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National Plan Drafts 10/29/95

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TO JL - OUTLINE A. K95

Letter from Patsy/Acknowledgments

The national epidemic and international pandemic of HIV and AIDS is a public health crisis of unprecendeted 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 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 predjudice 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 also a system that has been further crippled by the cuts in Medicare and Medicaid brought forth by the 105th??? Congress. Scientifically, we have made much progress, but the virus continues to be a formidable advesary, tesing the best and brightest amongst 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 gameplan *** to this epidemic.

This is the first time an agency-wide national plan has been developed -- it links programs to national objectives. Previous administrations' planning efforts ranged from being overly narrow in focus to lacking altogether, requiring in many cases tremendous effort to overcome a pattern of neglect before foward progress could be made. 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 committment 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 committment 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 Interdeparmental 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 comphrehesive 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 governemtn-wide, and guide us in refining our goals and ojectives in response to the changing face of the epidemic of HIV and AIDS.

There are those who would say that AIDS receives enough funding, that other diseases are more worthy of federal funding. They are wrong. This epidemic of HIV and AIDS already threatens the economic progress of many countries around the world. In the United States HIV is now the leading cause of death among Americans aged 25-44. This is not a time to stop but to move forward and build upon our efforts -- the future of our children depend on it (?? too much ...).

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.

Other ideas --

- Add exhaustion issue ??? i.e. -- realize people and communities are becoming burnt out and exhausted as we enter the 16th year of the epidemc.

- Administration will do its part to ensure that programs are appropriatley focused and well-run, Congress must also do its part by not be short-sighted and adequately funding AIDS programs.

- this plan presents -- the current \

- AIDS has changed who we are as a nation ...

what this plans broad goals, priorities and current federal activities.

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

Executive Summary

What the plan is first time --- ddiffers from other plans which have focused on the pHS

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 ..... [redacted] research funding ->

Findings ???

Summary of what the major activities are in each area.

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 HIV diseases which have arisen over the course of history, ~~AIDS~~ 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.

We as a nation are at a point in history where ...

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.

In addition to the ongoing increase in infections, the demographics of the epidemic have also 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 (44%??) 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. Pediatric cases are also on the rise. 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 in pediatric infections continues, 80,00 American children wil have been orphaned by AIDS by the end of this decade.

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

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. An while most cases are still reported from urban areas, the rate of reported cases in non-metropolitian 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 Organziation (WHO) estimates that since 1981, 2.4 million cases of AIDS have occured worldwide. WHO has estimated that as of mid 1995, 18.5 million adults and more than 1.5 million chidlren have been infected with HIV since the beginning of the pandemic. Add from Balanced Report.

Unlike other public health threats, such as heart disease and cancer, AIDS is an expanding danger. ** more ....*** yes - how much we're spending.

[need to be more human? -- any sidebars re infected persons

The Social Impact

Unfortunatley, predjudice 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 lablr force. Premature deaths due to AIDS result in the loss of many preductive years of life and in many cases depreive young children of their parents. In terms of years of potential lef lost (YPLL), in 1994 AIDS ranked fourth among all leading causes of death.[1] In developing countries, the pandemic threatens to reverse decades of presgress 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..... Medicare + Medicaid Stuff.

Goal of National Plan

The goal of comprehensive national plan is set common goals and priorties for charting our course in combatting the epidemic of

collapse paragraph

Around

National Plan -- Draft 10/29/95

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. There are three primary goals:

- Provide strong support for research in order to find a cure for those currently infected and a preventive vaccine for the unifected.
- 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.

Within these three overall goals, the Office of National AIDS Policy has identified 6 priority areas for 1996. Many of these are continuation of policies and activities that have been ongoing, while others represent a major reshaping in our approach to certain aspects of the epidemic. Given current status of epidemic, these areas require greater effort

How we chose these? Because they were identified as important by members of the President's Advisory Council, and from trips to the field + past correspondence received by the President, staff discussions here with,

Came out priority areas identified by the agencies IDTB members,

1. Strengthening prevention activities.
2. Supporting diversified research approaches. to broaden
3. Strengthening approaches to substance abuse **
4. Stemming the impact of Medicaid and Medicare cuts Reversing? Current MOE?
5. Improve Translation to Practice ----
   Implementation of 076 recommendations. CDC reports that nearly all HIV infections reported in children occurred perinatally. Implementing 076 would result in fewer infections, stave off the human toll, fewer orphans, etc... Throught the Medicaid program, states should be covering counseling and testing ...
6. Improve accoutability and priority setting Really prevention and not 076,

