

## **INTRODUCTION**

The data presented in this report serve to guide prevention and service efforts, to justify and obtain funding for the implementation of prevention and service programs, and to evaluate programs and policies throughout Vermont. Multiple data sources were used to create a thorough and comprehensive document, which addresses both core epidemiological questions and questions relating to the Ryan White Care Act including:

1. What are the sociodemographic characteristics of the general population in Vermont?
2. What is the scope of the HIV/AIDS epidemic in Vermont?
3. What are the indicators of risk for HIV/AIDS infection in Vermont?
4. What are the patterns of utilization of HIV services by persons in Vermont?
5. What are the number and characteristics of persons who know they are HIV-positive, but who are not receiving primary medical care?

Each section of the report includes relevant data and interpretation.

## **BACKGROUND**

The 2007 Profile was developed with input from end-users. The 2007 Profile also followed the guidance of the 2005 Epidemiological Profile Advisory Committee and the recommendations of Irum Zaidi (from the CDC) who provided direction in preparing an epidemiologic profile for a rural, low incidence state. Additional sources of aggregate data were considered for the 2007 Profile. We anticipate that these additional data sources will help create a comprehensive and multi-perspective profile useful for both HIV prevention and care planning. The 2007 Profile was developed in conjunction with the *CDC's Integrated Guidelines for Developing Epidemiologic Profiles*.

## **PROFILE DATA SOURCES**

Data were compiled from a variety of sources to provide the most complete picture of HIV incidence in Vermont as possible. When reading this document, please keep in mind that each of the data sources has strengths and limitations, and these should be considered when interpreting the data. Below is a brief description of each of the data sources used in the profile. It should be noted that not all data sources available to other states are available for Vermont. (For a more detailed description of these sources, please refer to Appendix A.)

### **Core HIV/AIDS Surveillance Data**

In 1982 the Vermont Department of Health implemented AIDS case surveillance under its Communicable Disease Regulations. The Vermont legislature added HIV infection

reporting by unique identifier code to the Communicable Disease Regulations in 1999, and HIV reporting was implemented in March of 2000. 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. In addition, death certificate data are used for active case finding and to update vital status on a quarterly basis. According to an evaluation conducted by the CDC in September of 2001, AIDS reporting was estimated to be more than 85% complete. HIV surveillance data may underestimate the number of recently infected persons because some infected persons either do not know they are infected or they 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 in Vermont reported to the health department may be 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. Consistent with national standards for the conduct of HIV/AIDS surveillance, HIV and AIDS cases are counted only in the state in which they resided at the time of their HIV or AIDS diagnosis. Therefore, Vermont surveillance data include some individuals who no longer reside in Vermont, and do not include individuals who now live in Vermont but were diagnosed while living in other states. The completeness of HIV data is unknown; the code-based system is unevaluated. This will also pose a challenge as Vermont moves to name-based reporting.

## **Supplemental HIV/AIDS Surveillance Projects**

### ***HIV Testing Survey (HITS)***

HITS assesses HIV testing patterns, reasons for seeking or avoiding testing, knowledge of state policies for HIV surveillance, and risk behaviors among a sample of persons at high risk for HIV. HITS is an anonymous, venue-based survey administered to persons who are at least 18 years of age and at high risk for HIV infection. The data can be used to supplement HIV surveillance data by determining the characteristics of persons who delay testing, who test anonymously, or who avoid testing. Information collected is self-reported and may be subject to recall and/or reporting biases. In 2001, HITS was conducted among men who have sex with men (MSM) and injection drug users (IDU) in Vermont. Interviewees were recruited at gay bars (MSM) and street locations (IDU). Because HITS data surveyed only people identified as at a higher risk for HIV infection they may not represent the entire high-risk population in Vermont. Participants who reported testing positive for HIV were not included in the analyses because the focus of the survey is on the potential for infection as it relates to high risk behaviors. 2001 is the only year in which the survey was conducted in Vermont.

