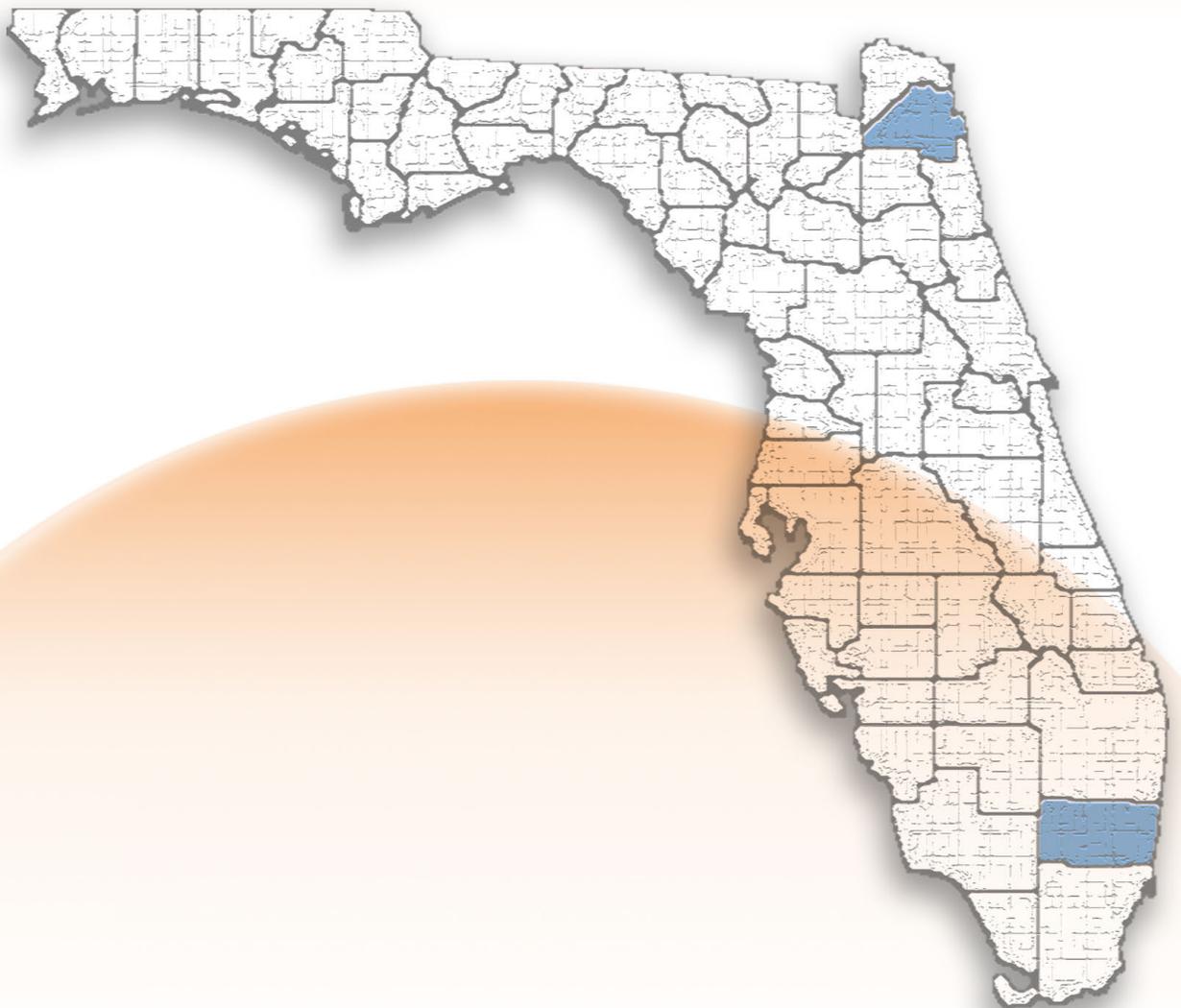




Evaluating Medicaid Reform in Florida



Medicaid Reform Preliminary Baseline Findings From Longitudinal Study



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MEDICAID REFORM
PRELIMINARY BASELINE FINDINGS FROM
LONGITUDINAL STUDY

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MEDICAID REFORM PRELIMINARY BASELINE FINDINGS FROM LONGITUDINAL STUDY

EXECUTIVE SUMMARY

Effective July 1, 2006, the Florida Agency for Health Care Administration began implementing changes to the Medicaid program in Broward and Duval Counties. Essentially, the state mandated that most Medicaid beneficiaries enroll in HMOs or Provider Service Networks (i.e., health plans). For individuals enrolled in the state's primary care case management program, this represented a significant change in how they would receive their healthcare services.

As articulated in the Section 1115 Waiver Application, a major principle guiding Medicaid Reform is patient responsibility and empowerment (Florida Agency for Health Care Administration, 2005). As such, Medicaid Reform is designed to encourage greater consumer involvement in their health and health care leading to an improvement in health outcomes. Implicit in this process is enrollee capacity, ability, and desire to make these choices. The "Longitudinal Study" component of the Medicaid Reform Evaluation is designed to elicit enrollee attitudes and beliefs about health care and Medicaid and to capture in-depth and contextual information about their experiences under Reform. Study participants will be interviewed or will participate in focus groups several times throughout the life of the evaluation. Reported here are baseline findings from qualitative interviews conducted with enrollees between October 2006 and May 2007.

A total of 37 beneficiaries were interviewed from both Broward and Duval Counties. All participants are early enrollees to Medicaid Reform or were about to be enrolled in Medicaid Reform plans. Consequently, these enrollees do not have long-term experience with Medicaid Reform. Therefore, the views expressed by these respondents should not infer success or failure of the Reform effort, but rather provide a sense of how Medicaid consumers may respond to the program changes. The following key issues, however, are worth noting and following throughout the evaluation period.

- **Control of Health is Influenced by Individual Belief, Money and Resources, and Faith.** Respondents noted that maintaining health is related to an individual's belief in their own ability to influence their health. Other factors, notably money and resources, and faith in God are also key to maintaining or regaining health. Consequently, the lack of resources (e.g., money for healthy food or to sign up for an exercise program) may deter initial participation and program completion in the Enhanced Benefit Program. Thus, although consumers may appreciate being rewarded for healthy behaviors, this may not provide sufficient incentive to get them involved in healthy behaviors, especially those behaviors that are not paid for by the Medicaid program.
- **Relationships with Physicians are Important to Consumers.** Medicaid consumers cherish their relationships with their physician providers. Health plan choice is almost

always dictated by advice from the physician or physician office staff and a desire to remain with that physician.

- **Medicaid Consumers Actively Pursue Health and Healthcare Information.**

Although physicians are major sources of health information, consumers also look to a variety of other resources (e.g., the internet, library) for information on their health and health care. Notably, social networks are key to gaining information on providers and health plans. Among the consumers interviewed, the Choice Counseling program had not yet emerged as a major source of health information, but instead is used as a mechanism to select a health plan.

- **Experiences with Medicaid and the Healthcare System are Not Always Positive.**

Respondents spoke of non-Reform related issues such as re-enrollment, restricted prescription drug coverage, perceived restrictiveness of MediPass relative to the traditional fee-for-service arrangement, and difficulty finding specialty providers and dentists who will take Medicaid. Medicaid Reform does not specifically address these issues. It is important to consider these barriers and the extent to which they may impact the stated goals of Medicaid Reform.

- **Consumer Knowledge of Medicaid Reform is Uneven.**

General consumer understanding of the concept of “Medicaid Reform” is limited. When asked, individuals may have heard of specific aspects, but the terminology such as Choice Counselors or Enhanced Benefits were unfamiliar to many respondents. Several consumers had heard of the Enhanced Benefit Program, but none had participated in the program. None were aware of the Opt-out program.

INTRODUCTION

Effective July 1, 2006, the Florida Agency for Health Care Administration (AHCA) began implementing changes to the Medicaid program in Broward and Duval Counties. Essentially, the state mandated that most Medicaid beneficiaries enroll in HMOs or Provider Service Networks (i.e., health plans) and would no longer be allowed to enroll in MediPass, Florida's Primary Care Case Management Program. For individuals enrolled in the state's primary care case management program, this represented a significant change in how they would receive their healthcare services.

As articulated in the Section 1115 waiver application, a major principle guiding Medicaid Reform is patient responsibility and empowerment (Florida Agency for Health Care Administration, 2005). As such, Medicaid Reform is designed to encourage greater consumer involvement in their health and health care. Notably, consumers are expected to have a greater choice of health plans, including the option to enroll in employer-sponsored plans. The state also established Enhanced Benefit Accounts to provide credits or rewards to individuals who engage in an approved list of healthy behaviors. Consumers can use these credits to purchase non-covered health-related items from pharmacies.

A key element to empowering consumers is the development and dissemination of accurate, timely, and easily understood information via the Choice Counseling program. The state anticipates that increased choice and overall greater empowerment will lead to "improvement in individual health outcomes as people take an active role in managing and understanding their health care needs" (Florida Agency for Health Care Administration, 2005). Implicit in this process is enrollee capacity, ability, and desire to make these choices. Also critical to the success of Medicaid Reform is understanding how individual experiences may influence enrollee responses to program changes.

