

DATA SOURCES

Data were compiled from a variety of sources to provide the most complete picture possible. When interpreting the data, keep in mind that each of the data sources has strengths and limitations. A brief description of each of the data sources follows. (For a more detailed description, see Appendix A.)

Core HIV/AIDS Surveillance

HIV/AIDS Surveillance Data

In 1984, the Louisiana Office of Public Health established a surveillance system to track newly diagnosed AIDS cases. This surveillance system was expanded in February 1993 to include confidential name-based HIV reporting. Standardized case report forms are used to collect sociodemographic information, mode of exposure, laboratory and clinical information, vital status (i.e., living or dead), and referrals for treatment or services. According to state evaluations (Louisiana HIV/AIDS Program), HIV infection reporting is estimated to be more than 85% complete for persons who have tested positive for HIV. HIV surveillance data may underestimate the number of recently infected persons because some infected persons either do not know they are infected or have not sought testing. Persons who tested positive at an

anonymous test site and have not sought medical care (where they would be confidentially tested) are not included in HIV surveillance statistics. Therefore, HIV infection data can provide only minimum estimates of the number of persons known to be HIV infected. In addition, newly diagnosed cases may be reported to the health department at any point along the clinical spectrum of disease. Consequently, HIV infection data do not necessarily represent characteristics of persons who have been recently infected with HIV. The characteristics of persons who are tested anonymously differ from those who are tested confidentially. Whites and males are more likely to be tested anonymously. Females and blacks are more likely to be tested confidentially. Also, older persons are more likely to be tested anonymously; while younger persons tend to be tested confidentially.

Enhanced Perinatal Surveillance

Perinatal HIV/AIDS surveillance is the ongoing and systematic collection of information on HIV-infected pregnant mothers and on perinatally exposed (i.e., exposed around the time of birth) and HIV-infected children. Extensive medical record abstractions are conducted for all HIV-exposed children and their mothers, and the children are followed up until their infection status is determined. These data address the prevention of perinatal transmission and describe prenatal care, HIV counseling and testing during pregnancy, and use of zidovudine (ZDV) or other antiretroviral drugs for pregnant mothers and neonates. Also, questions regarding treatment issues for women infected with HIV and their children are answered. Enhanced perinatal surveillance data provide perinatal-specific data that can be used to determine the extent to which testing is conducted and ZDV is prescribed in clinical practice, and to identify barriers to the implementation of Public Health Service guidelines. The perinatal data may underestimate the number of mother-infant pairs, because some pregnant women may not know they are infected or have not been tested for HIV. Perinatal data include only those women who have had a positive result from a confidential HIV test and their infants. Perinatal testing for HIV is not required in Louisiana.

Supplemental HIV/AIDS Surveillance Projects

Adult/Adolescent Spectrum of HIV Disease (ASD) Study

The ASD study tracks the spectrum and progression of HIV disease among HIV-infected persons enrolled in the study. Data have been collected since 1990 among persons 13 years and older who have a diagnosis of HIV infection and have received health care at a participating facility. Patient records are abstracted for 12 months before enrollment and at 6-month intervals thereafter until patients die or are lost to follow-up. Louisiana's ASD study is based in 3 publicly funded facilities in New Orleans that provide health care to most of the persons living with HIV infection in the New Orleans area. ASD data are useful for assessing the prescription of prophylactic and antiretroviral treatment over time and for monitoring the clinical manifestations of disease. However, because the ASD study is not population-based, information from this study is not generalizable to HIV-infected persons statewide.

HIV Testing Survey (HITS)

HITS assesses HIV testing patterns among persons at high risk for HIV, evaluates reasons for seeking or avoiding testing, and examines knowledge of state policies for HIV surveillance. In addition, HITS collects behavioral risk information from persons at high risk for infection. The data can be used to evaluate the representativeness of HIV surveillance data by determining the

characteristics of persons who delay testing, who are tested anonymously, or who are not tested at all. In 2001, the survey was conducted in Louisiana in New Orleans (Orleans Parish), Baton Rouge (East Baton Rouge Parish), and Monroe. HITS is an anonymous, venue-based survey that targets persons at least 18 years of age and at high risk for HIV infection—men who have sex with men (MSM), injection drug users (IDUs), and high-risk heterosexual adults. Interviewees were recruited at gay bars (MSM), at street locations (IDUs), or in sexually transmitted disease (STD) clinics (high-risk heterosexual adults). The information collected is self-reported and may be biased by what persons are able to remember or feel comfortable reporting. Further, HITS data are not population-based and may not represent the entire high-risk population of an area.

