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Events - 10/97 - Miss America Visit

Stack:	Row:	Section:	Shelf:	Position:
S	66	6	2	3

- block grants
- relationship between risk factors for women, children & IDUs

AGENDA
Kate Shindle, Miss America
8 October 1997
472 OEOB
1:30 – 2:20 pm

I. What is NORA? (David Harvey and Miguelina Maldonado)

II. The current state of AIDS: New Hope, New Challenges (Christine Lubinski)

a. Reduction in deaths.
   1. new treatments
   2. prevention

b. The epidemic is not over.
   1. Continued need for services.
   2. New infections/increases in STD rates.
      i. women (especially women of color and gay youth)

c. AIDS versus other diseases.

III. Overview of federal AIDS programs and funding. (Winnie Stachelberg)

a. Care/Treatment
   1. Ryan White
   2. Medicaid

b. Housing – HOPWA

c. Research – OAR/NIH and FDA

d. Prevention
   1. Abstinence only
   2. Needle exchange

IV. Special Issues, Special Populations

a. Women (Miguelina Maldonado)
   1. Needle Exchange

b. Youth (David Harvey and Mike Shriver)

c. Needle Exchange (Jane Silver)

V. Further discussion, questions and answers.

NATIONAL ORGANIZATIONS RESPONDING TO AIDS

National Organizations Responding to AIDS

The Federal Government and AIDS

The federal government has a responsibility to fight the AIDS epidemic, care for those who are sick and dying, and conduct research to find a cure.

Congress should not pit funding for one disease against another. Congress must adequately fund prevention, care, and research for all diseases.

The federal government and Congress must be committed to all federal AIDS programs related to care, research, prevention, and housing.

Needle exchange programs work to prevent HIV transmission and must be a part of comprehensive HIV prevention services.

NORA
A coalition convened by
AIDS Action Council
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NATIONAL ORGANIZATIONS RESPONDING TO AIDS

NATIONAL ORGANIZATIONS RESPONDING TO AIDS (NORA) MISSION STATEMENT

Ratified by a vote of NORA coalition members on January 9, 1995

National Organizations Responding to AIDS (NORA) is a diverse coalition of national organizations responding to the AIDS epidemic. NORA's mission is to engage in concerted federal advocacy on national public policy on HIV and AIDS. The Coalition provides a forum for the discussion of emerging legislative, policy and programmatic issues surrounding the AIDS epidemic and for the comprehensive analysis of pending legislation and regulation for the purpose of determining priorities for legislative and administrative action.

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NORA
NATIONAL
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RESPONDING
TO
AIDS

NATIONAL ORGANIZATIONS RESPONDING TO AIDS (NORA)
MEMBER ORGANIZATIONS

Academy for Educational Development
Advocates for Youth
AFL-CIO
AIDS Action Council
AIDS Drug Assistance Program Working Group
AIDS National Interfaith Network
AIDS Network of the Tri-State Area
AIDS Policy Center for Children, Youth and Families
Alan Guttmacher Institute
American Academy of Family Physicians
American Academy of Pediatrics
American Association for Marriage and Family Therapy
American Association of Dental Schools
American Association of Family and Consumer Sciences
American Association on Mental Retardation
American Bar Association
American Civil Liberties Union
American College Health Association
American College of Physicians
American Counseling Association
American Dental Hygienists Association
American Federation of State County and Municipal Employees
American Federation of Teachers
American Foundation for AIDS Research
American Friends Service Committee
American Health Care Association
American Health Information Management Association
American Hospital Association
American Jewish Committee
American Lung Association
American Medical Association
American Medical Student Association
American Nurses Association
American Optmetric Association
American Psychiatric Association
American Psychological Association
American Public Health Association
American Red Cross
American Social Health Association
American Society of Internal Medicine
Americans for Democratic Action
Association for the Care of Children's Health
Association of Black Psychologists
Association of Maternal and Child Health Programs
Association of Nurses in AIDS Care
Association of Reproductive Health Professionals
Association of Schools of Public Health
Association of State and Territorial Health Officials
Biotechnology Industry Association
Broadway Cares/Equity Fights AIDS
Catholic Charities USA
Catholic Health Association of the United States
Center for Women Policy Studies
Child Welfare League of America

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NORA MEMBER ORGANIZATIONS, CONT.

Children Affected by AIDS Foundation
Children's Defense Fund
Children's Hospital AIDS Program
Cities Advocating for Emergency AIDS Relief Coalition
City of Chicago - Washington Office
City of Dallas, Washington Office
City of New York
City of Philadelphia
Coalition for the Homeless
Committee for Children
Committee of Ten Thousand
Consortium of Social Science Associations
Council of Chief State School Officers
Council of Jewish Federations
Department of Health and Human Services
Design Industries Foundation for AIDS
Disability Rights Education and Defense Fund
Federation of Parents & Friends of Lesbians and Gays
Federation of Protestant Welfare Agencies
Funders Concerned About AIDS
Gay and Lesbian Medical Association
Global AIDS Action Network
Hospice Association of America
Human Rights Campaign
Infectious Diseases Society of America
Institute for Family-Centered Care
Intergovernmental Health Policy Project/George Washington University
International Association of Fire Fighters
Legal Action Center
Log Cabin Club
March of Dimes Birth Defects Foundation
Michigan Dept. of Health HIV/AIDS Prev. & Intervention
Mobilization Against AIDS
Mothers' Voices
National Advocacy Coalition on Youth and Sexual Orientation
National AIDS Fund
National AIDS Policy Office
National AIDS Treatment and Advocacy Program
National Alliance for the Mentally Ill
National Alliance of State & Territorial AIDS Directors
National Alliance to End Homelessness
National Assembly of State Arts Agencies
National Association for Home Care
National Association of Alcohol and Drug Abuse Counselors
National Association of Children's Hospitals & Related Institutions
National Association of Community Health Centers
National Association of Counties
National Association of County Health Officials
National Association of Medical Equipment Suppliers
National Association of Pediatric Nurse Associates and Practitioners
National Association of People with AIDS
National Association of Protection and Advocacy Systems
National Association of Public Hospitals and Health Systems
National Association of School Nurses
National Association of Social Workers
National Association of State Alcohol and Drug Abuse Directors

