CSTE

Council of State and Territorial Epidemiologists

HIV SURVEILLANCE COORDINATOR

Orientation Manual

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Acknowledgements

This guide was based on a document, "AIDS Director Planning Guide and Toolkit," produced for the National Alliance of State & Territorial AIDS Directors. Some sections of that guide, in particular those describing the structure and purpose of public health programs, were so useful that only minor changes were made for inclusion in this document. Another important source was "Surveillance for HIV/AIDS in the United States," written by Eve Mokotoff and M. Kathleen Glynn, Chapter 16 of Infection Disease Surveillance, edited by Nkuchia M. M'ikanatha, Ruth Lynfield, Chris A. Van Beneden, and Henriette de Valk, 2007. This document was developed by the CSTE HIV/AIDS surveillance coordinators in conjunction with the CSTE National Office.

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CHAPTER

1

Introduction

Welcome

This manual was developed by the Council of State and Territorial Epidemiologists (CSTE) and CSTE members who are HIV surveillance coordinators. The manual is intended for state, territorial, and city HIV surveillance coordinators. CSTE strongly encourages new surveillance coordinators to review the Centers for Disease Control and Prevention's (CDC's) Technical Guidance volumes: Centers for Disease Control and Prevention and Council of State and Territorial Epidemiologists, Technical Guidance for HIV/AIDS Surveillance Programs, 2005. You are encouraged to use the other resources at the end of this manual, especially the National Alliance of State and Territorial AIDS Directors' planning guide and the surveillance chapter acknowledged at the beginning of this manual.

How this Manual is Organized

This orientation manual supplements the Technical Guidance for HIV/AIDS Surveillance Programs, volumes I–III (available at https://team.cdc.gov). The CDC guide details everything a surveillance coordinator needs to know and should be consulted as a thorough reference of required activities and standards and suggested best practices. This manual, in contrast, is a quick guide to consult for an overview of the position of surveillance coordinator. It will walk you through important meetings to attend, places to find resources, and ways CSTE can help you.

CHAPTER

2

What a new surveillance coordinator needs to know

First Steps in Your First Days

1. Contact your CDC Program Consultant and Epidemiologist for Core HIV/AIDS Surveillance. The CDC Program Consultant is your liaison between the CDC grants management staff, who are responsible for the financial aspects of your cooperative agreement, and the program staff, who are responsible for the protocols of your day-to-day surveillance program activities. If you do not have direct contact information, call the CDC HIV incidence and Case Surveillance Branch's general number at (404) 639-2050.

   a. Request a briefing from your assigned Program Consultant and Epidemiologist about the current status of your program objectives, activities, and funding. CSTE recommends you have contact with them regularly.
   b. Request your contact information be updated and shared with the appropriate CDC program staff so you will immediately begin receiving important information about the projects for which you are funded, including e-mail distribution lists. Find out the dates of routine conference calls for the projects for which you are funded. (Also see #3 for the monthly CSTE conference call for Surveillance Coordinators.) Find out how to sign up for CDC's limited-access portal that has protocols, policies, fact sheets, and other important information for surveillance coordinators (https://team.cdc.gov).
   c. If you are responsible for transmitting data to CDC, find out how to get the certificates needed to transfer data through CDC's Secure Data Network (SDN). This may require assistance from your program's information technology personnel. You will need to apply annually for a new digital certificate.

2. Obtain a copy of CDC's Technical Guidance volumes, a primary training and information tool. If your office does not already have a copy, you can obtain an electronic copy on CDC's SiteScape Web site (also called the "CDC Team" site) at https://team.cdc.gov.

   a. One of the most important sections of this document is the Confidentiality and Security Guidelines, found in Volume 3. These requirements are absolutely paramount to all of your program activities and responsibilities. Your program should have a local written policy that addresses all of the required standards. If one is not in place, establishing one is a very high priority. To get started, ask other Surveillance Coordinators to share their policies with you (see "How Can CSTE Help You," page 19), but this policy should be specific to your state's laws and practices.
   b. Determine whether your program has local operations manuals or protocols developed in accordance with the new Technical Guidance standards. As of December 2008, many surveillance programs still were developing their local manuals. The Technical Guidance is a thorough reference for required activities and best practices for surveillance programs, but programs need to write their own local simplified manuals to ensure the Guidance requirements and standards

apply in your program's day-to-day practices.

3. Contact CSTE to inquire about resources. Call the national office at (770) 458-3811, and ask for the program staff person in charge of the HIV/AIDS subcommittee. CSTE staff will be able to help you with the following:

a. Becoming a CSTE member
b. Updating your contact information with CSTE
c. Loggin onto the CSTE website and discussion forum
d. Updating the HIV contact board
e. Finding out about regularly scheduled calls and meetings, as well as contact information for the current CSTE and subcommittee leadership
f. Assessing peer-to-peer technical assistance needs

4. Meet your jurisdictional AIDS director. Surveillance programs are responsible for providing critical information to prevention and services programs for planning, evaluation, and local and federal resource allocation. In general, AIDS directors are responsible for managing these HIV-prevention and -services programs. Many surveillance coordinators report directly to the state or territorial AIDS director; some do not. A collaborative relationship is important because surveillance program activities directly inform and support prevention and care programs and directly impact the funding received by your jurisdiction for services to people with HIV. If you are not sure who to contact in your area, contact the National Alliance of State and Territorial AIDS Directors at www.nastad.org or (202) 434-8090.

5. If you will be responsible for submitting grants or the annual or interim progress reports, find out from your director whether you need to register for an account with www.grants.gov. Most CDC grant applications and reports are submitted electronically through this portal. Navigating the enrollment process may take a few weeks, so start early, especially if you have applications or reports due soon. Your Program Consultant can assist you if you have any difficulties.

6. Review the laws and rules that dictate HIV and AIDS reporting practices in your state, which may vary considerably. You need to know the restrictions these laws/rules place on the practices of your program.

7. Look at the calendar of key events and deadlines for surveillance program activities.

8. Visit CDC's public Web sites for additional information about HIV prevention and surveillance. By visiting www.cdc.gov/hiv/, you can get general information about CDC's prevention activities and access fact sheets, podcasts, surveillance data, slide sets, and publications.

a. CDC's Statistics and Surveillance link on the Web site (www.cdc.gov/hiv/topics/surveillance/index.htm) has resources specific to surveillance. Look for the page to sign up for e-mail updates and alerts.
b. For a quick, helpful overview of HIV/AIDS surveillance terminology, data, and history, review CDC's new HIV/AIDS surveillance fact sheet (See Appendix I, or download from www.cdc.gov/hiv/topics/surveillance/resources/factsheets/pdf/surveillance.pdf.)
c. The National Prevention Information Network is an additional resource for information (http://www.cdcnpin.org). It contains electronic mailing lists for important updates, most importantly the Connections bi-monthly newsletter and the Prevention News mailing list.

Timeline of Key Events

Surveillance coordinators should keep in mind several important dates throughout the year. Consult with your Prevention and Care and Treatment programs so you can be aware of applications, planning processes, and other analyses needed each year.

Ongoing

1. Monthly CSTE call with CSTE leadership to discuss timely issues and to hear from guests on specific topics.
2. Quarterly conference call hosted by CDC HIV Incidence and Case Surveillance Branch staff to provide important updates and to improve collaboration and communication among the HIV surveillance coordinators and CDC.
3. Regular project-specific conference calls. (Ask your CDC Epidemiologist for details.)
4. Monthly transmission of data to CDC. (Different projects have different mechanisms and expectations for transferring data; consult your CDC Epidemiologist.)

January 1	Start of the new grant year for surveillance cooperative agreements. Review your plans to monitor and achieve the program objectives anticipated in your cooperative agreement application(s).
March 31	Financial status report and final progress report due to CDC from each funded project site. Consider whether and when to request any unobligated funds that remain from the prior grant year, if applicable. Contact your Program Consultant for assistance.
June	CSTE Annual Conference
Summer	Annual meeting for Surveillance Coordinators (sometimes in conjunction with CSTE Annual Conference)
September	Usual due date for the interim progress report or subsequent year's application to CDC
November	Award notices for subsequent grant year are usually released late in the month. Budget revisions may be necessary if the amount of the award differs from the proposal.

CHAPTER

3

What is Surveillance?

HIV surveillance, also referred to as HIV reporting, is the ongoing, systematic collection, analysis, interpretation, and dissemination of information about persons in whom HIV and AIDS are diagnosed. HIV reporting monitors the entire spectrum of the disease from HIV infection and diagnosis to AIDS diagnosis, opportunistic infections, and death. In many areas, perinatal exposure to HIV also is monitored. The information collected through HIV reporting includes demographic characteristics (i.e., sex, race/ethnicity, age, place of diagnosis), mode of exposure (risk), initial immune status and viral load, opportunistic infections, and vital status. Timely analysis and dissemination of the comprehensive data collected through HIV reporting is integral to the activities of the programs responsible for HIV prevention, control, and care. In particular, federal funding from the Human Resources and Services Administration for primary care and support services for people living with HIV use surveillance data to allocate funds throughout the country.

