Behavioral and Social Sciences and the HIV/AIDS Epidemic

National Commission on AIDS
WASHINGTON, DC • UNITED STATES OF AMERICA

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The National Commission on Acquired Immune Deficiency Syndrome (AIDS) was established by Public Law 100-607 "for the purpose of promoting the development of a national consensus on policy concerning AIDS and of studying and making recommendations for a consistent national policy" concerning the HIV epidemic. The Commission is a bipartisan body whose members were appointed by the President, the United States Senate, and the United States House of Representatives.

Under its legislative mandate, the National Commission on AIDS will cease operation on September 3, 1993. After that time, Commission reports can be obtained through the CDC National AIDS Clearinghouse, P.O. Box 6003, Rockville, Maryland 30849-6003, Tel. 1-800-458-5231, TDD 1-800-243-7012. Official records of the Commission and the proceedings are lodged within the National Archives and Records Administration, Office of Federal Records Center, Washington, D.C. 20408, Tel. 202-501-5425.

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PREFACE

The Commission's consideration of the behavioral and social sciences builds upon efforts by then-President Reagan's Commission on the HIV Epidemic, and by a number of other expert advisory groups. Strong technical guidance in behavioral sciences has been provided by the work of the National Research Council of the National Academy of Sciences (NRC/NAS).

Relevant testimony has been offered in a number of hearings held by the Commission over the past several years. In February 1990, during hearings in Boston convened by the Commission's Social/Human Issues Working group, there was considerable discussion of the need for a better understanding of the mental health issues confronting persons who have recently received a positive HIV diagnosis. In a hearing in May of that year, the Commission heard from representatives of the NRC/NAS group then working on the series of reports issued by the Committee on AIDS Research and the Behavioral, Social and Statistical Sciences. Among concerns voiced by these witnesses was the dearth of specific information regarding drug use and its social context. In July 1990, testimony delivered in Washington during hearings on acute personnel shortages in the HIV/AIDS epidemic touched on the workforce problems faced by research scientists in AIDS, and on the need to recruit and retain more ethnic-minority researchers in the battle against the disease. In March of 1991, a hearing on adolescents and HIV disease informed the Commission that funds for studying at-risk and infected youth were in dangerously short supply. Hearings held in New Orleans in 1992 on the issue of sexual behavior included commentary on the dearth of research in this field and warnings about the unacceptable human cost of restrictions on sexual behavior research, the virtual non-existence of information on the barriers to safer sexual practices in some population groups such as gay Latino males, and the pressing need for a comprehensive reform of the way the federal government conducts its HIV prevention activities. In Kansas City we heard testimony on the cutting edge in communication arts, such as advertising, social marketing, and use of media in behavior change programs. At its final hearing in Austin, Texas, the Commission was updated on what has been learned thus far, the need for further research in these disciplines, and the need to protect funding and support for the behavioral and social sciences through governmental structures designed to improve management of AIDS research.

Throughout this period, the Commission took a number of actions in support of behavioral and social science research: a statement on bleach and HIV prevention research was released (November 1989); a statement endorsing the AIDS Prevention Act was issued (May 1990); and, a letter was written to Congressional leadership supporting the funding of behavioral and social science research (July 1991). In its report that year, *America Living With AIDS*, the Commission (reinforcing the views of preceding study groups) issued a clear call for additional research in the behavioral and social science arena:

> During the first decade of the HIV epidemic the need for epidemiologic and behavioral research was recognized. . . . There remains, however, a lack of knowledge in several areas crucial to education and prevention. . . .
>
> Greater priority and funding should be given to behavioral, social science and health services research. . . .
>
> It is critical that researchers clearly identify what does and does not work in prevention. The cost of not knowing will be measured not only in dollars spent and opportunities missed, but also in lives lost. (NCOA, 1991, pp. 34-35)

The report made very specific recommendations regarding behavioral and social science research activity that should be supported by the federal government, emphasizing the critical importance of providing technical assistance to prevention workers.

This report integrates what the Commission has heard and concluded regarding the need for attention to behavioral and social science research on HIV/AIDS. It reflects all of the major Commission statements to date, as well as new information generated by the most recent round of hearings. Additional input from experts in the field was solicited to insure that the Commission's findings and recommendations accurately reflect current scientific needs.

This report considers virtually exclusively activities of the Public Health Service (PHS) of the Department Health and Human Services (HHS). There are several other agencies in the federal government with an important role in this research agenda, such as the U.S. Agency for International Development and the Department of Defense. Other than to note the need for coordination with these other agencies, important issues regarding programs and policies of non-HHS agencies could not be addressed here due to the impending closure of the Commission.

This report, prepared in parallel with our final report, reflects our findings in an area whose potential contributions to confronting the HIV/AIDS epidemic we continue to neglect at our peril.

June E. Osborn, M.D.
Chairman

David E. Rogers, M.D.
Vice Chairman

ACKNOWLEDGMENTS

The Commission is indebted to many individuals whose expertise and experience guided its understanding of the relevance of the behavioral and social sciences to the HIV/AIDS epidemic. Aiding in the development of the Commission's views were the witnesses at various hearings, particularly those held in Washington, D.C., May 1990, New Orleans, May 1992, Kansas City, June 1992, and Austin, March 1993. (See Appendix A.)*

We also thank witnesses who addressed behavioral and social science issues in other hearings and participants in the Working Group on Social and Human Issues, which met in February and July, 1990.

Major assistance in preparing this document was provided by the American Psychological Association (APA). The Commission would like to thank the following individuals from the APA staff for their efforts: Bill Bailey, Jacqueline Gentry, and Brian Wilcox.

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* A complete list of witnesses participating in Commission hearings is included in the Commission's final report, *AIDS: An Expanding Tragedy,* June 1993.

Executive Summary

The HIV/AIDS epidemic is driven by behavior and social conditions. HIV is transmitted through very specific behaviors—unprotected sexual intercourse and sharing of drug injection equipment—and these behaviors are strongly affected by social, cultural, and economic conditions. These facts suggest that the behavioral and social sciences should be a major component of the U. S. effort to control the HIV/AIDS epidemic. Yet to a very disturbing extent, the potential contributions they could make have not been utilized in the fight against AIDS.

There have been many reasons for the failure to appropriately utilize the behavioral and social sciences in combatting AIDS. The most important reasons have been:

1. A national tendency to seek 'technological fixes' rather than address the complex issues—behavioral, social, and economic—that promote the spread of many infectious diseases. Our approaches thus far have had an incomplete vision of what is really needed to confront the HIV/AIDS epidemic effectively.
2. The erroneous belief that behavioral and social science research merely confirms 'intuition' or 'common sense.' Actually, 'common sense' has been a very poor guide to combatting AIDS. At the start of the epidemic, "common sense" said that gay identified men and injection drug users would not be able to change their behavior in response to AIDS. Many studies have since demonstrated very large-scale AIDS risk reduction in these groups and revealed other counter-intuitive findings.
3. An historical neglect of financial support for behavioral and social sciences in the United States, particularly during the early phases of the AIDS epidemic.
4. Active political interference in research on sexual and drug use behavior. Important, approved studies of sexual behavior were defunded and drug abuse researchers were denied access to federal funds to evaluate syringe exchange programs. Key information for limiting HIV transmission was thus lost.
5. Political and funding limitations on prevention programs that kept them from utilizing the behavioral and social science knowledge that was available. Rather than implementing specific prevention programs designed to be effective with each of the wide variety of different groups at risk for HIV infection in the United States, prevention efforts have often been limited to the most innocuous messages, have often failed to provide the skills or means for reducing risk behavior, and have reached far too few people.

Prevention works and more is needed. At the start of the HIV/AIDS epidemic in the United States, the relevant research base for prevention programming was severely limited. The most relevant research on sexual behavior was more than three decades old, and almost nothing was known about the conditions under which injection drug users would or would not share injection equipment. With the behavioral and social science research on AIDS that has been conducted in recent years, we are now in a position where effective prevention programs could, if rigorously implemented on a national scale, probably reduce the number of new HIV infections by half or more. Failure to do so will cost hundreds of thousands of lives and billions of dollars in future medical costs.

Implementing science-based prevention programs that could reduce the number of new HIV infections by half or more would be a great improvement over the present situation in the United States, but should not be considered a satisfactory end-point any more than a 50% effective vaccine would be considered a satisfactory end-point for vaccine research. Additional behavioral and social science research for better prevention programs is needed. In summary, to use what knowledge we now have and improve what we do, we should:

- properly integrate behavioral and social science into the mainstream of the U.S. response to HIV/AIDS through development of a plan for a National Prevention Initiative;
- expand research: in behavioral epidemiology, on what occurs; in cognitive science, on why it occurs; on cultural and ethnographic factors that influence behavior; in intervention research, to determine what works in reducing risks; in mental health research, to support those infected; on behavioral aspects of using 'technological' interventions, such as drugs, vaccines, or condoms; and on organizational issues, studying how to manage systems better;
- expand and improve training in the behavioral and social sciences;
- improve the transfer of 'technologies' from behavioral and social science research into application in prevention programs;
- improve evaluation of prevention efforts, to learn what works better;
- ensure behavioral and social science expertise is represented more fully in senior policy making and management positions in the relevant federal government agencies;
- substantially expand investment of new resources in prevention programs and prevention research: the choice is simple—pay now or unavoidably pay much more later.

The many decisions that have limited the contributions of the behavioral and social sciences to fighting AIDS have resulted in more HIV infections than should have occurred. Continuation of this situation is morally indefensible.

Introduction

Specific behaviors and socio-cultural conditions perpetuate the AIDS epidemic. Thus, logic suggests that behavioral and social science expertise should be fully utilized in our national response to the epidemic, particularly in prevention efforts. The National Commission on AIDS has heard extensive testimony regarding the role and potential contribution of the behavioral and social sciences in the context of the AIDS epidemic. This commentary has included observations that:

- The human immunodeficiency virus (HIV) is transmitted through specific behaviors and these behaviors are malleable;
- social, cultural, and economic factors influence behavioral norms;
- psycho-social support for persons with HIV infection is an important component of their care;
- federal support for behavioral and social science research has been inadequate;
- ideological or political restrictions on research projects and prevention efforts have had pernicious effects;
- there is a need for improvements in technology transfer between behavioral researchers attempting to identify effective HIV prevention strategies and HIV/AIDS prevention workers;
- there is a need to incorporate behavioral and social science expertise at the senior levels of federal agencies responsible for HIV prevention; and
- despite impediments to research, there is an expanding knowledge base ready to be applied.

Yet, to a very disturbing extent, the potential contributions of behavioral and social sciences have not been utilized in the battle against AIDS.

The history of this policy shortfall was outlined by Dr. Martin Fishbein of the University of Illinois, presently a Guest Researcher at the Centers for Disease Control and Prevention (CDC), during hearings in Austin, Texas, in March 1993: "In the early days of the epidemic, almost all support for AIDS research was directed at the medical and epidemiological communities. And, it wasn't until epidemiologists identified the modes of HIV transmission that it became clear to many that primary prevention was, first and foremost, a behavioral problem. Even with this recognition," Dr. Fishbein continued, "support for behavioral research was relatively slow in coming. Funding was and still is [disproportionately] directed at medical research. . . ."

Dr. Fishbein applauded the growing awareness of the need to evaluate prevention methods designed to reduce risky behavior and to promote safer behavior. He cautioned the Commission that, "[m]uch of this intervention oriented AIDS research is in its infancy and it will have to be nourished, if we are going to [effectively target] populations varying in age, gender, ethnicity, education, [religion], and life-style. . ." (Fishbein, 1993, pp. 21-22).

A persistent barrier to the full utilization of the behavioral and social sciences in the fight against AIDS has been the failure to recognize, in those instances where specific behavior and asymptomatic spread play a significant role in pathogen transmission, the limitations of the traditional public health model of responding to infectious diseases. The traditional mode of responding to contagious infectious diseases is rapid location of disease cases followed by treatment or cure, and isolation to prevent spread, with vaccination, if available, for those at risk.

This approach does not transfer effectively to the realities of containing the AIDS epidemic. HIV can be transmitted during the long 'latency' period before there is a 'case' of AIDS. There is no significantly life-prolonging treatment or way of rendering those infected non-infectious, and isolation of all HIV-infected individuals is both impractical and inappropriate since the spread of HIV does not occur through chance or casual interactions. Further, a true AIDS cure or useful vaccine is unlikely in the foreseeable future (Cohen, 1993).

For combatting HIV and those other diseases where much of the spread is attributable to specific behavior by asymptomatic individuals, the disease case-finding approach has severe limitations. Tracking HIV infection through testing and partner notification can play a role if handled without infringing on individual rights, but these approaches tackle—incompletely—the spread that has occurred already and do not, by themselves, initiate behavior change even in that segment of the risk population tested. Moreover, disease case-finding and HIV testing do not address the fundamental problems: namely 'risky' behavior by many millions of individuals that are not yet infected, many of whom do not recognize they are at risk, and the social conditions that perpetuate such behavior.

A direct approach to reducing risk behaviors that actually drive HIV transmission (such as unprotected sex or needle sharing) is essential, and must be a major component of any national strategy to reduce the threat of AIDS. Unlike HIV-related health services, prevention programs are not necessarily directed at individuals, but often at groups, communities, or the general public. Furthermore, primary prevention programs cannot rely on the immediate motivation to take action that occurs when an individual is sick. We need a new approach to infectious disease control for AIDS and similar diseases that appropriately embraces behavioral and social science. Many infections and deaths—perhaps half—could have been avoided if such an approach had been adopted earlier (Chin, 1993).

Policy makers in the Administration and Congress must recognize that behavior change approaches to prevention have been severely curtailed by their level funding in recent years. Substantial increases in resources for prevention, specifically for behavior change interventions, must be made a priority—requested and appropriated—over the next few years.

Neglect of behavioral and social science research may have been fueled to a significant extent by an unfortunate misperception that it merely serves to confirm what intuition or 'common sense' would have indicated anyway. This view is not only simplistic, but also empirically wrong and potentially life threatening. Examples include:

- 'Common sense' tells us that fear-invoking messages will get the attention of their intended audiences and should lead to reduction in risk behavior. But research has shown that messages which create too high a level of anxiety in individuals with risk behavior lead them to deny their risk and ignore the personal relevance of the message.

- Intuition tells us that if individuals are intellectually aware of risks they will avoid them, where as research shows that factual knowledge alone does not lead to behavior change.
- 'Common sense,' many would have us believe, tells us that drug "addicts" do not care about their health. But research has shown that a significant fraction of persons who continue to inject drugs do adopt precautions that reduce their risk of HIV infection when properly informed and enabled to do so.
- 'Conventional wisdom' holds that all teenagers feel invulnerable, but research shows this also is too simplistic a notion.

The behavioral and social sciences can not only offer insights—often counter-intuitive—into how to tackle problems but, through quantitative studies on the extent to which risk occurs, can also help rank their magnitude.

