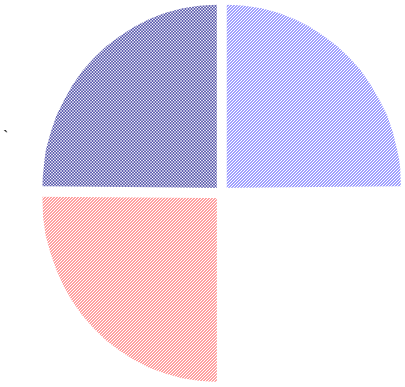


DOCUMENTING A CONTINUUM OF HIV/AIDS SERVICES AS PART OF THE NEEDS ASSESSMENT PROCESS

Written by the: Partnership for Community Health, Inc.
245 West 29th Street
Suite 1202
New York, NY 10001

Primary Contact: Mitchell Cohen, Ph.D.
Executive Director
Partnership for Community Health
Telephone: 212.564.9790 X 26
Fax: 212.564-9781
E-mail: PCH@pchealth.org

CONTINUUM OF HIV SERVICES

INTRODUCTION 1
GOAL AND OUTCOMES OF A CHS 2
- Outcomes of A CHS 2
  - Process Outcomes 2
  - System Outcomes 2
- Linkages 4
- Summary of the CHS Framework 4

REVIEW OF THE EXISTING CONTINUUMS OF CARE 5
- Types of Continuums of Care 5
  - Linear Model 6
  - Client-Need Centered Model 8
  - Hierarchical Model 10
  - Functional Model 14
- Service Categorizations in the Models 17
- Additional Continuum of Care Information 18

DEVELOPING A CONTINUUM OF CARE 19
- Functional Model with Explicit Outcomes 19
- Recommended Framework for Developing a Continuum of HIV/AIDS Services 23
  - Objectives for a CHS 23
  - Graphic Description of CHS 23
  - Defining the Services and Eligibility 26
  - Defining the Consumer - Using the Epidemiological Profile and Census Data 26
  - Determining Coverage for the Services 26
- Designing and Supporting the Care System 27
  - The Administrative Arm of the CHS 27
  - Creating the Linkages 28
  - Training the Providers 28
  - Informing and Training the Consumers 28
  - Assessing the System 28

1. ADOPTING A CONTINUUM OF HIV/AIDS SERVICES:

INTRODUCTION

A continuum of Care (COC) is defined by HRSA[1], as "a coordinated delivery system, encompassing a comprehensive range of services needed by individuals or families with HIV infection to meet their health care and psychological service needs throughout all stages of illness." A HIV/AIDS COC can be used to inform and guide HIV Care Councils, Consortia, providers, and consumers in establishing priorities and funding HIV/AIDS services. It will provide the information that will enable planners to make the adjustments necessary to meet the continuing and changing needs of PLWH/A. As COC's evolve to include a more comprehensive system of prevention and care services, the more general name of Continuum of HIV/AIDS Services (CHS) is used in this text.

This objectives of this chapter are to:

1. Provide a theoretical framework within which to describe the creation of a CHS for an eligible area receiving RWCA funds.
2. Recommend a structure for a CHS.

A comprehensive CHS includes several key constituencies that interact to ensure that services are available and accessible to PLWH/A. They include:

- The general public, whose support is needed for prevention and care services.
- At-risk populations who are HIV negative, and targets of prevention services.
- PLWH/A who participate in the planning process and are consumers of HIV and AIDS services in the private and public sectors.
- Service providers who, cumulatively, establish the capacity of the system to provide needed prevention and care services.
- The grantees for the Ryan White Care Act and prevention grants who provide technical assistance and contract monitoring for the Councils, Consortia, and CPG.
- The Councils, Consortia, and PPCs who establish need, measure barriers, set priorities, and, for the Councils, determine levels of resources.
- The local, State, Federal and private funders who require accountability for service systems and provide the resources and governing regulations for the entire system of prevention and care.

In addition to these various constituencies, the CHS includes the set of services and linking mechanisms that a Ryan White Planning Council, Consortia, and affected communities feel should be available to reach their vision for providing HIV/AIDS services.

[1] Self Assessment Module, JSI, 1998.

GOAL AND OUTCOMES OF A CHS

The goal of a CHS is to specify and show the linkages between a full range of client-centered, cost-effective prevention and treatment services among those at risk for HIV and among those living with HIV and AIDS[2] within a designated service area.

Outcomes of A CHS

A CHS should have process and system outcomes. They should be measurable and monitored to assure that the CHS is being implemented according to a comprehensive plan, and that it produces the expected process and system outcomes.

Process Outcomes

The process outcomes for a comprehensive coordinated delivery system include that services be:

1. Client centered: Clients must have input into defining their needs, assessing services, and modifying/changing services to meet their needs. This is achieved by assuring that: 1) PLWH/A participate in the planning process, and 2) feedback from PLWH/A is obtained through needs assessment and consumer satisfaction surveys and an accessible grievance procedure.
2. Inclusive of all communities needing services: The CHS should identify and include un- and under-served communities in the process of creating and updating a CHS.
3. Proactive: Consortia, Councils, Community Planning Groups, and providers should review the services and linkages in the CHS on a regular basis to anticipate the changing needs of PLWH/A and the system has to be flexible to meet new needs.

System Outcomes

The system goals of a dynamic and comprehensive CHS should be informed by the mission and vision statements of the HIV Care Councils, Consortia, and Community Prevention Groups. The vision statement of the Orange County HIV Planning Council suggests the combination of a continuum of care that prevents a seamless continuum ranging from prevention services through care for end-stage HIV infection. It reads:

> *Through partnerships that reflect the combined efforts of the Orange County HIV Planning Council, affected communities, services provider, philanthropists, and public health professionals, there is an accessible continuum of HIV prevention and care services that fosters individual self-sufficiency and results in no new HIV transmission.*

The CHS must assure that services are:

- *Available* to meet the needs of the consumers and caregivers;
- A*ccessible* to all populations infected or affected by HIV/AIDS;

[2] This goal is based on workshops and information gathered in defining the COC in Houston, Texas.

- A*ffordable* to all populations infected or affected by HIV/AIDS;
- *Appropriate* for different cultural and socio-economic populations and care needs; and
- *Accountable* to the funding sources and clients for providing contracted services at high quality.

Examples of more specific system outcomes are noted in Table 1 below:

Table 1 System Outcomes

Dynamic CHS
• Provide services in a seamless manner as a consumer moves among the different levels of services. • Include coordinating mechanisms that can be utilized to ensure effective linkages are established and maintained
Comprehensive services
• Educate the general public to provide continuing support to PLWH/A through publicly funded programs that provide services. • Promote awareness of HIV status to those at risk so that they can receive early care and protect others from infection. • Provide prevention services to those who are HIV negative. • Identify and address the care needs of insured and under- and uninsured PLWH/A. • Provide care to those who are at all stages of HIV infection.
Available services to all populations in need
• Advocate for the service needs of PLWH/A. • Encourage cooperation necessary for the coordination and delivery of services. • Fill service needs and gaps and overcome barriers to prevention and care services. • Address capacity needs of the system.
Accessible services to all populations in need
• Assure that the community in need is aware of available prevention and treatment resources. • Provide support services that facilitate access to prevention and treatment. • Promote the dissemination of information about services to all constituencies.
Appropriate services to reach all populations in need
• Provide culturally appropriate services. • Assure that the system is free of discrimination based on race, color, creed, gender, religion, sexual orientation, disability, or age.
Accountable for providing services that have results
• Provide services in an efficient and effective manner . • Provide high quality services. • Prevent HIV negative persons from becoming HIV positive. • Prevent persons in early stages of infection with HIV from progressing AIDS. • For PLWH/A, improve or maintain health status. • For PLWH/A, sustain or improve their quality of life. • For people at the end stage of AIDS, providing a dignified death.

Linkages

Continuums of HIV/AIDS Services ideally link services in a seamless manner for a consumer accessing the system. According to the HRSA guideline for developing a continuum of care, linkages refer to those inter-entity structures that result in:

- Better client care coordination. Clients with multiple needs or those who move from one intensity level to another should have a well coordinated treatment plan understood by all involved.
- Integrated information systems where one client record that combines financial, clinical and utilization information is available for multiple users, without breaching the confidentiality of the clients.
- Integrated systems of financing that allow for access to all aspects of the system through some mechanism of financial support.
- Portability of insurance among and between private and public insurers.

While not all continuums of care will incorporate all of these elements, they are guideposts for improving service integration, efficiency, and effectiveness.

Some of the mechanisms presented in the HRSA guidelines for establishing the necessary linkages include:

- Participation on councils by those infected and affected by HIV and AIDS;
- Joint planning meetings between different planning bodies and providers;
- Joint prioritization activities by grantees of the different titles;
- Contractual arrangements for service linkages;
- Joint case conferences between providers;
- Standardized practice procedures across different providers;
- Uniform intake forms throughout the care systems;
- Shared client information between providers;
- Shared staff arrangements among grantees and providers.

Summary of the CHS Framework

In summary, The CHS describes a system that links prevention and care services so that the CHS fulfills the mission and vision of Councils, Consortia, and or Community Planning Groups. The CHS describes a dynamic and comprehensive system of HIV/AIDS services that ensure that they are available, accessible, and affordable to communities infected and affected by HIV and AIDS.

