CHAPTER 3: ASSESSING NEED IN THE EMA.

3.1. Introduction.

Twenty years ago, HIV/AIDS treatment funding decisions were based on the best information possible. Today is no different. Now, however, a substantial amount of information is collected regarding consumer need. Planning councils are legislatively required to base their strategic plans, funding priorities and allocations on data. Before these decisions can be made, great care is taken to assess the medical and support service needs of the population served. Chapter 3 of this comprehensive plan presents the evidence-based assessment of need for PLWH/As in the Baltimore EMA.

The previous chapters painted the picture of the demographics and scope of the HIV/AIDS epidemic in the EMA, with comparisons to the state and nation as a whole. Informed by the demographics and epidemiological data presented in chapters 1 and 2, chapter 3 will describe the service needs of PLWH/As in the Baltimore EMA.

Several sources are used to estimate consumers needs: HRSA's unmet need framework, the planning council's triennial consumer survey, updates from the council's PLWH/A Committee, and stakeholder and community forum feedback.

3.2. HRSA Unmet Need.

The term "unmet need" is used by HRSA to define the population of persons known to have HIV/AIDS that are not receiving primary medical care for their HIV.

3.2.1. HRSA-defined Need.

HRSA's definition of unmet need recognizes that all HIV-infected individuals need to be assessed by an HIV/AIDS primary medical care provider promptly following their diagnoses. This ensures that their disease status is monitored so that their providers can initiate antiretroviral (ARV) treatment when necessary. The unmet need estimate can be utilized by planners to assess approximately how many people have been lost between diagnosis and treatment. This enables planners to build capacity or amend referral strategies to ensure that those who test positive for HIV are linked to HIV/AIDS care providers.

3.2.2. Unmet Need Estimate.

The HRSA-acceptable proxies to determine the population in care are the number of persons receiving CD4 tests, receiving viral-load tests, or receiving prescribed ARV medications (BCHD 2010). Using the HRSA unmet-need framework, Maryland's Infectious Disease and Environmental Health Administration estimates that 40.9 percent of PLWH/As in the Baltimore EMA are not currently in care (see table 3.1).

To create the 2010 Baltimore EMA unmet-need estimate, IDEHA used laboratory reporting data, ARV medication use data, the Medicaid database, and HIV/AIDS surveillance data (BCHD 2010). Table 3.1 presents the calculations for unmet need. An estimated 40.9 percent of the known persons living with HIV/AIDS in the Baltimore EMA — approximately 6,965 PLWH/As — were not in primary medical care for their HIV in 2010.

Starting in 2004, all Maryland licensed laboratories were required to report positive HIV test results, all CD4+ T-lymphocyte cell tests, and all HIV viral load tests using the patient's name, date of birth, and other information. Laboratory reports not matching existing name-based HIV or AIDS cases were investigated as potential new cases and, following investigation, were added to the name-based HIV/AIDS registry. The Maryland AIDS Drug Assistance Program and the Maryland Medical Assistance Program (Medicaid) provide ARV medications to low-income PLWH/As (BCHD 2010).

To determine the numerator in the unmet need equation, IDEHA used the subset of all laboratory reports for CD4 or viral load test results in Maryland residents and identified all persons receiving antiretroviral medications through the Maryland AIDS Drug Assistance Program (MADAP) and Medicaid databases between July 1, 2009 and June 30, 2010. Using these sources, IDEHA estimated that there were 17,142 people in care residing in Maryland. This number was used as the numerator in the unmet need equation (BCHD 2010).

To determine the denominator, IDEHA needed to estimate the prevalence of HIV/AIDS. Using an integrated HIV/AIDS surveillance system combining data from provider and laboratory reporting, health department surveillance and death certificate verification, an estimate of persons known to have HIV/AIDS was determined. Using the prevalence number for December 31, 2009 (midpoint of the one-year period), 29,021 people are estimated to be living in Maryland with HIV/AIDS, with 17,015 of those in the Baltimore EMA (BCHD 2010).

The calculation of the estimated number of persons in care used names-based reported data from the entire state and did not include local geographic information. The statewide figure was

Table 3.1.

Baltimore EMA 2010 Unmet Need Framework

Input	Value	Data Source
Population Sizes		
A. Number of persons living in Maryland with HIV/AIDS (PLWH/A) during comparison period.	**29,021**	HIV/AIDS registry, prevalence on December 31, 2008, as reported through December 31, 2009.
B. Number of persons living in the Baltimore EMA with HIV/AIDS during comparison period.	**17,015**	HIV/AIDS registry, prevalence on December 31, 2009, as reported through August 31, 2010.
Care Patterns		
C. Number of persons in Maryland with CD4 or viral load tests, or receiving antiretroviral medications during comparison period.	**17,142**	1) Laboratory reporting database, test results during July 1, 2008 through June 30, 2009, as reported through September 30, 2009. 2) ADAP database, program participants during July 1, 2008 through June 30, 2009. 3) Medicaid database, program participants during July 1, 2008 through June 30, 2009.
Calculated Results		
D. Proportion of PLWH/A in Maryland receiving primary HIV medical care.	**59.1%**	(C/A) x 100
E. Number of PLWH/A in the Baltimore EMA receiving primary HIV medical care.	**10,050**	(D/100) x B
F. Number of PLWH/A in the Baltimore EMA not receiving primary HIV medical care.	**6,965**	B - E
G. Percent of PLWHA in the Baltimore EMA not receiving primary HIV medical care (quantified estimate of unmet need)	**40.9%**	(F/B) x 100

Source: BCHD 2010.

extrapolated from to get the prevalence specific to the Baltimore EMA. The resulting calculation estimates that there were 6,965 PLWH/As not in care in the Baltimore EMA (BCHD 2010).

