

## **Using Data for Decision Making Part 1 Notes**

“Without data, all anyone has are opinions. Data elevates the probability that you’ll make the right decisions.” – W. Edwards Deming

### **What is Data-based Decision Making?**

Decision making that is guided and supported by documented information – data – rather than based primarily on personal experience, observation, anecdotes, or intuition/insight.

The Planning Council should use data that is quantitative (information expressed as numbers, counted, or compared on a scale i.e. epidemiological data) and qualitative data (information not easily measured or expressed in numbers i.e. narrative data from a focus group, consumer town hall meeting, open-ended interview) from multiple sources and is gathered using several different approaches.

### **Importance of Data**

Data-based decision-making is essential to establishing, supporting, and improving a system of quality care

Data guide the entire planning process –essential for all Planning Councils:

- Understanding service needs, barriers, and gaps in your service area –overall and for PLWH subpopulations
- Making sound decisions about use of available funds
- Targeting funds to particular service models, geographic areas, and PLWH subpopulations
- Improving care for disproportionately affected groups

### **How Planning Councils Use Data to Illuminate and Address Disparities**

#### **Four Common Types of Disparities Addressed Through HIV Planning**

- Unmet needs
- Service gaps
- Availability of services
- Geographic disparities

## Unmet Need

**What it is:** Refers to individuals with HIV in a jurisdiction who know their status but are not receiving HIV-related medical care

**How it's measured:** Estimate based on a HRSA/HAB Unmet Need Framework, now being updated –basic approach:

- *Determine the number of PLWH in the jurisdiction through surveillance data*
- *Subtract the number who are “in care” based on measures like viral load or CD4 count –the rest are assumed to be out of care and have unmet need.*

**How it can be addressed with HIV planning:** Provide funding for service categories and help develop strategies that link PLWH to care immediately after diagnosis and for find, relink, and retain in care those who dropped out.

## Service Gaps

**What it is:** The identified unfulfilled need for HIV-related services other than primary medical care among individuals who know their HIV status and live in a specified geographic area.

- *This term is used to avoid confusion with the HAB definition of “unmet need” as referring to primary medical care.*

**How it's measured:** Through needs assessment & recipient data

- *A PLWH survey asking what services they needed but didn't receive*
- *Recipient identification of services with waiting lists or appointment delays*

**How it can be addressed with HIV planning:** Provide funding or directives designed to make needed services more available.

## Availability of Services

**What it is:** Level or number of available “slots” within a service category in a specified geographic area, and whether there are waiting lists

**How it's measured:** As part of a Resource Inventory or Profile of Provider Capacity and Capability, asking providers (Part A and non-Part A) how many service slots they have for each HIV service, and whether they have more demand than slots

**How it can be addressed with HIV planning:** Increase funding for service categories with insufficient slots or explore refined service models

## **Geographic Disparities**

**What it is:** Differences in access to needed services based on where an individual lives

**How it's measured:** By comparing the number (or capacity) of service providers offering needed services across geographic areas in the EMA or TGA in an accessible way

**How it can be addressed with HIV planning:** EMAs and TGAs can use this information, found in the needs assessment, to better understand and address geographic disparities and inequities in access to care.

## **Types and Sources of Data Commonly Used for RWHAP Planning**

### **Epidemiologic Profile**

**What it is and what it shows:** A document that describes the burden of HIV on the population of an area including distribution of HIV in various populations in an area in terms of sociodemographic, geographic, behavioral, and clinical characteristics

- Includes characteristics of the general population, persons newly diagnosed with HIV infection, persons living with HIV disease, persons at risk for HIV
- Trends in the epidemic

### **Where it comes from:**

- Provided by state or local HIV surveillance staff, from eHARS (enhanced HIV/AIDS Reporting System) data
- Usually based on a calendar year

### **How it's used:**

- Provides an overall picture of HIV in the service area
- Helps in identifying subpopulations and geographic areas with increasing rates of HIV
- Enables recipient and planning council to develop or refine services to ensure appropriate care for emerging groups
- For an integrated prevention and care planning council, helps in identifying populations for primary prevention, testing, and prevention for HIV-positive individuals
- Helps in identifying populations for focused special attention in assessment of PLWH service needs and barriers

