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THE WHITE HOUSE
WASHINGTON

Adolescent report
differed on whether focus
should be in school
youth, or youth in high risk
or all youth.

Undercurrent is
basic lack of resources.

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**CDC ADVISORY COMMITTEE
ON THE PREVENTION OF HIV
INFECTION**

**SUBCOMMITTEE FOR IMPROVING PUBLIC
UNDERSTANDING OF THE HIV EPIDEMIC**

FINAL REPORT

CDC ADVISORY COMMITTEE ON THE PREVENTION OF HIV INFECTION
SUBCOMMITTEE FOR IMPROVING PUBLIC UNDERSTANDING
OF THE HIV EPIDEMIC
FINAL REPORT

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BACKGROUND

The National AIDS Information and Education Program (NAIEP), Centers for Disease Control (CDC), has the mandate to inform the American public about the human immunodeficiency virus (HIV) and acquired immunodeficiency syndrome (AIDS). Since 1987, NAIEP has operated a broad-based program which includes a mass media communication effort entitled "America Responds to AIDS" (ARTA); a national information hotline and a clearinghouse for the general public and HIV/AIDS professionals; initiatives designed to create new partnerships with the private sector in increasing HIV/AIDS awareness; and evaluation/research to determine the impact of NAIEP activity.

PROCEDURES USED BY THE SUBCOMMITTEE

The Subcommittee for Improving Public Understanding of the HIV Epidemic visited the Centers for Disease Control and Prevention in Atlanta, Georgia on May 4-6, the CDC National AIDS Clearinghouse in Rockville, Maryland on May 18-19 and The CDC National AIDS Hotline in Research Triangle Park, North Carolina on June 22-24. In addition, three members of the Subcommittee observed a needs assessment meeting of users of the National AIDS Clearinghouse in Rockville, MD on May 12. During these visits, the Subcommittee toured the facilities, heard a number of presentations and discussed the information received. During the last two and a half days of its final meeting, the Subcommittee identified overall strategic issues and principles, reviewed the strengths and weaknesses of each of the programs examined, made both general recommendations as well as specific recommendations for each program, and generated the following report to be submitted to the Center for Disease Control Advisory Committee on the Prevention of HIV Infection.

THEORETICAL FRAMEWORK USED BY THE SUBCOMMITTEE

The Subcommittee agreed that its analysis should proceed from a firm base of prevention and communication science. Programs such as the Stanford Three and Five Community Studies have demonstrated that communication can play an important role in disease prevention. While communication cannot compensate for a lack of health care services nor produce behavior change without a supportive environment, it can be effective in informing, influencing and motivating institutional and public audiences. The health communication process is grounded in theories about motivating behavior change taken from social psychology and sociology, theories about how people receive and process information taken from mass communication, theories about consumers and how they make purchasing decisions taken from marketing, and examples of how to apply these theories to the practical world of health behavior taken from health education and promotion. The Subcommittee articulated the following salient principles from the health communication process:

- Health communication programs have a critical role to play in disease prevention and must be provided with adequate resources (financial, human and infrastructure) to perform that role effectively.
- Federal health communications programs are complex, involving many audiences, channels, and messages. Strategic planning is essential to coordinate all these activities to work together to achieve objectives.
- Health communication programs should not focus exclusively on individual behavior change but also should consider societal changes that would contribute to desired outcomes.

- Federal health communication programs must involve regional and local constituencies in the conceptualization of the programs as well as in their implementation.

Health communication programs are most effective if audiences are segmented and messages specifically targeted to these segments.

Systematically soliciting feedback from target audiences during the developmental phases (formative evaluation) produces more effective messages.

- A long term communication program must employ rigorous outcome evaluation in order to constantly improve its effectiveness.
- Risk reduction education should be used as a lever for behavior change (awareness alone is ineffective).
- Health communication programs should use multiple channels to disseminate information. Considerable evidence exists to demonstrate the power of combining mass media and interpersonal channels, for example.

Using these principles to guide its deliberations, the committee examined in detail each component of the current NAIEP and agreed that the following three issues were significant for all of the components:

1. In the early days of the epidemic, increasing the American public's awareness and sensitivity to HIV/AIDS was important. Data from national/state/local surveys indicates awareness has been achieved. As we enter the second decade in the epidemic, explicit, factual and targeted information is needed for persons at risk.
2. Government campaign efforts to date have failed to provide explicit information on how HIV is transmitted. They also have failed to aggressively promote the value of condoms in disease prevention, causing other national organizations (e.g. AMFAR) and selected states and cities to launch their own campaigns to provide targeted and helpful information.
3. Political influences, external and internal to the CDC, have impeded the development of effectively designed and targeted messages. When useful targeted messages are proposed, they are often needlessly delayed or altered resulting in bland, broadly-based material which diffuses any expected impact.

The Subcommittee's recommendations are organized into two broad categories: those that pertain to the entire NAIEP and are labeled Pivotal Strategic Challenges and those that are specific to each of the components of NAIEP and are labeled Program Recommendations.

Pivotal Strategic Challenges

The Subcommittee believes that the following strategic challenges apply to all of the preventative initiatives under review; specifically, these challenges apply to health communications issues as follows:

Issue: An overall strategic communications plan does not exist, and the NAIEP program specifically needs one.

Recommendation: Develop a strategic communications plan, two of the objectives of which should be to prioritize limited funds and to insure that programs are firmly rooted in the theory and practice of communication science and public health.

Issue: A hostile political environment inhibits appropriate communication response, including inadequate staffing and budget, interference with development of appropriate messages, and inappropriate clearance procedures.

Recommendation:

- Congress must come to respect the public health and communication science expertise of the CDC and legislatively empower the agency to proceed in accordance with its strategic plan.
- CDC leadership must be a more aggressive advocate for its own interests and for the public health science it represents.
- The Secretary must be convinced to become a more aggressive advocate for CDC interests and for the public health science it represents.

Issue: CDC is not employing existing communication science to construct messages and, as a result, inappropriate and ineffective risk reduction messages are widely disseminated.

Recommendation: Criteria for developing messages should be developed and promulgated based on public health efficacy and sound communication science.

Issue: The federal bureaucracy has not acted upon AIDS as a crisis situation. Examples of this are Public Affairs and Office of Management and Budget clearances that make it difficult to create timely and scientifically appropriate responses to the development of the HIV epidemic.

Recommendation: Management systems and decision processes should reflect the magnitude of the crisis and the need for rapid responses. The bureaucracy should be encouraged/pressured to examine existing policies and procedures and, if they do not fit the crisis, new ones should be developed.

Issue: Because of the early decision to focus communications on a mainstream audience, the populations most affected by the HIV crisis (gay men, African-Americans, and Hispanics) don't experience the response as relevant, specific, and appropriate to them.

Recommendation: CDC should involve these populations in the communication strategic planning process as well as in all phases of execution of that plan. Priorities must shift from a focus on the public as a whole toward populations at enhanced risk of infection.

Issue: CDC communications products and services are not considered to be relevant to the needs expressed by states and community-based organizations (CBOs).

Recommendation: CDC should involve states and CBOs in communications strategic planning as well as in all phases of execution of plans. CDC should work to mobilize CBOs as advocacy partners for the implementation of sound public health communications strategies.

Issue: A basic lack of communication exists among individual units of the CDC, and their missions seem to be overlapping or in conflict.

Recommendation: Clarify missions, roles, and responsibilities of individual units within the CDC and systematize communications among them.

Issue: Current scientific understanding of risk behavior and risk reduction is inadequate to fully respond to this epidemic.

Recommendation: Behavioral and risk reduction research is urgently needed to provide an underpinning for sound communication strategies and to develop appropriate risk reduction interventions.

PROGRAM EVALUATIONS

The Subcommittee's mission was to review current CDC approaches to achieving public understanding of HIV/AIDS. NAIEP has evolved into a communication system with several components. The Subcommittee reviewed each of these components and did not identify any as unnecessary but did conclude that demands on many of the components had exceeded resources and that difficult decisions needed to be made about priority audiences and services. The following recommendations for each component reflects this general analysis.

CDC National AIDS Clearinghouse (NAC)

The CDC National AIDS Clearinghouse operates a comprehensive information data base for the general public, health professionals, and managers of AIDS programs providing information on available services, educational documents, funding sources, and research/clinical trials.

Strengths:

- NAC is integral (with the Hotline) to providing access to information.
- NAC has a large archival capability.
- NAC has a committed, knowledgeable staff.
- NAC has a committed, knowledgeable management.
- NAC databases are wide in scope.

Issues:

- Cost recoupment policies represent a significant service barrier to many community-based organizations.
- Public confusion exists about NAC's mission and services.
- NAC is under-utilized because of the lack of targeted promotion.
- NAC is indiscriminate about materials sent out; it is not driving the system to provide needed materials.
- Red Cross and CDC materials distributed by NAC are often considered irrelevant to community-based organizations, who use them only because they are the only low-cost materials available.

Needs:

- NAC needs to conduct user-satisfaction studies and to use the results.
- Without further financial commitment, NAC will have to prioritize targeted users in the future.
- NAC should be targeted to CBOs and others on the "front lines," a secondary audience should be individuals served by CBOs..

Recommendations:

- NAC should define priority target audiences; based on our experience, we believe the priority audience should include front-line service delivery providers—CBOs involved in prevention activities.
- NAC should tailor services to meet the needs of audiences and consider satellite distribution centers that can further address regional needs.
- NAC should develop a method for periodic communication with priority users to establish their needs and to determine if these needs are being met.
- NAC should market services to priority users.
- NAC should reinstate the external review process for scientific accuracy, currency, and educational design and should solicit feedback from users on the appropriateness and usefulness of distributed materials.
- NAC should acquire the best community-oriented publications and assure easy and rapid access by targeted audiences.
- NAC should identify gaps in information/educational materials and CDC should develop strategies to fill them.

CDC National AIDS Hotline (NAH)

The CDC National AIDS Hotline operates a 24-hour service providing anonymous or confidential information in English, Spanish, and for the hearing impaired. Trained specialists answer questions about HIV/AIDS and provide information about services available nationally or at the state and local level.

Strengths:

- NAH offers direct contact with people.
- NAH has a strong training component.
- NAH has the ability to refer, down to the zip code.
- NAH offers comprehensive services (e.g. 24 hour, English, Spanish, TDD).
- NAH has initiated a National Hotline Conference to establish a network among hotlines at various levels.

Issues:

- No potential caller input exists in the design of NAH services.
- The NAH system is overloaded at peak times.

- NAH lacks a user satisfaction assessment.
- NAH collects and analyzes data but doesn't apply these results adequately in design of the system.
- NAH has no strategic marketing plan.
- NAH often experiences difficulty responding to fast-breaking news because of a lack of adequate advance notice.
- NAH has systems in place to make referrals at a community level but experiences difficulty keeping this information up to date.
- NAH has high staff turnover, which limits public access to experienced information specialists.

Recommendations:

- As part of the broader CDC communications strategy plan, there should be a long-term strategic plan developed for NAH (e.g. to deal with NAH usage "peaks" and "spikes").
- NAH should establish a partnership to develop a network with state and local hotlines in order to share information and technology.
- NAH should create a system to quickly access emerging information and to develop and generate appropriate responses.
- NAH needs to resolve the issue of turnover among information specialists without sacrificing the quality of their services.
- NAH needs to establish a mechanism for potential user input and client satisfaction evaluation.

National Public Service Advertising (PSA) Campaign - ARTA

This mass media communication effort has launched six (6) phases, each designed to build on previous phases and to be used at the national, state, and local levels. These phases include:

- October 1987 - General Awareness: Humanizing AIDS - targeting the general public for the purpose of increasing public awareness, public sensitivity, and reducing fear regarding casual transmission.
- April 1988 - Understanding AIDS: A National Mailout - a message from the Surgeon General mailed to all U.S. households.
- October 1988 - Women at Risk/Multiple Partner Sexually Active Adults - targeting women at risk along with adults who have multiple sexual partners.

- April 1989 - Parents and Youth - an AIDS prevention guide for parents when discussing AIDS with their children.
- July 1990 - Prevention of HIV Infection and AIDS; Taking the Next Step - an effort to increase personal support for those already infected and to motivate those at risk to undergo counseling, testing, and treatment.
- October, 1992 - Americans Working Together to Prevent HIV/AIDS - including Business Responds to AIDS Initiative.

The ARTA campaign uses a bookshelf philosophy where new materials do not replace existing materials; rather they are used to build and compliment the information base. All campaigns are intended to provide information which will stimulate use of national, state, and local hotlines and clearinghouses.

Strengths:

- ARTA contributes to raising and sustaining public awareness.
- ARTA is well-accepted by PSA directors.
- ARTA PSAs have received more free air-time than other PSAs.
- ARTA PSAs have generated phone calls to NAH.
- ARTA has recently committed to comprehensive evaluation.

Issues:

- ARTA is not oriented to risk reduction practices or people at highest risk.
- ARTA is not appropriate for people at risk (e.g. injecting drug users).
- ARTA demonstrates a lack of coordination with other agencies (e.g. with National Institute of Drug Abuse and Center for Substance Abuse Prevention).
- ARTA inadequately shares local PSA development.
- PSAs are viewed internally as a public relations activity, thus are subject to political considerations that are in conflict with public health goals.
- ARTA has attempted to involve the AIDS community in planning and preparing campaigns but AIDS community advice and recommendations have often been overturned for political reasons.
- The scientific base for developing risk reduction messages has been selectively applied.
- Formative and summative evaluation have been inadequate because messages are not always tested in their final forms.

Recommendations:

- If the climate of censorship continues, CDC should not invest in PSAs.
- CDC should develop a strategic communications plan on public health grounds to address audiences and messages. The strategic plan development, implementation, and review should include formal involvement of both local level AIDS staff and communications program experts.
- CDC should broaden media strategies beyond PSAs (e.g. news, paid advertisements, collaborative advertisements).
- A new evaluation plan should be aggressively pursued.
- CDC should provide tools to develop a system for identifying, collecting and sharing consumer research, strategies, and products. CDC should develop tools to build the capacity of states and communities to use the media effectively and to avoid duplication.
- Media programs should be oriented toward risk reduction, and messages should be based on risk reduction methods of demonstrated efficacy.
- Messages should not be released before being tested in their final forms.

State and Local Cooperative Agreements

The purpose of the HIV Prevention Cooperative Agreement Program is to assist state and local health agencies, in collaboration with other agencies and organizations working at the local, state, regional and national levels, to prevent the transmission of HIV and to reduce associated morbidity and mortality. An important component of these cooperative agreements includes resources for public information programs.

The Subcommittee does not have enough information to evaluate the strengths and issues of these public information initiatives, but it does see a structural problem when the goals, objectives, and accountability are not lodged in the same office. Because this is the biggest item in the budget, the Subcommittee believes that this structural problem is a significant issue.

Recommendations:

- Responsibility for public information funds should be moved to NAIEP along with resources to manage it.
- Funding to states needs to be accompanied by tools and technical assistance from NAIEP.
- NAIEP should collect, compile, and share with the states information about use of funds and effects.

- CDC should issue a policy statement regarding the importance and functions of communications in HIV prevention and should include this information in their training programs.
- States and CDC should form a partnership to integrate health communications, improve strategic planning for communication, minimize duplications and make decisions about how funds should be used. (The Subcommittee requested information from the CDC's National Center for Prevention Services as to how funds were dispersed nationally, for what purposes, and what proof exists that the money made a difference, but the documentation was never received.)

National Partnerships

CDC/NAIEP currently engages in partnership agreements with twenty (20) national organizations representing business and labor, the religious community, voluntary organizations, and the media. Partnership agreement tactics include engagement of social networks that function well; listening to what people want and can offer; and assisting or facilitating in the work of partner organizations. The American Red Cross, which is linked to the CDC through its blood surveillance/biomedical services as well as by a collaborative agreement, is addressed separately in this section.

Strengths:

- CDC utilizes the unique resources of many non AIDS-specific national organizations.
- CDC fosters collaboration between non-AIDS and AIDS-specific organizations.
- CDC promotes networking and sharing of information within participating organizations.
- The organizations broaden access to more people, creating multiple information channels for general audiences.
- The organizations leverage resources.
- Network awards acknowledge achievements of people in the field who are working at the grassroots level.

Issues:

- No strategic plan exists to determine who should be partners, and to provide outreach to get them involved in a productive way.

Recommendations:

- CDC should develop one strategic plan with multiple considerations to direct and shape partnership activities.
- CDC should examine how critical funding is to the partnership involvement (e.g. direct funding to partners vs. increased emphasis on funding conferences and other kinds of partnership building activities).

The Red Cross

Strengths:

- The Red Cross provides excellent training.
- The Red Cross provides creative approaches and develops sound materials for AIDS education.
- The Red Cross provides a broad network for coverage at the community level.
- The Red Cross is a credible institution for mainstream America.

Issues:

- Traditional Red Cross volunteers are not appropriate for high risk populations.
- Lack of support exists for AIDS education at the chapter level in some communities.
- A disagreement exists about appropriate target audiences for Red Cross HIV activities.

Recommendations:

- The evolution of basic AIDS educator training should continue to be evaluated.
- CDC should pair Red Cross training abilities with organizations that have credibility within at risk communities to train CBO staff to conduct the education programs.
- CDC should encourage National Red Cross leadership to motivate all chapters to engage in AIDS activity appropriate for their communities.
- The Red Cross primary focus should be on training the staff and volunteers of low income, urban, minority, community-based organizations that are in the best positions to deliver the educational

programs to high risk people. The Red Cross should market their training program to these organizations.

Health Communications for Racial and Ethnic Minority Populations

This was not identified as a separate program; so no strengths or issues have been evaluated. However, the Subcommittee does have recommendations.

Recommendations:

- Expert regional minority advisory groups should be formed to assist CDC in development and execution of communications efforts:
 - a. Two priority groups are African Americans and Puerto Ricans.
 - b. One strategic plan is needed to address minority groups with emerging priority needs (e.g. Mexicans, Pacific Islanders, and Native Americans).
- Methods for assessment and sharing of the best practices should be developed.
- Incremental resources, more and/or earmarked funds, and new resources should be allocated.

Training/Technical Assistance:
(Health Communications/Social Marketing)

Strengths:

- Expertise is available.

Issues:

- Limited expertise exists in HIV programs (varies by state health departments).
- Resources are under-utilized (a wealth of experience, which no one knows about, exists).

Recommendations:

- Health communications should be an integral part of all CDC sponsored HIV prevention programs.
- Prioritization should occur both in the ways assistance is delivered and to whom.
- CDC should link funding priorities with technical assistance priorities.

- CDC should use technical assistance capacities of other entities rather than always focusing on building CDC capacity.
- CDC should develop and provide cross-training for public health professionals in media skills and media professionals in public health knowledge with emphasis on hard to reach groups.
- Additional funds should be allocated for technical assistance.
- A role for the CDC Office of Health Communications should be established re: inter- and intra-agency training and technical assistance.

Communications Evaluation

The NAIEP currently has limited human resources for evaluation; it has, however, designed a new evaluation initiative. The approach the CDC plans to take in its evaluation efforts was described as "deliberate, interdisciplinary, interactive, systematic, comprehensive and centralized."

Strengths:

- The practice of extensive formative research already exists.
- An outcome evaluation is planned.

Issues:

- Historically, little outcome evaluation has been done.
- Coordination of evaluation efforts (among various entities) is lacking.
- Overall evaluation strategy does not exist.
- Clearance hinders timely feedback.
- Arbitrary censoring and editing are overriding sound formative research results.

Recommendations:

- Outcome evaluations should be performed by methodological standards of scientific publications (a distinction between outcome/formative evaluations).
- CDC should distribute only materials that have been rigorously evaluated.
- A formal sharing process of lessons learned in previous efforts should be employed to avoid repetition of mistakes.
- Formative/summative evaluations should be used as tools for constituency building for communication implementation.

- Standard evaluation tools should be developed, accompanied by training, to insure that appropriate methodologies are used for intended purposes within CDC and elsewhere.

CONCLUSION

The Subcommittee found the staff of the CDC, along with their partner organizations, to be uniformly committed to HIV prevention, highly skilled in various disciplines, imaginative, and compassionate. We applaud their many contributions to date.

However, it is not possible—or fair—to evaluate overall progress without recognizing the hostile political context within which critical strategic and practical decisions were made.

Given the content of inappropriate Congressional mandates and censorship that was present and continues to exist in federal HIV/AIDS prevention activities, coupled with the lack of executive leadership and restrictions on Congressional appropriations, the CDC has done a credible job in advancing public awareness and understanding of this unprecedented and growing national health challenge.

The Subcommittee recognizes the strengths of the CDC, including staff expertise in research, evaluation, and the practice of health communication. The Subcommittee encourages the CDC to learn from the accomplishments and shortcomings of the past, to involve and learn from the populations they intend to serve, and to incorporate these experiences in planning for improvement in the future.

