

“Knowing is not enough; we must apply. Willing is not enough; we must do.”

–Goethe

## CHAPTER 6

### THE IDEAL CONTINUUM OF CARE.

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#### 6.1. Introduction.

In chapter 4 of this comprehensive plan we presented the Baltimore EMA’s current continuum of care. This chapter describes the planning council’s vision of an ideal continuum of care — conceptualizing the ideal continuum is a prerequisite of effective strategic planning.

The ideal continuum of care provides HIV-positive individuals with continual access to services, supports them as they learn about HIV, helps them to cope with the changes that HIV causes in their lives and encourages/empowers them to make informed decisions about their care. The ideal system of care ensures that HIV-infected individuals are identified as early as possible through coordination with prevention initiatives, including counseling, testing and referral services.

Continuous access to comprehensive medical and ancillary services that meet quality care standards, is an essential component of the ideal system. The ideal continuum provides high quality care with a minimum of administrative cost for providers and payers; eliminates, where possible, duplication of services; and has a monitoring and evaluation process for each service and the system as a whole.

As the chapter will show, while there is room for improvement, the administrative mechanism is on the right path to providing an ideal continuum of care for those infected with, and affected by HIV in the Baltimore EMA. The chapter will first address what makes the ideal truly ideal. This will be followed by a description of the ideal continuum of care. The chapter will conclude with a brief discussion of the gap

between the actual and ideal continuum of care. A strategic plan for addressing these gaps is the topic of the next chapter.

#### 6.2. What Is Ideal?

##### 6.2.1. DHHS’s Healthy People 2010.

The U.S. Department of Health and Human Services (DHHS) described its ideal health services model in *Healthy People 2010: Understanding and Improving Health (Healthy People 2010)* (DHHS 2000) and *Healthy People in Healthy Communities: A Community Planning Guide Using Healthy People 2010* (DHHS 2001). Since its publication, *Healthy People 2010* has been the standard for taxpayer-funded health initiatives in the U.S. *Healthy People 2010* has two overarching goals: to increase quality and years of healthy life, and to eliminate health disparities. DHHS believes that the first goal of increasing quality and years of healthy life requires the active participation of knowledgeable and motivated individuals in decisions about their health (DHHS 2001). They believe that the second goal of eliminating health disparities requires a holistic approach, embracing all aspects of a person’s social condition (i.e., a community-based approach).

##### 6.2.1. HRSA’s Guidance.

HRSA, the DHHS agency that oversees funding and programming for emergency HIV services through Ryan White, was instrumental in producing several of the chapters included in *Healthy People 2010*. As such, it is not surprising to see many of the themes of *Healthy People 2010* echoed in HRSA’s guidance to the 22 councils planning Ryan White Part A services, nationally. In its guidance, HRSA outlines

the following four strategies: eliminate barriers to care; eliminate health disparities; assure quality of care; and improve public health and health care access (BCHD 2004).

#### 6.2.2. Planning Council's Vision.

*The ideal continuum includes only services that have been shown to deliver positive care outcomes.*

The planning council's vision for Ryan White Part A service delivery in the EMA incorporates every aspect of the HRSA guidance detailed above. The belief that "needed services are developed and funded to sustain quality care for uninsured clients" touches on all four dimensions of the HRSA guidance (Keruly 2008). The envisioned provision of health services to the uninsured requires that the

council address barriers to care and health disparities, and improve public health and health-care access. Realizing the vision of sustained quality of care is impossible without first assuring that such care exists. It must be noted that there are also elements of the council's vision that are not found in the HRSA guidance.

The balanced and continued participation of providers, consumers and government in defining the ever-evolving continuum of care is one of the most important facets of the council's vision (Keruly 2008). This local input and control is both the strength and weakness of the current HIV health delivery system. The participation of the patient as a care partner is increasingly seen as an important element in the successful management of disease. Patients who are actively involved in understanding their illness and making decisions about treatment are more likely to follow their medical plan and have better medical outcomes. Much of *Healthy People 2010* is predicated upon the logic that the same will hold true for engaged communities in creating better community health outcomes. However, this

paradigm of consumer participation is not complete.

