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OA/ID Number: 9005
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Comments on n:\text6.g96 (Jeffery Levi, Patsy Fleming)

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people who deal with this are our fellow Americans and that most of them share our values and our hopes and our dreams and deserve dignity and decency in the treatment we give them, we forget a very great thing that makes this a special country. And we forget it at our own peril.

In one way or another nearly every person in America at one time in his or her life has been subject to some sort of scorn. Woodrow Wilson once said that you could break a person with scornful words just as surely as with sticks, and beat him. And I think that's an important thing, too, to remember.

The American people need to know that everybody in this country and, indeed, throughout the world, is now vulnerable to this disease. We need to identify what our responsibilities are in this country, and our responsibilities to developing countries, are to deal with the problem, to search for a cure, to search for a vaccine, to deal with the treatment issues. But I'm not sure it doesn't begin with dealing with our own hearts and minds on this. That's where you have to come in.

Int'l
quote

Frederick Douglas said, during the great struggle against slavery, that it was not light that is needed, but fire; not the gentle shower, but thunder; the feeling of the nation must be quickened, the conscious of the nation must be roused. That's what you came here to do.

Don't forget this -- most Americans are good people. The great burden we have as Americans is that when we have to deal with something new, too often we can't deal with it from imagination and empathy, we have to actually experience it first. I do not want to wait until every single family has somebody die before we have a good policy -- (applause) --.

So I ask you -- I understand anger and frustration, but I will never understand it until someday and something happens to me and I know the sand is running out of my hour glass. So I can't totally understand it. But I ask all of you to remember this -- this is fundamentally a good country. Alexis de Tocqueville said in the 1830s that this was a great country because we are a good country. And if we ever stop being a good country, we would no longer be a great country.

So I ask you to use this moment to give America a chance to be great about this issue, give our people a chance to feel this the way you feel it, to see it the way you see it, to know it the way you know it.

When I was getting ready for the conference yesterday, I called Bob Hattoy sitting back there in the room. I said, what do you think I ought to say tomorrow? What do you think is going to happen? We were talking. And he said, I think you ought to think about all the people who waged this battle with us in 1992 who aren't around anymore. And so we just went through them name by name.

CLINTON QUOTATIONS

"Our common goal must ultimately be a cure, a cure for all those who are living with HIV, and a vaccine to protect all the rest of us from the virus. A cure and a vaccine, that must be our first and top priority." Dec. 5, 1995, White House Conference on HIV and AIDS. *Research*

"We have to reduce the number of new infections each and every year until there are no more new infections." Dec. 5, 1995, White House Conference on HIV and AIDS. *PX*

"Every person with HIV or AIDS is someone's son or daughter, brother or sister, parent or grandparent. We cannot allow discrimination of any kind to blind us to what we must do." May 20, 1996, signing the Ryan White CARE Act Reauthorization. *DR*

"AIDS has taken too many friends and relatives and loved ones from everyone of us in this room. It has shaken the faith of many, but it has inspired a remarkable community spirit." May 20, 1996, signing the Ryan White CARE Act Reauthorization. *C+S*

"For nearly every American with eyes and ears open, the face of AIDS is no longer the face of a stranger. Millions and millions of us have now stood at the bedside of a dying friend and grieved. Millions and millions of us now know people who have had AIDS and who have died of it who are both gay and heterosexual. Millions and millions of us are now forced to admit that this is a problem which has diminished the life of every American." Dec. 1, 1993, Georgetown University. *Overall/beginning*

Int'l

n:1 quotes

AHCPR

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Agency for Health Care Policy and Research

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risk of viral transmission from mother to child. Early studies showed an association of anti-V3 antibodies with protection.^{3,4} However, subsequent studies have failed to show any correlation between levels of anti-V3 antibodies and decreased risk of vertical transmission.^{5,6}

Kliks et al. did not find a correlation between anti-V3 antibody levels and protection from vertical transmission of HIV. However, they were able to show that the viruses isolated from six infected infants were resistant to neutralization by their mothers' serum. (Neutralization of mother's autologous HIV-1 by her own serum in vitro showed a trend, but did not reach significance [$p < 0.07$]). In two of the infants, enhancement of viral replication was measured (indicated by increased reverse transcriptase activity in cultured isolates) when serum was added (in one of the infants, mother's autologous serum; in the other infant, heterologous, HIV antibody positive serum). Thus, the authors postulate that the viruses transmitted to the infants may represent neutralization-resistant or "escape" variants, or that their variants may somehow have been enhanced by an antibody-mediated mechanism. The latter disturbing suggestion is supported by recent reports that high antibody titers to the V3 and the immunodominant region of GP-41 are positively associated with maternal-infant transmission,^{7,8} and highlights the need for caution in developing vaccines to combat HIV-1 (see also Epstein H et al. pp 350 in this issue).

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Schur, C.L., et al., Health insurance coverage of persons with HIV-related illness: Data from the ACSUS Screener. *AIDS Cost and Services Utilization Survey (ACSUS) Report No. 2. AHCPR Pub. No. 94-0009 Rockville, MD: Agency for Health Care Policy and Research, 1994.*

The AIDS Cost and Services Utilization Survey (ACSUS) is a longitudinal study of persons with human immunodeficiency virus (HIV)-related disease in which a combination of personal interviews and abstraction of medical and billing records is used. Information was collected on more than 1,900 HIV-infected adults and adolescents—including approximately 350 women—and 140 HIV-infected children under 13 years of age in a series of interviews over an 18-month period from spring 1991 to fall 1992. The interviews gathered information on:

- age, sex, and race or ethnicity
- exposure category.
- insurance status.
- income sources and employment history
- living arrangements and social support network
- functional status and quality of life
- perceived barriers to receiving care

Following the interviews, medical and other service providers identified by the study subjects were contacted twice during an 18-month period. Data on enrollees' use of and charges for services as well as clinical and laboratory information were abstracted from billing and medical records.

The sample design for ACSUS involved a three-stage process: selection of geographic areas, selection of health care providers in those areas, and selection of persons with HIV-related illness receiving treat-

ment from those providers during an enrollment period of approximately four months. The geographic areas were selected to provide regional diversity in terms of the service delivery systems, the distributions of persons with HIV infection by source of payment and exposure category, and the rate of incidence of acquired immunodeficiency syndrome (AIDS) cases in each area. The following geographic sites were included in the sample: New York City, Newark, Philadelphia, Baltimore, Miami, Tampa, Chicago, Houston, Los Angeles, and San Francisco.

Hospitals, clinics, and private practitioners providing care to HIV-positive persons were then sampled based on the projected number of persons treated. Twenty-six providers, all delivering care to a significant proportion of persons with HIV-related illness in their communities, participated in the study. Within each provider setting, all patients receiving care within the enrollment period were asked to complete a screener questionnaire eliciting information on HIV status, age, sex, race or ethnicity, usual source of payment for care, exposure category, and symptoms and HIV-related conditions experienced. Using these screener responses, patients were stratified by illness stage, exposure category, and payment source, and a systematic probability sample was drawn. Selected persons were then recruited into the study by site coordinators.

Although ACSUS is not a national probability sample, its broad representation of persons with HIV-related illness over an extended period of time allows examination of a wide range of issues. In particular, patterns of use of medical and nonmedical services, expenditures for medical services and the relationship between use and source of payment for care, and changes in these factors over the course of the illness can be analyzed for HIV-infected persons receiving care from major providers located in large urban centers.

Commentary. Although health care services for persons infected with HIV are financed by the same public and private sources of payment as is care for the rest of the population, the relative importance of each type of health insurance coverage is markedly different. The role of Medicaid, for example, is more central to financing care for persons with HIV-related illness than it is for other care, and that of private insurance and Medicare is less significant. The outcome is a larger residual pool of persons with no outside source of payment for care and less adequate benefits for those who are covered.¹

Despite the significant interest in understanding patterns of health insurance coverage among the HIV population, important gaps in knowledge remain. The Agency for Health Care Policy and Research designed the ACSUS to meet the needs of health services researchers and health policymakers concerned with HIV. ACSUS is a longitudinal survey of persons with HIV-related illness in ten major cities. Although ACSUS is not a national probability sample and thus should not be used for deriving national estimates of the HIV population, its broad representation of persons with HIV-related illness allows examination of a wide range of issues related to the financing of care for this population.² Because survey respondents were identified through major providers of care to the HIV population, all information collected pertains to persons already receiving care for the illness. The data in this report are based on a screener questionnaire completed by 5,899 persons; these persons formed the sampling frame from which the ACSUS sample was selected.

Data presented in this report (see Tables 1-3) suggest that type of health insurance coverage, if any, is related to self-reported stage of illness among persons who are infected with HIV. There are two primary reasons why source of payment may change over the course of the disease. First, as the illness progresses, persons infected with HIV may become unable to work and are at risk of losing their employment-related insurance. Second, as individuals' resources diminish or as they become disabled, both the previously insured and the uninsured may become eligible for Medicaid. In controlling for stage of illness, however, wide variation is observed in type of coverage by exposure category and race or ethnicity. Thus, although a number of clear relationships are suggested between personal characteristics and source of payment for care, there remains variation that cannot be explained with the current set of information.

Further exploration of the variation in source of payment across the population with HIV-related illness requires a more detailed base of information than the ACSUS screener questionnaire provides. Data from the first and subsequent rounds of ACSUS will allow more in depth analysis of sources of coverage, including changes in source of payment over time. Further data also will provide the opportunity to examine the relationship between insurance and utilization of care so that access to care for this population as a whole and for specific subgroups of the HIV population can be assessed.

Table 1. Number and Percent Distribution of Asymptomatic HIV-Positive Persons, by Health Insurance Coverage and Selected Characteristics: 1991

		Insurance Coverage		
Characteristic	Number	Private	Public	None
		Percent distribution		
Total	985	31.4	37.3	31.4
Age				
13-30 years	272	20.2	42.7	37.1
31-40 years	408	34.8	35.0	30.2
41 years and over	263	39.2	35.0	25.9
Sex				
Male	771	36.1	30.3	33.6
Female	213	14.1	62.4	23.5
Race or ethnicity				
White	360	51.9	19.4	28.6
Black	289	18.3	53.3	28.4
Hispanic	315	19.7	42.6	37.8
Exposure category				
Male				
Homosexual or bisexual	514	45.7	21.4	32.9
IDU	96	7.3	57.3	35.4
Sex with IDU	38	23.7	39.5	36.8
Other	121	22.3	43.8	33.9
Female				
IDU	47	6.4	74.4	19.2
Other	166	16.3	59.1	24.7

Abbreviations: IDU, injecting drug user.

Note: Persons were classified by stage of illness according to responses to a self-administered questionnaire listing 4 symptoms and 17 conditions related to HIV illness. Numbers may not add to totals because of missing values for certain characteristics. Adolescents ages 13-17 years are grouped with adults ages 18-30 because the number of adolescents is too small to be analyzed separately.

Source: Agency for Health Care Policy and Research: Data from the Screener Questionnaire, AIDS Cost and Services Utilization Survey.

Table 2. Number and Percent Distribution of Symptomatic Non-AIDS Persons, by Health Insurance Coverage and Selected Characteristics: 1991

Characteristic	Number	Insurance Coverage		
		Private	Public	None
		Percent distribution		
Total	2,523	29.0	49.5	21.4
Age				
13-30 years	681	17.0	54.7	28.2
31-40 years	1,122	32.0	48.8	19.2
41 years and over	636	38.1	44.8	17.1
Sex				
Male	2,089	33.3	44.1	22.6
Female	429	8.4	75.8	15.9
Race or ethnicity				
White	1,212	42.5	34.3	23.3
Black	662	14.7	68.3	17.1
Hispanic	604	18.2	59.1	22.7
Exposure category				
Male				
Homosexual or bisexual	1,386	43.7	32.2	24.2
IDU	405	8.6	74.6	16.8
Sex with IDU	82	17.1	64.7	18.3
Other	211	18.5	56.4	25.1
Female				
IDU	157	2.6	83.4	14.0
Other	272	11.8	71.3	16.9

Abbreviation: IDU, injecting drug user.

Note: Persons were classified by stage of illness according to responses to a self-administered questionnaire listing 4 symptoms and 17 conditions related to HIV illness. Numbers may not add to totals because of missing values for certain characteristics. Adolescents ages 13-17 years are grouped with adults ages 18-30 because the number of adolescents is too small to be analyzed separately.

Source: Agency for Health Care Policy and Research: Data from the Screener Questionnaire, AIDS Cost and Services Utilization Survey.

Table 3. Number and Percent Distribution of Persons with AIDS, by Health Insurance Coverage and Selected Characteristics: 1991

Characteristic	Number	Insurance Coverage		
		Private	Public	None
		Percent distribution		
Total	2,303	25.9	62.3	11.9
Age				
13-30 years	467	17.1	65.5	17.3
31-40 years	1,177	25.6	63.4	11.0
41 years and over	610	33.9	57.2	8.9
Sex				
Male	2,002	28.8	58.5	12.7
Female	301	6.3	87.4	6.3
Race or ethnicity				
White	1,127	37.4	50.7	11.9
Black	620	11.8	76.0	12.3
Hispanic	512	16.8	71.9	11.3
Exposure category				
Male				
Homosexual or bisexual	1,308	39.8	48.0	12.3
IDU	410	2.9	83.4	13.7
Sex with IDU	77	10.4	75.4	14.3
Other	197	17.8	68.5	13.7
Female				
IDU	122	1.6	92.7	5.7
Other	179	9.5	83.8	6.7

Abbreviation: IDU, injecting drug user.

Note: Persons were classified by stage of illness according to responses to a self-administered questionnaire listing 4 symptoms and 17 conditions related to HIV illness. Numbers may not add to totals because of missing values for certain characteristics. Adolescents ages 13-17 years are grouped with adults ages 18-30 because the number of adolescents is too small to be analyzed separately.

Source: Agency for Health Care Policy and Research: Data from the Screener Questionnaire, AIDS Cost and Services Utilization Survey.

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Document: 1

Record from database: AIDSLINE

Title

Schur, C.L., et al., Health insurance coverage of persons with HIV-related illness: data from the ACSUS Screener. AIDS Cost and Services Utilization Survey (ACSUS) Report No. 2. AHCPR Pub. No. 94-0009 Rockville, MD: Agency for Health Care Policy and Research, 1994.

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Schur CL; Berk ML

Source

Pediatr AIDS HIV Infect, 5: 6, 1994 Dec, 362-6

Abstract

Abstract not available online.

Language of Publication

English

Unique Identifier

95368374

MeSH Heading (Major)

HIV Infections [*EC]

Insurance, Health [*EC/UT]

MeSH Heading

Adolescence

Adult

Child

Child, Preschool

Female

Health Surveys

Human

Longitudinal Studies

Male

Publication Type

JOURNAL ARTICLE

ISSN

1045-5418

Country of Publication

UNITED STATES



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Document: 1

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AHCPR

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1045-5418

Country of Publication

UNITED STATES



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No. 2 • April 1994

ACSUS *Report*

AIDS Cost and Services Utilization Survey

Health Insurance Coverage of Persons With HIV-Related Illness: Data From the ACSUS Screener

by Claudia L. Schur, Ph.D., and
Marc L. Berk, Ph.D., Project HOPE

Introduction

Although health care services for persons infected with HIV (human immunodeficiency virus) are financed by the same public and private sources of payment as is care for the rest of the population, the relative importance of each type of health insurance coverage is markedly different. The role of Medicaid, for example, is more central to financing care for persons with HIV-related illness than it is for other care, and that of private insurance and Medicare is less significant. The outcome is a larger residual pool of persons with no outside source of payment for care and less adequate benefits for those who are covered (discussed in Baily et al., 1989, among other sources).

Despite the significant interest in understanding patterns of health insurance coverage among the HIV population, important gaps in knowledge remain. The Agency for Health Care Policy and Research designed the AIDS (acquired immunodeficiency syndrome) Cost and Services Utilization Survey, or ACSUS, to meet the needs of health services researchers and health policymakers concerned with HIV. ACSUS is a longitudinal survey of persons with HIV-related illness in 10 major

cities. Although ACSUS is not a national probability sample and thus should not be used for deriving national estimates of the HIV population, its broad representation of persons with HIV-related illness allows examination of a wide range of issues related to the financing of care for this population. (A more detailed description of the study design and objectives is provided in Berk, Maffeo, and Schur, 1993.) Because survey respondents were identified through major providers of care to the HIV population, all information collected pertains to persons already receiving care for the illness. The data in this report are based on a screener questionnaire completed by almost 6,000 persons; these persons formed the sampling frame from which the ACSUS sample was selected.

Data presented in this report suggest that type of health insurance coverage, if any, is related to self-reported stage of illness among persons who are infected with HIV. There are two primary reasons why source of payment may change over the course of the disease. First, as the illness progresses, persons infected with HIV may become unable to work and are at risk of losing their employment-related insurance. Second, as individuals' resources diminish or as they become disabled, both the previously insured and the uninsured may become eligible for Medicaid. In controlling for stage of illness, however, wide variation is observed in type of

continued on page 3

Survey Overview

The AIDS Cost and Services Utilization Survey (ACSUS) is a longitudinal study of persons with HIV-related disease in which a combination of personal interviews and abstraction of medical and billing records is used. Information is being collected on more than 1,900 HIV-infected adults and adolescents—including approximately 350 women—and 140 HIV-infected children under 13 years of age in a series of interviews over an 18-month period from spring 1991 to fall 1992. The interviews are gathering information on:

- Age, sex, and race or ethnicity.
- Exposure category.
- Insurance status.
- Income sources and employment history.
- Living arrangements and social support network.
- Functional status and quality of life.
- Perceived barriers to receiving care.

Following the interviews, medical and other service providers identified by the study subjects are contacted twice during the 18-month period. Data on enrollees' use of and charges for services as well as clinical and laboratory information are abstracted from billing and medical records.

The sample design for ACSUS involves a three-stage process: selection of geographic areas, selection of health care providers in those areas, and selection of persons with HIV-related illness receiving treatment from those providers during an enrollment period of approximately 4 months. The geographic areas were selected to provide regional diversity in terms of the service delivery systems, the distributions of persons with HIV infection by source of payment and exposure category, and the rate of incidence of AIDS cases in each area. The following geographic sites were included in the sample: New York, Newark, Philadelphia, Baltimore, Miami, Tampa, Chicago, Houston, Los Angeles, and San Francisco.

Hospitals, clinics, and private practitioners providing care to HIV-positive persons were then sampled based on the projected number of persons treated. Twenty-six providers, all delivering care to a significant proportion of persons with HIV-related illness in their communities, are participating in the study. Within each provider setting, all patients receiving care within the enrollment period were asked to complete a screener questionnaire eliciting information on HIV status, age, sex, race or ethnicity, usual source of payment for care, exposure category, and symptoms and HIV-related conditions experienced. Using these screener responses, patients were stratified by illness stage, exposure category, and payment source, and a systematic probability sample was drawn. Selected persons were then recruited into the study by site coordinators. For detailed information on sampling and data collection procedures as well as the study's analytic objectives, see Berk, Maffeo, and Schur (1993).

Although ACSUS is not a national probability sample, its broad representation of persons with HIV-related illness over an extended period of time will allow examination of a wide range of issues. In particular, patterns of use of medical and nonmedical services, expenditures for medical services and the relationship between use and source of payment for care, and changes in these factors over the course of the illness can be analyzed for HIV-infected persons receiving care from major providers located in large urban centers.

Data Collection Schedule

Screener interview	March 20 - July 24, 1991
Time 1	March 20 - August 14, 1991
Time 2	July 15 - October 9, 1991
Time 3	October 21, 1991 - January 29, 1992
Time 4	January 27 - May 6, 1992
Time 5	May 4 - July 29, 1992
Time 6	September 1 - November 25, 1992

coverage by exposure category and race or ethnicity. Thus, although a number of clear relationships are suggested between personal characteristics and source of payment for care, there remains variation that cannot be explained with the current set of information.

Financing of Care

Recent estimates of the distribution of sources of payment for care of persons with AIDS were published in the 1991 report of the National Commission on AIDS; those figures indicated that 29 percent of persons with AIDS were covered by private health insurance, 40 percent were covered by Medicaid, and 2 percent by Medicare, leaving 29 percent uninsured (Davis et al., 1991). The estimate of the proportion of AIDS patients covered by Medicaid echoes that made by the Health Care Financing Administration (1990). These studies of health insurance coverage for HIV-related illness have dealt exclusively with persons with AIDS rather than those in earlier stages of the disease. Data presented in this report, in contrast, allow separate analyses of persons with AIDS and persons who report HIV-related symptoms but no AIDS-defining conditions, as well as HIV-infected persons who report being asymptomatic.

When comparing the relative importance of the sources of payment for persons with HIV with the entire U.S. population, differences exist for a number of reasons related to the manner in which health insurance coverage is made available. For most persons, private health insurance is an employment-related benefit. Low-income persons, who are disproportionately represented in the HIV population, are less likely to have employment-related health benefits (Mohr, Schur, and Juday, 1991; Fleishman and Mor, 1991). Moreover, the clinical progression of AIDS may make those who initially have private job-related benefits unable to continue working and at risk of losing private coverage.

In contrast, Medicaid coverage is available to persons with HIV-related illness when they are categorized as disabled and are eligible through the Supplemental Security Income program or,

in many States, if their medical costs are high relative to their income or resources (i.e., they are "medically needy"). Although this second path to Medicaid eligibility may require "spending down" (i.e., depletion of assets), large expenses are not uncommon with AIDS. Medicaid also may be available for women through categorical eligibility for Aid to Families with Dependent Children (AFDC). The Medicare program is an alternative for only a small proportion of persons with HIV illness because of the extensive waiting period—usually longer than mean survival time—for eligibility under the Social Security Disability Insurance program.

Study Population

The study population for this report consists of 5,811 respondents to the ACSUS screener questionnaire who were 13 years of age and over.¹ These are persons who visited 1 of 26 sample health care providers in 10 geographic areas during an enrollment period of approximately 4 months and reported that they had previously tested positive for HIV infection. This screener population is the group from which respondents were selected for participation in ACSUS and is about 2½ times as large as the sample drawn for participation in the actual survey.

All of the geographic areas are large urban areas with substantial numbers of HIV-infected persons, but considerable heterogeneity exists in the respondent populations across areas. These differences stem from a variety of factors—some of which are related to characteristics of the geographic areas and their residents and some of which are attributable to the study design—that may have a substantial effect on the distributions of source of payment. For example, an area in which the racial or ethnic composition and socioeconomic status of the HIV-positive population is predominantly minority or poor will likely have a higher

¹ There were a total of 5,899 respondents to the screener questionnaire, representing a response rate of 96 percent. For 88 respondents, however, information on either stage of illness or source of payment was missing. Data for these respondents were excluded from the analysis.

proportion of persons without coverage. The extent of Medicaid or other public coverage will be affected, in part, by the generosity of the State Medicaid program in terms of eligibility requirements, as well as the availability of public funding other than Medicaid.

In terms of study design, the selection of patient care sites within the geographic areas had an effect on rates of insurance coverage. Of the 26 provider sites, for example, 2 are office-based private physician practices where rates of private insurance coverage are relatively high. Two other sites are clinics where all patients seen must be qualified to receive county-funded care; thus, respondents from these two sites are likely to report public funding other than Medicaid as their usual source of payment. The remaining sites were hospitals, both public and private, with sizable HIV-infected patient loads.

A summary of the characteristics of the study population is provided, not to attempt to characterize the larger population with HIV, but to provide a context for looking at patterns in source of payment among the screener respondents. Almost one-half of respondents (48 percent) were ages 31-40, with those remaining split evenly between the group ages 13-30 (25 percent) and those 41 years of age and over (27 percent).²

Slightly more than 80 percent of this population was male. Almost one-half of the persons in the study population (46 percent) classified themselves as white, slightly more than one-quarter as black (27 percent), and the remaining one-quarter as Hispanic. Of male respondents, two-thirds reported that they had been exposed to HIV through homosexual activity. Another 19 percent reported exposure through their own use of injected drugs and 4 percent through sex with a drug user. On the other hand, slightly more than one-third of women reported exposure through their own drug use.