Through cooperative agreements, or grants, CDC provides funds to support HIV reporting activities in 65 jurisdictional areas covering every U.S. state and territory, with separate direct funding to seven cities (Chicago, Houston, Los Angeles, New York, Philadelphia, San Francisco, and Washington, DC). The designated health agencies in these areas are uniquely positioned to conduct these activities because of the expertise, statutory authority, and confidentiality protections afforded to public health disease reporting systems. The data from these areas represent the primary source of population-based data on persons living with HIV and AIDS in the United States. (For an overview of the federal structure for public policy that affects HIV and public health, see Appendix I).

HIV/AIDS Reporting History and Surveillance Program Activities

In 1982, CDC began receiving reports of the spectrum of illnesses that became known as AIDS. With the advent of diagnostic testing for HIV in 1985, reporting of HIV became possible. However, without treatment and with considerable concerns about discrimination, adoption of name-based HIV reporting was slower and more variable. Many areas adopted variations on code-based reporting which have been used until more recently. As of April 2008, all areas have name-based HIV reporting and no longer use a coded system.

To support the essential case reporting and data dissemination functions of surveillance programs, all jurisdictions receive funds for what CDC calls "Core Surveillance." The Technical Guidance volumes I–III detail the recommended and required activities and standards to support Core Surveillance. Reporting is the foundation of the "Core" surveillance system. Programs must work with providers, such as laboratories, health-care practitioners, hospitals, and clinics, to establish and maintain mechanisms by which those providers will report cases to the health department. Health department surveillance staff members also ascertain new cases and case updates by contacting health-care practitioners and reviewing medical records in hospitals and clinics. Primary case reports are derived from health-care practitioners and facilities, whereas secondary case reports are from death records, hospital discharge summaries, AIDS drug-assistance programs, and other sources.

HIV reporting is based on specific rigorous case definitions and reporting criteria, which are defined in the Technical Guidance. Jurisdictions may use locally developed case report forms for documenting case investigations. However, certain minimum variables must be documented for a reported case to be recorded locally and included in the national surveillance database.

All jurisdictions are required to use standardized surveillance software for reporting de-identified data to CDC. By 2009, all jurisdictions are expected to replace the DOS-based HIV/AIDS Reporting System (HARS) software with eHARS, an SQL-based software developed by CDC that allows collection of limitless numbers of documents for each case and evaluation of the completeness of reporting.

The primary activities of Core Surveillance include

- Monitoring the number of HIV diagnoses each year, the prevalence of persons living with HIV, and HIV-related morbidity
- Monitoring perinatal exposure and transmission
- Monitoring behaviors related to HIV testing, risk for infection, and access to care among persons living with HIV
- Monitoring changes in trends in transmission
- Providing data to guide local resource allocation for prevention and services programs
- Providing data to inform and evaluate local prevention and services programs
- Conducting ongoing efforts to ensure the completeness, timeliness, and accuracy of the jurisdiction's surveillance data to ensure the quality of the national data

In addition to Core Surveillance, CDC supports other, more focused surveillance activities that provide valuable information for understanding the epidemic and for informing and evaluating prevention and care/treatment programs. Funding for these programs is, in many cases, awarded to programs that meet the specific eligibility requirements (e.g., a minimum number of reported cases or a mature name-based HIV reporting system) and that successfully compete for the activity. The other main components of CDC's surveillance program are listed below. The Technical Guidance and other

related procedural documents are available on the CDC Team Web site, https://team.cdc.gov.

- Enhanced Perinatal Surveillance: Through comprehensive review of maternal and pediatric medical records, this program monitors the impact of efforts to reduce mother-to-child transmission of HIV, prevention failures, and the efficacy of recommended treatments to reduce perinatal transmission to exposed children and prevent opportunistic infections among children who become infected.

- HIV Incidence Surveillance: HIV incidence surveillance was developed to provide reliable and scientifically valid estimates of the number of newly acquired HIV infections each year. Jurisdictions funded to conduct incidence surveillance collect testing and treatment history as a part of routine surveillance activities. In addition, sites work closely with commercial, private, public, and hospital-based laboratories to acquire remnant blood specimens to test for recent infection. The information collected through surveillance in combination with the results of additional testing allows jurisdictions and CDC to calculate population-based estimates for HIV incidence.

- Variant, Atypical, and Resistant HIV Surveillance (VARHS): Data from this system are used to estimate trends in the prevalence of drug-resistant strains of HIV among persons in whom HIV infection is newly diagnosed. Similar to HIV Incidence Surveillance, sites work to acquire and test remnant specimens from persons with newly diagnosed HIV infection, unless such testing has been done as a part of HIV care. Expanding laboratory surveillance to include reporting of resistance results is paramount.

- Medical Monitoring Project: This newly developing surveillance system will constitute a nationally representative sample of HIV-infected persons receiving medical care in the United States. The project uses HIV care providers to collect the data to supplement Core Surveillance data with linked medical record abstractions and patient interviews; provide data to estimate quality of care, clinical outcomes, risk behaviors, health-care use, and unmet needs among HIV-infected persons receiving medical care; and provide population-based data to aid in policy planning, resource allocation, and evaluation of prevention and treatment initiatives in the United States.

- The National HIV Behavioral Surveillance: The goal of this project is to measure an extensive set of HIV risk behaviors and related risk factors among selected high-risk populations. Through anonymous interviews and, in some cases, HIV testing, the project attempts to identify the prevalence of trends in risk behaviors among men who have sex with men, injection-drug users, and heterosexuals with high-risk behaviors.

Confidentiality

Confidentially is the cornerstone of all HIV/AIDS surveillance program activities. CDC's security and confidentiality guidelines are available at www.cdc.gov/hiv/topics/surveillance/resources/guidelines/guidance/index.htm. State and territorial laws to protect public health data apply to HIV/AIDS data as well. Data transferred to CDC should not contain any personal identifying information and should be encrypted. CDC requires that HIV/AIDS case data be maintained in physically secure environments with limited access by authorized personnel only. Each year, surveillance programs must certify compliance with the confidentiality and security requirements, confirm the program has written confidentiality agreements from and annual confidentiality training completed by all personnel, and identify the Overall Responsible Party.

Public health surveillance staff, including HIV surveillance staff, are exempt from Health Insurance Portability and Accountability Act (HIPPA) laws. A 2003 MMWR article, "HIPPA Privacy Rule and public health: guidance from CDC and the U.S. Department of Health and Human Services" (www.cdc.gov/mmwr/pdf/other/m2e411.pdf) provided guidance and documented the provisions that allow HIV surveillance programs to follow up on patient data for surveillance purposes.

CHAPTER

4

Surveillance Coordinator Description

Every health department is organized differently. In some locales, the HIV/AIDS surveillance program reports to the "AIDS Director," who is responsible for HIV-prevention and -services programs. In other areas, HIV/AIDS surveillance may be organized within the section that oversees surveillance of sexually transmitted diseases. In still others, HIV/AIDS surveillance may be organized in the general epidemiology section. Coordination with all of these programs is important.

The roles and responsibilities of the surveillance coordinator also differ between programs. In some areas the surveillance coordinator is responsible primarily for Core Surveillance activities; in others the surveillance coordinator oversees many or all of the HIV/AIDS surveillance activities and projects. Below is an example of a surveillance coordinator role with fairly comprehensive responsibilities and a delineation of the knowledge and skills the coordinator should have or be able to develop.

Essential Duties and Responsibilities:

The program must be guided and directed by an individual who is able to understand, observe, and evaluate the processes involved in HIV/AIDS surveillance; the individual must be able to coordinate and modify these processes as needed so that surveillance objectives are achieved. The surveillance coordinator must be able to determine and ensure the most efficient and effective use of resources; ensure appropriate protections to maintain the confidentiality and security of HIV/AIDS surveillance information; facilitate communication between the health department and reporting sources; maintain links with other HIV/AIDS public health programs; and interpret, present, and disseminate surveillance information. The Coordinator should ensure that the program has sufficient staff to perform all the required activities of an HIV surveillance program, including responding rapidly to data requests.

The person in charge of the surveillance program must ensure that the organization runs efficiently, staff are well-trained and competent, basic operations are stable and predictable, the unit meets the expectations of higher-level officials, and the results of the unit's work are effectively communicated within and outside of the health department. Specifically, the surveillance coordinators duties may include

- Administrative responsibility for all HIV/AIDS surveillance projects
- Preparing grant applications and progress reports for CDC
- Maintaining regular communication with the program's assigned CDC Program Consultant and Epidemiologist
- Programmatic responsibility for Core Surveillance activities, such as case ascertainment and completeness of required case information, investigations of cases of public health importance, database management, data analysis, and dissemination of data
- Oversight of other HIV/AIDS surveillance projects through the respective coordinators to ensure appropriate inclusion of cases or participants, adherence to protocols, data management, and data analysis
- Oversight of evaluation/validation studies to determine the completeness, timeliness, and accuracy of the surveillance system(s)
- Coordination between surveillance and other health department programs, coordination between surveillance and prevention programs, and coordination between surveillance and HIV care and treatment programs
- Internal Review Board review and approval, as necessary
- Timely analysis and dissemination of surveillance data through standard reports and publications, special reports and fact sheets, slide sets, and presentations; and respond to special data requests from the public, media, researchers, planning groups, and others as appropriate with confidentiality/security requirements and data analysis guidelines
- Coordination of the provision of technical support to the Community Prevention Planning Committees and Ryan White consortia
- Assurance of compliance with CDC and state security and confidentiality standards and procedures
- Hiring and supervision of personnel, and personnel evaluations

Recommended knowledge and skills include the following:

- Ability to communicate effectively orally and in writing
- Ability to coordinate the work of others, and provide leadership and program direction
- Familiarity with HIV disease process and pathology, surveillance case definitions, and public health issues related to HIV-infected adults and children
- Extensive knowledge of record keeping, budgeting, problem identification methods, program planning, consultation methods, and research methods, and the ability to apply these to HIV surveillance programs
- Knowledge of local, state, and federal laws and regulations related to HIV surveillance and confidentiality
- Working knowledge of the health-care–delivery system, including hospitals; clinics; laboratories; health department programs; state, county, and municipal agencies; prisons/jails; and

organizations that provide related supportive services
- Working knowledge of state and federal departments and agencies that have programs or services affecting HIV testing and counseling, including in-depth knowledge of the health department and its services and policies
- Familiarity with data management and analysis principles and software (e.g., Statistical Analysis Software

TIP:

Most surveillance components (Core, Incidence, VARHS, etc.) have developed Technical Guidance documents, including recommended staffing roles. Use the Technical Guidance, your CDC Epidemiologist, or a CSTE counterpart to help clarify the coordinator's responsibilities because they are particular to the different surveillance program components. The Guidance documents also provide helpful information about other roles that may be needed.

