

Maryland Department of Health & Mental Hygiene

AIDS Administration

2006 Statewide Coordinated Statement Of Need

A Needs Assessment for HIV/AIDS Medical and Support Services



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PREAMBLE

The Maryland AIDS Administration, established in 1987 as a division of the Maryland Department of Health and Mental Hygiene, leads public health initiatives regarding HIV (Human Immunodeficiency Virus), the virus that causes AIDS.

To achieve its mission of reducing HIV transmission and helping Marylanders already infected live longer and healthier lives, the MD AIDS Administration supports programs in three broad, sometimes overlapping areas: education, prevention, health and social services.

The MD AIDS Administration funds services for persons with HIV disease or AIDS, operates Maryland's ADAP (AIDS Drug Assistance Program) and health insurance premium payment assistance programs, educates the public and health care professionals about HIV and AIDS, funds programs designed to prevent HIV transmission and monitors the disease in Maryland. Most services are delivered through third parties, including local health departments, other governmental organizations, community or hospital-based health care facilities, and community-based organizations in every part of the state. In addition, the MD AIDS Administration conducts program evaluation, health services research, and analysis and surveillance of the epidemic.

Mission Statement

Maryland AIDS Administration's mission is to work with public and private partners to reduce the transmission of HIV and help Marylanders already infected live longer and healthier lives. This is accomplished by promoting and developing comprehensive, compassionate and quality services for both prevention and care. The MD AIDS Administration provides leadership, encourages input from affected communities, and uses scientific knowledge, to guide the development of responsible, compassionate, and effective policies and programs.

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I. PURPOSE OF THE STATEWIDE COORDINATED STATEMENT OF NEED

The Ryan White Comprehensive AIDS Resources Emergency (CARE) Act Amendments of 1996 require CARE Act grantees to develop a Statewide Coordinated Statement of Need (SCSN). According to the federal Health Resources and Services Administration (HRSA), the SCSN is a mechanism for addressing key HIV/AIDS care issues and enhancing coordination across CARE Act programs and titles. (HRSA Care Act Title II Manual, 2003) This document is intended to serve as a framework for programmatic action that will strengthen Maryland's response to PLWH/A over a three-year planning cycle. The Maryland AIDS Administration, as the state Title II program, is responsible for coordinating the SCSN for the state of Maryland. All titles and grantees are expected to participate in the SCSN process.

A multi-step process was used to gather information, extract relevant data, obtain additional input, and complete the document. First, needs assessment documents were collected to identify service needs and barriers at the state level and within the state by region. Subsequently, community open forums were held in each region, culminating in a statewide meeting held to bring the range of regional data together for the state as a whole. These findings were summarized and analyzed, compared to epidemiological trends, and finally, synthesized to form this document.

The purpose of this document is to report progress since the last SCSN, and to identify the emerging trends in HIV/AIDS health and support services, critical gaps in services in Maryland and the issues which cut across all titles of the CARE Act in Maryland. The SCSN is intended as a broad statement of need upon which future plans and funding applications can be based. The partner document, the 2006-2008 Title II HIV Services Comprehensive Plan for HIV/AIDS Medical and Support Services outlines future priority goals, principles, and strategies to enhance the quality of care across the state of Maryland, as well as to monitor progress in meeting these goals and objectives.

II. DEVELOPING THE 2006 SCSN

The 2006 SCSN was developed through a participatory process that included input from a wide variety of consumers, providers and public agency representatives, and a review of epidemiological and needs assessment data. A multi-step process was used to gather information, extract relevant data, obtain additional input, and complete the document.

Step One: Collect needs assessment documents and review information that identifies service needs and barriers to care on a regional and state level.

In the summer of 2005, Maryland AIDS Administration staff began a comprehensive review of needs assessment documents from various sources throughout the state. Title I EMA grantees and Planning Council members, Title II grantees, and providers holding contracts with the MD AIDS Administration or other governmental agencies were asked to forward such documents in an effort to amass significant information delineating needs and barriers in specific regions or special populations.

The reports and documents reviewed in these analyses include: the Titles I, II and IV Client Satisfaction Survey results, Maryland AIDS Drug Assistance Program Client Survey results, the 2002 Case Management Survey Report, Behavioral Surveillance Study Data, the Suburban Maryland Title I Year 15 and Year 16 Planning Public Input Report, Title I Consumer Knowledge Survey results, the results of the Community Health Assessment of Somerset, Wicomico, and Worcester Counties, the 2005 Maryland Whitman Walker Clinic Closure Survey Report, and the Co-occurring Mental Health and Substance Abuse Provider Survey Summary. The complete list of the documents included in the review can be found in Appendix A.

Documents varied in content, format, and timeframe, ranging from statewide needs assessment to regional public input summaries to agency survey results. Also included were articles published in medical journals, research and evaluation summaries, surveillance study analyses, focus group reports, and consumer knowledge survey results. All identified needs, including prevention and policy issues are summarized in this document.

Step Two: Conduct regional community forums and a statewide providers meeting.

Five regional community open forums were held in the fall of 2005. Efforts were made to include a wide range of participants for the open forums, successfully drawing a total of 119 clients, community

members, and providers. These forums served as a venue to hear consumers' voices. Consumers were given the opportunity to share concerns, suggestions, and experiences according to service categories. PLWHAs comprised approximately 39% of the open forum attendees.

Step Three: Hold a statewide SCSN meeting. Conduct and analyze SCSN Survey.

In late fall of 2005, the Maryland AIDS Administration hosted a SCSN meeting. The purpose of the meeting was to hear from *providers and consumers* what gaps in knowledge and services still existed throughout the State of Maryland. Titles I, II, III and IV grantees serving Maryland residents, consumers, planning council, and consortia co-chairs were invited to attend. The list of participants can be found in Appendix B.

Participants were divided into small groups according to topics. Led by a facilitator, each group identified, discussed, and summarized critical gaps, trends, crosscutting issues, special populations, and possible solutions. Topics included: Access to Medications, Ambulatory Outpatient Care, Case Management, Client Advocacy, GLBTQ, Homeless, Housing, Immigrants, Mental Health, Oral Health, Pediatrics, Perinatal, Recently Incarcerated, Rural, Substance Abuse, Treatment Adherence, and Youth. Comprehensive notes were taken and later synthesized.

A SCSN survey was also developed and implemented at the SCSN meeting. This survey served as a tool to identify the greatest needs and barriers across the state.

Step Four: Summarize and compare HIV/AIDS epidemiological data.

The Maryland AIDS Administration Center for Surveillance and Epidemiology produced graphic and tabular data on reported HIV and AIDS cases and persons living with HIV and AIDS, which are presented in Section III of this document. These data highlight variables such as race/ethnicity, gender, age, and mode of HIV transmission, and trend information on cases and deaths. The information is presented on a statewide and regional basis.

Step Five: Summarize emerging trends, special populations, and service needs and barriers.

Emerging trends that impact the HIV/AIDS epidemic are described in Section IV. The issues outlined in this section are crosscutting statewide trends that need to be taken into consideration for future planning. These include:

- ◆ Impact of the Ryan White CARE Act Reauthorization on the State of Maryland
- ◆ Introduction of Medicare Part D
- ◆ HIV Testing Rates/ Behavioral Surveillance
- ◆ Transitioning Youth Into Adult Care
- ◆ Unmet Need/Viral Load Reporting
- ◆ Coordination of Care
- ◆ Client Self-management
- ◆ Stigma and Discrimination

All needs assessment documents, consortia minutes, SCSN meeting discussions, and priority setting results were collected and synthesized, culminating in a comprehensive list of service needs and barriers that will be given high priority in future planning. Section V-A outlines the following service needs:

- ◆ Ambulatory Outpatient Medical Care
- ◆ Case Management
- ◆ Dental care
- ◆ Housing Assistance
- ◆ Medication and Treatment Adherence
- ◆ Mental Health
- ◆ Prevention and Education
- ◆ Substance Abuse and Addictions Services

Discussions regarding special populations that are disproportionately affected by the HIV/AIDS epidemic are found in Section V-B of the document. This section provides an overview of the following special populations that require focused attention in the State of Maryland:

- ◆ Persons with Limited-English Proficiency
- ◆ Immigrants
- ◆ Youth
- ◆ Pediatric HIV clients
- ◆ Recently incarcerated
- ◆ Homeless Persons
- ◆ Pregnant HIV-positive women
- ◆ Substance Abusers
- ◆ Rural Persons
- ◆ Gay, Lesbian, Bi-Sexual, Transgender or Questioning– GLBTQ Persons

Step Six: Prepare, finalize, and distribute the SCSN document.

Using the synthesis of information gathered above, the SCSN was written and used as a guide to create priority goals for the three-year Title II HIV Services Comprehensive Plan.

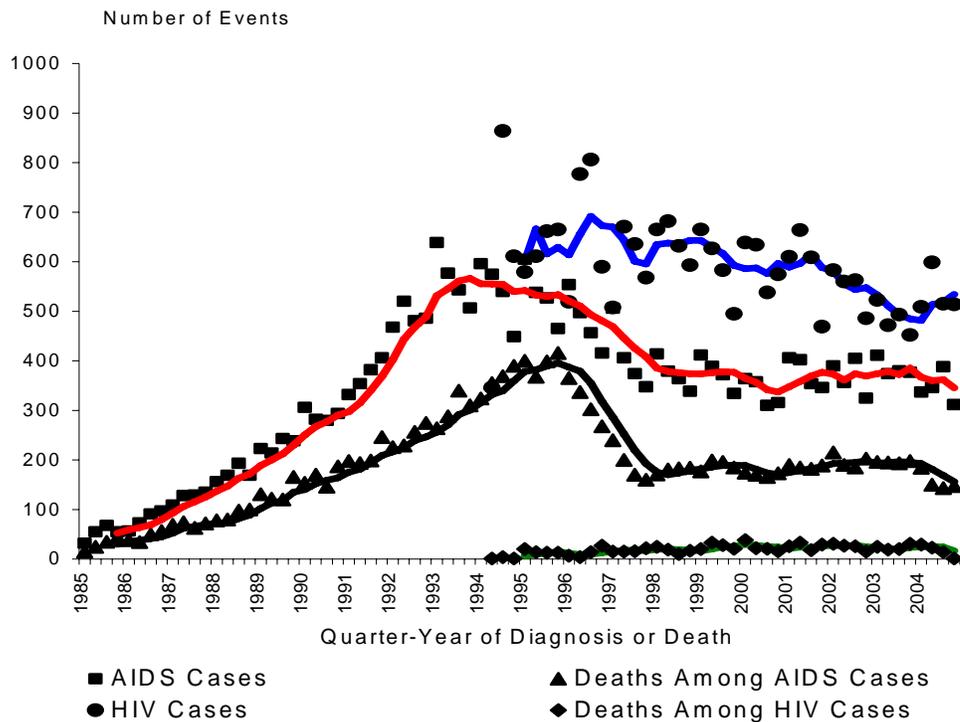
III. EPIDEMIOLOGICAL PROFILE

State of Maryland

This section contains data from the epidemiological profile for the entire state. The regional profiles are in Appendix C.

Maryland AIDS cases are reported to the state health department by health care providers and facilities. HIV positive test results are reported by all laboratories licensed to perform HIV tests on Maryland residents. HIV data are available only for those tested since 1994, when HIV surveillance began. HIV and AIDS incident cases are not necessarily mutually exclusive since HIV cases may have progressed to AIDS during the presented time period. HIV and AIDS prevalent cases are mutually exclusive categories; therefore, HIV prevalent cases are only those cases that have not developed AIDS. Due to the delay in case reporting, the data presented here describe all cases diagnosed through the end of September 2004 as reported through September 30, 2005. It is estimated that over 90% of cases had been reported by this date. Exposure information for reported HIV cases in Maryland is incomplete at present, however follow-up investigations are currently being conducted and this information will be more complete in the future.