There have been many reasons for the failure to appropriately utilize the behavioral and social sciences in combatting AIDS. The most important reasons have been:

- neglect of research and training in the behavioral and social sciences in the decades prior to AIDS;
- failure to properly differentiate basic behavioral and social science research from applied research or demonstration projects, and consequentially the failure to recognize basic research's potential value in generating new insights for possible interventions—just as basic biomedical research serves to reveal new potential targets against which drugs can be developed;
- inadequate financial support for AIDS-related behavioral and social science research from the federal government;
- a lack of coordination of federal efforts to utilize existing knowledge; and finally,
- political interference with the legitimate scientific process of acquiring and applying new knowledge.

Despite these formidable barriers, behavioral and social science research findings have provided helpful direction for HIV prevention. In the Commission's final report, *AIDS: An Expanding Tragedy,* produced in parallel with this document, we summarized the current knowledge as follows:

> It has become clear that, to be successful, HIV prevention efforts need to provide information, build skills to reduce risk, and provide easy access to the means to do so, for example, access to condoms and sterile injection equipment. They must also be culturally sensitive, reiterated, sustained over time, and complemented by broader efforts over the long haul, both to change behavioral norms within communities at risk and to empower individuals to change. It is also clear that those at highest risk *can* be reached and will change behavior in significant numbers if appropriate motivations are identified, explicit and targeted campaigns are developed, and natural and credible channels of communication are used. . . .

> Evidence to date has taught that prevention will be most effective when specific communities are involved in all facets of planning and implementation; the only way to communicate effectively with each cultural group what we know about avoidance of HIV is to use the language and vernacular of the intended audiences. (NCOA, 1993, pp. 7-8)

The final report points out that we are not yet properly applying what we already know. Many more people must be reached. We desperately need a national prevention initiative founded upon what we have learned—an initiative that incorporates greatly expanded technical assistance to community-based prevention workers.[1] Providers of prevention services must be updated continually about the state-of-the-art in effective intervention strategies.

Tracking and Predicting the Course of the Epidemic

The AIDS epidemic is now in its second decade. It has been predicted that the worst of the pandemic—which already has spread to most countries—may still lie ahead. Most observers believe that the epidemic is broadening in the United States, but some have suggested that it is localizing in particular marginalized groups. Clearly, a better understanding of the epidemic's patterns must be gained and communicated. We need sound and sophisticated methods of tracking and predicting the epidemic.

Worldwide, over 70 percent of all cases of HIV infection are transmitted heterosexually. In the United States, however, male-to-male sexual behavior and sharing of drug injection equipment account for the largest number of AIDS cases reported thus far, although heterosexual sex is now the most rapidly increasing mode of HIV transmission. As the epidemic has evolved, it appears that there is no longer a single face of AIDS, but varied faces, representing a diversity of populations each with its own socio-cultural norms.

We cannot overstate the critical importance of the behavioral and social sciences in tracking and predicting the course of the AIDS epidemic through the study of sexual and drug-using behaviors in various population subgroups. Misplaced sensitivities have severely restricted such efforts, and they have sometimes halted them altogether. Some of the large-scale behavioral research projects which could have provided urgently needed indicators of risk of HIV transmission have not been conducted. The predictions made by epidemiological models do not have the accuracy otherwise possible due to lack of critical 'real world' information. The consequences of this deficit of information about risky

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[1] Throughout this report, the terms prevention workers and prevention researchers are used to differentiate those front-line, community-based service providers whose activities are intended to interrupt HIV transmission from scientists whose primary purpose is to develop new knowledge about effective means of preventing HIV infection. Some researchers actually provide prevention services, usually in collaboration with community-based organizations; these collaborative services tend to be high quality, model programs. Prevention programs may be directed at individuals, groups, communities or the general public.

behavior are two-fold: first, less effective targeting of resources, and second, lack of needed baselines against which to measure progress in bringing about behavioral change.

Understanding Why Behaviors Occur

The range and variety of human sexual activity is influenced considerably by social, cultural, and economic factors, as well as biological ones. The values and meanings which people place upon sexual activity need to be understood, along with the broader context in which behavior occurs (e.g., gender power relationship, stigmatization) in order to formulate potentially effective strategies for reducing those behaviors which pose a risk to health.

Similarly, to even begin to think about changing drug use or the facets of it that pose a particular risk of HIV infection (such as sharing of injection equipment), we need to understand many things beyond its pleasurable and addictive nature. Some of these will relate to individuals and their relationships with others, some will relate to the socio-economic—and even legal—environments in which individuals function.

The failure to properly value basic research in the behavioral and social sciences has affected this area of research—striving to understand "Why?"—particularly severely. Without improving this fundamental, but sometimes complex, underpinning of knowledge based on research, the design of behavioral prevention interventions can only proceed from those which would be promulgated as 'common-sense'—which, as noted above, is often flawed, if not downright wrong.

Better Design and Evaluation of Prevention Strategies

Too often, we hastily launch prevention programs without taking the time to examine lessons we can learn from work in other settings, or to build in and implement procedures for evaluating the successes and failures of our own efforts. The sense of urgency around the epidemic has been an overriding cause of failure to conduct proper outcome evaluations—an urgency so intense that any reason for delaying direct action has often been viewed as part of the problem. In addition, overall funding levels for prevention programs have been grossly insufficient, leading in some cases to absence of any prevention efforts and often to the neglect of evaluation. We will not be able to benefit fully from the experience we gain until funding for all necessary activities—research, demonstration projects, programs and evaluation—is adequate.

A number of priority issues exist in regard to implementing better prevention programs. The critical needs for more basic research, and better linkages between prevention researchers and prevention workers so that the most effective program designs are developed and employed, are discussed elsewhere in this document. Other important challenges amenable to research include relapse prevention, accessing so-called hard-to-reach populations, serving the needs of groups that are not receptive to traditional interventions and tailoring messages to specific target groups. Innovative methods for communicating information to the general public—to inform of risk and to decrease discrimination—must also be identified.

Political Restriction of Prevention Research

AIDS prevention research and services continue to be the object of intense controversy in the United States. Part of the opposition to forthright HIV prevention stems from the cultural climate in which prevention programs must operate. Some Americans have displayed substantial discomfort with the population groups currently identified as having the greatest need for preventive intervention. These groups are drug users, gay men, racial and ethnic minorities, and sexually active adolescents. When combined with politics, the aversion has been harnessed into a powerful force—one that has militated against the heralded American values of individualism and tolerance of diversity.

Opposition to HIV prevention has meant that resources are diverted from key tasks, such as research, or planning and implementing prevention programs, to the defense of peer-reviewed and approved projects against non-scientific attack and to endless rounds of review to ensure that prevention messages do not offend ill-defined community standards. The Commission condemns this unnecessary drain on scarce resources, and, as noted below in its final report, admonishes against practices that impinge on high quality research or effective prevention efforts.

Mental Health Research

With approximately one million persons already infected with HIV, considerable thought needs to be given to preserving their well-being and slowing their progress to AIDS—so-called secondary prevention. In testimony to the Commission in Austin, Texas, Dr. Anke Ehrhardt, Director of the Center for Clinical and Behavioral Studies at Columbia University, explained that mental health concerns are intrinsic issues in the clinical care of AIDS patients. She called for substantial increases in support for behavioral and social science efforts to enable clinicians to improve mental health services for HIV-infected individuals. Her comments reflect a recurrent theme in the Commission's proceedings: the behavioral and social sciences *can* make a major contribution to improving or sustaining the mental health and well-being of those with HIV or AIDS, and to devising sound coping strategies for persons whose lives are affected by the disease (Ehrhardt, 1993).

Behavioral and social scientists are needed to assess the unique challenges that HIV places upon an infected individual, to understand the interactions between physical symptomatology or deterioration and behavioral and emotional reactions, and to tailor models of social support and mental health services to help confront the challenges. Moreover, behavioral and social science research can assist in the development of strategies for responding to the stigma of the disease—diminishing the harsh realities of discrimination that assault those with HIV on a daily basis. Lessons from behavioral and social scientists' studies of coping strategies must be integrated into the design of clinical and supportive services.

Recently, we have started to direct more attention to the AIDS prevention needs of persons with mental illness, and to the most suitable methods of care of the severely and persistently mentally ill who have HIV disease. Such attention is long overdue, since seroprevalence data from New York City indicate that between five to twenty percent of the homeless population is HIV-infected, and the mentally ill represent a significant percentage of the homeless population.

Behavioral Approaches and Biomedical Research

There are a host of problems which arise during attempts to utilize 'technologies,' such as drugs, vaccines, and condoms, for which the behavioral sciences are best equipped to provide solutions.

When an experimental treatment or vaccine is ready for safety and efficacy tests, behavioral and social scientists can help develop clinical trial designs that will be successful in recruiting and retaining individuals from high-risk populations, and in providing answers that are not put into doubt by behavioral variables which were not measured in the trial. Once drugs (prophylactic or therapeutic) or vaccines are ready to be marketed, behavioral and social scientists can develop and implement effective means of ensuring their proper utilization including ways of supporting adherence to long and possibly complex treatment regimes. They can also play a central role in dispelling any myths the public may harbor about magical cures or total risk elimination. Other issues that call for social and behavioral approaches include maintaining the safety of the blood supply and safety in the health care environment.

Often, behavioral and social scientists are consulted only when problems arise in using technologies. The sometimes mistaken purpose of such consultation is to rectify the perceived problem with the intended beneficiary of the technology, rather than to address flaws in the technology as it relates to the reality of the intended beneficiary's situation. Everyone stands to gain if those developing 'technologies'— whether they be drugs, vaccines, new condoms for men or women, or microbicidal foams—collaborate at the earliest stages with those who can provide expertise on the likely utilization of such products.

Summary of Recommendations

1. **The National Commission on AIDS believes it is critically important to immediately make effective use of behavioral and social science knowledge in the national response to the HIV/AIDS epidemic. It is also necessary that this knowledge base be expanded. The Commission calls for the behavioral and social sciences to be properly integrated into the mainstream of the HIV/AIDS response in the United States.**

   To highlight neglected fields and to emphasize the breadth of relevant information, this report identifies some priority areas within behavioral and social science research on AIDS. The central concern of the Commission, however, is not establishing research priorities. Rather the objective is that from this point onward, behavioral and social sciences play an appropriate and central role in the overall battle against AIDS through expanded research and its application. In many cases, only multidisciplinary efforts will produce the comprehensive information required by HIV prevention workers and care providers. Greater inclusion of behavioral and social scientists at policy formulation, and research and program management levels of PHS is required.

   We must employ all available tools to thwart the AIDS epidemic. As the Ninth International Conference on AIDS held in Berlin, in June 1993, made clear, equivocating about such action in the hope of near-term 'magic bullets' would be foolhardy.

2. **For the critical task of reducing HIV transmission, substantial increases in resources for prevention, specifically for behavior change interventions and behavioral and social science research, must be requested by the Administration and/or appropriated by Congress.**

   The level appropriations for prevention and prevention research in recent years have—in the face of an expanding epidemic—left a 'prevention gap' and substantial increases in resources for prevention will be needed over the next few years to catch up. Increases for prevention must not be to the detriment of research or services that will benefit persons with HIV infection.

Research Priorities

Findings from Behavioral and Social Science Research Relevant to HIV/AIDS

Although under-supported, the behavioral and social sciences have demonstrated their potential contributions to curtailing the HIV epidemic. The status of knowledge of sexual behavior and injection drug use was thoroughly reviewed by the NRC Committee on AIDS Research and the Behavioral, Social, and Statistical Sciences. They found that overall patterns of sexual behavior have been studied periodically, but not in detail or systemically. (See NRC, 1989b, pp. 78-185.) Knowledge of trends, their causes, or specific information on certain topics (e.g., sexual partner networks or sexual practices in different groups, such as adolescents) is limited. However, recent studies (e.g., Catania et al., 1992; CDC, 1992a,b) show that these topics and others (e.g., condom use) can be investigated fruitfully.

Injection drug use was also studied prior to the onset of the AIDS epidemic. (See NRC, 1989b, pp. 186-255.) The broad social factors that contribute to drug use and its approximate dimensions have been described, and there are now thought to be about 1 to 1.5 million injection drug users in the United States. But there has been little systematic research conducted on the relative effectiveness of fundamentally different approaches (e.g., coercive versus 'supportive') to counteracting injection drug use. Most recent research on injection drug use has been intervention-oriented, and has demonstrated that those approaches which gain the trust of the target subjects can be successful in reducing risk behavior, as measured by less frequent sharing, or use of bleach to clean injection equipment, even where drug injection continues. Research has also shown that those who receive treatment are more likely to reduce their risk of HIV than those who continue to inject.

Our understanding of *why* behavior occurs is more general than our ability to specify what occurs. From behavioral and social science research prior to AIDS, a number of general theories of behavior and behavior change had been developed. The major theories—the Health Belief Model, the Social Cognitive Learning Theory and the Theory of Reasoned Action—and their competitors essentially represent different perspectives (public health v. clinical v. social psychological, respectively) on the understanding and prediction of behavior. For practical purposes, they utilize very similar variables to predict behavior. In summary, they suggest that for a person to perform a given behavior, one or more of the following must be true:

1. the person has formed a strong positive intention (or made a commitment) to perform the behavior;
2. there are no environmental constraints that make it impossible for the behavior to occur;
3. the person has the skill(s) necessary to perform the behavior;
4. the person believes the advantages of performing the behavior outweigh the disadvantages;

5. the person perceives more social pressure to perform the behavior than not to perform it;
6. the person perceives that the behavior is consistent with their self-image and does not violate their personal standards;
7. their emotional reaction to performing the behavior is positively reinforcing; and
8. they believe they can execute the behavior (Fishbein et al., 1991).

Recent research has confirmed that these factors are important to HIV/AIDS-related behavior. Interventions utilizing these concepts as a foundation for their design have been successful in reducing risk behavior in specific groups at risk of HIV, namely men who have sex with men (Kelly et al., 1991), injection drug users (O'Keefe, Kaplan, and Khoshnood, 1991), adolescents in school (Howard and McCabe, 1990) and runaway street youth (Rotheram-Borus et al., 1991).

Thus, the general validity of the eight variables identified in the composite theoretical behavioral model has been demonstrated. But research and experience has shown that what shapes the knowledge, attitudes and beliefs that are captured in the eight factors noted above is very complex and varies by socio-cultural background and environment. Unfortunately, the social, cultural, developmental, environmental, economic, legal, and biological factors which influence sexual and/or drug use behavior for any group (defined by race, ethnicity or sexual orientation) are not yet well established. Thus, there is a solid generic information base on what happens and why from which to proceed, but it must be refined so that it can be adapted to the needs of different situations.