Several caveats should be made about classification by exposure category. As with all data presented in this report, exposure category is self-reported and likely to be subject to ambiguity or error. The categories labeled

"other" for both males and females are surprisingly large and may be related to a reluctance to acknowledge drug use or homosexual activity. For males, unwillingness or inability to identify exposure route is more common among black and Hispanic respondents; 5 percent of white males reported being in this category, compared with 18 percent of black and 17 percent of Hispanic males.

As shown in Figure 1, 53 percent of respondents reported some form of public coverage for their medical care. Another 28 percent were covered by private insurance, and 19 percent had no source of payment other than themselves or their families. It should be noted that these data are self-reported and, although the majority of those with public coverage are probably covered by Medicaid, the exact proportion cannot be determined from the screener data. Even though this breakdown by usual source of payment is within the bounds of distributions reported elsewhere, such similarities may be only coincidental. It is emphasized that the study population was not derived to reflect national probabilities.

Statistics in this report combine all types of public coverage because it is believed that some respondents reported "other public" coverage even though they were covered by Medicaid. For example, some respondents referred to a specific local program as "other" coverage even though it is known to be a Medicaid program. Although many reporting errors were found during data preparation, other incorrect reports cannot be identified. Estimates are that Medicaid may account for three-quarters of respondents classified as having public coverage, or almost 40 percent of the total study population. Data obtained from medical providers in later stages of the project will provide more precise data about source of payment.

Although this report presents cross-sectional data only, later analyses from ACSUS will allow examination of the transition to AIDS along with related changes in socioeconomic and treatment variables. Abstraction of clinical and laboratory information from medical records during the survey will also make possible more precise and standardized classification of disease stage.

² Only 8 persons (less than 1 percent of the study population) were under 18 years of age. Although adolescents may differ from the adult population, their inclusion is not likely to affect study findings.

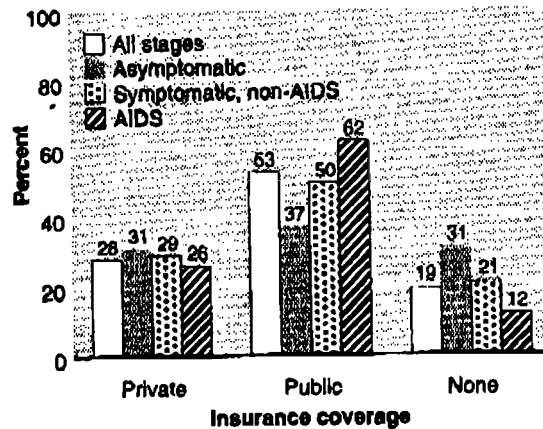
Stage of Illness

For purposes of sample selection, individuals who completed the screener questionnaire were classified by stage of illness according to their responses to a list of symptoms and conditions related to HIV illness. Respondents were asked if they had ever been told by a doctor that they had any of a list of 17 AIDS-defining conditions: candidiasis (thrush), PCP (pneumocystis carinii pneumonia), KS (Kaposi's sarcoma), lymphoma, wasting syndrome, tuberculosis, cryptococcosis, CMV (cytomegalovirus), MAI (mycobacterium avium infection), cryptosporidiosis, dementia, herpes simplex, histoplasmosis, toxoplasmosis, isosporiasis, leukoencephalopathy, and salmonellosis. If they responded yes to any of the conditions, they were classified as having AIDS. One exception was that if they reported only herpes and/or thrush, they were classified as "symptomatic, non-AIDS." Respondents who had none of the conditions were asked if they had experienced any of four symptoms related to HIV infection: swollen glands (lymph nodes), persistent fever, diarrhea, and unintentional weight loss. If they responded yes, they were classified as "symptomatic, non-AIDS." If they had no symptoms or conditions, they were categorized as "asymptomatic." All eligible persons reported that they were HIV positive. According to these responses, 17 percent of the screener population was classified as asymptomatic, 43 percent as symptomatic, non-AIDS, and 40 percent as AIDS. All remaining statistics in this report are presented by stage of illness.

Asymptomatic

Persons in the study population who reported being asymptomatic when they responded to the screener questionnaire were less likely to have public coverage and more likely to have no outside source of payment than the study population as a whole. Of asymptomatic persons, 31 percent had private coverage, 37 percent were covered by Medicaid or some other public source of funding, and 31 percent had no coverage, as shown in Figure 1. As noted previously, this report provides statistics on relationships between variables within the study population. The extent to which these relationships can be

Figure 1. Percent distributions of HIV-positive persons 13 years of age and over, by health insurance coverage and stage of illness: 1991



Note: Persons were classified by stage of illness according to responses to a self-administered questionnaire listing 4 symptoms and 17 conditions related to HIV illness. N = 5,811.

Source: Agency for Health Care Policy and Research; Data from the Screener Questionnaire, AIDS Cost and Services Utilization Survey.

extrapolated to the entire HIV population is unknown.

The likelihood of having some form of private insurance to help defray medical costs for those who reported being asymptomatic increased with age, from 20 percent for persons 13-30 years of age to 39 percent for those 41 years of age and over (Table 1). The reverse pattern was observed for persons without insurance. Only 26 percent of persons 41 years of age and over had no coverage, compared with 37 percent of those ages 13-30. This pattern mirrors the distribution of health insurance coverage in the United States (Short, Monheit, and Beauregard, 1989).

Males were 2½ times as likely to be covered by private insurance as females were but only half as likely to have some form of public coverage. As noted earlier, because of potential Medicaid eligibility through AFDC, females are more likely than males to have this source of public funding available, particularly in early stages of the disease before they are disabled or have been classified as medically needy. White persons were substantially more likely to have private coverage and less likely to be covered by any public funding mechanism than were either black or Hispanic persons. Hispanic persons were more likely than either black or white

Table 1. Number and percent distribution of asymptomatic, HIV-positive persons, by health insurance coverage and selected characteristics: 1991

Characteristic	Number	Insurance coverage		
		Private	Public	None
		Percent distribution		
Total	985	31.4	37.3	31.4
Age				
13-30 years	272	20.2	42.7	37.1
31-40 years	408	34.8	35.0	30.2
41 years and over	263	39.2	35.0	25.9
Sex				
Male	771	36.1	30.3	33.6
Female	213	14.1	62.4	23.5
Race or ethnicity				
White	360	51.9	19.4	28.6
Black	289	18.3	53.3	28.4
Hispanic	315	19.7	42.6	37.8
Exposure category				
Male:				
Homosexual or bisexual	514	45.7	21.4	32.9
IDU	96	7.3	57.3	35.4
Sex with IDU	38	23.7	39.5	36.8
Other	121	22.3	43.8	33.9
Female:				
IDU	47	6.4	74.4	19.2
Other	166	16.3	59.1	24.7

Note: Persons were classified by stage of illness according to responses to a self-administered questionnaire listing 4 symptoms and 17 conditions related to HIV illness. Numbers may not add to totals because of missing values for certain characteristics. IDU is injecting drug user. Adolescents ages 13-17 years are grouped with adults ages 18-30 because the number of adolescents is too small to be analyzed separately.

Source: Agency for Health Care Policy and Research; Data from the Screener Questionnaire, AIDS Cost and Services Utilization Survey.

persons to have no health insurance coverage (38 percent compared with about 29 percent).

In terms of exposure category, homosexual or bisexual males were most likely to be covered by private insurance (46 percent); both males and females exposed to HIV as injecting drug users (IDUs)³ were least likely to have such coverage (about 7 percent for both males and females). For males who contracted HIV through sexual relations with an IDU and for non-IDU females, rates of coverage by public

programs were quite different. The difference for females probably was due, in part, to categorical eligibility for Medicaid through AFDC. Almost 60 percent of this subgroup of females were covered by Medicaid or another public program, but only 40 percent of males in this category had a public source of payment for care. Males in this category were more likely to have no coverage than were females (37 percent versus 25 percent). Differences between males and females were also apparent among IDUs: 74 percent of female IDUs had public coverage, compared with 57 percent of male IDUs.

³ The term IDU is used to denote injecting drug users, or persons who reported exposure to the HIV virus through "injecting drugs with a needle." Until recently, the term used by the Centers for Disease Control was intravenous drug user, or IVDU.

Symptomatic, Non-AIDS

In contrast to persons who reported being asymptomatic, those classified as symptomatic, non-AIDS reported having experienced at least one of the following HIV-related symptoms: swollen glands, persistent fever, diarrhea, and unintentional weight loss. Persons in this group (Table 2) were more likely to have some form of public coverage than were those classified as asymptomatic. This is related to the methods of obtaining public coverage (particularly Medicaid), described previously.

Although overall rates of coverage by source of payment vary by stage of illness, most of the patterns across age, gender, race or ethnicity, and exposure group categories are the same for

those with HIV-related symptoms as for those who are asymptomatic. Persons in the upper age groups were more likely than younger persons to have private coverage and less likely to have no coverage. The divergence in rates of private coverage by gender was greater for symptomatic than for asymptomatic persons: males were four times as likely to be covered as females. In this stage of illness, females were still more likely than males to have public coverage, but the difference was slightly smaller than for asymptomatic persons.

The proportion of persons with no health insurance coverage was 10 percentage points lower for persons who were symptomatic but non-AIDS than for those who were

Table 2. Number and percent distribution of symptomatic, non-AIDS persons, by health insurance coverage and selected characteristics: 1991

Characteristic	Number	Insurance coverage		
		Private	Public	None
		Percent distribution		
Total	2,523	29.0	49.5	21.4
Age				
13-30 years	681	17.0	54.7	28.2
31-40 years	1,122	32.0	48.8	19.2
41 years and over	636	38.1	44.8	17.1
Sex				
Male	2,089	33.3	44.1	22.6
Female	429	8.4	75.8	15.9
Race or ethnicity				
White	1,212	42.5	34.3	23.3
Black	662	14.7	68.3	17.1
Hispanic	604	18.2	59.1	22.7
Exposure category				
Male:				
Homosexual or bisexual	1,386	43.7	32.2	24.2
IDU	405	8.6	74.6	16.8
Sex with IDU	82	17.1	64.7	18.3
Other	211	18.5	56.4	25.1
Female:				
IDU	157	2.6	83.4	14.0
Other	272	11.8	71.3	16.9

Note: Persons were classified by stage of illness according to responses to a self-administered questionnaire listing 4 symptoms and 17 conditions related to HIV illness. Numbers may not add to totals because of missing values for certain characteristics. IDU is injecting drug user. Adolescents ages 13-17 years are grouped with adults ages 18-30 because the number of adolescents is too small to be analyzed separately.

Source: Agency for Health Care Policy and Research: Data from the Screener Questionnaire, AIDS Cost and Services Utilization Survey.

asymptomatic. The difference in the proportion of uninsured persons across stages is particularly marked for Hispanics and males who contracted the disease through use of injected drugs or sexual contact with an HIV-infected IDU.

AIDS

As described earlier, persons with HIV illness can be eligible for Medicaid by being classified as disabled and unable to work, by "spending down" and becoming medically indigent, or through categorical eligibility such as for AFDC. Thus, it is not surprising that persons with AIDS are more likely than persons in the other illness stages to be Medicaid eligible (through either of the first two routes). The proportion of persons with some form of public payment for care increased from 37 percent of asymptomatic persons, to 50 percent of persons who were symptomatic, non-AIDS, to 62 percent of persons with AIDS. Males were substantially less likely than females to be covered by public programs in all illness stages, although the difference narrowed somewhat for those with AIDS (Table 3). Black persons were more likely to have public coverage than either Hispanic or white persons regardless of stage, although this gap also closed somewhat in the later stages.

Both the proportion of persons with private insurance and the proportion with no insurance were lower among persons with AIDS than among persons in earlier stages of infection. The difference across disease stages was substantially larger for the group with no coverage. In other words, the higher proportion of persons with public insurance coverage in later disease stages is due more to a decrease in the number of persons with no insurance coverage than to a decrease in the privately insured. Patterns of coverage across exposure group categories were quite similar in different illness stages; homosexual or bisexual males were least likely and female IDUs were most likely to have public coverage in all stages.

Race or Ethnicity

Analysis of characteristics of persons with HIV-related illness in the ACSUS screener population indicates that this is a heterogeneous group. The considerable variation in usual source of payment for care among this population appears to be related to a number of factors, including stage of illness, exposure category, and race or ethnicity. (As discussed earlier, some of the variation in insurance coverage is related to the selection of specific health care provider sites.) In Figures 2-4, the distribution of the study population by health care coverage is examined in terms of both exposure category and race or ethnicity. Again, statistics are presented separately for each illness stage. Even controlling for stage of illness and exposure category, race or ethnicity appears to have an independent effect on source of payment status for some population subgroups.

With the exception of male IDUs, non-Hispanic white persons were consistently more likely to have private insurance coverage than either black or Hispanic persons regardless of illness stage. For male IDUs, race or ethnicity had little effect on the likelihood of having private insurance, and rates of coverage among this group were almost negligible.

Although black persons, overall, were more likely to have public coverage than either white or Hispanic persons, in several subgroups—particularly females and male IDUs with AIDS—Hispanic persons had higher rates of public coverage than did black persons. For homosexual or bisexual males, the difference in rates of coverage between black persons and Hispanic persons was smaller in the later stages than for those who were asymptomatic.

Table 3. Number and percent distribution of persons with AIDS, by health insurance coverage and selected characteristics: 1991

Characteristic	Number	Insurance coverage		
		Private	Public	None
		Percent distribution		
Total	2,303	25.9	62.3	11.9
Age				
13-30 years	467	17.1	65.5	17.3
31-40 years	1,177	25.6	63.4	11.0
41 years and over	610	33.9	57.2	8.9
Sex				
Male	2,002	28.8	58.5	12.7
Female	301	6.3	87.4	6.3
Race or ethnicity				
White	1,127	37.4	50.7	11.9
Black	620	11.8	76.0	12.3
Hispanic	512	16.8	71.9	11.3
Exposure category				
Male:				
Homosexual or bisexual	1,308	39.8	48.0	12.3
IDU	410	2.9	83.4	13.7
Sex with IDU	77	10.4	75.4	14.3
Other	197	17.8	68.5	13.7
Female:				
IDU	122	1.6	92.7	5.7
Other	179	9.5	83.8	6.7

Note: Persons were classified by stage of illness according to responses to a self-administered questionnaire listing 4 symptoms and 17 conditions related to HIV illness. Numbers may not add to totals because of missing values for certain characteristics. IDU is injecting drug user. Adolescents ages 13-17 years are grouped with adults ages 18-30 because the number of adolescents is too small to be analyzed separately.

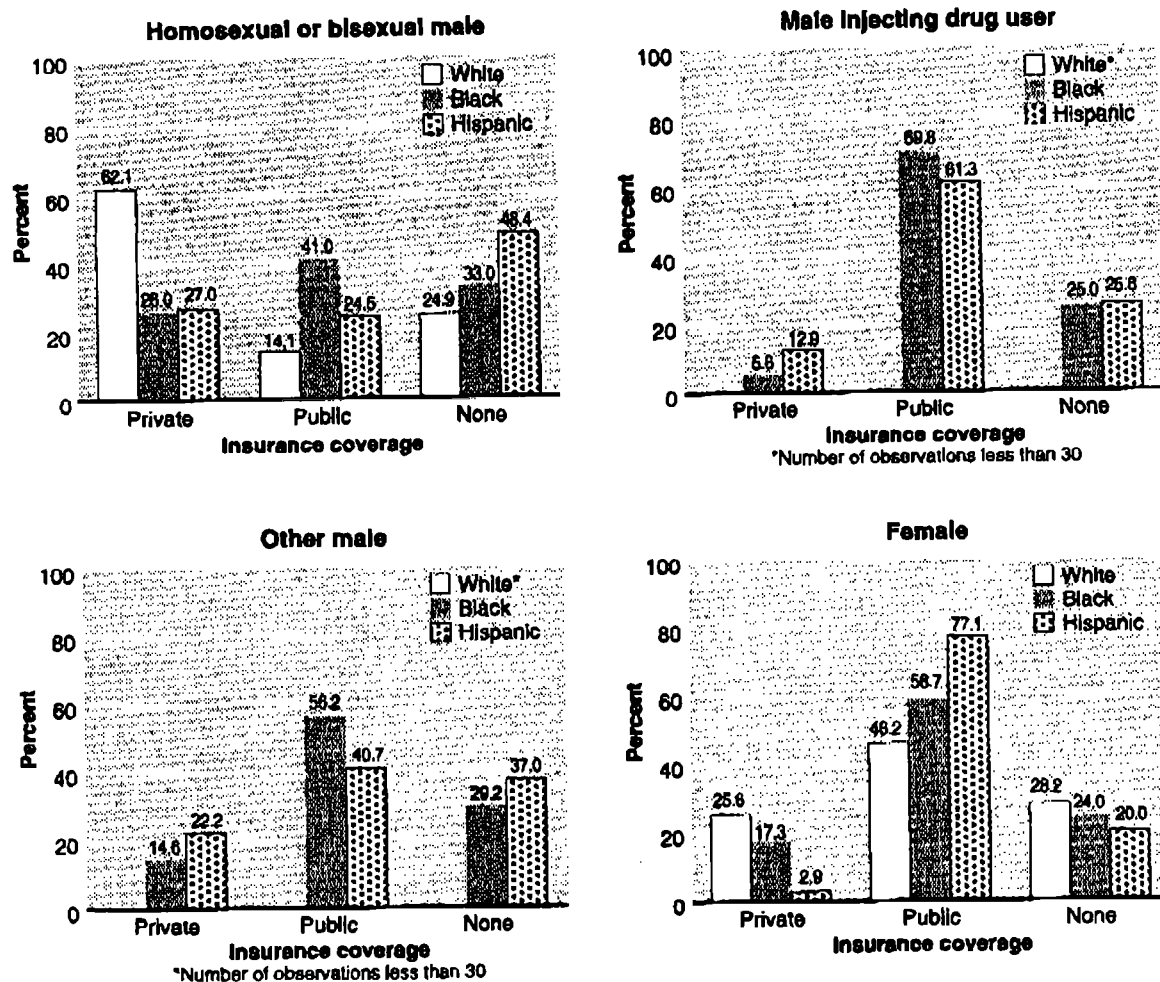
Source: Agency for Health Care Policy and Research: Data from the Screener Questionnaire, AIDS Cost and Services Utilization Survey.

Future Research

Further exploration of the variation in source of payment across the population with HIV-related illness requires a more detailed base of information than the ACSUS screener questionnaire provides. Data from the first and subsequent rounds of ACSUS will allow more

indepth analysis of sources of coverage, including changes in source of payment over time. Further data also will provide the opportunity to examine the relationship between insurance and utilization of care so that access to care for this population as a whole and for specific subgroups of the HIV population can be assessed.

Figure 2. Percent distributions of asymptomatic, HIV-positive persons 13 years of age and over, by health insurance coverage, exposure category, race or ethnicity, and sex: 1991



Note: Persons were classified by stage of illness according to responses to a self-administered questionnaire listing 4 symptoms and 17 conditions related to HIV illness. N = 5,811. Males who reported contracting HIV through sexual contact with an injecting drug user are included in the homosexual or bisexual category.

Source: Agency for Health Care Policy and Research: Data from the Screener Questionnaire, AIDS Cost and Services Utilization Survey.

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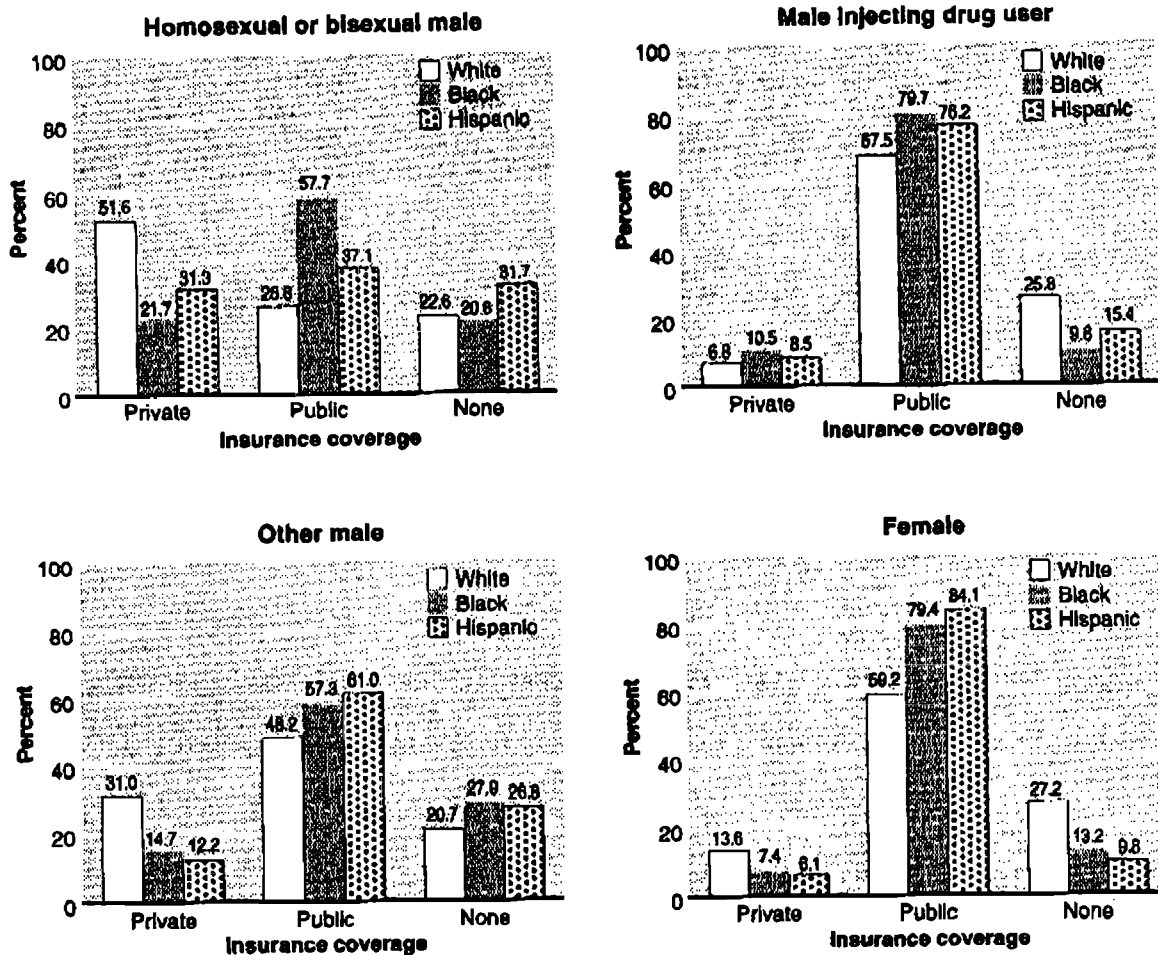
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Figure 3. Percent distributions of symptomatic, non-AIDS, HIV-positive persons 13 years of age and over, by health insurance coverage, exposure category, race or ethnicity, and sex: 1991



Note: Persons were classified by stage of illness according to responses to a self-administered questionnaire listing 4 symptoms and 17 conditions related to HIV illness. N = 5,811. Males who reported contracting HIV through sexual contact with an injecting drug user are included in the homosexual or bisexual category.

Source: Agency for Health Care Policy and Research: Data from the Screener Questionnaire, AIDS Cost and Services Utilization Survey.

