Focus Group Results

BACKGROUND INFORMATION

Focus group discussions were designed to expand the depth of understanding of Houston-area consumers' needs. Focus group discussions were designed to solicit detailed information to validate, challenge and augment the results from the consumer survey, provider inventory and other sources. When conducted, the focus groups were dynamic, discussions generated ideas, provided detailed insight into motivations and actions, explored attitudes/issues and presented a variety of opinions.

The specific objectives of the Houston EMA focus group discussions were to:

- Identify PLWHA unfulfilled service needs, barriers to care and perceived gaps in services for each priority population targeted in this study;
- Gain insight into PLWHA motivations and behaviors relating to service access, needs and barriers to care;
- Discuss the types of programs that are effective for the each population under study;
- Identify recommended solutions to issues surrounding barriers to care and continuum gaps; and
- Compare providers' perceptions of the system of care, consumer needs and barriers to care with those of consumer participants.

Consideration of both consumer and provider focus groups allowed comparison of attitudes and beliefs of these two groups.

The focus populations were determined by the Joint Data Collection Group using a preliminary report of consumer survey results, published after the first month of consumer survey administration. This report identified key findings and issues for the priority populations under study. The Joint Data Collection Group decided to conduct focus groups with:

- African-American men (heterosexual);
- Men of color who have sex with men;
- White/Anglo men who have sex with men;
- African-American women of childbearing age;
- Homeless PLWHA;
- PLWHA who were recently released from jail/prison (within last 12 months);
- Substance users in recovery for less than 12 months;
- Monolingual Spanish-speaking Latina women;

- Monolingual Spanish-speaking Latino men;
- PLWHA who delayed accessing HIV medical care for one year or more after diagnosis;
- Case management supervisors; and
- Non-Ryan White funded providers.

A focus group of rural residents was considered, but the Joint Data Collection Group felt expanded consumer survey sampling of rural residents via telephone would be preferable. Focus group participants were selected from an application process publicized at agencies serving PLWHA, and both urban and rural consumers were included.

The following focus group discussion analysis presents results and verbatim remarks by service category and when appropriate, by population. It should be noted that since focus groups are *qualitative* research, individual comments are explanatory and should not be generalized to the total population.

AMBULATORY OUTPATIENT MEDICAL CARE

Focus group participants were satisfied with many aspects of HIV medical care services. When asked directly if they were *pleased* or *satisfied* with care received, most participants responded positively. Comments reflecting satisfaction included:

- *The clinic I go to, they give you a psychiatrist…The way that people take care of you, the way they treat you, the wait on seeing the doctor is no more than 30 to 45 minutes, they make sure you get all the tests you need to get.* (Substance Users)
- *Care and respect (makes ___ clinic good).* (Substance Users)
- *They want to help, and every time I go, it's the same thing.* (Homeless)
- *My care now is perfect, especially after I got my Social Security. I can pay for everything now.* (Recently Released)

Nevertheless, areas for improvement were identified. In discussing HIV medical care services, focus group participants' most frequent concerns centered on the level of personal service provided. This was manifest in comments about lack of confidentiality in the environment, staff care and respect and the amount of time spent with physicians and other personnel.

Members of almost all groups discussed the busy clinics and the limited time spent with personnel during visits. Comments included:

- *I expect more from my doctor than being a number.* (White MSM)
- *At doctors offices they have medical assistants, they have PAs (physician*

assistants)—they line you up in a room and the doctor, all he wants to do…high volume… quantity not quality." (White MSM)

- *I just don't like in and out of my doctor, and I think I'm changing because I feel like I'm in a revolving door.* (Homeless)
- *It's so overpopulated, they just run you through like a bingo thing.* (Homeless)
- *We don't get good services. The doctors see so many patients that come through there, they're trying to get you out of there so they can get out. They're tired.* (Substance User)

Similarly, comments were made about the crowded conditions and waiting time in some clinics:

- *Both of the (clinics) are overloaded.* (African-American Men)
- *You have to wait so long there.* (Substance User)
- *You have to pack a lunch to go there.* (Substance User)
- *People like that who are newly diagnosed and they're still working, they don't have time to go down there and sit.* (White MSM)

While some in the white MSM group commented that actions are being taken to improve confidentiality at their medical care providers, comments about confidentiality demonstrate continued consumer concern:

- *Don't talk about someone's lab work with another patient. (White MSM)*
- *My whole thing in switching from ___ (clinic) to ___ (clinic) is confidentiality. When I first went there, they totally blurted out my HIV status. (White MSM)*
- *Now I'm very open about my status, but in 2001, when I first started seeing the doctor, it doesn't matter if you are HIV or not, you need to keep it confidential.* (White MSM)
- *You don't want to go to ___(clinic), 'cause so many people might know you there.* (African-American Women)

Comments reflecting concerns about lack of respect by clinic staff included:

- *I just don't feel like I'm getting the care that I want. I want staff who will care.* (White MSM)

People with a history of substance use discussed physicians' unwillingness to prescribe HIV medication when they were still using street drugs:

- *You've got to put it in your mind that you cannot have drugs and HIV medication…If you're not ready to leave drugs alone, don't do medication.* (African-American Men)
- *I wanted my doctor to look at me, and she said, 'Woo-oo…Don't come back unless you come* back *from a drug program.* (African-American Men)

Lack of trust in medical care, particularly related to medication and clinical trials, was a topic among African-American women:

- *I trust God. I don't trust the medication.* (African-American Women)
- *They trial you on the medication. I won't let them do that.* (African-American Women)
- *I refuse to let them put me on this and try me on that and this here experiment.* (African-American Women)
- *They just gave me the run around. The meds they have me on doesn't help me. I'm constantly in pain.* (African-American Women)
- Y*ou're not going to put me on one of those cocktails and mess up my organs.* (African-American Women)

Similarly, some feel that medication may be withheld due to its cost. One white MSM commented on the need for more genotyping and phenotyping, but stated that it is not performed due to the cost of the tests.

- *My doctor didn't put me on medication because the medication is very costly*… (Substance User)

VISION CARE

African-American men briefly mentioned vision care, stating that a downtown Houston church offers free glasses. No other need for vision care was identified by focus group participants.

CASE MANAGEMENT

Case Management

Many focus group participants, across all population groups, feel their case managers provide excellent and much needed services. Specific positive comments include:

- *I must admit, I have best case manager in the city of Houston. She knows what I need before I need it.* (White MSM)
- *They have worked hard for me. They called and checked to make sure I was doing ok and they are really conscientious.* (White MSM)
- *And he (my case manager) is real good. When I have an appointment or something for the doctor and it's raining, he comes gets me, and takes me and brings me back. When I need vouchers for like Fiesta food, he gives and also my son gets them.* (Homeless)
- *He (my case manager) works for me. He does things like my food stamps, he gets my paperwork signed…There's a lot of stuff my case manager does.* (African-American MSM)

Some PLWHA use their case managers as "safety nets," and like the feeling that

they are available if needed.

