



**2009 Atlanta EMA Needs Assessment of Mental Health and
Substance Abuse Services for Ryan White Clients**

2010

**Prepared for the Fulton County Government Ryan White Part A Program and the
Metropolitan Atlanta HIV Health Services Planning Council**

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TABLE OF CONTENTS

EXECUTIVE SUMMARY	1
OVERVIEW	1
KEY FINDINGS	2
RECOMMENDATIONS	3
INTRODUCTION	4
METHODOLOGY	4
RESULTS	
Key Informant Interviews	7
Participant Questionnaire	8
Most Important Services	10
Access to Care	15
RECOMMENDATIONS	18
SUMMARY	20
REFERENCES	21
<hr/>	
APPENDICES	23
A: Qualitative Data Coding Chart	A:1
B: IRB Determination Letter	A:2
C: Recruitment Material	A:3
D: Participant Screening Tool	A:4
E: Informed Consent Information Sheet	A:5
F: Participant Questionnaire	A:9
G: Moderator Guides	A:14
H: Key Informant Interview Guide	A:22

EXECUTIVE SUMMARY

The 2009 Atlanta Eligible Metropolitan Area (EMA) Needs Assessment of Mental Health and Substance Abuse Services for Ryan White Clients was conducted by the Center for Applied Research and Evaluation Studies (CARES) at the Southeast AIDS Training and Education Center (SEATEC), Department of Family and Preventive Medicine in the Emory University School of Medicine on behalf of the Fulton County Government Ryan White Part A Program and the Metropolitan Atlanta HIV Health Services Planning Council. The purpose of this project was to identify the needs of important client subpopulations to supplement the 2007-2008 Atlanta EMA HIV Consumer Survey and support the Planning Council's priority setting process.

Thirty-six Ryan White clients, at least 18 years of age, that accessed mental health and/or substance abuse services in the Atlanta EMA during the previous twelve months, participated in this assessment. The primary method of data collection was focus groups. Key informant interviews with community stakeholders were conducted to inform the development of focus group questions. Ryan White client level data provided context for the interpretation of study results. Recommendations are based on study results, a review of established approaches to addressing the service needs of People Living with HIV/AIDS (PLWHA) accessing mental health or substance abuse services, and an understanding of the Ryan White HIV service delivery system in the Atlanta EMA.

OVERVIEW

The lack of integration of mental health, substance abuse, and HIV primary care services can make it difficult for PLWHA with a dual or triple diagnosis to access the care they need (Uldall, Palmer, Whetten & Mellins, 2004). Weaver, Conover, Proescholdbell, Arno, Ang & Ettner, found that only 33% of HIV positive patients with a mental health and substance abuse disorder diagnosis received treatment for both (2008). Furthermore, African Americans and Non-white Hispanics are less likely to access outpatient mental health services or concurrent mental health and substance abuse treatment than their White counterparts, which has been attributed to structural and cultural barriers rather than a lack of desire for treatment (Burnam et al., 2001, Weaver et al., 2008).

PLWHA's ability to cope with their substance abuse and mental health problems and associated stigma significantly impacts their motivation to seek care and adhere to suggested medical

regimens including antiretroviral therapy (Rajabiun et al., 2000, Turner et al. 2001). For example, untreated mental health issues, most commonly depression, are a barrier to obtaining HIV care and mental health treatment (Rajabiun et al., 2000). Lack of mental health treatment can often lead to individuals self medicating with drugs or alcohol, resulting in the development or perpetuation of substance abuse disorder (Rajabiun et al. 2000). Among PLWHA, drug use is more closely associated with lower adherence to antiretroviral therapy than mental health issues, which may be the result of clinicians' unwillingness to start patients who are actively using drugs on an antiretroviral regimen (Tucker et al. 2003). In addition, symptoms of mental illness can be misinterpreted by clinicians as a normal part of HIV disease progression or treatment medications (Leserman, 2008; Sambamoorthi, Walkup, Olfson & Crystal, 2000; Turner et al., 2001).

In the Atlanta EMA, new clients complete a case management intake and assessment to determine if they need referrals for mental health or substance abuse services. In most cases, clients receiving mental health and/or substance abuse treatment are also assigned a case manager who assists in the coordination of treatment and services. According to the 2009-2011 Atlanta EMA Comprehensive HIV Health Services Plan, once clients access either mental health or substance abuse services, they are also linked with additional medical and support services including housing services. The Fulton County Ryan White Part A Program recognizes that mental health and substance abuse are often interconnected and funds agencies that provide care to clients with dual diagnoses.

KEY FINDINGS

Ryan White clients utilizing mental health and substance abuse services in this needs assessment discussed a number of topics associated with their ability to effectively access treatment for HIV, mental health and/or substance abuse. Topics included the most important services received and barriers to accessing services in the Atlanta EMA.

Housing was the greatest need among focus group participants. In the Atlanta EMA, housing assistance is funded primarily through the City of Atlanta's Housing Opportunities for People With AIDS (HOPWA) program. Research shows that stable housing is positively associated with reduced risk behavior and positive health outcomes among PLWHA (HRSA, 2009). Often PLWHA enter into care with complex personal histories of trauma and/or in times of crisis, which contributes to their inability to sustain permanent housing and non-compliance with regimens for their multiple diagnoses (Whetten, Reif, Whetten & Murphy-McMillan, 2008). Some participants

in this assessment cited housing as the most important service that they needed but did not receive in the past year. Other participants stated housing was the most important service they used in the past year.

RECOMMENDATIONS

The following recommendations are suggested to assist the Atlanta EMA more comprehensively support the needs of Ryan White clients accessing mental health and substance abuse treatment services. The recommendations highlighted below are based on focus group results, best practices, and supporting literature. Further details can be found on page 19.

1. Increase services that address mental health and substance abuse dually.
2. Provide cultural competency and motivational interviewing training for case managers.
3. Utilize peer counselors.
4. Design and implement programs for after post-treatment and crisis care.
5. Collaborate with non-Ryan White mental health and substance abuse programs to improve continuity of care.

INTRODUCTION

This needs assessment was conducted by the Center for Applied Research and Evaluation Studies (CARES) at the Southeast AIDS Training and Education Center (SEATEC), Department of Family and Preventive Medicine in the Emory University School of Medicine on behalf of Fulton County Government and the Metropolitan Atlanta HIV Health Services Planning Council.

Primary data include key informant interviews with community stakeholders and four focus groups with 36 HIV positive adults in the Atlanta EMA who received mental health and/or substance abuse services at Ryan White-funded agencies and non-Ryan White-funded agencies. Secondary data such as epidemiological and Ryan White programmatic data provide context for the interpretation of results.

METHODOLOGY

Planning for this needs assessment began in March 2009 at a meeting attended by Fulton County Government and CARES staff. At this meeting, target audiences for data collection and the scope of topics to be covered in the focus groups were determined.

Key informant interviews with community stakeholders were conducted to get input on the design of the focus groups. The data collection protocol was designed to collect perceived service use, service needs, and barriers to receiving needed services among PLWHA accessing mental health and substance abuse treatment services in the Atlanta EMA. Data collection and sampling strategies were guided by epidemiological and program data. CARES staff provided the Assessment Committee of the Metropolitan Atlanta HIV Health Services Planning Council and the Fulton County Government Ryan White Part A Program staff a draft of the key informant interviews, focus group questions, and demographic questions. Their input was incorporated on final versions of the project design including recruitment and focus group questions.

All protocols, recruitment, informed consent materials, and data collection instruments were submitted by CARES staff to the Emory University Institutional Review Board. The project was designated “Non-Research” and was not subject to full review (see Appendix B). A copy of the designation letter from Emory University Institutional Review Board was provided to the Grady Research and Oversight Committee.

Focus Group Design. CARES staff, along with staff from Fulton County Government, examined the survey instruments used in the 2007-2008 consumer survey and the winter 2009

youth and self-managed adult focus groups to develop the questions asked in these focus groups. The instrument was modified to reflect feedback from key community stakeholders in the Atlanta EMA who work closely with PLWHA that utilize the services, Planning Council leadership and PLWHA. A standardized focus group protocol was developed to ensure consistency across groups. Focus group moderators and study staff received a two-part training on moderation skills and administration of the protocol. The demographic questionnaire and focus group questions are found in Appendices G and H.