Table 1. HIV and AIDS Case Trends: Incident (Newly Diagnosed) HIV and AIDS Cases and Deaths among HIV and AIDS Cases by Quarter-Year through Third Quarter 2004 as Reported through 9/30/05

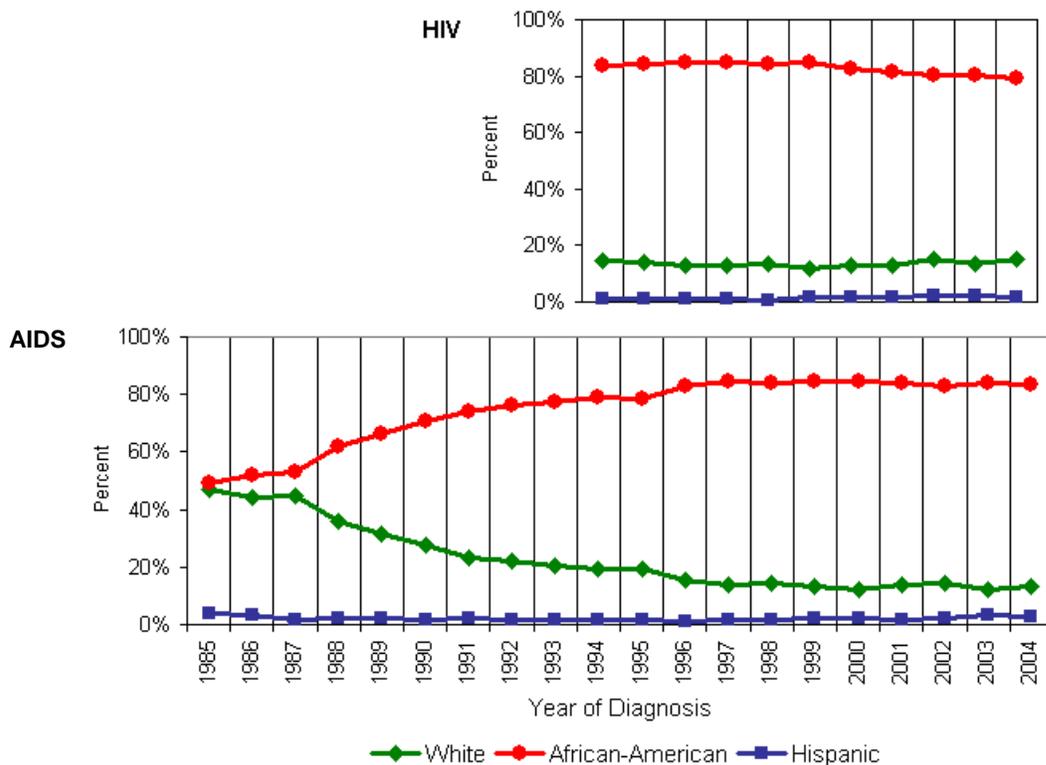


The number of incident (new) AIDS cases diagnosed within each quarterly period increased through 1995, with an artificial rise around 1993 due to changes in the AIDS case definition. The number of deaths among AIDS cases also increased through 1995. Beginning in 1996 and coincident with the introduction of protease inhibitor therapy, there has been a substantial decline in both the number of new cases of AIDS (to 388 in the third quarter of 2004) and in deaths among AIDS cases (to 143 in the third quarter of 2004). The number of new AIDS cases and deaths has been stable since 1999. The number of deaths among AIDS cases declined at a faster rate than the number of new AIDS cases per year, resulting in a slow increase in the number of people living with AIDS each year (prevalence). The number of new HIV cases reported each quarter was stable from 1994 and has been slightly declining since 1994 (to 515 in the third quarter of 2004). However, the total number of living HIV cases (reported since 1994) and AIDS cases has been steadily increasing. The number of deaths among HIV cases has remained low and stable since 1994.

There were a total of 28,327 living HIV and AIDS cases in the state of Maryland as of September 30, 2004, of which 15,973 (56%) were HIV cases and 12,354 (44%) were AIDS cases. Fifty percent of all reported living HIV and AIDS cases in Maryland were residents of Baltimore City at time of diagnosis. The Central Region, which includes Baltimore City and the surrounding counties, Anne Arundel, Baltimore, Carroll, Harford, and Howard, reported a total of 62% of all living cases. The two counties adjacent to Washington, D.C., Montgomery and Prince George's counties (with 8% and 15% of cases,

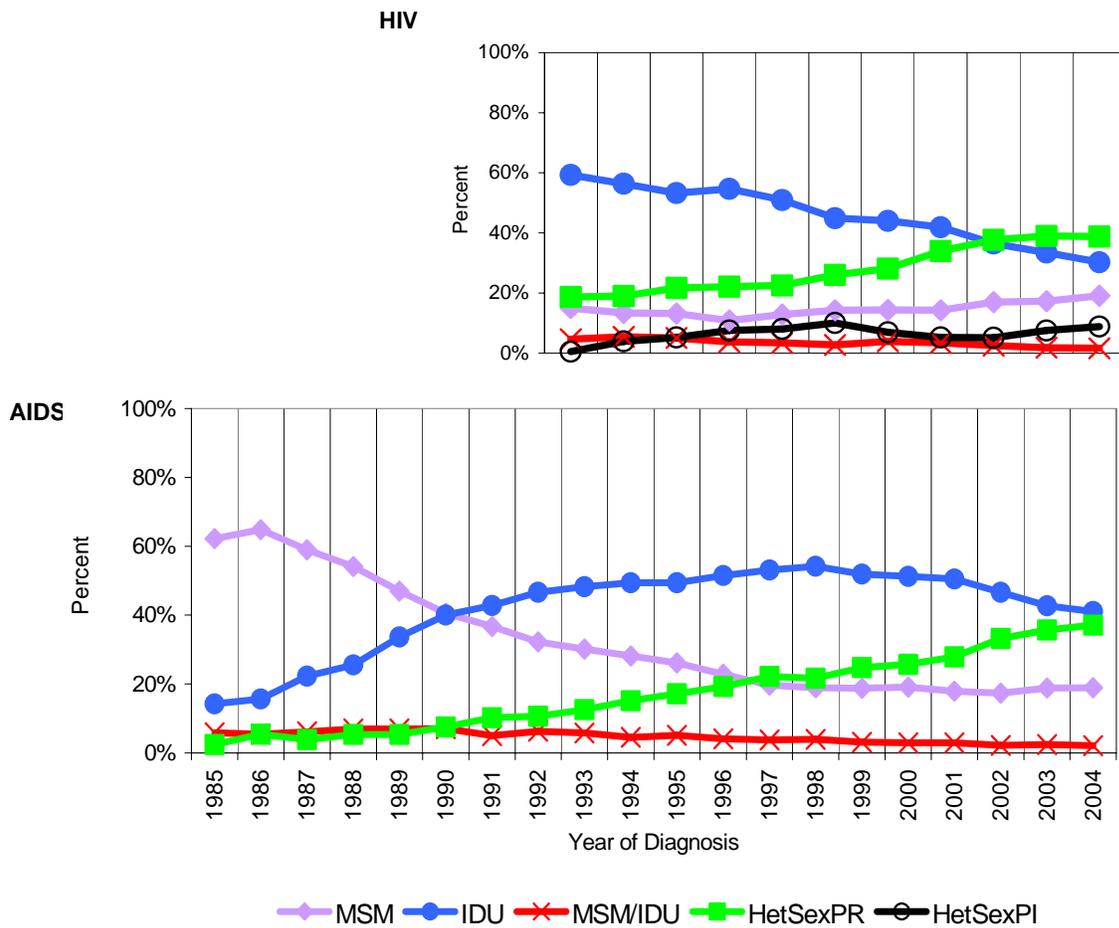
respectively) make up the Suburban Region with 23% of living cases. A large percentage of HIV and AIDS cases are diagnosed within the state correctional system (11% of living HIV cases and 7% of living AIDS cases). The rural Eastern Region (Caroline, Cecil, Dorchester, Kent, Queen Anne's, Somerset, Talbot, Wicomico, and Worcester counties) reported 3% of all living cases. The rural Western Region (Allegany, Frederick, Garrett, and Washington counties) reported 2% of all living HIV and AIDS cases and the rural Southern Region (Calvert, Charles, and Saint Mary's counties) reported 1% of all living HIV and AIDS cases.

Table 2. HIV and AIDS Case Race/Ethnicity Trends: Proportions by Race/Ethnicity of Incident (Newly Diagnosed) Cases during each Calendar Year Reported through 9/30/05



Maryland living HIV and AIDS cases are predominantly African-American (82%), male (65%), and middle-aged (68% of cases are 30-49 years old). The largest single demographic grouping is African-American males, ages 40-49, with 21% of all HIV and AIDS cases. The percentage of female cases has been increasing over time. Of all AIDS cases diagnosed in 1985, 10% were female. This proportion has steadily increased to 36% of AIDS cases in 2004. Thirty-eight percent of all HIV cases in 2004 were female. The percentage of African-American cases has been increasing over time. Of all AIDS cases diagnosed in 1985, 49% were African-American. This proportion has steadily increased to 83% in 2004. Seventy-nine percent of all HIV cases in 2004 were African-American.

Table 3. HIV and AIDS Case Exposure Category Trends: Proportions by Exposure Category of Incident (Newly Diagnosed) Cases during each Calendar Year Reported through 9/30/05



Men who have sex with men (MSM) was the most common mode of HIV transmission for AIDS cases until 1990. In 1991, injection drug use (IDU) became the most commonly reported exposure among newly diagnosed AIDS cases. Heterosexual contact with a partner who has or is at risk for HIV (HetSexPR) has represented an increasing proportion of reported exposure among all new AIDS cases and surpassed MSM in 1997. Exposure information for reported HIV cases in Maryland is incomplete at present, however, follow-up investigations are currently being conducted and this information will be more complete in the future. Injection drug use was the predominant mode of HIV transmission for HIV cases, until 2002, when heterosexual contact surpassed it.

IV. EMERGING TRENDS AND CROSSCUTTING ISSUES

Emerging trends are defined as “evolving circumstances, thought, policies, procedures, or resources which affect service delivery.” Participants statewide identified various emerging trends and existing circumstances that have had an impact on the service system. Crosscutting issues are defined as “concerns shared by a number of agencies, communities, geographic areas or populations.” Since the emerging trends and cross cutting issues overlap, they have been combined in this report.

A. Impact of the Ryan White CARE Act Reauthorization on the state of Maryland

Reauthorization of Ryan White CARE Act was a hot topic in 2005. The reauthorization of the Ryan White CARE Act was due on September 30, 2005 and was extended through November 17, 2006. Major issues for this reauthorization include modifying Title I and II formulas based on AIDS cases to a formula including the number of living HIV cases and eliminating the overlap in funding for Titles I and II.

HIV has emerged as a crisis among individuals in rural communities and for racial and ethnic minorities. Individuals living with HIV from emerging and newly revealed populations require appropriate and culturally relevant medical care and medical support services. Many HIV positive individuals who are aware of their diagnosis are not receiving care. Early and continuous treatment contributes to better and less costly treatment outcomes. However, funds are not always available to assist those into care. Connecting people to care and ensuring "standard of care" treatment has been challenging with the flat level funding and would be difficult if there is a reduction of Title II funds. As the number of people in care increases, the funds are not sufficient to provide adequate services to people with HIV/AIDS.

B. Medicare Part D

Obtaining affordable prescriptions is often a challenge for individuals with HIV/AIDS. The Medicare Part D drug benefit provides more comprehensive pharmacy benefits for low income and senior participants with various benefit levels based on income. In order to meet individual needs, Medicare requires the beneficiary to make a choice from among several options. HRSA requires Medicare-eligible ADAP (AIDS Drug Assistance Program) participants to enroll in a Medicare Part D Prescription Drug Plan. MADAP (Maryland's AIDS Drug Assistance Program) is working with participants and the community to provide access to the most comprehensive coverage available. With the changes in the system, there will be an increased burden on case managers and program staff to assist with the selection of the Part D PI and applications for Subsidy and/or Assistance Programs. Implementing a new system ID

presenting initial challenges until participants and services providers understand the process, requirements, and options available for Medicare Prescription Drug Plans. However, in the long run, clients will be provided with more comprehensive benefits and the MADAP program is projected to have a total cost savings of 1.5 million dollars in calendar year 2006.

C. Testing / Behavioral Surveillance

With the advancement and availability of HIV drug therapies, getting people into care for continued treatment to suppress viral replication has become a national strategy to decrease HIV transmission. Many do not get tested for HIV; thus, many HIV-positive individuals do not know their serostatus. Knowing one's HIV status is shown to prevent partner infections by reducing high-risk behaviors. Results of a behavioral surveillance project for men who have sex with men in the Baltimore metropolitan area showed surprisingly high HIV prevalence rates among African-Americans in particular and most of those infected were not in HIV primary medical care. Of those infected, two thirds of the population were unaware of their status. A Rapid Response Team was formed to pool resources and develop a programmatic response. New projects, using funds from CDC, HRSA Title I and Title II, and SAMHSA have been developed to target MSM.

D. Transitioning Youth Into Adult Care

Adolescents comprise an increasing percentage of new HIV infections in Maryland. The lack of access of many adolescents and young adults to culturally competent medical services and the fact that teenagers who are most likely to become HIV-infected are often those who are the most disenfranchised, contribute to this disturbing trend in the epidemic. Even when adolescents know their status, many do not receive the care they need. Efforts have been made by service providers to determine appropriate ways to transition youth into adult care and to reach those youth that are not in care. Qualitative information was collected from the Ryan White Title IV Youth Initiative Community Advisory Board (CAB) to determine needs for youth program planning, development and funding. For example, surveys and focus groups were conducted to identify primary barriers for youth when accessing and receiving services, identify life skills needs and identify effective approaches when assisting youth transitioning into adult care. These findings assisted program staff and providers to tailor services for transitioning youth into adult care. Quality care and treatment of HIV-positive adolescents is a priority for providers throughout the state.

