



Prepared by InterGroup Services, Inc. for the  
Greater Baltimore HIV Health Services Planning Council

## **Greater Baltimore HIV Health Services Planning Council**

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### ***Engaging PLWH/As in Care: Lessons Learned for the Baltimore EMA***



*Funded by the Ryan White program  
through the Baltimore City Health Department*



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## 1. EXECUTIVE SUMMARY

The Greater Baltimore HIV/Health Services Planning Council is a 40-member, volunteer blue-ribbon panel appointed by the mayor of Baltimore to oversee expenditures of federal Ryan White program, Part A funds granted to the city for low-income HIV health services, some \$20 million annually. These funds are used to provide health and supportive services of last resort to persons living with HIV/AIDS (PLWH/As) in Baltimore City and Anne Arundel, Baltimore, Carroll, Harford, Howard and Queen Anne's counties, a region referred to in this context as the Baltimore eligible metropolitan area (EMA). The Ryan White program is administered by the HIV/AIDS Bureau (HAB) of the Health Resources and Services Administration (HRSA) in the U.S. Department of Health and Human Services (HHS).

The planning council has long been concerned by national and local research suggesting that large numbers of PLWH/As are not receiving HIV medical care on a regular basis, or at all. Many such PLWH/As eventually enter care, of course, but often only when their health has reached a crisis point. In addition to the toll this takes on the health and life expectancy of these individuals, the care that they require at this crisis stage is considerably more costly than it would have been if they had entered care sooner after being diagnosed with HIV.

But while the problem of not-in-care PLWH/As is well documented, what is less clear is how best to locate and engage such people in care. The planning council commissioned this report in the fall of 2006 to compile and analyze relevant research on the subject, with the hope that strategies for locating not-in-care PLWH/As and engaging them in care that had proved successful elsewhere might provide starting points for new approaches in the Baltimore EMA.

### 1.1 Unmet Need in the Baltimore EMA

HRSA uses the term "unmet need" to describe people who know that they are HIV positive but are not in HIV primary medical care. Estimates of the magnitude of unmet need in the Baltimore EMA range from 16-35 percent of the EMA's approximately 18,000 PLWH/As (also an estimate). Precise numbers are not currently available in Maryland because the state has only recently — spring 2007 — begun implementing a names-based HIV case-reporting system. However, the 35 percent estimate is consistent with HRSA's 2006 estimate of unmet need among the then 51 EMAs nationwide, 36 percent. In light of a U.S. Centers for Disease Control (CDC) estimate that 42-59 percent of PLWH/As in the U.S. are not receiving HIV medical care, it would not be surprising to learn that Baltimore, with one of the highest HIV infection rates in the country, has even more not-in-care PLWH/As than the 35 percent estimate suggests.

### 1.2 Strategies for Reducing Unmet Need

Unsurprisingly, there is no magic bullet. The problem of unmet need for HIV primary medical care is a complex one, resulting from many different causes manifesting at the individual, provider and systems levels of the health-care continuum. Some of the more prominent causes identified by national research include low health literacy, varying levels of "readiness" for entering/maintaining health care, lack of ready access to affordable health care, incarceration, lack of social supports, HIV-related stigma, mental health problems, substance abuse, distrust of the health-care establishment (particularly among African-Americans) and transient residence. These causes are overlapping and synergistic, and strategies that are appropriate to one cause or

set of causes may be ineffective for others. Because of the significant expense involved in implementing strategies to address all such causes, HRSA is considering directing that EMAs focus more on affirmative efforts to retain PLWH/As in care — i.e., prevent dropouts — rather than devoting funds to locating and engaging PLWH/As who have never been in care.

Nonetheless, a substantial body of national research has examined a wide range of programs and interventions designed to locate and engage PLWH/As in care, in addition to retaining those already in care. While little of this research is specific to the Baltimore area, much of it has examined populations similar to those with particularly high rates of unmet need in this EMA, such as African-American men who have sex with men, the currently and formerly incarcerated, and the homeless.

Successful programs and interventions for addressing unmet need typically rely on what are known as theories of health-behavior change, or frameworks used to consider why people make certain decisions regarding health care and how best to influence them to make better ones. Two theories are discussed in this report, the Health Belief Model and the Transtheoretical Model. The Health Belief Model originated with the U.S. Public Health Service and takes a behavioral view of human psychology in which people are assumed to make rational calculations of their own best self-interest. This theory, while useful for helping providers think about a client's readiness to engage and comply with care, may fail to explain the behavior of some low-income PLWH/As, who may not think of the issues of health and illness in the same way that planners and researchers do.

The Transtheoretical Model is based on a cognitive view of human psychology and was initially used to understand the behavior of quitting smokers. This model suggests that individuals pass through stages in which they apply different strategies and decision-making processes concerning their health and well-being. This model is useful for thinking about how best to meet specific clients where they are, with strategies designed for someone in their precise stage of change. The Transtheoretical Model also suggests certain “processes of change” appropriate at different stages, such as consciousness raising, role playing, formal self-evaluations and environmental evaluations, formation of helping relationships, instruction in the substitution of healthy behaviors for unhealthy, and others.

Again, there is no single strategy for engaging and retaining PLWH/As in care. Common elements of the strategies described in this report include dedicating staff members to and training them specifically for engaging and retaining PLWH/As in care, meeting the clients where they are with mobile and community-based programs, using staff members with similar cultural backgrounds to those of clients, meeting with incarcerated PLWH/As to plan post-release care, assigning staff to transport/accompany PLWH/As to appointments (and help explain technical clinical information in lay terms, as necessary, between PLWH/As and clinical staff), and others. Another vital consideration, as alluded to above, is the possibility that PLWH/As facing acute problems like eviction, substance abuse, bankruptcy or family problems may not place a high priority on adhering to a care regimen for a disease that may not appear to place them in immediate — as opposed to long-term — danger. Programs that help clients meet what the clients consider to be more pressing needs — even if these are not directly related to HIV treatment specifically or health care in general — typically improve their retention rates. Again, the programs reviewed in this report enjoyed only limited success in locating PLWH/As who were not in care, as opposed to retaining those who were already engaged in care, however lightly.

### 1.3 Recommendations

Certain particularly useful sources for information on engaging and retaining PLWH/As in care were identified in the course of researching this report; planners are urged to consult these sources, many of which offer specific tools, such as forms and process flow charts, that may be adapted for local use. Specific recommendations include implementing an unduplicated client-level tracking system so that retention-related baselines and outcomes can be measured, continuing and expanding public education campaigns with elements specifically designed to decrease HIV-related stigma and counter distrust of the health-care establishment, the adoption of procedures through which clients' readiness to receive health care is routinely estimated and monitored at the provider level, provision of HIV-related medical services outside of business hours, and others.

A number of models and programs for retention are described and discussed in chapters 7, 8 and 9. These programs can be simple, such as using mobile units for other medical services besides HIV care, which reduces clients' fear of stigma upon being seen entering the van. (If it is popularly known in the neighborhood as the "primary-care van," instead of the "HIV van," clients will experience no shame if seen going up to it.) Or these programs can be multifaceted, such as the Retention Care Coordinator Program at the Whitman-Walker Clinic in Washington, D.C., which hires employees — retention care coordinators — whose specific job is to retain clients in care. What all the programs described have in common is a shared understanding that getting it right initially, keeping people in care initially, is more cost effective than losing clients, which can carry the high likelihood of future emergency-room visits and continued high-risk behavior.

Finally, the planning council may wish to consider mounting a survey of health-care utilization patterns, attitudes and beliefs, targeting vulnerable EMA subpopulations — the homeless, the incarcerated or formerly incarcerated, sex workers, etc. — as a whole, as opposed to targeting just PLWH/As. The advantages of a "wide net" survey of this kind are a reduction in the risk of "outing" HIV-positive respondents and an increased likelihood of buy-in from and collaborative funding with non-Ryan White entities. Meanwhile, the barriers to care and patterns of successful entry into care for non-PLWH/As identified by such a survey are likely to apply to PLWH/As as well.

## 2. INTRODUCTION

Since the beginning of the HIV/AIDS epidemic, there have been remarkable advances in preventing and treating HIV/AIDS. The reduction in perinatal transmission, widespread availability and use of diagnostic and screening tests to promote individual knowledge of HIV infection status, and securing the nation's blood supply against contamination by this virus are only some of the impressive successes in the fight against this deadly communicable disease (CDC 2006f). Despite these successes, many challenges remain. One of the most bedeviling of these challenges concerns people who know that they are HIV positive but are not receiving HIV medical care, a circumstance HRSA refers to as "unmet need." To better address the changing landscape of the HIV/AIDS epidemic and work toward a more responsive system of HIV health care delivery, HRSA requires EMAs to assess and address unmet need, particularly unmet need among those from disproportionately affected and historically underserved populations.

The Greater Baltimore HIV Health Services Planning Council, also known as the planning council, commissioned this report with three objectives: (1) to learn more about reducing the time between an individual's receipt of a positive HIV diagnosis and his or her entry into HIV-related primary medical care; (2) to further understand what barriers keep certain groups of PLWH/As from accessing care earlier (e.g., availability of services, knowledge, beliefs, etc.); and (3) to learn about effective evidence-based strategies for contacting not-in-care PLWH/As in an effort to connect them to medical care earlier. The planning council's concerns are timely given the growing wave of concern nationwide surrounding the number of individuals infected with HIV who are not engaged in primary medical care.

As background to the problem of unmet need for HIV medical services in this area, sections 3 and 4 of this report offer socio-demographic and epidemiological profiles of the Baltimore EMA. In section 5, HRSA's various conceptual frameworks for estimating, assessing and addressing unmet need are described. Sections 6 and 7 present research findings relating to why some PLWH/As are not in care and how to correct this problem, including findings from two of the planning council's past consumer surveys. Section 8 briefly profiles local Ryan White program-funded outreach efforts, and conclusions and recommendations are presented in section 9. Section 10.1 offers an annotated list of particularly useful resources that local planners may wish to consult for ideas that might be adapted to local outreach and retention efforts. This report uses many acronyms; please refer to the appendix in section 10.2 for a key to these, as necessary.

### 3. PROFILE OF THE BALTIMORE EMA

Part A of the federal Ryan White program pays for HIV-related medical and support services in localities particularly hard hit by the HIV epidemic. These funds are disbursed to groups of local jurisdictions — typically a city and its surrounding suburbs — called eligible metropolitan areas (EMAs). The Baltimore EMA consists of Baltimore City and six neighboring counties. Within its boundaries, this EMA contains some of the poorest and wealthiest parts of Maryland; the resulting range of demographic, cultural and socio-economic diversity presents stiff challenges for planners attempting to improve care for the EMA’s more than 18,000 PLWH/As. This section of the report describes the geography of the Baltimore EMA, the demographic and socio-economic status of its populace, and the availability of health care in the area.

#### 3.1 Geography and Population

Situated in central Maryland, the Baltimore EMA includes Baltimore City (an independent jurisdiction equivalent to a county) and six surrounding counties: Anne Arundel, Baltimore, Carroll, Harford, Howard and Queen Anne’s. Although this region encompasses just over a quarter of Maryland’s total land area (2,608.9 out of 9,773.8 square miles), it is home to nearly half of the state’s population, or approximately 2.7 million of Maryland’s 5.9 million residents (MDP 2006f).

The seven jurisdictions that make up the Baltimore EMA are vastly different in terms of size and population density, as illustrated in table 1. The smallest of Maryland’s jurisdictions, covering only 80.8 square miles, Baltimore City is the most densely populated, with 7,869 persons per square mile. By contrast, Baltimore County, the largest of the jurisdictions within the EMA, covering 598.6 square miles and directly neighboring Baltimore City, has a population density of 1,313 persons per square mile. After Baltimore County, the second-largest EMA jurisdiction, Carroll County, has an area of 449.1 square miles and a population density of 375, followed — in descending order of size — by Harford County (size: 440.3 square miles; density: 543); Anne Arundel County (size: 415.9 square miles; density: 1,228); Queen Anne’s County (size: 372.2 square miles; density: 123); and Howard County (size: 252.0 square miles; density: 1,069) (MDP 2006f).

|                    | <i>A. Arundel</i> | <i>Balt. City</i> | <i>Balt. Co.</i> | <i>Carroll</i> | <i>Harford</i> | <i>Howard</i> | <i>Q. Anne’s</i> |
|--------------------|-------------------|-------------------|------------------|----------------|----------------|---------------|------------------|
| Area (sq. mi.)     | 415.9             | 80.8              | 598.6            | 449.1          | 440.3          | 252.0         | 372.2            |
| Population         | 510,878           | 635,815           | 786,113          | 168,541        | 239,259        | 269,457       | 45,612           |
| Population density | 1,228             | 7,869             | 1,313            | 375            | 543            | 1,069         | 123              |

Source: MDP 2001, 2006f.

Like the nation as a whole, the Baltimore EMA has seen a marked shift of its population from urban to sub- and exurban areas over the past several decades. This dramatic reduction in the urban population is consistent with the population trends that occurred nationwide beginning in the 1970s as one effect of the phenomenon of suburbanization, i.e., people leaving central cities to seek more space, lower crime rates and better schools in the outlying suburbs. As a result,

| <b>Table 2. Population for the EMA’s Jurisdictions, 1970 &amp; 2005</b> |             |             |               |
|---|-------------|-------------|---------------|
|   | <i>1970</i> | <i>2005</i> | <i>Change</i> |
| A. Arundel  | 297,539     | 510,878     | +71.7%        |
| Balt. City  | 905,759     | 635,815     | -29.8%        |
| Balt. Co.   | 621,077     | 786,113     | +26.6%        |
| Carroll   | 69,006      | 168,541     | +144.2%       |
| Harford   | 115,378     | 239,259     | +107.4%       |
| Howard  | 61,911      | 269,457     | +335.2%       |
| Q. Anne’s   | 18,422      | 45,612      | +147.6%       |
| Source: MDP 2003, 2006f.  |             |             |               |

many suburbs have experienced immense growth over the years in the phenomenon commonly referred to as “sprawl.”

As one illustration of this phenomenon, table 2 shows that, while Baltimore City’s population declined by 29.8 percent between 1970 and 2005 (from 905,759 to 635,815 residents), all other jurisdictions within the EMA witnessed remarkable growth during these years. Most striking is Howard County’s population increase of 335.2 percent (from 61,911 to 269,457), followed by — in descending order of growth — Queen Anne’s County (growth: 147.6 percent; from 18,422 to 45,612 residents); Carroll County

(growth: 144.2 percent; from 69,006 to 168,541 residents); Harford County (growth: 107.4 percent; from 115,378 to 239,259 residents); Anne Arundel County (growth: 71.7 percent; from 297,539 to 510,878 residents); and Baltimore County (growth: 26.6 percent; from 621,077 to 786,113 residents) (MDP 2003, 2006f).

### **3.2 Demographic Composition**

The Baltimore EMA is predominantly white, as can be seen in table 3. Baltimore City is the only jurisdiction in this EMA where the majority — almost two thirds — is black, accounting for 64.4 percent of the city’s population (MDP 2006d). Native Americans account for approximately 0.2 percent of the EMA’s total population. Howard and Baltimore counties are home to the majority of the Asian population within the EMA, with Asians representing 10.9 percent and 3.9 percent of the two counties’ populations, respectively (MDP 2006d, 2006b).

| Table 3. Population by Race for the EMA's Jurisdictions, 2005 |            |            |           |         |         |         |           |
|---|------------|------------|-----------|---------|---------|---------|-----------|
|   | A. Arundel | Balt. City | Balt. Co. | Carroll | Harford | Howard  | Q. Anne's |
| Total Population  | 510,878    | 635,815    | 786,113   | 168,541 | 239,259 | 269,457 | 45,612    |
| African-American  | 14.4%      | 64.4%      | 23.8%     | 2.9%    | 11.3%   | 15.8%   | 7.8%      |
| Asian-American*   | 2.8%       | 1.9%       | 3.9%      | 1.3%    | 1.9%    | 10.9%   | 0.9%      |
| Hispanic**  | 3.6%       | 2.2%       | 2.4%      | 1.5%    | 2.4%    | 4.0%    | 1.4%      |
| Nat. Am./Alaska Nat.  | 0.3%       | 0.3%       | 0.3%      | 0.2%    | 0.2%    | 0.2%    | 0.2%      |
| White Alone   | 77.4%      | 30.1%      | 68.4%     | 93.3%   | 82.8%   | 67.1%   | 89.0%     |
| Other***  | 1.5%       | 1.1%       | 1.2%      | 0.8%    | 1.4%    | 2.0%    | 0.7%      |

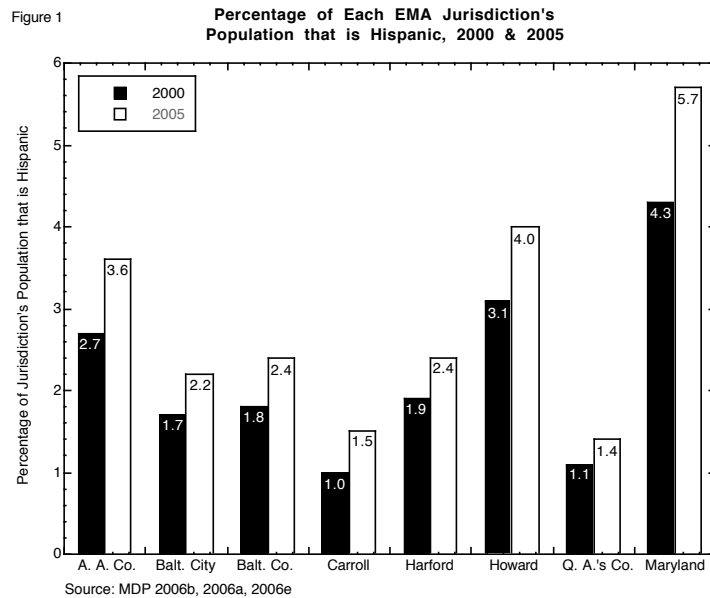
Source: MDP 2006d, 2006b.

\* The Asian-American population includes Native Hawaiian and other Pacific Islanders.

\*\* The Hispanic population is considered an ethnic and not a race category. Hispanics can be of any race, although in the Baltimore EMA the overwhelming majority (83.9 percent) is white.

\*\*\* The "other" category represents two or more races.

Statewide, minority population growth has made up nearly 96.0 percent of the total population growth from 2000 to 2005 (MDP 2006c). Among the fastest growing minority groups is the Hispanic population; due to the smaller population base, Hispanics had the largest percentage gains in Maryland during this time (from 4.3 percent of the state's population in 2000 to 5.7 percent in 2005) (MDP 2006e). This also holds true in the EMA. As can be seen in figure 1, each jurisdiction experienced an increase in its Hispanic population between 2000 and 2005. The jurisdiction with the largest proportion of Hispanic residents is Howard County, where the Hispanic population increased from 3.1 to 4.0 percent of county residents between 2000 and 2005. After Howard County, the jurisdiction with the second-highest proportion of Hispanic residents, Anne Arundel County, experienced an increase from 2.7 percent to 3.6 percent between 2000 and 2005,



followed — in descending order of the proportion of Hispanic residents — by Harford County (increased 1.9 to 2.4 percent); Baltimore County (increased 1.8 to 2.4 percent); Baltimore City (increased 1.7 to 2.2 percent); Carroll County (increased 1.0 to 1.5 percent); and Queen Anne's County (increased 1.1 to 1.4 percent) (MDP 2006b, 2006a).

### 3.3 Socio-economic Status

There are several important socio-economic differences between Baltimore City and the six surrounding counties of the Baltimore EMA. For one, the poverty rate in Baltimore City far surpasses the poverty rates in all six outlying counties. As table 4 shows, an estimated 18.8 percent of all families in Baltimore City live below the federal poverty level, compared to 3.6 percent in Anne Arundel County, 4.5 percent in Baltimore County, 2.7 percent in Carroll County, 3.6 percent in Harford County, 2.5 percent in Howard County and 4.4 percent in Queen Anne’s County. Moreover, for families with children under 18 and 5 years of age in Baltimore City, the poverty rate jumps to 26.2 percent and 32.2 percent, respectively (CB 2000a).

|  | <i>A. Arundel</i> | <i>Balt. City</i> | <i>Balt. Co.</i> | <i>Carroll</i> | <i>Harford</i> | <i>Howard</i> | <i>Q. Anne’s</i> |
|--|-------------------|-------------------|------------------|----------------|----------------|---------------|------------------|
| All families                                     | 3.6%              | 18.8%             | 4.5%             | 2.7%           | 3.6%           | 2.5%          | 4.4%             |
| Families with children < 18 yrs.                 | 5.1%              | 26.2%             | 6.5%             | 3.7%           | 5.1%           | 3.5%          | 6.6%             |
| Families with children < 5 yrs.                  | 6.6%              | 32.2%             | 8.3%             | 4.6%           | 7.4%           | 3.7%          | 7.5%             |
| All female-headed households*                    | 13.4%             | 31.5%             | 13.8%            | 13.6%          | 16.8%          | 10.1%         | 17.4%            |
| Female-headed households with children < 18 yrs. | 18.1%             | 38.3%             | 18.3%            | 19.6%          | 22.8%          | 13.4%         | 20.9%            |
| Female-headed households with children < 5 yrs.  | 28.2%             | 48.5%             | 26.8%            | 28.2%          | 35.3%          | 20.2%         | 41.9%            |

Source: CB 2000a.

\* Female-headed households are defined as households with no husband present.

Female-headed households — i.e., those with no husband present — experience the most severe poverty rates in all jurisdictions within the EMA, particularly in households with children under 18 and 5 years of age, also shown in table 4. In Baltimore City, the poverty rate soars to 38.3 percent among female-headed households with children under 18 years of age and 48.5 percent with children under 5 years of age (CB 2000a). In the surrounding jurisdictions, female-headed households with children under 18 and 5 years of age have the following respective poverty rates: 18.1 percent and 28.2 percent in Anne Arundel County; 18.3 percent and 26.8 percent in Baltimore County; 19.6 percent and 28.2 percent in Carroll County; 22.8 percent and 35.3 percent in Harford County; 13.4 percent and 20.4 percent in Howard County; and 20.9 percent and 41.9 percent in Queen Anne’s County (CB 2000a).

Low educational attainment and unemployment exacerbate the pervasive poverty in certain neighborhoods in Baltimore City, especially African-American communities. Citywide, nearly 60.0 percent of blacks 25 or older have less than or only a high school education — 9.4 percent have less than 9<sup>th</sup> grade, 22.2 percent have some high school education and only 28.2 percent have earned a high school diploma or the equivalent (CB 2000b). Furthermore, the overall unemployment rate<sup>1</sup> for Baltimore City, 6.0 percent, is two to three times as high as the rates in

<sup>1</sup> People are classified as unemployed if they do not have a job, are currently available for work and have actively

the outlying counties: 2.1 percent in Anne Arundel, 2.8 percent in Baltimore County, 1.9 percent in Carroll, 2.1 percent in Harford, 1.8 percent in Howard and 1.9 percent in Queen Anne's County (CB 2000b).

### 3.4 Snapshot of Baltimore City

The most populous city in the state of Maryland and a major U.S. seaport, Baltimore is home to 11.6 percent of Maryland's population, all living within 0.8 percent of the state's total land area (MDP 2006f). Over the years, blighted neighborhoods and dilapidated housing have marred much of Baltimore's landscape, particularly in areas situated west and east of downtown. These same neighborhoods are inundated with gang activity, violent crime, open-air drug markets and other unsafe living conditions. In fact, in a recent analysis of 2005 Federal Bureau of Investigation (FBI) crime statistics, Baltimore was ranked 2<sup>nd</sup> among the most dangerous cities with populations over 500,000, and ranked 12<sup>th</sup> overall among the total 371 cities ranked. However, cities with considerably smaller populations were identified as being much more dangerous, such as Camden, New Jersey (ranked: 5<sup>th</sup> overall; population: 79,904) (MQP 2006).

Homelessness is a persistent problem for many people in Baltimore City. The U.S. Department of Housing and Urban Development (HUD) considers a person to be homeless if that individual "lacks a fixed, regular, and adequate nighttime residence." Individuals residing in temporary living accommodations such as welfare hotels, congregate shelters and transitional housing for the mentally ill, "or a public or private place not designed for, or ordinarily used as, a regular sleeping accommodation for human beings (e.g., a car)," are considered homeless under HUD's definition (HUD 2006).

A Baltimore City homeless census conducted over the course of one night in January 2005 found nearly 3,000 individuals who fitted HUD's definition (BHS 2005). Of these nearly 3,000 individuals, over 75 percent were male, 82 percent were African-American and the median age was 44 years. Almost one third reported veteran status and more than half reported having completed at least high school (BHS 2005).<sup>2</sup>

As can be seen in table 5, survey respondents reported becoming homeless for a variety of reasons, including health or disability problems (38 percent), lack of income (23 percent), housing problems (15 percent), family problems (12 percent), discharge from an institution (5 percent) and unspecified reasons (7 percent). Lastly, and hardly surprisingly, over 60 percent of the people surveyed identified lack of affordable housing as their number one unmet need (BHS 2005).

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sought employment in the previous four weeks (BLS 2001). The latter is an important distinction. While unemployment rates only capture people actively seeking work, many additional people who are willing and able to work may have given up on finding a job and stopped looking, especially in an area that has recently lost so many blue-collar industrial jobs.

<sup>2</sup> The surprisingly high education level of this population, at least when compared to, say, the 28.2-percent rate of high-school completion among the city's African-American adults (mentioned earlier in section 3.3), is explained in part by the fact that so many of the city's homeless are military veterans; a high school diploma or GED is a standard prerequisite for joining any branch of the U.S. armed services.

It is estimated that between 3,000 and 4,000 individuals are homeless on any given night in Baltimore City. However, surveys like the one described above significantly under-represent

| <b>Table 5. Reported Reasons for Homelessness, Baltimore City, 2005</b> |          |
|---|----------|
| <i>Problem</i>  | <i>%</i> |
| Health or disability problem  | 38       |
| Lack of income  | 23       |
| Housing problem   | 15       |
| Family problem  | 12       |
| Discharge from an institution   | 5        |
| Unspecified   | 7        |
| Source: BHS 2005.<br>N = 2,943 respondents.                             |          |

those who are homeless for a short period of time, instead reflecting higher proportions of people who have been homeless for an extended period of time. In other words, the number of people who become homeless over the course of a year is much higher than those who are homeless at any given point in time. The official estimate is that just over 7,000 individuals of Baltimore City residents (or more than 1 percent of the population) will experience homelessness over the course of one year (BHS 2005).

Among several serious, chronic health-care issues homeless individuals often experience, it is estimated that 12 percent of Baltimore City’s homeless population is HIV positive (BHS 2005). (By comparison, only 2.3 percent of the city’s population as a whole is HIV positive.) Because of homeless

people’s limited access to health care, their acute and chronic health conditions, including HIV/AIDS, often worsen.

Contributing to the problem of homelessness in Baltimore City is the shortage of affordable housing (commonly defined as housing that costs no more than 30 percent of one’s annual income). When families and/or individuals need to spend too much of their incomes on housing, they may sacrifice other basic necessities, such as medical care. According to a 2006 report by the Baltimore Neighborhood Indicators Alliance (BNIA), in 2000, 40.0 percent of Baltimore households that rented, and 31.6 percent of households that owned, reported they paid more than 30 percent of their income on housing. Furthermore, the report found that in 2004, the proportion of properties where the owner was the principle resident (single family homes and condo units only) was 61.7 percent, a decrease from 2000, when 65.2 percent of the homes were occupied by the owner (BNIA 2006).

Additionally, according to the 2005 report on the Baltimore City homeless census, the waiting list for public housing exceeded 18,000 households, and the waiting list to enter the Section 8 rent-subsidy program contained 16,000 households with an expected wait time exceeding two years (BHS 2005).

Encouragingly, there is reason to hope for some improvements to the city’s overall housing situation. Over the last few years, the city has experienced renewal in several of its neighborhoods. Many neighborhoods are increasingly attracting young professionals seeking, for instance, more affordable housing options compared to the high cost of housing in other large cities (e.g., Washington, D.C.). Community development corporations, non-profit organizations that work to revitalize and rebuild neighborhoods and focus on housing production, economic development and job creation, are active in many parts of Baltimore City. The community development corporations work to leverage resources from private foundations, public agencies and other entities to improve the “bricks and mortar” in an area (BNIA 2006).

Also, several neighborhoods in Baltimore City have implemented the Healthy Neighborhoods Initiative (HNI), a program, initiated by former Mayor Martin J. O’Malley, which measures

various “vital signs” (crime rates, ownership rates, etc.) in target blocks and surrounding neighborhoods, in order to generate interest in investing in the rehabilitation of homes, strengthen the housing market and build the community. In 2002, the program was implemented in specific blocks in the following neighborhoods: Belair-Edison, Garwyn Oaks, Midtown, Southern Mondawmin, Ednor Gardens, Patterson Park and Reservoir Hill. In 2004, target blocks were added to the seven designated neighborhoods and three additional HNI areas were created: Greater Lauraville, Highlandtown and Charles Village (BNIA 2006).

### 3.5 Access to Health Care

Disease and disability disproportionately affect poor and underserved populations; in turn, these populations are also least likely to access acute care, let alone seek preventive and screening services. Because disease occurs within the context of economic status, social position, culture and physical environment, these circumstances help shape health outcomes and quality of life. Therefore, access to health care, or lack thereof, only partially explains such disparities. However, improving access to quality health care is the most direct step planners can take to improve health outcomes in a given area.

In the 2006 Baltimore Safety Net Access-to-Care survey conducted by Baltimore REACH (Research, Education, Advocacy and Community Health), a consortium promoting social justice and community health in Baltimore, 190 interviewer-administered surveys were conducted at nine “safety-net” provider sites<sup>3</sup> within the city of Baltimore. The results, although not surprising, reveal some important characteristics about the clients of these sites: the average annual income was \$9,276; 59.7 percent of participants had been without health insurance within the past two years; 52.6 percent suffered from a chronic mental health condition (44.2 percent of whom suffered depression); 55.0 percent reported unstable living conditions; and 35.0 percent reported they were recovering from drug addiction. Furthermore, of those without health insurance, 52.0 percent reported difficulty in accessing primary medical care, and 48.0 percent reported having difficulty accessing specialty care (BR 2006).