1. Prevention
2. Diversified Research Approaches. Strong support for the Office of AIDS research.
support their evaluation, planning process, and single appropriation ... collaboration, cooperation, efficient use of funds
resources -- include improved coordination .....
4. Substance Abuse has been a neglected part of the epidemic

5. More than ever need support for programs that augment/support the Dismantling the health care infrastructure.
6. Improve Translation to Practice ----
Implementation of 076 recommendations. CDC reports that nearly all HIV infections reported in children occurred perinatally. Implementing 076 would result in fewer infections, stave off the human toll, fewer orphans, etc... Throught the Medicaid program, states should be covering counseling and testing ...
7. Surveillance ????? -- can be part of acountability and data gathering
2. Increased accountability for --- we are in time of tight

This is the first time an agency-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 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 to be updated -- by utilizing this baseline of where we are governemtn-wide, and guide us in refining our goals and ojectives in response to the changing face of the epidemic of HIV and AIDS.

This federal strategy for HIV and AIDS has been developed from the bottom up. Through the Interdeparmental 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. Therefore, the expertise and experience of those who work closely with communities, service and research organizations, and infected persons is brought into this ongoing planning process.

Previous administrations' planning efforts ranged from being overly narrow in focus to lacking altogether, requiring in many cases tremendous effort to overcome a pattern of neglect before foward progress could be made. To date, planning has been primarily focused in the public health service as evidenced by a series of planning 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] 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.

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. Unlike other public health threats, it is a growing epidemic in which more persons are infected every year, in every geographic area, ethnic/race group, and age range. From the time the first case reports of *Pneumocystis carinii* pneumonia were identified in the CDC's June 1981 Morbidity and Mortality Weekly Report (MMWR)[7], the HIV epidemic has been an evolving challenge, requiring specific types of expertise and approaches at different points in time. There was first the search for risk factors, identification of the etiologic agent, and the development of a test to diagnose infected persons and protect the blood supply. Once this preliminary work was accomplished, efforts shifted to a more aggressive pursuit for treatments, characterizing HIV pathogenesis and natural history, communicating to the public how HIV was transmitted, and formulating prevention strategies. In some areas significant progress has been made -- people with HIV infection now live twice as long as they did a decade ago, and with the results of the NIH-sponsored ACTG 076 we now have the ability to prevent perinatally acquired HIV infection in some newborns.

Scientifically, we are now at stage where many scientists believe a vaccine may be possible, where before there was considerable uncertainty. There are some treatments available for both primary infection and opportunistic infections. And while anti-retroviral therapies have found to be modestly effective, many questions regarding HIV pathogenesis remain unanswered, thereby hindering there most efficient use by clinicians.

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. More people are becoming infected by HIV every day -- the CDC estimated that in 1994 alone there were xxx,xxx new infections. 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 ifections. And from societal perspective, we still have a long way to go in overcoming fear and discrimination.

Description of Activities

The scope and nature of the HIV/AIDS by epidemic has affected many activities of the federal government. Federally-sponsored activities range from the direct funding of research grants, health care infrastructure support, setting policies to encourage private sector activity, coordinating a variety of activities, information dissemination, and prosecuting civil rights violations. The comprehensive plan for HIV and AIDS has therefore been organized around these substantive areas: prevention, research, services, information dissemination, international, and civil rights. Current agency activities have not been organized around adminstrative structures, but by substantive areas. *** more? *** 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.*****

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 that directly fund AIDS-specific activities (i.e. NIH, CDC, HRSA, SAMHSA, AHCPR, FDA) while other agencies maintain programs and activities that support a broad range of activities, of which HIV-related activities are one among many (i.e. USAID, USIA, DOD, VA, Bureau of Prisons ...). 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 and 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.

The final section identifies the key areas of the plan that have been identified as critical for continued progress against the HIV/AIDS epidemic.

PREVENTION

- data collection
    - needed to plan and evaluate ---

        - could tie evaluation into Government Performance and Results Act.

        - could tie to Health People 2000

    - HIV incidence data ...
    - data collected can be in turn shared with states and local cities, counties, etc. to help them assess their position, give them an opportunity to compare themselves to other areas which may have similar problems or populations and ask for help, show them where their limited resources would best be targeted.
    - at the CDC -- their tracking of HIV strains could be helpful in vaccine development

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

    · 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).

    · constituency involvement is also an area for improvement ... (i.e AHCPR.., CDC...)

    - Idea -- if government cannot or will not develop the kinds of messages community people say are needed for effective prevention programs, perhaps better to have tax incentives.. say we can't ... How does GMHC do it?

- 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.