The CHS is more than a list of services, however, it is a plan for maintaining, improving and adding the strategic linkages that promote efficient and effective service delivery. It specifies process and system outcomes that are measurable and assure that provider are accountable for providing quality services that result in effective prevention and care.

REVIEW OF THE EXISTING CONTINUUMS OF CARE

In reviewing the existing COCs throughout the nation[3], fifty-one eligible metropolitan areas (EMAs) were found to receive Title I funding. Of those, 45 Planning Council Chairperson or other Ryan White personnel were contacted in the contiguous United States to provide information about their COC. After multiple attempts, twenty-three of the Councils responded. While all of the EMAs had a description of their service delivery system, only six could provid a visual representation or model of their existing COC.[4] This visual model provides a snapshot of how planners can delineate and arrange services and linkage mechanisms within an HIV/AIDS system of care. Attachment 1 shows the demographic profiles of the six EMAs that provided a representation of a COC.

Types of Continuums of Care

For the purpose of this chapter, the continuums of care received from the six EMAs have been categorized into four basic types: 1)*linear*, 2)*client-need centered*, 3)*hierarchical*, and *4)functional*.[5] Like most categorizations, they are meant to capture the major characteristics of different COC, but may also simplify and understate the complexity of some of the COC described. Table 2 summarizes the four types of models.

Table 2 Continuum of Care Model Typology

Type	Characteristic	Example
Linear	- Straight line from infection to death - Uses disease trajectory to define service delivery system	Cleveland, OH
Client-need Centered	- Movement defined by client needs - Flexible structure	Hudson County/Jersey City, NJ
Hierarchical	- Relational classification - Organized around core set of services	Austin, TX Los Angeles, CA
Functional	- Represents functional categorization of client needs - Services are placed together because they represent similar functions	Riverside/San Bernardino, CA New York, NY Orange County, CA

[3] This review was conducted in 1999 with incremental updates.

[4] It is important to distinguish between the service delivery system and the existence of a visual presentation of the COC. The six EMAs providing a visual presentation were Cleveland, Ohio, Hudson County/Jersey City, New Jersey, Austin, Texas, Riverside/San Bernardino, California, New York City, New York, and Orange County, California. Further, the existence of a COC model does not assure that it is implemented or descriptive of the actual service system.

[5] Keep in mind that models assessed are visual representations of much more complex processes and systems. In addition, the snapshot view of the continuum of care as presented in these one-page models does not delineate how planners might go about arranging services and linkage mechanisms to operationalize the model.

Linear Model

The linear model suggests that services travel along a single line from entry into the system to HIV end stage illness. The Cleveland model (see Figure 1 on the following page) is an example of this type of representation. The client's entry into the service system is determined by the clients' stage of disease, as defined by T-cell count. The client starts with the initial positive test and ends with a T-cell count of 0 to 50, and movement within the system follows the progression of the disease toward death. Services are categorized according to this progression. For example, a client may start with referral to care, which becomes primary care in the early stages of infection and then ongoing care, medical care, intermittent disability, and then hospice services as ability for independent living decreases and the need for professional health care increases.

This model has several positive features. It demonstrates that many services are needed throughout the disease process, and that the *character* of the services may change as the disease progresses. For instance, legal issues are generally different at stage one than they are at the final stages.

The biggest drawback to this model is that it presents a dated notion of HIV and AIDS services. Today, the health and well-being of PLWH/A do not usually follow a linear progression from infection to death. In addition, as a working model, it presents two particular problems:

1. The model does not emphasize the linkages that might be necessary throughout a system to make it most accessible and flexible to those who need it.
2. The format creates a fair amount of redundancy in the listing of services. For example, transportation is listed four different times.

Figure 1 Linear COC - Cleveland, OH.

Initial Test +	**Early Infection CD4 > 400**	**Middle Stage CD4 200-400**	**AIDS CD4 100-200**	**AIDS CD4 50-100**	**AIDS CD4 0-50**
Partner Notification	Spanish Speaking Practitioner	Spanish Speaking Practitioner	Spanish Speaking Practitioner	Spanish Speaking Practitioner	Spanish Speaking Practitioner
Referral to care	Primary Care	Ongoing care	Medical care, including hospitalization	intermittent disability, skilled and non-skilled home care, hospital	Home services
Emotional support	Medication	Medication	Increased medication	Increased medication	Increased medication
Evaluate family needs	Insurance benefits	Insurance benefits	Insurance benefits	Insurance benefits	Insurance benefits
Substance assessment	Emotional support/counseling	Emotional support / social isolation counseling	Fear loss of indep., buddy support; family/individual counseling	Family/indiv. counseling; emotional support; buddy	Active coping; death and dying issues, grief counseling
	Child emergency care	Respite	Respite	Respite	Respite
	Emergency financial assistance	Emergency financial assistance	Emergency financial assistance	Emergency financial assistance	Emergency financial assistance
	Food/Nutrition consultation	Food/Nutrition consultation	Food/Nutrition consultation	Food/Nutrition consultation	Food/Nutrition consultation
	Transportation	Transportation	Transportation	Transportation	Transportation
	Secondary prevention education	Secondary prevention education	Secondary prevention education	Secondary prevention education	Secondary prevention education
	Medicaid spenddown	Medicaid spenddown	Medicaid spenddown	Medicaid spenddown	Medicaid spenddown
	Employment issues	Employment issues	Employment issues	Employment issues	Employment issues
	Housing issues	Housing issues	Housing issues	Housing issues	Housing issues
	Substance treatment	Substance treatment	Substance treatment	Substance treatment	Substance treatment
	Legal issue – wills, Power of Attorney, children	Legal issues	Legal issues	Legal issues	Estate planning, guardianship issues
	Alternative therapy	Alternative therapy	Alternative therapy	Alternative therapy	Alternative therapy
			Home services / Hospice	Home services / Hospice	Home services / Hospice
	Case Management	Case Management	Case Management	Case Management	Case Management
	Training	Training	Training	Training	Training

Client-Need Centered Model

The client-need centered model has the client as its focus. The model allows for a flexible structure, but the organization of and movement within the model are defined by client needs and characteristics, and it is designed for direct client use.

The Hudson County/Jersey City, NJ, model, as shown in Figure 2 is a good example of a client-need centered model. Hudson County refers to its model as a "care map", and it is a step-by-step guide of where to go for HIV/AIDS services. It is the client's individual situation and needs that drive the structure of the model. For example, if a client is concerned about getting tested, he or she can find out which services are available by going to a "care map" and following the arrows. For example, in the care map shown in Figure 2, once a test is positive, the client goes in one direction if they are a child or adolescent, another if they are an adult, and another if they are an adult with special needs.

This type of model's greatest strength is in providing the user with a clear entry point into the system and a clear path to the outcomes of care. The "care maps" are also good tools for case managers, giving them a cursory view of how the system works and allowing them to coordinate care and shows linkages to services for their clients.

However, while it is important for a COC to be responsive to client needs, this particular representation is not as helpful a tool for planners in designing and modifying the system. It does not show the system as a whole and does not demonstrate how the system needs to be designed, evaluated, or modified over time. This is particularly true in relation to portraying the linkages and coordinating mechanisms that are necessary to keep a complex system of care functioning efficiently and effectively.

Figure 2 Client Need Centered - Hudson County/Jersey City, NJ

CARE MAP I

WHERE CAN I GO TO BE TESTED FOR HIV?

HIV Testing

Anonymous[1] Testing

- Jersey City Medical Center
- St. Michael's Medical Center

Confidential[2] Testing

- St. Michael's Med Center
- Jersey City Med Center
- Palisades ER Residential Corp. (PERC)
- Jersey City Sexually
- Transmitted Disease
- (STD) Clinic
- Your private doctor

If Negative Results

- Repeat testing every 6 mo. if risk behaviors continue

If Positive Results

- **See Care Map II**

1. **Anonymous Testing** means that you are the only person who will know the results of your test. You will be assigned a number when you are tested, and you must bring that number with you when you get your test results. At no time during the testing process is your name used or recorded.
   Pros: You have total control over who learns of your HIV status.
   Cons: If you are HIV positive, and would like to receive services, you will need to be retested using the "Confidential" method in order to have proof of your HIV status with your name on it.
2. **Confidential Testing** means that your name, and other identifying information, will be recorded at the testing site, and if you are HIV positive, this information will become part of your record.
   Pros: If you are HIV positive and want to receive services, you already have the proof of your HIV status that you need.
   Cons: Although great care is taken to protect your confidentiality, there is a small chance that your HIV status may become known to others without your consent.

CARE MAP II

IF I AM POSITIVE, WHERE SHOULD I GO FOR SERVICES?

One place to start your care is with a Medical Case Manager who will help you determine what your needs are, work with you as your needs change, and make sure that you are linked with the right services. HIV Medical Case Management services are available at several places in Hudson County. The following information will help you choose the right Medical Case Management Service for you.[3]

HIV Positive Test Results

For Children & Adolescents

- Jersey City Medical Center (JCMC) – Regional Pediatric Treatment Center

Necessary Referrals

For Adults

- Jersey City Medical Center (JCMC) – AIDS Health Service
- F.A.I.T.H Services
- Horizon Health (women only)

Necessary Referrals

For Adults with Special Needs

If Homeless

- Medical and Social Services for the Homeless

Necessary Referrals

If Serious Emotional & Substance Abuse Problems

- Jersey City Med. Center (JCMC) – AIDS Health Service

Necessary Referrals

3. **NOTE:** The above Case Management agencies will link you with other appropriate providers, as needed.

