



Low-Income Uninsured Focus Groups Final Report

Health Insurance Flexibility and Accountability
(HIFA) Waiver

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SECTION I EXECUTIVE SUMMARY

Introduction

It is well documented that Louisiana has one of the highest percentages of uninsured citizens in the nation, with 20% of Louisiana residents lacking health insurance coverage. This is 33% higher than the national average of 15%¹. When children and the elderly – who are covered in LaCHIP and Medicare respectively – are excluded, the number increases to 25%, or one in four for people aged 19 to 64. Furthermore, when we also exclude individuals with incomes above 200% of the federal poverty level, or \$36,800 for a family of four, the uninsured rate for those remaining – non-elderly low-income adults – is 43%, or more than 435,000 adults.²

In order to explore options for addressing this situation, Act 813 of the 2003 Legislature directed the Department of Health and Hospitals (DHH) to develop a Health Insurance Flexibility and Accountability (HIFA) waiver proposal to extend coverage to the uninsured. Under HIFA, the federal Centers for Medicare and Medicaid Services (CMS) gives states flexibility and federal funding to increase health insurance coverage for individuals with incomes below 200% of the federal poverty level (FPL) while promoting enhanced coordination between Medicaid and employer sponsored insurance. The vehicle for accomplishing this is the granting of Medicaid and SCHIP waivers under the authority of section 1115 of the Social Security Act.

DHH worked with a broad-based advisory committee in developing a draft waiver proposal. The advisory committee included representatives of:

- ❑ Consumers
- ❑ Public sector insurers
- ❑ Private sector insurers
- ❑ Employers
- ❑ Health care providers
- ❑ Representatives of regional indigent health care efforts

The work of DHH and the advisory committee received technical support by EP&P Consulting, Inc. (EP&P), a Washington, DC-based health care consulting firm with extensive experience in designing waiver approaches to cover the uninsured, including HIFA.

The draft HIFA proposal that was developed with input from the Advisory Committee targeted uninsured parents and childless adults with incomes below 200% of the FPL. Coverage under the draft proposal would be provided through three vehicles:

¹ Source: Kaiser Family Foundation, State Health Facts Online, 2002 data.

² Source: Current Population Survey (CPS) combined data for 2000-2003.

- ❑ A public coverage expansion for parents of Medicaid children with incomes between 16% and approximately 50% of the FPL, and childless adults with incomes below approximately 25% of the FPL (100% of the FPL is \$8,980 for a single individual and \$18,400 for a family of four);
- ❑ LaChoice, which would offer subsidized health insurance for employees of small businesses that have not offered coverage in at least 12 months, for parents and childless adults with incomes below 200% of the FPL; and
- ❑ Premium assistance for existing employer-sponsored insurance (ESI) for parents and childless adults with incomes below 200% of the FPL.

As part of the process of developing the HIFA waiver, DHH asked EP&P to conduct focus groups with low-income uninsured individuals across the state. As Section II explains, the geographic locations of these groups were chosen with an eye toward obtaining a cross-section of urban and rural participants and to include representation from employees in industries that tend to have uninsured workers. Locations of the focus groups were:

- ❑ New Orleans (2)
- ❑ Baton Rouge
- ❑ Abbeville
- ❑ Iowa
- ❑ Woodworth
- ❑ Shreveport
- ❑ Delhi

The focus groups were convened during the last week in January and the first week in February of 2004. This report summarizes the focus group discussions in four general areas:

- ❑ Overall viewpoints on insurance
- ❑ Patterns of care for the uninsured
- ❑ What people want from insurance, and how their patterns of care would change
- ❑ Thoughts on stigma and related issues

Within these areas, a number of themes emerged across the groups. The following subsection includes brief summaries of the various themes, while Section III provides a detailed discussion of the conversations that occurred at the focus group meetings. These themes cover the waterfront, from the high cost of health insurance, to the financial and health insecurity uninsured individuals experience, to the strategies uninsured individuals have for avoiding the need to seek medical care and the places they go for assistance in paying for health care.

Discussion of Themes

Theme 1: Health Insurance is Unaffordable

The first theme that consistently arose was the high cost of insurance relative to ability to pay for our focus group participants. Although many of our participants had access to insurance through an employer, all who had access indicated it was too expensive for them to purchase. Participants talked in great detail not only about the cost of the premium, but also the cost of deductibles and co-payments. In some cases, participants said they did not consider insurance a good value for the money because even after paying a monthly premium they may not see any real benefits because of the need to meet a deductible.

Theme 2: Having Health Insurance Means Having Security

It was very clear that participants feel a great sense of vulnerability around both their health and their financial status due to not having insurance. Members of the focus groups spoke very eloquently about their fears of illness and financial ruin, and said they would not need to be as worried about these things if they had coverage.

Theme 3: Uninsured People Will Go to Great Lengths to Avoid Visiting the Doctor

Not surprisingly, many focus group members told us they do everything in their power to avoid seeking medical care when they are ill, including using home remedies, over-the-counter medications, leftover prescription medications from friends, and just trying to “wait it out.” They also spoke of the costs of not seeking medical treatment, including worsened conditions, time lost from work, and increased discomfort.

Theme 4: The Charity Hospital System is the First Line of Defense for Many

In general, respondents in each of the eight groups mentioned using the Louisiana State University (LSU) charity hospitals and their associated clinics for medical care. There was mixed feedback on individuals’ experiences with the charity hospital system, with many individuals saying they had to wait a long time for care although as a whole the participants seemed satisfied with the quality of care. Participants in some areas also mentioned other sources of care, such as rural clinics and private physicians’ offices in rural areas.

Theme 5: People use a Blend of Formal and Informal Supports to get Assistance in Paying for Services

Another theme that emerged among our participants was that in the absence of insurance, people rely on a vast array of formal and informal supports to get assistance in paying for medical care. However, the nature of the supports is piecemeal, and there is not a coordinated source of information about the supports that are available.

Theme 5: What Benefits are Most Important Depends Both on an Individual's Health Status and on an Assessment of Risk

When we asked participants what benefits were most important to them from a list that included hospital care, visits to the doctor's office, outpatient surgery, laboratory tests and x-ray services, and prescription medications, most participants ranked either hospital care or doctor visits first or second. We asked probing questions about the specific choice focus group members made, and we often heard that hospital care was important because of the fear of a large hospital bill that would cause an individual to "lose everything." On the other hand, some participants did not rank hospital care as highly because of the availability of the LSU charity hospital system. Some focus group members, including those with chronic conditions tended to rank doctor's visits (including visits to specialists) very highly. Another benefit that was ranked very highly because of its cost is prescription drugs.

Theme 6: Most People would Change their Behavior if they had Insurance

Almost without exception, focus group members said that if they had health insurance, they would change their health care-related behavior. Participants would be more likely to seek care and address longstanding health issues, they would be more likely to comply with doctor's orders (such as getting prescriptions filled) and they would change to providers that they consider more convenient or appropriate for their needs. Taking advantage of the ability to schedule appointments and minimize time and money lost from work was often cited as a direct change in behavior that would occur if they had insurance coverage.

Theme 7: There is Mixed Feedback on Whether Being Uninsured Carries a Stigma

This was a point on which there was not unanimous agreement. While some focus group members spoke about being treated poorly by either health professionals or office staff because of their uninsured status, others said they did not experience any differential treatment.

