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National Plan Drafts 11/3/95

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As of June 1995, African-Americans accounted for 34% of reported AIDS cases. Hispanics represented 17% of new cases through June 1995.

- Areas of High Prevalence
  Evidence that stopping before the spread happens is effective (Des Jarlais article)

- Relative Poverty (??include??? ***)

- Developing countries
  WHO??? estimates that 90% of the new infections occur in developing countries. [Get from LaHoma contact for newest international numbers.]

In the absence of a vaccine or cure, education and prevention are our best hope for controlling the transmission of HIV. Several of the 6 high priority areas pertain directly to prevention, they are:

- Strengthening prevention activities;
  here means actual interventions -- public/private, not overlap but complementary
- Supporting diversified research approaches;
  here means not only funding different areas of research but also different approaches within a research area.

  Research here means behaviorally-related research -- research geared towards producing a preventive vaccine is in the research section????
- Strengthening approaches to substance abuse prevention;
  here means research and treatment --
- Improve accountability and priority setting;
- Translation to Practice

  research and practice -----

Strengthening prevention activities
** may need to mention primary and secondary prevention stuff ---- or define as that prevention here is focused in primary prevention.

There have been success stories with prevention, especially among

gay men, where changes in behavior were initiated by community organizations and have helped to reduce the incidence of HIV in this population. Studies have also indicated that community-based HIV risk reduction programs that are gender relevant and culturally sensitive can be effective. However, many gaps remain. They are --

- need for better/population-targeted prevention messages like PSAs, and ...

- Messages need to be relevant and appropriate to the community they are trying to reach.
  · especially important in the area of prevention messages. Prevention messages are most effective when presented by credible sources -- what is credible to each group (racial, ethnic group, age group, socioeconomic group is different).

- educate the public about behaviors which promote HIV infection (highlight the CDC's new PSAs?)

- Continue constituency involvement. through constituency involvement, enhance responsiveness of federally-funded programs to local needs -- should continue and be refined.

- Linkages -- increase return for marginal increase in resources. Examples , AHCPR studies added on to the infrastructure that has already been established in clinical trials, medicaid, ...

- Coordinating of prevention efforts
We are also in need of strengthened (i.e message appropriate) prevention programs and strategies. At the moment, prevention is the only cure.

- government should complement community efforts -- like GMHC???

Supporting diversified research approaches

As part of a diversified approach to addressing this epidemic, it is important to include solid support for prevention research. Research efforts should not only focus gaps and pay special attention vulnerable oppulations; most promising intervention models; diverse array of levels of intervention; levleo appropriate to the populations (... social marketing ....); research-based interventions useful to communities.

-- support OAR and their review.

For even though there are extensive efforts underway to develop effective treatments for those currently infected, and a vaccine for the infected (?) and uninfected, a cure and preventive vaccine appear to be years away.*****

Part of the comprehensive research approach to address primary and secondary prevention.

Evidence that prevention can work -- but there is still much that is unknown with regard to the psychosocial and behavioral aspects of AIDS. A complicated mix of behavioral, social, cognitive, and biologic factors combine to place individuals at increased risk for HIV infection. Need ---

- research to discern interrelationships among these factors
- methodology improvement -- Improving measurement of both predictors and outcomes in behavioral research
- more information about knowledge, attitudes, and beliefs about AIDS and other STDs that places people at risk
- more information about decision-making processes that lead to high-risk v. protective behaviors and factors that encourage behavior change

Translation to Practice

There is a critical need to improve translation to practice in the area of prevention. Currently, there are any number of good models for prevention interventions which are not making their way to those on the front-lines of the epidemic.

Therefore, there is a great need to establish a closer tie between basic behavioral research and applied prevention interventions. There needs to be TA, and training, and ideally a community-based clinical trials effort that could test these models in a real-world setting.

NIH-sponsored scientific opportunity.

Strengthening approaches to substance abuse prevention

Substance abuse is driving the HIV epidemic in the US. In the U.S., approximately 30% of the AIDS cases are IDUs. Half of all females with AIDS have a history of injecting drug use, and still others are the non-injecting sexual partners of IDUs. In addition, most sexual transmission has a substance abuse component.

Need --

- more research on drug use
- programs targeting drug users

- integrate treatment into more general care services and .. strengthen public health initiatives that address drug abuse and sexually transmitted diseases
- needle exchange --- get into?

Improve accountability and priority setting

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, estimate future directions of the epidemic, and assess the effectiveness of prevention interventions.

Need --

· Linkage of surveillance and epidemiological data to priority setting and design of prevention programs. This may require reconfiguring of currently collecteed data to address these needs.

