TITLE

By June E. Osborn, M.D. and

David E. Rogers, M.D.

The National Commission on AIDS was created by Federal statute in 1989. Its major legislative mandate was to provide ongoing oversight of the nation's involvement in the HIV epidemic and to report on the response to the President, the Congress and the American people. We have issued public statements when particular AIDS policy issues have taken on national importance.

The time to speak out has come again. Recently two issues have risen again which threaten to divide us as we move into the 13th year of the HIV epidemic. They are deceptively simple:

1) Should HIV prevention programs be narrowly targeted towards those certain "at risk" groups or should prevention programs focus more broadly on the universality of risk among all people?

2) Since drug use is now linked to more than one-third of all new HIV infections, how aggressively should we move into syringe exchange programs, both as one way of reducing HIV transmission, and as a bridge to move more people into drug abuse treatment programs?

These two questions have reemerged in part because of the interpretation stemming from the National Research Council's February, 1993 report, *The Social Impact of AIDS in the United States*, and the more recent General Accounting Office report, *Needle Exchange Programs; Research Suggests Promise as an AIDS Prevention Strategy*, released in March, 1993.

The NRC report, which has caused the most controversy, has been seen as a rationale for deemphasizing a national prevention strategy in favor of prevention efforts targeted at a relative handful of identifiable neighborhoods or behavior "groups." Emotions were triggered by sections of the report such as one that said "the limited responsiveness of institutions can in part be explained because the absolute numbers of the epidemic, relative to the U.S. population, are not overwhelming, and because U.S. social institutions are strong, complex, and resilient. However, we believe that another major reason for this limited response is the concentration of the epidemic in socially marginalized groups." From this was drawn the conclusion that the AIDS epidemic could be nearly completely contained by treating it less as a national event and more as a localized problem calling for intensive prevention programs focused in a relatively small number of "marginalized" communities where infection rates are high.

~~The National Commission~~ We take~~s~~ serious issue with that view. We feel that a fake message would be conveyed, that is the vast majority of people outside those specific neighborhoods could "deny" the epidemic's threat, ignore the need for their own preventive actions, and thus accelerate the virus' spread through all segments of society. Although clearly not the intent of the NRC, the "marginalization" theory sets up a number of problems, not the least of which is the strong implication that some among us are less worthy. This interpretation of the report let many readers conclude that HIV/AIDS will disappear into the socially invisible substrata of society. It is difficult to describe what a devastating impact that cruel inference had on those living with HIV, their families and loved ones.

Such a view has intensified widespread denial by the general public and has threatened to move HIV/AIDS further off the national agenda of critical issues. For the National Commission on AIDS, which has been struggling for more than a decade to improve public policy with respect to this massive epidemic, the report was a truly painful setback. Prejudice against those with HIV has always been a major barrier to progress in all aspects of epidemic response. Stereotyping of people living with HIV -- "us" against "them" -- again raises this barrier.

Throughout the world, denial has been a predictable early response to AIDS. Twelve years into the epidemic, one would think Americans, at least, would have gotten beyond that stage. The number of new diagnoses each year is greater than the number of paralytic cases in the worst of those frightful summers of epidemic poliomyelitis before the vaccine. Yet for AIDS, no vaccine is in sight and HIV is *not* under control.

To turn to the second issue:

After the National Commission on AIDS released its July, 1991 report entitled *The Twin Epidemics of Substance Use and HIV,* Representative Charles Rangel of New York, who was chairman of the House Select Committee on Narcotics Abuse and Control requested GAO to conduct the study of needle exchange cited above. The Commission report had recommended that drug abuse treatment slots be made available to all who apply, and that "legal barriers to the purchase and possession of injection equipment" be removed as one way to help break the chain of HIV transmission among injection drug users.

The Commission's own analysis had two important findings; first, that needle exchange programs did not lead to more drug use and, second, that they did result in behavior change likely to lead to reduced transmission of HIV.

The conclusions of the GAO report generally concurred with both of those assertions after their audit of more than 800 research and abstract citations as well as specific review of the studies of numerous independent needle exchange programs in the United States and five foreign countries. The GAO report said "most projects suggest that programs do not increase injection drug use," and that "some research suggests programs may reduce AIDS-related risk behavior."

Despite these results, Rep. Rangel maintained his opposition to needle exchange. In a statement following his release of the GAO report, he said, "As an elected official, I cannot condone my government telling communities ravaged by the twin epidemics of drugs and AIDS that clean needles are the best we can do for you." The Commission shares at least part of Chairman Rangel's concerns. The principle recommendation in our "Twin Epidemics" report was that there needs to be a major expansion of drug treatment programs such that treatment should be readily accessible to all addicted persons who seek it. Needle exchange programs, which we believe are necessary to slow HIV transmission among injection drug users, are supported as a potentially life-saving stop gap measure while treatment capacity is being expanded.

* * *

Returning to the NRC report briefly: in its opening chapter, there was a contention that public health responses had been guided by what was called "AIDS exceptionalism," as if that were an established term or school of thought. There is no such school of public health. However, there is a school to which most of us belong that says we should use our best science in the interest of public health; that in the light of new knowledge (new virology, new epidemiology, new behavioral science insights, new health education approaches) we should use our very best strategies to curtail this deadly virus at the earliest moment. If that is called exceptionalism, then the exceptional part is the virus of AIDS.

To resurrect quarantine or other frightening, mandatory approaches to try to affect private, personal behavior over the ten-year silent interval of HIV infection is archaic and ultimately counter productive. Gay people, African Americans, Latinos and other minority communities have historically valid reasons to distrust the establishment's institutions and strictures. Further threats to their individual and civil rights in the guise of public health would drive these people away from the health care community, when they should be comforted by its care and counseling in this time of viral menace.

