

2007-2008 Atlanta EMA HIV Consumer Survey

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

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DATA COLLECTION SITES

- Absolute Wellness
- AID Atlanta
- AID Gwinnett
- Atlanta Interfaith AIDS Network
- Atlanta Legal Aid
- Cobb/Douglas Department of Public Health
- DeKalb County Board of Health
- The Edgewood
- Fulton County Department of Health and Wellness
- Grady Infectious Disease Program
- Infectious Disease Associates/Clayton County Health Department
- Emory Infectious Disease Clinic at Emory Crawford Long Hospital
- Jerusalem House
- The Living Room
- Matthew's Place
- Our Common Welfare
- Open Hand
- Positive Impact
- SisterLove, Inc.
- St. Joseph's Mercy Care Services

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GLOSSARY OF CONSUMER SURVEY TERMS

Certain terms were used during the data collection process, as well as throughout this report. The most commonly used terms are defined in this glossary.

Adoption or foster care help: Temporary care for your children when you become very ill or permanent care for your children if you pass away.

CAREWare: A free software application provided by the Ryan White HIV/AIDS Program used to manage and monitor HIV clinical and supportive care data.

Case manager: Someone who helps you with referrals, filling out forms, benefits counseling, etc.

Childbearing age: Women between the ages of 15 and 44 (for the purposes of this project childbearing age is defined as women 18-44).

Childcare: Someone to watch your child at a center or in a house when you go to the doctor.

Client Level Data (CLD): Demographic and service information for each unique client in the EMA unduplicated using the Unique Record Number (URN) generated in CAREWare.

Drug or alcohol counseling: Talking to a trained counselor about your substance abuse problems.

Drug or alcohol day program: A place you go during the day, like aftercare, where trained staff focuses with you on substance abuse issues.

Drug or alcohol treatment: Inpatient or outpatient medical treatments at a hospital or a program run by trained staff, but not a day program.

Eligible Metropolitan Area (EMA): A geographic area eligible to receive Part A Ryan White HIV/AIDS Program funds. Eligibility criteria include having a population over 500,000 and reporting more than 2,000 cumulative AIDS cases for the most recent five-year period. The EMA includes the following counties: Barrow, Bartow, Carroll, Cherokee, Clayton, Cobb, Coweta, DeKalb, Douglas, Fayette, Forsyth, Fulton, Gwinnett, Henry, Newton, Paulding, Pickens, Rockdale, Spalding, Walton.

Home nursing or home infusion care: When a nurse comes to your home to provide you with medical care other than hospice care.

Hospice care: Care in your home or at a facility when you are in the late stages of HIV disease.

Legal help services: Assistance with legal issues like housing and insurance discrimination, writing a will, social security disability claims, etc.

Medications other than antiretrovirals: Any medications you take to prevent yourself from getting sick like Bactrim and antidepressants.

One-to-one peer counseling: Not a relationship with a friend or a sponsor, but a formal relationship with someone who has HIV or is in recovery that you talk to about your feelings or problems.

Other medications: Any medications you take other than those we have already talked about. This would include medication for high blood pressure or diabetes but does not include over the counter medications.

Primary medical care: When a person goes to a clinic or agency to see a doctor or nurse for medical care.

Professional mental health counseling/therapy: A trained counselor that you can talk to about how you feel.

Ryan White HIV/AIDS Program Annual Data Report (RDR): An aggregate report required of service providers that receive funding from the Ryan White HIV/AIDS Program detailing aggregated information on all the clients they served during the course of a calendar year.

Support groups: Talking to people in a group setting about how you feel, but does not include 12 step meetings.

Translator/Interpreter services: You need someone to explain things to you in a language other than English such as Spanish, French or Sign.

EXECUTIVE SUMMARY

The 2007-2008 Atlanta EMA HIV Consumer Survey 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, who requested this project to support the fiscal year 2009 priority setting process.

Three hundred and fifty (350) anonymous interviews were conducted in English or Spanish with People Living with HIV/AIDS (PLWHA) who were at least 18 years of age and were accessing services at Ryan White and non-Ryan White funded agencies in the Atlanta Eligible Metropolitan Area (EMA). The final sample was proportionally consistent with the race and gender of people reported to be living with AIDS (PLWA) as of December 31, 2005.

Both epidemiological and Client Level Data (CLD) were utilized to provide additional information through which to interpret the HIV consumer survey results. Recommendations are based on previously published research as well as knowledge of the existing HIV care system in the EMA.

OVERVIEW

As in the United States over the past 13 years, the EMA has seen a decline in reported new AIDS cases and an increase in the number of PLWA. Client Level Data show that Ryan White providers have been serving an increasing number of PLWHA over the past six (6) years; also, more of these PLWHA are women, Blacks, and over the age of 50. Overall, the EMA appears to have responded well in providing comprehensive care to the changing population, adapting to both demographic changes and the increase in the number of people who need services. Of the 26 services that were examined in the HIV consumer survey, eight (8) met the criteria for having service gaps (greater than or equal to 15% of participants reported needing but not receiving the service). Some of the successes in the EMA include:

- 77% of survey participants reported receiving primary medical care
- 73% of survey participants reported taking antiretroviral medications

- 78% of all survey participants reported they had a case manager¹
- 50% of all women of childbearing age reported having received information to protect their baby from contracting HIV/AIDS during pregnancy
- The number of people served by Ryan White providers has increased over the past 10 years

CHALLENGES AND POSSIBLE NEXT STEPS

While the EMA met the majority (18/26) of the service needs addressed in the HIV consumer survey, there were eight (8) services that met the criteria of having service gaps. The following discussion highlights the top four (4) of the eight (8) services for which there was an unmet need: dental care, food pantry, home-delivered meals, and legal help. All survey participants were asked about the barriers they encountered for the services that they needed but did not receive. These responses were coded into one of nine (9) categories: capacity, system, information, financial, medical, personal issues, began process, other and don't know.²

Current challenges are presented in three areas: barriers, top services needed but not received, other factors, and demographics. These challenges are based on interpretation of the multiple data sources previously discussed. Possible next steps, presented where feasible, are based on existing research and propose approaches that have previously been useful to other providers.

Barriers to Services

Personal barriers were the most frequently reported barrier to receiving services in the EMA. For the purposes of this study, personal barriers were defined as issues related to the individual such as they had not done it yet, they are uncomfortable or too proud to ask about or for a service, or they rely on family or friends. Women, women of childbearing age, and Hispanics reported personal barriers less frequently than males or other racial/ethnic groups.

Personal barriers are a challenge to system-level interventions in the EMA primarily because they are insufficiently understood. Recent studies have found that perceived stigma, health

¹ This proportion was higher than a national study where 59% of participants reported a case manager and the 2002-2003 HIV Consumer Survey, where 65% of participants reported having a case manager (Cunningham et al. 2006)

² Definitions for these categories can be found on page 35 of this document.

beliefs, or lack of trust in care providers and the government can be barriers to health service use among those living with HIV/AIDS (Bradford et al. 2007; Rumpitz et al. 2007; Whetten et al. 2006). Additional research focused on the role of patient knowledge and beliefs as barriers to care in the EMA may help to support a better understanding of issues defined here as personal barriers to receiving care.³

Information and capacity barriers were also frequently reported. Information barriers were defined as not knowing where to go or who to ask for the service or not knowing that the service was available, while capacity barriers were defined as the need for more specific services to meet needs. Information barriers were reported most frequently by women, women of childbearing age, and Hispanics across service categories.

Information barriers emphasize the need to examine methods to increase the knowledge of PLWHA about available services and assist them in accessing services. Possible approaches could include peer counseling programs, case management or marketing campaigns. Increased information about the services would also be anticipated to increase the demand for the services. One recent study showed that a time-limited case management intervention linking newly diagnosed HIV positive people to care was effective with the exception of active drug users (Gardner et al. 2005). While such intensive case management interventions may be costly, targeted interventions may be effective both in terms of cost and health outcomes in the long run (HRSA 2008a).

Top Services Needed but Not Received and Associated Barriers

As in the 1999-2000 and 2002-2003 HIV consumer surveys, dental care was most frequently reported, by 46% of participants, as being needed but not received in the EMA. Greater proportions of dental care need were reported by Black survey participants (50%) than Hispanics (46%) or Whites (33%). Similarly, men also reported a higher proportion of unmet oral health need (48%) than women (41%) or women of childbearing age (37%). This continuing service

³ Rumpitz et al. (2007) found that the following beliefs were significant barriers to engagement in care: faith will help with HIV; too healthy, basic needs take precedence, medication side effects, mistrust in health care system, and no cure for HIV.

gap is consistent with research that shows the unmet oral health care needs of PLWHA are higher than the general population (Marcus et al. 2005).

Moreover, studies have noted that Blacks have higher unmet dental needs than Whites and report more episodic preventive dental care (IOM 2003; Newman and Gift 1992; Hudson et al. 2007). In addition, the South, as compared to other regions, has the highest levels of dental care need for PLWH (Marcus et al. 2000). The most frequently reported reason that survey participants did not get dental care was for personal reasons, followed closely by capacity and financial barriers. Hispanics, however, reported financial and system barriers more frequently than personal or capacity barriers. A recent study of 137 HIV-positive Blacks found that fear of status disclosure was a significant barrier to patients accessing oral health services (Rohn et al. 2006). This mirrors findings reported in a North Carolina study which found that cost and fear were the primary barriers to receiving dental care; cost was a perceived barrier regardless of whether or not it was an actual barrier, given that many of the clients qualified for low or no cost services (Patton 2003). This study also noted that cost being reported as a barrier may have been reflective of a lack of knowledge about available services or being unable to find a provider.

Previous studies highlighted high unmet dental care need with corresponding low capacity. The number of dentists in Georgia showed a promising increase from 1998 to 2001 (from 4,567 to 5,105) however, 2005 levels (4,269) fell below those from 1998 (CDC 2008a). Nationally, the number of practicing dentists has been static since 1990 (HRSA 2008b). Given this limited oral health workforce, increases in funding alone may not address the issue of capacity. In 2005, the Priorities Committee of the Metro Atlanta HIV Services Planning Council allocated additional funding to oral health services in the EMA, resulting in increased capacity. Client utilization data in the EMA show an increase in the number of dental clients and services at a higher rate than clients overall from 2006 to 2007. In addition, CLD data show that the proportion of clients who have received at least one dental service has increased from 16% of clients in 2002 to nearly 25% of clients in 2007.

Oral health care has been linked to improved access to health care, improved health status, and improved quality of life for PLWHA. Moreover, PLWHA experience the same oral health problems as non-PLWHA, but weakened immune systems result in an increased number of rare oral conditions that cause problems with nutritional intake and absorption of HIV medications

(HRSA 2008b). With PLWHA living longer, increasing numbers of Blacks and Hispanics entering the care system, and increasing numbers of newly diagnosed HIV clients in the Ryan White system over the past ten years; the need for dental care is likely to be impacted and continue to increase gaps in services with oral health care services beyond preventive care. There are anecdotal reports that clients who currently receive dental services need more extensive care that may not be provided by all providers in the EMA.

In order to increase the number of dental providers that provide these services, existing dentists and dental professionals may need additional training on HIV related issues to increase their ability to respond to this need. At the trainings, barriers such as the willingness to treat HIV infected persons and stigma need to be addressed. The EMA may learn from HRSA's Special Projects of National Significance (SPNS) HIV/AIDS Oral Health Care Initiative launched in 2006. For example, one demonstration site has partnered with dental hygiene programs, federally qualified health centers, and local health departments to make use of existing space for the provision of oral health care (HRSA 2008b).⁴

To address perceived financial barriers to receiving dental care, which may be tied to misinformation, individuals need to be informed about available reduced or no cost services in both English and in Spanish. However, increased awareness about these services may underscore the capacity issues already raised, lengthening already long waiting periods for appointments. Finally, examining Medicaid's ability to provide more extensive dental coverage for adults may be a long term effort, but this should be coupled with interventions designed to increase the number of providers willing and able to provide dental services beyond preventive care in the EMA for HIV infected persons.

Food pantry, home-delivered meals, and legal help were the remaining top services for which there was an unmet need, mirroring those services noted in previous consumer surveys.⁵ Survey participants reported information and personal barriers for these services although the order

⁴ See also the Evaluation Center for HIV & Oral Health (ECHO) providing multisite evaluation coordination and technical assistance at <http://www.hdwg.org/echo/>.

⁵ In the 2002-2003 survey, there were additional categories of emergency help paying utility bills and emergency help paying for groceries and free groceries, with the remaining top services being legal help and transportation assistance. There was an additional category in the 1999 consumer survey of emergency help paying rent, with the remaining top services being free food, emergency help paying for groceries, rent and utility bills.

varied. Specifically, participants reported a lack of information most frequently as the barrier to receiving food pantry and legal help, followed by personal barriers for each. Participants reported information and personal barriers at similar rates for home-delivered meals; these were followed by system barriers.

Client Level Data (CLD) extracted from CAREWare show an increase in the number of clients using both food bank and home-delivered meal services and emergency financial assistance in the EMA from 2006 to 2007. However, CLD data show that the number of legal help clients and services decreased in the same period. Consumer survey participants who self-reported as Hispanic had a higher level of unmet need for food pantry services (25%) than other ethnic/racial groups. Blacks and Hispanics had higher levels of need for home-delivered meals (both 29%) than Whites (21%).

Respondents 50 years of age or older also reported a higher level of unmet need for home delivered meals (33%) than others. Income was not a major indicator related to those who reported needing but not receiving home delivered meals.

Other Factors: Housing, Case Management, and Health Literacy

Analysis of the data showed that factors such as housing status, functional health literacy, and case management may impact specific services. Specifically, individuals who reported having trouble with housing in the last twelve months reported more services needed but not received and were more likely to need services such as dental care (51%), home delivered meals (35%), food pantry (35%) and legal help services (24%). Individuals who did not have trouble getting housing were more likely to use dental care (43%) and food pantry (24%). A recent review of the literature concluded that increased housing stability was positively associated with improved health outcomes (Leaver et al. 2007). By contrast, homelessness and unstable housing is associated with increased HIV risk behavior (Kidder et al. 2007). Personal and information barriers were most frequently reported by those who had trouble with housing. Case managers and peer counselors may be an effective way to address the information barrier.

In 2005, the Metro Atlanta HIV Services Planning Council approved quality management standards for case management that included a screening and assessment process where clients

can be categorized as self-managed either upon entry as a new client in the system or as a result of “graduating” from case management during a regular assessment by the case manager. In part, self-managed clients are determined to be able to access medical care without the services of a case manager and are provided referrals to the AIDS Drug Assistance Program (ADAP), peer counseling services as well as being provided referral and service information in a resource packet. Self-managed clients are re-screened after reporting emergent needs resulting in serious and immediate consequences for the client if left unmet.⁶ Thus, case managed clients are expected to have more unmet needs and barriers to accessing services in the EMA. Given this system, case management was anticipated to impact service use and need based on the findings of other studies that found a beneficial relationship between case managers and physical health for clients not already receiving a recommended HAART regimen (Cunningham et al. 2008). However, participants who reported having a case manager used most services at similar rates to those reporting no case manager. Those with a case manager reported personal barriers most frequently, followed by information and capacity barriers. Those without a case manager reported more services needed but not received and were less likely to report financial barriers. Field interviewers reported that some participants did not know whether they had a case manager or not while those who reported being self-managed were counted as having no case manager. Thus, this study was not able to capture the frequency of use, need, or barriers to services specific to self-managed consumers. Additional research may be necessary to evaluate the success of this system as well as to explore the specific needs and barriers of those determined to be self-managed.

Functional health literacy, such as understanding medical instructions, continued to be an issue of the clients participating in the consumer survey. Specifically, survey participants who reported they could not remember their T-cell count reported more services needed but not received. They were also more likely to report system barriers. Research suggests that PLWHA who do not remember their T-cell counts may have lower health literacy. Persons with lower health literacy have been shown to be more likely to be hospitalized, perceive their health as poorer, have more compromised immune systems, and greater viral burden. They are also less likely to adhere to antiretroviral medications, more likely to doubt the potential benefits of

⁶ EMA Quality Management Standards and Measures: Case Management. 2005.

medical treatment and more likely to distrust their providers (Kalichman and Rompa 2000). This was evident in the current consumer survey, where people who could not remember their T-cell counts were also less likely to use HIV medications, dental care, mental health services, peer counseling, and have information about support services. Proposed solutions to this challenge by researchers include targeted interventions and methods of patient education that match the skills and abilities of lower literacy patients such as simplified instructions and color coded medicine bottles and pillboxes (Kalichman and Rompa 2000). In addition, linking these individuals to a case manager or peer counselor may help to address the system and information barriers reported.

Demographics: Race, Gender, and Age

Hispanics and Blacks reported more services needed but not received compared to Whites. Hispanics were more likely to report information and capacity barriers. In addition, Hispanic participants reported needing but not receiving support groups, peer counseling, and transportation assistance more than other ethnic/racial groups. Blacks were more likely to use support groups while Whites were more likely to use professional mental health counseling. Given that the number of Hispanics and Blacks is growing in the Ryan White system, it is essential to ensure the services they use and need exist. Case management or peer counseling services may prove particularly valuable for Hispanics to assist with service linkage and understanding about service requirements. In addition, increased translation services could help to address information and system barriers.

A defining feature of the HIV/AIDS epidemic in the U.S. has become the increasing number of women, particularly women of color and women of childbearing age, who live with the disease (Kaiser Family Foundation 2007). Epidemiological data show that approximately 85% of female PLWA in the EMA at the end of 2005 were women of color.⁷ According to CLD data, in 2007, 93% of the women served by the Ryan White system in the EMA were women of color. Of the 87 female consumers surveyed as part of this study, 95% were women of color and 53% were of childbearing age (18-44).

⁷ Women of color are those who self-reported their race/ethnicity as Black/African American, Hispanic, or Other.

In general, female survey participants reported using services similar to men, with women of childbearing age also frequently reporting use of transportation assistance. Unlike men, women and women of childbearing age reported that they needed but did not receive transportation assistance more frequently than home-delivered meals or legal help. They also reported needing but not receiving referrals to services more frequently than consumers surveyed overall. Women and women of childbearing age reported information barriers most frequently, followed by personal, capacity and system barriers. Targeted case management or peer counselors may be an effective way to address information barriers. One study showed that the provision of transportation was effective in retaining women in medical care, while transportation coupled with an individualized nurse counseling intervention also improved attendance to medical care (Anderson et al. 2007).

