

## **Appendix A: Data Sources**

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

#### ***AIDS Surveillance***

**Overview:** AIDS is a reportable condition in all states and territories. Since 1993, all states and territories base their reporting practices on the 1993 CDC case definition for AIDS surveillance. The AIDS Surveillance system was established to monitor incidence of the disease and the demographic profile of AIDS cases; describe the modes of HIV exposure among persons with AIDS; guide the development and implementation of public health intervention and prevention programs; and to assist in the evaluation of the efficacy of public health interventions. The Vermont HIV/AIDS Reporting System (HARS) provides a data set that includes information on sociodemographic variables (sex, age, race/ethnicity, county of residence), date of diagnosis, mode of exposure, laboratory and clinical findings (including viral load), vital status, and referrals for treatments or services. In Vermont, name-based AIDS case surveillance began in 1982.

**Population:** All persons in Vermont who meet the 1993 CDC AIDS surveillance case definition.

**Strengths:** This is the only source of AIDS information that is available in all states. The data reflect the effect of AIDS on communities and trends of the epidemic in communities. AIDS surveillance has been determined to be >85% complete. In addition, at least 85% of the reported cases included risk information.

**Limitations:** Because of the prolonged and variable period from infection to the development of AIDS, trends in AIDS surveillance do not represent recent HIV infections. Thus AIDS surveillance data is limited by the fact that someone may have been infected with the virus for a quite a while prior to the development of AIDS, therefore AIDS cases do not represent recent HIV infections. Incomplete HIV or CD4+ T-cell testing may interfere with the completeness of AIDS reporting. Further, the widespread use of HAART complicates the interpretation of AIDS case surveillance data and the estimation of the HIV/AIDS epidemic in an area. Newly reported AIDS cases may reflect treatment failures or the failure of the health care system to halt the progression of HIV infection to AIDS. AIDS cases represent late-stage HIV infections. Consistent with national standards for the conduct of AIDS surveillance, AIDS cases are counted only in the state in which they resided at the time of their 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.

## *HIV Surveillance*

**Overview:** Since the human immunodeficiency virus was identified and a test for HIV was licensed, CDC and other professional organizations have recommended the reporting of HIV infections to local health authorities as an integral part of AIDS surveillance activities. As part of ongoing, active HIV surveillance, state and local health departments educate providers on their reporting responsibilities, establish active surveillance sites, and establish liaisons with laboratories that perform HIV testing of samples. The Vermont HIV/AIDS Reporting System (HARS) provides a data set that includes information on sociodemographic variables (sex, age, race/ethnicity, county of residence), date of diagnosis, mode of exposure, laboratory and clinical findings (including viral load), vital status, and referrals for treatments or services. HIV reporting was implemented in Vermont in March of 2000 and is based on unique-identifiers. Only individuals who receive confidential tests are included in HARS.

**Population:** All persons who test positive for the human immunodeficiency virus (HIV) by confidential testing (anonymous testers are not reported to the Vermont Department of Health).

**Strengths:** HIV surveillance data represent more recent infections, compared with AIDS surveillance data. HIV surveillance provides a minimum estimate of the number of persons known to be HIV infected and reported to the health department, identifies emerging patterns of transmission, and can be used to detect trends in HIV infections among populations of particular interest (e.g., children, adolescents, or women) that may not be evident from AIDS surveillance. Additionally, HIV surveillance provides a basis for establishing and evaluating linkages to the provision of prevention and early intervention services and can be used to anticipate unmet needs for HIV care. The completeness of HIV surveillance data is difficult to measure due to the code-based surveillance system in place from 2000-2007. Beginning in 2008, HIV cases will be reported by name to the Vermont Department of Health.

**Limitations:** HIV surveillance data may underestimate the level of recently infected persons for three reasons. First, some infected persons either do not know they are infected or have not sought testing. Second, persons who have 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. Third, reporting may not be complete. Also, consistent with national standards for the conduct of HIV surveillance, HIV cases are counted only in the state in which they resided at the time of their HIV 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.

## Supplemental HIV/AIDS Surveillance

### *HIV Testing Survey (HITS)*

**Overview:** HITS was conducted in Vermont 2001 in an effort to assess HIV testing patterns among persons at high risk for HIV, evaluate reasons for seeking or avoiding testing, and examine knowledge of state policies for HIV surveillance. In addition, HITS collected behavioral risk information from persons at high risk for infection. Two populations were surveyed, MSM (recruited from two gay bars in Vermont) and IDU (recruited from street venues). All participants were 18 years of age or older and had been state residents for at least one year. Participants who reported testing positive for HIV were excluded from the analyses.

**Population:** Individuals 18 years of age or older who: were able to give informed consent, did not identify as HIV positive but did identify as MSM or IDU, had been Vermont residents for at least a year, and were at one of Vermont's two gay bars or at a street venue or needle exchange program when researchers were recruiting for this study in 2001. Additional behavioral criteria applied to each risk group. Men at gay bars were eligible if they had sex with a man within the past 12 months. Injection drug users must have injected drugs within the past 12 months.