There are many other issues of concern as we enter the 13th year of this pandemic. The virus of AIDS is broadly sown now. With 1 million to 2 million children and young adults already trapped in a dreadful morass of illness and blighted hope, society has been irreparably harmed. No cure or vaccine is in sight. Treatments are palliative, disappointing and enormously expensive. Drug-using behavior is widespread, yet access to treatment for drug addiction is not yet high on the list of national priorities. Sexuality is universal, and our adolescents are at special risk.

We have chosen to focus on two issues here since they have a critical impact on 'effective' response; its scope and, above all, the national commitment that is needed.

Denial of this tragedy is ultimately the AIDS virus' most lethal cofactor. This is a time for exceptional actions, exceptional policies (yes, even needle exchange), and exceptional leaders.

* * *

Dr. Osborn is Chairman of the National Commission on AIDS and Dr. Rogers is Vice Chairman.

Fact Sheet
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Five members of the Commission were appointed by the Senate, five by the House and two by President Bush. In addition, the Secretary of Defense, the Secretary of Health and Human Services, and the Secretary of Veterans Affairs are non-voting members of the Commission.

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Members of the Commission were appointed by Democratic and Republican members of Congress and by the President of the United States. They represent a broad array of expertise in medicine, public health, law, public administration, community-based organizations, minority issues, and religion.

In addition to Dr. Osborn and Dr. Rogers, there are ten other voting members of the Commission.

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The Executive Director of the Commission is Roy Widdus who is the former Staff Director of the Global Program on AIDS of the World Health Organization.

Mission Statement

The National Commission on Acquired Immune Deficiency Syndrome exists to create a broad public agreement on the magnitude, scope and urgency of the HIV/AIDS epidemic, inspire leadership at all levels of both the public and private sector, and put in place effective, cooperative and non-discriminatory systems and resources required for preventive education, comprehensive care, and the research effort necessary to halt the epidemic.

17 July 1990

TALKING POINTS ON THE NATIONAL COMMISSION ON AIDS

- Created by Public Law 100-607, the Commission was authorized for two years, giving the President the option to extend the Commission for an additional two years. President Bush included $3 million in his budget proposal for FY93, essentially a freeze at last year's level. The Senate bill continues funding at $3 million; the House has included $2 million for FY93.

- The Commission was fully constituted in August 1989 and has been operating for the last two years. During these two years the Commission has held numerous public hearings and site visits around the country, heard from more than one thousand people, and issued five Interim Reports and an Annual Report to the President and the Congress. Interim Report Number One addressed the Failure of the U.S. Health Care System to Deal with HIV Epidemic; Report Number Two addressed the need for a national HIV plan, the need for the Ryan White Care Act programs, and the urgent need to pass the Americans with Disabilities Act; Report Number Three called for improvements in our federally funded HIV clinical trials program, the need to address the national shortage of health care providers, and highlighted the particular needs of rural communties in the HIV epidemic; Report Number Four highlighted concerns about HIV disease in Correctional Facilities; and Report Number Five focussed on the twin epidemics of drug addiction and HIV infection.

- The Commission will be releasing a Comprehensive Report on issues related to HIV prevention, care, research and financing on September 26, 1991. The Commission includes a series of recommendations on these issues in its Comprehensive Report.

- In its third year, the Commission intends to monitor the implementation of these recommendations at the federal, state, and local level. The Commission also plans to monitor the implementation of the Ryan White CARE Act, as well as the implementation of the Americans with Disabilities Act. The Commission will continue to travel and conduct studies, when appropriate, to effectively monitor these programs and advise the President and the Congress on them.

- Housing still remains a crucial concern for people with HIV disease and the Commission will be focusing on this particular area in its third year.

- By law, the Commission is to make recommendations to the Congress and the President for a consistent national policy concerning AIDS. The Commission has utilized this advisory authority on a variety of issues over the past two years particularly on issues related to discrimination, immigration and the need for increased attention and funding for HIV care and prevention programs. The Commission fully intends to continue its advisory role to the President and the Congress over the next year.

CHARTER

NATIONAL COMMISSION ON ACQUIRED IMMUNE DEFICIENCY SYNDROME

Purpose

The National Commission on Acquired Immune Deficiency Syndrome was established under Title II, Subtitle D, of the Health Omnibus Programs Extension of 1988, Public Law 100-607, which was approved on November 4, 1988. The general purpose of the Commission is to carry out activities promoting the development of a national consensus on policy concerning acquired immune deficiency syndrome (AIDS).

Authority

42 U.S. Code 300cc Note. The Commission is governed by the provisions of Public Law 92-463, (5 U.S.C. Appendix 2), which sets forth standards for the formation and use of advisory committees.

Functions

The Commission shall perform the following functions:

(1) Monitor the implementation of the recommendations of the Presidential Commission on the Human Immunodeficiency Virus Epidemic, modifying those recommendations as the Commission considers appropriate.

(2) Evaluate the adequacy of, and make recommendations regarding, the financing of health care and research needs relating to AIDS, including the allocation of resources to various Federal agencies and State and local governments and the roles for and activities of private and public financing.

(3) Evaluate the adequacy of, and make recommendations regarding, the dissemination of information that is essential to the prevention of the spread of AIDS, and that recognizes the special needs of minorities and the important role of the family, educational institutions, religion, and community organizations in education and prevention efforts.

(4) Address any necessary behavioral changes needed to combat AIDS, taking into consideration the multiple moral, ethical, and legal concerns involved, and make recommendations regarding testing and counseling concerning AIDS, particularly with respect to maintaining confidentiality.

(5) Evaluate the adequacy of, and make recommendations regarding, Federal and State laws on civil rights relating to AIDS.

(6) Evaluate the adequacy of, and make recommendations, regarding the capability of the Federal Government to make and implement policy concerning AIDS (and, to the extent feasible to do so, other diseases, known and unknown, in the future), including research and treatment, the availability of clinical trials, education and the financing thereof, and including specifically--

> (A) the streamlining of rules, regulations, and administrative procedures relating to the approval by the Food and Drug Administration of new drugs and medical devices, including procedures for the release of experimental drugs; and
>
> (B) the advancement of administrative consideration by the Health Care Financing Administration relating to reimbursement for new drugs and medical devices approved by the Food and Drug Administration.

