

2009 Atlanta EMA Needs Assessment of Young People Living With HIV/AIDS



2010

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

**By the Center for Applied Research and Evaluation Studies
Southeast AIDS Training and Education Center
Department of Family and Preventive Medicine
Emory University School of Medicine**

ACKNOWLEDGMENTS

This needs assessment would not have been possible without the input and assistance of HIV/AIDS care consumers, service providers in the Atlanta Eligible Metropolitan Area, and the Ryan White Assessment Committee (RWAC) of the Metropolitan Atlanta HIV Health Services Planning Council. The Southeast AIDS Training and Education Center (SEATEC), on behalf of Fulton County Government, would like to thank these individuals and organizations for participating in this project.

This needs assessment was made possible by a grant from the Fulton County Government Ryan White Part A Program. Members of the project team included: Rebecca J. Culyba, PhD; Yvette M. Wing, MPH, CHES; Sridevi Wilmore, MPH; LaDawna Jones, MPH; Dennis Flores, RN; and Kathryn S. Daouda Paul, MPH. The team extends special thanks to Mary Cowans; Michelle Broth, PhD; and Kevin Williams, MSW for their assistance.

TABLE OF CONTENTS

EXECUTIVE SUMMARY	1
OVERVIEW	1
KEY FINDINGS	2
RECOMMENDATION	3
INTRODUCTION AND METHODOLOGY	4
METHODOLOGY	4
LIMITATIONS	6
RESULTS	6
DEMOGRAPHIC	6
MOST IMPORTANT SERVICES	9
BARRIERS	12
TRANSITION TO ADULT CARE	14
RECOMMENDATIONS	16
SUMMARY	18
REFERENCES	19

APPENDICIES	21
A: QUALITATIVE DATA CODING CHART	A:1
B: IRB DETERMINATION LETTER	A:2
C: RECRUITMENT MATERIAL	A:3
D: LAY SUMMARY	A:5
E: ASSENT INFORMATION SHEET	A:6
F: PARTICIPANT QUESTIONNAIRE	A:8
G: MODERATOR GUIDE	A:12

EXECUTIVE SUMMARY

The 2009 Atlanta EMA Needs Assessment of Young People Living With HIV/AIDS 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 as a supplement to the 2007-2008 Atlanta EMA HIV Consumer Survey and in support of the Council's priority setting process.

Twenty-three Young People Living with HIV/AIDS (YPLWHA) ages 13-24 years old and accessing services at Ryan White funded agencies in the Atlanta Eligible Metropolitan Area (EMA) participated in this assessment. The primary method of data collection was focus groups. Additionally, Ryan White client level data provide context for the interpretation of results. Recommendations are based on analyses of these data, a review of established approaches to addressing the service needs of YPLWHA, and an understanding of the Ryan White HIV service delivery system in the Atlanta EMA.

OVERVIEW

In the past decade, great strides have been made in the prevention of mother-to-child perinatal transmission of HIV/AIDS in the U.S. Although health care providers have been able to successfully reduce the number of children born HIV positive, the rate of youth contracting the disease continues to increase each year (D'Angelo, Samples, Rogers, Peralta, & Fridman, 2006). Nationally, there are an estimated 23,524 young adults 13-24 years of age reported to be living with HIV/AIDS, which is less than 5% of all People Living with HIV/AIDS (CDC, 2007). Georgia has followed the national trend of increasing numbers of YPLWHA. However, in Georgia, YPLWHA ages 13 to 24 account for a larger proportion of newly diagnosed HIV cases than other age groups; 25% in 2005, 30% in 2006, and 24% in 2007 (Georgia DCH, 2006, 2009). Of the 22,489 people living with HIV/AIDS in the Atlanta EMA for calendar year 2007, 15% were aged 13-24 years. In 2008, the EMA served 667 youth and young adult clients (ages 13-24) accounting for about 6% of all PLWHA¹ served.

¹ Client Level Data (CLD) extracted from the Atlanta EMA Ryan White Part A CAREWare database.

KEY FINDINGS

Youth in this assessment discussed a range of topics including services used, services needed but not received, barriers to care, service satisfaction, and transition to adult care. In general, the period of adolescence is one of great change for most young people, but particularly so for those with HIV/AIDS because they are oftentimes making a transition from a pediatric to adult health care setting (Catalozzi & Futterman, 2005; Fernet et al., 2007). Adolescents in the HIV care system face a number of challenges to accessing services where they are required to be more fully engaged in their disease management as they come of age than ever before in the life of their medical care (McKay et al., 2007). Having to negotiate a number of health-related tasks independently, including finding the right medical providers, maintaining social support networks, adhering to medication regimens, and transitioning from pediatric to adult HIV care can be overwhelming and seemingly abrupt for youth (Catalozzi & Futterman, 2005; Johnson et al., 2003; McKay et al., 2007).

While focus group participants generally reported being satisfied with their ability to regularly access outpatient/ambulatory care and medical and non-medical case management as part of their routine HIV care in a pediatric clinical setting, they were often concerned with their ability to navigate the system and obtain these services in an adult setting. The transition of adolescents to adult care is a more familiar concept in chronic disease management than HIV care (Callahan Winitzer & Keenan, 2001; Miles, Edwards & Clapson, 2004); however, with the overwhelming numbers of HIV-infected adolescents reaching adulthood, these chronic disease models have been explored with regard to their effectiveness in HIV care and in many cases implemented to help young people navigate the care system (Miles et al., 2004; Weiner, Battles, & Ryder, 2007). Studies have shown that the transition from pediatric to adult care should be an expected and welcomed process where the goal is to provide parallel services without interruption while acquiring more developmentally appropriate medical care (Callahan et al., 2001); however, effective transition of YPLWHA to adult care has many challenges. Particularly, the psychosocial effects of transitioning from adolescent to adult HIV care can contribute to young adults dropping out of care, putting themselves at risk for opportunistic infections, drug resistance, and increasing their overall morbidity and mortality (Battle, & Wiener, 2002; Weiner et al., 2007a). Focus group participants viewed the familial environment of the pediatric clinical care setting as an overwhelming strength and feared this connection would be lost in the transition to adult care.

In addition, focus group participants frequently described time as their greatest barrier to care in the EMA. They highlighted spending prolonged periods of time in the clinic seeing health care providers, case managers, and getting lab work done. Moreover participants noted that they are not always able to be seen for an acute problem, especially in the dental clinic where the next available appointments may be four to five months away. Finally, focus group participants expressed frustration with the time-consuming recertification process required every six months to remain eligible for services. The length of time spent in the clinic is a burden for clients and accompanying family members who may have to miss school or work to accommodate these lengthy appointments.

Finally, participants expressed the need for peer support, especially access to and a reinvigoration of support groups. Participants were overwhelmingly positive in their descriptions of the peer support they experienced at a camp for HIV infected youth and past support groups. Kadivar, Garvie, Sinnock, Heston, & Flynn,(2006) found that newly infected adolescents and young adults are more likely to come from unstable home environments, including being reared in homes where youth are exposed to “high levels of sexual abuse, depression, school drop-out, prior justice system involvement, and parental substance abuse” (p. 546). Caring for youth with these complex histories of psychosocial and socioeconomic factors requires a comprehensive system of service provision that integrates routine medical care with social support services in its approach (Catalozzi & Futterman,2005; Johnson et al., 2003;Kadivar et al., 2006).