The focus groups were conducted with a convenience sample of People Living with HIV/AIDS who were at least 18 years old and received mental health or substance abuse services in the last 12 months in the Atlanta EMA. Participants were recruited to participate in four mixed gender focus groups. To ensure reliability, issue specific groups were conducted for clients identifying either mental health or substance abuse as their primary service area. Two groups were conducted for each area, totaling four. Although issue specific groups were conducted, most participants indicated using both mental health and substance abuse services. Each group took approximately two hours to complete. Demographic data were collected using a questionnaire administered to all participants before the start of the group. Once the questionnaires were complete and participants were informed of their rights, they were asked to discuss their perceptions of the importance of available services, satisfaction or dissatisfaction with services, experience with barriers to care, experience accessing care, and suggestions to improve HIV service delivery in the Atlanta EMA.

Data Collection. Data collection took place in August and September 2009. During this time, a total of 36 HIV positive adults volunteered to participate in the four focus groups. To ensure culturally appropriate facilitation, focus groups were conducted by a consultant with an HIV/AIDS mental health and counseling background experienced in mental health crisis. CARES staff acted as note takers. Prior to the start of data collection, staff at the agency where the focus groups were held were provided with recruitment materials describing the needs assessment. At no time during the course of this project were agency staff used to conduct interviews or gather any other forms of data.

All focus groups were voluntary, confidential, conducted in English, and tape recorded with the permission of participants. Consumers were informed that they could refuse to participate in the focus group at any time. Written consent was obtained before the start of each focus group. Participants completed a demographic questionnaire at the beginning of each session. They

were instructed not to provide their names in writing or verbally at any time during the focus group session at any time. Project staff provided participants with a number (1-10). The numbers were used in place of participant's names to sign the informed consent information sheet and when referring to each other during the recorded sessions. Numbers were written on table tents placed in front of each participant and on name tags to remind participants to use these numbers when referring to themselves and others. Tapes were transcribed by a consultant transcriptionist and edited by CARES staff for accuracy. Participants were provided with refreshments and a gift card for their participation.

Data Analysis. Study staff analyzed questionnaire data in SPSS. Qualitative data collected in the focus groups were analyzed using Atlas.ti, a qualitative data analysis software package. Content analysis was used to identify themes and categories of analyses merged from the data rather than testing a hypothesis (Glaser & Strauss 1967). These data were analyzed separately by three staff members. Once the data were coded individually, study staff met to discuss the similarities in codes and came to agreement on core codes. After the codes were finalized, each focus group was then recoded to reflect the core themes identified during coding. The strongest, and most frequently cited, of these themes are highlighted in this report.

Limitations of the Study. While the data presented here provides valuable insight into the needs and priorities of mental health and substance abuse clients in the Atlanta EMA, there are several limitations to the study. In general, findings reflect perceptions of service needs and barriers and are not based on objective measures. Data collection took place at sites where participants were receiving services, which may have resulted in an over-reporting of specific service use. Also, the sample population was obtained through a convenience sample and may not be reflective of epidemiological or client level data available for this population. These limitations should be taken into account when interpreting findings in this report.

RESULTS

During focus group planning, community stakeholders were consulted to assist the project team in identifying the scope of the issues, developing recruitment strategies, and designing questions to assess the needs of clients accessing mental health and/or substance abuse services in the Atlanta EMA. Seven key informants, including service providers, consumers, and representatives of community-based organizations, volunteered to participate in interviews conducted either in person or over the phone. The key informant interview guide is included in Appendix H.

Key Informant Interviews

Overall, key informants perceived the EMA's mental health and substance abuse service delivery system to be effective in engaging and retaining clients in care now more than ever, especially in maintaining the linkages between primary care and substance abuse and mental health services. Even with these improvements to accessibility and quality of services, informants identified areas of concern that still need attention and ideas for improving the system of care. Key informants addressed the importance of improving infrastructure and the provision of continuous care services. Suggestions for improvement included (1) collaborating with non-HIV specific primary care sites to integrate access to mental health services, (2) extending crisis care (3) implementing after-care programs, and (4) increasing the availability of mental health screening. Similarly, with regard to the most important services for consumers in need of substance abuse treatment services, key informants highlighted (1) the necessity for mental health treatment to be offered in tandem with substance abuse treatment (2) increasing the number of beds and safe houses for consumers who need to have drugs cleared from their systems prior to enrolling in treatment or support services (3) comprehensive after treatment care and (4) programs that support clients with families trying to access treatment.

Key informants stated that barriers to addressing these needs were both personal and structural. Personal barriers such as stigma, client perceptions about mental health or substance abuse treatment, cultural perceptions, and competing interests like housing or child care were identified. In addition, structural barriers like lack of cultural competency, required paperwork, limited number of slots for eligible clients, and lack of flexible or non-traditional clinic hours were also cited as barriers to care in the EMA. Suggestions for minimizing or eliminating these barriers for clients included: reorganizing the distribution of funds and other resources given to agencies providing mental health and substance abuse services; fast-tracking clients in

crisis; holding workshops to orient clients to mental health services and to address fears and myths; having client navigators or peer counselors assist clients accessing primary care, mental health, and substance abuse treatment; and training case managers in harm reduction techniques.

Finally, stakeholders were interested in having the results of the focus groups presented to the community at-large and then used to improve current standards focused on mental health and substance abuse treatment services and care in the Atlanta EMA.

Participant Questionnaire

Demographic. Participants were predominantly African American (89%) and male (75%). Females accounted for 25% of the focus group participants and only 6% of all participants were White. No participants identified as Hispanic and all selected English as their preferred language. Participants were slightly more likely to report being heterosexual (56%) than homosexual (44%), and had a mean age of 47.

Table 1. Demographics by Group¹

	MH1	SA1	MH2	SA2	Overall
Female	33%	0%	33%	30%	25%
Male	67%	100%	67%	70%	75%
Black (non-Hispanic)	89%	100%	100%	70%	89%
White (non-Hispanic)	11%	0%	0%	10%	6%
Heterosexual	56%	50%	33%	80%	56%
Homosexual	44%	50%	67%	20%	44%

Socio-Economic. Most participants reported that they rented or owned an apartment or house (61%) at the time of the assessment. Other living arrangements included living in a halfway house or drug treatment program (17%), shelter (11%), hotel or inn (8%), and living with family (3%). The highest level of education reported among participants was a high school diploma/GED (47%), followed by some college (22%), an Associate’s degree (11%), vocational certification (8%), some high school (6%), and a Bachelor’s degree (6%). Overall, most participants reported that they were currently unemployed (44%), with only 17% reporting full or part-time employment. Participants also cited other work (17%), school (8%), and volunteer work (8%) when asked to identify their current employment status.

¹ MH1/SA1 and MH2/SA2 labels represent data collected in mental health/substance abuse focus group 1 or 2 respectively.

Primarily, Medicare (28%) was the most reported health insurance provider among participants followed by Medicaid (25%), other sources such as the Veteran’s Administration (VA) (6%), and private insurance (3%). Other participants reported having no insurance at all (28%).

Table 2. Medical Care Funding Source by Group

	MH1	SA1	MH2	SA2	Overall
Medicaid	44%	25%	22%	20%	25%
Medicare	11%	12%	44%	40%	28%
Private Insurance	0%	0%	11%	0%	3%
None	33%	38%	11%	30%	28%
Other	0%	0%	11%	10%	6%

Medical. The majority of participants in this needs assessment were diagnosed with HIV ten or more years ago (76%). The remaining clients reported learning they were HIV positive more than 5 years ago (11%), less than five years ago (6%), or as recently as less than a year ago (6%). In general, participants in this assessment were more likely to have a case manager (70%) than not (25%). Of those that reported not having a case manager, 19% attributed this to being self-managed and 6% reported other unspecified reasons. Participants rated their health very good (47%), good (31%), fair (11%), and poor (3%). Accordingly, 50% of clients recalled receiving medical attention fewer than five times or not at all in the past 6 months and 44% reported five or more visits. Seventy eight percent of participants reported taking combination antiretroviral drugs. Most reported having the cost of their medications covered by AIDS Drug Assistance Program (ADAP) (31%), while others reported Medicaid (28%), other sources including the VA and Medicare (22%), private insurance (3%), and clinical trials (3%). The majority of clients reported their recent CD4 count as between 200-500 (61%) or over 500 (25%) and that the test was taken within the last three months (89%). Further, clients reported a viral load between undetectable-50 copies/ml (81%) taken within the last three months (89%).

Table 3. Antiretrovirals (ART) by Group

	MH1	SA1	MH2	SA2	Overall
Currently Taking ART	56%	63%	100%	90%	78%
ART Payer Source by Group					
Medicaid	44%	25%	11%	30%	28%
ADAP	22%	50%	33%	20%	31%
Private Insurance	0%	0%	11%	0%	3%
Other	11%	12%	44%	30%	25%

Behavioral. Participants were asked to respond to a number of questions about mental health and substance abuse history before concluding the questionnaire. Fifty-six percent of participants reported being dually diagnosed with a mental health and substance abuse condition. In addition, 58% of consumers indicated that they had been prescribed psychotropic medications in the past year. In the same period, some clients reported having been hospitalized for a mental health related issue (19%), arrested for a drug or alcohol related issue (6%), or hospitalized for a drug/alcohol related issue (6%).

