Confronting the AIDS Pandemic:

Principles and Priorities for the Second Decade

A Publication of the

Governor's Advisory Council on AIDS

Governor's Advisory Council on AIDS

On 24 October 1991 Governor James J. Florio created the Governor's Advisory Council on AIDS. Executive Order No. 45 mandated the Council to advise the executive branch on policy concerning New Jersey's efforts to coordinate and deliver critical HIV/AIDS services efficiently and cost effectively to its citizens.

The Council is comprised of a diverse and multidisciplinary group of 48 volunteer members appointed by the Governor. Its membership is designed to bring together the broad spectrum of expertise, opinions and values of all New Jerseyans. By law, the Council includes representatives from the Senate and General Assembly; designees of the Commissioners of Health, Corrections, Education, Human Services, Community Affairs, and Insurance; designees of the Attorney General, the Public Advocate and the Chancellor of Higher Education, and thirty-five members appointed from the public at large.

On the basis of its findings, the Advisory Council provides recommendations to the Governor, the Legislature and all New Jersey citizens. Through this and other publications, the Council seeks to enhance an humane understanding and reasoned response to the HIV/AIDS pandemic.

To obtain a copy of this report, please write to the:

Governor's Advisory Council on AIDS
CN 363
Trenton, New Jersey 08625-0363
or call (609) 984-5874

Confronting the AIDS Pandemic:

Principles and Priorities for the Second Decade

State of New Jersey
James J. Florio, Governor

A Publication of the Governor's Advisory Council on AIDS

December 1992

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Acknowledgement

All at the Governor's Advisory Council on AIDS wish to express their gratitude toward Robert S. Olick, M.A., J.D., Ellen B. Friedland, J.D., and Sally M. Sutphen, B.A. for their signal scholarship and voluntary efforts in the publication of this document, *Confronting the AIDS Pandemic: Principles and Priorities for the Second Decade.*

[W]e... have not done enough as a nation to stop the spread of AIDS or to help those who are living with it. Most of us have preferred to believe AIDS is not our problem, that it's a problem for a few particular or isolated groups in our society -- that it only affects gay men and IV drug users....But the truth is, it is everybody's problem -- not only because it is spreading throughout society but because... the sheer cost and burden of dealing with the AIDS crisis may absolutely consume all the gains we hope to make in straightening out the other problems in our health care system....Americans are dying of the world's most curable affliction -- ignorance -- and we need to cure that first....[D]ealing with AIDS requires us to be more personally responsible to prevent the spread of the disease... to create more opportunity so that we can lengthen life and make it as full as possible and... to develop a greater sense of community, of sensitivity and compassion and concern for one another....

President-Elect Bill Clinton, "Fighting the AIDS Crisis," delivered at the Justice Brennan Courthouse, Jersey City, New Jersey, October 29, 1992.

> AIDS is a preventable disease. You can protect yourself. We need to get the word out. Sometimes the message will have to be hard-hitting and explicit. It won't always be comfortable. But then again, AIDS isn't comfortable....Tackling AIDS is not just a job for public health professionals. We need a public/private partnership. We defeated polio by mobilizing business leaders, clergy, doctors, educators and civic groups. We all must work shoulder to shoulder again...We also need to keep in mind that the AIDS crisis is closely tied to our health care cost crisis. And that a solution for one must address the problems of the other.

Governor James J. Florio, "Ten Principles for Combating AIDS in New Jersey," Atlantic City, New Jersey, October 11, 1991.

> The people of the United States have arrived at a crossroads in the history of the HIV epidemic. In the months to come they must either engage seriously the issues and needs posed by this deadly disease or face relentless, expanding tragedy in the decades ahead. In just ten years the human immunodeficiency virus (HIV), the causative agent of AIDS, has claimed more American lives than did the Korean and Vietnam wars combined. If, from this day forward, there were never another instance of new infection, the upcoming decade would still certainly be much worse. The amount of human suffering and number of deaths will be much greater.

The National Commission on Acquired Immune Deficiency Syndrome, *America Living With AIDS: Transforming Anger, Fear, and Indifference Into Action* (1991), p. 1.

State of New Jersey
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11 December 1992

The Honorable James J. Florio
Governor, State of New Jersey
State House
Trenton, New Jersey 08625

Dear Governor Florio:

On behalf of the Governor's Advisory Council on AIDS it is our privilege to provide the Council's report, *Confronting the AIDS Pandemic: Principles and Priorities for the Second Decade.* In preparing this, our first interim document, we have endeavored to fulfill and address the important office and tasks set forth in your 24 October 1991, Executive Order Number 45.

Appreciating its responsibilities to the pluralistic society it serves, as well as its role in the political process, the Advisory Council firmly committed to holding all its hearings, meetings and deliberations in full view of the public. The open nature of the process is, in large measure, responsible for the substance, quality, tone and texture of the Council's recommendations and we hope will serve as well as a foundation for public confidence in our labors.

The presence of the HIV/AIDS pandemic in New Jersey and the absence of a cure for the deadly virus have shaped the character of your Advisory Council's strong recommendations and impelled its diverse members to call, in one voice, for immediate, concerted and compassionate leadership. In keeping with the purposes of Executive Order Number 45, we have prepared this report for the benefit of all our citizens. Our analyses contain a discussion of the important principles animating these recommendations and it is the Council's belief that a full account of the basic moral, social and professional concerns underlying them will engender an humane understanding and reasoned response to the crisis of HIV/AIDS in New Jersey.

We thank you again for the privilege of service on the Governor's Advisory Council on AIDS and iterate our promise of dedicated, vocal and unwavering commitment to the critical tasks confronting New Jersey in this the second decade of the peril of AIDS.

Sincerely,

Paul W. Armstrong

(P.W. Armstrong)
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Peter W. Jewell
Peter W. Jewell
Vice-Chairman

Rosemarie A. Johnson
Rosemarie A. Johnson
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INTRODUCTION

The national crisis of the AIDS pandemic has been particularly felt in New Jersey. New Jersey ranks fifth in the nation (since 1981) in the number of its citizens infected with HIV/AIDS. While New Jersey has recorded more than 13,500 cases of AIDS as of June 1992, as many as 50,000 New Jerseyans may currently be infected with HIV. The HIV/AIDS epidemic is not just a disease of the gay community or of injection drug users ("IDUs"). The epidemic in New Jersey disproportionately affects IDUs (55% of our state's AIDS cases), not including their sexual partners and offspring). But New Jersey also has the nation's largest proportion of cases of women with AIDS (double the national rate); this is the fastest-growing category of people with AIDS in the state. New Jersey now ranks third in the number of infants and children totaling AIDS with 10% of the nation's cases. The spread of infection through heterosexual transmission in adults continues to increase, and recent reports also suggest an alarming rate of infection among teenagers. AIDS threatens not just individuals, but whole families: New Jersey ranks third among the states in the number of stricken infants and young children who have contracted HIV through perinatal transmission. The future of our next generation is at risk. While HIV/AIDS affects all segments of our society, poor and minority communities have been hardest hit by the epidemic. Two-thirds of New Jerseyans with AIDS are African-American or Hispanic. Emphasizing this point, as a consequence of what the National Commission on AIDS terms a "synergy of plagues," drug-abusing African-American men in some of our inner cities are less likely to reach the age of 65 than are men in Bangladesh.

The economic cost of HIV/AIDS also is enormous. For example, the average annual cost of treatment for a person with AIDS has been estimated at $32,000, more than 3/4 of which is spent on inpatient care. The average lifetime cost for one person is estimated to be in excess of $85,000. Existing cases of HIV infection alone therefore represent a potential cost in excess of $4 billion. With estimated growth in the rate of infection and the inflation rate for health care costs, needed health care expenditures could reach as high as $10 billion in the next several years for HIV/AIDS alone. (And this figure does not account for the potential epidemic of associated multiple drug resistant tuberculosis.) Much of the cost must be borne by state and

federal programs. The strategies recommended here, in particular prevention, education, early intervention and alternative care models, all contribute to cost containment. In short, failure to vigorously engage a comprehensive fight against HIV/AIDS is both morally and fiscally inexcusable.

In New Jersey, as in the nation, many have stepped forward to join the struggle against HIV/AIDS. Many others, however, have chosen to ignore or deny the epidemic -- or worse, to discriminate against and stigmatize the stricken. Our response to HIV/AIDS has been at times disjointed, inadequate, and often too slow. It has not been imbued with that spirit of compassion and community in the face of disaster that, in the past, has been a symbol of American society. No clear consensus on how to comprehensively deal with HIV/AIDS has emerged, but postponing decisive action limits strategic options and costs lives. The Governor's Advisory Council on AIDS ("Advisory Council" or "Council") sincerely hopes that this report and its continuing work will join dialogue, forge consensus, and provide an initial blueprint for a swift and effective response.

In the fall of 1990, Governor James J. Florio directed the Commissioner of Health to prepare a plan of action against AIDS designed to coordinate all statewide efforts to fight this epidemic. The subsequent report issued in January 1991, made more than 40 recommendations. Some of them have been implemented; many have not. Perhaps most striking, little has been done to sever the Gordian knot binding HIV infection and injection drug abuse which has been, and continues to be, the single most important factor driving the epidemic in New Jersey.

Recognizing the distance we have yet to travel in combatting HIV/AIDS, and mindful that HIV/AIDS "present[s] a serious public health concern for the state of New Jersey," on 24 October 1991, Governor Florio created the Governor's Advisory Council on AIDS. The Council's charge is to advise the Governor, the legislature and all of New Jersey's residents on the state's efforts "to coordinate and deliver critical [HIV/AIDS] services efficiently and cost effectively to its citizens." This report is our initial response to that charge. The report makes a number of recommendations, some of which will be controversial and politically sensitive. This is inevitable -- even desirable -- for HIV/AIDS raises the most basic questions of balancing individual freedoms with the larger public interest, and of our collective responsibilities to one another.

This interim report is organized into two parts. Part One discusses the Advisory Council's history and process and presents the conclusions and recommendations of the Council's deliberations. The more than 45 specific recommendations are intended to provide a foundational blueprint for the most important principles and priorities for confronting the HIV/AIDS pandemic in the coming decade. The recommendations are followed by a brief analysis of the epidemiology of HIV/AIDS -- of the many faces of HIV/AIDS in New Jersey, now and in the foreseeable future.

Part Two of the report contains a summary of the rationale and approach that informs the Council's recommendations. For purposes of clarity in thought and presentation, both the recommendations and the background discussion of part two are organized around six general themes: A) Prevention and Education; B) Counseling and Testing; C) Care and Treatment; D) Substance Abuse; E) Living With HIV/AIDS: Survival Needs; and F) Government Responsibilities. The Council firmly believes that all of these components must be part of a comprehensive approach to the HIV/AIDS pandemic. The Council stands ready to offer more detailed analysis of the basis for particular recommendations as may be needed to effectuate the goals set forth here.

Much of the Council's deliberative process was conducted by smaller Task Forces which then reported their conclusions to the full Council. The summary reports of these task forces are reproduced in the Appendix to this report. The appendix also contains a number of charts which make more vivid the epidemiology of HIV/AIDS in our state, and reproduces the Governor's Executive Order creating the Advisory Council.

In this report the Council reaches out to all in New Jersey -- to lawmakers, business leaders, health care providers, advocacy groups and citizens -- to join together in making difficult decisions and to implement the policies that must be vigorously pursued. We ask the Governor to step forward and become the leader we lack -- a leader who will enlighten New Jerseyans about HIV/AIDS, help us all to reach consensus on what must be done and how to do it, and galvanize this state to action.

THE ADVISORY COUNCIL'S HISTORY AND PROCESS

Executive Order No. 45 directs the Advisory Council to advise the executive branch on policy concerning "New Jersey's AIDS/HIV efforts to coordinate and deliver critical services efficiently and cost effectively to its citizens." Seeking to confront the many problems posed by the HIV/AIDS pandemic in New Jersey, the Governor mandated the Advisory Council on AIDS to:

a. Advise the Governor on policy relating to AIDS issues;

b. Monitor the Department of Health's implementation of its plan to fight AIDS in the 1990's;

c. Recommend legislation to the Governor;

d. Advise the Governor as to what measures need to be taken to coordinate State efforts concerning AIDS research and treatment; [and]

e. Advise the executive branch concerning its relationship with voluntary agencies and private sector entities involved in AIDS-related activities, including funding sources for research.