Hierarchical Model

The hierarchical model is arranged by a relational system of classification organized around a core set of services. The model presumes that until a basic set of needs related to physical health, or survival, are met, the next level of need, which may be more related to quality of life, cannot be realized.

The Austin model, as seen in Figure 3, is an example of a hierarchical COC. The core of the model is the basic needs category, or those services a PLWH/A needs for survival. The independence and life skills categories are the successive steps in the hierarchy reaching toward optimum emotional and physical well-being. At the bottom of the model are the resources, infrastructure, case management, and outreach functions that are required to maintain the system. They serve as integrating mechanisms for the delivery of services across all categories. With good resources, a sound infrastructure, and case management and outreach systems in place, a client can move from one service to another and one category to another.

Unlike in the linear model, there is no element of time implied. A client is not held to a particular service at a particular stage of disease. It is organized with the goal of living with HIV/AIDS and is flexible to meet the needs of the individual. The model is also a useful tool for planners because it represents all necessary services in an HIV/AIDS COC.

Another example of a hierarchical model is the Los Angeles Continuum of Care, shown in Figure 4. Conceptually, the continuum is composed of a core of primary health services that are essential to improving health outcomes through the delivery of primary physical and emotional health care, including medical outpatient services, dental care, nutritional counseling, mental health services, substance abuse services, end-stage hospice care and patient education, counseling and testing, health education/risk reduction activities, treatment adherence services, and prevention efforts. The continuum recognizes that in order to sustain improved health outcomes, each of these types of services comprise a critical component of primary health care.

The core is surrounded by “wrap-around” services clustered according to the following sets of services:

- Removal of Barriers Services that optimize “critical paths” through access, utilization, retention, adherence, transportation, child care, housing, food services, psychosocial case management, and client advocacy. These key services provide low-income PLWH/A access to care which meets their basic needs and that allow them to focus on their HIV primary health care. Studies have shown that PLWH/A who do not have their basic housing and nutritional needs met, or who have no or poor transportation to services, are unlikely to seek and maintain primary health care.
- Patient Care Coordination and Language Services offer PLWH/A a choice in care coordination approaches (patient care coordinators, nurse case managers, medical case management, etc.) and language services for non- or limited English proficiency populations. Patient care coordination services respond to the complexity of the health care system and by providing expert guidance in to clients seeking and accessing services

provided in the continuum of care. Case management is viewed as critical to assisting PLWH/A obtain and maintain their proper regimens of care. For those who do not speak English or who experience difficulties with English comprehension, translation and interpretation services are an essential factor in patient care coordination.

- Economic Well-Being Services that create direct, working, effective linkages and collaborations with services and community developments related to amelioration of poverty, workforce re-entry services, health insurance (and other benefits) access and continuation of services. Economic well-being measures include legal services and permanency planning. Both of these types of services significantly impact the continuity of care for families, in particular addressing the needs of HIV-positive and -negative children of parents who are HIV+.

The third tier of services, "self-enhancement", are designed to enhance the core and wrap-around services, and the quality of life for PLWH/AIDS. The wrap-around and self-enhancement services are intended to mitigate disparities in care and ensure client access to appropriate primary health care services. Self-enhancement services improve clients' quality of life through activities such as self-help services, peer support, buddy companion services and pastoral care.

There are additional "boxes" provided for "program support" and "planning council support".

One problem with the model shown is that it is limited to a care system, and it is not a comprehensive COC. Another is the relative arbitrary placement of services, which may not reflect the values of the PLWH/A who are using the services. For example, what one client sees as a service to reach a higher level of independence, another may view as a core need. To the extent that the hierarchical arrangement might determine resource allocation, this placement of services could be a potential problem. It is likely that services needed by smaller target groups will be viewed as less "core" and possibly be under- or un-funded.

Figure 3 Hierarchical Model - Austin, TX.

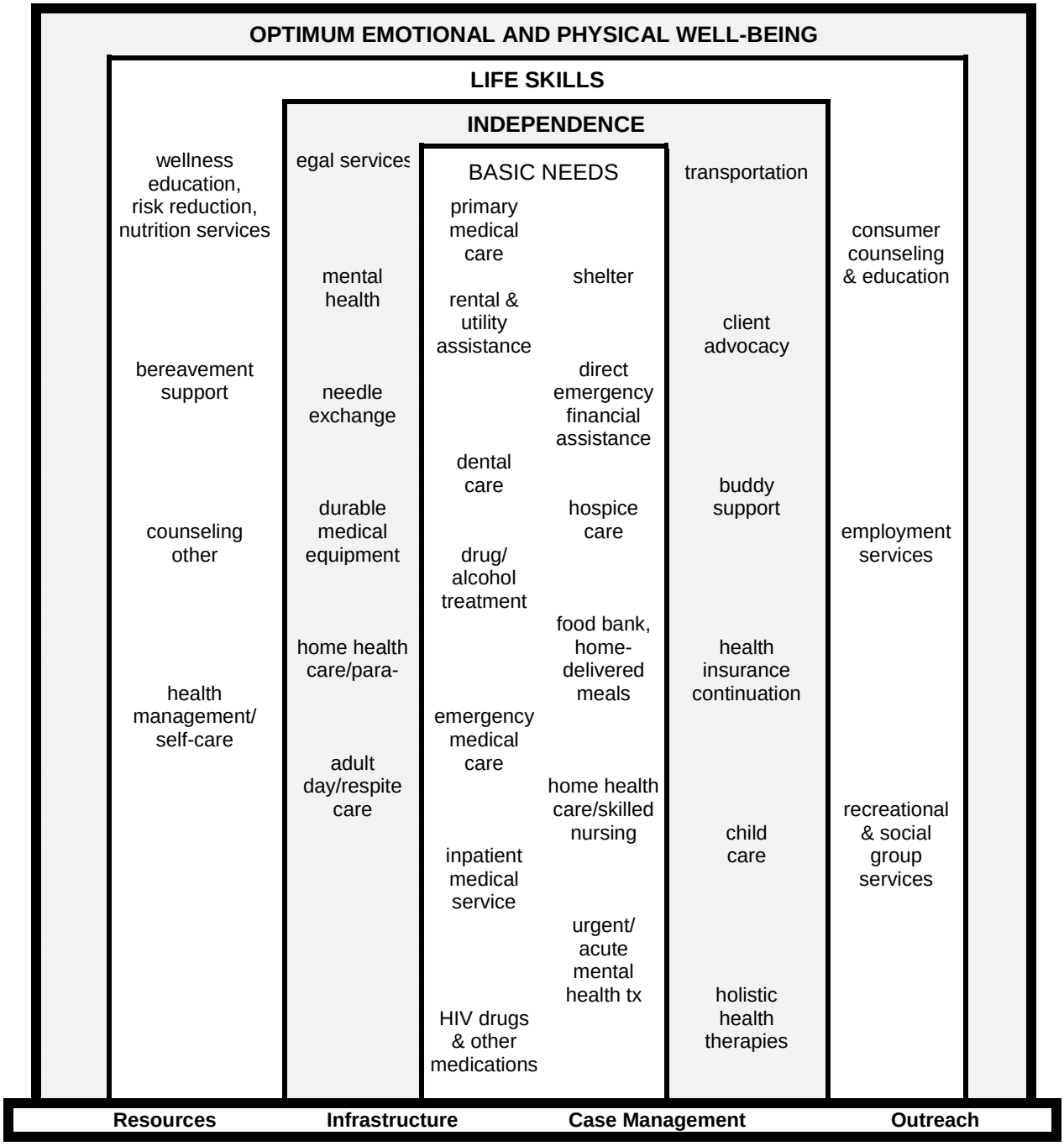
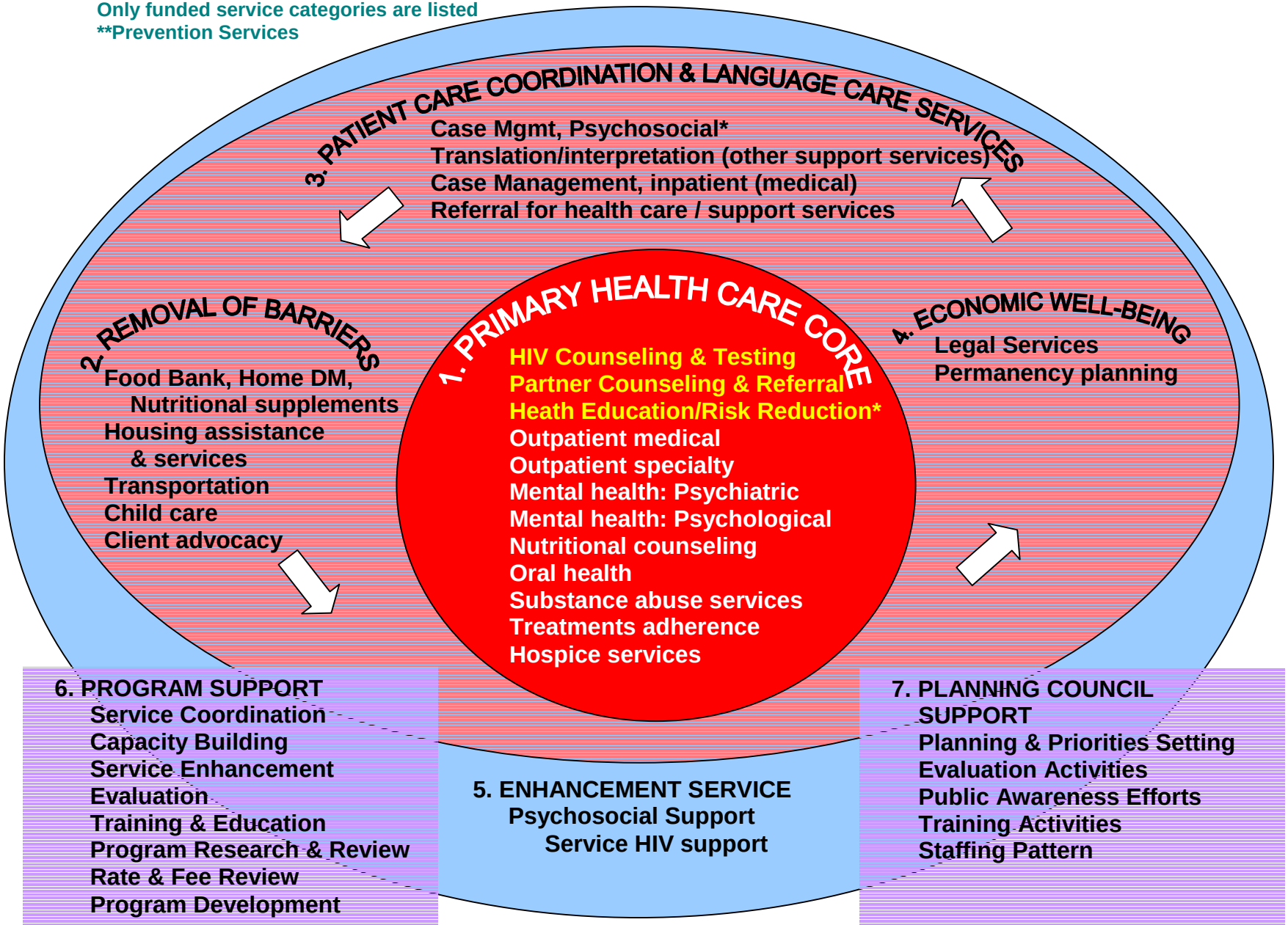


