

**Florida HIV/AIDS Health Care Needs
Assessment:
Qualitative Studies Of Selected Special
Populations
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Contents

Introduction.....	4
Context: The Overall Needs Assessment	
Rationale	
Link to other studies	
Methodological philosophy	
Research Purposes	
Focus Group Study: Methods and Findings	
Purposeful sampling process	10
Data collection and analysis processes:.....	12
Findings from the Focus Group Analysis:	13
1. Groups of People Who May be Overlooked for Care	
2. Barriers to Treatment or Care	
3. Testing Concerns	
4. Prevention Issues	
5. Areas where additional training is needed	
6. Integration of substance abuse and mental health care	
Summary of the Focus Group Analysis	34
Methods: Ethnographic Interview Studies of Selected Populations	
Preparation for the Ethnographic Interview Studies	35
Proposals and Instrument.....	38
Institutional Review Board Approval Process.....	39
Data Collection	39
Interview Data Transcription.....	42
Analysis of the Ethnographic Interview Studies.....	42
Results within each selected population group.....	44
Formerly Incarcerated Group.....	44
Overview	
Tables	
Summary	
Migrant Laborers Group.....	69
Overview	
Tables	

Summary

Young Adults 18-25 Group..... 94

Overview

Tables

Summary

Conclusions: Focus Groups and Ethnographic Interview Studies with Selected Populations

References 129

Acknowledgments 131

Appendix A: INTERVIEW SCHEDULE FOR The Formerly Incarcerated

Appendix B: INTERVIEW SCHEDULE FOR Migrant Workers

Appendix C: INTERVIEW SCHEDULE FOR Young Adults

Florida HIV/AIDS Health Care Needs Assessment Qualitative Studies of Selected Special Populations

INTRODUCTION

Context: The Overall Needs Assessment

These Qualitative studies were designed as part of a larger Statewide Needs Assessment. The Statewide HIV/AIDS Health Care Needs Assessment is designed to provide the Florida Department of Health, HIV/AIDS service providers and other HIV/AIDS planning entities with information to:

- 1) establish resource allocation priorities and to implement positive changes in service delivery,
- 2) correct service delivery gaps in various client need categories throughout the state of Florida,
- 3) formulate culturally competent service responses in the form of new or revised programs or initiatives,
- 4) identify unmet needs, service needs of individuals not currently in care as well as those who are in care but whose needs are only partially met or not being met, and
- 5) determine major barriers to accessing services.

The challenge in developing the overall needs assessment methodologies was to build on existing data or information to assimilate, synthesize, interpret and disseminate a useable synopsis of the large volumes of data and information in a form, including

recommendations, that could be effectively used for planning purposes. The following sources of data were used for the Assessment: 1. FL Department of Health (DOH) has comprehensive HIV/AIDS surveillance data. 2. Each region that receives federal grants (Ryan White Titles I & II) provided extensive needs assessment data sets for their respective regions covering all of Florida's geographic boundaries. 3. A small number of areas, predominantly urban areas in either southeastern or northeastern Florida conducted federally sponsored ethnographic studies of communities with large high-risk populations. 4. Other studies conducted throughout Florida, primarily in response to local community interests and available resources.

The statewide needs assessment is comprised of four major components:

- 1) An analysis of existing sources of surveillance data, providing an HIV/AIDS epidemiological profile of the state of Florida
- 2) A Meta Evaluation of the Regional needs assessments conducted by the HIV Planning Councils and the HIV Planning Consortia covering the Title I and Title II regions of Florida
- 3) A Meta Evaluation of the federally funded RARE studies completed in Southeastern and Northeastern urban areas of Florida.
- 4) Qualitative studies, using an extensive, multilayered and multimethod design of three selected populations in different regions of FL to provide more representative geographic and demographic characteristics of the state.

Rationale

This report describes two distinct yet coordinated phases of the development of the qualitative studies of the three selected populations. These two phases are: 1.) The focus group study of the Florida Community Planning Group care and prevention stakeholders and key informants (November 2001). 2. The formative development, implementation and analysis of each of the three ethnographic interview studies of the selected populations (Summer/Fall 2002). Together, these two coordinated areas of emphasis provide a multidimensional understanding of the issues within in the context of the issues.

The focus group studies of the prevention and care groups of the FCPG and the qualitative studies of three selected populations serve two main functions: First, these projects yield in-depth insight into and understanding of the patterns of the use of health care services by specific communities identified as being potentially underserved. These groups were identified as outside the cultural mainstream of society or outside the stereotypical culture of those people who are at high risk for HIV/AIDS. Second, the studies were designed to provide some geographic and demographic balance to earlier federally funded Rapid Assessment, Response, and Evaluation Project (RARE) studies that were conducted in the larger urban areas on the Eastern side of the state.

Links to Other Studies

The studies of selected populations being reviewed here were conducted within the Northwest, Central and Southwest regions of FL to provide regional balance to recent qualitative information provided through the RARE method funded by the Office of Public Health and Science, and the Office of HIV/AIDS Policy. These RARE projects

were conducted in the Jacksonville (the Northeast area of the state) in Palm Beach County, and in Miami Dade (the Southeast area of the state). Each of these earlier RARE projects was conducted by a different team and using somewhat different methodologies.

Conceptualized as a supplement complementary to existing HIV/AIDS assessments available in FL, these three qualitative data gathering projects were conducted within three different regions of the State. The main goal was to highlight three unique populations with diverse, complex and potentially conflicting needs that had not been studied previously. The methodological approach used was stakeholder-focused ethnographic inquiry similar to, but more extensive than, the processes used in the previously conducted RARE projects.

Methodological Philosophy

Traditionally, ethnographic methods of inquiry have been grounded in the assumption that any group of people interacting together in a community will evolve a culture that can be studied to provide insights into the people and their community (Creswell 2002; LeCompte and Schensul 1999; Schensul, Schensul and Le Compte 1999; Tashakkori and Teddle 2003). This inquiry method it is possible to understand the complex systems that influence a community's or population groups' rules, beliefs, norms, assumptions and behaviors. Understanding the complexity and contradictory nature of people's realities can provide useful insights which can contribute to effective intervention, policy change and support strategies (from an ecological perspective).

Because of a unique ability to highlight context, ethnographic methods have emerged as a design for assessment and evaluation (Fetterman, D. 1984, 1989; Denzin and Lincoln 1994; LeCompte and Schensul 1999; Tashakkori and Teddle 2003). The

emphasis on culture and context can facilitate changes in program processes and/or highlight policy level outcomes at the individual and social-environmental levels. However, research to examine the lived experiences and cultures of overlooked or vulnerable populations will be most trustworthy if it is guided by stakeholders and key informant input. Stakeholder-informed ethnographic inquiry provides many levels of data collection and analysis creating a dependability audit to verify triangulation (Cresswell, 2002; Guba and Lincoln 1989; Miles and Huberman, 1994; LeCompte and Schensul 1999b).

Building on this methodological grounding, and providing the first stage of the audit, the beginning stage in these ethnographic interview studies of selected populations included stakeholder and key informant focus groups. Without this layer of input it would not be possible to ensure that the voices of individuals and groups with different and conflicting viewpoints and cultures could be included in the assessment and evaluation (Guba and Lincoln, 1989; Bie Nio Ong 1996; Schensul, Schensul and LeCompte 1999). The next stage of the studies involved a systematic process for gaining entry to the selected populations. The implementation of this stage provided additional processes for the dependability audit. The third stage of the studies involved the implementation of the ethnographic interviews with the selected populations. These individual study processes provided a continuation of the audit for each of the three separate populations.

Research Purposes

Health care programs are in place and functioning throughout the state. These programs are monitored through surveillance data and this information is compiled in the Epidemiology section of this Needs Assessment. However, not all populations use health care services or interact with health care systems in the same way. In our system of counting people we serve or counting people at risk, we can only count whom we can define. Because the morbidity and mortality information indicates we may be failing at many of our efforts to intervene (SOUTHERN STATES AIDS Coalition Report 2002), the potential exists that many groups are underserved, ineffectively served or overlooked. In many cases these groups are so isolated that providers and system developers lack enough understanding to begin to effectively plan for their involvement and care. Consequently, to make significant change in the increasing epidemic, methods of assessment are needed that will focus on peeling back the layers of our lack of understanding. In qualitative evaluation, this is called diversity focus: giving voice to different perspectives on and illuminating various experiences of HIV/AIDS, even if these experiences (or lack thereof) are contradictory.

No single conclusion or summary judgment will emanate from this series of studies. It is not the goal of this process to reduce all the information to numbers (though frequency of types of answers will be provided), rather it is the goal of these processes to create a greater depth of understanding of the complex realities of peoples experiences. By utilizing the multidimensional processes of stakeholder-focused planning for the ethnographic interview studies, significant suggestions will emerge that are relevant and

timely. These suggestions and recommendations will facilitate more effective entry into overlooked populations, they will provide a greater understanding of the complexity of the issues and/or the recommendations will provide organizational input into policy changes to better serve individuals, groups or communities (Patton 2002; Schensul, Schensul and LeCompte 1999)

Focus Group Study: Methods and Findings

An ecological model contributed to the development of the methods used in the development of each of these studies (Brownson, et. al. 2003; LeCompte and Schensul 1999; Institute of Medicine 2003b). Using this model helps ensure that needs are communicated through a multidimensional perspective. This multifaceted view can help identify areas of potential change by highlighting the adaptability and flexibility of various levels of social systems. Using an ecological model to learn how social systems adapt and how people, communities and their environments flow, can provide multiple points of entry and facilitate effective intervention strategies grounded in empowerment and collaboration (Brownson, et. al. 2003). The model keeps the focus on the synergistic interactions between ecological levels, rather than focusing on just one level, and keeps findings from being used to reify stereotypes (Le Compte and Schensul 1999; Peterson and Alexander 2001).

Purposeful sampling process: Building a strategy to access the participants

The original proposals for the qualitative studies were designed to build on existing regional information. The proposal stated that qualitative data would be

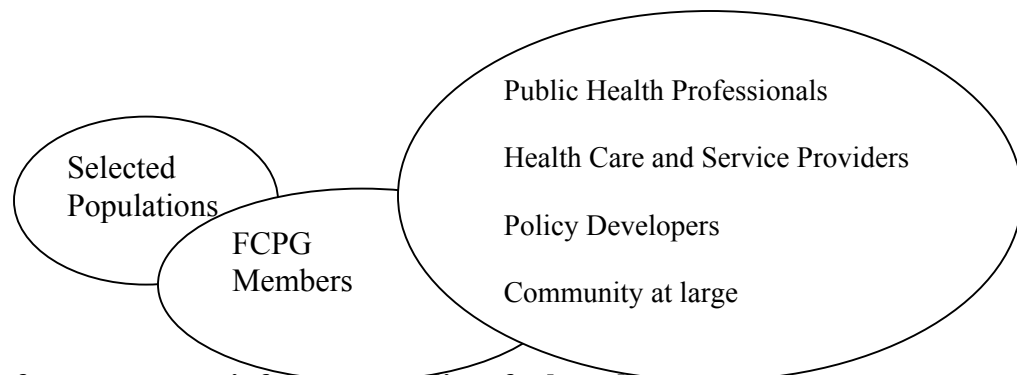
gathered through face to face semi-structured, open-ended interviews with members of each of the three selected groups in order to accomplish the following: 1.) to develop a greater understanding of special population differences in terms of *their* needs, 2.)to highlight *their* understanding of existing health care services, 3.) to comprehend why *they* may or may not access health care systems and services, and, 4.)to learn how the system might be improved to enhance *their* health care accessibility.

Macro level sampling: Focus groups

A purposeful sampling approach was used for this part of the project. Purposeful sampling is a fundamental sampling process associated with these types of projects. It is used to ensure the selection of information-rich cases strategically and purposefully for the depth of understanding they can provide within a context rather than for generalizability to other situations.

Gaining access to overlooked, vulnerable populations can be conceptualized as “peeling back” layers of an onion with each of the multiple layers being the multiple assumptions that could synergistically block understanding of the issues. If you conceptualize the inside layers of the onion as the realities of the most vulnerable and overlooked populations, then the layers next to these populations could be the realities and knowledge of the street level professionals, community agency people, outreach workers, consumers and consumer members of planning groups who may be part of or may have entry into these populations. The FCPG members who participated in the focus groups are connected simultaneously with the overlooked populations, the health care professionals and the public health professionals. Though they do have barriers to

access, they are closer the populations than other gatekeepers. The following visual displays the relationships between the groups:



Conducting focus groups to inform the studies of selected populations

The specific populations to be used for the three ethnographic interview studies were selected through focus groups comprised of the FCPG stakeholders. In keeping with the assumptions that must be met to conduct focus group research, these individuals are people particularly knowledgeable about the situation and are able to articulate their knowledge. These insights can be particularly useful in helping observers understand what is happening and why (Patton 2002). In this case a large group of HIV/AIDS providers, consumers and activists who meet quarterly to engage in statewide HIV/AIDS planning served as the stakeholders or gatekeepers

The FCPG is made up of two sets of participants, the prevention focused group and the care-focused group. Three focus groups were conducted with both of these subgroups. E.g., while the prevention groups were involved in the focus groups, the care group was conducting a separate meeting. Though the focus groups were larger than expected (each containing more than fifteen people), the participants were extremely well informed and participated in a lively discussion, which was rich in insights.

Data Collection and Analysis Processes

The focus groups were audio taped and the tapes were transcribed by a professional, bonded transcription service. In addition to the taping, observers took copious notes during the interactions. The analysis process involved multiple reviews of the transcripts, coding of the transcripts, comparative analysis of the transcripts (Denzin and Lincoln 1994; LeCompte and Schensul 1999b; Miles and Huberman 1994; Tashakkori and Teddlle 2003), conversations with focus group facilitators and computer-assisted analysis to assess “examples” and “non-examples” of themes. The analysis documented that the emerging themes were not question dependent, but rather they surfaced throughout the focus group sessions. These multiple analysis processes provide triangulation and trustworthiness requirements of qualitative research that are parallel to validity and reliability in quantitative research (Creswell 2002; LeCompte and Schensul 1999b; Noblit and Hare 1988).

The findings of the focus groups were presented in two stages. The initial “macro” analysis of the focus groups, conducted by the researchers who conducted the focus groups, was used to select the populations to be the focus of ethnographic interview studies. This analysis process also provided a framework for the types of questions to be asked. The second, more in depth stage of the analysis has been ongoing, has complemented the ethnographies and has provided a foundation for the analysis of the interviews. It is this in depth analysis that is presented in this section of the report in such a way as to simultaneously provide input into the total needs assessment findings and the protocol development process.

Findings from the Focus Group Analysis

The findings for this report will be presented in several sections. Each section of the report reflects a major theme which emerged from the constant comparative analysis. These themes are: Groups of people who may be overlooked for care, barriers to treatment, testing concerns, prevention efforts or secondary prevention efforts that may be overlooked, areas where additional training is needed and concerns about substance abuse and mental health care integration. Since the main purpose of this report is to highlight the complexity of life situations and allow the stakeholders to inform the recommendation process, this report will emphasize the voice of the stakeholders as each theme is reviewed. Quotes or quoted passages of conversation from the participants in the focus groups are used to illuminate the meaning or dimensions of the themes. The quotes and passages have been chosen to demonstrate the variations within each theme. The primary themes are reviewed in the following sections of this report. The quotes/passages are italicized. When necessary, names or locations have been removed to protect confidentiality.

1. Groups of People Who May be Overlooked for Care

One theme that was consistently presented by the participants was that people who contract HIV/AIDS are just people. They may not be risk takers or they may not feel like risk takers. Describing people who contract HIV/AIDS as “at risk” or “risk takers” reflects how people can use “categories developed by experts” to separate themselves from the risk of AIDS. The focus group participants could list groups of people overlooked for care or people at the greatest risk. However, they also articulated concern about creating categories/indicators as this keeps people from feeling at risk. Creating these categories or indicators may be a barrier which prevents professionals

from understanding the complexity of the issues. This idea is communicated in the following passage from the transcript:

“The greatest people at risk are the people who don’t feel they are at risk. It doesn’t matter what age group, there is no sense of risk. It can be old, young, married, anybody.”

Further indication that creating categories of risk insulates people from facing the fact that they are at risk is the following:

“The promotional messages out there are all about statistics. If you’re black or 15 or older, whatever. You don’t hear (in the messages) if you’re having unprotected sex, or if you share needles, if you do those things, its always if you fall into these categories.”
“You get a picture of what the category is.”

There was a clear indication that the stakeholders prefer the message that risk is everywhere. However, there were several groups or types of people mentioned by the participants as being overlooked for care or prevented from receiving care. These groups (young adults, undocumented workers, formerly incarcerated prisoners, transgender individuals, deaf or hard of hearing, homeless, mentally ill, rural, women who have sex for money or drugs and elderly populations) will be described in the order of the depth, intensity and strength of the theme presented.

The first group described was the **“youth or young adults”** group. This group was mentioned frequently because they are not in the system but they are perceived to be at great risk due to their behaviors and attitudes. They are also not perceived to be a group of people whom the medical community considers at risk, so interventions or testing efforts are not typically aimed at them. It was reported that the medical community is not very youth friendly, which creates a barrier to entering the system. The following passage helps to illustrate this:

“There’s also a resistance to be (or get) tested in the late adolescence to early adult when they’re not having any symptoms at all. They’re not displaying much in the way of symptoms because the . . . conversion may have only been in the last month or two or three or year. They’re doing fine because they’re healthier to begin with because of their age and their general well being.”

“They may go for years without any symptoms. That’s their most sexually active period.”

“(Go to) a college town. (Go to) those after bar parties . . . see what goes on. It’s horrifying.”

In addition, the participants noted that, although youth may be isolated, difficulty in accessing them physically is not the real issue. Participants noted a level of frustration with how they are able to access youth because inconsistent policies make it difficult to approach them. It was noted that:

“It’s not ‘how do we access youth?’ It’s what is the barrier to accessing youth. Youth itself is not the barrier. Schools and parents and churches are barriers. There is evidence when you look in the literature of increasing numbers of places across the country where kids are taking it upon themselves, or kids who have been involved in other programs outside the schools have taken it on themselves, to become peer educators or to develop programs for everything from abstinence to just safer sex. But when the system limits your access you can’t say that youth is the problem.”

Participants also noted that there is a significant and growing population of youth or young adults who were born with HIV and who have been receiving care who are now on their own. These young adults may now be falling through the cracks. This is expressed in the following passage:

“We don’t pay them the same attention we did. Remember early on we have all kinds of support. They have case managers who follow them around. If their parents don’t bring them in we have people who go out to them. We paid a lot of attention to that population then all of a sudden the 13, 14, and 15 are now away at college. You are an adult now and you are expected to come in on your own but without all this attention like before. This has been a real problem.”

The next group that emerged in the analysis was the **“undocumented” and migrant workers**. The participants described a population that is disenfranchised and frequently unable to access care. In addition to their potentially undocumented status,

access to care, fear, transportation issues, cultural issues, and language issues are concerns for this population. The following quote documents some of these concerns:

“When you’re dealing with . . . the (migrant) population, the first thing they are going to think is they are going to call INS on them, even though you try very hard to tell them we don’t ask anything if they are undocumented. We are not going to put that on paper but it becomes an issue when they do become positive. What do you do with them when it comes to treatment? I mean they need to be documented to go through the system. So that has been a never ending fear for both, us as providers and also for the community, for the undocumented community.”

Participants expressed concern that the migrant workers are also unique because of two things: the language barrier and the fact that they are not consistently in one area or even not consistently in this country:

“I think also we’re missing undocumented residents. (We have) a whole lot of undocumented residents. There is not a whole lot of options for those.”

“I think being in the migrant community alone whether they’re documented or undocumented because of the nature of the work. Being a migrant in and out of the country, in and out of the area.”

The **recently released or formerly incarcerated population** was discussed in several focus groups. The participants expressed concerns about how the recently incarcerated get infected, get care and/or get care when they are released. The following passage highlights the issues in this theme:

“We have decent care for them while they’re in prison, but once they get out of the detention center... it may be a multitude of problems. It may not just be HIV; it may be substance abuse or mental health issues. They have to jump through hoops to access care.”

“There’s a lot of politics involved in particular with that population.”

“More trust issues and everything else.”

“The jails are so full that if they’re to be discharged on November 7th, at midnight they start the paperwork and they get out at 3:00 am. They’re not going home. They’re going right back where they came from. So that’s the system failing the people . . . It’s hard to break the cycle, particularly when you can’t get linked to treatment at 3:00 am.”

Another example of the concerns relayed about the recently incarcerated population is the difficulty they experience as they attempt to re-enter society. This is a complex milieu, with multiple barriers, as described in the following quote:

“... People . . . have been in jail for 20 years and come out... In 20 years there’s been a lot of changes in healthcare and how we access it. They have no idea. They’re just turned out with the clothes on their back and ten bucks.”

“They don’t even have the names of the groups to go to much less where to go.”

“They’re not eligible for Section Eight if they have felony convictions so low-income housing isn’t available to them.”

“They’re not even eligible for some healthcare. They’re totally disenfranchised.”

“It’s hard to get jobs. You can only be at homeless shelters at night.”

Though the participants noted that some programs have been effective at linking these individuals with care, they also noted that people might refuse to participate and that these programs are not available to all prisoners being released.

An additional population of great concern was the **transgender** population. Participants indicated that this group might not lack information as much as they feel oppressed. The following passage highlights some of the concerns expressed:

“Another population that I’d throw in the ring that was most oppressed would be transgender. . . . It’s certainly under the radar. Part of that is certainly due to the small number. But it’s certainly at risk. A credible risk. . . . Probably most of the community planning partnerships don’t have representation of a transgender patient. They’re just out of the loop, out of the system altogether.”

“And again, I think it’s probably one of those populations that people just definitely don’t know how to reach and how to deal with.”

Focus group participants saw these groups as isolated and likely to experience discrimination. It was reported that they feel a stigma, though this is not only because of HIV.

“People are afraid of being judged. I think like the transgenders in particular are educated enough in terms of the HIV information with regard to transmission. I know some transgenders who share needles for their hormones, but they also know how to

clean with bleach, and they're very safe, if you can be. So it's not from lack of information. It's from shame or fear of not being accepted once they access care."

Many participants discussed the **deaf** or hard of hearing population. Participants noted that this population has become highly sexually active and they are at risk because they do not get specific prevention/intervention messages. The concerns about this population are illuminated in the following passage from the transcript:

"We don't ask if you're deaf. We ask about cultural stuff, but we don't ask if they're deaf. And we also have the language barrier. It's a cultural barrier. I believe they are the most oppressed people in the nation in most every aspect."