The Council is directed to prepare for the Governor an annual report of its findings and recommendations and has the authority to issue interim reports. In fulfilling its mandate, the Advisory Council has an unique opportunity to work in partnership with the Governor, Legislature, courts, state agencies, the Bioethics Commission, health care professionals, professional associations, civic leaders, faith communities, and all of New Jersey's citizens in the complex effort to shape future HIV/AIDS policy for the state.

Advisory Council Appointments

The Advisory Council on AIDS is composed of a diverse group of forty-eight (48) members. The Council's membership includes representatives of the executive and legislative branches of state government, educators, labor representatives, health care providers, persons with HIV/AIDS and their advocates, major statewide professional and health care associations, faith communities, and New Jersey's professional and public communities. By law, the Advisory Council includes two members of the Senate (one from each political party) and two

members of the General Assembly (one from each political party);* designees of the Commissioners of Health, Corrections, Education, Human Services, Community Affairs, and Insurance; as well as designees of the Attorney General, the Public Advocate, and the Chancellor of Higher Education. In addition, there are thirty-five public members appointed by the Governor. On December 10, 1991, Governor Florio designated Paul W. Armstrong, Esq. as the Advisory Council's Chairman, Mr. Peter Jewell its Vice-Chairman, and Ms. Rosemarie Johnson its Vice-Chairwoman.

The Advisory Council is created as a large and diverse body with a broad spectrum of expertise, opinions and perspectives. The composition of the Advisory Council ensures that a wide range of serious and competing points of view are ably, forcefully and openly articulated, in keeping with New Jersey's pluralistic traditions. In fostering a compassionate and comprehensive response to the epidemic, the Council's work may recommend new or different obligations, duties and responsibilities for health care professionals, policymakers and the wider community. The Council believes that its broadly representative character, combined with its open deliberative process, will facilitate the acceptance of its recommendations by the professional community, government officials and the public.

The Advisory Council's Process

In recognition of its role in the political process and its need to respond to a pluralistic society, the Advisory Council opened all its meetings to the public and to public comment, and will continue to do so. The Advisory Council met eight times between December of 1991 and September of 1992, at various locations throughout the state of New Jersey.** All Advisory Council meetings are open to the public and are attended by members of interested groups, New Jersey's private citizens and the press. Notice of these meetings and hearings is placed in the New Jersey Legislative Calendar, and New Jersey's major newspapers are notified of the Advisory Council's meeting schedule and agenda.

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* To date none of the legislative members of the Council have participated in the Council's deliberations.

** A list of Advisory Council meetings appears in Table B of the Appendix.

In addition, on May 27, 1992, the Advisory Council conducted a full day public hearing at the Labor and Education Center at Rutgers University in New Brunswick, New Jersey. At this hearing the Council received oral and written testimony from a broad spectrum of professional, institutional, personal and moral perspectives on a range of HIV/AIDS issues. The testimony addressed the medical, legal, ethical, social, religious and family dimensions of the HIV/AIDS epidemic in New Jersey, and offered a range of very helpful suggestions for proper public policy responses.* (A transcript of the hearing and its written submissions is available for public review.)

The Governor's Advisory Council believes that this openness to public participation and scrutiny accurately reflects the public policy role given to it by Governor Florio. The open process has positively shaped the quality of the Advisory Council's deliberations, and should establish a foundation for public confidence in its work. As the Advisory Council's proposals are submitted for consideration it is hoped that this will foster the necessary basis for informed support by the Governor, legislature, citizens and professional communities.

Council Task Forces

The Governor's Advisory Council has the executive authority to empanel ad hoc task forces for in-depth study of particular issues. The Advisory Council has created six active task forces: Prevention and Education; Counseling and Testing; Care and Treatment; Substance Abuse; Living with AIDS: Survival Needs; and Legislative Initiatives. An additional task force to study budgetary issues has also been empaneled. Like meetings of the full Council, all task force meetings are open to the public.

Advisory Council task forces are established in an effort to take advantage of diversity of expertise in particular areas and to allow input into the Advisory Council's deliberations by a larger segment of the community. In addition to a core group of Advisory Council members, each task force consists of individuals selected for their relevant professional expertise and experience. All task force chairs are members of the full Advisory Council. Each Task Force is charged with addressing the different needs of the varied populations affected by HIV/AIDS. Task forces may conduct public hearings on selected topics to ensure that the positions of

* A list of witnesses who testified at the public hearing is provided in Table C of the Appendix.

various advocacy groups, public agencies, health care organizations, and the general public are properly presented.

Task forces advise the full Council and present recommendations to it for approval. As a matter of both executive requirement and Advisory Council policy, the Council retains final authority and responsibility for all recommendations which are ultimately forwarded to the Governor and the people of New Jersey.

RECOMMENDATIONS OF THE ADVISORY COUNCIL ON AIDS

The HIV/AIDS epidemic cries out for constructive, aggressive, and compassionate leadership at all levels of society, especially at the highest levels of policymaking and government. The state of New Jersey shares with its sister states the urgent need to develop and implement a comprehensive and coordinated approach to the fight against HIV/AIDS, informed by the following fundamental principles and goals:

1. Preventing the spread of HIV/AIDS;
2. Educating the public and professionals about the risks of HIV transmission;
3. Assuring access to needed care and treatment for all persons with HIV infection;
4. Improving the quality of care and treatment for all persons with HIV infection;
5. Fostering more widespread availability and use of voluntary testing and counseling services;
6. Breaking the link between substance abuse and HIV infection;
7. Combatting, through both education and systemic reform, stigmatization and discrimination against persons living with HIV/AIDS ("PLWAs");
8. Acknowledging the need for cultural and ethnic sensitivity in education and provision of services; and
9. Overcoming differential treatment between men and women in research and access to care.

The Council believes it imperative that HIV/AIDS be considered first and foremost a public health problem, with the goals of public health clearly in view. Safeguarding the public health requires that we cast aside ideology, moralism, scapegoating, and partisanship for the common good. The Council also believes it imperative that all existing programs, as well as future legislative and regulatory initiatives, be funded at levels necessary to make these goals a reality.

To these ends, the Council makes the following specific recommendations for action it considers to be most important and most urgent. The central principles and rationale underlying the recommendations are briefly set forth in Part Two of this report.

A. Prevention and Education

1. Educational efforts should stress a strong role not only for health care professionals and trained counselors, but also for educators with whom the target population can readily identify, such as peers and community members. Sometimes the messenger can be as important as the message.

2. Community-based educational programs must be a high priority throughout the state, especially for communities already hard hit by the epidemic. Education must be tailored to the special social, linguistic, gender, cultural, and other characteristics of each community.

3. HIV/AIDS education should be *mandated, evaluated and enforced for all schools and all grades*, in accordance with defined criteria and appropriate content for the age and nature of the student population. It should be integrated into a comprehensive school health education program which also includes substance abuse prevention and family life education.

   - *Condoms should be made available for students at the ninth grade level and above*, as part of comprehensive school health education and prevention programs.*
   - These programs should be in place no later than the 1993-94 school year.

4. Educational programs should be jointly developed by the State Departments of Health and Education, in consultation with community-based professionals, to ensure the accuracy of the message and consistency of its implementation.

   - HIV/AIDS education should *not* be left entirely up to local school boards.
   - Lists of materials, sources, and costs should be provided directly to school boards, administrators, and medical and counseling professionals in school settings.

5. The Board of Higher Education must address HIV/AIDS education for our highly vulnerable young adult population as an *immediate* priority by developing guidelines for content, implementation and evaluation of comprehensive HIV/AIDS curricula.

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* The Department of Education has no plan to consider policies regarding the distribution of condoms in public schools. Under current Department regulations, local district boards may consider adopting such measures if they believe it is in the best interests of their pupils to do so.

6. The Executive and legislative branches should encourage, support and, when necessary, fund mechanisms for evaluating state and privately-sponsored educational programs and materials.

7. New Jersey's public and private sector leadership must be educated on HIV/AIDS issues in order to ensure the effective implementation of all education policies. Initially, the Council urges the Governor to actively endorse education efforts by convening, and personally participating in, a statewide leadership conference within 90 days.

8. HIV/AIDS education efforts should be mandated for all state and county correctional facilities and should be jointly developed by the State Departments of Health and Corrections in consultation with community-based professionals.

9. Education efforts must also recognize and address the emerging and related problem of tuberculosis.

B. Counseling and Testing

1. All primary care providers should incorporate HIV/AIDS education and counseling, with an option for testing, as part of the routine provision of health care.

2. HIV testing should *always* be accompanied by pre-test and post-test counseling, and by documented informed consent. The one exception to this requirement is that pre-test counseling may be waived at blood donor sites.

3. The state should maintain and increase the availability of both confidential and anonymous testing sites throughout New Jersey.

4. Statute or regulation should provide that insurance companies performing HIV testing be required to provide pre-test counseling and to obtain written informed consent.

   - The law should also require that insurance companies promptly inform individuals of their test results and of the availability of post-test counseling in cases in which the test is positive.
   - All test results must be kept confidential, and all persons must be assured of protection against insurance discrimination, regardless of their HIV status.

5. At this time, the Council rejects mandatory testing policies (testing without voluntary informed consent) in any circumstances, including but not limited to cases of routine prenatal care; application for a marriage license; for sexual assault; or needle stick injuries.*

   - Voluntary testing should be encouraged during hospitalization, routine office visits with a physician, and other contacts with the health care system.

6. All individuals providing HIV/AIDS counseling should complete mandatory training, including continuing education requirements. The Department of Health should establish an HIV counseling certification program and should evaluate the need for continuing education of physicians, nurses and other licensed health care professionals.

7. Counseling should be available in the individual's primary language.

8. Male condoms should continue to be made available at all counseling and testing sites. The message should emphasize that using condoms is *safer* sex, not safe sex.

9. Voluntary HIV testing should also be available throughout state and county correctional facilities.

   - The Department of Corrections should examine measures to prevent the spread of HIV and other communicable diseases within correctional settings, including making condoms available in correctional facilities. The Department of Corrections is urged to report its conclusions to the Governor and the Council within 3 months.
   - If necessary, any existing legal obstacles to making condoms available in correctional facilities should be removed.**

10. HIV testing and appropriate counseling should be available at all centers where adolescents seek medical care. The law should permit minors to obtain HIV testing without parental consent.

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* The Medical Society of New Jersey believes that mandatory testing is appropriate in certain circumstances.

** The Department of Corrections does not believe that condoms should be made available in state and county correctional facilities and does not support that portion of recommendation nine above.

C. Care and Treatment

1. Using existing studies and data, a systematic and comprehensive analysis should be made of the availability of HIV/AIDS treatment, gaps in the delivery of services throughout New Jersey, and sources of payment for those services.
   - The goal of the study should be to improve access to affordable care and treatment within reach (geographically and culturally) of affected populations.
   - Approaches to addressing gaps in funding must be identified and implemented.

2. All caregivers must be encouraged to reach out to those with special needs and difficulties in accessing services, including women, children, the incarcerated, the drug-dependent, adolescents, gay and lesbian individuals, and those with physical and/or psychological impairment.

3. Administrative barriers to meeting eligibility requirements for care and treatment must be minimized.
   - The state should develop presumptive eligibility for all state-funded care of people with HIV infection.
   - Eligibility requirements should be revised to eliminate all age gaps for HIV-infected persons and those at risk.

4. The state should develop a *comprehensive* and readily available directory of services in New Jersey for HIV-infected and at-risk individuals and their families.
   - The directory should incorporate all services, including inpatient, outpatient, community-based, home care, case management, preventive, curative, drug-related, and others.
   - Information facilitating access to transportation, volunteer services, and financial resources is also vital.

5. Comprehensive case management should be required in *all* state and federally-funded facilities treating HIV-infected individuals and should be a part of every delivery system for treatment of HIV infection.
   - Among the approaches to explore are New Jersey's AIDS Community Care Alternatives Program ("ACCAP") case management system, which has proven particularly useful, cost-effective, and patient-sensitive.