Theme 8: Most People Would Not Care if the Insurance Program Being Proposed Would be Public or Private

There was virtually unanimous consent amongst the focus group participants that it would not make a difference whether the program was public (a Medicaid look-alike) or private (a health insurance card with no mention of Medicaid). Participants stated in no uncertain terms that health care coverage is sorely needed, whatever the form or source.

Theme 9: Most Participants Have Had Previous Experience with Insurance Coverage

During the focus group discussions, it became clear that many, if not most, focus group participants had been insured at some point in the past. In other words, being uninsured

was not a lifelong condition. Examples of reasons people became uninsured were divorce, change in jobs, pre-existing health conditions, moving from a state with more generous Medicaid eligibility criteria, or “aging out” of a parent’s health insurance policy.

Conclusion

Information gathered through the focus groups is intended to inform the process of designing the waiver, from developing the coverage models, to formulating outreach strategies for the target population, to deciding which providers should be in the networks. In addition, the groups were intended to gather information about how uninsured individuals might change their patterns of care if they became insured, in order to give DHH insights on how the waiver might affect current providers.

Based on the focus group discussions, it is clear that being uninsured has many costs in terms of time lost from work, fear of illness, and fear of financial ruin. It is also clear that participants consider insurance very expensive, so it is not likely there will be a great deal of take-up unless the program seems to have value in terms of benefits gained in comparison to the out-of-pocket cost. Furthermore, it does seem to matter whether the program resembles a public or private coverage program, but it is important that benefits such as hospital care, doctor’s visits, and prescription drugs all be included.

SECTION II FOCUS GROUP METHODOLOGY

Introduction

In preparing a proposal for a Health Insurance Flexibility and Accountability (HIFA) demonstration for the State of Louisiana, EP&P Consulting, Inc. (EP&P) conducted a series of eight focus groups with low-income uninsured residents across the state. These focus groups were conducted in 2004 during the last week of January and the first week of February. Section II presents a detailed discussion of the methodology used to conduct these focus groups. The section breaks the discussion down into the following topic areas:

- ❑ Choice of locations
- ❑ Recruitment of focus group participants
- ❑ Conduct of focus group meetings

Developing a HIFA waiver, or any other program to cover the uninsured, involves looking at a range of quantitative data including:

- ❑ Number and percent of low-income uninsured individuals
- ❑ Composition of the uninsured population
- ❑ Cost of uncompensated care
- ❑ Cost of various benefits that may be offered through the program

These data come from a variety of sources, including the Census Bureau, Department of Health and Hospitals (DHH), Louisiana Hospital Association, and the household survey conducted by Louisiana State University under contract with DHH. These data are used to estimate the cost of a certain benefit package, determine how many individuals can be covered within available resources, and assess the impact of the program on the uninsured population. In developing the HIFA proposal, EP&P has conducted a great deal of analysis of these data sources.

The purpose of focus groups is to add another dimension to this quantitative information by gathering qualitative information on such things as attitudes about health insurance, patterns of care, relative values of various potential benefits, and changes in behavior that would occur if uninsured individuals obtained health insurance coverage. These topics are discussed in small group settings, typically with no more than 10 individuals at a time.

The type of information we sought to gather includes:

- ❑ *How the uninsured view health insurance.* In addition to asking about insurance, we asked about perceptions of public and private coverage. Answers to these questions will help determine the likelihood that the

uninsured will seek coverage under the demonstration, and whether there are design elements that should be considered to make uninsured individuals more likely to seek coverage.

- *How and where the uninsured access health care.* Understanding the usual patterns of care, as well as strategies the uninsured use to avoid seeking formal care, will be of great value to policymakers. For example, if the uninsured seek primary care in hospital emergency rooms, which is a costly venue, we will be able to draw the conclusion that Louisiana would benefit from covering primary care in order to avoid unnecessary trips to the emergency room. In addition, understanding where the uninsured access care will help with designing outreach strategies for the demonstration and in deciding which providers to include in the network for the HIFA demonstration.
- *How behavior patterns would change if the uninsured had insurance.* In addition to understanding the usual patterns for accessing care (or in some instances for avoiding seeking formal health care), it is important to understand how individuals' behavior patterns would change if they were insured, including whether people would change provider types.
- *What health care benefits would be of most value to the uninsured.* In order to design benefit packages that best meet the needs of the target population, it will be important to understand what benefits would induce individuals to enroll.

Information gathered in this fashion is not meant to replace quantitative data, but rather to enhance it. The participants are not randomly selected, and the sample size is small compared to a broad survey such as a statewide household survey. Thus, the information gathered in focus group settings is not intended to be generalized to the population as a whole. The main advantage of collecting information in focus group settings is the ability to explore attitudes and other issues that are difficult to quantify. The small group setting and the discussion format also makes it possible to explore these issues in more depth than is possible in a written or telephone survey.

EP&P had two partners in conducting the focus groups, Agenda for Children and the Southwest Louisiana Area Health Education Consortium. Because of their familiarity with the state, the role of the partners was to find locations to hold focus groups, recruit participants, both directly and through other community-based organizations, and make all local arrangements. These partners were chosen because of their independence from any providers who may be affected by the HIFA demonstration. Because one of their important roles was to recruit focus group participants, the use of independent parties was essential to avoid recruitment bias. In each case, the local partner also worked with other community-based organizations. A complete list of participating organizations is included in the Appendix.

EP&P's role was to work with DHH in choosing focus group locations, guide the work of the local partners, develop the focus group questions, facilitate and document the focus group meetings, and prepare the focus groups report.

The following subsections present details on the key aspects of this project.

Choice of Locations

Geographic locations for the focus groups were chosen jointly by DHH and EP&P based on a desire to have as diverse a sample as possible in terms of urban vs. rural areas and prevalent occupations. In addition, DHH desired that we cover as broad a cross-section of the state as possible.

In keeping with this, we conducted the eight focus groups in:

- ❑ New Orleans (2 groups)
- ❑ Baton Rouge
- ❑ Abbeville
- ❑ Iowa
- ❑ Woodworth
- ❑ Shreveport
- ❑ Delhi

The New Orleans, Baton Rouge and Shreveport locations were chosen in order to represent the urban centers of the state. The Abbeville and Iowa locations in Southwest Louisiana were intended to draw representation from the fishing, agriculture, and oil/petrochemical industries. Both Woodworth and Delhi were intended to draw from the agriculture industry, including forestry and cotton. The Delhi location, which was intended to draw from Louisiana's poorest parishes, was also chosen to represent the Mississippi delta region.

Our focus group locations included both the most and least populated areas in Louisiana. Orleans and Jefferson parishes, which were represented in the New Orleans group, are the first and second most populous parishes in the state, according to 2000 Census data. East Baton Rouge Parish, which was represented in the Baton Rouge group, is third, and Caddo, which is fourth, was represented in Shreveport. By contrast, West and East Carroll parishes which rank 57th and 63rd, respectively, were represented in the Delhi focus group.

Figure II.1 shows the locations of each of the groups.

Figure II.1
Map of Focus Group Locations



Recruitment of Focus Group Participants

As mentioned above, focus group participants were not scientifically or randomly selected. The local organizations were asked to recruit members who were from the target population for the waiver (low-income uninsured adults) and who had experiences with health care services for the uninsured. Specifically, the recruiters were asked to look for:

- ❑ Individuals from age 19-64 who are uninsured and whose family income is below 200% of the federal poverty level (FPL)
- ❑ A mixture of individuals with and without dependent children
- ❑ A mixture of individuals representing the geographic area intended to be captured
- ❑ Individuals who currently access care through a variety of means, including but not limited to federally qualified health centers, rural health centers, charity hospitals, and other providers

As compensation for their time and participation, focus group members were paid a \$60 stipend, generally in cash at the conclusion of the meeting. In some cases, checks were mailed to participants after the meeting.

