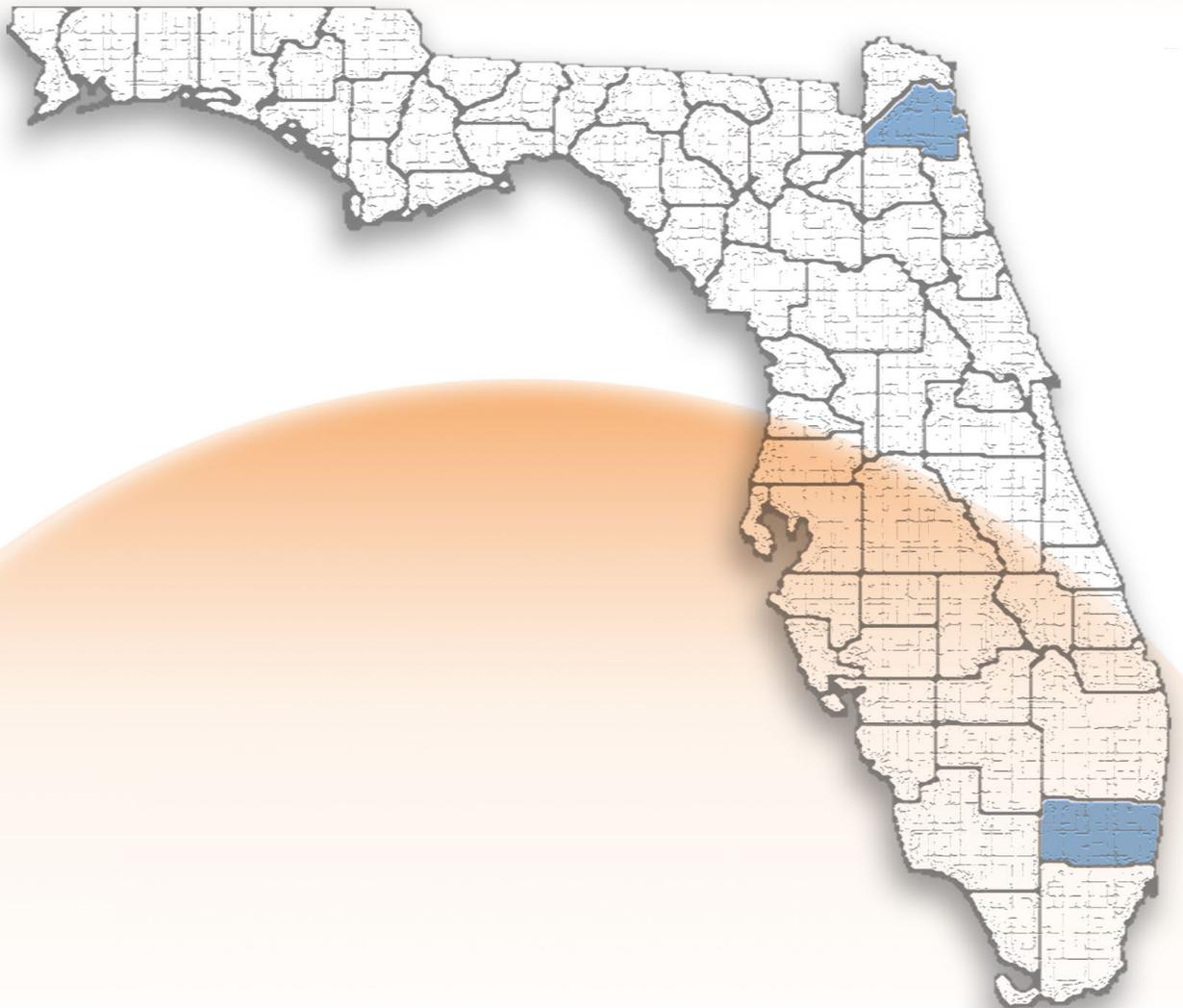




Evaluating Medicaid Reform in Florida



Medicaid Reform Interim Findings from Round 2 of the Longitudinal Study





MEDICAID REFORM:
INTERIM FINDINGS FROM ROUND 2 OF THE
LONGITUDINAL STUDY

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MEDICAID REFORM: INTERIM FINDINGS FROM ROUND 2
OF THE LONGITUDINAL STUDY

EXECUTIVE SUMMARY

The “Longitudinal Study” component of the Medicaid Reform Evaluation is designed to elicit consumers’ views about their health, their health care, and experience obtaining care as the changes occur to Florida’s Medicaid program. The study is termed “longitudinal” because it is designed to track a subset of enrollees throughout the life of the evaluation. Early experiences were reported on in July 2007. This report provides preliminary findings from interviews and focus groups conducted between July 2007 and December 2007.