**Strengths:** HITS collected public health information from groups at high risk for HIV; the information includes HIV testing attitudes, history and behaviors, as well as knowledge of testing and risk behaviors.

**Limitations:** There were a small number of participants (62 IDUs, 59 MSM) that may not be representative of their respective high-risk populations. It should also be noted that HITS data was collected as a one time project over six years ago (2001) and thus may not represent recent trends. HITS relied on a convenience sample for participation. Information collected was self-reported and may have been subject to recall bias. Further, HITS data may not represent the entire high-risk population of an area. Also, data on MSM were collected only in gay bars; MSM who frequent gay bars may not be representative of the entire population of MSM.

### *Comprehensive Care Clinic (CCC) Questionnaires*

**Overview:** CCC Patient Questionnaires are filled out by CCC patients at intake and during follow-up visits. These questionnaires address basic demographic information including insurance and employment information, participation in AMAP/DCAP, HIV exposure categories, and health status. During 2000 the Patient Questionnaire was updated to include housing status.

**Population:** All HIV or AIDS patients having at least one Comprehensive Care Clinic visit during a given year.

**Strengths:** Provides demographic, health, and housing information for all CCC patients. This represents a substantial number of the HIV positive individuals in Vermont.

**Limitations:** Data is limited to those receiving care at a CCC and is not generalizable to all HIV positive individuals in the state. The data does not differentiate homeless from non-permanently housed.

## Behavioral Surveys

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

**Overview:** 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. Each month, a sample of households is contacted and one person in the household who is 18 years or older is randomly selected for an interview. Multiple attempts are made to contact the sampled household. A Spanish translation of the interview is available. Respondents to the BRFSS questionnaire are asked a variety of questions about their personal health behaviors and health experiences. Questions concerning sexual behavior, HIV/AIDS knowledge, beliefs and testing and STD/IDU related questions have been included in the Vermont surveys.

**Population:** All noninstitutionalized adults, 18 years and older, who reside in a household with a telephone

**Strengths:** Data from the BRFSS survey are population-based. This means that the information gathered via the BRFSS can be generalized to the noninstitutionalized adult population of a state. BRFSS data is from a random sample of several thousand adult Vermont residents. Information collected from the BRFSS survey may be useful for planning communitywide education programs.

**Limitations:** BRFSS data are self-reported; thus, the information may be subject to recall bias. Because BRFSS respondents are contacted by telephone, the data are not representative of households that do not have telephones. In addition, BRFSS data are representative of the general noninstitutionalized adult population in an area, not just persons at highest risk for HIV/AIDS. In Vermont, sexual behavior questions have been limited to certain age groups (those younger than 50), so the sexual behavior data may be applicable only to residents ages 18 to 49.

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

**Overview:** The YRBS is part of the CDC's Youth Risk Behavior Surveillance System that was established to monitor six high-risk behaviors that contribute to the leading causes of mortality, morbidity, and social problems among youth and young adults in the United States. YRBS was developed to collect data that are comparable nationally, statewide, and locally. The YRBS is a self-administered questionnaire that is given to 8<sup>th</sup> through 12<sup>th</sup> grade students statewide. Every two years since 1985 the Department of Health's Division of Alcohol and Drug Abuse Programs and the Department of Education's Comprehensive School Health Program have sponsored this survey. A random selection of schools in Vermont is invited to participate, but participation by both schools and individual students is voluntary. Information is gathered on the following topics: 1) sexual behavior (percent of sexually active students, sexual orientation, number of partners, condom use, pregnancy, drug use concurrent with sex, amount of education provided in school re: HIV/STD transmission), 2) use of alcohol, tobacco and other drugs, 3) attitudes and perceptions about alcohol, tobacco and other drugs, 4) injuries, violence and safety, 5) body weight and nutrition, 6) physical activity, and 7) youth assets.

**Population:** Responses represent the population of Vermont students in 8<sup>th</sup> through 12<sup>th</sup> grade who were attending schools that disseminated the survey. The term "young MSM" is used in this document to refer to male YRBS respondents who reported ever having had sex with males.

**Strengths:** This survey can indicate what risk behaviors students are, or are not, engaging in, and the survey allows comparisons amongst groups of students in terms of each behavior or asset. The YRBS was developed to collect data that are comparable on the local, state, and national levels. The survey is anonymous to encourage honest responses by students, and over 100 consistency checks are run on the data to exclude careless, invalid, or logically inconsistent answers.

**Limitations:** The YRBS relies on self-reported information, thus under- or over-reporting of information may occur. Because the survey is administered in school the data are representative only of young people enrolled in school and cannot be generalized to all young people in Vermont. (For example, youth at highest risk may be more likely to be absent from school or to drop out of school, and thus they may be underrepresented in this survey). Also, participation in the survey is voluntary so schools and/or individual students may have declined to participate. The YRBS describes what behaviors youth are engaging in but the survey does not address why they are engaging in these behaviors.

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

**Overview:** Principal investigators on this project are Sondra Solomon, Carol Miller, and Rex Forehand (all professors in the psychology department at UVM). This is an NIMH-funded study that began in 2004. 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.