Several caveats result from the limitations of the geographic data. First, the numerator data did not include geographic location, while the denominator data did. This required a statewide estimate of the proportion of PLWH/As in care that could then be applied to the prevalence of the Baltimore EMA. Second, the denominator of the unmet need — estimated HIV/AIDS prevalence — only included persons who were Maryland residents when diagnosed with HIV/AIDS. Furthermore, PLWH/As residing in Maryland, but receiving care in other states, were not included in these data as PLWH/As receiving HIV care (BCHD 2010).

Other limitations must be considered as well. The HRSA unmet-need framework may underestimate the proportion of PLWH/As not in care because it only considers known HIV-positive cases and does not account for those unaware of their status. Chapter 2 discusses that an estimated 21 percent of PLWH/As in the U.S. are unaware of their status. Medication usage calculations consisted only of persons using MADAP and Medicaid programs, not all persons receiving ARV medications (e.g., some PLWH/As may have private insurance). On the other hand, the potential to overestimate is possible if the denominator includes persons whose death has not been reported, thereby inflating the number of known cases.

The unmet need estimate has dramatically varied over the years, from as low as 16 percent in 2002 (using data from various reporting sources) to as high as 61 percent in 2005 (using counts of ARV prescriptions), to 51.5 percent in 2008 (using HRSA's unmet-need framework). These estimates were created using different proxy measurements for HIV/AIDS primary medical care. Difficulties in comparing and analyzing trends in unmet need over time will continue until one methodology and a consistent data source are used.

3.3. Planning Council-defined Need.

The needs of PLWH/As are addressed through a variety of service categories. Medical needs such as primary care and mental health treatment are complemented by support services, such as medical transportation and psychosocial support. These needs may compete with survival needs such as housing assistance and food security. Understanding which services are in the highest demand is essential for establishing a continuum of care that meets the needs of the majority of consumers.

3.3.1. 2010 Consumer Survey.

The planning council conducts a triennial needs-assessment survey of Ryan White consumers in the Baltimore EMA to discover the service needs of PLWH/As. The latest consumer survey, conducted in 2010, is believed to be the nation's largest face-to-face survey of Ryan White clients. Of the 813 PLWH/As who completed the survey, 791 were from the Baltimore EMA (IGS 2011a). The previous 2007 survey was, we believe, the second largest such survey, with 745 respondents (IGS 2007).

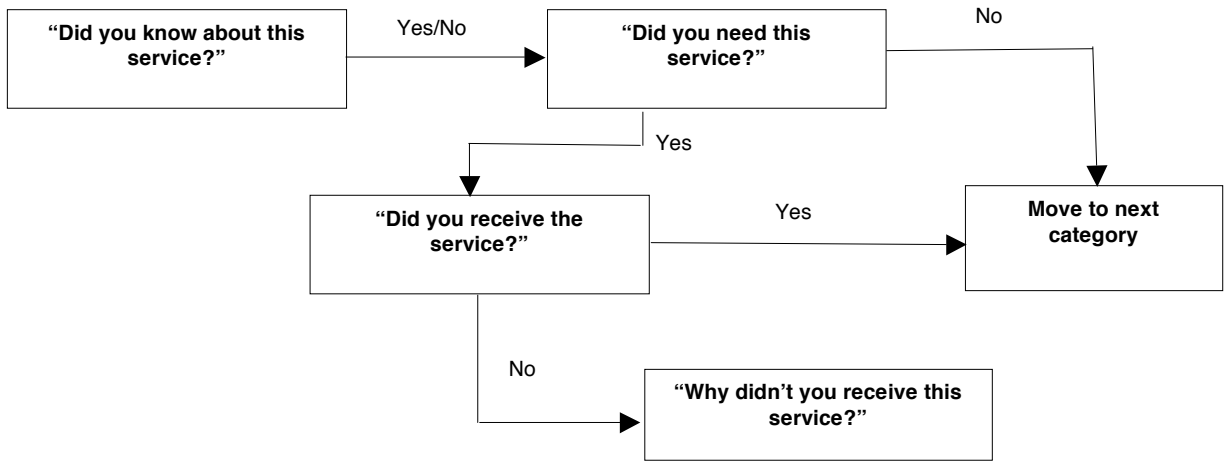
Twenty-one percent of PLWH/As in the U.S. are unaware of their HIV status.

Trained interviewers administered the 2010 consumer survey. Questions about demographics — age, ethnicity, mode of transmission — in addition to perceived need and receipt of core medical and support services were asked of the participants. Interviewers were crucial to ensure a high rate of survey completion, help respondents understand unfamiliar terms, clarify service category definitions, and assist with varying literacy levels. The 2010 survey was translated into Spanish and administered by Spanish-speaking interviewers as needed.

For each service category, two key concepts — service demand and unmet demand — were asked of respondents by asking the question patterns shown in figure 3.1. "Service demand" describes a respondent reporting needing any given Ryan White Part A funded HIV-related services.

Figure 3.1.

Basic Structure of Triennial Consumer Survey Interviews



Source: IGS 2007.

"Unmet demand" describes respondents needing but not receiving the service in question. The survey also identified where PLWH/As obtained each service and, if they left their respective jurisdictions for service, why. If clients cannot access the services they need to enable them to stay in treatment (i.e., experience unmet demands), they will be less likely to remain engaged in care. Failure to meet these needs (i.e., what HRSA refers to as service gaps) is designated in the council's consumer survey as "unmet demand" (IGS 2011a).