E. Unmet Need/Viral Load Reporting

Unmet need calculations are important for national and local planning and capacity building. Unmet need is defined as the proportion of persons known to have HIV/AIDS who are not receiving primary medical care. Primary medical care for HIV/AIDS is further defined as a patient having received either a CD4 count or a viral load test, or utilizing anti-retroviral medications during the prior year. Estimations of the number of people living with HIV/AIDS (PLWHA) who know their status but are not in care have a legislative foundation. Unmet need calculations provide input to Congress about the need for continued appropriations for HIV/AIDS treatment. More specific information about unmet need (e.g., geographic areas and populations most affected) also guides planning and resource allocations, including discretionary grant funds for capacity development.

Calculating unmet need using viral load reporting is recognized as the ideal. Maryland recently expanded its HIV/AIDS surveillance system to include HIV viral load reporting. Persons with HIV/AIDS receiving HIV viral load tests will count as persons receiving care and will be compared to the persons known to have HIV/AIDS, as reported through surveillance. This method will provide the best, unduplicated count of persons in care and permit very precise measures of the sub-populations and geographic locations of persons not in care (unmet need). Maryland began implementing viral load reporting in 2004. However, several major laboratories requested changes in the state's required HIV testing consent form in order to fully comply with the viral load reporting process. This change required approval by the Attorney General's office and was completed in April 2005. Laboratories have been notified of the change and the new consent forms have been distributed to providers. Using other methods to gauge unmet need, the unmet need calculation of 23.7% was applied to the total number of people living with HIV/AIDS to signify that an estimated 6,818 people did not receive care in 2004. Viral load data will be complete in 2006, and this gold standard for the unmet need calculation will be implemented.

F. Coordination of Care

Better coordination of HIV care among institutions and service providers was a major theme that emerged from the SCSN meeting. This is consistent with national and local trends. Coordination across Title I, Title II and Title IV occurs in pursuit of CARE Act goals to strengthen the service continuum for people living with HIV/AIDS and ensure that funds are used to fill gaps in care. An example of cross-collaboration and coordination is the joint Title I, Title II, and Title IV Client Satisfaction Survey that is implemented at all provider sites on an annual basis. This survey is conducted to assess clients' experience and satisfaction with the services of agencies funded by the Ryan White CARE Act (RWCA) and state funds in Maryland. This information is used to improve the system of care. Establishing "one-

stop shops” has been suggested throughout the SCSN process as a way to improve coordination of services across healthcare providers.

Expansion of Client Level Data

A way to assess coordination of HIV care is to collect complete client-level data. Since January 2004, all Title II, Title IV and state-funded HIV service providers have been required to submit client level data in an electronic, unduplicated format. In order to standardize submission of client level data and improve the data collected, providers are using or upgrading to Ryan White CAREWare 4, free public-domain software designed for grantees and providers. This upgrade will provide a more efficient method of data collection and quality data, which will improve the coordination of patient care among service providers. Ryan White services data is analyzed for service utilization patterns within geographical areas and by demographic trends. It is also used to gauge client utilization of core services and provide a more proficient way of collecting performance measures for program monitoring. The Baltimore and Washington Title I Programs have similar reporting requirements.

G. Client Self-management

Another crosscutting issue mentioned in the SCSN needs assessment and consortia meetings is the promotion of client self-management. The concept of client self-management is being supported by providers to build clients’ self-efficacy in managing their own health. To complement client self-management goals, participants from the SCSN meeting stressed the need for providers to have empowerment and skills training necessary to encourage PLWHA to maintain a healthy lifestyle. This was especially evident at the SCSN statewide meeting during the discussion on oral healthcare. Participants felt that if case managers stressed self-management during counseling sessions, clients would be encouraged to manage their own health better.

H. Stigma and Discrimination

Providers and consumers consider stigma and discrimination as on-going crosscutting issues in Maryland. Participants felt that stigma and discrimination exist on various levels as discussed in Section V-A: Service Needs and Barriers. According to the SCSN round table discussions, needs assessment results, and open forum meetings, consumers and providers stress that HIV stigma is a barrier to obtaining services for HIV care, mental health, oral health, affordable housing, and access to medication. Stigma and discrimination are also consistent concerns of the emerging and known special populations. The specific populations include persons with limited-English proficiency, immigrants, residents in rural areas, GLBTQ persons, incarcerated persons, homeless persons, substance abusers, and youth. (Refer

to Section V-B: Special Populations). As can be seen in across data sources, HIV stigma prevents disclosure to family members and obtaining services from healthcare providers.

V. SERVICE NEEDS AND BARRIERS

Participants in the 2006 SCSN process identified service needs and barriers. They also highlight populations with specific needs. This section will identify service needs and barriers first, followed by a brief description of special populations in Maryland.

A. Service Needs and Barriers

This section summarizes “documented” and “perceived” needs and barriers. Documented needs and barriers are those supported by specific evidence and/or quantitative information from sources outlined in Appendix A. Perceived needs and barriers are statements made by sources that are not in formal reports, such as notes from the community open forums or the SCSN meeting. Whether formally or informally documented, all accounts reflect the awareness of consumers and caregivers with direct experience accessing the delivery system, providers and case managers on the forefront of service delivery.

1. Ambulatory Outpatient Medical Care

In contrast with the 2001 SCSN where only minor adjustments needed to be made, clients and providers have identified a need to renovate the infrastructure of the service system in the following areas:

“One Stop Shops”

Clients propose that sites move to combine programs to provide comprehensive (Ryan White and non-Ryan White) services in a “one stop shop” location. This would better maintain the continuum of care and provide consistency for the client. This can also reduce reporting burden for vendors and improve the coordination of care between services. Furthermore, eligibility, funding and insurance processes can be streamlined for a more efficient and user-friendly system.

Collaboration and increased communication among agencies and providers.

The increase in the number of people living with HIV has been accompanied by a growth in service agencies and providers. Clients and providers alike identified the need for more collaboration and communication among agencies and providers. Collaboration would reduce duplication and maximize use of limited resources.

Training for providers

Along with the increased number of people living with HIV, the work load for service providers has increased, resulting in burn out and provider turnover. New providers need to be given more in-depth HIV training on a routine basis.

Privacy and confidentiality training and sensitivity and cultural competency training have been identified as growing needs, especially in the rural areas of Maryland. Several clients experienced breaches in confidentiality and perceived provider insensitivity. One suggestion would be to locate clinics in a "general medicine" setting to reduce stigma.

Accessibility and increase knowledge of available services

As identified in the 2001 SCSN, the need for increased days and hours and expansion of clinic locations and services is a need resulting from the rising number of PLWHA who live longer and are able to return to the workforce. While efforts have been made to increase service hours, days, and locations, access to care continues to be a concern.

Clients, especially in the rural regions, highlight the need for trained infectious disease providers to provide their general care in a manner that is appropriate for their HIV/AIDS needs. Moreover, there is an increasing lack of specialty care providers, including care for co-morbidities, OB/GYN, emergency, and pediatric care.

With the separate funding streams and changes in services at different care sites, it is difficult for clients and providers alike to stay abreast of where and when certain services are available. In the Baltimore EMA region, a Consumer Knowledge Survey (see Appendix A) found that "Lack of knowledge of available services was a barrier to care more than any other barrier—13.5 percent of those who needed but did not receive a service said it was because they did not know the service was available." (IGS 2005) Echoed in the Suburban Maryland Ryan White Title I Public Input, Title II Consortium, the SCSN Meeting, and the SCSN Survey, clients and providers have recommended the creation of a resource list/directory of providers. With a resource directory, clients will be able to locate needed services and providers will be able to more efficiently refer and link consumers to specialty care or other support services.

2. Case Management

Empowerment

A common theme that emerged from the open forums, the Suburban Maryland Public Input, and SCSN meeting was the need for client self-sufficiency. Participants expressed the need for empowerment and skills training in order for clients to take greater responsibility for their own health and disease management. This relates to the aforementioned need for training and support for increased client self-management.

Centralized case management

Participants also pointed out a need for centralized training among case managers. Many stated that there is inconsistency among case managers. Providers and clients alike are advocating a statewide training certification program, mentorship, networking, sensitivity and cultural competency trainings, and venues for sharing resources, new information, and etc. Others also proposed a centralized case management access system.

Caseload and turnover

According to the HIV Case Management Survey, the typical monthly unduplicated caseload for case managers varied from 52 clients in the Central region to 10 clients in Suburban Maryland, with an average of 42 clients statewide.

With increasing caseloads in many organizations statewide, it has been difficult to retain case managers. The high turnover rate creates difficulties and time constraints for both the agencies and the clients. Participants state that the standardized case management training, especially for new case managers, could contribute to a statewide standard of care for case managers. Not only are agencies burdened by the high turnover rates, the clients also face disruption of services. It is also difficult for clients to relive their stories by telling them again and again each time they face a change in case manager.

Adherence

The 2001 SCSN stated that increased adherence activities were needed as part of case management to assist clients with maintaining their medication and treatment regimens. Clients continue to express the need for supportive services that link with treatment to increase adherence and for broader client adherence education.

Referral system

Consistent with the 2001 SCSN findings, participants saw the need for case managers to link with Maryland managed care organizations and local health care practitioners and to engage in outreach to make the community aware of local health care and case management resources. While several participants stated that the referral system was not effective, others noted that accessibility was the problem.

3. Dental care

Consistent with the findings from the 2001 SCSN, 2006 SCSN participants agreed in the 2006 SCSN statewide meeting that there was a great need for more extensive oral health services.

Client and provider education

Several participants believe that oral health services are being underutilized. This may be due in part to the lack of oral health education. Clients often do not see the need for oral hygiene, and thus are not proactive until an emergency arises and services are needed immediately. Many patients had never seen a dentist until they became HIV positive and were told to see a dentist. Education is needed to stress the importance of oral health as part of HIV medical health.

Participants also indicate a need for sensitivity training for providers, increased cultural competency and social acceptance of people living with HIV/AIDS. With increased training, clients may be more apt to receive oral health care and utilize the services that are available.

Expansion of providers, service locations and hours

Although oral health services are available throughout the state, there is a need for more dental providers. This need is the greatest in rural Maryland, where some regions have only one dental provider per county. With the increased number of people living with HIV, there is also a growing need for increased days and hours and expansion of oral health clinic locations and services. Clients also report a need for more resources for dental supplies.

4. Housing Assistance

Not having access to stable housing was reported to be the second highest major problem faced by Maryland PLWHA. Stable housing is fundamental to success in the lives of persons with HIV/AIDS. This is particularly true because many struggle with co-morbid conditions that make the tasks of daily living even more challenging. Without a home, stress levels increase, further compromising already fragile

immune systems. Individuals are exposed to chaotic housing shelters or the uncertainty of life on the streets. Essential nutritional needs are easily neglected or forgotten. While coordination between health and social services is improving, some PLWHA have reported having to choose between attending medical appointments or standing in line to assure a place in a housing shelter for the night. Complex treatment regimens become more difficult to monitor and are frequently derailed when faced with unstable living situations. Appointments with health care and human service providers are more likely to be missed or not scheduled at all. Outreach workers are less likely to be able to find their clients in order to offer ongoing support and treatment. Ryan White-funded housing providers and HOPWA (Housing Opportunities for Persons with AIDS)-funded providers share two goals: to increase permanent, affordable housing resources for individuals and families with HIV/AIDS, and to promote integration of supportive service options for people with HIV/AIDS.

SCSN participants ranked transitional housing/shelter, long-term rental assistance, and other housing needs, as the three most inaccessible housing-related services. Furthermore, "Housing" was ranked the greatest need, above all other service categories. It is reported that neither HOPWA nor Ryan White funding for housing-related services is sufficient to meet the needs.

Housing needs are broken down into the following categories: Availability, Affordability, and Sustainability.

Availability

First, there is a lack of affordable decent housing for low-income individuals and families throughout the state of Maryland. In addition, there is a deficiency of housing assistance services. Regardless of HIV status, clients experience long housing wait lists and shortages in beds in existing transitional shelters. Stigma continues to be a major barrier. Landlords often are hesitant to rent to HIV positive tenants and it is difficult to develop and maintain a trust with the clients.

Affordability

With higher costs and minimal funding for housing, clients are left in unstable living conditions. Also, due to level or reduced funding from the federal Department of Housing and Urban Development's Housing Opportunities for Persons Living with AIDS (HOPWA) program, there is less funding to provide short-term/emergency housing, mortgage and utility assistance.

The housing laws now require credit checks for placement and landlords often rely upon credit scores to determine placement and eligibility. Furthermore, security deposits have drastically increased beyond that of the target populations' financial capability.