IMPROVING PUBLIC UNDERSTANDING OF THE HIV EPIDEMIC

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November 7, 1993

CDC Advisory Committee
on the Prevention of HIV Infection,
Sub-committee on Preventing Risk Behaviors
Among School-aged Youth

REPORT

Centers for Disease Control and Prevention
Atlanta, Georgia

Executive Summary

The four meetings of the CDC Advisory Committee on the Prevention of HIV Infection, Subcommittee on Preventing Risk Behaviors Among School-aged Youth were held June 13 & 14, June 28 & 29, July 22-23, and September 13 & 14, 1993. The first three meetings were held in Atlanta, Georgia. The last meeting was held in Washington, D.C. Stephen C. Joseph, MD, MPH presided as subcommittee Chair and Gene Wilhoit as Lead Consultant. The task of the group was to conduct an external review of CDC's programmatic activities for preventing risk behaviors among school-aged youth.

During the eight days of formal meetings and the extensive review and revision process, the committee identified eight (8) recommendations:

1. CDC should review, consolidate, and where consolidation is not practical, better coordinate programs aimed at youth and young adults.
2. CDC should ensure that HIV resources designated to prevent risk behaviors among youth are used for those purposes.
3. CDC should rank among its highest HIV priorities in the budgetary process funds to deal with the needs of youth at high risk, in and outside of the school setting, that are not being met currently.
4. CDC should have its programs and the programs it supports focus on youth, wherever they are, by working with the range of institutions that serve youth, not just school systems or institutions. Examples of where youth can be found include schools, colleges, community colleges, trade and technical (proprietary) schools, run-away settings, jail, youth detention centers, mental hospitals, group homes, foster care, the military, Job Corps, and the work force.
5. CDC should improve its management system for preventing risk behaviors among school-aged youth, to ensure that resources spent will have the greatest impact on the problems.
6. CDC should provide leadership at improving the coordination of activities targeted at youth among federal agencies, national organizations, and the fields of health and education at the state and local levels.
7. CDC's plans, activities, and evaluation efforts should reflect an increased involvement from a broad base of individuals affected by and helping prevent HIV in youth.
8. CDC-sponsored programs should be effectively designed and implemented. These programs should coordinate efforts of media, national organizations, schools, town meetings, clinics, parents and families, and one-on-one counseling in its HIV prevention efforts for youth.

Meeting of the CDC Advisory Committee on the Prevention of HIV Infection, Sub-Committee on Preventing Risk Behaviors Among School-aged Youth

Introduction

Overview

The four meetings of the CDC Advisory Committee on the Prevention of HIV Infection, Sub-committee on Preventing Risk Behaviors Among School-aged Youth were held June 13 & 14, June 28 & 29, July 22-23, and September 13 & 14, 1993. The first three meetings were held in Atlanta, Georgia. The last meeting was held in Washington, D.C. Stephen C. Joseph, MD, MPH presided as subcommittee Chair and Gene Wilhoit as Lead Consultant. The goal of the meeting was to conduct an external review of CDC's programmatic activities for preventing risk behaviors among school-aged youth.

During the discussions, the Committee identified several problems that are closely related to effective HIV prevention for youth. These need to be addressed if HIV programs are to be effective. Without solutions to these problems, any recommendations that the Committee makes fall short of what should be accomplished.

- A. There are neither adequate nor coordinated federal integrated approaches to a comprehensive effort aimed at improving the health of youth (addressing HIV, substance abuse, nutrition, violence, teen pregnancy, etc.). This is not a trivial issue. There will be great cost in both public dollars and in the quality of life for our young people if this problem remains unaddressed. CDC should provide a significant leadership role in addressing these inadequacies.
- B. There is no federal strategic programmatic and financial plan that is comprehensive, integrated, and coordinated for HIV prevention programs aimed at youth in high risk situations.

Currently there is a strategic plan for K-12 school-based HIV programs utilizing a comprehensive school health approach. However, there is inadequate programming for those youth in high risk situations whether they are in school or are not in school. The school-based strategic plan should be broadened to address all youth, in or out of school, so that the needs of youth in high risk situations are adequately addressed.

"Youth in high risk situations" are defined very specifically by CDC. The official CDC definition follows:

"Youth in high risk situations are aged 10-24. These youth include, but are not limited to youth who have run away or are homeless; are not in school and are unemployed; seek treatment for substance abuse, especially for injecting illegal drugs and using crack cocaine; are juvenile offenders; are medically indigent; require mental

health services; are in foster homes; are migrants; are gay and lesbians; have had sexually transmitted diseases, especially genital ulcer disease; have been psychologically, physically, or sexually abused; are pregnant; seek counseling and testing for HIV infection; exhibit signs or symptoms of AIDS or HIV infection without alternative diagnosis; barter or sell sex; are in alternative or continuation schools; and are in gangs."

Young people in high risk situations are in schools, institutions of higher education, in religious institutions and in other traditional and non-traditional youth-serving organizations, and anywhere else that teenagers and young adults can be found. In addition, youth can move rapidly from one setting to the next; for example, they might be in school one week and out of school the next. These factors, and the fact that one in five people diagnosed with AIDS are in their twenties, makes us believe that many young people, both in and out of school, are at risk of the HIV infection. Risk, for youth as well as adults, is a compound measure made up of the product of individual risk behavior and the prevalence of the virus in the individual's social environment.

- C. Comprehensive programs for the health of children, HIV prevention for youth, and HIV prevention for youth in high risk situations are seriously underfunded.

Consultants participating in the evaluation group included the following individuals:

1. Jay Coburn, AIDS Action Council
2. Alwyn Cohall, MD., Director, Adolescent Medicine Division, St. Luke-Roosevelt Mary Hospital
3. Lawrence Davenport, Ed.D., Chief Financial Officer, Seattle Public Schools
4. Sally Finney Brazier, M.Ed., Kansas Department of Health and Environment and the National Alliance of State and Territorial AIDS Directors
5. Christine Lovato, Ph.D., California College Health 2000, San Diego State University
6. Ric Loya, M.S., Teacher, Huntington Park High School, CA
7. Mary Jane Rotheram, Ph.D. HIV Center, Unit 29, Columbia University
8. Debra Sandau-Christopher, Director, HIV Education Program, Colorado Department of Education
9. Sharon Stumbo, MA, MHA, Deputy Commissioner Department for Health Services
10. Manya Ungar, The National PTA, Past President
11. Pedro Zamora, Peer Educator, Body Positive Griefwork Center

In addition, Christine Gebbie, R.N. was originally a part of the group.

Description of Process

The subcommittee used the following process to conduct the review. CDC staff, representing all CDC components providing services to adolescents, provided an overview

of all of the program activities. Presentations were made by representatives from the Division of Adolescent and School Health (DASH), the National Center for Prevention Services (NCPS), and the National AIDS Information and Education Program (NAIEP). The subcommittee also invited visitors outside CDC who represented relevant areas of expertise and experience. Visitors included youth, youth in high risk situations, and parents, individuals working in HIV prevention with youth in high risk situations, and individuals working in HIV prevention with youth in college. Subcommittee members reflect a wide variety of backgrounds in the fields of health and education. In addition, to extend the base of involvement, individual subcommittee members met with individuals from their networks to obtain additional input. In some cases, the involvement expanded to holding meetings with a group of individuals from the subcommittee members' networks. A list of all visitors and CDC representatives is included in Appendix I.

Subcommittee members, consultants, and visitors obtained additional information through formally scheduled question/answer sessions. In addition, the subcommittee asked key CDC DASH staff to remain. As the subcommittee discussed the questions, members obtained additional specific information from CDC staff. Subcommittee members also reviewed and discussed interim drafts of the report. The Chairperson devoted the last part of every meeting to public comment and plans for the next meeting. Copies of responses from the public are included in Appendix II.

The analysis and recommendations are described in more detail in the following section.

Analysis of Issues and Recommendations

During the eight days of formal meetings and the extensive review and revision process, the committee identified eight (8) recommendations:

1. CDC should review, consolidate, and where consolidation is not practical, coordinate programs aimed at youth and young adults.

CDC should conduct a thoughtful, objective, and careful review to ensure optimal placement of all youth-focused programs. For those activities that should not be organized within one institutional unit, CDC should ensure a functional and effective coordination of efforts. Programs aimed at youth should be managed by individuals at CDC with expertise in working with young people. For example, community-based, youth-serving programs that are directly funded by the Center for Prevention Services should be placed in one organizational unit that oversees all youth programming. One way that might be accomplished would be moving CPS HIV activities directed at youth to DASH.

All changes should result in an increased and better use of varied staff expertise and a reduction in the fragmentation and duplication of services.

2. CDC should ensure that HIV resources designated to prevent risk behaviors among youth are used for those purposes.

CDC should ensure that systems established to prevent HIV are directly addressing this goal, while also enabling an integrated approach to address other related health problems. In addition, CDC should ensure that youth in high risk situations are a much increased priority. CDC should create a significantly better coordinated program for youth in high risk situations.

"While CDC's strategic plan must continue to address the complete range of youth at all levels of risk, it must also bring a new focus on youth in high risk situations as the problem of greatest unmet need and urgency."

In the past, prevention strategies for all young people, primarily, if not exclusively, focused in the schools, has made sense as it also utilized comprehensive school health programs. This approach has worked well in the traditional school setting. New trends for high risk youth both within and outside the traditional school setting now require other approaches in conjunction with comprehensive school health program efforts. In some parts of the nation, the spread of HIV infection among young people has reached an emergency stage, demanding substantially greater resources and effort than has been available to date.

CDC now needs a broader strategic plan to more effectively deal not only with HIV efforts in the traditional school setting, but also more effectively with high risk youth **outside** the traditional school setting. CDC should include in the plan a needs assessment that clearly identifies where youth in high risk situations are to be found.

CDC should ensure that youth in high risk situations are a much increased priority in awarding all new and renewal cooperative agreements. CDC should not award new or renewal funds, unless grantees, as a part of their proposed activities, have assessed the needs of youth in high risk situations and have devised an aggressive prevention plan to meet these needs. Without detracting from the more general school-based prevention strategies for youth, this priority is essential. However, neither of these can occur without additional funding.

3. CDC should rank among its highest HIV priorities in the budgetary process funds to deal with the needs of youth at high risk, in and outside of the school setting, that are not being met currently.

4. CDC should have its programs and the programs it supports focus on youth, wherever they are, by working with the range of institutions that serve youth, not just school systems or institutions. Examples of where youth can be found include schools, colleges, community colleges, trade and technical (proprietary) schools, run-away settings, jail, youth detention centers, mental hospitals, group homes, foster care, the military, Job Corps, and the work force.

School is an important vehicle for reaching youth, since it is a primary and widespread institution serving youth. Thus, many youth can be reached within the school system. Further, schools can reach youth continuously across critical developmental stages from early childhood through adolescence. However, there are many programs in schools that do not effectively reach youth in high risk situations.

CDC should support the reform of any ineffective school programs and enhance efforts to supplement using schools as a vehicle to influence adolescent behavior. DASH's role should include providing a linkage to national and state efforts, supporting development of models, facilitating both the accomplishment of goals through other organizations and the cooperation between groups. There should be a planned, coherent, and consistent approach for youth in schools, in college, and in other settings in addition to what is being conducted. This approach should include school-based or school-linked health services and clinics.

5. CDC should improve its management system for preventing risk behaviors among school-aged youth, to ensure that resources spent will have the greatest impact on the problems. The improved management system should include the following components:
 - a. Develop a comprehensive strategic programmatic and financial plan for preventing risk behaviors for school-aged youth. This strategic plan should include the following:
 1. Identify the highest priority problems and needs.
 2. Identify the resources available and existing constraints.
 3. Develop a programmatic and financial strategic plan that includes the actions that will ensure that resources spent will have the greatest impact on the problems. The plan should include goals, objectives, tactical elements, and evaluation elements.
 4. Include a broad base of individuals affected by and helping prevent HIV in youth.
 5. Develop evaluation strategies and priorities. This would include:

- a. Refine and expand CDC's current well-developed surveillance systems to nationally monitor HIV behavior and related risk behaviors (YRBS) and the characteristics of school-based and community-based programs.
 - b. Use existing data bases and information gained in monitoring ongoing programs to make funding decisions and set priorities.
 - c. Prior to implementing new program initiatives, clarify the level of evaluation desired, as part of DASH's strategic evaluation. While the level of evaluation may vary, criteria must be established and used to evaluate and identify successful and unsuccessful programs.
- b. Develop an operational plan that identifies work to be accomplished, individuals responsible, and deadlines.
- c. expand and fully implement a system to routinely monitor and evaluate activities and to routinely and promptly identify and solve problems to ensure that the programs are effective..

CDC should ensure that evaluation is an integral part of every facet of the program and its day-to-day activities to influence program efforts. CDC should make objective evaluation of its effectiveness an integral part of its day-to-day operations. CDC should routinely continue efforts such as its current ad hoc committee evaluating activities, such as the project officer role and responsibilities. CDC should coordinate evaluation efforts within CDC. CDC's external review process should be commended and continued. DASH should maintain a systemic ongoing process to evaluate DASH program efforts by its consumers.

Information generated by evaluations is used in a variety of ways. Data is used on a national basis, by the DASH program, and at the state and local levels. The information is used to ensure accountability, improve and develop programs. CDC should expand efforts to develop program evaluation skills at the state and local level. As part of that effort, CDC should develop indicators of success to be used by and across projects.

There is a need to increase evaluation of efforts where gaps exist, including in following situations:

- youth in risk situations
- national organizations
- 17 - 24 year old youth.

6. CDC should provide leadership at improving the coordination of activities targeted at youth among federal agencies, national organizations, and the fields of health and education at the state and local levels. Examples of specific efforts are listed below:
 - a. Organizations and governmental agencies compete for the same clients, resulting in gaps in the service. CDC should analyze these different factors and identify possible solutions.
 - b. CDC should build into contractual agreements (such as grants and cooperative agreements) both incentives and funding prerequisites for cooperation and collaboration in planning and implementation.

Mandated efforts need to be relevant in the widely diverse local communities. Thus, mandates should pertain to the outcome, rather than to specific steps or partners (which may not be appropriate in the community). In addition, the contractual agreements should increase the likelihood that the agencies will continue working together after a grant is completed. For example, the agencies should be required to provide an operational plan for collaboration activities following completion of grant.

- c. CDC should continue and expand monitoring and assistance efforts to ensure cooperation and collaboration. CDC should build on the strengths of its current efforts in the YRBS to increase cooperation and collaboration between programs.
- d. CDC should help build skills at and create opportunities for collaboration at the state and local levels. Examples include the following:
 1. Create leadership training to equip individuals in SEAs, LEAs, and IHE's to prepare educators and counselors.
 2. Use the same strategies to overcome programmatic resistance.
 3. Identify ways to realign funding mechanisms and streams and to require states to assist and support local coordination.
 4. Help develop dual preparation and experience programs in which educators and public health workers are cross-trained.
- e. CDC should encourage each state to develop, establish, or expand a state youth consortium or School/College and Public Health Consortium to improve the planning and coordination of efforts and to integrate coordinated state funding and regulatory efforts. Help public health and educational groups to network into the HIV community and state-wide planning activities.

7. CDC's plans, activities, and evaluation efforts should reflect an increased involvement from a broad base of individuals affected by and helping prevent HIV in youth.

CDC should have broader, earlier, and more intensive input in the planning, implementation, and evaluation of its efforts from direct care providers, educators, peer counselors, school health personnel, advocacy groups, community groups, youth, and parents and families. In order to achieve this, CDC should improve its structure for obtaining input and develop more effective processes and procedures to guarantee follow-up. Specific examples of actions include the following:

- a. Establish ongoing community outreach programs with youth, parents, and families.
 - b. Establish ways to give youth and individuals working in the field, such as community advocates and community workers opportunities to work in DASH. In addition, give DASH staff opportunities to work in the field.
8. Consistent with current activities, CDC-sponsored programs should be effectively designed and implemented. These programs should coordinate efforts of media, national organizations, schools, town meetings, clinics, parents and families, and one-on-one counseling in its HIV prevention efforts for youth. CDC should use its public health leadership to provide the public with relevant data and research findings to support effective HIV prevention program design.

The Committee recognizes and commends DASH's current values, design, and implementation of the school-based activities. There is a concern that the same standards are not applied to HIV prevention programs for youth throughout CDC and at the implementation levels in the states and local communities. High priority and specific criteria which should be used in programmatic design and implementation for HIV programs should be:

- a. skill based and engage and empower the youth to think through and question the issues;
- b. individualized, personalized to student needs and interests and are culturally sensitive, appropriate, and competent;
- c. tied to the latest research and scientific knowledge;
- d. presented in the context of how the HIV epidemic affects the world's population;
- e. delivered by knowledgeable, trained, skilled, and caring professionals serving youth who are non-judgmental in their communications, and comfortable in discussing sexuality, substance abuse, and sexual orientation with adolescents;
- f. enhance the use of media and new technology;

- g. involve, support, and educate the parents and families. Incorporate successful parent-to-parent programs and earlier intervention through parents and families of younger children.

Conclusion

The subcommittee recommends that CDC take immediate action to address these recommendations beginning within the current planning and budgetary cycle and follow through with it in successive years. CDC needs to ensure that it immediately addresses the highest priority problems. In addition, CDC needs to institutionalize follow-up activities to ensure that CDC's efforts more effectively address the youth in high risk situations and to prevent HIV in youth.

Appendix I

Visitors and CDC representatives are listed below:

Visitors

A. Bryant	ASTHO
Patricia Funderbush	America for a Sound AIDS Policy
Bonnie Kenny	Prince George's County Health Department
Lynne McCombs	Teen AIDS
Kevin Mischka	Teen AIDS
Helen Morris	NSBA
Judith Ressallat	National Association of School Nurses

Visitors Formally Invited to Meetings

Jim Bolas	AIDS and Adolescent Network of New York
Jamie Dibacco	Boston Massachusetts
Trisha Dibacco	(Jamie's mother)
Jim Evans	Assistant Professor, Behavioral Sciences; Director, Chemical Dependency Counselor Training Program, San Diego City College
Robert Gaston	Los Angeles, California
Barbara Lewis	Steamboat Springs, Colorado
Jessica Lincoln	Steamboat Springs, Colorado
Annette Padilla	San Diego State University

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Patricia Riley	HIV Program Leader, Office of the Director, NCCDPHP
Christi Murray	Program Analyst, Office of the Director, NCCDPHP
William C. Parra	Deputy Associate Director, Office of the Director, HIV/AIDS
Steve Schindler	Public Health Advisor, Office of the Director, National Center for Prevention Services (NCPS)
Sandra H. Kerr	Public Health Analyst, Office of the Director, NCPS
John Moore, Ph.D	Staff Development, DASH
Peter Cortese, Dr.P.H.	Acting Chief, Program Development and Services Branch (PDSP), DASH
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Elizabeth Majestic, MPH	Acting Chief, Special Populations Program Section, PDSP, DASH
Pete Hunt, MPH	Acting Chief, School Programs Section, PDSB, DASH
Laura Kann, Ph.D	Chief, Surveillance Research Section, SERB, DASH
Deborah Rugg, Ph.D	Chief, Evaluation Research Section, SERB, DASH

FINAL REPORT FROM THE CDC HIV PREVENTION ADVISORY COMMITTEE
SUBCOMMITTEE ON MONITORING THE HIV/AIDS EPIDEMICS

November 12, 1993

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I. OVERVIEW

Since the recognition of Acquired Immunodeficiency Syndrome (AIDS) as a major global public health problem, a number of commission, council, and academy reviews and reports on the status of our nation's response to this problem have been formulated. The framework for the deliberations of "Subcommittee on Monitoring the HIV/AIDS Epidemic" is based on these previous efforts and our specific attempt to identify the public health priorities for monitoring HIV infection in this country for the year 2000. In particular, our recommendations reflect the effort that will be necessary from local, state, and public health agencies, including the Centers for Disease Control and Prevention (CDC). We believe that our nation's response to HIV infection will require us to consider new paradigms for understanding and responding to the crisis.

A. Objectives of Monitoring and Surveillance

Our subcommittee was faced with the formidable task of examining a number of major program areas at CDC and other federal and state public health agencies that relate to the surveillance and monitoring of HIV transmission, behaviors that facilitate transmission, virus strains, and opportunistic diseases and other complications experienced by persons with infection. For this reason, we have delineated the overall goals of these programs that we believe should assume the highest level of priority, as follows:

- 1) Monitoring must provide data that can be used to identify targets for primary and secondary prevention interventions;
- 2) Monitoring must provide data to evaluate the efficacy of prevention interventions;
- 3) Monitoring must provide data that can be used to determine eligibility for federal, state, and local health care resource allocations for HIV-related services;
- 4) Monitoring must provide data that allow local, state, and federal planning agencies to project the resources needed in the future to provide care to infected persons and prevention interventions for those at risk;
- 5) Monitoring must provide data that can be used to educate the public about the scope and impact of the HIV epidemics.

B. Current Status of Monitoring and Surveillance Activities

The Subcommittee reviewed the strengths and weaknesses of major CDC programs relevant to HIV/AIDS surveillance and monitoring (Appendix A). Our assessment of the extent to which the existing programs accomplish the major goals of surveillance (outlined above) is presented in Table 1 and highlighted here.