RECOMMENDATIONS

The following recommendations are suggested to assist the Atlanta EMA engage, retain, and improve the delivery of HIV care services to youth and young adults as they prepare to transition into adult care. The recommendations highlighted below are based on focus group results, best practices, and supporting literature. Further details can be found on page 17.

1. Develop an Individual Service Plan (ISP) for YPLWHA transitioning to adult care.
2. Utilize peer counseling.
3. Design and implement an orientation to adult care.
4. Incorporate a young adult clinic.
5. Facilitate routine support group meetings.

INTRODUCTION

The Southeast AIDS Training and Education Center conducted the Atlanta EMA HIV Youth Focus Groups in February 2009 on behalf of Fulton County Government and the Metropolitan Atlanta HIV Health Services Planning Council.

Primary data include four focus groups with 23 HIV positive youth (ages 13-24) in the Atlanta EMA who were receiving 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 first began in December 2006 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 HIV positive youth focus groups were determined.

The data collection protocol was designed to collect perceived service use, service needs, and barriers to receiving needed services among YPLWHA, a population not included in the 2007-2008 Atlanta EMA HIV Consumer Survey for statistical reasons. Data collection and sampling strategies were guided by epidemiological and program data. CARES staff provided the Assessment Committee of the Metropolitan Atlanta HIV Services Planning Council and Fulton County Government Ryan White Program staff a draft of the focus group and demographic questions and incorporated their input on final versions of the project design, including recruitment and focus group questions.

All protocols, recruitment and 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 (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 survey instruments used in the 2007-2008 consumer survey and the Ryan White

CARE Act Needs Assessment Guide (HRSA 2003) to develop the questions to be asked in the focus groups. The instrument was modified to reflect feedback from key community stakeholders in the Atlanta EMA in order to garner rich data about the needs of this group. 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 as well as administration of the protocol. The focus group questions and demographic questionnaire are found in Appendices F and G.

The focus groups were conducted with a convenience sample of YPLWH, ages 13-24. Two age-specific population segments were selected for this project: ages 13-17 and 18-24. Two focus groups were conducted with each segment to ensure reliability. Focus groups took on average 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 completed and youth were informed of their rights as participants, consumers were asked to discuss their perceptions of the importance of available services, their satisfaction or dissatisfaction of services, experiences of barriers to care, thoughts on transitioning from pediatric to adult care, and suggestions to improve the HIV/AIDS service delivery system in the Atlanta EMA.

Data Collection. Data collection took place in February 2009. During this time a total of 23 youth living with HIV/AIDS volunteered to participate in four focus groups. Each group was conducted in collaboration with a community-based partner agency that worked with CARES staff to identify potential participants and assist with logistics. Focus groups were conducted by a consultant to ensure community-engaged and culturally appropriate facilitation. CARES staff served as note takers. Prior to the start of data collection, agency staff 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. Participant recruitment was tailored to suit the environmental constraints of the data collection site. Agency staff referred all interested clients to CARES staff for participation in this assessment.

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

They were instructed not to provide their names in writing or verbally during the focus group session at any time. Project staff provided participants with a number (1-10), which was used in place of the participant's name to sign the informed consent information sheet and when referring to each other during the recorded sessions. Numbers were on table tents placed in front of each participant and on name tags to remind the youth to use these numbers when referring to themselves and others. Tapes were transcribed by a consultant transcriptionist and edited by CARES staff for accuracy. Youth 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 was analyzed using Atlas.ti, a qualitative data analysis software package. Content analysis was used to identify themes in using a grounded theory approach where categories of analyses merge 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 when saturation was reached. 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. While the data collected provide valuable insight into the needs and priorities of YPLWHA currently accessing care at Ryan White Part A funded and other agencies in the EMA, there are several limitations to the study. In general, findings reflect perceptions of service needs and barriers and are not based on objective eligibility criteria. Because data collection took place at sites where youth were receiving services, this may have resulted in an over-reporting of specific service use. Also, sample population was obtained through a convenience sample and may not be reflective of epidemiological or CAREWare data available for this population. These limitations should be taken into account when utilizing this report.

RESULTS

Consumers participating in this needs assessment were YPLWHA ages 13-24. In addition to their participation in the focus group, they were asked to complete a demographic questionnaire (Appendix F). This questionnaire was designed to gather data on the current social, economic, and medical status of needs assessment participants.

Demographic. Seventy percent of participants indicated being 18-24 years of age compared to

30% who were 13-17 years old at the time of the focus groups. The majority of the participants were female (61%), with males composing only 39% of the groups. Consumers were also more likely to identify as heterosexual (65%) than homosexual (35%) when asked their sexual orientation. Participants were primarily African American (87%), though 13% reported being Hispanic/Latino. All consumers indicated English as their preferred language.

Table 1. Demographics by Group

	1	2	3	4	Overall
Female (%)	75%	80%	25%	100%	61%
Male (%)	25%	20%	75%	0%	39%
Hispanic	38%	0%	0%	0%	13%
Black (non-Hispanic)	62%	100%	100%	100%	87%
Heterosexual (%)	75%	100%	38%	50%	65%
Homosexual	25%	0%	62%	50%	35%

Socio-Economic. When asked where they were currently living, most participants reported either living with family (65%) or renting/owning an apartment/house (30%). Only one consumer indicated that they were currently living with friends. Thirteen percent of participants indicated the highest level of education they completed was 8th grade or less. Sixty-one percent of all participants in this assessment reported having some high school or having a high school diploma/GED. Twenty six percent had a vocational certificate, some college or an Associate’s Degree.

At the time of the focus group, 35% of participants were employed at least part-time, 48% reported being unemployed, and 17% reported working as a volunteer. Only one participant reported other employment, which was unspecified. The majority of participants reported having either Medicaid (35%) or Medicare (17%) as their primary health insurance compared to those who either had private insurance (9%) or none at all (22%). Thirty percent of participants reported currently receiving services funded through the Ryan White program; however, the majority of consumers either reported not receiving Ryan White-funded services or were unsure (both 35%).

Table 2. Medical Care Funding Source by Group

	1	2	3	4	Overall
Medicaid	38%	40%	25%	50%	35%
Medicare	13%	20%	13%	50%	17%
Private Insurance	13%	0%	13%	0%	9%
Ryan White Funding	50%	0%	3%	0%	30%
None	25%	0%	38%	0%	22%

Medical. The majority of the participants in this needs assessment were diagnosed with HIV five or more years ago. In fact, 35% of consumers learned their HIV positive status 10 or more years ago with 17% having learned their status between five and nine years ago. Of those more recently informed of their HIV status, 26% learned that they were HIV positive between one and four years ago, and 9% less than 12 months ago. Consumers were more likely to rate their overall health as very good (61%), good (22%), or fair (17%) at the time of the focus group. Accordingly, youth were less likely to receive medical care five or more times in the past 6 months. More participants reported receiving medical attention fewer than five times (61%) or not at all (13%) in the past 6 months with 22% reporting five or more visits.