· Set performance measures -- these can be used as a basis for evaluation and program improvement.

11/3

PS

Patsy, Richard, & Jeff -

This is as far as I could get today & the power going down.

The plan sets out 3 "common goals" and under that 6 priority areas. I developed these out of a variety of ONAP documents/memos, issues raised when we went over the preliminary draft, and what struck me as I read through the plans themselves.

The substantive areas are still in pretty rough form - I'll be fleshing those out next week and on.

I look forward to your comments then — thanks,

Jane

AT

11.3.95 RS

National Plan -- Draft ~~10/31/95~~

TABLE OF CONTENTS

- where is housing

Jane - A truly excellent job. Very impressive. Two major concerns: ① Need to assertively say a major goal is to reduce new infections to zero.

② Where does housing fit in? Care?

Letter from Patsy/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. 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.

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 advent of block grants. Scientifically, we have made much progress, but the virus 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 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 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 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 ....~~?

~~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 threaten 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~~ depends 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.

Since 1981, more than 500,000 Americans have been diagnosed with AIDS and nearly 300,000 men, women, and children have lost their lives to this disease.

Executive Summary

- AIDS is bad and here are the numbers to prove it

- shifting demographics

- What the plan is the first of its kind

- Three goals and the six priority areas

- The plan has been organized by the following substantive areas: prevention, research, services, information dissemination, international, civil rights, and .....

- 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~~ remains 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.~~

[Need something more ...]

An Expanding Public Health Threat

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. *** couple of charts from CDC *****

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 and 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.

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% (** check number**) of all new cases are now related directly

or indirectly to substance abuse, particularly the use of injectable drugs.

Common modes of transmission .. 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. *** more ...***

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.

Unlike other public health threats such as heart disease and cancer, AIDS is an expanding danger. *** from AVOD piece ** more on how much we're spending for care, treatment **** see 1992 PHS report ***

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. **[More ....?]**

Unlike other leading causes of death, AIDS is a disease that strikes people in the prime of life -- it disproportionately kills younger people during their most productive years. As 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.

Lack of health care infrastructure to address the need of the infected... *** add medicare and medicaid language from Richard ***

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 cross-agency use of resources, it is imperative that we organize government-wide efforts so as to ensure optimal use of resources in combatting the epidemic.

This is the first time a 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~~ that 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 Syndrome[2], the Coolfont[3] and Charlottesville[4] reports, and the PHS Strategic Plan to Combat HIV and AIDS in the United States[5]. 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~~ that provides for a government-wide coordinated effort encompassing public health service activities in addition to 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

caregivers and activists

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 Office of National AIDS Policy staff have visited 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 on the front line of this 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~~ General 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~~ four common goals that have been identified are:

Others?

add Reduce new infections

- Provide strong support for research in order to find a cure for those currently infected and a preventive vaccine for the uninfected.
- Until there is a cure, provide solid support for treatment research in addition to creative and effective prevention strategies.
- 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:

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

Challenge of the HIV Epidemic

From the

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.

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 organziations in addition to state and local governments, which often have substantial surveillance, prevention, and health care responsibilities.

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

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.

NB -- these following substantive sections are pretty rough !

PREVENTION

As indicated with the attached agency-specific information, federal prevention efforts are broad and encompass the efforts of many federal agencies including the CDC, DOD, VA, IHS, SAMHSA, HRSA, NIH, and ..(how many will depend on the final classifications). The efforts are reflective of the agency's missions. Through the Centers for Disease Control and Prevention (CDC), the agency with primary HIV-prevention responsibilities, spends nearly $xxx per year in partnership with states, local governments, and community-based organizations to develop and disseminate education materials and programs. In some agencies there is support for primary and secondary prevention efforts as part of medical care, such as at the VA and the DOD. Other agencies focus on specific aspects of prevention, such as SAMSHA's efforts to stem the tide of drug use, and IHS outreach efforts.

In the absence of a vaccine or cure, education and prevention are our best hope for controlling the transmission of HIV. Several of the 6 high priority areas pertain directly to prevention, they are:

- Strengthening prevention activities;
- Supporting diversified research approaches;
- Strengthening approaches to substance abuse prevention;
- Improve accountability and priority setting;
- Translation to Practice

Strengthening prevention activities

There have been success stories with prevention, especially among gay men, where changes in behavior were initiated by community organizations and have helped to reduce the incidence of HIV in this population. Studies have also indicated that community-based HIV risk reduction programs that are gender relevant and culturally sensitive can be effective. However, many gaps remain. They are --

- need for better/population-targeted prevention messages like PSAs, and ...

