

CHAPTER 5: BARRIERS IN THE CONTINUUM.

5.1. Introduction.

There can be no truly effective universe of HIV treatment until barriers to care are eliminated or, at least, greatly minimized. Although there have been major advances in HIV service delivery in the past 30 years, there is still a great deal to be done. Chapter 2 provides evidence that HIV prevalence is rising, with some populations and communities disproportionately affected. The HRSA unmet need estimate in chapter 3 suggests that 40.9 percent of PLWH/As are not in HIV primary care in the EMA.

To establish an ideal continuum of care and tackle the HIV/AIDS epidemic in Baltimore, the barriers that prevent individuals from being tested, entering treatment and being stabilized in care must be identified. This chapter focuses on four main types of barriers: policy/regulatory barriers, program-related barriers, provider-related barriers, and client-related barriers. Certain challenges, such as stigma and funding decreases and interruptions, affect the entire continuum of care.

Recognizing barriers to service delivery is a critical component in achieving the ideal continuum of care in the EMA. Subsequent chapters discuss the strategic plan developed to manage these barriers in 2012-2015. Chapter 6 discusses the ideal continuum of care and chapter 7 provides the detailed plan for addressing the barriers identified in this chapter.

5.2. Regulatory Barriers.

Over the past several years, legislative changes have altered how providers and agencies deliver services in the Baltimore EMA. The implementation of the Affordable Care Act suggests that more policy and regulatory changes

are on the horizon that will affect medical and support services. Some of these changes will present barriers to care, while others will lead to a stronger, more comprehensive continuum of care. Several policies that target topics like routine testing, health care reform, legislative funding mandates, and decreased funding pose barriers in the EMA.

5.2.1 Routine Testing.

In September 2006, the CDC recommended that routine HIV screening be implemented in health-care settings for all adults ages 13-64. Furthermore, repeated testing — at least annually — for those identified to be high risk also was recommended. CDC recommended that testing be voluntary and opt-out, meaning the patient is notified the test is being performed and consent is implied unless that patient declines (Kaiser 2011a).

Guided by CDC recommendations, legislation in Maryland regarding routine, opt-out testing for pregnant women has been in place since July 1, 2008. This amended Maryland HIV testing law (COMAR 10.18.08) allows federally funded health centers to offer HIV tests without the requirement of a separate consent form. Known as “HIV Testing-Informed Consent and Treatment,”

the legislation urges health care providers to offer HIV testing as part of their routine medical care, helping to streamline the testing process and increase the number of individuals diagnosed with HIV (UMB 2008). Despite the testing guidance,

A strategic plan needs to be developed to ensure that the existing system can absorb the new clients identified through opt-out testing.

there are still a proportion of high-risk individuals that are not interested in getting a voluntary HIV test.

Routine HIV testing for all individuals has the potential to enhance HIV/AIDS care throughout the EMA. However, it is necessary that general health practitioners have training in HIV care. Further, they must be adequately prepared to make the necessary referrals if they cannot provide HIV specialty care themselves. Additionally, outreach workers and case managers need to have the capacity to serve additional clients. An increase in routine testing supposes an increase in the number of providers, who must be trained to provide counseling, testing and referral services. In turn, the network of primary care providers qualified to

treat the needs of PLWH/As must be expanded. A strategic plan needs to be developed to ensure the existing system can absorb the new clients identified through opt-out testing.

Length of time between testing and results, and assumptions about risk add difficulty to routine testing policy.

Although more people are being targeted through routine testing, individuals may need to wait up to two weeks to receive their results, creating challenges linking clients to care. The use of rapid HIV testing, which can give accurate results in as little as 10 minutes, has increased the ability to test more people in a greater variety of situations. Even with this testing technology in place, barriers to HIV diagnosis and linkage to care remain. If a client receives a positive rapid test result, it must be followed up with a confirmatory test that can take up to two weeks before a true diagnosis of HIV can be given (Branson 2005). If individuals cannot be contacted again to receive proper counseling and referrals, then routine and rapid testing does not help PLWH/As know their status and get into care.¹³

¹³ The CDC is working on regulatory changes to address this problem. It is anticipated that an initial positive HIV test will be sufficient to link individuals to care.

In addition to the length of time between testing and obtaining results, assumptions made about risk also present a barrier. All providers, from pediatricians to geriatricians should ask their patients about HIV risk behaviors and provide HIV testing (Edelson 2011). Sexually active older adults, in particular, are at risk for HIV transmission if they are engaging in unprotected sex. Assumptions that certain populations are not at a high risk for HIV should not eliminate people from having access to routine testing.

5.2.2. Mandated Inflexibility.

Several conditions have been attached to Ryan White legislation to ensure expenditures are consistent with legislative intent and Ryan White funds are the payer of last resort.

One legislative requirement is that at least 75 percent of direct service funds must go towards core medical services. The remaining 25 percent can be allotted to support services. Other funding streams are available to help cover medical care, medication and other medical services. Deemed critical by stakeholders, wraparound support services — such as medical transportation, housing and emergency financial assistance — usually do not have as much alternative funding as medical services. As evidenced in the planning council's FY 2012 priority setting and resource allocation documents, many support services have few, if any, funding streams other than Ryan White funds (IGS 2011c).

