**REPORT OF THE TASK FORCE ON AIDS ON** 

Development of Comprehensive HIV/AIDS Plan Pursuant to HJR 436

TO THE GOVERNOR AND THE GENERAL ASSEMBLY OF VIRGINIA



# **HOUSE DOCUMENT NO. 17**

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House Joint Resolution 436

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### **GUIDING PRINCIPLES**

Listed below are the guiding principles or underlying assumptions utilized by the Task Force in developing the plan. Future approaches for responding to the HIV epidemic should be governed by these principles.

- 1. Services for the prevention and treatment of HIV disease should be appropriate and sensitive relative to age, gender, ethnicity, culture, sexual orientation, literacy and language of the affected populations.
- 2. Persons affected by HIV disease should have protection of confidentiality and freedom from discrimination.
- 3. Individuals with HIV disease should receive cost-effective care at the level of services appropriate to their specific needs.
- 4. A full spectrum of services should be available which maximizes community-based care and home care, thereby minimizing hospital stays and facilitating independence of the individual.
- 5. To the extent possible, HIV-related reimbursement should not be HIV-specific. Attempts should be made to qualify individuals with HIV disease for the broadest set of appropriate benefits.
- 6. Responding to the challenge of the HIV epidemic requires a public and private sector partnership. The Virginia Department of Health and its local health departments share this responsibility with other state and local agencies, private and community-based organizations, private hospitals and health care practitioners.
- 7. While Virginia's efforts in responding to the HIV epidemic are commendable, significant gaps in services currently exist. The HIV epidemic is changing and continually presenting new challenges. Additional efforts must be initiated which build on successful efforts of the past.
- 8. HIV education, support, and treatment services are equally important; each should be adequately funded.
- 9. Funding decisions should be needs-based and should consider cost-effectiveness, with funds being invested in programs and services that have been demonstrated to be effective.
- 10. Whenever legislative mandates for HIV services are passed, there should be corresponding assurance of adequate funding to implement these services.

### EXECUTIVE SUMMARY

### BACKGROUND

Ten years into the epidemic, acquired immunodeficiency syndrome (AIDS) continues to be devastating. Few other diseases result in as much physical, psychological and social deterioration. AIDS, caused by the human immunodeficiency virus (HIV), often strikes people in the prime of their lives. The human and economic costs to society are overwhelming. Although the disease was initially concentrated in men who have sex with men and injecting drug users, HIV has begun to affect others.

While Virginia's efforts in responding to the HIV epidemic have been commendable, the epidemic is changing and continually presenting new challenges. Activities and programs have been initiated by the public and private sectors in response to the epidemic, without the benefit of a comprehensive long-range plan. The Joint Subcommittee Studying Human Immunodeficiency Viruses recommended that a comprehensive plan for AIDS be developed to cope with the epidemic. This comprehensive plan for HIV/AIDS is critical in providing guidance for future policy directions and resource allocations.

HIV is transmitted by sexual contact; by blood injection (most often through needle sharing behavior during drug use); and from an infected woman to her fetus or infant. HIV affects the immune system, which is essential for fighting disease, leaving the individual susceptible to a host of opportunistic and other diseases. Typically, individuals are symptom-free for years before they become ill. There is a gradual increase in symptoms over a varying period of time. Approximately one-half of infected individuals will be diagnosed with AIDS within ten years after infection. The terminology "persons with HIV disease" is used in this document to depict individuals at any stage of this disease continuum from asymptomatic infection to illness.

### **CHANGING TRENDS**

- As of August 5, 1991, 2504 cases of AIDS were reported in Virginia since reporting of AIDS began in 1982.
- Between July 1, 1989 and August 5, 1991, there were 2255 HIV infections reported.
- While 91% of AIDS cases in Virginia have occurred among men, the percentage among women has steadily increased over the last several years.
- Although people of color comprise 23% of Virginia's population, they represent 41% of the AIDS cases.

- The average age of reported AIDS cases is between 30 to 39 years.
- Pediatric cases of AIDS represent 2% of the total cases reported, but the number is increasing.
- Most AIDS cases report a transmission mode of men having sex with men (MSM). However, the percentage reporting MSM transmission has decreased from 71.0% in 1987 to 61.% in the first seven months of 1991, and the percentage reporting the transmission mode of injecting drug use has increased from 7.4% to 13.8% in the same time interval.
- Although urban areas report the highest number of AIDS cases, the rural areas of the state are seeing an increasing number of cases.
- Based on past trends, it is projected that by the year 2000, as many as 120,000 Virginians may have HIV infection, with over 14,000 having AIDS.

Further information concerning the current distribution and projected future number of cases of AIDS and HIV infection appears in Section II on page 11.

### **PREVENTION SERVICES**

Extensive HIV-related knowledge, attitudes, and behavior surveys have been conducted in Virginia on a variety of populations. These surveys show that while most people are aware of how HIV is transmitted, many still have misconceptions about casual contact, and are not significantly reducing behaviors which place them at risk. While many educational programs have been effective, messages are often vague and individuals do not perceive that they are at risk. Additional outreach efforts are needed to reach these individuals to decrease future human and economic costs related to HIV. (See Section III on page 22).

### HEALTH CARE PROVIDERS

Surveys of health care providers in Virginia conducted in 1988 and 1990 identified deficits in knowledge of HIV transmission and treatment as well as willingness to care for persons with HIV disease. Various programs targeted at recruitment, education, and attitudinal change have resulted in a decreased reluctance to treat HIV positive persons. Nonetheless, in 1990, 20% of physicians and nurses and 33% of dentists were still reluctant to treat HIV positive persons. (See Section IV on page 41).

### **COUNSELING AND TESTING SERVICES**

Early knowledge of one's HIV status provides a critical opportunity to extend life through medical intervention. Through pre- and post-test counseling an individual should be given sufficient information regarding the meaning of both positive and negative test results. While both confidential and anonymous testing are currently available in Virginia, surveys indicate that adequate pre- and post-test counseling is lacking in the private sector. (See Section V on page 53).

### PRIMARY CARE SERVICES

The ability to access medical care at all stages of HIV disease is essential to prolong and enhance the quality of life. Resources for primary care for persons with HIV disease vary in each region, and are concentrated in more populated areas. Factors such as income, insurance coverage, and lack of transportation limit accessibility of services. Care for indigent, uninsured or underinsured persons is managed primarily by public health departments, hospitals, and volunteer agencies; in some geographic areas, this care is not available. HIV surveillance data indicate ongoing increases in morbidity, which may overwhelm publiclyfunded health care systems. (See Section VI on page 58).

### **INPATIENT SERVICES**

Virtually all persons with AIDS will experience episodic hospital care during the end stage of their illness. There is no current or projected future shortage of hospital beds for AIDS patients; however, access is dependent upon payment source and/or location of the facility. Demands for inpatient care will be greatest for Virginia's teaching hospitals and those with a high indigent caseload. (See Section VII on page 64).

### LONG-TERM CARE SERVICES

Persons with HIV disease will usually require long-term supportive care both in the outpatient and inpatient setting. Situations occur in which an AIDS patient must be placed in a long-term care facility. There is a reluctance in Virginia and nationwide on the part of long-term care facilities to accept individuals with HIV disease. As of November 1991, only three long-term care facilities in Virginia are known to have admitted persons with HIV disease. (See Section VIII on page 68).

### MENTAL HEALTH SERVICES

Many individuals with HIV disease experience at least some difficulty with psychological or neuropsychiatric conditions. Because mental health services may be needed at any point in the illness, an array of programs is necessary to assist all people affected by HIV disease. Mental health services exist throughout Virginia, but not in adequate amounts to meet the needs of all clients. In addition, staff often lack training in the mental health needs of people with HIV disease. (See Section IX on page 71).

### SUBSTANCE ABUSE SERVICES

Injecting drug abusers (IDUs) constitute the second largest transmission category for HIV disease. Innovative approaches to education as well as adequate treatment programs are essential. Access to treatment for IDUs is inadequate. Other substance abusers are also at risk for transmission because they may engage in high-risk behaviors when under the influence of chemicals. (See Section X on page 74).

### CASE MANAGEMENT/SUPPORT SERVICES

Case management provides the person with HIV disease with a link to services. Most case management services are being provided through hospitals, AIDS Service Organizations and community-based organizations. There is a significant shortage of case managers to serve the needs of individuals with HIV disease. Many specialized services are needed to reach underserved populations. (See Section XI on page 77).

### HOUSING

The housing needs of an individual with HIV disease can be complex and may include hospice care, transitional housing care and in extreme cases, shelter care. Approximately six percent of the homeless are infected with HIV disease. A significant number of persons with HIV disease are at risk of becoming homeless due to the financial demands of HIV disease management. There are limited housing resources available to these individuals. Current local and state regulations make it very difficult for community-based organizations to open and operate transitional houses or hospices. (See Section XII on page 81).

### FINANCING

Based on projections derived from national cost of care data, the economic impact of HIV/AIDS in Virginia for direct patient care alone during the period 1991 - 2000 is projected to exceed five billion dollars. Indirect costs including lost earnings, decreased productivity and increased psychological burdens are incalculable. The annual per patient cost for direct medical care in 1991 is estimated to be \$5,614 for persons with HIV and \$34,880 for persons with AIDS; these costs are expected to double by the year 2000. The extent of current and expected funding for patient care will not meet projected needs. Often, persons with HIV and AIDS are denied or lack access to adequate third party coverage or become uninsured during the course of illness; some of these persons have no access to medical care. Medicaid and Medicare fail to provide coverage of all persons lacking benefits. (See Section XIII on page 84).

### RECOMMENDATIONS

The Task Force has developed recommendations aimed at preventing HIV infection and improving the provision of services for persons with HIV disease. A summary of priority recommendations follows. A complete listing of all recommendations appears in each of the sections previously referenced.

### PREVENTION SERVICES

- 1. Improve education/information campaigns by using television, radio and print media.
- Target prevention messages and outreach efforts to specific populations (e.g., general public, men who have sex with men, injecting drug users, people of color, adolescents, women, and inmates) and involve affected populations in the development of activities.
- 3. Include sexuality, substance abuse, and self-esteem issues as core components of comprehensive school health instruction.
- 4. Develop and strengthen organizations responding to HIV issues in communities of color.
- 5. Train, reward, and support HIV prevention education workers more effectively.
- 6. Consistent with the recommendations of the National Commission on AIDS, consider any approach that can be shown to be effective in slowing transmission of HIV among IDUs.
- 7. Expand funding for the AIDS Services and Education Grants Program established by the 1989 General Assembly through House Bill 1974.

### HEALTH CARE PROVIDERS

- 1. Continue and expand Regional AIDS Resource and Consultation Center (RARCC) programs, including counseling and testing training courses, which are offered in conjunction with the Department of Health.
- 2. Incorporate HIV/AIDS education into professional continuing educational programs and professional health care schools.
- 3. Elicit professional society support for increased willingness of health care providers to care for those with HIV disease and their families.

- 4. Increase access to clinical components of training for health care providers regarding management of HIV infection through the RARCCs and health care professional schools.
- 5. Endorse recent CDC "Recommendations for Preventing Transmission of Human Immunodeficiency Virus and Hepatitis B Virus to Patients During Exposure-Prone Invasive Procedures". Emphasize the necessity for all health care providers to utilize universal precautions with <u>all</u> patients and adopt adequate infection control policies in the work setting.

### COUNSELING AND TESTING SERVICES

- 1. Assess and change anonymous test site (ATS) locations where appropriate to improve geographic accessibility. A greater effort must be made to target voluntary testing campaigns toward people of color.
- 2. Provide CD4 cell count testing in each ATS and public clinic where screening is taking place at the time of post-test counseling.
- 3. Increase Division of Consolidated Laboratory Services staff to decrease the current 2-3 week wait for positive test results.
- 4. Expand the staff of the HIV antibody testing and counseling program in drug treatment centers throughout the state.

#### PRIMARY CARE SERVICES

- 1. Provide access to laboratory tests needed in the evaluation of HIV/AIDS and its complications and establish a central purchasing system (through the provision of funds or pharmacy services) for medications needed by indigent patients.
- 2. Develop an outreach health care model for providing primary care services to HIV/AIDS patients.

#### INPATIENT SERVICES

- 1. Enhance outpatient services to decrease the need for hospitalization.
- 2. Increase State and Local Hospitalization (SLH) funds to the necessary funding level to cover the number of indigent HIV/AIDS patients being treated.

### LONG-TERM CARE SERVICES

1. Provide respite care programs designed for AIDS patients in addition to traditional hospice care.

2. Ensure access to nursing home beds for persons with HIV disease. Nursing homes must be in compliance with existing civil rights laws and aware of the consequences of violating these laws.

### MENTAL HEALTH SERVICES

- 1. Expand public mental health services to alleviate lengthy waiting periods for clients with HIV disease and to address their numerous psychosocial and neuropsychiatric problems.
- 2. Incorporate HIV education and information into mental health inpatient and outpatient treatment.

### SUBSTANCE ABUSE SERVICES

- 1. Ensure that substance abuse treatment is available on demand.
- 2. Ensure that every client in a substance abuse treatment program receives HIV risk assessment, appropriate education, and counseling.
- 3. In collaboration with other human resource agencies, develop additional community-based treatment programs specifically designed for women, adolescents, IDUs, and inmates which address substance abuse and HIV issues.
- 4. Promote the identification of IDUs with HIV disease and ensure access to primary care services through improved linkages between primary care and substance abuse treatment.

### CASE MANAGEMENT / SUPPORT SERVICES

- 1. Expand comprehensive, effective case management and support services for persons with HIV disease. Services should be specialized to meet the diverse needs of specific populations.
- 2. Regional Care Consortia should assume a leadership role in coordinating case management among agencies in their regions. Data collection and analysis should be conducted in an effort to establish a statewide data base.
- 3. Expand the recruitment and training of volunteers.

### HOUSING

1. Increase the number of housing units available to the disabled through the offices of the Virginia Housing and Development Authority and the U. S. Department of Housing and Urban Development.

- 2. Increase options such as transitional housing for the homeless with HIV disease by utilizing the expertise of existing groups providing health care for the homeless, along with the Virginia Housing and Development Authority.
- 3. Require non-discriminatory access to transitional housing, hospices, and emergency shelters for individuals, including those with HIV disease.

#### FINANCING

- It is important to place the problem of health care financing for HIV/AIDS into a larger context. Universal health care coverage should be provided for all persons living in the U. S. to assure access to quality health care services.
- 2. Until universal health coverage is provided, pursue interim options including establishment of a premium buy-in program and risk pools.
- 3. The U. S. Congress should fund the Ryan White Care Act at its fully authorized level.
- 4. Increase direct state appropriations necessary to implement the recommendations contained within this plan. At a minimum, state allocations should increase proportional to the change in the number of reported cases of HIV/AIDS.

#### EVALUATION/MONITORING

- 1. The Department of Health should present annually to the Joint Subcommittee Studying Human Immunodeficiency Viruses, a brief status report on the implementation of the recommendations contained within this plan. Due to the dynamic nature of the HIV epidemic, this report should also provide any significant new information on HIV/AIDS and any new recommendations which might derive from this information.
- 2. There should be an increased awareness of and focus on the evaluation of HIV/AIDS prevention, services, and treatment.

### I. INTRODUCTION

A study of the effects of the AIDS epidemic has been conducted over the last several years by the Joint Subcommittee Studying Human Immunodeficiency Viruses. The Subcommittee recommended that a comprehensive plan for AIDS be developed to cope with the effects of the epidemic. Accordingly, the General Assembly, through House Joint Resolution 436, asked the Office of the Secretary of Health and Human Resources to develop a comprehensive plan for providing HIV/AIDS prevention, care, and services in the Commonwealth for the years 1991-2000. A copy of HJR 436 is included as Appendix A.

The Secretary of Health and Human Resources formed a 15-member Task Force to assist in the development of the plan. Task Force members included representatives from state agencies, medical schools, community-based AIDS organizations, Virginia Hospital Association, Virginia Pediatric Society, public and private sector medical community, and an individual with HIV disease.

In developing the plan, the Task Force convened four times during from July, 1991 to November, 1991, with the period six subcommittees meeting in the interim. The subcommittees were formed to address the following plan components: Prevention Services; Health Care Providers; Counseling, Testing and Primary Care Services; Case Management/Support Services and Housing; Inpatient, Long-Term Care, Mental Health, and Substance Abuse Services; and Financing. Subcommittee membership included individuals outside the Task Force. The Preface provides a listing of subcommittee membership, including Task Force members.

The purpose of the plan is to provide information to help planners and policymakers determine future policy directions and resource allocations. Additionally, the plan provides a baseline and historical perspective.

The plan set forth on the following pages describes the HIV epidemic in Virginia and projects the number of AIDS cases/deaths and HIV infection for each year 1991-2000. In addition, the following services/issues are examined relative to gaps and projected future needs: prevention, health care providers, counseling and testing, primary care, inpatient, long-term care, mental health, substance abuse, case management/support, housing, and financing. Recommendations for improvements are presented for each of these services/issues, with priority recommendations being italicized. A chronology of public agency HIV/AIDS initiatives in Virginia is included as Appendix B.

### II. HIV DISEASE IN VIRGINIA

### A. DESCRIPTION OF THE DISEASE, ITS COURSE AND TRANSMISSION

Acquired immunodeficiency syndrome (AIDS) is a disease caused by the human immunodeficiency virus (HIV). HIV is transmitted by sexual contact; by blood injection (most often through needle sharing behavior during drug use) and, rarely, by other exposures to blood; and from an infected woman to her fetus or infant.

HIV affects the immune system, which is essential for fighting disease, leaving the individual susceptible to a host of opportunistic and other diseases. Typically, individuals are symptom-free for years before they become ill. There is a gradual increase in symptoms over a varying period of time. Approximately one-half of the individuals will be diagnosed with AIDS within ten years after infection.

The Centers for Disease Control (CDC) defines a person as having AIDS if he/she has one or more of certain qualifying diseases and has either a positive test for HIV infection or absence of specified causes of underlying immunodeficiency. The CDC is in the process of revising the case definition, to be effective in the spring of 1992. The definition of AIDS will be broadened to include anyone who is HIV positive with a CD4 (helper cell) count below 200, regardless of symptoms.

### B. CONTINUUM OF SERVICES NEEDED FOR PERSONS WITH HIV DISEASE

HIV/AIDS is a long-term chronic disease. Individuals who have a positive HIV antibody test need a medical evaluation to determine the disease status. All individuals who have HIV disease should receive periodic medical follow-up as well as education and support. Early intervention services are proving to be a costeffective method of prolonging the symptom-free period.

When a patient's CD4 cell count falls below 500, he/she should be placed on antiretroviral medication as preventive medicine. For those with counts below 200, preventive medicine for pneumocystis carinii should be initiated. The vast majority of people with HIV disease will continue to work and function productively for years. However, access to treatment is still a problem for many individuals who lack support systems or ability to pay.

HIV disease differs from many other chronic conditions in the severity of psychosocial issues related to the illness. People affected by HIV are often members of populations that have been stigmatized by society (e.g. men who have sex with men, injecting drug users). Many people affected by HIV keep this information hidden from others, thereby limiting their access to support services.

As the degree of immune deterioration increases and individuals develop more opportunistic infections and cancers, a range of care is necessary depending on the clinical condition. Symptomatic individuals with HIV disease can experience a wide range of problems which will dictate the type of care each person requires. One particularly incapacitating condition is blindness, striking many persons who have cytomegalovirus retinitis. In addition to physical problems, many experience mental impairment which can affect their judgment and increase dependency. As they become increasingly dependent, the range of services needed and associated cost can be overwhelming.

Because this disease strikes people in their prime, they frequently experience overwhelming losses. Once they can no longer work, they may lose their health insurance and have difficulty paying for services. Many will eventually qualify for public assistance. Often individuals do not have adequate resources to live independently and do not receive support from family, friends and other loved ones. Availability of a coordinated continuum of care will facilitate provision of the appropriate level of care specific to individual needs. People with HIV disease spend less total time in the hospital than previously because of progress in medical treatment as well as increased availability of outpatient and home care. Despite progress in these areas, home care, nursing home care, and hospice care continue to be difficult to find in many communities. Where services are available and accesible, effective case management can assist individuals in finding the most appropriate level of care for their particular needs.

### C. CURRENT DISTRIBUTION OF CASES OF AIDS AND HIV INFECTION BY AGE, RACE, GENDER, TRANSMISSION MODE, AND GEOGRAPHICAL AREA

### 1. AIDS Demographics

From January 1<sup>st</sup> through August 5<sup>th</sup> 1991, there were 427 AIDS cases reported in Virginia, increasing the cumulative total to 2,504. AIDS cases were first reported in Virginia in 1982.

During the past ten years a number of trends have emerged which appear to be portents of coming changes in AIDS demographics. These changes involve the gender, racial, transmission mode and geographic composition of the epidemic.