**Population:** Participants ranged in age from 18-65 years old (mean age was 43 years) and the majority of participants (80%) were white. Forty-two percent identified as exclusively homosexual, 42% as exclusively heterosexual, and 16% as neither exclusively homosexual nor heterosexual. For each individual participant in the study with HIV/AIDS, between 10 and 13 members of that person's community were telephoned and asked a variety of questions related to health behaviors and attitudes in a phone interview. 2,444 community members completed their interviews. The majority of community members surveyed were female (64.5%), Caucasian (95%), were between 40 and 59 years of age (48%) and were high school graduates (95%).

**Strengths:** This study is NIMH approved and funded and has met the requirements of UVM's Institutional Review Board. This project recruited 203 people with HIV to participate from Vermont and neighboring states, the majority of whom were Vermont residents. This is an impressive number considering that there were 430 people in Vermont living with HIV or AIDS in 2004. This study provides a comprehensive profile of the experiences of being HIV positive rural areas, including Vermont. 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.

**Limitations:** Participation in this study is voluntary and all participants are compensated for their time. This is not a random sample of all HIV positive Vermont residents and therefore the results are not generalizable to all HIV positive individuals in the state.

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

**Overview:** Formerly called the NHSDA, the NSDUH is the primary source of statistical information on the use of illegal drugs by the U.S. population 12 years of age or older. This survey has been conducted by the Federal Government since 1971; data is collected data by administering questionnaires to a representative sample of the population through face-to-face computer assisted interviews at their places of residence. The survey is sponsored by the Substance Abuse and Mental Health Services Administration (SAMHSA) of the U.S. Department of Health and Human Services and is planned and managed by SAMHSA's Office of Applied Studies (OAS). Persons excluded from the survey include homeless persons who do not use shelters, military personnel on active duty, and residents

of institutional group quarters, such as jails and hospitals. NSDUH employs a 50-State sample design with an independent, multistage area probability sample for each of the 50 States and the District of Columbia to facilitate state-level estimation. Youth and young adults were over-sampled so that each state's sample was approximately equally distributed among three major age groups: 12 to 17 years, 18 to 25 years, and 26 years or older. Information captured by the NSDUH questionnaire 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 of binge drinking, marijuana use, or smoking.

**Population:** Noninstitutionalized, civilian population aged twelve years or older.

**Strengths:** NSDUH is national, standardized survey of drug use behaviors among the general population. Since 1999 information has been collected using a combination of computer-assisted interviewing methods in an effort to provide respondents with a more private and confidential means of answering questions about substance use and other sensitive behaviors.

**Limitations:** Due to changes in the survey instrument and the survey methodology, comparisons cannot be made between years prior to 2002 and more recent years (2002 to the present). Direct state-level estimates are available only for 8 states; other states (including Vermont) must rely on statistical estimates. NHSDA estimates represent behaviors in the general population, thus the survey may underestimate the level of substance use in the population at highest risk for HIV. Data for the NHSDA are self-reported and are subject to recall bias, which may result in under-reporting drug use behaviors.

## **STD Surveillance**

### ***Sexually Transmitted Disease (STD) Surveillance***

**Overview:** Chlamydia, gonorrhea and syphilis infections are reportable under Vermont's Communicable Disease Regulations. The Vermont Department of Health STD Program conducts statewide surveillance to determine sexually transmitted disease (STD) incidence and to monitor trends. It also conducts partner counseling and makes referrals for examination and treatment in order to reduce the spread of STDs. Laboratories, hospitals, physicians, insurance companies and other health care providers are required to report all cases of Chlamydia, gonorrhea and syphilis to the Vermont Department of Health. Basic demographic information (age, sex and race/ethnicity) is available for Chlamydia and gonorrhea cases, but historically there are extremely small numbers of syphilis cases.

**Population:** All persons who are diagnosed with an infection that meets the CDC case definition for the infection and are reported to the Vermont Department of Health.

**Strengths:** STD surveillance data can serve as the surrogate marker for unsafe sexual practices and demonstrate the prevalence of STDs in the state. Because of shorter incubation times between exposure and infection, STDs can serve as a marker of recent unsafe sexual behavior. In addition, certain STDs (i.e., ulcerative STDs) can facilitate transmission and/or acquisition of HIV infection. Finally, changes in trends of STDs may indicate changes in community sexual norms, such as unprotected sex.

**Limitations:** STDs are reportable in every state (indicating that cross-state and national comparisons can be made), but requirements vary across states. Reporting of STDs from the private sector providers may be less complete. Although STD risk behaviors result from unsafe sexual behavior, they do not necessarily correlate with HIV risk. Trends in Chlamydia infections may reflect changes in reporting and screening practices rather than disease trends.

## HIV Counseling and Testing Data

### *Counseling Testing System (CTS)*

**Overview:** Vermont's CTS was originally developed in 1988 to assist in collecting data on the population receiving counseling and testing services in the state. 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. The Vermont Department of Health collects information on counseling and testing services delivered, as well as the characteristics of clients receiving the services. The characteristics include demographics, insurance, risk information, and testing information (data, testing history, test result). No personal identifying information is collected.

**Population:** All clients who received confidential or anonymous HIV testing services at a counseling and testing site funded through a CDC cooperative agreement.