Approximately half (48%) of all youth participating in this needs assessment reported currently taking a combination of antiretroviral drugs. Most participants reported that the cost of medications was covered by Medicaid (61%), though some also cited receiving financial assistance from the AIDS Drug Assistance Program (ADAP) (17%), or other sources (9%). Most of the youth reported having had a CD4 cell count (52%) and viral load test (83%). When asked to report the frequency of each test, the majority of participants had their most recent CD4 and viral load tests in the past six months (96% and 82% respectively). Despite the overwhelming majority of participants being aware of both the CD4 and viral load tests, it is of note that some did not know when their last CD4 count was taken (48%) or if they ever had a viral load test (17%).

Table 3. Antiretrovirals (ART) by Group

	1	2	3	4	Overall
Currently taking ART	50%	40%	38%	100%	48%
ARV Payer Source					
Medicaid	50%	100%	38%	100%	61%
ADAP	13%	0%	38%	0%	17%
Other	12%	0%	12%	0%	13%

All of the female participants were defined as being of childbearing age (13-24 years old) and of these, 36% reported having had children. All of the mothers in this assessment reported having taken an antiretroviral drug regimen containing AZT or Combivir while pregnant and only one reported having given birth to an HIV positive child. Finally, one participant reported being pregnant and on an antiretroviral drug regimen at the time of the focus group.

Focus Group Results

After completing an Assent Information Sheet and the Questionnaire, focus group moderators led participants through 14 pre-developed questions designed to address five primary areas of concern: Service Availability, Utilization, and Access; Satisfaction with Services/Quality of Services; Barriers; Unmet Need (Transition to Adult Care); 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 coding².

MOST IMPORTANT SERVICES

Case management and primary medical care were undoubtedly the most important services received by youth followed by dental care and medication assistance through the AIDS Drug Assistance Program

"[It's] just like one-stop, I mean because they've got everything you need, like food stamps assistance, section 8 assistance, group assistance, I mean anything you need, I mean they pretty much provide it for you."

(ADAP). Overall participants in this assessment expressed satisfaction with the services being offered to them by agencies and providers. They also cited the coordination between their providers and the "one-stop shop" approach to care in the youth clinic as its strength.

Case Management. Participants discussed their experiences in the case management system in detail. All of the youth were accessing case management services and described having received care from their current case manager from as recently as two months ago to over a year. In addition, participants reported frequent monthly contact with their case manager including receiving reminder calls for upcoming clinic visits, being told about support groups and other research studies, and checking in on the status of medical and personal issues. The case manager is also the person who connects clients with a number of auxiliary support services like transportation assistance, housing assistance, and support groups.

"The social worker[s] makes it [feel] like home."

Youth associated feelings of comfort and familiarity in their relationships with case managers, which aided in making their HIV care experience much easier to navigate and more like home. Case managers, while generally looked upon favorably, were rated negatively by consumers

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.

with regard to their turnover rate and inability to have relationships with clients outside of their professional boundaries. Participants noted having had a number of case managers over the course of their treatment in the clinic, some reporting eight or more case managers and the impending transition to another. After having invested in the case manager relationship, clients feel that these changes are hard to cope with and can have an effect on the quality of their care and their motivation to access and remain in care.

Primary Medical Care. Overall, the youth in this needs assessment were satisfied with the quality of the primary care that they received.

They felt that the services offered were largely age appropriate and reasonably easy to access.

“I use medical care here... Basically this is what’s important to keep me healthy.”

Generally, youth pointed to primary medical care as the sole service that keeps them healthy and the most necessary component of their HIV care.

Like case managers, primary care physicians were also seen like family to participants, as many of them were informed of their HIV status as children by medical providers in the clinic.

Unfortunately, relationships with nurses and other medical personnel were a major point of contention among the youth. Many participants shared feelings of mistrust and dissatisfaction with nurses. Most of the dissatisfaction stemmed from perceived negative attitudes, long wait times, and gossip they attributed to nurses. It is important to note that while some participants could identify times when they encountered medical personnel who were less than welcoming, many of the youth who’ve attended clinic since infancy generally did not report having personally experienced such negative attitudes.

Dental Care. While some of the youth reported using dental care at the clinic, about half either didn’t know the service was available or received dental care off site. Of those who received

“If I can’t reach them or if I can’t get through, I go to Grady [emergency room] because I’ve got to get some medication for my pain.”

oral health care at the clinic, their major concern was wait time. Participants reported having to wait 3- 6 months for the next available appointment to be seen by a dentist for routine dental care and two weeks to

be seen for an emergency. Having to wait months for the next available appointment and then again once in the office for an available chair were both unfavorable options for youth and some even cited going to the emergency room to get care when they were unable to be seen immediately by a dental provider.

Medication Assistance. Many of the participants utilizing AIDS Drug Assistance Program (ADAP) for medication assistance

indicated that while the service provided was extremely important to their overall health, they experienced many problems with the recertification process. Youth

“When I did my paper work for ADAP, I started my paperwork in about September, and I just received my first medicines in January.”

reported that they were required to recertify for ADAP every six months and in many cases that was not enough time to get the qualifying documentation that they needed to continue receiving their medications without interruption. Some even cited the recertification waiting period outlasting the month of emergency medications that were provided to them. Youth often found themselves negotiating the tension between physicians stressing the importance of medication adherence and ADAP staff unable to provide crucial medication because necessary documentation for medication disbursements were missing. The perceived inefficiency of this process was discussed in detail by some participants. Youth recalled instances when they were unable to immediately resume their medication regimen even after submitting necessary documentation. Some indicated that this waiting period could last for several months before they continued receiving their HIV medications.

Peer Support. Finally, youth found opportunities created by the clinic to interact with their peers a very important component of their service delivery. Many of the young adults in this assessment have attended camp for HIV positive youth, support groups, conferences, and

“I mean it was a place where everybody that had the same thing, they were going through the same thing, and just go have fun and don’t got to worry about nobody talking about you or saying, oh my God, she got HIV, what she doing here?”

some have even served as peer counselors.

For many of the participants, going to camp was one of the major highlights of their HIV care experience. They recalled many fond memories from camp and discussed the bonds made with other HIV positive youth as

well as their clinicians. Camp, for those who participated, was both a place where the young people cited they could be truly themselves in a social setting, unafraid of the judgment and stigma associated with being HIV positive. Unlike camp, support groups received a much more mixed and more often negative response. Though most of the youth had attended past support group meetings held in the clinic, they felt that the groups were inconsistent, not well attended, topics were redundant, and the purpose of the groups generally lost. Support groups in the clinic generally start strong with positive feedback and large numbers, but youth cited that they often

end with low or no attendance, unstructured, and simply a holding pen for youth awaiting their medical appointment. Despite this, youth were still interested in participating in support groups and one even suggested adding an affinity group for single mothers.

"I don't think they transform well from the age groups. I mean they offer a group, but they don't give you any incentives to want to come, like the teen group in the beginning there's a lot of people. But eventually we're talking about the same thing, we're just sitting here eating snacks. It gets to the point where it's like what's the point of coming? It's not any benefit coming out of it. So you get to the point where you don't want to go."

Other peer support activities included participation in conferences and working as peer counselors for HIV positive youth. Those young adults who had the opportunity to serve as peer counselors spoke very highly of their experiences and enjoyed the chance to help other youth in the HIV care system or simply to provide a listening ear to their peers coping with the disease. Overall, youth were eager not only to participate in peer activities, but also to take on leadership roles through their work as peer counselors, attending conferences, camp, and other events suggested by their case managers.

