Ryan White
HIV/AIDS Program

Part A Manual

U.S. Department of Health and Human Services

Health Resources and Services Administration

HIV/AIDS Bureau
Revised 2013
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Section I: Overview of the Ryan White HIV/AIDS Program

I. Ch 1. Overview

The HIV epidemic has taken an enormous toll since its onset in the early 1980s. Approximately 619,400 Americans with an AIDS diagnosis have died, and many others are living with HIV-related illness and disability or caring for people with the disease. An estimated 50,000 Americans become infected with HIV each year. Today, more than 1.1 million Americans are living with HIV disease. The epidemic has hit hardest among populations who are poor, lack health insurance, have limited or no access to health care, and are from communities of color.


The Ryan White HIV/AIDS Program reaches an estimated 529,000 people each year. People living with HIV disease are, on average, poorer than the general population. By statute, the programs funded under the Ryan White legislation are the “payer of last resort,” meaning that the RWHAP grant funds may not be used for any item or service for which payment has been made, or can reasonably be expected to be made by any other payer. In 2008, more than 70 percent of Ryan White HIV/AIDS Program clients self-identified as members of racial or ethnic minority groups. In the same year, 67 percent of Program clients were male, and 33 percent were female. The FY 2012 funding for the Ryan White HIV/AIDS Program is $2.35 billion.

The Ryan White HIV/AIDS Program is administered by the U.S. Department of Health and Human Services (HHS), Health Resources and Services Administration (HRSA), HIV/AIDS Bureau (HAB).

I. Ch 2. Ryan White HIV/AIDS Program Legislation

The Ryan White HIV/AIDS Program is authorized and funded under Title XXVI of the Public Health Service (PHS) Act, as amended by the Ryan White HIV/AIDS Treatment Extension Act of 2009 (Public Law 111-87, October 30, 2009). The legislation was first enacted in 1990 as the Ryan White CARE


The Ryan White legislation has been adjusted with each reauthorization to accommodate new and emerging needs, such as an increased emphasis on funding of core medical services and changes in funding formulas. The legislation provides a flexible structure through which the RWHAP can address HIV/AIDS care needs on the basis of:

- Different geographic areas (large metropolitan areas, States, and communities across the Nation)
- Varying populations hit hardest by the epidemic
- Availability and access to HIV-AIDS-related services, and
- Service system needs (e.g., technical assistance for programs, training of clinicians, research on innovative models of care).

Legislative provisions (called Sections) address, for example, planning and decision-making, type of grants that are available, what funds may be used for, requirements for entities submitting applications for funding, and available technical assistance to help programs run more effectively.

I. Ch 3. Ryan White HIV/AIDS Program Structure

The Ryan White HIV/AIDS Program is divided into several “Parts,” outlined in the authorizing legislation.

- **Ryan White Part A – Eligible Metropolitan Areas (EMAs)**

  Ryan White Part A provides grant funding for medical and support services to Eligible Metropolitan Areas (EMAs) and Transitional Grant Areas (TGAs)—population centers that are the most severely affected by the HIV/AIDS epidemic. EMA eligibility requires an area to report more than 2,000 AIDS cases in the most recent 5 years and to have a population of at least 50,000. To be eligible as a TGA, an area must have 1,000 to 1,999 reported AIDS cases in the most recent 5 years.

- **Part B – States and Territories**

  Part B provides grants to States and Territories to improve the quality, availability, and organization of HIV/AIDS health care and support services. Part B grants include a base grant for core medical and support services; the AIDS Drug Assistance Program (ADAP) award; the ADAP Supplemental Drug Treatment Program for eligible entities; the Part B supplemental grant program, and grants to States with “emerging communities,” defined as jurisdictions reporting between 500 and 999 cumulative AIDS cases over the most recent 5 years. Congress designates a portion of the Part B appropriation for ADAP; the ADAP earmark is now the largest portion of the Part B appropriation. Five percent of the ADAP earmark is set aside for the ADAP Supplemental Drug Treatment Program to assist States needing additional ADAP funds.
• **Part C – Community-Based Programs**

Part C supports outpatient HIV early intervention services and ambulatory care. Part C grants are awarded directly to service providers, such as ambulatory medical clinics. Part C also funds planning grants, which help organizations more effectively deliver HIV/AIDS care and services.

• **Part D – Women, Infants, Children, and Youth with HIV/AIDS and Their Families**

Part D grants provide family-centered comprehensive care to children, youth, and women and their families.

• **Part F – Special Projects of National Significance (SPNS)—Research Models**

Part F grants support several research, technical assistance, and access-to-care programs, as described below:

**The Special Projects of National Significance (SPNS) Program** supports the demonstration and evaluation of innovative models of care delivery for hard-to-reach populations. SPNS also provides funds to help grantees develop standard electronic client information data systems.

**The AIDS Education and Training Centers (AETC) Program** supports a network of 11 regional centers (and more than 130 local associated sites) that conduct targeted, multidisciplinary education and training programs for health care providers treating people living with HIV/AIDS (PLWHA).

**The Minority AIDS Initiative (MAI)** was established in FY 1999 through Congressional appropriations to improve access to HIV/AIDS care and health outcomes for disproportionately affected minority populations. MAI-funded services under Parts A, C, and D were consistent with their “base” programs, whereas the Part B MAI focused on education and outreach to improve minority access to medication assistance programs, including ADAP. The Ryan White HIV/AIDS Treatment Modernization Act of 2006 made the Ryan White Part A and B MAI separate competitive grant programs for EMA/TGAs and States, respectively. Under the Ryan White HIV/AIDS Treatment Extension Act of 2009, however, Congress directed that Ryan White Part A and B funding be returned to a formula grant basis and synchronized with the Ryan White Part A and B grant awards, similar to the Part C and D MAI.

All Ryan White HIV/AIDS Program Parts can support the provision of oral health services. Two Part F programs, however, focus on funding oral health care for people with HIV:

**The HIV/AIDS Dental Reimbursement Program** reimburses dental schools, hospitals with postdoctoral dental education programs, and community colleges with dental hygiene programs for a portion of uncompensated costs incurred in providing oral health treatment to patients with HIV disease.
The Community-Based Dental Partnership Program supports increased access to oral health care services for people who are HIV positive while providing education and clinical training for dental care providers, especially those practicing in community-based settings.

Learn more: http://hab.hrsa.gov/abouthab/aboutprogram.html

I. Ch 4. Ryan White HIV/AIDS Program Administration

As noted, HRSA HAB administers the Ryan White HIV/AIDS Program. HRSA’s Office of the Associate Administrator for HAB manages the bureau; provides leadership and direction for HRSA’s HIV/AIDS programs and activities, including the Ryan White HIV/AIDS Program; and oversees collaboration with other national health programs.

The HIV/AIDS Bureau Mission and Vision


Mission: Provide leadership and resources to assure access to and retention in high quality, integrated care and treatment services for vulnerable people living with HIV/AIDS and their families.

The HIV/AIDS Bureau Organizational Chart

Please use this link for the organizational chart.
http://www.hrsa.gov/about/organization/bureaus/hab/haborgchart.pdf
HAB Offices and Divisions

HAB has six additional offices and divisions.

The Division of Metropolitan HIV/AIDS Programs (DMHAP) administers the Ryan White Part A Program.

The Division of State HIV/AIDS Programs (DSHAP) administers the Ryan White Part B Program.

The Division of Community HIV/AIDS Programs (DCHAP) administers Parts C and D, the Community HIV/AIDS Dental Partnership Program, and the HIV/AIDS Dental Reimbursement Program.

The Division of HIV/AIDS Training and Capacity Development (DTCD) administers the AIDS Education and Training Centers (AETC) Program. The division also administers the Global Program as well as the Special Projects of National Significance Program, which develops, implements, and evaluates innovative models of HIV/AIDS care delivery and supports the development of standard electronic client information data systems by Ryan White HIV/AIDS Program grantees.

The Division of Policy and Data (DPD) serves as HAB’s focal point for program data collection and evaluation, coordination of program performance activities, development of policy guidance, coordination of technical assistance activities, and development of analyses and reports to support HIV/AIDS decision making.

The Office of Operations and Management (OOM) provides administrative and fiscal guidance and support for HAB and is responsible for all budget execution tasks, personnel actions, contracting services, and facility management.

Learn more at http://hab.hrsa.gov/abouthab/programfactsheets.html.

I. Ch 5. Overview of the Ryan White Part A Program

Part A of the Ryan White HIV/AIDS Program provides assistance to Eligible Metropolitan Areas (EMAs) and Transitional Grant Areas (TGAs)—locales that are most severely affected by the HIV/AIDS epidemic.

Eligibility

To qualify for EMA status, an area must have reported at least 2,000 AIDS cases in the most recent 5 years and have a population of at least 50,000. The 2006 reauthorization (P.L. 109-415) established a grant program for transitional grant areas (TGAs), defined as metropolitan areas
with a population of at least 50,000 and with no less than 1,000 but fewer than 2,000 cumulative AIDS cases during the most recent five calendar years. Unless a TGA became an EMA, it would continue to be eligible as a TGA until it failed for three years to have (a) at least 1,000 but fewer than 2,000 cases of AIDS during the most recent five calendar years, and (b) 1,500 or more living cases of AIDS as of December 31 of the most recent calendar year. P.L. 111-87 permits a metropolitan area with a cumulative total of at least 1,400 but less than 1,500 living cases of AIDS to continue to be eligible as a TGA provided that not more than 5% of the TGA grant award is unobligated as of the end of the most recent fiscal year.5

EMAs and TGAs range in size from one city or county to more than 26 different political entities; some span more than one State. The boundaries of EMAs and TGAs are based on the U.S. Census designation of Metropolitan Statistical Areas.

Grantees and Administrative and National Policy Requirements

Grants are awarded to the Chief Elected Official (CEO) of the city or county that provides health-care services to the greatest number of PLWHA in the EMA or TGA. Successful applicants must comply with the administrative requirements outlined in 45 CFR Part 92 Uniform Administrative Requirements for Grants and Cooperative Agreements to State, Local, and Tribal Governments.

HRSA grant and cooperative agreement awards are subject to the requirements of the HHS Grants Policy Statement (HHS GPS) that are applicable based on recipient type and purpose of award. This includes any requirements in Parts I and II of the HHS GPS that apply to the award. The HHS GPS is available at http://www.hrsa.gov/grants/hhsgrantspolicy.pdf. The general terms and conditions in the HHS GPS will apply as indicated unless there are statutory, regulatory, or award-specific requirements to the contrary (as specified in the Notice of Grant Award).

Federal regulations require grantees to oversee their service providers. In April 2011, HRSA compiled existing requirements into a comprehensive document called the National Monitoring Standards. The standards are designed to help Ryan White Part A and Part B grantees meet Federal requirements for program and financial management, and to improve program efficiency.

Services

Part A grants assist eligible program areas in developing or enhancing access to a comprehensive continuum of high quality, community-based care for low-income individuals and families with HIV. A comprehensive continuum of care includes the 13 core medical services specified in law, and appropriate support services that assist PLWHA in accessing treatment for HIV/AIDS infection that is consistent with the Department of Health and Human Service (DHHS) Treatment Guidelines (see http://www.aidsinfo.nih.gov). Comprehensive HIV/AIDS care beyond

these core services may include supportive services that meet the criteria of enabling individuals and families living with HIV/AIDS to access and remain in primary medical care and improve their medical outcomes. Only those supportive services that enable individuals to access and remain in primary medical care are fundable under the Ryan White legislation.

Unless approved for a waiver grantees are required to spend at least 75 percent of their Part A grant funds on core medical services and no more than 25 percent on support services after administrative costs are subtracted. Section II. HIV Service Delivery System provides a listing of covered core medical and support services.

**HIV Health Services Planning Councils**

Before the EMA or TGA can receive Ryan White Part A funds, the Chief Elected Official (CEO) for the EMA/TGA must appoint a planning council, with the exception of new TGAs after the 2006 legislation that can opt to establish other community planning processes. Each EMA/TGA Planning Council sets HIV/AIDS related service priorities and allocates Ryan White Part A funds on the basis of the size, demographics, and needs of people living with or affected by HIV, with particular focus on individuals who know their HIV status but are not in care. Planning Councils are required to jointly develop a comprehensive plan with the Ryan White Part A Grantee for the provision of services; the plan must include strategies for identifying HIV-positive persons not in care and strategies for coordinating services to be funded through existing HIV prevention and substance abuse treatment programs. The 2009 amendments to the Ryan White HIV/AIDS Program legislation require Planning Councils to include in their comprehensive plan a strategy for the identification, diagnosis, and referral to care of all those who are unaware of their HIV status. Planning Council membership must reflect the local epidemic demographically and include members with specific expertise in health-care planning, housing for the homeless, health care for incarcerated populations, and substance abuse and mental health treatment or members who represent other Ryan White and Federal programs. At least 33 percent of the members must be consumers of Ryan White HIV/AIDS Program services. Please refer to Section XIII, Planning and Planning Bodies for additional information.

New TGAs established after 2006, have the option of not using a planning council as their required community planning process.

**Funding Considerations**

Ryan White Part A grants to EMAs and TGAs include formula and supplemental components as well as Minority AIDS Initiative (MAI) funds, which support services targeting minority populations. Formula grants are based on reported living HIV/AIDS cases in the EMA or TGA as of December 31 in the most recent calendar year for which data are available. Supplemental grants are awarded competitively on the basis of demonstrated need and other selective criteria. MAI funding is awarded by formula according to the distribution of living HIV/AIDS cases among racial and ethnic minorities.
I. Ch 6. The Division of Metropolitan HIV/AIDS Programs

The Division of Metropolitan HIV/AIDS Programs (DMHAP) within HRSA/HAB administers Ryan White Part A of the Ryan White HIV/AIDS Program. HAB/DMHAP has responsibility for the following programs:

Ryan White Part A grants for Eligible Metropolitan Areas (EMAs) and Transitional Grant Areas (TGAs) consisting of formula and supplemental grants.

The Minority AIDS Initiative (MAI) grants which are awarded by formula according to the distribution of living HIV/AIDS cases among racial and ethnic minorities.

Ryan White Part A Project Officers (PO)

The HRSA Project Officer is the official responsible for overseeing the programmatic and technical aspects of the HRSA grant. Project Officers in the HIV/AIDS Bureau (HAB), Division of Metropolitan HIV/AIDS Programs (DMHAP) are responsible for oversight of Ryan White HIV/AIDS Program Part A grantees. The DMHAP PO works with the HRSA Office of Financial Assistance Management’s Grants Management Specialists (GMS). The GMS is responsible for all business and financial management matters related to the grant’s review, negotiation, award, and administration. In addition, this individual interprets and enforces grants administration policies and provisions. PO monitors the technical progress and performance of the recipient through review and analysis of progress reports, grant applications, performance data, annual progress reports, Federal Financial Report, audited financial statements, prior-approval requests, communications with the grantee and other parties, and on-site reviews. The PO is also responsible for identifying and responding to specific technical assistance needs of grantees and planning councils. The PO is the point of contact to coordinate the technical assistance request. POs as well as the GMS serve as the primary point of contact for grantees, supporting them in maintaining compliance with program requirements.

Each Ryan White HIV/AIDS Program Part A grantee has an assigned Project Officer in DMHAP.

I. Ch 7. Technical Assistance for the Ryan White Community

The legislation authorizes technical assistance (TA) to help programs comply with Ryan White requirements. Ryan White Part A grantees can obtain TA from HAB through their assigned project officer. Assistance focuses on implementing legislative and programmatic requirements in order to improve health care access and quality of life for PLWHA.

I. Ch 8. References, Links, and Resources

For More Information


Section II: HIV Service Delivery System

II. Ch 1. Overview

The largest component of the Federal AIDS budget is health care services and treatment for PLWHA in the United States, totaling $15.6 billion in the FY 2013 budget request. This represents a 6-percent increase over FY 2012, primarily due to increased mandatory spending for Medicaid and Medicare, but also to increases in the Ryan White Program.

The Ryan White HIV/AIDS Program is the single largest Federal program designed specifically for people with HIV in the United States, estimated to reach more than half a million people with HIV each year. It is also the third largest source of domestic funding for HIV care. First enacted in 1990, it provides care and support services to individuals and families affected by the disease, functioning as the “payer of last resort” by filling the gaps for those who have no other source of coverage or face coverage limits.

The Ryan White HIV/AIDS Program requires Eligible Metropolitan Areas (EMAs) and Transitional Grant Areas (TGAs)—population centers that are the most severely affected by the HIV/AIDS epidemic—to develop coordinated service delivery systems of care for PLWHA. A comprehensive continuum of HIV/AIDS care requires grantees to develop collaborative, partnering and coordinating relationships between multiple sources of HIV testing, treatment, prevention and care service provider agencies on the State and local levels.

The Ryan White Part A Program grantees are expected to reflect these in their HIV comprehensive plan and community-based needs assessment and planning processes. Ryan White grantees must integrate the National HIV/AIDS Strategy (NHAS) goals and Early Identification of Individuals living with HIV/AIDS (EIIHA) strategies in addressing the service needs of newly affected and underserved populations.

II. Ch 2. Legislative Background

The Ryan White HIV/AIDS Program under Title XXVI of the Public Health Service (PHS) Act as amended by the Ryan White HIV/AIDS Treatment Extension Act of 2009 (Public Law 111-87, October 2009) includes formula and supplemental grants to assist eligible metropolitan in developing HIV/AIDS service delivery systems that reflect a comprehensive continuum of HIV/AIDS care accessible to eligible PLWHA in the EMA/TGA. The system of care should address the service needs of newly affected and underserved populations — including disproportionately impacted communities of color and emerging populations.

Ryan White HIV/AIDS Program legislation, under Section 2604(c) of the Act, requires that grantees funded under Part A use not less than 75 percent of grant funds, after Program

Administration and Quality Management reductions, for core medical services unless a waiver is approved. Core medical services are identified under Section 2604(c) of the Act.

In addition, Ryan White Program funds may be used for essential supportive services. These are described in Section 2604(d) of the Act as services “that are needed for individuals with HIV/AIDS to achieve their medical outcomes (such as respite care for persons caring for individuals with HIV/AIDS, outreach services, medical transportation, linguistic services, and referrals for health care and support services).”

Section 2602(b)(2) of the Act requires the CEO to “establish or designate an HIV health services planning council that shall reflect in its composition the demographics of the population of individuals with HIV/AIDS in the eligible area involved, with particular consideration given to disproportionately affected and historically underserved groups and subpopulations”

“(2) REPRESENTATION.—The HIV health services planning council shall include representatives of—
(A) health care providers, including federally qualified health centers;
(B) community-based organizations serving affected populations and AIDS service organizations;
(C) social service providers, including providers of housing and homeless services;
(D) mental health and substance abuse providers;
(E) local public health agencies;
(F) hospital planning agencies or health care planning agencies;
(G) affected communities, including people with HIV/AIDS, members of a Federally recognized Indian tribe as represented in the population, individuals co-infected with hepatitis B or C and historically underserved groups and subpopulations;
(H) non-elected community leaders;
(I) State government (including the State Medicaid agency and the agency administering the program under part B);
(J) grantees under subpart II of part C;
(K) grantees under section 2671, or, if none are operating in the area, representatives of organizations with a history of serving children, youth, women, and families living with HIV and operating in the area;
(L) grantees under other Federal HIV programs, including but not limited to providers of HIV prevention services; and
(M) representatives of individuals who formerly were Federal, State, or local prisoners, were released from the custody of the penal system during the preceding 3 years, and had HIV/AIDS as of the date on which the individuals were so released.”

Section 2602(b)(4)(D) of the Public Health Service (PHS) Act describes the planning council duty to develop a comprehensive plan for the organization and delivery of health and support services, that includes a strategy to identify individuals who know their HIV status and are not receiving such services; coordinates the provision of such services; is compatible with any State or local HIV/AIDS plan; and includes a strategy to identify individuals who do not know their HIV status, make them aware of their status, and refer them into care.
In addition, Section 2602(b)(4)(F) of the PHS Act requires the planning council to participate in the development of the Statewide Coordinated Statement of Need (SCSN) described under Part B. Additionally, Sections 2602(b)(4)(G) and (H) of the PHS Act describe the planning council role in assuring community input and in coordinating with Federal partners as follows:

“(F) participate in the development of the statewide coordinated statement of need initiated by the State public health agency responsible for administering grants under part B;
(G) establish methods for obtaining input on community needs and priorities which may include public meetings (in accordance with paragraph (7)), conducting focus groups, and convening ad-hoc panels; and
(H) coordinate with Federal grantees that provide HIV-related services within the eligible area.”

In addition, Sections 2605(a)(2) and (3) of the PHS Act speak to the important points of access and components of a health care system for PLWHA by requiring “assurances adequate to ensure —”

“(2) that the eligible area has an HIV health services planning council and has entered into intergovernmental agreements pursuant to section 2602, and has developed or will develop the comprehensive plan in accordance with section 2602(b)(3)(B);
(3) that entities within the eligible area that receive funds under a grant under this subpart will maintain appropriate relationships with entities in the eligible area served that constitute key points of access to the health care system for individuals with HIV/AIDS (including emergency rooms, substance abuse treatment programs, detoxification centers, adult and juvenile detention facilities, sexually transmitted disease clinics, HIV counseling and testing sites, mental health programs, and homeless shelters), and other entities under section 2604(b)(3) and 2652(a), for the purpose of facilitating early intervention for individuals newly diagnosed with HIV/AIDS and individuals knowledgeable of their HIV status but not in care;”

II. Ch 3. Ryan White Core Medical Services

Introduction

As of 2006 Ryan White legislation requires that not less than 75 percent of the funds be used to provide core medical services (including the co-occurring conditions of the individual) that are needed in the eligible area for individuals with HIV/AIDS who are identified and eligible under the Ryan White HIV/AIDS Program. The HIV care continuum and service delivery coordination efforts are dependent on the availability of core services through Ryan White funding and other payers. Core Services monitoring expectations are included in the National Monitoring Standards.
**Defined Core Medical Services**

As stated in the Ryan White legislation, the term “core medical services,” with respect to an individual infected with HIV/AIDS (including the co-occurring conditions of the individual) means the following 13 core medical services are fundable:

(A) Outpatient and ambulatory health services.
(B) AIDS Drug Assistance Program treatments in accordance with section 2616.
(C) AIDS pharmaceutical assistance.
(D) Oral health care.
(E) Early intervention services described in subsection (e).
(F) Health insurance premium and cost sharing assistance for low-income individuals in accordance with section 2615.
(G) Home health care.
(H) Medical nutrition therapy.
(I) Hospice services.
(J) Home and community-based health services as defined under section 2614(c).
(K) Mental health services.
(L) Substance abuse outpatient care.
(M) Medical case management, including treatment adherence services.

The most recent service definitions can be found in the Ryan White Services Report Instructions Manual that is available online at: [http://hab.hrsa.gov/manageyourgrant/files/rsrmanual.pdf](http://hab.hrsa.gov/manageyourgrant/files/rsrmanual.pdf).

**Waiver to Core Medical Services Requirement**


**Core Medical Services and the Coordination of Services**

The Ryan White HIV/AIDS Program requires services to be provided in a coordinated, cost-effective manner that ensures that Ryan White HIV/AIDS Program Part A funds are the payer of last resort for HIV/AIDS services. Planning should also be coordinated with all other public funding for HIV/AIDS to: (1) ensure that Ryan White HIV/AIDS Program funds are the payer of last resort, (2) maximize the number and accessibility of services available, and (3) reduce any duplication. Grantees are required to participate in established HIV community-based continuum of care if such continuum exists within the area and maintain appropriate referral relationships with entities considered key points of access to the healthcare system for the purpose of facilitating EIS for individuals diagnosed as being HIV positive.
II. Ch 4. Ryan White Support Services

Introduction

As of the 2006 Ryan White legislation requires that no more than 25 percent of service dollars to be spent on support services that are needed in the EMA/TGA for individuals with HIV/AIDS who are identified and eligible under the Ryan White HIV/AIDS Program. Services funded must be needed in order for PLWHA to achieve medical outcomes—defined as “outcomes affecting the HIV-related clinical status of an individual with HIV/AIDS.” The HIV care continuum and service delivery coordination efforts are dependent on the availability of core services through Ryan White funding and other payers. HIV Support Services are part of the monitoring expectations for Ryan White Part A and included in the National Monitoring Standards.

Defined Support Services

A total of 16 support services approved for funding by the Secretary of HHS based on the legislation:

A. Case management (non-medical)
B. Child care services
C. Emergency financial assistance
D. Food bank/home-delivered meals
E. Health education/risk reduction
F. Housing services
G. Legal services
H. Linguistics services (interpretation and translation)
I. Medical transportation services
J. Outreach services
K. Psychosocial support services
L. Referral for health care/supportive services
M. Rehabilitation services
N. Respite care
O. Substance abuse services—residential
P. Treatment adherence counseling


HIV Support Services and the Coordination of Services

The Ryan White HIV/AIDS Program requires services to be provided in a coordinated, cost-effective manner that ensures that Ryan White HIV/AIDS Program Part A funds is the payer of
last resort for HIV/AIDS services. Planning should also be coordinated with all other public funding for HIV/AIDS to: (1) ensure that Ryan White HIV/AIDS Program funds are the payer of last resort, (2) maximize the number and accessibility of services available, and (3) reduce any duplication. Grantees are required to participate in established HIV community-based continuum of care if such continuum exists within the area and maintain appropriate referral relationships with entities considered key points of access to the healthcare system for the purpose of facilitating EIS for individuals diagnosed as being HIV positive.

II. Ch 5. HIV Care Continuum

An HIV Continuum of Care is an integrated service network that guides and tracks HIV clients over time through a comprehensive array of clinical, mental, and social services in order to maximize access and effectiveness. The characteristics of a continuum include:

- coordination among provider treatment activities
- seamless transition across levels of care
- coordination of present and past treatment

![Continuum of Engagement in Care](image)

Figure 1: Continuum of Engagement in HIV Medical Care

A comprehensive continuum of care includes primary medical care and supportive services, which aim to promote health and enhance quality of life. The Ryan White HIV/AIDS Program requires EMAs/TGAs under Ryan White Part A to develop a comprehensive continuum of HIV/AIDS care accessible to eligible PLWHA. The system of care should address the service needs of newly affected and underserved populations — including disproportionately impacted communities of color and emerging populations. The HIV/AIDS care should be consistent with HRSA’s goals of increasing access to services and decreasing HIV/AIDS health disparities among affected subpopulations and historically underserved communities. A continuum of HIV
prevention and care services should be designed to address the needs of PLWHA across all life stages, from those unaware of his/her HIV status, through HIV counseling and testing, early intervention and linkage to care, to retention in care and treatment adherence.

Grantees’ comprehensive planning and State Coordinated Statement of Need processes must reflect full participation of entities within the jurisdiction that constitute key points of access to the health care system for individuals with HIV/AIDS including those that facilitate early intervention for individuals newly diagnosed with HIV/AIDS and individuals knowledgeable of their HIV status but not in care.

II. Ch 6. Coordination of Services and Funding Streams

Partnerships and Collaboration

In a continuum of care, the Ryan White HIV/AIDS Program expects to see collaboration, partnering and coordination between multiple sources of treatment, care and HIV testing, and HIV prevention service providers. In a mature continuum of care, collaboration between HIV testing sites, non-Ryan White Program providers, all Ryan White Program Parts (A, B, C, D, and F), Medicaid, and VA should be established and maintained in the planning and implementation of services.

Ryan White Part A grantees must coordinate planning with all other public funding for HIV/AIDS to: (1) ensure that Ryan White HIV/AIDS Program funds are the payer of last resort, (2) maximize the number and accessibility of services available, and (3) reduce any duplication. Other Federal and local sources, including other Ryan White HIV/AIDS Programs must be taken into consideration in planning for the continuum of HIV/AIDS care. Sources may include but are not limited to:

1. Medicaid.
2. Medicare, including Medicare Part D.
3. Children’s Health Insurance Program (CHIP).
4. Veterans Affairs.
5. Housing Opportunities for Persons With HIV/AIDS Programs (HOPWA).
6. CDC Prevention.
7. Services for Women and Children (e.g., Special Supplemental Food Program for Women, Infants, and Children (WIC) Program, and Substance Abuse Treatment Programs for Pregnant Women).
8. Other State and local Social Service Programs (e.g., General Assistance, Vocational Rehabilitation).
10. Local and Federal funds for Substance Abuse/Mental Health Treatment Services.
II. Ch 7. Collaborative Planning Processes

Ryan White Comprehensive Plan

HAB has required Ryan White Part A grantees to submit an updated Comprehensive Plan every three years. The purpose of this multi-year plan is to assist grantees in the development of a comprehensive and responsive system of care that addresses service delivery gaps and resource needs. The Comprehensive Plan is a living document that serves as a roadmap for the grantee and should be continually updated as needed. The comprehensive plan should also reflect input from area stakeholders on how best to plan, prioritize, and deliver HIV/AIDS services, particularly in the light of available Federal, State and local resources. The Comprehensive Plan must be compatible with existing plans including the Statewide Coordinated Statement of Need (SCSN).

In addition, Ryan White grantees must discuss how their comprehensive plan will address the goals of the National HIV/AIDS Strategy, as well as identify the specific goals being addressed, including:

1. Reducing new HIV infections.
2. Increasing access to care and improving health outcomes for PLWHA.

The Comprehensive Plan should also discuss how the Healthy People 2020 objectives will be addressed.

Statewide Coordinated Statement of Need (SCSN)

The Statewide Coordinated Statement of Need (SCSN) is a collaborative process and must be developed with input from all Ryan White HIV/AIDS Programs Parts. The Part B grantee is responsible for periodically convening a meeting for the purpose of developing an SCSN. The mechanism for developing an SCSN may be a statewide meeting or some other input process. All Ryan White Parts are equally responsible for the development of the process, participation in the process, and the development and approval of an SCSN. The Early Identification of Individuals living with HIV/AIDS (EIIHA) is a legislative requirement that focuses on individuals who are unaware of their HIV status, how best to bring HIV positive individuals into care, and how to refer HIV negative individuals into services that are going to keep them HIV negative. An important element in assessing statewide need includes describing the needs of individuals who are unaware of their HIV status.

II. Ch 8. References, Links, and Resources

For More Information

Department of Health and Human Services: http://www.aids.gov/
Section III: National HIV/AIDS Strategy and Ryan White Legislation

III. Ch 1. Overview
On July 13, 2010 the White House released the National HIV/AIDS Strategy (NHAS) for the United States, with an accompanying Federal Implementation Plan. The vision of the NHAS calls for the United States to “become a place where new HIV infections are rare and when they do occur, every person, regardless of age, gender, race/ethnicity, sexual orientation, gender identity or socio-economic circumstance will have unfettered access to high-quality, life extending care, free from stigma and discrimination.” The NHAS is the nation’s first-ever comprehensive coordinated HIV/AIDS roadmap with clear and measurable targets to be achieved by 2015.

Background
The U.S. Department of Health and Human Services (HHS), along with five other “lead Federal agencies” (i.e., the Departments of Justice, Labor, Housing and Urban Development, and Veterans Affairs, and the Social Security Administration), were called upon to develop and submit operational plans to the Office of National AIDS Policy (ONAP) and the Office of Management and Budget (OMB) “within 150 days” of the Strategy’s release date and the issuance of a Presidential Memorandum for the heads of Executive departments and agencies. The Memorandum directed that the operational plans include “appropriate actions to advance the Strategy,” as well as “steps to strengthen coordination in planning, budgeting for, and evaluating domestic HIV/AIDS programs within and across agencies.”

III. Ch 2. Goals for the National HIV/AIDS Strategy

The National HIV/AIDS Strategy (NHAS) has three primary goals: 1) reducing the number of people who become infected with HIV, 2) increasing access to care and optimizing health outcomes for people living with HIV (PLWHA), and 3) reducing HIV-related health disparities. The NHAS states that more must be done to ensure that new prevention methods are identified and that prevention resources are more strategically deployed. Further, the NHAS recognizes the importance of early entrance into care for PLWHA to protect their health and reduce their potential of transmitting the virus to others. HIV disproportionately affects people who have less access to prevention, care and treatment services and, as a result, often have poorer health outcomes. Therefore, the NHAS advocates adopting community-level approaches to identify people who are HIV-positive but do not know their serostatus and reduce stigma and discrimination against PLWHA. By 2015, the NHAS goals and outcomes will achieve the following:

1. Reduce new HIV infections.
   - Lower the annual number of new infections by 25%.
   - Reduce HIV transmission by 30%.
• Increase the percentage of PLWHA who know their serostatus from 79% to 90%.

2. Increase access to care and improve health outcomes for PLWHA.

• Increase the proportion of newly diagnosed patients linked to clinical care from 65% to 85%.
• Increase the proportion of Ryan White HIV/AIDS Program clients who are in continuous care from 73% to 80%.
• Increase the number of Ryan White clients with permanent housing from 82% to 86%.

3. Reduce HIV-related health disparities.

• Improve access to prevention and care services for all Americans.
• Increase the proportion of HIV-diagnosed gay and bisexual men with undetectable viral load by 20%.
• Increase the proportion of HIV-diagnosed Blacks with undetectable viral load by 20%.
• Increase the proportion of HIV-diagnosed Latinos with undetectable viral load by 20%.

III. Ch 3. NHAS and the Ryan White Part A Program

To the extent possible, Ryan White Program activities should strive to support the three primary goals of the NHAS. To ensure success, the NHAS requires the Federal government and State, tribal and local governments to increase collaboration, efficiency, and innovation.

HAB recognizes that EMAs/TGAs have used Ryan White Part A grant funds to develop and/or expand systems of care to meet the needs of PLWHA. This includes HAB and grantee efforts to estimate and assess Unmet Need and the number of individuals who are unaware of their HIV/AIDS status and to ensure that essential core medical services have been adequately addressed when setting priorities and allocating funds. At the same time, the CDC has ongoing initiatives that may identify significant new numbers of PLWHA that will be seeking services. This requires ongoing assessment of how EMAs/TGAs will ensure access to primary care and medications as well as the provision of critical support services necessary to maintain individuals in systems of care. A list of CDC initiatives can be found at http://www.cdc.gov/hiv/topics/prev_prog/index.htm.

The NHAS also calls for improved Federal coordination of HIV/AIDS programs, as evidenced by streamlining and standardizing data collection and reducing reporting requirements for grantees. Over the past year, the Office of HIV/AIDS and Infectious Disease Policy in HHS has worked with a group of Federal Agencies, National Partners and grantees to identify indicators, data systems, and elements used across HHS programs to monitor HIV prevention, treatment, care services. A set of common indicators is being catalogued within 7 domains: 1) HIV testing; 2) Late HIV diagnosis; 3) Initial linkage to HIV medical care; 4) Retention/engagement in HIV medical care; 5) ARV Therapy; 6) Viral Load suppression; and 7) Housing Status. These indicators are covered under the Ryan White HIV/AIDS Program Services Report (RSR) that grantees and service providers report to HRSA on an annual basis, and thus HRSA/HAB will be positioned to calculate and report on these indicators.
III. Ch 4. References, Links, and Resources


For More Information

Please refer to http://aids.gov.
Section IV. Grants Administration

IV. Ch 1. Overview

This Section brings together resources related to grant administration for Ryan White HIV/AIDS Program Part A grantees and subgrantees.

IV. Ch 2. Legislative and Regulatory Requirements

Governing Authorities for HRSA Grants

The following statutes, regulations, administrative requirements, OMB Circulars, HHS Grants Policy Directives are applicable to Ryan White HIV/AIDS Program grants.

The listing of the authorities is in accordance with their general order of precedence.

1. National Policy Requirements
   - 2 CFR Part 175 – Award term for trafficking in persons;
   - 2 CFR 376 – HHS codification of non-procurement debarment and suspension;
   - 2 CFR 382 – HHS codification of Drug-Free Workplace Act common rule;
   - 45 CFR 46 – Protection of Human Subjects;
   - 45 CFR 80, 81, 84, 85, 86, 90, 91 – HHS codification of nondiscrimination statutes;
   - 45 CFR 87 – Equal Treatment for Faith-Based Organizations; and

2. Program Regulations: Issued by HRSA, these regulations generally have a statutory basis and elaborate on the requirements contained in the authorizing legislation, Public Health Service Act, Sections 2601-2610 (42 USC 300ff-11 – 300ff-20), as amended by the Ryan White HIV/AIDS Treatment Extension Act of 2009 (Public Law 111-87), and Program policies and requirements.

3. Administrative Requirements: Provides definitions and requirements for a range of administrative requirements for the agency and grantees/cooperative agreements.

4. **OMB Circulars**

   • **2 CFR Part 220 – Cost Principles for Educational Institutions (OMB Circular A-21).**
   • **2 CFR Part 225 – Cost Principles for State, Local, and Indian Tribal Governments (OMB Circular A-87).**
   • **2 CFR Part 230 – Cost Principles for Non-Profit Organizations (OMB Circular A-122).**
   • **OMB Circular A-133 – Audits of States, Local Governments, and Non-Profit Agencies.**

5. **HHS Grants Policy Statement, January 1, 2007**

   • The HHS Grants Policy Statement (GPS) serves as the general terms and conditions of HRSA’s discretionary grant and cooperative agreement awards to organizations. Grantees are subject to these general terms and conditions unless there are statutory, regulatory, or award-specific requirements to the contrary (as specified in individual Notices of Award). The GPS can be found at [http://www.hrsa.gov/grants/hhsgrantspolicy.pdf](http://www.hrsa.gov/grants/hhsgrantspolicy.pdf).

**Administrative and Clinical Quality Management Cost Caps**

The Ryan White legislation Section 2604(h) defines administrative and clinical quality management activities for Ryan White Part A grantees and subgrantees and, also, limits the amount Ryan White Part A grantees can spend on such costs as follows:

- Not more than 10 percent of their grant on administration and planning council support activities
- In the case of entities and subcontractors to which the Chief Elected Official allocates grant funds, up to 10% of aggregate amount allocated can be expended for administrative expenses without regard to whether particular entities expend more than 10 percent for such expenses.
- Clinical quality management, additional amounts can be spent up to 5 percent or $3,000,000, not part of the 10% for grantee administration.

**Administrative Activities**

Section 2604 (h)(3)(A)-(B) of Title XXVI of the PHS Act as amended by the Ryan White HIV/AIDS Treatment Extension Act of 2009 (Public Law 111-87), describes activities and amounts to be used for administration as follows:
(A) Routine grant administration and monitoring activities, including the development of applications for Ryan White Part A funds, the receipt and disbursal of program funds, the development and establishment of reimbursement and accounting systems, the development of a clinical quality management program as described in paragraph (5), the preparation of routine programmatic and financial reports, and compliance with grant conditions and audit requirements; and

(B) all activities associated with the grantee’s contract award procedures, including the activities carried out by the HIV health services planning council as established under section 2602(b), the development of requests for proposals, contract proposal review activities, negotiation and awarding of contracts, monitoring of contracts through telephone consultation, written documentation or onsite visits, reporting on contracts, and funding reallocation activities.”

The Code of Federal Regulations, 74 C.F.R. 74.51(a) and 2 C.F.R. 215.51(a) state that “[r]ecipients are responsible for managing and monitoring each project, program, sub-award, function, or activity supported by the award.” Under 2 C.F.R. 215.51, monitoring generally includes a need for:

- Performance reports
- Comparison of actual accomplishments with goals and objectives
- Analysis and explanation of cost overruns,
- Notification to the Federal awarding agency of developments that have a significant impact on the award supported activities
- Site visits

**Maintenance of Effort**

Sections 2605(a) of the Ryan White legislation states:

“(1)(A) that funds received under a grant awarded under this subpart will be utilized to supplement not supplant State funds made available in the year for which the grant is awarded to provide HIV-related services as described in section 2604(b)(1);

(B) that the political subdivisions within the eligible area will maintain the level of expenditures by such political subdivisions for HIV-related services as described in section 2604(b)(1) at a level that is equal to the level of such expenditures by such political subdivisions for the preceding fiscal year; and

(C) that political subdivisions within the eligible area will not use funds received under a grant awarded under this part in maintaining the level of expenditures for HIV-related services as required in subparagraph (B).”

Section 2604(b)(1) reads: “In general—The chief elected official of an eligible area shall use amounts from a grant under section 2601 to provide direct financial assistance to entities described in paragraph(2) for the purpose of providing core medical services and support services” (emphasis added).
Imposition of Charges

Under Section 2605(e), grantees are responsible for developing a schedule of charges for certain persons as described below:

“e) REQUIREMENTS REGARDING IMPOSITION OF CHARGES FOR SERVICES.—
(1) IN GENERAL.—The Secretary may not make a grant under section 2601 to an eligible area unless the eligible area provides assurances that in the provision of services with assistance provided under the grant—
(A) in the case of individuals with an income less than or equal to 100 percent of the official poverty line, the provider will not impose charges on any such individual for the provision of services under the grant;
(B) in the case of individuals with an income greater than 100 percent of the official poverty line, the provider— (i) will impose a charge on each such individual for the provision of such services; and (ii) will impose the charge according to a schedule of charges that is made available to the public;”

IV. Ch 3. Public Health Service Grants Management Procedures

Introduction

The Federal rules governing grants management for Ryan White HIV/AIDS Program service providers are provided in OMB circulars and the Code of Federal Regulations (CFR). Ryan White Part A grantees are expected to be familiar with these documents and assure that all service providers comply with requirements outlined in these documents.

The HRSA Office of Federal Assistance Management (OFAM), Division of Grants Management Operations of the Health Resources and Services Administration oversees grant awards to Ryan White Part A eligible metropolitan areas (EMAs) and transitional grant areas (TGAs). As the counterpart to the business office of the grantee, OFAM handles business management aspects of the review, negotiation, award, and administration of grants, as follows:

- Receiving all grant applications.
- Monitoring the objective review process.
- Performing cost analysis prior to grant award and negotiating changes in budgets as necessary.
- Providing business management consultation and technical assistance.
- Signing and issuing grant awards, amendments to awards, and notices of suspension and termination.
- Receiving and responding to all correspondence related to business activities.
- Receiving all documentation submitted for compliance with the terms and conditions of the grant award (progress reports, financial reports, revised budgets, and other conditions of award).
• Maintaining the official grant file.
• Conducting continuous surveillance of the financial and management aspects of grants.
• Resolving audit findings.

Definitions

<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Subcontractors or First-Line Entities</td>
<td>The term &quot;subcontractor&quot; as used in the Ryan White legislation refers to entities that receive funding directly from the Part A grantee. This means that other entities that receive funding from those direct recipients of funds (non-first-line entities) are not subject to the 10 percent aggregate administrative cost cap. This chapter explains certain exceptions to this general rule.</td>
</tr>
<tr>
<td>Administrative or Fiscal Agent</td>
<td>This term refers to an organization, agent, or other entity (e.g., public health department, community-based organization) that functions in political jurisdictions within a Part A area to assist the grantee in carrying out administrative activities (e.g., disbursing program funds, developing reimbursement and accounting systems, developing requests for proposals, monitoring contracts). Fiduciary agents, fiscal and administrative agents management cost are part of the grantee administrative cost cap of 10 percent.</td>
</tr>
<tr>
<td>Direct Costs</td>
<td>These are costs that can be identified specifically with a particular award, project, service, or other direct activity of an organization. Direct costs can be either administrative or service-related.</td>
</tr>
<tr>
<td>Service Costs</td>
<td>Service costs typically include wages and benefits of employees who directly provide the service, and the cost of materials, equipment, and supplies used to provide the service.</td>
</tr>
<tr>
<td>Overhead</td>
<td>Overhead cost refers to costs that have been incurred for common or joint purposes including rent, utilities and facility costs. <strong>Note:</strong> For institutions subject to 2 C.F.R. Part 215 (OMB Circular 21), the term “facilities and administration” is used to mean indirect costs.</td>
</tr>
<tr>
<td>Indirect Cost Rate</td>
<td>Indirect costs are often charged to a grant by the use of an indirect cost rate. An indirect cost rate is a mechanism for determining, in a reasonable manner, the proportion of an organization's total indirect costs that each program should bear. The indirect cost rate is the ratio of the indirect costs to a direct cost base. Indirect costs are subject to the 10% administration limitation.</td>
</tr>
<tr>
<td>Indirect Cost Rate Agreement</td>
<td>The document that formalizes the establishment of indirect cost rates and provides information on the proper application of the rates. To be used as allowable expense must be an approved indirect cost rate agreement.</td>
</tr>
</tbody>
</table>

Table 1: Public Health Service Grants Management Procedures Definitions

A. Administration of Grants

Ryan White Part A grantees can find relevant information regarding the administration of grants in the following OMB Circulars (which can be obtained from OMB’s Office of Federal Financial Administration).

These regulations provide definitions and requirements for a range of administrative requirements for grantees and subgrantees including:

- Standards for financial management systems, including payments, program income, revision of budget and program plans, and non-Federal audits.
- Purpose of property standards, including the purpose of insurance coverage, equipment, supplies, and other expendable property.
- Purpose of procurement standards, including recipient responsibilities, codes of conduct, competition, procurement procedures, cost and price analysis, and procurement records.
- Purpose of reports and records, including monitoring and reporting, program performance, financial reports, and retention and access requirements.
- Purpose of termination and enforcement.
- Purpose of closeout procedures.

B. Principles and Standards for Determining Costs

The following resources establish principles and standards for determining costs applicable to grants, contracts, and other agreements entered into by the types of organizations specified:

- 2 CFR Part 220 - Cost Principles for Educational Institutions (OMB Circular A-21)
- 2 CFR Part 225 - Cost Principles for State, Local, and Indian Tribal Governments (OMB Circular A-87)

C. Government-Wide Standards for Non-Federal Entities Expending Federal Awards

Government-wide policies and standards for non-Federal organization-wide audits of recipients of Federal awards are explained in:

- OMB Circular A-133—Audits of States, Local Governments, and Nonprofit Organizations.
- Grantee and Provider Contract Requirements.

According to 45 CFR Part 92, local government grantees may use their own procurement procedures for issuing contracts, following applicable State and local laws and regulations.
However, these procedures must conform to applicable Federal law and the standards in 45 CFR Part 92.36.

A contract must contain clauses that are necessary to ensure requirements under the grant will be satisfied, since neither 45 CFR Parts 74 and 92 nor other documents are directly binding on a contractor.

**Grantee and Provider Contract Requirements**

According to OMB Circular A-102 (or 45 CFR Part 92), local government grantees may use their own procurement procedures that reflect applicable State and local laws and regulations, provided that the procurement procedures conform to applicable Federal law and the standards identified in the Circular (Part 92.36). Identified standards concern the following areas:

- Written code of standards of conduct for employees involved in the award and administration of contracts.
- Procedures to avoid the purchase of unnecessary and duplicative items.
- Making awards to responsible contractors.
- Maintaining records to detail the history of a procurement.
- Settlement of all contractual and administrative issues.
- Protest procedures to handle and resolve disputes.
- Providing for full and open competition.
- Written selection procedures for procurement transactions.

A contract must contain the clauses necessary to ensure that all requirements under the grant will be satisfied, since neither 45 CFR Parts 74 and 92 nor other documents are directly binding on a contractor. The contract should specify:

- Nature and number of services to be provided.
- Eligibility requirements for consumer enrollment in services.
- Line-item budget and/or a payment rate per unit per service.
- Nature and frequency of required reports.
- Data collection criteria and expected reporting.
- Processes for reimbursement payments including invoicing and time frames.
- Program and fiscal monitoring processes and time frame.
- Quality management expectations.

**IV. Ch 4. Costs for Administration and Quality Management**

**Introduction**

Administrative costs relate to oversight and management of Ryan White HIV/AIDS Program funds and include such items as contracting, accounting, data reporting, planning council support, and program support (such as capacity development and technical assistance).
There are several requirements regarding the use of Ryan White Part A funds to carry out administrative activities. Some of these requirements apply to grantees, while others apply to the entities that receive Ryan White funds from grantees.

**Grantee Administrative Costs**

Section 2604(h) of the Ryan White HIV/AIDS Treatment Extension Act of 2009 states that “the [CEO] of an eligible area shall not use in excess of 10 percent of amounts received under a grant awarded under this subpart for administrative expenses” and “[I]n the case of entities and subcontractors to which the [CEO] of an eligible area allocates amounts received by the official under a grant under this subpart, the official shall ensure that, of the aggregate amount so allocated, the total of the expenditures by such entities for administrative expenses does not exceed 10 percent (without regard to whether particular entities spend more than 10 percent for such expenses).”

Section 2604(h)(3) defines allowable administrative activities for Ryan White Part A to include:

A. Routine grant administration and monitoring activities, including the development of applications for Ryan White Part A funds, the receipt and disbursal of program funds, the development and establishment of reimbursement and accounting systems, the development of a clinical quality management program as described in paragraph (5), the preparation of routine programmatic and financial reports, and compliance with grant conditions and audit requirements; and

B. All activities associated with the grantee’s contract award procedures, including the activities carried out by the HIV health services planning council as established under section 2602(b), the development of requests for proposals, contract proposal review activities, negotiation and awarding of contracts, monitoring of contracts through telephone consultation, written documentation or onsite visits, reporting on contracts, and funding reallocation activities.”

**A. Calculating Administrative Cost Caps**

The grantee calculates its Administrative Cost Caps by multiplying their award by 10 percent.

The grantee should determine the aggregate amount of funds available for first-line entities (subgrantees) to use for administrative costs. To determine this amount, the grantee should:

- Subtract the grantee’s administrative costs (up to 10 percent) and the grantee’s clinical quality management costs (up to 5 percent or $3 million, whichever is less) from the total grant award.
- Multiply the remaining amount by 10 percent.

For example, suppose that a grantee receives $5 million in Ryan White Part A funds. The maximum this grantee may spend on grantee administrative costs is ten (10) percent of $5 million or $500,000. The maximum the grantee may spend on clinical quality management is
another five (5) percent of the total grant award, or $250,000. The funds remaining for other uses total $4.25 million ($5 million minus $500,000 for grantee administrative costs and $250,000 for the clinical quality management program). The administrative cost caps are calculated again for entities receiving Ryan White funds from the Ryan White Part A grantee. The maximum aggregate amount available for first-line entities to use on administrative costs is 10 percent of the $4.25 million, the amount of service dollars remaining after grantee administrative costs are subtracted, or $425,000. Regardless of how much an individual first line entity spends on administrative costs, when added across all such entities, administrative costs that are paid for with Part A Ryan White funds cannot exceed $425,000.

**Second or Third-Line Entities**  
Second and third line entities (sub-contracted providers) administrative costs are included as part of the aggregate administrative costs. Therefore their 10% cap would apply against the first line entity cap. The Grantee responsibility is to monitor all administrative costs to ensure they do not exceed the allowable rate. Indirect costs are considered an administrative cost.

**Clinical Quality Management Program Costs**

Clinical quality management costs are covered under Section 2604(h). The Chief Elected Official (CEO) of an eligible area shall provide for the establishment of a clinical quality management program to assess the extent to which HIV health services provided to patients under the grant are consistent with the most recent Public Health Services guidelines for the treatment of HIV/AIDS and related opportunistic infection, and to develop strategies for ensuring that such services are consistent with the guidelines for improvement in the access to and quality of HIV health services. The CEO may use funds for activities associated with the clinical quality management program not to exceed the lesser of 5 percent of amounts received under the grant or $3,000,000.

**Subcontractor Administrative Costs**

Section 2604(h)(4) defines allowable “subcontractor administrative activities to include:

- Usual and recognized overhead, including established indirect rates for agencies;
- Management and oversight of specific programs funded under this title; and
- Other types of program support such as quality assurance, quality control, and related activities.”

Typical examples of administrative costs for first-line entities include general administration and general expenses. Examples include: salaries and expenses of executive officers, personnel administration, accounting, the costs of operating and maintaining facilities, rent, and depreciation or use allowances on buildings and equipment. Included under management and oversight activities for first-line entities are costs associated with:

- Development of funding applications and proposals.
- Receipt and disbursal of program funds.
- Development and establishment of reimbursement and accounting systems.
• Preparation of routine programmatic and financial reports, including the minimum
requirements of completing the Ryan White HIV/AIDS Program Data Report.
• Compliance with contract conditions and audit requirements.
• Monitoring of and reporting on any subcontracts through telephone consultation, written
documentation, or on-site visits.

B. Applying Administrative Cost Caps

1. Grantees

The legislation requires that the grantee’s administrative activities charged to the Ryan White
Part A grant not exceed ten (10) percent of the grant award. If a grantee makes Ryan White Part
A funds available to one or more administrative or fiscal agents that perform grantee
administrative functions, then the costs of these activities are counted against the grantee’s
administrative cost cap. For example, a Ryan White Part A grantee’s city health department
might make funds available to the health department of an outlying county to fund service
providers in that county. The costs for the county to disburse those program funds, develop
reimbursement and accounting systems, develop requests for proposals, monitor contracts, etc.,
count against the city health department’s ten (10) percent administrative cost cap.

If the administrative or fiscal agent is also delivering a Ryan White-funded service, the costs of
that service and any administrative activities associated with providing it are not counted against
the grantee’s 10 percent cap. The administrative activities associated with the service are,
however, counted against the 10 percent aggregate cap imposed on first-line entities receiving
Ryan White HIV/AIDS Program funds (see discussion below).

Grantees must determine the amounts necessary to cover Grantee administrative and program
support activities. In addition, Planning Council (PC) Support costs are considered part of the
Grantee Administrative budget and together are capped at 10 percent. The grantee must also
ensure adequate funding for PC mandated functions within the administrative line item.
“Planning Council support should cover reasonable and necessary costs associated with carrying
out legislatively mandated functions.”

2. First Line Entities

The 10 percent aggregate administrative cost cap applies only to first-line entities. However,
given the clear Congressional intent to limit administrative costs, HRSA/HAB expects grantees,
through their contracts with first-line entities, to impose a separate 10 percent administrative cost
cap on any “second- or third-line” entities that receive Ryan White funds from a first-line entity.
That is, of the amount awarded to an individual second- or third-line entity, a maximum of 10
percent can be spent on administrative costs.

If a Ryan White Part A grantee makes Ryan White Part A funds available to an administrative or
fiscal agent that performs grantee administrative functions, then the entities to which that
contracted agent makes funds available are considered first-line entities and are therefore subject
to the 10 percent aggregate administrative cap. For example, a grantee’s city health department
might make funds available to the health department of an outlying county to fund service providers in that county. Organizations that receive funding from that county health department are considered first-line entities.

During the contracting process, grantees must work with their first-line entities to negotiate a final budget that appropriately classifies funded activities, personnel, supplies, material, etc., as administrative costs or service costs. Administrative costs count against the 10 percent aggregate cost cap; service costs do not. For those situations in which a unit cost system is used to pay a contractor, the unit cost must be broken down so that administrative and service costs can be distinguished. The administrative cost of the unit cost is part of the contractor administrative cost and subject to the 10% administrative cap.

Because of the diverse characteristics and accounting practices of governmental units and nonprofit organizations, it is not possible to specify all the types of costs that may be classified as administrative or service-related in all situations. A case management organization, for example, may include some telephone expenses as a service cost, as long as such calls can be directly related and documented as service delivery. A food distribution program may assign some or all rental expenses as a service cost because storing the food is directly related to delivering the service and its use can be documented.

In general, grantees should establish and use their own guidelines in making these classifications. Guidelines used to assign particular costs to Ryan White should be consistent with guidelines used to assign particular costs to local funds or to other, non-Ryan White, Federal funds. However, requirements specific to Ryan White, as defined earlier in this chapter, must be followed.

C. Compliance With Administrative Cost Requirements

1. Grantees

Ryan White Part A grantees are required to submit categorical budgets and narrative justifications to the DMHAP for approval. Budgets must be submitted for administration, planning council support, services, and clinical quality management programs. Project officers review the grantee budgets and determine whether the grantee’s administrative costs fall within the statutory limits.

2. First Line Entities

The Chief Elected Official (CEO), the Ryan White Part A grantee, (or designee) is required to sign program assurances with the grant application submitted to HRSA/HAB’s Division of Metropolitan HIV/AIDS Programs (DMHAP) for funding. Included among them is an assurance that the 10 percent aggregate administrative cost cap requirement will be met. As with all other program assurances and legal requirements, compliance is subject to audit by the Office of the Inspector General at the Department of Health and Human Services, the General Accounting Office, and others.
HAB/DMHAP strongly encourages grantees to require from contractors and provide to HAB/DMHAP a budget format that clearly identifies the costs for administration and the costs for services.

Ryan White Part A grantees are required to submit a Contract Review Certification (CRC), as a component of the Program Terms Report, that identifies the total amount of funds awarded for contracts, as well as certification that contracts were reviewed by the fiscal officer in charge of the Ryan White Part A grant and consistent with DMHAP policies and Federal grant requirements. The form must be signed by the grantee’s fiscal official for all contracts administered by the grantee. At the end of the budget period, the Grantee is required to certify that the actual amount of funds expended on administrative costs by “first-line” entities. The certification must state the total amount of funds expended for HIV-related services by contractors and the dollar amount, in the aggregate, actually expended on their associated administrative costs. The Financial Officer responsible for the Ryan White funds must sign the certification.

This certification is part of the final progress report submitted to the HRSA Office of Federal Assistance Management (OFAM), Division of Grants Management Operations, HIV/AIDS and Rural Health Branch. The Grantee’s fiscal officer in charge of the Ryan White grant must sign both the initial and final certifications of these figures.

IV. Ch 5. Fiscal Requirements for Grants Administration

Introduction

The HHS Grants Policy Statement and the Ryan White legislation form the basis for a number of grantee requirements related to program budget, sliding fee scale, caps on charges for services, as well as the use of program income to provide eligible services to eligible clients. At the same time, the grantee’s administration of Ryan White funds requires that such requirements also apply to subgrantees to ensure Federal regulations, legislation, and policies are fully enforced for all grantee funded programs. The National Monitoring standards provides guidance to Grantees in establishing the systems and performance indicators needed to ensure that their management of Ryan White funds is in accordance with governing laws and regulations.

A. Payer of Last Resort

By statute, the RWHAP funds may not be used for any item or service “for which payment has been made or can reasonably be expected to be made” by another payment source (Sections 2605(a)(6), 2617(b)(7)(F), 2664(f)(1) and 2671(i) of the Public Health Service (PHS) Act.). At the individual client level, this means that grantees must assure that funded providers make reasonable efforts to secure non-RWHAP funds whenever possible for services to individual clients. Consistent with past communication from HRSA/HAB, grantees and their contractors are expected to vigorously pursue Medicaid enrollment as well as other funding sources (e.g., Medicaid, CHIP, Medicare, state-funded HIV/AIDS Programs, employer-sponsored health insurance coverage, and/or other private health insurances, etc.) to extend finite Part A grant.
resources to new clients and/or needed services, and that such eligibility is consistently assessed and enrollment pursued.

In cases where the operations of the Part A Program and/or its eligibility determinations are made through a sub-contractual relationship, the assurance that Ryan White program funds remain the payer of last resort should be maintained. Contractors with the authority to conduct eligibility should also perform insurance verification, and make every effort to identify primary payer verifications. Such actions will reinforce the integrity of the Part A funds being spent on clients identified as eligible.

The Ryan White Program is the payer of last resort; with the exception of persons with HIV/AIDS who are eligible to receive benefits or services through the Indian Health Service or the Department of Veterans Affairs. These people are also eligible for Ryan White Program services and can choose to access the Ryan White Program for their care, rather than accessing services for the Indian Health Service or the Department of Veterans Affairs.

B. Imposition of Charges for Services and Limitation (Cap) on Charges to Clients

The Ryan White HIV/AIDS Ryan White Part A Program legislation requires that individuals be charged no more than a maximum amount in a calendar year according to the following criteria:

- If an individual’s income is less than or equal to 100% of the Federal Poverty Level (FPL), the individual may not be charged for services.
- For individuals with income from 101% to 200% of the FPL, cumulative charges in a calendar year can be no more than 5% of the individual’s annual gross income.
- For individuals with incomes from 201% to 300% of the FPL, cumulative charges in a calendar year can be no more than 7% of the individual’s annual gross income.
- For individuals with income over 300% of the FPL, cumulative charges in a calendar year can be no more than 10% of the individual’s annual gross income.

In addition, the legislation explicitly defines and includes as part of “cumulative charges” the charges for HIV-related services performed by providers other than the grantee or its subgrantees. The legislation explicitly refers to enrollment fees, premiums, deductibles, cost sharing, co-payment, coinsurance, or similar charges.

The cap on charges to clients applies to any charges made to clients for all HIV services performed by all providers.

HRSA/HAB Monitoring Standards on client charges states:

**HRSA/HAB Fiscal Monitoring Standards. Section D: Imposition & Assessment of Client Charges.** 1. Unless waived, Ensure grantee and subgrantee policies and procedures that specifies charges to clients for services, which may include a documented decision to impose only a
nominal charge. No charges imposed on clients with incomes below 100 percent of the Federal Poverty Level (FPL).

HRSA/HAB Fiscal Monitoring Standards. Section D: Imposition & Assessment of Client Charges 3. Charges to clients with incomes greater than 100 percent of poverty that are based on a discounted fee schedule and a sliding fee scale. Cap on total annual charges for Ryan White services (including ADAP) based on percent of patient’s annual income.

HRSA/HAB Monitoring Standards, Frequently Asked Questions. Is there a difference between the sliding fee and the limitation on annual client charges? Yes. According to the legislation, the sliding fee or discount on charges is different from setting a limitation on the total charges a client can be required to pay in a given year for HIV services (Ryan White HIV/AIDS Program funded or other), before Ryan White HIV/AIDS Program services are provided free for the remainder of the year. The legislation makes subgrantees or providers of services responsible for tracking not only the charges in their program or clinic, but also the charges made outside their program or clinic, such as hospital or pharmacy charges.

C. Program Income

Program Income: Ryan White HIV/AIDS Program legislation requires grantees to collect and report program income. The program income is to be returned to the respective Ryan White HIV/AIDS Program and used to provide eligible services to eligible clients. “Program income is gross income—earned by a recipient, sub-recipient, or a contractor under a grant—directly generated by the grant-supported activity or earned as a result of the award. Program income includes, but is not limited to, income from fees for services performed (e.g., direct payment, or reimbursements received from Medicaid, Medicare and third-party insurance); …and income a recipient or sub-recipient earns as the result of a benefit made possible by receipt of a grant or grant funds, e.g., income as a result of drug sales when a recipient is eligible to buy the drugs because it has received a Federal grant.” Direct payments include charges imposed by recipients and sub-recipients for Ryan White Part A services as required under Section 2605(e) of Program legislation, such as enrollment fees, premiums, deductibles, cost sharing, co-payments, coinsurance, or other charges. As specified on the Ryan White Part A notice of grant award (NGA), program income must be “Added to funds committed to the project or program and used to further eligible project or program objectives.”

Grantees are responsible for ensuring that sub-recipients have systems in place to account for program income, and for monitoring to ensure that sub-recipients are tracking and using program income consistent with grant requirements. See the HHS Grants Policy Statement, http://dhhs.gov/asfr/ogapa/grantinformation/hhsgps107.pdf, the Ryan White Part A NGA, and 45 CFR 92.25.

Unobligated Balances and Carryover of Funds

Legislative language in Title XXVI of the PHS Act as amended by the Ryan White HIV/AIDS Treatment Extension Act of 2009 (Public Law 111-87) interrelates the reporting of Unobligated Balances (UOB) with the uses of UOBs. Grantees are required to submit an Estimated Carryover
Request together with the estimated UOB 60 days before the end of the grant year. Failure to submit a timely carryover request and estimated UOB in the EHB portal can result in a grantee being ineligible to receive Ryan White HIV/AIDS program Part A formula carryover funds. Approved carryover funds will not cause an UOB penalty for the next fiscal year.

If a grantee does not request a waiver, and later identifies and reports unobligated Part A formula funds in the Final Federal Financial Report (FFR), the grantee will not be able to carryover any part of its UOB. Once the grantee carryover waiver request is approved by HRSA, the grantee will be able to expend the approved UOB in accordance with the purpose stated in the application. If funds are not expended in the carryover year, the funds will be cancelled and cannot be used in subsequent years.

The Ryan White HIV/AIDS legislation requires a waiver to request carryover of unobligated formula funds before the end of each fiscal year as necessary regardless of the amount of remaining funds. The carryover request must be submitted electronically using the Electronic Handbook application. The request must contain the following information:

- Estimate of the unobligated balance at the end of the grant year.
- Estimated amount of funds projected to be available for carryover including the methodology used for estimating the carryover amount.
- Source of the unexpended carry over funds (administrative, direct service, program support, certain provider categories).
- Proposed use (existing or new service, new priority, one-time use, maintenance of enhanced levels of service, and cost annualization in future years).
- Justification for use of funds (quantification of number of clients, units of service, link/responsiveness of proposed use to identified need).
- Time period proposed for use of funds and ability to use.
- Capacity of the grantee to make funds available for use and of the entities to utilize such funds in the designated time period.
IV. Ch 6. Maintenance of Effort

Introduction

The Ryan White legislation requires Ryan White Part A grantees to maintain, as a Condition of Award, EMA/TGA political subdivision expenditures for Ryan White core medical services and support services at a level equal to the 1-year period preceding the fiscal year (FY) for which the grantee is applying to receive a Ryan White Part A grant. In order to receive a Ryan White Part A award, EMAs/TGAs must comply with maintenance of level requirements, which include: a signed assurance that maintenance of effort has been maintained, a description of a consistent data set of local government expenditures for two previous years, and methodologies for calculating maintenance of effort expenditures.

To demonstrate compliance with this provision, EMAs/TGAs must maintain adequate systems for consistently tracking and reporting on expenditure data for core medical services and support services from year-to-year. Grantees are accountable to ensure that Federal funds do not supplant EMA/TGA spending but instead expand and enrich such activities.

This chapter describes the responsibilities of EMAs/TGAs regarding maintenance of effort:

- What data must be consistently reported year to year.
- What consistency means.
- What methodologies may be used.
- How maintenance of effort will be monitored by HRSA/HAB, Division of Metropolitan HIV/AIDS Programs (DMHAP) and HRSA’s Office of Federal Assistance Management (OFAM), Division of Grants Management Operations.

A. HAB/DMHAP Expectations

Ryan White Part A funds are not intended to be the sole source of support for HIV/AIDS care and treatment services in an EMA/TGA. The maintenance of effort requirement is important in ensuring that Ryan White funds are used to supplement existing local jurisdiction expenditures for these services and to prevent Ryan White Part A funds from being used to offset specific HIV/AIDS care and treatment budget reductions at the local level. The maintenance of effort provision requires grantees to maintain year-to-year HIV-related core medical and support service expenditures by political subdivisions within the eligible area.

