

**InterGroup Services
Client Report**

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2003
Needs Assessment
Compendium**

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1. EXECUTIVE SUMMARY

The five studies described in this report were undertaken by InterGroup Services (IGS), a Baltimore-based consulting and project management company, on behalf of the Greater Baltimore HIV Health Services Planning Council (the planning council). The planning council is the body that prioritizes the need for funds received under the Baltimore eligible metropolitan area's (EMA's) Title I program of the Ryan White CARE (Comprehensive AIDS Resource Emergency) Act (the CARE Act). The CARE Act provides emergency funding for primary medical care and other services for people living with HIV/AIDS (PLWH/A).

This report has three purposes. First, it describes the needs assessment requirements and process. Second, it describes each of the five studies undertaken to meet those requirements. Finally, it makes recommendations for funding priorities based on the results of those studies.

1.1 Assessing the Needs of PLWH/A in the Baltimore EMA

Each year the planning council is charged with the task of planning the allocation of funds into service categories based on an assessment of HIV consumer needs from the preceding and, where possible, current fiscal years. ("Service categories" are the broad expenditure types, such as primary medical care, substance-abuse treatment, etc., that the planning council funds; the planning council does not allocate funds to specific programs.) The planning council directs these emergency funds into service categories that meet the needs of PLWH/As. In an effort to distribute these funds most effectively, the planning council conducts yearly needs assessment activities for special populations. IGS implemented the planning council's needs assessment research design for 2003.

The guiding question that the needs assessment activities sought to answer was: what are the barriers that HIV-positive individuals in specific populations encounter when attempting to access primary medical care? The populations of special interest for 2003 were clients of select HIV service providers in the EMA, EMA county residents, youth between the ages of 13 and 24, ex-offenders (i.e., formerly incarcerated individuals) and African-American men who have sex with men (MSMs).

1.2 The 2003 Needs Assessment Studies

The first study included in this report is a meta-analysis of Baltimore EMA providers' needs assessment activities (see chapter 3). The meta-analysis involved a review of needs assessment data provided by the Health Education Resource Organization (HERO), Total Health Care, Inc., and the Baltimore City Health Department's quality improvement program. The meta-analysis enables the planning council to review synthesized results from separate but related studies of multiple populations.

The second, third and fourth studies included in this report are similarly structured assessments of the needs of three of the populations of special interest for 2003: EMA county residents (chapter 4), youth (chapter 5) and ex-offenders (chapter 6). Each of these assessments used the same data-collection methodology — a combination of surveys and focus groups — to identify the barriers that limit that population's ability to access HIV care. The EMA county residents were selected as a special population because of the many social, economic and demographic differences between the counties in the EMA and Baltimore City. Young people were selected as a special population

because of the unique challenges facing them as they strive to develop and assert their identities — identities that will be influenced by their HIV status. Like young people with HIV, ex-offenders with HIV face unique challenges that warrant special attention by the planning council; they must navigate a complex system of care while coping with the stress of being reintegrated into society.

The final study included in this report is an analysis of the access-to-care barriers encountered by African-American MSMs. The data were collected through facilitated surveys of 82 HIV-positive African-American MSMs. The planning council targeted this population because of the multiple biases it must contend with in seeking care — biases against race, sexual behavior and HIV status.

1.3 Planning Implications of the 2003 Needs Assessment Activities

Significant commonalities emerged quickly in the analysis of these disparate groups. Concerns with substance abuse and mental-health treatment availability do not stop at the county line. Consumers in all areas register dissatisfaction with wait times for service and trustworthiness of staff; conversely, service providers voice concerns with client retention and treatment adherence.

General conclusions apply to all the special populations despite their different circumstances. Specific barriers to care that apply to all special populations can be placed into one of six categories: substance abuse, mental health and psychosocial support, economic expense, provider attitudes and care environment, stigma and confidentiality, and automatic versus motivated access to care.

Substance-abuse treatment is essential to consumer retention and treatment adherence. Mental health and psychosocial support services must be provided as a precursor to treatment and especially in counseling after initial HIV diagnosis. Economic barriers such as medical expenses, transportation costs and child care frequently interfere with treatment. Provider attitudes, communication and consumer perceptions of disrespect or compassion discourage or encourage retention in care. Social stigma associated with HIV and a strong desire for confidentiality guide the treatment-seeking behavior of many PLWH/As. Access to care is often dependent on slowly emerging personal acceptance of HIV-positive status or the desperate motivation of severe illness. Ultimately, the process for moving from diagnosis to care must be streamlined and normalized.

— *InterGroup Services, Inc.*

2. BACKGROUND

In May 2003, the Greater Baltimore HIV Health Services Planning Council (the planning council) asked InterGroup Services, Inc. (IGS), a Baltimore-based consulting and project management company and holder of the planning council support contract, to assess the needs of four populations of special interest to the planning council. The planning council is the body that prioritizes the need for funds received under the Baltimore eligible metropolitan area's (EMA's) Title I program of the Ryan White CARE Act.

To ensure that it prioritizes needs appropriately, the planning council is required to conduct periodic assessments of the needs of the people in the communities it serves. Needs assessment activities include compiling data on HIV/AIDS cases in the EMA and identifying the needs of PLWH/As who know their HIV status but are not receiving care or services.

2.1 HIV/AIDS in the Baltimore EMA

The Baltimore EMA consists of Baltimore City and its surrounding counties: Anne Arundel, Baltimore, Carroll, Harford, Howard and Queen Anne's. The geographical proximity of the constituent parts of the EMA belies a fundamental difference in the needs and characteristics of PLWH/As in Baltimore City versus populations in the surrounding counties. In terms of readily measurable demographics, at least three relevant distinctions can be made in terms of race, income and transmission vectors.

The U.S. Census Bureau (Census 2000b) reports Baltimore City's population as 64.3 percent black, 31.6 percent white and 4.1 percent combined and other races. The surrounding counties have majority white populations, each with a less than 21 percent black population (see table 1).

	Anne Arundel County	Baltimore City	Baltimore County	Carroll County	Harford County	Howard County	Queen Anne's County
White	81.2%	31.6%	74.4%	95.7%	86.8%	74.3%	89.0%
African-American	13.6%	64.3%	20.1%	2.3%	9.3%	14.4%	8.8%
Other	5.2%	4.1%	5.5%	2.0%	3.9%	11.3%	2.2%

Source: Census 2000b.

Baltimore City has considerably lower median household income than the counties of the EMA in addition to higher than average rates of poverty and unemployment. Median household income for 2000 in Baltimore City was \$30,078 compared to nearly twice as much (or more) in surrounding counties: Anne Arundel County, \$61,768; Baltimore County, \$50,667; Carroll County, \$60,021; Harford County, \$57,234; Howard County, \$74,167; Queen Anne's County, \$57,037 (Census 2000a).

Conversely, while pockets of poverty exist throughout the region, Baltimore City bears the greatest concentration. Baltimore City's population living below the poverty level totals 22.9

percent of individuals (18.8 percent of families) compared with well below 7 percent throughout the rest of the EMA (see table 2).

	Anne Arundel County	Baltimore City	Baltimore County	Carroll County	Harford County	Howard County	Queen Anne's County
Individuals	5.1%	22.9%	6.5%	3.8%	4.9%	3.9%	6.3%
Families	3.6%	18.8%	4.5%	2.7%	3.6%	2.5%	4.4%

Source: Census 2000a.

Another important difference between Baltimore City and the counties involves the means of spreading HIV/AIDS. The transmission mode in Baltimore City is predominantly injection drug use (IDU) while the surrounding counties have higher reported rates of transmission by sexual contact between males. These differences in demographics and transmission modes between the two regional sub-populations add texture and depth to considerations of the needs of the targeted populations, and require that care be taken when designing research projects and analyzing results so as not to allow Baltimore City data to skew interpretations of data from the counties.

2.2 2003 Needs Assessment

To meet its CARE Act needs assessment requirements, the planning council conducts a comprehensive needs assessment study of the entire EMA every three years. In the interim years, the planning council conducts focused studies of populations of special interest. In May 2003, the planning council identified four populations of special interest: county residents, youth, ex-offenders and African-American MSMs.

IGS's approach to conducting this research was multi-layered. First, a meta-analysis of needs assessment activities performed by select HIV service providers in the EMA was conducted. Information gleaned from this meta-analysis helped inform the development of the methodologies used in future steps. Next, a series of community forums, at which surveys were administered and focus groups were conducted, was held with three of the populations: county residents, youth and ex-offenders. The goal of these community forums was to elicit answers to the central question of the 2003 needs assessment activities: what barriers prevent members of this population from accessing care and services? Finally, anonymous facilitated one-on-one surveys were administered to African-American MSMs. This population was approached differently from those whose needs were assessed during community forums due to the specific issues confronted by African-American MSMs; however, the goal of the survey given to this population was the same as the goal of the forums held with the other populations, which was identifying barriers to care.

The results of all of these efforts comprise the body of this report, and inform the planning implications and recommendations that appear in the final chapter. In that chapter, specific barriers to care that apply to all special populations are examined as six general categories: (a) substance abuse, (b) mental health and psychosocial support, (c) economic expense, (d) provider attitudes and care environment, (e) stigma and confidentiality and (f) automatic versus motivated access to care.

3. META-ANALYSIS: PROVIDERS' NEEDS ASSESSMENT ACTIVITIES

This chapter details the methodology and results of a meta-analysis of the needs assessment activities of the Health Education Resource Organization, Total Health Care, Inc. and the Baltimore City Health Department. The meta-analysis enables the planning council to review synthesized results from separate but related studies of multiple populations as it prioritizes the funding needs of the Baltimore EMA. In addition, information gleaned from this meta-analysis will inform the development of the methodologies used in future needs assessment activities.

3.1 Provider Overviews

Following are brief descriptions of each of the providers whose needs assessment activities are included in this analysis.

The Health Education Resource Organization (HERO) is a multifaceted community-based organization offering education, resources and services for Marylanders affected by HIV/AIDS. HERO provides comprehensive case management, housing services, mental-health services, legal services and prevention education. HERO also operates a community resource center, a primary care medical clinic and a drop-in center for people living with HIV/AIDS. Other resources provided by HERO are educational materials, a hotline and outreach to persons at risk for contracting HIV (HERO 2003).

Total Health Care, Inc. (THC) is a non-profit organization and a federally qualified health center. THC receives Ryan White CARE Act Title III funding for HIV-related primary medical care services. Funding for substance-abuse treatment programs at THC is provided through Ryan White CARE Act Title I and Title II programs (THC 2003).

The Baltimore City Health Department (BCHD) quality improvement program (QIP) was begun in 2001 in an effort to assure that HIV-positive individuals within the Baltimore EMA were receiving care consistent with the standards of the Ryan White CARE Act funding regulations. BCHD is the recipient of the Baltimore EMA's CARE Act funds; it passes the funds to Associated Black Charities, the contracted administrative agent, for distribution to HIV service providers.

3.2 Methodology

This meta-analysis involved a review and synthesis of the needs assessment data provided from the aforementioned entities. Two HERO needs assessment reports were included in the analysis. The first was a focus group report, which provided a plethora of information regarding the perception and utilization of services by clients from five vantage points: HERO clients, non-HERO clients, HERO staff, external support staff, and medical providers. The second HERO report reviewed in this analysis contained the results of a consumer assessment survey conducted by HERO.

The THC data included in this meta-analysis are from a report on a 2000 needs assessment survey conducted by THC among its clients.

The QIP report from the Baltimore City Health Department is a secondary data analysis of medical charts of Ryan White consumers from all Title I-funded primary care and case-management vendors across the Baltimore EMA. The needs-assessment portion of the QIP report

contains data from client chart abstractions from the 17 case-management vendors. The QIP report data are used here to triangulate the qualitative data from HERO and THC.

3.3 Results and Analysis

3.3.1 HERO Focus Group Report

The focus group report provided by HERO detailed the qualitative results of three separate focus groups: the first group consisted of HERO clients, the second of non-HERO clients, and the third of HERO staff, external support staff and medical providers. The report provided by HERO did not indicate the number of participants in each of the focus groups.

3.3.1.1 Client Groups' Responses

The same questions were asked of HERO and non-HERO clients. Medical service knowledge, perception and utilization were common themes in the focus group guides used for both client groups.

The two client groups were asked to define comprehensive HIV early intervention services (EIS). While the non-HERO client group was not specific in proposing a definition, the HERO client group agreed that EIS components included “collocation of services, an atmosphere of acceptance, and the provision of services that were all-inclusive” (Concentric Systems 2002). In addition, they listed substance-abuse treatment, mental health services, transportation, education, and program navigation tools as essential EIS components.

The client groups' knowledge of area facilities that offer HIV services was also assessed; both client groups were able to list several local resources (see table 3). In addition to their knowledge of specific facilities, HERO clients were also aware of clinic hours of operation and clinic staff (Concentric Systems 2002).

HERO Client Responses	Non-HERO Client Responses
<ul style="list-style-type: none"> ▪ Evelyn Jordan ▪ Johns Hopkins Moore Clinic ▪ Jai Medical Center ▪ Maryland General ▪ Mercy Hospital ▪ Johns Hopkins at Bayview ▪ Chase Brexton ▪ Bon Secours ▪ Baltimore City Health Department ▪ Health Care for the Homeless ▪ Men's Health Center ▪ Good Samaritan Hospital for wound care 	<ul style="list-style-type: none"> ▪ Evelyn Jordan ▪ Johns Hopkins Moore Clinic ▪ Jai Medical Center ▪ Maryland General ▪ Mercy Hospital ▪ Johns Hopkins at Bayview ▪ Chase Brexton ▪ Bon Secours ▪ Baltimore City Health Department ▪ Health Care for the Homeless ▪ Men's Health Center ▪ Good Samaritan Hospital for wound care ▪ Shepard's Clinic ▪ People's Clinic

Source: Concentric Systems 2002.

With regard to barriers that prevent those newly diagnosed with HIV from getting into care, both client groups expressed frustration with the waiting period for appointments and the length of time it took to schedule an appointment (Concentric Systems 2002). Additionally, some of the male participants in the non-HERO client group expressed concerns over the potential loss of sexual function as a side effect of the medications that they might be given once they began treatment for HIV. “Male participants were adamant about their desire to maintain sexual capacity and cited this side effect as the reason for staying out of care, or not being retained in HIV care” (Concentric Systems 2002). Sexual function side effects were not a concern of female participants. Interestingly, some non-HERO clients believed that “the toxicity of the HIV drugs was more likely to kill you than the infection,” and thus delayed accessing care (Concentric Systems 2002). Table 4 summarizes the barriers to care identified by the client groups.

Table 4 Barriers Preventing Newly Diagnosed Persons from Seeking HIV Medical Care	
<i>HERO Client Responses</i>	<i>Non-HERO Client Responses</i>
<ul style="list-style-type: none"> ▪ Denial ▪ Time to schedule appointments ▪ Wait time for appointments ▪ Anxiety ▪ Fear ▪ Mistrust 	<ul style="list-style-type: none"> ▪ Shame ▪ Substance abuse ▪ Physicians' attitudes ▪ Fear of HIV medication toxicity ▪ Fear of medication sexual side effects ▪ Prohibitively complex medical systems ▪ Anxiety ▪ Fear ▪ Mistrust

Source: Concentric Systems 2002.