Further, women face a unique set of burdens related to HIV/AIDS: first, women are more susceptible to infection than a male partner during heterosexual intercourse; second, women are more likely than men to take care of loved ones and children infected with the disease; third, women tend to be more economically dependent and experience more domestic violence and sexual coercion than men; and, finally, women have clinical manifestations and treatment requirements that differ from men (Culyba 2009). In addition, studies have shown that domestic violence and other trauma serve as barriers for HIV-positive women accessing regular health care (Lichtenstein 2006; Whetten-Goldstein and Nguyen 2002).

As a result of effective antiretroviral therapy, PLWHA are living longer. Older PLWHA may need additional or specialized health care to deal with coexisting conditions such as diabetes, age-related manifestations of HIV, as well as treatment for the side effects of antiretroviral therapy and/or resistance testing and adherence counseling to support changes in antiretroviral therapy regimens (CDC 2008b). One study found that PLWHA over 50 are isolated from traditional social networks due to stigma and ageism (Shippy and Karpiak 2005). Thus, the aging of clients in the EMA may present new challenges to the Ryan White system in Atlanta. While consumers over 50 reported barriers at similar proportions to those under 50, they reported personal barriers more frequently than younger participants. Monitoring of the growth and emerging needs of this population may be warranted.

SUMMARY

Addressing the needs of people living with HIV disease presents ongoing challenges to system-level interventions given the changing demographics and the shift from an acute to a chronic disease. The challenges that the uninsured and underinsured populations living with HIV currently face often preexist their HIV status complicating the Ryan White system's ability to comprehensively meet their needs. Strategies aimed at improving agencies' ability to adopt evidence-based practices, maximizing the sustainability of services, and incorporate the needs of the community into tailored services are potential system-level approaches (Bauermeister et al. 2008). Collaborating with other systems such as Medicaid, as well as with other Ryan White funded programs, in order to optimize existing resources will be crucial in the coming years, particularly as funding levels remain stagnant or decrease in the EMA.

What follows in this report is information collected and analyzed in an effort to help focus priorities to meet the needs of people living with HIV disease in the context of the Ryan White system in the EMA. Detailed data about services used, needed but not received and barriers to services are presented.

INTRODUCTION, METHODOLOGY AND REPORT FORMAT

From May 2007 to May 2008, 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 conducted the HIV Consumer Survey. This study was conducted on behalf of Fulton County Government and the Metropolitan Atlanta HIV Health Services Planning Council, who authorized this project to support the fiscal year 2009 priority setting process. This study is an update of the 2002-2003 HIV Consumer Survey.

The primary data collection methodology was anonymous in-person interviews with PLWHA in the Atlanta Eligible Metropolitan Area (EMA) who were receiving services at Ryan White Part A funded agencies and non-Ryan White Part A funded agencies.

METHODOLOGY

Study planning was initiated 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 issues to be addressed by the study were discussed. In April 2007, CARES staff met with the Assessment Committee of the Metropolitan Atlanta HIV Health Services Planning Council to discuss population-specific issues for the study. The data collection protocol was designed for implementation in two phases: phase I included data collection at Ryan White Part A funded agencies in the EMA only and phase II expanded data collection to non-Ryan White Part A funded agencies in the EMA. Data collection and sampling strategies were guided by epidemiological and Client Level Data, which also served to contextualize the data presented in the final report. All protocols, recruitment materials, and data collection instruments were submitted by CARES staff to Emory University Institutional Review Board (IRB00003846) and the Grady Research and Oversight Committee. Study approval was obtained from both entities.

Survey Design. CARES staff, along with staff from Fulton County Government, examined survey instruments used in the 1999-2000 and 2002-2003 consumer surveys. The instrument was modified from the 2002-2003 version of the survey to include changes in language and services offered to Ryan White consumers as requested by Fulton County Government staff. The zero-based allocation section of the survey was also modified. Instead of having consumers

assign dollar amounts to services that they thought were most important, they were asked to rank the medical and social services offered in the EMA that were of personal importance. The survey content was finalized on September 14, 2007. Interviewers were then trained to administer the survey tool which took about 25-30 minutes to complete.

The 2007-2008 consumer survey consists of three parts. The first part of the survey is designed to gather information about the current services used, needed but not received, and perceived barriers to obtaining necessary services. In the second part of the survey, medical and social services were ranked to gather information about consumer's own perception of the importance of available services and the priority of the services in the EMA. The third and final section of the survey is comprised of a number of demographic questions, specific HIV questions, and substance abuse and mental health screening questions. Substance abuse screening questions were adapted from the CAGE-AID, and the mental health screening questions were adapted from the EMA case management, substance abuse, and mental health screening tool.

Data Collection Sites. These sites were intended to include both Ryan White Part A funded and non-Ryan White Part A funded agencies. Fulton County Government staff provided a list of currently funded Ryan White Part A agencies at which PLWHA were receiving services as of April 2007. There were a total of 12 Ryan White Part A funded sites. In order to access potential participants who may not receive services at Part A sites, CARES staff utilized the agency listing compiled during the 2002-2003 EMA HIV Consumer Survey. CARES staff combined this list with a compiled list of agencies from current editions of Key Contacts and the African American Outreach Initiative (AAOI) Resource Book. Non-Ryan White Part A funded agencies had to meet the following inclusion criteria in order to be considered as a study site:

- Provide direct services to an HIV infected population
- Be an outpatient facility
- Be a non-profit agency
- Not be a part of the jail/prison system

The initial list consisted of 76 non-Ryan White Part A agencies. These agencies were contacted by CARES staff. Some agencies chose to self-select out of the study for confidentiality reasons or because they felt their client base would be too sick to participate. Other non-Ryan White Part A sites were not included for a variety of reasons including: no active HIV positive clients during

the data collection time period or because they did not provide direct services on site. A total of eight (8) non-Ryan White Part A funded agencies met the inclusion criteria and agreed to participate in the study. The final list of data collection sites was approved by Fulton County Government.

Data Collection. Data collection took place over the course of one year from between May 2007 and May 2008. During this time a total of 350 adults living with HIV/AIDS were interviewed for this study. CARES staff scheduled participant recruitment and planned data collection toward the goal of obtaining a representative demographic sample of PLWA in the EMA. Prior to the start of data collection, agency staff and sites were provided with recruitment materials and staff memos describing the study. At no time during the course of the study 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 sites. Generally, clients were either approached in an agency waiting room by a CARES staff member and asked to participate in the study or an agency staff person referred interested clients to awaiting CARES staff members. Spanish-speaking clients were interviewed by a bilingual member of the CARES research team. All interviews were voluntary and anonymous. Participants were not provided with any compensation for their participation and were informed that they could refuse to participate in the study at any time. Also, verbal consent was obtained before the start of each interview; and participants were told not to provide their names and that their names would not be recorded on the survey document at any time.

EPIDEMIOLOGICAL AND CLIENT LEVEL DATA

Epidemiological data were obtained from the HIV/STD Epidemiology Section of the Georgia Division of Public Health (GDPH). Georgia statute requires that any person in Georgia diagnosed with HIV/AIDS be reported to the Georgia Department of Human Resources for the purposes of monitoring the epidemic in the state. These data were gathered, maintained, analyzed and disseminated by the HIV/STD Epidemiology Section of the Georgia Department of Human Resources, Division of Public Health. Data were requested for people reported to be living with AIDS in the EMA from 1990 through 2005 and are presented based on date of diagnosis.

In addition to the epidemiological data, data from the EMA's centralized Client Level Data (CLD) system were utilized. Client Level Data report the services used at agencies receiving Ryan White Part A funding. Client Level Data from 2007 were utilized in addition to data from the 1997-2007 annual data reports to enhance the analysis.

REPORTING FORMAT

This document is presented in five sections. The first section includes a discussion of the study methodology and limitations, as well as an overview of Ryan White service delivery in the EMA. The second section seeks to contextualize study results through the presentation of epidemiological data of AIDS nationally, in the state of Georgia, and in the EMA. The third section of this report is dedicated to the social, economic, medical, and behavioral demographics of survey participants. In the fourth section of this report, results from the consumer survey are presented in two parts. The first part of the fourth section consists of a detailed analysis of the services needed but not received and reported barriers to receiving necessary services. The second part of this section discusses the results of the medical and social service ranking component of the survey. The final section of this report includes an analysis of Client Level Data, which highlights the utilization of services by consumers in the EMA's Ryan White system over the past year. Appendices include study correspondence, recruitment material, survey instrument, and a data table with the total number of barriers reported for each service category.

LIMITATIONS OF THE STUDY

While the data collected provide valuable insight into the needs and priorities of PLWHA 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 a perceived need and are not based on objective eligibility criteria. Because data collection took place at sites where individuals were receiving services, this may have resulted in an over-reporting of specific service use, such as primary medical care, antiretrovirals and other medications. In addition, some respondents ranked services based on their perception of the community's need, despite being given instructions to rank based on their own personal need. Moreover, given that the study did not ascertain whether an individual's case manager was funded through Ryan White Part A, verify that the person was actually a case manager, nor ascertain whether a client without a case manager was a self-managed client, the impact of case management may have been over-reported. Finally, although 75% of interviews were conducted within six months, data collection in its entirety happened over a 12 month period. These limitations should be taken into account when utilizing this report.

SERVICE DELIVERY SYSTEM IN THE EMA

The Atlanta Eligible Metropolitan Area encompasses a 20-county geographic area covering more than 6,000 square miles as defined by the U.S Census Bureau. This area includes the following counties: Barrow, Bartow, Carroll, Cherokee, Clayton, Cobb, Coweta, DeKalb, Douglas, Fayette, Forsyth, Fulton, Gwinnett, Henry, Newton, Paulding, Pickens, Rockdale, Spalding and Walton. Ten health districts are either partially or completely included in the EMA. Specifically, Clayton, Cobb/Douglas, DeKalb, Fulton and Gwinnett health districts are completely included in the EMA, while portions of the Athens, Dalton, Gainesville, LaGrange and Rome health districts are included in the EMA. The EMA has more extensive resources in comparison to other regions and supports a well-developed care system.

As seen in the table below, all Parts of Ryan White HIV/AIDS Program funding are distributed in the EMA with the exception of the Dental Reimbursement and Community Based Dental Partnership Programs. Three (3) of the ten (10) health districts (Cobb/Douglas, DeKalb and Fulton) as well as 12 community agencies receive Part A funding through subcontracts with Fulton County Government. The remaining health districts rely predominantly on Ryan White Part B resources to provide HIV care services. Several health districts within the EMA also receive Part C grant money to provide care services. Both Part A and Part B funding are awarded by the main grantee through a subcontract process, while Part C funding is directly allocated to agencies from the federal level.

The EMA has the smallest geographic area in the state of Georgia in which to provide services, but has the largest disease burden (approximately 68% of all reported PLWA as of December 31, 2005). The table below provides a summary of the Ryan White HIV/AIDS program grantees in the EMA.

Ryan White HIV/AIDS Program Grantees, EMA 2007							
Grantee	Part A	Part B	Part C	Part D	AETC	SPNS	Dental
AID Atlanta						✓	
AID Gwinnett, Inc.			✓ (EIS)				
Clarke County Board of Health/Specialty Care clinic			✓ (EIS)				
Cobb County Health Department			✓ (EIS)				
DeKalb County Board of Health			✓ (EIS)				
District Four Health Services*			✓ (EIS)				
Emory University					✓	✓	
Emory Infectious Disease Clinic at Emory Crawford Long Hospital			✓ (EIS)				
Floyd County Board of Health			✓ (EIS)				
Fulton County Government	✓						
Georgia Department of Human Resources Division of Public Health STD/HIV Section		✓				✓	
St. Joseph's Mercy Care Services			✓ (EIS)				

*Note: The main location of this health district does not fall in the EMA, but several of the counties in the health district do.

Due to the large demand for primary care in the EMA, primary care services are provided utilizing a triage model of service delivery. Asymptomatic patients with a T-cell > 200 are treated in the HIV/STD programs of local health departments or community health clinics. Once a patient's T-cell count measures ≤ 200 and/or the patient is symptomatic, he or she is referred to the Grady Infectious Disease Program for treatment of advanced HIV disease. Within the existing system, clinics at AID Gwinnett, Clarke, Cobb, DeKalb, Crawford Long, and St. Joseph's Mercy Care Services act as early intervention sites. These sites treat people in the early stages of HIV disease by providing medical and social services Monday through Friday. Most individuals who have progressed to AIDS are seen at the Grady Infectious Disease Program,

which is also open Monday through Friday. In addition, the Grady Infectious Disease Program has a transition or “drop-in” clinic which allows homeless individuals, and others who have historically had trouble keeping appointments, to receive same day services without an appointment. The Fulton County Department of Health and Wellness and the primary care clinic at AID Atlanta have expanded service hours, furthering access to treatment services and improving quality of life. AID Gwinnett and Fulton County Department of Health and Wellness operate satellite clinics to serve clients in underserved communities.

Given the array of funding available in this area, coordination of services and frequent assessment and modification are needed to ensure that individuals are receiving the level of care that is needed. The role of linking clients to these service locations, given the mixture of funding and services that exist, predominantly rests with AID Atlanta, as the centralized case management agency in the EMA.

The remainder of this section will review several different sources of information to provide guidance to HIV care providers in this region regarding potential areas for service modification and expansion. Using epidemiological data to examine trends, providing consumer input on service needs and barriers, and assessing the historical utilization of services in the Ryan White system in the EMA will enable providers to assess their response and continue to address new challenges as they emerge.

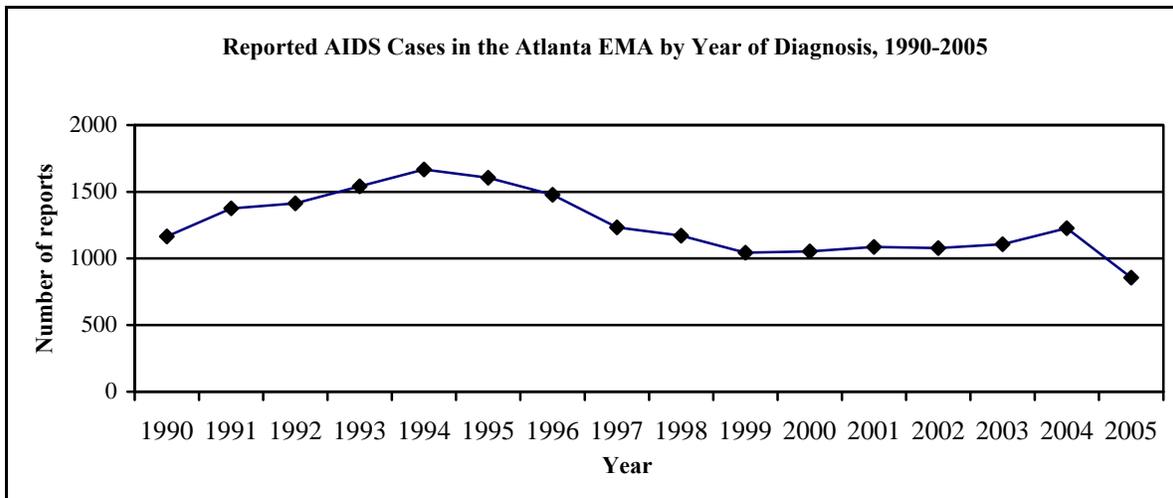
EPIDEMIOLOGY

AIDS reporting began in Georgia in the early 1980s. By contrast, HIV reporting by name began December 31, 2003. Thus, in 2005 Georgia's HIV surveillance system was still immature and the numbers of HIV non-AIDS cases represents an underestimate of all cases diagnosed with HIV infection in the state. However, if individuals were diagnosed with AIDS, their cases should have been reported to the Georgia Department of Human Resources. For the purposes of this report, reported and living AIDS cases as of December 31, 2005 are used.⁸ Reported AIDS cases are presented based on year of diagnosis, not year of report.⁹ This section specifically examines AIDS cases by gender, race and mode of exposure and identifies emerging trends that may impact the service delivery system in the EMA. These data are most useful in context with the other data sources in this report, specifically the HIV consumer survey and CLD.

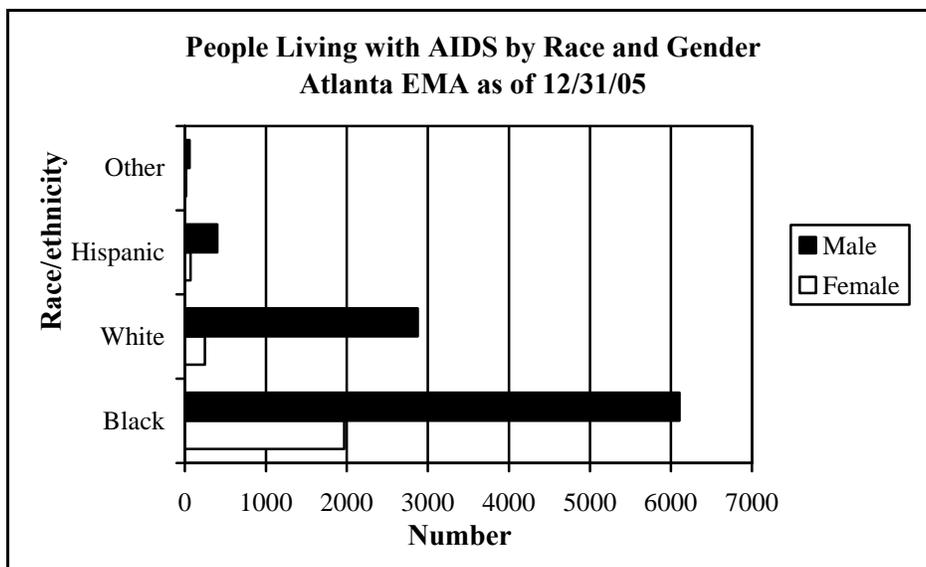
The EMA has been significantly impacted by the HIV epidemic. As of December 31, 2005, a cumulative total of 22,800 people in the EMA were reported with AIDS. Approximately 11,742 of these people were reported to be living with AIDS (PLWA) as of December 31, 2005, comprising roughly 68% of people reported to be living with AIDS in Georgia during the same time period. As illustrated below, over the last fifteen years, the annual number of reported AIDS cases based on year of diagnosis reached its highest point in 1994. Similar to the rest of the United States, in the EMA the advent of effective drug treatments and therapies has been responsible for delaying progression to AIDS as well as extending the lives of PLWA, resulting in fewer deaths.

⁸ Given reporting delays, specifically the time between diagnosis and reporting, the number of diagnosed and living AIDS cases may not reflect the true impact of the epidemic for more recent years. Subsequently, future epidemiological reports are likely to be more inclusive of recently reported data and therefore may not correspond to the information in this report.

⁹ Using diagnosis date rather than reporting date better reflects the trends of disease instead of the trends of reports.