GENDER - While AIDS has traditionally been a disease of men, the percentage of cases among women has been steadily increasing over the past several years. This increase in the percentage of female cases is demonstrated by comparing the 12.9% experienced during the first seven months of 1991 with the cumulative percentage of 9.3%.

Virginia AIDS Cases and HIV Infections By Gender									
	AIDS	% AIDS	ΗΙΥ	% HIV					
Male	2,271	90.7	1,766	78.3					
Female	233	9.3	486	21.6					
TOTAL	2,504		2,255						
Through August 5, 1991									

**RACE** - People of color in Virginia are experiencing higher rates of AIDS than whites. During calendar year 1990, the case rate among nonwhites was nearly three times that of whites (22.2 cases/100,000 compared to 7.6 cases/100,000). This trend is continuing in 1991 as 47.1% of the 427 AIDS cases reported during the first seven months of 1991 were people of color. People of color account for 64.4% of the cumulative female cases reported and 72.0% of cumulative pediatric cases reported. By comparison, nonwhites make up 22.7% of the population of Virginia according to the 1990 census.

	В	y Race		
	AIDS	% AIDS	ΗΙν	% HIV
White	1,476	58.9	751	33.3
African-Am.	936	37.4	1,356	60.1
Hispanic	76	3.0	45	20
Asian/Pac. Is.	10	0.4	7	0.3
Other	6	0.2	96	4.3
TOTAL	2,504		2,255	

AGE - The average age of the cases reported is between the ages of 30 to 39 years of age. The percentage of cases reported for each age group has been relatively stable over the course of the epidemic. The next most prevalent age group is the 20 to 29 category (22.5%). The age group with the lowest frequency is teenagers (0.3%). However, because of the long latency period, a portion of the 20 to 29 category would have been infected with the virus during their teen years.

Virginia AIDS Cases and HIV Infections By Age Category							
	AIDS	% AIDS	ΗIV	%HIV			
Under 13	50	2.0	8	0.3			
13 - 19	7	0.3	58	2.6			
20 - 29	564	22.5	911	40.4			
30 - 39	1,116	44.6	884	39.2			
40 - 49	524	20.9	29 <del>9</del>	13.3			
Over 49	243	9.7	95	4.2			
TOTAL	2,504		2,255				
Through August 5, 1991							

**PEDIATRIC** - As of August 5, 1991, Virginia had 50 cumulative pediatric AIDS cases representing 2.0% of the total cases reported. The number of pediatric cases appears to be increasing. During the first seven months of 1991, 13 pediatric cases were reported, already exceeding the 12 pediatric cases that were reported during the entire previous year. Due to the difficulties inherent in diagnosing AIDS in pediatrics, these case reports under-represent the impact of HIV/AIDS on this age group.

**TRANSMISSION MODE** - Most cases reported a transmission mode of men having sex with men (MSM). However, the percent of cases reporting this mode has dropped from 71.0% in 1987 to 61.8% during the first seven months of 1991. During the same time interval the percent of cases reporting injection drug use (IDU) has increased from 7.4% to 13.8%, bringing the cumulative total to 12.0%. However, an expansion of the AIDS case definition which occurred during 1987 may be responsible for a significant proportion of this increase. Cases reporting heterosexual transmission have increased from 3.7% to 8.0%, with a cumulative total of 5.2%.

Virginia AIDS Cases and HIV Infections By Transmission Mode							
	AIDS	% AIDS	HIV	% HIV			
MSM	1,671	66.7	695	30.8			
IDU	301	12.0	374	16.6			
Transfus/Hemophil	128	5.1	47	2.1			
MSM and IDU	112	4.5	39	1.7			
Heterosexual	131	5.2	637	28.2			
Other	161	6.4	463	20.5			
TOTAL	2,504		2,255				
Through August 5, 1991							

**GEOGRAPHIC DISTRIBUTION** - The Northern Region continues to report the highest number of cases, but the percentage of total cases has dropped from 45.4% during 1987 to 33.7% during the first seven months of 1991. Other areas with substantial numbers of cases include the Eastern Region (24.5%) and the Central Region (21.4%). The rural areas of the State are seeing an increasing number of cases. The Southwest Region has increased from 7.1% of the cases reported in 1987 to 13.1% of the cases reported during 1991. The Northwest Region has increased from 3.3% to 6.6% during the respective time periods.

By Region							
	AIDS	% AIDS	нιν	% HIV			
Northwest	169	6.7	82	3.6			
Northern	978	39.1	482	21.4			
Southwest	208	8.3	192	8.5			
Central	536	21.4	443	19.6			
Eastern	613	24.5	1,056	46.8			
TOTAL	2,504		2,255				

**RANK** - Virginia ranks  $16^{th}$  out of the 55 U.S. states and territories in terms of the number of adult cases reported and  $13^{th}$  nationally in terms of number of pediatric cases reported. In comparison, North Carolina ranks  $20^{th}$  for adults and  $17^{th}$  for pediatric, Tennessee ranks  $23^{rd}$  and  $22^{nd}$ , and the District of Columbia  $12^{th}$  and  $15^{th}$ .

### 2. **HIV Demographics**

From January 1 to August 5<sup>th</sup>, 716 HIV infections were reported and investigated, bringing the cumulative number of HIV infections to 2,255. HIV infection became a reportable condition in Virginia on July 1, 1989.

Demographic information from those reported HIV positive can be viewed as a predictor of the future of the AIDS epidemic in Virginia. Several of the changing AIDS trends described earlier (increasing percentages of females, minorities, and heterosexuals) have correlations with HIV infection data. For example, women comprise a higher percentage of HIV infections than of AIDS cases (21.4% to 9.3%). Also, the percentage of HIV cases relating to heterosexual transmission (single and multiple heterosexual transmission) totals 28.2% compared with 5.2% of AIDS cases. It should also be noted that the total percentage of HIV cases relating to the heterosexual transmission mode is 2.3% less than the homosexual/bisexual transmission mode. Due to the short time span over which HIV reporting has occurred, there is insufficient data from which to accurately identify trends within that data base.

### D. PROJECTION OF NUMBER OF CASES OF AIDS AND HIV INFECTION FOR EACH YEAR FROM 1991 - 2000

### 1. AIDS Projections

Projections of the number of AIDS cases which will occur in Virginia are based on the experience during the past five years. As these projections are based on a relatively small data set, they should be viewed as general indicators of future trends rather than as specific figures. Other factors which impact on the accuracy of projections include:

Latency Period - There have been a number of studies estimating the latency period between infection with the HIV virus and the onset of AIDS symptoms. One of the most widely accepted is based on the Frankfurt progression data which indicated a latency period of 8.2 years. Later studies have tended to indicate longer latency intervals.

**Changing Therapies** - Increasing availability and use of therapeutic regimens has increased both the latency period between HIV infection and the onset of symptoms as well as extended the time between AIDS diagnosis and death.

**Changing Case Definition** - It is anticipated that the Centers for Disease Control will be making a major revision to the AIDS case definition during the coming year. The impact such a change would have upon the number of cases reported can not be estimated at this time.

Under-reporting - AIDS cases which never get reported to the Department of Health are estimated at less than 20%. This estimate is based upon reviews of death certificates, hospital discharge summaries, and other evaluation tools. A major reason for not reporting a case is fear of discrimination. In addition, there are 21 anonymous testing sites for HIV in Virginia which are exempt from the disease reporting requirement.

Who gets treatment - Unfortunately, a number of persons in various categories have delayed or no access to health care. This includes individuals in categories such as the homeless, substance users/abusers, runaways, migrants, immigrants, etc.

Substance use/abuse - It is anticipated that substance use/abuse will play an increasing role in viral transmission. In addition to the traditional category of IVDU, this also includes individuals trading sex for drugs or sex for money for drugs. Thus, the increasing use of "Crack" and other non-IV drugs will be important factors in future disease transmission. Lag Time - The interval between the diagnosis of AIDS and the time the case is entered into the State data base is affected by delays in transmitting the disease reports from the health care provider to the Department of Health, incomplete case reports, and follow-up investigation time to obtain missing data (such as transmission mode information or missing demographics).

### Methods

Projections of the number of future AIDS cases were made by the Virginia Department of Health. They are based on the following data:

- 1. Actual number of AIDS cases reported for the years 1986 through 1990.
- 2. The number of AIDS cases reported for the first five months of 1991 annualized to a whole year.
- 3. A breakdown of the above cases by major transmission, gender, racial and regional categories.

These data were used as the input for a series of linear regression models. The results listed on the next page are based on the output of those models.

#### Assumptions

- 1. Trends seen in the AIDS cases reported during the past five years will continue.
- 2. The number of cases reported gives an accurate reflection of the number of cases actually occurring.
- 3. The current death rate of 64.1% will remain constant during the foreseeable future.

### Results

<b>Projected AIDS Cases/Deaths</b>								
1991 - 2000								
	New	Cumulative	Cumulative					
Year	Cases	Cases	Deaths					
1991	722	2,799	1,794					
1992	836	3,635	2,330					
1993	950	4,585	2,939					
1994	1,063	5,648	3,621					
1995	1,177	6,825	4,375					
1996	1,291	8,116	5,202					
1997	1,405	9,521	6,103					
1998	1,518	11,039	7,076					
1999	1,632	12,672	8,122					
2000	1,746	14,418	9,242					

Source: Virginia Department of Health

### Caution

Although projections are presented for ten years, these projections, which are based on small data sets, become less reliable with each future year. Also, it should be noted that the factors listed on pages 17 and 18 may have an impact on the future number of cases. The impact of those factors can not be accurately predicted at this time.

### 2. HIV Projections

### Methods

As HIV infections have been reported only since July of 1989, the small number of data points precludes using the above technique for projecting HIV infections. Therefore, the following methodology was utilized:

- 1. The Centers for Disease Control estimates there were 1.0 to 1.5 million persons infected with HIV in 1990.
- 2. This number is estimated to be growing at the rate of 80,000 per year.
- 3. Virginia accounts for 1.3% of the national AIDS cases.
- 4. Assuming that the percentage of national HIV infections which are Virginia residents approximates the percentage of national AIDS cases which are Virginia residents leads to the following calculation:

 $0.013 \times 1.0 \text{ million} = 13,000 \text{ infections}$ 

 $0.013 \times 1.5 \text{ million} = 19,500 \text{ infections}$ 

Thus, we can estimate that between 13,000 and 19,500 Virginians were infected with HIV in 1990.

5. Dividing the estimated HIV infections during 1990 with the cumulative number of AIDS cases reported that year yields a ratio of approximately 5.5 to 8.3 HIV infections per reported AIDS case. By multiplying the projected number of AIDS cases presented on the previous page by these multipliers, one may obtain a reasonable estimate of the number of Virginians who will be infected with HIV for the coming years. The results of these calculations are listed on the next page.

### Caution

Although projections are presented for ten years, these projections, which are based on small data sets, become less reliable with each future year. Also, it should be noted that the factors listed on pages 17 and 18 may have an impact on the future number of cases. The impact of those factors can not be accurately predicted at this time.

### Results

Projected HIV Infections 1991 - 2000						
	Low	High				
Year	Estimate	Estimate				
1991	15,395	23,232				
1992	19,992	30,169				
1993	25,215	36,051				
1994	31,064	46,876				
1995	37,538	56,648				
1996	44,638	67,363				
1997	52,364	79,022				
1998	60,716	91,626				
1999	69,693	105,174				
2000	79,297	119,666				

Source: Virginia Department of Health

### 3. Sources of Information Regarding Cases of AIDS and HIV Infection in Virginia

Information regarding the number of cases of AIDS and HIV infection in Virginia is obtained from a variety of sources. primary HIV/AIDS Surveillance source is the System The administered by the Virginia Department of Health. This system receives disease reports from physicians, health care facilities, and laboratories doing business in Virginia. Information derived from this source is supplemented with data from the HIV Seroprevalence Survey administered by the Virginia Department of This survey is part of a national effort to determine Health. the extent of HIV infection among various population groups. In addition to these sources, information on other sexually transmitted diseases, such as syphilis and gonorrhea, provides a short term indication of the future direction of HIV infection.

### III. PREVENTION SERVICES

### A. BACKGROUND

Unlike most sexually transmitted diseases, there is no cure for AIDS. Persons with HIV disease are infectious for life. Because HIV infection may go undetected for 10 years or more, simply avoiding known people with HIV disease is an ineffective prevention Education that produces long term behavior changes in strategy. individuals is the most effective option in stemming the AIDS The hysteria and misinformation that continues to epidemic. permeate society must be countered with the dissemination of scientifically sound information. Ensuring compassion for and the civil rights of people with HIV disease are equally meaningful goals of any education program. Efficacious prevention activities must be specifically tailored for each targeted population, taking into consideration its unique culture, status within the larger society, beliefs and behaviors.

Educational efforts have been addressed through one-on-one efforts, group settings, and mass distribution of information, particularly through the media. The target of these efforts has varied from the general public to people at identified risk to health care professionals. The Centers for Disease Control (CDC) materials developed as part of the "America Responds to AIDS" campaign have been distributed to radio and television stations throughout the state. Five Virginia television stations received national recognition for the amount of air time donated for HIV-related public service announcements. A statewide bus placard campaign placed HIV information inside transit buses.

A train-the-trainer approach has provided comprehensive week-long training for 250 individuals who represent a variety of public and private agencies. This program has created a statewide network of trainers. A recent survey of these educators showed that they had reached about 94,000 people from March 1990 through February 1991. These individuals provided the nucleus for the formation of regional coalitions to address educational needs. Recently, the Department of Education (DOE) funded the coalitions to develop youth education projects.

The severity of the epidemic and related complexity of issues has demanded that a variety of approaches be developed. Traditional methods are not sufficient. Partnerships have been developed among state agencies and between the public and private sector to network educational services. Community-based non-profit organizations have provided invaluable assistance in reaching people affected by HIV as well as providing feedback and direction towards state efforts. Many agencies maintain speakers bureaus. Approximately 20 AIDS Service Organizations (ASOs) provide extensive education to people affected by HIV, people at risk and the general public. Virginia Department of Health (VDH) funding has been provided to some of these agencies, assuring that every geographical area of the state is served by at least one ASO. Other community-based organizations also have programs focused on specific HIV priority areas, such as outreach to injecting drug users, inmates, and the homeless. Funds for these specific education projects that target hard-to-reach populations were allocated in 1989 through House Bill 1974.

While educational efforts thus far have ensured that most people are knowledgeable about how HIV is transmitted, indicators such as rising numbers of sexually transmitted disease show that behaviors that place people at risk for HIV have not changed.

Through VDH funding, extensive knowledge, attitudes and behavior (KAB) needs assessment surveys were conducted from 1988-1991 by Virginia Commonwealth University's Survey Research Laboratory. The surveys relative to the KAB findings presented on the following pages are listed in Appendix C. In addition to those, other KAB surveys were conducted including several addressing health care providers as discussed in Section IV.

Seven population groups are addressed separately on the following pages with regard to KAB results, current activities, gaps and projected future needs and recommendations. Priority recommendations are italicized. Additional priority recommendations not targeted to the specific population groups are presented at the end of the section.

### **B. GENERAL PUBLIC**

### 1. Results of Knowledge, Attitudes and Behavior Surveys

According to the KAB surveys, awareness of AIDS is widespread among all populations surveyed. Virginians are knowledgeable about HIV transmission, but substantial proportions of all groups are uncertain about transmission through casual contact. Significant numbers of all populations incorrectly believe that AIDS can be transmitted by insects, kissing, sharing utensils, or using a public toilet. The 1989 survey of the general public showed an increase in the belief that casual contact could transmit HIV compared to the 1988 survey. African-Americans, people with lower incomes and people with lower educational levels were more likely to believe that casual contact could transmit HIV. Twenty-one percent of the same populations did not know that a person with a positive antibody test could transmit HIV. People in all groups overestimated the likelihood of getting AIDS through a blood The media, mainly television, was identified as the transfusion. main source of information for all populations. Television was used as a source of information in the greatest amount by African-Americans, people with lower incomes, and people with lower educational levels.

### 2. Current Activities

Public education about AIDS was initially addressed through the establishment of a VDH toll-free AIDS hotline in 1985. This hotline has since expanded to include all sexually transmitted diseases (STDs) and has accessibility to the deaf through Telecommunications Device for the Deaf (TDD). A Spanish-speaking hotline is also available. In calendar year 1990, the hotline handled over 14,000 telephone inquiries regarding STDs or HIV. Caller profiles are as follows: White females, 37%; White males, 32%; African-American females, 21%; and African-American males, 10%.

Millions of STD/HIV/AIDS materials are annually distributed statewide. Topics of these materials range from general information to condom usage. Also included are lower reading level materials and brochures in different languages. In addition to print materials, the VDH maintains a comprehensive video lending library.

### 3. Gaps and Projected Future Needs

- a. General population messages lack specificity, therefore persons who participate in risky behaviors, but do not identify with a "risk group", will miss messages. For example, many men who have sex with men do not consider themselves gay or bisexual. Many upper class injecting drug users do not identify with prevention messages aimed at low income "street" users. Information targeted to the general public may be their only source of information so these messages must be relevant to sub-groups within the general public.
- b. As AIDS media coverage wanes, people begin to believe HIV is no longer a problem. As HIV affects people with less influence and power, the generic messages do not address the issues of many populations.

### 4. Recommendations

- a. Improve information campaigns
  - 1. Increase the use of public service announcements. Encourage the media to utilize CDC public service announcements though letters from the State Health Commissioner or other public officials.
  - Add "you can get involved" information to brochures and other message vehicles.
  - 3. Maintain information campaigns related to the safety of the blood supply and organ donation.

- 4. Evaluate the content, format, cost-effectiveness and distribution of pamphlets.
- 5. Increase the use of television as an educational medium.
- b. Use AIDS Hotline caller data to monitor the impact of media events and to assess educational needs.
- c. Continue to access people at risk through worksite education programs.
- d. Alter risk reduction messages for the general public so that specific and explicit information is provided to individuals who do not identify with traditional "risk groups".

### C. MEN WHO HAVE SEX WITH MEN

### 1. Results of Knowledge, Attitudes and Behavior Surveys

This population was surveyed in 1988 and in 1990. The sample consisted primarily of white men because of difficulty in obtaining adequate numbers of minority participants. Seventy-five percent of those surveyed said they knew quite a lot about AIDS and almost everyone answered knowledge questions correctly. Seventy-five percent reported that they had sex with other than a primary partner in the past year. Two-thirds said they had engaged in anonymous sex or one-night stands. One-third said they always used a condom with a primary partner and another 45% never did. Forty-three percent always used condoms with other partners and 26% never did. The majority agreed with the statement that they are more likely to have unsafe sex when they used mood-altering substances and two-thirds said they use alcohol or other drugs at least sometimes before having sex. Almost all men who have sex with men reported changing sexual behaviors because of AIDS, including having fewer partners, reducing certain activities, having safer sex and using condoms.

#### 2. Current Activities

Most ASOs conduct outreach to men who have sex with men. Efforts include safer sex seminars, development of specific materials, and distribution of condoms. Gay men have been responsible for the greatest amount of self-education of any population.

### 3. Gaps and Projected Future Needs

- a. Current VDH AIDS information does not specifically address gay/bisexual issues.
  - 1. The VDH does not provide brochures targeted to men who have sex with men. One was discontinued due to its lack of specificity and appeal.

- 2. There are few messages addressing the relationship between drugs and sex. Alcohol and drug use has been shown to have a negative impact on compliance with safer sex guidelines and condom use.<sup>1,2</sup>. This is especially relevant as 1/3 of gay/lesbian people are addicted to a chemical substance.<sup>3,4</sup>
- 3. There are no specific messages dealing with maintaining safer sex in long term relationships, nor with the problem of relapsing to unsafe sex after being safe for a time. A report of the U.S. Conference of Mayors stated\_a\_widespread need for reeducation because of relapse into unsafe sexual practices.<sup>5</sup>

Items 2 and 3 above apply to all populations at risk.

- b. HIV seropositivity among young men who have sex with men is increasing.<sup>6</sup> There is little information addressing sexual minority youth (gay, lesbian, bisexual, transvestite, or transgender). Many younger men who have sex with men have not felt the impact of the AIDS epidemic that older gay men have experienced through illness or death of friends.
- c. African-American men who have sex with men are often not a part of the mainstream gay culture and may miss educational efforts that are developed by and targeted to white gay men. Three separate sub-groups of these African-American men have been identified: gay African-American men who identify primarily with the gay community, African-American gay men who identify primarily with the African-American community, and men who have sex with both men and women. The diversity of these subgroups makes the development of appropriate intervention strategies complex.<sup>7</sup> While the percentage of AIDS cases among men who have sex with men is decreasing, cases among gay men of color are increasing. The lack of success in identifying effective interventions for gay men of color has been noted as a gap in prevention services throughout the country.<sup>5</sup>
- d. Many men who have sex with men do not consider themselves gay or bisexual. Cultural beliefs or fear of stigmatization result in denial of gay/bisexual identity or sexual contacts. These men miss education tailored to this population and fail to recognize their risk.
- e. A major obstacle in reaching men who have sex with men is the enforced closeting because of Virginia Crimes Against Nature laws (Virginia Code Section 18.2-361 and Section 18.2-10[F]) and the absence of state law preventing discrimination on the basis of sexual orientation. Individuals cannot come forward to gain information because of fear of exposure.