Not easily quantifiable were the client groups' responses to the question about how to overcome barriers to care and help those newly diagnosed with HIV access medical services. Both the HERO and non-HERO clients indicated that the importance of seeking HIV medical care does not become salient for newly diagnosed individuals until they become sick. Non-HERO clients suggested a mentoring program among clients and newly diagnosed individuals to get people into care sooner.

Once clients have overcome barriers that may have delayed their access to care, they may encounter barriers that discourage their continued participation in care (see table 5). The cost of care was a barrier for both client groups, and both groups felt that they are discriminated against because of their inability or the perception of their inability to pay for services. In addition, the HERO client group expressed concern over the rising cost of medical care and indicated that that concern influenced their decisions about accessing medical services. As a whole, non-HERO clients did not mention federally supported services such as Ryan White CARE Act funds or the Maryland AIDS Drug Assistance Program (MADAP), nor did they seem aware of the relevance of these resources to them (Concentric Systems 2002). The non-HERO client group brought up the role of client/provider relationships in treatment and appointment adherence when they indicated that they faced systemic mistreatment — from the support staff to the physicians — that discouraged them from continuing care (Concentric Systems 2002). Some clients also indicated that they took specific steps to avoid physician disapproval, such as not informing their physicians when discontinuing their medication (Concentric Systems 2002).

Table 5 Barriers Preventing Continuation of Medical Services	
HERO Client Responses	Non-HERO Client Responses
<ul style="list-style-type: none"> ▪ Difficulty concealing rigid regimens (threat to confidentiality) ▪ Quantity of medication ▪ Size of medication 	<ul style="list-style-type: none"> ▪ Undesirable side effects of medication ▪ Substance abuse ▪ Mental health problems ▪ Incarceration ▪ Insensitivity of providers ▪ Improved health ▪ Quantity of medication ▪ Size of medication

Source: Concentric Systems 2002.

The two client groups were asked if any local programs could serve as models for accessing hard-to-reach HIV-positive clients (see table 6). The HERO clients listed several programs that they felt included essential components of early intervention programs. In contrast, rather than citing specific programs, the non-HERO client group identified components that would make such programs effective.

Table 6 Models For Accessing Hard-To-Reach HIV-Positive Clients	
HERO Client Responses	Non-HERO Client Responses
<ul style="list-style-type: none"> ▪ Johns Hopkins Moore Clinic ▪ Chase Brexton ▪ Evelyn Jordan ▪ Greater Baltimore Medical Center ▪ Maryland General ▪ Good Samaritan Wound Center 	<ul style="list-style-type: none"> ▪ Create a comfortable atmosphere at provider sites ▪ Encourage clients to be diligent about receiving medical services

Source: Concentric Systems 2002.

The client groups were asked about the advantages and disadvantages of having medical services available in HERO's drop-in center. Both client groups saw two advantages: (a) the convenient one-stop shopping for HIV related services and (b) a likely decrease in the number of clients lost to referrals. However, non-HERO clients expressed concern about the capacity of HERO to support early intervention medical services in its current facilities. Overall, the interest in having collocated medical services was split among HERO clients. While they were concerned for those who frequented the drop-in center but lacked access to medical services there, they were also concerned about confidentiality. Some clients indicated that they "purposely sought social and medical services in separate locations" (Concentric Systems 2002).

Table 7 shows the suggestions that each group made for improving HIV-related medical services in Baltimore City. Common among the groups' suggestions is changing the provider/client relationship to improve communication and eliminate mistreatment and discrimination.

Table 7 Improving HIV-Related Medical Services In Baltimore City	
<i>HERO Client Responses</i>	<i>Non-HERO Client Responses</i>
<ul style="list-style-type: none"> ▪ Increased confidentiality ▪ Improved doctor/client communication 	<ul style="list-style-type: none"> ▪ Elimination of mistreatment and discrimination by health-care providers towards clients ▪ Increased compassion from the general community ▪ Greater family support

Source: Concentric Systems 2002.

3.3.1.2 Staff and Provider Groups' Responses

HERO's focus group report also included the results of focus groups and interviews with HERO staff, external support staff and medical providers.

Table 8 shows the responses of external support staff and medical providers to the question about barriers preventing people with HIV from receiving medical care. Introducing a concept that would be echoed throughout the focus-group session, external support staff stated that substance abuse impedes client access to HIV services, and suggested that providers' insufficient attention to clients' substance-abuse treatment needs is a significant barrier to care. HERO staff asserted that a reduction in the time a newly diagnosed person had to wait to be seen by a medical provider would go a long way toward getting clients into care, and suggested employing multidisciplinary outreach teams to engage newly diagnosed persons.

Table 8 Barriers Preventing the Delivery of HIV Medical Services		
<i>HERO Staff</i>	<i>External Support Staff</i>	<i>Medical Providers</i>
<ul style="list-style-type: none"> ▪ Wait time for appointments 	<ul style="list-style-type: none"> ▪ Managed care ▪ Substance abuse 	<ul style="list-style-type: none"> ▪ Clinic hours of operation ▪ Transportation ▪ Location of facilities ▪ Limited substance-abuse treatment slots ▪ Client perception of care

Source: Concentric Systems 2002.

HERO staff and external support staff listed a number of explanations as to why client retention is such a challenge (see table 9). Medical providers did not offer much explanation for why retention rates of HIV-positive consumers in primary medical care were so low, but suggested that working to develop trust between the provider and client as well as enabling clients to see the same doctor throughout their treatment would improve retention. Like the client groups, all three provider groups alluded to tension in the physician/client relationship; however, the provider groups disagreed about the cause of the tension. External support staff indicated that client wariness of HIV health-care systems is simply a component of the general mistrust of medical institutions by society at large, while HERO staff believed that insensitivity on the part of the providers toward clients was a contributing factor to the problem of retention (Concentric Systems 2002).

Table 9 Barriers Preventing Continuation of Medical Services		
<i>HERO Staff</i>	<i>External Support Staff</i>	<i>Medical Providers</i>
<ul style="list-style-type: none"> ▪ Physician/client relationship ▪ Lack of child care ▪ Location of services ▪ Substance abuse ▪ Incarceration ▪ Wait time to schedule appointment ▪ Wait time to receive appointments ▪ Prohibitively complex medical system 	<ul style="list-style-type: none"> ▪ Physician/client relationship ▪ Stigma ▪ Denial ▪ Distrust ▪ Unstable home environment ▪ Substance abuse ▪ Incarceration ▪ Wait time to schedule appointment ▪ Wait time to receive appointments ▪ Prohibitively complex medical system 	<ul style="list-style-type: none"> ▪ Physician/client relationship ▪ Clients' overwhelming personal responsibilities ▪ Client fatigue

Source: Concentric Systems 2002.

Medical providers also pointed out that treatment adherence was difficult for clients experiencing personal crises and fatigue in taking the medication. They noted that treatment adherence may be even more difficult for women who are the primary caregivers in families, as they tend to sacrifice their own medical needs for the sake of taking care of familial responsibilities. Stigma, denial, distrust, substance abuse, and fractured homes and communities were also indicated as additional barriers to treatment adherence.

The three provider groups were asked to describe the perception of clients who “shop around,” or seek similar services from multiple providers. All three groups stated that the act of shopping around for services was indicative of a fracture in the provider/client relationship. Medical providers did not seem to have a problem with clients’ shopping behaviors, although one provider noted that primary care from numerous sites might not be the best decision for clients. HERO staff felt that the shopping behavior of their clients was no different from the behaviors of clients of any service provider, but asserted that health-care service professionals viewed this behavior as an attempt to manipulate the system by getting from one provider what another provider refused to give — an assertion that was echoed by external support staff.

The provider groups were also asked about the advantages and disadvantages of having medical services available in HERO’s drop-in center. Medical providers felt that HERO’s reputation in the community, solid foundation of financial supporters and its tradition for providing wraparound services were advantages to the provision of medical services at HERO. HERO staff and external support staff both believed that providing medical services on site at HERO would enhance the one-stop shopping experience for its clients. Despite these advantages, all three groups expressed concern about HERO’s capacity to provide on-site medical services. Medical providers identified some administrative challenges that could impact the provision of medical services at HERO, such as liability, insurance billing and meeting the informational needs of the Title III program.

All three groups stated that increased attention to substance-abuse and mental-health treatment were critical changes that need to be made to HIV-related medical care in Baltimore. HERO staff indicated that “HIV care required simplification and that greater access to care must be made available to clients regardless of their point of entry” (Concentric Systems 2002), while external

support staff emphasized the role of managed care, universal health care and drug-trade reduction on HIV-related care in Baltimore.

3.3.2 HERO Survey

This survey was developed by HERO and distributed by HERO and the Housing Opportunities for People with AIDS program (HOPWA) to a convenience sample of HIV-positive individuals. HOPWA is a program administered by the U.S. Department of Housing and Urban Development (HUD) that provides funding to support housing for PLWH/As and their families. The survey contained 52 questions divided into five major sections: demographics, knowledge, service-access experience, current service utilization, and perception of HERO services. Prior to being distributed, the survey was piloted with randomly selected clients at HERO. Results from the pilot test suggested that the instrument be shortened and some of the questions reworded for clarity.

Seventy-four clients responded to the survey; most of the respondents (93.2 percent) had used or were currently using services at HERO (HERO 2002). Approximately 84 percent (62) of the survey participants were living with HIV/AIDS. Of those, 17 percent (11) also had family members that were HIV positive. Sixty-four percent (47) were male, 35 percent (26) were female and 1 participant was transgendered. The vast majority of respondents (86.5 percent) were African-American. There were six Caucasian, one Asian/Pacific Islander, one American Indian/Alaskan and two biracial/multiracial participants. (The rest did not answer this question.) Most (45.9 percent) of the respondents were between the ages of 40 and 49. The second-largest group (37.8 percent) was between the ages of 30 and 39. Five of the respondents (6.7 percent) were between the ages of 20 and 29 and seven (9.4 percent) were between the ages of 50 and 64.

Table 10 shows the type of housing in which the respondents lived at the time of the survey. A significant number of the respondents — 39.4 percent — reported that they had unstable housing (i.e., did not own or rent their home or apartment). The most frequently reported ZIP codes of residents were: 21217 (11), 21218 (8), 21201 (7) and 21229 (7).

Table 10 Current Housing of Past and Present HERO Clients	
Housing Type	Respondents (n=74)
Own home	5.4%
Rent house or apartment	54.1%
Live with family members	13.5%
Live with friends	4.1%
Transitional housing	9.5%
Recovery house/drug treatment center	4.1%
Homeless shelter	4.1%
Abandoned building/street/homeless	4.1%
No response	1.1%

Source: HERO 2002.

A significant number of survey participants had not graduated from high school (36.5 percent). However, 25.7 percent (19) of the respondents had a high school diploma or a general equivalency diploma (GED), 21.6 percent (16) had some college and 8.1 percent (6) had received a college degree. Three participants were still in high school and two indicated that they had no education. One respondent did not answer this question.

As shown in table 11, public transportation was the most common mode of transportation that clients used to get to their clinic appointments. A solid majority (69 percent) of clients reported no difficulty in obtaining transportation to clinic appointments. However, 15 percent (11) of the respondents felt that it was somewhat difficult to obtain transportation and 14 percent (10) felt it was very difficult. The majority (61 percent) of clients were able to get to the clinic in fewer than 45 minutes. Twenty percent (15) stated that it took them 46 minutes to an hour to get to the clinic and 14 percent (10) stated that it took them more than an hour.

<i>Mode of transportation</i>	<i>Respondents (n=74)</i>
Public transportation	67.6%
Walk	11.0%
Driving	5.4%
Taxi	2.7%
Ride from friend or family member	2.7%
Paid clinic transportation	2.7%
Other	5.4%
No response	2.7%

Source: HERO 2002.

Fifty-one percent (38) of respondents thought that it was important for those with HIV/AIDS to have their T-cell/CD4 count and viral load checked regularly, while 47 percent (35) believed that it was not important.

The four highest response categories for the question, “where did you find out that you were HIV positive?” were: from a clinic or doctor’s office (42 percent), in the hospital (20 percent), at a testing and counseling site (13 percent) and in prison (10 percent). Smaller response frequencies were assigned to mobile vans, sexually-transmitted infection (STI) clinics, and obstetrics and gynecology (OB/GYN) clinics.

The participants were asked about the information and services that they received upon being notified of their HIV-positive status; table 12 shows their responses. Considering the concerns about stigma, the provider/client relationship, and the prohibitive complexity of the HIV-care system identified by the providers in this study, it is noteworthy that only slightly more than half of the respondents reported receiving emotional support or referrals to other services at the time of their diagnosis.

<i>Service provided</i>	<i>Respondents* (n=74)</i>
HIV/AIDS information	69%
Emotional support	53%
Referrals for other services	53%
Referrals for medical care	64%
Saw medical provider	72%

Source: HERO 2002.

*Sum does not equal 100% as categories are not mutually exclusive.

One theme common to most Baltimore EMA needs assessment research involves the amount of time consumers must wait to be seen by a medical provider (see table 13). In this survey, half of the respondents had to wait one to two weeks before seeing a medical provider; only 12 percent (9) had their first medical appointment on the same day that they sought medical care. Other needs assessment research in this EMA, including data presented earlier in this chapter, indicate that the wait time to see a doctor is not only frustrating for newly diagnosed clients, but may discourage them from seeking care at all. Many (50 percent) of the respondents indicated that

they would have preferred to get medical care on the day of diagnosis. Twenty-four percent would have liked to receive medical care within the first week after diagnosis; 14 percent would have liked to be in care in one to four weeks after diagnosis.

Seven percent (5) of the survey participants noted that they did not go to a medical provider at all. Most (4) of these participants stated that they did not go because they were afraid. Other reasons for not seeking care included: “I didn’t think it was important,” “I felt too sick,” “I didn’t want others to know” and “I was in denial.”

<i>Time After Diagnosis</i>	<i>Respondents (n=74)</i>
Same day care, no wait	12%
One to two weeks	50%
Three to six weeks	7%
Two months or longer	11%
No response	20%

Source: HERO 2002.

The majority of survey participants (61 percent) had visits with their medical provider once every one to three months. Twenty-five percent of the respondents had visits with their medical provider more than once a month. It seems that once consumers get into care, continuing that care can be easy — overall, 81.1 percent of respondents indicated that they see their medical providers as often as they want.

When asked to rate the quality of their medical care, 39.2 percent of the respondents stated that the medical care they receive is excellent. Twenty-nine percent of respondents rated their medical care as “good,” while 24 percent rated it as “okay.”

Eighty-eight percent said that they felt it important to have an HIV/AIDS specialist. The majority of the respondents (85.1 percent) had been given a prescription for HIV/AIDS medications, but only 76 percent of those respondents had the prescription filled.