Initially, we intended to devote two groups solely to individuals who are employed, both with and without access to employer-sponsored insurance. These groups were the second

New Orleans group and the Delhi group. We had intended to ask questions specifically targeted to employed individuals in these groups. However, it turned out that many participants in the other focus groups were also employed. This is consistent with national data showing that most uninsured individuals live in households where there is at least one wage earner. In other words, being uninsured is not synonymous with being unemployed. There was a great deal of discussion in all groups about the unaffordability of employer-sponsored health insurance. Therefore, we did not end up asking a different set of questions at the two types of focus groups. Since the discussion in the various groups was quite similar, the report does not differentiate between groups where all participants were employed and groups where this was not the case.

In all, we ended up with a total of 61 participants across the eight focus groups. The breakdown of participants by group was as follows: New Orleans, 9 and 8; Baton Rouge, 5; Abbeville, 9; Iowa, 5; Woodworth, 7; Shreveport, 8; and Delhi, 10. The following subsections illustrate the demographic characteristics of the focus group participants, based on written responses we asked participants to provide.

Age

Our participants covered the spectrum of the age 19-64 population. There were 10 participants age 25 and younger; 32 participants age 26-45; 15 participants age 46-60, and 3 participants older than 60. One participant did not submit age information.

Gender

Of the 61 participants, 20 were male and 40 were female. One participant did not answer the question.

Marital Status

Most participants reported that they were unmarried. The breakdown was 18 married and 43 non-married participants.

Children

About half of the participants reporting having dependent children age 18 or younger. Thirty-two participants had children, and 29 did not have dependent children. We also asked whether the children were insured in instances where there were dependent children. In every case, participants reported that their children were insured, most (a total of 24) through the LaCHIP program.

Employment and Access to Employer-Sponsored Insurance

In keeping with the idea that a majority of the uninsured live in households where there is at least one wage earner, most of our participants were employed. Forty-two of the 61 participants were employed, while 19 reported being unemployed. Of the employed participants, 14 reported having access to employer-sponsored insurance.

Previous Experience with Insurance Coverage

Although this was not one of the questions for which we asked for a written response, it became clear that many, if not most, focus groups participants had been insured at some point in the past. In other words, being uninsured was not a lifelong condition. Examples of reasons people became uninsured were divorce, change in jobs, pre-existing health conditions, moving from a state with more generous Medicaid eligibility criteria, or “aging out” of a parent’s health insurance policy.

Conduct of Focus Group Meetings

The focus groups were held in a variety of locations, including clinics, restaurants, government facilities, a hospital conference room, and a conference center. The meetings were scheduled to last a maximum of three to four hours, but in all cases the groups were small enough so that the meetings lasted no more than two to three hours. Each meeting was conducted by a facilitator from EP&P. A second individual from EP&P was present at all times to document the discussion on a laptop computer. The facilitator also took notes on a large flip chart. The same team of two individuals, Yvonne Powell and Theresa Sachs, conducted all meetings. Ms. Powell and Ms. Sachs took turns facilitating the meetings.

After being greeted by the local organizers and EP&P facilitator, the participants were seated, generally in a roundtable formation. The EP&P staff introduced themselves, and the facilitator then spoke briefly about the purpose of the meeting. During the introductory portion of the meeting, participants were assured that their statements during the meeting were confidential. Participants were told that although there would be a report produced after the conclusion of the groups, specific statements would be not be attributed to specific individual participants. The group participants were encouraged to be as open as possible.

The meetings were conducted in an informal fashion. The facilitator used a core group of questions, which were developed by EP&P and reviewed by national focus group experts Mary Anne Casey and Richard Krueger of the University of Minnesota. Although all core questions were discussed in each group, the facilitator did not always ask the questions in the same order because of how the discussion unfolded. The facilitators made every effort to be responsive to the group dynamics and not lead the conversation in a heavy-handed fashion.

The questions that were discussed in each group were:

- We are trying to get an understanding of what people think about health insurance. When you hear the term health insurance, what comes to mind?
- How many of you have tried to get health insurance? Tell us about that.
- When you go to the doctor or get other health care, do you feel you are treated differently than other patients because you don't have insurance? How are you treated differently?
- We want to find out more about when you go to the doctor and when you don't go. I want you to think back over the last year or so to a time when you (or a family member) were sick, got hurt, or were worried about your health. You felt you should go to the doctor and you went even though you didn't have health insurance. Tell us about that time.
- Now think of a time in the past year or so when you (or a family member) were sick, got hurt, or were worried about your health. You felt you should go to the doctor, but you didn't. Tell us about that time.
- Let's say you were having a health problem today and it was keeping you from doing whatever you normally do. What would you do? If you had health insurance would you do anything differently?
- We are looking for ideas on how to provide health insurance to people. One idea is to cover certain types of services but not others. If you had a choice, which of these would you most want covered and why:
 - Hospital care including surgery
 - Doctor's visits
 - Prescription medications
 - Outpatient surgery
 - Lab and x-ray services
- When you need medical care, how long does it usually take you to get an appointment? How far do you have to travel and how do you get there?

The questions are largely open-ended, and the facilitators are experienced in asking probing questions to gather more detail on issues that are raised during the discussion. In addition, EP&P used facilitation techniques to encourage openness and participation across the group. For example, there may be one or two strong individuals in a group who attempt to dominate the discussion. One of the facilitator's important roles is to ensure that all participants have a chance to voice their viewpoints and discuss their experiences.

At the conclusion of each session, participants were thanked for their time. In cases where the local organizers had stipends available for the participants, the funds were distributed. Otherwise, participants were given information about how and when they would receive their stipend.

Section III outlines EP&P's findings about opinions and experiences of the low-income uninsured participants in the eight focus groups. For the most part we found the focus group participants to be quite open and eager to discuss their experiences with the health care system, as well as their desires as to the makeup of any new program to cover the uninsured. If there was one pervasive and consistent theme, it is that coverage is sorely needed, and the sooner the better. As you will see in Section III, being uninsured causes a tremendous amount of stress, and people do not seek care for medical conditions until their symptoms become quite severe.

SECTION III

FOCUS GROUP FINDINGS

Introduction

This section presents the viewpoints expressed in the eight low-income uninsured focus groups conducted across Louisiana by EP&P Consulting, Inc. (EP&P) during late January and early February 2004. The purpose of the groups, as stated in Section II, was to gather qualitative information on opinions and preferences related to health insurance coverage among representatives of the target population for the Health Insurance Flexibility and Accountability (HIFA) demonstration. Information gathered through the focus groups is intended to help policymakers in designing the waiver in a number of ways ,including:

- ❑ Developing the coverage models
- ❑ Deciding which benefits to include
- ❑ Formulating outreach strategies for the target population
- ❑ Deciding which providers should be in the networks.

In addition, the groups were intended to gather information about how uninsured individuals might change their patterns of care if they became insured, in order to give DHH insights on how the waiver might affect current providers.

The findings outlined in this report should not be interpreted to be representative of the viewpoints of a random sample of uninsured individuals in Louisiana. The purpose of focus groups is to add a human dimension to quantitative data available elsewhere. For example, data on uncompensated care can tell us how much of the care is delivered in various settings throughout the state, but only a face-to-face discussion can fill in details such as the fact that a person had to miss work and travel a long distance in an unreliable automobile in order to access that care.