- *It's good to stay in touch with them to me in case you are bed ridden, you've already got something set up and you don't have to start from scratch. It's good to have one. At least if you call them every six to eight months that's fine. As long as you're doing ok, and if you say you are having a problem they're very quick about helping you out.* (White MSM)

Case management supervisors also recognize this need:

- *We've been managing that case load and we've been transferring the consumers from open status to monitor status which means they change case managers-- they go from a case manager to a service linkage worker. And the thing is that just as soon as we do that, something happens and we have to kick back the other way … If consumers don't have needs we've been closing their cases, but just as soon as we do, there's a crisis and they realize, "Oh wait a minute. I wasn't ready to be away from that yet." And they call back in. It's a really challenging task to manage that.* (Case Management Supervisors)

During most focus groups, participants identified a clear need for case management for newly diagnosed PLWHA.

- *You're talking about someone who's newly diagnosed, I needed someone to reach out their hand to me.* (African-American Men).
- *What I say is that, you were diagnosed recently, and they are teaching you. When we have many years in this we know how to manage. Later you will not need it.* (Latina Women)

Case Management

The knowledge level of some case managers concerns some focus group participants.

- *I had a case manager and I knew more about the system than she did. She never turned anything in.* (Homeless)
- *I had a case manager who said, "You're the case manager. I'm just going to tell you what's out there, and you are going to have to go and get it.* (Homeless)
- *I'm talking about jumping through hoops, then the case manager, the first one I got was horrible. She made me feel like committing suicide really, and I went in and literally screamed at her and fired her.* (This related to accessing clothing voucher by Homeless)
- *Half the time you find out that you know more than your case manager, but it's good to have someone who it's their job to do that.* (Homeless)
- *Case management needs to have more real resources. I've had case managers where they sit down and talk to you and they ain't got a damn thing to offer*. (African-American Men)

Case managers seek to "empower" consumers, but focus group participants reveal

a fine line between empowerment and being considered unnecessary by the consumers. Comments reveal concerns that case managers are not contributing and should have funding reduced.

- *She's the one that came to the hospital the day I found out I was HIV positive and told me she was going be my social worker. She got me my bus card, but that was it. I'm fighting for myself.* (African-American Women)
- *The case managers ain't trying to help nobody. They say did you talk to ___ (agency)? Did you try ____ (agency)? Did you go to ___ (agency)? That's the problem. They're real bad. Lots of them are bad.* (African-American MSM)
- *First of all, a case manager's job is designed around HIV service needs. If you are getting paid to help with these service needs, you should make these calls. If I call and say, "Look, I got a delinquency notice on my lights. Do you know who can you help me pay my light bill?" and she should say, "How much is your light bill?" and I tell her, and she says, "Hold on just one minute." It shouldn't be, "Don't you have a Blue Book?"* (African-American MSM)

Some of the confusion between "empowerment" and feeling that case managers are not doing their jobs centers around the availability and use of the Blue Book. Some consumers feel that the Blue Book enhances access to services, while others feel that the case manager should be identifying and connecting them with services. A conversation during the African-American men's group typifies this issue:

> Consumer 1: *One biggest thing is that we don't use our Blue Book enough. We depend on other people. Some of us that use our Blue Book can come up with these things.*
>
> Consumer 2: *That's what we have case management for.*
>
> Consumer 1: *No, case managers are supposed to assist you and help you. I say get that Blue Book, go through it front to back, and then tell case management what you need.*

Case Management

Some focus group participants either do not have case managers or do not know who their case managers are:

- *I never felt I needed one but then everybody kept telling me I had to have one. I never understood that.* (White MSM)
- *At the clinic where I go when I need something they ask me, "Who is your case manager?" and I say, "I don't know, they never have told me." " What is it that you need?" "Well, I need this."" Well, then come tomorrow or it takes 48 hours before you can pick up the paper," but I never did see my case manager. I don't know who it might be.* (Latino Men)

Some focus group participants were dissatisfied with case management services received:

- *…after my time expired at that hotel, and I needed an extension, they wouldn't speak up to get me one. So basically I was out on the streets. And I had to stand on my own two feet…when all the while he was supposed to have stabilized me a place to stay. So half these case managers are not doing what they're paid to do, especially at the ___ (agency).* (Recently Released)
- *I mean really and truly these people don't care, some of them don't care, they're there just to get a pay check.* (African-American MSM)
- *They have a lot of money in case management, but that money could be going to other things.* (African-American MSM)

Latinos described difficulty navigating the system with the Blue Book, feeling they need bilingual case managers to make the calls and connections with English-speaking agencies:

- *Well, I have had various case managers and the first two I realized that, yes, they did help me a lot because they did their job the way a case manager should…But the rest that I have had only gave me the Blue Book, and you know that in the Blue Book everything is also in English. And one can call the number, but when they answer, what? I do not understand them and they do not understand me. And so, I need the case manager to translate at least. OK, I can dial the number but who will translate to me?* (Latina Women)
- *My case manager helps me a lot. He always looks for places where they speak Spanish. …He will say what to do, or they call and say that they have a person who does not speak English, is there someone who could help her, and if they say yes, he will tell me. Many people answer in English, but if someone does not ask if they speak Spanish, we will not know.* (Latina Women)

Case managers increasingly feel burdened with paperwork. Case management supervisors discussed the paperwork burden extensively.

- *Thinking about your contact with the client, your contact with the client is to record the client, it's not about the client. The clients feel that, and they don't want to have anything to do with it. That's what you get, and I think you deserve it.* (Case Management Supervisors)

CHILDCARE

Consumer focus group participants did not identify childcare as a need, but case management supervisors did. They mentioned that childcare is well utilized at clinics that currently provide it, and attempts are being made to offer childcare at other primary care sites. Case manager's comments included:

- *When you tell a woman, especially those who are able because they are doing better health wise, so you try to steer them into being self sufficient, getting their*

education, getting their GED or job training. The reality is we have a lot of women with a lot of children. And it's like "Ok, where are we gonna have these children? If we want them to do the things we want them to do to become empowered; I think that's an area that should be looked at.

- *They need daycare for daily things they have to do. They have to go various places to manage their life. They can't drag these children everywhere on the bus with them.*
- *They have to be home in time for children who are getting home from school. In summertime they miss appointments when they're out of school.*

EMERGENCY FINANCIAL ASSISTANCE

Consumer focus group participants did not discuss needs for emergency financial assistance in detail, but it was identified during three of the consumer groups as well as during the case management supervisors group.

A participant in the African-American men's group reported receiving a range of services, including emergency financial assistance, from churches throughout Houston.