Eighty-five percent (63) of the respondents were using services at HERO at the time of data collection. Eight percent stated that they were not currently using HERO services but had used them in the past. Seventy-two percent (53) of the survey participants stated that they would be interested in using medical care services at HERO should the organization start to provide it. Twelve percent (9) stated that would not be interested in medical care services at HERO and fifteen percent (11) said they did not know if they would be interested in such services.

3.3.3 Total Health Care, Inc. Survey

The 2000 needs assessment survey conducted by THC examined the population from which its clientele is drawn. The majority of THC clients resides in Baltimore itself and uses one of the four community-based primary care sites located in areas of the city with high incidence and prevalence rates of HIV and AIDS. These primary care sites are located in the following ZIP codes: 21215, 21218, 21223 and 21201. Combined, these sites serve approximately 18,000 consumers (Merrick 2003).

Additional study data show that 98 percent of THC clients are African-American, with the other 2 percent made of up whites or Hispanics. Females make up the largest portion of THC consumers, comprising 60 percent of the THC population.

In addition to identifying client characteristics and service needs, the THC study also looked at barriers to care. Both THC clients and staff were asked to identify barriers; table 14 shows their responses.

Table 14 Barriers Preventing Newly Diagnosed Persons from Seeking HIV Medical Care	
<i>THC Client Responses</i>	<i>THC Clinical and Support Staff Responses</i>
<ul style="list-style-type: none"> ▪ Fragmentation of services ▪ Lack of knowledge about HIV ▪ Poor quality of services ▪ Lack of funding ▪ Lack of HIV/AIDS providers 	<ul style="list-style-type: none"> ▪ Lack of medical appointment adherence ▪ Non-compliance with treatment ▪ Alcohol and substance abuse ▪ Lack of transportation ▪ Communication problems

Source: THC 2000.

3.3.4 Baltimore City Health Department QIP Report: Case Management

The needs assessment results from the BCHD case management QIP report were based on client chart abstractions from the 17 vendors providing case-management services under Ryan White CARE Act Title I funding. Case managers are responsible for identifying the unmet needs of their clients and developing their case plans, which document an agreed-upon course of action for meeting the clients' HIV care needs. The QIP report chart analysis was restricted to only those charts that contained a case plan. The inclusion criterion was met by 288 client charts, which represented 62 percent of the total number of client charts available from Title I vendors (BCHD 2002).

Demographic characteristics for each of the qualifying client charts were recorded. The sample included charts for 86 females, 196 males and 1 transgendered person; 5 charts did not have the gender of the client documented. African-Americans were the largest racial group represented, with 215 of the 288 charts. Forty-one whites, five Hispanics, three Asian/Pacific Islanders, two Native Americans and eight "other" identified client charts were considered in this analysis. Fourteen of the charts had missing or undocumented race information.

The needs assessment results presented in the QIP case management report were separated into six categories: income assistance, health insurance, housing, primary health care provider, substance-abuse treatment services and emotional counseling.

3.3.4.1 Income Assistance

The most commonly identified unmet need among all clients was income assistance; for 48 percent (108) of clients whose charts were analyzed, income assistance was a factor. Of those 108 charts, 92 documented activities with the goal of meeting that need. Documented activities to meet this need occurred more frequently for women. African-Americans identified a need for income assistance more than any other racial group (52 percent). Seventy-six percent of African-Americans who identified a need for income assistance had an established care plan for meeting that need; however, only 37 percent of them had had their need fulfilled. A large portion of whites (93 percent) had established care plan goals to obtain income assistance, but only 29 percent of whites had this need met. Overall, only 35 percent of clients with this need reported in their charts had their income assistance needs met during the review period.

3.3.4.2 Health Insurance

One hundred twenty-three clients (46 percent of all men and 36 percent of all women) reported not having adequate health care coverage. Of those, 109 charts had health insurance needs identified in the care plan. African-Americans were less likely to report health insurance as an unmet need compared to other racial groups.

One hundred four of the charts had documented case-management activities designed to meet the need for health insurance, and 61 percent (75) of those charts had that need met. One hundred percent of Hispanics, Asian/Pacific Islanders and Native Americans had this need fulfilled.

3.3.4.3 Housing

Forty-four percent (127) of clients indicated housing as an unmet need. One hundred six charts had care plans to address the need, and 98 of those documented activities designed to meet the need. Case-management activities were able to meet only 39 percent (49) of the clients' housing needs.

Men and women identified housing as an unmet need at approximately the same rate (45 percent and 42 percent respectively). The goals were more explicitly identified for women, but housing was more successfully secured for men.

Case-management activities attempting to meet the need for housing were equally documented across racial groups, although most (51 percent) of the requests for housing services came African-Americans. Thirty-eight percent of African-Americans requesting housing assistance had their housing needs met compared to 44 percent of whites.

3.3.4.4 Primary Health Care Provider

The provision of a primary health provider was both the most infrequent unmet need overall (29 percent) and the highest met need (90 percent) among charts with need that had been met during the review period. Men and women equally identified the need for primary health care. There was a high success rate for meeting this need across all racial/ethnic and gender groups.

3.3.4.5 Substance-abuse Treatment Services

Seventy-four charts identified substance-abuse treatment as an unmet need; of those, 69 documented case-management activities designed to meet the need. Sixty-three percent (55) of the clients who had identified a need for substance-abuse treatment had their needs met.

Slightly more women (62 percent) than men (59 percent) had their need for substance-abuse treatment met. Approximately one third (73) of African-Americans identified this as a need with 63 percent (46) of the one third having the need met. Fifteen percent of whites (6) identified substance-abuse treatment as a need with 83 percent (5) of these having achieved their care plan goals.

3.3.4.6 Emotional Counseling

Emotional counseling was the only service category in which self-reporting was the only criterion for defining unmet need. Forty-three percent of women (37) and 30 percent of men (59) identified emotional counseling as an unmet need — 96 clients in all. Seventy-eight (81 percent) of these clients' charts had documented a course of action, and the need for emotional counseling was met for 53 percent of all clients who identified the need.

3.4 Conclusion

Two major client needs emerged from this meta-analysis: substance-abuse treatment and timely access to medical services. Additional client needs revealed by this analysis were improvements in the provider/client relationship and patient education about HIV treatment.

3.4.1 Substance-abuse Treatment

Each of the needs assessment documents included in this analysis referenced the impact of substance abuse on consumer adherence to medical care and treatment. All five of the groups

participating in the HERO focus group research stated that substance abuse is a barrier to getting newly diagnosed clients into care and to keeping other clients in primary medical care. The environments from which THC draws its clients are heavily burdened with intravenous drug use (Merrick 2003). Substance-abuse treatment therefore is an essential component of effective comprehensive HIV care.

The QIP case management report states that 63 percent of the clients requesting substance-abuse treatment had that need fulfilled. Such results are promising for increasing the rate of adherence to medical treatment and care, but still more needs to be done with respect to the remaining 37 percent and other consumers like them who are not served (BCHD 2002).

3.4.2 Timely Access to Medical Services

Access to primary medical care is extremely important to the well-being of people who are infected with HIV. Adherence to medical treatment and care is of even greater import. As stated above, substance abuse is a barrier to successful primary medical treatment, but it is only one of the many barriers listed in the needs assessment documents. The length of time required to get an appointment and the length of time that consumers had to wait to be seen by a physician were heavily and repeatedly stressed as barriers to care in the results from the HERO needs assessments. Additionally, while many reported having their primary care needs met in the QIP case management report, the focus group report from HERO indicated that service professionals cited retention in primary medical care as a challenge. Problems with client retention may be due to the length in time that clients have to wait for medical appointments.

3.4.3 Additional Client Needs

Client/provider relationship tension was reported as another barrier to medical access and adherence. HERO and non-HERO clients alike noted that they were not content with their relationships with their primary medical care providers and/or other service professionals. In particular, clients reported being discriminated against or mistreated by providers with respect to the clients' ability to pay. Some clients engaged in shopping behaviors to seek providers that were more sensitive to their needs. Conversely, external support staff found this kind of behavior manipulative and suggested that shopping behaviors compromise the quality of care received by consumers.

The HERO client focus groups revealed that a significant barrier to care is a lack of understanding, or a misunderstanding, of HIV treatment. Beliefs about the lifestyle-altering or life-threatening side effects of medication are preventing those newly diagnosed with HIV from seeing care. Such misconceptions could be remediated through patient education at the time of testing.

4. COMMUNITY FORUM: COUNTIES

This chapter describes the background, methodology, and results of the planning council's counties community forum of May 30, 2003. The overarching goal of the community forum was to elicit information from county consumers concerning HIV service needs in the Baltimore EMA. The EMA county residents were selected as a special population because of certain social, economic and demographic differences between the counties in the EMA and Baltimore City.

4.1 County Profiles

Following are brief descriptions of each county in the EMA served by the planning council.

4.1.1 *Anne Arundel County*

Anne Arundel County is home to the state's capital, Annapolis, and the United States Naval Academy. Anne Arundel County is predominately a rural waterfront county extending south from Baltimore County. Whites make up the majority of the population (81.2 percent) and African-Americans are the largest minority (13.6 percent). Other minority groups residing in Anne Arundel County are Hispanics (2.6 percent), Asian/Pacific Islanders (2.4 percent), American Indians (0.3 percent) and others (0.9 percent). The median household income is \$61,768 with a poverty rate of 5.1 percent (Census 2000) and an unemployment rate of 3.2 percent (AACDH 2003).

Heart disease and cancer are the leading causes of death in Anne Arundel County. These causes are followed by stroke, chronic lower respiratory diseases, unintentional injuries, diabetes, septicemia, influenza and pneumonia, Alzheimer's disease and pnemonitis (AACDH 2003).

The rate of HIV infection in Anne Arundel County (1.1 percent) is less than one third of the state-wide infection rate in Maryland (3.4 percent) and represents five percent of the all living cases in the Baltimore EMA — though this still constitutes, within the EMA, the third-largest number of living HIV/AIDS cases, preceded by Baltimore City and Baltimore County, respectively (Flynn 2003).

4.1.2 *Baltimore County*

Baltimore County is the largest county in the Baltimore EMA. It is predominantly urban and suburban, though with substantial rural areas to the north and, to a lesser extent, east and west. It boasted a 2000 population of 754,292 residents, representing 14 percent of the total state population. The median household income in Baltimore County is \$50,667 with a 6.5 percent poverty rate (Census 2000) and an unemployment rate for 2001 of 4.4 percent. Demographically, Baltimore County is quite similar to other counties in the EMA in its racial composition — whites make up 74.4 percent of the population and African-Americans make-up 20.1 percent. The remaining population is made up of Asian-Americans (3.2 percent), those of multiple races (1.4 percent), and Hispanics of any racial origin (1.8 percent) (BCDH 2001).

The leading causes of death in Baltimore County are heart disease, cancer, stroke, chronic obstructive pulmonary disease (COPD), pneumonia, influenza, and unintentional injuries. There are higher incidences of death in Baltimore County compared to the entire state for COPD, suicide and liver disease. Baltimore County has lower rates than both the nation and the state for heart disease, breast cancer, prostate cancer, stroke, AIDS and homicide. Compared to the entire

United States, Baltimore County has higher rates of cancer (specifically lung and colorectal), pneumonia/influenza, diabetes and liver disease (BCDH 2001).

In 1999, 5.3 percent of the deaths in Baltimore County were attributed to AIDS (BCDH 2001). According to the most recent surveillance data, Baltimore County residents make up 11 percent of the HIV/AIDS cases in the Baltimore EMA (Flynn 2003).

4.1.3 Carroll County

West of Baltimore County, Carroll County is one of the two most rural counties in the Baltimore EMA. It extends from the western “bulge” of Baltimore County and neighbors the latter all the way to the Pennsylvania state line. Carroll County is home to Hampstead, Manchester, Mount Airy, New Windsor, Sykesville Taneytown, Union Bridge and Westminster.

The median household income is \$60,021 with 3.8 percent of the residents in Carroll County living in poverty. The unemployment rate for the county in 2002 was 3.8 percent. The gender ratio in Carroll County is nearly 1:1 with a 2000 population count of 74,470 males to 76,427 females. The county is predominately white (95.8 percent), with African-Americans (2.3 percent) making up the largest minority population (Census 2000). According to Maryland Department of Human Resources statistics, Carroll County is home to burgeoning Asian, Native American and Hispanic populations with a percentage increase in population between 1990 and 2000 of 54.3, 71.0 and 64.9 respectively (DHR 2002), albeit from very low starting points.

Only one percent of living HIV/AIDS cases resides in Carroll County.

4.1.4 Harford County

Harford County is the most northeastern county in the EMA. Like Carroll County, Harford County is predominately a rural county with suburban spillover communities for Baltimore County and Baltimore City commuters. Harford County has a poverty rate of 4.9 percent and 5.5 percent of the county’s population is unemployed. Whites (86.8 percent) make up the majority of the population, followed by African-Americans (9.3 percent). Hispanics (1.9 percent) and Asians (1.5 percent) make up the third- and fourth-largest racial groups in the county (Census 2000b). The median income in the county is \$57,234.

Two percent of the living HIV/AIDS cases in the EMA reside in Harford County.

4.1.5 Howard County

Howard County is located south and west of Baltimore County. It is the home of historic Ellicott City and the planned community of Columbia. The median income in Howard County is \$74,167 and the poverty rate is 3.9 percent. Howard County has the second-highest per capita income in the state (MCDPP 2000). The county is predominately white (74.3 percent) with African-Americans (14.4 percent) making up the largest minority (Census 2000b). Howard County has had significant increases in its Asian-American and Hispanic populations from 1990 to 2000 (135 percent and 102 percent, respectively).

Howard County also houses one of the largest correctional complexes in Maryland, the Maryland Correctional Institution at Jessup. In 1999, 3.6 percent of Maryland’s state and federal prison population was infected with HIV (Maguire 2000). Furthermore, in 2001, 9.3 percent of the HIV cases and 6.7 percent of the AIDS cases statewide were found among inmates in the Maryland Department of Corrections’ facilities. The population in the correctional facilities represents less than one percent of the total state population (DHMH 2002). Such high figures may in part be attributed to the fact that nearly half of all new inmates agree to be tested, but some of the

infection rate in this population may also be attributed to participation in the sort of high-risk behaviors that resulted in incarceration to start with, such a drug use (DHMH 2002).

Apart from the rates within Department of Corrections prisons, two percent of all living HIV/AIDS cases in the Baltimore EMA resides in Howard County.

4.1.6 Queen Anne's County

The EMA's other very rural county, located on the Chesapeake on the Eastern Shore, Queen Anne's County has a waterfront culture. The famous Chesapeake Bay Bridge connects it to the other counties in the EMA.

Queen Anne's County has a 6.3 percent poverty rate and a 3.8 percent unemployment rate. The median income in the county is \$57,037. Queen Anne's County has the second-highest poverty rate among the EMA counties, second only to Baltimore County (this is excluding Baltimore City). Like the other counties, Queen Anne's County is predominately white (89.0 percent), with African-Americans (8.8 percent) making up the largest minority group (Census 2000b).