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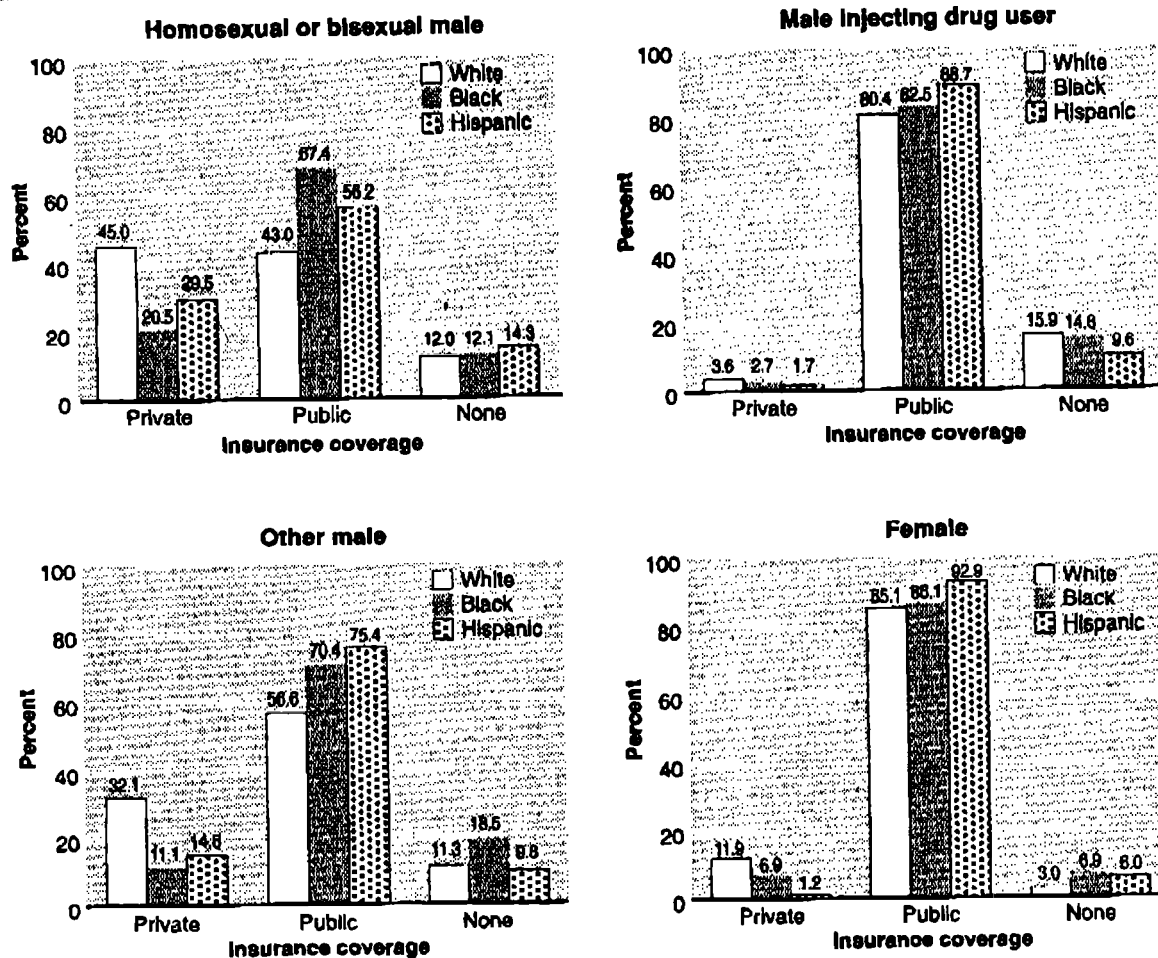
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Figure 4. Percent distributions of persons 13 years of age and over with AIDS, by health insurance coverage, exposure category, race or ethnicity, and sex: 1991



Note: Persons were classified by stage of illness according to responses to a self-administered questionnaire listing 4 symptoms and 17 conditions related to HIV illness. N = 5,811. Males who reported contracting HIV through sexual contact with an injecting drug user are included in the homosexual or bisexual category.

Source: Agency for Health Care Policy and Research: Data from the Screenshot Questionnaire, AIDS Cost and Services Utilization Survey.



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Suggested Citation

Schur, C. L., and Berk, M. L.: Health Insurance Coverage of Persons With HIV-Related Illness: Data From the ACSUS Screener. *AIDS Cost and Services Utilization Survey (ACSUS) Report, No. 2*. AHCPR Pub. No. 94-0009. Rockville, MD: Agency for Health Care Policy and Research, 1994.



U.S. Department of Health and Human Services
Public Health Service
Agency for Health Care Policy and Research
AHCPR Pub. No. 94-0009

April 1994

Comment Citation

Comment in: JAMA 1993 Dec 15;270(23):2810

Publication Type

JOURNAL ARTICLE

ISSN

0098-7484

Country of Publication

UNITED STATES



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Document: 1

Record from database: AIDSLINE

Title

Forecasts of the costs of medical care for persons with HIV: 1992-1995.

Author

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Division of Cost and Financing, CGHSER, Agency for Health Care Policy, Rockville, MD.

Source

Inquiry, 29: 3, 1992 Fall, 356-65

Abstract

This study concludes that the cumulative (national) cost of treating all persons with the human immunodeficiency virus (HIV) rose considerably over the past year and will continue to rise over the next several years. It is forecast that the cumulative cost of treating all persons with HIV will increase 48% from 1992 to 1995 (from \$10.3 billion to \$15.2 billion). It is estimated that the average yearly cost of treating a person with AIDS is \$38,300 and of treating an infected person without AIDS is \$10,000. The lifetime cost of treating a PWA is calculated to be \$102,000. This is the first study to use, along with other data, data from the AIDS Cost and Service Utilization Survey to estimate the cost of treating persons with the HIV. The study also projects the number of AIDS cases to be 66,300 in 1992, 76,200 in 1993, 86,800 in 1994, and 97,800 in 1995.

Language of Publication

English

Unique Identifier

93014085

MeSH Heading (Major)

Health Care Costs [SN/*TD]

HIV Infections [BL/*EC/TH]

HIV-1

Models, Econometric

Models, Statistical

MeSH Heading

Ambulatory Care [EC]

Antiviral Agents [EC/SD]

California

CD4-Positive T-Lymphocytes [CD 004 POSITIVE LYMPHOCYTES T]

Drug Costs [SN]

Forecasting

Health Expenditures [SN]

Health Services Research

Home Care Services [EC]

Hospitalization [EC]

Human

Length of Stay [EC]

Leukocyte Count

New York

United States

Publication Type

JOURNAL ARTICLE

ISSN

0046-9580

Country of Publication

UNITED STATES
CAS Registry/EC Number
0 (Antiviral Agents)

Document: 2

Record from database: AIDSLINE

Title

The lifetime cost of treating a person with HIV [see comments]

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Division of Cost and Financing, US Public Health Service, Rockville, MD 20852.

Source

JAMA, 270: 4, 1993 Jul 28, 474-8

Abstract

OBJECTIVE--To estimate the cost (total charges for services) of medical care for persons with human immunodeficiency virus (HIV) from the time of infection until death. **DESIGN AND SETTING**--Data from the AIDS (acquired immunodeficiency syndrome) Cost and Service Utilization Survey were used. **PATIENTS**--Data from interviews conducted during the spring and early summer of 1992 with 1164 respondents with HIV were analyzed. The respondents were recruited at 26 sites (hospitals, clinics, and physicians' offices) in 10 cities. Billing data from a survey of providers also were used. **OUTCOME MEASURES**--Estimates of the mean occupancy time in each of four disease stages were obtained from the San Francisco Men's Health Study. These estimates were multiplied by the monthly cost in each stage and summed to derive a synthetic estimate of the lifetime medical care costs of treating a person with HIV. **RESULTS**--It is estimated herein that the lifetime cost of treating a person with HIV from the time of infection until death is approximately \$119,000. The estimated cost of care from HIV infection until the development of AIDS is \$50,000, while the estimated cost from AIDS development until death is approximately \$69,000. These estimates define upper bounds because they assume persons receive treatment continuously from the moment of infection until death. **CONCLUSIONS**--This study found that the cost of treating a person with AIDS, which has risen rapidly in the past, has fallen as a result of a reduction in the use of inpatient hospital services.

Language of Publication

English

Unique Identifier

93308802

MeSH Heading (Major)

Episode of Care

Health Care Costs [*SN]

HIV Infections [*EC/IM/TH]

MeSH Heading

Acquired Immunodeficiency Syndrome [EC/IM/TH]

Ambulatory Care [EC]

Drug Costs

Health Services Research [MT]

Home Care Services [EC]

Hospitalization [EC]

Human

Leukocyte Count

Long-Term Care [EC]

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risk of viral transmission from mother to child. Early studies showed an association of anti-V3 antibodies with protection.^{3,4} However, subsequent studies have failed to show any correlation between levels of anti-V3 antibodies and decreased risk of vertical transmission.^{5,6}

Kliks et al. did not find a correlation between anti-V3 antibody levels and protection from vertical transmission of HIV. However, they were able to show that the viruses isolated from six infected infants were resistant to neutralization by their mothers' serum. (Neutralization of mother's autologous HIV-1 by her own serum in vitro showed a trend, but did not reach significance [$p < 0.07$]). In two of the infants, enhancement of viral replication was measured (indicated by increased reverse transcriptase activity in cultured isolates) when serum was added (in one of the infants, mother's autologous serum; in the other infant, heterologous, HIV antibody positive serum). Thus, the authors postulate that the viruses transmitted to the infants may represent neutralization-resistant or "escape" variants, or that their variants may somehow have been enhanced by an antibody-mediated mechanism. The latter disturbing suggestion is supported by recent reports that high antibody titers to the V3 and the immunodominant region of GP-41 are positively associated with maternal-infant transmission,^{7,8} and highlights the need for caution in developing vaccines to combat HIV-1 (see also Epstein H et al. pp 350 in this issue).

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Schur, C.L., et al., Health insurance coverage of persons with HIV-related illness: Data from the ACSUS Screener. AIDS Cost and Services Utilization Survey (ACSUS) Report No. 2. AHCPB Pub. No. 94-0009 Rockville, MD: Agency for Health Care Policy and Research, 1994.

The AIDS Cost and Services Utilization Survey (ACSUS) is a longitudinal study of persons with human immunodeficiency virus (HIV)-related disease in which a combination of personal interviews and abstraction of medical and billing records is used. Information was collected on more than 1,900 HIV-infected adults and adolescents—including approximately 350 women—and 140 HIV-infected children under 13 years of age in a series of interviews over an 18-month period from spring 1991 to fall 1992. The interviews gathered information on:

- age, sex, and race or ethnicity
- exposure category.
- insurance status.
- income sources and employment history
- living arrangements and social support network
- functional status and quality of life
- perceived barriers to receiving care

Following the interviews, medical and other service providers identified by the study subjects were contacted twice during an 18-month period. Data on enrollees' use of and charges for services as well as clinical and laboratory information were abstracted from billing and medical records.

The sample design for ACSUS involved a three-stage process: selection of geographic areas, selection of health care providers in those areas, and selection of persons with HIV-related illness receiving treat-

ment from those providers during an enrollment period of approximately four months. The geographic areas were selected to provide regional diversity in terms of the service delivery systems, the distributions of persons with HIV infection by source of payment and exposure category, and the rate of incidence of acquired immunodeficiency syndrome (AIDS) cases in each area. The following geographic sites were included in the sample: New York City, Newark, Philadelphia, Baltimore, Miami, Tampa, Chicago, Houston, Los Angeles, and San Francisco.

Hospitals, clinics, and private practitioners providing care to HIV-positive persons were then sampled based on the projected number of persons treated. Twenty-six providers, all delivering care to a significant proportion of persons with HIV-related illness in their communities, participated in the study. Within each provider setting, all patients receiving care within the enrollment period were asked to complete a screener questionnaire eliciting information on HIV status, age, sex, race or ethnicity, usual source of payment for care, exposure category, and symptoms and HIV-related conditions experienced. Using these screener responses, patients were stratified by illness stage, exposure category, and payment source, and a systematic probability sample was drawn. Selected persons were then recruited into the study by site coordinators.

Although ACSUS is not a national probability sample, its broad representation of persons with HIV-related illness over an extended period of time allows examination of a wide range of issues. In particular, patterns of use of medical and nonmedical services, expenditures for medical services and the relationship between use and source of payment for care, and changes in these factors over the course of the illness can be analyzed for HIV-infected persons receiving care from major providers located in large urban centers.

Commentary. Although health care services for persons infected with HIV are financed by the same public and private sources of payment as is care for the rest of the population, the relative importance of each type of health insurance coverage is markedly different. The role of Medicaid, for example, is more central to financing care for persons with HIV-related illness than it is for other care, and that of private insurance and Medicare is less significant. The outcome is a larger residual pool of persons with no outside source of payment for care and less adequate benefits for those who are covered.¹

Despite the significant interest in understanding patterns of health insurance coverage among the HIV population, important gaps in knowledge remain. The Agency for Health Care Policy and Research designed the ACSUS to meet the needs of health services researchers and health policymakers concerned with HIV. ACSUS is a longitudinal survey of persons with HIV-related illness in ten major cities. Although ACSUS is not a national probability sample and thus should not be used for deriving national estimates of the HIV population, its broad representation of persons with HIV-related illness allows examination of a wide range of issues related to the financing of care for this population.² Because survey respondents were identified through major providers of care to the HIV population, all information collected pertains to persons already receiving care for the illness. The data in this report are based on a screener questionnaire completed by 5,899 persons; these persons formed the sampling frame from which the ACSUS sample was selected.

Data presented in this report (see Tables 1-3) suggest that type of health insurance coverage, if any, is related to self-reported stage of illness among persons who are infected with HIV. There are two primary reasons why source of payment may change over the course of the disease. First, as the illness progresses, persons infected with HIV may become unable to work and are at risk of losing their employment-related insurance. Second, as individuals' resources diminish or as they become disabled, both the previously insured and the uninsured may become eligible for Medicaid. In controlling for stage of illness, however, wide variation is observed in type of coverage by exposure category and race or ethnicity. Thus, although a number of clear relationships are suggested between personal characteristics and source of payment for care, there remains variation that cannot be explained with the current set of information.

Further exploration of the variation in source of payment across the population with HIV-related illness requires a more detailed base of information than the ACSUS screener questionnaire provides. Data from the first and subsequent rounds of ACSUS will allow more in depth analysis of sources of coverage, including changes in source of payment over time. Further data also will provide the opportunity to examine the relationship between insurance and utilization of care so that access to care for this population as a whole and for specific subgroups of the HIV population can be assessed.

Table 1. Number and Percent Distribution of Asymptomatic HIV-Positive Persons, by Health Insurance Coverage and Selected Characteristics: 1991

Characteristic	Number	Insurance Coverage		
		Private	Public	None
		Percent distribution		
Total	985	31.4	37.3	31.4
Age				
13-30 years	272	20.2	42.7	37.1
31-40 years	408	34.8	35.0	30.2
41 years and over	263	39.2	35.0	25.9
Sex				
Male	771	36.1	30.3	33.6
Female	213	14.1	62.4	23.5
Race or ethnicity				
White	360	51.9	19.4	28.6
Black	289	18.3	53.3	28.4
Hispanic	315	19.7	42.6	37.8
Exposure category				
Male				
Homosexual or bisexual	514	45.7	21.4	32.9
IDU	96	7.3	57.3	35.4
Sex with IDU	38	23.7	39.5	36.8
Other	121	22.3	43.8	33.9
Female				
IDU	47	6.4	74.4	19.2
Other	166	16.3	59.1	24.7

Abbreviations: IDU, injecting drug user.

Note: Persons were classified by stage of illness according to responses to a self-administered questionnaire listing 4 symptoms and 17 conditions related to HIV illness. Numbers may not add to totals because of missing values for certain characteristics. Adolescents ages 13-17 years are grouped with adults ages 18-30 because the number of adolescents is too small to be analyzed separately.

Source: Agency for Health Care Policy and Research: Data from the Screener Questionnaire, AIDS Cost and Services Utilization Survey.

Table 2. Number and Percent Distribution of Symptomatic Non-AIDS Persons, by Health Insurance Coverage and Selected Characteristics: 1991

Characteristic	Number	Insurance Coverage		
		Private	Public	None
		Percent distribution		
Total	2,523	29.0	49.5	21.4
Age				
13-30 years	681	17.0	54.7	28.2
31-40 years	1,122	32.0	48.8	19.2
41 years and over	636	38.1	44.8	17.1
Sex				
Male	2,089	33.3	44.1	22.6
Female	429	8.4	75.8	15.9
Race or ethnicity				
White	1,212	42.5	34.3	23.3
Black	662	14.7	68.3	17.1
Hispanic	604	18.2	59.1	22.7
Exposure category				
Male				
Homosexual or bisexual	1,386	43.7	32.2	24.2
IDU	405	8.6	74.6	16.8
Sex with IDU	82	17.1	64.7	18.3
Other	211	18.5	56.4	25.1
Female				
IDU	157	2.6	83.4	14.0
Other	272	11.8	71.3	16.9

Abbreviation: IDU, injecting drug user.

Note: Persons were classified by stage of illness according to responses to a self-administered questionnaire listing 4 symptoms and 17 conditions related to HIV illness. Numbers may not add to totals because of missing values for certain characteristics. Adolescents ages 13-17 years are grouped with adults ages 18-30 because the number of adolescents is too small to be analyzed separately.

Source: Agency for Health Care Policy and Research: Data from the Screener Questionnaire, AIDS Cost and Services Utilization Survey.

Table 3. Number and Percent Distribution of Persons with AIDS, by Health Insurance Coverage and Selected Characteristics: 1991

Insurance Coverage and Selected Characteristics				
Characteristic	Number	Insurance Coverage		
		Private	Public	None
		Percent distribution		
Total	2,303	25.9	62.3	11.9
Age				
13-30 years	467	17.1	65.5	17.3
31-40 years	1,177	25.6	63.4	11.0
41 years and over	610	33.9	57.2	8.9
Sex				
Male	2,002	28.8	58.5	12.7
Female	301	6.3	87.4	6.3
Race or ethnicity				
White	1,127	37.4	50.7	11.9
Black	620	11.8	76.0	12.3
Hispanic	512	16.8	71.9	11.3
Exposure category				
Male				
Homosexual or bisexual	1,308	39.8	48.0	12.3
IDU	410	2.9	83.4	13.7
Sex with IDU	77	10.4	75.4	14.3
Other	197	17.8	68.5	13.7
Female				
IDU	122	1.6	92.7	5.7
Other	179	9.5	83.8	6.7

Abbreviation: IDU, injecting drug user.

Note: Persons were classified by stage of illness according to responses to a self-administered questionnaire listing 4 symptoms and 17 conditions related to HIV illness. Numbers may not add to totals because of missing values for certain characteristics. Adolescents ages 13-17 years are grouped with adults ages 18-30 because the number of adolescents is too small to be analyzed separately.

Source: Agency for Health Care Policy and Research: Data from the Screener Questionnaire, AIDS Cost and Services Utilization Survey.

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Project Hope

[Note: This could be reworked as a message from the President to the world or as a letter from Patsy to the President presenting the draft Strategy to him.]

"We must develop a clear, well-articulated national plan for confronting AIDS."

The Final Report of the National Commission on AIDS
June 1993

Message from the Director of the Office of National AIDS Policy

The epidemic of HIV and AIDS constitutes a public health crisis of unprecedented proportions. In 1993, the Office of National AIDS Policy (ONAP) was created by President Clinton to provide a national focus and direction for the government's response to HIV and AIDS. More recently, President Clinton asked ONAP to develop a comprehensive National AIDS Strategy that would detail the Federal government's long-term approach in responding to this epidemic. The National AIDS Strategy has been developed by the Clinton Administration to capitalize upon progress already made in fighting the epidemic and to catalyze collaborative efforts among Federal Departments and Agencies, communities, State and local governments, businesses, schools, churches, families, and individuals.

The President has identified the following national goals to guide our efforts against HIV:

- To provide strong continuing support for AIDS-related research in order to find additional treatments, a preventive vaccine to protect the uninfected, and a cure for those currently infected;
- To provide strong continuing support for effective AIDS prevention strategies [efforts?] to continue to reduce the number of new HIV infections in the U.S.;
- To ensure that people living with HIV have access to services that are affordable, of high quality, and responsive to their needs; and,
- To ensure that people living with HIV are not subject to unlawful discrimination. (homophobia is not unlawful!)

This document is a snapshot of where we are as a Nation and where we need to go in achieving these national goals. It summarizes

some of the ^{major} ~~the~~ (accomplishments) ~~of our Nation's~~ scientific and public health professionals and identifies key areas for further effort. In addition, the appendices to this report lay out, for the first time, detailed descriptions of the objectives, goals, and budgets of all Agencies involved in the Federal response to HIV in five major areas of HIV policy: prevention, research, care, civil rights, international activities, and translation of research into practice.

The National AIDS Strategy is intended to be a working document that requires regular updating and adjustment as goals are reached and new challenges emerge. This Strategy provides a reference point for continuing dialogues and collaborative efforts between the public and private sectors that are necessary to meet our national goals and objectives.

In that light, the Office of National AIDS Policy is seeking direct input from the Presidential Advisory Council on HIV/AIDS, national and community-based organizations, state and local government, clinicians and researchers, members of the infected and affected community, and other individuals and organizations who can contribute to this historic document. This Strategy is being released, first, in draft form to allow for maximum input to the first of an ongoing national effort to chart and plan Federal efforts in response to the epidemic of HIV/AIDS.

The development of a National AIDS Strategy is an ^{attempted} historic undertaking. No previous Administration has ~~undertaken~~ so broad a planning effort that: (1) involves all Federal Departments and Agencies that engage in HIV-related efforts; (2) reaches out to communities and the private sector; and, (3) identifies areas where the Federal government should focus its efforts.

The National AIDS Strategy was drafted in consultation with, and with guidance from, numerous groups and individuals. Within the Federal government, this effort began at the Agency level. Members of the Interdepartmental Task Force on HIV and AIDS (IDTF) representing all Federal Agencies involved in the national response to HIV and AIDS, identified their HIV-related goals, objectives, and highlighted areas requiring special attention.

Individuals living with HIV and AIDS, their families, friends, loved ones, and care givers made vital contributions to this Strategy. Numerous non-governmental groups and organizations have also been consulted including the Presidential Advisory Council on HIV/AIDS, participants in the historic White House Conference on HIV and AIDS, ² the ONAP-sponsored regional briefings, patient and consumer advocates, health care professionals, community-based

DRAFT: National AIDS Strategy
August 9, 1996 (n:\text6.g96)

organizations, educators, religious leaders, and business leaders. The earlier insights provided by the National Commission on AIDS, the Institute of Medicine and National Research Council, the General Accounting Office, and the Office of Technology Assessment have also been extraordinarily helpful in developing the National AIDS Strategy.

need better words → As a Nation, we face great challenges, but we are also facing ~~equally great~~ opportunities. After fifteen years, AIDS remains a terrible national tragedy that has affected -- and will continue to affect -- far too many people in this ~~Nation~~ ^{country} and around the world. But we have made tremendous progress in our understanding of HIV, ^{itself,} and HIV disease, ways we can treat those who are infected, and means by which we can prevent infection. Ultimately, HIV is a disease that we can defeat -- just as we have eradicated smallpox from our planet and polio from the western hemisphere. The National AIDS Strategy provides a foundation for the continuing public-private partnerships that are essential to our success. Together, with steadfast commitment, courage, and leadership, we will win the battle against HIV and AIDS.

Patricia S. Fleming
Director, Office of National AIDS Policy

~~WJC~~

~~William J. Clinton~~

"For nearly every American with eyes and ears open, the face of AIDS is no longer the face of a stranger. Millions and millions of us have now stood at the bedside of a dying friend and grieved. Millions and millions of us now know people who have had AIDS and who have died of it who are both gay and heterosexual. Millions and millions of us are now forced to admit that this is a problem which has diminished the life of every American."