BARRIERS

Though discussed earlier in part, wait time was a major barrier to receiving care for many of the participants in this assessment. Participants reported frequently having to wait for services longer than what they perceived normal in most facets of their care from setting appointments and obtaining transportation assistance to receiving referrals for support services and medical care. Other perceived barriers to care were financial, trauma associated with breaches in confidentiality, stigma, and disclosure.

Wait Time/Hours of Operation. Youth often asserted that the wait times they experienced

"I think it's convenient because there's not a lot of people out at that time of morning. You don't see a lot of faces, it's not daylight... So it's like you really can't be seen like that, or you don't be exposed all the time."

while attempting to receive HIV care were excessive. Time spent in the clinic routinely occupied all or most of their day. Many youth expressed having to plan their days around doctor appointments, which can be very challenging and inconvenient. Frequently,

young adults earning hourly wages expressed frustration because they not only had to miss work for routine medical care, but also had to explain to employers why their medical visits were so lengthy. In fact, youth described the average length of a routine medical visit being between

three to four hours. They also indicated that within the visit staff generally move relatively slowly which contributes to perceptions of deliberate inefficiencies with regard to time.

Generally, participants were satisfied with the location and hours of operation of the clinic. Some participants did discuss being uncomfortable with the location of the clinic because of an associated stigma with the building as an “AIDS clinic” and being in the middle of a popular part of town for homosexual men. Suggestions offered for minimizing the effect of stigma on those who attend clinic include offering a 24 hour clinic or extending the hours of operation past 5:00 PM when there was less of an opportunity to be identified entering and exiting the clinic.

Financial. Perceived financial barriers to HIV care were largely associated with prescription drug and other required copayments for services. Many of the young adults in this assessment were in school or otherwise not engaged in full time employment, which made copayments a challenge. Participants experienced financial barriers if they were hourly wage workers who missed income while attending medical visits, or lost ADAP or Medicaid benefits because of age or trouble with the recertification process. Participants also reported having applied for or receiving benefits from the Women Infants and Children (WIC) program, a rental assistance program through an agency associated with the clinic, and/or Ryan White for medical care. Those who needed but did not receive these services attributed the arduous application and certification processes for the unmet need.

Stigma, Disclosure and Breaches of Confidentiality. Issues of perceived stigmatization, trauma associated with disclosure of HIV

status, and breaches in confidentiality are major barriers for youth receiving HIV care. Youth were not explicitly asked to give accounts of times they experienced stigma, issues around disclosure of HIV status, or confidentiality but these topics emerged and were discussed in length in

“I just don’t like going to the emergency room and have to tell somebody that. And I ask my mom, I’m like do I really have to tell them? Can I at least wait until I get in the room and tell the doctor? Because I just, I don’t know, especially if I see young nurses, or if I see somebody with a little funky attitude, I don’t want to tell them my business.”

each group. Fear of stigma is a debilitating social condition for young adults that can adversely affect their health.

Many of the youth have been living with HIV for most, if not all, of their childhood and adolescence and are now negotiating the disclosure of their status to peers, medical personnel,

potential mates, family members and others. Fear of being labeled or gossiped about keeps the youth from being forthcoming about their HIV status in all areas of their interaction, not just their personal lives. Some participants expressed their reluctance in disclosing their HIV status to clinicians in emergency rooms when receiving care while others acknowledged the discomfort they felt when discussing their disease with new or alternate physicians unfamiliar with their medical histories. This perception of stigma was also reflected in the youths' awareness of being spotted entering the clinic, fear of being asked about medications they take when out with friends, self-consciousness about disclosing their HIV status, fear of being associated with the gay community because of the clinic's location, and a number of other discomforts associated with being considered less than or judged in the eyes of their peers, authority figures, and others.

Many of the youth learned they were HIV positive in a clinical setting by a medical provider. Some of the youth were told by their pediatrician that they were perinatally infected, others discovered during pregnancy, but most found out after submitting to an HIV test when seeking medical attention for some other health concern. Unfortunately, some of those who were informed of their HIV status when receiving care for other health concerns also experienced inappropriate breaches of confidentiality by medical personnel in the process. Other breaches of confidentiality included having medical personnel disclose HIV status to family members and commenting on the HIV status of others attending the clinic.

TRANSITION TO ADULT CARE

At age 24, young adults attending the clinic are required to cease receiving care in the pediatric clinic and instead begin to exclusively utilize services provided in the adult clinic. This process

"I feel forgotten, like they just forgot about me. It's either you're an adolescent or you're a [long-term] survivor or whatever they call it. But I'm just in between, there's nowhere for me to go."

is called transitioning. Unfortunately, there is an observed trend that many of the young adults reach transition age and drop out of care because they are no longer allowed to receive care in the familiar environment of the pediatric

clinic. Youth were asked to share their perceptions of the transition process from pediatric to adult HIV care, why some youth don't successfully transition, and what can be done to help young adults be more prepared and remain engaged in the process.

Challenges. There are a number of major challenges to engaging and retaining young adults in care when they reach the age of transition. Many of the 13-17 year olds don't want to think about or discuss transition in any detail until it's their time to transition. This coupled with the strong parental involvement in health care coordination presents major challenges when trying to prepare youth to become more actively engaged in their HIV care. The younger participants were largely unaware of what to expect in adult care and generally had not begun to have conversations about it with their health care providers or parents. In the older groups, a couple of the young adults had already transitioned to adult care in the clinic but still maintained close ties with the pediatric HIV clinic and staff and even expressed the desire to return to pediatric care if given the opportunity.

Young People Living With HIV/AIDS are faced with the challenge of moving from being a child with HIV, where their care was coordinated for them, to being an adult with all the responsibilities of coordinating their own care. They are also aware of the affect the impending transition has on the surrogate family they've built with their clinicians, case managers, support group members, and other clinic staff. All of these changes leave youth feeling unsure and uncomfortable about HIV care in the "wilderness" of the adult clinic where they don't know anyone and have to learn to rebuild their medical support network. Overwhelmingly, youth were consumed with fear that they would lose benefits or opportunities afforded to them in pediatric care when they transitioned to adult care.

When asked to discuss why some young adults drop out of the care system pending transition, participants cited various reasons.

"It's just doctors coming and going, social workers coming and going, and like we had another mental health lady...she's gone. It's just a lot of different changes, and some people can't get used to the fact that things are constantly changing over and over and over again. So they leave."

"If I have to go down there, I'm leaving the clinic. Because they don't look so happy, I mean they actually scare me. They're like they're [angry] at the world for what happened. It looks like they're still dealing with it [HIV diagnosis]."

The discomfort of "feeling like you're the new kid in school" and having to discuss complete medical history with a new team of clinicians aided in losing young people during transition. Others felt like the quality of care in the adult clinic was not comparable to what had been offered in the pediatric clinic and were preparing to relocate once it was time for their transition. Some of the participants felt uncomfortable with the idea of transitioning to the adult clinic because they'd experienced older clients trying to solicit dates and other intimate contact with them. Others felt that the clients in

the adult clinic looked “miserable” and like they were not as physically healthy as those they experienced in the pediatric clinic. Still, the most frequently cited reasons why young adults drop out of care during the transition process were feelings of being lost, not having a stable network of familiar providers, and having to start over in the care system without a safety net.