Queen Anne's County contributes less than one percent of the living HIV/AIDS cases in the EMA.

4.2 Methodology

The planning council's Needs Assessment Committee developed the survey tool and the focus group guide.

To enable cross-population analysis, the planning council chose to employ the same focus group instruments used in its 2003 youth forum (see chapter 5) and its 2003 ex-offenders forum (see chapter 6). Each focus group participant was given an 11-item survey to complete, from which demographic data were compiled (see section 4.3). In addition to the quantitative data gathered on the survey, qualitative data were gathered during discussion groups. Three of the groups were made up of consumers; the fourth group consisted of providers.

Trained facilitators conducting the discussion sessions followed a focus group guide containing questions designed to elicit answers to the central question of the planning council's 2003 needs assessment activities: what are your barriers to care? The guide contained four questions, one of which overlapped with a survey question so that the data could be triangulated.

4.3 Results and Analysis

The data analyzed in this report will be presented in two sections: first, quantitative and qualitative results for the consumers will be presented and summarized. Following that, quantitative and qualitative results for the providers will be presented and summarized.

4.3.1 Consumer Quantitative Results: Survey

Thirty-four people living with HIV/AIDS (PLWH/A) attended the forum. Participants hailed from Anne Arundel County (6), Baltimore County (23), Harford County (2) and Howard County (3). There were no consumer representatives from Carroll County or Queen Anne's County.

Twenty-five of the participants were African-American, one participant was Asian, seven were Caucasian and one participant was of Hispanic origin. The majority of participants were male (22); 11 were female. None of the participants reported being transgendered, and one participant did not answer the question about sex.

Eleven questions were administered in the participant information survey. Participants were asked to identify the EMA jurisdiction in which they received their HIV services; their responses are shown in table 15. While no Baltimore City residents were present at the forum, just under 24 percent (8) of the participants receive their HIV services in Baltimore City. While 23 Baltimore County residents were present, only 11 respondents indicated that they receive their HIV services in that county — a little under half — though this did represent a plurality.

Table 16 shows how the participants learned of their HIV status. Most of the participants indicated that they learned after seeking medical treatment. Five participants marked “other” in responding to the question; the circumstances they specified in the “other” field included requesting a test, in trade school, in jail and from an outreach worker. One of the respondents who marked “other” did not specify how he or she learned of his or her status.

The participants were asked if anyone told them of the next steps they should take after learning of their diagnosis. A significant majority of the respondents, 71 percent (24), indicated that they were informed of the next steps. Twenty-six percent (9) stated that they were *not* told of future steps. One participant did not answer the question.

The majority of participants, nearly two thirds, indicated that they sought medical treatment immediately after being diagnosed as being HIV positive (see table 17). However, nearly a quarter of respondents delayed care by six months or more.

Thirty-two of the thirty-four respondents said that they “see a doctor for blood tests related to HIV disease” at least twice a year. One respondent was not seeing a doctor or nurse, and one chose not to answer the question.

Table 15
EMA Jurisdiction Where HIV Services are Received

Jurisdiction	Respondents (n=34)
Baltimore City	23.5%
Baltimore County	32.4%
Harford County	5.9%
Howard County	8.9%
City plus one or more counties	14.7%
None of the EMA jurisdictions	2.9%
No response	11.8%

Source: IGS client survey.

Table 16
Circumstances of HIV Diagnosis

Jurisdiction	Respondents (n=34)
Sought medical treatment	58.8%
Testing site or van	20.5%
Gave blood	2.9%
Insurance screening	2.9%
Other	14.7%

Source: IGS client survey.

Table 17
Time Between Receiving HIV Diagnosis and Seeking Medical Care

Time after diagnosis	Respondents (n=34)
None (same-day care, no wait)	64.7%
Less than 6 months	11.8%
6 months to 1 year	8.8%
1 to 2 years	5.9%
2 to 5 years	5.9%
No response	2.9%

Source: IGS client survey.

4.3.2 Consumer Qualitative Results: Focus Group

After filling out the participant information survey, the participants were asked to participate in a guided dialogue in which three main topics were discussed: health information sources, time from diagnosis to care, and staying in care.

The first question asked in the small group discussions was related to trusted sources of HIV information. Table 18 shows the consumers' responses. The responses have been grouped into four categories: institutional sources, programmatic sources, health education sources and people.

Category	Source	Response Frequency
Institutions	• Moore Clinic	8
	• Baltimore County Health Department	7
	• Randallstown Resources Center	3
	• Johns Hopkins Hospital	2
	• Other	8
Programs	• HIV Support groups	3
	• Health seminars	3
	• Narcotics Anonymous and Alcoholics Anonymous meetings	2
	• Baltimore Substance Abuse Systems	1
	• Project LINK	1
	• HIV retreats	1
	• Community education programs	1
	• Advisory boards	1
Health Education Resources	• Internet	4
	• Library	3
	• Magazines	3
	• Television	3
	• Brochures	1
	• Committee meetings	1
	• Professional associations	1
People	• Case managers	5
	• Doctors	5
	• Other PLWH/As	4
	• Family	1
	• Peers	1

Source: IGS client survey.

A comparison of the survey and discussion responses yields an interesting discrepancy in the data. Most of the institutions identified as trusted sources of HIV health information by consumers during the discussion group were in Baltimore City, while a plurality (11) of the consumers indicated on the survey that they received most of their HIV care services in Baltimore County (see table 15).

The next question asked the participants to tell how long it took them to get into primary medical care for HIV after they were diagnosed (see table 19). The answers ranged from immediately to 13 years after diagnosis. Eight respondents indicated that they sought care immediately after diagnosis. Three stated that they had gotten into care within a week of their diagnosis, and seven participants sought care within 2 to 24 weeks. Nearly one third of participants waited more than 1 year before seeking care, with three of those waiting more than 6 years.

<i>Time between diagnosis and care</i>	<i>Respondents (n=34)</i>
None (same-day care, no wait)	23.5%
Less than 6 months	29.4%
6 months to 1 year	2.9%
1 to 2 years	5.9%
2 to 5 years	17.6%
More than 5 years	8.8%
No response	11.8%

Source: IGS client survey.

When these data are compared to the data in table 17 above, which shows the same participants' answers to the same question as it appeared on the self-administered survey, an interesting discrepancy appears (see table 20). On the survey, 64.7 percent of respondents said they received medical care on the same day as their diagnosis; however, in the discussion group, only 23.5 percent indicated that they received immediate care. On the survey, 11.8 percent of respondents said they received medical care within 6 months of diagnosis; in the discussion group, 29.4 percent indicated that they received care within 6 months. On the survey, 11.8 percent said they waited between one and five years to receive care; in the discussion group, the percentage saying that they waited that long was 23.5 percent.

These differences suggest that consumers may have a different perception of time after diagnosis than researchers do. For example, one respondent, a former substance abuser, noted that she had to hit rock bottom and accept the fact that she was HIV positive before she was able to get into care. On the survey, she indicated that she got into care immediately after being diagnosed; only probing

<i>Time between diagnosis and care</i>	<i>Survey Responses (n=34)</i>	<i>Focus Group Responses (n=34)</i>
None (same-day care, no wait)	64.7%	23.5%
Less than 6 months	11.8%	29.4%
6 months to 1 year	8.8%	2.9%
1 to 2 years	5.9%	5.9%
2 to 5 years	5.9%	17.6%
More than 5 years	0%	8.8%
No response	2.9%	11.8%

Source: IGS client survey.

during the discussion group revealed the intermediate steps she took before getting into care. This example not only illustrates some discrepancies that are to be expected when using a self-reporting tool to gather data, but it also suggests that in future studies we must not only look at time of diagnosis but also time of diagnosis acceptance. This period of time between diagnosis and acceptance may prove to be a crucial point of intervention.

Next, the participants were asked to list the things that help them keep their regularly scheduled appointments. Their responses have been divided into four categories: personal, interpersonal, external prompts, and services (see table 21). Personal refers to internal motivating factors; these factors are intimately tied to an individual’s state of readiness for behavioral change, thus it tends to be difficult to develop interventions around these factors. Interactions with persons or groups fall under the realm of the interpersonal. Thirty-five percent (12) of the participants cited their interaction with their case managers as having a significant effect on keeping appointments. The most common external prompts participants said they use to keep appointments are calendars or appointment books (10) and phone calls (8).

Table 21	
Factors That Facilitate Appointment Adherence	
Category	Responses
Personal	<ul style="list-style-type: none"> ▪ Being alive ▪ Wanting to follow the directions of my physician ▪ God ▪ Being clean and sober ▪ Desire to find out the results ▪ Too sick to make any other choice ▪ Motivation to get better ▪ Gratitude ▪ Personal responsibility ▪ Positive outlook on life ▪ Will to live
Interpersonal	<ul style="list-style-type: none"> ▪ Case managers ▪ Alcoholics Anonymous meetings ▪ Drug counselors ▪ Doctors ▪ Support of companion/significant other
External Prompts	<ul style="list-style-type: none"> ▪ Calendar/appointment book ▪ Phone calls ▪ Reminder notices ▪ Alarm clocks ▪ Bright colored appointment cards ▪ Automated notification
Services	<ul style="list-style-type: none"> ▪ Having appointments on the same day of the week ▪ Cab service or cab vouchers ▪ E-mail access to providers ▪ Flexible appointment scheduling ▪ Transportation

Source: IGS client survey.

The last question asked participants to state those things that help them to stay in care. Again, the answers were divided into categories (see table 22). The most common personal factors keeping participants in care were feeling sick and having a will to live. The most common interpersonal factors were interaction with and support from family members. The most common services were those that compensated for the participants’ lack of health insurance.

Table 22	
Factors That Facilitate Continuation of Medical Care	
Category	Responses
Personal	<ul style="list-style-type: none"> ▪ Sickness ▪ Staying off drugs or alcohol ▪ Having a will to live ▪ Sense of personal responsibility ▪ Relationship with God ▪ Gratitude ▪ Positive outlook on life ▪ Ability to maintain employment ▪ Wanting good health
Interpersonal	<ul style="list-style-type: none"> ▪ Family support, including children and partner/companion ▪ Access to current health information ▪ Social interaction with providers ▪ Wanting to be an example for others in care ▪ A sober support network ▪ Friends
Services	<ul style="list-style-type: none"> ▪ Subsidized health-care costs ▪ Transportation ▪ Improved appointment scheduling

Source: IGS client survey.

4.3.3 Provider Quantitative Results: Survey

The same survey distributed to consumers was also given to the providers. However, because some of the questions — those related to seeking and adhering to care — were not relevant to the providers, they were asked to respond to the demographic questions only.

Eighteen providers attended the forum. The providers represented agencies that provide services for all six counties in the Baltimore EMA. A significant number of providers resided in Baltimore County (5). Three lived in Anne Arundel County, two in the city of Baltimore, three in Harford County, three in Howard County, and one in Queen Anne’s County; one provider did not indicate his or her county of residence. Seventeen of the providers were female. There was a larger variation in age among providers compared to consumers; seven providers were 30 to 39, five were 50 to 59, one 20 to 24, one 25 to 29, one 60 to 64 and one was 65 or older.

Most of the providers were Caucasian and female (16 and 17, respectively). There were two African-American providers and one male provider. None of the providers was Hispanic. All of the providers indicated that they were not transgendered.

4.3.4 Provider Qualitative Results: Focus Group

After filling out the participant information survey, the participants were asked to participate in a guided dialogue in which three main topics were discussed: health information sources, time from diagnosis to care and staying in care.

Providers were asked to identify some of the resources that consumers have access to that provided health information about HIV; table 23 shows their responses.

Table 23	
Sources of HIV Information Available to Consumers	
Category	Source
Institutions	<ul style="list-style-type: none"> ▪ Hospitals ▪ Department of Social Services ▪ Referrals from rehab ▪ Detention services ▪ Legal system
Programs	<ul style="list-style-type: none"> ▪ Women, Infants and Children (WIC) program ▪ Home-delivered meal services ▪ “1-800” hotlines ▪ Church groups ▪ Shelters ▪ Family planning centers ▪ Testing sites
Health Education Resources	<ul style="list-style-type: none"> ▪ Newspaper ▪ Health fairs ▪ Internet
People	<ul style="list-style-type: none"> ▪ Co-workers ▪ Dentists ▪ Pharmacists

Source: IGS client survey.

The providers addressed the question of the time differential between diagnosis and care by mentioning the issues that prolong the time it takes an HIV-positive individual to seek primary medical care. Stigma is still an issue for many consumers, and some may get into care sooner as stigma decreases. The providers also noted that clients were going to different county and city locations for care to maintain confidentiality. According to providers, some consumers delay entering care until they have reached a point where they are able to confront their substance abuse.

Like the consumer discussion groups, the provider group was asked about factors that could help consumers keep their scheduled appointments; those factors are listed in table 24. These responses are grouped into categories similar to those used for the consumers’ responses; however, here an “outcomes” category replaces the “personal” category. Another difference between the two groups’ responses is that within the services category, the providers have suggested not only the provision of transportation as a factor, but its punitive corollary — the loss of transportation subsidies — as well.

Table 24	
Factors That Facilitate Appointment Adherence	
Category	Responses
Interpersonal	<ul style="list-style-type: none"> ▪ Case managers ▪ Nagging ▪ Explaining benefits of keeping appointments/persuasive education ▪ Support groups offer peer pressure to keep appointments ▪ Listening to client and showing respect ▪ Opportunity to connect with community ▪ Negotiation ▪ Increased bonding ▪ Importance of clinic setup and express confidence of services provided
External Prompts	<ul style="list-style-type: none"> ▪ Phone calls
Services	<ul style="list-style-type: none"> ▪ “One-stop shopping” care ▪ Condoms ▪ Food ▪ Transportation ▪ More pleasant environment ▪ Primary care incentives ▪ Having variable sites and including home visits ▪ Loss of bus passes if you miss too many appointments
Outcomes	<ul style="list-style-type: none"> ▪ Meeting their needs ▪ Successful treatments and undetectable viral loads ▪ Positive relationships of trust lead to return appointments

Source: IGS client survey.

Finally, the providers were asked to identify strategies that would help consumers stay in care. The providers reinforced the need to address substance abuse with clients. They also suggested coordination among providers to make medical appointments easier to keep, including providing child-care services during medical appointments and offering appointments during evening hours. Lastly, the providers stated that it is imperative that more provisions be made to allow clients to receive mental-health services.

4.4 Conclusion

In general, according to the data responses from consumers, most of the PLWH/As in attendance were in some form of primary medical care and could speak to the barriers that they faced in trying to access care. There seemed to be little discrepancy between consumer and provider responses on tools and strategies to keep scheduled appointments and to stay in care. Both acknowledged some logistical barriers in care adherence, such as child care, transportation and inconvenient scheduling of appointments.