"They're also very sexually active."

"Very sexually active because that is one avenue where they can be normal. So there's a lot of risk-taking from the youth. Like the girls or even the boys, to be sexually active, so they can be normal and like everyone else, or even faster than. To me that is one of the groups that we really don't address."

The participants described other populations that tend to be overlooked. These populations include: the homeless and near homeless population, elderly/seniors, residents of rural areas, prostitutes or people who have sex for needed resources, and mentally ill individuals. There were various reasons presented for the groups being considered overlooked, and there were conflicting reasons given for why public health and health care professionals have not learned how to effectively reach these populations, however there was consistent agreement that these groups need much greater attention. The following passage about the homeless population highlights some of the concerns and some of the complexity of the problems that need to be addressed:

"Did you put homeless (on the list)?" (Several respondents agreed.)

"And mentally ill."

"Homeless is huge because they get into issues like how can you take meds when you don't have any food to take the meds with? You don't have anyplace to keep it cool. The pharmacist is only going to give you a certain number of meds. Or you have to have an

address to be able to get a hospital card to go there for care. Being homeless just affects every part of it.”

Several participants highlighted the complex, resource-driven behaviors of some groups of women. The following quote, highlighting the difficulty in reaching people who have sex in exchange for needed life resources, documents the complexity of the issues:

“We put a great deal of pressure on talking with women about changing their behaviors and putting a great deal of unrealistic expectation a lot of times that certainly is not cultural, not safe for them, not safe for their children. If somebody is coming by and says we’re not using a rubber and I’m going to give you \$50.00 for your children’s food this week, you’re not going to use a rubber. So you can be educating me till the cows come home. . we continue to focus on that group of folk rather than the people who are putting them at risk.”

The rural population was also of concern to the participants because of the interactive effects of lack of access, fear, and lack of information. The following quote illuminates these concerns:

“It is just a big lack of providers. You know if they want care, they don’t have transportation to get to where there is care. They will be lost in the system.”
“Lack of information also about services that are available now in the rural areas.”
“And it also goes back to that they don’t want anyone to know that they are positive. In a rural area, the nurse knows and everybody can. Like she said, they go back into denial and they just don’t talk about it. They just keep it to themselves and infect other people sometimes.”

The elderly population was also of concern to the participants. The major issue was lack of awareness of risk for the population and a lack of emphasis on this from their providers. The following passage summarizes these issues:

That’s why it doesn’t dawn on gerontologist. They think that once we’re over 50 we’re not having sex anymore.” (Several respondents agreed.)
“Viagra works.”

“As long as it’s functional...”

“That’s a societal expectation in America. We’re not as sexually active when we get older.”

“Just the studies they’ve done (here) and the number of cases they’ve found (here), 60% of those cases in senior citizens were sexually transmitted.”

“I think our oldest client is close to 80. He’s great.”

“... large number of seniors in the waiting room.”

“Truthfully they’re just as shocked as the doctors are. They don’t expect it. That’s a young person’s disease. To be fair to the gerontologists the patients really don’t think that they’re at risk. We haven’t done a very good job of letting people know that.”

The above passages and quotes demonstrate how the participants identified specific groups and populations that have been overlooked for care. It is clear that participants believe that reaching these populations is a complicated, challenging process. Though many of the populations described above were defined as “overlooked,” hidden in the narrative were multiple issues that keep these populations vulnerable. They experience barriers to care. The following section of this report highlights the dimensions of the theme “barriers to treatment or care” that emerged from the analysis of the data from these focus groups.

2.Barriers to Treatment or Care

The ability to access care or the availability of care is a complicated theme. The issues vary depending on the population, however there were some consistent themes that emerged from the data. The main issues that emerged in this theme include issues of confidentiality and trust, availability of appropriate care or efforts to gain access to care (including the impact of drugs), the ability to successfully get people to access care once they have tested positive, retaining people in care who do access care, being uninsured or being unwilling to share HIV status with insurance company, having higher needs or priorities and issues specific to families accessing pediatric care.

The strongest theme in this analysis was the issue of confidentiality and trust. There were many dimensions to this theme including fear of being exposed as an HIV/AIDS client, the fear that other people will find out, the desire to avoid feeling the stigma and the fear of being judged. Also mentioned was the fact that the treatment community does not successfully market treatment to people the way we market prevention efforts. The following passages from the focus groups highlight these issues:

“If I go to the public health clinic, you (the people I see there) know my mother, you’re my neighbor, and there’s that whole thing about being found out. And I can’t get support from my church or my neighbors or my family, so I’m not going to go.”

“I’ve had friends and employees who knew their stats and refused to go for care. There are people who just could not deal with the stigma attached. Once they went in for care they would not have their family support them anymore. That person died. They didn’t have to, but they chose to do that because they couldn’t accept not being accepted by their family and their friends. Just because that stigma was there, if they told anyone about their status, they would have been on their own.”

Another issue highlighted in this theme is the **availability of appropriate care or the efforts needed to access care**. Clearly there are processes in place that do not consider the real lives of people. Cumulatively, these processes represent a barrier to care. The following quote highlights this concern:

“The biggest issue that people don’t come in for care is barriers. The service providers just sweep that problem under the rug. There is a two-hour intake, there is an hour wait . . . and you sit in the clinic for an hour. People don’t want to spend eight hours in the clinic. They want to get in quickly get what they need and get out. The system is not set up that way. They are very cumbersome. They consume time and are not efficient. We all have lots of room for improvement in all of our agencies, big and small, but it’s horrible. You have to go to this place to get an appointment to go to this place and go to draw labs go to this place to get this. It’s just crazy. Some systems are set up that you have to be a professional patient, where you have to spend five days a week, eight hours a day going here and there. Intakes and no one keeps anything. If these people are not real sick then they want to know why they are doing this. They think they are a symptomatic why should they put themselves through all of it. And to add to it, they have to get on a bus to get there.”

However, processes for accessing care can be understood differently. The participant below describes a decentralized process that can facilitate getting people into testing and care. The issue here is that there are communities that do not follow this example and the people in these communities have less access to care:

“In terms of linking people to care and treatment there are various ways to get people connected into the system, and different areas of the state operate differently. Most often there is a centralized intake area where people come in for services and then get divvied out to wherever their needs are. In . . . county we have a de-centralized system, so anyone can access care and treatment through various methods. I’ll give you some examples. If someone comes in for an STD, we do HIV testing. Now we have an entry. We have a Women’s Health. If someone comes in for pregnancy testing, we do an HIV test. This is all DOH. But if someone wants to go to say the . . . Community Center, and they’re going there to learn how to buy a home, and they see the little sign there, HIV testing, they may get tested, and now they’re looking into care and treatment.”

There are other issues that may make getting care a low priority for people. These may hinder our ability to facilitate the access to care. Some individuals may have higher needs or other priorities. Some groups of people have other concerns than HIV that may impede their access to care. These concerns may be for basic survival as described in the following quotes:

“I think typically the groups would be lower socio-economic people who already have poor health seeking behaviors. So HIV is just another issue. It’s not the major issue. The major issue might be getting the children fed. So I would think lower socio-economic, lower education, meaning the typical required education in the USA as the standard. So somebody who didn’t complete high school, let’s say.”
“Those are blocks to accessing care.”

Another example given by a drug addict mother:

“When I came, people didn’t treat me nice, plus it’s located in a place where they see me going into that building, they know I’m HIV infected, therefore I can’t get my tricks in to get my crack.”

There are many reasons that people do not access care, but many participants agreed that drug use is a primary reason. The previous and the following quote help to summarize this idea:

“The primary thing that keeps people out of care is drugs. People are busy doing drugs. They may or may not know they are infected but their health is their last priority.”

The ability to successfully get people to access care once they have tested positive is complicated by many factors. The following passage helps to highlight the complexity of this issue:

*“They aren’t sick so they don’t come back.”
“They have to have a reason to want to access care.”
“If there is something, they won’t come, if they aren’t sick enough, they won’t move.”
“When the pain is too much for them to stand, that’s when they make the move.”
“If they are feeling good, I don’t care how much you do, they do not hear that message. They cut that off until there is a problem. I know someone who died like that. We went down that same path and when he/she got too sick and went to the doctor, it was too late.” “In the early days of the epidemic, there was a problem of getting people tested because if you found out, there was nothing you could do, so why go through that? When the drugs came along, it was a different story. One problem you contend with now is even though you go in and they put you on a regiment of drugs, it’s not an easy process. It turns out to be more unbearable than people are willing to do. You’ve got to figure what are the incentives to get people in there. For people who test positive, there had to have been symptoms, signs, or keys along the line.”*

Another theme that emerged also related to the ability to access care is specific to **families accessing pediatric care**. Participants reported there is good access to care for children who are HIV positive. However, this may not be true for other members of their families because of time or logistics.

“Children who are infected within this state get really good care within the Pediatric AIDS Network. But their mothers oftentimes don’t have access. There are many pediatric sites where the mothers don’t have the same kind of access to healthcare. Many times they spend days getting their kid in and then they have to spend days at the Health Department themselves. They take care of the kid and they don’t take care of themselves.”

It was also revealed that mothers might lose their children if they fail to access care for them, but not if they fail to access care for themselves. In addition, the data indicate that the social service professionals deal with many complex issues when it comes to mothers and children who are HIV positive. They get pushed to the limit when it comes to deciding how to best handle this situation. The following quote helps to illuminate this concern:

“Why are the children pulled though?”

“In these cases, one case a young mother was positive, and she only had a child provider 70 miles away. She had two appointments, she missed both, and both times, she called to say I can’t make the appointment. They reported her because she missed two appointments for the positive child. Just the positive child was pulled, not all three.”

There are also issues related to retaining people in care who have previously accessed care. The following passage exemplifies the complexity of the efforts to retain people in care when other variables are involved. This is a difficult problem that is made worse by the limited amount of resources for care:

“ . . . We only have so much (money) to treat people who want help. What about the people who aren’t compliant? We could be helping people who want to participate. It’s not only getting them to treatment, but retaining them and making them active participants.”

“Providers need to try to figure out where those individuals are at that particular time. Even in the prison project, when they don’t follow through with what the doctor recommends, you know when they get out, they are not going to be compliant with their AIDS.”

“When you talk about statistic, for a drug addict, it takes them nine to ten attempts before they can come clean, if you know they have been an addict for a long time, you’re setting them up for another problem because of the resistance. Even though we want to save everybody, it has to be okay, it has to be reasonable, realistic.”

“You made an excellent point, in terms of people with drug addiction, you aren’t going to do anything about HIV until you cure the drug addiction. Unless you put money into that, you’re not going to get them into the care (and keep them) in treatment for HIV.”

Another theme that emerged from this analysis was client insurance status.

Clients may be unwilling to share HIV status with their private provider (or insurance company) or they may be uninsured. This impacts ability to access care. This can play out in many ways as documented by the following passage:

“A lot of people that I know that have or had insurance when they decide to go and get tested they don’t deal with their normal doctor. They go to the health department. They do all their HIV care at the health department. They keep those two medical records very separate so that insurance never finds out that they’re at the health department.”
“That’s another reason that we’re spending a lot of money in areas that we wouldn’t have to spend money on. A lot of people because they’re afraid of losing their insurance or are not aware of the insurance laws they would rather go to the health department and act like they never had a private policy. They may have a terrific policy.”
“Once again it’s the stigma.”

Another example of the issues related to insurance is the changing reimbursement levels being implemented by these insurance companies.

“They won’t pick up prescriptions or drugs or they have a ceiling of a \$1,000.00 or \$1,500.00 which to an AIDS patient for a year is nothing. The insurance industry is capping. This has hurt our ability to get people into care. The insurance companies have in many cases they have capped all of their medication no matter what the illness is at \$1,500.00 or \$2,000.00. Some are as low as \$500.00 a year. There are limitations. They realize that. They’re certainly not going to go in for care when they see that they’re going to have a problem. They’d rather go to the health department and not tell them about insurance.”

Being uninsured and not on Medicaid is an issue for many lower income people who need to access care. The following passage provides an example of how this issue was communicated:

“People who don’t have insurance just generally go to the emergency room. They just get emergent care.”
“The working poor make too much to be eligible for Medicaid but don’t make enough to pay \$1,500.00 every month for medication.”

The barriers to care are complicated. Though the participants described some programs that have resulted in barrier reduction, they still expressed frustration with many barriers that hinder access to care for multiple populations.

3. Testing Concerns

Another theme that emerged from the analysis of the data is a range of issues related to testing for HIV. Because knowledge of HIV and perceived risk of HIV varies, the likelihood of being tested can vary. But, this theme “testing concerns” has various meanings or functions that can include belief systems and personal behavioral choices that can be contradictory. These are documented in the following passage from the transcript:

*“The stigma is denial.” “You see that in young gay males.”
“It’s them and not us.”
“There is a hopelessness or inevitability here... They feel that it’s inevitable at some point they’re going to catch this. So what? That’s a hard nut to crack.”
“To be honest too they’ll come back and be tested every six months. (you tell them) Testing isn’t going to prevent . . .”
“Sex with a condom isn’t the same. . . Well dying isn’t better. Which one do you want to do?”
“I get that sometimes too. If I get tested every six months, I’m okay.”
“The test isn’t the barrier.”*

As illuminated above and below, there were descriptions of people who do not access health care but will continue to get tested. These people were consistently described as having drug problems that complicate their ability to effectively get counseled during the testing processes. This is communicated in the following passage:

*“They don’t go for healthcare anyway.”
“They have no reason to seek care.”
“It can be as simple as drug addiction. When I was doing outreach, counseling a crack addict female, looking at all the tests, she comes back negative, comes back negative, I said it’s going to happen, boom, she’s positive. You’ve got to get that blood drawn*

before the second appointment, she won't go, it's the addiction, first and foremost that's what I'll take care of."

Clearly testing is a complex issue. The above passages indicate that testing may be just a continual step toward becoming HIV positive. The following passage documents that testing can lead to different reactions in different people. Some people may not get the support they need to deal with the results.

*"Some of them don't come back to find out. We have no way of calling them."
"Then some people go into denial. They don't believe that it's really positive. So they want to be retested or they just take that positive result and just put it in the back of their mind. Okay, that is not true and they go on with life and not reenter the scene until they are very sick and have to seek medical care in the emergency room."*

The participants noted that there are women for whom testing can lead to abuse. The following passage illustrates how the system can contribute to abuse of women.

*"I know they (are) victims of abuse."
"They're safe to go to because they know if (a) person finds out they think the world is going to know about the abuse. If they get tested a lot of times they (officials) notify the partner. That's more abuse. I've seen them beaten."
"This can be extended to women in general especially in your smaller communities. They won't go for treatment because they don't want to be identified as being infected."*

In some cases the participants were somewhat self critical of the trends in testing. The following quote illuminates this issue yet also highlights the frustrations experienced by the professionals.

"We have a tendency to go to the same zip code areas and test the same type of people over and over again without expanding that testing. Sometimes we don't know where has the disease gone because we haven't tested where it may be."

4.Prevention Issues

Participants noted that there are groups of people or behaviors of concern which may be overlooked by prevention efforts. Secondary prevention opportunities may also be overlooked.

Although the following quotes were related to an event that was temporally connected to the timing of the focus groups, it is still important to note that these types of media and pharmaceutical company messages can be a challenge to the professionals who attempt to reinforce the message that AIDS is a major threat to life.

“Like Magic Johnson. He brought a lot of awareness to it, but at the same time a lot of kids are looking at him saying he has AIDS and look at him. He went back and played”

The following passage is another example of the difficulties experienced with prevention because of inaccurate messages from the media and pharmaceutical companies:

“I mean the other part of that is when they look at the media and the campaigns from the pharmaceutical companies, how they present the people that are positive that have AIDS. These people look wonderful so they are like oh, I can just take this medicine and I’ll be fine. They have that false image of how it really is to be HIV positive or have AIDS from the media and the pharmaceutical companies.”

“And it’s not just the media. They had Magic Johnson on yesterday morning. Every network, including ESPN. I mean all the major channels. He is talking about there are days that he doesn’t even think about HIV and that the virus is asleep in his body. He is giving the wrong message. He was on every network.”

“I mean just like when he was first diagnosed and Ebony said that he’s cured and he doesn’t have AIDS anymore.”

Another aspect of the theme of prevention issues is the perceived lack of professional honesty about the disease. There is also concern about how professionals in the system can create a negative situation when they disregard the need to be up front. Several examples of this concern were relayed. The following passage exemplifies this complex issue:

“One of the things we haven’t done as a community of providers is being truthful with people. We haven’t given them all the ugly statistics about the people who are dying. Everybody thinks they’re still going to live forever, even people with HIV. Hello. Congress is on its way to cutting major amounts of money for these programs. People have to understand that the reality of the late nineties, with the access to drugs, anyone could get them. You didn’t have to have a job; you could get disability and housing or whatever. But these people are not healthy. They don’t want to go to work. The ugly reality is a lot of people won’t qualify for the drug distribution programs and that more people are going to get more sick and they’re going to die.”

“We’re just seeing it. We’re just starting to see the effects, because the cocktails just came into effect in 1996. So now. . . We’re starting to see the virus mutate. It’s not responding to that cocktail; let’s just try a different cocktail. It’s not responding to that either, and we’re done. We don’t have any more meds to try. Kidney goes, liver goes.”

Opportunity for secondary prevention, intervening with people who are in treatment but are spreading the disease, is another issue that was raised by the participants. There are concerns that opportunities are being missed. These issues are illustrated in the following passage:

“I think we also have another problem that people don’t talk much about. That’s people who know they’re HIV positive who access care, and yet still have risky behaviors amongst themselves. So now we’re talking about secondary prevention. So if someone knows they’re HIV positive, and this other person knows they’re HIV positive, there’s no use in having safe sex . . . There are house parties with 100+ people where the doors open at nine and shut at ten, everybody take their clothes off, you can use every room in the house, don’t go outside, free beer and wine . . . Conversion Clubs? There are people who are saying they want to be HIV for whatever reason. I’ll never understand that one. Or Bug Chasing parties. That’s a huge fear for me personally that we’re not doing enough on secondary prevention. Just seeing what’s going on in the community or on the Internet. So that’s a whole other faction of HIV prevention that we don’t really pay enough attention to. And those are people who are accessing care.”

The participants reported that in some cases the professionals have a lack of information. They may not be cognizant of the consequences of these risky behaviors. When asked how the above information was important, the participants responded by stating that health department personnel need to be updated regularly. The following exemplifies this:

“They can be re-infected.”

“With a different strain of the virus or a drug-resistant strain. So if I’m on certain meds and you’re on certain meds, my virus might be resistant. So if I give you that virus now, those drugs are out for you. Now you have multiple strains of the virus in the body which could really weaken your immune system or progress the disease faster.”

Another passage provides an example of how complex this concern is:

“The awareness needs to be out there. The truth telling. You work in the health department, and you didn’t even realize that other people could have other strains of the virus . . . the whole secondary prevention thing. And you’re a public health worker.”
“We have health educators who don’t know that, and their job is to go out and educate.”
“That’s my whole point. If people aren’t hearing the truth and knowing what’s going on, and that’s anything I’ve ever done for the last five years, at the end, what can we do to get more people to come in for testing? They need to know more about the disease . . . There needs to be more awareness out there. We don’t have it out there. I’m not saying people will come in droves to get tested. But at least if someone has the truth about bare-backing or sharing needles, hearing it again, then maybe people will come in to get care.”

It is to balance intervention and the need for secondary prevention. In some cases mothers with children need some support or it is possible that they may avoid testing and treatment. Mothers who do not take their children for treatment may have them taken away, even if the situation is not their fault. If this happens there could be consequences as described below:

“What the Department of Children and Family Services had seen, they think its key for secondary prevention. If that word gets out (that their children can be taken away), these women are not going to get tested, they are not going to get care, and they are going to infect someone else. It’s a cycle waiting to happen.”

5. Areas where additional training is needed

There is a perceived need for professionals to have additional training to change attitudes and enhance skills. The stakeholders indicated that the ability of certain counties to effectively deal with the issue of concern is dependent on the vision of the

health department leadership. The following passage describes this reality. It is also presented to provide skills to effectively evaluate efforts:

“There are a lot of areas that don’t have anything but the health department.”
“The problem I think becomes that each health department has a director and that person, individually, dictates what goes on in that county’s health department over and above the state’s influence. That is where you get a lot of differences in counties. One director may be a little more open-minded and then the county next door might be closed minded, old fashioned. I don’t care what anybody says. I don’t care how much coats and training you put on, you have an ol’ rigged (sic) set in their ways (director) and it will not change. You are wasting your time.”
“That is why you have to push it a little bit further to evaluate and see what is going on as far as training.”

Clearly the participants expressed some frustration that the system can sometimes be a barrier. There is a need to emphasize community planning and empowerment rather than the traditional approaches frequently used by the health departments.

“There is a big part of the community planning process (for which) . . . I’m saying we have to circumvent the health departments, but there is a lot that can be done community wide . . . if we can show the different strategies working in our plan, that those can translate out to something state wide eventually. I mean for example, we have the opportunity to do two community mobilizations in (specific) areas and we’re obviously, no offense to the health department people, but that has not been their focus to use that. We need to use the resources that we have in our community to find some people in the community, train them in facilitating some discussion and empowering people in the community to get us some answers.”

An additional example of the need to learn how to make entry into certain populations and to go to where people is the following:

“Go to those groups. Don’t expect them to come to you. Don’t invite them to come to you. Go to them. Invite yourselves to them. And do it consistently, not just once. Go back two and three times. Get known in their turf. Even if you’re going to an organization, just go to them and don’t say come to us so we can get information. That’s the way to build that. . .”

Additional training concerns included social marketing skills development.

“The programs are there but if the people refuse to come and access those services and all kinds of efforts are making it possibly easier for them to access the services. We need to do some social marketing and change people’s attitudes. You know the problem with mistrust and not wanting anybody in the neighborhood to possibly see you going in that building. You know we need, you know we have prevention messages out there, but we don’t really have social marketing to change people’s attitudes about seeking treatment.”
“That is like the truth.” “A truth campaign.”

The participants emphasized that gatekeepers and key informants were needed to understand the thinking of clients. They reported the need for skill building to develop prevention messages that can counteract denial and change attitudes. The following somewhat sarcastic passage helps to illuminate this concern specific to rural communities:

“Many of the rural counties don’t have HIV. They don’t have drug addiction. That only exists in the big city. Their kids don’t fool around. I come from a farming town and let me tell you farm kids know about it long before anybody else does. There are a lot of dirt roads that you can go back on and do all kinds of things. You’re 13 and you’re driving a pick-up truck.”