The 75/25 requirement is a legislative barrier because it may limit the ability of the grantee to provide support services if/when the 25 percent cap has been reached. This requirement creates detrimental inflexibility to planners and providers if they cannot be responsive to the immediate needs of the EMA. To address the diverse and complex range of medical and support needs found in the EMA, diverse funding streams and funding flexibility are beneficial.

5.2.3. Decreased Funding.

Decreasing funding continues to challenge community planners and providers looking to

maintain services in the Baltimore EMA. State and federal funds for HIV services have been declining relative to need and this threatens the ideal continuum of care.

The state Infectious Disease and Environmental Health Administration saw a 2.4 percent decrease in federal funding and a 1.8 percent decrease in funding from the state's general fund in FY 2012 from FY 2010 (DLS 2011). The Baltimore EMA Part A grant (including MAI) declined 11.38 percent between FY 2003 (\$21,458,791) and FY 2011 (\$19,017,028) (BCHD 2003, Brisueno 2011).

Chapters 2 and 3 indicate that, despite the decreases in funds, the need for services in the EMA is not decreasing. The reality of more people requiring services combined with less funding places an increasing strain upon the Baltimore EMA's continuum of care. Decreased funding for HIV prevention and treatment continues to be a barrier to community planners, providers and consumers.

5.2.4. Financial Accountability.

Inter-program communication regarding financial accountability is also a barrier. One example of this is difficulty with pharmaceutical programs at pharmacies. Many medically adherent PLWH/As have difficulty obtaining their medication due to billing challenges each month in Maryland. Although Medicaid sets the price structure for pharmaceutical billing, some primary insurance companies decline payment and medication provision. They may believe MADAP is not paying enough even though all Ryan White programs are mandated to be the payer of last resort. This means that there are PLWH/As who are doing everything within their power to be medically compliant but who may miss days of medication due to financial-interface problems (Arlette 2012).

5.2.5. Other Policy/Regulatory Barriers.

Policies and regulations that require extensive documentation provide additional challenges to some consumers seeking Ryan White services. For

example, homeless individuals often lack the required paperwork to enroll in health insurance or Medicaid. Undocumented immigrants, and adult legal immigrants who are not pregnant and who have been in the U.S. for less than five years, are not eligible for Medicaid coverage (Kaiser 2010). Issues like these present significant barriers to accessing medical and support services for certain groups.

In 2008, HRSA issued a policy notice that would have placed a 24-month cumulative cap on short-term and emergency housing assistance to go into effect March 27, 2011 (HRSA 2011a). In May 2011, HRSA rescinded the 24-month cap for transitional housing, instead suggesting a 24-month service limitation to planning bodies (HRSA 2011a). If service providers or planning bodies instate a time cap on services, it would limit the time consumers could access transitional housing and increase the likelihood consumers would become ineligible for temporary housing while other housing options were processed.

5.3. Program Barriers.

Medicaid and Medicare are important government programs, providing medical and health services to millions of people. However, program barriers and funding decreases create barriers that challenge the ideal continuum of care throughout the EMA.

5.3.1. Medicaid.

Medicaid has played an important role in helping 59 million low-income Americans obtain health care by providing physician visits, long-term care coverage and prescription drugs to those who otherwise would not have access to care (Kaiser 2009a). In order to receive Medicaid coverage, an individual must meet an income eligibility requirement, though the income requirement varies depending on certain individual circumstances like age, pregnancy status, disabled status and parental status. HIV disproportionately affects low-income Americans. As a result, Medicaid pays for about 47 percent of all

Table 5.1.

HIV/AIDS Medicaid Enrollment as of April 2011

	HIV HealthChoice (Families & Children)	HIV HealthChoice (Disabled)	AIDS HealthChoice	HIV/AIDS PAC	HIV/AIDS FFS	Total, All Programs
Maryland	789	1,001	2,328	1,220	3,747	9,085
Baltimore EMA	516	860	1,924	906	2,807	7,031
Anne Arundel	31	24	54	54	155	318
Baltimore City	385	738	1,666	719	2,171	5,679
Baltimore County	77	75	171	109	359	791
Carroll County	4	6	7	6	16	39
Harford County	9	11	8	8	54	90
Howard County	10	6	18	10	52	96

Source: Middleton 2011b.

Note: Due to the small number of enrollees in Queen Anne’s County, the numbers are not included for each coverage group. A total of 18 PLWH/As are enrolled in all programs in Queen Anne’s County and these 18 are included in the statewide and EMA totals.

PLWH/As receiving care in the U.S. (Kaiser 2011b).

5.3.1.1. Medicaid Enrollment.

In Maryland, Medicaid and the Maryland Children’s Health Program (MCHP) provided benefits to more than 952,000 people in April 2011 — almost one in six Marylanders (Middleton 2011b). Table 5.1 shows the PLWH/As enrolled in Medicaid as of that time. There were 9,085 PLWH/As from Maryland enrolled in Medicaid. Of the 17,265 PLWH/As in the Baltimore EMA, an estimated 7,031 (40.7 percent) were enrolled in Medicaid. Of these, 5,679 (80.8 percent) live in Baltimore City (Middleton 2011b).