CDC
DOD
VA
IHS
ACF

RESEARCH

AHCPR
CDC
ENERGY

NIH
AHCPR
CDC
ENERGY

National Institutes of Health

Area	FY 95 Approp.	FY 95 Pres. Bud.	Bypass Budget	(Bypass) - (Pres.Bud)
Nat. Hist. & Epi.	179,014	188,822	237,271	48,449 (20.42%)
Etiol. & Path.	345,663	374,767	420,983	46,216 (10.97%)
Therapeutics	473,262	495,839	545,405	49,566 (9.08%)
Vaccines	111,831	118,128	154,771	36,643 (23.67%)
Behavioral	159,720	161,595	205,893	44,298 (21.5%)
Training & Infrast.	40,836	42,558	58,703	16,145 (27.50%)
Info.Diss.	15,400	16,115	18,527	2,412 (13.21%)

... 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
NIH

DOE -- helpful in many areas including describing the HIV virus itself and thereby providing valuable information for targeted drug development.
- The area of greatest unmet need was in .....
% of current funding in NIH is .....
Need coordination on vaccines .... DOD and NIH

Strong support for the OAR is needed.

- Role of government in market failures ... private/public partnerships ...
    - vaccines
    - provide access to sophisticated equipment and personnel
    - therapies in common use for which no information is available, such as alternative treatments

  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 ...)

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

- Support OAR -- finally good mechanism for coordination

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)

INTERNATIONAL ACTIVITIES

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

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 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

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

[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).

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 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

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[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.

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.

WHAT SHOULD WE BE DOING (Very rough ...)

10/23 --- what remain concerned about ....

- 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.

- 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.

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	Alcolhol, 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	*Mycobaterium 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.

Appendix:
IDTF Members

Other -- questions, thoughts, etc.
Areas of overlap, areas of duplication

- Standards of Care Guidelines -- who .. many)list ...)
  agencies seem to be doing this ...

JL -- what happens at the monthly coordinating meetings for HIV/AIDS ...?

Safety of the blood supply -- support any of the IOM recommendations?

JL -- process for getting the ultimate buy-in from groups.
  process for resolving overlaps,
In cases like ACF -- better to have no funds -- speak of collateral benefit .... include at all?
crib sheet for OMB -- most important areas?

International -- role of office of international health at OASH?

SSA notes

they have information dissemination
how to categorize ....paying for care

Don't forget to address ....

-- the information dissemination piece at NIH .... how linked to PHS, especially the information subcommittee ..
what are they NOT doing that they should be doing ...
linkage with professional organizations ....??

Dump file

From intro --
- basic demographic data, domestic and international
- bias/prejudice -- maybe quote from Koop
- why is AIDS different --- infectious for life, at present prevention is the only cure, fatal sexually transmitted disease, nearly 100% fatal -- unusual.

There has been a series of planning activities undertaken by various components/representatives/committees of the federal government (Coolfont, Charlottesville, other PHS plans????, National Commission on AIDS, etc).

... areas of unmet service need, unresolved policy issues, areas of scientific opportunity, data needs for planning and evaluation. In some cases the problem that existed near the beginning of the epidemic still exists unaltered. other policy, civil rights issues (ADA),

****HIV presents a unique planning challenge. Since HIV disease was first identified in 1981 through a Morbity and Mortatliy Weekly Report of PCP, significant progress has been made in identifying the infectious agent *** disease went from unknown status in 1981 to identifying the infecti

*** Unprecendeted advances have been made in the last 14 years in understanding this desease which was first identified in 1981. Since its identification, the infectious agent, HIV, has been identified, risk factors for tranmsission have been identified, and through improved treatments and medical management persons with AIDS live twice as long as they did a decade ago (**other?). for both conducting studies that would study possible treatments, now with some treatments, getting them into practice,

... there are have also been areas for frustation and further work.
through Medicaid, Medicare, the Department of Defensein addition
The federal governemnt roles include leadership, financial support to agencies, institituions, states; monitoring of civil rights; support for research and evaluations and dissemination of findings to improve access to care and treatment and a non-discriminatory environment for PWAs.

funding for research and prevention activities, providing health care, and taking a leadership role in supporting non-discriminatory policies for PWAs.

fed gov as necessary coordinates, leads, funds those better able, faciltates, sets policies to encourage private sector activity, ...

benefit -- research advances can come from unexpected areas.

- ??focus on major areas

    **** read legislation -- consequences of what Congress has eliminated ---- similar to what we wh is doing for medicare.....

In order to adequately address current needs and ultimately find a cure for HIV disease, a well-planned, well thought out, rational, coordinated approach and fiscally responsible use of available resources is essential.