NORA MEMBER ORGANIZATIONS, CONT.

National Association of State Boards of Education
National Black Women's Health Project
National Catholic AIDS Network
National Coalition for the Homeless
National Coalition of Hispanic Health and Human Services Organizations
National Community Mental Healthcare Council
National Conference of State Legislatures
National Council for International Health
National Council of Jewish Women
National Council of La Raza
National Council on Alcoholism and Drug Dependence
National Council on HIV Disease
National Education Association
National Education Association Health Information Network
National Episcopal AIDS Coalition
National Family Planning and Reproductive Health Association
National Foundation for Infectious Diseases
National Gay and Lesbian Task Force
National Health Care for the Homeless Council
National Health Law Program
National Hemophilia Foundation/DC Office
National Hospice Organization
National Latino/a Lesbian and Gay Organization
National Lesbian and Gay Health Association
National Mental Health Association
National Minority AIDS Council
National Native American AIDS Prevention Center
National Network for Youth
National Parent-Teachers Association, The
National Presbyterian AIDS Network
National Puerto Rican Coalition
National Ryan White Title III Coalition
National Task Force on AIDS Prevention
National Urban Coalition
National Urban League
National Women and HIV/AIDS Project
National Women's Health Network
National Women's Health Resource Center
National Women's Law Center
New York State Dept. of Health AIDS Institute
New York State Office of Federal Affairs
Office of National AIDS Policy Director
Oncology Nursing Society
Pan American Health Association
Partnership for the Homeless
Pediatric AIDS Foundation
Pettus-Crowe Foundation
Planned Parenthood Federation of America
Population Services International
Porter Novelli
Presbyterian Church USA
Project Inform
Religious Action Center c/o Union of American Hebrew Congregations
Service Employees International Union
Sex Information and Education Council of the U.S.
Society for the Advancement of Women's Health Research

NORA MEMBER ORGANIZATIONS, CONT.

St. Francis Center
The Sheridan Group
Therapeutic Communities of America
Treatment Action Group
United Food and Commercial Workers International Union
United Jewish Appeal-Federation of New York
United States Conference of Mayors
University of Medicine and Dentistry of New Jersey
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Revised May 1997

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NATIONAL ORGANIZATIONS RESPONDING TO AIDS

RYAN WHITE CARE ACT: KEY TO AMERICA'S RESPONSE TO AIDS

Next to the Medicaid program, the Ryan White CARE Act represents the single largest federal investment in the care and treatment of people living with HIV/AIDS in the United States. The CARE Act supports a wide range of community-based services, including primary and home health care, case management, substance abuse treatment, and mental health, dental, nutritional and housing services. The CARE Act also supports the AIDS Drug Assistance Program, state-administered programs that provide free or low-cost HIV prescription drugs to individuals who would otherwise have limited access to basic HIV treatment.

FUNDING MUST KEEP UP WITH GROWTH IN EPIDEMIC

In FY 1997, the current federal fiscal year, the CARE Act provides $996.3 million in care and treatment services through five distinct titles:

➤Title I -- HIV Emergency Relief Grant Program	$449.9 million
➤Title II -- HIV Care Grants to States	$250 million
AIDS Drug Assistance Program	$167 million
➤Title IIIB -- AIDS Early Intervention Service Grants to Clinics	$69.6 million
➤Title IV -- Services for Children, Youth, Women and Families	$36 million
➤Title V -- Special Projects of National Significance (SPNS)	3% of other titles
AIDS Education and Training Centers (AETCs)	$16.3 million
HIV/AIDS Dental Reimbursement Program	$7.5 million

COST EFFECTIVE

The CARE Act promotes cost-effective systems of care for people with HIV/AIDS. In many cases, people with AIDS do not need costly acute care.

Use of case management services and community-based alternatives ensures that the limited federal government resources are used effectively.

Antibody testing and early intervention services provided through Title IIIB allow individuals to monitor their health status on a regular basis and receive early, preventative care, rather than waiting until an acute episode requires costly hospitalization.

In FY 1998, AIDS advocates are requesting a $393.9 million increase in overall funding for the CARE Act in order to keep up with the growth in the HIV epidemic and the increasing costs of new HIV therapies and diagnostic testing.

QUALITY CARE AND LOCAL CONTROL ARE KEY

The CARE Act provides critically important direct service funding to people living with HIV/AIDS, providing increases in funding to areas of the country that are experiencing significant increases in their reported AIDS cases. The demographics of the AIDS epidemic differ dramatically from one area to another. For this reason, the local planning Consortia and Planning Councils are key to ensuring that the funds allocated to a specific area are used to effectively respond to the local needs of each community. CARE planning has served as the model for Department of Health and Human Services to ensure community control, diverse representation and, most importantly, the input of clients of the programs and other people living with HIV/AIDS. Through the consumer feedback the local planning bodies receive, they are able to respond to the needs of those in care and receive accurate assessments of the quality of the care provided.

