

Preface

This guide is one of a series of publications that are being developed by the HIV/AIDS Bureau of the Health Resources and Services Administration (HRSA) to assist Ryan White CARE Act (RWCA) grantees in designing and implementing evaluation studies. The series will consist of concise reports which, together, will provide guidance on a wide range of issues relating to program evaluation. Several reports will feature evaluation studies conducted by RWCA grantees. The goal of the series is to improve services for people living with HIV by enhancing the ability of RWCA grantees to conduct methodologically sound evaluations and to develop action plans based on study findings.

In April 1997, HRSA formed a Monograph Advisory Committee, consisting of one representative from each RWCA Title, to provide guidance and oversight for the series. Committee members are advising HRSA on evaluation topics that should be addressed in the series and the criteria that should be used to select publications. They also are reviewing draft reports to suggest ways of making the information more useful and understandable to RWCA grantees. Committee members include:

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This guide is based upon an earlier prevention-focused manual, *Using Data, Assessing Needs: A Guide for Community Members of HIV Prevention Community Planning Bodies*, that was written by Emily Gantz McKay, President, MOSAICA: The Center for Nonprofit Development and Pluralism, for the National Council of La Raza (NCLR) AIDS Center. The contents were adapted for use by RWCA grantees through John Snow, Inc.'s technical assistance contract with HRSA's HIV/AIDS Bureau. Community Health Solutions, Inc. edited the guide under subcontract with LTG Associates, Inc.

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Executive Summary

This guide is designed to strengthen the participation of people living with HIV (PLWH), service providers, and other community representatives in planning, setting priorities for, and evaluating services under the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act. It provides materials for orienting and training members of CARE Act planning groups to read statistical reports, conduct or oversee community needs assessments, and use epidemiologic and administrative data for HIV service planning and decision making.

CARE Act planning groups perform a variety of planning, priority- setting, and evaluation functions that require the collection, summarization, and analysis of data. Although some planning group members have extensive experience in conducting needs assessments and analyzing data, others need training on these topics to become full partners in the planning process. This guide is designed to help “level the playing field” by building a *shared understanding* of statistical terms, epidemiologic and administrative reports, and data collection and analysis techniques. By reading this guide, you will learn the “basics” of designing needs assessments, analyzing data, and effectively using the data for program planning and decision making. Most planning groups have access to experts who can provide more detailed information on data collection methodologies and analytic techniques.

The six major sections of this guide discuss how CARE Act planning groups can collect, analyze, and use data for a variety of needs assessment, planning, and evaluation activities. The sections are organized as follows:

Part 1. Using Secondary Data Sources: A Self-Learning Guide describes the types of data and reports that are most frequently used to understand the HIV epidemic, its impact on different populations, and the services that are available to PLWH. It presents basic epidemiologic concepts and provides examples of tables and charts from HIV/AIDS surveillance and HIV seroprevalence reports. Examples of Annual Administrative Report (AAR) data tables on Title I and II providers, clients, and services also are provided. The discussions are accompanied by self-tests to give you practice in analyzing the data.

Part 2. Needs Assessment: The Foundation for Priority Setting describes the components of a comprehensive needs assessment and the questions and issues that need to be considered during each stage of the needs assessment process. Part 2 includes the following subsections:

The Role of Needs Assessment discusses the importance of needs assessment and the five principles that should guide this process.

The Needs Assessment Process discusses the key issues that should be addressed at each stage of the needs assessment process and the roles that community representatives can play. Suggestions are offered for using data from multiple sources to identify service needs and prepare for priority setting.

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Part 3. Understanding Statistics: What Every Planning Group Member Should Know provides the basic information you will need to collect, analyze, and use data for planning and decision making. Part 3 includes the following subsections:

Becoming Comfortable with Statistics describes the ways in which CARE Act planning groups use data for planning and decision making. This subsection also discusses the widespread discomfort with numbers and mathematical concepts in the United States and offers a common sense approach to overcoming this “math anxiety.”

Key Statistical Terms and Methods presents some basic statistical concepts, sources and methods of data collection, and sample designs. This section also lists questions that should be asked when reviewing data.

Part 4. Methods of Data Collection describes the most common quantitative and qualitative research methods and the key factors that should be considered when using each data collection method. This section includes an overview of surveys, key informant interviews, focus groups, community forums, and public hearings.

Part 5. Conclusion suggests ways in which your newly-acquired knowledge of needs assessment and statistical analysis can be applied to other community health planning and service development efforts.

Part 6. Definitions and Resources provides brief definitions of terms commonly used in statistics, epidemiology, and the CARE Act. This section also suggests supplemental references and resources for readers who desire more in-depth information on topics covered in the guide.

Active and diverse community participation is extremely important for health and human services planning. By taking the time to critically review data, and encouraging others to do the same, you can improve the quality of community decision making. Your knowledge of the “basics” of designing needs assessments, analyzing data, and effectively using the data for program planning and decision making will make you a valued member of many planning and advisory groups. The end result should be a more equitable allocation of resources among the varied populations which together form the American mosaic.

Why and How to Use This Guide

Introduction

Purpose of Guide

This guide is designed to strengthen the participation of people living with HIV (PLWH), service providers, and other community representatives in planning, setting priorities for, and evaluating services under the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act. It provides materials for orienting and training members of CARE Act planning groups to read statistical reports, conduct or oversee community needs assessments, and use epidemiologic and administrative data for HIV service planning and decision making.

CARE Act programs are decentralized with many local and regional planning groups. The CARE Act requires Title I grantees to establish HIV Health Services Planning Councils to assess service needs, plan for the organization and delivery of HIV services, and establish priorities for the allocation of Title I funds. Many Title II grantees contract with HIV Care Consortia to carry out similar functions. The CARE Act Amendments of 1996 require the public health agency administering each State's Title II grant to periodically convene representatives of all CARE Act Titles, PLWH, service providers, and public agency representatives to develop a Statewide Coordinated Statement of Need (SCSN). The Division of Service Systems (formerly Division of HIV Services) in the Health Resources and Services Administration (HRSA), HIV/AIDS Bureau, provides guidance for CARE Act needs assessment and planning activities as part of its role in administering Titles I and II.

CARE Act planning groups perform a variety of planning, priority- setting, and evaluation functions that require the collection, summarization, and analysis of data. Although some planning group members have extensive experience in conducting needs assessments and analyzing data, others need training on these topics to become full partners in the planning process. This guide is designed to help “level the playing field” by building a *shared understanding* of statistical terms, epidemiologic and administrative reports, and data collection and analysis techniques. By reading this guide, you will learn the “basics” of designing needs assessments, analyzing data, and effectively using the data for program planning and decision making. Most planning groups have access to experts who can provide more detailed information on data collection methodologies and analytic techniques.

Contributions of Community Representatives to CARE Act Planning

Diverse community participation is an essential component of the CARE Act planning process. CARE Act planning groups seek the active participation of health and human service providers, non-elected community leaders, and community representatives who reflect the face of the local HIV epidemic, such as infected and affected racial/ethnic minorities, gay and bisexual men, women, caregivers for HIV-infected children and youth, and injecting drug users. The Division of Service Systems requires that at least 25 percent of Title I Planning Council members be PLWH and strongly urges Title II Consortia to maximize PLWH involvement.

If you are a community member of a CARE Act planning body, your knowledge of the problems faced by particular populations, your practical experiences with the service delivery system, and your perspectives on service needs can be very helpful in laying the groundwork for a comprehensive HIV services plan. You can contribute to the planning process by:

- identifying sources of data that increase understanding of the distribution of HIV/AIDS among various populations, service utilization patterns, and barriers to care;
- identifying culturally competent and linguistically proficient people to conduct needs assessment and evaluation studies;
- ensuring that needs assessments ask the right questions, in the right ways, so that the service needs of special populations are accurately assessed;
- suggesting ways to maximize the participation of infected and affected populations in community forums and public hearings;
- ensuring that resource inventories of HIV service providers include organizations and groups that target particular populations and geographic areas;
- ensuring that needs assessment and evaluation studies consider the unique characteristics and concerns of special populations and the appropriateness of services for these populations; and
- encouraging the planning group to establish service priorities that reflect the needs of different populations.

To make your best possible contribution to the planning effort, you must have a basic understanding of how to collect, analyze, and use data. This guide will familiarize you with the data sources, data collection methodologies, and analytic strategies that are most often used in the CARE Act planning process. CARE Act planning groups are encouraged to use this guide as the basis for a training program. By discussing and practicing what you have learned with other planning group members, you will find it much easier to master the new knowledge and skills.

Using the Guide

The content and format of this guide are based on several assumptions about the knowledge levels of readers and the context in which the guide will be used. The authors assume that:

- **The users of this guide have a basic understanding of HIV/AIDS.** Planning group members without this background should receive training on the human immunodeficiency virus, modes of exposure, and the epidemiology of HIV/AIDS in their service area before reading this guide. For help in orienting planning group members to these topics, use the *Training Guide: A Resource for Orienting and Training Planning Council and Consortium Members* listed in Part 6 of this guide.
- **The users of this guide have a basic understanding of the CARE Act and their roles as Planning Council or Consortium members.** Planning groups can use manuals, such as the *Ryan White CARE Act Title I Manual* and *Creating Partnerships That Work: A Developmental Manual for Ryan White Title II HIV Care Consortia*, to orient new members to their planning, priority-setting, and evaluation roles and HRSA policies on CARE Act implementation. (See References and Resources in Part 6.)
- **The users of this guide have varying levels of knowledge and experience related to needs assessment, data collection and analysis, and program evaluation.**
- **Planning groups will use the guide to provide interactive, experiential training.** Although the guide can serve as a self- instruction tool for readers with some data analysis experience, most planning group members will find it easier to understand and retain the material if they have opportunities to discuss and apply the concepts to actual planning group tasks. By offering formal training sessions, planning groups can tailor the material to fit the informational needs and educational levels of their members.

The six major sections of this guide discuss how CARE Act planning groups can collect, analyze, and use data for a variety of needs assessment, planning, and evaluation activities. The sections are organized as follows:

Part 1. Using Secondary Data Sources: A Self-Learning Guide describes the types of data and reports that are most frequently used to understand the HIV epidemic, its impact on different populations, and the services that are available to PLWH. It presents basic epidemiologic concepts and provides examples of tables and charts from HIV/AIDS surveillance and HIV seroprevalence reports. Examples of Annual Administrative Report (AAR) data tables on Title I and II providers, clients, and services also are provided. The discussions are accompanied by self-tests to give you practice in analyzing the data.

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Part 6. Definitions and Resources provides brief definitions of terms commonly used in statistics, epidemiology, and the CARE Act. This section also suggests supplemental references and resources for readers who desire more in-depth information on topics covered in the guide.

Part 1

Using Secondary Data Sources: A Self-learning Guide

Epidemiologic Terms

CARE Act planning groups use many different data sources to track the local HIV epidemic, assess service needs, and evaluate resources and programs.

Among the most important data sources are epidemiologic reports and administrative data on the clients and services of CARE Act-funded providers. These are *secondary sources* of data, meaning that they were collected by others for purposes that may have little to do with CARE Act planning. The advantage of using secondary data is that they are readily available—often at no cost. The primary disadvantage is that they may not fully address the questions of interest to your planning group.

Epidemiology is the study of factors associated with health and disease and their distribution in the population. In contrast to clinical studies that focus on groups of patients, epidemiologists investigate the causes of health and disease in *populations* in order to prevent or control poor health outcomes and improve health status.¹ Epidemiologists also track trends in the incidence (number of new cases) of disease, the cumulative number of cases, and the distribution of cases across geographic areas and populations.

Different types of epidemiologic data can help your planning group track and forecast trends in the local HIV epidemic. You can learn about the estimated number of people living with HIV or AIDS; their distribution by age, gender, racial/ethnic group, and exposure category; the estimated number of people diagnosed with AIDS-defining opportunistic illnesses; and other aspects of the local HIV epidemic that may influence the allocation of CARE Act resources.

- **If you want to know the number of people in a particular population who are HIV-positive, you need seroprevalence data.** *Seroprevalence* refers to the number of individuals in a population who test positive for HIV. The *seroprevalence rate*, actually a ratio, is the number of HIV-positive individuals divided by the total number of persons tested. Since the blood serum (*serology*) tests that are used to determine seroprevalence may include more than one specimen from the same individual, the seroprevalence rate can be more precisely defined as the number of HIV-positive serology specimens divided by the total number of specimens tested.

¹Oleske, Denise. *Epidemiology and the Delivery of Health Care Services: Methods and Applications*. New York: Plenum Press, 1995.

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- **If you want to know the number and rate of new AIDS cases reported in your service area in the past month or year, you need incidence data.** *AIDS incidence* refers to the number of new AIDS cases that occur during a specified time period. The *incidence rate* of reported AIDS cases is the number of AIDS cases per population per specified time period, often expressed per 100,000 population.
- **If you want to know the total number of AIDS cases that have been reported in your service area to date, you need cumulative incidence data.** *Cumulative incidence* refers to the total number of new AIDS cases that have been diagnosed and reported from the time reporting began to the most recent reporting date.
- **If you want to know the current number of persons living with HIV or AIDS in your service area, you need prevalence data.** *HIV prevalence* refers to the total number of people with HIV in a given population at a given time, including new and previously reported cases. Similarly, *AIDS prevalence* tells you the total number of people with AIDS in a given population at a given time.

Data Sources for Planning and Evaluating HIV Services

CARE Act planning groups often use epidemiologic reports prepared by State Health Departments or the Centers for Disease Control and Prevention (CDC) to plan and evaluate HIV services. In addition to these published reports, Title I Planning Councils periodically receive CDC estimates of the number of people living with HIV and AIDS in their Eligible Metropolitan Areas (EMAs). Some of the most commonly used reports are described below:

- **The HIV/AIDS Surveillance Reports** published by the CDC provide national data on new and cumulative reported AIDS cases, with breakdowns by State and metropolitan area, gender, age group, exposure category, race/ethnicity, and other categories. The *Surveillance Reports* also present case fatality rates (i.e., the percentage of deaths reported among people whose cases were diagnosed during a specified period) and the estimated incidence of AIDS-defining opportunistic illnesses.
- **HIV seroprevalence reports** measure the levels of HIV infection among selected populations that have been targeted for surveys. The CDC periodically publishes a *National HIV Serosurveillance Summary* which provides information on the percentage of people testing HIV-positive in high-risk groups, such as persons attending sexually transmitted disease (STD) clinics and drug treatment centers, and lower-risk groups, such as women having babies and military recruits. The report shows the median HIV seroprevalence rate and range of percentages for each type of testing site and geographic location. Sometimes, data are broken down by State or EMA or by gender, race/ethnicity, and exposure categories to show geographic and epidemiologic patterns of HIV infection. By reviewing data from different time periods, you can analyze trends in HIV seroprevalence rates.

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- **In 1995, CDC published an *Update for Volume 3*** which summarizes HIV seroprevalence data through 1993. Certain sections of this report can be accessed on CDC's Web site. In addition, you may be able to obtain HIV seroprevalence data for your EMA or State from your local or State health department.
- **HRSA periodically provides each EMA with HIV prevalence estimates.** CDC estimates the number of people living with HIV disease by gender, race/ethnicity, exposure category, and stage of disease, using data from the National HIV Survey of Childbearing Women (a multi-state anonymous screening of dried blood specimens from newborns for HIV-1 antibody) and other HIV/AIDS surveillance data. When these prevalence data are inconsistent with locally available estimates, the CDC works with the EMA to reach a mutually acceptable set of estimates.

Exhibit 1 lists key sources of epidemiologic data for CARE Act planning and evaluation. These data can be supplemented by data from your local health department and other organizations that provide HIV services. CARE Act-funded providers routinely submit data on clients and services as part of the Annual Administrative Reporting process described below.

Using Data to Assess HIV/AIDS Service Needs

Exhibit 1 Sources of HIV/AIDS Epidemiologic Data	
Title and Source of Publication or Study	Examples of Data
National Data on HIV/AIDS Cases	
<p>HIV/AIDS Surveillance Report CDC National AIDS Clearinghouse HIV/AIDS Surveillance Report CDC National AIDS Clearinghouse P.O. Box 6003 Rockville, MD 20849 1-800-458-5231 and http://www.cdc.gov/nchstp/hiv_aids/stats/haslink.htm on the World Wide Web</p>	<p>HIV/AIDS Surveillance Data on:</p> <ul style="list-style-type: none"> • AIDS cases and annual rates • AIDS cases by age group, exposure category, and sex • AIDS cases by sex, age at diagnosis, and race/ethnicity • AIDS cases by year of diagnosis and definition category • Estimated AIDS opportunistic illness incidence • AIDS cases, case-fatality rates, and deaths, by half-year and age group • HIV infection cases by State and age group • HIV infection cases by sex, age at diagnosis, and race/ethnicity
HIV Seroprevalence Data for Selected States and Metropolitan Areas	
<p>National HIV Serosurveillance Summary CDC National AIDS Clearinghouse maintains some State and local data from this Summary and http://www.cdc.gov/nchstp/hiv_aids/pubs/hivsero.htm on the World Wide Web HIV serosurveillance data for specific communities may be available from State or local health departments</p>	<p>HIV Seroprevalence Data on:</p> <ul style="list-style-type: none"> • Job Corps applicants by gender • Civilian applicants for military service • Childbearing women • Injecting drug users • Men who have sex with men • Blood donors • Adolescents by clinic setting and gender • Clients at sexually transmitted disease (STD) clinics • Data from the HIV Sentinel Hospitals Survey (blinded HIV antibody tests performed on blood taken from patients admitted to 39 large acute care hospitals in selected U.S. metropolitan areas)
<p>HIV Seroprevalence Studies (Study titles vary across States and metropolitan areas) CDC National AIDS Clearinghouse and State and local health departments</p>	<p>HIV Seroprevalence Data from:</p> <ul style="list-style-type: none"> • Methadone and other drug treatment programs • Family planning clinics • Blood and plasma donation sites • Emergency room admissions • Coroner cases associated with suicide or drug-related deaths • Pediatric HIV cases by clinic setting and sex
<p>National HIV Survey of Childbearing Women CDC National AIDS Clearinghouse and State and local health departments</p>	<p>This multi-state survey uses blood from routine newborn metabolic screening to test for HIV antibody. A positive HIV antibody test result reflects infection in the mother, but not necessarily the infant, because maternal antibodies to HIV are passed to the baby even when the virus is not. Databases maintained by participating States contain information on:</p> <ul style="list-style-type: none"> • Month of birth • Mother's county of residence • County of reporting hospital • Mother's age and race/ethnicity (not available in all States) <p>NOTE: CDC suspended this survey indefinitely at the end of 1995.</p>
<p>HIV Counseling and Testing in Publicly Funded Sites in the United States CDC National AIDS Clearinghouse and State health departments</p>	<p>HIV-positive tests reported by:</p> <ul style="list-style-type: none"> • Publicly funded testing sites • Location (50 States, District of Columbia, six large cities, and seven territories). Locations are ranked by percentage of HIV-positive serology specimens. • Demographic group, exposure category, and site type • Age group (within each age group by sex and race/ethnicity)

The administrative/lead agencies for EMAs and Consortia collect Annual Administrative Report (AAR) data from CARE Act-funded service providers at least annually. The data are sent to HRSA's HIV/AIDS Bureau, where they are summarized in a series of national data tables on (1) Title I programs; (2) Title II programs, including Consortium programs, direct services provided by States, and home and community-based care programs; (3) AIDS Drug Assistance Programs; and (4) Health Insurance Continuation Programs. Your planning group can use the client and service data submitted by local providers to gain an understanding of the populations being served, the types and amounts of services being delivered, and the characteristics of the organizations providing services. These data can be compared with national data tables prepared by the HIV/AIDS Bureau.

When analyzing epidemiologic and AAR data, you should consider the local context within which the HIV epidemic is occurring. Demographic data on the service area, such as unemployment rates, the percentage of families living below poverty level, and school dropout rates, can help you understand risk factors for HIV as well as the environment in which HIV services are provided. Trends in STD and teen pregnancy rates can be used as indirect measures of risk for HIV disease. Although race and ethnicity are not risk factors for HIV transmission, they can be markers for complex underlying social, economic, and cultural factors that influence personal behavior and health.² You can obtain demographic data from the *County and City Data Book* published by the U.S. Bureau of the Census, and STD and teen pregnancy data from local and State health departments. Studies of the unit costs for HIV services and the results of client satisfaction surveys also can be helpful for planning and service evaluation.³

Using HIV/AIDS Surveillance Reports

To effectively use epidemiologic reports for needs assessment and priority setting, you need to become familiar with their content and format. The *HIV/AIDS Surveillance Reports* published by CDC present HIV/AIDS data in a number of different formats. Some of the most useful tables and charts for the CARE Act planning process include the following:

Tables presenting "AIDS cases and annual rates per 100,000 population" by State and by metropolitan area

These tables summarize the number of AIDS cases reported in the two most recent years, annual AIDS incidence rates, and cumulative numbers of AIDS cases by State and metropolitan areas of at least 500,000 population. Cumulative totals are shown for adults/adolescents and for children under age 13. Exhibit 2 shows the State table from the 1996 year-end edition of the *HIV/AIDS Surveillance Report*. The table for metropolitan areas is formatted in the same way.

²National Commission on AIDS. *The Challenge of HIV/AIDS in Communities of Color*. Washington, D.C.: National Commission on AIDS, 1992.

³Moreau, Walter, and Christine Hager. *Determining the Unit Cost of Services: A Guide for Estimating the Cost of Services Funded by the Ryan White CARE Act of 1990*. Rockville, MD: U.S. Department of Health and Human Services, Public Health Service, Health Resources and Services Administration, 1994.

Exhibit 2

Table 1. AIDS cases and annual rates per 100,000 population, by state, reported in 1995 and 1996;¹ and cumulative totals, by state and age group, through December 1996, United States

State of residence	1995		1996		Cumulative totals		Total
	No.	Rate	No.	Rate	Adults/ adolescents	Children <13 years old	
Alabama	637	15.0	607	14.2	4,203	63	4,266
Alaska	69	11.5	36	5.9	358	5	363
Arizona	675	15.7	594	13.4	5,017	21	5,038
Arkansas	277	11.1	269	10.7	2,128	30	2,158
California	11,054	35.0	9,610	30.1	97,623	534	98,157
Colorado	672	17.9	522	13.7	5,728	27	5,755
Connecticut	1,645	50.3	1,112	34.0	8,347	170	8,517
Delaware	316	44.1	285	39.3	1,764	13	1,777
District of Columbia	1,027	185.2	1,262	232.3	9,272	142	9,414
Florida	7,979	56.3	7,330	50.9	57,678	1,233	58,911
Georgia	2,310	32.0	2,411	32.8	16,829	175	17,004
Hawaii	258	21.9	198	16.7	1,979	14	1,993
Idaho	48	4.1	39	3.3	364	2	366
Illinois	2,215	18.8	2,199	18.6	18,355	216	18,571
Indiana	523	9.0	596	10.2	4,391	33	4,424
Iowa	116	4.1	112	3.9	975	8	983
Kansas	304	11.9	239	9.3	1,836	10	1,846
Kentucky	296	7.7	401	10.3	2,205	19	2,224
Louisiana	1,079	24.9	1,470	33.8	9,016	110	9,126
Maine	129	10.4	50	4.0	747	8	755
Maryland	2,567	50.9	2,253	44.4	15,037	261	15,298
Massachusetts	1,438	23.7	1,307	21.5	11,880	187	12,067
Michigan	1,193	12.5	965	10.1	8,300	86	8,386
Minnesota	365	7.9	304	6.5	2,980	19	2,999
Mississippi	440	16.3	450	16.6	2,820	41	2,861
Missouri	786	14.8	858	16.0	7,209	50	7,259
Montana	25	2.9	34	3.9	225	2	227
Nebraska	115	7.0	100	6.1	780	9	789
Nevada	494	32.2	427	26.6	3,047	21	3,068
New Hampshire	110	9.6	93	8.0	705	7	712
New Jersey	4,400	55.3	3,613	45.2	32,256	670	32,926
New Mexico	164	9.7	205	12.0	1,437	5	1,442
New York	12,369	68.0	12,379	68.1	104,961	1,936	106,897
North Carolina	1,000	13.9	895	12.2	7,210	103	7,313
North Dakota	5	0.8	12	1.9	78	-	78
Ohio	1,101	9.9	1,161	10.4	8,637	106	8,743
Oklahoma	295	9.0	272	8.2	2,708	23	2,731
Oregon	458	14.5	463	14.5	3,848	14	3,862
Pennsylvania	2,370	19.7	2,348	19.5	17,190	233	17,423
Rhode Island	221	22.3	178	18.0	1,574	16	1,590
South Carolina	976	26.6	869	23.5	6,207	66	6,273
South Dakota	18	2.5	14	1.9	114	4	118
Tennessee	892	17.0	826	15.5	5,492	44	5,536
Texas	4,456	23.7	4,830	25.3	39,572	299	39,871
Utah	164	8.4	196	9.8	1,365	20	1,385
Vermont	43	7.4	25	4.2	295	3	298
Virginia	1,605	24.3	1,195	17.9	8,960	144	9,104
Washington	882	16.2	804	14.5	7,563	28	7,591
West Virginia	125	6.8	121	6.6	737	8	745
Wisconsin	349	6.8	270	5.2	2,762	24	2,786
Wyoming	18	3.8	7	1.5	140	-	140
Subtotal	71,073	27.0	66,816	25.2	554,904	7,262	562,166
U.S. dependencies, possessions, and associated nations							
Guam	-	-	4	2.8	17	-	17
Pacific Islands, U.S.	-	-	1	0.4	3	-	3
Puerto Rico	2,578	68.7	2,243	59.0	18,230	353	18,583
Virgin Islands, U.S.	39	37.4	18	17.2	266	12	278
Total²	73,767	27.6	69,151	25.6	573,800	7,629	581,429

¹See Technical Notes for a discussion of the impact of the 1993 AIDS surveillance case definition for adults and adolescents (implemented January 1, 1993) on the number of cases reported annually since 1993.

²U.S. totals presented in this report include data from the United States (50 states and the District of Columbia), and from U.S. dependencies, possessions, and independent nations in free association with the United States. See Technical Notes. Totals include 382 persons whose state of residence is unknown.