The AIDS case reporting system is a major thrust of CDC's existing surveillance efforts and provides the only current population-based data that can be used at the local, state, and national level to evaluate the prevalence of disease by gender, race/ethnicity, age, and mode of exposure. Monitoring AIDS cases will continue to provide critical information directly affecting decisions about current and future health care resource allocation. However, the value of this system has several limitations:

- 1) AIDS surveillance data cannot be used to identify recent trends in behaviors associated with transmission and the incursion of HIV into new populations because the time lag between infection and the development of AIDS is long. As a result, monitoring AIDS cases does not contribute to the timely identification of new prevention targets or to the evaluation of current prevention interventions.
- 2) Allocating health care resources solely on the basis of AIDS cases fails to account for the service needs of uninfected persons at risk and of persons with earlier stages of infection.
- 3) Focusing public attention on AIDS surveillance data detracts from the true scope and impact of the HIV epidemics.
- 4) The costs associated with the current AIDS case reporting system are significant and have substantially increased since the expanded case definition was introduced.

In order to address the shortcomings of AIDS surveillance, it is necessary to move the emphasis of monitoring activities to the "front end" of the epidemics. This begins by monitoring behaviors and correlating these to the extent possible, with other measures of HIV infection or AIDS. The Subcommittee found that in general, monitoring such behaviors is woefully inadequate at the national, state, and local level. Although many individual programs contribute

important data to the understanding of transmission risk in certain populations, the lack of a comprehensive and integrated system to monitor sexual and drug use behaviors among the general population, persons at high risk, and infected persons severely impedes the development of effective prevention programs.

In addition, the Subcommittee concluded that CDC should place high priority on expanding monitoring and surveillance activities that address the earlier stages of HIV infection. Accordingly, CDC should expand the capacity of state and local agencies to conduct targeted seroprevalence studies and seroincidence studies (where feasible). The use of markers of the duration of infection (e.g. new methods of measuring CD4 T-lymphocyte counts) is a promising strategy for estimating incidence through seroprevalence studies and should be explored further.

In recent years, CDC has encouraged states to require the reporting by names of cases of HIV infection to state and local public health departments as a means to improve population-based HIV infection surveillance. Twenty-five states currently require confidential named reporting of HIV infection, but few of the highest prevalence states have adopted such a policy. The Subcommittee recognizes that health departments have compiled an impressive record of protecting the confidentiality of HIV/AIDS-related surveillance information, but is also well-aware that due to adverse social and political issues, community fears regarding the systematic collection of names of HIV-infected individuals are genuine and that such concerns are prone to interfere with surveillance efforts.

Proponents of named reporting contend that the prevalence data obtained using this approach have been useful in monitoring epidemic trends, targeting prevention programs, projecting medical and social service needs, allocating resources to meet these needs more effectively, and promoting voluntary partner assistance programs. Opponents argue that named reporting creates a disincentive for voluntary testing, provides unreliable epidemiologic data, and that similar benefits could be obtained using alternate approaches such as HIV reporting programs that utilize coded identifiers.

The Subcommittee agreed that independent evaluation of named HIV reporting systems and alternatives to named reporting is imperative. Until this is accomplished, consensus on the public health utility and advisability of named reporting cannot be achieved.

C. New Directions in Surveillance

Recognition of Multiple HIV/AIDS Epidemics

While the leadership of CDC in the area of monitoring the AIDS epidemic in the United States is well recognized, surveillance efforts will necessarily require substantial change. First and foremost, we must recognize that there is no single epidemic of HIV/AIDS within our country, but rather, a series of multiple epidemics occurring in various communities, places, and time periods that are associated with one or more established risk behaviors for HIV transmission. The capacity of monitoring programs to detect and respond to the incursion of HIV infection into new communities at risk must be improved.

Emphasis on Local Surveillance

The Subcommittee believes that locally relevant data should provide the cornerstone upon which our understanding of the aggregate national picture of the HIV epidemics is built. Cities and counties must be responsible for conducting an inventory of available information on the prevalence and incidence of HIV infection, disease, and risk behaviors creating a potential for new infection in their community. Based on this inventory, an assessment of the need for additional epidemiologic data to accomplish the goals of local surveillance as well as state and national surveillance through the year 2000 should then be conducted. Resources to obtain these data will require a joint effort on the part of national, state, and local governments. It is important to emphasize that surveillance is primarily the responsibility of state health departments and the role of CDC is to assist with cooperative agreements, but the authority for surveillance arises from the states.

Enhancing the Capacity to Conduct Locally Relevant Surveillance

Streamlined programs for conducting surveillance activities must be developed to enhance the capacity of local and state agencies to obtain the data needed to accomplish their priority surveillance objectives in a cost-effective manner. The CDC should develop a core of model programs for local monitoring of risk behaviors, HIV prevalence, and HIV incidence among target populations and provide technical assistance to facilitate their implementation. Including both population-based and convenience sample-based surveillance protocols (perhaps modeled after the "Family of Surveys") that vary in scope and sophistication would allow health agencies to select the most useful programs to address their needs. Use of

these core programs will serve at least three functions: 1) local agencies can collect information relevant to the specific and unique HIV transmission issues in their communities; 2) these same factors can be compared across different geographic areas; and 3) data obtained from different locales can be aggregated where appropriate to formulate a regional and national picture of relevant trends.

Expanding Monitoring Activities Relevant to Prevention

While the primary emphasis of AIDS/HIV surveillance in this country has been to "count cases" of disease or infection, future surveillance activities must be expanded to monitor the behaviors that facilitate acquisition and transmission of HIV. Moving the focus of surveillance to the "front end" of the epidemic is a critical prerequisite to the identification, development and evaluation of prevention interventions.

Although we believe that the AIDS case reporting system addresses several critically important surveillance objectives and should not be dismantled, modifications that might decrease costs and free up resources for other monitoring activities should be evaluated by CDC. For example, limiting detailed case investigation to a smaller sample of persons with laboratory criteria for AIDS might be a feasible alternative to active investigation of every case that would still provide a reasonable estimate of the number of AIDS cases and their demographic characteristics.

Collaboration and Partnerships

Extensive coordination between surveillance programs, risk behavior prevention activities, and health care planning and delivery activities must occur at all levels. Moreover, partnerships between national, state, and local governments, planning councils, and community agencies will be required to accomplish the goals of surveillance.

Gaining broad-based support for surveillance and control efforts is a critical step in developing effective community/public health partnerships. Public health officials at all levels of government should specifically seek input from communities at risk and advocacy groups during relevant phases of program planning, implementation, and evaluation. CDC should collaborate with these groups to communicate the vital role of surveillance in understanding and controlling the epidemics. Moreover, the CDC should strive to address the concerns about confidentiality, civil rights, social discrimination, and trust that interfere with surveillance efforts.

II. SPECIFIC PROGRAMMATIC RECOMMENDATIONS

A. MONITORING KNOWLEDGE, ATTITUDES AND BEHAVIORS

1. The Public Health Service should assign to CDC the responsibility for providing leadership to develop, in conjunction with NIH and SAMHSA, a strategic plan for monitoring behaviors relevant to HIV transmission and prevention.
2. CDC should aggressively support, in collaboration with NIH and SAMHSA, research that will more clearly define the determinants of risky behaviors at the individual and group level. The CDC must improve its ability and gain political and social support to obtain explicit information about specific sexual and drug use practices that have a direct impact on prevention interventions.
3. CDC should aggressively support programs to evaluate circumstances especially likely to facilitate a rapid spread of HIV infection (e.g. sexually transmitted disease outbreaks, shooting galleries, dealers supplying needles, and settings where anonymous sexual activity occurs), either through the core programs provided to local health agencies or through more intensive targeted programs in specified areas.
4. The CDC should develop and validate a consensus core of survey questions relevant to assessing knowledge, attitudes, and especially sentinel behaviors affecting transmission risk.
 - a. Imbedding the survey core in new and ongoing monitoring programs will allow comparability and aggregatability of survey data obtained from different areas and groups over time.
 - b. Efforts to link data obtained from the survey core to seroprevalence and incidence studies should be enhanced to more clearly define the relationship between behavior and infection risk.
5. The CDC should conduct an ongoing population-based national study, which includes relevant core survey questions, of sexual and drug abuse behaviors associated with HIV transmission among adults and teenagers.

6. Surveys assessing behaviors among populations at higher risk for acquiring and/or transmitting HIV and surveys of infected persons should be conducted in parallel with the national survey.

B. MONITORING OCCUPATIONAL/NOSOCOMIAL EXPOSURE AND INFECTION

1. The CDC should evaluate the feasibility of integrating occupational HIV exposure and occupational infection surveillance activities with surveillance for other occupational infections (e.g. tuberculosis, hepatitis) through cooperative agreements or other funding mechanisms.
 - a. The CDC should develop a core panel of surveillance programs, modeled after the National Nosocomial Infection Surveillance program, that individual institutions could easily implement with minimal technical assistance (e.g. surveillance instructions, computer software) to conduct surveillance of occupational exposures to bloodborne pathogens, tuberculosis, and other important communicable diseases among health care providers.
 - b. Use of the core panel could improve the local capacity to conduct meaningful surveillance and allow local data to be aggregated so that an integrated regional and/or national picture of trends in occupational exposure and infection could be achieved.
2. The CDC should clearly define new goals for the Needlestick Surveillance Study and provide additional resources if needed to enhance their ability to obtain new and scientifically valid information from this project. If important surveillance goals cannot be met using the existing study design, then alternative studies to address these issues should be implemented.
3. The CDC should increase the level of support available to evaluate adherence to and efficacy of exposure prevention interventions, including safety devices.
4. The Public Health Service (PHS) should recognize the credibility gap created by political interference with the development of scientifically sound policies for managing HIV-infected health care providers and actively work to restore confidence in the integrity of the

process. The 1991 guidelines for preventing transmission of HIV during invasive procedures should be revisited to ensure that PHS policy corresponds to sound public health principles and the recognized professional consensus.

C. MONITORING HIV/AIDS INCIDENCE AND PREVALENCE

1. The CDC should increase its efforts to monitor HIV incidence.
 - a. The pilot research program assessing surrogate markers of recent infection among persons detected in prevalence surveys should be expanded.
 - b. Pilot programs to assess the utility of rapid serologic tests for HIV and other new diagnostic tests (e.g. saliva test) to monitor infection should be implemented.
 - c. The capacity to conduct dynamic cohort studies of persons at high risk for incident infections should be enhanced by strengthening linkages between existing test sites (e.g. sexually transmitted disease clinics) and monitoring programs.
 - d. Seroincidence studies should be linked to surveys of knowledge, attitudes, and behaviors to more accurately monitor the relationship of these variables in predicting transmission risk.
2. The capacity for conducting locally and regionally relevant HIV monitoring must be expanded.
 - a. A core of surveillance programs to monitor prevalence (and incidence, where feasible) that can be easily implemented by local and state agencies should be developed. Use of the model programs will facilitate collection of comparable data that can be aggregated to provide a more comprehensive picture of emerging trends.
 - b. The CDC should greatly enhance its capacity to provide technical support to communities where lack of human and financial resources not only impedes surveillance efforts but also diminishes their chance of competing successfully for federal support.

- c. The capacity to conduct targeted surveillance for infection among special populations e.g. rural youth, street youth, substance users, prostitutes, communities of color, young gay men, homeless persons, etc., should be increased through the core programs and/or through a larger number of specific cooperative agreements.
- 3. The CDC, in cooperation with other health agencies, should develop a comprehensive strategy to elicit support for HIV surveillance programs among communities at risk, the public health sector, legislative and administrative bodies, and the general public.
 - a. Information should be provided to communities at risk to improve understanding about why HIV surveillance is important in monitoring the epidemic and how the information can be used to improve prevention, education and medical care services.
 - b. The public health community, community planning councils, legislators, and private sectors must be educated about the need to protect the confidentiality of individuals involved in surveillance efforts.
 - 4. The CDC must continue and improve its leadership role in assuring the confidentiality of persons included in monitoring programs.
 - a. The CDC should establish a confidentiality standard that includes the following:
 - 1) restricts use and access to identifying information collected for surveillance purposes;
 - 2) provides for civil and/or criminal redress in cases of unauthorized disclosure.
 - b. Adoption and adherence to the confidentiality standard should be a mandatory condition of funding required for receipt of CDC directed funds and funds should be restricted when the tenets of the confidentiality standard are not met.
 - c. CDC should fund confidential named HIV reporting only if state/local health departments have an established confidentiality standard.

- d. CDC funding for HIV surveillance should not require reporting of names as a condition of eligibility.
 - e. To facilitate acceptance of HIV reporting, the CDC should encourage and support evaluation of programs utilizing coded (i.e. unique identifiers) surveillance reports in lieu of names reporting.
 - f. The CDC should encourage and support evaluation of the effects of names reporting on HIV-infected adults and children.
5. The CDC should encourage and support monitoring of HIV incidence, prevalence, and risk behaviors among injection drug users who are not in drug treatment programs.

D. MONITORING THE VIRUS

- 1. The CDC should establish clear goals for its virus monitoring program and improve collaboration with NIH research in this area.
- 3. The value of virus strain monitoring as an epidemiologic tool should be evaluated in the U.S..
- 4. Linkages between virus strain monitoring and seroincidence/seroprevalence studies should be strengthened.
- 5. Evaluating the relationship between virus strain and infectivity and virulence should assume a high priority. Closer collaboration with pathogenesis study groups, including sharing of virus isolates, should be developed.
- 6. Extramural funding should be made available to enhance the capacity of these programs. Request for proposals and peer-reviewed grants to individual investigators for epidemiologic and pathogenesis studies should be developed and funded.

E. MONITORING HIV-ASSOCIATED MORBIDITY

- 1. The CDC should ensure demographic representation of the sites and patients involved in the Pediatric and Adult Spectrum of Disease projects.

2. The validity and completeness of the Spectrum of Disease data should be evaluated by supplemental studies involving patient and care-taker interviews or other direct means of data collection.
3. The ASDP should be modified by conducting weighted sampling of special populations (e.g. newly affected populations, women) and less frequent monitoring (e.g. annually instead of semi-annually)
4. The CDC should develop a strategic plan for monitoring opportunistic infections and increase extramural support for these activities. Greater coordination between divisions of NCID responsible for specific pathogens and the HIV branch should be developed.
5. Guidelines for preventing opportunistic pathogens should be developed and disseminated with the shortest possible turn-around time.
6. The CDC should collaborate with local and state health department to improve monitoring of other reportable diseases among HIV-infected persons. In states with confidential named HIV reporting who uphold the confidentiality standard (proposed above), forms for reporting communicable diseases should be altered to encourage co-reporting of HIV infection.

F. MONITORING HIV-ASSOCIATED MORTALITY

1. A pilot study of post-mortem HIV testing by medical examiners and pathologists performing autopsies should be conducted to evaluate the frequency of unrecognized cases of infection.
2. The CDC should conduct a pilot study to validate the accuracy of death certificate data.
3. Additional states should be included in the National Death Index project to reflect changes in the patterns of the epidemics.

Figure 1. Current HIV/AIDS CDC Monitoring Activities by Behavior or Infection/Illness Status

	Behavior	HIV Incidence	HIV Prevalence	AIDS	Opportunistic Infections	Mortality
Current resource eligibility	o	o	o	●	---	•
Future health care resource planning	---	---	•	●	•	---
Public education/impact	o	o	•	●	---	●
Targets for prevention:						
HIV infection	o	o	o	---	---	---
Opportunistic diseases	---	---	•	●	•	---
Evaluating prevention	o	o	•	•	•	•

Key to symbols: o = inadequate or not doing at all; ● = currently adequate; • = limited information; --- = not applicable

APPENDIX A: DETAILED PROGRAMMATIC REVIEW

I. MONITORING KNOWLEDGE, ATTITUDES, AND BEHAVIORS

A. Overview

1. Understanding and monitoring the knowledge, attitudes, and behaviors conferring a risk of HIV transmission is prerequisite for developing effective prevention and education interventions and is a vital function of CDC.
2. The reliability of current monitoring programs is hindered by survey tools that are insensitive to the social, cultural, political, and interpersonal factors affecting the lives of the persons surveyed.
3. Linking behavioral surveillance to sero-surveillance can provide critical information about determinants of transmission risk.
4. Monitoring trends in knowledge, attitudes, and behavior is a critical component of prevention needs assessment and can provide important information about the success of intervention programs.

B. Evaluation of Existing Programs: Highlights

Strengths

1. The Youth Risk Behavior Surveillance System has demonstrated the need for educational interventions in schools and enhanced the willingness of funding agencies and school boards to support these programs.
2. Knowledge assessment through NHIS supplemental survey has been useful in identifying targets for public education and evaluating trends in AIDS awareness.

Weaknesses

1. CDC programs to monitor knowledge, attitudes, and behaviors are inadequate to meet the needs of most local, regional, and national agencies responsible for planning educational and prevention interventions.

2. The populations included in most current monitoring programs under-represent groups at highest risk for HIV infection (homeless persons, injecting drug users not in treatment, street youth, etc.).
3. The content of individual surveys is highly variable, too often unvalidated, prepared without adequate input from affected groups, often suffers from a lack of cultural sensitivity, and cannot be readily integrated with other surveillance data.
4. No current survey adequately monitors both sexual and drug using behavior in any population.
5. The failure of any single survey to evaluate relevant aspects of knowledge, attitudes, and behavior impedes evaluation of the inter-relationship of these variables.

II. MONITORING OCCUPATIONAL/NOSOCOMIAL EXPOSURE AND INFECTION

A. Overview

1. Fears of occupationally HIV transmission in the health care setting and other work places can impede access to care for HIV infected persons by discouraging testing and participation in treatment programs.
2. Addressing real and perceived risks of occupational and nosocomial HIV infection is a vital function of CDC.
3. Monitoring occupational exposure and infection among all categories of workers potentially exposed to HIV is an essential component of prevention interventions.
4. Fears about adverse consequences (including practice restrictions) associated with disclosure of HIV status impede surveillance of occupational and nosocomial transmission.
5. The CDC guidelines on preventing HIV transmission during invasive procedures and the process by which they were developed have undermined the agency's credibility.

B. Evaluation of Existing Programs: Highlights

Strengths

1. CDC surveillance of health care providers exposed to HIV has provided critical data about the magnitude of risk associated with discrete exposure events.
2. Monitoring the frequency and nature of exposures among select populations (e.g. surgeons, obstetricians/gynecologists, emergency care personnel) has contributed to an awareness of the potential for occupational infection by various routes and identified several targets for prevention interventions.
3. Data obtained by CDC have been widely disseminated in the MMWR and other publications and guidelines for prevention have been developed and periodically updated.
4. Surveillance of occupationally infected health care providers has increased knowledge of potential modes of transmission.
5. Lookback investigations have provided useful data for estimating the magnitude of risk experienced by patients receiving care from infected health care providers.
6. The "No Identified Risk" case investigation system have helped allay unwarranted fears about modes of HIV transmission.

Weaknesses

1. The efficacy of potential exposure prevention interventions, including universal precautions, safety devices, and technique changes, has not been adequately evaluated.
2. The population of health care providers included in current exposure surveillance programs is not representative of the population at risk for occupational infection.
3. Surveillance for occupational infections through the state and local health departments is incomplete and not likely to improve, given the lack of dedicated funding.
4. Key provisions in the guidelines for infected health care workers lack any public health purpose and serve mainly to inflame public anxiety and perpetuate HIV-related stigma.

III. MONITORING HIV / AIDS INCIDENCE AND PREVALENCE

A. Overview

1. CDC should make a concerted effort to redirect the public presentation of the epidemic from AIDS cases to HIV infection.
2. Misconceptions about the purpose and use of surveillance data along with rare instances where surveillance information has been misused impede surveillance efforts by adding to fears of discrimination and stigmatization associated with disclosure of HIV infection status.
3. The absence of social and medical prevention and treatment services as well impediments to accessing existing services adversely affects surveillance by discouraging persons at risk from learning their HIV status.

B. Evaluation of Existing Programs: Highlights

1. Adult/Adolescent HIV Surveillance

Strengths

- a. In some areas, HIV surveillance data have allowed early recognition of new epidemic trends.
- b. HIV case reporting provides a minimum estimate of the number of persons in an area that will require medical care and social services.
- c. HIV case reporting provides an opportunity to promote access to medical treatment and linkage to clinical trials, drug treatments, and social services.
- d. HIV case reporting facilitates provision of voluntary partner notification services and thereby provides an opportunity to reduce secondary HIV transmission.
- e. HIV case reporting allows an opportunity for evaluation and ongoing monitoring of access to and quality of health care and other services.
- f. HIV case reporting allows for the assessment of stage of illness at the time of the first positive test and a full characterization of factors related to delayed diagnosis.

- g. HIV case reporting facilitates early identification and investigation of HIV-transmission associated with unusual transmission circumstances (e.g. occupational exposures among health care, public safety, laboratory workers, and among those with no identified risk).
- h. HIV case reporting facilitates transmission-associated donor look-back studies thereby allowing early identification of infected recipients and exposed sexual partners.

Weaknesses

- a. In general, current HIV surveillance data are do not detect to local incidence trends and emergence of the epidemic in new populations, especially among adolescents and others who lack access to testing.
- b. Fear of potential adverse consequences to individuals identified with HIV infection may have a negative impact on the willingness of persons at risk to seek confidential HIV testing and lead to an underestimation of HIV incidence and prevalence.