After completing an informed consent sheet and participant questionnaire, focus group moderators led participants through pre-developed questions designed to discuss their experiences using mental health and substance abuse treatment services addressing five primary areas of concern: Service Availability, Utilization, and Access; Satisfaction with Services/Quality of Services; Barriers; Unmet Need (Mental Health and Substance Abuse); Gaps in Services; and Consumer Involvement. In this section, the data highlighted reflect the strongest themes that emerged from all group discussions. Please see the appendices for more detailed information on focus group data and coding.²

Most Important Services

The most important services cited by focus groups participants were housing, primary care, case management, medications, and mental health/substance abuse services. Most participants regarded housing as the most important and the most needed but not received service. Primary care and case management were the most important services used. Generally, participants were satisfied with services and considered them essential components of health maintenance. Both psychotropic medications and antiretrovirals are important to clients and they often accessed multiple payer sources for medication coverage. Finally, mental health and substance abuse services were discussed in detail by all groups as the basis for many of their successes and challenges in receiving HIV care and advocating for themselves.

Housing. Access to safe, clean housing was a major issue for participants who expressed their previous use or current need for housing assistance. Overall, clients felt that if their basic housing needs were not met it is difficult to maintain their HIV treatment, mental stability, and sobriety. Participants stated that large amounts of paperwork, rigid eligibility criteria for

² Data in the appendices include a compilation of responses for questions asked in the focus groups and are not intended to reflect specific individual participant responses.

programs, having children, lack of adequate knowledge about housing programs offered, and turnover of case managers are the major barriers to acquiring stable housing.

“But a lot of people with serious mental health issues that are also dealing with HIV/AIDS, they don’t have the capacity to look for themselves, that’s one of the reasons why they’re priorities. And like I’ve said, it’s also a big issue regarding having children because a lot of housing is geared towards, to be perfectly honest, single adults. They don’t even think about somebody with a child.”

Participants in the mental health groups noted that difficulties in

adhering to antiretroviral and mental health medications and the onset/progression of mental health problems such as depression are linked to lack of housing. Most in this group were also more likely to recall being denied housing earmarked for PLWHA because they were too healthy, had children, or had a current substance abuse issue.

The majority of participants in the substance abuse groups reported past homelessness. Also, they were more likely than those in the mental health groups to be linked to programs and services that provided housing as part of treatment or aftercare. Though substance abuse treatment programs offered the possibility of housing, many found that there were often no beds available or they had to go to local shelters before enrolling in residential treatment. Some participants shared their experiences of trying to get or remain sober while other shelter patrons openly used illegal drugs, which threatened their resolve to remain clean. Participants in all groups who were able to access services through the jail or the judicial system stated receiving more comprehensive linkages to substance abuse treatment programs, mental health care and housing assistance.

Primary Care. Primary care was also discussed as an important service. Overwhelmingly, participants in all groups were satisfied with the care available to them, their providers, and the agencies. Most of the clients in this assessment have been living with HIV for over 10 years

“I wouldn’t be this far if I didn’t go to my doctor on a regular basis because my primary care, which primary is the key word, if something’s going on with me and I’m talking to her.”

and have developed long-lasting relationships with their primary care providers or learned how to effectively advocate for themselves in this relationship to produce positive results.

Satisfaction with provider relationships was dependent on clients feeling comfortable with their primary care physician, having a relationship with their provider, being engaged in treatment decisions, having a provider that advocates on their behalf for medical and support services, and timeliness in provider response to inquiries and clinical procedures. Issues that negated

the positive primary care experience for clients included feelings that their providers were overburdened with large client loads or the lack of a relationship with their provider, but these perspectives were shared by only a few participants.

Case Management. While most participants acknowledged the necessity of having a case manager to assist them in navigating their dual and in some cases triple diagnosis, perceptions of the case manager and mental health or substance abuse client relationships were not positive. Participants considered relationships with case managers as inconsistent, difficult to manage and navigate, and more tense than their primary care provider relationships. Often participants utilized resource books, such as *Key Contacts*, and peers more frequently than a case manager because they felt talked down to or they felt that case managers were more interested in getting the clients to disclose personal information than providing services. Very few clients were satisfied with case management and as a result case managers were viewed more as a requirement rather than an effective and valued relationship in the care system.

Medications. The majority of participants in all groups were taking both antiretroviral and psychotropic medications at the time of the assessment, making access to and payment for medications very important services. Participants who were currently on an antiretroviral

“I was afraid of once the doctor told me I was bipolar, I’m thinking that all these many years I’ve been normal...So I was afraid of taking the meds and making me be another person, making me not be able to function.”

regimen found that access to these medications is important because they felt that medications helped manage their disease and improved their quality of life. Further, participants stated that they were resistant to taking medications for mental health problems when they were initially

prescribed by their provider. They also stated a discomfort with providers that “keep throwing drugs” at them. Participants in the

substance abuse groups, in particular, were less inclined to welcome the idea of taking medications to treat mental health conditions because of their history of addiction and desire to remain chemical free. Overall, participants discussed experiencing severe side effects, feelings of disconnection

“I’ve been to a couple of MSM groups, although I don’t have sex with men...trying to find a support group for straight guys...There’s one, and there’s one person that sits in the group, which is me...There’s nothing “marketed” to us. Every men’s group is MSM...There’s not even just a men’s group, per se...Now, sitting in those support groups, yeah, I have found more commonality than I have differences, but it just becomes kind of frustrating sometimes because even at the conference that I was at, everything was MSM...So I feel stigmatized or discriminated against because it’s like I have to sort of bend to get whatever services.”

from reality, and an inability to carry on daily functions including providing care for their minor children as barriers to adhering to mental health medication regimens. Participants addressed these barriers by sharing these experiences with their providers and trying alternative medications for their conditions. Once a suitable regimen was found, clients expressed feeling comfortable taking the medication, and more confident in maintaining their mental health and sobriety.

Support Groups. Virtually all of the participants had attended at least one support group in the past year. Most clients regularly attended affinity groups, either specific to women or Men who have Sex with Men (MSM), regularly and felt these groups contributed greatly to their HIV care. Participants reported using their time in support groups to connect with other PLWHA to build social networks, and to share information about providers, agencies, new treatments, and services available. Though many regarded support groups as a valued part of their care, other participants felt that the support groups did not provide the kind of support they needed and in some ways decreased their feelings of confidence and self efficacy. In particular, heterosexual men felt that there were no support groups that spoke to their experience and if they were to participate in groups with other men their only choice was to attend a group geared toward MSM. Also, some women felt the tone set in the women’s groups was negative, judgmental, and resembled a clique. This environment at times left them feeling worse emotionally after attending a group.

Mental Health Services. Most participants, regardless of the group they attended, stated that mental health services are important and critical. Generally, participants were satisfied with the mental health services and providers, both therapists and psychiatrists. Although many clients were referred to mental health services through their primary care provider, it is important to note that a number of clients were mandated by court or their substance abuse treatment program to seek care. No matter how they found their way to mental health care, most clients thought these services were essential to their HIV care experience.

Although most clients were satisfied, they shared that the journey to feeling stable and functional with their mental health and care providers was not smooth. Clients reported

“When I look back...I really couldn’t focus and I really couldn’t get stable because my mental health was unstable... I was very agitated, very angry, and I didn’t really trust anybody, I felt alienated from people and fearful...so that’s the reason why I would say mental health first because then that way, it’ll allow you to really accept other issues that you’re dealing with and be able to see them in a different light.”

either a personal history of trauma and/or a family history of mental health disease or substance abuse issues prior to their HIV diagnosis. Some participants attributed HIV diagnosis as a major cornerstone aiding in their desire to seek mental health care. Participants recalled great feelings of mistrust when encountering mental health providers, feeling judged in support groups, conflicts with providers, fearing psychotropic medications, stigma, and denial. The greatest hindrance for clients seeking to receive adequate mental health care was the provider relationship. Participants with negative provider experiences were less likely to disclose in therapy, follow the provider's recommendations, and keep appointments unless mandated by court. These barriers were overcome when they felt confident enough to advocate for themselves with the assigned provider or changed providers until they found the "right fit."