3.3.2. Needs Assessment Limitations.

The consumer survey results are utilized to guide planning for an ideal continuum of care and give consumers living in the EMA a voice in shaping that continuum. Survey data inform the comprehensive plan to ensure that the health-care and supportive needs of consumers are being addressed. The survey responses were aggregated by service category. The proportion of respondents indicating a need for each service (demand) and the proportion of those in need who did not receive the service (unmet demand) were calculated.

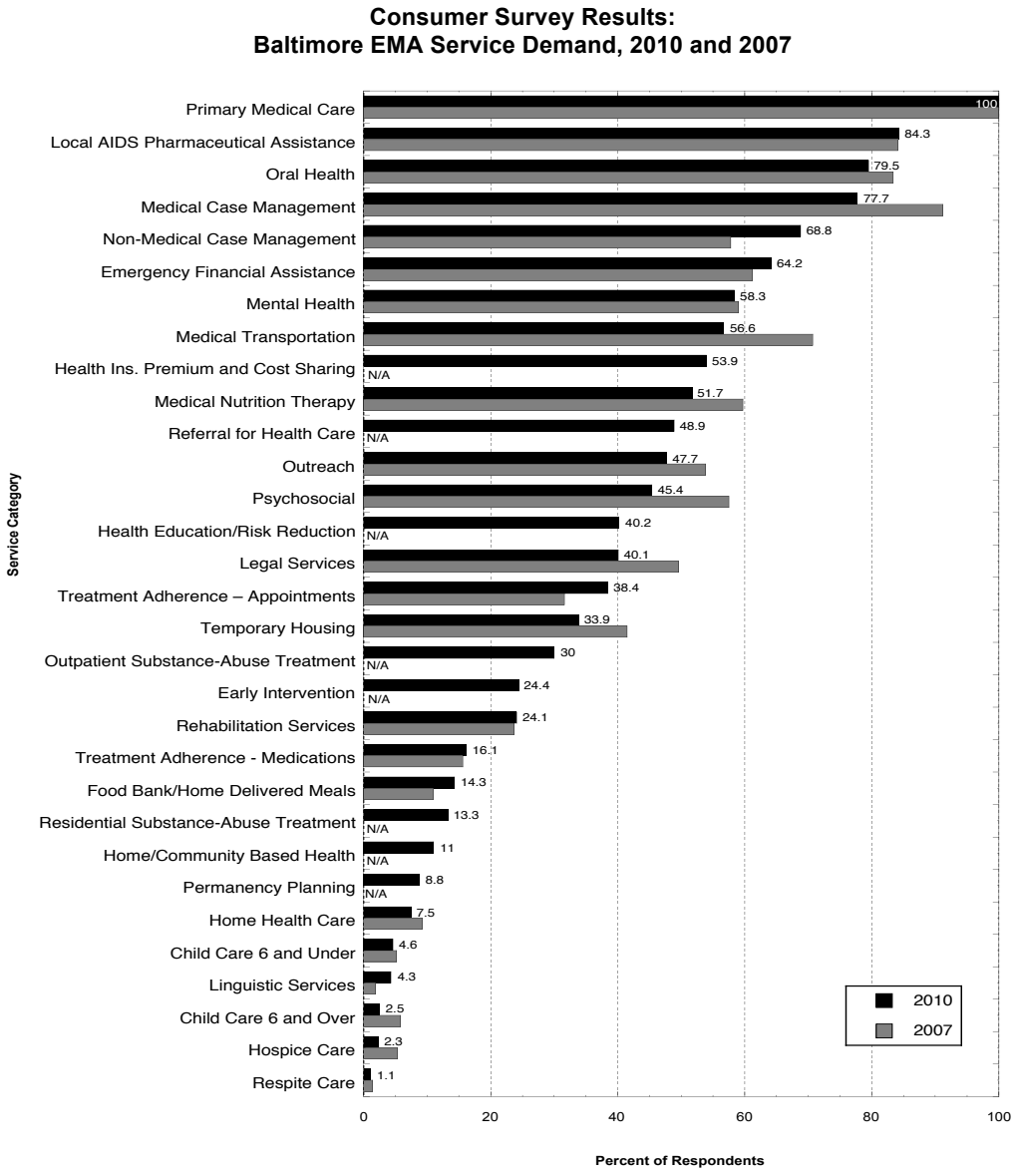
Although, the consumer survey obtained responses from nearly 800 HIV-infected individuals in the Baltimore EMA, there are some limitations to consider when evaluating the results. The survey utilized a convenience sampling method to maximize the number of respondents. Survey respondents were recruited for participation in the survey by service providers, by fliers posted at provider sites, by advertisements in local media outlets, and by word of mouth. As such, they were not chosen randomly. Though the survey participant population was similar to the HIV surveillance population monitored by DHMH, the results cannot be said to be representative of all PLWH/As in the Baltimore EMA. People who choose to take surveys are known to differ from those who do not. For example, by virtue of the convenience sampling method and location of advertisements and interviews, most respondents were already in some kind of HIV care.

In addition, negative response bias often occurs in self-selected samples. Most people like to present themselves in a favorable light, so they may be reluctant to admit to socially undesirable behaviors and activities (e.g., drug use or unconventional sexual behaviors and preferences). As a result, their responses may be biased toward what they believe is socially desirable or what they think the interviewer wants to hear. Furthermore, the consumer data were self-reported service needs. The responses were not verified by case records or

provider input. Consumers' self-assessment of their needs may differ from their providers' assessment.