The impact of Medicaid Reform on consumer experience, satisfaction, health empowerment, consumer choice, and consumer health will be largely evaluated using Consumer Assessment of Health Care Provider and Systems (CAHPS) surveys and secondary analysis of encounter data and data from the Healthcare Effectiveness Data and Information Set (HEDIS). However, to provide context for the findings that emerge from these analyses, it is important to have an in-depth understanding of consumer attitudes and beliefs about health and health care, their previous experiences with Medicaid and the overall healthcare system, and their current experiences under Medicaid Reform. Therefore, one component of the Medicaid Reform evaluation will be periodic in-depth interviews and conversations with consumers about their overarching health beliefs and healthcare experiences. The study described here represents baseline findings from the longitudinal qualitative component of the evaluation. This study uses both focus groups and in-depth telephone interviews to elicit enrollee experiences and delve into individual factors that affect these experiences.

BACKGROUND: PREVIOUS RESEARCH ON ENROLLEE EXPERIENCES WITH MEDICAID MANAGED CARE

In recent years many states across the nation have implemented Medicaid Managed Care (MMC) programs in an effort to contain escalating program cost and enhance inadequate access to more timely and suitable primary care (Garrett & Zuckerman, 2005; Chaudry, Brandon, & Schoeps, 1999). In 2006, the State of Florida implemented its Section 1115 Waiver Demonstration in Broward and Duval Counties. The key principles of Medicaid Reform include predictable growth, the ability to create a bridge between public and private coverage, marketplace decisions, patient empowerment, and individual responsibility (Florida Agency for Health Care Administration, 2005).

The theory behind states' desire to implement MMC is based on the principle that managed care could reduce health care cost by employing utilization management strategies and ensuring access to preventive and primary care through the creation of linkage between providers and patient education (Chaudry, Brandon & Schoeps, 1999). However, MMC is faced with the formidable challenges of providing service to the vulnerable populations often with multiple complex medical needs (Hawkinson & Frates, 2000). Medicaid enrollees are also disproportionately low income and disadvantaged, residing in communities with environmental and physical challenges. Beneficiaries often live in communities where poverty and complex social needs combine with other factors to shape health outcomes (Rowland, 2005).

Enrollee Access

During the dramatic rise of MMC during the 1990s researchers observed mixed results on enrollee access and utilization. A 1995 Kaiser Commission on the Future of Medicaid literature review (Rowland, Rosenbaum, Simon, & Chait, 1995) suggested that beneficiaries' utilization patterns appeared to change. This review highlighted that MMC was associated with reductions in non-urgent emergency room (ER) use and specialist visits. They observed mixed results with respect to physician visits and inpatient services. Evidence from this review also suggests that enrollee access to preventive care was neither improved nor impeded under MMC.

A more recent study (Garrett, Davidoff, & Yemane, 2003) examined the broad effect of MMC on access to care and use of services at the national level using the National Health Interview Survey (1991–1995). They observed that the effect of mandatory Health Maintenance Organization (HMO) programs on women resulted in reductions in some types of non-urgent ER use and increases in reports of unmet medical need. In children, the existence of mandatory HMO membership resulted in reduction in the reliance of Emergency Departments (ED) for non-urgent care, increased likelihood of having a usual source of care, and increased specialty visits. Garrett and colleagues found that in states with both Primary Care Case Management (PCCM) and HMO programs, there was a reduction in ED visits, while the use of other types of services, and healthcare access increased (Garrett, Davidoff & Yemane, 2003).

Other studies using the National Survey of America's Families (Garrett & Zuckerman, 2005; Zuckerman, Brennan & Yemane, 2002) both found that Medicaid beneficiaries under mandatory HMO exhibit less reliance on EDs as a source of usual care. However, there were mixed results with respect to probability of having an ambulatory care physician. While Garrett and Zuckerman (2005) observed that there was a 13 percent point decrease in the likelihood of MMC enrollees having an ambulatory physician and less use of preventive care. Zuckerman and colleagues (2002) found that enrollees experienced an increased probability of having an ambulatory physician and greater use of preventive care. In states with PCCM plans, researchers noted children benefiting from such programs but little effect on adult enrollees (Zuckerman, Brennan & Yemane, 2002). However, Garrett and Zuckerman (2005) found that PCCM programs affected adults by reducing physician visits yet had no effect on other measures of use.

Enrollee Experiences & Satisfaction

While earlier research suggests mixed results for the impact of MMC programs on access to care, there is limited knowledge on the contextual understanding of enrollee experiences relating to health belief, knowledge, and attitudes. Several studies have conducted focus groups during the early phases of managed care programs. Chaudry, Brandon, & Schoeps (1999) conducted six focus groups to describe Medicaid enrollee experiences under managed care. These researchers observed a general consensus with respect to improvement in access to primary care and continuity of care under MMC. However, participants also expressed displeasure with provider choice restrictions and emergency use. There was no consensus on which factors led to individual plan selection. The study also noted the recurring theme of discourteous treatment of Medicaid recipients by healthcare professionals that appeared to decline slightly under MMC.

Hynes, Resinger, Sisk, & Gorman (1998) conducted three focus groups to pilot the construction of a survey instrument that analyzed satisfaction, access, and service utilization during the early phase of the New York City voluntary MMC program. Researchers observed that more than half of the participants had enrolled in the MMC program and very few persons recognized the term "managed care" even among persons with health plan experiences. Participants also expressed anxiety about shifting from traditional Medicaid to MMC. The major apprehension of focus groups was being able to select a suitable provider (i.e., provider that cares and will spend sufficient time with their patients). Researchers also noted the pervasive belief of second-rate treatment of enrollees by healthcare professionals.

In another study, Woolridge et al. (1996) observed in three states (Tennessee, Rhode Island, and Hawaii) that managed care participants were generally satisfied with the medical care they received but highlighted delays in the enrollment process, lack of information about plans, and confusion in the selection of health plans and providers.

METHODOLOGY

The purpose of this study was to elicit consumer views about their health, their ability and strategies they employ to improve or maintain their health, and knowledge of Medicaid and Medicaid Reform. This study represents baseline views of consumers who will be interviewed periodically throughout the duration of the evaluation. Focus groups and in-depth interviews were conducted with consumers between October 2006 and May 2007.

Instrument Development

Instrument development was guided by various health belief, health communication, and health behavior theories (Glanz, Rimer & Lewis, 2002). Questions were developed based on the review of these theories and from reviews of the literature and other instruments.

Questions were initially developed for the focus group guide. The in-depth interview guide was refined and updated after the focus groups were completed. Interview questions focused on:

- attitudes and beliefs about health,
- experiences in getting health care and health information,
- past experiences with Medicaid, and
- knowledge and experiences with Medicaid Reform.

Recruitment

Two separate approaches were used to recruit participants for the focus groups and in-depth interviews.

Focus Groups

Community liaisons in Broward and Duval Counties assisted with recruitment. Solicitation flyers with the community liaison contact information were placed in hospitals, community centers, and medical practices where Medicaid beneficiaries were likely to visit. Liaisons also used their own social and community networks to recruit individuals. The sample inclusion criteria were anyone that participated in Medicaid or was the parent of an enrollee, lived in the respective counties, and were eligible to participate in Reform. All procedures were approved through the Institutional Review Board of the University of Florida. Individuals gave oral and written consent to participate in the study.

Three focus groups were conducted—two in Duval and one in Broward. Individuals received \$20 gift cards as compensation for participating. The focus groups had a total of 27 participants. The sample consisted primarily of African Americans (63%) and Hispanics (26%). Focus group participants reported varying educational attainment, including some high school (22%), high school graduates (41%), some college (19%), two-year college degree (15%), and four-year degree (4%).

In-depth Interviews

All current Medicaid enrollees (adults and children) eligible to participate in Reform were considered eligible to be recruited for in-depth interviews. From AHCA eligibility/enrollment files, a sample was drawn based on county level race, gender, age, and eligibility type including Supplemental Security Income (SSI) and Temporary Assistance for Needy Families (TANF). In the case of minors, the parents or guardians were considered proxy informants. An initial sample of four hundred was pulled from the AHCA database. However, from this initial dataset approximately 10% (39) of the persons were considered ineligible due to missing telephone numbers. These individuals were matched and replaced in the sample.

Two waves of recruitment letters were mailed on February 16, 2007, and April 17, 2007. Respondents willing to participate in the study completed a consent form and mailed it to the Longitudinal Study Team in the return envelope provided. A total of thirty persons (30) returned consent forms. Enrollees who completed and returned consent forms were contacted by telephone to schedule an interview. On average, three (3) attempts were made to schedule interviews with those who had mailed in the consent forms. Telephone interviews approximately 60 minutes long were conducted with ten (10) Medicaid beneficiaries. After the completion of each interview, each participant was mailed a \$10 gift card.

To ensure interview quality and integrity, two team members conducted each audio-recorded interview. Study sampling yielded N = 10 recruits (7 adults and 3 children). The sample had a majority of female participants (80%) whose ages ranged from 15 – 62 (Mean age of females = 36.3). The sample consisted primarily of African Americans (60%) followed by Other (20%) and White (20%). Educational attainment was not collected from this sample.

A total of 37 individuals participated in either the focus groups or the in-depth interviews.

Data Analysis: Analytic Approach

All focus groups and in-depth interviews were audio-recorded. All audio-recorded interviews were transcribed verbatim by professional transcriptionists.

