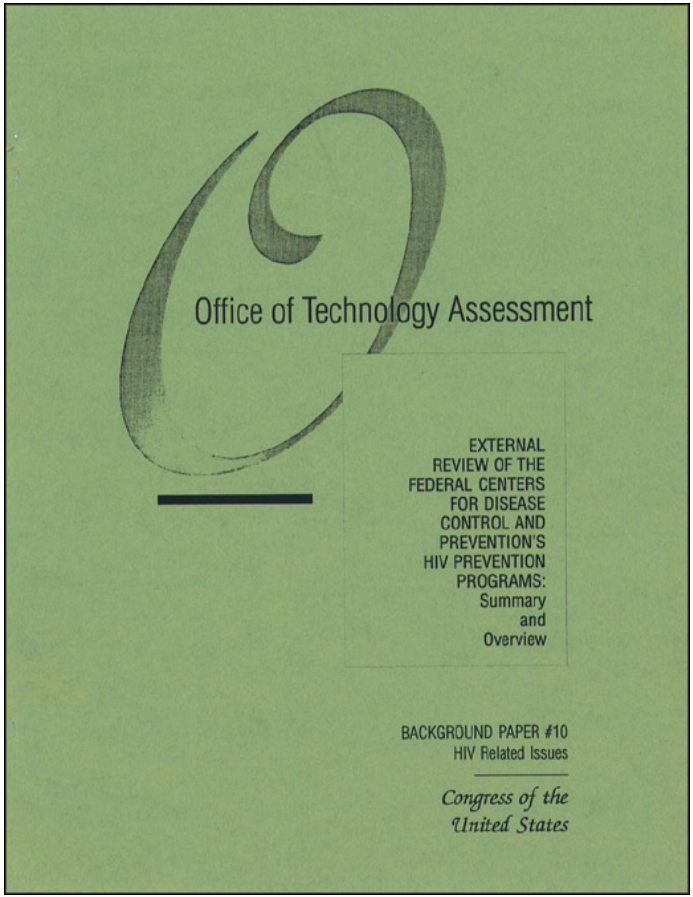
External Review of the Federal Centers for Disease Control and Prevention's HIV Prevention Program: Summary and Overview

September 1994



EXTERNAL REVIEW OF THE FEDERAL CENTERS FOR DISEASE CONTROL AND PREVENTION'S HIV PREVENTION PROGRAMS: SUMMARY AND OVERVIEW

Background Paper #10

HIV Related Issues

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Prepared for

Office of Technology Assessment

United States Congress

September 1994

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INTRODUCTION

In August 1994 the Subcommittee on Health and the Environment of the House Committee on Energy and Commerce requested that the Office of Technology Assessment (OTA) update its 1988 background paper, How Effective Is AIDS ***Education? As*** a prelude to this assessment the Subcommittee also requested that OTA provide a summary and overview of the recent review of HIV prevention programs by the federal Centers for Disease Control and Prevention's (CDC) Advisory Committee on the Prevention of HIV Infection (see Appendix B for the letter of request).

The Advisory Committee's review was conducted from April through October 1993 and the results published in June 1994 (l). In the interim between completion of the Advisory Committee's review and publication of its findings and recommendations, the CDC began to implement related internal and external actions (described later in this summary and overview); and in meetings with the Advisory Committee scheduled for October 11-12, 1994, CDC will be presenting its fill response to the Advisory Committee's findings and recommendations (2).

Two other related and significant reviews of federal HIV prevention programs are also currently being conducted. First in early 1994, at the request of the Secretary of the Department of Health and Human Services (DHHS), the Assistant Secretary for Health convened a DHHS HIV/AIDS Coordinating Committee "to assure that all aspects of the Department's HIV-related activities address the multiple challenges posed by the HIV epidemic in prevention, research, drug development and approval, health care services, and financing in a coordinated manner" (3). An HIV Prevention Work Group was created in June 1994, with the mission of helping the Department establish priorities for investment in HIV/AIDS prevention for FY 1996, and to work on an agenda for development of a more comprehensive plan for HIV/AIDS prevention activities across DHHS's agencies. The report and suggestions for an ongoing process for developing a comprehensive HIV/AIDS prevention plan were to be presented to the Assistant Secretary for Health and the Secretary of DHHS in September 1994 (3).

Second, in February 1994, the Center for AIDS Prevention Studies of the University of California, San Francisco, and the Harvard AIDS Institute began a two-year collaborative effort to rethink HIV prevention activities "because of the growing realization that prevention efforts need to be sustained for the long haul, the change in administrations in Washington that permits important shifts in direction, and the recognition that budget constraints compel the most effective use of resources for prevention activities" (4). This project is funded by the Henry J. Kaiser Family Foundation, whose Executive Vice-President assumed the Chair of the CDC Advisory Committee on the Prevention of HIV Infection after subcommittees of the Advisory Committee completed their work and prior to the synthesis of the subcommittees' findings and recommendations into the June 1994 report by the Advisory Committee.

The Advisory Committee was established and chartered by the Secretary of DHHS in accordance with P.L. 92-463 of the Public Health Service Act. According to CDC (1), its strategic

planning for HIV prevention began in 1989. Phase I established four general goals: 1) assess risks; 2) develop prevention technologies; 3) build prevention capacities; and 4) implement prevention programs. Phase II focused on four groups at increased risk for HIV infection: women and infants; injecting drug users; youth in high-risk situations; and men who have sex with men. In Phase III CDC outlined five program strategies expected to have the greatest HIV prevention impact:

1. strengthen current systems and develop new systems to monitor the HIV/AIDS epidemic, as a basis for directing and assessing HIV prevention programs;

2. increase public understanding of, and involvement in, and support for HIV prevention;

3. implememt comprehensive school health education programs to prevent the initiation of risk behaviors that lead to HIV prevention and other health problems in youth;

4. collaborate with prevention partners to prevent or reduce HIV-related risk behaviors; and

5. increase knowledge of HIV serostatus and improve referral systems to appropriate prevention and treatment services.