General Observations on Being Uninsured

As stated in Section II, many if not most participants had been insured at some point in the past. Therefore, they were in a position to compare their experiences as uninsured individuals with what it was like to have health insurance. Some of the participants' observations about the worst things are being uninsured were:

- ❑ *Constant worry about becoming ill.* This was a very real fear for our participants and affected people's lifestyles. Focus group members talked about staying inside in the rain and cold and being afraid to let their children play outside. One focus group participant even admitted to being afraid to attend the focus group for fear of catching a virus from a stranger.

- *Worry about “losing everything” due to an expensive illness.* Some focus group participants already had large unpaid health care bills, and many spoke of feeling very afraid that one serious illness, injury, or operation could bankrupt them.
- *Worry about having a disease such as cancer and not knowing it.* For some of our participants, this was a very plausible fear. One man who said he had gone for 10 years without a checkup lost both parents to cancer and constantly worried about becoming ill himself. Another woman said she had had a series of abnormal Pap smears but was not receiving follow-up checkups because she did not have a way to pay for it.
- *Not being able to go to a doctor when needed, and letting health problems “go to an extreme” before seeking medical care.* Many participants spoke of working when they were very ill and delaying care until the symptoms were unbearable instead of going for treatment early.
- *Having to use home remedies.* Not only did participants speak of using home remedies handed down in their families, such as honey and vinegar or a tea made from tree bark, they also spoke of using prescription medications borrowed from friends or obtained across the border in Mexico.
- *Having to choose between buying medicine and food or other necessities.* In some cases group members talked about not purchasing insurance through their employer because it would leave them without enough money for other necessities. In others cases, participants spoke of not getting prescriptions filled because they could not afford it. One woman even said she had been to the doctor and received a written prescription for some medication she needed, but she threw it in the trash on the way out of the office because she knew she could never afford to have the prescription filled.
- *Long waits in charity hospitals or clinics when seeking medical care.* Time after time, we heard stories of individuals waiting hours to be seen, and even leaving against medical advice because the wait was too long and they were too ill to endure it. Also, people spoke of extremely long waits – up to a year – to make appointments in the charity hospital system for routine medical care.

Similarities across Areas

In general, the nature of the discussions was very similar across the eight locations. The main topic on which there were differences in the responses was on specific health care providers used, as would be expected given that different providers are available in different areas. Another variation was in the sources of assistance in financing services, as resources vary by locality. Also, as would be expected, lack of transportation as a barrier to receiving care was

more frequently mentioned in the rural focus groups. With the exception of these issues, however, the feedback was very consistent across all the groups.

It is also important to note that this report represents an effort to faithfully recount the comments made by members of the focus groups. There is very little modification, except in terms of organizing the discussion along the broad themes that emerged. Where there are specific experiences mentioned, such as waiting many months to get an appointment, no attempt was made to document “facts and figures” surrounding the situation, and specific facilities are not mentioned in this report. The purpose of the focus group discussions was not to serve as a fact-finding mission on individual complaints but rather to convey the flavor of individuals’ experiences in obtaining care. Investigations of individual complaints would have been outside the scope of this project. Furthermore, we acknowledge – as did many participants – that some of the issues mentioned, including long waits for care in emergency room settings, would exist whether or not someone had insurance, and regardless of the type of hospital visited.

Organization and Themes

Section III organizes the findings into four general subsections as follows:

- ❑ Overall viewpoints on insurance
- ❑ Patterns of care for the uninsured
- ❑ What people want from insurance, and how their patterns of care would change
- ❑ Thoughts on stigma and related issues

Within these four subsections, several themes emerged very consistently across the eight focus groups. These themes are:

- ❑ Health insurance is unaffordable
- ❑ Having health insurance means having security
- ❑ People will go to great lengths to avoid visiting the doctor
- ❑ The charity hospital system is the first line of defense for many
- ❑ When insured people use a blend of formal and informal supports to get assistance in paying for services
- ❑ What benefits are most important depends both on an individual’s health status and on an assessment of risk
- ❑ Most people would change their patterns of care if they had insurance
- ❑ There is mixed feedback on whether being uninsured carries a stigma
- ❑ Most people would not care if the insurance program being proposed would be public or private
- ❑ Most participants have had previous experience with insurance coverage

Following is a detailed description of the focus group discussions in response to the questions we asked, which were listed in Section II. The following subsections provide more detail on the general observations outlined above. As you will see, our participants very eloquently discussed

what having insurance would mean to them, as well as articulating the cost of being uninsured in terms of stress, declines in health, and time lost from work and family activities.

Overall Viewpoints on Insurance

One of the questions we asked each group was what the term “health insurance” means to them. Although this was probably the most open-ended of all of our questions, it elicited surprisingly consistent answers. In one form or another, the two most common themes that arose in all groups were cost and security. Below is a detailed discussion of the feedback from focus group members.

Health Insurance is Unaffordable

The first theme that arose consistently was the high cost of health insurance relative to the target group’s ability to pay. Although many of our participants have access to health insurance through an employer, all those with access indicated that it is too expensive for them to purchase. For example, one participant noted that her paycheck in the public school system amounts to \$350, but insurance would cost \$200. The same was true of participants who are self-employed, or who do not have access to employer-sponsored insurance (ESI) and who looked into purchasing individual insurance policies.

Surprisingly, given the cost, many participants indicated that at one time or another they had looked into individual insurance policies. However, these were either unaffordable or covered too few benefits. One participant, a diabetic, said that at her current salary level she would need to work four jobs in order to be able to afford the individual insurance policy she had researched.

Some quotes that were typical of the discussion across all focus group are:

- “I’m choosing food over [coverage for] medicine.”
- “Health stops being a priority for most people. If I can’t afford it, why bother?”
- Even though health insurance would bring about peace of mind, one woman said she asks herself, “Can I afford peace of mind?”
- “Once you paid for insurance, you would have nothing to eat.”
- The choice is “either be in good health or starve.”

Many of our participants were self-employed. One participant, whose family works in the fishing industry, explained that “You work hard and get sick fishing, but you don’t go to the doctor because you can only make money six months out of the year. Then, in the winter you are not going to spend money on insurance because you need to make sure you have \$1,500 to \$2,000 in the spring to get the boat ready to go out onto the water.”

Cost of Deductibles and Co-Payments

In terms of the cost of health insurance, the issue is not only the premium, but also deductibles and co-payments/coinsurance. Some of our participants said they felt that even if they could afford to pay the premium for health insurance, they would not see any benefit because of the high deductibles that are sometimes required. One participant summed this up by saying “By the time you get done paying your deductible, it’s time to start all over again.” Another woman mentioned that even when she had insurance previously, she could not afford the co-payments. She had stopped taking medication she needed because it was too expensive, even with coverage. In designing a program to cover Louisiana’s uninsured, it will be important to ensure that cost sharing obligations do not present a barrier to participation.

Cost/Benefit Analysis

In light of the high cost of health insurance, some said they did not consider it a worthwhile expenditure in light of either the benefits offered, or the likelihood they would need care. One woman said she did not enroll in the health insurance program at her job because not only was it too expensive, she did not want to have to change doctors or put up with all the “hassles” that she perceived other employees to be subject to because of the rules of the insurance program. Another said that she considered premium expenditures “money lost” in light of the fact that she considered her risk of needing health care to be quite low. Another man said he did not enroll in employer-sponsored insurance previously because he thought the benefits were too low in comparison to the premium cost. It will be important to take these factors into consideration in designing a premium assistance component for the program. If employer policies are not attractive for reasons other than the premium itself, then simply offering a premium subsidy may not encourage take-up to the degree desired by policymakers.