Coding

A coding scheme was developed based on the focus group and in-depth interview instruments. Eight global themes were identified, including Introduction, Health Belief, Health Status, Health Information, Medicaid Experience, Medicaid Reform, Experience with Care, and General Opinion. Each transcript was coded and reviewed by all five team members. Discrepancies in coding were identified and consensus was obtained through discussion and clarification of coding categories and specified definitions. Domain analysis worksheets were developed to categorize the data. Focus group findings were coded using NVivo 2.0 software. In-depth interviews were coded using Atlas.ti 5.0 software.

FINDINGS

The focus groups and in-depth interviews provided insight into consumer experiences with health care and Medicaid specifically. In addition, the conversations revealed underlying knowledge, attitudes, and beliefs about health and health care that influence experiences. Findings were organized around five major themes that emerged from our analyses.

Theme I: Consumer Definitions of Health

Theme II: Strategies for Remaining Healthy or Regaining Health

Theme III: Getting Information about Health and Health Care

Theme IV: Experiences with Health Care, Medicaid, and Medicaid Reform

Theme V: Knowledge and Attitudes about Medicaid Reform.

Theme I: Consumer Definitions of Health

Participants were asked to define the concept of health. Many defined health by what it is not:

Good health means not having to go to the doctor on a regular basis.

No need for medication.

No pain.

No allergies.

Other comments reflected functional definitions of health and its relation to current quality of life and past experiences. Health is defined in terms of things you can and things you cannot do and the ability to complete tasks.

Heath means being able to take care of yourself.

For my child...health is doing exercise, walking, playing around.

You can do just about anything you want to do.

Being able to do the things that everyone healthy can do.

You can do just about anything you want to do.

Bad health was defined by doing or participating in activities that are negative (e.g., doing drugs, drinking alcohol, sex, smoking, not going to the doctor, or waiting too long to go to the doctor). To not be healthy is to be “*miserable and lonely*” and “*sick, sick, sick.*”

Several individuals who described themselves as being sick or ill noted that being unhealthy or unwell is a “state of mind.” These individuals stated that they were not going to “worry” about their illness and that they were going to live their lives as best as possible:

...but I am not going to let my weakness and my sickness bother me because I stay walking and I stay going you know, stay going everywhere, but the pains just come and go. And I am not going to let my pains bother me.

I don't worry about nothing, because if you are sick, you feel sick, that's all on your mind. When you think about it, you feel weak.

Be thankful that you can get around because some people can't walk.

Being mentally happy is not worrying and being able to figure things out for myself.

This “state of mind” view of health has a spiritual dimension as many participants indicated that faith in God through prayer enabled them to maintain positive attitudes.

I'm fine, I'm fine, and it's in the hands of God.

Though some enrollees expressed not using spirituality as an aid in their health, the majority indicated that spiritual health is paramount to overall health:

Interviewer: Ok. So what kind of role do you think spirituality, going to church, and all of that plays in your health?

Respondent: Oh I think a lot because we couldn't do nothing without that. That is the first thing right there.

Theme II: Strategies for Remaining Healthy or Regaining Health

Many of the phrases used to define health reflect actions to maintain health (e.g., having breakfast, going to the doctor, exercising, eating well and “*being careful what I do to not affect my body*”). Overwhelmingly, when asked about strategies to remain healthy or to regain good health, consumers focused on the role of nutrition and diet, and to some extent physical activity and exercise:

I would change the way I eat...like when you bake food, you don't use oil and you won't have that much calories.

...weight...it's the only thing I want to change.

So, before she (respondent's daughter) gets to my age, I try to instill in her no high salt. I am trying to put her on a diet (with) fruit...we wasn't brought up on fruit.

I cook with a little bit of margarine; this cuts the calorie down in whatever I am cooking. If I fry some chicken, I fry it in a little butter, some margarine butter. I don't use straight cooking grease.

I don't eat too much unhealthy food or whatever. I don't cook all that.

Stop eating salt and stop eating pork.

Respondents were asked about whether they thought they were able to “control” their health, or if they knew what actions were necessary. Individuals identified five primary factors that facilitate control of health.

Theme II.1: Individual ability

Theme II.2: Role of others such as family and friends

Theme II.3: Role of clinicians and the medical care system

Theme II.4: Money and resources

Theme II.5: God and prayer.

Theme II.1: Individual ability

Control of health lies chiefly with the individual. Respondents were generally motivated or empowered to control their own health. Many thought they could control their health and spoke of examples where they changed their lifestyle or behavior.

I am the best one to judge of what I want and who I want. What I need.

...Sometimes you just have to...take charge...you have to go in there and you have to read and you got to look and you got to move.

I am going to give you an example of controlling my health. I used to smoke. I smoked cigarettes for 8 years...I woke up in December of last year and I told myself I am going to quit smoking cigarettes and I quit smoking cigarettes.

Interviewer: Do you think you can control your health? Do you think you are responsible for controlling your own health?

Respondent: If I could put my mind to it.

I weigh 160 pounds and I don't have much money, but I want to (lose) weight. It is up to you if you want to go the extra mile to do certain things concerning your health. I am the type of person that will go the extra mile.

I don't let nobody control me.

While control of health is regarded as personal and individualistic, many acknowledged that it is very difficult to do and that they (beneficiaries) lacked the willpower.

Sometimes I can't control my health either.

You got to have a lot of willpower.

Interviewer: Do you have control over your health personally?

Respondent: No.

Interviewer. Why is that?

Respondent: Not now I don't.

Interviewer. Have you had in the past, do you think?

Respondent: Maybe when I was younger, If I had lost weight, knew more than I know now. Change my living and eating habits.

Interviewer: You don't think you can do these things now?

Respondent: Well, the damage is already done, so you can't undo what's already done.

Controlling my health...well, I used to be able to. I controlled my pain for the last eight years with over the counter drugs....but it doesn't work anymore. I have no control.

Interviewer: Why do you think you can't quit smoking?

Respondent: Just not ready to...I came a long way. I used to do drugs; I came a long way, so I am not ready to stop smoking cigarettes.

Interviewer: Do you think you can control your family's health?

Respondent: How could I go about doing that? I can't control their health.

Upbringing and culture also has an impact on an individual's ability to control their health. Some respondents spoke about their own diets as children.

Coming from how you was brought up. If you was never taught these things, how would you know? I thought that you could eat fried chicken, cause I was taught that. It didn't bother me until I found out from Dr. X you got to leave fried chicken alone...

Most black people, they don't eat fruit.....most of us was brought up on eating vegetables and leave the fruit out. Add carbohydrates and a piece of meat and you are good to go.

Theme II.2: Role of others such as family and friends

While some individuals did not speak to the degree to which their own health is controlled by factors other than themselves, many did recognize that they may need help and so seek information to gain control of their health. It is at this point that individuals rely on others, including their physicians, nurses, family members, and friends to provide the information and encouragement they need.

I try to control it myself, but if I can't control it, I see if I can get help.

I actually went through a program of trying to control my high blood pressure and that was the hardest thing for me to do because I didn't have a lot of resources. I don't know too many people that knew resources about high blood [pressure].

Interviewer: So, when you think you are losing all that weight, was someone helping you or were you doing it on your own?

Respondent: Someone was helping me...encouraging me to eat the right food and stuff...yes, like somebody to push me. If I try to do it on my own, it is not working.

Parents have a strong influence on controlling the health and health behavior of their children. This control may be exerted through diet, exercise, advice, and example.

Yes that's controlling it; they get their nutrition from what I cook. Cause I don't go for no take-out.

I put them (children) on a diet, what they aren't supposed to eat and what they can eat.

I make it a point (to) work them out...you know at least walk around the neighborhood with them for 20 minutes

I tell my daughters even or any kind of young person, do not use your back, use your knees [to lift].

It took some reconstruction of my thought processes to get me to where I am now because I notice my babies will follow my pattern....

Theme II.3: Role of clinicians and the medical care system

Consumers did recognize the links between health care behaviors (e.g., visiting the doctor, taking medications) and control of their health. Clinicians were viewed as key sources of information for controlling health.

They (doctors) be staying on me like you can't do this, do that, you have to do this and I appreciate it because they are keeping my health up.

Interviewer: So when the doctor or nurse tells you this information, do you listen to them, do you follow it?

Respondent: Yes, I do. High blood pressure ain't nothing to play with.

Interviewer: If you need information about your asthma, or to improve weight loss or anything related to you or your children, where do you get this information?

Respondent: The doctor.

Control of health is when you take medications, sleep and wake up, take your medication and go to the doctor, the psychiatrist, and go to my regular doctor for check-ups.

However, some consumers expressed negative views on the role of health care on overall health.

I don't pay no attention to the doctor. I hate to tell you this, because if I am taking a pill and it is not doing me right, I will know in two days...I will notify him and tell him so he has it on his record, but I will stop taking it and I will go to the health food store at that point and see what they have that I can take.

My one little boy, he gets ear aches all the time, but they just keep giving him antibiotics. I don't know why they can't just say or do something...They just keep bringing him back; because they know they are going to get their money...he (doctor) is a quack to me.

Theme II.4: Money and resources

Money, or lack of money, affects the ability to control health in several ways, including the purchasing of healthy foods, going to the doctor, and buying medications. The high cost of purchasing healthy foods was cited as the main effect of lack of money on the ability to control health.

Yeah because you got, in order to eat right you have to have money to buy the right kind of food. If you eat healthy it is going to cost you more money.

Interviewer: What would you do to take care of yourself a little better?

Respondent: In the future, start saving.