There is a need for the Section 8 Housing and HOPWA programs to devise new models concerning rental rates for PLWHA. The Department of Housing and Urban Development is charged with overseeing HOPWA programs as dictated by statute. Changes to rental guidelines and broad HOPWA mandates would have to come from amendments to current legislation.

Sustainability

Participants suggested integrating HIV support and housing services in housing facilities, including: life skills, medication management, budget management and trained staff to administer a behavioral health to address issues of "arrested development" and coping deficits that are common in the targeted populations. There is also a need for accurate assessments of a client's readiness for housing. This strategy would build a more comprehensive approach to existing service delivery systems.

5. Medications and Treatment Adherence

According to the results of the 2004 Maryland AIDS Drug Assistance Program (MADAP) Client Survey, approximately 96% of the respondents rated MADAP as an excellent or good program. Pharmacy staff also received favorable responses, where 73% stated that the pharmacy staff was courteous and helpful when they had questions. Regarding privacy, 75% felt their pharmacist protected their confidentiality very well. Despite this feedback, the sheer increase of the number of clients on anti-retroviral therapy has increased the need for collaboration and education efforts.

Increased collaboration

Participants agree that there is a need for enhanced collaboration between programs (the Maryland Medical Assistance and Pharmacy Assistance Program, Medicaid, MADAP) and between programs, service providers, and pharmacies in order for clients and case managers to receive timely assistance.

Increased education

Although efforts have been made to disseminate information regarding pharmacy assistance programs, clients still need education regarding pharmacy programs, MADAP, Medicaid and Medicare Part D. For example, some clients still are not aware that MADAP offers assistance for co-pays. Since co-pays are an extra expense for the client, they may choose not to obtain their medication. This in turn affects adherence to their medications.

Through the efforts of the Minority AIDS Initiative, almost 200 clients in FY2005 received treatment readiness education. These sessions including the following topics:

- ◆ How HIV works in your body
- ◆ Considering your options
- ◆ Quality of life
- ◆ Understanding anti-retroviral therapy
- ◆ Choosing anti-retroviral therapy
- ◆ Identifying support resources
- ◆ A Plan of Action

6. Mental Health

Participants during the SCSN meeting agreed that all persons with HIV could benefit from some form of mental health services. Furthermore, 58% of participants felt that mental health services were difficult for clients to access. Participants ranked mental health as the sixth greatest need for PLWHA, and one of the three greatest barriers to obtaining services. There are major cultural and stigma-related barriers to using mental health services.

Long-term care

Roughly half the HIV-infected population is receiving some form of mental health services. The major gap identified is in the lack of long-term mental health services. Clients complain that they only receive a strict 15 minutes with the psychiatrist per month, primarily to renew prescriptions. Although they are receiving mental health services, their mental health needs are not being met. Other counselors or clinical social workers are needed to take care of the counseling component of mental health. Non-traditional therapy options, as well as day programs and long-term services, should be examined.

Expansion of providers, service locations and hours

Although mental health services are available throughout the state, there is a need for more psychiatrists and counselors. There is also a growing need for mental health services for special populations, including the pediatric population and limited-English proficiency consumers. Services also need to be made available for family members of HIV-infected persons. With the increased number of people living with HIV who are in need of mental health services, there is a growing need for increased days, hours, clinic locations and services.

7. Prevention and Education

As a result of increased testing, earlier identification of HIV, and the introduction of HAART, many more people are living with HIV and AIDS. As a result, there is a greater need for prevention education and counseling for HIV-positive persons. In 2003, CDC issued recommendations on *Incorporating HIV*

Prevention into the Medical Care of Persons Living with HIV, which noted that “medical care providers can substantially affect HIV transmission by screening their HIV-infected patients for risk behaviors, communicating prevention messages, discussing sexual and drug-use behavior, positively reinforcing changes to safer behavior, referring patients for services such as substance abuse treatment, facilitating partner notification, counseling and testing, and identifying and treating other sexually transmitted diseases (STDs).” The Maryland AIDS Administration, in accordance with this guidance, has been integrating prevention with primary care.

HIV education

According to the 2005 Client Satisfaction Survey, respondents reported that 85.8% of providers explained information very clearly to them. In regards to Prevention for Positives education:

- 86.0% of clients reported that providers at their care site have talked to them about how to avoid spreading HIV to others.
- 79.4% of clients reported that providers at their care site have talked to them about how to tell a sex partner that they are HIV-positive.
- 84.6% of clients reported that providers at their care site have talked to them about how to protect themselves from being re-infected.

Despite these successes, SCSN participants report a continued need for basic HIV and AIDS education, as well as updates on new information for both clients and providers. Participants also indicate that there is a continued need to incorporate prevention education into HIV primary care.

Expansion of prevention resources and knowledge of what is available

Participants report that there is a lack of prevention resources and information on how to use these resources. Providers find that there is limited time and space to provide prevention services and note that increasing the length of an already long appointment can be taxing on the patient. Also, while clients are often not willing to listen to prevention messages, frequently enough, the providers are not adequately trained to provide them. Integrating prevention would require the need to cross train providers. The lack of funding may inhibit the inclusion of prevention in clinics.

8. Substance Abuse and Addictions Services

Integration of co-occurring services

There is a growing need for an integrated approach to providing substance abuse and addictions services for people living with HIV/AIDS. Some clients have argued that treatment services should be

expanded to include HIV treatment, while others believe that HIV treatment should be accompanied with substance abuse programs. Still others believe that these programs need to also integrate mental health services, as there are mostly just referrals that link the three services together. At present, participants reported not knowing if there were programs operating statewide that provide support specifically for PLWHA who also deal with substance abuse.

Expansion of services

There is a great need for more treatment slots in all modalities in accessible locations, especially inpatient and outpatient clinics outside of Baltimore City. For some regions, there is only one substance abuse treatment facility per county. Participants identified a need for 'treatment on demand' for clients in both urban and rural areas, but agreed that this is difficult to provide due to an already limited number of treatment slots. Also, as mentioned in the 2001 SCSN, outpatient treatment needs to be augmented by short and long term residential treatment. Participants suggest that clients would have higher success, if these services were available.

Cultural appropriateness and competency, and sensitivity training is a need in both outpatient and inpatient clinics. An expansion of services need to be made available to provide for growing special populations including persons with limited-English proficiency, pregnant woman and gay, lesbian, bisexual, and transgender clients.

Increased education on substance abuse

The increasing numbers of clients with substance abuse problems requires that case managers and other providers be educated about substance abuse, co-morbidity, cultural differences and other issues that may impact treatment outcomes.

Develop statewide resource list to assist in making appropriate referrals

Providers stressed a need for an extensive list of drug treatment resources to be made available to both providers and clients. The CBIS (Community Based Intervention System), which can serve as a centralized resource for community based organizations, is currently being developed at Johns Hopkins University.

9. Transportation

Transportation was identified as the third greatest need for PLWHA, and the overall greatest problem that clients face while trying to access care. The client-led priority setting process also reflected the significance of this need, as clients in each region voted transportation as one of the top five priorities.

According to the 2005 Client Satisfaction Survey, 49.8% of the clients use public transportation and 10.7% take a taxi to get to their care site. Though these results vary greatly by region, there is a distinct reliance on transportation services throughout the state.

Improve existing services

Clients state that public transportation and taxis are often unreliable, exceedingly late, expensive, limited in range, and especially in the rural regions, may breach one's confidentiality. Reported barriers include funding decreases, lack of public transportation in some areas where services are needed and a lack of transportation coordination.

Increase funding for transportation services

Providers report insufficient funding for client transportation. With rising gas prices and overall transportation costs, providers spend all of their transportation budgets early in their fiscal years.

Provide different types of transportation assistance

Clients suggest the need for a wider variety of options for transportation, including vouchers for gas, Metro tokens, bus passes, and cab fare.

Expansion of services

Participants state a need for more transportation that will cross-city and county lines. Also, since the public transportation system in the rural regions is less extensive than in the urban and suburban areas, there is a need for more transportation alternatives. Clients also propose the need for a local pharmaceutical delivery service.

B. Special Populations

This section addresses the specific needs outlined from needs assessment documents and community forum notes for the following populations: clients with limited English proficiency, immigrants, youth, pediatric cases, recently incarcerated persons, homeless persons, pregnant HIV-positive women, substance abusers, rural communities and gay, lesbian, bi-sexual, transgender and questioning (GLBTQ) persons. For each population, 2006 SCSN participants were asked to identify HIV service needs, barriers preventing these needs from being addressed, service gaps and strategies to connect the populations to the services they need.

1. Clients with Limited English Proficiency

Linguistically and culturally competent services were identified as the top needs for limited English proficiency PLWHA. SCSN participants indicated that it is challenging to find primary care and specialty providers that are bi-lingual. Additionally, these bi-or-multi lingual providers are often available on a limited basis, which creates a barrier to quality care. Translators are often not competent in medical terminology, and in general, translators may not be available when they are needed.

HIV-positive persons with limited English proficiency face many barriers to care including fear, stigma and lack of knowledge about available services and resources. Also, HIV-positive persons with limited English proficiency may also be undocumented immigrants without Social Security numbers. This may intensify concerns about HIV testing and treatment with regards to consent forms, deportation, and immigration status. These barriers to care may be more prevalent in smaller communities, such as with migrant laborers in the Eastern region.

SCSN participants discussed that HIV stigma is great in many cultures. Within close family and communal networks there can be stigma against a person's whole family due to one member's HIV positive status. Some individuals are not comfortable disclosing their status to their family members and therefore lack support for adhering to complex medication regimes and frequent appointments. Some individuals prefer to travel out of their community to receive care because they do not want to be seen by someone who knows them. This can make continuity of care difficult for providers who may not see the patient on a regular basis or know where patients are receiving primary or specialty care.

Additionally, lack of knowledge about what services are available presents a barrier to services for PLWHA with limited English proficiency. SCSN 2006 participants indicated that not only does this lack of awareness create a barrier to care, but also that this barrier is exacerbated by a lack of connection between community and healthcare services. SCSN participants responded that these barriers point to a need for more comprehensive case management system in order to help persons with limited English proficiency navigate counseling and testing as well as the larger healthcare and social services systems.

Linguistically competent case managers would make it easier for PLWHA with limited English proficiency to be aware of the services available to them and to know how to access these services. However, many clinics have expressed difficulty in identifying qualified, linguistically competent staff, particularly if the clinic is publicly funded and cannot compete with private sector salaries. Participants felt that diversity in health care provider staff and having materials and forms translated in a variety of languages would increase the number of patients with limited English proficiency who access care.

SCSN data suggest that immediate steps should be taken to improve services for people with limited English proficiency. These actions could include the sharing of materials and resources between providers and networking for social support services. Service providers should encourage partnerships between organizations especially pertaining to cultural competency, transportation, and translation services.

2. Immigrants

2006 SCSN participants indicated that the lack of knowledge about insurance and drug assistance programs is a prominent barrier facing immigrants who are living with HIV/AIDS. Additional barriers include stigma, isolation, shame (especially among women) and fear of disclosure of HIV serostatus. SCSN participants also discussed that many immigrants are not aware of services available to them regardless of their immigrant status (legal or illegal). Participants remarked that many providers would not start medications for migrant or transient patients because they anticipate that they will not be able to be treated if and when they move to another location.

Case managers are often not familiar with immigration laws and are uncertain how to deliver services to immigrants regardless of their legal/illegal status.

Another barrier to receiving care is undocumented immigrants' fear of accessing services provided by the government. Immigrants, therefore, are often wary of the local health departments. SCSN participants felt that this was further complicated in some counties where the health department is the only provider of HIV care.

Women may become aware of services and be connected to care through prenatal and child health providers. Immigrant men, however, are not linked to care in this way and therefore represent a sub-population that would benefit from increased community outreach strategies.

SCSN participants felt that there needs to be a connection between immigrants and community leaders. For example, a representative to participate in local and state planning and focus groups would provide immigrants with representation on the planning council and community planning groups.

Potential strategies suggested to overcome these barriers include a resource hotline in various languages for immigrants to learn of social and legal assistance. The local health department needs to place an emphasis on building rapport with immigrant communities. Faith based prevention efforts could

be used as a tool to recruit community leaders to raise awareness of available services and mobilize people to connect with a care provider.

SCSN participants indicated that there is a need for provider education about transient high-risk populations so that they may anticipate periods of time when seasonal workers are prevalent in an area and plan outreach strategies in advance. If providers know where clients plan to go next, the provider can connect clients with organizations where they can receive care.

3. Youth

The SCSN participants noted an overall need for services including primary care, mental health, and HIV prevention education to be specifically tailored for adolescents. Additionally, there is a need for programs to help transition adolescents to adult care (also refer to section IV, Part D). While Maryland is a Title IV Youth Initiative grantee, the project consists of only two sites in Baltimore City and there is a need for tailored care statewide.