Most Medicaid beneficiaries are enrolled in HealthChoice, Maryland’s managed-care program. Enrollees select one of seven managed-care organizations that contract with DHMH to provide Medicaid-covered services through their provider networks (Middleton 2011b). If an eligible individual does not qualify for HealthChoice, he or she may still receive Medicaid services through a fee-for-service (FFS) arrangement. Individuals ineligible for full-benefit Medicaid coverage may

be eligible for a limited benefit package in the Primary Adult Care (PAC) program. Appendix B illustrates the health insurance coverage, depending upon age and income level, provided by various medical programs administered by DHMH.

Among covered Medicaid services, those that are most relevant to PLWH/As are inpatient and outpatient hospital services, physician and laboratory services, long-term care, case management, and transportation to medical care (Middleton 2011b). Some services, such as medical case management services and oral health are not available for consumers enrolled in PAC (Middleton 2011c). In Maryland, Medicaid helps pay for low-cost and free prescription drugs for all enrollees, including those in PAC.

Oral health is a very important service that is not currently covered for all Medicaid beneficiaries. Further, Baltimore City has been designated a health provider shortage area in regards to the number of dental providers available to low-income persons (Bank 2012). The confluence of these two issues supports the need for Ryan White

funding to cultivate and support dental services for PLWH/As. Ideally, oral health care should be a Medicaid-covered service. As health-care reform moves forward, planners should follow oral health care to ensure proper coverage for PLWH/As.

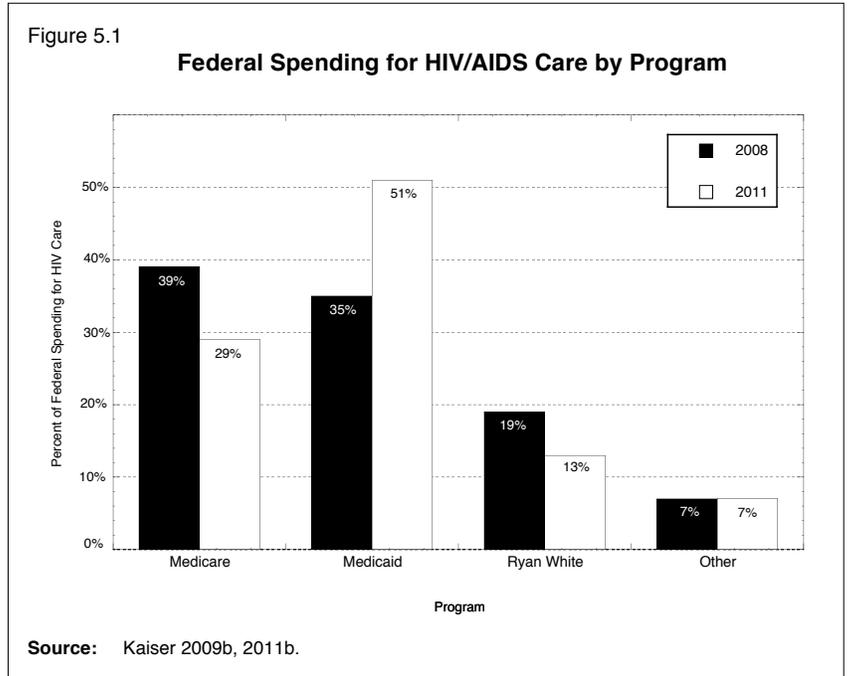
5.3.1.2. Medicaid Costs.

HIV care is expensive — frequent physician visits, prescription drugs, and ARV treatment are costly, as are the other medical and support needs of PLWH/As. Figure 5.1 shows federal spending for HIV/AIDS care. Medicaid spending is the largest source of federal HIV/AIDS spending, accounting for 51 percent in 2011, up from 35 percent in 2008. Federal and state Medicaid spending on HIV care was \$9.3 billion in FY 2011 (Kaiser 2011b). Monthly pharmacy costs for HIV/AIDS medications are approximately \$6 million in the Baltimore EMA (Middleton 2011a). Average health-care costs for Medicaid beneficiaries with HIV are almost five times more expensive than non-HIV equivalents. Nationally, mean per capita costs are \$24,867 and \$5,091, respectively per year (Kaiser 2011b). The biggest driver of per-user spending is prescription drugs, which overall are 11 times higher for Medicaid enrollees with HIV compared to their counterparts without the disease (Kaiser 2011b).

It is also important to note the co-morbidities that affect PLWH/As on Medicaid: 50 percent of enrollees with HIV suffer from mental illness and/or substance use, more than twice the proportion of enrollees without HIV (22 percent) (Kaiser 2011).

5.3.1.3. Medicaid Eligibility.

A major barrier to accessing Medicaid benefits is current eligibility restrictions. Until 2014, individuals must meet certain financial criteria that vary depending on age, disabled status, pregnancy and parental status (see section 5.3.1) in order to

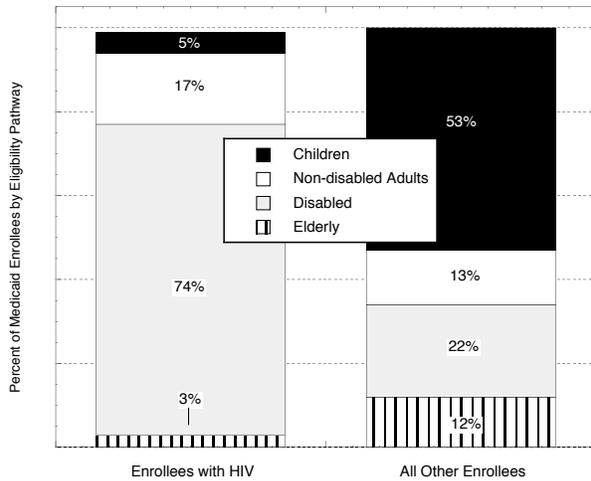


be eligible for Medicaid. As the HIV epidemic data in chapter 2 show, PLWH/As are likely to be male and typically do not have dependent children. Many of these individuals would only be eligible for PAC, unless they were eligible for Medicaid-proper by having a disability determination or meeting some other coverage category definition. To qualify, therefore, they must be considered disabled. On the other hand, if managed properly, HIV does not have to be a disabling condition.