Substance Abuse Treatment. Though many clients accessing substance abuse treatment utilized mental health services, as highlighted in the previous section, treatments for drug or alcohol addiction are very distinct and separate from those administered in mental health care. Generally, clients attempted to access treatment multiple times and participated in various treatment programs before committing to the recovery process. Participants found out about available treatment services through a number of avenues including the corrections system, peers, and their families.

"I was in a facility in Clark County that was probably 12 years ago. So I've kind of weaseled my way out of being in a treatment center. I don't like being told what to do. And I don't like being locked down. I was incarcerated for two years."

At the time of the assessment most of the clients also attended regular Alcoholics Anonymous (AA) and Narcotics Anonymous (NA) meetings and were satisfied with these groups. Participants with experience using

residential treatment facilities preferred programs that were publicly funded, highly structured, and included zero-tolerance policies toward drug and alcohol use during the program. Likewise, participants found that programs that required them to spend time in local shelters prior to enrollment were not conducive to

"I think they [providers], a lot of them believe that if you go into treatment, you're supposed to be well. You're not supposed to go back out and do any drugs. But that's what addicts do. Addicts do drugs."

maintaining sobriety because other shelter patrons were often using substances in their presence with no consequences. Participants were concerned about the lack of universal standards and oversight among public and private treatment programs. Other concerns were fears of being restricted or losing personal freedoms in the treatment center environment, fears of drug or alcohol relapse, and feelings that providers were not culturally competent when

dealing with addicted clients. Participants felt it is important for providers to be non-judgmental and understand that treatment does not always work on first attempts, especially for those mandated to do so by the courts.

Access to Care

Participants discussed their experiences accessing mental health and substance abuse services in detail, chronicling their journeys from the first time they learned about services until the time of the focus group. In doing so, many participants highlighted a number of barriers they encountered when seeking mental health and substance abuse services as well as the issues that arise from being dually and triply diagnosed in the Atlanta EMA.

Barriers. Some of the more common perceived barriers to receiving both mental health and

“Well, there’s nothing, unfortunately, in DeKalb, so anything outside of primary care, you sort of are forced to come to Fulton County.”

substance abuse treatment included excessive paperwork and required documentation needed from clients at intake, the lack of care services offered after office hours, the heavy concentration of mental health and substance abuse services in

Fulton County compared to surrounding counties, lack of care services available to clients after mental health or substance abuse crisis, and feelings of shame and stigma when working with mental health and substance abuse professionals.

Those clients living outside of Fulton County were able to access primary care services from Ryan White facilities relatively easily; however, mental health, substance abuse, and other support services were more difficult to find outside the city of Atlanta. Having to travel into Fulton County was a particularly difficult barrier to overcome for clients without transportation, employment/some form of income, or those without permanent housing. In addition to the disproportionate amount of services located in Fulton County, clients felt that the enrollment and verification processes were arduous and inefficient.

Given that most clients in all groups found themselves accessing care in a state of crisis, the idea of being prepared to provide agencies with picture identification, certain medical tests, and proof of income and residency was difficult to understand. In

“They want you to have a TB test, you have to ID, and an addict barely knows where their shoes are, so picture them having went to the doctor to get a TB test or have any type of ID.”

fact, the only clients prepared to provide the proper documentation necessary to enroll in mental health or substance abuse treatment and care were those recently released from jail or

mandated by the courts. This was an area of great concern for clients because until they are or were able to produce the proper paperwork there is or was no safety net in place to provide interim care. Many clients found this rejection to be a window where they re-engaged in high risk behavior further delaying their entry into mental health or substance abuse treatment services.

Finally, participants stated tension in their relationship with case managers as a barrier to care. Many felt that case managers withheld information about available services leaving them to put together their own service network and navigate the system alone, which was challenging given their mental health and/or substance abuse issues. Coupled with the reality that most treatment

"I lived in California and New York, and when you go there, they had it under one umbrella. You go there [and] you can get everything before you leave. And in Atlanta, it's like a little time consuming you've got to go to different places for different services... And actually, to access a lot of these services here, they require a case manager because a lot of times, people, when you go to certain places, don't really want to deal with you. They'll say, 'where's your case manager?' But the thing is, people don't always get hooked up with a case manager [and] a lot of people have had bad experiences with the case manager, so they don't want to go."

and care facilities require clients to have a case manager before they can access services, many participants found themselves in a very tough position. In order get around this barrier, some participants were willing to try to build better relationships with their case managers or find programs that would take them without their case managers. Unfortunately, the tension in the case manger-client relationship

often left clients feeling more stigmatized, judged, and alienated from services and care.

Multiple Diagnoses All of the participants were coping with the dual diagnoses of either HIV and mental health or HIV and substance abuse, and for many the convergence of issues did not stop there. Most of the clients were experiencing the effect of navigating the Ryan White care system in the EMA with the triple diagnoses of HIV, mental health, and substance abuse. The three major areas of concerns for clients facing triple diagnosis were their own perception about how this shaped their identity, how comfortable they felt communicating with three different providers, and how well all of their providers communicated with each other.

"My first experience was getting help through the court system because they recommended that I get help in lieu of being incarcerated. And it wound up being a pretty good experience, but at that time, I had a lot of issues dealing with mental issues that I couldn't focus. So I wasn't on medication, because I was using. Being bipolar and having a substance abuse problem is a double whammy."

First, the pressure that clients feel internally when learning that they not only have HIV, but also mental health and/or substance abuse problems is a an overwhelming reality to face. Often clients question their self-worth, fear judgment from loved ones, and retreat from treatment instead of pursuing it. Once motivated to seek care, participants reported facing the added hurdle of navigating three seemingly separate systems in order to get the care that they need. Some participants were fortunate enough to be linked to programs that provided for all of their care needs together. Others spent a great deal of time and energy going between appointments with three distinct providers often in different areas of town, which was a barrier for those without high levels of self-efficacy and strong social networks. As highlighted in previous sections, those who accessed services through jail and the court system were more likely to be linked to comprehensive care and more confident in their ability to succeed in treatment and care services.

Communication between clients and providers varied depending on the clients' level of comfort in discussing their care with all of their providers. Generally, clients were more comfortable disclosing information regarding their mental health and substance abuse issues to their primary

"I can say regarding providers, some of them will ask you, some of them won't. But one of the issues that's come up, speaking with a lot of people in the HIV/AIDS community is they're very hesitant about sometimes being open and frank and honest with the provider because they feel like that's going to be a way to spring them out of services."

care providers. Others were more comfortable discussing their HIV disease and substance abuse issues with their therapist and/or psychiatrist. Comfort was based on providers expressing an interest in learning about the client's progression in their other care experiences, feelings of acceptance or not being judged by providers, and how consistently

providers were helping to improve the client's overall health outcomes and not just those in their area of expertise. Similarly, collaborative communication between providers about consumers was discussed with participants. Most clients felt that their primary care and mental health providers were more likely to communicate with each other than with substance abuse providers when coordinating treatment regimens. Often participants were not confident that their mental health and substance abuse providers communicated with each other, and they did prefer more collaboration in this relationship. Overall, participants were more interested in having all of their providers communicate with each other to ensure that they receive the most comprehensive care possible. They were also very willing to sign consent forms to allow such communication

between providers and some saw it as a way to open communication lines between themselves and their providers.

RECOMMENDATIONS

The following recommendations are suggested to assist the Atlanta EMA more fully support the needs of Ryan White clients accessing mental health and/or substance abuse treatment and services:

- 1. Increase services that address mental health and substance abuse dually.** The difficulty of navigating three different systems was a recurring theme in the focus groups. Problems in obtaining services often come from the fact that mental health and substance abuse treatment systems may often be segregated and have separate funding streams. Navigating these two systems is often too difficult for clients and therefore they may not receive adequate care in one or both sectors (Havassy, Alvidrez, & Mericle, 2009). Participants who were able to receive at least two of their treatment options if not all three in the same place were overall happier with their quality of care and more able to maintain their care. Participants emphasized that communication between providers, particularly substance abuse and mental health providers was often lacking, but extremely important.
- 2. Provide cultural competency and motivational interviewing training for case managers.** Participants stated that relationships with case managers were inconsistent and often difficult to manage. Due to these inconsistent relationships participants frequently utilized resource books and peers to search for services. Participants felt disrespected by case managers and expressed the feeling that case managers were typically more interested in the client's personal information than providing services. Most participants were not satisfied with case management and as a result case managers were seemingly viewed more as a requirement rather than an effective and valued relationship in the care system. Motivational interviewing techniques can strengthen the communication between clients and case managers. This approach reinforces the principles of apathy, collaboration, and empowerment to meet the needs of the client (Welch, Rose, & Ernst, 2006). When employing motivational interviewing strategies, perceptions of judgment, paternalism, and disrespect have often been

overcome allowing for a more fruitful professional relationship between clients and care providers (Golin et al., 2007).