## HIV Care Continuum Data

### What it is and what it shows:

- Model that outlines the stages of HIV medical care that people living with HIV go through from initial diagnosis to achieving the goal of viral suppression and shows the proportion of individuals living with HIV who are engaged at each stage.
- Two kinds of care continuums: Prevalence based and diagnosis based

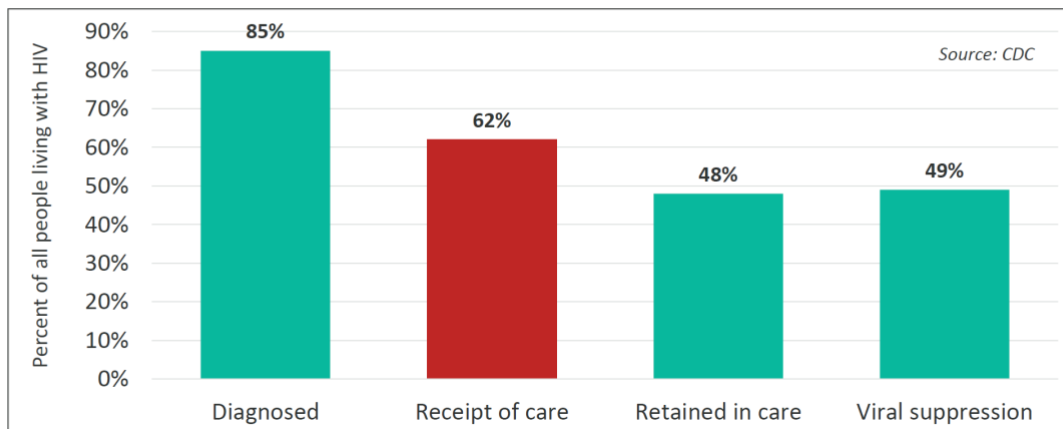
### Where it comes from:

- Data provided by state or local HIV surveillance staff
- Provided at least annually; sometimes more often

### How it's used:

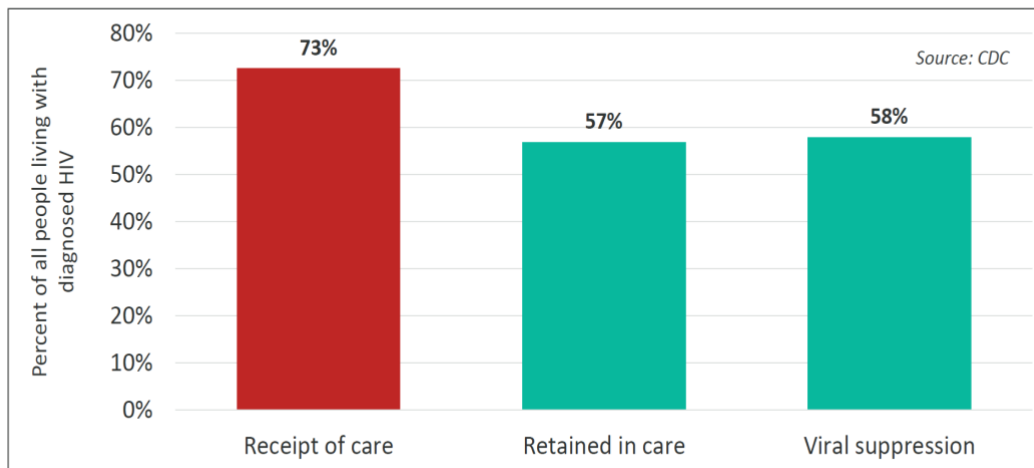
- Helps planning councils understand strengths and weaknesses in system of care and identify need for additional attention to particular steps (e.g., linkage, retention, viral suppression) and PLWH subpopulations.

## Prevalence-based HIV Care Continuum, U.S., 2014



This is called the *prevalence-based* HIV care continuum because it shows each step as a percentage of the total number of people living with HIV, including people who have been diagnosed and aware they are living with HIV and those who have not been diagnosed and don't know they are living with HIV.

## Diagnosis-Based HIV Care Continuum, U.S., 2014



This is called the *diagnosis-based* HIV care continuum because it shows each step as a percentage of people living with diagnosed HIV.