Many PLWH/As, however, cannot access the health care needed to manage their HIV and prevent disability. Some individuals may not qualify for full benefit Medicaid until they meet federal requirements for a disability determination. However, in 2014, all individuals at or below 133 percent of the federal poverty limit will be eligible for Medicaid. Figure 5.2 compares Medicaid enrollees nationally — those with HIV and those without — by eligibility pathway. Of enrollees with HIV, 74 percent receive Medicaid under disability, compared to 22 percent of non-HIV enrollees (Kaiser 2011b).

Figure 5.2

Medicaid Enrollees by Eligibility Pathway and HIV Status, FY 2007



Source: Kaiser 2011b.

enrolled in Part D; approximately one-fifth of people with HIV receive their health coverage through Medicare in the U.S. (Kaiser 2009b).

5.3.2.1. Part D Coverage Gap.

Medicare Part D, an opt-in benefit, offers subsidized prescription drug coverage that includes six protected drug classes, one of which is approved ARVs. Non-ARV drugs, however, are not guaranteed to be covered.

Although Part D benefits are available, a coverage gap — or “donut hole” — still exists. There is a temporary limit on what Medicare will cover for prescription drugs that starts when an individual spends \$2,930 on covered drugs. Coverage does not resume until the individual’s “true out-of-pocket costs” (TrOOP) reach a “catastrophic level.” In 2012, the catastrophic level is \$4,700 in TrOOP per year (Q1 Group 2011).

Current economic conditions in the recession, specifically the increase in individuals living in poverty and rising unemployment, coupled with the loss of employer-sponsored health coverage, pose an increase the number of Medicaid recipients (Kaiser 2009a). State budgets are already stretched thin and health-care reform aims to place more people on Medicaid. Insurance coverage does not guarantee that PLWH/As are able to successfully access the care they need. Additional barriers that face consumers that rely on Medicaid are addressed in section 5.5.

5.3.2. Medicare Part D.

Medicare is a federal health insurance program that covers seniors and younger adults with permanent disabilities. As seen in figure 5.1, it is currently the second largest source of federal spending on HIV/AIDS care in the U.S., with \$5.4 billion spent in FY 2011 (Kaiser 2011b). The implementation of Medicare Part D, which provides medications to Medicare recipients, has shifted most prescription drug costs from Medicaid to Medicare for dual-eligible beneficiaries. An estimated 100,000 PLWH/As are

AIDS Drug Assistance Program (ADAP) and other Ryan White funds bridge the coverage gap, helping to reduce costs. The Affordable Care Act changed which out-of-pocket expenses count towards the Medicare Part D annual TrOOP (Hopson 2010). Beginning January 1, 2011, ADAP clients who are Medicare Part D enrollees will now be able to move through the coverage gap phase into the catastrophic level where Medicare coverage resumes and picks up the costs (Hopson 2010). Prior to January 1, 2011, ADAP payments did not count toward an individual’s TrOOP and it was difficult, if not impossible, for ADAP members to reach the catastrophic phase (Kaiser 2009b). For more information about ACA implementation, refer to chapter 6.

Low-income beneficiaries can receive subsidies. Despite subsidies and cost-sharing programs, many consumers in Maryland still experience a coverage gap. This requires them to pay for costly co-payments, co-insurance costs, deductibles, and monthly premiums that they are often unable to afford.

5.3.2.2. Part D Late-enrollment Penalty.

The Part D late-enrollment penalty is another program barrier for PLWH/As. This fee may be added to a recipient's Part D premium if, at any time after the initial enrollment period there are 63 or more days in a row when the individual does not have Part D or other creditable prescription drug coverage (Medicare 2011). If PLWH/As do not enroll in one of the Part D formularies right away, they will end up paying more.

The late-enrollment penalty is calculated by multiplying 1 percent of the "national base beneficiary premium" (\$32.34 in 2011) by the number of full, uncovered months the recipient was eligible but not enrolled in a Medicare drug plan and went without other creditable prescription drug coverage (Medicare 2011). The final amount is added to the monthly premium and is an additional expense that may be difficult for many PLWH/A to afford. Patient navigators and case managers are important resources to prompt Medicare recipients to enroll in Part D immediately to avoid this penalty.

5.4. Provider Barriers.

Providers face a variety of barriers when providing PLWH/As with a high quality of care across the ideal continuum. These range from administrative burdens, funding decreases and delays, and client challenges such as appointment adherence.

