

FOIA MARKER

This is not a textual record. This is used as an administrative marker by the William J. Clinton Presidential Library Staff.

Collection/Record Group:	Clinton Presidential Records
Subgroup/Office of Origin:	National AIDS Policy Office
Series/Staff Member:	Patsy Fleming
Subseries:	National AIDS Strategy

OA/ID Number:	9003
FolderID:	

Folder Title:
National Plan Drafts 1/3/96 [1]

Stack:	Row:	Section:	Shelf:	Position:
S	66	5	11	2

JK
1/3/96

Notes:

Folks --

Here's the latest. The approach I took was a cut to the chase -- especially in the substantive sections (i.e goal, who's doing what, here are the major problems and what we're going to do about them). Other things:

- I neglected to copy in the information dissemination section so it's missing in this draft...
- all the #'s need to be checked
- tried to incorporate a "partnership" theme -- works? doesn't work?
- what's missing?
- Right now, the reference citations are inconsistent -- I think they should be moved to a list in the back or eliminated ...thoughts?
- Needle exchange -- wording? Consistent with other policies?
- Promises -- there are lots of promises in here ... any that

should go some that should be in her

- Overall, it needs to be tighter, but, it won't happen to today.

Thanks for your help --

A handwritten signature, possibly initials, consisting of a large 'S' and a large 'J' or 'G' intertwined.

TABLE OF CONTENTS

Letter from PF/Acknowledgments

Executive Summary

Scope of the HIV/AIDS Pandemic

Goal of National Plan

Challenge of the HIV Epidemic

Description of Activities

Overview of Activities

PREVENTION

RESEARCH

SERVICES

CIVIL RIGHTS

INFORMATION DISSEMINATION

INTERNATIONAL ACTIVITIES

Appendices:

Budget Tables

Acronym List

Glossary

List of Members of the Interdepartmental Task Force on AIDS

Letter from PF/Acknowledgments

The national epidemic and international pandemic of HIV and AIDS is a public health crisis of unprecedented proportions. As the President observed -- HIV/AIDS is the health crisis of this

*or Clinton Administration
need to decide*
century. The Office of National AIDS Policy believes that the HIV/AIDS epidemic poses a continuing public health crisis that

① requires sound support for multiple approaches to finding a cure, and until a cure is found we must persevere in our efforts to promote prevention, research, treatment, and ethical treatment of persons with AIDS.

⑤ This epidemic challenges our nation on many fronts. Because of how it is most often contracted, through sex and drug abuse, topics difficult for many Americans to confront directly, HIV has challenged us to look at things we would prefer to avoid. We are also confronted by fear -- fear of contracting this disease and unwarranted fear of those who are infected. Fifteen years into this epidemic, those persons living with HIV still endure prejudice and discrimination based on their HIV status. We are challenged by the inadequacy of a social and health care infrastructure -- a system that was, and still is, woefully unprepared to address the needs of the HIV-infected. It is a system that will be further challenged (to) by funding changes to Medicare, Medicaid, and the possible advent of block grants. Scientifically, we have made much progress, but the virus

*This is too strong a - it's almost attacks
recently made*

7

continues to be a formidable adversary, testing the best and brightest amongst us to find a cure.

But despite the difficulties, AIDS has also brought forth the compassionate and caring capacity of this nation. In my meetings around the country with persons living with HIV I have been inspired by their personal courage. I have been impressed by the compassion of those who care for the sick and the communities that have risen to the challenge of caring for their fellow citizens. It is an example of how this nation can rise to meet the most difficult challenges placed in its path. And those Americans living with HIV, their families, and their communities deserve a thoughtful and efficient plan to combat this epidemic.

for fighting HIV

This is the first time a government-wide national plan has been developed - it links programs to national objectives. A plan of this nature was one of the recommendations put forth by the National Commission on AIDS. The President, as part of his strong commitment to assuring an efficient coordinated effort, requested that the Office of National AIDS Policy develop a comprehensive plan to guide the federal response to this epidemic.

True agency-wide planning requires a commitment at all levels of government to work together toward clearly defined goals. Therefore, this plan for HIV and AIDS has been developed from the

bottom up. Through the Interdepartmental Task Force on HIV and AIDS (IDTF), a request went out for the agencies to identify their activities in relation to their goals and objectives. I would like to thank and credit the agencies for the thoughtful time and attention given by their staff^S in developing the individual portions of the comprehensive plan. With leadership from the President and in cooperation with the members of the IDTF, we have taken steps never before taken to prospectively assess and map out future action. As presented here, the national plan^{Lts} is intended to be a working document to be updated^J set a baseline of where we are government-wide^S link goals to budget objectives^S and guide^S us in refining our goals and objectives in response to the changing face of the epidemic of HIV and AIDS.

(4) The goal of the comprehensive national plan presented here is to set forth common goals and priorities for charting our course in combatting the epidemic of HIV and AIDS. It also includes an accounting of current federal activities in the areas of prevention, research, services, international activities, and civil rights. This document^{is} meant to compliment other planning documents such as the legislatively mandated NIH plan and the U.S. International Strategy on HIV/AIDS.

(7) There are those who would say that AIDS receives enough funding, that other diseases are more worthy of federal funding. They are

wrong. This epidemic of HIV and AIDS already threatens the economic progress of many countries around the world. In the United States HIV is now the leading cause of death among Americans aged 25-44. This is not a time to stop but to move forward and build upon our efforts -- the future of our children depend on it.

(9) This is a time of great challenges and great opportunity. And while AIDS is a terrifying tragedy that has already affected too many people around the world, I believe it is a disease that we can defeat -- just as we have defeated polio, many forms of cancer, and other scourges in the history of nation. We will be able to win our battle with HIV and AIDS with commitment, courage, and ~~with~~ leadership.

Executive Summary

- Letter from PF/Acknowledgments
- AIDS Demographics, shifting demographics
- Plan is the first of its kind
- Three goals and the six priority areas
- The plan has been organized by the following substantive areas
- Brief summary of federally sponsored activities in various areas

PREVENTION

RESEARCH

SERVICES

INTERNATIONAL ACTIVITIES

INFORMATION DISSEMINATION

CIVIL RIGHTS

Scope of the HIV/AIDS Pandemic --

The pandemic of human Immunodeficiency virus (HIV) and acquired immunodeficiency syndrome (AIDS) presents unique social economic, and public health challenges to people and governments here in the United States and worldwide. Unlike other infectious diseases ^{that} ~~which~~ have arisen over the course of history, HIV is infectious for life and almost always fatal. This national and international pandemic of HIV disease, now well into its second decade, is progressing virtually unabated. It also remains a deadly infection for which there are limited treatments, no vaccine, and the only cure is prevention.

An Expanding Public Health Threat

update ^{~~Dist~~} As of June 1995, the Centers for Disease Control and Prevention (CDC) reports that ^{50*} 476,899 cases of AIDS have been reported in the U.S. and an estimated 295,473 Americans have died as a result of complications related to HIV. Since 1987, AIDS has gone from being the 15th ranked cause of the death to the 8th, ⁵ ~~it~~ it is now the leading cause of death among Americans aged 25-44. In 1994 alone, nearly 81,000 cases of AIDS were reported to the CDC. The CDC estimates that ~~30,000~~ 40,000 American are becoming infected with HIV each year and that between 800,000 and one million Americans are currently living with HIV. (See attached charts.)

Don't
x 70
directly!
indirectly
IDU.

In addition to the ongoing increase in infections, the demographics of the epidemic have been shifting. The early years of the epidemic were dominated by cases involving gay or bisexual men living in major urban centers, such as New York, San Francisco, and Los Angeles; this group now represents less than half (43%) of all new cases. Among the populations being more heavily ^{affected} impacted now are young men between 20 and 24 (53% of cases in 1994) ^{many of whom are young gay men of color} and women (18%), and heterosexual injecting drug users (24%). In 1994 alone, over 14,000 women were diagnosed with AIDS and women now comprise 21% of reported HIV-infection cases. As of June 1995, pediatric cases have been on the rise, (although this trend will hopefully be reversed with the ^{recommendation for AZT treatment during pregnancy} implementation of the of the ACTG-076 recommendations.) In 1994 alone, over 1,000 new pediatric AIDS cases were reported -- an 8% increase in just one year. [It estimated that if this trend ^{not related} continues, 80,000 American children will have been orphaned by AIDS by the end of this decade.]

and disproportionately.

Communities of color are now being more severely affected. As of June 1995, African-Americans accounted for 34% of reported AIDS cases. Hispanics represented 17% of new cases through June 1995.

Of great significance is that the CDC estimates that more than 50% of all new cases are now related directly or indirectly to substance abuse, particularly the use of injectable drugs.

add # of gay men of color

more up - not related to ethnicity

Common modes of transmission are also changing. The prevalence

of HIV infection in IDUs and their sexual partners and children in the United States is on the rise. In the U.S., approximately one-half of new cases are related to drug use. Infection acquired through heterosexual contact is also on the rise.

Moreover, AIDS is no longer just an urban problem. AIDS cases have been reported in all 50 states, the District of Columbia, Puerto Rico, and the American territories. The HIV/AIDS pandemic is spreading to rural areas and the south. And while most cases are still reported from urban areas, the rate of reported cases in non-metropolitan areas is increasing faster than urban areas. In 1994, 35% of new AIDS cases were reported in southern states.

Internationally, the toll of the epidemic is even greater. The World Health Organization (WHO) estimates that since 1981, 2.4 million cases of AIDS have occurred worldwide. The WHO has estimated that as of mid 1995, 18.5 million adults and more than 1.5 million children have been infected with HIV since the beginning of the pandemic. The WHO projects that by the year 2000 at least 25 million people will become infected with HIV, or an average of 10,000 people a day.

The Social Impact

Unfortunately, prejudice and discrimination are still encountered by people living with HIV and their families and loved ones.

Persons with HIV have been denied medical services, emergency medical treatment, dental services, and medical insurance. They have been discharged from their jobs and denied housing. And unlike other infectious diseases, HIV and discrimination often go hand-in-hand.

Unlike other leading causes of death, AIDS is a disease that strikes people in the prime of life, ^{it} it disproportionately kills the younger ^{people} people during their most productive years. It is the leading cause of death among Americans 25-44, ~~in 1992~~ ^{that} ~~people in this~~ age group constituted 54% of the civilian labor force ^{in 1992}. Premature deaths due to AIDS result in the loss of many productive years of life and in many cases deprive young children of their parents. In terms of years of potential life lost (YPLL), in 1994 AIDS ranked fourth among all leading causes of death.¹ In developing countries, the pandemic threatens to reverse decades of progress in strengthening national economies and improving the health status and social well-being of millions of women, men, and children.

Goal of National Plan

The goal of a comprehensive national plan is to set common goals and priorities for charting our course in combatting the epidemic of HIV and AIDS. In order to ensure efficient ^{use} of federal and ⁿ private resources, it is imperative to organize government-wide

~~efforts so as to ensure optimal use of resources in combatting the epidemic~~

This is the first time ~~an~~ government-wide national plan for HIV and AIDS has been developed. This first edition of the plan links programs to national objectives in each federal agency ~~that~~ ~~which~~ supports AIDS activities, documents current federal activities in the HIV/AIDS arena, links goals to budget objectives, and lays forth the common goal and priority areas for HIV/AIDS based on current scientific opportunities, public health needs and priorities, and fiscal constraints. It is intended to be a working document that will be updated annually. By establishing this baseline of where we are government-wide, it will help guide federal agencies in refining goals and objectives in response to the changing face of the epidemic of HIV and AIDS.

The comprehensive national plan presented here is broader in scope than prior planning efforts. To date, planning has been primarily focused in the ~~public health service~~ as evidenced by a series of documents such as the Public Health Service Plan for the Prevention and Control of Acquired Immune Deficiency Syndrome², the Coolfont³ and Charlottesville⁴ reports, and the PHS Strategic Plan to Combat HIV and AIDS in the United States⁵. There have also been recommendations from a number of groups, including the National Commission on AIDS.⁶ There have also been significant planning efforts on the part of individual agencies,

such as the legislatively-mandated NIH plan for the their HIV-related research program. However, there has not been a national plan ^{that} ~~which~~ provides for a government-wide coordinated effort ^{not just} encompassing public health service activities ^{but also incorporate} ~~in addition to~~ ^{issues} ~~problems~~ such as housing, health care, and civil rights.

This federal strategy for HIV and AIDS has been developed from the bottom up. Through the Interdepartmental Task Force on HIV and AIDS (IDTF), a request went out for the agencies to identify their activities in relation to national goals and objectives. In addition, IDTF members have been crucial in identifying new areas of opportunity and those requiring special attention. In developing these priority areas we have also listened carefully to the of members of the Presidential Advisory Council on HIV/AIDS, to people on the front lines of the epidemic, and to the many HIV-infected persons and their loved ones ^{who} ~~that~~ have written to the President. We have listened to the activist community ^{which} ~~who~~ has spent too many years fighting the epidemic. We have also reviewed the insights provided by a number of groups including the former National Commission on AIDS, the Institute of Medicine and National Research Council, the ^{general} ~~Government~~ Accounting Office, and the Office of Technology Assessment. Therefore, the expertise and experience of those who work closely with communities, clinicians, researchers, service and research organizations, and infected persons is reflected in this ongoing planning process. ~~§~~ The three common goals that have been

WHCA attendees

identified are:

- Provide solid support for effective prevention strategies, so as to reduce the number of new infections each and every year *until there are no new infections*
- Provide strong support for research in order to find a cure for those currently infected and a preventive vaccine for the uninfected.
- Ensure appropriate care for and ethical treatment of persons with AIDS.

Drawing from these goals, the Office of National AIDS Policy has identified 6 priority areas that warrant concerted federal effort (i) ~~those being~~

- Strengthening Prevention Activities
- Supporting Diversified Research Approaches
- Strengthening Approaches to Substance Abuse
- Strengthening the Health Care Safety Net
- Improving Translation of Research to Practice
- • Improving Accountability and Priority Setting
Evaluation

NB:

we all need to discuss the order

Challenge of the HIV Epidemic

The epidemic of HIV and AIDS has posed a series of unique challenges since the discovery of the first AIDS cases in the early 1980s. The challenges we face today are very different than challenges we have faced so far. It is a growing epidemic in which more persons are infected every year, in every geographic area, ethnic/race group, and age range. We now know the risk factors, the etiologic agent, and we have a test to diagnose infected persons and protect the blood supply. Thanks to clinical research, significant progress has been made in some areas -- people with HIV infection now live twice as long as they did a decade ago. And with the results of the NIH-sponsored research we now have the ability to prevent perinatally acquired HIV infection in some newborns.

We are also facing new challenges. The challenge of getting people into care so they can receive the new treatments and educating health care professionals so they know the best way to administer them. Strengthening our prevention efforts has never been more important. Developing prevention messages that are specially targeted to the group they are intended to reach is critically important^e if we are to slow the tide of new infections. And from societal perspective, we still have a long way to go in overcoming fear and discrimination.

Description of Activities

Overview of Federal Efforts

The scope and nature of the HIV/AIDS epidemic has affected many federal responsibilities and activities. These activities range from the direct funding of research grants, health care infrastructure support, setting policies to encourage private sector activity, coordinating with international AIDS organizations, information dissemination, and prosecuting civil rights violations. While federal agencies are responsible for responding directly to the epidemic of HIV and AIDS, they also collaborate with and provide support for community-based organizations in addition to state and local governments, which often have substantial surveillance, prevention, and health care responsibilities.

main
clear

The comprehensive plan for HIV and AIDS has therefore been organized around these substantive areas: prevention, research, services, information dissemination, international activities, and civil rights. In this plan, current agency activities have not been organized around administrative structures, but by substantive areas. In cases where a single agency may have responsibility for more than one component of a substantive areas, such as prevention and research, documentation of their activities will be found ⁱⁿ the respective substantive sections. In many cases there are cross cutting issues ^{that} ~~which~~ could fall in

several categories, such as internationally-based treatment and prevention efforts. . . . *and what was done in those cases?*

Agency support of HIV/AIDS activities falls into three general categories, where HIV/AIDS activities are: (1) a central part of their mission; (2) a significant but not leading part of the mission, or (3) not an explicit part of their mission but AIDS-related activities receive collateral benefit from agency supported work and/or policies. There are a number of agencies for whom AIDS-specific activities are central to their mission (*e.g.*) (i.e.) NIH, CDC, and HRSA while other agencies maintain programs and activities that support a broad range of activities, of which HIV-related activities ~~which~~ are one among many (*e.g.* ~~the~~ USIA, DOJ). Agencies ~~which~~ ^{that} support research and provide shared access to highly sophisticated and expensive technology, such as the DOE's ~~and their~~ support of sophisticated imaging equipment, can assist a wide range of researchers including those studying HIV. Data are therefore presented in a manner consistent with the level of involvement an agency may have.

on
The following sections of prevention, research, services, international activities and civil rights describe current federal activity ^{to} and identify goals, funding levels, populations served, constituency involvement and unmet need ^s of the program.