In another case, a family made a choice to drop dependent coverage even though it was available. Coverage for the wage earner (the husband) was free, but for the rest of the family there was a premium plus a \$1,000 deductible for each of the family members. The family decided that it made more sense to “take chances” and rely on free clinics if other family members became ill. Another individual, who decided to drop coverage after six months because it was too expensive and no one in the family was ill, said “I would rather keep the money in my pocket.”

Some participants had lost health insurance because of job loss. Even though the federal government requires that individuals have access to continued coverage through their employer after leaving a job, which is referred to as COBRA coverage, this was seen to be especially unaffordable.¹ One individual, who had been laid off, looked into COBRA coverage but it would have cost \$800 per month to continue to be insured. Another participant said of COBRA coverage, “Why would anyone take that?”

¹ Under COBRA, individuals electing this coverage must pay the full premium plus a 2% administrative fee.

One of our focus groups included an employer, who said his construction firm offers insurance, but participation is very low. This is in spite of the fact that the firm pays half of the premium. “Even at half, most employees can’t afford it.”

Having Health Insurance Means Having Security

Another theme that emerged across all groups is that having health insurance would mean having security. If there was one point on which focus group members were especially unanimous, it was that being uninsured causes a great deal of insecurity, including:

- Fear of getting sick
- Fear of being sick and not knowing it because tests are unaffordable
- Worrying about whether they can afford care if something does happen
- Fear of losing everything because an illness would prevent them from working
- “Living with worry because you can’t get sick because you can’t pay the bills”

One individual, who said he already has creditors calling him because of \$10,000 in outstanding medical bills, said the main reason he would like to have insurance is to be covered in case “something major” happens. Another person said that with insurance, “you wouldn’t be out there dangling,” and yet another said that “You wouldn’t have to spend all your savings to go to the doctor and to pay all your bills.”

Fear of Undetected Medical Problems

Other participants mentioned living with fear that they have a medical problem that is undetected because they do not have insurance and therefore do not get regular checkups. One participant pointed out that both of his parents died of cancer and he continually lives with fear that he could be ill and not know it until too late because he has no opportunity for early detection.

Other participants mentioned living their lives more cautiously because they do not have health insurance. One woman noted “If I had insurance, I would not be as worried” and that she would be more likely to let her children play outside. Others said they did not go outside in the rain and one woman with a chronic illness mentioned that she had been hesitant to even attend the focus group meeting for fear of being exposed to an illness while there.

Patterns of Care for the Uninsured

Another line of questioning in the focus groups was how people access care given that they do not have health insurance. Not surprisingly, many participants told us that they do everything they can not to have to access care when they are ill, including applying home remedies and getting unused prescriptions from friends. When they do seek care, the charity hospital system is their first line of defense, although a great many other sources of care were mentioned, including clinics and local doctors in some of the rural areas. In terms of finding assistance in paying for

care in the absence of insurance, it became clear to us that people use a variety of different sources of assistance, including churches, local charitable organizations, free prescription or prescription discount programs, and family members.

When Uninsured People will go to Great Lengths to Avoid Visiting the Doctor

Some of the strategies our participants said they used to avoid seeking medical care include:

- Using home remedies
- Using over-the-counter medications
- “Live with it” and “Wait it out”
- Diagnosing their own problems, including researching medical conditions using the Internet
- Obtaining medications during visits to Mexico
- Obtaining unused antibiotics from friends
- “I try to make myself not get sick”

Living with a health problem and not seeking medical care does have its costs. Some participants mentioned missing time at work for a problem for which they did not seek medical attention. One man said he had a hernia in the past, but kept working even though he knew it needed to be addressed. Eventually, the hernia became strangulated. Since it was then a medical emergency, he knew it would be covered. Another woman said she has had abnormal Pap smears in the past and knows she should be getting regular checkups, but “It is going to have to wait until I have insurance.” In general, many participants mentioned that a health problem had worsened significantly in the past because they had not sought care early on. One woman said she waited over 12 months to receive a hysterectomy in an LSU hospital because she could not afford to pay the bill in a private hospital without insurance, and her condition advanced from pre-cancerous to cancer in the interim.

In some cases individuals choose not to take care of one condition because they know they are at risk for something else. One man who said he has frequent infections that need immediate attention said he has decided not to go to the dentist even though he has a cracked tooth because he knows he needs to save money for the next time he has an infection.

Need for Dental Care

Dental care was a common unmet need mentioned by focus group participants. One participant mentioning living for years with tooth decay before finding care through the LSU dental school. Another has had a root canal but could not afford to cap the tooth, so she still has unresolved problems. Yet another said, “If I had insurance, I would go to the dentist and get these three teeth fixed, but since I don’t I just load it down with orajel.” Another man said he knows people who have pulled their own teeth because they could not afford to visit a dentist for care.

Some costs that cannot be enumerated are the human costs. As one participant put it, “You suffer and you suffer, until you can’t suffer anymore.”

The Charity Hospital System is the First Line of Defense for Many

In general, respondents in each group mentioned using the LSU charity hospitals and their associated clinics for medical care. There was mixed feedback on the individual experiences with the charity hospital system, with the most frequently mentioned issue being long waits for appointments, and long waits to be seen in emergency room settings. Also, a point that was raised frequently was that a recent change in billing policy in the LSU system has made charity care less affordable.

Nearly every member of the focus groups had some experience with the charity hospital system. One individual in an urban group said he and his wife never visit a private doctor – the charity hospital is where they go when they are ill. Another said, “I just go to the [charity] emergency room. They can’t turn you down.”

For the most part, participants said they felt they received good care at charity hospitals. One woman summed up the situation by saying that there may be a long wait at the charity hospitals, but “I hope they never close.” Another said that despite all the issues associated with receiving care at a charity hospital, “It pays to go to [local charity hospital]” because health insurance is so expensive.

Affordability of Care at Charity Hospitals

Despite the above point, affordability of care at the charity hospitals was frequently raised as an issue, due to recent changes in policies for charging for care. According to participants, there is now a sliding fee scale for individuals with incomes under 200% of the federal poverty level, whereas care was previously free for such individuals. One woman who works at a charity hospital said she cannot afford to go there for care.

Continuity of Care

With the charity hospital system, the issue of continuity of care was frequently raised as an issue. Many participants discussed experiences whereby they had been to clinics for repeated visits but never saw the same doctor twice. One person mentioned having different residents repeat the same thing over and over again on consecutive visits, with no real continuity and no resolution of the problem. It should be pointed out, however, that some participants with chronic conditions such as diabetes or high blood pressure mentioned being enrolled in charity clinic programs that did provide good continuity of care and follow-up.

Long Waits for Appointments

Another issue that was frequently mentioned was the long wait for an appointment. One participant said if you made an appointment today with the charity hospital for a dental problem, you would probably not be seen for a year. Others mentioned waiting six months to a year for routine medical appointments. One participant said someone she knows has a diagnosis of cervical cancer, but the soonest she could get an appointment is two months, and the stress of knowing she has cancer is weighing heavily on her.