As the REACH survey suggests — and despite the state’s abundance of world-class health facilities and medical institutions — many Maryland residents face barriers in accessing quality, affordable health care. For individuals living with HIV/AIDS, accessing and maintaining the intensive medical care that is so often needed can be that much more of a burden. And an individual’s decision to seek care after being diagnosed with HIV is often influenced by outside forces (e.g., HIV-related stigma) or competing survival needs (e.g., housing, food, employment).

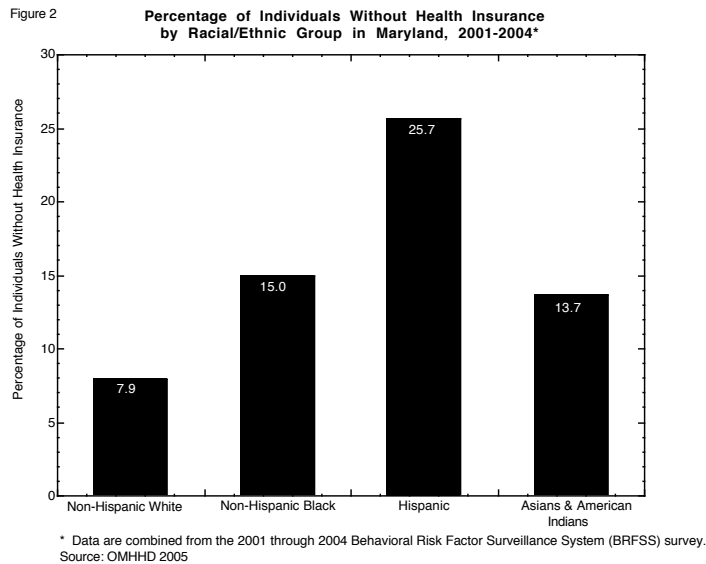
One of the biggest factors, of course, is health-insurance status: having no health insurance is an obvious barrier to obtaining timely and appropriate health care. Alarming, the number of uninsured individuals nationwide continues to rise. As of 2006, there were a record 46.1 million non-elderly Americans without health insurance, and even more who were considered underinsured. Moreover, 40 percent of the uninsured have no regular source of health care, and many delay or forego needed care to avoid medical bills (KFF 2006d). According to the Kaiser Family Foundation (KFF), 16.0 percent of Maryland’s non-elderly population (individuals 0-64 years of age) is without health insurance (KFF 2006c). As illustrated in figure 2, the uninsured are more likely to be members of a minority racial/ethnic group — 25.7 percent of Maryland’s Hispanics, 15.0 percent of Maryland’s non-Hispanic blacks, and 13.7 percent of Maryland’s

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<sup>3</sup> The nine “safety-net” provider sites include: Shepherd’s Clinic, Chase Brexton, Paul’s Place, Franciscan Center, Beans and Bread, Project PLASE, Open Gates, Adelante Familia and Caroline Street Clinic (BR 2006).

Asian and American Indians are without health insurance, as compared to 7.9 percent of Maryland's non-Hispanic white population (OMHHD 2005). (The relatively high proportion of uninsured Hispanics is probably partly explained by the large number of illegal immigrants in this population.)

Many uninsured people make use of hospital emergency rooms as their primary providers of health care. Not surprisingly, then, given the rise in the number of uninsured individuals, hospital emergency-room visits in Maryland have increased steadily in recent years, from 322 per 1,000 in 1999 to 389 per 1,000 in 2004 (KFF 2006c).



### 3.6 Conclusion

The Baltimore EMA is home to more than half of Maryland's population (2.7 million out of Maryland's 5.9 million people), and — as this section has illustrated — is comprised of a diversity of people with varied demographic and socio-economic backgrounds. Most striking is the contrast between the demographic and socio-economic characteristics of Baltimore City's residents and that of the neighboring jurisdictions that comprise the EMA.

Covering only 80.8 square miles, Baltimore City is the most densely populated jurisdiction not only within the EMA but also statewide, with 7,869 persons per square mile and a total population estimated at 635,815. Baltimore City is the only jurisdiction within the EMA where the majority — almost two thirds — is black, accounting for 64.4 percent of the city's population.

The city's poverty rate far surpasses the poverty rates in all six outlying counties — 18.8 percent of all families are living below the federal poverty level in Baltimore City compared to 4.5 percent in Baltimore County, 4.4 percent in Queen Anne's County, 3.6 percent in Anne Arundel County, 3.6 percent in Hartford County, 2.7 percent in Carroll County and 2.5 percent in Howard County. These poverty rates climb alarmingly higher in all jurisdictions when factoring in families and female-headed households with children under 18 and 5 years of age, most markedly in Baltimore City.

Low rates of educational attainment and employment, with significant attendant socio-economic implications, further distinguish Baltimore City from the outlying jurisdictions and illuminate the pervasive poverty that afflicts certain neighborhoods in the city, especially African-American communities. Nearly two thirds of the city's African-Americans 25 or older have only a high school education or less, and the unemployment rate is two to three times as high as rates in the outlying counties.

One of the fastest growing groups in the EMA is the Hispanic population. Between 2000 and 2005, the EMA, like the rest of the state, experienced an increase in its Hispanic population, most

of all in Howard County. Because of the various language, cultural and — for the many undocumented immigrants in their ranks — legal barriers Hispanics face when seeking medical care, the EMA’s planners must pay special attention to this population.

As the planning council continues to work in tandem with medical providers, community-based organizations and others to effectively respond to the changing needs of its PLWH/As, the geographic, demographic and socio-economic context in which the disease occurs is highly significant and must not be overlooked.

#### 4. EPIDEMIOLOGICAL PROFILE OF THE BALTIMORE EMA

Epidemiology is the study of the patterns, causes and control of health-related conditions or events (Green and Kreuter 1999). As this section will explain, the HIV/AIDS epidemic today disproportionately affects communities of color, which already tend to be plagued with high rates of substance abuse, incarceration, poverty, low educational attainment and homelessness.

In 2002, despite over 10 years of CARE Act funding for the Baltimore EMA, the mayor and city council president of Baltimore found it necessary to declare a state of emergency regarding HIV/AIDS because of the pervasive and severe impact the epidemic was continuing to have on the city (BCCC 2002). In a 2005 report, the Baltimore City Commission on HIV/AIDS re-emphasized that the city faces what amounts to an ongoing public-health crisis where HIV is concerned. The commission found that, in certain ZIP codes and among certain age groups, HIV-infection rates rivaled those in sub-Saharan Africa (BCCC 2005).

**Table 6. Ten Highest U.S. AIDS Case Rates, 2005**

| State              | Cases per 100,000 |
|--------------------|-------------------|
| D.C.               | 128.4             |
| New York           | 32.7              |
| Maryland           | 28.5              |
| Florida            | 27.9              |
| Georgia            | 25.7              |
| Louisiana          | 21.2              |
| Delaware           | 20.9              |
| Connecticut        | 19.9              |
| South Carolina     | 15.7              |
| U.S. Case Rate     | 14.0              |
| Source: KFF 2006b. |                   |

In fact, as can be seen in table 6, in 2005 the state of Maryland had the third-highest AIDS-case rate in the U.S., behind only the District of Columbia and New York state (KFF 2006b). While often classified as a state for reporting purposes, Washington is really better thought of as a city. This being the case, Maryland, among actual states, ranks second in AIDS caseload, behind only New York state, and then not by much.

To successfully respond to the epidemic and curb its transmission, it is imperative to understand where and in which populations HIV/AIDS is spreading most rapidly and what disparities in access to medical care these populations face. Section 4 describes the HIV/AIDS epidemic in the Baltimore EMA and analyzes recent trends in area incident (newly diagnosed) and prevalent (living) HIV and AIDS cases. Next, it discusses the number of deaths among PLWH/As since the beginning of the HIV/AIDS epidemic in Maryland and describes the distribution of PLWH/A deaths in the EMA. It then provides a profile of the EMA's PLWH/As by race, gender, age and mode of transmission.

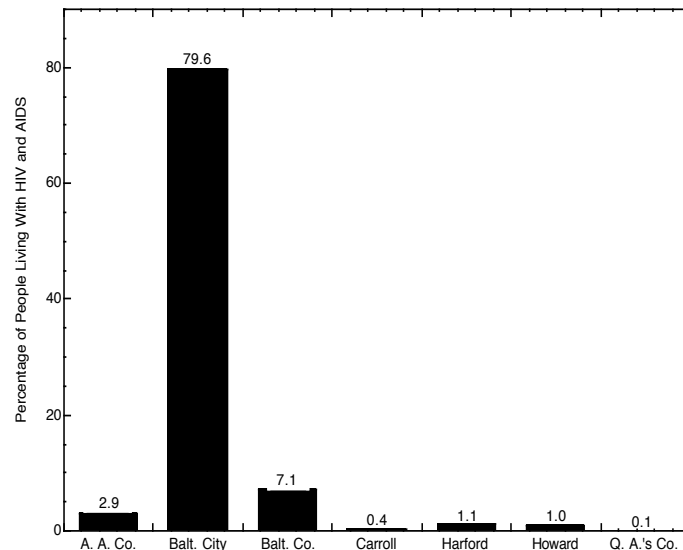
Because half of Maryland's PLWH/As live in Baltimore City, the section then examines the distribution of HIV/AIDS cases within Baltimore City and takes a closer look at parts of two example city ZIP codes that are particularly hard-hit. The section closes by examining subpopulations of particular concern in the EMA, followed by the socio-economic impact of the HIV/AIDS epidemic.

## 4.1 HIV/AIDS in the Baltimore EMA

According to the Maryland AIDS Administration, the number of Marylanders living with HIV/AIDS, as reported through March 2006, is about 29,247, of whom 62.1 percent (about 18,153 individuals) reside within the Baltimore EMA. As shown in figure 3, of the 18,153 PLWH/As within the Baltimore EMA, the vast majority, or nearly 80 percent, live in Baltimore City, followed by Baltimore County (7.1 percent), Anne Arundel County (2.9 percent); Harford County (1.1 percent); Howard County (1.0 percent); Carroll County (0.4 percent) and Queen Anne's County (0.1 percent) (DHMH 2006c). In fact, Baltimore City alone is home to just under half of all people living with HIV/AIDS in Maryland.

Figure 3

Distribution of the EMA's PLWH/As by Jurisdiction, 2006



Source: DHMH 2006c

Note: living cases on 03/31/05 as reported through 03/31/06.

### 4.1.1 Incidence

The incidence of a disease is defined as the number of new cases that occur during a specified period of time in a population at risk for developing the disease (Gordis 2000). Incidence is a measure of risk. It is a key indicator in determining where a disease is spreading most rapidly and, consequently, which populations should be targeted for prevention programs.

The numbers of newly diagnosed HIV and AIDS cases in a given year are used as measures of incident cases. Incident HIV (non-AIDS) case measures include individuals who progressed to AIDS within the same calendar year as their HIV diagnosis. Because there is a lag time in Maryland between diagnosis of an HIV or AIDS case and its entry into the respective registry, incidence data may be underestimated (DHMH 2005a).<sup>4</sup>

Following an all-time peak in 1994 of 2,611 new AIDS cases, Maryland experienced a steady decline through 1999, due in large part to the advent of antiretroviral therapy (ART) in the mid-1990s (DHMH 2005b). Despite continuing advancements in treatment and medical care, the number of newly diagnosed AIDS cases statewide has at times increased again since 1999: 1,317 cases in 2000; 1,750 cases in 2001; 1,807 cases in 2002; and 1,528 cases in 2003 (DHMH 2005a).

<sup>4</sup> The average time from diagnosis to report for HIV cases is less than one month and the average time from an AIDS diagnosis to entry into the AIDS registry is approximately five to six months (DHMH 2005a).

More recently, between 2004 and 2005, the number of newly diagnosed AIDS cases in Maryland rose from 1,474 to 1,665, as shown in table 7 (DHMH 2006c). This one-year, 13.0 percent increase in AIDS diagnoses in Maryland parallels the national AIDS-case-rate increase, which, during this same period, rose 12.0 percent (KFF 2006b). Of Maryland’s new AIDS cases, the Baltimore EMA accounted for 63.2 percent in 2004 and 63.8 percent in 2005. Within the EMA, the majority of new AIDS cases were reported in Baltimore City (76.9 percent in 2004; 78.8 percent in 2005). The corrections populations accounted for 5.3 percent of new AIDS cases in Maryland in 2004 and 4.0 percent in 2005 (DHMH 2006c).

| <b>Table 7. HIV and AIDS Incidence (New Cases) in 2004 and 2005</b> |                       |            |            |            |  |                       |            |            |         |
|---|-----------------------|------------|------------|------------|--|-----------------------|------------|------------|---------|
|   | <i>2004 Incidence</i> |            |            |            |  | <i>2005 Incidence</i> |            |            |         |
|   | HIV Cases             | % of Total | AIDS Cases | % of Total |  | HIV Cases             | % of Total | AIDS Cases | % Total |
| Maryland total  | 2,132                 | 100        | 1,474      | 100        |  | 2,401                 | 100        | 1,665      | 100     |
| Balt. EMA   | 1,370                 | 64.3       | 931        | 63.2       |  | 1,572                 | 65.5       | 1,063      | 63.8    |
| Corrections   | 78                    | 3.7        | 76         | 5.2        |  | 83                    | 3.5        | 67         | 4.0     |

Source: DHMH 2006c.

HIV incidence per 100,000 = (# of new HIV cases reported during a specified period of time / # of persons at risk of developing HIV during that time) x 100,000.

2004 cases reported from 04/01/04 to 03/31/05.

2005 cases reported from 04/01/05 to 03/31/06.

Since 1994, when Maryland added an HIV-surveillance program to its already established AIDS-surveillance program, the number of new HIV cases has decreased steadily, from 3,135 new HIV cases in 1994 to 1,941 in 2003 (DHMH 2005a). However, recent statistics are troubling: along with the increase in newly diagnosed AIDS cases observed between 2004 and 2005, there has been an upturn in new HIV cases, as well. As table 7 illustrates, in 2004, 2,132 new HIV cases were reported statewide, and, in 2005, 2,401 new HIV cases were reported, a 12.6 percent increase between 2004 and 2005 (DHMH 2005a, 2006c). Meanwhile, those housed in state correctional facilities accounted for 3.7 percent all new HIV cases statewide in 2004 and 3.5 percent in 2005 (DHMH 2006c).

Each year, over half of all new HIV cases statewide are reported in Baltimore City. Within the Baltimore EMA, which as a whole represented 64.3 percent of all new HIV cases reported in Maryland in 2004 and 65.5 percent in 2005, Baltimore City accounted for 79.0 percent of new EMA cases in 2004 and 79.5 percent in 2005, as illustrated in table 8. Following Baltimore City — in descending order of new HIV cases in 2004 and 2005, respectively — is Baltimore County (11.4 percent; 11.1 percent); Anne Arundel County (5.3 percent; 5.0 percent); Harford County (2.6 percent; 2.5 percent); Howard County (1.4 percent; 1.5 percent); Carroll County (0.3 percent; 0.2 percent); and Queen Anne’s County (0.1 percent; 0.2 percent).

| Table 8. HIV and AIDS Incidence (New Cases) in the Baltimore EMA in 2004 and 2005 |                |            |            |            |                |            |            |            |  |
|---|----------------|------------|------------|------------|----------------|------------|------------|------------|--|
|   | 2004 Incidence |            |            |            | 2005 Incidence |            |            |            |  |
|   | HIV Cases      | % of Total | AIDS Cases | % of Total | HIV Cases      | % of Total | AIDS Cases | % of Total |  |
| Balt. EMA total   | 1,370          | 100        | 931        | 100        | 1,572          | 100        | 1,063      | 100        |  |
| A. Arundel  | 72             | 5.3        | 59         | 6.3        | 79             | 5.0        | 44         | 4.1        |  |
| Balt. City  | 1,082          | 79.0       | 716        | 76.9       | 1,249          | 79.5       | 838        | 78.8       |  |
| Balt. Co.   | 156            | 11.4       | 113        | 12.2       | 174            | 11.1       | 127        | 11.9       |  |
| Carroll   | 4              | 0.3        | 5          | 0.5        | 4              | 0.2        | 5          | 0.5        |  |
| Harford   | 35             | 2.6        | 17         | 1.8        | 39             | 2.5        | 19         | 1.8        |  |
| Howard  | 19             | 1.4        | 20         | 2.2        | 23             | 1.5        | 24         | 2.3        |  |
| Q. Anne's   | 2              | 0.1        | 1          | 0.1        | 4              | 0.2        | 6          | 0.6        |  |

Source: DHMH 2006c.

Columns may not total 100 percent due to rounding.

HIV incidence per 100,000 = (# of new HIV cases reported during a specified period of time / # of persons at risk of developing HIV during that time) x 100,000.

2004 cases reported from 04/01/04 to 03/31/05.

2005 cases reported from 04/01/05 to 03/31/06.

### 4.1.2 Prevalence

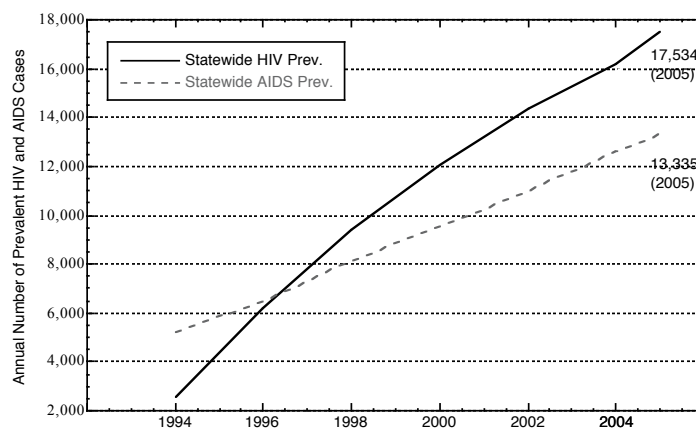
Prevalence is defined as the number of cases of a disease present in a given population divided by the total number of persons in that population (Gordis 2000). The measurement is an essential indicator for health planners interested in targeting specific populations for medical care and disease prevention.

When analyzing the prevalence of HIV/AIDS, it is important to consider the effect that highly active anti-retroviral therapy (HAART) and other advancements in HIV treatment have had on survival rates. Marked and sustained reductions in AIDS-related deaths and opportunistic diseases have been observed in the U.S. as a result of the extensive use of HAART regimens since 1996, meaning that — even if HIV-incidence rates remained flat over time — one would expect to see an increasing number of PLWH/As living longer, i.e., an increasing rate of prevalence.

Maryland's HIV- and AIDS-case prevalence trends can be seen as fitting this very scenario. Every year since case-reporting began, the prevalence of HIV and AIDS cases has grown fairly

Figure 4

HIV and AIDS Prevalence in Maryland:  
Annual Number of Living Cases, 1994 - 2005



Source: DHMH 2006c

consistently. As can be seen in figure 4, in 1994, there were 2,597 living HIV and 5,226 living AIDS cases in Maryland, and in 2005, there were 17,534 living HIV and 13,335 living AIDS cases (DHMH 2006c).<sup>5</sup> The lines cross at around the time HAART became available, with the HIV-prevalence line rising above the AIDS-prevalence line for the first time, perhaps because, from that point onward, the average person with HIV (who had access to HAART) was slower to develop AIDS.

As shown in table 9, there were an estimated 29,247 PLWH/As in Maryland (16,412 prevalent HIV/non-AIDS cases and 12,835 prevalent AIDS cases) as of March 2006. Maryland’s corrections population accounts for an estimated 9.1 percent of all PLWH/As statewide, or roughly 2,660 infected individuals (10.8 percent of these inmates are living with HIV and 7.0 percent are living with AIDS).<sup>6</sup> Also, as can be seen in table 9, the Baltimore EMA is home to well over half (62.1 percent) of Maryland’s PLWH/As (62.7 percent of Marylanders living with HIV and 61.2 percent of Marylanders living with AIDS) (DHMH 2006c).

| <b>Table 9. HIV and AIDS Prevalence (Living Cases), 2005</b> |            |                  |             |                  |                   |                  |
|--|------------|------------------|-------------|------------------|-------------------|------------------|
|  | <i>HIV</i> |                  | <i>AIDS</i> |                  | <i>HIV + AIDS</i> |                  |
|  | Cases      | % of Md. PLWH/As | Cases       | % of Md. PLWH/As | Cases             | % of Md. PLWH/As |
| Maryland total   | 16,412     | 100              | 12,835      | 100              | 29,247            | 100              |
| Balt. EMA  | 10,294     | 62.7             | 7,859       | 61.2             | 18,153            | 62.1             |
| Corrections  | 1,767      | 10.8             | 893         | 7.0              | 2,660             | 9.1              |

Source: DHMH 2006c.

HIV prevalence per 100,000 = (# of HIV cases present in a population at a specified time / # of persons in the population at that specified time) x 100,000.

Cases reported from 03/31/05 through 03/31/06.

As illustrated in table 10, Baltimore City contains 79.6 percent of the EMA’s prevalent HIV and AIDS cases, followed — in descending order of prevalence rates — by Baltimore County (11.4 percent); Anne Arundel County (4.7 percent); Harford County (1.8 percent); Howard County (1.6 percent); Carroll County (0.7 percent); and Queen Anne’s County (0.2 percent) (DHMH 2006c).

<sup>5</sup> By the CDC’s estimates, these numbers under-represent the true magnitude of the epidemic as they reflect only the reported cases; it is estimated that a quarter (or one in every four individuals) of the population living with HIV/AIDS does not know it is infected (KFF 2006).

<sup>6</sup> This number, however, presumably understates the number of PLWH/As in Maryland’s correctional facilities because, unlike in 35 other states, HIV testing is not mandatory upon incarceration in Maryland.

| Table 10. HIV and AIDS Prevalence (Living Cases) in the Baltimore EMA, 2005 |        |            |       |            |            |            |
|---|--------|------------|-------|------------|------------|------------|
|   | HIV    |            | AIDS  |            | HIV + AIDS |            |
|   | Cases  | % of Total | Cases | % of Total | Cases      | % of Total |
| Balt. EMA total   | 10,294 | 100        | 7,859 | 100        | 18,153     | 100        |
| A. Arundel  | 429    | 4.2        | 433   | 5.5        | 862        | 4.7        |
| Balt. City  | 8,302  | 80.6       | 6,141 | 78.1       | 14,443     | 79.6       |
| Balt. Co.   | 1,157  | 11.2       | 919   | 11.7       | 2,076      | 11.4       |
| Carroll   | 84     | 0.8        | 47    | 0.6        | 131        | 0.7        |
| Harford   | 161    | 1.6        | 161   | 2.1        | 322        | 1.8        |
| Howard  | 146    | 1.5        | 139   | 1.8        | 285        | 1.6        |
| Q. Anne's   | 15     | 0.1        | 19    | 0.2        | 34         | 0.2        |

Source: DHMH 2006c.

HIV prevalence per 100,000 = (# of HIV cases present in the population at a specified time / # of persons in the population at that specified time) x 100,000.

Cases reported from 03/31/05 through 03/31/06.

### 4.1.3 Deaths among PLWH/As

From the beginning of the AIDS epidemic in 1981, a total of 29,372 individuals were diagnosed with AIDS in Maryland through March 2006, of whom 15,930 (54.2 percent) had by that time died (DHMH 2006c), though not necessarily all of AIDS.<sup>7</sup> Between 1997 and 2004, the number of deaths among AIDS patients statewide has remained relatively stable, averaging 700 deaths per year (DHMH 2005a). Between 2005 and 2006, 921 AIDS deaths were reported statewide, 60.5 percent of which were reported in the EMA (DHMH 2006c). Within the EMA, 81.7 percent of AIDS deaths were in Baltimore City, followed — in descending order — by Baltimore County (10.8 percent); Anne Arundel County (4.5 percent); Harford County (1.3 percent); Howard County (1.1 percent); Queen Anne’s County (0.7 percent); and Carroll County (0 percent) (DHMH 2006c).

Strikingly, when compared with AIDS death rates in all Maryland counties, the state’s incarcerated population experienced the fifth largest number of AIDS deaths during this period of time, accounting for 5.8 percent of the state’s total AIDS deaths. This is a larger share of the state’s AIDS deaths than 5 of the 7 EMA jurisdictions, and, statewide, it lags behind only Baltimore City (56.6 percent), Prince George’s County (14.7 percent), Montgomery County (7.2 percent) and Baltimore County (6.5 percent) (DHMH 2006c). The number of deaths among HIV-positive individuals who have not developed AIDS is relatively small in number, totaling only 828 from 1994 through 2004 (DHMH 2005a).

## 4.2 Profile of PLWH/As by Race, Gender, Age and Exposure in the EMA

To better understand the impact of HIV/AIDS on the Baltimore EMA, it is important to examine the characteristics of those most affected. This section profiles EMA PLWH/As by race, gender, age and mode of transmission.

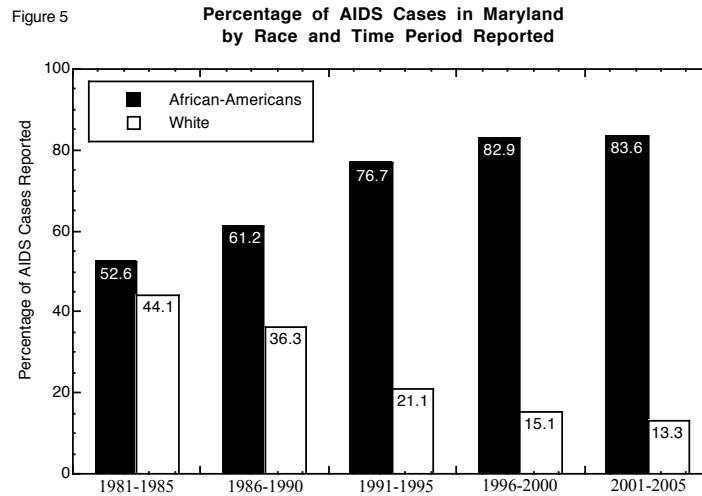
<sup>7</sup> AIDS and HIV deaths, as reported by the Maryland Department of Health and Mental Hygiene (DHMH), include all causes of death (DHMH 2006a).

### 4.2.1 Race Distribution of PLWH/As

African-Americans in Maryland and nationwide become infected with, and die from, HIV/AIDS far more than any other racial or ethnic group. The epidemic’s racial divide is not new, and the disease has long wreaked havoc on many African-American communities throughout the U.S., including in Maryland.

Especially in such communities, the disease has thus far outpaced efforts to control it using standard public-health infection-control procedures.

As illustrated in figure 5, dramatic shifts have occurred over the years in the relative proportions of African-Americans and whites infected with AIDS in Maryland (DHMH 2005b). From 1981 through 1985, African-Americans represented 52.6 percent of AIDS cases, while the white population accounted



Source: DHMH 2005b

for 44.1 percent. Since then, the disparity between blacks and whites in annual rates of AIDS has dramatically widened. Between 2001 and 2005, African-Americans represented 83.6 percent of AIDS cases in Maryland compared to the mere 13.3 percent represented by whites (DHMH 2005b).

African-Americans, although representing only somewhat over a quarter of the state’s population (MDP 2006e), accounted for 79.0 percent of the state’s newly diagnosed HIV cases and 84.1 percent of newly diagnosed AIDS cases as of March 2005, as illustrated in table 11 (DHMH 2006c). These rates were strikingly higher than the proportions of new HIV and AIDS cases that were white (15.2 and 12.3 percent, respectively), Hispanic (1.8 and 2.8 percent, respectively) or some “other” race (3.8 and 0.8 percent, respectively).

| <b>Table 11. Maryland HIV and AIDS Incidence by Race/Ethnicity, 2004</b> |                  |                   |                   |                   |
|--|------------------|-------------------|-------------------|-------------------|
|  | <i>HIV Cases</i> |                   | <i>AIDS Cases</i> |                   |
|  |                  | <i>% of Total</i> |                   | <i>% of Total</i> |
| Maryland   | 2,132            | 100               | 1,474             | 100               |
| White  | 236              | 15.2              | 182               | 12.3              |
| African-American   | 1,225            | 79.0              | 1,239             | 84.1              |
| Hispanic   | 31               | 1.8               | 41                | 2.8               |
| Other  | 59               | 3.8               | 12                | 0.8               |
| Missing*   | 581              | 0                 | 0                 | 0                 |

Source: DHMH 2006c.  
 Cases reported from 04/01/04 to 03/31/05.  
 \*Cases with missing race are excluded from percent distributions.

Moreover, as table 12 shows, African-Americans accounted for 81.7 percent of all living HIV/AIDS cases statewide as of March 2006, compared to the 14.8 percent of cases that were white, the 2.1 percent of cases that were Hispanic and the 1.4 percent that were some “other” race (DHMH 2006c).

| <b>Table 12. Maryland HIV and AIDS Prevalence by Race/Ethnicity, 2004</b> |            |                   |             |                   |                   |                   |  |
|---|------------|-------------------|-------------|-------------------|-------------------|-------------------|--|
|   | <i>HIV</i> |                   | <i>AIDS</i> |                   | <i>HIV + AIDS</i> |                   |  |
|   | Cases      | <i>% of Total</i> | Cases       | <i>% of Total</i> | Cases             | <i>% of Total</i> |  |
| Maryland total  | 16,412     | 100               | 12,835      | 100               | 29,247            | 100               |  |
| White   | 1,817      | 13                | 2,090       | 16.3              | 3,907             | 14.8              |  |
| African-American  | 11,235     | 82                | 10,336      | 80.5              | 21,571            | 81.7              |  |
| Hispanic  | 216        | 1.6               | 347         | 2.7               | 563               | 2.1               |  |
| Other   | 302        | 2.2               | 62          | 0.5               | 364               | 1.4               |  |
| Missing*  | 2,842      | 0                 | 0           | 0                 | 2,842             | 0                 |  |

Source: DHMH 2006c.  
 Cases reported on 03/31/05, as reported through 03/31/06.  
 \*Cases with missing race are excluded from percent distributions.