### 4. **Recommendations**

- a. Develop messages and campaigns that specifically address the needs of men who have sex with men.
  - 1. Develop educational messages addressing the link between substance abuse and unsafe sexual activity.
  - 2. Reinforce the message that safer sex should be practiced during all situations, including long term relationships.
  - 3. Incorporate information for men who have sex with men into pamphlets, presentations, etc. for general audiences.

(Items 1 and 2 apply to all populations)

- b. Create education and outreach programs for sexual minority youth (gay, lesbian, bisexual, transvestite or transgender), including college-age youth.
- c. Needs assessment studies of sub-groups such as men of color and sexual minority youth should be initiated in order to determine the most appropriate educational programs.
- d. Develop messages that specifically address men of color who have sex with men.
- e. Use general public information campaigns and messages to address the needs and issues of men who have sex with men but do not identify themselves as gay or bisexual.
- f. Health promotion efforts for gay/bisexual men should acknowledge the struggles that men who have sex with men encounter in a discriminatory society and should assist in the development of a positive self-esteem which is crucial to encouraging risk reduction behavior changes.
- g. Remove statutes governing crimes against nature that make it difficult for educators to reach men who have sex with men.

### **D. INJECTING DRUG USERS**

### 1. Results of Knowledge, Attitudes and Behavior Surveys

An initial attempt to conduct a street survey of injecting drug users (IDUs) did not yield useful data. Drug users in treatment programs provided sufficient information for analysis. IDUs in treatment may be substantially different from those who are not. More than one in four respondents began using drugs before the age of 17. Heroin and cocaine were the primary drugs of choice. Within the past year, 30% had used drugs in a shooting gallery and 20% had traded sex for money or drugs, indicating a high level of riský behaviors among these individuals. Seventy-two percent reported they had made changes in their behaviors because of AIDS. Not sharing works and reducing their number of sex partners were mentioned most frequently, but only 30% reported ever using a condom.

### 2. Current Activities

The most successful programs targeted to drug users have been those implementing one-on-one education to people on the streets. Limited street outreach activities take place in some of Virginia's larger cities including Norfolk, Virginia Beach, Alexandria, Richmond and Roanoke. Through a cooperative effort between the VDH and the Department of Mental Health, Mental Retardation and Substance Abuse Services (DMHMRSAS), HIV counselors have been placed in the 5 public methadone clinics to provide HIV education as well as pre and post test HIV antibody test counseling. Pocket-sized cards demonstrating the bleach- water method for cleaning works are available through the VDH. In addition, AIDS service organizations conduct presentations for drug users in treatment programs.

### 3. Gaps and Projected Future Needs

- a. Street outreach programs vary in intensity and method. Because of local prohibitions, not all programs distribute bleach.
- b. The current number of street outreach programs and resources is inadequate to serve the population of drug users. Street outreach has been shown to be one of the most effective methods of producing risk-reducing behaviors among IDUs. One study showed that before a street outreach program was undertaken, only 3% of the drug users interviewed reported using bleach to clean their works. One year after initiation of street outreach, 68% of the drug users interviewed reported using bleach.<sup>8</sup>
- c. AIDS educators who conduct street outreach are often paid less than other professionals working in the field of AIDS education.
- d. Current educational efforts for IDUs are more informationally based rather than behaviorally based resulting in little practical behavior change.
- e. The VDH and the DMHMRSAS have not undertaken a coordinated effort to train substance abuse treatment staff. Substance abuse treatment staff do not have adequate information and training about HIV. Seventy-six percent of Virginia substance abuse counselors who were interviewed said that the level of AIDS training they received was only somewhat adequate or not adequate.
- f. There is a lack of resources for substance abuse treatment. Detox programs are immediately accessible; however, the wait

for inpatient treatment for people without insurance ranges from several weeks to several months. Difficulty in placing clients was reported from every region of the state.<sup>10</sup> Dr. June Osborne of the National Commission on Acquired Immunodeficiency Syndrome states "The epidemic of illicit drug use is a serious public health problem in its own right, and failure to offer treatment for addiction to all drug users who seek it means that thousands of people remain at risk for HIV."<sup>11</sup> In addition, drug treatment programs do not have provisions for pregnant women or child care which discourages people from seeking treatment.<sup>3</sup>

g. Greater emphasis in addressing substance abuse is placed on the criminal justice system rather than through treatment modalities. The "war on drugs" has designated far greater resources to police and jails than to treatment. "It is fundamentally unjust, as well as unwise, to tell those who seek treatment for drug addiction that there is no room; but then tell them that the taxpayers are willing to spend thousands of dollars a year to keep them in jail."<sup>11</sup>

The number of HIV-infected people who report drug use (either injection of drugs or trading sex for drugs) as a risk behavior continues to climb. In Virginia the percentage of AIDS cases associated with injecting drugs has increased from 12.3% prior to 1986 to 17.3% in 1991. This does not include people infected because of exchange of sex for money or drugs. If the current trend continues, the need for education will become even more intense. Because only 20% of injecting drug users will enter treatment in a given year,<sup>12</sup> more emphasis must be placed on reaching drug users on the street.

### 4. Recommendations

a. Substance abuse treatment must be made available on demand.

- b. Consistent with the recommendations of the National Commission on Acquired Immunodeficiency Syndrome, any approach that can be shown to be effective in slowing transmission of HIV among IDUs should be employed. Increased efforts need to be directed toward street outreach programs. This includes widespread distribution of bleach and condoms as well as the initiation of a needle exchange program.
- c. In order to combat controversy regarding bleach distribution and/or needle exchange programs, legislators, law enforcement personnel and other elected officials should be educated about the growing body of research that points to the effectiveness of these programs.
- d. Support and reward educators who conduct street outreach.
  - 1. AIDS educators who conduct street outreach should receive salaries that correspond with the salaries of other AID:
educators. This is a significant factor in retaining effective messengers who work in dangerous settings.

2. Continuing education/professional development opportunities should be provided to educators who conduct street outreach. These individuals should have the opportunity to "rotate" off the streets periodically and perform/learn other responsibilities within their organizations. A psychological support system should also be provided for these individuals.

# E. PEOPLE OF COLOR

#### 1. Results of Knowledge, Attitudes and Behavior Surveys

African-Americans in low income neighborhoods were surveyed during 1990. Few respondents claimed to know a lot about AIDS. Younger people (18-29) were more likely to know a lot or some about AIDS than were their older counterparts. Most knew how AIDS is transmitted, but a significant number believed that a cure or vaccine for AIDS is available. Nineteen percent of those surveyed were doubtful of information supplied by federal public health officials and an additional 21% do not know what to believe. Virginia surveys of other African-Americans are being conducted.

## 2. Current Activities

Special programs provide outreach to populations of color in heavily impacted areas. The health departments of Norfolk, Alexandria, Arlington and Richmond City have received special funds to contract with community-based organizations serving people of color. Strategies include street outreach to injecting drug users and prostitutes, home health parties, education to church congregations, AIDS awareness days in public housing projects and Distribution of literature has been expanded to conferences. non-traditional settings such as beauty and barber shops, sporting events, and family reunions. Education is targeted primarily to African-American populations, although Hispanics are also targeted in the Northern Virginia area. VDH pamphlets and videos are available in Spanish with limited quantities of some materials available in approximately 12 other languages. The American Red Cross conducts a train-the-trainer program for educating African-Americans and Hispanics.

### 3. Gaps and Projected Future Needs

- a. Outreach to communities of color is not commensurate with the disproportionate prevalence of HIV in the population.
  - 1. Outreach to Asian/Pacific Islander and migrant communities is insufficient. Asian populations in Virginia have risen 140% in the past decade. These communities are located primarily in Northern Virginia and Tidewater.<sup>13</sup> While there are some resources in Northern Virginia, little outreach has

been undertaken in the Eastern region. These communities may not have the level of education that the general population has received. Socioeconomic status, language barriers and illiteracy all contribute to this problem.

- 2. There is little education targeted to Hispanics outside the Northern Virginia area.
- 3. Outreach to people of color, especially African-Americans, in rural areas is inadequate. Outside of metropolitan areas, there are no AIDS Service Organizations with a primary focus on people of color.
- 4. Messages are not always culturally sensitive and tailored to a particular community. This creates communication barriers.
- 5. There is a wide diversity in language, customs and beliefs within ethnic groups. This is not always recognized by educators who may utilize a single approach within an ethnic group.
- 6. Health clinic staff members are often burned out.<sup>14</sup> Health clinic staff frustrations are sometimes exacerbated in caring for people of color who may require unique understanding and sensitivity of their differences as these characteristics impact health care provision. The staff member who is burned out may be unwilling to meet this challenge. Therefore, often clients of color leave a clinic not understanding procedures, treatment or testing.<sup>15</sup>
- b. Many community-based organizations serving people of color provide superb services and can access individuals that are out of reach of the health department and other human service agencies. However, administrative details within organizations may lack sufficient coordination and follow-up. This can contribute to difficulty in competing for funds and completing contractual requirements.
- c. There is a reported belief among many African-American communities in Virginia and the United States, that HIV was created by the government to exterminate their race. These individuals are distrustful of any prevention messages offered by the government or the state.<sup>3,16</sup> A needs assessment conducted in Virginia showed that 40% of African-Americans surveyed either were doubtful of information supplied by health officials or did not know what to believe about AIDS.<sup>9</sup> This mistrust makes it difficult to convey vital prevention information.
- d. Because of socioeconomic status, jobs, housing, and food are daily concerns that take precedence over concerns about HIV and AIDS.<sup>3</sup>

People of color, specifically African-Americans, have shown a steady increase in Virginia AIDS cases. Before 1986, 24.5% of cases reported were African-Americans compared to 47% of cases reported in 1991. Sixty-two percent of HIV infections reported in Virginia are among people of color. The majority of women and children with AIDS in Virginia are African-American. This disproportionate trend demands increased efforts and resources.

#### 4. Recommendations

- a. Improve outreach to all people of color.
  - 1. Recruit additional people of color for health departments and AIDS service organizations.
  - 2. Because many people are reluctant to go to a clinic or lack transportation or financial means to do so, mobile units which can disseminate health information and provide testing should be utilized.
  - 3. Burn out and cultural sensitivity should be addressed for health clinic staff. Salaries that attract and retain qualified and committed staff must be offered.
  - Train health clinic staff to communicate clearly with people of color and ascertain understanding of procedures with these clients.
  - 5. Messages, programs, and formats intended to work for communities of color should be tested, evaluated, and tailored in such a way as to address the specific needs of those communities, using their language and working within their cultural systems.
- b. Develop and strengthen organizations responding to HIV issues in communities of color.
  - 1. Assist in the development of additional organizations whose purpose is to focus on communities of color, especially in rural areas.
  - 2. In order to help communities of color meet requirements for competitive funding, the VDH and regional consortia should provide additional technical assistance and support. This will help them to conduct the vital educational outreach for which they are uniquely qualified.
- c. Work with communities of color to address the perception of conspiracies and enhance trust of prevention messages.

### F. ADOLESCENTS

### 1. Results of Knowledge, Attitudes and Behavior Surveys

During the spring of 1992, the first statewide youth risk behavior study of high school students will be conducted. A middle school youth risk behavior survey will be developed and implemented during the spring of 1993, along with the second year of the secondary survey. A survey of college students was completed in 1990. As noted with other populations, most college students correctly identified how AIDS is transmitted, but a high proportion incorrectly identified activities which do not transmit HIV. More than two-thirds wanted more information on transmission and prevention. Seventy-five percent of the respondents report being sexually active; however, only 25% of those reported routine use of condoms. Women were less likely than men to report that condoms were used.

National data indicate that young women first engage in sexual intercourse at 16.2 years of age and young males at 15.7 years. Only 24% of sexually active adolescents use a contraceptive consistently and 1 in 6 teens contracts a sexually transmitted disease.<sup>19</sup>

### 2. Current Activities

Education targeted to youth has been coordinated through the Department of Education (DOE) with much attention focusing on training. comprehensive health education teacher Nine teacher-training centers are funded to train teachers and administrators in local school divisions. The Department has joined with the National Network of Runaway and Youth Services in providing training sessions for persons serving high risk youth. The Family Life Education Program, which is mandated for all school systems, includes HIV/AIDS information beginning at the fourth grade level. The Comprehensive School Health Education Curriculum also incorporates such information. AIDS education is mandated for students at institutions of higher learning. The American Red Cross sponsors youth facilitator programs and courses on outreach to youth in high-risk situations. Several ASOs, coalitions and other agencies conduct peer education programs for youth.

### 3. Gaps and Projected Future Needs

- a. A school survey conducted in Virginia showed that over 1,000 teachers of HIV/AIDS prevention education and Family Life Education need training in AIDS and sexuality issues.
- b. The content and amount of AIDS education varies drastically from school system to system.
- c. The majority of AIDS prevention information in schools focuses exclusively on abstinence.

- d. Youth in detention centers, street youth, and students with disabilities do not have equal access to HIV education. Runaways and street youth are at extreme risk for HIV infection.<sup>17</sup>
- e. There is considerable variability in the quality, accessibility, and availability of HIV prevention education and condoms for college and university students. A national study found higher than anticipated HIV infection rates among college students.<sup>18</sup>

Because youth are continually entering the educational system, consistent long-term efforts will need to be maintained. The age at which people are becoming infected with HIV is getting younger. In addition, HIV infection among adolescents shows a 1:1 ratio between males and females, indicating an increasing incidence of heterosexual transmission. Because of the incubation period of HIV, many people with AIDS who are in their 20s were infected as teenagers.

#### 4. Recommendations

- a. The Department of Education should continue and enhance its support and commitment to HIV/AIDS prevention education programs for children and adolescents.
- b. Any state programming should build coalitions with the National Association of School Boards, National Association of State Boards of Education, Council of Chief State School Officers, National PTA and American College Health Association.
- c. The importance of a comprehensive school health education program should be stressed to legislators.
- d. Sexuality, substance abuse, and self-esteem issues should be core components of comprehensive school health instruction.
  - 1. AIDS education should be incorporated into the substance abuse teacher training workshops and programs.
  - 2. All schools should be required to accomplish a minimum number of goals and provide a minimum number of hours of HIV/AIDS instruction.
  - 3. HIV prevention education programs of all agencies and institutions should include information at appropriate developmental stages, on abstinence, alternatives to sexual intercourse, and on the use of condoms for those who are already sexually active.
  - 4. Curricula should include instruction in decision-making skills needed to make safe choices.

- 5. The Departments of Education and Health should be the lead agencies in HIV inservice education and curriculum development.
- 6. Condoms should be made available to sexually active young people.
- e. HIV and sexuality education should be incorporated into teacher preparation programs in colleges.
- f. Youth with special needs should be provided with adequate levels of AIDS education.
  - 1. Youth in juvenile detention centers should receive education on a regular basis.
  - 2. Programs should be implemented that reach a wider range of youth including sexual minority youth, youth of color, out of school youth, and youth with disabilities.
- g. HIV prevention education, including skills-building, should be available to all college students.
- h. Private schools should be encouraged to include HIV education in their curricula.
- i. Coordinated efforts between the Department of Education and other agencies should be strengthened to encourage HIV prevention efforts within the school system.

# G. WOMEN

#### **1. Current Activities**

Issues specific to women have not been addressed through KAB surveys in Virginia. Women, especially women of color, are being targeted through several programs. Home health parties are being conducted in a few areas by community-based service organizations. Education is being provided in some shelters for women and in women's prisons. A statewide conference on women's issues which was sponsored by an AIDS service organization was held in 1990. Family planning and maternity clinics also provide HIV prevention education to women.

#### 2. Gaps and Projected Future Needs

- a. Current messages in Virginia inadequately address women's specific issues in HIV prevention.
  - Women are repeatedly told to convince their partner to wear condoms. Women may have very little control over this situation, especially battered women who risk physical injury if they insist on safer sex.

- 2. Some women believe the birth control pill will protect them from contracting sexually transmitted diseases.
- 3. Some women do not have the skills to negotiate sexual encounters. Men's expectations and women's perceptions of their role as passive and subservient to men's needs may prevent women from protecting themselves.<sup>20</sup>
- b. Prostitutes and pregnant women are often viewed as transmitters of HIV, not as people who are at risk for infection themselves.<sup>3,21</sup> There is a fear that criminalization of transmission to children will prevent women from seeking prenatal care.
- c. Virtually no information is available for lesbians. Many teenage lesbians have sex with men (especially gay men) in the process of recognizing their sexual orientation and are therefore at risk.<sup>22</sup> This may also place future sex partners at risk.
- d. Female partners of bisexual men may not know they are at risk. Men who have sex with men may be married to women.
- e. Health care providers, especially obstetricians and gynecologists, often do not recognize that their female patients may have a risk factor for HIV and deemphasize the need for testing.
- f. The women at highest risk for HIV, women of color and women who are partners of IDUs, lack access to traditional channels of information because of their socioeconomic status. Many men do not let their female partners know that they inject drugs.<sup>3</sup>

The percentage of AIDS cases among women in Virginia has steadily increased from 4.7% prior to 1986 to 12.9% in 1991. Women represent over 20% of the reported HIV infections in Virginia. Among teenagers with HIV, there is a 1 to 1 ratio of males to females. Increased attention must be given to preventing HIV among women, especially women of color who are overrepresented in seroprevalence data.

# 3. Recommendations

- a. HIV messages should be incorporated into the realm of all women's health issues. Situations in which family planning and birth control issues are discussed should include information on preventing STDs and AIDS.
  - 1. Educators should work with women to address significant issues in their lives (e.g. a hostile male partner who refuses to use a condom; coping with HIV risks after the end of a relationship).

- 2. Work with men on skill development that includes awareness of women's issues and addresses relationships, sharing power, and condom use. Increase awareness among educators and service providers that a woman's ability to enforce condom use by a partner is extremely limited.
- 3. Target campaigns on condom use directly to men.
- 4. Explore the availability and effectiveness of alternative prophylaxis that can be controlled by women.
- b. Avoid criminalizing transmission of HIV from women to their infants. Ensure that reproductive options for women with HIV disease are protected.
- c. Recognize that lesbians are also at risk for HIV infection. Develop specific information messages for women who have sex with women.
- d. Educate health care providers to recognize women's risk of acquiring HIV.
- e. The specific educational and service needs of women of color and lesbians should be determined through periodic needs assessment surveys that place emphasis on these populations. Educators should work more closely with women of color and lesbians to develop effective, culturally sensitive strategies.

# H. INMATES

#### 1. Results of Knowledge, Attitudes and Behavior Surveys

Questionnaires were administered to persons during intake into Virginia correctional facilities during 1989. The survey showed high levels of risk-taking behavior among these individuals. Eighteen percent of the men and 28% of the women admitted sharing IV drug needles. Only one in four said they knew a lot about AIDS. Most knew how AIDS was transmitted, but over half thought AIDS could be transmitted through casual contact. Seventy-two percent of the men and 36% of the women said they did not want to live around people with HIV. More than half of the respondents requested additional information about AIDS.

#### 2. Current Activities

Education to inmates is extremely limited and varies from area to area. AIDS Service Organizations are allowed into some facilities. The VDH maintains a contract with the Medical College of Virginia to educate staff of correctional facilities.

#### 3. Gaps and Projected Future Needs

- a. Condoms are not allowed in Virginia jails or prisons.
- b. Staff attitudes do not facilitate AIDS education. Some administrators report that they do not have the staff to monitor group educational sessions for inmates. Unless staff are educated, they may not see the value of inmate education.<sup>23</sup>
- c. Persons who express an interest in education may be suspected of being HIV positive or homosexual and risk physical injury from staff or other inmates.
- d. Incarcerated persons engage in activities that put them at risk for infection including sex, drug use and tattooing.

## 4. Recommendations

- a. Condoms should be made accessible for inmates. To allow distribution of condoms in prisons, remove Virginia statutes governing crimes against nature.
- b. A comprehensive education program for both staff and inmates should be implemented.
- c. Condoms and safer sex information should be included in pre-release activities.
- d. Education of inmates' families should be introduced.

In addition to the gaps presented for the seven population groups, education and outreach efforts targeted to the following populations were also identified as deficient: the hearing impaired, other people with disabilities, and hemophiliacs. The need to educate legislators about the disease and effective methods of HIV prevention was also emphasized. In addition to the recommendations already presented, the following priority recommendations not relating to specific groups were also identified:

- 1. Ensure that adequate resources are allocated so that prevention funds are not shifted to meet increasing service needs.
- 2. Expand funding for the AIDS Services and Education Grants Program established by the 1989 General Assembly through House Bill 1974. It has provided funding for some of the most innovative prevention education to underserved populations in Virginia, and can be used for reaching the target populations discussed in this section. The current \$200,000 appropriation for this program is less than half the amount that was initially recommended.