Using Data to Assess HIV/AIDS Service Needs

The annual AIDS cases and AIDS incidence rates published in the *HIV/AIDS Surveillance Report* reflect the number of AIDS cases **reported** in a given year. Due to reporting delays, this number is not the same as the number of cases **diagnosed** in that year. The data on new AIDS cases (first and third columns) can help you assess AIDS trends in each State but cannot be used to compare States because of different population sizes. By converting these numbers to AIDS rates per 100,000 population (second and fourth columns), you can identify the States that have been most severely affected by the AIDS epidemic. The last three columns of the table provide cumulative totals of the AIDS cases reported for adults/adolescents, children under age 13, and persons of all ages since the CDC began to systematically collect this information.

To illustrate how this table can be used, imagine that you are a member of a statewide HIV/AIDS advisory group in Alabama. By reviewing the table, you can obtain information on:

- **The number and rate of AIDS cases that have been reported annually for 1995 and 1996 and the trend for the two-year period.**

Alabama reported 637 new AIDS cases and an AIDS incidence rate of 15.0 per 100,000 population in 1995. In 1996, the number of new AIDS cases dropped to 607 (4.7% decrease) and the AIDS incidence rate dropped to 14.2 per 100,000 (5.3% decrease).

- **The cumulative number of AIDS cases reported for adults/adolescents, children under age 13, and people of all ages.**

As of December 31, 1996, Alabama had 4,266 reported AIDS cases of which 4,203 (98.5%) were adults/adolescents and 63 (1.5%) were children under age 13.

- **Comparative data on AIDS incidence rates and trends in other States.**

A comparison of AIDS incidence rates for Alabama and Alaska reveals that Alabama had a much higher incidence rate in both years (15.0 versus 11.5 in 1995 and 14.2 versus 5.9 in 1996). Over the two-year period, Alaska's incidence rate decreased 48.7 percent, as compared to only a 5.3 percent decline in Alabama.

Using Data to Assess HIV/AIDS Service Needs

Self-Test 1 provides a test of your ability to analyze the data in Exhibit 2.

Self-Test 1: Using Tables on State AIDS Cases and Rates

Try using the data in Exhibit 2 to answer the following questions. The answers are on page 38 at the end of this section.

- a. What State reported the largest number of AIDS cases during 1995 and 1996? What State had the largest cumulative number of reported AIDS cases?
- b. Where was the AIDS incidence rate highest in both years? How does this location differ from other States? Where was the rate second highest each year?
- c. What two States have had the largest cumulative number of reported AIDS cases among children under age 13?
- d. In most States, did the AIDS incidence rate increase or decrease between 1995 and 1996?
- e. Review the AIDS incidence rates for Louisiana and the District of Columbia for 1995 and 1996. Which State/District had the greatest rate of increase (percent change between the annual rates) over the two-year period?

Tables showing AIDS cases by exposure category and including demographic characteristics, such as age, sex, and race/ethnicity

These tables list the number of AIDS cases reported for each exposure category and the percentage of total AIDS cases attributable to each exposure category. The exposure categories differ for adult/adolescent and pediatric (under age 13) cases. Some tables include cases reported for each of the two most recent 12-month periods and cumulative cases; others include only cases reported for the most recent 12-month period and cumulative cases.

Exhibit 3 presents one of the exposure category tables from the 1996 year-end edition of the *HIV/AIDS Surveillance Report*. Because this table focuses on male adult/adolescent AIDS cases, the first column lists exposure categories for men. The exposure categories for adult/adolescent female cases exclude “men who have sex with men” and include a “sex with bisexual male” subcategory under heterosexual contact. The exposure categories for pediatric AIDS cases exclude “men who have sex with men,” “injecting drug use,” and “heterosexual contact” and include “mother with/at risk for HIV infection” with several subcategories.

This table presents 1996 and cumulative AIDS data by exposure category for five racial/ethnic groups: White, not Hispanic; Black, not Hispanic; Hispanic; Asian/Pacific Islander; and American Indian/Alaska Native. The last set of columns presents cumulative totals for each exposure category. Because the U.S. Census Bureau considers Hispanic to be an ethnicity rather than a race, their reports include people of Hispanic descent in specific racial groups (usually white or black) and also count them in a Hispanic category. Most AIDS reports try to avoid this “double

Exhibit 3

Table 4. Male adult/adolescent AIDS cases by exposure category and race/ethnicity, reported in 1996, and cumulative totals, through December 1996, United States

Exposure category	White, not Hispanic		Black, not Hispanic		Hispanic							
	1996		Cumulative total		1996		Cumulative total					
	No.	(%)	No.	(%)	No.	(%)	No.	(%)				
Men who have sex with men	16,224	(70)	188,022	(76)	6,678	(33)	58,795	(39)	3,965	(38)	36,928	(44)
Injecting drug use	2,530	(11)	21,874	(9)	6,349	(31)	54,332	(36)	3,377	(33)	31,082	(37)
Men who have sex with men and inject drugs	1,495	(6)	19,590	(8)	1,011	(5)	11,568	(8)	421	(4)	5,635	(7)
Hemophilia/coagulation disorder	208	(1)	3,366	(1)	52	(0)	450	(0)	32	(0)	363	(0)
Heterosexual contact:	609	(3)	3,560	(1)	1,871	(9)	9,495	(6)	785	(8)	3,855	(5)
Sex with injecting drug user	178		1,434		481		3,826		212		1,263	
Sex with person with hemophilia	3		21		4		12		-		7	
Sex with transfusion recipient with HIV infection	12		134		16		116		9		74	
Sex with HIV-infected person, risk not specified	416		1,971		1,370		5,541		564		2,511	
Receipt of blood transfusion, blood components, or tissue	145	(1)	2,991	(1)	86	(0)	925	(1)	44	(0)	504	(1)
Risk not reported or identified ¹	2,130	(9)	8,058	(3)	4,152	(21)	15,848	(10)	1,713	(17)	5,556	(7)
Total	23,341	(100)	247,461	(100)	20,199	(100)	151,413	(100)	10,337	(100)	83,923	(100)

Exposure category	Asian/Pacific Islander		American Indian/Alaska Native		Cumulative totals ²							
	1996		Cumulative total		1996		Cumulative total					
	No.	(%)	No.	(%)	No.	(%)	No.	(%)				
Men who have sex with men	316	(66)	2,768	(76)	87	(52)	778	(60)	27,316	(50)	287,576	(59)
Injecting drug use	27	(6)	188	(5)	30	(18)	192	(15)	12,333	(23)	107,784	(22)
Men who have sex with men and inject drugs	13	(3)	120	(3)	23	(14)	219	(17)	2,967	(5)	37,152	(8)
Hemophilia/coagulation disorder	6	(1)	58	(2)	2	(1)	26	(2)	301	(1)	4,269	(1)
Heterosexual contact:	20	(4)	91	(2)	10	(6)	26	(2)	3,299	(6)	17,040	(3)
Sex with injecting drug user	3		23		5		13		879		6,561	
Sex with person with hemophilia	-		-		-		-		7		40	
Sex with transfusion recipient with HIV infection	1		7		-		1		38		333	
Sex with HIV-infected person, risk not specified	16		61		5		12		2,375		10,106	
Receipt of blood transfusion, blood components, or tissue	4	(1)	98	(3)	1	(1)	6	(0)	281	(1)	4,534	(1)
Risk not reported or identified	94	(20)	320	(9)	13	(8)	53	(4)	8,156	(15)	29,945	(6)
Total	480	(100)	3,643	(100)	166	(100)	1,300	(100)	54,653	(100)	488,300	(100)

¹See figure 7.

²Includes 560 men whose race/ethnicity is unknown.

counting” by including all Hispanic people with AIDS in a Hispanic category and then labeling the white and black racial categories to indicate that Hispanics are not included. From this table, you can obtain information on:

- **The total number of male adult/adolescent AIDS cases reported for each racial/ethnic group during 1996 and cumulatively, and the total male AIDS cases for these same time periods.**

A cumulative total of 247,461 adult/adolescent AIDS cases were reported among white men through December 1996. Of these cases, 23,341 (9.4%) were reported in 1996. The cumulative male total for all racial/ethnic groups was 488,300 cases, of which 54,653 cases (11.2%) were reported in 1996.

Using Data to Assess HIV/AIDS Service Needs

- **The distribution of male AIDS cases within each racial/ethnic group by exposure category and subcategory.**

Among Hispanic males, 3,855 (5%) of the cumulative AIDS cases reported through December 1996 were attributed to “heterosexual contact.” Almost two-thirds of these heterosexually- acquired cases were reported as “sex with HIV-infected person, risk not specified.”

- **Variations among racial/ethnic groups in the percentage of male AIDS cases attributable to each exposure category.**

In 1996, the percentage of AIDS cases attributable to male-to-male sexual contact was 70 percent for whites, 66 percent for Asian/Pacific Islanders, 52 percent for American Indian/Alaska Natives, 38 percent for Hispanics, and 33 percent for blacks. During that same year, the percentage of “risk not reported or identified” cases ranged from 8 percent for American Indian/Alaska Native males to 21 percent for black males.

Using data from the table, you can calculate:

- **The percentage of cases in each subcategory of “heterosexual contact.”**

For example, about 40 percent of the cumulative “heterosexual contact” cases among black males can be attributed to “sex with an injecting drug user.”

- **Each racial/ethnic group’s percentage of the total male AIDS cases or of the male AIDS cases in a particular exposure category.**

For example, Hispanic men accounted for about 19 percent of the male adult/adolescent AIDS cases reported in 1996.

You also can compare each racial/ethnic group’s percentage of the total male AIDS cases with its percentage of the total U.S. population to see which groups are over- or underrepresented among male AIDS cases. For example, if Hispanic males accounted for only 11 percent of the U.S. male population in 1996, they would be *overrepresented* among male AIDS cases (19% versus 11%).

To calculate AIDS incidence rates, we have to know both the number of cases (numerator) and the size of the at-risk population (denominator). Because data are not available on the number of injecting drug users, men who have sex with men, etc., it is impossible to calculate incidence rates for the different exposure categories. Test your understanding of the exposure category table in Exhibit 3 by taking Self-Test 2.

Self-Test 2: Using Tables on AIDS Cases by Exposure Category

Use the data in Exhibit 3 to answer the following questions. The answers are on page 38 at the end of this section.

- a. How many male adult/adolescent AIDS cases were reported in 1996? How many cases were reported among white males? What percentage of the male AIDS cases reported in 1996 were white?
- b. What racial/ethnic group had the largest number of male adult/adolescent AIDS cases during 1996? What group had the smallest number?
- c. In 1996, what exposure category accounted for the largest number of AIDS cases among males in each racial/ethnic group? In two racial/ethnic groups, what exposure category included almost as many male AIDS cases?
- d. The table includes one double exposure category - "men who have sex with men and inject drugs." Although the numbers are small, the percentage of male AIDS cases in that category is especially high in one racial/ethnic group, both in 1996 and cumulatively. Which group is that?
- e. One of the heterosexual contact subcategories is "sex with injecting drug user." In 1996, which racial/ethnic group had the largest number of male adult/adolescent AIDS cases in this subcategory?
- f. In 1996, what percentage of the male adult/adolescent AIDS cases were black? If blacks accounted for about 12% of the total U.S. population in that year, were black males over- or underrepresented among AIDS cases?
- g. In 1996, what two racial/ethnic groups reported the highest percentages of male adult/adolescent AIDS cases in the "heterosexual contact" category? What racial/ethnic group reported the highest percentage of male adult/adolescent AIDS cases in the "injecting drug use" category?

Maps showing AIDS cases or annual rates by State

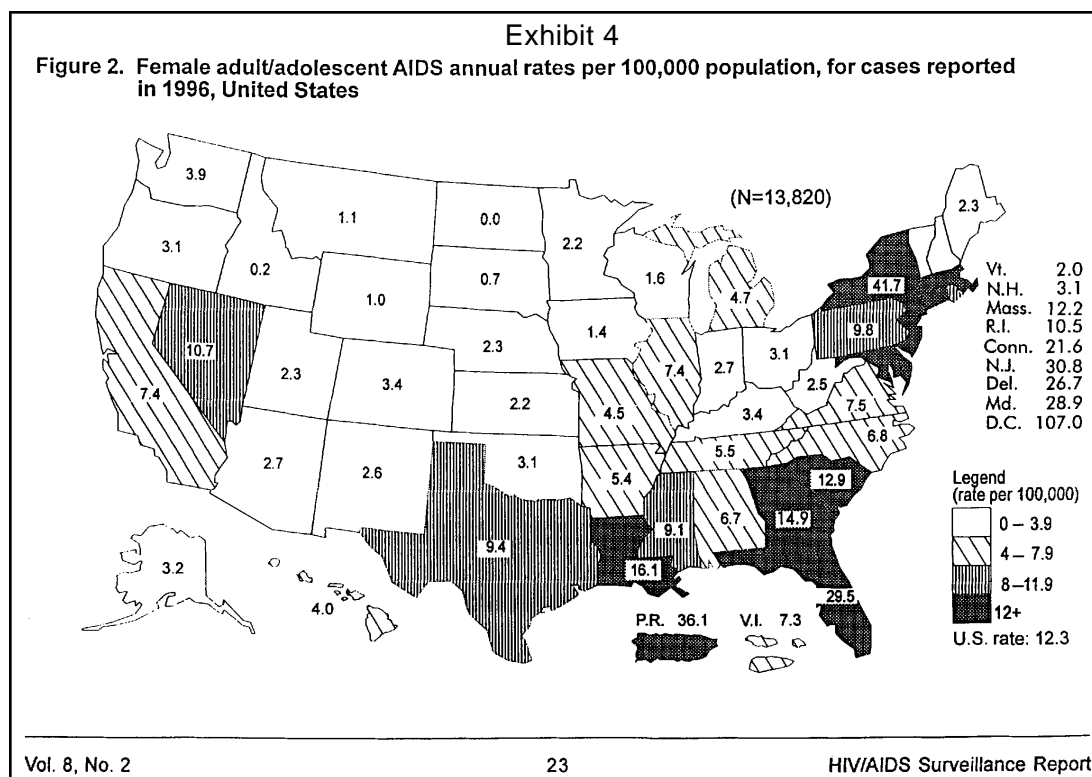
The map in Exhibit 4 presents AIDS annual rates for cases reported among U.S. adult/adolescent women in 1996. Pattern codes are used to group States with similar female AIDS rates. The map provides:

- **Female adult/adolescent AIDS annual rates per 100,000 population for each State, the District of Columbia, and Puerto Rico.**

For example, the 1996 AIDS incidence rate among New York women was 41.7 per 100,000, as compared to an AIDS incidence rate of 7.4 per 100,000 among California women.

- **Visual comparisons of female adult/adolescent AIDS rates among States.** The States with the darkest patterns have the highest reported annual rates.

For example, you can see that the highest female AIDS rates in 1996 were among several States in the Northeast and Southeast, Louisiana, and Puerto Rico. States with the solid dark pattern had female AIDS incidence rates of 12 per 100,000 or higher.



By comparing a map that shows AIDS annual rates for women with a similar map for men, you can identify gender differences in rates for the same States. Use Self-Test 3 to gain experience in using this type of map.

Self-Test 3: Using Maps Showing AIDS Annual Rates

Use the sample map in Exhibit 4 to answer the following questions about AIDS annual rates among adult/adolescent females. The answers are on page 39 at the end of this section.

- In 1996, what State had the lowest AIDS annual rate among adult/adolescent females?
- Identify at least five locations with annual rates that exceed 25 female AIDS cases per 100,000 population.
- What sections of the country had relatively low female AIDS annual rates in 1996?

Using HIV Seroprevalence Tables and Charts

This section provides examples of the tabular and graphic formats in which HIV seroprevalence data can be presented. Your planning group can use these data to project future service needs. The *National HIV Serosurveillance Summary* published by the CDC presents HIV seroprevalence data from many sources, using a variety of tables and charts. Similar tables can be found in other seroprevalence reports, and the CDC generates some special tables for Title I EMAs. Remember that these tables and charts provide information about people who are HIV-positive but who may not have been diagnosed with AIDS.

EMA prevalence estimates

HRSA periodically provides each EMA with CDC estimates of the number of HIV-positive individuals living in the service area. When local sources of prevalence data are available, CDC staff may work with the EMA to refine the estimates. EMAs receive four separate tables—two for HIV-infected adults/adolescents and two for HIV-infected children. The tables contain data on:

- **The number of HIV-positive males and females in each racial/ethnic group, by stage of disease (Exhibit 5).** Planning Councils can use this information to determine the need for various types of services and providers.
- **The number of females and males living with HIV by exposure category and stage of disease.** This information also can be helpful in determining current and future service needs. For example, if an EMA has a large number of HIV-positive women with a history of injecting drug use, the Planning Council may decide to recommend more Title I funding for outpatient drug treatment programs that are specifically designed for women.
- **The number of HIV-infected children, by race/ethnicity and by exposure category.** The information on children in each racial/ethnic group includes a breakdown on the number who are HIV-positive and the number who are living with AIDS. EMAs also receive estimates of the total number of children living with HIV and AIDS by exposure category—hemophilia/coagulation disorder; mother with or at risk for AIDS; receipt of blood transfusion, blood components, or tissue; and “other.” These data can build understanding of how local children are becoming infected and the service needs of different pediatric subgroups.

Exhibit 5
Stage of Disease Categories

HIV prevalence estimates for EMAs divide HIV-positive adults and adolescents into three categories based on stage of disease:

- Number who have been diagnosed with AIDS opportunistic infections (AIDS OIs)
- Number who have been diagnosed with CD4 counts below 200 (Diagnosed with CD4+ <200)
- Number who have not been diagnosed with AIDS

The computer-generated tables for each EMA show numbers but no percentages. When working with these tables, you should be aware that all comparisons are approximate because the numbers are rounded. Numbers between zero and five are rounded to five. Larger numbers are rounded to the nearest 10, 20, 25, 50, or 100, depending on the size of the number. Therefore, if you add up all the estimated numbers across categories, you may not get the same number as the total rounded estimate. Exhibit 6 provides additional information on the rounding process.

Exhibit 6
Rounding Used for EMA HIV Prevalence Estimates

Unrounded Estimate	Rounded Estimate
0 – 5	5
6 – 105	nearest 10
106 – 210	nearest 20
211 – 420	nearest 25
421 – 1025	nearest 50
> 1025*	nearest 100

* The symbol > is used to denote “greater than.”

Exhibit 7 presents a sample table that estimates HIV prevalence in a northeastern EMA by race/ethnicity, gender, and stage of disease. Use Self-Test 4 to become comfortable with the format of the EMA tables and to practice calculating percentages based on the numbers.

Using Data to Assess HIV/AIDS Service Needs

Exhibit 7

Estimated Number of HIV Infected Adults and Adolescents 12
By Race/Ethnicity and Sex. Estimates are rounded.

Stage of Disease	White Non-Hisp		Black Non-Hisp		Hispanic	
	Male	Female	Male	Female	Male	Female
# w/ AIDS OIs	275	70	325	140	140	50
# Diagnosed w/ CD4+ <200	200	70	225	140	100	50
# Not diagnosed with AIDS	650	160	1,400	600	325	140
Total HIV Prevalence	1,100	300	1,900	900	550	250

(CONTINUED)

Stage of Disease	Asian PI		Am Ind/AK Nat		Total	
	Male	Female	Male	Female	Male	Female
# w/ AIDS OIs	5	5	5	5	750	275
# Diagnosed w/ CD4+ <200	5	5	5	5	500	275
# Not diagnosed with AIDS	10	5	5	10	2,400	900
Total HIV Prevalence	10	5	5	10	3,600	1,400

Self-Test 4: Using EMA Prevalence Tables

Use the data in Exhibit 7 to answer the following questions about the adults and adolescents estimated to be living with HIV in this northeastern EMA. The answers are on page 39 at the end of this section.

- a. What stage of disease best characterizes the majority of adults and adolescents living with HIV in this EMA?
- b. Which of the three largest racial/ethnic groups has the lowest percentage of HIV-positive women?
- c. What percentage of all HIV-positive adults and adolescents in this EMA are men?

Tables showing HIV seroprevalence data

HIV seroprevalence data often are presented in summary tables. These tables show the percentage of people tested at STD clinics, reproductive health clinics, adolescent clinics, homeless and runaway youth clinics, and other sites who have blood serum evidence of HIV infection at a given time. Epidemiologists refer to these percentages as ***HIV seroprevalence rates***.

Exhibit 8 presents HIV seroprevalence data on young women and men who were tested at adolescent clinics during 1993. Tables of this type typically provide information on:

- **Clinic setting**, sometimes broken down by gender and by State or metropolitan area;
- **Total number of centers in each setting that reported test results** (e.g., seven juvenile detention centers reported test results in 1993, but only four reported test results for adolescent women);
- **Total specimens tested** for HIV during a specific (often one-year) period;
- **Number of centers analyzed** (this number may be less than the number of reporting centers because analyses are performed only on centers that report a specified minimum number of specimens);
- **The median HIV seroprevalence rate** (after calculating each center's percentage of HIV-positive serology specimens, the percentages are arrayed from highest to lowest to find the median rate); and
- **The range of percentages** (e.g., among adolescent females tested at three juvenile detention centers with an analyzable number of specimens, the percentage of HIV-positive serology specimens ranged from 0.7% to 5.0%).

Exhibit 8

Table 1. Summary of HIV seroprevalence data from adolescent clinics by clinic setting and sex, 1993

Clinic setting and client gender	Total centers ¹	Total specimens tested ²	Centers analyzed ^{3,4}	Percent positive	
				Median ⁵	(Range) ⁶
Adolescent medicine clinics					
Males	31	2,969	10	0.0	(0.0 - 3.4)
Females	31	10,224	29	0.0	(0.0 - 3.1)
Total	31	13,193	31	0.0	(0.0 - 3.2)
Homeless and runaway youth clinics					
Males	3	752	3	1.9	(0.0 - 2.9)
Females	3	971	3	1.1	(0.6 - 1.5)
Total	3	1,723	3	1.6	(0.4 - 2.0)
Juvenile detention centers					
Males	7	3,461	6	0.0	(0.0 - 3.6)
Females	4	363	3	2.8	(0.7 - 5.0)
Total	7	3,824	6	0.1	(0.0 - 3.9)

1 Includes centers funded to conduct unlinked surveys in 1993.
 2 Includes all specimens tested in 1993.
 3 Includes only clinics reporting at least 50 specimens collected and tested according to CDC protocol.
 4 Gender analyzed for centers reporting at least 50 specimens per group.
 5 The median rate for centers in each category.
 6 Range is the lowest and highest rates of centers in each category.

HIV seroprevalence tables sometimes provide additional data, such as the exposure categories of persons tested and breakdowns for each reporting State or metropolitan area. Exhibit 9 provides an example of a detailed table on HIV seroprevalence at STD clinics in 20 metropolitan areas. Such tables may display:

- **Median HIV seroprevalence rates for various at-risk groups, by gender and/or geographic location** (e.g., the median percentage of HIV-positive serology specimens in the four New York City STD clinics was 5.8%, as compared to 2.3% at four Los Angeles STD clinics);
- **Ranges of HIV seroprevalence rates for centers in different geographic locations** (e.g., the percentage of HIV-positive serology specimens at the four New York City STD clinics ranged from 2.6% to 9.8%, as compared to a range of 1.0% to 7.5% at the four Los Angeles STD clinics);
- **HIV seroprevalence rates for people with different risk factors** (e.g., at the two STD clinics in Washington, D.C., the median percentage of HIV-positive serology specimens was 50.9% for men who reported having sex with other men and 8.9% for men who reported using illicit drugs); and
- **Comparative rates by geographic location, risk factor, and gender** (e.g., the median percentage of HIV-positive serology specimens for men who reported having sex with other men was 9.2% in Portland and 15.0% in Seattle).

Using Data to Assess HIV/AIDS Service Needs

Exhibit 9

Table 3. Summary of HIV seroprevalence data from sexually transmitted disease clinics¹ by metropolitan area, exposure category, and sex, 1993

Geographic division/ metropolitan area	Total clinics ¹	Total specimens tested ²	Clinics analyzed ³	Men who have had sex with men since 1978	Median percent positive ^{4,5}				All clinics ³ percent positive Median ⁵ (Range) ⁶	
					Heterosexuals who have injected illicit drugs since 1978		No acknowledged risk			
					Male	Female	Male	Female		
New England Boston, Mass.	1	1,911	1	29.6	-	-	2.1	1.4	3.2	-
Middle Atlantic New York, N.Y. Newark, N.J.	4 2	7,223 3,282	4 2	33.6 -	- -	- -	5.0 4.2	3.2 4.2	5.8 5.3	(2.6-9.8) (4.7-5.9)
East North Central Chicago, Ill. Detroit, Mich.	5 2	3,928 4,368	2 2	24.3 -	- -	- -	1.9 0.6	0.4 0.5	2.9 0.9	(0.4-5.4) (0.4-1.5)
West North Central Minneapolis, Minn.	2	2,729	2	12.6	-	-	0.3	0.3	0.9	(0.7-1.1)
South Atlantic Atlanta, Ga. Baltimore, Md. Miami, Fla. Washington, D.C.	2 2 4 2	2,523 3,126 4,040 7,358	2 2 3 2	- - 29.8 50.9	- 29.1 -	- -	2.0 3.0 5.7 4.4	1.3 1.4 3.5 5.0	3.1 6.4 7.4 5.4	(2.6-3.6) (5.6-7.2) (5.4-7.8) (4.9-5.9)
East South Central Birmingham, Ala.	1	3,719	1	-	-	-	1.1	0.9	1.3	-
West South Central Dallas, Tex. Houston, Tex. New Orleans, La.	4 1 1	1,345 6,829 2,173	1 4 1	- 30.2 -	- -	- -	1.7 2.8 2.1	1.3 1.9 1.1	2.3 3.4 2.4	- (1.9-12.2) -
Mountain Denver, Colo. Phoenix, Ariz.	1 1	2,653 2,232	1 1	20.5 18.1	1.2 -	- -	0.3 0.5	0.1 0.1	1.8 0.9	- -
Pacific Los Angeles, Calif. Portland, Oreg. San Francisco, Calif. Seattle, Wash.	4 1 3 2	9,187 1,631 6,422 2,384	4 1 3 2	31.6 9.2 23.1 15.0	- 2.4 7.9 -	- 0.0 -	1.1 0.1 1.3 0.3	0.8 0.0 0.0 0.1	2.3 0.9 2.1 0.9	(1.0-7.5) - (1.4-9.4) (0.3-1.6)
Total	45	78,863	41	29.6	8.4	0.0	2.1	1.1	3.0	(0.3-12.2)

1 Includes all clinics funded to conduct surveys in 1993.
 2 Includes all specimens tested in 1993.
 3 Includes only clinics reporting at least 500 eligible specimens collected and tested according to CDC protocol.
 4 Subgroups analyzed for clinics reporting at least 50 specimens per group.
 5 The median rate for clinics in the metropolitan area.
 6 Range is the lowest and highest rates of clinics in the metropolitan area.