Individuals with HIV have a unique view of the service delivery system and the needs of the special populations most affected by the epidemic; however, they are less acquainted with the constraints of providing highly demanded services or with the fiscal realities of addressing several local, state and federal priorities, with limited public funding (taxes). The perspective of consumers needs to be supplemented with input from providers and representatives of government agencies: the ideal continuum, as envisioned by the planning council, includes the appropriate balance of all three perspectives.

The planning council also envisions "a responsive system of comprehensive care and prevention services that is evidence-based" (Keruly 2008). The ideal continuum of care includes only services that have been quantitatively or qualitatively shown to deliver positive care outcomes. Planning-council member Jeanne Keruly aptly summarizes the council's vision of an ideal continuum of care as "a balance that meets the medical, social and supportive needs of clients and is in compliance with HRSA" (Keruly 2008).

#### 6.2.3. Institute of Medicine of the National Academies, Committee on the Public Financing and Delivery of HIV Care.

Moving away from the Ryan White service apparatus, we see that there are knowledgeable, independent observers that agree with HRSA and the planning council's assessments of what constitutes an ideal continuum of care. One group of such observers, the Committee on the Public Financing and Delivery of HIV/AIDS Care of the Institute of Medicine of the National Academies, was convened to address this specific issue. In its final report, the committee noted that HIV disease combines a "complex range of factors including an infectious agent; potentially fatal consequences; rapid spread in vulnerable, hard-to-insure populations; and the real

potential for the development of drug resistant strains of the [HIV] virus” (IOM 2005:1). These complex factors, unique to HIV/AIDS, support the argument that, while it shares similarities with other chronic diseases, HIV “has the potential [to be] a more catastrophic epidemic and public health threat, which...justifies a special program for those who are infected” (IOM 2005:2).

The committee further notes that caring for individuals with HIV often requires multiple systems that address the co-morbid conditions of substance abuse and mental illness. The challenges of HIV management and treatment are impacted by the general health of the individual, his or her state of mind and behaviors. Although the committee has identified a number of problems with the current funding system for HIV care, it does not dispute that any system, regardless of how it is financed, needs to “improve the quality and duration of life for those with HIV and promote effective management of the epidemic by providing access to comprehensive care to the greatest number of low-income individuals with HIV infection.” As a result, the committee defines four objectives critical to any service delivery system: access to services, quality care, accountability and efficiency.

The committee has stated that the ideal system must ensure the following:

Early and continuous access to an appropriate, comprehensive set of medical and ancillary services that meet the standard of care; promotion and/or delivery of high quality services; minimal administrative costs for payers and providers and a minimal duplication of effort and accountability for meeting established standards of treatment and health outcomes for all eligible individuals (IOM 2005:15).

### 6.3. HRSA’s Overarching Goals.

In 2005, HRSA published a five-year strategic plan outlining its vision, mission and strategic goals for providing “comprehensive, culturally competent,

quality care...[to the] uninsured, underserved and special needs populations in its goals and program activities” (HRSA 2005).

The various conceptions of the ideal continuum of care for HIV/AIDS mentioned in the previous section match many of HRSA’s overarching goals (HRSA 2005):

- Improve access to health care.
- Eliminate health disparities.
- Improve the quality of health care.
- Assure cost effectiveness.
- Improve health outcomes.

Four of these goals are taken directly from HRSA’s 2005-2011 strategic plan; the fifth, “assure cost-effectiveness,” captures the other goals from HRSA’s strategic plan in a manner that is relevant for EMA-level community planning.<sup>67</sup> The planning council believes that these five overarching goals from HRSA should form the core of the ideal continuum of HIV/AIDS care for the Baltimore EMA.

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#### 6.3.1. Improve Access to Health Care.

In the last chapter the following barriers were identified: inadequate public transportation (especially in the counties); inadequate dispersal of treatment sites (especially in the counties); insufficient co-location of services at treatment sites; a lack of widely disseminated information concerning available HIV treatment resources; and excessive cost-sharing requirements and coverage gaps for those looking to transition to Medicaid and Medicare.