5.4.1. Administrative Burdens.

Extensive and burdensome paperwork poses barriers to providers when caring for PLWH/As. A study published in 2010, "Uncompensated Medical Provider Costs Associated with Prior Authorization for Prescription Medications in an HIV Clinic" in the *Clinical Infectious Disease* journal analyzed paperwork and administrative costs to providers. The investigators found that, on average, more than 30 minutes' time was spent on each prior authorization (PA), 26.8 minutes by a nurse practitioner and 6.5 minutes by a clerk. The average PA was 5.8 pages and the average cost was \$41.60 (Raper *et al.* 2010). Implications from these costs suggest that nurse practitioners and

other health-care providers are diverting time to paperwork instead of direct patient care. This negatively impacts operating margins for providers and their agencies (Raper *et al.* 2010).

According to the FY 2011 assessment of the administrative mechanism done for the planning council, providers indicated that, not only is there a large administrative burden, but it is disproportionate to the amount of Ryan White funding (IGS 2011a). The administrative requirements (i.e., the amount of paperwork and the time spent attending administrative meetings) are very burdensome relative to the funding received.

5.4.2. Funding.

Funding decreases and interruptions have impacted providers' ability to sustain services. The FY 2011 assessment of the administrative mechanism shows that 35 percent of agencies had begun to scale back internally in 2011 as a result have delayed funding (IGS 2011a). "Especially disturbing was the inability of some providers to have laboratory testing available for their patients" (IGS 2011a). Providers devised several alternatives to maintain service to clients, especially those with the greatest need. Some services were suspended or decreased, provider and staff salaries were decreased, new clients were not enrolled in services, and/or waitlists were established (IGS 2011a).

The administrative requirements — the amount of paper work and the time spent attending administrative meetings — are inconsistent with the funding received.

Some providers and agencies may not be able to restore services to prior levels as a result of funding decreases and delays. Even when partial funds are available to providers from the grantee, some large organizations lay off staff if a final grant award and corresponding ratified contract are not in place to cover their 12-month salaries.

These are contractual decisions made outside the control of the actual HIV programs at large institutions. For service categories that receive Ryan White funds that are salary driven, agencies may have challenges hiring and training new staff upon the resumption of funding following the permanent departure of laid-off staff.

Financial cuts result in unmet need. The most impacted services are primary medical care, oral health, mental health, food and housing services (IGS 2011a). Most of the services affected include those defined by the planning council's PLWH/A Committee as essential to the continued care of clients (refer to section 3.4).

5.4.3 Third-party Billing.

As the ACA and medical exchanges move forward, it is anticipated that third-party billing will become a necessity for providers to access payment. Third-party billing means that neither the provider nor consumer of services directly pays for the services provided. All PMC programs will have to bill Medicaid. Programs will get their providers empaneled with insurance companies in the state exchange after 2014. Additionally, Medicaid services and the number of beneficiaries will probably increase, making fee-for-service billing more common, if not essential. This fee-for-service structure is outside the typical grant funding for services. Since most community health centers providing HIV services currently rely on grants and similar funding streams, they may not be prepared to restructure their billing.

Moreover, a clear provider of technical assistance to assist community health centers in billing changes has yet to be determined. An additional challenge in providing technical assistance is the varying financial/billing structures between community health centers. This means that a general transition plan for all may not be feasible.

5.4.4. Provider/Patient Relationships.

Providers face several barriers in the ideal continuum of care as a result of the unique relationship between patient and provider.

5.4.4.1. Cultural Barriers.

Cultural differences, be they of race/ethnicity, gender, language or socio-economic status, may create barriers between PLWH/As and their health-care teams. Physicians tend to speak in a more technical and formal tone than their clients and not all physicians are capable of communicating in patient-appropriate language (Sowah 2011). Patient-appropriate language needs to be culturally sensitive and adjusted to the health literacy level of the patient. Minority patients usually want a higher level of familiarity with their providers (Sowah 2011). Providers are positioned with great leverage to help their patients meet their health care goals.

Stigma related to HIV and AIDS may prevent some clients from seeing an HIV specific doctor, such as an infectious- disease specialist (Sowah 2011). Perceived discrimination, either based on sexual orientation or race, also creates barriers between providers and their patients. Stigma and discrimination are elaborated on in section 5.5.3.

5.4.4.2. Appointment Adherence.

The frequency and complexity of HIV medical care introduce many barriers to care. In early stages of therapy, clients need to engage in regular communication with their physician. If clients do not have a permanent phone number or address, it is hard for providers to contact their patients for follow up or give appointment and/or medication reminders.

Transportation and various other needs can prevent PLWH/As from attending all of their appointments. Providers have busy schedules and large caseloads. Building a limited number of walk-in appointments into a physician's schedule is helpful to accommodate patients who have trouble keeping their regularly scheduled appointments (Bellesky 2011).

5.4.5. Late Entry into Care.

Surveillance data indicate that the number of PLWH/As enrolling into treatment at later stages of HIV/AIDS disease progression is increasing. An increasing number of patients are entering

treatment with a CD4 count of 200 or less. For 2009, in Maryland, 61 percent of patients were diagnosed with AIDS less than one year after their initial HIV diagnoses (Flynn 2011).

Late entry into care is a key consideration in the planning of services. Early identification and treatment of HIV infection may keep the individual's immune system from becoming severely compromised. This may delay or reduce the occurrence of opportunistic infections and slow the progression from HIV to AIDS as well as reduce HIV transmission (CDC 2009).