LOCAL CONTROL ALLOWS TARGETED LOCAL RESPONSE

The CARE Act provides maximum flexibility to cities and states, allowing them to develop local systems of care based on the specific service needs of people living with HIV/AIDS in their area. Title I of the CARE Act requires that each local HIV services planning council--comprised of local public health, community-based service providers and people living with HIV/AIDS--assess local needs and make recommendations as to which services are needed. Similarly, through Title II, each state is given maximum flexibility to craft a service mix that is responsive to the specific service needs in that state. The CARE Act rejects a one-size-fits-all approach to AIDS care, recognizing that the AIDS epidemic nationally is the combination of many local epidemics.

TITLE V OF THE CARE ACT

Title V of the CARE Act includes the Special Projects for National Significance (SPNS) program, funded through a 3% contribution from each of the other four Titles of the Act, and the AETCs and the HIV/AIDS Dental Reimbursement Program.

Model Programs For Special Populations

Through the SPNS program, the federal government supports community-based programs for the care and treatment of people with HIV/AIDS, including programs to assess the effectiveness of new or innovative models of care and treatment that might be replicated elsewhere in the country. The SPNS program also makes funding available for services for traditionally under-served populations such as individuals and families in rural area, adolescents, Native Americans, homeless individuals and families, the incarcerated and hemophiliacs.

Training Health Care Professionals

There are currently 15 AETCs and over 70 performance sites across the U.S. Their primary goal is to increase the number of health care professionals trained to counsel, diagnose, and treat people with HIV/AIDS and to assist in HIV prevention. The need to train and educate new health care professionals continues because of provider burn out and the fact that the epidemic continues to spread into new regions and affect new populations. Further, specialized training keeps health professionals up to date with new advances in HIV treatments and new standards of care.

HIV/AIDS Dental Reimbursement Program

The Dental Reimbursement Program partially offsets the rising, unreimbursed costs that participating dental education institutions face in providing care to nearly 70,000 people with HIV/AIDS, who suffer a high incidence of oral disease. The program encourages the provision of oral health care to people with HIV/AIDS across the country and provides extensive training for dental students and residents. The program is especially critical since dental benefits are seldom included in basic health insurance plans. While funding falls short of meeting the unreimbursed costs of the dental education institutions, they do serve as a kind of "matching fund" that allows these treatment centers to continue to expand oral health care to people with HIV/AIDS.

THE CARE ACT IS HOW AMERICA RESPONDS TO AIDS

AIDS continues to have a disproportionate impact on urban areas and, in 1996, African Americans accounted for a larger proportion (41%) of adult AIDS cases than whites (38%) for the first time in the epidemic. According to the CDC, AIDS prevalence will continue to rise, underscoring an increasing need for medical and other services for people with HIV/AIDS. This demographic change is occurring as the epidemic continues to expand into previously low incidence states, suburban, and rural communities; however, 74% of all reported AIDS cases are in Title I cities. The CARE Act's design, which emphasizes local planning, decision-making and control, gives communities the tools they need to respond to the epidemic. In 1996, historic advances were seen in the development of new combination treatments to combat HIV infection. The high costs of the drugs and the accompanying diagnostic tests to assess their effectiveness require proportionate increases in funding. The leadership of Congress will be needed to provide the additional resources required to make these life-prolonging and enhancing therapies available and accessible for the neediest people living with HIV/AIDS.

NATIONAL ORGANIZATIONS RESPONDING TO AIDS

MEDICAID AND PEOPLE WITH HIV/AIDS

News from the Centers for Disease Control and Prevention (CDC) that AIDS deaths fell 13% in the last six months of 1996 as a result, in part, of new medical treatments demonstrates the need to protect Medicaid as a life-saving safety net for people with HIV. Medicaid is the single most important health care program for people with HIV, providing access to health care for over 53% of all adults with AIDS and over 90% of all children with HIV/AIDS. In the FY98 budget cycle, the President and Congress have proposed to cut Medicaid. Cutting Medicaid now is unnecessary. According to projections for Medicaid spending released by the Congressional Budget Office (CBO) in January 1997, without any changes in law, Medicaid spending over the next five years will be $86 billion less than previously anticipated. In fact, spending is now expected to fall below Congressional proposals contained in the 1997 budget resolution.

CRITICAL IMPORTANCE OF MEDICAID FOR PEOPLE LIVING WITH HIV

➤In FY 1997, the Medicaid program will serve more than 100,000 people living with HIV/AIDS.

➤People living with HIV/AIDS represent less than one percent of all Medicaid beneficiaries and their care comprises only two percent of total Medicaid costs.

➤Although the number of people with HIV served by Medicaid is relatively small compared to the total number of people believed to be infected, Medicaid accounts for 70% of federal dollars spent on AIDS care.

➤HIV/AIDS is increasing significantly among women, people of color, and injection drug users. Tens of thousands of Americans with HIV, predominantly poor men and women of color, have become sick and/or died because they lacked access to quality health care and treatment. AIDS remains the leading cause of death among all Americans ages 25-44.