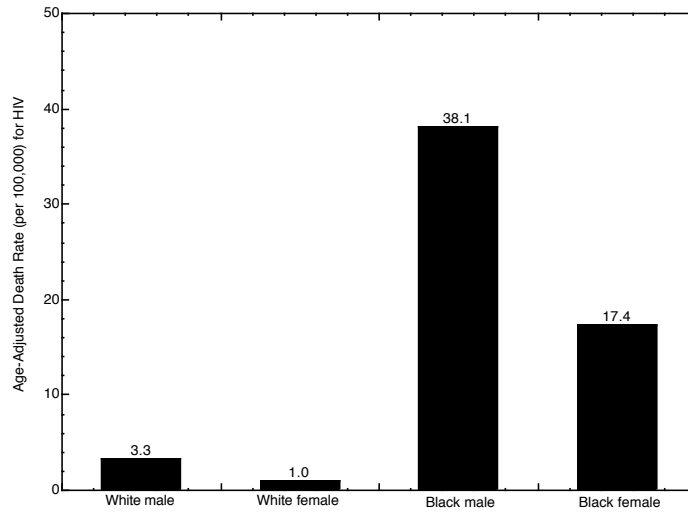
The racial disparities in deaths due to HIV/AIDS, especially for African-Americans, are cause for further concern. According to the Maryland Department of Health and Mental Hygiene (DHMH), HIV/AIDS in Maryland is the second leading cause of death among African-American women 25-44 years old and the fourth leading cause of death among African-American women 45-64 years old. By contrast, among white women 25-44 years old, HIV/AIDS is the seventh leading cause of death, and, for white women 45-64 years old, HIV/AIDS is simply not a common cause of death at all (DHMH 2005c).

Similarly, HIV/AIDS is the third leading cause of death among African-American men 25-64 years old (DHMH 2005c). By contrast, HIV/AIDS is the seventh leading cause of death among

white men 25-44 years old, and, among white men 45-64 years old, HIV is off the radar as a common cause of death (DHMH 2005c).

Furthermore, as seen in figure 6, Maryland's age-adjusted death rates<sup>8</sup> (per 100,000 population) for HIV among black males and females is 38.1 and 17.4, respectively, compared to only 3.3 and 1.0 for white males and females, respectively (DHMH 2005c). These disparities may be due to the higher poverty rates among African-Americans, which in turn may result in late HIV diagnosis and/or delayed entry into medical care, possibly along with other unhealthy lifestyle and living-condition factors.

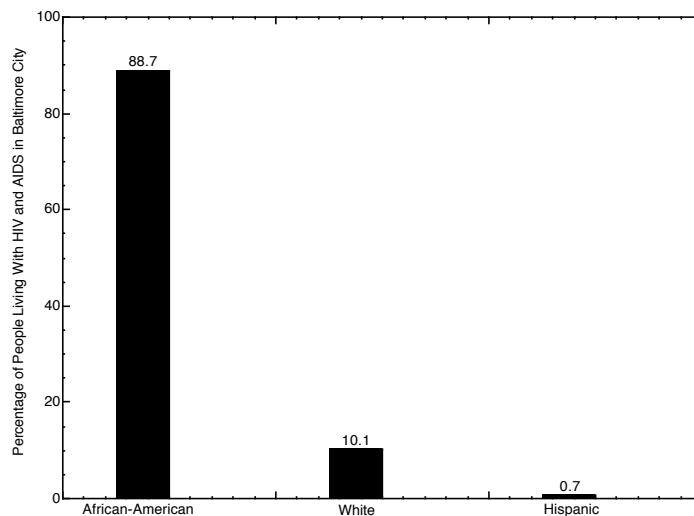
Figure 6 Age-Adjusted Death Rate for HIV by Race and Sex, Maryland, 2005



Source: DHMH 2005c

Baltimore City, the epicenter of the HIV/AIDS epidemic in Maryland, is home to approximately 14,443 PLWH/As, or just under half (49.4 percent) of the state's total number of living HIV/AIDS cases. As illustrated in figure 7, of the 14,443 PLWH/As in Baltimore City, an estimated 88.7 percent are African-American, followed by 10.1 percent who are white and 0.7 percent who are Hispanic (DHMH 2006a).

Figure 7 People Living With HIV and AIDS in Baltimore City by Race/Ethnicity as of March 2006



Source: DHMH 2006c

Looking beyond Baltimore City at the surrounding jurisdictions of the EMA, the racial disparities in the disease's effects are even starker. Although African-Americans represent only a small proportion of the county populations, they are much more heavily affected by the HIV/AIDS epidemic than are whites and other races.

<sup>8</sup> An age-adjusted death rate is a method used for comparing mortality differences across age groups in a given population by taking into account and correcting for the fact that people naturally die at different rates at different ages, independent of the particular cause of death being analyzed. Death rates can just as easily be adjusted for any characteristic such as sex, socio-economic status or race, and techniques are available to adjust for multiple variables simultaneously.

In Anne Arundel County, for example, African-Americans make up only 14.4 percent of the population, yet account for an estimated 53.0 percent of the county’s PLWH/As. In Baltimore County, African-Americans represent 23.8 percent of the population but account for an estimated 57.4 percent of the county’s HIV/AIDS cases. African-Americans are only 2.9 percent of Carroll County’s population but account for an estimated 40.6 percent of the county’s HIV/AIDS cases. In Harford County, African-Americans constitute 11.3 percent of the population but 48.5 percent of the county’s PLWH/As. African-Americans represent 15.8 percent of Howard County’s population, yet account for an estimated 50.7 percent of the county’s PLWH/As. Lastly, in Queen Anne’s County, African-Americans are 7.8 percent of the population but 41.7 percent of the county’s PLWH/As (DHMH 2006b).

Other racial and ethnic minorities residing in the Baltimore EMA represent even smaller proportions of the jurisdictions’ populations, and — unlike African-Americans — are under-represented among the EMA’s total living HIV and AIDS cases. Hispanics, for instance, are approximately 2.5 percent of the EMA’s total population but account for only 2.2 percent of the EMA’s total living HIV and AIDS cases (MDP 2006f, 2006b, 2006a, DHMH 2006b). The Asian and Native American populations make up an estimated 3.4 and 0.2 percent of the EMA’s total population respectively, while accounting for only approximately 0.4 and 0.6 percent of the EMA’s PLWH/As (MDP 2006d, 2006c; DHMH 2006b).

#### 4.2.2 Gender Distribution of PLWH/As

When AIDS first emerged in Maryland in the 1980s, those affected were predominantly male. As can be seen in table 13, between 1981 and 1985, males accounted for 91.1 percent of AIDS cases. However, over the years, the gap between male and female AIDS-infected populations has gradually narrowed. Between 1991 and 1995, Maryland AIDS cases were 77.1 percent male and 22.9 percent female, and, between 2001 and 2005, Maryland AIDS cases were 64.7 percent male and 35.3 percent female (DHMH 2005b).

| <b>Table 13. Percentage of AIDS Cases in Maryland by Gender and Time Period</b> |                  |                  |                  |                  |                  |
|---|------------------|------------------|------------------|------------------|------------------|
|   | <i>1981-1985</i> | <i>1986-1990</i> | <i>1991-1995</i> | <i>1996-2000</i> | <i>2001-2005</i> |
| Male  | 91.1             | 85.0             | 77.1             | 69.3             | 64.7             |
| Female  | 8.9              | 15.0             | 22.9             | 30.7             | 35.3             |
| Source: DHMH 2005b.   |                  |                  |                  |                  |                  |

This gender gap has closed slightly more among African-Americans. Of the 29,247 PLWH/As in Maryland as of March 2005, 21,571 were African-American, 63.8 percent of whom were

male and 36.2 percent of whom were female. Recent trends reveal a growing number of African-American women living with HIV, and, as of December 2004, African-American women accounted for 83.5 percent of prevalent HIV cases among women in Maryland (DHMH 2006c). Among the EMA’s PLWH/As, 62.8 percent are male and 37.2 percent are female (DHMH 2005a).

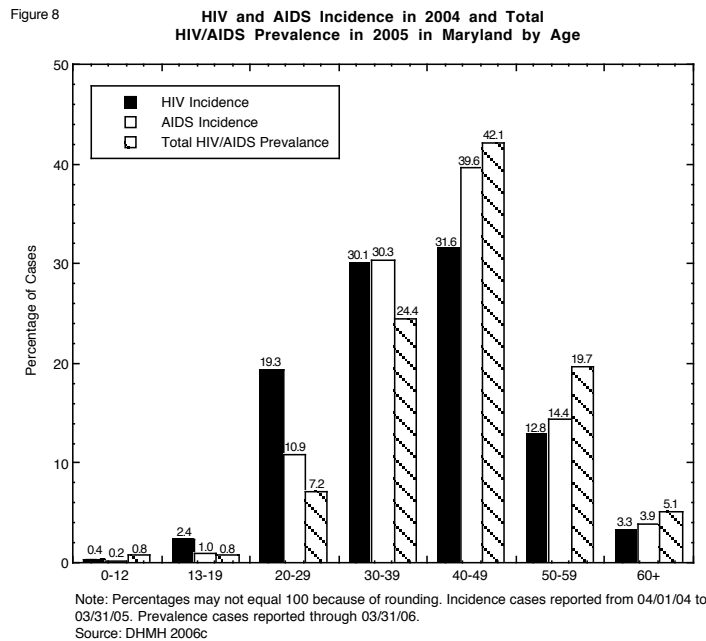
### 4.2.3 Age Distribution of PLWH/As

Over the years of the epidemic, there have been remarkable advances in preventing and treating HIV/AIDS; one such success is the dramatic reduction in mother-to-child (i.e., perinatal) transmission. In effect, this has led to fewer children becoming infected with HIV/AIDS in Maryland, as elsewhere. However, Maryland children less than 12 years of age are not untouched by this disease. Figure 8 shows Maryland's incident HIV/AIDS cases reported from April 2004 through March 2005 and prevalent HIV/AIDS cases reported through March 2006, by age. As shown in figure 8, between April 2004 and March 2005, children 12 years old or younger accounted for 0.4 percent of the state's new HIV cases, 0.2 percent of the state's new AIDS cases and 0.8 percent of the state's living HIV/AIDS cases. As of March 2006, there were 171 children 0-12 years of age (32 of whom were 0-4 years old and 139 of whom were 5-12 years old) living with HIV and 56 children living with AIDS (4 of whom were 0-4 years old and 52 of whom were 5-12 years old) in Maryland, the majority of whom resided in Baltimore City (DHMH 2006b, 2006c).

Throughout Maryland, the prevalence of HIV and AIDS, as well as the incidence of AIDS, is highest among those who are between the ages of 40-49 years, followed by those 30-39 years and 50-59 years old, as shown in figure 8. In summary, 42.1 percent of Maryland PLWH/As are 40-49 years of age, 24.4 percent are 30-39 years of age, 19.7 percent are 50-59 years of age, 7.2 percent are 20-29 years of age, 5.1 percent are 60-plus years of age, 0.8 percent are 13-19 years of age and 0.4 percent are 0-12 years of age. Of those newly diagnosed with AIDS, 39.6 percent are 40-49 years of age, 30.3 percent are 30-39 years of age, 14.4 percent are 50-59 years of age, 10.9 percent are 20-29 years of age, 3.9 percent are 60-plus years of age, 1.0 percent are 13-19 years of age and 0.2 percent are 0-12 years of age (DHMH 2006c).

Of those newly diagnosed with HIV in Maryland, 31.6 percent are within the 40-49 age group, 30.1 percent are within the 30-39 age group, 19.3 percent are within the 20-29 age group, 12.8 percent are within the 50-59 age group, 3.3 percent are within the 60-plus age group, 2.4 percent are within the 13-19 age group and 0.4 percent are within the 0-12 age group (DHMH 2006c).

The age distribution of PLWH/As in the Baltimore EMA generally parallels statewide statistics, i.e., prevalence of HIV/AIDS is highest among 40-49 year-old Marylanders (DHMH 2006b).

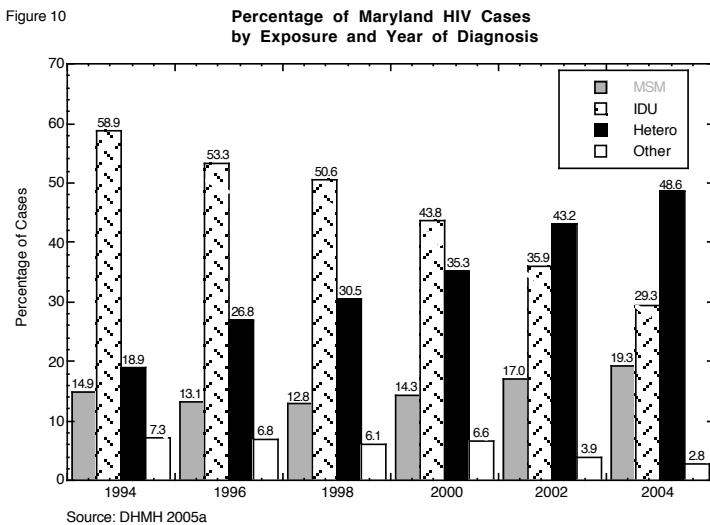
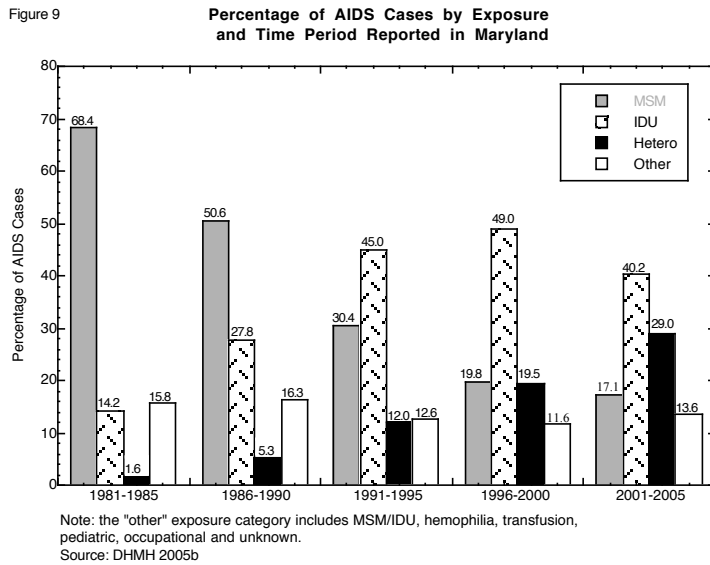


### 4.2.4 Exposure Distribution of PLWH/As

Over the course of the HIV/AIDS epidemic in Maryland, the primary HIV exposure modes have shifted. What was once predominantly a gay men’s disease is now transmitted primarily through heterosexual contact, followed by injection drug use (IDU) and men who have sex with men (MSM) (DHMH 2005b).

Figure 9 tracks these changes from the earliest years of the epidemic through 2005 by showing the percentage of Maryland AIDS cases associated with the transmission modes MSM, IDU, heterosexual sex and “other” (MSM/IDU, hemophilia, transfusion, pediatric, occupational and unknown). This view of the epidemic is distorted slightly by showing only AIDS cases; as a result of intravenous drug users’ generally poorer health, they are likely to progress to AIDS sooner than other PLWH/As, and this is why the graph does not reflect the fact that heterosexual sex is now the leading HIV-transmission mode in Maryland, as will be discussed further below.<sup>9</sup>

As illustrated in figure 9, during the epidemic’s initial five years (1981-1985) in Maryland, the primary transmission mode associated with the state’s reported AIDS cases was overwhelmingly MSM (68.4 percent), followed by IDU (14.2 percent) and heterosexual contact (1.6 percent). In the most recent five years for which Maryland AIDS Administration data have been published (2001-2005), the primary transmission mode among AIDS cases was IDU (40.2 percent), followed by heterosexual contact (29.0 percent) and MSM (17.1 percent).



<sup>9</sup> Maryland tracked only AIDS cases prior to 1994, when its HIV surveillance system was initiated.

percent). “Other” modes of transmission accounted for 13.6 percent of AIDS cases during 2001-2005 (DHMH 2005b).

In 1994, when Maryland’s HIV-surveillance system was initiated, the most common HIV-transmission mode was IDU (58.9 percent), followed by heterosexual contact (18.9 percent) and MSM (14.9 percent), as shown in figure 10. In 2004, IDU was responsible for only 29.3 percent of new HIV cases while HIV cases resulting from heterosexual contact had increased to 48.6 percent and MSM to 19.3 percent (DHMH 2005a).

#### **4.2.5 Distribution of PLWH/As in Baltimore City**

Within Baltimore City, which is home to about half of Maryland’s PLWH/As, certain neighborhoods are particularly hard hit. Not surprisingly, these same neighborhoods fare poorly on social and economic indicators such as educational attainment, unemployment and poverty rates.

Table 14 lists all Baltimore City ZIP codes, as of March 2006, and their corresponding HIV and AIDS incidence and total HIV/AIDS prevalence. Of the 30 ZIP codes listed, 5 are home to nearly half (47.5 percent) of the city’s PLWH/As: 21217 (12.4 percent); 21215 (10.0 percent); 21218 (9.0 percent); 21202 (8.1 percent); and 21213 (7.9 percent) (DHMH 2006a).

| Table 14. HIV and AIDS Incidence and Prevalence in Baltimore City by ZIP Code |                |            |      |            |                 |            |  |
|---|----------------|------------|------|------------|-----------------|------------|--|
| ZIP Code  | Incident Cases |            |      |            | Prevalent Cases |            |  |
|   | HIV            | % of Total | AIDS | % of Total | HIV + AIDS      | % of Total |  |
| 21201   | 40             | 4.3        | 35   | 4.9        | 834             | 6.1        |  |
| 21202   | 58             | 6.2        | 43   | 6.1        | 1,104           | 8.1        |  |
| 21205   | 26             | 2.8        | 26   | 3.7        | 561             | 4.1        |  |
| 21206   | 34             | 3.6        | 34   | 4.8        | 429             | 3.1        |  |
| 21207   | 27             | 2.9        | 21   | 3.0        | 325             | 2.4        |  |
| 21208   | 1              | 0.1        | 0    | 0          | 7               | 0.1        |  |
| 21209   | 5              | 0.5        | 2    | 0.3        | 38              | 0.2        |  |
| 21210   | 1              | 0.1        | 0    | 0          | 26              | 0.2        |  |
| 21211   | 8              | 0.9        | 6    | 0.8        | 141             | 1.0        |  |
| 21212   | 20             | 2.1        | 15   | 2.1        | 327             | 2.4        |  |
| 21213   | 83             | 8.9        | 47   | 6.6        | 1,087           | 7.9        |  |
| 21214   | 12             | 1.3        | 8    | 1.1        | 135             | 1.0        |  |
| 21215   | 75             | 8.0        | 66   | 9.3        | 1,370           | 10.0       |  |
| 21216   | 55             | 5.9        | 44   | 6.2        | 820             | 6.0        |  |
| 21217   | 111            | 11.9       | 72   | 10.2       | 1,700           | 12.4       |  |
| 21218   | 98             | 10.5       | 61   | 8.6        | 1,233           | 9.0        |  |
| 21222   | 1              | 0.1        | 0    | 0          | 5               | 0.0        |  |
| 21223   | 80             | 8.6        | 65   | 9.2        | 998             | 7.3        |  |
| 21224   | 49             | 5.3        | 34   | 4.8        | 505             | 3.7        |  |
| 21225   | 21             | 2.3        | 18   | 2.5        | 270             | 2.0        |  |
| 21226   | 4              | 0.4        | 3    | 0.4        | 28              | 0.2        |  |
| 21227   | 2              | 0.2        | 1    | 0.1        | 42              | 0.3        |  |
| 21228   | 0              | 0          | 0    | 0          | 2               | 0          |  |
| 21229   | 43             | 4.6        | 45   | 6.4        | 648             | 4.7        |  |
| 21230   | 26             | 2.8        | 22   | 3.1        | 355             | 2.5        |  |
| 21231   | 28             | 3.0        | 20   | 2.8        | 378             | 2.8        |  |
| 21234   | 5              | 0.5        | 3    | 0.4        | 55              | 0.4        |  |
| 21236   | 0              | 0          | 0    | 0          | 0               | 0          |  |
| 21237   | 5              | 0.5        | 0    | 0          | 38              | 0.3        |  |
| 21239   | 14             | 1.5        | 17   | 2.4        | 238             | 1.7        |  |
| No ZIP  | 150            |            | 8    |            | 744             |            |  |
| Total   | 1,082          | 100        | 716  | 100        | 14,443          | 100        |  |

Source: DHMH 2006c

Incident cases were reported from 04/01/04 to 03/31/05.

Prevalent cases on 03/31/05, as reported through 03/31/06.

A brief overview of four neighborhoods within two of these hard-hit ZIP codes will suffice to show some of the formidable challenges — in addition to HIV — faced by people living in these areas. The 21217 ZIP code has the highest level of HIV prevalence in the city. A large portion of this ZIP code consists of the Upton/Druid Heights (UDH) and Sandtown-Winchester/Harlem Park (SWHP) neighborhoods, where African-Americans make up over 95.0 percent of the

population. Of the UDH/SWHP population 25 years and over, approximately 76.5 percent have attained no more than a high-school diploma, with the majority not having attained even that. The percentages of the population 18 years and over living below the federal poverty level in UDH and SWHP are 47.4 percent and 37.0 percent, respectively. Furthermore, the percentages of the population 16 years or older who are unemployed or not in the labor force are also high — 10.2 percent are unemployed and 50.9 percent are not in the labor force in UDH, and 8.7 percent are unemployed and 52.0 percent are not in the labor force in SWHP (MDP 2002).

The Jonestown/Oldtown (JO) and Greenmount East (GE) neighborhoods are in ZIP code 21202, where the prevalence of HIV/AIDS is also severely high. JO and GE have similar characteristics to UDH and SWHP. African-Americans comprise 81.7 and 97.8 percent of the populations of JO and GE, respectively. Of the population 25 years and over, approximately 70.1 percent in JO and 77.7 percent in GE have attained only a high-school diploma or not even that. The percentages of the population 18 years and over living below the federal poverty level in JO and GE are 50.6 percent and 37.1 percent, respectively. Also, among individuals 16 years old and up, rates of unemployment and individuals not in the labor force are correspondingly high — 9.3 percent are unemployed and 58.8 percent are not in the labor force in JO, and 9.3 percent are unemployed and 55.3 percent are not in the labor force in GE (MDP 2002).

These examples make clear that HIV/AIDS is only one of many daunting challenges such neighborhoods face. Although certain “high-risk” populations are usually targeted for heightened prevention and treatment efforts, it is important to understand that their high-risk behaviors do not occur within a vacuum; rather, their behaviors occur within socio-economic, cultural and environmental conditions that must be taken into account by health planners combating HIV.

### **4.3 Populations of Special Interest**

Meeting the diverse needs of special populations of PLWH/As in the Baltimore EMA — i.e., groups that have a disproportionately severe need for HIV-related services — is a primary goal of the planning council, in accordance with HRSA’s emphasis on eliminating disparities in access and services. Research shows that members of traditionally underserved populations (e.g., racial and ethnic minorities, as well as people with co-occurring conditions or “co-morbidities” such as substance abuse, mental-health problems, and/or homelessness) are among those with the greatest need for and dependence on Ryan White program services.

Indeed, these vulnerable and marginalized groups of people are caught in what the National Research Council calls a “synergism of plagues,” in which “poverty, poor health, lack of health care, inadequate education, joblessness, hopelessness and social disintegration converge” (NRC 1993). These concurrent conditions limit access to care, adherence to medications and continuity of care, while increasing the chances of HIV infection and rapid progression to AIDS (NRC 1993). This is because, for populations facing so many other — and often more immediately threatening — obstacles, a positive HIV diagnosis is just an additional “problem” that may or may not merit immediate attention.

As increasing attention is paid to the convergence of societal ills and their impact on individual health, mounting research supports a shift in the HIV risk paradigm — away from focusing solely on individual behaviors and toward focusing on the contexts in which those behaviors occur, such as homelessness or incarceration. In other words, it is essential to understand both the high-risk behaviors that occur within certain subpopulations of PLWH/As and the larger context in which those behaviors occur.

While all PLWH/As in the Baltimore EMA require attention, some subpopulations are of particular concern, especially injection and non-injection drug users, individuals who are incarcerated or were formerly incarcerated, African-American MSMs and the homeless. Importantly, these subpopulations of PLWH/As are not mutually exclusive; there is significant overlap between them. Some examples of this overlap include drug users cycling in and out of the correctional system, formerly incarcerated persons becoming homeless and drug users among MSMs.

#### **4.3.1 Injection and Non-injection Drug Users**

Substance abuse, which includes alcohol as well as illegal-drug abuse, is a significant problem among residents of this EMA. Of particular concern to the planning council are the implications of substance abuse for people who are also infected with HIV/AIDS. Previous studies have shown that substance abuse is associated with delays in accessing HIV care, difficulty establishing care, poor adherence to medications and poor adherence to appointments once in care (Samet *et al.* 1998, Giordano *et al.* 2005). In addition to complicating HIV-disease management and treatment, substance abuse is associated with risky sexual behaviors that increase chance of infection (Latka *et al.* 2006).

Among the primary concerns relating to abused substances is opioid dependence, particularly heroin addiction, which has long been pervasive in Baltimore City. The impact of IDU on the HIV epidemic extends well beyond those actually using the drugs, affecting their fellow users, sexual partners and members of their families, especially children. A recent study notes a sudden increase in HIV incidence among IDUs in Baltimore City beginning in 2003 (Mehta *et al.* 2006). The researchers believe that this unexpected increase is most likely attributed to an increase in drug-related risk behaviors (like needle sharing) due to “safe injection fatigue,” as well as the decline in local HIV-prevention programs aimed at reducing such risks (e.g., syringe-exchange programs and distribution of bleach for disinfecting needles) and the scarcity of drug-abuse treatment programs. The study’s findings suggest that HIV-incidence rates among younger IDUs might be underestimated and that HIV infections continue to occur even among older IDUs in Baltimore (Mehta *et al.* 2006).

To more effectively meet the need for heroin treatment, Baltimore City, along with Baltimore HealthCare Access and Baltimore Substance Abuse Systems, introduced a buprenorphine initiative in 2006. The project aims to increase the number of physicians in the city who can prescribe buprenorphine, an effective alternative to methadone. In addition, the program aims to concurrently shift drug addicts away from conventional drug-treatment centers and into primary-medical-care facilities, where addicts’ overall health can be managed along with their recovery from addiction (Leinwand 2006). The implications of this program are particularly important for HIV-positive heroin addicts who never established medical care following diagnosis or are otherwise not receiving regular medical care.

Non-injection illegal drug use is also highly problematic among PLWH/As. Non-injection drugs, which include crack and powder cocaine, crystal methedrine, ecstasy, anabolic steroids, erectile-dysfunction drugs (e.g., Viagra) and pain killers (e.g., Oxycontin and Percocet) are of concern due to users’ lowered inhibitions and increased sexual desire, which may in turn lead to high-risk behaviors such as unprotected sex.

Another major, and often overlooked, recreational drug is alcohol. Although alcohol abuse has not traditionally been viewed as a critical issue when compared to other substance abuse among HIV-infected individuals — perhaps in part due to its legality — its influence is no less pernicious. In addition to alcohol being an obstacle for HIV prevention, its abuse is associated

with delays in seeking HIV medical care as well as difficulty establishing care (Samet *et al.* 1998, Giordano *et al.* 2005). Like many other recreational drugs, alcohol lowers inhibition, impedes judgment and can affect access to and retention in HIV care and treatment. Furthermore, drug-related crime can also lead to imprisonment; prisoners, in turn, are disproportionately burdened with many types of health problems, including HIV/AIDS, as discussed further below.

### **4.3.2 Incarcerated and Formerly Incarcerated Individuals**

The incarcerated population in the Baltimore EMA is of particular concern to the planning council. With rising national incarceration rates over the past 25 years, there are also more and more inmates being released from prison each year. The challenges of reentry for released prisoners, their families and the communities to which they return are many. HIV only complicates these challenges, and so it can be extremely difficult for released inmates to establish and maintain HIV medical care.

As of March 2005, the prevalence of HIV/AIDS among incarcerated individuals in Maryland, who are counted as an exclusive population, independent of jurisdiction, is an estimated 9.1 percent, or about 2,660 of Maryland's 29,247 PLWH/As. Of these estimated 2,660 HIV/AIDS cases, about 1,767 are HIV (non-AIDS) cases (10.8 percent of the state's HIV cases) and about 893 are AIDS cases (7.0 percent of the state's AIDS cases) (DHMH 2006c).

According to an Urban Institute report on prisoner reentry in Maryland, "prisoners today are typically less prepared for reintegration, less connected to community-based social structures, and more likely to have health or substance-abuse problems than in the past." Furthermore, "in addition to these personal circumstances, limited availability of jobs, housing, and social services in the community may affect the returning prisoner's ability to successfully reintegrate" (UI 2003). For offenders with HIV/AIDS, they have the additional burden of the stigma of HIV — fear of disclosing their status may interfere with reconnecting to family and friends, and their positive HIV status may affect their access to housing and employment, even despite laws against such discrimination. Then there is the grim cycle of reincarceration: the Maryland Department of Public Safety and Correctional Services reports that nearly half (49 percent) of incarcerated individuals who are released each year re-offend within three years of their release. Of the re-offenders, 80 percent commit drug-related crimes (DPSCS 2005).

According to the Urban Institute report, between 1980 and 2001, Maryland's prison population more than tripled, from 7,731 to 23,752 prisoners. In 2001, when 9,448 persons were released from Maryland prisons, 97 percent returned to communities in Maryland. Of those prisoners who returned to Maryland, nearly 60 percent (5,407 persons) returned to one jurisdiction in the state, Baltimore City, and — of prisoners returning to Baltimore — almost 30 percent (1,622 persons) returned to just 6 communities: Southwest Baltimore, Greater Rosemont, Sandtown-Winchester/Harlem Park, Greenmount East, Clifton-Berea and Southern Park Heights. The majority of released prisoners were male (91 percent) and African-American (76 percent). Additionally, one third of the released prisoners had been serving time for drug-related offenses (UI 2003). Importantly, these numbers only represent individuals released from Maryland *prisons* after serving sentences of one year or more. Approximately 5,000 additional inmates are released to Baltimore City each year after having served *jail* time, typically less than one year (UI 2003).