Participants suggested that barriers to care may exist because youth are not represented on Title I planning councils. Furthermore, limited daytime clinic hours are not conducive for high school students. SCSN participants noted that there is a lack of public media portraying youth PLWHA and that increasing visibility in the media may overcome barriers to testing, obtaining care and reducing stigma.

Participants indicated great need for primary care, mental health care, and HIV prevention education among youth sub-populations such as parenting youth, African American youth, substance abusing and/or homeless youth. There is also a need for expanded services for affected siblings and other family members in order to assist them in helping youth PLWHA. Other gaps in services for youth PLWHA include information on how to navigate the health system, health education, job training, mentoring and peer education.

Suggested methods for improving services for youth center on providing holistic services with increased availability to answer questions, provide referrals to care, and assist youth with developing their own skills. Increasing client advocacy and peer advocacy were also identified as strategies for transitioning youth PLWHA.

In order to improve the health of HIV-positive youth, SCSN meeting attendees recommend providing incentives to increase the number of youth providers that are both clinically trained and culturally competent. In addition, non-traditional clinic hours may make it easier for youth to access healthcare

and case management services and early prevention interventions to help prevent youth avoid high-risk behaviors.

4. HIV-infected Children (Pediatric Cases)

Needs specific to pediatric PLWHA include helping families deal with disclosure and helping children decide when it is the best time to disclose their HIV status. Participants expressed a need for more comprehensive assessments with regard to developmental and mental health needs of the whole family including caregiver support services.

Barriers to addressing these needs include lack of communication between the Department of Social Services, the school system and consumers with regards to the consumer's eligibility for services. SCSN participants noted that many parents perceive that the Department of Social Services and schools are not helpful and are therefore afraid to ask those organizations for assistance.

Strategies to bridge these gaps included providing caregiver support, and updated information on clinical issues and services in the community. SCSN participants noted that there are specific pediatric sub-populations especially in need of services, including: pre-adolescents, Latinos, African Americans, Asian Americans and immigrants.

Mechanisms discussed to implement these strategies included creating a database for providers to stay current on what is available for clients. This effort would require the involvement of other service providers (i.e. Social Services, Head Start). On-going HIV education for professionals (school teachers & administrators, nurses, doctors) should be mandated with an emphasis placed on maintaining a dialogue with the educational system. Sensitivity training for providers was also viewed as a priority to bridge service gaps and meet needs. This is especially necessary for emergency room providers and interns who may see clients on a one time or acute basis.

5. Recently-incarcerated

Identified needs for HIV/AIDS services and prevention with positives among the incarcerated focuses on three sub-populations: individuals currently incarcerated, those just entering the prison system, and those preparing to leave the prison system. The SCSN participants reported that access to proven prevention methods, including condom distribution during incarceration, is a need. Support systems for PLWHA are needed in incarcerated settings. The SCSN participants also recognized a need for

mandatory testing upon entry and proper medical attention. Improved coordination of transitional services, including primary medical care and medication continuity, is considered a significant need.

SCSN meeting attendees noted that perceptions of weakness and the fear of a breach of confidentiality prevent disclosure of HIV status while incarcerated. Lack of adequately trained staff in the penal institutions creates a setting in which these barriers are strengthened.

Strategies to address these service gaps include the visibility of case managers and representatives from community organizations “at the door of the jails” (pre-release and immediately upon release) to connect individuals with the services they will need. If more services and funding were available, holistic care could be possible for people transitioning in and out of the prison system. Better coordination between prison medical providers, case managers, and external service providers was also reported as a means to assist the recently incarcerated. Specific steps to implement this may include developing a guide for inmates with information regarding service providers and resources available post-release, along with a solid re-entry plan monitored by a case manager. In order to keep this population in the forefront of HIV/AIDS services planning, given that Maryland inmates represented 84 (3.9%) of new HIV cases and 83 (6.4%) of new AIDS cases in 2004, the SCSN attendees suggest requiring active involvement from the Maryland Department of Public Safety and Correctional Services in the Prevention Community Planning Group, the Title I Planning Councils, and the Title II Regional CARE Consortia.

6. Homeless Persons

Top needs reported for homeless PLWHA included the availability of permanent housing, life and employment skills, and treatment for other issues that may affect them, such as mental illness, substance abuse and lack of transportation. Sub-issues related to available housing include the need for proper storage of medication for HIV/AIDS prescriptions and other medications.

Among the significant barriers for homeless PLWHA is stigma. Landlords may not want to have HIV-positive tenants or tenants that have been homeless. Housing that is available may not meet codes and standards. Also, providers reported that staff working with this population often experience burnout due to limited resources. Staff turnover has a negative impact on the continuity of care provided to homeless individuals.

Strategies to address these gaps include increased staff training, especially training for case managers to properly assess a client’s readiness for housing in order to help place them. Additionally, training for case managers and landlords with regard to interaction between homelessness and HIV compared to

homelessness and other diseases (e.g., diabetes, etc.). Life-skills training for homeless persons was also identified as a strategy to improve access to services. Additional information is needed about opportunistic infections in order to bridge service gaps confronting homeless populations, especially homeless youth.

SCSN participants proposed that a consistent and meaningful definition of homelessness across all agencies, along with funding sources that focus on the person and not only the finances are necessary to help this population. Participants noted that homeless PLWHA should be represented on planning councils and in community forums to promote awareness of the issues facing this population and to also foster political empowerment among homeless PLWHA.

SCSN participants felt that it is necessary to educate the providers, funding sources, government, and community at large of the special needs of the homeless PLWHA population.

7. Pregnant HIV-Positive Women

SCSN participants identified the top needs for the pregnant HIV-positive women as HIV education, prenatal and HIV care referrals, and access to rapid HIV testing. Education pertaining to perinatal transmission for all providers and clients is needed along with referrals to appropriate care and specialists. There needs to be rapid HIV testing available in hospital labor and delivery units for all women presenting with an unknown HIV status. Hospitals must also have AZT and other drugs available to provide treatment once a woman with HIV disease presents for delivery. The SCSN attendees emphasized a need for HIV testing and care education for all pregnant women; training for obstetricians in HIV care, transmission and testing; enhanced access to substance abuse treatment for pregnant women; expanded efforts to identify HIV-positive pregnant women who are not under the care of a clinician; more pre-conception counseling for HIV positive women; expanded transportation in the counties; more bilingual capacity among obstetrical staff and; improved cultural competency among all staff working with HIV-positive pregnant women.

Participants suggested that perinatal HIV transmission is often a result of a lack of health insurance. Despite Maryland law that requires that all pregnant women be offered an HIV test, some private practices don't test their clients when they feel their clients are not at risk for HIV. HIV-positive pregnant women may be fearful of getting into care if they are actively using illegal drugs because they feel that they may have their baby away taken from them at delivery by the Department of Social Services. Women may be afraid to tell partners of their pregnancy or their HIV status, for fear of abandonment or violence.

Participants agreed that only a few Maryland delivery hospitals currently have rapid HIV testing and others do not have the necessary medications to help women who test positive during labor, delivery, or 3rd trimester appointments. SCSN participants recommend that to fill this gap all hospitals need appropriate tests and medications. Another service gap is that providers are not reaching individuals before they get pregnant. Strategies to address this include implementing pre-conception pregnancy counseling for all HIV-positive clients and providing trainings and formal resources for practitioners. For pregnant women who are HIV positive and substance abusers, there is a lack of adequate rehabilitation time for proper recovery. For these women, a strategy would be to implement a longer treatment time so clients can learn life skills, increased coping skills, obtain a GED, obtain job training and receive other holistic services paired with intensive case management.

Additionally, a statewide resource list or website would greatly assist clients in finding mental health counseling, medication assistance, transportation and childcare. This resource would be promoted in places such as the grocery stores, pharmacies, and other places pregnant women frequent.

8. Substance Abusers

SCSN participants identified top needs for substance abusing PLWHA included: long-term residential treatment facilities, education for providers and communities on substance abuse and other co-morbid conditions, and a statewide resource list to assist in making appropriate referrals.

Additional needs for this population include more accessible services in rural and other areas, decriminalization of substance abuse, and intensive case management. SCSN attendees also felt that care providers do not know where to go for information and resources. They do not know which facilities have treatment slots, and are in great need of capacity building. SCSN attendees reported that another barrier to care for substance abusers is the general misconception among communities that substance abuse can be corrected after a few days of detoxification, when instead it needs to be addressed as a “lifestyle change” in which the goal is life maintenance. Financial barriers exist as many treatment centers are private and cost too much money for average income people, especially medically underserved communities.

The overarching gap in service for this population is a need for more intensive case management for substance abuse clients and more extensive rehabilitation. This means more than just detoxification but also life skills training and holistic treatment. SCSN participants recommended the implementation of a website that individuals and organizations can access to see which treatment facilities provide various

services and also which centers may have open beds. This website would need to be updated daily to ensure accuracy.

SCSN participants noted that PLWHA substance abusers would greatly benefit if providers would actively link them to services that are effective in meeting consumers “where they are” in relation to their readiness for drug treatment. Additionally, longer treatment services are necessary to give clients an opportunity for success partnered with inter-agency collaborations that would help clients meet their needs.

9. Rural Populations

2006 SCSN participants reported that PLWHA in rural communities might not realize that there’s a place for them to get tested for HIV and receive HIV medical and support services. For many rural PLWHA, not knowing their status is a barrier to receiving care. Participants noted that many rural PLWHA find out their serostatus only when they are being hospitalized for something else, for example, an acute condition.

SCSN attendees reported that in order to break down barriers facing rural communities, there is a need for stronger partnership between private and public health care systems. Once stronger partnerships are established, care can be accessed more fluidly.

According to SCSN participants, rural PLWHA need to become more able to self-manage their own care. Participants feel that clients need to move away from depending on case managers and need to learn how to become more self-sufficient. It is especially difficult in rural regions because of stigma. With self-management, the client would need to take initiative to access care.

Participants described that in rural settings there is often a lack of an open PLWHA community. This is a “huge issue” as rural PLWHA feel they cannot disclose their HIV status to their family and friends and do not have any social support or peers. This lack of community and subsequent lack of support networks is also a barrier for youth PLWHA in rural areas.

SCSN participants confirmed that infectious disease providers who have specific training or experience in HIV are rare in rural areas. Participants believe that there need to be more incentives for specialized providers to serve rural communities. In addition to the lack of infectious disease providers in rural areas, there also needs to be more case management services especially for the Latino population and translator services for Spanish-speaking and deaf clients.

SCSN participants suggested that to reduce barriers and provide better care for rural communities, providers should network more and empower clients to be their own advocates. Local health departments should work to mobilize people, churches and community organizations to both provide and advocate for testing and education and encourage the formation of closer-knit communities to support residents.

10. Gay, Lesbian, Bisexual, Transgender and Questioning (GLBTQ) PLWHA

In order to serve the needs of GLBTQ individuals, SCSN participants felt that there needs to be more capacity building for community organizations, especially in rural communities. In addition, the participants felt that there is a great need for peer educators and support for organizations that train and manage peer educators. SCSN participants noted that greater visibility of peer educators would help people feel more comfortable with living with their disease and their sexual orientation. There is a lack of a support network because many GLBTQ and PLWHA keep both their disease and their sexual orientation to themselves for fear of stigma.

SCSN participants report that there is a large problem with stigma confronting this population. This stigma and also a lack of sensitivity and knowledge on the part of providers are barriers to care. According to SCSN participants, there are care providers that do not want to work with GLBTQ PLWHA.

Barriers confronting GLBTQ PLWHA include a lack of targeted resources and a lack of cultural sensitivity. These barriers may cause many people to become hidden within their community. SCSN participants feel that these barriers can be overcome when providers feel comfortable talking about sex and sexual orientation with their clients. Providers should ask clients questions so that clients do not need to initiate disclosure of their HIV status or sexual orientation in order to access information or case management services.

According to participants, GLBTQ clients often mistrust the healthcare system and are therefore hesitant to access care and disclose their HIV status, especially in rural regions. To overcome these barriers, participants report that providers need to help clients feel comfortable discussing sensitive issues with them. One way this may be accomplished is to tailor medical forms to be more inclusive of gender orientation and same sex partners/spouses' information. Additionally, SCSN participants commented that healthcare providers should be aware of other challenges facing clients that are GLBTQ. For example, if a client is transgender, it may be more difficult to get housing, which therefore makes it more difficult to manage their health and adhere to treatment.

One strategy to serve these populations suggested by SCSN participants is to establish a buddy system to help individuals navigate through the system, especially for youth. Additionally, funding is needed for community health centers to create advocacy programs that work specifically with GLBTQ PLWHA.