PREVENTION

as articulated by Pres Clinton,

The nation's prevention goal is to reduce the number of new infections each and every year until there are no new infections. Achieving this goal will require a true and dedicated alliance between the federal government, states, communities, and individuals. Achieving ~~such an~~ ^{this} ambitious ~~prevention goal~~ ^{end} will require a clear definition of what the federal government is able to do and an ongoing dialog ^{we} between the public and private ^{pers} sections. *about the responsibilities each has in reaching this goal.*

To achieve this goal the nation will need to continue to invest in a range of endeavors including data collection, research, and prevention programs. It will also require careful examination of what needs to be continued, what activities need to be initiated and a awareness that a reconfiguration of some program priorities may be required.

Delet 7

We know that prevention works. We also know that the prevention task faced by the United States in controlling the epidemic of HIV and AIDS has reached enormous proportions.¹ The Centers for

¹ This section will address primary prevention activities. Other aspects of prevention, such as secondary prevention (i.e. preventing complications of HIV infection), use of topical microbicides, the behavioral components of vaccine research, and international prevention activities will be discussed in the following research, services, and international activities sections.

Disease Control and Prevention (CDC) estimates that approximately 800,000 Americans are presently HIV-infected, many of whom are unaware of their infection status. Moreover, the CDC estimates that there are approximately 40,000 to 80,000 new infections each year. Many more Americans who are not presently infected are at risk for acquiring the virus. HIV infection is a unique prevention challenge because of the virus's virulence, long incubation period, long duration of infectiousness, nearly always fatal prognosis, and potential for exponential spread. Moreover, it is transmitted primarily as a result of personal and private individual behaviors -- sex and drug use. To be effective, HIV prevention programs must reach tens of millions of Americans who embody a vast diversity of age, race, ethnicity, geographic locale, sexual orientation, and drug use behaviors.

*See earlier for
* for
consideration*

Prevention activities are currently supported by a number of federal agencies. Most of the federal prevention efforts are sponsored by the Public Health Service, although other departments such as the Department of Defense (DOD), and the Department of Veterans Affairs (VA) also support prevention activities. Their efforts reflect a continuum -- from surveillance to research to social marketing initiatives. Agency activities are also reflective of their respective missions. For example, the Centers for Disease Control and Prevention (CDC), the agency with primary federal HIV-prevention responsibilities, supports a wide range of surveillance and prevention projects,

many in partnership with states, local governments, and community-based organizations. Other agencies focus on specific aspects of prevention. For example, the National Institute of Drug Abuse (NIDA) and the Substance Abuse and Mental Health Services Administration (SAMSHA) support a breadth of efforts to stem the tide of drug use. ~~and HIV infection~~ While other agencies support primary prevention efforts as part of medical care, such as at the Veterans Hospitals and the DOD. HSA

The efforts of federal agencies have been instrumental in expanding our knowledge base however, significant gaps remain. We know from both formal research and community experience that developing prevention programs that work requires knowledge of who is becoming infected and of the behaviors that are enabling transmission, an understanding of the motivations for those behaviors, and an understanding of how best to reach people with messages that will prompt behavior change.

The Nation's prevention priorities must be guided towards gaining knowledge that will improve our efforts to develop effective prevention programs. We need to better our understanding about the major modes of transmission, close gaps in scientific knowledge, and working towards eliminating gaps in program areas.

The following three sections identify areas for investment

necessary for the development of sound prevention interventions.

MODES OF TRANSMISSION

An important part of strengthening prevention activities is to have a clearer understanding of who is being infected and which behaviors are placing people at risk for infection. Recent epidemiologic data show that the epidemic of HIV in the United States is being driven by people who engage in injection drug use (50%) and their sexual partners (??), men having sex with men (25%), heterosexual transmission (> 20%), and vertical transmission (90% of the cases in the United States occur in women under 22 years of age). Moreover, the youth of our country are becoming infected at an alarming rate -- 50 percent of new infections in the United States are in persons under 25 years of age. HIV is the leading cause of death in Americans aged 25-44. It is likely that many of these people were infected while they were adolescents. (Add data from new NCI study) Minority Americans are also disproportionately represented among new HIV infections. As of June 1995, African-Americans accounted for 34% of reported AIDS cases and Hispanics represented 17% of new cases. These trends in the epidemic must be taken into consideration when prioritizing prevention research and service programs.

A crucial part of effective prevention strategies includes

supporting adequate surveillance of HIV infection and related diseases in order to estimate the burden of HIV illness, gauge future directions of the epidemic, and assess the effectiveness of prevention interventions. As previously noted, the CDC has the primary federal responsibility for monitoring the epidemic. The CDC AIDS case and case death reporting system provide useful data for assessing AIDS prevalence and mortality by gender, race/ethnicity, age, and mode of exposure. This surveillance system also provides worthwhile information on HIV-related opportunistic infections.

different wording?

There are however opportunities for improvement. Effective prevention intervention programs begin with sound information on who is at risk. Current CDC surveillance systems do not currently capture sufficient "front-end" information such as the prevalence of HIV (not AIDS) in the population, and trends in risk factors and new infections. We need to collect ~~this~~ ^{these} type of data in tandem with an enhanced effort to link surveillance and epidemiological data to priority setting, the design, and evaluation of prevention programs. These needs require that the CDC re-evaluate and reconfigure its data collection efforts; such a shift may require reconfiguring of currently collected data to address these needs.

GAPS IN SCIENTIFIC KNOWLEDGE

*Point to CDC.
efforts to implement
external reviews —
we want to show CDC they've already bought into
this — we're just giving them a prod.*

*Credit CDC w/
recognizing this
need as part of
community planning
process.*

Factors that place individuals at risk for acquiring HIV infection are a complex combination of behavioral, social, cognitive, and biologic influences. Given this complexity and the importance of preventing new infections, we must not assume we know what interventions will work, but base our efforts on sound research findings. Experience has taught us that prevention can work, but when it does it is because the intervention incorporated findings from experience and relevant research. Unfortunately, behavioral research is a relatively young science and there are currently more questions than answers. There are three areas where gaps in knowledge have been identified -- basic behavioral research, intervention research, and social marketing research.

Basic Research. Since behavior change is the primary prevention intervention immediately available for halting the spread of HIV infection, basic behavioral research should be the foundation upon which prevention programs are based. Basic behavioral research, similar to basic research in other areas of scientific inquiry, seeks to explain the determinants and causes underlying biological, behavioral, and social processes. HIV-related risk-taking behavior is often complex and influenced by a host of individual and environmental factors. Before we can begin approaching the formidable task of implementing successful HIV prevention programs that reach a diversity of Americans, more information on the determinants of HIV-associated sexual and

drug-using behaviors is needed. For example, although much has been learned about the basic biology of substance abuse, further elucidation of the mechanisms underlying addictive behavior may assist in the development of new therapeutic approaches to addiction, which in turn may reduce the number of new infections.⁷ And although we have some information on relevant risk-taking behaviors, more information about knowledge, attitudes, decision-making processes, and beliefs about AIDS and other STDs ^{is} ~~are~~ much needed. Data such as this enables ~~/~~ scientists to establish theories of behavioral change, which then provide researchers with tools for identifying what approaches may be most effective for an individual or a community.⁸

Intervention Research. A second major area that must be a funding priority is research to improve prevention interventions, i.e. research ^{that} ~~which~~ concentrates on identifying and modifying behaviors, such as those related to drug use and sex. This type of research can focus on both individuals and communities, which often hold norms which 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 HIV infection rates. This theoretically based intervention research has identified some significant predictors of changes in sexual and drug-using behaviors among gay men, adolescents, and heterosexual adults.⁹ Studies have shown that community-based HIV risk reduction

programs that are gender relevant and culturally sensitive can be effective.¹⁰ A recent study has also provided a reason for optimism that the spread of HIV can be contained among injecting drug user populations when there is early community outreach and access to sterile injection equipment.¹¹

However, despite these successes, there is more that we need to know if we are to develop effective programs for a diversity of Americans. We must couple findings from basic behavioral research with effective prevention interventions. Areas of high priority include research regarding strategies that facilitate sustained adoption and maintenance of HIV preventive behaviors, research on cultural barriers and strategies to reach populations resistant to behavior interventions, and research on the effectiveness of drug abuse, mental health, and alcoholism treatment for reducing HIV risk behavior. Agencies supporting 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.

Social Marketing Research. And lastly, it is critical that the findings from basic and intervention research are incorporated into prevention programs. We know from efforts in other countries that HIV related social marketing efforts can be successful. However, in the United States available information

about effective strategies is not being used consistently in the design and implementation of prevention interventions.

Currently, there are good models for prevention interventions ~~that~~ ^{which} are not making their way to those on the front-lines of the epidemic. Community-based organizations, which are responsible for developing a large portion of the prevention programs often do not, or are not able to take advantage of current knowledge about program effectiveness.

Agencies supporting social marketing activities need to strengthen efforts to understand barriers to the implementation and replication of promising prevention programs. Given the highly innovative nature of these endeavors, it is also crucial to strongly support the provision of technical assistance and training, and a community-based effort that would test these models in a real-world setting.

CURRENT GAPS IN PROGRAM AREAS

For prevention interventions to stop new infections they must reach the people at risk. For individuals to take control of their own lives in fighting the spread of this virus, they must first have the information and tools to protect themselves. Given that there are limited resources to expand the scope of prevention programs, it is important that they reach the

Will we see these priorities in the detailed history? Can we answer the Q - what are you doing to make these happen?

role of HIV in prevention?

uninfected and the groups that are now increasingly affected by the epidemic -- women and injecting drug users -- while maintaining efforts among youth and gay men.

One of the most important innovations in the prevention area is community planning. The community planning process is an outstanding model of a federal-local partnership. Through this effort, it ~~will~~ ^{is} possible to establish joint goals for the prevention of HIV that will meet federal standards while

remaining responsive to local needs. However, this process is early in its development and ~~will~~ ^{is significant, ongoing leadership} require technical assistance from the CDC if it is to fulfill its potential for good priority setting and decision making.

Injection drug use is one of the major forces driving the epidemic -- half of all new cases are related to this mode of transmission. Limiting the impact of this mode of transmission will require efforts on several fronts. First, we need to improve the integration of HIV prevention and substance abuse programs. The epidemics of substance abuse and HIV in this country are overlapping and highly inter-related so we must work to integrate HIV prevention into current substance abuse programs and integrate substance abuse issues into HIV prevention.

see p 107

Another major avenue for controlling the spread of HIV among addicted persons is to get them into treatment programs. At

Substance abuse
Treatment is a form of
HIV prevention

Continuing Need for Increased Treatment Services

present, there are too few treatment slots for persons seeking to control their addictions. (confirm from samsha) With the advent of changes to Medicare and Medicaid this problem will only worsen. Moreover, substance abuse problems that contribute to the spread of HIV are broader than injecting drug use. There is substantial evidence that use of alcohol and other substances can adversely influence risk-taking behavior. It is estimated that x% (check #) of the population is affected by alcohol and other drugs (AOD) in addition to injection drug use. It must be part of the federal response to increase the availability of treatments slots for a range of addictions.

The integration of HIV prevention into these treatment programs is important as well.
In addition to our efforts directed towards getting people into treatment for their addiction, we must also support harm reduction approaches for when treatment fails. Traditionally, harm reduction programs have not been well accepted in our country, yet experts feel that it is in ~~the~~ ^{this} area that we may be able to make our greatest impact in stemming the tide of the epidemic. There is scientific evidence that historically controversial harm reduction approaches, such as needle exchange programs, can be effective. Among the conclusions presented in recent study by the Institute of Medicine was that there is no credible evidence that drug use is increased among participants as a result of needle exchange programs that provide legal access to sterile equipment. The IOM went on to recommend that needle exchange programs should be regarded as an effective component of

*Defile
Harm Reduction
Supporting people
in their recovery
and preventing
HIV & STD
transmission
Needle exchange
programs
are a key
component
of harm
reduction
approaches
that
can
help
people
get
and
stay
in
treatment
for
their
addiction
and
prevent
HIV
&
STD
transmission
Needle
exchange
programs
are
a
key
component
of
harm
reduction
approaches
that
can
help
people
get
and
stay
in
treatment
for
their
addiction
and
prevent
HIV
&
STD
transmission*

a comprehensive strategy to prevent infectious disease.¹² There is also evidence, that needle exchange programs provide an opportunity to get people into treatment, thereby further reducing their risk and the risk for their sexual partners.

Given the continuing and growing public health threat posed by the HIV epidemic, this approach deserves reconsideration by local communities as a possible intervention in the face of this public health emergency.

Adopting these approaches, *because they are so controversial, should be a local decision. The federal government should provide the scientific data upon which such decisions should be made.*

To reach our prevention goals, we must improve the integration of prevention activities and messages into ^{also} primary health care services. This includes incorporating a patient's sexual history when a medical history is taken, offering HIV-related counseling and testing, and working with HIV+ patients so they do not infect others. It also means offering pregnant women information about and access to the ~~076~~ prevention regimen. Achieving this level of integration will require ~~the~~ active collaborative efforts on the part of individual physicians, nurses, clinicians, managed care plans, medical schools, ^{and} professional organizations in addition to local and federal governments.

^{is} An area of major concern ~~are~~ the planned changes to Medicare and Medicaid and the implications for persons living with HIV. For Americans living with AIDS, Medicaid is the single largest source of health care financing, providing coverage for more than 50 percent of such adults and more than 90 percent of children

living with AIDS. Maintaining this vital safety net is important for all Americans, but especially for those with HIV infection. There are opportunities right now for preventing new infections, but for this to happen, people must have access to medical care and services.

And finally, it is important to assess the effectiveness of the prevention interventions that have been implemented.

Prospectively set performance measures can be used as a basis for evaluation and program improvement. Incorporating effectiveness measures 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.

RESEARCH

One of the nation's common goals is a cure for those currently infected and a preventive vaccine for the uninfected. It is research that will enable us to reach these goals and until they are a reality, the nation must provide solid ongoing support for basic and clinical research. As with prevention, achieving this goal will require committed collaborative efforts between the federal government, researchers, communities, and the private sector. Realizing this ambitious goal will also require a clear definition of what the federal government is able to do and an ongoing dialogue between the public and private sectors.

At present, a number of federal agencies play a significant role in the nation's research efforts. These endeavors range from basic molecular research to clinical research to health services research. For example, the National Institutes of Health (NIH) supports a significant portion of these endeavors. The NIH funds research on natural history and epidemiology, etiology and pathogenesis, therapeutics, vaccines, and behavioral research. As part of their mission to protect and maintain a viable fighting force, the Department of Defense supports clinical vaccine and therapeutic research. The Agency for Health Care Policy and Research (AHCPR) funds research to help the nation determine which medical approaches are the most clinically and cost effective. The Department of Energy (DOE) through its

support of technologically advanced equipment, provides the opportunity for federal and private researchers to share resources and thereby analyze molecular structures that, without such equipment, would not be possible. And the Centers for Disease Control and Prevention (CDC) supports laboratories which have developed sophisticated methods for identifying virus strains, so critical to ensuring the safety of the blood supply. (???)

The nation has already reaped the benefits of supporting research funding in general, and HIV-related research specifically. Due in great part to federally-sponsored research, persons with HIV now live twice as long as they did a decade ago. AIDS-related conditions that used to mean a quick and often painful death for people living with HIV can be treated and even prevented. An NIH study found that it is possible to dramatically reduce the chance of transmission of HIV from mother to baby. Thanks to our investment in prospective epidemiological studies we are beginning to understand the factors that enable long-term non-progressors to live many years after infection virtually disease free. Understanding what happens in these non-progressors may help us develop better therapies and a vaccine.

And there is reason for hope -- scientists now believe that a vaccine is possible. New classes of anti-retroviral therapies appear to be powerful in controlling the virus. Combination

therapies are also showing great promise in this area. In addition, the Food and Drug Administration, through its accelerated approval program, is now approving drugs faster than any European nation.

*even before
and faster*

However, despite these advances there is more that needs to be done to reach the nation's goal of a vaccine and a cure. The epidemic of HIV and AIDS presents an unprecedented challenge. HIV is unique in that it attacks the very immune system which is supposed to protect us from infection and tumors -- mankind has never before encountered a virus such as this. Since the beginning of the epidemic identifying the best approaches to pursue and support has been and continues to be a challenging task. Identifying the most promising scientific avenues and having the appropriate structures and processes in place to ensure that the nation capitalizes on these opportunities will require a considered and coordinated effort.