**Strengths:** CTS data can be examined across years to evaluate trends in the type of tests conducted (anonymous or confidential, blood-based or saliva), the type of testing site, or the demographic characteristics of the people being tested (including the mode of exposure to HIV). Testing data may highlight the effect of prevention programs focused on specific populations.

**Limitations:** CTS collects test-based, rather than person-based data. Information is collected only from people who seek counseling and testing services or agree to be tested after consultation with a counselor at a testing site. Therefore, estimation

of HIV statewide prevalence is not possible with CTS data because the clients self-select for testing. Because a person can repeatedly seek testing, it is not possible to distinguish individuals who have been tested multiple times. Since the CTS system gathers data on HIV testing, changes in testing patterns may reflect changing program priorities rather than testing patterns of individuals.

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

**Overview:** PRAMS is a risk monitoring system through the Vermont Department of Health and the Centers for Disease Control and Prevention to improve the health of mothers and children by assessing maternal attitudes, behaviors and experiences before, during and shortly after pregnancy. In 2004 Vermont collected PRAMS data on HIV testing and counseling in addition to questions about prenatal care, alcohol and tobacco use, infant health, knowledge of pregnancy-related health issues, and maternal attitudes.

**Population:** All women who gave birth to low birth weight babies were sampled in Vermont. Four out of every 23 mothers of normal birth weight babies in Vermont were also sampled. In 2004 there was an 83% response rate.

**Strengths:** The sample is chosen from all women who have recently given birth, making it a representative sample of the state's population of women who have recently given birth.

**Limitations:** Although all women are sampled, there may be selection bias among those women who chose to respond to the survey participation request.

## **Substance Abuse Data**

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

**Overview:** The ADAP is located within the Vermont Department of Health and the program collects substance abuse treatment admissions data from facilities that receive state funding. All facilities receiving state funding are mandated to report sociodemographic information on all substance abuse treatment admissions, including the substance being abused. This data provides information on the sex, race/ethnicity and age group of the people admitted to state-funded drug treatment programs for specific substances.

**Population:** People who receive drug treatment at facilities that receive state funding.

**Strengths:** ADAP data offer an indirect measure of the prevalence of injection drug abuse in Vermont. The data may also serve as indication of substance abuse trends in the state; for example, rises in the number of treatment admissions for crystal methamphetamine have been associated with increases in HIV transmission in other areas of the country.

**Limitations:** Admissions data is admissions-based rather than person-based, meaning that multiple treatment admissions for one individual may be included in the data. Data is only representative of individuals in drug treatment programs that receive state funding and does not include information for individuals seen only by private practitioners; therefore this data is not a complete snapshot of substance abuse treatment in Vermont.

### *Vermont Crime On-Line*

**Overview:** This data provides information on the number of drug charges filed in Vermont district court. Ideally, this data provides a snapshot of the number of charges filed for certain types of drugs. Data is limited to the number of charges filed for specific substances in each region, and the sex and age of the person charged.

**Population:** Those who entered the district system with a drug charge.

**Strengths:** This data may provide an indication of drug use trends statewide and may indicate rises in the use and abuse of certain substances (such as crystal methamphetamine or heroin) that are associated with increases in HIV transmission. In the future, it may be possible to compare substance use in different geographic areas of Vermont, perhaps indicating a need for prevention and/or intervention efforts.

**Limitations:** 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**

### *Vital Statistics Data*

**Overview:** Federal law mandates the collection and publication of births and other vital statistics data. (The National Vital Statistics System is the federal compilation of this data, in cooperation with each state and the National Center for Health Statistics). Vermont's registration of vital statistics began in 1857; the current system gathers data on seven types of vital events: births, deaths, marriages, civil unions, divorces, fetal deaths, and abortions. Physicians must complete the cause of death information on death certificates prior to the filing of these certificates with the Vermont Department of Health, this whether HIV was an underlying or contributing cause of death.

**Population:** All live births and all deaths occurring within Vermont.

**Strengths:** Vital records include births and deaths in the state as well as births and deaths occurring in other states to Vermont residents. Reporting within the state is required, using standardized procedures to collect the data. The data for Vermont residents is considered 100% complete. Data are available statewide and can be used to determine the number of HIV-related deaths in various service areas of the state. Comparing the characteristics of persons living with AIDS to deaths among persons with AIDS may provide some indication of service disparities among groups. The data can also be used to summarize group-specific trends in terms of HIV-related mortality.

**Limitations:** Birth certificate data may not be complete for data that is obtained from patient medical records (i.e., smoking history, morbidity; data that may be useful for focusing prevention efforts). HIV infection may be underreported in the death certificate data because the physician completing the certificate may be unaware of the deceased individual's HIV positive status.

## Population Data

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

**Overview:** The Census Bureau collects and provides information about the people and economy of the U.S. The Census Bureau's Web site ([www.census.gov](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 percentage of persons living at or below the poverty level. Tables and maps of census data are available for all geographic areas to the block level. Summaries of the most requested information for states and counties are provided, as well as analytical reports on population changes, race, age, family structure, and apportionment. The most recent decennial census was completed in 2000. The American Community Survey (ACS) is a mandatory survey of 3 million households per year that is designed to replace the decennial survey. The ACS will eventually survey both residences and group quarters (nursing homes, prisons, college dorms, etc.) The ACS will be the largest household survey in the U.S. and will provide annual (or multi-year average) estimates of selected social, economic and housing characteristics of the population for geographic areas and subpopulations.