RECOMMENDATIONS

Amid sharing their fears, uncertainties, and frustrations with the impending transition to adult care, youth in this assessment were most concerned with being afforded the opportunity to make choices in the future for their HIV care and the assurance that the quality of care provided to them in the pediatric clinic would continue in adult care. The following recommendations are suggested to assist the Atlanta EMA engage, retain, and improve the delivery of HIV care services to youth and young adults as they prepare to transition into adult care.

- 1. Develop an Individual Service Plan (ISP) for YPLWHA transitioning to adult care.**

Adolescence is generally a time of great transition for many young people and often the time when both perinatally and behaviorally infected youth discover their HIV status.

Therefore, it is recommended that clinicians, case managers, and other care coordinators begin to engage youth in goal-setting for this phase of their lives including the initiation of an Individual Service Plan (ISP) (Callahan et al., 2001). An ISP will help youth map their transition into adulthood through highlighting major milestones in their care, potential resources, personal strengths and assets, as well as those areas where their readiness or self-efficacy to make the transition needs improvement (Los Angeles County Commission on HIV, 2008; Weiner, Zobel Battles, & Ryder, 2007b). The ISPs will need to be revisited annually and can be used as a tool for service providers in addressing young people’s fears and concerns with the transition process well before they are required to do so.

- 2. Utilize Peer Counseling.** Incorporating a peer counselor who has already transitioned to the adult clinic in the pediatric care model can be an invaluable tool in retaining young adults in care (Battles & Weiner 2002; Bettencourt, Hodgkins, Huba, & Pickett, 1998). The peer counselor should work closely with case management staff and be trained to reinforce health education messages, assist youth in managing their own care, and serve as a resource in retaining and linking young adults to varying levels of care. A peer counselor can also be utilized as the clinic’s initial point of contact for youth and can

be made available to clients outside of regular business hours. Finally, giving “graduates” of the pediatric clinic the opportunity to serve as a peer counselor can provide them with professional leadership skills, ability to travel to conferences if needed, and para-professional training to enhance their own career aspirations.

3. **Design and implement an orientation to adult care.** Developing routinely scheduled orientation sessions for youth preparing to enter the adult care system is another retention tool that can be utilized (Miles et al., 2004). During these orientation sessions youth and their families will be given a guided tour through the adult clinic, introduced to key contacts and other resource people in adult care, led through the process of recertification and other documentation processes that they will need to complete as a regular part of their care, meeting health care providers in the adult clinic, and have the opportunity to ask questions on the transition process and what to expect in adult care. Clinic staff can also engage youth at these regular intervals to evaluate the transition process, and introduce community partners and other outside linkages to care. This orientation would also be a place to introduce youth to the newer aspects of their medical decision-making while encouraging their personal involvement and investment in managing their own care.

4. **Incorporate a young adult clinic.** The initiation of a young adult clinic, while it requires resources and organizational change, can assist with keeping young people engaged in the care system. Such a clinic would only be available to young adults in the years immediately preceding and proceeding their 24th birthday. A young adult clinic may not require the acquisition of space, but can be accomplished by designating providers and clinic hours. In this way, young adults can schedule appointments with providers that have expertise and experience working with the specific physiological and psychological challenges of this age group and can retain connections to the pediatric clinic to ensure continuity of care (Wood et al., 2002). In addition, young adults may have the opportunity to see one another during wait times. Clinic hours should be extended so that patients can attend medical appointments outside of school and work hours. Studies have shown success in implementing a Saturday clinic for young adults to best engage and accommodate their schedules (Johnson et al., 2003). The young adult clinic can serve as a safety net for those leaving the comfort of the pediatric care model before they are fully engaged in adult HIV care and provide young adults the opportunity to develop a personal connection with their new providers.

5. **Facilitate routine support group meetings.** The young adults in this assessment desire a safe place for social interaction with other HIV positive youth. Toward that end, helping them to organize and facilitate regularly scheduled peer-led support groups may accomplish a number of goals. Youth largely want a non-judgmental environment where they can discuss issues unique to their experiences being HIV positive and to interact socially with their peers and service providers. These meetings could be held outside of the clinic, after school hours, and incorporate innovative non-HIV related topics for youth to enhance life skills and build social networks. Further, these groups can be used to communicate prevention messages for youth engaging in sexual activity, promote medication adherence, discuss any concerns with transitioning to adult care, and introduce youth to community partners in the HIV care system (Lightfoot, Rotheram-Borus, Tevendale, 2007).

SUMMARY

Easing the transition from adolescent to adult care is essential in providing comprehensive care to YPLWHA. The most important tool that medical providers and caregivers can have in aiding young people through this process is a transition plan. Adolescents and young adults have developed a personal relationship with the health care provider and are often very emotionally attached to their pediatric AIDS care team. The possibility of having experienced the loss of a parent and other loved ones to AIDS coupled with the harsh reality that HIV/AIDS is still a socially stigmatizing disease, further solidify the attachment (Weiner et al., 2007b). Pediatric AIDS clinicians and other staff are often the most consistent adult presence in the lives of the young people they serve so the idea of transitioning to an adult care clinic, with no ties to their previous care team, is one that causes great anxiety. Understanding that clear communication, assessment of readiness, expressions of self-confidence, and evidence of self-efficacy are essential tools in adopting or modifying any transition plan for YPLWHA (Weiner et al., 2007b). Ultimately, the goal of health care providers should be the facilitation of a comprehensive and seamless approach to transitioning pediatric clients into the adult care system subsequently ensuring that clients remain healthy and in care.

REFERENCES

- Battles H., & Wiener L., 2002. From Adolescence Through Young Adulthood: Psychosocial Adjustment Associated With Long-Term Survival of HIV. *Journal of Adolescent Health*. 30: 161-168.
- Bettencourt T., Hodgkins A., Huba G., & Pickett G., 1998. Bay Area Young Positives. *Journal of Adolescent Health*. 23s: 28-36.
- Callahan S., Winitzer R., & Keenan P., 2001. Transition from Pediatric to Adult Oriented Health Care a Challenge for Patients with Chronic Disease. *Current Opinion in Pediatrics*. 13: 310-316.
- Catalozzi M., & Futterman D., 2005. HIV in Adolescents. *Current Infectious Disease Reports*. 7: 401-405.
- Centers for Disease Control and Prevention. 2007. HIV/AIDS Surveillance Report. Retrieved from <http://www.cdc.gov/hiv/topics/surveillance/resources/reports/2007report/pdf/2007SurveillanceReport.pdf>
- D'Angelo L., Samples C., Rogers A., Peralta L., & Friedman L., 2006. HIV Infection and AIDS in Adolescents An Update of the Position of the Society for Adolescent Medicine. *Journal of Adolescent Health*. 38: 88-91.
- Fernet M., Prouix-Boucher K., Richard M., Levy J., Otis J., Samson J., ... & Trottier G., 2007. Issues of Sexuality and Prevention among Adolescents Living with HIV/AIDS Since Birth. *The Canadian Journal of Human Sexuality*. 16(3-4): 101-111.
- Georgia Department of Human Resources. 2006. Georgia HIV/AIDS Surveillance Summary. Retrieved from <http://health.state.ga.us/pdfs/epi/hivstd/2006%20HIV-AIDS%20Surv%20Summaryfinal.pdf>
- Georgia Department of Community Health. 2009. Georgia HIV/AIDS Surveillance Summary. Retrieved from http://www.health.state.ga.us/pdfs/epi/hivstd/Surv%20Summary%2007%20Data_FINAL.pdf
- Health Resources and Services Administration. 2003. Ryan White Comprehensive AIDS Resources Emergency (CARE) Act Needs Assessment Guide. Retrieved from <http://hab.hrsa.gov/tools/needs/>
- Johnson R., Botwinick G., Sell R., Martinez J., Siciliano C., Friedman L., ... Bell D., 2003. The Utilization of Treatment and Case Management Services by HIV-Infected Youth. *Journal of Adolescent Medicine*. 33s: 31-38.
- Kadivar H., Garvie P., Sinnock C., Heston J., Flynn P., 2006. Psychosocial Profile of HIV Infected Adolescents in Southern US cohort. *AIDS Care*. 18(6): 544-549.