President Clinton, December 1, 1993,
Georgetown University

I. INTRODUCTION

Bold : (see p.8 heading)

Scope of the HIV/AIDS Epidemic

Shouldn't these be combined?

The epidemic of Human Immunodeficiency Virus (HIV) and Acquired Immunodeficiency Syndrome (AIDS) presents unique social, economic, and public health challenges to governments and individuals here in the United States and around the world. While significant progress has been made in understanding the disease and developing treatments since the first case was reported in the U.S. in June 1981, HIV remains a deadly infection for which there is no vaccine, no cure, and for which there is an expanding but still limited inventory of available treatments. An average of 100 Americans are diagnosed with AIDS every day and a similar number of men, women, and children become infected with HIV every 24 hours. **[Richard -- are you certain these numbers are correct?]** Globally, 7,500 people become infected each day.

An Expanding Public Health Threat

As of December 1995, the Centers for Disease Control and Prevention (CDC) had received reports of 513,486 cases of AIDS among persons in the U.S. and 319,849 ~~of these persons have been~~ ^{are} reported to have died as a result of complications related to HIV. Since 1987, AIDS has risen from being the 15th cause of death among all Americans to the 8th. AIDS is now the leading cause of death among Americans aged 25 to 44 (See Figure 1). In 1995 alone, approximately 74,000 new cases of AIDS were reported in the U.S. and more than 46,000 AIDS-related deaths were reported to the CDC in 1994. CDC estimates that between 40,000 and 60,000 Americans are becoming newly infected with HIV each year, and that between 650,000 and 900,000 Americans are currently living with HIV.

As the epidemic in the United States has expanded, the demographics of the epidemic have changed. The early years of the epidemic were dominated by cases involving gay or bisexual men living in major urban centers ~~(e.g., New York, San Francisco, and Los Angeles)~~ ^{including}.

DRAFT: National AIDS Strategy
August 9, 1996 (n:\text6.q96)

men who have sex with men

is this true?
Today, ~~this group~~ *gay/bisexual men* represents less than half of all new cases, although they ~~still represent~~ *are* the majority of persons living with HIV and AIDS. Among the populations that are more heavily affected today are young ~~gay~~ *men*, women, and injecting drug users and their sexual partners as well as users of non-injecting drugs ~~like~~ *e.g.*, crack cocaine and alcohol). In 1995, nearly 14,000 women were reported to CDC as having been diagnosed with AIDS. Women now comprise 14 percent of cumulatively reported AIDS cases. If this trend continues, it is estimated that 80,000 American children will have been orphaned as a result of AIDS by the end of this decade. In 1995, approximately 800 new cases of pediatric AIDS cases were reported. (Footnote a)

Adolescents ~~(age 13-19)~~ *are* at increased risk for HIV infection. CDC estimates that one-quarter of new HIV infections in the U.S. occur among people under age 21. A significant number of young people are engaging at earlier ages in sexual intercourse and drug and alcohol use. This fact, coupled with the disturbing number of adolescents who are prone to high-risk behavior due to homelessness, sexual abuse, and other circumstances, places young Americans in a situation that leaves them extremely vulnerable to HIV infection.

Communities of color ~~OR~~ racial and ethnic minorities have been disproportionately affected by the epidemic of HIV and AIDS. African-Americans, who ~~represent~~ *are* approximately 12 percent of the U.S. population, accounted for 40 percent of newly reported AIDS cases in 1995. Hispanics, who ~~account for~~ *are* about 9 percent of the general population, represented 19 percent of new cases reported in 1995. The number of African-Americans and Hispanics affected by HIV and AIDS has risen dramatically. In 1982, Blacks and Hispanics ~~were represented~~ *were* 31 percent of all AIDS cases; however, as of December 1995, these groups comprised 52 percent of cumulative AIDS cases.

The HIV epidemic continues to spread into suburban and rural areas, with especially dramatic increases in certain regions of the South and Midwest. Between January 1993 and December 1995 the largest numbers of AIDS cases (86,462) were reported from the South. (Endnote 1)¹ While most cases are still reported from urban areas, the rate of reported cases in non-metropolitan areas is increasing more rapidly than in urban areas. AIDS cases have now been reported in all 50 States, the District of Columbia, Puerto Rico, Guam, and each of the U.S. territories (See Figure 2).

AIDS is an expensive disease. Average lifetime costs of medical care after diagnosis with HIV is \$119,000 (Footnote b). People living with HIV are disproportionately dependent on the public sector for their health care. Over 50 percent of people living

with AIDS are enrolled in Medicaid, including more than 90 percent of children with AIDS. In FY 1996, the Federal government spent \$1.8 billion on Medicaid benefits for people living with HIV and AIDS and another \$690 million on Medicare benefits. Social Security benefits for people disabled by HIV/AIDS total \$1.1 billion in FY 1996.

Globally, the toll of the epidemic is much greater and threatens to reverse decades of economic and public health progress in developing countries. The Joint United Programme on HIV and AIDS (UNAIDS) and the World Health Organization (WHO) estimate that 27.9 million people have been infected with HIV. Since the beginning of the pandemic, 6 million people, including 1.6 million children, have been diagnosed with AIDS. By the year 2000, WHO projects that between 30 million and 40 million people will have been infected with HIV and 10 million to 15 million children will be orphaned due to AIDS.

II. OVERVIEW OF FEDERAL EFFORTS

The scope and nature of the HIV/AIDS epidemic have drawn States, local governments, academic institutions, private foundations, health care institutions and community-based organizations and the Federal government into many HIV-related activities. The Federal government, through its public health responsibilities in such areas as research, prevention, health care, and housing has seen a dramatic increase in its activities since the beginning of the epidemic. In FY 1985 the Federal government spent \$212 million for AIDS research, surveillance, and care. By FY 1995 that figure reached \$6.8 billion. (See Appendix G).

In the past four years, under the leadership of President Clinton, spending for AIDS research, prevention, and care has increased by 47 percent. Funding for the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act alone has increased by 151 percent. Support for housing for people living with AIDS has increased by 91 percent. AIDS-related research funding has increased by 34 percent and AIDS prevention funding has increased by 24 percent. The National Institutes of Health Revitalization Act of 1993 provided the Office of AIDS Research with enhanced authority to prepare and carry out an annual AIDS research budget and plan. Approval of AIDS drugs by the Food and Drug Administration has been accelerated to record times. A community-based planning process has empowered local communities to develop innovative AIDS prevention programs. Eligibility for Social Security disability benefits for people with AIDS have been simplified and Federal laws prohibiting discrimination against people living with HIV and AIDS have been vigorously enforced.

As the epidemic continues, we must renew our vision for ending this epidemic. The sections that follow focus on six major policy areas: prevention, research, care and services, civil rights, international activities, and the translation of research advances into practice. They identify recent progress and future opportunities for further progress.

A. PREVENTION

"We have to set a goal. . . We have to reduce the number of new infections each and every year until there are no more new infections."

President Clinton, December 5, 1995, to the White House Conference on HIV and AIDS.

1. Record of Accomplishment

Since the epidemic began, the ^{U.S.} ~~Nation~~ has made important progress in prevention of HIV infection. In the early years of the epidemic, it was estimated that more than 100,000 Americans were becoming infected with HIV each year. Today, that total is between 40,000 and 60,000 people each year.

Sentinel accomplishments in prevention of HIV include:

- Identification in 1981 by the Centers for Disease Control and Prevention (CDC) of the first cases of AIDS;
- Identification in 1981 by the Centers for Disease Control and Prevention (CDC) of the risk factors associated with HIV infection; and behaviors
- Due in part to successful implementation of CDC-sponsored prevention strategies, a slowing ⁱⁿ the growth of the epidemic.

Since President Clinton took office in 1993, efforts in HIV/AIDS prevention have been accelerated. Actions include:

- Increasing ^{ed} funding for AIDS prevention by 24 percent;
- Launching ^{ed} the community planning partnership, which empowers local communities to make decisions about the development of innovative prevention efforts;
- Launching the Prevention Marketing Initiative, focusing on the risk to young adults (18 to 25) with frank public service announcements advocating sexual abstinence and the correct and, for the first time in the epidemic, the consistent use of latex condoms; and,
- Reorganizing AIDS prevention efforts at the Centers for Disease Control and Prevention to foster greater coordination with efforts to reduce sexually transmitted diseases and tuberculosis.

The efforts of Federal Agencies (see Appendix A) have been instrumental in expanding our knowledge base about HIV prevention. ~~The~~ CDC, the agency with primary Federal HIV surveillance and prevention responsibilities, has been pivotal in identifying risk factors associated with HIV transmission, seroprevalence of HIV in society, and trends in HIV infection.

Federal efforts have shown that HIV prevention programs can be effective. CDC's prevention projects, many in partnership with States, local governments, and community-based organizations, have demonstrated that prevention programs are most effective when designed and implemented at a local level. Biomedical, behavioral, and social science prevention research conducted and supported by the National Institutes of Health (NIH) has expanded and will continue to expand our understanding of the determinants of HIV-related risk behavior.

US
The ~~Nation~~ has also combatted the dual epidemics of HIV and drug abuse. The National Institute on Drug Abuse (NIDA) and the Substance Abuse and Mental Health Services Administration (SAMHSA) support efforts to prevent HIV infection among drug users. The Office of National Drug Control Policy has pursued efforts to counter the problem of substance abuse and its devastating consequences.

There have been advances in integrating primary prevention into health care service systems. The Health Resources and Services Administration (HRSA) and the Department of Veterans Affairs (VA) have encouraged broader access to prevention information through the integration of prevention interventions into primary health care services and through support of early intervention services. HRSA also has undertaken special initiatives designed to reduce perinatal transmission of HIV and has promoted primary prevention through the training of health professionals in the AIDS Education and Training Centers program.

2. Future Opportunities for Progress

Significant challenges remain if we are to reach the Nation's prevention goal -- no new infections. Primary to this progress are efforts to:

- Improve our understanding about the major trends in transmission and seroprevalence of HIV transmission;
- Close gaps in scientific knowledge, ~~which~~ *includes* identifying additional effective prevention models and strategies; and

- Eliminate gaps in HIV prevention program areas.

a. Improving Understanding of Trends in the Epidemic

An important aspect of strengthening prevention activities is to have a clearer understanding of those who are becoming infected and what behaviors are placing people at risk. Recent epidemiologic data show that the HIV epidemic continues to spread most rapidly among people who engage in injection drug use and their sexual partners, women, young and minority men who have sex with men, heterosexuals and infants who are infected through perinatal transmission. These trends must be considered when prioritizing prevention research and service programs.

A crucial element of effective prevention strategies is support for adequate surveillance of HIV infection and related diseases in order to gauge future directions of the epidemic and assess the effectiveness of prevention interventions. CDC's AIDS case and case death reporting system provides important data for assessing AIDS prevalence and mortality by gender, race/ethnicity, age, and mode of exposure.

Effective prevention interventions begin with sound information about who is at risk. However, current CDC surveillance systems do not capture sufficient "front-end" information on the incidence and prevalence of HIV prior to an AIDS diagnosis in the population and trends in modes of transmission and new infections. These data must be collected with appropriate confidentiality protections for the identity of those who are living with HIV. CDC is exploring additional innovative approaches for collecting HIV incidence information. These effort must continue. Collection of these data are needed as part of an enhanced effort to link surveillance and epidemiological data to priority setting as well as in the design and evaluation of HIV prevention programs.

The CDC has incorporated data collection design into its community planning process. Shifts in data needs may also require that CDC reevaluate and reconfigure certain of its data collection efforts. As part of the Agency's implementation of the recommendations set forth in the external review of CDC's HIV prevention strategies², CDC has initiated efforts to evaluate current data collection efforts and implement necessary changes.

b. Prevention Research: Closing Gaps in Scientific Knowledge
(Footnote c)

Factors that place individuals at risk for acquiring HIV infection

entail a complex combination of behavioral, social, cognitive, and biological influences. Given this complexity, we must not *assume* to intuitively know which interventions will work, but instead base our efforts on research findings. Development of effective interventions are based on sound research findings and evaluation. The three main gaps in current knowledge are: basic behavioral research, intervention research, and social marketing research.

Basic Behavioral Research. Information provided by basic behavioral research serves as the foundation for prevention programs. To capitalize on what is known and to improve HIV prevention programs that are targeted to reach diverse populations of Americans, more information on the determinants of HIV-associated sexual and drug-using behaviors is needed. Such data enable scientists to establish theories of behavioral change, which then provide researchers with tools for identifying approaches that may be most effective for an individual or a community.³

Intervention Research. Research to improve prevention interventions concentrates on modifying behaviors, such as those related to drug use and sex. Intervention research can focus on both individuals and communities, each of which often adhere to norms that influence personal behavior. Since the beginning of the epidemic we have made advances in our understanding of factors that are relevant to the design of intervention programs intended to reduce rates of HIV infection. There is more that we need to know if we are to develop more effective prevention programs. We must incorporate findings from basic behavioral research into effective prevention interventions. Agencies supporting intervention and behavioral research must include scientists from a broad range of disciplines in their planning activities and improve their data-sharing and collaborative efforts with Agencies responsible for implementing prevention programs. Intensifying the dialogue between researchers in these prevention-related fields will improve the development of effective prevention interventions.

Social Marketing Research. It is important that the findings from basic behavioral and intervention research serve as a foundation for prevention programs. Agencies supporting social marketing activities need to build on current knowledge in addition to strengthening efforts to understand barriers to the implementation and replication of promising prevention programs. As these models are developed, community-based organizations will require additional technical assistance and training in order to test those models in a "real-world" setting.

c. Strengthening Prevention Programs

For prevention interventions to be effective they must reach people at risk and be responsive to their needs. For individuals to take control of their own lives in fighting the spread of this virus, they must first have the information and skills to protect themselves. It is important that prevention planners carefully prioritize local efforts based on who is ~~and who is~~ becoming infected.

One of the most important innovations in HIV prevention is the creation of community planning. Through this public-private partnership it has been possible to establish joint goals for the prevention of HIV that are responsive to local needs. However, this process is early in its development and requires continuing significant leadership and technical assistance. Small, new, community-based organizations -- especially those serving minority populations -- often require additional technical assistance in order to compete for available resources. ~~The~~ CDC and other Agencies provide such assistance and will continue to do so.

Federal

It is crucial that prevention research results be disseminated and incorporated into prevention programs. Models of effective prevention interventions have been developed but often this valuable information is not reaching those people developing, implementing, and evaluating prevention programs. (See Section on Translation of Research Advances into Practice.)

Substance Abuse Prevention and Treatment. Injection drug use is one of the major forces driving the epidemic. One third of all new cases are directly or indirectly related to this mode of transmission. Limiting the impact of substance abuse on the epidemic will require efforts on several fronts.

First, we need to improve the integration of HIV prevention activities and substance abuse treatment and prevention programs. The epidemics of substance abuse and HIV in this country are overlapping and highly interrelated, however, many care and prevention service programs for HIV and substance are not optimally integrated. It is vital to continue and strengthen efforts to integrate HIV prevention into current substance abuse programs and integrate substance abuse prevention into HIV prevention.

A key to controlling the spread of HIV among substance abusers is enrollment into drug treatment programs. Substance abuse treatment is a major form of HIV prevention. Moreover, substance abuse problems that contribute to the spread of HIV are not limited to injecting drug use; use of non-injectable drugs such as alcohol and crack cocaine can adversely influence risk-taking behavior. The efforts of the Office of National Drug Control Strategy to motivate

Americans to reject illegal drugs and substance abuse are an important element in controlling the epidemic.

Work on these issues has begun and will continue. CDC has initiated State-by-State discussion, including meetings with State Legislators and the National Conference of State Legislatures regarding HIV prevention issues. SAMHSA's new "Knowledge Development Application (KDA) Program" will address emerging issues in the fields of substance abuse and mental health, including a focus on HIV and AIDS. CDC, HRSA, NIDA, and SAMHSA are co-sponsoring a national meeting of State and local officials from the fields of public health and drug abuse prevention to develop an action plan that more effectively integrates HIV and substance abuse prevention efforts.

Treatment for Sexually Transmitted Diseases and Tuberculosis. Research has shown that the presence of other sexually transmitted diseases (STDs) can significantly increase the efficiency of HIV transmission, by as much as twenty-fold. Studies have also shown that widespread treatment of STDs in certain communities has led to a 40 percent reduction in new HIV infections in these groups.^{4,5} These data suggest that treating STDs can be a very effective HIV prevention strategy and points to a need for all clinicians to be vigilant in efforts to prevent and treat STDs. NIH-supported research to further understanding of the effect of STD treatment on HIV transmission is underway and will continue.

It is important that Federal and State efforts to reduce the incidence of sexually transmitted diseases (STDs) include an HIV prevention element and that HIV prevention programs incorporate STD prevention and treatment efforts. The traditional model of targeting most STD prevention efforts towards individuals who have already contracted an STD is not necessarily effective for HIV prevention. Linkages between STD and HIV prevention efforts need to be established and, where they do exist, enhanced.

People living with HIV are at very high risk for developing active tuberculosis (TB) disease. Studies suggest that the risk of developing active TB disease is ~~70 to 80~~^{9,9} 10 percent per year for persons who are infected with both TB and HIV, whereas the risk is 10 percent per lifetime for persons not infected with HIV.⁶ In addition to the health implications for infected persons, there is an increased risk of transmission of TB to household members, health care workers, and other persons having regular contact with a person with active TB.

The newly organized National Center for HIV, STD, and TB Prevention

at CDC demonstrates the importance of integrating the interdependent aspects of the epidemic and illustrates the determination to integrate and coordinate HIV, STD, and TB prevention efforts.

Integration of Prevention Into Primary Care. To reach our prevention goal, we must also improve the integration of prevention activities and messages into primary health care services. HIV counseling and voluntary testing often provide an important bridge between HIV prevention and care for many at-risk persons. To assure that all persons seeking HIV testing can have access to such services, CDC's counseling and testing guidelines must acknowledge and address the needs of persons seeking such services, and provide training for personnel at CDC-funded sites.

Incorporating a person's sexual and drug use history when a medical history is taken, offering HIV-related counseling and voluntary testing, and providing prevention education to HIV positive individuals so they do not infect others is also important. In addition, to reduce perinatal transmission, all pregnant women should be offered HIV counseling and voluntary testing as well as information about and access to AZT. Training should be made available to improve primary care providers' skill, comfort level, and sensitivity in these areas.

Achieving this level of integration requires active collaborative efforts on the part of individual physicians, nurses, other clinicians, managed care plans, medical schools, and professional organizations in addition to State, local, and Federal governments. Presently HRSA's primary care, RWCA, and professional training programs emphasize the value of integrating prevention into primary care. These are important efforts that will continue.

Prisoners. Those in prison are at especially high risk for both substance abuse and HIV infection. There is often a high prevalence of behaviors that lead to both substance abuse and HIV infection in people entering prison. Given that prisoners often are at increased risk for HIV infection, offering educational programs during incarceration provides a unique opportunity to reach these individuals. Research has shown that people who are well informed about HIV and substance abuse issues modify their risk-taking behaviors. It is important that the Federal government build upon the knowledge and opportunity that currently exists to further improve HIV prevention efforts for incarcerated persons.

Evaluation. It is important to assess the effectiveness of the HIV prevention interventions. Prospectively-set performance measures can be used as a basis for evaluation and program improvement and

must become a routine part of all Federally-funded programs. It is only through sound evaluations that we will be able to determine whether our efforts have been effective in slowing the epidemic.

B. RESEARCH

"Our common goal must ultimately be a cure, a cure for all those who are living with HIV, and a vaccine to protect us from the virus."

*President Clinton, December 5, 1995, to
the White House Conference on HIV and AIDS*

1. Record of Accomplishment

Since the epidemic began in 1981, the ^{U.S.} ~~Nation~~ has made significant advances in HIV-related research advances. Sentinel points of that progress include:

- Identification of HIV as the etiologic agent for AIDS (April 1984);
- Development of a reliable test to determine exposure to HIV (March 1985);
- Approval of zidovudine (AZT), the first treatment of HIV primary infection (September 1986); and
- Development by the Food and Drug Administration of a system of expedited review of treatments for life-threatening diseases, including HIV.

Since he took office in 1993, President Clinton has escalated our AIDS research efforts by:

- Increasing AIDS research funding by 34 percent;
- Signing the NIH Revitalization Act of 1993, creating a permanent Office of AIDS Research at NIH and vesting it with new authority to plan and implement an annual AIDS research plan;
- Accelerating AIDS drug approval to record times. (Since 1993, the Food and Drug Administration has approved 12 new AIDS drugs and three new diagnostic tests.)
- Supporting research that led to finding that use of AZT during pregnancy, childbirth, and the first six weeks of life can reduce the transmission of HIV from mother to child by two-thirds;
- Launching a four-year, \$100 million research effort to develop effective topical microbicides;

- Facilitating creation of the Forum for Collaborative HIV Research to identify opportunities for clinical effectiveness research to improve care for HIV-positive individuals.

Contributions of AIDS Research to other Fields *(this section is too long)*

US Beyond the impact that AIDS research has had on the epidemic, the ~~Nation~~ has realized additional benefits of supporting such research. Several Federal Agencies play a significant role in AIDS research (see Appendix B). The effort to understand HIV and AIDS has produced scientific advances that benefit research on many other diseases. For example, AIDS research has accelerated study of the human immune system, which helps us to better understand and treat many other diseases, such as cancer; autoimmune diseases, including systemic lupus erythematosus; type I diabetes mellitus; rheumatoid arthritis; and multiple sclerosis. AIDS research also contributes to the prevention of other infectious diseases and provides a new paradigm for treatment of viral diseases.

Advances made in the treatment and prevention of HIV-related opportunistic infections have had an enormous impact on the care of patients with other immunodeficiency conditions who are susceptible to many of the same pathogens. This research effort has enhanced the care of cancer patients, patients who have received immunosuppressive therapy for transplants, or the treatment of diseases caused by elevated immune responses (i.e., allergies and lupus).

HIV research has assisted in identifying new infectious agents that may be responsible for malignancies, such as the recent discovery of the etiologic agent for Kaposi's sarcoma. These findings may help to identify other oncogenic agents. HIV research has led to a better understanding of the mechanisms by which infectious agents and inflammatory cells cross the blood/brain barrier, providing valuable clues for research on Alzheimer's disease, dementia, multiple sclerosis, neuropsychological disorders, encephalitis, and meningitis. Moreover, prior to the AIDS epidemic, little investment was made in research to treat viral diseases. Studies to develop anti-HIV therapies have improved our understanding of additional viral diseases and led to development of treatments.

Efforts to develop drugs for the treatment of HIV have accelerated the development of methods of rational drug design using sophisticated techniques of structural biology and advanced computer imaging methods. These advances have implications for drug design for virtually all disorders. Comparative clinical trials of poxvirus vectors and vaccine adjuvants in HIV vaccine candidates have supported safety information for cancer vaccines.

Research on HIV-related wasting has provided important information for research on nutritional disorders, metabolic abnormalities, and gastrointestinal dysfunctions.

Due in great part to Federally-sponsored AIDS research, a number of new and exciting research advances have brought optimism and opened new areas for investigation. One of the recent research advances has been the development of a new class of drugs, known as protease inhibitors. When used in combination with other types of anti-retroviral drugs, there is the potential to dramatically reduce the amount of HIV in the bloodstream and possibly improve a person's clinical status and reduce the risk of HIV transmission. A landmark advance in HIV prevention was the demonstration that AZT can dramatically reduce the risk of transmission of HIV infection from a pregnant woman to her child. Advances in effective treatments for HIV-related conditions can prolong and improve the quality of life of persons living with HIV. Breakthroughs in our understanding of the genes and proteins of the human immunodeficiency virus have allowed the development of increasingly effective anti-retroviral drugs.

