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MEDICAID 2.0 – VINELAND STUDY

QUALITATIVE RESEARCH SUMMARY REPORT

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Hispanic Research Inc. – www.hispanicresearch.com



Objective & Methodology

Background / Objective

The NJ Health Care Quality Institute (QI) is undertaking a one-year project to evaluate and develop recommendations for the NJ Medicaid program. As part of this Medicaid 2.0 project, the QI team is conducting two focus groups with Medicaid beneficiaries to understand their experience including what works well, what barriers they experience and what they would like to see in the future.

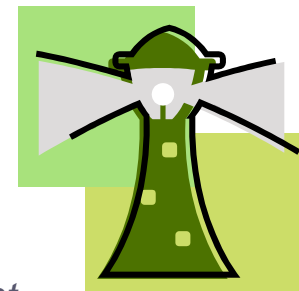
The first focus group was conducted in Vineland NJ and gathered insight on issues specific to the primarily Latino adult day patients. The discussion focused on their experience with eligibility and enrollment into Medicaid, timely access to quality providers, and their understanding of the health system including their understanding of their benefits as dually eligible for Medicaid and Medicare. This report summarizes the findings of that first qualitative group discussion.

Methodology

Eleven patients of the adult care facility participated in a two-hour discussion in Vineland, NJ on Thursday August 25, 2016.

- All participants spoke Spanish as a primary language.
- All were of Puerto Rican heritage.
- The discussion was conducted in Spanish.

Limitations and Clarifications



- *While we obtained a wealth of information in this study, we must remember that qualitative research is only directional in nature and cannot be used to predict the opinion of the population at large.*
 - ✓ *Respondents in these interviews were drawn from the population from whom we seek answers, but were not chosen on any statistical basis. The findings accurately represent the opinion of those individuals who attended the discussions. They should be used for clarifying existing theories, creating hypotheses, and for giving direction to future marketing research.*
- *This report is based on the analysis and interpretation of one focus group discussion. All quotes were spoken in Spanish and have been translated for this report.*
- *The terms Hispanic and Latino are used interchangeably in this report. In addition, the term “Latina” is used to denote a female Hispanic.*
- *The report also includes information from other sources, and the interpretation of the writer in order to give clarity and portray more actionable findings.*
- *The participants referred to the adult day care medical center that hosted the discussion as a community center. For the purpose of this report we will refer to the facility as the “center.”*

FINDINGS



Most participants had medical issues.

- When asked about their health and what they do to stay healthy, many participants said that they were not healthy.
 - Many of their medical issues had to do with age but some pointed out that Latinos in their community do not know how to be healthy.
 - While nutrition came up as an important part of staying healthy, it was clear that these Latinos had very little information about nutrition or were able to control their diet.
 - Some said that it is important to take care of themselves by doing things like walking carefully, resting, and avoiding drugs and alcohol.
 - Some felt that the center itself was a key to their wellbeing.
 - Following the doctor's instructions was also mentioned as an important part of staying healthy.
 - Many also gave thanks to God for helping them in dealing with health issues.

I am not healthy, my hands and feet go numb... I am getting worse.

We need to learn how to eat correctly. People eat what they like without thinking that some of it could be bad for them. We never learned how to be healthy.

I live alone and can only do so much on my own. I have to eat here and I eat what they give me; I do not have too much of a choice. Here they help me stay healthy.

All is good thanks to God and to me for taking care of myself.

They see a doctor on a regular basis but not everyone is happy with their doctor.

- All participants had a doctor that they see on a regular basis.
 - All said that they had a primary doctor.
 - The majority also had specialists that they see depending on their medical condition.
- Not everyone was happy with their doctor but most seem to continue to go to the same physician mainly because they do not know if they can change doctors or what the process would be to change doctors.

I have 7 or 8 doctors...

I am not sure about the effectiveness of my treatment. I am not getting better but they do not deviate from the treatment approach even when it is not working.

I was prescribed these patches and they worked but the new doctor now refuses to give them to me. He prescribed pills that are not what I need without even examining me. I am not taking that. I need to ask about changing doctors.

I do not like my doctor but do not know if it is possible to change doctors.