Interviewer: Saving to do what?

Respondent: So that I can be able to live right live healthy.

Well I can control my health providing that I have the tools and the means of buying the stuff I need.

Like people with diabetes, people with hypertension, see most of those people like that; they have to take most all of the income they got to stay healthy. It is the medicine... but the biggest overall is the food.

To eat healthy it cost more than just going to buy a bag of potato chips or going to McDonalds... You know they got the dollar menu but when you got to eat healthy is like you have to spend more money to eat healthy.

Yeah, because if you got a problem and you need to go to the doctor and you don't have the money, then you are just tough out of luck.

Although lack of money was cited as one of the primary factors that impact control of health, many individuals indicated that money is merely a tool and the responsibility to control your health is your own. To this end, some individuals exhibit resolve in getting care.

Money don't help you to feel good and it don't help you feel bad. The money is just a way to pay.

Because even if a lot of people can honestly say even if they did lower the prices on the healthy stuff that don't mean that we are going to eat it. [Laugh]....we are still gonna go against it...you have to be self-motivated.

Yeah, if I feel real bad, and I ain't got the money, I'm still going to the doctors, they just have to deal with me.

Nope, that's when I go to my son. I got seven kids, two girls and five boys. I go and ask them to pay for my prescriptions.

Beyond having enough money to purchase healthy foods, going to the doctor, and purchasing medications, many individuals were simply overwhelmed with the cost of living in general. This is compounded by the fact that many of the participants were too sick or unable to work. Worry about paying utilities and mortgages ultimately affect their mental health status.

If I got a bunch of money I wouldn't have to worry about my losing my house and that I think would, instead of taking all this medication I take, it might calm me down you know and make me feel better about myself, if I didn't have to worry about losing my place, the only place I have to live.

If I was rich or had more money coming in I'd like to think that it would make me happier because I would be able to do more things with my kids.

Theme II.5: God and prayer

Although control of health is regarded as very individualistic, faith in God has a profound impact on an individual's self-confidence and their perceived ability to control their own health. Individuals consider themselves subject to God and His will for them, and have faith that God will take care of them. This faith is built on reading the Bible and prayer.

I put God in the mix of it, and therefore that's what's helping me.

I tell God, I say I need help, my bills are due, my water's going to get cut off, my light's going to get cut off, and then just like when I go doing that, and then just like, when I talk to God and I pray and I tell God what's going in my life, and when I obey Him, then things start going good for me. Well, the minute I don't obey Him, it's just like, He just take His hand off of me and just let me just run, run wild like a chicken.

I prayed and I told God to give me a good doctor report when I go to the doctor. So when I go, I got a good doctor report.

Pray to God to keep my health up and in good health.

I think it (faith) really do plays a big role because a lot of times like I be sitting home at the house and my pressure would be so high and I could sit here in the den after taking my pills, and just sitting waiting on the medicine to kick in and then I just say Lord it is in your hands. And I sit here for a few minutes and then the next thing I know I just get my Bible and start reading and it will begin to, you know, like drop.

Theme III: Getting Information about Health and Health Care

Participants were asked to describe where they go for information about their health (e.g., information on specific ailments, healthy lifestyles, etc.) and health care (e.g., selecting a physician or health plan). Medicaid beneficiaries are highly motivated consumers and actively engage in seeking information about their health and health care.

So they had my gallstones out. I asked many people how many gallstones he (the doctor) took out, and how many patients did he get that day and how were they after they got out of surgery...how long they be hurting afterwards and stuff like that.

I pick where I want to go, I ask different people about which hospital to go to, whether he (the doctor) is up to date with all kinds of problems. Like if you have a heart problem, I want to go to a heart specialist doctor and then I want to know what he going to say and then if he say something different then I go to another doctor to see if that doctor tells me the same thing my doctor tells me.

She gave me a cholesterol test and said, oh, your cholesterol is high. I looked it up and it turns out that I shouldn't have eaten 24 hours before she did that test.

So, they were reading my MRI tests. The way it sounded, it was like nothing was wrong with my back and then I looked it up on the computer, and the doctors are saying one thing and what I read was another.

Theme III is further categorized into sources of health information and barriers to health information.

Theme III.1: Sources of health information

Providers and clinicians are a main source of information about health issues.

Interviewer: Where do you get information about your asthma or to improve weight loss or anything related to you or your children?

Respondent: The doctor.

Interviewer: Is there anywhere else or anything else that you will do or anywhere else you will go for information?

Respondent: Nope, just the doctor.

Interviewer: Where do you get information on your health?

Respondent: Through a doctor.

Interviewer: Is that the only way you get health information?

Respondent: Yes.

Beneficiaries primarily rely on their doctors for advice in selecting a health plan. Further beneficiaries are comfortable with their reliance on providers for advice regarding Medicaid.

At the doctor's office, they gave us a booklet on different changes like First Coast and all of them different little companies. And they (the doctor's office) was telling us which ones to switch to if you want to stay with that office.

Respondent: What I did was ask my physician what health care is good for the children.

Interviewer: What do you mean what health care is good for you?

Respondent: I mean HMO.

She asked me if I was on Medicaid, and I said yes. She told me to call my Medicaid (counselor) and talk to them and that they got plans that you can go in. So I called them and I talked to them and they told me they would send me a booklet of the different plans....the first plan I saw was Staywell. The doctor I went to did not have that plan so I went to Preferred. The Preferred doctor I like her, her nurses...they talk to me, explain everything about my health and everything.

Actually my doctor has really helped me, educated me about Medicaid.

Consumers utilize other resources for information about their health and health care. They will go to the library, search the internet, and review information provided by Medicaid and health plans.

I have a lot, you know, of books and magazines. I buy health and wellness magazines, Prevention, anything on health I buy it or take it out on the internet.

Sometime I see commercials about weight loss on TV.

Interviewer: Where do you look for information on how to better take care of yourself?

Respondent: TV, computer.

I read everything I take. I read all the papers that they give me on side effects. I have a son, he is in fourth grade, he can work the computer better than me, look up the computer about myself.

I also go to the library and look up our sicknesses, you know like sinus infection, high blood pressure, sickle cell anemia, what it comes from, what organs it affects.

Social networks, advice from friends and family play a significant role in healthcare choices.

I talk to people and see what they say, what is good, what is not good.

I get on the phone and make a phone call. Call and see what kind of doctor, is the doctor good, is the hospital good. I mean people talk, if it is something good, they are going to tell you, that's the way people talk about it. If it is good, they are going to talk about it, same if it ain't good.

I ask my friends if they can recommend anybody good...it is actually hard because some of my friends go to different doctors for different things. I have one friend who told me you can actually get brochures if you call Medicaid. They will actually send you a list of doctors and you can call around yourself.

Theme III.2: Barriers to health information

Beneficiaries described several barriers to getting good health and healthcare information. Although most were able to get some of the information they needed from providers, a few indicated that providers did not always have what patients needed.

I was asking for information on arthritis and they did not have one pamphlet. It's a big clinic and they didn't have one pamphlet on arthritis, and they did not have no pamphlets on diabetes....doctors tell you different things wrong with you, but there is no information....and even one of the nurses said they did not have anything to offer the patients. My doctor told me to contact the arthritis foundation. Yeah, that's what she told me and that's what I did. I had to contact the arthritis foundation. And then I have an orthopedic[doctor] and he has nothing in his office either.

I don't get too much from the doctor, that's for sure. They don't tell you nothing.

I asked them what was the doctor doing, what was their plan and they said they had to read the chart. But the one nurse said she was having problems reading the doctor's notes, could not read them. I did not know I was going home until they come in last night and said I was going home.

Others noted that language and terminology were sometimes difficult to understand.

Make it more easy lingo, understandable instead of using big words, make it more simple.

You know they use big words sometimes, those make it difficult to understand.

You know when you receive bulk mail like that is just overwhelming, you know, where do you begin to read? Where you know, by the time you get to the last paragraph of the first letter you are confused. And then you know, for example, I mean I know that if you would open this too, is probably easy. I mean, if you could really sit down and have the time to look at all of this information, but ...

It breaks it down by the age of the children, all the plans, is just a lot of information and it requires a lot of reading. I personally don't have the time that I need to probably sit down to take the time to read it, I am sure if I could that I would understand something, it is just very overwhelming.

Theme IV: Experiences with Health Care, Medicaid, and Medicaid Reform

Interviewees reported both positive and negative experiences with Medicaid prior to Medicaid Reform, which began in September 2006. Many stated that they were grateful for the role Medicaid plays in ensuring them access to healthcare services.

Interviewer: Have you had any bad experiences with Medicaid, or negative experiences with Medicaid?

Respondent: No, none at all. Well if I didn't have Medicaid I wouldn't be able to see the doctor or get my medicine but yet I don't have a choice of doctor.

The good thing is that they are there for me.

Experiences with Health Care, Medicaid, and Medicaid Reform were further categorized in the following five sub-themes.

Theme IV.1: Longstanding relationships with providers

Theme IV.2: Barriers to care

Theme IV.3: Belief that Medicaid beneficiaries receive unfair treatment

Theme IV.4: Preferences for certain hospitals

Theme IV.5: General opinion of the healthcare system

Theme IV.1: Longstanding relationships with providers

Medicaid consumers value their longstanding relationships with their physicians who were often viewed as major sources of information and as attentive and caring. Health plan choices reflect a strong desire to maintain existing relationships with physicians. In addition, consumer responses reflected a high degree of comfort with utilizing providers to facilitate navigation through Medicaid and as a major source of health information.