### Needs Assessment Data

#### What it is and what it shows:

- Number, characteristics, service needs and barriers of PLWH, both in and out of care
- Provider resources available to meet those needs
- Service gaps, overall and for various PLWH subpopulations

#### Where it comes from:

- Data from needs assessment activities conducted by planning councils, including staff and/or consultants
- Usually a multi-year cycle, with some new data collected each year

#### How it's used:

- Set priorities, allocate resources, develop directives, and improve service access and quality, overall and for specific populations

## **Resource Inventory Data**

### **What it is and what it shows:**

- A regularly updated, comprehensive listing and description of HIV-related services available to PLWH in the EMA or TGA, regardless of funding source
- Provides information on types of services provided, location and hours, number of clients served, and funding sources –often in chart form
- Often includes information on levels of funding from non-Part A sources

### **Where it comes from:**

- Usually developed as part of the Needs Assessment, under PLANNING COUNCIL supervision

### **How it's used:**

- Used in integrated/comprehensive plan development and during the PSRA process
- Often used to develop Resource Guide for service providers and clients

## **Service Expenditure and Cost Data**

### **What it is and what it shows:**

Projected and actual expenditures by service category, plus:

- Costs for one unit of service, such as 1 case management visit lasting 30 minutes
- Cost to serve one client for a year

### **Where it comes from:**

Recipient or administrative agency

- Expenditures usually provided monthly, with an annual summary

### **How it's used:**

- Helps planning councils make funding decisions, adjusting allocations based on actual use of funds and determining costs to serve additional clients

## **Client Characteristics and Service Utilization Data**

### **What it is and what it shows:**

- Information about the use of RWHAP Part A services, including the number and characteristics of clients, overall and by service category, and the amount or units of service provided

### **Where it comes from:**

- Recipient, usually gathered through its client-level data system and included in the RWHAP Services Report (RSR)
- Provided annually

### **How it's used:**

- Helps planning councils understand demand for specific services and identify differences in use of services by various PLWH groups

## **Addressing Gaps in Data**

### **Dealing with Data Gaps**

No PLANNING COUNCIL has all the data needed for decision-making.

Data gaps often caused by:

- Limited resources
- Limited needs assessment and data analysis skills and experience on the part of planning council and/or recipient staff
- Lack of agreements with state surveillance staff to provide newer types of data
- Limited time for data gathering or analysis, given other responsibilities
- Lack of agreement between planning council and recipient regarding data needs and how best to meet them

Become familiar with the various types of data that *should* be available to the planning council based on sound practice and HRSA/HAB guidance

Incorporate data sharing agreements into your Memorandum of Understanding (MOU), including:

- What data the recipient will provide
- In what formats
- On what schedule

Explore what data needs can be met by the planning council, planning council staff, or consultants through needs assessment, town halls, roundtables, or other approaches

Maximize use of existing data through improved analysis

Make a chart showing needed data types, content, use, and current or potential sources

Develop a plan to fill remaining gaps

- Explore what PLANNING COUNCIL members, service providers, or other stakeholders can provide
- Seek help from area universities

### **Assessing Data Quality & Usefulness**

#### **Not All Data are Created Equal!**

**There are multiple ways data can be 'of poor quality'**

##### **Outdated**

- Example: Care continuum developed using data from 10 years prior

##### **Incomplete**

- Example: Service expenditure data with several service categories missing

##### **Unclear**

- Example: Resource inventory data does not specify RWHAP funding source for services (e.g. RWHAP Part A, Part B, Part C, etc.).

**Data quality is important!**

### **Assessing Data**

#### **PLANNING COUNCIL member roles:**

- Review data from multiple sources
- Ask questions about how data were gathered, tabulated, and analyzed
- Compare and weigh data from different sources and studies
- Decide how much confidence to place in the data
- Give the greatest weight in decision making to the "best data"

#### **PLANNING COUNCIL Support Staff, Consultants, and Recipient Staff roles:**

- Provide/present data from various sources



- Understand and share information on data quality and limitations

### **Importance of Using Multiple Data Sources for Decision-Making**

#### **Data Triangulation**

- A planning council can have additional confidence in findings found in more than one needs assessment activity, study, or data set, and can use multiple methods to increase understanding of a topic or issue –that process is called triangulation.
- **Bottom line:** Review more than one data source when available.

#### **Triangulation of Data**

The process of comparing data on the same topic from 2 or more sources or research studies to:

- See whether they report similar findings –“cross check” or “cross-validate” the data
- Increase understanding of the topic

Planning councils can have greater confidence in findings that are reported from several different studies or sources, or obtained through different methods