

CHAPTER 5

BARRIERS TO AN EFFECTIVE CONTINUUM OF CARE.

5.1. Introduction.

While there have been many advancements in HIV service delivery over the first 25 years of the epidemic, there is still much to be done — many barriers continue to prevent people living with HIV and AIDS from being tested and entering into treatment. Several such barriers will be described in this chapter.

The chapter focuses, in turn, upon policies and/or regulations; changes to Medicaid, Medicare and Medicare Part D; infrastructure deficits; and other impediments to an effective continuum of care. The needs and objectives of consumers, community planners and providers are all addressed in this chapter on the barriers to providing care in the Baltimore EMA.

This chapter finds that the barriers confronted by consumers, community planners and providers include legislative funding mandates; decreased funding; new testing guidance; the lack of coordinated prevention planning; Medicaid, Medicare and Medicare Part D requirements; limited accessibility; late entry into care; lack of consumer knowledge, continued stigma and misperceptions.

Understanding these barriers to service delivery is a critical component in the development of a strategic plan that strives to achieve the ideal continuum of care. Subsequent chapters discuss how the EMA will manage these barriers over the next three years. The ideal continuum of care (i.e., a continuum minus these barriers) is the topic of the next chapter and a detailed plan for addressing these barriers will be found in the goals, objectives and strategies outlined in table 7.1 of chapter 7.

5.2. Policy/Regulatory Changes.

Over the past three years, several policy/regulatory changes have affected the provision of services in the Baltimore EMA. Many of these changes have led to a stronger, more comprehensive continuum of care, while other changes have posed challenges. Among the policy/regulatory changes that have the potential to obstruct service provision over the next three years are legislative funding mandates, decreased funding, new testing guidance, the lack of coordinated prevention planning, and Medicaid and Medicare requirements.

5.2.1. Legislatively Mandated Inflexibility.

The intent of Congress, reaffirmed in the Ryan White HIV/AIDS Treatment Modernization Act of 2006, is to provide temporary, emergency resources for PLWH/As requiring medical care. Several stipulations have been attached to Ryan White grants to ensure that expenditures are consistent with legislative intent. These stipulations range from the requirement that a minimum of 75 percent of direct-service money awarded under Part A (including MAI allocations) must be directed to core medical services, to the determination that no individual may, over his or her lifetime, receive more than 24 months of housing support from Ryan White programs.

The needs of consumers are as diverse as they are complex. While Ryan White serves a specific purpose (i.e., to provide emergency relief while transitioning clients to more permanent sources of assistance), the path that each individual takes to achieve this goal will differ. Minimum standards are a necessity but to the extent that

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administrators, community planners, and providers are able to maintain flexibility throughout the continuum of care, they will be better prepared to address the diverse and complex range of needs found in the EMA.

5.2.2. Decreased Funding.

Decreasing funding levels are an ever-present challenge to community planners and providers looking to maintain a sufficient continuum of care in the Baltimore EMA. Federal and state funding for emergency HIV services have been declining relative to need. For example, the budget presented by Maryland’s executive branch anticipates a 7.5 percent decrease in federal funding and a 3.2 percent decrease in funding from the state’s general fund for the Maryland AIDS Administration in state fiscal year 2009 from FY 2008 (DLS 2008). The Baltimore EMA Part A grant (including MAI) declined 4.0 percent between FY 2003 (\$21,458,791) and FY 2008 (\$20,594,272) (BCHD 2003, 2008).

*“the more you test
 the more you
 de-stigmatize...”*

-Redfield

At the same time that funding has decreased, the amount of need has increased throughout the EMA. The number of HIV and AIDS prevalent cases in Maryland increased from 21,653 to 32,811 between 2000 and 2006. As of December 31, 2007, EMA jurisdictions accounted for just under two thirds of Maryland’s total caseload, so it is likely that much of the state’s increasing burden is due to increases in the EMA (DHMH 2008a). The result of more people requiring services combined with less funding is an increasing strain upon the Baltimore EMA’s continuum of care. Decreased funding for HIV prevention services continues to be a barrier to community planners, providers, and consumers alike.

