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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 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, Wirth document, and 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 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.

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 Health Care Safety Net
- Improving Translation of Research 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 organizations 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.

Jeff -- here's the prevention section. It still needs work but I'm intellectually stale at this point -- thanks for looking at it. Concerns at this point:

- tone -- strong enough?
 - level of detail for agency activities
 - level of detail for what we need to do
 - political stuff -- needle exchange, medicare/medicaid
 - tone at present is uneven -- how much, if any, of the rhetoric from earlier sections
 - I think we need more on Medicare/Medicaid -- Chris Jennings may have more info. than RS
 - details about how we are going to link all this to budgets areas of collaboration that need to be addressed?
- In the text below (still very rough) I would leave this part out for draft to Council.]

As indicated with the attached agency-specific information, federal prevention efforts are broad and encompass the efforts of a many federal agencies including the Centers for Disease Control and Prevention (CDC), the Department of Defense (DOD), and the Department of Veterans Affairs (VA). (The listing of agencies supporting prevention-related activities can be found in Appendix _____, Prevention Activities).

These efforts are reflective of the agency's missions. 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.

PREVENTION

The prevention task¹ faced by the United States in controlling the epidemic of HIV and AIDS has reached enormous proportions.

¹ Note that the Prevention section will address primary prevention, the behavioral components of vaccine research -- the other aspects of preventive vaccine development will be addressed in the research section. Also, secondary prevention will be discussed in the Research and Services sections and international prevention activities will be discussed in the International Activities section.]

The Centers for Disease Control and Prevention (CDC) estimates that approximately 1 million (check #) 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 (check #) 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 spreads primarily as a result of personal and private individual behaviors that most Americans would prefer not to address directly -- sex and drug use. To be effective, the national HIV prevention program must reach tens of millions of Americans who embody a vast diversity of age, race, ethnicity, geographic locale, sexual orientation, and drug use behaviors.

The development of effective prevention activities must be based on knowing who is becoming infected, knowing the behaviors that are enabling transmission, and understanding the motivations for those behaviors. Both formal research and the practical experience of communities have demonstrated that interventions can reduce risk behaviors. We know that it is important that messages be tailored to their target audience, but there remain many unknown factors that may contribute to the effectiveness of these messages. Despite advances in knowledge in recent years, we are only beginning to understand how to help people translate knowledge into behavior change on the basis of that information. And even if we had complete understanding of the motivations behind behaviors, if prevention interventions do not reach their intended audience, then all the research efforts could be fruitless.

Therefore, prevention priorities should be guided by the major modes of transmission, gaps in scientific knowledge, and current gaps in program areas. Preventing new HIV infections will require a commitment from all levels of government to work in collaboration with communities across America. It is therefore essential, with no cure or vaccine on the horizon in the near future, that strengthening prevention activities must be one of the government's highest priority areas in attacking the spread of the epidemic of HIV and AIDS.

The following three sections address the high priority areas of the comprehensive national plan and 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 sex (> 20%**), and vertical transmission (90% of the cases in the United States occur in women under 22 years of age). (check #s) [IOM study, p 1] 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. 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 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, estimate future directions of the epidemic, and assess the effectiveness of prevention interventions. We therefore need linkage of surveillance and epidemiological data to priority setting and design of prevention programs. This may require reconfiguring of currently collected data to address these needs.

Address specific agencies here? --- in draft? in final document?

GAPS IN SCIENTIFIC KNOWLEDGE

Factors that place individuals at risk for acquiring HIV infection are a complex combination of behavioral, social, cognitive, and biologic factors, and there is much that we have yet to learn about what influences these risk factors in developing effective interventions. There is a need to strengthen our understanding on a broad range of scientific areas including basic behavioral research, factors influencing addiction, and understanding which factors contribute to effective motivational, educational, and social marketing approaches to HIV infection. Filling the gaps in these areas must be a federal priority.

Since behavior change is the primary prevention intervention for HIV infection, behavioral research must be the foundation upon which prevention programs are based. However, much basic research is still in its early stages. The behavioral research program must focus on closing gaps in scientific knowledge by strengthening behavioral science efforts and researching innovative approaches for preventing new HIV infections, with special focus on vulnerable populations. Areas of highest priority must include research to: understand behaviors

associated with transmission of HIV and discern the interrelationships among these factors; improve measurement of both predictors and outcomes in behavioral and mental health research; gather more information about knowledge, attitudes, and beliefs about AIDS and other STDs that places people at risk; and collect more information about decision-making processes that lead to high-risk and protective behaviors; and identify factors that encourage behavior change.

A second major area that must be funding priority is research to improve prevention interventions. Since the beginning of the epidemic there have been federal, community-based, school-based, and workplace-based prevention efforts targeting a variety of groups. 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.⁷ Although social marketing strategies have not been widely applied to AIDS prevention in the United States, they have had demonstrated impact on other health problems in this country and on HIV transmission in other countries.⁸

However, despite these successes there is much that we do not know. There is a need for more research in order to translate findings from behavioral and social science research to design, implement, and evaluate interventions in diverse settings and populations (list these groups?). Successfully coupling findings from basic behavioral research with effective prevention interventions will improve our ability to prevent new infections. Areas of high priority must include research that will:

- improve our understanding of strategies that target sustained adoption and maintenance of HIV preventive behaviors, including factors which weaken the intention-behavior relationship;

- increase the effectiveness of drug abuse, mental health, and alcoholism treatment for reducing HIV risk behavior; and

- enhance the effectiveness of strategies to increase the recruitment, retention, and adherence to low-risk behavior in prevention research, including vaccine studies.