The first plan, like I said was Staywell, the doctor I went to did not take that plan, so I had to change and then I went to Preferred.

She actually started at Shands...and I was like her second patient. And she and me started talking...and I told her when I pick my doctor, she was going to be my doctor and once she left Shands...I followed her wherever she went.

Actually, my doctor has really helped me, educated me about Medicaid.

Consumers liked their existing providers because they viewed them as attentive, caring, and thorough.

A doctor that's being concerned, a doctor that helped. I like a doctor that asks questions. I like to be able to ask questions, that's what I mean about a good doctor.

Interviewer: In what way would you say your doctor is good?

Respondent: Because she gave me a good examination, a thorough examination from head to toe.

When we met first, she talked to me first, then she talked to my son, then she told my son she hoped that he enjoyed the service she gonna give him. I mean she was very, I mean she is great. I would recommend her to anybody with kids.

Participants expressed concern that the current Medicaid program fosters disruption in these long-standing relationships. Consumers did not necessarily attribute these disruptions to the recent changes to the Medicaid program, but rather thought it was just a common occurrence.

Well I have been to some specialists in the past that don't take Medicaid anymore, and I have had to change doctors.

Like I wanted to go back to the old dentist, he quit taking Medicaid because they wouldn't pay [his] bills and I had to get out searching for another [dentist who takes Medicaid].

I had one doctor that was, he took the insurance, MediPass, but he told me he couldn't take me no more and I had been to him almost two years with my high blood pressure.

It makes you feel bad because you done got a relationship with this doctor, then all of a sudden things change cause of the insurance and you feel discriminated, you feel deprived and say the hell I ain't going to no more doctors, I'm just gonna, I'm not going to go, ... until it hits you, you got sick again, your medicine runs out, you got to find another doctor and you got to go through all this all over, getting to know a doctor and really trust him.

And that is what I am going through, trying to find a doctor that will take MediPass besides having to go out to Shands Hospital.

Theme IV.2: Barriers to care

In addition to disruptions in long-standing relationships, enrollees reported other challenges in receiving care such as the lack of transportation, wait time for services, gaps in coverage, limited prescription drug coverage, and the Medicaid authorization process. There were significant barriers to care expressed by participants, including the prior authorization processes, lack of choice in providers and difficulty finding specialists, and perceptions of unfair treatment.

Oh, when I had the surgery, it was, it was a wait. I had to wait. I had to get approved by Medicaid to make sure they could do the surgery on me and stuff like that. It was a wait. I mean I had to wait 'til the next day before they could even do the surgery. I had to wait for three days. I had to make a couple phone calls, the hospital made a phone call and I made some more phone calls. The third day that I was in there they told me that they got approved for more money to do the surgery.

The negative that I know of, you can't get all your medicine off Medicaid. You have to pay like 50 or 60 percent off the Medicaid, then Medicaid don't cover everything. You got a prescription to go to the doctor and the doctor give you a prescription form, sometimes Medicaid pays half of your medicine and you got to pay the other half. And other medicine they don't cover at all.

Respondent: I had to take my son to the dentist, because he had a toothache and they wouldn't see my son and told me I had to bring him back on a Friday.

Interviewer: Why did they tell you had to bring him back on a Friday?

Respondent: Because they said his Medicaid hadn't kicked in because I had just renewed the papers.

How Medicaid does the people, they cut you off...they don't contact you and let you know.

It's frustrating that Medicaid doesn't cover all of your medicine.

Cause I got Medicaid and I got to fight trying to pay all this money for different kinds of prescriptions.

I have had bad experiences in not getting my medication, they would not prescribe my medications sometime. And I would have to call my doctor, and they would have to authorize it so that I can get my medication.

Interviewer: Why is it so hard for you to get transportation?

Respondent: I call them and they refuse me. They say they can't help because I have an HMO. I have major problems with transportation.

Almost all of the consumers who were interviewed expressed concerns about finding new physicians or specialists.

It was hard (to find a gynecologist), because I only had a few to pick from. She was the closest and she told me no.

I think the hardest part about Medicaid is just finding a doctor that you can communicate with. The good thing is that it (Medicaid) is there for me, although it is like digging a ditch to get someone that understands exactly what you mean.

And everybody you ask, don't take Medicaid. And then you call Medicaid and ask them and they send their booklet. And there is only one dentist listed in Baker or Duval County that takes Medicaid.

If I could find me a better doctor, I would love to.

Several respondents who had experience with fee-for-service Medicaid thought MediPass was far more restrictive.

MediPass is worse than straight Medicaid.

MediPass is a limited branch of Medicaid. It kind of limits where you can go. Doctors sometimes do not want to take it, we don't take MediPass, we take Medicaid...and if they take you they don't treat you as good as somebody with Medicaid.

They don't have too many doctors that really take MediPass.

Medicaid is the gold card. MediPass is just like a white paper, a pass.

Theme IV.3: Belief that Medicaid beneficiaries receive unfair treatment

Stigma also appeared to be a challenge for enrollees. Several respondents mentioned that they thought they received unfair treatment because they were Medicaid recipients.

Right, I think if I had better insurance... they would have kept me there and run a lot of tests that they felt needed to be run and wouldn't have sent me home. They told they were thinking I had a blood clot. Do you send somebody home with a blood clot without doing tests to find out? No you don't. But they did. Said I had to do it as an outpatient.

Interviewer: So being on Medicaid means that people treat you differently or that is what you said?

Respondent: Yeah, they look down their nose at you and are different towards you. You get not as good care as if you had a pile of money.

I feel like cattle at most of the time.... I feel like they really don't care, that they know that they are getting their money from the state and here's your prescription, bye, see you in 30 days. You know. That is how they all make me feel. I think I get treated differently being poor, you know, and being on Medicaid. I think that that they don't care as long as they get their money from the state. They know that they will get it, you know.

When he come in he come in like he rushing like he's ready to get off now, and he wasn't really listening to my concerns that I was telling him what my son was going through.

They will just be so fast, to get you in and out of there. I know they have other patients, and I know that, but it is just how you can say things to people, your expressions, your eyes, body language.

Theme IV.4: Preferences for certain hospitals

Respondents had very clear preferences for certain hospitals. There seemed to be a general level of agreement that certain types of hospitals provided a higher level of care while other hospitals were stigmatized.

I don't like Plantation Hospital because they didn't help me when I was sick one time. So, I like Broward Hospital and Imperial Point. They helped me out and made sure I got well.

Respondent: To me [Shands] is the lowest rate of hospitals that you can go to in Jacksonville, and you don't get just one doctor. You have to take whatever you see. Interviewer: And when you say the lowest hospital in Jacksonville, could you define the lowest?

Respondent: Because it is a county hospital, it takes county patients, people who do not have money or insurance.

Theme IV.5: General opinion of the healthcare system

In general, study participants indicated that the healthcare system is designed to help them get the care that they need, but the care that they do receive may not be the best quality.

I had to have a cardio cath so they said I had to run tests, that's a lot of stuff, so I had to have that done. I had bone density tests and I had physical therapy. So, overall I would say I have got good care, it might've wasn't the best but it was good, it wasn't bad, bad.

It is a good thing they are there, I am not being ungrateful, I think they are doing the best they can.

The nurse and doctors do not act like they are concerned. They are just here to make their money.

Individuals who had serious health conditions and lower perceived ability to control their health were more likely to have a negative opinion of health care and the healthcare system.

Health Status	Health Belief: Ability to Control Health	Opinion of Health Care
Epilepsy (memory loss after epileptic episodes), depression, mental disorder, smoker, past drug user (clean for 14 months)	<i>Smoking cigarettes which I do, is not healthy when I do that. That's the only thing I do now. Just not ready to [quit smoking].</i>	<i>I don't like Plantation Hospital, they didn't help me when I was sick one time. So I like Broward Hospital, and Imperial Point, they helped me out and make sure I got well.</i>
Three kinds of arthritis and gout, two knees that need replacing, knee cancer, recently admitted to hospital, excessive weight loss (due to cancer)	<i>The only control I have now is, is to try not to eat things that would affect gout and arthritis and all like that.</i> <i>Well, the damage is already done so you can't undo what is already done.</i>	<i>I think it stinks. The state of Florida especially stinks as far as health care is concerned, of helping people, people that even works that makes a living everyday and they still don't have insurance, they can't afford the insurance, but yet they can't get help for no one else.</i>

Health Status	Health Belief: Ability to Control Health	Opinion of Health Care
Headaches, stroke at age 5: left side weak, bad kidney (according to doctors only), child with asthma, pain, children mainly get colds only	<p><i>It all depends what I do.</i></p> <p><i>Sometime I can't control my health either.</i></p>	<p><i>That's what I'm saying, the doctors they so rushed, so many people, they don't give you really the time, the care, they just rush you in and rush you out.</i></p>

Theme V: Knowledge and Attitudes about Medicaid Reform

Most of the respondents who were interviewed had limited or a vague knowledge of the concept of “Medicaid Reform.”

Interviewer: Ok, so are you aware that the State is changing the way that Medicaid services are being offered?

Respondent: No, I didn't know.

Interviewer: With the Medicaid Reform there are programs such as the Opt-Out program, or Enhanced Benefits, and Choice Counseling. Have you heard of any of these?