5.2.3. New Testing Guidelines.

It is the belief of some researchers, such as Robert Redfield, that “the more you test, the more you de-stigmatize [HIV]” (Redfield 2008).⁵¹ Redfield believes that strictly voluntary testing, secret coding and other measures taken in the past to protect PLWH/As only heightened the stigma associated with the disease. His assessment echoes the belief long held by many African AIDS professionals who began pushing the international AIDS community to allow African clinics to provide HIV testing as a part of standard medical care as early as 2004 (Morah 2005).

Legislation passed in Maryland regarding routine, opt-out testing has been in place since July 1, 2008 to address these concerns. Guided by CDC recommendations, Maryland’s new legislation allows federally funded health centers to offer an HIV test without the requirement of a separate consent form. Entitled “HIV Testing-Informed Consent and Treatment,” the legislation streamlines HIV testing into routine medical care, and may also help in reducing the stigma associated with being tested, diagnosed and treated for HIV.

Decreasing the length of time between a person’s HIV-positive diagnosis and his or her first case management or HIV primary care appointment is a critical first step to addressing many of the challenges that prevent people from accessing HIV care (like the need for services such as substance-abuse and mental-health treatment, housing, etc.). Routine HIV testing has the potential to enhance HIV/AIDS care throughout the EMA, but only if general health practitioners are adequately prepared to make the necessary referrals, and outreach and case management providers are given the resources to locate and serve new clients.

As the number of general health practitioners entering the world of HIV

⁵¹ Robert Redfield is the associate director of the University of Maryland’s Institute of Human Virology.

counseling, testing and referrals increases, so does the need to expand the network of primary care providers who are knowledgeable about HIV-related services and programs such as Ryan White. Ensuring adequate resources for outreach and case management services will assist in developing a system that can absorb the new clients identified through opt-out testing.

5.2.4. Lack of a Coordinated Prevention Plan.

The lack of a coordinated prevention plan poses challenges to comprehensive prevention efforts in the EMA.⁵² Without a coordinated plan, service providers have difficulty ascertaining where and to whom they should be targeting their prevention messages in what is transforming from several population-specific epidemics into a generalized epidemic. As a result, many who need prevention messages are not receiving them. Behavioral surveillance studies show that only 10 to 15 percent of respondents reported having any exposure to behavioral messages or interventions (Holtgrave 2008).

At present, prevention messages in the EMA are largely targeted to high-risk groups. Some area researchers contend that this is a misguided prevention strategy for a generalized epidemic; individuals who may not fit snugly within a high-risk category may have very limited access to prevention education under the current system (Redfield 2008). This has spurred some local advocates to propose targeting geographic areas with high seroprevalence rates such as the hotspots — the 8 (of 30) ZIP codes with more than two thirds of the HIV and AIDS prevalent cases in Baltimore

City (Redfield 2008).⁵³ However, there is still a need for prevention efforts that target high-risk groups. These initiatives continue to be critical in capturing individuals from key subpopulations who are often difficult to identify and/or reach (e.g., injection drug users [IDU], transgender, men who have sex with men [MSM], the elderly and the homeless).

Targeting high prevalence geographic areas and high-risk groups are both valid strategies that, if implemented together, could produce substantial prevention improvements. However, the lack of a prevention strategic plan makes it challenging for providers and agencies to coordinate their efforts for maximum impact in the EMA. It is for this reason that the Baltimore City Commission on HIV/AIDS Prevention and Treatment recommended in its 2007 interim report that Baltimore work to “develop a consistent and clear prevention message for the city to be used in a coordinated way among implementing partners adapted to specific constituencies” (BCCH/A 2007). Their message was echoed by John Bartlett who listed the need for a prevention plan as one of the six most pressing priorities for addressing HIV in Baltimore today (Bartlett 2008b).⁵⁴

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5.2.5. Other Policy/Regulatory Barriers.

