the DHS office. She worked with a case worker to begin the application process, but was constantly being kicked off the Access Arkansas website whenever she would get to the income questions. Instead, she was given a paper application which she completed at home. Approximately a week after submitting her application she was informed that based on her family’s income she did not qualify for the Private Option. She was extremely upset and frustrated that “one agency says 'you qualify' then the second says 'you’re no longer qualified' but it's the same income.” She explained her concerns about the way income is reported because her husband is often able to work overtime hours which he needs to do to support their family. Because the overtime hours are not regular hours the respondent thinks that income needs to be “relook[ed]” at since it is not a reliable source of income they can always count on.

UPDATE: After completing her interview, the respondent provided an update stating that she received another letter saying the exact opposite of what her first letter indicated: that she did in fact qualify for the Private Option. She has now scheduled an appointment with her doctor. Overall, the respondent wanted to note that when people need help, they should be helped and that “people need to be re-educated on what to do to assist people when coming in to apply [at the DHS office.] Don’t look at people as if they are less than anyone else. If people need assistance, then that’s what they need. Be mindful of people have needs and not to look down on anyone.”
Josh Visnaw is a 27-year-old male from Michigan who is pursuing his career in public service in Arkansas. Josh has type 1 diabetes—an autoimmune disease where the pancreas is no longer capable of producing insulin, an important hormone that controls blood sugar levels. Josh needs constant treatment with insulin plus monitoring with a glucometer and test strips to control his diabetes.

Health insurance coverage has been a struggle for Josh the last couple years. He was covered by his parents’ health insurance when he was diagnosed as a teenager, but when he turned 26 years old he was dropped from their plan. “I didn’t have any health insurance for two years,” Josh says. He has struggled to get the insulin he needs during this time without insurance and without any assistance from the government. He has relied on a diabetic friend who has given him the test strips he needs to monitor his glucose levels.

Josh, as many other students pursuing higher education, has to pay for his tuition and costs and does not have a significant income source while in graduate school. This income situation makes the possibility of having private health insurance almost financially impossible. Moreover, Josh says he has felt discriminated against in the past because it is not his fault he has diabetes, but his condition has resulted in higher medical bills, premiums and co-payments, as well as limiting his insurance prospects because of the preexisting conditions clause prior to the Affordable Care Act.

After Josh watched the Arkansas Medicaid expansion pass, he applied for coverage using a paper application, but was told by DHS that the paperwork he was given was outdated so he completed an online application instead. “I am still waiting for approval,” Josh said on May 1st, 2014. In search of answers, he used the 1-800 number on www.healthcare.gov and has been assigned a case worker to investigate his situation. He started his application shortly after the enrollment period began in October 2013.

“I have spent two years of my life trying to NOT GET SICK, so now, I understand exactly what I need in terms of health services, copayments and treatment,” said Josh. “I need affordable copayments.” Josh hopes that if his application gets accepted his monthly out of pocket expenses will go down by 90% because his testing supplies, medications and other services are currently very expensive. In addition, Josh says that having health insurance will benefit his overall health because it “will change the way I treat myself.” He is aware of the essential services that are included in the plans and said that screenings, outpatient care, prescriptions and lab tests are what he needs most. He also noted that “out of Arkansas emergency services coverage is not clearly described.”

While Josh continues to wait for his application to be approved, he believes that “it is important that DHS offers a more patient-centered service when helping people to enroll. DHS needs to focus on people who don’t have internet access or have a limited understanding of the enrollment process.” He also commented that the Arkansas legislators “have to think about the benefits that the new health coverage brings to people with chronic conditions.”

**UPDATE:** Josh was finally approved and received coverage under a Private Option plan on May 13, 2014.
Mr. Norman Montgomery is a 61-year-old male who has been out of work since January of this year. It has been many, many years since he has had adequate health insurance. All he had before was only emergency and accidental medical insurance provided by his employer. Because of the Affordable Care Act, he was recently able to obtain health insurance in the Marketplace. He initially sought the help of an In-Person Assister, but with the glitches in the system the sign-up was unsuccessful. He tried to get help from an insurance agent again unsuccessfully; but at “almost the last minute” he was able to select a silver healthcare plan over the phone with a Marketplace representative.