The counties community forum was a useful endeavor for two reasons. First, it encouraged both providers and consumers to perform a thorough examination of the current barriers to care. This examination prompted the introspection needed to inspire comprehensive methods for removing those barriers. What may prove helpful in the future is to have a dialogue on what kind of

interventions would actually help consumers to overcome stigma barriers. Providers still view stigma as a significant major hurdle that consumers must overcome.

Additionally, the data gathered in the forum can be compared to data gathered in previous years' forums, allowing the planning council to identify trends in the needs of the EMA. For example, the issue of substance-abuse treatment services also appeared in the 2002 counties community forum report (Coleman 2002). The frequency with which substance-abuse treatment was mentioned in this year's forum suggests that substance abuse continues to be a much needed area of support in the counties.

5. COMMUNITY FORUM: YOUTH

The vast challenges facing Baltimore area youth warrant special attention to their needs and development. Particularly compelling are how these challenges affect the ability of HIV-positive youth between the ages of 18 and 24 to seek primary medical care. Such care is crucial for insuring a positive trajectory on which bright futures for this population can be plotted. To better understand the challenges faced by HIV-positive youth in the Baltimore area and the impact of those challenges on their access to care, the planning council conducted a series of interviews and focus groups with members of this population. This chapter describes the background, methodology and results of that research.

5.1 Background

Globally, it is estimated that half of all new HIV infections occur among people under the age of 25, with approximately 7,000 of them becoming infected every day. Alarming, 30 percent of the 40 million people worldwide living with HIV/AIDS are young people between the ages of 15 and 24. In 2000, the White House announced that half of all new HIV infections are thought to occur in young people under 25. Even greater are the estimates that youth between the ages of 13 and 24 are contracting HIV at the rate of 2 per hour (The Body 2000). A large percentage of these young persons are not aware of their HIV-positive status and, for those engaging in sexual activity, do not know the status of their partners (WHO 2002a).

Young people are particularly vulnerable to HIV infections because they do not perceive the severity of HIV/AIDS, its modes of transmission or how to protect themselves. Additionally, adolescence is the period in which the influence of peers becomes paramount. This influence is compounded by the trailing knowledge and attitudes of significant adults in their lives about HIV/AIDS (WHO 2002b).

The youth subpopulations in the greatest jeopardy of being exposed to HIV are women, men who have sex with men, minorities, and youth who have dropped out of school, have been sexually abused, are incarcerated or are in unstable housing (The Body 2000). A look at the breakdown of reported AIDS cases in the United States by exposure category reveals some behavioral trends among sub-populations of youth between the ages of 13 and 24. According to the *Hopkins HIV Report* for May 2002, the most prevalent modes of transmission for males between the ages of 13 and 19 are sexual contact with men (34 percent) and hemophilia (32 percent). For men ages 20-24, the majority (62 percent) reported sexual contact with men as their mode of transmission. Following this, intravenous drug use was the next largest reported exposure category (12 percent) (Ellen 2002). For females between the ages of 13 and 24, more than half of the reported AIDS cases noted heterosexual contact as the mode of transmission (Ellen 2002).

Youth in the Baltimore EMA, like youth of other urban areas, are heavily influenced by popular urban culture. Baltimore, however, presents its own unique backdrop where powerful educational, social and economic forces influence how youth between the ages of 13 and 24 operate in their surroundings. During the 2002-2003 school year, 43 percent of Baltimore City public school students failed to be promoted to the next grade level. A shocking 39,000 students were invited to participate in summer school in 2003 in the midst of substantial budgetary restraints in the school system (Tyehimba 2003a). In addition to contending with the pressures of adolescence and the changes associated with it, Baltimore's young people must deal with what

are apparently significant deficits in the school system's ability to equip its students with the tools necessary to be productive in life.

Baltimore is a city plagued with violent crimes where youth are not only the victims but the perpetrators as well. Data from 1997 show that more than 50 percent of shooting victims *and* suspects were 24 and under (OJJDP 2003). According to juvenile justice officials, the percentage of cases they handle each year that are related to drug offenses or violent crimes is increasing (GBC 2002). Additionally, there is a correlation between being seen by the child welfare system and appearing in the juvenile justice system: 35 percent of youth facing charges have been previously seen by a child welfare social worker (GBC 2002).

The unemployment rate in the Baltimore metropolitan area in August 2003 was 4.9 percent. If Baltimore City is isolated from the surrounding counties that make up the Baltimore EMA, the unemployment rate increases from 4.9 percent to 8.6 percent in August 2003 for the city alone (DLLR 2003). The rates of unemployment in Baltimore City are extremely high when compared to both the state and national unemployment rates of 4.1 and 6.1, respectively (DLLR 2003, BLS 2003). With such a high unemployment rate in Baltimore City, the job market seems rather bleak in terms of what it offers to individuals between the ages of 18 and 24. While a certain percentage of those youth may be presented with opportunities to further their education, others may seek alternative ways of making a living, for even those who are able to find a legitimate job are not guaranteed benefits or a living wage.

5.2 Methodology

To enable cross-population analysis, the planning council chose to employ the same focus group methodology used in its 2003 counties forum (see chapter 4) and its 2003 ex-offenders forum (see chapter 6). Each focus group had both a facilitator and a recorder. Before the forum, the facilitators were trained to assist in quality assurance.

5.2.1 Recruitment

The planning council and two collaborating agencies (see section 5.2.2) worked together to recruit youth to participate in the needs assessment focus groups. Representatives from each of the agencies scheduled and promoted the focus groups. A catered dinner and paid transportation were offered to encourage targeted youth to participate. The goal for each agency was to provide 10 to 15 HIV-positive youth to participate in each of the three focus groups.

5.2.2 Collaborating Agencies

Two sites in the Baltimore EMA, while not exclusively catering to HIV-positive youth, are known for their care for HIV-positive youth and therefore were asked to help recruit eligible youth for this project. These sites are the Intensive Primary Care (IPC) Clinic at the Johns Hopkins Children's Center and the Special Teens At-Risk, Together Reaching Access, Care and Knowledge (STAR TRACK) program at University of Maryland Medicine. Following are brief descriptions of each of these collaborating agencies.

The IPC Clinic at the Johns Hopkins Children's Center is a resource for HIV-positive children and young adults to receive primary medical care. While it does not exclusively see HIV-positive patients, the clinic currently serves 68 HIV-positive youth between the ages of 13 and 24, most of whom contracted the disease through perinatal exposure to the virus. Fifty-nine percent of the 68 HIV patients seen at the IPC Clinic are African-American, 32 percent are female, and the vast majority reside in Baltimore City. More than half of IPC Clinic's HIV patients are on medical assistance, and most are of lower socio-economic status (Hutton 2003).

The STAR TRACK adolescent HIV program at the University of Maryland is the only clinic in Maryland that exclusively offers care to youth between the ages of 12 and 24 who are HIV positive or at risk of being exposed to HIV (UMM 2001). Services provided at STAR TRACK include primary medical care, community outreach, counseling and testing, network referrals, case management and support groups (UMM 2003, CHIPTS 2003). The 2003 STAR TRACK program population comprised 75 clients: 80 percent were female, close to 90 percent were African-Americans, and about 25 percent were AIDS defined. Most of the clients were from Baltimore City. Some 90 percent of the youth were of lower socio-economic status, with approximately 10 percent from middle-class families. Approximately half of the youth in the program were on medical assistance for at least part of the year and approximately half had no insurance coverage during at least one clinic visit (Griffin-Deeds 2003). Among STAR TRACK clients, five percent of the males noted heterosexual contact as their mode of exposure to HIV with the remaining majority acquiring HIV from MSM activity. Most young females in the STAR TRACK program indicated heterosexual contact as their mode of exposure (Griffin-Deeds 2003).

5.2.3 Instrumentation

The Needs Assessment Committee of the planning council developed the survey tool and the focus group guide.

Each focus group participant was given an 11-item survey to complete, from which demographic data were compiled (see section 5.3). In addition to the quantitative data gathered on the survey, qualitative data were gathered during discussion sessions. Facilitators conducting the discussion sessions followed a focus group guide containing questions designed to elicit answers to the central question of the planning council's 2003 needs assessment activities: what are your barriers to care? The guide contained four questions, one of which overlapped with a survey question so that the data could be triangulated.

5.3 Results and Analysis

Five youth participated in this study. Each of the sites had been asked to recruit 10 to 15 youth to participate in the focus groups, and representatives at both the IPC Clinic and STAR TRACK were extremely helpful in their attempts to do so. However, most youth who initially agreed to participate failed to show up at the designated time and place — a fact that may exemplify the challenges faced by those trying to help youth access and adhere to care. The five young people who ultimately participated in this project were all recruited from the STAR TRACK program. The participants offered information helpful in trying to identify those things that may prompt other HIV-positive youth to seek and access care.

5.3.1 Quantitative Results: Survey

Four out of the five participants were between the ages of 20 and 24; the other was between the ages of 13 and 19. Three of the participants were male and two were female. All participants were African-American, and three of them indicated that they were also of Hispanic origin. All of the participants lived in Baltimore City, with three out of five residing in the 21202 ZIP code.

Only one of the five participants learned of his or her HIV-positive status from a testing site; the other four indicated that they learned of their status after seeking medical treatment for unrelated issues. All noted that they were told about the steps that they should take after learning that they were HIV positive. Four out of five indicated that they got into care immediately after learning of their status. One respondent entered care within six months of receiving the HIV test results. Four out of five stated that they see a doctor who orders blood tests at least once a year.

5.3.2 Qualitative Results: Focus Group

After filling out the participant information survey, the participants were asked to participate in a guided dialogue in which three main topics were discussed: health information sources, time from diagnosis to care and staying in care.

It is important to know where youth are getting their health information about HIV/AIDS and whether this information is about treatment or prevention. This knowledge is important for two reasons. First, it helps to identify sources that youth deem most trustworthy. Second, it helps planners know what resources to target for disseminating treatment information to the youth population. Table 25 shows the participants’ responses to the question about trustworthy sources of HIV/AIDS. The responses have been grouped into three categories: programmatic sources, health education resources and people.

Table 25 Sources of HIV Information Considered Trustworthy by Youth with HIV/AIDS	
Category	Source
Programs	<ul style="list-style-type: none"> ▪ STAR TRACK ▪ Back to Basics ▪ Maryland AIDS Administration ▪ Support groups
Health Education Resources	<ul style="list-style-type: none"> ▪ Health brochures ▪ <i>Vibe</i> magazine ▪ School health fairs ▪ Internet ▪ Television
People	<ul style="list-style-type: none"> ▪ Case managers ▪ Providers ▪ Peers

Source: IGS client survey.

All participants had accessed the STAR TRACK program at one time or another, and four out of five participants cited the program as being their primary source for HIV/AIDS information. All noted that the information that they received on HIV/AIDS from all sources was about both prevention and treatment.

With regard to seeking care after being diagnosed as HIV positive, one respondent felt that being busy made the wait time for an appointment easier to bear; the respondent explained, “I sought care within a week of being diagnosed. It wasn’t that hard of a process to go through because I had other things to do. I had to work so I really didn’t think about it until I had to go in [to the doctor] that Monday.” Three of the participants alluded to the fact that there was a psychological process that they had to go through after learning that they were HIV positive. One participant explained it this way, “When I first got diagnosed, [I thought] ‘What if somebody found out?’ or ‘They could be wrong.’ It’s just a lot of mental stuff within yourself that you have to come to terms with.” One participant’s decision to go to the doctor was prompted by his or her unwillingness to look unattractive; the participant explained, “I was sick and unattractive looking so I wanted to fix it. So I figured I would go to a doctor so that they can fix it and so I don’t have to look like that any more.” When that participant was asked whether he or she would have sought medical care if the illness had had no effect on appearance, the participant replied, “Probably not.”

The participants were asked to identify those things that would help them keep their scheduled appointments. One participant responded that the provider’s environment has an important role in whether people attend their doctor’s appointments, and two other participants agreed. The

participant's comment speaks volumes to the need for primary care facilities to create an environment that is welcoming to youth:

There are times when I just don't feel like I want to be bothered and I am not going into a place where I am not 100 percent comfortable.... You don't want to be around people's negative attitudes, their bad vibes, so that really plays a big part of [wanting to be in] successful health care and wanting to seek care for anything that is wrong with you. So I know there are plenty of times when I walk into the clinic and I am automatically defensive and automatically ready to go because it feels like a totally different environment.

Seven of the responses to the question of keeping appointments had to do with quality of life, such as, "I know I need the medicine," "I was sick and unattractive looking," and "You want to be healthy. You want to live a productive life, being *normal*, so to speak." Four of the five participants stated that their case manager was the catalyst that enabled them to keep their scheduled appointments. Other methods of keeping appointments included clinical reminders (5) having child care (2), transportation (4), and support from medical and social work personnel (5).

Participants were asked some additional questions to explore what barriers prevent them from keeping their scheduled appointments. Child care was explicitly cited by two of the respondents as a barrier to keeping appointments. Three other respondents described the lack of child care as a barrier for their HIV-positive peers, saying, "a lot of people have kids, and for them to be able to make appointments they have to drop their kids off somewhere for a couple of hours for someone to watch them." Additionally, some expressed concerns about the inability to schedule doctors' appointments to accommodate transportation arrangements and school/GED classes. The participants were asked how much transportation, child care, school, and GED activities affect the regularity with which they see their doctors. One respondent replied, "Big time, it's a huge thing. Transportation — not everyone can afford to get down to the clinic or support group. School — being able to schedule your appointments around school and GED programs. Those are key parts to keeping your appointments." Further discussion of barriers revealed that while transportation passes are currently provided to youth, the physical appearance of the passes discourages the youth from using them. Said one participant, "We don't want to use those [overly large] green handicap passes. They hook up old people [with taxi vouchers] and leave us hanging out to dry." Lastly, two of the respondents mentioned having insurance problems and not knowing how they were going to pay for medical treatment. One respondent was worried about losing coverage on an upcoming nineteenth birthday; the other was overwhelmed by the medical bills received in the mail and was deterred from seeking any additional care because of an inability to pay for the care already received.

5.4 Conclusion

The sole purpose of conducting needs assessment activities is to provide the planning council with information to make important planning decisions for special populations. Valuable data were collected from the participants of this study. This information has crucial implications for the allocation of funds and services to this special population.

Stigma is still a barrier for young people accessing care. Young people may be more susceptible than adults are to the effects of stigma, as young people are striving to develop and assert their identities. As young adults, they have to consider how their HIV-positive status influences their identity. Planners need to examine ways of encouraging young people to seek primary medical care while simultaneously ensuring that their HIV status is not given away by association with a particular clinic, institution or agency.

The social climate of care facilities may further alienate young clients from accessing care on a regular basis. The youth in this study mentioned that they were not comfortable with some of the settings that administer care. Their general feeling was that they were either treated as children, incapable of making decisions, or ignored and left to sit in the waiting room for hours. It is difficult to convince HIV-positive individuals to seek primary care; once they reach the point where they can see the value in getting care, it is crucial that the environment in which they receive that care be one that encourages them to continue receiving it.