A total of 45 enrollees participated in 14 in-depth telephone interviews and four focus groups conducted between July 2007 and December 2007. To date, nine of these interviews have been transcribed and coded. The following themes have emerged from this initial analysis:

- **The process of plan and primary care provider selection is problematic for some but not all enrollees.** Compared to baseline findings consumers are more aware of the health plan selection process and Choice Counseling. Health plan selection appears to be based on maintaining relationships with existing providers. Consumers spoke of several problems, notably finding a primary care provider and misinformation or incorrect information provided by the Choice Counselors.
- **There is some discontentment with aspects of care once enrolled.** Discontentment was linked with perceived greater restrictions associated with referral processes, maintaining continuity of care with primary care providers, gaining access to specialty services, limitations on prescription drugs, and transportation barriers.
- **The Enhanced Benefits Account (EBA) program continues to be a relatively untested concept among enrollees.** Although most enrollees had heard about the EBA program, there were mixed opinions about whether or not they would participate in the program.

During 2008, the Longitudinal Study Team will continue to talk with Medicaid enrollees about their health care experiences. Key issues that will be explored include:

- the ability of the Choice Counseling program to provide accurate and up-to-date information on primary care provider availability to enrollees;
- the availability of an appropriate and adequate distribution of primary care and specialty care providers;
- the impact of drug formulary restrictions on the health of enrollees;
- the availability of transportation providers;
- enrollee participation in the EBA program; and
- the extent to which there are differences across health plans in enrollee experience with care.

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 required that mandated Medicaid beneficiaries select a Health Maintenance Organization (HMO) or a Provider Service Network (PSN) and would no longer be allowed to enroll in MediPass, Florida's Primary Care Case Management Program. For individuals enrolled in MediPass, 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 (AHCA, 2005). As such, Medicaid Reform is designed to encourage greater enrollee involvement in their health and health care. Notably, enrollees are expected to have a greater choice of health plans, including the option to enroll in employer-sponsored plans. The state also established the EBA program to provide credits or rewards to individuals who engage in an approved list of healthy behaviors. Enrollees can use these credits to purchase non-covered health-related items from pharmacies.

A key element to empowering enrollees 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" (AHCA, 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 enrollee experience, satisfaction, health empowerment, enrollee choice, and enrollee health will be largely evaluated using Consumer Assessment of Healthcare 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 a full understanding of enrollee 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. One component of the Medicaid Reform Evaluation will consist of periodic in-depth interviews and conversations with enrollees about their overarching health beliefs and healthcare experiences with Medicaid Reform. This component of the evaluation is called the "Longitudinal Study" because it is designed to track a subset of enrollees throughout the life of the evaluation. These enrollees will be interviewed or will participate in focus groups periodically until 2010. This interim report summarizes a subset of the in-depth interviews and focus groups conducted in Broward, Duval, Baker, Clay, and Nassau Counties from July 2007–December 2007.

BACKGROUND

Medicaid Enrollee Experiences with Accessing Care

According to the Center for Medicare and Medicaid Services (CMS), in 2002 almost \$211 billion was spent to cover Medicaid services nationally. Fee-for-services (FFS) accounted for the greatest proportion of all expenditure (CMS, 2007). While the focus of this evaluation is to emphasize enrollee experiences under Medicaid Managed Care (MMC), it is equally important to highlight enrollee experiences in traditional Medicaid programs.

Zuckerman and colleagues suggest that traditional FFS is thought to be a threat to enrollee access to care partly because states have set provider reimbursement rates far below other insurers. Consequently, only a subset of clinics provide care for recipients and enrollees are more likely to rely on emergency room services (Zuckerman, Evans, and Holohan, 1997). Chaudry, Brandon and Schoeps (1999) also noted this in their research. They also observed that Medicaid enrollees in traditional programs experience access barriers, such as the inability to find providers who accept Medicaid and long waits for appointments.

A recent study that examined barriers to care faced by low-income parents while accessing pediatric healthcare services found that individuals were frustrated about Medicaid's restrictive enrollment criteria. Participants also struggled with locating Medicaid providers, traveling extended distances, and perceptions of feeling unwelcome (DeVoe et al., 2007).

Although poor access under traditional Medicaid programs has historically been cited as a challenge, it was observed that enrollees in MMC were more likely to be satisfied than their FFS counterparts (Chaudry, Brandon, and Schoeps, 1999; Hynes et al., 1998; Woolridge et al., 1996). The recurring theme of discourteous treatment of Medicaid recipients who participate in either MMC or FFS may erode benefits achieved by improved access.

The Medicaid Reform Evaluation Longitudinal Study

Baseline telephone interviews and focus groups were conducted in 2006 and the first half of 2007. Those conversations focused primarily on understanding the health beliefs of Medicaid enrollees, their prior experiences with obtaining health care, their early understanding of Medicaid Reform, and how they obtain information about their health and health care. Findings from these baseline interviews were intended to provide context for understanding enrollee responses to Medicaid Reform in the coming years (Hall, Young, Bell, Thompson, and Elliott, 2007). The following key themes emerged from these initial conversations:

- control of health is influenced by individual belief, money and resources, and faith;
- relationships with physicians are important to consumers;
- Medicaid consumers actively pursue health and healthcare information;
- experiences with Medicaid and the healthcare system are not always positive; and
- consumer knowledge of Medicaid Reform is uneven.