- Lightfoot M., Rotheram-Borus M., Tevendale H., 2007. An HIV Preventive Intervention for Youth Living With HIV. *Behavior Modification*. 31(3): 345-363.
- Los Angeles County Commission on HIV. 2008. Standards of Care: Case Management, Transitional Services. 22-23.
Retrieved from http://hivcommission-la.info/cms1_047775.pdf
- McKay M., Block M., Mellins C., Traube D., Brackis-Cott E., Minott D., ...& Abrams E., 2007. Adapting a Family-Based HIV Prevention Program for HIV-Infected Pre-Adolescents and Their Families. *Social Work in Mental Health*. 5(3-4): 355-378.
- Miles K., Edwards S., Clapson M., 2004. Transition from Pediatric to Adult Services Experiences of HIV Positive Adolescents. *AIDS Care*. 16(3): 305-314.
- Weiner L., Battles H., & Wood L., 2007a. A Longitudinal Study of Adolescents with Perinatally or Transfusion Acquired HIV Infection: Sexual Knowledge, Risk Reduction, Self-Efficacy and Sexual Behavior. *AIDS Behavior*. 11:471-478.
- Wiener L., Zobel M., Battles H., & Ryder C., 2007b. Transition From Pediatric HIV Intermural Clinical Research Program to Adolescent and Adult Community-Based Care Services: Assessing Transition Readiness. *Social Work Health Care*. 46(1): 1-9.
- Wood E., Samples C., Singer B., Peters N., Trevithick L., Schneir A., ...& Huba G., 2002. Young People and HIV/AIDS: The Need for a Continuum of Care: Findings and Policy Recommendations from Nine Adolescent focused Projects. *AIDS & Public Policy Journal*. 17(2): 1-20.

APPENDICES

A. Qualitative Data Coding Chart	A: 1
B. IRB Determination Letter	A: 2
C. Recruitment Material	A: 3
D. Lay Summary	A: 5
E. Assent Information Sheet	A: 6
F. Participant Questionnaire	A: 8
G. Moderator Guide	A: 14

APPENDIX A: Qualitative Data Coding Chart

Code	Sub-code	Examples/Open codes
Most Important Services	Case Management	Care coordination, Staff turnover, Relationship with case manager, Satisfied, Feels like home, Professional boundaries, Frequency of contact with case manager, Number of case managers, New case manager, Case management coordination issues
	Primary Medical Care	Choose new doctor, Feel welcome, Limited service only, One stop, Outpatient/ambulatory care, Outside clinic, Staff are nice, Private practice, See different provider at visits, See same provider, Quality of medical care/services/staff
	Dental Care	Access to oral health, Private insurance, Wait time, Emergency Room
	Medication Assistance	Recertification, Stop medicine, Eligibility
	Peer Support	Support groups, Peer counselors, Peer Relationships, Relationship with provider
Barriers	Wait time/Hours of Operation	Access to care, Inaccessible services, Missing school, Needed not received, Optical care, Service issues, Miss work
	Financial	Medicaid, Medication assistance, Medications, Co-pay, Payment issue, Home delivered meals, WIC, Transportation assistance
	Stigma, Disclosure, and Breaches of Confidentiality	Disclosure of HIV status to clients, Finding out HIV positive, Hospital, <i>HIPAA/PHI violations</i> , <i>Privacy</i> , Mental health
	Wait time	Appointments, Discharge, Emergency room, Length of time with provider, Timely
Transition to Adult Care	Challenges	Age, Appropriateness of adolescent services, Drifting apart from provider, Feel comfortable, Getting older, Housing, Medications, New doctor, Patients staring at or hitting on other patients, Quality of care, Relationship with provider, Scared of adult patients, Stop coming, Choose new doctor, Involvement with planning HIV care, Young adult clinic

APPENDIX B: IRB Determination Letter



EMORY
UNIVERSITY

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

A2

If you want to make HIV Services in the Atlanta area better...

...and you are a teen or young adult

We Want to Hear from You!



The Southeast AIDS Training and Education Center (SEATEC) at Emory University is looking for HIV positive youth volunteers to participate in a study about HIV care needs.

About the study:

- Participation is voluntary
- You will not be asked to give your name
- Information will be collected through focus groups
- Each focus group takes about 2 hours
- Refreshments will be provided

Eligibility:

- Must be between 13-24 years old
- HIV Positive

Your help may improve services for people living with HIV/AIDS in Atlanta!

If you or someone you know would like to participate, please contact Yvette M. Wing, Special Studies Coordinator at **(404) 727-1550**.

APPENDIX C: Recruitment Material

Want to Improve HIV Services? We Want to Hear from You!

The Southeast AIDS Training and Education Center (SEATEC) at Emory University is looking for self-managed HIV positive volunteers to participate in a study about HIV care needs. Your help may improve services for people living with HIV/AIDS in Atlanta!

About the study:

- Participation is voluntary
- You will not be asked to give your name
- Information will be collected through focus groups
- Each focus group takes about 2 hours

Eligibility:

- Must be at least 18 years old
- HIV Positive
- Not in case management

Call Yvette Wing, study coordinator at (404) 727-1550 to participate

*This study is being conducted on behalf of Fulton County Government and the Metropolitan Atlanta HIV Health Services Planning Council. For more information, feel free to contact Rebecca Culyba, Project Director, at (404)727-4909.

APPENDIX D: Lay Summary

Metropolitan Atlanta HIV Needs Assessment Focus Groups Lay Summary

Problem of interest:

HIV/AIDS is a leading cause of illness and death in the United States. Georgia and other southern states have been especially hard hit, particularly among African Americans. To date, the Atlanta metropolitan area stands out as one of the hardest hit by HIV/AIDS. Fulton County Government receives federal funding under the Ryan White Program (formerly called the Ryan White CARE Act), to provide medical and support services to people living with HIV and AIDS (PLWHA) in twenty counties in and around metro Atlanta. Since these services are provided as part of a large network of service programs in the area and since the HIV/AIDS epidemic changes with the advent of new treatment and prevention methods, it is necessary to periodically evaluate existing services, including identifying needs that are not currently met by this network and barriers that PLWHA face when trying to access services in the network. The Southeast AIDS Training and Education Center (SEATEC) conducted the 2007-2008 Metropolitan Atlanta HIV Consumer Survey. This study built on similar studies conducted by SEATEC in 1999 and 2002. Fulton County Government has asked SEATEC to conduct a follow-up study with special populations of PLWHA in the twenty county region of the Atlanta metropolitan area to find out their current HIV care needs and any barriers they face when accessing medical and support services. SEATEC has conducted focus groups as part of the Georgia Statewide HIV Prevention Needs Assessment in 2002 (SHB-IRB 106-2002) and the Atlanta EMSA Housing Needs Assessment for People Living with HIV/AIDS (SHB-IRB 1268-2004) in 2005.