At the request of the CDC, the Advisory Committee, with the assistance of outside experts, reviewed these five program areas to evaluate what had and had not been effective to date. Five subcommittees were formed each chaired by an Advisory Committee rnember and a lead consultant and assisted by subject area experts selected by the Advisory Committee. Public meetings were held to visit program sites, meet with governmental and nongovernmental~ representatives, and discuss program strategies and activities. One Advisory Committee member has described the review process as follows: "When we made the decision to go to the cities, it was to gather information form around the country to see the diversity of programs. But... in our report we don't have to limit ourselves to what we've heard. We are experts and can use our own judgement and expertise in drafting the recommendations " (5). Each subcommittee produced a report for review by the full Advisory Committee, which developed the executive summary of the final report.

THE ADVISORY COMMITTEE'S FINDINGS AND RECOMMENDATIONS

The Advisory Committee's report: 1) identified nine common * that the members viewed as important to highlight; and 2) Summarized the findings and recommendations of the five subcommittees. Thus, the full Committee did not evaluate and synthesize/reconcile the subcommittee reports, and there may be inconsistencies and contradictions between the findings and recommendations of the five subcommittees (6). For example, the subcommittee on "Preventing Risk Behaviors Among School-Aged Youth" could not reconcile differences among its members and submitted two reports, both of which were included in the final report. While these

two reports would seem nearly identical to the casual reader, the full Committee found it necessary to publish both reports because of "the differing approaches taken by subcommittee members regarding results of tie review" (l). While both factions agreed that the needs of high-risk youth should be addressed both inside and outside the school setting, they differed on the degree to which prevention efforts ought to be targeted toward the general kindergarten to 12th grade population, as is the current approach, or ought to be targeted toward high-risk youth both in and out of school.

The general findings of the Advisory Committee were as follows:

1. **Prevention is necessary and urgent** With neither a cure nor a vaccine *on the* immediate horizon the only promising barrier against the virus is widespread adoption and maintenance of personal behaviors that eliminate the chances of exposure and infection. However, a lack of commitment from all levels of government to prevention, along with restrictive federal policies, has weakened the prevention effort since the onset of the epidemic, and prevention has been relegated to a status secondary to treatment.

2. **Behavior can be changed.** Both formal research and the practical experience of communities demonstrate that intensive interventions can reduce risk behaviors. The essential but still unanswered question is what set of interventions can change most people's behavior most of the time, over a lifetime.

3. **Prevention should be guided by science.** **The** nation has invested inadequately in prevention research, especially as it concerns human sexuality and drug-use behaviors, and substantial increases are needed in funding for prevention research. The key role for CDC is to develop, synthesize, and promulgate scientific guidance for the HIV prevention activities carried out by community organizations and state and local health authorities.

4. **Prevention requires sustained, long-term efforts.** Pressures to come up with fast, easy solutions have left us with a prevention model that is inadequate to address the lifetime risk of HIV infection. We must both initiate and sustain changes in risk behaviors; we need generational changes in social norms.

5. **Partnerships and collaboration are key.** Although the CDC has the lead in funding, planning, and implementing prevention activities, opportunities have clearly been missed for establishing and promulgating a unified agenda for prevention services and research. CDC, or some other federal entity, must take responsibility for developing fictional alliances, promoting participatory planning, encouraging communication, and ensuring coordination. A local organization's deep commitment to HIV prevention and strong community ties do not guarantee it the requisite knowledge and skills to design and successfully carry out a broad, long-term prevention program. The line between support and responsible supervision on the one hand, and arbitrary interference on the other, presents a major challenge for the CDC and other federal agencies.

6. **Prevention interventions must** strike a balance between targeted efforts and efforts to change general community norms. Nearly all Americans are at some risk of HIV

infections, but their degree of risk varies dramatically. Those charged with carrying out prevention must choose strategies and allocate resources with this uneven risk in mind. There can be no standard formula; we ***must*** constantly question whether the right balance is being achieved.

7. **More funding for prevention is needed. The** level of federal financial commitment to HIV prevention is inadequate to address the overwhelming need for long-term, sustained, individual-level behavior change interventions for millions of at-risk and HIV-infected persons. Restrictive policies and Congressional earmarks attached to these funds have further curbed flexibility and prevented the implementation of innovative and important prevention approaches.

8. **Stigmatization and discrimination continue to adversely affect prevention efforts.** A continuing effort to dispel misconceptions about HIV transmission and to protect the confidentiality and human rights of those with or at risk for HIV infection must be an integral **part** of the national prevention agenda.

9. **CDC's organizational structure may be hindering prevention efforts.** CDC's HIV prevention programs are dispersed among ten centers that compete internally for resources. Although CDC's structure has been reviewed more than once over the past several years, the Committee's members generally agree that another look is merited. Testimony from those working at the community level suggests that the current structure is sufficiently dysfunctional as to warrant immediate action.

The findings and recommendations of the five subcommittees that were highlighted by the Advisory Committee were as follows:

Monitoring the epidemic. The main thrust of CDC's monitoring efforts has been the AIDS case-reporting system. The subcommittee recommends a shift in emphasis toward the "front end" of the epidemic, advocating a wider view of monitoring that includes precursors to AIDS, **including sexual** and drug-use behaviors,

Improving public understanding of the epidemic. The subcommittee concluded that the goal of the early years, to increase general awareness of AIDS, has been achieved, and it was **now time to shift away** from the emphasis on the general public and toward specific populations at increased risk of HIV infection.

Preventing risk behaviors among school-aged youth. This subcommittee called for better coordination of CDC's youth-related programs and expansion of the strategic plan for school-based programs to address the prevention needs of all young people, in or out of school.

Developing partnerships for HIV prevention. This subcommittee concluded that HIV prevention partnerships were characterized by ill-defined goals, poor communications, lack of trust, conflicting roles, dwindling resources, competition for finding, and anger related to lack of technical assistance and confusion about CDC's role. It called for CDC to become a strong

national advocate for HIV prevention and to provide the leadership, funds, skills, and training needed to forge effective, participatory partnerships.

Promoting knowledge of serostatus. **This** subcommittee concluded that HIV antibody testing has too often been erroneously equated with HIV prevention. While acknowledging its benefits as a diagnostic tool to help infected persons obtain medical treatment, the subcommittee found its benefits as a prevention tool to be much less clear. Therefore, it disputed the view that CDC's counseling, testing, referral, and partner notification (CTRPN) program should continue as the cornerstone of the national effort to prevent HIV infections and recommended shifting the emphasis **away** from testing as the main prevention intervention toward: 1) ongoing, individual-level behavior-change interventions for those at highest risk of HIV infection and those already infected; and 2) large-scale community-level interventions aimed at changing community norms.