“A lot of people in the rural areas use transportation as excuses. As soon as you work out the transportation issues there is something else.”

“That denial that none of this stuff exists and their kids don’t do anything... It’s a real problem. Everybody else in the country buys into that thought of rural America.”

“It’s wholesome and clean.”

“Where do they think they’re going when they wash their truck on Friday evening?”

6. Integration of substance abuse and mental health care

Several stakeholders noted the need for integration of services. When participants were asked to what extent HIV services are integrated with mental health and substance abuse services the following dialogue was recorded:

“Not enough.” (Several respondents agreed.)

“There is some collaboration, there is some integration, but somewhere somebody dropped the ball. Like (name) was saying, (name) got tested when (name) went into substance abuse treatment, and that’s true, like with the county. It’s just so cursory. It’s not in the depth that it should be. And yeah, I guess they still refer people to the health department. And we had our substance abuse people at one point going and becoming

HIV pre- and post-test counselors, but I think it's stopped now. This has to be continued. And it's not to the degree that it should be."

"It's not a coordinated effort."

"And depending on different administrations, it will continue or stop, or lessen"

A participant noted a concern that the clients do not necessarily perceive the need for integration of these services:

"In (one) district there're doing a needs assessment right now and (they) did a consumer survey and.. a provider survey. They asked each group to prioritize the needs of people with HIV. The lowest items on clients list of priority was mental health and substance abuse care. The providers listed it as number one."

". . . If a person is using they're not inclined to admit."

"You can have the best services available. It's that saying... you can bring a horse to water but you can't make him drink."

"But we're in a society where it is a weakness to ask for help with emotional issues. In many cases people don't reach out for that help. They have to be kind of pushed in that direction."

Another participant noted that there is not enough emphasis on the need for mental health care and the lack of emphasis in the culture leads to a lack of emphasis for the clients:

"Under the Democrats, who was it that suffered from depression?"

"Tipper Gore."

"It was like, she's out of the closet. It was great. People everywhere were accessing mental health services. Tipper's gone."

"You don't even talk about it anymore. It's a shame."

Summary of the Focus Group Analysis:

This analysis provides a framework for peeling back the many layers of assumptions that can be barriers to a more in-depth understanding of needs. The "thick description" provided through the analysis of these focus groups provides an opportunity to highlight the voice of stakeholders usually eliminated from assessments. This

description of themes provides an opportunity to emphasize the constantly changing, complex, contradictory realities as perceived by these stakeholders.

Needs are not absolute, undisputed, unequivocal or unchanging (Peterson and Alexander 2001) because they are the realities of people's lives. For assessments of needs to serve a holistic purpose and lead to constructive change in health status or quality of life outcomes they should be both described and validated by all stakeholders. Consequently, needs assessments require input from many perspectives. They require comparative needs defined by experts, "wanted, desired or felt" needs defined by populations, expressed needs (demands for service), extrapolated and comparative needs (Peterson and Alexander 2001). People who conceptualize change, especially those with the power to make change, need this broad understanding of issues to build into policy change the flexibility and adaptability needed to facilitate positive impacts and outcomes. This focus group analysis, because it highlights many types of needs from many perspectives, provides input that can enhance the validity and usefulness of this assessment. When examined within the context of the ethnographies of selected populations, this analysis will reduce the possibility of defining the needs illuminated in this assessment as narrow indicators.

Methods: Ethnographic Interview Studies of Selected Populations

Preparation for the Ethnographic Interview Studies of Selected Populations

Entry into the field to conduct evaluation research involved several preliminary preparation steps. In each region, northeast for the Young Adults 18-25, central for the

Formerly Incarcerated, and the southwest for the (Spanish speaking) Migrant Laborers, it was necessary to engage in separate rounds of reconnaissance work in order to determine the most likely sites for encountering and gaining access to the populations. After identifying possible key locations for contacting the subject populations, it was then necessary to identify the on site gatekeepers of those locations. These gatekeepers were able to provide/facilitate access to the study populations. The gatekeepers for each population in each location were screened by the project manager to verify their familiarity with the proposed study populations to determine if they could grant access to this population and provide a suitable place for interviewing.

Using a process called *snowball sampling* (LeCompte and Schensul 1999) the gatekeepers were probed for insight into what problems might be encountered when trying to talk with people from the selected groups. In addition, they were asked if they had knowledge of other gatekeepers, locations and methods for contacting the key informants of the selected populations. Using the snowball approach the original circle of contacts became bigger and bigger, then eventually overlapped. Soon a number of people or sites had been mentioned repeatedly. This allowed the convergence of search efforts for appropriate sites. Since snowballing can become unwieldy, a log was kept for each segment of the study that detailed interaction with gatekeepers. This process supported the dependability audit built into the studies that helped to ensure trustworthy results (Denzin and Lincoln 1994).

In some instances the trail lead through several contacts from the first person to answer the phone to a person in a position to grant permission. Along the way critical contact names, numbers, advice and details of requirements for obtaining permission in

each place was noted, enabling the researchers to plan, follow up with each site, and launch the field portion of the study with relative ease.

It was necessary to negotiate with multiple gatekeepers in each region in order to gain their co-operation and assistance for each section of the project. One challenge to gaining access to the interview populations centered on getting through the various authoritative layers of gatekeepers. Another challenge was the wide-ranging number of diverse sites to be assessed such as governmental and private agencies, businesses, schools and migrant labor housing camps. In this process, it was necessary for the project manager to elicit cooperation from those whose attitudes ranged from the distant and/or protective to the outright negative as well as the eager and helpful. Although permission to access some potential sites was denied (including certain migrant housing areas for the migrant laborer study segment and malls, clubs, and pool halls in the Young Adult segment,) over all, access was obtained for a more than adequate variety of sites in each region.

The degree of difficulty in accessing populations through gatekeepers can depend on the purpose of the fieldwork. The element of concern can generate resistance both real and anticipated. In this case, the encountered resistance stemmed from unexpected concerns articulated by the gatekeepers. For example, in the migrant housing areas there was concern expressed that since the researchers represented the Health Department that the project report might find fault with the housing area and gatekeepers at the various malls were concerned that this project would disrupt people's focus on shopping.

In negotiating access to various locations it was always necessary to preserve the integrity of the study by explaining that these interviews were for the Statewide

HIV/AIDS Needs Assessment. It was also valuable to alleviate possible anxiety generated by this topic by further explaining that through this study an opportunity was provided for people to voice their thoughts, and that these interviews could help the policy makers understand how people from different groups access health care and what they think about existing services.

Most of the gatekeepers were very cooperative once they understood that they would be providing assistance in this capacity and that the participants recruited from their sites could freely decline participating, remain anonymous, and were not going to be asked intensively personal questions that might cause them embarrassment. Once the permission/cooperation was obtained from the gatekeepers, a trip was scheduled for each segment of the project in order for the interview teams to spend time in each area recruiting and interviewing subjects. Considerable investigation was conducted in spite of short budgets and long distances between the research center and the field sites.

Proposals and instruments

After determining the research question, the populations, and the method, research proposals were developed outlining the procedure for contacting, recruiting and interviewing members of these special populations within the three selected regions. Issues of privacy protection, data transportation, storage, transcription and data access were detailed. According to the statute 46.117(b) (1) written consent documents were developed in the appropriate languages, English and in the case of the Migrant Laborers, Spanish. These consent forms were drafted in such a way to ensure that they contained all of the elements for effecting legally informed consent while maintaining appropriate comprehensible language levels for the participants.

Interview guides appropriate for each subject population were also prepared for the interviewers to use. The use of interview guides ensured that all interviewers followed the same basic lines of inquiry with each subject. While the interview guides and suggested probes (additional leading questions) were designed to hold the focus of the interviews to the specific areas of inquiry allowing for systematic data collection, the nature of semi-structured interview technique also permitted the freedom of additional exploration as needed. The questions developed for the interviews were formed by the focus groups of the FCPG and research into the populations.

Institutional Review Board

The completed research proposals for each subject group were then submitted as per Federal regulations that require all research projects involving human subjects to be submitted for review by an Institutional Review Board (IRB). The IRB was conducted by the Florida Department of Health Review Council (RCHS). Permission to conduct the research projects with the three selected populations was granted.

Data Collection

This investigation focused on selected stakeholder population members who were *key informants* within selected regional communities throughout the state.

Following the research protocol, investigators were trained prior to each trip in techniques of administering informed consent, conducting semi-structured interviews, issues of cross-cultural interviewing, proper transportation and housing of data, and privacy protection for human subjects. In the case of the migrant laborers, this training was also given to the interpreters who were hired to support the study.

The interview subjects were all volunteers. The Formerly Incarcerated were pre-recruited by the gatekeepers who let potential subjects know in advance that the interview teams would be in certain locations on specific days. Anyone who was formerly incarcerated and wished to voluntarily participate as an interview subject could come to those locations and do so. The Young Adults 18-25 were volunteers that were recruited directly by verbal invitation by the interview team members as they visited various locations. The locations, not the individuals, were pre-arranged for this study. The (Spanish speaking) Migrant Laborers were also recruited by verbal invitation from a variety of sites. Some sites required permission to access and some were public venues. All sites were recommended by the gatekeepers. Interviews with these subjects were facilitated through the use of interpreters who worked with the interviewers. The interview locations themselves in each area were selected to cover different socio-economic levels, and a variety of life activities including Health Care locations.

The volunteer subjects were selected on the basis that they were willing to participate in interviews. The volunteer subjects were all offered an incentive to participate in the interview process. The amounts of the incentives were developed in concert with the agency/community gatekeepers. The Recently Incarcerated were offered \$20, the Young Adults were offered a \$5 calling card and the Migrant Workers were offered \$5. These incentives were approved by the IRB.

When the participants agreed to the interviews, the informed consent process was conducted. They were told that if they wished to participate, they would be asked questions about their knowledge and opinions concerning both general and HIV/AIDS related health care services in their areas. Observations were made of the subjects only

during the interviews. No personal identifying data was gathered and all possible measures were taken to protect the privacy of the subjects including administering and obtaining informed consent through one researcher while the actual interview was conducted by another so that even the subject's name was unknown to the interviewer. The consent documents could not be connected to particular interview content. Further privacy protection was provided by the stripping of unintentional potential identifiers from the final transcripts of the interviews. The original recordings that may hold such unintentional identifiers were to be destroyed following final analysis as per the protocol. Subjects were all adults of legal age and able to consent to being interviewed.

Fully informed consent was obtained from each participant. Avoiding potential issues of literacy, each potential subject was read the consent form by a researcher. In the study segment involving Spanish-speaking migrants, these forms were translated into Spanish and the translation was approved prior to taking them into the field. The interpreters, after several hours of training, under the direct supervision of one or more researchers, orally administered/obtained informed consent from the Spanish-speaking migrants in the field. These subjects were provided with the Spanish version of the consent form, and provided with the appropriate contact information. All subjects for the other segments of the project, the Young Adults 18-25, and the Formerly Incarcerated, were also consulted at each point of the consent process to make sure that they understood, and any/all of their questions were answered, and a copy of the consent form was given to each subject. All consent forms contained information for contacting the investigators at any future time if the subjects should have other questions they wish to ask. During the Migrant Laborer portion of the project, a few of the migrant laborer

subjects who agreed verbally to participate, were administered the informed consent, indicated that they understood, but declined to sign the form out of concern for their legal status or an inability to write. This request was granted.

Every subject was asked for his or her permission to collect audio or digital recordings of the interviews. Most of the subjects gave their consent for voice recording. In the very few cases where consent to audio record was not given, the interview transcripts are based entirely on the interviewers notes. Some interviewers notes are very extensive and capture the conversation of the subject almost as completely as an audio recording, revealing the subject's full response. Other sets of notes are admittedly sparse, yielding only the basics such as yes or no responses, without the depth of comment that the subject may have made.

The interview teams visited each region and conducted field interviews with the volunteer subjects at the various listed sites. Demographic information was collected but it is provided with a caution to the reader not to apply quantitative method analysis for quotas and quantities to this information. This information was not acquired for this purpose and making such calculations is not relative to *qualitative* research.

Interview Data Transcription

The interview data which was gathered through either tape recordings or digital voice files and supplemented by notes taken by the interviewers was transported to the research center and the recordings were then transcribed by a professional transcription service. During this transcription process, all remaining possible identifiers were deleted as per the approved protocol. Transcription was a considerable challenge due to the

noisy life-related background sounds of the field interviews, however, the data loss here was very minimal, an estimated 3-5% which allowed for a solid foundation for analysis.

Analysis of the Ethnographic Interview Studies

The ongoing data analysis was conducted in a multi-layered process, using multiple analysis methods. The process was developed to enhance the trustworthiness of the findings with an emphasis on triangulation. The triangulation involved multiple processes of assessment and the use of multiple researchers. The analysis process was conducted using continuous documentation to contribute to a dependability audit (LeCompte and Schensul 1999b; Miles and Huberman 1994; Noblit and Hare 1988).

There were two simultaneous processes used throughout these projects. One researcher approached the analysis through a process of constant comparative analysis (Creswell 2002; LeCompte and Schensul 1999b), coding transcripts for themes while simultaneously referring back to the focus group findings for direction of the theme meanings. The second researcher conducted a thorough, more micro level coding of the data in the transcripts. This process led to a first level of analysis, a frequency-driven compilation of direct responses to open-ended questions across all of the cases. This process was grounded in the development of matrices (references) both at the participant level (the first process) and the question level (the second stage process). In hand coding the data the following processes took place: 1) answers to each question were compared across all of the interviews, 2) transcripts were scoured for information in different parts of the interview that were related to other questions and 3.) these segments of information were then reorganized and added to the applicable areas. The frequency responses were

then compiled into matrices described above. The tables of findings for each question from each of the three selected population ethnographic interview studies presented here represent the second stage of analysis matrix construction.

All of the transcripts were compared through the use of qualitative data analysis software. This multi-step independently conducted analysis of the data from a different analytical perspective, emphasizing the word level/theme based assessment, enhanced triangulation and trustworthiness. It also serves as a check and balance system through which the results of data gained through qualitative collection methods may be verified for consistency, dependability and trustworthiness.

RESULTS WITHIN EACH POPULATION GROUP

THE FORMERLY INCARCERATED

Total Number of Subjects Interviewed: 119

African American Females	African American Males	Caucasian Females	Caucasian Males	Hispanic Females	Hispanic Males	Race or Gender Unknown	Self-disclosed HIV+ or AIDS
24	51	5	23	0	3	5	40
Jail Experience Only							
2	0	2	3	0	0	0	4
Out of State Prison Experience Living in Florida							
		1					

Locations where subjects were interviewed: 8

Types of locations:

- 3 Drug and Rehabilitation Centers
- 4 Agencies
- 1 Community Center (on three separate occasions)

Areas:

- 3 Urban cities in Central Florida

Four interviewers, one white female, two African-American male, one Filipino-American male traveled to central Florida and spent four days interviewing subjects at the previously listed locations from early morning until late at night at the end of the summer 2002.

Formerly Incarcerated: Response Summary Tables

Familiarity With People Who Have HIV/AIDS

One hundred and nineteen subjects were asked whether they knew of someone with HIV or AIDS; eighty-five percent stated that they did. The respondents who acknowledged knowing someone with HIV or AIDS were then asked if they could, without naming anyone, describe the relationship between themselves and that person. The largest number of subjects classified their relationship as that of friend. This was followed in order of frequency by the following designations: acquaintances, family, through rumor, cellmate, block mate, or lover.

Table: 1.1: Responses to Question 1

Subjects were asked if they knew of anyone with HIV or AIDS (without naming them) and how close that person(s) might be to them.										
Report		Yes	No	Lover	Friend(s)	Aquaint.	Rumor	Family	Cell/Block mate	
Totals:		101	16	3	43 (7 stated more than one friend)	29 (4 stated more than one acquaintance)	12	17 (2 stated more than one family member)	9	5

Perceived Responses to HIV Diagnosis

When asked for their perception of how people who have been to prison might respond to the diagnosis of HIV or AIDS, sixty-eight percent stated that that person would seek standard medical care. However, twelve of those subjects qualified that response by pointing out that the medical care would only be received in prison. A few others also qualified their positive response by saying that only some would seek standard medical care. Some of the subjects responded to the probes to this question, however of those who did respond, the following information was given: Forty-four percent thought that people would either ignore or deny the fact that they had the disease. Twenty-five percent thought it likely that the person would hide the fact that they had the disease, only one of these respondents stated that they would only hide the disease at first. When asked whether they thought the person receiving the diagnosis might turn to alternative medicines such as acupuncture, herbal medicines etc. the responses were nearly evenly divided between yes and no. When those who thought that people would turn to alternative were questioned whether they were likely to use alternatives with or instead of standard medical treatments the response was again evenly divided between

yes and no. Twenty-four percent suggested that people might turn to religious or faith healing, and three of the subjects claimed to know of someone who had been cured of HIV by God. Again the response was nearly evenly divided between those who thought that religion would be used with standard medical treatments, and those who thought that it would be used instead of those treatments. Only ten subjects thought that people would go to a different area or a different country to seek medical treatment, and nearly each one of these suggested a different country. Those countries that were mentioned are: Mexico, Canada, Switzerland, Haiti, Europe, and Africa or the state of California. Also mentioned was the possibility of going to other towns for better care.

Table 1.2: Responses to Question 2

Subjects were asked for their thoughts on how people who have been to prison might respond to a diagnosis of HIV/AIDS. They were further asked about what types of treatment they thought people might seek.										
Report	Q	Standard	Ignore or Deny	Hide	Alternative		Religious		Dif. Area Country	
					Yes	No	Yes	No	Yes	No
Totals		81 (12 stated that care would only be received <i>in</i> prison and a few others answered yes, but it was a qualified yes, as in “some would, some wouldn’t”)	53	30 (1 said that people would hide it at first.)	27 (2 thought that people would use alternatives with medicine and 2 without)	25	29 (3 claimed to have known someone who was cured by God. 7 thought people would use this with meds, and 8 without)	16	10 Mexico Canada Switzerland California Haiti Europe Africa Or other towns suggested	32
Note: 10 didn't know/weren't asked										

Awareness of Health Care Locations

Fifty-one percent of the subjects thought that people who have been to prison would know where they should go in order to obtain general health care. Forty percent did not think that people who have been to prison would know where to go. Six percent answered “yes and no,” some would know where to go but others would not.

Table 1.3: Responses to Question 2

Inquiring whether people who have been to prison <i>know</i> where to go for general health care.			
Yes and No answers	Yes	No	Didn't know/weren't asked
7	61	48	3

Perceived Awareness of Health Care Access

The subjects were asked where people who have been to prison would go for general medical treatment. The most frequently cited location was the Health Department with fifty percent of the subjects suggesting it. This might have actually been a higher number as those who indicated “Clinics” or “Health Centers” may have meant those affiliated with the Health Department. Many indicated some information was given in prison. However, they may not act on the information to avoid being stigmatized. They fear people would back away from them. The second most frequent response was that of “I don’t know”. Other locations cited area as follows in order of descending frequency: Hospital/ER, Clinic or Health Centers, Agencies (Both those that manage HIV/AIDS and Rehabilitative programs), Other, and the Homeless Clinic. The category of Other included suggestions like: going to friends who have medical knowledge, or to friends who have medicines, hiding the fact that they are sick, going to HRS for medical care, seeking a charity hospital, going to a private doctor, or going nowhere. Comments related to this question also yielded the following: several subjects stated that inadequate information about Health Care Locations was given, *if* it was given, upon release from prison, that some people are in denial and will not seek help, that going to the Health Department or to the free clinics are the only options for people who are coming out of prison because they have no money, no jobs, and no insurance.

Table 1.4: Responses to Question 4

Subjects were asked where they thought people who have been to prison would go to get general medical treatment.							
	Health Dept.	Clinics or Health centers	Homeless clinic	Agencies	Hospital/ ER	Don't know	Other
Totals	60	14	5	12	15	22	7

Perceived Awareness of Alternatives

When asked whether they thought that treatment for HIV or AIDS might also be obtained at the places they had listed for general medical care, fifty-eight percent of the subjects thought that it was available at those locations. Those who answer no, that treatment for HIV or AIDS was not available, were asked to state where they thought such treatment could be found. Those answers all involved the Health Department, but in opposite ways. Some thought that if you couldn't get care for HIV at the Health Department then you could go to the indigent clinic, and conversely if you couldn't get treatment at the ER then the Health Department was the place to go.

Table 1.5: Responses to Question 5

Subjects were asked whether they thought that treatment for HIV or AIDS could also be obtained at the places they had cited in the previous question.			
Weren't asked/didn't know	Yes	No	If not, then where?
38	70	11 (2 suggested locations)	If not Health Dept then indigent clinic If not ER then Health Dept.

Ease of Access to Care

When asked whether or not health care is easy to obtain, thirty-two percent responded that they thought health care is easy to obtain, while forty-eight percent of the subjects did not think so. Thirteen percent of the subjects answer both yes and no to the question indicating that health care services at certain places, or for certain diseases, or under certain circumstances such as having insurance or money, are easier to obtain than under other conditions. More subjects offered reasons why health care is difficult to obtain than those who thought that it was easy, and many subjects offered multiple reasons for each. The most frequently stated reason for the ease of obtaining care was the idea that if you want [desire] the help it would be forthcoming. Elements involved in the process of obtaining health care cited as the greatest difficulty included paperwork, time consuming requirements, a long time to become qualified, and long waits in the facilities. The second most frequent category was not having what it takes to obtain care. This included such things as: not having an address, no phone, no identification, lacking proper documents, lack of money, and lack of transportation.

Table 1.6a: Responses to Question 6 part a

Subjects were asked whether or not they think health care is easy to obtain. They were also asked to give the reasons for their answers.				
Yes and No answers	Yes	No	Why?	Why not?
16	38 (23 are self declared HIV+)	57 (19 are self declared HIV+ or AIDS)	61 offered reasons See table 1.6a below	78 offered reasons See table 1.6b below
	8 didn't know/weren't asked		Note: responses such as "it's easy" were not coded.	Note: responses for why obtaining health care is <i>not</i> easy were much longer than responses for why it is easy.