Before health insurance coverage, Mr. Montgomery stopped going to the doctor because he could not pay. He states that he prayed a lot and has a medical issue right now that has not been addressed properly and one he feels will eventually cost him everything he has in the long run. Mr. Montgomery pays $116 per month, which he says is manageable, and has a co-pay of $25. He reports the insurance carrier is a complete service company, and that his deductible is $3,000 which he feels is comparable to what he had many years ago. Although he received his insurance card in January he has not used his insurance yet. He states that at times the $25 is hard to come by, so he is currently compiling a list of doctors he needs to see and he plans on using it soon.

He is also concerned that, to his understanding, there is no provision for someone like him whose employment status changes (due to a change in employment) and wonders if there is a way to make premium adjustments to reflect that change.

Overall, he feels the services that people are going to get are adequate; however the enrollment process “could have been smoother.” For example, he saw a TV advertisement about a health market that offered to help people decipher all of the plans. Mr. Montgomery feels that this is what the Marketplace should have been set up to do, and states that “the process should work like the car insurance brokers, people call in, give the information and get a quote on the lowest rates. It was insane for them to think that anyone could call and have a hundred and something options of insurance and be able to figure out which one would be the best. That was insanity.”

In closing, he would tell policy makers “There was a high price to pay politically and financially, but it has turned out very well in accessibility. The services that people are going to get are adequate, but we can and should do better. Kill the deductibles – quit throwing our money at the insurance companies.”
Kaitlin Lott is a 29 year old, married mother of two. She is considered part of the high-risk pool and is categorized as medically frail because she is a type-1 diabetic and has a few other health conditions. Before receiving insurance, she had to pay for her medications up front at the pharmacy where her insulin alone costs $750 a month. The costs associated with the health care she needs to manage her diabetes and other needs has been very difficult for the family—due to $25,000 in medical debt they had to file bankruptcy in 2007. Now seven years later, they still have about $600 in medical bills left to pay in addition to an increased financial burden of student loans she and her husband took out to attend the University of Arkansas at Little Rock.

Ms. Lott was sent a message in October of 2013 stating that she was pre-approved for Medicaid. Both she and her husband signed up for health insurance through the www.insureark.org website. Due to her medically frail status, her plan was assigned to her and she is now covered under traditional Medicaid. The problem she has encountered is that Medicaid has prescription limitations; her plan only allows for her to receive three prescriptions a month. She has two machines that help her monitor her diabetes, so this prescription plan may not meet her medical needs.

Her husband, who has been uninsured for about 5 years and rarely went to see a doctor, was able to compare plans offered by the Private Option to see what doctors were covered under each plan and assess what would best meet his needs. He was looking for a plan that would provide him with both dental and vision coverage due to an eye condition and he wanted the lowest out-of-pocket cost possible. He is a borderline type-2 diabetic and was afraid to be clinically diagnosed due to the past pre-existing condition clause. Now that this clause is no longer valid, he was able to receive the insurance coverage he needed. Both husband and wife voiced that the pre-existing condition scenario has been a large stressor for them for several years.

Ms. Lott and her husband have both been officially approved and both have their insurance cards. Previously, Ms. Lott had an out-of-pocket maximum of $2000, meaning she had to pay full price for every doctor visit until she reached this maximum. This made the beginning months of the year very difficult for the family financially. Now they find their monthly payments to be much more affordable as they have no monthly premiums and the co-pays have decreased substantially. Ms. Lott can now get the monthly insulin that used to cost $750 for just $3. “I’ll take it. I can find that in my couch cushions” she said happily. She will also be able to continue to visit the same doctor which she was pleased about, since her medical records are all in one place and her physician knows her and is familiar with her conditions and medications. She explained that both she and her husband will be more likely to use needed health services like preventive care and mental health services because the costs are so much lower.
Ms. Jones is a 56-year old woman who recently lost her job and currently works for a temporary agency. She successfully enrolled in a health insurance plan through Access Arkansas. She previously worked at the University of Arkansas for Medical Sciences where insurance was provided for her, but she no longer works for an employer that offers insurance. Fortunately, the passage of the Private Option has allowed her to have health insurance again.