- 3. Utilize peer counselors.** Focus group participants expressed difficulty in navigating three separate systems as well as a lack of trust in case managers. Utilizing peer counselors who are familiar with the systems as well as recovering from drug use or mental illness themselves can help to fill this gap in services. Programs utilizing peer counselors who have lived the experience of substance abuse and mental health disorders have been found particularly effective in treating clients suffering from the same diagnosis. Reports from clients participating in programs utilizing peer counselors have expressed increased felt empathy, caring, and relating to the clients situation (O'Campo, Kirst, Schaefer-McDaniel, Firestone, Scott, & McShane, 2009).
- 4. Develop and implement programs for after treatment and crisis care.** Participants expressed concern for the lack of available services after a mental health or substance abuse crisis. Since many participating clients began accessing care in a state of crisis, being able to provide all the necessary documents was difficult for them. In addition participants expressed a greater need for compassion from case workers realizing that recovery does not always work the first time and that clients may need different kinds of aftercare during the beginning stages of recovery.
- 5. Collaborate with non-Ryan White mental health and substance abuse programs to improve continuity of care.** Participants expressed a need for all providers to actively communicate with each other in order to receive the best care possible. Research has demonstrated a positive correlation between integration of systems and client continuity of care. Integration refers to the implementation of interventions that are designed to create continuity of care for clients without altering the existing systems providing services. Allowing for providers and agencies across mental health, recovery, and HIV care service sectors to collaborate and effectively meet all the needs of the clients will improve service delivery and provide greater continuity of care (Durbin, Goering, Streiner, & Pink, 2006).

SUMMARY

For PLWHA, navigating the complexities of HIV, mental health and/or substance abuse care can be a challenging task even for the most informed clients. For consumers with multiple diagnoses, unsuccessful attempts to commit to treatment programs and personal histories of trauma or engagement in the judicial system compounded with the stigma of living with HIV make it very difficult to have all of their needs met in the existing system. The EMA would benefit from more actively engaging Ryan White clients accessing mental health and substance abuse services by incorporating these clients in decision making processes at all levels to ensure the nuances of their experiences are appropriately addressed. Further, more comprehensive services should be made available to those with multiple diagnoses. Upon implementation of recommendations and increased collaboration among clients, providers, agencies, and community stakeholders to address the identified issues and barriers, the gaps in service delivery for triple diagnosed clients may begin to lessen and eventually close.

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APPENDICES

- A. Qualitative Data Coding Chart
- B. IRB Determination Letter
- C. Recruitment Material
- D. Participant Screening Tool
- E. Informed Consent Information Sheet
- F. Participant Questionnaire
- G. Moderator Guide
- H. Key Informant Interview Guide

Appendix A: Qualitative Coding Chart

Code	Sub-code	Examples/ Open codes
Most Important Services	Housing	Homelessness lead to support groups, Housing criteria too restrictive, Housing difficult to access, Housing important, Housing is the priority
	Primary Care	Convenient one stop shop, Providers respectful, Relationship with providers important
	Case Management	Case Managers not helpful, Case managers unavailable, Case manager difficult to access, Case management important, Case manager instability, Case management issues, Conflicts with case managers, Joint substance abuse and mental health issues
	Medications	Individualized medication assessment is Important, Medication is important, Medications are the priority, On too many mental health medications, Psychotropic drugs, Anti-retroviral (ARV) medications
	Support Groups	Lack resources, Info sharing, More peer support groups, Non-MSM (male) support groups
	Mental Health	Attentive therapist helpful, Experiences with agencies, Experiences with mental health providers, Entering mental health service system, Emergency room, Family history, Jail/prison/judicial system, <i>Key Contacts</i> , Counseling at diagnosis critical, Difficult to access, Trauma, Need services outside normal business hours, Another layer of stigma, post treatment care
	Substance Abuse	Early substance abuse intervention important, Education, Entering treatment, Experiences with agencies, Homelessness, Hospitalization, Jail/prison/judicial system, <i>Key Contacts</i> , Lack of residential beds, multiple entry, outreach, post-treatment care
Access to Care Services	Barriers	Atlanta overcrowded, Paperwork, Agencies lacking resources, Difficult accessing services, Difficult dealing with HIV, Disclosure, Discomfort, Dissatisfaction, Fear mental health medications, Financial, Kicked out system, Lack of knowledge at diagnosis, Multiple entry into treatment system
	Multiple Diagnoses	Care coordination, Communication between providers, Doctor informed about mental health, referred to substance abuse treatment, Mental health co-diagnosis, Hospitalization, Navigating the system, Programs don't collaborate

Appendix B: IRB Determination Letter



Institutional Review Board

November 24, 2008

Ira Schwartz, MD
School of Medicine, Department of Family Medicine
113D WHSCAB

RE: Determination: No IRB Review Required
IRB00012813; Metropolitan Atlanta HIV Needs Assessment Focus Groups
PI: Ira Schwartz, MD

Dear Dr. Schwartz:

Thank you for requesting a determination from our office about the above-referenced project. Based on our review of the materials you provided, we have determined that it does not require IRB review because it does not meet the definition of "research" involving human subjects or the definition of "clinical investigation" as set forth in Emory policies and procedures and federal rules, if applicable. Specifically, in this project, you will be conducting a needs assessment for HIV services in Fulton County, with the results of that assessment being delivered to the County for service improvement purposes.

This determination could be affected by substantive changes in the main aims of the study. If the project changes in any substantive way, please contact our office for clarification.

Thank you for consulting the IRB.

Sincerely,

Rebecca Rousselle, CIP
Lead Research Protocol Analyst
This letter has been digitally signed

Appendix C: Recruitment Material

Stand Up and Be Counted!

Let Your Voice be Heard!

We Need to Hear From You!

The Southeast AIDS Training and Education Center (SEATEC) at Emory University is looking for volunteers who have used **Mental Health or Substance Abuse** services in the Atlanta area in the past year to participate in a focus group

You may be eligible to participate in a focus group if you are:

- At least 18 years old
- HIV positive

Participation is voluntary. You will not be asked to give your name. Each focus group takes about 2 hours. Refreshments will be provided.

Mental Health services may also be called counseling, therapy, or group

Substance Abuse services may also be called detox, AA or NA meetings, or treatment



If you or someone you know would like to participate, or for more information please call:

Yvette M. Wing at (404) 727-1550

* This needs assessment is being conducted on behalf of Fulton County Government and the Metropolitan Atlanta HIV Health Services Planning Council to assist with program planning and improvement and was determined to not need full review by Emory University Institutional Review Board (IRB00012813). For more information feel free to contact Rebecca Culyba, Project Director at (404)727-4909.

Appendix D. Participant Screening Tool

1. How did you hear about the focus group? (What staff member or agency?)

2. Are you 18 years of age or older?

Yes No

If No, thank them for their interest and tell them they are not eligible. If they have questions call 404-727-4909 to speak with Project Director.

3. Are you HIV positive?

Yes No

If No, thank them for their interest and tell them they are not eligible. If they have questions call 404-727-4909 to speak with Project Director.

4. During the last 12 months, have you used mental health services in the Atlanta area?

Yes No

If Yes,

a. On average, how often do you receive these services in a month? _____

b. When was last visit to mental health provider? _____

5. During the last 12 months, have you substance abuse treatment services in the Atlanta area?

Yes No

If No to both #4 and #5, thank them for their interest and tell them they are not eligible. If they have questions call 404-727-4909 to speak with Project Director.

If Yes,

a. On average, how often do you receive these services in a month? _____

b. When was last visit to substance abuse provider? _____

c.

Before we schedule you for a focus group, do you have any questions?

schedule participant for appropriate focus group

Substance Abuse

#2-4 = yes

Agency referral diversity

Mental Health

#2-3, and 5 = yes

Agency referral diversity

If yes to #4 and #5, determination for group based on #4a, 4b and 5a, 5b. Most recent and frequent contact will determine placement whenever possible. Agency referral diversity will be considered.

Appendix E: Informed Consent Information Sheets

Fulton County Mental Health Focus Groups Informed Consent Information Sheet

Introduction/Purpose:

The Southeast AIDS Training and Education Center at Emory University was asked by Fulton County Government to find out about the mental health care needs of people living with HIV/AIDS in the Atlanta area.

In order to collect this information, SEATEC will hold focus groups throughout metro Atlanta with adults living with HIV who have experience with mental health services. Because a focus group is a very formal conversation, we will be asking everyone to answer specific questions to help us find out the mental health service needs of people living with HIV or AIDS. Your input will help decide the HIV care services available for people living with HIV/AIDS in Atlanta.