Additionally, insufficient outreach and linkage services create additional barriers to connecting PLWH/As to providers. This further extends the length of time from diagnosis to treatment.

5.5. Client Barriers.

Ryan White, Medicaid and Medicare currently help low-income, elderly and disabled PLWH/As obtain health care and insurance. Health care reform will expand insurance enrollment and provide additional coverage. However, consumers will still encounter barriers in the form of accessibility to services, stigma, high costs, and difficulties in navigating a complex health care system.

5.5.1. Accessibility to Services.

Several obstacles present barriers to consumers regarding accessibility to services. Many PLWH/A clients, especially those living in Baltimore City and the rural areas of the EMA, are already at a socio-economic disadvantage. Services such as substance abuse and mental health treatment, legal services, and child care are in high demand, as documented in chapter 3. They encounter challenges regarding the availability of co-located services and transportation to and from appointments. As stated earlier, these support services are also the first services to experience fiscal hardships in times of reduced funding.

5.5.1.1. Co-located Services.

A large percentage of the PLWH/As in the Baltimore EMA suffer from co-morbid conditions such as substance abuse, mental health and homelessness. These, in addition to other health issues such as heart disease and cancer, must be addressed in tandem with an individual's HIV.

Agencies, facilities and providers that do not incorporate co-location of services require consumers to make separate treatment and transportation arrangements.

Community planners and administrators must consider co-location of services when funding services. Providers and case managers should provide referrals to PLWH/As that take into account the patient's needs as a whole.

Agencies, facilities, and providers that do not incorporate co-location of services require consumers to make separate treatment and transportation arrangements.

If consumers need to see several providers in different locations across the EMA, a substantial barrier to care results. Transportation costs are increased, child care (if necessary) must be provided, and multiple co-pays are incurred — all of which decrease appointment adherence. The easier services can be accessed by PLWH/As, the more likely they are to stabilize in care.

5.5.1.2. Infrastructure.

Infrastructure-related barriers impede PLWH/As from utilizing medical and support services that are offered in the EMA. Medical transportation is cited as a service demand for over half of PLWH/As, and a third of them face an unmet need (IGS 2011b).

Counties residents face a difficult time accessing services located in the city without private transportation. Services are often located in areas with high numbers of clients. This results in more services being located in Baltimore City, where the HIV epidemic is more concentrated, than the

Table 5.2.

Medical Transportation in FY 2010

Primary Modes	Expenditures	
	EMA-wide	Counties
Taxi Rides	\$57,500	\$143,783
Bus Tokens/Passes	\$57,769	\$648
One-way Van Rides	\$55,458	\$6,205
Total	\$170,727	\$150,636

Source: BCHD 2011a, 2011b.

surrounding jurisdictions in the EMA. As a result, many counties residents are referred to providers in Baltimore City (IGS 2011e).

Although mass transit is available that serves the city and adjacent suburban communities, these services are limited in scope. Most Baltimore-based public transit options have limited service in Baltimore County and Anne Arundel County. Although other counties within the EMA, such as Harford and Carroll, do have public transit options, these services do not extend outside the respective counties. Public transportation in the Baltimore EMA is a challenge as a result of route, inconvenient and changing service schedules, and multiple transfer points. Parking fees and tolls add additional costs to transportation.

Table 5.2 shows FY 2010 costs to the Baltimore Ryan White program for transportation, well over \$320,000 — about \$171,000 was expended under EMA-wide funding, and the counties set aside more than \$150,000 for counties residents alone. EMA-wide, more than 2,200 unduplicated clients received transportation services and nearly 34,000 bus tokens were issued (BCHD 2011b).

To address infrastructure barriers related to sparse services in the counties, each county health department schedules clinic days throughout the month to provide specialized HIV care to residents (IGS 2011e). Even with these measures in place, some counties’ “floating” clinics may only occur once or twice a month and not every PLWH/A can be accommodated. So some county residents need

to travel into the city to receive HIV-related services.

In Baltimore’s surrounding counties, 277 unduplicated clients received Ryan White transportation services in 2010. Table 5.2 shows the high costs incurred by taxi rides from the counties (\$143,783 in FY 2010), consisting of 4,215 one-way taxi trips with an average cost of \$34 (BCHD 2011a). Rising energy costs contribute to the high cost of transportation.

5.5.2. Cost Sharing.

Expensive co-payments, co-insurance costs, deductibles and monthly premiums may cause financial barriers to care. Many individuals and families affected by HIV and AIDS are living in poverty, unemployed, homeless or are otherwise economically disadvantaged. PLWH/As are often unable to afford the high cost of multiple HIV medications and complex treatment regimens, posing a challenge to maintaining clients in HIV care.

5.5.3. Stigma and Discrimination.

Stigma can result in avoidance, ostracism, discrimination and even violence against PLWH/As. As a result, stigma is identified as one of the most significant barriers to seeking services, including testing and medical care. Almost 20 percent of respondents in the 2010 consumer survey indicated that “not having help getting over fear or shame” was a reason that they were discouraged from seeking care in the EMA (IGS 2011b).