Other Research conducted by this organization has shown that cultural differences affect the Latino perception of a doctor. Hispanics generally complain about their relationship with “American” doctors. They feel that the doctors in the U.S. lack warmth and do not often relate to the patient as a person. The physicians are sometimes criticized for not truly caring for the Latino patient and are perceived as cold and hardhearted. Hispanics are looking for doctors who take the time to learn about them and their family at a personal level. They want a doctor who looks at them in the eye and gives them a physical examination. Looking at a computer screen and asking questions without a physical examination is often perceived as not caring about the patient’s wellbeing. They are seen as not wanting to listen to, or to spend the necessary time to understand Latino concerns. They are always seen in a rush and seem inattentive. This lack of “humanity” leads to trust issues. Latinos look for a doctor that they can relate to at an emotional level. They want to be able to trust their doctor. If they have a trusting relationship with their physician, they will pay attention to the doctor without questioning.

Many said they do not like going to the doctor.

- While they see a doctor on a regular basis, it was clear that most do not like going to the doctor and some in the group regarded themselves as healthy and actively avoided visiting a physician.
 - Most of the hesitation in going to the doctor is based on fear. Many other projects conducted by this organization have validated this fear, which is primarily rooted in a fear of death.

- *The fear of death is very strong in the Latino community. It is a subject that everyone loves to avoid.*
- *Any illness that is perceived as terminal, or is related to death, in the Latino mind is considered taboo.*
- *Latinos fear death because of its effect in other areas like not accomplishing their life's mission, their physical and emotional suffering as death approaches, and most importantly: the effect that their death may have on their families and loved ones.*

I went to the doctor and they found something wrong with my kidney, but I feel perfect so I do not understand.

I do not want to know anything about the future. Tell me if there is something wrong now but do not tell me that I may be sick next year because I will start worrying and become sick!

I am afraid of what I do not know. I do not know if a colonoscopy will hurt.

If I feel well, why should I get a colonoscopy?

If I do not know, I sleep well!

With men it's fear of the prostate exam.

Most do not go to the dentist and are afraid of doing so.

- While all of the participants visited a doctor on a regular basis, the overwhelming majority said that they avoid going to the dentist.
 - The thought of going to the dentist seems to drive a lot of anxiety. Most of the anxiety is based on a fear of experiencing pain during a dental procedure.
 - While they all have access to dental services if needed, this is something that they are clearly not seeking.
 - Our analysis indicates that they see the issues with their teeth as less serious than other medical issues. They do not understand the repercussions of having an infection as a result of their dental neglect.
 - Other research we have conducted also confirms that Latinos fear the actual discomfort of medical exams; and even the discomfort of being in a hospital or a medical clinic. Dental work in particular has a stigma for being extremely painful.

I have never been to a dentist. I should because it hurts but I am afraid.

I have to make an appointment. Have been saying that for many years.

My son translated and said that the dentist wanted to take all of my teeth out!

I do not want to even look at a dentist... I am that afraid.

I have only two teeth left.

I had a bad experience in PR. It has to do with the way they treat you. I saw the guy with a big needle and he was smiling-happy to inflict pain. My blood pressure went up and I never went back.

The overall experience with the health system depends on the patient's point of reference.

- Patients who had experience with healthcare in other areas immediately judged the services in Vineland based on what they knew from their prior experience.
 - This went both ways. Compared to some services in Puerto Rico some participants were very happy with the system. In comparing it to services in Orlando, however, one patient said that Orlando was better.
- The attitude toward services are also differently judged based on culture. Latinos, and particularly older folks, often do not have a problem waiting a doctor's office and are likely to enjoy the time socializing with others in the waiting room. This is well documented on other studies conducted by this organization- especially when it comes to the Puerto Rican culture.
 - Not surprisingly, waiting times were not regarded as a big issue among these patients.

I compare everything with Orlando and must say that the services were much better there.

I have been in Vineland a long time and do not know anything else, so to me it works just fine.

Sometimes you wait a long time for a doctor and other times you do not. I think it is normal to wait for doctors.

I do not mind waiting but there needs to be communication with the center because the other day we were so late that we missed lunch, and my wife is diabetic and I'm sure they were worried. They need to know if there is a delay.

Everyone had some experience with the emergency room.

- Everyone had some experience with emergency room services.
- They go to the emergency room when they do not have a choice. Many of them live alone and do not have a support system outside of the center so they rely on the emergency room and call 911 for transportation.
- One problem that was identified with emergency room services was that the treatment information does not get automatically communicated to their primary care physician. This is seen as creating a lack of cohesiveness in medical care.

I go to the emergency room all the time because if there is an issue I need to call 911. Even if it is minor it is the only way to go to a doctor sometimes.

I think twice before going to the emergency room; sometimes it is better to put up with the pain.

A problem with the emergency room is that they do not communicate with your doctor. I am the one who makes sure that my doctor has the information. This should be all tied. Communication across the health system is terrible.