In addition, the Food and Drug Administration through its expedited review and accelerated approval programs is now approving drugs more rapidly than ever before. Recent planning efforts on the part of various Federal Agencies, such as the annual NIH plan for HIV-related research and the Federal Biomedical and Behavioral Research Plan for HIV and AIDS have greatly improved the coordination of HIV research.

2. Future Opportunities for Progress

we?

Despite these advances, many complex biomedical and behavioral challenges remain. We must ensure that ~~the Nation~~ capitalizes on the most promising scientific opportunities.

Coordinating Federal Research. Developing and implementing the Federal government's AIDS research agenda presents both scientific and logistical challenges. Planning and overseeing a Federal effort of this magnitude requires coordinating efforts at two levels: First, within NIH and second among the Departments and Agencies supporting HIV research.

Within NIH, research is ~~supported~~ ^{*distributed*} throughout 24 institutes, centers, and divisions (~~and~~). In order to better plan, coordinate, evaluate, and fund the AIDS research activities of these ICDS the NIH Revitalization Act Amendments of 1993, provided the Office of AIDS Research (OAR) with new oversight and budget

authorities. It is crucial that the authority granted OAR in the revitalization legislation, including the consolidated appropriation, be maintained.

Add RS language about the Levine Report

For the government to effectively support a diversity of promising approaches, these research efforts must also be well-planned and coordinated. To achieve this the Director of the Office of National AIDS Policy created an inter-departmental working group, chaired by the Director of the Office of AIDS Research, charged with developing a coordinated plan and budget for HIV and AIDS research across all Agencies.

On December 6, 1996, at the White House Conference on HIV and AIDS, President Clinton directed OAR Director Dr. William Paul to develop the first Federal Biomedical and Behavioral Research Plan and Budget for HIV and AIDS. This plan was completed in April, 1996. The development of this plan brought together representatives from the National Institutes of Health, the Centers for Disease Control and Prevention, the Food and Drug Administration, the Department of Defense, the Department of Energy, and the Department of Veterans Affairs. This plan provides an blueprint to focus and coordinate all Federal HIV/AIDS research initiatives and serves as a foundation for continued planning and evaluation.

Vaccine Development. Several major challenges currently face the U.S. and the world in the development of an effective HIV vaccine or vaccines. The first is to surmount the daunting scientific and social challenges and the second is to ensure the development and testing of promising vaccine candidates.

On the scientific level, researchers are pursuing two approaches to vaccine development. One approach is based on the belief that gathering additional basic science information offers the best hope in steering vaccine development. The second approach is guided by the belief that data gathered from clinical efficacy trials in humans can lead to the development of a successful candidate. This group maintains that if a safe candidate is available, it is not necessary to resolve all of the scientific questions before proceeding with human trials, and, that in the face of a global emergency, testing in people should be begin immediately. Both approaches ^{are} have valid arguments.

Developing a vaccine cannot be accomplished by the government or the private sector working apart: a continuing public-private partnership is needed. In order to identify areas for fruitful collaboration and to accelerate the pace of development for

vaccines, in February 1996, Vice President Gore convened a meeting of government scientists and leaders of the pharmaceutical and biotechnology industries to identify barriers to the development of these agents. Further dialogue involving key players regarding critical problems, and opportunities for development, and viable solutions has begun and will continue.

Microbicides. Many scientists believe that in the absence of a vaccine the development of safe and effective mechanical or chemical barrier methods that will block HIV transmission or prevent other sexually transmitted infections could dramatically reduce the sexual transmission of HIV. Worldwide over 80 percent of HIV infections are acquired heterosexually and women are more easily infected than men. Moreover, the risk of becoming infected or infecting others is substantially increased by the presence of other STDs⁷.

Condoms, the barrier methods that are currently available, have limitations. Most require consent, if not active participation of both partners and therefore cannot be independently used at the discretion of one partner. An easily available and inexpensive microbicide could provide a prevention option for millions of people worldwide.

The development of this important prevention option will depend on strong and continuing support for basic and clinical research. Microbicides are a promising approach, but will require preliminary Federal support before they reach a stage where pharmaceutical or biotechnology companies can assume a lead role. Discussions among Federal Agencies, the private sector, and advocacy groups have been ongoing and should continue in order to identify areas for worthwhile collaboration and hasten the pace of development.

Examining the Impact of HIV on Youth. HIV-related research has made great strides on many fronts, however, adolescents have not received the full benefit of research discoveries. There is evidence indicating that HIV may behave differently in infected adolescents. We need more information on impact of puberty on the course of HIV infection and behavioral trends that play a key factor in HIV treatment and prevention. Adolescents also must factor more significantly into the research process. NIH and the Food and Drug Administration (FDA) are examining options for lowering barriers to participation of adolescent in clinical trials and research protocols and will continue to encourage sponsors to enroll adolescents when feasible and appropriate, in such trials. The efforts of the collaboratively-funded Adolescent Medicine HIV/AIDS Research Network (Footnote D) are important in improving our understanding of HIV disease in adolescents and will continue.

New and More Effective Therapies. Strong and continuing research to develop new and more effective therapies for HIV infection and its associated conditions must be a priority if we hope to transform HIV disease into a chronic, manageable condition. Due to the FDA's accelerated approval program (Footnote E), the Federal government is now approving new treatments in record numbers and at record speed, but it is not always known whether a treatment confers a clinical benefit for patients. While some treatments have shown promise based on surrogate markers and/or laboratory tests data regarding long-term clinical effectiveness are unavailable. Patients may be receiving less effective treatments or combinations of treatments, and private insurers and Federal programs such as Medicaid and Medicare may be paying for treatment strategies that are not optimally effective.

It is incumbent upon the government and the private sector to ensure that post-marketing effectiveness studies, currently mandated through regulation, are carried out. In order for the results to be relevant to as many persons as possible, it is necessary that these studies include people representing a diversity of race, ethnicity, gender, age, and drug-using behaviors. Through the efforts of Vice President Gore, the Forum for Collaborative HIV Research has been established to assess approaches for accelerating clinical effectiveness research.

Public-Private Partnerships. A key role for the Federal government is to act in partnership with the private sector and support research that would be beneficial to the public health in areas where there is a market failure. For example, it is unlikely that the free market system will push the implementation of head-to-head clinical trials of therapies that have been approved or are in development. However, information about these therapies is critical to improving patient care. The National Institutes of Health (NIH) and the Department of Veterans Affairs (VA) have been successful in carrying out this type of valuable research in collaboration with the pharmaceutical industry. It is unlikely that the private sector would support research for therapies that are on the market but have not been tested in controlled clinical trials, such as alternative therapies. However, through collaborative partnerships that include the NIH, studies of alternative therapies have been and will continue to be conducted.

It also is cost-effective for the government to provide access to sophisticated equipment and personnel that can be shared among many researchers in both the private and public sectors. The Department of Energy (DOE) has made available the use of sophisticated imaging equipment that would be prohibitively expensive for individual researchers or companies to purchase. This shared resource has

accelerated our understanding of molecular structures in a number of research fields, including HIV research. Information gained from this research can form the basis for targeted drug design and development.

Continued Support for Research. Research is an investment in our future. It must receive consistent and adequate funding if we hope to bring the best and the brightest to meet the research challenges that will lead to a cure, better therapies, ~~and~~ a vaccine. At present, NIH receives many more outstanding research applications than it is able to fund; these unfunded proposals represent ~~a~~ lost opportunity for scientific progress. Other Departments and Agencies, such as DOD and VA, also support crucially important research that strengthens the overall U.S. research effort. Research has been key to prolonging and improving the quality of lives and the Nation must continue to make this investment.

Scientists

*and
a microbicide.*

C. CARE & SERVICES

"AIDS has taken too many friends and relatives and loved ones from everyone of us in this room. It has shaken the faith of many, but it has inspired a remarkable community spirit."

President Clinton, May 20, 1996

Signing of the Ryan White CARE Act Reauthorization

1. Record of Accomplishment

Since the epidemic of HIV and AIDS began in 1981, more than 500,000 Americans have been diagnosed with AIDS and required care. As the number of Americans living with AIDS increased, the demands on the U.S. health care system increased dramatically. Federal, State, and local governments along with community-based organizations and private clinicians have responded with compassionate, high-quality medical care. Among the sentinel achievements of these efforts are:

- Enactment in 1989 of the Housing Opportunities for People with AIDS (HOPWA) program; and
- Enactment in 1990 of the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act.

U.S.
The Nation has made significant efforts to ensure that people living with HIV have access to services that are affordable, of high quality, and responsive to their needs. As the number of people with HIV has increased, so did their need for care. In 1985, Federal expenditures for HIV-related care and services were \$xxx, by 1995 the Federal share reached \$xxx.

Since he took office in 1993, President Clinton has, as one of his highest priorities, sought to increase the national commitment to care for people living with HIV or AIDS. Among those actions are:

- Signing the Ryan White CARE Act Amendment of 1996, and increasing funding for the Ryan White CARE Act by 134 percent;
- More than doubling funding for the AIDS Drug Assistance Program, which helps uninsured and underinsured individuals purchase prescription drugs;
- Increasing funding for Housing Opportunities for People

with AIDS by 96 percent;

- Fighting to preserve the Medicaid guarantee of coverage for ~~the nearly~~ ^{more than} 50 percent of people with AIDS and ~~90~~ ⁹⁰ percent of children with AIDS who rely on this program for their health coverage; and
- Revising eligibility rules for Social Security Disability Insurance to make it easier for people living with HIV to qualify for benefits.

Background

In the early years of the epidemic, the health care infrastructure was particularly unprepared to accommodate the health care needs of persons with HIV. To meet their complex health care needs, HIV-positive persons were often forced to negotiate a fragmented system of care. There were few programs designed to meet the unique care needs of positive individuals. Moreover, available ~~health services~~ ^{services} ~~were~~ often directed towards meeting the acute care needs of persons diagnosed with AIDS, rather than the early stages of HIV disease. While we still have far to go, the quality and availability of services for HIV-positive persons has improved significantly.

People living with HIV now access finance necessary health care services in a variety of ways. Currently, over 50 percent of adult Americans and 90 percent of children living with AIDS receive their medical coverage through the Medicaid program and another 5 percent receive Medicare benefits. An estimated 15 percent of people living with AIDS have private health insurance and the remaining 30 percent are uninsured and must rely on personal payment or charity care.¹ However, ~~for a~~ ^{for a} disproportionate number of people living with HIV and AIDS, ~~their lives~~ ^{their lives} ~~often~~ depend on the Federal health care safety net. ^{redundant}

For those who qualify, care and services are provided through a number of Federal Agencies (See Appendix C), many in cooperation with local organizations and the AIDS community, that have admirably served those living with HIV. Taken together, these efforts form a valuable, if still incomplete, ^{this} safety net for some of the most vulnerable people in ~~our Nation~~ ^{Country}.

Medicaid, a jointly financed Federal-State program of health care for the poor and the disabled, is the primary source of care for

¹ JL cite. Add Vancouver numbers.

people living with AIDS and a major source of care for those who are living with HIV. In FY 1996, Federal Medicaid expenditures for people living with AIDS totaled \$1.8 billion. The Medicaid statute authorizes Federal matching payments to the (states to provide services to eligible individuals. *redundant*

In addition to Medicaid, the centerpiece of the national safety net consists of programs funded through the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act of 1990, administered by the Health Resources and Services Administration (HRSA). The CARE Act programs were established to fill gaps in coverage and build systems of care to create access to health care for people living with HIV and AIDS. The CARE Act is comprised of four separate titles:

- Titles I and II of the CARE Act provide funds for outpatient care, support services, and case management ~~that are given~~ to cities and States primarily on a formula basis. Title II also provides drug reimbursement funding for persons living with HIV/AIDS under the AIDS Drug Assistance Program (ADAP).
- Title IIIb of the CARE Act provides early intervention services such as counseling and testing, medical care, and educational services for medically underserved persons with the goal of reducing HIV-related illness.
- Title IV seeks to increase the availability of care and services for women, infants, children, and youth in a community-based family-centered system of care. *research link*

HRSA also provides primary care to persons living with HIV through its Community Health Centers and Maternal and Child Health Programs. Other sources of primary care supported by the Federal government include the Department of Defense, the Department of Veterans Affairs, and the Indian Health Service (IHS) which provides health care for HIV-positive Native Americans and Alaska Natives. Additionally, the Bureau of Prisons within the Department of Justice provides care for HIV-positive people in Federal prisons. *e*

People living with HIV and their families face significant obstacles to locating affordable housing. Housing assistance for people living with HIV/AIDS is provided by the Department of Housing and Urban Development (HUD) through its Housing Opportunities for Persons with AIDS (HOPWA) and other programs, such as the Section 811 Supportive Housing Programs for Persons with Disabilities. These programs work in partnership with local initiatives incorporating housing assistance into a community's

continuum of services.

To further foster community involvement, HUD also has established the Consolidated Planning process for communities that receive funds under the Department's economic and community development programs, including recipients of HOPWA formula allocations. The Community Development Block Grant (CDBG), the HOME affordable housing program, as well as public housing programs are key resources that are available to communities.

2. Future Opportunities for Progress

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• The challenge before us today is to ensure that persons living with HIV receive the care they need so they may have the opportunity to live productive lives. AIDS care and service programs must continue to expand access to care for those without insurance coverage, improve prioritization and accountability and increase the cost-effectiveness of services they provide. As treatments improve and extend the productive lives of people with HIV, we must continually reexamine the range of services that are needed.

and health
Preserving Medicaid. Medicaid is a lifeline of support for Americans living with HIV and AIDS. As the epidemic continues to spread in lower-income communities, the need for Medicaid coverage of people living with HIV/AIDS will increase. The need to maintain the historic Federal-State partnership on Medicaid has never been greater. Proposals in Congress to convert Medicaid into a block grant would endanger access to care for people living with HIV/AIDS. In particular, proposals to eliminate the Federal guarantee of coverage for people living with disabilities would have a dramatic impact on people living with HIV/AIDS. President Clinton has vetoed one such proposal and has promised to veto any such future proposals that reach his desk.

will have this
Continuing Support for Ryan White CARE Act. The five-year reauthorization of the CARE Act signed by President Clinton on May 20, 1996 ~~provides people living with HIV/AIDS with peace of mind that support from the Federal government will be there through FY 2000.~~ As the demand for care continues to grow so must the resources for the CARE Act. President Clinton has proposed \$827.5 million for this program in FY 1997; enactment of that request is essential.

assures that persons
Expanding Support for Housing Services. Without stable housing a person living with HIV has diminished access to care and services and a diminished opportunity to live a productive life. It is estimated that up to 50 percent of people living with HIV and AIDS are or will become homeless during the course of their illness.⁸

President Clinton has requested \$196 million in FY 1997 for HOPWA; it is imperative that Congress approve that request.

Providing consistent funding for the housing component of the safety net will continue to be a Federal priority. Integrating AIDS housing services into other programs and ensuring a shared responsibility among Federal, State, local governments and community organizations is another important step in assisting communities to build seamless systems of support for our most vulnerable citizens.

Integrating the Continuum of Care. One of the most effective approaches to treating people living with HIV is providing access to an integrated continuum of health care services. A powerful method of recruiting people into primary care is knowledge of HIV serostatus. People who know their HIV status are more likely to seek health care and act to prevent HIV transmission. Counseling and confidential voluntary testing services serve as a gateway to care. Linking HIV-positive people with care also provides an opportunity for education about behaviors which may reduce their chances of infecting others.

Achieving this level of integration requires active collaborative efforts by physicians, nurses, other clinicians, insurance plans, medical schools, and professional organizations in addition to State, local and Federal governments.

Improving Program Coordination. Organizations receiving funding from the Federal government in providing AIDS-related care often require support from several Federal Agencies. For example, creating a community-based program that integrates primary care, substance abuse treatment and prevention, and sexually transmitted disease screening, HIV prevention, access to clinical trials, and housing assistance requires separate applications to SAMHSA, HRSA, CDC, NIH, and HUD.

As part of its effort to "reinvent government," [Do we know if this effort is part REGO?] the Clinton Administration has been working to simplify Federal funding applications to facilitate improved integration of service programs. HRSA and SAMHSA have issued joint programs announcements and HUD and HRSA have also issued a joint ~~program~~ announcement for the Special Projects of National Significance (SPNS) program. These efforts to improve integration will be continued and expanded. *similar*

Improving Quality of Care. Federally-supported programs can and should consistently provide high-quality care. Ensuring consistency in care delivery requires increased training for health

care professionals and greater accountability through the use of performance measures for quality care. It is also essential that practical information on research advances for practicing clinicians and their patients be provided in a timely manner. (See Section Translation of Research Advances in Practice.) Achieving these goals requires the cooperation of Federal Agencies, States, professional organizations, professional and medical schools, and individual clinicians.

Evaluating Program Effectiveness. Strong Federal support for safety net programs must be accompanied by improved accountability and priority setting. Evaluating current activities provides valuable information for planners and those at the front lines of the epidemic and assist in providing better care to people living with HIV.

D. CIVIL RIGHTS

"Every person with HIV or AIDS is someone's son or daughter, brother or sister, parent or grandparent. We cannot allow discrimination of any kind to blind us to what we must do."

President Clinton, May 20, 1996

Signing of the Ryan White CARE Act Reauthorization

Discrimination against people living with HIV or AIDS violates the human rights of individual Americans and undermines our Nation's efforts to prevent and treat HIV infection. The extraordinary stigma that has been attached to HIV disease hampers the ability of people living with HIV/AIDS to live full lives, free of fear.

Discrimination also undermines the Nation's efforts to prevent and treat HIV infection and bring the epidemic under control. Because of fear of discrimination and stigma, many people do not voluntarily seek testing for HIV, remain unaware of their HIV status, and consequently do not seek the care that could help them live longer, healthier lives. Opportunities to educate people are also lost as people at risk avoid prevention programs because of the stigma associated with HIV.

1. Record of Accomplishment

During the early years of the AIDS epidemic, protection of the civil rights of people living with HIV/AIDS was sporadic, at best. Individual lawsuits were the first line of action. By the late 1980s, however, the Federal government began to respond more aggressively. Sentinel achievements include:

- Enactment of the Harkin-Humphrey Amendment to the Civil Rights Restoration Act, clarifying that Section 504 of the Rehabilitation Act of 1973 applied to people with contagious diseases, including HIV; and
- Passage of the Americans with Disabilities Act of 1990 (ADA) which protects individuals living with HIV and AIDS, and people perceived to be at risk for HIV [Are we sure this is true?], from discrimination in housing, employment, and public accommodation.

Since he took office, President Clinton has directed relevant agencies to make enforcement of the civil rights of people living with HIV/AIDS a priority. Key actions include:

- Vigorously enforcing the ADA by the Justice Department, the Equal Employment Opportunities Commission, and the Department of Health and Human Services. The Federal government has resolved nearly 800 charges alleging discrimination against people with HIV and AIDS obtaining monetary benefits of more than \$6.1 million; [Are these figures correct? ... source(s)?]
- Vigorously enforcing Section 504 of the Rehabilitation Act of 1973 as it pertains to recipients of DHHS funds such as hospitals, nursing homes, and social service agencies;
- Forcefully opposing the so-called "Dornan Amendment," which would require the discharge of all military personnel who are living with HIV. President Clinton declared the proposal unconstitutional and directed the Department of Justice not to defend it if challenged in court. The President led a successful effort to repeal the "Dornan Amendment" and continues to oppose its enactment;
- Establishing an AIDS education program for all Federal workers; [Do we want highlight this?] *yes*
- Using the Presidential "bully pulpit" to ~~continually~~ speak out against discrimination against people with HIV and AIDS.

2. Future Opportunities for Progress

Enforcing Rights. Efforts to protect the civil rights of people with HIV/AIDS must be ever-vigilant. The Federal government must continue to exhibit strong leadership on this issue through its enforcement of the Americans with Disabilities Act and public condemnation of discriminatory acts or statements. Of particular concern is discrimination in health care facilities. A joint effort by the Department of Health and Human Services and the Department of Justice aimed at nursing homes is a significant step forward.

Protecting Workers. The Federal government is actively working to examine its own existing policies related to the exclusion of people living with HIV from employment. The Director of the Office of National AIDS Policy is working with Federal Agencies to examine individual policies to determine whether they comply with Federal guidelines. [What guidelines?] *CDC Vol. testing & Couns.*

Opposing Discriminatory Legislation. The Administration will continue to oppose, in the strongest terms possible, efforts by the Congress to discriminate against people living with HIV/AIDS.

Providing Leadership. Leaders of government have an obligation to use the power of their elected office to speak out against acts or words of discrimination against any group of people. President Clinton has used and will continue to use his position to oppose discrimination against people living with HIV/AIDS.

E. INTERNATIONAL ACTIVITIES

Insert quote:

AIDS is a global epidemic. Eighty percent of new infections occur in developing countries. In the United States it is estimated that between 650,000 and 900,000 people are currently infected with HIV. The World Health Organization (WHO) estimates that 27.9 million adults and over 1.5 million children are currently infected worldwide and there will be 10 to 15 million orphans worldwide attributable to HIV/AIDS by the year 2000. WHO also estimates that two to three million new HIV infections can be expected annually, and by the year 2000, thirty to forty million people will have been infected around the globe.

The epidemic jeopardizes decades of economic and social advances in many developing nations. In the nations of Africa and Asia, economic advances are threatened and in some cases may be reversed due to HIV and AIDS. Socio-economic studies have shown a decrease in overall domestic savings and investment levels, negative effects on foreign investments, reductions in the volumes of imports and exports, and a reduction in receipts from tourism.' In many countries governments will be forced to cope with increasing numbers of cases, weakened health care systems, a deleterious economic impact on the most productive segments of society, and the reduction in the number of healthy men and women able to serve in the government and the military.

1. Record of Accomplishment

Since it began, HIV/AIDS has been a global concern. The U.S. has worked closely with developed and developing nations to design an international response that is both vigorous and coordinated. Sentinel achievements include:

Founding of the Global Programme on AIDS in 1987, and
Participation in development of Paris AID Summit agreement
Founding of the United Nations Programme on AIDS (UNAIDS)
in 1995 (correct date?).

Operational Jan 96
and signing
Joint and Cosponsored
The United States is the largest contributor to international efforts to combat the pandemic of HIV/AIDS. Several Federal Agencies are working slow the AIDS epidemic internationally. (See Appendix D.) The Department of State works with other Departments, Agencies, and non-governmental organizations to develop a framework to guide U.S. foreign policy in the global efforts against HIV and AIDS. The major areas of U.S. leadership in the HIV arena are: preventing new infections; reducing the personal and social impact

of the pandemic; and mobilizing and unifying national and international efforts.

The U.S. Agency for International Development (USAID) also plays leadership role in the global HIV effort through development assistance, research, and policy formation. USAID focuses its efforts on developing prevention programs based on proven interventions; addressing social, cultural, regulatory and economic issues related to HIV/AIDS and other sexually transmitted infections; and developing and testing new interventions and methods to prevent transmission and mitigate the impact of the epidemic. The Peace Corps trains a portion of its volunteers to directly address HIV-related concerns in their countries of placement. The U.S. Information Agency (USIA) supports programs that promote dissemination of U.S. policies and information related to HIV and AIDS.

In addition, several Agencies support research overseas, including the National Institutes of Health, the Centers for Disease Control and Prevention, and the Department of Defense. The DOD is conducting clinical trials of candidate HIV vaccines in Thailand and NIH (working in collaboration with USAID), supports basic scientific studies on social and behavioral aspects of AIDS in developing countries. The results of the studies ultimately will be used to develop interventions to reduce behaviors that place individuals at risk for contracting HIV infection.