Policies/regulations that require substantial documentation are challenging to some consumers seeking Ryan White services. For

⁵² While prevention-related services are most often provided at counseling, testing and referral service sites that are generally funded by the Centers for Disease Control and Prevention (not by Ryan White grants), prevention and treatment are directly linked — many of the barriers that affect prevention prove themselves harbingers of the problems that beset Ryan White Part A clients during treatment.

⁵³ The hotspots are 21217 (12.5 percent of the HIV and AIDS prevalent cases in Baltimore City), 21215 (10.0 percent), 21218 (8.9 percent), 21202 (8.3 percent), 21213 (7.9 percent), 21223 (7.2 percent), 21201 (6.2 percent) and 21216 (6.1 percent); together these ZIPs contain more than two thirds of the city’s PLWH/As.

⁵⁴ John Bartlett is the Stanhope Bayne-Jones professor of medicine at the Johns Hopkins University Division of Infectious Diseases.

example, homeless individuals often lack the required identification to secure services, and are often unable to access care. Additionally, some policies exclude entire classes of individuals in need of care from certain Ryan White services (e.g., individuals with felony drug convictions are not eligible for some services, including subsidized housing).

5.3. Medicaid.

Medicaid, the largest source of federal funding for HIV/AIDS care in the United States, is estimated to provide access to care for more than 44 percent of PLWH/As, nationally (Kaiser 2006b:2). Eligibility varies by state, but, on the whole, individuals can qualify for Medicaid if they are both low-income and part of a group that is categorically eligible (e.g., disabled, blind, elderly, children or women who are pregnant).⁵⁵

The HIV Cost and Services Utilization Study (HCSUS), the only nationally representative study of PLWH/As in care, found that more than 44 percent were covered by Medicaid in 1996, including approximately 29 percent by Medicaid alone, and 12 to 13 percent dually covered by Medicaid and Medicare (Kaiser 2006c:2).

The next largest source of coverage was private insurance (31 percent). About one fifth of PLWH/As were uninsured (Kaiser 2006c:2).

As of June 2008, an estimated 5,638 PLWH/As in the Baltimore EMA (28 percent of all PLWH/As in

the EMA) were enrolled in Medicaid — 4,685 (83 percent) of whom resided in Baltimore City. (There were 7,265 PLWH/As from Maryland enrolled in Medicaid.) (Middleton 2008). Most people in Medicaid are enrolled in Maryland’s

Medicaid managed-care program, whereby seven organizations contract with DHMH to provide Medicaid covered services through their provider networks in return for monthly capitation payments (Middleton 2008).⁵⁶

To participate in Medicaid, states must provide certain services. Among these services, those that are most relevant to PLWH/As are inpatient and outpatient hospital services, physician and laboratory services and long-term care (Kaiser 2006b:2). States may also cover certain optional services and receive federal matching funds. Prescription drug coverage, an “optional” benefit available for Medicaid beneficiaries residing in Maryland, is perhaps the most important optional benefit needed by people with HIV/AIDS (Kaiser 2006b:2).

5.3.1. Barrier to Consumers: Cost Sharing.

Despite attempts to limit the cost of medications for Medicaid beneficiaries, prescription co-payments remain a key barrier to consumers in Maryland. Adult fee-for-service (FFS) recipients are charged \$1.00 co-payments for all HIV medications (brand name and generic) (DHMH 2008a). For all other drugs, they are charged \$1.00 for generic and \$3.00 for brand-name prescription drugs (DHMH 2008a). Primary Adult Care (PAC) recipients pay co-payments of \$7.50 for brand-name drugs and \$2.50 for generic drugs, including HIV medications (Middleton 2008).⁵⁷

⁵⁶ Several Medicaid organizations are also providing basic dental services for adults as well.

⁵⁷ The Maryland Primary Adult Care (PAC) program provides primary care, outpatient mental health, family planning, and low-cost or free prescription drug coverage and is for people aged 19 and over, who do not have dependent children and are not eligible for Medicare. They must have an income below \$1,005 a month for one person (\$1,167 monthly per couple). Their assets, such as bank accounts, must be below \$4,000 for one person (\$6,000 per couple) (DHMH 2008b).

Twenty-eight percent of the EMA’s PLWH/As are enrolled in Medicaid.

