

## *2- External Review of the Federal Centers for Disease Control and Prevention's HIV Prevention Programs: Summary and Overview*

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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. *s t r e n g t h e n* 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. implement 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 member* 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 from 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” (1). 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 funding, 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 full 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 funding 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

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*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 planning process" (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 (1), 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