Developing and implementing the nation's AIDS research agenda presents a number of challenges. Within the NIH, the agency with the largest HIV-related research portfolio, research is supported throughout 24 institutes, centers, and divisions (ICDs). In order to better plan, coordinate, and fund the AIDS research activities of these ICDs the Congress, through ^{the} NIH Revitalization Act Amendments of 1993, provided ^{the} Office of AIDS Research (OAR) with new oversight and budget authorities. As

HIV and AIDS research across all departments within 90 days.

The nation must also acknowledge that reaching our goals will require the joint commitment of government and the private sector. This ^{is} especially true in the arena of vaccine development. Several challenges currently face the nation and the world in continuing the vaccine development effort. One major ^{challenge} centers on the involvement of pharmaceutical and biotechnology companies. In order to identify areas for fruitful collaboration and ^{to} accelerate the pace ^{of that effort,} the Vice President will convene a meeting of government scientists and leaders of the pharmaceutical and biotechnology companies to identify barriers to the development of vaccines. [slight change in promise from POTUS speech] ^{and therapeutics}

Will this have happened?

At present there are fundamental ^{about} differences ~~in~~ the approach to vaccine development that should be taken. Some scientists believe that we need to return to ~~of~~ basic science to gather more information to guide us, while others believe that in the face of a global emergency we must empirically test candidate vaccines in people immediately. Both groups have ~~some~~ valid arguments. The issues that are driving this debate are both scientific and social, moreover different parts of the world are experiencing the epidemic in different ways. Unfortunately, the history of vaccine development does not provide simple answers. It is vitally important that serious consideration is given to all the

avenues
Can both be legitimately pursued?
Can we state that? (Yes)

part of fulfilling the requirements of the law, the OAR develops a yearly NIH plan and budget for AIDS research and receives directly from the President and the Office of Management and Budget (OMB) a single appropriation for AIDS activities at NIH. This single appropriation allows the OAR to effectively prioritize research resources on the basis of sound scientific judgement and provides flexibility for pursuing the most promising research opportunities. It is crucial that the authority granted OAR in the revitalization legislation, including the single appropriation, be supported and maintained. With such a large research enterprise it is essential that there is oversight and accountability so the most promising approaches are vigorously pursued and the [usually autonomous] Institutes have both the scientific and administrative assistance they need to effectively collaborate with other NIH institutes.

It is also clear that while NIH supports a significant portion of HIV-related research, other agencies and departments also play a significant role in our search for a cure and a vaccine for HIV. It is time to improve our efforts if the nation is to effectively support a diversity of promising approaches government-wide. These research efforts must also be well-planned, coordinated, and establish accountability. To achieve this the Director of the Office of National AIDS Policy will coordinate an inter-departmental working group, chaired by the Director of the Office of AIDS Research, ^{whose charge it is to} will develop a coordinated plan and budget for

data that are available and that that information is shared and used by scientists as we move forward in vaccine development process.

It is also important to strike a balance between basic and clinical research.

We are producing new drugs in record numbers and at record speed, but do not know how they work.

With the advent of accelerated approval by the FDA it will be incumbent on

the government to ensure that the efficacy studies, currently mandated by law are carried out. Conducting these studies will

require the efforts of clinicians who have demonstrated their ability to carry out the long-term follow-up of patients that

such clinical effectiveness studies require. It is also

essential that these studies, like all studies, include persons representing a diversity of race, ethnicity, gender, and drug

using behaviors. If these studies are not done, patients may be taking less effective treatments or combinations of treatments, and federal programs such as Medicare and Medicaid and private insurers may be paying for these less effective treatments.

One of the most difficult tasks for clinicians comes in interpreting the patchwork of data and articles regarding

treatments and converting that into a therapeutic strategy for the patient that sits in front of them. With every research

breakthrough, this task becomes more difficult. It is essential that practical information for practicing clinicians and their

Need more on basic (vs. vaccine)

different concept: efficacy

based on limited data

explain

As a result,

we won't know which of the available treatments is

more effective and for whom, under what circumstances

patients is provided in a timely manner. The nation must develop a mechanism for ensuring periodic assessment of the state of the art and disseminating that information widely. This will require collaboration with industry, government, and professional groups.

A key role for the federal government is to act in partnership with the private sector and support areas where there is a market failure -- i.e. areas where industry is unlikely, for financial reasons, to pursue research that would be beneficial to the nation's public health. The area of vaccine development is one, but there are others. For example, topical microbicides (i.e. [^]~~female-controlled~~_Q chemical barrier methods for preventing HIV transmission) are a promising approach, but will require preliminary support before they will be at a stage where the private sector can assume a lead role. It 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. This has been done at the Department of Energy -- by supporting sophisticated imaging equipment that would be prohibitively^{ive} costly for individual researchers or companies to purchase, ~~providing~~ a shared resource has accelerated our understanding in a number of research fields, including that of HIV. Such information can form the basis for targeted drug design and development. It is also unlikely that the free market will conduct head-to-head clinical trials of therapies that have been approved or in development. However,

information about these therapies is important to improving patient care and ensuring that the nation's health dollars are wisely spent. Similarly, it is unlikely that the private sector would support research for therapies that are in common use but for which little information is available, such as alternative treatments. Americans are spending millions of dollars per year on such therapies for which little is known. The government must ensure that treatments brought to market are safe and effective. Similarly, ensuring safety of the blood supply is a responsibility unlikely to be assumed by the private sector. These are areas where the government must step in to serve and protect the nation.

And finally, research is an investment in our future. ~~It cannot grow and mature with the vicissitudes of the federal budget~~ process, it must receive consistent funding if we hope to bring the best and the brightest to solve the research challenges that will find a cure and a vaccine. Research has been ~~to~~ key to improving lives and the nation must continue this investment.

payline issues??? -nw

Also:

- a) format: subheads may help
- b) content: add a § re contribution of AIDS research to other diseases.

This needs reworking given budget negotiations

CARE & SERVICES

Plan to
An important part of the national goal is ensure appropriate care for all persons living with HIV and AIDS. Achieving this ambitious goal will require a true and dedicated alliance ~~between~~ *among* the federal government, states, the private sector, communities, community-based organizations, clinics, families, and individuals.

At present, care and services are provided through a number of federal agencies, many in cooperation with local organizations and the AIDS community who have admirably served those living with HIV. A major source of care is provided through Ryan White Care Act (RWCA) which is overseen by the Health Resources and Services Administration (HRSA). The RWCA provides funds for care, *plus,* drug reimbursement, and case management that are given to states and cities *mostly on a* ~~under a~~ formula basis so ~~as~~ the areas most affected by the epidemic receive a proportional share of available dollars. Housing assistance is provided by the Department of Housing and Urban Development (HUD) through their Housing Opportunities for Persons with AIDS (HOPWA) program. Medical care is provided through several avenues. *and others* Medical care for many HIV infected incarcerated persons is provided under the direction of the Department of Justice's (DOJ) Bureau of Prisons (BOP). *elsewhere* ~~But~~ by far the largest sources of care for persons living with HIV are Medicaid and Medicare. Taken together, these

*{ 5070
4270 }*

- 41
- ① Medicaid
 - ② RW; other HRSA funded
 - ③ HOPWA
- prop - CHCs
MCH*

programs form an invaluable safety net for some of the most vulnerable people in our nation.

The challenge before us today, especially in light of the restricted fiscal environment, is to ensure that persons living with HIV receive the care they need so they may have the opportunity to live productive lives. To achieve this, AIDS care and service programs must build upon past successes, continue to improve their prioritizing, improve accountability, and increase the cost-effectiveness of services they provide.

We must continue to fund the program that is the cornerstone of care -- Medicaid. Medicaid is the lifeline of support to millions of Americans. It provides health care for nearly half of the Americans living with AIDS, including 90 percent of the children with AIDS. It provides access to doctors, hospitals, and treatments -- the services that allow people to live longer more productive lives. [Present Congressional plans (may need to change ...) cut the Medicaid program overall by \$169 billion and turn it into a block grant which in effect reverses this nation's 30 year national commitment to the poor and those in need.] Cutting Medicaid [to this level] would cut the lifeline for millions of Americans, including those living with HIV and AIDS. Maintaining this program in a viable format must be a national priority.

modify based
on outcome of
budget talks 42

With the potential cuts in Medicaid and welfare, the importance of the public health safety net increases for all vulnerable populations -- disproportionately so for people with AIDS. This will require ~~several~~ ^{full} responses. First, no one federal program will be able to absorb the unmet need that may be created by proposed changes to the Medicaid, Medicare and welfare programs. All federal programs, along with state and local organizations, must ~~bear the share of~~ the responsibility for serving and caring for people with AIDS. This must include the integration of HIV-related care into ^{programs that serve the needs, such as} community health centers. ~~Second, in light of~~ ^{& MCH} ~~these proposed reductions and possible advent of block grants for entitlement programs,~~ it is important for programs such as those funded under the RWCA maintain sufficient funding so as to maintain the safety net. In addition, AIDS programs must do a better job of prioritizing what services they can provide -- and federal agencies must assist grantees in this regard. Treatment and primary care must come before ancillary services. It is not ^{discuss} a prudent use of resources to provide services such as case management when a primary care services system does not have the resources to care for patients. And finally, the shift to managed care will have implications for programs such as the Ryan White Care Act programs. HRSA will need to provide more technical assistance to prepare grantees to work with and not against managed care.

Housing is also an important element in the fight against AIDS.

It is the foundation upon which any program of care or services must build -- without stable housing, a person with HIV/AIDS has diminished access to programs and services and a diminished opportunity to live a productive life. It is estimated that 50 percent of persons living with HIV and AIDS will become homeless or are at risk for becoming homeless during the course of their illness. Discrimination against HIV-infected persons is illegal (see section on Civil Rights), however it still occurs. It is estimated that the cost of providing housing services in a HOPWA-funded residential facility is less than one-tenth, and some estimate as low as one-twentieth of the amount for the average day in the hospital. HOPWA dollars reduce the use emergency health care services. The HOPWA program must be protected, but it must also be acknowledged that HOPWA cannot do it alone. Protecting this component of the safety net and providing housing for persons living with HIV must be a shared responsibility between federal, state, local governments and community organizations.

*integrate
into other programs*

There are also people, such as prisoners, who fall outside these traditional safety net programs. Ensuring access to quality care for this group is especially challenging. Prisoners do not have the choice of seeking care and are dependent upon the Bureau of Prisons to ensure that appropriate care is provided. They also may experience difficult issues regarding confidentiality, trust, and access to research opportunities that do not face the non-

*and most
state*

incarcerated population. Improving access to appropriate HIV-related care must be a priority. This effort can be accomplished by the effective collaboration and consultation between agencies and that have experience with providing care and agencies which have responsibility for providing care for prisoners.

Strong federal support for these safety net programs must go hand-in-hand with improved accountability and priority setting. We must ensure that these programs consistently provide quality care. In this country, through the efforts of researchers and clinicians, we have shown that we can do HIV treatment well, but we do not do so consistently throughout the health care system. Ensuring this consistency will require increased training for all health care professionals in addition to more accountability through the use of performance measures for quality care. Achieving this goal will require the cooperation of federal agencies, professional organizations, medical schools, and individual clinicians.

And finally, for care and services to have the most beneficial impact they should be coordinated and comprehensive. However, for organizations on the front lines of the epidemic, putting together a comprehensive integrated program requires applying to numerous federal agencies. For example, putting together a program that integrates primary care with substance abuse treatment and prevention, and sexually transmitted disease

screening and prevention would require applications to SAMSHA, HRSA, and CDC. Adding housing assistance and a research component would require additional applications to HUD and the NIH. The federal government needs to simplify its funding structures so that primary care, prevention, and treatment can be integrated in order to provide HIV-infected persons and persons at risk for HIV, such as substance abusers and their partners, cost-effective integrated services. Through the Interdepartmental Task Force for HIV and AIDS (IDTF), key agencies must identify approaches for facilitating the development of integrated care and prevention programs at the implementation level.

And finally, if we are to provide high quality cost-effective care and services for HIV-infected persons, we must carefully evaluate our activities. Evaluating current activities can provide valuable information for planners and those on the front-lines of the epidemic. It can assist us in providing better care to persons living with HIV. In an era of limited resources coupled with a demand for high quality, cost effective services, we must use all the tools available to us if we are to help those persons living with HIV.

INTERNATIONAL ACTIVITIES

HIV and AIDS are a global pandemic. In the United States it is estimated that 800,000 people are currently infected.

Internationally, the World Health Organization (WHO) 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. Unfortunately, unlike other infectious disease epidemics such as cholera or plague, AIDS is not likely to run its course and subside.

This pandemic presents a unique set of health, social, economic, and political challenges. It most usually affects people aged 25 -44, those in the most productive years of life. The incubation period from initial infection to disease onset can be many years, during which time the infection may unknowingly be spread. The WHO estimates that there will be 10 - 15 million orphans worldwide attributable to HIV/AIDS by the year 2000. A World Bank and U.S. Census Bureau calculated that by 2015, Africa's total gross domestic product could be reduced up 22 percent in comparison to a non-AIDS scenario. In Asia, economic advances are threatened and in some cases reversed due to the epidemic of HIV and AIDS. 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 of healthy men and women to serve in the military.

Due to the enormous proportions of the epidemic, it is clear that if we do not stop the epidemic globally, we will not be able to halt its spread in the United States.

At present a number of federal agencies are working on slowing the epidemic worldwide. The United States Department of State has worked with U.S. Departments and Agencies to identify a framework to guide U.S. international activities, those being to prevent new infections, reduce personal and social impact, and to mobilize and unify national and international efforts. The United States Agency for International Development (USAID) supports a range of activities ^{that} ~~which~~ strengthen local efforts to combat the epidemic. The United ^d States Information Agency (USIA) supports programs ^{that} ~~which~~ promote dissemination of U.S. policies and information related to HIV and AIDS, while the Peace Corps trains a portion of its volunteers to directly address HIV-related concerns in their nations of placement. In addition, a number of Departments support research overseas, including the National Institutes of Health, the Centers for Disease Control and Prevention, and the Department of Defense. For example, 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.

DOD vaccines

Internationally, the United States has established a leadership role in combatting the epidemic -- this leadership must continue. The U.S. strongly supports the new established Joint United Nations Programme on AIDS (UNAIDS). Moreover, the Director of the Office of National AIDS Policy leads the U.S. delegation to UNAIDS. Supporting UNAIDS and its innovative prevention efforts, and its goal of assuring that treatments and vaccines^{are} made available is not only morally fitting, but by supporting these efforts we are also protecting U.S. interests by promoting economic and social stability worldwide.

One of the most challenging aspects of the U.S. effort is effective coordination among a host of agencies with varied missions and activities. The State Department and agencies such as USAID and USIA are primarily focused on international activities, which include HIV-related endeavors. Research agencies, such as NIH and CDC, plan their activities not around where they take place, but around scientific gaps and interests. These differences in focus present challenges in effectively planning, coordinating, and evaluating the overall U.S. international effort. Therefore, in order improve the U.S. international effort, the agencies supporting international activities on the Interdepartmental Task Force for HIV and AIDS must develop a mechanism for identifying and coordinating this effort.

Immigration???

20

INFORMATION DISSEMINATION

[This section's on another disc the section covers coordinating between agencies, i.e 076 implementation]

CIVIL RIGHTS

One of the nation's common goals is to ensure the ethical treatment of persons with AIDS. Discrimination based on HIV status, beyond being morally wrong, 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 seek voluntarily testing for HIV. As a result they remain unaware of their HIV status and cannot take advantage of care which can help them live longer more productive lives. In addition, ^{opportunities to educate are lost...} they may not engage in behaviors that will prevent the spread of infection to others.

The nation has made progress in fighting discrimination. The enactment of the Americans with Disabilities Act provided protection against HIV-related discrimination in employment, housing, and public accommodations. However, the enactment of the ADA in and of itself is insufficient to end discrimination. We as a nation need to be vigilant in our efforts to fight discrimination. This is a responsibility that must be shared among federal agencies, states, communities, and the citizens of this country. As a nation we must first remedy our own discriminatory policies, and, actively prosecute private sector violations.

State and federal laws exist to protect persons with HIV. Many

of the more common legal issues faced by people living with HIV and AIDS, such as family law issues, estate planning, landlord/tenant problems are regulated by state law. The primary source of federal statutory protection for people living with AIDS is the Americans with Disabilities Act of 1990 (ADA).

(Federal agencies are prohibited from discriminating against people with disabilities under the Rehabilitation Act of 1973.)