Definitions

The following resources establish principles and standards for determining costs applicable to grants, contracts, and other agreements entered into by the types of organizations specified:
<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Consistent</td>
<td>Remaining unchanged. A consistent data set has the same elements listed from year to year, although there may be instances where changing needs result in new data elements replacing older ones.</td>
</tr>
<tr>
<td>Eligible Metropolitan Area / Transitional</td>
<td>The geographic area eligible to receive Ryan White Part A funds. The boundaries of the metropolitan statistical area are defined by the Office of Management and Budget (OMB). Eligibility is defined by the cumulative number of HIV/AIDS cases in the most recent five year period.</td>
</tr>
<tr>
<td>Grant Area</td>
<td></td>
</tr>
<tr>
<td>Core Medical Services and Support Services</td>
<td>Terms are defined in Sections 2604(c)(3) and 2604(d) of Title XXVI of the Public Health Service Act and the HIV/AIDS Bureau (HAB) Ryan White HIV/AIDS Program Annual Data Report.</td>
</tr>
<tr>
<td>In-kind Contributions</td>
<td>Non-cash contributions that an EMA/TGA or State may provide to support HIV-related activities. These non-cash contributions must be fairly valued and may include plant (offices), equipment, or services.</td>
</tr>
<tr>
<td>Political Subdivision</td>
<td>For Ryan White Part A, the components defined by OMB as Census Bureau areas, comprising the cities and counties of the EMA/TGA.</td>
</tr>
</tbody>
</table>

Table 2: HAB/DMHAP Expectations Definitions

C. Determining the Elements that Constitute Maintenance of Effort

The elements, or items, that grantees use to document maintenance of effort compliance are defined in the legislation as core medical services and support services. Grantees are directed to include core medical services and support services for which a line item can be identified in the budgets and subsequent expenditure reports of the cities and/or counties of the EMA/TGA. The fiscal year for reporting is the same as that of the political subdivision.

Grantees may determine which expenditures are of a nonrecurring nature and are therefore excluded from the maintenance of effort calculations. An example of a nonrecurring expenditure is a one-time infusion of funds into a political subdivision program on an emergency basis, where the appropriations or other authorizing language clearly identifies it as a one-time-only commitment.

Core medical services and support services to be counted, including cash and in-kind, must be allowable under the applicable cost principles (OMB Circular A-87, Cost Principles for State, Local, and Indian Tribal Governments). Such costs are subject to audit for purposes of establishing compliance with the maintenance of effort requirement.

D. Ryan White Part A Grantee Documentation Requirements

The Secretary of Health and Human Services may not make a grant under Ryan White Part A unless the EMA/TGA demonstrates compliance with maintenance of effort requirements. In every grant application, EMAs/TGAs must document that the maintenance of effort requirement has been met. This documentation consists of a signed assurance in the Ryan White Part A grant application. In addition, EMAs/TGAs must report on and have in place a system to track and document local government expenditures for core medical services and support services. This
means the grantee for the EMA/TGA must obtain written information from the political subdivisions. For example, the grantee must provide maintenance of effort information (amount and methodologies) in the Ryan White Part A grant application from the city or county governments and government agencies represented in the EMA/TGA. If the political subdivisions contacted refuse to comply with the request for expenditure information, the grantee should inform them of the negative consequences for Ryan White Part A funding and contact HAB/DMHAP for further guidance.

Compliance with the maintenance of effort requirements means that EMAs/TGAs must develop and maintain a written, auditable system that is, adequate to document compliance. For documentation purposes, all communication between the EMAs/TGAs and their political subdivisions regarding maintenance of effort must be in writing.

When working with their local political subdivisions, Ryan White Part A grantees may start by presenting them with HRSA/HAB’s definitions of core medical services and support services for use by these entities in identifying relevant categorical budget line items, and subsequent expenditure line items. EMAs/TGAs should be able to understand the written explanations of methodologies used by each entity. For consistency, each EMA/TGA is expected to calculate and report expenditures for the same items from year to year. If a change is made, the entity must explain the change in writing to the grantee. In its documentation, grantees must explain to HAB/DMHAP why a change occurred. An example of the kind of fundamental change in HIV/AIDS funding that should be accommodated is elimination of State funding for a category of service and the initiation of local funding or significant enhancement of such funding for another category.

Consistency does not mean that each EMA/TGA or city government agency must use the same methodology, but rather that an overall calculation for an EMA/TGA must be arrived at in a consistent manner over time. There is wide latitude in the types of methodologies that may be used, and still greater latitude in the locally defined element of the maintenance base. There is no HAB/DMHAP expectation or requirement that complicated mathematical exercises be undertaken, for example, to quantify the portion of a public hospital’s non-specific inpatient expenses. To ensure year-to-year comparability, it is important that the EMA/TGA should work with the information it has, develop a written procedure for internal use in preparing an annual expenditure report, and maintain records of the numbers reported.

Requirements are that:

- Each political subdivision or city government agency explains its methodologies to the grantee.
- A clear, written paper trail documents the methodologies and definitions.
- A reasonable attempt to determine core medical services and support services expenditures by the political subdivisions or city government agencies is demonstrated by the EMA/TGA.
E. EMA/TGA Documentation Guidance to Political Subdivisions

The EMA/TGA should provide written guidance to their Ryan White Part A political subdivisions and city government agencies that:

- Expenditures, not budgeted or appropriated amounts, should be reported.
- The political subdivisions or city government agencies should report on core medical services and support services as defined by HRSA/HAB.
- Expenditure data and the explanation of the methodology used must be reported in writing.

A timeline for reporting expenditures should be provided that accommodates both the entities’ accounting systems and the EMA’s/TGA’s schedule for submission of reports to HAB/DMHAP.

EMAs/TGAs should review and attempt to clarify any questionable data or omission of data submitted by political subdivisions or city government agencies before that information is reported to HAB/DMHAP.

In their grant applications, EMAs/TGAs are required to:

- Describe the methodology used for compiling core medical services and support services data from local accounting systems.
- Report their core medical services and support services expenditures funded locally using a consistent data set.
- Explain any changes in the data set derived from changes in the purposes of core medical services and support services expenditures.
- Document that the overall level of expenditures for core medical services and support services has been maintained year to year for the previous two complete fiscal years.

EMA/TGA commitments to HIV/AIDS services may cover a wide range of services and also vary considerably. The purposes to which EMAs/TGAs allocate resources may also change over time because of changes in the epidemic and the clinical management and service needs of those who are infected. Therefore, significant changes in the components of expenditures must be explained with documentation that the overall level of such expenditures has been maintained year to year.

F. Monitoring and Compliance

HAB/DMHAP will work with EMAs/TGAs so that proper documentation of maintenance of effort is submitted. If an EMA/TGA cannot comply with the maintenance of effort requirements, the Ryan White Part A grant must be withheld until documentation that the requirement is met is received by the HRSA Office of Federal Assistance Management (OFAM), Division of Grants Management Operations, Grants Management Officer.
IV. Ch 7. References, Links, and Resources

HHS.gov, Regulations: http://www.hhs.gov/regulations/index.html

National Monitoring Standards: https://careacttarget.org/category/topics/program-monitoring


ADAP Manual 2012: https://careacttarget.org/content/adap-manual

Section V: Grantee and Subgrantee Monitoring

V. Ch 1. Overview

Monitoring is a HRSA requirement that applies to any project program sub-award, function or activity supported by the Ryan White Part A award (formula, supplemental, and Minority AIDS Initiative (MAI)). Therefore, monitoring applies to grantees, subgrantees of the EMA/TGA, fiscal agencies, fiduciaries and/or subgrantees. Monitoring includes both program monitoring and fiscal monitoring but is not limited to the need for: 1) performance Reports, 2) comparison of projected goals and objectives with actual outcomes, 3) evaluation of funded activities, and 4) site visits.

V. Ch 2. Legislative Background

Section 2604(h) of Title XXVI of the PHS Act as amended by the Ryan White HIV/AIDS Treatment Extension Act of 2009 (Public Law 111-87), describes grantee and subgrantee monitoring and related activity as an administrative activity as follows:

“(h) Administration-
(1) LIMITATION- The chief elected official of an eligible area shall not use in excess of 10 percent of amounts received under a grant under this subpart for administrative expenses.
(2) ALLOCATIONS BY CHIEF ELECTED OFFICIAL- In the case of entities and subcontractors to which the chief elected official of an eligible area allocates amounts received by the official under a grant under this subpart, the official shall ensure that, of the aggregate amount so allocated, the total of the expenditures by such entities for administrative expenses does not exceed 10 percent (without regard to whether particular entities expend more than 10 percent for such expenses).
(3) ADMINISTRATIVE ACTIVITIES- For purposes of paragraph (1), amounts may be used for administrative activities that include--
(A) routine grant administration and monitoring activities, including the development of applications for Ryan White Part A funds, the receipt and disbursement of program funds, the development and establishment of reimbursement and accounting systems, the development of a clinical quality management program as described in paragraph (5), the preparation of routine programmatic and financial reports, and compliance with grant conditions and audit requirements; and
(B) all activities associated with the grantee’s contract award procedures, including the activities carried out by the HIV health services planning council as established under section 2602(b), the development of requests for proposals, contract proposal review activities, negotiation and awarding of contracts, monitoring of contracts through telephone consultation, written documentation or onsite visits, reporting on contracts, and funding reallocation activities.
(4) SUBCONTRACTOR ADMINISTRATIVE ACTIVITIES- For the purposes of this subsection, subcontractor administrative activities include--
(A) usual and recognized overhead activities, including established indirect rates for agencies;
(B) management oversight of specific programs funded under this title; and
(C) other types of program support such as quality assurance, quality control, and related
activities.”

The Code of Federal Regulations, 74 C.F.R. 74.51(a) and 2 C.F.R. 215.51(a) state that
“[r]ecipients are responsible for managing and monitoring each project, program, sub-award,
function, or activity supported by the award.” Under 2 C.F.R. 215.51, monitoring generally
includes a need for:

- Performance reports
- Comparison of actual accomplishments with goals and objectives
- Analysis and explanation of cost overruns,
- Notification to the Federal awarding agency of developments that have a significant
  impact on the award supported activities
- Site visits

V. Ch 3. Ryan White Part A National Monitoring Standards

grantees were developed by HRSA/HAB in response to several Office of Inspector General
(OIG) and Government Accountability Office (GAO) reports. The reports identified a need for
HRSA/HAB to provide clear guidance to grantees regarding monitoring expectations of
subgrantees and grantees. The Standards consolidate existing HRSA/HAB requirements for
program and fiscal management and oversight based on Federal law, regulations, policies, and
guidance documents including:

1. Title XXVI of the Public Health Service Act, 42 U.S.C. 300ff-11, Sections 2611-23 (as
   amended by Ryan White HIV/AIDS Treatment Extension Act of 2009 (Public Law 111-
   87).
4. Department of Health and Human Services (HHS), and Public Health Service grantees
   management policies.
5. HRSA/HAB policy notices, letters and guidelines.
7. Notices of Grant Award and Conditions of Award.
9. Manuals and Guides issued by HRSA/HAB.

The Standards are part of the terms of the Notice of Award and Ryan White Part A grantees are
expected to comply with the Ryan White Part A Fiscal and Program Standards as well as the
Universal standards (applies to both Parts A and B). Grantees are required to meet specific
requirements regarding the monitoring of both their grant and their provider/subgrantees as
detailed in the National Monitoring Standards for Ryan White Grantees. The National
Monitoring Standards can be accessed at the following link:
V. Ch 4. Monitoring Program

A. Monitoring Grantees

HRSA is responsible for overseeing the Ryan White Part A programs and conducting routine monitoring of grantees’ performance and compliance with statutory requirements, regulations, and guidance. Routine monitoring of grantees includes regularly scheduled monthly monitoring calls, reviews of grantee reports, and the provision of technical assistance to grantees.

The monitoring of grantees is based upon OMB circulars and the Code of Federal Regulations (CFR) as well as Ryan White HIV/AIDS Program legislation and policy guidance. The Grantee and subgrantee assessments include adherence with PHS treatment guidelines, the extent to which grantees are providing coordinated systems of care, and adherence with programmatic and fiscal requirements.

The monitoring of grantees includes the provision of technical assistance assessments which may be requested by project officers or by grantees. Technical assistance can be provided using a range of modalities, including on-site visit, tool and resource development, telephone consultation, and webinar. If a grantee does not correct legislative and programmatic non-compliance findings in a timely manner, and does not request technical assistance to correct such deficiencies, more intensive monitoring will result. This can include a “conditions of award,” which is a way of repeating obligations set forth in the original monitoring report. The conditions include a clear statement of the obligations that are not being met and a timetable for making a correction.

B. Monitoring Subgrantees

The grantee retains ultimate accountability to HRSA for all contracts awarded through its Ryan White Part A Program. For example, in the case of an OIG visit that results in repayment of Federal dollars, the EMA/TGA, not the subgrantee, is responsible for repaying the debt out of non-Federal dollars. Grantees should use the monitoring process to reinforce and underscore mutual obligations between funder and provider. The grantee should designate a person or team to review fiscal and program reports, conduct site visits, interact on an ongoing basis with contracted providers, and implement remedial steps or corrective action plans if necessary. A grantee may distribute monitoring functions across its organization. For example, fiscal
monitoring activities are frequently handled by a different person, team, or even division within a health department than program monitoring activities.

The grantee should have a process to monitor subgrantees as well as assure that administrative agents have in place a process to monitor their sub grantees that includes annual site visits. Grantees should require administrative agents to submit annually their subgrantees A-133 audits, sub grantee monitoring reports and/or corrective action plans. When problems with a sub-contractor become apparent, grantees or administrative agents must undertake some form of corrective action. Grantee or administrative agents generally releases a report of the findings or areas of improvement.

Grantees should have in place a corrective action process that provides the subgrantee with a number of mechanisms to resolve any compliance issues. This should include but not be limited to technical assistance. If informal efforts fail and formal mechanisms are necessary, a graduated problem-solving approach should be used before termination of the contract is necessary.

Creating and operating a monitoring program requires understanding of the following:

1. How program and fiscal monitoring activities as stated in the standards differ from evaluation or auditing.

   Single audits (A-133 audits) are performed by independent auditors in accordance with Government Auditing Standards (GAS) who submit an opinion on the agency’s financial statements based on samples and on compliance with major Federal programs. Evaluation focuses on documentation of program accomplishments and outcomes. Monitoring activities differ from both in that the activities review and test compliance with applicable laws, regulations, assesses efficiency of operations, and effectiveness in achieving program results. If warranted, the monitoring process makes recommendations to enhance agency operations, promote economy, efficiency and compliance with Federal and programmatic requirements.

2. What to have in place before a monitoring program begins.

   A monitoring manual can assist in providing a standardized and transparent process for in-house processes such as desk compliance audits, analysis of performance reports, scope of work and other required program and fiscal reports. In addition, the manual should describe and outline the process to be followed prior, during and after a monitoring site visit.

   There should be two sets of site visit tools: one that measures fiscal standards, and the other that measures program requirements, including standards of care, and universal standards.
Standards and supporting materials should be shared with program and fiscal staff that have monitoring responsibilities. Staff should review the Standards and help plan for implementation and compliance.

There should be opportunities to sit down with staff to review current monitoring systems, procedures, and tools to see where the Standards are already being met and where changes are needed.

There should be meetings with providers/subgrantees to introduce the Standards and clarify compliance issues. The frequency for training subgrantees regarding eligibility or any other compliance issue is at the discretion of the grantee.

3. Key staff, skills, and their roles

Fiscal desk audits are performed by the staff position that approves sub-contractors’ invoices. The Quality staff usually assesses the services provided, including the impact on consumer satisfaction. The Program staff appraises compliance with the scope of work.

4. Development of tools for corrective measures when providers fail to meet standards.

A corrective action plan should be developed that identifies the areas of non-compliance and allows sub-contractors to provide a time-sensitive corrective action plan that outlines the corrective actions to be taken when subgrantee outcomes do not meet program objectives and grantee expectations. These may include:

- Improved oversight.
- Redistribution of funds.
- A “corrective action” letter.
- Sponsored technical assistance.

Further, the grantee must follow through to ensure completion of the goals of the corrective action plan. (Standard 3; Section E, Universal Monitoring Standards)

See: Universal Monitoring Standards: Ryan White Part A & B (PDF - 117 KB)

C. Site Visits

1. Grantee

Site visits are key component of HRSA/HAB oversight to verify: 1) compliance with Ryan White legislative requirements, 2) compliance with Ryan White Part A Program requirements, 3) the provision of high quality HIV clinic care and compliance with HHS guidelines, and 4) administrative and fiscal integrity resulting in a technical assistance plan that addresses program deficiencies and brings a program into compliance.
HRSA has implemented a risk based strategy for selecting grantees for site visits. The strategy includes but is not limited to:

- Comprehensive Site visits on a periodic basis—at least once every 5 years.
- An initial site visit for newly awarded grantees.
- Low score on recent competitive application or poor non-competing applications.
- Habitual and problematic grantee staff turnover.
- Problematic spend-down patterns (PMS requests) and/or multiple years with unobligated balances.
- Consistently failing to meet work plan objectives.

2. Subgrantee

The awarding agency, HHS, prescribes the frequency of the monitoring activities. The monitoring standards for Ryan White Part A grantees describe the frequency of site visits to subgrantees as annually. The standards require an annual comprehensive monitoring site visit as delineated in Section I.E. of the Part A and B Universal Standards. The visit must test compliance with Fiscal, Programmatic, and Universal Standards. The Monitoring Standards require as a minimum an annual visit to all providers. The usefulness of desk audits and any timelines for their use are determined by the grantee. Desk audits may not be used as a substitute for comprehensive annual site visits.

There is a site visit waiver process via EHB Prior Approval Portal. For the waiver request, using the EHB portal, the grantee must submit a letter that describes:

- Barriers and challenges binding the program from conducting annual visits.
- Frequency and/or schedule of site visits the program can conduct.
- Site visit protocol (if available, send as attachment).
- A monitoring plan for the years the visits will not be conducted.
- Process for corrective action plans.
- Number of staff participating on the site visit team.
- The number of providers/subgrantees that the Ryan White Part A grantee funds.

Within 30 days of the date of receipt of the request, the HAB Project Officer reviews the exemption request to ensure it includes all required information. If the request is missing information, the Project Officer will submit a change request in EHB requesting additional information. The Division Director/Deputy Director review the exemption request and will have 30 days from date of receipt from the Project Officer for approval or denial of exemption.

If the exemption request is approved by the Division Director/Deputy Director, the Project Officer will notify the grantee via EHB. If the exemption request is denied, the Project Officer will notify the grantee via EHB and detail the reasons for the denial. If the initial request is denied, the grantee may modify the request by addressing the reasons provided by HRSA/HAB. HRSA/HAB will follow the process outlined above when considering the resubmitted request.
Once an annual site visit exemption request approval has been provided to the grantee, the HAB Project Officer will monitor adherence to the revised site visit timeline during monthly monitoring calls and comprehensive site visits. Grantees will also provide updates on site visit monitoring activities when responding to future Funding Opportunity Announcements (FOA).

When structuring a monitoring program, grantees that are also service providers must be careful to avoid conflicts of interest. Contracted providers have an inherent conflict of interest when they are involved in monitoring their own contracts or services. For example, a health department that is the administrator of the Ryan White Part A funds and the provider of Ryan White Part A core and support services. A grantee may decide to share some of its monitoring responsibilities with a local agency such as a fiduciary.

When establishing a site visit monitoring process, grantees should ensure from the beginning that subgrantee/contractors understand the monitoring process. Thus, the grantee may want to outline the process as follows:

- Site Visit Review Team plans a calendar of visits.
- Conference calls with subgrantees/contractors to verify visit dates, draft an agenda, and explain the process once on site.
- Site visit tools and documentation are explained.
- Visit should start with an entrance conference (opportunity to explain visit and subgrantee/contractor has an opportunity to present its program).
- Visit should end with an Exit Meeting where the monitoring teams get an opportunity to discuss the areas of non-compliance and the proposed recommendations with agency staff.

The grantee should develop fiscal and program site visit monitoring tools to use to ensure that contractual obligation is reviewed in sufficient detail. A site visit might include staff interviews, observation of services, client records or chart reviews, a facility tour, and a review of documentation and testing relating to the following compliance aspects of sub-contractor operations.

There is no expectation that all client records must be reviewed. A random sampling methodology should be established as part of the monitoring protocols. The sample size is not specified in the standards, because it depends on the size of the client population being sampled and on the number and complexity of the variables you are reviewing. For a client population of 50 or less, the norm is to review 100% of folders; 50% or less is acceptable for a population of 51 to 100. The percent to be sampled gets smaller as the population gets larger – from 10% for a client population of 500 or more to 3 to 5% for a client population of 1000 or more.

V. Ch 5. References, Links, and Resources

1. National Monitoring Standards:
   - Fiscal Monitoring Standards: Ryan White Part A (PDF - 492 KB) & Part B (PDF - 301 KB)
- Program Monitoring Standards: [Ryan White Part A](PDF - 428 KB) & [Part B](PDF - 492 KB)
- Universal Monitoring Standards: [Ryan White Part A & B](PDF - 117 KB)
- [Frequently Asked Questions](FAQs) (PDF - 161 KB)


**For More Information**

Please refer to the HAB Target Center at [https://careacttarget.org](https://careacttarget.org).
Section VI: Data and Reporting Requirements

VI. Ch 1. Overview

A. Introduction and Legislative Background

HRSA/HAB’s Division of Metropolitan HIV/AIDS Programs (DMHAP) provides grantees with instructions and formats for Grantee Reporting Requirements each year. The annual application guidance also provides specific information for reporting requirements as does the notice of award. The HRSA/HAB/DMHAP is designated to receive Ryan White HIV/AIDS Program Ryan White Part A reports from grantees. Grantees must provide progress and data reports in accordance with applicable provisions of 45 CFR Part 92 and the terms and conditions of award.

In general, reports are required for one or more of the following reasons:

1) To assure grantee compliance with the Conditions of Award a set criteria or limits on how grant funds may be used.

2) To monitor the fiscal and programmatic integrity of the grant program, as required by Public Health Service (PHS) Grants Management Policy.

3) To monitor program accomplishments, prepare HRSA reports on program trends, and respond to information requests from Congress, Office of Management and Budget (OMB), the media, and the public at large.

VI. Ch 2. Required Program and Fiscal Reports

A. Introduction

Grantees are required as a Condition of Award to provide certain program and fiscal reports each year. Below is a brief description of each report including the report’s purpose, and reporting deadline. During the grant year, HAB distributes detailed instructions on how to prepare and submit each individual report or report package, using both standard forms and suggested reporting formats. All reports are submitted through the HRSA Electronic Handbook (EHB).

B. Program and Fiscal Reports

1. Program Terms Report (Due 90 days following final award issue date) is an aggregate report that all grantees are required to submit as a requirement of their grant award. It combines all program term requirements into one report and includes the following:
a. **Ryan White Part A and MAI Planned Allocations Table and Planning Council (PC) Chair(s) Endorsement Letter** – this table reports the priority areas established by the Planning Council and the dollar amount of Ryan White Part A and MAI funds allocated to each prioritized core medical and support services categories. The letter from the PC chair(s) indicates their endorsement of the allocations and program priorities.

b. **Planning Council Membership Roster and Reflectiveness Report** – reports the number of PC members as required in the By-Laws and includes the mandated membership category, name, agency affiliation, and term of office. Included with the roster is a report on the reflectiveness of the PC based on the prevalence of HIV disease in the EMA/TGA as reported in the most recent grant application.

c. **Revised SF-424 and Budget Narrative/Justification** is a revision of the planned Ryan White Part A budget submitted by the grantee with the grant application based on the actual grant amount awarded to the grantee. The SF-424 budget forms can be found at http://www.hhs.gov/forms/phs-5161.doc. Instructions specific to Ryan White Part A program content can be found later in this section.

d. **Implementation Plan** is an annual plan that describes the planning council’s service priorities and funding allocations for each prioritized service category. Additionally, the Implementation Plan describes goals, objectives and outcomes developed to support achievement of the Comprehensive Plan’s goals and objectives. All services identified in this plan must be consistent with the Ryan White Part A and MAI planned allocations report.

e. **Consolidated List of Contractors (CLC)** identifies each Ryan White Part A funded contract provider, the contract amount, and the service/activity to be provided under that contract. This summary information helps HRSA monitor and track the use of grant funds for compliance with program and grants policies and requirements.

f. **Contract Review Certification** requires Grantees to certify that all Ryan White Part A and MAI direct service contracts have been executed in compliance with all applicable policies and regulations, for example procurement. It also certifies that all budget costs in the contracts are allowable according to applicable OMB circulars.

2. **Annual Progress Report** is made up of seven components. Each component reports on various aspects of the EMA/TGA Ryan White Part A program’s progress in meeting program goals as well as other program requirements. Instructions for completing and submitting the Report are distributed each year by the HAB/DMHAP. Following are brief descriptions of each of the reports components.

a. **Final Program Implementation Plan, including the Local Pharmacy Assistance Profile** is an updated version of the previously submitted Implementation Plan that shows actual expenditures and service utilization for the grant budget period (March 1 through February 28). It also includes reporting on end of year outcomes. The Local Pharmacy Assistance Profile form is completed by EMAs/TGAs that allocated funds during the grant year for medications distributed through a Local Pharmacy Assistance program.
b. **Planning Council Activities** is a narrative report on planning council accomplishments and challenges related to implementation of legislative requirements and efforts to address unmet need.

c. **Early Identification of Individuals with HIV/AIDS (EIIHA) Update** is a data report on the outcome of implementing the EMA/TGA EIIHA strategy and plan.

d. **Administration Final Expenditures** compares the approved Administrative budget by object class categories (e.g. personnel/fringe, travel, equipment, supplies, etc.) with actual expenditures.

e. **Technical Assistance** is a narrative report describing the outcome of any HRSA sponsored technical assistance received by the EMA/TGA during the report period. It also identifies any technical assistance needed that would help address challenges identified in the Final Program Implementation Plan and Planning Council Activities report.

f. **Certification of Aggregate Administrative Costs** is required to verify that the actual amount of funds expended on administrative costs by “first-line” entities did not exceed 10% in the aggregate of the amount of funds available for HIV-related services. The certification must state the total amount of funds expended for HIV-related services by contractors and the dollar amount, in the aggregate, actually expended on their associated administrative costs. The aggregate administrative cost amount is calculated by subtracting the grantee’s administrative costs (up to 10%), and the grantees quality management costs (up to 5% or $3,000,000 whichever is less) from the total grant amount and multiplying the remainder by 10%. The Financial Officer responsible for the Ryan White funds must sign the certification.

g. **WICY Expenditures Report** is based on Title XXVI of the Public Health Service Act, as amended by the Ryan White HIV/AIDS Treatment Modernization Extension Act of 2009. The legislation requires Ryan White Part A to use a proportionate amount of their grant dollars to provide services to women, infants, children and youth (WICY) living with HIV/AIDS. Each year, updated WICY data needed to prepare the EMA/TGA’s report of WICY expenditures is provided separately. For further guidance on preparing your report, also use the Guidelines for Implementing the Minimum Expenditure Requirement to Provide Services to Women, Infants, Children and Youth (WICY) Guidelines. These guidelines were prepared by HAB to assist Ryan White Part A grantees with continued implementation of the WICY requirement and the preparation of their required annual WICY Reports. Grantees may use the Ryan White Part A FY 2013 WICY Report template provided.

3. **Ryan White Part A and MAI Final Expenditure Table** reports on end of grant year Ryan White Part A and MAI expenditures by service category.

4. **MAI Annual Report** documents how Ryan White Part A MAI funds were used during the grant year, the number and demographics of clients served and outcomes that were achieved.
5. **Part A MAI Annual Plan** is prepared for the current grant year and describes how the EMA/TGA will use the funds. It also reports on the estimated number of unduplicated clients expected to receive funded services, client demographics, and anticipated outcomes. HAB distributes detailed reporting instructions each year.

6. **Final Federal Financial Report (FFR)**, is an annual financial report, SF-425, that is due no later than 90 days after the end of the grant period. The report indicates how much money has been drawn down through the Payment Management System (PMS), what funds were expended, and the remaining balance left at the end of the reporting period. The report must also include program income collected during the budget period. The report, available in the EHB, requires the grantee to report the cumulative expenses within the budget period. The cumulative expenses must not include unliquidated obligations and must agree with the PMS report of disbursements and advances for the budget period being reported. If the grantee has an unobligated balance, it must do one of the following:
   
   a. Submit a completed carryover request through the EHB Prior Approval module, even if the request is attached with the submission of the FFR.
   b. Indicate on the FFR their intent to submit a carryover request separately, and submit the request via the Prior Approval module, within 30 days of the FFR submission.
   c. Indicate on the FFR their intention to not submit any carryover request.

7. **Unobligated Balance (UOB) Estimate and Carryover Waiver** is a report on the estimated amount of Ryan White Part A formula grant funds the EMA/TGA anticipates will be unobligated at the end of the grant budget year and a written waive/request to carryover any unobligated Ryan White Part A formula funds. This UOB Estimate and carryover waiver/request must be submitted by December 31 of each year. **There are statutory penalties specific to UOB that exceeds five percent of the Formula award.** For detailed information on the UOB Estimate and Carryover Waiver see HAB Policy Notice 12-02 – *Ryan White Part A and Part B Unobligated Balances and Carryover Provisions*: [http://hab.hrsa.gov/manageyourgrant/pinspals/habpartauobpolicypdf.pdf](http://hab.hrsa.gov/manageyourgrant/pinspals/habpartauobpolicypdf.pdf).

8. **Ryan White Services Report (RSR)** is a data reporting system for Ryan White Program grantees and service providers to report information on their programs and the clients they serve to HAB. The Report is submitted annually and is comprised of three components, which are described below.
   
   a. **The Grantee Report.** Grantees will complete this report online through the HRSA Electronic Handbooks (EHBs) using a web-based data entry system. Besides providing basic information about their organization, they will view, update, and verify a pre-filled list of their service provider contracts that were active in the most recent reporting period. For each of the contracts, grantees will view a list of Ryan White Program services and then check the boxes next to all services that their organization funded under the contract.
   
   b. **The Service Provider Report.** Service providers will complete this report online. In addition to providing some basic information about their organization,
providers will view a pre-filled list of their active service provider contracts for the most recent reporting period. For each of the service contracts, providers will view a list of Ryan White Program services and check the boxes next to all services that their organization delivered to RW Program clients during the reporting period.

c. **The Client Report.** Each service provider will submit this report online as an electronic file upload using a standard format. Each upload file will contain one record per client. Each client record will include information on demographic status, HIV clinical information, HIV-care medical and support services received, and the client’s ‘UCI’, an encrypted, unique client identifier. More information on the RSR can be found at the following links:

http://hab.hrsa.gov/manageyourgrant/clientleveldata.html

https://www.careacttarget.org/category/topics/ryan-white-services-report-rsr.

9. **Comprehensive Plan** is a Ryan White Program reporting requirement. The DMHAP requires Ryan White Part A grantees to submit an updated Comprehensive Plan every three years. The purpose of this multi-year plan is to assist grantees and planning councils in the development of a comprehensive and responsive system of care that addresses needs and challenges as they change over time. The Comprehensive Plan is a **living document** that serves as a roadmap for the grantees and planning councils and should be continually updated as needed. The Comprehensive Plan should also reflect the community’s vision and values regarding how best to deliver HIV/AIDS services, particularly in the light of the cutbacks in Federal, State and local resources. The DMHAP provides detailed instructions for preparing the Comprehensive Plan. For more information on the Comprehensive Plan, see Section XII of this Manual.

VI. Ch 3. Submission of Reports

In an effort to increase the efficiency and effective of its management of grantee records, HRSA has developed an electronic record keeping system. The HRSA Electronic Handbooks (EHB) system provides a one-stop, grants management online tool for project officers as well as grantees by making Funding Opportunity Announcements (FOA), grant applications, notices of award (NOA), non-competing continuation applications, progress reports and other types of post-award reports accessible online. The EHB allows grantees and project officers to view award history, view past NOAs, monitor report activity as well as deadlines, and access reports such as the Ryan White Program Services Reports (RSR).

Any information and data required from the grantee, such as applications, draw down restriction requests, reports, and waivers, must be submitted using the format provided by HRSA, as outlined in the EHB. The HRSA EHB reporting formats help to assure that correct information is reported across all Ryan White HIV/AIDS program grantees. This, in turn, allows HRSA to track and report national program trends, identify technical assistance needs, and prepare aggregate summary reports for Congress, grantees, and the public at large.
The Project Director of the grant (listed on the NOA) and the Authorizing Official of the grantee organization are required to register within HRSA’s Electronic Handbooks (EHBs). Information on EHB registration as well as general information on use of the EHBs portal can be accessed at the following link:

VI. Ch 4. Reporting Deadlines
In establishing the deadline for a report, HRSA/HAB takes into consideration the following:

- Purpose of the report.
- Grant program’s fiscal year.
- Application/award process and schedule.
- Any mandated timeframes for reporting specific information to the Congress or OMB.
- Program monitoring and reporting standards set by PHS Grants Management Policy.
- Feedback from grantees on reporting issues specific to the program.

For the precise deadline date, refer to the Condition of Award and/or the EHB dateline instructions issued each year by HRSA/HAB. To meet the deadline, the information must be in the EHB on the due date. Grantees are expected to comply with all reporting deadlines. Once the deadline date passes, the EHB will close submission access and the grantee must request the Project Officer or Grants Manager to open the file. If late reporting persists, special Terms and Conditions may be imposed on the grantee until the problem of late reporting has been corrected.

For access to the EHB system go to: https://grants.hrsa.gov/webexternal/login.asp

Additional help is available from the HRSA Call center at:
- Phone: 877-Go4-HRSA/877-464-4772
- Time: 9:00 a.m. to 5:30 p.m. Eastern Time
- Day: Monday through Friday
- Email: CallCenter@HRSA.GOV

VI. Ch 5. References, Links, and Resources

1. Ryan White CAREWare: http://hab.hrsa.gov/manageyourgrant/careware.html
4. Information and instructions on the SF-424 budget forms can be found at http://www.grants.gov/assets/InstructionsSF424A.pdf

For More Information

Please refer to the HAB Target Center at https://careacttarget.org.
Section VII. Clinical Quality Management

VII. Ch 1. Overview

The Department of Health and Human Services (HHS) released the National Quality Strategy in March 2011 and put forth 3 broad aims to “guide and assess local, State and national efforts to improve the quality of health care.” The aims are (1) Better Care, (2) Healthy People / Healthy Communities, and (3) Affordable Care. The National Quality Strategy provides a roadmap requiring continuous advancement of measurement and initiatives with a collaborative stakeholder process.

As part of HHS, HRSA/HAB defines quality as “the degree to which a health or social service meets or exceeds established professional standards and user expectations.” In order to continuously improve systems of care, evaluations of the quality of care should consider the service delivery process, quality of personnel and resources available, and the outcomes. The overall purpose of a quality management program is to ensure that:

- Services adhere to HIV/AIDS treatment guidelines and established clinical practice.
- Develop strategies for improvement of services provided, including clinical services and supportive services.
- Demographic, clinical and utilization data are used to evaluate and address characteristics of the local epidemic and quality of care.
- Appropriate leaders and stakeholders are included throughout the quality improvement process.
- Continuous processes to improve quality of care are in motion.

Quality management is a systematic, structured, and continuous approach to meet or exceed established professional standards and user expectations. Quality management is implemented by using tools and techniques to measure performance and improve processes through three main components: quality infrastructure, performance measurement and quality improvement.

Quality infrastructure is the structure and supports that allow the organization to measure performance and improve processes. Quality infrastructure components include leadership, quality improvement teams, quality related training/capacity building, and a written quality management plan. It is often difficult to sustain a success quality management program if the infrastructure components are missing or weak.

When most people think about quality management, performance measurement and quality improvement come to mind. Performance measurement is the routine collection and analysis of data. The analysis is completed by defining the data elements used to calculate the numerator and denominator. Performance measures must be based on established professional standards and/or evidenced based research, when possible. An example of a performance measure is viral load suppression. HAB has developed, released, and refined performance measures for use by Ryan White Program grantees. HAB performance measures were developed using professional standards such as the Department of Health and Human Services HIV Clinical Guidelines including *Guidelines for the Use of Antiretroviral Agents in HIV-1-Infected Adults and*
Quality improvement is a method that uses the tools of quality in an effective, logical and systematic process to solve problems, improve efficiency and eliminate non-value adding steps in the work flow. The most common quality improvement method is the Plan-Do-Study-Act or PSDA.

It is important to conduct performance measurement and quality improvement activities in balance. That is to say that you do not want to do one without the other and you want to implement equally amounts of each. You would not want to develop and implement a quality improvement project without regularly measuring performance to see if the project is having an impact.

VII. Ch 2. Legislative Background

Clinical Quality Management

Clinical Quality Management activities and costs are covered under administration costs and activities are defined in Section 2604(h)(3) and (5):

“(3) ADMINISTRATIVE ACTIVITIES- For purposes of paragraph (1), amounts may be used for administrative activities that include--
(A) routine grant administration and monitoring activities, including the development of applications for part A funds, the receipt and disbursal of program funds, the development and establishment of reimbursement and accounting systems, the development of a clinical quality management program as described in paragraph (5), the preparation of routine programmatic and financial reports, and compliance with grant conditions and audit requirements;”

Section 2604(h)(5)(A) of Title XXVI of the PHS Act as amended by the Ryan White HIV/AIDS Treatment Extension Act of 2009 requires that “…the Chief Elected Official of an eligible area that receives a grant under this subpart shall provide for the establishment of a clinical quality management program to assess the extent to which HIV health services provided to patients under the grant are consistent with the most recent Public Health Service guidelines for the treatment of HIV/AIDS and related opportunistic infection, and as applicable, to develop strategies for ensuring that such services are consistent with the guidelines for improvement in the access to and quality of HIV health services.”

Additional language under Section 2604(h)(5) administrative expenses sets limits on the amounts to be expended as follows:
“(B) USE OF FUNDS-
(i) IN GENERAL- From amounts received under a grant awarded under this subpart for a fiscal year, the chief elected official of an eligible area may use for activities associated with the clinical quality management program required in subparagraph (A) not to exceed the lesser of--
(I) 5 percent of amounts received under the grant; or
(II) $3,000,000.
(ii) RELATION TO LIMITATION ON ADMINISTRATIVE EXPENSES- The costs of a clinical quality management program under subparagraph (A) may not be considered administrative expenses for purposes of the limitation established in paragraph (1).”

VII. Ch 3. HAB Program Expectations

The Ryan White Program places major emphasis on enhancing the quality of care for PLWHA. The complexity of HIV care and the Program’s commitment to equal access to quality care for all HIV-positive individuals require systematic efforts to ensure that the Ryan White Program services are delivered effectively.

It is important to remember that the Ryan White legislative requirements for clinical quality management apply to both the clinical and support services funded and subgrantees.

In 2011, HAB released the *Ryan White HIV/AIDS Program Part A and B Monitoring Standards*. In the *Part A Program Monitoring Standards*, Section D is entitled *Quality Management* the Ryan White legislative requirement for clinical quality management (as mentioned above). The legislative requirements are referred to as the “standard” in the Monitoring Standards. The “performance measure” identifies what one would look for in order to understand if the grantee was meeting the “standard.” The “responsibility” states what the grantee and provider/subgrantee need to complete in order to meet the “standard.”

At a minimum, Part A grantee quality management must have:

- Established and implemented a quality management plan with annual updates.
- Established processes for ensuring that services are provided in accordance with the Department of Health and Human Services (HHS) treatment guidelines and standards of care.
- Incorporated quality-related expectations into Requests for Proposals (RFPs) and EMA/TGA contracts, including at the sub-recipient level.

A successful quality management program should:

- Have identified leadership, accountability, and dedicated resources available to the program.
- Use data and measurable outcomes to determine progress toward evidenced-based benchmarks.
- Focus on linkages, efficiencies, and provider and client expectations in addressing outcome improvement.
• Be adaptive to change and fit within the framework of other programmatic quality assurance and quality improvement activities (i.e., Joint Commission on the Accreditation of Healthcare Organizations [JCAHO], Medicaid, and other HRSA programs).

• Ensure that data collected are fed back into the quality improvement process so that goals are accomplished and improved outcomes are realized.

**HAB/DMHAP Monitoring**

DMHAP will monitor grantee compliance with clinical quality management requirements through questions in funding opportunity announcements, progress reports, and site visits. EMAs/TGAs must sign assurances in their annual applications attesting that appropriate quality management programs are in place.

**VII. Ch 4. Quality Management Concepts**

**Model for Improvement**

The Model for Improvement was developed by Associates in Process Improvement and is a simple yet powerful tool for accelerating improvement. This model has been used very successfully by hundreds of health care organizations in many countries to improve many different health care processes and outcomes. The model has two parts:

- Three fundamental questions, which can be addressed in any order.
- The Plan-Do-Study-Act (PDSA) cycle** to test changes in real work settings. The PDSA cycle guides the test of a change to determine if the change is an improvement.

1. Plan – Identify problems (including their components—not just the big picture) and then plan strategies/tests that might result in improvements.
2. Do – Use strategies that are designed to address problems.
3. Study – Collect and analyze data to see if strategies have resulted in improvements.
4. Act – If the strategies are effective, make them an ongoing activity. If they are not effective, return to the Plan stage. Use collected data to identify new ways to address problems.

**Measuring Clinical Quality**

HAB has created performance measures that Ryan White HIV/AIDS Program grantees can use to monitor the quality of care and services they provide. The performance measures can be used at the provider or system level—in their current format or further modified to meet grantee needs. HAB also created Frequently Asked Questions (FAQ) to assist in the use of these performance measures. The FAQs are also available on the HAB website.
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<td>• Substance Use Screening</td>
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<td>• Tobacco Cessation Counseling</td>
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<td>• Medical Visits</td>
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| Oral Health   | • Dental and Medical History  
                • Dental Treatment Plan  
                • Oral Health Education  
                • Periodontal Screening or Examination  
                • Phase I Treatment Plan Completion | pdf (70KB)        | pdf (38KB)    |
| ADAP          | • Application Determination  
                • Eligibility Recertification  
                • Formulary  
                • Inappropriate Antiretroviral Regimen | pdf (61KB)        | pdf (55KB)    |
| Systems-Level | • Waiting Time for Initial Access to  
                • Outpatient/Ambulatory Medical Care  
                • HIV Test Results for PLWHA  
                • Disease Status at Time of Entry Into Care  
                • Quality Management Program  
                • System-Level Performance | pdf (231KB)       | pdf (52KB)    |
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| Pediatric | • Adherence Assessment and Counseling  
• ARV Therapy  
• CD4 Value  
• Developmental Surveillance  
• Diagnostic Testing to Exclude HIV Infection in Exposed Infants  
• Health Care Transition Planning for HIV-infected Youth  
• HIV Drug Resistance Testing Before Initiation of Therapy  
• Lipid Screening  
• Medical Visit  
• MMR Vaccination  
• Neonatal Zidovudine Prophylaxis  
• PCP Prophylaxis for HIV-Exposed Infants  
• PCP Prophylaxis for HIV-Infected Children  
• Planning for Disclosure of HIV Status to Child  
• TB Screening | pdf (160KB) | pdf (229KB) |

Table 3: Clinical Quality Performance Measures

**National Quality Forum HIV Measures**

The HAB regularly reviews its portfolio of performance measures for gaps and relevance. As part of recent reviews, the HAB sought national endorsement for a selection of HIV performance measures in 2012. The National Quality Forum conducts the process by which performance measures are endorsed. National endorsement is important as many payers of health care, including insurance companies and the Centers for Medicare and Medicaid Services, choose or favor nationally endorsed performance measures when selecting measures to include in their programs. The performance measures that received national endorsement are also part of other programs within the Department of Health and Human Services. See the table below describes that HAB performance measures that received national endorsement and their role in other Department of Health and Human Services programs.

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<tr>
<th>in+care Campaign</th>
<th>HHS HIV Measure</th>
<th>National Quality Forum (NQF) Endorsement</th>
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<td>HIV positivity</td>
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<td>Late HIV diagnosis</td>
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<td>Linkage to HIV medical care</td>
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<td>Housing status</td>
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<td>Gap in medical visits</td>
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<td>Newly enrolled in medical care</td>
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<td>24 Month medical visit frequency</td>
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<td>X</td>
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<tr>
<td>Prescription of antiretroviral therapy</td>
<td>X</td>
<td></td>
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<td>Viral load suppression</td>
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Table 4: National Quality Forum HIV Measures


Other Important Quality Topics

There are many concepts that come to mind when reviewing, monitoring, and/or implementing a clinical quality management program. Below are a brief selection of the more common concepts that surface when thinking about a clinical quality management program.

- **Benchmarking and Best Practices.** Benchmarking is the process of comparing one’s performance to that of a higher performing organization of similar characteristics, determining the best practices that has led to the higher performance, and implementing the best practices. The goal is to make changes to a process that will result in higher performance. Some organizations use their own data as a baseline benchmark against which to compare future performance.

- **Clinical Practice Guidelines.** Clinical practice guidelines general are written by a respected authority and based on the most recently available state of knowledge, clinical research, and expert opinion. The purpose of guidelines is to provide recommendations on how to screen, treatment, and provide care and services. The *Guidelines for the Use of Antiretroviral Agents in HIV-1-Infected Adults and Adolescents* developed by the Department of Health and Human Services (HHS) Panel on Antiretroviral Guidelines for Adults and Adolescents (a Working Group of the Office of AIDS Research Advisory Council) are a well-known set of guidelines in HIV care and treatment. These guidelines are updated annually. Guidelines are often the basis for developing performance measures and standards of care.

- **Critical Pathways.** A critical pathway is an evidence-based process that describes each of the steps that need to be taken when provide diagnosis, care, and/or treatment for a specific medical condition. The aim of a critical pathway is the maximize health outcomes by reducing variability and promoting efficiency in the provision of care and treatment.
• Standards of Care. Standards of care are principles and practices for the delivery of health and social services that are accepted by recognized authorities and used widely. Standards of care are based on specific research (when available) and the collective opinion of experts. Standards of care are often informed by guidelines, clinical research, and patient experiences.

VII. Ch 5. References, Links, and Resources

A. HAB Performance Measures – List of performance measures and FAQ (PDF)  
http://hab.hrsa.gov/deliverhivaidscare/habperformmeasures.html

B. National Quality Center (NQC). The purpose: of NQC is to provide no-cost, state-of-the-art technical assistance to all Ryan White funded grantees to improve the HIV/AIDS care and the services they provide. NQC aims to build capacity for quality improvement across all Parts as the nation’s premiere improvement resource in HIV care nationwide. Website:  
http://nationalqualitycenter.org

NQC Quality Academy – An internet-based modular learning program on quality improvement, accessible 24/7 and free of charge. The currently available tutorials stress quality improvement theories and methodologies, real world examples from other HIV providers, and methods for applying this information in HIV programs. Website:  
http://nationalqualitycenter.org/index.cfm/17263

C. HRSA Quality. HRSA’s primary goal is to “Improve Access to Quality Health Care and Services” and has a longstanding commitment to improve the quality of healthcare for people who are uninsured, isolated or medically vulnerable the in the United States. HRSA is active in improving quality at the Federal, state and local levels and at the point of care. The HRSA Quality website (http://www.hrsa.gov/quality) provides a centralized source of information and technical assistance for HRSA grantees and the safety net population.

D. Agency for Health Research and Quality. AHRQ is the lead Department of Health and Human Services (HHS) agency supporting research to improve quality of care, reduce costs, and increase access to essential services. Website:  
http://www.ahrq.gov

E. The Center for HIV Quality Care conducts research on issues including appropriate standards of HIV care, including ancillary services at all stages of illness, and the cost of HIV care that corresponds to these standards of care. The effort is to create a national picture of Medicaid managed care benefit packages and capitation rates. For further information, contact the Infectious Diseases Society of America, Arlington, VA 22209, 703-299-0204,  
http://www.idsociety.org, info@idsociety.org.

F. The National Quality Measures Clearinghouse (NQMC). Under development by ECRI through a contract from AHRQ, the National Quality Measures Clearinghouse is designed to provide an Internet-based resource of evidence-based quality measures. Using a standardized language and common platform, the NQMC links two well-established AHRQ resources:
• **The National Guideline Clearinghouse (NGC)**, a public resource for evidence-based clinical practice guidelines sponsored by AHRQ in partnership with the American Medical Association and the American Association of Health Plans. An Internet-based repository of clinical practice guidelines, it allows for detailed comparisons across different guidelines. Summaries of guidelines are provided for clinical, methodological, and bibliographic areas. Website: [http://www.guideline.gov/](http://www.guideline.gov/).

• **CONQUEST**, the Computerized Needs-Oriented Quality Measurement Evaluation System, a set of computerized databases of clinical performance measures developed by AHRQ. It provides information on tools to assess the quality of health care delivered by providers. CONQUEST is being enhanced and updated through the project. Website: [http://www.qualitymeasures.ahrq.gov/](http://www.qualitymeasures.ahrq.gov/).

The NQMC will allow users to search these databases in combination and receive a report that lists evidence-based quality measures and guidelines.

G. **National Quality Forum.** This private, nonprofit organization has responsibility for the creation of comprehensive quality measures that are consistent with national aims for quality improvement. Website: [http://www.qualityforum.org](http://www.qualityforum.org).

H. **Business and Higher Education Developed CQI and Total Quality Management (TQM) Information.** Business-focused CQI information can often be applied to the health care setting and used to advance the quality of HIV/AIDS services. Many business-oriented websites require a fee or membership to access CQI and TQM information. See the following:

• **American Society for Quality (ASQ).** The ASQ website includes an introduction to quality, an online catalog including a listing of education courses and conferences, an on-line directory for products and services for quality and continuous improvement, and a quality search option. Website: [http://www.asq.org](http://www.asq.org).

• **National Committee for Quality Assurance.** The NCQA website includes resources, information, and training opportunities on evaluating health care. This site includes information on the Health Plan Employer Data and Information Set (HEDIS), a performance measurement tool that contains a set of standardized measures specifying how health plans collect, audit, and report on their performance in important areas of health and customer satisfaction. Website: [http://www.ncqa.org](http://www.ncqa.org).

I. **HRSA CARE Action, August, 2010**

K. HAB Performance Measures
http://hab.hrsa.gov/deliverhivaidscare/habperformmeasures.html
Section VIII. Insurance Programs

VIII. Ch 1. Overview

Most Americans receive health insurance coverage through their employers under group policies, while a smaller proportion buys individual policies. Group and individual health insurance policies are offered through private health insurance companies or self-administered plans that employers fund. Complementing private coverage are public programs that offer health insurance coverage similar to private plans. It is within this health insurance marketplace that Ryan White HIV/AIDS Programs have the option of purchasing health insurance for their clients instead of paying solely for HIV/AIDS medications and other services. Options include:

- **Coverage on the Individual Health Insurance Market.** State Health Insurance Exchanges will be fully operational in 2014, providing expanded options to purchase individual and small group health insurance coverage.

- **State High-Risk Pools.** Risk pools are mechanisms to provide insurance for people in a variety of situations: when individuals have lost their coverage, are ineligible for Medicaid or Medicare, cannot purchase insurance due to eligibility criteria that exclude pre-existing conditions, and/or cannot otherwise afford insurance.

- **Pre-existing Condition Health Insurance Plans (PCIP).** This Affordable Care Act provision (scheduled to end December 31, 2013) is a Federal version of State high risk pools. Federal funds enabled States to establish state-administered PCIPs or default to the Federally-administered PCIP. Persons eligible for PCIPs must have a pre-existing condition, be a U.S. citizen, and be uninsured without creditable coverage for the prior six months. Ryan White funds may be used to pay the premiums, co-pays and deductibles for clients that are enrolled in a PCIP, just as they may for other health insurance.

VIII. Ch 2. Legislative Background

The Ryan White legislation defines core medical services, including:

Section 2604(c)(3)(F) of Title XXVI of the Public Health Service (PHS) Act allows: Health insurance premium and cost sharing assistance for low-income individuals in accordance with section 2615.

**SEC. 2615. [300ff–25] CONTINUUM OF HEALTH INSURANCE COVERAGE.**

(a) IN GENERAL.—A State may use amounts received under a grant awarded under section 2611 to establish a program of financial assistance under section 2612(b)(3)(F) to assist eligible low-income individuals with HIV/AIDS in—

1. maintaining a continuity of health insurance; or
2. receiving medical benefits under a health insurance program, including risk-pools.

(b) LIMITATIONS.—Assistance shall not be utilized under subsection (a)—
(1) to pay any costs associated with the creation, capitalization, or administration of a liability risk pool (other than those costs paid on behalf of individuals as part of premium contributions to existing liability risk pools); and
(2) to pay any amount expended by a State under title XIX of the Social Security Act.

In addition, HAB Policy 07-05 and 10-02, and policy letters provide further guidance to grantees on health insurance purchase option under Ryan White HIV/AIDS Program grants.

Ryan White (ADAP) funds may be used to pay for public and private health insurance premium payments, risk pools, co-payments and deductibles for low-income individuals who are unable to pay; and subject to any other requirements for use of grant funds for health insurance. Such requirements include demonstrated cost effectiveness, cost neutrality, and equivalent or better prescription coverage.

HAB Policy Notice 10-02 defines eligible individuals and service categories representing allowable uses of Ryan White HIV/AIDS Program funds, including health insurance continuation:

“9. Health Insurance Co-payments and Deductibles
Funds awarded under Parts A, B and C of the Ryan White HIV/AIDS Program may be used to support a Health Insurance Premium and Cost-Sharing Assistance Program, a core medical service, for eligible low-income HIV-positive clients.

- Under this service category, funds may be used as the payer-of-last-resort to cover the cost of public or private health insurance premiums, as well as the insurance deductible and co-payments.
- Consistent with the Ryan White HIV/AIDS Program, ‘low income’ is to be defined by the EMA/TGA, State or Part C Grantee.”

HAB’s Dear Colleague letter on insurance plans states, in part:

HAB’s Pre-existing Condition Insurance Plan and the Use of Ryan White Funds “Dear Colleague” letter dated March 15, 2011: Ryan White funds may be used to pay the premiums, co-pays and deductibles for clients that are enrolled in a PCIP, just as they may for Medicare Part D or other health insurance. Ryan White funds may not be used to pay for administrative costs associated with PCIP. See HAB’s policies and program letters: [http://hab.hrsa.gov/manageyourgrant/policiesletters.html](http://hab.hrsa.gov/manageyourgrant/policiesletters.html).

VIII. Ch 3. Private Insurance Coverage for HIV/AIDS Care

Historically, PLWHA have had a difficult time obtaining private health insurance and have been particularly vulnerable to insurance industry abuses. Private insurance still represents a significant source of coverage for individuals with HIV/AIDS.
Employment often comes with group health insurance or private insurance. Many of these programs cover comprehensive medical care, including hospital visits, outpatient care (clinic settings) prescription coverage and specialist visits. Persons with HIV/AIDS who are insured in the group insurance market tend to have the most comprehensive coverage and experience less problems obtaining and keeping that coverage. By law, an employer cannot refuse insurance coverage to any employee who is covered by the group plan and meets the eligibility requirements. In other words, an employee cannot be denied insurance coverage by a group plan based on a pre-existing health condition such as HIV. An employer also cannot require an employee to pay an increased rate for insurance based on a pre-existing condition. All employees are expected to pay the same amount of money for the same type of coverage.

Under Federal COBRA (Consolidated Omnibus Reconciliation Act) legislation, employers are required to offer individuals leaving their workforce continued health insurance coverage, at the individual’s expense, under the employer’s group plan. Coverage can be continued for 18 months and a person may become eligible for an extension of the maximum time period in two circumstances. The first is when a qualified beneficiary (either the individual or a family member) is disabled; the second is when a second qualifying event occurs. Persons are expected, however, to pay the full amount of the monthly premium.

Persons with HIV/AIDS may be able to buy an individual health insurance policy, but they tend to be more expensive and require a pre-screening application that may exclude coverage for pre-existing conditions, like HIV disease.

The insurance market is largely regulated at the State level; however, the Health Insurance Portability and Accountability Act of 1996 (P.L. 104-191), also known as HIPAA, established basic national standards for insurance regulation in the small group insurance market (firms with 2 to 50 workers) and, to a lesser extent, in the individual insurance market. Protections covered in HIPAA included the following:

- **Portability.** Exclusions of preexisting medical conditions are limited to a maximum of 12 months.
- **Nondiscrimination.** Insurers in the group market are prohibited from conditioning persons’ eligibility for group coverage on their health status. This does not apply to individual policies.
- **Guaranteed issue.** Insurers must offer all of their small-group policies to any small employers that want to purchase coverage for their workers.
- **Guaranteed renewal.** Insurers must allow all policies—group and individual—to be renewed.

**VIII. Ch 4. Public Health Care Programs**

**Introduction**

Currently, fewer than one in five (17%) PLWHA has private insurance and nearly 30% do not have any coverage. Medicaid, the Federal-State program that provides health care benefits to low-income people and those living with disabilities, is a major source of coverage for PLWHA,
as is Medicare, the Federal program for seniors and people with disabilities. The Ryan White HIV/AIDS Program, funded through the Title XXVI of the PHS Act as amended by the Ryan White HIV/AIDS Treatment Extension Act of 2009 (Public Law 111-87) is another key source of funding for health and social services for this population.

There are a number of Federal and State-sponsored programs and initiatives that are available to the public to pay for healthcare needs.

**Medicaid: Coverage for Persons with HIV/AIDS**

Medicaid, Title XIX of the Social Security Act, is the largest source of public financing for HIV/AIDS care in the United States. Created in 1965, Medicaid is a jointly funded, jointly administered Federal–State health insurance program for low-income people who meet one or more of several categorical eligibility requirements, including disability. The program is administered through the Centers for Medicare and Medicaid Services (CMS). Through Medicaid, the Federal Government provides matching funds to States that meet certain minimum Federal standards in operating their Medicaid programs. States have broad flexibility in designing their Medicaid programs, and consequently there is significant variation in eligibility, benefits, provider payments, and other aspects of the program at the State level.

State Medicaid policies vary considerably even among similar-sized and or adjacent States. Thus, a person who is eligible for Medicaid in one State might not be eligible in another State; and the services provided by one State may differ from those of another State. Because many people with HIV/AIDS are low income—or become low income—and disabled, Medicaid is an important source of coverage.

To be eligible for Medicaid, a person must meet the categorical and financial eligibility criteria in his or her State’s Medicaid program. Most adults with HIV/AIDS who qualify for Medicaid do so because they meet the disability and income and assets criteria of the Federal Supplemental Security Income (SSI) program for persons who are aged, blind, or disabled. For purposes of SSI eligibility, a person is disabled if he or she is unable to engage in any gainful activity due to a medically determined physical or mental impairment expected to result in death or last for a continuous period of at least 12 months. Some States, known as 209(b) States, may apply more restrictive eligibility rules under SSI. People with HIV may also qualify for Medicaid through a State’s medically needy program that enables those who meet categorical eligibility requirements, such as disability, to spend-down their incomes to meet their State’s income eligibility threshold, which varies among States. Individuals must also meet a State’s resource test.

Federal rules require States participating in Medicaid to cover a set of mandatory services to eligible people in order to receive Federal matching payments (Box 3-1). States may also choose to provide optional services and receive matching payments. Food and Drug Administration-(FDA) approved prescription drugs are an optional benefit that all States have chosen to provide. Medicaid coverage of prescription drugs includes all FDA-approved highly active antiretroviral therapy (HAART) drugs, but coverage of these drugs is at State option and subject to amount, duration, and scope limits (e.g., limit on the number of prescriptions), nominal co-payments for
adults, and prior authorization controls. Other optional services that can be important for people with HIV/AIDS include case management, prevention services, tuberculosis-related services, and hospice services. States may also seek waivers to cover certain services that would not otherwise qualify for Federal matching funds, and a number have done so.

Ryan White Program funds can be used to fill service and population gaps not covered by Medicaid. When a State’s Medicaid program does not cover a specific service, Ryan White funds can be used for payment.

Some State Medicaid programs require some participants pay an out of pocket “share of cost” each month in which they incur service needs prior to becoming eligible for Medicaid. In cases where the participant has not paid their share of cost for a particular month, they are not eligible for Medicaid services. Therefore, Ryan White HIV/AIDS Program is the payer of last resort.

In cases where the client cannot pay the share of cost, Ryan White Program funds cannot be used to pay the share of cost on behalf of the client. This practice is prohibited by Medicaid policy.

**Medicare: Coverage for Disabled and Elderly Persons With HIV/AIDS**

Medicare (Title XVIII of the Social Security Act) is the nation’s Federal health insurance program for the elderly and disabled. It was established in 1965 and is also administered by CMS. Medicare is an important source of coverage for people with HIV/AIDS who are disabled, have sufficient work history to qualify for disability insurance, and live long enough to qualify for Medicare. As people with HIV/AIDS live longer, the number of people with HIV/AIDS on Medicare is expected to grow, and Medicare spending is also expected to increase. Some individuals with Medicare coverage also qualify for Medicaid because they have low income levels; they are considered to be dual-eligible. For these individuals, Medicaid provides varying levels of coverage, including payment of premiums, some cost sharing, coverage of services during the waiting period (for those under 65 years), and coverage of prescription drugs.

Most Americans ages 65 and older are entitled to Medicare as soon as they are eligible for Social Security payments. People under age 65 who receive Social Security Disability Insurance (SSDI) benefits and individuals with end-stage renal disease may also qualify for Medicare. People with HIV/AIDS who meet SSDI eligibility criteria are eligible for Medicare benefits. The Social Security Administration defines disabled to mean that an individual 18 years or older is unable to engage in any substantial gainful activity due to any medically determinable physical or mental impairment(s) that can be expected to result in death or that has lasted or can be expected to last for a period of not less than 12 months (SSA, 2004). In addition, individuals must have paid Social Security taxes through their workplace for a minimum number of fiscal quarters. Federal law, however, requires a 5-month waiting period after disability determination to receive SSDI benefits and then a 24-month waiting period before an SSDI beneficiary can join Medicare, resulting in a total of 29 months before receipt of health benefits (SSA, 2004).
• Medicare Part A covers inpatient hospital services, skilled nursing facilities, home health services, and hospice care.
• Medicare Part B helps pay for the cost of physician services, outpatient hospital services, medical equipment and supplies, and other health services and supplies.
• Medicare Part C allows beneficiaries to choose to enroll in a health maintenance organization or other managed care plan, a preferred provider organization or to choose a medical savings account.

A significant number of PLWHA are dually eligible for both Medicare and Medicaid. Despite coverage by both sources of public insurance, gaps in care may exist.

The Ryan White HIV/AIDS Program: Health Insurance Continuity Program

Introduction

Within Part B, one of the five program components specified under Title XXVI of the Public Health Service (PHS) Act for which Ryan White Program funds may be spent is a continuum of health insurance coverage for PLWHA. Loss of health insurance or lack of coverage is always a fearful prospect and even more so for people dealing with costly disease such as HIV.

The number of such programs, and the amount of Ryan White Program resources devoted to them, has increased since initial passage of the Ryan White HIV/AIDS Program legislation. Health insurance continuum of coverage programs has received greater attention for the following key reasons:

• **Cost Effectiveness.** Paying health insurance premiums for individuals disabled by HIV disease can be less expensive, in some cases, than covering medical expenses directly under financially stretched programs like ADAP. According to the National Alliance of State and Territorial AIDS Directors (NASTAD), States report cost savings in spending in covering health insurance premiums for persons diagnosed with AIDS.

• **Expanded Access to Care.** Health insurance can improve access to care, including antiretroviral therapies and prevention and treatment of opportunistic infections.

• **Reforms in State and Federal Health Insurance Laws.** A large number of States have enacted reforms that have the potential to broaden access to individual and small group health insurance; similar provisions have been enacted at the Federal level under the Health Insurance Portability and Accountability Act (HIPAA).
Insurance Funding Options

Health insurance continuity programs generally operate as premium payment plans. HIV-specific programs were initially created to continue payment of employment-related, group health insurance premiums, through COBRA, for individuals who became disabled and could no longer work. COBRA coverage lasts 18 months plus a 20-month extension for individuals leaving employment due to a disability. When COBRA coverage expires, individuals can obtain a conversion policy, which may provide the same benefits as their previous group plan but often at higher rates.

While COBRA coverage and conversion coverage are standard in most continuums of coverage programs, some have broadened their scope and purchase new health insurance coverage for hard-to-insure individuals through mechanisms like insurance purchasing projects or State-run risk pools. Continuity programs often work closely with public programs to transition clients as they become eligible for public benefits.

Since health insurance is primarily governed by State laws, the implementation of health insurance continuity programs varies from State-to-State with respect to certain specifics (e.g., use of State funds to support the program; and administration by the HIV/AIDS program office, the State’s Medicaid program, or community agencies). However, many programs share the following characteristics:

- Continuity programs typically require health insurance policies to cover HIV-related care and prescription drugs in order to be eligible for continuation. The prescription drug formulary must be equivalent and cost effective compared to the cost of paying full price for medications. Policies without such coverage are not typically worth continuation given the care needs of a person living with HIV disease.
- All programs cover COBRA premiums, and many continue paying premiums for individual policies when COBRA group coverage expires.
- Most continuity programs exclude Medicaid-eligible individuals because programs under Title XXVI of the PHS Act as amended by the Ryan White HIV/AIDS Treatment Extension Act of 2009 (Public Law 111-87) are the payer of last resort and, in some States, Medicaid may operate such a program.
- Programs are defined as a transitional step prior to eventual coverage by Medicaid or Medicare.
- Most continuity programs involve intensive staff work in tracking policies and monitoring benefit changes. They begin covering an individual’s premium payments immediately upon enrollment in the program in order to avoid termination of the policy due to nonpayment of premiums.
- Eligibility criteria usually include an AIDS diagnosis, disabling HIV status, maximum income (as a percentage of the Federal poverty level), a cap on assets, and residency within the State.

Benefits of Health Insurance Continuity Programs

Experience shows that States should study the applicability of continuity programs relative to their own unique fiscal and political circumstances. For some States, the most important...
consideration may be the cost savings realized by operating a health insurance continuity program. For others, it may be the ability to enhance the continuity and comprehensiveness of care for its residents with HIV/AIDS. Benefits of continuity programs include:

- Maintaining a continuum of coverage in health care services for participants.
- Sharing the cost of providing care to persons with HIV/AIDS across private and public health insurance programs, thereby reducing the fiscal impact on publicly funded programs.
- Allowing clients to continue working part-time without risking a loss of insurance coverage (in contrast with public health insurance, where rising income results in a loss of eligibility and services).
- Providing assistance until persons disabled by HIV disease can qualify for Medicaid or Medicare.

VIII. Ch 5. References, Links, and Resources

5. ADAP Manual 2012: https://careacttarget.org/content/adap-manual

For More Information

Please refer to the HAB Target Center at https://careacttarget.org.
Section IX. Chief Elected Official Guide

IX. Ch 1. Overview

The Ryan White HIV/AIDS Program legislation provides Federal funding to metropolitan areas known as EMAs/TGAs and States to fill gaps in care for PLWHA. Under two programs of the Ryan White HIV/AIDS Program—Ryan White Part A (Metropolitan areas) and Part B (States)—responsibility for managing these funds falls to chief elected officials (CEOs), such as mayors, county executives and governors. In turn, CEOs often delegate implementation to staff within their own offices or to agencies like health departments.

As the recipient of Ryan White Part A funds, the CEO spearheads the development of a comprehensive HIV/AIDS service system. Ryan White awards include both formula grants based on the number of HIV/AIDS cases and competitive supplemental funds for areas with demonstrated need.

In using these resources, CEOs are required to work in partnership with communities to plan and deliver HIV/AIDS services. CEO partners include the administrative agency designated by the CEO to oversee the program (e.g., the health department), the planning body and its diverse voices of expertise, and PLWHA. Other Ryan White partners include city or county finance or grants offices that disburse and account for funds.