At the end of 2005, 52% of the 22,800 reported AIDS cases in the EMA were known to be living with AIDS. Although the large majority of living AIDS cases in the EMA at the end of 2005 were males (80%), women have been making up an increasingly larger proportion of PLWA in the region (from 7% in 1990 to 20% in 2005).



At 68%, Blacks accounted for the majority of PLWA in the EMA. Whites accounted for 27%, Hispanics represented 4%, and less than 1% of cases were of other races at the end of 2005. The EMA has mirrored the national trend of Blacks making up an increasing proportion of PLWA over the past fifteen years.

In 2005, HIV/AIDS related conditions were the leading cause of death for Black women aged 25-34 (Anderson et al. 2002). Examining gender distributions among racial/ethnic groups indicate that females accounted for 21% of all Blacks reported to be living with AIDS in the EMA, a slightly lower proportion than statewide (25%). Among White PLWA, females accounted for 8%, which is consistent with the statewide proportion (8%). Eighteen percent of all Hispanics reported to be living with AIDS in the EMA were female, which is slightly higher than statewide (16%).

Of the 11,742 PLWA in the EMA, 11,682 (99%) were diagnosed as adults or adolescents. Six (6) risk factors are examined here: men who have sex with men (MSM), injection drug users (IDU), MSM and IDU (MSM/IDU), high risk heterosexual non-IDU (heterosexual), other risk factors and no identified risk (NIR). Over half (56%) of males were reported with a primary risk factor of sex with other men. High risk heterosexual contact was reported as a primary risk factor for 5% of males and 37% of females. Injection drug use with or without additional risk was reported as a primary risk factor for 18% of males, and injection drug use alone was noted for 18% of females. By the end of 2005, nearly 20% of males and 42% of females reported to be living with AIDS had no identified risk factor.¹⁰ Over the past fifteen years, there has been a noticeable increase in the proportion of people reported with AIDS with no identified risk (from 6% in 1990 to 24% in 2005).

Heterosexual contact increased as a reported risk factor from 1990 to 2000 (8% in 1990 to 15% in 2000), but has decreased since then to 12% in 2005. Injection drug use, which gradually increased as a reported risk factor from 1990 to 1995 (15% in 1990 to 22% in 1995), has decreased over the last ten years (16% in 2002 to 13% in 2005). The proportion of non-IDU MSM has decreased from 72% in 1990 to 56% in 2005. However, MSM/IDU accounted for 7% of the risk for males at the end of 2005.

¹⁰ If a person reports a risk factor that does not meet the standards for inclusion into one of the risk factor groups defined by CDC, the person is considered to have no identified risk factor (NIR). For example, if a person reports heterosexual contact but cannot confirm that his/her partner has HIV infection or that his/her partner has a history of MSM, IDU, or receipt of blood products, then that person would be categorized as having no identified risk factor (NIR) (Georgia Department of Human Resources 2005).

Distribution of Risk Factors Among Adults Living with AIDS Atlanta EMA as of 12/31/05				
Adult/Adolescent Risk Factors	Males		Females	
	#	%	#	%
Men who have sex with men (MSM)	5316	56.3	--	--
Injection Drug Use	1045	11.1	424	18.4
MSM/Injection Drug Use	618	6.5	--	--
High Risk Heterosexual contact	505	5.4	844	36.6
No identified Risk	1880	19.9	966	41.9
Pediatric	36	<1%	47	2.0
Other	38	<1%	23	<1%
Total	9438	100%	2304	100%

Examining primary risk factors of infection by gender and race indicate some racial differences among men, but few racial differences among women. While MSM was the most frequent primary risk factor for men of all races, it was reported at much higher rates for White men (74%) compared to Blacks (48%) and Hispanics (52%). In addition, White males were reported with risk factors of MSM/IDU at higher rates (8%) than Blacks or Hispanics (6% and 5% respectively). Conversely, IDU among Black and Hispanic men was reported more frequently (15% and 8% respectively) than among White men (4%). Similarly, heterosexual contact was reported more commonly among Black and Hispanic males (7% and 8% respectively) than among White males (2%). In addition, fewer White men (12%) had no identified risk, compared to Black (23%) and Hispanic men (28%).

Racial differences among reported primary risk factors for women are less evident. Heterosexual contact was the most frequently reported risk factor for all women. Other risk factors were reported at similar rates, with the exception of NIR. Black women (43%) were reported more frequently with no identified risk than both Hispanic (42%) and White women (32%).

Distribution of Risk Factors Among Adults and Adolescents Living with AIDS by Race, Atlanta EMA as of 12/31/05						
Adult/Adolescent Risk Factors	African American		Hispanic		White	
	Males N=6106	Females N=1966	Males N=400	Females N=72	Males N=2874	Females N=249
Men who have sex with men (MSM)	48%	--	52%	--	74%	--
Injection Drug Use	15%	18%	8%	14%	4%	24%
MSM/Injection Drug Use	6%	--	5%	--	8%	--
High Risk Heterosexual contact	7%	36%	8%	43%	2%	39%
No identified Risk	23%	43%	28%	42%	12%	32%
Pediatric	<1%	2%	<1%	0%	<1%	3%
Other	<1%	1%	0%	1%	1%	2%

The EMA, like much of the United States, is facing changes in AIDS epidemiology that may require the region to continue to make modifications to the existing care network. Women, as well as Black individuals, make up a larger proportion of PLWA in the region, and it appears this trend will continue. Data from the HIV consumer survey and CLD may assist in projecting any needed shifts in service delivery.

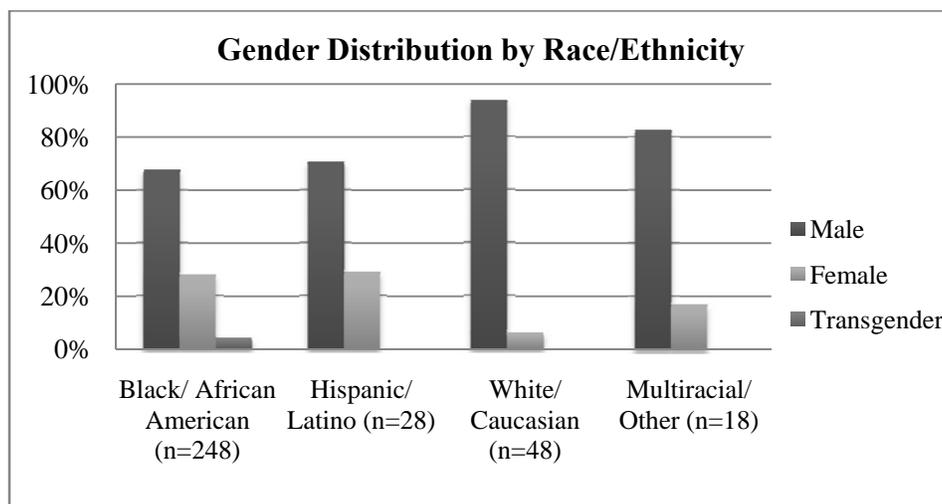
DEMOGRAPHICS OF SURVEY PARTICIPANTS

A total of 350 consumers participated in the interview process at HIV service agencies in the EMA. Data were collected at 12 Ryan White Part A funded sites and eight (8) non-Ryan White Part A funded sites. Interviews were conducted at agencies representing a spectrum of HIV care services agencies, including medical care, substance abuse treatment, and housing for people living with HIV disease. Nine (9) data collection sites provide a range of medical and support services, while 11 sites provide support services only. This section describes the social, economic, and behavioral characteristics of the survey participants.

SOCIAL

In addition to questions about their perceptions of service usage, need, and barriers to services in the EMA, survey participants were also asked to provide information about their race and ethnicity, gender, and age.

Seventy-two percent (n=252) of the consumers who participated in the survey were male, a lower percentage than those reported to be living with AIDS in the EMA (80%) in 2005. Conversely, women comprised 25% of all consumers surveyed, a higher percentage than reported to be living with AIDS in the EMA as of 2005 (20%).



Finally, transgender consumers accounted for 3% of the participants surveyed. The majority of consumers (71%) interviewed self-identified as Black/African American, 8% were

Hispanic/Latino, and 15% were White/Caucasian. Multiracial and consumers of other racial/ethnic groups represented 5% of consumers interviewed.¹¹

The representation of Black consumers in this survey was consistent with, though slightly higher than, the proportion of Black PLWA in the EMA as of 2005 (68%). Whites were underrepresented in this study based on the proportion of White PLWA reported in the EMA (27%). Though Hispanics account for only 4% of PLWA in the EMA, they were intentionally oversampled in the study population for purposes of conducting separate analyses.

Survey participants ranged in age from 18-76 years, with an average age of 43 years. Fifty-three percent of women participants who provided their ages were of childbearing age.¹² This group of women is of particular interest as women of childbearing age are one of the fastest growing sub-populations of newly infected HIV/AIDS cases nationally and locally (Kaiser Family Foundation 2007). Though the majority of the consumers interviewed were under 50 years old (76%), 23% of the study population was 50 years of age or older which is consistent with the representation of PLWA over 50 in Georgia (25%) (Georgia Department of Human Resources 2006) and the growing trend of older Americans with HIV/AIDS (CDC 2008c).

When asked to indicate the highest level of school completed, of the 350 consumers interviewed, 26% indicated that they had less than a high school diploma, 35% were high school graduates or had a GED, 20% reported some college education, and 19% were college graduates. These data should be interpreted cautiously as field interviewers noted that reported education level was not an accurate predictor of literacy level.

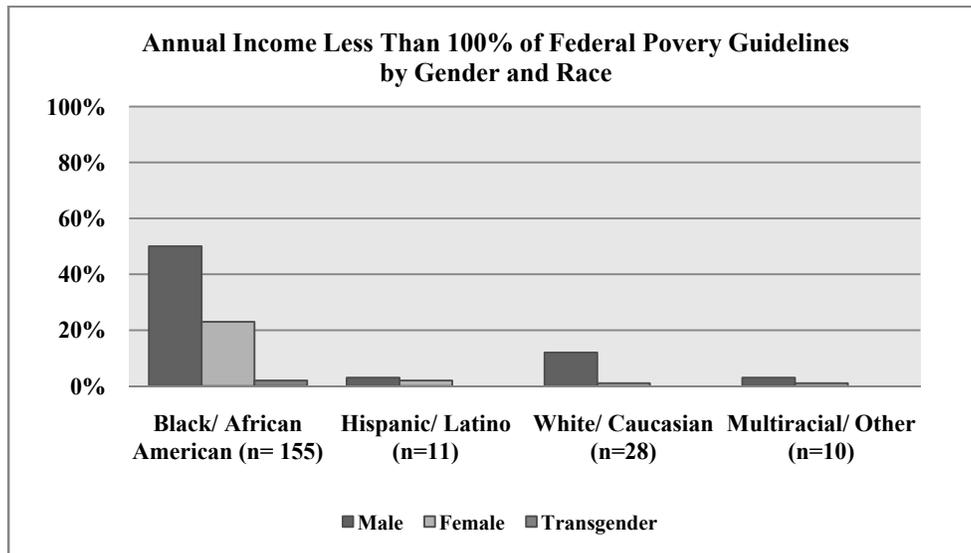
ECONOMIC

Consumers were asked to report their highest educational level achieved, annual income level, the number of other people (including children) supported by that income, if they were homeless, and if they had trouble getting housing in the past year.

¹¹ The “other” category of racial/ethnic groups includes consumers who self-identified as American Indian/Alaska Native, Asian/Pacific Islander, other ethnicities, and those who reported being multiracial.

¹² For the purposes of this study, women of childbearing age are those between 18-44 years.

Of the 350 consumers surveyed, 58% (n=204) reported earning an annual income less than \$10,210 per year, which was 100% of the federal poverty guidelines in 2007. Twenty-one percent of consumers earned an annual income between \$10,210 and \$20,420, 200% of the federal poverty guidelines in 2007.



Finally, 19% of consumers reported either earning an annual income at or above 300% of the federal poverty guidelines for 2007 or did not answer the question. Thirty-five percent of all consumers reported that their household income went to support at least one (1) person under the age of 24 years, though only 20% reported supporting anyone other than themselves with their annual income.

Two percent of all consumers surveyed reported that they were homeless at the time of the interview. Though a small proportion of consumers reported being homeless, this does not fully capture the number of consumers who experienced some instability with housing in the past year. In fact, 35% of consumers reported that they had trouble with housing in the past year and 27% received government or other organizational assistance to support the cost of their housing. In addition, the majority of consumers reported receiving assistance paying for ARVs (77%) and other medications (60%).

Funding Sources for ARVs and Other Prescribed Medication		
	ARVs	Other Prescribed Medications
	% (n=244)	% (n=206)
ADAP	42% (103)	26% (53)
Medicaid	18% (43)	19% (39)
Medicare	11% (27)	11% (22)
Veteran's Benefits	1% (3)	0
Private Insurance	7% (18)	8% (17)
Out-of-Pocket	1% (2)	11% (23)
PAP¹³	1% (3)	2% (4)
Other¹⁴	5% (13)	8% (17)
Multiple Sources	13% (32)	15% (31)
Don't know/refused to answer	0	0

As illustrated above, consumers often access multiple payer sources in order to pay for ARVs and other prescribed medications. These data should be interpreted cautiously as field interviewers noted that some respondents were unsure about the payer source's official name, reporting instead the location where they picked up medications.

MEDICAL

Participants were asked a number of questions about their recent medical history including both their most recent viral load and T-cell counts and about their adherence to current medications including ARVs. The tables that follow detail consumer responses to questions about their viral loads and T-cell counts.

¹³ PAP is the acronym used to describe the Pharmaceutical Assistance Program.

¹⁴ Consumers choosing "other" largely listed the place where they picked up their medications or their insurance provider; for example: Wal-mart, AID Gwinnett, Evercare, AID Atlanta, Grady, Fulton County Health and Wellness, Dekalb County Board of Health. Some consumers reported additional sources of funding including a study drug (1), Ryan White (10), PPA-1 (1), Cobra and getting pills from friends (1).

What is Your Most Recent T-cell Count?	
Under 200	19% (67)
Between 200-350	14% (50)
Over 350	45% (159)
Awaiting results	5% (19)
Can't remember	15% (51)
Don't know if I ever had one done/not told results	0
Don't know what a T-cell is	< 1% (1)
Refused to answer	< 1% (1)

What is Your Most Recent Viral Load?	
Undetectable or below 50	47% (166)
Between 50-55,000	18% (63)
Over 55,000	5% (18)
Awaiting results	5% (17)
Can't remember	21% (75)
Don't know if I ever had one done/not told results	1% (3)
Don't know what a viral load is	1% (5)
Refused to answer	< 1% (1)

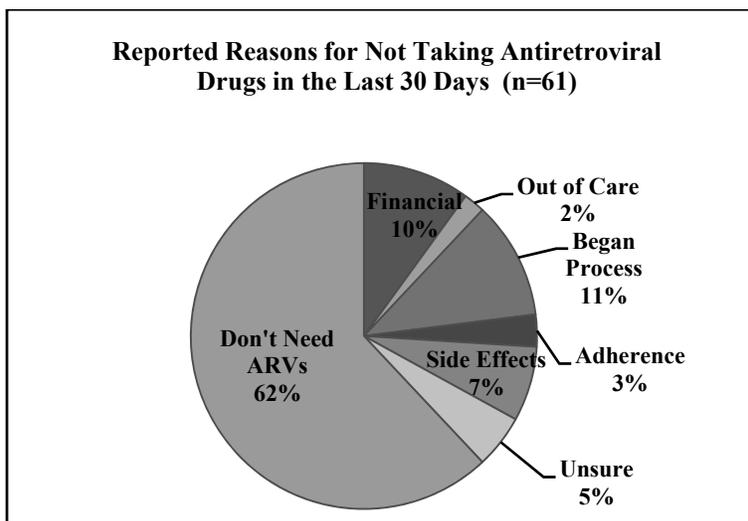
Forty-five percent of consumers reported a T-cell count over 350 and 47% with a viral load that was undetectable. However, 15% of participants reported not being able to remember their most recent T-cell count and 21% could not remember their most recent viral load test results.¹⁵ It is important to note that these numbers are self-reported and were not verified at any time by study staff.

Seventy-three percent of consumers reported taking antiretroviral drugs including protease inhibitors in the past 30 days and 63% reported taking other medications prescribed by their doctor.¹⁶ Ninety-two consumers (26%) reported that they had not taken antiretrovirals in the past 30 days. As detailed in the chart below, these consumers were asked to respond to the following: “Please tell me why you are not taking antiretroviral medications.” Open-ended responses were coded into the following seven (7) categories to reflect trends in the data: don’t need, financial, out of care, began process, adherence, side effects, and unsure. Of the 92 consumers reporting that they did not take ARVs in the past 30 days, 66% (n=61) provided an explanation for not taking the medication. Of these, 62% reported not needing antiretrovirals for these reasons: T-cell count too high, too healthy for medications, a doctor or other medical professional took me off, and doctor or other professional did not prescribe them. Consumers who cited financial

¹⁵ Studies indicate that not being able to recall test results and other medical information may be an indication of health illiteracy, which is related to poorer health outcomes.

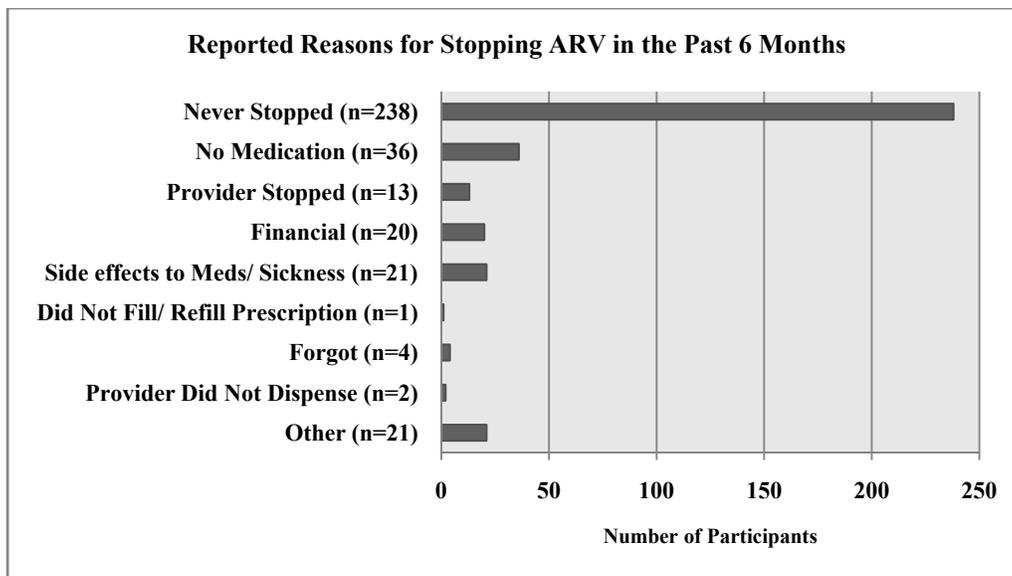
¹⁶ This number is a composite of those consumers who reported taking doctor prescribed medications other than ARVs in the past 30 days.

reasons for not taking antiretroviral drugs were largely awaiting approval for financial assistance programs before beginning a medication regimen.