Reviewing these tables can help you target subpopulations with high HIV seropositivity rates for needs assessment and service planning. For example, if the HIV seroprevalence data in Exhibit 8 were drawn from adolescent clinics in your service area, you might decide to allocate more CARE Act funds to programs for homeless and runaway youth since they have the highest median HIV seroprevalence rate. On the other hand, if you were a member of the HIV Health Services Planning Council in Washington, D.C., the high median seroprevalence rate among gay and bisexual men at STD clinics (Exhibit 9) might prompt you to investigate the adequacy of services for this subpopulation and the extent to which STD clinics are integrated into the continuum of care. Self-Test 5 can help you learn to analyze HIV seroprevalence data.

Self-Test 5: Using Summary HIV Seroprevalence Data Tables

Use the data in Exhibit 8 to answer the following questions about HIV seroprevalence among young women and men attending adolescent clinics. The answers are on page 39 at the end of this section.

- a. If you compare the median HIV seroprevalence rates of young men and women in different types of adolescent clinics, is there a clear pattern?
- b. Why were female HIV seropositive rates analyzed for only three of the four juvenile detention centers that reported data on females?
- c. Of the three groups of adolescents, which one has the highest HIV seroprevalence rate among females? Why should this conclusion be viewed as tentative?

Use the data in Exhibit 9 to answer the following questions about HIV seroprevalence in STD clinics.

- d. Looking at the data for all clinics (far right of chart), what two geographic locations have the highest median percent positive? What five locations have the lowest median percent positive?
- e. In what geographic location are HIV seroprevalence rates highest among men who have had sex with men since 1978?
- f. In what geographic location were the largest number of total specimens tested? Smallest number?
- g. It is difficult to gain an understanding of HIV seroprevalence among women from this table. Why?

Line charts showing trends in HIV seroprevalence rates for different populations

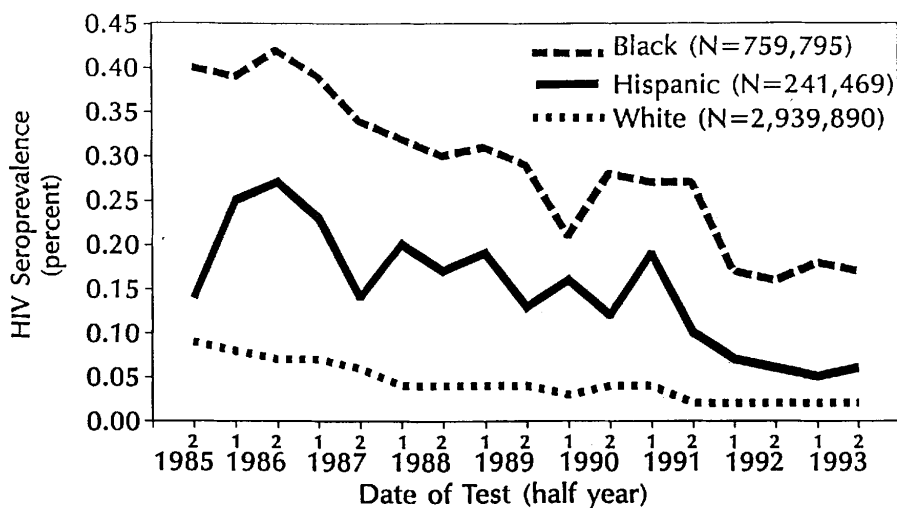
Line charts plot the median HIV seroprevalence rate once or several times each year and then connect the points in a line that shows trends. Most line charts show separate rates for women and men and for different racial/ethnic groups. These charts provide two important kinds of information:

- **A summary of trends in HIV seroprevalence rates for a particular population over time; and**
- **Comparisons across populations over the same time periods.** HIV seroprevalence rates for different populations can be compared during a given year or over several time periods.

Line charts display approximate values for each half-year or year. The precise data often can be found in a table or in the text of the report. Exhibit 10 presents a line chart of HIV seroprevalence among civilian applicants for military service, by test date and race/ethnicity. After reviewing Exhibit 10, take Self-Test 6 to test your understanding of the uses and limitations of line charts.

Exhibit 10

Figure 6. HIV seroprevalence among civilian applicants for military service by test date and race/ethnicity, United States, October 1985 through December 1993



Source: Department of Defense

Self-Test 6: Using Line Charts

Use the line chart in Exhibit 10 to answer questions about HIV seroprevalence among civilian applicants for military service. The answers are on page 40 at the end of this section.

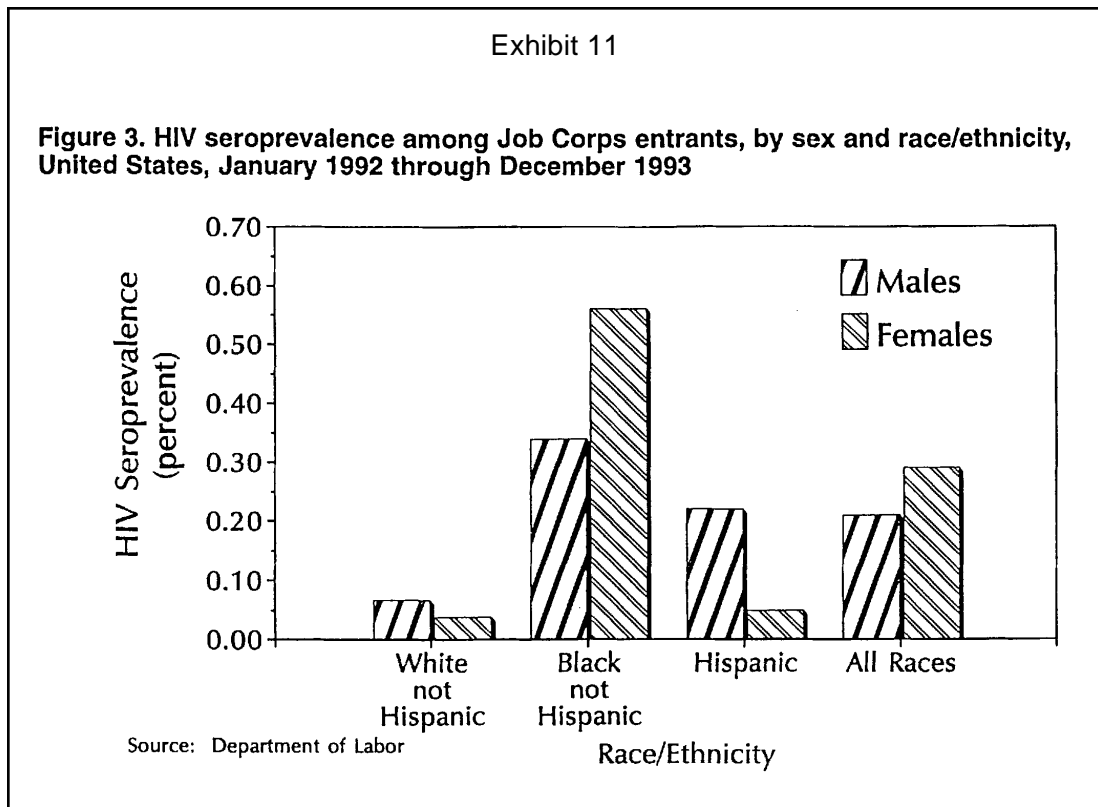
- What does the chart tell you about HIV seroprevalence among black, Hispanic, and white civilian applicants for military service? Which racial/ethnic group has the highest rates, which has the lowest rates, and which falls in the middle?
- What seems to be the predominant trend in HIV seroprevalence rates? How do trends differ by racial/ethnic group?
- Which racial/ethnic group had the highest HIV seroprevalence rate and in what year?

Bar charts providing comparisons across populations

Bar charts provide a clear and understandable picture of HIV seroprevalence among different populations. Often, you will find comparative rates for females and males and for different racial/ethnic groups in the same chart. For example, Exhibit 11 shows HIV seroprevalence rates among Job Corps entrants, by sex and race/ethnicity for 1992-1993. This chart provides information on:

- **The relative HIV seroprevalence rates for females versus males in each racial/ethnic group; and**
- **Comparative HIV seroprevalence rates for females versus males across racial/ethnic groups.**

Like line charts, bar charts usually do not display precise HIV seroprevalence rates, although some bar charts use labels at the top of each bar for this purpose. To practice using this type of chart, take Self-Test 7.



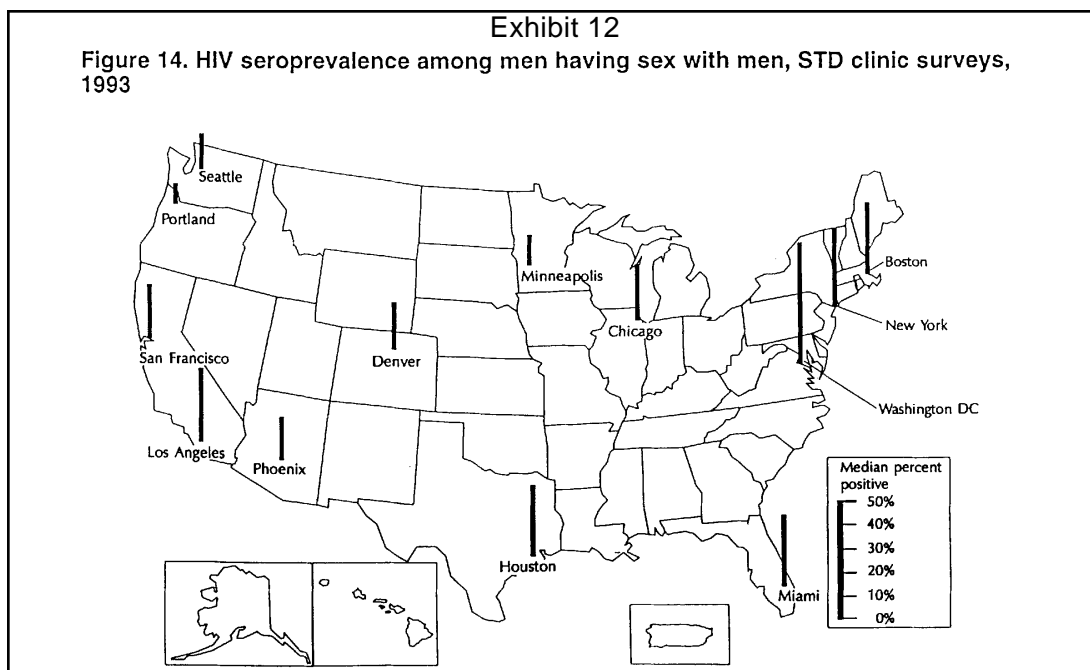
Self-Test 7: Using Bar Charts

Use the bar chart in Exhibit 11 (HIV seroprevalence among Job Corps entrants) to answer the following questions. The answers are on page 40 at the end of this section.

- How do HIV seroprevalence rates among females and males differ by racial/ethnic group? Is there a "typical" relationship?
- Which racial/ethnic group has the highest HIV seroprevalence among female Job Corps entrants? Which racial/ethnic group has the highest HIV seroprevalence among male Job Corps entrants?
- A visual inspection of this chart suggests that a high proportion of all female Job Corps entrants during the two-year period were black. How might you reach this conclusion?

Maps using bars to show comparative HIV seroprevalence rates by State or metropolitan area

The HIV/AIDS Surveillance Report and the National HIV Serosurveillance Summary both use maps to show the number of AIDS cases, AIDS annual rates, and HIV seroprevalence rates by State. Some maps use small bars to show HIV seroprevalence rates for States and selected metropolitan areas. The map in Exhibit 12, for example, compares HIV seroprevalence among STD clinic patients reporting male-to-male sexual contact in selected metropolitan areas of the United States. The taller the bar, the higher the HIV seroprevalence rate (i.e., median percent positive) reported for that location. Use Self-Test 8 to become familiar with the uses and limitations of this kind of map.



Self-Test 8: Using Maps with Bars

Use the map in Exhibit 12 to answer the following questions about HIV seroprevalence among men who reported having sex with men in 1993 STD clinic surveys. The answers are on page 40 at the end of this section.

- a. Can you identify the metropolitan areas with the highest HIV seroprevalence rates?
- b. Can you identify any metropolitan areas with a median rate of 0% positive?

Guidelines for Reviewing Epidemiologic Reports

This guide presents typical tables and charts from two major HIV/AIDS epidemiologic reports. Many other reports present similar kinds of information in somewhat different formats. When you review an epidemiologic report, it may be helpful to:

- **Begin by skimming the report to identify the kinds of tables and charts that are typically used.** Most reports display data in just a few tabular and graphic formats, so once you understand these formats you should be able to “make sense” of the report.
- **Carefully examine the tables and charts for information on data sources, time periods, and the populations and geographic locations covered.** You may find, for example, that data are not reported for key subpopulations, or that limited data are reported for your State or service area. If data tables do not specify the number of cases being reported or their sources, you may be able to find that information in an accompanying narrative or appendix.
- **Use narrative summaries to identify the major findings.** Then re-examine the tables and charts to obtain more detailed information on populations and locations that are of special interest to you.
- **If there is limited or inadequate analysis and discussion of the data, go back to the tables and mark the most important information.** Then do your own analysis and interpretation or ask someone with statistical expertise to perform these tasks.

When reviewing epidemiologic reports, you also should consider the limitations of the data. Some of the most common limitations that you will encounter are as follows:

- **The data are based on a limited number of individuals, geographic locations, or reporting sites.** For example, if you are reviewing HIV seroprevalence data from a study of women who were tested for HIV antibodies at family planning clinics in 10 cities, the findings may help you understand HIV trends among family planning clientele *in these cities*, but they cannot be generalized to a larger population. The cities, clinics, and women would have to

Using Data to Assess HIV/AIDS Service Needs

be randomly selected to be able to draw conclusions about HIV seroprevalence among all U.S. women attending family planning clinics. (See discussion of probability sampling in Part 3.)

Some groups, such as the Jobs Corps and the military, test all entrants for HIV antibodies and report HIV seroprevalence rates by age group, race/ethnicity, and/or gender. These studies allow you to draw conclusions about the *specific group tested*. However, the findings cannot be generalized to all U.S. residents with similar demographic characteristics.

- **Data on HIV and AIDS cases contain incomplete information on mode of exposure.** Tables in the *HIV/AIDS Surveillance Report* include a “risk not reported or identified” exposure category. Heterosexually-acquired cases in which the partner’s risk behavior is not identified are labeled as “sex with HIV-infected person, risk not specified.” If a high proportion of HIV/AIDS cases fall into these “risk not specified” categories, the percentages presented for other exposure categories are likely to be underestimates.

If you see possible limitations in the data, you should bring these issues to the attention of planning group members and staff. You may also have suggestions on additional data that should be gathered. When making these suggestions, keep in mind that primary data collection requires time and money. If your planning group has limited resources, some of the data that you would like to have for planning and priority setting may not be attainable.

Using Annual Administrative Report (AAR) Data

Your planning group can obtain information on the clients, services, and expenditures of CARE Act-funded organizations from administrative databases maintained by the administrative/lead agency for the EMA or Consortium. As described on page 11, administrative/lead agencies collect data on CARE Act-funded providers for inclusion in HRSA’s national AAR data tables. Some EMAs and States also collect and analyze client-level demographic and service data. This section describes the content and format of AAR data tables and presents several illustrative tables.

The national AAR data tables summarize information by State or EMA based on the provider-based reports that each State and EMA submits annually to HRSA’s HIV/AIDS Bureau. Your planning group can use these data to:

- **analyze the number, characteristics, and mix of providers in your continuum of care;**
- **compare the range of providers and services in your network with the provider profiles of other EMAs or States; and**
- **compare characteristics of your provider networks with the national profile.**

Using Data to Assess HIV/AIDS Service Needs

Because the tables do not contain information on individual service providers, you cannot assess the adequacy of your network simply by comparing it with the profile of another EMA or State. For example, if your EMA funds two hospital-based clinics and another EMA funds eight, you would need additional information on each clinic's range of services and service capacity, and the availability of alternative primary care providers, to assess whether two hospital-based clinics is "good" or "bad."

The AAR data tables for Title I and Title II have a consistent format. Each EMA or State is assigned a row in the far left column. The remaining columns in that row are used to present information about CARE Act providers and/or clients. Exhibit 13 provides an example of the table format. The first column lists the EMAs that received Title I funding in 1995. Columns 2-12 classify the reporting service providers in each EMA by type (e.g., hospital-based clinic, community health center, PWA coalition, health department) and show the number of providers in each category. Column 13 shows the number of service providers in each EMA who meet the definition of "minority provider" (i.e., an AIDS service organization in which the majority of Board members and staff are minorities based on national population trends and definitions). Columns 14-20 provide information on provider ownership (e.g., public local agency, private nonprofit organization, private for-profit organization, unincorporated). HRSA's HIV/AIDS Bureau generates a similar table for Title II. Use Self-Test 9 to gain familiarity with this type of table.

Exhibit 13

Service Providers Funded Under Title I
 Table 1.a. Provider Characteristics: EMA and U.S. Totals
 Source: Annual Administrative Report, Reporting Period January 1 to December 31, 1995

EMA	Number of Providers by Types										Number of Providers by Ownership						Number of SAARs Submitted	
	Reporting	Hospital-based Clinic or Hospital	Community Health Center	Community Mental Health Center	Other CBO	PWA Coalition	Health Department	Other Public Agency	Private Medical Practice	Other Private Agency	Unknown	Public - Local	Public - State	Public - Federal	Private - Non-profit	Private - For Profit		Unincorporated
Anaheim	8	1	2	1	5	1	1	1	1	1	1	1	1	1	6			8
Atlanta	24	2	1	1	8	1	4				6	4	1	1	19			24
Baltimore	86	21	1	1	49	1	12				1	31	1	1	53	1		86
Bergen/ Passaic	22	5			11	2	1				3	9			17	1		22
Boston	77	6	10	1	48	1	3				7	9			68			77
Chicago	62	8	5	1	37	5	2				4	7	3		52			62
Dallas	31	1			28	1	1				4	2			22	5	1	31
Denver	24	3			11	1	2				5	2	3		18			24
Detroit	29	4	1	1	19	2					2	7	5		29			29
Fort Lauderdale	19	1	2		6	1	2				3	2	1		9	4		19
Houston	40	5	1		33		1				1	23	1		32	4		40
Jersey City	16	3	4		9						1	11			16			16
Kansas City	29	3	1	1	13	5					3	10	3		18	5		29
Los Angeles	88	9	6	1	57	1	4				7	59	11		74	3		88
Miami	35	3	5	1	15	1	2				7	31	2		26	6		35
Nassau/ Suffolk	22	3	1		9	1	4				4	5	4		15			22
New Haven/ Fairfield	27	1	1	1	13	5	1				5	13	6		20	1		27
New Orleans	15	1	1	1	7	1	1				2	10	2		13			15
New York City	194	35	8	5	113	9	8				13	141	31		157		1	194
Newark	42	11	1		30						3	28			38	1		42
Oakland	35	3	3		26	2	2				1	19	4		31			35
Orlando	13	1			8	3	1				1	2	1		9			13
Philadelphia	60	11	2		45	1	1				1	33	3		55			60
Phoenix	19	1	1	1	11	2	2				1	2	5		14			19
Ponce, PR	13	1			8	1	1				2	13	1		10	1		13
Riverside/ San Bernardino	8				6	2	2				6	5	2		6			8
San Diego	32		7		21	3	1				3	19	4		27			32
San Francisco	80	11	6	3	51	4	1				3	31	12	3	65			80
San Juan	21	4	2		12	1	1				1	21	4		15			21
Seattle	27	2	5	1	13	3	1				2	4	3		21		1	27
St. Louis	18				10	4	4				4	7	3		12	2		18
Tampa/ Saint Petersburg	35	4	2	1	17	1	3				6	12	1	4	28			35
Washington, D.C.	62	2	2	1	35	1	8				7	28	15		44	2		62
West Palm Beach	12		1	1	10							3	1		11			12
U.S. Total	1,325	165	82	24	794	13	95	34	17	101	0	676	182	45	8	1,050	35	1,325
% of Total	100%	12.5%	6.2%	1.8%	59.9%	1.0%	7.2%	2.6%	1.3%	7.6%	0.0%	51.0%	13.7%	3.4%	0.6%	79.2%	2.6%	100%
Number of EMAs = 34																		

Information on provider type comes from Standard and Modified AARs; information on ownership and minority providers comes only from Standard AARs.

Self-Test 9: Using AAR National Data Tables on Title I
Provider Characteristics

Use the table in Exhibit 13 to answer the following questions about service providers funded under Title I of the CARE Act. The answers are on page 41 at the end of this section.

- a. Based on the data for Detroit, answer the following questions: (1) How many service providers are included in the AAR report? (2) What type of provider is most common in Detroit? (3) How many and what percentage are minority providers? (4) What percentage of the providers are public agencies?
- b. Nationally, what percentage of Title I-funded providers are community health centers? other community-based organizations? health departments?
- c. Nationally, what percentage of Title I-funded providers are classified as minority?
- d. Nationally, what percentage of Title I-funded providers are public agencies?
- e. Nationally, how many PWA coalitions are funded by Title I? What percentage of all Title I-funded providers do they represent?

The national AAR data tables also provide information on the number and characteristics of clients served by CARE Act-funded providers in each EMA and State. These tables can give you a general sense of what clients in your EMA or State “look like” demographically, but the numbers need to be interpreted with caution. Each CARE Act provider reports each client only once, no matter how many times s/he comes to the provider for services during the year. However, clients who receive services from more than one provider are reported by *each* provider who serves them. As a result, the combined client data shown in the AAR data tables are not “unduplicated.” They contain an unknown number of clients who have been reported more than once.

Exhibit 14 displays a sample AAR table on the clients served by Title I-funded providers in EMAs. The first column lists the EMAs in alphabetical order. The remaining columns show total clients, new clients, and anonymous clients (those for whom demographic data are not collected); the estimated percentages of clients with HIV and AIDS; and the distribution of clients by gender, race/ethnicity, and age. Use Self-Test 10 to become familiar with this type of AAR table.