⁵⁵ Individuals who qualify for Medicaid cannot receive coverage from the Maryland AIDS Drug Assistance Program (MADAP) (Middleton 2008).

Currently, six of the seven contractors providing Medicaid managed care waive co-payments for most prescription drugs, but not HIV/AIDS medications. Costs for these medications are “carved out” of managed care and paid for by DHMH; non-pregnant adult enrollees are charged a \$1 co-payment (Middleton 2008). While the co-payments discussed in this section appear to be nominal, the financial capacity of Medicaid beneficiaries, as well as the average number of prescription drugs needed for PLWH/As, must be considered in order to fully grasp how prescription co-payments are a barrier to care for consumers in the Baltimore EMA.

5.3.2. Barriers to Planners: Reduced Funding and Increased Need.

Community planners also face barriers as a result of the current Medicaid program. More specifically, plans to reduce future funding streams for Medicaid-covered services (i.e., reductions to federal matching funds), coupled with the ever present need for increased case management for PLWH/As, make it progressively more difficult for community planners to organize services in the Baltimore EMA.

Currently, the federal government matches state Medicaid spending for most states — Maryland receives 50 percent federal matching for most Medicaid services (Middleton 2008). Reductions in federal matching funds present barriers to community planners as they are faced with the possibility of substantial decreases in the funds available to plan services to PLWH/As in the Baltimore EMA. An estimated \$20 to \$49 billion in federal savings (cuts to programs) is predicted over the next five years (HMMWG 2008:1).

Maryland spends approximately \$150 million annually on case management for Medicaid (MNT 2008), and the need for increased case management continues to be of concern to community planners, as well as to consumers who rely on these services to receive care. *Medical News Today*

published an article on February 6, 2008, stating that Maryland could lose up to \$75 million in Medicaid reimbursements if recently passed federal regulations concerning reimbursement for Medicaid case management take effect (MNT 2008).

5.4. Medicare and Medicare Part D.

Medicare is a federal health insurance program that covers both seniors and people with permanent disabilities. It is the second-largest source of federal spending on HIV/AIDS care in the U.S., second only to Medicaid. An estimated 60,000 to 80,000 AIDS-defined individuals in the U.S. are recipients of this program, and an estimated 100,000 Medicare beneficiaries living with HIV/AIDS also rely on the program for their medical care, including prescription drug coverage (SFAF 2007:1). An estimated 80 percent of PLWH/As that are Medicare recipients are also eligible for Medicaid (HMMWG 2008b:1).

Medicare Part D Prescription Drug Coverage assists with the costs associated with all FDA-approved drugs except those covered under Medicare Parts A and B, as well as seven categories that are considered “excluded drugs” (HRSA 2008a). Excluded drugs that are relevant to HIV-related care include those for weight gain or loss, over-the-counter drugs, vitamins and minerals, and benzodiazepines (HRSA 2008a).⁵⁸ While cost-sharing requirements vary, each plan is required to cover both generic and brand-name prescription drugs. In order to eliminate the possibility of discrimination, the Centers for Medicare and Medicaid Services (CMS) require access to all, or substantially all, drugs in six drug classes in the formulary (HRSA 2008a). Antiretroviral drugs are included in the formulary (HRSA 2008a).

⁵⁸ While HIV-related drugs used for weight loss or gain are not covered under Medicare Part D, drugs used for AIDS-related wasting or cachexia are part of the formulary (HRSA 2008a).

5.4.1. Barriers to Consumers.

Despite being well intentioned, current Medicare and Medicare Part D programs are not optimally assisting eligible individuals with their health-care needs. The barriers to consumers that will be discussed in this section include administrative burdens; cost-sharing measures (i.e., prescription co-payments); the coverage gap (a.k.a. the “Medicare donut hole”); and the ineffectiveness of the Part D appeals process.