Procedures:

Each focus group session will have no more than 10 people and last about 2 hours. SEATEC needs your honest answers and asks that you not talk about personal information shared in the groups with anyone. To help protect what you share in the groups, we ask that you do not give your name in the group or sign your name on any of our forms. Instead of using your name, we will give you a participant number to use in the focus group and to sign this form.

Each focus group will be tape-recorded to help us with our notes on what is said in the group. We will be taping the focus groups to help us remember what was said by the whole group. After all of the groups are done, SEATEC will give a report to Fulton County on the mental health needs of HIV positive adults in Atlanta. Your name will not be used in this report. The tapes will be destroyed after we present the report to Fulton County.

Benefits:

Taking part in this needs assessment may not benefit you personally, but your input will affect how money is spent for services for people who are living with HIV/AIDS in Atlanta. There is a chance that during the focus group you could feel uncomfortable, embarrassed, sad, or afraid to answer some of the questions we ask. We will do all that we can to help you with these feelings and you can stop at anytime if you want to. We will ask the group to keep everything we talk about private. If you think you have been hurt by this needs assessment, please call Rebecca Culyba at (404)727-4909.

Voluntary Participation and Withdrawal:

This is a volunteer needs assessment. Your healthcare providers cannot force you to be a part of this focus group. You can agree to be in the focus group and change your mind later or choose not to say anything while in the group. You can also leave the focus group at any time. No one from SEATEC staff or any HIV/AIDS service agencies will treat you differently or punish you in anyway if you decide not to be a part of this needs assessment.

Confidentiality:

We will do everything we can to keep anything that you share in the focus groups confidential or private. To help us, please do not use names when talking to people in the group or to talk about anyone outside of the group. Only the people in the room during the focus group will know what we talk about unless you tell us information that could be harmful to yourself and others. Then we will tell an agency staff person at the end of the session so that you can get help. None of your personal information will be used in the report summary. The tapes will be destroyed after the data is presented to Fulton County or after 2 years.

**Fulton County Mental Health Focus Groups
Informed Consent Information Sheet**

Costs and Compensation:

There will be no cost to you for participating in this needs assessment. We will have food and drink during the focus group and you will get a \$20.00 gift card for participating in the focus group. You will need to pay for your own travel and parking expenses.

You will be provided emergency care if you are injured by participating in this needs assessment.

Contact Persons:

If you have any questions about this needs assessment or believe that taking part in this focus group has harmed you, please contact Rebecca Culyba, project director at 404-727-4909 or rculyba@emory.edu.

You may contact the Emory University Institutional Review Board if you have any questions about your rights as a participant in this needs assessment at (404) 712-0720 or toll free at 1-877-503-9797.

Entitlement of Consent Form and Agreement:

You will receive a copy of this informed consent document. Please put your participant number below to let us know that you have read this form, we have gone over it with you, we have answered all of your questions, and you agree to be in this needs assessment focus group.

**If You Have Read this Document and Agree to Be In This Focus Group,
Please Sign Below:**

Participant Number

Date

Fulton County Substance Abuse Focus Groups Informed Consent Information Sheet

Introduction/Purpose:

The Southeast AIDS Training and Education Center at Emory University was asked by Fulton County Government to find out about the substance abuse care needs of people living with HIV/AIDS in the Atlanta area.

In order to collect this information, SEATEC will hold focus groups throughout metro Atlanta with adults living with HIV who have experience with substance abuse services. Because a focus group is a very formal conversation, we will be asking everyone to answer specific questions to help us find out the substance abuse service needs of people living with HIV or AIDS. Your input will help decide the HIV care services available for people living with HIV/AIDS in Atlanta.

Procedures:

Each focus group session will have no more than 10 people and last about 2 hours. SEATEC needs your honest answers and asks that you not talk about personal information shared in the groups with anyone. To help protect what you share in the groups, we ask that you do not give your name in the group or sign your name on any of our forms. Instead of using your name, we will give you a participant number to use in the focus group and to sign this form.

Each focus group will be tape-recorded to help us with our notes on what is said in the group. We will be taping the focus groups to help us remember what was said by the whole group. After all of the groups are done, SEATEC will give a report to Fulton County on the substance abuse needs of HIV positive adults in Atlanta. Your name will not be used in this report. The tapes will be destroyed after we present the report to Fulton County.

Benefits:

Taking part in this needs assessment may not benefit you personally, but your input will affect how money is spent for services for people who are living with HIV/AIDS in Atlanta. There is a chance that during the focus group you could feel uncomfortable, embarrassed, sad, or afraid to answer some of the questions we ask. We will do all that we can to help you with these feelings and you can stop at anytime if you want to. We will ask the group to keep everything we talk about private. If you think you have been hurt by this needs assessment, please call Rebecca Culyba at (404)727-4909.

Voluntary Participation and Withdrawal:

This is a volunteer needs assessment. Your healthcare providers cannot force you to be a part of this focus group. You can agree to be in the focus group and change your mind later or choose not to say anything while in the group. You can also leave the focus group at any time. No one from SEATEC staff or any HIV/AIDS service agencies will treat you differently or punish you in anyway if you decide not to be a part of this needs assessment.

Confidentiality:

We will do everything we can to keep anything that you share in the focus groups confidential or private. To help us, please do not use names when talking to people in the group or to talk about anyone outside of the group. Only the people in the room during the focus group will know what we talk about unless you tell us information that could be harmful to yourself and others. Then we will tell an agency staff person at the end of the session so that you can get help. None of your personal information will be used in the report summary. The tapes will be destroyed after the data is presented to Fulton County or after 2 years.

**Fulton County Substance Abuse Focus Groups
Informed Consent Information Sheet**

Costs and Compensation:

There will be no cost to you for participating in this needs assessment. We will have food and drink during the focus group and you will get a \$20.00 gift card for participating in the focus group. You will need to pay for your own travel and parking expenses.

You will be provided emergency care if you are injured by participating in this needs assessment.

Contact Persons:

If you have any questions about this needs assessment or believe that taking part in this focus group has harmed you, please contact Rebecca Culyba, project director at 404-727-4909 or rculyba@emory.edu.

You may contact the Emory University Institutional Review Board if you have any questions about your rights as a participant in this needs assessment at (404) 712-0720 or toll free at 1-877-503-9797.

Entitlement of Consent Form and Agreement:

You will receive a copy of this informed consent document. Please put your participant number below to let us know that you have read this form, we have gone over it with you, we have answered all of your questions, and you agree to be in this needs assessment focus group.

**If You Have Read this Document and Agree to Be In This Focus Group,
Please Sign Below:**

Participant Number _____

Date _____

Appendix G: Participant Questionnaire

****Note:** Please be sure to answer all questions below. All the information collected here will be kept strictly confidential. If you feel uncomfortable answering any question, you can leave it blank. Thank you for your participation.

1. Gender

Female

Male

Transgender

2. Age _____

3. Ethnicity & Race (Please answer both parts of this question.)

a. **Ethnicity:** (choose only one)

Hispanic or Latino

Not Hispanic or Latino

b. **Race:** (You may choose more than one.)

American Indian or Alaska Native

Asian

Black or African American

Native Hawaiian or other Pacific Islander

White

Other (Specify) _____

Don't know

4. Where do you live now?

Rent/own house/apartment

Live with family

Staying with friends

Halfway house or drug treatment program

Shelter

On the street - no home

Other (specify) _____

5. What is your current zip code? _____

What is your sexual orientation?

Heterosexual/straight

Gay/Lesbian

Bisexual

Other (specify) _____

6. What language do you speak at home?

English

Spanish

Other (specify) _____

7. Highest level of education completed

8th grade or less

Some high school but didn't graduate

High school diploma or GED

Vocational/ Technical school

Some college

Associate's degree

Bachelor's degree

Graduate/ Professional degree (Master's/Ph.D.)