- 3. In order to monitor the effectiveness of educationa. intervention, continue to assess the knowledge, attitudes, and behaviors of the public at a minimum of every 3 years.
- 4. Involve affected populations in the development of prevention messages and outreach efforts.

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# IV. HEALTH CARE PROVIDERS

# A. BACKGROUND

The provision of comprehensive, multidisciplinary care to the person with HIV disease and significant others is contingent upon the availability and accessibility of health care providers (HCPs). An effective HCP must be knowledgeable about the disease, willing to treat the HIV population, geographically accessible, and linked with a network of case management services.

In an effort to document potential educational and service gaps, the Virginia Department of Health (VDH) contracted with the Virginia Commonwealth University Survey and Research Lab (SRL) to conduct and analyze knowledge, attitudes, and behavior (KAB) surveys of physicians, dentists, social workers and counselors, emergency medical technicians (EMTs), and nurses. Most of these groups were initially surveyed in 1988 or 1989 and again in 1990 or 1991, thus providing trend data.

The table below presents the geographic distribution of HCPs who have cared for at least one HIV positive patient. Data from the spring of 1990 shows a general concentration of HCPs in the northern, eastern, and central regions, respectively. This approximates HIV morbidity.

## GEOGRAPHIC DISTRIBUTION OF VIRGINIA HEALTH CARE PROVIDERS HAVING CARED FOR AT LEAST ONE HIV POSITIVE PATIENT Spring 1990

	NW	Northern	SW	Central	Eastern	Total
Physicians	1,761	3,227	1,862	2,622	3,029	12,501
Dentists	390	919	520	683	820	3,314
RNS	6,901	12,594	8,483	9,465	11,850	49,293
LPNS	3,009	1,755	5,225	4,678	5,425	20,092
Licensed Counselors	186	238	173	219	278	1,094
Social Workers	139	437	85	276	304	1,241
Substance Abuse Staff	386	384	691	309	572	2,342

Unfortunately, these numbers overrepresent the amount of HCPs actively treating persons with HIV disease as distance and lack of willingness to treat such patients can be prohibitive. Trend data below demonstrates a two-year increase in the experience of these HCP groups. Dramatic gains are noted in all areas, most impressively with dentists. However, less than 40% of the surveyed dentists, EMTs and mental health clinicians have knowingly treated an HIV positive patient as of the time of the 1990 survey.

#### EXPERIENCE WITH HIV



Percentage that have treated HIV patient

• no 88 data on SA staff/90 data on EMTa

Reluctance by a HCP to care for HIV positive patients or those who exhibit high-risk behaviors was also surveyed. As shown on the graphs on the following page, in 1988 alarmingly high rates of reluctance, especially among dentists, physicians, and EMTS were documented. By the time of resurvey in 1990, this reluctance had declined. This may be related to the statewide efforts of the VDH, professional societies and specific leaders in those societies, as well as the implementation of the Regional AIDS Resource and Consultation Centers (RARCC) to educate and support HCPs who treat or are considering treating persons with HIV disease. **RELUCTANCE TO TREAT HIV PATIENTS\*** 



\*Percentage not too/not at all willing

#### RELUCTANCE TO PROVIDE CARE TO HIGH RISK GROUPS\*



1988

\*Percentage not too/ not at all willing

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However, the survey data is still disconcerting. One in five surveyed nurses and physicians is reluctant to care for persons with HIV disease. More than one out of three dentists is unwilling or hesitant to provide such care.

The source of this reluctance may be inadequate professional preparation in HIV/AIDS, misconceptions about transmission with resultant fear, lack of support/case management services to assist the individual provider, concerns for reimbursement, or the lack of awareness of anti-discrimination laws. The table below captures trend data on perceptions of HCP subgroups regarding transmission of HIV in an effort to measure the knowledge basis and fears of HCPs.

## PERCEPTIONS ABOUT TRANSMISSION OF HIV 1988/1990

Percentage that said transmission was very or somewhat likely when procedure performed on HIV patient.

	MD	DDS	RN	LPN	EMT*	CLIN
Stuck with needle used on HIV pt.	80/87	86/85	80/95	83/95	81/-	NA**
Being splattered by blood	55/63	57/60	51/81	53/89	73/-	NA
CPR with mouth-to mouth rescue.	51/56	51/52	49/70	60/74	52/-	NA
Being splattered by saliva	32/32	32/30	29/49	38/62	42/-	NA
Performing/asst. with surgery	39/43	NA	25/66	32/73	37/-	NA
Oral surgery	NA	48/51	NA	NA	NA	NA
Dressing wounds	29/27	NA	19/54	32/66	43/-	NA
Being splattered by urine	26/27	NA	31/50	38/65	43/-	NA
Tooth extraction	NA	44/48	NA	NA	NA	NA
Doing a physical or intraoral exam	2/3	4/5	4/9	7/17	10/-	NA
Entering room with HIV patient	2/2	1/2	4/6	5/11	13/-	NA
Touching same objects as pt.	NA	NA	NA	NA	NA	1/1

\*1990 data for EMTs is not yet available. \*\*"NA" refers to "not asked." Of note are the increasing concerns for transmission by nurses when exposed to body fluids such as saliva and urine or when merel entering a room. These are activities noted by the Centers for Disease Control (CDC) to be of very low personal risk. Of concern, too, is the small but increasing percentage across the subgroups who perceive performing a physical or intraoral exam as very or somewhat likely to be a potential for transmission of HIV. Keep in mind that the most common sources of nonprofessional medical information for HCPs (as denoted in the survey) were newspapers and television.

Cross-training of substance abuse staff and HIV/AIDS staff has become increasingly vital as seroprevalence data identify increasing HIV infection in the injecting drug user and decreasing infection within homosexual/bisexual populations. Paired surveys of direct care staff and clinical directors of substance abuse programs provided documentation of the substantial HIV-related training needs.

The table on the following page presents survey data relative to AIDS training and information needs of substance abuse direct care staff. As shown on the table, the percentages of substance abuse direct care staff who stated a need for more information on a broad range of HIV topics ranged from 34% who needed more information about prevention methods to 68% who needed more information about advances in treatment and prevention. Two-thirds wanted more information about psychological effects on staff who work with persons with HIV disease--an especially significant finding i light of the impact reluctance to provide care has been shown to have on client access and quality of service.

In a related KAB survey, substance abuse program clinical directors felt training needs were even more dramatic. Seventy-two percent expressed concern about the psychological effects on staff working with persons with HIV disease; 79% felt more training was needed about the psychological effects of AIDS on clients. Well over three-fourths of clinical directors felt their programs and staff were deficient in knowledge about the legal issues associated with HIV/AIDS, as well as about current advances in treatment and prevention.

### AIDS TRAINING AND ONGOING INFORMATION NEEDS SUBSTANCE ABUSE DIRECT CARE STAFF 1990

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TOPIC	HAVE HAD N	TRAINING* %	<b>WANT</b> N	INFO** %
Methods of AIDS prevention	441	96%	199	34%
AIDS-related symptoms	; 368	80%	278	48%
Psychological effect of AIDS on clients	287	62%	362	62%
Effect of AIDS on client's life	281	61%	274	47%
AIDS support services in the community	272	59%	213	54%
How to give pre- vention education	257	56%	298	51%
Advances in treat- ment/prevention	242	53%	393	68%
Effect of AIDS on family and friends	243	53%	296	51%
Medical care for HIV-infected clients	219	48%	300	52%
Legal issues	162	35%	339	58%
Psychological effects on staff who work wit HIV-infected clients	143 h	31%	388	67%
Cultural issues for AIDS counseling among minorities	95	21%	317	55%
Financial help for HIV-infected clients	73	16%	342	59%

- \*Among respondents who have had on-the-job training about AIDS, percentage who said this topic had been addressed in their training session.
- \*\*Percentage of all respondents who said they would personally like to have more information about the topic.

Reimbursement, especially for indigent care, also influences a HCPs' willingness to accept persons with HIV disease. With the seroprevalence shifts to more indigent populations, financial constraints as a reason to avoid providing care will increase. Unless a broader base of HCPs is developed, unreasonable demands will be placed on those individuals and institutions currently providing care for the person with HIV infection or AIDS.

HCPs may also be unaware of antidiscrimination legislation under Section 504 of the Rehabilitation Act of 1973. This act prohibits discrimination on the basis of handicap in programs or activities receiving or benefiting from Federal financial assistance. Persons with AIDS or HIV disease, including those who are asymptomatic and currently show no signs of infection, are considered to be handicapped under Section 504. As such, they have the same right as anyone else to employment, health care, and welfare and social services. As persons with HIV disease become more aware of their civil rights, these issues may be tested in health care settings.

A recent issue of national impact that will likely also increase the reluctance of HCPs to care for persons with HIV disease is the concern about HCPs with HIV disease. The AIDS Medical Advisory Committee (AMAC) of the VDH and the AIDS Task Force support the CDC "Recommendations for Preventing Transmission of Human Immunodeficiency Virus and Hepatitis B Virus to Patients During Exposure-Prone Invasive Procedures," as presented in the July 12, 1991 Morbidity and Mortality Weekly Report (MMWR). The major points of the quidelines follow:

- 1. All HCPs should adhere to universal precautions and should comply with current guidelines for disinfection and sterilization of reusable devices used in invasive procedures.
- 2. Current data provide no basis for restricting the practice of HCPs with HIV or hepatitis B virus (HBV) infection who perform procedures not identified as exposure-prone and who comply with universal precautions and current recommendations for sterilization and disinfection.
- 3. Exposure-prone procedures should be identified by medical/ surgical/dental organizations and institutions at which procedures are performed. (A more explicit definition of "exposure-prone" procedures will be developed by the CDC with input from experts, health care organizations and professional societies and will be published in November 1991.)
- 4. HCPs who perform exposure-prone procedures should know their HIV antibody status and their HBV surface antigen (HBsAg) status.
- 5. HCPs with HIV or HBV infection and are hepatitis B e antigen positive (HBeAg) should not perform exposure-prone procedures

unless they have sought counsel from an expert review panel and have been advised under what circumstances, if any, they may continue to perform these procedures. Such circumstances would include notifying prospective patients of the HCPs seropositivity before they undergo exposure-prone invasive procedures.

6. Mandatory testing of HCPs for HIV antibody, HBsAg or HBeAg is not recommended.

Mandatory testing of HCPs is not recommended by AMAC and the AIDS Task Force for the following reasons:

- 1. the lack of sensitivity of the HIV antibody test.
- 2. the window period phenomenon, where the antibody test does not become positive for at least 6 weeks to 6 months after acquiring the virus. A negative test does not guarantee that an individual is free of HIV infection.
- 3. the cost of testing, including not only the cost of the test itself but the cost of extensive record keeping by institutions or health regulatory groups. These high costs would divert resources from needed treatment and prevention programs.
- 4. uncertainty about the appropriate frequency of testing.
- 5. the high rate of false positives in low prevalence populations.
- 6. the extremely low risk of transmission from infected health care workers to patients, even when exposure-prone procedures are performed. It is more likely that transmission of HIV occurred in the Florida dentist's office due to inadequate sterilization techniques than due to direct dentist to patient transmission.
- 7. uncertainties concerning the effect on overall health care delivery.
  - a. decreases in the number of HCPs who are willing to care for persons with HIV disease and to assume a risk of acquiring HIV. The risk of acquiring HIV from a patient is much greater than the risk of transmission to a patient in a health care setting.
  - b. decreases in the number of persons choosing to enter patient care fields.

As a result of the CDC recommendations, the AIDS Task Force recognizes that it be the standard of care that HCPs who perform exposure-prone procedures know their HIV antibody status and follow CDC guidelines concerning counseling and obtaining patient consent prior to performing exposure-prone procedures if they have HIV disease.

The health care delivery system may also be negatively affected by the CDC recommendations. Unfortunately the impact cannot yet be quantified for a number of reasons which include: 1) the number of HCPs with HIV disease is unknown, and therefore the number of HCPs with HIV disease who will be unable to perform exposure-prone procedures is unknown, and 2) the number of HCPs who will be unwilling to treat persons with HIV disease for fear of personal infection with risk of employment losses is undetermined. It is reasonable to state, however, that the CDC recommendations are likely to decrease the willingness of HCPs to treat persons with HIV disease and to add another burden to the health care delivery system.

### **B. PAST AND CURRENT ACTIVITIES AND RESULTS**

#### Regional AIDS Resource and Consultation Centers

In an effort to increase the number of HCPs providing care to persons with HIV disease, the General Assembly in 1989 funded three Regional AIDS Resource and Consultation Centers (RARCC) through House Bill 1974, with a fourth resource center added in 1990. These centers have assisted the health care community in a variety of ways. Each of the centers provides timely access to professional consultation and education on HIV-related issues through a toll-free telephone line. Centers have developed or are developing multidisciplinary teams of HCPs to provide didactic, clinical, and on-site training concerning the management of all aspects of HIV care. All centers are supported by an AIDS Resource Library, located at the University Library Services of Virginia Commonwealth University, which provides informational and library services on HIV-related topics to HCPs statewide through the resource centers. promote resource center utilization, To brochures have been developed by each resource center and are distributed to HCPs throughout each region.

Below is listed the statistical data for State FY91 furnished to VDH by the resource centers, concerning education, training and support services provided to HCPs in Virginia. As indicated, a large number of programs and consultations have been provided to HCPs through the resource centers, with significant expansion of clinical training programs anticipated in the coming years.

Educational Presentations	712
Health Care Provider Participants	23,215
Consultations Provided	5,429
Literature Distribution	119,102
Library On-line searches	156
Interlibrary loan requests filled	1,259
Clinical preceptorship program trainees	71

#### AIDS Education and Training Centers Serving Virginia

1. Mid-Atlantic Education and Training Center (MAARETC)

In the spring of 1988, the MCV AIDS Program became the Virginia Area Resource Center of the MAARETC under subcontract with the University of Maryland. This contract expired on May 31, 1991. As of June 1, 1991 the MCV AIDS Program became the central office for the recently funded Mid-Atlantic AIDS Education and Training Center (ETC). The ETC is funded through the Health Resources and Services Administration of the Public Health Service to provide training programs for HCPs in Virginia, with а focus in recent years on the training of dental professionals, home health providers, and clinical training of all HCPs. The focus of ETC-funded training for the present funding cycle concerns management of persons with HIV infection is directed to primary care providers, including and physicians, physician assistants, dentists, dental hygienists, and nurses and nurse practitioners.

2. District of Columbia AIDS Education and Training Center (DCAETC)

The DCAETC is a joint effort of Howard University Hospital and the George Washington University Medical Center, serving five counties in Maryland and six in northern Virginia. The goals of the DCAETC are: 1) to increase the number of health care practitioners who are able to address the special HIV/AIDS needs of the diverse populations in the region; 2) to increase the number of practitioners who can function as HIV educators to other health care providers; and 3) to act as a resource center for current, accurate information on HIV. Services developing available include consultation for agency lectures, workshops, educational programs, symposia and clinical preceptorships.

Virginia Area Health Education Center (AHEC)

Federal and state funding has been provided for the creation of a statewide Area Health Education Center (AHEC) in Virginia through the cooperative efforts of the three medical schools, the Virginia Department of Health and the Virginia Primary Care Association. The goal of the statewide AHEC is to increase access to education for primary care providers in the state. The AHEC will address the education of HCPs concerning care of persons with HIV disease as one priority and will be working closely with the resource centers and the ETC to expand HIV/AIDS education efforts for primary care providers throughout the state.

# C. GAPS AND PROJECTED FUTURE NEEDS

Through federal and state-funded efforts complementing individual, institutional and nonprofit ventures, great strides have been made which enhance the level of HIV-related knowledge among most disciplines of HCPs within Virginia. As shown by KAB studies and the expansion of HIV/AIDS referral lists compiled by VDH, these educational efforts have had a documented effect on the knowledge level and recruitment of providers to care for persons with HIV disease. This, however, is only a beginning as recent CDC recommendations mentioned earlier, negative attitudes towards those with HIV infection and those at risk, geographic barriers, reimbursement issues and case management concerns continue to dissuade a HCP from caring for persons with HIV disease.

The RARCCs have provided programs with a positive impact on recruitment, education, and attitudinal changes of HCPs in Virginia. These programs will be of increased need in the 1990s as the populations of those with HIV infection shift to those with greater medical and psychological management needs and as options for medical management and early intervention increase. As the number of people with HIV disease and with advanced immunosuppression grows and as the lifespan of an individual with HIV infection increases, the need for competent HCPs willing to care for those with HIV disease will also increase. Sixty-three percent of the cities surveyed by the U.S. Conference of Mayors Report in June of 1991 reported strains in staffing as major problems, including shortages, education needs, and staff burnout and turnover. Therefore, increased demands will be placed on the RARCCs to recruit and maintain competent staff as the demands for resource center services increase.

The RARCC will continue to work closely with the federally funded ETC to expand education and training opportunities for all HCPs concerning AIDS related issues. Resource centers and the ETC will be working closely with the recently established AHEC program to focus training on primary care providers working in medically underserved areas in Virginia.

#### D. RECOMMENDATIONS

- 1. Continue and expand RARCC programs. The on-site clinical component of these programs which provides hands-on experience with persons with HIV infection should be expanded. The consolidation of current information at these referral sources will avoid duplication of educational efforts and help meet the HCP's need for clinical updates. Counseling and testing training courses also will need to be expanded as the demand for HIV antibody testing increases.
- 2. Incorporate HIV/AIDS education into professional continuing educational programs and professional health care schools.

Programs should routinely offer continuing education (CEU or CME) credits to increase program participation. Programs should not only increase the provider's knowledge base, but should also effectively address prevention counseling strategies, attitudes of providers towards persons with HIV disease, and the ethical responsibility to treat such persons.

- 3. Elicit professional society support for increased willingness of HCP providers to care for those with HIV disease and their families, with expanded awareness of the obligation to treat and the implications of anti-discrimination legislation.
- 4. Increase access to clinical components of training for HCPs regarding management of HIV infection through the RARCCs and health care professional schools.
- 5. Endorse recent CDC "Recommendations for Preventing Transmission of Human Immunodeficiency Virus and Hepatitis B Virus to Patients During Exposure-Prone Invasive Procedures". Emphasize the necessity for all HCPs to utilize universal precautions with <u>all</u> patients and to adopt adequate infection control policies in the work setting.
- 6. Increase training of HCPs in both substance abuse and HIV related issues and the interrelation of these two health care areas. As HIV infection increasingly moves into the substance abusing population, professionals will need to be educated in both areas to meet client needs. Increase cooperation between the Departments of Health and Mental Health, Mental Retardation, and Substance Abuse Services.
- 7. Personalize caring for persons with HIV disease through public service announcements and testimonials which address health care professionals' fears and attitudinal changes. Television and print media should be utilized to effect attitudinal change towards those with HIV infection.
- 8. Continue to provide case management for the Commonwealth for persons with HIV disease to provide support for primary care providers through the promotion of comprehensive, multidisciplinary care.

Recommendations 1, 2, 4, and 6 are consistent with recommendations made by the National Commission on AIDS.

#### References

 The United States Conference of Mayors, <u>The Impact of AIDS on</u> <u>America's Cities</u>: <u>A 26 City Report for the U.S. Conference of</u> <u>Mayors Task Force on AIDS</u>. June 1991.

# V. COUNSELING AND TESTING SERVICES

# A. BACKGROUND

The fundamental purpose of HIV counseling and testing programs is to educate individuals about risk behavior and risk reduction, inform them of their HIV status, and promote individual action that will interrupt HIV transmission, including the initiation of early intervention services.

Many persons with HIV disease in Virginia are unaware of their HIV status, and are thus unable to access early intervention services at the most opportune time. In the absence of an HIV disease cure, behavior change is considered the greatest hope in altering the course of the disease. Studies indicate that many individuals are more likely to change their sex and needle-sharing behavior after having gone through the testing and counseling process, where personalized risk assessment is an integral part of the interview (Godfried, 1987). Counseling and testing services assist individuals with reduction decision-making regarding risk (including risks to themselves and the risk of infecting others), partner notification, and early medical intervention steps that can enhance and prolong life. Discussion regarding counseling and testing services must focus on the proper role of tests for HIV infection. A number of factors must be taken into account when considering appropriate uses of HIV antibody testing: the social and psychosocial ramifications of the test, the expense of testing and the labor-intensive nature of counseling, the accuracy of the test in terms of the number of false-positive and false-negative results, and the degree to which test information can be protected from unauthorized access. Benefits of testing include:

- 1. The assurance of a safer blood supply, through screening of blood, tissue, and organ donations;
- 2. Voluntary testing opportunities for individuals at risk who may benefit from early medical intervention;
- The availability of important information that may assist individuals with decisions regarding risk behaviors, pregnancy and employment;
- 4. Enhanced medical diagnosis;
- 5. Follow-up of occupational exposures.