Exhibit 14

Service Providers Funded Under Title I
 Table 1.d. Clients Served - Numbers, Demographics, and HIV Status: EMA and U.S. Totals
 Source: Annual Administrative Report, Reporting Period January 1 to December 31, 1995

EMA	Providers Reporting		Clients Served		HIV/AIDS Status*		Race/Ethnicity					Age					
	Total Clients (Sum of Unrounded Counts)	New Clients (Sum of Unrounded Counts)	Anonymous Clients (Sum of Unrounded Counts)	No. Providers Reporting HIV Status	Estimated Percent of Clients with HIV	Estimated Percent of Clients with AIDS	Missing / Unknown	White	Black	Hispanic	Asian/Pacific Isl.	American Indian	Missing / Unknown	Under 13 Years	13-19 years	Age 20 and Over	
Anaheim	6,330	1,760	2,310	6	35.4%	62.3%	110	3,110	730	2,550	150	30	60	40	200	5,560	510
Atlanta	11,150	4,560	10	19	71.6%	28.4%	1,200	3,170	7,030	210	20	20	410	540	80	10,530	#
Baltimore	21,540	9,660	3,880	70	48.4%	43.9%	1,100	2,670	19,240	190	130	10	1,600	1,130	740	18,620	2,350
Birmingham	5,850	3,630	8,970	21	59.1%	38.0%	2,780	3,270	3,250	2,000	10	30	1,100	180	100	7,400	1,280
Boston	14,800	7,600	1,060	74	56.6%	38.9%	4,600	7,630	3,520	2,700	70	90	700	910	200	13,530	170
Chicago	49,460	9,930	910	56	57.0%	43.0%	10,620	18,100	20,040	9,350	1,650	50	280	1,200	720	47,180	350
Dallas	13,740	3,440	10,150	28	39.0%	59.1%	2,290	7,910	3,980	1,690	50	80	80	440	150	13,150	#
Denver	5,790	2,400	4,730	22	36.1%	62.2%	850	3,720	970	1,690	10	20	20	80	30	5,680	#
Detroit	6,010	4,050	7,410	27	49.8%	39.2%	2,040	3,200	5,550	140	10	10	310	180	40	7,710	110
Fort Lauderdale	19,970	7,420	70	18	57.2%	40.6%	1,110	7,490	10,370	1,520	150	40	400	710	400	18,530	330
Houston	22,380	8,100	11,880	38	42.3%	54.5%	1,650	9,170	9,500	3,540	40	140	920	920	1,350	20,060	10
Jacksonville	12,910	6,780	4,750	16	39.8%	56.0%	1,200	2,570	4,850	4,090	60	40	1,300	920	550	10,260	1,180
Kansas City	6,540	1,110	43,400	24	45.6%	54.0%	810	3,170	1,880	330	40	60	3,060	80	100	5,300	3,070
Los Angeles	53,780	28,050	61,500	78	52.1%	46.8%	10,570	15,720	14,440	20,220	1,160	480	1,740	2,800	4,030	48,480	450
Miami	18,480	8,240	2,470	35	53.0%	46.8%	1,670	3,870	6,230	20	20	10	70	710	220	17,510	40
Nassau Suffolk	4,620	2,080	3,890	19	46.8%	52.8%	2,750	1,060	1,590	700	20	20	40	50	30	4,460	60
New Haven/Fairfield	4,100	2,670	360	25	39.4%	60.8%	1,120	910	1,940	50	10	20	130	230	50	3,760	50
New Orleans	2,810	1,710	0	12	39.4%	60.8%	1,850	1,120	610	1,940	50	10	330	230	50	2,530	60
New York City	108,570	57,870	480,100	131	47.3%	38.8%	81,660	45,940	37,070	1,500	780	2,530	4,970	5,610	8,770	82,170	8,210
Newark	24,780	8,930	1,790	37	54.2%	31.3%	1,250	3,200	14,970	20	10	240	1,240	1,240	2,140	21,660	610
Oakland	5,820	2,920	1,020	32	46.9%	51.7%	1,400	1,700	3,210	470	60	110	50	50	20	5,000	50
Orlando	17,860	7,730	0	12	76.1%	23.8%	1,730	6,240	6,680	2,350	110	70	230	320	2,530	14,570	250
Philadelphia	28,980	15,190	107,430	51	53.6%	39.5%	8,590	4,330	15,710	3,860	270	40	2,750	760	610	18,940	5,650
Phoenix	7,870	4,610	7,250	18	63.6%	28.3%	1,680	5,060	3,310	1,100	70	260	70	230	260	7,310	70
Ponce, PR	1,810	610	0	13	46.4%	53.8%	530	1,080	530	#	#	#	#	100	40	1,470	#
Riverside/San Bernardino	4,110	1,660	330	7	11.0%	47.5%	3,400	2,460	610	180	40	60	130	30	30	3,970	80
San Diego	40,680	13,870	48,230	21	55.5%	39.1%	10,710	11,000	18,710	6,500	530	2,470	3,480	2,880	6,840	17,860	13,060
San Francisco	43,830	24,930	10,280	77	42.2%	55.9%	7,390	24,750	10,960	5,310	1,400	630	610	470	400	43,280	60
San Juan	13,850	10,640	3,330	20	56.6%	42.1%	1,020	#	13,530	#	#	#	510	370	120	12,850	510
Seattle	13,240	5,610	9,550	28	25.0%	54.3%	2,740	10,700	1,220	670	310	220	120	250	60	12,820	#
St. Louis	3,630	2,330	0	16	76.7%	21.3%	610	2,070	1,650	40	10	20	20	150	50	3,730	#
Tampa/Saint Petersburg	6,280	3,550	520	28	56.0%	39.7%	1,100	4,460	2,750	800	40	10	160	420	80	7,610	180
Washington D.C.	11,680	3,260	1,940	51	43.1%	42.3%	3,340	2,690	7,480	630	40	10	600	620	120	10,550	360
West Palm Beach	7,210	3,220	320	12	56.2%	43.8%	3,060	1,960	4,240	620	10	350	350	1,180	170	10,550	50
U.S. Total	1,325	283,940	902,090	1,145	51.3%	43.4%	424,690	197,030	252,630	138,050	8,010	5,990	24,920	25,460	28,140	532,200	40,820
% of Total	100%	45.3%	67.8%	30.4%	51.3%	43.4%	1.8%	31.4%	40.3%	22.0%	1.3%	1.0%	4.0%	4.1%	4.5%	84.9%	6.5%

Counts are rounded to nearest 10 (to 10 if between 1 and 14), except that # replaces demographic values less than 6. U.S. totals are calculated on unrounded data.
 EMA and national percentages of clients with AIDS and with HIV (not AIDS) are averages weighted by the number of clients.
 Information for this table comes from Standard and Modified AARs.
 * Providers with missing or incomplete data on HIV/AIDS status are not represented in this section of the table.
 # denotes an EMA for which the sum of reported clients in component categories of a characteristic (e.g., Male plus Female) exceeds reported total clients, causing the calculated value of Missing / Unknown clients to be negative.

Self-Test 10: Using AAR National Data Tables on Clients
Served by EMAs

Use Exhibit 14 to answer the following questions on clients served by Title I-funded providers in EMAs. The answers are on page 41 at the end of this section.

- a. Based on the data for Miami, answer the following questions: (1) How many clients were reported by service providers during 1995? (2) What percentage of all reported clients were new clients? (3) What percentage of reported clients had AIDS? (4) What percentage of reported clients were female? (5) What was the most frequently reported race/ethnicity of clients? (6) How many and what percentage of clients were under age 20?
- b. The information provided about Miami does not provide a precise client profile. Why not?
- c. Based on the U.S. totals, answer the following questions: (1) What percentage of clients reported in 1995 were new clients? (2) What percentage had AIDS? (3) What percentage were female? (4) What was the most frequently reported racial/ethnic background? (5) What percentage of clients were under age 20?
- d. Based on the reported information, do the demographic characteristics and HIV/AIDS status of Miami clients seem similar to the national profile of clients served by EMAs?

Data on your State's AIDS Drug Assistance Program (ADAP) and comparative data from other States can be obtained from AAR data tables. Because each State uses a unified intake process that eliminates the possibility of duplicated counts, the AAR should provide an accurate demographic profile of ADAP clients in your State. The tables include information on:

- **ADAP characteristics** (e.g., type of administrative agency, medical eligibility criteria, length of processing period for new applications, frequency of required recertification, existence of a waiting list, and number of people on the waiting list at the end of the reporting period);
- **ADAP funding and expenditures;**
- **client numbers and characteristics; and**
- **drugs dispensed.**

Exhibit 15 displays a sample ADAP table. The first column lists the 42 States (including District of Columbia and Puerto Rico) that reported ADAP programs in 1995. The remaining columns present the same kinds of client demographic data reported for Title I and Title II clients but, in this case, the numbers are precise because the counts are unduplicated. Use Self-Test 11 to gain familiarity with this table.

Exhibit 15

AIDS Drug Assistance Programs
Table 3.c. Clients Served (Unduplicated): State and U.S. Totals
 Source: Annual Administrative Report, Reporting Period January 1 to December 31, 1995

State	Reporting Period, Months	Clients Served		Gender		Race/Ethnicity							Age			
		Total Clients	New Clients	Male	Female	Missing / Unknown	White	Black	Hispanic	Asian / Pacific Isl.	American Indian	Missing / Unknown	Under 13 Years	13-19 Years	Age 20 and Over	
Alabama	12	1,060	290	890	170	#	480	560	#	#	#	#	#	#	1,050	#
Alaska	12	640	410	580	60	#	460	40	130	40	#	#	#	#	630	#
Arizona	12	13,380	6,410	12,190	1,150	50	6,350	2,210	3,970	240	80	530	10	30	13,220	120
California	12	710	370	640	60	#	450	80	120	#	#	60	#	#	710	#
Colorado	12	1,450	880	1,100	350	#	470	490	350	#	10	120	10	#	1,430	#
Connecticut	12	110	40	80	30	#	60	50	10	#	#	#	#	#	110	#
Delaware	12	390	390	300	90	#	70	270	40	#	#	#	#	#	390	#
District of Columbia	12	8,060	4,060	6,720	2,300	40	3,030	4,340	1,460	20	20	170	60	100	8,860	#
Florida	12	1,260	530	1,010	270	#	400	660	20	#	#	#	#	10	1,270	#
Georgia	12	140	50	130	10	#	80	#	10	40	#	#	#	#	140	#
Hawaii	12	60	10	50	10	#	50	#	10	#	#	#	#	#	60	#
Idaho	12	2,050	1,450	1,860	180	#	1,020	610	290	60	60	#	#	#	2,040	#
Illinois	12	470	180	420	40	#	380	70	10	#	#	#	#	#	410	60
Indiana	12	140	70	120	20	#	110	10	#	#	#	#	#	#	130	#
Iowa	12	220	30	190	30	#	200	30	10	#	#	10	#	#	220	#
Kansas	12	330	190	290	40	#	200	80	10	#	#	40	#	#	300	30
Kentucky	12	420	170	330	100	#	150	230	30	#	#	10	#	#	420	#
Massachusetts	12	1,020	660	860	160	#	400	100	220	#	10	290	10	#	1,010	#
Michigan	12	320	130	280	30	#	190	110	20	#	#	#	#	#	320	#
Minnesota	12	450	0	410	30	#	370	40	20	#	10	10	#	#	450	#
Mississippi	12	840	280	650	190	#	330	500	#	#	#	10	#	#	820	#
Missouri	12	1,420	660	1,270	150	#	950	400	20	#	50	10	10	#	1,400	#
Montana	12	30	10	20	#	#	20	#	#	#	10	#	#	#	30	#
Nebraska	12	180	90	160	20	#	130	40	10	#	#	#	#	#	170	#
Nevada	12	260	80	230	40	#	180	30	40	#	#	#	#	#	250	#
New Hampshire	12	110	50	90	10	#	50	#	#	#	#	40	#	#	110	#
New Jersey	12	2,300	950	1,600	700	#	850	850	530	#	#	70	40	10	2,240	#
New York	12	17,140	5,280	13,130	3,410	600	5,950	5,610	5,390	160	40	150	70	16,920	#	
North Dakota	12	20	10	10	#	#	10	#	#	#	#	#	#	20	#	#
Ohio	12	590	210	520	70	#	430	120	20	#	10	20	#	#	580	#
Oklahoma	12	450	130	360	70	#	360	60	20	#	20	#	#	#	450	#
Puerto Rico	12	5,550	2,530	3,520	1,460	630	#	#	4,960	#	590	40	40	4,880	590	#
Rhode Island	12	130	60	110	20	#	70	10	20	#	30	#	#	130	#	#
South Carolina	12	460	250	350	140	#	130	330	10	#	10	10	#	460	#	#
South Dakota	12	40	20	30	#	#	30	#	#	#	#	#	#	40	#	#
Tennessee	12	180	110	150	30	#	100	80	#	#	#	#	#	180	#	#
Texas	12	4,710	1,500	4,030	680	#	2,380	1,150	1,030	10	10	120	20	10	4,660	#
Utah	12	120	60	110	10	#	100	10	10	#	#	#	#	120	#	#
Virginia	12	850	480	660	160	30	290	470	30	#	#	60	10	840	#	#
Washington State	12	720	280	660	60	#	550	50	80	10	20	10	#	720	#	#
West Virginia	12	60	20	60	#	#	60	10	#	#	#	#	#	60	#	#
Wisconsin	12	270	90	250	20	#	190	60	20	#	#	#	#	270	#	#
U.S. Total		70,090	29,490	56,440	12,290	1,360	28,060	19,950	18,940	580	320	2,250	440	320	68,530	810
% of Total		100%	42.1%	80.5%	17.5%	1.9%	40.0%	28.5%	27.0%	0.8%	0.5%	3.2%	0.6%	0.5%	97.8%	1.2%

Number of States = 42
 Counts are rounded to nearest 10 (to 10 if between 1 and 1.4), except that # replaces demographic values less than 6. U.S. totals are calculated on unrounded data.

Self-Test 11: Using AAR National Data Tables on ADAP Clients

Use Exhibit 15 to answer the following questions on clients served by State AIDS Drug Assistance Programs. The answers are on page 42 at the end of this section.

- a. Based on the data for California, answer the following questions: (1) How many clients did the ADAP serve in 1995? (2) About what proportion of the total clients were new? (3) Among the ADAP clients whose gender was reported, what percentage were female? (4) What was the most common race/ethnicity among ADAP clients?
- b. Compared to most other States, were California clients more or less likely to be under 20 years of age?
- c. Based on the U.S. totals, answer the following questions: (1) What percentage of total ADAP clients were new clients in 1995? (2) What percentage were female? (3) What was the most common race/ethnicity?
- d. What State served the most ADAP clients in 1995? What State served the fewest ADAP clients?
- e. These counts are not exact. How do you know?

The AAR data tables provide valuable information for needs assessment, service planning, and program evaluation. The information summarized in the national tables, and the more detailed data that the administrative/lead agency collects from individual service providers, can help your planning group analyze the continuum of care and the types of clients and services that require more resources. These and other secondary data sources should not be overlooked when making decisions on the uses and distribution of CARE Act funds.

Answers to Self-Tests 1 and 2

Self-Test 1: Using Tables on State AIDS Cases and Rates

- a. New York: 12,369 in 1995, 12,379 in 1996. New York also reported the largest cumulative number of cases (106,897).
- b. District of Columbia: 185.2 in 1995; 232.3 in 1996. The District is different because it is a city, but it is counted with the States because of its special status. Second highest were Puerto Rico in 1995 (68.7) and New York in 1996 (68.1).
- c. New York: 1,936; and Florida: 1,233.
- d. AIDS incidence rates *decreased* in most (38) States. They increased in 14 States and stayed the same in one (count includes District of Columbia, Puerto Rico, and Virgin Islands).
- e. Louisiana: AIDS incidence rate rose from 24.9 to 33.8, an increase of 36%
($33.8 - 24.9 = 8.9$; $8.9 \div 24.9 = .36$; $.36 \times 100 = 36\%$). The District of Columbia rate rose from 185.2 to 232.3, an increase of 25%. Although the annual AIDS rates were higher in the District of Columbia, Louisiana had a higher *rate of increase*.

Self-Test 2: Using Tables on AIDS Cases by Exposure Category

- a. A total of 54,653 male adult/adolescent AIDS cases were reported in 1996. Since 23,341 of these cases were white males, this racial group accounted for 43% of the reported cases
($23,341 \div 54,653 = .43$; $.43 \times 100 = 43\%$).
- b. Whites, non-Hispanics had the largest number of cases (23,341); American Indians/Alaska Natives had the smallest number (166).
- c. "Men who have sex with men" accounted for the largest number of cases among males in each racial/ethnic group. Among blacks and Hispanics, nearly as many cases were in the "injecting drug use" exposure category.
- d. American Indians/Alaska Natives - 14% of 1996 cases and 17% of cumulative cases.
- e. Blacks (481 cases in 1996).
- f. 37% ($20,199 \text{ black male AIDS cases} \div 54,653 \text{ total male AIDS cases} = .37$; $.37 \times 100 = 37\%$). Blacks were overrepresented among male AIDS cases. Their rate was more than three times higher than what would be expected ($37 \div 12 = 3.1$).
- g. Heterosexual contact: Blacks (9% of 1996 cases) and Hispanics (8% of 1996 cases). Injecting drug use: Hispanics (33% if only the "injecting drug use" exposure category is considered; 37% if the "injecting drug use" category and the "men who have sex with men and inject drugs" categories are combined).

Answers to Self-Tests 3, 4 and 5

Self-Test 3: Using Maps Showing AIDS Annual Rates

- a. North Dakota (reported as "0.0," which means less than 0.05 female AIDS cases per 100,000 population).
- b. District of Columbia, 107.0; New York, 41.7; Puerto Rico, 36.1; New Jersey, 30.8; Florida, 29.5; Maryland, 28.9; Delaware, 26.7.
- c. Most of the western half of the country (except for California, Nevada, and Texas) - the Plains, Rocky Mountain, and Northwestern regions.

Self-Test 4: Using EMA Prevalence Tables

- a. "Not diagnosed with AIDS" (3,300 adults/adolescents-2,400 males and 900 women-are in this disease stage out of 5,000 total HIV cases).
- b. Whites - 21% ($300 \div 1,400 = .21$; $.21 \times 100 = 21\%$). Women account for 32% of the black cases and 31% of the Hispanic cases. (Numbers for Asian/Pacific Islanders and American Indian/Alaska Native groups are very small. Because of rounding, it is impossible to obtain accurate gender percentages for those populations.)
- c. 72% ($3,600 \div 5,000 = .72$; $.72 \times 100 = 72\%$).

Self-Test 5: Using Summary HIV Seroprevalence Data Tables

- a. No. In adolescent medicine clinics, the median percent positive rates for females and males are the same (0.0% versus 0.0%). In homeless and runaway youth clinics, the median percent positive rate is higher for males (1.9% versus 1.1%). In juvenile detention centers, the median percent positive rate is higher for females (2.8% versus 0.0%).
- b. Footnote 4 explains that gender was analyzed only for centers reporting at least 50 specimens per group. Specimens also had to be collected and tested according to CDC protocol (footnote 3). Apparently, one juvenile detention center had fewer than 50 female specimens meeting these requirements.
- c. The median percent positive was highest (2.8%) among adolescent women at juvenile detention centers. This conclusion should be viewed as tentative because of the limited number of testing sites and female specimens tested in two of the three clinic categories (homeless and runaway youth clinics and juvenile detention centers).
- d. Highest: Miami (7.4%) and Baltimore (6.4%). Lowest: Detroit, Minneapolis, Phoenix, Portland, and Seattle (all 0.9%).
- e. Washington, D.c. (median percent positive - 50.9%).
- f. Largest number: Los Angeles (9,187). Smallest number: Dallas (1,345).
- g. Of the three exposure categories analyzed, only two apply to women. Data on HIV seroprevalence among heterosexual women who have injected illicit drugs are available for only two metropolitan areas. The most extensive data on women are reported in the "no acknowledged risk" category.

Answers to Self-Tests 6, 7 and 8

Self-Test 6: Using Line Charts

- a. Throughout the study period, black military applicants have the highest HIV seroprevalence rates, Hispanic military applicants are in the middle, and white military applicants have the lowest rates.
- b. Since 1985, HIV seroprevalence rates have decreased among military applicants in all three racial/ethnic groups. Although the relationship among the three groups stayed the same throughout the study period (blacks with the highest rates, Hispanics in the middle, and whites with the lowest rates), the trend lines for the three groups look different. The white rate started low and the line was relatively "flat." The Hispanic trend line fluctuated more than the black or white trend lines.
- c. The HIV seroprevalence rate among black military applicants peaked during the second half of 1986 when it was above 0.40% but below 0.45%.

Self-Test 7: Using Bar Charts

- a. There is no "typical" relationship. Between January 1992 and December 1993, white and Hispanic female Job Corps entrants had lower HIV seroprevalence rates than their male counterparts. Black female Job Corps entrants had a higher HIV seroprevalence rate than their male counterparts.
- b. Among female Job Corps entrants, black females have the highest HIV seroprevalence rates (about 0.55%). Among male Job Corps entrants, black males have the highest HIV seroprevalence rates (about 0.35%).
- c. The male/female bars for "all races" indicate that female Job Corps entrants have a higher HIV seroprevalence rate than men. However, in two of the racial/ethnic groups (white and Hispanic) female applicants have lower rates than men. Because the female bar for "all races" looks similar to the bar for black females, it appears that black women account for a high proportion of all female Jobs Corps entrants. Only a rough visual estimate is possible since the report does not provide precise figures on the number of persons in each racial/ethnic group.

Self-Test 8: Using Maps with Bars

- a. HIV seroprevalence among men having sex with men appears to be highest among men tested at STD clinics in Washington, D.C. Houston, New York, Boston, Los Angeles and Miami also seem to have high seroprevalence rates. You would need a ruler to compare the rates more precisely.
- b. No. The information provided on the map does not allow you to differentiate locations with median rates of 0% from locations where no tests were reported.

Answers to Self-Tests 9 and 10

Self-Test 9: Using AAR National Data Tables on Title I Provider Characteristics

- a. (1) Detroit submitted reports for 29 providers. (2) "Other CBOs" are the most common type of provider (19 providers). (3) Of the 29 Detroit providers, 17 (58.6%) are minority providers. (4) None of the providers are public agencies. All 29 are private-nonprofit organizations.
- b. Nationally, 6.2% of the Title I-funded providers are community health centers, 59.9% are "other CBOs," and 7.2% are health departments.
- c. 51%.
- d. 17.7%. (Sum the local, State, and Federal public agency columns to get this answer.)
- e. Thirteen PWA coalitions are funded by Title I. They represent 1% of all Title I-funded providers.

Self-Test 10: Using AAR National Data Tables on Clients Served by EMAs

- a. (1) Miami service providers reported 18,480 clients. (2) New clients accounted for 44.6% of all reported clients ($8,240 \div 18,480 = .446$; $.446 \times 100 = 44.6\%$). (3) An estimated 46.9% of the clients had AIDS. (4) Females accounted for 28.5% of reported clients ($5,270 \div 18,480 = .285$; $.285 \times 100 = 28.5\%$). (5) The largest number of clients were black. (6) Of the clients whose age was reported, 930 (5%) were under age 20 ($710 + 220 = 930$; $930 \div 18,440 = .05$; $.05 \times 100 = 5\%$).
- b. The combined client data are not "unduplicated." If a client was receiving services from several providers, s/he was reported several times—once by each provider.
- c. (1) In 1995, new clients accounted for 45.3% of all clients reported. (2) Of the total clients, 43.4% had AIDS. (3) About 30.4% of the clients were female. (4) The most frequently reported race/ethnicity was black (40.3%). (5) About 8.6% of the clients were under age 20 (4.1% + 4.5%).
- d. The Miami and U.S. client profiles are fairly similar in terms of the percentage of new clients, the percentage of clients with AIDS, the percentage of women, and the racial/ethnic distribution of the clientele. However, Miami had a lower percentage of clients under age 20 (5% compared to 8.6% nationally), a higher proportion of Hispanics (33.7% compared to 22% nationally) and a higher proportion of blacks (44.8% compared to 40.3% nationally).

Using Data to Assess HIV/AIDS Service Needs

Answers to Self-Test 11

Self-Test 11: Using AAR National Data Tables on ADAP Clients

- a. (1) The California ADAP served 13,380 clients in 1995. (2) New clients accounted for a little less than half of the total clients ($6,410 \div 13,380 = .479$; $.479 \times 100 = 47.9\%$). (3) About 8.6% of the ADAP clients whose gender was reported were female ($1,150 \div 13,340 = .086$; $.086 \times 100 = 8.6\%$). (4) ADAP clients were most likely to be white.
- b. California clients were more likely to be under age 20. Only six other States reported clients in both the "under 13 years" and "13-19 years" age groups.
- c. (1) Nationally, 42.1% of ADAP clients were new clients in 1995. (2) About 17.5% of all clients were female. (3) Clients were most likely to be white (40%).
- d. New York served the most ADAP clients in 1995. The 17,140 New York clients accounted for nearly one-quarter of the nation's ADAP clients. North Dakota had the smallest ADAP caseload (about 20 clients).
- e. All numbers in the table end in a 0 which shows that they have been rounded. The note at the bottom of the table indicates that all counts of 6 and above are rounded to the nearest 10; counts of less than 6 are shown as "#" in the table.

Part 2

Needs Assessment: The Foundation for Priority Setting

The Role of Needs Assessment

Importance of Needs Assessment

Needs assessment refers to the process of gathering and analyzing information from a variety of sources in order to determine the current status and unmet needs of a defined population or geographic area. The focus may be on a single issue, such as HIV/AIDS, or on a wide range of issues. The resulting information on service needs, available resources, and access barriers can be used to identify service gaps and develop strategies for filling these gaps.

Needs assessment is the cornerstone of the CARE Act planning process. Setting appropriate priorities for the allocation of CARE Act resources requires an understanding of the local HIV epidemic, current and projected service needs, and the resources that are available to meet these needs. This information provides a solid foundation for developing, improving, and/or expanding the HIV/AIDS continuum of care. State and local health departments, AIDS service organizations, and other community-based organizations can use the information to plan new HIV prevention and care initiatives and to secure external funding for these services. Advocates can use the information to justify their recommendations for policy and programmatic changes. Needs assessments also encourage cooperative action by highlighting areas in which public, private, and community sectors can work together to use limited resources more efficiently.

Exhibit 16 summarizes CARE Act requirements for Planning Council and Consortium needs assessments. Although these planning groups are not required to conduct a comprehensive needs assessment each year, they are expected to consider and integrate new information as it becomes available. By conducting annual reviews of HIV prevalence estimates and periodically examining changes in service needs and networks, CARE Act planning groups can ensure that their priorities and strategies are responsive to emerging issues and trends. The epidemiologic data maintained by public health departments and the surveillance expertise of their staff make them valuable partners in this process.

Exhibit 16

CARE Act Requirements for Needs Assessment

HIV Health Services Planning Councils are required to establish priorities for the allocation of Title I funds and strategies for meeting these priorities based on:

- the documented needs of the HIV-infected population;
- the cost and outcome effectiveness of proposed strategies and interventions (if such data are reasonably available);
- the priorities of the HIV-infected communities for whom the services are intended; and
- the availability of other governmental and nongovernmental resources.

HIV Health Services Planning Councils also are required to:

- establish methods for obtaining input on community needs and priorities;
- assist the grantee in demonstrating a severe need for supplemental Title I funds by identifying co-morbidity factors (e.g., sexually transmitted diseases, substance abuse, severe mental illness) and new or growing subpopulations with HIV disease in the needs assessment; and
- participate in the development of a Statewide Coordinated Statement of Need.

HIV Care Consortia seeking State assistance under Title II must:

- demonstrate that they have conducted an assessment of service needs, established a plan to meet these needs, and involved PLWH in these processes;
- provide assurances that service needs will be addressed through the coordination and expansion of existing programs before new programs are created; and
- demonstrate that adequate planning has occurred to meet the special needs of families with HIV disease, including family-centered and youth-centered care.

The CARE Act does not require each HIV Care Consortium to participate in the development of a Statewide Coordinated Statement of Need, but HRSA guidance requires fair representation from each Title.

Needs assessments require the active and informed participation of PLWH, service providers, and other community representatives. This participation is particularly important when CARE Act planning groups are developing data collection instruments, identifying ways of reaching infected and affected populations, and interpreting study results. You can prepare for these roles by becoming familiar with the characteristics and components of effective needs assessments and the steps in the needs assessment process.

Principles for Needs Assessment

To produce valid and credible findings, CARE Act needs assessments should be guided by five principles. The following principles are part of a “standard protocol” for conducting needs assessments that was developed by Title I representatives and Division of HIV Services (now Division of Service Systems) staff in 1993.

1. Needs assessments should be comprehensive, covering a broad range of service categories, populations, and geographic areas.