Figure 4 Los Angeles Continuum of Care Model

Only funded service categories are listed
**Prevention Services



Functional Model

The functional model represents a planner's best understanding of how a system addresses a client's needs. Services are placed together because they represent like functions or serve similar functions within the overall system. The functional models serve as good tools for guiding Councils, Consortia, and grantees to help them conceptualize the service delivery system and focus on how to prioritize resource allocation and improve service delivery and integration.

Three of the models in this report fall into the functional category. They are New York City, Riverside/San Bernardino, and Orange County, CA. The Riverside/San Bernardino model, shown in Figure 5, organizes services into three categories: core, ancillary, and access. Core services address the basic needs of PLWH/A, that is, food, housing, safety/security, and health care. Beyond that are the ancillary and access services, which support health care and social needs and allow PLWH/A to address barriers to care.

The Orange County, California, model seen in Figure 6, uses a four-column chart with the following service categories: Early Intervention Services, Medical Health Care Services, Practical Services, and Supportive Services. Placement of services in each category is defined by actual practice - vision care is a medical service, a food bank is a practical service, and day/respite care is a supportive service. This is a flat representation with no demonstration of a relationship between the services. What is interesting, however, is the use of italics to show services that are available but not funded by Ryan White.

The New York model, shown in Figure 7, uses four intersecting circles to describe its system. Each contains its own set of services: targeted, access, physical and life sustaining, and capacity building. This model was developed with the New York Planning Council in mind, and the letter-number combinations in the COC refer to specific work groups and their prioritization of services within the Council.

Disadvantages of this model are that they are more or less static, and they may not anticipate future client needs. The nature of the categories may not allow for the inclusion of new or emerging services that are necessary to the well-being of the client group. While they serve to address individual needs, they may not be very helpful to the everyday lives of PLWH/A because the total context of their need may not be addressed.

A second disadvantage of the presentations of the models is that some are not user-friendly. The New York model, for example, uses language unfamiliar to the general consumer. In addition, while the inclusion of services geared to specific populations is commendable, the wording and placement leads to a fair amount of redundancy in the listing of services and the uncertainty of where they are most appropriate.

Figure 5 Functional Model - The Riverside/San Bernardino, CA.

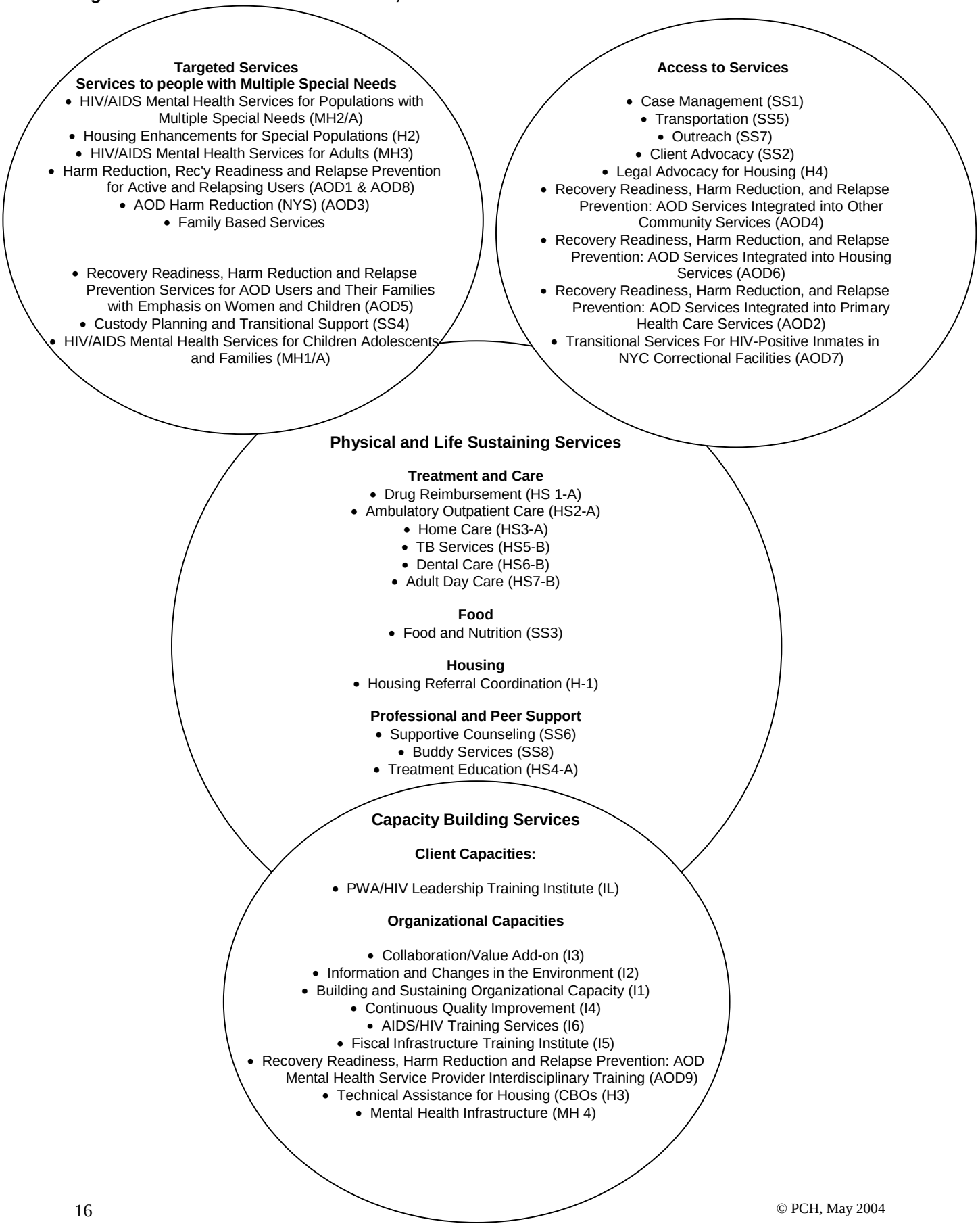
Core	Ancillary	Access
Adult day health care	Adoption	24-hour information and referral
Ambulatory medical care	Adult day care (social model)	Benefits counseling/advocacy
Apartments	Adult protective services	Case management
Buddy support	Behavior change support	Child care
Dental care	Child protective services	Health insurance premium continuation
Emergency response	Client advocacy	Translation/interpretation
Food pantry	Consumer counseling/education	Transportation
Grocery vouchers	Development disabilities services	
Home-delivered meals	Employment services	
Hospice	Foster care	
In-home supportive services	Legal services	
Inpatient care for acute illnesses	Protection from fraud	
Mental health counseling	Provider education and training	
Pharmacy	Recreational and social groups	
Rent/utility assistance		
Single-room occupancy units		
Skilled nursing facilities for long-term		
Spiritual care		
Substance abuse treatment		
Supportive housing		

Figure 6 Functional Model - Orange County, CA.