Table 1.6b: Responses to Question 6 part b

Subjects thought health care <i>is</i> easy to get:									
If HIV+	At Some places Unspecified	At Health Dept.	At Agencies	At the Hospital/ER	In prison	Out of Prison	If you <i>want</i> help	If you know where to go	If you have lots of \$ or no \$
7	4	8	7	3	1	1	10	7	6

Table 1.6c: Responses to Question 6 part c

Why they thought health care is <i>not</i> easy to get: (Note: some subjects gave multiple reasons)				
Lack of knowledge	Don't qualify	Discouraged by the process	Don't have what it takes to obtain care	Discouraged by attitudes of providers
8	21	33	24	5

Qualifying as a Barrier

Sixty-eight percent of the responses indicated that thinking that they didn't qualify for health care *would* stop people who had been to prison from seeking it.

Table 1.7a: Responses to Question 7 part a

Subjects were asked whether thinking that they didn't qualify for health care would keep them from seeking it.						
Yes and No answers		Yes	No	Didn't know/weren't asked		
3		81	30	5		
Reasons given for thinking that they wouldn't qualify for Health Care						
Own attitude	Society's Attitude	Don't know	Frustration with the process	Think it's too expensive	Told they didn't qualify	Can't qualify if been to prison
7	2	10	4	5	3	6
Reasons give for thinking that they would qualify for Health Care						
If you put in the effort you will qualify		Most people can get help	People with HIV or who have been to prison should be helped		Know services are available	
7		2	1		4	

Embarrassment as a Barrier

When the subjects were asked whether they thought the possibility of embarrassment might stop people who had been to prison from seeking health care, eighty-seven percent indicated that embarrassment would indeed be a barrier to obtaining care. Most of these respondents gave reasons that revolved around privacy/confidentiality concerns. Many were afraid that if it became known that they had the disease then people would assume that this meant that they had participated in homosexual activities while they were in prison, and while they may or may not have engaged in such practices, being perceived this way by others was intolerable.

Table 1.7b: Responses to Question 7 part b

Subjects were asked whether embarrassment would stop them from seeking healthcare.			
Yes and No answers	Yes	No	Didn't know/weren't asked
9	95	12	3

Peers and Family as a Barrier

Seventy-three percent of the subjects indicated that they would not seek health care if they thought that their friends or family might find out. Specific fears included being shunned, embarrassed, thinking that their family might not be able to handle the news, not wanting people to know that they are gay, being let down, and being disowned. However, the seventeen percent who stated that they were not afraid for their family and friends to find out tended to support their answer with reasons such as needing the support from others, believing that their family cares for them, needing to get health care no matter what anyone thought, and concern that someone would have to know what their condition was eventually. The six percent who answered yes and no to the question stated that they would be afraid for either their family or friends to find out, but not both.

Table 1.7c: Responses to Question 7 part c

Subjects were asked whether being afraid that their family or friends would find out would stop them from getting health care.			
Yes and No answers	Yes	No	Didn't know/weren't asked
7	87	20	5

Perceived Respect as a Barrier

Fifty percent of the subjects thought that the health care providers would treat them with respect. They cited reasons for this answer based on previous experiences which had been good while a few added that if they didn't receive respectful treatment at one place they would simply go somewhere else, or file complaints to get things changed.

However, thirty-seven percent thought that care providers would not treat them respectfully and that this would make people who have been to prison less likely to seek health care. The types of actions described as disrespectful included health care providers acting funny about coming into the room with them, acting like they didn't want to touch them, acting like it is just a job or a paycheck while not treating the patients with concern, thinking that health care providers tend to treat formerly incarcerated differently from other patients, and generally making them feel "like dirt". Six percent of the answers were yes and no, as in subjects felt that doctors outside of prison would treat them respectfully, but doctors inside prison would not.

Table 1.7d: Responses to Question 7 part d

Subjects were asked whether they thought that health care providers would treat them with respect.			
Yes and No answers	Yes	No	Don't know/weren't asked
7	59	44	9

Cost as a Barrier

Sixty-one percent of the subjects indicated that they thought people who have been to prison would think that they could not afford health care and that this would keep them from seeking it. Nearly equal numbers of respondents were divided between thinking that this would not keep them from seeking health care and not knowing one way or the other.

Table 1.7e: Responses to Question 7 part e

Subjects were asked whether thinking that they couldn't afford health care would keep those who have been in prison from seeking it.			
Yes and No answers	Yes	No	Don't know/weren't asked
2	73	24	20

Trust as an Access Issue

Fifty-four percent of the responses indicated that the formerly incarcerated would trust the doctors to help them. Eighteen percent said that they would not trust doctors to help them. However, thirteen percent answered both yes and no. When the reasons behind these yes/no answers were explored a definite pattern emerged: doctors in the prisons were not trusted and doctors outside the prison were.

Table 1.7f: Responses to Question 7 part f

Subjects were asked whether people who have been in prison would trust the doctors to help them.			
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Yes and No answers	Yes	No	Don't know/weren't asked
15	64	22	18

Transportation as a Barrier

When asked whether it is difficult to get to a health care location, sixty percent of the responses indicated that it is not. The twenty-four percent who did think that it is difficult to get to a health care location often added that they might not have a car, or did not have enough money for other transportation such as a bus. Another element that entered into the difficulty of getting to health care was the multiple trips needed to get paperwork to get qualified, or to get treatment at multiple sites. The yes/no answers indicated that there are options for help with transportation but that these are limited to certain providers or that they are available and people don't know about them.

Table 1.7g: Responses to Question 7 part g

Subjects were asked whether it is difficult to get to a health care location.			
Yes and No answers	Yes	No	Don't know/weren't asked
10	29	72	8

Hours of Access as a Barrier

Sixty-eight percent of the responses were positive indicating that they thought people who have been to prison are able to access the health care services during existing hours. Ten percent did not think that they could access the services during existing hours and nearly that many did not know. Seven percent gave both yes and no as answers stating that yes they could access health care, but no they couldn't find health care at night or on the weekends unless they went to the Emergency room. Another point which was discussed was the fact that if they were working they would be forced to take time off from work in order to seek medical care, this in the case of persons living with AIDS could cause some problems/suspicious/loss of confidentiality at the workplace.

Table 1.7h: Responses to Question 7 part h

Subjects were asked about the hours during which health care services are available and whether they are able to utilize services during these hours

Yes and No answers	Yes	No	Weren't asked/don't know
8	81	12	18

Perceived Desirability of Combined Services

Seventy-eight percent of the subjects stated that they thought people who have been to prison *would* go for health care if it were offered at a combined services site-a clinic that also offered mental health or substance abuse services. Comments about these answers indicated that most thought that this would be easier than traveling to several facilities around the area to receive those types of treatments and that they thought it likely that HIV patients might need more than one of those types of services. The five percent who didn't think that people who have been to prison would go to a facility offering combined services explained that it could be embarrassing for them to be seen there, that the other people would assume that they were there for services that they were not in need of and this would create a stigma. Furthermore the thoughts of embarrassment and stigma could keep them from seeking health care. The seven percent who answered yes and no tended to use the previously mentioned reasons in combination: yes it would be more convenient, but no I wouldn't want to be seen there.

Table 1.7i: Responses to Question 7 part i

Subjects were asked whether they thought people who had been to prison would go for health care services if those services were located in a clinic which also gave mental health or substance abuse care.			
Yes and No answers	Yes	No	Don't know/weren't asked
8	93	6	12

Health Information Distribution

To the question of whether they had ever noticed anyone giving health care information to people, sixty-two percent answered that they had, while twenty-nine percent had not. Two subjects answered both yes and no stating that although they knew information was available they had not noticed it being given out. Some of the subjects were asked what they thought could be done to capture the attention of people in order to get healthcare information to them, most of these answers revolved around drawing people to an event with the offer of incentives such as food, music or radio announcements.

Additionally, the positive answers could be divided into two themes: the method of delivery/or location (how the health care information was delivered) and the

types/subjects of health care information that they had noticed being offered. The method of delivery most frequently cited was people coming around in the neighborhoods, either by car to post up flyers, or walking through and talking to people. Other methods were mentioned by location as follows: at the Health Department, at the Medicaid office, through the pastor, at the drug store, at an HMO. The subjects/types of health care information are as follows: condoms, HIV, importance of taking medicines on time, HIV testing, tracts [pamphlets], flyers, drugs and alcohol, Hepatitis C, Cancer, STD's, Tuberculosis, and where to get your health checked.

Table 1. 8: Responses to Question 8

Subjects were asked if they had ever noticed anyone in the community giving health information to people			
Yes and No answers	Yes	No	Don't know/weren't asked
2	74	34	9

Awareness of HIV Prevention Services

The subjects were asked whether they knew of any HIV prevention services in the area. However, the interviewers noticed that the subjects might not identify certain activities with the term “prevention services” and were giving negative answers. Knowing that there were prevention service in the area, the interviewers began to question the subject more closely by asking them if they knew of the following specific activities: the distribution of condoms, clean needle exchange/cleaning kits for drug users, classes about HIV, and HIV/AIDS literature. Of the subjects who were questioned closely, all were able to identify some or all of those prevention services in the area. The one service that was completely absent was that of HIV prevention for drug users through the exchange of needles or needle cleaning kits.

Table 1.9: Responses to Question 9

Subjects were asked if they knew of any HIV or AIDS prevention services in the area.			
Totals	Yes	No	Don't know/weren't asked

	84	21	14
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Awareness of Testing

When the subjects were asked if they knew where a person could go to get tested for HIV or AIDS 105 eighty-eight percent of them stated that they did. When asked where that testing might be done, the subjects listed the following sites in order of frequency: Agencies/Rehabilitation programs, Health Department, other clinics (Such as the homeless clinic, or even branches of the Health Department), Outreach (People in the neighborhoods), Hospitals/private doctors, other, jail. The category of “other” places for testing included calling the hotline to find out where to go, testing thru the mail, and going to the blood bank. Most subjects listed more than one location for testing. Those that mentioned agencies tended to list several of them. People mentioning outreach tended to cite a specific person they knew in their neighborhood who offered HIV on a regular basis, the key point emphasized in outreach was the fact that it was available at all hours, including very late at night.

Table 1.10a: Responses to Question 10

Subjects were asked if they knew where a person could go to get tested for HIV or AIDS			
Totals	Yes	No	Didn't know/weren't asked
	105	2	12

Table 1.10b: Location

The subjects cited these locations for HIV testing.							
Health Dept.	Other Clinics	People/ Outreach	Jail	Agencies/ Rehabs	Hospitals	Private Doctor	Other
68	14	8	2	85	7	7	5

Outreach Testing for HIV

It is interesting to note that although sixty-nine percent of the respondents had noticed HIV testing in the community very few of them suggested outreach testing as a place where people could go to take an HIV test. Several of the subjects who had noticed testing in the community noted that testing events attracted people by means of incentives. The following incentives were mentioned: free music, coupons for a free dinner, gift certificates, money, and clothing.

The most frequently listed site for testing offered in the community was the Health Department. This was followed by agencies doing outreach or fairs/booths. Also named but not listed in order of frequency: doctors, hospitals, outreach vans, people on the street, and the homeless shelter/clinic. The three percent who offer yes and no answers stated that they *thought* testing was done in the community, but that they hadn't seen it themselves.

Table 1.11: Responses to Question 11

Subjects were asked whether they had ever noticed anyone in the community offering HIV tests to people			
Yes and No answers	Yes	No	Don't know/weren't asked
3	82	17	17

General Barriers to HIV Testing

When asked whether they had any reasons for not wanting to be tested, the most frequent response by far was fear. This was followed in order of frequency by: feeling of shame or guilt, stigma, denial, privacy concerns, don't want to know, don't care/want to die, already know/no reason. Some subjects listed more than one reason, and several of these categories are interlinked. Fear itself is a complex answer since subjects stated their reasons as fear, but then expressed that fear in different ways. Some of the faces of fear are as follows: thinking they may have HIV/AIDS, fear of being "shanked" (Knifed) in prison if they are known to have HIV, fear of dying more quickly, fear of loneliness, fear that they cannot survive on the streets, fear that they will not be insurable, afraid of losing their job if they become too ill, or if their employer learns that they are positive, fear of loss of reputation/loss of family, fear of not knowing what to do and how to deal with the disease.

Subjects were also asked about their feelings on the matter of mandatory HIV/AIDS testing in the prisons. Of those who were asked or who responded to the question, thirty seven percent were in favor of the idea. The main reason cited for being in favor of mandatory testing centered around the idea of safety for the general prison population, since homosexual activity is a given in this environment regardless if it is a women's or a men's facility. The secondary reason cited was that people would then know that they are positive, and would be able to receive treatment. Thirteen percent were opposed and they focused upon the right of the individual to choose for themselves what to do about their health. The four percent who answered both yes and no, stated both of the previously given reasons: it would be good for the population and the individual, however it should not be done in a manner that takes away the right for them to choose for themselves.

Table 1.12a: Responses to Question 12

Respondents were asked to offer reasons why people who have been to prison might not want to be tested.									
Already know	Denial	Don't want to know	Privacy Concerns	Feelings of shame or guilt	Fear	Don't care or want to die	Stigma	No reason	Didn't answer Or weren't asked
2	17	14	16	19	50	12	18	2	12
Note: some subjects listed more than one reason.									

Table 1.12b: Responses to Question 12 part b

Subjects were asked what they thought about mandatory HIV testing in the prisons.			
Yes and No answers	Agree with it	Disagree with it	Didn't answer/weren't asked
5	44	15	65

Barriers to Outreach Testing

The subjects were asked not only whether they thought people would take an HIV test if it were offered free of charge in the community, but also whether they themselves would take the test. Fifty-five percent of the responses were positive; the subjects thought that people would be willing to take the test if it were offered. However, only twenty-six percent stated that they themselves would be willing to take the test. The predominant reason cited for people not wanting to take the test was the issue of privacy. Privacy concerns included not wanting to be seen at a testing booth, not trusting testing that was “out in the open” in exposed locations, thinking that people who are getting tested have the disease and not wanting to stand in line with anyone who might have HIV, and not trusting the confidentiality of the results in this type of testing environment.

Table 1.13: Responses to Question 13

Subjects were asked a two-part question. 1) If someone came here to offer HIV testing (for free) did they think that people would be willing to take it? 2) Would they themselves take the test?

Yes and No answers	Yes	No	Didn't answer/weren't asked	Would you take it – yes:
12	66	21	20	31

Tested Self Report

When asked whether they themselves had ever been tested for HIV (without revealing any test results), the response was overwhelmingly positive, with eighty-one percent of the subjects having been tested. However, few of those who had been tested also stated that they had been tested more than once. Only two subjects said that they had never been tested and sixteen percent of them either didn't answer or weren't asked.

Table 1.14: Responses to Question 14

Subjects were asked, without revealing results, if they had ever been tested.			
	Yes	No	Didn't answer/weren't asked
Total	97	2	20

Personal Barriers to HIV Testing

Sixty percent of the subjects said they had no reason for not wanting to be tested. Six percent stated that they have reasons for not wanting to be tested. These reasons included fear of finding out that they are HIV positive, believing that they would find out through other means, stating that they can't take it, and being worried about the confidentiality of the results.

Table 1.15: Responses to Question 15

Subjects were asked if they had any reasons why they would not want to be tested.			
	Yes, have reasons, would not want to be tested	No reason not to	Didn't answer/weren't asked
Totals	7	72	40

Response to Health Information in Community

When the subjects were asked whether they would be interested in receiving health care information if they noticed someone in the community offering it, ninety-two percent of the responses were positive. The subjects stated that they would be interested, or that they would make an effort to collect health care information if it was being offered. Reasons for wanting the information were: to give/tell others, educating self, wanting to learn anything new about the disease, and being interested in other health subjects besides HIV/AIDS. Those who did not want information stated that either they feel that they know enough about HIV/AIDS, or that they don't want to be seen getting information about it because then people might assume that they have it.

Some of the subjects were asked for their advice on the best way to reach people with health care information. The most frequent suggestion was for face-to-face instruction either given at centers, or by people going door to door/ passing through the neighborhoods. This was followed by flyers, meetings/billboards/incentives/other, radio, pamphlets, and churches/newspapers. In the category other were included ideas such as mobile health units in neighborhoods, mailing information to everyone, and using a blimp to advertise events.

Table 1.16a: Responses to Question 16

Subjects were asked if they would be interested in receiving health care information if they noticed someone in the community offering it.			
	Yes	No	Didn't answer/weren't asked
Totals	110	7	2

Table 16b: Responses to Probe for Question 16

Some subjects were asked what would be the best way to reach people with health care information.									
Local Paper	Flyers or Posters	Radio	Billboards	Face to Face Instruction	Through or at Churches	Pamphlets	Incentives	Other	Meetings
1	10	3	3	12	1	2	4	4	4

Recommendations for Location of Services

When asked for their recommendations for locating health care services, sixteen percent of the subjects believe that the current health care locations are satisfactory and adequate. Only four subjects did not answer this question while most subjects had multiple suggestions. The central theme that tied all of the divergent answers together was the idea of convenience, having centers close by or as one subject put it, “they should franchise” and another said they should be like “7 Elevens” - one on every corner”. The most frequently cited suggestion was to place centers in neighborhoods, particularly low-income neighborhoods where issues of transportation make traveling to health care difficult. This was followed by the generic idea that there should just be more clinics, including mobile clinics. This was followed by the idea of community-based locations such as community centers, churches, and agencies. Other specific sites suggested were: the inner city, drug/prostitution areas, in the suburbs, on bus routes/in bus stations, in jails/prisons/shelters, and in hospitals.

Table 1.17: Responses to Question 17

Subjects were asked <i>where</i> they thought health care services should be located to make them more accessible to people who have been in prison										
Nbrhd.	Current location	More locations	Community based locations	Misc.	Inner City	On bus routes In bus stations	Drug Prost. Areas	Suburbs	Jails Prison And Shelters	Hptl.
32	19	16	16	12	11	11	8	6	6	5

Note: only four subjects didn’t answer this question and most subjects had multiple suggestions.

Personal Experience as a Barrier

The interviewees were asked whether they knew of anyone who had had a bad experience with health care. Forty-three percent reported knowledge of someone having a bad experience, while thirty-eight percent had not, and seventeen percent did not answer this question. Of those who reported a bad experience, the types of problems encountered were as follows in descending order of frequency: poor attitude from providers, being barred from health care services, getting the wrong medicines or the wrong diagnosis/not being able to obtain the prescribed medicines or treatments, long waits to be seen, and violations of privacy in health care settings. Very few suggestions were made as to what could have made a difference. These included; more courteous/compassionate attitudes,

perhaps through training, for the providers, more workers to alleviate long waits; being more careful in diagnosis/prescription/dispensation of medicines.

Table 1.18a: Responses to Question 18

Subjects were asked whether they had ever had any bad experiences with health care, to describe these experiences without naming any particular doctor or facility, and to suggest what might have made a difference.			
	Yes	No	Didn't answer/weren't asked
Totals	52	46	21

Table 1.18b: Responses to Question 18 part b

Bad experiences with Health Care					
Violations of privacy	Barred from Health Services	Service providers poor attitude	Long waits	Wrong medicines or misdiagnosed	Couldn't get prescribed medicines or treatment
3	8	18	6	7	7

Recommendations for Increasing Access

Ninety-two percent of the subjects had one or more suggestions for making health care more accessible to people who have been to prison. The most frequent response was that of increasing the amount of education about health care prior to release. This include classes for HIV or other health concerns, information on filling out the paperwork; information about the qualifications for various health care options, where, when and how to contact health care in the area they go to after they are released. Seventeen percent of the subjects related a hope that attitudes towards formerly incarcerated could be improved in the health care settings. Some of these expressed the belief that they are given or deserve lower standards of health care because they have been to prison. Other reasons cited are as follows in descending order of frequency: being able or being helped to apply for health care prior to release or being connected to an agency, being able to get affordable insurance, having existing services that are adequate, or having a gap services between release and stability. Among the miscellaneous reasons were the following: increases in funding for health care services, testing in prison so people are aware that

they need health care when they get out, increased advertising for health care services, and increased privacy.

Table 1.19: Responses to Question 19

Subjects were asked what they thought could be done to make health care more accessible to people who have been in prison.								
Affordable Insurance	Services are good	Better attitude towards Ex-inmates	More education Prior to release	Connect or apply health care prerelease	Greater health follow up after release	Gap services	Misc.	NA
9	9	20	33	16	4	9	13	10

Other Barriers to Care

When asked if they could give any other reasons why the formerly incarcerated might not get health care, many of the responses reflected reasons that had already been explored earlier in the interview. However, the most frequent new reason stated was: that they are not looking for or don't want health care. Lack of knowledge was cited just as frequently, but had been an oft-repeated theme throughout the interviews.

Table 1.20a: Responses to Question 20

Subjects were asked if they could think of any other reasons why people who have been to prison might not get good health care.															
Privacy	Apathy	Denial	Drug abuse	Anger	Lack of Knowledge	Attitude to excons	Can't afford	Think not qualified	Not looking don't want	Fear	Lack of job	No insurance	Give up on process	Pride	Lack other essentials
9	10	10	5	3	18	10	11	3	18	6	4	5	4	3	3

Answers to Probe for Question 20

Since most of the subjects interviewed in this project have some access to health care, it was decided to ask a few of them where and how we would be most likely to find people who had been to prison, but who are not accessing health care services in the interest of future studies. The following responses were given: Homeless shelters, crack houses, the waiting rooms of the Health Department, on street corners, parks, go into the neighborhoods, drug rehab centers*, community centers*, contact family members, go into the prisons and talk about health care, go to construction/concrete work sites.

*This type of site was visited during this project

Summary: Formerly Incarcerated

This population was accessed primarily through agencies, community, and drug and rehabilitation centers. Sixty-four percent of interviewees were African American. All participants were volunteers. Many freely discussed their HIV/AIDS status. Though they were asked not to tell their status; of these interviewees, approximately 33% declared they were HIV+ during their interviews.

One of the main themes that emerged in this group was the overwhelming sense that embarrassment was a barrier to getting health care. When asked if people would be embarrassed to go to a health clinic one interviewee said, “Yes. Probably it would be they see somebody that knows them and it would get back to their family, or wife, or whatever. You know?” Another interviewee noted that the recently incarcerated individuals need to hide their status.

“You got a group of people that have HIV and they won’t take their medicines cause their need makes them non-HIV, it makes them not (positive). And then places of employment are never . . . like they’ll let you go if you have HIV. So they have to hide it to people at their jobs. A lot of people hide it to stay in families. A lot of people just hide their health so they have somewhere to live.”

Eighty-seven percent feared there would be no privacy or confidentiality if they accessed health care, possibly because of previous experiences.

“I don’t trust the ones in jail because they talk too much in there . You understand? Like the nurses who take the test. . . The ones in there have a tendency to take the information in there and they run it from one of them to the other talking. I’ve seen them in there gossip. You know. The people have a tendency to shun you.”