The CEO ensures that Ryan White partners meet their legislative requirements and submits written assurances that requirements are being met. Assurances are submitted as part of the annual funding application to HRSA/HAB’s, Division of Metropolitan HIV/AIDS Programs.

This guide outlines CEO responsibilities as follows:

1. Assuring that grant funds are administered appropriately, and
2. Facilitating planning in partnership with planning bodies/community input processes to best meet the needs of PLWHA.

This guide is to be used to orient staff of administrative agencies and planning bodies in working with the CEO to implement Ryan White Part A programs.

IX. Ch 2. Legislative Background

The Ryan White Part A CEO has key responsibilities in a number of areas. Under Section 2602(a) of Title XXVI of the Public Health Service Act (42 U.S.C. § 300ff–12), (the PHS Act). The CEO has the responsibilities to:

“(A) IN GENERAL.—To receive assistance under section 2601(a), the chief elected official of the eligible area involved shall—
(i) establish, through intergovernmental agreements with the chief elected officials of the political subdivisions described in subparagraph (B), an administrative mechanism to allocate funds and services based on—
(I) the number of AIDS cases in such subdivisions;
(II) the severity of need for outpatient and ambulatory care services in such subdivisions; and
(III) the health and support services personnel needs of such subdivisions; and
(ii) establish an HIV health services planning council in accordance with subsection (b).”

Related to the HIV Planning Council, the CEO’s responsibilities are clearly delineated under Section 2602(b) of the PHS Act:

“(b) HIV HEALTH SERVICES PLANNING COUNCIL.—
(1) ESTABLISHMENT.—To be eligible for assistance under this subpart, the chief elected official described in subsection (a)(1) shall establish or designate an HIV health services planning council that shall reflect in its composition the demographics of the population of individuals with HIV/AIDS in the eligible area involved, with particular consideration given to disproportionately affected and historically underserved groups and subpopulations.”

Under Section 2603 the Chief Elected Official (CEO) or designee in the EMA/TGA has to meet the legislative requirements to disburse funds quickly, closely monitor their use, and ensure that the Ryan White HIV/AIDS Program is the payer of last resort. In addition, Section 2603 addresses the timely obligation of Ryan White HIV/AIDS Program fund by the CEO which ensures that services can be provided as rapidly as possible and decreases the possibility that unobligated funds will remain at the end of the program year.

With respect to services, Section 2604 describes the CEO’s responsibilities related to the use of grant funds for the purpose of providing core medical services and support services in accordance to priorities established the planning council, and taking into account WICY provisions.

Section 2605 describes the key assurances that the CEO must make in receiving Ryan White funds such as MOE, supplanting, maintenance of a continuum of care and appropriate relationships with entities that constitute key points of access.

IX. Ch 3. Overview of the Ryan White HIV/AIDS Program

Introduction

The Ryan White HIV/AIDS Program is the largest Federal program focused exclusively on HIV/AIDS care. The program is for individuals living with HIV/AIDS who have no health insurance (public or private), have insufficient health care coverage, or lack financial resources
to get the care they need for their HIV disease. As such, the Ryan White HIV/AIDS Program fills gaps in care not covered by other funding sources.

The most recent Ryan White legislation is called the Ryan White HIV/AIDS Treatment Extension Act of 2009 (P.L. 111-87, October 30, 2009). The legislation was first enacted in 1990 as the Ryan White CARE (Comprehensive AIDS Resources Emergency) Act (P.L. 101-381, August 19, 1990). It has been amended and reauthorized four times: in 1996, 2000, 2006, and 2009. The Ryan White legislation has been adjusted with each reauthorization to accommodate new and emerging needs, such as an increased emphasis on funding of core medical services and changes in funding formulas.


See Section 1, Chapter 1 for a complete overview of the Ryan White HIV/AIDS Program.

IX. Ch 4. CEO Duties

A. Introduction

The CEO of a metropolitan area in an EMA/TGA is the official recipient of Ryan White funds and is ultimately responsible for administering all aspects of Ryan White funds and ensuring that all legal requirements are met. As such, the CEO has ultimate responsibility for the grant and for ensuring that all Ryan White partners meet legislative requirements, as well as the expectations of HAB/Division of Metropolitan HIV/AIDS Programs. CEO responsibilities occur in two major areas: Administration of Funds and Planning. The EMA/TGA CEO may be a mayor, county executive, city council, county commission chair/president, or a county judge. The CEO often delegates responsibility for grant administration to an agency such as the health department. In such cases it is referred to as the grantee, the term used to describe the entity that receives Ryan White funds and has responsibility for administering the award.

B. Responsibilities of the CEO: Administration

Administration/Use of Funds

The CEO establishes a mechanism to administer funds for the timely delivery of essential services to PLWHA throughout the Eligible Metropolitan Area/Transitional Grant Area (EMA/TGA). Ryan White HIV/AIDS Program funds must be used to address gaps in HIV services not being met by other programs. Services must be provided regardless of an individual’s ability to pay. Local funding of Ryan White core medical and support services must be maintained at a level at least equal to the prior year’s level to ensure that Ryan White funds are used to supplement, but not replace, local spending.
Other administrative responsibilities of CEOs are as follows:

- **Establishing the Administrative Mechanism**
  The Administrative Mechanism is how funds are disseminated locally. The CEO may delegate administrative responsibility for the grant (usually to the health department) but is responsible for ensuring that the program meets legislative mandates and that all Ryan White partners work together to deliver quality care and services to PLWHA. CEOs must ensure that funds are allocated fairly across the service area and target underserved populations.

  The planning council assesses the effectiveness of the funding allocations process, but the CEO helps make sure that funds get out to service providers in a timely manner. The CEO should respond quickly to concerns regarding allocation of Ryan White funding and make needed corrections.

- **Establishing Intergovernmental Agreements**
  The CEO must establish Intergovernmental Agreements (IGAs) with the CEOs of those political jurisdictions that provide HIV health services and include not less than 10 percent of the reported AIDS cases in the EMA.

- **Services to Women, Infants, Children, and Youth**
  The CEO must ensure that funding for services to women, infants, children, and youth is proportionate to their representation among the EMA’s/TGA’s total HIV/AIDS cases. A waiver may be granted when an EMA/TGA can demonstrate that the needs of these populations are being met through other sources, such as Medicaid, the Children’s Health Insurance Program (CHIP), or other Federal/State programs, including Ryan White programs.

  Ryan White defines these populations as follows:

  - Women – 25 years and older
  - Youth – 13-24 years old
  - Children – 2-12 years old
  - Infants – less than 24 months old

- **Filling Gaps in Care and Maintenance of Effort**
  CEOs must ensure that Ryan White funds are used only to fill gaps in care, not to pay for services covered by other available health care funding sources, such as Medicaid or Medicare. Grantees must ensure that PLWHA are enrolled in other health care programs for which they are eligible. Further, CEOs must assure that grantees maintain their prior year’s level of spending for Ryan White [HIV-related] core services and provide services regardless of an individual’s ability to pay or his/her health condition.

- **Clinical Quality Management Programs**
  The CEO assures that the grantee develops and implements CQM programs to ensure both that PLWHA eligible for treatment and health-related services have access to those services, and that the quality of those services meets certain criteria. CEOs must sign assurances that CQM programs are in place and meet their objectives.
Coordination with Early Intervention Service Providers (EIS)
The CEO must ensure that services are coordinated with other Ryan White programs, existing prevention activities and other federally funded HIV related programs and services. Special emphasis is given to PLWHA who know their HIV status but are not receiving services from a system of care with maintenance of appropriate relationships with “key points of entry” to assure referrals into care for PLWHA.

C. Responsibilities of the CEO: Use of Funds

Ryan White legislation specifies the following:

- No more than 10 percent of Ryan White Part A funds may be used for administrative expenses, such as developing annual funding applications, program and financial reports, meeting audit requirements, reimbursement and accounting systems, awarding local contracts, planning council support, capacity development, and development of a CQM program.
- Of this amount, up to 5 percent or $3 million, whichever is less, may be used for CQM programs to ensure that HIV health services are consistent with HHS Treatment Guidelines and to monitor the improved health status of HIV-positive clients.
- No more than 10 percent may be spent collectively by providers and subcontractors on administrative costs such as “usual and recognized” overhead, management and oversight of programs, and program support activities such as quality assurance, quality control and related activities.
- Funds may not be used for construction, land purchase, or cash payments to intended recipients of services.

Eligible Services

Core medical services (not less than 75 percent of grant funds unless a waiver is granted), defined as: outpatient and ambulatory health services; ADAP treatments; AIDS pharmaceutical assistance; oral health care; early intervention services; health insurance premium and cost sharing assistance for low-income individuals; home health care; medical nutrition therapy; hospice services; home and community-based health services; mental health services; substance abuse outpatient care; medical case management, including treatment adherence.

Support services (defined as services “that are needed for individuals with HIV/AIDS to achieve their medical outcomes (such as respite care for persons caring for individuals with HIV/AIDS, outreach services, medical transportation, linguistic services, and referrals for health care and support services).”

Eligible Providers

Funding may be awarded to public or nonprofit entities, such as community-based organizations, hospices, ambulatory care facilities, community health centers, migrant health centers, homeless
health centers, substance abuse treatment programs, mental health programs, hospitals, and hospices. Private for-profit entities are eligible to receive funding if they are the only available provider of high quality HIV care in the area.

**D. Responsibilities of the CEO: Planning**

The CEO must establish a planning council and, once the planning council is established, appoint members through the planning council’s nominations process. For the TGAs funded after 2006, the CEO has the option of establishing a planning council or a process for securing community input. Planning council membership must meet legislative requirements for representation and be selected through an open nominations process that has been approved by HRSA. Members must be trained to enable them to fulfill their responsibilities, in accordance with guidance from HAB/Division of Metropolitan HIV/AIDS Programs. CEOs must enable planning councils to carry out their legislatively mandated responsibilities:

- Conduct an assessment of local community needs.
- Develop a comprehensive service plan, compatible with existing State and local plans.
- Allocate funds according to service priorities set by the planning council.
- Participate along with other Ryan White partners in the development a Statewide Coordinated Statement of Need (SCSN) to enhance coordination among Ryan White HIV/AIDS Program programs in addressing key HIV/AIDS care issues.
- Coordinate with Federal, State, and locally funded grantees providing HIV-related services.
- Assess the efficient administration of funds.

CEOs must assure that the designated planning body undertakes planning for the use of Ryan White funds. CEOs appoint planning council members who conduct needs assessments, set service priorities for the allocation of funds, and develop a comprehensive plan to guide them in managing the HIV service delivery system. The grantee contracts for services based on the planning council’s allocation of funds to their established priorities.

**Planning Councils**

The planning council membership must reflect the demographics of the population of individuals with HIV/AIDS in the EMA/TGA. Special consideration must be given to historically underserved populations and those experiencing significant disparities in access to services. No less than 33 percent of planning council members must be PLWHA who receive Ryan White Part A services (in the case of minors, this would include their caregivers) and who are unaligned with provider agencies that receive Ryan White Part A funding. Alignment is defined to include board membership and employment and consulting arrangements with agencies receiving Ryan White Part A funding.

In addition to the 33 percent PLWHA, planning council members must include:
• Health care providers, including Federally qualified health centers.
• AIDS service organizations (ASOs) and community-based organizations (CBOs) serving affected populations.
• Social service providers, including housing and homeless services providers.
• Substance abuse treatment providers.
• Mental health providers.
• Local public health agencies.
• Hospital planning agencies or health care planning agencies.
• Affected communities, including people with HIV/AIDS, members of a Federally recognized Indian tribe as represented in the population, individuals co-infected with hepatitis B or C, and historically underserved groups and subpopulations.
• Non-elected community leaders.
• State Medicaid agency.
• State agency administering the Part B program.
• Ryan White or other programs serving women, children, youth and families.
• Part C grantees.
• Grantees under other Federal HIV programs, including but not limited to HIV prevention providers.
• Formerly incarcerated PLWHA or their representatives.

Planning Council Operations

CEOs must assure that planning councils have in place a variety of policies and procedures, including the following:

• Nominations for members based on an open process, with criteria clearly stated and publicized, including a conflict of interest standard.
• Training for planning council members so they are able to fully participate (Grantee applications need to include plans for training new members, including training timelines, goals, and budgets. The CEO and planning council chairs will need to submit signed assurances, along with the funding application, that such training will take place.
• Leadership procedures ensuring that the planning council is not chaired solely by an employee of the grantee.
• Planning council meetings that are open to the public and minutes that are publicly available and that protect the medical privacy of individuals.
• Bylaws that establish how the planning council will conduct business.
• Grievance procedures with respect to funding, including procedures for submitting grievances that cannot be resolved informally or by mediation to binding arbitration.
Assessing Needs

Needs assessment is a collaborative activity of the planning council, grantee, and community, and is used as the basis for other Ryan White planning activities including priority setting and resource allocation and planning. Needs assessments determine needs in specific areas such as:

- PLWHA who know their HIV status but are not in care.
- Disparities in access to care for certain populations and underserved groups.
- Coordination between care programs and providers of HIV prevention and substance abuse treatment services.
- Outreach and early intervention services.

Priority Setting and Resource Allocation

Based on the findings of the needs assessment, the planning council establishes priorities for the provision of HIV services in the local community. Service priorities are based on:

- The size and demographics of the population of individuals with HIV/AIDS and their needs, including those who know their HIV status but are not in care.
- Compliance with the legislative requirement to use not less than 75 percent of funds to provide core medical services.
- Cost effectiveness and outcome effectiveness of proposed services and strategies
- Priorities of PLWHA for whom services are intended.
- Coordination of services with programs for HIV prevention and treatment of substance abuse.
- Availability of other governmental and non-governmental resources in the service area.
- Capacity development needs, resulting from disparities in the availability of services for underserved populations.

Once service priorities are established, the planning council makes resource allocations, in accordance with the legislative requirement to use not less than 75 percent of funds to provide core medical services. The priority setting and resource allocation process involves the planning council in determining how much funding will be dedicated to each service category. The planning council does not, however, select the providers to deliver services, or participate in the management of service provider contracts.

Comprehensive Plan

The CEO must assure that the planning council develops a comprehensive plan for services, which is compatible with other State, and local plans for the delivery of HIV services. This plan should be updated every three years.
Planning is done by a broad group of people representing the epidemic in the EMA/TGA, including PLWHA. Planning is based on needs assessment results. HAB/Division of Metropolitan HIV/AIDS Programs expects EMAs/TGAs to develop multi-year comprehensive plans that will:

- Address disparities in HIV care, access, and services among affected subpopulations and historically underserved communities.
- Ensure the availability and quality of all core medical services within the EMA/TGA.
- Address the needs of those that know their HIV status and are not in care, as well as the needs of those who are currently in the care system.
- Address clinical quality measures.
- Include strategies that:
  
  a. Identify individuals who know their HIV status but are not in care and inform these individuals of services and enable their use of HIV-related services.
  b. Eliminate barriers to care and disparities in services for historically underserved populations.
  c. Provide goals, objectives, and timelines (as determined by the needs assessment)
  d. Coordinate services with HIV prevention programs including outreach and early intervention services.
  e. Coordinate services with substance abuse prevention and treatment programs.
  f. Identify individuals with HIV/AIDS who do not know their HIV status, making such individuals aware of such status, and enabling such individuals to use the health and support services with particular attention to reducing barriers to routine testing and disparities in access and services among affected subpopulations and historically underserved communities.

**Coordination**

The CEO must ensure that Ryan White Part A programs coordinate their services with other Ryan White Parts and other Federal HIV programs operating in the EMA/TGA, including providers of EIS. This is necessary to ensure referral into care for those who are newly diagnosed with HIV and those who know their HIV status but are not participating in a system of care. Another goal of coordination is to ensure that Ryan White funds are used to fill gaps in service, and that PLWHA are enrolled in non-Ryan White programs for which they are eligible.

Representatives of the Ryan White Part A grantee and the planning council are required to participate in the SCSN process.

**Prevention—Care Coordination**

CEOs must assure that care-prevention coordination ensures that PLWHA enter care systems and receive ongoing treatment. Particular emphasis should be placed on identifying those who know their HIV status but are not receiving treatment.
anticipated long-term impact is to normalize screening for HIV in diverse social service and health care settings and help reduce barriers to care for the traditionally underserved by expanding the network of referrals.

CEOs must assure that Ryan White providers maintain appropriate relationships with “key points of entry” into the health care system (e.g., HIV counseling and testing centers, emergency rooms, substance abuse treatment programs, STD clinics, homeless shelters). Since EIS can only be funded if other sources of funding are insufficient to meet current needs, needs assessment must document that EIS gaps exist prior to using Ryan White funds.

SCSN

The CEO must participate in the development and updating of the SCSN, for which Part B has lead responsibility. Representatives of the Ryan White Part A grantee and the planning council are required to participate in the SCSN process.

IX. Ch 5. HAB Expectations of Ryan White Part A CEOs

HAB expects CEOs to ensure that Ryan White programs meet all legislative requirements. Policies and guidances have been developed to assist CEOs and planning bodies in implementing Ryan White legislative provisions.

The legislation also authorizes technical assistance to help grantees comply with legislative requirements, including peer-delivered technical assistance and guidance to planning bodies. Technical assistance is provided through HAB/Division of Metropolitan HIV/AIDS Programs. Requests for assistance must be made to HAB/Division of Metropolitan HIV/AIDS Programs project officers through the Ryan White Part A grantee.

IX. Ch 6. When the CEO Designates Responsibility

A. Introduction

The following EMA/TGA experiences provide insight on how the CEO can ensure effective planning and implementation when Ryan White Part A responsibilities are delegated. The CEO is ultimately responsible for ensuring that all Ryan White Part A programs in a service area meet legislative requirements and HAB/Division of Metropolitan HIV/AIDS Programs expectations.

B. Avoiding Problems

When responsibility of administering the Ryan White Part A program is delegated to the health department or some other government agency or office, the CEO can help prevent or resolve problems by taking the following steps:
• Choose someone with related knowledge and skills. Someone with a strong public health background, knowledge/experience with the Ryan White HIV/AIDS Program, and direct access to you and your office is best.
• Make sure administrative staff is competent, knowledgeable, and diverse. Ensure staff has strong HIV/AIDS experience and pertinent technical skills.
• Ensure clear lines of communication among all partners. Consider establishing a team of people to conduct ongoing, regular activities to keep you informed.
• Require linkages among Ryan White programs, and between Ryan White and other HIV/AIDS programs and activities. Consider a working group or task force comprised of Ryan White Part A partners, Part B, HIV prevention providers, Medicaid, CHIP offices, providers of homeless services, representatives of the incarcerated, State and/or local AIDS entities, AIDS policy groups, etc.
• Be sure that Intergovernmental Agreements (IGAs) are monitored and followed.
• Require the administrative agency to build and maintain relationships with infected and affected communities. Use methods such as community forums and hotlines to obtain consumer and community input.

Making IGAs Meaningful

The Ryan White legislation requires that the CEO establish an IGA with any covered (as per law) political subdivision(s) within the EMA/TGA. The IGA must provide an administrative mechanism to allocate funds and services based on the:

• Number of HIV/AIDS cases in the eligible area.
• Demonstrated need for services in the eligible area.
• Health and support service needs of the eligible area.

IGAs can be useful to promote access to CEOs in other jurisdictions that are part of EMA/TGA and involve these elected officials in the Ryan White Part A process.

IGAs should also include the following:

• Indicate a minimum number of seats on the planning council that will be set aside for residents of the jurisdiction.
• Specify how residents of the jurisdiction can be nominated for planning council membership.
• Require specific efforts to determine the unmet need for HIV-related health services in these jurisdictions.
• Establish periodic meetings between the Ryan White Part A CEO and other CEOs of the other jurisdictions or their representatives.
• Specify a periodic evaluation of how the IGA is working, in terms of services and administration.
Staff Roles

The experiences of EMAs/TGAs suggest that staff involvement is important whenever administrative responsibility for Ryan White Part A has been designated to another department. CEO staff can help with the following:

- Attend meetings, make community contacts, and make themselves available to key stakeholders, including PLWHA communities.
- Build relationships with other CEOs in an EMA/TGA, including those with whom the CEO has IGAs in place. These relationships can help encourage cooperation in ensuring delivery of HIV services, protect the CEO when signing assurances on behalf of the EMA/TGA, ensure maintenance of effort in a positive way, and minimize the potential for grievances.
- Require attendance at planning body meetings to keep the CEO informed of the process and any related issues, and to provide CEO input to planning.
- Maintain close relationship with an external administrative agency or fiscal agent to ensure that CEO expectations are communicated and that the CEO is apprised of any problems with the disbursement of funds.
- Communicate information from the CEO to other AIDS policy or program offices within city, county, and State governments.
- Promote collaboration among Ryan White partners and between Parts A and B and other HIV/AIDS-related entities in needs assessment and planning activities, prevent duplication of efforts, and prevent adversarial relationships among agencies.
- Require the administrative agency to serve as a direct mediator between Ryan White partners or between Ryan White programs and other public agencies that report to the CEO. They can help resolve problems quickly so that care and services to PLWHA are not compromised or interrupted.

C. Anticipating and Solving Problems

The CEO can help resolve some common problems with Ryan White programs. Following are some examples.

1. The Problem: The planning council is not representative

The planning council is not reflective of the epidemic in the EMA/TGA. PLWHA are not adequately represented and the membership from a particular community is far short of what it should be. These issues can result in the CEO becoming the target of angry consumers, who feel their voice is not being heard in decision making. Further, the level of Ryan White Part A funding may be jeopardized, and HAB/Division of Metropolitan HIV/AIDS Programs may require changes in membership as a Condition of Grant Award.
What the CEO Can Do:

- Arrange for an assessment of the problem. Establish a task force of representatives from the CEO office, the administrative agency, and the affected community to discover what is causing recruitment problems.
- Have the planning council or CEO (or designee) seek technical assistance from HAB/Division of Metropolitan HIV/AIDS Programs.

2. The Problem: Fund disbursement is delayed

Disbursements to service providers are taking twice as long as they should. In some organizations, this is causing services to clients to be interrupted. The CEO is getting calls from angry providers who are saying they will have to lay staff off and stop certain services, and from consumers who now have to go further from home to receive services from unfamiliar organizations and providers. The planning council is preparing to file a formal grievance with the CEO.

What the CEO Can Do:

- Arrange for an assessment of the problem by the appropriate unit within your local government, a representative of your office, or an independent consultant. Be sure to have the planning body representatives and the affected community provide their input. Take corrective action based on the results of the assessment.
- Assign one of your staff to be a liaison with the administrative agency to monitor its activities, including its interaction with the planning body.
- Seek technical assistance from HAB/Division of Metropolitan HIV/AIDS Programs.

3. The Problem: Planning council discord and public perceptions of CEO disinterest

There is a perception in the community that HIV is not a priority for the CEO and that he/she is uninterested in the needs of PLWHA. A growing conflict between two provider groups erupted at a recent planning council meeting. The local paper reported that HIV providers are putting the needs of PLWHA second to their own individual agendas.

What the CEO Can Do:

- Keep abreast of the Ryan White Part A process and be knowledgeable about the personalities and issues that influence the process.
- Ensure that problems are resolved or addressed before they become highly visible and/or explosive.
- Ensure that your staff and liaisons maintain active lines of communication among all key stakeholders and represent you as a leader who is accessible and knowledgeable.
4. The Problem: Contracting not reflective of planning council priorities

The administrative agency is making contracts to provider agencies that are not in line with the service priorities that have been established by the planning council. Due to a number of vacancies on the planning council and a number of new members who are still learning their roles, the planning council has been unable to effectively monitor and oversee the allocations process. PLWHA groups are calling your office to complain and demand that the situation be corrected.

What the CEO Can Do:

- Ensure that planning council vacancies are filled in a timely manner to avoid a lack of balance between the planning council and the administrative agent.
- Ensure that you and your staff are monitoring the activities of the administrative mechanism. Make sure it is responding to the direction of the planning council.
- Ensure that planning council members are diverse, talented, and appropriately trained to fulfill their responsibilities, and that they have the capacity to evaluate the administrative agent.

Effective CEO Problem Solving

When the planning council in one city confronted the CEO about the poor performance of the administrative agency, the CEO—rather than simply defending his administrative agency—formally mediated and facilitated discussions between the planning council and administrative agency staff. An HIV Coordinating Team was established with representatives from both groups and the CEO’s office liaison as a way to identify and resolve problems as they arise and maintain cross communication. A new HIV Program Coordinator position was established within the administrative agency to assure that all components within the administrative agency were working together to meet their responsibilities.

Attachment 1: Responsibilities of Ryan White Partners

Successful planning and implementation of the Ryan White HIV/AIDS Program requires the CEO and Ryan White partners to know what to expect from each other. Typical expectations are outlined below and will guide CEOs in clarifying expectations and resolving problems that may occur.
<table>
<thead>
<tr>
<th>CEO Expectations of the Planning Council</th>
<th>Planning Council Expectations of the CEO</th>
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<tbody>
<tr>
<td><strong>Membership</strong></td>
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<tr>
<td>An open nominations process for planning council membership. Membership that reflects the demographics of the local epidemic and includes representation from required categories.</td>
<td>Timely appointment of planning council members from among nominees selected through the open nominations process. Not naming political appointees to the planning council. Not appointing a CEO employee as sole chair. However, an employee of the grantee may serve as co-chair, if bylaws permit.</td>
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<tr>
<td><strong>Planning Body Operations</strong></td>
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<td>Bylaws or other procedures that govern member attendance. Timely communication concerning members who are not participating, prior to taking action to remove them.</td>
<td>Support of planning council bylaws or other procedures that govern member attendance.</td>
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<td>Adoption and implementation of grievance procedures.</td>
<td>Support of the grievance process and its results.</td>
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<tr>
<td>Adoption and consistent implementation of conflict of interest policies, with binding arbitration as the final step in the grievance process.</td>
<td>Support for conflict of interest policies and their consistent implementation.</td>
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<td>Regular communication regarding both successes and problems related to implementation of the planning council’s assigned responsibilities.</td>
<td>Regular communication about perceived successes and problems related to the implementation of the planning council’s assigned responsibilities (including public and agency concerns).</td>
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<tr>
<td>Intervention, as needed, to resolve problems with funds disbursal.</td>
<td>Support of the evaluation of the EMA/TGA’s administrative mechanism to ensure that funds are allocated in a timely manner, providers are reimbursed efficiently, and contracts are monitored properly.</td>
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<tr>
<td><strong>Needs Assessment</strong></td>
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<td>CEO Expectations of the Planning Council</td>
<td>Planning Council Expectations of the CEO</td>
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<tr>
<td>Work with the grantee to conduct the needs assessment. Conduct needs assessment that includes: (1) updated information about local HIV/AIDS demographics; (2) needs of PLWHA, especially those who know their status and are not in care; (3) disparities in access to services among PLWHA; (4) capacity development needs of HIV service providers; (5) need for EIS and outreach services; and (6) needed coordination with other programs like prevention and substance abuse treatment.</td>
<td>Awareness of needs assessment activities and results and the use of these results as appropriate for other types of health planning.</td>
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<tr>
<td>Development and periodic updating of the comprehensive services plan for the EMA/TGA.</td>
<td>Awareness of the comprehensive services plan. Assistance in coordinating Parts A and B with other HIV programs, including Medicaid managed care, other AIDS services, and other health and support services funded by local jurisdictions, where appropriate.</td>
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<td><strong>Priority Setting/Resource Allocation</strong></td>
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<tr>
<td>Annual determination of service priorities and related funds allocations. Timely direction to the administrative agency on the best ways to provide those services, including language around using Ryan White funds as the payer of last resort. Use of a process that is clearly defined. Ensuring service coordination with providers of EIS, prevention, and substance abuse treatment services for the purposes of retaining PLWHA in care. Increasing access to services for PLWHA who know their HIV status and are not currently receiving services. Reducing general barriers to care.</td>
<td>Awareness of the priority-setting and resource-allocation processes and public support for the planning council role. If necessary, provide help to the planning council in ensuring that priorities and allocations are reflected in procurement process.</td>
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<td>Participation in the development of the SCSN.</td>
<td>Linkage and advocacy with the State on important HIV care issues.</td>
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<td><strong>Clinical Quality Management</strong></td>
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<tr>
<td>Grantee Activity Develop standards of care for funded services.</td>
<td>Planning Council standards of care will be used as basis for monitoring CQM by grantee.</td>
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</table>

*Table 5: Responsibilities of Ryan White Partners*
## Attachment 2: Expectations of the CEO and Administrative Agency

### Expectations of the CEO and Administrative Agency

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<tr>
<th>CEO Expectations of the Administrative Agency</th>
<th>Administrative Agency Expectations of the CEO</th>
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<tr>
<td><strong>Fair/Appropriate Use of Funds</strong></td>
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<td>Assistance in developing, monitoring, and</td>
<td>Periodic attention to IGAs, including help in</td>
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<td>updating IGAs, to encourage services and</td>
<td>preventing and resolving conflicts with other</td>
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<td>minimize grievances across the service area.</td>
<td>jurisdictions and their CEOs.</td>
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<td>Help in establishing linkages between all</td>
<td>Support in establishing linkages across</td>
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<td>Ryan White programs and other HIV/AIDS,</td>
<td>agencies, including EIS, prevention, and</td>
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<td>health, and support service programs</td>
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<td>including linkages with EIS, prevention, and</td>
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<td>substance abuse programs.</td>
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<td>Assistance in monitoring the use of Ryan</td>
<td>Support in funding allocation decisions to</td>
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<td>White funds as the payer of last resort, and</td>
<td>ensure that Ryan White is the payer of last</td>
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<td>allocation of funds in accordance with</td>
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<td>established service priorities.</td>
<td>service priorities established through the</td>
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<td>comprehensive planning process.</td>
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<td><strong>Grant Administration</strong></td>
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<td>Regular communication about HAB/Division of</td>
<td>Active assistance in resolving problems with</td>
</tr>
<tr>
<td>Metropolitan HIV/AIDS Programs concerns or</td>
<td>HAB/Division of Metropolitan HIV/AIDS Programs</td>
</tr>
<tr>
<td>failure to comply with conditions of grant</td>
<td></td>
</tr>
<tr>
<td>award.</td>
<td></td>
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<tr>
<td>Preparation of complete grant applications</td>
<td>Assistance in ensuring cooperation from other</td>
</tr>
<tr>
<td>for Ryan White Part A funds; timely</td>
<td>agencies and offices in preparing grant</td>
</tr>
<tr>
<td>communication concerning problems or</td>
<td>applications. Assistance in resolving</td>
</tr>
<tr>
<td>weaknesses prior to submission of the grant</td>
<td>potential problems prior to application</td>
</tr>
<tr>
<td>application.</td>
<td>submission. Sign-off on application or</td>
</tr>
<tr>
<td></td>
<td>delegation of authority for such sign-off.</td>
</tr>
<tr>
<td><strong>Procurement</strong></td>
<td></td>
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<tr>
<td>Establishment and implementation of clearly</td>
<td>Public and private support for the</td>
</tr>
<tr>
<td>stated, equitable, and publicly disseminated</td>
<td>administrative agent’s procurement and</td>
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<tr>
<td>procurement and contracting procedures.</td>
<td>contracting procedures.</td>
</tr>
<tr>
<td>Procurement and contract monitoring that</td>
<td>Ongoing commitment to maintain the</td>
</tr>
<tr>
<td>ensure use of funds is consistent with the</td>
<td>integrity of the procurement process.</td>
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<tr>
<td>service priorities and resource allocations</td>
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<tr>
<td>of the planning council.</td>
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<tr>
<td><strong>CEO Expectations of the Administrative Agency</strong></td>
<td><strong>Administrative Agency Expectations of the CEO</strong></td>
</tr>
<tr>
<td>--------------------------------------------------</td>
<td>--------------------------------------------------</td>
</tr>
<tr>
<td>Implementation of program contract monitoring and fiscal monitoring procedures that ensure funds are used as specified in contracts, and providers are reimbursed promptly.</td>
<td>Support for equitable and consistent contract monitoring and fiscal management procedures; support for rapid allocation of funds; assistance in breaking logjams.</td>
</tr>
<tr>
<td>Updates on procurement process including information on provider performance that may lead to negative reaction or grievances.</td>
<td>Assistance in resolving potential problems with procurement and contracting.</td>
</tr>
<tr>
<td>Recommendations to the CEO for increasing the efficiency of funds disbursal.</td>
<td>Leadership in improving the process of disbursing funds.</td>
</tr>
</tbody>
</table>

**Grievance Procedures**

<table>
<thead>
<tr>
<th><strong>CEO Expectations of the Administrative Agency</strong></th>
<th><strong>Administrative Agency Expectations of the CEO</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Establishment of grievance procedures, including procedures for submitting grievances that cannot be resolved to binding arbitration.</td>
<td>Support for the grievance process and results.</td>
</tr>
<tr>
<td>Regular communication concerning any situations that may lead to grievances, negative publicity, or negative public or community action.</td>
<td>Prompt attention to potential problems and efforts to resolve them before they lead to negative public reactions.</td>
</tr>
</tbody>
</table>

Table 6: Expectations of the CEO and Administrative Agency
Attachment 3: Expectations of the CEO and PLWA

<table>
<thead>
<tr>
<th>CEO Expectations of PLWHA/Affected Community</th>
<th>PLWHA/Affected Community Expectations of the CEO</th>
</tr>
</thead>
<tbody>
<tr>
<td>Direct communication about issues or concerns so the CEO can attempt to resolve them before they lead to serious problems or public reactions.</td>
<td>Access to the CEO to communicate concerns and needs, and leadership in resolving issues.</td>
</tr>
<tr>
<td>Active participation in the Ryan White planning process. Help in identifying nominees for planning council membership.</td>
<td>Selection of PLWHA planning council members who reflect the local epidemic and meet representation requirements. Not making political appointments to the planning council. Not appointing a CEO employee as the sole chair of the planning council. Appointing a CEO employee as co-chair only if bylaws permit.</td>
</tr>
<tr>
<td>Active involvement with local and State agencies and legislative bodies, supporting funding, policies, and other actions to increase and improve HIV/AIDS services.</td>
<td>Promoting HIV programs/policies with other elected officials and local/State agencies. Leadership in seeking Medicaid managed care systems that meet the needs of PLWHA.</td>
</tr>
</tbody>
</table>

Table 7: Expectations of the CEO and PLWA

IX. Ch 7. References, Links and References


For More Information

Please refer to the HAB Target Center at [https://careacttarget.org](https://careacttarget.org).
Section X. Planning Council Operations

X. Ch 1. Overview

Most Ryan White funds are grants awarded to EMAs/TGAs and State to address the needs of PLWHA. Many decisions about how to use the money are made by local planning councils and State planning groups, who work as partners with their governments in making decisions about how to use the funds.

Before the EMA or TGA can receive Ryan White Part A funds the CEO must appoint a planning council. Beginning in 2006 new TGAs can establish a community planning process that does not require a planning council. The CEOs in those TGAs decide whether to form a planning council or obtain consumer and community input in some other way.

The Ryan White legislation requires planning councils to have members from various groups and organizations. At least one third (33 percent) of the planning council members must be PLWHA who receive Ryan White Part A services and are “unaffiliated.” This refers to consumers who do not have a conflict of interest, meaning they are not staff, consultants, or Board members of Ryan White Part A funded agencies.

The Planning Council must find out what Ryan White services are needed and what populations need care (needs assessment). Next, it decides what services to fund in the EMA/TGA (priority setting) and decides how much Ryan White Part A money should be used for each of these services (resource allocation). The planning council works with the grantee to develop a long-term plan on how to provide these services (comprehensive plan). The planning council also looks for ways that Ryan White Part A services work to fill gaps in care with other Ryan White programs (through the Statewide Coordinated Statement of Need or SCSN) as well as other services like Medicaid and Medicare (coordination). The planning council also evaluates how efficiently providers are selected and paid and how well their contracts are monitored (assessment of the efficiency of the administrative mechanism).

In order to respond to these important responsibilities, the planning council (and its staff) must carry out many complex tasks to ensure smooth and fair operations and processes in such areas as bylaws, grievance procedures, conduct of public meetings, member recruitment, and training.

X. Ch 2. Legislative Background

Ryan White legislation specifies the following mandated activities that planning councils must accomplish and other requirements and prohibitions related to its operations.

Planning Body Operations

Section 2602(b)(5)(A) of Title XXVI of the Public Health Service (PHS) Act prohibits the planning council from being “directly involved in the administration of a grant” under and does...
not permit it to “designate (or otherwise be involved in the selection of) particular entities as [sub]recipients” of Ryan White Part A funds.

Section 2602(b)(6) of the PHS Act requires the planning council to “develop procedures for addressing grievances with respect to funding [allocation of funds],” and to describe these procedures in its bylaws.

Section 2602(b)(7)(A) of the PHS Act prohibits the planning council from being “chaired solely by an employee of the grantee.”

Section 2602(b)(7)(B) of the PHS Act states that:

i. “The meetings of the council shall be open to the public and shall be held only after adequate notice to the public.

ii. The records, reports, transcripts, minutes, agenda, or other documents which were made available to or prepared for or by the council shall be available for public inspection and copying at a single location.

iii. Detailed minutes of each meeting of the council shall be kept. The accuracy of all minutes shall be certified to by the chair of the council.

iv. This subparagraph does not apply to any disclosure of information of a personal nature that would constitute a clearly unwarranted invasion of personal privacy, including any disclosure of medical information or personnel matters.”

Needs Assessment

Section 2602(b)(4) of the PHS Act requires the planning council to:

A. “determine the size and demographics of the population of individuals with HIV/AIDS, as well as the size and demographics of the estimated population of individuals with HIV/AIDS who are unaware of their HIV status;

B. “determine the needs of such population, with particular attention to:

   i. individuals with HIV/AIDS who know their HIV status and are not receiving HIV-related services;
   ii. disparities in access and services among affected subpopulations and historically underserved communities, and
   iii. individuals with HIV/AIDS who do not know their HIV status.”

Section 2602(b)(4)(G) of the PHS Act requires planning councils to “establish methods for obtaining input on community needs and priorities which may include public meetings, conducting focus groups, and convening ad-hoc panels.”

Priority Setting and Resource Allocation

Section 2602(b)(4)(C) of the PHS Act requires planning councils to “establish priorities for the allocation of funds within the eligible area, including how best to meet each such priority and additional factors that a grantee should consider in allocating funds under a grant based on the:
i. size and demographics of the population of individuals with HIV/AIDS (as determined under subparagraph (A)) and the needs of such population (as determined under subparagraph (B));

ii. demonstrated (or probable) cost effectiveness and outcome effectiveness of proposed strategies and interventions, to the extent that data are reasonably available;

iii. priorities of the communities with HIV/AIDS for whom the services are intended;

iv. coordination in the provision of services to such individuals with programs for HIV prevention and for the prevention and treatment of substance abuse, including programs that provide comprehensive treatment for such abuse;

v. availability of other governmental and nongovernmental resources, including the State Medicaid plan under Title XIX of the Social Security Act and the State Children’s Health Insurance Program under Title XXI of such Act to cover health care costs of eligible individuals and families with HIV/AIDS; and

vi. capacity development needs resulting from disparities in the availability of HIV-related services in historically underserved communities…”

In establishing priorities and allocation of resources, planning Council must consider relevant legislative requirements.

Required Funding for Core Medical Services

Section 2604(c)(1) of the PHS Act requires that at least 75 percent of funds be spent on "core medical services:"

"With respect to a grant under section 2601 for an eligible area for a grant year, the chief elected official of the area shall, of the portion of the grant remaining after reserving amounts for purposes of paragraphs (1) and (5)(B)(i) of subsection (h), use not less than 75 percent to provide core medical services that are needed in the eligible area for individuals with HIV/AIDS who are identified and eligible under this title (including services regarding the co-occurring conditions of the individuals)."

Section 2604(c)(2)(A) of the PHS Act states that the Secretary of HHS may grant a waiver for a grant year:

"if the Secretary determines that, within the eligible area involved-

   i. there are no waiting lists for AIDS Drug Assistance Program services under section 2616; and

   ii. core medical services are available to all individuals with HIV/AIDS identified and eligible under this title."

Core medical services include the following, as stated in Section 2604(c)(3) of the PHS Act:

A. Outpatient and ambulatory health services.
B. AIDS Drug Assistance Program treatments in accordance with section 2616.
C. AIDS pharmaceutical assistance.
D. Oral health care.
E. Early intervention services described in subsection (e).
F. Health insurance premium and cost sharing assistance for low-income individuals in accordance with section 2615.
G. Home health care.
H. Medical nutrition therapy.
I. Hospice services.
J. Home and community-based health services as defined under section 2614(c).
K. Mental health services.
L. Substance abuse outpatient care.
M. Medical case management, including treatment adherence services.

Funding for Support Services

Funding may be provided for support services as specified in Section 2604(d):

“The term ‘support services’ means services, subject to the approval of the Secretary [of Health and Human Services], that are needed for individuals with HIV/AIDS to achieve their medical outcomes (such as respite care for persons caring for individuals with HIV/AIDS, outreach services, medical transportation, linguistic services, and referrals for health care and support services.”

“The term ‘medical outcomes’ means those outcomes affecting the HIV-related clinical status of individuals with HIV/AIDS.”

Allocation of Funds to Services for Infants, Children, Youth, and Women

Section 2604(f)(1) of the PHS Act specifies that "[f]or the purpose of providing health and support services to infants, children, youth, and women with HIV/AIDS, including treatment measures to prevent the perinatal transmission of HIV, the chief elected official of an eligible area, in accordance with the established priorities of the planning council, shall for each of such populations in the eligible area use, from the grants made for the area under section 2601(a) for a fiscal year, not less than the percentage constituted by the ratio of the population involved (infants, children, youth, or women in such area) with HIV/AIDS to the general population in such area of individuals with HIV/AIDS.”

This provision does not require planning councils to create a special priority for services to these populations. A waiver to this provision can be granted when EMAs/TGAs can demonstrate that the needs of each population or combination of these populations is being met through other programs such as Medicaid, the Children's Health Insurance Program (CHIP), or other Federal or State programs.
Comprehensive Planning

Section 2602(b)(4)(D) of the PHS Act requires the planning council to “develop a comprehensive plan for the organization and delivery of health and support services described in section 2604 that:

i. “includes a strategy for identifying individuals who know their HIV status and are not receiving such services and for informing the individuals of and enabling the individuals to utilize the services, giving particular attention to eliminating disparities in access and services among affected subpopulations and historically underserved communities, and including discrete goals, a timetable, and an appropriate allocation of funds;

ii. includes a strategy to coordinate the provision of such services with programs for HIV prevention (including outreach and early intervention) and for the prevention and treatment of substance abuse (including programs that provide comprehensive treatment services for such abuse); and

iii. is compatible with any State or local plan for the provision of services to individuals with HIV/AIDS; and

iv. includes a strategy, coordinated as appropriate with other community strategies and efforts, including discrete goals, a timetable, and appropriate funding, for identifying individuals with HIV/AIDS who do not know their HIV status, making such individuals aware of such status, and enabling such individuals to use the health and support services described in section 2604, with particular attention to reducing barriers to routine testing and disparities in access and services among affected subpopulations and historically underserved communities.”

Coordination

Section 2602(b)(4)(F) of the PHS Act calls for the planning council and grantee to “participate in the development of the statewide coordinated statement of need initiated by the State public health agency responsible for administering grants under Part B.”

Section 2602(b)(4)(H) of the PHS Act requires the planning council to “coordinate with Federal grantees that provide HIV-related services within the eligible area.”

Assessment of the Administrative Mechanism and Effectiveness of Services

Section 2602(b)(4)(E) of the PHS Act requires planning councils to “assess the efficiency of the administrative mechanism in rapidly allocating funds to the areas of greatest need within the eligible area, and at the discretion of the planning council, assess the effectiveness, either directly or through contractual arrangements, of the services offered in meeting the identified needs.”
Planning Councils in Transitional Grant Areas

Section 2609(d)(1) of the PHS Act specifies that:

- The Chief Elected Official of a new TGA “may elect not to comply with the provisions of section 2602(b) if the official provides documentation to the Secretary that details the process used to obtain community input (particularly from those with HIV) in the transitional area for formulating the overall plan for priority setting and allocating funds from the grant” and
- Through fiscal year 2013, this exception “does not apply if the transitional area involved received funding [under Ryan White Part A] for fiscal year 2006.”

### ENTITIES IN THE RYAN WHITE PART A STRUCTURE

Community planning and local decision making are at the core of the Ryan White Part A Program. Many parties are involved in carrying out Ryan White planning and implementing the Program. This structure provides for diverse input into the decision-making process but also involves challenges in managing conflicts of interest, multiple political and programmatic agendas, and competition for scarce resources. Key entities in Ryan White Part A in addition to the planning council include: HAB/DMHAP, the Chief Elected Official (CEO) of the EMA/TGA, the designated local entity administering Ryan White Part A funds, service providers, affected communities, and PLWHA.

- **Chief Elected Official (CEO).** The official recipient of Ryan White Part A funds in each EMA/TGA is the CEO of the city or county that administers the public health agency providing health care to the greatest number of individuals with AIDS. Usually, the CEO is a mayor, county executive, or chair of the county board of supervisors. The CEO has ultimate responsibility for establishing the planning council and appointing its members, administering the Ryan White Part A program, and ensuring that all legal requirements are met.

- **Grantee.** The CEO is the official Ryan White Part A grantee. However, the CEO usually delegates authority for administering Ryan White Part A funds to a public agency or unit—most often the health department. This entity is also referred to as the grantee. Using the terms CEO and grantee helps to distinguish between the person ultimately responsible for the Ryan White grant (the CEO) and the entity responsible for day-to-day operations associated with the program (the grantee).

- **Administrative or Fiscal Agent.** Sometimes the grantee agency administers the Ryan White Part A program directly. Sometimes it chooses another organization, agent, or other entity (e.g., public health department, community-based organization). This entity is called an administrative or fiscal agent because it assists in carrying out administrative activities (e.g., disbursing program funds, developing reimbursement and accounting systems, developing requests for proposals, monitoring contracts).

Table 8: Entities in the Ryan White Part A Structure
X. Ch 3. Planning Council Responsibilities

Introduction

Planning councils are responsible for their smooth and fair operations; and, carrying out mandated duties under the Ryan White legislation. Operations include bylaws, open meetings, grievance procedures, and conflict of interest standards. It also involves establishing and maintaining a productive working relationship with the grantee, developing and managing a budget, and ensuring necessary staff support. Planning council duties include planning, priority setting and resource allocation processes as well as assessment of administrative mechanisms and effectiveness.

A. Planning Council Operations

The ability of the planning council to carry out its legislative responsibilities depends on an appropriate structure, policies, and procedures to guide planning council operations. Among these considerations are the following:

- **Open Meetings.** The legislation requires that planning council meetings be open to the public and that appropriate public notice be provided for all meetings. This includes meetings of planning council committees and task forces as well as the full planning council.

- **Council Chair.** The planning council needs a chair or co-chairs. The legislation does not permit an employee of the Ryan White Part A grantee to serve as the chair of a planning council. An employee of the grantee may serve as a co-chair, provided the bylaws of the planning council permit or specify that arrangement. Bylaws should specify whether there is to be a chair or co-chairs and how they are selected. They may specify that the chair is to be appointed by the CEO or elected by the Planning Council. Often, if the chair is appointed by the CEO or is an employee of the grantee, bylaws require that the planning council elect the co-chair. Sometimes bylaws require that one co-chair be a PLWHA.

- **Meetings and Minutes.** To comply with legislative requirements around open meetings and public access to minutes and other planning council documents, planning councils must:
  
  o Ensure that meetings are open to all members of the general public and maintain a system that provides for public written notice of all council meetings. This includes publication of the meeting notices in local print media and through other forums accessible to the disabled (i.e., the hearing- or speech-impaired). Meeting times and locations should be announced on the planning council or health department website and on other appropriate online media.

  o Have a summary of the minutes that has been approved by the planning council and certified by the chair of the planning council available for public inspection. Both the minutes and other documents or materials made available to or prepared for the
planning council should be available to the public within six weeks after the meeting date.

- Have a publicly accessible location where minutes and other legislatively required information can be inspected and copied if requested. It is important that detailed minutes are required. Some Planning Council’s are making their minutes concise, just the outcomes. Minutes need to be able to show how the Council arrived at their funding decisions, especially if there is a grievance.

  - Section 2602.b.7.(ii) of the PHS Act: The records, reports, transcripts, minutes, agenda, or other documents which were made available to or prepared for or by the council shall be available for public inspection and copying at a single location.

  - Section 2602.7.B (iii) of the PHS Act: Detailed minutes of each meeting of the council shall be kept.

- Take appropriate steps to guard against disclosure of personal information that would constitute an invasion of privacy. For example, minutes should not indicate the HIV status of planning council members unless they are publicly disclosed, and should never provide medical or health status information about a member.

- Make available for public inspection records of the recommendations made by committees or other subgroups to the planning council, as well as the subsequent actions taken by the planning council. A sound practice to implement this requirement is to post approved planning council and committee minutes on the planning council website.

- Where local, county, or State regulations, ordinances, or statutes are more stringent than Ryan White requirements, follow these more stringent requirements. For example, many States and municipalities have open meeting laws that have very specific public notice or other requirements. Planning councils must adhere to these requirements, and planning council members and support staff should receive information and training about these requirements.

### B. Planning Council Duties

#### Needs Assessment

One of the main planning tasks for the planning council is to conduct a needs assessment to find out what services are needed, what populations need care, and what the gaps in the current system of care are. Needs assessment must include consideration of PLWHA who know their status but are not in care and people who are HIV-positive but unaware of their status. (See the Needs Assessment chapter.)
Priority Setting and Resource Allocation

Based upon the results of the needs assessment, and other information, the planning council sets priorities for the allocation of funds. (See Priority Setting and Resource Allocation chapter.)

Comprehensive Planning

The planning council develops a comprehensive plan on how to provide these services. (See Comprehensive Planning chapter.)

Coordination

The planning council shares responsibility with the grantee for ensuring that Ryan White services and funds are coordinated with other programs and services, to provide a comprehensive continuum of care for PLWHA. This includes looking for ways that Ryan White Part A services can work with other Ryan White and non-Ryan White programs to fill gaps in care. The planning council learns about service needs and gaps from the perspective of all Ryan White Parts through the Statewide Coordinated Statement of Need (SCSN) that is developed at least every three years under the coordination of the Part B program; special attention should be given to early intervention services, HIV prevention, and substance abuse prevention and treatment; and ongoing coordination with other services like Medicaid. (See chapters on Coordination, Care/Prevention Collaborative Planning, the SCSN, and Coordination of Payers and Programs.

Assessment of the Administrative Mechanism

The planning council assesses the efficiency of the administrative mechanism, which involves how rapidly funds are allocated. This is the only situation in which the planning council considers issues related to procurement and contract management, which are the grantee’s sole responsibility. The purpose is to assure that funds are being contracted for quickly and through an open process, and that providers are being paid in a timely manner. The planning council should not be involved in how the administrative agency monitors providers, nor should the names or situations of individual providers be included in the assessment.

Generally, assessments are based on time-framed observations of procurement, expenditure, and reimbursement processes. For example, the assessment could identify the percent of funds obligated within a certain time period (e.g., 90 days) from the date of grant award and the percent of providers that are reimbursed within a specified number of days following submission of a monthly invoice. Reimbursement processes can be tracked from date of service delivery through invoicing to payment, with documentation delayed payments and, where feasible, any adverse impact on clients or providers. This information is usually obtained from the grantee in aggregate form. Sometimes the planning council will arrange to obtain information directly from providers. In such situations, it is important that someone other than a planning council member receives and aggregates the information so the planning council receives only the combined data.

In assessing the administrative mechanism, communication between the grantee and planning council is essential so that information sharing is timely and efficient. The assessment is
conducted annually. Prior to the beginning of the procurement process, the planning council and grantee should agree on the process, documentation, responsibilities for data gathering and data sharing, deliverables, review and response process, and timeline. This information should be written in a memorandum of understanding which is then approved by both parties.

The grantee must communicate back to the planning council the results of its procurement process. The planning council may then assess the consistency of the contracted service dollars with its stated service priorities and allocations. If the council finds that the existing mechanism is not working effectively, it is responsible for making formal recommendations for improvement and change, and the grantee is responsible for responding in writing, indicating how it will address these recommendations.

HAB/DMHAP will occasionally request information about the assessment or require EMAs/TGAs to submit a copy of the most recent administrative assessment as part of progress reports or grant applications.

The planning council may also assess whether the services that have been procured by the grantee are consistent with stated planning council priorities, resource allocations, and instructions as to how to meet these priorities. However, assessing the administrative mechanism is not an evaluation of the grantee or individual service providers, which is a grantee responsibility. (See the Outcomes Evaluation chapter in this section of the manual.)

**Evaluation of Service Effectiveness**

The planning council and grantee should determine what impact services are having on client health outcomes (outcomes evaluation) and also examine the cost-effectiveness of the services being delivered. As discussed in the chapter on Outcomes Evaluation, the planning council has the option of evaluating the “effectiveness of the services offered in meeting identified needs.”

**Relationships Among Ryan White Part A Entities**

In order for planning councils to function efficiently, it is important to understand the relationships between and among grantees, planning councils, PLWHA, and planning council support staff (including consultants and shared staff of the council and grantee).

**The Planning Council and the Grantee**

The planning council is a legislatively constituted body with clearly defined responsibilities in Ryan White planning and decision making. Its members are appointed by and it is ultimately responsible to the CEO. It works in partnership with the grantee but not under its direction.
The planning council is expected to be given full authority and support to carry out its roles and responsibilities. While the authority to appoint the planning council is clearly vested in the CEO, the planning council is not intended to be advisory in nature. It has legislatively provided authority to carry out its duties.

**Table 9: Planning Council**

**Separation of Planning Council and Grantee Roles**

While the CEO may designate a specific department within local government to administer the program, it is not appropriate for the grantee to perform duties related to the planning council’s legislative responsibilities. A separation of grantee and planning council roles is necessary to avoid conflicts of interest. This is why the legislation prohibits the planning council from being “chaired solely by an employee of the grantee.” The two entities must work closely together, however.

**Memorandum of Understanding**

To clarify the roles of the planning council and the grantee, and to encourage a collaborative working relationship, HAB/DMHAP recommends that these two entities develop a written agreement (a Memorandum of Understanding) that identifies the individual and shared responsibilities of both parties, lists and provides a timeline for sharing of information or reports that will be regularly provided by each body, and specifies communication mechanisms and a process for solving conflicts. The role of planning council staff should also be included. The MOU should be consistent with planning council bylaws and operating procedures.

A clear delineation of roles and responsibilities will help ensure timely and efficient completion of the Ryan White Part A tasks necessary for obtaining and making effective use of Ryan White Part A funds and for developing and continually strengthening a continuum of care that addresses the needs of PLWHA.

**Planning Council Support**

The planning council needs funding to carry out its responsibilities. HAB/DMHAP refers to these funds as “planning council support.” Planning Council Support funds are part of the 10 percent administrative funds available to the grantee for managing the Ryan White Part A program. The planning council must negotiate the size of the planning council support budget with the grantee and is then responsible for developing and managing that budget within the grantee’s grants management structure.

Planning council support funds may be used for such purposes as hiring staff, developing and carrying out needs assessments and estimating unmet need, sometimes with the help of consultants, conducting planning activities, holding meetings, and assuring PLWHA participation. During the planning process for each program year, the grantee and planning
council will determine the amount or percentage of administrative funds to be used for planning council support.

The planning council, with the help of its support staff, will then develop a budget that enables it to complete its legislative responsibilities and provide that budget to the grantee. The grantee will ensure that the budget meets both Ryan White Part A and grantee requirements, and will allocate and manage those funds, providing regular reports to the planning council. The planning council will be responsible for determining the need for any budget modifications during the program year.

**Procedures for Selecting Support Staff and Consultants**

The procedures to be used in hiring planning council support staff or contracting with consultants need to be agreed upon ahead of time with the grantee and should be a part of any MOU between the planning council and grantee. Planning council staff may be employed through the grantee’s payroll system, but measures must be taken to ensure that the planning council, not the grantee, directs the work of the planning council’s staff.

A planning council is not permitted to be directly involved in selecting particular entities to receive Ryan White funding for services, but it can be involved with selecting entities and people to carry out activities directly related to planning council functioning and responsibilities, such as planning council support staff and consultants. It should be keenly attuned to potential conflicts of interest (real or perceived) in these hiring decisions. The planning council determines the scope of work, sets criteria for selection, and evaluates proposals, while the grantee ensures that these procedures meet its procurement requirements.

**Shared Staff of Grantee and Planning Council**

HAB/DMHAP discourages the practice of having the same staff person perform work for the grantee and provide support to the planning council. However, sometimes—because of limited funds—this situation is unavoidable. The challenge presented in such situations is to balance that dual role with the legislative intent of Ryan White legislation to provide the planning council with full authority and autonomy to carry out its mandated responsibilities. Having a single staff member perform dual roles could compromise objectivity. A special complication is the planning council’s responsibility to assess the grantee’s administrative mechanism for distributing and managing Ryan White Part A funds. A single staff member who performs both grantee and planning council support roles may be in the conflicted position of evaluating his/her own work.

To address this challenge, a planning council and grantee sharing a staff member should:

- Define in writing the functions/activities of planning council and grantee staff.
- Clarify assignments and responsibilities.
- Cost out time and ensure that resource needs are reflected in the budget justifications for grantee administrative expenses (which include planning council support).
Clearly specify lines of communication and reporting for the staff member so that work performed for the grantee is reported to the grantee contact and planning council support work is reported to the planning council chair, a committee, or the full council.

**People Living With HIV/AIDS**

In fulfilling its roles and responsibilities, a planning council must include PLWHA in all its activities. The Ryan White legislation, in Section 2602(b)(5)(C) of Title XXVI of the Public Health Service (PHS) Act, requires that at least 33% of voting planning council members be consumers of Ryan White Part A services who are not officers, employees, or consultants of any entity that receives Ryan White Part A funds. The individuals who meet the 33% unaligned definition must (like the planning council as a whole) reflect the demographics of the population of individuals with HIV/AIDS in the EMA/TGA.

Inclusion of PLWHA brings unique benefits, including a consumer perspective to all decision making and a link between the planning council and the community served. It also presents challenges, such as the need for:

- Training and mentoring to make new members familiar with the legislation and the roles and responsibilities of a Ryan White Part A planning council.
- Flexibility to address changing health status.
- Methods to help PLWHA become comfortable with the planning council’s processes, which often involve difficult decision making, challenges related to relationships, and frustrations due to the time required to accomplish needed improvements in the system of care.
- Especially for representatives with limited incomes, resources to address transportation, child and other dependent care, and other direct financial costs of planning council membership.

HAB/DMHAP strongly recommends that planning councils adopt a variety of strategies to strengthen the effective participation of PLWHA. It helps planning councils to successfully address the challenges of recruiting and maintaining the active participation of PLWHA in planning council processes.

**Program and Fiscal Monitoring**

Program and fiscal monitoring are grantee responsibilities as part of Ryan White Part A grant administration. Program and fiscal monitoring are related functions, and both involve ensuring that funded providers meet Federal standards and Ryan White specific requirements, such as the Ryan White Part A National Monitoring Standards.

- Program monitoring involves assessing the quality and quantity of the services being provided by a particular contractor in such terms, as whether services are being provided, how well they are being provided, and whether goals of the contract are being met. Such monitoring might include reviewing program reports, making site visits, and/or reviewing client data and utilization rates.
Fiscal monitoring involves assessing how quickly, efficiently, and appropriately contractors use Ryan White funds. This type of monitoring includes review and assessment of monthly expenditure patterns for groups of service providers, as well as processes to ensure adherence to Federal, State, and local rules and guidelines on the uses of Ryan White funds. Planning councils should request that the grantee or administrative agency provide them with aggregate summary reports of the information collected during these site visits, ideally on a regular quarterly or biannual basis. Grantees should not provide and planning councils should not have access to individual provider information, but should receive data by service category and/or across service categories. (If a service category has only one provider, the planning council should receive the data, but without identification of the provider.)

Planning councils can benefit greatly from knowing, for example, the percentage of agencies within a particular service category that have been able to meet established goals for serving specified numbers of clients with regard to race/ethnicity and gender, number and size of waiting lists, and the extent to which providers are meeting HRSA/HAB performance standards, implementing clinical quality management programs, documenting client health outcomes, and documenting system changes. Such information will be particularly valuable during implementation of health care reform, helping the planning council to determine the need for changes in service models or allocations.

Data provided by the grantee can help planning councils evaluate the expenditure patterns of the EMA/TGA as a whole as well as service categories. If money is not being spent in an efficient manner, planning councils can know early on and reallocate funds to another service category.

Grantees may redirect funds within a service category without planning council approval, but require such approval for reallocation across service categories. Any redistribution of funds by the grantee that is not consistent may lead to a grievance by the planning council. The planning council must be informed of the changes to service priority allocations that result from any redistribution of program funds by the grantee. As with the initial disbursement of funds, the outcome of any redistribution must be consistent with the priorities and resource allocations of the planning council. Any redistribution of funds by the grantee that is not consistent may lead to a grievance by the planning council.

X. Ch 4. Planning Council Membership

Introduction

Since its inception, the Ryan White HIV/AIDS Program has mandated that the membership of the planning councils responsible for planning and decision making about the use of Ryan White Part A funds include a range of representative categories in order to ensure broad community input. Amendments to the legislation have expanded membership requirements for consumers, providers, care disciplines, and historically underserved populations. These changes are designed to ensure that membership is broadly representative and reflects the local HIV/AIDS epidemic.

Each category of membership meets a specific need. Involvement of those who use Ryan White services ensures crucial input from persons closest to care delivery. Legislative provisions
require that consumer members be free of conflict of interest in relation to funding decisions. Other membership categories—comprising government, service providers, and health professions—are intended to enhance service planning and delivery. This includes coordination of funding streams to address gaps in care, avoid overlaps in services, and create comprehensive service delivery systems that meet the multiple care needs of clients. All categories of membership are designed to bring together expertise in such areas as health planning, service delivery, client perspectives, and financing of care.

Of course, effective participation in planning council decision making requires more than simply filling designated membership slots. Fostering active and meaningful participation of members requires other mechanisms, including training for planning body members, efficient planning council operations, and access to sound data.

A. Legislative Background

Section 2602(b)(1) of Title XXVI of the Public Health Service (PHS) Act requires a Ryan White Part A planning council to “reflect in its composition the demographics of the population of individuals with HIV/AIDS in the eligible area involved, with particular consideration given to disproportionately affected and historically underserved groups and subpopulations.”

Section 2602(b)(2) of the PHS Act lists specific membership categories that must be represented on the planning council. They include:

A. “health care providers, including federally qualified health centers;
B. community-based organizations serving affected populations and AIDS service organizations;
C. social service providers, including providers of housing and homeless services;
D. mental health and substance abuse providers [considered two separate categories];
E. local public health agencies;
F. hospital planning agencies or health care planning agencies;
G. affected communities, including people with HIV/AIDS, members of a Federally recognized Indian tribe as represented in the population, individuals co-infected with hepatitis B or C, and historically underserved groups and subpopulations;
H. non-elected community leaders;
I. State government (including the State Medicaid agency and the agency administering the program under [P]art B) [considered two separate categories];
J. grantees under subpart II of [P]art C;
K. grantees under section 2671 [Part D], or, if none are operating in the area, representatives of organizations with a history of serving children, youth, women, and families living with HIV and operating in the area;
L. grantees of other Federal HIV programs, including but not limited to providers of HIV prevention services; and
M. representatives of individuals who formerly were Federal, State, or local prisoners, were released from the custody of the penal system during the preceding 3 years, and had HIV/AIDS as of the date on which the individuals were so released.”
Section 2602(b)(5)(C) of the PHS Act states that no less than 33 percent of the members must be consumers who:

- “are receiving HIV-related services” from Ryan White Part A-funded providers;
- “are not officers, employees, or consultants” to any providers receiving Ryan White Part A funds, and “do not represent any such entity”; and
- “reflect the demographics of the population of individuals with HIV/AIDS” in the EMA/TGA.

This means that the demographics of the HIV/AIDS epidemic must be reflected by the whole planning council membership and by the consumer membership. In addition, at least two of these consumer representatives must publicly disclose their HIV status.

**HAB/DMHAP Expectations**

The Ryan White HIV/AIDS Program has emphasized representation and reflectiveness from its inception, and this has been enhanced with each reauthorization. For example, the Senate Report from the 1996 Amendments, S. REP. NO. 104-25, at 13-14 (1995), emphasized the importance of planning council membership and the responsibility of HRSA to provide clear guidance and monitor planning councils to ensure representation and reflectiveness. The 2000 amendments, (P.L. 106-345), in Section 101, required that 33% of planning council members be consumers of Ryan White services who are not affiliated with funded providers as staff, board members, or consultants, to avoid conflict of interest.

Section 101 of the 2000 amendments also added recently incarcerated individuals or their representatives to planning council membership. Section 106 of the 2006 re-authorization (P.L. 109-415) added representatives of federally recognized Indian tribes and individuals co-infected with Hepatitis B or C. Similarly, HAB's Division of Metropolitan HIV/AIDS Programs (DMHAP) and its predecessor, the Division Service Systems (DSS), have consistently emphasized that planning councils can be truly effective in meeting their legislated responsibilities only if they have well-supported consumer participation and membership reflective of the local demographics of the HIV/AIDS epidemic.

**Monitoring**

HAB/DMHAP is responsible for providing guidance that establishes a standard for all EMAs/TGAs regarding planning council membership and helps them meet that standard. This includes regularly monitoring planning council membership to ensure that requirements are met in each of the following three areas:

- Representation.
- Reflectiveness.
- Consumer membership.

In turn, planning councils should monitor their membership requirements at the local level with tools used consistently across all EMAs/TGAs. (See attachments to this chapter.)
Implementation of Membership Requirements

Representation, reflectiveness, and consumer membership are essential to fulfilling legislative requirements on planning council membership. They are to be addressed as follows.

**Representation** is the extent to which the planning council includes individuals from the legislatively defined categories of membership. Requirements are as follows:

The planning council must include at least one member to separately represent each of the designated membership categories (unless no entity from that category exists in the EMA/TGA). (See exceptions to this rule, below.) Separate representation means that each planning council member can fill only one legislatively required membership category at any given time, even if qualified to fill more than one. As membership on the planning council changes, an individual member may be moved from one representation category to another to meet legislative requirements. The planning council may choose to include additional representatives within any category to achieve what it considers adequate community representation.

The category “grantees under other Federal HIV programs” is to include, at a minimum, a representative from each of the following:

- Federally-funded HIV prevention services.
- A grantee providing services in the EMA/TGA that is funded under Part F’s Special Projects of National Significance (SPNS), AIDS Education and Training Centers (AETCs), and/or Ryan White Dental Programs.
- The Housing Opportunities for Persons With AIDS (HOPWA) program of the U.S. Department of Housing and Urban Development (HUD).
- Other Federal programs that provide treatment for HIV/AIDS, such as the Veterans Health Administration.

There are three exceptions to the rule on separate representation:

- One person may represent both the substance abuse provider and the mental health provider categories if his/her agency provides both types of services and the person is familiar with both programs.
- A single planning council member may represent both the Ryan White Part B program and the State Medicaid agency if that person is in a position of responsibility for both programs.
- One person can represent any combination of Ryan White Part F grantees (SPNS, AETCs, and Dental Programs) and HOPWA, if the agency represented by the member receives grants from some combination of those four funding streams (e.g., a provider that receives both HOPWA and SPNS funding), and the individual is familiar with all these programs.