- Messages need to be relevant and appropriate to the community they are trying to reach.
  - especially important in the area of prevention messages. Prevention messages are most effective when presented by credible sources -- what is

credible to each group (racial, ethnic group, age group, socioeconomic group is different).

- educate the public about behaviors which promote HIV infection (highlight the CDC's new PSAs?)

- Continue constituency involvement. through constituency involvement, enhance responsiveness of federally-funded programs to local needs -- should continue and be refined.

- Linkages -- increase return for marginal increase in resources. Examples , AHCPR studies added on to the infrastructure that has already been established in clinical trials, medicaid, ...

- Coordinating of prevention efforts
We are also in need of strengthened (i.e message appropriate) prevention programs and strategies. At the moment, prevention is the only cure.

- government should complement community efforts -- like GMHC???

Supporting diversified research approaches

Evidence that prevention can work -- but there is still much that is unknown with regard to the psychosocial and behavioral aspects of AIDS. A complicated mix of behavioral, social, cognitive, and biologic factors combine to place individuals at increased risk for HIV infection. Need ---

- research to discern interrelationships among these factors
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Therefore, there is a great need to establish a closer tie between basic behavioral research and applied prevention interventions. There needs to be TA, and training, and ideally a

community-based clinical trials effort that could test these models in a real-world setting.

NIH-sponsored scientific opportunity.

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Need --

- more research on drug use
- programs targeting drug users
- integrate treatment into more general care services and .. strengthen public health initiatives that address drug abuse and sexually transmitted diseases
- needle exchange --- get into?

Improve accountability and priority setting

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, estimate future directions of the epidemic, and assess the effectiveness of prevention interventions.

Need --

· Linkage of surveillance and epidemiological data to priority setting and design of prevention programs. This may require reconfiguring of currently collecteed data to address these needs.

· Set performance measures -- these can be used as a basis for evaluation and program improvement.

RESEARCH

Our primary goal is a cure for those currently infected and a preventive vaccine for the uninfected. Until there is a cure, provide solid support for treatment research must also be a significant area of endeavor. Many agencies play a role NIH, AHCPR, CDC, ENERGY. NIH is a major part the nation's research effort. More ...

Several of the 6 high priority areas pertain directly to research they are:

- Supporting diversified research approaches;
- Improving Translation to Practice;
- Improve accountability and priority setting

(NIH's contribution to strengthening approaches to substance abuse prevention and treatment discussed in Prevention)

Supporting diversified research approaches

Research has been to key to improving lives. People with AIDS now live twice as long as they did a decade ago. Key for the federal government to act in partnership with the private section and support areas where there is a market failure, that is where industry is unlikely to pursue research that would be beneficial to the nation's public health.

Important that the research portfolio not let the pendulum swing too far in one direction -- balance between basic and clinical, primary infection and OIs, early safety and clinical efficacy studies, vaccines and treatment, etc.

- Role of government in market failures ... private/public partnerships ...
  - vaccines
  - provide access to sophisticated equipment and personnel i.e DOE -- helpful in many areas including describing the HIV virus itself and thereby providing valuable information for targeted drug development.
  - therapies in common use for which no information is available, such as alternative treatments
  - doing head-to-head and combination studies
  - The role of government is to balance the 'research ambitions' of individual researchers against the public good.
  - ensuring treatments brought to market are safe and effective
  - ensuring safety of the blood supply (IOM report recs ...)

Improving Translation to Practice

> ... we now have some treatments, but not yet sure how best to use many of the treatments we do have .... where will do our vaccine studies ... weaving in secondary prevention with treatment
>
> Community-based research -- important to go beyond and know how therapeutics work in the real world. Practical information for clinicians.
>
> far better job of communicating research results and implications -- more in information dissemination section.

Improve accountability and priority setting

- Strong support for the OAR is needed -- finally good mechanism for coordination and prioritization

- support recommendations of ADDTF (?)
- Need coordination on vaccines .... DOD and NIH

CARE & SERVICES

- data collection
    - needed to plan and evaluate ---
      - evaluation important vis-a-vis Ryan White -- (go out and say Ryan White needs more evaluation ... need to first document what services they are providing ...)

      - could tie evaluation into Government Performance and Results Act.

policy -- insurance coverage,

.... PWAs tend to be poorer ... access to care ...
... defining a standard of care ... do people have access to the care that is available.
HRSA
DOD
VA
HCFA (MEDICAID, SOCIAL SECURITY)
HUD

INTERNATIONAL ACTIVITIES

USIA -- unmet need (any increase in resources would increase ability of USIA to communicate US policy or information, including AIDS information.)