IX. CONCLUSION

The process used to develop the 2006 SCSN brought together a group of diverse individuals involved in HIV/AIDS services across the state. For many people living with HIV/AIDS, it was an opportunity to voice needs and concerns in order to influence the HIV care system. The process gathered information from a variety of perspectives and several funding streams and identified overarching themes related to emerging trends, critical gaps in services and special populations. In addition to representing different consumer and provider constituencies, SCSN participants represented all different regions of the state. The 2006 SCSN serves as a guide for the goals and objectives developed for the 2006-2008 Title II HIV Services Comprehensive Plan.

APPENDIX A: RESOURCE INVENTORY

ACCESS TO CARE QUALITATIVE STUDY

Department: MD AIDS Administration CSE

Purpose: Examine the factors that hinder HIV-positive patients promptly obtaining HIV testing and when positive, from entering medical care

Cycle: Completed in 2001

Respondents: 18

Method: One-on One Interview

Findings:

- ◆ Stigma and fear of being "found out" adversely affects going for HIV testing and entering medical care in a prompt manner
- ◆ Biggest barrier was that people didn't want to step foot in the clinic
- ◆ Need for public health education to normalize and humanize the HIV experience

BEHAVIORAL SURVEILLANCE STUDY

Department: MD AIDS Administration CSE

Purpose: To reduce high-risk behaviors related to the transmission of HIV among HIV-positive individuals.

Cycle: 1st Phase completed in 2005, In 2nd Phase

Respondents: 1,072, 899 used for analysis

Method: Interviews and Testing

Findings:

- ◆ 95%+ HIV tested
- ◆ One-third HIV positive
- ◆ Three-fifths of the positives were new cases
- ◆ Referred over 150 men to care
- ◆ Outcome: Prevention for Positives Initiative

CASE MANAGEMENT SURVEY

Department: MD AIDS Administration CSE

Purpose:

- ◆ Gain a better understanding of how CM functions and who is providing CM in the Ryan White Title II program
- ◆ What barriers impede the delivery and receipt of needed client services?

Cycle: Completed in 2004

Method: Survey

Findings:

- ◆ Typical caseload state: 42; Central: 52; Suburban: 10; Eastern: 19.3; Western: 21.8; Southern: 27.6
- ◆ Concerns their clients have: 93% Finances; 90.7% Housing; 79.1% Medicare/Medicaid/DA; 76% Transportation
- ◆ Needs not available: Housing, Substance Abuse Treatment
- ◆ Case Manager recommendations: Decrease paperwork; Increase personnel

CLIENT SATISFACTION SURVEY

Department: MD AIDS Administration CSE

Purpose: To understand HIV and AIDS clients' experience with the services of agencies

Cycle: Annual

Method: Survey

Respondents: 1,701 clients

Findings:

- ◆ 92.3% reported services- excl/good
- ◆ 78.6% treated like an individual
- ◆ 75.9% knows to make a complaint

COMMUNITY ASSESSMENT PROJECT

Department: MD AIDS Administration CSE

Purpose: Gain an understanding of the social environment in Northwest Baltimore City, an area hit hardest by the epidemic

Cycle: Completed in 2001

Method: One-on One Interview

Findings:

- ◆ People have too many other concerns
- ◆ Stigma and denial keep people from getting tested
- ◆ HIV positive people are not accessing care and are not reducing transmission risks

CONGRESSIONAL BLACK CAUCUS/ MINORITY AIDS INITIATIVE REPORT

Department: MD AIDS Administration HS/CSE

Purpose: Increase minority enrollment into two of Maryland's pharmacy assistance programs

Cycle: Annual

Method: Tracking Forms

Findings: FY2004: completed 128 MADAP applications. Of those, 35 (27%) MADAP applications were accepted.

Additionally, 94 clients were on MPAP, and 86 clients were enrolled in Medicaid

CO-OCCURRING MENTAL HEALTH AND SUBSTANCE ABUSE PROVIDER SURVEY SUMMARY

Department: Wicomico County

Purpose:

- ◆ Assess current resources for those with co-occurring disorders
- ◆ Identify service gaps, unmet needs and barriers to appropriate service for those with co-occurring disorders
- ◆ Consider suggestions for improvement of services to those with co-occurring disorders

Cycle: Completed

Respondents: 19 providers

Method: Survey

Findings:

- ◆ Programs providing addictions services are almost twice as likely as programs providing mental health services to provide co-occurring services to their clients
- ◆ The provision of addictions services was more equally split between private and public providers than was true for mental health services where 89% of providers were private
- ◆ Medical Assistance reimbursements accounted for less than 30% of funding. More than 50% of mental health funding comes from Medical Assistance reimbursements.
- ◆ General area of professional qualifications and availability is a top concern among respondents

DOES THE PRESENCE OF A CURRENT PSYCHIATRIC DISORDER IN AIDS PATIENTS AFFECT THE INITIATION OF ANTIRETROVIRAL TREATMENT AND DURATION OF THERAPY?

Department: JHU- Seth Himelhoch, MD, MPH, et al.

Purpose: Investigate whether a current psychiatric disorder: 1) affected the time to initiation of HAART, 2) predicted the likelihood of being prescribed HAART for at least 6 months, and 3) affected survival in urban AIDS patients.

Cycle: Completed

Respondents: 549 patients

Method: Retrospective Cohort study

Findings: Patients with a psychiatric disorder were 37% more likely to receive HAART, had greater than twice the odds of being prescribed HAART for at least 6 months, and were 40% more likely to survive as compared with those without a psychiatric disorder

ENHANCED PERINATAL SURVEILLANCE

Department: MD AIDS Administration CSE

Purpose: Identify areas of missed opportunities in the cascade of services that should be provided to HIV positive pregnant women to eliminate perinatal HIV transmission

Cycle: Completed in 2005

Respondents: 318

Method: Birth registry match; Chart reviews

Findings:

- ◆ Missed opportunities: CTR & PNC
- ◆ Women who begin PNC early & have routine visits t/o pregnancy have more chance to hear educational info that can help them determine if they are at risk for HIV
- ◆ Frequent monitoring of high-risk women through PNC allows providers to provide ART or preventative drugs
- ◆ Mothers of HIV- infants were more likely to receive ART during pregnancy/labor and more likely to initiate PNC during the 1st trimester

EPIDEMIOLOGICAL DATA

Department: MD AIDS Administration CSE

Cycle: Quarterly

Method: Surveillance

HOSPITAL DISCHARGE DATA

Department: MD AIDS Administration CSE

Purpose: To identify pockets of people not in care

Cycle: Continuous

Method: Analysis of hospital administration records

Findings:

- ◆ Rates of PCP were highly concentrated in Baltimore City
- ◆ Outcome: Set up intervention at University of MD reaching out to those with PCP diagnosis

LANGUAGE BARRIERS TO CARE STUDY

Department: MD AIDS Administration CSE

Purpose: To learn what kinds of language services are available for HIV patients throughout Maryland

Cycle: Completed in 2001

Method: Survey of all Title II programs; 35 responded

Findings: One third of agencies provide no language services and for those agencies that do provide services, Spanish is the most frequently provided language service

MADAP CLIENT SURVEY

Department: MD AIDS Administration CS/CSE

Purpose: Assess client satisfaction with MADAP

Cycle: Two years, Completed in 2004

Respondents: 704

Method: Survey

Findings:

- ◆ 71% clients rate MADAP as an excellent program
- ◆ 25% rate it as good/above average

MEDICAL RECORD REVIEWS

Department: MD AIDS Administration CSE

Purpose: Convenient sample to access quality of care and services not received

Cycle: Continuing

Method: Chart review

PRC COMMUNITY HEALTH ASSESSMENT

Department: Peninsula Regional Medical Center & The Somerset, Wicomico, and Worcester County Health

Purpose:

- ◆ Determine the health status, behaviors and needs
- ◆ To improve residents' health status, increase their life spans, and elevate their overall quality of life
- ◆ To reduce the health disparities among residents

- ◆ To increase accessibility to preventive services for all community residents

Cycle: Completed in 2004

REGIONAL CONSORTIA MEETINGS

Department: MD AIDS Administration HS

Cycle: Quarterly

REPORT ON THE SURVEY OF HIV PREVENTION IN MARYLAND HIV CARE SETTINGS 2004

Department: MD AIDS Administration Prevention

Purpose: Identify the strengths; weaknesses, and needs of MD HIV providers in the delivery of HIV prevention interventions targeting HIV infected persons

Cycle: Completed in 2004

Method: Survey and phone interviews of staff

2006 MARYLAND STATEWIDE COORDINATED STATEMENT OF NEED SURVEY

Department: MD AIDS Administration

Purpose: Conduct a statewide assessment of needs and barriers and evaluate availability of services

Cycle: Completed in 2005

Respondents: 56

Method: Survey

Findings:

- ◆ Type of care most difficult to access: Housing
- ◆ Greatest needs: Housing, Primary Care, Transportation, Case Management and Client Advocacy, and Dental Care
- ◆ Barriers to care: Transportation, Concerns about Privacy, Mental Health Co-Morbidity

SUPPLEMENT TO HIV AND AIDS SURVEILLANCE

Department: MD AIDS Administration CSE

Purpose: Collected supplemental descriptive information for persons with HIV infection.

Cycle: Completed (at Chase Brexton, Eastern Shore & Prince George's County)

Method: Cross-sectional, 45-60 min. 1-on-1 interviews

Findings:

- ◆ Patients continue to engage in risky behaviors, even after testing HIV+ and entering care
- ◆ Patient awareness about details of their HIV disease is mixed
- ◆ 95% said their doctor had talked to them about resistance, but only 69% said they were fully adherent with their HIV meds in the past month

SUBSTANCE ABUSE AND HIV NEEDS ASSESSMENT

Department: MD AIDS Administration HS

Cycle: Completed

Method: Survey

Findings: Unmet Needs & Recommendations

Funding (Transportation, Child care, Enhanced services, Family services, Housing, RW slots, Higher reimbursement rate, Specialty care)

Linkages: Treatment programs, F-U, Primary care, Special needs, Recovery house, Enhanced services

SUBURBAN YEAR 15+16 PLANNING PUBLIC INPUT

Department: Suburban Regional Planning Group

Cycle: Annual

Method: Public Input

TITLE I 2004 CONSUMER SURVEY

Department: InterGroup Services, Inc

Purpose: Determine what services consumers felt they needed, were needs being met, and what barriers consumers encountered when trying to access services

Cycle: Annual

Respondents 609

Method: Interview Administered Survey

Findings:

- ◆ Percentage of Clients' needs NOT met: Hospice (84%), Home (75%), Legal (75%), Day/Respite-Child 6+ (63%) Adult (60%), Transl. (62.5%)
- ◆ Insufficient consumer knowledge of available services serves as a greater barrier to care than any other barrier

TITLE I 2005 CONSUMER KNOWLEDGE SURVEY

Department: InterGroup Services, Inc

Purpose: Follow up to the 2004 Consumer Survey, which found that insufficient consumer knowledge of available services served as a greater barrier than any other barrier

Cycle: Annual

Respondents 422

Method: Anonymous interviews

Findings:

- ◆ Insufficient knowledge of available services plays a significant role in consumers' inability to access care. (13.5% needed a service they didn't know was available)
- ◆ Services needed, not received, and didn't know: Oral, DEFA, & Legal
- ◆ Knowledge gap is greater for support services
- ◆ 11% of those interviewed had never heard of Ryan White programs
- ◆ The average time between receipt of a positive test result & consistent participation in primary medical care is 2.5 years

TITLE 1 CONSUMER SURVEY TREND ANALYSIS 1998-2004

Department: InterGroup Services, Inc

Purpose:

- ◆ Analyze the utilization of HIV/AIDS-related services in and around Baltimore
- ◆ Determine the frequency with which residents of one EMA jurisdiction cross into another EMA jurisdiction to receive services

Cycle: Annual

Method: Service utilization data submitted by service providers

TITLE 1 SERVICE UTILIZATION IN THE BALTIMORE EMA

Department: InterGroup Services, Inc

Purpose:

- ◆ Analyze the utilization of HIV/AIDS-related services in and around Baltimore
- ◆ Determine the frequency with which residents of one EMA jurisdiction cross into another EMA jurisdiction to receive services

Cycle: Annual

Method: Service utilization data submitted by service providers

Findings:

- ◆ Relatively few of the single-provider clients residing in the suburban jurisdictions sought services inside Baltimore City
- ◆ Inter-jurisdictional movement by multiple-provider clients seemed much higher
- ◆ Single-provider clients were in slightly better health than multiple-provider clients (they were slightly less likely to have progressed to AIDS-defined status)
- ◆ Multiple-provider clients were in need of more specialized care, some of which is available only in Baltimore City

TITLE IV YOUTH LIFE SKILLS SURVEY

Department: MD AIDS Administration HS/CSE

Purpose: Assess what information and knowledge members of the CAB would most like to gain while participating in the CAB