CHAPTER

5

Coordination with Key Public Health Partners

HIV Prevention and HIV Care and Treatment

HIV/AIDS surveillance has been the cornerstone of national efforts to monitor the transmission of HIV infection in the United States and to target HIV-prevention programs and health-care services. These programs use surveillance data are extensively to 1) identify what intervention programs are needed, 2) know where they are needed, 3) prioritize activities, 4) allocate funding, and 5) evaluate programs. Below is a brief overview of prevention and services programs and how they intersect with surveillance programs.

Prevention

Each jurisdiction's HIV-prevention program is organized differently. Programs may focus on a variety of HIV-prevention strategies and approaches, depending on the nature and size of the local epidemic and local political climate. Many areas invest state financial resources into their HIV-prevention programs in addition to support provided through cooperative agreement with CDC. Similar to surveillance, CDC funds prevention activities through cooperative agreements with states, cities, and territories, as well as some directly funded agencies. Components of prevention include counseling, testing, and referral); partner services; effective behavioral interventions; community, group, and individual-level Interventions; Structural Interventions; Health Communication/Public Information; and prevention of perinatal transmission. CDC's prevention plan can be found at www.cdc.gov/hiv/topics/prev_prog/AHP/default.htm. This plan may be updated in 2009 with the increased national focus on HIV prevention that followed release of the national HIV incidence estimate. For more information about this release, visit www.cdc.gov/hiv/topics/surveillance/resources/factsheets/response.htm.

- What do prevention programs need from surveillance?
  Surveillance data are essential to local planning and resource allocation. Through a process that involves representative community input, prevention programs are required to develop a comprehensive plan to prioritize local prevention activities. The goal is to ensure evidence-based, culturally competent HIV-prevention services that respond to community needs and priorities. Surveillance programs provide data and, if staff resources permit, technical assistance to this planning process. Some prevention programs also work closely with surveillance programs to identify individuals to be contacted for Partner Services.

- What do surveillance programs need from prevention programs?
  With HIV Counseling and Testing, a major focus of CDC's prevention strategy, local prevention programs are critical players in local HIV surveillance systems. Similar to any other diagnosing provider, surveillance programs must establish processes to ensure complete and timely reporting from Counseling/Testing programs. In addition, a strong partnership is necessary because changes in the area's Counseling/Testing program, such as the implementation of rapid testing or changes in the information collected during counseling, can directly impact surveillance programs' processes and programs (such as Incidence Surveillance). Partner Services programs can be a resource for surveillance programs, in particular with their ability to collect risk and other information needed for case investigations.

Care and Treatment

HIV care and treatment programs provide comprehensive HIV/AIDS care, treatment, and support services to people living with HIV or AIDS. Health departments may administer certain programs that are supported with state/local funds, but the largest source of funding, aside from Medicaid, comes from the federal Ryan White HIV/AIDS Treatment Modernization Act of 2006. The Health Resources and Services Administration administers the Ryan White funds through grants to states, cities, territories, and with some program components, direct funding to entities that successfully compete to provide a particular service. In addition, the Housing Opportunities for People Living with AIDS Program (HOPWA) has funding available through grants to support housing programs through the federal Department of Housing and Urban Development. See the Kaiser Family Foundation's brief for an overview of the Ryan White HIV/AIDS Treatment Modernization Act program components in Appendix II or download at www.kff.org/hivaids/upload/7582_04.pdf or visit http://hab.hrsa.gov/treatmentmodernization/. See www.hud.gov/offices/cpd/aidshousing/programs/ for information about HOPWA.

- What do care and treatment programs need from surveillance?
  Historically, allocation of federal funds under the Ryan White Program has been based on the reporting of AIDS cases to CDC, causing states to prioritize AIDS reporting over HIV reporting. Starting in 2007, formula-based funding for the various components is now determined using HIV and AIDS case data. The timeliness, completeness, and accuracy of your surveillance system directly impact funding locally and nationally. Supplemental funds are based on "demonstrated need," which, among other things, entails epidemiologic profile of the state and local HIV epidemic using surveillance data.

Surveillance data (through standard reports or special data requests) also are used at the local level for targeting programs and allocating resources. Many areas employ a planning process with community input, similar to prevention programs. Cities that receive Ryan White funding directly from HRSA (Part A programs) historically have engaged a representative planning council for planning and prioritization, and they are likely to request data from your program. Surveillance data also are used to estimate "unmet need" (the proportion of persons who have HIV but who are not accessing medical care).

- What do surveillance programs need from care and treatment programs?
  Services programs are important partners in your reporting system. At a minimum, reporting mechanisms should be established with the programs that provide clinical services (Part B programs). Part D programs are important partners for ensuring comprehensive case ascertainment of children perinatally exposed to HIV. Directly funded cities (Part A, Emerging Communities) and the state program (Part B) are key partners for ongoing reporting or periodic validation of the surveillance system. Where data collection and analysis for services planning and evaluation purposes are extensive, surveillance programs should consider partnering with those programs to share resources.

Other Partners

Many HIV/AIDS programs are linked with sexually transmitted disease (STD), tuberculosis (TB), and viral hepatitis programs. These four areas are housed under one center at CDC, the National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention (NCHHSTP) (refer to Appendix III for an overview). Having a collaborative relationship with these areas is important, regardless of whether, in your jurisdiction, they are closely related.

CHAPTER

6

Program Monitoring

Evaluation is the systematic collection of information about a program to make a judgment and guide decisions about that program. Evaluation should be an ongoing part of HIV surveillance. In 1999, CDC established key minimum performance standards required to ensure a rigorous HIV/AIDS surveillance system. HIV/AIDS surveillance systems should be evaluated routinely to ensure 1) accurate case counts with complete case ascertainment, 2) timely case reporting, and 3) maximal ascertainment of HIV transmission factors. To assist surveillance programs in measuring and achieving these minimum standards and to provide a framework for improving performance, in 2005, CDC and CSTE developed technical guidance for local and state health departments and conducted regional trainings for surveillance staff. These guidance documents outline structural requirements needed to achieve success in specific areas, process requirements or steps to be taken to achieve success, and outcomes to be measured to evaluate success.

The performance standards for surveillance activities usually are defined in the "Outcome Standards" or "Outcome Measures" of each subchapter in the Technical Guidance. A helpful summary of the standards for Core Surveillance activities that can be used to help surveillance coordinators understand the important measures at a glance is reproduced below from an article published by CDC and a state surveillance coordinator. Having high-quality data is critical for targeting prevention programs and for designing programs for persons in care. Refer to the next section of this manual that explains how surveillance programs support and inform prevention and care and treatment programs.

Process and outcome standards for HIV/AIDS case surveillance in the United States	
Process standards	Outcome
Death ascertainment	Routine record links of HIV/AIDS case reports (all cases without minimum death information) and death certificate records (most recent year of deaths available), once a year (minimum)
Intrastate duplicate review	To be conducted monthly
Interstate duplicate review	To be conducted at least semiannually
Outcome standards	
Completeness	≥85% of expected number of cases for a diagnosis year reported by 12 months after the diagnosis year
Timeliness	See time component of completeness standard On the basis of the time from date of diagnosis to the time of report to surveillance program (report date = date document was received at the health department or, if not available, date document was entered in the surveillance system), the minimum performance standard is ≥66% of cases for a diagnosis year reported within 6 months after diagnosis, assessed at ≥85% completeness 12 months after the diagnosis year
Edits	≥97% of case records pass all standard data edits. The standard is assessed for the most recent diagnosis year at 12 months after that diagnosis year
Risk factor ascertainment	≥85% of reported cases or a representative sample for a diagnosis year have an identified HIV risk factor within 12 months after the date of the initial HIV/AIDS case report, measured at 12 months after the diagnosis year
Proportion of death-certificate-only cases	≤5% of cases have only a death certificate for each diagnosis year. The standard is assessed at 24 months after the death/diagnosis year
Intrastate duplicates	≤5% duplicates, assessed for each diagnosis year at 12 months after the diagnosis year
Interstate duplicates	≤5% duplicates in the national database, assessed for each diagnosis year at 12 months after the diagnosis year
Data reporting and dissemination	Annual HIV/AIDS surveillance report published by the local or state surveillance program
CD4 reporting	For each calendar year, at least 50% of persons newly diagnosed as having HIV/AIDS who are aged ≥13 years, have an initial CD4 count (i.e., CD4 specimen collected within 3 months after HIV diagnosis) reported to the national HIV/AIDS surveillance system no later than 12 months after diagnosis
Source: H. Irene Hall and Eve D. Mokotoff for the Advisory Group for Technical Guidance on HIV/AIDS Surveillance (2007). Setting standards and an evaluation framework for human immunodeficiency virus/acquired immunodeficiency syndrome surveillance. Journal of Public Health Management and Practice, 13 (5):519–523.	