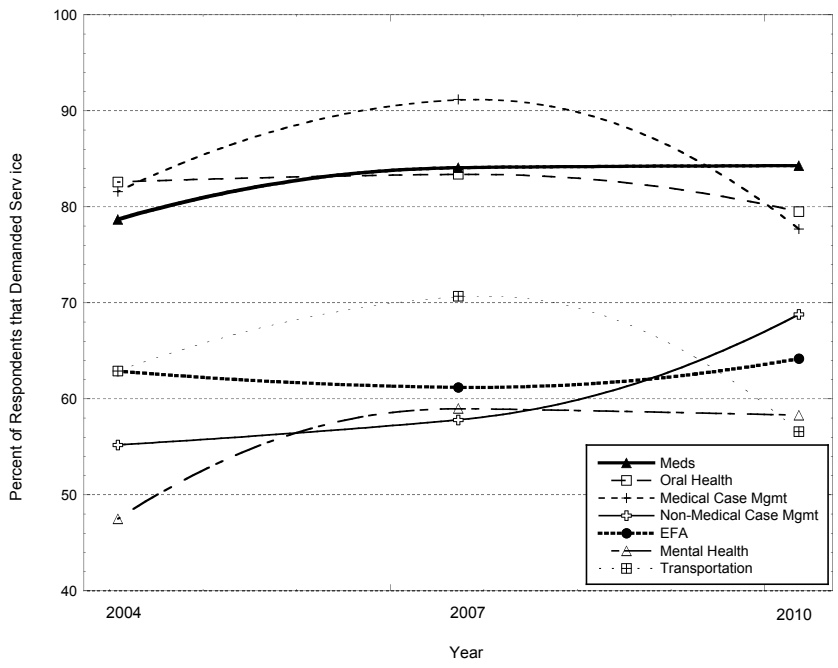
Another caveat is that some consumers may have identified a need for services that they were not eligible to receive or did not require. For example, a consumer is only eligible for Ryan White-funded child-care services while the HIV-positive parent/ guardian attends medical or support service appointments, not while he or she is at work or running errands (IGS 2011a). Even though trained interviewers conducted the surveys, if the respondent did not fully understand the definition of eligible activities associated with a service category, demand and unmet demand might be over- or under-stated.

Figure 3.2.



Source: IGS 2007, IGS 2011a.

Figure 3.3.



Source: IGS 2005, IGS 2007, IGS 2010.

The cross-sectional design of the survey is only able to assess the service demands and unmet needs that the respondents experienced the day of the survey and the prior 12 months. The evolving needs of PLWH/As are likely to change throughout the course of a year. Therefore, a respondent may have declined a service at one point during the 12-month period, but felt he or she needed it at the time of the survey. The opportunity a respondent had to be linked to the service in the past is not captured by the need data collected in the survey. (The survey also served a dual role as an informative tool for respondents. After being introduced to a service category or service definition, a respondent may have felt that that he or she was in need of a previously unknown service. However, he or she likely had not had the opportunity to discuss his or her need or eligibility with a provider and, therefore, had not been able to begin receiving the service.)

Results from the consumer survey were evaluated in terms of the percentage of respondents who indicated they had service demands and unmet demands. Because the survey instrument used in the 2010 survey was similar to the ones used in the 2007 and 2004 surveys, the results can be compared to gain insight as to how these needs may have changed over time.

3.3.3. Service Demand.

Figure 3.2 compares the percentage of respondents reporting a demand in each service category in 2010 and 2007. Several service categories were added between 2007 and 2010; hence, "N/A" represents service categories with no comparison category.

Need was at or above 50 percent in 10 service categories in 2010, one more than in 2007. For planning purposes, all PLWH/As were considered to have a need for primary medical care; therefore, the "demand" for this was automatically 100 percent in 2010 and 2007. The second most demanded category was AIDS pharmaceutical assistance (84.3 percent), followed by oral health (79.5 percent), medical case management (77.7 percent), and non-medical case management (68.8 percent) (IGS 2011a).

The similarities between the 2004, 2007, and 2010 survey instruments allow for comparisons to assist planners in understanding the changing needs of the EMA's PLWH/As. Figure 3.3 compares demand levels for the most demanded services (near or above 60 percent demand) in the 2010 survey to their demands in the 2007 and 2004 surveys.

Some interesting trends are revealed. Medical case management and transportation have convex shapes, indicating greatest service demand in 2007, and lower in 2004 and 2010. Emergency financial assistance (EFA) and oral health have the flattest slopes, indicating a mostly constant demand across all three surveys. Non-medical case management and medication assistance have

increasing, positive slopes with demand rising every year (IGS 2005, IGS 2007, IGS 2011a).