The other issue raised regarding waiting for care is the waiting time to be seen when you go in for an immediate problem. As one participant put it, when you are going to the charity hospital, “Pack your lunch, pack your dinner,” in order to prepare for the long wait ahead. Another mentioned bringing books to read and the need to “just be patient.” As was mentioned in the introduction to Section III, many participants did acknowledge that they realized long waits for emergency care (particularly for non-emergency conditions) would be a reality in any type of hospital. Several participants did mention, however, that they would not use the emergency room at the charity hospitals for less severe conditions if they had health insurance.

Waiting a long time to be seen has ramifications not only for the individual needing medical attention, but for employers as well. One participant who is an employer said he knows that if an employee who is uninsured needs to visit a charity hospital for care, he can count on the employee not being there for the entire day. Several people even said that they scrape together the \$75 fee to be seen a private physician’s office rather than go to the charity hospital because they cannot afford to miss an entire day’s work. The long wait can also deter people from seeking care. A couple of participants mentioned not seeking care even though they were very ill, because they felt too sick to wait in the waiting room. Still others mentioned leaving emergency rooms because they were waiting too long to be seen.

Transportation Issues

In some areas, transportation and distance traveled to receive care was mentioned as an issue. As would be expected, transportation is less of an issue in the urban areas. One urban focus group participant noted, “All buses lead to charity.” However, another participant noted that there is medical transportation to the charity hospitals, but only if you are on Medicaid. For participants outside of the urban areas, transportation and proximity to care are a major issue. One woman mentioned traveling two hours to a hospital in order to receive care she needed. In rural areas, participants mentioned needing to “bum a ride” or take a church van in order to get to medical appointments.

This raised the issue, however, of the need to schedule medical appointments around someone else’s availability to provide a ride (or in the case of the urban participants, scheduling appointments around a bus schedule). In rural areas, even where people have their own transportation, they mentioned their vehicles not being able to withstand the wear and tear of being driven to distant medical appointments. One rural participant mentioned a family member

choosing not to receive follow-up care because it would have involved a 260-mile round trip weekly to the nearest charity hospital that offered the particular therapy services that were needed.

Other Sources of Care

There are also other sources of care depending upon an individual's location and situation. For example, a participant in one of the New Orleans focus groups who works as a musician said he uses the musician's clinic for care. Because of the availability of this clinic, he had recently had his first checkup in 10 years. However, this clinic has its limitations. The individual noted that when an appointment is needed, it is necessary to visit the clinic in person rather than trying to make the appointment by telephone because it is unlikely that someone will call back. Even with that, it takes 3 to 4 months to schedule an appointment. Other non-LSU sources of care mentioned included local clinics. In the rural areas, private doctors were also mentioned as a source of care. One woman mentioned being sent to a local mental health clinic that was a "lifesaver," because even when she had insurance she could not afford her medications and she had stopped taking them until she was referred to the mental health clinic.

Even when someone finds a source of free care, there is the issue of affordability of other services such as medications. One woman recounted her experience in receiving what she considered good care at a free clinic when she had a serious spider bite. However, she said that the prescriptions she needed afterwards were very expensive.

Some individuals mentioned using private hospitals, sometimes because they were experiencing a medical emergency that precluded taking the time to travel to a charity hospital. One woman said that if she had a relatively minor problem such as a sprained ankle, she would go to the charity hospital and endure the long wait to be seen, but if she were experiencing a medical emergency she would go to the nearest hospital even if it were not a charity hospital, and let them send her a bill. As would be expected, patients are often left with unpaid bills after such visits. One man said he was seen for 15 minutes at a private hospital and was left with a bill for \$400.

One issue that was mentioned in conjunction with seeking care from various sources is that participants feel uncomfortable owing money to a medical provider, particularly in smaller towns where people tend to know each other. Even when there is an arrangement to pay for medical care over time, participants were reluctant to visit a provider to whom they already owe money. This is the case whether or not the provider has a formal policy requiring payment of balances before making future appointments.

People Use a Blend of Formal and Informal Supports to get Assistance in Paying for Services

Another theme that emerged was that low-income uninsured residents of Louisiana lean on a vast array of formal and informal supports to get assistance in paying for needed services. These range from free clinics to pharmacy assistance programs to having family help them pay medical

bills. However, many participants said there is not enough information available about obtaining assistance, and that the assistance that is available leaves gaps in terms of who is eligible or what services can be provided. Also, due to the local nature of some of the support programs, assistance is unevenly available across the state, with the urban areas tending to have more resources, as one would expect. In addition, participants spoke about the need to go to multiple locations for assistance, which consumes a great deal of time and energy.

Pharmacy Assistance

Many individuals mentioned having a pharmacy discount card to help with purchasing prescription drugs. In addition, participants talked about a drug store chain having a “price match” program for prescriptions – in the event another pharmacy sells the drug cheaper, the chain will match the price. Individuals also talked about getting prescriptions from church-based charitable organizations or local foundations. Other ways to get assistance in paying for prescriptions included assistance from pharmaceutical manufacturers. Participants mentioned that clinics can contact the manufacturers to find out if there is assistance for particular medications. Other mentioned using mail order pharmacies that would provide a larger supply of a medication for the same price as a smaller supply obtained in a retail setting.

Informal Sources of Assistance

Some individuals mentioned using informal supports such as friends or family. One individual mentioned that when she had taken care of a family’s children, the family had pitched in to help her pay for medications that she needed. Another mentioned that her church had helped her with medical expenses, “but they can only help you so much.” Others mentioned having their parents help them with medical expenses. This was not only the case with college students, as one might expect, but also with other individuals. One woman mentioned having her mother pay for her insulin, and another mentioned family members pitching in to pay for care for an older relative.

In some areas, participants mentioned local insurance coverage programs for ambulance transportation. For less than \$100 per year, ambulance transportation would be covered (but not payment for services rendered while in the ambulance).

Gaps in Assistance

Some participants mentioned that there are wide gaps in the assistance that is available. For example, one community has a free clinic system for the working poor and one for the homeless. There is no assistance except for the local charity hospital for someone who is unemployed. Another participant pointed out that it is very difficult for the working poor to pay for medical care in general: “You have to be dirt poor or well off to survive.” In addition, there are gaps in items for which assistance is available. Several participants mentioned contacting pharmaceutical assistance programs only to learn that their particular medication was not included.

A very consistent theme was the piecemeal nature of the supports that are available. One man said that if you are uninsured it is important to “piece together what you can” out of the supports available in the community from various sources. Participants mentioned how important it is to be your own advocate. One woman noted, “I try to find any venue I can to help myself,” including always making sure to ask providers if there is financial assistance available for individuals with low incomes. Others mentioned always asking physicians or clinics if they have free samples of prescription medications.

There were quite a few comments about how difficult it is for individuals to obtain information on what assistance is available. In fact, the focus groups provided a way for people to share information about where to go for assistance. From time to time, participants traded information about programs that are available. Many participants noted that even when financial assistance is available, providers do not volunteer that information. Several recommended that when the new coverage program is available, there should be a concerted effort to publicize it, because right now the only way to find out what is available is through word of mouth.

Lastly, another issue is the time spent tracking down assistance from multiple sources. People often go from place to place – e.g., one location offers free medical care while another offers assistance with prescription medications – which consumes a great deal of time and energy for individuals who have work and child care responsibilities.

What People Would Want from Insurance, and How their Patterns of Care Would Change

Another line of questioning in the focus groups addressed insurance coverage itself. One topic area was what benefits participants would consider most important in an insurance program. Another was how their patterns of care would change if they were uninsured. It is important to get a sense of the former in order to design a benefit package that will appeal to the target population. The latter is important in order to gauge the impact of the waiver on current providers.