Testing is an important attraction in being able to provide risk reduction and health promotion in an effective one-on-one setting, which has been shown to be the most effective method in helping individuals personalize HIV messages.

# **B. PAST AND CURRENT ACTIVITIES AND RESULTS**

When screening for HIV antibody began in the state's blood banks in 1985, four alternate (anonymous) testing sites were established in the state in an effort to provide access to testing outside the blood banks for those felt to be at higher risk of infection. HIV antibody testing and counseling training for health care providers began in April 1986 in all regions of Virginia. Staff from the public health sector received training initially, with private sector participation beginning later in 1986. Counseling and testing services were first offered in local health department STD clinics in May 1986; family planning, maternity and TB clinics began offering these services during the next year. In April 1988, the State Board of Health directed that HIV antibody testing (with the informed consent of the patient) be routine in all STD clinics.

Other agencies and institutions also initiated HIV antibody counseling and testing. These included the Department of Corrections (DOC), the state's Methadone Treatment Centers, and Substance Abuse Treatment Centers. The Division of Consolidated Laboratory Services (DCLS) of the Department of General Services provides Elisa and Western Blot testing for specimens from the health departments, anonymous testing sites and some other state agencies.

Since HIV testing first began, two types of testing were offered - confidential, for which the patient provided his/her name and other identifying information, and anonymous, for which the patient is identified only by a coded number. House Bill 1974, effective July 1989, mandated informed consent for HIV antibody testing, and added HIV antibody positivity to the list of reportable diseases and conditions in Virginia. It also established 16 additional anonymous testing sites (ATS) and exempted them from the reporting requirement, as information necessary for reporting is not available.

Disease reporting and control regulations were changed by the State Board of Health (and authorized by House Bill 1974) to include voluntary partner notification services so that those individuals exposed to HIV could be located, counseled and offered testing.

Collection of demographic data on HIV counseling, testing, and partner notification in STD clinics began in September 1986. From September 1986-May 1991, 222,124 persons presented for services in STD clinics statewide; 189,876 patients were pre-test counseled. Pre-test counseling serves as a valuable HIV/AIDS education experience, emphasizing motivational messages designed to alter risk-associated behavior. As of May 1991, 78,814 (41.5%) of those persons pre-counseled elected to be tested. Anonymous testing is provided currently at 18 sites in the state; two sites are in the process of being relocated to improve accessibility. The number of patients utilizing ATS continues to increase; the number tested has increased from an average of 123/month in CY 1987 through CY 1989 to nearly 368/month in CY 1990, and 410/month during the first five months of 1991. Accessibility of anonymous testing/counseling is variable around the state based on the ATS waiting time, which ranges from 1 to 30 days.

Voluntary HIV antibody testing was implemented in five drug treatment centers in Virginia in 1989 through a CDC cooperative agreement. The number of tests performed in these sites has increased steadily since the first quarter of 1990. (One hundred sixty-three patients tested first quarter 1990 vs. 309 patients tested second quarter 1991.)

The DOC has been working closely with AIDS education staff from the Medical College of Virginia since 1988 in developing a statewide AIDS testing/counseling policy for incarcerated populations. Currently, HIV antibody testing is available to inmates upon request.

Due in part to concerns related to the appropriate use of testing, and to safeguard the identification of those being tested, those state and local agencies for whom the Division of Consolidated Laboratory Services (DCLS) provides testing coordinate their programs with local health departments. The DCLS has the capacity to perform 200 - 400 Elisa tests a day. The more specific Western Blot testing is used to confirm the results of the Elisa test, and is technically more difficult to perform. Positive Elisa tests are "batched" for Western Blot testing, which occurs once a week. Turnaround time for the testing process (from receipt to mailed out report) is 7 - 21 days. The current demand per week is 1,500 Elisa tests, or 72,000 per year.

The number of tests by all private sources currently being provided is difficult to assess, since such data are not collected; however, two major reference laboratories were queried and at least 37,000 tests per year are being provided to health care providers contracting with these laboratories.

Obstetric and Gynecology (OB/Gyn) practices geographically representative of the state were surveyed regarding the counseling/testing provided for their clients. Of the 28 practices surveyed, none stated that counseling and testing is provided for all clients; eleven stated that testing was provided mainly for clients suspected to be at risk; eight stated that testing was mandatory for all OB patients.

# C. GAPS AND PROJECTED FUTURE NEEDS

- 1. Telephone surveys of 28 private OB/Gyn practices in Virginia indicate that adequate pre- and post-test counseling is lacking. When surveyed regarding the availability of counseling and risk assessment, responses ranged from "physicians will answer patients' HIV-related questions if asked," to "the physician brings the subject up if there is some suspicion of risk." Many private OB/Gyn practices require HIV testing of OB patients despite the lack of adequate counseling. Patients seeking retests at ATS as a "second opinion" consistently report that little or no risk assessment/risk reduction education has occurred previously with the private clinician.
- 2. Staffing levels in both confidential and anonymous test sites are often insufficient. Needs assessment data compiled by recent Ryan White Title II funding applicants cite the problem of insufficient staff as a hindrance in providing adequate counseling time to assure patient understanding before giving informed consent. More involvement is needed from mental health professionals to assist clients in dealing with complex issues related to HIV.
- 3. Substance abuse centers lack adequate numbers of staff trained in HIV pre- and post-test counseling. Of the 5 funded HIV counselors, 3 are located in one region; trained staff should be available in all regions.
- 4. HIV pre- and post-test counseling and personalized risk assessment for substance abusers is limited mainly to those in treatment.
- 5. Street outreach staff and AIDS Service Organizations report that an "information gap" exists regarding HIV testing; many at-risk individuals are unaware of the availability of testing and the medical benefits of early detection of HIV infection.
- 6. Turnaround time for positive HIV antibody tests is currently 2-3 weeks. Private laboratories report a 7-day turnaround time. In order to protect against the possibility of patients realizing (or assuming) that their test result is positive, all clients tested in public clinics and ATS must wait 2-3 weeks to receive test results and post-counseling. Patients reveal in post-counseling sessions and in calls to the state STD/AIDS hot line that the extended waiting period often heightens stress and anxiety.
- 7. CD4 count testing to determine the progression of HIV infection is currently unavailable in the vast majority of confidential and anonymous test sites.

- Monitoring of plasma centers throughout Virginia is inadequate. Physician surveys and hot line calls reveal concerns regarding continued participation of at-risk individuals in plasma center donations.
- 9. There is a need for development and production of ageappropriate (including adolescent) and reading-level appropriate educational and informational materials about the importance of HIV antibody testing and risk reduction measures.

# D. RECOMMENDATIONS

- 1. Assess and change anonymous test site locations where appropriate to improve geographic accessibility. A greater effort must be made to target voluntary testing campaigns toward people of color.
- 2. Provide CD4 cell count testing in each ATS and public clinic where screening is taking place at the time of post-counseling.
- 3. Increase Division of Consolidated Laboratory Services staff to decrease the current 2-3 week wait for positive test results.
- 4. Expand the staff of the HIV antibody testing and counseling program in drug treatment centers throughout the state.
- 5. Continue to offer HIV antibody testing and counseling training to appropriate health care providers in all regions, through collaborative efforts of the Virginia Department of Health and the Regional AIDS Resource and Consultation Centers. Increase the level of involvement in the training by private sector representatives. Enhance the collaborative effort between test site staff and mental health specialists, in order to increase psychosocial support and counseling services for individuals considering or undergoing testing.
- 6. Public education related to medical information and its release and use needs to be continually provided. Include information regarding HIV testing and counseling in educational presentations in order to highlight the benefits of knowing one's HIV status and to reduce anxiety regarding the testing process.
- 7. Continue to offer voluntary, confidential partner notification assistance for infected individuals who may be afraid, embarrassed, or unwilling to notify partners themselves.

# VI. PRIMARY CARE SERVICES

# A. BACKGROUND

Primary care providers include nurses, nurse practitioners, physician assistants, dentists, dental hygienists, and physicians whose specialties include general medicine, pediatrics, obstetrics and gynecology, internal medicine, and family practice. These individuals have a critical role in addressing the HIV epidemic. Other disciplines contributing to the holistic care of the patient include registered dietitians, social workers, mental health and substance abuse counselors, and AIDS Service Organization staff. While most people with HIV disease will require inpatient hospital services on occasion, more attention must be focused on the more frequently needed community-based services. A basic goal is to provide care in the familiar surroundings of a local setting in order to promote general wellness, enhance the quality of life of those affected, and to lessen the burden on the health care system.

When provided with up-to-date medical information and access to appropriate medical consultation through Regional AIDS Resource and Consultation Centers, primary care providers can coordinate the total care of their patients. A continuum of care will depend upon establishing relationships among public health agencies, volunteer and community-based organizations, hospitals, home health agencies, nursing homes, private practitioners, and community health centers.

As the number of indigent patients increases, the burden of taking care of this epidemic may fall primarily on the Commonwealth's publicly-funded health systems, which may be inundated by a wave of patients as the changing epidemiological trends emerge. Preliminary HIV surveillance data indicates ongoing increases in the number of persons with HIV disease among heterosexuals (primarily women), injecting drug users, and newborns. Appropriate accessory volunteer community support groups will also have to grow proportionately with the increasing need.

## **B. PAST AND CURRENT ACTIVITIES AND RESULTS**

The availability/accessibility of health care services and primary care providers varies geographically in Virginia with marked differences between urban cities and rural counties. Accessibility to primary care providers is impacted significantly by such factors as lack of transportation, income, patient awareness and, of course, health insurance coverage. Of primary importance is the need to be able to afford and obtain services and medications close to home.

Senate Joint Resolution 179, passed by the 1991 General Assembly, required each health district director within the Department of Health to coordinate a community effort to assess community primary

care needs and to develop a public/private cooperative plan to meet those needs. Needs assessments have been completed and plans will be developed during 1992.

Throughout the Commonwealth, availability of primary care services for persons with HIV disease can be generally reflected by the "willingness to care" response provided by survey participants from the <u>AIDS-Related Knowledge, Attitudes and Behavior of Virginia</u> <u>Health Care Providers: The Statewide AIDS Needs Assessment, Volumes 1 & 2, 1988, 1989 (VDH, VCU/SRL).</u> According to survey results in 1989, the majority of health care professionals are willing to care for persons with HIV disease. The providers surveyed, the percentage indicating willingness to care, and their knowledge of infection are reviewed below:

<u>Willingness to care</u>	Knowledge
80%	90-97%
55%	80-100%
78%	80-100%
96%	80-100%
	<u>Willingness to care</u> 80% 55% 78% 96%

The resources for primary care for persons with HIV disease in each region are varied. Services are limited in the Eastern Region; many persons with HIV disease must seek services in Richmond at the Medical College of Virginia, due to the lack of local providers. In the Eastern region's South Hampton Roads cities, private practice providers and residents from the Eastern Virginia Medical School and the Medical College of Virginia supply evaluation and medical management in their offices, in hospital clinics, and in family practice residency sites. Indigent care is available through outpatient clinics at DePaul and Sentara Norfolk General Hospital; however, this care is available for Norfolk City residents only. In the Northern region primary care services for indigent, uninsured or underinsured persons unable to access care from private providers is managed largely by the Alexandria, Arlington, Fairfax, Loudoun, and Prince William County Health Departments and the Fairfax Hospital System. Many Northern Virginia residents access services at the District of Columbia's The Southwest region's Lynchburg Health Whitman-Walker Clinic. Department offers a pilot comprehensive HIV clinic for patients from throughout the district. Services offered include medical care, pharmacy services, laboratory evaluation, case management, personal care, home health, and mental health services. In the Central Region, health care is available through the Virginia Commonwealth University/Medical College of Virginia, and the Richmond AIDS Consortium. Volunteer sources are also providing primary care services. The Fan Free Clinic and the Crossover Health Clinic are two such agencies.

In each region early intervention services are provided through local health departments on a limited basis directly or by

arrangements with local providers. Physician referral networks for indigent patients are available through some regional AIDS Service Organizations.

# C. GAPS AND PROJECTED FUTURE NEEDS

- 1. At this point in the HIV epidemic, primary care services are concentrated in more populated areas as is the prevalence of the infection. Persons in rural areas needing care frequently must travel to population centers for services, increasing the likelihood of hospitalization for care and the compliance problems associated with treatment.
- 2. Primary care services for the "working poor" (non-Medicaid eligible, but with no health care insurance or other third party guarantor) may be limited by the budget of the recipient. Costs of medications and laboratory monitoring necessary for treatment are the elements of care most frequently cited as impediments to care by persons with HIV disease.

The majority of the needs assessments conducted by the health districts in response to SJR 179 reported that a problem requiring a great deal of attention is access to primary care for the indigent and working poor not covered by public funding or private insurance. This lack of access results in poor management of chronic disease and compromised continuity of care. Some districts specifically cited the problem of access relative to provision of STD/AIDS services.

- Continued stigma, fear of discriminatory behaviors or ostracism may promote reluctance to seek care, particularly in rural areas.
- 4. Professional stigma or loss of clients may impact on the reluctance of health care professionals to provide care for persons with HIV disease; however, this gap seems most acute in the area of dental care. All regions in Virginia have cited the unwillingness of dentists to treat persons with HIV disease as a service gap.
- 5. Referral sources for nutritional assessment, counseling and follow-up are inadequate in all regions.
- 6. Gynecological health needs of reproductive age women with HIV disease are not being met. OB/Gyn specialists affiliated with Virginia's teaching hospitals report that Gyn care, when available, is often difficult to obtain. Indigent patients in particular may not be referred appropriately for GYN care. Recommended services are often denied patients who do not meet Medicaid eligibility; rules are not altered to meet complex needs of HIV patients. Contraception is difficult to obtain for uninsured women.

- 7. The provision of sophisticated Gyn care (colposcopy, for example) is insufficient. This specialized care is especially important for women with HIV disease.
- 8. Telephone surveys of private OB/Gyn practices and patient reports indicate a physician education gap regarding risk assessment and risk reduction education for patients. Physicians are reluctant to obtain adequate sexual and substance use histories on patients.
- 9. Child care problems exist in all regions, making it difficult if not impossible for parents to keep their own medical appointments.
- 10. Pediatric care is inaccessible to many, as it is often restricted to institutions in urban centers. For example, the majority of pediatric cases in Northern Virginia are referred to Children's Hospital in Washington, DC, compounding compliance and transportation problems.
- 11. Facilities and personnel for establishing and maintaining a patient data base are critical needs. Consideration for establishing a network with other regions and the State Health Department is vital. At present, lack of this data base is inhibiting delivery of optimal primary care services, prohibiting the ability to view the present scope of the problem, and limiting adequate projections for necessary future resource needs.

# **D. RECOMMENDATIONS**

- 1. Provide access to laboratory tests needed in the evaluation of HIV/AIDS and its complications and establish a central purchasing system (through the provision of funds or pharmacy services) for medications needed by indigent patients.
- 2. Develop an outreach health care model for providing primary care services to HIV/AIDS patients; this model might be similar to the State Health Department Tuberculosis clinics of the past, and would supplement existing systems of care.
  - The actual and specific organization of the outreach health care model may not be homogeneous throughout the Commonwealth, but designed to respond to the different needs of each district. The optimal goal of this model remains the provision of primary outpatient care to promote general wellness and good health and thus avoid more expensive hospitalization as often as possible.
  - Outreach health care teams will provide clinic services onsite at existing and expanded community service agencies or health department clinics, depending on local resources. Sites and schedules will vary from locality to locality.

- Each facility will be staffed with a patient care coordinator (case manager), whose responsibilities will include 1) coordinating access to local primary care services and the outreach team, 2) scheduling and monitoring laboratory assessment, 3) coordinating treatment alternatives and 4) accessing community-based organizations. A patient care coordinator with a nursing background could appropriately triage patients according to clinical symptoms and psychosocial needs. Fifty cases maximum (at one time) per patient care coordinator is suggested because of the complexity of the disease and the demographics in mountainous and/or rural areas.
- The composition of the outreach health care team should include physicians with HIV/AIDS experience, clinical nurse specialists, social workers, registered dietitians, respiratory therapists, pharmacists, mental health workers, and substance abuse counselors. At each clinic visit the physician, clinical nurse specialist and patient care coordinator will see scheduled patients and also consult with local primary care providers. The other members of the team will attend clinic sites on an as-needed basis. All members of the team will be available for consultation on an ongoing basis.
- The provision of drugs to indigent patients will likely involve one or more of the following methods, some already established and some new:
  - a. through the local health department pharmacy,
  - b. prepackaged forms dispensed by fixed or mobile health care clinics,
  - c. through a hard plastic patient card the patient can present this card to any pharmacy in the state and get HIV-related medications, and
  - d. through a combination of the above methods.
- AIDS Service Organizations and support groups are an integral part of primary care and are critical to the model. Various types of patient support groups are needed. For instance, support groups for women, substance abusers and adolescents are already in place in different areas of the state. Other possible support groups may consist of male/female patients, families and their friends, or the uninfected children of AIDS parent(s).
- 3. District primary care plans developed in response to SJR 179 should address the needs of persons with HIV disease.

- 4. Integrate HIV risk assessment and risk reduction education into the health promotion aspects of all adolescent and adult primary care settings (e.g., obtain sexual and drug histories as routine components of all health histories as are smoking habits, diet, etc.)
- 5. Existing child health assessment programs should be extended to cover HIV-related conditions such as developmental disabilities.
- 6. Increase specialty care for women, including sophisticated Gyn care and substance abuse treatment. Many OB/GYN specialists treating women with HIV disease believe that current screening for GYN complications (i.e., pap smears) is often inadequate for HIV patients, which necessitates the use of more advanced tests and procedures to enhance the definitive diagnosis of GYN complications.
- 7. Enlist the support and assistance of medical societies in recruiting physicians who are willing to provide indigent care. Examples of medical disciplines that should be included are: Family Practice, Internal Medicine, Pediatrics, Obstetrics, Gynecology, Dentistry, Oncology, Cardiology, and Radiology.

# VII. INPATIENT SERVICES

# A. BACKGROUND

Presently it can be anticipated that virtually all persons with HIV disease will experience episodic hospital care during the end stage of their illnesses. The average annualized number of hospitalizations per year for a patient with AIDS is 2.74. The average estimated length of stay is 15.85 days for each admission and the average lifetime cost per AIDS patient for acute care hospitalization is \$63,840.<sup>1</sup>

Limited Virginia data are available relative to AIDS inpatient utilization. Data reported by ten Virginia hospitals responding to a National Public Health and Hospital Institute survey revealed that in 1988, an average of 30 AIDS patients were seen in each hospital with an average 1.76 admissions per patient yearly and an average length of stay of 17 days. More recent data from selected Virginia hospitals show decreased length of stays. In 1991 the length of stay for an AIDS patient at MCV was 9.5, compared to 13.5 days in 1987. Similarly, the average length of stay for an HIVrelated admission in the Fairfax Hospital System (four hospitals) in 1990 was also 9.5 days. Sentara Norfolk General Hospital reports an average length of stay of 14.14 days for an AIDS patient and an average stay of 9.6 days for patients with HIV.

Inpatient services are available to persons with HIV disease in Virginia through 101 short-term non-federal hospitals having 22,530 licensed beds. In 1990, the overall percent occupancy in Virginia hospitals was 57.7, with percentages ranging from a high of 63.0% for Health Service Area II (Northern VA) and a low of 53.5% in Health Service Area III (Southwest VA). Variances exist in the occupancy rates of individual hospitals, ranging from a high of 83.3% in Fairfax Hospital to a low of 18.5% in Buchanan General-Grundy location. (This excludes some short-term children's and ear, nose and throat hospitals which had occupancy rates outside this range.)

# **B. PAST AND CURRENT ACTIVITIES AND RESULTS**

The state has implemented several community-based care initiatives in an effort to decrease the need for hospitalization. These include the Medicaid AIDS Waiver Program, which was implemented in January 1990. This program provides reimbursement for persons with HIV disease who would otherwise need care in long-term care facilities. A limited number of patients have qualified for this program.

The Health Resources and Services Administration (HRSA) provided one-time funding for limited community-based services for patients with HIV disease. This grant provided the Department of Health with \$177,536, most of which was contracted to six personal care agencies. Additional HRSA funding under Ryan White Title II in 1991 provided \$970,120 for community care through HIV care consortium and the purchase of HIV medication. This funding provides for a range of outpatient services, including clinic care, transportation to services, case management, and dental care. Funding is not adequate to meet the anticipated outpatient needs.