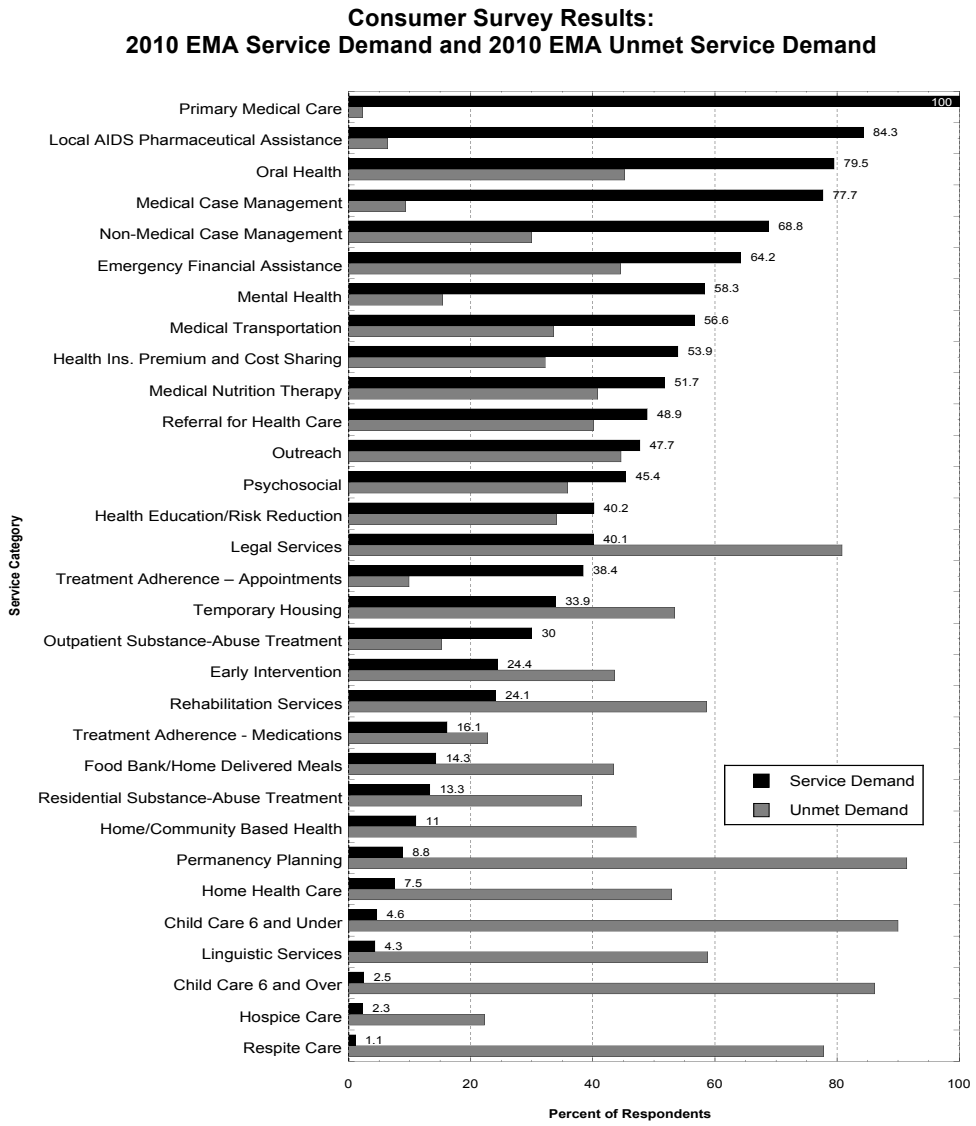
3.3.4. Unmet Service Demand.

Unmet demand was calculated by dividing the number of respondents who said they needed but did not receive a service by the total number of respondents who indicated a need for the service.

There were nine categories that had levels of unmet demand over 50 percent, one fewer than in 2007, and two fewer than in 2004 (IGS 2005, IGS 2007, IGS 2011a). Those with the highest unmet demand in 2010 were permanency planning (91.4 percent), child care for those with children over 6 years of age (90.0 percent), child care for those with children 6 years old and younger (86.1 percent), and legal services (80.8 percent) (IGS 2011a).

While unmet service demand may be high for some service categories, it does not imply that a large number of respondents failed to receive the service. Further, the service categories with the highest unmet demand typically had the smallest demand. This is an indicator of efficient planning.

Figure 3.4.



Source: IGS 2007, IGS 2011.

To highlight this concept, look at respite care. Although the unmet demand appears high at 77.8 percent, the service demand was the lowest at 1.1 percent. Figure 3.4 illustrates the inverse relationship between demand and unmet demand. The two categories with the highest levels of demand were the categories with the least unmet demand: primary medical care had the lowest unmet demand level, at 2.3 percent in 2010 (IGS 2011a). Local AIDS pharmaceutical assistance was the second lowest unmet demand, at 6.4 percent in 2010 (IGS 2011a).

Referrals from providers and support from advocacy groups to alert consumers of the variety of life saving services are critical.

Analysis of the consumer survey suggests that overall, unmet demand declined in many service categories from 2004 to 2010 (IGS 2011a). The majority of respondents indicated that most of their core medical needs were being met, such as primary medical care and medication assistance. The largest unmet needs were centered in support services, such as housing, transportation, and childcare. As a result, consumers were placed on waiting lists for support programs. Increased collaboration between medical and support programs may increase PLWH/As' ability to access the life saving care they need.

3.4. PLWH/A-defined Need.

The planning council's PLWH/A Committee is comprised entirely of volunteers infected with HIV/AIDS who provide the planning council with information about consumer needs on an ongoing basis. These committee members participate in all levels of the planning council's decision-making process to ensure that the needs of PLWH/As are always considered.

As outlined in the planning council's bylaws, the PLWH/A Committee is specifically tasked with prioritizing the service needs of the HIV/AIDS-affected community for the comprehensive plan (IGS 2010b). The committee has identified early intervention services, outpatient/ambulatory health services, AIDS drug assistance, case management, and mental health services as the top five medical service needs (IGS 2008). The PLWH/A Committee reaffirmed these service needs in September 2011 (IGS 2011c). These services are considered indispensible to an ongoing continuum of care and critical interventions to engage, stabilize, and maintain consumers in HIV care.