➤Medicaid provides for mandatory categories of beneficiaries that include low-income children, people with disabilities and persons over 65 who need long-term care. Additionally, states may elect to extend coverage to additional categories of beneficiaries. For people with HIV, the most important optional eligibility category is the medically needy program. This program allows people with disabilities who become impoverished due to health care expenses to receive Medicaid services.

➤The Ryan White CARE Act is an essential supplement to the Medicaid program. It was established to fill in the HIV/AIDS health and social service gaps for persons ineligible for Medicaid.

➤In 1996, Congress took several actions to weaken the Medicaid safety net by eliminating or restricting Medicaid coverage for legal immigrants, children with disabilities and individuals with substance use and alcoholism treatment needs.

RECOMMENDATIONS FOR THE 105TH CONGRESS

➤**Cutting Medicaid is not necessary.**
With CBO projecting less Medicaid spending than contained in both Republican and Democratic balanced budget proposals, it is unnecessary to cut or restructure Medicaid.

➤**Per capita caps or block grants would eliminate Medicaid's guarantee to services.**
Per capita caps are per person spending limits and block grants are total program spending limits. Both of these mechanisms would encourage states to limit or eliminate Medicaid services or eligibility. There would be no guarantee that all people with HIV who currently rely on Medicaid would get the care they need.

➤**Consumer participation is fundamental to improving Medicaid quality.**
Medicaid reforms have been proposed that would eliminate the requirement that states apply for waivers in order to enroll Medicaid beneficiaries into managed care. The involvement of the Health Care Financing Administration (HCFA) and consumers in the waiver process has been essential to ensuring that the needs of persons with special health care needs are protected.

➤**Consumers must be protected in Medicaid managed care.**
State Medicaid programs have been rushing to adopt mandatory managed care programs as a quick fix to control Medicaid costs. Experience with Medicaid managed care in states across the nation demonstrates that people with special health care needs, including people with HIV, are vulnerable to being denied care or receiving substandard care. Strong consumer protections must be enacted at both the state and federal levels to protect beneficiaries.

➤**DSH Funds must be targeted to support essential community and safety net providers.**
The disproportionate share hospital (DSH) program was established to support hospitals that shoulder a disproportionate burden of Medicaid and uncompensated care. Although some states have abused the program in the past, it is nevertheless essential to support the safety net providers on the front lines of the HIV epidemic. Any changes in this program must ensure that these providers are protected.

WHAT IS MEDICAID?

✚Established in 1965 as Title XIX of the Social Security Act, Medicaid is a federal-state partnership for providing health care to the nation's low-income and disabled residents.

✚Medicaid served 36.8 million beneficiaries in 1996.

✚Beneficiaries are comprised of low-income women and children, people with disabilities and the elderly.

✚Medicaid provides for inpatient and outpatient hospital, physician, laboratory, x-ray, nursing home and home health care services. States can also provide a range of optional services including prescription drugs, clinic services, hospice services and case management services.

✚The Medicaid entitlement guarantees that eligible individuals have access to a minimum level of benefits regardless of the state in which they live.

✚Medicaid is the single largest source of federal funds to the states, representing 40% of all federal payments to the states.

NATIONAL ORGANIZATIONS RESPONDING TO AIDS

PEOPLE WITH AIDS NEED HOUSING

People with HIV/AIDS face a staggering array of barriers to obtaining and maintaining affordable, stable housing. Despite Federal and State anti-discrimination laws, many people with AIDS still face illegal eviction from their homes when it is discovered they have AIDS. Others lose their housing when, as a result of illness and lost wages, they are unable to pay their rent or mortgage. A growing number of people with HIV/AIDS are already homeless when they become ill and are shuffled between acute care hospitals, medically unsafe shelter facilities, and the streets, at an enormous cost to their health. Without stable housing, people with HIV/AIDS cannot access care or the promising new therapies that can greatly improve the quality and duration of their lives.

HOPWA WORKS!

HOPWA is the only federal housing program that provides comprehensive, community-based HIV-specific housing programs. Ninety percent of HOPWA funding is distributed by HUD directly to cities and states with high AIDS caseloads, through a formula grant. The remaining ten percent is awarded on a competitive basis to projects of national significance.

Locally Controlled

HOPWA gives local communities hardest-hit by the AIDS epidemic desperately needed resources and local control over the use of those resources to meet the local housing needs of people with AIDS.

Flexible

HOPWA gives local communities the capability to devise the most appropriate and effective housing strategies for community members with HIV/AIDS and their families. Communities may use HOPWA funds to develop any of a broad range of housing and support services including short-term supported housing, rental assistance for low income persons with HIV/AIDS, community residences, or coordinated home care services.

Cost Effective

Cities and states control the use and administration of HOPWA funds. To ensure funds are used for housing activities, administrative costs are capped by law at 3 percent for formula grantees who administer the funds and 7 percent for the community-based "project sponsors" who actually provide the housing assistance.

