Part 4. Conclusion

The knowledge and skills emphasized in this guide — how to understand and interpret statistics, and how to help assure a thorough and community-relevant needs assessment — can be applied to many situations. In addition to the HIV Prevention Community Planning process, needs assessments and comprehensive plans are being developed to help guide HIV/AIDS treatment, including funding through the Ryan White CARE Act. A similar emphasis on community-Inclusive planning is growing in other areas of health care, from mental health to maternal and child health. In any aspect of health planning and priority-setting, a community member who not only understands a specific population but also knows the planning process, and particularly the needs assessment process, represents a valuable and valued group member. As a community representative who has participated in the HIV Prevention Community Planning process, you are likely to find yourself in considerable demand for other planning and advisory groups.

These skills can be applied to many situations. For example, you can:

- Review surveys and studies about the community, asking important questions about their methodology, and the validity of their results;
- Question public officials about program priorities and funding decisions, to determine whether they have adequately considered the needs and concerns of various populations;
- Question “experts” who claim to know how to solve community problems, to see if there is adequate documentation to support their claims;
- Serve on advisory committees or oversight groups, knowing how to demand that decisions be based on solid community-relevant information;
- Serve on the governing boards of nonprofit organizations, and help assure that they carry out appropriate planning, needs assessment, and decision-making processes;
- Testify effectively about the needs of your community before public bodies, using appropriate statistical and qualitative research; and
- Advocate effectively for your community in other situations, able both to use and to question needs assessments, evaluations, and other studies and statistics.

Assuring diverse and active community participation in planning and priority setting is extremely important to the community as a whole, and to the specific population you represent. Community groups and leaders recognize the great importance of being a part of any effort which leads to decisions about how human service funds will be targeted and allocated. Only by participating in the needs assessment and decision-making process can you ensure that the process will be truly broad-based and comprehensive, and that it will adequately and appropriately consider the status and concerns of differing groups. Such participation involves a significant time commitment, but brings considerable benefits. Moreover, once you have become familiar with the processes and terminology and with reviewing — and questioning — statistical reports, you are likely to be comfortable not only with full participation but also with taking on leadership responsibilities.

Comprehensive community planning requires that more community representatives have the opportunity to develop these skills. Increasingly, training in using statistics, carrying out needs assessments, understanding policy analysis, and serving on Boards of Directors and other kinds of committees has become a part of grassroots leadership efforts. You may be able to help other community members by sharing your knowledge and skills, formally or informally. For example, you might use a recent community needs assessment or study as a case study, and work with a group to show them how to review its design, sampling, data
collection, analysis, and data presentation to see to what extent they are appropriate and culturally sensitive. You might also review some newspaper articles and see how accurately they summarize the report, identifying common errors in reporting statistics. When you see inappropriate statistics or poorly designed needs assessments, you can share this information with affected communities. Better still, you can help other community members to participate in planning efforts by sharing your experience of how to review study designs, epidemiologic studies, and other statistical reports, so that the needs assessments generated will be community-relevant. In short, you cannot only continue to use your own skills, but share them with others. Over time, this will greatly increase community involvement in HIV/AIDS and other health planning, and improve the quality of planning and decision making affecting all the diverse populations which together form the American mosaic.
Part 5. References and Resources

I. GLOSSARY OF TERMS*

Following are summary definitions and explanations of a number of terms which you may encounter in dealing with statistics and with community needs assessments, particularly related to HIV prevention. The descriptions are designed to be clear and practical and to describe terms as they are likely to be used in reference to HIV/AIDS statistics; they do not attempt to provide a full technical explanation for each term. More extensive and precise definitions and descriptions can be found in several of the technical references cited in this manual. No attempt is made to include technical terms which relate specifically to HIV/AIDS; it is assumed that community members of planning groups will obtain this information from other sources.

Average - a way of describing the typical value or central tendency among a group of numbers, such as average age or average income; three commonly used types of averages are mean, median, and mode (See each in the Glossary).

Bar Chart or Bar Graph - a visual way to show 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.

Closed-Ended Questions - questions in an interview or survey format that provides a limited set of pre-defined alternative responses; for example, a survey might ask respondents if they have been sexually active over the past six months, and then ask, "How often in the past six months have you used a condom during sexual intercourse?" and provide the following response options: Always, Usually, Sometimes, Never.

Coding - the process of "translating" data from one format to another, usually so the information can be entered into a computer to be tabulated and analyzed; often, coding involves assigning numbers to all the possible responses to a question, such as Yes = 1, No = 2, Not Sure = 3, No Response = 0.