Ms. Jones’s experience enrolling in the Private Option was simple and fast. She received assistance from an In-Person Assister (IPA) at a Goodwill store on Scott Hamilton Road in Little Rock. Initially, she went to the store to shop; coincidentally, there was an insurance booth set up so she decided to take a look. As a result of her curiosity, she now has health insurance. She was extremely pleased with the accurate and speedy service provided by the IPA: “the In-Person Assister was quite accurate. She was really fast,” remarked Ms. Jones. “It only took like 15 minutes. Everything she gave me was precise. When my card came out was the same information that she gave me.”

Ms. Jones received a silver health plan and is thrilled with it. She feels “protected” and “a little more secured when it comes to [her] health.” She stated the plan was perfect because there is “no monthly payment. No deductions. Zero! Zero! Thank God! I wouldn’t be able to afford it right now if I did have one.” Ms. Jones considers herself a relatively healthy person although she has asthma and hypertension; but indicated that both conditions are easy to monitor and keep under control when she is able to make appointments with her doctors and have insurance coverage for her medications. The insurance provides what she needs for those conditions, but Ms. Jones also has ulcers and a hiatal hernia which require an expensive medication that is not covered by her health plan. If she doesn’t take her medication for ulcers she may end up needing surgery. Ms. Jones plans to thoroughly review the details of her plan to see if she can get it approved, or see if she may need a different insurance plan to accommodate her medication needs.

Overall, Ms. Jones is extremely excited about her new insurance plan and she is very optimistic that everything will work out for her and others receiving health insurance plans. The only advice she would suggest to a person in the process of applying is “definitely make sure that they get the insurance that’s going to accommodate their needs.”
Ms. Valorie King is a 53 year old divorced female who works through a temporary agent doing custodial work with an annual income of $10,000 or less. She has been unable to work full time since taking a fall on the job in 2000 when she was working at a local restaurant. Ms. King has been uninsured since 1998 when she had to leave her hospital job because of a complicated pregnancy. She was uninsured while working at the restaurant where she was injured.

She sustained a tailbone injury from that fall which left her unable to stand for long periods of time. Ms. King also had injuries from a previous car accident which left her with a pinched nerve and whiplash. Her injuries have just compounded because she was not able to get the necessary treatment. Recently she fell on the ice in December 2013 which aggravated her old injuries again. She has needed to see a neurologist since her car accident but could not afford to do so without insurance. Now that she has signed up for health coverage she has been able to schedule an appointment with a specialist.

Not only will Ms. King be able to see the neurologist, she will also be able to make routine visits to her primary care provider and not utilize the emergency department for care. The greatest benefit is going to see a doctor and “not worry about running up a bill. It takes a lot of stress off knowing you can go to doctor, knowing you don’t have money to pay for it but now knowing it’s covered.” She had her first appointment in January and said “it felt good to walk in there and hand them my card.”

Ms. King is immensely satisfied with her plan and grateful to have coverage. She said it was a simple process and she does not understand why people are making a fuss about it. She explained that she received a letter from the Pulaski County Food Stamp office informing her of her eligibility. She stated, “I think everyone receiving food stamps, on government assistance, should receive a letter. That’s the easiest way.” Ms. King received the letter in November with paperwork to complete. She immediately sent it in and by December she was notified that she had been approved for an insurance plan and received her card by the first of January. While she was not familiar with the term “private option,” she understood that a health plan had been assigned to her and that she would finally be eligible for health insurance. The insurance company sent her a package which explained the various plans which she repeated “everything is in the book – it’s very simple.” Although her plan was pre-selected she seems to be satisfied and knows that she has 30 days to change it if she wants.

Ms. King is very pleased. She is not responsible for any monthly payments or co-pays when seeing a doctor. The only one thing she wished for was additional dental coverage. Currently the plan covers routine teeth cleaning and tooth extraction but she would appreciate having a more comprehensive dental plan. “It’s part of health too so I think they should cover it.” Ms. King has two front teeth missing and would love to have them replaced. In a humorous tone she stated, “All I want is my two front teeth.”

Although Ms. King is very satisfied, she stated “Why make it hard? Everyone who does not exceed the income, send them a letter...people need to sign up....it’s not a hard process.” The message she had for decision makers was, “they need to get on board. Get in the wagon because they are going to pay one way or the other, on the front end or the back end. They have insurance and are not worried about how they are going to pay so why make everyone else miserable?” Ms. King lastly added with a sense of relief, “Thank you Jesus for my insurance.”
Mara D’Amico is a 27-year-old graduate student at the Clinton School of Public Service originally from Michigan. She had health insurance for her entire life through her parent’s plan until the end of 2013 when she turned 26. After a four month long process she was finally able to acquire insurance through the Affordable Care Act and the Arkansas Medicaid expansion using a combination of online applications, paper applications, Medicaid office visits, call center representatives and in person assisters.