They also feared that people would assume that they had engaged in homosexual activity and this would be intolerable to them. Seventy-three percent said that

embarrassment would keep them from seeking health care as they do not want other people to find out. Several reported that they would not want other people to know they are gay, would not want to be disowned or let people down.

“There is a lot of homosexuality going on in prison it’s a fact, from the straightest of guys I swear, they got their wives coming to visit them and then they poking the boy in the booty in the shower and that’s just the way the prison life goes down. Guys get their thrill by any means necessary, not saying that every guy participates, but there is a lot of them that will never admit it, it is pretty famous for that in there.”

Many could not afford health care. Only a few noted transportation or hours of access to be barriers to care. Seventy-eight percent said that combining health care with substance abuse and mental health care would be a good idea.

“If it is a straight HIV/AIDS clinic a lot of people would be embarrassed to go there cause everybody knows what that clinic is there for. Once you got a variety of things in one building, they don’t know what cha there for, you know what I mean? It is probably easier for them.”

Another interviewee explained:

“It’s almost like taking everything that is confidential to you and putting it under one umbrella, and you develop a relationship with one set of medical experts, or people that’s supporting you. You don’t have to have information sent and everything sent out to this person and if they find out about you case and this one here. . if it is like working under one umbrella then that’s wonderful thing most of the time it is a complicated thing to get the services. If your information has to go to that person and more people then there is for more to know about your situation so you always feel uncomfortable.”

The concept of preventing HIV, having resources available to prevent the spread of the disease, was somewhat difficult to comprehend. It is unclear if the concept was understood, but specific activities were described. Participants could identify specific activities they had seen, such as condom distribution, but noted that needle exchange was not available. Several participants noted that if information is provided in the community it should be face to face, at centers or by going door to door in the neighborhoods.

Participants were able to describe where to go to get tested for HIV/AIDS. The barriers to testing were: fear, shame, guilt, stigma and denial. Fifty five percent said they would take the test if offered in community. But, many noted that fear of loss of privacy, lack of trust. When describing why someone would not want to be tested an interviewee said, “Just out of fear of knowing. Some people would just rather hide the truth. They think that if they don’t know, it’ll make it different of something, you know?” Another interviewee noted,

“Cons are afraid, they don’t know nothing about HIV. Privacy is a big issue. Some of them if they find out they have it they will get stressed and kill themselves.”

Others described not wanting to be seen getting the test because people might assume they are gay, would be barriers to being tested. When asked if there should be mandatory HIV tests in prison, 37% agreed there should be. The reason most frequently given was for safety. They said that homosexual activity is a given in both men’s and women’s prisons. It was also acknowledged that this activity can be forced. Some participants acknowledged that HIV status, if known, could be a reason for abuse in prison.

“I would not want to find out in prison (because) there is a chance you might be getting killed, you could be shanked or something, you know someone is finding out. Well, you know, you understand, they have sex with a gay person because they don’t have no other choice. You know? I mean there’s not much to choose from. I can see why. They would have sex but if they knew they were gay and HIV positive, you more than want to get them out of the way. That way you don’t take the chance (on) them.”

Participants noted that health care should be “franchised” – more conveniently located throughout neighborhoods, especially low-income neighborhoods where transportation can be an issue. Some people noted that the location of services in the black neighborhoods is a deterrent to getting care because people do not want to be seen going into those settings. Several people noted that health care should be located in the

inner cities where drugs and prostitution are. There is not consistency about where care should be located.

“ . . . if a person sees you at the health department it’s something, it’s just embarrassing because if a person sees you it’s something that, especially when it comes to HIV, you could be just going for a simple check up or the test or anything and they’re going to say, Oh, she’s dying or he’s dying, I mean it’s they don’t want to hear that. And the opportunity to spread rumors . . . it all comes down to confidentiality.”

Many participants (forty three percent) noted that they had had a bad experience with health care. Most of the bad experiences described focused on the poor attitude of the provider.

“You know I been incarcerated myself for six years and I seen a lot of inmates (with HIV) die, because the people that works there scorn ‘em like they’re scared to touch them.”

Several stated the perception that the attitude of health care providers toward recently released prisoners needs to be improved. Some participants said they were barred from care, some got the wrong medications, some also reported a long wait or that they “got a wrong” diagnosis.

Many reported that increased education about health care prior to release from prison was very important.

“Just upon release, you know, giving them information. Filling them in on where to go, how to do it. You know? Get ‘em a social worker or some sort, someone they contact you know, if, if they’re willing to get help for their problem. You know, help them out! Don’t just throw them out there and say you are on your own you’ve got this disease, but you know. Cause a lot of people when they find out they’re scared about it. A lot of people don’t want to deal with it, like, I didn’t want to deal with mine. I’m just coming to grips with it now.”

Many also reported that it would be very helpful to be connected to care before release. One interviewee suggested, “people should be able to apply for Medicaid while they are in prison.” Another noted:

“It would have been nice when I got out of prison to be informed where the local health care facilities are. Knowing that I’m coming to the . . . area, even going through a transitional assistance upon release from prison, nobody told me where a medical facility could be ascertained, you know, there was nothing there.”

It was not possible to document if the amount of time since release from prison was related to this perceived need.

It is also important to note that participants also recognized that some recently incarcerated individuals just do not want care. One interviewee noted that homeless recently incarcerated individuals,

“have tried to work the system, by doing the right thing and then after all that being denied. And so now just, you know, some people now homeless, they feel like ‘cause they homeless they cain’t (sic) get help. They just, they just feel like why bother?”

Another interviewee noted,

“a lot of them say forget it until they really get to a point where then need help and they can’t survive without it, you know that and then they may go back and try a second time. But then the second time they been denied and they just say to heck with it altogether.”

They recognized that there can be apathy or denial involved.

“Once they get out? Well from my experience and what I’ve seen, uh, they look over it. They ignore it. ‘Cause they so relieved from being released from prison. You know? That’s the main thing. The excitement. They forget about the fact that was actually happening.”

Some individuals may just give up, be it lack of knowledge or lack of work.

“When you go to prison you get the medication in there because, you know, we don’t have no other choice. But like when you hit the streets you know, you on the drugs, you forget all about your health, until you come down to the point on your death bed then that’s when you realize, you know, that you’re sick that you got something that like to hide it, you know.”

These interviewees were asked where follow up researchers might find the recently incarcerated individuals not connected with the agencies (that functioned as

gatekeepers for this study population). They said that some might be found in parks, in rehab centers, in homeless shelters, in crack houses and at construction worksites.

MIGRANT LABORERS SEGMENT

Migrant Agricultural Laborers Interviewed: 65

Service Providers Interviewed: 2

Total Number of Subjects Interviewed: 67

Number of Interviews Not Included in Analysis Due to Early Termination: 7

Number of Interviews Analyzed: 58

Caucasian		Mexican		Unspecified Hispanic		Native American (Mesteco, Mayan or other)		Guatemalan		Non-migrant service providers	
Female	Male	Female	Male	Female	Male	Female	Male	Female	Male	Female	Male
	1	4	12	14	16	4	1	3	3	2	

Locations where subjects were interviewed: 11

Types of locations:

- 2 Health Departments in separate counties
- 2 Migrant Housing Areas in separate counties
- 1 Labor Cooperative
- 1 Catholic Migrant Services Center
- 1 Migrant Clinic
- 4 Public gathering points

Area:

Three counties in South Florida

Two interviewers, one white male, one white female and two interpreters, one white female, one Hispanic female, as well as one African-American observer traveled to Southwest Florida and spent four days interviewing subjects at the previously listed locations at the beginning of the citrus harvest season. This included meeting potential subjects at public gathering spots as early as 4:30 in the morning as the workers arrived to board the busses headed to the field jobs each day or in the late evening as they returned from the fields.

Migrant Laborers: Response Summary Tables

Length of Time in Florida

Fifty-eight subjects were asked how long they have lived in the area. The highest number of responses, seventeen percent, fell around the three-year mark. Some of the subjects measured time by the seasons that they had harvested crops in the area, others stated the total time that they had lived here while indicating that they had and do live in other places either following the crops to other states, or going back to their home countries periodically so their three years worth of time actually spent in Florida might be spread out over a much longer time period.

Table 2.1: Responses to Question 1

Subjects were asked how long they have lived in this area.														
<6m	>6m	1yr	2yrs	3yrs	4yrs	5yrs	6yrs	7yrs	8yrs	9yrs	10yrs	11yrs	12yrs	>12yrs
4	1	6	7	10	4	6	3	2	2	0	2	2	0	9
Note: some answered this question in terms of total number of seasons they had been in this area. These answers have been converted to years.														

Perceived Community Health Concerns

Since reconnaissance research had led to the understanding that HIV/AIDS might be a sensitive subject which the interviewees might be hesitant to talk about, they were first asked what they thought the major health concerns were in the community. They were later asked specifically about their perceptions of this disease.

Thirty-six percent of the subjects listed what they perceived to be the greatest health concerns of the community. Most of these listed several types of illnesses or issues the most frequently cited was that of flu. The conditions or concerns that the subjects offered were somewhat different than traditional lists of major health problems. Perhaps this is due to the fact that they are members of a relatively young, healthy working population. Another factor alluded to throughout the interviews may be that they are generally unfamiliar with healthcare systems, particularly in their native countries. In this table, the category of “other” included heart attacks, rats, body aches, and depression.

Table 2.2: Responses to Question 2

Subjects were asked what they thought the biggest health concerns are in the community.								
Note: Most subjects listed more than one health problem								
Problems From Chemicals	Diabetes	Headaches	Strokes/heat	Vomiting & Diarrhea	Flu/fever Coughing	Insects	Dirty Water	Cancer
6	7	5	5	2	14	4	2	3
Misc. Fevers	Alcohol & Drugs	Asthma	No Health Problems	STDS	HIV AIDS	Allergy	Other	No answer
6	6	1	5	2	6	3	6	12

Perceived Importance of HIV/AIDs in Community Health

In the previous question, the subjects were asked about their perception of the major health concerns in their community, HIV/AIDS was only mentioned by ten percent of them. In this question, the subjects who had not mentioned HIV/AIDS were asked directly whether they thought that this disease was also a problem in their community. After this closer examination, sixty-six percent agreed that HIV/AIDS is a concern. When the six subjects who previously stated that HIV/AIDS was a problem are added to the total it becomes a total of seventy-eight percent. Three subjects declined to answer at all. They seemed to be genuinely uncomfortable with the subject out of a sense of modesty so they were not pressured and were reassured that they didn't have to speak about things that made them feel uncomfortable. Nineteen percent of the subjects denied that HIV/AIDS is of any concern in their area.

Table 2.3a: Responses to Question 3 part a

Subjects were asked whether they thought HIV/AIDS was also a problem in the community.		
Yes	No	Didn't answer/weren't asked
38	11	9

Cultural Nomenclature

Since HIV/AIDS can be considered a delicate subject with some members of the migrant community, subjects were asked if the disease had other names, or euphemisms. Twenty-one percent stated that it was called SIDA, which is standard Spanish for AIDS. This was followed in frequency with nineteen percent who called it HIV pronounced in the Spanish alphabet. Seven percent responded that it was called the reverse VIH, while four percent stated a shortened version of V.H. (Vey, Hache). Amongst all of the subjects who responded to this question, HIV and AIDS seemed to mean the same thing, they did not seem to differentiate between different stages of the disease. In fact many of them indicated that a diagnosis of HIV was equal to a death sentence one way or another.

Table 2. 3b: Responses to Question 3 part b

Subjects were asked if people ever call HIV or AIDS (El virus, or SIDA) by other names, and if so, what names had they heard this disease called.				
HIV (Pronounced phonetically in Spanish)	VIH (Pronounced phonetically in Spanish)	SIDA	VH (Pronounced phonetically in Spanish – this may not be a separate category from VIH)	Didn't answer/weren't asked
11	4	12	2	29

Familiarity with People Who Have HIV/AIDS

When the subjects were asked whether they knew of someone with HIV or AIDS; fifty-nine percent stated that they did not know of anyone with either. Although usually, they answered that they didn't know anyone with "it" indicating a lack of differentiation between HIV and AIDS. Ten percent of the subjects said that they *did* know of someone with HIV or AIDS. Of these responses, all of the relationships were described as somewhat distant. The most frequently cited relationship between themselves and the person with HIV/AIDS was that of rumor. They had simply heard of someone who might have the disease. One subject listed more than one person known to them through rumor. This response was followed in frequency by acquaintance, then by friend.

Table 2.4a: Responses to Question 4 part a

Subjects were asked if they knew of anyone with HIV or AIDs, without naming them.		
Yes	No	Didn't answer or weren't asked

11	34	13
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Table 2.4b: Responses to Question 4 part b

Subjects were asked if they could describe how close was that person was to them by using these descriptions: a relative, a friend, an acquaintance, or just someone they had heard about (Rumor).			
Acquaintance	Rumor	Friend	Relative
3	6*	2	0

*One subject reported knowing of two people through rumor.

Perceived Responses to HIV Diagnosis

When asked for their perception of how people might respond to a diagnosis of HIV/AIDS, sixty-two percent stated that they thought the person would seek standard modern medical care. This was followed by thirty-one percent whose answers fell in the category of “other”. This category, though the answers varied widely in specifics, were similar in essence and each answer centered on the theme of death. Essentially these respondents viewed HIV/AIDS as a diagnosis of no hope, one that only leads to the variations of death such as death by either neglecting themselves or surrendering to the disease, death by killing themselves to preempt a slower death by disease, or even killing themselves to avoid shame or being a burden to their families, going back to their own countries to die so that they would have the benefit of relatives to tend their graves or death “shared” by giving the disease to others. Paying for medical treatments was not an option to these particular respondents. They stated that option was a waste of money, one not worth considering. The third most frequent response was that they would probably go to another country or area for treatment, while ten percent of the subjects thought that they would seek religious healing or help from the church. Equal numbers of subjects, nine percent, suggested that people receiving a diagnosis of HIV/AIDS would either ignore/deny the fact that they had the disease or hide their status from others. Seven percent thought that people would seek alternative medicines and in this case alternative medicines would include what the migrants referred to as “healers”. Throughout the interviews healers were discussed as people they could turn to instead of the standard medical system. The benefits of going to a healer were related as follows: healers cost less than doctors, people who seek healers can be seen and treated quickly, they can get medicine rather than a prescription from the healer which they regarded as evidence of the healer doing more for them than a doctor who sends them to a pharmacy. Even though a relatively small number of subjects thought that a person receiving a diagnosis of HIV/AIDS would turn to alternative medicines such as healers, knowing about the role of and existence of these healers within the migrant community is paramount in

understanding cultural patterns of respect, expectations, and education as related to standard medical care.

Table 2.5: Responses to Question 5

Subjects were asked for their thoughts on how people might respond to a diagnosis of HIV/AIDS. (Probes: Would they go for standard medical treatment, go to a healer/seek alternative treatments, go to a religious person, or a different country, eat special foods etc?)						
Standard	Ignore/Deny	Hide	Alternative Medicines	Religious	Different Area/country	Other
36	5	5	4	6	9 1 was a Yes/No	18 *

*Other answers given: Commit suicide or let themselves die, go back to the country where their family lives in order to die, spread the disease to others.

Awareness of Health Care Locations

Sixty-six percent of the responses indicated that people who work on the farms and in the fields *do* know where to go for health care. Forty-eight percent did not think that they knew where to go. Nineteen percent answered both yes and no. Subjects answering both yes and no stated that while people who are newly arrived do not know where to go for health care but that they eventually learn this information from other members of the migrant community and that nearly all the people who have worked in the area for a while know where to go.

Table 2.6a: Responses to Question 6 part a

Inquiring whether they thought people who work on the farms and in the fields know where to go for health care.			
Yes	No	Yes and No answers	Don't know/weren't asked
36	28	11	5

Perceived Awareness of Health Care Access

The subjects were asked *where* they thought people who work on the farms and in the fields would go for health care. Twenty-eight percent cited clinics as the place where they would go. In two of the three counties where the interviews were conducted, an answer of “clinics” meant the local health department. In the third county, an answer of “clinics” could have meant either the health department or a migrant laborer clinic. Only one subject cited the health department specifically. The hospital was the second most frequently cited location for receiving health care, but this was only listed by three percent of the subjects.

Table 2.6b: Responses to Question 6 part b

Subjects were asked where people who work on the farms and in the fields go for health care.					
Clinic	Hospital	Dr.	Health Dept.	Other	Didn't answer
16	2	1	1	1	37

Perceived Awareness of Alternatives

When asked whether they thought that treatment for HIV or AIDs might also be obtained at the places they had previously listed for general medical care, forty percent of the subjects thought that it was available at those locations. Sixteen percent did not think that treatment for HIV or AIDS could be obtained at the same location as general health care services. Those who answered no to the first question were asked to state where they thought such treatment could be found. Most answered that they thought people who went to clinics for HIV/AIDS would be referred or sent to hospitals or to specialists for treatment. One subject answered that they would have to go to both a specialist and to the hospital for treatment.

Table 2.7a: Responses to Question 7 part a

Subjects were asked whether they thought people could also get medical treatment for HIV (El Virus) or AIDS (SIDA) at the health care locations they previously cited.		
Yes	No	Don't know/weren't asked
23	9	26

Table 2.7b: Responses to Question 7 part b

Subjects were asked if people could not receive treatment for HIV/AIDS at those locations then where could they?		
Note: one subject gave two answers.		
Specialist	Hospital	Clinic

3	6	1
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Ease of Access to Care

When asked whether or not health care is easy to obtain, thirty-four percent responded that they thought that it *is* easy to obtain, however an equal number answered that they thought health care *is not* easy to obtain. Those who said that health care was easy to get used the following reasons for their answer: people must go to the Dr. if they don't want to die, the boss will take them to the Dr., the facility is easy to get to, they can pay the bill little by little over time, if they have insurance they can go anytime, people help each other get to care, it is easy to receive care if you have patience and can wait "patiently." Those who said that health care was not easy to get used the following reasons to illustrate their answers: Fear or anticipation of the expense, embarrassment either at having to seek care or in thinking that the health care providers might turn them away, fearing deportation if they seek medical care without having the proper documents, and the length of time it takes to get health care. The issue of time is related to the lack of money. The subjects stated that they could not afford to take time off work to seek health care. If they miss the labor buses in the morning to go to the clinic they loose a whole day of work, so to them, seeking medical care is costs twice as much: once in the lost day of pay that it takes to go to the clinic, and the second time in the expensive fees and medicines that they pay.

Table 2.8: Responses to Question 8

Subjects were asked whether or not they think health care is easy to obtain.			
Yes	No	Yes and No answers	Don't know/weren't asked
20	20	8	10

Reasons given by subjects for why health care is <i>not</i> easy to get:							
Lack of Money	Lack of Knowledge	Fear	Embarrassment	Lack of Time	Lack of Documents	Lack of Insurance	Other
12	3	2	2	4	4	2	2

Qualifying as a Barrier

Sixty-four percent of the subjects thought that they would qualify for healthcare, while twenty-one percent did not. Five percent responded both yes and no, thinking that

they would qualify for some types of care such as the clinic, but not other types such as a specialist.

Table 2.9a: Responses to Question 9 part a

Subjects were asked whether they thought they qualified for health care.			
Yes	No	Yes and no answers	Don't know/weren't asked
37	12	3	6

Embarrassment as a Barrier

When the subjects were asked whether they thought the possibility of embarrassment might stop them from seeking health care, forty-seven percent said that it would not, and thirty-six percent said that it would. Five percent answered both yes and no, the reasoning being that they would not be embarrassed to seek general health care, but that they or others would be embarrassed to seek care for sexual diseases or HIV/AIDS.

Table 2.9b: Responses to Question 9 part b

Subjects were asked whether they would feel embarrassed to go to a health clinic.			
Yes	No	Yes and no answers	Don't know/weren't asked
21	27	3	7

Perceived Respect as a Barrier

Fifty-three percent of the subjects thought that the health care providers would show respect to farm workers, while nineteen percent did not think that they would be shown respect. Fourteen percent answered both yes and no, that some health care providers act respectfully towards farm workers but some do not. Some of the subjects mentioned the possibility of certain prejudices existing between health care workers who may be “second generation” immigrants and patients who might be new arrivals to this country, or attitudes of superiority from those who are Spanish speaking and who have health care jobs towards those who are farm laborers.

Table 2.9c: Responses to Question 9 part c

Subjects were asked if they think that the people at the health clinic would show respect to farm workers.			
Yes	No	Yes and No answers	Don't know/weren't

			asked
31	11	8	8

Language as a Barrier

When asked if language is an obstacle in receiving health care, sixty-four percent of the subjects said that it was, while sixteen percent said that it was not. Three percent answered both yes and no, yes language could be a problem, but they could use interpreters or some of the health care providers in the community could speak Spanish. The subjects were then asked what language(s) would be good for health care providers to use. Among those that responded, fifty-seven percent said that Spanish would be the best language for providers to use. This was followed in frequency by nineteen percent who said that they should use English. Some said that the health care providers should use English because this is America, and that they the laborers should learn English. This was interesting because throughout the interviews, which were conducted in Spanish, the subjects had added information that it is difficult for them to learn English because: They don't have time or they do not know where or when classes are available, they do not have transportation to classes. Languages or suggestion that fall within the category of "other include: "Quechua" (which is understood by many Guatemalans even if they speak a regional dialect.) Creole, and Sign language (This was not a suggestion for sign language as is used by the hearing impaired, rather the subject described health care workers communicating by means of gestures to people of different languages.)

Table 2.9d(1)(2): Responses to Question 9 part c sections (1) and (2)

(1) Subjects were asked whether language is a problem in receiving health care. problem?			
Yes	No	Yes and No answers	Don't know/weren't asked
37	9	2	10
(2) Subjects were asked what language they thought would be good for health care workers to use with people in this area.			
Spanish	Dialects	English	Other
33*	3	11	4

Cost as a Barrier

Sixty-nine percent of the subjects indicated that they thought health was expensive and that this fact alone would keep them from seeking it. Seven percent stated that health care was not expensive. Three percent gave yes and no answers, in that the

clinic might not cost a lot but that going to a hospital or an emergency room would be expensive.

Table 2.9e: Responses to Question 9 part e

Subjects were asked if they think it costs a lot to get health care.			
Yes	No	Yes and no answers	Don't know/weren't asked
40	4	2	12

Trust as an Access Issue

When asked if people would trust the doctors to help them, sixty-nine percent of the subjects said that they would, while sixteen percent stated that they would not. Among those who said that people would trust the doctors to help, the most frequently cited reason was that the doctors are the ones with the knowledge to help them. Those who didn't think that people would trust the doctors to help them stated that not having a Social Security card or not having enough money would keep the doctors from doing anything to help them. One subject answered both yes and no, stating that some people would trust the doctors but that there are people who make bad choices in their lives and they do not trust anyone.