5.4.1.1. Administrative Burdens:

The extensive application process for beneficiaries’ drug coverage poses a challenge to consumers in need of care (MRC 2008). In part to address early concerns about this problem, the Medicare Prescription Drug, Improvement, and Modernization Act (Pub.L. 108-173, 117 Stat. 2066) was enacted in 2003. As a result, dual eligibles (those eligible for both Medicare and Medicaid) receive all of their prescription drugs, and substantial premium and cost-sharing assistance through Medicare Part D (Kaiser 2006c:2). However, dual eligibles remain subject to substantial paperwork.

In the Part D program, beneficiaries’ access to prescription drugs is a function not only of whether a particular drug is on a plan’s formulary and whether it is subject to utilization management tools, but also how plan sponsors make individualized coverage decisions when requested. If the necessary paperwork is not accurately completed, potential beneficiaries can encounter great difficulty in acquiring the necessary funding for their health care needs.

5.4.1.2. Cost Sharing.

The high cost of HIV medications and complex treatment regimens that require multiple medications poses a challenge to

maintaining clients in HIV care. An individual is eligible for “extra help” with prescription drug costs within the Part D program if his or her assets (not including primary residence) are valued below \$11,990 (SSA 2008). If individuals are not qualified under these terms, they are still able to join a Medicare drug plan, but will be responsible for paying a monthly premium, co-payments and a deductible, which will vary depending on the plan they choose (HRSA 2008a). Premiums average approximately \$36.00 or more per month in addition to a \$275 deductible per year for services (PAF 2008, HRSA 2008a).⁵⁹

5.4.1.3. Coverage Gaps.

Medicare Part D enrollees that do not qualify for the low-income subsidy program have to pay their deductible of \$275 before they can begin to benefit from the plan. They are then responsible for 25 percent of their medical cost up to \$2,510. Medicare Part D enrollees that do not qualify for extra help have to pay 100 percent of their drug costs above \$2,510 until catastrophic coverage kicks in once they have \$5,726.25 in total drug costs or \$4,050 in true out-of-pocket (TrOOP) (HRSA 2008a).⁶⁰ The out-of-pocket expenditures resulting from the coverage gap between \$2,510 and \$5,726.25 of total drug cost for Part D enrollees that do not qualify for the low-income subsidy program are a major barrier to care. A PLWH/A in the Baltimore EMA, with total assets valuing just over the \$11,990 maximum for “extra help” will still find it extremely difficult or even impossible to afford cost sharing.⁶¹

⁵⁹ Part D enrollees are able to choose the Medicare prescription drug plan that is best for them by using the Medicare Prescription Drug Plan Finder online or by calling the CMS help (HRSA 2008a).

⁶⁰ Upon reaching catastrophic coverage, Medicare Part D enrollees are only required to cover approximately five percent of prescription costs (\$2 per generic or \$5 per brand-name drug) (HRSA 2008a).

⁶¹ Ryan White funds are available to help Medicare beneficiaries with HIV/AIDS to cover Medicare

Medicare Part D enrollees are responsible for 100 percent of total drug expenditures between \$2,510 and \$5,726.25.

To account for this problem, the Maryland General Assembly passed House Bill 1492, entitled “Senior Prescription Drug Assistance Program/Subsidy for Medicare Part D Coverage Gap and Sunset Extension” in March 2008 (MGA 2008). This bill put four million additional dollars in the Maryland Health Insurance Plan to provide a subsidy for the Medicare Part D coverage gap through December 2010. While this is expected to mitigate part of the problem, many consumers in Maryland are still experiencing a coverage gap that leaves them responsible for costly co-payments, co-insurance costs, deductibles and monthly premiums that they are often unable to afford.

5.5. Infrastructure.

Several infrastructure-related barriers obstruct PLWH/As (i.e., potential Ryan White consumers) in their search for life-saving antiretroviral therapy and primary care that can improve their quality of life. For a large percentage of the PLWH/As in the Baltimore EMA, co-morbid conditions of substance abuse and mental health are inherent barriers to treatment that must be addressed in tandem with an individual’s HIV. However, a lack of infrastructure for the co-location of services often requires consumers to make entirely separate treatment arrangements; thereby defeating the purpose of co-located services (to ensure greater accessibility to services and improving adherence).