The committee believes that "without the support services consumers would be prevented from seeking and maintaining the essential medical services that they need to maintain a high quality life with HIV/AIDS" (IGS 2008). The top support service needs listed were housing, food bank/home-delivered meals, medical transportation, psychosocial support, and emergency financial assistance (IGS 2011c).

Housing assistance has been identified as a critical support service because securing stable housing for PLWH/As keeps them in care and encourages positive health outcomes. The PLWH/A Committee has identified possible strategies and solutions to barriers encountered when accessing housing such as: developing a list of landlords that accept housing vouchers, conducting seminars to educate clients on the housing application process, and developing a list of subsidized housing that is accessible to the public (IGS 2010a). Preventing homelessness has been a top concern for the committee. Although HRSA has rescinded the 24-month service cap for transitional housing, it has suggested a 24-month service limitation to planning bodies (HRSA 2011). More barriers that consumers encounter are elaborated on in section 5.5.

Finally, medical and support services provide no benefit if PLWH/As do not know about them or know how to access them. Referrals from providers and support groups to alert consumers to the variety of life-saving services are critical. Professionals are needed to help PLWH/As navigate the changing landscape and scope of services available (Commander 2011). Client navigation and medical case-management services are essential to making sure clients are made aware of all medical and support services available to them and to making the proper arrangements to access those services. If the availability of case management or client-navigation services is reduced, the likelihood that consumers will be able to access those services is also reduced. This is

especially true for those new to care. Clients who cannot access these essential services are more likely to be lost to care or to become non-adherent to care because immediate survival needs take priority over medical care (IGS 2011c).

3.5. Stakeholder-defined Need.

Another assessment of need in the Baltimore EMA is derived from community members with a direct interest in the HIV/AIDS epidemic in the Baltimore EMA. This group of stakeholders consists of providers and consumers of HIV/AIDS services, social service providers, HIV/AIDS researchers, health department officials, and community health planners. This section defines stakeholder-identified needs as those compiled from participants in community forums and the Statewide Coordinated Statement of Need (SCSN), a Ryan White Part B deliverable and planning document for the HIV/AIDS epidemic for the entire state of Maryland.

3.5.1. Community Forum.

Community forums are commonly used to generate interactive discussion, solicit input from stakeholders, extract candid insight, and search for innovative strategies for improvement.

A community forum to launch the development of this strategic comprehensive plan was convened by the planning council in April 2011 for HIV treatment and prevention stakeholders in the Baltimore EMA. Follow-up interviews and workgroups were scheduled with community forum participants to extract more detailed information regarding topics and strategies discussed at the meeting.

The forum was organized into four topics, with a panel of experts anchoring the discussion and eliciting dialogue, questions and feedback from the audience. These topics were systems, engagement, stabilization and maintenance. The systems discussion was designed to increase collaboration among HIV prevention and treatment programs and foster capacity building initiatives across agencies and funding streams.

The next three tropics — engagement, stabilization and maintenance — were based on HRSA's continuum of care and the planning council's care goals established by its Comprehensive Planning Committee (Slaughter 2011). "Engagement" refers to identifying and linking those aware of their HIV status to care. Stabilization occurs when PLWH/As enter HIV care. Maintenance is achieved when an individual receives consistent medical care. These goals are expanded upon in the ideal continuum of care in chapter 6 and the strategic plan in chapter 7. Themes and findings from the forum are discussed in section 3.5.3.

3.5.2. Statewide Coordinated Statement of Need.

This chapter utilizes findings from the 2009 Statewide Coordinated Statement of Need as a secondary source of stakeholder-identified needs. IDEHA (formerly the Maryland AIDS Administration) is the HRSA-funded Part B grantee for the state and is responsible for developing the SCSN. The purpose of the SCSN is to serve as a mechanism to address key HIV/AIDS issues and coordinate action across Ryan White programs and parts. A statewide statement of need that encompasses all of Maryland is developed in the SCSN over a three-year planning cycle. The next report is due to HRSA in June 2012. Findings from this Part B document, therefore, were not available to be considered in this Part A comprehensive plan.

The purpose of the SCSN is to serve as a mechanism to address key HIV/AIDS issues and coordinate action across Ryan White programs and parts.

The 2009 SCSN was developed in a five-step process. First, needs assessment documents were collected and reviewed to identify needs and barriers to care. Second, five regional community dialogues were held in fall 2008 with consumers, community members, and providers. IDEHA organizes the state into five regions — central, eastern, southern, suburban and western, each of

which had its own forum.[8] Third, HIV/AIDS epidemiological data were summarized and compared on a statewide and regional basis. In step four, environmental considerations and emerging trends, special populations, service needs and barriers were analyzed. Needs assessments results, IDEHA's Regional Advisory Committee minutes, priority-setting results and other data were analyzed to crosswalk statewide trends and develop an agenda for future planning. Finally, all of this information was synthesized to guide and create priorities and goals for the three-year Part B SCSN. The planning council and its PLWH/A Committee were active contributors to the development of the 2009 SCSN.

Grassroots-level client navigation and outreach help to form relationships and build trust with newly diagnosed PLWH/As.

3.5.3. Stakeholder Need Themes.

Findings from the planning council's April 2011 stakeholder meeting and the 2009 IDEHA SCSN were evaluated and aggregated into four main areas of consumer need: assistance managing and adapting to legislative changes; improving the linkage between services; consumer empowerment; and a seamless continuum through the lifecycle.