Transportation, flexible scheduling and child care were critical issues for focus group participants. The youth mentioned that finding accessible transportation was a problem. They were also deterred by the provision of handicap bus passes. The perception associated with getting on a bus with such an identifier discouraged them from using this resource. More discreet passes would alleviate some of their concerns.

Access to care still largely depends on individual readiness to receive care. Although most of the participants indicated that they sought care within a month of learning of their status, many still admitted to needing time to come to terms with what it meant to be HIV positive. To help dispel some of this angst, specialized mental health services should be provided for youth to coach them through this difficult time.

6. COMMUNITY FORUM: EX-OFFENDERS

The purpose of this project was to better understand the specific health care needs of HIV-positive ex-offenders. Their concerns regarding access to care may be unique when compared to the broader HIV-positive population because, in addition to coping with the burden of actively seeking medical care, ex-offenders also have to contend with the stress of being reintegrated into society. Getting into medical care may fall lower on the priority list for some individuals if their primary needs of food, shelter and clothing are scarcely being met. To better understand the challenges faced by HIV-positive ex-offenders in the Baltimore area and the impact of those challenges on their access to care, the planning council conducted a series of interviews and focus groups with members of this population. This chapter describes the background, methodology and results of that research.

6.1 Background

Meeting the needs of HIV-positive ex-offenders is a major goal of the planning council. Ex-offenders have been identified as a special population, not only by the planning council, but also by the U.S. Centers of Disease Control and Prevention (CDC) and the U.S. Health Resources and Services Administration (HRSA). With over two million people across the country incarcerated in jails and prisons and an overwhelming three quarters of this population made up of African-Americans and Hispanics, the need to make provisions for HIV-positive ex-offenders re-entering communities is urgent (HRSA 2000). HRSA recognizes that “in the transition from correctional facilities back into the community, health care is usually not coordinated. Moreover, many inmates with HIV return to the community never having received HIV testing, and thus continue to be unaware of their HIV status” (HRSA 2000).

Several studies have been done on the prevalence of HIV in correctional facilities because “a major portion of the nation’s Hepatitis B & C, HIV, STD and TB infected patients pass through prison and jail doors” (Hammett 1999). Within prison populations, there is a heavier burden of HIV among people of color and women than their white and male counterparts (Hammett 1999). A prevalence study of Maryland correctional facilities found that newly incarcerated females and newly detained females have higher rates of HIV, syphilis and hepatitis C than newly incarcerated and detained males (DHMH 2003a). Of the newly incarcerated women in the study, 12.5 percent were infected with HIV, compared to 3.7 percent of newly incarcerated men (DHMH 2003a). The difference in prevalence among all detainees is smaller, with an 8.9 percent HIV prevalence rate among female detainees and a 7.1 percent prevalence rate among male detainees (DHMH 2003a).

Additionally, among the prison population in Maryland, there is a high co-infection of hepatitis C virus (HCV) with HIV. According to state data, “Of the HIV positive individuals, 64.6% of inmates and 65.7% of detainees were co-infected with HCV” (DHMH 2003a). Moreover, HIV-positive inmates and detainees also have other co-morbid conditions such as substance abuse, psychiatric illnesses and chronic medical conditions that further complicate their medical treatment and care (Hammett 1999).

The HIV infection rates in Maryland’s prison system are among the highest in the nation. Seventy-five percent of the state’s prisoners come from the Baltimore area (Bykowicz 2003). Upon release, a large number of ex-offenders return to the Baltimore area to live. This information, combined with the high overall HIV prevalence rates within Maryland’s correctional

facilities, warrants the focus on providing HIV treatment services to ex-offenders in the Baltimore EMA.

6.2 Methodology

To enable cross-population analysis, the planning council chose to employ the same focus group methodology used in its 2003 counties forum (see chapter 4) and its 2003 youth forum (see chapter 5). Each focus group had both a facilitator and a recorder. Before the forum, the facilitators were trained to assist in quality assurance.

6.2.1 Recruitment

The planning council worked with area HIV service providers to recruit HIV-positive ex-offenders to participate in the needs assessment focus groups. A catered dinner and paid transportation were offered to encourage targeted youth to participate.

Two individual interviews were conducted, one with a consumer recruited by staff at the Moore Clinic at Johns Hopkins Hospital, and one with a consumer recruited by a case manager from the Baltimore County Department of Health. One of the interviews was done in person while the other was done via telephone. The information gathered from these two interviews is included in the aggregate data from the focus groups. In addition to those two individual interviews, three focus groups were scheduled with participants recruited by two collaborating agencies: STAR and HERO.

6.2.2 Collaborating Agencies

Sisters Together and Reaching, Inc. (STAR) is a non-profit organization founded to address the barriers to primary care for HIV-infected African-American women and their families. Services provided by STAR include case management, local and national capacity building assistance, financial assistance, support groups, outreach, resource information, referrals, art and writing therapy, pastoral counseling, a telephone help line, prevention education, volunteer training workshops and buddy support. Since its inception in 1991, STAR has been able to provide services to over 8,000 HIV-infected and -affected individuals (Prettyman 2003). Staff members at STAR recruited eight eligible participants from their support groups to be a part of this study.

As described in chapter 3, HERO is a community-based organization offering education, resources and services for Marylanders affected by HIV/AIDS (HERO 2003). HERO staff members were able to recruit 12 participants for these needs assessment focus groups.

6.2.3 Instrumentation

The Needs Assessment Committee of the planning council developed the survey tool and the focus group guide.

Each focus group participant was given an 11-item survey to complete, from which demographic data were compiled (see section 6.3). In addition to the quantitative data gathered on the survey, qualitative data were gathered during discussion sessions. Facilitators conducting the discussion sessions followed a focus group guide containing questions designed to elicit answers to the central question of the planning council's 2003 needs assessment activities: what are your barriers to care? The guide contained four questions, one of which overlapped with a survey question so that the data could be triangulated.

6.3 Results and Analysis

Nineteen HIV-positive ex-offenders agreed to participate in this study. Three focus groups and two individual interviews were conducted to obtain the data presented below.

6.3.1 Quantitative Results: Survey

The majority (11) of the ex-offenders involved in this study were between the ages of 40 and 49. Three participants were between the ages of 50 and 59, four participants were between the ages of 30 and 39, and the youngest participant was between the ages of 25 and 29.

Eighteen out of nineteen participants lived in Baltimore City with one participant residing in Baltimore County. The most frequent ZIP codes among this sample were 21202 (7) and 21218 (4). There were two respondents in each of the following ZIP codes: 21201, 21217 and 21230. One participant lived in 21222 and one participant chose not to respond to this question.

Three females and 16 males took part in this study, one of the females being transgendered, male to female (17 other respondents reported not being transgendered and one did not answer that particular question).

Seventeen respondents identified themselves as African-Americans. Two of the respondents were white. One respondent also reported being of Hispanic origin.

Eight participants indicated that they learned their status from an HIV testing site or van (see table 26). Seven learned of their status after seeking medical treatment. One participant learned after giving blood. Three participants marked “other,” then wrote the specific means by which they learned that they were HIV-positive. Those written responses were, “my girlfriend told me,” “in substance abuse rehab” and “in jail.”

With regard to care, most of the participants (10) sought care immediately after learning their status (see table 27), a behavior possibly influenced by post-test counseling — most of the participants (14) were told the next steps that they should take after being told they were HIV-positive. Nearly all of the participants (18) indicated that they are currently in care, meaning that they see a physician who orders blood tests at least twice a year; one participant declined to answer the question about how often he or she sees a doctor.

Table 26 Circumstances of HIV Diagnosis	
Location or means	Respondents (n=19)
HIV testing site or van	42.1%
Unrelated medical treatment	36.9%
Blood donation	5.3%
Other	15.8%

Source: IGS client survey.

Table 27 Time Between Receiving HIV Diagnosis and Seeking Medical Care	
Time between diagnosis and care	Respondents (n=19)
None (same-day care, no wait)	52.6%
6 months to 1 year	15.8%
1 to 2 years	5.3%
2 to 5 years	5.3%
5 to 10 years	5.3%
More than 10 years	5.3%
No response	10.5%

Source: IGS client survey.

6.3.2 Qualitative Results: Focus Group

After filling out the participant information survey, the participants were asked to participate in a guided dialogue in which three main topics were discussed: health information sources, time from diagnosis to care and staying in care.

Participants identified several trusted sources of health information. Their responses, shown in table 28, have been divided into four categories: institutions, programs, people and services.

Category	Source
Institutions	<ul style="list-style-type: none"> ▪ Baltimore County Health Department ▪ HERO ▪ STAR ▪ Project PLASE ▪ Chase Brexton ▪ Johns Hopkins Hospital ▪ The Moore Clinic at Johns Hopkins Hospital
Programs	<ul style="list-style-type: none"> ▪ HIV trainings ▪ Support groups ▪ Workshops
Health Education Resources	<ul style="list-style-type: none"> ▪ <i>Baltimore City Paper</i> ▪ Internet
People	<ul style="list-style-type: none"> ▪ Case managers ▪ Doctors ▪ Co-workers ▪ Other PLWH/As

Source: IGS client survey.

When asked in the discussion group about the time it took them to get into primary medical care after learning of their HIV-positive status, 16 out of 19 participants indicated that they got into care in a year or less. One participant started to receive primary medical care within three years, one within seven years, and one within 12 years. When these data are compared with the same participants' answers to the same question as it appeared on the self-administered survey (see table 27), a small but interesting discrepancy appears. On the survey, only 68.4 percent (13) of respondents said that they sought medical care within one year, while in the focus group 84.2 percent (16) said they were in care within a year. A similar discrepancy appeared in the results of the community forum held with county residents (see section 4.3.2). As with the data for the county residents, the data for ex-offenders suggest that consumers may have a different perception of time after diagnosis than researchers do. For example, when asked what had hindered them from seeking care, most respondents alluded to a need to come to terms with the magnitude of what it means to have HIV. Some needed to overcome denial, while others needed to recognize that they could still live productive lives. One participant stated, "Before I got educated I was ignorant and scared of dying. I was educated that I could live with it [HIV]." Given these results, it seems that many consumers calculate the time it took them to seek care not from the point of diagnosis, but from the point of diagnosis acceptance.

The participants were asked to identify the things that help them to keep their regularly scheduled doctors' appointments for HIV care; table 29 shows their responses.

Table 29	
Factors That Facilitate Appointment Adherence	
Category	Responses
Personal	<ul style="list-style-type: none"> ▪ Declining health ▪ Fear of dying ▪ Desire to stay healthy ▪ Wait time for appointments
Interpersonal	<ul style="list-style-type: none"> ▪ Narcotics Anonymous meetings ▪ Case managers ▪ Counselors ▪ Family support ▪ Provider staff
External Prompts	<ul style="list-style-type: none"> ▪ Calendars ▪ Beepers ▪ Letters ▪ Phone calls ▪ Verbal reminders ▪ Consistent scheduling

Source: IGS client survey.

A similar question was asked of participants to identify those things that help HIV-positive ex-offenders continue medical treatment (see table 30). Having health insurance was a concern for two of the participants. Said one, “My medical assistance was cut off while I was in jail so I wasn’t sure how I would be able to afford care.” The social climates of some care facilities further alienate clients from accessing care on a regular basis; one participant indicated that the positive attitude of the staff encourages retention in care. Transportation and flexible scheduling may aid in keeping individuals in care. During the interview, one participant noted that, because of transportation issues, one must set aside a whole day for medical appointments so as to minimize the amount of time one needs to take off from work. The provision of transportation was a common theme in insuring adherence to care.

Table 30	
Factors That Facilitate Treatment Adherence	
Category	Responses
Personal	<ul style="list-style-type: none"> ▪ Desire to live ▪ Positive outlook on life ▪ Desire for treatment effectiveness ▪ Sobriety ▪ Personal responsibility
Interpersonal	<ul style="list-style-type: none"> ▪ General support ▪ Social worker ▪ Substance abuse HIV specialist support ▪ Family support ▪ Case worker support
Services	<ul style="list-style-type: none"> ▪ Transportation ▪ Health insurance

Source: IGS client survey.

6.4 Conclusion

Stigma is still a barrier that prevents people with HIV/AIDS from accessing care. In addition to societal biases against ex-offenders, the participants in this study face the stigma associated with being HIV positive. One participant told a story of how the mere association with some agencies carried a certain level of stigma with it and potentially disclosed the status of any individual seen there.

Substance abuse recovery and services came up frequently among the different focus groups and interviews that were held with HIV-positive ex-offenders. The recurrence of this topic suggests a need for more substance-abuse treatment.

Specialized support, such as that from case managers, social workers and drug counselors with specific knowledge of HIV, is a catalyst for the continuation of care among ex-offenders. Release counselors and support professionals should be knowledgeable about HIV/AIDS and well equipped to assimilate ex-offenders into a system of HIV care upon their re-entry into society.

Given that the amount of time it took the participants in this study to get into care ranged from directly following diagnosis to 12 years, access to care seems to still largely depend on individual readiness to receive care. Long-term post-test counseling may help individuals get into care sooner.

7. SURVEY: AFRICAN-AMERICAN MEN'S HEALTH

African-American men face unique challenges with regard to the treatment of HIV disease. In addition to facing the stigma associated with HIV, African-American men must contend with societal biases associated with their race. In addition, engaging in homosexual sex may carry a greater stigma within the African-American community than within society as a whole, meaning that stigma may be more of a barrier to care for African-American men than for other populations. The planning council identified African-American men who have sex with men as one of the populations of special interest for its 2003 needs assessment activities. This chapter describes the background, methodology and results of a research project designed to assess the needs and barriers to care for African-American males.

7.1 Background

Activist Frances Beale coined the term “double jeopardy” to describe the compounded effects of the intersection of race and gender on the social mobility of groups in society (Beale 1970). Deborah King, seeing more than an additive effect of the intersections of race, class and gender, expanded Beale’s theory under the term “multiple jeopardy” (King 1998); in other words, to be black and female means more than adding the biases associated with each to come up with a composite picture of the “lived” experience of black women. Underlying King’s argument is the assumption that race, gender, class, sexuality and other social characteristics have an exponential interplay that contributes to the degree in which individuals and groups are isolated from mainstream society.

Much debate and criticism has been applied to the double and multiple jeopardy theories, but their founding principles with regards to the mobility of certain groups in society with highly complex identities are particularly useful in examining African-American men who have sex with men who are HIV positive. This population suffers from multiple jeopardies that, when combined, further alienate them from their community and isolate them from accessing needed services and resources. In fact, the racism that exists in larger society and compels black men to identify primarily with their black community may increase their exposure to the strong biases that exist within that community toward homosexuality. As the stigma associated with homosexuality decreases in the larger population, many African-American MSMs continue to have sex with males in secret, “products of a black culture that deems masculinity and fatherhood as a black man’s primary responsibility” (Denizet-Lewis 2003).