- The ACCAP (Medicaid) Waiver program and other modes of care should be regularly re-evaluated to assure full utilization and to ensure that there are enough treatment slots for prompt admission into the program for all in need who meet the eligibility requirements.
- Uniform standards are needed for case management.

6. The need for additional institutional long-term care for HIV-infected individuals should be evaluated.
   - The state should promote the expanded availability of long-term care beds in order to anticipate the increase in long-term and chronic care needs for persons living longer with HIV/AIDS.
7. All licensed long-term care facilities in the state should be required to accept cases based on specific patient needs, regardless of the patient's HIV status or age.
8. Home and inpatient hospice care should be made more widely available and accessible.
9. The state should encourage the continued development of AIDS resource centers, consortia, and similar networking models, while seeking to eliminate unnecessary duplication of services.
10. Access for women to HIV/AIDS care and treatment should be enhanced, such as by inclusion of gynecologic care as part of HIV/AIDS care, thereby eliminating the need for an additional visit (or an additional physician). Gynecologists statewide should be educated and trained about HIV infection in women.
11. In the future, the HIV/AIDS pandemic will demand continuing and better education of all health care practitioners and other caregivers, including infectious disease specialists, pediatricians, gynecologists, nurses and social workers, as well as the next generation of caregivers. Development of adequate specialties, such as dental services, nursing and social work is also essential. The state should:
    - Foster the development of alternative practice models, such as multi-specialty group practices committed to HIV/AIDS care;
    - Evaluate the causes for poor response to provider education programs and develop new educational methods which are more effective and better received; and
    - Create a state-funded program of practice fellowships for the treatment of those infected with, and affected by, HIV.

D. Substance Abuse

1. Recognizing the urgent need to break the link between needle sharing and the spread of HIV, the Council strongly recommends the immediate development and implementation of programs making clean needles and other infection-free injection equipment available to IDUs.

   - As has been done in at least 39 other states, New Jersey law should be changed to make needles available over the counter, without a prescription.
   - Following the lead of several other states, New Jersey should also implement needle-exchange programs.
   - The Council stands ready to work with the Department of Health to study the largely positive impact of programs that have been implemented elsewhere and to develop an approach best-suited to New Jersey.

2. Active substance users should have much greater access to drug treatment programs and other services, including HIV prevention and education. These services should stress continuity of care and treatment.

3. Certification and re-certification of substance abuse and alcohol counselors should require HIV/AIDS-specific training, including understanding issues of cultural and class differences and sexual orientation.

4. The public and private sectors should establish drug treatment programs for HIV-positive, pregnant, substance-using women and their children.

5. Male condoms should continue to be available at all alcohol and substance abuse treatment sites. The prevention message should emphasize that using condoms is *safer* sex, not safe sex.

E. Living With AIDS: Survival Needs

1. The state should identify major areas of need, evaluate existing resources, and commit additional resources as necessary to support the needs of persons living with HIV/AIDS.

2. Entitlement programs that provide funding to PLWAs should be increased to assure that no one falls below the poverty level and to further assure that basic living needs are met.

3. A full spectrum of housing options should be made available, including independent and assisted living, group homes, interim housing, homelessness prevention programs, boarding homes, foster care, residential health care, and skilled nursing care.

   - The location selected must assure that family, friends and others in the PLWA's support system can visit.
   - Public housing restrictions that prevent families from caring for loved ones at home should be waived to support caregivers' willingness to "take in family members requiring care."

4. As HIV/AIDS increasingly affects whole families, more resources should be committed to meeting the needs of both children and parents, with an emphasis on maintaining parent-child-family unity.

   - Child care, foster care and respite care services are limited and should be expanded.
   - Support for "orphans to AIDS" -- children who lose their parents to the epidemic -- should be expanded both to assist children caring for their parents and other family members and to provide for their future parenting needs.

5. Eligibility requirements for entitlement and related programs should be broadened to facilitate greater access to needed therapies, earlier intervention (such as by permitting access for asymptomatic HIV-infected persons), and future health care cost savings.

   - Processing of applications should be streamlined to reduce delays in access to needed services.
   - Barriers to access, such as restrictions on eligibility for community resources while hospitalized, should be eliminated.

6. Division of Youth and Family Services ("DYFS") policies relating to HIV/AIDS should be reviewed, with emphasis on maintaining the family unit through the course of the parent's illness.

7. Programs of supportive work and sheltered employment should be developed to provide meaningful work experience that helps PLWAs maintain their dignity and self-reliance during the course of their illness.

F. Government Responsibilities

1. In order to garner the necessary resources and unite the public and private sectors in the fight to meet this crucial challenge, the New Jersey Senate and General Assembly should establish a joint, bipartisan legislative committee with a mandate to coordinate and develop a comprehensive package of legislative initiatives to combat the HIV/AIDS epidemic.

   - The executive and legislative branches, as well as the private sector, *must* be involved in this effort.

2. Legislative initiatives should approach HIV/AIDS as a public health issue with complex and interrelated components.

   - The Council rejects *any* initiative which seeks to employ the engine of the criminal law as a public health measure.

3. The battle against HIV/AIDS should receive strong funding support targeted to assuring accountability, affordability, and availability of quality treatment, care and supportive services.

   - HIV/AIDS should be a central component of approaches to assessing access to quality care for all while containing health care costs as New Jersey confronts the imminent need for widespread reform of our health care system.

4. The Governor should take the lead in a multi-media public education campaign.

5. In order to allow the Advisory Council to meaningfully contribute to the development of HIV/AIDS policy, in the future the Council should be funded at a level necessary to work with a much-needed professional staff and should not be forced to rely solely on volunteer staff support.

The pages that follow present in summary fashion the underlying rationale for the conclusions and recommendations set forth in this interim report. First, however, it is critical to look at the face of the AIDS epidemic in New Jersey, a face distinctly different from that of the national epidemic.

THE UNIQUE NATURE OF THE HIV/AIDS EPIDEMIC IN NEW JERSEY*

New Jersey has been one of the states hit hardest by the HIV/AIDS epidemic. Our state ranks fifth among all states in the number of reported AIDS cases, with 13,572 cases reported as of June 30, 1992. The number of reported AIDS cases has doubled since April 1989, representing 6% of the nation's total. It is estimated that 30,00 to 50,000 New Jerseyans are infected with HIV, all of whom will eventually develop AIDS or AIDS-related illnesses, most likely before the next decade.

At current and projected rates of HIV transmission the number of New Jerseyans affected by HIV/AIDS will increase dramatically in the years ahead. A small indication of the potentially dramatic growth of New Jersey's HIV/AIDS epidemic is that the rate of heterosexual transmission has increased from 7% to 13% of all AIDS cases in the past five years. Heterosexual contact is the fastest-growing mode of HIV transmission. Equally significant is the recent proposed expansion of the Center for Disease Control's ("CDC") case definition for AIDS. The new CDC case definition, which is likely to be adopted by early 1993, includes a broader range of signs and symptoms in women and injection drug users as indicative of reportable AIDS cases. Initial estimates of the impact of the definition posit an alarming 50% to 70% increase in the number of AIDS cases both in New Jersey and nationally in the next year. These are but two illustrations of the enormous crisis we confront. In the words of Dr. June E. Osborn, Chairperson of the National Commission on AIDS, "Numerically, the HIV epidemic in the decade of the 1990's will be far worse than what we have seen so far, and it will touch us all."

AIDS and AIDS-related conditions caused by HIV infection have become the leading causes of death among large segments of our population. HIV is the single leading cause of death for all New Jerseyans age 25-44. HIV is the leading cause of death among white and black males age 25-44 in New Jersey. For women in the same age group, HIV ranks among white females second and first among black females as a cause of death. While HIV affects persons of all ages (it was the eighth leading cause of death for persons age 45-64), it poses a

* This section is based on information provided to the Council by the Division of AIDS Prevention and Control of the Department of Health.

substantial and growing threat to young adults, teenagers and children. HIV/AIDS has become the second leading cause of premature death preceded only by cancer. And the HIV virus does not discriminate based on age. As forcefully illustrated by the American Association of Retired Persons (AARP) commitment to the battle against HIV/AIDS in its 1992 public policy agenda, the epidemic threatens as well our elderly citizens and their families.

The HIV/AIDS epidemic has had a disproportionate impact on New Jersey's minority communities. AIDS cases among African-Americans and Hispanics account for 67% of the state's total, in contrast to 45% nationally. More than three in four (78%) of New Jersey women with AIDS are African-American or Hispanic. And more than four in five (81%) of pediatric cases are among African-American or Hispanic families.

What also makes New Jersey's HIV/AIDS epidemic and the battle before us unique are the disproportionate numbers of HIV/AIDS cases among women, children, and injection drug users, relative to the rest of the nation. New Jersey ranks third nationally in the cumulative number of reported AIDS cases among women; 2,942 as of June 30, 1992. Women represent nearly 25% of all New Jersey cases (more than 10% of the number of women with AIDS nationally). With the expected adoption and implementation of the expanded CDC definition this number will dramatically increase. That 33% of women contract HIV through heterosexual contact is disturbing; equally disturbing is the fact that 60% contract the virus through sharing of injection drug equipment. Sharing of needles and other injection drug equipment is the most frequent mode of HIV transmission among women and newborns, and in our African-American and Hispanic communities. Fifty-four percent (54%) of our state's AIDS cases are the result of injection drug use, well above the national average of 23%. And this number likely does not include many who contract HIV through sexual contact with IDU partners. The goal of breaking the link between substance abuse and HIV cannot be overstated.

New Jersey also has the third highest number of pediatric AIDS cases of any state. Our seroprevalence rate for newborns is 5.45 for every 1,000 births, placing New Jersey third only to the District of Columbia and New York in frequency of infection per number of births. Pediatric cases are heavily concentrated in the Newark metropolitan statistical area, which includes Essex, Morris, Sussex and Union counties. An overwhelming majority of newborn HIV cases (94%) are the result of perinatal transmission from mother to fetus. (The other 6%

of cases of children with HIV have been caused by blood transfusions, such as in treatment of hemophilia). The extraordinary frequency of perinatal transmission makes even more poignant that HIV/AIDS is increasingly becoming an epidemic of families, putting our future generations at grave risk.

The Council's deliberations have been highly cognizant of both the size of the epidemic and the particular populations most affected by HIV/AIDS in New Jersey. Part two of this report sets forth in summary fashion the principles and rationale that inform the Council's conclusions and recommendations. Assessment of the Council's positions requires that we keep before us the many faces of the HIV/AIDS pandemic that run throughout our diverse and pluralistic communities.

PART TWO: SUMMARY RATIONALE AND APPROACH

PREVENTION AND EDUCATION

The ways in which HIV is transmitted are well documented. HIV can be transmitted through sexual contact; through sharing of contaminated drug injection equipment; during the gestational period or at birth (and possibly through breastfeeding); and through exposure to infected blood or blood products (such as through needle stick injuries). Transmission of HIV is the result of certain behaviors. Until we have a vaccine or cure, effective education that reduces risk-prone behavior is our most vital weapon for preventing the spread of HIV infection, AIDS, and associated illnesses and health problems. Education campaigns are also essential in the effort to change public perceptions about HIV/AIDS and PLWAs that underlie discrimination against PLWAs, whether overt or covert.

The goal of HIV/AIDS education is to alter attitudes and behavior so that personal conduct is both risk averse and based on scientifically accurate and psychosocially appropriate information. The educational effort should include among its core features: 1) current and valid information about the health and medical aspects of prevention and intervention; 2) sensitivity to the human issues related to HIV and AIDS; and 3) awareness of emerging problems related to HIV and AIDS. Effective tools for regular evaluation of the impact of these efforts should be a part of any education strategy.

In New Jersey many individuals and organizations have committed themselves to HIV/AIDS education. We owe a huge debt of gratitude to the numerous professionals and volunteers who have carried the education and prevention message into our schools, communities, workplaces, and public forums. Strategies designed to prevent new HIV infections as well as those targeted to slow the disease process through early diagnosis, treatment and continuing care have proven effective in changing attitudes and reducing risk behaviors. But we need to do much more, with greater coordination, persistent commitment, wider participation, and active government involvement.