Appendix C contains the fill text of the Advisory Committee's findings and recommendations.

The Advisory Committee concluded its report as follows: "This external review is the first step in what the Committee hopes will be a continuing process of assessment and "course correction." Unfortunately, the structure of the review precluded an analysis of CDC's ***overall*** approach to HIV prevention: the plan, the objectives, the acceptable outcomes, the components of the prevention mix that are (and are not) achieving success. Such an analysis is a logical-and necessary-next step" (1),

RELATIONSHIP TO OTHER ACTIVITIES

Followup Activities by CDC

In late 1993, in response to the Advisory Committee's "developing partnerships" recommendations, CDC introduced community planning into its state and local health department HIV Prevention Cooperative Agreement grants, awarding approximately $12 million in new funds in January 1994 to establish plans for the use of HIV prevention resources awarded under the Cooperative Agreements (7). HIV Prevention Community Planning is defined as "an ongoing process whereby grantees share responsibilities for developing a comprehensive HIV prevention plan with other state/local agencies, nongovernmental organizations, and representatives of communities and groups at risk for HIV infection or already infected" (7). Additional guidance for such community-based planning was provided under contract with the CDC by The Academy for Educational Development (8,9). Applications for CDC finding under the Cooperative Agreements for FY 1995 and beyond must be based on such Comprehensive HIV Prevention Plans (7).

In January 1994, the CDC also announced its Prevention Marketing Initiative (PMI), an application of marketing techniques and consumer-oriented communications technologies, based on science and directed in the first phase to the prevention of the sexual transmission of HIV and other

sexually transmitted diseases among young adults 18-25 years of age. The PMI is a multi-level approach which includes a national health communications component, focusing on condom effectiveness and usage, a national prevention collaboration and transfer of technology and information, local demonstration sites to utilize social marketing methods to develop and implement HIV prevention programs that build on the messages of the national campaign, and application of prevention marketing principles within the HIV prevention community planningprocess" (2).

As stated in the Introduction to this Summary and Overview, CDC has also been preparing its response to the Advisory Committee's June 1994 report (l), and will present these responses to the ***Advisory Committee*** on October 11-12, 1994 (2).

Finally, CDC representatives are participating in the DHHS HIV/AIDS Coordinating Committee and in the Committee's HIV Prevention Work Group, with initial recommendations scheduled to be presented to the DHHS Secretary and the Assistant Secretary for Health in September 1994 (3).

DHHS HIV/AIDS Coordinating Committee's HIV Prevention Work Group

The Coordinating Committee was convened in early 1994, and the HIV Prevention Work Group was created in June 1994 (3). The Work Group consists of senior HIV/AIDS agency staff from the CDC, Health Resources and Services Administration, the National Institutes of Health, including the National Institute on Drug Abuse and National Institute of Mental Health, the Food and Drug **Administration, the Indian** Health Service, the Office of Minority Health, the Substance Abuse and Mental Health Service Administration and the Health Care Financing Administration; consultants from outside government, including HIV-infected persons and persons from populations affected by HIV and at risk for infection with expertise in HIV prevention; persons representing community-based and national HIV prevention service and advocacy organizations; and researchers, epidemiologists, health providers, substance abuse specialists, educators, and communications and social marketing specialists. Its goals are to: 1) draft recommended priorities for investment in DHHS's prevention efforts for FY 1996; 2) develop a process for review and comment on the draft priorities by DHHS and non-governmental experts; 3) submit recommendations for priorities for FY 1996 to the Assistant Secretary for Health and the Secretary for review; and 4) develop recommendations for an ongoing process to assess DHHS HIV prevention activities and to set priorities. Its recommendations are expected to be released in October 1994:

UCSF Center for AIDS Prevention Studies/Harvard AIDS Institute HIV Prevention Project

This two-year project, initiated in February 1994, "is dedicated to rethinking HIV prevention activities as the second decade of AIDS unfolds" (4). The project is examining various

aspects of what works in prevention, including standards for programs, evaluation methodologies, cost effectiveness, the role of cultural specificity and targeting of interventions, and addressing ways to encourage better two-way communications between those who staff or administer prevention programs and behavioral scientists. The likely focus for seared-year (1995) activities will be "the policy impediments continuing to vex effective HIV prevention... identifying what those policy impediments are, what progress had been made on them over the past 10 years, and what strategies might be pursued to push forward on them over the next decade" (4).

CONCLUSIONS

Behavioral research, a crucial component of recommended HIV/AIDS prevention policy, is vulnerable to influences from outside the research community, because its application often involves humanconduct over which segments of our society have conflicting values, beliefs, and opinions. If a commitment to behavioral science-based HIV prevention of the scope and redirection called for by the CDC Advisory Committee on the Prevention of HIV and others is to be initiated, much less achieved, then there needs to be leadership, flexibility, and new partnership arrangements.

The difficulty in implementing and sustaining a long-term, substantial behavioral science-based approach to HIV/AIDS prevention is succinctly summed up by the Advisory Committee's call for "generational changes in social norms." But this will be possible not only through sustained and substantial funding, but also through program flexibility that allows for true experimentation in behavioral approaches. This means a difficult period ahead. Past HIV prevention efforts have been characterized by: charges of micromanaging by Congress; detailed directives from the funding agencies which at the same time have not taken enough risks through support of strong and targeted behavioral interventions; unrealistic expectations; and many community-based activities that are so localized and dispersed as to be unevaluable and unaccountable.

Congressional and Executive Branch leadership in resetting the HIV/AIDS prevention agenda is critical. Actions to be considered by Congress include: a broader approach to prevention, concentrating on outcomes rather than on specific programs and activities; federal agencies' roles and funding in basic and applied behavioral research and the interrelationships between these federal agencies; and the relative roles and finding of behavioral and biomedical approaches to the HIV/AIDS epidemic. One long-time observer of national AIDS/HIV policy summarizes his view of Congress's role as follows: "I think Congress (beyond its general oversight responsibilities to make sure the programs are really working as intended) should limit its role to perhaps requiring of the CDC and/or the Public Health Service, a prevention plan to accompany its budget request along the scale of that now required of the NIH for AIDS research. This would be a way to assure Congress that prevention spending is based on a systematic review of the science, of existing programs, of the epidemiology, and of community needs" (10).