Respondent: I think I have, but I am not sure.

However, when asked about the specific components of Reform, several spoke of their recent experiences with selecting a health plan.

Interviewer: Ok, well, the state agency, AHCA, decided they wanted to make some changes to Medicaid to make it better for people who are on Medicaid. Medicaid Reform began in Broward and Duval County. Under Reform there will be more health plans and people will have to pick a plan that is more specific to the needs of the people. Is any of this ringing a bell?

Respondent: No.

Interviewer: Ok, well, the state agency really wanted people to have help in picking a health plan. So they have these people called choice counselors who you can call and ask questions about the different health plans and they help you pick a plan. Nothing ringing a bell?

Respondent: No. Oh, it might be the thing they sent me a paper.

Interviewer: What did the paper look like?

Respondent: It said I had a choice to pick what plan I wanted to be in, like Staywell, different things like that.

Interviewer: Did it come in a green and blue envelope, do you remember the bright color?

Respondent: Yeah, that was it.

Interviewer: Ok, so did you call the number that they gave you?

Respondent: That's the number how I picked the medical plan.

Interviewer: So how did you go about picking the plan?

Respondent: I had to call them and tell them what I wanted.

Interviewer: So did you talk to a choice counselor?

Respondent: Oh, I see, I didn't know who that was...I just told them what plan I wanted.

Interviewer: Going back to when you called the number to pick your plan, tell me a little bit about that. Did they ask you questions, what happened?

Respondent: I just called them and told them I wanted to change because the doctors I had when I had psoriasis did not take Staywell. So, I had to change to Preferred. That's the plan that I am on now.

I called the number and I told them I wanted to be on the Medicaid plan and they told me they was sending me a booklet with different plans in it. They sent me the booklet and I picked the plan I wanted.

Respondent: I think somebody had came by here and they was offering, they offered the people that was on Medicaid and they offered them that program.

Interviewer: Oh, ok, so someone came to your house?

Respondent: Yes.

Interviewer: Do you know, who did they say they were?

Respondent: I think they said they were from Healthcase, they was going around to who was all on Medicaid and they was offering to the ones that was on Medicaid...

Interviewer: So did you sign up that day?

Respondent: Yes ma'am. I signed up that day but it didn't start until about two months later.

As noted earlier, plan selection was often driven by provider recommendation.

At the doctor's office, they gave us a booklet on different changes like First Coast and all of them little different small companies. And they was telling us which ones to switch to if you want to stay at that doctor's office.

My doctor is important in my picking a plan with me and him sitting down, if he had the time or whatever.

A few had heard about the new Enhanced Benefit Program. However, although none had had any experience with the program at the time of the interviews, some speculated that they would likely use the benefit.

Interviewer: Now, the second thing is that they have an enhanced benefit account and that means that if your son was to participate in any healthy behavior he would earn credits in his personal health account.

Respondent: Oh yeah, they sent me a pamphlet the other day. I just got it in the mail last week. You earn points. I would probably participate in that because it is getting what you don't have.

However, it is unclear whether the Enhanced Benefits Program will provide sufficient motivation for some beneficiaries to engage in healthy behaviors.

Interviewer: Remember, they have a list of behaviors that if you participate in them, you can earn money. Would that encourage you to change your health, your behaviors?

Respondent: Nope. I ain't changing nothing different, no way. I am going to be going to do the same thing I have been doing.

Interviewer: Oh, so you wouldn't do it even if they are giving you free money to help you?

Respondent: Nope.

Respondent: Well it kinda makes sense [referring to Enhanced Benefit], but I don't believe in doing it like that.

Interviewer: Why not?

Respondent: Because it is just a waste of time....some of it will still have to come out of your pocket to do it.[referring to participating in the Enhanced Benefits program]

None of the consumers interviewed were aware of the Opt-Out program and since they were unemployed would not be eligible for this benefit. However, some speculated that if they could get employer-based coverage access to care would improve.

This program would allow me to go to the doctor more often.

SUMMARY AND CONCLUSIONS

The focus groups and in-depth interviews provided an overview of how Medicaid consumers view their health and health care and provided context for understanding enrollee responses to Medicaid Reform. It is important to recognize the comments expressed by these respondents represent baseline views only on Medicaid Reform. All participants are early enrollees to Medicaid Reform or were about to be enrolled in Medicaid Reform plans. Consequently, these enrollees do not have long-term experience with Medicaid Reform. Caution must be used in utilizing the findings from this qualitative study to infer success or failure of the Reform effort. Several key issues are worth noting, however, and following throughout the evaluation period.

Control of Health is Influenced by Individual Belief, Money and Resources, and Faith

Being healthy is of value to Medicaid consumers, and they often defined health in terms of their ability to function and carry out the activities of living. Strategies for remaining healthy or for regaining health were often described in terms of improved diet, weight loss and exercise, and to a lesser extent, in terms of health care utilization such as doctor visits.

Respondents noted that maintaining health is related to an individual's belief in their own ability to influence their health. Other factors, notably money and resources, faith in God, and support from others, are also key to maintaining or regaining health.

These observations have some important implications on the success of the Enhanced Benefit Program to empower individuals to make healthy lifestyle choices. While the list of approved behaviors (e.g., well visits and weight loss programs) that can earn credits in the Enhanced Benefit Program are likely viewed as activities that a consumer would engage in, the lack of resources (e.g., money for healthy food or to sign up for an exercise program) may deter initial participation and program completion. Thus, although consumers may appreciate being rewarded for healthy behaviors, this may not provide sufficient incentive to get them involved in healthy behaviors, especially those behaviors that are not paid for by the Medicaid program.

It is also worth noting that spirituality plays an important role in the health of Medicaid consumers. Disease management and enhanced benefit activities (e.g., weight loss classes) may have greater success if a spirituality component is incorporated into the programs.

Relationships with Physicians are Important to Consumers

Medicaid consumers cherish their relationships with their physician providers. Among the consumers interviewed, health plan choice was almost always dictated by advice from the physician office staff and a desire to remain with that physician. In addition, consumers look to physicians for health information. Health plans may wish to consider engaging their physician panels more fully in general health education.

Medicaid Consumers Actively Pursue Health and Healthcare Information

Although providers are major sources of health information, consumers also look to a variety of other resources (e.g., the internet, library) for information on their health and health care. Notably, social networks are key to gaining information on providers and health plans. Among the consumers interviewed, the Choice Counseling program has not yet emerged as a major source of health information, but instead is viewed as a mechanism to select a health plan.

Experiences with Medicaid and the Healthcare System are Not Always Positive

Consumers spoke of feeling stigmatized because they have low incomes and are on Medicaid. In addition, although there was some appreciation for the role Medicaid plays in assisting consumer access to their health care, respondents spoke of non-Reform related issues such as re-enrollment, restricted prescription drug coverage, perceived restrictiveness of MediPass relative to the traditional fee-for-service arrangement, and finding specialty providers and dentists who will take Medicaid. There also seemed to be a link between individuals having more serious health conditions and lower perceived ability to control their health, and a negative opinion of health care and the health care system. It is important to consider these prior experiences and barriers to care and their impact on the stated goals of Medicaid Reform.

Consumer Knowledge of Medicaid Reform is Uneven

General consumer understanding of the concept of “Medicaid Reform” is limited. When asked, individuals may have heard of specific aspects, but the terminology, such as Choice Counselors or Enhanced Benefits, was unfamiliar to respondents. Most consumers had already selected a new plan through the Choice Counseling process, had decided to remain with their current health plan and therefore knew they had to take no action, or had received some information in the mail. As mentioned earlier, however, Choice Counselors do not appear to be a major source of information. Instead consumers seek advice from their providers on plan choice.

NEXT STEPS

The 37 focus group and in-depth interview respondents will be contacted for a second round of in-depth interviews beginning late summer and early fall 2007. The second round of interviews will almost exclusively focus on their experiences since the last interview with obtaining health care under Medicaid Reform. In addition, we will recruit an additional 10 more individuals from each county who will participate in a first round of interviews.

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APPENDIX 1: FOCUS GROUP PROTOCOL

Date: _____
Facilitator: _____
Moderator(s): _____

INTERVIEW PROTOCOL FOR FOCUS GROUP

Introduction

Good afternoon and thank you for joining us today.

My name is _____, and I am working with the University of Florida Medicaid Reform Evaluation team.

The state of Florida has decided to change the way people who have Medicaid get their health care. The University of Florida has been contracted by the Florida Agency for Health Care Administration (the state Agency that manages Medicaid) to monitor the changes to the Medicaid program. Part of this monitoring involves talking with consumers, like yourself, about your experiences with getting healthcare services. We will be using group interviews like this one, to develop questions to ask others in your communities about their experiences with getting health care.

Our session today should last about 1–1.5 hours. The purpose of this group interview is to get your ideas on the best way to reach people in your community so that they can participate in our study and share their experiences and opinions about getting health care—especially in light of the changes that have occurred with Medicaid. We appreciate your willingness to be here today and help us develop our study methods and questions.

Your participation today is entirely voluntary. At any time, you can stop being a part of the group. You can also decide not to answer a specific question. Although we may use some of the information you give us when we write our report to the Florida Agency for Health Care Administration, your name will never be mentioned. It is important that you remember that there are no right or wrong answers to our questions. Also, we would like to keep this informal, so you need not raise your hand to speak. Nevertheless, we ask that you please be respectful when others are talking. Similarly, after you leave today, we ask that you refrain from talking with others about specific things individuals said during our session. Your identity will remain confidential; that is, only the study team will know you participated in this interview. We will be taping today's session, but if you ever need the tape recorder stopped, just let us know and we will do that.