Early Intervention Services	Medical and Healthcare Services	Practical Services	Supportive Services
➢ *Counseling* • *Pre-post test counseling* • *Risk assessment* • *Post-test counseling* • *Partner counseling and referral services (PCRS) for HIV+ clients* ➢ *Distribution of risk reduction and educational materials* ➢ *Prevention case management (PCM)* • *For HIV+ clients* • *For high-risk repeat HIV, STD testers* ➢ *Referral and Linkages* • *Referral/linkages to case management and supportive services for HIV+ clients* • *Referral to prevention services* ➢ *Testing* • *Confidential HIV, STD, HCV, HBV testing* • *Anonymous testing* • *Enhanced Disclosure*	➢ Alternative Therapies ➢ Dental Care ➢ Health Insurance Continuation ➢ Home Health/Hospice Care ➢ Medical Care • Ambulatory care • Family-centered care • Specialty medical services • *Hospitalization* ➢ Medications • Local drug reimbursement program • *AIDS Drug Assistance Program (ADAP)* ➢ Mental Health Services ➢ Nutritional Counseling ➢ Pharmacist Consultation ➢ Treatment Advocacy and Adherence ➢ *Outpatient Substance Abuse Treatment* ➢ *Rehabilitative Care* ➢ *Vision Care*	➢ Food Services • Food Bank • Food/Grocery vouchers • Home-delivered meals • Nutritional supplements • Therapeutic nutrients • Home-delivered meals • *Food Stamps* • *Women, Infants and Children Program* ➢ Housing Services • Emergency/transitional housing • Long-term tenant based rental assistance • Rental and utility assistance • Transitional housing for substance users • *Residential treatment ofr substance users* ➢ Transportation Services • One-way bus, taxi, and van rides ➢ *Employment and Training Services* ➢ *Income Support Programs*	➢ Buddy/Companion and Peer Support ➢ Care management • Benefits counseling • Case management • Client advocacy ➢ Education and Outreach ➢ Independent Living Skills ➢ Legal Services ➢ *Adoption/Foster Care Assistance* ➢ *Behavioral Support* ➢ *Day/Respite Care* ➢ *Pastoral Care*

Note: Services shown in italics are available to PLWHs in Orange County although not funded through Ryan White CARE Act or HOPWA at the present time.

Figure 7 Functional Model - New York, NY.



Service Categorizations in the Models

There is little agreement on what should be basic or secondary services within the COCs. As shown in Table 3, Riverside/San Bernardino lists twenty-one services as basic needs, while Austin lists fourteen “basic services”, and New York lists eleven “basic services”. Austin, New York, and Riverside agree on three basic services, ambulatory care, dental care, and drug reimbursement. While some of these differences in categorizations reflect unique needs in each of the EMAs, the process of defining "core" or "basic" services tends to be somewhat arbitrary. What one population may need as a basic service, others may not. For example, housing is a basic need for the homeless, but may not be a basic need for the majority of infected and affected PLWH/A.

Table 3 Functional Models Service Categories

	EMA		
Services	**Austin**	**New York**	**Riverside/ San Bernardino**
Ambulatory care	X	X	X
Dental care	X	X	X
Drug reimbursement	X	X	X
Adult day care		X	X
Buddy services		X	X
Emergency shelters	X		X
Food bank	X		X
Home care/skilled nursing	X	X	
Home-delivered meals	X		X
Hospice care	X		X
In-patient medical services	X		X
Mental health treatment	X		X
Rental/utility assistance	X		X
Emergency financial assistance	X		
Emergency medical care	X		
Emergency response			X
Food and nutrition		X	
Food – grocery vouchers			X
Housing / Apartments			X
Housing referral coordination		X	
Housing - Single room occupancy units			X
Housing - supportive housing			X
In-home supportive services			X
Skilled nursing facilities			X
Spiritual care			X
Substance abuse treatment	X		X
Supportive counseling		X	
TB services		X	
Treatment education		X	

Additional Continuum of Care Information

In addition to the six models presented above, information related to two additional EMAs provides insight into the organization of services. In Sacramento, California, like other EMAs, the COC is organized around Core Services, or those "essential to the infected person's health, longevity, and quality of life." These are augmented by "Primary Linking Services" and "Support Services" which enable people affected by HIV/AIDS to obtain the core services and stay in care. Like New York, the entire system is enhanced by Community Capacity Building Services designed to continually improve the system of care. The focus on linking services with capacity suggests a different organization of services than the six mentioned above.

In New Haven, Connecticut, the continuum has the goal of "sustain[ing] a seamless provision of services to safeguard the quality of life throughout all stages of the life cycle of this disease." The services are grouped into four categories: 1) health care, 2) psychosocial (including case management), 3) social service (food, transportation, etc.), 4) substance abuse treatment, and 5) extended care services. In this COC, case management has extensive collaboration networks and well-developed referral systems among all service. These networks and referral systems are a key element in the COC.

In the New Haven model, there are three additional notable features that suggest a dynamic system. 1) Clinic Coordinators who oversee aspects of the clinic operations, including maintaining relations with clients and linking with case managers; 2) Early Linkage, a program designed to help transition a client from prevention services into the care delivery system and diminish the gap between testing positive and entry into primary care service; and 3) interagency collaboration as a condition of funding through the Planning Council.

DEVELOPING A CONTINUUM OF CARE

Functional Model with Explicit Outcomes

Several models that have a visual representation have been developed by EMAs. Most COCs have lists of services organized in linear, client-centered, hierarchical, or functional systems, and their characteristics, strengths, and weaknesses are outlined above. Recently, PCH has assisted in the development of COC's that borrows from the functional model. It has the added advantage of being dynamic and including populations served, eligibility, and outcomes.

The initial application of this model was used to develop the Houston COC in 1999. The COC was conceive of as a "rail system" made up of six lines that move passengers up and down the tracks to different stations.

As shown in Table 4, the lines, which represent general types of services, are defined by their starting and ending points. The starting points define the key identifying factor for the passenger. The destination is the outcome for the consumers. "Eligibility" refer to the key characteristics of consumers who qualify to use the lines.

Table 4 Continuum of Care Lines

LINES	START	DESTINATION	ELIGIBILITY
1. Public Education	No awareness of AIDS	Support for HIV/AIDS services	General public
2. Outreach	No awareness of serostatus	Awareness of serostatus	High risk behaviors
3. Prevention	Aware of negative status	Maintaining negative status	Knowledge of negative status
4. Early Treatment	Awareness of infection	No progression to AIDS	Early knowledge of HIV positive status
5. AIDS Treatment	AIDS diagnosis	Improved health status & quality of life (or) Death with dignity.	PLWA

Consumers for lines 1, "Public Education", are the general public whose support is needed to educate their legislators, vote for candidates that support continued funding for prevention and health care, and generally provide public support for continued HIV/AIDS services. Public awareness and contributions to AIDS services play a critical role in sustaining a prevention and care system.

Consumers for line 2, "Outreach", are those individuals at relatively high risk for HIV infection. While each eligible area must conduct an epidemiological review to specify high risk communities, they often include communities of color, MSM, and IDUs. Often heterosexual women, particularly African Americans, are at increasing risk of infection and progression to AIDS. While pediatric HIV and AIDS is generally declining, the number of families infected and affected by a positive member is dramatically increasing in most eligible areas. High risk individuals also include immigrants, mono-lingual Hispanics or others who speak little English, and undocumented individuals.

Lines 4, "Early Treatment" and 5, "AIDS Treatment", provide care services. Consumers for these lines fall into three categories:

1. *C*onsumers with private insurance. They tend to have higher incomes, their insurance typically covers medical out-patient and in-patient care, substance abuse treatment and other direct services. While they tend to have greater access to out-patient and in-hospital services to those without insurance, they often do not have access to support services that are only accessible to those who have lower income. For example they may not have access to aggregate meals, certain types of drug reimbursement, dental, or vision care. They are also subject to co-pays, deductibles, limits on drug formularies and limits on coverage. These often present barriers to receiving care. If a person leaves work or become disabled he or she is eligible for COBRA and there is continual dynamic in the system as persons move insurance benefits from one job to the next, or move from private to public insurance.

   In an increasing number of eligible areas, insurance is paid for through Ryan White CARE Act funds, usually ADAP but also through Title I insurance reimbursement services. In many instances only high risk pools are available to PLWH/A and these policies may have limited enrollment, restrictions, co-pays, deductibles, and other restrictions on services.
2. Consumers are those who are disabled and otherwise eligible for Medicaid (MediCal) and/or Medicare and/or other public insurance. Depending on regulations in the eligible area, Medicare and Medicaid place limits on coverage, require co-pays, "pay-back", and deductibles depending on income level and State regulations. In some instances these consumers do not have adequate insurance to obtain a full range of services or drugs desired to manage HIV and AIDS.
3. Consumers are those PLWH/A who have no insurance and rely on RWCA emergency funds or other public and private funds to procure the services they need. While ADAP, Ryan White, and HOPWA are primary sponsors of grant funded services, they are sometimes limited by providers willing to provide services, and they often have severity or income level criteria for eligibility. EMAs set different levels and availability of services.