Leaders in the Executive Branch-at a minimum, the Secretary of DHHS, the Assistant Secretary for Health, and the Director of the CDC-must set the tone and challenge for their agencies' efforts to elevate HIV prevention activities to a significantly higher plane of attention and resources, and to improve the behavioral science base of these activities. An immediate indication of this commitment to a long-term strategy for HIV prevention will be the report of the DHHS HIV/AIDS Coordinating Committee and its subsequent use in influencing Executive Branch HIV/AIDS policies.

Flexibility of PHS agencies' responses will also be critical. As the Advisory Committee stated, "(u)nfortunately, the structure of (its) review precluded an analysis of CDC's ***overall* approach to HIV** prevention: the plan, the objectives, the acceptable outcomes, the components of the **prevention mix that are** (and are not) achieving success. Such an analysis is a logical-and **necessary-next step"** (l). The CDC's October 1994 response to the Advisory Committee's findings and recommendations should include its response to the Advisory **committee's query as to** whether CDC's organizational structure may be hindering prevention efforts. Subsequent queries should also inquire into the continued viability of CDC's five program strategies (strengthen current systems, increase public understanding, implement school health education programs, collaborate with prevention partners, and increase knowledge of HIV serostatus), as the HIV prevention efforts are clearly entering a Phase IV, and CDC previously had changed its program strategies with each new phase.

Finally, a clear message of the Advisory Committee's report is the need for new partnership arrangements between the finding agencies and community-based governmental and nongovernmental organizations, and the CDC has responded quickly with community-based planning in its cooperative Agreements. However, much more technical assistance is needed by both health departments and community-based organizations if their preventive activities are to "be **guided** by science." Moreover, CDC's operating paradigm is the classical public health model, not behavioral health, so it must forge closer alliances with behavioral science agencies and researchers.

In this second decade of the HIV/AIDS epidemic, there are both opportunities and a necessity for a substantially larger effort in, and transformation toward, behavioral science-based methods of HIV prevention. The External Review of the CDC's Advisory Committee on the Prevention of HIV Infection has been a catalyst for this potential turning point, and widespread participation in its review process has raised expectations of a major shift in emphasis. The extent of such a commitment and its proposed strategies, are about to be unveiled.

Appendix A

Acknowledgments

OTA wishes to thank the individuals and organizations listed below for their assistance with this background paper. These individuals and organizations do not necessarily approve, disapprove, or endorse this report. OTA assumes full responsibility for the report and the accuracy of its content.

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Appendix B

Congressional Letter of Request

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August 4,1994

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Draft due 8/9

Dr. Roger Herdman
Director
Office of Technology Assessment
Congress of the United States
Washington, DC 20510

Dear Roger:

AS you know, the Subcommittee on Heath and the Environment has maintained a strong interest in the AIDS epidemic since its first identification in 1981. Since that time the OTA has provided much of the background and information for Subsommittee activity, and we are most grateful for your ongoing assistance.

I am writing now to request your help in continuing Congressional oversight on the reduction and prevention of HIV and AIDS. In particular, I would request that the OTA update its 1988 background paper "How Effective is AIDS Education?" Within that update, I would ask particularly if the OTA would review what can reasonably be expected from information, education, reduction, and prevention efforts; what is known of the effectiveness and appropriateness of the availiable interventions used to reach persons at highest risk of infection, traditionally disadvantage populations, and adolescents and young adults, and the effectiveness of mass media activities. If, as part of this update, the OTA could also provide a background and genera! review of the broader issues, both substantive and methodological, in nonclinical prevention and education, that, too, would be appropriate.

As an interim measure, I would also ask if the OTA could provide a summary and overview of the recent Centers for Disease Control External Review of its prevention programs and of other relevant extant reviews. This interim report would be most useful at some time toward the end of September.

Thank you for your assistance in this matter. If you or your staff have questions regarding this rquest, please do not hesitate to contact Tim Westmoreland of the Subcommittee staff.

Sincerely,

Henry A. WAXMAN
Chairman, Subcommittee on
Health and the Environment

Appendix C

CDC Advisory Committee's Findings and Recommendations

The CDC Advisory Committee on the Prevention of HIV Infection External Review of HIV Prevention Strategies

Final Report

Thirteen years after its recognition, the epidemic of human immunodeficiency virus (HIV) infection continues to pose an enormous threat to American health. Approximately **40,000 to 80,000 new HIV infections still occur yearly among** men, **women and children in the United States. Each costs the American people dearly in direct medical costs and far more in** lost earnings, social upheaval, and personal suffering. **The resulting HIV-related deaths from a year's new U.S. infections are equivalent to the total mortality of the Vietnam War. The stakes in devising and implementing more effective ways to prevent new HIV infections are therefoe immense.**

The **prevention task has also reached immense proportions. Approximately three quarters of a million Americans are estimated to be HIV infected, with many unaware of their inflection status. Their sex or drug-use partners arc at very high risk of acquisition of HIV infection and need to be reached with interventions to prevent continued transmission. Millions of others have a short-tam risk that is currently lower, but nonetheless real, especially over time. To address this great need the national HIV prevention program must reach tens of millions. This is a massive effort requiring insightful and committed leadership, science-bad policies and strategies, careful planning, ample resources, strong public and private sector allliances, and a comprehensive system of health services. While much has been accomplished constraints in each of these areas have hamperedpreventionl efforts since the early years of the epidemic, and much remains to be done.**

CDC's HIV PREVENTION PROGRAM

The lead responsibility for implementing the federal HIV prevention program lies with the Centers for Disease Control and Prevention (CDC). The program has evolved since the mid 1980s to include support for state and local health department programs a national public information network, and education programs in the nation's schools--as well as epidemiologic, behavioral, health services, and laboratory studies, and disease monitoring. These activities are dispersed among ten centers, institutes, and offices within CDC, administered **separately, and coordinated by the Office of the Associate Director for HIV/AIDS. (See Appendix A.)**

CDC's strategic planning for HIV prevention began in 1989. Phase I established *four general goals:*

1) Assess risks
2) **Develop prevention technologies**
3) **Build prevention capacities**
4) **Implement prevention programs**