This report focuses on interim findings from Year 2 of the Longitudinal Study. Although interviewers continued to ask enrollees about their health beliefs, the focus of Year 2 interviews and focus groups was predominantly on learning about their care-seeking experiences under Reform.

METHODOLOGY

A total of 45 enrollees participated in 14 in-depth telephone interviews and four focus groups conducted between July 2007 and December 2007. The in-depth telephone interviews were conducted with individuals who were enrolled in Medicaid Reform for at least one year in Broward and Duval Counties. Three of the focus groups were conducted in each expansion county: Baker, Clay, and Nassau. The other focus group conducted in Duval County was completed one year after the initial focus group in December 2006.

This qualitative study provides in-depth exploration of enrollee experiences with health care in general, and Medicaid Reform specifically. Qualitative methods produce a wealth of detailed information from a small sample of individuals. The type and volume of data collected in this research study dictates a comprehensive analytical approach involving transcription, coding, continuous code review, and theme validation in order to present a clear and comprehensive review of enrollee experiences. This interim report presents a snapshot of enrollee experiences of nine of the 14 in-depth telephone interviews conducted within the study period. The complete report on the remaining interviews and focus groups, along with additional data collected between January 2008 – June 2008 will be reported in July 2008.

Instrument Development

The initial development of the focus group and telephone interview instruments was guided by various health belief, health communication, and health behavior theories (Glanz, Rimer and Lewis, 2002). Questions were based on the review of these theories, literature reviews, and other instruments. Qualitative research allows for the constant evolution of the study instrument commensurate with the increased skill and experience of the researcher. Consequently, the interview and focus group guides were modified, refined, and updated as interviewers gained experience, and as the conversations revealed additional questions and issues from enrollees. Interviewers were trained to develop the skill and competence to use the study instrument to capture detailed perspectives of enrollees.

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

In order to obtain a broad perspective of enrollee experiences of the overall Medicaid Reform population, as well as the unique viewpoints of individuals with disabilities and chronic health concerns, we used three strategies to recruit participants into the study: community partner liaisons recruited participants for the focus groups, names were obtained from the Medicaid eligibility files for the in-depth interviews, and we solicited participants from focus groups held by an advocacy organization, Florida Community Health Action Information Network (CHAIN). To participate in the study, individuals had to be enrolled in Medicaid or be the parent of a Medicaid enrollee, live in the Reform counties, and participating or eligible to participate in Medicaid Reform. Emphasis was placed on recruiting parents of children enrolled in Medicaid Reform, males, individuals who received Supplemental Social Security Income (SSI), and individuals diagnosed with HIV/AIDS.

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, eligibility type including SSI and Temporary Assistance for Needy Families (TANF), and HIV/AIDS diagnosis. In the case of minors, the parents or guardians were considered proxy informants. An initial sample of 470 was pulled from AHCA's database with oversampling for children, males, SSI eligibility category, and diagnosis of HIV/AIDS.

Two waves of recruitment letters were mailed every two months for the first four months within the study period (July and September). Respondents willing to participate in the study completed a consent form and mailed it to the Longitudinal Study Team in the return envelope provided. Enrollees who completed and returned consent forms were contacted by telephone to schedule an interview. On average, each person who mailed in the consent form was contacted three times to schedule an interview. The Longitudinal Study Team members were invited to attend Florida CHAIN's focus groups held during the spring of 2007. Announcements were made during the CHAIN focus groups about the University of Florida Study. Participants interested in the University of Florida Study were invited to provide contact information. Three of the nine participants who participated in the in-depth interviews included in this report were recruited from Florida CHAIN focus groups.

Telephone interviews were approximately 60 minutes long. Interviews were conducted with 14 Medicaid enrollees. Before the interview was conducted, participants provided oral consent. Each participant was mailed a \$10 gift card upon completion of the interview.

Focus Groups. In collaboration with the Longitudinal Study Team, the Health Planning Council of Northeast Florida, Inc., (local liaison) facilitated the recruitment of individuals to participate in the four focus groups. The local liaison used their social and community networks to help recruit individuals. Solicitation flyers were posted in hospitals, community centers, and medical practices where Medicaid enrollees were likely to visit.

Before the focus groups were conducted, individuals provided oral and written consent to participate in the study. One focus group was conducted in each of the following counties: Baker, Clay, Nassau, and Duval. Individuals received \$20 gift cards as compensation for participating. Thirty-one individuals participated in the four focus groups.

Demographics

Forty-five individuals participated in either the focus groups or telephone interviews. The sample consisted primarily of individuals who reported their race or ethnicity as White, Black, or Hispanic. One participant reported Vietnamese. Focus group and in-depth interview participants reported varying educational attainment, including some high school, some high school graduates, and some college. The sample had a majority of female participants whose ages ranged from 22-71.