Local grantees of, or participants in, other Federal categorical HIV and STD programs should be considered for representation on the planning council, but they are not specifically required.
Reflectiveness is the extent to which the demographics of the planning council’s membership look like the epidemic of HIV/AIDS in the EMA/TGA. Requirements are as follows:

- Reflectiveness should be based upon the combined total of HIV prevalence and AIDS prevalence in the EMA/TGA. This includes at least the following: race/ethnicity, gender, and age at diagnosis.
- As stated above, reflectiveness means that the local HIV/AIDS epidemic must be reflected in both the whole planning council membership and the consumer membership.
- PLWHA should be selected for planning council membership without regard to the individual’s stage of disease.

Reflectiveness does not mean that membership must identically mirror local HIV/AIDS demographics (i.e., it does not mean that if 1.5 percent of local AIDS cases are Asians and Pacific Islanders, then 1.5 percent of planning council members must be from that community).

Consumers are individuals “receiving HIV-related services” from Ryan White Part A providers and include PLWHA receiving services themselves and the parents and caregivers of minor children who are receiving such services.

Consumers are further defined as unaligned. Unaligned means they do not have a conflict of interest, because they have no financial or governing interest in Ryan White Part A-funded agencies – they do not serve as staff, consultants, or board members of such agencies. Consumer representatives counted towards the 33 percent PLWHA/consumer representatives must be unaligned. Consumers who volunteer with a Ryan White Part A-funded provider are not considered to “represent” that entity and are eligible for consumer membership on the planning council as unaligned members. The legislation permits a PLWHA to serve as a volunteer at a Ryan White Part A-funded agency and still be considered unaligned. See the chapter on Conflict of Interest for more information about criteria for determining which members can be included in the 33 percent consumer membership category.

Attachments

Tools for Measuring Representation and Reflectiveness

Attached are tools to help EMAs/TGAs meet legislative requirements for representation and reflectiveness.

**Attachment 1: Planning Council Information Sheet** gathers information from individual planning council members or nominees to help the planning council decide if its current membership meets representation and reflectiveness standards. A “record number” could be used instead of the name. (Forms completed by current members can be tallied on Attachments 2 and 3.) This form can also be used during membership recruitment to gather information about nominees, including membership categories, affiliations, demographics, and skills and interests. For recruitment, you can tailor the areas of interest and expertise listed to reflect the needs of your planning council.
**Attachment 2:** Planning Council Representation Membership by Category helps your planning council ensure that its membership includes all the legislatively required categories.

To complete Attachment 2, for each mandated category, enter the number of planning council members by race/ethnicity and gender. Each individual member should be included on this chart only once. In the second TOTAL row at the bottom of the table, enter the number of unaligned PLWHA by race/ethnicity and gender. The totals at the bottom of Table 3 should add to the total number of planning council members.

**Attachment 3:** Determining Reflectiveness of Unaligned PLWHA on the Planning Council helps you determine the reflectiveness of your planning council overall and of the unaligned PLWHA membership. In column 1, enter the demographics of the HIV/AIDS epidemic in your EMA/TGA in terms of race/ethnicity, gender, and age at diagnosis. Then in Column 2, enter data on the composition of the unaligned PLWHA membership. This process will help you understand the extent to which current planning council membership and PLWHA membership are reflective of the epidemic of HIV/AIDS in your EMA/TGA.

**Attachment 1: Planning Council Information Sheet**

**Planning Council Information Sheet**

Member or Nominee Name or Number: _____________________________________________

**NOTE:** The race/ethnicity and HIV transmission categories on this form are those used by the Centers for Disease Control and Prevention (CDC) for HIV and AIDS reporting and monitoring. The information you provide on this form will be combined with that of other people across our community to help us ensure that our planning council is reflective of the epidemic in this community. Please select the categories with which you most closely identify, even if you don’t use the same terms in describing yourself. All information will be kept confidential and anonymous.

I am: ____ Male  ____ Female  ___ Transgender

I: ____ do self-identify as HIV-positive and am publicly disclosed  
   ____ do self-identify as HIV-positive but am not publicly disclosed  
   ____ do not self-identify as HIV-positive

Ryan White HIV/AIDS Program mandated membership category or categories that I am qualified to represent: (Check as many as appropriate)

   ____ Health care providers, including federally qualified health centers  
   ____ Community-based organizations (CBOs) serving affected populations/AIDS service organizations  
   ____ Social service providers, including housing and homeless services providers  
   ____ Mental health providers  
   ____ Substance abuse providers
Local public health agencies
Hospital planning agencies or health care planning agencies
Non-elected community leaders
Affected communities, including PLWHA and historically underserved groups and subpopulations,
Members of a Federally recognized Indian tribe as represented in the population
Individuals co-infected with Hepatitis B or C
State Medicaid agency
Ryan White HIV/AIDS Program Part B State agency
Ryan White HIV/AIDS Program Part C grantees
Ryan White HIV/AIDS Program Part D grantees, or organizations in the area with a history of serving children, youth, and families with HIV
Ryan White HIV/AIDS Program Part F – SPNS grantees
Ryan White HIV/AIDS Program Part F – AIDS Education and Training Center (AETC)
Ryan White HIV/AIDS Program Part F – Dental Program grantees
Housing Opportunities for Persons With AIDS (HOPWA) grantees
Federally funded HIV prevention programs
Formerly incarcerated PLWHA or their representatives

I can contribute to the planning council in the following areas of interest or experience:
(For each area or population group for which you have interest/experience, enter a 1, 2, or 3, with “1” being the most important)
Men of color who have sex with men
White men who have sex with men
Women
Children
Youth
Injecting drug users
PLWHA aged 55 or older
African Americans
Hispanics/Latinos
Immigrants and refugees
Asians/Pacific Islanders
American Indians/Alaskan Natives
Gay, Lesbian, Bisexual, and Transgender populations
General public health care
Outpatient primary medical care
Antiretroviral therapies
Substance use/abuse services
Mental health services
Non-medical support services
HIV prevention
Needs assessment
Comprehensive planning
Performance standards and service outcomes
Quality Management
Program evaluation
### Mandated Categories of Representation and Reflectiveness of the Epidemic in the EMA/TGA

<table>
<thead>
<tr>
<th>Category</th>
<th>White/not Hispanic Male</th>
<th>White/not Hispanic Female</th>
<th>Black/not Hispanic Male</th>
<th>Black/not Hispanic Female</th>
<th>Hispanic Male</th>
<th>Hispanic Female</th>
<th>Asian/Pacific Islander Male</th>
<th>Asian/Pacific Islander Female</th>
<th>American/Indian/Alaska Native Male</th>
<th>American/Indian/Alaska Native Female</th>
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<tbody>
<tr>
<td>1. Health care providers, including federally qualified health centers</td>
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<td>2. Community-based Organizations (CBOs) serving affected populations and AIDS service organizations (ASOs)</td>
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<td>3. Social service providers, including housing and homeless services providers</td>
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<td>4. Mental health providers</td>
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<td>5. Substance abuse providers</td>
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<td>6. Local public health agencies</td>
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<td>7. Hospital planning agencies or other health care planning agencies</td>
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<td>8. Affected communities, including people with HIV/AIDS, members of a Federally recognized Indian tribe, individuals co-infected with Hepatitis B or C, and historically underserved subpopulations</td>
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<td>9. Non-elected community leaders</td>
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<td>10. State Medicaid agency</td>
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<td>Mandated Categories of Representation and Reflectiveness of the Epidemic in the EMA/TGA</td>
<td>White/not Hispanic Male</td>
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<td>Black/not Hispanic Male</td>
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<td>11. State Part B Agency</td>
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<td>12. Part C grantees</td>
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<td>13. Part D grantees, or if none present, representatives of organizations addressing the needs of children, youth, and families with HIV</td>
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<td>14. Grantees of other Federal HIV programs, including HIV prevention programs, Ryan White Part F programs, and Housing Opportunities for Persons with AIDS (HOPWA) grantees</td>
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<td>15. Formerly incarcerated PLWHA or their representatives</td>
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Table 10: Planning Council Representation: Membership by Category: Race/Ethnicity, and Gender
### Attachment 3: Determining Reflectiveness of Unaligned PLWHA on the Planning Council by Demographic Group

<table>
<thead>
<tr>
<th>Race/Ethnicity</th>
<th># and % Living with HIV/AIDS in the EMA/TGA</th>
<th># and % of Unaligned PLWHA on Planning Council</th>
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</thead>
<tbody>
<tr>
<td>White, not Hispanic</td>
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<td>Black, not Hispanic</td>
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<td>Hispanic/Latino</td>
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<td>Asian/Pacific Islander</td>
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<td>American Indian/Alaska Native</td>
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<td>Not Specified</td>
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<td><strong>Total</strong></td>
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<td><strong>Gender</strong></td>
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<td><strong>Total</strong></td>
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<td><strong>Age at Diagnosis (Years)</strong></td>
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<td>&lt;13 years</td>
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<td>13-19 years</td>
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<td><strong>Total</strong></td>
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Table 11: Attachment 3: Determining Reflectiveness of Unaligned PLWHA on the Planning Council by Demographic Group
X. Ch 5. Planning Council Nominations

Introduction

An open nominations process is necessary to obtain a planning council whose membership meets both legislative requirements and the practical needs of the Ryan White Part A program. This requirement is to ensure broad community representation on the planning council, membership that reflects the epidemic of HIV/AIDS in the eligible metropolitan area (EMA) or transitional grant area (TGA), and a diverse range of perspectives during planning council deliberations.

Legislative Background

The Ryan White Part A Program requires an open nominations process for planning council members. The Act also places affiliation and conflict of interest limitations on consumer members of planning councils, which must be reflected in the criteria used to recruit and select planning council members.

Section 2602(b)(1) of Title XXVI of the Public Health Service (PHS) Act states that:

“Nominations for membership on the council shall be identified through an open process and candidates shall be selected based on locally delineated and publicized criteria. Such criteria shall include a conflict-of-interest standard that is in accordance with paragraph (5).”

Section 2602(b)(5)(B) of the PHS Act includes conflict of interest requirements governing individual members of the planning council. The legislation states that:

“An individual may serve on the planning council under paragraph (1) only if the individual agrees that if the individual has a financial interest in an entity, if the individual is an employee of a public or private entity, or if the individual is a member of a public or private organization, and such entity or organization is seeking amounts from a grant under section 2601(a), the individual will not, with respect to the purpose for which the entity seeks such amounts, participate (directly or in an advisory capacity) in the process of selecting entities to receive such amounts for such purpose.”

Section 2602(b)(5)(C)(i) of the PHS Act states that:

“Not less than 33 percent of the council shall be [unaligned] individuals who are receiving HIV-related services” under Section 2601(a) [Part A], “are not officers, employees, or consultants to any entity that receives amounts from such a grant, do not represent any such entity, and reflect the demographics of the population of individuals with HIV/AIDS” in the area.
HAB/DMHAP Expectations

Expectations of CEOs

The Chief Elected Official (CEO) within the EMA/TGA is ultimately responsible for ensuring that the planning council has an open nominations process. HAB/DMHAP expects the following from the CEO:

- The CEO will approve and/or appoint as planning council members only individuals who have gone through the open nominations process.
- Appointments to the planning council will be made in a timely way, to ensure minimal disruption of planning council activities.
- The CEO and the planning council will work together to develop and implement the nominations process and ensure that it is incorporated into the planning council’s bylaws.

Minimum Standards for an Open Nominations Process

An open nominations process must meet the following minimum standards:

- Be described and announced before the nominations process begins.
- Specify clear criteria on the planning council composition being sought to ensure that membership:
  1. Includes the legislatively required positions (membership categories).
  2. Reflects the epidemic of HIV/AIDS in the EMA/TGA.
  3. Reflects the geography of the EMA/TGA.
  4. Reflects any other locally determined membership needs.
  5. Incorporates conflict of interest requirements.
- Be publicized, including advertisements in local HIV publications, notices to service providers, notices in the press, announcements on the planning council website, and other community announcements.
- Allow individuals to apply for membership or to be nominated by others.
- Inform nominees of:
  1. The roles and responsibilities of planning council members.
  2. The time commitments involved in serving on the planning council, including meeting attendance and committee participation.
  3. Conflict of interest standards.
  4. HIV disclosure requirements for consumer members. [Note: HRSA/BMHAP requires that at least two members with HIV/AIDS be publicly disclosed; some planning councils have additional disclosure requirements.]
- Provide for obtaining and review of information from nominees about their experience and background using a standardized, plain-language application form.

Use a representative and impartial nominations or membership committee that reviews all nominations, preferably including interviews with nominees using a consistent set of questions and enabling the nominee to ask questions about membership requirements and expectations.
Implementing an Open Nominations Process

Following are suggestions for meeting legislative requirements and ensuring a diverse planning council.

**Specify Requirements in the Bylaws.** Bylaws should list the legislatively required membership categories and any additional categories considered necessary to meet EMA/TGA planning needs. They should specify terms of office, preferably calling for staggered terms to ensure membership continuity. For example, if members serve three-year terms, one-third of members should have terms ending each year. Be sure that the EMA/TGA membership requirement are reviewed and updated as needed following each Ryan White reauthorization.

Based on the local epidemic of HIV/AIDS and service system, the EMA/TGA may want to establish additional local membership criteria consistent with Federal requirements. For example, Bylaws might specify geographic requirements appropriate for the EMA/TGA, such as membership representation from particular regions or counties or from more than one State if the EMA/TGA crosses State lines. Reflectiveness requirements should also be specified. Bylaws should indicate that the planning council will develop and use an open nominations process (which can be detailed in a separate policy).

**Recruit Widely.** HAB/DMHAP encourages planning councils to work with the CEO’s to carry out broad-based recruitment of nominees, so that selections can be made from a broad spectrum of applicants. Special recruitment is often necessary to reach traditionally underserved populations, involving approaches such as the following:

- Ongoing solicitation of nominees by existing council members and service providers.
- Outreach to service providers and individual staff who serve clients with HIV/AIDS to identify unaligned PLWHA nominees to meet the requirement that 33 percent of planning council members be consumers of Ryan White Part A services that are not directors, staff, or consultants of Ryan White Part A-funded providers.
- Distribution of flyers at various community events.
- Advertising in the print and electronic media, including use of targeted newspaper advertisements in special audience newspapers.
- Posting of the announcement on the planning council website, and use of social media such as Facebook pages where applicable.
- Close cooperation with the planning council’s consumer committee and/or area PLWHA groups.
- Use of outreach programs/committees.
- Word of mouth at planning council, committee, and community meetings.

**Clarify Membership Criteria.** To ensure that planning council composition meets legislative requirements and HAB/DMHAP policy, the nominations process must ensure that all the required membership categories are filled and address the following:

- The overall membership and PLWHA membership must be reflective of the epidemic of HIV/AIDS in the EMA/TGA.
• Chairs and co-chairs of planning councils must reside within the boundaries of the EMA/TGA.
• Planning council members that represent affected communities, PLWHA, non-elected community leaders, or historically underserved groups and subpopulations must reside within the boundaries of the EMA/TGA for the length of term they are serving on the planning council.
• Where feasible, individuals who fill legislatively mandated organizational positions (e.g., other Ryan White HIV/AIDS Program projects, service agencies, other Federal HIV programs) should live within the EMA/TGA, but this is not required. In some cases, such as State agencies that operate in the State capital, this may not be possible. However, such organizational representatives must provide services within the EMA/TGA.

Publicize Membership Criteria. Once developed or revised, membership criteria should be widely publicized. The EMA/TGA should list and/or describe the required membership categories and desired planning council composition in the public announcements used to seek nominations and in the application form.

The announcements should also include a brief description of the process and/or a contact person to call for more information about the nominations process and about time commitments and other demands of planning council membership, as well as where to obtain an application for membership or how to nominate another person for membership.

Address Conflict of Interest Requirements. The nominations process must include a conflict of interest standard that addresses legislative requirements for all planning council members and for consumer representatives. Other local standards or conflict of interest requirements may also be included at the EMA’s/TGA’s discretion. For more information, see the Conflict of Interest chapter.

Use an Application Form. Anyone who wants to be considered for planning council membership should be required to complete an application form that:

• Collects information about the nominee’s characteristics, experience, and background, with specific attention to legislatively mandated membership categories and the characteristics of the local epidemic.
• Includes one or more open-ended questions so nominees can describe their experience, what they feel they bring to the planning council, and why they want to serve.
• Provides information to potential members about time commitments and other demands of planning council membership, meeting schedules, HIV disclosure requirements, and the conflict of interest standard.
• Provides a written description of the nominations process.

Establish and Maintain an Active Membership Committee.

A single Nominations or Membership Committee must consider all nominees to the planning council. HAB/DMHAP realizes that some membership categories are so narrowly defined that only one nominee may meet the criteria. However, all nominees should still be considered by the
committee, which then recommends qualified nominees to the full planning council for review or directly to the CEO depending upon planning council by laws or procedures.

**Provide Nominees to the CEO.** Requirements for an open nominations process do not eliminate or change the authority of the CEO to appoint members of the planning council. However, CEOs must support the established Membership or Nominations committee and process used to screen all nominees. The committee selects candidates for appointment to the planning council and submits a list of one or more candidates for each available position to the planning council, which approves nominees. The names are then sent to the CEO, with qualifications and the demographic information needed to show that the nominees will enable the planning council to meet reflectiveness as well as representation requirements.

From this list the CEO appoints members. Often the CEO will carry out additional screening required for nominees to boards and commissions. If the CEO does not wish to appoint a candidate put forward by the committee, and this decision will create or maintain a vacancy on the planning council, the established nominations process must begin again to identify other candidates. HAB/DMHAP expects the CEO to appoint members expeditiously and not create or leave a vacancy on the planning council by rejecting a candidate without providing clear justification.

**X. Ch 6. PLWHA/Consumer Participation**

**Introduction**

The Ryan White HIV/AIDS Program recognizes the essential role of PLWHA, especially those who are consumers of Ryan White Part A services, in planning and implementing programs to successfully serve targeted populations. A hallmark of Ryan White Part A participatory planning is meaningful and substantial involvement by PLWHA.

PLWHA/consumer involvement requirements have increased since the passage of the original Ryan White legislation. The 2000 legislation requires at least 33 percent of planning council members to be consumers—an increase from earlier provisions requiring at least 25 percent representation. To be included in the 33 percent, they must be consumers of Part A services but have no financial or governance affiliations with funded providers. In addition, consumer members must reflect the demographics of the HIV/AIDS epidemic in the EMA/TGA, paralleling the requirement that the entire planning council membership reflects the local demographics of HIV disease.

Transitional Grant Areas (TGAs) established following the 2006 reauthorization are not required to have planning councils. However, if the TGA decides against establishing a planning council, the CEO is required to provide documentation of the process used to obtain community input, particularly from PLWHA, in formulating the overall plan for priority setting and resource allocations.

Obtaining and maintaining effective PLWHA involvement has major benefits but can also be a major challenge. Barriers to eliciting and maintaining effective PLWHA involvement include
time constraints, complex planning duties, costs of participation, and health concerns. Recruitment measures using a variety of outreach measures are needed to identify consumers prepared to serve actively on the planning council. Retention measures are needed to help members stay engaged and participate fully, such as orientation and training, mentoring, and financial support for the costs of participating.

A. Legislative Background

Section 2602(b)(1) of Title XXVI of the Public Health Service (PHS) Act requires each Ryan White Part A planning council to “reflect in its composition the demographics of the population of individuals with HIV/AIDS in the eligible area involved, with particular consideration given to disproportionately affected and historically underserved groups and subpopulations.”

Section 2602(b)(2) of the PHS Act identifies the groups that must be represented on the planning council.

Among them are representatives of:

- “affected communities, including people with HIV/AIDS, members of a Federally-recognized Indian tribe as represented in the population, individuals co-infected with hepatitis B or C and historically underserved groups and subpopulations;”
- “individuals who formerly were Federal, State, or local prisoners, were released from the custody of the penal system during the preceding 3 years, and had HIV/AIDS as of the date on which the individuals were so released.”

Section 2602(b)(5)(C) of the PHS Act requires that “Not less than 33 percent of the council shall be individuals who:

- “are receiving HIV-related services pursuant to a grant under” [Ryan White Part A]; individuals are “considered to be receiving such services if the individual is a parent of, or a caregiver for, a minor child who is receiving such services.”
- “are not officers, employees or consultants to any entity” receiving Ryan White Part A funds “and “do not represent any such entity”; and
- “reflect the demographics of the population of individuals with HIV/AIDS” in the EMA/TGA.

Section 2609(d)(1) of the PHS Act specifies that

The Chief Elected Official of a TGA established after the 2006 reauthorization “may elect not to comply with the provisions of section 2602(b) if the official provides documentation to the Secretary that details the process used to obtain community input (particularly from those with HIV) in the transitional area for formulating the overall plan for priority setting and allocating funds from the grant.”
B. HAB/DMHAP Expectations

Following are expectations of HAB’s Division of Metropolitan HIV/AIDS Programs (DMHAP) for planning councils in maintaining full and meaningful PLWHA participation.

- **Recruitment of PLWHA.** Attaining diverse PLWHA representation requires systematic outreach into many different communities, with the help of a variety of individuals and community groups, such as the planning council’s consumer committee or caucus, other PLWHA groups, and Ryan White and other providers of HIV-related services (See section below on Recruitment).

- **Orientation and Training.** In meeting Ryan White Part A requirements for consumer representation, HAB/DMHAP expects planning councils to provide appropriate orientation and training and other supports that enable consumers to be fully active participants. This includes ensuring that members understand their roles and responsibilities, expectations for participation, how work is done and decisions are made, and policies and ground rules, and have skills that make them comfortable participating actively in meetings (e.g., understanding of Robert’s Rules of Order). All planning councils need such training, but there may be additional needs for consumers and for other planning council members without prior experience in community planning. Also required is understanding by all planning council members of the importance of PLWHA participation.

- **Monitoring of the “Local HIV Epidemic to Maintain Reflectiveness.** In meeting requirements for consumer as well as overall planning council reflectiveness of the local HIV/AIDS epidemic, planning councils should establish a policy and procedures to keep membership abreast of the area’s changing HIV/AIDS demographics.

- **Engagement of Unaligned Consumers.** As noted, since 2000, the Ryan White legislation has required that the 33 percent of members who are defined as consumers must be Ryan White Part A clients (defined as receiving HIV-related services from Ryan White Part A providers) and must be unaligned (defined as having no financial or governing interest in Ryan White Part A-funded agencies, such as being a board member, employee, or paid consultant to a Ryan White Part A-funded provider). The law permits consumers to be volunteers at Ryan White Part A-funded providers.

  NOTE: Of course, planning council membership may be more than 33 percent consumers and more than 33 percent PLWHA, although the preceding definition must be followed for the purposes of meeting the percentage requirement. Any additional consumer or non-consumer PLWHA members above the required percentage may be aligned with Ryan White Part A providers.

- **Consumer Representation of Recently Incarcerated Populations.** Because of the high infection rate among the incarcerated, Congress has mandated that at least one seat on each HIV planning council be filled by either a recently incarcerated person or a...
representative of the formerly incarcerated. An individual who is formerly incarcerated must meet the following three criteria:

1. Have been in Federal or State prison or local jail and released during the preceding three years,
2. Have been HIV-positive on the date of release, and
3. Be able to adequately represent the health care and support services needs of formerly incarcerated persons.

A person who is not formerly incarcerated but represents this population must have strong linkages with formerly incarcerated and the knowledge and experience to meet the third criterion. One example is the director of a project or organization that serves the formerly incarcerated, including PLWHA.

- **Self-identification as HIV-positive.** HAB/DMHAP does not require that all consumer representatives self-identify at HIV-positive. It does expect that at least two consumer representatives will publicly identify themselves as PLWHA. EMAs/TGAs may establish additional policies around disclosure of HIV status.
BENEFITS OF CONSUMER PARTICIPATION

In addition to being a legislatively-mandated requirement, consumer participation in Ryan White Part A programs has many benefits:

- **Consumer Perspective.** PLWHA provide a critical consumer perspective on Ryan White service planning, delivery, and evaluation. Consumers should reflect the diversity of the local epidemic, which provides for a range of perspectives that contributes to informed decision making.
- **Reality Check.** PLWHA help keep the planning council focused and on track by reminding them of the real issues facing PLWHA and their families, and sharing their actual experiences in seeking and obtaining services.
- **Help in Needs Assessment.** PLWHA can help ensure that needs assessments consider the needs of PLWHA from differing populations and geographic locations, including those receiving care and those not in care. They can help recruit other PLWHA for town halls, focus groups, and other input sessions.
- **Identification of Service Barriers.** PLWHA can identify service barriers that may not be evident to others and can help plan to overcome those barriers.
- **Outreach.** PLWHA can help identify ways to reach PLWHA communities that need to be served, including minority and other special populations with unmet need for services.
- **Quality.** PLWHA who are clients of Ryan White Part A services can give direct feedback on the quality of services (although they should not focus on the quality of services provided by specific providers). Their input helps the planning council determine what services are needed and how best to meet service priorities, including how to improve service delivery models.
- **Community Liaison.** PLWHA can provide an ongoing communications link with diverse segments of the community. They can bring community issues to the planning council and research and care information to the community.

Table 12: Benefits of Consumer Participation

C. Ensuring PLWHA Participation

Planning councils must set up operations to carry out planning tasks smoothly and fairly, and to support strong PLWHA participation as members and as a part of the public. This includes such features as bylaws, open meetings with public comment periods, grievance procedures, and conflict of interest standards. (See below and chapters on Grievance Procedures and Conflict of Interest.) Effective systems and procedures make it easier for all members, including PLWHA, to participate actively.

1. Recruitment of PLWHA

The whole planning council is responsible for recruitment of PLWHA members. Planning councils often use personal contacts and other individual interactions as the chief means of PLWHA recruitment. Recruitment generally requires personal contacts with potential members, but outreach beyond individual networks is important in widening the search. Membership and
outreach committees help overcome recruitment problems. Many such committees have identified the following useful practices in recruiting PLWHA:

- **Establish and Explain Guidelines Regarding PLWHA Member Representation and Affiliation.** Conflict of interest guidelines and grievance procedures should be clearly stated. Clearly define what constitutes an “unaligned consumer.” This requirement is designed to ensure that PLWHA members can represent the interests of PLWHA in the community without conflict of interest.

- **Formalize Recruitment, Nominations, and Outreach Procedures.** The Ryan White HIV/AIDS Program requires that planning councils use an open nominations process to recruit members, and HAB/DMHAP has provided guidance on the components of an open process. (See the Chapter on Open Nominations in this section.) Recruitment and nomination procedures should be formalized, usually summarized in the planning council’s bylaws and further detailed and adopted as policy by the full council. Nominations procedures should address the special importance and challenges of recruiting “unaligned” consumers to the planning council. Then the Nominations or Membership Committee can coordinate recruitment based on this clear and publicly known process.

- **Implement a Formal Outreach and Recruitment Process.** Effective recruitment requires a formal outreach process including contacts throughout the community, not focused on a single organization or limited to individuals or groups personally known to planning council members. The responsibility for PLWHA recruitment should be shared and not placed primarily on the current PLWHA members. Methods of outreach include:
  
  o Contacts with a wide range of non-HIV-specific health groups, social service agencies, and PLWHA groups.
  o Advertisements in local publications and websites, especially those targeting HIV-positive people, racial and sexual minorities, and underserved populations.
  o Posting of opportunities for membership and need for PLWHA members on the planning council Web site.
  o Use of social media such as Facebook.
  o Contacts with local community colleges and universities.
  o Public meetings arranged in consultation with Ryan White Part A service providers and PLWHA groups.

  Outreach materials and programs should emphasize commitment to a diverse HIV-positive membership and be specific about populations that need to be represented.

- **Communicate Expectations Clearly.** Like other planning council members, PLWHA need to know what is expected of them in terms of time requirements, travel, roles and responsibilities, public visibility, etc. A job description is especially helpful. Planning councils should clearly state expectations that PLWHA be clients of Ryan White Part A-funded providers and limitations regarding affiliation with AIDS service organizations (ASOs) or other Ryan White Part A-funded providers. Recruitment materials should also
clearly state what supports are available, such as expense reimbursement, transportation assistance, and child or partner care.

- **State Participation/Attendance Requirements.** Explain required levels of participation in both planning council and committee activities. Make it clear that the planning council has procedures to support participation, such as reimbursement of direct expenses and the use of technology, such as teleconference calls, to enable PLWHA who are ill to participate in meetings. Also explain that attendance requirements are enforced, and that procedures exist for timely removal and replacement of members, including consumer members, who do not participate.

- **Make the Process Efficient and Timely.** If the nominations and selection process is lengthy, planning councils may have PLWHA vacancies for many months, and nominated individuals may lose interest. The selection process should be efficient in filling all membership slots, but especially PLWHA slots. One way to minimize vacancies is to allow PLWHA to serve as members of planning council-related committees, including PLWHA committees or caucuses, both to become familiar with the work of the council before nomination and to remain engaged while awaiting appointment to the planning council.

- **Ensure That Members Reflect Changes in the Local Demographics of HIV/AIDS.** The planning council should revisit its reflectiveness each time a new epidemiologic profile is prepared, then recruit with this information in mind.

- **Do Ongoing Recruitment.** Ongoing recruitment is required because of the changing health status of PLWHA members, as well as to replace members who move, become employees (or consultants or Board members) of a provider and therefore are no longer considered unaligned, change their employment or family status, get burned out, or change their community priorities.

### RECRUITING DIVERSE PLWHA MEMBERSHIP

<table>
<thead>
<tr>
<th>Recruit Diverse PLWHA Membership</th>
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<tbody>
<tr>
<td>Determine the demographics of the HIV epidemic in the EMA/TGA</td>
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<tr>
<td>Establish a policy that planning council membership will reflect the local epidemic</td>
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<tr>
<td>See that planning body leadership is diverse and inclusive, including consumer representation</td>
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<tr>
<td>Set targets, then use a systematic, targeted approach to recruit specific populations</td>
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<tr>
<td>Develop awareness and appreciation of diversity within and between groups</td>
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<tr>
<td>Work for inclusion of groups such as injection drug users, the homeless, and the formerly incarcerated</td>
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<tr>
<td>Develop and consistently implement policies ensuring and requiring member orientation and training, and publicize this commitment</td>
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Table 13: Recruiting Diverse PLWHA Membership
BARRIERS TO PLWHA RECRUITMENT

Recruitment of PLWHA requires first understanding and then overcoming a number of barriers that prevent or discourage PLWHA membership. Barriers may exist within the planning council, the community, and PLWHA. Following are frequently identified barriers, from the perspective of PLWHA and planning councils:

- Lack of PLWHA awareness of Ryan White programs and planning councils
- Lack of knowledge about how to become involved
- Lack of written criteria for membership
- Unclear member roles, responsibilities, and expectations
- Lengthy nomination and selection process
- Lack of consumer representation among planning council leadership
- Belief that PLWHA members are not taken seriously
- Fear of disclosure of HIV status, sexual orientation, drug-using behavior, etc.
- Uncertainty about financial costs of participation
- Limited physical capacity
- Distrust of public programs and providers
- Lack of understanding and/or discomfort with formality and complexity of planning council procedures

Table 14: Barriers to PLWHA Recruitment

2. Maintenance of PLWHA Involvement

Recruiting a diverse PLWHA membership is only the first step in effective PLWHA involvement; sustaining and maintaining effective PLWHA involvement require continuing attention. Many factors – related to the community, the planning council, and the individual – can cause a PLWHA member to become inactive or resign from a planning council.

Many factors that aid in PLWHA recruitment also contribute to their effective and sustained involvement. Outlined below, they include orientation, training, and mentoring to enable PLWHA to participate actively in deliberations and also make participants, including PLWHA members, feel valued.

Orientation. Orientation should occur prior to the new member’s first meeting. All new members – including consumers – should receive a practical orientation to their roles and responsibilities as planning council members, the workplan and timeline of the planning council, policies and operating procedures for meetings (e.g., bylaws, Robert’s Rules of Order), and a typical planning council agenda. They also need an understanding of the structure-committees, their mandates, when they meet, and their leaders’ names and contact information. They should receive a full planning council roster including committee assignments. This kind of orientation offers new members access to the people who are part of the system. The orientation should be
supplemented with a member binder that includes copies of bylaws and policies, roles and responsibilities, as well as information about the system of care and the work of the planning council, but written materials are no substitute for an interactive orientation process.

**Training.** Ongoing training provides the technical knowledge and skills needed for full participation in the planning council’s activities. Planning council members are expected to participate in ongoing training. Training should provide an understanding of the Ryan White legislation and implementation process, the service delivery system and provider profiles, the importance and sources of data, and specific skills related to particular planning and related tasks (i.e., needs assessment, priority setting and resource allocation, comprehensive planning, evaluation).

Training should prepare members to use and understand epidemiologic data and to participate actively in needs assessment, priority setting, and other key processes. HAB/DMHAP provides publications and other assistance to planning councils in providing training as a requirement of the Ryan White HIV/AIDS Program. Through training opportunities, planning council members will recognize complexities within the HIV/AIDS system and understand some of the constraints within the HIV/AIDS service delivery systems.

**Mentoring.** Mentoring helps PLWHA, including new members, feel welcome, learn individual member perspectives, and become comfortable with planning council processes and interaction.

Some planning councils assign each new member to a “veteran” member who takes special responsibility for making sure the new member understands the background and context of discussions and actions, and gets an explanation of the many acronyms used in meetings. Mentoring typically lasts for three to six months.

**Relationship Building.** Developing positive relationships between PLWHA and other planning council members can greatly enhance the planning process through mutual understanding and communication. Periodic retreats or other facilitated sessions build a sense of teamwork and trust among all the planning council members.

**Planning Council Representation.** Requiring PLWHA representation on all committees is another way to increase PLWHA involvement and participation. Such a requirement demonstrates that PLWHA input is needed and valued at all levels of planning council activity.

**Access to Information.** It is important that PLWHA receive information important to them and the consumer community. Address this need by ensuring that materials from the grantee and from the various committees are shared with all planning council members and with PLWHA caucuses.

**Financial Support.** One of the greatest obstacles to PLWHA involvement in planning councils is the financial cost of participation. Costs of attending planning council meetings may involve transportation, child or other dependent care, and meals. Additional expenses may include sending and receiving faxes, making telephone calls, preparing materials, and accessing the Internet. These expenses can present a problem for PLWHA on disability or with very limited
incomes, and for PLWHA who do not have jobs that provide them access to office equipment and supplies.

Financial reimbursement for the direct costs of PLWHA involvement needs to be addressed with respect to several different categories of issues:

- What kinds of Ryan White or other funds are available for use in providing financial support for activities related to PLWHA involvement?
- What kinds of expenses can be covered for PLWHA within legislative requirements regarding “reasonable costs?” and
- What allowable expenses need to be covered in order to ensure strong PLWHA participation in the planning council?

Under Ryan White Part A grants, funds are available not only for administrative costs but also for Planning Council Support. Ryan White funds can be used to cover actual expenses for PLWHA such as child or dependent care, transportation, or other meeting-related costs, as well as for costs related to committee participation, particularly for consumers serving as committee chairs. Planning councils should establish, explain, and consistently implement specific policies related to expense reimbursements for planning council members. These policies should specify what types of expenses are reimbursable, under what conditions, required documentation, and expenditure limits.

Ryan White funds cannot be used to provide cash payments such as stipends or honoraria. The payments must represent reimbursements for actual allowable expenses, backed up by documentation such as taxi receipts.

Generally, expense reimbursement is provided only for unaligned consumer members of the planning council.
### BARRIERS TO SUSTAINED PLWHA PARTICIPATION ON PLANNING COUNCILS

Planning councils and PLWHA have identified many of the following obstacles to sustained PLWHA participation.

#### PLANNING COUNCIL BARRIERS

- Lack of clearly defined roles and responsibilities
- Lack of – or insufficient or poorly planned – orientation and training or mentoring of PLWHA members
- Poor relationships or conflict within the planning council
- Lack of demonstrated respect for PLWHA input – such as lack of PLWHA in committee or overall leadership positions
- Lack of communication within the planning council and limited access to information
- Bureaucratic processes and long delays before “results” are seen
- Unrealistic time/commitment expectations given PLWHA capacities at various stages of illness
- Lack of ongoing supports such as accessible meeting locations, expense reimbursements, rest breaks during long meetings
- Financial costs that are not reimbursed, such as meal costs
- Lack of support for members with special needs (e.g., visually or hearing impaired, limited English proficient)
- Lack of or inadequate commitment to meeting needs of PLWHA
- Lack of flexibility regarding participation (not allowing telephone hook-ups or leaves of absence during periods of illness)

#### COMMUNITY BARRIERS

- Discrimination against PLWHA
- Discrimination against sexual minorities
- Discrimination against people of color
- Large geographic areas requiring time-consuming, long distance travel

#### PERSONAL BARRIERS

- Poor health
- Burnout
- Competing family, professional and/or personal demands on time and energy
- Lack of financial resources – for example, insufficient funds to cover costs even if they will be reimbursed
- Discomfort with processes and requirements of the planning council
- Change in affiliation

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*Table 15: Barriers to Sustained PLWHA Participation on Planning Councils*
3. Nonmember Involvement

All planning councils need input from PLWHA who are not members of the planning council.

Only a small number of HIV-positive individuals are members of planning councils, and they cannot fully represent the entire consumer community. PLWHA should not feel that they are expected to know everything about people infected with or affected by HIV/AIDS. To avoid this additional — if unintentional — pressure on PLWHA, planning councils should encourage broader community input. Either unilaterally, or in partnership with PLWHA committees or caucuses, planning councils can more effectively enhance PLWHA community and public input by:

- Welcoming community PLWHA to planning council and committee meetings.
- Providing a public comment period at each planning council meeting.
- Opening non-governance committees like Needs Assessment to non-planning council members.
- Including in bylaws a consumer or PLWHA standing committee with membership including both planning council members and non-members.
- Providing PLWHA opportunities for input into Ryan White Part A needs assessment and comprehensive planning processes through methods like town hall meetings, sessions with PLWHA caucuses, and focus groups.
- Involving non-planning council members on task forces and work groups so that they can have an active voice in the process without making long-term commitments.
- Providing regular feedback and information access to appropriate segments of the community. The following approaches have been helpful in various communities:
  - Development of methods for involving those who don’t attend meetings, such as a telephone call-in number to connect them to the meeting, enabling them to listen, provide information, or ask questions.
  - Use of online media and publications, including mainstream media and newsletters of PLWHA caucuses and other community organizations, to request input and publicize hearings and community meetings.
  - Holding of periodic community meetings to inform PLWHA about planning council activities as well as to obtain input and feedback.
  - Establishing formal communication structures with special PLWHA caucuses and support groups.

Ryan White funds cannot be used to reimburse expenses of non-members to attend planning council meetings as observers. However, the planning council can reimburse actual meeting expenses for consumers who serve on committees or task forces or make requested presentations to the planning council.
X. Ch 7. Grievance Procedures

Introduction

Ryan White Part A grantees and planning councils are both legislatively mandated to have in place a grievance process regarding funding decisions. The intent is to provide an orderly and fair process for addressing dissatisfactions. Ideally, the best way to deal with grievances is to prevent them by using clear decision-making processes, making decisions in public view, and using a variety of informal methods to resolve potential problems early on. Informal methods can save time and help build positive relationships between consumers and planning council members. When grievances cannot be resolved in this manner, formal written grievance procedures must be available.

A. Legislative Background

Legislative provisions related to grievance procedures are as follows:

Section 2602(b)(6) of the PHS Act requires planning councils to “develop procedures for addressing grievances with respect to funding under this subpart, including procedures for submitting grievances that cannot be resolved to binding arbitration. Such procedures shall be described in the by-laws of the planning council and be consistent with the requirements of subsection (c).” [See below.]

Section 2602(c)(1)(A) of the PHS Act requires the Secretary to “develop model grievance procedures [to guide planning councils and grantees]. Such model procedures shall describe the elements that must be addressed in establishing local grievance procedures and provide grantees with flexibility in the design of such local procedures.”

Section 2602(c)(1)(B) of the PHS Act requires “the Secretary [to]…review grievance procedures established by the planning council and grantees under this subpart to determine if such procedures are adequate. In making such a determination, the Secretary shall assess whether such procedures permit legitimate grievances to be filed, evaluated, and resolved at the local level.”

Section 2602(c)(2) of the PHS Act states that “to be eligible to receive funds under this subpart, a grantee shall develop grievance procedures that are determined by the Secretary to be consistent with the model procedures developed under paragraph (1)(A). Such procedures shall include a process for submitting grievances to binding arbitration.”

B. HAB/DMHAP Expectations

HAB’s Division of Metropolitan HIV/AIDS Programs (DMHAP) expects planning councils to meet the legislative intent for locally defined policies and procedures to address grievances related to Ryan White HIV/AIDS Program funding, with review and assistance by HAB/DMHAP to ensure that these procedures adequately address potential grievances. The legislation calls for local flexibility in the development of grievance procedures and the resolution of grievances through progressive steps that lead up to binding arbitration when
grievances cannot otherwise be resolved. The Ryan White HIV/AIDS Program requires both Ryan White Part A planning councils to establish procedures to address grievances related to funding. At local discretion, grievance procedures can also address other types of disputes faced by planning councils. Costs for filing a grievance are determined locally and must be reasonable.

HAB/DMHAP has developed model grievance procedures to guide local efforts in adequately addressing potential grievances. Many localities had such procedures in place long before Ryan White HIV/AIDS Program requirements and are urged to use or adapt them in meeting legislative requirements. There should be periodic local review of grievance procedures and their implementation to ensure that legislative requirements are being met and grievances are being resolved in a timely and appropriate manner. Any revisions in these grievances should be sent to the HAB/DMHAP project officer to be approved and kept on file.

C. Steps in Dealing With Grievances

The best way to deal with grievances is to avoid them through various dispute prevention measures (see below). When grievances arise, planning councils are expected to follow the steps under the Grievance Procedures described below. First steps should involve non-binding negotiations. For cases that cannot be resolved in this manner, planning councils should undertake the subsequent steps, with binding arbitration as a last resort.

Dispute Prevention

Planning councils can minimize disagreements through dispute prevention, which entails creating a climate of cooperation and open decision making. Dispute prevention measures (which are not a part of the grievance process itself) should be incorporated into the bylaws and operating procedures of each planning council. Similarly, grievance procedures need to be a part of a grantee’s operating procedures. They include, but are not limited to:

- Clear written statements on how decisions are made.
- Open communication during the grant-making process, allowing groups to obtain clarification and an understanding of the criteria used.
- Opportunities for interested parties to provide feedback on ways to improve the decision making process.
- Training of planning council on ways to make decision-making processes inclusive and transparent.
- A designated advocate or ombudsman on staff or on call to work internally with questions or concerns.
- Conflict of interest policies and procedures that are available to the public.

Model Grievance Procedures

These model grievance procedures outline minimum elements that must be addressed in local grievance procedures. They include the following five components:

1. Who may bring a grievance.
2. Types of grievances covered.
3. Non-binding procedures for resolving conflicts.
4. Use of binding arbitration for conflicts that cannot be resolved using non-binding procedures.
5. Rules governing the grievance process.

Each is described below.

1. Who May Bring a Grievance

Individuals or entities directly affected by the outcome of a decision related to funding must be eligible to bring a grievance. Each planning council must define “directly affected.” At a minimum, directly affected parties must include all of the following:

- Providers eligible to receive Ryan White HIV/AIDS Program Part A funding.
- Consumer groups/PLWHA coalitions and caucuses.
- The planning council [the planning council may present a grievance to the grantee].
- Other affected entities and individuals as determined locally, which might include individual consumers or individual planning council members.

Careful consideration should be given to the inclusion of other affected individuals. A balance must be struck between restricting the process too narrowly, which can create tension and distrust, and opening the process too widely, which can overburden and delay the decision-making process.

2. Types of Grievances That Must Be Covered

Decisions with respect to funding must be addressed in local grievance procedures. For planning councils, grievance procedures must cover the process of establishing priorities (including any language regarding how best to meet the established priorities), allocating funds to those priorities, and any subsequent process to change the priorities or allocations.
TYPES OF GRIEVANCES

IN RELATION TO PLANNING COUNCIL ACTIONS

(Priority-setting and Resource-allocation Process) Grievance procedures must allow directly affected parties to grieve:

- Deviations from an established, written priority-setting or resource-allocation process (e.g., failure to follow established conflict of interest procedures).
- Deviations from an established, written process for any subsequent changes to priorities or allocations.

Grievance procedures must allow planning councils to grieve:

- Contracts and awards not consistent with priorities (including any language regarding how best to meet those priorities) and resource allocations made by the planning council.
- Contract and award changes not consistent with priorities and resource allocations made by the council.

Table 16: Types of Grievances

3. Non-Binding Procedures

Non-binding procedures must be in place for attempting to resolve grievances. One such procedure is mediation -- a process in which a third party assists the parties to a dispute in airing concerns and perspectives, finding areas of agreement, and reaching a conclusion that they can accept. Another approach is facilitation, which is similar to mediation except that the facilitator does not typically become as involved in the substantive issues. Yet another technique is an ombudsman, who investigates a grievance and makes a non-binding report to the parties involved.

Non-binding procedures must:

- Designate a person or organization to receive grievances on behalf of the planning council or grantee.
- Provide a form to initiate non-binding dispute settlement that includes at least the following (a sample form is attached):
  - Names, addresses, and telephone numbers of the parties involved.
  - Issue(s) to be resolved and how the person or organization seeking resolution (the grievant) has been directly affected by the decision of the planning council or grantee.
  - Remedy sought by the grievant.
  - Place where or person to whom the form should be delivered.
  - Designated person or position to register the form and notify the grievant of any determinations or decisions that are made.
• Statement of any reasonable administrative fee to be paid by the grievant, and whether payment must be made when the form is filed.

- Specify rules that will apply to non-binding dispute settlement processes (see “Rules for the Grievance Process,” below).
- Provide a mechanism to inform the grievant of the rules that will apply to the process.
- Outline steps the grievant should take if there is no resolution of the grievance within the appropriate time period and the grievant wishes to initiate binding arbitration.

4. Binding Arbitration

Grievance procedures must specify the use of arbitration to resolve disputes when other methods have failed. Arbitration, the use of an independent and impartial third party to decide disputes, is the final stage in the dispute resolution process. Under the grievance process, the decision of the arbitrator is binding on the parties to the dispute.

If the non-binding approach selected by the parties is not successful within a designated time period, or if the third party determines that there is no further purpose to continuing the non-binding process, the grievant has the option of continuing to seek resolution through binding arbitration. Any party that has initiated a grievance that has not been resolved in whole or in part through non-binding procedures must have access to the arbitration process.

At a minimum, arbitration procedures must include the following:

1. A designated person or organization to receive a request for binding arbitration on behalf of the planning council or grantee
2. A form to initiate binding arbitration that includes at least the following:
   - Names, addresses, and telephone numbers of the parties involved.
   - Issue(s) to be resolved and how the person or organization seeking resolution has been affected by the decision of the planning council or grantee.
   - Remedy sought by the grievant.
   - Place where or person to whom the form should be delivered.
   - Designated person or position to register the form and notify the grievant of any determinations or decisions.
   - Previous steps taken under non-binding procedures that have not resulted in agreement.
   - Acknowledgment of the binding nature of the process.
   - Statement of any reasonable administrative fee to be paid by the initiator and whether payment must be made when the form is filed.

3. Rules that will apply to the binding arbitration process (see “Rules for the Grievance Process” below).
4. A mechanism for informing the grievant of the rules that will apply to the process.
5. Rules for the Grievance Process

Both non-binding procedures and binding arbitration must have rules. They provide both the grievant and other parties, including the third party, with a common understanding of how the procedures will be conducted, what is expected of each party, and the time limits and costs of the procedures. Some third parties, or the organizations sponsoring them, have their own set of rules.

Third parties that do not have their own rules may wish to designate an existing set of rules such as those summarized below.

Non-Binding Rules

Non-binding rules must specify at least the following:

- Degree of confidentiality of the process.
- Maximum time period between filing the form and response from the other party.
- The process and time period for designating a third party.
- Time period for holding a meeting of the parties, if necessary.
- Designation of a place for that meeting.
- Maximum length of time that a non-binding process can continue without agreement, after which the third party must end the process and inform the parties of any additional steps (e.g., arbitration) that are available to them.

Binding Arbitration Rules

Binding arbitration rules must specify at least the following:

- Steps in the arbitration process.
- Maximum time period allowed between filing the form and response from the other party.
- Time period set aside for holding a hearing, if necessary.
- Designation of a place for that hearing.
- Time period allocated for the arbitrator to render a decision.
- How the decision will be presented.
- Whether the decision will apply retroactively to the decision that led to the grievance or only to future decisions.

Timing

Grievance procedures that contain time limits on various activities allow for an effective use of the process without resulting in undue delay in the delivery of needed HIV/AIDS services. Time periods must be specified for at least the following:

- Length of time after a decision related to funding has been made, during which a grievance may be brought – the time limit after which a decision or an award can no longer be challenged.
• Time periods for conducting various non-binding processes, including the maximum time allowed to complete the process once initiated.
• Length of time after the conclusion of non-binding processes for the grievant to initiate binding arbitration.
• Time period for conducting the arbitration process.

It is up to the local planning council and grantee to decide the time following a funding decision during which a grievance may be filed. Thirty calendar days (or 20 business days) after the decision is made, or after the decision is announced or made public, probably provides sufficient time for a potential grievant to decide whether to challenge the decision-making process or the funding decision itself.

Non-Binding Resolution. After the request for a non-binding resolution is received, the following time periods, which run consecutively, should be considered for inclusion in local rules (all these times are business days):

• Determination that the grievance or grievant falls within scope of the procedures: 2-5 days.
• Notification of the other party: 1-2 days.
• Selection of a third party: 5-10 days.
• Meeting(s) with parties: 10-15 days.
• Resolution or decision by the third party not to continue (impasse): 5 days.

Binding Arbitration. After the form requesting binding arbitration is received, the following time periods, which run consecutively, should be considered for inclusion in local rules (all these times are business days):

• Determination by the grievant to use binding arbitration: 5-10 days.
• Notification of the other party: 1-3 days.
• Agreement of the parties to arbitrate and selection of an arbitrator: 5-10 days.
• Hearing (if necessary): 10-15 days.
• Decision by arbitrator: 5-10 days.

Costs

Because grievance procedures typically entail costs, rules should address costs of administering the process, including at least:

• Reasonable costs that may be involved for administering the process and for the services of the third party, how they will be allocated between the parties, and when they are due.
• Costs or transfers of funds that may be called for in any settlement agreed to by the parties or a decision of an arbitrator.

Administrative fees are allowable in order to recover reasonable costs of administering the grievance process but should not be so burdensome that they discourage filing of legitimate grievances. It is permissible to require a grievant to pay a reasonable administrative fee to initiate
the process and to require grievants to share in the costs of mediation and arbitration. Third parties (e.g., arbitration services) may also charge a fee for their services. Local procedures should specify any costs that might be involved and how the costs will be allocated in the absence of agreement among the parties.

Funding of Projects After a Grievance Is Filed

Grievance procedures should address how to handle the funding of projects after an award has been made but while a grievance is pending. Procedures should balance the legislative requirement that permits legitimate grievances but not unduly disrupt the expeditious distribution of Ryan White HIV/AIDS Program funds or cause disruption of services. Local procedures should clearly address whether the results of the grievance should be prospectively addressed (i.e., not requiring reversals of decisions such as approved expenditures), or allow for retroactive resolution (e.g., changes in funding decisions).

Review of Grievance Requests

A process should be defined for determining what issues can be grieved and whether the grievant is eligible to bring the grievance. An impartial and diverse committee can be used for this purpose. The purpose of the review is not to add an extra step to the grievance process, but to provide a broader consideration of filed grievances to ensure that decisions are consistent with the purposes and spirit of the grievance procedures as called for in the Ryan White Part A Program.

This process should meet the legislative requirement that procedures should “permit legitimate grievances to be filed, evaluated, and resolved at the local level.”

Selection of Third Parties

Procedures must identify how third parties will be selected for non-binding dispute settlement procedures and for arbitration. Among the factors that should be considered in the third party selection procedures are:

- Conflicts of interest.
- Training and experience.
- Cost.
- Availability during the required time period.

Third parties should be independent of the specific process that is the subject of the dispute and should not have a direct interest in the decision. Procedures must specify the time period and process for selecting third parties for both nonbinding processes and arbitration. Methods for selecting a third party include:

- Advance naming of independent and impartial third parties who can be drawn on to resolve a particular grievance.
• Advance designation of an organization that identifies and provides independent and impartial third parties to resolve a particular grievance.
• Appointment of an independent and impartial third party by the Chief Elected Official (CEO).

To ensure impartial and mutually acceptable third parties, a useful approach is to submit the names of several third parties, with each party asked to cross off any unacceptable names, and the remainder considered acceptable by both. If after several lists, no third party acceptable to both parties has been identified, a designated person or organization should select the third party.

Selecting a group or entity in advance reduces the administrative burden on the planning council but may involve administrative costs for the group selected. Normally, arbitrators and other third parties are approved by all the parties to the dispute. However, the CEO may appoint a third party in a manner that is consistent with these model procedures. A third party designated by the CEO should complete a written statement disclosing any conflicts of interest that might exist between the third party and the parties to the grievance. The parties should be given the opportunity to review the statement.

An issue of concern to many groups or individuals seeking third-party resolution of disputes is where to find third parties. A number of entities can provide assistance, and individual mediators and arbitrators can also be found in many localities. For example, the following organizations maintain lists of trained and impartial mediators and arbitrators and/or organizations that mediate disputes:

• The American Arbitration Association (AAA), which maintains a National Register of Arbitrators and Mediators (http://www.adr.org).
• The Better Business Bureau (BBB), which operates several dispute resolution programs (http://www.bbb.org/us/Dispute-Resolution-Services/); local offices can provide lists of trained volunteer mediators and arbitrators.
• The National Association for Community Mediation (NAFCM), which has a membership of mediation centers (http://www.nafcm.org), typically nonprofit or local government agencies that mediate disputes either free or for reduced fees.
• The Association for Conflict Resolution (http://www.acrnet.org), a professional association of arbitrators, mediators, and other dispute resolution professionals that has an Advanced Practitioner roster.

Many State and Federal court systems run alternative dispute resolution programs, some States have offices of dispute resolution, and both Federal Executive Boards and university-based conflict resolution programs may be able to identify neutral third parties.

Costs and fees for these third parties vary.
Attachment 1: Sample Grievance Form

Ryan White Part A Planning Council

Grievances may be filed against the Planning Council for the following deviations from policy:

- Deviations from an established, written priority-setting or resource-allocation process (for example, failure to follow established conflict of interest procedures); and
- Deviations from an established, written process for any subsequent changes to priorities or allocations.

The procedures that will govern the handling of this grievance are attached.

If you wish to file a grievance with the _____________ EMA/TGA Ryan White Part A Planning Council, this form must be completed, submitted, and received by the [identify designated position and/or office for receiving grievance forms] within 30 calendar days after the date of the alleged deviation or within 30 written days after the decision was made public. You will be contacted within ten (10) business days of the receipt of this form by [specify position]. There is no administrative fee associated with filing this grievance. [Or specify fee.]

When completed, submit this grievance form to the [specify office and address].

Name(s) of Person(s) or Organization(s) Filing the Grievance):

________________________________________________________________________

Address:  _____________________________________________________________

________________________________________________________________________

Telephone Number daytime): _____________________________________________

Date of alleged deviation from established policy: ____________________________

Which policy was allegedly deviated from? _________________________________

Describe in detail the alleged deviation, including how you were directly affected and what remedy you seek:

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

[Add additional pages as needed.]
X. Ch 8. Conflict of Interest

Introduction

Conflict of interest can be defined as an actual or perceived interest in an action that will result—or has the appearance of resulting—in personal, organizational, or professional gain. To illustrate, conflict of interest occurs when a planning council member has a monetary, personal, or professional interest in a planning council decision or vote. Any group making funding decisions for a Ryan White program should be free from conflicts of interest.

Ryan White legislative provisions on conflict of interest for the planning council as a whole are limited to restrictions on planning council involvement in the management of grant funds and participation in the selection of particular entities as recipients of those funds. In addition, planning council membership requirements for unaligned consumer members require attention to conflict of interest.

Because the potential for conflict of interest is inherent in all the activities of the planning council, HAB/DMHAP has broader expectations and requirements regarding minimizing and managing conflict of interest in the functioning of the planning council. Each of these areas is discussed below.

A. Legislative Background

Ryan White legislative provisions on conflict of interest prohibit three types of activities:

- Planning council involvement in the management of grant funds.
- Planning council participation in the selection of particular entities as recipients of those funds (procurement).
- A financial or governance relationship with funded providers on the part of “unaligned” consumer members of the planning council.

Ryan White legislative provisions governing these restrictions are as follows:

Section 2602(b)(1) of Title XXVI of the Public Health Service (PHS) Act requires that candidates for planning council membership “be selected based on locally delineated and publicized criteria” and that “such criteria shall include a conflict-of-interest standard that is in accordance with paragraph (5).”

Section 2602(b)(5)(A) of the PHS Act (the “paragraph 5” referenced above) addresses conflict of interest for the planning council as a whole. It states that “the planning council…may not be directly involved in the administration of a grant… [and] may not designate (or otherwise be involved in the selection of) particular entities as recipients of any of the amounts provided in the [Ryan White Part A] grant.”

Section 2602(b)(5)(B) of the PHS Act addresses conflict of interest for individual members of the planning council. It states that “[a]n individual may serve on the planning council…only if
the individual agrees that if the individual has a financial interest in an entity, if the individual is an employee of a public or private entity, or if the individual is a member of a public or private organization, and such entity or organization is seeking [Ryan White Part A funding], the individual will not, with respect to the purpose for which the entity seeks such amounts, participate (directly or in an advisory capacity) in the process of selecting entities to receive such amounts for such purpose."

As explained in the Conference Report from Congress that accompanied the CARE Act Amendments of 1996, H.R. REP. NO. 104-545, at 33-34 (1996) (Conf. Rep), which included these provisions, it is the intent of the legislation that the planning council “provide guidance to the grantee regarding the types of organizations that may best meet each service priority established by the planning council” and “help to guide the grantees in how best to meet the established service priorities.” It is not intended “that the planning council select which particular organizations receive funding, either by specific direction or by narrowly describing a type of organization. The legislation clearly states that such a planning council role is prohibited.” *Id.* at 34.

Regarding conflict of interest by unaligned consumer representatives on planning councils, Section 2602(b)(5)(C) of the PHS Act requires that consumer representatives be individuals “who are receiving HIV-related services” from Ryan White Part A funded providers; but “who are not officers, employees, or consultants to any entity that receives amounts from such a grant, and do not represent any such entity.”

**B. HAB/DMHAP Expectations**

Below are HAB/DMHAP expectations and requirements for addressing conflict of interest—overall and in specific areas.

**General Requirements**

Ryan White HIV/AIDS Program conflict-of-interest provisions reinforce the distinction between the planning council’s responsibility to set priorities and the grantee’s responsibility to procure particular services.

Specifically, the law prohibits the planning council as a whole from being directly involved in either the administration of a grant or the selection of particular entities to receive Ryan White Part A funds. This means that planning councils may not:

- Name, recommend, or approve particular entities for funding.
- Be involved in the management of the contracts that govern the procurement of services.
- Participate or otherwise be involved in the review of funding applications or selection of providers of services.

Because of an individual members’ relationship to the planning council, sound practice is not to have them serve on external review panels for the selection of Ryan White Part A providers.
Procurement and contract monitoring activities are responsibilities of the grantee and/or the administrative agent of the grantee. They include developing requests for proposals (RFPs), conducting technical assistance and bidders’ conferences, conducting the application review process (typically using external review panels), negotiating contracts, awarding funds, developing reimbursement and accounting systems, and conducting program and fiscal monitoring.

Because planning council members may include representatives of the Ryan White Part A grantee, use of Ryan White Part A funds by the grantee may pose conflict of interest issues. Use of Ryan White Part A funds by the Ryan White Part A grantee for delivery of particular services (e.g., medical care through a health department clinic) should be based on direction from the planning council and/or an objective review process. While local rules on procurement of services may allow the grantee to use funds it administers for its own services, HAB/DMHAP expects that such use will be subject to a public process if other entities in the community could provide the same services. Such a process is in keeping with the spirit of the Ryan White Program, which bases the appropriate and efficient use of scarce resources on input from community and organizational representatives who are directly affected by the HIV epidemic.

**Planning Council Support**

While the legislation prohibits planning councils from participating or otherwise being involved in selecting particular entities for funding, they may be involved in selecting particular entities and individuals to carry out activities directly related to planning council functions and responsibilities. These activities include:

- General planning council administrative duties.
- Needs assessments, such as PLWHA surveys and studies of barriers to care.
- Assessment of service delivery patterns.
- Planning activities such as writing the comprehensive plan.
- Assessment of the administrative mechanism.
- Technical assistance.
- Program evaluation.

In making determinations about who will carry out these activities, planning councils should be keenly attuned to potential conflicts of interest (real or perceived). HAB/DMHAP expects that planning councils and grantees will work together to ensure that high quality planning council support is available and that conflict of interest is minimized through a mutually agreeable process. The planning council must use an open, public process to contract for planning council support services – preferably a competitive RFP process under the direction of the grantee. If a planning council’s procedures allow planning council members or the agencies they represent to compete in this process, the planning council must define specific parameters and processes to manage real or perceived conflicts of interest. A planning council member who has a financial interest in, is an employee of, or is a member of that entity should not be involved or otherwise participate in the selection process.
Conflict of Interest and How Best to Meet Priorities

The Ryan White legislation gives planning councils the responsibility not only to set priorities, but also to establish how best to meet those priorities. The intent of this legislative provision is to establish a role for the planning council in guiding the grantee in identifying the types of organizations and service delivery models or mechanisms that best meet each service priority established by the council. Types of organizations may include, for example, outpatient clinics, community-based organizations that serve affected populations and historically underserved communities, and other types of entities that have been identified as effective in serving identified populations. Planning councils may also identify certain population groups that need to be served, geographic areas in which services should be delivered, and particular State or local government programs that the planning council feels best meet the needs of PLWHA (e.g., a State AIDS Drug Assistance Program [ADAP] or health department clinic). They can identify service models that are effective in reaching and service specific populations.

The language developed by the planning council regarding how best to meet each service priority may not name particular providers as recipients of funds. Nor may the planning council participate or otherwise be involved with drafting specific contract proposal review criteria, reviewing funding applications, or selecting service providers. The grantee, not the planning council, is responsible for developing and implementing an RFP and contract award process. The grantee is obligated to ensure that the outcome of that process meets the priorities established by the council, including directions from the planning council regarding how best to meet the priorities and the dollar amounts allocated to each priority area.

HAB/DMHAP recognizes that in some EMAs/TGAs and for some service categories with a small provider pool, language on how best to meet the priority may result in only a few or a single provider applying for funds. As long as the planning council does not name a particular provider, however, the council is not in violation of the conflict of interest requirements in the Act. A planning council’s designation of the State ADAP program and/or a local health department program as the best way to meet a service priority does not violate conflict of interest requirements.

Monitoring of Contracts and Redistribution of Funds

The planning council is prohibited from being involved in grant administration, and therefore, may not be involved in monitoring the fiscal or program performance of individual contractors. These activities are the responsibility of the grantee. Planning councils cannot name, recommend, or otherwise be involved in the approval of particular providers if a grantee redistributes program funds within a service category based on monitoring of individual contracts.

The grantee must share information about subcontract awards and expenditures with the planning council so that both can monitor spending on each of the service categories identified as priorities by the planning council. The planning council should be able to readily evaluate the level of expenditure, number of people served, and other aggregate information for particular service categories and target populations, and compare actual and projected expenditures and

service utilization. Sound practice is for planning councils to receive data on projected and actual expenditure of funds on a regular quarterly or biannual basis given the need to ensure that funds are fully expended and meet priority PLWHA needs.

If money is not being spent in a timely fashion, or target populations are not being served, the planning council can reallocate funds to another service category. Planning Council prior approval is required before funds can be reallocated from one service category to another. The grantee and the planning council must work together to share appropriate information and ensure that any changes to the planning council priorities are reflected in the grantee’s disbursement (or re-disbursement) of funds.

C. Managing Conflict of Interest

HAB/DMHAP expects planning councils to include in their bylaws and operating procedures provisions for handling conflict of interest in carrying out all planning council activities. Provisions should define conflict of interest and outline ways to manage it. These areas are described below.

Defining Conflict of Interest

Conflict of interest can be defined as *an actual or perceived interest by the member in an action that results or has the appearance of resulting in personal, organizational, or professional gain*. As appropriate, the definition may cover both the member and a close relative, such as a spouse, domestic partner, sibling, parent, or child.

This actual or perceived bias in the decision-making process is based on the dual role played by a planning council member who is affiliated with other organizations as an employee, a Board member, a member, a consultant, or in some other capacity. Most State and local governments have conflict of interest standards in place. Planning councils may wish to refer to them and assess whether they are applicable or can be adapted to the needs of the planning council.

Areas Where Conflict of Interest Can Happen

Although the legislation does not define conflict of interest beyond its relationship to the selection of particular entities, the potential for conflict of interest is present in all Ryan White Part A processes, among them needs assessment, comprehensive planning, priority setting, allocation of funds, and evaluation. Because the activities of the planning council are so central to the allocation and disbursement of resources within an EMA/TGA, the actions of any one member or a group of planning council members can actually be – or be perceived to be – based on individual rather than common interest. It is the responsibility of the planning council as a whole to define conflict of interest, and to specify those actions to which it applies and the types of relationships and decision making covered by it.

Following are conflict of interest considerations for specific areas:
Membership. In most instances, conflict of interest does not apply to PLWHA whose sole relationship to a Ryan White Part A-funded provider is that of a client receiving services or an uncompensated volunteer. However, PLWHA, like other planning council members, should not be involved in decisions that can affect entities in which they have a financial interest or a governance responsibility. Examples of financial interest include being officers, Board members, employees, or paid consultants to Ryan White Part A provider agencies or to the administrative agency that administers that Ryan White Part A grant.

Many members wear “multiple hats” and thus need to clearly identify the perspective they are representing in their membership. A good example of this is the member who is an employee of a funded provider, is a PLWHA, and is a member of a community of color.

Expectations should be clearly defined for members who represent a community. A good planning process gathers diverse perspectives. However, the role of a representative should be communicated clearly, including a job description stating how the representative is expected to communicate with members of the community they represent. This would help deal with a problem where PLWHA either come with a personal agenda or advocate for a particular service provider.

Leadership. An actual or perceived conflict of interest can occur when planning councils are chaired solely by a representative of the grantee. Therefore the Ryan White legislation stipulates that councils cannot be chaired solely by an employee of the grantee. It can, however, be co-chaired by a grantee representative along with another member of the council. Some planning councils require that one co-chair be a consumer or PLWHA.