Survey participants were asked to report if, in the past 6 months, they had stopped taking their prescribed antiretroviral medications for any reason, except for missing a single dose. Sixty-eight percent (68%) of consumers reported that they never stopped taking their prescribed antiretroviral drugs, 10% reported not being prescribed antiretroviral medications (“no medication”), 6% reported they could not afford their medications, 6% reported that antiretrovirals made them sick, 4% reported being told by a doctor or nurse to stop taking antiretroviral medications, 1% forgot to take their medication, less than 1% reported that their provider did not give medications to them, and less than 1% reported never refilling their prescription. In addition, 21 consumers reported “other” reasons for not adhering to their antiretroviral medication regimens.¹⁷

¹⁷ “Other” includes the following reasons: personal (ran out of meds, did not like the medications, felt overwhelmed taking meds, left them at home, no reason, missed appointments, personal choice, too lazy to take them), recreational and other drug use (cited by consumers who stopped ARVs because of a recreational drug addiction or due to the use of other drugs), housing (homelessness or moving to a new geographic location), insurance (awaiting insurance approvals before starting their ARVs), providers stopped (medications were stopped while incarcerated or after release or having been taken off meds by a healthcare professional) and medication change (stopped ARVs awaiting the start of newly prescribed medications).



SYSTEM

Participants were asked how they found out they were HIV positive. Thirty-nine percent (39%) of all consumers reported discovering they were HIV positive after requesting an HIV test. Nineteen percent (19%) reported becoming aware of their HIV status after going to a hospital emergency room for another concern and 17% reported having the test recommended by a healthcare provider or required as part of a physical exam. The remainder of responses included becoming aware of their HIV status while in jail (8%), while donating blood (3%), and while seeking pre-natal care (2%). Ten percent (10%) reported a variety of other ways including being told by a partner or relative.

Interviewers asked participants to tell them who first helped them get into services after finding out they had HIV. Thirty-three percent (33%) of those interviewed identified a doctor or medical professional as the first person to help them get into HIV care services. This was followed by nobody (15%) or other persons (15%). Other responses largely included AIDS service agencies and other outreach organizations as having helped them into services. Eleven percent (11%) reported a case manager or social worker followed by friend (10%), family member (6%), prison or jail (6%), and the person who gave them their HIV test results (4%).

Survey participants were also asked to report if they currently had a case manager. Seventy-seven percent (77%) indicated that they had a case manager, most of whom could identify either

their case manager's name or the agency at which they receive case management services. Nineteen percent (19%) of participants reported that they did not currently have a case manager and 3% were unsure if they had a case manager at the time of the interview.

BEHAVIORAL FACTORS

Participants were asked questions about possible high risk behavior before being diagnosed with HIV/AIDS, how they found out their HIV/AIDS status, and current risk behavior. Finally, participants were asked substance abuse and depression questions taken from the EMA Case Management, Substance Abuse and Mental Health screening tool and are taken from the CAGE-AID substance abuse tool and the Primary Care Evaluation of Mental Disorders screening tool respectively.

Consumers were asked if they engaged in any of the following potential risk behaviors before learning their HIV status: sex with a man, sex with a woman, sex with an injection drug user, sex with someone believed to be a bisexual, sex with someone known to be HIV positive, receiving clotting factor for hemophilia or other clotting disorder before 1985, receiving blood transfusion or components before 1985 or in an another country. Ninety-one percent (91%) of all survey participants reported engaging in at least one form of high risk sexual behavior prior to being diagnosed with HIV. The table below details the sexual behavior, by race and gender, that consumers told interviewers they engaged in prior to finding out they had been diagnosed with HIV/AIDS. These data should not be interpreted as the relative prevalence of either heterosexually infected or male-to-male sexually infected persons in the EMA. Instead they represent a descriptive analysis of the sexual risk behavior of the consumers in this study before being diagnosed with HIV/AIDS. In addition to high-risk sexual behavior, 7% reported receiving a blood transfusion before 1985 and 2% of consumers reported receiving clotting factor for hemophilia or another clotting related condition.

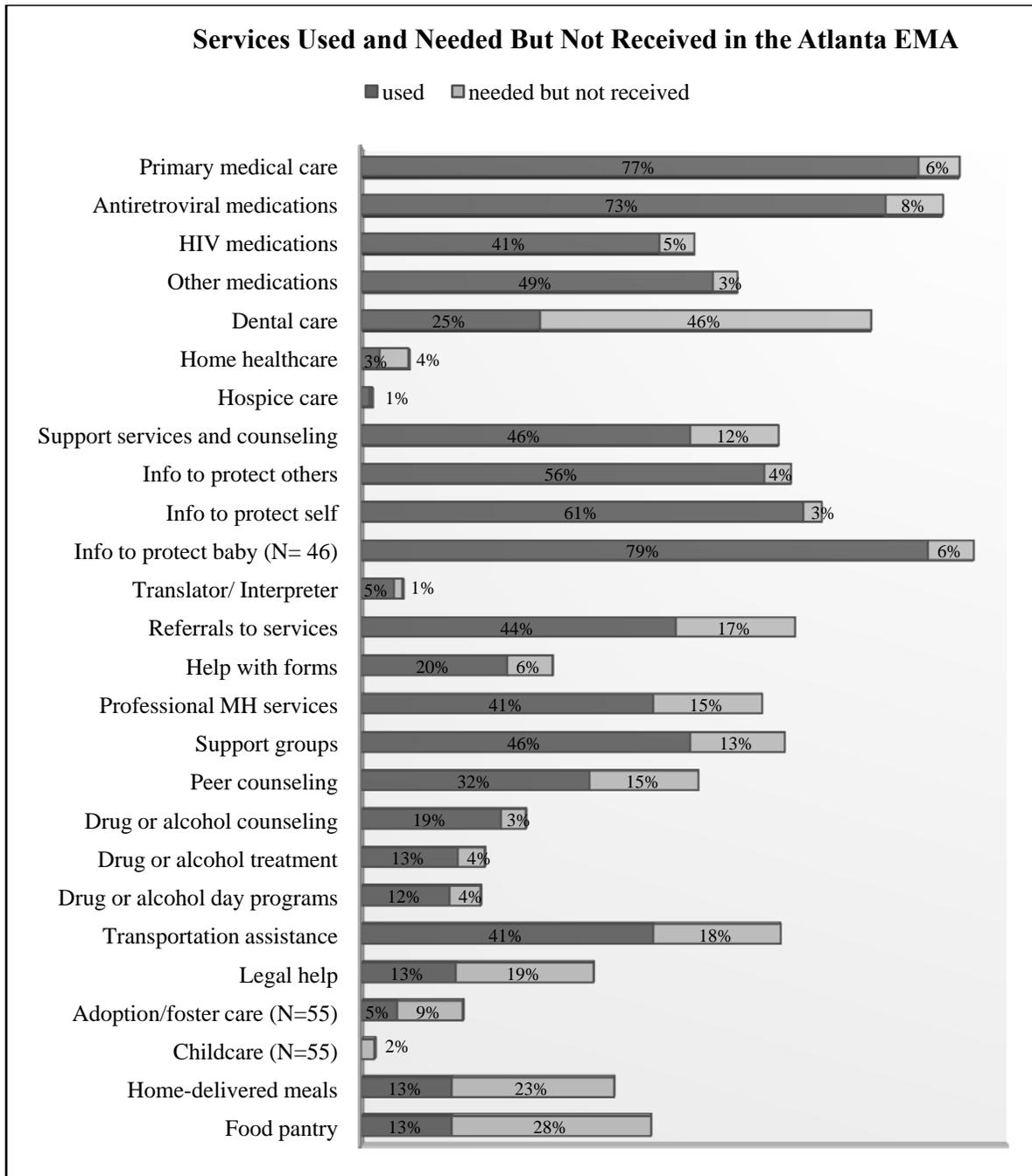
Sexual Risk Behavior Before HIV/AIDS Diagnosis					
	Sex with man	Sex with woman	Sex with IDU	Sex with bisexual	Sex with HIV+ person
Men	74%	63%	19%	51%	18%
Women	91%	18%	28%	24%	7%
Women 18-44	91%	9%	15%	15%	7%
Black	75%	50%	20%	41%	12%
White	90%	54%	29%	56%	31%
Hispanic	79%	25%	4%	36%	11%

When asked about behavior in the last six months, survey participants reported a range of high risk behaviors including drinking alcohol (40%), using crack or other street drugs (18%), having had unprotected sex (18%), having been in jail or prison (11%), exchanging sex for drugs, food, or shelter (3%), and injection drug use (2%).

Finally, participants were asked screening questions regarding substance abuse and mental health taken from the EMA Case Management, Substance Abuse and Mental Health screening tool. These questions are based on the CAGE-AID and Primary Care Evaluation of Mental Disorders screening measures. The CAGE-AID screening includes four questions regarding drug and alcohol use. Based on CAGE-AID scoring, individuals answering “yes” to two or more of these questions warrant additional screening for substance abuse. Of those participants who completed the screening (n=313), 80 (26%) consumers were in need of additional substance abuse assessment. The mental health screening includes series of questions about the participants’ feelings in the past 30 days including the day of the interview. These tools can indicate a need for follow-up assessment, but are not a diagnostic instrument. Participants who answer “yes” to one or more questions are considered in need of additional mental health assessment. Based on the scoring for this screening, 39% (n=136) of all consumers surveyed were in need of additional mental health assessment.

SERVICES USED, SERVICES NEEDED BUT NOT RECEIVED, AND BARRIERS

A total of 350 consumers in the EMA participated in the survey. During the first part of the interview, participants were asked if they used or needed any of the 26 available services for eligible Ryan White consumers in the EMA in the last 30 days.



If participants responded that they did not use a service, they were then asked whether they needed the service in the last 30 days. Survey participants were asked to identify barriers for any services they needed but did not receive. Participants were not limited in the number of barriers they could mention. Barriers were coded by interviewers during data collection. Barriers falling outside the coding scheme were collected as “other” and were coded after the completion of data collection. A listing of the barrier categories, as well as a brief description, is provided in the overview section below. Cumulative responses are listed in the appendices by specific service category including complete coding guidelines and barrier data tables.

Results are initially presented as an overview of services used, those needed but not received and reported barriers. Additional discussion by individual service is presented following the overview. Where possible, statistically significant differences by subpopulations are also discussed; however, differences in barriers by race for individual services are not statistically tested. Given the relatively small population sizes, caution should be used when interpreting results.

OVERVIEW

Services Used. Consumers reported using medical and information services at high rates in the past 30 days. Primary medical care (77%) was the most frequently used service followed by antiretroviral medications (73%). Information about how to protect themselves (61%) was used frequently by participants followed by information to protect other people from getting HIV from them (56%) and other medications (49%). In contrast, the least used service was childcare (1%), and no participants reported using adoption or foster care services.

Services Needed But Not Received. Dental care (46%) was the most frequently reported service needed but not received in the past 30 days. The other services that consumers reported needing but not receiving were support services such as food pantry (28%), home-delivered meals (23%), legal help (19%), and transportation/ride assistance (18%). Referrals to services were needed but not received at similar levels (17%). In addition, 15% of participants reported needing but not receiving professional mental health counseling and 15% reported needing but not receiving peer counseling services. Very few participants (<5% each) expressed needing but not receiving drug or alcohol treatment, day programs or counseling. Translator/interpreter

services (1%) were the least reported of services needed but not received. Finally, no participants reported needing but not receiving hospice care.

Barriers. Overall, 263 consumers (75%) reported barriers to services that they needed but did not receive. The most commonly reported barriers for consumers were personal (26%), followed by information (19%) and capacity (16%).

Barrier Categories¹⁸		
Category	Description/ Subcategories	
Capacity: More services are needed	<ul style="list-style-type: none"> • Waiting list time • Couldn't get appointment • Service unavailable/restricted 	<ul style="list-style-type: none"> • Proximity to service • Eligibility • Language
System: Services exist but delivery needs modification	<ul style="list-style-type: none"> • Regulations • Medicare/Medicaid • Case management issues 	<ul style="list-style-type: none"> • Dissatisfaction • Confidentiality/ stigma • Responsiveness
Information	<ul style="list-style-type: none"> • Don't know where to go/who to ask about service 	<ul style="list-style-type: none"> • Unaware of service
Financial	<ul style="list-style-type: none"> • Homeless/other housing issues 	<ul style="list-style-type: none"> • Cost of service
Medical	Consumer was either too ill or too healthy to get service	
Personal	An individual's own reasons or issues for not accessing services	
Began Process	Participants started the process to receive a service but have yet to receive it	
Don't Know	Consumer unsure of why they were unable to get a service	

System issues represented 15% of reported barriers. Financial and began process barriers represented 10% and 8%, respectively, of total barriers. Consumers who reported that they did not know why they did not receive services (2%) and medical barriers (1%) constituted the lowest proportions of barriers reported. A more extensive review of these barriers showed that, in general, the most commonly stated barriers were consistent across all demographic groups for the majority of service categories listed. However, statistical tests revealed differences in the rate barriers were reported.

¹⁸ Two additional barrier categories, "no barrier" and "other," were analyzed but not included in this report due to the small number of participants who chose these options.

Type of Barriers Reported in the EMA by Demographic Sub-Population											
Participant Sub-Populations	Total Number of Consumers	% Consumers Reporting Barriers	Total Number of Barriers Reported	Barriers							
				Capacity	System	Information	Financial	Medical	Personal	Began process	Don't know
Race/Ethnicity											
Black	248	81%	853	16%	15%	18%	10%	1%	24%	9%	3%
White	48	49%	105	22%	8%	15%	5%	0%	38%	2%	3%
Hispanic	28	82%	101	12%	20%	33%	11%	0%	20%	5%	0%
Gender											
Male	252	71%	810	16%	14%	17%	10%	1%	28%	8%	2%
Female	87	84%	287	15%	15%	31%	6%	2%	19%	5%	2%
Women 18-44	46	78%	149	16%	13%	37%	5%	3%	16%	3%	1%
Age											
< 50 years	265	76%	795	18%	17%	25%	8%	1%	28%	9%	3%
≥ 50 years	80	74%	199	16%	17%	22%	9%	1%	33%	5%	3%
Have at least a high school diploma?											
Yes	258	73%	690	17%	16%	23%	10%	2%	30%	9%	3%
No	90	81%	301	19%	19%	25%	6%	0%	26%	7%	2%
Annual Income											
< \$10, 210	206	74%	592	20%	20%	22%	7%	2%	26%	9%	3%
≥ \$10, 210	116	73%	323	13%	10%	28%	11%	0%	34%	7%	2%
Trouble getting housing in the last 12 months?											
Yes	124	85%	472	19%	17%	22%	8%	1%	29%	10%	3%
No	221	70%	517	17%	16%	26%	9%	1%	28%	7%	3%
Do you have a case manager?											
Yes	271	77%	885	16%	14%	21%	7%	1%	27%	7%	2%
No	66	71%	194	14%	17%	21%	11%	2%	22%	7%	2%
Remember most recent T-cell count?											
Yes	276	74%	786	19%	17%	23%	9%	2%	28%	8%	2%
No	72	82%	210	15%	15%	25%	9%	0%	32%	10%	4%
Remember most recent viral load?											
Yes	247	72%	645	19%	16%	25%	9%	2%	29%	6%	1%
No	101	82%	351	16%	19%	22%	8%	1%	29%	13%	5%
Total	350	75%	1126	16%	15%	19%	10%	1%	26%	8%	2%

Specifically, capacity (20%) and system (20%) barriers were reported by consumers earning an annual income less than 100% of the federal poverty level. Information barriers were reported more frequently by Hispanics (33%), women (31%), and especially women of childbearing age

(37%). Personal barriers, the most commonly reported of all barriers, experienced the highest statistically significant rates for men (28%). Finally, survey participants stating that they began process were more frequently those that could not remember their most recent viral load (13%) or those who experienced trouble with housing in the past 12 months (10%).

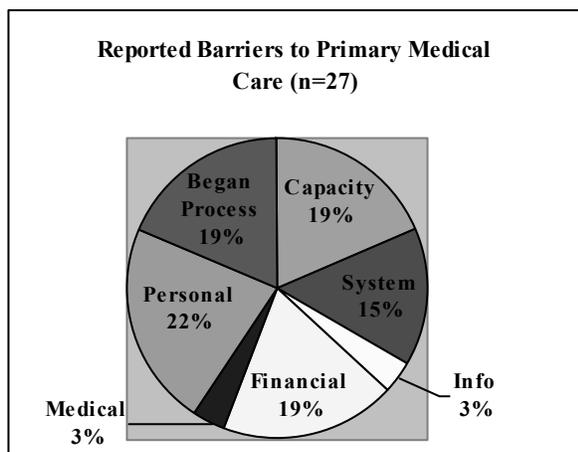
RESULTS BY SERVICE CATEGORY

Medical and Other Services

- ❖ **Primary medical care**
- ❖ **HIV medications**
- ❖ **Dental care**
- ❖ **Hospice care**
- ❖ **Antiretroviral medications**
- ❖ **Other medications**
- ❖ **Home healthcare**

Primary medical care was the most frequently reported service used by survey participants (77%). Antiretroviral medication use was reported at similarly high rates (73%) making it the second most frequently used service by survey participants. Other medications and HIV medications were also frequently stated as services used by 48% and 41% of consumers respectively. Dental care services were used by 25% of consumers. Home healthcare and hospice care services were among the least reported services to be used or needed by consumers, 3% and 1% respectively. A more detailed discussion of services used, services needed but not received, and barriers to needed services follows below.