- Policy -- international,
USAID
PEACE CORPS
DOD
NIH
CDC
OASH/OIH

INFORMATION DISSEMINATION
CDC
NIH
HRSA
OASH
AHCPR
USIA ?

- What to do when there are breakthroughs -- i.e 076 --- some very good things have been done, such as HRSA's conference calls, ... lessons learned for next time ...can be a model for implementation of next breakthrough ... [bigger picture ... AIDS can be a model for other diseases as well ....]

- translation to practice:

  Now at a point where there are some treatments that work -- in comparison to the beginning of the epidemic when there were no treatments, we didn't know the risk factors, etiologic agent, didn't have an inexpensive test, etc. Each new breakthrough ushered in new challenges and required new approaches. Therefore, combatting the HIV/AIDS epidemic has required both federal and local agencies to frequently reassess their plans and approaches and make changes. Rapid change is often challenging, especially in area of program funding where there process can be long... cannot turn an oil tanker on a dime ....

  This phase of the HIV/AIDS epidemic is no different. We are now faced with the enormous task of facing an epidemic that is spreading into rural, heterosexual populations, where the disease is spreading rapidly amongst teenagers, now the leading cause of death for all Americans between the ages of 25-44. And while we now have some treatments, and in fact persons with AIDS are now living twice as long as they did a decade ago, providing access to these treatments can be problematic with the country's market-force driven health care system. ... poor ....

translation to practice also means preparing medicare and medicaid to deliver and cover new services ... private insurers also tend to follow lead of what these federally sponsored programs do ...

AHCPR research indicates that clinicians don't know universal precautions, don't know about transmission ..., etc .. Areas for information dissemination and training. **Which agency should have the lead for information dissemination?** With the demise of OASH -- what nascent efforts there are will be lost. Function for ONAP?

Are there improved ways of linking with professional organizations that traditionally provide training/updates in the field with CMEs and CEUs --- providers are already linked into this network .....

HOPA, HUD?

CIVIL RIGHTS

Agencies Involved: Department of Justice, Equal Opportunity Commission, and Department of Labor

****- Legal role of government to provide care to prisoners -- ensure standard of care.

- Civil Rights/ Discrimination
  Many people live in fear of persons with HIV disease and many PWAs continue to experience discrimination in health care, housing, and employment. ******

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 and benefits issues fall within the state police and commerce powers, and are therefore regulated by state law. It is only when an individual's rights have been statutorily or constitutionally conferred to the protection of the Federal government that Federal law comes into play.

In both state and Federal claims brought by people with disabilities, most include charges that a complainant's Constitutional rights have been violated. For example, an individual bringing suit against her employer, on grounds that she was fired because she has AIDS would charge first that the firing violated Title II of the Americans With Disabilities Act and that the
her dismissal on the basis of her disability violated the Amendment Fourteen of the United States Constitution. Like discrimination on the basis of race or gender, discrimination on the basis of disability implicates the Fourteenth Amendment of the Constitution, guaranteeing a disabled individual's right to equal protection of the law.

Federal Legal Protections.

The primary source of Federal statutory protection for people living with AIDS is the Americans with Disabilities Act of 1990 (hereinafter ADA). Various other Acts were previously relied upon in piecemeal fashion to prevent discrimination on the basis of disability, including AIDS and HIV status.[1] Federal agencies are prohibited from discriminating against people with

[1]For example, the Air Carrier Access Act of 1986, and the Fair Housing Amendments Act of 1988.

disabilities under the Rehabilitation Act of 1973.[2] *

Title I of the ADA prohibits discrimination against otherwise qualified disabled individuals in employment settings. The Act requires potential or current employers to provide reasonable accommodations for an individual's disability, enabling them to perform a job's requirements, so long as such an accommodation does not impose an undue hardship on the covered entity or employer. 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. Subtitle B of Title II proscribes standards for access to public transportation providers. Title III prohibits discrimination on the basis of discrimination in public accommodations and, like Title II, proscribes standards for maintaining non-discriminatory access and "full and equal enjoyment of the goods, services, facilities, privileges, advantages or accommodations" of such public entities.[3] The Department of Justice (DOJ) is responsible for enforcing Titles II and III. [4] *

As stated, discrimination as regards employment by Federal agencies is governed by the Rehabilitation Act of 1973. The Employee Standards Administration of the Department of Labor, through the Office of Contract Compliance Programs, enforces §503 of the Act, which extends the prohibition of discrimination on the basis of disability to government contractors and subcontractors.

Other Federal Responsibilities.