- *You have to go mainly to the white churches for that. I go over here on ___ (street). I get light bill paid, they don't pay no luxuries—phone bill or nothing like that—but they pay lights, water, gas, get clothes, get food. Can go downtown and get clothes once in a while. Can get glasses, free dental, check for ID, free medical help for the kids. Then you work your way back up north way up the north side and get a bag of groceries.* (African-American Men)

A Latina woman stated that not having access to a telephone is a barrier to care and an African-American woman stated that her top service priority is finding more financial assistance… for rent and medication.

Case management supervisors confirmed the need for financial assistance:

- *I think more than that we hear they need money for housing, rent and utilities and financial assistance. They just don't know where to go…We are constantly hearing that they need rent and utility assistance; they need financial assistance and they don't know where to go to get it.* (Case Management Supervisors)

FOOD SERVICES

Issues of poverty and the need for food services are critical to poor people living with HIV disease. Since CARE Act funds are to be used as the payer of last resort, those accessing Ryan White services will necessarily be among the most needy

and poorest PLWHA. For these people, food services are often a priority. Consumer focus group participants discussed both their needs for food and perceptions of recent changes in the Ryan White Title I funding for food services.

Consumer *focus* group participants feel that access to food services is being restricted, not only by Ryan White but by other programs. Homeless PLWHA were very concerned about the availability of food.

- *I get $18 per month for food. Without food stamps, I would starve*. (Homeless)
- *They cut my food stamps, … So for me food and my childcare (are most important needs)* (Homeless)
- *…Right now I need immediate food assistance. The check I get, it does take care of my rent and all that, my utilities, I'm just low on my food*. (Homeless)
- *On the application, it specifically asked you about adjudication for felonies. That's why I try to get food from the pantries because I can't get food stamps.* (African-American Women)

Case management supervisors validate consumers' concerns.

- *Food pantries are very much still needed--food stamps are harder to qualify for.* (Case Management Supervisors)
- *…But how do you say, "Okay, you have medications but you don't have adequate food and nutrition?" That is counterproductive*. (Case Management Supervisors)

Consumer focus group participants discussed changes at food pantries. From the discussion, consumers perceive that:

- *Availability of food pantry services will be more restrictive;*
- *Availability of fresh food will also be limited;*
- *Food vouchers will be more prevalent than canned or fresh food; and*
- *A person may tap multiple agencies during the course of a month, with each offering limited* services.

Access to food pantries will be determined by severity of illness with some comments that people must have an AIDS diagnosis to access Ryan White food services.

- *Now, there are many agencies that provide food, but one must look.* (Latino Men)
- *Everybody with HIV is going to the two pantries, and that was confusing at one time. Then it was determined that there was enough food pantries …You can go to almost any food pantry if you meet qualifications and they shouldn't ask you your status.* (African-American Men)

- *My card expires in October but they told me that once it expires they will not renew it. It will be over.* (Latina Women)
- *What we need most are natural foods, than can goods. Another thing, that day I went and the person who is there said you need to select two things from this and this; the can goods were expired. And so I say, it is not his fault, but…we should not eat food in cans that is expired? And so, this is a point that we need a place where they would give us what is considered food. Vegetables, which is what we need most*…(Latina Women)
- *They now have to take a doctor's letter stating that you are diagnosed with AIDS. Otherwise they do not, because that is what happened to me, I took a statement that said positive, but the doctor determines the status by filling-out, I think that says that if you are HIV symptomatic or AIDS, and he writes there if you have AIDS or not.* (Latino Men)
- *One thing is the food pantries (2 agencies mentioned). A lot of people go there because they really absolutely need the food… Social security just going in there telling them you have HIV, you had better have other symptoms, like second stage AIDS before they will give you anything.* (African-American Women)
- *They told me I cannot get anything from the food pantry because I am not sick enough. You have to be so, so sick in order to get food or help from the food pantry.* (African-American women)
- *I was also told that only the persons diagnosed with AIDS, the ones who can't walk, the ones who are ill, who are diagnosed with AIDS*. (Latina Women)

HEALTH EDUCATION & RISK REDUCTION (HE/RR)

Targeted health education and risk reduction programs were suggested by consumer focus group participants. These included programs targeting: recently released, youth and young adults, African-Americans, affected family members, peer counseling for PLWHA. Specifics on these suggestions include:

RECENTLY RELEASED

- *There's a tremendous amount of stress on dudes getting out anyway, and there's dudes coming out with that HIV thing. There's things I can learn, and there's things they can learn. They can pick up information that will be valuable and help them so* they *won't go back—so they can get some help…Everyone that's released, should be required to go to some kind of program where they can get information, have the gold card. That should be mandatory*. (Recently Released)

YOUTH

- *I know so many people out there with this disease, there's some kind of way we've got to get out there to the young people and educate them about this disease. To go in and get tested…There needs to be some kind of way we educate our young people*. (African-American Men)
- *Try to educate our youth more. A lot of them they don't know what they're doing, destroying themselves and a lot of other people.* (Substance Users)

AFRICAN-AMERICANS

- *I would say the same thing. Educating the other people about how, especially blacks. I think blacks are the main people that are terrified of it. White people, they educate themselves on it. Blacks, more education for us, so they don't fear it as much and they don't fear you as much.* (Substance Users)

AFFECTED FAMILY MEMBERS

- *And even working with clients and their families, some of their families are so ignorant about HIV. We've had clients whose families have made them eat off a separate kind of dish, live in a separate quarter of the house, use separate towels, wash their clothes separately, you know just, "Oh no, we have a washing machine, but I have to go to the Laundromat." What? It's so lacking. And it's so horrible for the clients to be experiencing this because their families are ignorant about HIV. We tell them we can talk with the families, we have a volunteer HIV educator that can come in and talk to all of you to help you understand…The HIV education has already been cut as far as funding goes, but we have a volunteer who does it because we know how important it is*. (Case Management Supervisors)

Programs targeting the general population in ways that humanize HIV were also suggested:

- *I think a lot more people need to become a lot more aware of HIV and AIDS, they really do. Just sit down with somebody they don't even know that has it and they will be more educated that way.* (African-American Men)
- *I think they should have more education about it…I think they need to start in the schools, teaching the children about it. They really do, they need to teach them about it.* (Substance Users)

Providing education in a group format, similar to the focus group was suggested.

- *If they had more groups like these (the focus group) where people could come in that didn't have, explain to about this disease, so you can learn about it, so you can go tell other people and people won't be so scared. That would make it a whole lot better.* (Substance Users)

Peer educators are suggested as an effective means to target PLWHA.