CHAPTER

7

Budgeting and Resource Management

As a surveillance coordinator, you must understand the federal and local funding sources that support your program. One of your tasks will be to learn about the status of all these programs and to understand the funding mechanisms for each of these funding sources, the budget period and reporting requirement for each, and how all of these sources of funding dovetail into the requirements for submitting your program's budget. Budget development can be challenging, in part because of the difference in fiscal years and grant years. For example, the federal fiscal year runs from October through September, but individual state fiscal years may differ. CDC runs on a calendar year, and the HRSA Ryan White Part B Program runs from April through March.

The federal government now requires that health departments apply at www.grants.gov for federal funding for any cooperative agreement, grant, or project. In general, notices about ongoing programmatic funding are sent from your assigned CDC Program Consultant, but you can be regularly informed of other opportunities for special projects and research studies. Some distinct and specific reporting requirements exist for different funding from different agencies and different types of funding. However, some concepts and requirements are uniform across all funding sources.

To better understand your program's funding, you can request a briefing from your CDC Program Consultant and Epidemiologist and, if you have local funding, from state or local officials.

Key terms include

- The Procurement and Grants Office (PGO) is an office within each U.S. Department of Health and Human Services (HHS) agency that sets policy regarding its funding mechanisms. A liaison from the program branch usually is assigned to work with PGO on the intersection of fiscal policy and programmatic concerns.
- Grants Management Specialists assist the Program Officer or Program Consultant with budgetary information and procedures.
- The grantee is defined as the recipient of the funding.
- Program Consultants are the program liaisons with your federal funding entity. This position functions like a contract monitor to ensure you comply with their funding requirements.
- An objective review is a blinded review by reviewers outside the agency's branch to score the application with an unbiased or "objective" eye. This review is usually done in the first year of a new program cycle.
- A negotiation is a call with the federal project officer and a PGO representative to review outstanding issues related to your application and any discrepancies in the budget.
- The Notice of Grant Award (NGA) is the official documentation of the amount of funding being awarded to your program. Read this carefully because it usually contains the reporting requirements for future progress reports. If you do not have a copy of the NGA, contact your CDC Program Consultant.
- Financial Status Reports are annual reports of expenditures, unobligated balances, and unliquidated obligated funds.
- Carry-over is the use of unobligated funds awarded but not obligated in a prior budget period. The current federal policy is that funds can be carried over only from the budget period immediately preceding the current one.

CHAPTER

8

CSTE: The Council of State and Territorial Epidemiologists

The Organization

CSTE is a professional association of public health epidemiologists working in state and local health agencies. CSTE comprises a diverse membership of public health professionals who work to establish more effective relationships among state and other health agencies. Technical advice is available, as is assistance to partner organizations, such as the Association of State and Territorial Health Officials (ASTHO), and to federal public health agencies, such as CDC. CSTE members have surveillance and epidemiology expertise in a broad range of areas including infectious diseases, immunizations, chronic diseases, environmental health, occupational health, injury control, and maternal and child health.

During the 1950s, Alexander Langmuir, CDC's first Epidemiology Division Director, recognized the importance of state input in decision making, and asked ASTHO to convene the state epidemiologists and charge them with the responsibility of deciding which diseases should be reported nationally. The first fully documented list of reportable diseases was generated at the Conference of State and Territorial Epidemiologists, held in 1951. CSTE continues to establish and endorse definitions for diseases and conditions and to recommend and determine procedures for state and nationwide morbidity and mortality reporting and voluntary reporting to CDC.

In August 1992, CSTE opened its national headquarters office in Atlanta, Georgia, with two employees. The national office programmatic and operational staff including research analysts, trained in epidemiology and public health, specializing in health policy, informatics, workforce development, and HIV/AIDS activities. CSTE is governed by a 10-member Executive Board comprising four officers and six members-at-large. Three of the members-at-large are epidemiologists who work in each of three areas: infectious diseases, chronic diseases, and environmental and occupational health. The CSTE Executive Board conducts quarterly 2-day meetings to provide a forum at which federal and state programs can collaborate on topics of mutual interest. An annual conference is held with breakout workshops and presentations on many different topics.

CSTE and CDC collaborate to improve the public's health by supporting the efforts of epidemiologists working at the state and local levels and by promoting the effective use of epidemiologic data to guide and improve public health practice.

Surveillance Coordinators and CSTE

Since 2003, the HIV/AIDS surveillance coordinators have been members of CSTE's infectious disease committee with the key purpose of having a unified voice for communicating with CDC. The HIV/AIDS surveillance coordinator subcommittee has grown to include activities such as establishing and strengthening partnerships with CDC; promoting best practices in surveillance; ensuring the presence of surveillance support in other groups such as ASTHO and the National Alliance of State &Territorial AIDS Directors; and promoting the importance of HIV/AIDS surveillance. In achieving these goals, the subcommittee has written and submitted position statements, developed an epidemiologic capacity survey, assisted in the development of CDC's Partner Services Guidelines, and co-written Surveillance Technical Guidance documents with CDC.

CSTE membership is open to all public health professionals that practice epidemiology at the local, state, and territorial public health levels. CSTE encourages all surveillance coordinators to become CSTE members. Because types of membership vary, refer to www.cste.org for more information.

How Can CSTE Help You?

- Program Forum
  www.cste.org/dnn/ProgramsandActivities/CSTEProgramForums/tabid/202/Default.aspx
  The CSTE Web site includes a discussion board called "CSTE Program Forums" for members and registered guest users. The program forum is a hybrid of a listserv and a discussion board. Benefits of this technology include being able to see everyone's questions and answers, getting email notifications of a post, creating and tracking conversations, and gaining access to past documents.

- E-mail distribution lists
  CSTE maintains an e-mail distribution list for HIV surveillance purposes. to distribute important and timely information. CSTE members may join an HIV/AIDS interest distribution list for other more general issues that are distributed by CSTE subcommittee leadership and the National Office.

- HIV Contact Board
  www.cste.org/dnn/ProgramsandActivities/HIVContactBoard/tabid/211/Default.aspx
  CSTE maintains an HIV Contact Board on its Web site for health departments to view the contacts for HIV-related personnel. The contact board is accessible through the link above. CSTE staff can delete obsolete contacts, but states themselves can edit and update contact information as needed. Each

state has a state-specific log in and password, which differs from the member-specific log in and password for the CSTE general Web site. This site and the list of contacts for different surveillance purposes, such as Routine Interstate Duplicate Review, is extremely important to maintaining security and confidentiality, and surveillance coordinators should update it regularly.

- Peer-to-Peer technical assistance
  Peer-to-peer technical assistance is available to help new surveillance coordinators gain valuable information, experience, resources, and mentorship. This program allows new surveillance coordinators to visit another site for one-on-one training with an experienced HIV surveillance coordinator. You may want to visit a site whose program may be similar to yours in size of the epidemic or staffing structure. Surveillance coordinators seeking peer-to-peer technical assistance can identify a site to visit on their own or with CSTE's help and should be prepared to write a brief description of the anticipated goals of the training. After the site is chosen, the surveillance coordinator visits the site once; ongoing follow-up contact may continue after the site visit. Participants in this program write a short report describing their experience. CSTE funding makes this program possible; contact the CSTE office for more information.

CHAPTER

9

Key National Advocacy Organizations

The National Alliance of State & Territorial AIDS Directors (NASTAD) represents the nation's chief state health agency staff who have programmatic responsibility for administering HIV/AIDS health-care, prevention, education, and supportive service programs funded by state and federal governments. NASTAD is dedicated to reducing the incidence of HIV/AIDS infection in the United States and its territories, providing comprehensive, compassionate, and high-quality care to all persons living with HIV/AIDS, and ensuring responsible public policies. NASTAD provides national leadership to achieve these goals and to educate about and advocate for the necessary federal funding to achieve them, as well as to promote communication between state and local health departments and HIV/AIDS care and treatment programs. NASTAD supports and encourages the use of applied scientific knowledge and input from affected communities to guide the development of effective policies and programs. The CSTE HIV/AIDS Sub-Committee works closely with NASTAD to help ensure coordination of efforts related to HIV surveillance. Additional information about the organization can be found at www.nastad.org.

