Washington, DC Regional PLANNING COMMISSION on HEALTH and HIV

*The **Washington, D.C. Regional Planning Commission on Health and HIV** (COHAH) will invigorate planning for HIV prevention and care programs that will demonstrate effectiveness, innovation, accountability, and responsiveness to our community.*

RESEARCH & EVALUATION COMMITTEE (REC)
MEETING AGENDA
TUESDAY AUGUST 21, 2018 – 3:00PM TO 5:00PM

DC HEALTH HEADQUARTERS - HAHSTA
899 N. CAPITOL ST., NE; 4TH FLOOR; WASHINGTON, DC 20002

Note: all times are approximate

3:05 pm	**1. Call To Order and Moment of Silence** **2. Welcome and Introductions**
3:15 pm	**3. Committee Leadership Appointment**
3:20 pm	**4. Assessment of the Efficiency of the Administrative Mechanism for GY'27**
4:00 pm	**5. DC Cohort Longitudinal HIV Study - Leah Varga, PhD**
4:45 pm	**6. Needs Assessment – Volunteers Needed**
4:50 pm	**7. Announcements and Adjournment**
NEXT RESEARCH & EVALUATION COMMITTEE (REC) MEETING:	**Tuesday September 18, 2018** **3:00pm to 5:00pm**

CONFERENCE CALL INFORMATION:

Dial In #:1-866-809-0886
Participant Code: 8289221#

RESEARCH & EVALUATION COMMITTEE (REC)

MEETING MINUTES

TUESDAY – JULY 17, 2018 – 3:00PM TO 5:00PM

DOH-HAHSTA - 899 N. CAPITOL ST., NE; 4TH FLOOR; WASHINGTON, DC 20002

ATTENDEES/ROLL CALL					
Commissioners	**Present**	**Absent**	**Guests**	**Present**	**Absent**
Wallace Corbett	X		John Brooks	X	
Derrick Cox	X		Hellen Flores	X	
Traci Dean	X				
Demarc Hickson	X				
Jenne Massie	X				
Dennis McBride	X				
Lenora McClain	X				
Ka'leef Morse	X				
HAHSTA/ Administrative Agent Representatives			**HAHSTA Office**		
Leah Varga	X		Patrice Bailey	X	
			Lamont Clark	X	

AGENDA	
Item	**Discussion**
Call to Order	Meeting called to order 3:15pm by Ka'leef M. followed by a moment of silence. Attendees introduced themselves.
Review and Approval of the Agenda	NA.
Review and Approval of the Minutes	NA
Research & Evaluation Committee Leadership	Demarc H. expressed interest in being Co-Chair for the committee. Lamont C. noted that Betelhem M. expressed interest in leadership of the committee. David H. also expressed interest in a leadership role.
Research & Evaluation Committee Brainstorming Discussion	Ka'leef M. began the meeting by discussing the structure and purpose of the committee, including the Assessment of the Efficiency of the Administrative Mechanism (AEAM). Ka'leef stressed to attendees that those who decide to be a part of the committee that they should take into consideration all of the suggestions they had for the Needs Assessment, and consider what, if any, other projects the committee would be involved in. He noted that they committee should always be aware of the shrinking of resources and the increase of the needs. He said committee members should think about two questions: 1) What are some topic areas and activities the committee should work on moving forward?, and 2) How will the work of the committee impact the overall goals of the Planning Commission as a whole? He stated that those who are interested in being a part of the committee should complete an application and be prepared to answer these questions. Next month the committee should start preparing the "roadmap" for the committee. Ka'leef encouraged members to consider becoming a part of the leadership team for the committee.
Needs Assessment 2018	Leah V. gave an overview of the 2016-2017 Needs Assessment process and findings done by the Needs Assessment and Comprehensive Planning Committee of the Ryan White Planning Council. She noted that this new committee would likely look at creating a Needs Assessment around people who are not connected to care. She said she still has qualitative data that still needs to be analyzed from the 2016 – 2017 Needs Assessment. She discussed multiple aspects of the Needs Assessment including Provider Engagement (or lack thereof) and developing new relationship with DC Cohort. She noted that the Needs Assessment could be used as a guide for what to do and/or what not to do for the next assessment and that the fresh ideas from the new members were very much welcomed to the next process.
ANNOUNCEMENTS/OTHER DISCUSSION	

HANDOUTS

MEETING ADJOURNED	4:30 PM
NEXT MEETING	August 21, 2018 DOH-HAHSTA 899 N. Capitol St. NE; 4th Floor Washington, DC 20002

D.C. Cohort Longitudinal HIV Study

Please note the new URL for this information: http://go.gwu.edu/dccohort

The DC Cohort is a longitudinal research project that will collect clinical data from approximately 10,000 consenting HIV-infected outpatients receiving care at fifteen large treatment clinics in the District of Columbia. The DC Cohort is sponsored by the National Institute of Allergy and Infectious Diseases (NIAID) of the National Institutes of Health (NIH).

The primary project goal is to improve the quality of care and treatment of HIV-infected patients at large clinics in the District of Columbia by:

- Linking data from fifteen large treatment clinics to enable evaluation of HIV/AIDS care provided in the District of Columbia
- Monitoring socio-demographic data, clinical status, and treatment regimens of HIV-infected patients in DC over time
- Providing clinic sites with routine reports on their patient population that will enable them to benchmark and improve their standards of clinical care
- Contributing to the research of emerging issues in the prevention, treatment, and long term effects of HIV/AIDS-infected persons.
- Evaluating the impact of HIV screening and prevention programs in collaboration with the DC Department of Health

The project's scientific objectives are to contribute to the knowledge regarding HIV-infected patients and their treatment through:

- Evaluating the outcomes of HIV treatment regimens over time
- Examining resistance patterns over time in relationship to treatment patterns and patient characteristics
- Assessing the extent and impact of co-morbidities, such as hepatitis, diabetes, lipidemia, and STDs, on clinical outcomes
- Advancing research on emerging issues in HIV and its treatment

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.

For further information, see HAB Program Letter, *Use of Funds and Activities for Program Development,* at http://www.hab.hrsa.gov/manageyourgrant/pinspals/capacitydevelopment2012.pdf

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 co-morbidity 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.

STATEWIDE COORDINATED STATEMENT OF NEED (SCSN) AND COORDINATING NEEDS ASSESSMENTS

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.

CROSS-PART COLLABORATION
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 Announcement s 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 data 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 requires 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.