Cycle: Completed in 2005

Respondents: 8

Method: Survey

Findings:

- ◆ 85% of respondents said they felt somewhat or very ready to begin receiving care at adult clinic
- ◆ Respondents suggested having a mentor or another CAB member attend appointments with an adolescent in transition

TITLE IV YOUTH CAB FOCUS GROUP

Department: MD AIDS Administration HS/CSE

Purpose: Identify what the CAB has gained from participating and ascertain needed skill & resource to better transition into adult care

Cycle: Completed in 2005

Respondents: 10

Method: Focus group

Findings:

- ◆ Identify key mentors
- ◆ Address basic needs of youth

WHITMAN WALKER CLINIC SURVEY

Department: Whitman Walker

Purpose:

- ◆ Obtain gen. info re: WWC clients in MD/VA
- ◆ Identify clients' intentions for alt service sites

Cycle: Completed

Respondents: 250

Method: Telephone Survey

Findings:

- ◆ 87% of Respondents were aware of the closing of WWC.
- ◆ 72% were planning to try to get services through the clinic in DC, 11% were not planning to get services in the DC site, and 17% were not sure

APPENDIX B: ALPHABETICAL LIST OF PARTICIPANTS OF THE 2006 SCSN MEETING

Yohannes Abaineh, People's Community Health Center
Linda Anders, Maryland AIDS Administration
Wes Andrews, Western Region Title II CARE Consortia
Deborah Anne, Frederick County Health Department
Josephine Ansah, D.C. Department of Health, HIV/AIDS Administration
Sheila Ashley, Baltimore Title I Planning Council
Jeanne Aydelotte, Talbot County Health Department
Pat Balducci, Harford County Health Department
Carrie Baum, Maryland AIDS Administration
Patti Beauchamp, Somerset County Health Department
Karen Bellesky, Chase Brexton Health Services
Jack Bonner, Johns Hopkins Psychiatry
Evelyn Bradley, Intergroup Services, Inc.
Dale Brewer, Park West Medical Center
Kate Briddell, Baltimore Homeless Services, Inc.
Ralph Brisueno, Baltimore City Health Department, Division of Health Promotion and Disease Prevention
Jody Buechler, Baltimore County Health Department
Denise Burke, Prince George's County Health Department
Beth Bush, Dorchester County Health Department
Hope Cassidy-Stewart, Maryland AIDS Administration
Kip Castner, Maryland AIDS Administration
Phillipe Chilliade, Whitman Walker Clinic
Phil Clemmey, UMBC-Dept of Psychology
Eric Cvetnik, Garrett County Health Department
Barbara Davis, Project Access, BCHD
Barbara Davis, Montgomery County Department of Health and Human Services
Iris Davis, Baltimore Title I Planning Council
Carlo DiClemente, UMBC-Dept of Psychology
Lillian Donnard, Glenwood Life Counseling Center
Penny Doty, Dorchester County Health Department
Nathalia Drew, Maryland AIDS Administration
Pam Dudek, Baltimore County Health Department
Jonathan Ellen, MD, Johns Hopkins University, Intensive Primary Care Clinic
John Farley, MD, University of Maryland School of Medicine, Department of Pediatrics, Division of Immunology
Linda Fenlon, Charles County Health Department
Colin Flynn, Maryland AIDS Administration
Linda Frank, University of Maryland, Adult HIV Program
Stephen Freeman, The League for Persons with Disabilities
Kristie H. Gittere, Good Samaritan Hospital, Center for Primary Care
Bryna Grant, Maryland AIDS Administration
Lenny Green, JHU School of Public Health Project SELF
Henry Gregory, UMBC-Dept of Psychology
Kate Hale, Intergroup Services, Inc.
Phyllis Hall, Baltimore County Health Department
Robin Hamlett, Central Region CARE Consortia Co-Chair
Debra Hickman, Sisters Together and Reaching
Lance Hogue, FreeLance Medical Consultants
Melissa Huber, Cecil County Health Department

Nancy Hutton, MD, Johns Hopkins University, Intensive Primary Care Clinic
Marilyn Jews, Park West Medical Center, Inc., Hidden Garden
Lynne Johnson, Black Mental Health Alliance
Jacq Jones, Maryland AIDS Administration
Hazel Jones-Parker, University of Maryland, Adult HIV Program
Lynn Kane, Allegany County Health Department
Jean Keller, Johns Hopkins University, OB/GYN Services
Jeanne C. Keruly, Johns Hopkins University School of Medicine, Adult Infectious Disease
Christopher King, Greater Baden Medical Services
Indira Kotval, Project PLASE
Cyd Lacanienta, Intergroup Services, Inc.
Valerie Lareska, Caroline County Health Department
Mercedes Lawrence, Prince George's County Health Department
Joyce Levy, Queen Anne's County Health Department
Bonnie Lewis, Caroline County Health Department
Elisabeth Liebow, Regional Perinatal Advisory Group
Christine Lim, Maryland AIDS Administration
Richard Matens, Baltimore City Health Department, Division of Health Promotion and Disease Prevention
Kabibi Matthews, Sisters Together and Reaching
Mary Lou Mazzuca, Howard County Health Department
Maryellen McManus, Anne Arundel County Health Department
Timothy M. Meagher, Eastern Region Title II CARE Consortia Co-Chair
Marissa Medrano, Kent County Health Department
Valli Meeks, University of Maryland Dental School
Awilda Mendez, University of Maryland, IHV
Wendy Merrick, Total Health Care
Debbie Middleton, Carroll County Health Department
Dan Mills, Dorchester Department of Social Services
Karol Moen, Montgomery County Department of Health and Human Services
Mary Adda Moore, Kent County Health Department
Tiffany Moritz, University of Maryland, Adult HIV Program, Evelyn Jordan Center
Lyn Nasir, UMB School of Medicine, Department of Pediatrics, Division of Immunology;
Leo Ortega, Health Education Resources Organization
Christian Pelucia, Suburban Region Title II CARE Consortia
Ligia Peralta, MD, University of Maryland, Adolescent Services
Deanne Phelps, BCHD- STD Program
Jessica Pollak Kahn, Maryland AIDS Administration
Renee Powell, Wicomico County Health Department
Stephanie Pons, University of Maryland at Baltimore
Wendy Potts, Maryland AIDS Administration
Ann Price, Maryland AIDS Administration
Glen C. Pruitt, Delaware HIV Consortium
Devi Ramey, Prince George's County Health Department
Rosemary Ramroop, Johns Hopkins OB/GYN
Melanie Reese, Baltimore Title I Planning Council

Dionna Robinson, AIDS Administration
Debbie Rock, Chair, Baltimore Title I Planning Council, c/o Intergroup Services
Jamie Rogers, Johns Hopkins University, Intensive Primary Care Clinic
Susan Rucker, Johns Hopkins University, School of Medicine, Adult Infectious Disease
Walter Samuel, Baltimore Title I Planning Council
Dale Schacherer, Montgomery County Department of Health and Human Services
Raymond Shattuck, Baltimore Title I Planning Council
Madeleine Shea, Maryland AIDS Administration
Krupe Shinde, Health Education Resources Organization
Brian Shird, Central Region Title II CARE Consortia Co-Chair
Lt. Ivy Simmons, People's Community Health Center
Mary Slicher, Project PLASE
Barbara Smith, Chair, Metropolitan Washington Regional Health Services Planning Council
Laurence Smith, Suburban Consortia Co-Chair
Lynda Smith, Black Mental Health Alliance
Debra Stevens, Worcester County Health Department
Jami Stockdale, Maryland AIDS Administration
Jamie Storm, Charles County Health Department

Jenny Taylor-Gray, Washington County Health Department
Lydia Temoshok, University of Maryland, IHV
Vicki Tepper, Department of Pediatrics, Division of Immunology; UMB School of Medicine
Erika Terl, Maryland AIDS Administration
Carnell Thomas, Jr., Baltimore City Planning Council
Julius Thompson, United Community Ministries Eastern Shore Services
Naomi Tomoyasu, Maryland AIDS Administration
Louise Treherne, Health Care for the Homeless
Glenn Treisman, JHU Psychiatry
Lisa Waddell, People's Community Health Center
Rebecca Wald, University of Maryland, IHV
Trammell Walters, D.C. Department of Health, HIV/AIDS Administration
Angela Williams, Title IV Youth Initiative JHU Advocate
Gail Williams-Glasser, Associated Black Charities
Alt Vance Williams-Statts, Good Samaritan Hospital, Center for Primary Care
Alicia Wright, Southern CARE Consortia Chair
Joan Wright-Andoh, Prince George's County Health Department
Mary Yancy, Queen Anne's Health Department
Ernest Young, Family Health Centers of Baltimore
Gwendolyn Young, Family Health Centers of Baltimore

APPENDIX C: REGIONAL EPIDEMIOLOGICAL NARRATIVES

CENTRAL REGION

Maryland AIDS cases and symptomatic HIV cases are reported to the health department by health care providers and facilities. HIV positive test results are reported by all laboratories licensed to perform HIV tests in Maryland. HIV data are available only for those tested since 1994, when HIV surveillance began. HIV and AIDS incident cases are not necessarily mutually exclusive since HIV cases may have progressed to AIDS during the presented time period. HIV and AIDS prevalent cases are mutually exclusive categories; therefore, HIV prevalent cases are only those cases that have not developed AIDS. Due to the delay in case reporting, the data presented here describe all cases diagnosed through December 31, 2003 as reported through March 31, 2005. It is estimated that over 90% of cases had been reported by this date. Exposure information for reported HIV cases in Maryland is incomplete at present, however follow-up investigations are currently being conducted and this information will be more complete in the future.

The number of incident (new) AIDS cases diagnosed within each quarterly period in the Maryland Title II Central Region (Baltimore City and Anne Arundel, Baltimore, Carroll, Harford, and Howard Counties) increased through 1995 to a high of around 350 cases per quarter, with an artificial rise around 1993 due to changes in the AIDS case definition. The number of deaths among AIDS cases also increased through 1995, to a high of 269 in the first quarter of 1995. Beginning in 1996 and coincident with the introduction of protease inhibitor therapy, there was a substantial decline in both the number of new cases of AIDS (to 195 in the fourth quarter of 2003) and in deaths among AIDS cases (to 148 in the fourth quarter of 2003). The number of deaths among AIDS cases declined initially at a faster rate than the number of new AIDS cases per year, resulting in a slow increase in the number of people living with AIDS each year (prevalence). However, the decrease in AIDS deaths stopped in 1998 and the number of deaths per quarter has been stable since then. The number of new HIV cases reported each quarter has been decreasing since surveillance began in 1994 (to 294 in the fourth quarter of 2003).

The total number of living HIV cases (reported since 1994) and AIDS cases has been steadily increasing. There were a total of 16,928 living HIV and AIDS cases in the Maryland Title II Central Region as of December 31, 2003, of which 9,583 (57%) were HIV cases and 7,345 (43%) were AIDS cases. Sixty-two percent of all living HIV and AIDS cases in Maryland were residents of the Central Region at time of diagnosis. Of the cases in the Central Region, 80% were residents of Baltimore City and 10% of Baltimore County.

Central Region living HIV and AIDS cases are predominantly African-American (84%), male (63%), and middle-aged; 70% of cases are 30-49 years old. The percentage of female cases has remained steady over time at 38% of new HIV cases. The percentage of African-American cases has also remained steady over time at 83% of new HIV cases. The percentage of cases aged 40-49 at time of diagnosis has also risen to 35% of new HIV cases in 2003.

Until 1989, men who have sex with men (MSM) was the most common mode of HIV transmission for AIDS cases, however, since that year injection drug use (IDU) has comprised the highest percentage. In 1997, heterosexual contact with a partner who has or is at risk for HIV (HetSexPR) also surpassed MSM to become the second most common mode of transmission. These trends are also reflected in the exposure categories for HIV cases, where IDU and HetSexPR are the most common categories, followed by MSM and the additional category of heterosexual contact with a partner of indeterminate risk for HIV (HetSexPI), which is not recognized by CDC for AIDS cases.

Forty-nine percent of all living HIV and AIDS cases with known transmission risk report injection drug use (IDU), 24% report heterosexual contact with a partner who has or is at risk for HIV (HetSexPR), and 17% report men who have sex with men (MSM) as mode of exposure. Injection drug use is the predominant mode of exposure reported among both men and women in the Central Region.

EASTERN SHORE

Maryland AIDS cases and symptomatic HIV cases are reported to the health department by health care providers and facilities. HIV positive test results are reported by all laboratories licensed to perform HIV tests in Maryland. HIV data are available only for those tested since 1994, when HIV surveillance began. HIV and AIDS cases are mutually exclusive categories; therefore HIV cases in this profile are cases that have not yet developed into AIDS. Due to the delay in case reporting, this profile describes all cases diagnosed through December 31, 2003 as reported through March 31, 2004. It is estimated that these data are over 90% complete.