**********we must redouble our efforts to promote research, treatment and ethical treatment of persons with AIDS.
AIDS is terrifying tragedy that has already affected too many people areound the world. But ultimately 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.

***The Office of National AIDS Policy believes that the HIV/AIDS epidemic poses a continuing public health crisis that requires sound support of multiple approaches to finding a cure, in addition to identifying effective prevention and treatment approaches until a cure is found. ***

AIDS diagnoses reflect infections that on average took place 10 years perviously and therefore do not portray a clear picture of who is getting infected today.

The continued increase in HIV The World Bank (ref.???) that HIV and AIDS now threatens the economic progress that has been made in many third world countries

Betsy --- we're not looking for home runs, we're looking for answers .....
answering questions that are important to primary care providers ... cure may not be around the corner ... market failure stuff ...

****
Thank agencies/people that provided information, helped pull report together.

- Why a plan is needed (coordination, most efficient use of resources, etc.)
- Fulfills National Commission recommendation.
- President asked for a national plan reflecting the goals and objectives of the federal government in combatting AIDS.
- Thank agencies/people that provided information, helped pull report together.

****
10/23 -- there are those who would say that AIDS receives enough funding, that other disease 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.

Since taking office the President has responded to recommendations from the National Commission on AIDS .....

Need to overcome ignorance and fear ...
The previous administation's efforts ranged from inadequate to lacking altogether, requiring in many cases tremendous effort to overcome a pattern of neglect, before beginning to be able to move forward.

[from national commisssion] In this first report of the National Plan for HIV and AIDS, we attempt ot accomplish the following objectives:

** what we're doing now .... plans that primarily grew up out of independently planned strategies .....*

summarize prjections of the future scope and dynamics of the spread of HIV and its destruction of human life over the remainder of the decade.

project the need for expanded efforts to care for the vast numbers of youg adults who assuredly will become ill during the next decade .... outline where we believe federal efforts will be most needed and effective .... Medicaid message .... vaccines.... research .... care .....

AIDS knows no boundaries ... it is an equal opportunity killer

National Plan -- Draft 10/29/95

.....

****
10/24

In my meetings around the country with persons living with HIV and struck by the personal courage ... I have been struck by the compassion of those who care for the sick ... the communities that have risen to the challenge of caring for their fellow ?? ...

Ultimatley this plan is about hope ... it is about drawing together as a nation, attacking this devasting epidemic head-on, and ensuring a healthy future for all people ....

10/25
As former surgeon general C. Everett Koop noted --"we learned more in [in the first] 6 years of the AIDS epidemic as we had learned about polio in fourty" -- but there is still more to be done. ...

There are many who feel 'burned out' with the epidemic --- mothers who have buried their sons, community organizations that been serving the sick for over 15 years, and people who have buried so many of their friends that have lost count.

HIV and AIDS is also an unprecendented public health challenge that requires unprecedented (novel) approaches. It requires a well-planned, coordinated approach, and fiscally responsible use of resources across all federal agencies.

President asked for a national plan reflecting the goals and objectives of the federal government in combatting AIDS.

Thank agencies/people that provided information, helped pull report together.

- Why a plan is needed (coordination, most efficient use of resources, etc.)
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And because this epidemic has affected so many disenfranchised people in our country, we are also forced to face the precarious state of our social and health care safety nets and infrastructure.

Goals = Cure ... prevention ..... domestically and abroad (?)
Identify Priority Areas for the upcoming year ..... and outyears.

what are plans --
[[from education -- to accomplish our agenda and reform the way we do business, we have prepared a strategic plan with goals, priorities, stategies, and preformance indicators plus a set of organizational values to guide implementation. The strategic poane does not cover every importatn activity in the department -- the plan focuses attentionon a few areas that have been selected as priorities, primarily as arelust of legislatve successes and recommendations for the National Preformance Review. This plan is not a static document -- it will be refined as the Department develops better indicator s of performance and gathers new feddback from our customers.]]

> [from ONDCP -- The 1195 nNational Drug Control Strategy provides a concise, action-oriented approach ot drugr prevention and treatment, law enforcement, local program implementation, and internation/interdiction. Furthermore, the Administration's action plans are grounded in four basic convictions ....]

It will be updated annually to reflect the changing scientific opportunities, shifts in demographics, changes in the health care delivery system, and new prevention opportunities.

????In order to understand the context of the this plan, it is importatn to understand what has preceeded it.

forward advances with regard to treatments for primary infection, opportunistic infections, and vaccines.

and in federal response has therefore been broad ranging.

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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. get reference for MMWR of June 1981 -- cases of PCP in ?? men