S/dep
Title I of the ADA prohibits discrimination against qualified disabled individuals in employment settings. The Equal Employment Opportunity Commission (EEOC) is responsible for enforcing Title I. Title II of the ADA prohibits discrimination on the basis of disability with regard to public services while Title III prohibits discrimination on the basis of disability in public accommodations. The Department of Justice (DOJ) is responsible for enforcing Titles II and III.

Acknowledge how much enforcement

strengthen
The federal government will continue to aggressively pursue and prosecute private sector violations of the ADA. Under this provision the government has been successful in prosecuting a range of cases, including clinicians who have refused to care for HIV infected patients and employers who have dismissed persons based on their actual or perceived HIV status. In addition to ongoing efforts, a joint Department of Justice and Health and Human Services program will seek to combat nursing home discrimination against persons living with AIDS.

The federal government must also actively work to remedy any of its own existing discriminatory policies. In order to identify areas of possible concern, the Director of the Office of National AIDS Policy to conduct a systematic review of agency and department testing programs. The Administration will also oppose Congressional attempts to force discharge of infected military personnel who are still able to serve their country.

Immigration?? 

■ Budget Tables

■ Glossary/Acronym List

Acronyms:

ACTG	AIDS Clinical Trial Group
ADA	Americans with Disabilities Act of 1990
ADC	AIDS Dementia Complex
AHCPR	Agency for Health Care Policy and Research
AIDS	Acquired Immune Deficiency Syndrome
AOD	Alcohol and other drugs
ATOD	Alcohol, tobacco, and other drugs
ATSP	?? (from USAID's plan)
BCC	?? (from USAID's plan)
BOP	Bureau of Prisons
CDC	The Centers for Disease Control and Prevention
CMV	
CNS	Central Nervous System
CPCRA	Terry Beirn Community Programs for Clinical Research on AIDS
DOJ	Department of Justice
DOL	Department of Labor

EEOC	Equal Employment Opportunity Commission
FDA	Food and Drug Administration
GCRC	General Clinical Research Centers Program (NIH)
HCFA	Health Care Financing Administration
HIV	Human Immunodeficiency Virus
HOPWA	Housing Opportunities for Persons with AIDS
HRSA	Health Resources and Services Administration
HSV	Herpes Simplex Virus
HUD	Department of Housing and Urban Development
HTLV-1	
ICD	Institute, Center, Divisions (at NIH)
IDTF	Interdepartmental Task Force on HIV and AIDS
IHS	Indian Health Service
IOM	Institute of Medicine
JC	xxxxxxxx virus
MAI	
MTB	<i>Mycobacterium tuberculosis</i>
NCRR	National Center for Research Resources, NIH
NGO	Non-governmental Organization

NIH	National Institutes of Health
NREN	National Research and Education Network (NIH sponsored)
OAR	Office of AIDS Research, NIH
OI	Opportunistic Infection
OMB	Office of Management and Budget
PCP	<i>Pneumocystis carinii</i> pneumonia
PHS	Public Health Service
PLWH	?? (from USAID's plan)
PSA	Public Service Announcement
PVO	Private Voluntary Organization
PWA	Person with AIDS
RFIP	Research Facilities Infrastructure Program (NIH)
RPRC	Regional Primate Research Center (NIH)
RWCA	Ryan White Care Act
SAMHSA	Substance Abuse and Mental Health Services Administration
SPF	Specific Pathogen-Free
SSA	Social Security Administration
SSI	Social Security Insurance
TA	Technical Assistance

UNAIDS

USAID

USIA

WHO World Health Organization

Glossary:

Best Practice: Used by USAID

Incidence:

Population-based: type of epi study -- look at old epi books.

Prevalence:

Primary Prevention:

Secondary Prevention:

Social marketing: application of commercial marketing
 strategies to social issues, is one method
 that can be used to encourage behavior change
 and maintain behaviors.

Translation to Practice:

076:

Appendix:

IDTF Members

Summary of Promises

PREVENTION --

- Trends in the epidemic must be taken into consideration when prioritizing research and service programs.

- We need to collect this type of data in tandem with an enhanced effort to link surveillance and epidemiological data to priority setting, the design, and evaluation of prevention programs. These needs require that the CDC re-evaluate and reconfigure its data collection efforts; such a shift may require reconfiguring of currently collected data to address these needs.

- Agencies supporting behavioral research must improve their data-sharing and collaborative efforts with agencies responsible for implementing prevention programs. *** Agencies supporting 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. ***

- Agencies supporting social marketing activities need to strengthen our efforts to understanding barriers to the implementation and replication of promising prevention programs. Given the highly innovative nature of these endeavors, it is also

critical to strongly support the provision of technical assistance, and training, and a community-based effort that would test these models in a real-world setting.

- TA for community planning. However, this process is early in its development and will require technical assistance from _____ if it is to fulfill its potential for good priority setting and decision making.
- Improve the integration of HIV prevention and substance abuse programs.
- In addition to our efforts directed towards getting people into treatment for their addiction, we must also support harm reduction approaches for when treatment fails.
- Given the continuing and growing public health threat posed by the HIV epidemic, needle exchange programs deserve reconsideration by local communities as a possible intervention in the face of this public health emergency.
- It must be part of the federal response to increase the availability of treatments slots.
- And finally, to reach our prevention goals, we must improve the integration of prevention activities and messages into primary

health care services. Achieving this level of integration will require the active collaborative efforts on the part of individual physicians, nurses, clinicians, managed care plans, medical schools, professional organizations in addition to local and federal governments.

■ Maintaining Medicaid and Medicare

RESEARCH

■ It is research that will enable us to reach these goals and until they are a reality, the nation must provide solid ongoing support for basic and clinical research.

■ It is essential that the authority granted OAR in the revitalization legislation, including the single appropriation, be supported and maintained.

■ To achieve this the Director of the Office of National AIDS Policy will coordinate an inter-departmental working group to be chaired by the Director of the Office of AIDS Research to develop a coordinated plan and budget for HIV and AIDS research across all departments within 90 days.

■ In order to identify areas for fruitful collaboration and accelerate the pace the Vice President will convene a meeting of

government scientists and leaders of the pharmaceutical and biotechnology companies to identify barriers to the development of vaccines, therapeutics, and topical microbicides.

- It is vitally important that serious consideration is given to all the data that are available and that that information is shared and used by scientists as we move forward in vaccine development process.

- With the advent of accelerated approval by the FDA it will be incumbent on the government to ensure that the efficacy studies, currently mandated by law are carried out.

- The nation must develop a mechanism for ensuring periodic assessment of the state of the art and disseminating that information widely. This will require collaboration with industry, government, and professional groups.

- These are areas of market failures where the government must step in to serve and protect the nation, i.e. vaccine development; access to sophisticated equipment and personnel; head-to-head clinical trials; alternative treatments; ensuring safety of the blood supply.

CARE & SERVICES

- Maintaining Medicaid in a viable format must be a national priority.

- All federal programs, along with state and local organizations, must bear the share of the responsibility for serving and caring for people with AIDS. This must include the integration of HIV-related care into community health centers.

- Maintain sufficient funding for RWCA.

- AIDS programs must do a better job of prioritizing what services they can provide -- and federal agencies must assist grantees in this regard. (Treatment and primary care must come before ancillary services. It is not prudent use of resources to have a perfect case management system if there is no primary care system into which to case manage patients.)

- And finally, the shift to managed care will have implications for programs such as the Ryan White Care Act programs. HRSA will need to provide more technical assistance to prepare grantees to work with and not against managed care.

- The HOPWA program must be protected, but must also be acknowledged that HOPWA cannot do it alone. Protecting this component of the safety net and providing housing for persons living with HIV must be a shared responsibility between federal,

state, local governments and community organizations

■ Improving access to appropriate HIV-related care for prisoners must be a priority. This effort can be accomplished by the effective collaboration and consultation between agencies and that have experience with providing care and agencies which have responsibility for providing care for prisoners.

■ Ensuring this consistency in clinical care will require increased training for all health care professionals in addition to more accountability through the use of performance measures for quality care. Achieving this goal will require the cooperation of federal agencies, professional organizations, medical schools, and individual clinicians.

■ Through the Interdepartmental Task Force for HIV and AIDS (IDTF), key agencies must identify approaches for facilitating the development of integrated care and prevention programs at the implementation level.

■ And finally, if we are to provide high quality cost-effective care and services for HIV-infected persons, we must carefully evaluate our activities.

CIVIL RIGHTS

- Ending discrimination -- This a responsibility that must be shared among federal agencies, states, communities, and the citizens of this country. As a nation we must first remedy our own discriminatory policies, and, actively prosecute private sector violations.

- The federal government will continue to aggressively pursue and prosecute private sector violations of the ADA. In addition, a joint Department of Justice and Health and Human Services program will seek to combat nursing home discrimination against persons living with AIDS.

- The federal government must also actively work to remedy any of its own existing discriminatory policies. In order to identify areas of possible concern, the Director of the Office of National AIDS Policy to conduct a systematic review of agency and department testing programs. The Administration will also oppose Congressional attempts to force discharge of infected military personnel who are still able to serve their country.

INTERNATIONAL

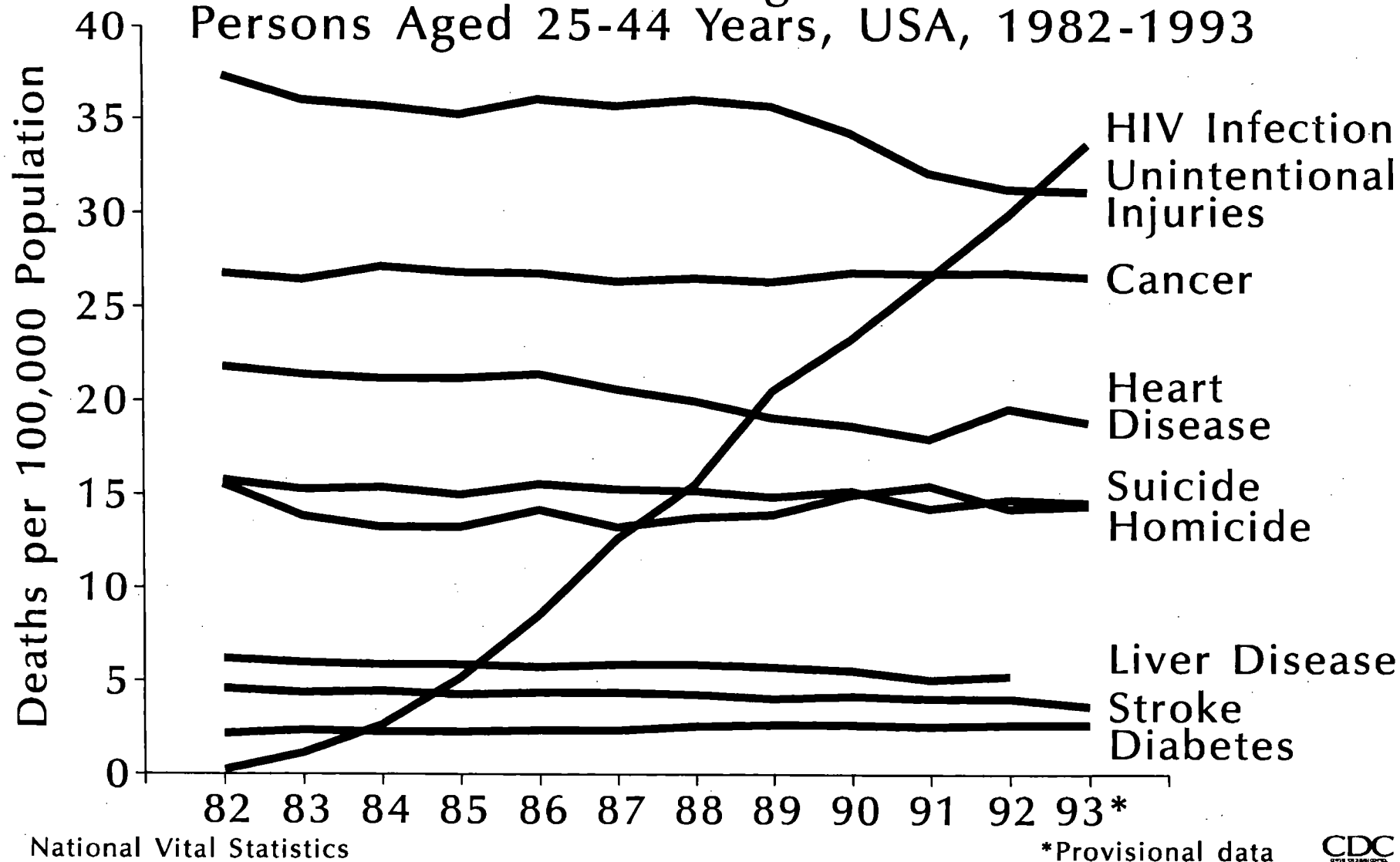
- Support for UNAIDS

- Therefore, in order improve the U.S. international effort, the agencies supporting international activities on the

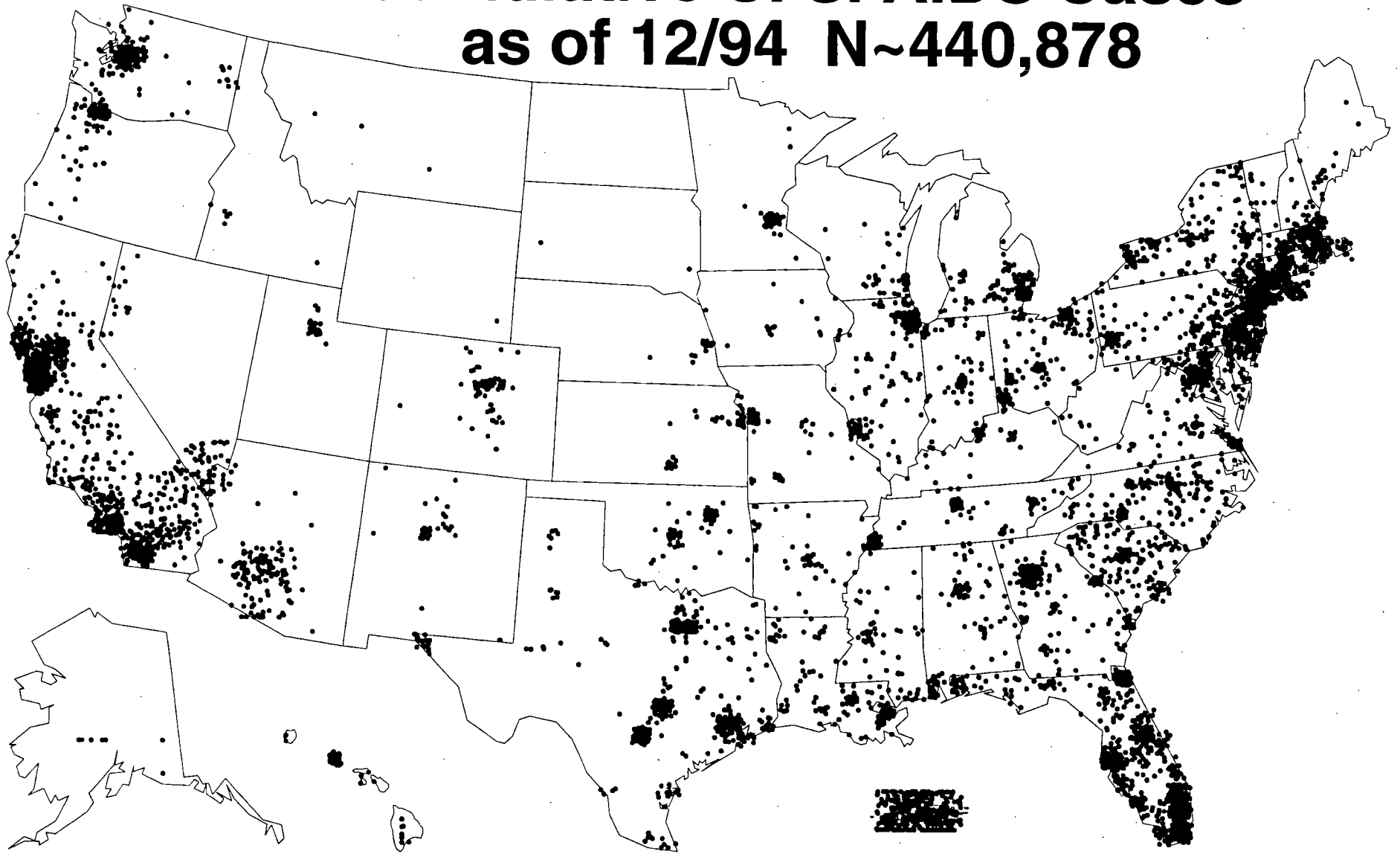
11. Don C. Des Jarlais, Holly Hagan, Samuel R. Friedman, Patricia Friedmann, David Goldberg, Martin Frischer, Steven Green, Kerstin Tunving, Bengt Ljungberg, Alex Wodak, Michael Ross, David Purchase, Margaret E. Millson, Ted Myers. Maintaining Low HIV Seroprevalence in Populations of Injecting Drug Users. JAMA, October 18, 1995 -- Vol. 274, No. 15. pp 1226-1231.