### C. GAPS AND PROJECTED FUTURE NEEDS

Interviews conducted in August, 1991 with the directors of the Central, Eastern, and Western Virginia AIDS Resource and Consultation Centers and the director of HIV Services at Fairfax Hospital System revealed the following gaps relative to the availability and accessibility of inpatient services:

- 1. Although acute care hospitalization is available in the state, access is dependent upon payment source. By the time clients require the greatest amount of inpatient care, it is not unusual for them to have exhausted all their resources and be on public disability support or fall into the indigent care category. Patients without a payment source may have to travel extended distances to receive care at an acute care facility or a public or university-affiliated hospital. In non-emergency situations, accessing transportation to an acute care facility is difficult.
- 2. In areas where no public or university-affiliated hospitals exist, indigent persons with HIV or AIDS often access inpatient care by presenting at hospital emergency rooms. In one region, access to inpatient care is limited through the emergency room unless the patient has an admitting physician. When entering through the emergency room, patients are assigned to a physician on-call or to a house physician who provides medical care during the hospital stay. Referral sources upon discharge for indigent patients are scant as many primary care providers do not accept symptomatic patients. This not only leads to inadequate follow-up but more frequent and results in longer hospitalizations.
- 3. In instances where indigent patients receive primary care at MCV or UVA (as a consequence of many private primary care providers not accepting Medicaid or Medicare), community hospitals willing to accept indigent clients for emergency or inpatient care experience several obstacles in providing care. First, the attending physician is often unfamiliar with the patient's medical history which is vital for diagnostics and appropriate care. Second, expertise and specialized technological equipment may be inadequate in some hospitals.

Based on the overall state percentage of bed occupancy (57.7%) in Virginia's short-term non-federal hospitals, it appears that there is presently no shortage of beds for patients with HIV
disease. It is difficult to predict the future need for inpatient services because it is dependent upon the availability of outpatient services, clinical advances in disease management and the changing populations affected by the epidemic.

The following table provides a projection of the number of hospital beds which may be occupied on any one day by AIDS patients in Virginia for each year 1992-2001. The projection is based on Hellinger's estimate of 2.74 annualized admissions for AIDS patients and the average length of stay of 11.05 days based on data provided by MCV, Fairfax Hospital System and Sentara Norfolk General Hospital. One should be cautioned that the factors mentioned previously could alter these projections and that neither national nor local data on the average length of hospital admissions may be accurate for future projections of need.

YEAR	PROJECTED NUMBER OF AIDS PATIENTS ALIVE	NUMBER OF HOSP. BEDS OCCUPIED BY AIDS PT. ON ANY ONE DAY
1992	1305	108
1993	1646	137
1994	2028	168
1995	2450	203
1996	2914	242
1997	3418	284
1998	3963	329
1999	4550	377
2000	5176	429
2001	5843	485

Given the existing overall low utilization of hospital beds in the Commonwealth, it is anticipated that the projected level of hospital utilization can be managed. However, hospitals which serve more than the average number of indigent patients or hospitals which, because of their location in a metropolitan area or their reputation for providing high quality specialized services admit more than their share of patients with AIDS, may be affected more than others. In addition, some hospitals may experience problems financing acute care as the HIV population shifts from men who have sex with men to people of color, persons with multiple heterosexual partners, and women and children.

## D. RECOMMENDATIONS

- 1. Enhance outpatient services to decrease the need for hospitalization.
- 2. Increase State and Local Hospitalization (SLH) funds to the necessary funding level to cover the number of indigent HIV/AIDS patients being treated.

- 3. Continue providing educational programs for physicians and hospital personnel through Resource and Consultation Centers, particularly regarding the following:
  - a. Clinical treatment and nursing care.
  - b. Use of universal precautions and infection control practices.
  - c. Policies relative to HIV testing, HIV and Hepatitis B exposure of health care workers and confidentiality.

#### References

 Fred J. Hellinger, PhD, "Updated Forecasts of the Costs of Medical Care for Persons with AIDS, 1989-93". <u>Public Health</u> <u>Reports.</u> January-February, 1990.

# VIII. LONG-TERM CARE SERVICES

## A. BACKGROUND

Persons with HIV disease are living longer and their needs resemble those of others with chronic debilitating diseases. Patients often develop symptoms of dementia and neurological deficiencies, as well as physical deterioration that will require long-term supportive care. An array of services from nursing homes, hospice facilities, and home care are necessary to meet the needs of the end-stage AIDS patient.

The following is a breakdown of the long-term care services currently available in Virginia.

- 245 Licensed nursing homes in Virginia
- 28 Long-term care hospital units
- 496 Homes for adults
- 150 Personal Care Agencies
- 12 Medicare Certified Hospice Agencies
- 30 Non Medicare Certified Hospice Agencies
- 180 Certified Home Health Agencies

Long-term care services can be provided in either an outpatient (e.g. home) or inpatient (e.g. nursing home) setting. Most people prefer to receive care in an outpatient setting. In addition, a community-based care system often presents the most cost-effective option. Many of the needs of persons with HIV disease are extensive, but often do not require high technology. Many needs are basic including nutrition, transportation and personal care services. Although long-term care services exist in all regions, the availability and accessibility of services vary.

### **B. PAST AND CURRENT ACTIVITIES AND RESULTS**

The episodic nature of HIV disease is such that great benefit can be gained from care received outside the hospital in the community and even in the home. However, systems of financing and reimbursement for health care tend to be weighted in favor of institutionally-based care. The state has attempted to increase community-based care with the following programs:

- 1. Personal care/homemaker program federally funded in 6 agencies in Virginia.
- 2. Five regional HIV Care Consortia, supported by federal funds, funded to provide a range of outpatient services.
- 3. Medicaid Waiver Program established to provide reimbursement for community based and long-term care for persons with HIV disease.

4. To date 70% of all nursing home beds are Medicaid beds. In an effort to adequately compensate nursing homes, the Department Medical Assistance of Services (DMAS) increased the reimbursement rate for AIDS patients. The enhanced reimbursement rate by DMAS for special care unit AIDS patients did not spur a significant number of facilities to designate additional "AIDS" beds. Cameron Glenn, located in Reston was the only facility in Virginia to designate any "AIDS" beds as a result of this program. Construction grants were offered through the certificate of need process to nursing homes and long-term care facilities in Virginia to establish special care units.

Although nursing homes are widely distributed throughout Virginia, they are reluctant to accept persons with HIV disease. An informal survey of community-based organizations indicates that only two nursing homes in Virginia have been known to have admitted persons with HIV disease. This experience is consistent with a similar reluctance on the part of nursing homes nationwide. Nursing homes express concern regarding transmission of HIV within their settings. Educational programs in Virginia are continuing to be directed toward nursing home staff. Community-based agencies report that there is also reluctance on the part of Adult Homes to accept persons with HIV disease.

Hospices can provide essential services for individuals with terminal illnesses. However, traditional hospice care may not meet the needs of all persons with HIV disease. Many patients want aggressive treatment modalities which may conflict with the hospice model of palliative care. When patients and their caregivers do not participate in a hospice program, they may also find limited access to respite care. Without relief from the daily demands of providing care, the chance of caregiver burn out increases. Respite care services should be available for persons with HIV disease even if these individuals do not participate in a hospice program.

According to the Virginia Department of Medical Assistance Services, AIDS patients continue to be assessed for community services based on traditional chronic illness guidelines. Although AIDS has been termed a chronic illness, it remains unique by its episodic nature.

Increasingly, patients are turning to the public sector as they exhaust their financial resources paying for medical care. Currently, Medicaid provides reimbursement at pre-determined rates for skilled home health care, hospice care and personal care. In July, 1991, Medicaid began using a fee-for-service methodology in reimbursing for skilled home health services. Home health providers continue to voice concern that this methodology does not meet the cost of providing care. Providers of Personal Care Waiver services also voice concern that Medicaid reimbursement does not meet the cost of providing this service.

## C. GAPS AND PROJECTED FUTURE NEEDS

- 1. The greatest identified gap has been in the area of nursing home placement. Discharge planners, social workers and case managers statewide continue to express difficulty in placing their patients with HIV disease in nursing homes within their communities. The reluctance of nursing homes to accept these patients is a national problem.
- 2. Another gap has been the underutilization of hospice care. This may be due to several factors such as the difficulty of younger patients coming to terms with a projected life span of six months, the decision to accept no new treatment, the reluctance to reveal their status to the community, and the episodic nature of the illness.

#### D. RECOMMENDATIONS

- 1. Provide respite care programs designed for AIDS patients in addition to traditional hospice care.
- 2. Ensure appropriate access to nursing home beds for people with HIV disease. Nursing homes must be in compliance with existing civil rights laws and aware of the consequences for violating those laws.
- 3. Offer special training sessions to nurses, social workers, physicians and others who assess patients for community services.
- 4. Increase Medicaid reimbursement for home health and personal care services to meet cost of care.

# IX. MENTAL HEALTH SERVICES

#### A. BACKGROUND

HIV disease has a wide range of psychological and neuropsychiatric implications. Psychiatric reactions can be symptoms of psychological stresses or can result from actions of the virus or other opportunistic diseases or cancers. A range of psychological conditions can be expected from an individual experiencing any chronic life-threatening illness. HIV disease can be even more stressful because there is no cure for this chronic disease which frequently strikes people in the prime of their lives. People affected by HIV disease are often isolated and rejected because of the stigma attached to AIDS. Those with the illness are viewed as being out of the mainstream and frequently blamed for their illness.

Although the majority of persons with HIV disease cope adequately with their illness, many experience periodic problems and a few experience ongoing difficulties.<sup>1</sup> Factors contributing to a person's ability to cope are varied and include the stage of the illness, the degree of support from others, the individual's personality, and attitudes and beliefs about the illness.<sup>1</sup>

Mental health services may be needed at any point in the illness. Early intervention can help patients develop coping skills that will assist them in the later stages. Psychiatric symptoms are often detected in patients who have just learned that they are HIV positive. Stress usually decreases as patients adjust to their condition. However, the advent of physical symptoms will often by accompanied by an increase in psychological distress.

The risk of suicide varies at different stages of the illness, increasing at time of AIDS diagnosis and again at the later stages of the disease. Of hospitalized AIDS patients, 30% are referred for depressed mood. A number of national studies have shown that suicide rates for People with AIDS (PWA) are substantially greater than for people with other life-threatening illnesses.<sup>1</sup>

Organic impairment of the nervous system is common with HIV disease and as many as 65% of hospitalized AIDS patients suffer from acute or chronic brain syndromes. Some of these patients will experience AIDS dementia, a progressive dementia found in AIDS patients that is unrelated to secondary brain infections or other gross neuropathy.<sup>1</sup>

The person with HIV disease should not be treated apart from his/her significant others. Those close to the person have a multitude of psychological needs as they attempt to deal with the impact of this disease. Over time they may need to help him/her cope with an overwhelming number of losses, which can include loss of physical independence, job, physical attractiveness, home, and ultimately, life itself. Mental health service needs for persons with HIV disease and their significant others include 1) support groups, which offer a non-therapeutic setting for individuals to share with others in similar situations, 2) outpatient therapy, 3) psychiatric consultation within a medical setting, and 4) acute psychiatric inpatient treatment.

## **B. PAST AND CURRENT ACTIVITIES AND RESULTS**

Mental health services are provided across the state under the auspices of 40 community service boards (CSBs), and through the private sector. The actual number of persons with known HIV receiving services from the CSB system is believed to be far below the need. Data relative to the private sector is unavailable; however, persons with insurance or a payment source are able to find services. The array of services offered through the CSBs include local inpatient, outpatient, day programs, residential services, emergency services, prevention and early intervention. The CSBs also conduct preadmission screening to state hospitals. In addition to services provided by CSBs, all state mental hospitals accept clients with HIV infection.

The Virginia Comprehensive Plan for FY 1992-2000, developed by the Department of Mental Health, Mental Retardation, and Substance Abuse Services (DMHMRSAS), included HIV-related objectives. DMHMRSAS plans to participate with the Department of Health in joint program planning and provision of mental health care to AIDS patients. Another objective is to expand interaction between CSBs and local health departments on HIV testing, especially targeted to injecting drug users (IDU).

## C. GAPS AND PROJECTED FUTURE NEEDS

- 1. A survey mailed to all 40 CSBs in August 1991 indicated services in Virginia are available and accessible; however, they are provided in insufficient amounts. There is a general shortage of publicly-funded mental health services for all types of clients, including those with HIV. This is consistent with the national trend as was outlined in the U.S. Conference of Mayors Task Force on AIDS report of June 1991. In addition, private insurance companies are decreasing mental health coverage.
- 2. There is a shortage of mental health staff who are knowledgeable about the special mental health problems related to, or caused by HIV. As cited earlier, persons with HIV disease have numerous psychological needs. To date there has been little focus placed on the training of mental health professionals in the area of HIV. During times of budgetary restraint staff education and training are often reduced.

## D. RECOMMENDATIONS

- 1. Expand public mental health services to alleviate lengthy waiting periods for clients with HIV disease and to address their numerous psychosocial and neuropsychiatric problems.
- 2. Incorporate HIV education and information into mental health inpatient and outpatient treatment.

## References

 Jose Catalan, "Psychiatric Manifestations of HIV Disease," <u>Balliere's Clinical Gastroenterology</u>, June 1990, Vol. 4, No. 2.

# X. SUBSTANCE ABUSE SERVICES

## A. BACKGROUND

Injection drug use is the second most common method of HIV transmission. As presented previously, statistics show that from 1987 through 1991 the percent of cases reporting this transmission mode increased from 7.4% to 13.8%, bringing the cumulative total to 12.0%. Although the evidence linking substance use to HIV transmission is undeniable, the report of the working group on social/human issues to the National Commission on AIDS stated that drug treatment has not received support commensurate with its importance in ending the epidemic.

HIV infection among injecting drug users (IDUs) is spread when IDUs share needles and works that have not been sterilized. When blood remaining in the needle used by an infected user is injected into the bloodstream of a person who is not infected, the needle-sharing partner is at great risk of infection because this is the most efficient method of HIV transmission.

Both injecting and non-injecting drug users face additional risk of contracting HIV through unsafe sex, which numerous studies have shown increases after substance abuse. HIV infection is therefore associated with abuse of all substances, including alcohol. Professionals working in the field report an increase in the number of people who trade sex for drugs or money to purchase drugs. In settings such as crack houses, these individuals often have sex with large numbers of anonymous clients.

Substance abuse among the inmate population is a critical concern. An estimated 80% of Virginia's male inmates and 75% of the female inmates need substance abuse education or treatment. Sexual partners of IDUs are at increased risk of acquiring HIV. Many of them report that they were unaware that their partners were injecting drugs. Approximately 50% of the cases of AIDS among women are attributed to a sexual relationship with an IDU.

Nearly all the people currently served by CSB's substance abuse programs abuse more than one type of substance. Many abuse alcohol in addition to other drugs.

## **B. PAST AND CURRENT ACTIVITIES AND RESULTS**

Community substance abuse treatment services are provided through a public network of 40 community services boards (CSBs) and the private sector. Emergency services, case management, and outpatient services are available through all CSBs, as are limited inpatient and residential services. About half of the CSBs also have access to day treatment. Virginia has 250 licensed public and private drug treatment centers, of which five offer methadone treatment. These five centers also receive funding for counseling, testing, partner notification, case management, and referral services for clients, as well as HIV staff training and community education.

The Department of Mental Health, Mental Retardation, and Substance Abuse Services (DMHMRSAS) addresses the needs of substance abusers for treatment, with emphasis on adolescents, the elderly, women, the criminal justice population, and persons who inject drugs.

Across the Commonwealth, access to inpatient treatment can be difficult. In FY 1990 CSBs reported 458 admissions to community hospital-based inpatient substance abuse services. State hospital facilities accounted for an additional 1,594 admissions for alcoholism (17.2% of total hospital admissions) and 510 for drug dependence (5.5% of total admissions). Although all communities have access to inpatient and residential services, availability is limited because of the small number of beds. In comparison, 44,489 clients were served in CSB outpatient facilities.

## C. GAPS AND PROJECTED FUTURE NEEDS

- 1. A telephone poll of a sampling of CSBs around the state revealed that the range of waiting periods for admission to residential substance abuse programs is 3 weeks to 3 months. Services for persons who abuse drugs intravenously are filled to capacity, and outreach to this population is very difficult.
- 2. In its Comprehensive Plan for 1992-2000, DMHMRSAS identified gaps in substance abuse services for pregnant women, lack of residential services for adolescents, and lack of services for people involved with the criminal justice system.
- 3. In its Comprehensive Plan, DMHMRSAS has identified treatment needs for substance abusers. These include the need for improved access to: 1) appropriate treatment in all communities and settings, 2) health care for the medically indigent, and 3) programs for pregnant women which address both their medical and substance abuse treatment needs.
- DMHMRSAS has projected that in the 1992 94 biennium, 281 IDUs with HIV disease will need public substance abuse treatment, at a cost of \$1,304,000.

### **D. RECOMMENDATIONS**

- 1. All substance abuse treatment programs should develop HIV policies and assure that every client receives HIV risk assessment, appropriate education, and counseling.
- 2. In collaboration with other human resource agencies, develop additional community-based treatment programs or components of

programs specifically designed for women to include components on HIV. These programs should provide for special needs such as child care.

- 3. Develop additional community-based services to meet the alcohol and other drug abuse treatment needs of Virginia's youth. Programs should address special developmental issues of adolescents and treatment should be specifically geared for this population. Substance abuse treatment programs should include education related to sexuality and sexual orientation, such as HIV/AIDS, sexually-transmitted diseases and pregnancy.
- 4. Develop procedures to expand and enhance coordination and collaboration between criminal justice and treatment agencies. Expand HIV programs for adults in the criminal justice system who need substance abuse treatment.
- 5. Expand and enhance substance abuse treatment services to people who abuse drugs intravenously, as well as their families and significant others. Also expand treatment programs for people other than IDUs (e.g. crack users).
- 6. Promote the identification of IDUs with HIV disease and ensure access to primary care services through improved linkages between primary care and substance abuse treatment.
- Ensure adequate funding to implement the initiatives relative to substance abuse in general as well as those specific for IDUs with HIV disease proposed in the Virginia Comprehensive State Plan 1992 - 2000 for DMHMRSAS.
- 8. As detailed in Section III-Prevention Services, any approach that can be shown to be effective in slowing transmission of HIV among IDUs should be employed. Substance abuse treatment must be made available on demand.

# XI. CASE MANAGEMENT / SUPPORT SERVICES

## A. BACKGROUND

Case management services provide a comprehensive system of coordinating care and problem-solving for persons with HIV disease. This is accomplished through a step-by-step process which includes developing resources and services for the person with HIV disease needs as well as providing access to them. Case management includes coordination of the following:

-initial intake assessment,

-ongoing assessments, minimum contact every three months,

-monitoring of medical care,

-crisis intervention,

-access to medical, social, educational, psychological, legal, dental and other community services,

-assistance assessing Social Services, Social Security,

federal, state and local assistance programs,

-liaison with other agencies to adequately represent clients, -community outreach services,

-transportation,

-volunteer support system including buddies, home/hospital visitors, housekeeping support, respite for caregivers,

-support groups,

-day care and personal care services,

-nutritional support and supplementation,

-emergency financial support,

-medical equipment and supplies,

-discharge planning,

-housing and referrals,

-liaison for extended family members, foster families, or adoptive families.

Case management provides the person with HIV disease with the link to services. Support services are defined in a broad way, involving all those non-medical services which promote client physical and psychosocial independence. It is important that these individuals are linked with services before the advanced stages of AIDS. Community-based organizations (CBOs) cannot use the same admission criteria for a person with AIDS as they do with the elderly population or persons with other terminal illnesses, due to the episodic nature of the virus.

## **B. PAST AND CURRENT ACTIVITIES AND RESULTS**

The Virginia Department of Health's Bureau of STD/AIDS through both federal and state grants, currently funds fourteen (full-time and part-time) case management positions. There exists at least one in each Health Region. These funded positions exist primarily at Regional Resource Centers, AIDS Service Organizations (ASOs) and CBOs. There are additional case management positions at various private and public hospitals, and in certain local health departments.

Presently in Virginia, there exists only one Pediatric AIDS Organization providing case management to children. This organization also provides support services to the child's parents, foster parents or principle care provider.

The Department of Medical Assistance Services has established a Medicaid Waiver Program which has a higher provider reimbursement rate for medical and support services provided to persons with HIV disease. The largest service provided under this program is case management. All applicants must undergo a Medicaid screening process to be eligible for these services. There is a program cap of 200 clients at any one time.

#### C. GAPS AND PROJECTED FUTURE NEEDS

- 1. Based on actual numbers of persons with HIV disease, there presently exists an inadequate number of case managers in Virginia. The number of people needing case management is growing at a much higher rate than people providing case management. One major medical center in Virginia is trying to meet the needs of over 750 individuals with only two case managers. This medical center saw its caseload grow from 350 to 750 clients in one year, although some of these clients received additional case management services from local ASOs. A study in November, 1988 by the U.S. Department of Health and Human Services concluded that effective case managers should not have more than fifty assigned clients.
- There exists a large gap in case management/support services 2. to meet the needs of the pediatric population. This underserved population needs access to respite services, day care, educational alternatives and to services provided by the According to a report by the Medicaid Waiver Program. Association for the Care of Children's Health, pediatric AIDS differs from AIDS in adults in several important aspects. An estimated 93 percent of children with HIV disease suffer developmental disabilities that result in some degree of mental and/or physical impairment. Since more effective treatments are now available, the longevity of their lives with HIV increases. This will create a need for the educational system to provide developmental services for the disabled population of children with HIV disease as they reach school age.