The ultimate result of research should be the translation of research results into practice. There remains a significant gap between what is known about effective interventions and what strategies are incorporated into the design and implementation of actual prevention interventions. Community-based organizations,

which are responsible for a large portion of the prevention programs that are developed in the United States, often do not or are not able to take advantage of current knowledge about program effectiveness. Currently, there are a number of good models for prevention interventions which are not making their way to those on the front-lines of the epidemic. If we are to hope to effectively stem the tide of new infections, it is critical that programs use all basic scientific knowledge currently available to improve the implementation of prevention interventions.

Therefore, there is a great need to establish a closer tie between basic behavioral research and applied prevention interventions. Areas of high priority must include research that will:

- increase our understanding of barriers with the implementation and replication of promising prevention programs;

- enhance the effectiveness of existing prevention and intervention strategies and the development of new behavioral interventions; and

- improve the effectiveness of educational interventions, including the development and use of culturally sensitive strategies in different populations at high risk of acquiring and transmitting HIV infection.

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.

CURRENT GAPS IN PROGRAM AREAS

For prevention interventions to stop new infections they must reach the people at risk. Access to medical care is an important mechanism to the enhance prevention opportunities. It is critical that prevention programs support a broad array of activities that will reach a diversity of risk groups and populations if we are to effectively curb the increase in new infections.

One area of major concern to the Clinton Administration 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. (Do we have any data on HIV negative at risk populations who are on Medicaid?) There are opportunities right now for preventing new

infections, but for this to happen, people must have access to medical care and services.

One of the greatest advances in stopping the spread of HIV has been the results of an NIH sponsored study which showed that the chances vertical transmission could be dramatically reduced by giving AZT to the mother during pregnancy and delivery and to the baby for the first six weeks after birth. While NIH-sponsored researchers discovered this innovation in preventing perinatal transmission, the challenge before the nation now is to provide women and their infants with the opportunity to take advantage of this breakthrough therapy. It is critical that counseling, testing, and appropriate care are available to all women who want it. ... need more??

Persons with substance abuse addictions, the group that is now a major driving force behind the epidemic, are at great risk of suffering from and spreading this epidemic if there is not adequate access to care. Moreover, getting people into care also provides a mechanism for getting them into treatment. In the United States, approximately 30% of the AIDS cases are IDUs. Most sexual transmission cases have a substance abuse component, and half of all females with AIDS have a history of injecting drug use, and still others are the non-injecting sexual partners of IDUs.

There is evidence that a variety of interventions are effective in controlling the spread of HIV among addicted persons and their sexual partners. There is evidence that aggressive intervention programs can prevent the spread and maintain low HIV prevalence rates, and hence transmission rates, in high drug use areas. (DesJarlais study) By reducing the number of infected injecting drug users in a community, it is possible to keep HIV infection rates down. [Any programs for partners ...?]

Another major avenue for controlling the spread of HIV among addicted persons, is to get them into treatment programs. At present, there are woefully too few treatment slots for persons seeking to control their addictions. (get data 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% of the population is affected by AOD in addition to injection drug use. It must be part of the federal response to increase the availability of treatments slots [private too?? or just via Medicaid??]

There is also evidence that traditionally controversial 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 a comprehensive strategy to prevent infectious disease.⁹ 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.

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

- 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

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 sector 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 ...)

There is a critical need to integrate behavioral and social science research with biomedical research to obtain a more complete understanding of the complex factors that contribute to the transmission and disease progression among different groups of people.

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

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

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 requires several responses:

Safe

All programs must bear the share of the responsibility for serving and caring for people with AIDS (. There needs to be a mixed response of community health centers [[general attitude at HRSA that since there are separate discretionary dollars for Ryan White, they can simply refer people to RW programs

Funding increases for RWCA are even more important with changes in Medicare, Medicaid, and the advent of block grants.

Given that the current fiscal environment is restricted ***, AIDS programs must do a better job of prioritizing what services they can provide -- and HRSA must give grantees direction 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.

The shift to managed care will have implications for programs like Ryan White. HRSA will need to provide more technical assistance to prepare grantees to work with and not against managed care.

- 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

- 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

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

USAID --- working with NIH to support basic scientific studies on social and behavioral aspects of AIDS in developing countries and to gather information on high-risk behaviors and behavioral changes related to the transmission of HIV throughout the life course. The results of the studies ultimately will be used to develop interventions to reduce behaviors that place individuals at risk for contracting HIV infection.

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

INFORMATION DISSEMINATION

- 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

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.² Federal agencies are prohibited from discriminating against people with disabilities under the Rehabilitation Act of 1973.³ *

²For example, the Air Carrier Access Act of 1986, and the Fair Housing Amendments Act of 1988.

³See Leckelt v. Board of Commissioners of Hospital Dist. No.1, 714 F.Supp 1377, aff'd, 909 F.2d 820 (5th Cir. 1990).

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.⁴ The Department of Justice (DOJ) is responsible for enforcing Titles II and III.⁵ *

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 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

⁴ADA, §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.

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	xxxxxxxxx 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)
OI	Opportunistic Infection
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)

SAMHSA Substance Abuse and Mental Health Services
 Administration
SPF Specific Pathogen-Free
SSA Social Security Administration
SSI Social Security Insurance

TA Technical Assistance

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:

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:

Appendix:

IDTF Members

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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. JAMA article used in PRIM&R speech
8. The Effectiveness of AIDS Prevention Efforts. Office of Technology Assessment, Congress of the United States. September 1995.
9. 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