In a study published by *AIDS Patient Care and STDs*, researchers found that 71 percent of people receiving HIV treatment felt discriminated against based on race or color, and 66 percent reported discrimination based on socio-economic status, position or social class (APCS 2004). Race and socio-economic status discrimination has been linked to greater levels of depression and post-traumatic stress, more AIDS-related symptoms, lower general health, less satisfaction with their health care, and poor physician-patient relationships. Additionally, discrimination is

negatively correlated with medication adherence and attended doctor’s appointments (APCS 2004).

MSMs, the homeless and transgender individuals also face increased levels of stigma and discrimination. Bringing HIV care into conventional sex education and dialogue, promoting leadership within the HIV community, strengthening enforcement of civil rights laws, and increasing awareness and acceptance can help reduce the stigma and barriers faced by PLWH/As (ONAP 2010).

5.5.4. Vulnerable Populations.

The Early Identification of Individuals with HIV/AIDS¹⁴ initiative distinguishes several subgroups as high-risk populations. Vulnerable populations face additional barriers accessing the continuum of care described in chapter 4 — prevention, engagement, stabilization and maintenance — compared to the general population. The National Academy of Sciences has written that the epidemic “continues its entrenchment in vulnerable populations suffering from co-morbid conditions that can complicate their seeking and obtaining care” (NAS 2005). In the Baltimore EMA, the Comprehensive Planning Committee of the planning council has identified the most vulnerable populations as the formerly incarcerated, MSMs, substance abusers, individuals with mental health disorders, the homeless, transgender people, youth, counties residents and aging adults (IGS 2011d).

5.5.4.1. Formerly Incarcerated.

The prevalence of HIV/AIDS is higher among inmates of correctional facilities than among the general population. In Maryland, 2.5 percent of inmates had HIV or AIDS in 2008 (Maruschak 2009). A safe mechanism for inmates to access HIV testing and treatment in a confidential way is critical, since having a highly stigmatized disease in prison presents unique barriers. Further, continuity of care once inmates are released is important to stabilize their health and HIV disease (Blattner 2011).

Additionally, recently released inmates have less social support and have more difficulty adhering to ART upon release (Science Daily 2009). Formerly incarcerated persons also are more likely to experience substance-abuse problems; mental health disorders; and participate in high-risk behaviors, such as unprotected sexual contact and syringe sharing (Malebranche 2011).

5.5.4.2. Men Who Have Sex with Men.

MSMs are severely affected by the HIV/AIDS epidemic in the EMA, as suggested by the data and trends presented in chapter 2. The high prevalence among gay and bisexual men means that MSMs face a greater risk of infection with each sexual encounter (CDC 2011). Complex factors, such as complacency about risk, social discrimination, cultural issues and substance abuse contribute to the high HIV/AIDS prevalence among MSMs (CDC 2011).

5.5.4.3. Substance Abusers.

Substance abusers are a vulnerable population, as transmission *via* IDU is still a major, if declining, mode of transmission in the EMA (see chapter 2). Substance users are more likely to engage in high-risk behavior and have more challenges with appointment and treatment adherence.

5.5.4.4. Mental Health.

Mental health services are highly demanded in the EMA, with 58 percent of individuals reporting a need (IGS 2011b). Many mental health conditions common in Baltimore complicate chronic disease management. Depression, bipolar disorder, attention deficit disorder, violence-related post-traumatic stress, as well as lead paint toxicity-related learning disorders all contribute to both individual vulnerability in acquiring HIV, as well as decreased adherence in treatment of HIV.

Youth face unique barriers that include limited resources, fear of ostracism from family and peers, and growing up in an era where HIV has shifted out of national priorities.

¹⁴ EIIHA is elaborated on in chapter 6, the ideal continuum of care.

5.5.4.5. Homelessness.

Stable housing helps to minimize risky behaviors such as drug use, crime and prostitution. Homeless individuals are a marginalized subpopulation at extremely high risk for HIV/AIDS. Lack of resources and proper identification make homeless individuals more likely to be unemployed with less access to health care.

According to Health Care for the Homeless, “The experience of homelessness causes health problems (frostbite and hypothermia from the cold, communicable diseases from crowded shelter conditions), exacerbates existing illnesses (cuts lead to infection, frostbite results in amputation or even death), and seriously complicates treatment (medications are lost or stolen, lack of transportation to access health providers, lack of health insurance)” (HCFTH 2011).

5.5.4.6. Transgender People.

Though the transgender community represents only a small fraction of the general population, estimates of HIV prevalence among this population are among the highest. Transpeople are often at higher risk and a large proportion are believed to be unaware of their status. A CDC meta-analysis found that the average HIV prevalence among transwomen was 28 percent, but only 12 percent were aware (HRSA 2011b).

Transpeople face unique barriers related to their gender non-conformity. Stigma and discrimination often lead to an increase in risk factors, such as higher rates of substance abuse, incarceration, survival sex (bartering sex for food or shelter), sex working, violence and mental health issues (NGLTF 2011). Social marginalization can result in denial of employment, lower education and homelessness (HRSA 2011b).

Many transpeople have had negative experiences with the health-care system due to insensitivity, ignorance or discomfort of medical providers that create additional barriers to engagement and stabilization in care. Some transpeople face discrimination and have been refused medical care as a result of their status. Identification documents

(birth certificates, drivers licenses, etc) may not match the gender or name of the individual, causing barriers for insurance, employment and other social services (HRSA 2011b).