The Communities Advocating Emergency AIDS Relief (CAEAR) Coalition represents 420 grantees under Part A and Part C of the Ryan White HIV/AIDS Program, including the 56 major metropolitan areas most adversely affected by the HIV/AIDS epidemic, as well as providers and consumers of Ryan White CARE Act-funded services. The CAEAR Coalition also advocates for adequate funding for the AIDS Drug Assistance Program in Part B of the CARE Act. As a leading voice in Washington, DC, for HIV/AIDS care and treatment for over a decade, the CAEAR Coalition has led the successful annual federal appropriation advocacy effort for Part A and Part C of the Ryan White Program. Additional information about the organization can be found at www.caear.org.

The AIDS Alliance is the advocacy group representing Ryan White Part D Programs. Additional information about this organization can be found at www.aids-alliance.org.

The Urban Coalition for HIV/AIDS Prevention Services (UCHAPS) consists of a coalition of community members and health departments from the seven cities directly funded by CDC to implement local HIV-prevention programs (Chicago, Houston, Los Angeles County, New York City, Philadelphia, San Francisco, and Washington, DC). UCHAPS' activities include advocacy, technical assistance, and technology transfer activities among member jurisdictions. Additional information about the organization can be found at www.aidsaction.org/uchaps.

The Association of State and Territorial Health Officials (ASTHO) is the national nonprofit organization representing the state and territorial public health agencies of the United States, the U.S. territories, and the District of Columbia. ASTHO's members, the chief health officials of these jurisdictions, are dedicated to formulating and influencing sound public health policy, and to ensuring excellence in state-based public health practice. Additional information about the organization can be found at www.astho.org.

The National Associations of County and City Health Officials (NACCHO) is the national organization representing local health departments. NACCHO supports efforts that protect and improve the health of all people and all communities by promoting national policy, developing resources and programs, seeking health equity, and supporting effective local public health practice and systems. Additional information about the organization can be found at www.naccho.org.

Appendix I: CDC fact sheet

HIV/AIDS Surveillance

CDC HIV/AIDS Facts

July 2008

Through its national HIV/AIDS surveillance system, CDC can monitor many aspects of the HIV/AIDS epidemic, including HIV/AIDS and AIDS diagnoses, deaths among persons with AIDS, people living with HIV/AIDS or AIDS, and beginning in 2008, the number of new HIV infections. All of these components work together to provide the most complete profile of the epidemic that is possible.

Definitions

CDC publishes reported and estimated data for HIV and AIDS.

Reported cases are those that CDC receives from state and local health departments. As of 2008, all 50 states, the District of Columbia, and five US dependent areas report HIV cases to CDC.

Reported cases reflect the number of cases reported in a given year, regardless of when they were diagnosed. They are useful for monitoring the reporting and validity of a surveillance system and are the basis of the estimated cases.

Estimated cases are the reported cases after CDC has applied appropriate adjustments to them. Only states that have been conducting name-based HIV surveillance for at least four years (to date, 33 states and 5 areas) are included in the estimated data in order to allow for data adjustments and stabilization of the data. Estimated cases are considered a more accurate reflection of the epidemic than reported data because they are adjusted for reporting delays.

Estimated cases reflect the number of cases diagnosed in a given time period and are useful for planning, resource allocation, and program evaluation.

CDC monitors data on HIV, HIV/AIDS, and AIDS. Within those categories, it monitors diagnoses, deaths, prevalence, and incidence.

HIV/AIDS diagnoses are the number of individuals diagnosed with HIV, at any stage of disease, in a given time period.

- The current CDC surveillance report contains reported HIV/AIDS cases from 45 states with confidential name-based HIV infection reporting as of 2006. As of 2008, all 50 states, the District of Columbia, and five US dependent areas are now reporting HIV/AIDS cases to CDC. These data will be included in future reports.
- Estimated HIV/AIDS diagnoses currently include the 33 states with long-term name based HIV reporting (mature HIV surveillance systems) and 5 US dependent areas. The number of states represented in the estimated diagnoses will increase in the coming years as the surveillance systems mature from the states that only recently implemented a name-based surveillance system. In 2012, all 50 states, the District of Columbia, and the 5 US territories will be represented in CDC's estimated data.

Uses of these data: HIV/AIDS diagnoses data have historically served as a marker for new HIV infections (incidence). However, a person can be infected with HIV for a long time before receiving a diagnosis. Therefore, and particularly with the establishment of the new HIV incidence system, HIV/AIDS diagnoses are now best used to monitor the epidemic in younger people, who will not have been infected for very long, as well as to help correlate and monitor testing and treatment patterns. HIV/AIDS diagnoses data are also useful to monitor the HIV epidemic in local areas that do not have HIV incidence surveillance at this time. HIV diagnoses data are the basis for the incidence calculations.

AIDS diagnoses and deaths of individuals with AIDS are the number of individuals diagnosed with AIDS and the number of individuals with AIDS who have died in a given time period.

- Reported AIDS cases and deaths among persons with AIDS are from 50 states, the District of Columbia, and US dependent areas.
- Estimated AIDS diagnoses and deaths among persons with AIDS are from 50 states, the District of Columbia, and US dependent areas. Because all areas implemented AIDS reporting in the early 1980s, their AIDS data can be adjusted to arrive at the estimations.

Uses of these data: AIDS diagnoses and AIDS death data provide trends since the beginning of the epidemic and are useful to track the time from an HIV diagnoses to an AIDS diagnoses and/or death. Discrepancies between populations in time from HIV diagnoses to AIDS diagnosis or time to AIDS death will point out inequities in access to testing and care; this knowledge can help direct resource allocation.

HIV/AIDS prevalence and AIDS prevalence are the number of people living with HIV/AIDS or AIDS in a given population. CDC reports prevalence as the number of people living with HIV/AIDS or AIDS and also prevalence rates, usually calculated per 100,000 people.

Uses of these data: Prevalence is useful for planning and resource allocation. Prevalence rates are useful for comparing HIV/AIDS between populations and for monitoring trends over time.

HIV incidence is the number of new HIV infections in a specific population during a specific time period.

Uses of these data: Incidence estimates are useful for planning and allocation of funds, as well as evaluating the impact of prevention programs.

	YEARS	PROCESS	WHO PARTICIPATES	WHAT THE DATA TELL US	WHY THEY ARE IMPORTANT
AIDS Surveillance Data	1981-present	CDC receives standardized data from states, the District of Columbia, and US dependent areas. This is called reported data. CDC makes adjustments to the reported data to allow for trend comparisons and to compensate for missing information, reporting delays, or duplications. The resulting data are the estimated data.	Reported data: 50 states, District of Columbia, US dependent areas. Estimated data: 50 states, District of Columbia, US dependent areas.	The number of people, as reported to CDC, who were diagnosed, living with, or who died with AIDS in a certain time period. CDC adjusts the reported data and provides the estimated numbers of people who were diagnosed, living or who died with AIDS in a certain time period.	Knowing how many people are diagnosed with AIDS each year is important to planning and resource allocation and for monitoring trends within the epidemic and discrepancies between groups. For example, a short time between HIV diagnoses and AIDS diagnoses could imply that members of a group may not have the same access to testing or care as members of a group with a longer time between an HIV diagnoses and an AIDS diagnoses.
HIV/AIDS Surveillance Data	1985-present	In 1985, the diagnostic test for HIV was licensed. Over time, states have implemented HIV surveillance along with their AIDS surveillance. In 1994, CDC integrated the HIV reporting and AIDS reporting data systems; 25 states were initially included. CDC receives standardized data from the states, the District of Columbia, and US dependent areas. This is called reported data. CDC makes adjustments to the reported data to allow for trend comparisons and to compensate for missing information, reporting delays, or duplications. The resulting are the estimated data.	Reported data: 50 states, District of Columbia, US dependent areas.* Estimated data: 34 states, 5 US dependent areas.* * The current surveillance report, which uses 2006 data, has reported cases from 45 states and 5 US dependent areas and estimated data from 33 states and 5 US dependent areas.	The number of people, as reported to CDC, who were diagnosed or living with HIV/AIDS in a certain time period. CDC adjusts the reported data and provides the estimated numbers of people who were diagnosed or living with HIV/AIDS during a certain time period.	HIV/AIDS diagnoses have often served as a marker for new HIV infections (incidence). However, a person can be infected with HIV for a long time before receiving a diagnosis. Therefore, HIV diagnoses are best used to monitor the epidemic in younger people, who will not have been infected for very long, as well as to help correlate testing and treatment patterns with estimated HIV/AIDS diagnoses.
Prevalence Estimate	1981-Present	CDC receives standardized data from states and dependent areas. After adjustments, prevalence estimates are derived. Estimated HIV/AIDS prevalence in CDC's surveillance reports is limited to those states with long-term, name-based HIV reporting. Other publications calculate prevalence estimates for the entire United States.	AIDS: 50 states, District of Columbia, US dependent areas. HIV/AIDS: 34 states, US dependent areas.* *The current surveillance report, which uses 2006 data, has data from 33 states and 5 US dependent areas.	The number of people living with HIV or AIDS in specific areas, including the entire United States.	Knowing how many people are living with HIV/AIDS is important for planning purposes, allocations of funds, and monitoring the epidemic. A growing number of people living with HIV/AIDS mean that treatment regimens are enabling more people to live longer after a diagnosis of HIV/AIDS. It also means a larger pool of people who can potentially transmit the virus.
HIV Incidence Estimate	2008	A laboratory test (STARHS) that can determine recent from long-standing HIV infections is applied to blood samples from newly diagnosed HIV/AIDS cases in certain states in the HIV/AIDS reporting system. These findings are then extrapolated to the United States.	22 states	The number of people newly infected with HIV in a given year.	Knowing how many new infections occur each year is vital to planning and allocation of funds, as well as to evaluating the success of prevention programs.