Table 2.9f: Responses to Question 9 part f

Subjects were asked whether people would trust the doctors to help them.			
Yes	No	Yes and No answers	Don't know/weren't asked
40	9	1	8

Transportation as a Barrier

When asked whether it is easy or difficult to get to a health care location, forty-seven percent answered that they thought it was difficult, and twenty-two percent said that it was not difficult. Seventeen percent answered both yes and no, stating that in some cases it was difficult and in others it was not. Those who said that it was difficult cited the long time periods between buses, lack of bus stops, or complete lack of public transportation in some areas, particularly near the rural housing areas. They also cited barriers to owning their own vehicles such as a lack of documents in order to qualify for a

driver's license. Other barriers were listed such as the long distances to walk to the clinics when they are sick, or a lack of directions to the health care locations for people who would be going to them on foot, or that the cheaper facilities might be further away and therefore too difficult to get to. Those who said that it was easy stated that some clinics provide transportation for pregnant women, and the general willingness of people in the community to help each other get to the facilities as needed.

Table 2.9g: Responses to Question 9 part g

Subjects were asked if they thought it is difficult or easy to get to a health care place.			
Easy	Difficult	Easy and Difficult (It depends on different factors)	Don't know/weren't asked
13	27	10	8

Hours of Access as a Barrier

When asked whether they thought the health care centers are open when people are able to get there, forty-seven percent did not think that they were, while twenty-eight percent did think so. The main reason given by those who did not think that people could get to the health care facilities during existing hours was the fact that they would have to give up work to do so. Many suggested that a clinic that would be available after work hours, such as in the evenings or on Sundays, would be helpful. Saturday clinics would not help migrants because they work on Saturdays and their only day off is Sunday. The subjects explained that currently if migrants go to the clinic during any part of the day, they have missed a whole day of work because they were not on the labor buses in the morning and since they do not have their own transportation they cannot drive to and from the work fields to attend appointments. Many said that they would just go to work and ignore health problems to save money, or if they were too sick to work that they would stay home because it would be too difficult to get to a health care facility when they were ill and that way they would save money by not spending it on doctors fees or on medicines.

Table 2.9h: Responses to Question 9 part h

Subjects were asked if they thought the health care centers are open when people can/are able to go there.		
Yes	No	Don't know/weren't asked
16	27	15

General Barriers to Health Care

When asked if there were other reasons that would prevent people from getting health care, forty-one percent said no, and nineteen percent said that there were other reasons. However when they were asked what those reasons were, they cited the same issues as before: it is expensive, they cannot take off work to go, they don't know how to get care, and they cannot be understood.

Table 2.9i: Responses to Question 9 part i

Subjects were asked if there were any other reasons that would prevent people from seeking care.		
Yes	No	Don't know/weren't asked
11	24	23

Personal Experience as a Barrier

The subjects were asked if they could describe any bad experiences they or anyone had ever had with health care, thirty-eight percent said that they had never had a bad experience and didn't know of anyone who had, however nineteen percent described bad experiences with health care. These bad experiences are listed in order of frequency: turned away from service/service provider's poor attitude, received the wrong diagnosis for a condition/had to spend too much time for care, doctor did not provide an adequate explanation.

Table 2.10: Responses to Question 10 a

Without naming any patients or doctors or specific programs, subjects were asked if they could describe any bad experiences that anyone in this community has had with health care.		
Described a bad experience	Never had a bad experience	Didn't answer/weren't asked
11	22	25

Types of problems cited:				
Wrong diagnosis	Service provider's poor attitude	Doctor didn't explain adequately	Couldn't get or were turned away from service	Too much time involved.
2	3	1	3	2

10b) What do you think could have been done to make that a better experience for the person seeking health care?

The following suggestions were made: doctors should pay more attention and take time with the patient, health care providers should have good attitudes toward the patients, and clinics should provide transportation. Additional suggestions included: health care providers should go at a faster pace or people will just turn to healers so they don't lose a lot of work time, and more doctors should speak Spanish, because the few who do are over-worked.

Health Information Distribution

When asked whether they had ever noticed people giving health education information to people in the community, forty percent of the subjects had never noticed this, while twenty-two percent had either noticed it or received information themselves. Those who reported having seen or receiving information were asked if they could recall the subject matter of the information offered. They cited the following subjects: HIV/AIDS; diabetes; health insurance; hazards of or handling information for agricultural chemicals; asthma; flu shots; and high blood pressure.

Table 2.11: Responses to Question 11

Subjects were asked whether they have ever noticed anyone coming into this community to give health education information to people.						
Yes		No			Don't know/weren't asked	
13		23			22	
Health care topics/information subjects reported not being offered in the community						
HIV/AIDS	Diabetes	Health Insurance	Agricultural Chemicals	Asthma	Flu Shots	Blood Pressure
4	2	2	2	1	1	1

Awareness of HIV Prevention Services

The subjects were asked if they were aware of any HIV/AIDS prevention services in the area. Fifty-nine percent stated that there were none that they knew of. Twenty-four percent said that there were services. When some subjects were questioned more closely about certain types of HIV/AIDS prevention services, twenty-one subjects said that free condoms were not available in the community, while twelve said that they were, but only in the clinics. Some added that they couldn't afford to purchase condoms. Six subjects

said that they thought there were classes about HIV/AIDS somewhere in the community, but only one stated a location saying that sometimes the churches gave a little information. Twelve subjects stated that there were no classes in their communities. When asked whether there was HIV/AIDS literature available only two subjects answered that there is not. This coincided with observations in several clinic settings that there was little or no health care information literature and that which was present was in written in English with few or no pictures for nonreaders. Ten subjects said that there was information about HIV/AIDS available, mostly at the clinics through discussion or testing.

Table 2.12: Responses to Question 12

Subjects were asked whether there are any HIV or AIDS Prevention Services in this area that they know of.			
Yes	No	Yes and No answers	Don't know/weren't asked
14	34	2	8

Awareness of Testing

The subjects were asked where someone could go to get tested for HIV. Forty-five percent responded that they could go to a clinic. Other responses seven percent each for doctors and hospitals, while three percent mentioned outreach sites.

If someone wanted to get tested for HIV or AIDS did the subjects know where they could go?				
Clinics	Doctors	Hospitals	Outreach sites	Didn't answer/weren't asked
26	4	4	2	22

Outreach Testing for HIV

When asked if they had seen HIV testing offered in the community, sixty-two percent of the subjects had not seen any testing, while seventeen percent reported that they had noticed testing in the area.

Table 2.14: Responses to Question 14

Subjects were asked if they noticed any HIV testing offered in the community.		
Yes	No	Don't know/weren't asked
10	36	12

Barriers to Outreach Testing

The subjects were asked whether they thought people would take an HIV test if it were offered free of charge in the community. Forty-seven percent of the responses were positive, while sixteen percent of the subjects did not think that people would take the test. The most frequently cited reason for not taking the test was privacy. They did not want to be seen taking the test. Other reasons included not wanting to give their blood for the test, and thinking that they had no reason to be tested.

Table 2.15: Responses to Question 15

Subjects were asked if someone came here to offer free HIV testing if they thought people would be willing to take the test.			
Yes	No	Yes and No answers (E.g., if private)	Don't know/weren't asked
27	9	10	12

Tested Self Report

When asked whether they themselves had ever been tested for HIV (Without revealing any test results), forty-one percent of the subjects said that they had not been tested, while twenty-nine percent had. Among those who had been tested, many were women who had been tested at the clinic during their pregnancies. It was suggested by some of the subjects that the husbands who do not discuss such things with their wives would be more willing to take the test if information about testing or even testing itself was done at their work sites so that they could keep it private.

Table 2.16: Responses to Question 16

Subjects were asked, without revealing results, if they had ever been tested.		
Yes	No	Didn't answer
17	24	17

Response to Health Information in Community

When asked if they would be interested in receiving health care information, eighty-four percent of the subjects said that they would. As learned throughout the interviews, health care information would have to be given in certain ways before it would be useful to the various culture groups that make up the migrant community. Many mentioned the fact that written information was of little use to people who cannot read. Others suggested videos about health information would be good but only if sensitive subjects were not shown in public places such as waiting rooms where mixed gender groups or children might be, or that videos that were to visually explicit, such as showing people kissing might offend people and keep them from getting the information. Many suggested that health care information taught in person, which would allow them to ask questions, would be the preferred method.

Table 2.17: Responses to Question 17

Subjects were asked if they would be interested in receiving health care information if they noticed someone in the community offering it.		
Yes	No	Didn't answer/weren't asked
49	0	9

Best Method of Distributing Health Care Information

When asked what would be the best method of reaching them with health care information, most of the subjects had multiple suggestions. These responses are listed in order of frequency: face-to-face instruction, radio, TV, clinic, flyers, videos, newspapers, pamphlets, at church, at community meetings. Face to face or one on one instruction was the most favored because people wanted to have the opportunity to ask questions and they expressed the idea that face to face instruction allows them a greater understanding of the material being covered. Many suggested that people come into the communities and teach especially at the hangouts where people are before and after work. Radio, TV, and video as well as pamphlets designed with lots of pictures were suggested as a way to reach those who do not read. Radio was also cited as a way to reach people during the time that they work, as many are able to listen to radios while they are in the fields. The newspaper was suggested with the added explanation that in some areas a free Spanish language newspaper is available to the workers. One subject summed it up with “people don't know how to read, but would love more information.”

Table 2.18: Responses to Question 18

Subjects were asked what would be the best method of reaching them with health care information.								
Radio	TV	Clinic	Flyers	Video	Community Meetings	Face to Face Instruction	Church	Newspaper or Pamphlets
11	9	8	8	8	4	26	7	8

Summary: Migrant Workers

Most of the Interviewees reported that they had been in this country for, on average, a total of three years, however this information was based on the number of and length of planting seasons they had spent in this country. For example, they include in this assessment the times they migrate around to various areas based on the seasons. The time out of country is not included in their assessment.

It was very clear that these interviewees were sensitive about and somewhat uncomfortable with the topic of HIV/AIDS. There were many cultural barriers to this topic, so the interviews were structured in such a way as to get to the topic slowly.

When asked what the main health issues were in their communities, the answers were varied. The “flu,” diabetes, chemicals and pests, rashes were described as problems. HIV was a concern for some, but this topic had to be probed as it was rarely mentioned without prompting. Most people could describe the various names they give to HIV – these are reported in the findings. Important to note is that many indicated the belief that HIV is a death sentence. One interviewee said, “they (the people with HIV) don’t tell their own families to keep from embarrassing them. But, if it is a terminal illness, it is better to die quickly.” Fifty-nine percent said they did not know anyone with HIV/AIDS. HIV/AIDS seemed to be all one problem, not a disease with multiple stages. If they admitted knowing anyone personally with HIV/AIDS, which was infrequent, they called it “by rumor.” These people were frequently perceived to be sexually promiscuous.

Most sixty two percent of interviewees reported that, if they got a HIV diagnosis, they would seek care. However, they also reported there was no hope if you get that diagnosis and that getting the diagnosis might equal death.

“Yes, I understand that there is medical treatment available, but . . . it is incurable. You can, uh, take the medications, but it will worsen, the severity, it will not cure the disease. It’s in the blood, you can try to take care of yourself, but you have it.”

They might try to access health care, but several thought that some people would “surrender to the disease” by neglecting themselves. Some thought that others might kill themselves to avoid shame or to not be a burden on their families.

“I would kill myself. . . would not seek care because of a waste of money. There is not a cure for this. You suffer . . . You cannot live the same life that you had. . . suicide would be the answer.”

In some cases it was not clear if people would actively kill themselves or just allow themselves to die due to neglect. Some reported that individuals might go back to their own country to die so that their families could tend their grave.

“ . . . they may go back to their country because it is so far to die away from family. They need to have the grave in their own country where their family can put the flower on the grave. Even though medicine exists they don’t try because it is too expensive and they can’t afford it. They don’t even consider it, they just die.”

Recent reports have indicated that a growing percentage of HIV+ people in Mexico were infected in the US or were infected by a migrant worker who returned from the US. Consequently, this is a very important issue. A few interviewees said there could be people who would “share” their death by giving the disease to others. It was not clear if this would be intentional.

Many reported that paying for health care is not an option.

“You have to take care of yourself, you have to keep yourself healthy because the clinics won’t take care of you. If you have money they’ll take care of you, if you don’t they won’t.”

It was considered by some to be a waste of money. Others reported people might ignore the problem or deny they need care. Some reported they could go to a healer because the healer might give medications whereas the doctors in health care settings send you to the pharmacy.

Forty-eight percent did not know where to go for care. However, this seemed to be inconsistent or non-specific as thirty-four reported that health care was easy to obtain. This group reported that health care was easy to obtain because you can “pay the bill a little at a time,” you can get help with transportation from “each other” and “if you have patience and can wait tranquilly, it is easy to get care.” The thirty four percent that reported that health care is difficult to obtain explained that it was difficult due to fear, expense, embarrassment, fear of being turned away and fear of deportation because of lack of documents.

“Wherever you go the first thing they are asked is what is their social security number and driver’s license, green card and insurance. They cannot have the license. The reason is they have no legal papers and cannot drive. Cannot drive, no good job, then no money and no medical insurance, then, if sick, no money.”

Time was frequently reported to be a major issue. People cannot take time from work because they would lose pay and have to pay for the health care.

“. . . sometimes you have to pay and then you may have to, uh, you may have to go find another doctor, yes, who is willing to take care of you. And so it gets into this (vicious cycle). But the problems create more problems but they are poor so they can’t pay, so they don’t want to treat them so they have to go somewhere else which causes them to lose more work.”

They might have to ignore illness to save money.

“ . . . the work, you know the work would stop them from going to the clinic to get medical care. Of course it is better to see to your health than work.”

Later this same interviewee said that not being open in the evening is a problem for workers. Costs were generally reported as too high. Transportation is an issue, though people try to help each other out.

“(it is) . . . difficult (to get to care) because of appointments. To get to these they have to walk and it is very far away from home to the clinic. When (I) was here the boss let (us) borrow the car and suddenly they took the keys and (I) do not know why.”

There are few public transportation opportunities. The communities with transportation have long waits or the transportation does not take them where they need to go to get health care. In the more rural areas transportation is a major problem.

Several reported that they are especially embarrassed to seek sexual health care. There were gender issues involved in this embarrassment.

“. . . sometimes people are embarrassed to go. Education could change that to try to make them feel more comfortable. Some people come from remote places and they don't feel comfortable talking about themselves. (She had some experience with someone who was working but pregnant.) She was scared to go to the doctor because she was afraid she would be sent back to Mexico. She had someone from the community (who spoke English) take her to the hospital and she had her baby there, but she also had an STD so she was very embarrassed.”

Many reported that they trust doctors because the doctors have the knowledge of health care. This appeared to be a socially appropriate response. It was not clear if they trust the doctors to keep things confidential or if they simply trust them as the medical expert.

Several interviewees also reported that there are prejudices against “new arrivals” in the health care setting. Some Spanish-speaking workers in these settings were reported to discriminate against farm workers. This seems to be a problem that is larger than just the health care setting. Sixty-four percent said that language is a barrier to getting health

care. Many reported that they would like to learn English, but that the classes were during work hours or there was no transportation to classes.

Some participants reported that they had seen health education conducted in the community. When asked about prevention services, the concept was not understood. When specific services were described, such as condom availability or brochures, then people could report some knowledge of these activities. However, there was limited exposure to this or it was too sensitive to be discussed. One woman noted, “no one give out condoms, you have to buy them and who can afford such things?” When asked about prevention services in the area one man said:

“What do you mean? No, none. (I) try to avoid HIV by myself, by my own intelligence and wisdom, but they don’t have anything here. Public bathrooms would be a good place or places where they live would be a good place for condoms and information. When (I) used to live in Guatemala the doctor used to come to the dorms often and check them. I am clean and want to stay that way. I am scared that if I get contaminated and go home that (I) could pass the disease to family. Some workers get sick here and don’t know they are sick and carry it home, back to country and contaminate family. . . (I) know a woman who is sick and who is going around infecting men (prostitute).”

The interviewers were not able to locate much information about HIV in the clinics or other interview settings. When asked how prevention messages could be most effectively delivered to the community, many interviewees noted that videos (as long as they were not suggestive) would be helpful. These should be gender specific, not offensive (no kissing) and not viewed in groups. Children should not be present. Participants also noted that face-to-face teaching would be helpful. They would want to be able to ask questions, within a certain comfort level. Going to a place to get this information might required a woman to get permission, so incorporating this education into other services would be most effective. They also suggested that providing

prevention activities before and after work to men in the fields or at “hangouts” would be good. Another shared idea was to use the radio as workers frequently listen to the radio when in the fields. They advised the interviewers that creating messages that need to be read would be less helpful. But, brochures with many pictures would be helpful.

HIV testing was perceived to be no more visible than the prevention. However, sixty-two percent reported that they had not seen testing in the community. Many noted that testing would have to be private. No one would want to be seen at a testing site. Forty-one percent said they had been tested – many during pregnancy. Several women suggested that testing should be taken to their husbands at their worksites. They suggested this because men do not discuss this type of thing with their wives.

YOUNG ADULTS 18-25

Total Number of Subjects Interviewed: 60

African American Females	African American Males	Caucasian Females	Caucasian Males	Hispanic Females	Hispanic Males	Asian Females	Asian Males	Other	
								F	M
24	11	10	6	1	1	4	1	1	1

Locations where subjects were interviewed: 6

Types of locations:

2 Public Universities

1 Community College

1 Technical Training Center

1 Club

1 Community Center in Lower Income Neighborhood

Area:

North Florida

Three interviewers, 2 African American males and one white Female interviewed Young Adults 18-25 who were verbally recruited from the previously listed locations over a three-day period in the fall of 2002.

Young Adults 18-25: Response Summary Tables

Familiarity With People Who Have HIV/AIDS

Sixty subjects were asked whether they knew of someone with HIV or AIDS. Sixty-three percent of the subjects stated that they did *not* know anyone with HIV or AIDS. Twenty-eight percent of the respondents acknowledged knowing someone with HIV or AIDS. These subjects were then asked if they could, without naming anyone, describe the relationship between themselves and that person. The relationships were most likely to be reported as distant, as in having heard of someone with the disease, but not classifying that person as a relative, friend or even acquaintance.

Table 3.1: Responses to Question 1

Subjects were asked if they knew of anyone with HIV or AIDS and how close that person(s) might be to them.						
	<u>Yes</u>	<u>No</u>	<u>Friend</u>	<u>Acquaintance</u>	<u>Relative</u>	<u>Rumor</u>
Totals:	17	38	4	4	3	8 (One subject reported more than one person)

Perceived Responses to HIV Diagnosis

When asked about their perception of how young adults or teenagers might respond to the diagnosis of HIV or AIDS, seventy percent of the respondents stated that they would seek standard medical treatment. A few added caveats to their answer, such as ‘if they could afford it’ or ‘maybe not at first, but eventually’. Sixty percent of the subjects’ thought that young adults or teenagers would either ignore, deny, or hide the fact that they had HIV or AIDS. Twenty-five percent of the respondents thought that young adults or teens receiving this diagnosis might try alternative medicines and that they would use them instead of, not in conjunction with standard medicine. Alternative methods mentioned included: acupuncture, herbal remedies, vitamins, or Ancient East Asian medicine. Twenty-three percent believed that young adults or teens receiving this diagnosis might turn to religious or faith healing. Additionally, one tenth of the subjects thought that people would seek treatment in other countries or areas. The reasons cited

for going to other areas included: privacy, better hospitals/care elsewhere, and going to Africa for a rumored cure.

Table 3.2a: Responses to Question 2

Subjects were asked for their thoughts on how young adults or teenagers might respond to diagnoses of HIV/AIDS. These thoughts were probed as to what type of treatment they might seek.												
	Standard		Ignore/Deny		Hide	Alternative		Religious		Different Area		Other
	Yes	No	Yes	No	/////	Yes	No	Yes	No	Yes	No	////////
Totals	42 (5 are conditional)	4	20 (3 are conditional)	5	16	15 (2 with Rx)	7	14 (1 conditional)	5	6	11	See inset below

Table 3.2b: Other Reactions

Suicide/depressed/sad/cry	Panic/scared	Spread it	Angry	Get answers/counseling	Didn't know
10 (3 of these also answered Ignore/Hide the disease)	5	3	2	3	3

Awareness of Health Care Locations

Fifty-five percent of the subjects thought that young adults and teens would know where they should go in order to obtain general health care, while thirty-seven percent did not. Seven percent answered both yes and no, as in some young adults and teens would know where to go, but some would not.

Table 3.3: Responses to Question 3

Inquiring whether young adults or teenagers know where to go for general health care.			
Yes	No	Yes and no answers	Don't know/weren't asked
33	22	4	1

Perceived Awareness of Health Care Access

The subjects were asked where young adults or teens would go to get general health care, thirty-two percent reported general health clinics, as the place most would go. Other responses follow in descending order according to the number of responses: campus or school clinics, hospital(s)/emergency room, health department, personal doctor. Some subjects listed multiple locations.

Table 3.4: Responses to Question 4

Subjects were asked where they thought young adults or teenagers would to get general health care.					
Campus/school clinics	Hospital(s)/ER	Other clinics *(Some might have meant the Health Dept.)	Health Department	Doctor, personal or local	No answer
18	16	19	8	9	9

Perceived Awareness of Alternatives

Forty-three percent of the subjects thought that treatment for HIV or AIDS could be obtained at the same locations at which they thought young adults or teenagers would go to for general health care. Ten percent of the subjects did not think that treatment for HIV or AIDS could be obtained in the locations previously cited. Forty-seven percent didn't know or weren't asked.

Table 3.5: Responses to Question 5

Subjects were asked whether they thought that treatment for HIV or AIDS could also be obtained at the places they had cited in the previous question.			
Totals	Yes	No	Don't know/weren't asked
	26	6	28

Ease of Access to Care

When asked whether or not health care is easy to obtain, forty-two percent of subjects gave a positive response indicating they think health care *is* easy to obtain. Thirty percent did not think that health care is easy to obtain, and twenty percent of the subjects did not know. The reasons cited for health care being easy to obtain tended to be rather unspecific and indicated general faith on the part of the subjects that if help was needed it would be found. A few cited the availability of Medicaid or knowledge of free clinics as being the reason they thought health care is easy to obtain. The reasons cited for health care being difficult to obtain fell along two lines of the same theme: cost. 1) lacking insurance, this included those who lacked a job that would provide access to insurance 2) just not being able to pay out of pocket for health care. Eight percent of the subjects gave a yes and no response to the question, such as yes, health care is easy to obtain if you have insurance, but no, it is not easy to obtain if you do not have insurance.