The Centers for Disease Control Secretary's Work Group on Pediatric HIV Infection and Disease, points out that the caring for children with HIV disease is often difficult because of family circumstances. A child's birth parents may be ill with HIV disease themselves, and in addition, may be struggling with drug dependency and poverty.

- 3. Specialized services are also needed to reach the following other underserved groups: people of color, men who have sex with men, women, adolescents and hemophiliacs. Men who have sex with men are often difficult to reach through conventional means. These individuals need all the services that other people with HIV disease require, including respite and day care. Many psychosocial, as well as discrimination issues must be approached by the case manager as well. When counseling these men, the case manager must be comfortable addressing sexual health issues as they relate to this sexual orientation. The case manager must be able to work with significant others and extended family not normally associated with "traditional families".
- 4. Day care and respite services are needed for adults as well as children.
- 5. The increasing cost of treatment as more effective medications are identified and clients live longer, is creating a need for more financial support.
- 6. There is a lack of transportation services for medical care, especially in rural areas of Virginia.
- 7. The majority of ASOs and CBOs rely on volunteer staff to assist in care of individuals they serve. Based upon a formula derived by both the United Way and the American Red Cross, each volunteer devotes five hours a week, forty-eight weeks a year at a conservative estimate of ten dollars per hour. In Virginia, there are an estimated 1000 active volunteers who work with people affected by HIV. This equates to 2.4 million dollars per year in volunteer time. However, a gap is developing relative to the recruitment of these volunteers. Many volunteers have reached a stage of "burn out" or may themselves be ill and in need of the services provided by the organization. An increasingly important need will be to develop approaches and to recognize the value of volunteer efforts, to provide specialized training, support and evaluation to volunteers. There is a need to conduct outreach to all segments of the population affected by HIV to increase volunteer participation in the service delivery system.
- 8. An effective communication network is inadequate in some areas between case managers and service providers that would insure the client of receiving appropriate services and referrals.

### D. RECOMMENDATIONS

- 1. Expand comprehensive, effective case management and support services for persons with HIV disease. Services should be specialized to meet the diverse needs of specific populations.
- 2. Regional Care Consortia should assume a leadership role in coordinating case management among agencies in their regions. Data collection and analysis should be conducted by these groups, along with local agencies, in an effort to establish a statewide data base. The data base should maintain a confidential unduplicated count of persons provided case management services. Such a data base would be a time-saving mechanism for all case managers trying to access services for their clients.
- 3. Expand the recruitment and training of volunteers.
- 4. In order to effectively identify service needs and validate significant gaps in case management and support services, a statewide needs assessment survey should be conducted. The instrument for this survey has already been developed by the VCU Survey Research Laboratory and should be utilized. Periodic review of this survey should be conducted in order to re-evaluate and plan for incremental changes in the needs of the affected population and the efforts of individual communities to meet those needs.

## XII. HOUSING

## A. BACKGROUND

The housing needs of persons with HIV disease in Virginia are diverse. As the illness progresses, many people who live independently in their own home or apartment may be forced to give up their residence due to health or financial reasons. Individuals will then have to move in with family/friends or will require transitional housing, a hospice, or in extreme cases, an emergency shelter. The progression of the virus may result in individuals needing several levels of housing services each providing more intensive care.

Thousands of men, women and children are homeless. Each night, especially during winter months, people are turned away from shelters and/or winter cot programs because there exists a lack of beds. This situation is extremely difficult for any homeless individual, much less a person with HIV disease. Since licensing is not a requirement in Virginia for groups to open a shelter program, often discrimination occurs among those selected for shelter. Many shelters, due to a lack of staff and volunteer education, readily turn individuals away that they know have HIV disease. Virginia data are not available relative to the number of persons with HIV disease who have housing needs. According to a survey by the U.S. Conference of Mayors, described in Impact of AIDS on America's Cities, in New York City approximately six percent of the homeless population are HIV positive. Applying this percentage to the estimated 20,000 homeless individuals in the state of Virginia, it is believed that as many as 1200 could have HIV disease.

A large number of persons with HIV disease will need housing other than traditional shelters. As the effects of the virus progress, many of these people will need some form of transitional housing and hospice care. Many do not have any form of health insurance or the ability to pay for hospice care. Often unable to work, many individuals have experienced eviction from their place of residence and are living temporarily with family or friends who cannot provide proper care and/or financial support.

Although adequate housing is a basic necessity of life for everyone, the provision of housing alone cannot create a stable living environment for many persons with the disability of HIV. Housing is one component in the spectrum of services needed for persons with this disability to live independently in the community. For many individuals who are experiencing physical disabilities related to HIV, additional support services may be needed. A person who has HIV disease and receives adequate housing and nutritional care can possibly delay and/or prevent the onset of an opportunistic disease characterized as AIDS. Persons with HIV disease who reside in a shelter, a hospice or in transitional housing need accessible support services.

## **B. PAST AND CURRENT ACTIVITIES AND RESULTS**

Over the past several years, housing for persons with HIV disease has been very limited. There is no one agency charged with providing housing for the homeless. Although the Virginia Coalition for the Homeless recognizes the need for shelter for persons with HIV disease, they do not have the resources to provide shelter for those requiring more specialized assistance. At present there is only one organization in Virginia that operates transitional housing for people with HIV disease. These two houses are both in Richmond and can collectively only accommodate a total of seven clients. The monies needed for these homes are provided through private donation and most of the staffing consists of volunteers.

Beginning in 1991, the U.S. Department of Housing and Urban Development (HUD) allocated funds for the renovation or construction of housing for people with disabilities including individuals living with AIDS. In HUD Region III, which includes Virginia, \$8,466,000 in funding is available.

At present, only limited organizations serving persons with HIV disease can provide financial assistance to prevent their clients from losing their homes. However, these monies assist clients in keeping their home only on a short-term basis while searching for another place of residence. These Community-Based Organizations (CBOs) have very limited budgets and cannot go outside of their client base when allotting funds.

## C. GAPS AND PROJECTED FUTURE NEEDS

1. Throughout Virginia, housing for persons with HIV disease and in need of housing is inadequate. There is a need for each of the following types of housing:

-more public, subsidized housing, -assisted living situations, -access to emergency shelters, -hospice, -financial assistance to prevent homelessness, -communication and coordination of existing programs (eg. funding availability and home sharing).

2. The criteria that HUD uses to provide monies for Section 811 housing does not apply to persons with HIV disease without an AIDS diagnosis. Also excluded in the Section 811 definition for disability along with HIV infection are the impairments of alcoholism and drug addiction. Placing alcoholics, drug addicts and persons with HIV together in the exclusion category can instill the wrong message to the community providing housing.

- 3. There is lack of HIV/AIDS education and training for shelter management, staff and volunteers. Although education and training have been made available, it has not always been utilized due to fears and prejudices.
- 4. Transitional housing in Virginia is very limited for persons with HIV disease. Less than ten beds have been identified in the state for those individuals that need this type of care. Current state and local licensing and zoning regulations make it prohibitive for most AIDS Service Organizations (ASOs) to open and operate a transitional house or hospice. Secondly, the expense of such housing and the volunteer support staff required heavily tap existing resources.

#### D. RECOMMENDATIONS

- 1. Increase the number of housing units available to the disabled through the offices of the Virginia Housing and Development Authority and the U.S. Department of Housing and Urban Development.
- 2. Increase options such as transitional housing for the homeless with HIV disease by utilizing the expertise of existing groups providing health care for the homeless, along with the Virginia Housing and Development Authority.
- 3. Require non-discriminatory access to transitional housing, hospices, and emergency shelters for individuals, including those with HIV disease.
- 4. Enhance communication between Regional Housing Authorities and the U.S. Department of Housing and Urban Development with case management providers regarding the availability of funds and other housing resources.

## XIII. FINANCING

## A. INTRODUCTION / METHODOLOGY

This section contains a summary of the projected economic impact of HIV/AIDS in Virginia through the year 2000 and includes the following: 1) cost projections for treatment and care for persons with HIV infection and persons with AIDS, 2) existing financial allocations for fiscal years 1988 - 1992 from the public and private sector, 3) financial resources available to clients for care, and 4) recommendations.

To project the costs for treatment and care of HIV infection and AIDS during the period 1991 - 2000, a multidisciplinary working group of health professionals representing a variety of agencies was convened in an effort to identify and collect existing statewide data. Professional areas of representation on the working group included: trade associations for hospices, hospitals, longterm-care facilities, and pharmaceutical firms; a hospital-based clinic for the treatment of HIV/AIDS; a medical school; an insurance company; an AIDS Service Organization, an AIDS resource and consultation center; the Virginia Department of Medical Assistance Services; the Virginia Department of Health; and the Bureau of Insurance of the State Corporation Commission.

Following a meeting of this working group, it became apparent that definitive data to make valid statewide cost projections is not available. The decision was made to utilize existing current national data for the projection of cost estimates for Virginia.

An extensive search of existing literature on cost of care as well as contact with several national research and special interest groups was made. Contacts were made with the AIDS Action Council, the Health Insurance Association of America, and the Intergovernmental Health Policy Project of George Washington University.

The recognized authority on national cost of care, Dr. Fred J. Hellinger, Director, Division of Cost and Financing, Agency for Health Care Policy and Research, U.S. Department of Health and Human Services, was consulted. Dr. Hellinger provided the most recent and comprehensive data regarding patient cost of care, which forms the basis of the cost estimates presented on the following pages. In short, the annual cost calculations developed by Dr. Hellinger were applied to Virginia HIV/AIDS data to determine cost of care estimates.

## **B. COST ESTIMATES**

Projections for the financial costs of HIV/AIDS for the period 1991 - 2000 are provided for persons with HIV infection and persons with

AIDS. It should be noted that the indirect costs of the HIV/AIDS epidemic have not been considered in this report. These costs, which are very difficult to fully determine, include lost earnings, decreased productivity, and drastically increased psychosocial burdens to affected individuals, their families, and friends. These indirect costs are especially significant for HIV/AIDS as the majority of affected persons are between the ages of 25 and 50 which are considered to be the prime earning years.

#### 1. Cost of Patient Care for Persons with HIV Infection

Persons with HIV infection include all individuals infected with HIV, regardless of symptomatic involvement, who do not meet the Centers for Disease Control (CDC) AIDS case definition. With the data obtained from Dr. Hellinger, a model was developed to project the total cost of treatment and care for persons with HIV infection for the period 1991 - 2000.

A four-step process was used to determine the annual number of persons living with HIV infection. First, the annual cumulative total of persons with HIV infection was projected for the period 1982 - 2000 by multiplying the annual cumulative number of AIDS cases each year by the multiplier 5.5, which represents a low estimate of the number of HIV infections per AIDS diagnosis. From the cumulative totals, the annual incidence was calculated, as presented in Table 1.

	Reported/ Projected <u>AIDS Case</u>	s*	Multipl By 5.5	ied	Cumulative Estimated/ Projected <u>HIV_Cases</u>	Projected Annual Incidence of HIV
1982	6	x	5.5	=	33	33
1983	27	x	5.5	=	149	116
1984	69	x	5.5	=	380	231
1985	171	x	5.5	=	941	561
1986	337	х	5.5	=	1,854	913
1987	607	x	5.5	=	3,339	1,485
1988	983	x	5.5	=	5,407	2,068
1989	1,428	x	5.5	=	7,854	2,447
1990	2,078	x	5.5	=	11,429	3,575
1991	2,799	x	5.5	=	15,395	3,966
1 <b>992</b>	3,635	x	5.5	=	19,992	4,597
1993	4,585	x	5.5	=	25,215	5,223
1994	5,648	x	5.5	z	31,064	5,849
1995	6,825	x	5.5	=	37,538	6,474
1996	8,116	x	5.5	=	44,638	7,100
1997	9,521	x	5.5	=	52,364	7,726
1998	11,039	x	5.5	2	60,716	8,352
1999	12,672	x	5.5	-	69,693	8,977
2000	14,418	х	5.5	=	79,297	9,604

Table 1:	Projected Annual	Incidence	of	HIV	Infection
	In Virginia				

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Actual reported data is presented for 1982 - 1990. Data for 1991 - 2000 is projected, as described in Section II.

\*\* As stated in Section II, the multiplier of 5.5 represents the number of HIV infections per AIDS diagnosis, which is considered a low estimate.

Secondly, the annual rates of survival with HIV without progression to AIDS were calculated (see Table 2). Data about the natural history of HIV infection in a 1978 - 1980 cohort of gay men was obtained from the San Francisco Department of Public Health. It represents the most recent and comprehensive information available regarding the length of time from initial infection with HIV to the development of AIDS. Specifically, the annual percentages of persons with HIV who developed AIDS during the first ten years of infection were obtained. For example, 99.8% of all men in the cohort who were infected with HIV had not developed AIDS by the end of their first year of infection. By the end of the second year of infection, 99.0% had not developed AIDS. By the end of the tenth year, only 48% had not developed AIDS. A regression model was used to project the survival rates for the eleventh through the twenty-second years of infection. The source data for the regression model were the survival rates from the fifth through the tenth year of infection, as reported from the San Francisco study.

## Table 2: Survival With HIV Infection Without Progression To AIDS - Actual and Projected, Years 1 - 22 of Infection

SAN FRANCIS	CO COHORT DATA	REGRESSION	MODEL DATA
Year Of Infection	Percent <u>Without AIDS</u>	Year Of <u>Infection</u>	Percent <u>Without AIDS</u>
1	99.8	11	39.3
2	99.0	12	31.2
3	97.0	13	23.0
4	92.0	14	14.9
<b>-</b> '		15	6.8
5	88.0	16	00.0
6	81.0	17	00.0
7	72.0	18	00.0
8	62.0	19	00.0
9	56.0	20	00.0
10	48.0	21	00.0
		22	00.0
regr	cession source data	a	

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Thirdly, the annual rates of survival with HIV without progression to AIDS (Table 2) were multiplied by the annual incidence of HIV during 1982 - 2000 (Table 1). The results provided the estimated number of persons living with HIV infection during 1991 - 2000. Lastly, national cost of care estimates were multiplied by the projected annual number of persons living with HIV to determine the annual cost. The annual cost of care for all persons living with HIV infection is estimated to increase from 81 million in 1991 to 727 million in 2000 (see Table 3).

		-	Total
Year	Total Persons Living With HIV	Individual Annual Of Care	Annual Cost of Treatment/Care
1991	14,448	\$5,614	\$ 81,111,072
1992	18,459	\$6,119	\$112,950,621
1993	22,844	\$6,669	\$152,346,636
1994	27,568	\$7,270	\$200,419,360
1995	32,568	\$7,924	\$258,068,832
1996	37,795	\$8,637	\$326,435,415
1997	43,187	\$9,414	\$406,562,418
1998	48,721	\$10,262	\$499,974,902
1999	54,339	\$11,185	\$607,781,715
2000	59,645	\$12,192	\$727,191,840

Table 3:	Projected Annual Cost of Care For Persons
	With HIV Infection In Virginia*

TOTAL CUMULATIVE COSTS \$

**s** \$3,372,842,811

- \* Exact projections are impossible to determine. Projections will change upon revision of the CDC AIDS case definition. Any changes in one or more of the following assumptions could dramatically change the projections which are offered here:
  - The annual per patient cost of care is estimated at \$5,150.00 in 1990 dollars (adjusted at a 9.0% annual inflation rate which is the average increase/year) and includes the following: zidovudine, aerosol pentamidine, and other drugs; outpatient care; laboratory tests; patient counseling; and inpatient hospital care.
  - 2. All persons projected to be infected with HIV will be tested, diagnosed and will receive care.
  - 3. There will be no changes in HIV treatment modalities.
  - 4. There will be no changes in the natural history of HIV infection.
  - 5. Cost estimates are based on providing care for adults only.

## 2. Cost of Patient Care for Persons with AIDS

Persons with AIDS include all individuals diagnosed with AIDS as defined by the Centers for Disease Control. The model for projecting the cost of treatment and care for persons with AIDS during 1991 - 2000 is based on the predicted number of annual living cases multiplied by the annual cost of care, provided by Dr. Hellinger, as outlined in Table 4.

The annual cost of care in Virginia for all persons living with AIDS is estimated to increase from 35 million in 1991 to 392 million by the year 2000.

Table 4: Annual Cost of Care For Persons With AIDS In Virginia\*

			ANNIIAT. P	ANNUAL ER PATTENT	
	CUM.	CUM.	LIVING	COST	TOTAL
<u>YEAR</u>	CASES	DEATHS	CASES	OF CARE	ANNUAL COST
1991	2,799	1794	1005	\$34,880	\$ 35,054,400
1992	3,635	2330	1305	\$38,019	\$ 49,614,795
1993	4,585	2939	1646	\$41,441	\$ 68,211,886
1994	5,648	3620	2028	\$45,171	\$ 91,606,788
1995	6,825	4375	2450	\$49,236	\$120,628,200
1996	8,116	5202	2914	\$53,667	\$156,385,638
1997	9,521	6103	3418	\$58 <b>,</b> 497	\$199,942,746
1998	11,039	7076	3963	\$63,762	\$252,688,806
1999	12,672	8122	4550	\$69,501	\$316,229,550
2000	14,418	9242	5176	\$75 <b>,</b> 756	\$392,113,056
		TOTAL	CUMULATIVE	COSTS	\$1,682,475,865

TOTAL CUMULATIVE COSTS

Exact projections are impossible to determine. The annual per patient cost of care for persons with AIDS provided by Dr. Hellinger is estimated at \$32,000 in 1990 dollars (adjusted at a 9.0% annual inflation rate which is the average increase/year) and includes the following: inpatient and outpatient care; longterm-care (when available); home health care; counseling services; and drug costs. All other assumptions used in making these determinations are the same as those used for persons living with HIV infection (see Table 3).

## C. DIRECT FUNDING FOR HIV/AIDS IN VIRGINIA

#### 1. Public Sources

In Virginia, direct state funds for HIV/AIDS are largely provided through the Department of Health. Federal funds, allocated to Virginia by the Health Resources and Services Administration and the Centers for Disease Control, are routed through the Department of Health or the Department of Education. In addition, Medicaid and Medicare programs administered in Virginia also provide direct assistance to persons with HIV/AIDS (see section D). Funding allocations for the Departments of Health, Education and Medical Assistance Services for HIV/AIDS-related initiatives appear in Table 5. The extent of local government funds allocated for HIV/AIDS is limited.

## TABLE 5

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## VIRGINIA HIV INFECTION/AIDS-RELATED EDUCATION, PREVENTION, AND PATIENT CARE INITATIVES ANNUAL FUNDING ALLOCATIONS 1988 - 1992\*

		1988		1989		1	1990		1991		1992	
		STATE	PEDERAL	STATE	FEDERAL	STATE	FEDERAL	STATE	PEDERAL	STATE	PEDERAL	TOTALS
Ι.	Department of Education	0	215,000	0	280,748	0	289,869	0	242,768	0	NOT KNOWN	1,028,385
Π.	Department of Health											
	A. Education/Prevention											
	1. Minority Initiative <sup>1</sup>	0	116,600	0	345,980	0	350,900	0	358,557	0	358,557	1,530,594
	2. Public Information	0	0	0	40,000	0	42,000	0	46,000	0	46,000	174,000
	3. Counseling, Testing, Referral, & Partner Notification in Drug Treatment Centers	0	101,500	0	550,740	0	516,400	0	516,909	0	516,909	2,202,458
	<ol> <li>Health Education, Risk Reduction</li> </ol>	64,100	338,000	154,600	396,500	154,600	384,305	184,600	282,056	234,600	344,656	2,538,017
	5. Regional AIDS Resource Consulation Centers	£ 0	0	0	0	960,000	0	1,053,198	Û	1,284,880	0	3,298,078
	6. Anonymous Testing Site:	52,000	36,000	70,000	50,000	550,000	55,000	417,800	50,000	417,800	50,000	1,748,600
	7. Professional Health <sup>2</sup> Education	190,000	0	190,000	0	190,000	Û	87,500	0	70,000	Û	727,500

<sup>4</sup> Federal funding adjusted for state fiscal years. <sup>1</sup> Pilot program to develop educational strategies to reduce the transmission of HIV in minority populations. <sup>2</sup> Training for health care providers on the clinical, laboratory, epidemiological, and educational aspects.