An accurate, consistent, and centrally coordinated approach to education about how HIV is transmitted, how its spread can be prevented, and what to do if one believe he or she has been exposed to HIV is critical. The message must be explicit and culturally sensitive in dealing with

questions of safer sex, regardless of sexual orientation. We must also confront forthrightly the social and cultural dimensions of the link between HIV-infection and the sharing of injection drug equipment and the consequences of perinatal transmission for families and children living with HIV/AIDS.

While the medical and scientific basis for such discussion is well-established (though medical knowledge continues to progress), the moral foundations for HIV/AIDS education have been the source of considerable controversy. Concerned individuals harbor sincere disagreements about such issues as personal responsibility for engaging in risk-prone behavior; social tolerance (if not acceptance) of traditionally "taboo" or marginalized conduct involving sex and drugs; exposure of our youth to sexually explicit material and conversation; and the proper role of government in promoting and supporting HIV/AIDS education. In fact, as noted by the National Commission on AIDS, most of the disagreement in our society is not about goals, but about how we should strive to achieve those goals, and who should decide the methods to be used.*

The Council strongly believes that the content of all HIV/AIDS education and evaluation of its effectiveness must be based on its ability to alter behavior and increase the prevalence of risk-averse conduct among our citizenry. The Council's position echoes the powerful voice of the National Commission on AIDS:

> Constraints on discussions of sex, whether imposed by law, political considerations, issues of morality, language, or culture, have been a substantial barrier to the creation and implementation of effective HIV prevention programs. There is a cruel irony at work here, for reticence about discussing sex has become an obstacle to the implementation of lifesaving prevention programs. This withholding of potentially lifesaving information raises serious ethical problems.**

When human lives hang in the balance, moral judgments about personal lifestyle, sex education or other concerns which prevent access to life-saving information are improper, counter-productive, and dangerous.

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* National Commission on Acquired Immune Deficiency Syndrome, *America Living with AIDS: Transforming Anger, Fear, and Indifference Into Action* (Wash., D.C. 1991), p. 21.

** *Id.*

As noted above, medical and scientific understanding of HIV transmission, its signs and symptoms, the efficacy of available treatments, and personal health management are only some of the components of a comprehensive education program. Prevention education must also confront and be tailored to the social, cultural, psychological, linguistic and human dimensions of the pandemic in our pluralistic communities. Often we look to health care professionals to provide medical and public health education, and health care professionals have a vital role in HIV/AIDS education. But a multi-dimensional educational message requires a multi-faceted army of educators: from certified HIV counselors to family, friends and religious leaders; from community-based organizations to the Governor and legislative leaders. Indeed, each of us has a responsibility of self and collective education and prevention. Here, the Council wishes to emphasize that in order to be most effective the target population, the educated, must identify with the educator. Establishing a bond of trust is often a pre-condition to opening the ears and mind of the listener. Sometimes the messenger can be as important as the message. Support for community-based educational programs must be a high priority throughout the state, especially for the multitudes of communities living within our inner cities most affected by the epidemic.

Some may argue that we cannot afford to undertake such a massive education campaign. The Council's response is that we cannot afford not to. Beyond the incalculable cost of human lives, there is good evidence that HIV/AIDS education is in fact cost-effective in economic terms. For example, recent federal data involving an AIDS population in Brooklyn, New York reveal that the prevention of just one case of AIDS saves approximately $33,000 per year in health care costs alone. Large-scale aggressive education and prevention efforts mean cost savings in untold ways, including in expenditures of the health care dollar.

HIV/AIDS Education in the Schools

One of the fastest growing and often ignored dimensions of the HIV/AIDS crisis is the spread of HIV among our teenagers. AIDS is the sixth leading cause of death among 15 to 24 year olds, and the fifth leading cause of death for young adults in New Jersey. Nationally, AIDS cases in this age group have increased 77% in the past three years. Heterosexual transmission accounts for twice as many cases of HIV among young people as in the general population. Forewarning the expanding crisis proportions of the epidemic, recent reports project

that HIV is spreading rapidly and unchecked among adolescents, regardless of socioeconomic status.

HIV/AIDS education should be *mandated* in all New Jersey schools and for all grades. Comprehensive programs and curricula should be developed under the authority of the Departments of Health and Education in consultation with community-based professionals. The education program should be implemented in accordance with defined criteria with age-appropriate content. HIV/AIDS education criteria and content must be non-judgmental, culturally appropriate, gender-specific, developed through valid research, supported through quality management techniques, and related to life-skills and family-life education. Educational approaches should be articulated through multiple media. Discussion of HIV/AIDS must be frank and to the point, and should emphasize peer support groups and discussion. Of special importance, misplaced feelings of invulnerability ("it can't happen to me") must be confronted, as must means of resisting peer pressure to participate in risky behavior. All programs should be regularly evaluated for impact, the chief measure of which should be behavioral outcome.

The most controversial and visible debate over HIV/AIDS and sex education in the schools is not so much about the content of school education as it is about whether condoms should be available in our school systems. And yet, the scientific prescription for safer sex is clear. Short of abstinence, use of a condom is the most effective method of protection against HIV.

In responding to this critical issue, it is imperative that the goals of public health be kept clearly in view at all times, unclouded by the narrow and often conjectural objections that condoms are immoral, will promote sexual activity, or simply have no place in the public schools. In the Council's judgment condoms should be available as part of a comprehensive school health education program for all students at the ninth grade level and above. The Council wishes to note that the recommendation to integrate condoms as part of a safer sex component of the curriculum at the ninth grade level and not earlier is a prudential judgment, and clearly one with which others may disagree. It is felt, however, that this approach properly balances the reality that most teenagers are or may become sexually active by age 15 with concerns that younger students may not be sufficiently mature for discussion of condoms, which must be explicit to be appropriate and effective.

At present, the Department of Education advocates HIV/AIDS education within a comprehensive school health education program. The Department has developed very good and widely recognized instructional guides, which the Council endorses. The Department requires the inclusion of HIV-related education in school curricula, but interpretation and implementation of this mandate is left to individual school boards. The result has been variation in curricula that ranges from excellent and comprehensive to virtually non-existent. There also is no effective mechanism to ensure implementation of HIV/AIDS curricula. In order to ensure the accuracy and appropriateness of the education message and, most importantly, to ensure consistent and uniform implementation throughout the state, HIV/AIDS education should not be left entirely up to local school boards. Coordination of resources should include direct distribution of appropriate lists of materials, resources and costs to school boards, administrations, and medical and counseling professionals in school settings. Furthermore, the Board of Higher Education must consider HIV/AIDS education as a priority issue, and should work with the Department of Health and the Department of Education to develop guidelines for content, implementation and evaluation of comprehensive education efforts.

In the development of secondary and higher education programs, the state should encourage and fund the evaluation of state and privately sponsored programs and materials used in HIV/AIDS education. Currently, a wide gamut of programs, articles, brochures, videos, public service announcements, newsletters, comic books and speaker panels address HIV/AIDS. A means of evaluating their appropriateness and effectiveness as well avoiding duplication in the face of limited resources is needed. At the very least, the state-supported efforts must beexternally reviewed. Comprehensive HIV/AIDS education should be in place no later than the 1993-94 school year.

Government and Private Sector Leadership in HIV/AIDS Education

Full funding of HIV/AIDS is critical, but it is not enough. The state's government and private sector leaders must themselves be educated on HIV/AIDS issues. This will serve to assure effective implementation of all HIV/AIDS education policies and programs. New Jersey's Governor, legislators, college presidents, state department heads, judges, chief executive officers, correctional facilities superintendents, insurance executives, and other key decisionmakers and opinion leaders must be fully informed of the magnitude of the HIV/AIDS epidemic and the need for educational intervention. Current HIV/AIDS education efforts and

activities are generated and supported largely at the lower levels of public and private sector agencies and institutions with little, if any, endorsement or support from their leadership. This must change. As an initial step, the Council recommends that the Governor actively endorse education efforts by convening, and personally participating in, a statewide leadership conference, within 90 days.

HIV/AIDS Education in Correctional Facilities

We cannot ignore the presence of HIV/AIDS in New Jersey's correctional facilities. HIV/AIDS education efforts should be mandated for all state and county correctional facilities. The criteria and content of HIV/AIDS education for these facilities should be jointly developed by the Departments of Health and Corrections, in consultation with community based professionals. Education and prevention efforts should build on those limited programs in the juvenile and adult correctional facilities of the state, and should assure consistency as well as sensitivity to differences among institutional settings and their particular populations. Attention to the particular education and health care issues for women must be addressed in all facilities housing women.

Emerging and Future HIV/AIDS Related Problems and Threats

The awareness of potential and emerging threats must be addressed as a part of the education process. Implementation should include a mechanism for keeping up-to-date on HIV/AIDS developments. This will require, among other things, close cooperation between the Department of Education and the Department of Health's Division of AIDS Prevention and Control. A stance of proactive education in anticipation of emerging issues should be adopted. In particular, education efforts must recognize and address the emerging problem of tuberculosis (TB). A second epidemic of tuberculosis, and specifically multiple-drug resistant TB, is emerging as a complication and consequence of the HIV/AIDS pandemic. The state of New Jersey is especially at high risk for drug-resistant tuberculosis because of its large number of HIV-infected and at-risk populations. Proactive TB education should be implemented at this time.

COUNSELING AND TESTING

Widespread testing for HIV infection is an essential component of effective prevention, care and treatment efforts. Testing should always be coupled with pre and post-test counseling (with rare exceptions). When accompanied by appropriate counseling, presentation for an HIV test is an opportunity for education about HIV infection and how to prevent transmission of the virus to others. A positive test result can promote entry to the health care system and for many, early intervention, bringing the benefits of preventive maintenance, care and treatment, as well as access to new treatments, to larger numbers. As recommended by the Department of Health in its January 1991 AIDS Plan, health care professionals and workers should encourage widespread HIV testing, especially for sexually active people. Indeed, all of us should seek to enhance awareness of the benefits of HIV testing.

If we are to succeed in encouraging more widespread presentation for HIV testing, individuals must be protected from possible discrimination and ostracization should positive HIV status become known to others (or even knowledge of merely having had an HIV test). New Jersey law should be strictly enforced (and if necessary changed) to assure that HIV positive persons are not denied health care coverage or access to needed care because of their HIV status, and that they are not the victims of other more subtle forms of discrimination. Currently, HIV testing is available in New Jersey on both a "confidential" and "anonymous" basis, both of which are intended to protect the privacy of personal information and minimize opportunities for discrimination. Confidential testing restricts personal identifying information to limited persons, such as the physician and nurse who have obligations to guard the privacy of this information and to report positive results to the Department of Health. Anonymous testing is conducted without personal identifying information. Each option has its advantages and disadvantages. For example, confidential testing better allows follow-up counseling and intervention, while anonymous testing may be the only option for those distrustful of the health care system and unwilling to disclose their HIV status even to health care workers. Both options should continue to be available and expanded; both are currently available at Department of Health supported counseling and testing sites.

Voluntary vs. Mandatory Testing

The debate over HIV testing is often framed as a question whether testing should be voluntary or mandatory. Confronting this issue demands that we balance individual rights and liberties with public health imperatives. This may seem a difficult balance, particularly in cases of perinatal care or non-compliant patients. Proposals for mandatory testing have focused on particular occasions for interaction between persons and institutions -- on "captive" populations such as hospital patients, prisoners, or applicants for a marriage license.