Needs Assessment. An actual or perceived conflict of interest can occur in the conduct of a needs assessment, particularly with respect to its implementation in planning, priority setting, and resource allocation. Conflict of interest can emerge at decision points of the needs assessment process such as the following:

- How to conduct a needs assessment.
- Which groups to survey.
- What providers to contact when seeking PLWHA to participate in surveys or focus groups.
- What questions to ask.
- How to phrase the questions.
- How to interpret the results.
- How to review external data, such as epidemiologic data.
- Which data to use.
- Which results to implement.

A good needs assessment contains input from consumers and Ryan White Part A providers, as well as agencies beyond the currently funded providers. As such, examples of conflict of interest regarding their input into a needs assessment process might include the following:

- A provider convinces the council to overemphasize the input of its own clients.
• A provider representative determines which agency clients (e.g., the happy ones!) should be targeted for the needs assessment.
• The needs assessment is limited to soliciting the opinions of planning council members rather than focusing on obtaining community input.

**Priority Setting and Resource Allocation.** Examples of conflict of interest in the priority-setting process include the following:

• Failure to use the council’s criteria to set priorities.
• Priorities that are set based on who was the most vocal at the priority-setting meeting.
• Efforts by members affiliated with providers to influence priorities and allocations for their own benefit.
• Efforts by individual members to advocate narrowly for the interests of a particular subpopulation or geographic community instead of basing decisions on the needs of all the eligible PLWHA in the EMA/TGA.
• A choice to fund services that do not match the needs identified in the needs assessment.

When setting priorities, planning councils should look at the big picture—the continuum of care—rather than focus on individual categories of funding. An overall plan minimizes the chances for a single advocacy group to dominate. Priorities should reflect the service needs of all PLWHA throughout the service area. The setting of priorities and the allocation of resources should flow from the data, such as the results of the needs assessment and client utilization data, not from the individual interests of the members. Funding decisions should reflect changes in the local epidemic and be designed to meet the service gaps and unmet need of PLWHA in their region. In justifying priorities, planning councils should discuss the availability of other funding sources to lessen the need for Ryan White Part A funding of a particular service and reduce duplication of effort. The more data-based the decision-making process, the less likely it is that conflicts of interest will influence the process.

**Comprehensive Planning.** In comprehensive planning, conflict of interest can lead to problems such as the following:

• Inadequate planning for underserved populations and subpopulation groups.
• Focus on particular service categories or service models based on provider interests rather than identified needs of PLWHA in and out of care.
• Lack of follow-through in using the results of needs assessments to set goals and objectives.
• An ineffective planning process that results in an ineffective service delivery system not responsive to a changing epidemic.

For effective planning, the planning council should develop a structure that includes specific steps in the development of a plan and a timeline for implementation. A clearly defined planning process provides for broad community input with emphasis on unaligned consumers and prevents persons or organizations with conflicts of interest from directing the process in a biased or unfair way and helps ensure that a plan is followed.
**Assessment and Evaluation.** Planning councils are responsible for assessing their own planning process and have the option of evaluating the cost-effectiveness and efficiency of funded services in meeting the needs identified by their needs assessment. The results of this evaluation should be used to improve the council’s ability to plan and the EMA’s/TGA’s ability to deliver high quality, cost-effective services to meet the needs of PLWHA in their communities. However, conflict of interest can influence: [NOTE: The planning council does not deliver services.]

- The extent to which evaluation is conducted.
- How it is conducted.
- Who can conduct it.
- What the results are.
- How the results are interpreted and used.

Conflict of interest can lead to a stagnant process where the status quo is maintained, with no real evaluation of the planning council’s efficiency and effectiveness or the cost-effectiveness and outcomes of the services provided by the EMA/TGA.

**Techniques for Managing Conflict of Interest**

HAB/DMHAP expects planning councils to employ a variety of strategies to minimize conflict of interest and its potential adverse effects, such as keeping members self-aware of the potential for conflict of interest and using procedures that can minimize or address conflicts. In a broader sense, where the planning council’s deliberations are open and accessible to consumers and the broader public, members are less likely to engage in behavior that reflects narrow concerns or conflict of interest. Examples of useful strategies are as follows:

- **Conflict of Interest Policies and Procedures.** Successful resolution of conflict of interest situations requires adoption of conflict of interest policies and their routine and consistent application in planning council deliberations and decision making. Broad standards should be outlined in the planning council’s bylaws and detailed in separate policies and procedures. The planning council needs to decide what it considers to be a fair and practical method to manage and resolve conflict of interest issues, recognizing that no solution is perfect. Conflict of interest cannot be fully prevented or resolved; it can be managed consistently and fairly. Specific standards and procedures include the following:
  
  - Define conflict of interest to cover not only the individual member but also his/her close relatives.
  
  - Prohibit those with a potential conflict of interest from voting on issues relating to a particular category of service or other matters that directly affect organizations with which they are affiliated. Permit them to vote only on a slate of priorities or a combined set of allocations.
o Ask anyone with a potential conflict of interest to leave the room during the discussion of that category of service or issue as well as while a vote is being taken. There may be cases where a person can answer direct questions without initiating discussion about a specific service category for which that person has a potential conflict of interest. In such cases, the planning council will need to make a determination of the value of the input and the extent of the conflict.

o Assign a co-chair or a committee to review all conflict of interest concerns. Authorize any planning council member to make a request for review of a perceived conflict of interest; define the process of review in writing, establishing timelines so that any review is undertaken in an expeditious manner; and establish policies for dealing with members who engaged in a conflict of interest and/or refused to cooperate in a conflict of interest review.

- **Disclosure Forms.** Many planning councils require members to complete forms that identify any affiliations that may create real or perceived conflicts of interest. The form might include all of the following:

  o A listing of all relationships the member has to organizations that could benefit from an action by the planning council (such as a current or potential Ryan White Part A provider).
  o The relationship that causes the potential conflict of interest (e.g., member serves on the Board, partner is an employee).
  o The duration of the conflict of interest.
  o A description of what actions will be used to prevent or resolve a conflict of interest.

Disclosure forms should be updated annually or whenever an affiliation changes, to maintain accurate information.

- **Public Disclosure:** Members might be required to declare their potential conflicts of interest verbally once a year, semiannually, or even at every meeting. Sometimes disclosure is specifically required during priority setting and resource allocation. Planning council members should be required to provide a verbal disclosure any time discussion or decision making involves an entity or situation in which the member has a real or perceived conflict of interest.

- **Reminders of conflict of Interest.** Among other actions that may be useful in increasing planning council member awareness of conflict of interest are the following reminders:

  o Provide a written or projected matrix of members and their conflicts of interest at every meeting.
  o Provide members with the planning council’s mission statement to remind them of the purpose of their work.
  o Require members to sign a declaration of commitment to the purposes of the planning council.
- **Well Publicized Open Meetings.** Planning council meetings and most committee members are open to the public. Where members of the public, including consumers, are present, planning council members are reminded of their responsibility to represent and serve the community.

- **Input During Meetings.** Orderly processes that can reduce conflict of interest include allowing for regular input from community members at meetings. Requests for time to comment on concerns should be submitted in advance of meetings and the time allocated for public comment should be limited, while allowing for diverse expression and full debate.

- **Other Forums for Input.** Input beyond the planning council membership can include consumer caucuses, provider caucuses, support groups, and ad hoc committees to get input at each step of the process.

- **Clear Processes With Open Participation.** Processes that are well defined and open to the public protect the interests of all planning council members. Included in those processes should be avenues for broad and balanced input from a variety of sources. The needs assessment process, for example, must include input from providers and consumers as well as other interested parties and should not be dominated by a particular group. Similarly, comprehensive planning activities should be based on a clear structure and process that identifies action steps, timelines, and specific roles and responsibilities. Perhaps most important, the setting of priorities and the allocation of resources must flow from the results of the needs assessment and comprehensive planning process.

- **Member Term Limits and Staggered Terms.** This can allow for new voices to be heard.

- **Grievance Procedures.** In cases where a conflict of interest evolves into a dispute, particularly in relation to a funding decision, the planning council may need to turn to grievance procedures to resolve the situation (See the chapter on Grievance Procedures in this section).

**X. Ch 9. Effectiveness of Funded Services to Meet Identified Need**

**Introduction**

The Ryan White HIV/AIDS Program requires that services be provided in a manner that is coordinated, cost effective, and ensures that Ryan White Part A funds are the payer of last resort for HIV/AIDS services. A belief in the cost effectiveness of community-based, ambulatory HIV/AIDS services is at the core of the Ryan White HIV/AIDS Program.

The underlying assumption is that Ryan White services reduce hospitalizations for PLWHA and are more cost effective than inpatient care. An important responsibility for Ryan White Part A entities is to provide programs that make a difference in the most cost efficient manner.
A. Legislative Background

Section 2602(b)(4)(C) of Title XXVI of the Public Health Services (PHS) Act requires Ryan White Part A planning councils to “establish priorities for the allocation of funds within the eligible area, including how best to meet each such priority and additional factors that a grantee should consider in allocating funds under a grant” based on factors that include:

“(ii) demonstrated (or probable) cost effectiveness and outcome effectiveness of proposed strategies and interventions, to the extent that data are reasonably available.”

Section 2603(b)(1) of the PHS Act requires that supplemental grants be based on applications that, among other factors, “(D) demonstrates the ability of the area to utilize such supplemental financial resources in a manner that is immediately responsive and cost effective.”

B. HAB/DMHAP Expectations

Ryan White Part A grantees should be able to compare the relative costs of providing a specific service among different providers. This necessitates having service standards, service units, and unit costs for each service. Quality of service is also a factor in determining cost effectiveness and needs to be considered both in selecting providers and in monitoring Clinical Quality Management programs.

Planning councils need cost-effectiveness data to determine how to prioritize services and allocate funds. This is closely tied to outcomes evaluation in that services with better outcomes may be more costly but nonetheless more cost effective when outcomes are considered. Also important to consider is the way services are provided. For example, bus tokens may be cheaper than but not as effective in assuring access and maintenance in care as taxi vouchers.

Defining Cost Effectiveness

Cost effectiveness includes two interrelated dimensions: outcomes and costs. Ryan White Part A programs should accomplish positive results (be effective) and do so at a reasonable cost (be cost effective). Cost effectiveness can be described in several ways:

- A service or program is considered cost effective when the unit cost is reasonable and acceptable relative to the benefits and outcomes received.
- A service may be considered cost effective if it can be provided less expensively than other similar services, but provides an equal or better outcome. For example, a case management program that is cheaper to operate than other case management programs and serves clients as well or better would be considered cost effective.
- A service is cost effective if it provides an additional benefit worth the additional cost. For example, a case management system that costs more than other systems but is able to document that its results are superior is cost effective.
Uses of Cost-Effectiveness Evaluation

Cost-effectiveness approaches may be used to evaluate any service, activity, or process, so long as it is possible to measure outcomes and determine costs. Cost-effectiveness methods can be used to evaluate:

- Individual providers.
- Categories of service, such as case management or primary care.
- The entire network of services provided through the Eligible Metropolitan Area’s/Transitional Grant Area’s (EMA’s/TGA’s) continuum of care, and Grantee systems and procedures.

Challenges of Cost-Effectiveness Evaluation

Among the greatest challenges of cost-effectiveness evaluation are the following:

- Determining outcomes can be complicated.
- Outcome measures that can serve as indicators for standards of care are still in the development stage in many EMAs/TGAs.
- Calculating unit costs (costs per service unit) or per-client costs is time consuming and often difficult. Many community-based providers do not budget by service unit or client, nor do they record expenses on this basis.
- The larger the unit of assessment, the more complicated the process. It is challenging but least complicated to assess the cost effectiveness of a single provider, more difficult to determine the cost effectiveness of an entire service category, and considerably more challenging to determine the cost effectiveness of the EMAs/TGAs entire continuum of care.

Despite these challenges, approaches to cost-effectiveness evaluation are being developed and improved by many EMAs/TGAs. Materials are available from HRSA/HAB to calculate the unit costs of HIV/AIDS services, and many EMAs/TGAs and grantees have developed unit-cost determination procedures.

Measurement of service outcomes is greatly facilitated by the development of standards of care and indicators addressing expected or desired service results, including the HRSA/HAB performance measures, and the move to collection and reporting of client-level data including clinical measures.

Steps in Evaluating Cost Effectiveness

A typical approach for evaluating the cost effectiveness of services using standards of care includes the following steps:

1. Define and describe the service to be assessed
2. Agree on the standards of care or benchmarks related to service outcomes
3. Determine the unit or per-client costs of these services
4. Determine the outcomes of the service
5. Describe the cost effectiveness of the service in terms of a ratio of cost to attain a specific outcome (e.g., it costs an average of $846 in case management funds to ensure that a client has obtained access to specified core services)
6. Compare and analyze the cost effectiveness of several services using these ratios, or compare the service with stated benchmarks or standards of care, and
7. Revise the priorities, allocations and comprehensive plan to reflect the results of the cost-effectiveness evaluation as appropriate.

Unit Cost Determination

Unit cost is the cost to produce or deliver one unit or product or service. Unit costs have many uses. They can provide the basis for cost comparisons across services, providers, or geographic areas, and provide a benchmark for performance measurement. They are the basis for understanding units of service delivered. Unit costs are also an essential component of cost-effectiveness analysis. However, unit-cost data are descriptive information; used alone, they do not measure efficiency, effectiveness, quality, or content of services. They cannot easily be compared across agencies unless standards have been developed and implemented, since if more than one provider delivers the same categories of service, the intensity of service, model of care, and quality of care may be different.

Analysis of trends in unit costs can provide insights. An increase in costs over time may signal an increase in resource costs, a decline in productivity, or a change in the content or quality of the service provided. Changes in unit costs flag these situations, but do not explain what is occurring. It is sometimes valuable to review the cost per client—rather than the unit cost—for a particular service. Viewed as a unit cost, counseling may cost an acceptable $50 an hour, but if the typical client requires 100 hours of counseling, the cost per client would be an unacceptable $5,000. For planning councils allocating Ryan White Part A funds, cost per client may be a more useful measure than unit costs.

There are five basic steps to determining unit costs:

1. Define the exact units of service.
2. Count the total number of units in a given time period.
3. Determine all the direct and indirect costs of producing the units of service.
4. Add these components of full cost for the same time period.
5. Divide the full cost by the total number of service units to arrive at the average unit cost during a particular time period.

For a more comprehensive discussion on determining average unit costs, contact your project officer and consider accessing the array of TA resources available from HRSA/HAB.

See the TARGET Center at https://careacttarget.org to learn more.
X. Ch 10. Outcomes Evaluation

Introduction

Outcomes evaluation looks at the effectiveness of a service or program in achieving its intended results. It can help Ryan White programs determine if they are making a difference in the lives of PLWHA. Documentation of outcomes can be used in multiple ways, including:

- Ensuring and improving service quality.
- Helping guide program planning.
- Setting priorities and allocating resources.
- Securing funding from public and private resources.

Policy and funding decisions at the Federal level are increasingly being determined by outcomes. This includes the Ryan White HIV/AIDS Program, where outcomes evaluation is used to document changes in HIV-related health disparities for racial/ethnic minority populations served.

In their work with providers, Eligible Metropolitan Areas/Transitional Grant Areas (EMAs/TGAs) should include outcomes data requirements in their Requests for Proposals (RFPs) and provider contracts so they can document results. Use of standardized outcomes data—such as HRSA/HAB’s core clinical performance measures—can show how standards of care are being met. This approach demonstrates how outcomes evaluation is related to Clinical Quality Management, which programs use to identify how service delivery impacts health status outcomes and to make needed program and service changes.

In addition to outcomes evaluation requirements in the Ryan White legislation, outcomes evaluation is driven by other considerations:

- The Government Performance and Results Act (GPRA) directs all Federal programs to document progress towards specific measurable objectives.
- The Inspector General has recommended establishment of evaluation systems at the national, State, and local levels to support outcomes evaluation, and Municipalities often require documentation of program impacts, whether they are supported solely through Ryan White HIV/AIDS Program resources or by a combination of public and private funding sources.

A. Legislative Background

Section 2602(b)(4)(C) of Title XXVI of the Public Health Services (PHS) Act as amended by the Ryan White HIV/AIDS Treatment Extension Act of 2009 (P.L. 111-87) requires Ryan White Part A planning councils to “establish priorities for the allocation of funds within the eligible area, including how best to meet each such priority and additional factors that a grantee should consider in allocating funds under a grant” based on factors that include:

“(ii) demonstrated (or probable) cost effectiveness and outcome effectiveness of proposed strategies and interventions, to the extent that data are reasonably available.”
Section 2602(b)(4)(E) of the PHS Act states that the planning council may, at its discretion, “assess the effectiveness, either directly or through contractual arrangements, of the services offered [in the EMA/TGA] in meeting the identified needs.”

Section 2604(d) of the PHS Act requires that support services funded under Ryan White Part A be “needed for individuals with HIV/AIDS to achieve their medical outcomes,” which are defined in Section 2612(c)(2) as “those outcomes affecting the HIV-related clinical status of an individual with HIV/AIDS.”

B. HAB/DMHAP Expectations

HAB’s Division of Metropolitan HIV/AIDS Programs (HAB/DMHAP) requires that EMAs/TGAs document the impact of Ryan White HIV/AIDS Program funds on improving access to quality care including medical treatment. EMAs/TGAs also need to ensure that they have in place clinical quality management and evaluation mechanisms to assess the impact of Ryan White HIV/AIDS Program resources on improving health-status outcomes.

HAB does not require a specific type of outcomes evaluation. Every planning council and grantee may determine for itself what outcomes indicators and approaches it will use in evaluating program results. However, many Ryan White programs have indicated a need for guidance from HAB on outcomes evaluation. Several outcomes evaluation guides and evaluation monographs have been developed to address this need. Materials from the Outcomes Evaluation Technical Assistance Guide: Getting Started are used in this chapter.

Outcomes evaluation is often a part of Clinical Quality Management. HAB has developed a set of recommended performance measures. Many include some outcomes measures.

In their applications, as part of their Clinical Quality Management discussion, Ryan White Part A grantees are expected to describe “ongoing activities and/or specific concrete plans to use data to show how Ryan White Part A-funded services, including support services, are improving HIV-related clinical health outcomes of PLWHA in the EMA/TGA.”

Outcomes evaluation requires human and financial resources. Prior to the Ryan White CARE Act Amendments of 2000, administrative caps could make it difficult for grantees and planning councils—especially those in small EMAs/TGAs—to carry out program evaluation and clinical quality management activities with Ryan White HIV/AIDS Program funds. The 2000 Amendments (P.L. 106-345) specifically permitted the use of grant funds for evaluation as part of the required Clinical Quality Management programs, and the 2006 Amendments and the 2009 Treatment Extension Act continue this provision under Clinical Quality Management (CQM), in Section 2604(h)(5) of Title XXVI of the Public Health Service Act. Part A grantees may spend up to 5 percent of grant funds or $3 million, whichever is less, on such programs, per Section 2604(h)(5)(B) of the PHS Act.
C. Issues and Challenges in Outcome Evaluation

Obtaining Clinical Data on Client Health Status and Links to Primary Care

HIV/AIDS care is now based largely on a medical model of service delivery designed to reduce morbidity and mortality. Determining the effectiveness of Ryan White HIV/AIDS Program services therefore requires understanding whether, overall, such services are helping clients to access and remain in primary care and realize improved health status. This means that outcomes evaluation for almost any Ryan White HIV/AIDS Program-supported service category, from case management to transportation, needs to include an indication of whether program participation can demonstrate linkages to primary care, since it is medical care that is most directly linked to improved clinical outcomes. Provider access to data on client health status is improving. In addition, providers can document their ability to link clients to primary care using other data measures (e.g., helping them enter primary care, keep appointments, and adhere to medications).

Because the Ryan White HIV/AIDS Program is the “payer of last resort,” many Ryan White clients also get care through other payers like Medicaid, Medicare, Veterans Affairs, and private insurance. Ryan White pays for care not otherwise covered by these other payers. Obtaining client-based clinical data from such sources is a particular challenge, and providers of other services need to identify other types of outcomes data that are more accessible.

Ryan White HIV/AIDS Programs are collecting client-level data as of January 2009. This system captures information necessary to demonstrate program performance and accountability, including data on client health status, and greatly facilitates data availability for evaluation of outcomes related to client health status.

Evaluating Systems of Care

Ryan White Part A programs typically help to support a system of HIV/AIDS services, and grantees and planning councils want evaluation data that can guide decision making about program priorities and resource allocations. Ideally, this means understanding the outcomes associated with not just one category of service (e.g., primary medical care or case management) but rather a combination of primary care and support services—or an entire system of care.

Evaluation linking supportive or enabling services to health outcomes often requires some form of system-level evaluation. This has been extremely challenging, in part because of the lack of client-level data. Once Ryan White agencies have fully implemented their client-level data systems, this type of evaluation should become more feasible.

See Outcomes Evaluation TA Guide and see other technical assistance resources in the TARGET Center.
X. Ch 11. Planning for Ryan White Part A Programs Without a Planning Council

Introduction

The Ryan White Part A programs to support medical and support services to eligible metropolitan areas (EMAs) and transitional Grant areas (TGAs), areas that are most severely affected by the HIV/AIDS epidemic. EMAs are areas that reported more than 2,000 cases in the most recent five years and have a population of at least 50,000. TGAs are areas that report 1,000 to 1,999 AIDS cases in the most recent 5 years.

For Ryan White Part A grantees, a planning council must be appointed. The planning council is required to have members from various groups and organizations, and at least 33% of the council members must be PLWHA will receive Ryan White Part A services. The planning council plays a significant role in the development and implementation of policies and procedures for its operation, assessing needs of the area, comprehensive planning, setting priorities and allocating resources, ensure coordination with other entities, serve as the administrative mechanism, and develop standards of care.

The only exceptions to this requirement are the five new TGAs that began receiving Ryan White Part A funds in 2006, as required by the 2006 legislative reauthorization. The CEOs in those TGAs can decide whether to form a planning council or to obtain consumer and community input in another way.

Legislative Background

Section 2609(d)(1)(A) of Title XXVI of the Public Health Service (PHS) Act as amended by the Ryan White HIV/AIDS Treatment Extension Act of 2009 (P.L. 111-87) states: “IN GENERAL - The provisions of Section 2602 [Planning Council requirements] apply with respect to a grant… for a transitional area to the same extent and in the same manner as such provisions apply with respect to a grant under subpart one for an eligible area, except that… the chief elected official of the transitional area may elect not to comply with the provisions of Section 2602 (b) if the official provides documentation to the Secretary that details the process used to obtain community input (particularly from those with HIV) in the transitional area for formulating the overall plan for priority setting and allocating funds from the grant…”

Entities Covered by the Provision

The entities covered by this provision are those TGAs that received Ryan White Part A funds for the first time in 2007, and are:

- Baton Rouge, Louisiana
- Charlotte, North Carolina
• Indianapolis, Indiana
• Memphis, Tennessee
• Nashville, Tennessee

In 2013, an additional TGA in Columbus, Ohio will receive funding for the first time and will be covered by this provision. This TGA will also have the option to form a planning council or to obtain consumer and community input in another way.

A. Planning Mechanisms Utilized

Of the six TGAs that received Ryan White Part A funds for the first time since 2007, the Indianapolis, Memphis and Nashville TGAs have opted to form planning councils. The Baton Rouge and Charlotte TGAs use other mechanisms to obtain consumer and community input.

TGA Alternative Community Planning Process

Charlotte, North Carolina

The TGA in Charlotte has implemented a Quality Management Committee that functions much like a planning council, which includes those people representing a wide range of agencies, interest, and expertise. This committee is to ensure an inclusive planning and decision-making process for the area served by the TGA.

Members of the Quality Management Committee represent the general public, consumers, Ryan White Part A, service providers, and other health and social service organizations in the area. The committee works to identify the care needs and service gaps of PLWHA and assists in reviewing the quality and outcomes of the services provided, and improving the system of care. The quality management committee meets quarterly, and its members are required to actively participate in at least one subcommittee.

X. Ch 12. References, Links, and Resources

For More Information

Please refer to the HAB Target Center at https://careacttarget.org.
Section XI. Planning and Planning Bodies

XI. Ch 1. Overview

Under Ryan White Part A (metropolitan areas), the responsibility for managing Ryan White funds falls to Chief Elected Official (CEO), usually a mayor or county executive. The CEO, as the recipient of Ryan White Part A funds, is responsible for managing the Federal funds and more importantly for establishing the planning body that will spearhead the development of a comprehensive HIV/AIDS service system for the EMA/TGA.

Ryan White Part A planning bodies consist largely of planning councils appointed by the CEO of the EMA/TGA, although TGA established after 2006 have the option of establishing a community planning process that does not involve a planning council. Both the CEO and the planning council have designated responsibilities in the areas of planning and delivery of Ryan White services. The EMA/TGA responsibilities require broad membership involvement in order to bring diverse experience and input into such tasks as needs assessments, developing a comprehensive plan, setting priorities, and allocating funds to service categories. Ensuring smooth operation of planning bodies also requires planning bodies to have in place operating policies and processes as well as conflict of interest and grievance procedures to guide their decision-making.

XI. Ch 2. Legislative Background

Needs Assessment

Section 2602(b)(4) of Title XXVI of the Public Health Service (PHS) Act requires the planning council to:

A. “determine the size and demographics of the population of individuals with HIV/AIDS, as well as the size and demographics of the estimated population of individuals with HIV/AIDS who are unaware of their HIV status;

B. “determine the needs of such population, with particular attention to:

i. individuals with HIV/AIDS who know their HIV status and are not receiving HIV-related services;

ii. disparities in access and services among affected subpopulations and historically underserved communities, and

iii. individuals with HIV/AIDS who do not know their HIV status.”

2602(b)(4)(G) of the PHS Act requires planning councils to “establish methods for obtaining input on community needs and priorities which may include public meetings, (in accordance with paragraph (7)), conducting focus groups, and convening ad-hoc panels.”
Priority Setting and Resource Allocation

2602(b)(4)(C) of the PHS Act requires planning councils to “establish priorities for the allocation of funds within the eligible area, including how best to meet each such priority and additional factors that a grantee should consider in allocating funds [procuring services] under a grant based on the:

i. size and demographics of the population of individuals with HIV/AIDS (as determined under subparagraph (A)) and the needs of such population (as determined under subparagraph (B));
ii. demonstrated (or probable) cost effectiveness and outcome effectiveness of proposed strategies and interventions, to the extent that data are reasonably available;
iii. priorities of the communities with HIV/AIDS for whom the services are intended;
iv. coordination in the provision of services to such individuals with programs for HIV prevention and for the prevention and treatment of substance abuse, including programs that provide comprehensive treatment for such abuse;
v. availability of other governmental and nongovernmental resources, including the State Medicaid plan under Title XIX of the Social Security Act and the State Children’s Health Insurance Program under Title XXI of such Act to cover health care costs of eligible individuals and families with HIV/AIDS; and
vi. capacity development needs resulting from disparities in the availability of HIV-related services in historically underserved communities…”

Comprehensive Planning

2602(b)(4)(D) of the PHS Act requires the planning council to “develop a comprehensive plan for the organization and delivery of health and support services described in section 2604 that:

i. “includes a strategy for identifying individuals who know their HIV status and are not receiving such services and for informing the individuals of and enabling the individuals to utilize the services, giving particular attention to eliminating disparities in access and services among affected subpopulations and historically underserved communities, and including discrete goals, a timetable, and an appropriate allocation of funds;
ii. includes a strategy to coordinate the provision of such services with programs for HIV prevention (including outreach and early intervention) and for the prevention and treatment of substance abuse (including programs that provide comprehensive treatment services for such abuse); and
iii. is compatible with any State or local plan for the provision of services to individuals with HIV/AIDS; and
iv. includes a strategy, coordinated as appropriate with other community strategies and efforts, including discrete goals, a timetable, and appropriate funding, for identifying individuals with HIV/AIDS who do not know their HIV status, making such individuals aware of such status, and enabling such individuals to use the health and support services described in section 2604, with particular attention to reducing barriers to routine testing
and disparities in access and services among affected subpopulations and historically underserved communities.”

Coordination

Section 2602(b)(4)(F) calls for the planning council and grantee to “participate in the development of the statewide coordinated statement of need initiated by the State public health agency responsible for administering grants under Part B.”

Section 2602(b)(4)(H) requires the planning council to “coordinate with Federal grantees that provide HIV-related services within the eligible area.”

Assessment of the Administrative Mechanism and Effectiveness of Services

2602(b)(4)(E) requires planning councils to “assess the efficiency of the administrative mechanism in rapidly allocating funds to the areas of greatest need within the eligible area, and at the discretion of the planning council, assess the effectiveness, either directly or through contractual arrangements, of the services offered in meeting the identified needs.”

Planning Councils in Transitional Grant Areas

Section 2609(d)(1) of the PHS Act specifies that

- The Chief Elected Official of a new TGA “may elect not to comply with the provisions of section 2602(b) if the official provides documentation to the Secretary that details the process used to obtain community input (particularly from those with HIV) in the transitional area for formulating the overall plan for priority setting and allocating funds from the grant” and
- Through fiscal year 2013, this exception “does not apply if the transitional area involved received funding [under Ryan White Part A] for fiscal year 2006.”

Priority Setting and Resource Allocation

Ryan White Part A planning councils are responsible for setting service priorities, determining how best to meet those priorities, and allocating resources to them as stated in Section 2602(b)(4)(C) of the PHS Act. (TGAs that are not required to create planning councils, and that decide not to do so, must establish a process to obtain community input, particularly from those with HIV, in the transitional area for formulating the overall plan for establishing priorities and allocating funds.) Planning council funding related decisions must be based on documented need. (Note: Since 2006, the legislation has stipulated that not less than 75 percent of service dollars are to be used for core medical services. This requirement, along with waiver provisions established by HRSA, needs to be factored into the priority setting process.)
Statewide Coordinated Statement of Need

Ryan White Part A programs are required to participate in the SCSN process, and use its findings, under the following provisions:

- Section 2602(b)(4)(F) of the PHS Act requires the planning council to “participate in the development of the statewide coordinated statement of need initiated by the State public health agency responsible for administering grants under Part B.”
- Section 2603(b)(1)(G) of the PHS Act requires the Ryan White Part A application for supplemental funding to “demonstrate the manner in which the proposed services are consistent with the local needs assessment and the statewide coordinated statement of need…”
- Section 2605(a)(8) of the PHS Act requires Assurances as part of the Ryan White Part A application “that the applicant has participated, or will agree to participate, in the statewide coordinated statement of need process where it has been initiated by the State public health agency responsible for administering grants under Part B, and ensure that the services provided under the comprehensive plan are consistent with the statewide coordinated statement of need.”

Capacity Development

There is no specific legislative language or authority for capacity development for Parts A and B. However, the Division of Metropolitan HIV/AIDS Programs has reminded grantees and Part A HIV Planning Councils/planning bodies that system-wide program support or technical assistance may be considered capacity development activities. Capacity development is defined as activities that increase core competencies that substantially contribute to an organization’s ability to deliver effective HIV/AIDS primary medical care and health-related support services.

Capacity development activities should increase access to the HIV/AIDS service system and reduce disparities in care among underserved persons living with HIV/AIDS. Under Part A, planning for capacity development activities is expected to be identified primarily in two ways: 1) needs assessment process within the EMA/TGA should identify disparities in access and services, and 2) establishment of priorities by the EMA/TGA Planning Council or other advisory body based on disparities identified in the needs assessment.


XI. Ch 3. Needs Assessment

Introduction

Ryan White HIV/AIDS Program needs assessment is a process of collecting information about the needs of PLWHA—both those receiving care and those not in care. Steps involve gathering data—from multiple sources—on the number of HIV and AIDS cases, the needs and service
barriers of PLWHA, and current resources (Ryan White HIV/AIDS Program and other) available to meet those needs. This information is then analyzed to identify what services are needed, what services are being provided, and what service gaps remain, overall and for particular groups of PLWHA.

Needs assessment is an interconnected part of most Ryan White planning tasks. Results from the needs assessment should be used in setting priorities for the allocation of funds, developing the comprehensive plan, and crafting the annual implementation plan and specific strategies for addressing needs. Needs assessment results can also provide baseline data for evaluation and help providers improve services.

It is important to first determine the kinds of information needed for each component of the needs assessment, and then to decide the most appropriate methods for obtaining those data. Often, the same method can be used to collect data for several needs assessment components.

Needs assessment steps include identifying:

- **Data on HIV cases and AIDS cases.** HIV/AIDS epidemiologic data indicate the current size and characteristics of the populations living with HIV and AIDS as well as trends in the epidemic.
- **Needs of PLWHA in and out of care.** Insights on needs can be obtained through comorbidity and socioeconomic data and such methods as surveys, focus groups, community meetings, and individual interviews.
- **Existing services available to PLWHA.** A resource inventory can show what services and organizations currently exist. An assessment of provider capacity/capability can determine provider ability to deliver HIV/AIDS care overall and to specific populations. Both the inventory and the provider profile should include core services and support services.
- **Unmet needs/service gaps that Ryan White projects should address.** Comparing available services to identified needs reveals unmet needs and service gaps (see definitions below). This should include an examination of unmet needs for HIV-positive individuals who know their status but are not in care; service gaps for those who are currently in care; disparities in care; and capacity development needs of providers and the overall system of care. Analysis of unmet needs/service gaps might include not only a determination of overall needs but also identification of particular service needs for specific PLWHA populations.
### Definitions of Unmet Need and Service Gaps

**Unmet need** means the unmet need for HIV-related primary health care among individuals who know their HIV status but are not receiving such care (not “in care”).

**Service gaps** are all service needs not currently being met for all PLWHA except for the need for primary health care for individuals who know their status but are not in care. Service gaps include additional need for health services for those already receiving HIV-related primary medical care (“in care”).

A person is considered to be **in care** if receiving HIV-related primary medical care within the past 12 months.

To avoid confusion, the term **unmet need** is used only to denote the need for primary health care by **PLWHA not in care**, and **service gaps** are used for all other service needs.

**Table 17: Definitions of Unmet Need and Service Gaps**

#### A. HAB/DMHAP Expectations

Needs assessment is expected to generate information about:

- The size and demographics of the HIV/AIDS population within the service area.
- The needs of PLWHA, with emphasis on individuals with HIV/AIDS who know their HIV status and are not receiving primary health care, individuals with HIV/AIDS who do not know their status, and disparities in access and services among affected subpopulations and historically underserved communities.

#### Definitions and Descriptions Related to Individuals Who Do Not Know Their HIV/AIDS Status

**Individuals with HIV/AIDS Who Do Not Know Their HIV Status:** Any individuals who have **NOT** been tested for HIV in the past 12 months, any individuals who have **NOT** been informed of their HIV result (HIV positive or HIV negative), and any HIV-positives individual who have **NOT** been informed of their confirmatory HIV result. These individuals are not in HIV-related primary medical care because they are unaware of their status.

**Early Identification of Individuals with HIV/AIDS (EIIHA) Process:** The identifying, counseling, testing, informing, and referring of diagnosed and undiagnosed individuals to appropriate services, as well as linking newly diagnosed HIV positive individuals to care.

HRSA/HAB uses the acronym EIIHA to refer to the process of addressing legislative requirements related to individuals with HIV/AIDS who do not know their HIV status.
HAB/DMHAP expects Ryan White Part A needs assessments to meet all legislative requirements and to provide a sound information base for planning and decision making.

Planning bodies and grantees are expected to apply the following principles and strategies in their needs assessment efforts:

- **Needs assessment is a partnership activity** of the planning council, grantee, and community, with the planning council taking the lead role.
- **Needs assessment is the basis for other Ryan White HIV/AIDS Program planning activities.** Assessment plays an important role in the development of an array of services for PLWHA. Ryan White programs use its results to help prioritize service needs and allocate funds, develop a comprehensive plan, and craft strategies to address these needs through the implementation plan and appropriate service models.
- **Needs assessments focus on particular areas of need,** with an emphasis on reaching those not in care or not aware of their status, identifying disparities in care, and identifying ways to enhance the service delivery system. Areas for attention are as follows:
  
  - Focus on PLWHA not in care and disparities in care. Many needs assessments have primarily targeted PLWHA who were receiving HIV-related services (individuals already “in care”). The Ryan White HIV/AIDS legislation requires planning councils to expand their needs assessments to also determine the needs of those individuals who know their HIV status but are not in care and to determine strategies for identifying HIV-positive people who do not know their status and ensuring that they are tested and linked to care. Particular attention must also be paid to identifying disparities in access and services among affected subpopulations and historically underserved communities. [Section 2602 (b)(4)(B)(i-ii)]
  
  - Identify capacity development needs. Capacity development needs exist when disparities in the availability of HIV-related services are identified, particularly in historically underserved communities. In planning for capacity development, EMAs/TGAs must determine the number and characteristics of subpopulations experiencing disparities in access and services. If the needs assessment identifies gaps in its ability to reach and address the needs of underserved populations or communities (e.g., insufficient access points, cultural or language barriers), the planning council and grantee must address capacity development needs. Ryan White funds can be allocated for capacity development only if they are tied to a specific service category or categories. [Section 2602 (b)(4)(C)(vi), and Section 2654(c)(1)(B)]
  
  - Address coordination with HIV prevention and substance abuse prevention and treatment. Because Ryan White resources are only one source of HIV/AIDS care, needs assessments should identify where coordination across services is needed. Of particular importance is coordination with HIV prevention and with substance abuse prevention and treatment programs, including programs that provide comprehensive substance abuse treatment. Coordination with these services can enhance efforts to
identify individuals with HIV who do not know their status and individuals who know their status but are not receiving primary health care, provide risk reduction services to these individuals, enable them to access and remain in care, and result in better attention to the full range of their needs. [Section 2602 (b)(4)(C)(iv)]

- Identify need for outreach and early intervention services (EIS). The Ryan White legislation allows Ryan White Part A areas to fund EIS. In order to consider this service for funding, the entity must demonstrate “to the satisfaction of the chief elected official for the eligible area involved that Federal, State, or local funds are otherwise inadequate for the early intervention services that the entity proposed to provide; and the entity will expend funds pursuant to such paragraph to supplement and not supplant other funds available…” These services should be provided at “public health departments, emergency rooms, substance abuse and mental health treatment programs, detoxification centers, detention facilities, clinics regarding sexually transmitted diseases, homeless shelters, HIV/AIDS counseling and testing sites,” as well as federally qualified health centers, and other points of access to health services. [Section 2604(e)(1-2)]

- Identify need for outreach based on the EMA/TGA Unmet Need Calculations (number of PLWHA out of care). The planning council should identify specific populations for outreach in order to engage and retain PLWHA in care.

- Obtain PLWHA input. The Ryan White legislation requires planning councils to determine the size and demographics of individuals living with HIV/AIDS within their EMAs/TGAs and the needs of this population. Planning councils are expected to use methods such as community/public meetings, focus groups, and ad hoc panels for obtaining input on community need and priorities. Such input enables them to fulfill the legislative requirement to establish priorities for the allocation of Ryan White funds with attention to the needs of PLWHA. [See Section 2602 (b)(4)(G)]

- **EMAs/TGAs should establish a needs assessment cycle.** Ryan White Part A programs are not expected to conduct a comprehensive needs assessment each year. Given limitations in administrative funds, most programs do not have sufficient funds to conduct such a needs assessment in a single year. In addition, needs assessment is extremely time consuming and can lead to “consumer fatigue” as well as grantee and planning council overload, given other responsibilities such as comprehensive planning (which is generally done every three years). HAB/DMHAP recommends a three-year needs assessment cycle, with a schedule for collecting updated information to address special areas and support priority-setting and resource allocation activities. Epidemiologic data should be obtained annually, information on new populations added, and special circumstances—such as the impact of advances in medical treatments on service needs or the impact on health care reform on coordination of care—addressed promptly. The estimate of unmet need should be updated at least every two years. [See Attachment 1, Sample Three-Year Needs Assessment Schedule.]

- **Needs assessment should include analysis of the impact of changes in the health care system and the HIV/AIDS continuum of care.** Especially during times when considerable changes are occurring in the health care system and in the HIV/AIDS
continuum of care and payers, needs assessment should include efforts to understand the implications of such changes on PLWHA. For example, if more PLWHA become eligible for Medicaid or for subsidized private insurance under the health insurance exchanges authorized by the Affordable Care Act, what are the implications for the demand for Ryan White services? What services will not be available through the State Medicaid system or through the exchange, and therefore will continue to be needed from Ryan White? If the transition is causing some PLWHA to fall out of care, then Ryan White services may need to be restructured to address this problem.

### HOW “DEMONSTRATED NEED” RELATES TO NEEDS ASSESSMENT

Ryan White Part A applications for supplemental funding should use data in documenting demonstrated need—and thus the need for supplemental funding. The 2006 and 2009 legislation use the term “demonstrated need” in place of what earlier legislation referred to as “severe need.” Demonstrated need is the degree to which providing primary medical care to people with HIV/AIDS in any given area is more complicated and costly than in other areas, based on a combination of the adverse health and socio-economic circumstances of the populations to be served. Section 2603(b)(2)(B) lists factors to be considered for demonstrating need.

**Table 18: How “Demonstrated Need” Relates to Needs Assessment**

### HOW THE EARLY IDENTIFICATION OF INDIVIDUALS WITH HIV/AIDS (EIIHA) RELATES TO NEEDS ASSESSMENT

The 2009 legislation (P.L. 111-87) requires Ryan White Part A applications for supplemental funding to provide the EMA/TGA’s EIIHA strategy (including goals); its plan for identifying individuals, informing them of their status, and referring and linking them to care; and data on its progress using an EIIHA data matrix provided by HRSA/HAB. The strategy and plan should be based on an understanding of what groups of PLWHA are most likely to be unaware of their status—which is a part of needs assessment. For example, surveillance staff might provide a profile of PLWHA who were diagnosed during the past year or two and were “late testers”—they were diagnosed with AIDS at the time they were tested or within one year after that date. Or the needs assessment may include geo-mapping of community viral load; geographic areas with high viral loads are likely to include a high proportion of individuals who are. The foundation for a successful plan for outreach, testing, and linkage to care is needs assessment data and analysis.
Coordination among needs assessment efforts is extremely important and is increasing, both among Ryan White Parts and between Ryan White and HIV prevention community planning processes. In particular, the Statewide Coordinated Statement of Need (SCSN) represents an opportunity to coordinate needs assessment activities that are conducted across Ryan White Parts.

The SCSN is a collaborative process used to identify and address significant HIV/AIDS care issues related to the needs of PLWHA, and to maximize coordination, integration, and effective linkages across Ryan White HIV/AIDS Program Parts. It is a process convened in the State by the Part B grantee. The result of the SCSN process is a written SCSN document that reflects the input and approval of all Ryan White HIV/AIDS Program Parts. All organizations funded under the Ryan White HIV/AIDS Program are required to coordinate with each other in the delivery of core and supportive services and are expected to participate in the SCSN process.

The SCSN is not a comprehensive community-based needs assessment requirement nor is it a requirement for a comprehensive plan of HIV care and service delivery. The SCSN also does not override or supersede local autonomy and decision making. However, the SCSN must reflect existing needs assessments and identify cross-cutting service delivery gaps/issues and broad goals.

SCSN development is greatly enhanced by cross-Part collaboration in the needs assessment process. This occurs, for example, when Ryan White Part A and Part B bodies collaborate within a regional service area, when consortia across a State cooperate or collaborate on their individual needs assessments, or when Part C or Part D programs participate in Ryan White Part A or Part B needs assessment efforts. [For more information, see the chapter on SCSN in this manual (XI. Ch 6.).]

Table 19: Statewide Coordinated Statement of Need (SCSN) and Coordinating Needs Assessments

**B. Components of a Needs Assessment**

A comprehensive needs assessment includes specific components. On an annual basis, select components should be expanded and/or updated, depending on trends and special issues facing the EMA/TGA. The major components of a comprehensive needs assessment are:

1. **Epidemiologic profile**, which describes the current status of the epidemic in the EMA/TGA, specifically the prevalence of HIV and AIDS overall and among defined subpopulations. The Centers for Disease Control and Prevention (CDC) and HRSA’s Integrated Guidelines for Developing Epidemiologic Profiles provide guidance for preparing such a profile and is available on the CDC website. The profile should also describe trends in the epidemic. In States without complete and reliable HIV reporting, EMAs/TGAs should determine the number of individuals living with HIV by using...
epidemiologic measures developed by the U.S. Department of Health and Human Services (HHS) through HRSA/HAB, CDC, and others.

The epidemiologic profile should provide the best available information to better understand the probable characteristics of individuals who have HIV/AIDS but are unaware of their status, such as percent of late testers and their characteristics and place of residence. It should also provide data on the treatment cascade where possible; a treatment cascade follows PLWHA over a period of years, documenting data such as the number of people who are tested, test positive, are linked to care, receive anti-retroviral therapy (ART), remain in care, and achieve viral suppression.

2. **Estimates of the number and characteristics of PLWHA with unmet need and of individuals with HIV/AIDS who are unaware of their status.** It is important to understand approximately how many people in the EMA/TGA are unaware of their status and how many are out of care, who they are, and where they are most likely to live. Methods for making these estimates are discussed later in this chapter. Needs assessment based on analysis of epidemiologic data can provide an understanding of populations most likely to be undiagnosed, including their race/ethnicity, age, gender, risk factors, and places of residence. Analysis of epidemiologic data can provide profiles of people who know their status and are not in care.

3. **Assessment of service needs** (including core services and support services) among affected populations, including barriers that prevent PLWHA both in and out of care from receiving needed services or from continuing in care. A needs assessment should gather an array of information in order to identify trends and common themes. EMAs/TGAs should collect this information from multiple sources, among them PLWHA and other community members, health departments, the State Medicaid agency, community-based providers and, where applicable, grantees of other Ryan White Parts. Information must be obtained from and about HIV-positive individuals who know their status and are not in care.

4. **Resource inventory,** which describes organizations and individuals providing the full spectrum of services available to PLWHA. The goal of the resource inventory is to develop a comprehensive picture of services, regardless of funding source. At a minimum, the resource inventory includes for each provider a description of the types of services provided, number of clients served, and funding levels and sources. (Note: A resource inventory can often be turned into a resource for clients and providers to use in locating services, especially online. In this format, data on number of clients served and funding levels is usually removed.)

5. **Profile of provider capacity and capability,** which identifies the extent to which services identified in the resource inventory are available, accessible, and appropriate for PLWHA, including specific subpopulations. Estimates of capacity describe how much of which services a provider can deliver. Assessment of capability addresses staff knowledge and skills to provide high quality services to various groups of PLWHA.

- Availability focuses on the number of providers overall and by community or county within the EMA/TGA and the extent to which providers have the ability to serve additional clients, since caseloads may increase as a result of increased attention to
HIV testing and linking those testing positive to care—a response to the persistent national challenge that a significant proportion of HIV-infected individuals in the U.S. do not know their status, as emphasized in the 2009 legislation.

- Accessibility involves factors like provider hours (including weekend and evening hours) and location, how easily facilities can be reached via bus or other rapid transit, the extent to which they have parking available, and whether they can be accessed by individuals with physical disabilities.
- Appropriateness describes the degree to which a provider has the expertise to provide high quality services for specific subpopulations—defined by race/ethnicity, sex/sexual identity, gender orientation, age, and risk factor—including staff with needed training, experience, language skills, and cultural competence.

A careful assessment of how issues of provider capacity and capability can create barriers for PLWHA receiving services is an important aspect of this component. Some provider profiles also explore client perceptions of service accessibility and appropriateness through PLWHA surveys, focus groups, or other methods. However, assessment of client satisfaction (as opposed to client needs) is more often undertaken in the grantee’s clinical quality management process.

6. Assessment of unmet need/service gaps, which brings together the quantitative and qualitative data from all the other components on service needs, resources, providers, and barriers. This should include an assessment of unmet needs for PLWHA who know their HIV status but are not in care and an assessment of service gaps for all PLWHA—both in and out of care. This should include identification of both categories of service that are unavailable or insufficiently available, or service gaps for specific population groups.

C. The Needs Assessment Process

A needs assessment sets the stage for the planning process by identifying the needs of the HIV/AIDS community, the services available to meet those needs, and the gaps between needs and services. This is a meaningful exercise only if it is planned and implemented carefully and inclusively.

To develop a needs assessment in a timely and efficient manner, begin by outlining a needs assessment process. The typical steps in needs assessments are as follows:

1. Plan for the needs assessment.
2. Design the needs assessment methodology.
3. Collect the information required for the needs assessment.
4. Analyze the information and present the results in useful formats.

Each of these steps is summarized below.
1. Plan for the Needs Assessment

The first step is to reach consensus on the scope, timetable, budget, and responsibilities for the needs assessment.

Scope

Decide on needs assessment scope by posing and answering the following questions:

- What is the desired scope of the needs assessment? If you use a three-year needs assessment cycle that meets legislative requirements and local planning needs, your needs assessment efforts each year will focus on one or two specific components plus perhaps updating or expanding components carried out during the past two years. Which components will be your focus this year? [See Attachment 1 for a sample three-year schedule.] Are there any special issues that should be considered because of changes in the system of care or other current topics (e.g., impact on availability of mental health services following severe cuts in non-Ryan White-funded services, probable impact of health care reform on Ryan White enrollment and types of services most needed after PLWHA enroll in expanded Medicaid programs or health insurance exchanges)?

- Whose needs are being assessed and what information will be sought about each of these populations? Based upon the epidemiologic profile for the area, what target populations are essential for the assessment? Does the EMA/TGA need to better understand the service needs of particular PLWHA groups that represent a growing proportion of the PLWHA population (e.g., PLWHA over 55), or are particularly likely to delay testing or be out of care (e.g., young MSM of color, Latino or African immigrants, or residents of a particular geographic area within the EMA/TGA)?

It is important to assess the needs of the entire PLWHA population in the EMA/TGA, but data need to be collected and analyzed so that there is adequate representation of specific PLWHA populations. You cannot make decisions about service needs of specific populations (e.g., women, Latinos/as, gay men of color) unless collecting information about these groups is an integral part of the needs assessment. This means being sure that information can be analyzed and presented separately for important population groups or geographic areas as well as combined to give an overall picture of PLWHA in your service area. The analysis should present, compare, and contrast all components of the service population.

- Who are the groups you will target to obtain information or your assessment? Knowing whom to target can present challenges. Some areas make the mistake of targeting providers as the primary source of needs data. The assumption here is that providers have intimate knowledge of their clients’ needs. While this may be true, the priorities of providers may be different from the priorities of their clients. Providers also may be less knowledgeable about the needs of populations not in their care system, or not receiving any HIV-related services.
The Ryan White legislation requires and a sound needs assessment ensures that needs assessment information is sought directly from PLWHA. This means locating PLWHA throughout the service area (in and out of care) and asking them about their needs using well-designed data collection tools. It also means consulting with diverse service providers serving varied client populations, since they are part of the solution. The challenge and goal is to structure a process that allows for an appropriate balance, including information from diverse PLWHA about their perceived service needs.

- What programs and services will be addressed and which will receive the most attention? Over time, your needs assessment should cover all the HIV-related services that are part of your continuum of care (both core and support). When you develop the needs assessment plan and tools for any particular year, you will need to identify what programs and services should be given priority. It may be helpful to use several focus groups early in the process to determine priorities. Developing a resource inventory will also help point to service areas that may need particular attention. This helps in developing questions for PLWHA surveys or interviews and determining which providers to focus on including in provider panels or surveys.

- What specific tables or narrative information for the comprehensive plan or for your Ryan White Part A application must be developed based on needs assessment data? Does the latest HAB/DMHAP application guidance call for new tables or additional information or analyses? Application requirements around unmet need, other “demonstrated need,” and EIIHA, as well as descriptions of emerging populations, depend upon sound, current needs assessment data.

**Timetable and Budget**

Determine the timeline and budget by addressing the following questions:

- What is the timetable for the needs assessment? What are the deadlines for specific tasks such as collection of information, analysis of data, and preparation of the needs assessment report?

The key question is by what date must the planning or decision-making body that will use needs assessment receive the report and a presentation in order to allow time for review of information and use of results in priority setting and resource allocation, comprehensive planning, and/or preparation of an application for Ryan White HIV/AIDS Program funding? For example, the Ryan White Part A application is usually due early in the fall, and most EMAs/TGAs do priority setting and resource allocations in the summer, with a data presentation in May or June to begin the process. The comprehensive plan is due every three years, but timing varies. If several titles (or Ryan White Part A and the HIV Prevention Planning Group) are collaborating, what are the differing timetables and how can they all be met?

- What is the budget for the needs assessment? Are funds available for a consultant? What in-kind resources can be used, such as assistance in conducting interviews or focus
groups from staff of local agencies or university students, or assistance in data analysis from the health department or another agency? How can joint funding (e.g., across Ryan White HIV/AIDS Program titles, with HIV prevention community planning) be coordinated?

The Ryan White legislation limits grantee administrative costs to 10%, including planning council support costs. As a result, some Ryan White Part A programs cannot cover the costs for a comprehensive needs assessment in a single program year. HRSA/HAB recommends that programs consider budgeting costs over three years, and then do an annual budget based on which components of the needs assessment will be implemented or updated each year.

**Responsibilities for Conducting and Overseeing the Needs Assessment**

Agree on responsibilities for conducting and overseeing the needs assessment by posing the following questions:

- Can some parts of the needs assessment be conducted jointly with other Ryan White Parts, and/or the HIV Prevention Planning Group? If so, how can funds and efforts best be pooled?
- Who will conduct and monitor the needs assessment? Will it be conducted and overseen by the planning council, planning council staff, a needs assessment committee, a consultant, or some combination of volunteers and paid staff? If a consultant is to be used, what criteria will be used to select the consultant (e.g., social science research background, experience with community needs assessment, understanding of HIV/AIDS core medical and support services) and how will the consultant’s work be monitored? What will be the division of responsibility between the planning council and the grantee or administrative agency, and how much help will be available from health planners or surveillance staff?

In most EMAs/TGAs, the planning council oversees needs assessment through a committee with specific responsibility for overseeing this task. Usually, some funds are available for consultant assistance to supplement the efforts of planning council and grantee staff.
HAB strongly encourages cross-title collaboration in needs assessment.

For example:

- Part C and Part D Guidances require grantees and applicants to collaborate in State and/or local HIV-related needs assessments.
- The Part B Manual encourages coordination of needs assessment activities with other entities including Ryan White Part A planning councils and Part C and Part D providers to stretch available dollars and contribute to a more comprehensive effort.
- Ryan White Part A planning councils are required to include representatives of area Part C and Part D programs among their voting members.
- Representatives of all Parts must participate in the Statewide Coordinated Statement of Need.
- Planning bodies are urged to share needs assessment findings and reports with other area planning bodies and other programs serving some of the same populations (e.g., Medicaid, State Children’s Insurance Program (SCHIP), Social Security).

Table 20: Cross-Part Collaboration

### Obtaining Community Input

Establish a process for community input by posing the following questions:

- What procedures will be used to obtain broad PLWHA and other community input from individuals who are not part of the planning council or needs assessment committee? What additional efforts are needed to help ensure that the needs assessment results will be accepted by the community?
- How will the needs assessment be used to help the EMA/TGA determine the “priorities of the communities with HIV/AIDS for whom the services are intended” (as required by Section 2602(b)(4)(C)(iii) of the PHS Act)?
- How will the needs assessment reach and obtain input from HIV-positive individuals who know their status but are not in care? What links with prevention programs, substance abuse treatment programs, homeless shelters, counseling and testing sites, EIS providers, and other community sites will help in reaching these individuals?

It is important that planning ensure that PLWHA will be a part of the entire needs assessment process, from planning through review of findings and identification of their implications for planning. Participation is easy to arrange when a planning council has strong and effective PLWHA membership – especially unaligned consumers – requires consumer membership on all committees, and has an active PLWHA standing committee or caucus. (See the PLWHA-Consumer Participation chapter of Section VI.)

### Analysis, Presentation, and Use of Results

Look ahead to what will be done once results are obtained by addressing the following questions:
• How will the Ryan White Part A program summarize and present needs assessment results? Will results be a part of an annual data presentation as input to the priority setting and resource allocations process?
• If this is a collaborative needs assessment, how will the specific information needed by each Part or program be analyzed and presented? Will separate reports be required?
• How will the results be linked to and supportive of the development of a comprehensive plan for the EMA/TGA and/or an annual operating plan?
• What tables and narrative information need to be prepared for the annual Ryan White Part A application?
• How else will needs assessment results be used? For example, what information is most critical for priority setting? What separate analyses are needed by population group, risk factor, service category, and/or geographic area?
• How can results best be presented so they are easy to use? In addition to a narrative report, will a PowerPoint presentation be used? Can results be summarized in other ways that help ensure that they are used for decision making?

It is important that plans be made to ensure that results are presented in plain language, with technical terms defined. Laying out “dummy” tables at this stage helps ensure that all needed information is collected.

Hints for Managing the Needs Assessment Process

Conducting a well-organized needs assessment entails assigning responsibility for both implementation and monitoring of the data collection and analysis process. The experiences of Ryan White planning bodies and grantees suggest several different ways to divide responsibilities.

“Staffing” the needs assessment. The needs assessment may be conducted and overseen by a needs assessment committee, staff, a consultant, the full planning council, or some combination of volunteers and paid staff. Typically, planning council members or other volunteers do not have the time – and may lack the expertise – to carry out a comprehensive needs assessment themselves. At a minimum, they can and should provide oversight, help plan the needs assessment and provide input to design of data collection tools, arrange town halls or community forums, ensure that all affected populations are reached and included in the needs assessment process, and carefully review draft results. Some members may be able to help with specific activities such as contacts with entities with clients needed for PLWHA surveys, conducting of client focus groups, or outreach to people not in care. Planning council and grantee staff will also need to devote time to the needs assessment. An epidemiologist, often from the local HIV surveillance unit, typically prepares the epidemiologic profile and updates it annually.

The technical expertise of both Ryan White HIV/AIDS Program and other staff can be particularly helpful, especially in initial planning. Many health departments have staff with extensive needs assessment experience. Grantees can also help ensure that Ryan White-funded providers cooperate with needs assessment efforts providing clients the opportunity to participate in PLWHA surveys and assisting with recruitment of PLWHA for focus groups, town halls/community forums, or other information-gathering efforts.
Typically, consultants or non-Ryan White staff will be needed to work with the needs assessment committee and staff in planning and implementing the needs assessment. If so, the planning council will need to prepare an appropriate scope of work and select consultants using the EMA/TGA’s contracting procedures. Sometimes university researchers will help with the process at low-cost or pro bono, perhaps making the needs assessment a student project.

**Planning council “ownership.”** Whatever process is used, the planning council needs to develop and maintain “ownership” of the needs assessment, usually through a standing committee such as the Needs Assessment Committee, with support from the PLWHA committee or caucus. If consultants or staff are used, they should be seen as the planning council’s representatives. Consumers will feel ownership if they play a substantive role in the needs assessment process, if the report or an executive summary is widely disseminated, and if other planning council members acknowledge their contributions.

**Dealing with conflict of interest.** Responsibility for implementing a needs assessment process entails recognizing and managing conflict of interest. Be sure that the committee or task force reviewing the needs assessment tool and overseeing the needs assessment process is broadly representative and balanced. Include individuals knowledgeable about the range of Ryan White services, so that no one individual or group has control of questionnaire design or data analysis.

Be aware of the possibility of unintended biases. For example, a clinic director is likely to focus on information about primary health care needs, a substance abuse provider on the need for drug treatment, and a gay rights organization on the needs of Gay, Lesbian, Bisexual and Transgender (GLBT) PLWHA. Have a neutral party (such as a consultant) design, or at least carefully review, all instruments to be sure that individuals do not overemphasize a particular service need or approach that may be of special interest to their organization or reflect their personal priorities, or exclude other important services or issues.
FREQUENTLY USED DATA SOURCES

Secondary source (already existing) data that are typically used in Ryan White needs assessments include the following; the data are mostly quantitative (numerical):

- Epidemiologic data obtained primarily from local and State health departments and the CDC (e.g., AIDS cases, HIV cases or estimates, late testing, data on co-morbidities)
- Data on PLWHA treatment participation, performance measures, and clinical outcomes, often collected by the grantee as part of Clinical Quality Management (CQM) or “treatment cascade” analyses
- Monitoring data on PLWHA, such as EIIHA data required by HAB, often maintained by surveillance staff or other health department personnel
- Client service utilization data obtained from providers and aggregated by the grantee and/or HAB (Ryan White Services Report or RSR)
- Aggregate data on HIV/AIDS clients from Medicaid, the State ADAP program, and/or other health care providers, and
- Socio-demographic data obtained from public sources such as the Census Bureau (e.g., overall population characteristics, poverty status, health insurance status).

Primary source (newly collected) data are often collected, using such methods as:

- PLWHA and provider surveys
- Interviews with PLWHA
- Focus groups
- Key informant interviews
- Community forums or town hall meetings
- Public hearings or informal public input sessions
- Informal discussions with groups of program clients

Often, special studies will use a mix of primary and secondary data collection approaches, from chart reviews to interviews and focus groups.

Surveys and structured interview results, which consist largely of quantitative data, can be presented in user-friendly tables, charts, and graphs, with narrative explanation. The other methods often produce primarily qualitative data, which is usually presented in narrative summaries.

Table 21: Frequently Used Data Sources

2. Design the Needs Assessment Methodology

The next step is to develop a specific design for the needs assessment. Keep in mind that the focus is on identifying the needs of PLWHA in and out of care, the Ryan White and other services currently available to meet those needs, and service gaps. An analysis of this information is then used to help set priorities and allocate resources.

The needs assessment methodology may be designed by a needs assessment committee, staff, or consultants (paid or volunteer) with committee oversight. Representatives of affected
communities should be invited to review the design of the needs assessment. Focus on the following questions:

- What existing information (secondary source data) is available? What populations does it address or not address? Have the grantee, planning body, and/or individual providers carried out epidemiologic studies, client satisfaction studies, or evaluations that can contribute to the needs assessment?
- What new information (primary source data) is needed and what approaches are planned to collect this information? Will there be a PLWHA survey using probability sampling techniques, so that findings can be generalized to (assumed to represent) the entire population with HIV/AIDS? How will PLWHA not in care be identified and included? Will providers of HIV/AIDS-related services be surveyed to obtain their perceptions of need as well as information about the service network and its capacity and capability? Will qualitative information be obtained from specific PLWHA groups, providers, or other target groups through such methods as focus groups, community forums, or key informant interviews?
- Who will develop and review the instruments for collecting new information? Can tools from others be used or refined?
- What common set of questions should be asked so that responses can be compared across sources and methods in order to identify trends or themes?
- Who will collect the information collected, and how will these people be trained?
- How will confidentiality be protected? Will PLWHA be able to participate anonymously?
- How will quality control be maintained? What procedures will be used to ensure that findings are valid and activities are completed on time? How will data collection staff be monitored to ensure that information is collected appropriately? Has time been built in to revise data collection instruments based on pilot test results? Who will monitor expenditures and completion of tasks?
- How will data be analyzed? How will quantitative and qualitative information be integrated? How will data be analyzed according to desired data characteristics—such as by populations or services—and how will quantitative and qualitative data be compared and interpreted in order to gain a deeper understanding of service needs and gaps?
- When, how, and in what form will information be presented?

At the end of the design phase, the grantee and planning council should have a clear plan for every part of the needs assessment process, including the kinds of information that will be available, who will collect it, what tools will be used, and the kinds of analysis that will be done. The timeline for each step in the process should be clearly stated.

3. Collect the Information Required for the Needs Assessment

The required information must be collected—quantitative and qualitative, primary and secondary—and then reviewed in “raw” (not aggregated) form. The data collection should follow the procedures determined during the design phase.

Be sure that those responsible for data collection consult with the committee and the full planning council regularly. The entire planning council should hear progress reports from this
group during any major needs assessment effort. In overseeing the information collection process, be sure to consider questions and issues such as the following:

- Is comprehensive information about the present extent, distribution, and impact of HIV/AIDS on defined populations being obtained and analyzed? Does the data collection ensure that information about different PLWHA groups and geographic locations can be analyzed separately and compared?
- Is available information about the characteristics of recent and late testers being reviewed to obtain a sense of the probable profile of individuals with HIV/AIDS who are unaware of their status (HIV-positive/unaware)? [See Section F below for more information on needs assessment for this population.]
- Are the needs of PLWHA in and out of care being assessed, by contacting them directly or through other methods? Is there a specific plan for identifying and assessing the needs of individuals who know their HIV status but are not receiving primary health care? Are PLWHA surveys reaching PLWHA who reflect the diversity of the epidemic in the service area? If your EMA/TGA covers several States or a large geographic area, are PLWHA in all areas included?
- Are existing community resources being inventoried and their service capacity determined? For multi-State or large EMA’s/TGA’s, have resources in all parts of the EMA/TGA been identified and inventoried?
- Has there been careful quality control of the entire information collection process?

**Hints for Successful Data Collection**

The following are insights gained by various Ryan White planning bodies and grantees through experiences conducting needs assessment data collection activities.

- Obtain copies of survey instruments and methodologies used by others rather than “starting from scratch.” Some resources are available from HAB (see TARGET Center website); also contact other EMAs/TGAs, State or local health departments, and Ryan White HIV/AIDS Program-funded providers.
- In developing data collection tools, use consistent terminology to describe service categories, using the services defined in the HAB/DMHAP Funding Opportunity Announcements and the National Monitoring Standards. This will maximize the usefulness of surveys and allow for comparisons across geographic areas and Parts.
- Do not assume that findings from a survey represent an entire population (such as all PLWHA in the EMA/TGA) unless the methodology uses a *random or probability sample*—a sample in which every member of the population being sampled has an equal probability of being included. A *stratified random sample* may be required in order to generalize findings to subpopulations; it is a random sample drawn after dividing the population being studied into several subgroups or *strata* based on specific characteristics. Sub-samples are then drawn separately from each of the strata. For example, if you plan to interview a random sample of the clients of a particular provider that serves a diverse client group, the population might be stratified by race/ethnicity before random sampling.
When a complete list of PLWHA cannot be obtained for sampling (as is usually the case with a PLWHA survey) a **purposive sample** can be used. It should be designed to require interviews with specified numbers of people from a variety of PLWHA populations or with specific characteristics. To determine the appropriate numbers of people in each subgroup of your sample, use data from the epidemiologic profile that indicates the proportion of PLWHA in each demographic category.

- **Focus groups** can provide valuable qualitative information from specific groups (e.g., factors that influence whether women of color or youth do or do not access and remain in care). Findings can be used to determine key questions for surveys or to look more in-depth at survey results. However, this information does not necessarily represent the views of the entire subpopulation and should not be your primary source of data about PLWHA needs. The number of individuals in a focus group is small and the participants are not randomly selected, so results cannot be “generalized” to the population targeted.

- **Some planning councils and grantees** believe that open meetings, such as community forums and public hearings, have limited value as a source of consumer perspectives on service needs for a care-focused needs assessment. Fears about visibility and negative repercussions may make some PLWHA unwilling to publicly disclose their status or to criticize the continuum of care or discuss barriers affecting access to specific providers. Ryan White HIV/AIDS Program experience suggests that in-depth information about the service needs of PLWHA, especially women, minorities, and other severe need populations, is usually best obtained through other methods, such as focus groups and key informant interviews. However, useful information can be obtained through a well-planned town hall meeting or a session that is based on carefully developed questions, provides for in-depth discussion, and controls participation by working through a PLWHA caucus or permitting only PLWHA and the facilitator to be present.