Decreased funding is not only a policy/regulatory barrier, it also threatens the existing infrastructure. Other factors, such as accessibility to treatment facilities, and a lack of fundamental resources (e.g. housing) also create roadblocks along the path to treatment.

premiums, deductibles, co-insurance and co-payments. These funds, however, cannot be counted toward an individual’s TrOOP, which are essential in reaching the catastrophic level where Medicare picks up most costs (HRSA 2008a).

5.5.1. Co-locating Services for Co-morbidity and Vulnerable Populations.

Co-morbidities such as substance abuse, mental health and homelessness pose serious challenges to effective treatment and healthy outcomes. Contributors to the Baltimore EMA’s FY 2008 Ryan White Part A federal application noted the enhanced risk posed by severe mental illness and homelessness when they wrote “[i]ndividuals diagnosed with a severe mental illness are at a significantly enhanced risk of infection with HIV” and “[h]omeless individuals are more likely to contract HIV/AIDS because they engage in high-risk behaviors or have mental illnesses that impair decision-making” (BCHD 2007).⁶² Reflecting on this phenomenon, 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 2005:39).

Programmers and advocates working with the homeless population in Baltimore have also addressed this theme in informational interviews.⁶³ Louise Treherne has noted addiction, a lack of proper identification, stigma within the homeless populations and a lack of resources as the challenges that make it increasingly difficult for the homeless to access care (Treherne 2008).⁶⁴ Mary Lee

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⁶² Homelessness poses several barriers for PLWH/As. Lack of proper identification, for example, is one of the many barriers that homeless PLWH/As face, as they are unable to receive services without adequate identification. Additionally, individuals with felony drug convictions are prohibited by law from receiving many services (i.e. subsidized housing). This further exacerbates homelessness in the EMA.

⁶³ Informational interviews were conducted to capture various perspectives, including those of consumers, providers and community planners, for inclusion in this strategic plan.

⁶⁴ Louise Treherne is the vice president of clinical affairs for Health Care for the Homeless, Inc.

Bradyhouse has explained that it is often difficult for homeless individuals to find housing that keeps them away from risky behaviors such as drugs and prostitution (Bradyhouse 2008).⁶⁵

The availability and suitability of the infrastructure that is currently in place remains an ongoing challenge to addressing co-morbidities and providing services to vulnerable populations in the Baltimore EMA. Community planners, administrators and providers are continuing efforts that are already underway to co-locate services such as substance-abuse treatment and primary medical care at the same treatment location (i.e., allow consumers access to several key services during the same visit), but this is difficult with the facilities that are currently available.

Fewer resources for HIV surveillance make it increasingly difficult to evaluate need.

The more that key services can be provided in the same location, preferably a location already frequented by co-morbid and/or vulnerable populations, the easier it will be to engage and retain these special populations in care.

5.5.2. Declining Resources.

A decline in resources makes it difficult to enhance services for consumers and to maintain the current level of infrastructure. The struggle to maintain a strong continuum of care at maximum capacity during a time of economic uncertainty and funding decreases is not unique to HIV. It is, however, critical to HIV planning to consider the impact of reducing resources at a time when opt-out testing laws have recently been enacted and not enough data collected on the number of potential clients the new policy could yield.

In 2008, Maryland experienced a reduction in surveillance funding during the same period it was working to implement the mandated names-based coding system (Hauck 2008). Decreased surveillance funding makes it increasingly difficult to evaluate need, the length of time an individual has been HIV positive and increasing levels of drug resistance in the population.'

5.5.3. Inadequate Accessibility to Services.

The need for an adequate mass transit system was discussed in the EMA's previous comprehensive plan (IGS 2005:69). While there is a transit system that serves the city and the suburban communities adjacent to the city, changes to bus routes, service schedules and transfer points make transportation a challenge even for city dwellers. Most residents of the six counties are dependent on personal transportation, taxi, commercial sedan services or other commercial services. Arrangements for these services often require special coordination between the service provider paying for the service, the transportation provider and the individual needing the transport.