Building on this broad strategy, Phase 11 **focused on four groups at increased risk for HIV infection: women and infants, injecting drug users, youth in high-risk situations, and men who have sex with men In Phase III, CDC outlined *five program strategies*** expected to have the greatest HIV **prevention impact. These strategies, and their corresponding programmatic focs within CDC, are as follows:**

1. **Strengthen current systems and develop new systems to monitor the HIV/AIDS epidemic, as a basis for directing and assessing HIV prevention programs**

   CDCs HIV/AIDS monitoring activities arc concentrated in the National Center for Infectious Disease ***(NCID).*** **This Center maintains AIDS case surveillance; monitors the prevalence of HIV infection; supports studies of HIV-associated morbidity and mortality; provides technical assistance to standardize HIV infection reporting and evaluate other monitoring efforts; conducts epidemiologic studies to describe the natural history of and risk factors for HIV infection; assesses the nature/frequency of blood exposures, infection risks, and efficacy of** preventivc measures in health-care settinbgs; and conducts laboratory studies to identify **factors involved in HIV *virulence*, transmission, and disease. The National Center for Health Statistics (NCHS) and National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP) also conduct important surveillance activities, especially relatcd to attitudes and risk behaviors.**

2. **Increase public understanding of, involvement in, and support for HIV prevention**

   These activities arc centered in the National AIDS Information and Education Program (NAIEP), located in the Office of the Associate Director for HIV/AIDS. As CDCs national public information program, NAIEP helps ensure access to information about HIV/AIDS and improve community support for behavior chnage. Since 1987, NAIEP has operated the mass media communication effort "America Responds to AIDS", the CDC National AIDS Hotline, the CDC National AIDS **Clearinghouse, initiatives to create partnerships with the private** sector, and **evaluation research.** In addition, the National Center **for Prevention Services (NCPS) provides funding to the public information components of the** cooperative agreements with State and local health departments.

3. **Implement comprehensive school health education programs to prevent the initiation of risk behaviors that lead to HIV infection and other health problems in youth**

   School health activities are administered by CDC's NCCDPHP. Since 1987, NCCDPHP has undertaken initiatives to help **schools develop, implement, and evaluate** HIV/AIDS **education programs.** The **Center supports the training of teachers, administrators, policymakers** and **representatives from youth-serving organizations** on effective HIV prevention education **methods.** A **limited number**

of activities are also directed to youth who are not in school. In addition, the NCPS funds community-based organizations to provide outreach, counseling, testing, and referral programs for out-of-school youth. The NAIEP also targets youth through its public information campaign.

4. **Collaborate with prevention partners to prevent or reduce HIV-related risk behaviors**

NCPS administers CDC's prevention partnerships with federal agencies, health departments, non-governmental organizations, and conmunity groups involved in HIV-related behavior-change activities. NCPS provides support to these organizations by either direct funding or indirect funding via cooperative agreements with health departments and/or the U.S. Conference of Mayors. Collaboration has evolved to include technical assistance, training, education, behavioral research and outreach Target audiences, which have expanded over the years in response to the changing demographics of the epidemic, include persons with hemophilia, men who have sex with men, substance users, out-of school youth, commercial sex workers, the homeless, persons in correctional facilities, and women in high-risk situations.

5. **Increase knowledge of HIV serostatus and improve referral systems to appropriate prevention and treatment services**

The main focus of CDC's HIV prevention effort has been the counseling, testing, referral, and partner notification (CTRPN) program, also administered by NCPS. State-based CTRPN activities currently constitute the largest proportion of funding for HIV prevention services by health departments and other organizations. Their stated purpose is to provide persons at risk for HIV infection an opportunity to 1) learn their serostatus, 2) receive prevention counseling, 3) obtain referrals for additional services, and 4) if infected, help their sex and needle-sharing partners recieve prevention services and referrals.

EXTERNAL REVIEW OF CDC'S FIVE HIV PREVENTION STRATEGIES

In early 1993, CDC initiated an external review of these five program strategies

Acknowledging that the prevention program was built rapidly in response to recognition of the epidemic in the 1980s. CDC staff believed it appropriate to step back, assess their approach to prevention, and obtain recommendations to enhance future success.

Each of the five program strategies therefore became the subject of an investigation by one of five external review groups. Over an 8-month period, each group reviewed CDC's current activities related to one of the five strategies, consolidated their fundings, and developed recommendations. Functioning as subcommittees of the CDC Advisory

Committee on the Prevention of HIV Infection (ACPHI), the groups were each composed of approximately ten members, including three representatives from the CDC ACPHI, onc of whom served as Chair. The other. participants, all subject experts from outside CDC, served as consultants, with a lead consultant acting as Co-Chair.

Each review group developed its own process and produced a comprehensive summary report The complete reports are included in this document. They provide essential descriptions of each group's review process in addition to detailed findings and recommendations.

Representatives of the five groups formally presentcd these reports to the CDC ACPHI on Novembcr 17-18, 1993.

GENERAL FINDINGS

The full Advisory Committee's review and discussion of the subcommittees' reports **yielded nine common themes that the members viewed as important to highlight:**

1. **Prevention is necessary and urgent.**

   HIV infection is an urgcnt, and unique, prevention challenge because of the virus' virulence, long incubation period, length of infectiousness, grave prognosis and potential for exponential spread. The epidemic is fostered by a complex interaction of biological, behavioral, and social forces. It is a growing problem in disenfranchised communities that are faced with a multitude of other compelling problems. And it emanates from the most personal and private of individual behaviors--sex and drug use. With neither a cure nor a vaccine on the immediate horizon--and with a huge national reservoir of infection--tk only promising barrier against the virus is widespread adoption and maintenance of personal behaviors that eliminate or minimize the chances of exposure and infection.

   Preventing new HIV infections requires a commitment from all levels of government to the diverse neighborhoods of America The lack of such a commitment, along with restrictive federal policies, has weakened the prevention effort since the onset of the epidemic--constmining funding, limiting flexibility, discouraging innovation, and thwarting prevention specialists in their efforts to use resources where they would be most effective. Added to this set of problems is the relegation of prevention to a status secondary to that of treatment. Although progress in treatment of those already HIV infected must and will continue, it is not a substitute for prevention. With the prospect of ever-more-complex and expensive treatment regimens, prevention will continue to get short shrift unless the nation's leadership maintains a clear financial and moral commitment to prevention as the fundamental weapon against continued of the epidemic.