Primary Medical Care. Overall, primary medical care was the highest reported service used by all survey participants (77%). Hispanics reported using this service at higher rates (93%) than

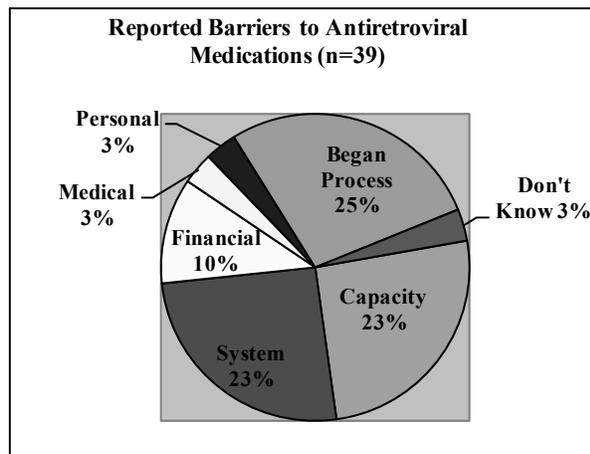


Whites (82%), and Blacks (74%). Use of primary medical care was also reported more frequently by participants 50 years of age and older (88%) compared to those under 50 (75%). Also, those participants who could not remember their most recent viral load reported using services more (83%) than those who did remember their viral load (75%). Only 6% of consumers reported needing but not receiving

services and 16% reported not using or needing primary medical care services in the past 30 days. Of the 20 participants that indicated needing but not receiving primary medical care in the past 30 days, 27 barriers to receiving this service were cited, the most frequent being personal, capacity, financial, and began process.

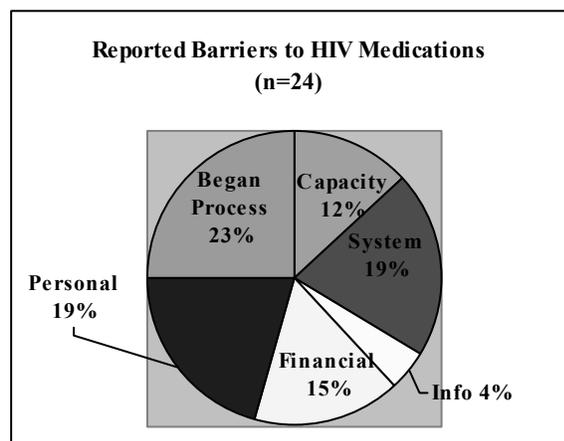
Antiretroviral Medications. Use of antiretroviral medications (ARVs) was also reported by a large proportion of consumers (73%), second only to primary medical care. Whites reported using ARVs at higher rates (92%) than both Hispanics (82%) and Blacks (69%).

Participants aged 50 and older reported using ARVs more often (81%) than those younger than 50 (70%). Also, those consumers who were able to remember either their most recent viral load or T-cell count reported using ARVs more frequently (79% and 74% respectively) than those who did not (60%



and 69% respectively). Eight percent (8%) of survey participants (n=28) reported needing but not receiving antiretrovirals, compared to the 18% (n=64) who reported neither using nor needing this service. Thirty-nine (39) barriers to receiving ARVs were reported, with began process, system, and capacity barriers being stated most frequently.

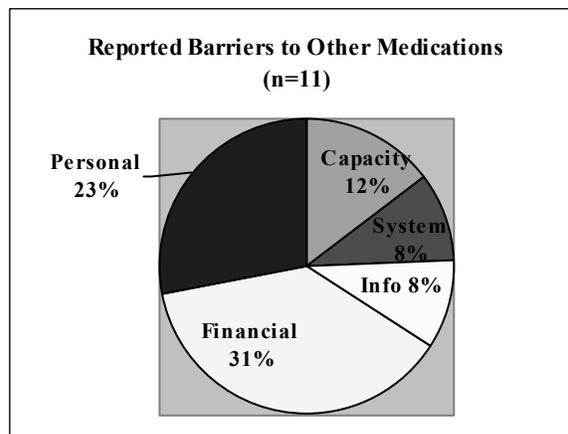
HIV Medications. Forty-one percent (41%) of consumers reported using HIV medications



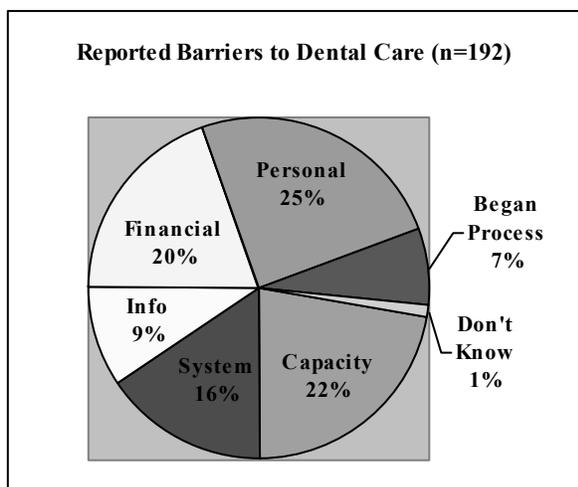
other than ARVs in the past 30 days, with minimal differences between subpopulations. Five percent (5%) of consumers reported needing but not receiving HIV medications other than ARVs, while 51% reported not using or needing this service. Twenty-four (24) barriers to receiving HIV medications other than antiretrovirals were reported with began process, personal, and system reported most frequently.

Other Medications. Approximately half (49%) of the participants interviewed reported having used other, non-HIV, prescription medications in the past 30 days. Whites reported using other medications more often (63%) than Blacks (47%) or Hispanics (39%). Consumers over 50 years old reported using other prescription medications more (65%) than those under 50 (45%).

Also, 53% of those participants who reported earning less than 100% of the federal poverty level for 2007 indicated using other medications more frequently than those earning an annual income greater than 100% of the federal poverty level (47%). Overall, 3% of consumers reported needing but not receiving services, and 46% reported not using or needing other medications. Of the 11 barriers reported, financial and personal were reported most frequently.



Dental Care. Only 25% of participants reported using dental care in the past 30 days. Accordingly, almost half of the participants reported needing but not receiving dental care in the

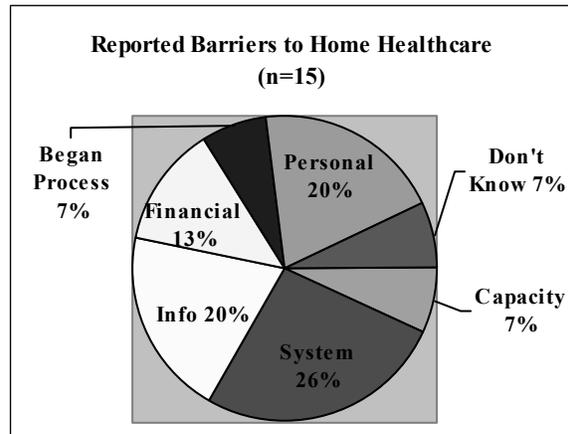


last 30 days (46%). These results are similar to previous EMA consumer surveys conducted in 1999-2000 and 2002-2003, where dental care was also the most frequently reported service needed but not received. Additionally, 28% percent of participants reported not using or needing the service. Blacks reported needing but not receiving dental care more frequently (50%) than Hispanics (46%) and Whites (33%). Consumers

who indicated that they had trouble with housing in the past year reported needing dental services more (51%) than those who did not report trouble with housing (43%), and non case-managed consumers more frequently reported needing but not receiving dental services (53%) than those with a case manager (45%). In all, 192 barriers to receiving dental care were reported with capacity, financial, and personal barriers reported most frequently. Hispanics more frequently reported system barriers to accessing dental care (33%) compared to Blacks (13%) and Whites (17%). Blacks reported personal barriers most often (26%) and Whites stated a higher proportion of capacity barriers (28%). Women were found to attribute more personal barriers (31%) with not receiving necessary dental care in contrast to men who cited more

capacity barriers (23%), and women of childbearing age who reported higher rates of system, financial and personal barriers (all 21%).

Home Healthcare. Participants reported low rates of using home healthcare in the past 30 days (3%). Only 4% of consumers (n=14) reported needing but not receiving services, stating 15 barriers. Of those, system, information, and personal were reported most frequently.



Hospice Care. Four consumers reported using hospice care in the past 30 days. Only one (1) participant reported needing but not receiving this service citing medical and personal barriers.

Information and Help Getting Services

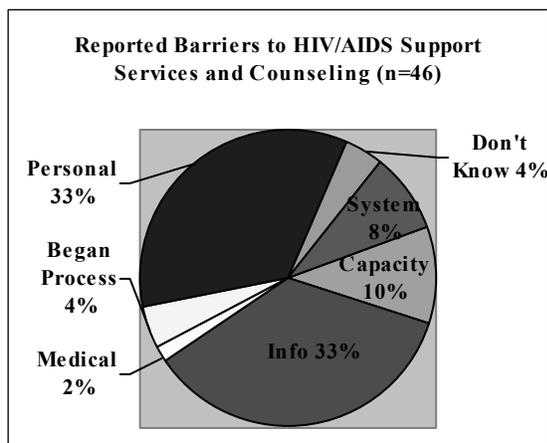
- ❖ **Information about HIV/AIDS support services and counseling**
- ❖ **Information about how to protect others from getting HIV from you**
- ❖ **Information about how to protect yourself from getting STDs from others**
- ❖ **Information about how to protect your baby from getting HIV from you**
- ❖ **Translator/Interpreter services**
- ❖ **Referrals to needed services**
- ❖ **Help filling out forms**

Consumers reported using information and help getting services at consistent rates, with five (5) out of seven (7) services being used over 40% of all consumers. Information about how to protect themselves from getting sexually transmitted diseases (61%) and information about protecting others from getting HIV (56%) were among the top five (5) services used by all consumers. Eight percent (8%) of women of childbearing age reported receiving information about preventing HIV transmission to their baby. Forty-six percent (46%) of consumers used information about HIV/AIDS support services and counseling and 44% reported receiving

referrals to services in the past 30 days. Only 5% of consumers reported using translator/interpreter service.

Services in this section were some of the least reported services to be needed but not received overall with only one service reported as needed but not received by more than 15% of all consumers. Referrals to needed services was reported most frequently by consumers (17%) followed by information about HIV/AIDS support services and counseling (12%). A more detailed discussion of the services used, needed but not received, barriers to necessary information, and help getting services follows below.

Information about HIV Support Services and Counseling. Forty-six percent (46%) of consumers, (n=160) reported having received information about HIV/ AIDS support services and



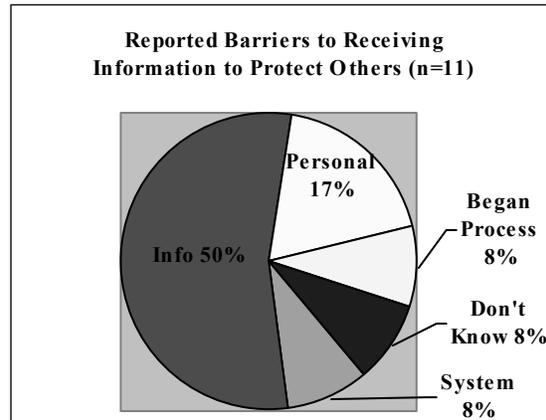
counseling in the past 30 days. Fifty-five percent (55%) of participants who reported having had trouble with housing in the past year and 53% of participants earning an annual income less than 100% of the federal poverty level reported receiving this service at higher rates than those who did not have trouble with housing (41%) or those earning greater than 100% of the federal poverty level (36%). In addition, 50% of case managed

consumers reported using this service compared to 29% of those without a case manager. Twelve percent (12%) of survey participants (n=43) reported needing but not receiving services, while 42% (n=146) reported that they did not need or receive information about HIV/AIDS support services. Of the 46 barriers reported, information and personal barriers were cited most frequently.

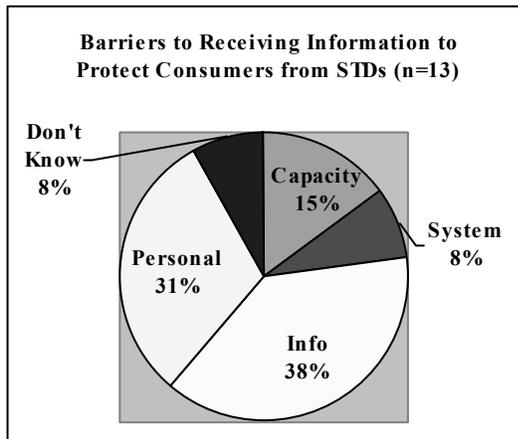
Information about How to Protect Others from Getting HIV from You. Secondary prevention information was received by more than half of the participants (56%). Consumers with at least a high school diploma (64%) reported receiving this service more frequently than those without at least a high school diploma (53%). Hispanics reported receiving this service more frequently (71%) than Blacks (60%) and Whites (33%). Women of childbearing age also

reported higher rates of receiving this service (63%) when compared to men (56%) and the total number of women surveyed (55%).

Four percent (4%) of the participants surveyed reported that they needed but did not receive secondary prevention information in the last 30 days while 41% reported that they did not need or receive this service. Of the 11 barriers to receiving information to protect others from contracting HIV from them, information was reported most frequently.



Information about How to Protect Yourself from Getting STDs from Others. Similarly, consumers reported receiving information to protect themselves from STDs with great frequency. Overall, 61% (n=215) of consumers reported having received this service. Eighty-



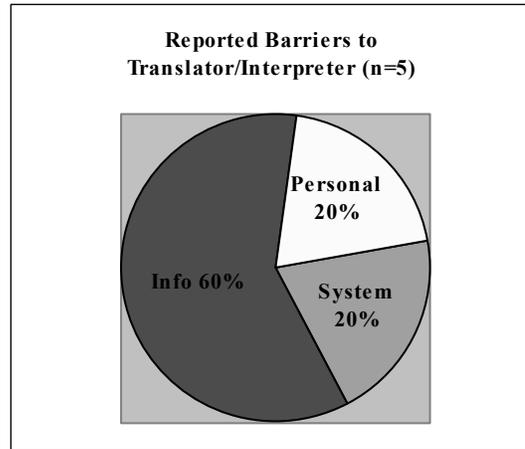
two percent (82%) of Hispanic participants reported receiving services compared to 64% of Blacks and 38% of Whites. Women of childbearing age (67%) reported receiving information to protect themselves from other STDs more than men (62%) and all women (61%). Though half of the participants without a case manager reported receiving services (n=33), those with a case manager (65%) reported higher rates of service use. Overall, 3% of consumers

reported that they needed but did not receive information to protect themselves from STDs compared to 35% who stated they did not need or receive services. Information was the most common of the 13 barriers reported.

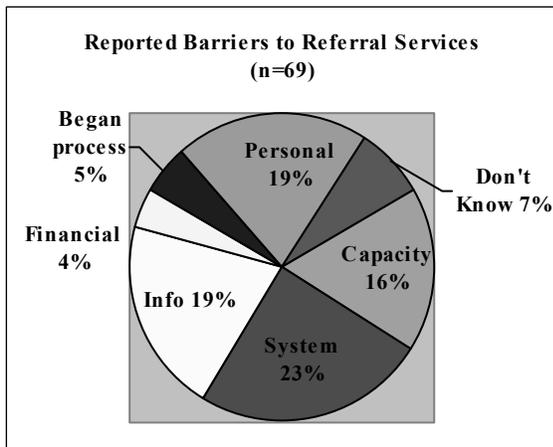
Information about How to Protect Your Baby from Getting HIV from You. Female consumers of childbearing age were asked if they had received information on preventing HIV transmission to their babies if pregnant. Of the 46 women interviewed, half of them reported having received information to protect their baby from getting HIV during pregnancy. Two (2) women of childbearing age (4%) reported needing but not receiving this service and 46% stated

they did not need or receive this service. Capacity, system, and personal barriers were cited most frequently.

Translator/Interpreter Services. Five percent (n=16) of consumers reported using translator or interpreter services in the past 30 days. Those who reported using this service largely self-identified as Hispanic (81%), having a case manager (81%), or male (75%). Four (4) consumers reported needing but not receiving translator/interpreter services, stating information barriers most frequently.



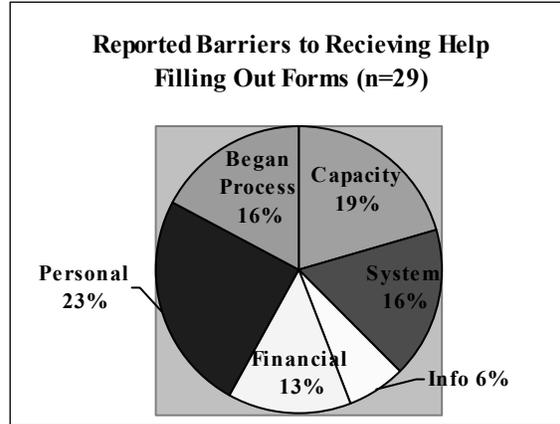
Referrals to Needed Services. Forty-four percent (44%) of the consumers interviewed reported having received referrals to the services they needed, 17% reported that they needed but did not



receive referrals, and 40% stated that they did not need or receive services. Consumers who reported having trouble with housing in the past year also reported receiving referrals more frequently (56%) than those who did not have trouble with housing (37%). Consumers over 50 years of age and participants with a case manager also reported higher rates (both 50%) of receiving services than consumers younger than 50 years of age (42%) and

those without a case manager (21%). Of the 69 barriers reported for referral services, the most frequent were system, information, and personal. In addition, two (2) consumers reported barriers in the “other” category, which included physician relocation and loss of personal transportation.

Help Filling Out Forms. Twenty percent (20%) of consumers reported receiving help filling out forms for medications or services in the past 30 days. Seventy-three percent (73%) of consumers reported not needing or receiving this service and 6% needed but did not receive help filling out forms. The most frequently reported barriers were capacity and personal.



Counseling, Treatment, and Support Services

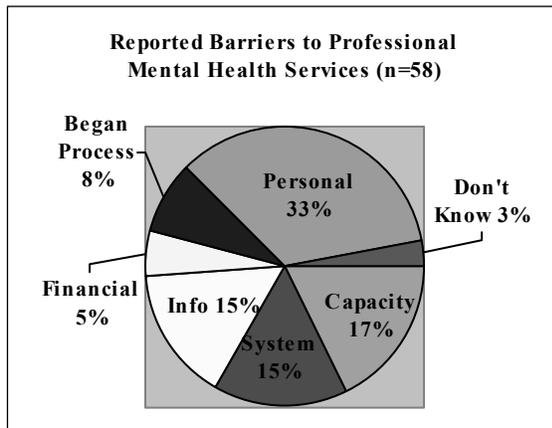
- ❖ **Professional mental health counseling**
- ❖ **One-to-one peer counseling**
- ❖ **Drug or alcohol treatment**
- ❖ **Support groups**
- ❖ **Drug or alcohol counseling**
- ❖ **Drug or alcohol day program**

As with the 2002-2003 consumer survey, almost half of consumers (46%) reported using support groups in the past 30 days. Forty-one percent (41%) of participants reported using professional mental health counseling while 31% reported using one-to-one peer counseling. Drug or alcohol counseling was the most frequently used drug and alcohol service (19%), while fewer consumers used treatment (13%) and day programs (12%). Only 6% reported needing but not receiving drug or alcohol support services. More importantly, fifteen percent (15%) of consumers reported needing but not receiving professional mental health counseling, one-to-one peer counseling (15%), and support groups (13%) while less than 5% of consumers reported needing drug or alcohol counseling (3%), treatment (4%), or day programs (4%). Personal barriers were most frequently reported for all services.