A comprehensive needs assessment should include five major components:

- An ***epidemiologic profile*** that describes the current status of the epidemic in the service area, specifically the prevalence of HIV and AIDS among defined subpopulations. The profile also should describe trends in the epidemic since its onset, with a focus on trends in the last two years and projections of expected trends for the next three to five years.
- An ***assessment of service needs among affected populations*** that explores the perspectives of PLWH, service providers, and other community representatives. A careful assessment of barriers to the receipt of services is an important aspect of this component. Information should be solicited from PLWH who use services and those who are not in care. Service providers also can contribute to an understanding of PLWH needs. However, if provider and client priorities differ, the focus must stay on the needs expressed by PLWH.⁴
- A ***resource inventory*** that provides a comprehensive picture of the continuum of services for PLWH in the service area, regardless of the funding source.
- A ***profile of provider capacity and capability*** that examines the extent to which services identified in the resource inventory are available, accessible, and appropriate for PLWH. Assessments of ***capacity*** describe how much of which services a provider can deliver (i.e., the number of service units and/or the estimated number of clients who can be served). Assessments of ***capability*** describe the extent to which each provider’s services are geographically and physically accessible, culturally appropriate, and available at convenient times. Some needs assessments also explore the ***acceptability*** of services, as indicated by client satisfaction surveys.
- An ***assessment of gaps in services*** that brings together all of the quantitative and qualitative data on service needs, resources, and barriers to help set priorities for resource allocation.

⁴John Snow, Inc. *Ryan White CARE Act Title I Manual*. Prepared for the Division of HIV Services, Health Resources and Services Administration, Bureau of Health Resources Development. Boston, MA: John Snow, Inc., 1997.

A comprehensive needs assessment gathers data from a variety of primary and secondary sources. Some of the most common information-gathering techniques include individual interviews, mail surveys, interviews with “key informants” (i.e., people with special knowledge about a subpopulation), focus groups, community forums, public hearings, and visits to particular communities or service delivery sites. Your planning group also can obtain useful data from secondary sources, such as HIV/AIDS surveillance reports, HIV seroprevalence studies, special studies of PLWH subpopulations, and HIV-related surveys conducted by other groups. AAR data tables, the activity reports submitted by CARE Act-funded providers, and the results of client satisfaction surveys can help you assess provider capacity and capability.

2. Needs assessments should be broadly participatory and should seek input from special population groups affected by the local epidemic.

CARE Act needs assessments should consider a wide range of perspectives. PLWH and other community representatives on your planning group should be actively involved in planning and overseeing the needs assessment process. Special outreach efforts may be needed to locate and involve people who have not publicly disclosed their HIV status; rural residents with HIV disease; and “special need” groups, such as women, youth, homeless people, and PLWH with co-morbidities. Maintaining the participation of infected and affected populations also should be a high priority.

CARE Act planning groups vary in the extent to which members are directly involved in conducting the needs assessment. The extent of member involvement typically depends on the scope of the needs assessment or update; the size and funding level of the planning group; the availability of staff support; the amount of primary data collection and analysis that will be required; and the amount of time that members are willing and able to spend on the process. If a consultant is retained to design and implement the needs assessment, your planning group or a designated committee may assume responsibility for specific tasks, such as updating a specific component, convening community forums, or analyzing secondary data. At a minimum, your planning group should be involved in reviewing the consultant’s study design, data collection instruments, plans for involving infected and affected communities, and final study report.

3. Needs assessments should include both quantitative and qualitative information.

Quantitative data should be the starting point for needs assessments. Most CARE Act planning groups find it helpful to supplement these data with qualitative (nonnumerical) information on service availability, accessibility, and appropriateness. Quantitative data can be obtained from epidemiologic reports, surveys, and administrative databases. Qualitative information can be obtained through key informant interviews, focus groups, community forums, and public

hearings. The information collected through interviews or guided discussion usually is summarized in a narrative, although it is possible to code the responses for statistical analyses.

4. The needs assessment process should be developed and followed in a manner that encourages community acceptance of the findings.

CARE Act planning groups that involve representatives of infected and affected communities in determining the purpose, scope, and methods of the needs assessment are more likely to attain community acceptance of the study findings. Decisions must be made on the populations and services to be targeted, the needs assessment components to be updated, and the methods that will be used to obtain this information. By involving PLWH and other community representatives in these decisions, your planning group can ensure that the study findings are relevant and important to key constituencies.

Community acceptance also depends upon the credibility of the team that conducts the needs assessment. To achieve this credibility, the members of the study team should be knowledgeable about HIV/AIDS services and the populations being assessed, have skills and experience in conducting and analyzing needs assessments, and have a strong commitment to fair and objective analysis. The team should include members who understand and can work effectively with people of different races, ethnic backgrounds, and sexual orientations. The planning group or committee that oversees the process also must be perceived as fair and objective and representative of diverse communities.

The results of needs assessments should be widely shared and discussed with infected and affected communities. Your planning group should be clear about *how* you are going to use these results to prepare or update the comprehensive HIV services plan, set resource allocation priorities, and make positive changes in the organization and delivery of HIV/AIDS services. Because many low income and minority communities have been “studied to death,” you need to be able to demonstrate that the needs assessment process will lead to improved services for PLWH and their families. Discussions also should focus on the ways in which the needs assessment data can support the planning and resource development efforts of HIV service organizations and PLWH groups.

5. The needs assessment should provide the information necessary for priority setting.

The design and conduct of the needs assessment should be guided by the information needs of your planning group. What specific questions need to be answered to evaluate the continuum of care and set resource allocation priorities? What special populations need to be studied? Effective needs assessments also require a *shared commitment* to using the results of the needs assessment as the basis for priority setting.

The Needs Assessment Process

Steps in the Needs Assessment Process

A sound needs assessment process involves multiple steps. As shown in Exhibit 17, these steps involve planning for the needs assessment, developing the study design, collecting primary and secondary data, and analyzing and presenting the study results. This section summarizes the key issues and questions that should be addressed at each stage.

Exhibit 17
Typical Steps in Needs Assessment

1. Plan for the needs assessment.
 - Determine the scope and uses of the study.
 - Identify the target populations.
 - Develop the timetable and budget.
 - Decide who will conduct and oversee the needs assessment process.
 - Establish a process for broad PLWH and community input.
2. Design the needs assessment methodology.
 - Identify desired data and possible data sources.
 - Develop the data collection strategy and instruments.
 - Develop an analysis plan.
3. Collect the information required for the needs assessment.
 - Obtain and review secondary data on the local HIV epidemic, service needs, and community resources.
 - Collect new data on the needs of PLWH in and out of care and the capacity and capability of HIV service providers.
4. Analyze the information and present the results in useful formats.

1. Plan for the needs assessment

The first step in the needs assessment process is to reach consensus on the purposes, scope, and organization of the needs assessment. You can contribute to this discussion by ensuring that each of the following questions is carefully addressed:

- **What is the desired scope of the needs assessment?** Will this be a comprehensive needs assessment or an update of an existing needs assessment? What populations, programs, and services will be addressed? Are there any special local or State issues that should be considered (e.g., enrollment of Medicaid-eligible PLWH in managed care plans)?
- **Whose needs are being assessed?** Based on the epidemiologic profile for your service area, what exposure categories, racial/ethnic groups, and other population groups should be targeted?
- **What is the geographic area for the needs assessment, and how will it be subdivided?** What steps will be taken to ensure that the service needs of PLWH in rural and underserved communities receive adequate attention?
- **What is the timetable for the needs assessment?** What deadlines need to be established for specific tasks? By what date must your planning group receive the final report in order to use the information for priority setting and resource allocation?
- **What is the budget for the needs assessment?** Can any of these expenses be covered by “in-kind” contributions of staff, space, or equipment from the administrative/lead agency, local colleges and universities, or other local organizations?
- **Who will conduct the needs assessment?** Will the study be conducted by your planning group, a Needs Assessment Committee, staff of the administrative/lead agency, a consultant, or some combination of volunteers and paid staff? If a Needs Assessment Committee is formed, what steps will be taken to ensure a representative and diverse membership? If a consultant is used, what criteria will be used to select this individual? Who will be responsible for monitoring the quality and timeliness of the consultant’s work?
- **What procedures will be used to obtain input from representatives of infected and affected communities who are not planning group members?** Community members should be involved at every step, from planning the assessment through implementing and interpreting it. This input may be sought by forming a Community Advisory Group, appointing community representatives to the Needs Assessment Committee, scheduling neighborhood meetings to discuss each stage of the needs assessment process, and/or asking planning group members to serve as liaisons with particular communities.

- **How will the results of the needs assessment be used?** What specific information does your planning group need to develop or refine the comprehensive HIV services plan and to establish service priorities? What separate analyses are needed by population group, exposure category, and/or geographic area? How will services be categorized? If you plan to use the service categories in the Title I/Title II grant application guidance as the basis for setting priorities, you should use these same categories in the needs assessment.

2. Design the needs assessment methodology

The next step is to develop a specific design for the needs assessment. If a comprehensive needs assessment is planned, you will need an epidemiologic profile, an assessment of the service needs of PLWH in and out of care, and a resource inventory. If you are updating an existing needs assessment, you will want to review recent epidemiologic data for the service area as well as information on particular populations and services. Ideally, both quantitative and qualitative approaches should be used to collect information. Part 4 describes the most common quantitative and qualitative research techniques and key factors that should be considered when using each data collection method.

The needs assessment may be designed by a Needs Assessment Committee, staff of the administrative/lead agency, or consultants. If staff or consultants are asked to design the needs assessment, your planning group or a designated committee should provide oversight. Representatives of infected and affected communities should be invited to review the design of the needs assessment, the populations to be targeted, the methods of data collection, and the plans for data analysis. Your review of the proposed study design should focus on questions such as the following:

- **What information is available from existing data sources?** Can relevant information be obtained from other needs assessment or planning efforts, such as studies conducted by HIV Prevention Community Planning Groups? Does your planning group have access to the most current HIV/AIDS surveillance and seroprevalence data? Have service providers or the administrative/lead agency conducted client satisfaction surveys or other evaluation studies that can contribute to the needs assessment?
- **What additional information is needed, and how will this new information be collected?** Will there be a PLWH survey to identify service needs and access barriers? Will HIV service providers be surveyed? If surveys are planned, will probability sampling techniques be used to select the samples? (See Part 3.) Will the proposed sample designs and sample sizes capture enough cases to carry out meaningful analyses for important subpopulations and geographic areas? What qualitative information is needed about particular populations and services, and how will it be collected?
- **Who will develop and review the data collection instruments?** Does the study team include PLWH members who are reflective of key HIV populations in your service area? How will representatives of infected and affected communities be

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involved in instrument development and review? Who will review the clarity and appropriateness of the questions for different populations? Is there a plan for pilot testing the data collection instruments with different populations?

- **Who will collect the new information, and how will these people be trained?** Do the proposed interviewers and focus group moderators have experience in working with people of different races, ethnic backgrounds, and sexual orientations? If the study team needs help recruiting HIV-positive, minority, or bilingual interviewers, can your planning group provide them with a list of PLWH coalitions, minority AIDS groups, minority-focused research organizations, and other possible recruitment sites? How will the interviewers be trained and monitored?
- **How will confidentiality be protected?** Procedures for protecting confidentiality should be part of the study design. *No one other than the study team should have access to identifying information on the individuals who participate in interviews, surveys, and focus groups.* Although it may be necessary to include code numbers on questionnaires, PLWH should be assured that their names and other identifying information will not appear on the forms, and that their answers will be grouped with others' responses when the findings are reported. Focus group discussions should not be taped unless participants have given their informed consent, and the tapes should be erased after notes have been taken. Some PLWH may be unwilling to participate in community forums because they do not want to disclose their HIV status. Your planning group may be able to include them in the needs assessment by publicizing a telephone number that they can call during specified hours without giving their names.
- **How will quality control be maintained?** What quality control procedures will be used to ensure that the study produces valid findings, and that it is completed on time? If surveys are planned, does the study design specify who will monitor the interviewers' work, follow up on missing responses, and verify that people really were interviewed? Has the study team allowed sufficient time to revise the data collection instruments based on pilot test results? Who will monitor the study team's expenditures and adherence to the timetable?
- **What are the plans for analyzing and integrating quantitative and qualitative information?** An analysis plan should be developed during the study design stage to ensure that data are collected in an analyzable form, and that they are sufficiently detailed to answer questions about specific populations and services. If both qualitative and quantitative data are being gathered, the analysis plan should indicate how these data will be compared and combined to gain a deeper understanding of service needs. Researchers often prepare "dummy tables" to show how quantitative data will be analyzed and presented. By reviewing these dummy tables, you can learn what information will be available to you in what form and determine whether any important information is missing. Exhibit 18 presents a dummy table for displaying the number and percentage of PLWH expressing a need for various services.

Exhibit 18
Sample Dummy Table
Expressed Need for Health Services (n =)

Service Category	Number of PLWH Indicating Need	Percentage of PLWH Indicating Need
Ambulatory/outpatient medical care		
Dental care		
Pharmaceuticals/medications		
Home health care		
Hospice services		
Mental health therapy/counseling		
Rehabilitation care		
Substance abuse treatment/counseling		

- **When, how, and in what form will study data be presented to your planning group?** Representatives of infected and affected communities should review the data at an early stage of analysis to be sure that the assumptions and interpretations are appropriate for different PLWH subpopulations and racial/ethnic groups.

3. Collect the information required for the needs assessment.

Once the data collection process has begun, your planning group or a designated committee should monitor the study team’s progress to be sure that data collection is proceeding on schedule and according to plan. All changes that might affect results should undergo careful review. When overseeing the data collection process, you should ask questions such as the following:

- **Are sufficient epidemiologic data being collected to assess how, and to what extent, HIV/AIDS is affecting defined populations?** As noted in Part 1, there are many different sources of data for epidemiologic profiles. At a minimum, the study team should review HIV/AIDS surveillance reports, HIV seroprevalence studies for different population groups, vital statistics data on AIDS-related mortality, and surrogate measures of risk for HIV disease, such as teen pregnancy and STD rates. If an HIV Prevention Community Planning Group is functioning in your service area, their data also should be reviewed.

- **Are PLWH in and out of care being contacted regarding their service needs and priorities?** The needs assessment should seek input from diverse PLWH populations and geographic areas. To reach HIV-positive people who are not in care, the study team may need assistance from groups such as PLWH coalitions; gay men of color organizations; AIDS advocacy groups and activists; and human service agencies, such as homeless shelters, substance abuse treatment agencies, and adolescent health clinics.
- **Are existing community resources being inventoried to assess the availability, accessibility, and appropriateness of services for PLWH?** Have any service providers been overlooked in the resource inventory?

4. Analyze the information and present the results in useful formats.

The analysis stage brings data from primary and secondary sources together to answer questions about specific populations and services. Using the analysis plan as a guide, you should ask the study team to:

- **Catalogue primary and secondary data by topic and subcategory.** For example, epidemiologic data can be organized by gender, racial/ethnic group, exposure category, and age group. Data on provider capacity and capability can be organized by service type, geographic area, individual provider, etc. Service needs can be organized by PLWH subpopulations, geographic area, and PLWH in and out of care.
- **Analyze the data.** The purpose of analysis is to identify key needs, trends, and critical issues. If the study team collected quantitative data, they may perform “descriptive analyses” to calculate the number of times that different needs or access barriers were mentioned or to compute the mean and median scores for particular survey items. (See Part 3.) They also may analyze how needs and access barriers vary by subpopulation, geographic area, gender, and other factors. With secondary source data, re-analysis of existing data or further analysis of “raw” data may be appropriate.

Qualitative information also requires analysis. The study team may perform a content analysis on data gathered from key informant interviews, focus groups, and other sources, using specially-designed software. If they do not have access to this software, they may summarize the major themes and/or report the number of times that each need or access barrier was mentioned.

- **Present the data in formats that are understandable and useful to planning group members.** Ask the study team to present a report outline and samples of tables and charts for review and approval by your planning group. If you feel that the report will be difficult for some planning group members to understand, request that the format be revised or simplified. You may want to recommend that more complex tables and technical discussions be placed in appendices.

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Charts can be used to summarize some kinds of information. For example, a map showing the locations of HIV service providers and their service areas would be an effective way of illustrating the geographic distribution of various types of services. The study team could use different colors, symbols, or patterns to distinguish among various types of services or programs serving different populations. The map also could show the mileage from each program to a bus stop and mark programs that provide parking facilities, transportation, and/or outreach services.

Using Needs Assessment Results

By examining HIV/AIDS trends, the service needs of PLWH, and the scope and capacity of the current continuum of care, a needs assessment provides the substantive information needed to establish service priorities and develop strategies for improving services. You can assist the planning group in making effective use of this information by encouraging discussion on the following questions:

- **What information do we have about overall HIV service needs and priorities?** Make this a major topic of discussion at one or several planning group meetings. Divide the presentations by topic-trends in the HIV epidemic, perceived service needs, and existing resources. Based on the planning group's concept of a "core continuum" of care, what services are missing or in short supply?
- **What do we know about the service needs and priorities of different subpopulations?** How do perceived service needs and access barriers differ by subpopulation and for PLWH in and out of care? If we compare each subpopulation's percentage of CARE Act clients with its percentage of local AIDS cases, are there certain groups that appear to be underserved? How do service availability and accessibility vary by geographic location?
- **How should we weigh information from different sources when they do not agree?** The CARE Act states that Title I funds should be allocated based on the priorities of HIV-infected communities. If PLWH say that they need more funds for medications and service providers disagree, what objective data can be used to assess the severity of the problem? If provider activity reports show high rates of utilization and long waiting lists for services that are not identified as priorities by PLWH focus groups, should we use surveys or some other strategy to further investigate the need for these services? If HIV-positive women and men disagree on the amount of CARE Act funding that should go for child care and transportation, how should these different perspectives be reconciled?
- **How should we use evaluation data in our decision making?** The CARE Act encourages Planning Councils to consider the cost and outcome effectiveness of proposed strategies when determining priorities for the allocation of Title I funds. HIV Care Consortia must demonstrate that they have procedures for evaluating the cost and outcome effectiveness of service delivery mechanisms. Does the

Using Data to Assess HIV/AIDS Service Needs

planning group have data on the unit costs and outcomes of HIV services? Are these data being effectively integrated with needs assessment data to set service priorities? If evaluation data suggest that a particular service model is ineffective, should alternative models be recommended to service providers?

- **What should we do if there is not enough CARE Act funding to provide all of the needed services?** Are there other funding streams that can help support these services? What principles should guide our decision making?

All relevant data should be reviewed and discussed before planning group members begin to advocate for specific services. One option is to suggest that each member review the needs assessment results from the perspective of a particular service population. The assigned perspective should be different from that usually taken by the member based on her/his affiliations but not so different that the member will find it difficult to assume the perspective. This role-playing exercise can help planning group members overcome differences in values and viewpoints to reach consensus on service priorities.

Be sure that the needs assessment considers important community factors. For example, changes in the racial/ethnic composition of certain neighborhoods may require a re-evaluation of the cultural appropriateness of existing HIV services. Your resource inventory should track changes in the HIV services offered by health and human service organizations, including new grants that HIV service providers have received and programs that are being downsized or terminated due to lack of funds. You also should consider changes in entitlement programs and the local economy that may reduce access to HIV services.

Exhibit 19 presents a possible situation or “scenario” to demonstrate the ways in which a CARE Act planning group can use data from multiple sources to identify service needs and prepare for priority setting. Use the questions in Self-Test 12 to analyze the information presented in the scenario.

The findings and implications of the needs assessment should be shared and discussed with representatives of infected and affected communities and widely publicized through a variety of media. You can assist with this process by speaking at community meetings, providing information to mainstream and specialized media, and making yourself available to community groups that are seeking needs assessment information. When meeting with community groups, ask them to suggest additional data that should be gathered over the next year to identify service gaps.

Exhibit 19

Scenario: Using Needs Assessment Results

Suppose that your EMA or Consortium service area includes one medium-sized city and several smaller towns and rural areas. Last year, your planning group designated primary care as the top service priority, followed by case management, transportation assistance (e.g., bus tokens), nutrition services (e.g., nutrition supplements and a food pantry), emergency financial assistance for housing and food, and substance abuse treatment. You have never addressed special issues of PLWH subpopulations or geographic areas in your priority setting, although you are aware that these are matters of concern.

This year, you and your colleagues updated the existing needs assessment by reviewing new epidemiologic data, convening PLWH focus groups and a public hearing, and conducting an informal survey of clients at two primary care facilities (a public hospital clinic and a community health center). Your findings were as follows:

- New epidemiologic data - New AIDS cases among women increased 30 percent over the past year. The majority of new AIDS cases were among people with a history of injecting drug use. A large number of new cases were identified among Hispanics, probably because of improved linkages between a multicultural case management provider and a bilingual clinic that conducts confidential testing in a largely rural area that has no CARE Act funding.
- PLWH focus groups - Four focus groups were conducted with women, injecting drug users, African Americans, and men who have sex with men. All of the groups felt more services were needed for their populations. The women's focus group pointed out that women with children cannot access substance abuse treatment because these programs do not provide child care, and two require attendance at evening counseling sessions.
- Public hearing - Thirty-seven PLWH and provider representatives testified at this public hearing. PLWH advocates recommended more State and local funding for medications and less funding for case management. Service providers recommended continued funding for case management, with the understanding that case managers would be trained to help clients comply with medication instructions. You also heard from Hispanic advocates about the need for bilingual case management and support services in the rural areas where former farmworkers most often live. A housing group presented data showing a large increase in homelessness among substance abusers and HIV-positive women with children.
- Informal survey of clients - The survey found that women were having great difficulty accessing primary care due to the lack of transportation and child care and long waits for service (often six or seven hours at the public clinic). African American and Hispanic clients expressed concern about a lack of cultural sensitivity among clinic staff.

Self-Test 12

Questions about Scenario: Using Needs Assessment Results

Exhibit 19 presents needs assessment information from several different sources. Use this information to answer the following questions. Some suggested answers can be found on page 59 at the end of this section.

- a. What important themes or issues can you identify by reviewing information from more than one source?
- b. How do the perceived needs of PLWH differ by gender and racial/ethnic group?
- c. How do PLWH and service providers differ in their perceptions of service needs?
- d. What information gaps in the needs assessment would you like to see filled before the planning group sets service priorities for the following year?

HRSA's HIV/AIDS Bureau has developed a self-assessment module to help CARE Act planning groups evaluate the effectiveness of their needs assessment activities. The module contains questions on the structure and components of the needs assessment; the implementation process; and the ways in which the results of the needs assessment have been used to define or refine the continuum of care, develop a comprehensive plan, and set priorities for resource allocation. The module also contains useful information on methods of collecting and analyzing data. (See References and Resources in Part 6.)

By following the steps outlined in this section, your planning group can produce a needs assessment that is maximally useful for planning and decision making. Exhibit 20 summarizes the key questions that should be addressed when planning, implementing, and reviewing a needs assessment.

Exhibit 20
Questions to Ask at Different Stages of the
Needs Assessment Process

Planning and Design Stage:

- Whose needs are being assessed?
- What kinds of information are needed for planning and priority setting?
- What information is available from secondary data sources?
- What new information is needed, and how will it be collected?
- How will confidentiality be protected?
- What quality control procedures will be used to ensure that the study produces valid findings and that it is completed on time?
- Is there a plan for analyzing and integrating quantitative and qualitative information?

Implementation Stage:

- Is data collection proceeding on schedule and according to plan?
- Are sufficient epidemiologic data being collected to assess how, and to what extent, HIV/AIDS is affecting different populations?
- Are PLWH in and out of care being contacted regarding their service needs and priorities?
- Are existing community resources being inventoried to assess the availability, accessibility, and appropriateness of services for PLWH?

Analysis and Review Stage:

- Are the data presented in formats that are understandable and useful to planning group members?
- Have the quantitative and qualitative data been adequately analyzed and integrated?
- Are the study team's assumptions and interpretations appropriate for different PLWH populations and racial/ethnic groups?
- Have important community factors been considered?
- Have the findings and implications of the needs assessment been shared and discussed with representatives of infected and affected communities?
- Are the results of the needs assessment being effectively used for planning and priority setting?

Suggested Answers to Self-Test 12

- a. Women and Hispanics have growing service needs, some of which are not being met by the current continuum of care. The information on women with HIV/AIDS comes from the epidemiologic update, the women's focus group, the public hearing, and the client survey. The information on Hispanics with HIV/AIDS comes from the epidemiologic update, the public hearing, and the client survey. Additional services also are needed for co-morbidity groups, such as homeless people and substance abusers. This information comes from the epidemiologic data, the focus groups, the public hearing, and the informal client survey.
- b. HIV-positive women are having difficulty accessing primary health care and substance abuse treatment due to the lack of transportation and child care, inconvenient hours of service, and long waiting times. Housing appears to be a critical problem for women with children and substance abusers. For Hispanics in rural areas, bilingual case management and support services are a priority. Both African American and Hispanic PLWH see a need for greater cultural sensitivity on the part of some health clinic staff.
- c. PLWH at the public hearing recommended more funding for medications and less funding for case management. Service providers supported continued funding for case management, with the understanding that case managers would be trained to help clients comply with medication instructions.
- d. More information on the service needs of Hispanics with HIV/AIDS would be helpful. This information could be obtained through a survey, focus groups, or key informant interviews. More information also is needed on the continuum of care, including the capacity and capability of HIV service providers. What housing, transportation, and child care options are available for PLWH in the service area? What sources of funding are available to expand these services? How do primary care clinics and substance abuse treatment programs need to adapt their services to be more culturally and logistically accessible to clients? What eligibility requirements, formulary restrictions, and/or utilization controls imposed by the State ADAP or Medicaid Program might explain why PLWH are having difficulty obtaining needed medications?

Part 3

Understanding Statistics: What Every Planning Group Member Should Know

Becoming Comfortable with Statistics

Importance of Data in the Planning Process

Much of the work of CARE Act planning groups involves collecting or overseeing the collection of data and then analyzing and interpreting the data. HIV Health Services Planning Councils and HIV Care Consortia are expected to establish service priorities for their service areas based on a sound information base that includes the results of needs assessments, data on the clients and services of CARE Act providers, and evaluation data on service outcomes and cost effectiveness. Exhibit 21 lists planning group activities that require data collection and analysis. Two of the major components of a comprehensive needs assessment—*an epidemiologic profile* and *an assessment of service needs*—are particularly likely to require familiarity with statistical concepts and methods.

Exhibit 21

CARE Act Planning Group Activities That Require Data

Title I Planning Councils perform five functions that are likely to require the collection and analysis of data. These functions include:

- establishing priorities for the allocation of Title I funds;
- developing a comprehensive plan for the organization and delivery of health services;
- assessing the efficiency of the grantee's administrative mechanism in allocating Title I funds to the areas of greatest need;
- participating in the development of the Statewide Coordinated Statement of Need; and
- evaluating the effectiveness of services in meeting identified needs.