In this COC there are several "stops" representing services between the starting points and destinations. Provided consumer are eligible and know about services, they can choose to stop or skip each service COC. Consumers can decide to use or skip the services at different times and go back and forth using different services as needed. If they are eligible, they can move between lines. For lines 4 and 5 that provide care, the type of services provided are, in part, determined by the insurance status of the individual.

In addition to the "lines" of service, the COC has an administrative structure that provides program support, planning, and technical assistance. This is usually the function of the grantee or subcommittees of the Councils, Consortia, or CPGs.

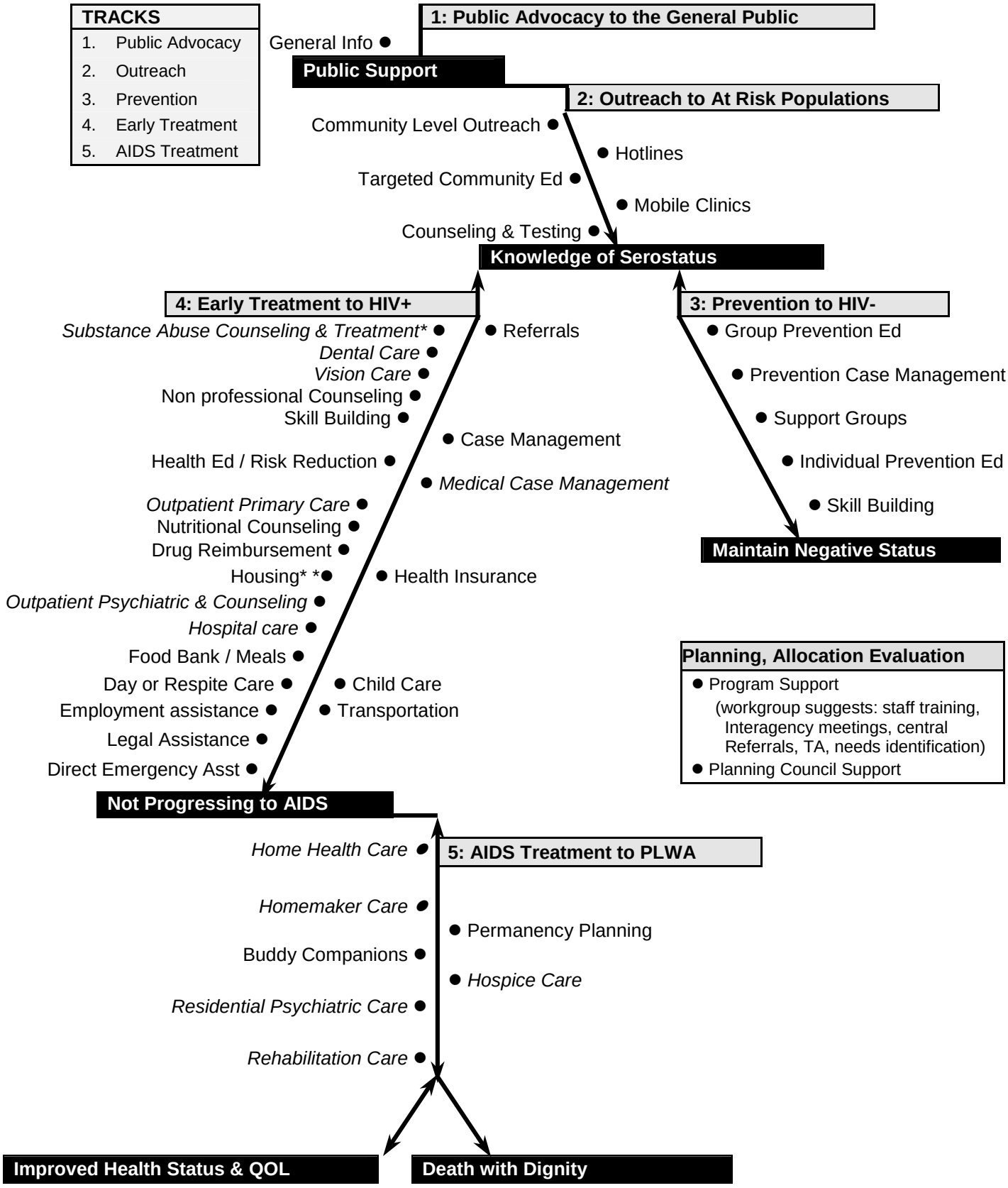
Figure 8, on the following page, shows what the COC looks like for the Houston Health Services Delivery Area (Title II) and the EMA. For the HIV positive lines, 4 and 5, the “stops” on the left are those that provide access to the services on the right. Following the

Figure is a more full description of system. Stops in italics are those that are likely to be reimbursed by public or private insurance.

To summarize the features of this system:

- It has several lines, each defined by its outcomes.
- Consumers can enter the system at any point on the line, provided they are qualified.
- Consumers can "travel" up or down the line.
- For the care lines, consumers' access to services differs by insurance status.

Figure 8 HIV/AIDS CONTINUUM OF CARE, HOUSTON, TX.



Italicized services are those that are reimbursable by insurance carriers .
*Includes Residential and medical detox; **Housing includes scatters site, aggregate, and temporary housing

Recommended Framework for Developing a Continuum of HIV/AIDS Services

Following from the Houston Model, PCH as worked with prevention networks and Councils who wish to further incorporate prevention services into the Continuum of HIV/AIDS Services (CHS). An added feature is the incorporation of services that promote communication between partners and within social networks that advocate for safer behavior and support adherence to medical regimes. An example of this type of continuum was developed for Sacramento. The weakness in the Sacramento model is a relatively under-developed continuum for care services.

Objectives for a CHS

The objectives of the CHS are shown in Table 5.

Table 5 Objectives and Outcomes for CHS

OBJECTIVES	OUTCOME
A. Increasing public awareness of the risk of HIV infection	1. Public support for prevention services. 2. Individual assessment of risk for HIV infection.
B. Outreach to at-risk populations	1. Knowledge of serostatus. 2. Knowledge of related co-morbidities. 3. Increased safer behaviors (condom and needle use). 4. Lower rates of STDs and TB. 5. Understanding about abstinence from sex / drug use.
C. Prevention services to HIV -	1. Maintain negative status. 2. Adopt and maintain safer sex and needle use activities. 3. Lower rates of STDs and TB. 4. Understanding of abstinence from sex / drug use.
D. Care and prevention services to PLWH/A	1. Increased percentage of PLWH/A receive and maintain primary care. 2. Decreased gap between need and utilization of support services related to seeking medical care. 3. Maintain and improve health status of PLWH/A. 4. Maintain and improve the physical and emotional health status of PLWH/A. 5. Increased use of primary care by those who are out-of-care. 6. Improved adherence to drug regimens. 7. Increased LOA for linkages and increased number of referrals to appropriate services. 8. Increased adoption and maintenance of safer behaviors.
E. Prevention and care services to partners where one or both are HIV positive	1. New and implemented protocols for family support services. 2. Increased partner notification. 3. Increased number of mutual commitments to safer sex and needle use strategies.
F. Training and technical assistance services to providers	1. Increased capacity to provide effective care and prevention services.
G. Assessment and evaluation of services by grantee	1. Accountability of funds and services to consumers and funders. 2. Improved client satisfaction and reduction of barriers to care and prevention services.

Graphic Description of CHS

Based on the objectives shown in Figure 9, the HCS might be visualized as a seven-track system that identifies those at-risk, identifies those infected, provides care and support

services to PLWH/A, and assures that the services are of high quality and accountable to funders and consumers. As shown in Figure 9, the tracks are defined by their starting point – the objective. This is shown in the black bar on top on each section in Figure 9. Each track has outcomes that are measurable and those are shown in the gray bars beneath the black bars. The services offered to achieve the outcomes are shown in the lightly shaded boxes in Figure 9.

The tracks represent the general type of services, some of which are funded by Ryan White Care Act, CDC, other federal, State, local, private and other sources. For the services provided to PLWH/A the major funding sources are insurance, including Medicaid, Medicare, and private insurance. One of the difficulties in determining gaps in services is determining the existing capacity of the system outside of the Ryan White Care Act funded services. Five of the tracks are for consumers: 1) public, 2) high-risk populations, 3) HIV negative, 4) HIV positive, and 5) partners where one or both are HIV positive. Another track is for providers and shows services that support prevention and care providers. Last, there is a track targeted to the grantee, Council and Prevention Planning Group, who are responsible for assessment and evaluation of services.

Each track has eligibility criteria and a desired outcome. For example, those eligible for tracks four and five must be HIV positive or partnered with someone HIV positive, and those eligible for track three have to be engaged in high-risk behaviors or be members of high-risk communities (e.g. MSM, IDUs, "party-drug" users, bath-house patrons, heterosexuals with IDU partners, sexually active heterosexual in high incidence areas, incarcerated, and recently released). As shown by the arrow, only those who know their HIV status (through counseling and testing) are eligible for tracks three through five. Because infection is spread by activities of partners, certain prevention services are directed to negative, positive, and discordant couples that allow them to negotiate safer practices with the outcome being a commitment to use safe practices.

In order to assure that services are effectively implemented, providers should be trained to identify and develop individualized service plans and have the organizational skills to provide services. Consequently, there are infrastructure development and training services to increase provider capacity to provide services. Listed next to services in parenthesis is the corresponding ranking as decided by the Council for 2004-2005.