Of concern to this report, of course, is the HIV/AIDS status of returning prison and jail inmates. In Maryland, an estimated 3.5 percent of inmates are HIV positive (UI 2003). Because Maryland does not have a mandatory HIV testing policy for individuals entering the correctional system, it is likely that this number underestimates the prevalence of HIV among those who are incarcerated. Indeed, national research has found that many individuals who enter into the system

forego testing for fear of being tagged “sick,” “homosexual” or even “mentally ill,” characteristics that would place them in a vulnerable position within the prison culture (UI 2002). Even if those who are incarcerated choose to disclose their HIV-positive status upon entry into the system, or opt to get tested for HIV and receive a positive result, the environment in prison is generally hostile to treatment compliance.

In an article published in the January 11, 2007 issue of *The New England Journal of Medicine*, Susan Okie, a contributing editor of the journal, explored HIV prevention in prisons. Okie writes: “It has been estimated that, each year, about 25 percent of all HIV-infected persons in the United States spend time in a correctional facility, as do 33 percent of persons with hepatitis C virus (HCV) infection and 40 percent of those with active tuberculosis” (Okie 2007). These are sobering statistics, with especially grave implications for African-Americans, who account for about 40 percent of the country’s prison population (Okie 2007) while representing merely about 13 percent of the total U.S. population.

In the U.S. prison culture, where tattooing, drug use and high-risk sexual activity are common, the probability of HIV transmission is high. Yet Okie says that, despite the fact that the World Health Organization (WHO) and UNAIDS (a program of the United Nations) have for more than 10 years recommended distributing condoms in prisons, as well as providing inmates with drug treatment (e.g., methadone) and bleach for cleaning injection supplies, the U.S. rarely makes such resources available to prisoners, as opposed to the practices of the several western European countries that have adopted some or all of these recommendations (Okie 2007). According to Okie, condoms are currently provided on a limited basis in only two state prison systems in the U.S. (Vermont and Mississippi) and five municipal jail systems (New York City, Philadelphia, San Francisco, Los Angeles and Washington, D.C.). Correctional-system methadone-maintenance programs are rarer still, and no U.S. prison has ever implemented a needle-exchange program (Okie 2007).

### **4.3.3 African-American Men Who Have Sex With Men**

Another population of special interest in the Baltimore EMA are MSMs, particularly African-American MSMs. MSMs account for an estimated 45 percent of newly diagnosed HIV/AIDS cases in the U.S. and almost 54 percent of cumulative AIDS diagnoses since the epidemic began (CDC 2006f, 2005a). The data for African-American MSMs are particularly worrying — from 2001 to 2004, African-American MSMs accounted for nearly half (49 percent) of HIV diagnoses among African-American men (CDC 2005a).

In 2002, the CDC developed the National HIV Behavioral Surveillance (NHBS) System to assist state and local health departments in monitoring selected HIV-related behaviors and assessing the use of prevention programs and services in groups at highest risk for HIV infections. A survey of MSMs was conducted between November 2003 and April 2005 in 17 metropolitan statistical areas (MSAs), including Baltimore. Of the 10,030 participants who were sampled from randomly selected venues (e.g., bars/clubs, fitness clubs, parks, beaches, restaurants/cafes, retail businesses, sex establishments, etc.), 4,510 (45 percent) were non-Hispanic white, 1,739 (17 percent) were non-Hispanic African-American and 2,680 (27 percent) were Hispanic (CDC 2006d). Nearly all participants (98 percent) identified as homosexual or bisexual. In Baltimore, 563 men participated in the survey (CDC 2006d). Although participant characteristics, including race, were not broken down for each MSA, the aggregate data for Baltimore are thought provoking.

Of the 563 MSMs surveyed in Baltimore, the following behaviors were reported to have occurred during the preceding 12 months: only 64 percent reported having been tested for HIV; nearly 25 percent reported having had unprotected anal sex with a casual partner; nearly 40 percent reported

having had unprotected anal sex with a “main partner”;<sup>10</sup> 34 percent reported having had sex with both male and female partners; and almost half (49 percent) reported non-injection drug use. Injection drug use was reported among only 6 percent of the *total* number of participants (10,030), of whom merely 2 percent had reported injecting drugs during the preceding 12 months (CDC 2006d).

Another recent study conducted by the CDC found that, of 1,746 MSMs who were also sampled from randomly selected venues (e.g., bars/clubs, organizations and street locations) in five large U.S. metropolitan cities — Baltimore, Los Angeles, Miami, New York City and San Francisco — approximately 25 percent were infected with HIV, of whom nearly 50 percent were unaware of their HIV infections. Strikingly, the infection rate among the African-American MSMs contacted in this study was more than double that among the white MSMs. Among the 444 African-American men who were tested for HIV, nearly half (46 percent) tested positive (compared to 21 percent of the 616 white men in the study), and roughly two thirds (67 percent) were unaware of their status (compared to 18 percent of the white men) (CDC 2005b). Of the five cities in which MSMs were tested, HIV incidence was highest in Baltimore (8.0 percent), followed by Miami (2.6 percent), New York City (2.3 percent), Los Angeles (1.4 percent) and San Francisco (1.2 percent) (CDC 2005b).

#### **4.3.4 Homeless Persons**

The homeless population in the Baltimore EMA is another population of special interest to the planning council. The high co-occurrence of homelessness and HIV/AIDS has been well documented. As discussed earlier in section 3.4, it is estimated that between 3,000 and 4,000 individuals are homeless on any given night in Baltimore City, and that just over 7,000 individuals (over 1 percent of Baltimore City’s population) will experience homelessness over the course of one year (BHS 2005). Alarming, an estimated 12 percent of Baltimore City’s homeless population is HIV positive (BHS 2005).

People living with HIV/AIDS are at increased risk of becoming homeless, and national research shows that housing is the greatest unmet service need among persons living with HIV/AIDS. According to the National AIDS Housing Coalition, the prevalence of HIV/AIDS is up to nine times higher among persons who are homeless or transient compared with persons in stable, adequate housing (NAHC 2006).

In general, people who are homeless have higher rates of chronic diseases than people who are housed, due in part to the effects of lifestyle factors (e.g., drug, alcohol or tobacco use), exposure to extreme weather, nutritional deficiencies and violence (NCH 2006).

Difficulties associated with serving homeless PLWH/As include problems maintaining their treatment regimens, difficulty locating these individuals when they are out of care, and increased risks of infection from staying in crowded homeless shelters or encampments. In addition, homeless individuals are: more likely to miss appointments; require greater effort from registration, social and outreach workers to reconnect them to care; and require more intensive and expensive medical care (NCH 2006). The transient and unpredictable nature of the population means that continuous and ongoing outreach efforts are necessary to keep these individuals in medical care.

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<sup>10</sup> “Main partner” was defined as a man with whom the participant had sex and to whom he felt most committed (e.g., boyfriend, significant other or life partner) (CDC 2006e).

#### 4.4 Socio-economic Impact of HIV/AIDS

The socio-economic impact of the HIV/AIDS epidemic is substantial. Coinciding with the increasing number of PLWH/As nationwide, the public cost of HIV/AIDS treatment continues to climb. A 2006 study published in the journal *Medical Care* reported that optimal medical care and treatment for the 40,000 new HIV cases in the U.S. each year will cost about \$12.1 billion annually (Schackman *et al.* 2006). Based on a projected life expectancy of 24.2 years for HIV-positive people who receive optimal medical care, the undiscounted lifetime cost of medical care is \$618,900 for HIV-positive adults who begin antiretroviral treatment with CD4 counts greater than 350, according to the study.<sup>11</sup> In addition, the study found that for HIV-positive people who begin antiretroviral treatment with CD4 counts of 200 and greater, the anticipated life expectancy is 22.5 years, and the undiscounted lifetime cost for medical care is \$567,000. According to the study, 73.0 percent of the cost is for antiretroviral drugs, 13.0 percent is for inpatient care, 9.0 percent is for outpatient care, and 5.0 percent is for other HIV-related laboratory and medication costs (Schackman *et al.* 2006).

Though Baltimore-specific cost estimates are not available at this level of specificity, it is plain to see that, aside from the social and public-health impact of the HIV epidemic, massive economic costs are involved as well. It may be that this aspect of the epidemic offers a means of convincing otherwise uninterested citizens to support increased funding for prevention and education activities that may lower the substantial public costs involved.

#### 4.5 Conclusion

As discussed in this section, the Baltimore EMA accounted for over 65 percent of new HIV cases and over 63 percent of new AIDS cases in Maryland in 2005. Characteristics indicating a particularly high risk for HIV in this EMA include being: African-American, male (though recent trends reveal a growing number of African-American women being infected with HIV) and/or 40-49 years of age. Furthermore, as noted in this section, HIV/AIDS is a leading cause of death among both African-American males and females statewide.

Within the EMA, Baltimore City is the epicenter of the disease: in 2005, the city accounted for nearly 80 percent of the EMA's new HIV cases and over 78 percent of the EMA's new AIDS cases. Moreover, the city is home to nearly 80 percent of the EMA's PLWH/As, many of whom reside in the most severely impoverished and high-crime neighborhoods.

While several subpopulations of PLWH/As in the Baltimore EMA merit concern, injection and non-injection drug users, individuals who are incarcerated or formerly incarcerated, African-American MSMs and the homeless stand out above the others, particularly in Baltimore City. These and other subpopulations are among those with the greatest need for and dependence on CARE Act services.

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<sup>11</sup> As defined by the researchers, "undiscounted" cost estimates represent the upper range of costs for treatment, such as for individuals without the benefit of group discounts and who are not using generic drugs, i.e., individuals who are essentially paying "list price" for treatment.

## 5. UNMET NEED

A positive HIV-test result does not automatically lead to timely medical care and treatment. In fact, some HIV-infected individuals may never enter primary medical care at all, while others may fall in and out of care for years. By the CDC's estimation, of the 1.2 million PLWH/As in the U.S. today, 42-59 percent know their HIV status but are not receiving regular primary medical care (KFF 2006b); HRSA describes this circumstance as "unmet need." In addition to the greatly increased cost of caring for PLWH/As who postpone entry to care until their health has deteriorated to a crisis point, delays in PLWH/As' entry to care also postpone opportunities to educate these individuals on risk reduction strategies that might help them avoid infecting others. Clearly, a reduction in the rate of unmet need would be to the benefit of PLWH/As, their sexual partners, and the care continuum as a whole.

In response to growing concern over the number of PLWH/As who are not receiving regular primary medical care, the Ryan White CARE Act Amendments of 2000 called for the secretary of the U.S. Department of Health and Human Services (HHS) to develop epidemiological measurements for "establishing the number of individuals living with HIV disease who are not receiving HIV-related health services" (i.e., unmet need) as well as to prepare state and national estimates of unmet need to provide to Congress (McKay *et al.* 2006). Per the 2000 amendments, all Part A and B Ryan White-program grantees and planning bodies must conduct periodic assessments of the unmet needs and barriers to care of PLWH/As who "know their HIV status and are not receiving HIV-related services," especially those from "disproportionately affected and historically underserved populations" (HRSA 2002).

But while it is simple enough to state that the reduction of unmet need is desirable, the obstacles to this reduction are many and complex. As section 5.1.1 explains in greater detail, there is, first, the difficulty of defining an individual's care status. In order to be defined as "in care," how regularly must PLWH/As receive medical care? How many appointments can they miss? What constitutes medical care: viral-load testing, CD4 cell monitoring, provision of anti-retroviral therapy, oral-health care, outpatient mental-health care, outpatient substance-abuse treatment, etc.?

Also, what strategies should be used to engage the diverse and fragmented HIV-positive population in care? Should these strategies vary based on individuals' different degrees of engagement in care? Certainly, engagement strategies must at the very least take into account an individual's circumstances and the specific obstacles keeping that person from entering care, but this requirement only increases the complexity of the problem. Research has documented multiple obstacles to connecting HIV-positive persons to/retaining them in care, including: low health literacy; varying levels of "readiness" for entering/maintaining health care; health status and risk perceptions; access to medical care; lack of health insurance; prior or current incarceration; varying levels of social support; HIV/AIDS-related stigma; mental-health problems; negative physical and emotional consequences following diagnosis; history of substance abuse; distrust of the health-care establishment; and transient residence (Bogart and Thorburn 2006, Cunningham *et al.* 1999, Cunningham *et al.* 2006, Giordano *et al.* 2006, Krawczyk *et al.* 2006, Molitor *et al.* 2006, Relf *et al.* 2005, Samet *et al.* 1998, Turner *et al.* 2000). Any not-in-care PLWH/A may be affected by any number of these and other obstacles to care, and addressing such obstacles can require patience, precision and a great deal of money. (Research into barriers to care is discussed in greater detail in section 6.2.)

Because of the intrinsic complexity of defining care status, as well as the difficulty of engaging certain subpopulations in medical care, federal agencies, including HRSA, are currently grappling with an important question — with limited resources, should planners focus more on retaining individuals who are at risk of falling out of care than on reaching out to individuals who are not yet connected to care at all (HRSA 2006)? At this point, the answer is unclear. But this uncertainty should by no means discourage planners from efforts to reach disengaged PLWH/As and connect them to care. Rather, it should serve as an impetus for even more resourceful and innovative thinking among grantees and planning bodies.

As a whole, section 5 discusses certain concepts and frameworks used by HRSA to describe (and prescribe solutions to) the problem of not-in-care PLWH/As. Among these frameworks is HRSA's requirement that states and EMAs plan their responses to this problem under the headings of *estimating*, *assessing* and *addressing* unmet need. These concepts are discussed in sections 5.2.1-3, although in-depth discussion of research findings related to actual strategies for addressing unmet need is saved for section 7.

Section 5 first examines the difficulty of delineating who is in care/not in care under HRSA's definitions related to unmet need. Next, it discusses HRSA's new conceptual framework — the “engagement-in-care continuum” — which provides a more realistic and accurate description of PLWH/As' relationship to HIV-related primary medical care. Legislative requirements and HRSA's expectations regarding estimating, assessing and addressing unmet need are subsequently explained, along with related tools and strategies. Next, the importance of early and ongoing intervention following HIV diagnosis is briefly discussed. Section 5 closes with an examination of the most current unmet-need estimate for the Baltimore EMA and a discussion of the limitations of the estimate.

## 5.1 Determining Care Status

To facilitate the process of estimating, assessing and addressing unmet need, HRSA has propagated working definitions of several terms related to the subject, definitions that EMAs are expected to adopt and operationalize. These terms — particularly “unmet need,” “primary medical care” and “in care” — are important to understand since they are frequently used by HRSA, other federal agencies, states, EMAs, grantees and planning bodies.

As table 15 shows, HRSA considers PLWH/As to be “in care” only if they are receiving regular, HIV-related primary medical care. For example, a PLWH/A who is seeing a substance-abuse counselor but otherwise receiving no regular HIV-related clinical evaluations or care would *not* be considered “in care.” If this PLWH/A knows his or her HIV status, he or she would fall into HRSA's definition of “unmet need.”

| <b>Table 15. HRSA Definitions Related to Unmet Need</b>  |
|--|
| <p><b>Unmet Need for Health Services</b> (also referred to as unmet need)</p> <ul style="list-style-type: none"> <li>The need for HIV-related primary medical care by individuals with HIV who are aware of their HIV status, but are not receiving regular primary health care.</li> </ul>  |
| <p><b>In care</b></p> <ul style="list-style-type: none"> <li>A person is considered to be in care when s/he is receiving regular primary HIV-related medical care (clinical evaluation and clinical care). This medical care should meet U.S. Public Health Service guidelines for the treatment of HIV/AIDS.</li> </ul>   |
| <p><b>Primary medical care</b></p> <ul style="list-style-type: none"> <li>Medical evaluation and clinical care that is consistent with U.S. Public Health Service guidelines for the treatment of HIV/AIDS. Such care must include access to anti-retrovirals and other drug therapies, including prophylaxis/treatment of opportunistic infections and combination antiretroviral therapies.</li> </ul> |
| <p><b>Other primary health care</b></p> <ul style="list-style-type: none"> <li>Includes HIV-related health services other than primary medical care: oral-health care, outpatient mental-health care, outpatient substance-abuse treatment, nutritional services, and specialty medical care referrals.</li> </ul>   |
| <p><b>Non-medical supportive services</b></p> <ul style="list-style-type: none"> <li>Other services that contribute to PLWH/As accessing and remaining in primary medical care.</li> </ul>   |
| <p><b>Service gaps</b></p> <ul style="list-style-type: none"> <li>All service needs for all PLWH/As, except primary health services, for those who know their status and are not in care. (The term unmet need is used only to describe need for HIV-related <i>primary health care</i>.)</li> </ul>   |
| <p><b>Estimating unmet need</b></p> <ul style="list-style-type: none"> <li>Determining the approximate number of individuals in your service area (EMA, region, or state) who are HIV positive (AIDS or HIV/non-AIDS), know their status, and are not receiving regular primary medical care.</li> </ul>   |
| <p><b>Assessing unmet need</b></p> <ul style="list-style-type: none"> <li>Determining the characteristics, service needs, gaps and barriers of the individuals who are not in care and seeing how they compare to those of the overall population of people living with HIV and AIDS in your service area.</li> </ul>  |
| <p><b>Addressing unmet need</b></p> <ul style="list-style-type: none"> <li>Finding people who are not in care, getting them into primary medical care and keeping them in care.</li> </ul>   |
| <p>Source: Excerpted from MUNTAC 2004a:2.</p>  |

### 5.1.1 Challenges in Determining Care Status

HRSA’s definitions related to unmet need (table 15, above), while useful for some purposes, do not in and of themselves provide the level of nuance needed by planners working to connect more PLWH/As to care. This shortcoming arises from the fact that any two not-in-care individuals may have almost nothing else in common; as a result, an outreach strategy that is highly effective in one case may fail utterly in another. For example, there is a big difference between someone who has recently dropped out of care after 10 years of adherence and someone who has never been in care at all, and entirely different outreach strategies may be necessary as a result. The dichotomy of being “in” or “out” of care — because it does not accurately reflect the various degrees of

engagement that individuals have with health care providers over time — may mislead planners by suggesting more similarities than actually exist among various subpopulations of not-in-care PLWH/As.

Another ambiguity in the definitions in table 15 concerns what it means to be “receiving care” at all. HRSA defines unmet need as “individuals who know their HIV status and are not receiving primary health care” (HRSA 2002), but certain measures of primary-medical-care status may mislead as well. For instance, receipt of a viral load test or CD4 cell count at least every 12 months are widely used indicators of being “in care” (MUNTAC 2004a), yet having gotten either test does not necessarily equate to a well-planned and monitored program of care; by this standard, a person may appear to be more “in care” than he or she really is.

In addition, people who are receiving and have every intention of remaining in care may find their care interrupted from time to time due to circumstances such as loss of a job, death of a loved one, substance abuse, mental-health issues, domestic violence, cycling in and out of the corrections system and/or housing difficulties. The care that is received, therefore, is of lower quality.

Furthermore, the standard of care for HIV-positive individuals is complicated and variable since not all patients require the same HIV-related care (e.g., anti-retrovirals). Routine medical evaluation and monitoring, as directed by an HIV medical-care provider, may be sufficient (HRSA 2006), and so a person who appears to be only lightly engaged in care may in fact be following a doctor’s entirely appropriate recommendations to a tee.

Collectively, these challenges in defining care status create a need for a new paradigm that recognizes the range of possible degrees of engagement in care and provides a more realistic foundation for moving forward.

### 5.1.2 HIV Primary Medical Care — Degrees of Engagement

Recognizing the need for a new conceptual framework that more accurately reflects the precarious or sometimes non-existent relationships between patients and HIV-medical-care providers, HRSA recently published a more fluid definition of care status — an “engagement-in-care continuum” (table 16).

| Table 16. HRSA/HAB Engagement-in-care Continuum                               |   |   |   |  |  |
|---|---|---|---|--|--|
| <i>Degrees of Engagement</i>  |   |   |   |  |  |
| <i>Not in Care</i>  |   |   | <i>In Care</i>  |  |  |
| 1   | 2   | 3   | 4   | 5  | 6  |
| Unaware of HIV status (never tested or never received positive test results). | Knows HIV status (never referred to care or did not keep referral). | May be receiving other medical care but not HIV primary medical care. | Entered HIV primary medical care but dropped out (“lost to follow up”). | In and out of HIV primary medical care or infrequent user. | Fully engaged in HIV primary medical care. |
| Source: Adapted from HRSA 2006:3.   |   |   |   |  |  |

According to HRSA’s continuum, there are six different degrees of engagement in care, ranging from individuals who are unaware of their HIV status and are therefore not in care to those fully engaged in HIV primary medical care. As discussed in section 5.1.1 above, many PLWH/As fall somewhere between these two extremes of engagement with HIV-health-service providers (HRSA 2006). Persons falling into categories 1-5 could all be referred to as being “not in care” in one sense or another; however, and most importantly, strategies for engaging them in care would necessarily differ from one category to the next.

Ideally, anyone receiving a positive HIV-test result would immediately move all the way to the right side of this continuum, becoming “fully engaged” in care. Realistically, however, PLWH/As tend to move back and forth through the different degrees of engagement as they come to terms with their HIV-positive diagnosis while also attending to competing priorities and life events (e.g., job status, child care, illness, imprisonment, housing troubles, etc.). The utility of HRSA’s engagement-in-care continuum is that it allows for a more accurate description of these PLWH/As’ relationship to HIV-related primary medical care than does the more simplistic distinction between “in care” and “not in care.” This higher level of accuracy can help planners tailor more precise outreach efforts for the populations they are attempting to connect to care.

## 5.2 Estimating, Assessing and Addressing Unmet Need

HRSA’s definitions related to unmet need and engagement-in-care continuum (discussed in sections 5.1 and 5.1.2, respectively) are important to this report as they relate to the goal of accurately and efficiently estimating, assessing and addressing unmet need. As mentioned earlier, the 2000 amendments to the CARE Act require Part A and B grantees to assess and address (1) the service needs of people living with HIV “with particular attention to individuals with HIV disease who know their HIV status and are not receiving HIV-related services” and (2) the “disparities in access and services among affected subpopulations and historically underserved communities” (HRSA 2002). Specifically, the amendments direct grantees and planning bodies to:

- “Determine the size and demographics of the population of individuals with HIV disease” (i.e., *estimate* unmet need).
- “Determine the needs of such populations, with particular attention to individuals with HIV disease who know their HIV status and are not receiving HIV-related services... [and assess the] disparities in access and services among affected subpopulations and historically underserved communities” (i.e., *assess* unmet need).
- “Develop a comprehensive plan for the organization and delivery of health and support services” that “includes a strategy for identifying individuals who know their HIV status and are not receiving such services and for informing the individuals of and enabling the individuals to utilize the services... including discrete goals, a timetable, and an appropriate allocation of funds” (i.e., *address* unmet need) (MUNTAC 2006a).

By carrying out these three activities, it is hoped that planners can help people who receive a positive HIV-test result move through the engagement-in-care continuum expeditiously, particularly people who require the most help establishing and maintaining routine primary medical care. (Current research on connecting vulnerable PLWH/As to care is presented in chapter 7, so addressing unmet need is discussed only briefly in section 5.2.3, below.)

### 5.2.1 Estimating Unmet Need

To accomplish the first step in this process (i.e., estimating unmet need), HRSA requires every state and EMA to adopt working definitions of “in care” and “out of care” based on a simplified “unmet-need framework” developed for HRSA and shown in table 17. This unmet-need framework is designed to use information likely to be equally available in both low- and high-HIV-incidence states. The unmet-need framework is a minimum, and individual states and EMAs are welcome to adopt more stringent definitions. For example, the “in care” definition in this framework does not rise to the level of the care “meet[ing] U.S. Public Health Service guidelines” that is mentioned under HRSA’s general definition of “in care,” mentioned in section 5.1. However, states and EMAs may choose to use that more demanding definition if they want (MUNTAC 2004a).

| <b>Table 17. Unmet-need Framework for HIV Primary Medical Care</b>   |
|--|
| <p>An individual with HIV or AIDS is considered to have an <i>unmet need for care</i> (or to be <i>out of care</i>) when there is no evidence that he or she received any of the following three components of HIV primary medical care during the preceding 12 months:</p> <ol style="list-style-type: none"> <li>1. Viral load (VL) testing,</li> <li>2. CD4 count, or</li> <li>3. Provision of ART.</li> </ol> <p>A person is considered to have <i>met need</i> (or to be <i>in care</i>) when there is evidence of <i>any one or more</i> of these three measures during the specified 12-month time frame.</p> |
| <p>Source: excerpted from MUNTAC 2004a:4.</p>  |

The unmet-need framework shown in table 17 is designed to provide a consistent measure of whether PLWH/As are in or out of care, but further information is needed before the best outreach strategies can be determined. In particular, determining *who* these not-in-care PLWH/As are and *where* they live is critical. Two important tools used to this end are demographic and geographic analyses, although the precision of these analyses varies according to the nature of a state’s HIV/AIDS case-reporting system (MUNTAC 2006a). Positing — for the sake of argument — a state with a comprehensive names-based reporting system, such a state has only to query its database for cases meeting the conditions of the unmet need framework and then compile demographic and geographic data on these cases. Planners in such a state could then fine-tune their outreach efforts according to the populations they would now know they must reach, e.g., 75 recently incarcerated residents of a certain ZIP code, and so forth.

Some states — including Maryland — will not have such an easy time performing demographic/geographic analyses on their not-in-care populations, however. For instance, because Maryland has only recently begun switching to a names-based HIV case-reporting system, demographic and geographic information on HIV (as opposed to AIDS) cases is available only for those individuals enrolled in programs such as Medicaid or the Maryland AIDS Drug Assistance Program (MADAP), a mostly “in-care” subset of the state’s HIV-positive population. Instead of simply calling up the known demographic/geographic data for all known or suspected not-in-care cases, then, a state like Maryland must instead use statistical sampling and other methods to describe its overall PLWH/A population. Then, using what is known about predictors

of not-in-care status, educated guesses must be made concerning the likely size, nature and location of the various subpopulations who are most likely to be out of care in a particular state or EMA.

Some of the most important data points concerning not-in-care PLWH/As are:

- Disease status (i.e., HIV/non-AIDS or AIDS).
- Gender.
- Race/ethnicity.
- Age.
- Mode of transmission/identified risk factor.
- Residence jurisdiction/ZIP.

Each one of these factors, when known about a given individual or group of individuals, can provide a wealth of information about why individuals may not be accessing care, where to find such people and how best to approach them. The residence-jurisdiction/ZIP information can be plotted on maps, allowing planners to see whether people in some areas seem to face greater barriers to care than those living elsewhere. As mentioned above, however, Maryland is limited in its ability to perform such analyses, since it is only possible to obtain statistically likely data (as opposed to concrete facts about known cases).

### **5.2.2 Assessing Unmet Need**

Once unmet need has been estimated, grantees and planning bodies must next assess and address this unmet need. Having used the best tools available to describe the size and characteristics of a state's or EMA's not-in-care population, the next step is assessing that population's need for services and the barriers preventing that population from obtaining these services. This assessment can be accomplished through any number of methods, including interviews, surveying, focus groups and community forums. To learn more, consult HRSA's 2003 *Needs Assessment Guide* (available on-line at <http://hab.hrsa.gov/tools/needs/>). The Baltimore EMA's needs-assessment activities are described in section 5.3.

But determining the service barriers and service gaps of not-in-care PLWH/As requires first locating them. Among other tactics, this may mean coordinating with counseling and testing facilities and using outreach workers in order to contact consumers of services that are not part of the Ryan White program. Especially important are providers who constitute "points of entry" into HIV-related primary medical care. Ryan White legislation identifies a number of such points of entry, including:

- HIV counseling and testing sites.
- Emergency rooms.
- Substance-abuse treatment programs.
- Detoxification programs.
- Adult correctional and juvenile detention facilities, as well as halfway houses for recently released individuals.
- STD clinics.
- Mental-health programs.

- Homeless shelters.
- Community-based organizations that provide services to people of limited resources, such as food banks and inner-city ministries.
- Community-based organizations that serve sex workers.
- Community support groups and informal or formal organizations of subpopulations with high HIV rates and high barriers to care (MUNTAC 2006a).