How the problem will be studied:

SEATEC will collect information through focus group interviews with PLWHA who agree to participate in the study. SEATEC staff will conduct focus groups with self-managed and adolescent PLWHA in metro Atlanta. Participants will be recruited from AIDS service organizations, community agencies, substance abuse treatment centers and primary care centers. Organizational staff will initiate contact with clients and ask them if they are interested in participating in the study. If clients express interest, a member of the research team will review study information with them. Final results from the study will be compiled into a report and presented to Fulton County Government as well as to the Metropolitan Atlanta HIV Health Services Priority Committee for use in local level planning.

Advancement of human health:

The information gathered as part of the HIV Consumer Survey will be used by Fulton County Government and the Metropolitan Atlanta HIV Health Services Planning Council to evaluate the current HIV service delivery network in order to develop future plans and identify areas in need of change. It will affect HIV/AIDS care services planning, delivery and evaluation. It is a unique opportunity for PLWHA to voice their concerns and have a say in the way that money is given to different programs and services that they use. This study will continue to enable Fulton County Government to meet the changing needs of PLWHA in the Atlanta metropolitan area.

APPENDIX E: Assent Information Sheet

Metropolitan Atlanta HIV Needs Assessment Focus Groups

Assent Information Sheet

Introduction/Purpose:

My name is _____ and I am a researcher with The Southeast AIDS Training and Education Center at Emory University.

Fulton County Government has asked that we, the Southeast AIDS Training and Education Center (SEATEC), find out more about the needs of HIV positive adults and youth in Atlanta. You are being asked to be a part of this research study because you are between the ages of 13-24, use HIV services in the Atlanta area, and have been or are currently in care. Your opinion on the services you use or need will help Fulton County to decide the HIV care services available for people living with HIV/AIDS in Atlanta.

In order to find out the needs of HIV positive youth, SEATEC will hold volunteer focus groups with HIV positive youth from all over Atlanta. In a focus group 8-10 different people sit around a table and answer questions asked by a facilitator and co-facilitator. They are asked to share their opinion to help us understand the needs of different people on different subjects. What we share in the focus groups will help us get to know what HIV services are needed by people living with HIV or AIDS in Atlanta.

Procedures:

Each focus group will last about 2 hours. There will be about 10 HIV positive youth in the group with you. You will be asked not to use your name in the focus groups and we will give you a number instead. 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 needs of HIV positive youth 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 and Risks:

We do not know for sure if you will be helped by being in this study but it will help the way Fulton County uses money and gives services to HIV positive youth 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. Also we will not use your name when we write our summary of the focus groups. If you think you have been hurt by this research, please call Rebecca Culyba at (404)727-4909.

Voluntary Participation and Withdrawal:

This is a volunteer study and you will not be treated any differently if you say "no" or that you do not want to participate. You do not have to be in this study if you don't want to. You don't have to answer questions when you don't want to and can leave the group anytime. Nobody will be mad or punish you if you don't want to be in the study. You can say yes today and change your mind later. Your doctors, nurses, and case managers will still take care of you if

APPENDIX E: Assent Information Sheet

you don't want to be in the study. If you do decide to be in this research study you will take part in a focus group with other HIV positive youth in the Atlanta area to talk about your health care needs.

Confidentiality:

The things we talk about in the group are just between us and we will not talk about them with anyone. This is called keeping things confidential. So we will not tell others what you said in the group, and your service providers will not treat you differently for being a part of the group.

We will not take your name at any time during the study. You are asked to not use names when talking to each other and to not to use the names of anybody else even if they are not a part of the group. Everyone will be given a participant number before the group starts. Please use this number instead of names.

We will keep all facts about you private. Only the people in the group will know what is said in the focus group unless you tell us something that could be you or others. Then we will tell an agency staff person at the end of the group so that you can get help. None of your personal information, like name, will be used in the report summary and the tapes will be destroyed in 2 years after we give the report to Fulton County.

Costs and Compensation:

There is also no cost to you for being in this study. . We will have food and drinks during the group for everyone and you will get a \$20 gift card for your participation in the focus group.

You will be provided emergency care if you are hurt by this research. However, Grady Health System has not set aside funds to pay for this care or to compensate you if a mishap occurs.

If you have any questions about this study or believe that taking part in this study has harmed you, please contact Rebecca Culyba, project director at 404-727-4909 or rculyba@emory.edu. If you are a patient receiving care from the Grady Health System, and you have a question about your rights, you may contact Dr. Curtis Lewis, Senior Vice President for Medical Affairs at (404)616-4261. You may contact the Emory University Institutional Review Board if you have any questions about your rights as a participant in this research study. Their telephone numbers are: (404) 712-0720 or toll free at 1-877-503-9797.

Entitlement of Assent Form and Agreement:

You will get a copy of this assent form. Please put your participant number below to let us know that someone has gone over this form with you, answered all of your questions, and you agree to participate.

If You Agree to Be In This Study, Please Sign Below:

Participant Number

Date

*Person Soliciting Consent:*_____

APPENDIX D: Participant Questionnaire

Metropolitan Atlanta HIV Needs Assessment Focus Groups

PARTICIPANT QUESTIONNAIRE

Note: All the information collected here will be kept strictly confidential. If you feel uncomfortable answering any question, you can leave it blank.

1. Gender

Female

Male

Transgender

2. Age

13 to 20 years

21 to 30 years

31 to 40 years

41 to 50 years

Over 50 years

3. Answer both parts of this question.

Ethnicity:

Hispanic or Latino

Not Hispanic or Latino

Race: (You may choose more than one.)

American Indian or Alaska Native

Asian

Black or African American

APPENDIX D: Participant Questionnaire

Native Hawaiian or other Pacific Islander

White

4. Where are you living 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 zip code?

6. What is your sexual orientation?

Heterosexual/straight

Gay/Lesbian

Bisexual

Other (specify)

7. What is your preferred language?

English

Spanish

Vietnamese

Other (specify)

APPENDIX D: Participant Questionnaire

8. Highest level of education completed

- 8th grade or less
- Some high school but didn't graduate
- High school graduate or GED
- Vocational certification
- Associate degree
- Some college
- Graduated College

9. Current employment status

- Employed full-time
 - Employed part-time
 - Unemployed
 - Volunteer work
 - Other (specify)
-

10. What type of health insurance do you have?

- Medicaid/(HMO/MCO)
- Medicare
- HMO (like Kaiser Permanente)
- Private insurance (not an HMO)
- Private insurance (HMO)
- None

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

- Less than 12 months

APPENDIX D: Participant Questionnaire

1 to 4 years

5 to 9 years

10 years or more

12. In general, how would you rate your overall health at the present time?

Very good

Good

Fair

Poor

13. 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

14. Are you taking a combination of antiretroviral drugs?

Yes

No

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

Pay for them myself or get help from family or friends

Private insurance

Medicaid

Medigap policy

Clinical Trials

AIDS Drug Assistance Program (ADAP)

Other (specify)

APPENDIX D: Participant Questionnaire

16. What was your last CD4 count?

Less than 200

200-500

Over 500

Don't know

17. When was your last CD4 count taken?

within the last 3 months

3 - 6 months

more than 6 months ago

18. Measuring the amount of HIV in your blood is called a viral load test.

Have you ever had a viral load test?