The Council strongly believes that there is no role for mandatory testing at this time. In principle, mandatory testing policies would constitute an undue invasion of traditional commitments to the value of personal liberty, choice, and privacy. While some argue that such policies offer important opportunities for intervention, they are equally likely to have the opposite effect by chasing people from the system. Furthermore, as a practical matter, mandatory testing would offer limited additional scientific benefit. Given the latency period for seroconversion, a negative test assures only that the individual was free of HIV at that point in time. How often will each person be re-tested? Existing protections against discrimination once HIV status is known, such as impairment or loss of health care, insurance, employment, housing, or social networks are highly inadequate. Moreover, the economic cost of mandatory testing is enormous, even without follow-up testing.* In short, mandatory testing comes at too high a price. If (when) medical science develops more effective treatments in the battle against HIV/AIDS and can offer realistic prospects for a cure or a preventive vaccine, the value of early intervention could well shift the balance the other way. (Presumably a consequence of these medical advances would be a substantial decrease in public fear and discrimination.)**

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* For example, Senate bills 98 and 182 call for mandatory HIV testing for all applicants for a marriage license. In 1988, there were 61,000 couples married in New Jersey. At an average cost of $35 per HIV test (a conservative estimate), the total annual cost of this proposal would be more than $4 million.

** The Council believes that the issue of HIV testing for patients and health care workers is a part of a larger set of issues surrounding the physician-patient-health care professional relationship that warrants further study. The Council concurs with current CDC guidelines which reject mandatory testing of either patients or health care workers.

Counseling

HIV-testing should always be coupled with pre and post-test counseling and documented informed consent. HIV counseling is essential to modifying behavior. Equally important, counseling helps individuals to cope with the psychological burdens of an HIV-positive test (and simply having the test in the first place), and guides future changes in behavior. Furthermore, in accordance with established principles of medical ethics and law, the patient-health care professional dialogue should facilitate a level of understanding necessary for the patient to give informed consent to testing. For the benefit of both patients and providers and to ensure informed decisionmaking the patient's informed consent should be documented. The Council notes as an exception to this rule that it is acceptable to waive pre-test counseling at blood donor sites.

Effective counseling demands accurate and current knowledge of HIV/AIDS and associated illnesses; understanding of personal, social and cultural dimensions of living with HIV/AIDS; and ability to access information needed to refer HIV-infected persons to appropriate services and resources. All individuals providing HIV/AIDS counseling should complete mandatory training. The training program should include continuing education requirements. As part of this effort, the Department of Health should establish an HIV Counseling certification program and should evaluate the need for continuing education for physicians, nurses and other health care professionals. In addition, coordination of services is needed to assure that counseling is readily available in the patient's primary language, whether in the counseling and testing site, the hospital, or the doctor's office. All counseling and testing sites should make male condoms available as part of the counseling/education program. Again, the message should stress that use of condoms is safer.

In the effort to encourage wider resort to HIV testing, voluntary testing should be encouraged in the course of routine interactions with the health care system, such as during office visits and hospitalization. Particular attention should be paid to offering counseling and encouraging testing for adolescents, such as at centers where adolescents seek medical care. In this regard, the Council urges that the law expressly permit minors to consent to HIV testing without the need to obtain parental consent (or discuss the issue with their parents). All primary care providers should incorporate HIV counseling and education as part of the routine provision of health care. The option of testing on a confidential or anonymous basis should be offered.

Counseling and Testing in Correctional Facilities

As with prevention and education, the Council recommends that priority be given to HIV testing and counseling in the state's correctional facilities. While inmates receive some HIV/AIDS education, the state should make voluntary HIV testing and counseling available in all state and local correctional facilities in accordance with the principles discussed above. The Council recommends that the Department of Corrections study measures to prevent the spread of HIV and other communicable diseases in its facilities and report its conclusions to the Governor and Council within three months. The Council notes the Department of Corrections position that condoms should not be made available as part of prevention education and counseling services in correctional facilities. The Council respectfully disagrees. As with other persons affected by HIV, condoms are an essential component of effective counseling and education to practice safer sex.

Insurance Coverage for Persons With HIV-infection

As noted in several places throughout this report, failure to provide strong protection against HIV/AIDS discrimination in insurance is fatal to an effective campaign against HIV/AIDS. The risk of losing health or life insurance, or of significant impairment of benefits, deters many from seeking early HIV testing before the onset of illness. Others will not be tested at all, or feel compelled to disguise information for fear of losing existing coverage or being unable to obtain a health insurance policy. In some cases such perceptions may be ill-founded (and the remedy education), but for many insurance discrimination is a real and devastating dilemma. Statute and regulation must be strictly enforced, and if necessary changed, to eliminate insurance industry discrimination against persons with HIV. All citizens must be assured that the state will actively enforce this policy.

Again, the importance of counseling and informed consent to HIV testing cannot be understated. And the insurance industry is no exception. Statute or regulation should mandate that insurance companies performing HIV-testing are required to obtain written informed consent and to provide pre-test counseling. All insurers should also be required to promptly inform individuals of their test results. For those with a positive test result, information about the availability of post-test counseling should be provided.

The Council would welcome the opportunity to work with lawmakers, the Departments of Insurance and Health, and insurance industry representatives to effectuate these recommendations.

CARE AND TREATMENT

Persons who are at-risk for HIV/AIDS, HIV-positive, or PLWAs have wide-ranging care needs that vary in particular populations and with the extent of illness. Broadly defined, this care may encompass any or all of the following: acute, palliative and terminal care; psychological counseling and support; drug treatment; living and social service assistance (including, but not limited to, such basic needs as housing and food); testing; counseling; and education. For the most seriously ill, care may mean the involvement of acute-care facilities and aggressive treatment, or hospice and home care; for others with less progressive illness it may mean community-based organizations, assisted living and support services.

HIV/AIDS treatment cannot be simply defined. AIDS and AIDS-related conditions manifest a broad array of opportunistic infections and may involve a number of organs and organ systems. Further, many people who are HIV-positive or have AIDS either were or are substance users whose treatment needs differ markedly from those of other patients. Accordingly, appropriate care and treatment for those with HIV/AIDS encompasses an extensive spectrum of needs and services. The ultimate goal of a care and treatment plan should be to enhance quality of life, optimize individual choice, and reduce institutional-based care.

Whatever the degree and nature of care required, it is imperative that the services are accessible to those in need. Access is denied when programs providing treatment or support services are geographically out of reach, tailored only to specific cultural or gender groups, or financially unaffordable. The Council therefore recommends that a systematic and comprehensive analysis of the availability of HIV/AIDS treatment in New Jersey be conducted. Gaps in service delivery and in sources of payment must be identified, addressed and implemented. Further, administrative barriers to meeting eligibility requirements of care and treatment must be minimized. The Council urges the state to develop presumptive eligibility for all state-funded care for HIV-infected persons and to revise the eligibility requirements to eliminate age gaps for the HIV-infected and those at risk. An additional recommended tool for improving access to services is the creation of a comprehensive and readily available directory incorporating all services, including inpatient, outpatient, community-based, home care, case management, preventive, drug-related, and others for HIV/AIDS individuals and their families. The directory should also include information that facilitates access to transportation, volunteer services, and financial resources.

Acute and Long-Term Care

Acute care in the hospital setting is appropriate for many AIDS patients suffering from a wide range of ailments as well as HIV positive patients with opportunistic infections. Yet, the acute care setting offers the least autonomy to patients and generally is the most expensive. Not all patients in acute-care facilities require highly aggressive care. In fact, hospitals too often become the dumping grounds for HIV/AIDS patients who are refused access to nursing homes, residential health care facilities and hospice programs better suited to their needs. In addition, a number of medical procedures that once required hospitalization can now be performed on an outpatient basis. Many patients are indigent, without health care insurance or under-insured, aggravating the financial drain on all hospitals, particularly inner city hospitals. Finally, with the anticipated exponential increase in the numbers of persons with HIV/AIDS, the quantity of available and fully funded acute-care hospital beds in health care facilities which have appropriate medical and social services for this population may soon prove inadequate.

While some New Jersey nursing homes care for AIDS patients, many have been resistant to admitting them. One significant exception is the Wanaque Convalescent Center in Wanaque which maintains a substantial number of skilled nursing beds for persons with AIDS. It is a commendable beginning, but the number of patients in need of the care that can be provided in such a setting far exceeds the number of openings at Wanaque. An evaluation should be conducted of the need for additional institutional long-term care, the state should promote the expanded availability of long-term care beds at existing or new facilities, and home and inpatient hospice care for terminally ill AIDS patients should be made more widely available and accessible. The Council therefore recommends that all licensed nursing home facilities in the state should be required to accept cases based on specific patient needs, regardless of the patients HIV status or age, and provide the services they require.

Case Management

Comprehensiveness, integration and coordination are keys to meaningful health care delivery. Traditional acute-care and long-term care models for thinking about health care delivery are crucial components but they cannot be the sole lens through which HIV/AIDS is viewed.

Outpatient care is the preferred means for dealing with those at-risk for HIV/AIDS, HIV-positive or with AIDS. It offers the least restrictive environment for the individual at the lowest cost. However, proper outpatient care requires that an individual's numerous health care and social service needs be satisfied outside of the institutional setting. Case management often serves as the organizational framework for outpatient and community-based care.

Case management generally involves the coordination of medical care services, entitlement and other income support programs, and social service needs. In some cases, case management programs are government-funded and linked to hospital discharge plans; in others, they are community-based and track individuals in and out of acute-care settings. Case management programs may also originate in Medicaid waiver programs or in health maintenance organizations. A case manager may be a nurse, social worker or physician. Ideally, case management provides for care and services throughout the course of the illness, and may include arranging for visiting nurses, delivery of medications, dental care, transportation and babysitting. The case manager should know how to obtain all the necessary services at the lowest possible cost.

One case management approach that has been implemented in New Jersey is the Early Intervention Program ("EIP") (formerly part of the comprehensive care model known as the Treatment Assessment Program). EIP is predicated on the importance of providing services to those who are still asymptomatic and whose immune systems are not yet severely compromised in an attempt to ensure longer, healthier lives and fewer medical expenses. The EIP case manager develops a plan for each individual, referring the person to a variety of providers and agencies, including drug treatment programs, government-offered social services, specialty medical clinics, long-term care facilities, local hospitals, private providers, social security and welfare offices, and an assortment of appropriate community-based organizations. There are currently seven designated EIP sites in the state, which together enroll over 5,000 people.*

* These are St. Michael's Medical Center, UMDNJ Stratford/Camden, Jersey City Medical Center, Raritan Bay Medical Center, St. Joseph's Hospital and Medical Center, Elizabeth General Medical Center, and Atlantic City Medical Center.

Yet, the goals of early intervention are too often frustrated by late entry into the system. In practice, relatively few persons actually present as asymptomatic. Consequently, persons with HIV/AIDS need a broader range of services and more intensified case management from the outset of the case manager-client relationship.

A federally sponsored case management program was established in 1990 pursuant to the terms of the Ryan White Comprehensive AIDS Resources Emergency Act. Under Title II, the Act appropriates funds to improve the medical care and support services for individuals with HIV/AIDS and their families. Six community-based networks of social service providers, called HIV Care Consortia, exist in New Jersey covering eleven (11) counties.* The consortia are mandated to organize systems of care by developing public/private partnerships of necessary providers and community-based organizations; identify gaps in service needs, develop a comprehensive continuum of services to meet those needs; coordinate and integrate community resources; employ effective case management; and provide cost-effective alternatives to acute care settings. Five of the consortia house HIV/AIDS "one-stop shop" resource centers to direct HIV/AIDS individuals to appropriate medical and social services. The centers also organize public awareness and prevention education programs. Each consortium is designed to fit the needs of the specific populations it serves.

Newark and Jersey City/Hudson County were the recipients of Title I Ryan White Funds, designated for areas disproportionately affected by the disease and in need of emergency assistance. Thirty-eight organizations constitute the Hudson County AIDS Consortium. The Newark program is a consortium of 26 organizations which provide medical and social care to people with HIV/AIDS in Newark, East Orange and Irvington. While administrative problems have made full delivery of services difficult for some programs, significant services have been provided to these communities. It is worth noting that the organization of the two Title I programs was already in place before the federal funds became available. The programs were preceded by the AIDS Health Services Program (funded by the Robert Wood Johnson Foundation) which developed a network of community-based health and social services for HIV/AIDS patients in Newark and Hudson County.

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* They include: Coalition on AIDS in Passaic County; Middlesex County Health Department; AIDS Coalition of South Jersey; Shore Area Health Education Center; Bergen County AIDS Coalition; and Union County AIDS Coalition.