- *Educating people, but primarily people that are HIV infected. Just go along telling people. Like me personally on the drug thing, I'd rather talk to somebody that's been on the drug versus someone who's not. Not that I'm ashamed, but I'd rather talk to somebody who's been there.* (Substance Users)

HOUSING ASSISTANCE

Funding for rent and utility assistance is a need identified by consumer focus group participants. It was felt that funding may be available but is difficult to access due to lack of information or difficult processes. Comments about limited information include:

- *They help with rentals. This place pay mortgage, this place pay rent. This one person I know has all this knowledge. By the time he tell us, it's gone. (African-*American Women)
- *No one in our complex knew they were giving people at ___ (agency) help with rent and electricity and all that. It was offered to the but it wasn't offered to our building or anybody in our building. Nobody knew about it. If you offer it to one, you should offer it to all.* (White MSM)

Comments about difficulty in accessing funding included:

- *Funding for* utility *assistance. You have to go through all this red tape in order to get your light bill paid.* (African-American MSM)
- *I mean, rental assistance is very difficult to get. We need it. I mean, rent is 4 or 5 hundred dollars a month. That's our whole social security check. There needs to be more money into housing.* (African-American MSM)
- *I was told to call to ___ (agency) where they have a certain day that they help with rent but when I called at the time that they tell me, and the lines are already busy, and there is no response, and the call-in is only one hour and one is calling the whole hour, and the call never gets through. And also, I called ___ (name), and she said bring me the eviction letter and if you want help for electric bill and everything bring the red-colored bill, which means disconnection. And I will not call the company to ask them to send a letter with an order for disconnection if we pay on time. But we need it to buy other things that we need in order for the money to last to pay for everything. (*Latino Women)

HOUSING SERVICES

Housing is an ongoing problem for PLWHA with members of all groups discussing housing needs African-American women agreed that it is a problem.

- *I think it (Ryan White funding) just needs to keep focusing on the housing. (Recently Released)*

- *It's very difficult to get on the HOPWA funds.* (White MSM)
- *It's (Housing's) a big problem.* (African-American Men)
- *They need housing for single men. They have housing for women with children.* (African-American Men)
- *I've been on the waiting list now since 2002.* (African-American Men)
- *Housing for clients with HIV, not only families, not only for women with children. No housing for HIV couples, whether it is male to male, female to female or male to female.* (African-American MSM)
- *Being diagnosed in '99 I do not qualify for things they have now…I had to say I had a drug problem just to get into ___(housing). I had to do rehab, when I had never taken drugs. To get off the street, I had to lie.* (Homeless)
- *I'm trying to find me a place, a house, a room with my own restroom, a kitchen. So I can go out and take care of my business and come back in.* (Homeless)

Transportation and housing were identified by several members of the non-Ryan White providers as the two most essential needs to link PLWHA with the care system. Case management supervisors also discussed the ongoing need for housing:

- *How do you get a client to focus on their medical needs if they're not eating or they have no shelter? It's hard to say "Let's cut housing so we can put more money into medications" because then they have no place to stay.* (Case Management Supervisors)

Housing Services

Housing needs are so severe, PLWHA are willing to live in undesirable and potentially unhealthy conditions, (leaky pipes and dampness that leads to mold). Members of the African-American MSM group, several of whom live in the same housing complex, described concerns in coming forward with complaints.

- *I've really got to say, there's a lot of plumbing problems…And the reason that we don't complain is that we pay a third of our income. And in that area, you can't get a one bedroom for less than $600 per month. We are scared to death that we will be misplaced and put out, you know what I'm saying? If they shut that place down, we're screwed. They could shut that place down if they come out there. There are no fire extinguishers, no fire alarms.* (African-American MSM)
- *Again, I think people are afraid to really stand up because they are afraid they will shut that place down, that whole place, and where would they go? I have been on the ____ waiting list for four months. Some of these people have no where else to go. So they deal with some plumbing problems.* (African-American MSM)
- *If you call or write, … then they are going tell them that they got a call from one of the tenants and give our name and tell them that we are complaining and that they should take care of it. Tonight, when ____(name) come in, your ass is*

going to be chewed out. You know why? Because you should have gone through the chain of command. They are going to find a way to get rid of you. (African-American MSM)

Opinions on HIV-specific housing units varied. Some participants feel stigmatized living in housing for PLWHA while others advocate developing more.

- *No, no, no (not housing for people with HIV), just housing.* (Homeless)

African-American women, currently living in HIV-specific housing, made the following comments:

- *The only place we have to go is facilities just housed for HIV people. And then it's a wait.* (African-American Women)
- *And then we don't want to live like this. We want to live like everybody else. (Agreement)* (African-American Women)
- *It's like they're trying to separate us from everyone else. To me that's stereotyping. You're pointing a finger at everybody that has HIV. That's not fair.* (African-American Women)
- *We are in yellow apartments, and everybody knows its HIV—(much discussion and agreement) Bright yellow, canary yellow.* (African-American Women)
- *Some of the people across the street from us, said, "Those are those people who are HIV." We can't take our kids to the park.* (African-American Women)
- *I think the housing. Discrimination. You know, just not have it where these is for people with HIV. Have it where we can live just like everybody else and not discriminate against us. More food. And be more supportive of us.* (African-American Women)
- *(Advocating* for *HIV housing) Once you to get financial means, you could pay 30% of your income, or half or whatever. You have to participate in different support groups that will help you better yourself as a person, help you cope with the HIV, you're living with HIV and getting along with your fellow peers. Things like that because some people have a rough time with that kind of re-entry and they're not too fond of, some people that's why they're called cell-bound, they just stay confined to they're cell and they never come out. Now they're out here in society and they have to mingle and they really don't like that. So, it should be based on things, criteria, like, in other words it shouldn't be a flop house.* (Recently Released)

A Houston-based agency provides 30-day temporary housing for recently released PLWHA. Coming from prison, these consumers can immediately access housing, allowing them a window to reorganize their lives. Some focus group participants take advantage of this opportunity while others are unprepared at the end of 30 days and must move into a homeless shelter or other setting. A case management supervisor discussed release to *leave facilities.* She stated,

"The operation feels almost like a minimal security facility, and you can't access the client there...trying to get the client a phone message or a letter can be very difficult.

Homeless shelters are considered unhealthy environments by consumer focus group members who had used them.

- *He gave me a list of the ___ (homeless shelters), contaminated places for, you know, you understand what I'm saying?* (Recently Released)
- *I had to move rather suddenly (due to family situation). And I asked her (case manager) for help and she gave me a list of homeless shelters. I'm not saying I'm all that, but I didn't want to do that. So I said, " Don't you have places where people with HIV can go?" She said she only had shelters…But, like the housing thing, that's my main concern.* (Recently Released)

A new homeless information management system that will include 188 Houston-area housing resources was discussed during the non-Ryan White providers focus group. During the eight months from November 2003 until July 2004, 9,770 people came into the system that have declared homelessness and have back-up documentation of homelessness. A goal of this system is to enhance service access for the Houston-area homeless by reducing the intake process.