(7) Evaluate the adequacy of, and make recommendations regarding, international coordination and cooperation concerning data collection, treatment modalities, and research concerning AIDS.

(a) HEARINGS. - For the purpose of carrying out its mandate, the Commission may conduct such hearings, sit and act at such times and places, take such testimony, and receive such evidence, as the Commission considers appropriate. The Commission may administer oaths or affirmations to witnesses appearing before the Commission.

(b) DELEGATION. - Any member or employee of the Commission may, if authorized by the Commission, take any action that the Commission is authorized to take.

(c) ACCESS TO INFORMATION. - The Commission may secure directly from any executive department or agency such information as may be necessary to enable the Commission to carry out its mandate, except to the extent that the department or agency is expressly prohibited by law from furnishing such information. On the request of the Chairman of the Commission, the head of such department or agency shall furnish nonprohibited information to the Commission.

Structure

(1) APPOINTMENT. - The Commission shall be composed of 15 members as follows:

(A) Five members shall be appointed by the President -
    (i) three of whom shall be -
        (I) the Secretary of Health and Human Services;
        (II) the Administrator of Veterans' Affairs; and
        (III) the Secretary of Defense;
    who shall be nonvoting members, except that, in the case of a tie vote by the Commission, the Secretary of Health and Human Services shall be a voting member; and
    (ii) two of them whom shall be selected from the general public on the basis of such individuals being specially qualified to service on the Commission by reason of their education, training, or experience.

(B) Five members shall be appointed by the Speaker of the House of Representatives on the joint recommendation of the Majority and Minority Leaders of the House of Representatives.

(C) Five members shall be appointed by the President pro tempore of the Senate on the joint recommendation of the Majority and Minority Leaders of the Senate.

(2) CONGRESSIONAL COMMITTEE RECOMMENDATIONS. - In making appointments under subparagraphs (B) and (C) of paragraph (1), the Majority and Minority Leaders of the House of Representatives and the Senate shall duly consider the recommendations of the Chairmen and Ranking Minority Members of committees with jurisdiction over laws contained in chapter 17 of title 38, United States Code (relating to veterans' health care), title XIX of the Social Security Act (42 U.S.C. 1901 et seq.) (relating to Medicaid), and the Public Health Service Act (42 U.S.C. 201 et seq.) (relating to the Public Health Service.)

(3) REQUIREMENTS OF APPOINTMENTS. - The Majority and Minority Leaders of the Senate and the House of Representatives shall -

(A) select individuals who are specially qualified to serve on the Commission by reason of their education, training, or experience; and

(B) engage in consultations for the purpose of ensuring that the expertise of the 10 members appointed by the Speaker of the House of Representatives and the President pro tempore of the Senate shall provide as much of a balance as possible and, to the greatest extent possible, cover the fields of medicine, science, law, ethics, health-care economics, and health-care and social services.

(4) TERM OF MEMBERS. - Members of the Commission (other than members appointed under paragraph (1)(A)(i)) shall serve for the life of the Commission.

(5) VACANCY. - A vacancy on the Commission shall be filled in the manner in which the original appointment was made.

(b) CHAIRMAN. - Not later than 15 days after the members of the Commission are appointed, such members shall select a Chairman from among the members of the Commission.

(c) QUORUM. - Seven members of the Commission shall constitute a quorum, but a lesser number may be authorized by the Commission to conduct hearings.

Management and support services shall be provided jointly or separately by the Department of Health and Human Services and the Department of Veterans Affairs.

Meetings

After the initial meeting, the Commission shall meet at the call of the Chairman or a majority of its members, but shall meet at least three times per year during the life of the Commission.

Meetings shall be open to the public, except as determined otherwise by the Executive Director of the National Commission on Acquired Immune Deficiency Syndrome. Notice of all meetings shall be given to the public.

Meetings shall be conducted, and records of proceedings kept, as required by applicable law and regulations.

Compensation

Members of the Commission who are not officers or employees of the United States shall receive, for each day they are engaged in the performance of the functions of the Commission, compensation at rates not to exceed the daily equivalent of the annual rate in effect for Grade GS-18 of the General Schedule, including travel time; and all members, while so serving away from their homes or regular places of business, may be allowed travel expenses, including per diem in lieu of subsistence, in the same manner as such expenses are authorized by Section 5703 of Title 5, United States Code, for persons in the Government service employed intermittently.

Annual Cost Estimate

Estimated annual cost for operating the Commission, including compensation and travel expenses for members but excluding staff support, is $1.5 million. Estimate of annual man-years of staff support required is 10, at an estimated annual cost of $750,000.

Reports

(a) INTERIM REPORTS --

(1) IN GENERAL - Not later than 1 year after the date on which the Commission is fully constituted, the Commission shall prepare and submit to the President and to the appropriate committees of the Congress a comprehensive report on the activities of the Commission to that date.

(2) CONTENTS - The report submitted under paragraph (1) shall include such findings, and such recommendations for legislation and administrative action, as the Commission considers appropriate based on its activities to that date.

(3) OTHER REPORTS - The Commission shall transmit such other reports as it considers appropriate.

(b) FINAL REPORT --

(1) IN GENERAL - Not later than 2 years after the date on which the Commission is fully constituted, the Commission shall prepare and submit a final report to the President and to the appropriate committees of Congress.

(2) CONTENTS - The final report submitted under paragraph (1) shall contain a detailed statement of the activities of the Commission and of the findings and conclusions of the Commission, including such recommendations for legislation and administrative action as the Commission considers appropriate.

Termination Date

The National Commission on Acquired Immune Deficiency Syndrome shall cease to exist 30 days after the date on which it submits its final report to the President and the Congress. The charter for the Commission shall expire two years from the date it is approved.