For more information on HIV/AIDS surveillance, visit http://www.cdc.gov/hiv/topics/surveillance.

HIV/AIDS RESOURCES

CDC HIV/AIDS
http://www.cdc.gov/hiv
CDC HIV/AIDS resources

CDC-INFO
1-800-232-4636
Information about personal risk and where to get an HIV test

CDC National HIV Testing Resources
http://www.hivtest.org
Location of HIV testing sites

CDC National Prevention Information Network (NPIN)
1-800-458-5231
http://www.cdcnpin.org
CDC resources, technical assistance, and publications

AIDSinfo
1-800-448-0440
*http://*www.aidsinfo.nih.gov
Resources on HIV/AIDS treatment and clinical trials

Appendix II: KFF Fact Sheet

THE HENRY J. KAISER FAMILY FOUNDATION

HIV/AIDS

HIV/AIDS POLICY FACT SHEET

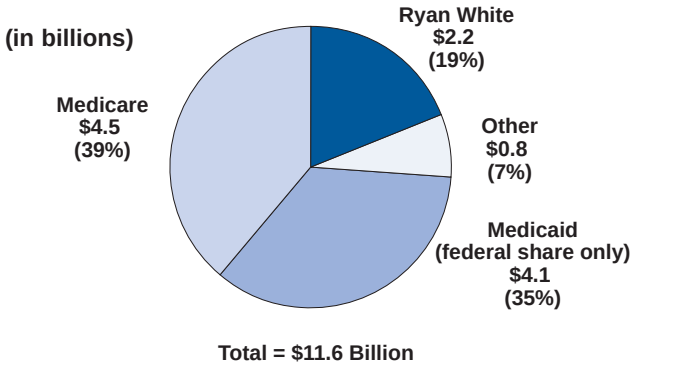
The Ryan White Program

June 2008

The Ryan White HIV/AIDS Program is the single largest federal program designed specifically for people with HIV/AIDS in the United States. First enacted in 1990, it provides care and support services to individuals and families affected by HIV/AIDS, functioning as the "payer of last resort"; that is, it fills the gaps in care for those who have no other source of coverage or face coverage limits. Federal Ryan White grant funding, which must be appropriated by Congress each year, is provided to cities, states,[1] and directly to providers and other organizations. The Ryan White Program has been reauthorized by Congress three times since 1990 – in 1996, 2000, and 2006 – and is due to be reauthorized again in 2009.[2]

As the number of people living with HIV/AIDS in the U.S. has grown over time, the Ryan White Program has played an increasingly critical role in HIV care. Administered by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services, the program is estimated to reach more than half a million people with HIV each year.[3] It is the third largest source of federal funding for HIV/AIDS care in the U.S., after Medicare and Medicaid (see Figure 1).[4] In addition to federal Ryan White funding, some states and localities also provide funding to their Ryan White services (including through state matching funds requirements in certain cases).

Figure 1: Federal Funding for HIV/AIDS Care by Program, FY 2008[4]



Ryan White Parts, Grantees, & Structure

The Ryan White Program consists of several "Parts" (formerly referred to as Titles), through which funding is provided across the country (see Figure 2). Eligible entities for funding vary by Part, and include states, cities, and directly-funded public and private providers, community-based organizations (CBOs), and other institutions. Most funding is provided to states (55% in FY 2008) followed by cities (29%),[4] with the remainder provided directly to organizations. Much of the funding provided to states and cities is in turn channeled to local providers as well. Community-based organizations make up the largest single group of Ryan White-funded entities serving clients (45% in 2004).[5]

In recognition of the varying and changing nature of the HIV/AIDS epidemic, Ryan White grantees have been given discretion to design many aspects of their local programs, including setting client eligibility requirements and service priorities. For the first time, however, the recent reauthorization[6] of the Ryan White Program added a requirement that at least 75% of funds be spent on "core medical services" under Parts A through C (see Figure 3) and a minimum formulary requirement under the AIDS Drug Assistance Program (ADAP). In addition, funding distribution for Parts A and B is now based on living HIV and AIDS cases, instead of estimated living AIDS cases (the prior method). Such data are only permitted from states that have name-based HIV reporting systems; states with former code-based systems can receive an exemption, and are allowed up to 4 years to complete their transition to names, but their code-based counts will be reduced for funding purposes in the interim (as of April 2008, all states had implemented a name-based system).[6,7] The major Parts of the Ryan White Program are:[6]

- **Part A:** Funds to "eligible metropolitan areas" (EMAs), those with cumulative total of more than 2,000 reported AIDS cases over most recent 5-year period, and "transitional grant areas" (TGAs), those with 1,000–1,999 reported AIDS cases over most recent 5-year period. Two-thirds of funds are distributed by formula based on an EMA or TGA's share of living HIV and living AIDS cases; the remainder is distributed via competitive, supplemental grants based on "demonstrated need". At least 75% of Part A funds must be spent on core medical services. EMAs are required to establish Planning Councils, local bodies tasked with assessing needs, developing a plan for the delivery of HIV care, and setting priorities for the allocation of funds. TGAs are not required to have Planning Councils (unless they are "grandfathered"[8] EMAs).
- **Part B:** Funds to all 50 States, the District of Columbia, Puerto Rico, Guam, the U.S. Virgin Islands, and 5 other territories and associated jurisdictions. States provide services directly (e.g., health department clinics), through sub-grantees, and/or through Part B "Consortia" (associations of organizations set up to plan for and deliver HIV care). At least 75% of funds must be spent on core medical services. Part B components include:
  - *Base & Supplemental:* Funds distributed by formula to states based on a state's share of living HIV and AIDS cases, weighted to reflect the presence or absence of EMAs/TGAs. Part B "supplemental" grants are available for states with "demonstrated need."[9]

Figure 2: Ryan White Program by Part, Funding & Grantees[3,4,10,11]

Part	FY 2008		Number of Grantees
	$	%	
Part A	$627.1	29%	22 EMAs; 34 TGAs
Part B	$1,195.2	55%	59 States/Territories; 19 ECs
ADAP (non-add)	*$794.4*	--	59 States/Territories
Part C	$198.8	9%	357 EIS, 22 Capacity/Planning
Part D	$73.7	3%	90 Grantees
Part F AETC	$34.1	2%	4 National, 11 Regional Centers
Part F Dental	$12.9	1%	65 Reimbursement; 12 Partnership
Part F SPNS	$25.0	1%	54 Grantees
TOTAL	$2,166.8	100%	

- *ADAP & ADAP Supplemental:* Funds are "earmarked" under Part B by Congress for state ADAPs to provide medications to people with HIV/AIDS (or pay for health insurance that provides medications). ADAP supplemental grants available to states with "severe need" (5% of earmark reserved).
- *Emerging Communities (ECs):* A portion of Part B base funds set-aside for grants to ECs, metropolitan areas that do not yet qualify as EMAs or TGAs, but have 500–999 cumulative reported AIDS cases over most recent 5 years. All funding is distributed via formula using all living HIV/AIDS cases in all eligible ECs.

- **Part C:** 75% of funds must be spent on core medical services. Public and private organizations are funded directly for:
  - *Early Intervention Services (EIS):* to reach people newly diagnosed with HIV. Services include HIV testing, case management, and risk reduction counseling.
  - *Capacity Development & Planning Grants:* to support organizations in planning for service delivery and building capacity to provide services.
- **Part D:** Funds to public and private organizations to provide family-centered and community-based services to children, youth, and women living with HIV and their families. Services include outreach, prevention, primary and specialty medical care, and psychosocial services; also supports activities to improve access to clinical trials and research for these populations.
- **Part F:** Includes the following three components:
  - *AIDS Education and Training Centers (AETCs):* national and regional centers that provide education and training for health care providers who treat people with HIV/AIDS;
  - *Dental Programs:* Includes the Dental Reimbursement Program, which reimburses dental schools/dental care providers serving clients with HIV, and the Community-based Dental Partnership Program, which funds programs to increase access to dental care for people with HIV and to provide education and training to dental care providers.
  - *Minority AIDS Initiative (MAI):* The MAI, created in 1998 in response to growing concern about the impact of HIV/AIDS on racial and ethnic minorities in the United States, provides funding across several DHHS agencies/programs, including Ryan White, to strengthen organizational capacity and expand HIV-related services in minority communities. The Ryan White component of the MAI was codified in the recent reauthorization. In FY 2008, the MAI was funded at $402.6 million including $135.1 million through Ryan White.[4]
  - *Special Projects of National Significance (SPNS):* address emerging needs of clients and assist in developing standard electronic client information data system. SPNS is funded through "set-asides" of general Public Health Service evaluation funding, separately from the amount appropriated by Congress for Ryan White.

Figure 3: Core Medical Services (75% of funds under Parts A through C)[6]

Outpatient and ambulatory health services; medications; pharmaceutical assistance; oral health care; early intervention services; health insurance premium and cost sharing assistance for low-income individuals; home health care; medical nutrition therapy; hospice services; home and community based health services; mental health services; substance abuse outpatient care; and medical case management, including treatment adherence services.