Some states and EMAs have discovered that it is easier to contact people who are not in care by considering such individuals' connections with prevention or care services (similar to HRSA's engagement-in-care continuum, discussed in section 5.1.2). According to the Mosaica Unmet Need Technical Assistance Center (MUNTAC), not-in-care individuals can be categorized into four groups (as shown in table 18): (1) the newly diagnosed; (2) those who are receiving other Ryan White-program HIV/AIDS services but are not in primary medical care; (3) those formerly in care but now dropped out; and (4) those never before in care (the hardest to reach). For each group, table 18 presents strategies that have been employed by various states and EMAs to identify and locate these various populations (MUNTAC 2006a). (More detailed research findings on connecting vulnerable populations to care are presented in section 7.)

| <b>Table 18. Categories of Individuals Who Are Not in Care and Strategies to Identify and Locate Them</b>   |   |
|---|---|
| <b>Category and definition</b>  | <b>Strategies to identify and locate them</b>   |
| <p><b>Newly diagnosed</b></p> <p>Individuals who have recently learned that they are HIV positive and have not yet obtained primary medical care — often most easily identified through counseling and testing sites, other entities that do HIV testing such as STD clinics and mobile vans, rapid testing sites and various early intervention services</p> | <p>Requires improved links between prevention and care, and strategies such as:</p> <ul style="list-style-type: none"> <li>• Joint committees focusing on unmet need.</li> <li>• Referral to primary care or case management on same day person receives test results and counseling.</li> <li>• Peer advocates who contact patients immediately after diagnosis and accompany them to first few appointments.</li> <li>• Joint outreach workers, jointly funded.</li> <li>• Links with “prevention for positives” programs.</li> <li>• Use of rapid testing and immediate referral.</li> <li>• Primary care and case management provider agreements with testing sites and prevention programs.</li> </ul> |
| <p><b>Receiving other Ryan White HIV/AIDS services but not in primary medical care</b></p> <p>Individuals who are in the Ryan White system of care but are not receiving primary medical care services (e.g., nutrition services, case management, housing assistance or other services)</p>  | <ul style="list-style-type: none"> <li>• All funded providers should ask clients if they are in primary medical care.</li> <li>• Arrangements for immediate referral for those not in care.</li> <li>• Requirement that anyone receiving non-core services who is not in care be offered one primary-care appointment.</li> <li>• Primary care provided at the sites of other providers and/or use of mobile units or off-site services.</li> <li>• Outreach at support-service providers.</li> </ul>   |
| <p><b>Formerly in care but now dropped out</b></p> <p>Individuals who have received HIV-related primary medical care in the past, but are not currently receiving any HIV-related services (i.e., have not received any services in the previous 6-12 months)</p>   | <ul style="list-style-type: none"> <li>• Contractual requirements that primary-care providers follow up on clients who miss appointments.</li> <li>• Case manager follow-up through arrangements with primary-care providers.</li> <li>• Use of peer advocates to get people back in care.</li> <li>• Follow up by insurer (public or private).</li> <li>• Discharge planning and outreach to recently incarcerated (including jails).</li> <li>• Identify and overcome barriers to care that contributed to dropping out.</li> </ul>   |
| <p><b>Never in care (hardest to reach)</b></p> <p>Individuals who have known their HIV status for months or years but have never received regular HIV-related primary medical care</p>  | <ul style="list-style-type: none"> <li>• Street outreach targeted to specific populations and locations.</li> <li>• Continuation of outreach-worker support through first 2-3 medical visits.</li> <li>• Use of peer advocates from underserved groups.</li> <li>• Primary-care provider agreements and active links with points of entry such as homeless shelters, substance-abuse treatment programs, halfway houses, etc.</li> <li>• Training of non-AIDS-focused providers.</li> <li>• Education efforts, especially peer led.</li> <li>• Consumer assistance in finding people not in care.</li> </ul>  |
| <p>Source: MUNTAC 2006b.</p>  |   |

### 5.2.3 Addressing Unmet Need

After estimating and assessing unmet need, grantees and planning bodies must ultimately *address* the problem of unmet need. Having identified/located various not-in-care subpopulations and the barriers to care affecting them, planners have a variety of strategies available to them for reaching out to these people and connecting them to care. These strategies are discussed in section 7.

In addition to reaching out to not-in-care populations, it is worth pointing to the importance of early intervention after diagnosis, i.e., preventing the newly diagnosed from *becoming* “not in care.” The potential benefits of early and ongoing intervention following HIV diagnosis are substantial, while the consequences of non-intervention can be serious and detrimental for both patients and the HIV-care continuum. In fact, the period of time between individuals’ receipt of positive HIV-test results and their entry into medical care is widely considered a crucial window for intervention and education (Giordano *et al.* 2005, Samet *et al.* 1998, Turner *et al.* 2000). Delays in entry into care limit opportunities to educate infected individuals on risk-reduction strategies, such as how to reduce the risk of infecting their sexual partners and others.

According to the CDC’s revised recommendations for HIV testing, the first steps for medical personnel counseling newly HIV-diagnosed persons are to obtain a complete medical history from and conduct a thorough physical examination of the patient, including lab tests (e.g., CD4 lymphocyte cell count and viral load) to evaluate immune-system functioning and the need for antiretroviral treatment or other therapy (CDC 2006e). There is extensive research suggesting that antiretroviral therapy and opportunistic-infection prophylaxis can greatly extend the lives of PLWH/As and reduce co-morbidity (Samet *et al.* 1998). Ongoing clinical monitoring and diagnostic testing are essential for tracking any changes in HIV-infection status or other co-infections (CDC 2006e). In addition to medical care, active efforts should be made to link persons to counseling, support and prevention services as necessary to promote their retention in care.

Any delay or disruption in receiving medical care represents increased risk of further immune dysfunction, development of opportunistic infections and transmission of HIV to other individuals (Samet *et al.* 1998). Moreover, early and ongoing medical intervention has been found to help prevent individuals from having to use cost-intensive health-care services such as hospital emergency rooms (Uphold and Mkanta 2005, Turner *et al.* 2000). Delay in receiving HIV care, on the other hand, is often preceded by a lengthy delay between HIV infection and diagnosis. The longer the delay, the higher the chance that patients’ immune systems are already failing by the time they enter care (Samet *et al.* 1998, Turner *et al.* 2000). Of primary concern is the progression to serious AIDS-defining complications that can occur in susceptible, untreated individuals within only a few years after initial infection (Turner *et al.* 2000). This is particularly worrisome for planners in an area like the Baltimore EMA, with its high African-American population: according to recent estimates by the CDC, 40 percent of African-Americans who test positive for HIV are diagnosed with AIDS within one year of their HIV diagnosis (KFF 2006a).

Timely medical intervention following HIV diagnosis, then, has substantial benefits and must be an integral component in any plan to address unmet need.

### 5.3 Unmet Need Estimate in the Baltimore EMA

Current estimates of unmet need in the Baltimore EMA range from 16 to 35 percent of the EMA's population of approximately 18,000 PLWH/As.<sup>12</sup> This discrepancy results from the fact that Maryland only very recently began implementing a names-based HIV case-reporting system, meaning that estimates of unmet need in the Baltimore EMA necessarily involve some amount of guesswork. Also, as defined by HRSA, a prerequisite for individuals falling into the "unmet need" category is knowledge of their HIV status, but not all PLWH/As in the EMA who are factored into either of these two estimate have received their HIV-positive test result.

Consequently, it is not entirely accurate to call these "unmet-need" estimates since it is possible that some of the counted individuals are unaware of their status; rather, a more accurate label for this population might be "out of care."

As shown in table 19, the Baltimore planning council support office's (PCSO) estimate was calculated by applying the unmet-need framework discussed in section 5.2.1. The PCSO's 35-percent figure is derived from two main categories of information: (1) the Maryland AIDS Administration's estimated total number of PLWH/As in the EMA, and (2) the estimated number of people who are "in care" (as defined in the unmet-need framework), based on various data sources from various years (in each case, the most current information available at the time).

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<sup>12</sup> The 16 percent unmet-need estimate was used in the EMA's *Ryan White Title I [now Part A] EMA 2006 Application*, based on HIV/AIDS registry data through 2002 (BCHD 2006b). The 35 percent unmet-need estimate was calculated by the planning council support office (PCSO) and published in the *Comprehensive Plan for HIV Service Delivery: Baltimore EMA 2006-2008* (IGS 2005a).

| <b>Table 19. Planning Council Support Office's Estimate of Unmet Need in the Baltimore EMA, 2004</b>                  |              |   |
|---|--------------|---|
| <b>Input</b>  | <b>Value</b> | <b>Data Source</b>  |
| <b>EMA Population of PLWH/As</b>  |              |   |
| A. Number of PLWH/As as of December 31, 2004.   | 18,001       | This estimate uses data reported through 3/31/2005 (Flynn 2005:2).  |
| <b>Care Patterns</b>  |              |   |
| B. RW Part A — Uninsured PLWH/As receiving primary HIV medical care from Part A (2004 data).                          | 2,209        | Part A served 10,096 people in 2004, providing primary medical care (PMC) to 6,312. The 2,209 reported here had no other insurance (35%). The other 65% of those receiving Part A PMC had other primary coverage and are counted below (private insurance 10%, Medicare 10%, Medicaid 32%, other public or other 13%) (Brisueno 2005:9,13). |
| C. RW Parts B and D — PLWH/As receiving primary HIV medical care at Part B- or D- or state-funded agency (2002 data). | 1,242        | Administrative reports for Part B- or D- or state-funded agencies for 2002, multiplied by factor used in 2006 application (2,485 multiplied by 0.5).  |
| D. RW Part C — PLWH/As receiving primary HIV medical care at Part C agency (2004 data).                               | 1,133        | Numbers served in primary care reported by 3 programs, estimated for fourth program based on award amount and average cost per capita (reported by programs for priority setting, July 2005).   |
| E. Private health insurance — PLWH/As covered by private health insurance (2004 data).                                | 1,800        | Part A serves 56% of the EMA's PLWH/As. Vendors report that 10% of Part A clients report having private health insurance as their primary funding source. Assumption made that 10% of those not seeking care from Part A also are covered by private health insurance.  |
| F. Medicaid — PLWH/As identified in Medicaid HealthChoice program (2004 data).  | 2,843        | Medicaid report to Part A planning council, July 2005.  |
| G. VA — PLWH/As receiving primary HIV medical care at Veterans Administration facilities (2002 estimate).             | 627          | The Baltimore VA reporting station served 627 HIV patients in 2002 (VA 2003:13).  |
| H. Medicare — Estimated PLWH/As having PMC covered by Medicare (2004 estimate).                                       | 1,800        | Part A serves 56% of the EMA's PLWH/As. Vendors report that 10% of their Part A clients have Medicare as their primary funding source. Assumption made that 10% of those not seeking care from Part A also are covered by Medicare.   |
| <b>Calculated Results</b>   |              |   |
| I. In care — Estimated unduplicated number of PLWH/As receiving primary HIV medical care.                             | 11,654       | The sum of B through H.   |
| J. Not in care — Number of PLWH/As not receiving primary HIV medical care.  | 6,347        | A, less the sum of B through H (18,001-11,654).   |
| K. Unmet need estimate — Percent of the EMA's PLWH/As who are not receiving primary HIV medical care.                 | 35%          | J as a percent of A.  |
| Source: Excerpted from IGS 2005a:52, table 4-4.   |              |   |

By subtracting (1) the total number of people who are estimated as being in care from (2) the total number of people who are estimated to have tested positive for HIV, a not-in-care estimate of approximately 6,347 people was determined, i.e., 35 percent of the EMA's estimated number of PLWH/As.

As mentioned above, some caveats concerning the PCSO estimate are in order. Because the estimated number of not-in-care PLWH/As is arrived at through elimination, and because there are no reliable case-level data on this subpopulation as a whole, it is not possible to say with certainty how many of these cases know their HIV status; that is, the 35 percent estimate includes a subset of unknown size containing individuals who never received their test results. This subset could be quite large: in 1995, the CDC found that 25 percent of individuals testing HIV positive at publicly funded clinics never returned for their test results (CDC 1998). However, with the introduction of rapid HIV tests, it is safe to assume that the proportion of individuals testing HIV positive *and* receiving their test results is increasing, because rapid HIV tests allow health-care providers to provide definitive negative and preliminary positive results to patients within an average time of 10 minutes, versus 1-2 weeks with the conventional enzyme immunoassay test (CDC 1998).

On the other hand, given that the CDC believes that 42-59 percent of PLWH/As in the U.S. are not in care (KFF 2006b), it would not be surprising to learn that even *more* than 35 percent of the EMA's PLWH/As are also not in care, especially considering the relative severity of the epidemic in Baltimore compared to most other U.S. cities. There is another reason to suspect that the 35 percent figure may be an underestimate: the possible duplication of cases in the in-care figures for the various care patterns (rows B-H in table 17). Case data reported by the EMA's Ryan White providers lack client identifiers, making it impossible to merge and unduplicate cases across service providers. Clients may be receiving services from multiple sources, for example, and a provider may not always know if a client has received or is currently receiving services elsewhere (HRSA 2006). As a result, duplication of data occurs with unknown frequency, leading to a potential overestimate of the number of people in care and, consequently, an underestimate of unmet need.

All caveats aside, the PCSO estimate for the Baltimore EMA *is* similar to the average estimated unmet need among the 51 Part A (Title I) EMAs for fiscal year 2006, as table 20 illustrates: 36 percent for PLWH/As, 42 percent for PLWH (non-AIDS) and 29 percent for individuals living with AIDS (MUNTAC 2006c).

| <b>Table 20. National Estimates of Unmet Need Among the 51 Part A (Title I) EMAs, Fiscal Year 2006</b> |                 |                     |             |
|--|-----------------|---------------------|-------------|
|  | <i>HIV/AIDS</i> | <i>HIV/non-AIDS</i> | <i>AIDS</i> |
| Median estimated % of PLWH/A population  | 36              | 42                  | 29          |
| Aggregate estimated % of PLWH/A population   | 37              | 47                  | 27          |
| Source: MUNTAC 2006c.  |                 |                     |             |
| Note: Two EMAs did not provide separate estimates for HIV/non-AIDS and AIDS.                           |                 |                     |             |

## 5.4 Conclusion

Delayed entry into and/or disruptions in HIV care are unfortunately common, particularly in subpopulations with few resources and limited access to care. Delineating who is in care and not in care — and the appropriate outreach strategies to use — is made difficult as a result.

Recognizing the need for a new conceptual framework, HRSA’s more fluid definition of care status — an “engagement-in-care continuum” — reflects the different degrees of engagement HIV-infected individuals may have with medical-care providers, in order to help both providers and policymakers design programs to meet these widely varying needs.

But first, it is important for states and EMAs to determine just how many PLWH/As are out of care, i.e., make an accurate estimate of unmet need. While HRSA works to improve methods for quantifying unmet need, the current unmet need framework discussed in this section provides states and EMAs a means to at least estimate the scope of the problem. Current estimates of unmet need in the Baltimore EMA range from 16 to 35 percent. These numbers provide a starting point, but, until well designed and standardized client-level data-collection systems are in place, clinical and supportive-service outcomes, including unmet need, cannot be assessed and tracked adequately.

## 6. WHY SOME PLWH/AS ARE NOT ENGAGED IN CARE

Efforts to address unmet need must start with an attempt to understand why certain PLWH/As have difficulty engaging in and maintaining primary medical care. This section begins by examining a selection of results from consumer surveys conducted in the Baltimore EMA — specifically, what the EMA’s consumers have said about the length of time it took them to enter medical care following their HIV-positive diagnosis. The section closes with an examination of some of the more prominent national research findings about why certain groups of people with HIV/AIDS have difficulty engaging with and staying in care.

### 6.1 The Baltimore EMA’s Consumers’ Perspective

Ryan White legislation requires all EMAs to conduct needs-assessment research sufficient to determine which health and other service needs of PLWH/As are not being met. To this end, the Baltimore EMA’s planning council uses a variety of needs-assessment methods to gather data that, when combined, provide a sense of consumers’ perceptions of unmet need and service gaps. One of those methods is the large-scale consumer survey, which the planning council has conducted every three years since 1999.

| Months               | %    |
|----------------------|------|
| More than 12         | 17.7 |
| 6 to 12              | 0.2  |
| 1 to 6               | 14.4 |
| Less than 1          | 57.1 |
| Unknown              | 10.5 |
| Source: IGS 2005c.   |      |
| N = 609 respondents. |      |

Some findings from the 2004 consumer survey have particular relevance to this report.<sup>13</sup> As illustrated in table 21, of the 609 survey respondents, a majority of respondents (57.1 percent) waited less than 1 month after diagnosis to seek care, but sizable proportions of the respondents delayed entry for up to 6 months (14.4 percent) and more than one year (17.7 percent) (IGS 2005c). According to the final report, “lack of knowledge of available services was cited as a barrier to care more than any other barrier — 13.5 percent of those who needed but did not receive a service said it was because they did not know the service was available” (IGS 2005c).

Findings from a follow-up survey, the 2005 *Consumer Knowledge Survey*, revealed some intriguing details, particularly with respect to post-HIV-diagnosis behavior. As opposed to the 2004 survey, which asked respondents to recall the amount of time that had elapsed between their HIV diagnosis and when they accessed medical care, the 2005 survey asked two separate questions regarding the time between diagnosis and care. In the first question, according to the survey instrument, respondents were asked: “After you were told that you were HIV positive, how long was it before you *came to terms* with your diagnosis?” In other words, how many months or years was it before you “accept[ed] your diagnosis, feeling ready to seek medical care?” Secondly, respondents were asked: “After *coming to terms* with your diagnosis, how long was it before you first sought care from a doctor or nurse?” (IGS 2005b). Survey results found that respondents generally took longer to accept their diagnoses than to seek care once they had accepted their diagnoses. As shown in table 22, of the 422 respondents, most (62.3 percent) took less than one year to accept their diagnoses, 19.7 percent took 1-3 years, 13.5 percent took 4-9 years and 4.5 percent reported accepting their HIV diagnoses more than 10 years after they were diagnosed (IGS 2005b).

<sup>13</sup> Full results from the 2007 consumer survey were not available at press time.

| <b>Table 22. Time Between Diagnosis and Care, 2005</b> |                                    |                               |
|--|------------------------------------|-------------------------------|
| <i>Time</i>  | <i>Diagnosis to acceptance (%)</i> | <i>Acceptance to care (%)</i> |
| More than 10 years                                     | 4.5                                | 3.8                           |
| 4 to 9 years   | 13.5                               | 7.3                           |
| 1 to 3 years   | 19.7                               | 10.7                          |
| Less than 1 year                                       | 62.3                               | 78.2                          |
| Source: IGS 2005b.                                     |                                    |                               |
| N = 422 respondents.                                   |                                    |                               |

Once participants had accepted their HIV diagnoses, the majority of them seem to have sought care in less time than “acceptance” had required. That is, 78.2 percent of respondents reported waiting less than 1 year to seek care once they had accepted their HIV diagnosis, 10.7 percent of respondents 1-3 years, 7.3 percent of respondents 4-9 years and 3.8 percent of respondents more than 10 years (IGS 2005b).

In summary, the 2005 survey found that respondents, on average, needed 1.5 years to accept their HIV diagnosis but only another 1.0 years before entering consistent medical care. Moreover, according to a report analyzing the results of the 2005 survey, “when the average time to accept their diagnosis is combined with the average time to seek consistent care, consumers’ average time between diagnosis and care is 2.5 years — a very different result from the one month suggested by the 2004 consumer survey” (IGS 2005b).

The report provided a potential explanation for this striking difference between survey results: the fact that the information is self-reported and that “persons may define the time after diagnosis differently than researchers do.” According to the report, “instead of counting the delay from the time they received their positive test result, consumers may count the delay from the time they psychologically accepted their test result” (IGS 2005b). (The results also suggest that respondents may have received care for HIV-related emergency conditions despite not yet having “accepted” their diagnoses.)

The factors reported to discourage consumers’ care-seeking behavior, according to the 2005 survey, include: concern that HIV-positive status would require lifestyle changes that they were not yet ready to make; fear of stigma and inconvenience; and the belief that receiving care would not preserve or extend their health in any way (IGS 2005b).

These two surveys, although not statistically representative of the EMA’s PLWH/As, suggest that some consumers struggle not only with accepting their HIV status but also with deciding to seek care. But even once they have decided to seek care, lack of knowledge of available services may hamper them. It is important to note, by the way, that most of the survey respondents were engaged in care, at least to some degree. Therefore, we are not fully privy to the specific needs of persons living with HIV/AIDS in the EMA who have never established care, although — as discussed in section 6.2 below — research on this topic has identified several dominant barriers to care for those most in need.

## 6.2 National Findings

Although delays in accessing HIV medical care are common (Samet *et al.* 1998, Turner *et al.* 2000), these delays are not fully understood. There is extensive research into predictors of delayed presentation to HIV medical care following diagnosis, as well as into factors that create or contribute to difficulty establishing and maintaining care. Though none of the research that is presented here is Baltimore specific, most of it has been performed in large urban centers and provides at least some insight into the complex web of factors that inhibit access to and retention in care in areas with many similarities to this EMA.

Some of the more prominent influential factors researchers have identified as predicting difficulty accessing and maintaining HIV medical care include: low health literacy; varying levels of “readiness” for entering/maintaining health care; health status and risk perceptions; access to medical care; lack of health insurance; prior or current incarceration; lack of social support; HIV/AIDS-related stigma; mental-health problems; negative physical and emotional consequences following diagnosis; history of substance abuse; distrust of the health-care establishment; and transient residence (Bogart and Thorburn 2006, Cunningham *et al.* 1999, Cunningham *et al.* 2006, Giordano *et al.* 2006, Krawczyk *et al.* 2006, Molitor *et al.* 2006, Relf *et al.* 2005, Samet *et al.* 1998, Turner *et al.* 2000). The independent, synergistic and/or modifying effects of these barriers and others can significantly contribute to delayed entry into and poor maintenance of HIV medical care.

Researchers in one study, which analyzed a national probability sample of HIV-positive persons receiving care, identified several salient factors associated with delayed care.<sup>14</sup> First, having a usual source of care at the time of HIV diagnosis was associated with a 30-40 percent reduction in delay. Second, persons with Medicaid coverage at the time of HIV diagnosis were significantly less likely to delay seeking care than persons with private insurance. (The authors surmise that those with private insurance were more apprehensive of the potential socio-economic consequences of their HIV diagnosis or of losing insurance coverage once their status became known.) Third, a high level of trust in the health-care provider was associated with a lower likelihood of delay after HIV diagnosis. Finally, African-Americans were more likely to delay seeking care when compared with their white counterparts (Turner *et al.* 2000).

In another study, in which researchers conducted a medical-record review of 404 new indigent patients at an urban HIV clinic in 1998, nearly half (48 percent) of patients known to have HIV entering outpatient care failed to establish regular care within six months after the initial intake visit. Of that subset, 37 percent attempted but found it difficult to establish regular care (they saw a physician during the six months after the intake visit, but then experienced a gap in care of at least another six months), while 11 percent failed to return at all in the six months following initial intake (Giordano *et al.* 2006).

In reviewing the patients’ medical records, the researchers identified some prominent common factors predicting failure to engage with care. For one, drug and alcohol abuse emerged as a predictor of difficulty establishing and remaining in care, which is consistent with other research. Based on this finding, the authors suggest that all identified substance abusers who test HIV positive receive substance-abuse treatment early in their care even if there are no immediate plans for beginning antiretroviral therapy. Second, higher CD4 cell counts and younger age were identified as indicators of difficulty establishing care, while those individuals who had more

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<sup>14</sup> Two samples of patients were examined: Cohort A (n = 1,540) was diagnosed by February 1993 and was in care within 3 years; and cohort B (n = 1,960) was diagnosed by February 1995 and was in care within 1 year of diagnosis.

advanced HIV or were older were more successful in establishing care (Giordano *et al.* 2006). That is, the sicker people feel, the more likely they are to go to the doctor; to use the study's terms, feeling "sick" can probably be understood here as a factor increasing patients' perception of the risk posed by the disease.

In another study examining factors associated with delayed presentation to HIV primary care, 189 consecutive outpatients without prior primary care for HIV infection were assessed at two urban hospitals in Massachusetts. Of the 189 study participants, nearly 40 percent had delayed medical care for more than 1 year, 32 percent had delayed for more than 2 years and 18 percent had delayed more than 5 years (Samet *et al.* 1998). In the Massachusetts study, three major characteristics of patients were associated with significant delay: history of substance abuse, poor social support and being unaware of their HIV-risk status at the time of testing. The third characteristic helps estimate the patient's readiness to receive care: according to the researchers, "the patient's element of surprise and the associated delay in medical linkage suggest that HIV testing for this group initiates the process of seeking help" (Samet *et al.* 1998).

The Massachusetts study found that the populations most likely to delay entry into care were: injection drug users (delayed 19 months longer than those without a history of such behavior), male alcohol abusers (delayed 14.6 months longer than non-alcohol-abusing men) and those who were unaware of their HIV risk at the time of HIV testing (reflecting their readiness to seek care). In addition, not being told one's test result in person, not having a living mother and not having a spouse or partner were each significantly associated with delay (Samet *et al.* 1998).

In another study that examined the impact of competing subsistence needs in a nationally representative sample of 2,864 adults receiving HIV care, more than one third of the sample went without or postponed care at least once in a six-month period as a result of at least one of the following four reasons: (1) they needed the money for food, clothing, or housing; (2) they lacked transportation; (3) they could not get time off from work; and/or (4) they were too sick. The researchers add that racial/ethnic minorities, substance abusers, uninsured persons, persons with lower education, persons with lower income, youth and women were all more likely to report these problems (Cunningham *et al.* 1999). Taken together, these findings reaffirm that, while *providing* medical care is an HIV-care provider's top priority, *receiving* it may not be the top priority among certain HIV-infected persons, whose other, more immediately pressing concerns may affect their ability or willingness to engage in HIV care.

HIV/AIDS-related stigma has also been found to play a significant role in whether infected persons access or maintain primary medical care. One recent study examined the level and impact of HIV-related stigma in a culturally diverse sample of persons attending an urban HIV clinic. Using a combination of quantitative and qualitative methods, the researchers found that "stigma emerged as an insidious deterrent to integrating HIV primary care (e.g., medications, clinic appointments) into daily life" (Relf *et al.* 2005).

Disclosing their HIV serostatus to others, study participants reported, carried the risk of emotional injury, loss of relationships and/or employment termination. In fact, some reported expending considerable energy to keep their HIV status a secret. Homophobia and racism, although not solely HIV related, were also reportedly experienced by participants. The participants recounted stories about "how their trust of health care providers was undermined by unprofessional behaviors that left them feeling demeaned, disenfranchised, or devalued." Participants who had been in prison or were struggling with drug and/or alcohol use also

discussed facing obstacles due to preconceived notions about their personal character (Relf *et al.* 2005). In summary, according to the investigators, “these participants experienced HIV-related stigma that not only impeded personal disclosure of their HIV serostatus to others but also eroded their self-esteem and obstructed their willingness to seek treatment for their infection” (Relf *et al.* 2005).

Another obstacle to HIV care is conspiracy beliefs concerning the medical establishment, a widespread problem among African-Americans in particular. (That African-Americans show distrust of the medical establishment is not surprising, given such examples as the U.S. Public Health Service’s infamous syphilis experiment in Tuskegee, Alabama.) In an effort to better understand the socio-demographic characteristics of African-Americans who hold conspiracy beliefs related to HIV/AIDS, researchers conducted two comprehensive studies: (1) HIV/AIDS conspiracy beliefs as a barrier to HIV prevention; and (2) the relationship of socio-economic characteristics to the belief in conspiracies about HIV/AIDS and birth control (Bogart and Thorburn 2005, Bogart and Thorburn 2006).

Using a relatively large national sample<sup>15</sup> of African-Americans, researchers found that over half (53 percent) endorsed the HIV/AIDS conspiracy belief that “there is a cure for AIDS, but [it] is being withheld from the poor,” and nearly half (48 percent) believed that “HIV is a manmade virus” (Bogart and Thorburn 2005). Strikingly, these beliefs were not concentrated among African-Americans with lower educational attainment or low income; rather, the beliefs were widespread across all participants. Socio-demographic characteristics, the researchers purport, had only a small effect on respondents’ endorsement of conspiracy beliefs (Bogart and Thorburn 2006).

Moreover, conspiracy beliefs were found to be strongly associated with low condom and other contraceptive use: “African-American men who strongly endorsed HIV/AIDS conspiracy beliefs were less likely to use condoms consistently, suggesting that belief in conspiracies may be a barrier to HIV prevention” (Bogart and Thorburn 2005). In general, African-American men were more likely than African-American women to endorse conspiracy beliefs, according to the researchers (Bogart and Thorburn 2005).

These two studies examining conspiracy beliefs are highly significant in that they suggest that African-Americans have a profound distrust of the U.S. public health system and the medical establishment in general. Importantly, the findings show that conspiracy beliefs are widespread across a broad segment of the African-American population, with important implications for HIV policy makers (Bogart and Thorburn 2005 and Bogart and Thorburn 2006).

### 6.3 Conclusion

Barriers to care are numerous, subtle and synergistic. In the face of mounting concern surrounding estimating, assessing and addressing unmet need, and in the context of finite resources and competing interests, it is vital that the voices of those living with HIV/AIDS be heard in order to facilitate their engagement/retention in primary medical care.

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<sup>15</sup> A cross-sectional, anonymous telephone survey was conducted with a targeted random sample of African-Americans of all income levels, levels of educational attainment, etc., aged 15-44 years, living in the U.S. Five hundred African-Americans completed interviews out of 794 eligible respondents (Bogart and Thorburn 2005, Bogart and Thorburn 2006).

The planning council's 2004 consumer survey (the most recent for which data are available), found that lack of knowledge of available services was cited more than any other barrier to care. Additionally, sizable proportions of respondents delayed entry into care. A follow-up survey found that "acceptance" of an HIV diagnosis plays an important role in an individual's progression towards establishing HIV medical care.

Several national studies provide further insight into the various barriers that PLWH/As face in accessing and maintaining care. Collectively, the studies unearth many predictors of delayed entry into HIV primary care as well as the challenges associated with retaining people in care. One overarching implication of many of these studies is that, as HIV incidence increases among marginalized populations, the traditional means by which HIV-infected persons connect to care are becoming less effective.

Some of the more widely noted barriers to care include low health literacy, varying levels of "readiness" for entering/maintaining health care, poor health status and unrealistic risk perceptions, lack of access to medical care, lack of health insurance, prior or current incarceration, lack of social support; HIV/AIDS-related stigma, mental-health problems, negative physical and emotional consequences following diagnosis, history of substance abuse, distrust of the health-care establishment, and transient residence.

Aside from the various immediate barriers to accessing and maintaining HIV medical care discussed above, other barriers worthy of consideration but beyond the scope of this report include the myriad institutional and systemic barriers that exist (e.g., public and private financing of HIV/AIDS care, fragmentation of service delivery, etc.), in addition to current policies, practices and/or laws that have unintended negative consequences for those living with HIV/AIDS.

As Paul Farmer, a world-renowned medical anthropologist, argues, health planners must attempt to understand the "pathogenic effects of social inequalities, including racism, gender inequality and the growing gap between rich and poor," as well as the "mechanisms [through which] noxious events and processes become embodied as adverse health outcomes" for some people while others are spared (Farmer 2003). These efforts are particularly necessary today given the surge of HIV infection among the most vulnerable segments of American society.

## 7. HOW TO ENGAGE PEOPLE IN CARE: SOME LESSONS

Growing interest in reaching PLWH/As who have never been in care or who are at risk of falling out of care has inspired several recent studies and interventions, all of which provide insight into how to better respond to the unmet needs of people who know their HIV-positive status but are not in regular medical care. One common thread in much of this research is the idea of *access* — who does and does not have access to care and why.

Inequitable access — sometimes also referred to as “health-care rationing” — has been common throughout history. Whether health care is considered a right or a privilege, every society faces problems of unequal access, just as they struggle with the disparities in health outcomes that are the result. As with any illness, HIV/AIDS medications and comprehensive care are expensive, but hospitalizations, decreased productivity and drug resistance, not to mention the more intangible social costs of family disintegration.