Of the nine telephone interview transcripts that have been coded so far, four individuals identified themselves as Black, three identified themselves as White, and one as Hispanic. One participant was from Duval, while eight were from Broward County. One participant did not identify race or ethnic background. Six participants had SSI eligibility and one participant had TANF eligibility. The Medicaid eligibility status of two of the individuals was unknown. Six participants were female.

Data Analysis

For this interim report, the Longitudinal Study Team completed the analysis of nine of the 14 in-depth telephone interviews. Findings from the remaining five interviews and four focus groups will be reported in July 2008.

All in-depth telephone interviews and focus groups were audio-recorded. Each audio-recorded interview and focus group was transcribed verbatim by professional transcriptionists. Transcripts did not include personal identifying information of the participant. Groups of two team members conducted each audio-recorded interview to ensure quality and integrity.

Coding. A coding scheme was developed based on the initial focus group and in-depth interview instruments. Seven global codes were identified including health beliefs, health status, health information, Medicaid experience prior to Medicaid Reform, Medicaid Reform, overall experience with care, and general opinions of the healthcare system. Paragraphs and statements from each transcript were assigned codes using *Atlas ti 5.0*. In team meetings, discrepancies in coding were identified and consensus was obtained through iterative discussion and clarification of coding categories and specified definitions.

A Note on Qualitative Research

Readers will observe that this report does not focus on figures, charts, or tables. It does not provide percentages, rates, ratios, measures of association, or tests of statistical significance. It is not based on statistically representative sampling, and is not intended as a source from which to make generalizations to a larger experience. Such information is not the intended outcome of qualitative research. Rather, the objectives of qualitative research are to discern themes, understand texture, and provide context that will help inform the more common analyses that emerge from quantitative research such as CAHPS surveys, examination of claims or other administrative data, fiscal analyses, and the like (Patton, 2002). Readers are cautioned that the findings reported here reflect views of a relatively small number of enrollees who were not selected by statistical protocol to be representative of the entire population of enrollees in the Reform demonstration. The study participants are certainly experiencing the Reform process, and their views are valid.

representations of their own experiences. They express both positive and negative views and inferences should not be drawn about how frequently one might expect to find those positive and negative views among other enrollees.

FINDINGS

This interim report is based on data from nine of the 14 in-depth interviews conducted within this study period. The subsequent report will include data from the remaining five in-depth interviews, four focus groups, and additional in-depth interviews and focus groups. Each direct quote has been italicized and clarifiers denoted by brackets have been included to facilitate easier comprehension by the reader.

Overall, this round of in-depth interviews revealed that enrollees were aware of Medicaid Reform and had both positive and negative experiences with the various Reform elements. While many of the comments about Reform were negative, they were not overwhelmingly so. Key concerns raised by enrollees center around facilitating adequate choice and selection of primary care and specialty care providers, greater restrictions associated with specialty care referrals and use of prescription drugs, and transportation barriers to care.

I. Some enrollees are having no problems

This new round of focus groups and in-depth interviews revealed that some enrollees had positive experiences with Reform.

So far we haven't had any trouble. It's been real good...I guess I have been pretty lucky.

Well, I liked the doctor I was assigned to. Any time I called I didn't have any problems or anything. I was able to get an appointment soon, even like the next day, or whatever depending on the situation.

II. The process of plan and primary care provider selection was difficult for some, but not all participants

Active Participation in Health Plan Choice—Compared to baseline findings, enrollees are more aware of the Choice Counseling and health plan selection process. Some enrollees spoke of their active participation in the selection process.

Yeah, but then I had questions. I had to call them and then, like, sometimes I wrote down the different doctors that they didn't accept and they did, and then if I misplaced my paper I called them back and they helped me again.... Well I just had to keep looking through all of the plans, and look at my doctors, and see if they was on [the] plans and keep calling back to the Medicaid what the insurance program to make sure that all of my doctors was on there and scratch off the ones that they didn't accept that I was going to. So I had to wait and do a check and balance.

It was very simple. I called the choice counselor when I got the blue-green letter, and told them to leave me exactly where I was.

Maintaining continuity of care with a primary care or specialty care provider was a key determinant in health plan selection.

I had to visit all my doctors to see what doctors were covered in whatever...I still had to see what doctors did, would do. Would I still be able to have all my specialist[s] under this new program? So that was my main concern.

I just went with the list I received from Choice Health Care [referring to Choice Counselor] and asked every one of my doctors, "Which of these HMOs are you under?" And I would circle the ones they were under.

In addition, some enrollees selected health plans based on hospital affiliation with a plan or prior experience with that plan before Reform.

One of the reasons I chose Humana [is] because it works with Memorial Health System.

I picked Humana Medicaid because they were helpful to me in the situation I have been in. You know, my sickness and everything. I never had no problem with them. So it was like, if something is good to you, you want to stick with it.

Problems associated with finding a Primary Care Provider—For many enrollees, being able to see their established primary care provider was a critical factor in health plan selection. Not being able to maintain this continuity was a source of dissatisfaction.

I love my primary care doctor, but when the switch was made, he doesn't take Humana. I had to get a new primary healthcare doctor, and this man [referring to physician] doesn't know me from Adam.