5.5.4.7. Youth.

Young people are a subpopulation seeing an increase in HIV incidence. Sexual risk factors such as lack of recognition of a partner’s risk factors, higher rates of STIs, and inequality in relationships may increase exposure to HIV (CDC 2008). For young black MSMs that partner with older black men, among whom HIV prevalence is high, risk is even higher (CDC 2011). Experimentation with drugs and alcohol may lead youth to engage in risky behavior.

Youth face unique barriers that include limited resources, fear of ostracism from family and peers, and growing up in an era where HIV has shifted out of national priorities (CDC 2008). This complacency about risk stems from not personally experiencing the severity of the early AIDS epidemic. As such, youth are challenged to maintain consistently safe behaviors over time because they may underestimate their personal risk and have a false belief that HIV is no longer a serious health threat (CDC 2011).

5.5.4.8. Counties Residents.

Chapter 2 illustrated the different trends between Baltimore City and the EMA’s six surrounding counties. County residents are not seeing the same decreases in new reported cases as Baltimore City. Between 2006 and 2009, new HIV cases in Baltimore City decreased 48.3 percent while the counties only saw a 4.7 percent decrease.

County residents are particularly sensitive to the accessibility barriers discussed in section 5.5.1. To alleviate some of the barriers faced by these populations multiple key services can be provided in locations already frequented by co-morbid and/or vulnerable populations. This makes it easier to engage and retain these special populations in care.

5.5.4.9. Adults Over 50.

Researchers estimate that people with HIV can now expect to live more than 22 years after diagnosis (Edelson 2011). Nationally, the over-50 population has become the fastest growing segment of the HIV/AIDS population. By 2015, the CDC estimates that such people will account for over 50 percent of the total population of living HIV/AIDS cases. The results of the 2010 consumer survey indicate that 65.2 percent of respondents in the EMA were between 45-64 years old, up from 54.1 percent in 2007 and 40.2 percent in 2004 (IGS 2011b).

The CDC recommends HIV testing up to age 64. Many individuals, however, remain sexually active and at risk for HIV transmission past that age, especially if they engage in high-risk behaviors such as unprotected sexual intercourse. Older adults may be less likely to utilize condoms — viewing them as unnecessary since they no longer need them for contraceptive reasons — even though condoms are still important for disease prevention (Fowlkes 2011). Physicians do not routinely question older persons about their sexual health and may assume their patients are no longer sexually active. Conversely, older patients may not voluntarily disclose to their doctor, especially a younger doctor, that they are sexually active (Fowlkes 2011).

The aging population of PLWH/As faces unique barriers and complex co-morbidities prominent in the aging population, such as hypertension, diabetes, cancer and obesity. PLWH/As are at an increased risk for many non-AIDS defined cancers such as lung cancer, anal cancer, liver cancer and Hodgkin's lymphoma (Edelson 2011). New research is being released that measures the side effects of powerful antiretroviral medications that may contribute to co-morbidities found in older PLWH/As.

Furthermore, aging PLWH/As may suffer from loneliness, depression, and embarrassment. They may fear rejection and discrimination from family, friends, children and grandchildren (Fowlkes 2011). Older adults often do not have adequate

income because HIV/AIDS and other health conditions may prevent them from finding and keeping employment.

5.5.5. Complex Medical System.

The complex medical system, along with changing eligibility requirements of Medicare, Medicaid and Ryan White, create barriers to consumers. Clients are not capable of engaging in the EMA's continuum of care if they do not know what services and resources are available and/or where to find them. The use of case managers and development of client navigator programs is important in helping PLWH/As identify and enroll in medical and support services and reinforce the ideal continuum.

5.5.6. Disparities in Response.

Even when clients do access care, there are racial differences in the effectiveness and availability of HIV treatments. Although few studies have assessed the effect of race on the effectiveness of highly active anti-retroviral therapy (HAART) medications, the current body of research shows that African-American PLWH/As experience a higher rate of mortality associated with medication use. Research also shows that this population has a slower virologic response rate to certain types of medication and a higher chance of treatment failure (Malebranche 2011).

Clients are not capable of engaging in the EMA's continuum of care if they do not know what services and resources are available and/or where to find them.

5.6. Conclusion.

This chapter set out to look at barriers related to the effective provision of emergency HIV/AIDS services in the Baltimore EMA. These barriers were separated by whether they were based on policies and regulations, programs, providers, or clients.

Policy and regulatory barriers include routine testing, legislatively mandated inflexibility, financial accountability, and decreased funding. Program-related barriers and coverage gaps that stem from Medicare and Medicaid create challenges for PLWH/As to maximize their access to quality health care. Under current Medicaid eligibility rules, some PLWH/As are only eligible for limited services under PAC. This will change in 2014, when all individuals at or below 133 percent of the federal poverty level will be eligible for Medicaid. Provider-related barriers, such as administrative burdens, third-party billing, client-provider relationships and linkage to care have been discussed in this chapter. Consumer-related barriers include cost sharing, accessibility to services, stigma, vulnerable populations, multiple co-morbidities and a complex medical system.

Identifying and addressing these barriers to provide an adequate continuum of care in the Baltimore EMA requires a coordinated effort. Federal, state and local governments; health care providers; consumers; community planners; and other stakeholders: all must collaborate to meet the needs of the HIV infected and HIV affected. The next chapter depicts what the ideal continuum of care would look like if these barriers to service provision were mitigated or eliminated.

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