With the continual rise in HIV incidence among socially and economically disadvantaged populations, more and more unorthodox and innovative strategies are needed to ensure that those populations have equitable access to medical care and treatment. Moreover, much of the research has found that — even once participants are connected to care — every effort must be made to develop and maintain a trusting, safe and supportive relationship between the patient and medical care provider.

This section examines a selection of lessons drawn from engagement and retention efforts that have been conducted in culturally and socio-economically diverse settings in cities throughout the U.S., involving a wide range of HIV epidemiological and funding characteristics. The research has been conducted in an array of service-provider settings, including health departments, HIV/AIDS service organizations, housing services, community-based organizations, faith-based organizations, clinics, hospitals and substance-abuse treatment centers.

The research presented here offers practical suggestions on reaching subpopulations of disengaged PLWH/As with life-prolonging health services. In effect, the lessons discussed provide additional tools that HIV-health-care providers and planners can use at the client, provider and systems levels to decrease health-care access disparities for PLWH/As and — ultimately — improve their health outcomes.

To preface the discussion, this section first briefly discusses two prominent theories of what is known as “health-behavior change”, i.e., theoretical foundations for the development and implementation of effective health interventions, including facilitating linkage to care.

### 7.1 Theories of Health Behavior in Linking People to Care

Programs designed to influence health behavior,<sup>16</sup> including health-promotion and -education programs and interventions, are most likely to benefit participants and communities when the program or intervention is guided by a theory, or a proposed explanation and/or prediction, of the target population’s health behavior. Theories of health behavior identify the targets for change and the methods for accomplishing changes. Such theories also inform the evaluation of efforts to

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<sup>16</sup> Broadly speaking, “health behavior” refers to “the [health-related] actions of individuals, groups, and organizations as well as their determinants, correlates, and consequences, including social change, policy development and implementation, improved coping skills, and enhanced quality of life” (Glanz *et al.* 2002).

change health behaviors by identifying measurable outcomes and suggesting timeframes and methods of study to be used. Such theory-driven health promotion and education efforts stand in contrast to programs based on precedent, tradition, pragmatism, intuition or general principles. Effective health education/intervention depends on marshaling the most appropriate theory and practice for a given situation. Which theory is appropriate will vary depending on whether efforts are being directed at/by individuals, groups or organizations.

Behavior-change theories provide insight into the links between behaviors and causes (i.e., precursors) or other variables of some sort such that condition  $x$  can be said to precede, cause, or be linked in some other way to behavior  $y$ . In articulating any theory, one is also specifying the kind of information that is needed to assess whether or not the theory is true or false. Theories of health behavior attempt to explain: (1) why people decide to act certain ways; (2) what influences people to act or not act; and (3) what individual and social processes are involved.

The two health-behavior theories discussed below are rooted in behavioral, cognitive and humanistic psychology. In general, behavioral psychology focuses on humans as bundles of desires that can be conditioned and takes little or no interest in an individual's consciousness, emotions, thoughts or beliefs. Cognitive psychology, on the other hand, focuses on mental processes (e.g., perception, attention, learning, reasoning, problem solving, decision making, etc.) and their effects on human behavior, as opposed to merely focusing on the outward behaviors. Lastly, humanistic psychology focuses on self-actualization as the most basic human drive — i.e., the desire to fulfill one's potential is the ultimate cause of behavior. The Health Belief Model, discussed in section 7.1.1, is based in behavioral and cognitive psychology, with an emphasis on the latter; the Transtheoretical Model, discussed in section 7.1.2, applies elements of all three psychological theories.

### **7.1.1 Health Belief Model**

One of the most widely used theories of health-behavior change is the Health Belief Model (HBM). The HBM originated in the 1950s from the U.S. Public Health Service's attempts to understand why people did not participate in disease-prevention and -detection programs and, later, to understand people's behaviors in response to diagnosed illness, particularly adherence to medical regimens. Today, the model is often used to examine various public-health concerns related to preventive and illness behaviors (Glanz *et al.* 2002).

As illustrated in table 23, the HBM posits six conditions that influence people to take action to prevent, screen for or control a condition of ill-health:

1. They believe they are susceptible to the condition (i.e., there is a perceived threat).
2. They believe the condition and the consequences of inaction are severe (i.e., there is a perceived threat).
3. They perceive that taking a known action has some benefit in terms of reducing the threat as well as other benefits (i.e., there is a benefit that outweighs costs).
4. They perceive that the barriers to taking the action are not too great (again, there is a benefit that outweighs costs).
5. There are cues to action or triggers to increase their readiness to act.
6. They are confident in their ability to successfully perform a behavior that will produce the desired outcome (i.e., they have a sense of self-efficacy).

| <b>Table 23. Key Concepts and Definitions of the Health Belief Model of Health Behavior Change</b> |   |   |
|--|---|---|
| <b>Concept</b>   | <b>Definition</b>   | <b>Application</b>  |
| Perceived susceptibility   | One's belief in his/her susceptibility to a condition   | Define population(s) at risk, risk levels<br><br>Personalize risk based on a person's characteristics or behavior<br><br>Make perceived susceptibility more consistent with an individual's actual risk |
| Perceived severity   | One's belief that the condition and its consequences are severe                                     | Specify consequences of the risk and the condition  |
| Perceived benefits   | One's belief that taking action has benefits, including reducing the threat                         | Define action to take: how, where, when; clarify the positive effects to be expected  |
| Perceived barriers   | One's belief that the barriers to taking the action are not too great                               | Identify and reduce perceived barriers through reassurance, correction of misinformation, incentives, assistance  |
| Cues to action   | Strategies to activate one's readiness  | Provide how-to information, promote awareness, employ reminder systems  |
| Self-efficacy  | One's confidence that he/she can successfully do the behavior that will produce the desired outcome | Provide training and guidance in performing action<br><br>Use progressive goal setting<br><br>Give verbal reinforcement<br><br>Demonstrate desired behaviors<br><br>Reduce anxiety                      |
| Source: Adapted from Glanz <i>et al.</i> 2002:49, table 3.1.                                       |   |   |

According to this theory, an individual's decision to change his or her behavior is largely a function of perception of benefits minus perceived barriers and/or costs. Research has provided support for the HBM as a useful model, with perceived barriers being the most powerful predictor of behavior, and perceived susceptibility and perceived benefits the next strongest (Glanz *et al.* 2000).

This model, however, has a drawback. Under the HBM (just as in economic theory), humans are assumed to act in their own best interest. In other words, individuals are thought to make decisions based on rational "calculators," weighing the costs and benefits of various behaviors and making decisions that support the goal of a positive health outcome. The theory assumes that people are inherently oriented toward actions that increase health and, to some degree, also assumes that all individuals are equally free or at least equally positioned to make rational calculations about health behavior (Glanz *et al.* 2002). As a result, there is the risk that providers/planners may make assumptions regarding the value placed on health and illness that are inconsistent with the cultural beliefs and socio-economic priorities of the target population. For example, a health professional with a stable job and high health literacy may reflexively place a high priority on receiving treatment for any disease, even one whose ill effects may be years distant; on the other hand, someone who is not sure where his or her next meal is coming from may consider such concerns to be abstract and not worth worrying about.

Aside from this caution, the model is useful in many contexts, including efforts to engage and retain hard-to-reach HIV-infected persons in care. For example, employing the concepts of this model together with HRSA's "engagement-in-care continuum" may provide a sound client-oriented foundation that facilitates readiness for establishing care. By helping HIV-care providers assess newly-HIV-diagnosed individuals' perceptions of (1) the severity of having HIV, (2) the benefits of entering into medical care and (3) the barriers to entering care, the model may help illuminate what services patients need to move them along in the engagement-in-care continuum.

### **7.1.2 Transtheoretical Model (Stages of Change)**

The Transtheoretical Model (TTM), also commonly referred to as the Stages of Change Model, is a composite of several behavior-change approaches. The model was initially used in studies of smokers trying to quit. Researchers found that smokers used different approaches at different stages of quitting, suggesting that health-behavior decisions have a temporal dimension and that an individual's process of deciding to change certain behaviors is developmental (i.e., the individual progresses, in order, through a series of definable stages) (Glanz *et al.* 2002). The TTM posits that there are generally six stages of change people go through, and that each stage of change calls for a different intervention approach. The stages of the model are shown in table 24.

| Table 24. Stages of Change in the Transtheoretical Model of Health-behavior Change |   |
|--|---|
| Stage construct  | Description   |
| Precontemplation   | <p>Individuals in this stage have no intention of taking action/changing behavior in the foreseeable future, usually measured as the next 6 months.</p> <p>Individuals may be uninformed or under-informed about the risks/possible change strategies, may not think they can change, or may have tried to change previously to no avail.</p> <p>Precontemplators are said to think very little if at all about their risky behavior or changing it — often labeled the “hard to reach.”</p>  |
| Contemplation  | <p>Individuals in this stage intend to change within the next 6 months, although they may remain in this stage longer than 6 months.</p> <p>Individuals are more aware of the pros and cons of changing but, in weighing them, ambivalence may result, leaving them in this stage for long periods of time. Individuals often procrastinate in this stage.</p> <p>Contemplators are not ready for traditional action-oriented programs that expect participants to take immediate action.</p> |
| Preparation  | <p>Individuals intend to take action in the immediate future, usually measured as the next month.</p> <p>Individuals in this stage typically have taken some significant action in the past year, and may already have a plan of action (e.g., seeing a counselor, attending a program or class, etc.).</p> <p>These are the people who should be recruited for traditional, action-oriented interventions.</p>   |
| Action   | <p>Individuals in this stage have made some specific modifications in behavior within the previous 6 months, modifications that meet some scientific criteria for reducing/preventing the health condition at issue, such as successfully establishing HIV primary care following a positive HIV diagnosis.</p>   |
| Maintenance  | <p>Individuals in this stage strive to remain in care (or otherwise follow the recommended regimen for their condition).</p> <p>In this stage, individuals are in the process of increasing their confidence that the behavior change can be maintained.</p> <p>This stage may last indefinitely.</p>   |
| Termination  | <p>Individuals in this stage no longer succumb to the temptation of falling out of/interrupting care and have developed self-efficacy in maintaining the changed behavior.</p> <p>This stage is not attained by many people, so a constant state of maintenance (the stage preceding this one) is viewed as the end stage most individuals are likely to reach.</p>   |
| Source: Glanz <i>et al.</i> 2002   |   |

Throughout the six stages, individuals weigh the pros (i.e., benefits of changing) and cons (i.e., costs of changing). Self-efficacy (an individual’s confidence that he or she can cope with high-risk situations without relapsing to unhealthy or high-risk behavior) plays a pivotal role throughout the six stages. Ten processes of change, with associated interventions and activities, are thought to influence movement through the stages:

1. Consciousness raising — increasing subjects’ awareness of causes, consequences and/or cures of “problem behaviors” through various interventions.

2. Dramatic relief — increasing subjects’ emotional motivation through psychodrama, role-playing, testimonials and other similar activities.
3. Self-reevaluation — examining subjects’ cognitive and affective self-assessments related to an unhealthy behavior, through “value clarification,” consideration of healthier role models and other techniques.
4. Environmental reevaluation — combining cognitive and affective assessments of how behavior affects others in the social environment, through empathy training, family interventions, media campaigns and other techniques.
5. Self-liberation — increasing subjects’ belief in and commitment to change, through resolutions, contracts, testimonials, etc.
6. Helping relationships — drawing subjects into caring, trusting, open and accepting relationships, such as with counselors, mentors, case managers, patient advocates, etc.
7. Counter-conditioning — helping subjects learn healthier behaviors that can substitute for unhealthy ones.
8. Contingency management — influencing subjects toward change through systems of consequences (e.g., rewards or punishments), which may involve contracts, group recognition and/or reward systems.
9. Stimulus control — removing cues for unhealthy habits and adding prompts for healthier alternatives through self-help groups, avoidance of certain high-risk groups or places, etc.
10. Social liberation — involving subjects in some social change or health promotion effort (Glanz *et al.* 2002).<sup>17</sup>

In summary, the TTM assumes that no single theory can account for behavior change; behavior change unfolds over time; stages of change are both stable and open to change; most at-risk populations are not prepared to take immediate action, meaning that traditional behavior-change programs may not work; and different processes/principles of change should be applied at different stages (Glanz *et al.* 2002).

Some researchers have questioned the idea of such a linear model, arguing that people do not go neatly from one stage to another but rather jump back and forth between stages (Glanz *et al.* 2002). Even so, research suggests strong relationships between certain of the processes described above and certain stages of change, and these relationships suggest strategies for engaging and retaining PLWH/As in care once their “stage of change” has been identified. For example, tailoring messages to HIV-infected individuals who are out of care and do not yet intend to seek care (i.e., in the precontemplation stage) and informing them of what medical care and support services are available (i.e., the locations of these services and their hours of operation, and how they can get there) may move them to the next, or “contemplation,” stage and thus closer to care.

As with the Health Belief Model previously discussed, the Transtheoretical Model may also be useful for HIV-care providers in assessing HIV-infected individuals’ readiness to establish *and* maintain care. Targeting interventions to the various stages of change may facilitate moving PLWH/As along in the engagement-in-care continuum.

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<sup>17</sup> One example of “social change” effort is the involvement of PLWH/As in a policy-making body like the planning council or an activist group like LifeLine, an informal advocacy group to which many of the Baltimore planning council’s members belong.

## 7.2 Findings from a HRSA Outreach Consultation

Over two days in April 2005, HRSA assembled a body of experts from local, state and federal agencies from across the country to discuss common difficulties and successes in engaging and retaining PLWH/As in care. During the two-day meeting, participants shared various outreach models and generated a wide range of ideas and recommendations on ways to enhance these efforts (HRSA 2006).

One of the major findings from this meeting was that, overall, programs have had limited success reaching HIV-infected individuals who have never had contact with the care system following their diagnosis. There has been greater success in retaining high-risk clients in care or finding those who have fallen out of care. In light of this, HRSA and other federal agencies are wrestling with whether to shift policy away from (1) focusing on reaching PLWH/As who have never been in care and toward (2) retaining people already in care who may be at risk of falling out and (3) finding those who have fallen out of care. HRSA stated the question as follows: “Should efforts focus more on sporadic users of care, [i.e.] those already somewhat within the system, as part of a more immediate ethical obligation of care providers to treat current clients?” (HRSA 2006).

Nonetheless, HRSA still advises grantees and planning bodies to continue efforts to identify PLWH/As who are out of care so that localities can determine how many PLWH/As they are reaching and engaging in care, direct resources to those in greatest need and monitor and demonstrate outcomes. Also, at a minimum, Ryan White grantees are advised to begin to develop indicators enabling them to track retention of clients and identify potential barriers (e.g., waiting times for appointments, phone coverage and timeliness of returned calls, comfort and accessibility of physical facilities, etc.). An assessment of current “points of entry” across *all* agencies, systems and funding sources is also advised (HRSA 2006).

Several types of outreach programs and their strategies were highlighted during the April 2005 meeting. The programs were characterized by their target populations’ positions on the engagement-in-care continuum (e.g., initial engagement of the newly tested, re-engagement of those who have fallen out of care, etc.) and the interventions the programs employed (e.g., street outreach, engagement in clinical and corrections settings, use of case managers and peers to conduct intensive interventions, support for clients, etc.). Sections 7.2.1-3 discuss several specific programs highlighted at this conference; a summary of all of the programs’ common features is presented in section 7.2.4. Roughly half of the programs that were highlighted can also be found, described in greater detail, in a 2006 publication from the Boston University School of Public Health’s Center for Outreach Research and Evaluation, Health and Disability Working Group (CORE/HDWG), *Making the Connection: Promoting Engagement and Retention in HIV Medical Care Among Hard-to-Reach Populations* (see Rajabiun *et al.* 2006). These particular programs will be discussed in section 7.3.

### 7.2.1 The CDC’s Antiretroviral Treatment and Access Studies (ARTAS)

One program featured at the HRSA outreach consultation meeting that enjoyed success in linking newly HIV-diagnosed individuals to care is the CDC’s Antiretroviral Treatment and Access Studies (ARTAS), which uses short-term case management to help clients overcome barriers to accessing primary care (e.g., fear, lack of readiness, lack of knowledge about services, etc.). ARTAS takes an active approach to linking clients to services by, for example, accompanying clients to appointments, arranging transportation to the first medical visit, etc. ARTAS II, a CDC-funded two-year project initiated in September 2004, is an extension of the original ARTAS study (ARTAS I), which demonstrated that, when people with a recent HIV diagnosis meet with a linkage case manager at least five times during a three-month period, they have an increased

likelihood of connecting to care (measured by keeping two or more appointments with an HIV primary care provider within a 12-month period) (HRSA 2006).

To date, 78 percent of clients with ARTAS case managers maintained care six months or longer compared to only 60 percent of patients who received a more passive referral to care. After 12 months, 64 percent of ARTAS case-management clients were still connected to care while only 49 percent of passively referred clients remained in care (HRSA 2006). The ARTAS II project will compare rates of linkage to HIV-care providers before and after instituting the linkage case management that was shown to be effective in the first ARTAS study (HRSA 2006). It is hoped that the findings will further strengthen understanding of how well linkage case management works in typical HIV-program settings throughout the country. Of the 10 collaborating sites for ARTAS II, five are local or state health departments and five are community-based organizations (CBOs), one of which is Total Health Care in Baltimore City.

### **7.2.2 The Yale AIDS Program**

Another highlighted program at HRSA's outreach consultation meeting, the Yale AIDS Program, is a community-based intervention that conducts street outreach through a mobile van. The target population is HIV-positive IDUs, particularly people of color, living in inner-city New Haven. The van is staffed with a clinician, case manager, HIV counselor/tester and outreach workers who resemble the targeted group demographically. Provided services include testing for tuberculosis, STD and HIV testing, physical exams, hepatitis B vaccine (HBV), primary care with free medicine and on-site substance-abuse treatment with buprenorphine. Importantly, because of the array of services, the van is not viewed as the "HIV van," but rather a "primary-care vehicle," which, findings suggest, helps assuage client discomfort or fear and increases utilization (HRSA 2006).

### **7.2.3 The Prevention and Access to Care and Treatment Project (PACT)**

The Prevention and Access to Care and Treatment (PACT) Project, based in inner-city Boston, was also presented at the HRSA conference as an effective program for linking people to care. The program's target population is low-income minorities reliant on supplemental security income (SSI), Medicaid and/or other public payers. PACT receives referrals of clients who are non-adherent or who are using drugs and/or alcohol, have CD4 counts below 350 and have had viral loads over 1,000 for the past 12 months. Upon intake, client needs and barriers to adherence are assessed, and the individual's position on the engagement-in-care continuum is determined. PACT staff members help non-adherent or at-risk clients move toward self-management of their HIV/AIDS infection. The intensity of the intervention depends on the client's needs. At three and nine months, clients are evaluated and the level of intervention is adjusted if necessary (HRSA 2006).

In addition to the usual physicians, social workers and case managers, the PACT program also relies on "health promoters" recruited from the affected community and extensively trained to conduct "engagement counseling" with clients. The health promoters provide HIV and other health education, adherence support and counseling. Health promoters can also help put clinicians' treatment recommendations into layman's terms, accompany clients to appointments, provide in-home support and facilitate access to and utilization of resources (HRSA 2006).

### **7.2.4 Common Features of the SPNS Outreach Programs**

These and other programs highlighted in the HRSA outreach consultation conference report have all achieved some measure of success at linking hard-to-reach individuals to HIV primary care. Regardless of the different approaches employed by the programs, certain common client-level,

provider/clinic-level and systems-level features emerged as having significant influence on engaging individuals in care, as shown in table 25.

| <b>Table 25. Common Features of Engagement Programs: Findings from the HRSA/HAB Outreach Consultation, 2005</b>   |
|---|
| <p><b>Client-level Features</b></p> <ul style="list-style-type: none"> <li>• <i>Intensive services and support</i> — those who have difficulty staying in care require intensive support (e.g., transitional case-management services for soon-to be released prisoners, housing assistance, home-based visits, transportation to appointments, etc.).</li> <li>• <i>Assessment of client needs</i> — client needs differed among the programs, but included mental health, substance abuse, housing, entitlement, legal, medication and medical care, transportation, child care and other support services. Assessment of client needs includes evaluation of barriers to treatment adherence, home environment and supports.</li> <li>• <i>Develop client trust</i> — because many clients have had limited or no experience with the health-care system, building trusting relationships (i.e., being non-judgmental and accepting of clients regardless of substance use, sexual behaviors, mental health or other issues or behaviors) is a prerequisite to engagement in care.</li> <li>• <i>Meet client priorities first</i> — recognize and address client-perceived high-priority needs (e.g., housing, food, clothing, legal, dental, and/or substance-abuse-treatment needs) before engaging them in HIV primary care.</li> <li>• <i>Readiness for care</i> — assessing individuals' stage of readiness for care at intake may be required in order to effectively connect and retain them in care (e.g., by using the Transtheoretical Model and stages of change).</li> <li>• <i>Client health beliefs and health literacy</i> — assessing health beliefs during outreach, at intake and at various intervals during a program intervention is critical to enrolling/engaging clients in care.</li> </ul> |
| <p><b>Systems-level Features</b></p> <ul style="list-style-type: none"> <li>• <i>Collaboration</i> — to facilitate client access to services and streamline care, collaborations among agencies are important (e.g., linking outreach and testing referral programs with case management and care programs; strengthening referral relationships with providers of critical support services such as mental-health and substance-abuse treatment; coordination across systems).</li> <li>• <i>Multi-level collaboration</i> — partnerships at <i>both</i> the agency leadership and staff level are essential, and agencies must be knowledgeable about one another's target populations, eligibility/referral guidelines, services provided and areas of expertise.</li> <li>• <i>Data sharing</i> — referral and client tracking across systems is critical to following individual clients and demonstrating program success. However, cross-agency data sharing can be difficult due to non-standardized monitoring methods and database layouts, especially across funding sources.</li> <li>• <i>Community and provider education</i> — educating community service providers on the goals, methods and staffing of outreach/linkage projects or positions (e.g., linkage case managers, retention coordinators) can facilitate the transfer of clients and strengthen the network of providers.</li> </ul>   |

**Provider/Clinic-level Features**

- *Get out into the community* — programs must go to the places/locations where target populations can be reached, and must employ the techniques that work best with specific target groups. Regardless of the techniques used, however, programs report great challenges in identifying the undiagnosed and HIV-positive individuals never connected to care via such outreach work.
- *Be welcoming and accessible* — clients' experiences with a provider/clinic influence their willingness to come, return to or stay in care (e.g., welcoming clinic space and staff, especially the receptionist; adequate and courteous phone coverage and call-back systems; flexible hours; etc.).
- *Break down physician resistance* — building clinician “buy-in” to outreach and retention efforts through teaching them its benefits (e.g., added support to clinicians' work) is important. Physician acceptance is most likely to occur when intensive interventions enhance client adherence to care regimens.
- *Staffing* — several titles exist for workers whose mission is to engage people in care (e.g., social networkers, recruiters, transitional case managers, linkage coordinators, retention coordinators, promoters, etc.). Successful programs have demonstrated flexibility and creativity in use of staff.
- *Staff training* — training or re-training staff members enhances or develops new skills that will enable them to better fulfill their specific role and collaborate with others (e.g., cross-training on different provider or agency roles and responsibilities).
- *Peers and community members* — employing HIV-positive individuals, at-risk community members and others to translate HIV-related information and treatment issues for clients and communicating client concerns to service providers. However, using peers and community members is not universally embraced by outreach programs and can present problems for management staff.
- *Measuring outcomes* — attention to quantifiable results is essential for judging program effectiveness. Various measures can be used by programs as a means to evaluate their effectiveness, such as: numbers of clients identified and referred to care; clinic visits and appointments kept; various clinical markers; referrals; client health and mental-health indicators; and evaluation of clients' health literacy and health beliefs.

Source: HRSA 2006.

### 7.3 Findings from SPNS Outreach Initiative Programs

In 2001, HRSA implemented a “targeted outreach and intervention” initiative, a multi-site “special project of national significance” (SPNS) under part F of the Ryan White program. A central goal of this project was to use creative outreach strategies to find hard-to-reach HIV-positive persons and engage them in medical care. The initiative supported the development, implementation and evaluation of nine outreach programs throughout the country. The Health and Disabilities Working Group (HDWG) at Boston University's School of Public Health provided evaluation and program support for the project.

This initiative was specifically designed to locate HIV-infected people and connect them to medical care in 16 CARE Act-funded sites throughout the country. Venues for conducting outreach varied and included clients' neighborhoods, churches and/or other community organizations, public medical clinics in low-income areas, bars, mobile vans, homeless shelters or Section 8 single-room occupancy residences, jails, and parks. Targeted groups were defined locally by each program and included people of color; active drug and/or alcohol users, indigents, sex workers, incarcerated persons, black men who have sex with men, individuals with a history of mental illness, and the homeless. All of the outreach programs provided supportive services to connect and/or retain PLWH/As who had never before established care, were inconsistent users of care or were at risk of falling out of care (Rajabiun *et al.* 2006).

With funding from HRSA, HDWG published a 2006 guide that provides an overview of each of the nine case studies and preliminary findings from their evaluations. The participating outreach programs and their locations, target populations and interventions can be found in table 26. Sections 7.3.1-5 offer more detail about the SPNS outreach initiative's target population and three of the nine programs studied.

| <b>Table 26. Description of the SPNS Outreach Programs</b>  |   |  |
|---|---|--|
| <b>Program and location</b>   | <b>Target population</b>  | <b>Intervention</b>  |
| CareLink Program,<br>Cascade AIDS Project<br><br>Portland, Ore.   | HIV-positive people with mental-health and substance-abuse issues, low socio-economic status and/or homelessness; and Hispanics with language and cultural barriers to HIV care.                          | Outreach and advocacy by building a niche in the continuum of HIV services to find and connect people living with HIV/AIDS to care.                              |
| Caring Connections,<br>University of Miami<br><br>Miami, Fla.   | HIV-positive pregnant and non-pregnant women who are known sporadic users of prenatal and primary care.   | Motivational intervention in a clinical setting to retain women in care.   |
| Drew University Mobile<br>Health Outreach<br>Project/UCLA<br><br>Los Angeles, Calif.                                | Sex workers, runaway youth, the homeless, undocumented workers, gang members, teen parents, women of childbearing age, adult and adolescent MSMs of color and transgendered/transsexual persons of color. | Enhanced case management to engage and retain people in HIV care.  |
| The Fenway Institute,<br>Fenway Community<br>Health<br><br>Boston, Mass.  | HIV-positive individuals who are currently out of care or are sporadic users of care, including people of color, IDUs, ex-offenders, sex workers, and MSMs.   | Community-wide efforts to engage and retain people living with HIV/AIDS in care through assistance with health-system navigation.                                |
| Horizons Project, Wayne<br>State University<br><br>Detroit, Mich.   | Newly diagnosed HIV-positive youth who are lost to follow-up from medical care/sporadic users of medical care; at-risk youth of unknown HIV status.   | Motivational intervention by peer and professional staff to connect people to and retain them in care through enhanced training and supervision of staff.        |
| Konnect II Client<br>Advocacy Program,<br>People of Color Against<br>AIDS Network<br>(POCAAN)<br><br>Seattle, Wash. | Communities of color, primarily people (1) newly diagnosed with HIV, (2) dropped out or at risk of dropping out of HIV care, and/or (3) otherwise in need of culturally relevant support.                 | Strengthening community partnerships to serve people of color through outreach, advocacy and substance-abuse and mental-health counseling.                       |
| Project Bridge, Miriam<br>Hospital<br><br>Providence, R.I.  | Formerly incarcerated HIV-positive men and women.   | Management systems to track staff efforts in retaining hard-to-reach PLWH/As in care through case management, outreach and life-skills/health-literacy training. |
| Well-being Institute<br><br>Detroit, Mich.  | HIV-positive women, predominantly African-American, with a history of substance abuse and mental illness who are loosely connected to care.   | An algorithm to determine which of two levels of nursing-outreach service delivery is most appropriate (brief or extended).                                      |
| Retention Care<br>Coordinator Program<br>(RCCP), Whitman-<br>Walker Clinic<br><br>Washington, D.C.                  | HIV-positive individuals at risk of falling out of medical care, including communities of color, people with a history of incarceration and people in recovery from drug addiction.                       | Retention care-coordinator program: adaptation of internal program services to retain the most vulnerable clients in care.                                       |
| Source: Adapted from Rajabiun <i>et al.</i> 2006:3.   |   |  |

At the start of the initiative, the nine programs faced several common challenges, including:

- Explaining their role in engaging and retaining clients in HIV care to other providers in the continuum of care in their communities.
- Establishing relationships and referral mechanisms with other providers.
- Defining and identifying those individuals with the highest risk of non-engagement in medical care.
- Retraining staff (many of whom formerly provided traditional outreach and HIV-prevention education) in the skills needed to motivate clients to seek HIV medical care and help them navigate the care system.
- Training managers to support and supervise the staff in their new roles.
- Implementing monitoring and quality-assurance systems as a means to evaluate effectiveness at engaging and retaining people in care (Rajabiun *et al.* 2006).

In the sections following are brief summaries and preliminary findings of three of the nine participating outreach programs — the CareLink Program, the Retention Care Coordinator Program (RCCP) and Project Bridge — all three of which target populations that are also of particular concern in the Baltimore EMA. These programs use strategies that appear to be effective at engaging and retaining these populations in care and so may be useful models to the Baltimore EMA. For more details on the programs, please consult source Rajabiun *et al.* 2006, listed in this report's bibliography.

For background, the section begins with a 2006 study that compares the demographic, clinical and health-care-utilization characteristics of participants in the SPNS outreach initiative to a 1998 nationally representative study of people with HIV/AIDS receiving regular or ongoing medical care for HIV infection

### **7.3.1 SPNS Outreach Initiative: Characteristics of Subject Population**

In a benchmark study published in the November 2006 issue of *Medical Care*, researchers William E. Cunningham and a number of associates compared socio-demographic, clinical and health-care-utilization characteristics of HIV-infected adults from two nationally representative samples: 1,286 PLWH/As from the 2001-2002 Targeted HIV Outreach and Intervention Initiative<sup>18</sup> described above, and 2,267 PLWH/As who were interviewed in 1998 for the HIV Costs and Services Utilization Study (HCSUS), the only nationally representative study of people with HIV/AIDS receiving ongoing medical care for HIV infection (Cunningham *et al.* 2006).