At any given time, approximately 30% of people with HIV disease in acute-care hospitals are there only because there is no other community-based residential alternative, at an average cost of $1,085 per person, per day. The cost of providing housing and services at a HOPWA-funded residential facility is between one-tenth and one-twentieth of that amount. HOPWA reduces the use of emergency health care services by an estimated $47,000 per person, per year. HOPWA regulations allow funds to be spent out over a three-year period, and projects often spend funds in advance of actually drawing from their HUD accounts, due to planning, lengthy development pro-

HOMELESSNESS AND AIDS

- 60% of people with HIV/AIDS will require housing assistance at some point during their illness.
- One-third to one-half of all people with AIDS are either homeless or in imminent danger of losing their homes.
- In 1992 the National Commission on AIDS estimated that 15% of homeless people are HIV positive.
- The CDC found an HIV infection rate of up to 21.4% in selected U.S. homeless populations.
- People living with HIV/AIDS have historically had difficulty accessing federal housing programs. Many have waiting lists that are longer than the average lifespan of a person with AIDS. HUD has taken the position that housing programs for people with disabilities generally cannot be used to create AIDS-specific housing. This led Congress to enact the AIDS Housing Opportunities Act (HOPWA) in 1990.

cesses, reservation of funds for periodic rental assistance, etc. Despite this, however, HUD has stated that HOPWA's spendout rates are better than most housing programs, including HOME, for example.

INCREASED FUNDING FOR HOPWA IS DESPERATELY NEEDED

States and localities across the nation face severe funding shortfalls in their ability to address the growing housing needs of their citizens with HIV/AIDS. As the number of AIDS cases continues to grow, the number of jurisdictions eligible for HOPWA funding grows as well. Each year, 10 to 13 new jurisdictions become eligible for formula grants based on increases in caseload. If HOPWA funding remains level, jurisdictions actually see cuts in the funding despite increasing need, because newly-eligible jurisdictions must be accommodated.

Other Programs Can't Replace HOPWA

Congress created the HOPWA program in 1990 because other programs failed to respond to the needs that cities and states have for specific resources and flexibility to enable them to address the housing crisis that the AIDS epidemic poses locally.

Simply listing AIDS housing as an eligible activity for funding under other "block-grant" type programs will neither ensure that needs are addressed on the local level nor provide sufficient resources and guidance to enable localities to address those needs. Failing to increase funding for HOPWA will only reduce resources to cities and states and increase local competition for those resources, while undermining years of local planning and development. HOPWA is one of the few existing HUD programs that already provides the supposed benefits of block grants: formula funding to cities and states based on need, funding that cities and states decide how to spend.

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NATIONAL ORGANIZATIONS RESPONDING TO AIDS

HIV PREVENTION WORKS: SAVES LIVES & DOLLARS

AIDS is now the leading cause of death of men and women age 25-44. Increased prevention funding is needed to ensure that effective, well-funded and well-documented prevention programs targeting populations at risk can be implemented. By reducing the number of new HIV infections, we can reduce the expensive demand for care services in the future. Currently, prevention is the only cure for stopping HIV transmission.

COMMUNITY INVOLVEMENT LEADS TO BETTER PREVENTION

Several studies of federal AIDS prevention programs have concluded that effective behavior change/risk-reduction activities targeted to populations at greatest risk have been severely underfunded. The Centers for Disease Control and Prevention (CDC) instituted HIV Prevention Community Planning as a means of increasing community participation and better targeting of prevention programs.

HIV Prevention Community Planning is an ongoing collaboration in which state and local health departments, social service agencies, nongovernmental agencies, representatives of communities impacted or affected by HIV, and other representatives of communities/groups at risk for HIV infection work in partnership to plan and prioritize an appropriate mix of HIV prevention programs that are responsive to community-identified needs within target populations.

As a result, science-based prevention programs are prioritized by communities to meet their local needs, not the needs of government. The goal of HIV Prevention Community Planning is to ensure that limited prevention funds target populations most at risk for HIV/AIDS. FY 1998 funding increases will help fund a large pool of unmet prevention needs identified by communities across the United States.

FEDERAL APPROPRIATIONS

Preventing AIDS will not only eliminate needless suffering and death but will also reduce expensive health care and other economic costs. The lifetime medical cost of treating a person with HIV from the time that he or she becomes infected until death is more than $100,000. People with AIDS who stop working can no longer generate income and pay taxes and are often forced to draw upon entitlement programs. There continue to be urgent, underfunded priorities in HIV prevention as the virus continues to move into communities of color, women, and adolescents. Cuts in HIV prevention programs will reduce federal spending in the short term, but will lead to increased costs in the future.

PREVENTION WORKS!

Numerous studies show that HIV prevention interventions can change behaviors, in a broad range of populations including, injecting drug users in treatment, gay men at risk and homeless/runaway youth.

Simple informational materials and programs are not enough. To be effective, prevention programs must:

- reach people in a variety of settings (schools, churches, the workplace, clinics and neighborhoods), be culturally specific,
- be intensive and long-term,
- provide populations at risk with the information, support and skills to change high-risk behavior.

NIH CONSENSUS CONFERENCE

In February 1997, the National Institutes of Health (NIH) convened a panel of outside experts to review current trends in the HIV epidemic and the most current research on interventions to prevent HIV risk behaviors and, after weighing the scientific evidence, develop a consensus statement. The panel's conclusions and recommendations include:

➤Interventions are effective for reducing behavioral risk for HIV/AIDS: needle exchange programs, drug abuse treatment, and outreach programs for drug users not enrolled in treatment are particularly effective for reducing risk in drug abuse behavior; information about HIV/AIDS and building skills to use condoms and negotiate the interpersonal challenges of safe sex are effective for risky sexual behavior.

➤The epidemic is shifting to young people, particularly gay and ethnic minority youth; effective interventions for these populations must be developed; AIDS is steadily increasing in women and transmission to their children remains a major public health issue. Interventions focused on their special needs are essential.

➤Regional monitoring of changes in behavioral risk is necessary.