## **Behavioral Surveys**

### ***Behavioral Risk Factor Surveillance System (BRFSS)***

In 1984, the CDC established the BRFSS to collect state-level data yearly on personal health behaviors using a standard core questionnaire that would be comparable across states. The BRFSS is conducted via a random-digit-dialed telephone survey of adults. This data is used to monitor the state-level prevalence of the major behavioral risks associated with premature morbidity and mortality. Respondents are asked about their personal health behaviors and health experiences. The survey is population-based, meaning that the information gathered can be generalized to the adult population of the state and not just to those people at highest risk for contracting HIV. Questions about condom use with main and casual partners were asked between 2001 and 2005. Questions about HIV testing behaviors were asked between 2001 and 2006.

### ***National Survey on Drug Use and Health (NSDUH)***

The NSDUH is an annual nationwide survey designed to collect data on substance abuse patterns and behaviors in the United States civilian population aged 12 or older. Youth are over-sampled to ensure precise estimates of substance abuse among younger persons. 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 about substance abuse and other sensitive behaviors, computer-assisted interviewing methods have been used since 1999 to provide respondents with a highly private and confidential means of responding to questions. National data is used in this report. However, the data collected through the NSDUH are self-reported and therefore subject to recall bias and potential underreporting. Furthermore, because the NSDUH estimates represent behaviors in the general population the survey may underestimate the level of substance use in the population at highest risk for contracting HIV.

### ***Youth Risk Behavior Survey (YRBS)***

The Vermont YRBS is part of the CDC's Youth Risk Behavior Surveillance System which collects information on health-risk behaviors among youth and young adults in each of the following categories: behaviors that contribute to unintentional injuries and violence; tobacco use; alcohol and other drug use; sexual behaviors that contribute to unintended pregnancy and sexually transmitted diseases, including HIV infection; unhealthy dietary behaviors; and physical inactivity. Since 1993, the Vermont Office of Alcohol and Drug Abuse Program (ADAP) has administered the YRBS surveys every two years to a representative sample of Vermont students in grades eight through twelve. Because the YRBS relies upon self-reports there may be some recall bias of the different behaviors. Also, because of the sensitive nature of the behaviors asked about in the survey, youths may have under or over reported certain behaviors. 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 who are frequently absent from school or who drop out of school may be at a

higher risk for engaging in these risk behaviors and would be underrepresented in this survey.

### ***Person Environment Zone Project***

This is an NIMH-funded study that was conducted between 2004 and 2006. This project tests a theoretical model of how the stigma associated with HIV affects the risk behaviors of people with HIV/AIDS in rural settings. Principal investigators on this project are three faculty members in the Psychology Department and the University of Vermont: Sondra Solomon, Carol Miller, and Rex Forehand. This study provides information on the experiences of being HIV-positive in Vermont and neighboring states. This is the only project focusing on the stigma and behavior of HIV-positive individuals in Vermont, and one of the few projects in the U.S. addressing HIV/AIDS in rural areas.

## **STD Surveillance**

### ***STD Case Reporting***

Laboratories, hospitals, physicians, insurance companies, and other health care providers are required to report all cases of *Chlamydia trachomatis* infection, gonorrhea, and syphilis in Vermont to the Vermont Department of Health. STD reporting, demographic and risk history information are entered into the National Electronic Telecommunications System for Surveillance (NETSS) and transmitted to the CDC (without identifiers) on a weekly basis. STD surveillance data can serve as a surrogate marker for unsafe sexual practices and demonstrate the prevalence of changes in a specific behavior. 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. 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 HIV Counseling and Testing System (CTS) was originally developed in 1988 to assist CDC-funded HIV prevention project areas (including Vermont) in collecting data on the population receiving HIV counseling and testing services. Funding from the CDC supports the Vermont Counseling, Testing, and Referral (CTR) system, which consists of anonymous and confidential voluntary HIV counseling, testing, and referral services with emphasis on a client-centered risk-reduction counseling model. In Vermont there are 44 testing sites throughout the state that offer anonymous and/or confidential HIV testing. Demographic and behavioral data as well as HIV test results are reported to the Vermont Department of Health by each testing site. Data are entered into CTS software provided by the CDC and are transmitted to the CDC on a monthly basis. 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. The data are used to guide the development of HIV prevention programs and to estimate the need for early intervention service for persons with HIV infection. A limitation of the data is that it cannot distinguish multiple tests on the same individual. Because clients self-select for testing and because the data cannot be unduplicated, CTS data cannot be used to estimate statewide HIV seroprevalence.