We know your time is valuable so to show our appreciation we will be **giving you a \$20 gift card to Wal-Mart.** Thank you for taking the time to participate in our group discussion.

The information you provide will be extremely useful to the communities we are striving to serve and to the organizations interested in monitoring Medicaid Reform. Do you have any questions or concerns? **Do you consent to participate in the study?**

SECTION 1. Health means many different things to different people. Let us start by asking about your health in general.

1) What does being in good health mean to you?
(Probe: When you hear the word “health”, what does it mean to you?)

2) What do you have to do to be healthy?
*(Probe: Do you think that these behaviors allow you to control your health?
Are you able to get health care when you need it?
Are you able to manage your health?
Do you feel that the way you see “control of health” is similar to others?
What types of words should I use if I am trying to find out what “control of health means to others?)*

SECTION 2. Now we want to ask you about your experiences with: a) getting good health, b) getting good health information.

3) Describe how you get health services?
*(Probe: Describe these services? Good or bad?
What are some of the barriers to care [long waiting room stay, unhelpful staff]?)*

4) What does getting good health care mean to you?
(Probe: How would you make it better? What are some specific things I should ask about if I was interested in finding out what good or bad health care would look like?)

5) How would you describe a good physician?
(Probe: Are you able to talk to your provider?)

SECTION 3. We would now like to ask you about your experiences with getting healthcare services and Medicaid.

6) Does your experience with health care affect whether you use health care services, if so in what way?
*(Probe: Talk about your experiences when you are not getting health care services.
Do you use ER services? Why? Why not? Describe your experiences in the ER.*

7) How do you currently get information about your health care?

8) How do you feel about being on Medicaid?

9) Describe some of the ways in which you get information about Medicaid?

(Probe: Choice counselor, advertisements, friend?)

10) Please tell me about a good and bad experience you had using Medicaid?

(Probe: For example with gaining access, quality of physicians, or counselors)

SECTION 4 - Many of you may already be aware that the state is changing how Medicaid services are being offered. If you do not know about these changes, that is fine, what you can do is tell me how, if at all, your health plan has been changed.

11) What have you heard about the changes in Medicaid/Medicaid Reform?

(Probe: Did any of you receive the “Check it out Package”/ the green and blue envelope?

What do you know about this package or about the changes to Medicaid?)

12) Talk about some of your concerns about Medicaid or Medicaid Reform?

(Probe: What are some of the barriers to care [long waiting room stay, unhelpful staff]?

What are some frustrations/good experiences that you have had with Medicaid? What questions do you think we should ask when we want to learn about Medicaid users’ issues with Medicaid and/or Medicaid Reform?

What would be some good questions to ask about how Medicaid helps/hinders your health care?)

13) Is there anything else that you would like to share?

THIS IS THE END OF THE SEMI-STRUCTURED QUESTIONS. THE FOLLOWING QUESTIONS ARE LOGISTIC QUESTIONS.

SECTION 5. We are interested in giving people the best opportunity to be a part of our study so that they can tell us about their Medicaid health care experiences. We would want them to participate every 6 months over the next four years.

14) Do you think it would be better to ask people these questions in a group discussion like our session today, or via an interview with each individual over the telephone?

(Probe: Why or why not?)

15) What would be a good way of asking people to describe their experiences picking health plans, or staying enrolled in Medicaid?

(Probe: Is this an easy process, do you feel aware of the benefits, are you confused about what to do next?)

16) What would be some good ways to get others like you to participate in our study? That is, participating in interviews every 6 months over the next four years?

(Probe: Please tell me what you think it would take to get people to come to a discussion like this about the changes in Medicaid in this county [e.g., transportation stipend?])

17) In your opinion, when would it be easiest (or most convenient) for people to come (day, day of week, time, etc) to this type of group discussion?

(Probe: Describe why one day would be better in general than the other?)

18) In your opinion, what characteristics should the person who asks leads the discussion by asking questions have? For example, what type of person should lead a discussion of older males?

(Probe: Would you explain further?)

19) In your opinion, where would individuals feel most comfortable and safe to talk openly about their concerns about Medicaid? (such as enrolling in Plan A/B/C, or dies-enrolling/opting out)? In other words, where should our group discussions be held? Where should they NOT be held?

(Probe: Describe where)

20) Finally, I'm going to read you several questions that we have brainstormed for our study. Please provide any suggestions you have for making these questions better.

- a. How would you describe your health?
- b. Do you believe you have much control over your health?
- c. Medicaid now has a program that if you: take smoking class, go for check-ups, etc., you will get more Medicaid benefits (like medicine you do not need a prescription for). Have you heard of this? If so, would you participate in the program? Why or why not?
- d. Do you believe that the healthcare system is designed to help you get the best care possible?
- e. Describe a specific positive or negative experience.
- f. When you signed up for Medicaid, were you told that you had to pick a health plan?
- g. Everyone in Medicaid has to pick a health plan. Tell me a little bit about the process of picking a plan.
- h. Since we last spoke, have you (or your children) changed health plans (e.g., the last 6 mo.).
- i. Why did you switch? Probe: Plan didn't suit my needs—why or why not; problems with plan?

Comments: Thank you for agreeing to participate in this study. We appreciate your input. The information you have provided will be very relevant and useful.

APPENDIX 2: IN-DEPTH INTERVIEW PROTOCOL

Date: _____
Interviewer: _____
Listener: _____

INDIVIDUAL INTERVIEW PROTOCOL

Introduction

Greeting: Good Morning/Afternoon/Evening and thank you for allowing us to interview you today.

My name is _____, and I am work for the University of Florida.

The state of Florida has decided to change the way people who have Medicaid get their health care. The University of Florida has been contracted by the Florida Agency for Health Care Administration (the state Agency that manages Medicaid) to monitor the changes to the Medicaid program. Part of this monitoring involves talking with consumers, like yourself, about your experiences with getting healthcare services. Our interview today should last about 1 hour. The purpose of this interview is to get your ideas on your experiences and opinions about getting health care—especially in light of the changes that have occurred with Medicaid. We appreciate your willingness to be here today and help us develop our study methods and questions.

Your participation today is entirely voluntary. At any time, you can stop being a part of the study this interview. You can also decide not to answer a specific question. We may use some of the information you give us when we write our report to the Florida Agency for Health Care Administration; however, your name will never be mentioned. It is important that you remember that there is no right our wrong answer to our questions. Your identity will remain confidential, that is, only the study team will know you participated in this interview. We will be taping today's session, but if you ever need the tape recorder stopped, just let us know and we will do that. There will also be another person in the room taking notes and taping the conversation.

We know your time is valuable so as a token of our appreciation we will be **giving you a \$10 gift card to Wal-Mart.** Thank you for taking the time to participate in this interview.

The information you provide will be extremely useful to the communities we are striving to serve and to the organizations interested in monitoring Medicaid Reform. Do you have any questions or concerns? **Do you consent to participate in the study?** Thank you for agreeing to be a part of our study.

(Note to interviewer: make sure you get an Affirmative response on tape)

SECTION 1. DEMOGRAPHICS

Before we get started we would like some basic information from you. We would also like to confirm your contact information.

Medicaid

- a. Are you presently enrolled in Medicaid?
- b. How long have you been in Medicaid?
- c. Do you have any children?
- d. How many of your kids have Medicaid?

Age/Health status/Gender

- e. How old are you?
- f. What is your Gender?
- g. What are your major health concerns?
- h. What are the major health concerns of your children?

Contact

- i. Has your address changed lately? This is important because we want to make sure that if there are any changes, we are able to contact you to continue the interviews and so that we can send you your gift card. [Get contact information beforehand to confirm it]
- j. What is your Race/Ethnicity?
- k. What is your date of birth?

Health Care Utilization

- l. Have you been to the doctor?
- m. Have you been to the emergency room in the last three months?
- n. Have you been to the hospital in the last three months?

SECTION 2. BELIEFS ABOUT HEALTH

Health means many different things to different people, so let us start by asking you about your health in general.

1) What does being in good health mean to you?

Instructions for interviewers—be sure to draw out the different aspects of health specifically mental, physical, spiritual, etc.)

PROBES

- Describe health
 - When you hear the word “health,” what does it mean to you?
 - What does good mental and physical health mean?
 - Describe what it is like to not be healthy?
 - What role does faith and spirituality play in being healthy?
- Describe own health and/or that of their child
 - How would you describe your health or your child’s health?
 - Do you have any chronic illnesses?
 - How do you feel today? What words would you use to describe how you feel today?

2) What does control of health mean to you?

PROBES

- Give examples of instances when you have been able to control your health. Instances when you can’t control your health.
- Do you have examples of when people or yourself have tried to control their health—but failed or succeeded?

- Do you believe personally, that controlling your health is something you can do? Is this something that other people can do? Give examples
- Does cost impact people's ability to be healthy?
- Why or why not?
- How much control do you have over the health of your family?
- Does taking care of your family impact how you are able to take care of yourself?

3) If you wanted to change the way you take care of yourself in the future what would you do?