Federal Agency Support. The behavioral and social science knowledge base that exists today is largely the result of support by a relatively small number of agencies. The National Institute of Mental Health (NIMH) is the largest funder of behavioral and social science research related to HIV/AIDS among the National Institutes of Health (NIH) institutes. It has focused considerable effort on the neurological and mental health consequences of HIV infection and has also supported a number of large scale, controlled intervention research projects that have been very important in identifying predictors for successful risk reduction programs. The National Institute on Drug Abuse (NIDA) has supported epidemiological studies on drug-related behavior and intervention-oriented research for risk reduction among injection drug users. More recently, it has begun supporting intervention-oriented research targeting the sexual partners of drug users. Historically, and continuing today, the National Institute of Child Health and Human Development (NICHD) has—because of its interest in reproductive health, population, and human development—been a major supporter of research related to sexual development and sexual behavior, including condom use. The National Institute on Alcohol Abuse and Alcoholism (NIAAA) has recently expanded its portfolio to include support for studies on the HIV-related risk behavior consequences of alcohol-related impairment of decision-making. The National Institute of Allergy and Infectious Diseases (NIAID) has included—to a limited extent—behavioral risk variables in its cohort epidemiological studies on HIV/AIDS. It has also recently started to address behavioral issues in its preparations for vaccine trials. More generally, the National Cancer Institute (NCI) and National Heart, Lung and Blood Institute (NHLBI) have historically funded large-scale, behavior-oriented prevention research efforts for their respective areas of interest.

A variety of strategies to prevent HIV transmission are being investigated for effectiveness by CDC in its intervention research program. These include:

- HIV counseling and testing delivered in STD clinics, methadone treatment centers, detoxification clinics, acute care hospitals, and other settings;
- HIV prevention street outreach services for injection drug users and youth in high-risk situations;
- clinic- and community-based prevention programs targeting women with high-risk behaviors for HIV infection;
- national public information campaigns for the general population and specific subpopulations;
- comprehensive school-based health education;
- behavioral interventions targeting communities of color for prevention of HIV infection;
- intervention designed to change community norms regarding high-risk behaviors for HIV infection; and
- behavioral interventions targeted to persons with hemophilia and their sexual partners.

These evaluations are being conducted in collaboration with national organizations, health departments, community and academic organizations. To strengthen its behavioral and social science research capacity and linkages CDC has utilized the Guest Researcher mechanism to bring senior academic personnel to its Atlanta facility.

Additionally, CDC has initiated work assessing the costs, cost-effectiveness, and cost-benefit of prevention interventions, through an HIV Prevention Effectiveness Working Group (Holtgrave et al., 1993).

Behavioral and Social Science Research Categories

Behavioral and social science, as it pertains to the HIV epidemic, is as broad and varied as biomedical science. Just as it would be inappropriate to blur distinctions among individual biomedical sciences (e.g., virology, immunology, epidemiology) so too it is inappropriate to use the term 'behavioral science' without indicating the rich variety of scientific disciplines and approaches represented by fields that range from anthropology to experimental psychology. For reasons that are unclear, there is a puzzling lack of appreciation for the potential contributions of behavioral science. This point was well articulated by Dr. James Curran of CDC:

> Behavioral science is the foundation of most of our prevention efforts and it needs to be. . . . [G]ood disease prevention programs are based upon [a] firm scientific foundation. [But] we lack patience and we misunderstand behavioral science and behavioral scientists. We don't trust them.
>
> [I]t is really quite strange that we have more confidence in therapy for HIV and in vaccines for HIV than we do in behavioral science. [A]re behavioral interventions really less successful than anti-retrovirals ultimately? Are we less likely to learn something about preventing HIV

> through behavioral interventions than we are with an HIV vaccine? (Curran, 1993, pp. 64-65)

The categories in this section provide a taxonomy of the relevant behavioral and social science disciplines pertaining to AIDS. Such research includes psychological, sociological, economic, and cultural studies, and spans the scientific spectrum from basic to applied investigations.

Just as it is necessary to conduct basic virological and immunological studies in order to elucidate pathophysiology and to make the development of vaccines and treatments possible, it is also necessary to conduct studies of basic behavioral and social processes that may have implications for interventions. To illustrate, studies of gender relations, sexual identity formation, and the impact of substance use on judgment processes may improve intervention design by providing a better understanding of the negotiation of safer sex by women and of risk behavior. For their part, the one-hundred-year-old cognitive psychology subfields of attention, information processing and memory have not been brought to bear on the problem of transmitting preventive health information. There must be research in these areas for which the immediate application cannot necessarily be foreseen, just as there is basic research in the various biomedical disciplines. A major problem that has thwarted basic behavioral researchers is that expectations for immediate applicability of research results have been too high. This has resulted in a reluctance to support basic behavioral research. As Dr. John Gagnon of the State University of New York at Stony Brook testified in 1992, sex research questions have unfortunately been framed in terms of what this can tell us about stopping HIV, rather than what this does contribute to our underlying understanding of sexual behavior (Gagnon, 1992).

Even if vaccine and more effective treatments are developed, basic and applied behavioral research will continue to be needed. Experience in treating other sexually transmitted diseases (e.g., gonorrhea, syphilis) and in immunization has shown that drugs and vaccines are not expected to be 100 percent effective, that access to timely information and medical care will not be universal, and that adherence to medical advice will not be complete. Thus, there will be a continuing need for further behavioral interventions, as well as strategies for treating those who continue to become infected. Furthermore, the behavioral and social sciences can help ensure that the efficacy of biomedical agents then available is realized to the highest practical extent in routine use.

The research categories outlined below are useful to structure thinking about a research agenda but projects may span more than one category.

Behavioral Epidemiology. Experience in public health prevention and treatment programs has underscored the need to identify specific populations at risk, to understand thoroughly the nature of at-risk populations and subpopulations, and to know in detail the determinants of high-risk behavior in order for effective interventions to be developed. Determinants of risk are broad and include psychological variables (e.g., knowledge, susceptibility, and perceived norms), economic variables, social, and cultural factors. Dr. Jose Pares-Avila, a clinical psychology fellow at Harvard Medical School, illustrated the need for comprehensive research with different population groups in his testimony to the Commission during the New Orleans hearing in May 1992:

> The gay community is looking now at relapse prevention as we enter the second wave of the epidemic. What is wrong with this picture? Well, Latino gay and bisexual men were never reached by these efforts, and we have never seen slower infection rates, as was seen in the Anglo gay community. (Pares-Avila, 1992, pp. 191-192)

In describing behaviors and their determinants both quantitative and qualitative approaches described below are needed. Quantitative techniques derived from survey research and epidemiology can help to pinpoint the prevalence and incidence of risk behaviors in specific populations. Recent experience with studies funded by NIH has demonstrated that individuals will participate freely in such studies and that they will give reliable information.

It should be recognized that behaviors and their determinants are not static and need regular monitoring. Each birth cohort potentially represents a new wave of behaviors and attitudes as it becomes sexually active and at risk for drug use, and these behaviors and attitudes can evolve over their life course.

Cognitive Science. A key theme in the behavioral and social science research is the relationship(s) among the many factors which support or impede AIDS prevention behaviors, particularly those associated with sex and drug use—especially drug injection behavior—that pose a risk of HIV transmission. Research that seeks to identify the basic processes that drive behavior and that effect behavioral change should also be supported, because efforts to change the specific behaviors that increase the risk of HIV infection must draw upon a broad understanding of the factors that motivate human beings to act. An understanding of these interrelationships can be used to develop more effective prevention interventions. As Dr. Vickie Mays noted at the Commission's hearing in New Orleans these determinants may vary with age, gender, and socio-cultural context, and they will certainly need to be taken into account in deciding the nature, scope and content of AIDS prevention programs (Mays, 1992).

In addition to quantitative research (which identifies what occurs), qualitative research (on why it occurs) must also be conducted. Qualitative approaches include learning from those whose risky behavior we seek to modify; a prevention program that grows out of a realistic understanding of its target audience is far more likely to achieve its goals. Such research and consequent interventions necessarily will be interdisciplinary in scope.

Cultural and Ethnographic Studies. Such are needed to describe the context in which risk behaviors occur and the broader social and cultural issues that may influence risk status for specific individuals and populations. NIDA's prevention outreach research, funded through its Community Research Branch, has helped to pioneer this type of research in the AIDS arena. But broader applications of these approaches are greatly needed. Qualitative approaches are especially suited to elucidating the meanings of quantitative results; both are needed to understand as fully as possible what factors influence risk perception and risk taking. From cultural and ethnographic studies we can learn how to structure interventions for different groups, including the most credible channels through which to deliver messages.

Intervention Research. This research is needed at several levels. Public education about risk is the cornerstone of AIDS prevention efforts, as it is for many other disease prevention programs. But we know from studies of other health risk areas that communication about risk is itself complex (NRC, 1989a) and that knowledge by itself will not necessarily bring about changes in behavior to reduce risk. This is particularly true of efforts to change sexual or drug use behaviors which are strongly motivated, pleasurable, complex, social, and poorly understood. Public education must be supplemented by interventions which will motivate individuals to reduce their risks, teach the skills for effective prevention, make available what is necessary to reduce risk (e.g., condoms or sterile injection equipment), and modify the social and cultural context in order to reduce risk taking on a societal level.

Studies are needed to examine the impact on individuals of one-to-one or small group interventions. At the same time, more expensive and more complicated studies are needed to examine methods of changing larger institutions (e.g., schools or prisons) or entire communities to determine if the social norms that influence so much risk behavior can be modified effectively for large groups of people at risk. Finally, the cost-effectiveness of various approaches must be estimated to assist in putting into place the best portfolio of activities possible within available resources.

Mental Health Research. In addition to directing efforts that fall wholly within their own disciplines, behavioral and social scientists have an important role to play within the context of care for those with HIV disease. The overall well-being of persons with HIV infection would be significantly improved by research addressing their mental health status. This could be accomplished through both free standing studies looking at mental health issues, as well as 'piggyback' studies, which add mental health indicators to clinical studies. It is noteworthy that the discussion of alternative end-points in AIDS treatment research has largely ignored the potential for using quality-of-life and behavioral indices to measure effectiveness of particular interventions.

HIV has neurological and psychological effects. Long before the virus leads to central nervous system (CNS) damage, people often react to the knowledge of their HIV infection with profound psychological responses ranging from depression to anger. Reactions may change and/or evolve over time. Behavioral scientists can assist in conducting research to determine the prevalence, incidence, and predictors of these effects. Additional research is needed to determine the efficacy of interventions designed either to ameliorate the CNS effects of HIV or to preserve mental health.

For some of those with HIV infection, families and friends will be supportive. But others will face diminished support or even rejection. Discrimination from prospective employers and insurers may also occur. As Dr. Anke Ehrhardt reminded the Commission in March 1993, "All aspects of HIV infection and AIDS are plagued by stigma and discrimination. Thus, progress in prevention and clinical care is continuously hampered by negative consequences to people who we want to reach and who need to be reached. Social science is crucial to understanding and overcoming these barriers to effective outreach and treatment" (Ehrhardt, 1993, p. 32).

Research is needed to better document and understand the situations that lead to adverse societal reactions such as stereotyping, stigmatization, discrimination, and the perturbing incidence of violence against persons living with HIV (NAPWA, 1992). Its findings would help in the design of effective interventions aimed at modifying the causes of negative social reactions and their effects on mental health. A further important area for study is the specific HIV risks of, and prevention strategies for, the mentally ill.

Behavioral Aspects of Technological Interventions. Current clinical trials of therapeutic drugs have been hampered by difficulties in enrolling and retaining selected participants—particularly women and individuals from racial/ethnic minority groups— and by poor adherence with medication protocols even though preliminary screening is sometimes designed to select those likely to be adherent. Predictably, vaccine trials will suffer from the same problems, and have additional ethical, social, and behavioral science research issues associated with them. For example:

- If a vaccine is likely to be only 60 to 70 percent effective, what strategies can be used to inform individuals about what this means?
- What might the social impact of such a vaccine be? Will more infections result because individuals will feel that they are now protected, or can they be motivated to continue to reduce risk even when they are 'immunized?'
- If studies are conducted in developing countries which have medical personnel shortages and language barriers, how can true informed consent be obtained?

For HIV infection, the goal of a true cure may not be attainable. Hence, it is likely that prophylactic and therapeutic drug regimes may need to be followed for years, often by individuals who are asymptomatic. Experience with tuberculosis (TB) has clearly demonstrated that maintaining patients' adherence to even moderately long drug regimes (of six months) is extremely difficult when patients are asymptomatic. Further, options used for TB therapy, such as promoting adherence by assigning care providers to observe drug ingestion, are not likely to be economically feasible or to be used for HIV disease since it is not contagious. Believing that research focusing on patients' adherence to drug regimes is not necessary because future generations of drugs will have characteristics that will make adherence easier is to deny what we know about the nature of HIV disease and adherence in general. It also holds out false hope of miraculous 'magic bullets' (curative drugs or preventive vaccines). In these circumstances, research on factors that affect the full achievement of the potential benefit of therapeutic or prophylactic agents under conditions of normal patient use is a legitimate research investment.

Behavioral factors obviously need to be considered as other technologies, such as microbicidal foams for women, are developed. A person's degree of comfort in dealing with sexual matters has already been identified as an important variable influencing the likelihood of condom use. Further understanding of these issues will suggest suitable approaches to building skills to use technologies properly or for modifying the technology to enhance its usefulness.

Answers to the above questions will hold the key to the successful and ethical conduct of vaccine trials and effective use of drugs, vaccines, and other technologies; but very little (if any) research, however, appears to be currently conducted in this area. Responsibility for such research and its application should be assigned within NIH for conduct of the research, and within PHS for its application.

Organizational Studies. Organizational studies can address issues within health care and social service systems—ongoing needs repeatedly brought to the attention of the

Commission. Health care worker burnout is an example of a topic brought most poignantly to the fore by a witness in the Commission hearing on Adolescents and AIDS in Chicago, in March 1991:

> My mother, two years ago, she basically had a nervous breakdown because she was working with AIDS patients . . . she was attending funerals just monthly of the people she had taken care of. And it—it was devastating.
>
> And what I did when I saw her doing this, I kind of . . . closed myself off and I thought . . . this is really awful, but what can I do and everything else? And I saw her emotional stress and I didn't know how to deal with it. (Jacobs, 1991, p. 175)

Another area that should be addressed under rubric of organizational studies is the delivery and utilization of health care services for persons with HIV/AIDS.

Summary of Recommendations

3. **Research should be expanded in the following behavioral and social science categories:**

   A. ***Behavioral epidemiology,* which seeks to establish the prevalence and determinants of risk behaviors. For example, it remains to be determined to what extent, nationally, young gay men are failing to adhere to the norms of safer sex that some older gay populations have established.**

   B. ***Cognitive science,* which employs field studies and laboratory investigations to understand cognitive processes and social psychology, and their relationship to behavior. We need to know more about the antecedents and determinants of sexual intercourse and drug use behavior. We need to get to the specifics of such behaviors, i.e., which factors (such as peer pressure, etc.) carry the most weight in determining values, attitudes, and actual behavior, so that we can design interventions to target the critical variables.**

   C. ***Cultural and ethnographic studies,* which investigate determinants of behavior within varying cultural groups. For example, we need to conduct the research needed to clarify the meaning of concepts such as risk, health, and personal responsibility to those who have an elevated risk of HIV infection. Cultural and ethnographic studies will not only help tell us what to target in interventions for different groups but can also help in ensuring that interventions are culturally sensitive and delivered through appropriate channels. For example, designing the most attention-grabbing and memorable stimuli possible for social marketing of condoms, or countering stigmatization and discrimination, in different populations.**

   D. ***Intervention research,* which employs controlled designs to judge the relative effectiveness of various theory-based intervention strategies. For example, we have not, as yet, pinpointed the elements in prevention programs for young adolescents that are necessary and sufficient to delay the age of first** sexual intercourse, and to foster early and consistent use of barrier methods of contraception/disease prevention when intercourse is initiated. Research into the most effective risk reduction strategies among sexual partners of at-risk drug users is also a significant unmet need.