D’Amico has Type I diabetes and a thyroid condition, which up until recently would have prevented her from being covered under most other insurance plans. She requires multiple and regular doctors’ visits, as well as costly daily medication in order to stay alive. During her gap in coverage and while wading through the enrollment process she had to cancel many doctor appointments and relied on her stockpile of insulin and other diabetes supplies because she knew that she wouldn’t be able to afford to pay for them out of pocket.

As an educated student with reliable transportation, a computer, and a flexible work schedule, she was amazed at how convoluted and complicated the process was. She worries about people who don’t have access to these opportunities and resources in obtaining healthcare coverage for themselves. D’Amico recalls “between October and early December I probably tried 40 to 50 times to sign up.” It once took her nine hours on hold waiting to talk with representatives and was made to return multiple times to the same office with various pieces of information, often being given different explanations as to why she was or was not Medicaid-eligible (and later discovering her income had been inaccurately documented). She also never received a single piece of information in the mail though she was promised that many times. She eventually got signed up through the federal website in late December through the assistance of a telephone representative, selected a plan in mid-February, and as of March has still yet to receive her Medicaid paperwork and insurance card. “All in all it was a very frustrating process that’s taken over a hundred hours of my life. And I still don’t have coverage with the plan that I want.”

Still, D’Amico explains, “Although I was really frustrated [and] I think it was incredibly difficult...in the end I am just so thankful that this is available to me and to all of the millions of people that were without insurance.” She says she feels so relieved to know that if she has a diabetic or other major medical emergency that she is able to receive the care that she needs and be able to afford to pay for it. “It was incredibly stressful for me in that time I didn’t have insurance...I feel healthier just knowing that I have the option of going to see a doctor or getting the preventive care that I need.” The Medicaid expansion is a genius idea that is a bipartisan approach she says. “I hope that it continues to be funded,” D’Amico says, “because my life depends on it.”

**UPDATE:** D’Amico was approved for her insurance plan through the Private Option in mid-March and her plan began at April 1st. She has had doctors’ appointments with those she had to cancel during her wait time.
Arkansas has been characterized as a state where vulnerable communities are frequently denied healthcare access. The Affordable Care Act and Arkansas’s Private Option is changing the landscape of health care outcomes for residents. This project offered newly enrolled individuals the opportunity to share their experience in their own voice. Despite the challenges interviewees faced during the enrollment process, nearly everyone said having health insurance has brought them peace of mind. Those on the Private Option without cost sharing commented specifically on the relief it brings that they are able to get the care they need without worrying about being able to pay the bills. When asked what they would like policymakers to know, many interviewees expressed concern about reauthorization of the program and the potential of losing coverage. With over 200,000+ Arkansans enrolled in these plans, we hope this report will provide one way for those individuals to have a voice in the policy making process.

MESSAGES TO THE POLICY MAKERS

Every participant was asked if there was a message they would like to share with the policy makers. The following are excerpts from their messages.

“Thank you, it makes a huge difference in my quality of life and my ability to just function and take care of my family and try and improve my life.”

“Give everyone the opportunity to receive health care. I’m for change. I’m all for it. I’m good. But change has to be more constructive and moving forward, not just for their votes and for their image.”

“Don’t delete ObamaCare and keep it coming for the American people. We need it in order to have a healthy nation.”

“I want to be able to get whatever the rich has available to them. If I hurt find out what it is and not say it’s just psychologically related, find out. I want the same thing as the other person and not be treated like I am from the wrong side of the track which dictates what’s available.”

“I’m just thankful that we got on this plan and we don’t have to be struggling and be scared as much anymore.”

“Bringing the wages up will help too. I mean it’s hard for someone who makes ten bucks an hour to get health insurance.”

“I hope that it continues to be funded because my life depends on it. I hope that our legislators are able to understand that and do the right thing and provide health coverage for the people in Arkansas that really need it.”