Title II Consortia use data to carry out functions, such as:

- conducting needs assessments;
- developing a comprehensive plan for service delivery;
- establishing priorities for the allocation of Title II funds; and
- evaluating their success in responding to identified needs in a cost-effective manner.

CARE Act planning groups vary considerably in the extent to which they use quantitative data as a foundation for their decision making. Some planning groups place heavy reliance on nonnumerical *qualitative* information obtained through key informant interviews, focus groups, and community forums. Such information is important, but it needs to be supported by *quantitative* data on the service needs, service utilization patterns, and access barriers of different PLWH subpopulations.

Statistics can be misleading if they are based on incomplete or inaccurate reporting, small or unrepresentative samples, or inappropriately worded survey questions. By becoming familiar with statistical concepts and methods, you should find it easier to identify faulty assumptions, poorly-worded survey questions, and questionable study findings.

Everyday Uses of Statistics

Despite the widespread use of statistics, many Americans find it difficult to understand statistical concepts and even basic math. Others have a good foundation in math but suffer from *math anxiety*, meaning that they are uncomfortable dealing with numbers. If you don't feel you can read and interpret statistical reports, understand graphs, or compare data about different population groups, you are not alone! However, by developing your knowledge and capabilities in these areas, you can make a much greater contribution to the CARE Act planning process.

Most of us routinely use percentages, averages, and other statistics to make decisions. We also read tables and charts. For example:

- **In food shopping, we decide among brands and sizes by comparing “unit costs.”** Unit pricing signs often help us compare the cost per pound of canned fruit or per quart of juice. We may buy “house” brands because they cost less per pound or quart than “name” brands.
- **When deciding whether we can afford a particular apartment, we use ranges and averages.** The rent may be a fixed amount, but our “real” monthly cost depends upon the cost of utilities. By calling the local electric or gas company, we can learn the *average* monthly cost of utilities for that apartment. We also can inquire about the *range* of costs. What was the lowest and what was the highest monthly cost during the year?
- **When taking advantage of extra discount sales, we use percentages.** For example, a jacket may be marked “25 percent off the already reduced price.” To find out how much it will cost, we have to calculate one-quarter of the sale price and subtract it from the sale price, to know today's price.
- **In evaluating our own health status, we may use statistics about the general population.** For example, we may decide whether we are overweight by comparing our weight with the “average” weight of women (or men) in the same age group.

These examples demonstrate that many people with math anxiety really do have the knowledge to analyze and use statistics. Understanding statistics does not require a knowledge of higher math. It simply requires becoming familiar with some basic concepts and applying the same kinds of logic and life experience to quantitative data as you do to other kinds of information. This guide introduces some statistical concepts and analytical techniques that will help you make more effective use of data when assessing service needs, setting service priorities, and determining which services should continue to receive CARE Act funding.

Key Statistical Terms and Methods

Introduction

To understand the data being presented and discussed at planning group meetings, you need to become familiar with basic statistical concepts. This section describes some important statistical concepts and provides practical examples of how statistics can be used in CARE Act planning and decision making. You also will learn what questions to ask when reviewing data.

Types of Data

The data used for HIV service planning and evaluation can take different forms and come from a variety of sources. Perhaps the most basic distinction is whether the data are in numerical (*quantitative*) or nonnumerical (*qualitative*) form. The data may be *primary source* data collected by your planning group, or they may be obtained from a *secondary source*, such as the U.S. Census Bureau or the CDC. Exhibit 22 summarizes the types and sources of data used by CARE Act planning groups.

Exhibit 22
Data Types and Sources

The term "data" refers to information that is organized for analysis or used as the basis for decision making. There are two major types of data:

- Quantitative data are presented in numerical terms. For example, the data on AIDS cases reported in CDC's semiannual HIV/AIDS Surveillance Report are quantitative.
- Qualitative data are presented in nonnumerical (usually narrative) form. For example, if your planning group convened a focus group of case managers to identify and discuss the access barriers faced by Hispanic PLWH, the written summary of their comments would be qualitative data.

Data may be collected by your planning group or drawn from existing databases and reports. Depending upon how the data are obtained, the data may be classified as primary or secondary.

- Primary source data are original data that your planning group collects and analyzes to answer planning or evaluation questions. For example, if your planning group surveyed a sample of clients to assess their satisfaction with various services, the results would be primary source data. The findings from the focus group mentioned above also would be primary source data.
- Secondary source data are data collected by others to answer questions that may or may not be of interest to your planning group. Some secondary source data do not require further analysis. For example, if your local university recently published a report on the percentage of women testing HIV positive at prenatal care sites, you might be able to use these secondary data to assess the need for HIV services among pregnant women.
- Even when data are available in tabulated form, your planning group may perform additional calculations. For example, CDC's HIV/AIDS Surveillance Report lists the number of reported AIDS cases for different racial/ethnic groups, but if you want to know each group's percentage of total AIDS cases, you have to calculate the percentage yourself. When the secondary data are available in "raw" or unanalyzed form, your planning group can perform special analyses. For example, you could use Census data on the service area to calculate the percentage of each racial/ethnic group with incomes below poverty level.

Statistics can tell you *what is occurring, where the situation is occurring, and how many people are affected, but it is not always clear why the situation exists.*

For example, national data show that some States have more AIDS cases per 100,000 population than others. If these statistics are published in a report, an accompanying narrative may offer reasons for the differing AIDS rates. Exhibit 23 demonstrates how a narrative can help with data interpretation.

Exhibit 23
Narrative Explanations of Data

Statistical reports often include a narrative explanation of the data. Narratives can help you understand what the data mean, decide whether the statistics are believable, and assess the implications of the data for HIV service planning.

For example, suppose you are reviewing the following data on the racial/ethnic distribution of PLWH in a large metropolitan area:

Racial/ Ethnic Group	Estimated Number of HIV-Positive Persons
White Non-Hispanic	5,177
Black Non-Hispanic	818
Hispanic	787
Asian/Pacific Islander	26
American Indian/Alaska Native	31
Other	237
Total, All Racial/Ethnic Groups	7,076

This table provides estimates of the number of HIV-positive persons in each racial/ethnic group, and it tells you that most of these people are white. However, the chart is not self-explanatory. A narrative is needed to answer the following questions:

How were the estimates of HIV-positive people calculated?

How recent are these estimates?

How many people are estimated to have AIDS?

What racial/ethnic groups are included under "other?"

Are some racial/ethnic groups disproportionately affected by the HIV epidemic?

Sampling

When reviewing statistics, you should know whether they are based on a total population, such as the U.S. Census, or on a sample of people selected from the total population. Survey research usually is conducted with a sample of people drawn from a larger population. The sample is drawn from a list, called the **sampling frame**, which specifies who is eligible for inclusion in the survey. For example, an HIV Health Services Planning Council that wants to obtain information on the HIV counseling and testing practices of prenatal care providers could obtain a list of all obstetricians/ gynecologists, family practitioners, and general practitioners in the EMA and then select a sample of physicians to receive the questionnaire.

If you want to generalize from the sample to the target population, it is essential to use a probability sampling method. A probability sample design relies on the laws of chance (i.e., random selection) to select the people who will be in the sample. For example, the Planning Council could obtain a probability sample of prenatal care

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providers by entering an ID number for each physician on the computer and creating a program that would select every 10th name after some randomly assigned starting point. By selecting the sample in this fashion, the Council would be able to use well-developed statistical methods for estimating within what range of error, and with what level of confidence, the results reflected the “real” population value.⁵ If the Planning Council chose a nonprobability sampling method, such as a **convenience sample** of prenatal care providers attending a workshop on HIV infection in women, they would not know the total population from which each provider was selected or the probability of his or her being chosen. Conclusions could be drawn only about the prenatal care providers in the sample.

Exhibit 24 presents information on two probability sample designs - a simple random sample and a systematic random sample. These sampling approaches allow you to generalize findings to the **target population**, but you may not be able to analyze and compare data for **subpopulations**, such as particular racial/ethnic groups or PLWH with a history of substance abuse, severe mental illness, or other comorbidities. Separate information about a particular subpopulation may be very important to your planning process because:

- the subpopulation is overrepresented among current AIDS cases or accounts for a growing proportion of individuals with HIV;
- the subpopulation accounts for a growing proportion of residents in your service area;
- existing HIV services do not seem to be reaching and adequately serving the subpopulation; and/or
- you want to know the kinds of services that are most needed by the subpopulation.

⁵Aday, Lu Ann. *Designing and Conducting Health Surveys*. San Francisco: Jossey-Bass, 1996.

Exhibit 24

Simple Random Sampling and Systematic Random Sampling

A sample is a group selected from a *total population* or *universe* with the expectation that studying the group will provide important information about the total population. If you want to be able to generalize from the sample to the total population, you will need to use a probability sample design, such as a *simple random sample* or a *systematic random sample*.

- A simple random sample is selected one person at a time by a chance process that gives every person in the population a known, nonzero, and equal chance of being included in the sample. To obtain a simple random sample of clients receiving case management at an AIDS service organization, you would first decide on the size of your sample. After assigning each client a unique identifying number, you would use either a random numbers table or a lottery procedure to select client numbers until the required sample size was reached.
- A systematic random sample is drawn by choosing a random starting point on the sampling frame and then selecting cases at a specified sampling interval. Using this approach, every person in the population has a known chance of being included in the sample. For example:

Suppose you want to survey PLWH at primary care sites about their service needs. The first step would be to compile a numbered list of all clients receiving primary care. If there are 639 clients and you want a sample of 80 clients, you would divide 639 by 80 to determine the sampling interval. Since the result is about 8, you would include every 8th name on the client list in your sample. If Client #23 was your random starting point, you would take every 8th client thereafter (e.g., Client #31,

A stratified sample approach is used when you want to be sure that certain groups are included in your study. If you need information on the service needs of American Indians with HIV disease and there are very few HIV-positive American Indians in your target population, a simple random sample or systematic random sample may result in none or a very small number of this subgroup being included. Stratified sampling, on the other hand, allows you to divide the sampling frame into different racial/ethnic groups of interest and then use a simple random or systematic random sampling process to select cases from each group. To ensure that you survey enough HIV-positive American Indians to draw valid conclusions about their service needs, you may choose to sample that group at a higher rate than others - a process that is known as **oversampling**. Exhibit 25 provides additional information on stratified sampling.

Exhibit 25
Stratified Sampling and Oversampling

A random sample typically is used to obtain data on a single population. However, if you need information on subpopulations, such as specific racial/ethnic groups or men versus women, in addition to the population at large, you should consider a stratified sample. To obtain a stratified sample, you divide the sampling frame into subgroups (strata) and then draw random samples from each of these subgroups. This technique allows you to generalize study findings to subpopulations of interest as well as the entire population. If you are planning to include a large number of people in your random sample, stratification may not be necessary. A statistician can advise you on whether this procedure is needed.

- Suppose you want to know the level of awareness and use of support services among PLWH who receive primary care from the four clinics and community health centers in your service area. Your sampling frame will be all PLWH who receive care at the four sites. A statistician can calculate the number of clients that need to be included in the sample in order to produce findings that are representative of the PLWH clientele at these clinics.
- If you wish to examine how service use varies by gender and racial/ethnic group, the statistician will need to know the gender breakdown (e.g., 80% male; 20% female) and how clients are distributed among different racial/ethnic groups (e.g., 65% White Non-Hispanic, 15% Hispanic, 15% Black Non-Hispanic, and 5% Asian/Pacific Islander). When determining the proportion of cases to be selected from each stratum, the statistician may recommend that certain groups be oversampled to obtain enough cases for meaningful analyses. Rather than sampling 5 percent of the Asian/Pacific Islanders, for example, the statistician may recommend that these PLWH be sampled at a higher rate to be able to compare their responses with other racial/ethnic groups.

Remember that the sampling procedure is only as good as the sampling frame from which the sample is drawn. If you want to determine the unmet needs of PLWH in your community and your sample is drawn from current clients of CARE Act providers, you cannot generalize to the entire PLWH population because you are excluding people who are not receiving services. Also, “special need” populations such as the homeless, substance users, the mentally ill, women, and youth may be underrepresented among current clients.

The size of the sample also affects the level of confidence that you can have in the study. The sample size should be large enough to yield data that are capable of answering the study questions. Generally speaking, larger samples produce more reliable estimates of population characteristics. A statistician can help your planning group determine sample size. However, a large sample is no more representative of the target population than a small sample if the study participants are selected by nonprobability sampling methods.

Data Analysis

Many statistical approaches are used to analyze data. Although some analytical techniques require knowledge of computer statistical packages and extensive training in statistics, others are very straightforward. This guide reviews some of the most common methods of summarizing and analyzing data.

Percentages

Percentages often are used to present data. A percentage is calculated by dividing the part of the whole by the whole and multiplying the result by 100. For example, if there are 20 CARE Act-funded providers in Region A, and 12 of them are nonprofit community-based organizations, then **60 percent** of providers are community-based organizations (12 divided by 20 = 0.6; 0.6 x 100 = 60%). If you know that 60 percent of the 20 CARE Act-funded providers are community-based organizations, then the actual number of community-based organizations would be **12** (60% divided by 100 = 0.6; 0.6 x 20=12).

Most people find it easier to compare percentages than numbers. An earlier table (Exhibit 23) presented “raw numbers” of HIV-positive persons by racial/ethnic group for a large metropolitan area. There were 5,177 whites, 818 blacks, 787 Hispanics, 26 Asian/Pacific Islanders, 31 Native American Indian/Alaska Natives, and 237 people from “other” racial/ethnic groups. If we look only at these numbers, it is hard to picture the size of each racial/ethnic group relative to the overall HIV-positive population. By transforming these numbers into percentages, as shown in Exhibit 26, you can see that almost three-fourths (73%) of the HIV-positive population are white; about 12 percent are black; 11 percent are Hispanic; and a very small percentage are Asian/Pacific Islander, American Indian, or “other.”

The data become even more meaningful if we compare each group’s percentage of the HIV-positive population with its percentage of the total population. Exhibit 26 shows that blacks and Hispanics are *over*represented among the HIV-positive population, and that whites are *under*represented. Although blacks account for only 6 percent of the total population, they make up 12 percent of the HIV-positive population. Hispanics account for 9 percent of the total population and 11 percent of the HIV-positive population. Whites account for 73 percent of the HIV-positive population, a percentage that is smaller than their proportion of the total population (80%). **Of course, these comparisons do not tell you why some groups are overrepresented in the HIV-positive population.** To answer this question, you would need additional information on risk behaviors and social environments.

Exhibit 26
Racial/Ethnic Group Percentages of
HIV-Positive Population and Total Population

Racial/ Ethnic Group	Number of HIV+ Persons	Percent of HIV+ Population	Percent of Total Population
White Non-Hispanic	5,177	73	80
Black Non-Hispanic	818	12	6
Hispanic	787	11	9
Asian/Pacific Islander	26	<1*	2
American Indian/ Alaska Native	31	<1*	1
Other	237	3	2
Total, All Racial/ Ethnic Groups	7,076	100	100

The percentage of the HIV-positive population from each racial/ethnic group is calculated by summing all persons who are HIV-positive and then dividing the number of HIV-positive people in each racial/ethnic group by the total number of HIV-positive persons. For example, whites account for 73 percent of the HIV-positive population ($5,177 \div 7,076 = .73$; $.73 \times 100 = 73\%$). The percentage of the total population from each racial/ethnic group is calculated by dividing the number of people in that racial/ethnic group by the total population.

* The symbol < is used to denote "less than."

It is important to know the numbers upon which percentages are based. Sometimes the number of subjects in a sample is too small to draw valid conclusions about the population of interest. One helpful hint is to use "the rule of two." Lewis Cope, a reporter who often reviews research studies, explains how to use that rule:

- If someone makes some numerical claim, I look at the numbers, then see how much I might change the finding by adding or subtracting two from any of the figures. For example, someone says there are five cases of cancer in a community. Would it seem meaningful if there were three?
- Or if there were eight cases this year but four the year before - a 100 percent increase - I ask myself, "If I add two cases to last year's total and subtract two from this year's, is there a chance things haven't changed, except by chance?" This approach will never supplant refined analysis. But by playing around with the numbers this way-I sometimes try three instead of two-a reporter can often spot a potential problem or error.⁶

⁶Cohn, Victor. *News and Numbers: A Guide to Reporting Statistical Claims and Controversies in Health and Other Fields*. Ames, IA: Iowa State University Press, 1989, p. 21.

Exhibit 27
Percentages Based on Small Samples

Suppose you receive the following information:

- Of the individuals found to be HIV-positive during the past three months at an STD clinic, the overwhelming majority were African American, although African Americans represented a small proportion of the total population tested.

Racial/ Ethnic Group	Percent (%) of Total Persons Tested	Percent (%) of HIV+ Persons
White	70	33
African American	15	67
Hispanic	15	0
Total	100	100

This could be an important finding if:

- 2,000 were tested (1,400 white, 300 African American, 300 Hispanic).
- 100 were found to be HIV positive.
- 67 of the 100 were African American.

However, if 100 people were tested (70 white, 15 African American, and 15 Hispanic), 3 were found to be HIV positive, and 2 of the people testing positive were African American, the number of HIV-positive people would be too small to determine actual rates of HIV infection among the three racial/ethnic groups.

Exhibit 27 shows how percentages can be misleading when based on very small numbers.

Percentages often are used to compare groups. Exhibit 28 shows each racial/ethnic group's estimated percentage of the total U.S. population in 1997. If you use *percentages* to compare two racial/ethnic groups, you can determine the relative size of each group. If you compare two racial/ethnic groups using *percentage points*, you cannot determine the relative size of the groups.

Exhibit 28
Percentages Versus Percentage Points

U.S. Census estimates for 1997 indicate that the population is 73 percent white non-Hispanic, 12 percent black non-Hispanic, 11 percent Hispanic, 3 percent Asian/Pacific Islander, and 1 percent American Indian/Alaskan Native. To compare the size of the black and Hispanic populations, you can correctly say any of the following:

Using percentage points:

- U.S. Census estimates for 1997 indicate that the black population is one percentage point larger than the Hispanic population.

To calculate the percentage point difference, simply subtract one percentage from the other ($12 - 11 = 1$). Be sure to state the difference not as a percentage difference but as a percentage point difference.

Calculating the relative size of the two racial/ethnic groups with percentages:

- U.S. Census estimates for 1997 indicate that the black population is 9 percent larger than the Hispanic population.

To calculate the percentage difference, decide which racial/ethnic group is your reference population and subtract that group's number from the other number. Divide the resulting number by the reference number and multiply by 100.

In this case, Hispanics are the reference population

$(12 - 11 = 1; 1 \div 11 = .09; .09 \times 100 = 9\%)$.

- U.S. Census estimates for 1997 indicate that the Hispanic population is 8 percent smaller than the black population.

In this case, blacks are the reference population

Measures of Central Tendency

In addition to percentages, CARE Act planning groups often use *measures of central tendency to analyze and compare data*. Measures of central tendency show the “average” or “typical” value for a set of scores. This guide describes three such measures: the mean, median, and mode.

The *mean* tells you the average score, response, or value for a particular data set. It is calculated by summing the individual scores in the data set and dividing by the total number of scores. Means can provide important information on the characteristics, service needs, and service utilization patterns of PLWH in your service area. For example, when planning services for HIV-positive injecting drug users, it may be helpful to know the mean age at which they are being diagnosed with the disease and the mean length of time that it takes to link them with early

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intervention services. Means also are useful for comparing the characteristics or behaviors of different groups. For example, you might want to compare the mean CD4 lymphocyte counts of female versus male patients at an HIV clinic or the mean number of primary care visits per year for urban versus rural PLWH. A statistician or epidemiologist can advise you on the proper statistical tests to make these comparisons.

If you arrange a data set in order of increasing size, the *median* is the value of the middle observation in the series. It shows the “typical” score or response for the data set. Statistical reports often present both the mean and the median. If the two measures are quite different, the median usually is a more accurate representation of central tendency since it is less likely to be influenced by extreme values in the data set.

The *mode* refers to the most frequently occurring value in the data set. A data set may have several modes. For example, if you ask 10 PLWH how many pills they take each day, their replies might be 7, 8, 8, 8, 9, 10, 12, 12, 12, 16. There are two modes for this data set-8 and 12. Exhibit 29 shows how to calculate the mean, median, and mode for a data set.

Exhibit 29

Calculating Measures of Central Tendency

Measures of central tendency describe the “average” or “typical” value of a set of scores. Suppose your planning group is reviewing data from a survey of young HIV-positive adults, ages 30 and under, who are new clients of CARE Act-funded primary care providers, and you want to know the “typical” age of these new clients. The 15 survey respondents reported the following ages:

18, 29, 27, 19, 30, 20, 17, 21, 27, 23, 19, 15, 23, 27, 15

The “typical” age could be any of the following:

- 22, which is the mean or average age. The mean is calculated by summing the individual values (i.e., the ages of all young adults in the sample) and dividing by the total number of young adults surveyed ($330 \div 15 = 22$).
- 21, which is the median. The median is the central value, the one that falls in the middle of all the values when they are arrayed from highest to lowest. To calculate the median, you would reorder the values as follows: 30, 29, 27, 27, 27, 23, 23, 21, 20, 19, 19, 18, 17, 15, 15, and then count down to the middle. In this case, the middle value is 21. If you have an even number of values, take the two values in the middle, add them together, and divide by two. For example, if the last “15” in this list was eliminated, you would have 14 values. The median would be determined by adding the seventh and eighth values and dividing by two ($23 + 21 = 44$; $44 \div 2 = 22$).
- 27, which is the mode. The mode is the most frequently occurring value. Three young adults in the sample are 27 years old.

The mean and median for this data set are very similar because the range of ages (15-30 years) is quite narrow. If the data set had not been restricted to young adults, you might have seen some very young clients and some very old clients. When a data set contains extreme values, the median may provide a more accurate measure of central tendency than the mean.

Measures of Dispersion

Although measures of central tendency provide important information about a data set, you also need to know the amount of variability among the scores.

Suppose you are examining the CD4 lymphocyte counts of patients at an HIV clinic as one measure of the effectiveness of a new treatment program. The mean CD4 count is 550 cells/mm³. However, when you review the range of CD4 counts, you discover that the clinic has a number of patients with CD4 counts less than 200 cells/mm³ and several with CD4 counts greater than 900 cells/mm³. Simply knowing the mean CD4 count does not give you an accurate picture of the clinic population.

Measures of dispersion tell you how “spread out” or “how far from the typical value” a set of scores are. The *range* of a data set is the difference between the largest and smallest scores. If the highest and lowest CD4 counts in the above example were 950 cells/mm³ and 50 cells/mm³ respectively, the range would be 900. The *variance* of a data set reflects the degree to which the scores deviate from the

mean. Most statistical reports use the square root of the variance (i.e., the *standard deviation*) as the measure of spread. A statistician can help you calculate and interpret standard deviations. **The main thing you need to know is that the mean value of a data set can be very misleading if there is considerable variability among the scores.** Without knowing the spread of the data, you may end up allocating too many or too few resources for a particular service or target group.

Statistical Significance

When a study reports differences among population groups, such as different levels of emergency room use by HIV-positive women and men, it is important to know whether these differences are *statistically significant*. Research findings are considered to be statistically significant if there is only a small probability that the observed result could have occurred by chance alone. If the findings are not statistically significant, they still may provide useful insights, but you should be cautious in using them to set service priorities or make resource allocation decisions.

To illustrate what is meant by statistical significance, imagine that you're reviewing the results of a study of prenatal care providers in Baltimore and Atlanta. The researchers report that 76 percent of the Baltimore prenatal care providers and 55 percent of the Atlanta prenatal care providers support routine HIV counseling and voluntary testing for all women of childbearing age. If the researchers had surveyed every prenatal care provider in Baltimore and Atlanta, we would be able to say definitively that there is much greater support for routine HIV counseling and testing among Baltimore prenatal care providers. However, since only a *sample* of prenatal care providers were surveyed, the observed results may be due to chance variation alone.

By performing a significance test on the data, the researchers can derive a probability (*p*) value from which to judge whether there is a real difference between providers in the two cities. If they report that “the difference between Baltimore and Atlanta prenatal care providers is significant at the 5 percent level,” this means that there is a 5 percent chance that the sample would have shown a difference even if there was no real difference between providers in the two cities. Another way of stating this result is, “only 1 sample out of 20 would show as great a difference as this sample did if the percentages of prenatal care providers favoring routine counseling and testing are about the same in the two cities. Exhibit 30 provides a brief summary of statistical significance and probability values.

Exhibit 30

Statistical Significance and Probability Values

A research finding is considered to be statistically significant if there is only a small probability that the observed result could have occurred by chance alone. Research reports and journals express significance levels in terms of probability (p) values. Statistical results usually are regarded as significant if there is less than a 5 percent probability—five times out of 100—that the observed difference or relationship was due to chance alone. In such situations, the p -value is said to be less than .05 ($p < .05$). A more stringent p -value is $< .01$, which means that there is less than a 1 percent chance—one time out of 100—that the observed difference or relationship occurred by chance alone. Research reports should present p -values so that readers will know how much confidence to place in the findings. Although non-researchers often use the term “significant” to denote something important, this term should not be used in a study report unless tests of statistical significance have been performed.

It is important to differentiate between statistical significance and practical importance. If you have a large enough sample, you are likely to find some significant differences among subgroups. However, the differences may be too small to have any practical importance. Some researchers suggest that you assess the *practical importance* of differences before testing for statistical significance. For example:

Suppose your needs assessment finds that African American and Hispanic women with HIV disease report different levels of need for transportation to primary care sites. If the difference is small (e.g., 53% of African American women and 48% of Hispanic women say they need transportation assistance) you may not care whether it is statistically significant. On the other hand, if 73% of African American women and 33% of Hispanic women say they need transportation assistance, this difference is large enough to affect your priority-setting and resource allocation decisions, and you will want to know whether it is statistically significant.

Although statisticians will carry out the tests of statistical significance, you should be aware of the need for these tests and ask whether they have been conducted.