E. *Mental health research,* which strives to understand and intervene in stress, coping, substance abuse, and other psychopathologies in order to preserve the well-being of those with, or at risk of, HIV infection.

F. *Behavioral aspects of technological interventions,* an area which seeks to determine the non-medical factors influencing utilization of 'technological' medical intervention. It is critically important to assess the ways we can get the maximum benefit out of existing and future agents (such as drugs, vaccines, or condoms) by ensuring they are used properly. Clinical trials of vaccines and other therapeutics would be greatly improved by research on the inclusion and retention of people of color and women into these trials. In addition, we need interdisciplinary studies on the development and use of female-controlled prevention methods. Such studies should recognize that insistence by some women on condom use for HIV and STD protection may be extremely difficult if not impossible, due to such factors as the threat of violence or sexual abuse. Behavioral utilization studies should be an early part of product research and development.

G. *Organizational studies,* which seek to understand the dynamics of organizational life and the interaction between individuals and organizations. For example, a major unmet need is identifying effective means of volunteer recruitment, staff retention and burnout prevention among health care providers and workers in AIDS organizations.

Training and Recruitment of Behavioral and Social Scientists for AIDS Prevention

In the early days of the AIDS epidemic, CDC was designated the federal agency with primary responsibility for AIDS surveillance and prevention activities. CDC attempted to evolve rapidly to respond to this important charge. Unfortunately, the traditional public health paradigm for infectious disease control, as discussed in the Introduction, may have delayed development of a vision for an appropriate response to a behaviorally-transmitted, slow-acting viral agent with no vaccine or cure.

Behavioral and social science expertise was called for but, even in the late 1980s, CDC employed fewer than 40 Ph.D.-level behavioral scientists out of a staff of 4,500 (NRC, 1989b), and it had limited connections with the behavioral science community at large. As a result, the agency lost valuable time in mounting a prevention campaign based on sound behavior change strategies with demonstrated effectiveness. In 1989, the NRC/NAS Committee pointed out the urgent need for CDC to strengthen its capacity in the behavioral and social sciences (see NRC, 1989b, p. 24); some progress has been made, but much more is needed. As Dr. James Curran of CDC admitted in his statement to the Commission in March 1993, "One of the problems with behavioral scientists is that to some extent, through NIH and throughout CDC, they are kind of like new kids on the block" (Curran, 1993, p. 66). Behavioral and social scientists are very sparsely represented in senior management positions in CDC. There are also few permanent staff with the background to make the most of consultation with external experts in the behavioral and social sciences. This situation will cause further delays in integrating behavioral and social science expertise into the struggle to limit the spread of HIV. The situation at CDC is not unique to the Public Health Service or other public health institutions. The process of integrating the behavioral and social sciences is still in its relatively early phases in most places but should be accelerated.

Creating an appropriate behavioral and social science infrastructure has been a concern of CDC's senior management, but there are cultural and structural barriers to achieving this goal within the organization. For example, it appears that those with M.D. degrees are hired and promoted far more readily at CDC than those with Ph.D. degrees in behavioral science, and relatively few branches of the organization emphasize behavioral approaches.

A major avenue to professional level employment at CDC is the Epidemiologic Intelligence Service (EIS) course. EIS officers receive training in epidemiology and supervision in research, and are subsequently awarded preferential status in hiring. The EIS has been overwhelmingly composed of physicians since the inception of the program in 1951; out of a total of 1,917 individuals, it has trained only 52 statistician/demographers, nine anthropologist/sociologists, and 16 others with non-medical doctoral degrees. Encouragingly, there does appear to be a trend to greater inclusion of behavioral and social scientists in recent years, however, there is considerable room for improvement. Although the EIS staffing is only one example of CDC's structural bias against behavioral and social scientists, it illustrates the extent of organizational change required to address the need to better incorporate behavioral and social science expertise in the response to the epidemic.

For a number of years NIH institutes, primarily NIMH and more recently NIDA, have funded training in the behavioral and social sciences related to AIDS, at Columbia University, Emory University and the University of California at San Francisco. These programs are extremely valuable but the scale of this effort needs expanding and extending to other NIH institutes.

An inclination against preventive, behavioral approaches to HIV/AIDS is reflected in training, recruitment, and funding practices across the entire public health system. Provision of care is obviously needed but lack of attention to prevention is short-sighted. As Sue Neuhauser of the Chicago Department of Health noted in the Commission's hearings in Chicago:

> . . . both the federal and local governments must begin to re-evaluate their funding priorities. More importance must be placed on health education and prevention activities and less emphasis on testing and tracking activities. Counseling and testing activities are currently funded at three to four times the amount of health education in risk reduction activities. (Neuhauser, 1991, p. 33)

Redressing this imbalance would require shifting funding priorities so that behavior-related prevention activities receive a greater absolute amount, or a larger proportion, of available resources. However, across federal agencies, expenditures for surveillance, testing, counselling, prevention activities, and behavioral research have remained approximately stable for the last three years (DHHS, 1992).

Training needs are also evident in the behavioral and social science communities. More of these researchers should be exposed to epidemiology and public health. The formation of collegial research relationships among scientists steeped in different disciplines will help somewhat, but cross-training mechanisms should be developed. As Dr. David R. Smith, Texas Commissioner of Health, suggested to the Commission in Austin:

> You need to create a new discipline, particularly in the realm of what we call medicine, but more specifically what you should call health, because you should foster the same kind of community responsive system where, in fact, research for prevention and primary care and behavioral science is part of the curriculum and revered in the same way that we revere some of the other research. (Smith, 1993, p. 45)

Whether this is achieved through multi-disciplinary training or multi-disciplinary teams, such new ways of thinking about health and behavior could serve as a catalyst for future collaborative efforts.

In addition to academic excellence, training goals for NIH and CDC must also include increased recruitment of behavioral researchers from racial or ethnic minorities into the area of AIDS research. One recruitment model CDC should explore is the highly successful NIH minority supplement award program, which provides additional funds to existing grantees to recruit and train individuals from minority groups.

Finally, social and behavioral scientists could serve as a training resource. They could help to develop a badly needed cadre of prevention workers capable of designing community-based prevention activities that are informed by the latest scientific knowledge and include behavioral risk indicators for evaluation. Proper documentation of such activities should feed back into ongoing evaluation in a continual process of intervention refinement (NRC, 1991).

Summary of Recommendations

4. **CDC's HIV/AIDS prevention efforts, including public health education, epidemiological training, and service programs, need to more fully take into account knowledge from behavioral and social science research. While CDC has made strides to recruit more behavioral scientists over the past several years, it still must do more to infuse its programs with those trained in the behavioral sciences, who should be vested with significant policy-making responsibility and authority. Moreover, CDC should endeavor to promote a more behaviorally-oriented methodology and theoretical framework in the prevention efforts it supports. Collaboration with NIH agencies supporting basic and applied behavioral and social science research should be strengthened.**

5. **There is a pressing need to recruit and train more individuals from racial and ethnic minorities, more women, and those already involved in community-based AIDS prevention and services delivery as researchers. In addition to current post-doctoral opportunities, federal agencies should facilitate HIV-related research training efforts within graduate programs, develop practicum and field placement approaches, and provide career research awards.**

Application of Behavioral and Social Science Research Findings

Important information is now being generated by behavioral and social science research, especially with regard to primary HIV prevention. We now have clear indications that certain prevention strategies *can* reduce the risk of HIV transmission among gay and bisexual men, injection drug users, and homeless or runaway youth. During the hearing in Austin, Dr. Fishbein noted that:

> . . . in the past 10 years we have witnessed major changes in various sexual practices among at least some segments of the gay community, as well as major changes in needle use behavior, both cleaning and sharing, among some injection drug users. Although the behavioral sciences cannot take credit for most of these changes, there is growing evidence that well-designed interventions can be effective in producing such changes. (Fishbein, 1993, p. 23)

We must be clear, however, as to the limits of our present knowledge. We know some strategies can work, but we are far from knowing, in each of the variety of situations we are faced with, what works best.

In order for the development, testing, refinement, and application of prevention strategies to proceed as rapidly as possible, prevention workers and researchers must collaborate, high-quality evaluation research must be supported, and social and behavioral scientists must be brought into the development of a national prevention strategy.

Collaboration: Building Bridges Between Behavioral and Social Science Researchers and Prevention Workers

In testimony to the Commission, Dr. Charles Turner, Director of the Committee on AIDS Research and the Behavioral, Social, and Statistical Sciences of the NAS/NRC, acknowledged the difficulties—but highlighted the benefits—of collaboration between behavioral and social science researchers and prevention workers. He described some of the demands and rewards of this essential collaboration in a 1989 report he edited with Heather Miller and Lincoln Moses:

> [M]uch of the best behavioral and statistical research on AIDS has resulted from the joint efforts of university scientists, government agencies (at all levels), and organizations rooted in the communities that have borne the brunt of the AIDS epidemic. Although these collaborations have not always been easy to arrange or free from conflict, the practical and scientific payoffs have been substantial. . . .

> Differences in social origins, economic status, or life-style may sometimes lead to misunderstandings on both sides. Yet despite such misunderstandings, the differences that can at times make these collaborations difficult also make them indispensable. Efforts to design and implement effective AIDS education without the collaboration of local communities will only multiply these misunderstandings. (NRC, 1989b, pp. 364-365)

The active and equitable collaboration of persons in the target populations with "outside" scientists and researchers can provide important safeguards against such misunderstandings. To have credibility in the target communities suffering high rates of HIV infection and to maximize the likelihood of successfully preventing the further spread of infection, the Committee recommended, "intervention programs at all levels increase the involvement of minority researchers and minority health care workers to assist in reaching and involving the black, Hispanic, and gay communities" (NRC, 1989b, p. 365).

In addition, the Committee recommended that special support be provided to foster what are often weak linkages among practitioners (those best positioned to deliver services) and researchers and to remove or reduce the organizational impediments to the establishment of those relationships.

How can we foster collaboration between the frontline providers of AIDS care and prevention and the academic researchers working in the social and behavioral sciences? It must be made clear that, while there are many tensions in this arena, ultimately both groups need each other. The prevention workers need assistance in assembling convincing evidence that their programs work. Only data from high quality outcome evaluations suffices to demonstrate the efficacy of their interventions to the satisfaction of governmental or private funding agencies. Fundamentally, of course, frontline prevention workers have a need to know if their own efforts are having a real impact. For their part, researchers must collaborate with prevention workers because the latter are 'gatekeepers' to the populations that researchers wish to study, and with whom they should test approaches that are ready for empirical assessment. In addition, for community-oriented or applied research to have real relevance, researchers must have the ear of prevention workers who can put their findings into action.

Despite the mutual benefits of working together, a separation has developed between many prevention workers and researchers. Without concrete efforts to bring these two groups together, the rift between these two constituencies will not narrow.

Too frequently, in the judgment of prevention workers and health service providers, researchers merely seek study subjects, often offering a program's clients little in the way of personal benefits in exchange for their participation in research. Providers fear that when the intervention ceases and the researchers leave, their client population, which has come to rely on the services provided in the research study, will feel abandoned. Research institutions are perceived as large, well-financed entities that often give back little to the community studied.

For their part, researchers sometimes believe that prevention workers or service providers either do not understand or appreciate the demands of the scientific process, and are sometimes unwilling to subject their programs to rigorous evaluation of effectiveness. Sometimes disparities of race, ethnicity, sexual orientation, class, or economic status present significant barriers to collaboration. Funding agencies should create incentives to overcoming barriers to collaboration, promote mutual information exchange between researchers and practitioners, and greatly expand the availability of technical assistance in behavioral and social science disciplines for prevention workers.

It is particularly troubling to see how these conflicts between providers and researchers translate into problems with the responsible federal agencies. The component institutes within NIH that emphasize behavioral research reflect, embrace and embody the research/academic culture. Research supported by NIH institutes is most often investigator-initiated and is tied, appropriately, to the peer review process to ensure quality. The NIH mission is inherently linked to the pursuit of scientific knowledge, and its guiding credo is that general advancement of basic scientific knowledge will produce results that will be useful in the battle against a host of killing diseases.

Along with NIH, the Public Health Service also includes CDC, the Health Resources and Services Administration (HRSA), and the new Substance Abuse and Mental Health Services Administration (SAMHSA). Most of these agencies, which are the largest sources of funding for HIV/AIDS service and prevention activities, have long histories of support for service delivery. In general, they have only modest backgrounds in evaluation and make little or no investment in basic biomedical or behavioral research. Consistent with the history of the researcher/prevention worker tension at the local community level, the federal research and service agencies have a poor record of collaboration. Their staffs tend to reflect either the research or the public health services tradition. Their funding patterns show little overlap. NIH supports research institutions and individual investigators. CDC and HRSA predominantly fund state or local health departments, community health service providers, and other community-based organizations. While it does fund some data gathering, SAMHSA primarily funds state substance abuse and mental health service agencies, as did the service delivery entities within its predecessor, the Alcohol, Drug Abuse and Mental Health Administration (ADAMHA). This compartmentalized structure has generated few institutionalized mechanisms for utilizing new research results in program design. Moreover, officials of the respective agencies often reflect agency perspectives within the Public Health Service.

To combat this segregation of research and service agencies, innovative methods to ensure collaboration and linkages must be developed to ensure the transfer of 'technologies' from research to application. The December 1992 workshop on prevention interventions, bringing together prevention workers and researchers, cosponsored by NIMH, CDC and HRSA, is an encouraging sign that this need has been recognized but a variety of mechanisms will be needed to promote cross-fertilization across activities and continuing collaboration. The possibility of a national prevention conference should be considered.

Evaluation: The Need to Know What Works

Detailed evaluation of the effectiveness of prevention interventions is a complex and costly process. In Austin, Dr. Fishbein reminded the Commission that:

> It is no more possible to develop an effective behavioral intervention overnight than it is to develop an effective vaccine. Interventions can change behaviors, but to do so, they have to be theoretically and empirically based, and they should be carefully tested before they are administered [broadly] to a given population. (Fishbein, 1993, p. 28)

Citing Zaslow and Takanishi, Dr. Fishbein argued that the acquisition of valid and useful information requires:

1) A descriptive (or qualitative) phase of understanding the norms, and range of behavior, of a particular group whose sexual or drug use behavior we have targeted to modify (e.g., adolescents);
2) Development of specific hypotheses and theories about why such behavior occurs based on such descriptive data;
3) Design and implementation of theory-driven intervention strategies;
4) Documentation of the integrity of the programs that are implemented;
5) Evaluation of the short-term impact of the prevention programs by using comparative designs, with random assignment to groups, and by using proven behavioral outcome measures that are conceptually related to the hypotheses;
6) Distinguishing the short-term effects of the intervention, in terms of population subgroups and particular facets of behavior;
7) Attempting to describe the underlying processes that affect the program; and
8) Conducting longitudinal studies to determine the extent to which the effects of the programs are sustained (Zaslow and Takanishi, 1993).