<sup>67</sup> HRSA’s other goals were to improve the public health and health care systems; enhance the ability of the health care system to respond to public health emergencies; and achieve excellence in management practices (HRSA 2005).

All of the barriers listed above share a common attribute: they prevent people in need of care from accessing it. The ideal continuum of care will either eliminate or, where the obstacle is external, take steps to fully mitigate the effects of these barriers. As noted in the last comprehensive plan, “[a]n ideal, comprehensive care system ensures that geographical, economic, social, capacity, or infrastructure obstacles preventing PLWH/As from accessing that system are minimized or eliminated” (IGS 2005:77).

**6.3.2. Eliminate Health Disparities.**

The second component of an ideal continuum of care is the elimination of health disparities. AIDS disproportionately affects African-Americans, MSMs and other special populations in the Baltimore EMA. Factors such as fear, misperception and discrimination have also disproportionately affected these groups, and one of the myriad results is that these groups are not currently accessing health care at the same rate as larger and more mainstream groups. In the ideal continuum of care, all PLWH/As would access all of the HIV health services that they require: there would be no health disparities.

**6.3.3. Improve the Quality of Health Care.**

Late entry to care, insufficient co-location of services, decreased funding and legislatively mandated inflexibility with respect to Ryan White service provision are all barriers to providing the best health care possible. Not only is this level of care desirable for its own sake, as noted in the last comprehensive plan, but “[h]igher-quality services are more effective at interrupting the progression of HIV disease” (IGS 2005:78). Improving the quality of health care is the ultimate purpose of the ideal Ryan White continuum of care.

**6.3.4. Assure Cost Effectiveness.**

With limited resources available, the ideal continuum of care will ensure that the administrative mechanism delivers services in the most cost-effective manner. Barriers such as the lack of adequate client-level tracking leading to the duplication of services to the same client must be eliminated. Adequate support and adherence services must be provided to ensure that providers do not waste time and space waiting for appointment-breaking clients (no-shows) or that valuable resources are not wasted by clients falling out of care. Burdensome administrative requirements must be eliminated to the greatest extent possible while still maintaining adequate safeguards against waste and corruption. These are just a few of the ways that cost effectiveness would be assured under the ideal continuum of care.

**6.3.5. Improve Health Outcomes.**

Ultimately, all the other components of and activities resulting from the ideal continuum of care are meant to lead to the same place — improved health outcomes. Figure 7.1, HRSA’s Overarching Goals, outlines the components of an ideal continuum of care. The planning council has used these overarching goals or components to create the goals, objectives and strategies for the Baltimore EMA for the next three years.

Because the central purpose of Ryan White is getting PLWH/As into care and ensuring that they stay in care and adhere to their medical regimens, at the core (center) of the model are both medical care and the supportive services that help PLWH/As stay in care. Because it is important that these various medical and support services be delivered in a coordinated and consistent manner, the care circle is surrounded by services that facilitate or arrange access to medical and supportive services and promote stabilization in treatment. This core of medical, supportive, and coordination services does not exist in a vacuum: it exists in the context of goals that promote access and ensure that high-quality services are