8. Current employment status (choose all that apply)

Employed full-time

Employed part-time

Unemployed

Student

Volunteer work

Other (specify) _____

9. What type of health insurance do you have?

Medicaid

Medicare

HMO

Private insurance

None

Don't know

10. How long ago did you learn you were HIV- positive?

- Less than 12 months 1 to 4 years
 5 to 9 years 10 years or more

11. In general, how would you rate your overall health?

- Very good Good
 Fair Poor

12. In the last 6 months, how many times have you received medical attention?

- Not at all 1 time 2 to 4 times
 5 to 8 times 9 or more times

13. Are you taking a combination of antiretroviral drugs?

- Yes No Don't know

14. How do you get (cover the cost of) your medications?

- Pay for them myself or get help from family or friends Private insurance
 Medicaid Clinical Trials
 AIDS Drug Assistance Program (ADAP) Other (specify) _____

15. What was your last CD4 count?

- Less than 200 200-500
 Over 500 Don't know

16. When was your last CD4 count taken?

- Within the last 3 months 3-6 months
 More than 6 months ago Don't know

17. What was your last viral load count?

- Undetectable or below 50 Between 50-55,000
 Over 55,000 Don't know

18. When was your last viral load count taken?

- Within the last 3 months 3-6 months
 More than 6 months ago Don't know

19. Do you have a case manager?

- Yes No, I'm self-managed
 No, not self-managed Don't know

20. In the past year, have you been arrested for a drug or alcohol related issue?

- Yes No Don't know

21. In the past year, have you been hospitalized for a drug or alcohol related issue?

- Yes No Don't know

22. In the past year, have you been hospitalized for a mental health related issue?

- Yes No Don't know

23. In the past year, have you been prescribed medications to help with a mental health condition?

Yes

No

Don't know

24. Have you ever been diagnosed with both a mental health condition and a substance abuse issue at the same time?

Yes

No

Don't know

Thank you for your participation!

Appendix H: Moderator Guides

Fulton County Mental Health Focus Groups Moderator Guide

Design:

- Structured focus group (keep participants on topic and stick to the questions in the guide)
- Qualitative Inquiry- begins with the general and ends with specific questions
- Two hours has been allotted for each group in addition to another 1½ hours for set up and break down

Preparation:

- Note taker (designate note taker and have supplies ready)
 - Provide focus group guide for facilitator
 - Disseminate questionnaire before the starting the group
 - Test recorder and microphone
 - Have extra batteries and tapes for recorder.
1. Greet participants as they arrive.
 2. Ask them to take a seat and make themselves comfortable. (If there are refreshments, encourage them to help themselves).
 3. Distribute participant questionnaire and ask participants to complete it while they wait for the focus group to begin. Explain that the questionnaire will provide us information about their background; and that this information will be used for descriptive purposes only. In other words their names will not be on the survey, and we will never use any identifying information such as their name or the name of the agency where they get services in any of our reports.
 4. Also, distribute consent forms and name tents with participant numbers for those who agree to participate in the focus group.

Introduction: *[After all of the questionnaires have been collected]*

Welcome and thank you for coming today. My name is _____ and this is _____ the note taker for this group. We are from the Center for Applied Research and Evaluation Studies at the Southeast AIDS Training and Education Center at Emory University in Atlanta. We were asked by Fulton County Government and the Metro Atlanta HIV Services Planning Council to find out about the HIV care needs of people living with HIV and AIDS in Atlanta. In order to collect this information, SEATEC will conduct consumer focus groups throughout metro Atlanta with people from different communities.

This focus group is for people who are HIV positive, have used **mental health** services in the Atlanta area in the last year, and are at least 18 years old. Your input may impact HIV care services for people living with HIV/AIDS in Atlanta.

A focus group is a roundtable discussion with several individuals led by a facilitator, to gather information about certain issues, in hopes of assessing needs in different areas. The purpose of

this group is to help us to identify the **mental health** service needs of people living with HIV or AIDS in the Atlanta metropolitan area.

I will be leading today's discussion. My role is to make sure that we get through our agenda, keep to the time frame, and ensure that you all have a chance to talk. _____ will help me do these things, and she will also be taking notes. We will be asking the group to respond to a number of specific questions during our discussion today. In addition we will be audio taping the session, to ensure that we record the discussion accurately. Today's focus group should take about 1 ½-2 hours.

2. Participant introductions

Now, let's go around the room and have each of you introduce yourselves using the participant number assigned to you when you arrived. Please feel free to share any other information about yourself, other than your name, that you want with the group. **[Moderator: introduce the idea of using participant numbers instead of their names and indicating number before speaking once we begin taping the session].**

3. Confidentiality

Your participation is completely voluntary and we will never ask for your name. You may skip questions if you want to and can stop at any time. Our staff and any other HIV/AIDS service agencies will not change how they treat you if you decide not to take part in the needs assessment. We need honest input from participants and we will ask that everyone at the session respect the confidentiality of other participants by not sharing anything personal about others outside the session. All information gathered during this needs assessment will remain confidential to the extent permitted by law. To ensure confidentiality, please do not use names when speaking to each other and to not refer to any individuals outside of the session by name. We will keep all facts about you private.

To develop accurate notes on the session, each focus group will be tape-recorded. The tape recording will only be used to develop a summary of the views expressed during the focus groups of **mental health** service needs of people living with HIV/AIDS in metro Atlanta. SEATEC will be consolidating information obtained from this group with that from other groups then presenting the results to Fulton County Government who will use this information to plan for HIV care services. **Also, our staff or any HIV/AIDS agencies will not pay you for lost income or care.**

If you have any questions about this needs assessment or think that talking to me has hurt you, please call Rebecca Culyba. **[Point out the contact information on the information sheet.] [Point out the contact information on the information sheet.]** If you have any questions or concerns about your child's rights for taking part in this needs assessment, you may the Emory University Institutional Review Board. **[Point out the contact information on the information sheet.]**

Are there any questions about this needs assessment?

Getting Started: Thank you again for participating in this focus group. Your feedback very important and will really help Fulton County in its effort to address the needs of clients in the Atlanta metro area with HIV/AIDS who use mental health services.

Let me begin our discussion by reviewing a few things about how we will run the session. During this discussion, we would like you to focus on topics that are of particular interest to us. We are interested in what everyone has to say about our discussion topics. If someone throws out an idea that you want to expand on, or if you have a different point of view, please feel free to speak up. Occasionally, I may have to interrupt the discussion in order to bring us back to a particular topic to make sure that we cover everything on our agenda.

There are several common courtesies that we will follow during this session:

1. We want all of you to express your opinions about the discussion topics. We are interested in multiple points of view about them. There are no right or wrong answers, and we are not here to resolve any issues you may bring up.
2. Please do not hold side conversations. Side conversations not only disrupt the discussion but because we are also recording the session it would really help us if you could speak up so that everyone can hear you. Also, your opinions are valuable and would like you to share them with the entire group.
3. Please say your participant number before or after you make your comments.

Are there any questions so far? If you're ready to get started, I am going to turn on the microphone and recorder so that we can begin this focus group. Remember to use your participant number instead of your name while the session is being recorded.

1. How did you first learn about mental health services?
(Probes: How did you become aware that you needed services? Who referred you to mental health/ substance abuse services?)
2. Think back to when you first got into mental health services in the Atlanta area, what was that experience like for you?
(Probes: What was the start up/intake process like? Who was your primary contact person if you needed help? How often did you get services?)
3. What are the most important services or care that you are using now or have used in the past year? *(list answers on a flip chart and have participants rank them)*
(Probe: primary care, dental, case management, transportation services, housing, financial assistance, support groups, treatment, medications, detox, AA, NA, therapy, counseling)
4. Based on your experiences getting treatment and support, what programs or services have been the most helpful? What has been the least helpful or could have been done better?
5. Based on your experiences what are some of the challenges or roadblocks that you've had getting the mental health services that you need?

(Probes: What would have made the process easier for you? How did you get the services that you needed?)

6. How, if at all, do your primary care providers deal with your mental health issues? Similarly, how well, if at all, do your mental health providers discuss primary care issues with you?
(Probes: Do providers ask you these questions? Are you comfortable sharing this information? What would help you feel more comfortable sharing this information with your providers?)
7. When receiving treatment for a mental health issue, how well do your providers deal with any substance abuse issues that you may have?
(Probes: Have you ever been diagnosed with both conditions? Do providers ask you these questions? Are you comfortable sharing this information? What would help you feel more comfortable sharing this information with your providers?)
8. Looking back over everything we've discussed today what changes, if any, would you suggest to the mental health services offered to you or other people living with HIV/AIDS in the Atlanta area?
9. If you knew a new client in HIV/AIDS care who also needed mental health services what advice would you give them about getting services in the Atlanta area? *(Probes: What would you tell them about these services?)*
10. Because we're interested in how to improve the mental health services offered to people living with HIV/AIDS, before we finish the focus group for today we just want to make sure that we covered everything. Is there anything you think we missed? *(Probes: Anything else to add? Is there anything you came here really wanting to say but haven't had a chance to share? Or are there any questions that I can answer for you before we end)*

Wrap Up: Thank you very much for participating in this focus group. The information you have provided has been very helpful. This information will be used to help Fulton County Government and the Atlanta HIV Health Services Planning Council to make informed decisions about service priorities and use of resources.