Community Needs Assessment - a systematic process designed to determine the current status and unmet needs of a defined population or geographic area; may focus on a particular program topic such as HIV/AIDS, or on a broader issue area such as health.

Data Analysis - careful, rigorous study of data; usually involves studying various elements of information and their relationships.

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; the more numbers or decimal places used, the more precise the number; for example, 34.03 has two decimal places.

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

* These definitions and explanations are designed to be as practical and clear as possible. Statistical terms were checked against definitions provided in W. Paul Vogt, Dictionary of Statistics and Methodology: A Nontechnical Guide for the Social Sciences, Newbury Park, California: SAGE Publications, 1993; medical and public health terms were checked in The Bantam Medical Dictionary, New York: Bantam Books, 1990.
**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 comprehensive HIV prevention plan.

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

**Executive Summary** - brief summary of a longer report, usually including the most important results or recommendations plus other information needed by policy makers or other individuals who are unlikely to read the full report.

**Exposure Category** - in describing HIV/AIDS cases, same as *transmission categories*; how an individual may have been exposed to HIV, such as injecting drug use, men who have sex with men, and heterosexual contact.

**Focus Groups** - information collection method consisting of a carefully planned discussion, led by a trained moderator, in which a small group of selected individuals give their opinions of and reactions to a concept, approach, or sample product.

**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 teenagers who are sexually active provided information about how often they used condoms during intercourse over the past six months, the frequency distribution might be 5 = Always, 4 = Usually, 7 = Sometimes, and 4 = Never.

**Generalizability** - the extent to which findings or conclusions from a sample can be assumed to be true of the entire population from which the sample was drawn; findings can be generalized only when the sampling procedure and the data meet certain methodological standards.

**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.

**Innumeracy** - a lack of skills in understanding and using numbers and mathematical concepts; often compared to illiteracy, a lack of reading and writing skills.

**KAB Studies** - Knowledge, Attitude, and Behavior Studies; in the AIDS field, studies which attempt to study people reached through specific HIV/AIDS prevention activities or messages and determine changes in knowledge and attitudes about HIV and its transmission, and behavior change related to risk factors such as unprotected sex and needle sharing.

**Math Anxiety** - a feeling of discomfort when dealing with numbers.

**Mean** - arithmetic average, calculated by adding up all the values or the responses to a particular question and dividing by the number of cases; for example, to determine the mean age of 12 youth in a prevention program, add up their individual ages and divide by 12.

**Median** - a type of average which calculates the central value, the one that falls in the middle of all the values when they are listed in order from highest to lowest; for example, if the annual incomes of seven families were $37,231, $35,554, $30,896, $27,432, $24,334, $19,766, and $18,564, the median would be $27,432.
Mode - a type of average which identifies the most frequently occurring value; for example, suppose a prevention project included 13 children of the following ages: 16, 16, 15, 14, 14, 14, 14, 13, 13, 12, 12, 11, 10; the mode would be 14, which occurs four times.

Open-Ended Questions - questions in an interview or survey format that allow those responding to answer as they choose, rather than having to select one of a limited set of predefined alternative responses.

Overrepresentation/Underrepresentation - terms often 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; for example, Hispanics and African Americans are both overrepresented among AIDS cases, compared to their percentage in the U.S. population, while Asians/Pacific Islanders are underrepresented.

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 tabulation and analysis of that group; for example, minorities are often oversampled to permit separate analysis of data by racial/ethnic group as well as comparisons among racial/ethnic groups.

Percent - literally, per hundred; a proportion of the whole, where the whole is 100; percent is calculated by dividing the part of interest by the whole, and then multiplying by 100; for example, if you want to know what percent of AIDS cases are Hispanic, take the number of Hispanic AIDS cases (the part of interest), divide by the number of total AIDS cases (the whole), and multiply by 100; if your community has a total of 70 AIDS cases and 14 are Hispanic, divide 14 by 70 (=.2) and multiply by 100, and you get 20%.

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

Population Count - data which describe an entire population and were obtained from that entire population without sampling; the U.S. Decennial Census is a population count since it attempts to obtain information from everyone living in the United States.

Prevalence - The total number of persons living with a specific disease or condition during a given time period.

Prevalence Rate - the total case rate of a disease or condition in a given population at a given time (compared to the incidence rate, which refers to new cases).

Primary Source Data - original data that you collect and analyze yourself.

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

Probability Value - the probability that a statistical result — an observed difference or relationship — would have occurred by chance alone, rather than reflecting a real difference or relationship; statistical results are often considered to be significant if the probability or p value is less than .05, which means that there is less than a 5% chance — 5 out of 100 — that the result would have occurred by chance alone.
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 35 new AIDS cases have been reported in the community in the past year and 7 of them are women, the proportion of female AIDS cases is 7 divided by 35 or 1/5 (.2).