Table 3.6: Responses to Question 6

Subjects were asked whether or not they think health care is easy to obtain. They were also asked to give the reasons for their answers.			
Yes and No answers	Yes	No	Don't know/weren't asked
5	25	18	12

Qualifying as a Barrier

Seventy-three percent of the subjects indicated that thinking that they didn't qualify for health care *would* stop young adults or teenagers from seeking it. Most of these elaborated on the idea by explaining that they thought people either need to get a job which includes health care or they need to be on some type of insurance policy (such as their parent's policy or student health policies) before they *can* qualify for or access health care. Twenty-two percent didn't think that this would deter young adults or teenagers from seeking health care.

Table 3.7a: Responses to Question 7 part a

Subjects were asked whether thinking that they didn't qualify for health care would keep them from seeking it.			
	Yes	No	Don't know/weren't asked
Totals	44	13	3

Embarrassment as a Barrier

When the subjects were asked whether they thought the possibility of embarrassment might stop young adults or teens from seeking health care, seventy-two percent of the responses indicated that embarrassment would indeed be a factor that could be a barrier to obtaining care.

Table 3.7b: Responses to Question 7 part b

Subjects were asked whether embarrassment would stop them from seeking healthcare.		
	Yes	No
Totals	43	17

Peers and Family as a Barrier

Seventy percent of the subjects indicated that they would not seek health care if they thought that their friends or family might find out, particularly in cases of STDs or HIV. Specific fears about being shunned, feeling like they had let people/parents down, and the possibility of being ostracized or disowned were mentioned as reasons. Twenty-two percent did not think that the idea of family or friends finding out would deter young adults or teenagers from seeking health care.

The two subjects who answered both yes and no to the question specified that although they would be afraid of their friends finding out, they would not be afraid of their family to finding out.

Table 3.7c: Responses to Question 7 part c

Subjects were asked if being afraid that their family or friends would finding out would stop them from getting health care.			
Yes and No answers	Yes	No	Don't know/weren't asked
2	42	13	3

Perceived Respect as a Barrier

Seventy-eight percent of the subjects thought that the health care providers would treat them with respect. Additional responses indicated that the subjects thought that the healthcare providers *should* treat young adults and teens with respect, however ten percent of the subjects thought that providers would *not* treat young adults or teens respectfully. Those reporting that they thought providers would not treat them respectfully seemed to speak from experience and described the lack of respect demonstrated through judgmental attitude on the part of the service providers, or in other subtle ways such as body language, or impersonal treatment.

Table 3.7d: Responses to Question 7 part d

Subjects were asked whether they thought that health care providers would treat them with respect.			
	Yes	No	Don't know/weren't asked
Totals	47	6	7

Cost as a Barrier

Eighty-five percent of the responses indicated that young adults or teenagers do *not* think that they can afford health care. Ten percent of the subjects stated that young adults or teens would think that they could afford health care. Five percent didn't answer or weren't asked.

Table 3.7e: Responses to Question 7 part e

Subjects were asked if they thought that young adults or teenagers could not afford health care.			
	Yes	No	Don't know/weren't asked
Totals	51	6	3

Trust as an Access Issue

Forty-eight percent of the subjects indicated that they thought that young adults and teens would trust the doctors to help them. Their reasons indicated that this is due to a societal norm. They were taught to be accepting of doctors, to believe that doctors know what they are doing, and to trust them implicitly. Fifteen percent of the responses indicated a lack of trust for reasons that varied widely with impersonal service being the only answer that was given by more than one subject. Twenty-seven percent of the subjects gave both yes and no answers indicating the complexity of the issue of trust. Some of these mixed answers indicated a degree of trust in doctors, but a dislike for medical procedure itself such as fear of hospitals.

Table 3.7f: Response to Question 7 part f

Subjects were asked whether young adults and teenagers have trust in the doctors and think that the doctors will help them.			
Yes and No answers	Yes	No	Don't know/weren't asked
16	29	9	6

Transportation as a Barrier

Sixty-eight percent of the subjects stated that it was not difficult to get to a health care location. They stated that they could use the bus, their personal vehicles, and taxis, or obtain rides from people they knew. The twenty-eight percent who thought that it was difficult to get to a health care location indicated that the greatest difficulty is in knowing *where* the facility is and how to find it, rather than how to get to it.

Table 3.7g: Responses to Question 7 part g

The theme of transportation was explored and the subjects were asked about the difficulty of getting to a health care location.		
	Yes	No
Totals	17	41

Hours of Access as a Barrier

Forty-three percent of the responses were positive, indicating that the subjects thought that young adults and teens are able to access the services during existing hours. Three percent answered both yes and no with rationales such as although young adults can access health care services during existing hours it might not be convenient to do so. The rest of the subjects were divided between those who didn't think they could get to health care services during the hours that they are open, and those who didn't know *when* their local health care services were open.

Table 3.7h: Responses to Question 7 part h

Subjects were asked about the hours that health care services are available and whether they are able to utilize services during these hours.			
Yes and No answers	Yes	No	Don't Know/weren't asked
2	26	18	18

Perceived Desirability of Combined Service Sites

Seventy seven percent of the subjects stated that they thought young adults and teens *would* go for health care if it were offered in a combined service site- a clinic that also offered mental health or substance abuse services. Comments also indicated that it might be easier if everything was in one location, or that extra services such as mental health might be needed for persons receiving a diagnosis of HIV. Seventeen percent, those who didn't think that young adults or teens would go for health care in this type of clinic most frequently cited embarrassment at being seen there and/or being thought of as needing mental health services as factors that would keep them from seeking health care services at a combined services site. One subject answered yes and no, yes it would be convenient to have all the services in one place, but people might not want to go there.

Table 3.7i: Responses to Question 7 part i

Subjects were asked whether they thought young adults or teenagers would go for health care services if those services were located in a clinic that also provided mental health or substance abuse care.			
Yes and No answers	Yes	No	Don't know/weren't asked
1	46	10	3

Health Information Distribution

Fifty-five percent of the subjects responded that they had *not* noticed anyone giving health information to people in the community, or that they knew information was being given out but had not directly observed its distribution. The thirty-seven percent of the subjects who responded that they had observed the distribution of health care information in the community were also asked if they remembered what the information was about. The following subjects were cited and are listed here in order of frequency: STDs, birth control, nutrition, cancers, cholesterol, blood pressure, meningitis, viruses, HIV awareness, and AIDS treatment.

Table 3.8: Responses to Question 8

Subjects were asked if they had ever noticed anyone in the community giving health information to people.			
Yes and No answers	Yes	No	Didn't know/weren't asked
2	22	33	3

Awareness of HIV Prevention Services

Sixty-eight percent of the responses were negative for the initial question that asked if the subjects knew of any HIV prevention services in the area. However, the interviewers, after realizing that the subjects where probably not identify certain activities with the term “prevention services” began to question the subjects more closely about specific types of activities associated with HIV prevention such as the distribution of free condoms. After instating this specific line of questioning, the rest of the subjects did report awareness of various prevention services in the area. All of the subjects who were asked whether free condoms were distributed in the community stated that they knew of or saw this activity. That nearly unanimous positive response was repeated when they

were asked whether literature about HIV/AIDS was available. Additionally, more than half who were asked whether there were classes available about HIV/AIDS stated that they either knew of such classes or had taken them.

Table 3.9: Responses to Question 9

Subjects were asked if they knew of any HIV or AIDS prevention services in the area.			
	Yes	No	Don't know/weren't asked
Totals	15	41	4

Awareness of Testing

Subjects were asked if they knew where a young adult or teen could go for HIV testing. Eighty- seven percent of them listed one or more locations where they thought HIV testing could be done. Ten percent did not know where they could go for HIV testing, however some of this group also stated that they could find out where to go for testing if they needed to. They cited information sources such as brochures, friends, or the Internet. None of the subjects recommended outreach or community testing.

Table 3.10: Responses to Question 10

If a young adult or teenager wanted to get tested for HIV or AIDS where could they go?					
		Yes	Don't know/weren't asked		
Totals Note: Some subjects listed multiple sites		52	8		
Subjects suggested the following places for testing:					
Health Dept.	Other Clinic (some may have meant the Health Dept.)	Hospital/ER	Campus Clinic	Private Doctor	Other
9	23	12	11	6	4

Outreach Testing for HIV

When asked if they had ever noticed anyone in the community offering HIV tests, sixty percent of the responses were negative. Among the seventeen percent who had noticed HIV testing, the most frequently mentioned testing sites were college campuses rather than out in the general community.

Table 3.11: Responses to Question 11

Subjects were asked whether they had ever noticed anyone in the community offering HIV tests to people.			
Yes and No type answers	Yes	No	Don't know/weren't asked
3	10	36	11

General Barriers to HIV Testing

Ten percent of the subjects did not list reasons, or stated that there were no reasons why young adults or teenagers would not want to be tested for HIV or AIDS. Among the ninety percent who did list reasons, the most common reason by far was fear. However, they stated that fear in different terms. Those terms are listed here in descending order of frequency: fear of knowing the results, fear of someone finding out, and suspecting they already have HIV. Also mentioned were elements of shame/embarrassment, denial/not wanting to know, and concerns over privacy- not wanting anyone else to know that they are being tested for HIV.

Table 3.12: Responses to Question 12

Respondents were asked to offer reasons why young adults or teenagers might not want to be tested for HIV or AIDS.		
	Listed reasons	No reasons
Totals	54	6

Barriers to Outreach Testing

The subjects were asked not only whether they thought people would take an HIV test if it were offered for free in the community, but also whether they themselves would take the test. Sixty percent of the responses were positive; the subjects thought that people would take the test if it were offered. Only three of these qualified their answer by adding that only some or a few would take the test. Among the thirty-three percent of subjects who thought that people would *not* take the test, the reason most frequently cited was the issue of privacy - not wanting to be seen taking the test. Additionally, 26 stated that they themselves would take the test whether they thought others would or not.

Table 3.13: Responses to Question 13

Subjects were asked a two-part question. 1) If someone came here to offer HIV testing (for free) did they think that people would be willing to take an HIV test? 2) Would they themselves take the test?			
Yes and No answers	Yes	No	Would you?
1 Note: 3 didn't answer	36 3 of these were qualified	20	26

Tested Self Report

When asked whether they themselves had ever been tested (without revealing any test results), the responses were divided nearly equally between those who have been tested (forty-three percent) and those who have not been tested (forty-five percent). Of those who answered yes, only two subjects stated that they had been tested on more than one occasion.

Table 3.14: Responses to Question 14

Subjects were asked, without revealing results, if they had ever been tested			
	Yes	No	Didn't answer
Totals	26	27	7

Personal Barriers to HIV Testing

When asked whether they had any reasons for not wanting to be tested, the most frequent response was that there was nothing preventing them from getting tested. Following that, the second most frequent response were variations of statements indicating a belief that they themselves had no need to be tested. This belief was cited in many forms demonstrating varying degrees of safety/vulnerability and knowledge of HIV. These reasons are listed in the order of frequency of response: never having been sexually active, not currently involved in risk behaviors, not thinking that they have it, and getting married soon.

Table 3.15: Responses to Question 15

Subjects were asked if they had any reasons why they would not want to be tested.							
	<u>Other</u>	Believe they have no need	Dislike needles	Testing booths aren't real medical care	Haven't gotten around to it	Not wanting to know	No reasons/no answer
Totals	3	12	1	1	1	1	41

Response to Health Information in Community

When asked whether they would be interested in receiving health care information if they noticed someone in the community offering it, eighty-five percent of the subjects responded positively and only ten percent stated that they would not want the information if offered. The subjects stated that they would be interested, or that they would make an effort to take the health information if it were being offered. Some of the reasons for doing so were: everyone needs knowledge, depends on the subject of the information, and wanting to give the information to their friends. Those who said that they were not interested thought that they were not at risk, or that they feel well educated already, or that they could get the information later if they needed it.

When asked for their suggestions on how we might better reach young adults and teens with health care messages, the greatest number of suggestions centered around offering incentives to attract people to information booths or fairs. Incentives mentioned were: food, music, phone cards, and condoms. Greater advertising was also suggested, especially having radio stations attract people to HIV testing events, or information fairs. In one case it was suggested that signs that say AIDS would scare people off. It would be better to attract people with free food and then give them messages without labeling the event. It was also suggested by two subjects that the materials such as brochures could be improved by gearing them more towards a youthful audience.

Table 3.16: Response to Question 16

Subjects were asked if they would be interested in receiving health care information if they noticed someone in the community offering it.			
	Yes	No	Don't know/weren't asked
Total	51	6	3

Recommendations for Location of Services

When asked for their recommendations for locating health care services, only five subjects did not have suggestions; with one subject stating that they thought the current locations were fine. The remaining subjects made the following suggestions. Some listed more than one location. However, all of the recommendations revolved around two central ideas 1) placing health care in proximity to centers of youth activity 2) making health care centers available by keeping them within walking distance.

Table 3.17: Responses to Question 17

Subjects were asked where they thought health care services should be located to make them more accessible to young adults or teenagers.									
	Neighborhoods	Schools/campus	Community	Parks	Mall	Near Library	Near Clubs	Where they are	Other
Totals	10	29	5	1	6	2	2	1	10

Personal Experience as a Barrier

The interviewees were asked whether they had ever had any bad experiences, or knew of anyone who had had bad experiences with health care. Seventy percent had never heard of anyone having a bad experience. Of the twenty-five percent who reported knowing of bad experience with health care, the types of difficulties mentioned are listed in descending order of frequency: people not getting health care because they couldn't afford it or because their insurance wasn't accepted by a particular provider, misdiagnosis/or incorrect test results, waiting a long time to be seen, poor communication from the provider, too much paperwork to do when you are sick. Very few suggestions were made as to what could have made a difference. These suggestions included, in descending order of frequency: being listened to/paid attention to by the provider, greater

efficiency/checking work, having things arranged before getting sick so as not to have to do paperwork or be turned down.

Table 3.18: Responses to Question 18

Subjects were asked whether they had ever had any bad experiences with health care, to describe these experiences without naming any particular doctor or facility, and to suggest what might have made a difference.			
	Yes	No	Didn't answer/weren't asked
Totals	15	42	3

Recommendations for Increasing Access

More than ninety percent of the subjects had one or more suggestions when they were asked what they thought could be done to make health care more accessible to young adults or teenagers. The most frequently cited suggestion was advertising, however this central theme was paired with many specific ways to increase the advertisement of health care or health care facilities. These ideas follow in order of frequency: television advertisements that tell how to get health care, where to go for it, or how to get insurance, more health care advertisements during “black shows”, putting up signs to direct people to clinics, more information on the internet, more health fairs, and health fairs held in conjunction with job fairs to reach more people at a time.

Table 3.19: Responses to Question 19

Subjects were asked what they thought could be done to make health care more accessible to young adults or teenagers.									
	Information about getting Insurance	Advertising	Provide Transportation	Providers come to locations/schools and talk	Lower cost or free	Longer hours	More locations	Less paperwork	Better customer service/more workers
Totals	3	19	4	7	11	5	5	3	3

Other Barriers to Care

When asked if they could give any other reasons why young adults or teens might not get health care, many of the responses reflected reasons that had already been mentioned during the interview, however, the most frequent new reason stated was that of young adult or teen attitude. Comments included: they feel invincible; they deny that they are sick, or they don't take health care seriously. This response was given in conjunction with another reason that of "bad attitude" towards health care. "Bad attitude" included: not liking doctors, or not wanting to go to hospitals. These responses that centered on attitude serve to underscore how much this impacts the decision making process of young adults when they need health care.

Table 3.20

Subjects were asked if they could think of any other reasons why young adults or teenagers might not get health care.

Home-less	Invincible, Denial, Don't take seriously	No further reasons or didn't answer	Scared	Cost	No time	Trans.	Bad attitude towards Health Care	Don't know about Health Care	Don't qualify/not insurance
1	12	18	13	16	5	2	6	6	2

Summary: Young Adults

Two thirds of the interviewees were African American. Of all of the interviewees twenty-eight percent reportedly knew someone with HIV and sixty-three percent did not.

When asked what they would do if they found out if they were HIV+, seventy percent reportedly would seek medical care. However, sixty percent thought people might also ignore it, deny it or hide it. Others reported that people might become depressed, try to ignore it, commit suicide, become very scared, angry or, perhaps, spread the disease.

One interviewee noted that people who found out they had HIV would “not want to rock the boat.” One interviewee said they might be scared to find out, so it would be like “out of mind out of sight or out of sight out of mind.” Another interviewee explained,

“I think they probably keep it hush hush and don’t really tell many people. I think some of ‘em are still sleeping with people. Doing the same thing.”

And, another interviewee noted,

“I have heard of incidences where, you know, guys, and females also, will just go around, knowing they have the disease, and still sleep and have unprotected sex. I don’t know if it is on purpose, or just trying to (not) acknowledge it, or just trying to, you know, deny it.”

Fifty five percent reported that they knew where to go to get health care. Forty three percent reported that they thought that they could get HIV care in the community and forty two percent reported that health care was easy to obtain. Many reported that if they needed it help could be found. It appeared that many had never needed help. For those who thought it might be difficult to find health care, the problems would be cost, lack of

insurance and not having a job that provides health insurance. When asked if it is easy to get health care one interviewee said,

“ . . . the county really sucks. They’ll give you an appointment for like, four months in advance, but if you have something wrong with you today, you are out of luck. You need some insurance.”

When asked what they thought young adults would do if they perceived they would not qualify for health care, seventy three percent reported they would not seek care. Eighty five percent of the young adults did not think they could afford health care on their own.

Seventy two percent reported that embarrassment would not be a barrier to seeking care. However seventy percent also said that they would not seek care IF family would find out, particularly if they needed care for “STDs of HIV.” They would not want to be shunned, estranged, “disowned” or to let people down.

“They would, they would just be embarrassed by it, you know, if they found out they had like an STD of something, then, you know, then you’re embarrassed by that and they think their family’ll disown ‘em and, you know, friends’ll disown ‘em.”

Forty eight percent said that doctors should be trusted to help them if they need care. They said this is a “norm.” They reportedly have been taught to accept doctors. Seventy two percent thought they would be treated with respect if they sought health care. Some feared judgment in the form of negative body language or impersonal treatment by providers.

Several participants reported that transportation is not a barrier to care. However it was not clear that everyone agreed as noted by the statement from the following interviewee,

“If they don’t have transportation . . . then they could call, like, they have like (a bus service) or something, maybe they could come pick them up. “Cause a lot’d feel

embarrassed if they had to ask their friends, you know, 'could you take me to the clinic?' And parents, if you ask them, then you know how parents are, they wanna ask a ton of questions."

Though many of these individuals did not know where they would be required to go to access care. Many reported that they could access care during the currently available hours, but again, many reported that they did not know what hours were currently available. One interviewee noted that health centers may not be open when young people need to go there,

"Well, most young adults are in school or at work and by the time they get off or are able to get over there, the, they're not open."

Seventy seven percent reported that they thought blending health care with substance abuse treatment and mental health care was a good concept as it would put these services together in one location. There was some concern that people might know they had a problem if they were seen going into such a facility.

Fifty five percent had not seen information about HIV/AIDS in the community. Sixty eight percent had not seen prevention services. However, when asked about specifics, many had seen condom distribution and information sharing classes. Over half of the interviewees had known of or attended these classes. Eighty seven percent knew of 1 or more locations for HIV testing, many reporting clinics. Sixty percent knew of HIV testing done by outreach workers. However, ninety percent noted that there were barriers to getting tested. When asked if someone were offering testing in the community one interviewee said,

"Some would (take the test), but I wouldn't say most of them. A lot of times people ignore booths and things."

The barriers to testing included fear of results, fear of someone finding out, shame, embarrassment, denial, etc.

“They’d be scared somebody would see them takin’ an AIDS test. It’d be more like a social thing. Like, they wouldn’t want anybody to see them, wouldn’t want anybody, anybody to know they have an AIDS test ‘cause otherwise they might have somethin’ like AIDS.”

Many thought that outreach worker testing would be good, but only if privacy was clear. Over half had been tested, but only 2 interviewees had been tested two or more times. A few people added that barriers to getting tested or reasons to choose not to be tested included not currently being involved in risky behavior, getting married soon and reporting that they never had sex. One interview gave insights on the dimensions of denial,

“(if there is a possibility that they could be, they’re just in denial, they wouldn’t want to be tested, because they wouldn’t want to face (the) reality. Especially if they’re still, if they got it from being sexually active, because then if you get tested and you’re positive, then you have to go back to all the people and, like, you know, tell them and all them (is) thinkin’ about it. You’d have to go through that.”

Eighty five percent noted that there had been health information available in the community. They suggested that incentives were important to get young people to attend this type of education. These incentives should be in the form of food, music or phone cards. If these events are held they should not be labeled as health or HIV education in any way. Participants also suggested more radio ads and more advertisements on ‘black shows’ would attract youth to such events.

Participants reported that health care should be more accessible. It should be located near centers where youth congregate such as neighborhood locations, schools, campuses, malls, etc. Twenty five percent of interviewees had known of someone who had had a

bad experience when accessing health care. One interviewee explained a situation a female friend had experienced,

“She went to a particular clinic, and um, they told her, you know, come back. She needed a PAP, or whatever. Whll, when she came back, they sent her to another office and gave her a D&C. She had all along she had been getting this stuff in the mail, talkin’ about how she was pregnant, but they, they never told her. You know, they typed her a letter saying she wasn’t pregnant. Turns out she was pregnant and she had (had) a miscarriage.”

Another interviewee noted,

“Yeah, there was actually one time I had a bad experience. Because, I had, um, something was wrong with me and I was sick and they kept telling me that I had an STD and I knew that I didn’t. And they were trying to treat me for one and I didn’t have one and they tested me and it was all negative and the lady, the doctor actually kind of yelled at me and I was in there ‘cause I was telling her no. And she (was) like, listen, you know, and I was like, no. . . And she, you know she was telling my mom, and my mom was all upset with me, and I was like, ‘Mom, I don’t’” . . . so that was pretty bad.”

These experiences were reportedly because of cost, paperwork requirements, lack of insurance or poor diagnosis. One interviewee noted how young adults’ perceptions of health care may be influenced by the media,

“I mean a lot of ‘em watch TV and everything, there’s all these horror stories about the doctors and the treatments and the physicians of the facilities and everything.”