7.1.1 *African-American Men who Have Sex with Men in Maryland*

Nationally, the rate of AIDS among African-Americans is nearly 10 times that of whites (Kaiser 2003). In Maryland, African-Americans make up a mere 28 percent of the total population, yet they represented 80 percent of the 2001 HIV cases and 84 percent of the 2001 AIDS cases. By exposure category, the number of incident (new) HIV cases in Maryland among African-Americans in 2001 was 39 for MSMs and 16 for MSMs who are also injection drug users (IDUs). That same year, among African-Americans, the number of incident AIDS cases was 154 for MSMs and 25 for MSM/IDUs. Incidence of both HIV and AIDS was greater for African-Americans than for all other races combined across all exposure categories (DHMH 2003b).

7.2 Methodology

To determine the specific access-to-care barriers that prevent HIV-positive African-American MSM from seeking and being adherent to primary medical care, the Needs Assessment Committee of the planning council designed an anonymous survey to be given to a convenience sample of HIV-positive African-American men, with a special emphasis on African-American MSMs.

To create an anonymous space where African-American MSMs could participate without revealing their sexual orientation or HIV status, neither the consent form that respondents were required to sign nor the survey itself identified the survey as specifically being for HIV-positive African-American MSMs; rather, all paperwork related to the survey identified it as an African-American Men's health survey.

To ensure compliance with the survey protocol and reduce the errors often associated with self-reported data, the survey was administered by facilitators from two organizations: Baltimore Black Gay Pride, Inc. (BBGP), and Project PLASE, Inc. An advisory board formed by InterGroup Services, Inc., the planning council support contractor, and composed of members of local community organizations and governmental institutions identified facilitators. In addition to survey administration, the facilitators were also responsible for recruiting participants.

7.2.1 Instrumentation

The survey was based on an African-American men's sexual health survey conducted in Washington, D.C., through the collaboration of a Washington-based outreach organization, Us Helping Us, People Into Living, Inc., and the Washington, D.C. Department of Health's HIV/AIDS Administration. To determine if and how the Washington, D.C. study needed to be modified for distribution in the Baltimore EMA, a pilot test was conducted by BBGP with a convenience sample of 15 African-American men to clarify understanding of the target population's definitions of certain terms. (As it turned out, the Washington study required no substantive changes.)

Each study participant was given a 41-item survey to complete, from which demographic data were compiled (see section 7.3). This population was approached differently from the other populations included in this report due to the specific issues confronted by African-American MSMs; however, the goal of the survey given to this population was the same as the goal of the forums held with the other populations, which was identifying the population's barriers to care.

7.3 Results and Analysis

Eighty-two men completed the survey. Seventy-eight of the respondents identified themselves as African-American, one as Hispanic, and one as Afro-Caribbean/West Indian; two people did not respond to the question about race. Twelve of the respondents were between the ages of 20 and 29, twenty-four were between the ages of 30 and 39, and thirty-six were between the ages of 40 and 49; the remainder were 50 or older.

Most of the respondents (48) earned under \$20,000 per year (see table 31), yet a significant majority (66) had at least a high school diploma (see table 32). While 30 of the respondents were unemployed, 30 also had full-time employment (see table 33).

Given what the literature review and the pilot study revealed about the stigma associated with being African-American and gay, it is not surprising that none of the respondents who self-identified as heterosexual listed sex with men as his mode of exposure. Nonetheless, sex with men was the dominant exposure mode overall, at 43 percent; however, all participants who listed that exposure mode identified themselves as homosexual or bisexual.

With regard to health-care behaviors, most of the respondents (79) indicated that they receive health care, and many (34) receive it from a private doctor (see table 34). Of those who do not receive care from a private doctor, 18 receive care from a community-based free clinic, and 24 from another type of clinic or hospital.

When asked why they might not have received care in the last six months, 73.2 percent of the respondents indicated that the question did not apply to them, that in fact they had been in care within the last six months. Of those who had not received care within the last six months, 4.9 percent said that they were not sick, 2.4 percent that they did not know how to get free health care, 1.2 percent that their family needed them, and 1.2 percent that they did not like doctors or nurses.

Although the vast majority of respondents to this survey were in care and half of them had sought care immediately, of the other respondents, 14.6 percent did not seek care for up to 6 months, 9.8 percent for between 6 months and 1 year, and 4.9 percent for between 6 and 10 years.

Table 31 Annual Household Income	
<i>Income Range</i>	<i>Respondents (n=82)</i>
Under \$10,000	34.1%
\$10,000 to \$19,999	24.4%
\$20,000 to \$29,999	9.8%
\$30,000 to \$39,999	13.4%
\$40,000 to \$49,999	7.3%
\$50,000 to \$59,999	1.2%
\$60,000 to \$69,999	2.4%
Above \$70,000	3.7%
No response/Don't know/Can't remember	3.7%

Source: IGS client survey.

Table 32 Highest Level of Education Attained	
<i>Education Attained</i>	<i>Respondents (n=82)</i>
Did not complete high school	14.6%
High school/GED	30.5%
Some college or some vocational school	29.3%
College degree or vocational school diploma	14.6%
Graduate school	6.0%
No response	4.9%

Source: IGS client survey.

Table 33 Employment Status	
<i>Income Range</i>	<i>Respondents (n=82)</i>
Unemployed	36.6%
Part-time	12.2%
Seasonal	3.7%
Full-time	36.6%
Don't know/No response	11.0%

Source: IGS client survey.

The question about barriers to care was asked both objectively and subjectively; in other words, in addition to being given a list of responses to choose from, participants were also asked to write down what kept them from seeking care from a doctor or at a clinic. Most participants either skipped the open-ended question or wrote in that they had no problem seeking care. Of the 43 written responses, 14 indicated actual barriers. Of those 14 barriers, 3 appeared 4 times each: lack of money or insurance, fear of being identified as HIV positive, and transportation. Listed twice were work-related issues (i.e., concern about missing time from work).

On the multiple-choice barrier question (see table 35), for which respondents could select more than one answer, nine respondents indicated that stigma or stigma-related issues kept them out of care, four indicated that transportation was a factor that kept them out of care, and two cited drug and alcohol use as a barrier.

Among those respondents who cited one or more barriers to HIV care, the cost of care or lack of insurance was cited more than once as a barrier. Only 15 of the survey respondents had private health insurance, despite the fact that 30 of the respondents were employed full-time; the other respondents had some combination of Medicaid (26), Medicare (12), Pharmacy Assistance (11), no insurance at all (11), MADAP (10), Veteran's Administration (3) or Ryan White (5).

Provider	Respondents* (n=82)
Don't receive health care	3.7%
Private doctor	41.4%
Emergency room	6.1%
STD clinic	7.3%
Health department	6.1%
Community-based free clinic	22.0%
Other clinic/hospital	29.3%
Don't know/can't remember	0%

Source: IGS client survey.

*Sum does not equal 100% as categories are not mutually exclusive.

Barrier	Respondents (n=82)
None; easy to get care	58.5%
Substance abuse	2.4%
Transportation	4.9%
Lack of free services	1.2%
Forget to go	3.6%
No time to go	1.2%
Need child/family care	0%
Feeling ashamed, guilty or embarrassed	3.6%
Not wanting anyone to find out	3.6%
Worry about stigma	3.6%
Disrespectful doctor/nurse	0%
Doctor/nurse not knowledgeable about my needs	0%
Don't know or can't remember / Other	17.1%

Source: IGS client survey.

7.4 Conclusion

This study revealed that stigma prevents black men with HIV/AIDS from accessing care. Biases against homosexuals, and people who are HIV positive, were factors that prevented the men in this study from receiving care. Stigma may not actually *prevent* a person from seeking care forever, but it can significantly *delay* someone's efforts to seek care, and that delay could be costly.

8. 2003 NEEDS ASSESSMENT RESULTS: PLANNING IMPLICATIONS

A consideration of the preceding chapters provides a broad overview of needs and services in the Baltimore EMA. A substantial, but by no means exhaustive, segment of clients and providers is represented in these reports on the clients of select HIV service providers, county residents, youth, ex-offenders and African-American men who have sex with men. These analyses offer a number of intriguing results.

Demographic information plainly points to two very different sub-populations in Baltimore City and the surrounding counties. Baltimore City is home to more African-Americans, more unemployed or underemployed, more extremely poor citizens, and more injecting drug users than are the counties. The city also carries the disproportionate share of 80 percent of the EMA's PLWH/As versus 20 percent in all the counties combined. However, these numbers may overstate the differences between city and counties when it comes to PLWH/As seeking and obtaining services. The studies summarized in this report describe very different special populations yet offer strikingly similar conclusions. The consistent barriers to care for all the groups examined here can be divided into six general categories: substance abuse, mental health, economic expense, provider attitudes and care environment, stigma and confidentiality, and lack of automatic versus motivated access to care. These categories include and determine questions of time elapsed between diagnosis and treatment, service fragmentation versus "one-stop shopping" for consolidated care, personal acceptance of HIV-positive status versus denial, and the alarming role of incarceration as a barrier to treatment or even an incubator of disease. All of these considerations are not independent problems but rather tend to reinforce and interpenetrate one another in complex ways.

8.1 Substance Abuse

All of the special populations and providers accessed in this study reported a need for greater substance-abuse treatment. Substance abuse, especially but not exclusively IDU, is widely recognized as both a contributor to HIV infection and a powerful barrier to treatment seeking and adherence. An addicted individual has little chance of recognizing and accepting HIV-positive status or taking steps to protect his or her own health as well as others'. Substance-abuse treatment must be a top priority not just for the welfare of abusers but also to stem the spread of HIV throughout their communities.

8.2 Mental Health and Psychosocial Support Services

Mental illness is frequently co-morbid with substance abuse but can also independently interfere with care. Mental health and psychosocial support services must be available to evaluate and treat all manner of conditions. Counseling to overcome anxiety, fear and denial is crucial from the first day of HIV-positive diagnosis. In these studies, severe illness long after HIV testing was often reported as an ultimate motivator to overcome fear or denial and seek treatment. Access to care often depended on individual readiness to receive care and emotional acceptance of HIV-positive status. Early psychological intervention could drastically shorten the time between HIV diagnosis and treatment. Such a simple expedient could preserve both lives and funds spent on later stage physical treatments.

8.3 Economic Expense

The cost of medical and ancillary services was frequently cited as a barrier to care. The participants in these studies frequently reported hesitating to get care because they lacked insurance or were under-insured. Some consumers reported discrimination from providers because of inability or perceived inability to pay. Some providers suggested that managed care may be a barrier to consumers' receiving proper care. Non-medical expenses like child care and transportation also added up, thus impeding adherence to scheduled appointments and treatment regimens.

8.4 Provider Attitudes and Care Environment

Each special population repeatedly emphasized concerns about the relationship between providers and consumers. PLWH/As consistently voiced mistrust of staff and a perception of disrespect, mistreatment or insensitivity. All special populations felt discriminated against economically based on their ability to pay and youth further protested that they were ignored and dismissed as children. Consumer suggestions for improving treatment adherence and client retention centered on a desire for improved communications and demonstrations of compassion from doctors and support staff. For their part, providers demonstrated concern with client perception of care. Some providers sympathized with consumer complaints while others sensed possible manipulation or undermining of treatment, especially among clients who "shop" for services (i.e., frequently change providers in an effort to get from one provider services that another provider refused to give).

Consumers and providers agreed that the social climate of care facilities might either alienate PLWH/As or encourage their retention. Several concrete policy suggestions arose repeatedly. Long waiting times for making and receiving appointments discourage retention. A reduction in wait time for newly diagnosed PLWH/As getting into care and a reduction in wait time obtaining appointments for those continuing in care would be a marked improvement. Flexible scheduling, including evening hours, would help consumers plan around work, school and child care. Concentrating all needed services at one site and preferably in one day is preferable to fragmentation of services over space and time and may help curtail less productive "shopping" behavior.

8.5 Stigma and Confidentiality

PLWH/As continue to experience severe social stigma and the respondents cited here consistently expressed the desire to maintain confidentiality in treatment. Stigma was especially pronounced in, but by no means limited to, the youth and ex-offender populations. Youth expressed strong concern about being identified by peers in a clinical or social-services setting or even using tools like special-access bus passes that might indirectly identify them as health-care consumers. Ex-offenders reported that they feel the dual pressures of HIV-positive stigma and the stigma of having been incarcerated. While especially pronounced among the youth and ex-offender populations, all of the populations examined in these studies reported concern with stigma from situational association with service providers. The mere presence of individuals at an institution identified with HIV treatment compromises their privacy; the risk of disclosure sometimes influenced retention and treatment adherence.

It may be productive to combine increased institutional sensitivity toward consumer privacy with additional counseling for consumers aimed at decreasing their sensitivity to social stigma

associated with PLWH/As. Confidentiality can at once be improved and rendered less critical compared with health and wellness issues.

8.6 Automatic versus Motivated Access to Care

Numerous and excellent care providers operate within the Baltimore EMA. Most publicize HIV services and provide community outreach, yet many PLWH/As find it difficult or daunting to get into care. There is often no smooth transition from diagnosis to care, and many people, after learning of a positive test result wait weeks, months or even years to see a doctor. Often individuals must be highly motivated, by severe illness for example, to seek out and obtain medical services. This situation suggests that a more automatic and systematic approach to moving people from diagnosis to care is in order. In addition to the need for immediate and sustained individual post-diagnosis counseling discussed above, there is also a need for societal institutions to streamline access to HIV treatment after a positive test result, before depression and denial set in.

One institution that appears possibly in need of reform regarding HIV treatment is the criminal justice system. Incarceration was consistently reported as an obstacle to obtaining or adhering to treatment. Many ex-offenders reported being unaware of their HIV status while incarcerated, but there is a compelling social benefit to identifying and treating prisoners before they are released back into society. To be successful, such treatment must address co-infection such as hepatitis C virus and co-morbidities with substance abuse, mental illness and other chronic conditions. A monitoring and counseling system is already in place for ex-offenders. Release counselors and social workers need to be equipped to transition ex-offenders into an HIV care system upon return to society. This transition support could increase individual readiness to receive care and decrease lag time between diagnosis and care. Perhaps a successful ex-offender transitional program could serve as a model for other segments of society that need more automatic access to HIV/AIDS services.

9. APPENDICES

9.1 Community Forum Survey

Participant Information Survey

1. What is your age in years?
 Under 13 40-49
 13-19 50-59
 20-24 60-64
 25-29 65 and over
 30-39

2. Where do you get your HIV services?
 City of Baltimore
 County (Specify: _____)
 Both
 Neither

3. Where do you live?
 Anne Arundel County Harford County
 Baltimore County Howard County
 Carroll County Queen Anne's County
 City of Baltimore

4. What is your ZIP Code? _____

5. What is your sex?
 Female Male

6. Are you transgendered?
 No
 Yes—Male to Female
 Yes—Female to Male

7a) Are you of Hispanic/Latino/Spanish origin?
 Yes No

b) What race are you? (Please check all that apply.)
 African-American/Black
 American Indian/Alaskan Native
 Asian/Pacific Islander
 Caucasian/White

8. How did you find out that you were HIV positive?
 HIV test site/van
 Sought medical treatment and happened to learn I was HIV-positive
 Pregnancy
 Gave blood
 Insurance Screening
 Other: _____

9. After you learned you were HIV positive, did anyone tell you about the next steps you should take?
 Yes No

10. After first learning you were HIV positive, how long was it before you went to a doctor or nurse for HIV/AIDS care?
 Immediately
 Less than 6 months
 6 months to a year
 1-2 years
 2-5 years
 5-10 years
 More than 10 years
 Never

11. Do you see a doctor that orders a blood test for HIV disease at least twice a year?
 Yes No

9.2 Community Forum Focus Group Guide

Focus Group Guide

Instructions to the Facilitator:

Please read the following script at the start of the session. Be sure to ask if the directions are clear to everyone and handle questions appropriately. Refer to the participants only by their chosen name, so that we can maximize confidentiality. Repeat the question before moving on to the prompts located in the parentheses. Please make every effort to stay within the time frame for each focus group (approximately 20 minutes per question).