2. Adult/Adolescent AIDS Case Reporting

Strengths

- a. The AIDS case reporting system provides population-based data stratified by age, gender, transmission mode, race/ethnicity, and time accessible by all state and local agencies to evaluate the prevalence of AIDS.
- b. The AIDS case reporting system is successful in monitoring the population of persons with the most serious opportunistic infections and malignancies who are likely to require medical services.
- c. Overall, the reliability of the national AIDS surveillance data is good.
- d. The AIDS case definition has been periodically modified to reflect changes in the understanding of HIV-related disease.

Weaknesses

- a. The changes in the AIDS case definition have a negative impact on the interpretability of surveillance data, at least during the transition period.
- b. AIDS surveillance detects HIV infection trends years after they first occur.

- c. AIDS case reporting does not allow for an accurate estimate of the number of persons with symptomatic HIV disease who may require services even though they do not meet the criteria for AIDS.
- d. AIDS case reporting minimizes the full extent of the HIV epidemics to the public.

3. Pediatric AIDS Case Surveillance

Strengths

- a. Pediatric surveillance has provided an overall "snapshot" of the epidemics in children.
- b. Surveillance of cases among newborns have provided important information on epidemic trends.

Weaknesses

- a. The full extent of the epidemics is not monitored because only those children with serious illness are detected.
- b. Some children with chronic multi-system disease fail to meet the case definition and die without being reported.
- c. AIDS case surveillance under-estimates the true burden of care and need for services since not only infected children but also those at risk require ongoing diagnostic tests, monitoring of immune status, prophylaxis and treatment.
- d. Availability of prenatal testing for HIV is not standardized across the country and infected women may be missed and their infants not recognized to be at risk.

4. Seroprevalence/Seroincidence Studies

Strengths

- a. In some areas, seroprevalence studies among subsets of persons at risk have provided data essential to local prevention and care activities.
- b. Anonymous serosurveys have provided vital information on the location and numbers of HIV-infected women delivering newborns and the number of infants at risk for HIV infection.

Weaknesses

- a. The recent cutbacks in the Family of Surveys and other seroprevalence studies have severely attenuated the ability of local agencies to identify epidemic trends and plan needed interventions.
- b. There is poor representation of many communities at risk among the sites selected to receive funds for seroprevalence studies.
- c. Seroprevalence studies are not often linked to behavior surveys.
- d. The urgent need to develop creative strategies for monitoring HIV incident infections has not been adequately addressed.

IV. MONITORING THE VIRUS

A. Overview

1. Monitoring virus strains is a vital function of CDC essential to identifying patterns of transmission and incursion of the epidemic into new populations.
2. Monitoring virus strains may identify genotypes and phenotypes associated with virulence and infectivity and provide critical information relevant to vaccine development.
3. Monitoring virus strains for genotypic and phenotypic markers of antiviral drug resistance will promote improved clinical care for affected persons and help establish treatment research priorities.

B. Evaluation of Existing Programs: Highlights

Strengths

1. The CDC supported virus strain monitoring program in Thailand has led to a more accurate understanding of the separate evolution of the epidemics among drug users and heterosexuals in that country and demonstrated the potential utility of this approach to defining transmission patterns.
2. The CDC use of virus strain mapping to define the source of infection in the Florida dental office outbreak and other isolated instances has played an important role in shaping public policy discussions and demonstrates the value of molecular epidemiology in defining the sources of transmission.

3. The CDC has developed the expertise and infrastructure to conduct limited surveillance of virus strains in the U.S..

Weaknesses

1. The current monitoring program is limited in scope and has not impacted prevention efforts.
2. Lack of human and financial resources severely handicaps the capacity of CDC to expand this function.
3. The current plan to evaluate a sample of 100 virus strains obtained from a cross-section of incident infections in the U.S. is too limited in size and scope.
4. CDC has not adequately utilized data from these studies in research and prevention efforts.

V. MONITORING HIV-ASSOCIATED MORBIDITY

A. Overview

1. Monitoring disease stage, HIV-related complications, service needs, and delivery of services for those infected with HIV is a critical mission of the CDC.
2. Identifying the risk factors for acquisition and transmission of these infections and the impact of prophylactic and treatment interventions is essential to prevention and treatment efforts.
3. Monitoring the burden of illness among HIV-infected persons has important implications for resource allocation from federal and local agencies.
4. Monitoring HIV-related morbidity can assist in the identification of medical care and/or access patterns in need of correction e.g. demographic differences in receipt of prophylactic therapies.

B. Evaluation of Existing Programs: Highlights

1. Pediatric Spectrum of Disease Project

Strengths

- a. Overall, the project includes a good representative sample of infected children of sufficient size to obtain useful epidemiologic and clinical data about common illnesses and trends.
- b. Data are useful in determining needs for resource allocation in this population.

- c. The project provides useful expertise and information to local clinicians.

Weaknesses

- a. Data are extracted only from medical records and are not supplemented with direct information from clinicians, caretakers or patients
- b. The accuracy and completion of the data set has not been evaluated.
- c. The project sites are not entirely representative of all affected children.
- d. Data include both infected as well as exposed but uninfected children but the cost/benefit of this approach has not been evaluated.

2. Adult Spectrum of Disease Project

Strengths

- a. The project includes a large sample of subjects monitored through chart reviews at 6 month intervals.
- b. The morbidity data could be useful in planning for resource allocation for health care needs.
- c. The data provide a cross-check on the validity of the AIDS case definition.
- d. The data are useful in identifying specific complications of HIV requiring more research.

Weaknesses

- a. Data is based entirely on chart reviews at study sites (which may be incomplete) and may not include information on conditions diagnosed or treated outside the study center (private offices, other geographic locations).
- b. The sample size is large and growing rapidly
- c. The study sites and populations studies are not representative of many affected groups.
- d. Even though the overall sample size is large, the analysis of subsets (e.g. pregnant women) is precluded by low accrual rates in specific populations other than gay men and injection drug users.
- e. The project is underfunded relative to the Pediatric Project.

3. Opportunistic Infection Surveillance

Strengths

- a. Surveillance has identified complications of HIV that became apparent after the epidemics matured.

- b. Surveillance allows prioritization of research funding in the area of opportunistic infections and AIDS-related malignancy.

Weaknesses

- a. Surveillance for specific opportunistic infections is poorly coordinated, incomplete, and in many cases, entirely lacking.
- b. Information about potential risk factors for acquiring many opportunistic infections (e.g. cryptococcal disease) is not available. Moreover, even when data are available, dissemination is incomplete (e.g. risks associated with household pets, foods).
- c. The potential role of person-to-person spread of many opportunistic infections in hospitals and other settings has not been adequately defined.
- d. CDC surveillance for HIV-related malignancies is (apparently) non-existent.
- e. Existing programs are not geographically representative and do not include some important at-risk populations (e.g. women, adolescents) in sufficient numbers to generate meaningful data.
- f. Surveillance of co-infection with HIV and other reportable diseases (e.g. foodborne enteric illnesses) is inadequate. Moreover, linkages are not established between HIV surveillance and surveillance of other conditions.
- g. Surveillance of microbial resistance to drugs commonly used to treat AIDS-related conditions (eg. fluconazole) is lacking.
- h. Integration of opportunistic infection surveillance efforts with agencies funding clinical trials (e.g. NIH) is poor.

4. Hospital Discharge Evaluation

Strengths

- a. Hospital discharge evaluation provides a cross-check on the spectrum of diseases studies of serious opportunistic infection meeting the AIDS-case definition.
- b. Discharge evaluation includes monitoring for serious non-AIDS-defining condition which may allow future expansion of the AIDS case definition.
- c. The project provides cost data on hospitalization to help define the overall resource needs for inpatient HIV care.

Weaknesses

- a. Data reliability is entirely dependent on the reliability of ICD-9 codes which are not independently validated.
- b. Data cannot be used to directly cross-check the reliability of AIDS surveillance data.
- c. Significant reporting delays and a large amount of data for analyses prevent rapid turn-around of results.
- d. The survey includes less than 10% of U.S. hospitals.

VI. MONITORING HIV-ASSOCIATED MORTALITY

A. Overview

1. Monitoring HIV-related mortality is a cost-efficient method of demonstrating the seriousness of the epidemic to the public and can have an important impact on resource allocation for HIV related care.
2. Mortality data serve as a useful cross-check on AIDS case reporting and provide indirect information on patterns of migration.

B. Evaluation of Existing Programs: Highlights

1. Vital Statistics

Strengths

- a. Monitoring vital statistics obtained from death certificates relies on existing data and is relatively inexpensive.
- b. These data allow direct comparison of age-specific death rates from HIV to other causes of death and emphasize the impact of the epidemics in comparison to "traditional" causes of death in the U.S.
- c. Vital statistic data provide a cross-check on AIDS case-reporting.

Weaknesses

- a. The accuracy of death certificates and completeness of reporting HIV-related conditions as a primary or underlying cause of death are not validated.
- b. Persons with HIV/AIDS who die from unrelated causes (e.g. accidents, diabetes) or indirectly related (e.g. suicide) are unlikely to be detected.

- c. Persons with HIV/AIDS who die from disease not considered to be typical opportunistic infections that contribute to HIV morbidity and mortality are not likely to be detected.
- d. The time lag from data collection to analysis and publication is long.

2. National Death Index Project

Strengths

- a. The confidentiality requirements mandated for participating health departments are exemplary.
- b. Data provide a locally-relevant cross-check on HIV/AIDS surveillance completeness and patterns of migration between diagnosis and death.
- c. The project can detect changes in location of death patterns (home vs hospital).

Weaknesses

- a. Not all states are funded to participate in this project and there is underrepresentation of some geographic areas.
- b. As with the vital statistic data, the accuracy of data extracted from the system is dependent entirely on the accuracy of death certificate data and is not independently validated.
- c. Deaths indirectly related to HIV (e.g. suicide) are not included unless the individual has been reported to have HIV/AIDS in that state.

CDC Advisory Committee
on the
Prevention of HIV Infection

EXTERNAL REVIEW OF PROGRAMS AND SERVICES
PROMOTING KNOWLEDGE OF SEROSTATUS (CTRPN)

FINAL REPORT

November 17, 1993

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EXECUTIVE SUMMARY

- CDC's counseling, testing, referral, and partner notification (CTRPN) program is not implemented as designed and is not working effectively. CDC should develop and implement a quality assurance program that sets a standard of practice for CTRPN and should immediately implement ongoing retraining of CTRPN staff.
- CDC-funded CTRPN programs should target those who are or might be HIV infected, their partners, and others who have high-risk behaviors.
- Even if the problems with CDC-funded CTRPN programs were resolved, these programs would not be sufficient to effect the major behavioral changes that are needed to halt the HIV/AIDS epidemic.
- CTRPN is only one part of a continuum of HIV prevention services. CDC should support two major types of prevention programs: 1) ongoing individual-level behavior-change interventions for those at highest risk of HIV infection including those already infected, and 2) large-scale community-level interventions aimed at changing community norms.
- The current administrative structure of CDC's HIV/AIDS activities is inadequate to provide appropriate management of HIV prevention programs. CDC should be restructured so there is line authority to direct HIV/AIDS programs while promoting synergy with STD and other programs.
- Substantial increases are needed in federal, state, and local funding for HIV prevention services.
- The overwhelming focus of resources on testing rather than on a range of HIV prevention services has resulted in a woefully inadequate prevention effort. CDC should require that decisions about the relative allocation of prevention resources be determined through a representative local needs assessment and planning process.
- The Public Health Service and CDC should require the linkage/referral of HIV-infected persons to primary care, substance abuse treatment, and prevention systems. It is unethical and illogical to have a CTRPN program without ensuring access to care.
- With or without health-care reform, there should be continued federal funding for both specialized anonymous and confidential HIV testing and behavior-change services.
- Partner notification should be redefined as partner counseling. CDC should ensure professionalism in the implementation of partner counseling by providing specific guidelines, training, and technical assistance.

I. FINDINGS AND RECOMMENDATIONS FOR PROGRAM POLICIES AND STRATEGIES

A. INTRODUCTION

The current HIV/AIDS epidemic in the United States poses an immense threat to American health. There are 40,000 to 80,000 new HIV infections estimated to occur each year. The resulting HIV-related mortality from each year's new infections will be equivalent to the total mortality of the Vietnam War. Each infection costs the American people more than \$100,000 in direct medical costs and far more in lost earnings and personal misery. Thus, the incentives to do something effective are immense.

B. FOREWORD

1. Our Charge as a Subcommittee and How We Undertook It

- We examined the counseling, testing, referral, and partner notification (CTRPN) programs funded by the Centers for Disease Control and Prevention (CDC). These programs constitute the largest proportion of funding for HIV prevention services sent to state/local health departments and community-based organizations.
- Our methodology included developing ideal goals; making site visits to Dallas, Miami, New York City, Raleigh, and Seattle; holding a public hearing in New York City; soliciting and reviewing public comments and expert presentations; reviewing research findings; having discussions with CDC staff; and using the experience and expertise of members of the committee.
- Minutes of our meetings are available for those who wish to learn the details of our process (see Appendix). This report is designed to articulate our key findings.

2. Background/Framework

- CDC has fought the HIV/AIDS epidemic with overly limited resources and with inappropriate restrictions on those resources. A successful national HIV prevention program requires sound policy, adequate resources, and a functional delivery system. Both Congress and the political leadership in previous administrations have prevented the implementation of innovative and proven approaches to HIV prevention -- from targeted, frank education programs to needle exchange. This external review process provides an opportunity to design effective programs, fund them adequately, and deliver them efficiently.

- Funding for CDC's prevention programs has been essentially flat over the last three years (with an actual decrease in FY 1992). Administration policies and Congressional funding mandates (earmarks) have limited the flexibility of HIV prevention programs. For example, Congress has dictated the division of funds between CTRPN and health education/risk reduction (HE/RR) and has earmarked funds within those programs for specific initiatives. These restrictions have prevented professionals from using resources where they would be most effective; they have also discouraged development of innovative strategies.
- Restrictions on the content of HIV prevention messages imposed in 1986 have had a chilling effect on the ability of CDC grantees to deliver the prevention messages needed to be successful.
- A clear definition of counseling is important to program design, implementation, evaluation, quality assurance, and staff training. Many of the problems with CTRPN programs have come about because "counseling" is a generic term with many different meanings. We identified three distinct functions of counseling: (1) informed consent, (2) behavior-change intervention, and (3) psychosocial support. Risk assessment is an additional activity that may determine the type and extent of counseling that is needed.

3. Ideal Goals

The subcommittee determined ideal goals for CTRPN and for outreach prior to performing site visits. (See Background and Current Status of Program, page 24.)

The ideal goals which we determined for counseling, referral, and partner notification were not substantially different from those CDC has stated. We also reviewed public comments (22 letters and a public hearing), and for the most part, these were also not substantially different.

What we found at the site visits was, however, substantially different from what was stated in the ideal goals:

- There was little effort to assist people in reducing high risk behaviors. Many people with persistent high risk behavior were given condoms and advised to return for repeat testing in 6 months (3 months in one state, for no apparent reason).
- Several counselors expressed frustration that people with high risk behaviors continued those behaviors but returned for testing every 6 months to see if they had become infected.

- Referral services for people with high risk behaviors were usually non-existent. When they did exist, counselors at the CTRPN sites were unaware of them.
- Partner notification programs seemed to exist, at least in two of the 5 states visited, for the sole purpose of identifying for the states the names of those infected. Referrals to change high risk behavior did not exist.
- Outreach in most communities was usually done via mass media. Thus when an individual such as Magic Johnson announced his HIV infection, many people at low risk flooded the CTRPN programs. No mechanism for providing tests to large numbers of low risk individuals, while preserving testing opportunities for those at high risk, were present in most communities.
- Targeted outreach existed to a limited extent in some communities and was effective, but was too limited in scope.

4. Acknowledgements

We thank persons living with HIV/AIDS, community organizations, service providers, and state and local health departments for their contributions and openness. We thank CDC staff for their commitment to this process and their openness to a frank discussion of the difficulties this program faces. We also acknowledge the hard work and dedication of those working within the various CTRPN programs.

C. GENERAL CONCLUSIONS

1. Prevention works.

Both formal research and the practical experience of community experts demonstrate that prevention programs can change behavior. While CDC efforts have operated under a cloud of suspicion that risky behavior cannot be changed, CDC-sponsored and other programs have demonstrated that risk behaviors can be changed. Although expanded evaluations of behavior-change interventions are needed to determine which interventions work best with whom, even modest behavioral changes should be viewed as successful -- given the enormous social and economic costs of an HIV epidemic permitted to run its course. The following generalizations have emerged from the subcommittee's work.

- Behavioral interventions have been shown to be effective in reducing risky behavior. Interventions aimed at sustained reduction in risk behaviors are more effective if not limited to one-time interventions or "pretest and posttest counseling." In some persons, knowledge of serostatus contributes to the

effectiveness of behavioral interventions. This is especially true for persons who test seropositive.

- It is inappropriate to consider behavioral interventions failures if they do not eliminate 100% of all risk behaviors. Such standards have not been required for other public health interventions, such as vaccines.
 - Targeted community-based and social marketing interventions are promising for changing community norms that support individual behavior changes. These interventions can best be designed at the community level. Targeting is important because prevention messages must speak to the particular subpopulations they are trying to reach. In the absence of such interventions, CTRPN programs are less likely to succeed.
 - HIV prevention strategies are more effective if they take into account the culture-specific norms, values, and realities of the target populations. Stressing abstinence alone is not an effective HIV prevention message for sexually active persons. Little information is available about the value of stressing abstinence alone for potentially sexually active persons in preventing high risk behaviors.
 - HIV prevention programs have been shown to reduce risky behavior among multiethnic groups of urban adolescents. These programs should be in the context of a broader-based prevention effort to achieve substantial changes in risk behaviors.
 - Access to clean needles has been shown to be effective in reducing risk from injection drug use for those not ready to stop injecting. Programs for substance users must also include interventions for reducing sexual transmission. Community context is as important in shaping intervention strategies to reduce risk of substance-use transmission as it is for sexual risk reduction.
 - Substance-abuse treatment is a key component of HIV prevention. Substance-abuse treatment must be available on demand for those seeking treatment.
 - Intensive behavioral interventions with HIV-discordant (i.e., different serostatus) heterosexual couples have shown significant reductions in high-risk behavior and HIV transmission. Ongoing behavioral and psychosocial interventions should be available for all HIV-discordant couples.
2. The CTRPN program, as currently designed and implemented, needs major changes.
- The four major goals of the current CTRPN program are to: (1) provide HIV testing to those who wish to know their serostatus, (2) provide interventions to

reduce high-risk behaviors in infected and uninfected persons, (3) provide referrals for medical and psychosocial services for those who are HIV infected, and (4) help sex and needle-sharing partners receive prevention services and referrals.

- While all the goals are important and appropriate, the overall priority has been primarily to get people tested.
- Additionally, there is no established goal for outreach in CTRPN program design.
- For the most part, CTRPN programs do not meet the guidance CDC has issued.
- Even if CDC guidance were followed, with the current resources and program structure, CTRPN programs would not be sufficient to change high-risk behaviors.

D. FINDINGS AND RECOMMENDATIONS

1. **FINDING:** The CTRPN program has had to meet the demand for increased testing over the last several years without increased resources. Much of the increased demand has occurred among persons with little apparent risk for HIV infection.

- Increased demand for testing has occurred in an era of flat or reduced funding.

<u>Year</u>	<u>Tests</u>	<u>Seropositive (%)</u>	<u>Funds</u>
1990	1,491,715	56,064 (3.8)	\$ 100,849,173
1991	2,090,635	57,879 (2.8)	\$ 102,751,773
1992	2,689,056	55,024 (2.0)	\$ 102,742,506

- The public health message encouraging testing has not been successfully targeted to those at significant risk. Therefore, increased testing has not resulted in a proportional increase in identification of those infected, nor even in an increase in the number of HIV-infected persons identified annually.
- CTRPN programs as currently constituted generally do not differentiate interventions based on a person's real or perceived risk and readiness for change. This undifferentiated approach means that a low-risk person gets the same/similar quality and quantity of counseling as a high-risk person. This is not an efficient use of resources.

- In 1992, 41.1% of persons who were HIV tested in sexually transmitted disease (STD) clinics (including both seropositives and seronegatives) received their test results. Low rates of receiving HIV test results, particularly in STD clinics, have many causes. These include inadequate pretest counseling, poor risk assessment practices, time constraints due to patient volume, negative attitudes of some staff toward clients, and a philosophy centered on treatment rather than behavior change. STD clinics, as currently conceived and managed, are not designed to operate the kind of behavioral intervention programs required to prevent HIV infection and other STDs.
- In 1992, 28% of all HIV antibody tests were in persons reporting previously negative tests (based on the 28 project areas that routinely collected this information). Counselors report that many seroconverters with persistent high-risk behavior interpreted previously negative tests as an indication that their previous high-risk behaviors were safe. Obviously, current interventions did not change that misconception. Counselors also report that some seronegative persons seek repeat testing because it is the only emotional support service available in their community. More appropriately, counselors report that some persons with prior high risk behavior use CTRPN programs for behavior-change support.
- In every site visited, uninfected persons are being advised to return in 3 to 6 months for repeat testing. Counselors have been trained to encourage repeat testing because of the "window period." The result of this practice is to substantially increase the volume of tests and the costs of the program. If repeat testing is construed by clients to have a protective effect, it may inadvertently reinforce high-risk behavior.