3.5.3.1. Legislative Changes.

When planning for HIV/AIDS services, the HIV care system representatives observed the need to define the new legislative environment in the EMA. National health-care policy has been evolving quickly: health-care reform is underway; the National HIV/AIDS Strategy has been released; the Affordable Care Act has been passed (and is now before the U.S. Supreme Court); the Comprehensive Primary Care Initiative has been launched by the U.S. Centers for Medicare and Medicaid Services (CMS); Medicare and Medicaid eligibility requirements are evolving; and there is the possibility that Ryan White will sunset in 2013. Consumers and providers — both integral parts of the system — need to understand new policy implications and allow for flexibility in adapting to a changing landscape.

The future of Ryan White remains uncertain. Stakeholders at the community forum envisioned that Ryan White will remain an entry point for PLWH/As, provide insurance for undocumented individuals, help re-engage those lost to care, and provide wraparound services to all eligible PLWH/As. Stakeholders identified that modifying intake processes and adapting payer infrastructure will assist in maximizing resources.

Case managers across the state expressed concern during the 2009 SCSN process about the increasing challenge of helping clients manage their interaction with the range of insurance programs with which they participate. Case managers maintain that they are spending increased amounts of time learning about what medical and pharmaceutical insurance companies cover, advocating for clients regarding problems with coverage, and coordinating benefits (DHMH 2009). Additional training is needed for both consumers and providers on how to manage changing requirements and legislation.

Participants in the 2011 community forum discussed capacity-development needs in light of the changing legislative landscape and reduced funding. Suggestions to maximize funding include investigating new federal funding streams and soliciting funding from local foundations, athletes, fraternities and sororities, universities, alumni groups, and entrepreneurs. By incorporating blended funding — multiple, diverse and creative funding streams — the EMA can make the best use of available resources. Forming a united front also may help to eliminate financial competition among organizations that share a common goal. Making collaboration a priority and utilizing coalitions may capitalize on available and potential resources while assisting consumers in accessing the services they need.

[8] The central region includes Baltimore City and the surrounding counties of Anne Arundel, Baltimore, Carroll, Harford and Howard, covering the same area as the Part A EMA, with the exception of Queen Anne's county. The suburban region is composed of the two counties adjacent to Washington, D.C.: Montgomery and Prince George's. The rural eastern region includes the counties of Caroline, Cecil, Dorchester, Kent, Queen Anne's, Somerset, Talbot, Wicomico and Worcester. The western region is composed of Allegany, Frederick, Garrett, and Washington counties, while the southern region includes Calvert, Charles and St. Mary's counties (DHMH 2009).

3.5.3.2. Linkage Between Services.

Stakeholders identified strengthening the linkage between medical and support services, specifically prevention and treatment services, as a need. Finding and identifying those who are positive and connecting them to primary medical care and support services is paramount. Grassroots-level client navigation, case management and outreach help to form relationships and build trust with newly diagnosed PLWH/As. Improved provider/client relationships also are necessary to engage clients in the referral process and to facilitate a smoother transition into care.

Supportive services, such as treatment adherence counseling and psychosocial support, are essential for enabling clients to remain in care. Attendees at the 2011 stakeholder forum identified housing, case management, transportation and outreach as critical support services.

Co-location of services establishes a "one-stop shop" where consumers can tend to various needs in one place at one time. By making it easier for clients to receive care (by locating medical, support, and social services in one place), consumers are more likely to stay in care. Similarly, the SCSN identified improving the accessibility and availability of services as a critical step to improving health outcomes (DHMH 2009).

HIV/AIDS medical providers report, and local surveillance findings show, that clients are entering care with more advanced stages of HIV infection. In Maryland, 29 percent of 2009 HIV diagnoses were diagnosed with AIDS within one year (Flynn 2011). For people receiving an AIDS diagnoses in Maryland during 2009, 61 percent were diagnosed with HIV less than one year earlier (Flynn 2011). Without treatment, AIDS usually develops 8 to 10 years after initial HIV infection (CDC 2011). For Marylanders however, the average time between HIV diagnoses to AIDS diagnoses was 2.8 years (Flynn 2011). These data suggest that Marylanders are entering care late in their disease state. Consumers, therefore, are missing links between prevention, testing, care and treatment. Greater linkages with testing, referrals, and case management may facilitate early identification and intervention.

Being fully engaged in HIV treatment involves commitment to take medications at the prescribed time, maintain regular appointments with HIV/AIDS providers, balance other medications, and manage side effects of ARV medications. Treatment adherence support has been recognized as a need in Maryland in the 2006 SCSN and remains critical (DHMH 2006). Consequently, PLWH/As need a variety of supportive activities that enhance treatment adherence. Stakeholders at the community forum identified medication and appointment reminders, peer mentors, and support groups as treatment adherence activities needed by PLWH/As.

3.5.3.3. Consumer Empowerment.

A common theme that emerged in the SCSN process was the need for client self-sufficiency. This need was pressing as individuals are living longer with HIV and AIDS and health-care funds are increasingly unable to meet their ongoing needs. To complement client self-management goals, providers and case managers can encourage PLWH/As to maintain a healthy lifestyle. Empowerment and positive self-management training (PSMT) may be needed in order for clients to take greater responsibility for their own health and disease management (DHMH 2009).

Arming PLWH/As with the tools to manage their HIV may empower them to maintain a healthy lifestyle, thus helping to prevent the transmission of HIV and reduce future health care costs.