2. **Behavior can be changed.**

Both formal research and the practical experience of communities demonstrate that intensive interventions can reduce risk behaviors. Relatively little is known, however, about the comparative effectiveness of different approaches to induce desired changes. Despite advances in knowlege in recent years, we are only beginning to understand how to help people make the leap from possessing information about health to changing their behavior on the basis of that information. Nonetheless, given the enormous social and economic costs of the HIV epidemic if permitted to run its present course, even modest behavior changes must be viewed as successfull. The essential question--still unanswereddd-- is what *set* of interventions can change *most* people's behavior *most* of the *time- over a lifetime.*

3. **Prevention should be guided by science.**

Since behavior change is the main prevention intervention for HIV infection, behavioral research must be the foundation upon which the national program is based Unfortunately, the nation has invested inadequately in prevention research, especially as it concerns human sexuality and drug-use behaviors. Thus, much essential knowledge still eludes us. The key role for CDC is to develop, synthesize, and promulgate scientific guidance for the HIV prevention activities carried out by community organizations and state and local health authorities. This means clarifying goal, definitionsa, and measures of effectiveness; idcntifying successful and unsuccessful strategies; and developing and applying quality standards. The task will require considerable strengthening of the science base as well as substantial increases in funding for prevention research.

4. **Prevention requires sustained, long-term efforts,**

Despite hopes to the contrary, the HIV/AIDS epidemic is not a transitory crisis with a quick fix." Pressures to come up with fast, easy solutions have left us with a prevention model that is inadequate to address the *lifetime risk* of *HIV* infection. We must both initiate *and sustain* changes in risk behaviors; wc need *generational changes in social norms.* The urgency of the escalating epidemic calls for an accelcration of both the scale and the scope of the national prevention agenda CDC must move away from the short-term infectious disease control model and instead mount a long-texm effort similar to those instituted for smoking cessation and prevention of heart disease. This does not mean that the sense of urgency should be lost; on the contrary, short-term "emergency" efforts are still needed, with scientific lessons summarized and applied as soon as possible. But, just as some research involving treatment of breast cancer or diabetes takes many years to yield valid results, so, too, must HIV prevention efforts have long-term support.

5. Partnerships and collaboration are key.

Problems with programmatic cohesion both within the federal government and with others involved in HIV prevention at the natioal, state, and local levels has severely hampered the prevention effort. Several federal agencies in addition to CDC, as well as health departments, non-governmental organizations, corporations, religious organizations, and academic institutions au have parts to play in funding, planning, and implementing prevention activities. Although CDC has the lead in these efforts, opportunities have clearly been missed for establishing and promulgating a unified agenda for prevention services and research. CDC, or some other federal entity, must take responsibility for developing fictional alliances promoting participatory planning, encouraging communication, and ensuring coordination.

CDC's recent initiation of a community planning process for the awarding of HIV prevention grants is a welcome response to some of these problems. But the process will need to be monitored closely to ensure that communities have sufficient time and technical assistance to meet their new responsibilities. There is also the danger that "bottom-up" community planning will lead to abdication of CDC's responsibility to provide needed oversight and scientific guidance. A local organization's deep commitment to HIV prevention and strong community tics does not guarantee it the requisite knowledge and skills to &sign and successfully carry out a broad, long-term prevention program The line between support and responsible supervision on the one hand, and arbitrary interference on the other, presents a major challenge for the CDC.

6. Prevention interventions must strike a balance between targeted efforts and efforts to change general community norms.

HIV prevention is complicated by a problematic epidemiologic reality: nearly all Americans are at some risk of HIV infection, but their *degree* of risk varies dramatically. Those charged with carrying out prevention must choose strategies and allocate resources with this uneven risk in mind Them can be no standard formula; we must constantly question whether& right balance is being achieved. Insufficient attention to the highest-risk populations will squander resources and fail to halt the epidemic's spread Limitation of outreach to *only* those at highest risk will promote a false sense of security, miss some opportunities to prevent HIV infection, and limit public support for national prevention efforts.

7. More funding for prevention is needed.

Excessively limited resources and inappropriate restrictions on their use have **hampered HIV prevention efforts. Although CDC's total HIV prevention budget has grown from $200,000 in fiscal year 1981 to $498.2 million in fiscal year 1993, finding for the prevention program was essentially flat over the last 3 years (with an** actual decrease in fiscal year 1992). Despite an increase to $543 million

in 1994, the level of federal financial commitment to HIV prevention is inadequate to address the overwhelming need for *long-tem, sustained, individual-level behavior change interventions for millions* of at-risk and HIV-infected persons. Restrictive policies and Congressional earmarks attached to these funds have further curbed flexibility and prevented the implementation of innovative and important prevention approached The Committee recognizes that although HIV prevention is expensive, the alternative-unchecked spread of infection continuing indefinitely-is many times more costly.

8. Stigmatization and discrimination continue to adversely affect prevention efforts.

Despite progress in the development of a caring and compassionate national attitude toward persons with HIV infection and AIDS, ignorance, bigotry, and discrumination still pose obstacles to prevention. A continuing effort to dispel misconceptions about HIV transmission and to protect the confidentiality and human rights of those with or at risk for HIV infection must be an integral part of the national prevention agenda.

9. CDC's organizational structure maybe hindering prevention efforts.

CDC's HIV prevention programs arc dispersed among ten centers that compete internally for resources; the effort lacks a clear line of authority for policy, programming, and budget from HIV leadership to staff. CDC's main HIV prevention activities are subsumed within the Division of STD/HIV Prevention in NCPS. Some view this as lessening the perceived priority of HIV prevention, isolating sexual transmission from other modes of spread, and inappropriately imposing the operational' model of STD control on HIV prevention. Another key question is how to strengthen the capability to do good *science in the* prevention program. Key activities that*should be* tied to prevention--disease monitoring, epidemiologic studies, laboratory investigation are situated in the NCID, which shares neither staff nor programmatic emphasis with NCPS. Broader ramifications at the non-federal level center on fragmented funding streams, barriers to integration, and a pieccmeal approach to the work of prevention.