RECOMMENDATIONS:

- 1.1 Since there will always be a large number of persons who want to learn their serostatus outside the traditional health-care delivery system, CDC should ensure that both specialized anonymous and confidential testing services and behavioral intervention services continue to be readily available.
- 1.2 CDC-funded CTRPN programs should specifically target those who are or might be HIV infected, their partners, and others who are engaging in or have engaged in high-risk sexual or drug-using behaviors.
- 1.3 CDC and states should encourage private and publicly funded physicians and other health-care providers to offer HIV antibody testing to their patients in areas where the seroprevalence rate is high enough to warrant doing so.
- 1.4 Where HIV testing has become a standard of routine medical care (e.g., tuberculosis clinics, prisons, ob-gyn settings), CDC should encourage the

regular provider/payor to cover the cost of this service. The cost of testing in public programs (e.g., substance-abuse treatment and family planning services) should be shifted from the CDC-supported HIV prevention program to those funding streams.

- 1.5 At all levels (CDC, state, and local), more flexibility in designing testing programs allows better use of limited resources. CDC should encourage programs to innovate by use of alternative means of service delivery (e.g., telephone pretest risk assessment; rapid testing techniques).
 - 1.6 CDC or other evaluations of CTRPN programs should not be based solely on the number of tests performed, but should also consider the quality and array of services provided. Clients should not be pressured to accept testing by program staff trying to boost test numbers.
 - 1.7 CDC should develop guidelines on approaches to ensure that persons tested receive their test results. For low-risk populations, this may mean telephone notification of test results where local laws permit.
 - 1.8 CDC must provide CTRPN programs with flexibility in service delivery through innovative approaches to reaching high-risk persons (e.g., mobile counseling and testing sites).
 - 1.9 CDC should develop guidelines for the appropriate use of repeat testing.
 - 1.10 CDC should redesign STD clinics to include prevention as part of the services provided.
 - 1.11 CDC must encourage substance-abuse treatment HIV prevention activities to address sexual transmission as well as injecting drug use transmission. Further, since use of many non-injected psychoactive substance (e.g., crack cocaine, alcohol) has a relationship to high-risk sexual activity, HIV prevention programs must also address the use of these other psychoactive substances.
- 2. FINDING: CTRPN programs as currently implemented are not adhering to CDC guidelines in many jurisdictions.**
- Most CTRPN sites have not implemented new CDC guidance on HIV counseling.
 - HIV counseling under the previous guidance is often perfunctory or inappropriate to clients' needs.

- CDC is not communicating effectively through project officers and field staff to ensure that project areas receive proper guidance and technical assistance.
- Levels of technical assistance and program evaluation from CDC and state health departments to projects are inadequate. CDC staff should facilitate communication between state and local programs.
- Referral programs are limited at best; many communities lack referral resources for prevention services for HIV-infected or high-risk uninfected persons. Referral to care services for HIV-infected persons is more successful but is still not always adequate.
- In some communities testing and identification of those infected has been the primary goal. Testing without the availability of psychosocial support services and referral for behavioral intervention and medical treatment is inappropriate and illogical.
- Partner notification programs sometimes do not adhere to CDC standards of professionalism and respect for confidentiality. In some instances, partner notification programs are punitive and therefore counterproductive to effective prevention. Two of the five site visits found repeated complaints of violations of CDC partner notification procedures (see Appendix, Minutes and Amendment to Minutes of Meeting Three, 30-31 July 1993).

RECOMMENDATIONS:

- 2.1 CDC should develop a quality assurance program for CTRPN. This would include defining minimum "standards of practice" for each of the different functions of counseling, and ensuring their implementation in the field.
- 2.2 CDC needs to make immediate and dramatic improvements in the training, supervision, and quality assurance of counselors, supervisors, and other CTRPN staff. Training should be ongoing.
- 2.3 CDC should define counseling more specifically -- distinguishing among education/information communication, behavior intervention, psychosocial support, and risk assessment. CDC should provide appropriate guidelines for these different interventions.
- 2.4 CDC and states should mandate that HIV testing never be offered without informed consent.
- 2.5 CDC should encourage flexibility in program design to address clients' individual needs (e.g., availability of behavior-change interventions without

testing; video presentation of pretest information; testing with only informed consent for selected clients who have very low exposure risk determined after accurate risk assessment).

- 2.6 CDC should set a standard of practice requiring programs that offer HIV testing to have immediate crisis support and ongoing emotional support available onsite or by referral.
 - 2.7 CTRPN is only one part of a continuum of prevention services. CDC should support two major types of prevention programs: 1) ongoing individual-level behavior-change interventions for those at highest risk of HIV infection, and 2) large-scale community-level interventions aimed at changing community norms. CDC should give programs the flexibility to use prevention funds to develop a referral system that includes longer-term prevention interventions with HIV-infected and high-risk uninfected clients.
 - 2.8 CDC should redefine partner notification as partner counseling. Partner counseling should be implemented within general parameters set by CDC and in accordance with a state's community planning process. CDC should ensure professionalism in the implementation of partner counseling by providing specific guidelines, training, and technical assistance.
 - 2.9 CDC should resume a strong technical assistance role to grantees, as it has done successfully in the past. CDC and its grantees should implement strong quality assurance and evaluation programs.
3. **FINDING: CDC's data collection requirements influence HIV prevention programmatic directions. The data collection instrument has been used as a checklist for counseling sessions, and therefore may drive the content of the interaction between the counselor and the client.**
- Current data collection requirements stress the process of testing and not the other components of CTRPN. Tests alone are not an indicator of the extent of services delivered.

RECOMMENDATION:

- 3.1 CDC should revise its data collection requirements to measure progress toward achieving each of goals of the HIV prevention program. This would ensure that all the ideal goals in addition to testing are met.

4. **FINDING:** Even if problems with CDC's CTRPN programs were resolved, these programs would not be sufficient to effect the major behavior changes that are needed for this epidemic. There is little evidence for the belief that testing alone will change most people's behavior. The overwhelming focus of resources on testing rather than on a range of prevention services has resulted in a woefully inadequate prevention effort. Testing must be provided in the context of a continuum of prevention services, many of which will need to be provided outside of CTRPN programs.

RECOMMENDATIONS:

- 4.1 CDC must promote the full continuum of prevention services, which are critically needed and long overdue. These services include: CTRPN; community-based, ongoing behavioral interventions; treatment programs for substance abuse; and expansion of primary health services which include behavioral interventions for HIV-infected persons and their partners.
- 4.2 CDC should allow decisions about the relative allocation of resources to components of the continuum of prevention services to be determined through a local needs assessment and planning process. The needs assessment and program should respond to the local epidemiology and the unique needs of each community. State and local health departments, working with their communities, should have flexibility in determining the relative allocation of resources among the various prevention functions.
- 4.3 CDC should clearly state that substance abuse is a public health issue. Access to substance abuse treatment and to harm-reduction services for substance users (e.g., needle exchange) must be integrated into CDC's HIV prevention programs.
- 4.4 The Public Health Service and CDC should require the linkage/referral of HIV-infected persons to primary care, substance abuse treatment, and prevention systems. It is unethical and illogical to have a CTRPN program without ensuring access to care.
- 4.5 The Public Health Service and CDC should require that the primary care system include prevention services. Special attention must be paid to the ongoing prevention needs of newly diagnosed clients entering the care system. Thus, for HIV-infected persons, Ryan White CARE dollars should be available for prevention services. HIV prevention and care planning processes should be linked to accomplish this goal.
- 4.6 Research has shown that some behavior-change interventions are effective in certain populations. CDC should broadly disseminate these findings and

encourage their use in the development of community prevention service programs.

- 4.7 Additional behavior-change research is needed to demonstrate long-term behavior change, especially in hard-to-reach populations. CDC, NIDA, and NIMH must fund these studies and rapidly disseminate their findings.
- 4.8 CDC should work with the Assistant Secretary for Health to ensure that various HIV-related programs and funding streams result in a comprehensive HIV/AIDS prevention program.

5. FINDING: The current administrative structure of CDC's HIV/AIDS activities is inadequate to provide integration of policies and programs. This adversely affects the quality of the CTRPN program and its integration with other HIV/AIDS programs at CDC.

- There is no clear line of authority for policy, program, and budget from the HIV leadership to the staff implementing the programs.
- HIV programs are dispersed among ten centers that compete with each other internally for resources. For example, CTRPN is in a totally different center from HIV/AIDS surveillance.
- HIV prevention programs are subsumed under the Division of STD/HIV Prevention. This lessens the perceived priority of HIV/AIDS prevention. It also inappropriately imposes the model of STD control on HIV prevention and isolates sexual transmission from substance-use-related transmission.
- The model of STD control has historically focused on treatment of an index case and finding and treating of contacts. There has been minimal focus on a continuum of care and prevention. This approach minimizes the importance of perinatal HIV transmission and transmission related to substance use.

RECOMMENDATION:

- 5.1 CDC should be restructured so there is line authority to direct HIV/AIDS programs while promoting synergy with STD and other programs. Epidemiology, research, surveillance, laboratory, and prevention activities should be in a single organization. One option is a Center for HIV/AIDS.

6. **FINDING:** Research findings as well as counselor and client reports indicate that many CTRPN clients with persistent high-risk behavior do not accurately perceive their risk and consequently have not been contemplating behavior change.
- An estimated 1 million Americans are infected with HIV; many of these persons are unaware of their infection status. If each has an average of two sex or drug-use partners per year, then the behavior of 3 million Americans must be changed to prevent continued HIV transmission. It is of course impossible to specifically identify those 3 million people. Therefore, to effect behavioral changes in those 3 million persons will require that efforts be made to reduce high-risk behavior in tens of millions of persons.
 - Behavior change is an ongoing process that requires interventions of varying intensity and type, depending on client needs and readiness to change. CTRPN programs alone do not have the program design, capacity, and resources to meet these needs. CTRPN programs reach people at a single point in time. Both community-level and individual-level interventions are needed and are usually not available at present.

RECOMMENDATIONS:

- 6.1 CDC must ensure that two major types of prevention programs are provided:
- Ongoing individual-level behavior-change interventions for HIV-seropositive persons, seronegative partners of seropositive persons, and seronegative persons with high-risk behaviors
 - Large-scale community-level interventions aimed at changing community norms to reduce high-risk behaviors in large numbers of persons, including men who have sex with men, adolescents, women, substance users, and members of underserved populations
- 6.2 CDC must serve as a catalyst to educate the public and elected officials about the health, social, and financial benefits of successful HIV prevention programs.
7. **FINDING:** Persons in correctional systems have a significantly higher rate of HIV infection compared to the general population. HIV prevention efforts for persons in correction systems, including after release, are extremely important.

- The subcommittee saw programs where CTRPN staff struggled mightily to deliver HIV prevention services in correctional facilities, but could not accomplish their mission because of limited resources and programmatic restrictions.

RECOMMENDATION:

- 7.1 CDC should work with grantees to assure greater resources and integrated HIV prevention programs for incarcerated individuals during imprisonment and after release. CDC should work with the Department of Justice to adopt policies consistent with public health objectives.

8. **FINDING:** Not enough resources have been devoted to HIV prevention at the federal, state, or local levels. The historically modest federal financial commitment to HIV prevention cannot effectively address the overwhelming need for behavior change in millions of at-risk and HIV-infected persons.

- Demand for HIV testing continues to increase. Limited funding available for prevention is being used to provide testing services frequently to persons with little identifiable risk.

RECOMMENDATIONS:

- 8.1 Substantial increases are needed in federal, state, and local funding for HIV prevention services.
- 8.2 Irrespective of whether additional resources become available:
 - Flexibility should be provided to state and local health departments, working with their communities, in determining the relative allocation of resources among the various aspects of HIV prevention programming.
 - CDC should provide funding to require state and local health departments to institute a representative and participatory community planning process. There should be no conflict of interest for those participating in this process. CDC should provide strong guidance to ensure adequate inclusion of all affected constituencies.
 - CDC's guidance should emphasize improved behavior-change interventions. The emphasis on HIV testing as an end in itself is wrong.
 - CDC should make efforts to reduce inappropriate testing and inappropriate repeat testing.

- Partner notification (counseling) programs should be implemented only when they will lead to significant benefits in care and prevention.

9. FINDING: HIV prevention services are not now integrated into programs that cross several Public Health Service agencies – CDC, HRSA, and SAMHSA. This results in uncoordinated approaches to prevention and increased difficulty in gaining access to comprehensive services.

- Persons with HIV infection access the system through multiple entry points -- STD clinics, HIV testing and counseling programs, substance-abuse treatment sites, Ryan White CARE Act primary-care programs, and other Public Health Service programs. There is little financial encouragement for grantees in these programs to integrate prevention services into care and vice versa. Indeed, grantees who seek to integrate these services face numerous fiscal and programmatic obstacles to accomplishing this goal.

RECOMMENDATION:

- 9.1 CDC should work with the Assistant Secretary for Health to ensure that various HIV-related programs and funding streams result in a comprehensive HIV/AIDS prevention program and that all care-related programs integrate HIV prevention into their services.

10. FINDING: There is an expectation that health-care reform will occur in the near future. Even if clinical preventive services are incorporated into health insurance reform without copayments or deductibles, this change will not eliminate the need for separate HIV prevention, intervention, and outreach programs.

- There will be an extended phasing-in period for the universal coverage envisioned under health-care reform. Even after the goal of "universality" is achieved, many persons at risk for HIV (e.g., migrant and seasonal workers, undocumented residents, prisoners) will not be covered by the health plan.
- Health-care reform will not overcome the distrust and disenfranchisement many feel toward the health-care system. These persons will still seek alternative systems for accessing HIV prevention services for various reasons, including a desire to avoid discrimination and to receive more culturally sensitive services.
- The availability of health care does not guarantee that those at risk will access it. Outreach and incentive programs to help people identify their risks and seek HIV-

related prevention services will still be needed. Assistance is also needed to overcome barriers (e.g., transportation, child care) to accessing care.

- The reformed health-care system may have copayments and deductibles that pose barriers to accessing HIV-related prevention services. Alternative systems that provide these services without charge will still be needed.

RECOMMENDATIONS:

- 10.1 The federal government must continue to fund separate HIV prevention and outreach activities, including HIV testing. This public health objective is critical to ensuring that the HIV prevention message is heard and responded to, ultimately saving the reformed system from high health-care-related expenditures.
- 10.2 All HIV prevention programs providing individual services to clients -- from testing to behavior-change interventions -- should be eligible for reimbursement under the new health-care plan, to the extent that clients are willing to seek such reimbursement. These programs should have sufficient resources to meet the needs of clients who are not eligible for coverage under the new system, who choose not to seek reimbursement, or who cannot afford copayments or deductibles. Reimbursement should cover services provided in non-traditional settings, such as mobile units.
- 10.3 Congress should develop confidentiality and anti-discrimination protections for HIV-related information collected under the reformed system.

II. EXTERNAL REVIEW PROCESS

Since 1985, CDC has collaborated with federal agencies, state and local health departments, and national and community organizations to implement a comprehensive HIV prevention program. The program provides financial and technical support to all states and territories and selected cities for the planning, implementation, and evaluation of HIV prevention activities.

The largest component of this publicly funded effort is the counseling, testing, referral, and partner notification program (CTRPN). As part of an external review of CDC's HIV prevention strategies, a subcommittee of the CDC Advisory Committee for the Prevention of HIV Infection was charged with examining the CTRPN program. Over a 5-month period, the subcommittee members and a group of 13 invited consultants critically reviewed the goals and activities of the program, participated in site visits to observe these activities, assessed program needs, and developed recommendations for improvement.

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B. DATES OF REVIEW MEETINGS

The full subcommittee (Advisory Committee members and consultants) met four times in Atlanta, Georgia. The schedule for the meetings was as follows:

Meeting 1: May 24-25, 1993
Meeting 2: June 21-22, 1993
Meeting 3: July 30-31, 1993
Meeting 4: September 13-14, 1993

C. SITE VISITS

The subcommittee members and consultants formed teams to visit five cities where they observed CTRPN and community outreach activities and participated in on-site discussions of local issues with health department staff, representatives of community-based and non-governmental organizations, and persons with HIV infection. The locations, dates, and teams for the site visits were as follows:

New York, NY	July 12-13, 1993	H. Edgar, J. Levi, J. Lovelace, R. McAlister, J. Mitchell, N. Schram
Raleigh, NC	July 13-14, 1993	W. Freeman, S. Thurman
Dallas, TX	July 14-16, 1993	R. McAlister, C. Vega
Seattle, WA	July 19-20, 1993	D. Francis, S. Hernandez, P. Nolan
Miami, FL	July 27-28, 1993	N. Schram, A. Vaughn, C. Vega

D. ASSESSMENT GOALS

The subcommittee was charged with reviewing CDC's CTRPN program. The goals of the review were to determine how well the program provides persons at risk for HIV infection with convenient opportunities to:

- Learn their serostatus
- Receive HIV prevention counseling
- Obtain referrals for additional prevention and other services
- Assist sex and needle-sharing partners in receiving prevention services and referrals

E. OBJECTIVES AND ISSUES TO BE ADDRESSED

To ensure the broadest possible input into this process, the subcommittee members and consultants requested comments from interested parties on the following questions:

1. What should be the ideal goals for the CDC HIV prevention program as well as each component of CTRPN programs (counseling, testing, referral, partner notification)? What should be the relative emphasis of each component? How should progress be measured?
2. How well does the current program meet the ideal goals?
3. How should the program be changed to meet the ideal goals?
 - a) What should be the relative investment in and priority of CTRPN in relation to other HIV prevention programs and activities?
 - b) What information and data do CDC, health departments, and service providers need to continually improve the program?
4. What are the impediments to improving the program and to better achieving the ideal goals?

III. BACKGROUND AND CURRENT STATUS OF PROGRAM

Since 1985, CDC has entered into cooperative agreements with and awarded funds to state and local health departments to conduct HIV prevention activities that include HIV counseling, testing, referral, and partner notification (CTRPN). Publicly funded CTRPN services for persons at risk of acquiring or transmitting HIV comprise a key component of CDC's National HIV Prevention Program, the goals of which are to:

- Establish and maintain effective HIV/STD prevention programs implemented in collaboration with state and local health departments, other state and local agencies, community-based organizations, health-care providers, and national organizations throughout the United States and its territories;
- Effect and evaluate the initiation and maintenance of behavioral change among persons whose behavior places them at risk for HIV infection and other STDs;
- Increase access to prevention and early intervention services for HIV-infected persons in order to reduce risks of further transmission, as well as to maintain the health of asymptomatic clients;
- Increase collaboration and support among agencies, organizations, groups, and constituencies providing HIV prevention services.

Although the CTRPN program continues to be viewed by CDC as the cornerstone of the national effort to prevent HIV infection, questions have been raised about its emphasis, management, and effectiveness.

A. SUBCOMMITTEE'S IDEAL GOALS

In regard to primary prevention of HIV infections, the major goal of the national CTRPN program should be to reduce high-risk behaviors.

Outreach programs in the context of CTRPN should be designed to reach three different populations:

- People with HIV infection: to get them into counseling and other prevention, medical, and social services.
- People who engage in high-risk behaviors: to get them into long-term counseling and other prevention services.

- People who are not at risk: to give them information about HIV and how it is and is not transmitted, and to reduce their demand for unneeded HIV prevention services.

The ideal goals of counseling are to:

- Help people assess their risk of HIV transmission.
- Assist people with high-risk behaviors reduce those behaviors.
- Assist people who are vulnerable to initiating high-risk behaviors in preventing such behaviors.
- Offer different quantities, intensities, and types of behavior-change interventions based on the individual.

The ideal goal of HIV testing is to promote the knowledge of HIV infection status in a reliable, convenient, and timely way. Knowledge of test results can then be used as a tool to provide access to prevention and appropriate health services.

The ideal goals of referral are to:

- Prevent transmission of HIV infection.
- Ensure that all HIV-infected persons receive high quality medical care by:
 - Linking HIV-seronegative clients with high-risk behavior to HIV prevention counseling, and
 - Linking all HIV-infected clients to long-term services that provide medical, behavioral, psychosocial, and case management services.

The ideal goals of partner notification are to:

- Notify people who might otherwise not be aware that they were exposed to HIV.
- Encourage those exposed to be tested.
- Bring into services and obtain a reduction in high-risk behaviors from sex and needle-sharing partners of seropositive individuals.

B. EVOLUTION OF CTRPN

A key component of the national HIV prevention program has since its inception been the testing of persons at risk of acquiring or transmitting HIV infection. The first commercial test to detect antibodies to HIV was licensed in 1985 and used initially to screen donated blood. Soon after, the need to provide wider access to HIV antibody testing at locations other than blood banks led to the initiation of a nationwide network of "alternate test sites" where persons concerned about their HIV serostatus could go for testing. CDC guidelines issued in March 1986 recommended that persons in "high risk groups" be given the opportunity to know their HIV serostatus so they could take appropriate steps to prevent further transmission. The recommendations also encouraged counseling for "high-risk" seronegative persons and for seropositive persons and emphasized partner notification for sex and needle-sharing partners who may have been exposed to HIV.