Information about healthcare comes from the health center and word of mouth.

- When asked about sources of information regarding healthcare, everyone agreed that they would ask someone at the center for assistance.
 - They see the center as the place where all of their healthcare needs are handled.
- Some get information from word of mouth or through a relative who is able to use the internet.
 - None of them had direct access to the internet or knew anything about seeking information online.

I do not have a computer. I need anything I ask the nurse here and if she needs to use the computer she looks it up.

I do not know how to work computers. Sometimes I call my daughter in Puerto Rico and she looks it up.

Sometimes we learn by talking to each other. You learn through the other person's experience.

Prior research conducted by this organization has shown that Hispanics are generally at a disadvantage because they do not have access to the same information that is available to the general market. The lack of information can be attributed to the following reasons:

- 1. Companies develop their materials in formats that are best suited for general market communication. While Anglo Americans, for example, often prefer a formal written explanation in order to make decisions on serious matters like healthcare, Hispanics prefer a more personal communication approach.*
- 2. Hispanics generally have a lower level of education. Healthcare information is usually not communicated in a way that can be easily grasped by someone with little formal education.*
- 3. Language is a large communication barrier for new immigrants that speak little or no English.*
- 4. Ethnic communities do not have the same level of access to information. They lack the know-how to conduct their own research; they are more likely to work on blue-collar jobs that have limited access to HR information; they are culturally shy and afraid to ask questions; they often lack access to general market media channels; they are less likely to have Internet access; and they are often subjected to prejudice and discrimination, which affects their ability to learn from their experiences.*

All are very appreciative of the center and see it as their second home.

- These Latinos clearly depend on the center for their health and wellbeing. They are extremely appreciative of the services they receive and acknowledge that they depend on the care given at the facility.
- They like the center not only because of the services provided to them but also because it represents their primary social community. The patients clearly know each other very well and often interjected to add clarity to a story being shared by their friend.
 - Our analysis indicates that while the center may not provide medical behavioral health services, it does provide a community that is extremely important to the mental health of these Latino patients.
 - Almost everyone in the focus group referred to the center as their second home.
- The services provided at the center take care of issues that would otherwise be unsurmountable; like making medical appointments or dealing with health insurance.

Here I am happy because otherwise I would be alone.

This place is like a magnet that attracts everyone... it is a wonderful place.

Nothing is perfect but here we feel like a big happy family.

Here everyone takes care of me.

The experience with medical services is tied to the services that the center provides.

- It was very difficult for the participants in this study to separate the care they receive at the center from the experiences with medical care in general.
 - Medicaid and the center were often spoken about as one and part of the same.
- Most did not have any major complaints with healthcare primarily because they are very pleased with the adult care center.
 - Getting an appointment, for example, is not a problem because it is taking care of at the center.

Medicaid is great because they really take care of you here.

There are no problems in making or getting an appointment because the center takes care of all of that.

Health insurance is complicated and difficult to understand.

- Health insurance is a mystery for most people (this is well documented), but it is more so for older lower education Hispanics who speak little or no English.
 - Participants expressed frustration through many stories regarding Medicaid coverage.

My wife needed new eyeglasses and got lenses that were covered by Medicaid. We were told they have a 30-day return policy. They took three weeks to come in and something was wrong because she could not see correctly. We went back to the store that weekend, only 4 days after receiving the glasses and were not allowed to return them because the 30 days were from when the order was placed. We were told that that was the insurance policy.

I have no clue about how Medicaid works!

They do not know the difference between Medicare and Medicaid

- Patients were not at all clear on the difference between Medicare and Medicaid and sometimes were unsure of what they had.
 - Some expressed an interest in learning the difference between the two programs.
 - Those who said that they had some sense of the difference were clearly confused. In explaining their understanding they ended up promoting misinformation.
- While they do not quite understand how it works, all were very grateful about having health insurance.

I do not know the difference. I would like an explanation.

I think the difference is that one pays for medications and the other one for the services.

I think they are complementary in that the one covers what the other one does not.

I have no idea... the only important thing is that everything is covered by insurance.

I would be lost without health insurance... probably would have died.

They have had Medicaid and/or Medicare for a long time and do not remember the enrollment process.

- Participants were unclear about the enrollment process.
 - Many said simply that they do not remember because it was “many years ago”.
 - Others said that someone else handled that for them so they do not know.
- There was no frustration regarding the enrollment process because they simply do not recall enrolling.
 - Our analysis indicates that most of these patients probably received assistance with the enrollment, which is why they do not remember. We must point out that at least one of the patients interviewed admitted to being illiterate and unable to handle any kind of paperwork. Almost all of these Latinos have come to rely on the center for anything relating to healthcare.
- When asked about the best way to enroll in Medicaid they all agreed that it would be best to do it in person with someone at the center.