In addition to enforcing relevant provisions of the ADA and litigating civil rights cases involving discrimination based on an individual's real or perceived HIV status, DOJ is responsible for programs that affect populations that have been hit especially hard by the epidemic. In the DOJ's Bureau of Prisons (BoP), the Department has initiated preventative measure directed at both BoP staff, and at inmates. Measures regarding inmates include random testing for HIV though only about 10 percent are actually tested. The Department has also put in place a prevention program for officers and staff of the Drug Enforcement Administration (DEA), and the Federal Bureau of Investigation (FBI), both of which include training and education regarding

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[2]See Leckelt v. Board of Commissioners of Hospital Dist. No.1, 714 F.Supp 1377, aff'd, 909 F.2d 820 (5th Cir. 1990).

[3]ADA, §302(a).

Title IV provides for access to telecommunications services and technology for people with disability, and Title V is the Act's "Miscellaneous Provisions" section.

bloodborne pathogens, as well an investigative safety procedures. The Department of Labor has also enacted Federal employee AIDS awareness and training programs.

The DOJ has provided similar staff training in its administration of the Immigration and Naturalization Service (INS). Furthermore, the INS has provided for limited testing of detainees suspected or diagnosed with HIV or AIDS, or at the detainee's request. INS provides pre- and post- test counseling for detainees believed at risk.

CROSS-CUTTING ISSUES

- general coordination
  with the demise of OASH/OHAP, where does coordination function go. PHS coord to OS? Could leave ONAP in stronger position to fill void. Other issues ONAP should be pushing for vis-a-vis the OASH reorganization.

Glossary/Acronym List

Acronyms:

ACTG	AIDS Clinical Trial Group
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)
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
HRSA	Health Resources and Services Administration
HSV	Herpes Simplex Virus
HTLV-1	
IHS	Indian Health Service
JC	xxxxxxxx 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)
OI	Opportunistic Infection
PCP	*Pneumocystis carinii* pneumonia
PHS	Public Health Service

PLWH	?? (from USAID's plan)
PVO	Private Voluntary Organization
PWA	Person with AIDS
RFIP	Research Facilities Infrastructure Program (NIH)
RPRC	Regional Primate Research Center (NIH)
SAMHSA	Substance Abuse and Mental Health Services Administration
SPF	Specific Pathogen-Free
SSA	Social Security Administration
SSI	Social Security Insurance
WHO	World Health Organization

Glossary:
Best Practice: Used by USAID
Population-based: type of epi study -- look at old epi books.
Primary Prevention:
Secondary Prevention:
Translation to Practice:

Appendix:
IDTF Members

n:\np\outline5.k95

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.

11/3

Patsy, Richard, & Jeff - handwritten RS comments

This is as far as I could get today & the power going down.

The plan sets out 3 "common goals" and under that 6 priority areas. I developed these out of a variety of ONAP documents/memos, issues raised when we went over the preliminary draft, and what struck me as I read through the plans themselves.

The substantive areas are still in pretty rough form - I'll be fleshing those out next week and on.

I look forward to your comments then — thanks,

Jane

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Letter from Patsy/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. 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.

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 advent of block grants. Scientifically, we have made much progress, but the virus 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 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 ....?

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

- AIDS is bad and here are the numbers to prove it

- shifting demographics

- ~~What~~ the plan is the first of its kind

- Three goals and the six priority areas

- The plan has been organized by the following substantive areas: prevention, research, services, information dissemination, international, civil rights, and .....

- 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.

[Need something more ...]

An Expanding Public Health Threat

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. *** couple of charts from CDC *****

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 and 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.

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% (** check number**) of all new cases are now related directly

or indirectly to substance abuse, particularly the use of injectable drugs.

Common modes of transmission .. 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. *** more ...***

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.

Unlike other public health threats, such as heart disease and cancer, AIDS is an expanding danger. *** from AVOD piece ** more on how much we're spending for care, treatment **** see 1992 PHS report ***

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. **[More ....?]**

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. As 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.

Lack of health care infrastructure to address the need of the infected... *** add medicare and medicaid language from Richard ***

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 cross-agency use of resources, it is imperative that we 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 Syndrome[2], the Coolfont[3] and Charlottesville[4] reports, and the PHS Strategic Plan to Combat HIV and AIDS in the United States[5]. 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.

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 Office of National AIDS Policy staff have visited 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 on the front line of this 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. The three common goals that have been identified are:

- Provide strong support for research in order to find a cure for those currently infected and a preventive vaccine for the uninfected.
- Until there is a cure, provide solid support for treatment research in addition to creative and effective prevention strategies.
- 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:

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

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.

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 organziations in addition to state and local governments, which often have substantial surveillance, prevention, and health care responsibilities.

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

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.

NB -- these following substantive sections are pretty rough !