It was suggested that McKinney-Vento housing funds from HUD can be complemented by Ryan White funds for support services targeting homeless PLWHA. The following comment about the system's potential is revealing:

- *A number of the agencies are utilizing that (new housing information system) to better serve the clients, improve their ability to fully understand what the client has gone through. We're moving toward a bed reservation system where a person can go into a service organization that does not provide beds, go onto the system and reserve beds at a Salvation Army rather than having to go and wait in line. So it's pretty significant. We believe that over time it's going to change the face of services.* (Non-Ryan White Providers)

LEGAL (ADVOCACY) SERVICES

In three consumer focus groups, participants expressed concern about voicing dissatisfaction with or complaints about services. Latino men specifically stated that a *defender of rights* is needed. This was defined as *someone who takes your complaints and tries to resolve them.* Another member of this group discussed his mother's positive experience when her case manager served as her advocate.

In discussing plumbing and mold problems in an HIV housing unit, African-American MSM discussed reluctance to complain about these potentially unhealthy conditions due to fear of reprisals, including harassment and eviction from the property.

Finally, a member of the white MSM group described harassment when he lodged a complaint against a case manager. Others may not have been as strong in dealing with this situation.

- *I had a case manager call me at home at ten o'clock at night. "How dare you! How dare you go to my supervisor and complain about me." Well I told her supervisor about that and she was fired for that. But that was the only repercussion that I've had like that.* (White MSM)

MEDICATION - HIV

In most cases, consumers did not express concern over access to and payment for HIV medication/antiretrovirals. A number of comments related to the negative aspects of taking them including side effects, adherence, building resistance and having a *life ruled by pills.*

Some consumer focus group participants discussed deliberate decisions to take medication *vacations* while continuing to monitor CD4 and viral load levels. Others have made conscious decisions not to take HIV medication until absolutely necessary. They are in the care system, monitoring their HIV status with laboratory tests.

Both Latina women and Latino men report long waits at the pharmacy to receive medication. The Latina women attribute the wait to a language barrier.

- *I have not had any barriers with the medications… It does require a lot of time waiting at the pharmacy to get your medicine…sometimes it is many hours.* (Latino Men)
- *Well, I try to leave to go out, to go to eat something, some medicines I have to order, and then I see the doctor and then when I return, the medicine is ready, sometimes it take a little too long, but not too long. Until now at least, nothing has happened that I have to say anything, or complain*. (Latino Men)

Finances, even five dollars per prescription, can be a barrier to accessing HIV medication. Consumer focus group participants discussed limiting access to medication or postponing medication due to the co-payment.

- *In the past the medication was totally free when I started. Now…I have to pay five dollars...There are occasions when they tell me that my medications are ready and I do not have enough dollars to go pick them up. I have to wait until I get a check, because I have rent, electricity, telephone, and one does not have it…I sometimes wait two or three weeks before picking up the medication*. (Latino Men)
- *It was easy, but now it's getting to be a little difficult because of the ADAP thing. If they don't have a lot of money they have to go through a lot of trips to get it. If*

you don't have the co-payment. And most people that go to those clinics don't have co-payments. (African-American Men)

Similarly, without adequate insurance, consumers may not take necessary HIV medication.

- *It's been fairly easy to get the medicine thus far. But when I wasn't on the program and I had Medicare, Medicare doesn't pay for any medicine. Medicaid does but Medicare doesn't…I was not getting my medicine because my medicine was over $1000 dollars a month, and I wasn't on the state. I didn't take medicine for a whole year because of that. I've been back on my meds for about almost two months, I would say two months.* (African-American MSM)
- *The difference is, Medicaid, you can get three prescriptions per month. Now, Medicare…it's for the doctor and hospitalization...you won't get you any medication.* (African-American MSM)
- *I am a veteran, so I get it a lot better than some other people. I am on Vet-Care covers all my medication and my medical. I know other people have to buy it, pay for it. I feel for other people that can't get theirs like I can get mine.* (African-American MSM)

Case management supervisors report the cost of HIV medication is a barrier to returning to the workforce.

- *It concerns a lot of them. We had a few clients who talked about they finally got themselves on their feet and they are working again and they are off disability. When they are on disability, they find all kinds of very creative ways of stashing away money because they know when they come off disability they won't have medication.* (Case Management Supervisors)
- *There's a tremendous stress level, I find, that's one of the key things for a lot of the clients. Whether they're getting it or the absence of getting it, the stress* level *is just super high* about *their medications and they're concerned about the future with not being able to get anything.* (Case Management Supervisors)

MEDICATION - NON HIV

Both consumer focus group participants and case management supervisors discussed the need for funding for non-HIV medication. Consumers with limited incomes find the cost of non-HIV medications prohibitive.

- *Those pills (for prostate condition) are 80 bucks a month. I have to decide every month whether I want to eat or pee.* (White MSM)
- *(Five months ago) I had got shingles real bad on one side, and the nurse said it was $400 for one thing of pills. And they wanted me; I was in pain. It's a pain that you can't* describe*. And they said I would have to wait seven days for them*

to fill a script…I ended up paying a hundred dollars just for five pills. (Homeless)

In addition, the first service need identified by case management supervisors was for non-HIV medication. Most group members agreed that these medications are difficult for their clients to access. Comments from this group included:

- *The thing I hear most about are complaints about medication and access to medication, different types of medication—there are problems with medication.*
- *Those persons who need medication they're not necessarily antiretroviral medication--heart medicine, diabetes, symptoms that come after the HIV.*
- *Psychotropics and other disease medications (are needed).*

Non-HIV medication coverage varies significantly between insurers, both consumers and case management supervisors discussed these differences:

- *We've had clients who have literally chewed us out because they only got approved for the three HIV medications*. *The other seven medications for the diabetes, the heart problems, the high cholesterol, the depression, you know all those things that are considered non HIV medications are denied.* (Case Management Supervisors)
- *If they've got Medicare sometimes it takes a while to get that if the Medicare has just been enacted. If they've got Medicaid, it depends on if they have Part A and Part B. That's only three meds in Part A.* (Case Management Supervisors)
- *That's the thing. They have to wait until they've got all the approvals in order to get everything covered, if they've got those things. If they don't have any kind of insurance in place when they come in, it's the luck of the draw.* (Case Management Supervisors)
- *If it's a caused side effect, then you can (get it paid for).* (Recently Released)
- *Well, I have to pay a co-payment for my medication now actually.* (Recently Released)
- I*t's just a bill they have for you even till they die. There'd be times when I did have it when I said I don't just to see if they'll still give it to you.* (Recently Released)
- Another member of the group advised him about a Medicare prescription card that results in significant savings on non-HIV prescriptions. A medication was mentioned that went from $65 to $24.

Two homeless focus group participants report being referred from one clinic to another when Ryan White funds at the first location had *run out.*

MENTAL HEALTH THERAPY AND COUNSELING SERVICES

Consumer focus group participants using mental health therapy and counseling are very satisfied with service quality. They report readily accessible services. Stigma, however, continues to be a barrier to accessing mental health services.