**Population:** U.S. population

**Strengths:** A wide range of online statistical data on the U.S. population is available in different formats (e.g., tables, maps). State- and county-specific data are easily accessible. Links to other census information Web sites are provided. Data on the number of non-white Vermont residents is important in gauging the impact of the HIV epidemic on these populations (which have traditionally shown higher rates of infection). Information is also available on in- and out-migration of specific populations.

**Limitations:** ACS population estimates are more up to date than decennial population estimates, but these numbers do not yet include individuals in group quarters (colleges, prisons, etc.); thus the people in these living situations in Vermont may be underrepresented in these population estimates.

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

**Overview:** The Vermont Department of Health uses estimates that are a modification of the estimates produced by the 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 however, do not accurately estimate the numbers of very young Vermonters (age < 5) when compared to the numbers of VT resident births. The VDH produces our own estimates for the under 5 population by county, then makes adjustments to Census/NCHS data so that the state and county totals match those sources. Some minor adjustments are made to the town 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).

**Strengths:** The Census/NCHS utilize detailed administrative records data in producing their estimates, making them the most accurate available source for population estimates (particularly for the over 65 age group which are estimated using Medicare enrollment data). Use of locally available data (birth records) to enhance the Census/NCHS numbers ensures we are getting the most accurate possible estimates of the under 5 population. Since young children are the focus of many VDH programs, it is critical that we have a solid estimate of how many young children there are in Vermont.

**Limitations:** The major cost of using the more accurate VDH modification of the Census/NCHS estimates is that timeliness suffers. Less accurate estimates are available much sooner than these numbers are available to us. The Census/NCHS estimates as of July 1 for a given year are not available until August or September of the following year. Then VDH staff time is required to perform the calculations necessary for the in-house modifications.

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

**Overview:** The Kaiser Family Foundation is a private, non-profit organization focusing on issues of health and health care. The Kaiser Family Foundation contracts with outside organizations and provides independent analyses of health and healthcare issues.

**Population:** Depends on the specific project. See web pages cited in text for information regarding specific projects referenced in this document.

**Strengths:** Specific strengths depend on the data source, although generally speaking, this data provides an indication of access to care for various populations and can be used to compare access across geographic areas. This data is indicative of the overall state of health care.

**Limitations:** Depends on the specific project. See web pages cited in text for information regarding specific projects referenced in this document.

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

**Overview:** The Vermont Department of Health utilizes ESRI ArcViewer/ArcGIS mapping software. The Vermont Center for Geographic Information is the state data warehouse and source for most of the base data used to produce the maps in this document.

**Population:** Depends on the data being mapped.

**Strengths:** The GIS system provides easy to access, visual depiction of HIV-related information for readers.

**Limitations:** Maps can become confusing if too much information is provided on a single map. Someone must be trained to use and access this system.

## **Ryan White CARE Act Data and Services Data**

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

**Overview:** This project represents an effort to identify gaps in care for Vermonters living with HIV. The measure of unmet need used for this project is based on analysis of two HIPAA compliant data sets. One data set (HARS) includes basic demographic information regarding Vermont residents with HIV/AIDS. The other data set includes basic demographic information regarding individuals who receive HIV related medical services in Vermont. Because these data sets do not include unique person identifiers, the analysis uses the method of statistical Probabilistic Population Estimation. Probabilistic Population Estimation provides valid and reliable estimates of the number of unique individuals shared across data sets. These estimates are based on the distribution of date of birth and gender in the data sets.

**Population:** Data on individuals currently identified as HIV positive in the Vermont Department of Health surveillance system (HARS) and individuals receiving medical care for HIV in the state are utilized to estimate the number of people who are not currently receiving medical care for their HIV.

**Strengths:** Probabilistic Population Estimation has been used in multiple studies to measure the amount of overlap in populations that do not have a unique

identifier. This is one of the only sources of information regarding unmet need for people living with HIV in Vermont.

**Limitations:** The data are based on estimates, not on an actual census of need.

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

**Overview:** The federal Ryan White CARE Act provides health care for people with HIV disease. Enacted in 1990, it fills gaps in care faced by those with low-incomes and little or no insurance. Vermont receives federal funding under Parts B and C of the Ryan White CARE Act. Part B provides money to states for primary health care and support services for people living with HIV and their families. Part C monies support early intervention and outpatient primary medical care services by directly funding private and non-profit organizations. Vermont does not receive Part A funds which provide emergency assistance to localities disproportionately affected by the HIV/AIDS epidemic. Although Vermont does not receive Part D funds for coordinated services and access to research for children, youths and women, 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 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. Data 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. Only if funding for these services is paid for through other sources can Part B dollars be used for "non-core services" such as food assistance, transportation, rent, etc.