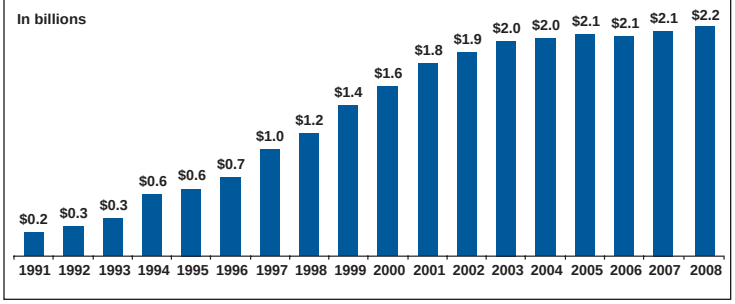
Ryan White Program Clients

HRSA estimates that more than half a million people receive at least one medical, health, or related support service through Ryan White each year; many clients receive services from multiple parts of Ryan White. Most Ryan White clients are low-income, with nearly three-quarters (72%) having annual household incomes at or below the poverty level,[5] and most are either uninsured (33%) or underinsured (56%).[3] Clients are primarily male (although one-third of those served are women), between the ages of 25 and 44, and most are people of color (72%).[3,5] Looking at the ADAP program specifically, which had close to 146,000 enrollees last year, 43% of clients had incomes at or below the poverty level and two-thirds (69%) were uninsured.[12]

Funding for the Ryan White Program [4,13]

Federal funding for the Ryan White Program began in FY 1991 and increased significantly in the mid-nineties, primarily after the introduction of highly active antiretroviral therapy (HAART). Over the last 10 years, funding has increased but at a slower rate, with most increases being targeted to ADAPs, for the provision of medications.

Figure 4: Federal Funding for the Ryan White Program, FY 1991–2008[3,4,13,14]



The Future Outlook

The Ryan White HIV/AIDS Program, first enacted as an emergency measure, has grown to become a main part of the fabric of HIV care and services in the United States, playing a critical role in the lives of low-income people with HIV/AIDS who have no other source of care. However, because it is a discretionary federal grant program, its funding depends on annual appropriations by Congress, and funding levels do not necessarily correspond to the number of people who need services or the actual costs of services. As a result, not all states and communities can meet the needs of all people living with HIV/AIDS in their jurisdictions. In addition, as payer of last resort, the Ryan White care system is sensitive to the current capacity of and changes in the larger health care system around it. Recent signs of a new economic downturn at the national and state levels, for example, may mean increased demands on Ryan White-funded services at a time when less funding is available for the program. Finally, changes made to the program during the most recent reauthorization are just now beginning to be felt at the state and local levels, and it will be important to monitor their impact on people with HIV/AIDS, their providers, and communities over time.

References

1 The term "state" used here includes territories and associated jurisdictions.
2 For legislative history, see: http://hab.hrsa.gov/law/leg.htm.
3 DHHS HRSA, Justification of Estimates for Appropriations Committee, FY 2009
4 OMB and DHHS Office of the Budget, April 2008.
5 HRSA, *Ryan White CARE Act Annual Data Summary* (CY 2004), August 2006.
6 Ryan White HIV/AIDS Treatment Modernization Act of 2006 (Public Law 109-415, December 19, 2006).
7 CDC, *Current Status of HIV Infection Surveillance*, as of April 2008.
8 Grandfathered EMAs are those that move from EMA to TGA status, based on their reported AIDS cases.
9 The Part B Supplemental has never been used due to lack of funding.
10 HRSA, HIV/AIDS Bureau, personal communication, May 2008.
11 HRSA: www.hrsa.gov.
12 KFF/NASTAD, *National ADAP Monitoring Project Annual Report*, April 2008.
13 HRSA, HIV/AIDS Bureau, http://hab.hrsa.gov/reports/funding.htm.
14 Includes funding for SPNS.

The Kaiser Family Foundation is a non-profit, private operating foundation dedicated to providing information and analysis on health care issues to policymakers, the media, the health care community and the general public. The Foundation is not associated with Kaiser Permanente or Kaiser Industries.

Additional copies of this publication (#7582-04) are available on the Kaiser Family Foundation's website at www.kff.org.

Appendix III: Federal Government Infrastructure for HIV/AIDS Initiatives

In the Executive Branch of the federal government, which includes the Department of Health and Human Services (HHS), the White House drives both national and international HIV/AIDS policies. Generally, HIV/AIDS prevention, services, and surveillance programs are coordinated and funded through HHS, which encompasses many other organizations, such as CDC, HRSA, the National Institutes of Health, and the Center for Medicaid and Medicare Services.

At CDC, the National Center for HIV/AIDS, Viral Hepatitis, STD and TB Prevention (NCHHSTP), within the Coordinating Center for Infectious Diseases, is responsible for public health surveillance, prevention research, and programs to prevent and control HIV/AIDS. Center staff collaborate with government and nongovernment partners at community, state, national, and international levels, applying well-integrated programs of research, surveillance, technical assistance, and evaluation. More information can be found at www.cdc.gov/nchhstp/. Within the NCHHSTP are the Divisions of HIV/AIDS Prevention (DHAP). The DHAP Intervention Research and Support branch (DHAP-IRS) includes the branches that oversee prevention programs, the DHAP Surveillance and Epidemiology Branch (DHAP-SE) includes the HIV Incidence and Case Surveillance Branch (HICSB) and the Behavioral and Clinical Surveillance Branch, which oversee the main surveillance program components that local surveillance programs administer. Be sure to visit the DHAP Web site at www.cdc.gov/hiv/aboutDHAP.htm for additional information about DHAP programs and activities and a link to a current organizational chart.

Housed within HRSA, the HIV/AIDS Bureau administers the programs and resources of the Ryan White Program, which provides care and treatment services for people living with HIV/AIDS. An overview of the various Ryan White Program components has been developed by the Kaiser Family Foundation (see Appendix II or www.kff.org/hivaids/upload/7582_04.pdf). Surveillance Coordinators should have a good working understanding of these program components and the data needed by the programs for planning, evaluation, grant applications, and special reports.

Below is a brief overview of some of the major U.S. government departments and offices that coordinate activities and programs related to HIV/AIDS.

Administration

- White House Office of National AIDS Policy (ONAP) drives the HIV/AIDS policy in the Executive Branch. ONAP's stated mission is to coordinate an integrated approach to domestic AIDS policy. Information at www.whitehouse.gov/infocus/hivaids/.

- President's Emergency Plan for AIDS Relief (PEPFAR) initiative—global response to HIV/AIDS. Information at www.pepfar.gov/.

- U.S. Global AIDS office in the Administration: www.whitehouse.gov/ask/20061201.html.

U.S. Department of Health and Human Services (HHS)

- Office of HIV/AIDS Policy (OHAP) is the principle office advising the Assistant Secretary of Health on HIV/AIDS programs across HHS agencies. Information at www.hhs.gov/ophs/ohap/index.html.

- President's Advisory Council on HIV/AIDS (PACHA) is an independent body that provides recommendations to HHS Secretary on domestic and global HIV/AIDS programs. Information at www.pacha.gov/aboutus/.

• CDC-HRSA AIDS Advisory Council (CHAAC) is convened to provide input and make recommendations to CDC and HRSA on their HIV and STD prevention and treatment activities and programs.

• Centers for Disease Control and Prevention (CDC)
  National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention: www.cdc.gov/nchhstp/
  Surveillance and Prevention: www.cdc.gov/hiv
  STDs: www.cdc.gov/std/
  Global AIDS Program: www.cdc.gov/globalaids/default.html

• Health Resources and Services Administration (HRSA)
  HIV/AIDS Bureau (responsible for administering the Ryan White Program): http://hab.hrsa.gov/

• Center for Medicaid and Medicare Services (CMS) administers the Medicare and Medicaid programs. The Medicaid program is a needs-based entitlement program jointly funded by the federal and state governments and run by the states. Medicare is an entitlement insurance program for the elderly and disabled. Both Medicare and Medicaid provide prescription drug coverage. State AIDS programs often have to navigate a complex system to provide "wrap-around services" for the shortfalls that individuals on Medicaid/Medicare experience with these programs. Many surveillance programs have been able to establish data sharing agreements to allow one-time or ongoing matching with Medicaid for the purposes of case ascertainment or evaluation of the area's HIV case surveillance system Information at www.cms.hhs.gov/.

• Substance Abuse and Mental Health Services Administration (SAMHSA) houses the Center for Substance Abuse Prevention, the Center for Substance Abuse Treatment, and the Center for Mental Health Services. They provide grants and funding to states and include a strong focus on the co-occurring epidemics. Substance Abuse Prevention and Treatment Block Grant recipients with an AIDS case rate of 10 per 100,000 of population or greater are required to set aside 2%–5% of their annual Block Grant funding for HIV Early Intervention Services. SAMHSA receives Minority AIDS Initiative funding. Most recently, SAMHSA has funded rapid HIV testing initiatives. They also offer technical assistance and mental health grants. Information at www.samhsa.gov/Matrix/matrix_HIV.aspx.