Finally, in any effective CHS there is a feedback mechanism for assuring the system is self-adjusting and dynamic. This involves the assessment and evaluation of services to assure that prevention services are accountable and to modify services to better meet the needs of consumers.

Figure 9 Continuum of HIV/AIDS Services

Track 1: Increasing Public Awareness Of The Risk Of HIV Infection		
Outcomes	*1. Public Support*	*2. Personal Risk Assessment*
Services	Place Advertisements / PSAs in mass and small media, billboards, brochures, and leaflets. Write articles & editorials advocating HIV/AID prevention. Circulate newsletters. Conduct group educational intervention such as HIV/AIDS prevention curriculum, drama or theater presentation, and World AIDS day presentation. Have a hotline or other type of information exchange, etc. Organize rallies, public meetings, write-in campaigns. Use advocacy / educational volunteers or interns. Provide advocacy / educational training. Solicit financial support for HIV/AIDS prevention advocacy.	

▼

Track 2: Outreach To At-Risk Populations				
Outcomes:	*1) Knowledge of serostatus*	*2) Knowledge of co-morbidities and lower rate of STDs*	*3) Increased safer behaviors*	*4) Abstinence from sex and drug use*
Services:	Offer HIV Testing and Counseling	Health education and risk reduction through targeted group and community level interventions including schools, street outreach, house parties, health fairs, public sex venues such as parks or bath houses, bars, STD and health care clinics, etc. Conduct 1-1 contact with high –risk individual. Operate a mobile van. Harm Reduction. Distribute bleach kits. Distribute condom. Offer STD testing. Offer TB testing. Offer Substance Abuse treatment, detox, and methadone maintenance. Offer 12-step and other abstinence. Offer care at neonatal and other women's clinics. Offer family planning to populations at high risk for HIV infection.		

▼

	Track 3: Prevention Services To HIV-	**Track 4: Care and Prevention Services to PLWH/A**	**Track 5: Prevention And Care Services To Partners Where One Or Both Are HIV Positive**
Outcomes:	1) Maintain negative status	1) Maintain and improve health status 2) Linkages to, initiating, and maintaining health care 3) Commitment to safer behaviors	
	1) Obtain STD treatments and lower rates of STDs 2) Abstinence from sex/drug use 3) Adopt and maintain safer behaviors (condom and needle use) 4) Maintain or improve quality of life		
Prevention Services:	Offer HIV/AIDS re-test Offer 1-1- counseling / prevention case management.	Provide adherence programs. Monitor HIV status. Offer 1-1- counseling / prevention case management. Work with criminal justice system.	Develop partner agreements. Partner notification Provide partner negotiation. Partner counseling and referral.
	Provide skill-building workshops (Condom use, needle cleaning, partner negotiation). Conduct behavioral modification programs. Provide peer education / support. Circulate newsletters. Offer support groups.		

Track 6 Services To Providers
***OUTCOMES**:* *Increase capacity to provide effective services*
Services: Training. Infrastructure support. Program development. Newsletters.

Track 7 Program Assessment & Evaluation
***OUTCOMES**:* *1 Accountability to consumers and funders* *2. Improvement of services*
Program Monitoring. Needs Assessment. Consumer Satisfaction.

Care Services (for HIV+ and Partners only) ** Number in Parenthesis is 2004-5 priority.* *** Not ranked*	**Core:** Ambulatory medical, specialty, care & labs (1)* Dental care (3) Substance abuse (residential) (7) Substance abuse services (outpatient, counseling) (9) Mental health services (individual and group) (5) Hospice and residential care (PLWA) (12) Adherence counseling (Pediatric) (14) Home health care** **Primary Linking and Access Services** Case Management (2) Benefits Counseling Advocacy Transportation (voucher and trips) (8) Insurance continuation (15) Outreach** **Support Services** Emergency financial asst (4) Medical reimbursement / medication (non-ADAP) ADAP co-pay assistance Food vouchers, utility assistance, other critical need Housing (Emergency housing, referrals, long term housing) (6) Food bank/home delivered meals (10) Psycho-social support services / groups (11) Nutritional counseling (non-nutritionist) Peer counseling Complementary (acupuncture, chiropractic, massage) Child care (13)

The CHS is useful as a framework for determining service needs and unmet needs. Several tasks in defining needs and unmet needs refer to the CHS. They include:

Defining the Services and Eligibility

The first task is reviewing the services and their placement on the system. Are the services on the right track? For the Council the eligibility for the HIV/AIDS Care services are usually based on the allowable services specified by HRSA and the past experience of the Councils or Consortia. Services not funded by HRSA may be included if they are considered important in reaching the system outcomes specified in the CHS.

Eligibility for services should be established based on the need of PLWH/A and the capacity of the system. A challenge in defining the CHS is to set eligibility for each service based on consumer need, their ability to pay, and within the capacity of the HIV/AIDS care system.

Defining the Consumer - Using the Epidemiological Profile and Census Data

The second major task in using the CHSC to project needs and unmet needs is to estimate the number and type of consumers who are likely to need each service. This should be done for at least the current and next fiscal year. The number of consumers using the services is defined by the number in the population and, for Ryan White funded services, the subset that is eligible for the services.

Census data and the epidemiological profile provide estimates of the potential number of consumers at each stage of infection within different demographic (sex, race, and age) and risk groups who need the services. To determine the capacity for each of the five "lines" in the COC estimates are needed for different demographic and risk groups including:

1. The number of persons in the general population;
2. The number of persons at risk for HIV infection;
3. The number of persons who are HIV positive persons in the system;
4. The number of persons who are HIV positive out of care;
5. The number of persons who are living with AIDS;
6. The number of PLWA at the end-stage of the disease.

These estimates will allow planners to determine the total number of persons who potentially need services. The system should have the capacity to provide services to everyone who is in need. Since not all those in need seek services, actual capacity should be based on expected demand for services.

Determining Coverage for the Services

The next step is to determine which funding streams allow coverage for each of the services and what limitations they place on coverage. This requires estimating:

- The proportion of PLWH/A who are covered under private (commercial), Medicaid, Medicare or other health insurance and the extent of coverage under different policies;
- The proportion of PLWH/A who do not have coverage for services by their insurance.

For those who access services not covered by insurance, the following should be calculated:

- The proportion of PLWH/A whose services are paid by Ryan White CARE Act funds (including the reimbursement for insurance premiums).
- The proportion of PLWH/A whose services are paid by non-Ryan White CARE Act funds. Typically they are provided through other federal programs, private, and foundation grants or through direct payment by PLWH/A. For example, State grants, federal funds from Housing Opportunities for People with AIDS (HOPWA), State and Federal funded substance abuse and mental health services, Maternal and Child Health Care block grants, clinical trials, pharmaceutical company compassionate use programs, etc.

The capacity of the system to provide services under these streams of funding and the number of persons who are eligible to obtain services should be estimated.

From the above estimates it is possible to calculate:

1. The extent to which private and public insurance programs meet the aggregate health and social service needs of PLWH for each service category.
2. The extent to which services are available outside of the Ryan White CARE Act.
3. The extent to which services are available through Ryan White CARE Act Emergency funds.

Designing and Supporting the Care System

The Administrative Arm of the CHS

In most areas there are several administrative bodies that provide planning, prioritization, and allocation of funds for different services. When there is an agreed upon CHSC different funding streams for services are assessed so that there will not be a large excess capacity for any service. At the same time, sufficient capacity for each service should be anticipated so that there will not be huge waiting lines for services. In addition, a well-operating system will ensure that there are adequate ways for people to feed into the system and to access services.

One goal of this process is for the grantees and Council is to determine the best use for RWCA emergency funds and to examine methods of increasing the use of other entitlements for services. For example, in creating the CHS the populations that can access services provided through Medicaid and Medicare ad other public and private insurance channels should be documented. Planners also should determine if managed care providers will increase access to the services.

Creating the Linkages

When planning the placement of service on the CHS, and adding new services, the linkages between services are equally as important as the services themselves. There are competing objectives:

1. Reduce redundancy of administrative burden and services in the system while ensuring adequate access to those who live in distant areas.
2. Provide adequate input of services through multiple points of access. For HIV and AIDS services, it is necessary to design direct outlets (testing), but also adequate links to emergency rooms, drug treatment, STD clinics, and acute care facilities.
3. Facilitate services while not overburdening the staff and capacity of the system.
4. Ensure continuity of services so that consumers find that they are able to move around the system and will not be stuck at any one station while assuring confidentiality.

Training the Providers

Training providers and their staff is key to having a well-running system. Without trained staff and assurances that they have adequate benefits, any system will break down. In designing the CHS, planner have to ask, "Is there adequate formal and informal training?" Another area to explore is the continuity of staff. Often staff leave because of "burn-out" or low wages. To encourage continuity, the COC should recommend a reasonable benefit structure for the provider staff."

Informing and Training the Consumers

In designing the system the planners of the system should make sure that the consumer has direct input into the systems through the use of needs assessment surveys and participation on the various planning bodies.