- *Yes. They have helped me a lot. I see a counselor, ___ (name), and he is very good. And we are with the ___ (agency) group as well.* (Latina Women)
- *The most knowledgeable person I have come in contact with was my therapist. He knew everything, so he would kind of direct me professionally. "You might want to think about this, I can't really tell you but…" He would say that's a good agency but, and he would direct me to another agency.* (White MSM)
- *She asks me about my medication, how am I doing, asks about my progress, we talk about drugs, you know, just a one on one. She's my therapist. I'm not embarrassed about that because somebody told me, "Man you need to talk to somebody about the things you're going through." So I started going to see her. I don't mind admitting that I go to see a therapist.* (African-American Men)
- *Mental health is there, but it's not always offered. If you ask for it or talk about it, they'll give it to you, but they have this stigma that if you ask for a psychiatrist you're crazy…It's just that you need to talk to somebody, it's not that you're crazy.* (African-American Men)

Consumer focus group participants discussed the need for mental health therapy and counseling services at critical times. These include at diagnosis and when negative information about disease progression is given, such as when a person progresses from HIV to AIDS:

- *My case manager referred me to a psychologist, when I realized that my cells began to decrease. …all turned out perfect because it helped me. Totally, he made me understand that there was no problem with that, and so I could have 1, 2 or 0 and one can continue living as long as I take care of myself, everything is OK. (Latino Men)*
- *I think that the first two years that we are diagnosed it is important that they give us psychological help, with a therapist, because there has been people who do not know how to get out of this abyss. When they tell us it is an abyss, and it is very difficult, for everyone, very difficult the first year. I believe that the first two years we should be sent to therapy, some help, to get out*. (Latina Women)

The literature indicates that depression is common among PLWHA, consumer focus group participants confirm this.

- *I am going to see Dr. _____, and it has helped quite a bit because I suffered from depression. I could not sleep, it happens to one, like one does not know sleep, and when worrying about family and children, and what will happen tomorrow, when one feels bad, many things come to mind, and the service here… has helped.* (Latino Men)
- *The depression gets to where I don't want to live. If I have to wake up and do*

that deal…It takes me too much to get back. (African-American MSM)

- *That's what gets us started on drug use is depression. We were depressed and we felt we didn't belong and we needed something to make us feel good about ourselves because we didn't feel good about ourselves. When you take drugs you're mostly feeling some kind of pain. If you're depressed you want to get up or if you're mad you want to come down.* (Substance Users)

Both consumers and case management supervisors identify the need for support groups. A variety of groups are needed to meet the needs of a wide range of consumers. One member of the Latino men's group described the benefits of a focus group for affected children after his mother died of AIDS.

- *When my mother died, my brothers, all of us went…(It helped me), in ways that I did not think it would*. (Latino Men)

Participants of the African-American men's focus group expressed a need for a support group and even discussed the benefit of the focus group as a support group.

- *I think they need a lot more support groups like this (focus group and other participants agree)* (African-American Men)
- *I don't know any (support groups)* (African-American Men)
- *I don't know (if there are any ongoing support groups specifically for black men).* (African American Men)
  - *Yep, at ____ (2 agencies) at least they used to. I haven't been over there. They have HIV groups that are all black males. They also have HIV all women, too.* (African-American Men)
  - *You know we have a support group. Every Monday night we have a support group at the HIV program where I live, the apartments where I live...The people there want to know how to live. They want to know about HIV, and you could start comin' to join the groups yourself. They brought some vouchers, we get free haircuts.* (African-American Men)

Case management supervisors identified a need for professionally facilitated support groups targeting women. Comments included:

- *(Among women PLWHA) You've got some serious disclosure issues. Some serious isolation. Low self-esteem. Disclosure. You're really gonna have to get them feeling more empowered. You have to address that.* (Case Management Supervisors)
- *Not that peer facilitation. They need a therapist in there (agreement).* (Case Management Supervisors)
- *(Need support groups for women) Across the board with all degrees of functioning for women. We have some high functioning women who want support groups too and they're just not there.* (Case Management Supervisors)

- *It's hard to get them to that situation (to attend).* (Case Management Supervisors)
- *I think that depending on time and availability and those sorts of things you can probably get more people coming. And I think word of mouth will spread that it feels safe for people coming. And it's safe for the children.* (Case Management Supervisors)
- *We have one that offers daycare…We deal with different topics. We have parenting. We deal with self esteem. We do a job and career workshop to help them because a lot of them are going to lose some of their assistance in various areas, and they're going to learn how to be self-sufficient. Within that framework, because the women are all there in that six-week program, some of them form some type of bonding. It becomes an offshoot support group.* (Case Management Supervisors)

Case management supervisors discussed the need for programs integrating mental health therapy and counseling with substance abuse treatment for patient with dual diagnoses.

- *One point I want to add which is very important, you know, we hear substance abuse and I think a better assessment needs to be done because I have been finding out that people who have substance abuse symptoms, you know, they are using drugs, but what they have missed is maybe the other mental health diagnosis*. (Case Management Supervisors)
- *(Listing programs) It's (mental health services) available. Other than ____ (program) for women, we don't have programs that combine mental health and substance abuse.* (Case Management Supervisors)
- *Right, but she's talking about going to different people for similar or connected issues; if the psychiatrist is doing medication, the therapist is seeing them for counseling, they're going somewhere else for substance abuse detox, it's exhausting to the client is what I'm thinking.* (Case Management)

ORAL HEALTH (DENTAL)

Focus group participants made few comments about dental care services. It was not a "top of mind" service need. A member of the African-American men's group mentioned the accessibility and availability of free dental services in *downtown* Houston. He did not identify any barriers to care.

One homeless focus group participant described red tape as a barrier to access dental services:

- *They told me to go to ___ (clinic) to get my teeth fixed. So I went through all*

those hoops but I missed my appointment and they threw me out of the system. It's too much work. (Homeless)

PREVENTION EDUCATION

- *I feel the same way. Try to educate our youth more. A lot of them they don't know what they're doing, destroying themselves and a lot of other people.* (Substance Users)
- *I think they should have more education about it because... I think they need to start in the schools, teaching the children about it. They really do, they need to teach them about it.* (Case Management Supervisors)
- *Right they die of complications. But still we've got to educate our public. We've got to educate our youth. Our youth are such a fast growing population of HIV right now too. But we have to go across the board because we've also seen rises in our senior citizen population. We've got to do more. We have to do more at the local and national. We just have to do more. We have to approach it in a different way. We have to bombard.* (Case Management Supervisors)
- *We need some rudimentary education for the black community as a whole. The younger black people, they have this hip-hop thing. I went to T-Bob's and a Chili's thing, and they asked some questions that get to the real root—what is it and how you can get it.* (African-American Men)
- *I think a lot more people need to become a lot more aware of HIV and AIDS, they really do. Just sit down with somebody they don't even know that has it and they will be more educated that way. I enjoyed it.* (African-American Men)

SUBSTANCE ABUSE TREATMENT

Views on the availability and accessibility of substance abuse treatment in the Houston region vary. On one hand, consumers in the substance users focus group reported that substance abuse treatment is readily available, while on the other hand, case management supervisors and other consumers feel that treatment options are limited by HIV status and ability to pay. In addition, the need for targeted substance abuse treatment programs was identified.