First, I want to thank you for taking the time to help us with a project on behalf of the Greater Baltimore HIV Health Services Planning Council. The information that we collect today will help in determining how to deal more effectively with the HIV/AIDS epidemic.

I also want to take a couple of moments to explain how we ensure your confidentiality. This focus group will be tape-recorded so that we can track responses, but we are asking you to choose a name for this session and write it on the nametag (make sure it's only a first name or a nickname—absolutely no whole names). During this session we will refer to you by the name you've picked. At the end of the session, we will ask that you destroy the nametags.

As I mentioned, this session will be tape-recorded, so I will need you to speak up clearly. What you have to say is very important, so we may ask you more questions to make sure that we understand what you are saying.

1) Where do you get your health information about HIV? (Who or what is your most trusted source for health information? Is the information about treatment or prevention?)

2 a.) For those of you who are seeing a doctor or nurse for HIV/AIDS, how long did it take you to see them after you found out that you were HIV positive? (What finally made you decide that it was time to see a doctor?)

2 b.) It's okay if you are not seeing a doctor or nurse, we still want to know how long it has been since you learned that you were HIV positive. (Why have you decided not to see a doctor or nurse?)

3) For those of you who are regularly seeing a doctor, what helps you to keep your doctor's appointment?

4) What would help you start seeing a doctor?

9.3 MSM Survey

African-American Men's Health Survey, 2003

The purpose of the survey is to examine the problems faced by African-American/black men in the Baltimore area in accessing the health-care system, in general, and the HIV-care system, in particular, if applicable.

Before completing this survey, you must read and sign a consent form. If you have not already done this, please do it now. The consent forms will be stored separately from, and therefore cannot be tracked to, the completed survey forms.

You may either fill in this questionnaire yourself or, if you would prefer it, the interviewer can ask you the questions and check off the boxes that you tell him to check off. Either way, the interviewer will be present during the entire process to answer any questions you may have.

For each question, you should check just one box unless the question specifically says you can check more than one. In that case, it will say, "Check all that apply."

Remember, all answers are completely confidential.

A. About You

We will start with a few general background questions about you.

1. What is your age in years?

- | | |
|----------------------------------|--------------------------------------|
| <input type="checkbox"/> 13 - 19 | <input type="checkbox"/> 40 - 49 |
| <input type="checkbox"/> 20 - 29 | <input type="checkbox"/> 50 - 59 |
| <input type="checkbox"/> 30 - 39 | <input type="checkbox"/> 60 and over |

2. What ethnic background best describes you? (Please choose only one.)

- Black/African-American
- Hispanic/Latino
- Biracial/Multicultural
- Afro-Caribbean/West Indian
- African
- Other (specify): _____
- Don't know

3. What is your yearly household income?

- | | |
|---|---|
| <input type="checkbox"/> Under \$10,000 | <input type="checkbox"/> \$50,000 to \$59,999 |
| <input type="checkbox"/> \$10,000 to \$19,999 | <input type="checkbox"/> \$60,000 to \$69,000 |
| <input type="checkbox"/> \$20,000 to \$29,999 | <input type="checkbox"/> Above \$70,000 |
| <input type="checkbox"/> \$30,000 to \$39,999 | <input type="checkbox"/> Don't know or can't remember |
| <input type="checkbox"/> \$40,000 to \$49,000 | |

4a. What is the ZIP code where you live? If you don't know your ZIP code, just tell us the name of your neighborhood or town.

ZIP: ☐☐☐☐☐ or

Name: _____

4b. What is the ZIP code where you spend most of your social or relaxation time? If you don't know the ZIP code of the place, just tell us the name of the place, neighborhood or town.

ZIP: ☐☐☐☐☐ or

Name: _____

5. How far did you go in school? (Please choose only one.)

- Did not complete high school
- High school/GED
- Some college or some vocational school
- College degree or vocational school diploma
- Graduate school

6. What is your employment status? (Please choose only one.)

- Unemployed
- Part-time employment (fewer than 30 hours a week)
- Seasonal employment
- Full-time employment
- Other (specify): _____
- Don't know

B. About Your Sexuality

The following are a few questions about your sexual identity and what you do sexually. Sex means oral, anal or vaginal intercourse. All answers are confidential.

7. How would you describe yourself? (Please choose only one.)

- Gay (homosexual)
- Straight (heterosexual)
- Bisexual (liking sex with men and women)
- Transgendered
- Other (specify): _____
- Don't know

8a. If you have had sex with **men**, about how often have you had sex with men?

- This question doesn't apply to me; I don't have sex with men
- I am abstinent and don't have sex with anyone
- More than once a day
- Once a day
- A couple of times a week
- Once a week
- A couple of times a month
- Once a month
- Less than once a month or just a few times a year

8b. If you answered that you have had sex with men, **on average**, how many different men have you had sex with in a month?

- This question doesn't apply to me; I don't have sex with men
- I am abstinent and don't have sex with anyone
- Less than 1 man a month, but not always the same one
- 1 man a month, **always** the same one
- 1 man a month, but **not** always the same one
- 2 to 5 different men a month
- 6 to 10 different men a month
- 11 different men or more a month

9a. If you have had sex with **women**, about how often have you had sex with women?

- This question doesn't apply to me; I don't have sex with women
- I am abstinent and don't have sex with anyone
- More than once a day
- Once a day
- A couple of times a week
- Once a week
- A couple of times a month
- Once a month
- Less than once a month or just a few times a year

9b. If you answered that you have had sex with women, **on average**, how many different women have you had sex with in a month?

- This question doesn't apply to me; I don't have sex with women
- I am abstinent and don't have sex with anyone
- Less than 1 woman a month, but not always the same one
- 1 woman a month, **always** the same one
- 1 woman a month, but **not** always the same one
- 2 to 5 different women a month
- 6 to 10 different women a month
- 11 different women or more a month

10. Whom have you told that you have sex with *men*? (Check all that apply.)

- This question doesn't apply to me; I don't have sex with men
- I have told no one
- Wife or girlfriend
- Male lover or partner
- Parents
- Children
- Other family members
- Health-care provider
- Friends
- Other (specify): _____
- Don't know or can't remember

C. About Your Health Care

The next two questions are open-ended questions about health care in general. That is to say, there are no check boxes for you to choose from. You may write in whatever answers come to mind. Remember, there are no right or wrong answers. These open-ended questions are then followed by some check-box questions.

11. What problems keep you from going to a doctor/clinic?

12. What would help you to start going to a doctor/clinic on a regular basis?

13. What health insurance(s) do you have? (Check all that apply.)

- None, I have no health insurance
- Medicaid (Medical Assistance)
- Private health insurance
- MADAP (Maryland AIDS Drug Assistance Program)
- Pharmacy Assistance
- Medicare
- VA (veterans' benefits)
- Ryan White (Title I, Title II)
- Other (specify): _____
- Don't know or can't remember

14a. Where do you get health-care information? (Check all that apply.)

- I don't get health care information
- My doctor/nurse
- TV/radio
- Newspaper/billboards/magazines
- Internet
- Relatives
- Friends or support groups
- Caseworker or case manager
- Phone hotlines
- Other (specify): _____

14b. Where do you go to get health care? (Check all that apply.)

- I don't receive health services
- Private doctor
- Emergency room
- STD clinic
- Health department
- Community-based free clinic
- Other clinic/hospital
- Other (specify): _____
- Don't know or can't remember

15a. In general, *on average*, how often do you go to a doctor/clinic? (Choose only one.)

- 1 time or more every week
- 1 time or more every month
- 1 time or more every three months
- 1 time or more every six months
- 1 time a year
- Only when I'm sick or symptomatic
- I don't go to doctors/clinics
- Other (specify): _____
- Don't know or can't remember

15b. If you have not been to a doctor/clinic in the last 6 months, why not? (Check all that apply.)

- This question doesn't apply to me; I have been within last 6 months
- This question doesn't apply to me; I'm not sick
- Don't know how to get free health care
- Too difficult to get into the "system"
- My family needs me (child care, elder care, etc.)
- I don't like doctors or nurses, etc.
- I don't have a way to get there (transportation)
- Other (specify): _____
- Don't know or can't remember

16. Have you ever had any of these infections or illnesses? (Check all that apply.)

- Depression/anxiety
- Hepatitis
- Tuberculosis (TB)
- HIV/AIDS opportunistic infection
- STD or STI (gonorrhea, syphilis, herpes)
- Serious mental illness (bipolar disorder, schizophrenia, etc.)
- Substance abuse
- Problem with alcohol
- Other (specify): _____
- Don't know or can't remember

17. Have you ever been treated for any sort of mental illness?

- Yes No Don't know

18. Are you taking any medications for mental-health reasons?

- Yes No Don't know

D. About Your Housing

19. Have you experienced a period of homelessness? (Please choose only one.)

- Yes, within the past year
- Yes, more than 1 year ago
- No

20. Where do you mostly live right now? (Please choose only one.)

- On the streets
- In a shelter
- Hotel or motel
- Living or staying or crashing with others
- Staying with family
- Drug/alcohol treatment center
- Halfway house
- HIV/AIDS housing facility
- Assisted living
- Medical facility
- Rent a room in a house
- Rent an apartment, house, condo or mobile home
- Own an apartment, house, condo or mobile home
- Other (specify): _____

E. About Drugs and Alcohol

Now we have a few questions about drug and alcohol use. All answers are confidential. No information will be reported to the authorities.

21. Have you used needles to inject street drugs or prescription drugs for non-medical purposes? (Please choose only one.)

- Yes, within the past month
- Yes, within the past year
- Yes, more than 1 year ago
- No, I have never injected street drugs

22. What type of street drugs, alcohol or prescription drugs for non-medical purposes have you used? (Check all that apply.)

- This question doesn't apply to me; I don't use drugs/alcohol
- Poppers
- Speedball
- Cocaine
- Crack
- Club drugs (ecstasy, hallucinogens)
- Meth (methamphetamine, ice, crystal)
- Methadone
- Heroin
- Steroids
- Marijuana (grass, hashish)
- Blunts
- Wine coolers
- Malt liquor
- Other alcohol
- Oxycotin
- Other (specify): _____
- Don't know or can't remember

23a. About how often do you use drugs, including alcohol, *on average*?

- This question doesn't apply to me; I don't use drugs/alcohol
- More than once a day
- Once a day
- A couple of times a week
- Once a week
- A couple of times a month
- Once a month
- A couple of times a year
- Once a year

23b. If you answered that you *do* use drugs or alcohol, how many different *types* of drugs do you use in an *average* month? The word "drug" includes alcohol, but different sorts of drink only count as one (for example, beer and wine count as one type of drug, not two).

- This question doesn't apply to me; I don't use drugs/alcohol
- 1 drug a month, always the same type
- 1 drug a month, but not always the same type
- 2 to 5 different types of drug a month
- 6 to 10 different types of drug a month
- 11 different types of drug a month

F. About HIV and AIDS

Now we have a few questions about HIV and AIDS use. All answers are confidential. No information will be reported to any health insurer.

24a. What is your HIV status? (Please choose only one.)

- I'm HIV negative (do **not** have HIV)
- I'm HIV positive (**do** have HIV)
- I **think** I'm positive but I haven't been tested
- I don't know my status

*If you are **definitely** HIV negative, you may skip to the last question. Even if you only **think** you may be HIV positive, please try to answer the following questions.*

24b. How do you believe you got HIV? (Please choose only one.)

- Sharing needles or works for drugs
- Sex with women
- Sex with men
- Other (specify): _____

24c. How long have you known your status? (Please choose only one.)

- Less than 6 months
- 6 months to 1 year
- 1-2 years
- 3-5 years
- 6-10 years
- 11 years or more
- Other (specify): _____

25. In the last year, were you ever too sick from HIV/AIDS or opportunistic infections (OIs) to go to work or school or do your usual activities?

- Yes
- No
- Not sure

26. Have you ever seen a doctor specifically for HIV?

- Yes
- No

27. How long did it take you to see a doctor after you found out that you were positive?

- I have never been to a doctor about HIV, even though I have HIV
- Immediately
- Less than 6 months
- 6 months to a year
- 1-2 years
- 3-5 years
- 6-10 years
- 11 years or more

28. Where do you get HIV health services? (Check all that apply.)

- I don't receive HIV health services, even though I have HIV
- Private doctor
- Emergency room
- STD clinic
- Health department
- Community-based free clinic
- Other clinic/hospital
- Other (specify): _____
- Don't know or can't remember

29. What makes it hard for you to go see a doctor/nurse for HIV/AIDS care? (Check all that apply.)

- Nothing, it's easy to get HIV/AIDS care
- Using drugs or alcohol
- It's hard to get there, transportation is bad or too expensive
- I don't know about free services
- I forget to go
- I don't have time to go
- I need help with child care or family care
- I feel ashamed, guilty or embarrassed
- I don't want anybody to find out
- I'm worried about stigma
- My doctor/nurse does not show me respect
- My doctor/nurse does not know how to deal with my health needs
- Other (specify): _____
- Don't know or can't remember

30. After you found out that you were positive, what would have helped you to get HIV/AIDS care sooner? (Check all that apply.)

- Knowing whom to call or where to go
- Knowing about HIV support networks
- Knowing about free HIV/AIDS care
- Knowing how important seeing a doctor/nurse is for my good health
- Having help to get over fear or shame or stigma
- Getting help to stop drug or alcohol use
- Getting over denial or coming to terms with my status
- Getting care in a private setting
- Other (specify): _____
- Don't know or can't remember

31. Whom have you told that you are positive? (Check all that apply.)

- I have told no one
- Wife or girlfriend
- Male lover or partner
- Parents
- Children
- Other family members
- Health-care provider
- Friends
- Other (specify): _____
- Don't know or can't remember

32. Where did you find out you were HIV positive?

- HIV test site/van
- Sought medical treatment and happened to learn I was HIV positive
- Gave blood
- Insurance screening
- In prison
- Other (specify): _____

*Please answer the last question **even if you are not HIV positive.***

33. Regardless of your HIV status, do you know where to get HIV health services?

- Yes
- No
- Not sure

This concludes the survey. Thank you very much for your participation.

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