Survey of HIV Disease and Care (SHDC)

SHDC is a review of medical records conducted among a sample of HIV-infected persons receiving medical care in Louisiana. Demographic and clinical information include whether patients are receiving preventive services and therapy recommended by current treatment guidelines. SHDC is designed to collect data from a representative sample of patients receiving HIV care so that population-based estimates of the proportion of HIV-infected persons receiving recommended standards of care can be made. However, trends in care cannot be assessed over time, and the quality of the data depends on the completeness of documentation in the patient's medical record. SHDC collects some behavioral information (e.g., drug use, STDs), but self-reported adherence to therapies may not be known. In addition, data from SHDC may underestimate the amount and type of medical care if the patient received medical care from more than one provider. For example, gynecologic care may be underreported if the provider of this care was not an HIV specialist.

Behavioral Surveys

MSM Outreach Survey (MOS)

During 1995–2000, outreach surveys were conducted across Louisiana at bars whose clientele are MSM. The survey was a 1-page, self-administered questionnaire distributed by outreach workers from 20 local community-based organizations (CBOs). Each CBO surveyed 50 to 150 MSM twice per year at 1 to 2 bars where they conducted outreach activities. Every person at the bar was approached. If the bar was very busy, the outreach workers selected a representative sample of persons at the bar (e.g., they approached every 3rd person who entered the bar). Respondents were asked about sex partners, history of condom use, history of receptive and insertive anal sex, and HIV status. Because these data were collected in bars, the data are representative of only the MSM who go to gay bars and cannot be generalized to all MSM.

Street Outreach Surveys (SOS)

SOS have been administered by CBOs in every region of the state since 1995. The surveys, 1-page, self-administered questionnaires, are distributed each quarter by outreach workers at 3 sites where they actively conduct street outreach activities. These sites are in neighborhoods with one or more of the following characteristics: high rates of HIV/STDs, high levels of drug use, exchange of sex for money or drugs, or "crack" houses. Questionnaires are collected between 3:00 p.m. and 8:00 p.m. at outdoor locations (i.e., street corners, at bus stops, in public housing developments, and locations outside convenience stores and apartment complexes). All surveys are generally conducted at the same sites each quarter. Every person at the site is approached, but workers select a representative sample of persons at the site (e.g., every 3rd person) if it is very

busy. Respondents are asked about sex partners, history of condom use, drug use, HIV testing history, and exposure to prevention programs. These data represent persons at particularly high risk for HIV and are not generalizable to the general population in the local community.

Behavioral Risk Factor Surveillance System (BRFSS)

The BRFSS is a state-based random-digit-dialed telephone survey of adults that monitors state-level prevalence of the major behavioral risks associated with premature morbidity and mortality. Respondents to the BRFSS questionnaire are asked about their personal health behaviors and health experiences. A sexual behavior module was added in 1994, 1995, 1996, 1998 and 2000. In this module, adults (aged 18–49) were asked about number of sex partners, condom use, and treatment for STDs. Data from the BRFSS survey are population-based; thus, estimates about testing attitudes and practices can be generalized to the adult population of a state, not just persons at highest risk for HIV/AIDS. However, because BRFSS respondents are contacted by telephone, the data are not representative of households that do not have telephones.

Youth Risk Behavior Survey (YRBS)

The YRBS is a self-administered questionnaire given every 2 years to a representative sample of students in grades 9 through 12 at the state and local level. In Louisiana, the survey is administered at the state level and in Orleans Parish public schools; however, only the survey administered to Orleans Parish high school students includes questions related to sexual behavior. The Orleans Parish YRBS collects information on 6 categories of behaviors; sexual behaviors that contribute to unintended pregnancy and STDs, including HIV infection, constitute 1 category. Questions are also asked about exposure to HIV prevention education materials, sexual activity (age at initiation, number of partners, condom use, past drug or alcohol use), contraceptive use, and pregnancy history. The YRBS is a standardized questionnaire, so comparisons can be made across participating jurisdictions. Jurisdictions may also add questions of local interest. However, because the YRBS project relies upon self-reported information, sensitive behavioral information may be underreported or overreported. Also, because the YRBS questionnaire is administered in school, the data are representative only of adolescents who are enrolled in school and cannot be generalized to all adolescents. For example, students at highest risk, who may be more likely to be absent from school or to drop out of school, may be underrepresented in this survey, especially those in upper grades. The questionnaire does not include questions about homosexual or bisexual behavior.