Most gave suggestions on how health care could be more accessible. The most frequently mentioned suggestion was the need to advertise. They suggested TV should be used to explain how to get insurance or to explain how to get low cost or free care, clearly based on the assumption that these things would be available and that people just need to know how to find them. They also suggested the Internet, fairs, and to use more “black shows” to make people aware of health care.

When asked why young adults or teens fail to access care or testing the participants said that these people “feel invincible.” They added that the population does not take health care seriously. They deny there could be anything wrong. They have a “bad attitude.” They also reported that young adults may not be able to afford the cost, may not know about the need for care or they are scared. One interviewee summed it up by saying,

“Because I guess they (some) know that they might have the disease, like, they, they might know that they have HIV or AIDS and just would be afraid to, to know after getting the test that they really, actually have it. I guess, I—it sounds confusing but . . . they know that they have it, but they don’t want to get a test just to confirm that they have it. It’s young people. Young people are . . . that is just how we are.”

CONCLUSIONS and RECOMMENDATIONS

When considered cumulatively, the findings of the interview studies of the Recently Incarcerated, Migrant Workers and Young Adults, reviewed above, illustrate how important it is to engage in stakeholder-focused qualitative research when assessing the needs of overlooked populations. The timing and comparable methodologies of these three studies, along with the input from the focus groups, provide an opportunity to conduct a trustworthy meta-analysis of the insights gained. The themes that emerge and the lessons learned in this multi-layered process are presented in this section.

The themes that emerged from the “thematic analysis” include: stigma and the fear of stigma; desire for confidentiality; the concept of prevention; the importance of understanding culture and context; the interwoven sets of complex issues and needs such as co-morbidities, disengagement, disempowerment, denial, fear, and, frequently, poverty; and barriers to accessing medical care and HIV testing. Both a description of the themes and suggestions of ways to implement changes that could build on the understanding of the themes are reviewed below.

Stigma and the Fear of Stigma

One of the strongest themes that surfaced throughout the meta-analysis of these interview studies was the stigma the participants of these studies perceive is associated with HIV/AIDS and the fear that the stigma could impact them individually or impact their professional efforts. This theme includes many dimensions. Some examples are the following: the general fear of stigma, the fear of being disowned, the fear of letting

people down, the fear of being injured because someone finds out, the fear of rejection for your sexuality, and the embarrassment that would go with any or all of these if someone knew you had HIV/AIDS. The fear of stigma motivates people differently and results in different outcomes, but, it is clearly a very critical motivator of people's behaviors or lack thereof. This is not to say that people reportedly changed their behaviors to avoid the stigma. Rather, they simply went to greater and greater lengths to hide what they do to avoid being stigmatized. In some cases, people reported their peers or clients would rather die than have other people know that they have HIV. In other cases the stigma was associated with other culturally dependent beliefs and norms, such as being black and gay or being a transsexual. The additional stigma apparently just becomes more personal baggage for people already burdened with complex lives. In many cases people reported that hiding the disease or even the desire to be tested for the disease was more important (or more motivating) than the fear of infecting others. Sometimes the fear of infecting others was not even on the radar screen. It is important to investigate how the anger or burnout caused by the living with multiple stigmas could be related to the lack of concern for infecting others.

There has been a large national and international effort to bring this issue of stigma to the forefront (www.kaiserfoundation.org). Many international groups have called for a closer examination of the impact of this stigma and how it contributes to the spread of HIV/AIDS. It is clear that the stigma is associated with discrimination and prejudice in society. The stigma is part of our US cultural milieu. People get stigmatized when they have engaged in behaviors outside of the accepted norms, however, since research rarely

highlights the voice of stakeholders or the impact of culture on public health, the power of stigma in our Florida communities has not been given enough attention.

As the populations at risk become more overlooked and less visible, the potential that fear of stigma is alienating them becomes more and more important. This issue is complicated and conflicting. It plays out very differently in diverse communities. However, even though many people are very sensitive to this issue, understanding how to de-stigmatize people's experiences is a difficult problem to solve. Keeping this concern before policy makers and community decision makers is crucial to getting and keeping people in the system of prevention and care.

Desire for Confidentiality

Another important concern across all populations was the issue of confidentiality. Closely associated with the potential for stigma and discrimination, the desire for confidentiality was a recurring theme. People who might get tested, might engage in prevention activities, get health or medical care, get HIV/AIDS treatment or attempt to prevent the spread of the disease will not do so if they cannot trust the confidentiality of the situation. They will also not go to treatment if they perceive that going to a specific location or attending a special clinic or seeing a specific case manager will remove their perceived sense of confidentiality. The ability to trust in confidentiality is a powerful force that needs to be better understood. The potential impact of creating this trust could go well beyond having a sense of respect for privacy.

The Concept of Prevention

The importance of prevention and early intervention is grounded in the public health literature. It is set of planned and organized activities to prevent the spread of disease

that involves community-level planning for primary, secondary and tertiary approaches. It is also a resource allocation issue and an evaluation concern because prevention is frequently assumed not to work when it may be just poorly evaluated. Another problem is that there is a persistent, shared belief that prevention is ‘education through the sharing of information’ and that provided information will change behavior. This belief is a barrier to effective change.

Major advances have been made in prevention science across all ecological levels. There have also been clear failures, such as the ‘just say no to drugs’ campaign. Examination of the focus group data indicates that prevention is an organizing construct that does not have shared meaning within the broader public health and medical care communities. Clearly the focus group participants highlighted this in their many discussions of the need for prevention, secondary prevention and training.

It was documented in these studies that when prevention of the spread of HIV/AIDS is implemented in the community it is described (or heard) in terms of the behaviors people need to change, or defining the people “at risk.” Population interviewees could describe specific activities though some groups were less familiar with these than others. Some could discuss condom distribution or bleach distributed in their communities or agencies, but they defined these as specific activities related to changing specific behaviors. However, few described these as “prevention” activities. Few, even the educated young adults, seemed to relay an understanding of the concept of population-based prevention. Nor did they seem to comprehend enough about science to understand the relationship between a multi-year impact virus and their own well being.

The fact that the public health community has failed to educate communities about prevention in general is a somewhat disturbing reality, but it is also well documented. For years the public health community has talked about prevention, but what is said and what is heard are apparently different things. And, since many of these individual behaviors or risk factors (which have been the focus of prevention) have had a powerful stigma attached to them, getting the messages across is a complicated process. The prevention efforts may have even contributed to the stigma.

The need to build the capacity of communities to design and participate in prevention was clearly described by the focus group participants, but, to accomplish this, the decision makers or “experts” need to better understand best practice of prevention science, using applied social and behavioral sciences within the context of the lives of the community to which it is being applied. Communities would need to be empowered to contribute to the organized prevention approach, facilitated by the public health community.

These interviews and focus groups produced a plethora of suggestions for prevention and intervention methods. The focus groups produced a clear understanding of the barriers to the perceived need for community empowerment focused prevention. Clearly strategies need to be developed to capitalize on and enhance the capacity of these groups. Though experts have asked their opinions before, without a clearer understanding of what community prevention is and what it can do community participants cannot effectively contribute.

The importance of understanding culture and context

Recent literature has reported that when needs are assessed for the populations impacted by the HIV/AIDS epidemic, they should be characterized as evolving needs. This was clearly demonstrated in the analysis of the interviews of these populations and the focus groups. Perhaps the strongest and most important theme that emerged from the data analysis across all three selected population groups and the focus groups is how very different these groups are both within the individual population groups and between the selected population groups.

Within the groups the differences were sometimes documented as gender based, age based, race based or ethnicity based. For example, there was a great deal of similarity in the responses of women in the migrant worker interviews. Many of their responses were grounded in strong cultural traditions brought with them from their countries. They demonstrated a great deal more consistency in responses than any other group. However, this was not the case with the other populations.

The many differences between the groups seemed overwhelming. Their styles of communication, the knowledge bases from which they worked, their perceptions of health and medical care, their ways of looking at the world and their expectations were all strikingly different. For this reason one of the most important things that can be learned from this theme is that there will be contrasts both within and between populations. Because there are contrasts between and within groups of people, the assumptions, research methods and best practices we employ will be most effective if validated by or derived from an accurate understanding of the specific populations or individuals of concern though generalized assumptions that have been made about populations. It is not

enough to say that the importance of culture and context is a very central finding of this study. It is not enough to avoid development of stereotypes about people or to avoid reducing this information to “risk factors” to count as a way to identify these populations. Drawing only these conclusions will cause us to continue to miss the valuable information that could make a difference in the effectiveness of our efforts. It is also not enough to say that public health practitioners and outreach workers must be culturally competent if they are working with these populations. Rather, they need the skills that will enable them to continually learn about culture to remain competent.

The message from these studies is that if we do not keep all of our focus on the constantly changing context and the norms and beliefs of the people in the communities we will certainly fail in our efforts to stop this evolving epidemic. It will be helpful if ongoing assessments and evaluations are grounded in both qualitative research and quantitative research methods to ensure that we continually highlight people’s experiences as we document change. In addition, practitioners and providers need the skill to assess and highlight assets as well as needs so that we have the ability to capitalize on community strengths as we engage them in development and evaluation of prevention and care. Another strategy that has been positively evaluated is the use of peer educators and lay health advisors. These programs have been successful in prisons, with college youth and with culturally diverse populations.

Interwoven sets of complex issues and needs: Co-morbidities, disengagement, disempowerment, denial, fear, and, frequently, poverty.

Each of the three selected populations displayed an array of complex realities. Ironically, they were the most alike in that they were all extremely different. They did not share the same constellation of substance abuse problems (though most groups had substance abuse issues). They did not share the same types of fear of being diagnosed with HIV (though all groups described different reasons for fear). All three selected groups did display an assortment of interwoven, complicated problems. Some of these problems were behavioral, some were social, and some issues were environmental. All of these problems were connected.

The focus group participants clearly documented the complexity of the issues, noting that drugs, basic survival concerns and other realities greatly complicate efforts to control the epidemic. As suggested by the ecological model, when the findings of these studies are considered from an ecological perspective it is possible to find various intrapersonal, interpersonal, community, organizational and policy-related problems that synergistically impact these populations and the systems of care and prevention. However, the constellation of issues would differ for each individual and will clearly change over time (Brownson, et. al. 2003).

The message from this theme is that public health practitioners and health care providers will be most successful if they keep their focus on a broad spectrum of possible issues. If practitioners and providers apply the ecological model when they plan, develop and implement strategies to get care to overlooked populations, they are likely to be more

successful. Approaching these individuals or groups from a biomedical perspective, reducing their concerns to a disease model and emphasizing our own expertise is not likely to prove successful in this evolving epidemic. The need to make this philosophical switch has been well documented elsewhere.

The multifaceted realities of the lives of people and the complexity created by these situations require more integration of care and more emphasis on client-focused resource decision-making. The members of the FCPG, the recently incarcerated individuals, migrant workers and young adults all demonstrated that the current system of care and prevention is organized around the experts and the biomedical model, not around the people and communities of concern. For example, the recently incarcerated study highlighted the complex issues of homosexuality, forced sex, and drug use that may be happening in prisons and does contribute to the spread of HIV/AIDS. It also documented how these issues may be part of the lived experiences of the prisoners when they are released.

It is not just the service or care areas that are of concern. Public health professionals and health care practitioners could use this ecological approach to develop effective advocacy strategies for and with the people and populations impacted by and impacting this epidemic. The ecological approach would provide the most effective format for organizing this activity.

Barriers to accessing medical care and HIV testing

Many of the issues relayed in the earlier findings and themes have an impact on efforts to access medical care. These include the stigma, the embarrassment, the denial, the effect of the co-morbidities, the culture and context of peoples lives, the fear of the loss

of confidentiality, the focus by medical care on the biomedical model of the epidemic, the availability of transportation, the cost or availability of adequate insurance, the sense of invulnerability or that lack of concern for one's own well being, the negative impact of marketing, the lack of depth of understanding of science and the relationship of a virus to well-being, etc.

What is unique about the themes that emerged from the meta-analysis of these studies is the amount of diversity in the ways that these issues synergistically impact the desire to access medical care. No two people conceptualized barriers or availability of medical care in the same way. There seems to be little perceived overlap between client realities and provider assumptions. The focus group participants documented the many missed opportunities as well as some examples of how things could be done differently.

It would be helpful to conceptualize prevention and care as a continuum rather than distinct aspects of the efforts to stop the epidemic. Recent research has shown that an integrated approach that simultaneously implements complementary processes for primary prevention, secondary prevention and early medical intervention, tertiary care and tertiary prevention may have good potential.

Summary of the Research Process

Needs assessments can be proactively designed to cast a "wide net" and involve the multiple stakeholders in the process of highlighting issues (Lincoln and Guba, 1989 FGE). Or, they can be more traditionally developed to measure and compare only "rigidly-defined," preconceived indicators. Assessments can highlight the unexpected, complex, contradictory realities of the lives and communities of vulnerable, overlooked

populations or they can document problems in ways that reinforce the belief systems of experts which serves to reify a narrow, stereotypical viewpoint. Assessments can focus on hearing and seeing through the eyes of the community while simultaneously developing processes to improve the system if they incorporate strategies to include the voices and values of overlooked or unheard populations and the involved stakeholders.

It was the goal of the processes described in this report, the focus groups and the studies of selected populations, to highlight the complexity, contradiction and unexpected realities of overlooked populations. It was also the goal of the processes used to provide the richness and depth of understanding that could provide insights into opportunities to link communities and people to care or that could facilitate policy development and provide opportunities for training and program changes. In addition, this series of studies has provided the format and context for understanding the various components of this Florida HIV/AIDS needs assessment. The recommendations in the final assessment report will be offered within the context of the findings from these studies.

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Appendix A

INTERVIEW SCHEDULE FOR THE FORMERLY INCARCERATED

INTERVIEW SCHEDULE FOR THE FORMERLY INCARCERATED

OBTAIN THE SUBJECT'S PERMISSION BEFORE RECORDING THE INTERVIEW

1) Without telling us any names or identifying anyone, can you tell us if you have ever met or heard of any one who has been in prison who has HIV or AIDS? (PAUSE before offering probes) (Probe: Without identifying them could you classify how close that person is to you, would you say that they were a relative, a friend, an acquaintance, or just someone you heard of?)

2) What do people who have been to prison do if they have HIV/AIDS? (Probes: Would they seek standard medical treatment, try to ignore it, alternative medicines what kinds, or religious/faith healing, or go to a different country?)

3) Do you think that people who have been to prison know where to go for health care? (If yes then ask next question. If no, then proceed to number 6)

4) Where would people who have been to prison go to get general medical treatment in this area?

5) Can they also get medical treatment for HIV/AIDS there? If not then ask where.

6) Is it easy to get health care? Why or why not?

7) Would any of the following things make people who have been in prison decide not to get health care?

a) Thinking that they don't qualify for health care?

b) Feeling embarrassed to go to a health clinic?

c) Being afraid that their family or friends would find out?

- d) Not being treated with respect by the health care providers?**
 - e) Thinking that they couldn't afford health care?**
 - f) Do you think that people who have been in prison would trust the Doctors to help them? Why or Why not?**
 - g) Is it difficult to get to a health care location? What would make it easier?**
 - h) Are the health care centers open when people can/are able go there?**
 - i) Do you think that people who have been to prison would go for health care services if those services were located in a clinic that also gave mental health or substance abuse care?**
- 8) Have you ever noticed anyone coming into this community (area) and giving health information to people?**
- 9) Are there any HIV or AIDS Prevention Services in this area that you know of?**
- 10) If a person wanted to get tested for HIV or AIDS where could they go?**
- 11) Have you ever noticed anyone coming into this community and offering HIV tests to people? (Probes: When? Where? How often?)**
- 12) Are there any reasons why people who have been to prison might not want to be tested? What are they?**
- 13) If someone came here to offer HIV testing (for free) do you think people would be willing to take the test? Would you?**
- 14) Without telling us any test results, could you say whether you have ever been tested?**
- 15) Are there any reasons why you would not want to get tested?**

16) If you noticed someone in the community providing health information or HIV/AIDS prevention information would you be interested?

17) Where do you think health care services should be located to make them more accessible to people who have been to prison?

18) Without naming any names or identifying any particular Dr. or facility could you tell us about any bad experiences anyone you know might have had with health care services? What happened? What do you think could have made a difference?

19) What do you think could be done to make health care more accessible to people who have been to prison?

20) Can you think of any other reasons why people who have been to prison might not get health care?

(BE SURE TO THANK THEM)

Thank you very much for your time, your comments will be very helpful.

Appendix B

INTERVIEW SCHEDULE FOR MIGRANT WORKERS

INTERVIEW SCHEDULE FOR MIGRANT WORKERS

- 1) (Icebreaker) Have you lived in this area/community long?**

- 2) What do you think are the biggest health concerns for this area/community? If HIV/AIDS (El Virus/SIDA) is mentioned then proceed to question #4. If not, then continue.**

- 3) I understand that the problems you mentioned are all important problems, but HIV/AIDS (El Virus/SIDA) didn't seem to be on that list. Is it also a health problem in the community? (If the answer is "yes", then proceed. If the answer is "no", then terminate the interview.) (Probe: Do people ever call HIV or AIDS by other names? What names have you heard this disease called?)**

- 4) Without saying anyone's name could you tell us if you ever met or heard of anyone in this area who has HIV or AIDS? Could you describe how close was that person to you by using these descriptions: a relative, a friend, an acquaintance, or just someone you have heard of?**

- 5) What do you think people would do if they found out they had HIV or AIDS? (Probes: Would they go for standard medical treatment, go to a healer/seek alternative medicine, go to a religious person, or go to a different country, eat special foods?)**

- 6) Do you think that people who work in the fields/farms know where to go for health care? Where do they go?**

- 7) Do you think that they could also get medical treatment for HIV (El Virus) or AIDS (SIDA) there? (Probe: If not there then ask: Where can they get medical treatment for HIV/AIDS?)**

- 8) Is it easy to get health care? Why or why not?**

- 9) Do you think that any reasons on the following list would make people decide not to get health care?**
- a) Would they think that they can (qualify) have health care?**
 - b) Would they feel embarrassed to go to a health clinic?**
 - c) Do you think that the people at the health clinic would show respect to farm workers?**
 - d) Do you think that language might be a problem? (Probe: If so, what language would be good for health care workers use with people in this area?)**
 - e) Does it cost a lot of money to get health care?**
 - f) Do you think that people trust the Doctors to help them? (Probes: Why or Why not?)**
 - g) Is it difficult or easy to get to a health care place?**
 - h) Are the health care places open when people can/are able go there?**
 - i) Is there anything else that would prevent people from seeking health care?**
- 10) Without naming any patients or doctors or specific programs, could you describe any bad experiences that anyone in this community has had with health care? What do you think could have been done to make that a better experience for the person seeking health care?**
- 11) Have you ever noticed anyone coming into this community to give health education information to people?**
- 12) Are there any HIV or AIDS Prevention Services in this area that you know of?**

13) If someone wanted to get tested for HIV or AIDS do you know where could they go?

14) Have you ever noticed anyone coming into this community and offering HIV tests to people? (Probes: When? Where? How often?)

15) If someone came here to offer HIV testing (for free) do you think people would be willing to take the test? (Probes: Why or Why not?)

16) Without telling us any results, could you say whether or not you have you ever been tested for HIV (El Virus)?

17) If you noticed someone giving health education would you be interested?

18) What would be the best way for health care information to reach you? (If no answer, try suggesting the following: People on the street, radio, newspaper, television, flyers, meetings, church, health clinic, videos?)

Thank you very much for your time your comments will be very helpful.

Appendix C

INTERVIEW SCHEDULE FOR YOUNG ADULTS

INTERVIEW SCHEDULE FOR YOUNG ADULTS

1) Without telling us any names or identifying anyone, can you tell us if you have ever met or heard of any young adults or teenagers in this area who have HIV or AIDS? (Probe: Without identifying them could you classify how close that person is to you, would you say that they were a relative, a friend, an acquaintance, or just someone you heard of?)

2) What do you think young adults or teenagers do if they have HIV/AIDS? (Probes: Would they seek standard medical treatment, try to ignore it, alternative medicines (what kind), or religious/faith healing, or go to a different country?)

3) Do you think that young adults or teenagers know where to go for health care? (If yes then ask next question. If no, then proceed to number 6)

4) Where would young adults or teenagers go to get general medical treatment in this area?

5) Can they also get medical treatment for HIV/AIDS there? (Probe: If not then ask: Where?)

6) Is it easy to get health care? (Probes: Why or why not?)

7) Would any of the following things make young adults or teenagers decide not to get health care?

a) Would they think that they don't qualify for health care?

b) Would they feel embarrassed to go to a health clinic?

c) Would they be afraid that their family or friends would find out?

d) Do you think that the care providers at the health clinic would treat them with respect?

- e) **Would young adults or teenagers think they couldn't afford health care?**

- f) **Do you think that young adults and teenagers would trust the Doctors to help them? (Probe: Why or Why not?)**

- g) **Is it difficult to get to a health care location? What would make it easier?**

- h) **Are the health care centers open when young adults or teenagers can/are able go there?**

- i) **Do you think that young adults or teenagers would go for health care services if those services were located in a clinic that also gave mental health or substance abuse care?**

- 8) **Have you ever noticed anyone coming into this community and giving health information to people?**

- 9) **Are there any HIV or AIDS Prevention Services in this area that you know of?**

- 10) **If a young adult or teenager wanted to get tested for HIV or AIDS where could they go?**

- 11) **Have you ever noticed anyone coming into this community and offering HIV tests to people? (Probes: When? Where? How often?)**

- 12) **Are there any reasons why young adults or teenagers might not want to be tested? (Probes: What are they?)**

- 13) **If someone came here to offer HIV testing (for free) do you think people would be willing to take the test? (Probe: Would you?)**

- 14) **Without telling us any test results, could you say whether you have ever been tested?**

- 15) Are there any reasons why you would not want to get tested?**
- 16) If you noticed someone in the community providing health information or HIV/AIDS prevention information would you be interested?**
- 17) Where do you think health care services should be located to make them more accessible to young adults or teenagers?**
- 18) Without naming any names or identifying any particular Dr. or facility could you tell us about any bad experiences anyone you know might have had with health care services? What happened? What do you think could have made a difference?**
- 19) What do you think could be done to make health care more accessible to young adults or teenagers?**
- 20) Can you think of any other reasons why young adults or teenagers might not get health care?**

Thank you very much for your time, your comments will be very helpful.