Assistance in managing co-morbidities is important to help PLWH/As establish self-management skills. As indicated by the HIV/AIDS prevalence among IDUs described in chapter 2, substance abuse continues to plague a large proportion of PLWH/As in the Baltimore EMA. "The increasing numbers of clients with substance abuse problems requires that case managers and other providers be educated about substance abuse, co-morbidity, cultural differences, and other issues that may impact treatment outcomes" (DHMH 2009). Addressing mental-health issues is also a need. An estimated 26.3 percent of the general population in Maryland

has a diagnosis of either anxiety disorder or depressive disorder, with the highest prevalence in Baltimore City (DHMH 2009).

Stakeholders participating in the 2009 SCSN believed an integrated approach to providing substance abuse and addiction services for PLWH/As is key. SCSN participants felt that all persons with HIV could benefit from some form of mental-health services. Arming PLWH/As with the tools to manage not only their HIV, but also co-morbidities and life stressors, may empower them to maintain a healthy lifestyle, thus helping to prevent the transmission of HIV and reduce future health-care costs.

Attendees at the stakeholder's forum listed technology and social media as emerging opportunities to help consumers manage their own health. Social media platforms such as Facebook, Twitter and other messaging programs can help providers connect with their clients in familiar ways they already use. Applications for smart phones are available (and more are being developed) that remind clients to take medications and order prescription refills.

In 2011, planning council support office contractor IGS produced for BCHD the third edition of the popular "passport" booklet for PLWH/As. The *Passport to Managed Care* contains information regarding how to navigate managed-care health systems, services and entitlement programs available for individuals living with HIV/AIDS, and incorporates a directory of more than 200 Ryan White and other HIV service providers (IGS 2011b). A separate, easy-to-read personal health-care log to help empower consumers to manage their care is included. The health-care log included in the *Passport* gives consumers the opportunity to take charge of their health care through care-specific organizational tools, such as a calendars to log appointments and important dates. The care log also includes sections to document critical health-management data, next steps from case managers and client-navigation assistants, and health coverage information (IGS 2011b). This tool, available to all PLWH/As in the Baltimore EMA, will help clients to manage their disease. A list of Ryan White-funded service providers can also be found in appendix A of this document.

Stigma and discrimination create another barrier to treatment and deter clients from integrating HIV primary care into their daily lives (DHMH 2009). By taking action to reduce stigma and prevent discrimination, PLWH/As may be more comfortable disclosing their status to family and friends, obtaining services, adhering to treatment, and taking charge of their health. Stakeholders indicated that removing labels and stereotypes may help empower consumers. Lifelinc is a local advocacy organization with a goal of eliminating stigma, increasing access, empowering consumers, and educating the community.

3.5.3.4. Seamless Continuum.

As indicated in chapter 2, PLWH/As are living longer than ever before, and so an increasing number are experiencing health problems common to the general population, such as hypertension, diabetes and obesity. HIV accelerates the aging process as a result of long-term drug treatments used to control prevent disease progression. Potent ARV treatments create constant inflammation of the internal body system. Consumers need access to specialty care providers with the ability to manage these emerging medical conditions along with HIV/AIDS treatment.

In addition to caring for aging and older adults with HIV, the EMA now is seeing youth infected perinatally in the 1990s transitioning into adult care. Experts did not expect these patients to survive into adulthood. Programmatic transitions, specialized care and peer mentoring needs to be put in place to help address the unique challenges associated with these consumers.

To meet the needs of this demographic, qualitative information was collected from the Ryan White Part D Youth Initiative Community Advisory Board (CAB) to determine needs for youth program planning, development, and funding (DHMH 2009). Surveys and focus groups were conducted to identify primary barriers encountered by youth when accessing and receiving services and potential solutions. A lack of life skills was identified as a major barrier. Educational programs that provide life skills coaching and effective programs that assist youth transitioning into adult care were identified as potential solutions. These results will assist providers and case managers to

customize services to transition youth into adult care.

3.6. Conclusion.

This chapter of the strategic plan has used a variety of sources, methodologies and perspectives to develop a comprehensive picture of need of PLHW/As in the Baltimore EMA. Planners of HIV/AIDS services should be utilizing the assessments of service demands and the variety of outlooks on need to ensure that clients receiving an HIV-positive diagnosis are seamlessly linked to treatment and provided the supportive services they require to remain in care.

The planning council conducts a consumer needs assessment every three years to determine the needs of PLWH/As in the EMA. Respondents from the 2010 survey identified primary care, medications assistance, oral health and case management as the most needed service categories. Needs assessments identify locally demanded services to guide the building of a care continuum comprised of services aimed at fulfilling the identified needs.

The PLWH/A Committee of the planning council has shared its unique perspective to help shape the definition of need. The members' first-hand expertise gives credibility when defining the services most needed in their communities. Educational programs emphasizing life-skills coaching benefits all PLWH/As, considering the uncertain economic, social and political environment of today.

The views of various stakeholders have been obtained to round out the evaluation of need. Community members, providers and consumers were utilized during a community forum and in the development of the Statewide Coordinated Statement of Need. Key themes gathered from these stakeholders include: assistance adapting to and managing legislative changes; a better linkage between services; consumer empowerment; and sustainability of a seamless continuum through the lifecycle.

Data from the consumer survey and input from stakeholders and community forums must be put in their proper perspective. For example, members of the PLWH/A Committee, participants in the consumer survey, community forums and needs-assessment survey chose to participate and were not randomly selected. Therefore, regardless of whether or not there was an overall agreement throughout assessments, the findings were not necessarily representative of the sentiments of all providers, consumers or PLWH/As in the Baltimore EMA. Instead, these informal assessments coupled with the unmet need framework developed by HRSA, can be used as a basis for designing research questions, launching pilot studies, or — for the purposes of this document — identifying need and augmenting strategic planning efforts.

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