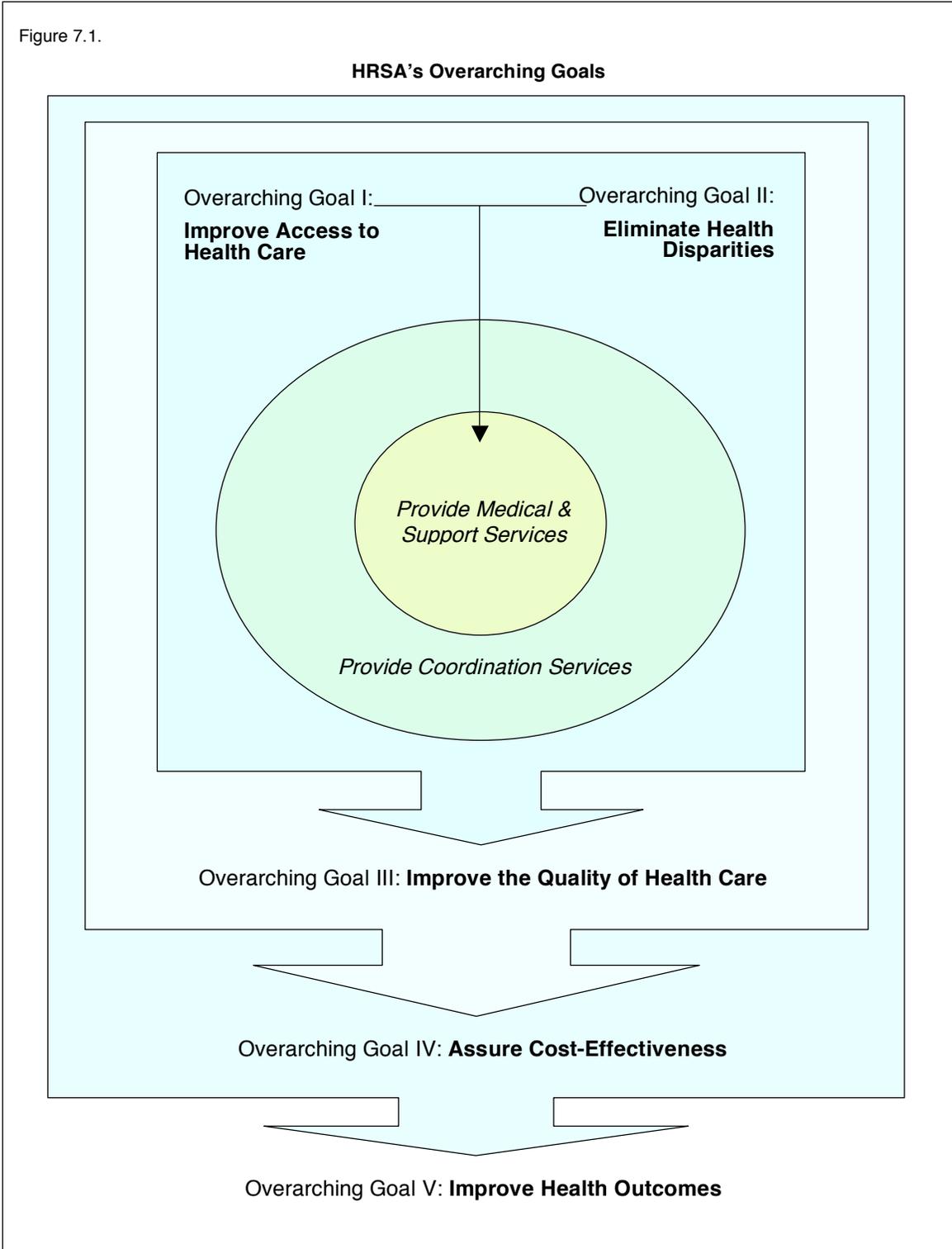
*Primary purpose of Ryan White is to get PLWH/As into care and to ensure that they remain in care.*

provided in a cost-effective manner. The entire continuum of care results in improved health outcomes (IGS 2005:73).

### 6.4. Engaging the Ideal Continuum.

The ideal continuum employs an evidence-driven, community-planning model, complete with consumer and provider

Figure 7.1.



*The ideal continuum is evidence driven and includes the perspectives of consumers and providers.*

perspectives, to establish the appropriate set of HIV services. It provides quality care to HIV-infected and HIV-affected individuals. The ideal continuum attracts consumers to and retains them in care by addressing the many obstacles, not all medical, that are present in the day-to-day life of poor HIV-infected and HIV-affected individuals. The end goal is for PLWH/As currently in care to be able to maintain their HIV care and utilize long-term care services.