The Commission concurs with testimony given in New Orleans (May 1992) by Dr. Thomas J. Coates of the Center for AIDS Prevention Studies at the University of California, San Francisco, that there is an additional, critical component and a desirable next step—namely, specific plans for the inclusion of the target population in planning and executing the research, and for the dissemination of results (Coates, 1992). However, the task of synthesizing findings from various studies and promoting their application rightly falls to agencies that support research and those that use it.

The NRC/NAS Committee published an extremely valuable report entitled *Evaluating AIDS Prevention Programs*, which details and evaluates methodological considerations in designing preventive interventions (NRC, 1991). Implementing the recommendations in that volume will require more resources than are currently available for the purpose of carefully evaluating "what works?"

Planning: Embracing Prevention Research Findings in a National Response

Throughout the course of the Commission's hearings, witnesses have pointed to the need to restructure and reorganize the way prevention activities have been conducted by the federal government. In response, the Commission has sounded repeated calls for a national prevention initiative, always envisioning full utilization of relevant knowledge from behavioral and social sciences, and the active participation of scientists from these fields in the planning process. During hearings in New Orleans, Dr. Coates asked the question:

> So how do we reform this whole process [of HIV prevention]? Well, the idea is to take what we have learned from care and perhaps apply it to prevention. . . . The first step is developing a vision. This Commission, in its report *America Living With AIDS*, called for just [such] a vision, and now I think it is time to take the next step. Somebody needs to

> create that vision . . . [I]t is time, and it needs to be done quickly, because more and more people are becoming infected. (Coates, 1992, pp. 11-12)

Perhaps the most valuable contribution that social and behavioral scientists can make to planning is to provide a digested synthesis of relevant research literature. They can also translate scientific jargon into action directives. Dr. Coates offered a sample of this kind of input in testimony to the Commission regarding local planning councils:

> . . . I realize that a key piece of the Ryan White CARE Act [is] the local planning councils, and that many people have asked the question, "Are the local planning councils worth the effort?" You get the groups together, and that takes time, and they have got a process, and they don't always understand the planning process.
>
> But what they do understand, [is] what the local needs are and how best to meet those needs in that community with an understanding of the standard of care for prevention.
>
> It probably goes a step further . . . [N]o group, and least of all the health departments, ha[s] any divine insight into what is going to work best in a community. Most often [however] the process works by a very different mechanism; that is, somebody makes a plan . . .
>
> [T]he most essential part of this [planning process] is community involvement, and if there is any key to behavior change, it is community involvement, and particularly if that community can be gotten together and helped to think about its underlying problems. (Coates, 1992, pp. 13-14)

In another example of the way behavioral and social scientists can condense a body of research literature into straightforward advice that can inform the national prevention plan, Dr. Anke Ehrhardt argued that prevention messages should be explicit, culturally relevant, and presented in the language and vernacular of the population targeted. In March 1993, Dr. Ehrhardt explained:

> Twelve years into the epidemic, our list of prevention messages is not only short, but is inappropriate for many. We have acted as though it is just a matter of telling people to be abstinent, or to have a monogamous lifelong relationship, or reduce the number of their sexual partners, or to ask their partner's sexual history, or to use condoms.
>
> These messages have been given to all people, whether old or young, men or women, gay or straight, black, white, Latino, or any other group. We have acted as though this is enough to formulate prevention messages without understanding or taking into consideration attitudes, motivation, power relations, pregnancy wishes, the stigma of getting an HIV test, etc. We have told drug users that they have to stop using drugs, without providing adequate and accessible treatment and without access to clean needles. (Ehrhardt, 1993, pp. 35-36)

The need for cultural relevance was elaborated by Dr. Vickie Mays of the University of California at Los Angeles, who noted that:

> [M]essages used for white gay men . . . did not have the same level of association of sexual practice [as] for some African American gay and bisexual men. For these men, sex was thought about and talked about with a different set of symbols and meanings.
>
> This should not come as a surprise to us since language and metaphors about sexual behavior differ in terms of various groups. They differ between heterosexuals and gays. They differ among ethnic groups and they also differ between men and women; yet, when such groups as African Americans, Latinos or women never see their experiences reflected in our prevention efforts, we can only take responsibility for the fact that they don't then embrace our advice. (Mays, 1992, pp. 65-66)

The codification of behavioral and social science knowledge and approaches into a written and accepted national prevention strategy should help to bring about sound, lasting change, rather than 'lip-service.' Indeed, with a clearer national plan for prevention, it should be easier to estimate and obtain the additional funds required to mount prevention activities on a scale commensurate with the threat of AIDS to the nation's health.

Summary of Recommendations

6. **Technology transfer and feedback between behavioral and social science research and prevention efforts must be improved, increased, and accelerated. There must be greater collaboration and cooperation between researchers and their nonresearcher counterparts working in AIDS prevention. To achieve this, strong linkages should be established so that researchers and prevention workers (e.g., NIH, CDC, HRSA, and SAMHSA grantees) come together to facilitate both prevention and treatment effectiveness and the conduct of research.**

   A variety of mechanisms can promote such linkages, and should include joint grants, workshops and the development of an interagency infrastructure that fosters collaboration; a national conference should be considered. Ethnic minority and women's health organizations should be included in formulating the research agenda. Agencies supporting prevention research and prevention programs have a responsibility to synthesize and disseminate the conclusions that can be drawn from work they support more systematically than has been done to date.

7. **A plan for a National Prevention Initiative should be formulated. It should embrace the following:**
   - **Improved prevention planning must be a central element of a restructured national HIV prevention effort. Federal, state, and local government agencies and community-based organizations involved in AIDS prevention efforts must join together to develop comprehensive plans for the delivery of HIV prevention services to individuals, communities and the population in general.**

- **Prevention resources should follow the epidemiology of HIV transmission and risk behavior. Where it is impossible to determine current rates of new HIV infection, surrogate markers for risk behavior (such as sexually transmitted diseases, like hepatitis B, unintended pregnancy, and injection drug use) should be used for the allocation of resources. All groups in which risk behavior occurs should be targeted by prevention programs.**
- **Prevention programs should reflect the best and most current knowledge generated from behavioral and social science research about AIDS-related behavior change.**
- **A key element of any kind of prevention reform must be greater involvement in the allocation of resources to prevention programs by those who are intended to benefit from them. Only by allowing local communities to assess their own local needs will such resources be appropriately targeted.**

  Local community groups and agencies representing populations at risk for HIV disease and persons with HIV who have been disenfranchised from funding allocations in the past, such as those serving women and racial/ethnic populations, must be included in the planning and decision-making process around HIV/AIDS prevention.
- **Prevention materials must include frank and explicit messages about how to stem the transmission of HIV, including culturally-sensitive and specific language and/or vernacular directed at targeted population groups.**
- **Technical assistance to local communities designing and delivering AIDS prevention programs must be provided by behavioral and social scientists experienced in preventive interventions.**
- **Careful consideration of the findings of the external review to which CDC is presently subjecting five of its HIV/AIDS program areas.**

  The Commission recognizes that much of the necessary reorganization and expansion of AIDS prevention efforts can be accomplished through administrative and regulatory actions. The newly-appointed National AIDS Policy Coordinator should give high priority to rapidly formulating a plan for a National Prevention Initiative and making any administrative changes it requires. A vigorous national prevention effort will require increased resources; the AIDS Policy Coordinator should consult with Congress in its formulation to ensure that its implementation is properly funded.

  If presentation of a plan for a National Prevention Initiative is unreasonably delayed, Congress should exercise a leadership role and enact a suitable framework for this effort. Any such legislation should reflect the fact that (1) such an initiative is, by nature, long-term; (2) flexibility will be needed to modify approaches and targets in the light of the evolving epidemic and knowledge base; (3) integrated planning at the local level should be emphasized; and (4) adequate resources must be appropriated for implementation.

8. **There must be a greater emphasis on improving methods of evaluation and on obtaining high quality evaluation of prevention efforts through CDC-supported HIV/AIDS prevention programs, such as demonstration projects. A realistic plan should be developed that matches the intensity of evaluation needed with the purpose of the activity to be evaluated. In this regard, a need identified to**

the Commission by recipients of small awards is for the recommendation of some indicators and methods of measuring them, whereby the effects of prevention efforts can be roughly estimated simply and cheaply. Appropriations should take into account the need for more attention to evaluation, which should not be at the expense of prevention programs *per se*.

9. Intervention research should be outcome-oriented, but should also investigate motivations, intentions, and barriers in addition to behavior change itself. Studies must be conducted on the effectiveness of prevention strategies with groups of various ages, from various ethnic/cultural backgrounds, and in a wide variety of socio-economic and environmental settings.

Governmental Structures

Neglect and Misunderstanding of Behavioral and Social Science Research

Expert advisory bodies have repeatedly identified the urgent need for more behavioral and social science information to use in understanding, projecting and ameliorating the future course of the HIV epidemic (IOM/NAS, 1986, 1988; NRC, 1989b, 1990; Presidential Commission on the HIV Epidemic, 1988; NCOA, 1991). Historically, however, the behavioral and social sciences have fared poorly for support and have been viewed by some among the NIH AIDS leadership as marginal to the mission of NIH. Moreover, many scientists in biomedically-oriented disciplines fail to appreciate the potential contributions of behavioral and social science research and the increasing sophistication of its techniques, leading to lack of awareness of the usefulness of such research. However, in AIDS, as in other areas, behavioral research has changed the way we can look at problems, as described in the Introduction, and has added to the solutions from which we can choose. Understanding from their previous work the relevance of behavioral and social science disciplines to HIV/AIDS, some of the NIH institutes—such as NICHD—aggressively sought to pursue their AIDS-related behavioral research responsibilities from the outset of the epidemic; others have largely ignored important research questions and activities that would help in confronting the epidemic.

Research on behavior change, related to various other health problems (such as smoking, diet, hypertension, and unintended pregnancy) has been conducted in a variety of NIH institutes, including NCI, NHLBI, and NICHD. Most research related to sexual or drug use behavior change was conducted by the previous ADAMHA research institutes and NICHD. Even with the relative behavioral awareness of the ADAMHA institutes, the value of AIDS-relevant behavioral research was underestimated in many quarters. Chronic under-valuation of AIDS-related behavioral and social science research and the difficulty of stabilizing its supporting infrastructure is tellingly illustrated by an incident reported at a meeting of the Commissioners in May of 1990. Dr. Charles Turner, who was then directing the NRC/NAS committee looking into AIDS behavioral research issues, testified that:

> . . . when the committee went to assemble the available data on drug using behavior, we discovered that an archive had been established to hold all of the data sets on drug using behavior that have been funded by the federal government in the last 10 years. [When] we went to the archive, we discovered the archive had been closed for lack of funding. (Turner, 1990, p. 27)

With the recent relocation of NIAAA, NIMH and NIDA from ADAMHA to the NIH, it becomes especially important to give voice, visibility, and priority to behavioral and social science research activities in the AIDS arena at NIH.

While the bulk of this discussion of governmental structures is restricted to NIH, it should be noted that CDC has supported an applied intervention research agenda in the area of HIV/AIDS for several years. Although it is not the mission of CDC to conduct basic research in the behavioral sciences, it is very important that the agency's work be informed by the best behavioral and social science advice. Thus, one task within the overall work of integrating a behavioral research agenda is the linkage of CDC with intramural and extramural NIH scientists. Elsewhere in this report CDC has been urged to increase the representation of behavioral and social scientists among its permanent staff and management, and to improve its linkage mechanism with the behavioral and social science research community. Once appointed, the new director of the agency is encouraged to consider ways to assign proper authority and structural visibility to the behavioral and social sciences at CDC and promote linkages with NIH and other relevant PHS agencies.

Ensuring Attention to Behavioral Research at NIH

While there has been some progress in the acceptance of the necessity of a strong behavioral research portfolio at NIH, much of this shift in attitude is due to congressional pressure. Congress has repeatedly urged NIH to conduct additional research on the promotion of healthy behaviors and, specifically, on the behavioral prevention of HIV transmission.

Through both the authorization process and the appropriations process for NIH in general, legislative language has been included directing attention to health-related behavior. One way attention has been forcibly directed to behavioral and social science research is by the establishment of special positions to focus on these areas. Currently, the Public Health Service Act includes mandates for Associate Directors for Prevention at the national research institutes on Cancer; Heart, Lung and Blood; and Child Health and Human Development. In addition, several institutes added social and behavioral scientists to their advisory councils after Congress directed them to do so.

Unfortunately, the results of these efforts have been mixed. There has been real success where there are systems in place to reinforce the mandated staff positions. Where there are no behavioral scientists on advisory councils or behavioral science mandates in the institute mission statement, the lack of institutional support fuels a disregard for behavioral research. When advisory councils and those responsible for prevention have been empowered with institutional support and staff, however, significant strides have been achieved.

To date, congressional support for prevention research in general has not greatly increased attention to HIV-related behavioral research at the NIH. Complicating the development of an integrated NIH approach to HIV-related behavioral research is the range of institutes that are involved (Fogarty International Center, NCI, National Center for Nursing Research (NCNR), NIAAA, NIA, NIAID, NICHD, NIDA, NIMH, etc.) and the fact that some of the ones most active in behavioral and social science research (NIAAA, NIDA, and NIMH) have been, until recently, operating under the now-disbanded ADAMHA, which was a separate branch of the Public Health Service. Further compounding the difficulty of integration of the behavioral and social science research agenda into an overall plan is the fact that the institute often regarded as taking the lead in the AIDS research effort, NIAID, has conducted very little behavioral research directly relating to HIV/AIDS, even on the behavioral aspect of drug and vaccine testing and use. The research related to behavioral prevention of STDs other than HIV that NIAID supports is organizationally separated from the HIV/AIDS program and is funded at a relatively low level. The process of developing an integrated NIH-wide behavioral and social science research agenda for HIV/AIDS has barely begun. The Commission called for such an integration in its January 1993 statement on strengthening the NIH Office of AIDS Research.

It appears that one potential impediment to expanding basic behavioral research at NIH is the limitation on personnel numbers. It is suggested that the Director of the Office of AIDS Research, when appointed, examine this issue and propose solutions to problems that may exist. In light of the critical nature of behavioral and social science research to the national response to HIV/AIDS, congressional flexibility in this area is desirable.

Development of the NIH Office of AIDS Research Portfolio

The NIH Revitalization Act of 1993 recently passed by Congress reorganizes the NIH Office of AIDS Research. Among the issues that must be resolved by this newly reorganized office are:

1. whether the areas of research responsibility for HIV/AIDS related work for NIH and each institute are sufficiently clear;
2. whether any intramural or extramural research programs at NIH institutes are duplicative;
3. what should be the appropriate areas for overlap and collaboration in the research mission at NIMH, NIAAA and NIDA relative to NICHD, NIAID or NCI, etc.;
4. how the NIH behavioral and social science mission dovetails with the research and service programs undertaken by other PHS agencies like CDC, HRSA, and the Agency for Health Care Policy Research (AHCPR);
5. whether the overall balance and collaboration between AIDS biomedical and behavioral research at the NIH is appropriate;
6. how to create appropriate coordination of behavioral and social science research across NIH institutes;
7. how to ensure research quality, through systematic review of study design proposals and successful execution through project monitoring, so that resources are used efficiently; and
8. how to most efficiently utilize the existing cadre of behavioral and social science expertise, which is concentrated in certain institutes, across all the areas in NIH where such expertise would be useful, and where new personnel should be added.