STD Surveillance

STD Case Reporting

The Louisiana Office of Public Health STD Control Program conducts statewide surveillance to determine the number of reported cases of STDs and monitor trends. Other services include partner counseling and, to help reduce the spread of STDs, referral services for examination and treatment. In Louisiana, chancroid, chlamydia, gonorrhea, lymphogranuloma venereum, and syphilis are reportable STDs. STD surveillance data (e.g., rates of rectal gonorrhea) can serve as a surrogate marker for unsafe sexual practices and demonstrate the prevalence of changes in a specific behavior. STD data are widely available at the state and local level. Because of shorter incubation periods between exposure and infection, STDs can serve as a marker of recent unsafe sexual behavior. In addition, certain STDs (e.g., ulcerative STDs) can facilitate the transmission or acquisition of HIV infection. Finally, changes in trends of STDs may indicate changes in

community sexual norms, such as unprotected sex. Some STDs are reportable, but state requirements for reporting differ. The reporting of STDs from private-sector providers may be less complete. Although STD risk behaviors result from unsafe sexual behavior, they do not necessarily correlate with HIV risk.

HIV Counseling and Testing Data

Counseling and Testing System (CTS)

The Louisiana Office of Public Health conducts HIV CTS services at more than 150 sites across Louisiana. These sites include STD, family planning, prenatal and tuberculosis (TB) clinics, drug treatment centers, CBOs, parish health units, community health centers, and mobile test sites. The CTS collects information on counseling and testing services and the characteristics of clients receiving the services, such as demographics, risk information, and testing information (testing history, test result). All sites offer anonymous and confidential testing. Of the persons tested in 2000, 84% received confidential testing. The CTS provides standardized data on clients who are tested for HIV, which may offer insights into HIV infection rates in an area's high-risk population. The CTS collects information only from persons who seek counseling and testing services or agree to be tested after consultation at one of the publicly funded sites. Therefore, estimation of HIV statewide seroprevalence is not possible with CTS data because the clients self-select for testing.

Substance Abuse Data

Treatment Episode Data Set (TEDS)

TEDS is a national data set maintained by the Office of Applied Studies, Substance Abuse and Mental Health Services Administration (SAMHSA), which accrues more than 1.5 million records of treatment admissions for substance abuse annually. TEDS comprises data routinely collected by states for the monitoring of their individual substance abuse treatment programs. TEDS collects information on client demographics, information about the number of prior treatments, usual route of administration for each problem substance, frequency of use, age at first use, and services provided. Most facilities that report TEDS data receive state funding for the provision of substance abuse treatment. Although TEDS does not represent the total demand for substance abuse treatment, it does include a significant proportion of all admissions to substance abuse treatment. The data also include admissions that constitute a burden on public funds. TEDS is based upon records of admissions and does not represent individuals. Thus, a person admitted to treatment twice within the same calendar year would be counted as 2 admissions.

Drug Abuse Warning Network (DAWN)

The DAWN is an ongoing, national data system that collects information on drug-related visits to hospital emergency departments and on drug-related deaths (provided by participating medical examiner offices). Emergency department estimates are produced for 21 large metropolitan areas and for the nation. Drug-related death data are collected in more than 40 metropolitan areas. DAWN was established to (1) provide national, state, and local areas with data for program planning and policy development; (2) identify substances associated with drug abuse deaths; (3) monitor drug abuse patterns and trends; (4) detect new drugs of abuse; and (5) assess adverse health outcomes associated with drug abuse. Standardized data collection and data management procedures are used to ensure the accuracy of DAWN data. Participation in DAWN is voluntary;

therefore, counts of drug abuse deaths do not represent the entire service area if participation is not universal. DAWN collects information only about drug abuse episodes that have resulted in a death that has been identified as a drug-induced or drug-related death. Finally, because DAWN relies on death investigation case files for reporting, drugs may be underreported (if not reported), or drug information may not be specific (if drug name is recorded differently).

National Household Survey of Drug Abuse (NHSDA)

The NHSDA is an ongoing survey on the use of illicit drugs by the U.S. population aged 12 or older. The information collected includes use of cocaine, receipt of treatment for illicit drugs, and need of treatment for illicit drugs during the past year; use of alcohol, tobacco, or marijuana during the past month; and perceived risk for binge drinking, marijuana use, or smoking during the past month. To increase the level of valid reporting, a combination of computer-assisted interviewing methods has been used since 1999 to provide respondents with highly private and confidential means of responding to questions about substance use and other sensitive behaviors. Direct state-level estimates are available only for the 8 states with the largest populations; therefore, the Louisiana data are based on statistical estimates. Because the NHSDA estimates represent behaviors in the general population, the survey may underestimate the level of substance use in the population at highest risk for HIV. Further, data from the NHSDA are self-reported and subject to recall bias; therefore, the level of a sensitive behavior may be underreported.