Perhaps the best way to understand the ideal continuum of care would be to follow the path of the non-ideal consumer. We

begin with a person that is not showing any symptoms, but knows that he or she has engaged in a high-risk behavior. Ideally, this person will encounter an outreach worker that mentions HIV testing and helps the individual locate a counseling, testing and referral site. A quick test is performed, and, if the test is negative, the individual is counseled about the importance of avoiding or reducing risky behaviors and the need to continue testing. If the test is positive, the person is provided enough information to understand what a positive on the quick test means, and that he or she needs to have blood drawn to confirm the positive result.

The outreach worker, in the ideal continuum, would then try to maintain contact with the person and prepare her or him for a medical referral — many persons who have no symptoms refuse to seek medical care. If the person refuses direct referral to medical care and has a problem with substance abuse, is homeless, or has mental-health problems, the outreach worker helps the individual get to a case manager who can help with referrals to HIV medical care and addictions/mental health treatment, as well as help locate more stable housing. The outreach worker helps the person

engage with the case manager. In addition to outreach workers, the ideal continuum of care would include awareness/promotional campaigns to inform the general public about the availability of and where to access services in the EMA.

The goal of case management is to get the individual into and retained in medical care, but the ideal case manager, much like the ideal outreach worker, will recognize that the individual may need help with many non-medical barriers before he or she is willing or able to think about making and keeping a medical appointment. Even those who are already sick may only keep enough medical visits to get rid of the immediate illness or symptoms when there are other problems that they have deemed more pressing than their general health. Ideally, case management will assist the individual with self-identified priorities such as housing insecurity, substance-abuse or mental-health care, with the hope that this will lead to trust between case manager and client, and a greater likelihood that the HIV-positive individual will move into and stay in medical care.

In the ideal continuum of care, the individual that has been reached by outreach and case management will begin medical treatment while continuing to receive support services with demonstrably positive impacts on care. Some of these services include transportation to get her or him to appointments, psychosocial support groups and adherence support to allay fears or address questions that she or he might have concerning medicines, symptoms or depression. With the natural ebb and flow of anyone's life, HIV-positive individuals need these services and supports to stay in medical care — to continue living and managing their chronic illnesses.

Moving in and out of HIV medical care increases the complexity of treating individuals. The ideal continuum of care will look to stabilize the social and health conditions of Ryan White clients, engaging

them in treatment. The continuum ends when the individual is transferred, as appropriate, to long-term care options, which, ideally, will also be geared to caring for the whole person.

#### 6.4.1. Components of the Ideal Continuum.

The section above is a general depiction of an ideal continuum of care; this section further describes how prevention, case management, outpatient ambulatory health and other services are integral components of the ideal continuum of care.

The ideal care system must include a vigorous strategy to prevent new infections. Prevention initiatives must be imbedded in primary medical care programs as well as integrated into counseling, testing and referral services. Health education and risk reduction messages must be developed for the general, low-risk populations, and promoted by the political leadership of the community, the faith-based community and the education system. Special messages with high-impact, fact-based information must be crafted for the most-at-risk groups where the epidemic is continuing to grow.

Outreach activities need to be included in the continuum based on the non-traditional outreach model that proactively targets areas or services in the community where HIV-positive individuals who are not in care are found. Locations, such as homeless shelters, drug-treatment programs and emergency rooms, are fertile areas for identifying HIV-positive individuals not in HIV health care. Ideally, outreach will satisfy the following responsibilities: the identification of individuals who need to be tested; the referral of these individuals to counseling, testing and referral sites; and the connection of HIV-positive individuals to the care system through direct referral to primary medical care or case management services.

Case managers serve as information resources (i.e., they guide people living with HIV/AIDS through the complex application processes to secure permanent housing or

entitlements). Case managers and peer educators can teach skills for improving treatment adherence. Patients who are having difficulties with basic needs (e.g., housing, finances, finding and maintaining a job, a safe environment) have little motivation to address long-term lifestyle changes. As mentioned in the previous section, these patients are better served through case management that addresses their immediate needs and ultimately improves the likelihood of treatment adherence (Koenigsberg *et al.* 2004).