2. Future Opportunities for Progress

These are strengths

International Leadership. The United States has established a global leadership role in combatting the epidemic. This leadership will continue. The U.S. strongly supports the newly established Joint and Co-sponsored United Nations Programme on AIDS (UNAIDS).¹⁰ The U.S. is a member of the governing body of UNAIDS and signed the 1994 Paris Declaration and the Greater Involvement of People Living with HIV/AIDS Initiative (GIPA).

The U.S. also supports efforts to more effectively access available resources as well as encourage non-traditional donor countries to provide much-needed contributions. Supporting UNAIDS organizations such as UNICEF, WHO, UNDP, the U.S.-Japan Common Agenda and its innovative programmatic efforts, and UNAIDS' goal of working to increase the availability of therapeutics (and vaccines when developed) to the residents of developing countries is not only morally correct, but also furthers U.S. interests by promoting economic and social stability worldwide.

Strengthening Partnerships. In addition to maintaining our

multilateral partnerships, we must strengthen and expand our bilateral programs and funds for HIV activities. We must reverse the current trend to reduce assistance to developing countries where more than 90 percent of the world's AIDS cases are found. (OK?)

yes

Sharing Technology and Bringing Lessons Home. Through USAID's "Lessons without Borders Project", the U.S. has gained valuable insights from experiences in participating countries and is applying them to communities here at home. The initiative brings lessons learned abroad back to inner city and rural areas with problems similar to those experienced overseas. These efforts will be continued and should be expanded. [Do we want to say this in light of the USAID cuts, reduced \$ in FY97 PB, etc?]

yes

Improving Program Coordination. One of the most challenging aspects of the U.S. effort is effective coordination among a host of Agencies with varied missions and activities. In order to ensure that efforts are productive, the Agencies supporting international activities must develop a mechanism for coordinating U.S. programs in a systematic and efficient manner.

F. TRANSLATION OF RESEARCH ADVANCES INTO PRACTICE

Insert Quote

An important element in our fight against AIDS is ensuring that research advances are translated into the care of HIV positive persons. The increasing presence of HIV in every community necessitates that all health care providers become knowledgeable about assessing risk, promoting prevention, and caring for people with HIV.

An example of the importance of such efforts is the translation of the research finding in AIDS Clinical Trial Group 076, which found that the use of AZT by pregnant women during pregnancy and childbirth and its application to newborns for the first six weeks of life can reduce the risk of perinatal transmission of HIV by two-thirds. Translation of these results required actions by the Centers for Disease Control and Prevention, which prepared guidelines for physicians caring for pregnant women and for consumers; the Health Resources and Services Administration, which provided guidance to grantees on coverage of such services; the Health Care Financing Administration, which provided similar guidance to State Medicaid Directors.

*AHCPR - brochures
for preg &*

1. Record of Accomplishment

Due in part to Federally-sponsored information dissemination activities, dramatic changes in the way HIV is treated have taken place. Ensuring dissemination of HIV-related information falls under the missions of several Agencies (See Appendix F). Key examples are:

- The National Institutes of Health (NIH) supports a broad range of efforts including a "Clinical Alerts" mechanism for the dissemination of clinical trials results to health professionals, the media, and the public;
- DHHS supports and directs the International HIV/AIDS Clinical Conference Call series, which disseminates critical, state-of-the-art clinical care information to primary care providers via live worldwide audio tele-conferencing;
- NIH supports publicly available computerized databases such as AIDSDRUGS, AIDSTRIALS, and AIDSLINE;
- The toll-free 1-800 TRIALS-A AIDS Clinical Trials Information Service (ACTIS) is co-sponsored by NIH, CDC, and FDA;

- The Centers for Disease Control and Prevention disseminates information through the National AIDS Hotline (1-800-342-AIDS); its toll-free 1-800-HIV-0440 HIV/AIDS Treatment Information Service (ATIS); and the AIDS Information Clearinghouse;
- The CDC also issues guidelines for health professionals through its *Morbidity and Mortality Weekly Report*;
- The Agency for Health Care Policy and Research (AHCPR) has published a series of HIV-related clinical practice guidelines for clinicians and companion pamphlets for their patients; and,
- The Health Resources and Services Administration directs a nationwide system of AIDS Education and Training Centers that provide state of the art HIV clinical information to health care providers. HRSA also has developed guidances for its Ryan White CARE Act grantees and funds an AIDS warmline that responds to questions from clinicians across the country.

2. Future Opportunities for Progress

There are opportunities for improvement in translating research advances into practice. They include:

Increasing Education and Training. As we continue to expand our base of knowledge about AIDS care, efforts to educate and train health care professionals in state-of-the-art care for people living with HIV/AIDS must be expanded. [How do we reconcile decrease in AETCs?] An AHCPR-supported study indicated that primary care physicians may miss significant HIV-related symptoms during patient examinations.¹¹ Other research indicates that a disturbing number of clinicians do not use universal precautions in the course of routine patient care.¹² Reference Kittanare (sp?) article.

Disseminating Guidelines. One of the most difficult tasks for clinicians and patients is interpreting the patchwork of data and articles regarding treatments and converting it into a therapeutic strategy for their patients. With every research breakthrough, this task becomes more difficult. It is essential that practical information for practicing clinicians and their patients be provided in a timely manner.

The Federal government currently supports a number of mechanisms for periodically assessing advances in clinical care. It is essential

that these assessment efforts continue and that crucial information be widely disseminated. This will require collaboration with industry, government, and professional groups.

Improving Coordination of Federal Activities. Enhancing coordination of information dissemination activities among Public Health Service Agencies is an important priority. Within DHHS, the Office of HIV/AIDS Policy (OHAP) has the lead responsibility for coordinating the HIV-related activities of the Public Health Service Agencies. Ensuring that information about a research breakthrough is easily available, ^{with} reaches the appropriate people and organizations, and that policies and standard-of-care practices for Federally-sponsored programs are modified to reflect the new standard, requires a continued ^{na} high level of cooperation and coordination among Public Health Service Agencies.

Disseminating Prevention Models. Improved dissemination ^{by} ~~efforts~~ also ~~are~~ needed ~~in the area of~~ primary prevention models. Models of effective prevention interventions have been developed, but often this valuable information is not reaching those people developing, implementing, and evaluating prevention programs. The Public Health Service will take the lead in ensuring that information that can be used to stem the tide of new infections reaches those who can make a difference.

Footnotes

a It is, however, believed that with greater use of AZT by HIV-positive pregnant women, the number of new cases in newborns can be reduced.

b (re-add footnote; check for Vancouver numbers).

c Information on NIH-supported behavioral and epidemiological research relevant to primary prevention can be found in Appendix B: Research.

d The Adolescent Medicine HIV/AIDS Research Network is cooperatively funded by the National Institute of Child Health and Human Development (NICHD), the National Institute of Allergy and Infectious Diseases (NIAID), the National Institute on Drug Abuse (NIDA), and the Health Resources and Services Administration (HRSA).

e The accelerated approval regulation permits companies to seek approval of drugs for serious or life-threatening diseases when the drug provides meaningful therapeutic benefit over existing therapies. Under these procedures, the FDA may approve drugs based on surrogate endpoints, such as CD4+ cell counts that reasonably predict that a drug provides clinical benefit. The company is then required to confirm this clinical benefit through additional human studies to be completed after marketing approval. The accelerated approval regulation provides for removal of the drug from the market if further studies do not confirm the clinical benefit of the therapy.

1. *Morbidity and Mortality Weekly Report*. U.S. Department of Health and Human Services, Public Health Service. November 24, 1995, vol. 44, No. 46.

2. External Review of HIV Prevention Strategies by the CDC Advisory Committee on the Prevention of HIV Infection. U.S. Department of Health and Human Services, Public Health Service. June 1994.

3. *AIDS and Behavior: An Integrated Approach*. Judith D. Auerbach, Christian Wypijewska, and H. Keith H. Brodie, Editors. Institute of Medicine. National Academy Press. Washington, DC. 1994.

4. Heiner Grosskurth, Frankc Mosha, James Todd, Extra Mwijarubi, Arnould Clotte, Kesheni Senkoro, Philippe Mayaud, John Chagalucha, Angus Nicoll, Gina ka-Gina, James Newell, Kokuugonza Mugeye, David Mabey, Richard Hayes. Impact of Improved Treatment of Sexually Transmitted Diseases on HIV Infection in Rural Tanzania: Randomized Controlled Trial. *The Lancet*, Vol. 346, August 26, 1995.
5. Maria Wawer, *Science*. 9.08.95, vol. 269, No. 5229
6. Personal communication from CDC Division TB Elimination.
7. Alan B. Stone, and Penelope J. Hitchcock. Vaginal Microbicides for Preventing the Transmission of HIV. *AIDS* 1994, 8 (suppl 1):S285-S293.
8. Housing and the HIV/AIDS Epidemic: Recommendations for Action. National Commission on AIDS. Washington, D.C. July 1992.
9. *HIV/AIDS Policy Guidance*. U.S. Agency for International Development. September 1995.
10. Until recently, the United Nations' response to HIV/AIDS was carried out primarily by the World Health Organization's Global Programme on AIDS. On January 1, 1996 the U.N. launched UNAIDS, co-sponsored by six U.N. agencies to strengthen coordination and focus support for HIV/AIDS activities at the global and country levels. UNAIDS has established three mutually reinforcing roles: to be a major source of policy development and research; provide technical support; and be an advocate for comprehensive, multi-sectoral responses to the pandemic.
11. Douglas S. Paauw, Marjorie D. Wenrich, J. Randall Curtis, Jan D. Carline, Paul G. Ramsey. Ability of Primary Care Physicians to Recognize Physical Finding Associated with HIV Infection. *JAMA*. 1995; 274:1380-1382.
12. Colombotos, J., Messeri, P., McConnell, M.B., et al: Physicians, Nurses, and AIDS: Findings From a National Study. Rockville, MD: Agency for Health Care Policy and Research; 1995. Grant No. HS06359. (NTIS Publication PB95-129185)

TABLE OF CONTENTS

MESSAGE FROM THE DIRECTOR OF THE OFFICE OF NATIONAL AIDS POLICY

I. INTRODUCTION

II. ~~OVERVIEW OF~~ FEDERAL EFFORTS

and opportunities for progress

Introduction

Prevention

Research

Care and Services

Civil Rights

International Activities

Translation of Research Advances into Practice

III. APPENDICES

Appendices A - F

(Prevention, Research, Care and Services, Civil Rights, International Activities, and Translation of Research Advances into Practice)

Appendix G

Budget Tables

IV. FIGURES, ACRONYMS, AND MEMBERS OF THE INTERDEPARTMENTAL TASK FORCE ON HIV AND AIDS

Figure 1

Death Rates from Leading Causes of Death in Persons Aged 25-44 Years, USA, 1982 -1993

Figure 2

Cumulative U.S. AIDS Cases: 2/83 through 12/94

Acronym List

Members of the Interdepartmental Task Force on HIV and AIDS

*Wherever possible
use "the U.S."
or "the country"
not "the Nation."*

RS Comments

Jane: My one remaining concern is that there isn't enough stuff in the prevention and research chapters that give a clear idea of our agenda for FY1997. Can we get some examples of action items from CDC and NIH?

Otherwise, these are a couple of suggested adds:

add to page 21 of research

At the Eleventh International Conference on AIDS, Health and Human Services Secretary Donna E. Shalala announced a four-year initiative to research and develop an effective topical microbicide. Funding from NIH and CDC is to total more than \$100 million over that four-year period.

Replace last paragraph on p. 21

Youth and HIV. On March 5, 1996, the Office of National AIDS Policy released a report to the President entitled "Youth and HIV/AIDS: An American Agenda." The report notes that we need additional information on the impact of puberty on the course of HIV infection and behavioral trends that play a key role in HIV prevention and treatment. The report identifies several concerns including the lack of sufficient participation of adolescents in HIV/AIDS research. NIH and FDA are examining options to increase participation of adolescents in clinical trials and research protocols. The efforts of the Adolescent Medicine HIV/AIDS Research Network (Footnote D) are an important step in improving understanding of HIV disease in adolescents.

add on page 26

Individuals with disabilities, including HIV, are automatically eligible for Medicaid benefits in all states once they qualify for Social Security Disability Insurance (SSDI). Such people qualify for Medicare benefits after 29 months on SSDI.

\$34 million
for micro-
youth, & SAs
prevention

FF to Kevin
Revised per disc. account.
- highlight plans
specific
- Review
2-3
Need specifics
in FY97
detail

TABLE OF CONTENTS

MESSAGE FROM THE DIRECTOR OF THE OFFICE OF NATIONAL AIDS POLICY

I. INTRODUCTION

II. OVERVIEW OF FEDERAL EFFORTS

Introduction

Prevention

Research

Care and Services

Civil Rights

International Activities

Translation of Research Advances into Practice

III. APPENDICES

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Acronym List

**Members of the Interdepartmental Task Force on HIV and
AIDS**

[Note: This could be reworked as a message from the President to the world or as a letter from Patsy to the President presenting the draft Strategy to him.]

"We must develop a clear, well-articulated national plan for confronting AIDS."

*The Final Report of the National Commission on AIDS
June 1993*

Since 1981, 1500,000 ...
Message from the Director of the Office of National AIDS Policy

The epidemic of HIV and AIDS constitutes a public health crisis of unprecedented proportions. In 1993, the Office of National AIDS Policy (ONAP) was created by President Clinton to provide a national focus and direction for the government's response to HIV and AIDS. ~~More recently, President Clinton asked ONAP to develop a comprehensive National AIDS Strategy that would detail the Federal government's long-term approach in responding to this epidemic. The National AIDS Strategy has been developed by the Clinton Administration to capitalize upon progress already made in fighting the epidemic and to catalyze collaborative efforts among Federal Departments and Agencies, communities, State and local governments, businesses, schools, churches, families, and individuals.~~

The President has identified the following national goals to guide our efforts against HIV:

- To provide strong continuing support for AIDS-related research in order to find additional treatments, a preventive vaccine to protect the uninfected, and a cure for those currently infected;
- To provide strong continuing support for effective AIDS prevention strategies ~~efforts~~ to continue to reduce the number of new HIV infections in the U.S.;
- To ensure that people living with HIV have access to services that are affordable, of high quality, and responsive to their needs; and,
- To ensure that people living with HIV are not subject to unlawful discrimination.

This document is a snapshot of where we are as a Nation and *look at* where we need to go in achieving these national goals. It summarizes

some of the key accomplishments of our Nation's scientific and public health professionals and identifies key areas for further effort. In addition, the appendices to this report lay out, for the first time, detailed descriptions of the objectives, goals, and budgets of all Agencies involved in the Federal response to HIV in five major areas of HIV policy: prevention, research, care, civil rights, international activities, and translation of research into practice.

The National AIDS Strategy is intended to be a working document that requires regular updating and adjustment as goals are reached and new challenges emerge. This Strategy provides a reference point for continuing dialogues and collaborative efforts between ~~the public and private sectors~~ that are necessary to meet our national goals and objectives.

*just and
the entire
it series*
In that light, the Office of National AIDS Policy is seeking ~~direct~~ input from the Presidential Advisory Council on HIV/AIDS, national and community-based organizations, state and local government, clinicians and researchers, members of the infected and affected community, and other individuals and organizations who can contribute to this historic document. This Strategy is being released, first, in draft form to allow for maximum input to the first of an ongoing national effort to chart and plan Federal efforts in response to the epidemic of HIV/AIDS.

The development of a National AIDS Strategy is an historic undertaking. No previous Administration has undertaken so broad a planning effort that: (1) involves all Federal Departments and Agencies that engage in HIV-related efforts; (2) reaches out to communities and the private sector; and, (3) identifies areas where the Federal government should focus its efforts.

The National AIDS Strategy was drafted in consultation with, and with guidance from, numerous groups and individuals. Within the Federal government, this effort began at the Agency level. Members of the Interdepartmental Task Force on HIV and AIDS (IDTF) representing all Federal Agencies involved in the national response to HIV and AIDS, identified their HIV-related goals, objectives, and highlighted areas requiring special attention.

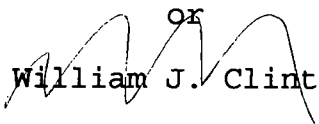
Individuals living with HIV and AIDS, their families, friends, loved ones, and care givers made vital contributions to this Strategy. Numerous non-governmental groups and organizations have also been consulted including the Presidential Advisory Council on HIV/AIDS, participants in the historic White House Conference on HIV and AIDS, the ONAP-sponsored regional briefings, patient and consumer advocates, health care professionals, community-based

DRAFT: National AIDS Strategy
August 9, 1996 (n:\text6.g96)

organizations, educators, religious leaders, and business leaders. The earlier insights provided by the National Commission on AIDS, the Institute of Medicine and National Research Council, the General Accounting Office, and the Office of Technology Assessment have also been extraordinarily helpful in developing the National AIDS Strategy.

As a Nation, we face great challenges, but we are also facing equally great opportunities. After fifteen years, AIDS remains a terrible national tragedy that has affected -- and will continue to affect -- far too many people in this Nation and around the world. But we have made tremendous progress in our understanding of HIV and HIV disease, ways we can treat those who are infected, and means by which we can prevent infection. Ultimately, HIV is a disease that we can defeat -- just as we have eradicated smallpox from our planet and polio from the western hemisphere. The National AIDS Strategy provides a foundation for the continuing public-private partnerships that are essential to our success. Together, with steadfast commitment, courage, and leadership, we will win the battle against HIV and AIDS.

Patricia S. Fleming
Director, Office of National AIDS Policy

or

William J. Clinton

"For nearly every American with eyes and ears open, the face of AIDS is no longer the face of a stranger. Millions and millions of us have now stood at the bedside of a dying friend and grieved. Millions and millions of us now know people who have had AIDS and who have died of it who are both gay and heterosexual. Millions and millions of us are now forced to admit that this is a problem which has diminished the life of every American."

*President Clinton, December 1, 1993,
Georgetown University*

I. INTRODUCTION

Scope of the HIV/AIDS Epidemic

The epidemic of Human Immunodeficiency Virus (HIV) and Acquired Immunodeficiency Syndrome (AIDS) presents unique social, economic, and public health challenges to governments and individuals here in the United States and around the world. While significant progress has been made in understanding the disease and developing treatments since the first case was reported in the U.S. in June 1981, HIV remains a deadly infection for which there is no vaccine, no cure, and for which there is an expanding but still limited inventory of available treatments. An average of 100 Americans are diagnosed with AIDS every day and a similar number of men, women, and children become infected with HIV every 24 hours. **[Richard -- are you certain these numbers are correct?]** Globally, 7,500 people become infected each day.

An Expanding Public Health Threat

As of December 1995, the Centers for Disease Control and Prevention (CDC) had received reports of 513,486 cases of AIDS among persons in the U.S. and 319,849 of these persons have been reported to have died as a result of complications related to HIV. Since 1987, AIDS has risen from being the 15th cause of death among all Americans to the 8th. AIDS is now the leading cause of death among Americans aged 25 to 44 (See Figure 1). In 1995 alone, approximately 74,000 new cases of AIDS were reported in the U.S. and more than 46,000 AIDS related deaths were reported to the CDC in 1994. CDC estimates that between 40,000 and 60,000 Americans are becoming newly infected with HIV each year, and that between 650,000 and 900,000 Americans are currently living with HIV.

As the epidemic in the United States has expanded, the demographics of the epidemic have changed. The early years of the epidemic were dominated by cases involving gay or bisexual men living in major urban centers, (*i.e., New York, San Francisco, and Los Angeles*).

Today, ^{gay men} ~~this~~ group represents less than half of all new cases, although they still represent the majority of persons living with HIV and AIDS. Among the populations that are more heavily affected today are young gay men, women, and injecting drug users and their sexual partners as well as users of non-injecting drugs (i.e., crack cocaine and alcohol). In 1995, nearly 14,000 women were reported to CDC as having been diagnosed with AIDS. Women now comprise 14 percent of cumulatively reported AIDS cases. If this trend continues, it is estimated that 80,000 American children will have been orphaned as a result of AIDS by the end of this decade. In 1995, approximately 800 new cases of pediatric AIDS cases were reported. (Footnote a)

Adolescents (age 13-19) are at increased risk for HIV infection. CDC estimates that one-quarter of new HIV infections in the U.S. occur among people under age 21. A significant number of young people are engaging at earlier ages in sexual intercourse and drug and alcohol use. This fact, coupled with the disturbing number of adolescents who are prone to high-risk behavior due to homelessness, sexual abuse, and other circumstances, places young Americans in a situation that leaves them extremely vulnerable to HIV infection.

~~Communities of color~~ ^{OR} racial and ethnic minorities have been disproportionately affected by the epidemic of HIV and AIDS. African-Americans, who represent approximately 12 percent of the U.S. population, accounted for 40 percent of newly reported AIDS cases in 1995. Hispanics, who account for about 9 percent of the general population, represented 19 percent of new cases reported in 1995. The number of African-Americans and Hispanics affected by HIV and AIDS has risen dramatically. In 1982, Blacks and Hispanics represented 31 percent of all AIDS cases; however, as of December 1995, these groups comprised 52 percent of cumulative AIDS cases.

The HIV epidemic continues to spread into suburban and rural areas, with especially dramatic increases in certain regions of the South and Midwest. Between January 1993 and December 1995 the largest numbers of AIDS cases (86,462) were reported from the South. (Endnote 1)¹ While most cases are still reported from urban areas, the rate of reported cases in non-metropolitan areas is increasing more rapidly than in urban areas. AIDS cases have now been reported in all 50 States, the District of Columbia, Puerto Rico, Guam, and each of the U.S. territories (See Figure 2).

AIDS is an expensive disease. Average lifetime costs of medical care after diagnosis with HIV is \$119,000 (Footnote b). People living with HIV are disproportionately dependent on the public sector for their health care. Over 50 percent of people living

with AIDS are enrolled in Medicaid, including more than 90 percent of children with AIDS. In FY 1996, the Federal government spent \$1.8 billion on Medicaid benefits for people living with HIV and AIDS and another \$690 million on Medicare benefits. Social Security benefits for people disabled by HIV/AIDS total \$1.1 billion in FY 1996.

Globally, the toll of the epidemic is much greater and threatens to reverse decades of economic and public health progress in developing countries. The Joint United Programme on HIV and AIDS (UNAIDS) and the World Health Organization (WHO) estimate that 27.9 million people have been infected with HIV. Since the beginning of the pandemic, 6 million people, including 1.6 million children, have been diagnosed with AIDS. By the year 2000, WHO projects that between 30 million and 40 million people will have been infected with HIV and 10 million to 15 million children will be orphaned due to AIDS.

II. OVERVIEW OF FEDERAL EFFORTS

Prevention The scope and nature of the HIV/AIDS epidemic have drawn States, local governments, academic institutions, private foundations, health care institutions and community-based organizations and the Federal government into many HIV-related activities. The Federal government, through its public health responsibilities in such areas as research, prevention, health care, and housing has seen a dramatic increase in its activities since the beginning of the epidemic. In FY 1985 the Federal government spent \$212 million for AIDS research, surveillance, and care. By FY 1995 that figure reached \$6.8 billion. (See Appendix G).

has In the past four years, under the leadership of President Clinton, spending for AIDS research, prevention, and care has increased by 47 percent. Funding for the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act alone has increased by 151 percent. Support for housing for people living with AIDS has increased by 91 percent. AIDS-related research funding has increased by 34 percent and AIDS prevention funding has increased by 24 percent. The National Institutes of Health Revitalization Act of 1993 provided the Office of AIDS Research with enhanced authority to prepare and carry out an annual AIDS research budget and plan. Approval of AIDS drugs by the Food and Drug Administration has been accelerated to record times. A community-based planning process has empowered local communities to develop innovative AIDS prevention programs. Eligibility for Social Security disability benefits for people with AIDS ~~have~~ been simplified and Federal laws prohibiting discrimination against people living with HIV and AIDS have been vigorously enforced.