The outreach initiative was designed to locate HIV-infected persons who had never before established care, or who had fallen out of care, and connect or re-connect them to medical care in 16 CARE Act-funded sites throughout the country. By contrast, HCSUS focused on HIV-positive patients who were already receiving care, of whom 99.0 percent reported having a regular source of care (Cunningham *et al.* 2006).

The study found that, compared to the HCSUS population, the SPNS outreach programs reached individuals who were less educated, had lower incomes, were more likely to be homeless and had higher rates of such co-morbidities as substance-abuse and mental-health problems. The SPNS

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<sup>18</sup> Further details about the SPNS outreach programs are available at: <http://hab.hrsa.gov/special/%5cspns05rpt%5coutreach.htm>.

group also had less-favorable health status and health-care-utilization characteristics; while much less likely to get routine outpatient care, the SPNS population was more likely to get acute care (e.g., emergency room or other hospital visit) (Cunningham *et al.* 2006).

Also, a much greater proportion of the respondents in the SPNS sample reported mental-health-care visits in the previous 6 months (45.9 percent) compared to the HCSUS sample (26.7 percent). Currently having a case manager was also higher in the SPNS sample (82.7 percent) compared with the HCSUS sample (59.2 percent). Unsurprisingly, a greater proportion of participants in the HCSUS sample were receiving antiretroviral treatment (87.0 percent of patients with CD4 counts under 500 and 89.7 percent with CD4 counts under 350) compared with the SPNS sample (59.6 percent of patients with CD4 under 500 and 62.1 percent with CD4 under 350) (Cunningham *et al.* 2006).

Cunningham and his colleagues also found that recent alcohol use was strongly associated with lower service utilization in the SPNS sample (i.e., with individuals who had never before established care or had fallen out) but not in the HCSUS sample (i.e., individuals already receiving care), suggesting that alcohol use is a barrier to care *specifically in underserved populations*. Therefore, Cunningham and his colleagues argue, “providing alcohol treatment services may be particularly beneficial in increasing ambulatory medical care use among persons reached through outreach efforts” (Cunningham *et al.* 2006).

### **7.3.2 The CareLink Program**

CareLink, a program of Cascade AIDS Project (CAP) in Portland, Oregon, began in March 2001 with Ryan White program, Part A (Title I) funding. CareLink is an outreach and advocacy program based on a combination of health-behavior-change models including the Transtheoretical Model/Stages of Change and the Health Belief Model (discussed in sections 7.1.1 and 7.1.2, respectively). The stated goal of CareLink is to “identify people living with HIV/AIDS who are out of medical care (or at risk of falling out of care), link them to medical and case-management services, and provide them with support to remain and be successful in care.” In its earliest stages, the program’s largest challenge was simply finding hard-to-reach populations (Rajabiun *et al.* 2006).

As a starting point, the program determined that it would need a mechanism to identify HIV-positive individuals who were out of care and posed three main questions:

1. “How do we identify those who are not connected to services but who do know their HIV status, especially if they don’t want to be found?”
2. “Where do we look for them?”
3. “How do we get them to engage in services?” (Rajabiun *et al.* 2006)

The most cost-effective means of reaching their target population was not through conducting outreach on the streets, but rather through developing a “niche” for their program in Portland’s continuum of HIV care. It was determined that “without buy-in from other providers, we would not be able to find the clients the program was charged with locating, nor would the program staff be able to help them access HIV medical care, case management, or other services.” In order to achieve the buy-in, CareLink staff educated the other service providers on how the program could fill a gap in the service continuum (by providing intensive, short-term, outreach-based services to out-of-care PLWH/As) and demonstrated how these services could assist the other providers in their own work with clients, resulting in a stronger, more complete continuum of care (Rajabiun *et al.* 2006).

| <b>Table 27. CareLink Program’s Key Activities and Preliminary Results (Cascade AIDS Project)</b>  |
|--|
| Establishing clear roles, responsibilities and accountability mechanisms   |
| <ul style="list-style-type: none"> <li>• Partner organizations were given program outreach materials, a program fact sheet, and a flow chart showing how clients could enter the program.</li> <li>• Memoranda of understanding (MOUs) were developed with each program, specifying CareLink’s role and relationship with each program and how referrals were to be made.</li> </ul>   |
| Building and maintaining relationships with key partner programs and staff   |
| <ul style="list-style-type: none"> <li>• CareLink staff developed strong relationships with key staff at each partner organization, including a CDC-funded HIV community testing site, a Part C HIV primary-care clinic and hospital-based HIV primary-care clinic that served low-income individuals, the county corrections medical unit, and the HIV case management program.</li> </ul>  |
| Linking outreach and case management to streamline the intake process, coordinate release of information, and establish consistent communication with key personnel  |
| <ul style="list-style-type: none"> <li>• Because a single organization hires, trains and deploys case managers in Portland, regardless of the medical facility in which they work, enhancing the relationship with the case-management system was a critical first step for CareLink to be successful.</li> <li>• A joint intake process was developed between CareLink and case-management staff that included an exchange of information between the two agencies (e.g., clients who sign a joint release and are lost to follow-up in case management were referred to CareLink for outreach, and clients who first came in contact with CareLink received an intake for case-management services).</li> <li>• Due to the potential of duplicating services, CareLink established a clear definition of roles, a consistent referral process and a communication strategy between CareLink and case-management staff.</li> <li>• CareLink staff members attended monthly case-management-team meetings to co-manage clients, monitor transitions and identify new clients in need of outreach.</li> </ul> |
| Getting involved with and informing planning councils  |
| <ul style="list-style-type: none"> <li>• CareLink staff frequently informed their CARE Act Part A planning council of their program’s activities and outcomes.</li> </ul>  |
| Preliminary results after 12 months  |
| <ul style="list-style-type: none"> <li>• 93 percent of clients had a regular provider.</li> <li>• The average number of primary-medical-care visits increased in the 12-month period from 2.5 to 3.4.</li> <li>• The mean number of emergency room visits decreased from 1.8 to .68 per person.</li> <li>• The mean number of missed appointments decreased from 1.13 to .84 per person.</li> <li>• The proportion of participants with undetectable viral loads increased from 22 percent to 43 percent.</li> </ul>   |
| Source: Rajabiun <i>et al.</i> 2006  |

The CareLink staff made two main points in selling their program: the current case-management system did not assist clients in the process of *accessing* medical care (at-risk clients were assigned to case managers only *after* they choose a medical provider); and case managers did not have the capacity to proactively track/conduct outreach with clients who missed appointments (Rajabiun *et al.* 2006).

Illustrated in table 27 are the key activities that CareLink staff employed to implement their intervention, along with some preliminary results. The client-oriented approach of the CareLink program consisted of: assessing clients’ current level of engagement in HIV care and other social services, barriers to accessing those services, and readiness to engage in services (both at baseline and throughout their participation in the program). The program cultivated a strong staff/client relationship and program staff members developed individualized, client-centered goal plans to guide their work with clients. Program staff members used motivational interviewing techniques

to influence clients' movement along the TTM readiness continuum (as described in section 7.1.2) until the clients engaged in medical care (Rajabiun *et al.* 2006).

Additionally, clients learned about HIV, the service system, self-advocacy and risk-reduction techniques, all of which was intended to improve clients' sense of self-efficacy and ability to transition into the traditional HIV case-management system. Health-literacy education in particular plays an integral role (Rajabiun *et al.* 2006).

### **7.3.3 The Retention Care Coordinator Program at Whitman-Walker Clinic**

The Whitman-Walker Clinic (WWC) is a fixture in the Washington, D.C. area — the largest provider of medical and social services to people living with HIV/AIDS in that area for over 20 years. The clinic serves 7,000 people at branches in D.C., Virginia and Maryland. Despite the availability of comprehensive HIV/AIDS services, however, clients at the WWC frequently miss appointments and sometimes even disappear for months at a time (Ukman 2005).

The Retention Care Coordinator Program (RCCP) was designed to address this problem. RCCP is a clinic-wide intervention whose primary goal is to retain at-risk patients in HIV-related medical care. As with the CareLink program previously described, RCCP's largest initial challenges were (1) identifying the patients most vulnerable to dropping out of care and (2) identifying a mechanism within the clinic to target this group of patients. Additionally, a new staff position was created (Rajabiun *et al.* 2006). The RCCP's key activities and preliminary results are shown in table 28.

| <b>Table 28. The Retention Care Coordinator Program's Key Activities and Preliminary Results (Whitman-Walker Clinic)</b>   |
|--|
| Analyzing past or current clinic data to get a picture of the most vulnerable clients  |
| <ul style="list-style-type: none"> <li>• A retrospective chart review of all new patients who entered the clinic over a six-month period was conducted to determine what combination of psychosocial and demographic characteristics predicted patients dropping out of care after an initial visit.</li> <li>• Statistical analysis identified three primary factors that, when taken together, were associated with non-retention in care: being a racial/ethnic minority, being unemployed and recent or current drug use.</li> </ul>   |
| Examining clinic systems and training existing staff   |
| <ul style="list-style-type: none"> <li>• A screening tool for new patients was developed to determine which patients might benefit the most from the intervention.</li> <li>• The most effective way to use the tool was determined by assessing where within the clinic the screening would occur (clinic's intake center) and who among the staff would do the screening (existing intake staff included the screen as part of the routine intake process).</li> <li>• For every new patient, the intake coordinator used a specially designed Excel spreadsheet, containing factor weightings, to calculate risk of being lost to follow up; anyone with a drop-out probability of 75 percent or greater was referred to the intervention.</li> <li>• Due to high case loads for existing staff, a new staff position called Retention Care Coordinator (RCC) was created to facilitate patients' entry into medical care by providing reminder phone calls for upcoming appointments; helping patients arrange transportation or child care; accompanying patients to medical appointments; explaining medical information; providing treatment and medication adherence support; and helping patients navigate services either at the clinic or elsewhere.</li> </ul> |
| Training new staff in appropriate skills for working with vulnerable clients   |
| <ul style="list-style-type: none"> <li>• All RCCs received a two-day training covering topics such as clinical aspects of HIV/AIDS; health literacy; poverty; abuse, neglect and violence; homelessness; drug and/or alcohol abuse; and communications.</li> <li>• RCCs took part in extensive role-playing scenarios to practice interacting with patients.</li> <li>• RCCs developed additional skills by attending seminars, training programs and workshops that addressed ancillary medical topics and/or behavioral health issues.</li> </ul>  |
| Establishing lines of communication and referrals between departments and staff  |
| <ul style="list-style-type: none"> <li>• The new screening tool and the new staff position (RCC) were not well received initially by clinic staff — staff was skeptical of both the validity and additional burden of the screening.</li> <li>• Meetings were held to assuage skepticism (by explaining the screening tool) and improve cohesion among staff, particularly between the intake coordinators and RCCs.</li> </ul>  |
| Addressing clinician resistance to the new role of the retention care coordinators   |
| <ul style="list-style-type: none"> <li>• Clinicians were initially resistant to the presence of the RCCs during patient medical visits, feeling that this violated doctor/patient confidentiality. RCCs, however, were only present at the request of the patient and were trained to excuse themselves if the doctor needed to perform an examination where their presence would be inappropriate.</li> <li>• After time, providers came to trust the RCCs and view them as additional support in their time-constrained environment.</li> </ul>  |
| Preliminary results  |
| <ul style="list-style-type: none"> <li>• Patients who worked with RCCs had a lower no-show rate for clinic appointments compared to other similar patients in the clinic who did not receive services.</li> <li>• At one WWC location, the no-show rate decreased from 36.5 percent to 30.6 percent after 6 months and to 29.7 percent after 12 months.</li> <li>• At another WWC clinic, the no-show rate decreased from 34.2 percent to 22.6 percent after 6 months but rose to 26.4 percent after 12 months.</li> </ul>   |
| Source: Rajabiun <i>et al.</i> 2006  |

### **7.3.4 Project Bridge**

Project Bridge, a program of the Miriam Hospital in Providence, Rhode Island, provides outreach and case-management services for HIV-positive individuals who are being released from the state's correctional facilities. The overall mission of Project Bridge is to retain HIV-positive ex-offenders in medical care through "social stabilization," i.e., by helping clients "meet their basic survival needs (food, clothing, transportation and shelter), their health-care needs (medical appointments, obtaining medications, health insurance and ancillary care) and their longer-term needs (readiness for mental-health and substance-abuse treatment, payment of fines, attending to outstanding warrants, reestablishing connections with family, education/employment, and developing a social network)" (Rajabiun *et al.* 2006).

Project Bridge's primary challenge is addressing the array of clients' needs, the numerous barriers to care they face, and the disjointed service system. One of the project's prominent features is that each client has a case-management team that includes a social worker with a master's degree in social work and an outreach worker, preferably with a bachelor's degree in social work (Rajabiun *et al.* 2006).

Table 29 describes the key activities conducted by Project Bridge staff in implementing the intervention, as well as the project's preliminary results.

| <b>Table 29. Project Bridge’s Key Activities and Preliminary Results (Miriam Hospital)</b>   |
|--|
| Working with other providers   |
| <ul style="list-style-type: none"> <li>• A management system was developed to track clients’ needs and service outcomes across providers.</li> <li>• Collaborative relationships with other service providers (including meeting in person) and written linkage agreements were established.</li> <li>• Routine conferences are held with other service providers (e.g., housing, mental health, health care, substance-abuse treatment) where a particular issue(s) can be discussed, roles can be clarified, expectations can be established and collaborative agreements can be made. Clients’ participation is welcome in these meetings to encourage their contribution and to develop an agreed-upon plan of action that they are able to carry out.</li> <li>• The routine conferences bolster provider accountability since all attendees, activities, decisions, plans and responsible parties are documented.</li> </ul>   |
| Developing accountability for client referrals/tracking, staff productivity and program effectiveness  |
| <ul style="list-style-type: none"> <li>• A system of program documentation and supervision that focuses on client-level tracking was implemented.</li> <li>• At the beginning of each day, the staff is convened to discuss daily schedules and any clients that have been identified as recently missing an appointment or out of contact with staff for a month without a known reason.</li> <li>• The program’s documentation system includes tracking all referrals by date, type of service, agency and outcome; staff contacts with clients; and clinic appointments. Progress toward clients’ treatment goals is tracked by updating a field on the treatment plan and completing progress notes and semiannual summary forms.</li> <li>• To improve consistency, the programs’ management system is overseen by one staff member who is responsible for data entry, filing and record security. Specific dates are established for staff to submit their logs, and the timeliness of these submissions is assessed during annual performance reviews.</li> <li>• Written standards were established and communicated to the staff on the frequency of client contact, desired caseload size and the percentage of time spent on direct service. Staff productivity is tracked and shared on a monthly basis.</li> <li>• A checklist is used at the front of each client’s record that includes important target and completion dates, baseline treatment plan, completion dates for updated plans at 6-month intervals, dates of semiannual summary submissions and closing dates. The dates of application for the AIDS Drug Assistance Program (ADAP) and notification of Health Insurance Portability and Accountability Act (HIPAA) rights are also recorded on the form.</li> </ul> |
| Preliminary results after 12 months  |
| <ul style="list-style-type: none"> <li>• 83 percent of participants were retained in care (i.e., 2 medical visits in the previous 6 months).</li> <li>• The proportion of participants with missed appointments decreased from 27 to 23 percent.</li> <li>• The proportion of participants taking HIV medications increased from 47 to 71 percent.</li> <li>• The proportion of participants with an undetectable viral load increased from 47 to 61 percent.</li> <li>• Community stability measures:             <ul style="list-style-type: none"> <li>– The proportion of participants with health insurance increased from 45 to 83 percent.</li> <li>– The proportion of participants with stable housing increased from 11 to 27 percent.</li> <li>– The proportion of participants with unmet needs decreased from 82 to 52 percent.</li> </ul> </li> <li>• Improved health literacy:             <ul style="list-style-type: none"> <li>– The proportion of participants who discussed a treatment plan with their health-care provider increased from 60 to 87 percent.</li> <li>– The proportion of participants who discussed lab tests with their health-care provider increased from 60 to 71 percent.</li> <li>– The proportion of participants with adequate scores on the test of functional health literacy in adults (TOFHLA) increased from 64 to 70 percent.</li> </ul> </li> </ul>   |
| Source: Rajabiun <i>et al.</i> 2006  |

### 7.3.5 Other Lessons from the SPNS Outreach Initiative Programs

The findings from all nine programs in the SPNS outreach initiative suggest many effective strategies and approaches for reaching various populations of people who are not in care and then engaging and retaining them in care and treatment. It remains starkly evident, however, that no single solution or approach stands above the rest or is a guaranteed fix for every population or locale.

According to the report, there are several additional points to consider when planning to engage and retain individuals in care.

- Six months may not be enough time to engage some people in care, while for others it is all that is necessary.
- Strengths and weaknesses exist in both clinic- and community-based engagement and retention services.
- Clear communication between and defined roles for outreach and case-management personnel are necessary to prevent the duplication of services.
- Establishing close relationships with other providers in the continuum of care, particularly with agencies providing basic services such as housing, food, clothing and other support, is essential to reaching and engaging hard-to-reach HIV-infected people in care.
- Establishing close relationships with counseling and testing agencies is important to ensure that newly HIV-diagnosed individuals are immediately connected either to care or to agencies working with populations at high risk for HIV infection (e.g., ex-incarcerated, active substance abusers and/or homeless).
- The qualifications and characteristics of staff should be considered for both strengths and weaknesses related to engagement and retention services (Rajabiun *et al.* 2006).

In accordance with other research findings, the report asserts that effective outreach and retention requires “a combination of strategies: the ability to go out and find people; [the ability] to provide services that address clients’ most urgent needs in addition to medical care; [the ability] to help people learn how to navigate the health-care system, improve their knowledge about living with HIV/AIDS, and empower them to obtain the necessary services; [the ability] to build a relationship that promotes change in health behaviors and promotes the self-acceptance and confidence to live with and manage HIV; and, in the process, [the ability to] take an approach that is client-centered and supported” (Rajabiun *et al.* 2006).

## 7.4 Findings from AIDS Action Foundation’s Connecting to Care Workbooks

Similar to the SPNS outreach initiative described above, the AIDS Action Foundation’s Connecting to Care initiative, in collaboration with HRSA’s HIV/AIDS Bureau (HAB), also provides a useful framework for education about and implementation of methodologies that help connect people living with HIV to appropriate medical care. The initiative, which has involved researching interventions and methodologies employed by various types of service providers in nine cities across the country, has produced two “workbooks”: (1) *Connecting to Care: Addressing Unmet Need in HIV* and (2) *Connecting to Care: Addressing Unmet Need in HIV, Rural and Currently/Formerly Incarcerated*. This initiative is not part of HRSA’s SPNS outreach initiative but compliments these and other national efforts to connect people to HIV medical care.

Though the profiled interventions presented in both workbooks did not occur in Baltimore, they all targeted at-risk populations that are also present in the Baltimore EMA and offer new ways to think about connecting HIV-infected individuals to medical care and treatment. Common features of these interventions are described in sections 7.4.1-2.

### 7.4.1 Workbook I — Connecting to Care: Addressing Unmet Need in HIV

The first workbook, published in 2004, is intended to help HIV-care providers explore the idea of unmet need and become acquainted with the experiences of other agencies in implementing activities that help clients connect to services within a wide scope of health-care settings. The workbook highlights 17 individual, group and community-level evidence-based interventions from nine different cities (AIDS Action 2004). Unlike the second workbook, which focuses on two specific populations (residents of rural areas and formerly/currently incarcerated individuals) the first workbook is more general in its scope.

The first workbook presents four categories of information about each intervention: (1) description, (2) logistics, (3) strengths and difficulties, and (4) outcomes. Tables 30 and 31 present brief descriptions and key characteristics of each intervention.

Table 30 lists the workbook’s individual-oriented interventions (as opposed to group- and community-oriented interventions), while table 31 lists group and community-based interventions from *Connecting to Care Workbook I*.

| Table 30. Connecting to Care Workbook I — Individual-oriented Interventions   |  |
|---|--|
| Interventions and Descriptions  | Key Characteristics  |
| <p><b>Early Intervention Nurse</b></p> <p>Provides a formal clinical link for a person newly diagnosed with HIV.</p>  | <ul style="list-style-type: none"> <li>• Development of an ongoing relationship between a recently diagnosed client and a skilled clinician.</li> <li>• Mobility of the nurse allows travel to any location to meet the client, provide basic information about HIV, accompany the individual through the initial stages of care and help him or her transition into regular HIV medical care.</li> </ul>  |
| <p><b>Adherence Protocol</b></p> <p>Designed to actively engage a PLWH/A and his or her HIV-medical-care provider in a clinical relationship based on a patient-centered<sup>19</sup> treatment approach.</p> | <ul style="list-style-type: none"> <li>• Based on two-way communication between HIV-infected patients and their health-care providers.</li> <li>• The person living with HIV manages the treatment process through an oral and written agreement.</li> <li>• The clinician and patient work together, adhering to the patient’s treatment choices.</li> <li>• The treatment-planning process teaches the patient to be fully in charge of his or her care in addition to training the HIV medical-care provider in the precepts of patient-centered care.</li> </ul> |

<sup>19</sup> In a patient-centered model, according to the Agency for Healthcare Research and Quality, “patients become active participants in their own care and receive services designed to focus on their individual needs and preferences, in addition to advice and counsel from health professionals” (AHRQ 2002).

|  |   |
|--|---|
| <p><b>“Snapshot” Viral Load Testing</b></p> <p>Permits PLWH/As to “get a picture” of their HIV status and participate in managing their health through monitoring their own HIV viral loads.</p> | <ul style="list-style-type: none"> <li>• Helps make living with HIV a tangible reality.</li> <li>• Helps the patient see the relationship between treatment and health status.</li> <li>• Provides a common language for both the clinician and patient to use when discussing treatment needs.</li> </ul>  |
| <p><b>“Heartline” Hotline</b></p> <p>Provides easy access to information about HIV and medical and support services.</p>   | <ul style="list-style-type: none"> <li>• Provides an anonymous caller with confidential information about HIV and available services.</li> <li>• Allows a caller the opportunity to have frank and honest conversations about HIV and risk situations.</li> <li>• Offers immediate assistance to HIV-positive callers in crisis situations.</li> <li>• Helps the caller develop next steps and action plans.</li> </ul>                                       |
| <p><b>After Care Plan</b></p> <p>Assists PLWH/As who are receiving substance-abuse services within a therapeutic-community setting to plan for their HIV needs upon discharge.</p>               | <ul style="list-style-type: none"> <li>• After-care planning for a person living with HIV commences from the beginning of his or her stay in a residential treatment center.</li> <li>• Patient plays a role in creating his or her after-care plan.</li> <li>• Non-judgmental and non-discriminatory attitude of the staff is emphasized.</li> <li>• Follow-up services are provided by the center.</li> </ul>   |
| <p><b>Woman-to-woman Support</b></p> <p>Offers safe, confidential and culturally appropriate support services for women who are at risk for HIV infection or who are HIV positive.</p>           | <ul style="list-style-type: none"> <li>• Trust is developed between the health educator and a particular community.</li> <li>• A safe and non-judgmental environment is created by the health educator in support of individual female clients.</li> <li>• Ongoing support is offered and provided to each woman as she learns about and understands her HIV status.</li> </ul>   |
| <p><b>Financial Advocacy</b></p> <p>Assists persons living with HIV in meeting their financial obligations while remaining in regular HIV medical care and services.</p>                         | <ul style="list-style-type: none"> <li>• Dedication of a full-time staff person to assist the clients with navigating the health-care financing system.</li> <li>• Commitment of the clinical staff to ensure that certain HIV-infected clients are not so overburdened by medical bills that they drop out of care.</li> <li>• Commitment of the clients to collaborate with the staff to coordinate their care and coverage of medical expenses.</li> </ul> |
| <p><b>Intake Housing Referral</b></p> <p>Telephone intervention that provides information and support to PLWH/As experiencing housing crises.</p>  | <ul style="list-style-type: none"> <li>• Links HIV-positive persons to case managers while on the waiting list for housing.</li> <li>• Minimizes the steps necessary for HIV-positive clients to achieve quality care.</li> <li>• Develops strong collaboration between housing agencies and community health services.</li> </ul>  |
| <p><b>HIV Care Coordinator</b></p> <p>Maintains a coordinated care plan for all persons with HIV who are clients of a larger medical center (e.g., Veterans Affairs medical center).</p>         | <ul style="list-style-type: none"> <li>• Ability to maintain and coordinate communication between the person living with HIV and the clinical treatment team.</li> <li>• Gives the client the most consistent and non-fragmented medical care possible within the hospital care system.</li> <li>• Provides crisis services and routine assistance in addressing HIV-related medical care needs.</li> </ul>   |
| <p>Source: AIDS Action 2004.</p>   |   |

| <b>Table 31. Connecting to Care Workbook I – Group- and Community-oriented Interventions</b>   |  |
|--|--|
| <i>Interventions and Descriptions</i>  | <i>Key Characteristics</i>   |
| <p><b>Inter-agency Networking</b></p> <p>A community-services “safety net” for people living with HIV who fall through the cracks of HIV medical care and community support systems.</p>       | <ul style="list-style-type: none"> <li>• Sharing of community resources between agencies.</li> <li>• Informal structure of the network supports rotating leadership.</li> <li>• Provides the opportunity for key agency personnel to meet and discuss service-delivery options.</li> <li>• Improves capacity to serve all persons living with HIV within the service area of the network members.</li> </ul>   |
| <p><b>Primary Care Liaison</b></p> <p>Addresses the problem of clients who have difficult relationships with the health care system or have “fallen out” of the system.</p>                    | <ul style="list-style-type: none"> <li>• Goes beyond the stage of merely identifying a client to actively offering concrete care options.</li> <li>• Peer and mentoring relationships are established with the clients.</li> <li>• Promotion of community-based services through word of mouth.</li> </ul>   |
| <p><b>ZIP Code Mapping</b></p> <p>Utilizes public records and health department statistical data to create a map of HIV hot spots within a specific geographic area.</p>                       | <ul style="list-style-type: none"> <li>• Outreach programs are able to estimate needs for services and identify specific locations for services across broad communities and populations.</li> <li>• Supports establishment of relationships with key community stakeholders.</li> <li>• Ability to target outreach, prevention education, counseling, testing and referral services to specific areas concentrated with HIV-infected persons.</li> </ul>  |
| <p><b>Deployed Case Management</b></p> <p>Provides supportive services to area organizations in order to address the needs of people with HIV who are currently clients of their programs.</p> | <ul style="list-style-type: none"> <li>• Outplacement of case managers to assess and refer HIV-positive people to medical and community services.</li> <li>• Use of case management in both rural and urban settings.</li> <li>• Placement of case managers in non-HIV service agencies in order to cover a wide spectrum of client and agency needs.</li> </ul>   |
| <p><b>Support Group</b></p> <p>Helps HIV-infected persons understand and learn to live with their diagnosis.</p>   | <ul style="list-style-type: none"> <li>• Creation of a confidential space for people to share their experience of living with HIV.</li> <li>• A focus group-style initial meeting determines the needs of the support group.</li> <li>• Facilitators are members of the target population.</li> <li>• Group participants play an active role in the development of the support group and selection of topics.</li> <li>• Experience of “ownership” felt by the support-group members.</li> </ul> |
| <p><b>Clinicians Reaching Out</b></p> <p>Develops the capacity of HIV clinicians and places them in the community as HIV health educators.</p>   | <ul style="list-style-type: none"> <li>• Active participation of HIV specialists as community members.</li> <li>• Demystifies the role of the clinician.</li> <li>• Develops community partnerships with HIV clinical staff.</li> <li>• Outreach to organizations and institutions as partners in building a shared response to HIV.</li> </ul>  |
| Source: AIDS Action 2004.  |  |

### 7.4.2 Workbook II — Connecting to Care: Formerly or Currently Incarcerated Populations

The second workbook, published in 2006, focuses on two specific populations: PLWH/As living in rural communities and currently or formerly incarcerated PLWH/As. The workbook describes 25 individual, group and community-level interventions that have been particularly effective in addressing barriers to care commonly experienced by these two populations (AIDS Action 2006). Just as in the first workbook, this workbook provides a detailed look at four categories of information for each intervention: (1) description, (2) logistics, (3) strengths and difficulties, and (4) outcomes. (The interventions targeting rural populations are not discussed in this report.) Table 32 lists individual-oriented interventions from the workbook. Table 33 lists group and community-oriented interventions in *Connecting to Care Workbook II*.