Guidelines issued in August 1987 continued to endorse the testing of persons at risk for HIV infection as "an important component of a prevention strategy" and also supported the coupling of testing with two sessions of one-on-one counseling (pretest and posttest counseling). The stated purposes of these testing and counseling efforts were to "help uninfected individuals initiate and sustain behavioral changes that reduce their risk of becoming infected and to assist infected individuals in avoiding infecting others." The new emphasis on risk reduction led CDC to rename the intervention "HIV counseling and testing" and to rename the alternate test sites "HIV counseling and testing sites." In 1989, after zidovudine and *Pneumocystis carinii* pneumonia prophylaxis were shown to provide medical benefits to persons in the early stages of HIV infection, referral of infected persons to appropriate medical and social care became a new component of the nation's counseling and testing program.

The expanded role of counseling and testing is reflected in the current designation of CDC's program as "CTRPN" (counseling, testing, referral, and partner notification). The stated purpose of the CDC-funded CTRPN program 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 receive prevention services and referrals.

Throughout the evolution of the CTRPN program, CDC's role has been to administer cooperative agreements with states, provide training, set standards, and manage national data related to CTRPN. Currently, CDC funds 65 HIV prevention programs in 50 states, 6 cities, 7 territories, the District of Columbia, and Puerto Rico. Through these programs, CTRPN services are provided at more than 7,000 sites. The variety of settings in which CTRPN is offered has expanded from free-standing counseling and testing sites and STD clinics to substance-abuse treatment, family planning, prenatal/obstetrics, tuberculosis, and primary-care facilities, as well as correctional institutions and miscellaneous other settings.

C. NCPS INVOLVEMENT AND ROLE

HIV prevention activities are administered by ten centers, institutes, and offices within CDC and coordinated by the Office of the Assistant Director for HIV/AIDS. The CTRPN program is administered through CDC's National Center for Prevention Services (NCPS), specifically by what is now called the Division of STD/HIV Prevention (DSTD/HIVP).

In the early 1980s, at the time that the first cases of AIDS were being reported, the STD division within NCPS was organized around a syphilis control model of case-finding and treatment. At this same time, however, the Division was beginning to acknowledge that syphilis was not the most important sexually transmitted infection for the subpopulations being served by the STD program and to recognize the need for organizational change. The advent of AIDS, and the ensuing stresses on the public health infrastructure at all levels -- including at CDC -- prevented these changes from occurring at that time.

At the beginning of the epidemic, AIDS was viewed in terms of a scientific quest to unravel a medical mystery. A CDC task force, weighted with STD research epidemiologists from NCPS, was formed to respond to the emerging epidemic. Most of these researchers, and their medical/scientific approach to the study of AIDS, were ultimately transferred to the National Center for Infectious Diseases (NCID). It was in this center that the epidemiologic research and surveillance activities evolved, where the bulk of new HIV/AIDS hiring took place, and where the view emerged of AIDS as a critically important disease that is "different" from other STDs in terms of the gravity of the diagnosis, chronic nature of the infection, and lack of a medical "cure."

The HIV prevention programs were assigned -- initially with few additional funds or staff -- to NCPS, the only Center with ongoing relationships with health departments. Existing STD field and headquarters staff were asked to append the new prevention program to an STD clinic system characterized by an eroding infrastructure, severe overcrowding, and a primary emphasis on syphilis and gonorrhea prevention. The staff charged with this new program lacked the benefit of any real interaction with the scientific staff in NCID who were seeing AIDS as a decidedly unique public health problem. When risk-behavior change was soon recognized as the primary intervention for HIV prevention, there was virtually no time or opportunity to undertake the research and staff training needed for effective program planning and management before widescale "prevention" programs were funded and implemented. The program continued to evolve without substantial retooling of the original system, retraining of staff, or systematic evaluation of program components.

CDC's HIV prevention program still operates through a matrix-management organizational structure in which the state and local prevention activities are administered separately from the surveillance, epidemiologic, laboratory, public information, and school health components. This structure was justified by CDC on the grounds that it encourages the use of, and thus strengthens, expertise from the different components of CDC rather than duplicates expertise within a dedicated AIDS center.

D. BUDGET OVERVIEW

CDC's total HIV prevention budget has grown from \$200,000 in fiscal year 1981 to \$498.2 million in fiscal year 1993. About two thirds (\$358.6 million) of the 1993 appropriation funds extramural activities, the largest share of which (61%) goes to state and local health departments. The CTRPN program accounts for nearly half of all resources that health departments receive from CDC for HIV prevention.

NCPS administers about half of CDC's HIV resources. The largest program is the HIV Prevention Cooperative Agreements with state and local health departments. Sixty-five project areas (50 states, 7 territories, 6 local health departments, Puerto Rico, and the District of Columbia) received a total of \$145 million in fiscal year 1992 to fund five program components: public information activities, minority initiatives, health education and risk reduction, HIV prevention activities in substance users, and CTRPN. Of all HIV prevention efforts, CTRPN services received the highest level of resource support (about 71% of the total award for HIV prevention). The proportion of dollars going to CTRPN has been mandated by Congress since 1990. The total amount awarded to health departments for CTRPN totaled \$102 million in fiscal year 1992.

E. CURRENT STATUS

The HIV prevention cooperative agreements are designed to assist state and local health departments, in collaboration with other agencies and organizations, to 1) prevent transmission of HIV, and 2) reduce associated morbidity and mortality of HIV-infected persons by increasing access to early medical intervention and psychosocial services. Current program guidance requires that CTRPN programs 1) be routinely offered to clients in high-risk settings, 2) include informed consent, and 3) be voluntary. Grantees must collaborate with other agencies and organizations that provide HIV prevention and related services. Major additional requirements include the following:

Counseling -- HIV counseling is required to 1) include individualized risk assessments, 2) be interactive and client centered, and 3) include development of a risk-reduction plan. Additional prevention counseling is encouraged for clients at very high risk of becoming HIV infected or transmitting HIV to others.

Testing -- Anonymous testing should be offered unless prohibited by local laws. Seropositive clients should be counseled on the benefits of receiving follow-up services under a confidential system.

Referral -- Key referral linkages include STD screening and treatment, tuberculosis testing and treatment, substance abuse counseling and treatment, family planning services, further HIV prevention counseling, and early medical intervention for HIV infection. States are to have a system to link CTRPN sites with providers of needed services.

Partner notification -- States are to establish standards and implement procedures for confidential, voluntary notification of sex and needle-sharing partners. Partner notification services should include both patient and provider-assisted referral.

Quality assurance -- When less than 50% of high-risk clients are receiving counseling and testing services, or when low return rates are identified, states must document reasons for the low rates and address significant barriers.

Evaluation -- States are required to develop and implement a plan for evaluation of all major program activities and services supported by CDC.

An estimated 9 million persons have been tested through the publicly funded CTRPN program from 1985 through 1992. The demand for HIV antibody testing has grown rapidly. From 1985 through 1989, approximately 2.5 million tests were performed. In 1992 alone, more than 2.6 million tests were provided at more than 8,000 sites. This represents an increase of 480,000 tests (23%) over 1991 and an increase of nearly 72% since 1990. About one third of tests are performed in free-standing test sites, about one fourth in STD clinics, 11 percent in family planning clinics, and the rest in other sites (substance-abuse treatment centers, prisons, etc.). In general, free-standing test sites provide their services anonymously, while other sites provide confidential testing services.

More than 224,000 persons have learned of their seropositive status through the CTRPN program. More than 55,000 persons (2.0%) tested in 1992 were found to be seropositive, and almost 30% of tests are performed on persons who have been tested before. The increase in the number of tests provided has been accompanied by a corresponding decline in the proportion of seropositive test results. Although hundreds of thousands of high-risk seronegative persons have received HIV prevention counseling and testing through the program, about 50% of clients served have low, no, or unknown HIV risk. It is in these categories that much of the increase in the testing volume has occurred.

CDC Advisory Committee on Prevention of HIV Infection

Report of the Subcommittee on
DEVELOPING PARTNERSHIPS FOR HIV PREVENTION

November 12, 1993

Mark Magenheim, M.D., M.P.H.
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**REPORT OF THE SUBCOMMITTEE
ON PARTNERSHIPS FOR HIV PREVENTION**

November 13, 1993

I. INTRODUCTION

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Sites Visited, 1993

<u>Date</u>	<u>Site</u>	<u>Region</u>	<u>Prevalence</u>
May 21	Minneapolis, Minnesota	Midwest	Low
June 3	Portland, Oregon	West	Medium
June 7	San Diego, California	West	High
June 21	Chicago, Illinois	Midwest	High
June 22	Gary, Indiana	Midwest	Medium
July 7	Newark, New Jersey	East	High
July 12	Memphis, Tennessee	South	Low

EXECUTIVE SUMMARY

During the first 10 years of the AIDS epidemic in the United States, there was a failure to fully recognize the impact of the disease on the nation, and to act decisively to control its spread. Recognizing this failure, the current administration asked the Centers for Disease Control and Prevention (CDC) to gather data on the effectiveness of federal efforts to date, and how resources could be better used for HIV/AIDS prevention. To this end, CDC asked its Advisory Committee for the Prevention of HIV Infection (ACPHI) to take charge of this review. The Advisory Committee formed five subcommittees to study the various aspects of current prevention programs. The subcommittee represented by this report, was charged with looking at "Partnerships for HIV Prevention".

The partnerships subcommittee selected seven cities for site visits from which to gather testimony about the relationships between and among federal agencies, state and local health departments, non-governmental organizations, and community-based groups actively involved in HIV prevention.

Several common themes emerged during our visits. Many of the non-governmental organizations represented, reported seeing the CDC as a large, uncaring, paternalistic agency that can fund, or not fund, programs at will, and at any monetary level it wishes. Few non-governmental groups seem to understand what CDC is, or how the overall policy and funding mechanism of government works. For all practical purposes, CDC is, for many organizations, "The Government" whose purpose is to make the local organizations' jobs tougher.

Because this view of CDC seemed almost universal, many of the same issues were raised at each site visit. Those issues include perceptions about CDC's: poor communication, lack of cultural

appropriateness, lack of diversity, excessive redtape, competitive Request For Proposal (RFP) process, lack of technical assistance in management, unwillingness to listen to "front-line" workers, funding methods that create cash flow problems, and general lack of coordination with other government agencies.

In short, the current "partnerships" are working poorly, if at all. The subcommittee's recommendations are based on the site-visit participants' views, as stated above, and the subcommittee members' expertise. These recommendations cover the following areas of concern: leadership, communication, equity, funding and coordination.

Additional topics discussed by participants include Rural Concerns, Bi-national Issues, HIV Prevention in Correctional Settings, and High-risk Youth Settings. An in-depth discussion of the subcommittee's findings and recommendations follows.

II. BACKGROUND AND CURRENT STATUS OF PROGRAM

Scientific Foundation for Program Activities

The first case of what is now called AIDS likely occurred in the U.S. in the 1970s. The first reported case of AIDS in the U.S. was identified in 1981 and official CDC reporting of AIDS began in January, 1984. By March of 1988, (using the case-definition at that time) more than 55,167 cases of AIDS had been reported to the CDC. By July 1993, over 315,390 cumulative cases of AIDS had been reported in the U.S. among the estimated 1.0 - 1.5 million Americans who are probably already HIV(+). Cases resulting from heterosexual transmission are increasing, and ethnic and minority populations throughout the U.S. have been and remain disproportionately affected by HIV infection and AIDS. It is projected that before the epidemic ends, more than 750,000 Americans may die of AIDS, more than have died in all U.S. wars combined.

The absence of either a vaccine or a curative treatment mandates that prevention activities must be more proactive in order to curb the spread of HIV infection. By 1982, community response to AIDS had already begun in some places in the U.S. These grassroots efforts were organized, developed, and coordinated by community organizations and were primarily involved with bringing about behavioral changes to reduce or prevent the spread of HIV. (These early efforts are all the more remarkable in that they were begun even before the virus had been identified).

The first of these community AIDS service organizations developed in the homosexual communities of New York and San Francisco. In 1984, CDC selected nine cities for studies to assess HIV education and risk reduction programs: San Francisco, Los Angeles, New York, Miami, Newark, Chicago, Washington DC, Houston, and Atlanta. CDC personnel visited these sites to evaluate AIDS service organizations and the effectiveness of their programs.

Also in 1984, the CDC responded to a request by the U.S. Conference of Mayors (USCM) to provide funds for an information interchange on AIDS. The following year CDC awarded the USCM new funds for AIDS prevention activities. The availability of funds for community-based demonstration projects was announced in 1985, but only public health entities were eligible for funding that year. In 1987, CDC began to enter into cooperative agreements with non-governmental organizations (NGOs). Nearly 500 organizations are now funded by the CDC, both directly and indirectly, through funding to health departments.

By 1986, AIDS was no longer seen as a problem solely among white homosexual and bisexual males. Race, age, and sex distribution of persons with AIDS, which had remained relatively stable since 1981, were revealing a disturbing trend. African-Americans and Hispanics were being disproportionately affected by the epidemic. In response to this awareness, CDC announced availability of funds in March 1987, to assist states and local health departments in maintaining HIV education and risk reduction activities. These programs were directed to African-American and Hispanic populations to fund minority, community-based organizations (CBOs) to promote HIV/AIDS prevention and education through new grant monies.

On September 28, 1987, 41 local minority organizations were funded directly by the CDC. Of these funds \$7.4 million were awarded for special minority initiatives, with \$5.6 million earmarked for contracts with CBOs exclusively (through a competitive award process). In 1988, this amount increased to more than \$12 million. The National Minority Information and Education Program, or National Minority Organizations (NMO) Program, was created in 1988 by the CDC as a means to access racial and ethnic minority communities (i.e. African-Americans, Alaska Natives, American Indians, Asian-Americans, Hispanic/Latinos, and Pacific Islanders) which, according to the statistics, were at an ever-increasing risk of HIV transmission. The concept behind this program was to empower existing NMOs to work in

partnership with CDC in the development of culturally competent programs for minority communities which, because of a variety of reasons, could not be reached by using the traditional public health education model.

Thirty-two agencies representing national and regional organizations that work with populations and communities in need of HIV prevention information were selected to receive funding under this program. The organizations were funded to provide 1) technical assistance for other organizations that would, in turn, educate local communities; 2) training for local activists who would deliver effective culturally appropriate messages; 3) outreach and education to persons at risk; and 4) community interventions that would help change community norms. The NMOs received a total of \$32 million over the 5-year project period.

In 1989, CDC added funds for non-profit CBOs in the metropolitan statistical areas (MSAs) that were most affected by AIDS. These are organizations that "represent and serve minority persons and whose governing body is composed of more than 50% racial and/or ethnic minority group members". In 1990, supplemental funds were offered "where minority populations have been heavily affected by the HIV epidemic". In 1993, CDC awarded over \$8.7 million to 39 minority CBOs in high and lower prevalence geographic areas. Since 1986, CDC has steadily increased funding to many organizations across the U.S. whose goal is slowing and eventually ending transmission of HIV infection in the U.S.

Development and Operation of Program

The CDC provides HIV/AIDS prevention funds to Non-Governmental Organizations (NGOs) either by 1) direct funding of National Minority Organizations (NMOs), Regional Minority Organizations (RMOs), and Community-Based Organizations (CBOs), or by 2) indirect funding through Cooperative Agreements with state and local health departments

(DOHs) and/or through the U.S. Conference of Mayors.

During the first five years of these activities, program elements have expanded to include technical assistance, resource development, training, prevention education, outreach, and counseling. Target audiences have expanded as well, including populations at increased risk such as hemophiliacs, males who report having sex with males, substance abusers, out-of-school youth, prostitutes, needle-sharing partners, the homeless, persons in correctional facilities, and women in high-risk situations.

Lessons learned from these activities indicate that NGOs have been creative and innovative in providing information and other resources to their constituencies, that they need more in-depth technical assistance and evaluation, and that the CDC could be more helpful if it were to provide clear policy guidelines and expectations regarding federal, state, and local governmental, as well as non-governmental partnership roles, goals, and responsibilities.

In the first 10 years of the AIDS epidemic in the US, there was a failure to fully recognize the impact of the disease on the nation, and to act decisively. Recognizing this failure, the current administration charged the CDC with gathering data on how effective federal efforts have been and on how resources could better be directed for future HIV/AIDS prevention. In turn, the CDC and its Advisory Committee for the Prevention of HIV Infection (ACPHI) formed subcommittees to present Findings and Recommendations on several key issues.

III. PREVIEW PROCESS

Objectives and Issues to be addressed:

The time-frame for the work of this ACPHI Subcommittee on "Prevention Partnerships" had to be compressed in order to meet expectations for a Report of Findings and Recommendations by November, 1993. Work began

in March 1993. The shortened time-frame was unavoidable due to CDC's budget cycle and the impact of reorganized agency resources at CDC, in line with new federal government initiatives and policies.

At the same time, the Subcommittee determined in May 1993, that it was important to have first-hand contact with communities in order to obtain in-depth local information. To gather this input for its report to the CDC regarding non-governmental organization (NGO) relationships with government at all levels, the ACPHI Subcommittee on "Developing Partnerships for HIV Prevention" undertook seven site visits during the summer of 1993. Cities were chosen based on geographic diversity, racial and ethnic composition, population size, their urban or rural character, and their HIV seroprevalence. The racial and ethnic minority groups considered were African-American, Alaska Natives, American Indians, Asian-Americans, Hispanic/Latinos, and Pacific Islanders. (See appendix 5 for site details).

Site visits consisted of a forum for invited speakers, from both governmental and non-governmental agencies; an "open microphone" time for anyone wishing to speak; and small, informal group sessions. In these sessions, some subcommittee members participated in discussions with NGOs, while other subcommittee members met separately with state and local health department representatives. At the committee's request, CDC placed notices in the Federal Register. Flyers were sent to individuals and groups in the site-visit areas, known to be actively involved in HIV prevention. The mailings were followed by fax messages and telephone calls. All funded CBOs and NMOs were invited, and a committee member familiar with each site, served as resource coordinator for selecting additional invitees.

Objectives for these sessions were:

To gather data which would assist in the development of a Report of Findings and Recommendations to CDC relative to CDC's relationships with NGOs and with state and local health departments, and to review

the current roles and proposed future roles of NGOs in relation to federal (CDC) HIV/AIDS prevention program and policy development.

The Findings and Recommendations contained in this report are derived from testimony which the Subcommittee received in oral presentations and in written form from many individuals and organizations from May through September of 1993. In addition, the Subcommittee has added its own views in this report based upon its own expertise, background, information, and research, and from its own experiences on the front-lines of HIV/AIDS prevention in the U.S. during the past decade. None of the Subcommittee's members are CDC or other federal government employees.

Assessment goals

The subcommittee sought answers to the following four questions relating to the development of partnerships for HIV prevention:

- 1) What could CDC do to promote and/or enhance HIV prevention partnerships among the CDC, targeted populations, NGOs, and state and local health departments?
- 2) What are effective characteristics of these partnerships?
(How are roles differentiated?)
- 3) What can CDC do to assess and meet the diverse technical assistance needs of non-governmental organizations (NGOs) and state and local health departments?
- 4) What could CDC do to further integrate HIV/STD/TB/Substance Abuse prevention activities?

IV. Priority Recommendations

CDC can take the following steps to assure the overall success of HIV prevention partnerships:

Leadership

- Take the lead in coordinating and integrating prevention services among federal agencies (Health Resources & Services Administration, SAMHSA, et al).
- Become a national advocate for HIV prevention and the attendant issues (eg. needle exchange, condom distribution, sex education in schools, and the elimination of discrimination directed toward Persons With AIDS (PWAs), HIV+ people, homosexuals, bi-sexuals, lesbians, IVDUs, etc.).
- Be a leader in promoting diversity among state and local health departments, CBOs/NMOs and targeted populations.
- Establishing and publishing recommended guidelines for a minimum standard of medical care and prevention within correctional facilities, which should include condom use and prevention strategies for substance abusers.
- Foster allied health professional mentorships for rural physicians, nurses, and other HIV/AIDS prevention and service providers.

Communication

- Improve, enhance, and encourage effective, thorough, clear and accurate communication between and among CDC, state and local DOHs, NGOs, CBOs, and targeted populations.
- Clearly articulate national HIV prevention goals so that grantees know what the goals and objectives are for their prevention programs.

- Review the roles and responsibilities of federal Project Officers, and articulate those roles to state and local DOHs and NGOs.
- Deliver HIV education and prevention messages in ways that are culturally and linguistically appropriate to the populations being addressed.

Equity

- Ensure that affected (targeted) populations are included in community needs assessments and planning processes.
- Recognize that mutual respect for each other's ability and meaningful communication are essential to facilitate trust, which is essential for effective partnerships. And, recognize that effective partnerships require substantial time, direct contact, and minimum core resources, before they can grow.
- Establish a system of checks and balances to ensure fairness and equity.