- **Client satisfaction surveys** are not the same as PLWHA needs assessment surveys. A client satisfaction survey may focus on the perceived quality of services received. A needs assessment survey should ask about an individual’s met needs and service gaps and priorities; it may also ask about client satisfaction with current services, but this is not its primary purpose. A limitation of client satisfaction surveys is that they reach only those already receiving services from Ryan White HIV/AIDS Program providers. Client satisfaction surveys are generally considered a part of quality management efforts rather than needs assessments.

- **Many Ryan White projects** have found that providing needs assessment survey forms at a provider site can influence the information provided, especially if the completed surveys are left at the site where staff may see them. Sometimes there is a perception that the survey will not be anonymous, and clients may fill out the form in a way that reflects perceived provider needs and priorities rather than those of the client. *For these reasons, it is very important that needs assessment surveys be administered or provided to PLWHA at locations other than provider sites and/or by a researcher not associated with the provider.* Anonymity also needs to be ensured by having the survey either given to that external person or mailed back to a central location unassociated with the provider. Provider staff must not see the surveys, and survey forms must be anonymous.

- **Surveys of PLWHA** should target both those currently receiving care from funded providers and individuals who are not receiving HIV-related services. Their service needs
may be quite different from those of current clients. Individuals not in care are often more difficult to reach than current clients and need to be sought out at a variety of locations, using a mix of street, service provider, and media outreach techniques, as described in Section E, below.

4. Analyze the Information and Present the Results in Useful Formats

Information tabulation and analysis should focus on answering the major needs assessment questions and generating the necessary tables and summaries, as determined during the planning phase. The process should also include organizing information and analyzing it (as collected from multiple sources) in order to identify key needs, trends, and critical issues. The results of the analysis must then be presented in narrative and/or chart form for use in priority setting, resource allocation, and developing the comprehensive plan. Usually, this is a multi-stage process, requiring at least the following activities:

- Catalogue or otherwise order information, including secondary source materials, by topic and subcategory (e.g., data on PLWHA overall, by race/ethnicity, and by mode of transmission, individuals receiving primary medical care and those not in care). Sometimes this includes grouping findings by service category. In carrying out this process, be specific about what information was obtained and from what populations, to prevent attempts to generalize findings to populations that were not surveyed using probability sampling.
- Tabulate primary source data into useful data tables or qualitative information summaries.
- If multiple or different analyses are to be done for different Parts, prepare for these differing analyses.
- Analyze the information—compare and contrast information by population group (e.g., gender, race/ethnicity), geography (e.g., zip code, city or county), or other characteristics of interest. Compare the reported service needs of individuals in care and out of care.
- Prepare summaries, tables, and charts that are clear and easily understood.

Ensure that tabulations and comparisons of quantitative and qualitative data match the analyses you wish to undertake and present results in the format you desire. Do not apply findings to populations that were not surveyed or were minimally represented in the needs assessment process – and be sure to identify these data limitations in your report. Be sure that representatives of various communities – ideally, planning body members from diverse population groups— see the data very early in the analysis process to check the accuracy of assumptions and interpretations.

Be sure that findings are presented in a format and level of detail that is understandable and useful for all planning council members, funders, and others in the community who will be using the results. Make sure information can be readily used in priority setting and resource allocation. Consider variations among members in technical background and familiarity with epidemiologic data.
Use of charts and tables can help make findings understandable. Some planning councils prepare
a summary matrix of needs assessment data – including epidemiologic data and client utilization
data – by source, highlighting findings by service category, PLWHA population group,
geographic area, and other factors. It is very helpful to compare perspectives on a particular
service category or populations as obtained through different needs assessment methods and
sources.

D. Estimating and Assessing Unmet Need

CDC and HRSA/HAB estimates suggest that about one-third of those who know their status are
not receiving regular HIV-related primary health care. These data demonstrate the need to get
more PLWHA into primary health care.

Since 2000, Ryan White Part A and Part B programs have been responsible for estimating the
number of PLWHA in their service areas who know their status but are not in care. The Ryan
White legislation in Section 2602(4)(b)(1)-(2) of the Public Health Service Act also requires
assessment of the unmet needs of PLWHA who “know their HIV status and are not receiving
HIV-related services,” particularly those from “disproportionately affected and historically
underserved groups and subpopulations.”

Estimating Unmet Need. HRSA/HAB has adopted an Unmet Need Framework that provides an
operational definition of unmet need. The definition was chosen to ensure that every State, EMA,
and TGA has access to the data necessary for estimating the number of PLWHA in its
service area who know they are HIV-positive but are not in care. For purposes of this estimate –
which is not designed to indicate “quality care” – a person has unmet need if s/he has not had
any of the following during the past 12 months:

- A CD4 count.
- A viral load test.
- A prescription for anti-retroviral therapy (ART).

The approach for estimating unmet need is straightforward: determine the number of PLWHA in
the service area as of a specified recent date. Subtract the number of PLWHA in the service area
who are known to have had a CD4 count, viral load test, or ART. The remaining people have
unmet need.

Data Challenges in Estimating Unmet Need. Estimating unmet need is not easy. Limitations in
data availability and access to existing databases include the following:

- **HIV reporting.** The total number of individuals who are HIV-positive and know their
  status is the starting point for estimating unmet need for this population. As more and
  more States have mature name-based HIV reporting, this information is becoming widely
  available, although concerns may exist about data completeness. All States now collect
  name-based data on HIV prevalence, but challenges exist around methodologies,
  reporting delays, and other technical factors.
Limitations of surveillance data/databases. CDC surveillance data provide information from all States about reported HIV and AIDS cases and deaths. However, available data vary by State and EMA/TGA. Many States and cities have supplemental data available through CDC’s Medical Monitoring Project (MMP).

Cross-Part issues regarding data collection and data sharing. Ryan White data reporting has been revised to improve comparability and sharing of data across Parts. However, Ryan White Part A programs may still face challenges in obtaining information about people receiving primary care or other services through other Ryan White Parts. A person who is “in care” but is not receiving Ryan White Part A services may not be counted in the estimate of unmet need unless client data are shared across Parts. Data on people receiving ADAP services through Part B may not be available to a Ryan White Part A program.

Incomplete laboratory reporting or data entry. Some States require all CD4 counts and viral load test results to be reported to and entered into the surveillance system. In such States, it is relatively straightforward to estimate unmet need. However, many States require reporting only of CD4 counts below 200 or of detectable viral loads, or may not enforce reporting from all sources. In such cases, it is difficult to determine whether people with higher CD4 counts or undetectable viral loads are in or out of care.

Lack of access to data from non-Ryan White HIV/AIDS Program sources/providers including other Federal agencies. Many people who receive Ryan White HIV/AIDS Program services obtain their primary care and their laboratory tests from other sources and/or through providers using other funding, such as Medicaid and Medicare, private health insurance, or Veterans Affairs. Some PLWHA, including the incarcerated and individuals with both private insurance and relatively high incomes, receive no Ryan White services. They are in care, but grantees may have no access to data about them unless the State HIV surveillance system requires that all laboratory test results be reported and entered into the system. Ryan White HIV/AIDS Program grantees often face great difficulties in obtaining access to primary care data on clients whose medical care is not supported through the Ryan White HIV/AIDS Program, even if the primary care provider receives other funding through the Ryan White HIV/AIDS Program or if the individual obtains medications through ADAP.

Lack of client-level data. A client-level database greatly facilitates efforts to estimate and assess unmet need/service gaps. It provides a unique client identifier and the ability to determine the unduplicated number of clients receiving primary care and other specific services through Ryan White. Lack of client-level data will diminish over time because – although there have been some delays – all Ryan White HIV/AIDS Program grantees were expected to begin collecting client-level data as of January 2009.

Problems in matching data from different databases. One way to estimate unmet need is to compare client data with surveillance data from CDC consumer and provider surveys or to link Medicaid, ADAP, and Ryan White client-level data. However, to match data from different databases is challenging, even if they use common client identifiers, because of differences in definitions, the exclusion of individuals who received anonymous testing, and difficulties with matching and unduplicating clients who may be included in more than one database.

Confidentiality concerns. Database matching, access to client-level data, and many other aspects of needs assessment may be complicated by concerns about client
confidentiality. The U.S. Department of Health and Human Services (HHS) has provided considerable guidance with regard to client confidentiality and the disclosure of client data for reporting and evaluation purposes. However, some providers are unwilling to provide access to any information that might permit client identification, despite these protections. Sharing of data is complicated by the requirements of the Health Insurance Portability and Accountability Act of 1996 (HIPAA), which includes security standards protecting the confidentiality and integrity of “individually identifiable health information,” past, present or future. Confidentiality is often a factor in cross-Part data sharing problems and in difficulties in obtaining data on Ryan White clients who receive their primary care from non-Ryan White sources.

Use of Multiple Data Sets. Given data limitations, many grantees estimate and assess unmet need by using information from multiple data sources. They may, for example, combine general surveillance data on HIV and AIDS cases and other data from the CDC with their own surveys of PLWHA, and other special studies of particular populations or geographic areas. This approach typically involves a number of estimations, with the result that estimates may be incomplete or imprecise.

Resource Limitations in Estimating and Assessing Unmet Need. Grantees and providers often have financial and personnel limitations in documenting unmet need, as follows.

- **Limited financial and personnel resources.** Many EMAs/TGAs have small staffs assigned to Ryan White planning and administration. Planning councils and grantees must budget funds for needs assessment out of their administrative funds.
- **Limitations of surveys and other needs assessment methods designed to assess unmet need.** Assessing unmet needs and service gaps of those not in care is more complex than for individuals already in the Ryan White or other public care systems because out-of-care individuals are difficult to find. Locating such individuals requires, for example, coordinating with HIV counseling and testing facilities and using outreach workers to link with providers of services other than direct HIV/AIDS services. Such other services might include homeless shelters and drug treatment facilities. Surveys based on random samples drawn from the population of PLWHA are generally feasible only in States with full laboratory reporting, through links with the CDC surveillance system. Without such links, it is difficult to use probability sampling. (Probability sampling gives every person in the population a known chance of being included in the sample and makes it possible to generalize from the sample to the total population.) This means that EMA’s/TGA’s cannot use sampling to project unmet needs for primary health care or other services for an entire HIV population. Even with access to HIV case data, grantees may lack the resources to conduct such large-scale surveys.

Locating PLWHA who are not in care. Assessing the service needs, barriers, and gaps of PLWHA who are not in care requires finding both individuals who have never been in care and individuals who have received HIV-related primary medical care in the past, but dropped out of care and remained out of care for at least 12 months. Following are some methods used to identify such individuals as part of needs assessment.
Some planning councils and grantees have been successful in locating PLWHA not in care by working with a wide range of service providers that may not be funded through the Ryan White HIV/AIDS Program but are likely to be providing services to PLWHA. They include public and private clinics, substance abuse treatment programs, maternal and child health programs, mental health programs, and runaway and homeless shelters. Many of these are considered “points of access” into care, and some provide early intervention services.

- PLWHA caucuses or committees can often help in identifying PLWHA who are not in care. Most consumers know PLWHA who are not in care.
- Outreach workers can conduct brief interviews with PLWHA not in care as part of their ongoing activities.
- Often, PLWHA not receiving HIV-related medical care are receiving support services such as food baskets, and are a part of the Ryan White system. EMAs/TGAs with client-level data can identify and interview or survey current clients who are not shown as receiving medical care.
- “Surrogate” (substitute) approaches can be used. For example, a PLWHA survey can ask people answering the survey who are currently in care to indicate whether they were out of care for a year or more during the last 3-5 years. It so, the survey can ask why they were out of care, what barriers they faced in entering or re-entering care, and what caused them to become linked to care. Some EMAs/TGAs ask providers to identify individuals who entered care within the last six months but were not newly diagnosed, and they can be asked similar questions.
- Often, the most effective way to identify such individuals and assess their service needs is to look for them and obtain this information on a continuing basis throughout the year, then aggregate and analyze the information quarterly.
- Planning councils and grantees can encourage PLWHA participation in such surveys by providing incentives (such as grocery vouchers) if allowed by their Part or paid for through non-Ryan White funds. Generally, incentives of this type can be provided if the gift card specifies that the card may not be used to purchase alcohol or tobacco products. Ryan White programs are generally not permitted to provide cash incentives.
- EMAs/TGAs should consult with their Project Officers to be sure they understand DMHAP requirements.
- Media, including public service announcements (PSAs), targeting PLWHA provides valuable publicity. PSAs can include a voice-mail number for PLWHA to call with options for speakers with limited English. Use of appropriate community newspapers, newsletters, and/or radio stations can help in reaching specific target populations. Involving people from these communities is an important way to identify where and how PLWHA from targeted communities can be reached.
- Some PLWHA not in care can be reached through social media and asked to complete online surveys. However, because many PLWHA do not have Internet access, this method should not be used as a primary method of reaching PLWHA who are not in care.

E. Individuals Who Are HIV-Positive but Unaware of Their Status

Estimating the Number and Assessing the Needs of Individuals Who Are HIV-Positive but Unaware of Their Status.
CDC estimates that over one million Americans are living with HIV/AIDS, of whom 18.1% are unaware of their infection. (HIV in the United States: At a Glance, http://www.cdc.gov/hiv/resources/factsheets/us.htm) As such, they are not getting care for their HIV disease. The 2009 Ryan White legislation (P.L. 111-87) requires Ryan White Part A and Part B programs to determine the approximate number of HIV-positive/unaware people living in their service areas, using the CDC’s 18.1% estimate, determine their probable characteristics, develop and implement strategies and a plan to help them learn their status and enter care, and report on progress made.

It is, of course, challenging to assess the needs of this population, because they do not know their own status. It is, however, possible to analyze existing epidemiologic data that can provide an understanding of the probable characteristics of the HIV-positive unaware. These efforts should be a part of each EMA/TGA’s needs assessment effort. For example:

- An analysis of the characteristics (age, gender, race/ethnicity, risk factor, and place of residence) of late testers identified over the past 2-3 years suggests what PLWHA groups appear most likely to delay testing – and therefore be HIV-positive/unaware
- A similar analysis of recently diagnosed PLWHA may suggest populations with increased HIV/AIDS incidence
- Geomapping of recent cases can help target communities likely to have high rates of HIV-positive unaware
- Community viral load analyses suggest locations where people are most likely to be infected and out of care – including HIV-positive/unaware individuals

In addition, needs assessment requires reviewing EIIHA data in order to identify needed changes in the continuum of care to encourage earlier testing and greater success in informing such individuals of their status, referring and linking to care, and retaining them in care. This includes overall data and data for particular populations regarding, on an annual basis:

- Number of HIV tests conducted.
- Number of individuals informed of their status.
- Number of individuals not informed of their status.
- Number of HIV-positive test results.
- Number of HIV-positive individuals informed of their status.
- Number of HIV-positive individuals not informed of their status.
- Number of HIV-negative individuals linked to prevention services.
- Number of HIV-positive individuals linked to care services.

An analysis of this information should be a part of needs assessment, and should help the planning council and grantee identify improved plans and strategies for addressing EIIHA.
### Attachment 1: Sample Three-Year Needs Assessment Schedule

<table>
<thead>
<tr>
<th>Needs Assessment Component</th>
<th>Year 1</th>
<th>Year 2</th>
<th>Year 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Epidemiologic Profile</td>
<td>Full written epi profile</td>
<td>Updated epi profile</td>
<td>Updated epi profile</td>
</tr>
</tbody>
</table>
| 2. Estimates of the Number and Characteristics of PLWHA with Unmet Need and Individuals with HIV/AIDS Who Do Not Know Their Status (HIV+/unaware) | • Unmet need estimate and profile  
• Estimate of number and probable characteristics of HIV+/unaware | • Updated estimate of number and probable characteristics of HIV+/unaware  
• Updated unmet need estimate and profile  
• Updated estimate of number and probable characteristics of HIV+/unaware | • Updated estimate of number and probable characteristics of HIV+/unaware |
| 3. Assessment of PLWHA Service Needs | PLWHA Survey | Assessment of service needs of PLWHA who are out of care  
• In-depth review of client utilization data from grantee or HRSA Ryan White Services Report (RSR) | Special studies of 2-3 PLWHA groups and their service needs  
• PLWHA community meetings |
| 4. Provider Inventory       | Provider inventory | Update of inventory | |
| 5. Profile of Provider Capability and Capacity | Provider panels for selected service categories | Provider profile survey and interviews | Provider community meeting |
| 6. Assessment of Unmet Need/Service Gaps [using data from all other needs assessment components] | Assessment of unmet need/service gaps | Updated assessment of unmet need/service gaps | Updated assessment of unmet need/service gaps |

Table 22: Attachment 1: Sample Three-Year Needs Assessment Schedule

### XI. Ch 4. Priority Setting and Resource Allocation

#### Introduction

Ryan White HIV/AIDS Program resources are limited and need is severe. With effective antiretroviral treatment, PLWHA are living longer, and increasing numbers of newly diagnosed individuals are entering care as a result of successful efforts to identify HIV-positive/unaware...
individuals and bring them into care along with individuals who know their status but have not been receiving HIV-related primary medical care. This heightens the responsibility of planning councils to use sound information and a rational decision-making process when deciding which services categories are priorities (priority setting) and how much funding to provide them (resource allocation).

The process of priority setting and resource allocation (PSRA) is linked to other planning tasks because it draws upon information compiled from those efforts. For example, data compiled through the needs assessment identifies service needs and gaps. However, planning councils must often make decisions with incomplete information, such as incomplete data on the unmet need for services or limited outcomes evaluation for current services. A thorough PSRA process can help planning councils address these information gaps when they make crucial decisions about which services to fund.

**Legislative Background and HAB/DMHAP Expectations**

Ryan White Part A planning councils are responsible for setting service priorities, determining how best to meet those priorities, and allocating funds to them consistent with Section 2602(b)(4)(C) of Title XXVI of the Public Health Service (PHS) Act. (Under Section 2609(d)(1)(A) of the PHS Act, TGAs that are not required to create planning councils, and that decide not to do so, must establish a process to obtain community input, particularly from those with HIV, in the transitional area for formulating the overall plan for priority setting and allocating funds.) Planning councils should consciously link needs assessment and comprehensive planning with priority setting so that the planning council has the information needed to make sound decisions about service priorities and use of resources. (Note: Since 2006, the legislation has stipulated that not less than 75 percent of service dollars are to be used for core medical services. This requirement, along with waiver provisions established by HRSA, needs to be factored into the priority setting process.)

**Priority Setting**

Section 2602(b)(4)(C) of the PHS Act states that Ryan White Part A planning councils are required to “establish priorities for the allocation of funds within the eligible area, including how best to meet each such priority and additional factors that a grantee should consider in allocating funds under a grant based on the:

1. “‘size and demographics of the population of individuals with HIV/AIDS’ and ‘the needs of such population…’;”
2. demonstrated (or probable) cost effectiveness and outcome effectiveness of proposed strategies and interventions, to the extent that data are reasonably available;
3. priorities of the communities with HIV/AIDS for whom the services are intended;
4. coordination in the provision of services to such individual with programs for HIV prevention and for the prevention and treatment of substance abuse, including programs that provide comprehensive treatment for such abuse;
v. availability of other governmental and non-governmental resources, including the State Medicaid plan under title XIX of the Social Security Act and the State Children’s Health Insurance Program under title XXI of such Act to cover health care costs of eligible individuals and families with HIV/AIDS; and
vi. capacity development needs resulting from disparities in the availability of HIV-related services in historically underserved communities.”

Resource Allocation

PSRA requires allocating resources across service categories, whether by absolute dollar amounts or as percentages of total funds. The planning council must decide the amount or proportion of Ryan White Part A program funds to be allocated to each of the service categories it prioritizes.

Resource allocation does not mean procurement. Planning councils are strictly prohibited from involvement in the selection of particular entities to receive Ryan White Part A funding. As stated in Section 2602(b)(5)(A), selection of those entities is the responsibility of the grantee, and “the planning council may not designate (or otherwise be involved in the selection of) particular entities as recipients of any of the amounts provided in the grant.”

As part of their responsibility to determine how best to meet stated priorities, planning councils may stipulate what provider characteristics the grantee should look for in its procurement process (e.g., community-based AIDS service providers, multi-service organizations or public agencies that provide a specific service or target a specific population). They may also specify that providers should be sought in specific parts of the Eligible Metropolitan Area (EMA) or Transitional Grant Area (TGA). However, they must not be involved in the selection of providers.

Legislative Requirements and Use of Funds

Ryan White law contains a number of provisions that must be considered in the resource allocation process, such as:

- **Core Medical Services and Support Services.** Section 2604(c)(1) of the PHS Act stipulates that not less than 75 percent of service dollars are to be used for core medical services. Section 2604(c)(2), however, establishes a waiver provision regarding this requirement.
- **Early Intervention Services.** Section 2604(e) specifies that Ryan White Part A and Part B funds may be used for Early Intervention Services (EIS) if the Chief Elected Official certifies that Federal, State, or local funds are otherwise inadequate and if funds expended for EIS will supplement and not supplant other funds available to the entity for EIS for the fiscal year.
- **Priority Setting and Services to Women, Infants, Children, and Youth with HIV/AIDS.** Section 2604(f) of the PHS Act requires that a certain proportion of Ryan White Part A funds be used for care and support services to women, infants, children, and youth with HIV/AIDS. The percent of the EMA’s/TGA’s total Ryan White Part A service
funds that go to services for women, infants, children, and youth must not be less than their percent of the total population with AIDS in the EMA/TGA. This provision does not require planning councils to create a special priority for services to these populations. A waiver to this provision can be granted when EMAs/TGAs can demonstrate that the needs of each population or combination of these populations is being met through other programs such as Medicaid, the State Children’s Health Insurance Program (SCHIP), or other Ryan White Parts.

**Definitions: Components of Priority Setting and Resource Allocation**

The priority setting and resource allocation process includes four components:

1. **Priority setting** is the process of deciding which HIV/AIDS services are the most important according to the criteria your EMA/TGA has established.

2. **Guidance to the grantee on how to meet priorities:** Sometimes referred to as “directives,” this guidance involves instructions for the grantee to follow in developing requirements for providers for use in procurement and contracting. This guidance usually addresses populations to be served, geographic areas to be targeted, and/or service models or strategies to be used.

3. **Resource allocation** is the process of distributing available Ryan White Part A program funds for your EMA/TGA across the prioritized service categories. Through resource allocation, the planning council instructs the grantee how to distribute the funds in contracting for different types of services.

4. **Reallocation** is the process of moving program funds across service categories after the initial allocations are made. This may occur right after grant award, since the award is usually higher or lower than the amount requested in the application, and during the program year, when funds are underspent in some service categories and additional needs exist in other service categories. The planning council must approve such reallocations.

**Additional Priority-Setting Considerations**

Following is additional guidance for addressing each of the priority-setting factors outlined in the legislation.

- **Size/Demographics of Population with HIV/AIDS, Priorities of Communities.** See Needs Assessment chapter in this manual.
- **Coordination of Services/Availability of Other Resources.** See Coordination chapters in this manual.

**Capacity Development.** The PSRA process conducted by the planning council must focus on efforts to minimize disparities in the availability and quality of treatment for HIV/AIDS in the EMA/TGA. Where disparities exist, Ryan White funds may be used to support service specific capacity development activities. The planning council must determine, through its needs assessment, if underserved communities or populations exist. Congress places special emphasis
on identifying and responding to unmet needs/service gaps of PLWHA from underserved geographic communities and people who know they have HIV/AIDS but are not in care, as well as individuals who are unaware that they are HIV-positive. HAB policy guidance defines capacity development as “activities that increase core competencies that substantially contribute to an organization’s ability to deliver effective HIV/AIDS primary medical care and health-related support services.” Capacity development should be directed toward agencies and service providers located in communities or with a history of serving PLWHA populations the planning council has identified as underserved. The result of capacity development activities must be an increase in the number of underserved PLWHA receiving treatment for HIV/AIDS.

A Model for Priority Setting and Resource Allocation

Overview

The following decision-making model is intended to help plan and implement decision-making processes to set Ryan White priorities and allocate resources among service categories and other program-related activities. It suggests steps that use documented needs in making decisions.

Examples are provided. The model is designed to meet legislative requirements and address HAB/DMHAP expectations. Also provided are guidelines and additional considerations for those with more experience, information, and/or resources. The model recognizes that the process used locally may vary based upon these factors.

HAB/DMHAP expects a Ryan White Part A planning council to decide on service categories and funding priorities for both regular Ryan White Part A and Minority AIDS Initiative (MAI) funds allocated to the EMA/TGA. It expects the planning council to ensure a single, coordinated system of funding and care.

Assumptions

This model includes the following assumptions:

- There is no “right” way to set priorities and allocate resources. This model provides a flexible approach that meets Ryan White requirements and HAB/DMHAP expectations and reflects actual planning body experience. Case study examples illustrate the process. For purposes of this document, one approach is carried through all the required steps. However, alternative approaches are suggested.

- Decisions about priorities and allocations should be data-based.

- Priority setting must be guided by Ryan White requirements for planning and priority setting, particularly the emphasis on determining the unmet need for services and eliminating disparities in access and services.

- Emphasis must be on sound practice, not merely meeting legislative requirements.

- Priorities should be reviewed annually, though decisions may be continuation of existing services.
• The decision-making process should consider many different perspectives. It should be responsive to identified consumer needs and preferences across diverse populations and address the needs of those Ryan White clients.

• Ryan White planning bodies are official decision-making entities. Their priority setting and resource allocation decisions are subject to public scrutiny and to grievance procedures. The process used to reach these decisions must therefore be public and fully documented in writing. Conflict of interest requirements must be fully addressed.

• Priority setting is the primary legislative responsibility of the whole Ryan White Part A planning council. While much of the preliminary work may be delegated to a committee, the entire planning body should make decisions about priorities and the allocation of resources among service categories. This model therefore assumes that committees will plan and oversee the process, make sure needed information is available, and make some recommendations, actual decision making will be done by the full planning body.

Steps in Priority Setting and Resource Allocation

The following steps outline how to prepare for and conduct priority setting and resource allocation. They should be carried out over a period of several months, by committees and the full planning body.

For purposes of this document, priority setting and resource allocation are described as separate steps, carried out in sequence with leadership by a committee and participation by the full planning body. Each planning body should view the steps provided as one example of a sound process and should feel free to adapt it as appropriate, given their unique circumstances.

<table>
<thead>
<tr>
<th>Steps in Priority Setting and Resource Allocation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Agree on the priority setting and resource allocation process, its desired outcomes, and responsibilities for carrying out the process.</td>
</tr>
<tr>
<td>1. Determine and obtain available information “inputs,” such as comprehensive plan, needs assessment, and client utilization data.</td>
</tr>
<tr>
<td>2. Review core medical and support service categories, including service definitions.</td>
</tr>
<tr>
<td>3. Agree on the principles, criteria, and decision-making process to be used in priority setting.</td>
</tr>
<tr>
<td>4. Implement the process: set service priorities, including how best to meet them.</td>
</tr>
<tr>
<td>5. Agree on principles, criteria, decision-making process, and methods to be used in allocating funds to service categories.</td>
</tr>
<tr>
<td>6. Estimate needs and costs by service category.</td>
</tr>
<tr>
<td>7. Allocate resources to service categories.</td>
</tr>
<tr>
<td>8. Provide decisions to the grantee for use in the application and procurement.</td>
</tr>
<tr>
<td>9. Identify areas of uncertainty and needed improvement.</td>
</tr>
<tr>
<td>10. Reallocate funds across service categories as needed.</td>
</tr>
</tbody>
</table>

Table 23: Steps in Priority Setting and Resource Allocation
1. **Agree on the priority setting and resource allocation process, its desired scope, desired outcomes, and responsibilities for carrying out the process.**

First, agree on the scope of the entire priority setting and resource allocations process, and then determine the specific tasks to be carried out and the expected outcomes. Usually the tasks will be decision making to set priorities and allocate resources to those priorities and to provide guidance to the grantee on how best to meet each priority. The planning council may prioritize and allocate funding to any of the legislatively specific core medical services and to any support service categories approved for funding by the Secretary of Health and Human Services.

The grantee may set aside up to 10 percent of the total grant for administrative costs (including planning council support) and up to 5 percent or $3 million, whichever is less, for Clinical Quality Management (CQM). The planning council’s responsibility is priority setting and resource allocations for the remaining funds, which are to be used for program services — not less than 85% of the total grant.

Before deciding on the process, the group responsible for coordinating the priority setting and resource allocations process should review legislative requirements and HAB/DMHAP guidances to ensure that the decision-making process developed is compatible with them. For example, the process needs to:

- Base priorities on the size and demographics of the population of individuals living with HIV/AIDS, needs of individuals who are in care and out of care, disparities in access and services, the priorities of communities with HIV/AIDS, coordination with HIV prevention and substance abuse prevention and treatment programs, and compliance with the core medical services funding requirement.
- Comply with HAB/DMHAP guidance regarding the core medical and support service categories that may be funded.
- Adhere to conflict of interest policies (State and local as well as Ryan White legislative requirements).

Because Ryan White policies may change over time, planning bodies should consult the Ryan White Part A Manual and on-line list of HAB policies and the most recent application guidance from HAB/DMHAP to identify other legislative factors and HAB/DMHAP expectations. Information obtained should be summarized in writing and used in developing the PSRA process and criteria for decision making.

Once legislation and HRSA/DHMAP expectations are understood, the responsible committee can lay out the PSRA tasks and desired outcomes, assign responsibilities, and agree on a format and level of detail for the completed priorities and resource allocations. In doing so, look back to the previous year and identify any changes or improvements needed in the service categories to be considered or the level of detail to be specified. For example, the following specific outcomes might be selected:

- A prioritized list of service categories.
- Directives to the grantee on how to meet these priorities, including a description of populations to be served, geographic areas in which services are delivered, or service models that will be used to provide these services.
- An explanation regarding any core service the planning council did not prioritize, to include in the Ryan White Part A application.
- A chart showing the actual dollars and percent of service funds to be allocated to each service category or subcategory.
- A fully documented description of the steps and decision-making processes used which can be shared with the community and used to support decisions. The priority setting and resource allocations process should be developed before the process begins, to guide the work, and then revised each year based on experience.

The PSRA process must be documented in writing and used to guide deliberations and decision making. Use the following outline as a starting point. Such documentation will make it clear at the end of the process how decisions were made. Since a grievance can be filed if the planning council deviates from its established process, this documentation will be very important.

<table>
<thead>
<tr>
<th>DOCUMENTING THE DECISION-MAKING PROCESS: SUGGESTED LIST OF MATERIALS TO BE COMPILED</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>I. OVERVIEW</strong></td>
</tr>
<tr>
<td>A. The Task and Desired Outcomes: Service Priorities and Resource Allocations</td>
</tr>
<tr>
<td>B. Legislation and HRSA/HAB Guidance</td>
</tr>
<tr>
<td>C. List of HRSA-approved Core and Support Service Categories, with HRSA-approved definitions</td>
</tr>
<tr>
<td>D. Service Categories and Priorities for the Past Year</td>
</tr>
<tr>
<td>E. Policies and Procedures for Managing Conflict of Interest</td>
</tr>
<tr>
<td>F. Information Inputs (e.g., epidemiologic data, needs assessment, cost and utilization data, performance measures)</td>
</tr>
<tr>
<td><strong>II. THE DECISION-MAKING PROCESS</strong></td>
</tr>
<tr>
<td>A. Committee and Full Planning Council Roles and Responsibilities</td>
</tr>
<tr>
<td>B. Ground Rules and Overall Approach</td>
</tr>
<tr>
<td>C. Principles</td>
</tr>
<tr>
<td>D. Criteria</td>
</tr>
<tr>
<td><strong>Agreed-upon Process and Decision-making Methods</strong></td>
</tr>
<tr>
<td><strong>III. RESULTS</strong></td>
</tr>
<tr>
<td>A. Chart of Service Priorities and Resource Allocations</td>
</tr>
<tr>
<td>B. Explanations/Rationale for the Grantee or Administrative Agent</td>
</tr>
</tbody>
</table>

Table 24: Documenting the Decision-Making Process: Suggested List of Materials To Be Compiled

Next, decide who will be responsible for carrying out various steps. Final decisions must be made by the full planning body, and HRSA/HAB recommends that the planning council as a whole be actively involved in deliberations around priority setting and resource allocation.
However, preliminary work can be delegated to a committee, usually a standing committee. If a committee approach is chosen, ensure that the committee:

- Is diverse enough to reflect the various population groups, geographic areas, and types of technical skills and experience needed for sound planning (a committee of at least 7 people is typical).
- Documents its work and brings process decisions such as proposed procedures and criteria for decision making to the full planning body for review and approval (see below).
- Leads a decision-making process with participation from the entire planning body in determining priorities and/or resource allocations.

Priority setting and resource allocation is generally done by a committee including only planning body members, because of the background information required and the issues around conflict of interest.

2. **Determine and obtain available information “inputs,” including comprehensive plans and needs assessments and client utilization data.**

Priority setting and resource allocation should be data-based, and many types and sources of data can be used. Ideally, most or all of the information listed in the table below will be available as “inputs” to decision making. This information will help in making decisions about service priorities and resource allocations. HAB/DMHAP does not expect all of these data components to be used, but many planning bodies find that using a combination of data provides the best results.

Identify missing information before priority setting begins to avoid conflict over any limitations in the process caused by a lack of data. Identifying information gaps will also help to improve the information inputs for next year’s decision making.

Often, the information listed will be available but not in an easily usable form. For example, the needs assessment may be quite lengthy. An important task is to determine the kinds of information needed from each of these inputs and prepare summaries in narrative or chart form for use in decision making. For example:

- Needs assessment information might be summarized to provide a prioritized list of service needs as identified by the various needs assessment activities.
- Non-Ryan White funding might be presented in terms of dollars available for each service category, broken down by service model, target group, and/or geographic location where available.

Where possible, data from all these sources should be prepared into a user-friendly summary and presented to the entire planning body during a data presentation held before priority setting begins. A matrix can be used to summarize needs assessment and other data from multiple sources for each service category, as well as for various geographic areas, and target populations within the EMA/TGA. See the Needs Assessment Chapter in this manual.
This allows time for members to ask questions about the data and clarify any information gaps. Many planning bodies require members to attend the data presentation in order to participate in priority setting and resource allocations.

Often, the annual PSRA process begins with a detailed data presentation, which provides PowerPoint presentations, charts and other handouts, summary information that may be in a matrix format (See Needs Assessment Chapter in this manual) and allocates significant time for discussion of the data. The data presentation often lasts several hours, and ensures a shared knowledge base for decision making.

<table>
<thead>
<tr>
<th>Check if used</th>
<th>Data/Information Used for Priority Setting and Allocation of Funds</th>
<th>Current as of (Mo./Yr.)</th>
<th>Used by:</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Epidemiologic Data/Profile</strong></td>
<td></td>
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<tr>
<td>Number and characteristics of individuals living with HIV/non-AIDS and living with AIDS in the service area (prevalence)</td>
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<tr>
<td>Number and characteristics of newly diagnosed people with HIV/non-AIDS and AIDS (incidence)</td>
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<tr>
<td>Trends/changes in HIV/non-AIDS incidence and/or prevalence</td>
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<td></td>
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<tr>
<td>Trends/changes in AIDS incidence and/or prevalence</td>
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<tr>
<td>Changes in the demographics of HIV/AIDS cases in relation to the total EMA/TGA population as a measure of disproportionate impact on specific populations</td>
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<tr>
<td>Information regarding populations with special needs, including barriers to care and other access issues</td>
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<tr>
<td>Information on the number, percent, and characteristics of late testers (individuals who had AIDS at diagnosis or within one year after diagnosis)</td>
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<tr>
<td>Early Identification of Individuals with HIV/AIDS (EIHIA) matrix data – number and characteristics of individuals tested, testing positive, informed of their results, and linked to care</td>
<td></td>
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<tr>
<td>Estimate of unmet need – quantitative data regarding the number and profile of persons living in the EMA/TGA who know they have HIV but are not receiving HIV/AIDS primary medical care</td>
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<tr>
<td>Other:</td>
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<tr>
<td>Check if used</td>
<td>Data/Information Used for Priority Setting and Allocation of Funds</td>
<td>Current as of (Mo./Yr.)</td>
<td>Used by:</td>
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<tr>
<td><strong>Performance and Outcomes Evaluation Data (e.g., effects on clients receiving specific services).</strong></td>
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<tr>
<td>Performance measures (as provided by HRSA)</td>
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<tr>
<td>Client-level health status outcomes – primary medical care (e.g., viral suppression)</td>
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<tr>
<td>Other health status outcomes</td>
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<tr>
<td>System-level health status outcomes, such as available “treatment cascade” data showing number and characteristics of individuals diagnosed with HIV/AIDS, entering care, retained in care, given antiretroviral therapy, and showing viral suppression</td>
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<tr>
<td>Other:</td>
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<tr>
<td><strong>Service Utilization Data (by service category)</strong></td>
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<tr>
<td>Numbers of unduplicated clients and their characteristics; numbers of units of service provided</td>
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<tr>
<td>Demographic information regarding who is and is not accessing care</td>
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<tr>
<td>What percent of previous year’s funding was spent</td>
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<tr>
<td>Existence of a waiting list for services</td>
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<tr>
<td>Other:</td>
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<tr>
<td><strong>Service Cost Data</strong></td>
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<tr>
<td>Unit costs for each service, known or estimated; if unavailable, costs per client per year for each service category</td>
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<tr>
<td>Cost-effectiveness data, if available</td>
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<tr>
<td>Other:</td>
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<tr>
<td><strong>Needs Assessment Data (other than epidemiologic data, listed earlier)</strong></td>
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<tr>
<td>Service needs as determined through methods such as PLWHA surveys, focus groups, key informant interviews, or town hall meetings</td>
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<tr>
<td>Assessment of unmet need – service gaps and barriers for PLWHA not in care</td>
<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Check if used</th>
<th>Data/Information Used for Priority Setting and Allocation of Funds</th>
<th>Current as of (Mo./Yr.)</th>
<th>Used by:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Assessment of probable characteristics of PLWHA who are unaware of their status</td>
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<td></td>
<td>Profile of Provider Capacity and Capability findings</td>
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<td></td>
<td>Results of any special needs assessment studies</td>
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<td></td>
<td>Identification and analysis of service gaps</td>
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<td></td>
<td>Other:</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>Other Relevant Data</strong></td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>Co-morbidity, poverty, insurance status data</td>
<td></td>
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<tr>
<td></td>
<td>Information on other funding streams</td>
<td></td>
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</tr>
</tbody>
</table>

Table 25: Checklist of Data/Information for Priority Setting and Resource Allocation

3. **Review core medical and support service categories, including service definitions.**

EMAs/TGAs are permitted to prioritize and fund only the 13 legislatively specified core medical service categories plus the support service categories approved by the Secretary of Health and Human Services (16 categories as of the end of 2012).
<table>
<thead>
<tr>
<th>Ryan White Service Categories</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Core Medical-related Services</strong> (from the definitions in Section 2604(c)(3) of Title XXVI the Public Health Service (PHS) Act)</td>
</tr>
<tr>
<td>1. Ambulatory/outpatient medical care</td>
</tr>
<tr>
<td>2. AIDS Drug Assistance Program (ADAP treatments)</td>
</tr>
<tr>
<td>3. AIDS pharmaceutical assistance (local)</td>
</tr>
<tr>
<td>4. Early intervention services (EIS)</td>
</tr>
<tr>
<td>5. Health insurance premium and cost-sharing assistance</td>
</tr>
<tr>
<td>6. Home health care</td>
</tr>
<tr>
<td>7. Home and community-based health services</td>
</tr>
<tr>
<td>8. Hospice services</td>
</tr>
<tr>
<td>9. Mental health services</td>
</tr>
<tr>
<td>10. Medical nutrition therapy</td>
</tr>
<tr>
<td>11. Medical case management</td>
</tr>
<tr>
<td>12. Oral health (dental) care</td>
</tr>
<tr>
<td>13. Substance abuse services - outpatient</td>
</tr>
<tr>
<td><strong>Support Services</strong> (from the definitions in Section 2604(d) of the PHS Act and the National Monitoring Standards (Appendix F))</td>
</tr>
<tr>
<td>1. Case management (non-medical)</td>
</tr>
<tr>
<td>2. Child care services</td>
</tr>
<tr>
<td>3. Emergency financial assistance</td>
</tr>
<tr>
<td>4. Food bank/home-delivered meals</td>
</tr>
<tr>
<td>5. Health education/risk reduction</td>
</tr>
<tr>
<td>6. Housing services</td>
</tr>
<tr>
<td>7. Legal services</td>
</tr>
<tr>
<td>8. Linguistic services (interpretation and translation)</td>
</tr>
<tr>
<td>9. Medical transportation services</td>
</tr>
<tr>
<td>10. Outreach services</td>
</tr>
<tr>
<td>11. Psychosocial support services</td>
</tr>
<tr>
<td>12. Referral for health care/supportive services</td>
</tr>
<tr>
<td>13. Rehabilitation services</td>
</tr>
<tr>
<td>14. Respite care</td>
</tr>
<tr>
<td>15. Substance abuse treatment services – residential</td>
</tr>
<tr>
<td>16. Treatment adherence counseling</td>
</tr>
</tbody>
</table>

These service categories are defined in the Ryan White Part A Program Standards, a part of the National Monitoring Standards [http://hab.hrsa.gov/manageyourgrant/files/programmonitoringparta.pdf](http://hab.hrsa.gov/manageyourgrant/files/programmonitoringparta.pdf). An EMA/TGA may choose a more limited definition than specified in the HAB/DMHAP service category definitions, but may not use a more expansive definition or fund service categories not on the approved list. For example, the planning council might choose to limit Home and Community-
based Services to home health aide and personal care services, excluding other allowable activities such as durable medical equipment. Following are helpful steps in defining the service categories:

- Review the approved list of service categories and definitions provided by HAB/DMHAP in the National Monitoring Standards or the annual application guidance.
- Review last year’s service priorities.
- Consider components and delivery mechanisms that are important to your continuum of care. They may need to be separately identified for consideration in priority setting and (more often) in resource allocation. These might include types of service interventions or activities included in a single category. For example:
  - The category of Food Bank/Home Delivered Meals/Nutrition Supplements might include home-delivered meals, food banks or food pantries, and food vouchers and nutritional supplements, and the planning council may choose to separately prioritize – and allocate resources to – these types of interventions.
  - The category of Emergency Financial Assistance can include essential services such as utilities, housing, food, or medications provided with limited frequency or for a limited period of time. These services may be separately prioritized and should have separate resource allocations, since funds spent on each must be separately reported to HRSA/HAB. The EMA/TGA may choose to prioritize or fund only a subset of these services.

Service categories provide options for consideration in meeting documented needs. For each HIV health care need identified, you will want to prioritize the service interventions that work best in your area. For example, your needs assessment might indicate that PLWHA need to have their care coordinated. This might be accomplished through medical or non-medical case management, two different service categories, or through some other service intervention, such as co-located services (which would be addressed through a directive on how best to meet the care coordination priority). The planning council should give greatest priority to the service categories it considers most needed by PLWHA in your EMA/TGA.

Once a list of service categories and any desired subcategories is developed, the committee should provide it to the full planning body with definitions for use for review and approval – and for use in priority setting.

4. **Agree on the principles, criteria, and decision-making process to be used in priority setting.**

Sound priority setting must be based on principles and criteria for decision making, which must be clearly stated and consistently applied. A first step is to identify-and obtain any needed review and approval of the principles that will be used in guiding the decision-making process (see examples below). Often, such principles have been discussed and reflected in the area’s comprehensive HIV services plan. In making decisions about priorities, the decision-making body should consider whether proposed priorities are consistent with these principles.
Sometimes documentation may not exist to apply all these principles. Where the lack of information limits the quality of decision making, specify additional information needed in future years and be sure the appropriate committee (e.g., Needs Assessment) is informed of data gaps.

### POSSIBLE PRINCIPLES TO GUIDE DECISION MAKING

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
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</thead>
<tbody>
<tr>
<td>1.</td>
<td>Decisions must be based on documented needs.</td>
</tr>
<tr>
<td>2.</td>
<td>Services must be responsive to the epidemiology of HIV in this service area.</td>
</tr>
<tr>
<td>3.</td>
<td>Priorities should contribute to strengthening the agreed-upon continuum of care.</td>
</tr>
<tr>
<td>4.</td>
<td>Decisions are expected to address overall needs within the service area, not narrow advocacy concerns.</td>
</tr>
<tr>
<td>5.</td>
<td>Services must be culturally appropriate.</td>
</tr>
<tr>
<td>6.</td>
<td>Services should focus on the needs of low-income, underserved, and disproportionately impacted populations.</td>
</tr>
<tr>
<td>7.</td>
<td>Equitable access to services should be provided across geographic areas and subpopulations.</td>
</tr>
<tr>
<td>8.</td>
<td>Services should meet HHS Treatment Guidelines and other standards of care and be of demonstrated quality and effectiveness.</td>
</tr>
</tbody>
</table>

Table 26: Possible Principles to Guide Decision Making

In addition to principles, agree on the criteria to be used in setting priorities. These criteria should be “weighted” to determine which ones are most important in making decisions. Suggest a limited number of criteria and indicate which are most important. The box below provides sample criteria.

An experienced planning body with extensive information “inputs” may want to add more criteria, based on the principles agreed upon. The criteria and their relative weight should be discussed and agreed upon by the full planning body.

Note that these sample criteria do not include financial considerations, such as availability of other funding streams or unmet demand. *Priorities should reflect the planning council’s judgment concerning what services are needed to provide a continuum of care, regardless of how these services are being funded.* Funding availability and unmet needs and service gaps associated with these service priorities are considered as part of the resource allocation process.

### SAMPLE CRITERIA FOR PRIORITY SETTING

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<table>
<thead>
<tr>
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<tbody>
<tr>
<td>1. Documented need, based on:</td>
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<tr>
<td></td>
<td>The epidemiology of the local epidemic</td>
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<tr>
<td></td>
<td>Service needs specified in the needs assessment including unmet needs of individuals who are HIV-positive but not in care and of historically underserved communities</td>
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<tr>
<td></td>
<td>Other structured sources of information</td>
</tr>
<tr>
<td>SAMPLE CRITERIA FOR PRIORITY SETTING</td>
<td></td>
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<td>---------------------------------------</td>
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<tr>
<td>2. Quality, cost effectiveness, and outcome effectiveness of services, as measured through outcomes evaluation, clinical quality management programs, client satisfaction surveys, and other evaluation methods.</td>
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<tr>
<td>3. Consumer preferences or priorities, including services and interventions for particular populations, especially those with severe need, historically underserved communities, and individuals who know their status but are not in care.</td>
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</tr>
<tr>
<td>4. Consistency with the continuum of care, and its underlying priorities.</td>
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<tr>
<td>5. Balance between ongoing service needs and emerging needs, reflecting the changing local epidemiology of HIV/AIDS.</td>
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</tr>
</tbody>
</table>

Table 27: Sample Criteria for Priority Setting

Once you have an overall PSRA process, understand service categories, and have agreed on principles and criteria to guide decision making, you’re ready to decide how priorities will be agreed upon. There is no single best decision-making process or method for priority setting. However, the considerations described below which reflect the experience of many planning bodies can help you develop a practical method for your EMA/TGA.

**Issues to Consider in Defining the Priority Setting Process**

Consider the following issues in defining a decision-making process:

- **Openness of Process.** All decisions should be made in an open forum, preferably by the full planning body. The public may provide input through needs assessment and public meetings, but because of conflict of interest issues and the need for in-depth understanding of the data, generally will not participate in the decision making. It should, however, be free to observe it as well as the resource allocations decision making. Therefore, a calendar of meetings should be agreed upon and publicized within the community, and all decision-making meetings should be held in large and accessible locations and at scheduled times designed to encourage community attendance. An appropriate committee of a planning body serving a large geographic area might hold meetings in several different locations to obtain input before making its final decisions about priorities.

- **Information Base for Decision Making.** Documented information in the form of summaries of the needs assessment and other information inputs should be made available to everyone through a single source, or ideally through a data presentation just before priority setting. All members should have access to the same summary information and be able to request full copies of documents if desired before the data presentation. Training or other assistance should be provided to members less familiar with the Ryan White HIV/AIDS Program so they will feel comfortable using the information.
• **Quorum Requirements.** Explicit quorum requirements should be stated for the committee and the full planning body.

• **Minimizing Conflict of Interest.** The decision-making process may create temptations for members to advocate narrowly for service categories or for interventions for populations and/or geographic areas served by a member’s agency (public or private). It is important to define conflict of interest and establish mechanisms to minimize it. This is particularly important because many planning bodies have a high proportion of members who are service providers. Mechanisms might include:
  
  o Require full disclosure at the beginning of the meeting of relationships with HIV/AIDS service providers and the types of services they provide.
  
  o Limit involvement in discussion by members with conflicts of interest by: not allowing them to participate in discussion of service categories in which they have a conflict of interest, allowing them to answer questions but not initiate discussion, or allowing them to participate in discussions but not vote.
  
  o Exclude providers with potential conflicts of interest from serving on the Priority-Setting Committee or ensure that individuals with a potential conflict constitute a minority on the committee.
  
  o Begin each meeting by reminding members of the mission of the planning body and the purpose and importance of priority setting.

The challenge is to manage conflict of interest without excluding from the discussion those with needed service knowledge and experience. [For additional guidance, see the Conflict of Interest chapter in this manual.]

• **Voting Procedures.** Voting procedures should be agreed upon in advance and approved by the full planning body.

• **Decision-making Method.** The procedure to be used in making decisions should be specified “up front.” Examples include a consensus method, a nominal group process, or some other procedure. Several of these methods are described below.

<table>
<thead>
<tr>
<th>METHODS FOR DECISION MAKING</th>
</tr>
</thead>
<tbody>
<tr>
<td>• <strong>Group discussion and consensus.</strong> The decisions to be made are listed, discussed formally or informally, and decisions reached without a formal vote – or a vote is taken only if consensus cannot be reached.</td>
</tr>
<tr>
<td>• <strong>Aggregate checklists or score sheets.</strong> The decision makers rank a list of items such as service categories in order of priority, individual rankings are aggregated, and the items with the top scores are selected or become the group’s priorities.</td>
</tr>
</tbody>
</table>
METHODS FOR DECISION MAKING

- **Nominal group process.** A series of small-group procedures are used that limit verbal communication so that ideas will not suffer due to premature evaluation, social pressures, etc. This method can be used with variations to include several groups operating at once, or calculation of the total votes across groups. The following sequential steps are typical:
  1. A small group such as a committee comes together and is given its assignment, such as prioritizing service categories, along with a list of all allowable service categories, with definitions.
  2. The task is explained – for example, “Rate all service categories in order of their importance to the overall PLWHA population in this EMA/TGA,” or “Rank all service categories that you feel should be part of the continuum of care; do not rank those you feel are not needed in this EMA/TGA.”
  3. Members individually write down their individual responses (such as a prioritized list of service priorities), without discussion.
  4. The group facilitator (a member of the group) asks group members to identify their priorities in a round-robin fashion (one at a time) until all responses have been offered and recorded by a moderator so everyone can see them. There might be several rounds, to identify services that were highest or lowest rated.
  5. The group discusses and clarifies all responses.
  6. Members vote individually, in writing, on their priorities. A summation of votes determines the top-ranked priorities.
  7. The priorities of the various groups are averaged to obtain a priority ranking of service categories.

Table 28: Methods for Decision Making

- **The Delphi method.** This consensus-seeking technique relies on a series of questionnaires to generate anonymous ideas that are successively reviewed and refined without any group interaction or discussion. A questionnaire is emailed or mailed to each decision maker (e.g., each planning council member, who responds individually and sends it back; responses are ranked and sent back for further ranking and refinement. This technique is most useful when participants cannot be brought together because of geographical or scheduling problems, when decision making involves several stages and some of them need to occur without meetings, or when the number of decision makers is large.

Other Considerations

- **Leadership.** The planning body should decide who will lead the decision-making process. Co-chairs might provide leadership to ensure that everyone is heard, the agreed-upon process is followed, and time limits are placed on discussion.
- **Decision-making Responsibility.** Responsibilities of the committee and the full planning body should be defined. The committee might begin by reviewing its definition of the task and planned outcomes and the agreed-upon responsibilities of the committee and full planning body, as decided in Step 1.
Committee Responsibilities. The committee might be charged with preparing and managing the data presentation and with reviewing the past year’s priorities and making recommendations for changes based on the available data. It might lead discussion of the data, identified needs, and service interventions to best meet these needs, and time-limited discussion of recommended priorities.

Full Planning Body Responsibilities. The full planning body is ultimately responsible for approving the priorities. If preliminary work is done by a committee, the planning council should be the final decision makers. Ideally, it should discuss review the committee’s recommendations, discuss the data, and then use one of the methods to make final decisions. This might involve voting or obtaining the consensus of the full body, resolving any areas of disagreement.

Meeting Schedule. Meetings necessary to carry out the process should be scheduled well in advance and widely publicized.

The first full planning council meeting on PSRA might be held after the planning body has approved a decision-making process, to review the process, criteria, and information “inputs” as a group and to train the planning body on the decision making method.

The committee might then hold on or more meetings, as needed, to prepare for the priority setting process and develop recommendations to the full planning body.

The entire planning body should participate in a data presentation providing the information base for decision making.

The entire planning body might then meet to set priorities, beginning with suggestions from the committee or decision making led by the committee to reach agreement on a final list of service priorities. Note: This meeting could be the first part of a combined priority setting and resource allocations session.

Providing guidance to the grantees on how best to meet the priorities. The development of this guidance, or Directives, may be done as part of the priority setting or as a separate process. Directives often address populations or geographic areas to be served, promising service models, or needed provided capability and experience. Often, needs assessment helps to identify populations or communities in need of additional services and/or service strategies that seem particularly promising. They may also be identified during discussion related to the data presentation or priority setting. Sometimes a committee responsible for care strategies develops suggested guidance during the program year. These ideas need to be put into written form and discussed with the grantee as part of the PSRA process. Since they may have funding implications which affect allocations, they should be identified and discussed in the priority setting phase of PSRA. For example, needs assessment may indicate that medical providers need evening or weekend hours to ensure access to care for PLWHA who are employed. If a requirement for such hours is to be made, then allocations will need to be increased to cover the costs associated with expanded hours.

Directives can be a good tool for reaching underserved populations. For example, you can direct that the grantee contract with providers to provide services within a specific community as defined by zip codes, as a way to distribute resources to a neglected area, or that some peer support or case management funds be targeted to women with children if existing programs are not meeting their needs.
Directives sometimes address characteristics or capacities of organizations that might deliver the services. The planning council might stipulate what provider characteristics or capacities should be looked for in the RFP that is issued for funding of service providers (such as bilingual/bicultural staff or weekend or evening service hours). However, selection of particular providers/agencies that should deliver a given service must be left to the contracting process.

In planning for your priority setting, be sure to decide how you will identify and discuss the development of directives.

5. Implement the process: set service priorities, including how best to meet them.

Once the planning body has adopted a priority setting process, including an agreed-upon method to make decisions, implement the priority setting process, with staff or consultant support. Following is a “case study” example of how one planning body carries out the decision-making meetings and follow up, involving both a preliminary meeting of a committee and a final priority setting meeting of the full planning body. In this planning council, the responsible committee coordinates a data presentation at a separate meeting prior to priority setting, ensures careful preparation for priority setting, and provides some initial recommendations for needed changes in the priorities. It then manages a meeting of the planning council in which the priorities are set.

<table>
<thead>
<tr>
<th>A PRELIMINARY PRIORITY SETTING COMMITTEE MEETING: PREPARING FOR PLANNING COUNCIL PRIORITY SETTING</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. A roll call ensures that committee members present represent the diversity necessary for informed input into the priority setting process.</td>
</tr>
<tr>
<td>2. To address conflict of interest concerns, the chair asks members of the committee to disclose any relationships with current and potential Ryan White service providers (e.g., employment as staff or consultant, board membership, close relative employment or board membership, other financial relationship) and indicate the kinds of HIV/AIDS-related services these providers offer. Two provider representatives disclose that they are the only provider in the service area that delivers a particular type of service. The Chair notes that all committee members are permitted to participate in discussion, but those with a conflict of interest may not initiate discussion or participate in any individual vote regarding any service category where they have a conflict of interest. They are permitted to vote on a slate of priorities.</td>
</tr>
<tr>
<td>3. The chair reads the principles and criteria that have been adopted to guide the priority setting process, and asks whether they are clear and understandable to all members. The chair also reminds the committee that they are expected to represent the interests of all PLWHA in the service area in all work related to the PSRA process.</td>
</tr>
</tbody>
</table>
### A PRELIMINARY PRIORITY SETTING COMMITTEE MEETING: PREPARING FOR PLANNING COUNCIL PRIORITY SETTING

<p>| | |</p>
<table>
<thead>
<tr>
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</tr>
</thead>
<tbody>
<tr>
<td>4.</td>
<td>Several members of the committee and planning body staff (previously assigned this responsibility) remind members of the previously completed data presentation to the entire planning council. They highlight key findings, including an increase in new diagnoses among PLWHA under 25 and over 55, challenges in linking to care and retaining in care recently diagnosed individuals with HIV/non-AIDS in care, reported difficulties reported by some PLWHA in obtaining referrals for supportive services from their medical case managers, and inadequate access to medical care for the increasing number of employed PLWHA. In addition, data from a special study indicated that recently diagnosed older PLWHA and immigrants are having difficulty accessing support groups and identify a need for more peer-based services.</td>
</tr>
<tr>
<td>5.</td>
<td>The committee reviews the HAB/DMHAP list and definitions of allowable service categories, including both core medical and support services. The EMA/TGA has decided to use the 29 HAB/DMHAP service categories, with some limitations on types of services to be provided through Home and Community Based Services and Emergency Financial Assistance.</td>
</tr>
<tr>
<td>6.</td>
<td>The committee notes that there have not been any legislative, policy, or guidance changes affecting the PSRA process.</td>
</tr>
<tr>
<td>7.</td>
<td>The committee reviews the list of prioritized service categories established last year, which ranked all 29 categories. It discusses what changes in priorities seem needed, given needs assessment findings and other data. The group agrees that Early Intervention Services (EIS), currently ranked 15th, should receive a higher ranking due to the linkage and retention issues identified; there is also agreement that Non-Medical Case Management may need higher priority to address the reported challenges in referrals for supportive services. Several other possible changes are suggested, but there is no consensus on them. Areas of disagreement are recorded for presentation to the full planning body.</td>
</tr>
<tr>
<td>8.</td>
<td>The committee reviews suggested guidance/directives to the grantee, which have been explored by a task force. Included are three proposed directives. One would require all outpatient/ambulatory medical care providers to be open at least two evenings and/or weekend days a month; cost implications are identified. Another would ask the grantee to provide incentives or give preference to case management providers who employ case managers with specific expertise in working with youth and with older PLWHA. The third calls for development of a peer support group model for older PLWHA. The committee adds a recommendation for development and testing of a peer-based Early Intervention Services model.</td>
</tr>
<tr>
<td>9.</td>
<td>The committee agrees on how to document the process and recommendations for presentation to the planning body.</td>
</tr>
</tbody>
</table>
6. **Agree on the principles, criteria, decision-making process, and methods to be used in allocating funds to service categories.**

All Ryan White Part A planning councils are responsible for resource allocations as well as priority setting. The extent of the resource allocation effort depends upon the planning body’s scope of responsibility. Some planning bodies are responsible for allocating funds from multiple sources – for example, both regular Ryan White Part A and MAI funds, and sometimes Part B funds for their region, local HIV/AIDS service dollars, and/or Housing Opportunities for People living with AIDS (HOPWA) funds.

The resource allocation process typically requires the following activities:

- Specify the sources and categories of funds to be allocated.
- Use the results of the priority setting process to specify the service categories to which funds may be allocated.
- Determine funding gaps for prioritized services by reviewing both last year’s service utilization and needs assessment data and the sources and amounts of funding allocated by other sources to support particular services. This will enable the planning body to determine if there is a funding gap to which it should respond.
- Determine the probable amount of funding (overall and from each source) that must be allocated, usually based on the level of actual funding received for the current program year (“flat funding”). This requires separate assumptions about regular Ryan White Part A and Ryan White Part A MAI funds.
- Allocate a specific number of dollars to the service categories, based on the identified need, projected number of PLWHA to be served, and the cost per client. Ensure that at least 75% of service dollars are allocated to core medical services and not more than 25% to approved support services.
- Present the resource allocations in summary form. Most often this means preparing a chart indicating service priorities and resource allocations to each of those services, including both dollars and percent of funds, with a separate column for each funding stream for which the planning body is responsible. The format for presenting the completed task might be as shown in the sample Priorities and Resource allocations Chart at the end of Step 9-if the planning body were allocating funds only for Ryan White Part A.

Resource allocations must be done before final figures are available on funding level, since they are included in the funding application to HRSA/HAB. Therefore, allocations can be based on various funding assumptions or multiple “scenarios,” such as:

- Funding will be unchanged from the prior year.
- Funding will be a specified percent—such as 5 percent or 10 percent—below the prior year.
• Funding will be a specified percent—such as 5 percent or 10 percent—above the prior year.

Alternatively, allocations can be based on an expected minimum level of funding, with information about how additional funds will be allocated, as in the first scenario described in Step 8.

Factors to use in resource allocation are usually similar to those used for priority setting, with some additions or refinements. The committee responsible for managing the resource allocations process should recommend and the planning body should review and approve these factors.

Regarding principles, the planning body might want to add the following, which reflect Ryan White legislative requirements:

• Ryan White will be considered the funder of last resort.
• Ryan White will not be able to meet all identified needs.

Regarding criteria, the planning body might want to add the following:

• **Lack of other funds.** Resources from other sources are not available to meet this service need.
• **Cost-benefit.** The service provides a high level of benefit for PLWHA relative to its cost.

Regarding the decision-making process, many issues need to be considered. The complexity of the resource allocation process makes it especially important that it be carefully developed by a committee, supported by staff work, then implemented with final decision making at a full planning body meeting. Often, the committee works closely with the grantee to develop estimates of the number of PLWHA likely to need each service and the costs involved. Where the actual allocations process is done by the full planning body, the committee’s responsibilities are to manage the process and ensure that needed information is available to the planning body for its decision making.

As with priority setting, the committee should recommend the process to the planning body, and the planning body should review and approve it. Many of the considerations are identical to those identified for priority setting; some additional considerations are described below.
ADDITIONAL ISSUES TO CONSIDER IN DEFINING THE RESOURCE ALLOCATION PROCESS

- **Baseline or Starting Point for Resource allocation Decisions.** Several different starting points can be used for resource allocation decisions. For example:
  - **The planning body can use a “zero-based budgeting” approach,** which means that all allocations are determined without using last year’s allocations as a starting point. If this approach is used, be sure to consider multi-year commitments and the content of your three-year comprehensive plan, as well as HAB/DMHAP requirements that 75% of service funds go to core services.
  - **Allocations from the previous year** can be used as a starting point, if you believe that last year’s allocation process was sound. Remember that these will be the allocations used for the current program year, and final expenditures will not be available. For this reason, some planning bodies look at both the most recent allocations and the prior year, for which final expenditure and costs per client information are available.

- **The second approach is likely to be easier for most planning bodies.** Its use requires attention to changes in service priorities as established in Step 5, planning body confidence that it implemented a fair process the past year, no large changes in the epidemic within the service area, and availability of updated information about service costs. Information on other funding streams to support priority service categories is needed regardless of which approach is used.

- **Decision-making Methods.** Methods such as consensus, nominal group process, and/or discussion and voting might be used in making decisions about resource allocations. This should be determined “up front,” as with priority setting.

Minimizing Conflict of Interest. Conflict of interest is generally managed and minimized the same way for priority setting and resource development. However, because allocation decisions help determine funding opportunities, the decision-making process may create greater temptations for members to advocate narrowly for allocations for the service interventions, populations, and/or geographic areas served by a member’s agency, public or private, or to a member’s own community. Members may also oppose funding to a particular category of service or population based on personal viewpoints. Those leading the allocations process must ensure continuing attention to conflict of interest to avoid such issues. See also Conflict of Interest and Planning Body Operations chapters in this manual.

Table 30: Additional Issues to Consider in Defining the Resource Allocation Process

7. Estimate needs and costs by service category.

Thoughtful resource allocation depends upon information available on:

- **The need and demand for specific services**
- **The costs of those services:** Some planning bodies consider service gaps in setting their priorities. If your planning body uses this approach, you may already have compiled this information (described below) by the time you begin the resource allocation process. If
so, make sure the materials are available for review as you determine resource allocations.

- **The availability of other resources to support them:** Several of your analyses will require an inventory of the sources and levels of other governmental and nongovernmental resources available to support HIV/AIDS-related services in your community. Such information is also necessary to assess and, to the extent possible, quantify gaps in services. This inventory of other funding streams may be a part of your needs assessment or may be compiled by the grantee for inclusion in the funding application.

- **Capacity development needs of providers:** These must be associated with service gaps or lack of appropriate services for particular populations or in particular geographic areas, and must be identified by service category

A planning body that has incomplete information on these topics can make best use of available information by compiling it in a summary format and examining it alongside approved service priorities.

The planning body should gather available information by service category. If information is available only for some types of services, use what is available and identify information gaps. It is particularly helpful to prepare charts that list service priorities in order and provide information needed for the allocations process. Examples of particularly useful analyses and charts follow.

*Prepare a comparison of the service priorities for the upcoming year with the priorities and allocations identified for the current year.* The chart format might look like this:

<table>
<thead>
<tr>
<th>Service Category</th>
<th>Priority for Next Year</th>
<th>Priority for Current Year</th>
<th>Percent of Current Year’s Allocation</th>
<th>Amount of Current Year’s Allocation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Outpatient/Ambulatory Medical Care</td>
<td>1</td>
<td>1</td>
<td>39.5</td>
<td>$1,020,000</td>
</tr>
<tr>
<td>AIDS Drug Assistance Program (ADAP treatments)</td>
<td>2</td>
<td>2</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>AIDS Pharmaceutical Assistance (local)</td>
<td>3</td>
<td>3</td>
<td>5.8</td>
<td>150,000</td>
</tr>
<tr>
<td>Oral Health Care</td>
<td>4</td>
<td>5</td>
<td>7.8</td>
<td>200,000</td>
</tr>
<tr>
<td>Medical Case Management</td>
<td>5</td>
<td>4</td>
<td>17.0</td>
<td>400,000</td>
</tr>
</tbody>
</table>

*Table 31: Service Priorities Comparison*

*Obtain information on the units of service provided and the costs per unit of service or per client for the service categories or components within them.* The most easily obtainable information might be the number of clients served in a year and the estimated costs per client per year. Your chart might look like this:
Table 32: Services and Costs

<table>
<thead>
<tr>
<th>Service Category</th>
<th>No. of Clients Served Per Year</th>
<th>Average Cost Per Client Per Year</th>
<th>Funding for Current Year</th>
</tr>
</thead>
<tbody>
<tr>
<td>Outpatient/Ambulatory Medical Care</td>
<td>1,008</td>
<td>$1,012</td>
<td>$1,020,000</td>
</tr>
<tr>
<td>City X</td>
<td>734</td>
<td></td>
<td></td>
</tr>
<tr>
<td>County A</td>
<td>170</td>
<td></td>
<td></td>
</tr>
<tr>
<td>County B</td>
<td>104</td>
<td></td>
<td></td>
</tr>
<tr>
<td>AIDS Drug Assistance Program (ADAP treatments)</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>AIDS Pharmaceutical Assistance (local)</td>
<td>360</td>
<td>$576</td>
<td>200,000</td>
</tr>
<tr>
<td>Oral Health Care</td>
<td>207</td>
<td>725</td>
<td>150,000</td>
</tr>
<tr>
<td>Medical Case Management</td>
<td>991</td>
<td>$444</td>
<td>440,000</td>
</tr>
<tr>
<td><strong>Table 32: Services and Costs</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

If available, provide a more extensive analysis of your most recent completed program year funding levels. For example, did funds for certain services (e.g., oral health care) run out before the end of the year, or were funds reallocated because of under-expenditure or low demand? Obtain the grantees or administrative agent’s projection of the unspent funds for each service category. If this information is available, make it a separate column on your chart.