Don't forget to pick up your gift card before you leave, and help yourself to any refreshments that are left. Thank you again for your help!

Fulton County Substance Abuse Focus Groups Moderator Guide

Design:

- Structured focus group (keep participants on topic and stick to the questions in the guide)
- Qualitative Inquiry- begins with the general and ends with specific questions
- Two hours has been allotted for each group in addition to another 1½ hours for set up and break down

Preparation:

- Note taker (designate note taker and have supplies ready)
 - Provide focus group guide for facilitator
 - Disseminate questionnaire before the starting the group
 - Test recorder and microphone
 - Have extra batteries and tapes for recorder.
5. Greet participants as they arrive.
 6. Ask them to take a seat and make themselves comfortable. (If there are refreshments, encourage them to help themselves).
 7. Distribute participant questionnaire and ask participants to complete it while they wait for the focus group to begin. Explain that the questionnaire will provide us information about their background; and that this information will be used for descriptive purposes only. In other words their names will not be on the survey, and we will never use any identifying information such as their name or the name of the agency where they get services in any of our reports.
 8. Also, distribute consent forms and name tents with participant numbers for those who agree to participate in the focus group.

Introduction: *[After all of the questionnaires have been collected]*

Welcome and thank you for coming today. My name is _____ and this is _____ the note taker for this group. We are from the Center for Applied Research and Evaluation Studies at the Southeast AIDS Training and Education Center at Emory University in Atlanta. We were asked by Fulton County Government and the Metro Atlanta HIV Services Planning Council to find out about the HIV care needs of people living with HIV and AIDS in Atlanta. In order to collect this information, SEATEC will conduct consumer focus groups throughout metro Atlanta with people from different communities.

This focus group is for people who are HIV positive, have used **substance abuse** services in the Atlanta area in the last year, and are at least 18 years old. Your input may impact HIV care services for people living with HIV/AIDS in Atlanta.

A focus group is a roundtable discussion with several individuals led by a facilitator, to gather information about certain issues, in hopes of assessing needs in different areas. The purpose of this group is to help us to identify the **substance abuse** service needs of people living with HIV or AIDS in the Atlanta metropolitan area.

I will be leading today's discussion. My role is to make sure that we get through our agenda, keep to the time frame, and ensure that you all have a chance to talk. _____ will help me do these things, and she will also be taking notes. We will be asking the group to respond to a number of specific questions during our discussion today. In addition we will be audio taping the session, to ensure that we record the discussion accurately. Today's focus group should take about 1 ½-2 hours.

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To develop accurate notes on the session, each focus group will be tape-recorded. The tape recording will only be used to develop a summary of the views expressed during the focus groups of **substance abuse** service needs of people living with HIV/AIDS in metro Atlanta. SEATEC will be consolidating information obtained from this group with that from other groups then presenting the results to Fulton County Government who will use this information to plan for HIV care services. **Also, our staff or any HIV/AIDS agencies will not pay you for lost income or care.**

If you have any questions about this needs assessment or think that talking to me has hurt you, please call Rebecca Culyba. **[Point out the contact information on the information sheet.] [Point out the contact information on the information sheet.]** If you have any questions or concerns about your child's rights for taking part in this needs assessment, you may the Emory University Institutional Review Board. **[Point out the contact information on the information sheet.]**

Are there any questions about this needs assessment?

Getting Started: Thank you again for participating in this focus group. Your feedback very important and will really help Fulton County in its effort to address the needs of clients in the Atlanta metro area with HIV/AIDS who use substance abuse services.

Let me begin our discussion by reviewing a few things about how we will run the session. During this discussion, we would like you to focus on topics that are of particular interest to us. We are interested in what everyone has to say about our discussion topics. If someone throws out an idea that you want to expand on, or if you have a different point of view, please feel free to speak up. Occasionally, I may have to interrupt the discussion in order to bring us back to a particular topic to make sure that we cover everything on our agenda.

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4. We want all of you to express your opinions about the discussion topics. We are interested in multiple points of view about them. There are no right or wrong answers, and we are not here to resolve any issues you may bring up.
5. Please do not hold side conversations. Side conversations not only disrupt the discussion but because we are also recording the session it would really help us if you could speak up so that everyone can hear you. Also, your opinions are valuable and would like you to share them with the entire group.
6. Please say your participant number before or after you make your comments.

Are there any questions so far? If you're ready to get started, I am going to turn on the microphone and recorder so that we can begin this focus group. Remember to use your participant number instead of your name while the session is being recorded.

11. How did you first learn about substance abuse services?
(Probes: How did you become aware that you needed services? Who referred you to mental health/ substance abuse services?)
12. Think back to when you first got into substance abuse services in the Atlanta area, what was that experience like for you?
(Probes: What was the start up/intake process like? Who was your primary contact person if you needed help? How often did you get services?)
13. What are the most important services or care that you are using now or have used in the past year? *(list answers on a flip chart and have participants rank them)*
(Probe: primary care, dental, case management, transportation services, housing, financial assistance, support groups, treatment, medications, detox, AA, NA, therapy, counseling)
14. Based on your experiences getting treatment and support, what programs or services have been the most helpful? What has been the least helpful or could have been done better?
15. Based on your experiences what are some of the challenges or roadblocks that you've had getting the substance abuse services that you need?

(Probes: What would have made the process easier for you? How did you get the services that you needed?)

16. How, if at all, do your primary care providers deal with your substance abuse issues? Similarly, how well, if at all, do your mental health providers discuss primary care issues with you?

(Probes: Do providers ask you these questions? Are you comfortable sharing this information? What would help you feel more comfortable sharing this information with your providers?)

17. When receiving treatment for a substance abuse issue, how well do your providers deal with any mental health issues that you may have?

(Probes: Have you ever been diagnosed with both conditions? Do providers ask you these questions? Are you comfortable sharing this information? What would help you feel more comfortable sharing this information with your providers?)

18. Looking back over everything we've discussed today what changes, if any, would you suggest to the substance abuse services offered to you or other people living with HIV/AIDS in the Atlanta area?

19. If you knew a new client in HIV/AIDS care who also needed substance abuse services what advice would you give them about getting services in the Atlanta area? *(Probes: What would you tell them about these services?)*

20. Because we're interested in how to improve the substance abuse services offered to people living with HIV/AIDS, before we finish the focus group for today we just want to make sure that we covered everything. Is there anything you think we missed? *(Probes: Anything else to add? Is there anything you came here really wanting to say but haven't had a chance to share? Or are there any questions that I can answer for you before we end)*

Wrap Up: Thank you very much for participating in this focus group. The information you have provided has been very helpful. This information will be used to help Fulton County Government and the Atlanta HIV Health Services Planning Council to make informed decisions about service priorities and use of resources.

Don't forget to pick up your gift card before you leave, and help yourself to any refreshments that are left. Thank you again for your help!

Appendix I: Key Informant Interview Guide

As a follow-up to the 2007-2008 Atlanta EMA HIV Consumer Survey, the Fulton County Ryan White Part A Program and the Metropolitan Atlanta HIV Health Services Planning Council has asked SEATEC to conduct focus groups with consumers to identify emerging needs in mental health and substance abuse services in the EMA. We are conducting key informant interviews with a sample of community stakeholders to gather information about perceived service availability/needs, barriers, and access for clients seeking mental health and substance abuse services from individuals with special knowledge and experience regarding these populations. Today, I would like to ask you about your perceptions and experiences about substance abuse and mental health services in the EMA and what information you think would be useful to collect as part of the focus groups.

Participation in this project is voluntary. If at any time you would like to stop the interview or not answer a particular question, just let me know.

Do you have any questions, before we begin?

1. What do you think are the most important services for clients in need of:
 - a. mental health services
 - b. substance abuse services
2. What are some of the challenges for clients receiving these services in the EMA?
 - a. Why do you think these challenges exist?
 - b. What can be done to minimize or eliminate these barriers for clients?
3. What are some challenges for providers who offer these clients mental health and substance abuse services?
 - a. Why do you think these challenges exist?
 - b. What can be done to minimize or eliminate these barriers for providers?
4. What is the single most important change that should be made to:
 - a. Mental health service delivery
 - b. Substance abuse service delivery
5. What are you most interested in learning from clients about mental health and substance abuse service delivery in the EMA?
6. If you could ask a single question to clients in these focus groups, what would it be?
7. Once the focus groups are completed, what would you most like to see happen with the results?
8. Is there anything else you would like to share that will help us plan these focus groups?

THANK YOU FOR YOUR PARTICPATION!