Decimal Points and Rounding of Data

Often statistics are presented with decimal points. For example, if 11 of the 80 clients participating in a drug treatment program test positive for HIV, you could say that 13.75 percent are HIV- positive ($11 \div 80 = .1375$; $.1375 \times 100 = 13.75\%$). The number to the left of the decimal point (13) is a whole number, and the number to the right of the decimal point (75) represents a fraction of the whole. If 5 of the 80 clients report more than 10 years of injecting drug use, this would convert to 6.25 percent ($5 \div 80 = .0625$; $.0625 \times 100 = 6.25\%$).

Statistical comparisons can be simplified by using the same number of decimal places (i.e., numbers to the right of the decimal point) for all numbers or percentages reported. You can do this by *rounding* each number to the nearest whole number or to the nearest tenth of a percent. If the number to the right of the decimal point is above five, you *round up*; if the number is less than five, you *round down*. If the number to the right of the decimal point is five, statisticians often recommend

that you round up odd numbers (e.g., 11.5 rounded to 12) and round down even numbers (e.g., 12.5 rounded to 12) to avoid any inflation in the distribution. In this example, 13.75 percent could be rounded to 14 or 13.8, and 6.25 percent could be rounded to 6 or 6.2. Rounding to one or two decimal places provides an acceptable degree of precision for most data.

Questions To Ask When Reviewing Data

If a study is being conducted by or for your planning group, the data should be summarized in a clear and understandable format. The following tips should enhance the usefulness of the data for planning and decision making:

- **Present data as both numbers and percentages.** It is important to know the number of observations on which percentages are based.
- **Descriptive data on a target population should include the mean, median, and standard deviation.** By reviewing these statistics, you will know the “typical” scores as well as the amount of variability in the scores.
- **Present separate data for each subpopulation whenever possible.** Combining several population groups into a catchall category, such as “minorities,” makes it impossible to identify and analyze differences among the groups.
- **When possible, compare each subpopulation’s percentage of total AIDS cases, CARE Act program clients, etc. with its percentage of the service area population.** This will help you determine whether certain groups are overrepresented or underrepresented among AIDS cases, CARE Act clientele, and other populations of interest.
- **If the study shows differences among subpopulations, ask the researchers to test for statistical significance.**

When reviewing secondary data, learn as much as you can about how the study was designed and conducted. If the study report does not describe the methodology, you may be able to contact the researchers for additional information. Try to obtain answers to the following questions:

Sample Design and Data Collection Process

- **What was the target population for this study?** How well did the sampling frame match the researchers’ definition of the target population?
- **How was the study sample selected?** Did the researchers use a probability sample design? If data are presented separately for different subpopulations, was a stratified sample approach used to ensure an adequate number of respondents from each subpopulation?

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- **Was the sample size large enough to yield data that are capable of answering the study questions?**
- **Did the researchers contact the study sample by mail, by telephone, or in person?** If face-to-face interviews were conducted, were the interviews held in people's homes, at service agencies, or in some other location?
- **Was the questionnaire pilot tested?** Did the researchers revise the questionnaire based on the pilot test responses?
- **Were data collected in a “culturally appropriate” manner?** Were people from diverse communities involved in writing and/or reviewing survey questions? If non-English speaking people were included in the sample, did the study employ bilingual interviewers or translate the questionnaire into appropriate languages? Were interviews conducted by people whose races, ethnic backgrounds, or sexual orientations were similar to the characteristics of survey respondents?
- **What percentage of the people in the sample actually completed questionnaires or participated in interviews?** Was this percentage sufficiently high to draw valid conclusions about the target population? Were there notable differences between respondents and nonrespondents that might have biased the study's findings?

Data Analysis

- **Do the data make sense, given your knowledge of the population or population subgroups?** Do any of the data appear to be contradictory?
- **Are the findings of this study consistent with similar studies that have been conducted elsewhere?** If not, are there differences in sampling frames, sampling and data collection procedures, data collection sites, time periods, etc. that might explain the inconsistencies?
- **Do the researchers' conclusions and recommendations seem reasonable, given the data that were presented?** Did they involve people from the target population(s) in interpreting the findings?
- **Are the limitations of the study described?** Did the researchers have problems locating survey respondents from certain groups (e.g., HIV-positive individuals who are not in care)? Was there a high rate of refusals? Was there any evidence that some of the questions were misinterpreted? Should the questionnaire have been administered at several time points to track changes in attitudes or behaviors?

Never be embarrassed to ask questions. Your knowledge of the service area and particular populations makes you an important reviewer of research methods, study findings, and interpretations of the data.

Part 4

Methods of Data Collection

Quantitative Versus Qualitative Research

Introduction

CARE Act planning groups often collect data to answer questions about service needs, service costs and outcomes, the effectiveness of programs in reaching target populations, and related issues. This process of *primary data collection* enables planning groups to gather data that are specific to their needs rather than having to rely on *secondary data* that others may have collected for different purposes. However, primary data collection requires significant commitments of time and money. Costs can range from \$2,000 to \$200,000, depending on the design of the study, the size of the study sample, the methods of data collection, the amount of data being collected, the level of detail that is needed, and other factors.⁷

Both quantitative and qualitative research methods can be used to collect primary data. Quantitative research methods provide information on *who, what, how many, and how much*. Qualitative research methods attempt to answer *how* and *why* questions. This section describes the most common quantitative and qualitative research techniques and key factors that should be considered when using each data collection method. All of these methods are subject to numerous pitfalls which can be avoided by involving methodological experts in the design and administration of the data collection process.

Surveys

Surveys provide a systematic way of collecting the information needed for service planning, priority setting, and evaluation. Many different steps are involved in designing and conducting surveys. Part 3 of this guide discusses sampling issues, and this section highlights some of the issues involved in questionnaire design.

Questionnaires should be constructed by individuals who are knowledgeable about issues of validity and reliability. *Validity* refers to the extent to which a data collection instrument or specific questions measure what they are supposed to measure. For example, if your planning group wants to know the extent to which PLWH *actually use* various services, a questionnaire that only inquires about *awareness* of these services would not produce valid information. *Reliability* refers to the consistency and dependability of a data collection instrument or measure. If you repeatedly surveyed the same people with the same or comparable questionnaire, would you get the same or similar results?

⁷HIV/AIDS Bureau. *Choosing and Using an External Evaluator*. Rockville, MD: Health Resources and Services Administration, 1997.

To ensure that questions are relevant and appropriate for the populations being studied, individuals from these population segments should participate in the development and review of the questionnaire. The draft questionnaire should be pilot tested on a small group of individuals similar to those who will be in the sample to assess whether they understand the questions and interpret them in the same way. This step is especially important for self-administered questionnaires that respondents complete without an interviewer present.

Self-administered questionnaires should be brief and easy to complete. CARE Act planning groups and service providers frequently use this method to conduct client satisfaction surveys. The advantages are evident—a short questionnaire with a self-addressed, pre-stamped envelope can be distributed to a random sample of clients at relatively low cost and, since respondents can return the questionnaire by mail, their anonymity is protected. This data collection method also has some limitations. Only short questionnaires with clear and simple questions can be used. Respondents may fail to read and/or answer some questions. Low-literacy or limited-English-proficient individuals may be unable to complete the questionnaire. Breaches of confidentiality may occur if questionnaires are mailed to PLWH rather than being distributed at service sites. Many PLWH groups oppose mail surveys for this reason.

Face-to-face interviews allow more flexibility in terms of the length of the questionnaire and the complexity of the questions. As compared to self-administered mail surveys, less follow-up is required to obtain a good response rate. However, a large number of interviews can be very costly to conduct. If this data collection method is used, the interviewers should be carefully selected, trained, and monitored to ensure that they ask questions, use probes, and record answers in a consistent fashion. Interviewers should be knowledgeable about the target population(s), comfortable with the content of the study, and well versed in confidentiality and field procedures. Bilingual interviewers should be used if the sample includes people who are limited-English-proficient.

Telephone interviews can be an efficient way of gathering information if your budget and timetable do not permit face-to-face interviews. Because the interviewers are located in one place, they can be more easily supervised than field interviewers. However, the questions need to be fairly short and simple so that respondents will remember all possible responses. When contacting PLWH by telephone, interviewers should be careful not to disclose any information about the nature or purpose of the survey to other household members. This method of data collection is not recommended if your target population includes a large number of people who lack telephones.

When constructing questionnaires, it is important to understand the difference between closed-ended and open-ended questions. Surveys with large samples usually rely heavily on fixed-choice, closed-ended questions that can be pre-coded for computer analysis. Each question has a set of predetermined responses, and the respondent or interviewer simply checks the appropriate box. This “forced choice” method makes the questionnaire relatively easy to complete and analyze. However, respondents who do not feel comfortable with the fixed answers may decide to skip questions, or they may choose answers that do not accurately reflect their “true” attitudes and practices. To avoid this problem, closed-ended questions sometimes include an “other (please specify)” category that allows respondents to write in their own answers.

Open-ended questions allow respondents to provide answers in their own words. Such questions are useful for stimulating free thought, soliciting suggestions, and clarifying positions. Open-ended questions also can be used in the pilot or pretest stage of a study to identify the response options that should be included with each closed-ended question. The major drawback of an open-ended format is that the responses are more difficult to code. Typically, the study team reviews the responses to a particular question and develops a set of codes that will cover the range of responses. Each person’s responses are then analyzed and coded according to the established categories. The coding must be done carefully to ensure that it accurately reflects what the respondent wanted to communicate, and that it is sensitive to small but important differences in responses. The coding also must recognize and accurately reflect cultural variations in responses. Exhibit 31 provides additional information on the coding of closed-ended and open-ended questions.

Exhibit 31

Coding of Closed-Ended and Open-Ended Questions

Coding refers to the process of “translating” survey responses into numerical codes that can be used in computer-based data analyses.

Closed-ended and precoded. Answers to survey questions often are closed-ended and pre-coded. For example, each predetermined response may have an assigned number.

Do you favor increased CARE Act funding for case management?

- Yes No
1 2

Open-ended. If you don't want to limit responses by providing a fixed set of answers, or you really don't know what kinds of answers to expect, some open-ended questions may be appropriate. Because respondents create their own answers and state them in their own words, the coding is done after the data are collected. Translating narrative information into numerical codes takes more time than coding closed-ended questions and may be less reliable across respondents.

Partially closed-ended questions offer a compromise. As illustrated below, respondents can select one of the fixed responses or choose “other” and fill in their own response.

Which of the following support services do you think should have highest priority for CARE Act funding? (Please choose only ONE.)

1. Direct emergency financial assistance
2. Food bank
3. Housing assistance
4. Transportation
5. Other (please specify)

Qualitative Research Methods

Key Informant Interviews

Key informants are people who have personal experience with, or special knowledge of, issues, subpopulations, or services that are important to your planning group. By interviewing key informants, you can gather in-depth qualitative information to supplement data from surveys and other sources. The interviews can be used to:

- obtain feedback on the adequacy of HIV services and gaps in the continuum of care;
- identify service barriers for different PLWH subpopulations; and/or
- identify issues that should be further explored in surveys and focus groups.

Key informants should be carefully selected to ensure diverse points of view, experiences, and concerns. Depending on what you are trying to learn, you may want to interview program staff, people of varying income and occupational groups, and/or people who are knowledgeable about different components in the continuum of care. Key informants can be especially helpful when you need information on a subpopulation that is difficult to interview, such as children with HIV/AIDS or severely mentally ill PLWH.

Because the discussion guides for key informant interviews are organized around major topics and issues rather than specific questions, the interviewer must be extremely knowledgeable about the subject and trained to probe for information without biasing the responses. The interviewer or an observer should take detailed notes during the interview. Permission should be sought to tape the interview so that no important points are missed. After all interviews have been conducted and summarized, the interviewer should prepare a report that describes overarching themes as well as specific points of agreement and disagreement.

Focus Groups

A focus group involves a small group of people whose discussion is carefully planned and led by an experienced moderator. Originally developed for marketing research, focus groups now are widely used by a variety of health and human service agencies to:

- evaluate proposed message concepts and service models;
- identify unmet service needs and access barriers;
- obtain feedback on concepts, approaches, and materials from hard-to-reach populations;
- test service approaches during development; and
- generate ideas for new services and programs.

Focus groups can be completed more quickly than a survey or a series of in-depth interviews and may be less expensive than these data collection methods. Because the groups are small and do not use probability sampling methods to select participants, the findings cannot be generalized to a target population. However, focus groups can offer some preliminary insights into the needs, issues, and concerns of different subpopulations that can be further explored through quantitative studies.

Focus groups should be designed, conducted, and analyzed by people who have training in this methodology. This section provides a brief overview of the issues involved in organizing and conducting focus groups. More detailed information can be obtained from books, such as *Focus Groups: A Practical Guide for Applied Research*. (See References and Resources in Part 6.)

A focus group usually consists of individuals from a clearly defined target population with common characteristics (e.g., adolescents with HIV disease, African American gay men, or male PLWH with a history of substance abuse). The more knowledgeable participants are about the issue or program being studied, the more valuable the information gained. Group discussion is guided by a skilled moderator who uses a predetermined outline to ensure that key issues and questions are addressed. Typically, the moderator asks participants to think about or write their individual opinions and reactions to a concept, issue, or program. This is followed by a group discussion. Exhibit 32 summarizes the key factors that should be considered when organizing a focus group.

Exhibit 32

Important Considerations for Organizing a Focus Group

- Specify the purpose for organizing the focus group.
- Develop a list of questions that you want answered.
- Develop a strategy for selecting focus group participants who are reflective of the target population.
- Recruit an experienced moderator who is knowledgeable about the topic but not directly involved with the program or activity being discussed.
- Be aware of limited literacy among focus group participants.
- Arrange for an observer to tape-record and take notes on the discussion.

A successful focus group exhibits the following characteristics:

- The objectives of the focus group are clearly defined and manageable.
- The group is a manageable size—large enough to encourage different viewpoints, but not so large that some members do not participate in the discussion. Typically, focus groups include between 8 and 10 people.
- The group composition is reflective of the target group. Participants should be as similar as possible in terms of variables such as race/ethnicity, gender, age, and language preference. Qualitative researchers recommend that at least two focus groups be conducted for each variable that is relevant to the topic area. For example, if you want to know how perceived service needs differ by gender, you should conduct two focus groups with women and two groups with men.
- The focus group location is accessible, comfortable, quiet, and suitable for good-quality audio taping.
- The audiovisual equipment works properly. All equipment should be tested before participants arrive.
- The moderator is knowledgeable about the topic and skilled at facilitating group discussions. This individual does not attempt to influence the discussion.
- The session is carefully scheduled and managed. Typical stages include an introduction to clarify the purpose of the session, a warm-up to introduce group members (usually first names only) and create a positive group atmosphere, general discussion to obtain broad opinions on HIV/AIDS issues, a presentation of the topic followed by discussion, a closing that recaps identified themes, and a thank you.

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- The topic outline clearly defines the scope of discussion and the major issues and questions to be covered. The outline is used flexibly but key issues are covered.
- The length of the session is appropriate for the topic being discussed. Participants are likely to tire after one and one-half hours, but the session can be longer if a break with refreshments is provided.
- If planning group members or administrative/lead agency staff observe the focus group, they do not participate in the discussion except at the invitation of the moderator. During the refreshment break, the moderator and observers can confer on issues that need clarification.
- Focus group participants receive some compensation for their participation. At a minimum, participants should be reimbursed for transportation and child care expenses. Refreshments or a light meal may be served.
- The planning group designates staff or members to meet with the moderator after each focus group to refine the topic outline and/or procedures.
- Once all focus groups have been completed, the moderator prepares a comprehensive report that summarizes and interprets each focus group's discussion, compares findings across groups, and includes verbatim comments when appropriate.

Community Forums

CARE Act planning groups often use community forums to gather information on the needs and priorities of infected and affected communities and to obtain feedback on the accessibility and appropriateness of services. By convening community forums in diverse locations, doing targeted outreach, and holding one or more forums in a language other than English, it is possible to obtain input from hard-to-reach populations such as the homeless, substance abusers, and non-English-proficient PLWH. Like other qualitative research methods, community forums can provide valuable insights about a target population, but the results cannot be generalized to the target population without further quantitative study.

Community forums tend to be larger and less formal than focus groups. Whereas focus groups consist of people with similar characteristics, community forums often involve people of different ages, racial/ethnic backgrounds, and sexual orientations. Participants may include clients of CARE Act-funded providers, residents of a particular neighborhood, or some other group with an interest in HIV/AIDS services. In many cases, the HIV status of participants is unknown.

A community forum ideally involves between 15 and 30 participants. At least two group leaders facilitate discussion on issues and questions identified in a topic guide, and observers are present to take notes and tape-record the comments. By keeping the forums at a manageable size, group leaders have less need to impose

formal procedures, such as recognizing people before they speak or setting time limits for each person's remarks. As a result, community forums are more interactive than public hearings.

Public Hearings

Public hearings provide opportunities for people from diverse community sectors to comment on HIV service needs and the effectiveness of funded services and programs. If a large gathering is expected, your planning group may wish to limit formal presentations to people who give advance notice of their desire to speak. You also may wish to establish guidelines and time limits for questions and comments from the audience.

Public hearings require careful planning and structuring. Make arrangements for an experienced moderator who can keep order while encouraging questions and discussion. The conduct of the public hearing can be enhanced by:

- announcing the specific issues to be addressed well in advance of the meeting;
- placing time limits on presentations (e.g., 3-10 minutes);
- asking speakers to specify their topics before the meeting so that people with related topics can be grouped into discussion panels;
- scheduling time for audience participation and placing microphones in the aisles to facilitate this participation; and
- preparing a written summary of the proceedings for distribution to participants and other interested groups.

Public hearings are likely to attract advocates for hard-to-reach populations, but the only way to ensure this input is through deliberate planning and outreach. Local service providers and community groups can assist with this effort. For example, you might work with a homeless shelter to organize a PLWH panel or enlist the help of a multicultural agency in providing interpreters for non-English-proficient PLWH. Local civic or church groups may be willing to help transport people to and from the meeting site.

Part 5

Conclusion

Your knowledge of the “basics” of designing needs assessments, analyzing data, and effectively using the data for program planning and decision making will make you a valued member of many planning and advisory groups. In addition to serving on a CARE Act planning group, you may wish to become involved with the HIV prevention community planning process, a substance abuse prevention task force, or a committee that is trying to improve maternal and child health. By discussing and practicing what you have learned in this guide, you can apply the skills to a variety of situations. For example, you can:

- critically review surveys and studies about your community;
- examine the processes used by public officials to set program priorities and allocate resources;
- examine the data provided by “experts” to determine whether they have adequate documentation to support their positions;
- help advisory committees or oversight groups obtain community-relevant information for decision making;
- help the governing board of a nonprofit agency plan and conduct a needs assessment that produces valid and credible findings; and
- effectively use quantitative and qualitative information to testify at legislative hearings and other public forums.

Comprehensive community planning requires that people at the grassroots level have an opportunity to develop needs assessment and statistical analysis skills. Through your linkages with various community networks, you can share your knowledge, both formally and informally. For example, you might use a recent CARE Act needs assessment as a case study to teach members of a PLWH coalition or other community group about sample designs, data collection strategies, and data analysis. You might also invite this group to help you critique the final study report and identify additional data needs.

Active and diverse community participation is extremely important for health and human services planning. By taking the time to critically review data, and encouraging others to do the same, you can improve the quality of community decision making. The end result should be a more equitable allocation of resources among the varied populations which together form the American mosaic.

Part 6

Definitions and Resources

Glossary of Terms

This section defines terms which you may encounter in CARE Act needs assessments and evaluation studies. The meaning of each term is described in a way that will be relevant and understandable to CARE Act planning groups. Alternative and expanded definitions can be found in several of the technical references cited in this guide.

CARE Act Overview and Terminology

Enacted in 1990 to improve the quality and availability of care for PLWH and their families, the CARE Act authorizes formula-based and supplemental grants to Eligible Metropolitan Areas (EMAs) that are disproportionately affected by the HIV epidemic (Title I) and formula-based grants to all States, the District of Columbia, Puerto Rico, and eligible U.S. territories (Title II). The Act also authorizes competitive grants to public and private nonprofit organizations for outpatient HIV early intervention services (Title III) and coordinated HIV services and enhanced access to research for children, youth, women, and families (Title IV). Other authorized programs include multidisciplinary HIV education and training programs for health care providers (AIDS Education and Training Centers), demonstration projects that develop and evaluate innovative models for HIV/AIDS care (Special Projects of National Significance), and an HIV/AIDS Dental Reimbursement Program.

The HIV/AIDS Bureau of the Health Resources and Services Administration (HRSA) administers the CARE Act. Within the HIV/AIDS Bureau, the Division of Service Systems (formerly Division of HIV Services) administers Titles I and II and the AIDS Drug Assistance Program. The Division of Community Based Programs administers Titles III and IV and the HIV/AIDS Dental Reimbursement Program. The Division of Training and Technical Assistance administers the AIDS Education and Training Centers and coordinates technical assistance, constituent relations, and AIDS Advisory Committee activities. The Bureau's Office of Science and Epidemiology administers the Special Projects of National Significance Program.

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Following are commonly used CARE Act terms. All acronyms referenced in the definitions have their own entry within the glossary.

AAR (*Annual Administrative Report*) - the primary national data collection system for Titles I and II of the CARE Act; a provider-based report generating client, provider, and service data for each State and EMA.

Administrative or Fiscal Agent - organization, agent, or other entity (e.g., public health department, community-based organization) that assists the Title I grantee in carrying out administrative activities, such as disbursing program funds, developing reimbursement and accounting systems, developing Requests for Proposals, and monitoring contracts. Some grantees do not use a separate administrative or fiscal agent.

ADAP (*AIDS Drug Assistance Program*) - Title II component that provides drug therapies for people living with HIV disease.

AETCs (*AIDS Education and Training Centers*) - Authorized under Part F of the CARE Act, these regional centers conduct targeted, multi-disciplinary education and training programs for health care providers in designated geographic areas. Their objective is to increase the number of health care providers who are educated and motivated to diagnose, treat, and manage individuals with HIV infection and to provide risk-reduction counseling.

ASO (*AIDS service organization*) - an organization that provides medical or support services primarily or exclusively to populations infected with and affected by HIV disease.

CARE Act (*Ryan White Comprehensive AIDS Resources Emergency Act*) - the primary Federal legislation created to address the health and support service needs of PLWH and their families in the United States; enacted in 1990 and reauthorized in 1996.

CBO (*community-based organization*) - an organization that provides services to locally-defined populations, which may or may not include populations infected with or affected by HIV disease.

CDC (*Centers for Disease Control and Prevention*) - the Federal agency within the U.S. Department of Health and Human Services that administers HIV/AIDS prevention programs, including the HIV Prevention Community Planning process. In addition to monitoring and reporting infectious diseases, the CDC administers AIDS surveillance grants and publishes epidemiological reports, such as the *HIV/AIDS Surveillance Report*.

CEO (*Chief Elected Official*) - the official recipient of Title I funds within the EMA, usually the mayor or chair of the county board of supervisors. The CEO is ultimately responsible for administering all aspects of the CARE Act in the EMA and ensuring that all legal requirements are met. In EMAs with more than one political

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jurisdiction, Title I funds are awarded to the CEO of the city or urban county administering the public health agency that provides outpatient and ambulatory services to the greatest number of people with AIDS.

Comprehensive Planning - the process used to determine how HIV services will be organized and delivered. Comprehensive HIV services planning requires Planning Councils and Consortia to answer four questions: (1) Where are we now? (2) Where should we be going? (3) How will we get there? (4) How will we monitor our progress?

Continuum of Care - a coordinated delivery system, encompassing a comprehensive range of health and social services that meet the needs of PLWH in all stages of illness.

Division of Community Based Programs - division of the HIV/AIDS Bureau, established under a 1997 HRSA reorganization, that is responsible for administering Titles III and IV and the HIV/AIDS Dental Reimbursement Program of the CARE Act.

Division of Service Systems (DSS) - division of the HIV/AIDS Bureau, restructured during a 1997 HRSA reorganization, that is responsible for administering Titles I and II and the AIDS Drug Assistance Program (ADAP) of the CARE Act.

Division of Training and Technical Assistance - division of the HIV/AIDS Bureau, established under a 1997 HRSA reorganization, that is responsible for administering the AIDS Education and Training Centers (AETCs) and coordinating technical assistance, constituent relations, and AIDS Advisory Committee activities.

EMA (Eligible Metropolitan Area) - a geographic area eligible to receive Title I funding because it is “disproportionately affected” by the AIDS epidemic. (See Formula Grant.) EMAs may include just one city, several cities and/or counties, or they may span more than one State.

Formula Grant - the amount of CARE Act funding that HRSA’s HIV/AIDS Bureau awards to CARE Act grantees based on the number of reported AIDS cases and other factors. EMAs are eligible for Title I formula grants if they have reported more than 2,000 AIDS cases in the preceding five years, and if they have a population of at least 500,000. (The latter provision does not apply to EMAs funded prior to Fiscal Year 1997). Title II formula grants are awarded to States based on (1) the estimated number of living AIDS cases and (2) the estimated number of living AIDS cases within the State but outside of Title I EMAs.

Grantee - the recipient of CARE Act funds. The CEO of each EMA is the official grantee for Title I funds. However, since the CEO usually delegates his/her authority to administer Title I funds to an organizational unit (e.g., the city or county health department), this entity also may be called the grantee. The terms “CEO” and “grantee” help to distinguish between the person ultimately responsible for the CARE Act grant (the CEO) and the entity that provides day-to-day administration (the grantee). Under Title II, the Governor designates a State agency (usually the State Health Department) as the grantee.

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HIV/AIDS Bureau - established by a 1997 HRSA reorganization, this bureau is responsible for administering the CARE Act.

HIV Care Consortium - an association of public and private nonprofit health and support service providers and community-based organizations that plans, develops, and delivers services for PLWH. The CARE Act authorizes States to use Title II funds to establish consortia in the “areas most affected by HIV disease.”

HIV Health Services Planning Council - a planning body appointed by the CEO of an EMA. The CARE Act authorizes Planning Councils to establish priorities for the allocation of Title I funds, develop a comprehensive plan for the organization and delivery of HIV-related services, and assess the efficiency of the Title I administrative mechanism in rapidly allocating funds to the areas of greatest need. Planning Councils also are encouraged to assess the effectiveness of the services offered in meeting identified needs.