Although CDC's structure has been reviewed more than once over the past several years, the committee members generally agree that another look is merited Indeed, testimony from those working at the community level suggests that the current structure is sufficiently dysfunctional as to warrantimmediate action. The CDC Director should seek the participation of affected constituencies--including state and local health departments and community grantees--in considering whether the current structure is optimal for meeting AIDS prevention needs.

SPECIFIC FINDINGS AND RECOMMENDATIONS

While acknowledging CDC's strong efforts to date, each of the five external review groups recommended some fundamental changes in the agency's approach to HIV prevention to understand and better respond to the national challenge of the HIV/AIDS epidemic. The following is a summary of their findings and recommendations.

Monitoring the Epidemic

The subcommittee found the AIDS case reporting system to be the main thrust of CDC's monitoring efforts, providing the only population-based data that are useful for evaluating disease prevalence by gender, race/ethnicity, age, and mode of exposure. Despite its continuing value as an information source, the system has limitations, most centering on the lengthy interval between HIV infection and AIDS. The subcommittee therefore recommended a *shift in emphasis toward the 'front end' of the epidemic*– advocating a wider view of monitoring that includes precursors to AIDS, including sexual and drug-use behaviors.

Details of the subcommittee's review of CDC's efforts to monitor HIV-associated behaviors, occupational and nosocomial exposures and infections the virus, HIV/AIDS incidence and prevalence, and HIV-associated morbidity and mortality can be found in the attached Subcommittee on Monitoring the Epidemic report. Key recommendations are that CDC should:

1. **Coordinate a strategic plan to define the determinants of risk behavior and seek support at the** highest **level of goverment for its implementation, including reinstituting the National HIV Behavioral Risk Factor Surveillance Survey.**

2. **Conduct an ongoing, long-term, population-bad national study of sexual and drug-use behaviors associated with HIV transmission.**

3. **Consolidate monitoring activities for occupational exposure to HIV with core hospital infection surveillance programs, and other monitoring systems.**

4. **Enhance efforts to identify incident HIV infections in affected communities and link incidence studies to behavioral data on HIV transmission risks through coordinated surveillance.**

5. **By use of more innovative cooperative agreements, improve the capability of local health departments and community organizations to determine the incidence and prevalence of HIV infection.**

6. **Define and enforce a strict confidentiality standard for reporting of HIV infection and** AIDS.

7. **Expand intramural and extramural laboratory and clinical research efforts to determine the relationship of different HIV strains to transmission and virulence.**

8. **Modify the "spectrum of disease" studies to detect differences in new populations at risk by weighted sampling. Integrate HIV infection surveillance with surveillance of opportunistic infections.**

9. **Speed the development and dissemination of prevention guidelines for opportunistic infections.**

The group emphasized that enhanced and redirected monitoring activities at the community level must be accompanied by guaranteed access to appropriate care and treatment services for persons with HIV infection. Although this is not CDC's primary responsibility, improved access care is another important step to enhance prevention opportunities. CDC should therefore assume an advocacy role for care and treatment to support its prevention efforts.

Improving Public Understanding of the Epidemic

The subcommittee reviewing NAIEP activities concluded that the goal of the early years of CDC's mass communication effort--to increase general awareness of AIDS-has been achieved. They therefore recommended a *shift away from the emphasis on the general public and toward specific populations at increased* risk of HIV infection. The urgent prevention needs of the second decade of the epidemic require provision of explicit, factual information targeted to persons at risk

Recommendtions related to NAIEP in general were as follows:

1. **CDC should develop a strategic communications plan to act priorities for usc of limited funds and ensure that programs are rooted in communication science and public health theory and practice.**

2. **Given that a hostile political environment has impeded an appropriate communications response, a) Congress must legislatively and fiscally empower CDC to carry out the strategic plan, b) CDC must be a more aggressive advocate for its own interests** and **for the public health science it represents, and c) the Secretary of Health and Human Services must become a more aggressive advocate for CDC's interests.**

3. **Criteria for developing risk-reduction messages should be developed and promulgated based on efficacious public health interventions, methods, and communications science.**

4. **Decision processes should reflect the magnitude and urgency of the HIV/AIDS crisis and the need for rapid responses.**

5. **CDC should involve affectcd populations in the development and implementation of the strategic plain**

The subcommittee also reviewcd each of the eight NAIEP components. Although none was seen as unnecessary, the group determined that demands on many of the components had exceeded resources and that CDC needs to make difficult decisions about priority audiences and services. The recommendationfor each component are included in the subcommittee's full report. Some key findings and recommendationsare highlighted below.

1. **National AIDS Clearinghouse services were determined to be underutilized because of lack of targeted promotion CDC should refocus services to meet the needs of priority audiences, especially front-line community organizations.**

2. **National AIDS Hotline staff demonstrated impressive expertise and commitment A concern was the difficulty in quickly assessing fast-breaking new items and generating responses to resulting peaks in usage. The main recommendation was to develop a long-term strategic plan to manage such peaks.**

3. **The America Responds to AIDS campaign, although acknowledged as contributing to public awareness, was seen as subject to political considerations that conflict with public health goals, not adequately targeted to people at highest risk, and only selectively based on prevention science. CDC was urged to broaden its media strategies beyond public service announcements. Media programs should be oriented toward risk education, with messages based on *specific methods* of demonstrated efficacy.**

4. **The public information components of the cooperative agreements with health departments could be improved by forming partnerships to integrate health communications, improve planning, minimize duplication, and makc funding decisions.**

5. **National partnership agreements with CDC showed many strengths. Recommendations were to develop one strategic plan to direct these partnerships and to examine the role of funding.**

6. **Health communications efforts for minorities were seen as a weakness of the program CDC should seek the assistance of minority advisory groups to enhance communications with diverse groups.**

Preventing Risk Behaviors among School-Aged Youth

This subcommittee called for better coordination of CDC's youth-related programs and *expansion of the strategic plan for school-based programs to address the prevention needs of all young people, in* or out of school. A subtext was the ongoing problem of targeting. Both general prevention approaches and strategies for youth at high risk are needed in schools and elsewhere. Given insufficient funding for both, challenges remain in achieving the appropriate balance between general prevention and targeted approaches for youth.