Funding

- Tie equity in funding allocation to interventions that are effective for each targeted community group. CDC can address issues of equity in allocations and administrative overhead by providing direction to ensure that partnerships operate on an equal basis.
- Set aside new money for demonstration projects for the integration of AIDS/STD/TB, without penalizing programs funded under the existing categorical funding structure.
- Guarantee increased funds to integrated prevention programs and provide funds for cross-training.

- Include cultural diversity and appropriateness as essential elements for program funding, and include constituencies traditionally left out of the RFP process.

- Conduct state and local technical assistance surveys and provide funds for evaluation.

Coordination

- Respond to the technical assistance (TA) needs of local communities by matching them with local universities that can provide assistance with: board training, planning, grant writing and management, coalition building, fiscal management, cultural diversity, evaluation (outcome and process), community organizing. This assistance should facilitate face-to-face consultations by using multiple methods and a variety of training styles. CDC needs to be open to receiving TA, especially in the areas of cultural diversity and appropriateness, as well as provide training and resources.

- Convening a multi-disciplinary task force, which would look at groups currently integrating the specified areas to see what works and what doesn't. The task force should make it's recommendations within one year's time. Members of the task force should be representative of all parties involved with the mentioned areas, including NGOs, DOHs, HRSA, other governmental and non-governmental agencies, and members of the affected populations. Issues to be studied include: reduced funds, less time for HIV prevention, cross-training needs, stigma, and confidentiality. The task force should also develop standards of practice for AIDS/TB/STD prevention and education, and encourage states to set qualification standards for service providers.

- Sponsor, in conjunction with state and local health departments, correctional departments and the criminal justice system (that system should be identified to include at a minimum corrections, parole, the division for youth, probation, and alternatives to incarceration

programs) multi-disciplinary interagency task force* to foster partnerships for HIV prevention in correctional settings, with the objective of implementing preventive mechanisms which have been proven to be scientifically effective. (* see appendix 6 for more on task force.)

- Look at the scope of prevention, not only within the context of the prison facility, but also the direct impact of prevention on the families and communities, to which inmates will be returning. Therefore, partnerships which acknowledge and include HIV prevention and linkages to care as part of pre-discharge planning should be promoted and enhanced both programmatically and financially.
- Aggressively address HIV prevention and education as a major health issue, in collaboration with the Mexican government, and the service providers on both sides of the border.
- Tie into existing efforts of the Indian Health Service, rural family and migrant health centers, local chapters of the American Red Cross, and to local civic and other community health organizations, in order to better serve rural communities.

IV. Findings and Recommendations

Question 1 - "enhancing partnerships"

A consistent and strong message heard in all communities visited, is that functional partnerships between and among PWAs, NGOs, state and local health departments, populations at increased risk, and CDC are essential if HIV prevention programs are to succeed. In all locations, this Subcommittee heard that working partnerships must recognize, affirm, respect and empower each member, acknowledging that everyone has important skills, knowledge, and ideas to bring to the relationship. Unfortunately, dysfunctional "non-partnerships", rather than true functional partnerships, have been the prevailing rule of HIV prevention efforts at all levels of governmental and non-

governmental agencies.

The subcommittee applauds the many dedicated people who are working daily in their communities, sharing personal time, energy, money, compassion, and other resources with those who so desperately need them. These caring individuals, often at great personal sacrifice, spend much of their days and nights fighting the spread of HIV infection. The future depends on our collective commitment.

To halt the destructive impact of this disease, we must form the types of functional partnerships which make our tasks easier. We must form the types of partnerships that are inclusive of all people. We must form partnerships that are culturally diverse and culturally appropriate. We must form true partnerships that are very different from the non-functional and dysfunctional relationships which now exist.

Strengths and weaknesses:

Current partnerships between and among the CDC, state and local health departments, NGOs, and populations at increased HIV risk, appear to be working poorly. The major reported reasons for this dysfunction are:

- poor communication
- poor or non-existent technical assistance
- weak, inappropriate or absence of evaluative procedures
- undefined or unclear expectations or goals
- lack of coherent federal HIV prevention policy
- lack of understanding and appreciation of differing roles
- lack of willingness or mechanisms to share power and resources
- lack of government experience in relating to NGOs
- limited and dwindling resources in the face of a growing epidemic
- changing roles and responsibilities.

Much of the public testimony the Subcommittee heard came from sophisticated HIV prevention persons, in their own communities, who are well known and well informed about HIV and its impact in their

neighborhoods, cities, states, and regions. Yet most of the people we talked with indicated that they did not know what CDC does, is supposed to do, can do, and can't do. CDC is often **perceived** as a powerful, monolithic, paternalistic, cumbersome bureaucracy that arbitrarily funds programs at any level it wishes, sets national public health policy at will, writes and enacts laws, and generally rewards or punishes constituencies as it sees fit according to some secretive private internal process.

In terms of this **perception**, it appears that CDC has clearly missed opportunities to communicate its correct role, responsibilities, authority, limitations, and purposes to the public. In some areas of communicating its functions, CDC seems to have done a good job and in other communication areas, CDC seems not to have done such a good job. As a consequence, based on testimony the Subcommittee received, the CDC is inaccurately perceived by many at the community level. On balance, CDC seems to have been weak in communicating and fulfilling its role and mission to the public regarding HIV prevention.

(A) The theme of communication, or the lack thereof, was reported as a consistent and persistent problem throughout the partnership networks. For its part, the CDC does not seem to communicate well either within, with other federal agencies, with NGOs, or with state and local departments of health. In turn, state and local health departments do not seem to communicate well enough with one another, or with the NGOs and CBOs in their jurisdictions. And in some cases, health departments do not communicate at all with CBOs that are not funded, or with those which are directly funded by CDC (and of which they may not be aware). There are many reported reasons for these communication gaps. The main observations and perceptions include the following:

- **Top-down communication** - Information, program and/or grant requirements, needs, resources, and rules are communicated from the CDC to the state DOHs, then from the state to the county/city, and from the

county/city to NGOs and CBOs. It is unclear whether anyone communicates information to/from/with populations at high-risk of HIV infection or to/from/with the general public. There is also some doubt as to the extent, inclusiveness, process, and quality of communication within agencies at all levels.

- **Unclear, conflicting roles and responsibilities** - State and local health departments and NGOs are not sure what their own roles and responsibilities are, or what each others' roles and responsibilities are in HIV prevention, nor do they understand CDC's role.

- **Lack of staff diversity and cultural appropriateness** - CDC, state and local DOHs, and many CBOs don't have staffs that reflect the social and cultural constituencies they serve. This goes beyond language and ethnicity. It includes specific knowledge of cultures which are considered non-traditional in American society. Health departments are constrained by lack of funding, weakened infrastructures, and civil service and union constraints. Serving diverse populations has been a strength of NGOs, but many of them now find that they are not staffed to serve changing populations at risk.

- **Lack of clearly defined roles for federal staff** - In all cities visited, the Subcommittee heard reports of confused, overlapping, duplicative, and frustrating relationships among and between CDC project officers in Atlanta, CDC field personnel, and state and local governmental and non-governmental agencies.

- **The eroding infrastructure of many public health agencies** at both state and local levels - In much testimony, the Subcommittee heard details of the decline of governmental public health resources and the problems of coping with community HIV needs without adequate resources.

(B) competition among "partners" was identified as a second major weakness in current dysfunctional relationships. Ideally, functional partnerships are those which are formed by people who share a common goal and agree to collaborate in order to reach it. Yet the competitive nature of the RFP process requires otherwise supportive groups with common goals to vie for the same limited funds. Then, once one or more groups is funded, all the other competing groups are expected to form collaborative partnerships, the nature of which are usually not clearly defined or delineated. This unrealistic expectation becomes a substantial hindrance to the process of building effective HIV prevention partnerships and is ultimately counter-productive.

- **Competition for funds** - Competition for funds not only occurs among NGOs, but also with health departments that are struggling to keep their programs funded. Competition and poor relationships were frequently heard complaints when the health departments and NGOs were separated for discussions in the afternoon sessions. The competition occurs within and among various levels of the health departments and NGOs. In some states, unions discourage pass-through grants that do not guarantee that certain staff positions will be maintained. This fear that "pass throughs" will eliminate jobs impacts intra and interagency relationships.

- **Difficulties with the RFP process** - The RFP process is very hard for the mainly small HIV prevention agencies at the local (or even state) level. These private (and public) agencies frequently lack the staff time and resources to "wade through" the paper work - as many have only one or two full- or part-time paid or volunteer staff. They usually have insufficient lead-time, money, and other resources to even begin to consider applying for competitive grants. One negative consequence of this process, then, is that large, more sophisticated and well-connected agencies continue to receive funds, even though they may not be cost-effective, appropriately-focussed, or

adequately serving those populations in the community most in need of HIV prevention services.

The RFP process used by HUD and by CDC (in Program Announcements 202) was suggested as a practical and better alternative to CDC's general RFP process. Interested agencies submit a concept paper stating the community's needs, how the agency plans to meet those needs, and the resources needed to reach those goals. If the concept is judged a "good" one, the agency is asked to provide more detail.

In contrast to usual CDC RFPs, which do not provide sufficient assistance in the grant application process, the federal HUD program openly provides assistance to help agencies refine, expand, and develop their concept, and to design the program. This allows small and/or new agencies an equitable chance of being funded.

(C) Criteria used to fund agencies was presented as another major weakness in the CDC prevention program grant process. The areas of concern relative to these criteria are:

- **Unclear funding criteria** - As reported to the Subcommittee, CDC grant rules/procedures/criteria are not usually generally known to potential grantees. It is the perception of many state and local government, as well as NGO agencies, that arbitrary decisions about funding are the norm and objective criteria are secondary.
- **Seroprevalence** - CDC funds are allocated by an objective criterion such as seroprevalence -- the higher the seroprevalence, the more likely an agency is to be funded, and the more funds it receives. However, successful prevention program data suggests that lower seroprevalence may, in fact, reflect a more successful prevention program. Therefore, agencies that do well at prevention and have lower seroprevalence numbers may be "punished" by future funding reductions.

Strategic needs

It is suggested that most of the weaknesses or barriers to effective partnerships listed above can be turned into strengths by incorporating key leadership strategies into the partnership process:

- FIRST AND FOREMOST, CDC needs to function as a strong public national health leader on scientific grounds. CDC needs to act as a prevention advocate to other agencies, as well as for the public in general.
- CDC needs to enact a participatory process to promote an HIV prevention agenda that is risk-taking, inclusive, meaningful, non-hierarchical, and has the impact to reduce HIV infection.
- CDC needs to build inclusive functional partnerships. CDC needs to reach out proactively to constituencies who want to be, and should be, included. CDC should offer grants and technical assistance to help emerging and small agencies conduct needs assessment. Processes must be inclusive of NGOs, PWAs, CBOs, CDOs, CROs, state and local DOHs, and other service providers, including those who serve prisons and those who provide treatment.
- Indirect and direct CDC fund allocations should be prioritized and publicized, so that existing and emerging needs can be met. For those RFP processes which remain competitive, the process needs to be stratified so that like size agencies compete among themselves.
- More lead time to respond to RFPs is needed, and start-up, non-competitive grants should be made available through a set-aside.
- Cash flow is a problem for many NGOs and CBOs. Many agencies, especially smaller ones, are unable to meet ongoing financial obligations or to provide needed services due to the time it takes for funds to filter down from the CDC through the state and city/county DOHs to

the agencies. Either direct funding on a continuation basis and/or "up front" reserve funds are needed. A more efficient CDC funds disbursement policy and procedure is desperately needed to support effective community HIV prevention.

- Funding criteria must be more flexible to allow for innovation, to reflect diversity, and to respond to unique local needs, to new or changing circumstances, and to meet emerging local problems.
- CDC must revamp its funding process and develop new criteria for the allocation and awarding of grant funds. Processes must include collaboration and consultation between and among NGOs, PWAs, state and local health departments. Representatives of recipient public and private agencies at state and local levels should be included in grant development, review, and approval work-groups at ALL stages of the CDC HIV prevention funding process.
- CDC needs to support and allow reasonable travel to be included in grantee budgets to facilitate partnerships and regional planning.
- CDC should sponsor regional and local forums and conferences for populations at increased HIV risk on how better to collaborate, enhance partnerships, and be inclusive.
- CDC needs to become aware of how each CDC-funded state, city, county, municipality, or township is structured and how it functions. The multiplicity of state laws and local ordinances which often affect each entity's ability to respond to and meet CDC grant requirements, can be either barriers or opportunities depending on CDC's understanding and flexibility vis-a-vis local governments.
- CDC needs to inform agencies and potential grantees of its established appeal process. It needs to review this process to ensure that it is a fair and feasible system of checks and balances that

provides a follow-up mechanism for agencies which are denied funding. This process must be open, it must be inclusive, and it must include local, state, and regional private and public agency representatives.

Issues for consideration

A number of other partnership issues were raised during site-visits:

- **the difference between education and prevention** is not clearly defined and leads to much confusion among CDC grantees, both public and private. This is further compounded by the fact that federal agencies apparently have different definitions of education and prevention, if they have any. Coordination of federal requirements and efforts is needed along with commonly accepted nomenclature. (The Subcommittee views the appointment of the new federal AIDS Interagency Policy Coordinator as a critical opportunity to address this problem).

- **many health departments aren't good at serving minorities.**

Largely due to lack of staff diversity, public agencies often miss important and critical input for effective HIV prevention. With decreasing resources, it is also difficult for health departments to hire new employees who might otherwise represent diverse populations. And, when there are funding cutbacks, minority employees are caught in the "last hired, first fired" conundrum.

Question 2: "effective partnership characteristics" -

The three characteristics of effective partnerships cited most often in the Subcommittee's meetings are 1) trust, 2) respect for cultural and other differences, and 3) functional communication. To these the Subcommittee would add 4) inclusiveness, 5) common goals, 6) equality, 7) shared power and responsibilities, and 8) equity.

Effective partnerships are those that are open in their dealings with one another. They acknowledge existing collaborations and try to

build on them. Effective partnerships include all interested and relevant members and affected populations in all phases of the needs assessment, planning, and fund allocation processes. In an effective partnership, partners know they are free to express their opinions and to use their discretion in choosing which are the most pressing needs of their constituents and of how best to respond to priority needs. True partners know that collaboration is safe, for all are respected by all others for their knowledge and capabilities and there is mutual support and cooperation.

Strengths and weaknesses:

Although many site-visit participants said that their partnerships lack all or most of the characteristics mentioned above, many also reported that their relationships are improving. Time was often cited as the major factor needed to improve relationships and to build trust through shared experiences and common problem-solving. Those partnerships which "work" seem to be characterized by roles which delineate a clear organizational structure arrived at through consensus of the member partners. The members of these partnerships are comfortable sharing their problems and needs with one another.

Many community speakers expressed the view that CDC "partnerships" are really forced participant linkages among non-natural collaborators, that are mandated by funding requirements. Some felt that these are the **only** successful partnerships, while others stated the view that mandated partnerships are always destined to fail. All agreed that they would work together with others if they "have to", but this is not a true partnership and was not preferred by anyone.

Strategic needs

Representatives of state and local DOHs, NGOs, and CBOs would like to see CDC take a strong, decisive leadership role to foster effective partnerships. The Subcommittee recommends the following actions:

- Institute a participatory process with NGOs and state and local governments to define partnership roles and responsibilities.
- Encourage funded organizations to work collaboratively with non-funded organizations to reduce duplication and administrative costs.
- Acknowledge that in some instances repetition and duplication of HIV prevention efforts provide needed multiple interventions. Not all duplication is undesirable; in some circumstances it may be preferred.
- Link funding allocations to effective interventions based on science. Expect future funding commitments to be contingent on demonstrated efficacy through rigorous evaluations of programs and methods.
- Develop clear definitions of "partnership" and of "collaboration" and provide technical assistance and support to assist communities on how to organize, promote, maintain, and enhance partnerships.
- Assist in providing diverse formats for leadership and for training in conflict resolution in diverse settings with multi-ethnic community representation and input. Develop training programs in full collaboration with focus groups and target audience participation.
- Clearly articulate national HIV prevention goals, so that grantees can better relate their goals and objectives to the national plan.
- Ensure within the partnership process that diversity of the partners is maintained and that linkages to prevention are inclusive.
- Encourage state and local governments to maintain financial commitments to current prevention efforts by not decreasing state and/or local funding as federal monies increase.

- Include NGOs, state and local governments, and persons with HIV/AIDS in all aspects of the review, allocation, and awards process.
- Maintain an on-going external review process for planning, monitoring, and evaluating HIV/AIDS prevention efforts.
- Share information to promote effective partnerships.

Issues for consideration:

An added concern raised by participants was that of unequal power:

- **Sharing problems among unequal peers** - It is difficult to share problems with partnership "peers" if the relationship is unequal. When one partner (CDC) is the monitoring agency and the other partner is the grantee, the funded agency is always in a "power-down" position.
- **Balance diversity with the capacity to provide** - Especially in areas of low seroprevalence where funds are extremely limited and where minority agencies may be few or non-existent, CBOs may have to trade-off being able to provide culturally appropriate services with being able to provide services at all. Also, where minority agencies are few, some general agencies may have better capacity to provide services to a minority community than would a minority agency. Means by which community agencies might better collaborate are much needed.

Question 3: "technical assistance" -

Each state visited, and each county, city, community, racial or ethnic group, and each organization and agency, considered itself unique; thus, entities frequently see their needs or problems as different from the needs and problems of others. As such, technical assistance from the CDC or from any "outside" source is seen as needing to be tailored to the individual circumstances of the specific locale of interest. A "one size fits all" response by the CDC is universally

regarded as inappropriate, inflexible, and of very limited usefulness, if at all.

The one comment made at every site we visited is, "WE should be giving technical assistance TO the CDC." State and local DOHs and especially CBOs, feel that they can offer much to the CDC in regards to geographic and cultural diversity and appropriateness. Many agencies feel they know the "how-to's" better than do their project officers.

Strengths and weaknesses:

Besides its **perceived** lack of responsiveness to special problems and concerns of local communities, the major criticism of CDC's current technical assistance program (when it exists at all) is that the CDC, (and often state and local DOHs as well) do not often **ask** what kind of technical assistance is needed by local communities and by CBOs. Rather, there is the perception at the local level that the government presumes what is needed by a community.

On the other hand, many agencies do not seem to know what government services are available, so they frequently don't know what to ask for, nor which agency to ask.

It was also generally reported that most DOHs as well as CBOs would like to work more closely with their CDC project officers. However, in far too many instances, local governmental and non-governmental agencies did not have an effective relationship with the CDC. In some instances, state and local governments and CBOs said they did not know who their CDC project officer is. Conversely, there were often confusing and overlapping relationships with as many as eight CDC project officers for the same project. It was reported that some PO's in Atlanta did not seem to know each other and sometimes were not aware of their common involvement in the same community project.

Communities seemed to feel that CDC POs could be useful, but that they need to be more visible, they need to be in regular contact with their projects, and they need critical personal attributes.

Communities expect CDC POs to be appropriately trained, to be competent in their jobs, and to have strong interpersonal skills. Communities want CDC POs and other staff to be culturally diverse, culturally appropriate, and available to help solve the community's problems. Such attributes were reported in many cases as frequently lacking in many CDC Project Officers and absent in most POs relationships with state and local governmental and non-governmental agencies.

As for other types of technical assistance (TA), tele-conferencing received mixed reviews. Some people liked it, and others said it will do only if face-to-face training or meetings are not possible. Many favored access to an (800) number at CDC for technical assistance and for travel funds to attend regional training conferences.

Strategic needs

CBOs, NGOs, and state and local DOHs have a variety of technical assistance needs depending on size, location, and age of the organization including:

- Provide program evaluation models and distribute information concerning effective evaluation methods. TA training to learn how to organize, implement, and analyze results of program evaluation are essential components for effective HIV prevention at the state and local levels. There needs to be a special TA emphasis on building evaluation into program design while developing appropriate objectives for measuring levels of behavior change.
- Assistance in identifying local community facilitators who can assist in community empowerment and provide support training.

- Dissemination of scientific facts to boost local credibility and to gain local support for known effective prevention programs.
- Promotion and support of community liaisons or identified local persons to facilitate local partnership development. Important in this process is that CDC and other government agencies not take sole responsibility for successful local partnerships, but rather provide "behind-the-scenes" support and continuity to assist local resources to achieve and sustain local cohesion and local program success.
- Provision of an annotated list of existing resources available at CDC and elsewhere to promote and link effective models and methods of effective T.A. and programs (e.g., brochures, videos, programs, etc).
- Endorsement and dissemination of specifically targeted materials with messages and social marketing techniques and methods that are scientifically-based, yet are appropriately tailored to various groups. The expanded range of options needed for effective national HIV prevention must include explicit materials for certain populations, including "warning labels" to note materials which contain explicit language and graphics and to identify intended audiences for such items.
- Validation of scientific accuracy, as well as repudiation of the unscientific inaccuracy and biases, of HIV publications and other materials produced by various sources along the full spectrum.

Issues for consideration:

CDC can further assist in HIV prevention T.A. by:

- Reviewing, coordinating, and possibly overseeing the responsibilities and roles of POs of other federal agencies involved in HIV prevention and articulating those roles to state and local DOHs and NGOs.