**Population:** 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 AMAP or DCAP services are included in this data.

**Strengths:** The program database is a comprehensive database that includes information on all persons receiving Ryan White Part B services. The database is important for monitoring which Ryan White resources are being utilized, how often and by whom. In 2002 the Vermont Department of Health HIV/AIDS Program established a standardized unique identifier reporting system with the six state- and federally-funded AIDS Service Organizations and the Comprehensive Care Clinics in order to reduce duplication of services and to determine the number of persons receiving services from these organizations. This provides a

more accurate picture of how many people are truly seeking care through services provided by Ryan White Part B.

**Limitations:** This data cannot be generalized to all HIV- infected persons living in this state, since the data is collected only on persons 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.

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

**Overview:** Both AMAP and DCAP are funded by Ryan White CARE Act Part B funds (described above). Part B funds may be used to provide a variety of health care and support services. The AMAP provides financial assistance for the purchase of prescription medications to Vermonters living with HIV who meet certain income guidelines. AMAP allows uninsured and underinsured individuals to access anti-retroviral and related therapies. DCAP provides financial assistance to meet the dental needs of underinsured and uninsured Vermonters living with HIV/AIDS. The services in this program include: diagnostic procedures including x-rays and evaluations; preventive care including cleanings; restorative treatments including silver fillings, tooth colored fillings and root canals; removable prostheses including complete and partial dentures and necessary oral surgery including extractions.

**Population:** 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 AMAP or DCAP services are included in this data.

**Strengths:** Data is collected on 100% of the people who receive services via AMAP/DCAP.

**Limitations:** This data cannot be generalized to all HIV- infected persons living in this state, since data is collected only on persons 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. Also, AMAP data represents individuals, while DCAP data represents claims made by individuals. Therefore, DCAP data may be duplicated.

#### ***Vermont Uniform Hospital Discharge Dataset***

**Overview:** Records for discharges are obtained through the Vermont Department of Health. These data are used by the Vermont Department of Banking, Insurance, Securities and Health Care Administration to create the Vermont Hospital Monograph Series. Records are classified by diagnosis related groups and major

diagnostic categories. For this profile, data from the utilization by diagnostic category and service area are utilized.

**Population:** Discharge data from inpatient services includes services sought by Vermonters in Vermont and adjacent states. Patient data is classified by Hospital Service Area (HSA). HSAs represent a geographically distinct population of Vermonters who seek medical care from a particular hospital or group of hospitals. There are 13 HSAs in Vermont.

**Strengths:** Data is collected from both hospitals in Vermont and in adjacent states, increasing the amount of information collected on Vermonters who utilize these services.

**Limitations:** Currently, data from some out of state hospitals on outpatient care and the emergency department are not comparable to data collected inside Vermont.

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

**Overview:** This study was carried out in 2004 in an effort to assess barriers to HIV/AIDS prevention, support and medical services for Vermont communities of color. This study was sponsored by the Office of Minority Health and the HIV/AIDS Program and was carried out under the guidance of HASAC. Three groups were studied: 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. Data were gathered via focus groups, individual interviews and surveys.

**Population:** Members of certain communities of color (Native Americans, African Americans, Hispanic-Latino individuals, African Refugees and Vietnamese refugees) living in northwestern Vermont (Chittenden & Franklin Counties). Individuals incarcerated in Vermont during May and June of 2004 in one of the six participating institutions. Providers of HIV/AIDS prevention, support or medical care services at one of seven sites statewide.

**Strengths:** This study provides much-needed data on the barriers to prevention and care services that are experienced by minority populations in Vermont. Data were collected from four focus groups (all held in Chittenden County), 48 structured interviews with members of communities of color from Chittenden and Franklin Counties, 934 completed surveys from incarcerated individuals in Vermont (including 220 persons of color), and structured telephone interviews with seven providers of HIV/AIDS prevention, support or medical care services (providers located throughout the state). An effort was made to collect data in a culturally sensitive manner, meaning that members of communities of color were directly involved in data gathering.

**Limitations:** The study encountered multiple challenges, including difficulty in guaranteeing anonymity and confidentiality due to the fact that Vermont's communities of color are relatively small so members know one another. The plan to recruit participants via CBOs was unsuccessful and the interviewers had to directly recruit participants. There were also issues with standardization of interview and focus group protocols for members of communities of color (this was not an issue with the provider interviews). Data gathered from these focus groups and individual structured interviews was limited to participants in the northwestern part of the state and should not be generalized beyond this area. The original study plan had to be modified due to difficulty accessing people who were not already known to the Vermont HIV community network.

## **Appendix B: Glossary**

**AIDS:** AIDS stands for acquired immunodeficiency syndrome. An HIV-infected person receives a diagnosis of AIDS after developing one of the CDC-defined AIDS indicator illnesses (see *opportunistic infection*) or on the basis of certain blood tests (i.e., having a CD4 count of less than 200 or a CD4 percent of less than 14). A positive HIV test result does not mean that a person has AIDS.

**Bias:** Bias occurs when there is a systematic error in data that leads to results that do not represent the true findings. For example, if individuals feel uncomfortable about reporting that they have engaged in high-risk behaviors, then these behaviors will be systematically under-reported. Consequently, conclusions about the occurrence of such behaviors would be considered “biased.”