It is important to note that other studies have concluded that client self-report is not always an accurate predictor of the need for substance abuse treatment services. Given this issue, objective information of possible substance abuse problems was also collected using the CAGE-AID screening. Results from this screening tool, assessed in conjunction with self-reported recent substance use, provided some indications that substance abuse treatment service needs may be at

higher levels.¹⁹ However, not all clients who have substance abuse treatment problems request or want treatment. All of these issues underscore the challenge in measuring need for this service.

Professional Mental Health Counseling. Professional mental health counseling or therapy was used by 41% of consumers. Those participants who self-identified as White reported using these services more (54%) than Blacks (40%) and Hispanics (36%). Also, consumers with housing trouble in the past year were more likely (52%) to use professional mental health services



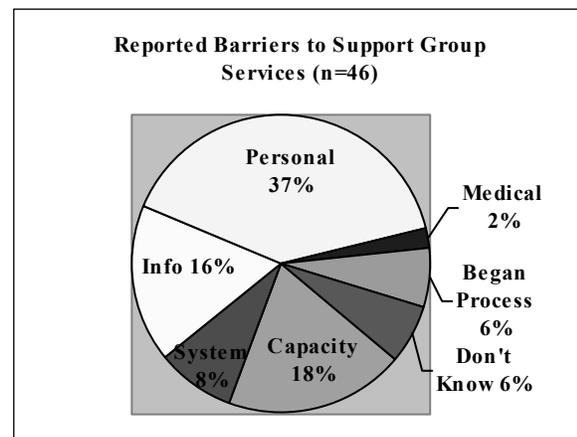
compared to those who reported not having trouble with housing in the past 12 months (34%).

Fifteen percent (15%) of consumers reported that they needed but did not receive this service and 44% stated they did not need or receive this service. Of the 58 barriers reported, the most commonly reported barrier to receiving professional mental health counseling or therapy was personal.

Support Groups. Forty-six percent (46%) of consumers reported using support group services.

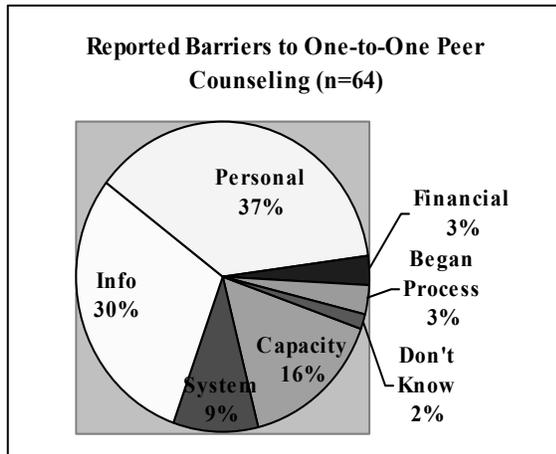
Thirty-nine percent (39%) reported not needing or receiving these services while 13% of consumers reported needing but did not receive support group services. Participants without a high school diploma (56%) reported using support groups more than those with at least a high school diploma (43%).

Consumers earning less than 100% of the federal poverty level for 2007 reported using support services more (53%) than those with an annual income over 100% of the federal poverty level (35%). Additionally, survey participants reporting either trouble with housing in the past



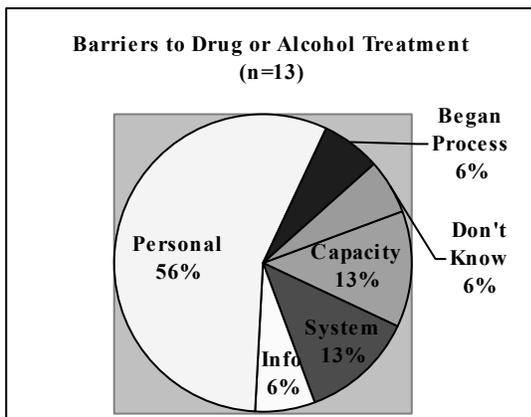
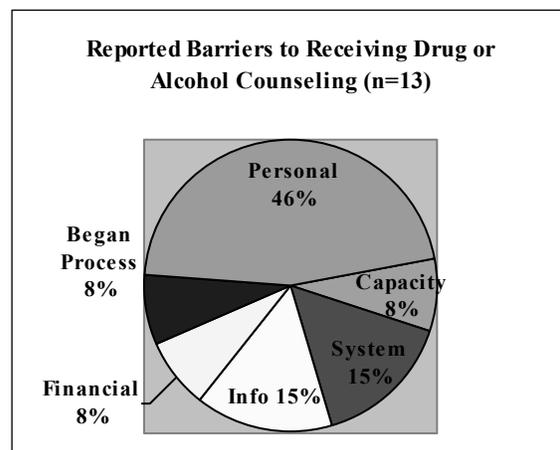
¹⁹ Results of the CAGE-AID screening are discussed in the Demographics section of this report.

year or having a case manager used support groups more frequently (54% and 52% respectively) than those without a case manager or housing trouble (27% and 41% respectively). Personal barriers to receiving support group services were reported most frequently by consumers.



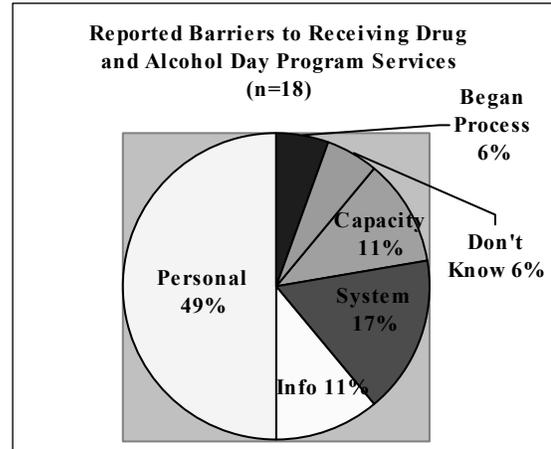
One-to-One Peer Counseling. One-to-one peer counseling services were used by 32% of the consumers interviewed. Overall, 15% of consumers reported that they needed but did not receive these services and 53% of consumers reported that they did not need the service in the last 30 days. The most frequently reported barriers to receiving one-to-one peer counseling services were information and personal.

Drug or Alcohol Counseling. Drug or alcohol counseling was the most frequently used service of substance abuse services with 19% of consumers reporting that they received the service in the past 30 days. By contrast, 76% of consumers reported that they did not need or receive drug or alcohol counseling services. Of the 3% of consumers who reported needing but not receiving services, the most commonly reported barrier was personal.



Drug or Alcohol Treatment. This service was used by 13% of participants and needed but not received by 4%. Personal barriers were the most frequently reported barrier to receiving drug and alcohol treatment services.

Drug or Alcohol Day Programs. Twelve percent (12%) of the participants interviewed reported using drug and alcohol day program services, 4% reported needing but not receiving these services, and 83% reported not needing or receiving services. The 18 consumers who stated needing but not receiving drug and alcohol day program services reported personal barriers most frequently. It is important to note that for each of these substance abuse related services, Hispanics did not report use, need, or any associated barriers to receiving these services.



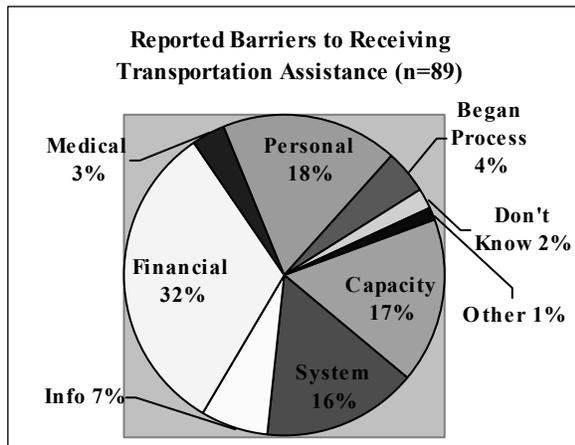
Support Services

- ❖ **Transportation/ride assistance**
- ❖ **Adoption or foster care**
- ❖ **Home-delivered meals**
- ❖ **Legal help services**
- ❖ **Childcare**
- ❖ **Food pantry**

In general, support services were not used at very high levels. The most frequently used support service was transportation/ride assistance (41%) while legal help services were used by 13% of participants. By contrast, no consumers reported using adoption/foster care services, with only 1% reporting it was needed but not received. Childcare services were reported at similarly low levels of use and need by participants (1% of participants for each). Food pantry (28%), home-delivered meals (23%), and legal help services (19%) were among the top five (5) services needed but not received. A more detailed discussion of the use, need, and barriers to services is included below.

Transportation/Ride Assistance. Transportation assistance services were used by 41% of the consumers interviewed while 18% of consumers reported that they needed but did not receive these services. Here, financial barriers to receiving services were reported most frequently. In fact, consumers earning less than 100% of the federal poverty level reported using transportation services more (50%) than those reporting higher annual incomes (23%). Similarly, survey participants that reported housing trouble in the past year used transportation services more

(58%) than those without housing trouble (31%). Finally, though women more frequently

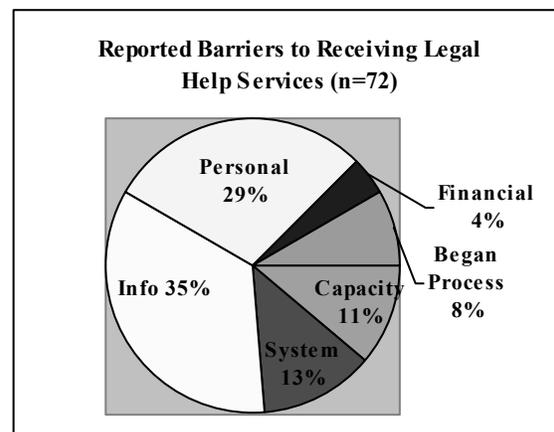


reported having received transportation services than men (47% and 38% respectively), women of childbearing age were more likely to receive this service than other gender subpopulations (50%) and to cite information barriers when needing but not receiving services.

When asked, “If you use or need transportation assistance what do you use or need it for?”

participants, who were allowed to select multiple responses, reported attending medical appointments and picking up medications most frequently (85% and 66% respectively). In addition, consumers frequently reported using transportation/ride assistance services for attending support groups/12 step meetings (59%). Thirty-eight percent (38%) of women of childbearing age who were asked this question reported using or needing transportation assistance to buy groceries.

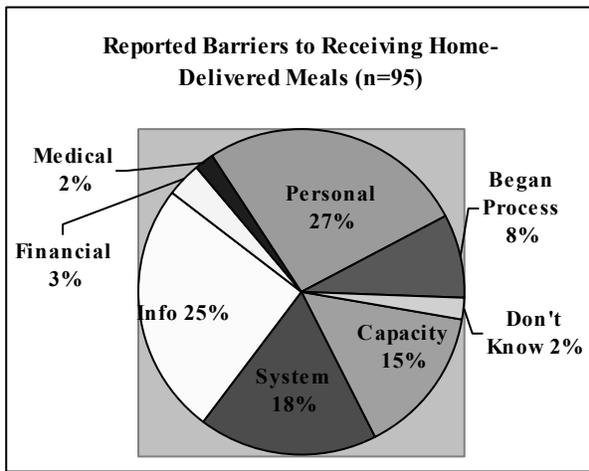
Legal Help Services. Legal help services were used by 13% of participants. With 19% of participants reporting that they needed but did not receive this service, legal help was among the top five (5) services reported as needed but not received in the past 30 days. Information and personal barriers were reported most frequently for these services.



Adoption or Foster Care. This service was not used by any participants and needed but not received at a low level (n=5, 1%). Of those reporting needing but not receiving adoption/foster care services, only one (1) consumer reported supporting at least one child with their annual income. Information was the most frequently reported barrier to adoption or foster care services.

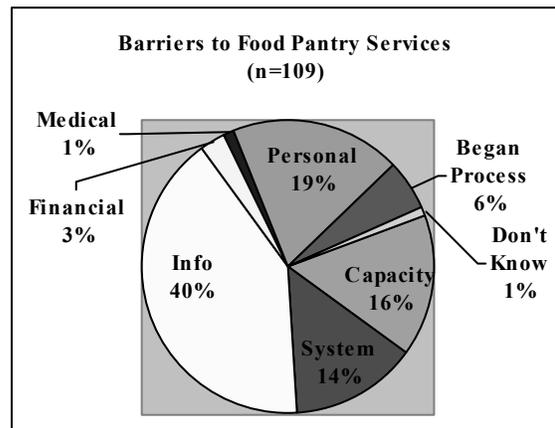
Childcare. One percent of survey participants reported using childcare services and 2% reported needing but not receiving childcare services in the past 30 days. Of those who reported needing but not receiving services, 5 out of 8 consumers reported supporting at least one child on their annual income. The most common barriers reported to receiving childcare services were system and information.

Home-Delivered Meals. Home-delivered meal services were used by 13% of all participants in the past 30 days, while 23% reported that they needed but did not receive services. This made home-delivered meals among the top five services needed but not received. Of those consumers that reported an annual income less than 100% of the federal poverty level, 24% reported needing home-delivered meals. The most frequently reported barriers to receiving home-delivered meals were information and personal.



the past 30 days, while 23% reported that they needed but did not receive services. This made home-delivered meals among the top five services needed but not received. Of those consumers that reported an annual income less than 100% of the federal poverty level, 24% reported needing home-delivered meals. The most frequently reported barriers to receiving home-delivered meals were information and personal.

Food Pantry. Similar to home-delivered meals, food pantry services were used by 13% of participants and needed but not received by 28% in the last 30 days. Fifty-seven percent (57%) of survey participants that needed but did not receive food pantry services also reported earning an income less than 100% of the federal poverty level. The most commonly reported barrier to receiving food pantry services was information.



SERVICE RANKINGS

Participants were asked to rank the importance of medical and support services to them, with 1 being the MOST important service and 10 being the LEAST important service. The service categories provided are listed in the tables below. Participants were asked to base their rankings on the services they perceived to be most important to themselves rather than consumers of HIV services in general. In addition, participants were instructed to apply a ranking for each service. Results of service rankings are reported as the proportion of consumers who applied a numeric rank of 1 to the service which they thought was most important. These results are consistent with the mean rank of each service.

Medical Service Rankings		
Rank	Medical Service	Proportion of Respondents
1	Medical Care	61%
2	Antiretroviral Medications	23%
3	HIV Medications	4%
4	Dental Care	3%
5	Case Management	2%
6	Support Services	2%
7	Mental Health Services	2%
8	Hospice	1%
9	Drug or Alcohol Counseling or Treatment	<1%
10	Home Health Care ²⁰	0%

Support Service Rankings		
Rank	Support Service	Proportion of Respondents
1	Housing Assistance	39%
2	Emergency Financial Help	18%
3	Peer Counseling	9%
4	Legal Services	6%
5	Transportation Assistance	6%
6	Home-Delivered Meals/Food Pantry	5%
7	Volunteer Help	2%
8	Childcare	2%
9	Translator/Interpreter	1%
10	Adoption/Foster Care	<1%

Medical Service Rankings. The top 3 services that were ranked most important by survey participants were medical care (61%), antiretroviral medications (23%), and HIV medications (4%). Conversely, drug or alcohol counseling or treatment was ranked least important by participants with only one participant ranking it as the most important service to them. In addition, none of the consumers in this study ranked home health care as the most important service offered in the EMA. Primary medical care was consistently ranked as the most important medical service in the EMA (n=135) across demographic subpopulations analyzed in this report.

²⁰ No consumers ranked home healthcare as the most important medical service.

Antiretroviral medications, the second most important service in the EMA, was frequently deemed most important (n=79) by consumers who reported remembering their most recent T-cell count (86%) or viral load (79%) and by participants with a case manager (76%). Dental care, the most needed but not received service, was not ranked highly by participants. Of the 11 participants who ranked dental care as the most important service in the EMA, 74% reported earning less than 100% of the federal poverty level for 2007 and 64% reported having a case manager.

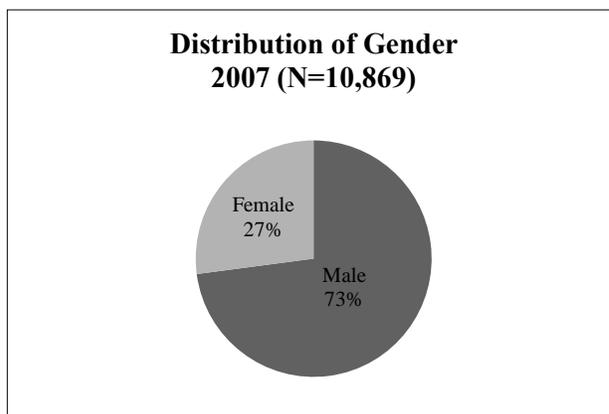
Support Service Rankings. The results presented here reflect responses from the 315 consumers that ranked the support services in this section. The top support services ranked by consumers as most important were housing assistance (39%), emergency financial help (18%), and peer counseling (9%). In contrast, translator/interpreter (1%) and adoption and foster care (< 1%) were ranked least important by survey participants. Consumers who chose housing assistance as the most important support service (n=135) were primarily Black (80%) and reported having a case manager (79%). Though it was not included in the service use and need section of the survey, consumers were asked to rank the importance of emergency financial assistance. This service (n=63) was frequently cited as most important by those with at least a high school diploma (78%) and consumers who did not experience trouble with housing in the past year (70%). More than half of survey participants earning an annual income less than 100% of the federal poverty level for 2007, ranked this service as the most important (54%). One-to-one peer counseling (n=30) was ranked as the most important social service more often by consumers who reported not having trouble with housing in the past year (84%), those with a case manager (83%), as well as those earning less than 100% of the federal poverty level for 2007 (60%).