APPROVED:

AUG 2 1989
Date

Louis W Sullivan
Louis W. Sullivan, M.D.
Secretary
Department of Health and Human Services

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DEPARTMENT OF HEALTH & HUMAN SERVICES
Office of the Secretary

Washington, D.C. 20201

AUG 2 - 1989

The Honorable Edward M. Kennedy
Chairman, Committee on Labor
and Human Resources
United States Senate
Washington, D.C. 20510

Dear Mr. Chairman:

A copy of the charter for the following committee is enclosed for your committee file in accordance with Section 9(c) of Public Law 92-463: National Commission On Acquired Immune Deficiency Syndrome

The Act requires the Department to file a copy of the charter for each advisory committee it utilizes with the standing committee of the Senate and of the House of Representatives having legislative jurisdiction of the Department, and with the Library of Congress.

Sincerely,

Ellen V. Washington
Department Committee
Management Officer

Enclosures

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(6) Evaluate the adequacy of, and make recommendations, regarding the capability of the Federal Government to make and implement policy concerning AIDS (and, to the extent feasible to do so, other diseases, known and unknown, in the future), including research and treatment, the availability of clinical trials, education and the financing thereof, and including specifically--

> (A) the streamlining of rules, regulations, and administrative procedures relating to the approval by the Food and Drug Administration of new drugs and medical devices, including procedures for the release of experimental drugs; and
>
> (B) the advancement of administrative consideration by the Health Care Financing Administration relating to reimbursement for new drugs and medical devices approved by the Food and Drug Administration.

(7) Evaluate the adequacy of, and make recommendations regarding, international coordination and cooperation concerning data collection, treatment modalities, and research concerning AIDS.

(a) HEARINGS. - For the purpose of carrying out its mandate, the Commission may conduct such hearings, sit and act at such times and places, take such testimony, and receive such evidence, as the Commission considers appropriate. The Commission may administer oaths or affirmations to witnesses appearing before the Commission.

(b) DELEGATION. - Any member or employee of the Commission may, if authorized by the Commission, take any action that the Commission is authorized to take.

(c) ACCESS TO INFORMATION. - The Commission may secure directly from any executive department or agency such information as may be necessary to enable the Commission to carry out its mandate, except to the extent that the department or agency is expressly prohibited by law from furnishing such information. On the request of the Chairman of the Commission, the head of such department or agency shall furnish nonprohibited information to the Commission.

Structure

(1) APPOINTMENT. - The Commission shall be composed of 15 members as follows:

(A) Five members shall be appointed by the President -
  (i) three of whom shall be -
    (I) the Secretary of Health and Human Services;
    (II) the Administrator of Veterans' Affairs; and
    (III) the Secretary of Defense;
  who shall be nonvoting members, except that, in the case of a tie vote by the Commission, the Secretary of Health and Human Services shall be a voting member; and
  (ii) two of them whom shall be selected from the general public on the basis of such individuals being specially qualified to service on the Commission by reason of their education, training, or experience.

(B) Five members shall be appointed by the Speaker of the House of Representatives on the joint recommendation of the Majority and Minority Leaders of the House of Representatives.

(C) Five members shall be appointed by the President pro tempore of the Senate on the joint recommendation of the Majority and Minority Leaders of the Senate.

(2) CONGRESSIONAL COMMITTEE RECOMMENDATIONS. - In making appointments under subparagraphs (B) and (C) of paragraph (1), the Majority and Minority Leaders of the House of Representatives and the Senate shall duly consider the recommendations of the Chairmen and Ranking Minority Members of committees with jurisdiction over laws contained in chapter 17 of title 38, United States Code (relating to veterans' health care), title XIX of the Social Security Act (42 U.S.C. 1901 et seq.) (relating to Medicaid), and the Public Health Service Act (42 U.S.C. 201 et seq.) (relating to the Public Health Service.)

(3) REQUIREMENTS OF APPOINTMENTS. - The Majority and Minority Leaders of the Senate and the House of Representatives shall -

(A) select individuals who are specially qualified to serve on the Commission by reason of their education, training, or experience; and

(B) engage in consultations for the purpose of ensuring that the expertise of the 10 members appointed by the Speaker of the House of Representatives and the President pro tempore of the Senate shall provide as much of a balance as possible and, to the greatest extent possible, cover the fields of medicine, science, law, ethics, health-care economics, and health-care and social services.

(4) TERM OF MEMBERS. - Members of the Commission (other than members appointed under paragraph (1)(A)(i)) shall serve for the life of the Commission.

(5) VACANCY. - A vacancy on the Commission shall be filled in the manner in which the original appointment was made.

(b) CHAIRMAN. - Not later than 15 days after the members of the Commission are appointed, such members shall select a Chairman from among the members of the Commission.

(c) QUORUM. - Seven members of the Commission shall constitute a quorum, but a lesser number may be authorized by the Commission to conduct hearings.

Management and support services shall be provided jointly or separately by the Department of Health and Human Services and the Department of Veterans Affairs.

Meetings

After the initial meeting, the Commission shall meet at the call of the Chairman or a majority of its members, but shall meet at least three times per year during the life of the Commission.

Meetings shall be open to the public, except as determined otherwise by the Executive Director of the National Commission on Acquired Immune Deficiency Syndrome. Notice of all meetings shall be given to the public.

Meetings shall be conducted, and records of proceedings kept, as required by applicable law and regulations.

Compensation

Members of the Commission who are not officers or employees of the United States shall receive, for each day they are engaged in the performance of the functions of the Commission, compensation at rates not to exceed the daily equivalent of the annual rate in effect for Grade GS-18 of the General Schedule, including travel time; and all members, while so serving away from their homes or regular places of business, may be allowed travel expenses, including per diem in lieu of subsistence, in the same manner as such expenses are authorized by Section 5703 of Title 5, United States Code, for persons in the Government service employed intermittently.

Annual Cost Estimate

Estimated annual cost for operating the Commission, including compensation and travel expenses for members but excluding staff support, is $1.5 million. Estimate of annual man-years of staff support required is 10, at an estimated annual cost of $750,000.