| <b>Table 32. Connecting to Care Workbook II — Individual-oriented Interventions</b>  |  |
|--|--|
| <i>Interventions and Descriptions</i>  | <i>Key Characteristics</i>   |
| <p><b>Medical Advocate Discharge Planning</b></p> <p>Provides inmates nearing release with a plan for accessing medical and social services after discharge.</p>   | <ul style="list-style-type: none"> <li>• The discharge planner is a registered nurse with clinical knowledge of HIV/AIDS.</li> <li>• Each inmate receives one-on-one attention from the discharge planner.</li> <li>• Development of trust between each inmate and the discharge planner as they work together to ensure a healthy transition back to community life.</li> </ul>   |
| <p><b>Rapid HIV Testing at Jail Intake</b></p> <p>Offers individuals, on a voluntary basis, an opportunity to learn or “re-learn” their HIV status upon entering a correctional facility.</p>                  | <ul style="list-style-type: none"> <li>• Inclusion of a conversation about HIV during the general medical intake process.</li> <li>• The HIV test is of a non-invasive nature.</li> <li>• Incentive packages provided to encourage greater participation.</li> <li>• Individual attention for inmates.</li> <li>• Opportunity to link promptly to HIV medical care.</li> </ul>   |
| <p><b>Transgender Post-release Case Management</b></p> <p>Links transgender HIV-positive individuals to health services before release from a correctional facility.</p>                                       | <ul style="list-style-type: none"> <li>• Face-to-face meetings with inmates in a local facility or collect-call conversations from distant facilities.</li> <li>• Use of case managers who are from the primary target population.</li> <li>• Acceptance and non-judgment of the clients.</li> <li>• Development of a risk-reduction plan that includes HIV-related and other health goals.</li> <li>• Tracking of the clients’ progress.</li> </ul> |
| <p><b>Substance-abuse Discharge Liaison</b></p> <p>Helps meet the immediate health and social-service needs of HIV-positive men and women with histories of substance use upon release from incarceration.</p> | <ul style="list-style-type: none"> <li>• Development of relationships between the substance-abuse treatment agency and correctional facility.</li> <li>• Continuity of care that begins inside the facility and continues after release.</li> <li>• Development of a treatment plan that identifies the clients’ goals and action steps.</li> <li>• Substance-use intake assessment that matches programs to client needs.</li> </ul>                |

|  |   |
|--|---|
| <p><b>“Getting Started” Intake Case Management</b></p> <p>Helps HIV-positive individuals transition from life within a correctional facility to life beyond it.</p>                            | <ul style="list-style-type: none"> <li>• Holistic approach taken by the case manager in assessing clients’ needs (i.e., both medical and non-medical needs).</li> <li>• Support and health education offered to clients through participation in support groups and case-management meetings.</li> <li>• Provision of “staple item” incentives which help clients meet basic hygiene and clothing needs.</li> </ul> |
| <p><b>Treatment Adherence Nurse</b></p> <p>Actively engages formerly incarcerated individuals who are HIV positive in the planning and follow through of their medical care.</p>               | <ul style="list-style-type: none"> <li>• Utilization of a nurse who specializes in HIV care.</li> <li>• Staff is knowledgeable about the population served.</li> <li>• Formal relationships established between the agency and local medical providers.</li> <li>• Client’s involvement in the development of the treatment-adherence plan.</li> </ul>  |
| <p><b>Peer-to-mentor Escort to Care</b></p> <p>Helps HIV-positive individuals recently released from a correctional facility navigate the community network of health and social services.</p> | <ul style="list-style-type: none"> <li>• Immediate connection established between the agency and clients upon their release.</li> <li>• Training and support system offered to the peer mentors.</li> <li>• Development of a trusting relationship between the client and peer.</li> </ul>  |
| <p><b>Family Mapping</b></p> <p>Helps HIV-positive persons understand characteristics of their families and draw on identified strengths in order to better engage with HIV medical care.</p>  | <ul style="list-style-type: none"> <li>• Respect paid to the family <i>as it is defined by the client</i>.</li> <li>• Creation of a visual account of a family’s relationships, achievements and resource network.</li> <li>• Non-judgmental, participant-driven activities.</li> </ul>   |
| <p>Source: AIDS Action 2006.</p>   |   |

| <b>Table 33. Connecting to Care Workbook II – Group and Community-oriented Interventions</b>  |   |
|---|---|
| <i>Interventions and Descriptions</i>   | <i>Key Characteristics</i>  |
| <p><b>Women’s Halfway House HIV Education</b><br/>Provides information on HIV and other health-care issues relevant to incarcerated women to aid their connection or re-connection to local health services.</p>              | <ul style="list-style-type: none"> <li>• Direct connection to medical care provided to participants.</li> <li>• Professional and approachable demeanor of the staff.</li> <li>• Building trusting relationships between the client and the agency.</li> </ul>   |
| <p><b>Community Resource Video Conference</b><br/>Helps inmates, on a voluntary basis, develop a discharge plan as they near their release from federal prison.</p>   | <ul style="list-style-type: none"> <li>• Provides motivation for inmates to begin to think about and plan for post-release life.</li> <li>• Opportunity for inmates to interact with community-service providers remotely.</li> <li>• Time allotted after the video conference for follow-up questions and assessment with facility case managers.</li> </ul> |
| <p><b>Lunch and Learn</b><br/>Enables correctional nurses to provide up-to-date, high-quality medical care to HIV-positive inmates, while earning continuing education credit for providing educational seminars.</p>         | <ul style="list-style-type: none"> <li>• Integration of care for HIV infection into primary medical care.</li> <li>• Information network built between the nurses and experts in related fields.</li> <li>• Focus on the relationship between nurses and their HIV-positive clients.</li> </ul>   |
| <p><b>Bus Route to Care</b><br/>Provides homeless individuals with free transportation to social service organizations and health clinics.</p>  | <ul style="list-style-type: none"> <li>• Promotes collaboration among area HIV and social-service providers.</li> <li>• Helpful and friendly demeanor of the caseworkers staffing the bus.</li> <li>• Emphasis is placed on allowing people to make their own decisions about the care they receive.</li> </ul>   |
| <p><b>Get There Together</b><br/>Helps formerly incarcerated, HIV-positive persons improve their health and relationships with medical providers by providing them with information on HIV infection and treatment.</p>       | <ul style="list-style-type: none"> <li>• Holistic approach to HIV education.</li> <li>• Participant-driven, flexible curriculum.</li> <li>• Comfortable, non-judgmental environment.</li> <li>• Participants are free to share personal concerns, stories and knowledge.</li> </ul>   |
| <p><b>Midnight Hour Outreach</b><br/>Seeks to link individuals with significant unmet health needs to agency services by strategically positioning outreach teams in key areas of the city during “unconventional” hours.</p> | <ul style="list-style-type: none"> <li>• Client-driven mapping of outreach locations.</li> <li>• Meeting the clients “where they do business.”</li> <li>• Staff’s familiarity with the community and site locations.</li> <li>• Distribution of incentive gift bags and individual outreach-worker calling cards.</li> </ul>                                  |
| Source: AIDS Action 2006.   |   |

As shown above, the AIDS Action Foundation’s “connecting-to-care” workbooks provide many examples of evidence-based strategies for effective responses to unmet need. Although the basic approaches of these strategies are not new, the descriptions in the workbooks can help planners understand fine details in and important elements of each approach, while emphasizing the importance of three principal “connections”: “connect[ing] to the experiences of other service

providers; connect[ing] to the elements of the specific activity that help engage a person in care services; and connect[ing] the lessons in this workbook to your particular service setting” (AIDS Action 2004). Baltimore EMA planners may wish to consult the workbooks to consider the feasibility of adapting some of these interventions for local use.

## 7.5 Conclusion

The array of approaches employed by the programs described above underscores the absence of a single, simple, universal solution to the problem of not-in-care PLWH/As. Indeed, the wide range of interventions in these programs reflects the fact that disparities in access to HIV-care services result from combinations of persistent factors that can differ greatly from state to state and from city to city.

One factor common to all successful approaches is a solid understanding of why certain subpopulations of PLWH/As are not getting services. Successful planners must first understand the causes of local health-care inequalities as an initial step toward developing policies that are customized to the needs of particular PLWH/As in particular settings. There will inevitably be at least some hardcore intransigents who cannot be reached by any intervention, but many other not-in-care PLWH/As will engage better with care if only certain barriers can be eliminated. The trick is figuring out what these barriers are.

In the programs described in this section, the hard work of answering the “why” questions and beginning to develop policies customized to different situations is made easier with a number of analytical tools designed to help planning bodies understand:

- Where subpopulations of PLWH/As live (critical for geographic targeting).
- Why certain subpopulations so often fail to come forward for services (e.g., household-level factors such as lack of knowledge or resources, community-level cultural factors like stigma and fear, etc.).
- Why public services so often fail to reach the most impoverished and marginalized (e.g., deficiencies in strategies, management, vision, etc.).
- How the private (not-for-profit and for-profit) sector can be effectively harnessed to complement public services for needy populations.

But analytical work alone is clearly not enough. Policies have to be fashioned, tested and implemented in order to take advantage of the most promising opportunities and to counter those factors that constitute the most significant bottlenecks. It is equally important to continue to cultivate ways of monitoring the extent to which PLWH/As have access to and use health and supportive services, in order to interrupt the cycle of certain subpopulations not accessing care and receiving treatment when necessary.

## 8. OUTREACH EFFORTS IN THE BALTIMORE EMA

According to the *Greater Baltimore HIV Health Services Planning Council Standards of Care Fiscal Year 2004*, the service definition for the Minority AIDS Initiative (MAI) outreach/linkage-to-care service category is as follows:

The terms “outreach” and “linkage to care” refer to those activities that promote the access to, and continuation of, appropriate services at the earliest possible stage of HIV disease by addressing the multitude of issues and service barriers that impact upon the individual. Services may be provided on the streets in areas where there is a demonstrably high incidence of HIV infection, in non-traditional HIV service settings and facilities, and within the traditional HIV health-care system (IGS 2004).

In fiscal year 2006, MAI outreach programs that were awarded Part A (Title I) funding in the Baltimore EMA included: the Baltimore Pediatric HIV Program, the Baltimore City Health Department, Build Fellowship, Manna House, Project PLASE, Sisters Together and Reaching, and Total Health Care. These agencies differ in the services they provide, types of clients they serve and overall missions. This section provides a brief description of each agency and their outreach services so that providers and planners can get a sense of their prominent features and strategies, as a precursor to possible collaboration and agreements.

### 8.1 Baltimore Pediatric HIV Program, Inc.

The Baltimore Pediatric HIV Program (BPHIVP) is a non-profit community-based organization, certified by the Maryland Department of Transportation as a minority business enterprise. BPHIVP, the only HIV/AIDS pediatric day- and respite-care program in Baltimore City, provides a range of services for children and families, particularly African-American, who are infected/affected by HIV/AIDS, including outreach services to high-risk individuals (e.g., MSMs and IDUs).

According to BPHIVP’s web site, its outreach efforts aim to “go outside of the boundaries of traditional community outreach and increase the number of HIV-positive African American women, children and men accessing and maintaining primary medical care” (BPHIVP 2005). Specifically, the program:

- Conducts HIV testing and counseling at their facility and various community-based locations (e.g., substance-abuse treatment centers).
- Makes referrals for case management and other services.
- Ensures proper connection to primary medical care and needed services.
- Provides follow-up for at least one year (BPHIVP 2005).

### 8.2 Baltimore City Health Department

The Baltimore City Health Department (BCHD) is the oldest continuously operating health department in the nation. The mission of BCHD is “to advocate, lead, and provide services of the highest quality in order to promote and protect the health of the residents of Baltimore.” BCHD offers and oversees services for “sexually transmitted infections, HIV/AIDS, family planning, maternal and infant health, immunizations, asthma, senior care, cancer screening, [and] lead poisoning prevention services, among others” (BCHD 2007).

BCHD’s MAI outreach program employs “case finders” who have completed extensive training

that includes elements of the CDC's sexually-transmitted-disease intervention training and traditional outreach training. Case finders have better access to at-risk populations, including MSMs, substance abusers, and others. Newly HIV-diagnosed individuals are referred to a case finder who makes efforts to recruit them into care. If a client agrees to enter care, the case finder has the client sign a release form permitting the collection of needed information, including appointments kept/missed, CD4 cell counts and viral loads (BCHD 2006a).

The case finder works with clients to assess and then eliminate barriers to care (e.g., need for transportation, need for treatment for substance use, etc.). The case finder is required to maintain contact with clients until they have successfully attended two primary-care and case-management appointments (BCHD 2006a).

### **8.3 Build Fellowship, Inc.**

Build Fellowship, Inc. is a faith-based, non-profit organization that provides "safe holistic-based environments" to low-income men and women who are recovering drug addicts and who are either transitioning from the correctional system or complying with court orders. Build Fellowship frequently receives referrals from parole and probation officers, drug court and substance-abuse treatment providers. The organization manages three halfway houses (two for men and one for women) where addiction treatment is provided as well as ancillary services to address residents' mental health, physical health and any other issues. Additionally, Build Fellowship provides HIV-specific outreach services to low-income, uninsured and underinsured individuals & families (BF 2007).

The Build Fellowship outreach program's specific focus is "HIV/AIDS-infected persons in Baltimore who are lost to follow-up in medical and social service care, predominantly African-American and Hispanic populations at or below the poverty level [who are] experiencing barriers in accessing services." In addition, Build Fellowship is trying to "effectively bring into care increased numbers of persons that know their HIV status, but have not been accessing HIV care...and ensure the quality and accessibility of services by strengthening [their] monitoring, data collection and analysis, planning, capacity development, quality assurance and evaluation activities" (BF 2007).

### **8.4 Manna House, Inc.**

Manna House is a non-profit community-based organization that provides assistance and support to the homeless, poor and needy of Baltimore City with services including a soup kitchen, a drop-in center, outreach, housing assistance, counseling, testing, referrals, psychosocial support and holiday meals (MH 2006).

Manna House's non-traditional outreach workers, according to the organization's web site, provide daily HIV educational meetings with persons in line to eat at the soup kitchen as well as follow-up meetings. Outreach workers are encouraged to develop strong relationships with clients or potential clients. The outreach workers identify and interview persons who are HIV positive but not receiving primary medical care and refer them to clinics. When necessary, clients are also referred to case managers, substance-abuse treatment centers and/or mental-health programs. Also, when necessary, outreach workers accompany clients to their appointments and stay with them to ensure that their service needs are met. Outreach workers also teach clients to advocate for themselves during appointments (MH 2006).

## 8.5 Project PLASE

Founded in 1973, Project PLASE, Inc. provides transitional and permanent housing and supportive services to the homeless. Project PLASE serves a particularly vulnerable and underserved population in Baltimore City, one that includes persons with mental illness, HIV/AIDS, addiction, developmental disabilities and individuals who were formerly incarcerated.

Project PLASE's HIV outreach workers screen all HIV-infected residents upon entry into their housing facilities and subsequently provide them with information and support. In addition to screening HIV-positive residents, outreach staff screen and educate all uninfected residents regarding at-risk behaviors, the importance of HIV testing and counseling, and HIV transmission. For those individuals who are HIV positive and need a medical provider, mental-health provider or substance-abuse treatment facility, an outreach worker schedules the appropriate appointments (PP 2007).

According to Project PLASE's web site, some of the core services outreach staff provide include: "HIV education, peer support, escorts to appointments, referrals, screening and compliance with medical, mental-health and substance abuse-treatment programs" (PP 2007). For individuals who require greater assistance in establishing compliance with the programs to which they are referred, outreach workers escort them to their appointments (PP 2007).

## 8.6 Sisters Together and Reaching

Since 1991, Sisters Together and Reaching (STAR), a faith-based non-profit organization, has been offering both HIV prevention and support services to women infected with HIV/AIDS through a holistic women's community center and mobile van unit. Although the program is centered on serving women, its services are also available to men and the gay/lesbian/bi-sexual/transgender (GLBT) community.

STAR's outreach program, according to the organization's web site, conducts the following activities:

- "Recruit community members for HIV/STI counseling, testing and referrals."
- "Identify and recruit HIV-positive persons who are not receiving care/treatment."
- "Identify and recruit persons to receive HIV-prevention services" (STAR 2006).

## 8.7 Total Health Care

Total Health Care (THC) is a non-profit community-based health center that provides primary health care, obstetrics/gynecology, pediatrics, pharmacy services, dental care and lab services. THC also provides health education, outreach and preventive services to uninsured and medically at-risk populations in Baltimore City, including free blood pressure, diabetes and HIV screenings.

Additionally, THC has an early intervention service (EIS) program that provides a range of services including substance-abuse treatment, free rapid HIV testing, case management, emergency financial assistance, transportation services, housing assistance, infectious disease specialty care, and pharmacy assistance.

THC also has a center for social and emotional health that provides licensed psychiatrists and psychologists, social workers, counselors and public-health administrators for clients with mental health needs.

## 9. CONCLUSION AND RECOMMENDATIONS

### 9.1 Conclusion

HIV-care providers and planners are increasingly concerned about the issue of unmet need, or people who know that they are HIV-positive but are not receiving HIV medical care. Not-in-care PLWH/As risk harming their own health and that of their sexual partners, and the expense of caring for them when their health reaches a crisis point places significant strain on an already sparsely funded service continuum. It is not possible to say with certainty how many of this EMA's approximately 18,000 PLWH/As are not in care, but estimates range from 16 to 35 percent (approximately 2,880-6,300).

PLWH/As — particularly those who are members of disproportionately affected and historically underserved subpopulations — face many barriers to care. Strategies for engaging and retaining PLWH/As in care must take into account the specific barriers faced by the populations and individuals being targeted. Designing and implementing such strategies for PLWH/As who have never been in care is often so cost ineffective that HRSA is considering whether it makes more sense to instead place official emphasis on retaining PLWH/As who are already in care or who have at least been in care, as opposed to seeking out those not in care. However, uncertainty as to whether HRSA will shift policy in this manner should by no means discourage ongoing and future efforts to reach all not-in-care PLWH/As and connect them to care. Instead, there is a clear need for even more resourceful and innovative thinking about the issue of not-in-care PLWH/As among grantees and planning bodies.

Research has identified many influential factors that contribute to delayed entry into/poor maintenance of HIV medical care, including: varying levels of “readiness” for entering/maintaining medical care; health status and risk perceptions; ease of access to medical care; lack of health insurance; prior or current incarceration; lack of social support; HIV/AIDS-related stigma; mental-health problems; negative physical and emotional consequences following diagnosis; history of substance abuse; distrust of the health care establishment; and transient residence. Although these barriers suggest some practical responses for connecting individuals to care, they also illuminate the sheer complexity of the issue as a whole, complexity resulting from the fact that barriers to care are not mutually exclusive and often have synergistic effects that significantly contribute to the precariousness of individuals' relationships with HIV health-care providers.

What does this mean for PLWH/As in the Baltimore EMA? Despite the extensive body of knowledge concerning barriers to care, it is tremendously important that planners in the Baltimore EMA continue efforts to uncover why certain subpopulations in this area are not engaged in or fall out of care. Doing so is important because, although certain subpopulations in this EMA may encounter one or more of the barriers previously mentioned, they also may have certain distinct needs that are specific to the cultural and socio-economic conditions present in the Baltimore EMA. Also, the possibility always exists that some idiosyncrasy or oversight within any region's continuum of care either presents a barrier to entry into care or pushes some clients out of care.

At this juncture, some questions worth asking may include: what are the demographic and socio-economic profiles of HIV-positive individuals not engaged in primary medical care? Where do they live in the EMA? What are their previous health-care-utilization patterns? How do they compare with similar people who *are* engaged in routine medical care? What are their beliefs, attitudes and levels of “readiness” for entering care? While it is true that the EMA's planners have a sense of the answers to many of these questions, it is also true that no large-scale study of

this issue has been performed locally. Furthermore, the EMA's lack of an unduplicated client-level tracking system severely handicaps any efforts to measure retention-related outcomes.

Planners wishing to grapple with the problem of unmet need for HIV medical care should familiarize themselves with HRSA's engagement-in-care continuum, a conceptual framework that offers a more nuanced way of describing the extent to which someone is "in" or "out" of care. The framework, described in section 5.1.2 of this report, helps planners and providers view clients in a more realistic light, as unique individuals who move back and forth through different degrees of engagement with health care as they deal with competing priorities and life events (e.g., changes in employment status, child care, illness, imprisonment, housing troubles, etc.). Using the engagement-in-care continuum, together with the health behavior theories discussed in section 7.1, planners are better equipped to tailor more precise outreach efforts for the populations they are attempting to connect to care.

Recent national research has much to say about evidence-based strategies for engaging and retaining hard-to-reach PLWH/As in care. The programs discussed in this report were implemented in culturally and socio-economically diverse settings throughout the country, capturing a wide range of HIV epidemiological and funding characteristics, including many similar to those of the Baltimore EMA. Although some of the strategies employed by the various programs are not new, their methods and achievements have now been documented in a rigorous manner that makes it easier for other programs to adopt the most effective elements. Other strategies that recent research has highlighted are, by contrast, unorthodox and innovative; such new ideas are becoming progressively more important as HIV incidence increases among marginalized populations, with whom the traditional methods of connecting HIV-infected persons to care are less effective.

Across all of the research presented in this report, certain common client-level, provider/clinic-level and systems-level features emerged. At the client level, some of the common features of programs that are effective at engaging and retaining PLWH/As in care include providing intensive services and support (e.g., transitional case management services for soon-to-be released prisoners, housing assistance, home-based visits, etc.); assessing and addressing clients' non-primary care needs (mental health, substance-abuse treatment, housing, legal, etc.); developing clients' trust; assessing clients' stage of readiness for entering care (e.g., using the Transtheoretical Model and stages of change); and assessing clients' health literacy, beliefs and level of distrust of the medical establishment.

At the provider/clinic level, some of the common features of effective engagement/retention programs include: getting out into the community (e.g., going to places/locations where target populations can be reached and developing a rapport with members of the targeted community); welcoming and accessible provider facilities; building clinician "buy in" to outreach and retention efforts; demonstrating flexibility and creativity in use of staff; training or re-training staff members to enhance or develop new skills (e.g., linkage case managers, retention coordinators, etc.); employing HIV-positive individuals and/or at-risk community members; and measuring outcomes to evaluate program effectiveness.

Lastly, at the systems level, some of the common features of effective engagement/retention programs include: inter-agency collaboration to facilitate client access to services and streamline care; partnerships at both the agency leadership *and* staff level; sharing of referral and client-level data across systems; and educating community health-service providers on the goals, methods and staffing of outreach/linkage projects.

The planning council is encouraged to consult the sources detailing these interventions, available in the annotated reference list in section 10.1. Although each intervention may not be entirely

replicable in this EMA for any number of reasons (e.g., funding characteristics, organizational structure, etc.), planners may still want to look at the various components of the programs and see if there are any elements that might be adapted for local use.

## **9.2 Recommendations**

As possible next steps, planning council members may want to consider the following recommendations, some of which directly address the original concerns that inspired this project while others address the EMA's HIV-care system more generally.

### **9.2.1 Standardized Client-level Tracking System**

Development and implementation of a standardized client-level tracking system/database that tracks demographic information, stage of illness upon diagnosis and at care entry, client retention, missed appointments, wait times, referrals, etc. would greatly enhance the Baltimore EMA's ability to respond to the needs of PLWH/As, including retaining them in care. Under the current system, it is not possible to measure retention-related outcomes, measurements that would be vital for establishing baselines and evaluating the success of any attempted interventions.

### **9.2.2 Public Health Education Campaign**

The design and implementation of public-health-education campaigns in the hardest-hit areas in and around Baltimore City is necessary so as to effectively address the barriers to care specific to certain communities and demographic subpopulations, raise awareness and knowledge of HIV/AIDS, provide culturally appropriate information on HIV services available in that community and combat HIV-related stigma. The campaign should target African-American MSMs, African-American women, and other high-risk groups. Gathering community input (e.g., health beliefs and health literacy, levels of distrust of medical providers, concerns regarding stigma and discrimination, effects of racism and homophobia, etc.) is an essential first step.

### **9.2.3 Community Engagement and Resources**

Engaging PLWH/As alone is not enough. Efforts to engage the entire community must be a top priority. This can be done by building coalitions and listening to the community as part of the process of improving access to care. Buy-in from churches and other credible, *community-recognized* leaders would be essential. Determining what resources are available in the most affected communities is another vital step. This includes identifying resource needs/gaps, demonstrating patterns of service delivery (i.e., who is accessing services and who is not), identifying locations of power and influence within communities and identifying the need for linkages between organizations.

### **9.2.4 Affordable Housing Advocacy**

Housing is a critical element of HIV medical care and prevention; PLWH/As without stable housing are extremely likely to fall out of or be non-compliant with care. Planners in the EMA should continue to advocate for subsidized, affordable housing (including supportive housing for those who need it). Assessing the impact and effectiveness of various housing models is also important, though doing so is hampered by the lack of the tracking system described at 9.2.1, above.

### **9.2.5 Assessment of Patient's Readiness**

By assessing the patient's readiness to receive care at the time of testing, his or her tendency to delay medical care may be revealed. In turn, retention efforts can be put into action earlier on.

According to researchers, “the patient’s element of surprise and the associated delay in medical linkage suggest that HIV testing for this group initiates the process of seeking help” (Samet *et al.* 1998).

### **9.2.6 Delivery of HIV Medical Services Outside Business Hours**

Providing HIV services outside regular business hours is critical to engaging PLWH/As who have difficulty accessing care during regular business hours (e.g., if they cannot get out of work). One study that examined the impact of competing subsistence needs and other barriers among a nationally representative sample of 2,864 adults receiving HIV care found that conflicts with work schedules was one of the top four barriers that led more than one third of the sample to go without or postpone care at least once in a 6-month period (Cunningham *et al.* 1999). A first step would be to determine how many EMA providers offer care outside business hours and which services they offer; anecdotal evidence suggests that non-business-hours care availability is limited in this EMA.

### **9.2.7 Retention Efforts**

There is evidence that suggests that retention efforts are much more cost effective than efforts to reach people who have never been in care, and HRSA has recently begun to recommend increased focus in this area. Two retention models discussed in this report are the Retention Care Coordinator Program at Whitman-Walker Clinic in Washington, D.C. and Project Bridge, a program of the Miriam Hospital in Providence, Rhode Island. Planning council members may wish to consult the HRSA “workbooks” listed in section 10.1 for more details on these programs.

### **9.2.8 Key Points of Entry Into Care**

Planners should identify key points of entry into care for PLWH/As in the EMA. Key points of entry are the first (and sometimes the only) means by which people seek and receive health care. Some potential points of service for those who know their HIV status but are not in care include adult/juvenile detention centers, homeless facilities, safe houses, STD clinics, food banks, immigration/legal services, back-to-work/welfare-to-work programs, mental-health programs, community and migrant health centers, family-planning clinics, emergency rooms and needle-exchange programs.

### **9.2.9 Survey of Health-care-utilization Patterns, Attitudes and Beliefs**

Conducting a health-care-utilization survey that addresses the following three questions may provide further insight into why certain groups of PLWH/As are not engaged in care: (1) among people who have been diagnosed with HIV or AIDS and are living in the Baltimore EMA, how many are utilizing medical care to treat their HIV; (2) what differences exist between those who are and those who are not receiving HIV primary medical care; and (3) how do people who have been diagnosed with HIV or AIDS interact with the health system?

In order to safely and effectively contact populations that are particularly threatened by HIV-related stigma, such as sex workers and the homeless, it may be advisable to design the study as a broad examination of *non-HIV-specific* health-care-utilization patterns, attitudes and beliefs (though it could still obtain HIV-related information). By accepting all interested respondents, as opposed to just the HIV positive, the risk of exposing the status of PLWH/As would be greatly lessened, thereby increasing participation rates; many of the barriers to health care experienced by HIV-negative respondents may be relevant to the HIV-positive population. Finally, by collecting non-HIV-specific information, such a survey may be of interest to non-Ryan White entities, creating opportunities for collaborative funding which would reduce the strain on planning council coffers.

## 10. APPENDICES

### 10.1 Resources for Engaging and Retaining HIV-Positive People in Care

Below are some suggested resources for engaging and retaining HIV-positive people in care, including general high-risk populations, incarcerated or formerly incarcerated populations and substance abusers. Planners are highly recommended to consult these sources.

#### 10.1.1 General High-risk Populations

- *Outreach: Engaging People in HIV Care: Summary of a HRSA/HAB 2005 Consultation on Linking PLWH Into Care.* August 2006. Available at: <http://hab.hrsa.gov/tools/HIVoutreach>.
- *Making the Connection: Promoting engagement and retention in HIV medical care among hard-to-reach populations.* 2006. Produced by the Center for Outreach Research and Evaluation, Health & Disability Working Group (CORE/HDWG), at Boston University School of Public Health. Available at: <http://www.hdwg.org/pdf/projects/Making%20the%20Connections.pdf>.
- *Connecting to Care: Addressing Unmet Need in HIV, Workbook I.* 2004. AIDS Action. Available at: <http://www.connectingtocare.net>.

#### 10.1.2 Incarcerated or Formerly Incarcerated Populations

- *Enhancing Linkages to HIV Primary Care in Jail Settings.* January 7, 2007. Prepared for HRSA/HAB by the Rollins School of Public Health, Emory University and ABT Associates, Inc. Available at: <http://www.careacttarget.org/librarysearchtemp4.asp>.
- *Connecting to Care: Addressing Unmet Need in HIV, Rural & Formerly/Currently Incarcerated, Workbook II.* 2005. AIDS Action. Available at: <http://www.connectingtocare.net>.

#### 10.1.3 Substance Abusers

- *Kaleidoscope of Care: Responding to the Challenges of HIV and Substance Abuse. Module II: Strategies for Engagement and Retention in Care.* 2004. HIV Training and Technical Assistance Center (HIVTAC). Available at: <http://www.aids-ed.org/aidsetc?page=et-04-03>.

## 10.2 Acronym Key

|        |   |
|--------|---|
| AIDS:  | Acquired immune deficiency syndrome.  |
| ARTAS: | Antiretroviral Treatment and Access Studies.                                  |
| BCHD:  | Baltimore City Health Department.   |
| BNIA:  | Baltimore Neighborhood Indicators Alliance.                                   |
| CAP:   | Cascade AIDS Project.   |
| CBO:   | Community-based organization.   |
| CDC:   | U.S. Centers for Disease Control and Prevention.                              |
| DHMH:  | Maryland Department of Health and Mental Hygiene.                             |
| EMA:   | Eligible metropolitan area (i.e., area eligible for Ryan White Part A funds). |

|         |   |
|---------|---|
| FBI:    | Federal Bureau of Investigation.  |
| HAB:    | HIV/AIDS Bureau, a bureau within HRSA.  |
| HBM:    | Health Belief Model.  |
| HBV:    | Hepatitis B vaccine.  |
| HDWG:   | Health and Disability Working Group.  |
| HHS:    | U.S. Department of Health and Human Services.   |
| HIV:    | Human immunodeficiency virus.   |
| HNI:    | Healthy Neighborhood Initiative.  |
| HRSA:   | U.S. Health Resources and Services Administration, a division of HHS.                       |
| HUD:    | U.S. Department of Housing and Urban Development.   |
| KFF:    | The Henry J. Kaiser Family Foundation.  |
| PACT:   | Prevention and Access to Care and Treatment project.  |
| PCSO:   | Planning council support office.  |
| PLWH/A: | Person living with HIV/AIDS.  |
| RCCP:   | Retention Care Coordinator Program.   |
| SPNS:   | Special projects of national significance, a component of part F of the Ryan White program. |
| SSI:    | Supplemental Security Income.   |
| TTM:    | Transtheoretical Model.   |
| WWC:    | Whitman-Walker Clinic.  |

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