CLIENT LEVEL DATA

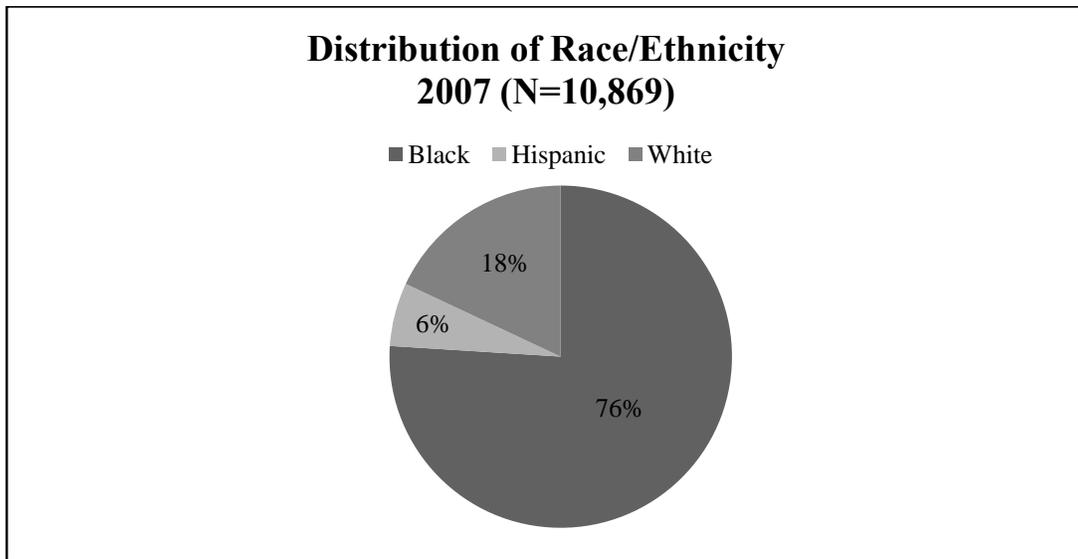
Client Level Data (CLD) includes demographic and service information for each unique client in the EMA unduplicated using the Unique Record Number (URN) generated in CAREWare. CLD provides information on client demographics and services used over a calendar year at agencies receiving Ryan White funding. These data can assist in planning when used in conjunction with consumer survey data. For the purposes of this section, client data were summarized for all HIV positive individuals for calendar year 2007. Specific aggregate processes that would impact the data are discussed in more detail in the corresponding sections. Changes in CLD data may be reflective in changes in data collection rather than service provision, so these data should be used and interpreted cautiously. Data for this section were provided by Fulton County Government's Ryan White Part A Program. Data presented are inclusive of agencies that received Ryan White Part A funding during calendar year 2007. In this section, social, economic, medical and system characteristics of Ryan White clients are presented in addition to a snapshot of service utilization during 2007.

SOCIAL

Ryan White providers in the EMA reported an increase in the number of individuals served over the past five years. By the end of 2007, there were 10,869 HIV infected and affected individuals reported by Ryan White providers to have received at least one service.



The proportion of women who participated in the consumer survey (28%) was consistent with CLD (27%).



Blacks accounted for the majority of individuals (76%) reported in the CLD data in 2007. Whites made up approximately 18% of individuals reported in the CLD data in 2007, 6% were Hispanic, and less than 5% were of other races. Blacks were represented at a slightly higher proportion in the CLD data (76%) than in the consumer survey (71%). The average age of individuals reported in the CLD data in 2007 was 40 years, fairly consistent with the average age of individuals who participated in the consumer survey (43 years). The proportion of women of childbearing age using Ryan White services was 51% in 2007, which was consistent with consumer survey participants (53%).

ECONOMIC

Ryan White providers report a number of issues regarding a client's socioeconomic status including housing/living arrangements and the number of clients with incomes less than 300% of federal poverty levels in the annual Ryan White HIV/AIDS Program Data Report (RDR). In 2007, Part A funded agencies in the EMA reported 9% of clients to be non-permanently housed and reported up to 2% of clients to be living in an institution. The proportion of individuals reported with income levels greater than 100% of poverty overall was 33% in 2007. Individuals who had an annual income less than 100% of poverty were reported at lower levels (67%) in the

CLD than in the consumer survey (90%). For the purposes of this analysis clients with missing housing and income data were not included.

SYSTEM

This section examines the number and the proportion of people reported in CLD to have received a particular service in 2007. Service utilization data are presented as core and support services as categorized in the 2007 RDR.

Core Service Utilization. Services captured in CLD must meet specific definitions for each specific service, thus differences in the consumer survey results are potentially reflective of this. CLD show that 79% of clients were reported as receiving at least one outpatient/ambulatory medical care visit in 2007. Twenty-five percent (25%) of clients received at least one oral health care service in 2007. Both of these are consistent with what participants reported in the survey.

In 2007, 63% of clients were reported as receiving at least one non-medical case management or medical case management service including treatment adherence counseling services. The proportion of those receiving case management services in 2007 is lower than those individuals in the consumer survey who reported having a case manager (78%), but given that participants in the consumer survey were not limited to Part A case managers only, as well as the fact that these are not consistent categories (one is a service and the other is a professional position), differences may be anticipated.

In 2007, 19% of clients were reported to have received mental health services and 10% were reported to have received outpatient substance abuse services. Proportionally, participants in the consumer survey reported higher levels of use for mental health counseling (41%).

However, consumer survey participants reported using outpatient substance abuse services at only slightly higher levels than reported in CLD where 19% were reported to have received drug or alcohol counseling, 13% were reported to have used drug or alcohol treatment, and 12% were reported used drug or alcohol day programs.

Core service category	Number of clients	Percentage of clients
Outpatient/ambulatory medical care	8,596	79.09%
Oral health care	2,709	24.92%
Mental health services	2,058	18.93%
Medical case management (including treatment adherence)	3,565	32.80%
Substance abuse services-outpatient	1,039	9.56%

Support Service Utilization. In 2007, 13% of clients received food-bank or home-delivered meal services in the EMA consistent with what consumer survey participants reported. About 11% of clients received at least one psychosocial support service in 2007. Participants in the consumer survey reported higher levels of use for support groups and one-to-one peer counseling (46% and 32% respectively). Psychosocial support services in the consumer survey included support groups and one-to-one peer counseling only, while the scope of this category for the RDR is broader (see glossary).

In 2007, 11% of clients used medical transportation services, a significantly lower percentage than reported in the consumer survey (41%). Similarly, only 1% of clients received legal help services according to CLD while 13% of survey participants reported using this service. Due to data limitations, this is not reflective of the actual percentage of Ryan White eligible clients receiving legal services. However, utilization of childcare services was consistent with service use reported by participants in the consumer survey (about 1% for both). Finally, about 2% of clients received linguistic services in 2007 while 5% of participants in the consumer survey reported using translation services. This slight difference may be due to oversampling of Hispanics for the survey.

Support services	Number of clients	Percentage of clients
Childcare services	148	1.36%
Emergency financial assistance	468	4.31%
Food bank/home-delivered meals	1410	12.97%
Legal services	112	1.03%
Linguistic services	262	2.41%
Medical transportation services	1176	10.82%
Psychosocial support services	1142	10.51%

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APPENDICES

A: SERVICES USED, NEEDED BUT NOT RECEIVED, AND BARRIERS

B: AGENCY CORRESPONDENCE

C: RECRUITMENT FLYER

D: INFORMED CONSENT INFORMATION SHEET

E: 2007-2008 CONSUMER SURVEY

APPENDIX A

Service	Service use/need (# of people)			Barriers								
	Use	Not Needed, Not Received	Needed But Not Received	Capacity	System	Information	Financial	Medical	Personal	Began Process	Don't Know	Total # Barriers
Medical and other services												
Primary medical care	271	56	20	5	4	1	5	1	6	5	0	27
Antiretroviral medications	255	64	28	9	9	0	4	1	4	10	1	38
HIV medications	145	179	17	3	5	1	4	0	5	6	0	26
Other medications	171	161	12	2	1	1	4	0	3	0	0	13
Dental care	87	98	161	42	30	18	38	1	47	14	2	202
Home healthcare	9	318	14	1	4	3	2	0	3	1	1	15
Hospice care	4	341	1	0	0	0	0	1	1	0	0	2
Information and help getting services												
Support service/ counseling	160	146	43	5	4	16	0	1	16	2	2	48
Info to protect others	196	142	13	0	1	6	0	0	2	1	1	12
Info to protect self	215	124	9	2	1	5	0	0	4	0	1	13
Info to protect baby	37	31	3	1	1	0	0	0	1	0	0	3
Translator	16	302	4	0	1	3	0	0	1	0	0	5
Referrals	153	140	58	12	17	14	3	0	14	4	5	73
Help with forms	71	257	22	6	5	2	4	0	7	5	0	31
Counseling, treatment and support												
Professional mental health services	142	153	53	10	9	9	3	0	20	5	2	60
Support groups	160	138	46	9	4	8	0	1	18	3	3	49
Peer counseling	111	186	53	10	6	19	2	0	24	2	1	67
Drug or alcohol counseling	68	266	12	1	2	2	1	0	6	1	0	13
Drug or alcohol treatment	47	288	13	2	2	1	0	0	9	1	1	16
Drug or alcohol day program	43	290	15	2	3	2	0	0	9	1	1	18
Support services												
Transportation asst.	142	146	62	15	14	6	29	3	16	4	2	89
Legal help	46	233	67	8	9	25	3	0	21	6	0	76
Adoption/foster care	0	338	5	0	0	2	0	0	3	0	0	6
Childcare	3	331	8	2	3	3	2	0	2	0	0	13
Home delivered meals	44	226	79	14	17	24	3	2	25	8	2	97
Food pantry	44	207	97	17	15	45	3	1	21	6	1	110
Total barriers reported				178	167	216	110	12	288	85	26	1082

APPENDIX B

Date:

Dear:

The Southeast AIDS Training and Education Center is conducting an HIV Consumer Survey for Fulton County Government and the Metropolitan Atlanta HIV Health Services Planning Council (IRB00003846). This 30 minute, anonymous interview will collect information about the HIV care needs of people living with HIV and AIDS in the Atlanta Eligible Metropolitan Area who are eligible for Ryan White Services. The results of this study will be used for HIV/AIDS care services planning, delivery and evaluation.

Participation in this study is voluntary and anonymous – at no time are participants asked to provide their names. All participants must be at least 18 years of age. Interviews will be conducted on the day that we have scheduled. Emory interviewers will work with designated agency representatives in order to both inform clients about the study, as well as to refer interested clients to the interviewers. Per our discussion, data collection has been scheduled for [DATE(S)/TIME(S)]

I am enclosing a memo and guidelines for the staff at [AGENCY] regarding the study and their role in informing participants. Also enclosed are flyers that may be posted, provided client confidentiality is maintained, and passed out to your staff and clients informing them of our study and the date Emory staff will be at [AGENCY] to conduct interviews. We request that all questions about the study be re-directed to Emory staff. Please note that the memo is intended for your staff and volunteers **only**, and should not be used to inform clients about the study.

We appreciate the opportunity to work with the staff and clients of [AGENCY]. Please call the project director, Rebecca Culyba at 404-727-4909 or myself, at 404-727-1550 if you have any questions. Thank you very much for your cooperation and input.

Sincerely,

Brandy Mobley, MPH
Program Associate

MEMO

Date:

To: AGENCY

From: Brandy Mobley, MPH

Program Associate, Southeast AIDS Training and Education Center

Re: 2007 HIV Consumer Survey

The Southeast AIDS Training and Education Center is conducting an HIV Consumer Survey for Fulton County Government and the Metropolitan Atlanta HIV Health Services Planning Council (IRB00003846). This 30 minute, anonymous interview will collect information about the HIV care needs of people living with HIV/AIDS in the Atlanta Eligible Metropolitan Area who are eligible for Ryan White Services. The results of this survey will be used for HIV/AIDS care services planning, delivery and evaluation.

Interviews will be conducted on the days that we have scheduled. Participation in this study is voluntary and anonymous – at no time are participants asked to provide their names.

The flyers I am sending may be posted, provided client confidentiality is maintained. The flyers may also be distributed to clients. The flyer informs clients about our study and the day(s) Emory staff will be conducting interviews at [AGENCY]. Your role as staff and volunteers of [AGENCY] is to inform the clients of our study using the flyer; additional questions about the study should be re-directed to Emory staff.

Interviewers will be on-site [DATES] from [TIMES].

We appreciate the opportunity to work with the staff and clients of [AGENCY]. Please call the project director, Rebecca Culyba, at 404-727-4909 or myself, at 404-727-1550 if you have any questions.

Thank you very much for your cooperation and input!

LET YOUR VOICE BE HEARD

Here's Your Chance to Make a Difference!

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

This is a study in which your input will influence funding decisions regarding services for people living with HIV/AIDS in Atlanta!

About the study:

- ❖ Information is collected through interviews
- ❖ You will not be asked to give your name
- ❖ Participation in the study is voluntary
- ❖ It takes about 30 minutes to be interviewed
- ❖

Who can participate?

- ❖ Anyone who is HIV positive and at least 18 years of age

How can I participate?

- ❖ If you would like to be interviewed for the study, Emory interviewers will be at [Insert AGENCY] on: (The Scheduled Dates and Times) Please contact the Project Coordinator, Brandy Mobley at 404-727-1550 to schedule a date and time for interviewers to be at your agency. Thank You!

This study has received Emory University Institutional Review Board Approval (IRB00003846) and is being conducted on behalf of Fulton County Government and the Metropolitan Atlanta HIV Health Services Planning Council



APPENDIX D

Study No.: IRB00003846

Emory University IRB
IRB use only

Document Approved On: 9/18/2007
Project Approval Expires On: 4/24/2008

Metropolitan Atlanta HIV/AIDS Consumer Survey Study 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 HIV care needs of people living with HIV and AIDS in Atlanta. Anyone who is at least 18, and has HIV or AIDS is being asked to participate. Your input will impact what HIV care services are available for people living with HIV/AIDS in Atlanta.

Procedures:

This interview will take about 30 minutes to complete. You will be asked questions about the services you use, the services you need, and the barriers you face in getting those services. You will also be asked some general questions. We will take what you say and add it to what other people living with HIV/ AIDS say. Then, we will present the results to Fulton County Government. They will use this information to plan for HIV care services.

Benefits:

Taking part in this study 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.

Voluntary Participation and Withdrawal:

Finishing the interview is up to you. You can stop at any time or choose not to answer questions. SEATEC staff or any other HIV/AIDS service agencies will not treat you any differently if you decide not to take part in the study.

Confidentiality:

Anything said during this interview will remain private to the extent allowed by law. Agency staff will not know what you said in this interview. Your name is not on this survey. I will not ask for your name at any time.

Costs and Compensation:

Please be aware that neither SEATEC nor any HIV/AIDS service agencies will pay you for lost income or care. You will be provided emergency care if you are injured 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 believe you have been injured by this research, you should contact Rebecca Culyba (Phone: 404-727-4909).

Contact Persons:

If you have any questions about this study or believe that taking part in this study has harmed you, please call Rebecca Culyba, the project director. She can be reached 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. If you have any questions or concerns about your rights for taking part in this study, you may contact Dr. Colleen DiIorio, Chair of the Emory University Institutional Review Board. She can be reached at (404) 712-0720 or cdiiori@sph.emory.edu.

Entitlement of Consent Form and Agreement:

You will receive a copy of this informed consent document. This form will be reviewed with you before we start the interview. You will have a chance to ask questions. You will be asked if you agree to be interviewed. Your response will be written down.

APPENDIX E

Interviewer Code: _____
Data Collection Site Number: _____
Rec. Number: _____

Date: ___/___/___
Time ____:____am/pm

(Introduce yourself, shake hands, make eye contact.)

Hi, my name is _____. You don't need to tell me your name because this is an anonymous survey. I am from the Southeast AIDS Training and Education Center at Emory University. I would like to tell you about this survey and how we will use the information that you are giving us. Fulton County Government and the Metropolitan Atlanta HIV Health Services Planning Council have asked us to find out what kinds of services people living with HIV and AIDS in Atlanta need. This information will influence funding decisions that impact the services for people living with HIV and AIDS.

Thank you for taking the time to participate in this survey.

Before we begin the interview, I want to make sure that you understand your rights as a participant in this survey.

Checked for entry: _____	1 st entry by (initials): _____	date: _____	2 nd entry by: _____
--------------------------	--	-------------	---------------------------------

INFORMATION REGARDING THIS SURVEY
(YOUR RIGHTS AS A PARTICIPANT IN THIS STUDY)

(Read rights to participant. Give them the information sheet to follow as you read. You don't need to repeat the first bullet since you just said it, except for the age statement. Also, when you get to the last bullet, specifically the phone numbers and emails, point to them on their copy and say that "you can call her at this number or email her here" rather than reading the number and the email)

- The Southeast AIDS Training and Education Center at Emory University was asked by Fulton County Government to do this study. They want to find out about the HIV care needs of people with HIV and AIDS in Atlanta. Anyone who is at least 18 and has HIV or AIDS is being asked to talk to us.
- Your talking with me will take about 30 minutes. You will be asked about the services you use and need. And, you will be asked why you can't get services. You will also be asked some general questions. We will take notes about what you say. We will add it to what other people say. Then, we will give the results to Fulton County Government.
- Talking to me may not help you. But what you say will shape how money is spent for services for people with HIV and AIDS in Atlanta.
- Doing the whole interview is up to you. You can stop at any time or choose not answer questions. SEATEC staff or any other HIV/AIDS service agencies will not change how they treat you if you decide not to take part in the study.
- Anything that we talk about will remain private to the extent allowed by law. Agency staff will not know what you said in this interview. Your name is not on this survey. I will not ask for your name at any time.
- SEATEC or any HIV/AIDS agencies will not pay you for lost income or care.
- If you have any questions about this study or believe that taking part in this study has harmed you, please call Rebecca Culyba, the project director. She can be reached at 404-727-4909 or rculyba@emory.edu. Call Dr. Colleen DiIorio, Chair of the Emory University Institutional Review Board, if you have any questions about your rights as a participant in this research study. She can be reached at (404) 712-0720.

Do you have any questions about the study?

(If no, continue. If yes, address the questions.)

Do you understand your rights as a participant in this study?

(If yes, continue. If no, review any areas of misunderstanding/questions.)

Would you be willing to participate in this study?

(If yes, continue. If no, stop and thank them for their time and end the interview. Oral Consent Obtained:

Yes (complete information below and continue with the interview)

No

Oral Consent Obtained:

Yes (complete information below and continue with the interview)

No

Today's Date: _____

Name of Staff Person Obtaining Oral Consent: _____

(Please read to participant.)

This interview is in 3 parts: the first part asks about what services you use and need. The second part will ask you to tell us how important specific services are to you. The final section will ask you some questions about yourself.

If it's alright with you, I will be taking some notes on this form so that we can have a better understanding of your needs and concerns.

Are you ready to begin?