12. Preventing HIV Transmission: The Role of Sterile Needles and Bleach. Jacques Normand, David Vlahov, and Lincoln E. Moses, Editors. National Academy Press, Washington, DC. 1995

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



Cumulative U. S. AIDS Cases as of 12/94 N~440,878



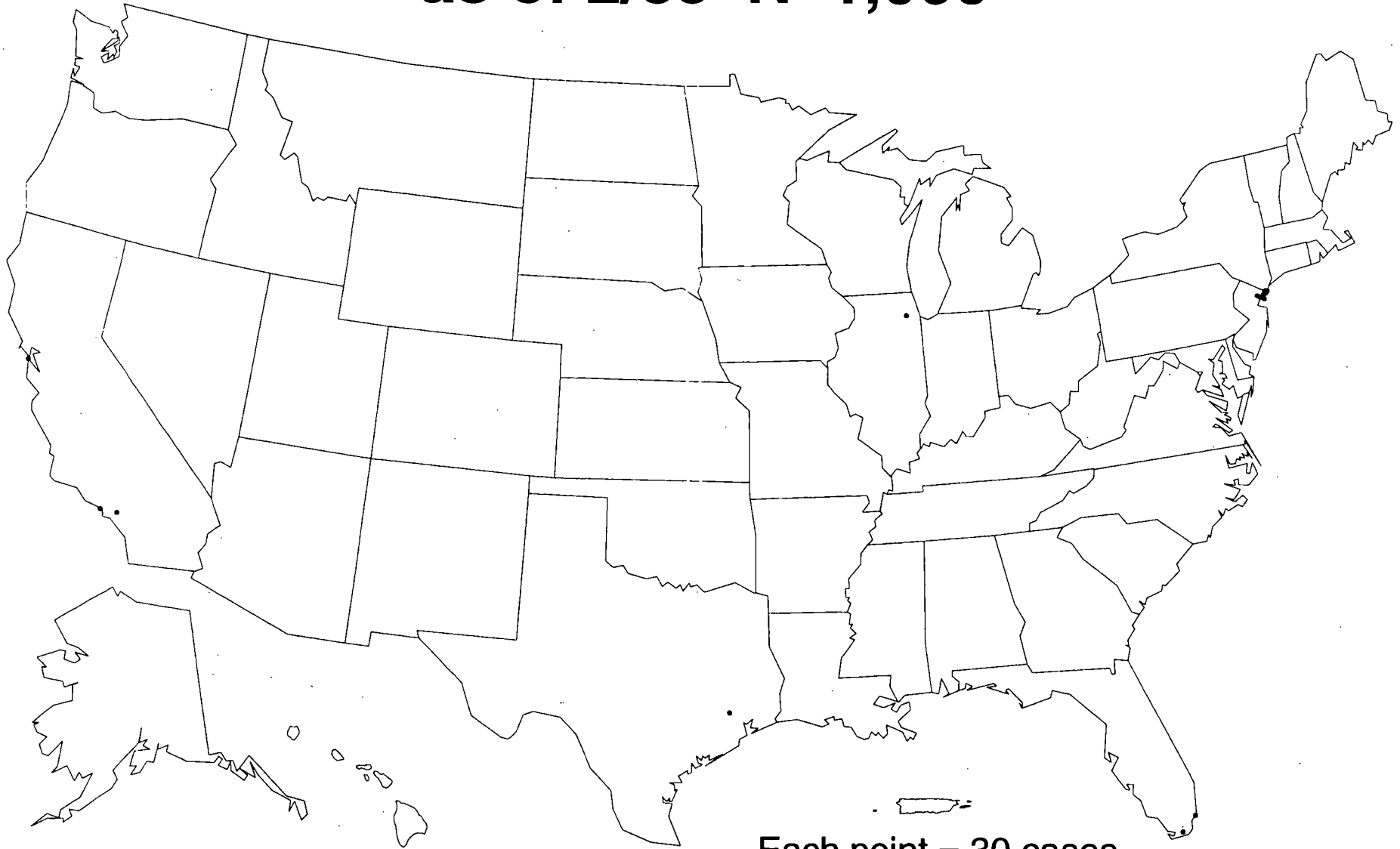
Each point = 30 cases

Cumulative U. S. AIDS Cases as of 5/85 N~10,000

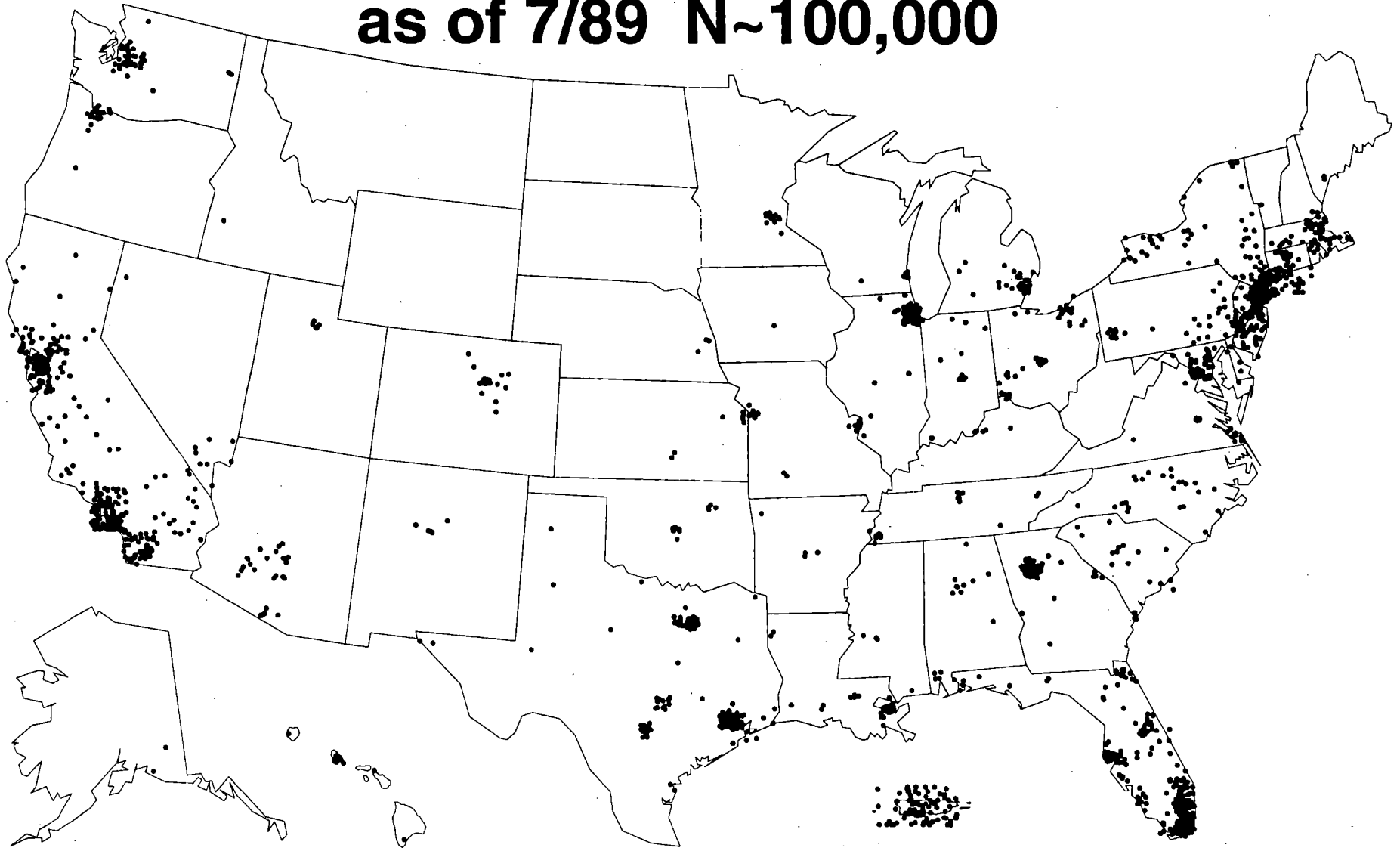


Each point = 30 cases

Cumulative U.S. AIDS Cases as of 2/83 N~1,000



Cumulative U.S. AIDS Cases as of 7/89 N~100,000



Each point = 30 cases

1.3.96 Meeting
C JL+RS

Notes:

Folks --

Here's the latest. The approach I took was a cut to the chase -- especially in the substantive sections (i.e goal, who's doing what, here are the major problems and what we're going to do about them). Other things:

- I neglected to copy in the information dissemination section so it's missing in this draft...
- all the #'s need to be checked
- tried to incorporate a "partnership" theme -- works? doesn't work?
- what's missing?
- Right now, the reference citations are inconsistent -- I think they should be moved to a list in the back or eliminated ...thoughts?
- Needle exchange -- wording? Consistent with other policies?
- Promises -- there are lots of promises in here ... any that

should go some that should be in her

- Overall, it needs to be tighter, but, it won't happen to today.

Thanks for your help --

TABLE OF CONTENTS

Letter from PF/Acknowledgments

Executive Summary

Scope of the HIV/AIDS Pandemic

Goal of National Plan

Challenge of the HIV Epidemic

Description of Activities

Overview of Activities

PREVENTION

RESEARCH

SERVICES

CIVIL RIGHTS

INFORMATION DISSEMINATION

INTERNATIONAL ACTIVITIES

Appendices:

Budget Tables

Acronym List

Glossary

List of Members of the Interdepartmental Task Force on AIDS

Letter from PF/Acknowledgments

The national epidemic and international pandemic of HIV and AIDS is a public health crisis of unprecedented proportions. As the President observed -- HIV/AIDS is the health crisis of this century. ^{Clinton administration} The ~~Office of National AIDS Policy~~ believes that the HIV/AIDS epidemic poses a continuing public health crisis that requires sound support for multiple approaches to finding a cure, and until a cure is found we must persevere in our efforts to promote prevention, research, treatment, and ethical treatment of persons with AIDS. ✓

too short. 1 paragraph order...

This epidemic challenges our nation on many fronts. Because of how it is most often contracted, through sex and drug abuse, topics difficult for many Americans to confront directly, HIV has challenged us to look at things we would prefer to avoid. We are also confronted by fear -- fear of contracting this disease and unwarranted fear of those who are infected. Fifteen years into this epidemic, those persons living with HIV still endure prejudice and discrimination based on their HIV status. We are challenged by the inadequacy of a social and health care infrastructure -- a system that was, and still is, woefully unprepared to address the needs of the HIV-infected. It is a system that will be further challenged to by funding changes to Medicare, Medicaid, and the possible advent of block grants. Scientifically, we have made much progress, but the virus

flag Medicaid as something to come back to...

[living document language 5...]

continues to be a formidable adversary, testing the best and brightest amongst us to find a cure.

But despite the difficulties, AIDS has also brought forth the compassionate and caring capacity of this nation. In my meetings around the country with persons living with HIV I have been inspired by their personal courage. I have been impressed by the compassion of those who care for the sick and the communities that have risen to the challenge of caring for their fellow citizens. It is an example of how this nation can rise to meet the most difficult challenges placed in its path. And those Americans living with HIV, their families, and their communities deserve a thoughtful and efficient plan to combat this epidemic.

This is the first time an government-wide national plan has been developed -- it links programs to national objectives. A plan of this nature was one of the recommendations put forth by the National Commission on AIDS. The President, as part of his strong commitment to assuring an efficient coordinated effort, requested that the Office of National AIDS Policy develop a comprehensive plan to guide the federal response to this epidemic.

True agency-wide planning requires a commitment at all levels of government to work together toward clearly defined goals.

Therefore, this plan for HIV and AIDS has been developed from the

bottom up. Through the Interdepartmental Task Force on HIV and AIDS (IDTF), a request went out for the agencies to identify their activities in relation to their goals and objectives. I would like to thank and credit the agencies for the thoughtful time and attention given by their staff in developing the individual portions of the comprehensive plan. With leadership from the President and in cooperation with the members of the IDTF, we have taken steps never before taken to prospectively assess and map out future action. As presented here, the national plan is intended to be a working document to be updated, set a baseline of where we are government-wide, link goals to budget objectives, and guide us in refining our goals and objectives in response to the changing face of the epidemic of HIV and AIDS.

The goal of the comprehensive national plan presented here is to set forth common goals and priorities for charting our course in combatting the epidemic of HIV and AIDS. It also includes an accounting of current federal activities in the areas of prevention, research, services, international activities, and civil rights. This document meant to compliment other planning documents such as the legislatively mandated NIH plan and the U.S. International Strategy on HIV/AIDS.

There are those who would say that AIDS receives enough funding, that other diseases are more worthy of federal funding. They are

wrong. This epidemic of HIV and AIDS already threatens the economic progress of many countries around the world. In the United States HIV is now the leading cause of death among Americans aged 25-44. This is not a time to stop but to move forward and build upon our efforts -- the future of our children depend on it.

This is a time of great challenges and great opportunity. And while AIDS is a terrifying tragedy that has already affected too many people around the world, I believe it is a disease that we can defeat -- just as we have defeated polio, many forms of cancer and other scourges in the history of nation. We will be able to win are battle with HIV and AIDS with commitment, courage, and with leadership.

Executive Summary

- Letter from PF/Acknowledgments
- AIDS Demographics, shifting demographics
- Plan is the first of its kind
- Three goals and the six priority areas
- The plan has been organized by the following substantive areas
- Brief summary of federally sponsored activities in various areas

PREVENTION

RESEARCH

SERVICES

INTERNATIONAL ACTIVITIES

INFORMATION DISSEMINATION

CIVIL RIGHTS

Scope of the HIV/AIDS Pandemic --

The pandemic of human Immunodeficiency virus (HIV) and acquired immunodeficiency syndrome (AIDS) presents unique social economic, and public health challenges to people and governments here in the United States and worldwide. Unlike other infectious diseases which have arisen over the course of history, HIV is infectious for life and almost always fatal. This national and international pandemic of HIV disease, now well into its second decade, is progressing virtually unabated. It also remains a deadly infection for which there are limited treatments, no vaccine, and the only cure is prevention. |

An Expanding Public Health Threat

October 1995 #4 - from SL

As of ~~June~~ 1995, the Centers for Disease Control and Prevention (CDC) reports that 476,899 cases of AIDS have been reported in the U.S. and an estimated 295,473 Americans have died as a result of complications related to HIV. Since 1987, AIDS has gone from being the 15th ranked cause of the death to the 8th -- it is now the leading cause of death among Americans aged 25-44. In 1994 alone, nearly 81,000 cases of AIDS were reported to the CDC. The CDC estimates that 40,000 American are becoming infected with HIV each year and that between 800,000 and one million Americans are currently living with HIV. (See attached charts.)

In addition to the ongoing increase in infections, the demographics of the epidemic have been shifting. The early years of the epidemic were dominated by cases involving gay or bisexual men living in major urban centers, such as New York, San Francisco, and Los Angeles -- this group now represents less than half (43%) of all new cases. Among the populations being more heavily impacted now are young men between 20 and 24 (53% of cases in 1994) and women (18%), and heterosexual injecting drug users (24%). In 1994 alone, over 14,000 women were diagnosed with AIDS and women now comprise 21% of reported HIV-infection cases. As of June 1995, pediatric cases have been on the rise, (although this trend will hopefully be reversed with the implementation of the of the ACTG 076 recommendations.) In 1994 alone, over 1,000 new pediatric AIDS cases were reported -- an 8% increase in just one year. [It estimated that if this trend continues, 80,000 American children will have been orphaned by AIDS by the end of this decade.]

stay out
in a
couple of
sentences.

women → link → to the women

Communities of color are now being more severely affected. As of June 1995, African-Americans accounted for 34% of reported AIDS cases. Hispanics represented 17% of new cases through June 1995. Of great significance is that the CDC estimates that more than 50% of all new cases are now related directly or indirectly to substance abuse, particularly the use of injectable drugs.

CDC
confirm
cumulative
1 year vs
cumulative

Common modes of transmission are also changing. The prevalence

careful
about
cases
infections

of HIV infection in IDUs and their sexual partners and children in the United States is on the rise. In the U.S., approximately one-half of new cases are related to drug use. Infection acquired through heterosexual contact is also on the rise.