*Estimate current service gaps in terms of unmet service demand by priority.* For example, given the current funding situation, estimate the number of PLWHA with unmet need who are not receiving primary care, medical case management, etc., and should be receiving such services. If possible, provide this information by service priority, and estimate the costs for meeting that need. Review costs per client or unit costs for the past year, and modify as needed to project for next year. Use a format such as the following:

<table>
<thead>
<tr>
<th>Service Gaps</th>
<th>Estimated Number of Persons Needing But Not Receiving Service</th>
<th>Estimated Additional Cost of Meeting Need (Above Current Funding)</th>
</tr>
</thead>
<tbody>
<tr>
<td>AIDS Pharmaceutical Assistance (local)</td>
<td>125</td>
<td>$72,000</td>
</tr>
<tr>
<td>Substance Abuse Treatment – women-focused</td>
<td>85</td>
<td>$97,155</td>
</tr>
<tr>
<td>Medical Case Management–Family-Centered; for Spanish-speaking clients</td>
<td>55</td>
<td>$24,420</td>
</tr>
</tbody>
</table>
### Service Gaps and Cost Estimates

<table>
<thead>
<tr>
<th>Service Gaps</th>
<th>Estimated Number of Persons Needing But Not Receiving Service</th>
<th>Estimated Additional Cost of Meeting Need (Above Current Funding)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ambulatory Medical Care in Outlying County X</td>
<td>80</td>
<td>$80,960</td>
</tr>
<tr>
<td>[List other unmet service needs or service gaps]</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Table 33: Service Gaps and Cost Estimates**

Prepare a combined chart of estimated total needs by service priority, both met and unmet, and available funding. Use the format shown in the chart below, and include the following:

- Service priorities, including specific components like subpopulations and geographic area needs (Column 1).
- Total need (including met and unmet need), in terms of either number of clients or service units (as shown in Column 2).
- Average cost per client estimated for the next year (Column 3).
- Total funds required to meet the need (Column 4).
- Identification of other available funds to meet service needs, by service priority, or (if dollar amounts are not available) the number of individuals served (Column 5).
- The level of gaps in service by needs category (Column 6), which is the difference between total funds required to meet the need (Column 4) and other available funds (Column 5) — or the total number of clients not served by other sources (Column 2 minus Column 5) multiplied by the Ryan White Part A cost per client (Column 3).

<table>
<thead>
<tr>
<th>Service Priority</th>
<th>Total Need Per Year (Number of Clients)</th>
<th>Average Cost Per Client Per Year</th>
<th>Total Funds Required to Meet Need</th>
<th>Other Available Funds/Clients Served</th>
<th>Unmet Need or Service Gap</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ambulatory Medical Care</td>
<td>2,100</td>
<td>$1,040</td>
<td>$2,124,000</td>
<td>1,052 clients - Medicaid</td>
<td>$1,089,920</td>
</tr>
<tr>
<td>AIDS Drug Assistance Program (ADAP)</td>
<td>1,450</td>
<td>$11,344</td>
<td>$16,550,896</td>
<td>$16,550,896 - Part B</td>
<td>$0</td>
</tr>
<tr>
<td>AIDS Pharmaceutical Assistance (local)</td>
<td>471</td>
<td>$576</td>
<td>$271,296</td>
<td>0</td>
<td>$271,296</td>
</tr>
<tr>
<td>Oral Health Care</td>
<td>622</td>
<td>$725</td>
<td>$450,950</td>
<td>300 clients served through Medicaid, Part F dental clinic</td>
<td>$233,450</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Service Priority</th>
<th>2 Total Need Per Year (Number of Clients)</th>
<th>3 Average Cost Per Client Per Year</th>
<th>4 Total Funds Required to Meet Need</th>
<th>5 Other Available Funds/Clients Served</th>
<th>6 Unmet Need or Service Gap</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical Case Management</td>
<td>1,546</td>
<td>$444</td>
<td>$686,424</td>
<td>396 clients - Part C and D grantees</td>
<td>$510,600</td>
</tr>
<tr>
<td>Emergency Financial Assistance (Housing)</td>
<td>420</td>
<td>$796</td>
<td>$334,320</td>
<td>$38,000 private funding</td>
<td>$296,320</td>
</tr>
<tr>
<td>Home-Delivered Meals</td>
<td>80</td>
<td>$1,620</td>
<td>$129,600</td>
<td>$75,000 - State funds</td>
<td>$54,600</td>
</tr>
<tr>
<td>Food Pantry/Food Bank</td>
<td>350</td>
<td>$582</td>
<td>$203,799</td>
<td>$155,000 private funding</td>
<td>$48,799</td>
</tr>
<tr>
<td>Food Vouchers</td>
<td>200</td>
<td>$160</td>
<td>32,000</td>
<td>$5,000 faith-based groups</td>
<td>27,000</td>
</tr>
<tr>
<td>[List other service categories]</td>
<td></td>
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</table>

**Table 34: Estimated Service Needs**

Once you have prepared this information for all prioritized service categories, you are ready to carry out your agreed-upon resource allocation process.

8. **Allocate resources to service categories.**

To allocate resources to the established priorities, you will need to agree upon and review the principles, criteria, and processes described in Step 6, and to develop and review the information described in Step 7. The allocations process might then proceed to the development of alternative scenarios or funding formulas, such as the following:

- Flat funding (same amount as prior year)
- Increased funding (5%)
- Decreased funding (5%)

Based on the Step 7 information charts, you can develop alternative scenarios or allocation formulas for the planning body’s review. Following are four possible resource allocation scenarios. Whichever scenario you use, be sure that at least 75% of funds are allocated to core medical services as specified in the legislation.
Sample Approaches for Resource Allocations

Approach 1

Divide priorities into tiers of services and other activities, as follows:

- First-tier categories that are considered “core” or “essential” services, including the most important core services and the most important support services.
- Second-tier priorities that should be funded if funds permit.
- Third-tier categories that should not receive funding this year, unless the program receives a funding increase.

Start by using Approach #1 (the flat funding scenario). First allocate the funds needed to ensure continuation of first-tier services for the same number of clients as the current year, if continued funding is needed. Once these “essential” services have received needed funding, allocate a specified proportion of additional expected funds (e.g., 60 percent) to second-tier service categories, deciding on amounts per category based on number of clients to be served and costs per client. Divide funds among categories based on your priorities and needs assessment results. Use the remaining funds to expand funding for first-tier categories towards the estimated total need. When you use the second increased funding scenario, first increase first-tier service categories to fill identified service gaps, then allocate funds to the second-tier services using the same allocations procedure as before. See how much money is left, and decide which, if any, of the third-tier categories to fund. When you use the third (decreased funding) scenario, consider which second-tier categories you may want to zero-fund in order to maintain essential services.

Approach 2

Using the first (flat funding) approach, decide which services are most important — perhaps your first 5-7 categories), and begin by allocating full needed funding to those categories. Determine how much funding remains, and allocate it to other prioritized services based on the number of people you need to serve in each service category and the cost per client per year. Under this scenario, you will provide most of your funding to the service categories you define as “essential,” and therefore will fund fewer service categories. Under the increased funding scenario, you will add service categories to the funding list. Under the decreased funding scenario, you will eliminate additional categories.

Approach 3

Continue to fund at the same level those services with high priority rankings, or those identified in the continuum of care as essential to life or essential to providing access to care. Cut other services by a specified percent (e.g., 21 percent). Use the pool of funds created by the cuts to fund new priorities or unmet components of high-priority service categories (e.g., substance abuse treatment services for women, medical case management services for Spanish-speaking PLWHA, ambulatory medical care in an outlying county). If the funding level is higher than expected, a set percentage of increased funds might go to new services, high-priority existing
services, and lower-priority existing services. If the funding level is lower, a set percentage in cuts might be applied across all services, or smaller cuts to high priority services.

Approach 4

Divide services into tiers as in Scenario #1. Continue to fund existing services in first and second tier, but decrease funding levels for second-tier services. Base these reductions on a careful review to identify services that are lower in priority, level of unmet need or service gap, and/or availability of other resources. Make sufficient cuts to generate a pool of $X dollars to allocate to new service priorities and to increase allocations to specific high-priority services that have high levels of unmet need and low availability of other resources.

In any scenario or approach, the highest-priority services within the EMA/TGA are not always the services that receive the largest allocations. The highest-priority services may cost less than other services and/or other Ryan White or non-Ryan White resources may be available to fund them. A Ryan White Part A program might, for example, identify ADAP as its number two service priority, but allocate little or no Ryan White Part A funding to the service category because sufficient funds are available through the State’s Ryan White Part A program. With the expected expansion of Medicaid in some states and establishment of health insurance exchanges in all states as of 2014, planning bodies may find that they will need to allocate less funding for outpatient/ambulatory medical care, ADAP, and other service categories covered through these programs. Similarly, a service category that is relatively lower priority but is not funded through other available grant funding streams or included in Medicaid or private health insurance might be allocated a larger proportion of Ryan White funds. See also the chapter on Planning Council Operations in this manual.

This approach to priority setting and resource allocation has the advantage that it applies regardless of changes in other funding streams. For example, if severe cuts were to occur in other funding for outpatient primary health care, the planning body would reallocate some of its resources. Similarly, if the demand for medications grew beyond the Part B State ADAP’s capacity to meet it, a planning body might choose to allocate additional funds for ADAP rather than other services.

Resource allocations are best made at a full planning body meeting. As with priority setting, it is helpful for a committee to present data on service needs and costs and make recommendations for service categories in particular need of increases, as well as categories where funds were underspent the prior year. The committee may make recommendations about resource allocations, and may ask the grantee to provide recommendations as well. Often, the committee and grantee provide their input, and the full planning body uses the three funding-level scenarios to do the allocations at an open meeting. Principles, criteria, needs and resource data, and the selected scenarios and approach should be presented and discussed at the beginning of the meeting. The full planning body reviews the information provided and recommendations made, and then does the final allocations using the agreed-upon process. It is important that the planning body discuss allocations choices and underlying data, based on the criteria and the needs and resource information. The planning body either reaches consensus on the resource allocations, or adopts them through a formal vote. Usually, votes are done for all groups of
service categories—such as all core services or all support services—but individual votes may also be taken for a single service category.

Staff document the resource allocation process and decisions along with the priority setting process and results (See Step 1 for a sample format for documentation). Once this process is completed, these priority setting and resource allocation decisions are reported to the community. The planning body publicizes its decisions through its own meetings and often through public hearings or meetings in several locations. Since the allocations are likely to be refined after the Ryan White Part A award is made and the precise funding level is known, some Ryan White Part A programs wait to present their allocations until after they have been finalized.

9. Provide decisions to the grantee for use in the application and procurement.

The planning body must provide the grantee or administrative agent with the results of the priority setting and resource allocation process, both to include in the Ryan White Part A application and as a basis for the selection of providers (the procurement process). The planning body’s priorities and accompanying directives on how best to meet the priorities will reflect specific population groups, geographic areas, and service delivery mechanisms. As noted previously, the grantee handles procurement. The planning council must not be involved in the selection of providers.

10. Identify areas of uncertainty and needed improvement.

Once the entire process has been completed for the year, the committee and the full planning body should review the experience and identify ways to improve the process in future years. A designated group should:

- Obtain written or oral feedback from the responsible committee and the full planning body.
- Identify missing or incomplete information that affected decision making, with emphasis on recent legislative requirements, policies, or guidelines.
- Review the decision-making process for weaknesses or problems and seek solutions, with special attention to any aspects of the process that might make the planning body vulnerable to a grievance.
- Review how conflict of interest was managed, and whether additional efforts are required.
- Make recommendations and plans for improvement, then assign responsibility for follow up to be sure they are carried out in the following year’s PSRA process.

11. Reallocate funds across service categories as needed.

Allocations happen before the annual Ryan White Part A application is submitted. Reallocation occurs after funds have been awarded, often at several times during the program year.

The Planning Council almost always needs to do some. The first occurs when the EMA/TGA gets its Notice of Grant Award from HRSA/HAB. Usually the amount will not be precisely what
Additional reallocation is generally needed during the program year. Under the 2009 Ryan White legislation, the EMA/TGA will lose future funding if it does not spend at least 95% of its formula grant. This means that the grantee must very carefully monitor provider expenditures. If it becomes clear that one provider cannot spend all the funds, the grantee has the authority to reallocate funds within the service category. But if more funds are needed in a different service category, the grantee must come back to the planning body and get its approval for reallocating funds to a different category. The grantee will often provide recommendations, but the planning body should review them and available cost and utilization data and then vote on reallocations. Because of the need to ensure that all funds are spent, the planning body needs a rapid reallocation process to use in the last several months of the program year, to help the grantee ensure that funds are fully spent. This may mean calling special committee or full planning body meetings on short notice. Sometimes the planning body has a policy that allows the grantee to reallocate up to a specified percentage of total service dollars (e.g., 3% or 5%) without its prior approval during the last 3-4 months of the program year. Sometimes there is prior agreement about how funds may be moved if they become available, so the grantee can act quickly once it knows how much money needs to be reallocated. This process must be worked out between the grantee and planning council.

XI. Ch 5. Comprehensive Plan

Introduction

Planning is central to the Ryan White HIV/AIDS Program’s focus on local and State decision making in developing HIV/AIDS care systems. Each grant year, Ryan White Part A planning councils establish service and resource-allocation priorities and implementation plans to address them. Comprehensive HIV services planning goes beyond this annual process and provides a road map for developing and improving a comprehensive and responsive system of care over time. It provides an opportunity for the planning council to step back from short-term tasks to review the current system of care and envision an “ideal” system of care, then develop a three-year plan for working towards it, based on a Guidance provided by HRSA/HAB. It does so by reviewing epidemiologic, needs assessment, and client utilization data; data on individuals who know their status but are not in care and HIV-positive individuals unaware of their status; existing resources to meet those needs; and barriers to care; and consulting with the community to obtain their perspectives about the system of care. Additional useful information to review includes performance measure and evaluation data (including data on cost effectiveness and outcome effectiveness of services) and contract monitoring data.

This information is used to set out long-term goals, objectives, and strategies for delivering services and improving the system of care. The plan reflects the community’s vision and values about how best to deliver HIV/AIDS care, particularly in light of increasing numbers of PLWHA entering care, more PLWHA needing care over many years due to improved treatments, and limited resources.
Participatory comprehensive planning often has tangible benefits that help enhance program implementation. Planning can help a group develop decision-making criteria and contingency plans, preparing the planning council and the community for changes in the epidemic or resources, including changes in the health care system as a result of health care reform. Planning also places services and systems of care in the context of many funding sources. By providing information, the process allows planning councils to examine ways to increase the efficiency of service delivery and to maximize the use of existing funding streams.

Comprehensive planning helps answer four basic questions:

1. Where are we now? (What does our epidemic look like and what is our current system of care?)
2. Where do we need to go? (What is our vision of an ideal system?)
3. How will we get there? (How does our system need to change to assure availability of and accessibility to core services? What steps will we take to develop this ideal system?)
4. How will we monitor our progress? (How will we evaluate our progress in meeting our short- and long-term goals?)

HAB/DMHAP Expectations

Multi-Year Comprehensive Plans and Relationship to Implementation Plans. Each year, planning councils establish priorities and allocate resources, which are then turned into goals and objectives in the funding application’s annual implementation plan. Comprehensive HIV services planning goes beyond this annual process. The comprehensive plan should drive development of goals and objectives in the annual implementation plan. In turn, the annual implementation plan is a tool to achieve goals and objectives in the comprehensive plan.

EMAs/TGAs are required to submit an updated comprehensive plan that reflects its most recent epidemiologic data and needs assessment, as well as substantive input from the community, especially consumers of Ryan White services. HAB/DMHAP expects updating of the comprehensive plan to occur every three years, at a minimum, and provides a Guidance that identifies issues of particular importance in preparing the plan. For example, for the 2012 plan, these issues included the early identification of individuals with HIV/AIDS (EIIHA), the National HIV/AIDS Strategy, the Affordable Care Act (ACA) and health care reform, and Healthy People 2020.

The planning council has lead responsibility for developing the plan, but the grantee should also be actively involved, and some of the goals and objectives should involve grantee tasks and responsibilities.

Use of Ryan White Part A Funds for Planning. Grantees fund planning council support activities out of their administrative budget, using formula and supplemental grant funds. Comprehensive planning activities can also be funded under these funds.
Focus of Comprehensive Plans. HAB/DMHAP expects EMAs/TGAs to develop multi-year comprehensive plans that will:

- Address disparities in HIV care, access, and services among affected subpopulations and historically underserved communities
- Ensure the availability and quality of all core medical services within the EMA/TGA.
- Address the needs of those who know their HIV status and are not in care as well as the needs of those who are currently in the care system.
- Address performance indicators and other clinical quality and outcome measures.
- Address the goals of the National HIV/AIDS Strategy.
- Outline how efforts are coordinated with and adapt to changes in the health care system, such as those occurring because of health care reform.
- Include strategies that:
  
  a. Identify individuals who know their HIV status but are not in care and inform these individuals of services and enable their use of HIV-related services
  b. Identify individuals with HIV/AIDS who do not know their HIV status; make them aware of their status; and, enable them to use HIV-related services with particular attention to reducing barriers to routine testing
  c. Provide goals, objectives, and timelines (as determined by the needs assessment)
  d. Coordinate services with HIV prevention programs including outreach and early intervention services
  e. Coordinate services with substance abuse prevention and treatment programs

Relationship to the SCSN. The comprehensive plan must be compatible with existing State and local service plans including and in particular the Statewide Coordinated Statement of Need (SCSN). The SCSN is a collaborative mechanism coordinated by the Part B program that is designed to identify and address significant HIV/AIDS care issues related to the needs of PLWHA, and to maximize coordination, integration, and effective linkages across all Ryan White HIV/AIDS Parts. It is updated every three years, often at the same time comprehensive planning is occurring.

Relationship to ECHPP. EMAs/TGAs whose jurisdictions are engaged in Enhanced Comprehensive HIV Prevention Planning and Implementation for Metropolitan Statistical Areas (MSAs) Most Affected by HIV/AIDS (ECHPP) Initiative are expected to describe in their comprehensive plan the role of the Ryan White program in collaborating with the ECHPP Initiative.

Contents of a Comprehensive Plan

The comprehensive plan should guide the planning council in the development of a coordinated system of care for PLWHA. It should include clear goals, objectives, and strategies for action as well as mechanisms for assessing progress. This section presents suggestions to help planning councils organize their planning information in a logical format to support decision making about HIV service priorities and funding allocations.
The content of a comprehensive plan document should be organized to provide clear answers to the four basic questions identified in the Introduction to this chapter. Where Are We Now? (What does our epidemic look like and what is our current system of care?)

This section of a comprehensive plan should describe the status of HIV services within the geographic area of the planning council and describe the needs of PLWHA. It should include the following, plus any additional content specified in the Guidance from HRSA/HAB:

- An epidemiologic profile of the community, including the current epidemic and emerging populations.
- An estimate of the number of people who know they are HIV-positive but are not receiving HIV-related primary medical care (estimate of unmet need).
- An estimate of the number of individuals in the EMA/TGA who are HIV-positive but unaware of their HIV/AIDS status (Early Identification of Individuals with HIV/AIDS estimate).
- The assessed health care needs of the affected population, both in and out of care, including prevention and care needs.
- A description of capacity development needs resulting from disparities in the availability of services in historically underserved communities and rural communities.
- A description of the current EMA/TGA response to the epidemic.
- A description of the current continuum of care.
- An inventory of community resources available to PLWHA in the service area (by core and support service categories), both Ryan White and non-Ryan White funded.
- An assessment of provider capacity and capability.
- An assessment of service gaps and barriers to care.
- An evaluation of progress towards the goals and objectives of the existing comprehensive plan.

Where Do We Need To Go? (What is our vision of an ideal system?)

Ryan White Part A programs are expected to use their funds “for developing or enhancing a “comprehensive continuum of high quality, community-based care for low-income individuals and families with HIV.” That continuum is expected to include (but not necessarily use Ryan White funds to support) “the 13 core medical services specified in law, and appropriate support services that assist PLWHA in accessing treatment for HIV/AIDS infection that is consistent with the HHS Treatment Guidelines….Comprehensive HIV/AIDS care beyond these core services may include supportive services that meet the criteria of enabling individuals and families living with HIV disease to access and remain in primary medical care to improve their medical outcomes.” (FY 2013 Ryan White Part A Application Guidance, HRSA 13-155, Funding Opportunity Description, page 1.)

This section of a plan should describe an ideal continuum of care for high-quality core services, and should include:
• A description of how the EMA/TGA plans to meet the challenges identified in the evaluation of progress towards the goals and objectives of the existing comprehensive plan, so that the EMA/TGA is better able to meet goals and objectives of the new comprehensive plan.

• A shared vision of what the planning council would like its system of care to look like. This description may be an operational definition of the local “continuum of care,” reflecting the specific circumstances and needs of the EMA/TGA. This approach makes the “continuum of care” concept a central focus of planning at an early stage.

• How the EMA/TGA will ensure coordinated efforts with other programs, such as Ryan White services provided through other Ryan White Parts, prevention programs, non-Ryan White-funded providers, community health centers/federally qualified health centers (CHCs/FQHCs), Medicaid, Medicare, and the State Children’s Health Insurance Program (SCHIP).

• Shared values or guiding principles that shape the HIV-related system of care in the region. Values may include immediate access to care, high-quality services, integration of HIV/AIDS into the larger health care system, the role of the grantee or planning council as the payer of last resort, etc. Goals, objectives, and strategies should be consistent with these values.

• Proposed program goals to help address needs and work towards the ideal system of care. Long-term systems, planning, evaluation, and service-related goals provide the foundation for the action plan to implement your comprehensive plan. You may not be able to meet these goals in three years, but your comprehensive plan should lead to towards the goals.

How Will We Get There? (How does our system need to change to assure availability of and accessibility to core services? What steps will we take to develop this ideal system?)

This section of the plan should provide a specific action plan including objectives, strategies, and activities to help reach comprehensive goals and work towards the ideal continuum of care. It may include the following information:

• Goals and objectives. These three-year systems, planning, evaluation, and service-related objectives and outcomes that help you work towards your long-term goals. The objectives need to be stated in very specific and measurable terms.

• Action plan. These are specific steps—strategies and activities—to undertake in implementing the plan. They should have time frames and responsibilities should be assigned.

When identifying service objectives, aim to strike a balance between addressing the community’s service needs and acknowledging the limited resources likely to be available to meet those needs. Choices may need to be made among competing needs. Comprehensive planning is more like resource allocation than priority setting. The plan should pursue a realistic plan for strengthening the HIV/AIDS care system.
# DEVELOPING OBJECTIVES FOR YOUR LONG-TERM GOALS

<table>
<thead>
<tr>
<th>Sample Long-term Goal. Service integration</th>
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**Information Needed to Address Goal.** Which services can be integrated throughout the region? How can providers share information effectively in order to make service integration possible? How would case management approaches need to change in a setting where services are integrated?

**Sample Short-term Objective.** Ensure the availability of HIV-related primary care that meets HHS Treatment Guidelines in all outlying counties.

**Information Needed to Address Objective.** What organizations, especially CHCs/FQHCs, currently provide primary care in outlying counties or might be able to expand their services and are interested in providing such services for PLWHA? If no providers are in the county, what are the service delivery options – e.g., a satellite center, mobile clinic, supplemental use of telemedicine?

What types of information would they need to obtain from other providers in order to provide appropriate services that meet HHS Treatment Guidelines? What training would be needed if a clinic were to begin HIV-related care?

These questions will need to be answered early in the period covered by your comprehensive plan, so that the objective can be met. Some should be answered by the planning council, while the grantee will be responsible for contracting with appropriate medical service providers.

**Strategies and Activities for Meeting Objectives:**

- Answer key questions
- Agree on desired service models/strategies
- Provide guidance to the grantee on service models and strategies
- Allocate additional funds if necessary to enable grantee to carry out procurement to select medical providers for the outlying counties

The planning council committee responsible for care strategies would probably take the lead on the first two activities, the full planning council would approve the directive and allocations, and the grantee would do the contracting.
ACTION PLAN

An action plan that includes strategies and activities will help achieve stated goals and objectives. Below is one approach to organizing the action plan:

Sample Goal. Increase access to primary medical care.

Sample Accompanying Objective. To offer primary medical care services at non-traditional times.

Strategies

- Arrange for alternative hours of operation by primary care providers.
- Publicize hours and services to ensure increased and appropriate utilization of services.

Activities

- Identify populations that are unable to access care during traditional hours of operation, such as employed PLWHA and caregivers who cannot leave dependents.
- Find out which alternative hours of operation would be most convenient to such consumers.
- Develop a directive to the grantee to require alternative hours of operation.
- Allocate additional resources if required.
- Together with program personnel, explore other strategies to increase access to care (such as increased access to child or dependent care)
- Develop guidelines to help increase utilization of services and reduce barriers to access.

Table 35: Action Plan

How Will We Monitor Our Progress? (How will we evaluate our progress in meeting our short- and long-term goals?)

This section should outline a plan to assess progress in achieving goals and objectives and to update the comprehensive plan. The monitoring and evaluation plan should describe a process for tracking changes in a variety of areas with a focus on improved use of client-level data, and use of performance measures and clinical outcomes such as viral suppression. Use EIIHA matrix data and treatment cascade data to obtain valuable information about the results of changes in the continuum of care. EIIHA data looks at efforts to identify HIV-positive individuals who are unaware of their status, inform them of their status, and link them to care, and is valuable for assessing comprehensive plan objectives related to testing and linkage to care. A treatment cascade follows groups of PLWHA from diagnosis through entry into care, anti-retroviral therapy, and retention in care, and determines viral suppression, and helps assess the overall clinical outcomes of your continuum of care, as well as specific components such as linkage to care, retention in care, and use of treatments. Planning councils can also use aggregate quality management data in their assessment of progress towards comprehensive plan goals and objectives.
The comprehensive plan should include specific guidelines for evaluating the decision-making process, the comprehensive plan itself, and the quality, costs, and effectiveness of services to be provided or refined as a result of plan implementation.

**Comprehensive Planning Process**

While there is no single approach to comprehensive planning, all planning bodies must develop a planning process and outline planning tasks. The foundation for this is a clear understanding of what the planning body wants to accomplish; the key players or “stakeholders” who should be involved; and how the completed plan will be used.

Generally, a sound Ryan White Part A comprehensive planning process and plan:

- Balance openness and inclusiveness with timely creation of a final product
- Provide for structured community input, especially from consumers
- Are developed in a coordinated manner with the statewide comprehensive Part B plan and the Statewide Coordinated Statement of Need
- Provide guidance to the planning council in making decisions and developing contingency plans
- Build upon and are coordinated with the planning council’s needs assessment process
- Reflect coordination with the planning council’s priority-setting and resource-allocations process
- Balance service needs with the resources available to meet them
- Include guidelines to help the planning council self-assess the planning process, and
- Provide for measurement of progress towards comprehensive plan goals and objectives (e.g., through use of client-level data, performance indicators and other evaluation data, and measurement of clinical outcomes).

Steps in the planning process are as follows:

- Plan to Plan
- Data Gathering and Analysis
- Plan Preparation, Approval, and Dissemination
- Plan Implementation

Each is described below.

**Plan to Plan**

During this phase, the responsible planning council committee carefully reviews the Comprehensive Plan Guidance from HRSA/HAB and agrees on the objectives, tasks, timelines, and responsibilities for the planning process. The committee is usually a standing committee of the planning council but can also be a special task force including representatives of multiple committees, with unaligned consumers, providers, and grantee representation.
PLWHAs and other community members of the planning council have a vital role to play in helping the planning council obtain community input, including identifying key contacts in the community, organizing community forums, and serving as a liaison with PLWHA caucuses. Their role should be defined at this stage.

The committee determines the planning questions to be posed about the HIV care delivery system in the EMA/TGA and the tasks required to generate answers to these questions and prepare the plan. The planning committee develops a plan and criteria for obtaining and analyzing data, makes recommendations to the planning council about a timeline and budget for the planning process, and assigns responsibilities for completing planning tasks. Both planning council and grantee staff play important roles in preparing the plan, and should be closely involved in the plan to plan. Some planning councils hire consultants to assist with data collection/analysis and preparation of the comprehensive plan, if resources are available. Sometimes it is possible to obtain pro bono planning assistance from a local university or public agency. Arrangements for such assistance need to be made as early as possible in the planning process.

The plan to plan should provide for key stakeholders to provide input during the planning process and to receive copies of the plan once it is completed. A dissemination plan should be developed during this phase.

It is important to have a clear blueprint for planning. It might take three to six months to develop a schedule for major planning activities and tasks.

**Data Gathering and Analysis**

Because the comprehensive plan is a guide to help the planning council and EMA/TGA respond to the service needs of PLWHAs, these needs first must be identified. Typically, the planning council uses information from its epidemiologic profile and other needs assessment data, as well as grantee cost and utilization data, as inputs to the planning process. If the plan is developed soon after submission of the Ryan White Part A application, recent data can often be obtained from the application, including the data tables.

Existing data—called “secondary data”—such as epidemiologic data, can be obtained from public health agencies and published and unpublished studies. Original data collected by the planning council—called “primary data”—can be gathered through surveys, interviews, focus groups, and other methods.

If needed data have already been collected, they must be reviewed and organized for use in the development of the plan. Sometimes additional information is needed. This means instruments to collect data must be developed and pilot tested, and data gathered. For community input, community meetings or town halls are arranged with the help of the PLWHA committee or caucus, and specific questions developed to generate in-depth input.

The planning committee can collect data with the assistance and input of the grantee, members of the planning committee, the needs assessment or other responsible committee, other planning...
council members, PLWHA committee or caucus, planning council staff, and/or paid consultants who have expertise in this area. If a consultant is hired, the planning council still retains responsibility for the planning process and needs to supervise the work of the consultant and ensure that the voices of PLWHA are heard.

Because the EMA’s/TGA’s needs assessment will generate much of the needs and services information to be used in the comprehensive plan, needs assessment and comprehensive planning committees both benefit from coordinating their efforts.

The information obtained through primary data gathering and review of existing data is then reviewed and discussed in terms of strengths and limitations, and usefulness in answering the questions about the HIV care delivery system in the EMA/TGA. Data are analyzed and formatted, and results are presented to the planning committee and planning council members in a manner that is easily comprehensible and useful in decision making about service priorities and major HIV service delivery issues. Some planning councils summarize information in a chart format or data matrix, with data sources listed horizontally along the top of the chart and service categories, geographic areas, and key populations – or key planning questions – listed vertically.

**Plan Preparation, Approval, and Dissemination**

Once the available data have been gathered and analyzed, it is time to outline and prepare a plan document. The outline should meet all requirements specified in the Comprehensive Plan Guidance and provide a logical framework for the plan. Then the responsible committee should focus on describing an ideal continuum of care for the EMA/TGA, and outlining possible goals, key objectives, and strategies for working towards that ideal, based on review of all the available information. Most EMAs/TGAs set service priorities and allocate resources on an annual basis. The comprehensive plan should provide goals and objectives that guide and are consistent with the annual priority-setting process. When writing the goals and objectives for the plan, the planning council needs to think about needs and resources three years down the road.

The planning council should receive a presentation of key information for the plan, including an overview of the various sections of the plan, especially the sections on the ideal system of care and the plan for getting there. The presentation is usually done in an open meeting to which the public is invited. The council has the opportunity to provide input around goals and key strategies and offer other suggestions. The committee then further develops its ideas for the plan, especially the goals and the action plan for implementation.

The draft plan is usually drawn up by staff or consultants, based on these discussions and the decisions of the committee. The committee usually is closely involved in the development of the action plan, approving objectives and activities and deciding who should be responsible for implementing those activities. Responsibilities should be specific – with assignments to specific committees, not just “the planning council,” and clear timelines provided meeting objectives.

The plan is then reviewed by the planning committee, and revisions are made as needed. The planning council may receive public comments and feedback about the draft plan at public hearings or through other venues such as community meetings, PLWHA caucuses, and provider
forums. The draft comprehensive plan is also provided to the full planning council for review and comments. The final plan must be approved by the full planning council and usually receives sign-off from the director of the Department of Health and/or the Chief Elected Official (CEO).

Once the plan is completed, the dissemination plan is implemented to ensure that key stakeholders receive copies of the plan and have an opportunity to provide assistance in implementing it. The completed plan can be presented at public hearings or through other venues such as community meetings, PLWHA caucuses, and provider forums.

**Plan Implementation**

The last and most important phase is to put the plan into action. In the implementation phase, the planning council uses the plan to make decisions about service priorities, service models, resource allocation, and other critical service delivery issues. To ensure implementation, the various activities in the action plan need to be made a part of the annual work plans for the planning council or specific committees, the grantee, or other entities.

The plan should help guide planning councils to consider services and systems of care in the context of a range of funding sources. By gathering information about existing services and methods of service delivery, the planning process allows the planning council to examine ways to improve coordination and to increase access to care for specific populations, the efficiency of service delivery, and the use of existing funding sources. The plan should prepare the planning council to respond appropriately to changes in the epidemic and to react efficiently to changes in the availability of resources.

A comprehensive plan should cover a three-year period, based on either calendar or program years. However, changes in the epidemic or legislation may render some plans in need of change in a shorter time frame, so a review of goals, objectives, and action plans should occur either annually or more often if significant changes occur in resources or in the external environment.

Implementation requires monitoring the achievement of the plan’s goals and objectives and assessing the effectiveness and quality of services on an ongoing basis. The schedule or vision for the plan can be adjusted and implemented along the way on an annual basis.

**Approaches**

Following are some suggestions to help in the development of a comprehensive plan that is sound, appropriate, and supported by key stakeholders.

**Community Involvement**

The comprehensive planning process needs input from the community, especially consumers of Ryan White services and other PLWHA. Planning bodies cannot plan for PLWHA unless they plan with them. Ensuring broad and meaningful community involvement in the planning process can be a challenge, particularly in rural areas or other communities where PLWHA and their family members are often very reluctant to identify themselves.
Encouraging Community Input to Planning

There are many ways of obtaining community involvement, from separate provider and PLWHA town hall meetings to individual input via telephone or computer. If the EMA/TGA has good PLWHA involvement in needs assessment, then it will have less new information gathering to do for the comprehensive plan. However, at a minimum, there should be public meetings and other opportunities for the infected and affected community and for service providers (Ryan White and non-Ryan White) to provide input.

Creative use of incentives can be the key to increasing community participation. For example, providing transportation to meetings may be especially helpful, especially in rural areas where long distances are involved. However, this must be done in the context of the HRSA/HAB policy regarding expense reimbursement. Community resources can be used for other expenses, such as refreshments, gift certificates, and vouchers for services. These incentives may encourage attendance at meetings or focus groups.

Confidentiality

In some EMAs/TGAs, especially large metropolitan areas, many PLWHA are publicly disclosed and are comfortable providing input to comprehensive planning in community meetings or other public forums. In other areas, including many smaller communities and rural areas, confidentiality may be a significant concern.

Planning bodies have identified ways to protect confidentiality by enabling PLWHA and their families to provide input without disclosing their names. For example, planning councils can publicize their interest in receiving input from PLWHA by providing a telephone number that individuals can use to contact entities involved in the planning process without identifying themselves. Similarly, an intermediary group or individual known in the PLWHA community can identify PLWHA and arrange for them to call in for key informant interviews, again without giving their names. A PLWHA task force that meets through teleconferencing can also provide input to planning council before it finalizes a plan. Community meetings can be open to anyone interested in HIV/AIDS, not targeted specifically to PLWHA, so attendance does not constitute a public disclosure of HIV status. Input can be obtained from established support groups or other entities whose members are already disclosed to each other. EMAs/TGAs need to identify the most appropriate mechanisms for obtaining broad PLWHA input regarding service needs and barriers and how well the current continuum of care is working for consumers.

Planning Committee Issues

The comprehensive planning process is demanding and requires a diverse group to work together and achieve consensus regarding both the planning process and the final document. If the members of the committee have worked together as planning council members, they may already feel like a team. If not, a group with diverse cultural or social backgrounds, professions, sexual orientation, HIV status, or work styles is likely to need some time to begin working together effectively.
Planning council members may contribute to the planning process in different ways and with varying degrees of intensity. The diversity of the planning council membership can enhance the planning process if appropriate steps are taken to address potential challenges related to member participation. The use of a standing committee that adds members for this task permits interested people to volunteer their participation. This level of choice can help ensure a high level of participation for the group that needs to be most deeply involved. Some tasks can be delegated to other committees to lessen the burden on the planning council as a whole.

Planning councils should consider the following factors before embarking on the planning process.

**Diversity of the Planning Committee**

The more diverse the planning committee, the more inclusive and representative your planning process. The group should not be limited to members of the planning council. It should include community members who can enhance the expertise of the group, including people with planning experience, expertise in specific topics such as health care reform or the National HIV/AIDS Strategy, consumers with varied backgrounds, and providers and health care professionals.

**Varying Expertise in Group Process and HIV Service Delivery**

Participants working on comprehensive planning bring different levels of education and expertise. There may be participants who have not been involved with HIV-related services for very long or who may be less familiar with committee meeting procedures and Ryan White legislation. PLWHA who have known about their HIV status for several years and serve on the planning council or are part of a PLWHA and many provider personnel, on the other hand, may be very familiar with both the planning process and the continuum of care.

If the planning committee consists of a significantly diverse group in terms of expertise and experience, there may be a need for some group process work prior to planning, as well as facilitation and support for members new to the planning process.

Throughout the process, planning committees may have to work with differences of opinion between groups such as providers, HIV-positive members, and individual health care professionals. People who are HIV-positive may emphasize the many immediate needs of PLWHA as they face the disease. Providers may be concerned with establishing a set range of services. Other participants may stress the need to create a methodically planned, well-orchestrated service system that is sustainable in the long run and actively involves non-Ryan White providers and non-HIV-specific services.

All of these perspectives can contribute to developing a realistic and effective comprehensive plan to guide the planning council. The planning committee leadership needs to integrate all these perspectives and voices into the final product and establish an effective planning team. This means establishing and enforcing Ground rules, maintaining an environment of mutual respect in which all members listen to the opinions of others, and all recognize that their
responsibility is to develop a plan that meets the needs of all PLWHA in the EMA/TGA that depend on Ryan White for services.

**Special Needs of PLWHA**

The effectiveness of current HIV medications means that many PLWHA will be in good health. However, some PLWHA members may not have the same amount of physical energy as other planning committee members. Planning bodies need to consider this factor when they arrange meetings, set deadlines, and assign responsibilities. Reaching consensus at the beginning on roles and expectations for all participants can help avoid unrealistic expectations or misunderstandings later on.

The planning council should provide ample opportunities for PLWHA to contribute to the planning process within the physical and psychological constraints the disease imposes on them. Those unable to serve on the planning committee should be offered opportunities to provide input through town hall meetings or participate in key review sessions.

**Maximizing Planning Resources**

Planning councils must find ways to maximize resources for comprehensive planning. The possibility of sharing some costs with other planning councils, other Ryan White Parts, and other HIV-related efforts in the region or State should be explored. For instance, in some cases, the State develops an epidemiologic profile that the planning council can use for planning.

Planning councils may also be able to share the cost and effort of developing an epidemiologic profile with the HIV Prevention Planning Group (PPG). The profile can be used by the local planning council and the State Part B program and may be useful to other Ryan White grantees as well.

Some EMAs/TGAs have already combined comprehensive planning for prevention and care, and are producing combined or closely linked plans. This enables them to respond to the interrelated goals of the National HIV/AIDS Strategy, the 2009 Ryan White legislative requirements around EIIHA, ECHPP, and the national prevention strategy announced in 2011 that emphasizes high-impact prevention, large-scale testing and prevention for positives. There is a growing overlap in roles between prevention and care, enhanced by a growing focus on “treatment as prevention.” Getting PLWHA into care and onto anti-retroviral therapy as quickly as possible after diagnosis has been shown not only to improve their clinical outcomes, but also to prevent HIV transmission. Shared comprehensive plans can be both cost-effective and beneficial in contributing to coordination of resources and services.

Planning councils need not “start from scratch” when designing a comprehensive planning process. Much information is available about other EMA/TGA methods and their successes and shortcomings. Reports and survey instruments from other planning councils are available on the TARGET Center website [http://www.careacttarget.org](http://www.careacttarget.org), and requests for technical assistance may be made to HRSA/HAB. Planning bodies do not learn how to plan in a few weeks. The best ways to learn are by developing a plan and by learning from others with more experience.
EMAs/TGAs can support comprehensive planning by developing suggested comprehensive planning processes and formats, providing training sessions on comprehensive planning, bringing planning councils and Part B consortia together to jointly address comprehensive planning responsibilities and needs, and encouraging coordinated efforts involving multiple planning bodies.

Grantees can assist planning councils in obtaining epidemiologic data and support coordinated needs assessment and comprehensive planning activities that ensure the availability of the information needed to conduct effective planning. Often, much of the epidemiologic and needs assessment data needed for the comprehensive plan have already been developed and used for priority setting and resource allocations, and for the Ryan White Part A application to HRSA/HAB. To fill information gaps, the grantee may also be able to provide the services of a planner or person skilled in data analysis who can help planning council members to make sound planning decisions. Such individuals may be available within State or local agencies or at universities.

### TIPS

Keep the following in mind when developing comprehensive plans:

- **Don’t re-invent the wheel.** There is a lot to be learned from the successes and shortcomings of other EMAs/TGAs and States. Many assessments have been done around the country and related assistance has been provided through Ryan White Technical Assistance Contract. Look for sample comprehensive plans and tools on the TARGET Center website [http://www.careacttarget.org](http://www.careacttarget.org) or consult with your HAB/DMHAP Project Officer. Use data already collected and analyzed in your needs assessment. Collect new information only if specifically needed for the plan.

- **Pool resources.** Think about what costs can be shared with other HIV-related efforts in your community or State.

- **Collaborate.** Work with other Ryan White programs and other local and State HIV planning institutions.

- **Allow extra time in complex EMAs/TGAs and rural areas.** The need to obtain epidemiologic and other data from more than one State takes extra time and effort. Distance and confidentiality issues may present additional challenges in obtaining community input in rural areas.

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### XI. Ch 6. Statewide Coordinated Statement of Need

**Introduction**

The purpose of the Statewide Coordinated Statement of Need (SCSN) is to provide a collaborative mechanism to identify and address significant HIV/AIDS care issues related to the needs of PLWHA, and to maximize coordination, integration, and effective linkages across the Ryan White HIV/AIDS Program Parts. In addition, the SCSN process is expected to result in a
The Statewide Coordinated Statement of Need (SCSN) is a written statement of need developed through a locally chosen collaborative process with other Parts of the Ryan White HIV/AIDS Program. The SCSN must reflect, without replicating, a discussion of existing needs assessments and should include a brief overview of epidemiologic data, existing quantitative and qualitative information, and emerging trends/issues affecting HIV/AIDS care and service delivery in the State. Important elements in assessing need include a determination of the population with unmet need, a full understanding of primary care and treatment in the State, and a consideration of all available resources. The SCSN process should consider total Ryan White HIV/AIDS Program resources in the State, both the amount of funds and what services the funds are supporting. For example, the number of full-time case managers funded with Ryan White HIV/AIDS Program funds, the total spent for core services, and the total amount spent for medications. Where possible, the value of non-Ryan White HIV/AIDS Program resources in the State should be considered in determining need. A consideration of the numbers of persons who know their HIV status but are not in care should be included. The SCSN must identify broad goals and critical gaps in life-extending care needed by PLWHA both in and out of care.

In developing a SCSN, States are expected to use needs assessments and comprehensive plans completed by other parts of the Ryan White HIV/AIDS Program in an effort to identify cross-cutting issues in the State. The cross-cutting issues and goals identified by this process will form the basis of the SCSN. The issues and goals identified in the SCSN should not be prioritized, but assessed equally. Some examples of cross-cutting issues and/or broad goals may include access to medications, increasing the number and percentage of cervical cancer screenings provided to women living with HIV/AIDS, developing and evaluating a clinical quality management program, and decreasing unmet need.

HRSA strongly encourage grantees to use the SCSN to support Statewide HIV/AIDS planning. This could include using the goals outlined in the SCSN to set measurable objectives, inform resource allocation decisions, create a Statewide plan, as well as conduct other activities to enhance HIV care and service delivery Statewide. The SCSN cannot supplant local needs assessment, planning, and priority setting processes.

Contents of the SCSN

At a minimum, the SCSN should contain:

- The most recent State HIV/AIDS epidemiology profile.
- A description of the process used to develop the SCSN.
- A list of participants in the process.
• A description of identified gaps and/or overlaps in services.
• A list of priorities identified, including addressing Unmet Need and gaps in Core Medical Services.
• A description of priorities addressing identified barriers to care for underserved populations in the State.

**Process**

The Ryan White HIV/AIDS Program assigns Part B Grantees the responsibility for periodically convening a meeting for the purpose of developing a SCSN and submitting the SCSN to HAB, Division of State HIV/AIDS Programs. However, HRSA views all Ryan White HIV/AIDS Program Parts equally responsible for the development of the process, their organization’s participation, and the development and approval of a collaborative SCSN. The mechanism for developing the SCSN can be a series of Statewide meetings, meetings organized based on epidemiologic data or some other locally developed process, as long as the criteria described in the Definition and Participation Sections are met. The mechanism must ensure participation of all other Parts.

**Participation in the Development of the SCSN**

The SCSN must be developed with input from: (1) representatives of all Ryan White HIV/AIDS Programs, including administrators of the AIDS Education and Training Centers, the Dental Reimbursement Program and Special Projects of National Significance Demonstration Grants operating in the State; (2) PLWHAs; (3) providers; and (4) public agency representatives. Ryan White Part A representation should include grantee and Planning Council representatives. Part B should include Consortia (if applicable), direct care providers, and grantee administrators. In cases where there are multiple grantees from a Ryan White HIV/AIDS Program, such as a State with multiple Part C programs, the State in concert with those grantees, should determine a mechanism of representation allowing a variety of interests and views to be fairly represented in the SCSN process.

*For the purpose of this guidance “provider” is defined as any individual or institution either receiving Ryan White HIV/AIDS Program funds or generally involved in the provision of health care and/or support services to PLWHA.*

In addition to Ryan White HIV/AIDS Program representation, States are also encouraged to include representation from other major providers or funders of services needed by PLWHA such as substance abuse, mental health, Medicaid, Medicare, HRSA -funded Health Centers, and Veteran’s Affairs.

**Special Considerations**

Ryan White Part A – In instances where the eligible metropolitan area (EMA) or transitional grant area (TGA) crosses a State border, the Ryan White Part A applicant will be given the option to use the SCSN that most appropriately applies to their population based on the epidemiological profile of that area.
Part B – States with only Part B funds will be required to develop a SCSN with participation from PLWHA, providers, and public agency representatives. The final document should reflect efforts made to meet new legislative requirements.

Funding for the SCSN Process

The use of Ryan White funds to assure participation in the SCSN must be consistent with each individual program’s requirements with regard to program expenditures.

Timetable

The SCSN should be reviewed and updated at least every three years and submitted to HRSA.

SCSN Review

HAB reviews each SCSN submitted and provides comments back to the Part B grantee. Review of the SCSN allows HAB/DMHAP to identify cross-cutting issues across jurisdictions.

XI. Ch 7. Capacity Development

Introduction

The Part C Capacity Development Grant Program was first authorized by Congress in 2000. It is designed to assist public and nonprofit entities in their efforts to strengthen their organizational infrastructure and to increase their capacity to develop, enhance, or expand access to high quality HIV primary healthcare services for PLWH who are at risk of infection in underserved or rural communities. Capacity development refers to activities that promote organizational infrastructure development leading to the delivery or improvement of HIV primary care services. It is to identify, establish, and strengthen clinical, administrative, managerial, and management information system structures.

HAB/DMHAP Expectations

While there is no specific legislative language or authority for capacity development for Parts A and B, activities that increase core competencies that substantially contribute to an organization’s ability to deliver an effective HIV/AIDS primary medical care and health related support services, increase access to the HIV/AIDS service system and reduce disparities in care among underserved populations living with HIV/AIDS, such as system-wide program support or technical assistance may be considered capacity development activities. See Eligible Individuals & Allowable Uses of Funds for Discretely Defined Categories of Services--Policy Notice 10-02: http://hab.hrsa.gov/manageyourgrant/pinspals/eligible1002.html.
Addressing Capacity Development

Capacity building activities under Part C include establishing or strengthening management systems, service delivery systems, infrastructure for ensuring client retention in care, implementing electronic medical records, and developing cultural competency.

Many of these activities are also applicable under Parts A and B. For example, capacity building in the areas of providing effective clinical services, managing program finances, developing and implementing quality management and improvement programs, staff training, service evaluation, and developing culturally and linguistically appropriate services are appropriate areas for capacity development.

XI. Ch 8. Member Involvement and Retention

Introduction

The Ryan White legislation puts planning in the hands of groups broadly representative of the local community. In general, membership should be as inclusive and as diversely representative as possible. This includes representatives from all populations directly impacted by HIV/AIDS and from the broader health care community. The typical planning body is composed primarily of people directly involved with HIV/AIDS, either as consumers or providers of health care services. The more perspectives that are represented in the planning process, the better the chances that decisions will reflect community needs and be supported by participants and the broader community.

Multiple areas of expertise should be represented in the membership of a planning body. Examples include expertise in what it is like to live with HIV; expertise in how to deliver care and treatment programs to PLWHA; technical expertise in the health care planning activities required of the planning body, including needs assessment, priority setting, comprehensive planning, resource allocation, and evaluation; and expertise in group process.

A possible formula for membership recruitment and maintenance is: The better organized and operated the planning body; the easier it is to recruit new members and to retain current members. Members will feel that they are making a worthy contribution to an effective enterprise if the following holds true:

- The mission is clearly defined.
- Policies and procedures are documented and agreed on by all members.
- New members received a thorough orientation and ongoing mentoring, and all members receive training when the planning body assumes new tasks.
- Tasks necessary to the mission are specified and pursued by the members themselves.
- The committee structure allows all participants to understand their roles and responsibilities.
- Meetings are conducted in a participatory, efficient, and timely manner.
The group acknowledges that everyone has an equally important contribution to make and that not everyone must be an expert in every aspect of the process.

**Different Types of Participation**

The Ryan White Part A planning councils and bodies have specified membership, such as service providers and PLWHA, and they are voting members. Many planning bodies also have non-voting members or other individuals that regularly attend meetings in an advisory role. The latter are usually grantee staff. Sometimes contracted service providers are not given a vote because of concern that assigning voting privileges to these members could lead to problems associated with conflict of interest. Other groups allow only a designated number of voting members from each of the perspectives represented—consumer, provider, and individuals with other types of affiliations and expertise. Additional representatives can participate as non-voting members. Often, a single organization can have only one voting member on a planning body. Finally, there are bodies that offer non-voting membership to people who cannot attend regularly.

While the body guides planning locally, membership should not be a requirement to participate in planning. Nonmembers can contribute needed expertise through participation on selected committees, caucuses, and task forces, respond to surveys, and participate in focus groups or key informant sessions to identify needs and service gaps. Some nonmembers with special expertise can be recruited to join in an advisory capacity, with limited duties. This approach has been used to involve experts, such as local physicians, who may have limited time. They might be asked to review needs assessment results and the draft comprehensive plan and give feedback.

**Obstacles to Participation**

Obstacles that can harm member participation in consortia and other planning bodies include the following:

- **Lack of clearly defined roles, responsibilities, and expectations for members.** New members who are unclear about their role may become observers rather than participants. Further, potential new members may not continue because they do not know how to contribute or where they fit into the process.

- **Lack of formal orientation and training.** New members need to be oriented and all members need ongoing training in the skills required to perform their duties. Without orientation, new members may feel discouraged because they do not understand what is happening. Without training, members who feel they cannot participate fully in all activities may simply attend meetings and observe – and then eventually stop attending. This dynamic sets up a situation where the process is dominated by a few members.

- **Lack of knowledge of the formality and complexity of planning body processes.** The primary tasks – needs assessment, comprehensive planning, priority setting, resource allocation, and evaluation – are complex. To understand and participate in them requires a fairly high level of knowledge and training. Additionally, procedures used to enact business, such as parliamentary procedures and the relationships of committees to the full consortium, can be confusing to participants.
• **Inaccessible meeting times or locations.** Members who participate as part of their job requirements because they are employed in agencies related to the activities of the body tend to prefer meetings during their work days. Members who are employed outside of the HIV/AIDS field often find it difficult to attend meetings during the day and prefer evening meetings. Location of the meeting can also affect who attends, and frequent changes of meeting times and locations can hurt attendance.

• **A meeting process that is filled with conflict and does not seem productive.** When meetings are badly run, overly long, or filled with anger and conflict, members tend to stop participating and then stop attending.

• **Lack of administrative support.** Some planning bodies do not receive enough funding to pay for administrative support, and the lead agencies often have to contribute these services. Members are often expected to volunteer large amounts of time to the process.

• **Lack of consumer knowledge about policies and procedures to support their involvement.** Sometimes appropriate policies and procedures do not exist. Sometimes, supports for consumers exist but are unknown to new members. New members may be unfamiliar with expense reimbursement policies and uncomfortable asking about them. They may be unaware that child care or transportation assistance can be arranged. They may be unclear about access to office equipment such as a fax machine or copier, or secretarial support available to assist them in carrying out tasks. Further, new members may not understand how to ask for what they need. They may not know how to sustain their involvement should they become ill or unable to participate for a period of time.

• **Lack of flexibility regarding participation.** Membership policies and procedures are sometimes rigid and inflexible and do not allow for remote participation (such as telephone hook-ups) or other flexibility necessary to encourage participation by consumers.

• **Burnout and over commitment.** Sometimes members, including PLWHA, are expected to serve on too many committees and take too much responsibility for tasks like reporting back to the community and recruiting new members. Some groups have unrealistic expectations of members and provide few opportunities for renewal and recognition.

### Ways to Encourage Participation

The following actions can help encourage participation:

- Formal membership plan.
- Orientation of new members.
- Ongoing training for all members.
- Clear roles and responsibilities.
- A culturally sensitive environment.
- Flexibility about meeting times, locations, and participation requirements.
- PLWHA participation as a priority.
- Creativity in finding solutions to administrative support needs.
- Action to prevent burnout and sustain member commitment.
- A membership removal process for those who do not participate.
Develop a Formal Membership Plan

Member recruitment and retention can be tracked and analyzed when there is a formal membership plan that addresses (1) representation, (2) diversity (key occupational, geographic, demographic, and social characteristics representative of the area and population served by the body) and (3) recruitment and selection of members.

**Representation** means the extent to which the planning body includes diverse membership, including legislated categories for planning council representation that provide multiple perspectives to the planning process; for example the categories under Section 2602(b) include:

(A) health care providers, including federally qualified health centers;
(B) community-based organizations serving affected populations and AIDS service organizations;
(C) social service providers, including providers of housing and homeless services;
(D) mental health and substance abuse providers;
(E) local public health agencies;
(F) hospital planning agencies or health care planning agencies;
(G) affected communities, including people with HIV/AIDS, members of a Federally recognized Indian tribe as represented in the population, individuals co-infected with hepatitis B or C and historically underserved groups and subpopulations;
(H) non-elected community leaders;
(I) State government (including the State Medicaid agency and the agency administering the program under part B);
(J) grantees under subpart II of part C;
(K) grantees under section 2671, or, if none are operating in the area, representatives of organizations with a history of serving children, youth, women, and families living with HIV and operating in the area;
(L) grantees under other Federal HIV programs, including but not limited to providers of HIV prevention services; and
(M) representatives of individuals who formerly were Federal, State, or local prisoners, were released from the custody of the penal system during the preceding 3 years, and had HIV/AIDS as of the date on which the individuals were so released.

**Diversity and reflectiveness** of the HIV epidemic in the service area, based on population characteristics such as the following:

- Geography, including neighborhoods in urban areas and counties or communities in rural areas
- Sexual and gender orientation, including heterosexual, homosexual, bisexual, and transgender
- Age, from parents of children with HIV/AIDS to young adults and senior citizens
- Racial/ethnic background, including the various ethnic and cultural communities within the consortium area
A process for recruitment and selection of members may include answers to the following:

- What nominations process will be used?
- How will members be recruited?
- How do nonmembers become members, and what are the membership criteria?
- What are the requirements to maintain membership?
- How will current members be prepared to help recruit new members?

Each of these questions is addressed in greater detail in Appendix A at the end of this chapter.

Orient New Members

Orientation of new members helps them understand the Ryan White program as well as planning body roles, responsibilities, and operating procedures, and prepares them to participate actively. Well-planned orientation and training activities demonstrate the value the group places on new member participation. Orientation activities might include the following:

- **An initial orientation** prior to each new member’s first meeting, which should cover how the Ryan White Part A program is organized, how the planning body is structured, their roles and responsibilities as members, the annual work plan, and timeline for activities and topics to be addressed at the next meeting. A new member Orientation Manual or Packet might include:
  - History and overview of the Ryan White Program.
  - Planning body history and mission.
  - Planning body roles and responsibilities and member job description.
  - Bylaws, policies, and procedures.
  - List of fundable core medical and support services.
  - Resource inventory or list of services provided in this service area.
  - Chart of the committee structure and responsibilities.
  - List of members including addresses and phone numbers (prepared according to the wishes of the membership).
  - Reimbursement policies and procedures.
  - Current comprehensive plan.

The orientation manual should not be used as a substitute for an interactive orientation.

Written materials should be compiled and adapted as necessary to accommodate the language preferences and literacy levels of new members. Materials should also be available on the planning body’s website.

- **A formal procedure to introduce and welcome new members** at meetings. Attending a full-membership meeting for the first time can be overwhelming and confusing, especially if there is no mechanism to acknowledge and integrate new members.
• **Debriefing** with new members after their first meeting.

• **A mentor or “buddy” system.** Assigning a current member to be a “buddy” to a new member, for at least three months, helps new members feel welcome, learn about individual member perspectives, and become comfortable with the processes and interactions of the group.

• **Training to address individual needs.** For example, training should address the problem of burnout, helping new members make realistic time commitments and avoid becoming overcommitted.

• **Sensitizing of all members to the importance of consumer input.**

### Provide Ongoing Training for All Members

Continuing education and training opportunities promote constructive working relationships among members, reward members for their time and effort, develop members’ knowledge and skills related to HIV/AIDS and organizational functioning, and advance the work of the group. The following educational opportunities can be useful for members:

• Strategic planning retreats.
• Trust-building and team-building workshops.
• Conflict-management workshops.
• Training on comprehensive planning, priority-setting methodology, using data and statistics to plan, and evaluation methodology.
• HIV/AIDS informational topic sessions (e.g., anti-retroviral therapies).
• Workshops on roles and responsibilities of consortium members.
• Development of skills for facilitation and chairing a successful meeting.

Even if the planning body has limited resources, often such training and briefings can be arranged at little or no cost, with help from the local health department, service providers, local universities, local chapters of public health-related associations, and other nonprofits.

### Clearly Outline Roles and Responsibilities

Clear information will enhance functioning, and should include clearly defined roles and responsibilities; policies and procedures that are written in plain language and available to all members; and written definitions of all operating concepts, abbreviations, and acronyms. Use agreed-upon ground rules for all meetings. Conflict of interest and grievance policies and procedures should be defined and distributed in writing to all members, and members should receive training to ensure that they understand and comply with conflict of interest policies.

Ryan White-specific activities often require specific information. To illustrate, all fundable service categories should be clearly defined before the needs assessment process begins, using...
the most recent HRSA/HAB definitions and explanations and differentiating core medical and support services. Establishing such definitions up-front is critical to all aspects of the planning process.

Create a Culturally Sensitive Environment

Never assume that there is only one way to conduct business of the group. The effort is a collaboration of many different people, all of whom bring their own expectations and backgrounds to the table. A formal process governed by parliamentary process and Robert’s Rules of Order does not necessarily work in all environments. As needed, modify and create procedures for doing work that meet the needs of most members, promote full participation and high levels of productivity, and create a comfortable atmosphere that is inviting to new members.

Be Flexible about Meeting Times, Locations, and Participation Requirements

Meeting times, locations, and requirements for participation should be revisited on a regular basis. The group changes as new members join, older members leave, and the requirements of the epidemic change. Many groups reported changes in their PLWHA participation following the widespread use of anti-retroviral therapy, as greater numbers of consumer members returned to work or became employed. They have been forced to change their meeting times accordingly. Some are only meeting as a full body on a quarterly basis and rely more and more on committees to complete operational tasks. Some use consumer and service provider caucuses to review the work of the full group and provide input, but do not require caucus members to participate in general membership meetings. Much more information is disseminated via email, websites, and social media. The key is flexibility and taking the time to develop a process that works best for your planning body.

Show that PLWHA Participation is a Priority

The following approaches will help assure PLWHA participation:

- Develop a formal PLWHA membership plan.
- Provide supports for PLWHA members with limited physical capacity or special needs.
- Demonstrate respect for PLWHA member input and recognition of contributions by paying attention to what PLWHA say, insisting on an atmosphere of mutual respect, encouraging everyone to participate, and maintaining an orderly process.
- Seek PLWHA representation on all committees at the same level as on the full planning body.
- Develop a formal leadership development training program for PLWHA.
• Have policies and procedures that recognize that PLWHA may need to participate in different ways based on their health status.

• Directly address grief and loss within the membership and the HIV/AIDS community.

For more information, see the chapter on PLWHA/Consumer participation in this section.

**Be Creative in Meeting Administrative Support Needs**

Take the time to assess administrative support requirements and resources available to meet them. Do not assume some members will volunteer to do all the work or that the lead agency will automatically agree to donate those services.

First, discuss administrative requirements and develop an administrative budget with the EMA/TGA grantee and/or its administrative agency (if it has one). EMAs/TGAs with higher prevalence rates often have sufficient administrative funds to meet staffing and planning needs. If the administrative cap is inadequate to meet planning body needs, alternative resources need to be found. There are many creative solutions to the barrier of administrative support. Some groups recruit specific people or entities to make targeted contributions, such as small business owners willing to photocopy documents as a contribution to the process. Others rely on local universities, colleges, or trade schools to provide interns to assist with administrative tasks, such as taking meeting minutes. In other areas, groups from adjoining regions have combined their administrative allocations and hired or contracted with a person to provide administration to multiple groups.

**Take Action to Prevent Burnout and Help Sustain Member Commitment**

Sustaining commitment and enthusiasm is challenging. All membership organizations experience an ebb and flow of involvement. Thus, it is important to bring in new members on an ongoing basis. They bring new energy and fresh perspectives. It is also important to rejuvenate existing members. Methods to sustain member commitment include the following:

• Acknowledge people for their contributions and give them positive feedback on an ongoing basis by thanking members at meetings, honoring them at special events, developing an awards program, or featuring members in newspaper or newsletter articles or on the planning body website. Celebrate accomplishments at an annual social event.

• Provide opportunities for continuing education, training, leadership development, and growth-promoting activities.

• Make meetings well organized and use members’ time effectively. Start by sending out an agenda and a packet of background information needed for decision making at least one week before the meeting. Specify when the meeting will begin and end. Start and adjourn on time. The meeting facilitator or leader should ensure that discussion does not stray from the agenda and that the discussion leads to an agreed-upon course of action on all items that require decisions.
• Consider scheduling time for optional socializing and networking immediately before or after the meeting. For some people, these opportunities represent a critical reason to remain involved.

Appendix A

Model Recruitment and Selection Process

Address the following topics in the process that is established:

• Nominations process.
• Recruitment methods.
• Process for becoming a member.
• Criteria for membership.
• Requirements for maintaining membership.
• Engagement of current members.

Nominations Process

An open nominations process might include the following minimum standards:

• Nominations process is described and announced before recruitment begins.

• Criteria are specified so that the planning body membership:
  1. Includes the legislatively required positions (membership categories)
  2. Reflects the HIV/AIDS epidemic in the EMA/TGA
  3. Reflects the geography of the EMA/TGA
  4. Reflects any other locally determined membership needs
  5. Incorporates conflict of interest requirements

• The need for members is publicized, including advertisements in local HIV publications, announcements on appropriate websites, notices to service providers, press releases, and other community announcements.

• Potential applicants are informed of:
  1. The time commitments involved in serving on the planning body.
  2. Conflict of interest standards.
  3. Any HIV disclosure requirements for PLWHA.

• A membership application is used to:
  1. Collect information about the nominee’s characteristics, experience, and background, with specific attention to legislatively mandated membership categories and the characteristics of the local epidemic.
  2. Include an open-ended response category for nominees to describe their experience and why they believe they would be an effective planning body member.
3. Provide information to potential members about time commitments and other demands of planning body membership, meeting schedules, HIV disclosure requirements, and the conflict of interest standard.
4. Describe the application and selection process.

- A representative nominations or membership committee reviews all nominations and conducts interviews of potential members.

**Recruitment Methods**

Methods for recruiting planning body members include:

- Disseminate an announcement of membership opportunities and the application form via email, website postings, and social media.
- Contact other organizations’ mailing lists and ask current members to send announcements to their personal email lists. If materials are mailed, take steps such as using unmarked envelopes to maintain confidentiality.
- Have planning body members telephone potential members who belong to targeted groups and talk to them about becoming members. Provide opportunities for potential members to attend a planning body or committee meeting. Consider use of a mentoring or buddy program where members agree to pick up potential members and drive them to meetings and help them understand the process.
- Engage in collaborative community networking. Planning body members should attend other organizations’ meetings and promote membership on the planning body in their public venues or during public comments periods at other meetings. Some planning bodies are developing speakers’ bureaus not only to provide education about HIV/AIDS and Ryan White-funded services, but also to advertise and promote planning body membership.
- Use newspapers and newsletters. Planning body meetings should be regularly advertised in local newspapers and member organizations’ newsletters, both online and hard copy.
- Assess the success of various recruitment methods and refine them based on what you learn. Distributing flyers at various locations certainly promotes the planning body but has generally seen little direct success as a technique for recruiting members.
- Consider translating announcements and the application form into the major language of populations targeted as planning body members.
- Use multiple methods to recruit consumers and other PLWHA. Do outreach to service providers and individual staff who serve clients with HIV/AIDS to identify unaffiliated PLWHA nominees. (Unaffiliated refers to consumers who do not have a potential conflict of interest, meaning they have no financial or governing interest in funded agencies.) Contact PLWHA coalitions as well.
Sensitivity to Special Needs

With recruitment in mind, members should show sensitivity to the special needs of many targeted populations by providing appropriate supports to enable them to participate fully. When recruiting, make it clear that the planning body will provide the following, for consumers:

- Transportation
- Child care

For any member with a need:

- Sign language interpreters for people who are hearing impaired
- Special presentations for those with visual problems
- Oral communication of printed materials for those with low literacy levels

Process for Becoming a Member

Following are pathways and steps for an individual in becoming a planning body member. More than one of these processes might be used as part of the selection process; most planning bodies require a written application once a potential member shows interest in being considered for membership, and many interview applicants using a consistent set of questions.