Reports

(a) INTERIM REPORTS --

(1) IN GENERAL - Not later than 1 year after the date on which the Commission is fully constituted, the Commission shall prepare and submit to the President and to the appropriate committees of the Congress a comprehensive report on the activities of the Commission to that date.

(2) CONTENTS - The report submitted under paragraph (1) shall include such findings, and such recommendations for legislation and administrative action, as the Commission considers appropriate based on its activities to that date.

(3) OTHER REPORTS - The Commission shall transmit such other reports as it considers appropriate.

(b) FINAL REPORT --

(1) IN GENERAL - Not later than 2 years after the date on which the Commission is fully constituted, the Commission shall prepare and submit a final report to the President and to the appropriate committees of Congress.

(2) CONTENTS - The final report submitted under paragraph (1) shall contain a detailed statement of the activities of the Commission and of the findings and conclusions of the Commission, including such recommendations for legislation and administrative action as the Commission considers appropriate.

Termination Date

The National Commission on Acquired Immune Deficiency Syndrome shall cease to exist 30 days after the date on which it submits its final report to the President and the Congress. The charter for the Commission shall expire two years from the date it is approved.

APPROVED:

AUG 2 1989
Date

Louis W Sullivan
Louis W. Sullivan, M.D.
Secretary
Department of Health and Human
Services

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Biographies of Members of the National Commission On AIDS

Chairman **June E. Osborn, M.D.**, is Professor of Epidemiology and Dean of the School of Public Health at the University of Michigan; she is also Professor of Pediatrics and Communicable Diseases at the University of Michigan Medical School. She has served on numerous federal and nonfederal committees, currently including the Global Commission on AIDS for the World Health Organization and the Robert Wood Johnson Foundation National Advisory Committee for the AIDS Health Services Project (Chair). Dr. Osborn has published extensively in the fields of virology, public health, and public policy. She earned her M.D. at Case Western Reserve University School of Medicine and did her pediatric residency at Harvard Hospitals. She is a member of both the American Academy of Pediatrics and the American Academy of Microbiology. In 1986 she was elected to membership in the Institute of Medicine of the National Academy of Sciences.

Vice Chairman **David E. Rogers, M.D.**, completed his M.D. in 1948 at Cornell University and served an internship and residency at Johns Hopkins. Among his important appointments are those of Dean of Medicine and Vice President for Medical Affairs at Johns Hopkins University and Medical Director of the Johns Hopkins Hospital. Dr. Rogers was appointed the first Walsh McDermott University Professor of Medicine at the New York Hospital-Cornell University Medical Center in November 1986. For the 15 years preceding this appointment, Dr. Rogers was President of the Robert Wood Johnson Foundation in Princeton, New Jersey, the largest philanthropy devoting its resources to alleviating problems in the health care of Americans. Dr. Rogers has been very involved in the problems of AIDS, holding appointments as Chairman of the Advisory Council of the AIDS Institute of New York State, member of the Citizens Commission on AIDS of New York and New Jersey, Chair of the National Community AIDS Partnership, and Chair of the New York City Mayoral Task Force on AIDS.

Diane Ahrens is presently serving her 17th year as Commissioner of Ramsey County, Minnesota. She chaired the Human Services Steering Committee of the National Association of Counties (NACO) from 1986-1988 and in 1988 was appointed chair of NACO's task force on HIV/AIDS, which formulated recommendations for all counties regarding their role in addressing the HIV epidemic. She earned her Masters degree in Religion and Higher Education at Yale University.

Rev. Scott Allen, of Dallas, Texas, serves as a consultant for Homeward, Inc., and specializes in transitional care. He has conducted extensive research on the spiritual, ethical, and psychological dimensions of AIDS. He also provides direct pastoral care for people with AIDS, and is often called upon to act as a liaison between people with AIDS and their religious community and/or family. In addition, Reverend Allen is the founder and Co-Coordinator of the AIDS Interfaith Network of Dallas, Chairperson of the Subcommittee on State Responsibility of the Special Texas Legislative Task Force on AIDS, and Board Member of AIDS ARMS, a program to meet the special human needs of people with AIDS. Reverend Allen earned his Masters in Divinity from the Golden Gate Theological Seminary and served as pastor of the Pacific Baptist Church in California and as Minister of Education and Youth for the First Christian Church in Colorado Springs before joining the Christian Life Commission in 1985.

Harlon L. Dalton is a Professor at Yale Law School and a leading authority on legal issues generated by the AIDS epidemic. His AIDS-related publications include AIDS and the Law: A Guide for the Public, and "AIDS in Blackface." Mr. Dalton serves on the AIDS Interfaith Network in New Haven (chairperson), the Advisory Board of the Connecticut Consortium of AIDS, the Editorial Board of the AIDS Alert, and the New Haven Mayor's Task Force on AIDS. He earned his J.D. from Yale Law School.

Don C. Des Jarlais, Ph.D., is currently the Director of Research for the Chemical Dependency Institute of Beth Israel Medical Center, Deputy Director for AIDS Research with Narcotic and Drug Research, Inc., and Professor of Community Medicine at Mount Sinai School of Medicine. He is an international leader in the fields of AIDS and intravenous drug use and during the past seven years has published over 100 scientific articles on the topics. He was the plenary speaker on intravenous drug use and AIDS at the 3rd, 4th, and 7th International Conferences on AIDS. He also serves as a consultant to various institutions, including the Centers for Disease Control, the National Institute on Drug Abuse, the National Academy of Sciences, and the World Health Organization. He is a Guest Investigator at Rockefeller University and a Visiting Professor of Psychology at Columbia University. Dr. Des Jarlais earned his Doctorate of Philosophy in Social Psychology from the University of Michigan.