In addition to a series of specific recommendations the subcommittee had four core recommendations:

1. **CDC's program for preventing HIV infection in youth is based on an existing strategic plan for school-based HIV education programs. CDC must now develop a national strategic plan to prevent HIV and related health risks among all youth by working not only with schools, but also with other youth-serving organizations, the media, and the business community. CDC should review its various youth-serving programs, with the intent of consolidating, or where consolidation is not practical, better coordinating youth initiatives.**

2. **CDC should continue to work through the schools to address HIV prevention directly, while also ensuring an integrated, comprehensive approach to preventing other FIIV-related health problems in youth.**

3. **CDC should take immediate action to more substantially address the needs of youth at particularly high risk of HIV infection, whether they are in *or out* of school, including strategies for working with youth-serving agencies and organizations other than schools. This expanded focus should not detract from general school-basal prevention strategies. Additional funding will be needed to adequately address both general school-based strategies and those targeted to youth in high-risk situations.**

4. **CDC should solicit broader, earlier, and more extensive input into program planning, implementation, and evaluation from direct-care providers, peer counselors, school health personnel, community groups, advocacy groups, young persons, and families.**

Developing Partnerships for HIV Prevention

This subcommittee concluded that HIV prevention partnerships are not working as well as they should Characterized by ill-defined goals, poor communications, lack of trust, and conflicting roles, they are further threatened by dwindling resources and competition for tiding. Anger related to lack of technical assistance and confusion about CDC's

role create additional barriers Health departments, nongovernmental organizations, community-based organizations, and affected populations are all looking to CDC to ***become a strong national advocate for HIV prevention and to provide the leadership, funds, skills, and training needed to forge effective, participatory partnerships.*** The group's priority recommendations **cover five areas of concern**:

Leadership. Recommendations centcred on the urgent need for CDC to take the lead in coordinating and integrating prevention services among federal agencies. CDC should articulate national HIV prevention goals "to restore itself to the high standards of science and to the legacy of commitment to the public health on which its reputation was built."

Communications. Four recommendations to improve communications among CDC, health departments, community organizations, and targeted populations focused on dispelling confusion about education versus prevention, articulating national prevention goals, clarifing roles and responsibilities, and ensuring cultural and linguistic appropriateness of prevention messages.

Equity. The group made a strong case for participatory planning. They stressed the need for mutual respect and meaningful communications to facilitate trust in partnerships, and emphasized that effective partnerships require time, direct contact, and a minimum level of core resources.

Funding. Among the **recommendations in this area were that CDC should 1) tie equity in funding allocations to interventions that are effective for each targeted group, 2) guarantee increased funds to integrated prevention programs, and 3) provide funds for cross-training.**

Coordination. CDC was urged to enhance coordination of HIV prevention activities by providing technical assistance, convening a multi-disciplinary task force to fostcr partnerships, and broadening the scope of prevention alliances.

The group **identified barriers to and strategic needs for 1) enhancing partnerships, 2) forging effective alliances, 3) providing technical assistance, and 4) integrating services. "Turf" issues were found to impede collaboration at the community level; these need to be overcome at the federal level before they can be effectively addressed by state and local agencies. The subcommittee also identified new prevention partnership opportunitices, with recommendations relatcd to 1) rural areas, 2) border health issues, 3) correctional facilities and 4) youth in high-risk settings.**

Promoting Knowledge of Serostatus

The group disputed the view that the CTRPN program should be the cornerstone of the national effort to prevent HIV infection and raised questions about its emphasis, management, and effectiveness. They concluded that CTRPN programs generally do ***not comply*** with guidance issued by CDC. Moreover, even if CDC guidance were followed

with current resource levels and program structure, CTRPN programs would not be sufficient to change high-risk behaviors.

In their lengthy discussion of findings and recommendations, the subcommittee noted that HIV antibody testing has too often been erroneously equated with HIV prevention While acknowledging the benefits of the HIV antibody test as a diagnostic tool to help infectcd persons obtain medical treatment, the group found its benefits as a prevention tool to be much less clear. Indeed, a negative HIV antibody test result may contribute to the continuation of high-risk behaviors by some person. The key recommendation was therefore *to shift the emphasis away from testing as the main prevention intervention.* The two needed alternatives are 1) ongoing, individual-level behavior-change interventions for those at highest risk of HIV infection and those already infected, and 2) large-scale community-level interventions aimed at changing community norms.

The group recommended that CDC require that decisions about the relative role of CTRPN in the prevention mix be determined through a representative local process. Health departments, working with their communities, should have flexibility in determining the relative allocation of resources among the various components of the "continuum of prevention services." At the same time, the availability of anonymous testing services must be ensured.

Practical problems with the current CTRPN program were also noted Suggested improvements included 1) ensuring professionalism in partner notification, 2) improving the current CDC structure for prevention, 3) improving quality assurance,a n d 4) ensuring access to care, including to prevention services.

CONCLUSION

The year-long external review documented by the following subcommittee reports represents an enormous effort by Advisory Committee members, consultants, and scores of volunteers who testified at site visits, attended meetings, and related their experiences with HIV prevention work in general and CDC programs in particular. Countless hours were also contributed by CDC staff, who were unfailingly cooperative and candid. The committee thanks all who were involved.

CDC is to be commended**for initiating and supporting this unprecedentcd effort. It is evident that the subcommittees' findings and recommendations have been taken seriously, and many have already been acted upon. The Committee looks forward to the agency's response to this report and intends to work to improve CDC's role as a leader in and advocate for HIV prevention.**

The past 13 years arc seen by many as being marked a national failure to recognize the impact of the HIV/AIDS epidemic, to mobilize prevention partnerships and resources

effectively, **and to act decisively to halt the spread of HIV infection.** Against the **backdrop of an expanding and still uncontrolled epidemic, tight resources, and a legacy of restrictive policies, CDC's prevention program continues to evolve. This external review is the first step in what the Committee hopes will be a continuing process of assessment and "course correction" Unfortunately, the structure of the review precluded an analysis of CDC's *overall* approach to HIV prevention: the plan the objectives, the acceptable outcomes, the components of the prevention mix that arc (and are not) achieving Success. Such an analysis is a logical--and ncccssary-next step. Although much has been done to understand the dynamics of the epidemic and to intervene to control its spin@ the struggle is far from over. And the most difficult part surely lies ahead.**

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