Start time ____: ____ am/pm

Part 1: First, I'm going to ask you about the services you are getting and what services you need.

Atlanta EMA HIV/AIDS Consumer Survey
IRB00003846

(Please read to participant.) For each of the services, please tell me if you have used this service **in the past 30 days**, if you **don't need** this service, or if you need the service and **haven't been able to get it**. (Use the barriers coding sheet to properly code barriers.

(THIS SECTION IS ABOUT MEDICAL AND OTHER SERVICES)

In the past 30 days have you used...	If "YES" go to the next service. If "NO" go to the next column.		Did you need the service in the past 30 days? If "NO" go to next service. If "YES" go to next Column.		Can you think of any reasons you did not get the service? (Circle all that apply.)									Please specify any OTHER reasons for not receiving service	Coding Only
					Capacity	System	Information	Financial	Medical	Personal	Began Proces	Don't know	No barriers		
Primary medical care- when you go to a clinic or agency to see a doctor or nurse for medical care.	Yes	No	Yes	No	1	2	3	4	5	6	7	8	9		
Antiretroviral medications- taking medications (Use medication sheet to define medications).	Yes	No	Yes	No	1	2	3	4	5	6	7	8	9		
HIV medications other than antiretrovirals- any medications you take to prevent yourself from getting sick like Bactrim, also includes antidepressants.	Yes	No	Yes	No	1	2	3	4	5	6	7	8	9		
Other medications- medications you take other than those we have already talked about. Includes medication for high blood pressure or diabetes. Does not include over the counter medications.	Yes	No	Yes	No	1	2	3	4	5	6	7	8	9		
Dental care- when you go to see the dentist or get your teeth cleaned.	Yes	No	Yes	No	1	2	3	4	5	6	7	8	9		
Home healthcare- when a nurse comes to your home to provide you with medical care other than hospice care.	Yes	No	Yes	No	1	2	3	4	5	6	7	8	9		
Hospice care- care in your home or at a facility when you are in the late stages of HIV disease.	Yes	No	Yes	No	1	2	3	4	5	6	7	8	9		

(THIS SECTION IS ABOUT INFORMATION AND HELP GETTING SERVICES)

In the past 30 days have you...	If "YES" go to the next service. If "NO" go to the next column..	Did you need the service in the past 30 days? If "NO" go to next service. If "YES" go to next Column.	Can you think of any reasons you did not get the service? (Circle all that apply.)									Please specify any OTHER reasons for not receiving service.	Coding Only
			Capacity	System	Information	Financial	Medical	Personal	Began proces	Don't know	No barriers		
Used HIV/AIDS support services and counseling such as child care, legal services, support groups, etc?	Yes No	Yes No	1	2	3	4	5	6	7	8	9		
Received information on how to protect other people from getting HIV from you?	Yes No	Yes No	1	2	3	4	5	6	7	8	9		
Received information on how to protect yourself from getting sexually transmitted diseases from other people?	Yes No	Yes No	1	2	3	4	5	6	7	8	9		
(Only Ask of all women of childbearing age 15-44) Received information on how not to pass HIV to your baby if you are pregnant?	Yes No	Yes No N/A	1	2	3	4	5	6	7	8	9		
Used translator/ interpreter services-- meaning you need someone to explain things to you in a language other than English such as Spanish, French or sign.	Yes No	Yes No	1	2	3	4	5	6	7	8	9		
Received referrals to services you need?	Yes No	Yes No	1	2	3	4	5	6	7	8	9		
Received help filling out forms for medications or services?	Yes No	Yes No	1	2	3	4	5	6	7	8	9		

Do you have a case manager? A case manager is someone who helps you with referrals, filling out forms, benefits counseling, etc. This is not a peer counselor – one on one peer counseling is when you talk to someone who has HIV or is in recovery.

- Not Sure
- No (Proceed to next page)
- Yes (Continue with following transition) - What is the name of your case manager and/or the agency he/she works for? _____

(THIS SECTION IS ABOUT COUNSELING, TREATMENT AND SUPPORT)

In the past 30 days have you used...	If “YES” go to the next service. If “NO” go to the next column..		Did you need the service in the past 30 days? If “NO” go to next service. If “YES” go to next Column.		Can you think of any reasons you did not get the service? <i>(Circle all that apply.)</i>									Please specify any OTHER reasons for not receiving service	Coding Only
					Capacity	System	Information	Financial	Medical	Personal	Began Process	Don't know	No barriers		
					1	2	3	4	5	6	7	8	9		
Professional mental health counseling/therapy -- meaning a trained counselor who you can talk to one on one about how you feel.	Yes	No	Yes	No	1	2	3	4	5	6	7	8	9		
Support groups -- meaning talking with people in a group setting about how you feel – does NOT include 12 step meetings.	Yes	No	Yes	No	1	2	3	4	5	6	7	8	9		
One to one peer counseling -- meaning not a friend or sponsor, but a formal relationship with someone who has HIV or is in recovery, to whom you talk to about your feelings or problems.	Yes	No	Yes	No	1	2	3	4	5	6	7	8	9		
Drug or alcohol counseling -- meaning talking to a trained counselor one on one about your substance abuse problems.	Yes	No	Yes	No	1	2	3	4	5	6	7	8	9		
Drug or alcohol treatment -- meaning inpatient or outpatient medical treatment at a hospital or a program run by trained staff, but not a day program.	Yes	No	Yes	No	1	2	3	4	5	6	7	8	9		
Drug or alcohol day program -- meaning a place you go during the day where trained staff focus with you on substance abuse issues like aftercare.	Yes	No	Yes	No	1	2	3	4	5	6	7	8	9		

(THIS SECTION IS ABOUT SUPPORT SERVICES)

In the past 30 days have you used...	If "YES" go to the next question. If "NO" go to the next column..		Did you need the service in the past 30 days? If "NO" go to next service. If "YES" go to next Column.		Can you think of any reasons you did not get the service? <i>(Circle all that apply.)</i>									Please specify any OTHER reasons for not receiving service	Coding Only
					Capacity	System	Information	Financial	Medical	Personal	Began Process	Don't know	No barriers		
Transportation/ride ASSISTANCE including MARTA fare, public vans like Medicaid vans or taxi vouchers. (Interviewer clarification on definitions sheet)	Yes	No	Yes	No	1	2	3	4	5	6	7	8	9		
If you use or need transportation assistance, what do you use or need it for? (Read categories. Check all that apply. Skip if didn't use or need) <ul style="list-style-type: none"> <input type="checkbox"/> medical appointments <input type="checkbox"/> support groups/12 step meetings <input type="checkbox"/> pick up medication <input type="checkbox"/> groceries <input type="checkbox"/> errands <input type="checkbox"/> entertainment <input type="checkbox"/> other --SPECIFY _____ 															
Legal help services for legal issues like housing and insurance discrimination, writing a will, social security disability claims, etc.	Yes	No	Yes	No	1	2	3	4	5	6	7	8	9		
Adoption or foster care help-- meaning temporary care for your kids when you are very ill or permanent for after you are gone.	Yes	No	Yes	No	1	2	3	4	5	6	7	8	9		
Child care-- meaning someone to watch your child at a center or in someone's house when you go to the doctor, run errands or go to work.	Yes	No	Yes	No	1	2	3	4	5	6	7	8	9		
Home delivered meals	Yes	No	Yes	No	1	2	3	4	5	6	7	8	9		
Food Pantry	Yes	No	Yes	No	1	2	3	4	5	6	7	8	9		

Part 2: What services do you need?

(Please read to participant.) In this section we would like to find out which services you consider to be **MOST IMPORTANT** for you. Please rank the services with 1 being the **MOST** important service and 10 being the **LEAST** important service.

	Medical care -Including doctors, nurses, nutritional counseling, medications for ongoing problems like hypertension and diabetes, and other medical care at an agency or clinic.
	Antiretroviral medications -Including protease inhibitors –see medication chart.
	HIV medications other than antiretroviral -Including medications that prevent you from getting sick like Bactrim. Also includes antidepressants.
	Dental Care
	Home health care, meaning care provided where you live -home nursing or infusion care, skilled nursing facility, rehabilitation care, paid helper to assist with bathing, feeding or shaving, medical equipment, etc.
	Hospice care -Including care in your home or at a facility when you have late stage HIV disease.
	Case management -help you get referrals to services, filling out forms, finding out more about what services you are able to get because you have HIV.
	Mental health services with a trained counselor -Professional or specially trained individuals to help you talk about your feelings one on one or in a group setting.
	Drug or alcohol counseling or treatment by a trained staff person
	Support services -Adoption/foster care; volunteer who helps with shopping or cooking; one on one peer counseling, support groups; child care; food pantry or home delivered meals; emergency help paying for groceries and utilities; help finding a place to live that you can afford; transportation assistance; translator/interpreter; legal services.

Part 2 Continued: What services do you need?

(Please read to participant.) This next section is similar to the one you just did. The support services listing from the previous page **(point to support services listing on previous page)** is now broken down into this list **(point to new sheet)**. We would like you to rank these services with 1 being the **MOST** important service and 10 being the **LEAST** important service.

	Adoption/foster care -temporary care for your kids when you are very ill or permanent for after you are gone.
	Volunteer who helps with shopping or cooking, cleaning, etc
	One on one peer counseling, support groups -without a counselor there.
	Child care
	Emergency short-term help paying for groceries, gas or electric bills
	Housing assistance -Help finding a place to live that you can afford.
	Transportation assistance -including mass transit tokens, public vans, or taxi vouchers.
	Translator/Interpreter
	Home delivered meals/food pantries
	Legal services

Part 3: (Please read to participant.) In this last section, I am going to ask you different questions about yourself. Some of these questions are personal, so if you're not comfortable answering them, just say you want to skip that question. **(Do not read responses of "Don't Know" or "Refused to answer".)**

1. Would you describe yourself as... **(Read categories as "Male, Female or Transgendered?" If participant has difficulty understanding Transgendered read alternate definition.)**
 - Male
 - Female
 - Transgendered --Male who identifies as female
 - Transgendered --Female who identifies as male
 - Don't know/Refused to answer

Alternate definition for Transgendered: NOT identifying with

2. What is your race/ethnicity? **(Open-ended. There can be multiple responses. Check all that apply.)**
 - American Indian / Alaska Native
 - Asian / Pacific Islander
 - Black/African American --Non-Hispanic
 - Hispanic/Latino
 - White --Non-Hispanic
 - Other --SPECIFY _____
 - Don't know/Refused to answer

3. What is the zip code of where you live now? _____ **(Interviewer, check here if person is homeless).**

4. How old are you? _____

5. What is your yearly income before taxes? **(Read choices to participant. You may need to help them calculate from their monthly check. If they seem uncomfortable with answering, let them know you have categories so they don't have to give their exact income. Check one only.)**
 - Under \$10,210
 - \$10,210-20,420
 - \$20,421-30,630
 - Over \$30,630
 - Don't know/Refused to answer

6. How many people are supported by this income?
 - 1 **(If 1, skip to question 8.)**
 - 2
 - 3
 - 4
 - 5 or more
 - Don't know/Refused to answer

7. Of these, how many people under the age 24 are supported by this income?
 - 0
 - 1
 - 2
 - 3
 - 4
 - 5 or more
 - Don't know/Refused to answer

8. In the past 12 months, have you had trouble getting housing?
- Yes
 - No
 - Don't know/Refused to answer
9. Does the government or another organization currently pay or help pay for your housing?
- No
 - Not sure
 - Not applicable (**homeless**)
 - Yes, (**Check all that apply.**)
 - You have a section 8 certificate or voucher
 - You get help with your rent from HOPWA (Housing Opportunity for Persons with AIDS)
 - You live in subsidized or public housing
 - You live in a home for people living with HIV or AIDS
 - You are getting help paying for your housing, but you don't know what it is called
 - You receive another form of help paying for your housing
9. In order to compare our survey results with the results from other studies. I'd like to know if you did any of the following things **before** you were first diagnosed as HIV positive. (**Check all that apply.**)
- Had sex with a man
 - Had sex with a woman
 - Had sex with an injection drug user
 - Had sex with someone you know or believe to have been bisexual
 - Had sex with someone who you knew at the time was HIV positive
 - Received clotting factor for hemophilia or another clotting disorder before 1985
 - Received transfusion of blood or components other than clotting factor before 1985 or in another country
 - Other --SPECIFY _____
 - Don't know/Refused to answer
10. How did you find out you were HIV positive? (**Open-ended. Read the responses if they are having difficulty remembering.**)
- Requested a test for HIV
 - Donated Blood
 - Went to the hospital or emergency room for something else
 - Recommended by healthcare provider as part of a physical exam or doctor's visit
 - (*for women*) As part of care while pregnant
 - While in jail or prison
 - Other --SPECIFY _____
 - Don't know/Refused to answer
11. Who **first** helped you get into services after you found out you had HIV? (**Read categories – If they say the person who gave me test results, ask if this was their doctor or medical provider.**)
- Family member
 - Friend
 - Doctor/medical provider
 - Person who gave you your test results (**Someone other than your doctor/medical provider**)
 - Case manager/social worker
 - Prison/jail
 - Nobody
 - Other --SPECIFY _____
 - Don't know/Refused to answer

12. What is your most recent T-cell (may also be called CD4 cell) count? (Open-ended. Check only one. If they are unsure, read the choices. If they don't know what a t-cell is, tell them not to worry about this question and select "Don't know what T-cell is.")
- Under 200
 - Between 200-350
 - Over 350
 - Don't know if I ever had one done / Never told results
 - I have never had a t-cell count done
 - Can't remember results
 - Waiting for results currently
 - Refused to answer
 - Don't know what a T-cell is
13. What is your most recent viral load? (Open-ended. Check only one. If they are unsure, read the choices. If they don't know what a viral load is, tell them not to worry about this question and select "Don't know a viral load is.")
- Undetectable or below 50
 - Between 50-55,000
 - Over 55,000
 - Don't know if I ever had one done/ Never told results
 - I have never had a viral load done
 - Can't remember results
 - Waiting for results currently
 - Refused to answer
 - Don't know what a viral load is
15. In the past 30 days, have you taken antiretroviral drugs including protease inhibitors? (Show the color chart of medications.)
- No – Please tell me why you are not taking antiretroviral medications:
 - Yes – Are any of your antiretroviral drugs paid for by the following sources? (Check all that apply.)
 - AIDS Drug Assistance Program (ADAP)
 - Medicaid
 - Medicare
 - Veteran's benefits
 - Private insurance
 - Out-of-pocket (not including co-payments)
 - Pharmaceutical Assistance Program (PAP)
 - Other --SPECIFY _____
 - Don't know/Refused to answer
16. Are you currently taking other medications prescribed by your doctor?
- No
 - Yes – Are any of your other prescription drugs paid for by the following sources? (Check all that apply.)
 - AIDS Drug Assistance Program (ADAP)
 - Medicaid
 - Medicare
 - Veteran's benefits
 - Private insurance
 - Out-of-pocket (not including co-payments)
 - Pharmaceutical Assistance Program (PAP)
 - Other --SPECIFY _____
 - Don't know/Refused to answer

17. People stop taking medications for many reasons. In the past 6 months, have you stopped taking your antiretroviral medications for any of these reasons? This does not mean missing just one dose. **(Provide categories. Ask question as written. Check all that apply.)**

- Never stopped
- No medication in last 6 months
- The doctor or nurse told you to
- They made you sick
- You forgot
- You couldn't afford them
- Your provider did not give them to you **(In prison or jail setting, the provider dispenses medication.)**
- Never refilled prescription
- Other --SPECIFY_____
- Don't know/Refused to answer

18. This question asks about your behavior in the last 6 months. Your answers will help us make our programs better to help you stay healthy. In the past 6 months, have you ... **(Read Categories on at a time and let participant answer each one. Check all that apply.)**

- Been in jail or prison
- Used needles to inject drugs
- Used crack or other street drugs
- Used alcohol
- Exchanged sex for drugs, food or a place to sleep
- Had unprotected sex
- None of the above
- Refused to answer

19. What was the last year of school that you completed? **(Open-ended. If participant answers "12th grade", check to see if he/she graduated or not. Check all that apply.)**

- 8th grade or less
- Some high school
- High school graduate / G.E.D.
- Vocational/ Technical school/ Associates degree
- Some college
- College degree
- Graduate degree
- Other_____
- Don't know/Refused to answer

20. This next set of questions is about using alcohol or drugs.

- | | | |
|--|-----|----|
| 1. Have you ever drank alcohol or done drugs? (If NO, skip to question 21.) | Yes | No |
| 2. During the past 30 days , have you felt you ought to cut down on your drinking or drug use? | Yes | No |
| 3. During the past 30 days , have people annoyed you by criticizing your drinking or drug use? | Yes | No |
| 4. During the past 30 days , have you felt bad or guilty about your drinking or drug use? | Yes | No |
| 5. During the past 30 days , have you had a drink or used drugs first thing in the morning to steady your nerves or to get rid of a hangover (an eye-opener)? | Yes | No |

21. This next set of questions is about how you have felt **in the past 30 days** including today.

- | | | |
|---|-----|----|
| 1. During the past 30 days , have you been hearing or seeing things that other people don't seem to hear or see? | Yes | No |
| 2. During the past 30 days , have you been bothered by feeling down, depressed, or hopeless? | Yes | No |
| 3. During the past 30 days , have you often been bothered by little interest or pleasure in doing things? | Yes | No |

(Read to participant) : You have completed this survey. Thank you again for your time.

End time ____ : ____ **am/pm**

Data Coding Sheet

(Data collectors please use this sheet to correctly code the responses provided in Section 1 for barriers.)

Barrier Categories

Category	Description/Subcategories
Capacity – more services are needed.	-Waiting time/list -Couldn't get an appointment -Service unavailable/restricted -Proximity to service -Eligibility -Language
System – services that already exist need to be modified in service delivery.	-Regulations issues -Medicare/Medicaid -Responsiveness -Confidentiality/stigma -Case management -Dissatisfaction
Information	-Didn't know where to go/who to ask for help -Unaware of/didn't ask know about service
Financial	-Cost -Homeless
Medical	-Participants are too ill or too healthy to get the service
Personal	-Issues related to the individual such as they had not done it yet, did not want to utilize that service, ashamed to ask, etc.
Began process	-Individuals have started the process to receive the service but have not yet received it
Don't know	-Participants don't know why they were unable to get the service
No Barriers	-Participant had no barriers that prevented them from getting the service

Section 1: Support Services

Transportation –Interviewer clarification: don't read this to client – assistance means actual transportation is provided, such as public vans, or financially assisted such as MARTA tokens or taxi vouchers. Does not include Half fare card.