Eunice Diaz, M.S., M.P.H., is Vice Chair of the Health Resources and Services Administration (HRSA) AIDS Advisory Council. She is also a private health consultant, is a nationally known expert and speaker on the subject of AIDS in the Hispanic community, and a former board member of AIDS Project Los Angeles. In addition, Ms. Diaz has served on numerous AIDS-related committees and panels, including the Los Angeles County Commission on AIDS, the Planning Committee for the Surgeon General's Conference on Pediatric AIDS, and most recently, the Task Force on AIDS of the Society for Hospital Marketing and Public Relations, American Hospital Association. Ms. Diaz earned her Master of Science in Public Health and Master of Public Health at the Loma Linda University.

Donald S. Goldman is an attorney in private practice as a partner in the West Orange, New Jersey, law firm of Harkavy, Goldman, Goldman & Caprio. Active in The National Hemophilia Foundation and its chapters for over 25 years, he served as its Chairman from 1983 to 1984 and its President from 1984 to 1986. Mr. Goldman coordinated The National Hemophilia Foundation's efforts to improve the safety of the nation's blood supply, began many of its efforts in HIV risk reduction, and introduced initiatives to improve hemophilia and HIV service delivery to minorities. Currently he is also Vice President of the National Health Council, Inc. Mr. Goldman earned his J.D. from Rutgers University and has published and lectured widely on legal aspects of hemophilia, HIV infection, and other medical and ethical issues. He is a member of the Bar of New Jersey, the United States Court of Appeals for the Third Circuit, and the United States Supreme Court.

Larry Kessler is a founding member and Executive Director of the AIDS ACTION Committee of Massachusetts, New England's largest AIDS service organization. Beginning in 1983 as its only paid staff member, Kessler organized a corps of volunteers to combat the AIDS epidemic through education, service, advocacy, and outreach. He now oversees a staff of 75 full-time employees and more than 2,000 volunteers who provide support services to more than 1,400 men and women living with AIDS and HIV, and educational programs for health care providers, the public, and communities at risk of HIV infection. Kessler continues to play a leading role in advocating on the federal, state, and local levels for fair and effective AIDS policy and funding. He was an original member of the Massachusetts Governor's Task Force on AIDS and the Boston Mayor's Task Force on AIDS, under appointments by Governor Michael S. Dukakis and Mayor Raymond Flynn, respectively. Kessler is a founding board member of the former National AIDS Network and the AIDS ACTION Council in Washington, on whose board he continues to serve. Most recently, he was named to the Advisory Boards of the Harvard AIDS Institute and the National Leadership Coalition on AIDS. In 1987, Simmons College in Boston awarded him an Honorary Degree of Doctor of Human Services.

Charles Konigsberg, M.D., M.P.H., is a public health physician. He most recently served as Director of the Division of Health of the Kansas Department of Health and the Environment from October 1988 to August 1991. Previously he was the District Health Program Supervisor and Broward County Public Health Unit Director for the Department of Health and Rehabilitative Services in Fort Lauderdale. In Florida Dr. Konigsberg represented the county health official perspective on the Governor's AIDS Advisory Task Force. Dr. Konigsberg has also served as a consultant to the Centers for Disease Control and the U.S. Public Health Service in the development of HIV prevention and control strategies. He earned his M.D. from the University of Tennessee Center for the Health Sciences and his Master of Public Health in Community Health Administration from the University of North Carolina School of Public Health.

Belinda Ann Mason (deceased) was a journalist and fiction writer who lived in rural Kentucky. In 1987 she was diagnosed with HIV and thereafter with AIDS. In 1988 she founded the Kentuckiana People With AIDS Coalition, the first organization of its kind in either Kentucky or Indiana. From 1989 to 1990 she served as President of the National Association of People With AIDS, and thereafter was its Chair Emeritus. In 1990 she served on the board of the AIDS Action Council in Washington, D.C. She was the recipient of numerous honors and awards including a distinguished leadership award from the Kentucky legislature.

J. Roy Rowland, M.D., is now serving his fifth term in the U.S. House of Representatives (Democrat, Georgia's Eighth Congressional District). As the only physician in Congress from 1985 to 1988, Congressman Rowland has provided leadership and insight on a number of health issues, such as infant mortality, rural health, the veterans' health system, and AIDS. His efforts on behalf of the AIDS community include sponsoring the legislation that authorized creation of the National Commission on AIDS and introducing a bill mandating study of AIDS among college students-an idea that was adopted administratively by the Centers for Disease Control. Congressman Rowland earned his M.D. from the Medical College of Georgia and maintained a family practice in central Georgia for three decades before pursuing a political career.

Ex Officio

Richard B. Cheney was nominated by President Bush to be Secretary of Defense on March 10, 1989, was confirmed by the United States Senate on March 17, 1989, and took the oath of office on March 21, 1989. In August 1974, when Gerald R. Ford assumed the presidency, Mr. Cheney served on the Ford transition team, beginning in September 1974 as a Deputy Assistant to the President. In November 1975, he was named Assistant to the President and White House Chief of Staff, a position he held through the remainder of the Ford Administration, until January 1977. He returned to his home state of Wyoming in May 1977 to resume private life. Mr. Cheney was elected to Congress in November 1978. He was reelected in 1980, 1982, 1984, 1986, and 1988.

Edward J. Derwinski, President Bush's choice to become the first Secretary of the newly created cabinet-level Department of Veterans Affairs, was confirmed by the Senate on March 2, 1989 and sworn in on March 15, 1989. Secretary Derwinski directs the activities of the federal government's second largest department, responsible for a nationwide system of health care services and benefits programs for America's 27.3 million veterans. A member of the U.S. House of Representatives from 1959 to 1983, representing Illinois' Fourth Congressional District, he was the senior minority member of the House Foreign Affairs Committee, Post Office Committee, and Civil Service Committee. He played a major role in the passage of landmark civil service reform, postal service reorganization, and foreign service reform legislation.