### ***Pregnancy Risk Assessment Monitoring System (PRAMS)***

PRAMS is a risk monitoring system through the Centers for Disease Control and Prevention that assesses maternal attitudes and experiences before, during and shortly after pregnancy. In 2004 Vermont collected PRAMS data on HIV testing and counseling in addition to data on prenatal care, alcohol and tobacco use, and maternal attitudes. Data was collected from all mothers of low birth weight babies and 4 of every 23 mothers of normal birth weight babies in Vermont. There was an 83% response rate in 2004, and results are weighted to represent the Vermont population.

## **Substance Abuse Data**

### ***Alcohol and Drug Abuse Program (ADAP)***

ADAP is located within the Vermont Department of Health. ADAP collects substance abuse treatment admissions data from facilities that receive state funding. All facilities receiving state funds are mandated to report sociodemographic information on all substance abuse treatment admissions, including the substance being abused. These data are collected at a person's admission to treatment for substance abuse in Vermont. These data offer a way to indirectly measure the prevalence of drug use in Vermont. However, the admissions data may not represent unduplicated individuals, but rather they may represent multiple admissions within a calendar year for an individual.

### ***Vermont Crime On-Line***

Vermont Crime On-Line is a source of Vermont crime statistics maintained by the Division of Criminal Justice Services, Vermont Department of Public Safety. The Vermont Crime On-Line database includes the types of drug crimes charged in Vermont and changes observed in drug crime charges. This data is charge-based, not person-based, meaning that one person may be represented more than once because s/he received multiple drug charges.

## **Vital Statistics Data**

### ***Birth and Death Data***

Statewide vital registration began in Vermont in 1857. The current vital statistics system in Vermont includes eight types of vital events: births, deaths, marriages, civil unions, divorces, fetal deaths, and abortions. All states use standard forms to collect birth and death data. The birth certificate form includes the demographic information of the newborn and the parents. 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. Birth and death certificates must be filed with the town clerk and a certified copy is sent to the Department of Health. Physicians must complete the cause of death information on a death certificate and sign the certificate. Vital records data are coded and entered into a database, and data are sent to the National Center for Health Statistics. Deaths resulting from, or whose underlying cause was, HIV infection may be underreported on a death certificate because the physician completing the form may be unaware of the individual's HIV status.

## **Population Data**

### ***US Bureau of the Census (Census Bureau)***

The Census Bureau collects data on demographic characteristics of the U.S. population, family structure, educational attainment, income level, housing status, and the percentage of persons who live at or below the federal poverty level. The most recent decennial census was completed in 2000. The American Community Survey (ACS) is a mandatory survey of 3 million households per year (as of 2006) that is designed to replace the decennial survey. Information from both surveys have are accessible through the Census Bureau website ([www.census.gov](http://www.census.gov)) Summaries of the most requested information for states and counties (including Vermont) are provided, as well as analytical reports on population changes, age, race, family structure, and apportionment.

### ***Vermont Department of Health Population Estimates***

The Vermont Department of Health uses population estimates that are a modification of the population estimates for the state that are produced by the US Bureau of the Census for the National Center for Health Statistics (NCHS). The Census/NCHS data provides us with town total population estimates and population by age/race/sex for Vermont Counties. These data do not accurately estimate the numbers of very young Vermonters (age < 5 years) when compared to the numbers of VT resident births. Thus, the VDH calculates population estimates for people the under the age of 5 by Vermont county, then makes adjustments to Census/NCHS data. Some minor adjustments are made to the town population estimates to account for round off error in the production of the county age/race/sex estimates, and to account for instances where the Census Bureau has estimated populations for what are believed to be uninhabited places (Lewis, Avery's Gore and Warner's Grant).