For others finding a primary care provider under Reform was problematic. Enrollees noted that some of the information given to them by choice counselors was incorrect.

The Choice Counselors gave me doctors to call for my Mom. Three doctors in the Plantation area was not taking Medicaid. They was not taking new enrollment Medicaid.

I called her [Choice Counselor] and said well the doctor is not taking no new patients, what do I do? She goes, "Well, we are trying to look for you in your area and so far there is no other doctor right now taking Medicaid."

When you get a brochure, you call to make an appointment; the doctor is no longer on that plan, or the doctor was never on that plan.

Interviewer: *Oh, OK, well, can you describe that to me a little bit, like the transition and what, and how it has affected you?*

Respondent: *Well, number one, I lost a couple of my doctors.*

Some enrollees expressed discontent with Choice Counselors—Enrollees noted that the Counselors sometimes were misinformed and provided incorrect information.

You cannot depend upon these Counselors; you've got to go to the place yourself and check it. You can't make phone calls. You've got to go to the site and check it out or have someone go with you, because if you depend over the phone with these Counselors or whatever, you're going to be messed up because they don't have enough education.

No, I was not satisfied, not satisfied, [with Choice Counselors]. I called maybe like 20 people— transfer to this person, this department, that department, the lady got aggravated, I got aggravated; I end up going to sleep with stress.

Let me put it this way, they, Choice Counselors, need a consumer seminar. They need to have us educate them [on] what they need to tell us.

Choice Counselors were useful to other individuals in primary care provider and health plan selection—Some enrollees had positive experiences with Choice Counselors and expressed satisfaction with the process.

Interviewer: *Would you say it was an easy or hard process to find this new doctor?*

Respondent: *It was easy because [of] the man at the health care [Choice Counselor]. They did the other; they were real nice to him. They put their time into trying to find the right one and close to where he wanted to go.*

Interviewer: *Did you try contacting them at all or have you ever had questions about your health plan and you called them?*

Respondent: *I have talked to them on special occasions, yes.*

Interviewer: *And what was that experience like?*

Respondent: *They were very helpful to me. They explained everything and you know just helpful to me.*

Interviewer: *And did you end up making a choice? Did they help you in choosing a health plan?*

Respondent: *Yes, they were very helpful and they explained things very clearly and nice you know.*

III. Discontentment with aspects of health care access once enrolled

Several enrollees expressed dissatisfaction when comparing their health care experiences before Reform to their health care experiences during Reform.

MediPass was great. She could have gone anywhere she wants to. Her doctor would see her with no problem...then Reform started and all hell broke loose.

I say go back to plain Medicaid, go back to the way Medicaid was: open access, you know, you just see whatever doctor you wanted to.

Before Reform, everything was beautiful.

Discontentment was associated with perceived greater restrictions associated with the referral processes, maintaining continuity of care with their primary care providers, gaining access to specialty services, limitations on prescription drugs, and transportation barriers.

Greater restrictions associated with referral processes and use of specialty services—Some of the discontentment expressed by enrollees was associated with the increased restrictions imposed by health plans in obtaining specialty care referrals.

Before, I didn't have to; my doctor would send me to any specialist without any problem, and they in turn would call the specialist, make an appointment, and I just would go to the appointment. Now the difference is that I will have to go to my PI, my primary healthcare doctor, ... tell them that I need to go to whatever specialist I need to go to, then they have to drop the paperwork and give me the referral in order for me to go to [the specialist] and make the appointment and have my whatever procedure I need to be done on that.

But now with Reform, even though you pick an insurance, an HMO, you are restricted to where you are going because this doctor is not working with that doctor, that doctor is not working with this doctor, and this doctor is not taking that insurance. Then you have a problem.

...the new injection [they give] patients of macular degeneration that goes directly into the eye. Referrals that are given from the doctors, just covers the regular, the check up that they want to do... it doesn't cover this injection. So they have to call... the primary doctor and sometimes they don't answer the phone and they leave the phone on the voice mail, and they still don't call back....

[My doctor] is just a little frustrated because of my blood work situation. They can no longer draw blood at the [previous sites]. I have to go outside to have my blood drawn... You are going to an outside laboratory... So I have to travel on a bus to get there...I have to take two buses to get there...

Interviewer: *Oh, OK, well, can you describe that to me a little bit, like the transition and what, and how it has affected you?*

Respondent: *Well, number one I lost a couple of my doctors. Number two, when I was hospitalized, I had major surgery done and the procedure is completely different than from when I had major surgery done before and was on the Medicaid. All my doctors would come and see me, you know, all the doctors except the ones that were involved in my operation would see me this time. I had, that person, I had no idea who they were, kinds of feeling. I had to be discharged by some other doctor. Every time I go to the doctor, I have to get a referral note. If I don't have a referral note, I can't see the doctor. Sometimes my primary healthcare doctor will sometimes, one time I had problems in getting uh, a referral and the reason because I have multitude problems because of the sickle cell anemia.*

Specialty care access is also hampered by the lack of available specialists willing to see patients with Medicaid.