As efforts are undertaken to resolve these questions, it is useful to bear in mind Dr. Ehrhardt's comments to the Commission in Austin: "It is of vital importance that behavioral and social science research be strongly reinforced and structurally empowered at the National Institutes of Health" (Ehrhardt, 1993 p. 41).

These issues require a thorough review and evaluation by an independent overseer who is also familiar enough with the programs themselves to grasp relevant detail. Any proposals about solutions, especially if they involve any kind of change in on-going institute activity, must be made by someone who speaks with authority and has some power to ensure enforcement. Many of these questions can and should be addressed in the context of NIH AIDS research strategic planning. Unfortunately, historical precedent suggests that behavioral research issues could be relegated to secondary status in such a process. However, the Commission is encouraged by initial steps taken since the legislation added the three former ADAMHA institutes to NIH. Hiring of a staff person within the Office of AIDS Research with behavioral and social science responsibility, the briefing of the NIH AIDS Program Advisory Committee (APAC) on the three institute's portfolios, presentations to APAC on behavioral research and, inclusion of the behavioral and social science components in the Office of AIDS Research briefings on NIH AIDS activities have served to increase awareness of this part of NIH's AIDS research portfolio. Also welcome is the recent extension to behavioral and social scientists of the loan repayment program for those pursuing AIDS research. In parallel with these preliminary NIH actions on AIDS-related behavioral and social sciences has been emerging attention to health behavioral issues across NIH as a whole.

While the Commissioners place great store in the commitment to behavioral research voiced by the Clinton Administration, it is impossible for the political leaders at the highest level of HHS, or even those in PHS, to monitor in detail the complex processes of the scientific funding enterprise. Only the assignment of senior staff to advocate for, manage, and monitor AIDS behavioral and social science research from within NIH and OAR structures will really achieve the kind of change necessary.

Summary of Recommendations

10. **Because behavioral and social science research on AIDS is currently conducted at various federal agencies and applied by others, including the states, it is critically important that, at a sufficiently high governmental level (e.g., in the office of the AIDS Policy Coordinator), staff resources are devoted to ensuring that the potential contributions of behavioral and social science are fully utilized and coordinated. This has particular relevance in the prevention arena where a comprehensive HIV prevention plan, which must fully integrate behavioral and social science research, is urgently needed. Steps to achieve the goal of increased collaboration among agencies should include a monitoring/advisory mechanism, a comprehensive prevention plan, joint grant-making programs between agencies such as CDC, NIH, SAMHSA, HRSA, and AHCPR, and a mechanism to facilitate collaboration.**

    Such coordination would be best achieved by a centralized office that should also coordinate and monitor programs of the Department of Defense, the Agency for International Development, and other agencies of government that are involved in behavioral, social science, and health research on AIDS. As an ongoing part of this coordination, progress in implementing recommendations made in reports by entities such as the Presidential Commission on the HIV Epidemic, the National Commission on AIDS, the NAS/NRC, and the Institute of Medicine should be assessed.

11. **Behavioral and social sciences should receive appropriate attention and support within the newly reorganized NIH Office of AIDS Research (OAR). To ensure continued emphasis, one or more senior positions with budgeting and planning**

responsibility and authority for behavioral and social science should be established in the Office of AIDS Research. In addition, at least one third of those appointed to the Office of AIDS Research Advisory Council should be behavioral or social scientists. Representatives of NIAID, NIMH, NIDA, NIAAA, NICHD, and other interested institutes should be included on this Advisory Council in an *ex officio* capacity. The categories similar to those identified in the research priorities section of this document should be used for budgeting, planning and structuring NIH/Office of AIDS Research behavioral and social science activities.

Promoting the Best Science and the Best Programs

Threats to AIDS Prevention Research

In its final report, prepared in parallel with this document, the Commission articulated the following as one of seven principles to guide the response to the HIV/AIDS epidemic: "The best science will yield the best public strategies. But the best science cannot flourish where it is blocked or constrained for ideological reasons or political convenience. Nor can it contribute properly where it is underfunded or its lessons are ignored in program designs" (NCOA, 1993, p. 12). The Commission issued this admonition in light of barriers to the acquisition and application of new knowledge that have been raised in the last decade of work on AIDS.

Since the 19th century, the federal government has recognized its responsibility for the conduct of science to promote public health and general welfare. Following its initial forays into science as a means of addressing constitutional responsibilities around human welfare, a notion of federal support for the generation of new knowledge for its own sake has become institutionalized. It has been commonly found that, in due course, beneficial applications of basic science have emerged, even where the exact application could not be predicted at the time of the research.

The pursuit of basic and applied research has been undergirded by an acceptance of the scientific method as the appropriate approach for federal scientific pursuits. Although a tension has existed almost from the outset between, on the one hand, the principle of broad political guidance of the scientific enterprise through the budget process, and the politically unfettered pursuit of scientific knowledge on the other, Congress and the Executive Branch have codified a system that recognizes the value of an independent research enterprise. This system allocates scientific resources and preserves quality by means of peer review by the knowledgeable scientific community, and has worked well in general.

Congress and Executive Branch agencies have periodically substituted ideological and politically convenient decision-making for the established scientific priority-setting process around sensitive, but scientifically legitimate, subjects of research. Congress has sometimes simply substituted its own judgment for a scientific assessment of an individual grant's merit. Such inappropriate substitution has accelerated during the last twenty years. Indeed, during the course of the AIDS epidemic, this substitution has become a regular feature of congressional involvement in the public policy response to this disease. For the first time in the history of federal support of investigator-initiated research, specific research grants reviewed and approved in the peer review process have been defunded, as in the case of the American Teenage Study, a national survey of adolescent sexual behavior canceled by Congress in 1991.

At times, entire areas of inquiry have been placed outside the purview of scientific investigation through budgetary proscriptions, despite the profound value of such investigations to the prevention of HIV disease. General restrictions on the explicitness of subject matter in federally-funded research or prevention programs have also been passed into law. At the Commission hearing in Austin, Dr. Ehrhardt commented that:

> Unfortunately, we have been seriously hampered by false morality and prejudices which have stopped researchers from conducting the large-scale sexual behavior surveys which could provide us with an updated blueprint on which to base our understanding and our predictions of the spread of the epidemic. (Ehrhardt, 1993, p. 34)

Due to the effective organizing by groups with non-scientific biases against certain types of scientific endeavors, research has been crippled in some areas of behavioral and social science. The impact of the infusion of politics into science has been the generation of a significant chilling effect on scientific inquiry, and questions which are regarded as critically important to effective prevention of HIV disease have not been pursued.

Sexual Behavior Research. The highest profile battle between behavioral scientists and their opponents was fought over sexual behavior research. The struggle is not over, and the fate of legitimate and potentially lifesaving scientific inquiry remains unclear.

Until the 1980s, the central development in the history of sexual behavior research in the United States was publication of the Kinsey Reports in the 1940s and 1950s. These studies, unprecedented in their day, provided the major source of data on U.S. sexual behavior until fairly recently.

In the absence of any further comprehensive research, the Kinsey Reports' data were central tools for AIDS epidemiology and prevention efforts in the 1980s. These data, used by CDC, other prevention services agencies, and the research community, served as the basis for estimating the number of men currently engaging in male-to-male sexual activity and in understanding the nature of behaviors which place individuals at risk of contracting HIV. Reliance on the Kinsey data was highly problematic, however; American sexual behavior changed since the 1950s, and profound problems in sampling and methodology made the Kinsey data less than perfect for these public health purposes in the first place.

By the late 1980s, numerous scientific bodies had acknowledged this deficit and urged the federal government to remedy the situation by conducting its own survey. They called for large-scale behavioral research that would seek to collect information about *what* is happening with regard to sexual behaviors and information about *why* it is happening. Such research would provide a range of information needed to address scientific, social, and health concerns. The scientific community affirmed that continued monitoring of these behaviors *is* essential for the effective allocation of resources to public health programs, and for assessing the success of these programs.

But these calls to update potentially lifesaving information met opposition. Imposition of funding restrictions on sexual behavior research (offered in the Senate), coupled with a decision made by then-Secretary of Health and Human Services Louis Sullivan to withdraw funding from an approved study of teen sexual behavior, conveyed the message to researchers that AIDS-related sexual behavior research was taboo. Until the congressional position on this issue was substantially reversed in 1992, NIH-sponsored sexual behavior research was crippled. Recently, the House of Representatives and Senate went on record as supporting sexual behavior research, but the question remains whether NIH now will actively solicit research in this area, and whether researchers will submit new applications. Considerable damage has been done to a research field of critical importance.

Even under the current Administration, significant problems have developed. Earlier this year, the House voted to defund an ongoing NIMH-reviewed and approved study designed to evaluate the effectiveness of telephone counseling as a way of reducing high-risk behavior among those who cannot be reached by face-to-face outreach programs, (because it involved discussing homosexual behavior). Congress must resolve to abandon its micromanaging of the process of scientific priority-setting, and allow potentially lifesaving research to proceed when this is judged scientifically appropriate.

Restrictions on Prevention Efforts

Restrictions on research have been a part of a larger ambivalence, even hostility, toward AIDS prevention in general. The consequence of this is evident; while CDC conservatively estimates that there are likely to be 40,000-80,000 new HIV infections in the coming year, the current scope of federal prevention programming is far from adequate to the job of confronting this threat. While research has shown that vague prevention messages do not yield behavior change, more effective, forthright prevention efforts have been opposed on grounds that are not scientifically supported. Opponents of the more effective approaches to AIDS prevention often have succeeded because of a lack of leadership in the United States.

Since the beginning of the epidemic, prevention has been a highly sensitive issue in the AIDS arena. This is a function of the fact that AIDS prevention must deal directly with issues that some segments of American society find discomforting to discuss, namely drug use and sexuality (including homosexuality and sexuality among young people).

Going back to at least 1987, AIDS prevention efforts have inspired contentious and difficult policy discussions within the U.S. Congress. That year, an amendment was offered on the Senate floor, that if passed, would have prohibited the funding of AIDS prevention programs that "promoted homosexuality." Ever since, there have been similar attempts to muzzle innovative AIDS programming and its scientific assessment.

The specter of male homosexuality has repeatedly been used to circumscribe AIDS prevention efforts. The result has been the development of local community review panels, as mandated by CDC, to avoid "offensiveness" (notwithstanding that effectiveness is a more justifiable standard when lives are at stake). For its part, HHS and its agencies fear congressional wrath if materials or programs become too forthright and, therefore, have undertaken self-censorship.

The electronic entertainment media must also bear some responsibility for thwarting prevention efforts through its censorship of condom advertisements. The Commission notes, and is encouraged by, CDC's intention to shift to a review standard for prevention materials emphasizing technical accuracy and responsiveness to the prevention needs of the target audience (letter by Dr. J. W. Curran, to the Association of State and Territorial Health Officials (ASTHO), July 9, 1993); it looks forward to new guidelines that CDC expects to be published in November 1992, in the hope that these will facilitate effective prevention and education efforts.

In 1989, during Senate consideration of the funding bill for all federal programs, Senate leaders made the first of many successful efforts to restrict bleach or sterile needle distribution to those who continue to inject drugs. Similar prohibitions have remained in various forms and have been incorporated into other legislation, including the annual funding bills adopted by Congress and, more recently, the bill that reauthorized and reorganized ADAMHA. While the current legislative situation allows for research on needle distribution and exchange—an important step forward in the AIDS prevention debate—restrictions on funding for actual programs remain in place.

This chilling climate has frequently been felt in the nexus between AIDS prevention policy, as laid out by the Congress, and AIDS prevention services and research as administered by federal agencies. The most disturbing example of the problems faced in the AIDS prevention arena is a political willingness to deny adequate funding for AIDS prevention in general and, indeed, to institute cuts in the funding of prevention activities. For instance, in 1991, in the face of a mounting epidemic, congressional appropriators cut back AIDS prevention efforts at CDC to $478 million in FY 1992 as compared to $494 million in FY 1991. In this regard, the increase for prevention in the Presidential budget request for FY 1994 is welcome and should be maintained or increased by Congress.

Summary of Recommendations

12. **While Congress has the right and responsibility to address research policy issues and priority setting broadly, it must take steps to ensure the integrity of the scientific peer review processes for the future, and to protect reviewed and approved grants from politically motivated interference.**

    NIH, CDC, and other federal agencies conducting AIDS behavioral and social science research and supporting prevention programs must be allowed to conduct their activities in a climate in which they are unhindered by inappropriate political intrusion, censorship or threats.

13. **Research and services in AIDS must be permitted to be culturally and linguistically relevant to the needs of their intended audiences. Scientists and prevention workers must be free to conduct research or prevention efforts, using the tools, the language, and the methods which are the most appropriate for their purposes.**

Funding

The History of Underfunding for Behavioral Research

Continuing a pattern begun in the late 1970s, the Reagan Administration substantially reduced research funding in the social and behavioral sciences in the early 1980s, undermining their already fragile base. These cutbacks had an extremely damaging impact on entire fields of research which must now inform the battle against AIDS. Support of research was drastically curtailed in areas such as sexual behavior, the socio-cultural context of drug use, and the role of discrimination and prejudice in determining public health and social policy. Research applications that proposed to address individual, social, or cultural determinants which were placing Americans at risk for HIV infection came to be seen as outside the appropriate purview of federal support.

With the stark realization of the scope of the AIDS epidemic, policy makers were forced to reexamine the views that previously—and inappropriately—determined the parameters of useful social science research. During Commission hearings in New Orleans on sexual behavior research, Dr. John Gagnon, from the State University of New York at Stony Brook, talked about the "empty cupboard" of sexual behavior research which greeted the public health community in their initial efforts to deal with the emerging AIDS crisis. "There had not been any consistent record of [sexual behavior] research," he said. "Much of the research . . . was against the grain [of funding trends]. There had been . . . a disinvestment in sex research over the prior two decades" (Gagnon, 1992, p.35).

In 1986, the Institute of Medicine-National Academy of Sciences (IOM/NAS), in its landmark study, *Confronting AIDS*, observed that,

> . . . the forces that shape human behavior, and the best approaches to influencing behavior to protect health, are among the most complex and poorly understood aspects of society's response to the AIDS epidemic. It is instructive to note that virologic research, having received reasonable levels of funding over the years, was well poised to begin addressing the many biological problems posed by HIV. In contrast, the knowledge base in the behavioral and social sciences needed to design approaches to encouraging behavioral change is more rudimentary because of chronic inadequate funding. This lack of behavioral and social science research generates some of the most important and immediate research questions surrounding the epidemic. (IOM/NAS, 1986, pp. 230-231)

Little was done, however, in the years immediately following to redress the prior neglect. Fortunately, there are some signs that real steps may be taken to reverse this decline. As Dr. Fishbein noted during the Commission hearings, ". . . we are now in a position where some of the blocks, certainly the political climate, has changed. There is some optimism that things can be done, that more direct messages will come out" (Fishbein, 1993, p. 43).