**CDC:** The Centers for Disease Control and Prevention (CDC), within the U.S. Department of Health and Human Services, is the lead federal agency for protecting the health and safety of the people of the United States. CDC accomplishes its mission through developing and applying disease prevention and control, environmental health, and health promotion and education activities designed to improve public health in the U.S. The CDC provides the majority of funding for HIV prevention, and all of the funding for HIV surveillance activities in Vermont.

**Exposure Category:** This term is used to summarize multiple risk factors that an individual may have had by including combination categories of the three most common ones (MSM, IDU, heterosexual contact); risk factors other than these three groups (e.g., receipt of a blood transfusion) appear only in single categories that are ranked lower than the combinations of MSM, IDU and heterosexual contact. This differs from transmission category which lists only the one risk factor through which HIV was most likely to have been transmitted.

**HASAC:** HIV/AIDS Services Advisory Council

**HAART:** Highly Active Antiretroviral Therapy (HAART) refers to aggressive anti- HIV treatments that usually include a combination of protease and reverse transcriptase inhibitors, which interrupt the HIV life cycle, and whose purpose is to reduce a person’s viral load to undetectable levels.

**HIPAA:** The Health Insurance Portability and Accountability Act required the Department of Health and Human Services (HHS) to establish national standards for electronic health care transactions and national identifiers for providers, health plans, and employers. It also addressed the security and privacy of health data.

**HIV:** HIV is an acronym for “Human Immunodeficiency Virus,” which is the virus that causes AIDS. A person who has contracted the virus is said to be HIV-positive or HIV-infected.

**HIV Disease:** HIV disease describes both individuals who have been diagnosed as HIV positive only and those diagnosed with AIDS. Individuals with either carry the HIV virus.

**Incidence:** Incidence refers to the number of new cases of disease that occur in a population during a specified time period, usually a year. Even though HIV data are often presented as “new cases of HIV,” these data do not represent new infections (true HIV incidence), because a person may not be tested for HIV in the same time period that he or she became infected. On the other hand, incidence can be presented for diseases (e.g., some STDs). These diseases have clear symptoms that are detectable when a person becomes infected, and which cause a person to be tested or to seek treatment shortly after infection.

**Median:** The middle value in a data set. Usually, approximately half the values will be higher and half will lower.

**N:** total number of people in a sample

**n:** a subgroup within a sample

**Opportunistic infection (OI):** Infection with HIV can weaken a person’s immune system to the point that it has difficulty fighting off certain infections. These types of infections are known as “opportunistic” infections because they take the opportunity a weakened immune system gives to cause illness. Some examples of opportunistic infections are *Pneumocystis carinii* pneumonia (PCP) and Kaposi’s sarcoma (KS). Opportunistic infections (OIs) are considered to be CDC-defined AIDS indicator illnesses, which means that an HIV- infected person receives a diagnosis of AIDS after developing them.

**Perinatal:** The word “Perinatal” means “around birth” and is used to describe events that occur during labor and birth, and immediately following delivery. When “perinatal” is used to describe HIV transmission, however, this word applies more broadly and describes any time that a mother may pass HIV to her child – either while she is pregnant, during birth, or through breast- feeding.

**Prevalence:** Prevalence refers to the total number of persons with a specific disease or condition at any given time. HIV prevalence data are generally presented as “persons living with HIV.” HIV prevalence data provided by HIV surveillance programs will underestimate the true HIV prevalence because HIV- infected persons who have not yet been tested or reported to the health department are not included. Persons who have died are excluded from prevalence data.

**Proportion (percentage):** A proportion is a type of ratio in which the numerator is included in the denominator. Because the numerator is a subset of the denominator, a proportion can be thought of as a ration of a “part” of the “whole.” A proportion is usually expressed as a percentage.

**Rate:** A rate is a special type of ratio that includes a specification on time. In epidemiology, rates express the probability or risk of disease or other events in a defined population over a specified period of time, often one year. For Vital Records, rates are not based on probabilities, but are calculations based on verified or repeatable counts.

**Reporting Delay:** The period of time between documentation of an infection or diagnosis of an illness, and the report of that infection or illness to authorities.

**Risk Factor:** Refers to the individual routes of exposure to HIV (before the person found out that s/he was HIV positive) for which data are routinely collected for surveillance of HIV/AIDS cases.

**Ryan White CARE Act:** The Ryan White Comprehensive AIDS Resources Emergency Act was created to provide federal assistance to increase the availability of primary health care and support services for persons living with HIV disease, to increase access to care for underserved populations, and to improve the quality of life for those affected by HIV. The CARE Act was first enacted by Congress in 1990 and was reauthorized in 1996 and 2000. HRSA implements the CARE Act and directs assistance through the following channels:

- Part A provides support to Eligible Metropolitan Areas (EMAs) with the largest numbers of reported AIDS cases, to meet emergency service needs of persons living with HIV;
- Part B provides support to all states and territories to improve the quality, availability, and organization of health care and support services for persons living with HIV and their families;
- Part C supports outpatient early intervention HIV services through funding to public and private nonprofit entities;
- Part D funds public and private nonprofit entities to conduct projects to coordinate services to children, youth, women, and families with HIV/AIDS;
- Part F provides support for Special Projects of National Significance (SPNS) to develop and evaluate innovative models of HIV/AIDS care, for AIDS Education and Training Centers (AETC) to conduct education and training for health care providers, and for the HIV/AIDS Dental Reimbursement Program to assist with providing oral health services to HIV- infected patients.