Community planners must also contend with economies of scale in efficient service provision, and the resulting impact upon the accessibility of specialized medical services in the counties. There are both fixed (administrative and logistical) and variable (per visit) costs associated with providing any service in a given locale. The greater the number of clients the lower the per-client administrative costs will be, making it more efficient to locate services in the areas that have the highest concentration of clients. Potential clients are not sufficiently clustered to take advantage of economies of scale at any particular county location. The result is that more specialty services are provided in Baltimore City, where clients are both more numerous and concentrated than in the EMA's other jurisdictions.

⁶⁵ Mary Lee Bradyhouse was the director of programs for Baltimore Homeless Services at the time of this interview.

To address problems with accessibility, clinic days are scheduled throughout the month in the counties to provide specialized HIV care to residents. This allows HIV clinicians and specialists to spend a larger portion of their time in Baltimore City where 80 percent of the HIV positive EMA clients reside, while still addressing the needs of clients in the counties. However, even with these measures in place, some county residents are still required to travel to the city to seek specialty services. Rising energy costs combined with an increasing PLWH/A population in the counties make accessibility to specialty services in the counties, or through the provision of medical transportation to Baltimore City, one of the greatest challenges facing the EMA over the next three years.

5.6. Other Barriers.

Policy/regulatory-, Medicaid-, Medicare- and infrastructure-related barriers are not the only challenges confronting consumers, community planners and providers. Stigma and misperception, late entry into care and a lack of consumer knowledge concerning available services also obstruct the effective provision of services in the Baltimore EMA.

5.6.1. Stigma and Misperception.

HIV-positive individuals (i.e., potential consumers) identify stigma as one of the most significant barriers to seeking services, including testing, for HIV infection. A recent national study conducted by the Kaiser Family Foundation indicated that many people still think that HIV can be transmitted through various forms of casual contact such as kissing (37 percent), sharing a drinking glass (22 percent) and touching a toilet seat (16 percent) (Kaiser 2006:7). Stigma and discrimination from the general population contribute to the fears associated with being tested and seeking treatment.

As with the rest of the country, stigma is also a problem in the EMA. A survey of consumer knowledge in 2004 found that “my friends/family/others will find out that I have HIV” was the second leading reason

that PLWH/As were discouraged from seeking care in the EMA (IGS 2005a). Stigma appears to be an even more pressing concern for and within some of the multiply marginalized PLWH/As subpopulations in the EMA.

Kalima Young of Connect to Protect: Baltimore released preliminary results of a study on young MSMs. This study recruited young men who were willing to participate from three public venues located in the 21217, 21201 and 21202 ZIP code areas. The results showed that 57 percent (43 of 75) of the surveyed young MSMs believed that “people would talk about you behind your back if you were positive” (Young 2008).⁶⁶ The next largest group of respondents to this question was young MSMs who refused to answer the question.

When interviewed by planning council support staff, Louise Treherne cited stigma as one of the biggest barriers to providing health services for the homeless population in Baltimore (Treherne 2008). However, her insight focused upon stigma within, not against, the marginalized population. According to Treherne, some within the homeless community are quick to “pick up on” a person's status and are willing to discriminate against their HIV-positive counterparts. She explained how a recent tuberculosis outbreak in the Baltimore homeless population led to discrimination that further exacerbated the fear of getting an HIV test in the shelter-dwelling community.

When asked if they thought people would avoid them if they tested positive for HIV, 48 percent (31 of the 64 males whose responses to this question were recorded) of the mostly young MSM respondents to the

⁶⁶ Young reported on a preliminary risk surveillance study conducted through the Connect to Protect: Baltimore project through the University of Maryland's STAR TRACK program. The study included 75 young men between the ages of 12 and 24 years, who were surveyed about their behavior and opinions on HIV.

Connect to Protect: Baltimore survey described earlier responded in the affirmative: 30 percent (19) disagreed (Young 2008). Nearly 40 percent (24 of 62) of the respondents that reported receiving an HIV test within the previous 12 months stated that they never went back for their test result. While there are myriad reasons why this phenomenon of not returning for test results exists, it is likely that fear of the stigma that is associated with being HIV positive deterred

About 40 percent of newly diagnosed PLWH/As become AIDS defined within one year.

some of these respondents.