### ***Kaiser Family Foundation***

The Kaiser Family Foundation is a private, non-profit organizations focusing on issues of health and health care. It provides independent analyses of health and healthcare issues. These data provide information about access to care for various populations and can be used to compare access across geographic areas.

### ***Geographic Information System (GIS) Data***

The GIS system provides access to visual depiction of HIV-related information for readers. The Vermont Department of Health utilizes ESRI ArcView/ArcGIS mapping software.

## **Ryan White CARE Act Data**

### ***Unmet Needs Project***

The Unmet Needs Project identifies gaps in care for Vermonters living with HIV. It is based on analyses of two HIPAA compliant data sets which do not include unique person identifiers; Probabilistic Population Estimation is used to estimate the number of people with HIV who are not currently receiving care. This is one of the only sources of information regarding unmet need for people living with HIV in Vermont.

### ***Ryan White Comprehensive AIDS Resources Emergency (CARE) Act***

The federal Ryan White CARE Act provides health care for people with HIV. Enacted in 1990, it fills gaps in care faced by those with low-incomes and little or no insurance. Vermont receives federal funding under Part B (CARE Grant Program) and C (Early Intervention Services) of the Ryan White CARE Act. Although Vermont does not receive Part D funds (Research, Demonstrations or Training) some Vermont residents do access Part D funds through services provided by the state of New Hampshire. Reports by the HIV/AIDS program's Part B Administrator are made to the federal Health Resources and Services Administration (HRSA) on a yearly basis. These Annual Data Reports are provider-based reports with aggregate client, provider, and service data for all CARE Act programs. Reports include information on all clients who receive at least one service during the reporting period. The Annual Data Report includes information on the demographics of all clients (sex, age, and race/ethnicity), exposure category, and the number of clients receiving each type of service. In 2005 Vermont began instituting HRSA's mandate to give priority funding to six core services: primary medical care, substance use treatment, mental health therapy, oral health, HIV medications and case management. A limitation of this data is that it only includes people who know they are HIV positive and who are seeking treatment. It cannot be used to estimate the prevalence of HIV in Vermont, which may be higher due to people's unawareness that they are infected or who are aware that they are infected but who seek treatment through private physicians and other services.

### ***HIV/AIDS Medication Assistance Program (AMAP)/ HIV Dental Care Assistance Program (DCAP)***

Both AMAP and DCAP are funded by Ryan White CARE Act Part B funds (described above). The AMAP provides financial assistance for the purchase of prescription medications to Vermont residents living with HIV who meet certain income guidelines. DCAP provides financial assistance to meet the dental needs of underinsured and uninsured Vermonters living with HIV/AIDS. Data is collected on all people who receive services via AMAP/DCAP. This data represents people who know their HIV serostatus, who are currently seeking care and treatment services through Ryan White Part B-funded providers, and who are financially eligible to receive services. Data collected through the AMAP program represents individual clients seeking services. Data collected through the DCAP program represents the number of claims made to the program, and may be duplicated as one individual may make multiple claims to the program in the course of a year.

### *Assessing Barriers to Prevention and Care Services*

This 2004 study, sponsored by the Office of Minority Health and the HIV/AIDS Program at the Vermont Department of Health and carried out by the HIV/AIDS Care and Services Community Planning Group of Vermont, focused on three groups of people 1) members of communities of color not already connected to HIV/AIDS service 2) persons incarcerated in Vermont institutions, and 3) providers of HIV/AIDS prevention, support or medical care. The study assessed barriers to HIV/AIDS prevention, support and medical services for Vermont communities of color. Data consisted of focus groups, individual interviews and surveys.

## **PROFILE STRENGTHS AND LIMITATIONS**

When making planning decisions, it is important to consider the overall strengths and limitations of this document. Although the profile is comprehensive and draws from a number of data sources, there are many things that the profile cannot explain.