Public Health Surveillance - an ongoing, systematic process of collecting, analyzing, and using data on specific health conditions and diseases, in order to monitor these health problems, such as the Centers for Disease Control and Prevention surveillance system for AIDS cases.

Ratio - a combination of two numbers that shows their relative size; the ratio of one number to another is simply the first number divided by the other, with the relation between the two numbers expressed as a fraction (X/Y) or decimal (X.Y/1), or simply the two numbers separated by a colon (X:Y); for example, the ratio of minority to white pediatric AIDS cases in a community with 75 total cases, 45 among Hispanic and Black children and 30 among white children, would be 45/30 (45:30), 3/2 (3:2), or 1.5:1.

Raw Data - data that are in their original form, as collected, and have not been coded or analyzed; for example, if a woman participating in an HIV prevention workshop is tested to determine her knowledge of HIV transmission and gets a score of 11, that is her raw score; if the score represented 11 correct answers out of 20, then the score could be converted to 11 divided by 20 times 100 or 55%, which is no longer a raw score.

Reliability - the consistency of a measure or question, in obtaining very similar or identical results when used repeatedly; for example, 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 population from which it was drawn, and therefore can be used to make inferences about that population.

Respondent - a person who completes — responds to — a survey form or interview.

Rounding - presenting numbers in more convenient units; rounding is usually done so that all numbers being compared have the same level of precision (one decimal place, for example); usually numbers under 5 are rounded down while 5 and over are rounded up; for example, you would round 3.08 to 3.1 and 4.14 to 4.1.

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

Secondary Analysis - re-analysis of data or other information collected by someone else; for example, you might obtain data on AIDS cases in your metro area from the Centers for Disease Control and Prevention, and carry out some additional analysis of those data.

Secondary Source Data - information that was collected by someone else, but which you can analyze or re-analyze.

Seroprevalence - the number of persons in a population who test HIV+ based on serology (blood serum) specimens; often presented as a percent of the total specimens tested or as a rate per 1,000 persons tested.
**Seroprevalence Report** - report which provides information about the percent or rate of people in specific testing groups and populations who have tested positive for HIV.

**Statistical Significance** - a measure of whether an observed difference or relationship is larger or smaller than would be expected to occur by chance alone; statistical results are often considered to be significant if there is less than a 5% chance — 5 out of 100 — that they would have occurred by chance alone.

**Statistics** - Information or data presented in numerical terms; quantitative data; often refers to numerical summaries of data obtained through surveys or analysis.

**Stratified Random Sample** - a random sample drawn after dividing the population being studied into several subgroups or strata based on specific characteristics; subsamples are then drawn separately from each of the strata: for example, the population of a community might be stratified by race/ethnicity before random sampling.

**Surrogate Measures** - substitute measures, used to help understand a situation where adequate direct measures are not available; for example, it may be difficult to obtain good HIV surveillance data on teenagers, but incidence rates of sexually transmitted diseases (STDs) among teenagers can be used as surrogate measures of high-risk sexual behavior, since HIV is an STD, and people get STDs when they engage in unprotected sex.

**Surveillance Reports** - reports providing information on the number of reported AIDS cases nationally and for specific locations and subpopulations; the Centers for Disease Control and Prevention issues such reports, providing both cumulative cases and new cases reported during a specific reporting period, such as each of the last two years.

**Survey Research** - research in which a sample of subjects is drawn from a population and then interviewed or otherwise studied to gain information about the total population from which the sample was drawn.

**Tabulation of Data** - ordering and counting of quantitative data to determine the frequency of responses, usually the first step in data analysis; typically involves entering data into a computer for manipulation through some form of data analysis program.

**Target Populations** - populations to be reached through some action or intervention; may refer to groups with specific characteristics (e.g., race/ethnicity, age, gender, socioeconomic status) or to specific geographic areas.

**Transmission Categories** - in describing HIV/AIDS cases, same as **exposure categories**; how an individual may have been exposed to HIV, such as injecting drug use, men who have sex with men, and heterosexual contact.

**Trend** - movement in a particular direction in the value of variables over time.

**Trend Charts** - line charts which show changes or movement in the values of a particular variable over time; usually, values are recorded periodically as points on a graph, and then connected to show how the values are changing; often used to provide comparisons, such as separate lines showing reported AIDS cases among different population groups over time.