Moreover, AIDS is no longer just an urban problem. AIDS cases have been reported in all 50 states, the District of Columbia, Puerto Rico, and the American territories. The HIV/AIDS pandemic is spreading to rural areas and the south. And while most cases are still reported from urban areas, the rate of reported cases in non-metropolitan areas is increasing faster than urban areas. In 1994, 35% of new AIDS cases were reported in southern states.

Internationally, the toll of the epidemic is even greater. The World Health Organization (WHO) estimates that since 1981, 2.4 million cases of AIDS have occurred worldwide. The WHO has estimated that as of mid 1995, 18.5 million adults and more than 1.5 million children have been infected with HIV since the beginning of the pandemic. The WHO projects that by the year 2000 at least 25 million people will become infected with HIV, or an average of 10,000 people a day.

The Social Impact

Unfortunately, prejudice and discrimination are still encountered by people living with HIV and their families and loved ones.

Persons with HIV have been denied medical services, emergency medical treatment, dental services, and medical insurance. They have been discharged from their jobs and denied housing. And unlike other infectious diseases, HIV and discrimination often go hand-in-hand.

Unlike other leading causes of death, AIDS is a disease that strikes people in the prime of life -- it disproportionately kills the younger people during their most productive years. It is the leading cause of death among Americans 25-44 -- in 1992 people in this age group constituted 54% of the civilian labor force. Premature deaths due to AIDS result in the loss of many productive years of life and in many cases deprive young children of their parents. In terms of years of potential life lost (YPLL), in 1994 AIDS ranked fourth among all leading causes of death.¹ In developing countries, the pandemic threatens to reverse decades of progress in strengthening national economies and improving the health status and social well-being of millions of women, men, and children.

Goal of National Plan

The goal of a comprehensive national plan is to set common goals and priorities for charting our course in combatting the epidemic of HIV and AIDS. In order to ensure efficient of federal and private resources, it is imperative to organize government-wide

efforts so as to ensure optimal use of resources in combatting the epidemic.

This is the first time an government-wide national plan for HIV and AIDS has been developed. This first edition of the plan links programs to national objectives in each federal agency which supports AIDS activities, documents current federal activities in the HIV/AIDS arena, links goals to budget objectives, and lays forth the common goal and priority areas for HIV/AIDS based on current scientific opportunities, public health needs and priorities, and fiscal constraints. It is intended to be a working document that will be updated annually. By establishing this baseline of where we are government-wide, it will help guide federal agencies in refining goals and objectives in response to the changing face of the epidemic of HIV and AIDS.

The comprehensive national plan presented here is broader in scope than prior planning efforts. To date, planning has been primarily focused in the public health service as evidenced by a series of documents such as the Public Health Service Plan for the Prevention and Control of Acquired Immune Deficiency Syndrome², the Coolfont³ and Charlottesville⁴ reports, and the PHS Strategic Plan to Combat HIV and AIDS in the United States⁵. There have also been recommendations from a number of groups, including the National Commission on AIDS.⁶ There have also been significant planning efforts on the part of individual agencies,

such as the legislatively-mandated NIH plan for the their HIV-related research program. However, there has not been a national plan which provides for a government-wide coordinated effort encompassing public health service activities in addition to problems such as housing, health care, and civil rights.

All executive agencies
This federal strategy for HIV and AIDS has been developed from the bottom up. Through the Interdepartmental Task Force on HIV and AIDS (IDTF), a request went out for the agencies to identify their activities in relation to national goals and objectives. In addition, IDTF members have been crucial in identifying new areas of opportunity and those requiring special attention. In developing these priority areas we have also listened carefully to the of members of the Presidential Advisory Council on HIV/AIDS, to people on the front lines of the epidemic, and to the many HIV-infected persons and their loved ones that have written to the President. We have listened to the activist community who has spent too many years fighting the epidemic. We have also reviewed the insights provided by a number of groups including the former National Commission on AIDS, the Institute of Medicine and National Research Council, the Government Accounting Office and the Office of Technology Assessment. Therefore, the expertise and experience of those who work closely with communities, clinicians, researchers, service and research organizations, and infected persons is reflected in this ongoing planning process. *WAF CA attendees..* ~~X~~ The three common goals that have been

identified are:

- Provide solid support for effective prevention strategies, so as to reduce the number of new infections each and every year, *until there are no*
- Provide strong support for research in order to find a cure for those currently infected and a preventive vaccine for the uninfected.
- Ensure appropriate care for and ethical treatment of persons with AIDS.

Drawing from these goals, the Office of National AIDS Policy has identified 6 priority areas that warrant concerted federal effort, those being:

for the coming year are the most pressing areas

The order

- Strengthening Prevention Activities
- Supporting Diversified Research Approaches
- Strengthening Approaches to Substance Abuse
- Strengthening the Health Care Safety Net
- Improving Translation of Research to Practice
- Improving ~~Accountability~~ and Priority Setting

Evaluation

Challenge of the HIV Epidemic

The epidemic of HIV and AIDS has posed a series of unique challenges since the discovery of the first AIDS cases in the early 1980s. The challenges we face today are very different than challenges we have faced so far. It is a growing epidemic in which more persons are infected every year, in every geographic area, ethnic/race group, and age range. We now know the risk factors, the etiologic agent, and we have a test to diagnose infected persons and protect the blood supply. Thanks to clinical research significant progress has been made in some areas -- people with HIV infection now live twice as long as they did a decade ago. And with the results of the NIH-sponsored research we now have the ability to prevent perinatally acquired HIV infection in some newborns.

We are also facing new challenges. The challenge of getting people into care so they can receive the new treatments and educating health care professionals so they know the best way to administer them. Strengthening our prevention efforts has never been more important. Developing prevention messages that are specially targeted to the group they are intended to reach is critically important if we are to slow the tide of new infections. And from societal perspective, we still have a long way to go in overcoming fear and discrimination.

Cops. for Federal

Description of Activities

a ~~the~~ nation
the Nation

Overview of Federal Efforts

The scope and nature of the HIV/AIDS epidemic has affected many federal responsibilities and activities. [These activities range from the direct funding of research grants, health care infrastructure support, setting policies to encourage private sector activity, coordinating with international AIDS organizations, information dissemination, and prosecuting civil rights violations.] While federal agencies are responsible for responding directly to the epidemic of HIV and AIDS, they also collaborate with and provide support for community-based organizations in addition to state and local governments, which often have substantial surveillance, prevention, and health care responsibilities.

not clear

can stand alone

- follows comma which (linked)
- not a comma that (linked) linked

The comprehensive plan for HIV and AIDS has therefore been organized around these substantive areas: prevention, research, services, information dissemination, international activities, and civil rights. In this plan, current agency activities have not been organized around administrative structures, but by substantive areas. In cases where a single agency may have responsibility for more than one component of a substantive areas, such as prevention and research, documentation of their activities will be found the respective substantive sections. In many cases there are cross cutting issues which could fall in

that

several categories, such as internationally-based treatment and prevention efforts. So, ...

Agency support of HIV/AIDS activities falls into three general categories, where HIV/AIDS activities are: (1) a central part of their mission; (2) a significant but not leading part of the mission, or (3) not an explicit part of their mission but AIDS-related activities receive collateral benefit from agency supported work and/or policies. There are a number of agencies for whom AIDS-specific activities are central to their mission (i.e. NIH, CDC, and HRSA) while other agencies maintain programs and activities that support a broad range of activities, of which HIV-related activities which are one among many (i.e. USIA, DOJ). Agencies which support research and provide shared access to highly sophisticated and expensive technology, such as the DOE and their support of sophisticated imaging equipment, can assist a wide range of researchers including those studying HIV. Data are therefore presented in a manner consistent with the level of involvement an agency may have.

The following sections of prevention, research, services, international activities and civil rights describe current federal activity and identify goals, funding levels, populations served, constituency involvement and unmet need of the program.

PREVENTION

The nation's prevention goal is to reduce the number of new infections each and every year until there are no new infections. Achieving this goal will require a true and dedicated alliance between the federal government, states, communities, and individuals. Achieving such an ambitious prevention goal will require a clear definition of what the federal government is able to do and an ongoing dialog between the public and private sections.

delete → *our prevention programs move clearly articulated goals, pop's, services, methods, evaluate*

To achieve this goal the nation will need to continue to invest in a range of endeavors including data collection, research, and prevention programs. It will also require careful examination of what needs to be continued, what activities need to be initiated and a awareness that a reconfiguration of some program priorities may be required.

We know that prevention works. We also know that the prevention task faced by the United States in controlling the epidemic of HIV and AIDS has reached enormous proportions.¹ The Centers for

¹ This section will address primary prevention activities. Other aspects of prevention, such as secondary prevention (i.e. preventing complications of HIV infection), use of topical microbicides, the behavioral components of vaccine research, and international prevention activities will be discussed in the following research, services, and international activities sections.

Disease Control and Prevention (CDC) estimates that approximately 800,000 Americans are presently HIV-infected, many of whom are unaware of their infection status. Moreover, the CDC estimates that there are approximately 40,000 to 80,000 new infections each year. Many more Americans who are not presently infected are at risk for acquiring the virus. HIV infection is a unique prevention challenge because of the virus' virulence, long incubation period, long duration of infectiousness, nearly always fatal prognosis, and potential for exponential spread. Moreover, it is transmitted primarily as a result of personal and private individual behaviors -- sex and drug use. To be effective, HIV prevention programs must reach tens of millions of Americans who embody a vast diversity of age, race, ethnicity, geographic locale, sexual orientation, and drug use behaviors.

Prevention activities are currently supported by a number of federal agencies. Most of the federal prevention efforts are sponsored by the Public Health Service, although other departments such as the Department of Defense (DOD), and the Department of Veterans Affairs (VA) also support prevention activities. Their efforts reflect a continuum -- from surveillance to research to social marketing initiatives. Agency activities are also reflective of their respective missions. For example, the Centers for Disease Control and Prevention (CDC), the agency with primary federal HIV-prevention responsibilities, supports a wide range of surveillance and prevention projects,

*VA, Defense
Dept, 109
Clinics.*

many in partnership with states, local governments, and community-based organizations. Other agencies focus on specific aspects of prevention. For example, the National Institute of Drug Abuse (NIDA) and the Substance Abuse and Mental Health Services Administration (SAMSHA) support a breadth of efforts to stem the tide of drug use. While other agencies support primary prevention efforts as part of medical care, such as at the Veterans Hospitals and the DOD.

*HRSA
integration
info 10*

The efforts of federal agencies have been instrumental in expanding our knowledge base, however, significant gaps remain. We know from both formal research and community experience that developing prevention programs that work requires knowledge of who is becoming infected and of the behaviors that are enabling transmission, an understanding of the motivations for those behaviors, and an understanding of how best to reach people with messages that will prompt behavior change.

The Nation's prevention priorities must be guided towards gaining knowledge that will improve our efforts to develop effective prevention programs. We need to better our understanding about the major modes of transmission, close gaps in scientific knowledge, and working towards eliminating gaps in program areas.

The following three sections identify areas for investment

necessary for the development of sound prevention interventions.

MODES OF TRANSMISSION

An important part of strengthening prevention activities is to have a clearer understanding of who is being infected and which behaviors are placing people at risk for infection. Recent epidemiologic data show that the epidemic of HIV in the United States is being driven by people who engage in injection drug use (50%) and their sexual partners (25%), men having sex with men (25%), heterosexual transmission (> 20%), and vertical transmission (90% of the cases in the United States occur in women under 22 years of age). Moreover, the youth of our country are becoming infected at an alarming rate -- 50 percent of new infections in the United States are in persons under 25 years of age. HIV is the leading cause of death in Americans aged 25-44. It is likely that many of these people were infected while they were adolescents. (Add data from new NCI study) Minority Americans are also disproportionately represented among new HIV infections. As of June 1995, African-Americans accounted for 34% of reported AIDS cases and Hispanics represented 17% of new cases. These trends in the epidemic must be taken into consideration when prioritizing prevention research and service programs.

penetrative (define...)
who give birth
check #5
not clear

A crucial part of effective prevention strategies includes

supporting adequate surveillance of HIV infection and related diseases in order to estimate the burden of HIV illness, gauge future directions of the epidemic, and assess the effectiveness of prevention interventions. As previously noted, the CDC has the primary federal responsibility for monitoring the epidemic. The CDC AIDS case and case death reporting system provide useful data for assessing AIDS prevalence and mortality by gender, race/ethnicity, age, and mode of exposure. This surveillance system also provides worthwhile information on HIV-related opportunistic infections.

There are however opportunities for improvement. Effective prevention intervention programs begin with sound information on who is at risk. Current CDC surveillance systems do not currently capture sufficient "front-end" information such as the prevalence of HIV (not AIDS) in the population, and trends in risk factors and new infections. We need to collect this type of data in tandem with an enhanced effort to link surveillance and epidemiological data to priority setting, the design, and evaluation of prevention programs. These needs require that the CDC re-evaluate and reconfigure its data collection efforts; such a shift may require reconfiguring of currently collected data to address these needs.

GAPS IN SCIENTIFIC KNOWLEDGE

CDC - doing something

> Credit CDC for doing this in community planning process

See this comment

Factors that place individuals at risk for acquiring HIV infection are a complex combination of behavioral, social, cognitive, and biologic influences. Given this complexity and the importance of preventing new infections, we must not assume we know what interventions will work, but base our efforts on sound research findings. Experience has taught us that prevention can work, but when it does it is because the intervention incorporated findings from experience and relevant research. Unfortunately, behavioral research is a relatively young science and there are currently more questions than answers. There are three areas where gaps in knowledge have been identified -- basic behavioral research, intervention research, and social marketing research.

Basic Research. Since behavior change is the primary prevention intervention immediately available for halting the spread of HIV infection, basic behavioral research should be the foundation upon which prevention programs are based. Basic behavioral research, similar to basic research in other areas of scientific inquiry, seeks to explain the determinants and causes underlying biological, behavioral, and social processes. HIV-related risk-taking behavior is often complex and influenced by a host of individual and environmental factors. Before we can begin approaching the formidable task of implementing successful HIV prevention programs that reach a diversity of Americans, more information on the determinants of HIV-associated sexual and

drug-using behaviors is needed. For example, although much has been learned about the basic biology of substance abuse, further elucidation of the mechanisms underlying addictive behavior may assist in the development of new therapeutic approaches to addiction, which in turn may reduce the number of new infections.⁷ And although we have some information on relevant risk-taking behaviors, more information about knowledge, attitudes, decision-making processes, and beliefs about AIDS and other STDs are much needed. Data such as this enables scientists to establish theories of behavioral change which then provide researchers with tools for identifying what approaches may be most effective for an individual or a community.⁸

Intervention Research. A second major area that must be a funding priority is research to improve prevention interventions, i.e. research which concentrates on identifying and modifying behaviors, such as those related to drug use and sex. This type of research can focus on both individuals and communities, which often hold norms which 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 HIV infection rates. This theoretically based intervention research has identified some significant predictors of changes in sexual and drug-using behaviors among gay men, adolescents, and heterosexual adults.⁹ Studies have shown that community-based HIV risk reduction

programs that are gender relevant and culturally sensitive can be effective.¹⁰ A recent study has also provided a reason for optimism that the spread of HIV can be contained among injecting drug user populations when there is early community outreach and access to sterile injection equipment.¹¹

However, despite these successes there is more that we need to know if we are to develop effective programs for a diversity of Americans. We must couple findings from basic behavioral research with effective prevention interventions. Areas of high priority include research regarding strategies that facilitate sustained adoption and maintenance of HIV preventive behaviors, research on cultural barriers and strategies to reach populations resistant to behavior interventions, and research on the effectiveness of drug abuse, mental health, and alcoholism treatment for reducing HIV risk behavior. Agencies supporting 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.

Social Marketing Research. And lastly, it is critical that the findings from basic and intervention research are incorporated into prevention programs. We know from efforts in other countries that HIV related social marketing efforts can be successful. However, in the United States available information

about effective strategies is not being used consistently in the design and implementation of prevention interventions.

Currently, there are good models for prevention interventions which are not making their way to those on the front-lines of the epidemic. Community-based organizations, which are responsible for developing a large portion of the prevention programs often do not, or are not able, to take advantage of current knowledge about program effectiveness.

Agencies supporting social marketing activities need to strengthen efforts to understand barriers to the implementation and replication of promising prevention programs. Given the highly innovative nature of these endeavors, it is also crucial to strongly support the provision of technical assistance, and training, and a community-based effort that would test these models in a real-world setting.

CURRENT GAPS IN PROGRAM AREAS

Clarity

not being done well

Square one

For prevention interventions to stop new infections they must reach the people at risk. For individuals to take control of their own lives in fighting the spread of this virus, they must first have the information and tools to protect themselves. Given that there are limited resources to expand the scope of prevention programs, it is important that they reach the

uninfected and the groups that are now increasingly affected by the epidemic -- women and injecting drug users -- while maintaining efforts among youth and gay men.