➤Prevention programs for HIV-infected individuals are essential.

➤Legislative restrictions on needle exchange programs must be lifted.

➤Legislative barriers discouraging effective programs for youth must be eliminated.

➤The erosion of funding for drug abuse treatment programs must be halted.

➤The catastrophic breach between the behavioral science of HIV/AIDS prevention and the legislative process must be healed.

BARRIERS TO EFFECTIVE PREVENTION

➤Restrictions on Content of Prevention Programs

Communities are best equipped to set priorities and develop and implement effective programs. Programs must not be restricted from using federal, state or local funds for preventions activities that they deem appropriate and consistent with public health. The federal government must not place restrictions or mandates on the content of HIV prevention programs.

➤Federal Funding Ban on Needle Exchange

The federal ban on the use of federal funds for needle exchange must be lifted. Numerous government reports and scientific studies, including the NIH Consensus Development Conference, an independent scientific panel, have sighted the overwhelming evidence supporting the effectiveness of exchange programs in reducing the rate of new HIV infections among IV drug users, their sex partners and children and concluded that the ban must be removed.

➤Coburn Legislation

HIV prevention efforts are threatened by legislation introduced by Rep. Tom Coburn (R-OK), the HIV Prevention Act of 1997. The bill includes mandatory HIV name reporting and testing provisions and withholds federal Medicaid funds from states that do not comply.

ADOLESCENTS AND AIDS

Finally, all attempts to deprive our nation's youth of comprehensive, appropriate and life-saving health education programs must be fought. The 1996 Welfare Reform Bill, which created a federally-mandated "abstinence-only" education program across all fifty states, highlights Congress' willingness to initiate this type of program in spite of scientific evidence to the contrary.

NATIONAL ORGANIZATIONS RESPONDING TO AIDS

SAVING LIVES THROUGH SYRINGE AVAILABILITY

An estimated 1 to 2 million Americans inject illegal drugs and the sharing of needles among injecting-drug users (IDUs) is a leading cause of HIV transmission. Through June 1996, approximately one-third of all reported adult AIDS cases were directly or indirectly related to injecting-drug use. In addition, more than half of all children with AIDS contracted the disease from mothers who were IDUs or the sexual partners of IDUs.

The scarcity of clean syringes is the result of federal, state and local laws restricting the sale, distribution and possession of syringes. Lowering the rate of injection-related HIV infections requires increasing the availability of drug treatment and increasing access to clean needles through changes in federal, state, and local laws and broad implementation of needle exchange programs.

Barriers to Clean Syringes

STATE AND LOCAL LAWS

Most paraphernalia and prescription laws, adopted to combat illicit drug use, were mostly enacted prior to the HIV/AIDS epidemic. Forty-seven states and two territories have laws that criminalize the sale or distribution of needles and syringes used to inject controlled substances. Eight states and the District of Columbia require a prescription for the purchase of a syringe. Research suggests that legal impediments to syringe possession encourage high-risk behavior while doing little to reduce drug use.

THE FEDERAL FUNDING BAN

Since 1988, Congress has enacted bans on the federal funding of needle exchange programs. The most recent federal ban is included in the Fiscal Year 1997 Omnibus Consolidated Appropriations Act. The ban prevents the use of federal funds for needle exchange programs unless the Secretary of Health and Human Services determines that such programs are effective in preventing the spread of HIV and do not encourage the use of illegal drugs.

The significance of the federal ban extends beyond prohibiting direct expenditure of federal funds. State public health officials and needle exchange program administrators claim that the federal ban has had a chilling effect on state government funding, making states less inclined to fund these programs.

The Clinton Administration has not exercised its discretion in lifting the ban. This position, however, has been contradicted by studies conducted by numerous prestigious organizations and the federal government's own analyses.

Needle Exchange Programs in the U.S.

Needle exchange programs exchange sterile needles or syringes for used ones to prevent the sharing of injection equipment and the accompanying risk of transmission of HIV or other blood-borne diseases. The programs dispose safely of the used needles and offer a variety of related services to participants, including referrals to drug treatment and HIV counseling and testing.

More than 100 exchange programs operate in more than 40 U.S. cities in 28 states. In 1994, approximately 8 million needles/ syringes were exchanged through these programs. Programs operate under a variety of legal and tolerated mechanisms, including exceptions to state statutes, such as health department waivers or local states of emergency.

Needle Exchanges:

➤REDUCE HIV INFECTIONS

Several major scientific studies have shown that needle exchange programs lower the rate of new HIV infections among injection drug users. One recent study showed a two-thirds decrease in HIV infections among participants in five New York City needle exchanges. In addition, exchanges have shown to reduce significantly the rates of hepatitis B and C among participants.

➤DO NOT LEAD TO MORE DRUG USE

There is no evidence that needle exchange programs lead to increased drug use by exchange clients or in the wider community. In fact, exchanges have been effective links to drug treatment programs.

➤ARE COST EFFECTIVE

One model estimates that over five years, needle exchange programs could prevent HIV infections among clients and their sexual partners and children at a cost of about $9,400 per infection prevented. That compares to the more than $100,000 lifetime cost of treating a person with AIDS.

➤SAYS WHO?