Substance users in recovery who feel that treatment is accessible *if you want the help* made the following comments:

- *I've had no trouble getting into treatment programs when I wanted the help. There are plenty of treatments places as long as I want them.. I screwed up on my own. I quit going to meetings, I did all the stuff myself.* (Substance Users)
- *There's a lot of options here in Houston. And over my course of trying to get this thing I take advantage, so there's some resources.* (Substance Users)
- *My point is, there's a lot more treatment options if you want the help.*

(Substance Users)

- *A lot of people think it's hard to get help. It's not really hard to get help, you just have to be on foot, go in and talk to people. Explain the situation and what you really are trying to do.* (Substance Users)
- *Treatment is real, real, real accessible in Houston…even if you don't have insurance. Different treatment and different sobriety methods work for different people.* (Substance Users)

Case management supervisors, however, disagreed. When asked *what components of the substance abuse treatment continuum are missing,* with a list of potential services, the response was *all of the above.* Services that were identified as lacking included:

- D*etox has become less and less in the community over the years as part of this campaign. There's not enough inpatient. I don't think there's adequate program to address women's issues. They kind of do a blanket thing. You hear women say, "I've been there, done that, gone through that program. (Agreement)* (Case Management Supervisors)
- *Our facility has done away with the detox and they're mainstreamed into the medicine wards, and I tell you, there is not very much sympathy for them in terms of treatment. "Here they are again… Get them out." It's not, "Get them into treatment, get them some help."* (Case Management Supervisors)
- *And they've done nothing because there are these general programs*. (Case Management Supervisors)

Consumer focus group participants identified a need for substance abuse treatment specifically for PLWHA.

- *___ (organization) has a … unit is for nothing but HIV people and AIDS diagnosed people. And so you get the drug treatment and you get the AIDS awareness and education and all that. The unit is just all your kind of people so you can talk to people about it, so I think that place, they need more places like that*. (African-American Men)
- *There needs to be more place than ___ (agency) and ____ (agency) for chemical dependency for people with HIV. They should be all around the metropolitan area. Both places have waiting lists. Even with the condition of our apartments, there are waiting lists. There needs to be more places for HIV positive people that are unnamed.* (African-American MSM)

In non-HIV specific programs, some PLWHA are unwilling to disclose their status to others in the program.

- *You don't have to tell your peers. You don't have to confess that unless you want to… Some people did (shared their HIV status) but I wasn't ready. I didn't have the confidence. How people treat you is from ignorance.* (Substance Users)

- *I've been in treatment centers where I'm positive and everybody else probably is not, I don't know. So a lot of times I was more focused on who knew I'm positive and I wasn't really focused on the drug treatment* (African-American MSM)

Not all consumers are willing to access HIV-specific substance abuse treatment. Issues of stigma and disclosure are barriers for some of the focus group participants. While most participating in the substance users' group were open about their status, one consumer stated that she would not be interested in HIV-specific treatment, saying "*I'm not part of it. I'm not ready for anybody to know."*

Case management supervisors identified the need to expand substance abuse treatment options for PLWHA as a significant need. Specific suggestions were discussed in detail and comments included:

- *There's a huge substance abuse problem that needs to be more addressed, AA meetings need to be set up somewhere in these clinics, NA meetings these people need to be in, it's like a vicious cycle.* (Case Management Supervisors)
- *Finding an AA or a NA meeting isn't difficult because we've got them in and around the city. But for them to be specific to the HIV population, I think, is more difficult…we find working with substance abuse clients is a lot of times they're very specific about the kind of meeting they want to go to.* (Case Management Supervisors)
- *I come from a TCADA background, and I just want to say that most TCADA funded agencies are not prepared to deal with the complex issues of HIV positive…HIV positive clients in those settings are alienated. I think we need to dedicate funding for a program with a more culturally sensitive HIV positive background.* (Case Management Supervisors)
- *We have a lot of substance abuse programs out in the community, but they're not sensitive to HIV.* (Case Management Supervisors)
- *And that's what we've found…We have a very strong substance abuse program, but the counselors and the people there were not very in tune to the HIV population. So they bring our staff who are experts in HIV to do their inservices on working with someone who is positive. We are needing to work closer together because populations are so similar and yet they feel so uncomfortable with it.* (Case Management Supervisors)
- *HIV positive patients will leave. It's not that they don't want to stay, it's because they don't feel comfortable there.* (Case Management Supervisors)
- *We need something where _____(clinic) is, in a community where there are a lot of Hispanics and blacks that are substance abusers. There's limited substance abuse or no substance abuse treatment for them in that area; for the one's that are HIV positive. It's nothing. They are there everyday, they're stoned out of their heads, they're all glassy eyed. Have something right there,*

catch them right there. (Case Management Supervisors)

Case management supervisors also identified a need for substance abuse treatment for women with children. These comments included:

- *A lot of women who are substance abusers resist going into treatment because they don't want to lose possession of their children… especially if they have younger children. A lot of women, even though they are using, still have a lot of concern in the back of their mind for their children.* (Case Management Supervisors)
- *…With intensive outpatient, there has to be arrangements for the children because the parents think, the moms think, they cannot make adequate arrangements for their kids, they won't do it*. (Case Management Supervisors)

Another need identified by case management supervisors was for programs for patients with dual mental health and substance abuse diagnoses.

- *We hear substance abuse and I think a better assessment needs to be done because I have been finding out that people who have substance abuse symptoms, you know, they are using drugs, but what they have missed is maybe the other mental health diagnosis. Why are people not staying in recovery? When you look at the real view underneath it, there is major mental health stuff going on. Unless you address that issue, the substance abuse problem will come back.* (Case Management Supervisors)
- *If the psychiatrist is doing medication, the therapist is seeing them for counseling, they're going somewhere else for substance abuse detox, it's exhausting to the client is what I'm thinking.* (Case Management Supervisors)

Ability to pay is a barrier to accessing substance abuse treatment and to the type and duration of treatment available. Both consumers and providers made the point that substance abuse treatment is accessible if the client has some type of insurance. Consumers in the substance users group were asked if they had trouble getting into treatment, and those with insurance did not.

- *I had no problems. Like she said as long as you have insurance.* (Substance Users)
- *Most of us have Medicaid so it's easy for us to get in.* (Substance Users)
- *No. (I did not have trouble accessing treatment) I got insurance. I've got Medicare.* (Substance Users)
- *If you have funding, if you are on Medicaid, they will come and find you. (Case Management Super*visors)

A member of the non-Ryan White providers group provides substance abuse treatment services and he made the following comment about the limitations of treatment access based upon ability to pay.