One of the most important innovations in the prevention area is community planning. The community planning process is an outstanding model of a federal-local partnership. Through this effort, it will be possible to establish joint goals for the prevention of HIV that will meet federal standards while remaining responsive to local needs. However, this process is early in its development and will require technical assistance from the CDC? if it is to fulfill its potential for good priority setting and decision making.

Role of HIV + in primary prevention... as well as the groups who are uninfected (and) at risk.

Injection drug use is one of the major forces driving the epidemic -- half of all new cases are related to this mode of transmission. Limiting the impact of this mode of transmission will require efforts on several fronts. First, we need to improve the integration of HIV prevention and substance abuse programs. The epidemics of substance abuse and HIV in this country are overlapping and highly inter-related so we must work to integrate HIV prevention into current substance abuse programs and integrate substance abuse issues into HIV prevention. *SA Rx form of HIV prevention.*

Another major avenue for controlling the spread of HIV among addicted persons is to get them into treatment programs. At

slots → capacity

present, there are too few treatment slots for persons seeking to control their addictions. (confirm from samsha) With the advent of changes to Medicare and Medicaid this problem will only worsen. Moreover, substance abuse problems that contribute to the spread of HIV are broader than injecting drug use. There is substantial evidence that use of alcohol and other substances can adversely influence risk-taking behavior. It is estimated that x% (check #) of the population is affected by alcohol and other drugs (AOD) in addition to injection drug use. It must be part of the federal response to increase the availability of treatments slots for a range of addictions.

In addition to our efforts directed towards getting people into treatment for their addiction, we must also support harm reduction approaches for when treatment fails. Traditionally, harm reduction programs have not been well accepted in our country, yet experts feel that it is in the area that we may be able to make our greatest impact in stemming the tide of the epidemic. There is scientific evidence that historically controversial harm reduction approaches, such as needle exchange programs, can be effective. Among the conclusions presented in a recent study by the Institute of Medicine was that there is no credible evidence that drug use is increased among participants as a result of needle exchange programs that provide legal access to sterile equipment. The IOM went on to recommend that needle exchange programs should be regarded as an effective component of

harm
Reduction
from SL

History of
Medicine

a comprehensive strategy to prevent infectious disease.¹² There is also evidence, that needle exchange programs provide an opportunity to get people into treatment, thereby further reducing their risk and the risk for their sexual partners. Given the continuing and growing public health threat posed by the HIV epidemic, this approach deserves reconsideration by local communities as a possible intervention in the face of this public health emergency.

To reach our prevention goals, we must improve the integration of prevention activities and messages into primary health care services. This includes incorporating a patient's sexual history when a medical history is taken, offering HIV-related counseling and testing, and working with HIV+ patients so they do not infect others. It also means offering pregnant women information about and access to the 076 prevention regimen. Achieving this level of integration will require the active collaborative efforts on the part of individual physicians, nurses, clinicians, managed care plans, medical schools, professional organizations in addition to local and federal governments.

An area of major concern are the planned changes to Medicare and Medicaid and the implications for persons living with HIV. For Americans living with AIDS, Medicaid is the single largest source of health care financing, providing coverage for more than 50 percent of such adults and more than 90 percent of children

living with AIDS. Maintaining this vital safety net is important for all Americans, but especially for those with HIV infection. There are opportunities right now for preventing new infections, but for this to happen, people must have access to medical care and services.

And finally, it is important to assess the effectiveness of the prevention interventions that have been implemented.

Prospectively set performance measures can be used as a basis for evaluation and program improvement. Incorporating effectiveness measures 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.

RESEARCH

One of the nation's common goals is a cure for those currently infected and a preventive vaccine for the uninfected. It is research that will enable us to reach these goals and until they are a reality, the nation must provide solid ongoing support for basic and clinical research. As with prevention, achieving this goal will require committed collaborative efforts between the federal government, researchers, communities, and the private sector. Realizing this ambitious goal will also require a clear definition of what the federal government is able to do and an ongoing dialogue between the public and private sectors.

At present, a number of federal agencies play a significant role in the nation's research efforts. These endeavors range from basic molecular research to clinical research to health services research. For example, the National Institutes of Health (NIH) supports a significant portion of these endeavors. The NIH funds research on natural history and epidemiology, etiology and pathogenesis, therapeutics, vaccines, and behavioral research. As part of their mission to protect and maintain a viable fighting force, the Department of Defense supports clinical vaccine and therapeutic research. The Agency for Health Care Policy and Research (AHCPR) funds research to help the nation determine which medical approaches are the most clinically and cost effective. The Department of Energy (DOE) through its

support of technologically advanced equipment, provides the opportunity for federal and private researchers to share resources and thereby analyze molecular structures that, without such equipment, would not be possible. And the Centers for Disease Control and Prevention (CDC) supports laboratories which have developed sophisticated methods for identifying virus strains, so critical to ensuring the safety of the blood supply.???

The nation has already reaped the benefits of supporting research funding in general, and HIV-related research specifically. Due in great part to federally-sponsored research, persons with HIV now live twice as long as they did a decade ago. AIDS-related conditions that used to mean a quick and often painful death for people living with HIV can be treated and even prevented. An NIH study found that it is possible to dramatically reduce the chance of transmission of HIV from mother to baby. Thanks to our investment in prospective epidemiological studies we are beginning to understand the factors that enable long-term non-progressors to live many years after infection virtually disease free. Understanding what happens in these non-progressors may help us develop better therapies and a vaccine.

And there is reason for hope -- scientists now believe that a vaccine is possible. New classes of anti-retroviral therapies appear to be powerful in controlling the virus. Combination

therapies are also showing great promise in this area. In addition, the Food and Drug Administration, through its accelerated approval program, is now approving drugs faster than any European nation.

However, despite these advances there is more that needs to be done to reach the nation's goal of a vaccine and a cure. The epidemic of HIV and AIDS presents an unprecedented challenge. HIV is unique in that it attacks the very immune system which is supposed to protect us from infection and tumors -- mankind has never before encountered a virus such as this. Since the beginning of the epidemic identifying the best approaches to pursue and support has been and continues to be a challenging task. Identifying the most promising scientific avenues and having the appropriate structures and processes in place to ensure that the nation capitalizes on these opportunities will require a considered and coordinated effort.

Developing and implementing the nation's AIDS research agenda presents a number of challenges. Within the NIH, the agency with the largest HIV-related research portfolio, research is supported throughout 24 institutes, centers, and divisions (ICDs). In order to better plan, coordinate, and fund the AIDS research activities of these ICDs the Congress, through the NIH Revitalization Act Amendments of 1993, provided Office of AIDS Research (OAR) with new oversight and budget authorities. As

part of fulfilling the requirements of the law, the OAR develops a yearly NIH plan and budget for AIDS research and receives directly from the President and the Office of Management and Budget (OMB) a single appropriation for AIDS activities at NIH. This single appropriation allows the OAR to effectively prioritize research resources on the basis of sound scientific judgement and provides flexibility for pursuing the most promising research opportunities. It is crucial that the authority granted OAR in the revitalization legislation, including the single appropriation, be supported and maintained. With such a large research enterprise it is essential that there is oversight and accountability so the most promising approaches are vigorously pursued and the usually autonomous Institutes have both the scientific and administrative assistance they need to effectively collaborate with other NIH institutes.



It is also clear that while NIH supports a significant portion of HIV-related research, other agencies and departments also play a significant role in our search for a cure and a vaccine for HIV. It is time to improve our efforts if the nation is to effectively support a diversity of promising approaches government-wide. These research efforts must also be well-planned, coordinated, and establish accountability. To achieve this the Director of the Office of National AIDS Policy will coordinate an inter-departmental working group, chaired by the Director of the Office of AIDS Research, will develop a coordinated plan and budget for

HIV and AIDS research across all departments within 90 days.

The nation must also acknowledge that reaching our goals will require the joint commitment of government and the private sector. This especially true in the arena of vaccine development. Several challenges currently face the nation and the world in continuing the vaccine development effort. One major centers on the involvement of pharmaceutical and biotechnology companies. [In order to identify areas for fruitful collaboration and accelerate the pace the Vice President will convene a meeting of government scientists and leaders of the pharmaceutical and biotechnology companies to identify barriers to the development of vaccines. [slight change in promise from POTUS speech]

timeliness ➤ ADDTF ➤ credit,

At present there are fundamental differences in the approach to vaccine development that should be taken. Some scientists believe that we need to return to a basic science to gather more information to guide us, while others believe that in the face of a global emergency we must empirically test candidate vaccines in people immediately. Both groups have some valid arguments. The issues that are driving this debate are both scientific and social, moreover different parts of the world are experiencing the epidemic in different ways. Unfortunately, the history of vaccine development does not provide simple answers. It is vitally important that serious consideration is given to all the

Two - approaches -
given current
state of know.
both can
+ should
are being
pursued.
90-day
plan.

data that are available and that that information is shared and used by scientists as we move forward in vaccine development process.

It is also important to strike a balance between basic and clinical research. We are producing new drugs in record numbers and at record speed, but do not know how they work. With the advent of accelerated approval by the FDA it will be incumbent on the government to ensure that the efficacy studies, currently mandated by law are carried out. Conducting these studies will require the efforts of clinicians who have demonstrated their ability to carry out the long-term follow-up of patients that such clinical effectiveness studies require. It is also essential that these studies, like all studies, include persons representing a diversity of race, ethnicity, gender, and drug using behaviors. If these studies are not done, patients may be taking less effective treatments or combinations of treatments, and federal programs such as Medicare and Medicaid and private insurers may be paying for these less effective treatments.

definition

don't always know how they work.

One of the most difficult tasks for clinicians comes in interpreting the patchwork of data and articles regarding treatments and converting that into a therapeutic strategy for the patient that sits in front of them. With every research breakthrough, this task becomes more difficult. It is essential that practical information for practicing clinicians and their

patients is provided in a timely manner. The nation must develop a mechanism for ensuring periodic assessment of the state of the art and disseminating that information widely. This will require collaboration with industry, government, and professional groups.

A key role for the federal government is to act in partnership with the private sector and support areas where there is a market failure -- i.e. areas where industry is unlikely, for financial reasons, to pursue research that would be beneficial to the nation's public health. The area of vaccine development is one, but there are others. For example, topical microbicides (i.e. female-controlled chemical barrier methods for preventing HIV transmission) are a promising approach, but will require preliminary support before they will be at a stage where the private sector can assume a lead role. It 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. This has been done at the Department of Energy -- by supporting sophisticated imaging equipment that would be prohibitly costly for individual researchers or companies to purchase, providing a shared resource has accelerated our understanding in a number of research fields, including that of HIV. Such information can form the basis for targeted drug design and development. It is also unlikely that the free market will conduct head-to-head clinical trials of therapies that have been approved or in development. However,

information about these therapies is important to improving patient care and ensuring that the nation's health dollars are wisely spent. Similarly, it is unlikely that the private sector would support research for therapies that are in common use but for which little information is available, such as alternative treatments. Americans are spending millions of dollars per year on such therapies for which little is known. The government must ensure that treatments brought to market are safe and effective. Similarly, ensuring safety of the blood supply is a responsibility unlikely to be assumed by the private sector. These are areas where the government must step in to serve and protect the nation.

And finally, research is an investment in our future. It cannot grow and mature with the vicissitudes of the federal budget process, it must receive consistent funding if we hope to bring the best and the brightest to solve the research challenges that will find a cure and a vaccine. Research has been to key to improving lives and the nation must continue this investment.

payline issues???

Good applications
going down.....

Subheads
AIDS research
to others and
vice-versa.
40

CARE & SERVICES

Needs reiterate after budget

An important part of the national goal is ensure appropriate care for all persons living with HIV and AIDS. Achieving this ambitious goal will require a true and dedicated alliance between the federal government, states, the private sector, communities, community-based organizations, clinics, families, and individuals.

① Medicaid ② RWCA ③ HRSA
CHC, Mat. + child health
More BOP somewhere else....

At present care and services are provided through a number of federal agencies, many in cooperation with local organizations and the AIDS community who have admirably served those living with HIV. A major source of care is provided through Ryan White Care Act (RWCA) which is overseen by the Health Resources and Services Administration (HRSA). The RWCA provides funds for care, drug reimbursement, and ^{support services} case management that are given to states and cities under a formula basis so as the areas most affected by the epidemic receive a proportional share of available dollars. Housing assistance is provided by the Department of Housing and Urban Development (HUD) through their Housing Opportunities for Persons with AIDS (HOPWA) program. Medical care is provided through several avenues. Medical care for many HIV infected incarcerated persons is provided under the direction of the Department of Justice's (DOJ) Bureau of Prisons (BOP). But by far the largest sources of care for persons living with HIV are Medicaid and Medicare. Taken together, these

*II → drugs,
not enough
in here.*

programs form an invaluable safety net for some of the most vulnerable people in our nation.

The challenge before us today, especially in light of the restricted fiscal environment, is to ensure that persons living with HIV receive the care they need so they may have the opportunity to live productive lives. To achieve this, AIDS care and service programs must build upon past successes, continue to improve their prioritizing, improve accountability, and increase the cost-effectiveness of services they provide.

We must continue to fund the program that is the cornerstone of care -- Medicaid. Medicaid is the lifeline of support to millions of Americans. It provides health care for nearly half of the Americans living with AIDS, including 90 percent of the children with AIDS. It provides access to doctors, hospitals, and treatments -- the services that allow people to live longer more productive lives. Present Congressional plans (may need to change ...) cut the Medicaid program overall by \$169 billion and turn it into a block grant which in effect reverses this nation's 30 year national commitment to the poor and those in need. Cutting Medicaid to this level would cut the lifeline for millions of Americans, including those living with HIV and AIDS. Maintaining this program in a viable format must be a national priority.

With the potential cuts in Medicaid and welfare, the importance of the public health safety net increases for all vulnerable populations -- disproportionately so for people with AIDS. This will requires several responses. First, no one federal program will be able to absorb the unmet need that may be created by proposed changes to the Medicaid, Medicare and welfare programs. All federal programs, along with state and local organizations, must bear the share of the responsibility for serving and caring for people with AIDS. This must include the integration of HIV-related care into community health centers. Second, in light of these proposed reductions and possible advent of block grants for entitlement programs, it is important for programs such as those funded under the RWCA maintain sufficient funding so as to maintain the safety net. In addition, AIDS programs must do a better job of prioritizing what services they can provide -- and federal agencies must assist grantees in this regard. Treatment and primary care must come before ancillary services. It is not a prudent use of resources to provide services such as case management when a primary care services system does not have the resources to care for patients. And finally, the shift to managed care will have implications for programs such as the Ryan White Care Act programs. HRSA will need to provide more technical assistance to prepare grantees to work with and not against managed care.

Housing is also an important element in the fight against AIDS.

In 1989 Congress created * [From HOPWA + other programs. R.S.]

It is the foundation upon which any program of care or services must build -- without stable housing, a person with HIV/AIDS has diminished access to programs and services and a diminished opportunity to live a productive life. It is estimated that 50 percent of persons living with HIV and AIDS will become homeless or are at risk for becoming homeless during the course of their illness. [National Commission on AIDS] Discrimination against HIV-infected persons is illegal (see section on Civil Rights), however it still occurs. It is dramatically estimated that the cost of providing housing services in a HOPWA-funded residential facility is less than one-tenth, and some estimate as low as one-twentieth of the amount for the average day in the hospital. [LWH CAI] HOPWA dollars reduce the use emergency health care services. The HOPWA program must be protected, but it must also be acknowledged that HOPWA cannot do it alone. Protecting this component of the safety net and providing housing for persons living with HIV must be a shared responsibility between federal, state, local governments and community organizations.

Must be integrated into other programs.

There are also people, such as prisoners, who fall outside these traditional safety net programs. Ensuring access to quality care for this group is especially challenging. Prisoners do not have the choice of seeking care and are dependent upon the Bureau of Prisons to ensure that appropriate care is provided. [Problems] They also may experience difficult issues regarding confidentiality, trust, and access to research opportunities that do not face the non-

Most prisoners
with HIV are
in state & local prisons

incarcerated population. Improving access to appropriate HIV-related care must be a priority. This effort can be accomplished by the effective collaboration and consultation between agencies and that have experience with providing care and agencies which have responsibility for providing care for prisoners.

Strong federal support for these safety net programs must go hand-in-hand with improved accountability and priority setting. We must ensure that these programs consistently provide quality care. In this country, through the efforts of researchers and clinicians, we have shown that we can do HIV treatment well, but we do not do so consistently throughout the health care system. Ensuring this consistency will require increased training for all health care professionals in addition to more accountability through the use of performance measures for quality care. Achieving this goal will require the cooperation of federal agencies, professional organizations, medical schools, and individual clinicians.