As the epidemic continues, we must renew our vision for ending this epidemic. The sections that follow focus on six major policy areas: prevention, research, care and services, civil rights, international activities, and the translation of research advances into practice. They identify recent progress and future opportunities for further progress.

A. PREVENTION

"We have to set a goal. . . We have to reduce the number of new infections each and every year until there are no more new infections."

President Clinton, December 5, 1995, to the White House Conference on HIV and AIDS.

1. Record of Accomplishment

Since the epidemic began, the Nation has made important progress in prevention of HIV infection. In the early years of the epidemic, it was estimated that more than 100,000 Americans were becoming infected with HIV each year. Today, that total is between 40,000 and 60,000 people each year.

Sentinel accomplishments in prevention of HIV include:

- Identification in 1981 by the Centers for Disease Control and Prevention (CDC) of the first cases of AIDS;
- Identification in 1981 by the Centers for Disease Control and Prevention (CDC) of the risk factors associated with HIV infection; and

Due in part to successful implementation of CDC-sponsored prevention strategies, a slowing the growth of the epidemic.

Since President Clinton took office in 1993, efforts in HIV/AIDS prevention have been accelerated. Actions include:

- Increasing funding for AIDS prevention by 24 percent;
- Launching the community planning partnership, which empowers local communities to make decisions about the development of innovative prevention efforts;
- Launching the Prevention Marketing Initiative, focusing on the risk to young adults (18 to 25) with frank public service announcements ~~advocating sexual abstinence and the correct and, for the first time in the epidemic,~~ the consistent use of latex condoms; and,
- Reorganizing AIDS prevention efforts at the Centers for Disease Control and Prevention to foster greater coordination with efforts to reduce sexually transmitted diseases and tuberculosis.

The efforts of Federal Agencies (see Appendix A) have been instrumental in expanding our knowledge base about HIV prevention. The CDC, the agency with primary Federal HIV surveillance and prevention responsibilities, has been pivotal in identifying risk factors associated with HIV transmission, seroprevalence of HIV in society, and trends in HIV infection.

Community
Federal efforts have shown that HIV prevention programs can be effective. CDC's prevention projects, many in partnership with States, local governments, and community-based organizations, have demonstrated that prevention programs are most effective when designed and implemented at a ~~local~~ level. Biomedical, behavioral, and social science prevention research conducted and supported by the National Institutes of Health (NIH) has expanded and will continue to expand our understanding of the determinants of HIV-related risk behavior.

treatment
The Nation has also combatted the dual epidemics of HIV and drug abuse. The National Institute on Drug Abuse (NIDA) and the Substance Abuse and Mental Health Services Administration (SAMHSA) support efforts to prevent HIV infection among drug users. The Office of National Drug Control Policy has pursued efforts to counter the problem of substance abuse and its devastating consequences.

There have been advances in integrating primary prevention into health care service systems. The Health Resources and Services Administration (HRSA) and the Department of Veterans Affairs (VA) have encouraged broader access to prevention information through the integration of prevention interventions into primary health care services and through support of early intervention services. HRSA also has undertaken special initiatives designed to reduce perinatal transmission of HIV and has promoted primary prevention through the training of health professionals in the AIDS Education and Training Centers program.

2. Future Opportunities for Progress

Significant challenges remain if we are to reach the Nation's prevention goal, ~~no new infections~~. Primary to this progress are efforts to:

Improve our understanding about the major trends in transmission and seroprevalence of HIV transmission;

Close gaps in scientific knowledge, which includes identifying additional effective prevention models and strategies; and

*Focus greater
often on vulnerable
pop. ie. women, SA,
youth
(CDC's budget
for FY 97 includes
targeted \$ for
them)*

Eliminate gaps in HIV prevention program areas.

a. Improving Understanding of Trends in the Epidemic

5 An important aspect of strengthening prevention activities is to have a clearer understanding of those who are becoming infected and what behaviors are placing people at risk. Recent epidemiologic data show that the HIV epidemic continues to spread most rapidly among people who engage in injection drug use and their sexual partners, women, young and minority men who have sex with men, heterosexuals, and infants who are infected through perinatal transmission. These trends must be considered when prioritizing prevention research and service programs.

A crucial element of effective prevention strategies is support for adequate surveillance of HIV infection and related diseases in order to gauge future directions of the epidemic and assess the effectiveness of prevention interventions. CDC's AIDS case and case death reporting system provides important data for assessing AIDS prevalence and mortality by gender, race/ethnicity, age, and mode of exposure.

Effective prevention interventions begin with sound information about who is at risk. ~~However,~~ Current CDC surveillance systems do not capture sufficient "front-end" information on the incidence and prevalence of HIV prior to an AIDS diagnosis in the population and trends in modes of transmission and new infections. These data must be collected with appropriate confidentiality protections for the identity of those who are living with HIV. CDC is exploring additional innovative approaches for collecting HIV incidence information. ~~These efforts must continue.~~ Collection of these data are needed as part of an enhanced effort to link surveillance and epidemiological data to priority setting as well as in the design and evaluation of HIV prevention programs.

~~The~~ CDC has incorporated data collection design into its community planning process. Shifts in data needs may also require that CDC reevaluate and reconfigure certain of its data collection efforts. As part of the Agency's implementation of the recommendations set forth in the external review of CDC's HIV prevention strategies², CDC has initiated efforts to evaluate current data collection efforts and implement necessary changes.

b. Prevention Research: Closing Gaps in Scientific Knowledge
(Footnote c)

Factors that place individuals at risk for acquiring HIV infection

entail a complex combination of behavioral, social, cognitive, and biological influences. Given this complexity, we must not ~~assume~~ *no ital* to intuitively know which interventions will work, but instead base our efforts on research findings. Development of effective interventions are based on sound research findings and evaluation. The three main gaps in current knowledge are: basic behavioral research, intervention research, and social marketing research.

Basic Behavioral Research. Information provided by basic behavioral research serves as the foundation for prevention programs. To capitalize on what is known and to improve HIV prevention programs that are targeted to reach diverse populations of Americans, more information on the determinants of HIV-associated sexual and drug-using behaviors is needed. Such data enable scientists to establish theories of behavioral change, which then provide researchers with tools for identifying approaches that may be most effective for an individual or a community.³

Intervention Research. Research to improve prevention interventions concentrates on modifying behaviors, such as those related to drug use and sex. Intervention research can focus on both individuals and communities, each of ~~which~~ *whom* often adhere to norms that influence personal behavior. Since the beginning of the epidemic we have made advances in our understanding of factors that are relevant to the design of intervention programs intended to reduce rates of HIV infection. There is more that we need to know if we are to develop more effective prevention programs. We must incorporate findings from basic behavioral research into effective prevention interventions. Agencies supporting intervention and behavioral research must include scientists from a broad range of disciplines in their planning activities and improve their data-sharing and collaborative efforts with Agencies responsible for implementing prevention programs. Intensifying the dialogue between researchers in these prevention-related fields will improve the development of effective prevention interventions.

Social Marketing Research. It is important that the findings from basic behavioral and intervention research serve as a foundation for prevention programs. Agencies supporting social marketing activities need to build on current knowledge ~~in addition to~~ *and* strengthening ~~ing~~ efforts to understand barriers to the implementation and replication of promising prevention programs. As these models are developed, community-based organizations will require additional technical assistance and training in order to test those models in a "real-world" setting.

c. Strengthening Prevention Programs

For prevention interventions to be effective they must reach people at risk and be responsive to their needs. For individuals to take control of their own lives in fighting the spread of this virus, they must first have the information and skills to protect themselves. It is important that prevention planners carefully prioritize local efforts based on who is, and who is becoming infected.

One of the most important innovations in HIV prevention is the creation of community planning. Through this public-private partnership it has been possible to establish joint goals for the prevention of HIV that are responsive to local needs. However, this process is early in its development and requires continuing ~~significant~~ leadership and technical assistance. Small, new, community-based organizations -- especially those serving minority populations -- often require additional technical assistance in order to compete for available resources. The CDC and other Agencies provide such assistance and will continue to do so.

It is crucial that prevention research results be disseminated and incorporated into prevention programs. Models of effective prevention interventions have been developed but often this valuable information is not reaching those people developing, implementing, and evaluating prevention programs. (See Section on Translation of Research Advances into Practice.)

Substance Abuse Prevention and Treatment. Injection drug use is one of the major forces driving the epidemic. One third of all new cases are directly or indirectly related to this mode of transmission. Limiting the impact of substance abuse on the epidemic will require efforts on several fronts.

First, we need to improve the integration of HIV prevention activities and substance abuse treatment and prevention programs. The epidemics of substance abuse and HIV in this country are overlapping and highly interrelated, however, many care and prevention service programs for HIV and substance are not optimally integrated. It is vital to continue and strengthen efforts to integrate HIV prevention into current substance abuse programs and integrate substance abuse prevention into HIV prevention.

A key to controlling the spread of HIV among substance abusers is enrollment into drug treatment ~~programs~~. Substance abuse treatment is a major form of HIV prevention. Moreover, substance abuse problems that contribute to the spread of HIV are not limited to injecting drug use; use of non-injectable drugs such as alcohol and crack cocaine can adversely influence risk-taking behavior. The efforts of the Office of National Drug Control ~~Strategy~~ to motivate

Americans to reject illegal drugs and substance abuse are an important element in controlling the epidemic.

7. Work on these issues has begun and will continue. CDC has initiated State-by-State discussion, including meetings with State Legislators and the National Conference of State Legislatures regarding HIV prevention issues. SAMHSA's new "Knowledge Development Application (KDA) Program" will address emerging issues in the fields of substance abuse and mental health, including a focus on HIV and AIDS. CDC, HRSA, NIDA, and SAMHSA are co-sponsoring a national meeting of State and local officials from the fields of public health and drug abuse prevention to develop an action plan that more effectively integrates HIV and substance abuse prevention efforts.

Treatment for Sexually Transmitted Diseases and Tuberculosis.

70. Research has shown that the presence of other sexually transmitted diseases (STDs) can significantly increase the efficiency of HIV transmission, by as much as twenty-fold. Studies have also shown that widespread treatment of STDs in certain communities has led to a 40 percent reduction in new HIV infections in these groups.^{4,5} These data suggest that treating STDs can be a very effective HIV prevention strategy and points to a need for all clinicians to be vigilant in efforts to prevent and treat STDs. NIH-supported research to further understanding of the effect of STD treatment on HIV transmission is underway and will continue.

It is important that Federal and State efforts to reduce the incidence of sexually transmitted diseases (STDs) include an HIV prevention element and that HIV prevention programs incorporate STD prevention and treatment efforts. The traditional model of targeting most STD prevention efforts towards individuals who have already contracted an STD is not necessarily effective for HIV prevention. Linkages between STD and HIV prevention efforts need to be established and, where they do exist, enhanced.

People living with HIV are at very high risk for developing active tuberculosis (TB) disease. Studies suggest that the risk of developing active TB disease is 7-to-10 percent per year for persons who are infected with both TB and HIV, whereas the risk is 10 percent per lifetime for persons not infected with HIV.⁶ In addition to the health implications for infected persons, there is an increased risk of transmission of TB to household members, health care workers, and other persons having regular contact with a person with active TB.

The newly organized National Center for HIV, STD, and TB Prevention

at CDC demonstrates the importance of integrating the interdependent aspects of the epidemic and illustrates the determination to integrate and coordinate HIV, STD, and TB prevention efforts.

Integration of Prevention Into Primary Care. To reach our prevention goal, we must also improve the integration of prevention activities and messages into primary health care services. HIV counseling and voluntary testing often provide an important bridge between HIV prevention and care for many at-risk persons. To assure that all persons seeking HIV testing can have access to such services, CDC's counseling and testing guidelines must acknowledge and address the needs of persons seeking such services, and provide training for personnel at CDC-funded sites.

Incorporating a person's sexual and drug use history when a medical history is taken, offering HIV-related counseling and voluntary testing, and providing prevention education to HIV positive individuals so they do not infect others is also important. In addition, to reduce perinatal transmission, all pregnant women should be offered HIV counseling and voluntary testing as well as information about and access to AZT. Training should be made available to improve primary care providers' skill, comfort level, and sensitivity in these areas.

Speed out
Achieving this level of integration requires active collaborative efforts on the part of individual physicians, nurses, other clinicians, managed care plans, medical schools, and professional organizations in addition to State, local, and Federal governments. Presently HRSA's primary care, RWCA, and professional training programs emphasize the value of integrating prevention into primary care. These are important efforts that will continue.

~~**Prisoners.** Those in prison are at especially high risk for both substance abuse and HIV infection. There is often a high prevalence of behaviors that lead to both substance abuse and HIV infection in people entering prison. Given that prisoners often are at increased risk for HIV infection, offering educational programs during incarceration provides a unique opportunity to reach these individuals. Research has shown that people who are well informed about HIV and substance abuse issues modify their risk-taking behaviors. It is important that the Federal government build upon the knowledge and opportunity that currently exists to further improve HIV prevention efforts for incarcerated persons.~~

Evaluation. It is important to assess the effectiveness of the HIV prevention interventions. Prospectively-set performance measures can be used as a basis for evaluation and program improvement and

DRAFT: National AIDS Strategy
August 9, 1996 (n:\text6.g96)

must become a routine part of all Federally-funded programs. It is only through sound evaluations that we will be able to determine whether our efforts have been effective in slowing the epidemic.

B. RESEARCH

"Our common goal must ultimately be a cure, a cure for all those who are living with HIV, and a vaccine to protect us from the virus."

President Clinton, December 5, 1995, to
the White House Conference on HIV and AIDS

1. Record of Accomplishment

Since the epidemic began in 1981, the Nation has made significant advances in HIV-related research advances. Sentinel points of that progress include:

- Identification of HIV as the etiologic agent for AIDS (~~April 1984~~); *in April 1984*
- Development of a reliable test to determine exposure to HIV (~~March 1985~~); *in March 1985*
- Approval of zidovudine (AZT), the first treatment of HIV primary infection (~~September 1986~~); and *in September 1986*
- Development by the Food and Drug Administration of a system of expedited review of treatments for life-threatening diseases, including HIV. *in 1987?*

Since he took office in 1993, ~~President~~ *Admin.* Clinton has escalated ~~our~~ *the* AIDS research efforts by:

- Increasing AIDS research funding by 34 percent;
- Signing the NIH Revitalization Act of 1993, creating a permanent Office of AIDS Research at NIH and vesting it with new authority to plan and implement an annual AIDS research plan;
- Accelerating AIDS drug approval to record times. (Since 1993, the Food and Drug Administration has approved 12 new AIDS drugs and three new diagnostic tests.)
- Supporting research that led to *the* finding that use of AZT during pregnancy, childbirth, and the first six weeks of life can reduce the transmission of HIV from mother to child by two-thirds;
- Launching a four-year, \$100 million research effort to develop effective topical microbicides;

- Facilitating creation of the Forum for Collaborative HIV Research to identify opportunities for clinical effectiveness research to improve care for HIV-positive individuals.

Contributions of AIDS Research

Beyond the impact that AIDS research has had on the epidemic, the Nation has realized additional benefits of supporting such research. Several Federal Agencies play a significant role in AIDS research (see Appendix B). The effort to understand HIV and AIDS has produced scientific advances that benefit research on many other diseases. For example, AIDS research has accelerated study of the human immune system, which helps us to better understand and treat many other diseases, such as cancer; autoimmune diseases, including systemic lupus erythematosus; type I diabetes mellitus; rheumatoid arthritis; and multiple sclerosis. AIDS research also contributes to the prevention of other infectious diseases and provides a new paradigm for treatment of viral diseases.

Advances made in the treatment and prevention of HIV-related opportunistic infections have had an enormous impact on the care of patients with other immunodeficiency conditions who are susceptible to many of the same pathogens. This research effort has enhanced the care of cancer patients, patients who have received immunosuppressive therapy for transplants, or the treatment of diseases caused by elevated immune responses (i.e., allergies and lupus).

HIV research has assisted in identifying new infectious agents that may be responsible for malignancies, such as the recent discovery of the etiologic agent for Kaposi's sarcoma. These findings may help to identify other oncogenic agents. HIV research has led to a better understanding of the mechanisms by which infectious agents and inflammatory cells cross the blood/brain barrier, providing valuable clues for research on Alzheimer's disease, dementia, multiple sclerosis, neuropsychological disorders, encephalitis, and meningitis. Moreover, prior to the AIDS epidemic, little investment was made in research to treat viral diseases. Studies to develop anti-HIV therapies have improved our understanding of additional viral diseases and led to development of treatments.

Efforts to develop drugs for the treatment of HIV have accelerated the development of methods of rational drug design using sophisticated techniques of structural biology and advanced computer imaging methods. These advances have implications for drug design for virtually all disorders. Comparative clinical trials of poxvirus vectors and vaccine adjuvants in HIV vaccine candidates have supported safety information for cancer vaccines.

Research on HIV-related wasting has provided important information for research on nutritional disorders, metabolic abnormalities, and gastrointestinal dysfunctions.

Due in great part to Federally-sponsored AIDS research, a number of new and exciting research advances have brought optimism and opened new areas for investigation. One of the recent research advances has been the development of a new class of drugs, known as protease inhibitors. When used in combination with other types of anti-retroviral drugs, there is the potential to dramatically reduce the amount of HIV in the bloodstream and possibly improve a person's clinical status and reduce the risk of HIV transmission. A landmark advance in HIV prevention was the demonstration that AZT can dramatically reduce the risk of transmission of HIV infection from a pregnant woman to her child. Advances in effective treatments for HIV-related conditions can prolong and improve the quality of life of persons living with HIV. Breakthroughs in our understanding of the genes and proteins of the human immunodeficiency virus have allowed the development of increasingly effective anti-retroviral drugs.

In addition, the Food and Drug Administration through its expedited review and accelerated approval programs is now approving drugs more rapidly than ever before. Recent planning efforts on the part of various Federal Agencies, such as the annual NIH plan for HIV-related research and the Federal Biomedical and Behavioral Research Plan for HIV and AIDS have greatly improved the coordination of HIV research.

2. Future Opportunities for Progress

Despite these advances, many complex biomedical and behavioral challenges remain. We must ensure that the Nation capitalizes on the most promising scientific opportunities.

Coordinating Federal Research. Developing and implementing the Federal government's AIDS research agenda presents both scientific and logistical challenges. Planning and overseeing a Federal effort of this magnitude requires coordinating efforts at two levels: First, within NIH and second among the Departments and Agencies supporting HIV research.

Within NIH, research is supported throughout 24 institutes, centers, and divisions (ICDs). In order to better plan, coordinate, evaluate, and fund the AIDS research activities of these ICDs the NIH Revitalization Act Amendments of 1993, provided the Office of AIDS Research (OAR) with new oversight and budget

authorities. It is crucial that the authority granted OAR in the revitalization legislation, including the consolidated appropriation, be maintained.

huh? Add RS language about the Levine Report

For the government to effectively support a diversity of promising approaches, these research efforts must also be well-planned and coordinated. To achieve this the Director of the Office of National AIDS Policy created an inter-departmental working group, chaired by the Director of the Office of AIDS Research, charged with developing a coordinated plan and budget for HIV and AIDS research across all Agencies.

5 On December 6, 1995, at the White House Conference on HIV and AIDS, President Clinton directed OAR Director Dr. William Paul to develop the first Federal Biomedical and Behavioral Research Plan and Budget for HIV and AIDS. This plan was completed in April, 1996. ~~The development of this plan brought together representatives from the National Institutes of Health, the Centers for Disease Control and Prevention, the Food and Drug Administration, the Department of Defense, the Department of Energy, and the Department of Veterans Affairs. This plan provides a blueprint to focus and coordinate all Federal HIV/AIDS research initiatives and serves as a foundation for continued planning and evaluation.~~ asked which

Vaccine Development. Several major challenges currently face the U.S. and the world in the development of an effective HIV vaccine or vaccines. The first is to surmount the daunting scientific and social challenges, and the second is to ensure the development and testing of promising vaccine candidates.

On the scientific level, researchers are pursuing two approaches to vaccine development. One approach is based on the belief that gathering additional basic science information offers the best hope in steering vaccine development. The second approach is guided by the belief that data gathered from clinical efficacy trials in humans can lead to the development of a successful candidate. This group maintains that if a safe candidate is available, it is not necessary to resolve all of the scientific questions before proceeding with human trials, and, that in the face of a global emergency, testing in people should be begin immediately. Both approaches have valid arguments.

Developing a vaccine cannot be accomplished by the government or the private sector working apart: a continuing public-private partnership is needed. In order to identify areas for fruitful collaboration and to accelerate the pace of development for

vaccines, in February 1996, Vice President Gore convened a meeting of government scientists and leaders of the pharmaceutical and biotechnology industries to identify barriers to the development of these agents. Further dialogue involving key players regarding critical problems, and opportunities for development, and viable solutions has begun and will continue.

Microbicides. Many scientists believe that in the absence of a vaccine the development of safe and effective mechanical or chemical barrier methods that will block HIV transmission or prevent other sexually transmitted infections could dramatically reduce the sexual transmission of HIV. Worldwide ~~over~~ ^{more than} 80 percent of HIV infections are acquired heterosexually and women are more easily infected than men. Moreover, the risk of becoming infected or infecting others is substantially increased by the presence of other STDs⁷.

Condoms, the barrier methods that are currently available, have limitations. Most require consent, if not active participation of both partners and therefore cannot be independently used at the discretion of one partner. An easily available and inexpensive microbicide could provide a prevention option for millions of people worldwide.

The development of this important prevention option will ~~depend on~~ ^{require} strong and continuing support for basic and clinical research. Microbicides are a promising approach, but will require preliminary Federal support before they reach a stage where pharmaceutical or biotechnology companies can assume a lead role. Discussions among Federal Agencies, the private sector, and advocacy groups have been ongoing and should continue in order to identify areas for worthwhile collaboration and hasten the pace of development.

Examining the Impact of HIV on Youth. HIV-related research has made great strides on many fronts, however, adolescents have not received the full benefit of research discoveries. There is evidence indicating that HIV may behave differently in infected adolescents. We need more information on impact of puberty on the course of HIV infection and behavioral trends that play a key factor in HIV treatment and prevention. Adolescents also must factor more significantly into the research process. NIH and the Food and Drug Administration (FDA) are examining options for lowering barriers to participation of adolescent in clinical trials and research protocols and will continue to encourage sponsors to enroll adolescents when feasible and appropriate, in such trials. The efforts of the collaboratively-funded Adolescent Medicine HIV/AIDS Research Network (Footnote D) are important in improving our understanding of HIV disease in adolescents and will continue.

New and More Effective Therapies. Strong and continuing research to develop new and more effective therapies for HIV infection and its associated conditions must be a priority if we hope to transform HIV disease into a chronic, manageable condition. Due to the FDA's accelerated approval program (Footnote E), the Federal government is now approving new treatments in record numbers and at record speed, but it is not always known whether a treatment confers a clinical benefit for patients. While some treatments have shown promise based on surrogate markers and/or laboratory tests data regarding long-term clinical effectiveness are unavailable. Patients may be receiving less effective treatments or combinations of treatments, and private insurers and Federal programs such as Medicaid and Medicare may be paying for treatment strategies that are not optimally effective.

It is incumbent upon the government and the private sector to ensure that post-marketing effectiveness studies, currently mandated through regulation, are carried out. In order for the results to be relevant to as many persons as possible, it is necessary that these studies include people representing a diversity of race, ethnicity, gender, age, and drug using behaviors. Through the efforts of Vice President Gore, the Forum for Collaborative HIV Research has been established to assess approaches for accelerating clinical effectiveness research.