In a small survey conducted by the Health Education Resource Organization, Inc. (HERO), 45 transgender persons were interviewed about their experience with discrimination and violence based on their transgender identity. Of the 45 people interviewed, 58 percent of them reported that they had delayed seeking medical care because of fear of how they would be treated based on their transgender status (Brevette 2008). The fear of stigma may prevent a consumer from seeking treatment, especially those who self identify as homosexual or transgender.

Whether against or within populations, stigma continues to be a major barrier for consumers seeking care in the EMA, and the providers looking to serve them. While there is not much that the public sector can do to address stigma in the general population beyond promoting awareness (which is not within the purview of Ryan White Part A), it is believed by some that certain steps, such as the introduction of opt-out testing, bring HIV care into the mainstream, and this helps reduce stigma.

5.6.2. Late Entry into Care.

Recent research indicates that the number of cases enrolling into treatment at later stages of HIV/AIDS disease progression is

increasing. When asked in April 2008 about emerging trends in the epidemic, John Bartlett pointed to the increasing number of people that clinicians are seeing enter treatment with a CD4 count of approximately 200 (Bartlett 2008a), the point at which an individual is considered to be AIDS-defined (Bartlett 2003).

Late entry into care is a key consideration in the planning of services. Early identification of HIV infection may get an individual into treatment sooner and thus slow the progression to AIDS by keeping the individual’s immune system from becoming severely compromised (Bartlett 2003). As Bartlett explains, “It takes an average of ten years to get AIDS,” but early care slows the progression of AIDS (Bartlett 2008b). Recent surveillance data show that approximately 40 percent of those testing positive for HIV become AIDS defined within one year of initial diagnosis (Bartlett 2008b). The short interlude between testing and becoming AIDS defined suggests that these individuals were HIV positive for several years prior to being tested.

5.6.3. Lack of Consumer Knowledge Concerning Available Resources.

Consumer knowledge is a problem commonly cited as a barrier to care by EMA providers. In her 2008 presentation to the Greater Baltimore HIV Health Services Planning Council, Karen Bellesky, Ryan White grants manager and staff dietitian of Chase Brexton Health Services, reported “people not knowing where they can get care, regardless of insurance or ability to pay” as one of the two main barriers confronting clients (Bellesky 2008).

For obvious reasons, clients are not going to be able to access the EMA’s continuum of care if they do not know where to find the services. The situation has improved over time, but providers, planners and other community leaders in Greater Baltimore are aware of the need to continue educating the public of services that are available to the HIV infected and HIV affected in the EMA.

5.7. Conclusion.

This chapter set out to look at policy/regulatory, infrastructure-related and other barriers to the effective provision of emergency HIV/AIDS services in the Baltimore EMA, from the perspective of consumers, providers and community planners. The barriers included the following: funding mandates, declining resources, new testing guidance, need for a coordinated prevention planning, changes to Medicaid and Medicare, co-morbidity and vulnerable populations, inadequate accessibility to services, stigma and misperception, late entry into care and a lack of consumer knowledge.

Confronting these barriers to provide an adequate continuum of care in the Baltimore EMA requires a coordinated effort from all stakeholders in the community. While some of the barriers (e.g., substance abuse and mental health) are within the purview of Ryan White programs to address on a short-term basis, Ryan White is only intended as temporary, emergency relief. Furthermore, barriers exist that are outside Ryan White's ability to address even on a short-term basis (e.g., insufficient prevention planning or decreases in other funding sources).

The barriers identified in this chapter call for improved collaborative efforts with existing, long-term programs such as Medicaid and Section 8 housing, to address the health care and basic needs of the HIV-infected and HIV-affected living at or just above the poverty level.

The next chapter depicts the ideal continuum of care (i.e., a continuum where the aforementioned barriers to service provision have been addressed or failed to materialize), while chapter 7 describes the steps that community planners and providers should take to address the anticipated barriers to care in the EMA over the next three years.

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