Numerous respected organizations have reviewed the research on needle exchange programs and come to the conclusion that needle exchanges are effective. Organizations that have reviewed the science include the:

- ➤Congressional Office of Technology Assessment
- ➤National Academy of Sciences
- ➤National Commission on AIDS
- ➤University of California, San Francisco in a study for the U.S. Centers for Disease Control and Prevention
- ➤U.S. General Accounting Office

The Tragic Cost of Not Acting

According to a June 1996 study, the number of HIV infections that could have been prevented between 1987 and 1995 in the U.S. had needle exchange programs been established is between 4,400 and 9,700. In addition, up to half a billion dollars in health care expenditures could have been avoided. The study also found that an additional 11,300 cases among IDUs, their sexual partners and children could be prevented by access to needle exchange programs through the year 2000.

Success in Connecticut

The Connecticut state legislature partially repealed the state's prescription and paraphernalia requirements in 1992. Prior to enactment, 74 percent of injecting-drug users obtained syringes on the street; following enactment, 78 percent obtained syringes through pharmacies. According to the Connecticut Department of Public Health, needle sharing among IDUs fell from 52 to 32 percent following the 1992 repeal.

Americans Support Needle Exchange

In March 1996, the Kaiser Survey on Americans and AIDS/HIV found that 66% of respondents favored "having clinics make clean needles available to IV drug users to help stop the spread of AIDS."

After reviewing the facts, numerous leading professional organizations have voiced their support for needle exchange as an important HIV prevention strategy. They include the:

- ➤Amercan Academy of Pediatrics
- ➤American Bar Association
- ➤American Medical Association
- ➤American Public Health Association
- ➤Association of State and Territorial Health Officials
- ➤National Academy of Sciences
- ➤National Black Caucus of State Legislators
- ➤U.S. Conference of Mayors.

NORA
NATIONAL ORGANIZATIONS RESPONDING TO AIDS

THE IMPORTANCE OF NIH AIDS RESEARCH

AIDS research at the National Institutes of Health (NIH) has led to major advances in the understanding and treatment of HIV and related opportunistic infections. NIH-funded researchers are now at the forefront of the global effort to build upon these findings and develop new, more effective treatment regimens. Success against AIDS and other diseases will only be possible with a vital national research effort as a whole. Therefore, we must support AIDS research and we must support NIH research overall.

AIDS RESEARCH AT THE NIH

The FY 1997 NIH AIDS research budget is $1.502 billion. The President's FY 1998 request is $1.540 billion. This includes funding in the following areas: epidemiology and natural history of the disease, basic science, development of AIDS treatments, AIDS vaccines and behavioral research.

THE LEVINE REPORT

In March 1996, NIH released the Report of the NIH AIDS Research Program Evaluation Working Group of the Office of AIDS Research Advisory Council. The report, developed by an independent cross disciplinary panel and chaired by Dr. Arnold Levine of Princeton University, is the first comprehensive review of AIDS research at the NIH and represents a real opportunity to expedite the search for a vaccine and a cure for HIV/AIDS. There are 14 major points to the blueprint including increased support for investigator-initiated research, more emphasis on vaccine development and the need to preserve a strong OAR.

FINDING EFFECTIVE TREATMENTS

AIDS research at the NIH has advanced the knowledge and treatment of HIV/AIDS, improving and lengthening the lives of people with AIDS. NIH AIDS research has:

- doubled the survival time of a person with AIDS, and improved quality of life.
- developed the ten FDA-approved drugs for the treatment of HIV infection, AZT, ddI, ddC, d4T, 3TC, nevirapine, indinavir, saquinavir, ritonavir, and nelfinavir.
- led to tremendous advances in the treatment and prevention of AIDS-related opportunistic infections, including CMV retinitis, *Pneumocystis carinii* pneumonia, and toxoplasmosis.
- demonstrated that AZT, when administered during pregnancy, may dramatically reduce HIV transmission from mother to fetus.
- demonstrated that combinations of protease inhibitors and other anti-HIV drugs can reduce the amount of virus in patients to undetectable levels. These new regimens are the most powerful weapons to date against HIV and have dramatically changed the medical management of HIV infection.

OFFICE OF AIDS RESEARCH

The NIH Revitalization Act of 1993 strengthened the authority of the Office of AIDS Research to develop an annual research plan and a consolidated bypass budget for all NIH AIDS research. Reauthorization for the NIH is scheduled again for this fiscal year, and the strategic planning and budget authority for the OAR must be maintained.

With AIDS research underway at all 24 ICDs at NIH, the Office of AIDS Research is essential to the successful prioritization and planning of NIH's AIDS research resources. Through this strategic planning process linked with the annual budget process, the OAR Director has the coordinating and fiscal authority to coordinate the NIH-wide AIDS research program.

The OAR's role is limited strictly to planning, prioritization and budgeting under a system that reduces bureaucracy and eliminates duplication of effort. The OAR neither reviews grants nor conducts research programs. These efforts continue to occur, appropriately, by the scientists at the NIH institutes. The multi-disciplinary nature of AIDS research makes the OAR structure more efficient, and more scientifically sound than a single AIDS institute or uncoordinated efforts across the 24 ICDs.

BROAD BENEFITS OF AIDS RESEARCH

AIDS research enhances and stimulates research in other fields, with broad implications for other diseases such as cancer, heart disease, Alzheimer's disease, and others.

▸Twenty-seven percent of NIH AIDS research funds is used for basic science research with broad implications across scientific disciplines.

▸AIDS research has accelerated study of the human immune system. NIH AIDS research is the main source of funds for immunological research.