Despite the success of EIP and Ryan White programs, case management has encountered several obstacles, many of which stem from inadequate program funding. As of the end of 1991, the spaces in the TAP program were filled, and only 20% of the HIV-positive population in New Jersey were able to take advantage of its offerings. Each site had a long waiting list of those eager to participate. Low levels of reimbursement hold back the expansion of the program, and outpatient providers receive poor reimbursement, reducing the number willing to be involved. Further, early intervention employs prescription drugs, for which there is little remuneration. Reimbursement is also inadequate for many of the social services to which case managers would like to refer their clients.

The AIDS Community Care Alternative Program ("ACCAP") community case management program, an innovative and award-winning New Jersey Medicaid waiver program, has proven successful for over 2,000 clients since its inception in 1987. Case managers at sites in each county serve as advocates to guide clients through the health care system, while also arranging for home care and support services. This program has been widely acknowledged for its useful, cost-effective and patient-sensitive service delivery. Despite ACCAP's success, however, service shortages and gaps remain a problem for this and all case management systems. Client surveys indicate that chief among these gaps are a lack of transportation and inadequate numbers of home care personnel. Case managers also report difficulty arranging for housing, dental care, and psychological services.

The Council fully supports case management and recommends that it be mandated in all state and federally-funded facilities treating persons infected with HIV. Moreover, comprehensive case management should be a part of every delivery system treating HIV patients. The Council urges the adoption of uniform standards for case management and regular re-evaluation of programs like ACCAP to assure full utilization as well as the availability of treatment slots. The Council encourages the continued development of AIDS resource centers, consortia, and similar networking models, simultaneously seeking to minimize unnecessary duplication of services in favor of valuable use of resources. Finally, the creation of alternative practice models such as multi-specialty group practices committed to HIV/AIDS care is urged. It is the belief and hope of the Council that continued development of case management programs will reduce the need for inpatient care, enhance the quality of life of persons infected with HIV, and help to control health care costs.

At the same time, the best financed and developed inpatient facilities or outpatient programs will nonetheless fail to accomplish many of their goals if the large variety of distinctive needs of the different populations they serve remain unmet. The care and treatment requirements of HIV/AIDS women, young children, adolescents, the poor, the homeless, the incarcerated, substance users, all differ and must be taken into account to be effective.

Women

As noted above, the needs of women with HIV/AIDS must be addressed as an immediate concern. Since the beginning of the pandemic women have been viewed primarily as vectors (sources) of transmission. As a result, much of the attention has focused on pregnant women and children. Consequently, the natural history of HIV in women has not been studied. Women with HIV have been stigmatized as persons who transmit HIV and have not been viewed as persons with specific health needs. Both education and treatment efforts have inadequately addressed survival and health care needs and access to treatments for women. Only recently has the survival rate for women increased, although it is still less than that of men. The state Department of Health has yet to produce a protocol for the identification and management of HIV in women although one exists for men and children. The development and completion of this protocol must be a priority. Health care professionals should be educated about the gynecological signs and symptoms of HIV infection, including those identified in the proposed new CDC case definition on AIDS. Too often significant symptoms and opportunities for early intervention go unnoticed.

Pregnant women have particular concerns. Their physical, nutritional, financial, and other needs require informed attention distinct from other affected populations. Psychological and emotional counseling and support, including assistance in planning how to provide for her infant is particularly vital. If facilities or programs do not provide for child care for those with children (an additional cost), opportunities to improve the quality and length of their lives may be lost. Further, as discussed below, there are few drug treatment slots for women, and even fewer for pregnant women.

Many efforts have been made to provide health care to pregnant women. Equal attention must be given to women regardless of childbearing intent. Attention to the needs of older women must be included in all education and treatment efforts.

Children and Adolescents

Children with HIV/AIDS are a particularly vulnerable group. Due to the lack of development of their immune systems, the infection often pursues different avenues than the course of HIV in adults. Moreover, children need access to wide-ranging and developmentally appropriate health and social services, much of which is not sufficiently reimbursed by Medicaid. Few acute-care facilities provide a full complement of care needs for children; more are sorely needed. Children who do not require hospitalization but who are awaiting foster placement or a return to their natural families need transitional pediatric residences. Very few such programs exist in New Jersey -- three are in place at St. Clare's Homes for Children. Similarly, day care centers are few and far between for HIV/AIDS children who are too ill or in some cases developmentally disabled to be mainstreamed. The Parent/Child Extension Center in Newark, which is the recipient of state and federal money for day care, pre-school programs and medical care, is one model to be emulated.[14] Further, case management programs designed to satisfy the special needs of children are needed. Pediatric AIDS Regional Treatment Centers providing family focused case management services currently serve over 700 children; however, the funds are limited and the needs of the pediatric HIV/AIDS population are not being satisfied.

Children of parents with HIV/AIDS eventually become "orphans to AIDS." Social service needs for these children must include obtaining foster and adoptive parents and establishing support networks. Parents should be encouraged and assisted to plan ahead for the welfare of their children, including drafting testamentary wills and designating a guardian for the children in the future. Development of standard forms for this purpose and legal services support should be encouraged.

Access and Resources for Other Affected Groups

Those who are poor but not on Medicaid frequently lack the financial resources needed to take advantage of many programs and services, including case management. One result is that overcrowded and under-funded hospitals often replace the role of the family physician or case manager. Ultimately, this means a decrease in the quality of life of the person who need not be a hospital inpatient, and unwarranted increases in medical costs. Additionally, those with HIV/AIDS who do not live in cities where medical or social services are readily available may be denied access to essential health care. Though the majority of HIV/AIDS cases in New

Jersey are centered in the state's northeastern cities -- Newark, East Orange, Jersey City, Paterson and Elizabeth -- HIV-infected individuals live in every city and county of the state. Transportation must be provided to ensure access to services of even the most destitute PLWAs. Information services to help patients and families access transportation would be an important resource and should be made available. Child care services, lack of which often prevents women from accessing care and treatment, should be established and maintained.

The homeless (estimated to constitute 10% of New Jersey's HIV/AIDS population) are an especially high-risk group. Without steady incomes, they suffer the same disadvantages as the poor. While homeless persons can receive outpatient care, lack of a permanent address makes them ineligible for ACCAP and for home care. Only one boarding home (Broughton House) exists in the state designed for homeless people with HIV/AIDS, and it has only 25 beds.

Emergency assistance and shelters are available in New Jersey upon application to county or municipal welfare offices. But after overcoming the hurdle of the application process, the person with HIV/AIDS experiences even more overwhelming obstacles. Shelters are usually closed during the day, and the diet, rest and administration of medication necessary for persons with HIV/AIDS are almost impossible in this kind of environment. Furthermore, overcrowded conditions promote the spread of opportunistic infections and, increasingly, tuberculosis.

In short, the HIV/AIDS population is composed of many groups, each with their own medical care and social service requirements. To be effective, the delivery of care and treatment must take into account the broadest possible spectrum of needs and be prepared to satisfy those of each group. The Council recommends that caregivers reach out to those with special needs and difficulties in accessing services and that access to affordable care and treatment within the geographic and cultural reach of affected populations be improved.

Incarcerated Persons

A significant number of incarcerated men and women have AIDS or are infected with HIV, yet they cannot take advantage of the outpatient programs offered elsewhere to persons with HIV/AIDS. The same services, including prevention education, treatment (including gynecologic care for women) and counseling and testing should be provided within the prison system. A significant barrier to providing these services is that security rather than treatment is the dominant concern within the correctional setting. Furthermore, managing the lives of the

incarcerated after release is difficult; add to it the complications of those who are HIV-positive or who have AIDS and the task is truly formidable. It is urged that the Department of Corrections work with community-based organizations to make continuity of care and case management and support a part of discharge/release planning.

Training and Education for Caregivers

Further burdening the care and treatment of persons who are at-risk for HIV/AIDS, HIV-positive or who have AIDS is the lack of sufficient medical, dental, and other health care professionals who are knowledgeable about HIV and/or want to provide the necessary services. Most health care providers were educated before HIV/AIDS was identified and are unfamiliar with its care and treatment. Others are reluctant to treat infected patients for reasons other than a deficiency of knowledge about the virus.

The Council recognizes the present and future need to focus on the education of those medical specialties the patients of which are likely to feel the impact of HIV/AIDS, such as infectious disease specialists, internists, family practitioners, obstetricians, gynecologists, and pediatricians. Education of dentists who are willing to provide adequate dental services is also a priority, since about 70% of HIV/AIDS patients have dental problems associated with the disease. Finally, there is a demand for education of nurses, social workers, and many other health care professionals whose work touches the lives of persons with HIV/AIDS every day.

Several programs to educate New Jersey health care professionals have already been initiated. The State Health Department has disseminated the Academy of Medicine Practice Guide *(Identification and Management of Asymptomatic HIV-Infected Persons in New Jersey: A Practical Protocol for New Jersey Clinicians)* to several thousand physicians. The Task Force recommends that the mailing be increased to include all physicians and dentists in the state. A training session conducted by the Department of Health in "universal precautions" reached more than 2,500 people in the first half of the 1992 state fiscal year; a newsletter entitled *AIDSLINE* is distributed to 4,700 health care professionals each month; ongoing and specialized education by the Rutgers AIDS Training Project reaches hundreds of people every year; and staff of the Department of Health offer training seminars to agencies which provide health care, prevention education and social services to persons who are HIV-positive.

Nonetheless, the appropriate training of health care professionals continues to be a large problem. The Council recommends that several additional educational approaches be utilized, independently and/or in conjunction with one another. One is the provision of clinical updates, which could include providing to physicians the most recent information about HIV/AIDS drugs and clinical trials. A second proposed strategy is the creation of state-funded fellowships for AIDS treatment or other incentive programs for professionals. Such projects would reward those who venture into this new area of health care and establish role models for future trainees. The Task Force suggests that a fellowship program in New Jersey might provide six spots for physicians, three for nurses and social workers, and one for a dentist, at each of eight selected teaching and practice sites. A third approach to educating health care professionals is the development of new educational materials and methods in medical, dental and other health care-related professional schools which would continue into post-graduate training, including residency and internship programs. Yet another idea, already implemented in some states, is to require continuing education training in HIV care as a prerequisite to relicensure.

Implementation of a number of these recommendations would undoubtedly open the door to better care and treatment for persons at-risk for HIV, HIV-positive or with AIDS. Nevertheless, many professionals will not walk through it. Some will refuse because of the complexity of the care involved. HIV involves a spectrum of illnesses and the treatment needs of any patient may span several specialties. Without the benefit of a multi-disciplinary practice site, few specialists are likely to feel comfortable in overseeing all care and treatment needs. And caretaker burn-out can be high, due to the psychological stress of treating many young, dying patients with numerous physical and psychological needs.

Other reasons for failing to care for HIV/AIDS patients may be less noble. Many physicians do not accept HIV/AIDS patients because of the very low Medicaid reimbursement rate. Others are deterred from treating patients because of fear of infection or discomfort in caring for substance users or gay or lesbian persons. Hopefully, better education will relieve such apprehensions and decrease the number of health care professionals harboring such attitudes. The Council believes, with the CDC, the American Medical Association, the National Commission on AIDS, and other authorities, that physicians have an ethical and legal obligation to care for patients regardless of HIV status if they are competent to do so.

In sum, persons with HIV/AIDS encounter too many obstacles in their deserved path to continuity of care, treatment and services. Prohibitive financial costs, lack of accessibility, shortage of appropriate health care facilities and treatments, administrative red-tape, poor reimbursement, professional burn-out, the numerous special needs of different populations, and the lack of adequate education and training of health care professionals, all contribute to the erection of barriers. It is hoped that the recommendations of this Council will serve to begin breaking down these hurdles in a pragmatic, efficient and cost-effective manner.

SUBSTANCE ABUSE

Attention to the connection between substance abuse and HIV/AIDS is particularly significant. In New Jersey, 54% of those with HIV/AIDS contract the virus through sharing of contaminated needles. Sixty percent of the state's women with HIV/AIDS are or were users of injection drugs. Further, an estimated 50% of injection drug users in New Jersey cities are believed to be infected.