Well the biggest problem was getting a diabetic specialist doctor. My doctor had none to refer me to. There was no doctor, period, under Staywell.

I need someone I can go to for arthritis...the girl in the office that takes care of the referrals hasn't found anybody [for me] to go to.

I went to one eye doctor and they you know questioned me before I came in, but when I went to the appointment they refused me because they didn't take the kind of Medicaid that I had. I felt very disappointed because I took my time to go there.

Enrollees couched this lack of specialty care access as limited choice of providers.

You don't get much choice. Sometimes you are down to only the one person you can see. And if you don't like him...oh well. I have a feeling when I see this endocrinologist it's not going to work out, but I am trying to have a positive attitude.

Prescription Drug Limitations—Some enrollees are also experiencing barriers to getting medicines that they are used to or medicines prescribed by their providers. There are reports that drugs prescribed by providers are not on plan formularies.

A couple of prescriptions I used to get on Medicaid, I can't get on Humana.

The doctor said to me, "How are you doing?" I said, "Well, I am doing OK, but I am not feeling completely balanced, completely centered." "Well, we can put you on Zoloft...here is a prescription and it's covered." I go to the pharmacy: "I'm sorry, this prescription is going to cost you \$80." "\$80?" "Yes, it's not covered." I find out why it's not covered. The pharmacy didn't realize to tell you that only 100 mg is covered and not 50 mg. Instead of calling the doctor and asking for 100 mgs and either readjusting the way I take it, they just tell me I can't get it.

In the month of February, the woman [Respondent's mother] ended up in the hospital because the pharmacy didn't have authorization for her medication...The doctor was not credentialed for the United insurance she had. I have been fighting with Walgreens, then Walgreens told me it's not them it is Medicaid and Medicaid Reform.

And insulin is not on the list. You want to know why? Because it gives you more than 2 or 3 doses a day of medicine...it's the most absurd thing I have heard in my life. Insulin is a life-sustaining medication. No insulin was on the list.

I was getting this medication for foot fungus. Unfortunately, when I went over to Humana, I wasn't able to get it. I am going back to my podiatrist and see if one of the anti-fungus ointment that he has may work for me, because the one that works for me, it's not on the Humana medical, pharmaceutical list.

You walk in and you can't get a medicine. You know you couldn't get it with this Reform change.

The Medicaid Reforms is a system that was designed that is not working. Now we can't get certain medications.

Transportation Barriers—As health plans contract with new transportation providers, some enrollees are reporting logistical issues associated with those companies. While these concerns reflect perceptions of Longitudinal Study enrollees, it should be noted that during the early phase of Medicaid Reform several non-Medicaid Reform events occurred in Broward County such as the sudden change to a new non-emergency transportation vendor. These issues may have been incorrectly attributed to Medicaid Reform.

Transportation had been given to me for the last 11 years.... It was working wonderfully. Then all of a sudden, this Medicaid Reform came in and I received a letter that I was being transferred to a company in Brevard County. I called the company as the letter said. They knew nothing about what was going on and they told me to call back after the Christmas holidays. I called back and they said they didn't know yet, but they would let me know. I called back and they said they were not accepting patients from the South Florida Community Network. January, I had to cancel my doctor's appointment.

At the time, they told me I would be receiving a bus pass every month. So I mailed them the form the first month—the fax number at the bottom of the form was not the right fax number. The next month when I sent off the form, I got [a] fax transmission, that it was received by them. Well, I am at the end of the month and I don't receive a bus pass and again I had to cancel my appointment.

Yeah, I take the transportation and it is not always that good because sometimes they might schedule two different people at the same time in two different directions, miles apart.

One individual indicated that transportation under Reform was working well.

I get there via the transportation under Staywell. And that's the one thing I gotta say—they are excellent on that. The people are very nice to deal with when you call to set up an appointment. They use Celebrity Wheelchair Service. They are superb, I have to say.

IV. Some access problems existed prior to Reform

Issues of specialty care access and limits on prescriptions existed previously under MediPass. Respondents in rural areas in particular noted the lack of access to specialty providers existed many years prior to Reform and that they did not expect that healthcare Reform would solve this problem.

There came a point, under Reform, that he [enrollee's Primary Care Physician] didn't have an endocrinologist, a diabetic specialist, for me. So I called them for the list that time. I went through the entire list, and only found one doctor. The majority of the times, the

phone calls were, “We no longer take Medicaid.” Then I finally found one in Hollywood that agreed to see me. This was two summers ago. So this doctor finally agreed to see me, but with a six-week wait, but fortunately God opened the door. Within three days he called and asked whether I can come in a couple of hours. I said I need two hours, you are in Hollywood, I am in Ft. Lauderdale.

This was the fifth time I was refused insulin in the last two years...the Ombudsman’s program I found via my pharmacist. I called the Ombudsman’s office and they said they are supposed to get you two to three days of medication at a time, until the insurance company makes a decision one way or another. **Q:** So the insurance company we are talking about is MediPass? **R:** Back then, yes.