Public pronouncements from the highest level of government confirm this change in direction. A transition report prepared by a number of individuals connected with the then-incoming Clinton Administration declared that "Ignorance is not social policy." The authors of this report, *Changing America: Blueprints for the New Administration*, recognized the need for much more social science research to fuel the fight against AIDS, stating that, "the Administration must base its efforts [in AIDS] on good social science . . . only government can fund such research" (Green, 1992). President Clinton, when he was a candidate for the presidency, responded to the call. His white paper on AIDS promised that, "my administration will increase funding for behavioral and social science research so that we can better understand the behaviors that put people at risk for HIV." During hearings before the House Energy and Commerce Committee earlier this year, Dr. Donna E. Shalala, the new Secretary of HHS, noted her support for sexual behavior research.

Funding for AIDS Behavioral Research at NIH

Despite the restrictive climate, by the end of the 1980s some congressional leaders and officials in the Executive Branch had begun a process of supporting important behavioral and social science research that would help to answer significant questions about AIDS. When plans were made public, however, they became the targets of criticism, and studies were often prohibited through legislative action. Thus, while some support was directed at important behavioral questions, funding levels overall were far lower than necessary given the importance and urgency of understanding risk behavior properly.

One of the major difficulties in grappling with the issue of the appropriate level of support for AIDS behavioral research is that there is no system for tracking AIDS behavioral research in place at NIH. The amorphous nature of the definition used for behavioral and social science research causes further difficulty, and the definition of what constitutes behavioral research is not clearly spelled out. To make matters worse, the term prevention often has been substituted for behavioral research. For instance, prevention-oriented research on the molecular action of a potential AIDS vaccine is obviously not behavioral research, yet it is prevention research.

Although some would argue that AIDS behavioral research is well-enough served at NIH, this assessment does not stand under close scrutiny. In FY 1992, the last year for which a full accounting is available, the overall NIH budget (including those institutes previously part of ADAMHA) was $10 billion. Of that, approximately eight percent, or $782 million, went to behavioral and social science research according to an analysis by the Consortium of Social Science Associations (COSSA). The AIDS research budget for NIH in FY 1992 was approximately $1 billion (including the previous ADAMHA institutes). A recent NIH Office of AIDS Research survey on funding for AIDS behavioral research at NIH, reported that AIDS behavioral research in FY 1992 totaled $142 million, or 13.5 percent of the total AIDS research dollars at NIH. The survey found, disturbingly, that this funding was concentrated in institutes that only recently rejoined NIH.

Last year, Congress passed legislation that incorporated the former ADAMHA institutes—NIMH, NIDA, and the NIAAA—into NIH. The behavioral research expenditures identified in the Office of AIDS Research survey were substantially increased by the inclusion of the former ADAMHA research institutes into the NIH picture. If the figures did not include the ADAMHA institutes' budgets, only $10 million (or one percent of the overall NIH AIDS research budget) was spent in FY 1992 on AIDS behavioral research.

The AIDS behavioral research portfolio can also be estimated by using the so-called "Mason categories," a system of AIDS budgeting for the entire Public Health Service developed during the tenure of former Assistant Secretary for Health James Mason. Using figures based on the categories from this algorithm, AIDS behavioral research at NIH in FY 1992 was funded at $125 million, or 12 percent of the total. The Mason categories also provide an historical baseline for assessment. For FY 1989 and FY 1990, funding of the behavioral research category at NIH was nine percent of the AIDS total at NIH. In FY 1991, this percentage increased to 12 percent, a figure that has more or less held for the subsequent two fiscal years. (For ease of comparison with FY 1992 figures above, these calculations include those institutes recently returned to NIH).

The issue of exactly what constitutes behavioral research continues to plague efforts at specificity. Official documents show that there is considerable variation in the kinds of research included in these categories. For FY 1992, the Mason category for behavioral research was $125 million, yet the retrospective survey conducted by the Office of AIDS Research identified a figure of $142 million.

This discrepancy can be partly accounted for by the methods of analysis. Some reports reflect budget totals, rather than individual grants, in branches or divisions which conduct behavioral and social science research; thus, some grants which are funded by a so-called behavioral branch are in fact biomedically-oriented, though they will be counted as behavioral dollars. Conversely the figure based on the Mason Categories for behavioral research does not include behavioral research within projects that are placed in other categories.

Balancing Research Portfolios

Given that transmission of HIV is overwhelmingly an issue of individual behavior and the social and cultural factors that influence it (unlike many of the problems NIH studies overall), the amounts and percentages spent on behavioral and social science research seem unreasonably low when compared to biomedical expenditures. The fact that the 13 percent figure is attained only by the addition of the former ADAMHA institutes is cause for considerable concern. Critical headway has been made by certain NIH institutes in identifying the highest risk behaviors and the risk factors for initiation of such behavior, in the investigation of mental health issues, in the development and evaluation of new interventions. These institutes should be commended for their leadership in moving forward on this agenda during a difficult political era. But many other NIH institutes conducting AIDS research have legitimate and important roles to play in advancing the behavioral and social science knowledge base relevant to HIV transmission and disease.

The NIH Office of AIDS Research and the leadership of NIH must recognize, through their allocation of financial resources, the importance of behavioral and social science research in the context of the epidemic. The budget submitted by President Clinton for FY 1994, is recent evidence that this kind of priority has not been recognized. Overall, the President has requested approximately a $200 million increase for AIDS research in FY 1994. However, institutes that have traditionally done the bulk of behavioral and social science research fared poorly in relative increases. The Commission believes that expenditures on this critical facet of the nation's response to the epidemic should be increased substantially but not to the detriment of other areas.

Summary of Recommendations

14. **The current levels of support for behavioral and social science activities on AIDS in each PHS agency should be accurately assessed, and detailed plans should be made to integrate behavioral and social science research into each component of the federal AIDS prevention and treatment effort.**

15. **Financial support for behavioral and social science research on AIDS at NIH should be increased overall by approximately 10 percent annually above the inflationary index over the next five fiscal years.**

    The Commission recognizes the need for increased behavioral and social science research efforts at NIH and suggests an overall specific funding target in order to determine whether real progress is being made. The target should be set in terms of absolute funding because funds should not be withdrawn from other critical areas in order to increase the percentage applied to behavioral and social sciences. The new Office of AIDS Research Director should assess where increases should be applied, after responsibilities are assigned for an integrated research plan.

16. **NIH support for interdisciplinary research should also be increased. It is imperative that behavioral and social science become more fully integrated into the biomedical AIDS research conducted and supported throughout the agency.**

Cumulative Recommendations

1. **The National Commission on AIDS believes it is critically important to immediately make effective use of behavioral and social science knowledge in the national response to the HIV/AIDS epidemic. It is also necessary that this knowledge base be expanded. The Commission calls for the behavioral and social sciences to be properly integrated into the mainstream of the HIV/AIDS response in the United States.**

   To highlight neglected fields and to emphasize the breadth of relevant information, this report identifies some priority areas within behavioral and social science research on AIDS. The central concern of the Commission, however, is not establishing research priorities. Rather the objective is that from this point onward, behavioral and social sciences play an appropriate and central role in the overall battle against AIDS through expanded research and its application. In many cases, only multidisciplinary efforts will produce the comprehensive information required by HIV prevention workers and care providers. Greater inclusion of behavioral and social scientists at policy formulation, and research and program management levels of PHS is required

   We must employ all available tools to thwart the AIDS epidemic. As the Ninth International Conference on AIDS held in Berlin, in June 1993, made clear, equivocating about such action in the hope of near-term 'magic bullets' would be foolhardy.

2. **For the critical task of reducing HIV transmission, substantial increases in resources for prevention, specifically for behavior change interventions and behavioral and social science research, must be requested by the Administration and/or appropriated by Congress.**

   The level appropriations for prevention and prevention research in recent years have—in the face of an expanding epidemic—left a 'prevention gap' and substantial increases in resources for prevention will be needed over the next few years to catch up. Increases for prevention must not be to the detriment of research or services that will benefit persons with HIV infection.

3. **Research should be expanded in the following behavioral and social science categories:**
   A. ***Behavioral epidemiology,* which seeks to establish the prevalence and determinants of risk behaviors. For example, it remains to be determined to what extent, nationally, young gay men are failing to adhere to the norms of safer sex that some older gay populations have established.**
   B. ***Cognitive science,* which employs field studies and laboratory investigations to understand cognitive processes and social psychology, and their relationship to behavior. We need to know more about the antecedents and determinants of sexual intercourse and drug use behavior. We need to get to the specifics**

of such behaviors, i.e., which factors (such as peer pressure, etc.) carry the most weight in determining values, attitudes, and actual behavior, so that we can design interventions to target the critical variables.

C. *Cultural and ethnographic studies,* which investigate determinants of behavior within varying cultural groups. For example, we need to conduct the research needed to clarify the meaning of concepts such as risk, health, and personal responsibility to those who have an elevated risk of HIV infection. Cultural and ethnographic studies will not only help tell us what to target in interventions for different groups but can also help in ensuring that interventions are culturally sensitive and delivered through appropriate channels. For example, designing the most attention-grabbing and memorable stimuli possible for social marketing of condoms, or countering stigmatization and discrimination, in different populations.

D. *Intervention research,* which employs controlled designs to judge the relative effectiveness of various theory-based intervention strategies. For example, we have not, as yet, pinpointed the elements in prevention programs for young adolescents that are necessary and sufficient to delay the age of first sexual intercourse, and to foster early and consistent use of barrier methods of contraception/disease prevention when intercourse is initiated. Research into the most effective risk reduction strategies among sexual partners of at-risk drug users is also a significant unmet need.

E. *Mental health research,* which strives to understand and intervene in stress, coping, substance abuse, and other psychopathologies in order to preserve the well-being of those with, or at risk of, HIV infection.

F. *Behavioral aspects of technological interventions,* an area which seeks to determine the non-medical factors influencing utilization of 'technological' medical intervention. It is critically important to assess the ways we can get the maximum benefit out of existing and future agents (such as drugs, vaccines, or condoms) by ensuring they are used properly. Clinical trials of vaccines and other therapeutics would be greatly improved by research on the inclusion and retention of people of color and women into these trials. In addition, we need interdisciplinary studies on the development and use of female-controlled prevention methods. Such studies should recognize that insistence by some women on condom use for HIV and STD protection may be extremely difficult if not impossible, due to such factors as the threat of violence or sexual abuse. Behavioral utilization studies should be an early part of product research and development.

G. *Organizational studies,* which seek to understand the dynamics of organizational life and the interaction between individuals and organizations. For example, a major unmet need is identifying effective means of volunteer recruitment, staff retention and burnout prevention among health care providers and workers in AIDS organizations.

4. CDC's HIV/AIDS prevention efforts, including public health education, epidemiological training, and service programs, need to more fully take into account knowledge from behavioral and social science research. While CDC has made strides to recruit more behavioral scientists over the past several years, it

still must do more to infuse its programs with those trained in the behavioral sciences, who should be vested with significant policy-making responsibility and authority. Moreover, CDC should endeavor to promote a more behaviorally-oriented methodology and theoretical framework in the prevention efforts it supports. Collaboration with NIH agencies supporting basic and applied behavioral and social science research should be strengthened.

5. **There is a pressing need to recruit and train more individuals from racial and ethnic minorities, more women, and those already involved in community-based AIDS prevention and services delivery as researchers. In addition to current post-doctoral opportunities, federal agencies should facilitate HIV-related research training efforts within graduate programs, develop practicum and field placement approaches, and provide career research awards.**

6. **Technology transfer and feedback between behavioral and social science research and prevention efforts must be improved, increased, and accelerated. There must be greater collaboration and cooperation between researchers and their nonresearcher counterparts working in AIDS prevention. To achieve this, strong linkages should be established so that researchers and prevention workers (e.g., NIH, CDC, HRSA, and SAMHSA grantees) come together to facilitate both prevention and treatment effectiveness and the conduct of research.**

   A variety of mechanisms can promote such linkages, and should include joint grants, workshops and the development of an interagency infrastructure that fosters collaboration; a national conference should be considered. Ethnic minority and women's health organizations should be included in formulating the research agenda. Agencies supporting prevention research and prevention programs have a responsibility to synthesize and disseminate the conclusions that can be drawn from work they support more systematically than has been done to date.

7. **A plan for a National Prevention Initiative should be formulated. It should embrace the following:**
   - **Improved prevention planning must be a central element of a restructured national HIV prevention effort. Federal, state, and local government agencies and community-based organizations involved in AIDS prevention efforts must join together to develop comprehensive plans for the delivery of HIV prevention services to individuals, communities and the population in general.**
   - **Prevention resources should follow the epidemiology of HIV transmission and risk behavior. Where it is impossible to determine current rates of new HIV infection, surrogate markers for risk behavior (such as sexually transmitted diseases, like hepatitis B, unintended pregnancy, and injection drug use) should be used for the allocation of resources. All groups in which risk behavior occurs should be targeted by prevention programs.**
   - **Prevention programs should reflect the best and most current knowledge generated from behavioral and social science research about AIDS-related behavior change.**
   - **A key element of any kind of prevention reform must be greater involvement in the allocation of resources to prevention programs by those who are**

intended to benefit from them. Only by allowing local communities to assess their own local needs will such resources be appropriately targeted.

Local community groups and agencies representing populations at risk for HIV disease and persons with HIV who have been disenfranchised from funding allocations in the past, such as those serving women and racial/ethnic populations, must be included in the planning and decision-making process around HIV/AIDS prevention.

- **Prevention materials must include frank and explicit messages about how to stem the transmission of HIV, including culturally-sensitive and specific language and/or vernacular directed at targeted population groups.**
- **Technical assistance to local communities designing and delivering AIDS prevention programs must be provided by behavioral and social scientists experienced in preventive interventions.**
- **Careful consideration of the findings of the external review to which CDC is presently subjecting five of its HIV/AIDS program areas.**

The Commission recognizes that much of the necessary reorganization and expansion of AIDS prevention efforts can be accomplished through administrative and regulatory actions. The newly-appointed National AIDS Policy Coordinator should give high priority to rapidly formulating a plan for a National Prevention Initiative and making any administrative changes it requires. A vigorous national prevention effort will require increased resources; the AIDS Policy Coordinator should consult with Congress in its formulation to ensure that its implementation is properly funded.

If presentation of a plan for a National Prevention Initiative is unreasonably delayed, Congress should exercise a leadership role and enact a suitable framework for this effort. Any such legislation should reflect the fact that (1) such an initiative is, by nature, long-term; (2) flexibility will be needed to modify approaches and targets in the light of the evolving epidemic and knowledge base; (3) integrated planning at the local level should be emphasized; and (4) adequate resources must be appropriated for implementation.