- Invitation to apply.
- Submission of an application for membership.
- Appointment or interview with membership committee representatives.
- Election by the full body.
- Formal voting membership following attendance at several planning body meetings or committee meeting.
- Formal voting membership after volunteering.
- Signing of a member commitment statement (see sample membership commitment statement at the end of this chapter).

Membership Criteria

Criteria for membership might include the following:

- Support for the mission of the planning body.
- Characteristics that provide for consortium diversity in such areas as race/ethnicity, place of residence, gender, or age.
- PLWHA or consumer status.
- Affiliation with a targeted type of service provider or agency.
- Experience with HIV/AIDS prevention or care.
- Some specific skills or experience identified as necessary for the consortium (e.g., health planning, substance abuse treatment).
Requirements for Maintaining Membership

Members may be required to do the following to maintain their membership:

- Participate on a committee.
- Participate in full planning body meetings.
- Meet attendance requirements.
- Participate in special projects or activities.
- Comply with planning body policies and procedures.

Current Member Engagement in Recruitment

All members have an investment in new member recruitment and should be encouraged to participate in recruiting new members. The most successful recruitment technique identified by planning bodies across the country is the personal connection of asking someone directly to join. The best way to recruit a potential member through communicating the importance of the group’s work is for someone with a prior personal connection to meet with the potential member.

When meeting with a prospective member, current members should do the following:

- Explain the mission and goals of the planning body.
- Connect on a personal level by explaining why they joined.
- Describe why the potential member is needed and the specific contribution they can make
- Candidly estimate the time commitment.
- Be clear about what is expected; go over the membership commitment statement (See example at the end of this attachment) or member job description).
- Explain the member selection process.
- Explain the member orientation process.
- Give the potential member time to consider membership.
- Follow up with a telephone call to assess the candidate’s interest and answer any questions.

XI. Ch 9. PLWHA/Consumer Participation

Introduction

Ryan White Part A Ryan White planning creates a participatory planning process to ensure that local health care and social service programs are responsive to the needs of PLWHA. Unique PLWHA perspectives are a major benefit of consumer involvement in such terms as design of appropriate services and identification of needs. Barriers to eliciting and maintaining effective PLWHA involvement include time constraints, lack of understanding about complex planning duties, and health concerns.
Recruitment measures are needed to secure representation on the planning body, such as a variety of outreach methods to identify potential members. Retention measures are needed to help consumer members stay engaged and participate fully, such as orientation and training, mentoring, and financial support for the costs of participating.

**Benefits of Consumer Participation**

- **Consumer Perspective.** PLWHA provide a critical consumer perspective on Ryan White service planning, delivery, and evaluation. Consumers should reflect the diversity of the local epidemic, which provides for a range of perspectives that contributes to informed decision making.

- **Reality Check.** PLWHA help keep the members of the consortium focused and on track by providing a first-hand perspective on issues facing PLWHA and their families. PLWHA can discuss their actual experiences in seeking and obtaining services.

- **Help in Needs Assessment.** PLWHA can help ensure that needs assessments consider the needs of PLWHA from differing populations and geographic locations, including those in and out of care. They can help recruit other PLWHA for town halls, focus groups, and other input sessions.

- **Identifying Service Barriers.** PLWHA can identify service barriers that may not be evident to others and can help consortia plan to overcome those barriers.

- **Outreach.** PLWHA can help identify ways to reach the PLWHA communities served, including minority and other special populations with unmet need for services.

- **Quality Management.** PLWHA who are clients of Ryan White services can provide direct feedback on the quality of services. Their voices can help determine what services are needed, including how to improve service delivery models.

- **Community Liaison.** PLWHA provide an ongoing link with the community. They can bring community issues to the group, as well as help to bring research and care information to the community.
### PLWHA Roles

When considering ways to increase involvement of PLWHA in Ryan White activities, assess what PLWHA involvement is wanted. Roles for PLWHA include regular membership, participation in a PLWHA caucus, committee membership, and participation in specific activities.

Success might be realized with recruiting PLWHA, but retention as active participants can be harder. Often, this is because PLWHA roles have not been clearly defined. Members may not have received orientation or training or other necessary support. Maintaining active involvement of PLWHA also requires effective utilization of the skills and resources that PLWHA bring to the planning process.

It should never be assumed that the only way a consumer can participate is to be an active member. Some consumers may feel they do not have the skills to participate or prefer not to assume the responsibilities of active membership. However, their voices and participation are valuable to the overall planning process, as are those of the PLWHA who are active members, sit on committees, and participate in mandated activities. Some planning bodies have active consumer caucuses that meet separately and send a representative to serve as a member. Others access local support groups for feedback at targeted points in the planning process. For example, the consumer caucus or support groups may participate in the needs assessment, provide input to the development of priorities being recommended, and review a draft of the comprehensive plan. Further, PLWHA input is often a specific component of quality management and evaluation (client satisfaction).

### Recruitment of PLWHA

Recruitment of PLWHA members is a responsibility of the entire group. Groups often use personal contacts and other individual interactions as the chief means of PLWHA recruitment. Recruitment generally requires personal contacts with potential members, but outreach beyond individual networks is important in widening the search. Membership and outreach committees are ways of overcoming problems encountered in recruitment. Many such committees have identified the following useful practices in recruiting PLWHA:

- **Establish and Explain Guidelines Regarding Representation and Affiliation.** This includes clearly stated conflict of interest guidelines that explain that a PLWHA is considered “unaligned” or unaffiliated when s/he has no financial or governance affiliation with a funded Ryan White Part A provider.

- **Formalize Recruitment and Outreach Procedures.** These may be summarized in policies and procedures, providing the membership/outreach committee and the full planning body with a clear and publicly known process to follow, year after year.

- **Implement a Formal Outreach and Recruitment Process.** The responsibility for PLWHA recruitment should not be placed primarily on the current PLWHA members but rather
shared by the entire planning body. Outreach should be extensive, ongoing, and culturally competent. Recruitment requires contacts throughout the community, not focused on a single organization or limited to individuals or groups personally known to consortium members. Methods of outreach include:

- Contacts with a wide range of non-HIV-specific health groups, social service agencies, and PLWA groups.
- Advertisements in local online and print publications, especially publications targeting HIV-positive people, racial and sexual minorities, and underserved populations.
- Posting of opportunities on the planning body or lead agency website.
- Use of social media such as Facebook.
- Contacts with local community colleges and universities.
- Public meetings arranged in consultation with Ryan White service providers.
- Outreach materials and programs that emphasize commitment to a diverse HIV-positive membership and are specific about populations that need to be represented.

• **Communicate Expectations Clearly.** PLWHA, like other members, need to know what is expected of them in terms of time requirements, travel, roles and responsibilities, and public visibility. A job description is especially helpful. Clearly state disclosure requirements and indicate limitations and expectations regarding affiliation with AIDS service organizations (ASOs) or other providers or membership preference for unaffiliated or "unaligned" PLWHA. Recruitment materials should clearly state available supports, such as expense reimbursement, transportation assistance, and child or partner care reimbursement.

• **Make the Process Efficient and Timely.** If the nominations and selection process is lengthy, planning bodies may have PLWHA vacancies for many months, and nominated individuals may lose interest. The selection process should be efficient in filling all membership slots, but especially PLWHA slots. One way to minimize vacancies is to allow PLWHA to serve as members of consortium committees, including PLWHA committees or caucuses, both to become familiar with the work of the planning body before nomination and to remain engaged while awaiting appointment.

• **Ensure That Members Reflect Changes in the Demographics of the Area’s HIV Epidemic.** As the demographics of HIV change, it becomes important for the membership to reflect these changes. Attaining diversity among PLWHA representation requires carefully planned outreach into many different communities with the help of a variety of individuals and community groups. Policies might state that the PLWHA membership will reflect the demographics of the HIV/AIDS epidemic in its service area.

• **Do Ongoing Recruitment.** Ongoing recruitment is required because of the changing health status of PLWHA members, as well as to replace members who move, become employees (or consultants or Board members) of a provider and therefore are no longer considered unaligned, change their employment or family status, are burned out, or change their community priorities.

**Barriers to PLWHA Recruitment**

Recruitment of PLWHA requires first understanding and then overcoming a number of barriers that prevent or discourage PLWHA membership. Barriers may exist within the planning body,
the community, and the person living with HIV/AIDS. Following are frequently identified barriers, from the perspectives of PLWHA and planning bodies:

- Lack of PLWHA awareness of Ryan White programs and planning bodies.
- Lack of knowledge about how to become involved.
- Lack of written criteria for membership.
- Unclear member roles, responsibilities, and expectations.
- Lengthy nomination and selection process.
- Lack of consumer representation among planning body leadership.
- Belief that PLWHA members are not taken seriously.
- Fear of disclosure of HIV status, sexual orientation, drug-using behavior, etc.
- Uncertainty about financial costs of participation.
- Limited physical capacity.
- Distrust of public programs and providers.
- Lack of understanding and/or discomfort with formality and complexity of planning body procedures.

**Maintenance of PLWHA Involvement**

Recruitment of a diverse PLWHA membership is only the first step in effective PLWHA involvement. Sustaining and maintaining effective PLWHA involvement requires continuing attention. Many factors—related to the community, the planning body, and the individual—can cause a PLWHA member to become inactive or resign.

Many of the factors that help with PLWHA recruitment also contribute to their effective and sustained involvement. Outlined below, they include orientation, training, and mentoring to enable PLWHA to actively participate in deliberations and also make all members, including PLWHA, feel valued.

**Orientation.** Orientation should occur prior to the first meeting. All new members – including consumers – should receive a practical orientation to their roles and responsibilities as members, the workplan and timeline of the group, policies and operating procedures for meetings (e.g., bylaws, Robert’s Rules of Order), and a typical planning body agenda. They also need an understanding of the structure of committees, their mandates, when they meet, and their leaders’ names and contact information. They should receive a full planning council roster including committee assignments. This kind of orientation offers new members access to the people who are part of the system. The orientation should be supplemented with a member manual and other handouts, but written materials are no substitute for an interactive orientation process.

**Training.** Further training can provide the technical knowledge and skills needed for full participation in the planning body’s activities. Training should provide an understanding of the Ryan White legislation and implementation process, the service delivery system and provider profiles, and planning and other tasks (i.e., needs assessment, priority setting, resource allocation, comprehensive planning, evaluation). Understanding and accepting some of the
constraints within service systems is an important area; orientation and training can help members understand processes and procedures for change and recognize some of the complexities within the system. Training should prepare members to use and understand epidemiologic, client utilization, and needs assessment data and to participate actively in needs assessment, priority setting, and other key processes.

Most of this training is needed by all new planning body members, but may be particularly important for members who have not previously been involved in community planning activities.

**Mentoring.** Mentoring helps PLWHA, including new members, feel welcome, learn about individual member perspectives, and become comfortable with processes and interaction. Some groups assign each new member to a veteran member who takes special responsibility for making sure the new member understands the background and context of discussions and actions, and gets an explanation of the many terms and acronyms used in meetings. Mentoring typically lasts for three to six months.

**Relationship Building.** Developing positive relationships between PLWHA and other members can greatly enhance the planning process through mutual understanding and communication. Periodic retreats or other facilitated sessions build a sense of teamwork and trust among all the members. Requiring PLWHA representation on committees is another way to increase PLWHA involvement and participation.

**PLWHA Representation on Committees.** Requiring PLWHA representation on all committees is another way to increase PLWHA involvement and participation. Such a requirement demonstrates that PLWHA input is needed and valued at all levels of planning body activity.

**Access to Information.** It is important that PLWHA members receive information important to them and the consumer community. Address this need by ensuring that materials from the State grantee, lead agency, and the consortium and its various committees are shared with all members and PLWHA caucuses.

**Financial Support.** One of the greatest obstacles to PLWHA involvement is the financial cost of participation. Costs of attending meetings may involve transportation, child or other dependent care, and meals. Additional expenses might include sending and receiving faxes, making telephone calls, preparing materials, and accessing the Internet. These expenses can present a problem for PLWHA on disability or with very limited incomes, and for PLWHA without access to office equipment and supplies.

Financial reimbursement to PLWHA for the direct costs of involvement needs to be addressed with respect to several different issues:

- What kinds of Ryan White funds are available for use in providing financial support for activities related to PLWHA involvement?
- What are the local, county, or city contracting restrictions and policies on reimbursement?
- What kinds of expenses can be covered for PLWHA?
• What constitutes “reasonable costs?”

Ryan White Part A grants allow for planning body administrative support. Federal guidelines allow Ryan White administrative funds to be used to cover expenses for unaligned PLWHA, such as child and dependent care, transportation, office supplies, or other costs directly related to participation. In addition, contracted services can be used, such as transportation or child care services, provided they are paid for through the administrative budget, not from service funds. Planning bodies should establish, explain, and consistently implement specific policies related to expense reimbursements for consumer members. These policies should specify what types of expenses are reimbursable, under what conditions, required documentation, and expenditure limits.

Planning bodies are permitted to provide budget support for PLWHA participation in local conferences. However, grantee contract guidelines may not permit use of the funds to cover expenses in this manner. Stipends or honoraria are not permitted as cash payments using Ryan White funds. The payments must represent reimbursements for actual allowable expenses, backed up by documentation such as taxi receipts. If alternate funds are available for stipends, planning bodies may give PLWHA the option of receiving or declining a stipend for services, since such income could affect eligibility for Medicaid coverage, Supplemental Security Income (SSI), or other entitlements that may have income caps. For further details, refer to the “Guidelines on Reimbursement of Individuals Serving on a Ryan White Part A Planning Council and/or Part B Consortium” (HAB Program Policy Guidance Number 9), which are included in this manual and available on the HAB website.

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<th>Resources for Training Consumers</th>
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<td>To facilitate the full participation of consumers in planning bodies, HAB provides training opportunities and provides technical assistance.</td>
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HAB maintains cooperative agreements with various national organizations that prepare training resources and conduct leadership and skills-building training for consumers who are members of Ryan White planning bodies. The HAB Website (http://hab.hrsa.gov) provides details about training resources for planning body members and the TARGET Center (http://www.careacttarget.org) provides a variety of resource documents, including training materials used by Ryan White programs.

**Barriers to Sustained PLWHA Participation on Planning Bodies**

Planning bodies and PLWHA have identified many of the following obstacles to sustained PLWHA participation.

**Barriers within Structures and Processes**

• Lack of clearly defined roles and responsibilities
• Lack of – or insufficient or poorly designed – orientation and training or mentoring of PLWHA members
• Poor relationships or conflict within the planning body
• Lack of demonstrated respect for PLWHA input – such as lack of PLWHA in committee or overall leadership positions
• Lack of communication within the consortium and limited access to information
• Bureaucratic processes and long delays before results are seen
• Unrealistic time/commitment expectations given PLWHA capacities at various stages of illness
• Lack of ongoing supports such as accessible meeting locations, expense reimbursements, rest breaks during meetings
• Financial costs that are not reimbursed, such as meal costs
• Lack of support for members with special needs (e.g., visually or hearing impaired, limited English proficient)
• Lack of or inadequate commitment to meeting needs of PLWHA
• Lack of flexibility regarding participation (not allowing telephone hook-ups or leaves of absence during times of illness)

Community Barriers

• Discrimination against people with HIV/AIDS
• Discrimination against sexual minorities
• Discrimination against people of color
• Large geographic areas requiring time-consuming, long distance travel

Personal Barriers

• Poor health
• Burnout
• Competing family, professional and/or personal demands on time and energy
• Lack of financial resources – for example, insufficient funds to cover costs even if they will be reimbursed
• Discomfort with processes and requirements of the planning body
• Change in affiliation

Nonmember Involvement

All groups need input from PLWHA who are not members. Only a small number of HIV-positive individuals are members, and they cannot fully represent the entire consumer community. PLWHA should not feel that they are expected to know everything about people infected or affected by HIV/AIDS. To avoid this additional— if unintentional—pressure on PLWHA, groups should encourage broader community input. Either unilaterally, or in partnership with PLWHA caucuses, consortia can do the following:

• Welcome community PLWHA to meetings and subcommittees meetings
• Provide a public comment period at each planning body meeting
• Open committees like Needs Assessment to non-planning body members
• Include in bylaws a consumer or PLWHA standing committee with membership including both planning body members and non-members
• Provide PLWHA opportunities for input into Ryan White needs assessment and priority-setting processes through methods like town hall meetings, sessions with PLWHA caucuses, and focus groups
• Develop small work groups so that people can have an active voice in the process without making long-term commitments
• Provide regular feedback to appropriate segments of the community

The following approaches have been helpful in various communities:

• Enable anyone to become a voting member of some planning bodies’ consortium committees after attending three consecutive meetings, even if he or she is not a member of the planning body
• Develop methods for involving those who do not attend meetings, such as a telephone call-in number to connect them to the meeting, enabling them to listen, provide information, or ask questions
• Use publications, including mainstream media and newsletters of PLWHA caucuses and other community organizations, to request input and publicize hearings and community meetings, and
• Set up a formal communication structure with special PLWHA caucuses and support groups where consortium information and draft plans can be presented and input and feedback solicited.

XI. Ch 10. Managing Diversity

Introduction

One of the greatest challenges in planning and maintaining an HIV/AIDS service delivery system under the Ryan White Program is ensuring and managing the diversity in planning body membership and community input required by the legislation in order to adequately consider the needs of populations with HIV/AIDS that “reside in traditionally underserved communities” and have “disparities in access and care.”

Managing a multicultural process can be approached on two levels: organizational and individual membership. On the former, this entails attention to planning processes like meeting rules and policies. Individually, approaches used for recruiting new members and orienting them once they join can enhance a smoothly functioning planning group. The ideal outcome, of course, is creation of programs that better meet the diverse needs of PLWHA in the service area.

The Challenge

Membership in a planning body should reflect the demographics of the HIV/AIDS epidemic at
the EMA/TGA or regional level. This requires active recruitment of people who represent diverse perspectives and have diverse characteristics in terms of race/ethnicity, age, gender identity, sexual orientation, age, and geography, among other factors. Also essential is securing a membership representative of different sectors and organizations in the community.

Recruiting the range of people that comprise an appropriately diverse planning body is challenging. Further, learning to communicate and creating a high-performing team within a diverse environment means understanding that there will be differences among people in many areas that affect how they interact in planning bodies. For example, there may be differences in language, attitudes and values, roles for individuals based on gender and age, the concept of time, nonverbal expression, social interaction, and views about the role of government and nonprofit organizations.

Understanding those differences and how they are reflected in the behaviors of diverse planning body members is another step in managing diversity. Integrating diverse values, norms, vocabulary, and rules into the activities of the group further moves everyone along the spectrum toward multicultural competency.

**Multicultural Competence Continuum**

Developing multicultural competence helps you to communicate and to interact effectively and positively with diverse individuals and groups in a diverse society. The multicultural competence continuum below shows a series of steps that define levels of awareness, sensitivity, and competence in dealing with people of various cultures.

**Cultural Destructiveness.** Making people fit the same cultural pattern, and excluding those who do not fit; forced assimilation. Emphasis on using differences as barriers.

**Cultural Blindness.** Not seeing or believing there are cultural differences among people; “everyone is the same.”

**Cultural Awareness.** Being aware that we live and function within a culture of our own and that our identity is shaped by it.

**Cultural Sensitivity.** Knowing that there are cultural differences and understanding and accepting different cultural values, attitudes, and behaviors.

**Multicultural Competence.** Having the capacity to communicate and interact effectively with culturally diverse people, integrating elements of their culture, vocabulary, values, attitudes, rules, and norms. Translation of knowledge into action.

Definitions become critical as groups attempt to understand their diversity. We all have values, act on stereotypes, hold prejudices, and—often unwittingly—practice discriminatory behavior. The key is acknowledging the existence of values, stereotypes, prejudices, and discrimination, and then being willing to change.
The following definitions are offered as a place to begin:

**Values** are established and accepted ideals, customs, and standards for deciding right and wrong, or deciding whether behavior is proper or improper.

**Stereotypes** are standardized and usually (but not necessarily) negative mental pictures of a group of people, representing an oversimplified opinion, attitude, or judgment. They result from limited contact with those we perceive as different and are an expression of our even more limited knowledge and understanding of what they are like. Stereotypes involve generalizations.

**Prejudice** involves negative views or beliefs about a group of people that reflect the formation of an opinion without taking the time to judge fairly. Prejudices are often the result of stereotypes.

**Discrimination** is behavior in which people are treated negatively because of specific cultural or diversity characteristics.

The following are basic steps in successfully managing diversity:

- Accept that there are differences.
- Learn what those differences are and how they manifest themselves.
- Move beyond being aware and sensitive to the differences and start respecting and valuing them.
- Integrate the differences into models, structures, policies, and procedures that are comfortable and appropriate for all participants at all levels of the Ryan White Part A process.

**Culturally Competent Organization**

A planning body should examine all aspects of its organization in terms of embracing and promoting diversity. Commitment to a diverse membership means that all aspects of the way the planning body conducts its business should be examined for how well they foster the comfort of all participants. If one culture or group’s values dominate, the membership tends to reflect only that one group or culture. Other cultures and groups do not feel comfortable, do not participate, do not feel valued, and are often treated as tokens.

All aspects of a planning body should reflect the values and norms of its diverse membership, from the way meetings are run to the language used to write policies and procedures. Diversity will not happen simply because diverse participants are invited to attend a meeting. The culture of the group must reflect commitment to competently managing diversity. All parts of the planning body must be examined and changed when necessary to create an environment that promotes a diverse team. The make-up of the group will ultimately reflect the quality of the resulting planning and programs.

The following elements need to be examined for cultural competency:
• Membership recruitment
• Orientation of new members
• Meeting locations and times
• Meeting process and rules of interaction
• Leadership
• Committees
• Policies and procedures documents.

Below is a list of questions for each of these areas that can be used as a checklist to evaluate how well diversity is being managed.

**Membership Recruitment**

Assess the cultural competency of membership recruitment by asking the following:

- Is there a formal policy for recruiting members which reflect the diversity in the community?
- Is the committee that is responsible for membership recruitment diverse enough?
- Have key contacts and leaders from all the targeted communities been identified and contacted?
- Have the different community leaders been asked specifically about the best way to solicit input and new members from their communities?
- Is there a membership recruitment plan that has been used by the consortium?
- Does the membership recruitment plan offer different strategies for reaching each targeted community?
- Are the outreach materials culturally and linguistically appropriate?

**Orientation of New Members**

Examine the cultural competency of new member orientation by asking the following questions:

- Is there a formal interactive orientation as well as written materials?
- Is there a mentoring program?
- Are the written materials culturally and linguistically appropriate?
- Are specific roles, responsibilities, and member job descriptions identified and articulated?
- Is the orientation conducted by members who are culturally competent?

**Meeting Locations and Times**

A failure to consider the needs of all members when setting meeting locations and times can limit the full participation of some. To determine how well diversity is being managed in terms of meeting arrangements, ask the following:
• Are the meetings held in locations that are comfortable to all participants?
• Are the meeting times appropriate to the most diverse membership possible?

**Meeting Process and Rules of Interaction**

Formal and informal ways of interacting at meetings and around decision making should be examined to make sure all members are comfortable with procedures and expectations. Ask the following:

• Are the meeting rules clearly understood by all members?
• Is the meeting process simple, written down, and understood by all members?
• Do members have the opportunity to be involved in discussions about any changes in the meeting process?
• Is the meeting process periodically evaluated by the members?
• Are the methods of changing the meeting process clearly communicated in writing?
• Is the meeting environment friendly and open?
• Is the style of running the meetings comfortable to most participants?
• Are all members comfortable with the way decisions are made?
• Do all members have opportunities to suggest ways to make the process more comfortable and appropriate?

**Leadership**

A culturally competent approach to leadership aims to open leadership positions to a diverse set of members. Ask the following questions:

• Is there a formal leadership development or mentoring program that specifically encourages diversity?
• Are leaders offered training?
• Has shared leadership been considered to encourage diversity (e.g., co-chairs or chair-elect)?

**Committees**

Committees must be open and accessible to diverse membership in order to foster the cultural competence of the whole group. Ask the following questions:

• Is committee leadership by members from diverse communities encouraged?
• Do committees meet in locations and at times that are comfortable for all members?
• Do committees welcome members who are not members of the consortium?
• Is the mission of the committee clearly understood by all members?
• Are all committee members given specific tasks to perform?
• Is there a committee workplan to meet its goals and objectives?
• Are meetings run in a way that is comfortable for diverse members?

Policies and Procedures Documents

Written policies and procedures reflect how well the group incorporates diversity. The following questions can be asked:

• Are the policies and procedures written in a straightforward, “plain language” style?
• Do the policies reflect an understanding of member diversity – for example, do documents refer to both spouses and domestic partners?
• Do all members have the opportunity to participate in the development and approval of any changes in the policies and procedures?
• Do all members have a complete set of all the policies and procedures?
• Is the method for making changes in policies and procedures clearly understood by all members?
• Are the policies and procedures periodically evaluated?
• Are the policies and procedures followed?

Approaches for Individuals in Groups with Diverse Membership

The following are some ways individual members can learn to work together as part of a diverse team:

• Pay attention to what others are saying to you.
• If someone is bothered by the actions of another group member, look for a way to address his or her concerns and resolve the problem.
• Treat everyone with the same level of respect, showing your recognition that everyone has equal rights.
• Learn about and welcome diversity; if your initial reaction to differences is negative, ask yourself if that reaction is due to fear of the unfamiliar.
• Do not engage in or condone intolerant behavior within the group; do not make jokes or stereotype individuals, and do not permit others to do so.
• Verbally and publicly support other members of the planning body in situations where outsiders fail to show respect.
• Discuss problems and try to explain your perspective; do not ignore concerns or problems.
• Talk about problems and concerns directly with the other person(s) involved, not behind their backs.
• If you cannot resolve a problem directly, seek a mediator.
• Do not make excuses if you are having trouble getting along with someone different from you.
• Ask for help.
XI. Ch 11. Managing Conflict

Introduction

Many people have been socialized to feel that conflict is bad and to be avoided at all costs. In fact, respectful conflict can benefit planning in the course of bringing together different perspectives. Too much agreement may signify a group’s failure to find creative solutions or recognize emerging challenges. It may mean that people are not voicing their concerns. When agreements come too easily, it may mean that final decisions do not really have the commitment of the entire group.

Conflict is necessary in participatory planning. Group members must hear one another’s differences before they can perform as a team. However, conflict that is not managed can result in negative consequences such as high member turnover and inadequate service planning that reduces the quality of care provided. Conflict that is well managed can encourage both cooperation and constructive conflict within an environment that respects open dialogue—and the conflicts that will inevitably arise. Helpful conflict management tools include policies and procedures, effective leadership, diversity of membership, and mutually agreed-upon ground rules for interaction.

If conflict management activities do not work, outside mediation can be used or, if that fails, binding arbitration. However, mediation and arbitration can be very costly. Every member must take responsibility for helping manage conflict and, as such, should not let high levels of conflict harm the group’s ability to develop and implement plans for HIV/AIDS care.

Areas of Conflict in Planning Bodies

Conflict in planning bodies often arises over the following matters:

- Where, when, and how meetings are conducted.
- Actual or perceived differences in values, interests, and personal styles (e.g., discrepancies in work output, commitment to service delivery, definitions of services, styles of expressing anger, frustration, discomfort and disagreement; differences in cultural backgrounds, sexual orientation, race, and class give rise to conflict and misunderstanding).
- Selection of service priorities.
- Interpretation of needs assessment results.
- Allocation of funds.
- Staffing decisions (planning body).

Actions That Promote Unproductive Conflict

The following attitudes, actions, and skill deficits may lead to unproductive conflict:

- Wanting to be right at all costs.
- Believing there is only one way (your way).
- Poor listening skills.
- Placing blame versus focusing on solving the problem.
- Attacking people or agencies viewed as potential competitors as opposed to attacking problems.
- Dredging up historical issues and failing to focus on the current moment and future plans.
- Stereotyping people.
- Presuming to know what others think before they have a chance to speak.
- Not being open and honest.
- Letting a few people dominate a meeting.
- Not sharing the same information with everyone.
- Letting ego, power, or status get in the way.
- Not acknowledging that every member needs something from the process.
- Refusing to take personal responsibility for one’s own conflict-handling style.
- Lacking understanding and/or appreciation of different communication styles.
- Engaging in power plays.
- Indulging in rivalries.

**Determining Your Conflict Style**

People deal with conflict in a variety of ways. Understanding how individuals deal with conflict will help the group manage conflict because—ultimately—the only behavior you can change is your own. Described below are three ways that conflict is typically handled: avoidance, confrontation, and collaboration. Note that these styles are not mutually exclusive. Most people possess the capacity for exhibiting more than one style.

**Style 1: Avoidance**

Some people will do anything to avoid conflict. They will agree simply for the sake of harmony and even hold back their own good ideas. Sometimes avoidance is caused by a fear of emotional confrontation that stems from beliefs about human behavior such as “It’s not nice to fight” and “If you don’t have something good to say, don’t say anything at all.” Acting on these beliefs, people who avoid conflict are less productive than they can be.

Successful groups create an atmosphere where all feel comfortable expressing their ideas and opinions without fear of ridicule or criticism. One way to draw out members who avoid conflict is to take the time to make sure everyone speaks before an important decision is made. The results will be better solutions to problems, higher quality decisions, and everyone’s commitment to support the decision.

**Style 2: Combative**

This style is the exact opposite of the first. Combative people give their opinions, ideas, suggestions, and comments very quickly, often without thinking about the consequences. They are passionate and direct with their words so you always know where they stand, but they are so
abrasive that people get offended by what they say and, especially, how they say it. Being combative may come across as being mean and uncaring when, in fact, the person may have very good intentions. The consequence of this style is that other members become fearful of saying anything that might be ridiculed or criticized. As other members say less, a combative person begins to dominate. After a while, members begin to resist the combative person’s ideas, even the good ones.

Successful groups help combative people become more aware of their style and its consequences. Making sure the group hears everyone before making a decision is helpful. So is setting time limits so each speaker has only a certain amount of speaking time and one person doesn’t dominate. Combative people need help in seeing that their style causes win-lose games, which is the opposite of what they want (win-win), and that actually they can achieve more by choosing their words more carefully, weighing consequences before they speak, and listening more than they talk.

**Style 3: Collaborative**

A story frequently told in negotiation seminars is of two girls fighting over the same orange. Their mother intervenes and cuts the orange in half. The first girl throws away the orange peel and eats the fruit. The second girl throws away the fruit and uses the peel to bake a cake. If the two girls had collaborated, they would have seen that underneath their conflict were needs that were not in conflict. Collaborative people don’t assume that there has to be both a winner and a loser. Instead, they communicate with the people they are in conflict with and, eventually, come to a mutually agreed-upon solution with which both parties can live and even thrive.

A collaborative member does not avoid conflict, but also does not create it unnecessarily. Members must learn to be collaborative and work through conflict to arrive at win-win solutions because win-lose solutions leave hurt feelings that hinder the members’ ability to work together and prevent the arrival at outcomes that are best for all parties.

**Strategies to Manage Conflict**

Creating an atmosphere conducive to open and honest discussion and respect for diverse viewpoints is the best way to prevent conflicts from degenerating into destructive rivalries and power plays. Helpful activities include the following:

- Establish ground rules.
- Ask each member to talk about his or her needs.
- Do not avoid conflict.
- Facilitate open communication.
- Create written policies and procedures for conflict management.
- Use mediation.
- Use arbitration.
- Check with your grantee.
Each of these strategies is discussed below.

**Establish Ground Rules**

Ground rules, agreed upon by all participants and reviewed at the beginning of every meeting, promote effective communication during meetings. Useful ground rules may include the following:

- One person speaks at a time; others listen and do not interrupt.
- Each person speaks for himself or herself, using “I”; individuals don’t claim to speak for others.
- Be polite. It’s acceptable to disagree, but do so respectfully. Insults and accusations are unacceptable.
- Observe confidentiality within established policies.
- Share group time fairly. Allow everyone a chance to speak and listen.
- Be open to listening to and learning from others’ viewpoints.
- When the group is locked in conflict, agree to stop the agenda and brainstorm creative options.
- Refer to written policy and procedures for handling conflict that cannot be resolved in a regular meeting.
- Allow adequate agenda time for particularly sensitive issues. Make sure that each person has time to discuss all aspects of the issue without unrealistic time constraints being imposed.
- Clarify who will monitor group interactions for compliance with the ground rules and agree to what happens to repeat offenders.

**Ask Each Member to Talk About His or Her Needs**

Every member is there for a reason. Whether they are consumers who want to ensure quality services for themselves and their friends, or service providers who want to secure funding, all members need something from their participation in the process. This is not wrong or bad. One of the great myths of the planning process is that everyone must be there for altruistic reasons that have nothing to do with personal needs, desires, and wants. Encouraging everyone to be up-front with their needs will not only help dispel this myth (e.g., a service provider should never need to apologize for wanting to secure funds to provide services) but will help minimize the number of hidden agendas that lead to unproductive conflict. This could be done annually as part of the formal disclosure process to comply with conflict of interest policies and procedures (see the chapter on Conflict of Interest in this manual). Simply ask members: “What do you need from this group?” or “What do you want to get out of your membership?”

**Do Not Avoid Conflict**

Acknowledge that differing points of view exist and that conflict is a natural part of the discussion process. Do not attempt to avoid conflict or sweep it under the carpet when it surfaces, but be careful to define the conflict. The more specifically the problem is defined, the
more suitable the solution is likely to be. The group should also distinguish between the issues and the individuals involved in the conflict. When conflict flares up, attempt to address and resolve it. If you must move ahead to other matters, make sure to return to the issue at a later date.

While acknowledging and dealing with conflict is important, it is also imperative to be careful that the conflict is appropriate. Some issues belong in other forums but are brought to the planning body because that process is often seen as more open. The mission should be clearly understood by all participants and, when issues outside the mission are brought forward, members need to refer the issue to a more appropriate forum. For example, if the consortium does not have responsibility for HIV/AIDS education and prevention planning under the Centers for Disease Control and Prevention’s (CDC) Prevention Community Planning Group initiative, then heated discussion about controversial changes in the use of the State’s CDC prevention dollars is not a good use of planning body time, even if it is a serious concern of some members.

**Facilitate Open Communication**

Facilitate the expression of opposing views by providing ample opportunity for their advocates to speak and to listen to each other. A process that is always hurried and driven by a need to move quickly almost always promotes unproductive conflict. Slow the process down when the decisions on the table are critical (e.g., during the annual priority setting process). As a first step toward proposing alternative solutions and attempting to reach a negotiated agreement, encourage each party to restate the other’s arguments to clarify any misinterpretations or misunderstanding. Understand that differences in experience, culture, class, gender, and personality influence how conflict is expressed. An effective chair or facilitator can facilitate the process of negotiation and help reach a solution that allows all parties to feel they have gained from the process, rather than that some people won and some people lost.

**Create Written Policies and Procedures for Conflict Management**

A written policy describing the mechanism for addressing and resolving internal disagreements may help in situations that cannot be resolved in ordinary group meetings. These policies should define what constitutes a conflict, how it should be resolved, what qualifies it as irresolvable, and what the next steps will be.

A sample policy could read: “A conflict could be defined as occurring when there is a designated percentage split in opinion between the voting members. If the conflict is unresolved after two meetings, an outside mediator will be requested. If mediation does not resolve the conflict to the satisfaction of both factions, and parties, then binding arbitration will be used.”

**Use Mediation**

A mediator is an unbiased third party experienced in conflict resolution techniques. A mediator should be used to manage conflict situations that have reached an impasse and threaten to disrupt or delay decision making or disbursement of funds. The mediator does not decide who is right and wrong and does not tell the parties what to do. Instead, the mediator requires both parties to
adhere to a step-by-step process that often facilitates a consensus agreeable to both parties.

**Use Arbitration**

In arbitration, the conflicting parties agree to a formal hearing before a neutral arbitrator or panel. All parties make a binding agreement to honor the decision of the arbitrator. Arbitration involves an initial agreement to arbitrate, preparation of the case, a pre-hearing conference to clarify procedures, a hearing, review of evidence, and the decision. (For more on arbitration, see the Grievance Procedures chapter in this manual.)

**Check with Your Grantee**

Disputes that advance to requiring mediation and/or arbitration, especially if they involve funds, could be taken out of the planning body’s hands. A consortium may not have the authority to make final decisions about when and how to take steps beyond the consortium’s dispute resolution process. This level of conflict management should be addressed with the grantee and could depend upon State law or contract provisions with the consortium or lead agency. Many grantees have language regarding conflict resolution in their guidance.

**XI. Ch 12. References, Links, and Resources**

**For More Information**

Please refer to the HAB Target Center at [https://careacttarget.org](https://careacttarget.org).
Section XII. Coordination Between Parts and Programs

XII. Ch 1. Overview

The Ryan White legislation, in Sections 2602-2605 of Title XXVI of the Public Health Service (PHS) Act contain requirements for coordination with all Ryan White Parts (A, B, C, D, and F) and non-Ryan White programs and payers from multiple sectors. Driving these requirements is not only the funding represented by these entities but also the potential to coordinate planning and service delivery. The anticipated outcome is better services for people living with HIV/AIDS (PLWHA).

XII. Ch 2. Legislative Background

Participation in Public Planning Processes

Section 2602(b)(2) of Title XXVI of the Public Health Service (PHS) Act identifies membership categories that must be represented on the planning council. Among them are Ryan White grantees from other Parts and multiple non-Ryan White entities, including:

- Health care providers, including federally qualified health centers.
- Social service providers, including housing and homeless services providers.
- Mental health providers.
- Substance abuse providers.
- Grantees of other Federal HIV programs, including HIV prevention programs.

Coordination with Other Payers

Section 2602(b)(4)(C) of the PHS Act states that Part A planning councils are required to “establish priorities for the allocation of funds within the eligible area, including how best to meet each such priority and additional factors that a grantee should consider in allocating funds under a grant based,” in part, on:

“(iv) coordination in the provision of services to such individual with programs for HIV prevention and for the prevention and treatment of substance abuse, including programs that provide comprehensive treatment for such abuse; and

“(v) availability of other governmental and non-governmental resources, including the State Medicaid plan under title XIX of the Social Security Act and the State Children’s Health Insurance Program under title XXI of such Act to cover health care costs of eligible individuals and families with HIV/AIDSs….”

Section 2602 (b)(4)(D) of the PHS Act requires the planning council to “develop a comprehensive plan for the organization and delivery of health and support services described in section 2604 that” in part:

“(ii) includes a strategy to coordinate the provision of such services with programs for HIV prevention (including outreach and early intervention) and for the prevention and treatment of substance abuse (including programs that provide comprehensive treatment services for such abuse); and

“(iii) is compatible with any State or local plan for the provision of services to individuals with HIV/AIDS....” Section 2602(b)(4)(H) requires that the planning council “coordinate with Federal grantees that provide HIV-related services within the eligible area.”

**Statewide Coordinated Statement of Need (SCSN)**

The Statewide Coordinated Statement of Need (SCSN) has been a Ryan White HIV/AIDS Program requirement since the 1996 reauthorization. Section 2602(b)(4)(F) of the PHS Act directs the planning council to “participate in the development of the statewide coordinated statement of need initiated by the State public health agency responsible for administering grants under Part B.”

**Ryan White Comprehensive Plan**

Section 2602(b)(4)(D) of the PHS Act requires EMAs/TGAs to: “develop a comprehensive plan for the organization and delivery of health and support services” as described under Section 2604 that shall include a description that—

“(ii) includes a strategy to coordinate the provision of such services with programs for HIV prevention (including outreach and early intervention) and for the prevention and treatment of substance abuse (including programs that provide comprehensive treatment services for such abuse);

(iii) is compatible with any State or local plan for the provision of services to individuals with HIV/AIDS; and

(iv) includes a strategy, coordinated as appropriate with other community strategies and efforts, including discrete goals, a timetable, and appropriate funding, for identifying individuals with HIV/AIDS who do not know their HIV status, making such individuals aware of such status, and enabling such individuals to use the health and support services described in section 2604, with particular attention to reducing barriers to routine testing and disparities in access and services among affected subpopulations and historically underserved communities”

**Use of Amounts**

Early Intervention Services (EIS) and outreach services are intended to increase access to primary care services for PLWHA. In funding EIS, Part A grantees must demonstrate that other sources of funds for EIS are insufficient before spending Part A funds on EIS and must make this determination in their needs assessment (particularly the resource inventory). For outreach services, Ryan White outreach programs must focus on reaching PLWHA who are not in care.
Ryan White providers are required to maintain appropriate relationships with entities providing “key points of access” to both identify and link PLWHA into care. These include, for example, providers of early intervention services, family planning clinics, substance abuse treatment providers, sexually transmitted disease clinics, community organizations, and correctional institutions.

XII. Ch 3. Identifying Key Entities in the Coordination of Parts, Payers, and Programs

Overview

Ryan White Part A EMA/TGA planning efforts should be coordinated with all other public funding for HIV/AIDS to ensure that Ryan White HIV/AIDS Program funds are the payer of last resort; maximize the number and accessibility of services available; and reduce any duplication of services. For Ryan White HIV/AIDS Programs, the goal of coordination is to enhance access to a range of services in order to both achieve better client health outcomes and use Ryan White resources wisely. Coordination within the Ryan White community occurs through specific efforts of grantees to work together, such as the collaborative planning process to develop the Statewide Coordinated Statement of Need (SCSN) which includes input from all Ryan White HIV/AIDS Programs Parts.

The Ryan White legislation contains requirements for coordination with all Ryan White Parts (A, B, C, D, and F) and non-Ryan White programs and payers from multiple sectors. Driving these requirements is not only the funding represented by these entities but also the potential to coordinate planning and service delivery. The anticipated outcome is better services for PLWHA with complex care demands, such as substance abusers and PLWHA who are not in care.

Among the non-Ryan White programs where coordination is required are Medicaid and Medicare. Both are much larger public sources of funding than Ryan White. Others—defined by their services as well as their payer status—include Veterans Affairs, substance abuse prevention and treatment services (funded extensively through State block grants and other public and private mechanisms), maternal and child health care, and HIV prevention. The latter includes Centers for Disease Control and Prevention (CDC) HIV prevention. CDC also funds outreach and early intervention services, both of which are also fundable under Ryan White but distinguishable because Ryan White must target PLWHA.

Private health insurance is yet another payer that has great potential to cover some of the service needs of Ryan White clients. Although many Ryan White primary care clients do not have private health insurance, mechanisms such as health insurance continuity payments and risk pools are potential payers of care.

Coordination— with both programs and payers—can occur in the following areas:

1) Planning. Coordination in Ryan White planning involves consideration of other programs in such areas as assessment of needs, priority setting, and resource allocation. Required representation of other Federal programs on planning councils is designed to ensure their participation in Ryan White Part A planning. To illustrate, needs assessments should
determine existing resources, regardless of funding stream, as part of efforts to identify areas of unmet need. In setting priorities, other resources must be considered in terms of how they help meet service demands so that Ryan White resources can be used to fill gaps.

2) Funding of Services. Ryan White grantees, including Ryan White Part A programs, are required to coordinate their services and seek payment from other sources before Ryan White funds are used. This makes the Ryan White HIV/AIDS Program the “payer of last resort,” meaning that funds are to fill gaps in care not covered by other resources. Major payers include, for example, Medicaid, Medicare, the Children’s Health Insurance Program (CHIP), and private health insurance.

3) Service Delivery. Ryan White requires coordination with specific services (i.e., outreach, substance abuse prevention and treatment, HIV counseling and testing, and early intervention services). Many are funded by other Federal, State, and local sources. For example, HIV prevention is funded through the CDC, while State and some EMA/TGA substance abuse programs are supported partially through block grants from the Substance Abuse and Mental Health Services Administration.

XII. Ch 4. Partnerships and Collaboration

The objective of coordination is to enhance access to the continuum of services. Ryan White grantees are required to build relationships with other Federal and State agencies, including State Medicaid agencies, CHIP, providers of HIV prevention and substance abuse prevention and treatment services, and incarceration facilities. Areas for coordination include planning; payment of services; and service delivery, as described below.

Planning with Other Programs

Grantees are required to collaborate with other publicly funded programs in the assessment of need, priority setting and resource allocation, and development of their comprehensive plans. Among the most important are Medicaid (by far the largest public payer of HIV care), Medicare (the second largest public payer of HIV care), CHIP, and private health insurance (a source of payment accessible to PLWHA through Ryan White via health insurance continuity payments, which can cover both continuation of existing policies and purchase of new ones).

Also important are community health centers and providers of services to the homeless and substance abusers. Planning coordination is evident in the following requirements, each of which is covered in greater detail in other chapters in this manual.

- Part A Planning Council Membership. Planning council membership must include representatives and providers of services from other Federal programs including:
  
  ---HIV prevention programs
  ---Substance abuse prevention and treatment providers
  ---Mental health providers, and
  ---Social service providers, including housing and homeless services providers.
• Needs Assessment. In order to adequately address priority setting, resource allocation and comprehensive plan requirements, needs assessments must address:

---Coordination with HIV prevention and substance abuse prevention and treatment programs (including outreach and early intervention)
---Compatibility with State or local plans for the provision of services to individuals with HIV/AIDS
---Coordination as appropriate with other community strategies and efforts for identifying individuals with HIV/AIDS who do not know their HIV status

• Priority Setting and Resource Allocation. Part A planning councils are required to conduct priority setting with consideration to multiple factors, to include:

---Coordination in the provision of services to PLWHA with programs for HIV prevention and the prevention and treatment of substance abuse, including programs that provide comprehensive treatment for such abuse, and
---Availability of other governmental and non-governmental resources, such as State Medicaid and CHIP programs, to cover health care costs of eligible individuals and families with HIV/AIDS.

• Comprehensive Plan. The comprehensive plan must include strategies to coordinate services with HIV prevention programs (including outreach and early intervention services) and substance abuse prevention and treatment programs. In addition, the comprehensive plan must be compatible with State or local plans for the delivery of HIV services.

• Statewide Coordinated Statement of Need (SCSN). Requirements for the SCSN (outlined in the SCSN chapter in this manual) address the focus of the SCSN and required involvement, which includes both the Part A grantee and planning council, Part B, other Ryan White entities, and other programs. In particular, HAB/Division of Metropolitan HIV/AIDS Programs (DMHAP) expects Part A programs to describe in their annual application how the Part A implementation plan relates to and is consistent with the SCSN.

**Coordination of Payers**

All Ryan White grantees are required to coordinate their services and seek payment from other sources before Ryan White funds are used, making the Ryan White HIV/AIDS Program the “payer of last resort.”

One specific area of payer coordination is services for women, youth, children, and infants. Each EMA/TGA must allocate funds for each group in an amount no less than the proportion that each is represented in the total number of living HIV/AIDS cases in the EMA/TGA. A waiver is provided when EMAs/TGAs can demonstrate that the needs of these populations are being met through other sources.
Private health insurance can also be coordinated in various ways with Ryan White funding, such as covering services not paid for by private insurance or paying health insurance premiums, if cost effective. Part B grantees may purchase health insurance for clients under the Health Insurance Continuity Program (HICP). HICP funds may only be used to purchase health insurance that includes the full range of HIV treatments and access to comprehensive primary care services and provides prescription coverage that is equivalent to the ADAP formulary. The total amount spent on insurance premiums cannot be greater than the annual cost of maintaining that same population on ADAP. Clients covered under the HICP may continue to qualify for some Part A services that are not covered by their health insurance.

Each State has different insurance laws and regulations, and EMAs/TGAs should become familiar with them. For example, some States have existing insurance programs, like risk pools, and Ryan White dollars might be used to pay premiums. If qualified HIV providers—sometimes including Part A-funded providers—are on the preferred provider list for these insurance policies, such pools may offer opportunities for payer coordination.

**Service Coordination and Points of Access**

Early Intervention Services (EIS) and outreach services are intended to increase access to primary care services for PLWHA. In funding EIS, Part A grantees must demonstrate that other sources of funds for EIS are insufficient before spending Part A funds on EIS and must make this determination in their needs assessment (particularly the resource inventory). For outreach services, Ryan White outreach programs must focus on reaching PLWHA who are not in care.

Ryan White providers are required to maintain appropriate relationships with entities providing “key points of access” to both identify and link PLWHA into care. These include, for example, providers of early intervention services, family planning clinics, substance abuse treatment providers, sexually transmitted disease clinics, community organizations, and correctional institutions.

**XII. Ch 5. Understanding Other HIV/AIDS Payers and Programs**

Federal agencies and programs such as the Centers for Disease Control and Prevention (CDC), the Centers for Medicare and Medicaid Services (CMS), the Department of Housing and Urban Development’s Housing Opportunities for Persons with AIDS (HOPWA) Program and the Federal Bureau of Prisons, among others are involved in Ryan White planning, priority setting, and service delivery activities at the state, regional, and local levels through planning bodies. Additionally, DHHS/HRSA is integrally involved at the Federal level in coordination, policy, and planning activities with other Departmental and Administration directives.

A key example of HRSA’s partnership with other Federal agencies is the National HIV/AIDS Strategy (NHAS). In July 2010, the White House released the NHAS. The NHAS has three primary goals: 1) reducing the number of people who become infected with HIV, 2) increasing access to care and optimizing health outcomes for PLWHA and 3) reducing HIV-related health disparities. The NHAS calls for improved Federal coordination of HIV/AIDS programs. The lead agencies in implementing NHAS are the:
The ultimate NHAS goal is to inform all HIV positive persons of their status and bring them into care in order to improve their health status, prolong their lives and slow the spread of the epidemic in the US through enhanced prevention efforts. The Part A (Early Identification of Individuals with HIV/AIDS) EIIHA legislative requirement calls for grantees to identify HIV positive individuals who are unaware of their HIV status and bring them into care. The NHAS Federal Implementation Plan outlines the specific steps to be taken by various Federal agencies to support the high-level priorities outlined in the Strategy which will require the commitment of Federal agencies, State, tribal and local governments, businesses, faith communities, philanthropy, the scientific and medical communities, educational institutions, PLWHA, and others. Additional information can be found in the NHAS Section of this manual.

In order to work more effectively with other health programs, particularly Federal programs that provide services for PLWHA, Ryan White grantees should learn more about these programs and payers. Among the most significant Federal programs that provide services for PLWHA are Medicaid, Medicare, CHIP, and private health insurance.

These programs and several other HHS programs are briefly summarized below.

**Medicaid**

Medicaid, the joint Federal/State health program for low-income and disabled Americans, is the largest public payer of health care services for PLWHA. The Medicaid program is administered by the Centers for Medicare and Medicaid Services (CMS), formerly the Health Care Financing Administration (HCFA). To be eligible for Medicaid, a person must either be very poor, have children, and/or be disabled (based on the Social Security definition). Thus, most PLWHA are not eligible for Medicaid until they become impoverished and disabled. HIV-infected women and children covered by Medicaid are often eligible for reasons other than their HIV/AIDS.

Medicaid programs vary from State to State. While there are basic eligibility rules and a core benefits package (such as hospital, physician, and nursing services), each State may elect to provide optional services (prescription drug benefits, clinic services), modify eligibility rules above the minimum and place beneficiaries in fee-for-services or managed care arrangements. Ryan White funds can be used to fill service and population gaps not covered by Medicaid. When a State’s Medicaid program does not cover a specific service, Ryan White funds can be used for payment.
Medicaid Managed Care

In the 1990’s, many States began enrolling Medicaid beneficiaries in managed care. Managed care is designed to reduce costs by eliminating inappropriate and unnecessary services and relying more heavily on primary care and coordination of care. Managed care is characterized by formal enrollment of individuals in a managed care organization, contractual agreements between the provider and a payer, and some gate keeping and utilization control.

For PLWHA, managed care systems can present some challenges to the receipt of appropriate services. These include:

---Access to primary care providers and specialists experienced in the treatment of HIV/AIDS,

and

---Adequate coordination between medical and social services.

Additionally, HIV/AIDS and other high-cost conditions present challenges to managed care plans and providers that contract with them where capitation rates do not reflect the real costs of treating HIV/AIDS.

Medicare

Medicare is the second largest source of Federal financing of HIV/AIDS care. Most people 65 and older are entitled to Medicare because they are eligible for Social Security payments. Disabled persons who receive Social Security Disability Insurance (SSDI) cash payments (because they have sufficient work history to qualify) become eligible for Medicare after a two-year waiting period. Medicare covers a significant number of PLWHA in care.

Medicare covers such services as inpatient hospitalization, skilled nursing and home health visits, physician and outpatient hospital services, and outpatient prescription drugs. Many beneficiaries purchase supplemental insurance to help with Medicare’s cost-sharing requirements and fill gaps in the benefit package. Some opt to enroll in managed care organizations that typically have lower cost-sharing benefits.

A significant number of PLWHA are dually eligible for both Medicare and Medicaid. Despite coverage by both sources of public insurance, gaps in care may exist.

State Child Health Insurance Program

CHIP, administered by the CMS Center on Medicaid and State Operations, was enacted in 1997 and allows States to expand health insurance coverage for low-income children. Children cannot be excluded from eligibility due to a disability or pre-existing condition.

States have great discretion in the design of their CHIP programs. For example, States can choose how they will determine family income and have flexibility in determining which groups of low-income children to cover (e.g., based upon age, disability status, where they live in the State). States also have flexibility to revise their child health plans over time.
Maternal and Child Health Bureau Programs

The Health Resources and Services Administration’s (HRSA) Maternal and Child Health Bureau (MCHB) addresses the health of mothers, infants, children and adolescents. A focus is on families with low income levels, those with diverse racial and ethnic heritages, and those living in rural or isolated areas without access to care.

Substance Abuse and Mental Health Services Administration (SAMHSA)

The Substance Abuse and Mental Health Services Administration (SAMHSA) supports programs in substance abuse prevention, substance abuse treatment, and mental health services. It oversees State block grants that support HIV early intervention services in substance abuse or mental health treatment settings. In addition, SAMHSA provides HIV/AIDS grants to cities to enhance the effectiveness of outreach in urban areas highly impacted by substance abuse and HIV infection.

HIV/AIDS Prevention/Counseling and Testing

Publicly funded HIV counseling and testing services have been provided under grants from CDC through local and State health departments since March of 1985. Both anonymous and confidential voluntary HIV counseling, testing and referral services are available and have evolved to focus on individual, client-centered risk reduction counseling models. CDC Guidelines for HIV Counseling Testing and Referral include many recommendations to ensure that HIV-infected individuals (as well as those at risk) have access to appropriate medical, prevention, and psychosocial support services.

XII. Ch 6. Making Coordination Work for Parts A and B Planning Bodies

Although they usually operate fairly independently, Part A and B planning bodies can work together in pursuit of common Ryan White goals to strengthen the service continuum for PLWHA and ensure that funds are used to fill gaps in care. More practical benefits can include reduced administrative and planning costs and lessened duplication of effort.

Coordination efforts are driven by grantee initiative and such Ryan White requirements as cross-Part membership in planning groups, consistency across State and local comprehensive plans, and joint work on the Statewide Coordinated Statement of Need (SCSN). Among the more visible areas of coordination is determining use of AIDS Drug Assistance Program (ADAP) dollars in Part A areas. Other areas for coordination with Part B include State programs like Medicaid and substance abuse block grants. Tools to streamline planning and enhance services might be jointly developed, thus benefiting providers who are funded under both Parts.

Coordination across Parts A and B can occur on multiple levels, from less formal information sharing to more structured efforts like:

---Cooperation on planning-related tasks (e.g., needs assessment, comprehensive plans)
---Joint service-related tasks (e.g., design of data collection processes, standards of care, quality management, evaluation), and
---Consolidation or even merger of planning bodies.

Making such collaboration work requires attention to differing legislative mandates for each Part. In addition, the specific planning task of resource allocation has significant legislative distinctions, with Part A planning council involvement being much more defined in this area.

Planning Activities

HRSA/HAB expects and encourages Part A and B coordination on a broad range of activities, even beyond those specifically mandated in law. This is especially true in those geographic areas where planning council and Part B planning body service areas overlap. In overlapping service areas, the following types of cooperation should be pursued:

- Inclusion of a representative of the other Part on each planning body. This might include joint committees. Notably, HRSA/HAB does not specifically promote consolidation of Part A and B planning groups into a single entity. Rather than prescribe a particular model of coordination, HRSA/HAB encourages planning bodies to determine the model that works best in their community.
- Information-sharing procedures to ensure effective communication between the two planning bodies.
- Coordinated needs assessment activities, where possible, particularly the epidemiologic profile and other specific needs assessment activities such as development of a joint resource inventory, and perhaps use of the same PLWHA survey instrument.
- Coordinated comprehensive plans.
- Consideration of joint priority setting.
- Collaborative contracts with providers that are funded by both Parts.
- Coordination of capacity development, outreach, and early intervention services (EIS), expectations for which are outlined in greater detail in both Ryan White and HRSA/HAB policies.
- Consideration of uniform data collection and reporting systems and collaborative approaches to evaluation and quality measurement.
- Mutual understanding of both how Part B funding is used in the EMA/TGA and what, if any, contribution Part A might make to State-administered programs (e.g., ADAP, health insurance continuity).
- Collaboration on planning body member training, which might include technical training on topics such as needs assessment, comprehensive planning, resource allocation, and understanding HIV treatments. Joint training for PLWHA members should also be considered.

Differences in Planning Body Authority and Autonomy

In exploring ways to work together, Part A and B planning bodies must consider the following differences in their respective authority and autonomy.
• Planning councils are public bodies established by the EMA’s/TGA’s Chief Elected Official (CEO). Legislation defines their key responsibilities, such as determining service priorities, allocating resources to priority service categories, and assessing the administrative agent’s timeliness in disbursing funds. The procurement process and monitoring of funded service providers are grantee responsibilities. Legislation forbids planning council participation in the procurement process.

• Since Part B planning bodies are not as defined in the legislation, they have a more varied structure and membership than planning councils. Part B bodies are shaped primarily by the Part B grantee. They may be incorporated bodies with responsibility not only for needs assessment and planning, but—unlike planning councils—also for procurement and contract management. In some areas, a separate local lead agency fulfills those roles or the State may serve as lead agency.

Benefits of Coordination

Experience with collaborative and merged planning bodies shows that many types of cooperative activities can be implemented.

• Joint needs assessments. Variations include use of a single needs assessment to cover both Parts A and B; EMA/TGA and State collaboration in conducting a joint needs assessment, with EMA/TGA responses separated out for use in planning; use of State-developed needs assessment methodologies or tools by Part A planning councils; or coordinated review of past needs assessments. Planning bodies need not merge to make this happen and can remain separate but use a single committee to conduct the needs assessment.

• Allocation of funds across Parts and funding streams. A coordinated allocations system to disseminate funds can occur through a shared system or a combined planning body.

• Uniform State and local reporting systems and unified management information systems. Uniform reporting requirements can be developed for use by all Ryan White providers, or the State can support common data collection and management systems that better support use of CAREWare and preparation of the Ryan White Data Report, whose use is required by all Ryan White grantees.

• Reduced duplication of provider contracts. A single request for proposals (RFP) process can be used for the two Parts so that a provider has just one contract for any type of service.

• Joint service models or Standards of Care (e.g., case management guidelines) and provider training. Such efforts are especially beneficial for providers funded under both Parts.

• Equity in access to services across areas. Some EMAs/TGAs contribute Part A funds to the State ADAP, increasing the number of drugs in the formulary and the number of clients served.

• Coordination of Services. For example, clients in an EMA/TGA might be served by State-supported providers, such as a statewide case management system that also does eligibility determination for both Parts.
XII. Ch 7. Care/Prevention and Collaborative Planning

Introduction

Federally funded HIV/AIDS prevention and HIV/AIDS care both use planning—and planning groups—to assess needs in their respective realms and develop plans on how to respond.

Although distinct, both care and prevention planning have common characteristics, providing a basis for collaboration. The Ryan White legislation includes provisions that seek to link PLWHA into care by bringing prevention and care closer together. Coordination of care and prevention planning can help bridge gaps across prevention and care and thus help individuals learn their HIV status and enter care if infected.

HAB/DMHAP Expectation

HAB/DMHAP expects Ryan White Part A planning councils and EMAs/TGAs to coordinate with prevention planning bodies and programs in the areas of planning body membership, conducting planning activities (e.g., needs assessments), and service delivery coordination (e.g., early intervention services, outreach), as follows.

Planning Body Membership

As called for in the Ryan White legislation, HAB/DMHAP expects Ryan White Part A planning councils to include Federally-funded HIV prevention programs as planning council members.

Planning Activities

HAB/DMHAP expects Ryan White Part A and Part B planning bodies to coordinate their needs assessment and priority setting activities with CDC’s HIV prevention community planning groups.

Planning of Services

Points of Entry. HAB/DMHAP expects Ryan White Part A programs and funded providers to establish and maintain formal, written relationships with points of entry into care—places where people with HIV who are not in care are likely to be found. Only through conscious and ongoing service coordination can Ryan White Part A programs identify people who know their status but are not receiving care and provide reliable referral channels to get them into the HIV/AIDS service system.

Outreach. Coordination between care and prevention should occur in the planning and delivery of local HIV outreach programs designed to identify PLWHA and help them learn about their HIV status and enter care. HRSA/HAB requires that outreach programs funded through Ryan White be planned and delivered in coordination with local HIV-prevention outreach programs and be targeted to populations known to be at disproportional risk for HIV infection. Outreach
should be provided at times and in places where there is a high probability that HIV-infected
individuals will be reached.

**Early Intervention Services.** If there is a shortage of early intervention services (EIS), including
HIV counseling and testing and referral services, then the planning council may prioritize and
allocate resources to such services. It should ensure that such funds supplement and do not
supplant existing funds by doing an inventory of existing services as part of its planning process.
Planning related to EIS will benefit greatly from communication and cooperation with the
prevention program planning.

**Reducing HIV Perinatal Transmission.** Coordinated planning should occur in developing
outreach activities that target women of childbearing age in order to reduce HIV perinatal
transmission rates. HAB/DMHAP expects planning councils to ensure that HIV-infected
pregnant women have access to therapy that will reduce the likelihood of HIV transmission to
newborns. There should be a coordinated effort to reach them through HIV education programs,
counseling and testing sites, and other community locations. Similarly, CPGs are expected to
plan for HIV counseling and testing of pregnant women at risk for HIV and to arrange
procedures to ensure that women found to be HIV-positive are referred immediately to
appropriate care settings. Care programs need to work with prevention programs to ensure that
women at risk have accurate information about the effectiveness of perinatal treatment and the
importance of obtaining treatment early in their pregnancy.

**XII. Ch 8. References, Links, and Resources**


**For More Information**

Please refer to the HAB Target Center at [https://careaccttarget.org](https://careaccttarget.org).
Section XIII. Technical Assistance

XIII. Ch 1. Overview

The Ryan White HIV/AIDS Program includes a technical assistance (TA) and training component to support the work of Program constituents, including grantees, providers, planning bodies, and consumers. Activities include provision of TA tools and documents, onsite and distance-based consultations, expert meetings, and specialized TA centers. HAB has developed program guidance policies which incorporate both OMB regulations and program specific requirements. Grantees, planning groups, and others are advised that independent auditors and auditors from the Department of Health and Human Services’ Office of the Inspector General may assess and publicly report the extent to which a grant is being administered in a manner consistent with program policies such as these. HAB provides technical assistance to grantees, planning councils, and consortia, where assistance with policy compliance is needed.

XIII. Ch 2. Legislative Background

Ryan White HIV/AIDS Treatment Extension Act of 2009 provisions related to Ryan White Part A training and technical assistance. Section 2606 requires HRSA to provide technical assistance, “including assistance from other grantees, contractors or subcontractors under this title to assist newly eligible metropolitan areas in the establishment of HIV health services planning councils and, to assist entities in complying with the requirements of this subpart in order to make such entities eligible to receive a grant under this subpart.” In addition, HRSA can make planning grants up to $75,000 to metropolitan areas.

HAB provides technical assistance to grantees, planning councils, and consortia, where assistance with policy compliance is needed. Specific policy notices and letters provide specific direction or instruction related to such assistance. Please refer to:
http://hab.hrsa.gov/manageyourgrant/policiesletters.html

XIII. Ch 3. Purpose and TA Topics

TA is provided in areas related to the legislative mandates and programmatic requirements of the Ryan White legislation. Critical topic areas include:

- Access to care
- AIDS Drug Assistance Program
- Clinical care
- Clinical program development
- Consumer development and training
- Cultural competency
- Data collection and programmatic reporting (including client-level data)
- Engagement in care: recruitment and retention
- Fiscal and program management
- Medical case management
• Needs assessment
• Patient-Centered Medical Home TA
• Patient flow evaluation
• Pediatric and Perinatal Guidelines facilitation
• Peer-to-Peer TA or training
• Planning body operations
• Program and capacity development
• Quality
• Stigma
• Strategic planning
• Training peers to serve in health-care teams
• Unit cost analysis
• Unmet needs
• Working with consumers to help address unmet needs by engaging others in care.

XIII. Ch 4. How TA Is Provided

TA and training are provided through the following methods:

• The Technical Assistance Resources, Guidance, Education, and Training (TARGET) Center Web site (http://www.careacttarget.org), which provides centralized, Web-based access to all HAB TA resources and facilitates networking among Ryan White Program Parts. The TARGET Center comprises a telephone help desk, a library of HAB- and grantee-developed TA tools, a TA calendar of upcoming events and trainings, and Web links to all grantees.
• Individualized and onsite peer and expert consultation through a national Technical Assistance Contract (TAC). The TAC also coordinates consultative meetings and conferences, site visits, and conference calls
• Assisting grantees in replicating successful Special Projects of National Significance (SPNS) to strengthen their capacity to deliver new methods of evidence-based HIV care.
• An array of cooperative agreements with national organizations to deliver TA in specific topics through local and regional workshops, Webcasts, Web-based learning modules, conference calls, onsite trainings, and technical publications and curricula.
• A logistics contract that supports the Ryan White All-Grantee Conferences and Clinical Update, and regional and consultative meetings.

XIII. Ch 5. How to Obtain TA

To obtain more information about TA, contact your HAB project officer. A list of TA products is available on the Technical Assistance Resources, Guidance, Education, and Training (TARGET) Center Web site (http://www.careacttarget.org). Additional sources of TA are discussed in other sections of this Manual. As a cross reference, several sections contain specific information on technical assistance availability, for example:

See Section I, Overview of Ryan White HIV/AIDS Program in this Manual for an overview of the provision of technical assistance for the Ryan White Community.
See Section IV, Grants Administration and Fiscal for technical assistance available to Grantees.

See Section V, Grantee and Subgrantee monitoring for a description of technical assistance available to both grantees and subgrantees.

See Section VI, Data and Reporting Requirements in this manual for more information on how TA is provided to assure compliance with reporting requirements.

XIII. Ch 6. References, Links, and Resources


For More Information

Please refer to the HAB Target Center at https://careacttarget.org.