V. The Enhanced Benefits Account program

Enrollee comments about the EBA program reflect the fact that it is a relatively untested concept for enrollees. For example, one enrollee said she would never participate in the program.

Interviewer: *Would this program encourage you to engage in the healthy behaviors I described?*

Respondent: *No, it doesn’t encourage me at all. I know what healthy behaviors you are supposed to be doing. Once a year you get a physical, by your own choice if you want to live longer. You are supposed to check yourself once a year. No one is going to force you to do it...your doctor, pediatrician telling you once a year to bring in the child, the school telling you to bring in the child, they already trained you when the child is a baby to continue this good pattern. So, why does Medicaid want to take the credit now? Healthy behaviors have been instructed in you since you were a child...I am not going to participate in it. My kids, my mom, we all take our physicals once a year...to me it could go up to a million dollars and I am not using it.*

Another enrollee, however, liked the concept.

Interviewer: *What do you think about the program like that [referring to the EBA program]?*

Respondent: *Love it. Because I am on a fixed income and sometimes I do not have money to buy, you know, the alcohol that [I] need to check my sugar and they give you wipes you know. And I am very grateful that I can choose that.*

Interviewer: *Would this program encourage you to engage in behaviors that I just described, like exercising and going to the doctor regularly?*

Respondent: *Yes, the exercise is helpful to your health, especially for my being diabetic.*

CONCLUSION AND ISSUES TO WATCH

During the past year, as would be expected, awareness and knowledge of the changes to the Medicaid programs have increased significantly among enrollees. Many enrollees have played an active role in selecting health plans and primary care providers. However, it does appear that maintaining continuity of care with primary and specialty care providers is problematic. In addition, some plan formularies have placed restrictions on access to prescription drugs and certain kinds of therapy.

For some Medicaid enrollees, this restriction in access may have a detrimental impact on their health. For others, changes to the Medicaid program may have no impact at all. This first year of the demonstration represents a period of time in which enrollees were learning to adjust to the changes, and AHCA was making programmatic modifications in response to enrollee needs and concerns. Thus, it is still too early to make conclusions about Medicaid Reform and its impact on enrollee access to care. Nevertheless, AHCA and the University of Florida must continue to monitor key issues over the long term. These issues include:

- the ability of the Choice Counseling program to provide accurate and up-to-date information on primary care provider availability to enrollees;
- the availability of an appropriate and adequate distribution of primary care and specialty care providers;
- the impact of drug formulary restrictions on the health of enrollees;
- the availability of transportation providers;
- enrollee participation in the enhanced benefit program; and
- the extent to which there are differences across health plans in enrollee experience with care.

NEXT STEPS

As Florida Medicaid Reform continues to evolve, so too will the experiences of Medicaid enrollees. The Longitudinal Study Team will continue to have conversations with enrollees about their interactions with the healthcare system. Immediate next steps will include coding and analysis of the remaining interviews conducted so far, new focus groups with consumers in the five Reform counties, and in-depth telephone interviews with existing and new Medicaid enrollees.

The longitudinal study was designed to track experiences of enrollees as they move through the system at varying points in time. Therefore, enrollees who were interviewed in 2006 and the first half of 2007 (either in focus groups or in-depth interviews) will be interviewed again in 2008. In addition, focus groups of consumers in Broward and in the three rural counties will be convened throughout the first half of 2008.

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APPENDIX 1: INTERVIEW PROTOCOL (REVISED 08/27/07)*

Date:	_____
Time:	_____
Facilitator:	_____
Moderator:	_____

*** NOTE: THIS INTERVIEW PROTOCOL WAS UTILIZED FOR BOTH THE IN-DEPTH TELEPHONE INTERVIEWS AND FOCUS GROUPS.**

INTRODUCTION

Good Morning/Afternoon/Evening [Interviewee Name] and thank you for allowing us to interview you today.

My name is [Interviewer Name] and I 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 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 enrollees, like yourself, about your experiences with getting health care 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 share your experiences with us.

Your participation today is entirely voluntary. At any time, you can stop being a part of this interview and study. 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 Agency for Health Care Administration; however, your name will never be mentioned. It is important that you remember that there is no right or 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 again 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?**

[Note to interviewer: make sure you get an **Affirmative Response** on tape]

Thank you for agreeing to be a part of our study.

SECTION 1: DEMOGRAPHICS

Before we get started we would like some basic information from you and confirm your contact information.

Questions	Answers
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. [Refer to the consent form for confirmation.]	
j. What is your Race/Ethnicity?	
k. What is your date of Birth?	
Health Care Utilization	
l. Have you been to the doctor in the last three months?	
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: HEALTH CARE INFORMATION AND BEHAVIOR DECISIONS

We want to go through your experiences using the healthcare system. 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 HEALTHCARE INFORMATION and about getting HEALTH CARE within the system, such as going to the doctor and getting labs. I want you to describe your experiences with getting healthcare information and using services.