PREVENTION

As indicated with the attached agency-specific information, federal prevention efforts are broad and encompass the efforts of a many federal agencies including the CDC, DOD, VA, IHS, SAMHSA, HRSA, NIH, and ..(how many will depend on the final classifications). The efforts are reflective of the agency's missions. Through the Centers for Disease Control and Prevention (CDC), the agency with primary HIV-prevention responsibilities, spends nearly $xxx per year in partnership with states, local governments, and community-based organizations to develop and disseminate education materials and programs. In some agencies there is support for primary and secondary prevention efforts as part of medical care, such as at the VA and the DOD. Other agencies focus on specific aspects of prevention, such as SAMSHA's efforts to stem the tide of drug use, and IHS outreach efforts.

In the absence of a vaccine or cure, education and prevention are our best hope for controlling the transmission of HIV. Several of the 6 high priority areas pertain directly to prevention, they are:

- Strengthening prevention activities;
- Supporting diversified research approaches;
- Strengthening approaches to substance abuse prevention;
    - Improve accountability and priority setting;
- Translation to Practice

Strengthening prevention activities

There have been success stories with prevention, especially among gay men, where changes in behavior were initiated by community organizations and have helped to reduce the incidence of HIV in this population. Studies have also indicated that community-based HIV risk reduction programs that are gender relevant and culturally sensitive can be effective. However, many gaps remain. They are --

- need for better/population-targeted prevention messages like PSAs, and ...

- Messages need to be relevant and appropriate to the community they are trying to reach.
    - especially important in the area of prevention messages. Prevention messages are most effective when presented by credible sources -- what is

credible to each group (racial, ethnic group, age group, socioeconomic group is different).

- educate the public about behaviors which promote HIV infection (highlight the CDC's new PSAs?)

- Continue constituency involvement. through constituency involvement, enhance responsiveness of federally-funded programs to local needs -- should continue and be refined.

- Linkages -- increase return for marginal increase in resources. Examples , AHCPR studies added on to the infrastructure that has already been established in clinical trials, medicaid, ...

- Coordinating of prevention efforts
We are also in need of strengthened (i.e message appropriate) prevention programs and strategies. At the moment, prevention is the only cure.

- government should complement community efforts -- like GMHC???

Supporting diversified research approaches

Evidence that prevention can work -- but there is still much that is unknown with regard to the psychosocial and behavioral aspects of AIDS. A complicated mix of behavioral, social, cognitive, and biologic factors combine to place individuals at increased risk for HIV infection. Need ---

- research to discern interrelationships among these factors
- methodology improvement -- Improving measurement of both predictors and outcomes in behavioral research
- more information about knowledge, attitudes, and beliefs about AIDS and other STDs that places people at risk
- more information about decision-making processes that lead to high-risk v. protective behaviors and factors that encourage behavior change

Translation to Practice

There is a critical need to improve translation to practice in the area of prevention. Currently, there are any number of good models for prevention interventions which are not making their way to those on the front-lines of the epidemic.

Therefore, there is a great need to establish a closer tie between basic behavioral research and applied prevention interventions. There needs to be TA, and training, and ideally a

community-based clinical trials effort that could test these models in a real-world setting.

NIH-sponsored scientific opportunity.

Strengthening approaches to substance abuse prevention

Substance abuse is driving the HIV epidemic in the US. In the U.S., approximately 30% of the AIDS cases are IDUs. Half of all females with AIDS have a history of injecting drug use, and still others are the non-injecting sexual partners of IDUs. In addition, most sexual transmission has a substance abuse component.

Need --

- more research on drug use
- programs targeting drug users
- integrate treatment into more general care services and .. strengthen public health initiatives that address drug abuse and sexually transmitted diseases
- needle exchange --- get into?

Improve accountability and priority setting

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, estimate future directions of the epidemic, and assess the effectiveness of prevention interventions.

Need --

· Linkage of surveillance and epidemiological data to priority setting and design of prevention programs. This may require reconfiguring of currently collecteed data to address these needs.

· Set performance measures -- these can be used as a basis for evaluation and program improvement.

RESEARCH

Our primary goal is a cure for those currently infected and a preventive vaccine for the uninfected. Until there is a cure, provide solid support for treatment research must also be a significant area of endeavor. Many agencies play a role NIH, AHCPR, CDC, ENERGY. NIH is a major part the nation's research effort. More ...

Several of the 6 high priority areas pertain directly to research they are:

- Supporting diversified research approaches;
- Improving Translation to Practice;
- Improve accountability and priority setting

(NIH's contribution to strengthening approaches to substance abuse prevention and treatment discussed in Prevention)

Supporting diversified research approaches

Research has been to key to improving lives. People with AIDS now live twice as long as they did a decade ago. Key for the federal government to act in partnership with the private section and support areas where there is a market failure, that is where industry is unlikely to pursue research that would be beneficial to the nation's public health.