8. **There must be a greater emphasis on improving methods of evaluation and on obtaining high quality evaluation of prevention efforts through CDC-supported HIV/AIDS prevention programs, such as demonstration projects. A realistic plan should be developed that matches the intensity of evaluation needed with the purpose of the activity to be evaluated. In this regard, a need identified to the Commission by recipients of small awards is for the recommendation of some indicators and methods of measuring them, whereby the effects of prevention efforts can be roughly estimated simply and cheaply. Appropriations should take into account the need for more attention to evaluation, which should not be at the expense of prevention programs *per se*.**

9. **Intervention research should be outcome-oriented, but should also investigate motivations, intentions, and barriers in addition to behavior change itself. Studies must be conducted on the effectiveness of prevention strategies with groups of various ages, from various ethnic/cultural backgrounds, and in a wide variety of socio-economic and environmental settings.**

10. **Because behavioral and social science research on AIDS is currently conducted at various federal agencies and applied by others, including the states, it is critically important that, at a sufficiently high governmental level (e.g., in the office of the AIDS Policy Coordinator), staff resources are devoted to ensuring that the potential contributions of behavioral and social science are fully utilized and coordinated. This has particular relevance in the prevention arena where a comprehensive HIV prevention plan, which must fully integrate behavioral and social science research, is urgently needed. Steps to achieve the goal of increased collaboration among agencies should include a monitoring/advisory mechanism, a comprehensive prevention plan, joint grant-making programs between agencies such as CDC, NIH, SAMHSA, HRSA, and AHCPR, and a mechanism to facilitate collaboration.**

    Such coordination would be best achieved by a centralized office that should also coordinate and monitor programs of the Department of Defense, the Agency for International Development, and other agencies of government that are involved in behavioral, social science, and health research on AIDS. As an ongoing part of this coordination, progress in implementing recommendations made in reports by entities such as the Presidential Commission on the HIV Epidemic, the National Commission on AIDS, the NAS/NRC, and the Institute of Medicine should be assessed.

11. **Behavioral and social sciences should receive appropriate attention and support within the newly reorganized NIH Office of AIDS Research (OAR). To ensure continued emphasis, one or more senior positions with budgeting and planning responsibility and authority for behavioral and social science should be established in the Office of AIDS Research. In addition, at least one third of those appointed to the Office of AIDS Research Advisory Council should be behavioral or social scientists. Representatives of NIAID, NIMH, NIDA, NIAAA, NICHD, and other interested institutes should be included on this Advisory Council in an *ex officio* capacity. The categories similar to those identified in the research priorities section of this document should be used for budgeting, planning and structuring NIH/Office of AIDS Research behavioral and social science activities.**

12. **While Congress has the right and responsibility to address research policy issues and priority setting broadly, it must take steps to ensure the integrity of the scientific peer review processes for the future, and to protect reviewed and approved grants from politically motivated interference.**

    NIH, CDC, and other federal agencies conducting AIDS behavioral and social science research and supporting prevention programs must be allowed to conduct their activities in a climate in which they are unhindered by inappropriate political intrusion, censorship or threats.

13. **Research and services in AIDS must be permitted to be culturally and linguistically relevant to the needs of their intended audiences. Scientists and prevention workers must be free to conduct research or prevention efforts, using the tools, the language, and the methods which are the most appropriate for their purposes.**

14. **The current levels of support for behavioral and social science activities on AIDS in each PHS agency should be accurately assessed, and detailed plans should be made to integrate behavioral and social science research into each component of the federal AIDS prevention and treatment effort.**

15. **Financial support for behavioral and social science research on AIDS at NIH should be increased overall by approximately 10 percent annually above the inflationary index over the next five fiscal years.**

    The Commission recognizes the need for increased behavioral and social science research efforts at NIH and suggests an overall specific funding target in order to determine whether real progress is being made. The target should be set in terms of absolute funding because funds should not be withdrawn from other critical areas in order to increase the percentage applied to behavioral and social sciences. The new Office of AIDS Research Director should assess where increases should be applied, after responsibilities are assigned for an integrated research plan.

16. **NIH support for interdisciplinary research should also be increased. It is imperative that behavioral and social science become more fully integrated into the biomedical AIDS research conducted and supported throughout the agency.**

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APPENDIX A: Hearing Agendas

(Panel participants listed alphabetically)

HIV/AIDS Research: Clinical Trials
Washington, DC
May 7-8, 1990

May 7

National Academy of Sciences Overview

Samuel O. Thier, M.D., President, Institute of Medicine, Washington, DC

Charles Turner, Ph.D., Director, Committee on AIDS Research and the Behavioral, Social, and Statistical Sciences, National Research Council, Washington, DC

Robin Weiss, M.D., Director, AIDS Activities, Institute of Medicine, Washington, DC

Drug Development and Approval Overview

Ellen C. Cooper, M.D., M.P.H., Director, Division of Antiviral Drug Products, Food and Drug Administration, Rockville, MD

John C. Petricciani, M.D., Vice President, Medical and Regulatory Affairs, Pharmaceutical Manufacturers Association, Washington, DC

Gerald Quinnan, M.D., Deputy Director, Center for Biologics Evaluation and Research, Food and Drug Administration, Rockville, MD

Joel Solomon, Ph.D., Director, Division of Blood and Blood Products, Center for Biologics Evaluation and Research, Food and Drug Administration, Rockville, MD

National Institutes of Health Overview

Anthony S. Fauci, M.D., Director, Office of AIDS Research, National Institutes of Health, Bethesda, MD

Janet Heinrick, Dr.P.H., R.N., Director, Division of Extramural Programs, National Center for Nursing Research, Bethesda, MD

Philip A. Pizzo, M.D., Chief of Pediatrics, Head, Infectious Disease Section, National Cancer Institute, Bethesda, MD

Community Needs and Perspectives

John Caldwell, Project Inform, San Francisco, CA

Jim Eigo, M.F.A., ACT UP, New York, NY

Luis Hernandez, Outreach Assistant Coordinator, Community Research Initiative, New York, NY

Rosa Martinez, Pediatric AIDS Advocate, Tampa, FL

Neil Schram, M.D., Chair, AIDS Task Force, American Association of Physicians for Human Rights, San Francisco, CA

Sonia Singleton, Community Outreach Education and Prevention, Inc., Miami, FL

May 8

Scientific and Care Community

Donald I. Abrams, M.D., Chair and Principal Investigator, Community Consortium, San Francisco General Hospital, San Francisco, CA

Gerald Friedland, M.D., Professor of Medicine, Epidemiology and Social Medicine, Albert Einstein College of Medicine, New York, NY

Cecelia Hutto, M.D., Assistant Professor of Infectious Diseases and Immunology, Department of Pediatrics, University of Miami School of Medicine, Miami, FL

Mathilde Krim, Ph.D., Co-Chair, Committee on Research, National Organization Responding to AIDS, New York, NY

Janet L. Mitchell, M.D., M.P.H., Chief of Perinatology, Department OB-GYN, Harlem Hospital Center, New York, NY

Ronald Sable, M.D., Co-Founder, AIDS Program, Cook County Hospital, Chicago, IL

Amy Simon-Kramer, R.N., M.P.A., National Hemophilia Foundation, New York, NY

George Perez, M.D., Medical Director, North Jersey Community Research Initiative, Newark, NJ

Melanie Thompson, M.D., President, AIDS Research Consortium of Atlanta, GA

Research and Demonstration Projects

Patricia McInturff, M.P.A., Director, Regional Division, Seattle-King County Department of Public Health, Seattle, WA

Anita Vaughn, M.D., Medical Director, Newark Community Health Centers, Inc., Newark, NJ

John K. Watters, Ph.D., Assistant Adjunct Professor, Department of Epidemiology and Biostatistics, University of California, San Francisco, CA

Adolescents and the HIV Epidemic
Chicago, Illinois
March 13, 1991

Opening Remarks - June E. Osborn, M.D.

Roundtable Discussion: Youth Issues

Susan Castillo, Youth Advocates Teen HIV Program, San Francisco, CA

Anthony Dekker, D.O., Chicago College of Osteopathic Medicine, Chicago, IL

DiAna DiAna, South Carolina AIDS Education Network, Columbia, SC

Mindy T. Fullilove, M.D., New York State Psychiatric Institute and Columbia University, New York, NY

Donna Futterman, M.D., Montefiore Medical Center, New York, NY
David Kamens, Washington, D.C.
Frances Kunreuther, Hetrick-Martin Institute, New York, NY
Su Neuhauser, M.A., Office of AIDS Prevention, Chicago, IL
Jackie Sadler, M.P.H., D.C. Public Schools HIV/AIDS Education Program, Washington, D.C.
S. Kenneth Schonberg, M.D., Montefiore Medical Center and Albert Einstein College of Medicine, New York, NY

Youth Panel

Overview
Margaret C. Heagarty, M.D, Columbia University, Harlem Hospital Center, New York, NY

Health Care Issues/Medical Dilemmas
Margaret C. Heagarty, M.D.
Sheila Swain, Jefferson, IA
Hermann Mendez, M.D., SUNY Health Sciences at Brooklyn, New York, NY
Janie Eddy, R.N., Children's National Medical Center, Washington, D.C.
Elizabeth C. Gath, M.D., Cook County Hospital, Chicago, IL

Social/Family Issues
Barbara J. Sabol, R.N., New York City Department of Human Resources, New York, NY
Joan McCarley, M.S.W., Terrific Inc., Grandma's House, Washington, D.C.
Ana Garcia, L.C.S.W., University of Miami School of Medicine, Miami, FL
Toni P., Person Living with AIDS
Dottie Ward-Wimmer, R.N., Children's National Medical Center, Washington, D.C.

Sex, Society and the HIV Epidemic
New Orleans, Louisiana
May 18-19, 1992

May 18

Sheila Webb, Louisiana Mayor's Office, Baton Rouge, LA

Toward A National Prevention Strategy
Thomas J. Coates, Ph.D., Director, The Center for AIDS Prevention Studies, San Francisco, CA

Research on Sexual Behavior: Implications for the HIV Epidemic
John H. Gagnon, Ph.D., State University of New York at Stony Brook, New York, NY

Culture, Ethnicity and Gender in Sex Research
Vickie M. Mays, Ph.D., Department of Psychology, University of California, Los Angeles, CA

May 19

Sex, Society, and HIV
Priscilla Alexander, Global Programme on AIDS, World Health Organization, Geneva, Switzerland
Richard Green, M.D., J.D., University of California, Los Angeles, School of Medicine, Los Angeles, CA
John Money, Ph.D., Johns Hopkins University and Hospital, Baltimore, MD
Jose Pares-Avila, M.A., Clinical Psychology Fellow, Harvard Medical School, Boston, MA
Carole Vance, Ph.D., M.P.H., Columbia University School of Public Health, New York, NY

Adolescents and Sexuality
Tim Haas, Person Living with AIDS
Robert Selverstone, Ph.D., Board Member, Sex Information and Education Council of the U.S. (SIECUS), New York, NY
Walter Shervington, M.D., Assistant Secretary for Mental Health, State of Louisiana, Baton Rouge, LA
Pedro P. Zamora, The Body Positive Resource Center, Inc., Miami, FL

Communications and the HIV Epidemic
Kansas City, MO and Kansas City, KS
June 15-16, 1992

June 15

What is Communication and Why is it Relevant to the Epidemic?
Mary D. Fisher, The Family AIDS Network, Boca Raton, FL
Robert Hornick, Ph.D., Annenberg School of Communication, University of Pennsylvania, Philadelphia, PA

How are the Public Perceptions on HIV and AIDS Shaped?
Mary Debus, Porter/Novelli, Washington, DC
Charles Eisendrath, M.A., University of Michigan, Ann Arbor, MI
Rita Lepicier, Executive Director, KCET Television, Los Angeles, CA
Theresa F. Rogers, Ph.D., Barnard College with Columbia University, New York, NY
Stephen B. Thomas, Ph.D., University of Maryland, College Park, MD

What is the Role of Communication in Primary Prevention?
Rashidah Hassan, R.N., Executive Director, BEBASHI, Philadelphia, PA
Ernesto Hinojos, M.P.H., Gay Men's Health Crisis, New York, NY
Jay T. Johnson, E.D., M.S.W., Topeka AIDS Project, Topeka, KS
Frederick C. Kroger, National AIDS Information and Education Program, Centers for Disease Control, Atlanta, GA
Michael Ramah, Porter/Novelli, AIDSCOM, Washington, DC

June 16

Honorable Joan Finney, Governor of Kansas

Care-Oriented Communication Issues
Mike Barr, AIDS Center, St. Vincent's Hospital, New York, NY
Lawrence S. Brown, M.D., M.P.H, Addiction Research and Treatment Corporation, Brooklyn, NY
John S. James, AIDS Treatment News, San Francisco, CA
Elena Perez, B.A., M.T, Center for Continuing Education in the Health Profession, Newark, NJ
Rochelle L. Rollins, M.P.H., Multi-Cultural AIDS Coalition, Boston, MA
Leonard A. Simpson, M.D., American Association of Physicians for Human Rights, San Francisco, CA

Prevention Strategies in the Workplace and Schools: Current Challenges
Austin, TX
March 10-11, 1993

March 10

Welcoming Remarks
David R. Smith, M.D., Texas Commissioner of Health, Texas Department of Health, Austin, TX

Behavioral Research and AIDS Prevention: Using the Workplace and Schools
Anke Ehrhardt, Ph.D., American Psychological Association, Washington, DC
Martin Fishbein, Ph.D., Professor of Psychology, University of Illinois, Urbana-Champaign, IL

The CDC's Role in Prevention Education in the Workplace and Schools
James W. Curran, M.D., M.P.H., Centers for Disease Control and Prevention, Atlanta, GA

AIDS and the Workplace
Sandy Bartlett, Coordinator, Central Texas AIDS in the Workplace Task Force, Austin, TX
Erline Belton, The Lyceum Group, Cleveland, OH

Jerald A. Breitman, Director, Professional Relations, Burroughs Wellcome Co., Research Triangle Park, NC

Carol Camlin, Manager, AIDS Education at Work, AIDS Action Committee, Boston, MA

Sharon F. Canner, Assistant Vice President, National Association of Manufacturers, Washington, DC

Alan Emery, Ph.D., Consultant, San Francisco, CA

Ledia Martinez, M.D., M.P.H., Office of HIV/AIDS Education, American Red Cross, Washington, DC

Brenda Moon, The George Meany Center for Labor Studies, Washington, DC

Barney Singer, J.D., Assistant Chief Counsel for Labor Policy, Small Business Administration, Washington, DC

B.J. Stiles, President, National Leadership Coalition on AIDS, Washington, DC

Benneville N. Strohecker, President, Harbor Sweets, Inc., Salem, MA

March 11

Welcoming Remarks

Honorable Glen Maxey, Representative, State of Texas

School and Youth Prevention Strategies

Kate Barnhart, Student, New York City Public Schools, Manhattan, NY

Jay Coburn, B.S., Director, Training and Technical Assistance, Center for Population Options, Washington, DC

Joanne G. Fraser, Ed.D., Director, HIV/AIDS School Health Education Project, South Carolina Department of Education, Columbia, SC

Marion Howard, Ph.D., Clinical Director, Teen Services Program, Grady Memorial Hospital, Atlanta, GA

Marvin Jeter, Teacher Living with AIDS

Gene Wilhoit, Executive Director, National Association of State Boards of Education, Alexandria, VA

Presentation by ACTT (Active Community Teen Theater), McAllen, TX