The number of incident (new) AIDS cases diagnosed within each year increased through 1995, with an artificial rise around 1993 due to changes in the AIDS case definition. The number of deaths among AIDS cases also increased through 1995. Beginning in 1996 and coincident with the introduction of protease inhibitor therapy, there has been a substantial decline in both the number of new AIDS cases (to 29 in 2002) and in deaths among AIDS cases (to 19 in 2002). The number of deaths among AIDS cases declined at a faster rate than the number of new AIDS cases per year, resulting in a slow increase

in the number of people living with AIDS each year (prevalence). Since the number of new HIV cases reported each year has been increasing, the total number of living HIV cases (reported since 1994) and living AIDS cases has been steadily increasing.

There were a total of 706 living HIV and AIDS cases in the Maryland Title II Eastern Region (Caroline, Cecil, Dorchester, Kent, Queen Anne's, Somerset, Talbot, Wicomico, and Worcester Counties) as of December 31, 2002. Of these 710 living cases in the Eastern region, 390 (55%) were HIV cases and 320 (45%) were AIDS cases. Of all reported HIV/AIDS cases in Maryland, 3% were residents of the Eastern Region at time of diagnosis. Of the cases reported in the Eastern Region, 32% were residents of Wicomico County and 14% were residents of Dorchester County.

Eastern Region HIV/AIDS cases are predominantly African American (63%), male (65%), and middle-aged - 71% of cases are 30-49 years old (Table 1). The percentage of female AIDS cases has increased slightly over time, while the percentage of female HIV cases has remained relatively constant. The percentage of African-American cases in the Eastern region has increased, and became the largest racial/ethnic group in 1995. The percentage of AIDS cases age 40-49 at diagnosis has been increasing and surpassed age group 30-39 to become the largest percent of new AIDS cases in 2002. The percentage of HIV cases age 40-49 has also been increasing since 1994, though there has been some decline in 2002 as age group 30-39 became once again the largest percent of new HIV cases.

Heterosexual contact with a partner who has or is at risk for HIV (HetSexPR) has represented increasing proportions of all new AIDS cases in the Eastern region and is currently the most common mode of HIV transmission. Similarly, HetSexPR is reported as the mode of transmission for the majority of new HIV cases in the Eastern region. Twenty-eight percent of all living AIDS cases are MSMs, 24% are IDUs, and 21% report heterosexual contact with a partner who has or is at risk for HIV (HetSexPR). Two sexual contact categories account for the majority of living HIV cases (45% MSM and 45% heterosexual contact with a partner who has or is at risk for HIV (HetSexPR), while 10% represent IDUs.

Thirty four percent of all living HIV and AIDS cases with known transmission risk report heterosexual contact with a partner who has or is at risk for HIV (HetSexPR), 30% are men who have sex with men (MSM), and 26% are injection drug users (IDUs).

SOUTHERN REGION

Maryland AIDS cases and symptomatic HIV cases are reported to the health department by health care providers and facilities. HIV positive test results are reported by all laboratories licensed to perform HIV tests in Maryland. HIV data are available only for those tested since 1994, when HIV surveillance began. For the purposes of this profile, HIV and AIDS cases are mutually exclusive categories; therefore, HIV cases include only those cases that have not developed AIDS. Due to the delay in case reporting, this profile describes all cases diagnosed through December 31, 2003 as reported through March 31, 2005. It is estimated that over 90% of cases have been reported by this date. Exposure information for reported HIV cases in Maryland is incomplete at present, however, follow-up investigations are currently being conducted and this information will be more complete in the future.

The number of incident (new) AIDS cases diagnosed within each year increased through 1996. There was an artificial rise in 1993 due to changes in the AIDS case definition (Figure 1). The number of deaths among AIDS cases also increased through 1995. Beginning in 1996 and coincident with the introduction of protease inhibitor therapy, there has been a decline in both the number of new cases of AIDS (to 19 in 2003) and in deaths among AIDS cases (to 9 in 2003). The number of deaths among AIDS cases declined at a faster rate than the number of new AIDS cases per year, resulting in a slow increase in the number of people living with AIDS each year (prevalence). The number of new HIV cases each year in the Southern Region increased since surveillance began in 1994 to 2000, and then decreased in 2001 (to 24 cases in 2001) and 2002 (to 21 cases in 2002). Overall, the total number of living HIV cases (reported since 1994) and AIDS cases has been steadily increasing (Figure 2).

There were a total of 329 living HIV and AIDS cases in the Southern Region (Calvert, Charles, and St. Mary's Counties) as of December 31, 2003, of which 172 (52%) were HIV cases and 157 (48%) were AIDS cases. One percent of all living HIV and AIDS cases in Maryland were residents of the Southern Region at time of diagnosis. Of the cases in the Southern Region, 58% were residents of Charles County, 22% of Calvert County and 20% of St. Mary's County (Figure 3).

Southern Region HIV and AIDS living cases are predominantly African American (66%), male (61%), and 30-49 years old (77%) (Table 1). The percentage of newly diagnosed female AIDS cases has decreased slightly over time (Figure 4). Following a period of apparent decline, the percentage of newly diagnosed female HIV cases rose substantially in 2000. The percentage of African-American HIV and AIDS cases has generally increased over time, and African Americans have been the predominant racial/ethnic group newly diagnosed with HIV/AIDS since 1994 (Figure 5). Notably, in 1999, there was a sharp increase in the percentage of newly diagnosed African-American HIV cases. Since 1988, 30-39 year olds have

consistently represented the highest proportion of new AIDS cases in Southern Maryland. In 1999 and in 2003, there were sharp increases in the percentage of 40-49 year old AIDS cases. The percentage of new HIV cases among 20-29 year olds has steadily increased over time until a sharp decline in 2000. Heterosexual contact with a partner who has or is at risk for HIV (HetSexPR) has represented increasing proportions of all new AIDS cases and is currently the most common mode of HIV transmission in the Southern Region (Figure 7). Thirty-five percent of all living AIDS cases in the Southern Region report HetSexPR as the mode of transmission, 31% are men who have sex with men (MSM), and 16% are injection drug users (IDU) (Figure 8). The two heterosexual contact categories account for the majority of living HIV cases (50% HetSexPR and 7% heterosexual contact with a partner of indeterminate risk (HetSexPI)). Of all living HIV cases, 16% are MSM and 16% are IDUs.

SUBURBAN REGION

Maryland AIDS cases and symptomatic HIV cases are reported to the health department by health care providers and facilities. HIV positive test results are reported by all laboratories licensed to perform HIV tests in Maryland. HIV data are available only for those tested since 1994, when HIV surveillance began. HIV and AIDS incident cases are not necessarily mutually exclusive since HIV cases may have progressed to AIDS during the presented time period. HIV and AIDS prevalent cases are mutually exclusive categories; therefore, HIV prevalent cases are only those cases that have not developed AIDS. Due to the delay in case reporting, the data presented here describe all cases diagnosed through December 31, 2003 as reported through March 31, 2003. It is estimated that over 90% of cases had been reported by this date. Exposure information for reported HIV cases in Maryland is incomplete at present, however follow-up investigations are currently being conducted and this information will be more complete in the future.

The number of incident (new) AIDS cases diagnosed within each quarterly period in the Maryland Title II Suburban Region (Montgomery and Prince George's Counties) increased through 1995, with an artificial rise around 1993 due to changes in the AIDS case definition. The number of deaths among AIDS cases also increased through 1995. Beginning in 1996 and coincident with the introduction of protease inhibitor therapy, there was a substantial decline in both the number of new cases of AIDS (to 120 in the fourth quarter of 2003) and in deaths among AIDS cases (to 19 in the fourth quarter of 2003). The number of deaths among AIDS cases declined initially at a faster rate than the number of new AIDS cases per year, resulting in a slow increase in the number of people living with AIDS each year (prevalence). However, the decrease in AIDS deaths stopped in 1998 and the number of deaths per quarter has been stable

since then. The number of new HIV cases reported each year has been generally increasing since surveillance began in 1994 (to 116 in the fourth quarter of 2003).

The total number of living HIV cases (reported since 1994) and AIDS cases has been steadily increasing. There were a total of 6,128 living HIV and AIDS cases in the Maryland Title II Suburban Region as of December 31, 2003, of which 2,983 (49%) were HIV cases and 3,145 (51%) were AIDS cases. Twenty-two percent of all living HIV and AIDS cases in Maryland were residents of the Suburban Region at time of diagnosis. Of the cases in the Suburban Region, 67% were residents of Prince George's County and 33% of Montgomery County.

Suburban Region living HIV and AIDS cases are predominantly African-American (78%), male (62%), and middle-aged; 42% of cases are 30-39 years old. The percentage of female cases has increased steadily over time to 41% of new HIV cases and 34% of new AIDS cases in 2003. The percentage of African-American cases has also been increasing, to 85% of new AIDS cases in 2003. The age group 30-39 year olds have consistently represented the highest proportion of new HIV and AIDS cases in Suburban Maryland.

Men who have sex with men (MSM) had been the most common exposure category for new AIDS cases since the beginning of the epidemic. However, the proportion of new AIDS cases due to injection drug use (IDU) and heterosexual contact with a partner who has or is at risk for HIV (HetSexPR) have been steadily increasing to where heterosexual contact has become the most common exposure category for new AIDS cases. Additionally, heterosexual contact categories have been the most common reported exposure for new HIV cases. The leading exposure category for new HIV cases has been the additional category of heterosexual contact with a partner of indeterminate risk for HIV (HetSexPI), which is not recognized by CDC for AIDS cases.

The two heterosexual contact categories account for the majority of living HIV/AIDS cases (36% HetSexPR and 9% HetSexPI) followed by 32% reporting men who have sex with men (MSM) and 18% report injection drug use (IDU). "Men who have sex with men" is the predominant mode of exposure reported among men while it is heterosexual contact for women in the Suburban Region.

WESTERN REGION

Maryland AIDS cases and symptomatic HIV cases are reported to the health department by health care providers and facilities. HIV positive test results using a non-name based unique identifier are reported by all laboratories licensed to perform HIV tests in Maryland. HIV data are available only for those tested since 1994, when HIV surveillance began. HIV and AIDS incident cases are not necessarily mutually exclusive since HIV cases may have progressed to AIDS during the presented time period. HIV and AIDS prevalent cases are mutually exclusive categories; therefore, HIV prevalent cases are only those cases that have not developed AIDS. Due to the delay in case reporting, the data presented here describe all cases diagnosed through December 31, 2003 as reported through March 31, 2005. It is estimated that over 90% of cases had been reported by this date. Exposure information for reported HIV cases in Maryland is incomplete at present, however follow-up investigations are currently being conducted and this information will be more complete in the future.

The number of incident (new) AIDS cases diagnosed each year in the Maryland Title II Western Region (Allegany, Frederick, Garrett, and Washington Counties) increased through 1995, with an artificial rise around 1993 due to changes in the AIDS case definition. The number of deaths among AIDS cases also increased through 1995. Beginning in 1996 and coincident with the introduction of protease inhibitor therapy, there was a decline in both the number of new cases of AIDS (to 29 in 2003) and in deaths among AIDS cases (to 11 in 2003). The number of deaths among AIDS cases declined at a faster rate than the number of new AIDS cases per year, resulting in a slow increase in the number of people living with AIDS each year (prevalence). There has been a slight increase recently in the number of new AIDS cases in Western Maryland. The number of new HIV cases diagnosed in Western Maryland each year has been increasing since surveillance began in 1994 (to 35 in 2003). In the state of Maryland, however, the number of newly diagnosed HIV cases has been slightly declining over time. The number of deaths among HIV cases in Western Maryland has remained low and stable since 1994.

The total number of living HIV cases (reported since 1994) and AIDS cases has been steadily increasing. There were 480 living HIV and AIDS cases in the Maryland Title II Western Region as of December 31, 2003, of which 270 (56%) were HIV cases and 210 (44%) were AIDS cases. Two percent of all living HIV and AIDS cases in Maryland were residents of the Western Region at the time of diagnosis. Of the cases in the Western Region, 43% were residents of Frederick County and 46% of Washington County.

Living HIV and AIDS cases in the Western Region of Maryland are predominantly white (62%), male (74%), and middle-aged (71% of cases are 30-49 years old). The percentage of female cases has remained steady over time. The percentage of African-American cases has been increasing over time.

"Men who have sex with men (MSM)" is the most common mode of transmission reported by living HIV and AIDS cases in Western Maryland. Heterosexual contact with a partner who has or is at risk for HIV (HetSexPR) has represented an increasing proportion of all new HIV and AIDS cases. MSM was the predominant mode reported by males living with HIV/AIDS whereas HetSexPR was the predominant mode reported by females living with HIV/AIDS.