Louis W. Sullivan, M.D., was sworn in as Secretary of Health and Human Services on March 10, 1989. As head of the Department of Health and Human Services, Dr. Sullivan oversees the federal agency responsible for the major health, welfare, food and drug safety, medical research, and income security programs serving the American people. Dr. Sullivan came to HHS from the Morehouse School of Medicine in Atlanta, Georgia. In July 1975, Dr. Sullivan became founding dean and director of the medical education program at Morehouse College. In July 1, 1981 when the School of Medicine became independent from Morehouse College he served as its first dean and president. In April 1985, the Morehouse School of Medicine was fully accredited and on May 17, 1985, the school awarded the M.D. degree to its first 16 graduates.

The National Commission on AIDS

DONALD S. GOLDMAN and JEFF STRYKER

A DECADE AFTER the first cases were recognized in the United States, AIDS continues to vex policymakers and fascinate the public. It has been said that AIDS acts as a prism, refracting a spectrum of controversial topics. For bioethicists, these topics include: equity in the allocation of resources for treatment and research; forgoing life-sustaining care and proxy decision making; informed consent in the context of HIV testing and screening; the ethical duties of health care workers to provide care for persons with HIV disease; and competing obligations of health care professionals to patients and to third parties who may be put at risk.

THE ROLE OF COMMISSIONS

If AIDS is the quintessential case study for bioethicists, it is a potential quagmire for politicians. The association of HIV disease with drug use and sexual behavior makes it a topic that all but the most courageous (or the most homophobic) politicians shy away from. A frequent political response is to form a commission.

Alexander Capron, who was executive director of the President's Commission for the Study of Ethical Problems in Medicine, has described some roles commissions play: a *watchdog,* overseeing the work of particular government agencies; a *crucible,* providing a means for "publicly hammering out conclusions on controversial issues when consensus, both in the public and in the relevant disciplines, is not yet apparent"; and "a *lightning rod* for public concern—or viewed less charitably, dumping ground for an issue that is too difficult for the ordinary political process to handle" (Capron 1983, p. 9).

Nearly every state has created a gubernatorial-level task force or commission on AIDS. The National Commission on AIDS was established under the Health Omnibus Program Extension (HOPE) Act of 1988, which was signed by President Reagan on November 4, 1988. The official charter of the commission was approved August 2, 1989 and its original two-year term was extended for a third year. The mission statement crafted by the commission to reflect its Congressional mandate reads:

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> The National Commission on Acquired Immune Deficiency Syndrome is an independent body of 15 members created to advise the President and Congress. The Commission seeks to build a broad public understanding on the magnitude, scope and urgency of the HIV/AIDS epidemic; provide and inspire leadership at all levels of both the public and private sectors; empower individuals and communities; and advocate for effective, cooperative and non-discriminatory resources required for prevention, comprehensive care, and the research necessary to halt the epidemic.

As the mission statement implies, the National Commission on AIDS has viewed itself from the outset not only as a crucible for policy analysis, but also as a forum for those affected by HIV disease. In site visits and hearings the commissioners have met with hundreds of people living with HIV disease, and with caregivers on the front lines. This odyssey has taken the commission on visits to homeless shelters in New York City; to "shooting galleries" where intravenous drug users congregate in Seattle; to Native American communities in four states; to private homes in rural Georgia; and to hospitals, HIV antibody testing centers, drug treatment clinics, and hemophilia treatment centers throughout the nation. It quickly became clear during the commission's travels that HIV disease cannot be understood outside the context of the racism, homophobia, poverty and unemployment that provide the medium that fosters its spread. It also became apparent that issues of HIV prevention, care and treatment, and clinical research are inextricably intertwined and must be dealt with as such.

EARLY INITIATIVES

Under the leadership of Chairperson June Osborn and Vice-chairperson David Rogers, the commission decided that the problems it saw in its first few meetings were too urgent to await a full-length annual report. Hence the commission entered the fray with a series of brief interim reports on particular aspects of AIDS. These reports enabled the commission to draw attention to urgent problems of limitations in access to health care and to underscore the plight of people with HIV disease who might otherwise garner little media attention, such as prisoners and drug users (National Commission on AIDS 1989, 1990a, 1990b, 1991b, 1991c). Throughout its tenure the commission has also issued a series of position statements on HIV policy choices facing Congress and other decision makers.

The commission endorsed federal funding of bleach distribution programs to encourage injection drug users to clean their injection equipment and for needle exchange and distribution programs. It also supported removal of restrictions on travel and immigration for people with HIV disease and AIDS.

The first official act of the National Commission on AIDS was to issue a statement of support for passage of the Americans with Disabilities Act (ADA). It is hoped that this new law, which will be phased into effect beginning in 1992, will be a significant step in leveling the playing field for people with HIV disease.

It extends protections from discrimination against a wide range of disabilities, including HIV disease, to the private workplace and to public accommodations.

Stigma and discrimination remain the fundamental obstacles to confronting AIDS. Although recent opinion polls reflect a moderation of harsh attitudes toward people living with HIV disease, discrimination persists. Surveys of court cases and complaints to human rights commissions reflect the changing character of discrimination—overt bias in the form of exclusion from the schoolroom or the workplace is being replaced by more subtle forms of discrimination including denial of basic health care services.

It would be naive to think that a single law could eliminate discrimination and injustice, any more than the civil rights legislation of 1964 has eradicated discrimination based on race. Nevertheless, the ADA will prove a useful tool in combating HIV-related discrimination, and the National Commission on AIDS is committed (in its watchdog role) to seeing that it is assiduously enforced and monitored. The commission recognizes that gaps remain in protection from discrimination (the ADA explicitly excludes active drug users, a significant proportion of people infected with HIV), and encourages states and localities to fill these gaps.

A NEW COMPREHENSIVE REPORT

In late September of this year, the commission summarized its first two years of activity in a comprehensive report entitled, *America Living with AIDS* (National Commission on AIDS 1991a). The report presents the views of the commission in some key areas of AIDS policy, including prevention and education, clinical research, and the delivery and financing of health care. The report addresses a number of subjects of interest to bioethicists, a few of which are summarized below.