• Office of Minority Health (OMH) is housed in the office of the HHS Secretary and focuses on minority health. OMH has periodic grant opportunities and many resources, including capacity building, conferences, information and referrals, a knowledge center, OMH newsletters, regional offices of minority health and a network of resource persons. Information at www.omhrc.gov/.

• The Indian Health Service (IHS) is responsible for providing health care services to American Indians and Alaska Natives in tribes and through urban Indian programs. The Consultant for the HIV/AIDS program primarily provides consultative services to IHS, tribal, and urban Indian facilities on HIV/AIDS issues. Information at www.ihs.gov/MedicalPrograms/HIVAIDS/index.cfm?module=program#top

• The Food and Drug Administration (FDA) regulates HIV/AIDS therapies and medications, HIV diagnostic tests (including the test used for STARHS), and other HIV/AIDS related products. Information at www.fda.gov/oashi/aids/hiv.html.

• The National Institutes of Health (NIH) is the federal agency responsible for medical research. Through 27 institutes and centers, NIH conducts or supports/funds research on the range of health issues that impact the nation's health. Information at www.nih.gov/. The following link includes information specifically about HIV. Of most relevance to HIV/AIDS and viral hepatitis, the National Institute of Allergies and Infectious Diseases conducts and supports basic and applied research on infectious diseases that has led to "therapies, vaccines, diagnostic tests and other technologies" that impact HIV/AIDS: www3.niaid.nih.gov/about/organization/daids/default.htm.

U.S. Department of Housing and Urban Development (HUD)

• HUD administers the Housing Opportunities for Persons Living with HIV/AIDS (HOPWA) program, which provides formula and competitive grants to states and localities to provide affordable housing to people living with HIV/AIDS. Information at www.hud.gov/offices/cpd/aidshousing/programs/.

U.S. Department of Veterans Affairs (VA)

• The VA is the federal agency that oversees the federal laws and regulations regarding veterans of the U.S. Armed Services. In addition the VA provides health care and benefits to the nation's military veterans and their families and/or survivors. Within the VA is an HIV Program focused on dissemination of information to patients and for clinicians on HIV/AIDS. They also provide hepatitis C services. Historically, many surveillance programs have had difficulties in establishing and/or maintaining case reporting from VA facilities because of a lack of clear permission or directive to report HIV/AIDS cases. Information at www.hiv.va.gov/.

U.S. Agency for International Development (USAID)

• USAID supports the implementation of PEPFAR in nearly 100 countries. Information at www.usaid.gov/our_work/global_health/aids/.

Appendix IV: Resources and Tools

Planning resources

- Creating reasonable, achievable goals for grant applications and general planning
  www.cdc.gov/dhdsp/state_program/evaluation_guides/smart_objectives.htm
- Strategic planning
  http://ctb.ku.edu/en/tablecontents/chapter_1007.htm
  www.sph.emory.edu/cphp/futures/
- Emergency preparedness
  www.bt.cdc.gov/planning/
  www.bt.cdc.gov/planning/responseguide.asp

Federal government resources:

- CDC HIV site: www.cdc.gov/hiv/
- CDC surveillance site: www.cdc.gov/hiv/topics/surveillance/index.htm
- Revised case definition for HIV infection in adults and children: www.cdc.gov/mmwr/preview/mmwrhtml/rr4813a1.htm
- U.S. government information about HIV/AIDS: www.aids.gov/
- National Institutes of Health MedlinePlus: http://medlineplus.gov/
- Grant Web site for the federal government: www.grants.gov
- HARS/eHARS Help desk: dhaphars@cdc.gov, or (877) 659-7725
- CDC Procurement and Grants Office (PGO): (770) 488-2800
- CDC assigns each surveillance jurisdiction a Program Consultant and a Technical Assistance Epidemiologist. If you do not have a listing of these individuals, call the HIV Incidence and Case Surveillance Branch main number: (404) 639-2050 for additional information.
- HICSB Cases Of Public Health Importance (COPHI): (404) 639-2050

CSTE resources:

- Council of State and Territorial Epidemiologists: www.cste.org
- CSTE's HIV Contact Board: www.cste.org/dnn/ProgramsandActivities/HIVContactBoard/tabid/211/Default.aspx

Partner organization resources:

- National Alliance of State & Territorial AIDS Directors: www.nastad.org
- National Coalition of STD Directors: www.ncsddc.org
- UN Program on HIV/AIDS: www.unaids.org/en/
- Kaiser Family Foundation: www.kff.org/hivaids/index.cfm
- International AIDS Society: www.iasociety.org/

Other sources of background information:

- The Forum for Collaborative HIV Research: www.hivforum.org/
- National HIV and STD Testing Resources: www.hivtest.org/
- HIV Resource for Health Professionals: www.thebodypro.com
- AIDS Education and Training Centers National Resource Center: www.aidsetc.org
- General AIDS information: www.aids.org
- Medical Advocates/ADAP Fund: www.medadvocates.org
- New England Journal of Medicine collection of HIV/AIDS articles: http://content.nejm.org/cgi/collection/hivaids
- University of California–San Francisco comprehensive resources: http://hivinsite.ucsf.edu/InSite

Appendix V: Acronyms Commonly Used in HIV/AIDS Surveillance

ACRF	Adult Case Report Form
ADAP	AIDS Drug Assistance Program
AIDS	Acquired Immunodeficiency Syndrome
ART/ARV	Antiretroviral Therapy
ARVDRT	Antiretroviral Drug Resistance Testing
ASTHO	Association of State and Territorial Health Officials
BCSB	Behavioral and Clinical Surveillance Branch at CDC
BLTR	Blood Transfusion
CAEAR	Communities Advocating Emergency AIDS Relief Coalition
CCID	Coordinating Center for Infectious Diseases at CDC
CDC	Centers for Disease Control and Prevention
CHAAC	CDC-HRSA AIDS Advisory Council
CLI	Community-Level Interventions
CLIA	Clinical Laboratory Improvement Amendments
CMS	Center for Medicaid and Medicare Services
COPHI	Case of Public Health Importance
CSTE	Council of State and Territorial Epidemiologists
CTR	Counseling, Testing, and Referral
CTS	Counseling and Testing Sites
DCR	Death Certificate Record
DHAP	Division of HIV/AIDS Prevention at CDC
DIS	Disease Intervention Specialist
DNA	Deoxyribonucleic Acid
DOC	Department of Corrections
ECR	Electronic Case Reporting
eHARS	Enhanced HIV/AIDS Reporting System
EIA	Enzyme Immunoassay
ELISA	Enzyme-Linked Immunosorbent Assay
ELR	Electronic Laboratory Reporting
EMR	Electronic Medical Record
FDA	Food and Drug Administration
GLI	Group-Level Intervention
HAART	Highly Active Antiretroviral Therapies
HARS	HIV/AIDS Reporting System (the DOS-based system that preceded eHARS)
HICSB	HIV Incidence and Case Surveillance Branch at CDC
HIPPA	Health Insurance Portability and Accountability Act
HIV	Human Immunodeficiency Virus
HOPWA	Housing Opportunities for People Living with AIDS Program
HRSA	Health Resources and Services Administration
HTC	Heterosexual Contact
HUD	U.S. Department of Housing and Urban Development
ICD	International Classification of Diseases
ICP	Infection Control Practitioner
IDU	Injection-Drug User
IHS	Indian Health Service
ILI	Individual-Level Interventions
IRB	Institutional Review Board
LOINC	Logical Observation Identifiers Names and Codes
MMP	Medical Monitoring Project
MMWR	Morbidity and Mortality Weekly Report
MOU	Memorandum of Understanding
MRN	Medical Record Number
MSA	Metropolitan Statistical Area
MSM	Male who has Sex with Other Males
NASTAD	National Alliance of State & Territorial AIDS Directors
NDI	National Death Index
NEDSS	National Electronic Disease Surveillance System

NGA	Notice of Grant Award
NHBS	National HIV Behavioral Surveillance
NIR	No Identified Risk
NRR	No Reported Risk
OHAP	Office of HIV/AIDS Policy
OMH	Office of Minority Health
ONAP	White House Office of National AIDS Policy
OOJ	Out of Jurisdiction
OOS	Out of State
ORP	Overall Responsible Party
PACHA	President's Advisory Council on HIV/AIDS
PCRF	Pediatric Case Report Form
PEPFAR	President's Emergency Plan for AIDS Relief
PHIN	Public Health Information Network
QA	Quality Assurance
RFP	Request for Proposals
RIDR	Routine Interstate Duplicate Review
RNA	Ribonucleic Acid
RWCA	1990 Ryan White Comprehensive AIDS Resources Emergency Act
RWHATMA	Ryan White HIV/AIDS Treatment Modernization Act of 2006 (replaced RWCA)
SAMHSA	Substance Abuse and Mental Health Services Administration
SAS	Statistical Analysis Software
SDN	Secure Data Network
SRS	Simple Random Sampling
SSN	Social Security Number
STARHS	Serologic Testing Algorithm for Recent HIV Seroconversion
STD	Sexually Transmitted Disease
STI	Sexually Transmitted Infection
SVSR	State Vital Statistical Records
TB	Tuberculosis
TMT	Transmission Mode Tracking
TTH	Testing and Treatment History Form (for Incidence)
USAID	U.S. Agency for International Development
VA	U.S. Department of Veterans Affairs
VARHS	Variant, Atypical, and Resistant HIV Surveillance