- *And we also have people that come in that are self pay, so our population is pretty broad and diverse. Of course the people that stay longer are the people that have more resources. People that have more resources are able to get medical care and they see their doctor. Somebody in their family has money. They get to their appointments and they do those things. The folks that of course have the greatest need are the people that are without resource and some of them are homeless, they have been homeless prior to coming into treatment. They are usually there seven to ten days, that's what we can usually get…the ___(Medicaid) care providers are pretty good about giving us a little extra time with people, and if they're homeless, helping us out trying to figure out where we can place them.* (Non-Ryan White Providers)

Consumers identified a need for more free drug treatment. A participant in the African-American men's focus group discussed his experiences:

- Consumer: *I've tried getting treatment there in the past and I've been there for days. You sit there for days. You sit there all day for days.*

  Moderator: *So it's easier to get drugs than it is to get treatment?*

  Consumer: *Well not really because if you really want treatment, you go there and you don't get seen in days, they take you to the mission, they have a van, they keep you all night, then they show you back the next morning. Then you spend another day. But you don't have to go back to the streets if you want some help. They'll hold you there, they don't got no bed for you right there, but they'll feed you and they'll take you to this place, and you stay all night, and they'll bring you back the next morning. If you're serious about getting some help, but a lot of people get discouraged by the end of the day, they want to leave*. (African-American Men)
- *I don't know of a place you can go get treatment from if you don't have any money.* (Case Management Supervisors)

TRANSPORTATION

The focus groups were conducted in Houston, and most, if not all, participants live in the city. The case management focus group included one rural case manager who stated that transportation is an ongoing challenge for her clients.

- *Especially in the rural counties we don't have transportation. It's hard to get to appointments, it's hard to get to your job….That's a big problem*. (Case Management Supervisors)

In both the provider focus groups, transportation was discussed as a need.

- *One of our challenges actually is transportation, I mean as simple as that sounds, I don't have an unlimited ability to transport people all over the place*

because I don't have that many staff members. We do the best we can and we help them out, we have bus tokens and all that, but sometimes it's actually a challenge to figure out how we're gonna get, if we have several people that need transportation on the same day, to get them to their clinic or get them to their doctor and get them seen and get them back on their meds have further evaluation. (Non-Ryan White Providers)

- *They've made a decision as to how they want it, that's why we have the bus passes, being provided system wide. And then we have the van and of course with funding being cut they don't catch a whole lot.* (Case Management Supervisors)
- *We do have a big transportation problem, especially sometimes with pregnant women and getting them around. They may be pregnant and they already have children, and they're trying to ride the bus. And they can't do it with their kids.* (Case Management Supervisors)

Providers also identified a need was also identified for bus passes for caregivers of homebound PLWHA.

- *(If) the client is sick, and the client's elderly parent is taking care of the client, but the parent can't get the bus pass even if they're the person who has to go pick up the food or get the medication. We can't give the pass to anyone but the client. It's very complicated.* (Case Management Supervisors)

Based upon consumer focus group participants' descriptions, transportation services have been reduced from previous levels, with most PLWHA receiving free bus passes. These passes, which can be used any time, are considered an excellent service by those who live near bus routes and are well enough to ride the bus, but negative aspects were discussed.

Transportation

- *Metro card is great if you don't have income.* (Homeless)
- *I will say this, I will give Metro their props. With the new trains and with them cutting out the service, the buses no longer go into town, we are definitely on the right track. It definitely is improving and that's what Metro can do. But that's not catered to HIV. (*African-American MSM)
- *Transportation in Houston is horrible, especially for a housebound person, a person with a walker, wheelchair, or cane. I have neuropathy. I am in a walker. (inaudible) There's an agency called _____. They screwed up the whole transportation program due to the fact you had three different services (lists the agencies) ____ was for the rural and part of the inner loop. But now you only have two transportations and that is ____ and ____.* (African-American MSM)
- *They told me that they would not offer transportation because I was not ill, that I was not disabled, that I can walk, but I told them that I do not know how to move around, that I wanted them to take me to the different places so that I would learn how to get around, that they need to teach me. And I have to teach myself*

everything. Like the woman said, it is necessary that there be transportation, because I would get my slacks very wet, and it is far where the Metro passes, and there is much rain and one gets a cold. (Latina women)

Information about "certification" for transportation services varied between groups. Most PLWHA stated that they were given bus passes for a year. One stated that he must be re-certified for van service every three months.

- *I live here in Houston now, but the thing about that is, every three months you have to do a waiver in order to still qualify to ride their transportation. If you're riding because you have high blood pressure, they want to know if you still have high blood pressure. If you are HIV, ain't nothing going to change—if you got the virus, you got the virus.* (African-American MSM)

Van transportation services are limited and used primarily to get patients to and from medical care. Satisfaction levels were mixed for the van transportation services offered. Some PLWHA discussed having to wait to be picked up or not arriving on time. Others were pleased with door-to-door service.

- *___(clinic) you call them three days in advance, they are either two or three hours early and then you have to sit there.* (Homeless)
- *They say be ready between 8:30 and 11 and they may not show up till 2 o'clock. I* was *staying over at the hotel. I have a bad heart, and I was walking almost a mile and a half just to get the bus.* (Homeless)

Case management supervisors and non-Ryan White providers identified the need for additional van service:

- *Transportation with more vans… _____ (agency) needs more drivers.* (Case Management Supervisors)
- *One of the main problems is transportation. How they get to the clinic. A lot of the times a token is not good enough. A pass is not good enough. They need, other than more than that, a lot of them need van transportation and they don't* have *a phone to call to pick them up, or there is this bridge and they can't get to the clinic.* (Non-Ryan White Providers)

Transportation

MetroLift is the service provided by the Houston Metro system for those who are disabled. One recently released participant stated that using MetroLift costs one dollar per trip.

- *I don't use MetroLift because if I go somewhere it costs me a dollar, you have to buy tickets. You gotta stay two hours, sometimes they may be late. When I leave at 8 o clock in the morning, I may go five or six places, so I just use my bus pass.* (Recently Released)

Some consumers stated that they are able to access taxi services, and are very

satisfied with that.

- *That's about the best transportation—_____(Medicaid) gets me _____ (company) Cab*. (Homeless)
- *My case manager calls a cab.* (Homeless)
- *I would love for them to go back and get a contract with a cab company. That nine dollars, you can pay one dollar, that you can go anywhere you want, you don't just have to go to medical appointments because we do want to go to the movies, we do want to go shop. And that deal they had with the taxi cabs, was excellent. It's door to door. It picks you up, it brings you back, wherever you want to go. It was great. I really don't know what happened. But they really need to try to get a contract with that.* (African-American MSM)

Others are unable to use taxi service and wish they could.

- *Cab vouchers are what we need.* (Homeless)

Few consumer focus group participants mentioned a need for gas vouchers. It was also perceived that gas vouchers are no longer available:

- *They can give a gas voucher but they don't do that any more.* (African-American Men)