- Serving as an information and referral resource to NGOs and to state and local DOHs by matching technical assistance inquiries with T.A. expertise. In many instances, it will be necessary for CDC to provide funding for this exchange, including site-visits, conferences, teleconferences, etc.
- Providing training on developing inclusive community partnerships ranging from coalitions organized to communicate and share ideas and concerns to those developing multi-agency prevention programs and services. Training on conflict resolution strategies should also be included.
- Providing on-going information re: behavior change and other scientific research findings and to maintain and expand community information components such as the TA Clearinghouse concept mentioned above.
- Streamlining useability of the existing federal CDC National AIDS clearinghouse.
- Providing substantially more information & TA on quality assurance.

Question 4 "integration of HIV/STD/TB/SA"

Many agencies reported that integrating HIV/STD/TB/SA prevention and services seem to make sense theoretically. However, the practical aspects regarding implementation of integration cause almost universal disquiet. An overriding fear is that integration may result in reduced funding levels for EACH programmatic area, resulting in the subversion of original intention and goals. It may also lead to a dilution of technical expertise needed for increasingly complex medical and social problems.

Many urban areas and a number of small agencies and rural areas are already integrating two or more of the four areas because they lack the funds or staff to offer separate services. The Indian Health

Board in Minneapolis, Minnesota is an example of effective integration of HIV/STD prevention and the State of Florida has recently integrated HIV/STD/TB services. A number of other jurisdictions are involved in similar integration of communicable disease programs and services.

Strengths and weaknesses

The strengths of integrating services greatly depend on the features and resources of individual programs and on the attitudes and training of the providers of such services. Methods appropriate for one group may not necessarily be appropriate for others. For example, in some cultures, such as with some Asian groups, HIV is perceived as too "scary" to be approached directly.

For some, going to a "one-stop-shop" lessens the fear of hearing about HIV and lessens the stigma of talking to the "AIDS" counselor. For others, the integration of services at a co-location site may be counterproductive in terms of time, cost, and convenience and may not be responsive to the cultural concerns of that particular community.

While the one-stop approach may be appropriate for many homeless persons, for example, it may also complicate responsiveness to their individual needs. On the other hand, when related services are made available at one site, it may minimize the need for referral to many different facilities (where it has often been reported that clients frequently fail to show up).

Co-location of integrated services has also been shown to be effective for women who attend WIC clinics, if they can also get other services needed for their children at the same place (and preferably at the same time). This approach reduces the need to hire a baby sitter or to leave small children behind when they need other services. Having such services in one place is often more convenient for some populations with common needs.

"One-stop-shopping" is not an effective or cost-effective approach for all groups, however. For example, it was reported that many gay white males will resist if they are forced to go to integrated service facilities serving TB/STD/and SA clients, as well as HIV clients. It appears that many gay white males do not view tuberculosis, sexually-transmitted diseases, and substance abuse as problems in their own communities. Rather, they often prefer that programs and services be designed and specifically offered by and for gay white males only.

This preference seems to apply to other groups as well, and it represents a real and substantial philosophical, prevention resource, and policy challenge for the foreseeable future.

To this problem must be added the additional prospect and fear of discrimination and stigmatization which can and has occurred in small and rural communities, where integrated services are the only choice. Sensitivity to local circumstances must be a part of how, and to what extent integration of these services and programs should be done.

Another concern is that a number of NGOs have reported that their own roles become unclear or non-existent where and when integration has occurred or might occur. There is a tendency for integrated HIV/STD/TB services to become clinic-based as opposed to community-based, and prevention is often not a priority, or a possibility, due to limited resources that are often directed toward treatment, first, or exclusively. Integration can also tend to leave less time for each program area or client need, making the prevention specialist's job even harder. CBOs further report that integration of services often results in conflicting priorities and can put up barriers to working together.

Notwithstanding these problems, arguably the biggest of all barriers to integrating HIV/STD/TB/SA services is the current fragmented "system" of separate federal funding streams associated with each of the four program areas. These "turf" issues impede collaboration and

integration of services at the community level and they need to be overcome at the level of the federal government first, before realistic and effective integration can be expected among state and local public and private agencies.

Strategic needs:

If the CDC decides that it truly wants to foster integration of local community HIV/STD/TB/SA prevention services, it needs to assist state and local DOHs and NGOs and CBOs by doing the following:

- Initiating interaction among CBOs, NGOs, state departments of health, local departments of health, and community representatives and users of such services so they can have vital and real input into health policy decisions.
- Ensuring that state HIV, TB and STD reporting policies, methods, and procedures adhere to strict standards of confidentiality and that they are maintained in full compliance with federal regulations and codes. The slightest hint of any questionable or unreliable practice or breach of confidentiality is completely unacceptable. Effective HIV prevention requires uniformity of reporting rules and regulations as well as common requirements and standards across categorical programs if there is to be functional integration of these programs.
- Facilitating communication among the different program and service areas by eliminating multiple POs for the same community or agency. Integration of programs at the community level will need parallel integration of PO function and assignments at the CDC level.
- Allowing flexibility in funding, so that project methods for multiple diseases can be coordinated and applied as needed.
- Providing progress reports on community efforts which already integrate services, and providing a forum and method for exchange of

information regarding "best practices" and benchmark models.

- Providing public messages about tuberculosis in communities with populations at increased risk for HIV infection.
- Establishing standards of practice for HIV/TB/STD/SA prevention and education, and encouraging states to set standards of qualification and certification for integrated service providers.
- Encouraging federal agencies to integrate health with other human/social services, as well as HIV/STD/TB/SA, when feasible.

Issues for consideration:

- Possible difficulties with professional qualifications and role definitions, with varying and frequently conflicting or restrictive state laws and professional regulations.
- Limited potential for integration based on natural history of diseases of interest. For example, tuberculosis does not seem to "fit" for integration of services as well as substance abuse services seem to do with HIV and STD services.
- The federal government has had a "checkered" past in some areas of STD control. This can and does hamper state and local confidence concerning program credibility and client protection as well as the confidentiality needs of clients being served through integrated STD/HIV programs.
- Assessing effectiveness of prevention activities can be difficult when program areas are combined in regions where demographics, project efficacy, and prevention activities may vary considerably.
- How will integration really be accomplished, assessed, monitored, and generally evaluated as to purpose and expected outcomes?

SPECIAL PREVENTION PARTNERSHIP OPPORTUNITIES:

(A) RURAL AREAS - The unique problems of rural and small town America bear special mention. Among these problems are: a lack of diversity among prevention and service providers, isolation of populations due to great distances, lack of access to information and HIV/AIDS prevention and service resources, low current incidence in many rural areas and locales, lack of categorical health programs of which HIV/AIDS is one, and special problems of rural clients with regard to prevention and health care access, confidentiality, and discrimination.

Rural areas are facing a tremendous crisis in providing health care in general, and HIV/AIDS prevention education and care, in particular. Rural health facilities often consist of small community hospitals, 35 or more miles from small towns. Medical Centers experienced in HIV/AIDS prevention education or services may be limited to one or two hospitals in state capitols or university settings. Community hospitals are often understaffed, under-funded, and, therefore, limited in the prevention programs they can offer.

As the epidemic progresses, more people with HIV/AIDS are returning to their childhood homes for health care and terminal AIDS care. Because HIV/AIDS prevention and education is often lacking, the medical and emotional needs of HIV/AIDS patients, and those who are at risk for HIV infection, are beyond the scope of what many rural health providers can offer. Problems of stigma and overt and covert discrimination are frequently intensified in rural communities. While some areas may be more sophisticated (often dependent upon the activism of local clients served), many other rural areas still need "intensive care" concerning HIV/AIDS education and prevention, as well as in HIV counseling and testing services.

RURAL HEALTH RECOMMENDATIONS:

1. Due to the often severe limitations in rural areas concerning the

availability of prevention education, services and service providers, CDC needs to foster allied health professional mentorships for rural physicians, nurses, and other HIV/AIDS prevention, education and service providers.

2. While most branches of the U.S. Public Health Service do provide well-coordinated efforts in rural locales, prevention efforts need to tie into existing efforts of the Indian Health Service, rural family and migrant health centers, local chapters of the American Red Cross, and to local civic and other community health organizations.

3. Prevention and education efforts in rural communities are only minimally funded. Greater access to funding and new project monies must be made available to rural communities, in the public and private sector, in order to reach those at risk for HIV "on the front lines."

4. Provision must be made for stipends and travel allowance for rural speakers and people with HIV/AIDS to participate in briefing sessions, as well as to streamline access for support for rural HIV/AIDS prevention programs.

5. Rural communities and small towns have the built-in problem of "everyone knowing everyone else." The assurance of confidentiality is necessary for people seeking HIV/AIDS prevention education or services. CDC must develop opportunities tailored to rural needs for people to receive prevention education and services in nearby towns or for bringing health care providers and prevention specialists from nearby towns to individuals in their own settings.

6. STD/TB prevention education and services needs to be drastically improved to keep pace with the HIV efforts to which they are being joined. The resurgence of TB in America cannot be underestimated. TB media education campaigns must be mounted in culturally appropriate and non-threatening ways which appeal to every American for testing

and treatment.

7. Substance abuse is a significant disease in the United States and a dual diagnosis of HIV disease requires a radically new approach to education and treatment. CDC must become an advocate, fiscally and politically, in funding substance abuse treatment slots, and in the decriminalization of needle and paraphernalia possession as being significant to prevention and as a scientific risk reduction mechanism.

(B) BORDER HEALTH ISSUES:

In addition to the problems cited above, persons at risk for HIV in the border states (those bordering Mexico in particular) have additional problems when they may need to cross the international US-Mexico border, in either or both directions, for a variety of medical, economic, and social purposes. These individuals often live in either the U.S. or Mexico, yet they may work or need services in the other country. Many of these persons are non-documented in the U.S., and for them to seek prevention education and medical care can be very threatening. Language, laws, customs, and religious and moral attitudes can impede effective HIV prevention and education for individuals who often have desperate or especially urgent needs.

Distrust of health officials (often as a result of valid distrust stemming from contact with other federal agencies) further interferes with access to prevention education and services. As well, the growing trend of denying health care to families of some immigrants, migrant laborers and non-documented aliens further thwarts effective HIV prevention. To improve prevention efficacy, CDC needs to aggressively address prevention in regard to bi-national issues, on public health grounds. CDC must state unequivocally, and in firm language, that such practices defy effective HIV prevention and are contrary to good health care. HIV prevention education must be culturally and linguistically appropriate with ties to the Mexican

government.

CDC must also consider funding bi-national collaborative projects in HIV/AIDS education and prevention strategies in border regions.

(C) CORRECTIONAL FACILITIES - In addressing prevention, the external review subcommittee deemed it necessary to respond to the need for prevention partnerships between governmental and non-governmental agencies, jails, prisons, and other correctional facilities. Essential to all effective partnerships are the elements of trust and common goals or aspirations. Without these two elements it is very difficult to promote or enhance partnerships. Yet the CDC, DOHs, prisons, and correctional facilities don't share the same mission. The physical appearance of prison walls (with observations points, barbed or razor wire fences, metal bars, high walls, and armed guards) are not visions which affirm a sense of trust. This environment itself affirms the reality of mistrust.

Nevertheless, based on relationships of limited trust and with collaborative interactions focused on the goal of HIV prevention, partnerships must be established between the health care and the criminal justice systems. Disease prevention is not the mission of a prison or correctional department. Therefore, in order to develop effective partnerships, there must be a multi-disciplinary interagency task force which minimally includes representatives of state and local health departments, state and local prison and correctional facility administrators, parole and probation departments, and members of the targeted population, with authority to address barriers to HIV/STD/TB and substance abuse prevention and institutional security.

HIV/AIDS is a definite and growing health problem in the nation's jails and prisons, and inmates in correctional facilities who are HIV(+) are a special crisis group. Although they are truly a "captive" audience, they receive little HIV prevention or care.

Though usually not officially acknowledged, sexual body fluid exchange does take place in prison, yet condom distribution is still forbidden in most facilities. Most inmates will be released back into society (most often sooner rather than later due usually to overcrowding), and the high-risk behaviors associated with this population, are likely to substantially increase the probability of new HIV infection in the community, when they do return to it. Therefore, effective HIV prevention is essential in correctional facilities in order to avoid the risk of increased HIV transmission through unsafe sexual practices both in correctional facilities, and afterwards when inmates return home.

To deal with the very real, immediate, and growing problems of HIV among inmates, an interagency HIV task force is needed. The tasks assigned to such an interagency task force should be to:

- Examine the issues of HIV prevention as it applies to prisons and correctional facilities.
- Establish both scientific and ethical HIV prevention objectives.
- Set procedural guidelines for effecting prevention and continuum of care objectives.
- Examine the issues of access and appropriateness of clinical trials for inmates.

In establishing these partnerships it must be clear to all parties involved that education is not the end-all to prevention. Education is only the beginning. It is not enough to empower people with HIV prevention knowledge without supplying the means of applying that knowledge. In the absence of a cure for HIV/AIDS, and in accordance with prevention messages recommended by CDC, it is unethical and life

threatening to prohibit the use of the preventive and risk reduction mechanisms -- condoms and sterile needles.

Strategies for prevention within the correctional system can only be effective by establishing collaborative partnerships among inter-governmental agencies, non-governmental organizations and the targeted populations. Members of this partnership must share the responsibility for the development of prevention strategies which are linked to a continuum of care. In making the linkage between prevention and care, the differences between the two must be clearly articulated. Where prevention is effective, a direct correlation is made in limiting the cost of care. Collaborative prevention efforts among corrections, health departments, labor unions, non-governmental organizations, and inmates should ensure that corrections staff (inclusive of counselors, corrections officers and administrators) receive ongoing HIV training. That training, at a minimum, must include information on HIV transmission, prevention, cultural appropriateness and universal precautions.

Partnerships in prevention should further ensure that CBOs or non-governmental organizations receive training in "prison culture" and operation. As with all prevention, cultural competency is essential in dealing with the ethnic diversity within the correctional system. CBOs, as well as health care providers, need to be cognizant of the needs and concerns of both the inmate population and the correctional staff. Effective HIV education must take into consideration both the expressed and unexpressed needs of this population. The social reality of substance abuse and sexual activity occurring in correctional facilities must be dealt with in order to prevent the spread of disease. Prevention and risk reduction messages should be directed to both staff and inmates.

Partnerships should incorporate inmates in the development and implementation of prevention programs. Peer models tend to foster

trust and be more effective in reaching targeted populations.

The development of prevention strategies must ensure the confidentiality of those who come forth for HIV information, testing or services. Where there is fear of psychological and physical injury due to HIV status, people are less likely to access counseling, testing and services. Lack of such confidentiality assurances undermines efforts to control the spread of the disease. Assurance of confidentiality would begin to establish an environment of trust and safety on which to build partnerships.

Corrections Health Recommendations

- CDC, state and local health departments, correctional departments and the criminal justice system (that system should be identified to include at a minimum corrections, parole, the division for youth, probation, and alternatives to incarceration programs) should sponsor a multi-disciplined interagency task force to foster partnerships for HIV prevention in correctional settings, with the objective of implementing preventive mechanisms which have been proven to be scientifically effective.
- The CDC can strengthen the development of partnerships by taking a leadership role in establishing and publishing recommended guidelines for a minimum standard of medical care and prevention within correctional facilities, which should include condom use and prevention strategies for substance abusers.
- The CDC, health departments and departments of corrections can sponsor regional training workshops for correctional health care providers and administrators on HIV prevention and universal precautions.
- CDC can foster collaborative efforts among corrections staff, inmates and CBOs by targeting funds for networks that can link and

coordinate services for prison culture that meet the diverse prevention needs of both correctional staff and inmate populations.

- CDC can stress the importance of client confidentiality as a means of enhancing partnerships and countering the fear of stigma because of one's HIV status.
- CDC can collaborate with governmental, non-governmental and members of the targeted populations to establish pilot program models which integrate substance abuse treatment, HIV/STD and TB prevention.
- CDC, state and local health departments, the criminal justice system, and non-governmental organizations must look at the scope of prevention, not only within the context of the prison facility, but also the direct impact of prevention to the families and communities, to which inmates will be returning. Therefore, partnerships which acknowledge and include HIV prevention and linkages to care as part of pre-discharge planning should be promoted and enhanced both programmatically and financially.

See Appendix 6: Testimony of New Jersey Association on Corrections.

(D) HIGH-RISK YOUTH SETTINGS - There was great concern expressed at each site concerning the increasing HIV infection rate among adolescents, particularly young females and young gay and bisexual males. Many schools are barely scratching the surface in terms of HIV education, let alone sexuality education. Participants expressed the urgent need for providing effective, explicit and comprehensive HIV education to young people at frequent intervals. (Adolescents' sexual activities start and stop at various intervals, increasing the need for timely and repetitive prevention education, accompanied by ready access to condoms.)

Many communities need technical assistance and resources for conducting needs assessments, planning inclusive culturally and age appropriate programs, developing relevant evaluation methodologies, and gaining community-wide support for youth HIV prevention efforts.

Prevention efforts also include HIV anti-body counseling and testing and follow-up interventions for both HIV(+) and HIV(-) youth. Technical assistance is needed to train the counselors in working specifically with adolescent populations.

SUMMARY

HIV prevention partnerships as now structured are, for the most part, not working. There is a lack of effective communication between, among, and internal to all levels of agency involvement.

To the extent that partnerships do exist, they are characterized by a profound lack of trust and respect, with minimal attention to and/or respect for, cultural specificity and appropriateness. Further contributing to the failure of these partnerships are funding limitations and competition.

State and local DOHs, NGOs, CBOs, and target populations all seem to want to improve their relationships with CDC and with each other. But they are all looking to CDC to provide the leadership, funds, skills, and training needed to get these partnerships on the right track.

In this work, CDC must become the national leader and advocate for HIV prevention education. It must restore itself to the high standards of science and to the legacy of commitment to the public health on which its reputation was built. It can regain a position of prominence in the fight against disease by taking a stand on critical HIV life and death issues facing our country -- such as needle exchange, condom distribution, sexuality education in our schools, and through frank, effective, and explicit media campaigns on national and local levels.

Appendix 1

Hotel
city, state
date

AGENDA

8:00 - 8:15am	Welcome and introductions
8:15 - 8:30	Background Moderators: Mark Magenheim Belinda Rochelle
8:30 - 10:15	Invited Comments
10:15 - 10:30	Break
10:30 - 12:00	Public Comments
12:00 - 12:15	Closing of Morning Session Moderators
12:12 - 1:30pm	Break
1:30 - 5:00	NGO representatives meet with committee members at hotel. Other committee members go to state or local health department to meet with officials.

Appendix 2

Criteria Used in Identifying Metropolitan Statistical Areas (MSAs)

Cities selected according to the following criteria:

- high, medium and low prevalence areas
- geographic representation (East, South, Midwest, West, Northwest, and/or Southwest)
- areas with directly funded CBOs and NMOs; and
- areas without directly funded CBOs and NMOs.

	<u>High</u>	<u>Medium</u>	<u>Low</u>
<u>East</u>	*Newark Boston Philadelphia Baltimore	Hartford/New Haven	Buffalo
<u>South</u>	Atlanta Miami New Orleans Dallas	San Antonio Baton Rouge	Birmingham *Memphis Nashville
<u>Midwest</u>	*Chicago	*Gary St. Louis Cleveland Kansas City Detroit	*Minneapolis Milwaukee Indianapolis
<u>West</u>	Los Angeles San Francisco Denver *San Diego	*Portland Seattle	Phoenix

* Indicates selected cities for site visits based on high, medium, and low prevalence area, geographic regions, and areas with and without directly funded NGOs.

Appendix 3

Acknowledgements

The Subcommittee thanks all the participants in this process. Without the diligence of the CDC support staff and the committee members who organized the meetings in each city, this review would not have been possible. We also give our deepest gratitude to the people who attended the meetings and so openly shared their stories with us. We will attempt to list them all, but if a name is omitted, please accept our apologies and our thanks.

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Appendix 4**List of Abbreviations**

ACPHI	Advisory Committee on Prevention of HIV Infection
AIDS	Acquired Immune Deficiency Syndrome
CBO	Community-based Organization
CDC	Centers for Disease Control and Prevention
CDO	Community Development Organization
CRO	Community Resource Organization
C&T	Counseling and Testing
DHHS	Department of Health and Human Services
DOH	Department of Health
GWM	Gay White Male
HRSA	Health Resources and Services Administration
HIV	Human Immunodeficiency Virus
HUD	Department of Housing and Urban Development
IDU	Injecting drug user
IHS	Indian Health Service
LHD	Local Health Department
MSA	Metropolitan Statistical Area
IVDU	Intra-venous drug user
MWHSWM	Men who have sex with men
NGO	Non-governmental agency
NMO	National Minority Organization
PHS	Public Health Service
PO	Project Officer
PWA	Person with AIDS

RFP	Request for proposal
RMO	Regional Minority Organization
SA	Substance Abuse
SAMHSA	Substance Abuse & Mental Health Services Administration
STD	Sexually transmitted disease
TA	Technical assistance
TB	Tuberculosis
USCM	U.S. Conference of Mayors