▸Several drugs that first received approval for the treatment of AIDS-related conditions, including fluconazole, clarithromycin, and EPO, have important uses in cancer and organ transplant patients.

▸NIH AIDS research has accelerated investigation into viruses, particularly retroviruses. NIH AIDS research has enhanced scientific understanding of all retroviruses, some of which may have important roles in other human diseases.

▸NIH AIDS research has been a driving force in the emerging biotechnology industry, one of the most important U.S. scientific and commercial endeavors of the last decade.

▸NIH AIDS research involving the blood/brain barrier has valuable implications for research on Alzheimer's disease, dementia, multiple sclerosis, encephalitis and meningitis.

COMPARISONS ARE COUNTERPRODUCTIVE

Comparisons of funding for different diseases are counterproductive and misleading. The health of the nation is dependent upon a strong national commitment to biomedical research across disciplines and diseases that benefits all Americans. Because the existing knowledge base, economic and human costs, and scientific opportunities of every disease are important it is inappropriate and unwise to pit research funding for one disease against another.

When discussing AIDS research appropriations, consider these facts:

▸AIDS is an epidemic infectious disease, which did not exist sixteen years ago and continues to spread through our nation.

▸Unlike other major diseases, AIDS is almost 100 per cent fatal.

▸AIDS disproportionately afflicts the young. AIDS is now the leading cause of death among Americans aged 25 to 44 years.

▸Between 1987 and 1992, AIDS grew from the fifteenth leading cause of death among all Americans to the eighth.

▸Scientific priority-setting should consider many factors. One of the most important factors is scientific opportunity. Scientists believe that the scientific opportunities presented by AIDS are enormous, similar to the opportunities that existed in cancer research during the 1970s, which eventually opened new avenues of research and are generally credited with providing the foundation for the molecular biological revolution of the late 1970s and 1980s.

N O R A
NATIONAL ORGANIZATIONS RESPONDING TO AIDS

3 September 1997

Senator Arlen Specter, Chair
Senate Labor, Health and Human Services and
Education Appropriations Subcommittee

Representative John Edward Porter, Chair
House Labor, Health and Human Services and
Education Appropriations Subcommittee

Dear Chairmen:

On behalf of the National Organizations Responding to AIDS (NORA), a coalition of over 175 health, labor, religious, and professional advocacy groups, we thank you for your strong support and awareness of the tremendous need in HIV/AIDS-related programs. We do not support reprogramming of funding between titles of the CARE Act or across AIDS programs. While funding levels in the respective bills demonstrate Congress' understanding of the need in these programs, we specifically request a total increase of $313 million for the nation's comprehensive response for the prevention, care/treatment, and research of HIV and AIDS.

This level of funding more closely reflects the actual need in these vital programs and we ask that you and your colleagues make every possible effort in securing it. Specifically, the requested $313 million reflects the higher funding levels recommended by the House and Senate appropriations committees for each of the following AIDS programs:

• HIV/AIDS Research*	+7.5%	Senate bill
• HIV Prevention:	+$30 million	Senate bill
• Ryan White CARE ACT		
• Title I	+$21.7 million	House bill
• Title II	+$144 million	House bill
• Title III	+$10 million	Senate bill
• Title IV	+$9 million	Senate bill
• AETCs	+$1 million	Senate bill
• Dental	+$400,000	House bill

* NORA supports an increase for AIDS research which is commensurate with the overall percent increase recommended for the NIH.

In addition, NORA consistently opposes any and all negative amendments that would adversely affect AIDS programs and their successful implementation in local communities.

NORA
A coalition convened by AIDS Action Council
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Thank you for the priority you have placed on this nation's fight against HIV/AIDS and providing greater access to life-saving, life-prolonging, and cost effective HIV/AIDS programs.

Your leadership is saving lives.

Sincerely,

Advocates for Youth
AIDS Action Council
AIDS Legal Referral Panel
AIDS Network of the Tri-State Area
AIDS Policy Center for Children, Youth, and Families
AIDS National Interfaith Network
American Association of Dental Schools
American Foundation for AIDS Research
American Nurses Association
American Public Health Association
American Red Cross
American Social Health Association
Association of Nurses in AIDS Care
Association of Reproductive Health Professionals
Association of Schools of Public Health
Center for Women Policy Studies
Cities Advocating Emergency AIDS Relief Coalition
Committee for Children
Consortium of Social Science Associations
Gay and Lesbian Medical Association
HIV Community Coalition of Metropolitan Washington
Human Rights Campaign
Mothers' Voices
National Alliance of State and Territorial AIDS Directors
National Alliance to End Homelessness
National Association of Pediatric Nurse Associates & Practitioners
National Association of People With AIDS
National Association of Protection and Advocacy Systems
National Association of Public Hospitals and Health Systems
National Association of Social Workers
National Catholic AIDS Network
National Coalition for the Homeless
National Council of Jewish Women
National Council of La Raza
National Health Care for the Homeless Council
National Latino/a Lesbian & Gay Organization
National Native American AIDS Prevention Center
National Task Force on AIDS Prevention

Oncology Nursing Society
Service Employees International Union, AFL-CIO, CLC
Title II Community AIDS National Network, Inc.
Treatment Action Group
Union of American Hebrew Congregations
Women's AIDS Network

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N O R A

NATIONAL ORGANIZATIONS RESPONDING TO AIDS

AIDS APPROPRIATIONS RECOMMENDATIONS

FISCAL YEAR 1998

A Coalition Convened by AIDS Action Council
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