Vital Statistics Data

Birth and Death Data

The National Center for Health Statistics receives information on births and deaths in the United States through a program of voluntary cooperation with state government agencies (i.e., state departments of health, state offices of vital statistics) called the Vital Statistics Cooperative Program. States use standard forms to collect birth and death data. The birth certificate form includes demographic information on the newborn and the parents, insurance status, prenatal care, prenatal risk factors, maternal morbidity, mode of delivery, pregnancy history, and clinical characteristics of the newborn. Death certificates include demographics, underlying cause of death, and contributions of selected factors to the death (i.e., smoking, accident, or injury) of all deceased persons. Reporting is approximately 100% complete for births and deaths. Therefore, inferences can be made concerning the number of live births in a service area. The data can also be used to determine the effect of deaths related to HIV infection in a service area. The data on birth certificates that are obtained from patient medical records (i.e., smoking history, morbidity) may be incomplete. In addition, deaths resulting from, or whose underlying cause was, HIV infection may be underreported on a death certificate. Clinical information related to HIV or AIDS may be missing. In Louisiana, death records are not available as promptly as AIDS case reports are.

Population Data

U.S. Bureau of the Census (Census Bureau)

The Census Bureau collects and provides timely information about the people and economy of the United States. The Census Bureau's Web site (<http://www.census.gov>) includes data on

demographic characteristics (e.g., age, race, Hispanic ethnicity, sex) of the population, family structure, educational attainment, income level, housing status, and the proportion of persons who live at or below the poverty level. Summaries of the most requested information for states and counties are provided, as well as analytical reports on population changes, age, race, family structure, and apportionment. State- and county-specific data are easily accessible, and links to other Web sites with census information are included.

Louisiana State Census Data Center

This data center is administered by the State of Louisiana. The Web site for the center (<http://www.state.la.us/census>) includes current population estimates and projections; socioeconomic, income, and poverty status information; demographic profiles and rankings; and geographic units from which census data are obtained (state, parishes, cities, and metropolitan areas). Parish population trends are also provided. Links to local affiliates of the state census data center and to other Web sites with census information are included as well.

Ryan White CARE Act Data

Title I and II Statewide HIV/AIDS Needs Report

Every 2 years, Ryan White Title I and Title II programs administer a detailed survey to persons living with HIV/AIDS in Louisiana. The purposes of the survey are to gain a greater understanding of the current level of HIV/AIDS service needs and to provide insight into consumers' perceptions of the availability and quality of HIV/AIDS services throughout the state. The 2000–2001 survey included a variety of demographic questions (residence, age, race, gender, income levels and sources, and type of health insurance coverage), as well as questions about HIV-related primary care, illness severity, and individual experiences with taking combination therapy. The sample population is weighted heavily toward persons who are in care, as potential respondents were encountered in primary care clinics, social service agencies, community health centers, Medicaid enrollment centers, substance abuse or mental health treatment facilities, homeless or transitional shelters, and local jails. Persons who were not in care during the relevant time period, not in care at all, or who were unwilling or unable to complete the questionnaire were not surveyed. Thus, the survey provides a measure of the needs of only the persons who were receiving some type of care and does not adequately address the needs of those who have not sought care.

Ryan White Title II CAREWare

Since 1993, the HIV/AIDS Program of the Louisiana Office of Public Health has collected data on persons served through Louisiana Ryan White Title II funding. In late 1999, the AIDS Drug Assistance Program (ADAP) data collection system was expanded into a more comprehensive database named Louisiana CAREWare. This database includes key information on all persons receiving assistance through any of the programs funded by Ryan White Title II, as well as through funds from State Formula Housing Opportunities for People with AIDS (HOPWA) funds. To be eligible for Ryan White Title II services, a person must be living with HIV/AIDS, be a resident of Louisiana, and have an income that is equal to or less than 200% of the current year's federal poverty level. Information collected from service providers throughout the state includes basic demographic and risk information on each of the clients, eligibility verification data (current address, current income, HIV diagnosis, Louisiana Medicaid number), the type of services received, the date and quantity of services received, the cost of these services, and other

pertinent information (history of substance abuse or mental health treatment, veteran status, current pregnancy status). CAREWare is an important tool for monitoring which Ryan White resources are being used, how often, and by whom. However, the data in Louisiana CAREWare cannot be generalized to all HIV-infected persons living in the state, because the data collected are only for persons who (1) know their HIV serostatus, (2) are not eligible for health coverage through private insurance or Louisiana Medicaid, (3) are currently seeking care and treatment services from providers funded through Ryan White Title II, and (4) are financially eligible to receive services.