Yes

No

If yes, when was it taken?

within the last 3 months

3 - 6 months

more than 6 months ago

19. Are you receiving services funded through the Ryan White CARE Act?

Yes

No

Not sure

APPENDIX D: Participant Questionnaire

20. Do you have any children?

Yes

No

21. If yes, what are the ages of
your children?

22. Are any of your children HIV-positive?

Yes

No

23. Were you on an antiretroviral drug regimen containing AZT or Combivir
during your pregnancy?

Yes

No

N/A

24. Are you pregnant now?

Yes

No

N/A

25. If so, are you on an antiretroviral drug regimen containing AZT or Combivir?

Yes

No

THANK YOU!

APPENDIX E: Moderator Guide

Design:

Structured focus group (keeps 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.

Greet participants as they arrive. Ask them to take a seat and make themselves comfortable. (If there are refreshments, encourage them to help themselves). 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 they should not write their names on anywhere on the survey. We will not be using any identifying information such as their name, agency where they receive services, or personal information (i.e., address, phone number) in any of our reports. Also, distribute lay summaries for participants to review 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 _____. We are both from the Center for Applied Research and Evaluation Studies at the Southeast AIDS Training and Education Center at Emory University in Atlanta (SEATEC). 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. Anyone who is at least 13, and has HIV or AIDS is being asked to participate. Your input will potentially impact HIV care services available for people living with HIV/AIDS in Atlanta.

A focus group is a roundtable discussion with a small group of people led by a facilitator and co-facilitator and is very structured, asking everyone to respond to specific, pre-developed questions. Focus groups are conducted to gather information about certain issues, and to gain a better understanding of different needs. We want to get information on the service needs of people living with HIV and AIDS in the Atlanta 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 s/he will also be taking notes. In addition we will be audio taping the session, to ensure that we record the discussion accurately. The discussion session today will take about 1 ½-2 hours.

APPENDIX E: Moderator Guide

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 do not use your name at any point during the focus group. Feel free to say any other information about yourself, other than your name, that you want to share with the group.

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 participating in this group 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 study. We need honest input from participants and we will ask that everyone at the session respect the confidentiality of other participants. Confidentiality means that whatever is said during the focus group should not be repeated to people who did not come to the focus group. All information gathered during this study will remain confidential to the extent permitted by law. To ensure confidentiality, please do not use your name or the names of other participants when speaking to each other. 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 write a summary of what was discussed in the focus group on HIV service needs in metro Atlanta. SEATEC will be combining the information from this focus group with the information from other focus groups to present 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 study or think that talking to me has hurt you, please call or have your parent or guardian call Rebecca Culyba. **[Point out the contact information on the information sheet.]** If you are a patient receiving care from the Grady Healthcare System and you have a question about your rights as a Grady patient, you may contact Dr. Curtis Lewis. He is the Senior Vice President for Medical Affairs for the Grady Health System. **[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 study, you may contact the Emory University Institutional Review Board. **[Point out the contact information on the information sheet.]**

Are there any questions about the study before we begin?

Getting Started: Thank you again for participating in this focus group. The information you provide is important and will really help Fulton County better address the needs of youth clients in the Atlanta metro area.

Let me start by going over how we will run the session. During this focus group, we are going to ask you a number of questions and we would like you to focus on answering those questions as best you can. Answer questions based on your personal experiences and knowledge of the topics. We are interested in what everyone has to say about our discussion topics. If someone throws out an idea that you want to give more information about, or if you have a different point of view, please feel free to say something. At some point, 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

APPENDIX E: Moderator Guide

There are some ground rules that we will follow during this session:

1. We want all of you to feel free to express your opinions about the topics. We are interested in everybody's point of view. There are no right or wrong answers, and we are not here to solve any issues you may bring up.
2. Please do not hold side conversations (talking to your neighbors while someone else is talking). Having side conversations not only disrupts the discussion but because we are recording this session, it would really help us if you could speak up so that everyone can hear you. Also, your opinions are valuable and we would like you to share them with the entire group.

Are there any questions, so far, about what was just covered? 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.

1. **What are the most important HIV-related services or care you are using now or have used in the last year?**
Prompt: medical care, dental care, case management, transportation, mental health, substance abuse counseling, support groups, etc
2. **What agencies or types of providers are you currently obtaining services from?**
For example, AIDS service providers, community-based organizations providing social services, neighborhood clinics, hospitals, etc.
3. **Do you have a case manager?**
Prompt: how many, how often do you see/contact him/her per week, how do you coordinate schedules, how do you get there (transportation), any problems, etc.
4. **Are you satisfied with the particular services you have used?**
Prompt: medical care, dental care, case management, transportation, mental health, substance abuse counseling, support groups, etc. **Why or why not?**

Probe: **Are you satisfied with the options you have for services?** (i.e., the providers/agencies available) **Why or why not?**
5. **Are you satisfied with the location and hours of operation of the services you currently use?**
Probe: **Why not, what is reasonable?**
6. **Are there instances when you have felt particularly welcome, comfortable, motivated by an agency?**
Prompt: (If examples are provided) did you ever tell anyone at the agency about your experience? What about your case manager, if you have one? Or someone else you know who is HIV-positive?
7. **Are there instances when you have felt particularly unwelcome, uncomfortable, discriminated at an agency?**
Prompt: (If examples are provided) did you ever tell anyone at the agency about your experience? (If so, did they respond in a way that helped or made you feel better? Did they respond in a way that made you feel worse?)
8. **Have you experienced any problems in trying to get services that you need?**
Probe: (unhelpful attitudes, behaviors, travel a great distance to receive service, transportation problems, inconvenient hours of operation, having to pay a fee for services, unmanageable waiting time to get an appointment or to see a provider once you are there, hassle by staff or other clients, language/cultural barriers)

Prompt: **Are services appropriate for you? (adolescents)**

APPENDIX E: Moderator Guide

9. What services or care do you need, but are unable to get?

Probe: (support groups, transportation, coordinated appointment schedules, HIV education, food, prescription drugs/medication, insurance coverage?)

10. What concerns do you have about transitioning into adult care and getting the services that you need?

11. What would be the single most important change you would suggest to improve services to adolescents?

12. If there was one thing you could change about services for adolescents, or one recommendation you could make to providers or those serving adolescents – what would it be?

13. Is anyone in this group or a family member involved with support groups or committees that discuss the planning of HIV care?

Probe: (Atlanta HIV Health Services Planning Council, Consumer Caucus, community advisory boards, spiritual/church groups, etc.) **If not, would you be interested? What would make it possible for you or a family member to become involved?**

14. Is there anything else you would like to add? Are there any questions that I can answer before we end the session?

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 reimbursement before you leave, and help yourself to any refreshments that are left. Thank you again for your help!