The HIV/AIDS surveillance system in Vermont is based on data on people who have been tested confidentially for HIV. Although this surveillance system has evolved since HIV reporting began in 2000, we suspect that HIV infections are under detected and underreported for four reasons. First, individuals who are tested anonymously are not reported to the VDH because no identifying patient information is collected. Second, people living in Vermont who do not receive care in Vermont or who are unaware of their HIV-positive status are not included in surveillance numbers. Third, individuals may be tested at different times along the continuum of their HIV infection, and some are not tested until HIV infection has progressed to AIDS which influences how people are classified once they are diagnosed. Fourth, information reported to VDH may be delayed (e.g. a report from December 2007 may not be entered until 2008), resulting in underreporting in a given year. Thus, it is important to remember that the data in this report do not necessarily represent the characteristics of persons who have been recently infected with HIV, nor do they provide a true measure of HIV incidence. Low incidence states such as Vermont do not currently have the resources to measure true incidence.

Analyses of many different data sets are presented to provide representations of particular subpopulations. However, demographic and geographic subpopulations are disproportionately sensitive to differences and changes in access to health care, HIV testing patterns, and specific prevention programs and services. All of these issues must be carefully considered when interpreting HIV data. Therefore, it is important to make appropriate comparisons across data sources to get the most complete picture of the impact of HIV/AIDS both nationally and in Vermont.

The most current analysis available is presented for each source of data; however, the most recent data collected varies from one source to another. One must also keep in mind that data sources are limited in Vermont, particularly with regard to additional/special HIV-related data sets due to a lack of funding for such projects.

## **PROFILE PREPARATION**

This Epidemiologic Profile is an updated version of the original document prepared in 2006 by the Vermont Department of Health, Division of Health Surveillance, HIV/AIDS Program and with guidance from the Centers for Disease Control and Prevention and the Epidemiological Profile Advisory Committee.

The Vermont STD Program provided guidance on the use and interpretation of STD (non-HIV) data. BRFSS data were provided by the Vermont BRFSS Program. The Internet was also utilized to obtain data. Sociodemographic data, vital statistics, and substance abuse data were obtained from both the Internet and the appropriate programs within Vermont state government.

Several of the internet sources compile their data from other organizations and agencies, such as the Kaiser Family Foundation (for insurance information) and the Health Resources and Services Administration (HRSA) (for the Ryan White HIV/AIDS Program Annual Data Report).

## **ORGANIZATION OF THE PROFILE**

The epidemiologic profile is organized into two main sections, within which the five key questions are addressed:

### **Section 1: Core Epidemiologic Questions**

This section of the report provides the reader with an understanding of the characteristics of the general population in Vermont, the distribution of HIV disease, and a detailed look at persons at risk for HIV infection. Section 1 is organized around three key questions:

**Question 1: What Are the Sociodemographic Characteristics of the General Population in Vermont?** Orients the reader to the overall demographic and socioeconomic characteristics of the general population of Vermont.

**Question 2: What Is the Scope of HIV Disease in Vermont?** Examines the impact of HIV disease among a number of population groups in Vermont, to help planners target prevention and care services.

**Question 3: What Are the Indicators of HIV Disease Infection Risk in Vermont?** Provides a detailed look at high-risk populations to the extent possible. Both direct measures of risk behaviors associated with HIV transmission and indirect measures that may serve as indicators of high-risk behavior are examined in this segment.

### **Section 2: Ryan White HIV/AIDS CARE Act Special Questions and Considerations**

This section focuses on questions that pertain to HRSA HIV/AIDS care planning groups. Section Two describes how people with HIV in Vermont use and access care, as well as

evaluates the standard of care provided. Section Two is organized around 2 key questions:

**Question 1: What Are the Patterns of HIV Service Utilization by Persons in Vermont?** Characterizes patterns in the use of services by a number of populations living with HIV/AIDS in Vermont. Information is provided from HRSA-funded programs.

**Question 2: What Are the Number and Characteristics of Persons Who Know That They are HIV positive But Who Are Not Receiving Primary Medical Care?** Describes studies currently underway in Vermont to assist in assessing the unmet needs of persons who know they are HIV positive, but who do not receive medical care.