What Benefits are most Important Depends both on an Individual’s Health Status and on an Assessment of Risk

During the focus group sessions, participants were asked to rank the following services in order of importance:

- Hospital care (including surgery in the hospital)
- Outpatient surgery
- Visits to the doctor’s office
- Laboratory tests and x-ray services
- Prescription medications

The table below presents the rankings of the various benefits across the focus groups. Please note, not every participant assigned a rank to each benefit, therefore, there will not be 61 responses in each category.

Table III.1: Frequency of Rank Order by Benefit Category

Benefit Category	Frequency of Rank Order				
	1st	2nd	3rd	4th	5th
Hospital Care	27	7	7	10	6
Outpatient Surgery	0	6	6	14	26
Doctor Visits	24	14	8	4	7
Lab/x-ray	1	9	17	21	5
Prescription Drugs	7	23	16	6	6

As can be seen from the table, the two benefits most likely to be rated as most important are inpatient hospital care and doctor visits. When looking at the first and second rankings in combination for these two benefits, the results are even more striking: 34 individuals ranked inpatient hospital care as either first or second, and 38 ranked doctor visits as first or second in importance. Coverage for prescription drugs was also considered important, with 30 individuals ranking this benefit as either first or second. It is clear that in order to be most attractive to the majority of individuals we talked with, an insurance program would need to include these three benefits.

Explanation of Choices

The rankings tell us which services individuals consider to be most important, but they do not fully explain the choices made by the participants in ranking the services. During the discussion, we asked probing questions about the thinking behind the rankings. It was clear from the ensuing conversations that there are two driving factors – a particular individual’s need for certain health care services, and fear of the high cost of inpatient hospital care. Participants also mentioned availability of other resources as reasons for not ranking certain services as highly.

Many participants who ranked inpatient hospital care as the highest priority explained their choice in terms of cost. Because inpatient hospital care tends to have the highest price tag, participants wanted to make sure that it would be covered in any new insurance program. One participant who had never been hospitalized, and did not anticipate any need for hospital care, said it was the most important because of the high cost. It is worth noting, however, that some

individuals ranked hospital care lower because of the availability of the LSU charity hospital system.

Importance of Preventive Care

By contrast, some participants said doctor visits were more important because preventive care can eliminate the need for hospital care. One participant, who said he recently had his first physical in 10 years and whose parents both died of cancer, said it was “scary” not to be able to visit the doctor and an insurance program that covers doctor visits would provide peace of mind because people could get regular medical care. Another said coverage of doctor visits would be important because it would enable her to see the same doctor each time instead of visiting a charity hospital where there would not be continuity of care. Still another said she tends to receive care in a hospital setting that could be received in a physician’s office, and she would like to have coverage of doctor visits so she did not have to go to the hospital in such cases.

Participants who had access to low-cost doctor visits through a clinic or some other avenue tended to rank coverage of other services as more important due to cost consideration. One participant mentioned being able to pay for visits to the doctor, but said that prescription drugs and lab tests are unaffordable. Some participants who ranked prescription drugs as important explained that they need medications in order to control chronic conditions such as diabetes or hypertension. However, because of the availability of pharmacy assistance programs in some areas, a number of participants did not rank prescriptions drugs highly because they could obtain assistance elsewhere.

We also asked participants to tell us if there were services that were important to them that did not appear on our list. The most frequent service that was mentioned was dental care. One participant noted that he had not seen a dentist in four years and knew that he had cavities, but did not have a way to pay for dental care. Another mentioned having had a root canal in the past, but being unable to afford to finish the procedure by having the tooth capped. Some participants did mention being able to receive dental care through the LSU dental school, however. In addition to dental care, vision care and ambulance services were also mentioned.

Most People Would Change their Patterns of Care if they had Insurance

Another very important line of questioning in terms of designing provider networks and in predicting the impact on current providers is how uninsured individuals might change their patterns of care if they had health insurance. It turns out that for many individuals, this was not merely an academic question. As discussed in Section II, in most cases being uninsured was not a lifelong situation for our participants. Therefore, people could draw on their previous experiences in thinking about what they would do differently if they were insured.

Being Able to Choose Doctors

Many individuals talked about having the ability to choose their own doctors. If you are uninsured, one woman noted, “Your doctors are pretty much chosen for you.” Another said that if she had insurance she would form a relationship with a doctor and be able to have someone to call to find out whether or not she needed to be seen, based on her symptoms. Without insurance, she said, she does not have that option. Others said they would be less likely to use the emergency room for routine care if they had health insurance.

Preventive Care

The idea of getting preventive care instead of waiting until there is an emergency was mentioned very frequently. Many participants said they would get regular checkups if they had insurance. Some participants said they anticipated that having more access to preventive care would improve their health status. Without good preventive care, one participant said, “Everything breaks down all at once.” This participant noted that health care in general would be less expensive if more people were insured because people would not need costly hospital care. Commenting on that same phenomenon, another participant noted, “This isn’t rocket science.” Another participant noted that she never had any primary care until she was 24 years old, and she suspected that she would not have as many medical problems if she had had earlier access to primary care.

Freedom to Choose Different Types of Providers

Other participants mentioned that they would see a private physician instead of visiting a clinic if they had insurance, because they could make an appointment for care and not miss as much work as is the case when they visit a clinic and wait their turn to be seen. Others said that if they had insurance, they would be more likely to seek care when ill instead of just trying to “deal with it,” as one participant put it. One man said, “You can tell people that’s got insurance or some other form of paying, because they just go [to the doctor when they are sick.] I probably would too if I had insurance.”

Others mentioned that they would use private hospitals instead of the charity hospital system, either because of personal preference or geographic proximity. Some individuals mentioned needing to travel long distances to the nearest charity hospital. If there were a private hospital near them that was included on the insurance plan, they would use that hospital instead. A number of individuals mentioned that they did not like the charity hospitals because of the long waits for care or because they do not see the same doctor each time, and indicated that if they had insurance they would choose a different hospital. One woman noted that she had recently had Medicaid coverage because of a pregnancy, and chose a private hospital to delivery her baby because she could see the same doctor each time. However, now that she has lost coverage after the post-partum period, she uses the charity hospital system.

Regarding the charity hospital system, it should be noted that some individuals said they were satisfied with the charity hospital system and would still use it even if they had insurance. Those who tended to be more satisfied indicated that because of a chronic illness, they were enrolled in programs at the charity hospitals that gave them care management and access to a regular doctor.

Following Medical Advice

Another theme was that people would be more likely to follow medical advice if they were insured. For example, our participant who indicated she has had abnormal pap smears in the past indicated that if she were insured, she would follow medical recommendations and have repeat tests every three months instead of letting it go as she does now. Many mentioned that they would be more likely to have prescriptions filled if they were insured. As mentioned before, participants indicated they are very reluctant to fill prescriptions without coverage – as illustrated by our participant who spoke of leaving her prescription slip in the trash can on the way out of the doctor's office because she knew she could not afford to fill it.

Another participant talked about making a one-month supply of blood pressure medication last 3 to 4 months by only taking pills when she had symptoms. Another mentioned that a doctor has recommended that she see a psychologist, but she has not followed through because she cannot afford to pay the bills. One woman, who suffers from diabetes, she if she had insurance she would use an insulin pump, which has been recommended in order to better control her disease. She previously had insurance, and used a pump, but can no longer afford it. She noted that her quality of life has decreased dramatically since she had to stop using the pump, with frequent trips to the emergency room.