I have always had Medicaid.
Cannot remember not having it.

It has been over 10 years; I
really have no recollection.

When I turned 62 I went to
Social Security and they did not
tell me anything about
Medicaid... I do not know how I
got it.

Best way to enroll would be
here at the center because they
do everything for you here.

Language can be a roadblock in receiving adequate health care.

- Language is definitely an issue that needs to be addressed. These Latinos often rely completely on the interpreter when the health service provider does not speak Spanish. Unfortunately, the services of a good interpreter are not always available.
 - The interpreters provided by the center for medical appointments were highly regarded and able to resolve the language barrier.
 - However, all patients related horror stories with experiences where interpreters were either not available or not capable of translating correctly.

I had to stay at the hospital and the morning nurse was not able to explain anything to me because she did not speak Spanish. I was told I had to wait until 10pm for someone who could translate for me.

At the hospital they do not have anyone... sometimes they get someone on the phone but they are difficult to understand.

I witnessed a nurse who spoke very broken Spanish trying to tell a patient at the hospital about needing a stool test. He was totally lost and I helped translate but he basically had to rely on a stranger which is not right.

The doctors are not Hispanic and speak only English so we have to rely on the interpreter. It is okay when they take us from here because the center provides a good interpreter but otherwise it is a huge issue.

A lot of times if you go to the hospital there is nobody to translate for you!

The other problem is that the follow up with the doctor is always in English; it would be nice if they called me back in Spanish... I don't understand!

They gave me an interpreter and I did not understand what he was saying... he spoke Spanish differently and sounded garbled to me.

Behavioral health services are very much needed.

- When asked about behavioral health services the participants were quiet at first. As the conversation evolved, however, it was clear that the services are very much needed in their community.
 - They want the center to make counseling available on a weekly basis.
 - They are in dire need of support- some of the stories the patients related were heartbreaking.
- They all said that they do not know of any behavioral health services that are available to them.

We do not have any mental health services but definitely should.

The center should have someone here for counseling once a week.

We do not have support- I stay at home looking at the ceiling because there is no one to talk to.

Being healthy is not all physical, we deal with a lot of issues.

Many times we need to learn how to deal with mental issues of a close relative. I am going through a lot with my husband but there is no help for me.

I deal with it by crying a lot.

I hope I am not out of line here but my friend here confided that he sleeps only 90 minutes every night and I feel he needs some medication or counseling as I know there is something keeping him from sleeping.

The idea of automatic re-enrollment in Medicaid elicited some worries among participants.

- Only one participant related a story about a lapse in coverage and it had to do with her husband.
 - Everyone else did not see a problem with this and said that it is something that the center takes care of for them.
- When asked about the idea of automatically re-enrolling in Medicaid the group was divided in their opinions.
 - Some said that it was a great idea because it would avoid having to requalify.
 - A few others, however, objected saying that there is not really a problem and that they rather have someone they trust at the center overlooking the re-enrollment. They feared that making it automatic could lead to them being kicked out of the system.

My husband was 4 months without services because he got suspended. I guess it was an error. Good thing that Larry was nice to allow him to still come. The center worked on it and figured it out but it took 3 months to get resolved. If it was not for Sam we would not have known what to do.

I think that in order to keep Medicaid I simply cannot go over the deductible.

We need to make sure we do not have a lot of money in the bank.

It is important to go to the doctor in order to keep it.

No problem with qualifying for Medicaid because they do everything for you at the center.

If it is automatic I worry that you may also get kicked out automatically... and then what?

I prefer that it stays as is because I never had a problem with that and they do everything for you here. I do not know how to write so I need assistance.

They want better education regarding health care, and offered other recommendations for the center.

- Everyone is looking for better information on healthcare and to become more educated.
 - An idea shared was to bring speakers to the center on a regular basis to teach them about different subjects.
- Other ideas shared included nutrition classes, exercise machines, and improvements in pharmacy services.

If I do not know about it I do not know that it is important.

It would be good to get education; sometimes we want to learn- it is important.

I put in a suggestion to the center to have more presenters coming in to teach us.

They should have some exercise machines to keep us healthy.

We need nutrition classes to learn how to eat correctly.

The pharmacy service needs improvement.. they waste a lot of money refilling prescriptions that we no longer take.