Important that the research portfolio not let the pendulum swing too far in one direction -- balance between basic and clinical, primary infection and OIs, early safety and clinical efficacy studies, vaccines and treatment, etc.

- Role of government in market failures ... private/public partnerships ...
  - vaccines
  - provide access to sophisticated equipment and personnel
    i.e DOE -- helpful in many areas including describing the HIV virus itself and thereby providing valuable information for targeted drug development.
  - therapies in common use for which no information is available, such as alternative treatments
  - doing head-to-head and combination studies
  - The role of government is to balance the 'research ambitions' of individual researchers against the public good.
  - ensuring treatments brought to market are safe and effective
  - ensuring safety of the blood supply (IOM report recs ...)

Improving Translation to Practice

> ... we now have some treatments, but not yet sure how best to use many of the treatments we do have .... where will do our vaccine studies ... weaving in secondary prevention with treatment
>
> Community-based research -- important to go beyond and know how therapeutics work in the real world. Practical information for clinicians.
>
> far better job of communicating research results and implications -- more in information dissemination section.

Improve accountability and priority setting

- Strong support for the OAR is needed -- finally good mechanism for coordination and prioritization

- support recommendations of ADDTF (?)
- Need coordination on vaccines .... DOD and NIH

CARE & SERVICES

- data collection
    - needed to plan and evaluate ---
      - evaluation important vis-a-vis Ryan White -- (go out and say Ryan White needs more evaluation ... need to first document what services they are providing ...)

      - could tie evaluation into Government Performance and Results Act.

policy -- insurance coverage,

.... PWAs tend to be poorer ... access to care ...
... defining a standard of care ... do people have access to the care that is available.
HRSA
DOD
VA
HCFA (MEDICAID, SOCIAL SECURITY)
HUD

INTERNATIONAL ACTIVITIES

USIA -- unmet need (any increase in resources would increase ability of USIA to communicate US policy or information, including AIDS information.)

- Policy -- international,

USAID
PEACE CORPS
DOD
NIH
CDC
OASH/OIH

INFORMATION DISSEMINATION
CDC
NIH
HRSA
OASH
AHCPR
USIA ?

- What to do when there are breakthroughs -- i.e 076 --- some very good things have been done, such as HRSA's conference calls, ... lessons learned for next time ...can be a model for implementation of next breakthrough ... [bigger picture ... AIDS can be a model for other diseases as well ....]

- translation to practice:

  Now at a point where there are some treatments that work -- in comparison to the beginning of the epidemic when there were no treatments, we didn't know the risk factors, etiologic agent, didn't have an inexpensive test, etc. Each new breakthrough ushered in new challenges and required new approaches. Therefore, combatting the HIV/AIDS epidemic has required both federal and local agencies to frequently reassess their plans and approaches and make changes. Rapid change is often challenging, especially in area of program funding where there process can be long... cannot turn an oil tanker on a dime ....

  This phase of the HIV/AIDS epidemic is no different. We are now faced with the enormous task of facing an epidemic that is spreading into rural, heterosexual populations, where the disease is spreading rapidly amongst teenagers, now the leading cause of death for all Americans between the ages of 25-44. And while we now have some treatments, and in fact persons with AIDS are now living twice as long as they did a decade ago, providing access to these treatments can be problematic with the country's market-force driven health care system. ... poor ....

translation to practice also means preparing medicare and medicaid to deliver and cover new services ... private insurers also tend to follow lead of what these federally sponsored programs do ...

AHCPR research indicates that clinicians don't know universal precautions, don't know about transmission ..., etc .. Areas for information dissemination and training. **Which agency should have the lead for information dissemination?** With the demise of OASH -- what nascent efforts there are will be lost. Function for ONAP?

Are there improved ways of linking with professional organizations that traditionally provide training/updates in the field with CMEs and CEUs --- providers are already linked into this network .....

CIVIL RIGHTS

Agencies Involved: Department of Justice, Equal Opportunity Commission, and Department of Labor

****- Legal role of government to provide care to prisoners -- ensure standard of care.

- Civil Rights/ Discrimination
  Many people live in fear of persons with HIV disease and many PWAs continue to experience discrimination in health care, housing, and employment. ******

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 and benefits issues fall within the state police and commerce powers, and are therefore regulated by state law. It is only when an individual's rights have been statutorily or constitutionally conferred to the protection of the Federal government that Federal law comes into play.