**Sample:** A group selected from a total population with the expectation that studying this group will provide relevant information about the total population.

**Surveillance:** In a public health context, surveillance refers to the collection and analysis of data concerning a certain disease that is monitored over time.

**Testing (anonymous, confidential):** In Vermont, an individual can choose to be tested anonymously or confidentially for HIV in a publicly funded testing site. Confidential HIV-positive test results are reported to the health department where information is maintained under the strictest security and confidentiality measures. Persons who are tested anonymously do not provide their names when taking the HIV test. Persons who are tested confidentially do provide their names when taking the HIV test. Only persons who are tested confidentially are included in the HIV surveillance data.

**Transmission category:** In order to monitor trends in HIV transmission, HIV/AIDS cases are classified into one of several transmission categories developed by the CDC. The transmission category indicates the risk factor through which HIV was most likely to have been transmitted.

- *Men who have sex with men (MSM)* refers to men who report having had sexual contact with other men, i.e., homosexual or bisexual contact.
- *Injection drug user (IDU)* cases are those who report ever using drugs that require injection. While it may be valuable to know that a person has used illicit drugs through other routes, this information would not be enough to classify a case as IDU.
- *MSM/IDU* refers to men who report having sexual contact with other men and who also report ever using non-prescribed drugs intravenously.
- *High-risk heterosexual contact (HRH)* cases have reported heterosexual contact with a partner who is at increased risk for HIV infection, i.e., a homosexual or bisexual man or an IDU, or a partner with documented HIV infection.
- *Hemophilia/Transfusion/Transplant* cases are those who report having received a transfusion of blood or blood products prior to 1985.
- *Perinatal* cases are cases of HIV infection in children resulting in transmission from an HIV positive mother.
- *Unspecified or “no identified risk” (NIR)* cases are those cases who have no reported history of exposure at the time of publication. This category includes persons for whom the surveillance protocols to document risk information have not yet been completed, persons whose exposure history is incomplete because they have died, persons who have declined to disclose their risk behavior or who deny any risk behavior, and persons who do not know the HIV status or risk behaviors of their sexual partners.

**Trend:** A long-term change in frequency, usually an increase or a decrease.

**Weighted N:** A mathematical procedure has been used to make the data representative of the sample from which it was drawn.

**Young MSM:** For the purposes of this document, young MSM are defined as male youth in 8<sup>th</sup> -12<sup>th</sup> grades who ever reported on the YRBS that they had ever had sex with a male.

## **Appendix C: Abbreviations**

**ACS:** American Community Survey (designed to replace the decennial census long form)

**ADAP:** AIDS Drug Assistance Program (this is known as **AMAP in Vermont** – HIV/AIDS Medication Assistance Program); within the Vermont Department of Health the division of Alcohol and Drug Abuse Programs is also referred to as ADAP

**AMAP:** HIV/AIDS Medication Assistance Program

**ASO:** AIDS Service Organization

**BRFSS:** Behavioral Risk Factor Surveillance System

**Ryan White CARE Act:** Ryan White Comprehensive AIDS Resources Emergency Act

**CBO:** Community Based Organization

**CCC:** Comprehensive Care Clinic

**CDC/CDCP:** Centers for Disease Control and Prevention

**CPG:** Community Planning Group

**CPS:** Current Population Survey

**CTR:** Counseling, Testing and Referral System

**DCAP:** Dental Care Assistance Program

**FDA:** Food and Drug Administration

**GIS:** Geographic Information Systems

**HAART:** Highly Active Anti-retroviral Therapies

**HARS:** HIV/AIDS Reporting System

**HASAC:** HIV/AIDS Services Advisory Council

**HIPAA:** Health Insurance Portability and Accountability Act

**HITS:** HIV Testing Surveys

**HMO:** Health Maintenance Organization

**HRSA:** Health Resources and Services Administration

**IDU:** Injection Drug User

**MSA:** Metropolitan Statistical Area

**MSM:** Men who Have Sex with Men

**N:** total number of people in a sample

**n:** a subgroup within a sample

**NCHS:** National Center for Health Statistics

**NSDUH:** National Survey on Drug Use and Health (*Formerly known as the NHSDA, the National Household Survey of Drug Abuse*)

**PEZ Projects:** Person Environment Zone Projects

**PLWHA:** People Living with HIV or AIDS

**PRAMS:** Pregnancy Risk Assessment Monitoring System

**SAMHSA:** Substance Abuse and Mental Health Services Administration

**STD:** Sexually Transmitted Disease

**VCJR:** Vermont Center for Justice Research

**VDH:** Vermont Department of Health

**YRBS:** Youth Risk Behavior Survey