**Universe** - the total population from which a sample is drawn.
Validity - the extent to which a survey question or other measurement instrument actually measures what it is supposed to measure; for example, a question which asks young adults how often they use a condom is valid if it accurately measures their actual level of condom use, and it is not valid if it is really measuring the extent to which they realize that they should wear a condom to reduce the risk of HIV infection.

Value - individual response or score; for example, if people responding to a survey are asked to state their age, each age is a value.

Variable - a characteristic or finding that can change or vary among different people or in the same person over time; for example, race/ethnicity varies among individuals, and income varies for the same individual over time.

Weighting - a procedure for adjusting the values of data to reflect each group's percent in the total population; for example, suppose you stratified the community population by race/ethnicity and oversampled the minorities so you could compare findings for each group; in order to combine your findings to describe the entire population, you would weight the data to reflect the percentage of the whole population that comes from each racial/ethnic group.
II. Published References and Resources

Following are a small number of references and resources, designed to:

- Help community representatives obtain information which can help you participate actively in every aspect of the HIV Prevention Community Planning process; and
- Suggest materials which state and local health departments may want to make available to their planning group members.

The resources and references are arranged by topic area.

A. Background on the HIV Prevention Community Planning Process


*Guidance and Supplemental Information, Non-Competing Continuation of Cooperative Agreements for Human Immunodeficiency Virus (HIV) Prevention Projects, Announcement Number 300, Fiscal Year 1995*. Atlanta, Georgia: Centers for Disease Control and Prevention, 1994.


B. Health Terminology


C. Needs Assessment


D. Statistics and Evaluation


Figure 16
Summary of HIV seroprevalence data from adolescent clinics by clinic setting and sex, 1991-1992

<table>
<thead>
<tr>
<th>Clinic setting and client gender</th>
<th>Total centers</th>
<th>Total specimens tested</th>
<th>Centers analyzed</th>
<th>Percent positive</th>
<th>Median</th>
<th>(Range)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adolescent medicine clinics</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Males</td>
<td>21</td>
<td>2,315</td>
<td>10</td>
<td>0.1</td>
<td>(0.0 - 1.4)</td>
<td></td>
</tr>
<tr>
<td>Females</td>
<td>19</td>
<td>8,441</td>
<td></td>
<td>0.2</td>
<td>(0.0 - 1.4)</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>21</td>
<td>11,756</td>
<td>21</td>
<td>0.3</td>
<td>(0.0 - 1.4)</td>
<td></td>
</tr>
<tr>
<td>Homeless and runaway youth clinics</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Males</td>
<td>5</td>
<td>1,699</td>
<td>5</td>
<td>4.5</td>
<td>(0.0 - 8.9)</td>
<td></td>
</tr>
<tr>
<td>Females</td>
<td>5</td>
<td>1,969</td>
<td>5</td>
<td>1.2</td>
<td>(0.0 - 3.2)</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>5</td>
<td>3,704</td>
<td>5</td>
<td>2.8</td>
<td>(0.0 - 6.3)</td>
<td></td>
</tr>
<tr>
<td>Juvenile detention centers</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Males</td>
<td>8</td>
<td>6,637</td>
<td>8</td>
<td>0.1</td>
<td>(0.0 - 1.0)</td>
<td></td>
</tr>
<tr>
<td>Females</td>
<td>6</td>
<td>804</td>
<td>4</td>
<td>0.9</td>
<td>(0.0 - 2.8)</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>8</td>
<td>7,470</td>
<td>8</td>
<td>0.1</td>
<td>(0.0 - 1.7)</td>
<td></td>
</tr>
</tbody>
</table>

1 Includes centers funded to conduct unlinked surveys in 1991 and 1992.
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.
7 Total includes persons with gender not recorded.

Figure 17
Self-Test IV: Using Summary HIV Seroprevalence Data Tables

Using Figure 16, presenting data from adolescent clinics, answer these questions (Answers are at the end of the chapter):

a. Is there a clear pattern in the relationship between HIV+ rates for males versus females? What do the rates indicate?

b. Why were data on females analyzed from only four of the six reporting juvenile detention centers?

c. What group of adolescents seem to have the highest HIV seroprevalence rates? Why should this information be viewed as tentative?

Using Figure 18, presenting data from STD clinics, answer these questions:

d. Looking at the data for all clinics (far right of chart), what two locations had the highest median percent positive? Which two had the lowest?

e. In what location were rates highest among female injecting drug users? Male injecting drug users?

f. In what location were the largest number of total specimens tested? Smallest number?

g. In most locations, which risk factor group typically had the highest median percent positive, men who have had sex with men or male heterosexual injecting drug users?