Assessing the System

The grantee and Council should establish standards for services that are explicit with outcomes that are measurable. They might be divided into two basic areas:

1. How the system provides the services? For example common criteria include waiting times, quality of services, consumer satisfaction, ability to spend the allocated funds on the contracted services

2. Did the system have the desired outcomes? As shown on the COC these include:
   - Increased public support from the general public;
   - Increased knowledge of serostatus for those at risk of HIV infection;
   - Maintaining negative health status for those who know they are negative;
   - Not progressing to AIDS to those who are HIV positive; and
   - Improved health status and quality of life for those people living with AIDS; or,

- Death with dignity for those at the end stage of the illness.

A common challenge in HIV/AIDS service systems is the lack of uniform standards and common data collection systems to enable planning for the future needs of communities affected and infected by HIV and AIDS. A comprehensive CHS is one tool to help meet this challenge.

Attachment 1 Demographic and Funding Comparions for EMAs Providing COC

The six EMAs that provided a visual representation of their COC were Cleveland, Ohio, Hudson County/Jersey City, New Jersey, Austin, Texas, Riverside/San Bernardino, California, New York City, New York, and Orange County, California. In theory a COC should reflect the particular needs of each environment. Below is demographic and funding information for each of these EMAs.

Demographics

The demographics related to a number of variables in these six sites are noted in Tables 1 – 5 at the end of this section.

Table 6, on page 32, summarizes population figures along with growth, projected growth and migration figures for each EMA. Table 6 indicates that:

- Of the six EMAs reviewed, Riverside/San Bernardino had the largest land area.
- New York City was first in population.
- Austin had a percentage of population growth (24.7%).
- Riverside/San Bernardino and Austin experienced a positive net migration between 1990 and 1996.

Table 7, on page 32, takes a look at the racial and ethnic make-up of each community included in this study.

- New York and Hudson County/Jersey City EMAs had a larger percentage of African Americans than the other EMAs. New York had the highest percentage at 21%, followed by Hudson County/Jersey City at approximately 16%.
- The Orange County EMA had the highest percentage of Asians/Pacific Islanders, with about 12% of the population.
- All the EMAs had approximately 1% or less of the population American Indian, Eskimo, or Aleut.
- In the breakdown by ethnicity, Hudson County/Jersey City had the highest percentage of the population with Hispanic origin, with 37% of the population. The Austin, Riverside/San Bernardino, and Orange County EMAs had between 25% and 30% of the population of Hispanic origin.

Client Profiles

Table 8, on page 33, details client characteristics of recipients of Ryan White CARE Act (RWCA) funding. Approximately 22% of the clients served by the Austin EMA in FY 1996 were female. Both the New York and the Hudson County/Jersey City EMAs served a higher percentage of female clients, with 43% and 39% female clients, respectively.

According to the Centers for Disease Control and Prevention (CDC), African Americans have the highest rate of HIV infection: 92.9 per 100,000 in 1995. Hispanics had the second highest rate: 46.2 per 100,000 in 1995 (CDC, 1998).

The Hudson County/Jersey City EMA had the largest percentage of children under 13 served, with approximately 8% of clients served. The New York EMA had both the largest percentage of adolescent clients in FY 1996, with about 11% of the clients served, and the largest percentage overall of children and adolescents under age 20, with about 17% of the clients served.

Table 9, on page 33, looks at information related to exposure category. Almost half of the clients served by the RWCA in the Riverside/San Bernardino EMAs were in the category of men who have sex with men (MSM). This percentage is more than double that of both the New York and Hudson County/Jersey City EMAs.

Approximately 10% of Austin clients were in the injection drug use (IDU) exposure category. This compares to 38% in the New York and 44% Hudson County, New Jersey EMAs. New York and Hudson County/Jersey City EMAs also had the highest percentage of clients in the heterosexual exposure category, with more that 25% in each EMA.

RWCA Funding[6]

Table 10, the final table at the end of this section, details the Title I and Title II expenditures for several of the EMAs. In FY 1996, the combined Title I and Title II Ryan White CARE Act funding for Austin was comparable to the Hudson EMA, with 38% and 35% of total funding from Titles I and II, respectively.

Both the New York and Riverside/San Bernardino EMAs had a higher percentage of RWCA funding, with approximately 50% of HIV services funded through Titles I and II for both EMAs. Approximately half of the clients served were new clients.

[6] Statistical information for Ryan White CARE Act clients and providers was not available for the Cleveland and Orange County EMAs, therefore these two EMAs are not included for comparison in Tables 3 through 5.

Table 6 EMA Demographics

EMA	Cleveland OH	New York NY	Austin TX	Riverside/ San Bern. CA	Hudson County/ Jersey City NY	Orange County CA
Land Area	2,708 sq. miles	1,148 sq. miles	4,226 sq. miles	27,270 sq. miles	47 sq. miles	790 sq. miles
Population	2,233,288	8,643,437	1,041,330	3,015,783	550,789	2,636,888
National Population Rank	21	2	55	11	88	5
Population Growth 1990-96	4.8 %	2.9 %	24.7 %	16.9 %	-0.4 %	9.4 %
Projected Pop. Growth 1996-2002	0.6 %	-0.3 %	14.2 %	14.7 %	-0.4 %	5.3 %
Net Migration 1990-96	- 59,448	- 976,137	+ 113,773	102,585	- 69,855	- 177,332

Source: American Community Network

Table 7 EMA Population Breakdown by Ethnicity

EMA	Cleveland OH	New York NY	Austin TX	Riverside/ San Bern. CA	Hudson County/ Jersey City NJ	Orange County CA
White*	92.0 %	72.0 %	89.0 %	87.0 %	75.9 %	85.4 %
Black	7.0 %	21.2 %	8.8 %	7.2 %	15.7 %	1.9 %
Asian or Pacific Islander	0.7 %	6.1 %	1.3 %	4.7 %	8.1 %	12.1 %
American Indian, Eskimo, or Aleut	0.2 %	0.3 %	0.4 %	1.2 %	0.3 %	0.6 %
Hispanic	2.0 %	19.1 %	25.7 %	29.8 %	37.0 %	26.1%

Source: American Community Network

*All federal record keeping and data presentation is required to use four race categories (White, Black, American Indian and Alaska Native, Asian and Pacific Islander) and two ethnicity categories (Hispanic and non-Hispanic). Race and ethnicity are treated as separate and independent categories.

Table 8 Ryan White CARE Act Client Statistics

EMA*	New York NY	Austin TX	Riverside/ San Bernardino CA	Hudson County/ Jersey City NJ
Clients served	101,510	3,260	3,740	9,170
Gender				
Male	57,600 (57.6%)	2,540 (77.9%)	3,160 (84.5%)	5,620 (61.3%)
Female	43,210 (42.6%)	710 (21.8%)	570 (15.2%)	3,550 (38.7%)
Ethnicity**				
White	15,040 (14.8%)	1,650 (50.6%)	2,210 (59.1%)	1,890 (20.6%)
Black	43,570 (42.9%)	910 (27.9%)	580 (15.5%)	4,110 (44.4%)
Hispanic	38,250 (37.7%)	620 (19.0%)	800 (21.4%)	3,020 (32.9%)
Asian/PI	1,510 (1.5%)	10 (0.3%)	40 (1.1%)	50 (0.5%)
Native Amer.	380 (0.4%)	20 (0.6%)	50 (1.3%)	6 (0.06%)
Age**				
Under 13 y/o	5,330 (5.3%)	90 (2.8%)	20 (0.5%)	770 (8.4%)
13-19 y/o	11,570 (11.4%)	10 (0.3%)	30 (0.8%)	320 (3.5%)
20 y/o & older	83,200 (82.0%)	3,150 (96.6%)	3,680 (98.4%)	8,060 (87.9%)

Source: Health Resources and Services Administration, HIV/AIDS Bureau
* Data unavailable for Cleveland, OH and Orange County, CA
** Percentages may not equal 100 due to missing data

Table 9 Ryan White CARE Act Percentage of Clients by Exposure Category

EMA*	New York NY	Austin TX	Riverside/ San Bernardino CA	Hudson County/Jersey City NJ
MSM	18.2%	37.7%	48.1%	13.6%
IDU	38.2%	9.3%	7.7%	44.3%
MSM/IDU	1.8%	4.8%	5.8%	0.1%
Heterosexual Contact	25.9%	6.8%	2.4%	27.8%
Other/Undetermined	15.9%	41.5%	36.0%	14.2%

Source: Health Resources and Services Administration, HIV/AIDS Bureau* Data unavailable for Cleveland, OH and Orange County, CA

Table 10 Ryan White CARE Act Provider Statistics

EMA*	New York NY	Austin TX	Riverside/ San Bernardino CA	Hudson County/ Jersey City NJ
# new AIDS cases for 1995 (% national total)	10,496 (14.70%)	323 (.45%)	768 (1.08%)	760 (1.06%)
CY 1996 Title I funding	$66,786,341	$1,709,019	$3,918,274	$5,031,492
CY 1996 Title II funding	$6,578,542	$634,130	$632,829	$166,687
% total HIV Service Funding from Titles I & II	50%	38%	47%	35%
Clients served	101,510	3,260	3,740	9,170
New clients	52,320	1,500	1,980	4,600
Estimated % with HIV**	53.8%	54.1%	46.2%	36.7%
Estimated % with AIDS**	37.1%	34.8%	51.9%	57.0%

Source: Health Re sources and Services Administration, HIV/AIDS Bureau
* Data unavailable for Cleveland, OH and Orange County, CA
** Not all providers report HIV status.