In both state and Federal claims brought by people with disabilities, most include charges that a complainant's Constitutional rights have been violated. For example, an individual bringing suit against her employer, on grounds that she was fired because she has AIDS would charge first that the firing violated Title II of the Americans With Disabilities Act and that the
her dismissal on the basis of her disability violated the Amendment Fourteen of the United States Constitution. Like discrimination on the basis of race or gender, discrimination on the basis of disability implicates the Fourteenth Amendment of the Constitution, guaranteeing a disabled individual's right to equal protection of the law.

Federal Legal Protections.

The primary source of Federal statutory protection for people living with AIDS is the Americans with Disabilities Act of 1990 (hereinafter ADA). Various other Acts were previously relied upon in piecemeal fashion to prevent discrimination on the basis of disability, including AIDS and HIV status.[1] Federal agencies are prohibited from discriminating against people with

[1]For example, the Air Carrier Access Act of 1986, and the Fair Housing Amendments Act of 1988.

disabilities under the Rehabilitation Act of 1973.[2] *

Title I of the ADA prohibits discrimination against otherwise qualified disabled individuals in employment settings. The Act requires potential or current employers to provide reasonable accommodations for an individual's disability, enabling them to perform a job's requirements, so long as such an accommodation does not impose an undue hardship on the covered entity or employer. 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. Subtitle B of Title II proscribes standards for access to public transportation providers. Title III prohibits discrimination on the basis of discrimination in public accommodations and, like Title II, proscribes standards for maintaining non-discriminatory access and "full and equal enjoyment of the goods, services, facilities, privileges, advantages or accommodations" of such public entities.[3] The Department of Justice (DOJ) is responsible for enforcing Titles II and III. [4] *

As stated, discrimination as regards employment by Federal agencies is governed by the Rehabilitation Act of 1973. The Employee Standards Administration of the Department of Labor, through the Office of Contract Compliance Programs, enforces §503 of the Act, which extends the prohibition of discrimination on the basis of disability to government contractors and subcontractors.

Other Federal Responsibilities.

In addition to enforcing relevant provisions of the ADA and litigating civil rights cases involving discrimination based on an individual's real or perceived HIV status, DOJ is responsible for programs that affect populations that have been hit especially hard by the epidemic. In the DOJ's Bureau of Prisons (BoP), the Department has initiated preventative measure directed at both BoP staff, and at inmates. Measures regarding inmates include random testing for HIV though only about 10 percent are actually tested. The Department has also put in place a prevention program for officers and staff of the Drug Enforcement Administration (DEA), and the Federal Bureau of Investigation (FBI), both of which include training and education regarding

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[2]See Leckelt v. Board of Commissioners of Hospital Dist. No.1, 714 F.Supp 1377, aff'd, 909 F.2d 820 (5th Cir. 1990).

[3]ADA, §302(a).

Title IV provides for access to telecommunications services and technology for people with disability, and Title V is the Act's "Miscellaneous Provisions" section.

bloodborne pathogens, as well an investigative safety procedures. The Department of Labor has also enacted Federal employee AIDS awareness and training programs.

The DOJ has provided similar staff training in its administration of the Immigration and Naturalization Service (INS). Furthermore, the INS has provided for limited testing of detainees suspected or diagnosed with HIV or AIDS, or at the detainee's request. INS provides pre- and post- test counseling for detainees believed at risk.

CROSS-CUTTING ISSUES

- general coordination
  with the demise of OASH/OHAP, where does coordination function go. PHS coord to OS? Could leave ONAP in stronger position to fill void. Other issues ONAP should be pushing for vis-a-vis the OASH reorganization.

Glossary/Acronym List

Acronyms:

ACTG	AIDS Clinical Trial Group
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)
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
HRSA	Health Resources and Services Administration
HSV	Herpes Simplex Virus
HTLV-1	
IHS	Indian Health Service
JC	xxxxxxxx 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)
OI	Opportunistic Infection
PCP	*Pneumocystis carinii* pneumonia
PHS	Public Health Service

PLWH	?? (from USAID's plan)
PVO	Private Voluntary Organization
PWA	Person with AIDS
RFIP	Research Facilities Infrastructure Program (NIH)
RPRC	Regional Primate Research Center (NIH)
SAMHSA	Substance Abuse and Mental Health Services Administration
SPF	Specific Pathogen-Free
SSA	Social Security Administration
SSI	Social Security Insurance
WHO	World Health Organization

Glossary:
Best Practice: Used by USAID
Population-based: type of epi study -- look at old epi books.
Primary Prevention:
Secondary Prevention:
Translation to Practice:

Appendix:
IDTF Members

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.