Public-Private Partnerships. A key role for the Federal government is to act in partnership with the private sector and support research that would be beneficial to the public health in areas where there is a market failure. For example, it is unlikely that the free market system will push the implementation of head-to-head clinical trials of therapies that have been approved or are in development. However, information about these therapies is critical to improving patient care. The ~~National Institutes of Health (NIH)~~ and the ~~Department of Veterans Affairs (VA)~~ have been successful in carrying out this type of valuable research in collaboration with the pharmaceutical industry. It is unlikely that the private sector would support research for therapies that are on the market but have not been tested in controlled clinical trials, such as alternative therapies. However, through collaborative partnerships that include the NIH, studies of alternative therapies have been and will continue to be conducted.

It also is cost-effective for the government to provide access to sophisticated equipment and personnel that can be shared among many researchers in both the private and public sectors. The Department of Energy (DOE) has made available the use of sophisticated imaging equipment that would be prohibitively expensive for individual researchers or companies to purchase. This shared resource has

accelerated ~~our~~ understanding of molecular structures in a number of research fields, including HIV research. Information gained from this research can form the basis for targeted drug design and development.

Continued Support for Research. Research is an investment in our future. It must receive consistent and adequate funding if we hope to bring the best and the brightest to meet the research challenges that will lead to a cure, better therapies, and a vaccine. At present, NIH receives many more outstanding research applications than it is able to fund; these unfunded proposals represent a lost opportunity for scientific progress. Other Departments and Agencies, such as DOD and VA, also support crucially important research that strengthens the overall U.S. research effort. Research has been key to prolonging and improving the quality of lives and the Nation must continue to make this investment.

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C. CARE & SERVICES

"AIDS has taken too many friends and relatives and loved ones from everyone of us ~~in this room~~. It has shaken the faith of many, but it has inspired a remarkable community spirit."

President Clinton, May 20, 1996

Signing of the Ryan White CARE Act Reauthorization

1. Record of Accomplishment

Since the epidemic of HIV and AIDS began in 1981, more than 500,000 Americans have been diagnosed with AIDS and required care. As the number of Americans living with AIDS increased, the demands on the U.S. health care system increased dramatically. Federal, State, and local governments along with community-based organizations and private clinicians have responded with compassionate, high-quality medical care. Among the sentinel achievements of these efforts are:

- Enactment in 1989 of the Housing Opportunities for People with AIDS (HOPWA) program; and
- Enactment in 1990 of the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act.

The Nation has made significant efforts to ensure that people living with HIV have access to services that are affordable, of high quality, and responsive to their needs. As the number of people with HIV has increased, so did their need for care. In 1985, Federal expenditures for HIV-related care and services were \$xxx, by 1995 the Federal share reached \$xxx.

Since he took office in 1993, President Clinton has, as one of his highest priorities, sought to increase the national commitment to care for people living with HIV or AIDS. Among those actions are:

- Signing the Ryan White CARE Act Amendment of 1996, and increasing funding for the Ryan White CARE Act by 134 percent;
- More than doubling funding for the AIDS Drug Assistance Program, which helps uninsured and underinsured individuals purchase prescription drugs;
- Increasing funding for Housing Opportunities for People

And Creating the Office of AIDS
at HUD,

with AIDS by ~~91~~ percent;

- Fighting to preserve the Medicaid guarantee of coverage for the nearly 50 percent of people with AIDS and 92 percent of children with AIDS who rely on this program for their health coverage; and
- Revising eligibility rules for Social Security Disability Insurance to make it easier for people living with HIV to qualify for benefits.

~~Background~~ A Growing Response

In the early years of the epidemic, the health care ~~infrastructure~~ ^{U.S. system} was particularly unprepared to accommodate the health care needs of persons with HIV. To meet their complex health care needs, HIV-positive persons were often forced to negotiate a fragmented system of care. There were few programs designed to meet the unique care needs of positive individuals. Moreover, available care services were often directed towards meeting the acute care needs of persons diagnosed with AIDS, rather than the early stages of HIV disease. While we still have far to go, the quality and availability of services for HIV-positive persons has improved significantly.

People living with HIV now access ~~finance~~ ^{more than} necessary health care services in a variety of ways. Currently, ~~over~~ 50 percent of adult Americans and 90 percent of children living with AIDS receive their medical coverage through the Medicaid program and another 5 percent receive Medicare benefits. An estimated 15 percent of people living with AIDS have private health insurance and the remaining 30 percent are uninsured and must rely on personal payment or charity care.¹ However, for a disproportionate number of people living with HIV and AIDS, their lives often depend on the Federal health care safety net.

For those who qualify, care and services are provided through a number of Federal Agencies (See Appendix C), many in cooperation with local organizations and the AIDS community, that have admirably served those living with HIV. Taken together, these efforts form a valuable, ~~if still incomplete~~, safety net for ~~some~~ ^{a very} of the most vulnerable people in our Nation.

Medicaid, a jointly financed Federal-State program of health care for the poor and the disabled, is the primary source of care for

¹ JL cite. Add Vancouver numbers.

*This whole is material
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people living with AIDS and a major source of care for those who are living with HIV. In FY 1996, Federal Medicaid expenditures for people living with AIDS totaled \$1.8 billion. The Medicaid statute authorizes Federal matching payments to the states to provide services to eligible individuals.

In addition to Medicaid, the centerpiece of the national safety net consists of programs funded through the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act of 1990, administered by the Health Resources and Services Administration (HRSA). The CARE Act programs were established to fill gaps in coverage and build systems of care to create access to health care for people living with HIV and AIDS. The CARE Act is comprised of four separate titles:

- Titles I and II of the CARE Act provide funds for outpatient care, support services, and case management that are given to cities and States primarily on a formula basis. Title II also provides drug reimbursement funding for persons living with HIV/AIDS under the AIDS Drug Assistance Program (ADAP).
- Title IIIb of the CARE Act provides early intervention services such as counseling and testing, medical care, and educational services for medically underserved persons with the goal of reducing HIV-related illness.
- Title IV seeks to increase the availability of care and services for women, infants, children, and youth in a community-based family-centered system of care.

HRSA also provides primary care to persons living with HIV through its Community Health Centers and Maternal and Child Health Programs. Other sources of primary care supported by the Federal government include the Department of Defense, the Department of Veterans Affairs, and the Indian Health Service (IHS) which provides health care for HIV-positive Native Americans and Alaska Natives. Additionally, the Bureau of Prisons within the Department of Justice provides care for HIV-positive ~~people~~ *individuals* in Federal prisons.

People living with HIV and their families face significant obstacles to locating affordable housing. Housing assistance for people living with HIV/AIDS is provided by the Department of Housing and Urban Development (HUD) through its Housing Opportunities for Persons with AIDS (HOPWA) and other programs, such as the Section 811 Supportive Housing Programs for Persons with Disabilities. These programs work in partnership with local initiatives incorporating housing assistance into a community's

continuum of services.

To further foster community involvement, HUD also has established the Consolidated Planning process for communities that receive funds under the Department's economic and community development programs, including recipients of HOPWA formula allocations. The Community Development Block Grant (CDBG), the HOME affordable housing program, as well as public housing programs are key resources that are available to communities.

2. Future Opportunities for Progress

The challenge before us today is to ensure that persons living with HIV receive the care they need so they may have the opportunity to live productive lives. AIDS care and service programs must continue to expand access to care for those without insurance coverage, improve prioritization and accountability, and increase the cost-effectiveness of services they provide. As treatments improve and extend the productive lives of people with HIV, we must continually reexamine the range of services that are needed.

Preserving Medicaid. Medicaid is a lifeline of support for Americans living with HIV and AIDS. As the epidemic continues to spread in lower-income communities, the need for Medicaid coverage of people living with HIV/AIDS will increase. The need to maintain the historic Federal-State partnership on Medicaid has never been greater. Proposals in Congress to convert Medicaid into a block grant would endanger access to care for people living with HIV/AIDS. In particular, proposals to eliminate the Federal guarantee of coverage for people living with disabilities would have a dramatic impact on people living with HIV/AIDS. President Clinton has vetoed one such proposal and has promised to veto any future proposals that reach his desk.

Continuing Support for Ryan White CARE Act. The five-year reauthorization of the CARE Act signed by President Clinton on May 20, 1996, provides people living with HIV/AIDS with peace of mind that support from the Federal government will be there through FY 2000. As the demand for care continues to grow so must the resources for the CARE Act. President Clinton has proposed \$827.5 million for this program in FY 1997; enactment of that request is essential.

Expanding Support for Housing Services. Without stable housing a person living with HIV has diminished access to care and services and a diminished opportunity to live a productive life. It is estimated that up to 50 percent of people living with HIV and AIDS are or will become homeless during the course of their illness.⁸

HOPWA up 96%
93 97
100 → 196

President Clinton has requested \$196 million in FY 1997 for HOPWA; it is imperative that Congress approve that request.

delete? { Providing consistent funding for the housing component of the safety net will continue to be a Federal priority. Integrating AIDS housing services into other programs and ensuring a shared responsibility among Federal, State, local governments and community organizations is another important step in assisting communities to build seamless systems of support for our most vulnerable citizens.

Integrating the Continuum of Care. One of the most effective approaches to treating people living with HIV is providing access to an integrated continuum of health care services. A powerful method of recruiting people into primary care is knowledge of HIV serostatus. People who know their HIV status are more likely to seek health care and act to prevent HIV transmission. Counseling and confidential voluntary testing services serve as a gateway to care. Linking HIV-positive people with care also provides an opportunity for education about behaviors which may reduce their chances of infecting others.)

Achieving this level of integration requires active collaborative efforts by physicians, nurses, other clinicians, insurance plans, medical schools, and professional organizations in addition to State, local and Federal governments.

Improving Program Coordination. Organizations receiving funding from the Federal government in providing AIDS-related care often require support from several Federal Agencies. For example, creating a community-based program that integrates primary care, substance abuse treatment and prevention, and sexually transmitted disease screening, HIV prevention, access to clinical trials, and housing assistance requires separate applications to SAMHSA, HRSA, CDC, NIH, and HUD.)

gls { As part of its effort to "reinvent government," (Do we know if this effort is part REGO?) the Clinton Administration has been working to simplify Federal funding applications to facilitate improved integration of service programs. HRSA and SAMHSA have issued joint programs announcements and HUD and HRSA have also issued a joint program announcement for the Special Projects of National Significance (SPNS) program. These efforts to improve integration will be continued and expanded.

Improving Quality of Care. Federally-supported programs can and should consistently provide high-quality care. Ensuring consistency in care delivery requires increased training for health

for what?

care professionals and greater accountability through the use of performance measures for quality care. It is also essential that practical information on research advances for practicing clinicians and their patients be provided in a timely manner. (See Section Translation of Research Advances in Practice.) Achieving these goals requires the cooperation of Federal Agencies, States, professional organizations, professional and medical schools, and individual clinicians.

Evaluating Program Effectiveness. Strong Federal support for safety net programs must be accompanied by improved accountability and priority setting. Evaluating current activities provides valuable information for planners and those at the front lines of the epidemic and assist in providing better care to people living with HIV.

D. CIVIL RIGHTS

"Every person with HIV or AIDS is someone's son or daughter, brother or sister, parent or grandparent. We cannot allow discrimination of any kind to blind us to what we must do."

President Clinton, May 20, 1996

Signing of the Ryan White CARE Act Reauthorization

Discrimination against people living with HIV or AIDS violates the human rights of individual Americans and undermines our Nation's efforts to prevent and treat HIV infection. The extraordinary stigma that has been attached to HIV disease hampers the ability of people living with HIV/AIDS to live full lives, free of fear.

Discrimination also undermines the Nation's efforts to prevent and treat HIV infection and bring the epidemic under control. Because of fear of discrimination and stigma, many people do not voluntarily seek testing for HIV, remain unaware of their HIV status, and consequently do not seek the care that could help them live longer, healthier lives. Opportunities to educate people are also lost as people at-risk avoid prevention programs because of the stigma associated with HIV.

1. Record of Accomplishment

During the early years of the AIDS epidemic, protection of the civil rights of people living with HIV/AIDS was sporadic, at best. Individual lawsuits were the first line of action. By the late 1980s, however, the Federal government began to respond more aggressively. Sentinel achievements include:

- Enactment of the Harkin-Humphrey Amendment to the Civil Rights Restoration Act, clarifying that Section 504 of the Rehabilitation Act of 1973 applied to people with contagious diseases, including HIV; and
- Passage of the Americans with Disabilities Act of 1990 (ADA) which protects individuals living with HIV and AIDS, and people perceived to be at risk for HIV [Are we sure this is true?], from discrimination in housing, employment, and public accommodation.

Since he took office, President Clinton has directed relevant agencies to make enforcement of the civil rights of people living with HIV/AIDS a priority. Key actions include:

- Vigorously enforcing the ADA by the Justice Department, the Equal Employment Opportunities Commission, and the Department of Health and Human Services. The Federal government has resolved nearly 800 charges alleging discrimination against people with HIV and AIDS obtaining monetary benefits of more than \$6.1 million; [Are these figures correct? ... source(s)?] EEOC
- Vigorously enforcing Section 504 of the Rehabilitation Act of 1973 as it pertains to recipients of HHS funds such as hospitals, nursing homes, and social service agencies;
- Forcefully opposing the so-called "Dornan Amendment," which would require the discharge of all military personnel who are living with HIV. President Clinton declared the proposal unconstitutional and directed the Department of Justice not to defend it if challenged in court. The President led a successful effort to repeal the "Dornan Amendment" and continues to oppose its enactment;
- Establishing a ^{voluntary} AIDS education program for all Federal workers; [Do we want highlight this?] yes
- Using the Presidential "bully pulpit" to continually speak out against discrimination against people with HIV and AIDS.

2. Future Opportunities for Progress

Enforcing Rights. Efforts to protect the civil rights of people with HIV/AIDS must be ever-vigilant. The Federal government must continue to exhibit strong leadership on this issue through its enforcement of the Americans with Disabilities Act and public condemnation of discriminatory acts or statements. Of particular concern is discrimination in health care facilities. A joint effort by the Department of Health and Human Services and the Department of Justice aimed at nursing homes is a significant step forward.

Protecting Workers. The Federal government is actively working to examine its own existing policies related to the exclusion of people living with HIV from employment. The Director of the Office of National AIDS Policy is working with Federal Agencies to examine individual policies to determine whether they comply with ~~Federal~~ ^{public health} guidelines. [What guidelines?]

Opposing Discriminatory Legislation. The Administration will continue to oppose, in the strongest terms possible, efforts by the Congress to discriminate against people living with HIV/AIDS.

DRAFT: National AIDS Strategy
August 9, 1996 (n:\text6.g96)

Providing Leadership. Leaders of government have an obligation to use the power of their elected office to speak out against acts or words of discrimination against any group of people. President Clinton has used and will continue to use his ~~position~~ to oppose discrimination against people living with HIV/AIDS.

Office

E. INTERNATIONAL ACTIVITIES

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AIDS is a global epidemic. Eighty percent of new infections occur in developing countries. In the United States it is estimated that between 650,000 and 900,000 people are currently infected with HIV. The World Health Organization (WHO) estimates that 27.9 million adults and over 1.5 million children are currently infected worldwide and there will be 10-to-15 million orphans worldwide attributable to HIV/AIDS by the year 2000. WHO also estimates that two-to-three million new HIV infections can be expected annually, and by the year 2000, thirty-to-forty million people will have been infected around the globe.

The epidemic jeopardizes decades of economic and social advances in many developing nations. In the nations of Africa and Asia, economic advances are threatened and in some cases may be reversed due to HIV and AIDS. Socio-economic studies have shown a decrease in overall domestic savings and investment levels, negative effects on foreign investments, reductions in the volumes of imports and exports, and a reduction in receipts from tourism.⁹ In many countries governments will be forced to cope with increasing numbers of cases, weakened health care systems, a deleterious economic impact on the most productive segments of society, and the reduction in the number of healthy men and women able to serve in the government and the military.

1. Record of Accomplishment

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Since it began, HIV/AIDS has been a global concern. The U.S. has worked closely with developed and developing nations to design an international response that is both vigorous and coordinated. Sentinel achievements include:

- Founding of the Global Programme on AIDS in 1987, and
- Founding of the United Nations Programme on AIDS (UNAIDS) in 1995 (correct date?).

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The United States is the largest contributor to international efforts to combat the pandemic of HIV/AIDS. Several Federal Agencies are working ~~slow~~ the AIDS epidemic internationally. (See Appendix D.) The Department of State works with other ~~Departments~~, Agencies, and non-governmental organizations to develop a framework to guide U.S. foreign policy in the global efforts against HIV and AIDS. The major areas of U.S. leadership in the HIV arena are: preventing new infections; reducing the personal and social impact

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of the pandemic; and mobilizing and unifying national and international efforts.

The U.S. Agency for International Development (USAID) also plays ^a leadership role in the global HIV effort through development assistance, research and policy formation. USAID focuses its efforts on developing prevention programs based on proven interventions; addressing social, cultural, regulatory and economic issues related to HIV/AIDS and other sexually transmitted ^{diseases} ~~infections~~; and developing and testing new interventions and methods to prevent transmission and mitigate the impact of the epidemic. The Peace Corps trains a portion of its volunteers to directly address HIV-related concerns in their countries of placement. The U.S. Information Agency (USIA) supports programs that promote dissemination of U.S. policies and information related to HIV and AIDS.

In addition, several Agencies support research overseas, including the National Institutes of Health, the Centers for Disease Control and Prevention, and the Department of Defense. The DOD is conducting clinical trials of candidate HIV vaccines in Thailand and NIH (working in collaboration with USAID), supports basic scientific studies on social and behavioral aspects of AIDS in developing countries. The results of the studies ultimately will be used to develop interventions to reduce behaviors that place individuals at risk for contracting HIV infection.

2. Future Opportunities for Progress

International Leadership. The United States has established a global leadership role in combatting the epidemic. This leadership will continue. The U.S. strongly supports the newly established Joint and Co-sponsored United Nations Programme on AIDS (UNAIDS).¹⁰ The U.S. is a member of the governing body of UNAIDS and signed the 1994 Paris Declaration and the Greater Involvement of People Living with HIV/AIDS Initiative (GIPA).

The U.S. also supports efforts to more effectively access available resources as well as encourage non-traditional donor countries to provide much-needed contributions. Supporting UNAIDS organizations such as UNICEF, WHO, UNDP, the U.S.-Japan Common Agenda and its innovative programmatic efforts, and UNAIDS' goal of working to increase the availability of therapeutics (and vaccines when developed) to the residents of developing countries ~~is not only morally correct, but also~~ furthers U.S. interests by promoting economic and social stability worldwide.

Strengthening Partnerships. In addition to maintaining our

✓ multilateral partnerships, we must strengthen and expand our bilateral programs and funds for HIV activities. We must reverse the current trend to reduce assistance to developing countries where more than 90 percent of the world's AIDS cases are found. (OK?)

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Sharing Technology and Bringing Lessons Home. Through USAID's "Lessons ~~Without~~ Borders Project", the U.S. has gained valuable insights from experiences in participating countries and is applying them to communities here at home. The initiative brings lessons learned abroad back to inner city and rural areas with problems similar to those experienced overseas. ~~These efforts will be continued and should be expanded. [Do we want to say this in light of the USAID cuts, reduced \$ in FY97 PB, etc?]~~

Improving Program Coordination. One of the most challenging aspects of the U.S. effort is effective coordination among a host of Agencies with varied missions and activities. In order to ensure that efforts are productive, the Agencies supporting international activities must develop a mechanism for coordinating U.S. programs in a systematic and efficient manner.

F. TRANSLATION OF RESEARCH ADVANCES INTO PRACTICE

Insert Quote

An important element in our fight against AIDS is ensuring that research advances are translated into the care of HIV positive persons. The increasing presence of HIV in every community necessitates that all health care providers become knowledgeable about assessing risk, promoting prevention, and caring for people with HIV.

An example of the importance of such efforts is the translation of the research finding in AIDS Clinical Trial Group 076, which found that the use of AZT by pregnant women during pregnancy and childbirth and its application to newborns for the first six weeks of life can reduce the risk of perinatal transmission of HIV by two-thirds. Translation of these results required actions by the Centers for Disease Control and Prevention, which prepared guidelines for physicians caring for pregnant women and for consumers; the Health Resources and Services Administration, which provided guidance to grantees on coverage of such services; the Health Care Financing Administration, which provided similar guidance to State Medicaid Directors.

1. Record of Accomplishment

Due in part to Federally-sponsored information dissemination activities, dramatic changes in the way HIV is treated have taken place. Ensuring dissemination of HIV-related information falls under the missions of several Agencies (See Appendix F). Key examples are:

- The National Institutes of Health (NIH) supports a broad range of efforts including a "Clinical Alerts" mechanism for the dissemination of clinical trials results to health professionals, the media, and the public;
- ~~X~~ HHS supports and directs the International HIV/AIDS Clinical Conference Call series, which disseminates critical, state-of-the-art clinical care information to primary care providers via live worldwide audio tele-conferencing;
- NIH supports publicly available computerized databases such as AIDSDRUGS, AIDSTRIALS, and AIDSLINE;
- The toll-free 1-800 TRIALS-A AIDS Clinical Trials Information Service (ACTIS) is co-sponsored by NIH, CDC, and FDA;

- The Centers for Disease Control and Prevention disseminates information through the National AIDS Hotline (1-800-342-AIDS); its toll-free 1-800-HIV-0440 HIV/AIDS Treatment Information Service (ATIS); and the AIDS Information Clearinghouse;
- The CDC also issues guidelines for health professionals through its *Morbidity and Mortality Weekly Report*;
- The Agency for Health Care Policy and Research (AHCPR) has published a series of HIV-related clinical practice guidelines for clinicians and companion pamphlets for their patients; and,
- The Health Resources and Services Administration directs a nationwide system of AIDS Education and Training Centers that provide state-of-the-art HIV clinical information to health care providers. HRSA also has developed guidances for its Ryan White CARE Act grantees and funds an AIDS warmline that responds to questions from clinicians across the country.

2. Future Opportunities for Progress

There are opportunities for improvement in translating research advances into practice. They include:

Increasing Education and Training. As we continue to expand our base of knowledge about AIDS care, efforts to educate and train health care professionals in state-of-the-art care for people living with HIV/AIDS must be expanded. [How do we reconcile decrease in AETCs?] An AHCPR-supported study indicated that primary care physicians may miss significant HIV-related symptoms during patient examinations.¹¹ Other research indicates that a disturbing number of clinicians do not use universal precautions in the course of routine patient care.¹² Reference Kittahare (sp?) article.

Disseminating Guidelines. One of the most difficult tasks for clinicians and patients is interpreting the patchwork of data and articles regarding treatments and converting it into a therapeutic strategy for their patients. With every research breakthrough, this task becomes more difficult. It is essential that practical information for practicing clinicians and their patients be provided in a timely manner.

The Federal government currently supports a number mechanisms for periodically assessing advances in clinical care. It is essential

that these assessment efforts continue and that crucial information be widely disseminated. This will require collaboration with industry, government, and professional groups.

Improving Coordination of Federal Activities. Enhancing coordination of information dissemination activities among Public Health Service Agencies is an important priority. Within DHHS, the Office of HIV/AIDS Policy (OHAP) has the lead responsibility for coordinating the HIV-related activities of the Public Health Service Agencies. Ensuring that information about a research breakthrough is easily available, reaches the appropriate people and organizations, and that policies and standard-of-care practices for Federally-sponsored programs are modified to reflect the new standard, requires a continued high level of cooperation and coordination among Public Health Service Agencies.

Disseminating Prevention Models. Improved dissemination efforts also are needed in the area of primary prevention models. Models of effective prevention interventions have been developed, but often this valuable information is not reaching those people developing, implementing, and evaluating prevention programs. The Public Health Service will take the lead in ensuring that information that can be used to stem the tide of new infections reaches those who can make a difference.