## VIRGINIA HIV INFECTION/AIDS-RELATED EDUCATION, PREVENTION, AND PATIENT CARE INITATIVES ANNUAL FUNDING ALLOCATIONS 1988 - 1992\*

			1988		1989		1	1990		1991		1992	
			STATE	FEDERAL	STATE	FEDERAL	STATE	PEDERAL	STATE	PEDERAL	STATE	PEDERAL	TOTALS
B.	Tre	atment/Care											
	1.	Zidouvudine	0	51,700	0	426,550	0	155,320	366,600	0	887,200	85,200	1,972,570
	2.	AIDS Service <sup>3</sup> Organizations	151,500	0	152,000	337,270	152,000	354,135	152,000	362,567	152,000	362,567	2,176,039
	3.	Special Education Grants	0	0	0	0	200,000	0	200,000	0	200,000	0	600,000
	4.	Model Treatment Center	0	0	0	0	40,000	0	40,170	0	40,170	0	120,340
	5.	Personal Care Grants	0	0	0	0	Û	0	0	44,383	0	133,153	177,536
¢.,	Rya	n White Care Act											
	ł.	Title I	0	0	0	0	0	Û	0	0	0	0	0
	2.	Title II	Û	0	0	0	0	0	0	379,320	0	590,800	970,120
	3.	Title III	0	0	0	0	0	0	0	0	Û	0	Û
Û.	HIV Su	Infection/AIDS erveillance	0	Û	0	Q	513,422	0	383,422	0	513,422	0	1,410,266
Ë.	HIV Se	Infection/AIDS proprevalence	0.	9,600	0	694,150	0	734,075	0	641,909	0	641,909	2,721,643

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\*3 Pederal funding adjusted for state fiscal years. Private community-based groups which provide AIDS educational outreach and patient support services.

(psychosocial counseling, legal assistance, and medical referral).

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## VIRGINIA HIV INFECTION/AIDS-RELATED EDUCATION, PREVENTION, AND PATIENT CARE INITATIVES ANNUAL FUNDING ALLOCATIONS 1988 - 1992\*

		1	988	1989		1990		1991		1992			
		STATE	PEDERAL	STATE	PEDERAL	STATE	PEDERAL	STATE	PEDERAL	STATE	PEDERAL	TOTALS	
	F. STD/AIDS Classified <sup>4</sup> Personnel	55,200	377,900	767,900	818,800	1,734,514	854,410	1,593,230	943,067	1,760,730	956,067	9,861,818	
	G. STD/AIDS Hourly Personnel	8,300	40,900	19,000	174,900	19,000	180,145	25,267	60 <b>,00</b> 0	25,267	60,000	612,779	
III.	Department of Medical <sup>5</sup> Assistance Services	t t	kk	403,460	403,460	<b>* *</b>	**	1,442,324	1,442,374	***	i t t	3,691,618	
	TOTALS	521,100	1,287,200	1,756,960	4,519,098	4,513,536	3,916,559	5,946,111	5,369,910	5,586,069	4,145,818	37,562,361	

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\* Pederal funding adjusted for state fiscal years.

\*\* Not available

\*\*\* Not applicable
\*\*\* Not applicable
5 Includes Community Health Service Cooperative budget.
Represents all health services for persons receiving AZT. It is not inclusive of all Medicaid dollars

allocated for HIV/AIDS.

## 2. Private Sources

HIV/AIDS claims data from Virginia-based insurance companies was not available. Only national information was available regarding the extent of third party payments for HIV/AIDS claims. According to the Health Insurance Association of America, it is estimated that \$500 million was paid out by insurance companies nationwide in 1989 for claims related to HIV/AIDS.

To determine the extent of private funding dedicated to HIV/AIDS services in Virginia, information was requested from the 18 AIDS Service Organizations (ASOs) in the state for fiscal years 1990 and 1991. This data is displayed in Table 6.

#### Table 6: Estimated Private Funds Provided To ASOs In Virginia

Region	FY <u>1990</u>	FY <u>1991</u>				
Northwest	\$ 65,000	\$107,200				
Northern	\$372,500	\$435,150				
Southwest	\$ 5,250	\$ 16,250				
Central	\$152,000	\$227,000				
Eastern	\$271,800	\$362,518				
TOTAL	\$866,550	\$1,148,118				

Includes data from the 18 AIDS Service Organizations in the Commonwealth

## D. ACCESS TO CARE

According to a 1990 survey conducted by the Survey Research Lab of Virginia Commonwealth University, approximately 16% of all Virginians are uninsured and approximately 9% are underinsured, i.e., the benefits are non-comprehensive. Thus, approximately one quarter of all Virginians lack rapid access to the type of quality medical care which comprehensive insurance coverage allows.

It is likely that the number of un/underinsured persons living with AIDS is higher than it would be for the general population. This is likely the case as persons diagnosed with AIDS, often in the prime of life, eventually are unable to continue working. Access to insurance coverage is greatly diminished when one is no longer working. Many persons with AIDS are faced with losing insurance coverage at a time when it is most important.

Table 7 presents a conservative estimate of the number of persons living with AIDS projected to be un/underinsured through the year 2000.

	ANNUAL	MULTI	PLIED BY		UN/UNDERINSURED		
YEAR	LIVING <u>CASES</u>	THE I <u>UN/UNDI</u>	PERCENT ERINSURED		PERS LIVING	SONS WITH	AIDS
1991	1005	x	25%	=		251	
1992	1305	x	25%	=		326	
1993	1646	x	25%	=		412	
1994	2028	x	25%	=		507	
1995	2450	x	25%	=		613	
1996	2914	x	25%	=		729	
1997	3418	x	25%	=		855	
1998	3963	ж	25%	=		991	
1999	4550	x	25%	=	1,	138	
2000	5176	x	25%	=	1,	294	

Table 7: Estimated Percentage of Un/Underinsured Persons Living With AIDS In Virginia, 1991 - 2000

## 1. Medicaid

Medicaid, the joint federal-state health insurance program for low-income persons, has emerged as the payer of last resort for persons with AIDS. Persons become eligible for Medicaid in one of two ways. First, they may become disabled and have low enough income and resources to qualify for the Federal Supplemental Security Income (SSI) program. In Virginia, Medicaid coverage is automatic for some SSI beneficiaries. Persons who are not financially eligible for SSI benefits may still qualify for Medicaid as "medically needy," because they are unable to pay their medical bills. Medically needy beneficiaries often "spend down," i.e., incur medical expenses sufficient to reduce their resources to a level eligible for Medicaid.<sup>1</sup>

At pre-determined rates, Medicaid will reimburse service providers for the cost of care to persons with AIDS. Since 1988, waivers have been authorized, expanding the scope of services available to Medicaid recipients. These waivers include: long-term care, personal home care, respite care, and case management. In 1991 waivers for persons with AIDS were established that include private duty nursing in the home environment. In addition to eliminating unnecessary hospitalization and thereby reducing the patient's psychosocial burden, these waivers are cost effective. According to Hellinger, the average daily cost for inpatient care is \$1000.00 in 1990 dollars. Providing home care alternatives is much less comfort.' expensive and increases the individual's level of Nationally, forty percent of adults with AIDS are covered by Medicaid and ninety percent of children with AIDS are covered. Whereas Medicaid pays for 11 percent of total health care costs in the United States, it funds approximately 25% of AIDS care.<sup>2</sup>

## 2. Medicare

Persons with AIDS who are no longer able to work may qualify for Social Security disability insurance after five months, if they have sufficient employment history. Recipients of Social Security disability benefits are eligible for Medicare coverage 24 months after the date benefits are initiated. Persons with AIDS are eligible for Medicare, but only if they survive a minimum of 29 months after initial diagnosis. Recent data indicate that the average time from initial diagnosis with AIDS to death is 20 months. Providers report that approximately 1% to 3% of all persons with AIDS are provided Medicare insurance coverage.<sup>1</sup> Medicare provides coverage for approximately 2 percent of people with AIDS nationally.<sup>2</sup>

### 3. Private Insurance

At present, private insurance remains a major source of financing for the care of persons with AIDS. Most people obtain private insurance by purchasing an individual policy or through employer group coverage. Private insurance is most often available to persons with AIDS as long as they remain able to work. Although persons are eligible to purchase their policy on a monthly basis (up to 18 months) after employment ends, the financial strain created by unemployment combined with the high cost of premiums often results in the loss of coverage.

Options exist for persons with life insurance benefits to cash in a portion of the face value of their policy. These options, often referred to as "living benefits" programs, are offered by private corporations and, sometimes, by the insurance underwriter. No regulatory obstacles exist in Virginia which would impede applicable persons with AIDS from taking full advantage of these services. The availability of cash from life insurance policies can greatly assist persons living with AIDS to maintain access to health care services, even following lapses in health care coverage.

#### 4. Gaps In Coverage

As the number of persons living with AIDS increases, the demand for public means of support will increase. Medicaid and Medicare coverage will become more essential to ensure that persons with AIDS maintain access to care.

As stated previously, persons with AIDS often lose their insurance coverage due to the inability to pay the cost of premiums once employment has been terminated. To close the gap created by this financial hardship, 12 states have established "premium buy-in" programs. Under these programs, the states pay the insurance premium once the person with AIDS meets established criteria. The advantages of these programs are two-fold. First, the person with AIDS maintains their insurance coverage. And the provision of care is uninterrupted. Secondly, the programs are exceptionally cost-effective. In Minnesota, for example, the cost of one month's insurance premium is less than the price of zidovudine alone.

For persons with AIDS who do not have private coverage, lapses can occur if they are not eligible for Medicaid or Medicare. Information provided from the Medical College of Virginia for the period January - June 1991 indicates that 16% of all patients were admitted under the category "self- pay." As stated, due to the 29 month waiting period prior to Medicare insurance eligibility, Medicare is not commonly available to cover health care costs.

## E. RECOMMENDATIONS

1. It is important to place the problem of health care financing for HIV/AIDS into a larger context. Recognizing the disintegrating state of the U.S. health care system in general, the Task Force reiterates and concurs with the following recommendation of the National Commission on AIDS, published in July 1991.

Universal health care coverage should be provided for all persons living in the U.S. to assure access to quality health care services. The commission believes universal health care coverage is a necessary step to ensuring access to quality health care. This coverage should be comprehensive and should include prescription drugs. In the interim, the commission recommends a series of immediate short-term steps to address the urgent problem of inadequate coverage for people with HIV disease.

To this end, the Task Force encourages the General Assembly to send this message to the United States Congress by any means possible. Further short-term steps to address the urgent problem of inadequate coverage for people with HIV/AIDS are offered below.

- 2. Establish a premium buy-in program. Under this program, the State would pay the private insurance premium for those individuals who would otherwise lose their coverage due to inability to pay. Programs such as these have been exceptionally cost-effective in other states.
- 3. Establish risk pools through the state to provide medical coverage for those uninsured individuals not eligible for Medicaid or Medicare. Premiums should be offered at a sliding fee scale so that no individual without coverage is denied.
- 4. The Task Force concurs with the National Commission on AIDS and the U. S. Conference of Mayors by recommending funding for the Ryan White Care Act at its fully authorized level. The Virginia General Assembly is encouraged to send this message to the United States Congress by any means possible. Virginia should continue to solicit and maximize the use of all available federal funding.
- 5. Increase direct state appropriations necessary to implement the recommendations contained within this plan. At a minimum, state allocations should increase in proportion to the change in the number of reported cases of HIV/AIDS.
- 6. Appoint a working group to collect financial data and assess the need for a statewide uniform data collection

system. Any uniform data collection system should be consistent with and interface with the types of data collected through the Ryan White CARE bill.

- 7. Encourage the use of "living benefit" programs currently available through private corporations and insurance underwriters. No regulatory obstacles exist impeding the use of such programs.
- 8. Increase financial support from the state for ongoing public/private collaborative efforts in HIV prevention, education, and health care delivery, as this has proven to be a cost-effective means of providing needed services.
- 9. Encourage local governments to increase their level of financial support to address the HIV/AIDS epidemic.

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Barner, Pat, Case Manager, Tidewater AIDS Crisis Taskforce

Clayborn, Denise, Department of Mental Health, Mental Retardation and Substance Abuse Services

Dreyfus, Emily, Case Manager, AIDS Support Group Inc.

Elliot, John, Support Services Coordinator, Central Virginia AIDS Services and Education

Fried, Audrey, Substance Abuse Case Manager, Northern Virginia AIDS Project of the Whitman-Walker Clinic

Harrison, Eleanor, Outreach Coordinator, Richmond AIDS Information Network

Lenton, Stephen, Ph.D., Commonwealth Professional Services

Lorenzo, Kelli, Director, Northwest Virginia Resource and Consultation Center

McCray, Joyce, African-American Taskforce on AIDS, Outreach Coordinator, Tidewater AIDS Crisis Taskforce.

McMillen, Donna, Director, Southwest Virginia Resource and Consultation Center

Moore, Mary Ann, Director, Eastern Virginia Resource and Consultation Center

Nichols, Robert, Ph.D., Fairfax County Mental Health Services

Soble, Beverly, Virginia Health Care Association

Whitney, Christy, Director, Hospice of Northern Virginia, Inova Hospital Systems

Whitt, Ellen, Director, AIDS Council of Western Virginia

# APPENDIX A

### GENERAL ASSEMBLY OF VIRGINIA--1991 SESSION HOUSE JOINT RESOLUTION NO. 436

Requesting the Secretary of Health and Human Resources to direct the development of a comprehensive plan to ameliorate the AIDS epidemic in the Commonwealth.

Agreed to by the House of Delegates, February 4, 1991 Agreed to by the Senate, February 12, 1991

WHEREAS, a careful study of the effects of the AIDS epidemic has been conducted by the Joint Subcommittee Studying Human Immunodeficiency Viruses over the last several years; and

WHEREAS, many effective programs have been developed by the joint subcommittee, including community education programs, the consultation and resource centers, and a pilot treatment program; and

WHEREAS, the demography and characteristics of the AIDS epidemic have evolved, thereby creating new and unexpected issues; and

WHEREAS, the joint subcommittee has received testimony that these changes will continue and multiply; and

WHEREAS, experts and citizens have also testified that continued and intensified planning will be essential to ameliorate the effects of the AIDS epidemic in Virginia; and

WHEREAS, the joint subcommittee knows that, in this time of financial exigency, careful justification must be provided for any new recommendations; now, therefore, be it

RESOLVED by the House of Delegates, the Senate concurring, That the Secretary of Health and Human Resources is hereby requested to complete, in cooperation with the Joint Subcommittee Studying the Issues, Policies, and Programs Relating to Infection with Human Immunodeficiency Viruses, a plan for providing HIV/AIDS prevention, care, and services in the Commonwealth for the years 1991-2000. This plan shall:

1. Project incidence, prevalence and epidemiologic trends in Virginia for 1991-2000, assessing their implications for providing and financing HIV prevention, care, and services.

2. Determine and assess currently available and anticipated resources for HIV prevention and care, including:

a. Federal funds and services.

b. Existing and projected state funds, positions, and programs.

c. Programs and resources provided by local government agencies and nonprofit community-based organizations.

d. Major private sector programs and resources.

3. Analyze current patterns of prevention, care and services for people with HIV disease in Virginia, especially:

a. Financing of care and services.

b. Availability of "early intervention" to individuals with asymptomatic or mildly symptomatic disease.

c. Preparation, commitment, and availability of health care providers, acute care hospitals, long-term care facilities, hospices, housing, and social service programs.

d. Identification and description of knowledge, attitudes and behaviors of people at risk for HIV disease.

4. Recommend strategies, and identify sources of funds, personnel, and facilities to correct current or expected deficiencies in HIV prevention, care, and services.

The Secretary may convene a task force of relevant experts and other: to assist in this effort. Because the services needed for persons infected with human immunodeficiency viruses and persons with AIDS are diverse and not all of the agencies delivering these services are within the Health and Human Resources Secretariat, the other secretaries within the Governor's cabinet shall also participate in the development of this plan.

The Secretary shall report to the Governor and the General Assembly by December 1, 1991, in accordance with the procedures of the Division of Legislative Automated Systems for the processing of legislative documents. However, in order to design any necessary implementing legislation and to plan for funding, the Secretary shall periodically report to and confer with the joint subcommittee on the development of this plan.

## APPENDIX B

#### CHRONOLOGY OF PUBLIC AGENCY HIV/AIDS INITIATIVES IN VIRGINIA

- 1982 First AIDS case in Virginia reported
- 1983 Reporting of AIDS became mandatory in Virginia
- 1984 Department of Health (VDH) AIDS activities placed within the Bureau of Sexually Transmitted Diseases (STD)
- 1985 Toll-free hot line established in VDH
  - Testing of all blood donations for HIV antibodies began
  - Four alternate (anonymous) testing sited (ATS) established to provide alternative method for people to learn their antibody status rather than through blood donation
  - AIDS Medical Advisory Committee convened for first time to advise State Health Commissioner and Board of Health in formulation of AIDS-related policies
  - Recommendations developed by the VDH for day-care and school attendance of children infected with HIV
- 1986 HIV testing, counseling and partner notification offered i local health department STD clinics
  - VDH initiated programs with AIDS Service Organizations for educational outreach and support services
  - VDH initiated first programs for health care provider education in conjunction with the Medical College of Virginia
- 1987 Department of Social Services (DSS) convened an AIDS task force. This task force was instrumental in developing "Practical Guidelines for Serving Clients with Acquired Immune Deficiency Syndrome" which has been distributed widely to local social service departments
  - HIV testing expanded to local health department tuberculosis, maternity and family planning clinics
  - "AIDS Manual for Virginia Physicians," developed by VDH and the Medical Society of Virginia, received national recognition through a letter of commendation from Surgeon General Koop
  - VDH initiated reimbursement for Zidovudine (AZT) for low income individuals
  - VDH initiated knowledge, attitudes, and behavior surveys c various populations

- VDH began seroprevalence surveys
- VDH received recognition from the Centers for Disease Control (CDC) for its HIV testing, counselling, and partner notification program
- VDH initiated special outreach programs for minority populations
- State Board of Education required that all students in grades 7 12 be offered AIDS education
- 1988 Department of Mental Health, Mental Retardation, and Substance Abuse Services (DMHMRSAS) developed "Client Service Management Guidelines for Mental Health and Substance Abuse Clients."
  - House Bill 652 required hospitals, nursing homes, homes for adults, and correctional facilities to notify funeral homes if the individual they are transferring to them was known to have had an infectious disease immediately prior to death
  - House Bill 1092 required health care facilities to notify emergency medical services agencies if a patient they have been asked to transfer has an infectious disease
  - Senate Joint Resolution 32 established a joint subcommittee to study AIDS, charged with evaluating needs and services, reviewing state policies, laws and regulations, and making recommendations for legislation.
  - First Regional AIDS Training program conducted by VDH for professionals from a variety of agencies dealing with HIV education
- 1989 HIV testing, counseling, referral, and partner notification offered in methadone clinics operated by DMHMRSAS
  - House Bill 1974 provided for the following:

Development of model guidelines for school attendance for children infected with HIV Development of HIV education for college students Establishment of a services and education grants program Establishment of pilot treatment centers and regional AIDS resources and consultation centers Mandatory reporting of HIV testing Confidentiality of test results Counseling requirements for HIV testing Situations involving deemed consent to testing Additional anonymous testing sites

Prohibition of donating blood, body fluids, organs and tissues by persons infected with HIV

- Telecommunications for the Deaf (TDD) capability was added to the STD/AIDS hot line

- American Association for World Health recognized the VDH fc outstanding achievements on World AIDS Day
- Department of Education (DOE) developed the HIV/AIDS resource guide for local school divisions
- Blue Ridge School Health Conference, a week-long training program for school and health department personnel, devoted substantial portions of the program to HIV/AIDS. HIV has been included in all subsequent programs.
- 1990 House Bill 814 provided immunity from liability for failure to report HIV test results except as required by law
  - House Bill 815 provided for testing of those charged/ convicted with sexual assault
  - Senate Bill 340 provided for testing of convicted prostitutes
  - House Bill 816 established procedures for isolation of certain persons with communicable disease
  - DOE collaborated with three national agencies to provide training to service providers for in-school and out-of-school youth
  - VDH contracted for a Spanish-speaking hot line
  - VDH contracted for personal care services with six agencies
  - DOE revised "Health Standards of Learning Objectives" and the HIV/AIDS resource guide for local school divisions
  - DOE and the American Red Cross developed a peer training program for high-risk youth
- 1991 House Joint Resolution 436 required the Secretary of Health and Human Resources to direct development of comprehensive AIDS plan for 1991 - 2000
  - VDH received federal funds under the Ryan White C.A.R.E. Act of 1990 to provide outpatient care
  - DOE contracted with nine colleges and universities to provide HIV/AIDS inservice training to teachers and administrators in local school divisions
  - DOE developed a HIV/AIDS training plan for professionals working with students with disabilities.

### APPENDIX C

#### KNOWLEDGE, ATTITUDES AND BEHAVIOR SURVEYS REFERENCED IN SECTION III-PREVENTION SERVICES

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