Thoughts on Stigma and Related Issues

Another area of discussion in the focus groups was about some of the intangible issues surrounding being uninsured, and receiving assistance for insurance. We asked participants whether they felt they were treated differently by health care providers because they were uninsured. We also asked them if it would make a difference to them whether a new insurance program were administered by private insurers or through the Medicaid program. It is important to understand the former in terms of knowing whether previous negative experiences with the health care system may serve as a barrier to accessing care when individuals become insured. The latter point is important in terms of designing and marketing health care coverage so that it is attractive to the target population. For example, if people would be unlikely to sign up for a public program because it is perceived as a “welfare” program, it would make sense to design the program as a private insurance product.

There is Mixed Feedback on Whether being Uninsured Carries a Stigma

On the topic of whether our participants felt they are treated differently because they are uninsured, we received mixed feedback. While some said they felt they were treated no differently because they were uninsured, others spoke of being subject to prejudice. Some said

that it depends upon the individual doctor, and some doctors “treat you like a second class citizen.” Still others said they did not experience poor treatment from doctors, but rather from office staff.

Most People Would not Care if the Insurance Program being Proposed Were Public or Private

Feedback on this point was very consistent. When asked whether it made a difference whether the program were a public program such as Medicaid or a program that resembled a private insurance product, nearly every participant said it would not make a difference. A couple of participants said they would rather carry a private insurance card than a Medicaid card, but this type of response was unusual. Most of the commentary was that insurance coverage is so sorely needed that it would not make a difference what the insurance card said on it. One man even said “You can call it health insurance for poor people if you want,” and he will still sign up. Another participant noted, “My health is more important to me than my ego.”

Most Participants Have Had Previous Experience with Insurance Coverage

Nearly all focus group members talked about having had insurance at some point in the past. Some had employer-sponsored insurance, either through their job or a spouse’s. Others had Medicaid coverage in a different state, or had been previously eligible for Louisiana Medicaid during a pregnancy.

The reasons mentioned for being uninsured included:

- ❑ Job change or unemployment
- ❑ Loss in work hours (change to part-time status)
- ❑ Divorce
- ❑ Moving from another state with difference Medicaid eligibility guidelines
- ❑ Aging out of a parent’s insurance policy

In addition, some participants mentioned voluntarily giving up health insurance coverage at work because it was unaffordable. Once someone is uninsured, particularly if they have a chronic health condition, it is very difficult to obtain insurance again.

The fact that so many had been covered by health insurance in the past gave participants a good vantage point from which to compare what it is like to be insured vs. uninsured. This added a great deal of depth to the discussion.

Conclusion

If there is one overwhelming conclusion to be drawn from the focus group discussions, it is that coverage is sorely needed, and the sooner the better. Our uninsured participants spoke of:

- ❑ Constant worry about becoming ill
- ❑ Letting medical problems become unbearable before seeking treatment
- ❑ Choosing between medical care and other necessities
- ❑ Not being able to fill prescriptions for needed medicines, despite the availability of some assistance programs
- ❑ Using home remedies or leftover medications from friends

Focus group participants said that having health insurance would improve their lives, in that they would feel more secure, would be more likely to follow through on treatment, and would be able to choose their own doctors and hospitals.

However, in light of the discussion about cost, it is clear that the program to be offered should not present barriers to enrollment such as high premiums and cost sharing obligations. Many participants spoke of not feeling that insurance was a good value to them because after they paid a premium every month, there would still be no benefits until after a deductible was satisfied. This observation has implications for both the public program – which should not have burdensome premiums or cost sharing obligations – as well as the premium assistance component.

As for the question of whether the program should be public (such as an extension of Medicaid) or private in nature, the feedback was virtually unanimous that there would be no difference in terms of the way people would view the program.

In sum, as long as the coverage program offers the benefit that are important to our participants – at a minimum, inpatient care, preventive care such as doctor’s office visits, and prescription drugs – at a reasonable cost, it should be an attractive option to a population that sorely needs health care coverage.

SECTION IV APPENDICES

List of Appendices

This section contains the following materials:

- Appendix A: Focus group locations
- Appendix B: Focus group questions
- Appendix C: Cooperating organizations

Appendix A

Focus Group Locations

January 26, 2004

Incarnate Word Church
8326 Apricot St.
New Orleans, LA

State Office Building
2150 Westbank Expressway
Suite 310
Harvey, LA

January 27, 2004

Family Road
323 E. Airport Ave.
Baton Rouge, LA

February 3, 2004

Big Daddy's Restaurant
301 E. Miller Ave.
Iowa, LA

February 4, 2004

Louisiana Methodist Conference Center
2350 Methodist Parkway
Woodworth, LA

Shumpert Hospital
1 St. Mary Place
Shreveport, LA

February 5, 2004

Hannah's Sideboard Restaurant
832 Broadway St.
Delhi, LA

Appendix B

Focus Group Questions

1. We are trying to get an understanding of what people think about health insurance. When you hear the term health insurance, what comes to mind?
2. How many of you have tried to get health insurance? Tell us about that. Some of you said you haven't tried to get health insurance. Tell us about that.
3. When you go to the doctor or get other health care, do you feel you are treated differently than other patients because you don't have insurance? How are you treated differently?
4. We want to find out more about when you go to the doctor and when you don't go. I want you to think back over the last year or so to a time when you (or a family member) were sick, got hurt, or were worried about your health. You felt you should go to the doctor and you went even though you didn't have health insurance. Tell us about that time.
5. Now think of a time in the past year or so when you (or a family member) were sick, got hurt, or were worried about your health. You felt you should go to the doctor, but you didn't. Tell us about that time.
6. Let's say you were having a health problem today and it was keeping you from doing whatever you normally do. What would you do? If you had health insurance would you do anything differently?
7. We are looking for ideas on how to provide health insurance to people. One idea is to cover certain types of services but not others. If you had a choice, which of these would you most want covered and why:
 - Hospital care including surgery
 - Doctor's visits
 - Prescription medications
 - Outpatient surgery
 - Lab and x-ray services
8. When you need medical care, how long does it usually take you to get an appointment? How far do you have to travel and how do you get there?

Appendix C

Cooperating Organizations

- ❑ Agenda for Children
- ❑ Americorps VISTA
- ❑ Bayou Teche Regional Health Network (ByNet)
- ❑ Catholic Life Center
- ❑ Central Louisiana Area Health Education Center
- ❑ Charity Hospital
- ❑ Children's Coalition of Northeast Louisiana
- ❑ Covering Kids and Families
- ❑ Daughters of Charity
- ❑ Delphi Hospital
- ❑ DSS, Office of Family Support
- ❑ Family Practice Clinic, East Carroll Hospital
- ❑ Family Road of Greater Baton Rouge
- ❑ Greater Baton Rouge Head Start
- ❑ Hanna's Sideboard
- ❑ Incarnate Word
- ❑ Lafayette Community Health Care Clinic
- ❑ Louisiana Business Group on Health
- ❑ Medicaid Region 7
- ❑ New Orleans Health Department
- ❑ OPH, Parish Health Unit
- ❑ Shirley Medical Clinic
- ❑ Shumpert St. Mary's Hospital
- ❑ Southwest Louisiana Area Health Education Center
- ❑ Southwest Louisiana Center for Health Services
- ❑ Vermilion Rural Health Network
- ❑ Vietnamese Initiatives and Economic Training (VIET)
- ❑ VOA - Baton Rouge, Partnerships in Child Care