Outpatient/ambulatory health services' primary medical care component is the nexus of all Ryan White Part A services: it is the center toward which all other service provision should be directed. However, for many HIV-positive individuals, HIV medical care is not their service priority. Until and unless other needed services are provided, many infected persons delay seeking or accepting referrals to medical care (Koenigsberg *et al.* 2004).

As a result it is necessary to include several other services in the ideal continuum of care — services like the support categories already mentioned, and additional core medical services, as defined in Ryan White, such as oral health, medical nutrition therapy, substance-abuse treatment, mental-health treatment and hospice care.

#### 6.5. The Actual *versus* the Ideal.

In many ways the Ryan White programs, more so than most other taxpayer-funded health initiatives in the U.S., embody the goals outlined in *Healthy People 2010*. While the Ryan White Act requires that a minimum of 75 percent of all direct service funds be apportioned to core medical services, it is unique in allowing the expenditure of up to 25 percent of Part A grants on the provision of support services

*The ideal care system must include a vigorous strategy to prevent new infections.*

that help clients and providers tackle the obstacles that prevent consumers from starting and remaining in care.

As noted in prior chapters, accessibility is often a reason that the actual continuum of care falls short of the ideal for many residents of the EMA, especially those residing in the counties. No amount of funding for transportation services can make up for the time that county residents will lose in having to travel to Baltimore City for services. In addition to distance, there are often shortages that limit access to services in high demand, such as housing.

*The typical HIV-infected person in the Baltimore EMA does not have private health insurance.*

Limitations on the types and length of service provisions also distinguish the actual from the ideal — the ideal would be far more flexible in linking core and support services to individual consumer needs. Two years may be enough time to move a consumer from an emergency situation to a stable care program. Some consumers may only require a few months or even a one-time assistance package. However, there are individuals who may require the kind of services that Ryan White provides for several years — the perpetual nature of their needs does not make their situations any less urgent. While it may be true that service providers may need an incentive to move clients from emergency status to a long-term program, it is not clear that time limits are the best solution.

From a strategic planning standpoint, the actual continuum is built to work in the context of unstable funding. An ideal continuum would be based on the decisions of a community benefiting from a more complete long-term perspective on the resources that will be available. For example, the problem of accessibility is not just a problem of concentration of need, it is also a function of a lack of infrastructure

dedicated to working with the HIV-infected and HIV-affected. Building infrastructure requires a longer planning horizon than is possible under the current funding structure.

## **6.6. Conclusion.**

Often the challenges surrounding access to medical care are compounded by the life circumstances and societal problems faced by the person. Poverty, crime and violence, high school drop-out rates, poor labor market, high rates of incarceration, large numbers of visible and invisible homeless, high number of substance abusers and chronically mentally ill persons are broad social ills, well beyond the scope of this three-year plan for the provision of emergency HIV services.

Nevertheless, the typical HIV-infected person in the Baltimore EMA is affected by most of these problems. According to John Bartlett, he is male, African-American, between the ages of 30 and 49, living below the federal poverty level for a single individual. He is also likely to have a history of substance addiction and/or mental illness, have experienced long periods of unemployment and, if an injection drug user, have a high probability of being infected with hepatitis C. The typical HIV-infected person in the Baltimore EMA also lacks health insurance (Bartlett 2008).

While medical care remains the primary focus of Ryan White programs, it is difficult to imagine an effective (and impossible to imagine an ideal) continuum of care that does not address both health and non-health related barriers to care — the ideal continuum of care addresses the whole person.

The next chapter will describe how the planning council will address the epidemic in the Baltimore EMA. It will outline the council's specific goals, objectives and strategies that tie directly to HRSA's five overarching goals. Further, chapter 8 will incorporate the concepts of HRSA's continuum of engagement model. This

model will illustrate how the service continuum identifies HIV-positive individuals, guides them through the testing process and HIV treatment system and stabilizes them in HIV care through the provision of an array of services until the individual is fully engaged in HIV primary medical care and ready to transition from Ryan White services to long-term care services.

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