Is HIV special?

The end of the first decade of AIDS was marked by increasing calls for the "mainstreaming" of AIDS—abandoning what has been dubbed "HIV exceptionalism" (Bayer 1991). For some, an end to HIV exceptionalism means abandonment of special requirements for HIV disease, such as specific written informed consent for HIV antibody testing and limitations on disclosure of HIV-related information. The rationale for this approach lies in part in the newly found capacity for early intervention to delay the progression of HIV disease—something can now be done for those who are HIV positive.

Unfortunately, HIV disease remains exceptional in morally relevant ways. People with it continue to be shunned and stigmatized. It is the nation's most rapidly growing cause of morbidity and mortality. And HIV disease remains a disease of sexual and drug-using behaviors that occur in private. HIV disease should not be treated "just like any other disease" in circumstances where it is critically different; part of the work of the commission involves analyzing such differences and similarities, to see where lessons from other diseases might usefully be applied to AIDS.

The commission has had to confront the degree to which HIV ought to be singled out for special treatment in making recommendations for financing reform. The commission recognizes that a financing reform proposal addressed solely to HIV disease would provide selectively and perhaps only temporarily for that population while ignoring the larger, more systemic problem. The commission thus makes forceful recommendations urging the President and Congress to address the health care problems of all people living in the United States by supporting universal health care coverage. In the interim, the commission makes a detailed series of recommendations that focus on some of the unique problems and limitations of public financing of care for HIV disease, recommendations that could reasonably be implemented incrementally for all people with serious chronic illnesses requiring expensive, recurring care.

HIV in the health care setting

The commission concludes that "health care practitioners have an ethical responsibility to provide care to those with HIV disease." This flatfooted statement notwithstanding, the commission notes a number of factors that might dissuade health care workers from meeting the challenge of HIV disease. Of the factors the commission addresses—disaffection with those at risk of HIV, lack of specialized knowledge, increased stress, and concerns about risk of occupational transmission of HIV—the latter has received the most attention.

If commissions can sometimes act as a lightning rod, lightning struck AIDS policy debates in the guise of Dr. David Acer, the Florida dentist who apparently transmitted HIV to five patients in the course of sloppy dental work before dying of AIDS. The only known instance of HIV transmission to patients in an occupational setting, this disturbing situation serves as a vivid reminder that the risks of HIV transmission in the health care setting are real, if remote, for both care providers and patients.

The Acer case generated increasing demands for mandatory, widespread HIV antibody testing of health care workers and patients. The commission believes that such proposals fail to recognize scientific realities and do not properly account for the interests of both caregivers and patients. Mass screening programs threaten to drive a wedge between patients and their caregivers. They also miss the point. Mass screening programs would be prohibitively expensive, interfere with the doctor-patient relationship, and provide a false sense of security because of the gap between the time infection develops and the time it shows up in antibody tests. Moreover, the fear that mandatory screening inflames would likley cause many to delay seeking medical attention, resulting in many more deaths than any hypothetical risk of HIV transmission.

Fortunately, the Centers for Disease Control (1991) eventually issued guidelines that outlined fairly reasonable recommendations regarding participation of HIV-infected health care workers in "exposure prone" procedures.

Expanded access to experimental treatments

Another subject dealt with at length in *America Living with AIDS* of special interest to bioethicists involves the development of new HIV treatments and the appropriate balance between the need for data to ensure the safety and efficacy of new HIV treatment drugs and the immediate needs of people living with HIV disease, for whom unproven therapies may represent the only hope of survival.

Scientists, regulators, statisticians, and bioethicists (Levine 1988; Levine, Dubler, and Levine 1991) are rethinking how clinical research should be conducted, with increasing input from AIDS activists. The strict entry criteria traditionally associated with randomized, controlled clinical trials has in the past excluded many who wish to participate in HIV-related trials. Women, active drug users, people with hemophilia, children, and adolescents, among others, were initially excluded from HIV-related trials because they did not meet strict entry criteria for participation. Such criteria made access to experimental therapies virtually impossible for whole communities of people with HIV disease. The appropriate medical management of people with HIV disease involves the use of many different drugs at one time and each new complication of HIV disease makes entry into a classically designed clinical trial difficult. A further complicating factor is that many who seek to participate in research protocols may have no other access to primary health care and may depend on the health care delivered in association with drug trials, potentially undermining the voluntariness of their initial or continued participation.

America Living with AIDS notes the ethical concerns unique to certain classes of potential subjects whose competence or voluntariness in consenting to participation in research may be suspect, such as children (especially those in foster care), adolescents, or prisoners. With regard to prisoners, the commission heard testimony about the impact of human subjects regulations on research in correctional facilities from bioethicists Robert Levine and Nancy Dubler. In its report, the commission notes that regulations originally adopted to protect prisoners from exploitation as subjects of nontherapeutic research may, in the context of HIV disease, act to preclude their participation in potentially life-saving therapeutic research. Although extant regulations may block prisoners' participation in only the placebo arm of clinical trials, there is a widespread perception in the research community that ethical, regulatory, and logistical hurdles are too great to even consider trying to enroll prisoners in clinical trials. The commission urges the Department of Health and Human Services to clarify how current regulations apply to research with prisoners with HIV disease, and to urge the Health Resources and Services Administration (HRSA) and the National Institutes of Health (NIH) to educate researchers and inmates about the eligibility of prisoners for therapeutic research protocols.

CONCLUSION

Ethical issues are at the heart of many of the controversial AIDS policy topics under consideration by the National Commission on AIDS. The threat that HIV poses to society, uncertainties about the modes of transmission, and its association with sexuality, drug use and marginalized individuals, make it exceedingly difficult to engage in the kind of dispassionate analysis that sorts out principle from prejudice and basic values from expedient policies. In the search for a consensus on sound AIDS policy, it is just this sort of analysis to which the National Commission on AIDS is seeking to contribute.

For more information on the commission, contact:

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