These statistics reflect only injection drug use and do not account for HIV/AIDS cases that can be linked to other forms of substance use. There are an estimated 650,000 non-injecting illicit substance users (excluding consumers of alcohol) in this state, as compared to approximately 50,000 users of injection drugs. Persons who intake alcohol and non-injected illicit substances such as crack cocaine and psychoactive drugs expose themselves to increased risks of contracting the virus due to impaired judgment and sexual risk taking. Hardest hit by the disease in New Jersey are the poor, unemployed, minority, and inner city families most exposed to both IDU and non-IDU substance use. However, substance use occurs in all segments of society. Thus, absent effective prevention and education programs, alcohol and illicit substances have the potential to contribute to the spread of HIV infection and AIDS to hundreds of thousands of New Jerseyans.

The alarming data suggest the imperative need for prompt action to curtail the problem of substance abuse in New Jersey. Of course, the most effective means of accomplishing this is by reducing the addiction to, dependence on, and desire for drugs and alcohol. While this may be achievable for some, it is unrealistic to expect total resolution of the problem of substance abuse. Consequently, we must consider additional approaches and be open-minded to the need to change a few laws in order to save many lives.

Drug Treatment Programs

There is no single cause of substance abuse; rather, various combinations of psychological, economic, social, physiological, and cultural reasons may underlie different individuals' addictions. Likewise, models for recovery differ in approach. For example, the "chemical dependency" model mirrors the Alcoholics Anonymous 12-step program and stresses "recovery" and "sobriety" instead of "cure." The medical/psychiatric approach treats substance abuse as a disease and aims at behavioral modification. The genetic and physiological aspects

of addiction are stressed in the neurotransmitter/neuronal model which in some cases employs methadone maintenance and in others behavioral change to attempt to curb substance use.

The success rate of the various models for treating addiction is not 100 percent, but a number of programs have shown very positive results. Studies indicate that substance users treated with methadone maintenance who stay with the program for at least one year reduce the risk of substance abuse, as do those who enter residential and outpatient drug-free programs for more than six months. Another survey found that substance abuse patients enrolled in drug treatment programs in New York City for more than two years were less likely to be HIV-positive than those enrolled for a lesser time. In short, drug treatment programs hold significant promise for curbing substance abuse and thereby reducing the spread of HIV infection. In addition, stopping drug use offers an important economic benefit: the cost of care and treatment for a person with HIV/AIDS is estimated to be more than $85,000 over a lifetime; the annual cost of methadone outpatient care ranges from $2,000 to $3,000, and residential treatment from $14,000 to $20,000, annually.

Despite the overwhelming life-saving and money-saving benefits of drug treatment, such programs are still unavailable for many New Jersey substance users, and ineffective for others. The estimated number of funded drug treatment slots in New Jersey (excluding treatment for alcoholism) is 8,568 -- obviously many less than the 650,000 non-alcohol, non-injecting illicit substance users and the 50,000 injecting drug users in the state. Moreover, opportunities for women, particularly pregnant women and women with children, are even more limited, since few treatment programs are tailored to fit their needs. Indeed, there are no existing drug treatment programs in New Jersey that accept HIV-positive drug-using pregnant women or HIV-positive substance-using women with their children. The Council recommends that the public and private sectors work together to establish drug treatment services for pregnant women and HIV positive women with children.

It is noteworthy that the lack of available spaces in drug treatment programs is not unique to New Jersey. One of the conclusions reached by the National Commission on AIDS is that "[t]he federal government should expand drug treatment so that all who apply for treatment can be accepted into treatment programs."* The number of drug treatment slots in New Jersey will

* National Commission on AIDS, p. 22.

soon [illegible] increasing by approximately 40%; in September 1991 the Office for Treatment Impro[illegible]nent of the federal Alcohol, Drug Abuse, and Mental Health Administration granted New Jersey $27.8 million for a three-year 360 bed drug treatment program based in Secaucus. The program is designed to include primary medical care facilities, including HIV-testing and counseling and early intervention therapy for infected patients. Despite this laudable advance, the basic problem remains: There will still be many more substance users in New Jersey than accessible spaces in drug treatment facilities. The Council urges that substance users be given much greater access to drug treatment programs and related services, such as education about HIV prevention and about care and treatment of HIV/AIDS patients. As in other settings male condoms should be made available at substance abuse and alcohol abuse treatment sites than non-use.

Although drug treatment programs provide a key to unlock the doors of substance abuse, as currently conducted, such projects also have some drawbacks. Anecdotal evidence suggests that discharge planning for HIV positive substance users is inadequate, and post-discharge continuing care and referrals to medical or other facilities that can meet the needs of these patients is, in many cases, wholly absent. Treatment effectiveness may also be curtailed because of an alleged lack of sensitivity on the part of many substance abuse counselors to issues related to sexuality, gender and cultural and class differences. Thus, the Council recommends that certification and re-certification of substance abuse and alcohol counselors require HIV/AIDS specific training, including issues of gender, cultural, sexual orientation, and class differences.

Drug treatment is not a realistic goal for all substance users. For some, such programs are ineffective; others choose (for a variety of reasons) not to seek treatment. However, with the necessary financial, legal and social service support, many substance users who do not participate in drug treatment programs (as well as those with whom they have sexual contact and offspring) can nonetheless be spared HIV infection.

Clean Needles and Needle Exchange Projects

Short of drug treatment, there are several methods that can be employed to reduce the risk of IDUs contracting HIV/AIDS. These include the legalization of over the counter purchases of hypodermic needles and needle exchange programs. The Council strongly urges immediate action to make clean needles legally available through these methods.

It is legal to sell hypodermic needles over-the-counter in 39 of our sister states, but not in New Jersey. States which permit over-the-counter needle sales tend to have fewer IDUs than states that ban such sales. While experience is not uniform nationwide, strong evidence suggests that legalization of over-the-counter sale of clean needles can be effective in reducing injection drug use and the spread of HIV. For example, one study conducted by the Committee on Law Reform of the New York County Lawyers Association, found that "[i]n nine states which ban over-the-counter sales, 31% of intravenous drug users were estimated to be infected with the AIDS virus.... In contrast, in nine states which allow over-the-counter needle sales, only 5% of intravenous drug users were infected."*

Needle exchange programs encourage IDUs to come to a controlled site where they can exchange their used needles for unused sterile ones. As a consequence, needle sharing is reduced, and used needles are discarded. Education efforts about substance abuse and HIV/AIDS usually accompany the exchange. Needle exchange programs create an opportunity for health care workers to offer education and counseling to IDUs, including encouragement to enter drug treatment programs.

The advisability of instituting needle exchange programs has been debated in many communities. Opponents of the programs maintain that needle distribution gives the impression of state sanction to illegal drug activity, encourages drug use, and sends conflicting messages to substance users. Opponents tend to assume that drug users are unconcerned about their health, are uneducable, and will continue to share needles as a form of social bonding.

Yet, the evidence strongly suggests the contrary. Needle exchange has proven effective in changing behavior and reducing the spread of HIV. As shown by projects in places as diverse as New Haven, Connecticut; San Francisco, California; Amsterdam, Holland; Liverpool, England; and Lund, Sweden, given the opportunity to use clean, unshared needles, a high percentage of IDUs choose that option precisely to prevent the transmission of HIV/AIDS. Whether as part of a needle exchange program or separately, ventures to provide bleach to sterilize needles have been another effective way to curb the spread of HIV. Evaluation of the

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* Citizens Commission on AIDS for New York City and Northern New Jersey, "AIDS and Drug Use: Breaking the Link" (1988), pp. 30-31 (quoting New York County Lawyers Association, Committee on Law Reform, "On Drug-Related AIDS and the Legal Ban on Over-the-Counter Hypodermic Needle Sales" (January 12, 1988)).

1986 San Francisco project demonstrated that in 1987, 47% of needle-sharers usually or always sterilized their needles with bleach as compared to 6% in 1985. The results have shown that needle exchange programs do not increase the number of injection substance users or the use of injected drugs and do stem the spread of HIV.

It is noteworthy that in the United States, where needle exchange programs are few in number, a handful of criminal actions have been brought against activists distributing clean needles. In all cases, the charges were dismissed. As one Manhattan judge stated: "The nature of the crisis facing the city, coupled with the medical evidence offered, warranted the defendants' action."* These incidents serve to illustrate as well the importance of working with law enforcement officials to assure IDUs that participation in needle exchange will not create a risk of prosecution.

In sum, several models exist for reducing the risk of HIV infection and AIDS among IDUs who are not in drug treatment programs. Research conducted thus far suggests that these approaches do not increase the use of illicit substances or enlarge the population of substance users. Moreover, the studies confirm that these approaches are and can be effective in persuading many IDUs to use sterile needles, thereby decreasing the spread of HIV. While the Council in no way endorses the use of illegal drugs, the Council strongly believes that the urgent need to curb the spread of HIV/AIDS, together with the positive results achieved elsewhere, outweigh other competing concerns. As former United States Surgeon General C. Everett Koop stated:

> When we are dealing with something as devastating as the AIDS epidemic, it doesn't matter what we do to reach the people that have to be reached, we have to do it....if clean needles will do anything to contain a part of the epidemic, we should not have any foolish inhibitions about so doing.**

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* National Commission on AIDS, p. 33.

** Citizens Commission on AIDS for New York City and Northern New Jersey, "AIDS and Drug Use: Breaking the Link," (1989), p. 30 (quoting Surgeon General C. Everett Koop addressing the California Department of Public Health National AIDS Conference, November 1987, quoted in *San Francisco Sentinel* (January 22, 1988), p.1).

The Council would welcome the opportunity to join with the Department of Health in designing and implementing the approach best-suited to New Jersey.

Substance Abuse Education

As noted above, drug treatment programs, needle exchange projects and other harm reduction approaches create opportunities for counseling and education. An essential component of any approach must be educating the targeted population about the risks of HIV/AIDS and of substance abuse, as well as about preventive measures. A 1986 New Jersey survey found that many IDUs entering drug treatment programs were aware of the symptoms of the virus as well as its means of transmission. In response to this and similar surveys, the state Department of Health launched several projects to increase awareness of the issues. One project employed former substance users and those then enrolled in methadone maintenance programs to act as street workers, giving information to IDUs within their communities. One in six substance users reported receiving information as a result of this program, and the cost of sterile needles reportedly increased in response to the increased demand. In a second project, street workers gave out vouchers to IDUs for free and immediate detoxification treatment. More than 80% of the vouchers were redeemed, 44% by patients who had never previously been in treatment. Twenty-eight percent continued treatment after the initial detoxification.

Successful education will depend, of course, upon the method employed. For instance, street outreach projects and community-based campaigns may be more effective approaches to distributing vials of bleach within the community. In contrast, testing, counseling and preventive and other information concerning HIV/AIDS are more readily and effectively provided at fixed sites, such as needle-exchange centers or pharmacies supplying over-the-counter needles. Drop-in centers or homeless shelters frequented by substance users may also be good places to cover this crucial information. Whatever the ultimate means chosen, it is imperative that the educational component be tailored to fit the varying needs of substance users in varying communities.

Long-held prejudices against substance users and legal efforts to prevent procurement of sterile injection equipment will not discourage drug use. They will, however, ensure continued growth in the number of persons with HIV/AIDS. This is devastating to substance users, their sexual partners, and, in many cases, their offspring. In balancing priorities, it is essential that

our legal and public policy err on the side of life, not on the side of discouraging morally offensive and illegal activity. Ironically, a well-conceived plan to encourage the safe use of needles integrated with a realistic educational campaign may well be more effective in stemming the problem of substance abuse than a corpus of traditional restrictive laws written to address less complex societal ills.

LIVING WITH HIV/AIDS: SURVIVAL NEEDS

Therapeutic advances in the treatment of HIV infection and opportunistic infections, early intervention, prevention, community organizations, support systems and personal responsibility for health needs have all contributed to the fact that persons are living longer with HIV/AIDS. As a consequence, traditional acute and long-term health care paradigms for treating illness increasingly address only portions of the needs of persons with HIV infection. A comprehensive approach must address the many ways in which confronting HIV/AIDS is a societal as well as a health care crisis. Immediate attention should be committed to meeting the basic living needs of persons with HIV/AIDS and to improving access to supportive care and services, including preventive therapies. Discrimination against persons with HIV infection is a major barrier to allowing PLWAs to lead meaningful and productive lives in society. The battle against discrimination calls on each of us to evaluate our individual and collective responsibilities as members of the community.