1. How do you make decisions about finding a good provider or hospital?

PROBES

Finding a Doctor

- *Tell me 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?*
- *What role does the nurse or doctor have in decisions you have to make?*

2. 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 healthcare information.*
- *Describe your experience with Choice Counseling. Did it help you or not?*
- *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?*

3. 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 and 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 [insert location mentioned] the 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?*
- *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?*
- *Did you understand what they said? Were they respectful? Did they answer your questions?*

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

- *Describe your experience getting prescription drugs. Has it changed for the better/worse? In what ways?*
- *Describe your experience getting the service that you need for your [include health concern(s) here, e.g., mental health needs, prescription drugs, etc.]*

- *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 3: MEDICAID and MEDICAID REFORM

Remember before, I asked you about your health and getting health information, now I want to focus on how you get health care. Some of the questions that we will be asking you next may be repeating information about plans and doctors [or insert whatever they’d talked about brief].

We have just talked to you about health and health information so now we want to talk to you about your experiences with Medicaid. 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.

4. Tell me about your experience with Medicaid. Describe what it is like to be in Medicaid.

PROBES

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

5. 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 Y. If No, say that you will tell them more about these changes and then ask questions labeled N.]

<u>(Yes) Y questions</u>	<u>(No) N questions</u>
Under the new Medicaid you had to <u>pick a health plan</u> . Describe this experience.	Under the new Medicaid you have to <u>pick a health plan</u> . In the past, you also had to pick a health plan. Describe this experience.
<p><u>Did you receive</u> information on the changes with Medicaid such as the Check it out Package/the green and blue envelope?</p> <ul style="list-style-type: none"> • <i>Describe the experience of receiving, understanding, and using this information.</i> • <i>Did you understand the enrollment time frame?</i> • <i>How did you pick your health plan?</i> • <i>Describe the factors that helped you make your health plan choice, e.g., did mental illness/prescription drug availability, etc.,</i> 	<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> <ul style="list-style-type: none"> • <i>Describe the experience of receiving, understanding, and using this information?</i> • <i>Did you understand the enrollment time frame?</i> • <i>How did you pick your health plan?</i> • <i>Describe the factors that helped you make</i>

<u>(Yes) Y questions</u>	<u>(No) N questions</u>
<p><i>help you make your choice?</i></p> <p>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><i>your health plan choice, e.g., did mental illness/prescription drug availability, etc., help you make your choice?</i></p>
<p>Summarize the changes quickly and make sure that they understand.</p> <p>As you know, with Medicaid Reform there are some new programs and services, for example the Opt-Out Program, the Enhanced Benefits Account Program, and the Choice Counseling Program</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.</p> <ul style="list-style-type: none"> • If you're employed, did your employer know about Opt-Out Program? • If yes, did you/would you participate? • Why or why not? <p><u>Enhanced Benefits</u> With Medicaid Reform, you can also earn dollar credits for participating in certain healthy 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 specific items at your Medicaid pharmacy.</p> <ul style="list-style-type: none"> • 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><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.</p> <ul style="list-style-type: none"> • Have you had any contact with them? If so, what kind of contact? Phone, in-person? 	<p>Tell participant what the changes are:</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 Account Program, and the Choice Counseling Program.</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). If you join the Opt-Out program you can use Medicaid dollars to purchase insurance offered through your jobs.</p> <ul style="list-style-type: none"> • Does your employer offer ESI? • Would that encourage you to join the Opt-Out Program? • Why or why not? <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.</p> <ul style="list-style-type: none"> • Would this program encourage you to engage in the behaviors I just described? • Why or why not? <p>What would make you take care of yourself?</p>

<u>(Yes) Y questions</u>	<u>(No) N questions</u>
<ul style="list-style-type: none"> • 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>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 Choice Counselor will provide information that can help you pick a plan that is best for you.</p> <ul style="list-style-type: none"> • Would using the services of Choice Counselors encourage you to engage in the healthy behaviors we talked about earlier? • Why or why not? • Do you think the Choice Counselors would help you make a choice? If not what other factors would lead you to make the decisions? • What other kinds of information would you like to have to help you with your choices?
<p>Have you participated in any of the new programs or used any of the new services? Opt-Out Program? Enhanced Benefits Program? Choice Counseling Program? Why or why not?</p>	<ul style="list-style-type: none"> • 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>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>[BE SURE TO PROBE ON THE IMPACT OF MEDICAID REFORM ON</p> <ul style="list-style-type: none"> • PHYSICIAN ACCESS • TRANSPORTATION • PRESCRIPTION DRUGS] 	<ul style="list-style-type: none"> • Are you looking forward to experiencing these new changes with Medicaid?

SECTION 4: BELIEFS ABOUT HEALTH

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

6. 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?*

7. 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.*

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

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.

9. Do you believe that the healthcare system—doctors, hospitals, ERs, Nurses, are 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 healthcare system set up affecting fulfilling your healthcare needs and in helping you make health choices?*

10. Is there anything else that you would like to share?

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