HRSA (*Health Resources and Services Administration*) - the agency of the U.S. Department of Health and Human Services that is responsible for administering the CARE Act as well as many other health programs for medically underserved and special populations. HRSA also administers programs that are designed to improve the education, training, distribution, and quality of the Nation’s health personnel.

IGA (*Intergovernmental Agreement*) - a written agreement between a Title I grantee and another governmental agency in the EMA. These agreements usually address the allocation of funds across agencies or jurisdictions.

Lead Agency - agency responsible for administering the Title II funds awarded to an HIV Care Consortium; also called a fiscal agent. An incorporated consortium sometimes serves as the lead agency.

Minority Provider - a service organization in which the majority of Board members and staff are minorities based on national population trends and definitions (e.g., African American, American Indian/Alaska Native, Asian/Pacific Islander, Hispanic).

Needs Assessment - the process of gathering and analyzing information from a variety of sources in order to determine the current status and unmet needs of a defined population or geographic area. The focus may be on a single issue, such as HIV/AIDS, or on a wide range of issues.

OSE (*Office of Science and Epidemiology*) - the office within the HIV/AIDS Bureau that administers the Special Projects of National Significance (SPNS) Program. This office also is responsible for program evaluation, special studies, and CARE Act-related data collection and analysis.

Part F - the part of the CARE Act that funds the AETC, SPNS, and HIV/AIDS Dental Reimbursement Program.

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PLWH (*People Living with HIV*) - people living with HIV disease or AIDS.

Priority Setting - the process used by HIV Health Services Planning Councils and HIV Care Consortia to establish service priorities for the allocation of CARE Act funds and to determine the best ways of meeting each priority.

Resource Allocation - process by which dollars or percentages of CARE Act funding are allocated to specific priority service categories. Title I of the CARE Act requires grantees to allocate funds in accordance with the priorities established by HIV Health Services Planning Councils and to consider additional factors, such as the documented needs of the HIV-infected population, the cost and outcome effectiveness of proposed strategies and interventions (to the extent that such data are reasonably available), the priorities of the HIV-infected communities for which the services are intended, and the availability of other governmental and non-governmental resources.

SCSN (*Statewide Coordinated Statement of Need*) - a written statement of HIV-related service needs for the entire State. The CARE Act requires the public health agency administering the State's Title II grant to periodically convene representatives of all CARE Act Titles, PLWH, service providers, and public agency representatives to develop a Statewide Coordinated Statement of Need.

SPNS (*Special Projects of National Significance*) - Authorized under Part F of the CARE Act, the SPNS Program supports the demonstration, evaluation, and dissemination of innovative HIV health and support service delivery models.

Supplemental Grant - Title I of the CARE Act authorizes the awarding of competitive supplemental grants to EMAs that demonstrate need and the ability to effectively use and manage the resources.

Title I (*CARE Act*) - provides formula and supplemental grants to Eligible Metropolitan Areas (EMAs) that are disproportionately affected by the HIV epidemic.

Title II (*CARE Act*) - provides formula grants to States, the District of Columbia, Puerto Rico, and eligible U.S. territories to improve the quality, availability, and organization of health care and support services for PLWH and their families.

Title III (*CARE Act*) - provides funding to public and private nonprofit entities for the provision of outpatient HIV early intervention services to low-income and medically underserved populations.

Title IV (*CARE Act*) - provides funding to public and private nonprofit entities for demonstration projects that coordinate HIV services and increase access to research for children, youth, women, and families.

URS (*Uniform Reporting System*) - Data collection system designed by HRSA to document the use of Title I and Title II funds. This system includes the AAR and voluntary client-level data.

Statistical, Epidemiologic, and Needs Assessment Terms

Acceptability - the extent to which consumers are satisfied with the availability, accessibility, cost, and quality of care.

Accessibility - the ability to obtain services in terms of economic, time, locational, cultural, and informational factors.

AIDS (*Acquired Immunodeficiency Syndrome*) - disease caused by the human immunodeficiency virus.

Availability - the supply of services and resources.

Average - the sum of individual scores in a data set divided by the total number of scores; also referred to as the mean.

Bar Chart - a visual way to display and compare scores or values for different categories of variables. For example, a bar chart might be used to show the number of reported AIDS cases who are from each major racial/ethnic group; the taller the bar, the larger the number of AIDS cases.

Capability - Assessments of provider capability describe the extent to which each provider's services are geographically and physically accessible, culturally appropriate, and available at convenient times.

Capacity - Assessments of provider capacity describe how much of which services a provider can deliver (i.e., the number of service units and/or the estimated number of clients who can be served).

Case Fatality Rates - percentage of deaths reported among people whose cases were diagnosed during a specified period. For example, AIDS case fatality rates might specify the percentage of deaths among AIDS cases diagnosed during the past five years.

CD4 Count - the absolute number of CD4⁺ lymphocytes per cubic millimeter of blood. The CD4⁺ count is used as a marker of the progression of HIV-related immunosuppression. A decrease in the number of CD4⁺ lymphocytes correlates with an increase in the risk and severity of HIV-related opportunistic infections. Under the CDC's case definition of AIDS, an HIV-positive person with a CD4⁺ lymphocyte count less than 200 cells/mm³ of blood is considered to have AIDS.

Closed-Ended Questions - questions in an interview or survey format that provide a limited set of predetermined responses; also called forced choice questions.

Coding - the process of "translating" survey responses into numerical codes that can be used in computer-based data analyses.

Co-morbidity - coexisting diseases or illnesses, such as AIDS and severe mental illness or AIDS and substance abuse.

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Community Forum - a small-group method of collecting qualitative information from community members. Community forums tend to be larger and less formal than focus groups. Group leaders facilitate discussion on issues and topics identified in a topic guide, and observers are present to take notes and tape-record the comments.

Convenience Sample - a form of nonprobability sampling. Rather than choosing a random sample from a target population, surveys or interviews are administered to people who happen to be available at the time.

Cultural Competence - the knowledge, understanding, and skills to work effectively with individuals from differing cultural backgrounds.

Cumulative Incidence - the total number of new cases of a disease that have been diagnosed and reported from the time reporting began to the most recent reporting date.

Data - information organized for analysis or used as the basis for decision making. Data may be presented in numerical or nonnumerical forms.

Data Analysis - the categorizing, ordering, manipulating, and summarizing of data to obtain answers to evaluation or research questions.

Decimal Places - number of digits to the right of the decimal point, which separates numbers with a value greater than one from numbers with a value of less than one.

Epidemic - the spread of an infectious disease through a population or geographic area.

Epidemiologic Profile - a description of the current status and projected future spread of an infectious disease (an epidemic) in a specified geographic area; one of the required components of a CARE Act needs assessment.

Epidemiology - the study of factors associated with health and disease and their distribution in the population.

Evaluation - the systematic collection of information about the activities, characteristics, and/or outcomes of programs/systems to make judgments about the program/system, improve program/system effectiveness, and/or inform decisions about future programming/approaches.

Exposure Categories - For surveillance purposes, CDC groups HIV/AIDS cases into categories based on the manner in which people were exposed to HIV (e.g., injecting drug use, men who have sex with men, heterosexual contact, etc.). Also referred to as transmission categories.

Focus Group - a qualitative method of information collection involving a small group of people whose discussion is carefully planned and led by an experienced moderator.

Forced-Choice Question - questions in an interview or survey format that provide a limited set of predetermined responses; also called closed-ended questions.

Frequency Distribution - a tally of the number of times each score or response occurs in a group of scores or responses. For example, if 20 women with HIV provided information about how they acquired the virus, the frequency distribution might be 8 = injecting drug use, 5 = heterosexual contact with an injecting drug user, 3 = heterosexual contact with bisexual male, 1 = receipt of blood transfusion, and 3 = don't know.

Generalizability - the extent to which findings from a study sample can be assumed to be true of the target population from which the sample was drawn.

HIV Disease - the entire spectrum of the natural history of the human immunodeficiency virus, from post infection through the clinical definition of AIDS.

Incidence - the number of new cases of a disease that occur during a specified time period.

Incidence Rate - the number of cases of a disease per population per specified time period, often expressed per 100,000 population. $\text{Incidence rate} = \frac{\text{Number of new cases of the disease that occur during a given time period}}{\text{total number of people in the population during the same time period}}$.

Key Informant Interview - a qualitative information collection method involving in-depth interviews with a small number of individuals carefully selected because of their personal experiences and/or knowledge related to the topic of interest. A discussion guide is used to ensure that major topics and issues are addressed.

Line Charts - show changes in the values of a particular variable over time. Values are recorded periodically as points on a graph and then connected to show trends.

Mean - the sum of individual scores in a data set divided by the total number of scores; also known as the arithmetic average.

Measures of Central Tendency - Term used to describe measures that show the "average" or "typical" value for a set of scores. The most common measures are the mean, median, and mode.

Measures of Dispersion - Term used to describe measures that show how "spread out" or how "far from the typical value" a set of scores are. The most common measures are the range, variance, and standard deviation.

Median - the middle item of a data set which shows the "typical" score or response. If a data set is arranged in order of increasing size, the median is the value of the *middle* observation in the series.

Mode - the *most frequently occurring* value in a data set.

Open-Ended Questions - questions in an interview or survey format that allow respondents to provide answers in their own words rather than selecting from a set of predetermined responses.

Opportunistic Infections - diseases that occur when a patient's immune system is weakened. The presence of certain opportunistic infections is used as an indicator that a person has AIDS.

Overrepresentation/Underrepresentation - terms used to indicate that a particular subpopulation makes up a larger proportion-or a smaller proportion-of a particular group than would be expected, given its representation in the total population.

Oversampling - a procedure in stratified random sampling in which a larger number of individuals from a particular group (or stratum) are selected than would be expected given their representation in the total population being sampled. This is done in order to have enough subjects to permit separate analysis of that group.

Percentage - a proportion or share of the whole; calculated by dividing the *part of the whole* by the *whole* and multiplying the result by 100.

Percentage Point - one one-hundredth; term used to describe numerical differences between two percentages without comparing relative size. For example, if 16 percent of AIDS cases are Hispanic and 32 percent are African American, the difference is 16 percentage points.

Population Count - data that are obtained from an entire population without sampling. The U.S. Census, conducted every ten years, is a population count since it attempts to obtain information from everyone living in the United States.

Prevalence - the total number of people living with a specific disease or condition at a given time. Prevalence includes both previously diagnosed and new cases of a disease.

Prevalence Rate - the total case rate of a disease or condition in a given population at a given time. Prevalence rate = number of cases of the disease existing at a given point in time ÷ total number of persons in the population at that time.

Primary Source Data - original data that the CARE Act planning group collects and analyzes.

Probability - the likelihood that a particular event or relationship will occur.

Probability Sampling - this type of sampling relies upon the laws of chance (i.e., random selection) to select the people who will be in the sample. If you want to generalize from a sample to a target population, it is essential to use a probability sampling method. (See simple random sample, systematic random sample, and stratified sample.)

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Probability Value (*p*-value) - the probability that a statistical result (an observed difference or relationship) could have occurred by chance alone. Statistical results usually are regarded as significant if there is less than a 5 percent probability that the observed difference or relationship was due to chance alone. In such situations, the *p*-value is said to be less than .05 ($p < .05$).

Proportion - a number smaller than one, which is calculated by dividing the number of subjects having a certain characteristic by the total number of subjects. For example, if a community reported 35 new AIDS cases over the past year and 7 of them were women, the proportion of female AIDS cases would be .2 ($7 \div 35 = 1/5$ or .2).

Public Health Surveillance - an ongoing process of information collection, analysis, interpretation, and dissemination to monitor the occurrence of specific health problems in populations.

Public Hearing - a qualitative method of collecting information through a structured open meeting with people from diverse community sectors. Participants may make formal presentations and/or engage in discussion with a decision-making or fact-finding body.

Qualitative Data - data presented in nonnumerical (usually narrative) form, such as the information collected from key informant interviews and focus groups.

Quantitative Data - data presented in numerical terms, such as survey data and data from epidemiologic reports.

Range - the difference between the largest and smallest scores in a data set.

Ratio - a way of showing the relative size of two numbers. The first number is divided by the other number to derive the ratio. This ratio may be expressed as a fraction (X/Y), or the two numbers may be separated by a colon ($X:Y$). For example, if a community reported 45 AIDS cases among African American children and 30 AIDS cases among white children, the ratio could be expressed as $45/30$ (45:30), $3/2$ (3:2), or 1.5:1.

Raw Data - data that are in their original form and that have not been coded or analyzed.

Reliability - the consistency and dependability of a data collection instrument or measure. If you repeated a blood test three times on the same blood sample, it would be reliable if it generated the same results each time.

Representative - term used to indicate that a sample is similar to the target population from which it was drawn and, therefore, can be used to make inferences about that population.

Rounding - a method of expressing a number approximately or only to a specified number of decimal places. For example, each number could be rounded to the nearest whole number or the nearest tenth of a percent.

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Sample - A group of subjects selected from a total population or universe with the expectation that studying this group will provide important information about the total population.

Sampling Frame - a list of the target population from which the sample will be drawn; specifies who is eligible for inclusion in the study.

Secondary Source Data - databases or reports available from previous studies or data collection efforts (e.g., HIV/AIDS surveillance data, hospital discharge data, vital statistics).

Self-Administered Survey - questionnaires are mailed or given to respondents who complete and return them without an interviewer present.

Serology - the study of blood serum and its component parts. Blood serum is the fluid that separates from clotted blood or blood plasma that has been allowed to stand. HIV testing is conducted using blood serum from the person being tested.

Seroprevalence - the number of persons in a population who test positive for HIV antibodies.

Seroprevalence Rate - the number of HIV-positive individuals divided by the total number of persons tested. Since the serology tests that are used to determine seroprevalence may include more than one specimen from the same individual, the seroprevalence rate can be more precisely defined as the number of HIV-positive serology specimens divided by the total number of specimens tested.

Seroprevalence Reports - reports which provide information about the percentage of people in specific testing groups and populations who have tested positive for HIV antibodies.

Simple Random Sample - a type of probability sample in which subjects are selected one person at a time by a chance process that gives every person in the population a known, nonzero, and equal chance of being included in the sample.

Standard Deviation - the square root of the variance of a set of scores; provides a measure of the degree to which the scores deviate from the mean.

Statistical Significance - a measure of whether an observed difference or relationship is larger or smaller than would be expected by chance alone. Statistical results usually are regarded as significant if there is less than a 5 percent probability that the observed difference or relationship was due to chance alone.

Statistics - information or data presented in numerical terms. The field of statistics encompasses the collection, summarization, presentation, and analysis of data.

Stratified Sample - a type of probability sampling in which the sampling frame is divided into subgroups (strata) and random samples are drawn from each of the subgroups. This sampling procedure can be used to ensure that certain groups are included in the study or to sample some groups at a higher (or lower) rate than others.

Surrogate Measures - substitute measures used to understand a situation when direct measures are not available. For example, incidence rates of sexually transmitted diseases (STDs) can be used as surrogate measures of risk for HIV disease because people get STDs when they engage in unprotected sex.

Surveillance Reports - reports providing information on the number of reported cases of a disease, nationally and for specific locations and subpopulations.

Survey Research - a systematic method of data collection in which a sample of individuals is selected from a target population to respond to a structured set of survey or interview questions. The information is used to generate group-level summary statistics and to generalize findings to the target population.

Systematic Random Sample - a type of probability sample in which subjects are selected by choosing a random starting point on the sampling frame and then systematically selecting cases at a specified sampling interval. Using this approach, every person in the population has a known chance of being included in the sample.

Target Population - the group or groups about which information is desired; also called the study universe.

Transmission Categories - For surveillance purposes, CDC groups HIV/AIDS cases into categories based on the manner in which people were exposed to HIV (e.g., injecting drug use, men who have sex with men, heterosexual contact, etc.). Also referred to as exposure categories.

Trend - movement in a particular direction, as reflected by changes in the value of variables over time.

Universe - the group or groups about which information is desired; also called the target population.

Validity - the extent to which a data collection instrument or specific questions measure what they are supposed to measure.

Value - individual response or score.

Variable - a symbol to which numerals or values are assigned. Variables that can assume a range of values are called *continuous variables* (e.g., CD4 count, income level, caseload size). Variables with discrete categories are called *categorical variables* (e.g., gender, race, exposure category).

Variance - a measure of the degree to which the scores in a data set deviate from the mean.

References and Resources

The following references and resources provide more detailed information on the topics covered in this guide. Most of the materials relating to Titles I and II of the CARE Act can be obtained from the Division of Service Systems (DSS) in HRSA's HIV/AIDS Bureau. Requests should be sent to: Publications, Division of Service Systems, HIV/AIDS Bureau, Parklawn Building, Room 7A-55, 5600 Fishers Lane, Rockville, MD 20857, Fax (301) 443- 8143. The HIV/AIDS Bureau has a Home Page on the World Wide Web: <http://www.hrsa.dhhs.gov/hab>.

Many of the data-based publications referenced in this guide are available from the CDC. Exhibit 1 provides telephone numbers and Web site addresses for some of the epidemiologic reports. Other publications and materials can be ordered by contacting the CDC National AIDS Clearinghouse at 1-800-458-5231 or <http://www.cdcnac.org/pubsordr.html>.

Ryan White CARE Act

1995 *Annual Administrative Report (AAR) National Data Tables*, Ryan White CARE Act, Title I and Title II. Prepared by the Division of HIV Services, April 1997.

Care/Preventative Collaborative Planning: HRSA AIDS Programs Title I and Title II Planning Bodies and CDC HIV Prevention Community Planning Groups. Prepared by the Division of Service Systems, HIV/AIDS Bureau/HRSA, and the Centers for Disease Control and Prevention (CDC), January 1998. Available from John Snow, Inc. (JSI), (617) 482-9485.

Collaboration between Ryan White Title I Planning Councils, Title II Consortia, and the National AIDS Education and Training Centers (AETC) Program, March 16, 1995. Report of a CARE Act Technical Assistance Conference call; prepared by Mosaica, Washington, D.C. Available from John Snow, Inc. (JSI), (617) 482-9485.

Comprehensive HIV Services Planning, February 1, 1996. Report of a CARE Act Technical Assistance Conference call; prepared by Mosaica, Washington, D.C. Available from John Snow, Inc. (JSI), (617) 482-9485.

Comprehensive HIV Services Planning, Self-Assessment Module for Ryan White CARE Act Title I HIV Services Planning Councils and Title II HIV Care Consortia. Prepared by John Snow, Inc. (JSI), Boston Massachusetts, 1996. By answering the questions in this module, CARE Act planning groups can evaluate the effectiveness of their comprehensive planning activities. Available from John Snow, Inc. (JSI), (617) 482-9485.

Creating Partnerships That Work: A Developmental Manual for Ryan White Title II HIV Care Consortia. Prepared by John Snow, Inc. (JSI), Boston, Massachusetts, May 1995. A detailed manual designed to help consortia successfully organize themselves and address issues related to structure, bylaws, policies and procedures, and roles and responsibilities. Available from John Snow, Inc. (JSI), (617) 482-9485.

Using Data to Assess HIV/AIDS Service Needs

Effective Integration of Consortium and Planning Council Activities, June 12, 1996. Report of a CARE Act Technical Assistance Conference Call; prepared by Mosaica, Washington, D.C. Available from John Snow, Inc. (JSI), (617) 482-9485.

Planning Council Primer. Prepared by the Division of Service Systems. January 1998. Available from John Snow, Inc. (JSI), (617) 482-9485.

PLWH Sourcebook. Prepared by Mosaica, Washington, D.C., July 1996. Provides information, contacts, and resources related to PLWH involvement in Titles I and II of the CARE Act. Available from John Snow, Inc. (JSI), (617) 482-9485.

“Quality Assurance and Improvement, August 3, 1995.” Report of a CARE Act Technical Assistance Conference Call; prepared by Mosaica, Washington, D.C. Available from John Snow, Inc. (JSI), (617) 482-9485.

Ryan White CARE Act Title I Manual. Prepared by John Snow, Inc. (JSI), Boston, Massachusetts, 1997. Extensive compendium of background materials, policies, guidance, technical assistance materials, terminology, and other information related to the implementation of Title I of the CARE Act. Available from John Snow, Inc. (JSI), (617) 482-9485.

“Summary of Methodology for Estimating HIV Prevalence in Metropolitan Areas,” sent as a Letter to Colleagues by the Division of HIV Services on March 6, 1996.

Most recent ***Title I Grant Application Guidance*** (combines formula and supplemental grant applications).

Most recent ***Title II Application Guidance***.

Training Guide: A Resource for Orienting and Training Planning Council and Consortium Members. Prepared by Mosaica, Washington, D.C., 1997. A summary of information about the CARE Act that can be used to orient and train Planning Council and Consortium members.

Health Terminology

The Bantam Medical Dictionary. New York: Bantam Books, 1990. Dictionary of medical terms, including health planning and epidemiological terms.

Needs Assessment

“Assessing HIV Service Needs in Hard to Reach Populations.” Prepared by P. Fairchild and others, ***XI International Conference on AIDS Abstract***, 1996. Available from the National AIDS Clearinghouse.

Gantz McKay, E. ***Developing a Community Needs Assessment***. Washington, D.C.: National Council of La Raza Office of Institutional Development, December 1993. Available from the National Council of La Raza Publications Distribution Center, (202) 604-7983.

Moving Forward: An Assessment of Needs and Services for the Evolving Epidemic of HIV in Massachusetts 1995 - 1999. Prepared by JSI Research and Training Institute, Boston, 1995. Example of a statewide needs assessment. Available from John Snow, Inc. (JSI), (617) 482-9485.

Naranjo, D. ***Healthy Horizon: A Guide for Developing Health Education and Promotion Programs***. Washington D.C.: National Council of La Raza Center for Health Promotion, 1994. (See Chapter V.) Available from the National Council of La Raza Publications Distribution Center, (202) 604-7983.

“Needs Assessment,” Chapter in ***Ryan White CARE Act Title I Manual***. Prepared by John Snow, Inc. (JSI), Boston, Massachusetts, 1997.

Needs Assessment, March 26, 1996. Report of a CARE Act Technical Assistance Conference Call; prepared by Mosaica, Washington, D.C. Available from DSS.

Needs Assessment: Self-Assessment Module for Ryan White CARE Act Title I HIV Health Services Planning Councils and Title II HIV Care Consortia. Prepared by John Snow, Inc. (JSI), Boston, Massachusetts, 1996. By answering the questions in this module, CARE Act planning groups can evaluate the effectiveness of their needs assessment activities.

Epidemiology and Statistics

Cohn, V. ***News and Numbers: A Guide to Reporting Statistical Claims and Controversies in Health and Other Fields***. Ames, Iowa: Iowa State University Press, 1989. Practical information about how to review statistics.

Gillings, D.B., & Douglass, C.W. ***BIOSTATS: A Primer for Health Care Professionals***. Chapel Hill, NC: CAVCO Publications, 1985. Presents basic statistical concepts and techniques, with practical examples and self-tests.

Oleske, D.M. ***Epidemiology and the Delivery of Health Care Services: Methods and Applications***. New York: Plenum Press, 1995. Describes basic epidemiologic measures and illustrates how they can be used in planning and monitoring the health of populations.

Vogt, W.P. ***Dictionary of Statistics and Methodology: A Nontechnical Guide for the Social Sciences***. Newbury Park, California: SAGE Publications, 1993. Defines and describes a wide range of statistical and research terms and techniques.

Evaluation and Research Methods

Aday, L.A. ***Designing and Conducting Health Surveys***. San Francisco: Jossey-Bass, Inc., 1996. Offers comprehensive guidance on designing and conducting surveys, including variable development, sampling, questionnaire construction, and data collection and analysis.

Choosing and Using an External Evaluator. CDC publication adapted for use by Ryan White CARE Act grantees by Community Health Solutions, Inc., Richmond, Kentucky, 1997. Describes a seven-step process for selecting and using external evaluators. Available from the Office of Science and Epidemiology, HIV/AIDS Bureau, (301) 443-6560.

Evaluation of Local HIV Service Delivery: Issues, Approaches, and Strategies Under Title I, The Ryan White CARE Act, May 1996. Summary of a meeting sponsored by the Division of HIV Services and the Office of Science and Epidemiology on March 4-6, 1996; prepared by K. Eilbert, Public Health Foundation, Washington, D.C. and R. Hines, Office of Science and Epidemiology, Rockville, MD.

Gantz McKay, E., and López, D.A. ***Evaluating HIV/STD Education and Prevention Programs: An Introduction.*** Washington, D.C.: National Council of La Raza AIDS Center, Center for Health Promotion, 1991. Describes how community-based organizations and community planning groups can evaluate HIV prevention programs; also relevant to other types of program evaluation. Available from the National Council of La Raza Publications Distribution Center, (202) 604-7983.

Krueger, R. ***Focus Groups: A Practical Guide for Applied Research.*** Newbury Park, CA: SAGE Publications, Inc., 1988. Provides practical advice on designing and conducting focus groups; also discusses the analysis and reporting of focus group results.

Leyva, M.A., and Gantz McKay, E. ***Understanding Evaluation Techniques: The Building Blocks of Evaluation.*** Washington, D.C.: National Council of La Raza AIDS Center, Center for Health Promotion, June 1993. Discusses a variety of evaluation methods and when to use them, with emphasis on the evaluation of HIV prevention programs. Available from the National Council of La Raza Publications Distribution Center, (202) 604-7983.

Local Evaluation of Ryan White Title I CARE Initiatives. Prepared by John Snow, Inc. (JSI), Boston, Massachusetts, February 1996. Reports Title I evaluation results and illustrates evaluation approaches that can be extended to Title II Consortia.

Posavac, E.J., & Carey, R.G. ***Program Evaluation: Methods and Case Studies.*** Upper Saddle River, NJ: Prentice-Hall, Inc., 1997. Provides a comprehensive and practical introduction to program evaluation. Case studies of completed program evaluations are used to illustrate applications of evaluation methods.

Ryan White Self-Assessment Modules For Title I HIV Services Planning Councils and Title II HIV Care Consortia. Prepared by JSI, Boston, Massachusetts. This six-module series is designed to help CARE Act planning groups assess and improve their operations. The topics include: Developing and Pursuing the Mission, Representation and Diversity, Needs Assessment, Comprehensive Planning, Priority Setting and Resource Allocation, and Continuum of Care.