PROBES

- Describe how you would achieve this change
- Is there something specific you would like to change or do differently to improve your health or your families' health?
- Have you tried to change or do this differently before?
- Did you succeed or not?
- Would you try again, why or why not?
- Could you do it on your own, or if someone gave you money to do it would that help, would that make you change the way you treat your body?
- What other things would help you change or improve the way you treat your body?

4) Describe where and how you get health information to change your health? Here we are talking just about your health—not your health care (e.g., going to the doctor)

PROBES

- Describe how easy or difficult it is to get this health information?
- What kinds of information do you look for?
- Where do you go to look for information?
- Describe recent experiences in getting health information?
- Is the information you obtain easy or hard to understand?
- When you went to the [insert what they said here (e.g., internet, the Doctor's/physician's office)], how would you make it better?

SECTION 3 MEDICAID and MEDICAID REFORM

We have just talked to you about health and health information so now we want to talk to you about your experiences with Medicaid. So I want you to think about Medicaid and your experiences with Medicaid. Remember Medicaid is the program that helps you gain access to doctors and hospitals. It is not run by the doctors and hospitals. I'm not talking about finding doctor yet, I'm going to be asking you about that later.

5) Please tell me about your experience with Medicaid /Please describe what it is like to be in Medicaid?

PROBES

- Good and negative things?
- Describe some of the things about your family and friends' Medicaid experiences?
- What are some frustrations/good experiences that you have with Medicaid?

6) You may already know that the state is changing how Medicaid services are being offered. Have you heard about these changes? If yes, ask questions labeled X. If no, say that you will tell them more about these changes and then ask questions labeled Y.

<p><u>(Yes) X questions</u> Summarize the changes quickly and make sure that they are on the same page as interviewer.</p>	<p><u>(No) Y questions</u> Tell participant what the changes are:</p>
<p>As you know, with Medicaid Reform there are some new programs and services for example the Opt-Out program, the Enhanced Benefits Accounts, and Choice Counseling.</p> <p><u>Opt-Out</u> If you're employed by a company that offers health insurance, you can apply your Medicaid premium toward the purchase of that insurance. If you're employed, did your employer know about ESI? If yes, did you/would you participate? Why or why not?</p> <p><u>Enhanced Benefits</u> With Medicaid Reform, you can also earn dollar credits for participating in certain health behaviors such as going to the doctor and participating in an exercise program. The credits are put in your Enhanced Benefit Account for you to use it to purchase certain items at your Medicaid pharmacy. Has this program encouraged you to engage in the behaviors I just described? Why or why not? What would make you take care of yourself? Does the incentive need to be higher?</p> <p><u>Choice Counselors</u> Choice Counselors are also available to help you understand your different health plan choices and provide information to help you choose the best plan that meets your needs. Have you had any contact with them? If so, what kind of contact? Phone, in-person? How did you hear about them? Did you see billboard ads? Where they helpful? What about the written material? How did you end up making a choice? What factors lead you to make the decisions? What additional kind of information would you like to have had?</p>	<p>Medicaid Reform began in Broward and Duval Counties in July, 2006. Under Medicaid Reform, healthcare services are provided by health plans. Health plans will offer services that are specific to the needs of a group of people and provide additional services not currently being offered by Medicaid. With Medicaid Reform there are some new programs and services, for example, the Opt-Out program, the Enhanced Benefits Accounts, and Choice Counseling.</p> <p><u>Opt-Out</u> Enrollees may Opt-Out of enrolling with a Medicaid health plan and enroll in their Employer Sponsored Insurance (ESI). ESI is a new program under Medicaid Reform that will allow you to use Medicaid dollars to purchase insurance offered through your jobs. Does your employer offer ESI? Would that encourage you to choose the Opt-Out option? Why or why not?</p> <p><u>Enhanced Benefits</u> Enrollees who participate in Healthy Behaviors will earn credits in their personal Enhanced Benefit Account. Healthy Behaviors are things that you can do to earn dollar credits (for example, participating in a weight-loss program, getting a mammogram, going for your annual exams) that are put in an Enhanced Benefit Account. These credits can be used to purchase items such as over-the-counter drugs, vitamins, and other health-related products at any Medicaid pharmacy. Would this program encourage you to engage in the behaviors I just described? Why or why not? What would make you take care of yourself? Does the incentive need to be higher?</p> <p><u>Choice counselors</u> Picking a health plan is a personal decision. Florida Medicaid Reform enrollees can now talk with a Choice Counselor for free. The</p>

	<p>Choice Counselor will provide information that will help the enrollee to pick a plan that is best for them.</p> <p>Would using the services of choice counselors encourage you to engage in the healthy behaviors we talked about earlier? Why or why not?</p> <p>Do you think the Choice Counselors would help you make a choice? If not what other factors would lead you to make the decisions?</p> <p>What other kinds of information would you like to have to help you with your choices?</p>
<p>Under the new Medicaid you had to <u>pick a health plan</u>. Describe this experience.</p>	<p>Under the new Medicaid you have to <u>pick a health plan</u>. In the past, you also had to pick a health plan. Please describe this experience?</p>
<p><u>Did you receive</u> information on the changes with Medicaid such as the “Check it out Package”/ (the green and blue envelope? Did you know how to use the information? In what way? <u>If you did not receive it</u> then how did you learn about the changes with Medicaid?</p>	<p><u>Did any of you receive</u> information on the changes with Medicaid such as the “Check it out Package”/ the green and blue envelope? What do you know or have heard about the changes to Medicaid?</p>
<p>Have you participated in any of the new programs or used any of the new services? Opt-Out? Enhanced Benefits? Choice Counseling? Why or why not?</p>	<p>Would you participate in any of the new programs that I explained earlier such as the Opt-Out program? The Enhanced Benefits? Or contact a Choice Counselor for help? Why or why not?</p>
<p>Describe your experiences with the new Medicaid system, such as length of time on it, problems you have had, good experiences you’ve had.</p>	<p>Are you looking forward to experiencing these new changes with Medicaid?</p>

SECTION 4 - HEALTH CARE INFORMATION AND BEHAVIOR DECISIONS

Some of the questions that we will be asking you next, may be repeating information about plans and doctors OR INSERT WHATEVER THEY TALKED ABOUT BRIEFLY, but we want to go through your experiences using the healthcare system. Remember before, I asked you about your health and getting health information, now I want to focus on how you get health care. When I say health care I mean going to the doctor, hospital or emergency room, getting lab work done, etc. Specifically, I want to talk to you about your experiences with getting good health CARE information and about getting health care within the system, such as going to the doctor, getting labs. I want you to describe your experiences with getting health care information and using services.

7) How do you make decisions about getting finding a good provider or hospital?

PROBES

Finding a Doctor

- Tell me the story about going to the Doctor?
- For example, if you had to find a new doctor, what would you do?
- Is it easy or hard to find a new doctor?
- How do you decide when to go to the doctor
- What role does the nurse or doctor have in decisions you have to make?

8) What does getting good health care information mean to you?

PROBES

- Describe where you receive health information?
- Describe how easy or difficult it is to get this health care information.
- We talked about choice counseling earlier, did this help you or not help you?
- What other sources did you go to get this information?
- What kind of healthcare information is important and useful to you?
- Do you have time to review the information?

9) Now I want you to describe getting care and any barriers you may have getting care. Again, I mean the people, places, and services that you obtain care from (e.g., from doctors, hospitals).

PROBES

Where to go

- Where do you go for medical care?
- Why did you decide to go to that location for care?
- Describe what helps you decide where to go for medical care?
- How did you decide where to go for care? Is X place where you have always gone?
- What are some of the barriers to care [long waiting room stay, unhelpful staff]?

When to go for care

- **Aside from when you (or your kids) are sick, what other factors determine when you seek care?**

Getting an appointment

- The last time you went to this place did you make an appointment? How hard was it to get that appointment? Did you have to wait in the waiting room for a long time?

Staff

- What about the attitude of the receptionist?
- Were the office and nursing staff polite? Helpful?

Your doctor

- What do you like about your current doctor?
- Do you understand what she/he had to say? Were they respectful? Did he/she answer your questions?
- Why is that important to stay with that doctor?
- Any issue with referrals or going to specialists? Finding a doctor that takes Medicaid
- Are you treated differently because you are on Medicaid, because of your ethnicity, age? How do you know this?
- Have you had any issues with the care you received? If so what were they?

Transportation

- Is transportation an issue? Why or why not?
- Based on your recent experiences, would you go back to that place for care? Would you return for the same kind of care?

Other services

- Did you have any other kind of care recently—hospitalizations, lab work, prescription drugs, ER?
- Describe this experience to me.
- Was it a good or bad experience?

Section 5. Wrap up

In wrapping up we would now like you to describe your opinions about how the healthcare system meets your needs and in what ways.

10) Do you believe that the healthcare system—doctors, hospitals, ERs, nurses—is designed to help you get the best care possible? If so in what way and if no why not? (conceptual)

PROBES

- Describe a specific positive or negative experience? For example with gaining access, quality of physicians, or counselors.
- What's your perception of how well the healthcare system meets the needs of people on Medicaid, who are low-income or are uninsured?
- Are there enough doctors and hospitals?
- Do the system doctors, nurses, etc., treat you as you should be treated?
- Is the way the health care system set up affecting fulfilling your healthcare needs and in helping you make health choices?

11) Is there anything else that you would like to share?

Comments: Thank you for agreeing to participate in this study. We appreciate your input. The information you have provided will be very relevant and useful.