And finally, for care and services to have the most beneficial impact they should be coordinated and comprehensive. However, for organizations on the front lines of the epidemic, putting together a comprehensive integrated program requires applying to numerous federal agencies. For example, putting together a program that integrates primary care with substance abuse treatment and prevention, and sexually transmitted disease

screening and prevention would require applications to SAMSHA, HRSA, and CDC. Adding housing assistance and a research component would require additional applications to HUD and the NIH. The federal government needs to simplify its funding structures so that primary care, prevention, and treatment can be integrated in order to provide HIV-infected persons and persons at risk for HIV, such as substance abusers and their partners, cost-effective integrated services. Through the Interdepartmental Task Force for HIV and AIDS (IDTF), key agencies must identify approaches for facilitating the development of integrated care and prevention programs at the implementation level.

And finally, if we are to provide high quality cost-effective care and services for HIV-infected persons, we must carefully evaluate our activities. Evaluating current activities can provide valuable information for planners and those on the front-lines of the epidemic. It can assist us in providing better care to persons living with HIV. In an era of limited resources coupled with a demand for high quality, cost effective services, we must use all the tools available to us if we are to help those persons living with HIV.

Give to Lattima

INTERNATIONAL ACTIVITIES

HIV and AIDS are a global pandemic. In the United States it is estimated that 800,000 people are currently infected.

Internationally, the World Health Organization (WHO) 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. Unfortunately, unlike other infectious disease epidemics such as cholera or plague, AIDS is not likely to run its course and subside.

This pandemic presents a unique set of health, social, economic, and political challenges. It most usually affects people aged 25 -44, those in the most productive years of life. The incubation period from initial infection to disease onset can be many years, during which time the infection may unknowingly be spread. The WHO estimates that there will be 10 - 15 million orphans worldwide attributable to HIV/AIDS by the year 2000. A World Bank and U.S. Census Bureau calculated that by 2015, Africa's total gross domestic product could be reduced up 22 percent in comparison to a non-AIDS scenario. In Asia, economic advances are threatened and in some cases reversed due to the epidemic of HIV and AIDS. 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 of healthy men and women to serve in the military.

Due to the enormous proportions of the epidemic, it is clear that if we do not stop the epidemic globally, we will not be able to halt its spread in the United States.

At present a number of federal agencies are working on slowing the epidemic worldwide. The United States Department of State has worked with U.S. Departments and Agencies to identify a framework to guide U.S. international activities, those being to prevent new infections, reduce personal and social impact, and to mobilize and unify national and international efforts. The United States Agency for International Development (USAID) supports a range of activities which strengthen local efforts to combat the epidemic. The United States Information Agency (USIA) supports programs which promote dissemination of U.S. policies and information related to HIV and AIDS, while the Peace Corps trains a portion of its volunteers to directly address HIV-related concerns in their nations of placement. In addition, a number of Departments support research overseas, including the National Institutes of Health, the Centers for Disease Control and Prevention, and the Department of Defense. For example, 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.

Add DoD Vaccine
Trials →

Internationally, the United States has established a leadership role in combatting the epidemic -- this leadership must continue. The U.S. strongly supports the new established Joint United Nations Programme on AIDS (UNAIDS). Moreover, the Director of the Office of National AIDS Policy leads the U.S. delegation to UNAIDS. Supporting UNAIDS and its innovative prevention efforts, and its goal of assuring that treatments and vaccines made available is not only morally fitting, but by supporting these efforts we are also protecting U.S. interests by promoting economic and social stability worldwide.

One of the most challenging aspects of the U.S. effort is effective coordination among a host of agencies with varied missions and activities. The State Department and agencies such as USAID and USIA are primarily focused on international activities, which include HIV-related endeavors. Research agencies, such as NIH and CDC, plan their activities not around where they take place, but around scientific gaps and interests. These differences in focus present challenges in effectively planning, coordinating, and evaluating the overall U.S. international effort. Therefore, in order improve the U.S. international effort, the agencies supporting international activities on the Interdepartmental Task Force for HIV and AIDS must develop a mechanism for identifying and coordinating this effort.

~~Immigration~~

INFORMATION DISSEMINATION

[This section's on another disc the section covers
coordinating between agencies, i.e 076 implementation]

*Prevention - models -
detail*

CIVIL RIGHTS

One of the nation's common goals is to ensure the ethical treatment of persons with AIDS. Discrimination based on HIV status, beyond being morally wrong, 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 seek voluntarily testing for HIV. As a result they remain unaware of their HIV status and cannot take advantage of care which can help them live longer more productive lives. In addition, they may not engage in behaviors that will prevent the spread of infection to others.

The nation has made progress in fighting discrimination. The enactment of the Americans with Disabilities Act provided protection against HIV-related discrimination in employment, housing, and public accommodations. However, the enactment of the ADA in and of itself is insufficient to end discrimination. We as a nation need to be vigilant in our efforts to fight discrimination. This is a responsibility that must be shared among federal agencies, states, communities, and the citizens of this country. As a nation we must first remedy our own discriminatory policies, and, actively prosecute private sector violations.

State and federal laws exist to protect persons with HIV. Many

of the more common legal issues faced by people living with HIV and AIDS, such as family law issues, estate planning, landlord/tenant problems are regulated by state law. The primary source of federal statutory protection for people living with AIDS is the Americans with Disabilities Act of 1990 (ADA).

(Federal agencies are prohibited from discriminating against people with disabilities under the Rehabilitation Act of 1973.) Title I of the ADA prohibits discrimination against qualified disabled individuals in employment settings. The Equal Employment Opportunity Commission (EEOC) is responsible for enforcing Title I. Title II of the ADA prohibits discrimination on the basis of disability with regard to public services while Title III prohibits discrimination on the basis of disability in public accommodations. The Department of Justice (DOJ) is responsible for enforcing Titles II and III.

The federal government will continue to aggressively pursue and prosecute private sector violations of the ADA. Under ~~this~~ *these laws* provision the government has been successful in prosecuting a range of cases, including clinicians who have refused to care for HIV infected patients and employers who have dismissed persons based on their actual or perceived HIV status. In addition to ongoing efforts, a joint Department of Justice and Health and Human Services program will seek to combat nursing home discrimination against persons living with AIDS.

*Are the
culture
bully people
- in actions
send important
messages*

*Beef it up - were doing it - RS accomplish
Successful
HCF A too*

The federal government must also actively work to remedy any of its own existing discriminatory policies. In order to identify areas of possible concern, the Director of the Office of National AIDS Policy to conduct a systematic review of agency and department testing programs. The Administration will also oppose Congressional attempts to force discharge of infected military personnel who are still able to serve their country.

Immigration???

■ **Budget Tables**

■ **Glossary/Acronym List**

Acronyms:

ACTG	AIDS Clinical Trial Group
ADA	Americans with Disabilities Act of 1990
ADC	AIDS Dementia Complex
AHCPR	Agency for Health Care Policy and Research
AIDS	Acquired Immune Deficiency Syndrome
AOD	Alcohol and other drugs
ATOD	Alcohol, tobacco, and other drugs
ATSP	?? (from USAID's plan)
BCC	?? (from USAID's plan)
BOP	Bureau of Prisons
CDC	The Centers for Disease Control and Prevention
CMV	
CNS	Central Nervous System
CPCRA	Terry Beirn Community Programs for Clinical Research on AIDS
DOJ	Department of Justice
DOL	Department of Labor

EEOC Equal Employment Opportunity Commission

FDA Food and Drug Administration

GCRC General Clinical Research Centers Program (NIH)

HCFA Health Care Financing Administration

HIV Human Immunodeficiency Virus

HOPWA Housing Opportunities for Persons with AIDS

HRSA Health Resources and Services Administration

HSV Herpes Simplex Virus

HUD Department of Housing and Urban Development

HTLV-1

ICD Institute, Center, Divisions (at NIH)

IDTF Interdepartmental Task Force on HIV and AIDS

IHS Indian Health Service

IOM Institute of Medicine

JC xxxxxxxxx virus

MAI

MTB *Mycobacterium tuberculosis*

NCRR National Center for Research Resources, NIH

NGO Non-governmental Organization

NIH	National Institutes of Health
NREN	National Research and Education Network (NIH sponsored)
OAR	Office of AIDS Research, NIH
OI	Opportunistic Infection
OMB	Office of Management and Budget
PCP	<i>Pneumocystis carinii</i> pneumonia
PHS	Public Health Service
PLWH	?? (from USAID's plan)
PSA	Public Service Announcement
PVO	Private Voluntary Organization
PWA	Person with AIDS
RFIP	Research Facilities Infrastructure Program (NIH)
RPRC	Regional Primate Research Center (NIH)
RWCA	Ryan White Care Act
SAMHSA	Substance Abuse and Mental Health Services Administration
SPF	Specific Pathogen-Free
SSA	Social Security Administration
SSI	Social Security Insurance
TA	Technical Assistance

UNAIDS

USAID

USIA

WHO World Health Organization

Glossary:

Best Practice: Used by USAID

Incidence:

Population-based: type of epi study -- look at old epi books.

Prevalence:

Primary Prevention:

Secondary Prevention:

Social marketing: application of commercial marketing
 strategies to social issues, is one method
 that can be used to encourage behavior change
 and maintain behaviors.

Translation to Practice:

076:

Appendix:

IDTF Members

Summary of Promises

PREVENTION --

- Trends in the epidemic must be taken into consideration when prioritizing research and service programs.

- We need to collect this type of data in tandem with an enhanced effort to link surveillance and epidemiological data to priority setting, the design, and evaluation of prevention programs.

These needs require that the CDC re-evaluate and reconfigure its data collection efforts; such a shift may require reconfiguring of currently collected data to address these needs.

- Agencies supporting behavioral research must improve their data-sharing and collaborative efforts with agencies responsible for implementing prevention programs. *** Agencies supporting 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. ***

- Agencies supporting social marketing activities need to strengthen our efforts to understanding barriers to the implementation and replication of promising prevention programs. Given the highly innovative nature of these endeavors, it is also

critical to strongly support the provision of technical assistance, and training, and a community-based effort that would test these models in a real-world setting.

■ TA for community planning. However, this process is early in its development and will require technical assistance from _____ if it is to fulfill its potential for good priority setting and decision making.

■ Improve the integration of HIV prevention and substance abuse programs.

■ In addition to our efforts directed towards getting people into treatment for their addiction, we must also support harm reduction approaches for when treatment fails.

■ Given the continuing and growing public health threat posed by the HIV epidemic, needle exchange programs deserve reconsideration by local communities as a possible intervention in the face of this public health emergency.

■ It must be part of the federal response to increase the availability of treatments slots.

■ And finally, to reach our prevention goals, we must improve the integration of prevention activities and messages into primary

health care services. Achieving this level of integration will require the active collaborative efforts on the part of individual physicians, nurses, clinicians, managed care plans, medical schools, professional organizations in addition to local and federal governments.

■ Maintaining Medicaid and Medicare

RESEARCH

■ It is research that will enable us to reach these goals and until they are a reality, the nation must provide solid ongoing support for basic and clinical research.

■ It is essential that the authority granted OAR in the revitalization legislation, including the single appropriation, be supported and maintained.

■ To achieve this the Director of the Office of National AIDS Policy will coordinate an inter-departmental working group to be chaired by the Director of the Office of AIDS Research to develop a coordinated plan and budget for HIV and AIDS research across all departments within 90 days.

■ In order to identify areas for fruitful collaboration and accelerate the pace the Vice President will convene a meeting of

government scientists and leaders of the pharmaceutical and biotechnology companies to identify barriers to the development of vaccines, therapeutics, and topical microbicides.

- It is vitally important that serious consideration is given to all the data that are available and that that information is shared and used by scientists as we move forward in vaccine development process.

- With the advent of accelerated approval by the FDA it will be incumbent on the government to ensure that the efficacy studies, currently mandated by law are carried out.

- The nation must develop a mechanism for ensuring periodic assessment of the state of the art and disseminating that information widely. This will require collaboration with industry, government, and professional groups.

- These are areas of market failures where the government must step in to serve and protect the nation, i.e. vaccine development; access to sophisticated equipment and personnel; head-to-head clinical trials; alternative treatments; ensuring safety of the blood supply.

CARE & SERVICES

- Maintaining Medicaid in a viable format must be a national priority.

- All federal programs, along with state and local organizations, must bear the share of the responsibility for serving and caring for people with AIDS. This must include the integration of HIV-related care into community health centers.

- Maintain sufficient funding for RWCA.

- AIDS programs must do a better job of prioritizing what services they can provide -- and federal agencies must assist grantees in this regard. (Treatment and primary care must come before ancillary services. It is not prudent use of resources to have a perfect case management system if there is no primary care system into which to case manage patients.)

- And finally, the shift to managed care will have implications for programs such as the Ryan White Care Act programs. HRSA will need to provide more technical assistance to prepare grantees to work with and not against managed care.

- The HOPWA program must be protected, but must also be acknowledged that HOPWA cannot do it alone. Protecting this component of the safety net and providing housing for persons living with HIV must be a shared responsibility between federal,

state, local governments and community organizations

■ Improving access to appropriate HIV-related care for prisoners must be a priority. This effort can be accomplished by the effective collaboration and consultation between agencies and that have experience with providing care and agencies which have responsibility for providing care for prisoners.

■ Ensuring this consistency in clinical care will require increased training for all health care professionals in addition to more accountability through the use of performance measures for quality care. Achieving this goal will require the cooperation of federal agencies, professional organizations, medical schools, and individual clinicians.

■ Through the Interdepartmental Task Force for HIV and AIDS (IDTF), key agencies must identify approaches for facilitating the development of integrated care and prevention programs at the implementation level.

■ And finally, if we are to provide high quality cost-effective care and services for HIV-infected persons, we must carefully evaluate our activities.

CIVIL RIGHTS

- Ending discrimination -- This a responsibility that must be shared among federal agencies, states, communities, and the citizens of this country. As a nation we must first remedy our own discriminatory policies, and, actively prosecute private sector violations.

- The federal government will continue to aggressively pursue and prosecute private sector violations of the ADA. In addition, a joint Department of Justice and Health and Human Services program will seek to combat nursing home discrimination against persons living with AIDS.

- The federal government must also actively work to remedy any of its own existing discriminatory policies. In order to identify areas of possible concern, the Director of the Office of National AIDS Policy to conduct a systematic review of agency and department testing programs. The Administration will also oppose Congressional attempts to force discharge of infected military personnel who are still able to serve their country.

INTERNATIONAL

- Support for UNAIDS

- Therefore, in order improve the U.S. international effort, the agencies supporting international activities on the

Interdepartmental Task Force for HIV and AIDS must develop a mechanism for identifying and coordinating this effort.

INFORMATION DISSEMINATION

n:\np\outline14.195

1.

Cancer	111,874 YPLL (in thousands)
Unintentional Injuries	1,796
Heart Diseases	1,324
HIV/AIDS	1,056
2. Public Health Service Plan for the Prevention and Control of Acquired Immune Deficiency Syndrome (AIDS), Public Health Reports 100:453-455, September-October, 1985.
3. Coolfont Report. A PHS plan for the Prevention and Control of AIDS and the AIDS Virus. Public Health Reports 101:341-348, July-August 1986.
4. Report of the Second Public Health Service AIDS Prevention and Control Conference. Public Health Reports. Vol. 103 Supplement No.1 (Revised). 1988.
5. The Public Health Service Strategic Plan to Combat HIV & AIDS in the United States. U.S. Department of Health and Human Services. 1992.
6. AIDS: An Expanding Tragedy. The Final Report of the National Commission on AIDS. Washington, DC. 1993.
7. AIDS and Behavior: An Integrated Approach. p.79.
8. 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.
9. AIDS and Behavior: An Integrated Approach
10. JAMA article used in PRIM&R speech

11. Don C. Des Jarlais, Holly Hagan, Samuel R. Friedman, Patricia Friedmann, David Goldberg, Martin Frischer, Steven Green, Kerstin Tunving, Bengt Ljungberg, Alex Wodak, Michael Ross, David Purchase, Margaret E. Millson, Ted Myers. Maintaining Low HIV Seroprevalence in Populations of Injecting Drug Users. JAMA, October 18, 1995 -- Vol. 274, No. 15. pp 1226-1231.

12. Preventing HIV Transmission: The Role of Sterile Needles and Bleach. Jacques Normand, David Vlahov, and Lincoln E. Moses, Editors. National Academy Press, Washington, DC. 1995

~~Book 234~~

~~scribble~~

Agencies



OMB



Printing



to OMB

~~SPIN~~
The National Commission