Basic Living Needs and Supportive Care and Services

PLWAs too often find themselves in poverty or on extremely limited resources nearing poverty level. While entitlement programs, in particular Medicaid, meet certain needs, support for basic living needs such as food, clothing and related daily essentials are inadequate. For example, support programs like food banks or Meals on Wheels are too few in number, have long waiting lists or fail to meet personal dietary regimens. Basic transportation is often unavailable (and typically not covered by third-party payment), contributing to painful isolation from vital resources and support systems. As an initial step, the state should increase entitlement programs to assure that none fall below the poverty line and that basic living needs of PLWAs are available, accessible and funded.

As discussed above, barriers to access to needed therapies must be removed. Here, two additional concerns warrant attention. First, eligibility requirements for programs that enable individuals to access care and services, and in particular early intervention such as treatment for asymptomatic persons with HIV infection, should be expanded. Barriers to access, such as restrictions on eligibility for community resources during hospitalization, should be eliminated. Second, the cost of supportive services, early intervention and other means to enable persons to

live longer and more productive lives with HIV/AIDS is easily justified when compared to both the human and economic costs of inaction.

Housing

The Council believes that meeting the housing needs of persons living with HIV/AIDS should be an immediate priority. The public and private sectors must work together to expand the availability of a full range of affordable housing options, including independent, assisted living, group homes, interim housing, boarding homes, residential health care and skilled nursing care. Support for homelessness prevention programs should be increased. The location of housing can be as important as its quality. Housing arrangements should be accessible to family, friends and support systems. Furthermore, restrictions preventing families from caring for loved ones at home should be waived to enable caregivers' willingness to "take in family members requiring care."

Fighting Discrimination

As noted above, HIV/AIDS predominantly affects those in the "prime of life" -- young adults and the working-age population. For persons living with HIV/AIDS the ability to continue to lead meaningful and productive lives as members of the community is highly valued. For many it means the difference between living with HIV/AIDS and merely surviving.

One of the most devastating barriers to living with HIV/AIDS is discrimination. On the basis of HIV status children have been denied school education; employees have been dismissed; job applicants have been rejected; health and life insurance have been denied; insurance benefits have been impaired; and adequate housing has been refused. The prevalence of discrimination is evidenced in part by the hundreds of discrimination claims filed before human rights commissions and courts nationwide. State and federal laws, such as the Americans With Disabilities Act, protect persons with HIV/AIDS against discrimination on the basis of HIV status. These laws should be strictly enforced.

The Council believes that immediate attention should be committed to protecting and expanding employment opportunities for PLWAs. Work is a focal source of productive life for many PLWAs; it enhances self-reliance and personal dignity. In addition to fighting

discrimination, programs of supportive work and sheltered employment should be developed to provide further options for meaningful work experience.

The importance of combatting insurance discrimination is discussed above in the context of testing, care and treatment. Yet we should not lose sight of the essential connection between employment and affordable health care. Approximately 40% of health insurance in New Jersey is provided by employers. Loss of employment also means loss of insurance, placing an additional strain on the PLWA and increasing the costs of health care. Companies with employee health plans are increasingly finding that rising premiums or even cancellation of policies bring additional financial pressures to discriminate against HIV infected persons.

Whatever the context, discriminatory practices most often are grounded in irrational fears and ignorance. Perhaps the greatest weapon against discrimination is again, education. All of us -- from school teacher to corporate executive, insurance representative to small business owner -- need to understand how HIV is transmitted and that HIV is not transmitted by ordinary casual contact. Behavioral stereotypes must also be dispelled.

Families Living With HIV/AIDS

HIV/AIDS has increasingly become an epidemic of families. Parents with AIDS take care of their families until they are too ill, then children and other family members must care for them. While some child care, respite care and foster care services exist, these services are limited and inadequate for women with HIV/AIDS trying to raise young children, and for grandparents providing care for their children and grandchildren. Availability of these forms of support services needs to be expanded, with an emphasis on maintaining the integrity of the family unit to the fullest extent.

When the Department of Youth and Family Services ("DYFS") becomes involved in managing the care of families living with HIV/AIDS, maintaining the parent-child-family unit through the course of the parent's illness should be a guiding principle for assuring the welfare of child and parent. DYFS policies should be reviewed and if necessary changed in accordance with this goal. Particularly critical is providing for the future of children who lose their parents to the epidemic.

GOVERNMENT RESPONSIBILITIES

The Governor's Advisory Council on AIDS joins President-elect Clinton, Governor Florio and the National Commission on AIDS in underscoring the central role of government in dealing with the critical peril of the HIV/AIDS virus. The dangers posed by the pandemic cry out for bi-partisan leadership in crisis. Sadly, the first decade of the disease is marked by either widespread governmental inattention or outright hostility towards those suffering among us. The health care community struggles daily with inadequate resources and is surrounded by prejudice and a catalogue of ill-founded fears and appeals to mistrust. Plagued equally by ignorance and disease, people living with AIDS confront a world marked by indifference, stigma, illness and death.

In the second decade, history has impelled the Governor's Council to recast government responsibilities by emphasizing public health concerns, eschewing criminalization of status, fully funding comprehensive public/private initiatives and calling for bi-partisan and large-spirited cooperation among all called to public service. No public policy recommendation contained in this Governor's Council report will succeed until we first join in casting the pandemic in human terms. In the absence of a cure for AIDS, a largeness of spirit coupled with a public health emphasis is the only sure path to prevention. Further, no serious effort to thwart the spread of AIDS can be mounted until we understand and address the economic as well as the human cost of the deadly virus. At its inception, the Council had planned to examine and to address in this report the initial questions of funding which ultimately drive our ability to respond fully to the HIV/AIDS epidemic. At that time, needed resources and information are not forthcoming from the Department of Health, and the Council turned its attention elsewhere. As a next step, the Council proposes to renew those efforts and to direct its immediate attention to a full scale inquiry and analysis of the all-encompassing economic and social costs of the presence of the HIV/AIDS in New Jersey. The Council looks forward to its continuing partnership with the Department of Health, other state agencies, and the private sector in this important endeavor.

The Advisory Council stands ready to continue its work with the Governor, Legislature, Department of Health, policy leaders and the public and private sectors to implement its recommendations. In so doing, the Council plans to examine critical issues addressed here in greater depth, as may be warranted. The Council also plans to pursue participation in

coordination of HIV/AIDS efforts through establishment of working liaisons with federal agencies, lawmakers, and the National Commission on AIDS, as well as the collective commitments of our sister states.

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Appendix

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PREVENTION AND EDUCATION

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HIV/AIDS education is vital to the people of New Jersey because it is the primary means of preventing the spread of HIV infection, AIDS and associated health problems. The goal of HIV/AIDS education is to alter behavior based on scientifically accurate and psychosocially appropriate information. The education efforts and processes should include:

(a) information about the health and medical aspects of prevention and intervention;
(b) sensitivity towards the human issues related to HIV/AIDS;
(c) awareness of emerging problems related to HIV/AIDS; and
(d) methodology for evaluation of the impact to these efforts.

It is emphasized that all education efforts must be prompted without moral judgement.

Experience reveals that peer involvement is frequently an effective approach to HIV/AIDS education. Therefore, to the extent possible, in addition to professionals and HIV-knowledgeable persons, education should be conducted by individuals with whom the target population can readily identify.

The Committee submits the following recommendations for the Council's consideration; and wishes to stress the urgency of the need for major and aggressive education efforts as the only effective preventive measures in the spread of the HIV/AIDS epidemic.

RECOMMENDATIONS

A. HIV/AIDS Education in Schools

1. HIV/AIDS education should be MANDATED of all schools, for all grades in accordance with defined criteria and developmentally appropriate content as jointly developed by the Departments of Health and Education.

2. In developing AIDS education criteria and content, the following characteristics must be addressed:
   - Non-judgmental

- Culturally appropriate
- Developed through valid research
- Supported through quality management techniques
- Related to life-skills and family-life education
- Articulated through multiple media
- Enhanced by ample, unintimidating discussion and question-and-answer sessions
- Sensitive to human aspects, and especially to the concerns of HIV-infected individuals
- Evaluated as to its impact, particularly with regard to behavioral outcomes

At the present, the Department of Education requires HIV related education to be included in the school curriculum. The interpretation of HIV related education is left entirely up to the individual School Boards. The result has been a wide spectrum of curricular information ranging from excellent to nearly nonexistent. The Department of Education advocates HIV/AIDS education within comprehensive school education program and has developed very good instructional guides on HIV/AIDS which the committee endorses. Currently, however, there is no mechanism to assure that the recommended curriculum, or other forms of HIV/AIDS education are being implemented.

B. HIV/AIDS Education in Institutions of Higher Learning

1. The Board of Education must consider HIV/AIDS education as a PRIORITY ISSUE; and devote commensurate attention to it, including but not limited to developing guidelines for content, implementation and evaluation.
2. The young adult population is the most vulnerable and the most at risk segment of the general population with respect to the HIV/AIDS epidemic. Clearly, the impact of HIV/AIDS in this group is no less significant than the current priorities of the Board of Higher Education which include such issues as affordability of education, attracting and retaining minority students and renewal of faculty.

C. Evaluation of HIV/AIDS Education

The State should encourage, support and when necessary, fund mechanisms for evaluating the state and private sponsored programs or materials for HIV/AIDS education.

Currently, a wide gamut of programs, articles, brochures, videos, public service announcements, newsletters, comic books and speaker panels are available on the topics on HIV/AIDS - to which an estimated 10% of the population has been exposed. The fostering of such state and private efforts should been encouraged. However, there is

need for a mechanism to evaluate the appropriateness and effectiveness of such methods, and to avoid duplication in the face of limited resources. At the very least, the state supported efforts must be evaluated through external review processes.

D. The role of Government and Private Sector Leadership on HIV/AIDS Education

The State's government and private sector leadership must themselves be educated on HIV/AIDS issues in order to assure effective implementation of all HIV/AIDS education policies. As an initial step in this direction, we recommend that the Governor actively endorse education efforts by convening and personally participating in a statewide leadership conference.

New Jersey's Governor, legislators, college presidents, state department heads, judges, chief executive officers of large corporations, county officials, school superintendents, correctional facility superintendents, insurance executives, and other key decision makers and opinion leaders must be fully informed of the magnitude of the HIV/AIDS epidemic and the need for education intervention in order to assure the State's HIV/AIDS education policies. The current efforts and activities related to HIV/AIDS education is by in large generated and self-supported at the lower levels of public and private sector agencies and institutions with little if any endorsement or support from top leadership. This must change.

E. Emerging and Future HIV/AIDS Related Problems and Threats

As a part of the education process, awareness of potential and emerging threats must be addressed. As a first step, education efforts must be directed to recognizing and addressing the emerging problem or tuberculosis.

There is every indication that a second epidemic of tuberculosis and specifically drug resistant tuberculosis, is emerging as a complication and sequela of the HIV/AIDS pandemic. The State of New Jersey is especially at high risk for the drug resistant type of tuberculosis because of its high number of HIV infected and at risk population. Proactive approach to education regarding TB separate from and in addition to HIV/AIDS education, should be implemented at this time. Other potential health threats related to HIV and AIDS may appear in the future and these are always more effectively addressed with a proactive and preventive approach.

F. Community Based HIV/AIDS Education

Community education must be a high priority for the population engaged in high risk behavior. Therefore, community based programs must be fostered, encouraged and appropriately funded, but coupled with methodology for impact and effectiveness.

G. HIV/AIDS Education for Correctional Facilities

HIV/AIDS education efforts should be mandated of all correctional facilities sponsored by county and state government. The criteria and content of HIV/AIDS education efforts for such facilities, should be jointly developed by the Departments of Health and Correction in accordance with the characteristics outlined under Recommendation I.

At the present time, the Juvenile Correctional Facilities of the state do include HIV/AIDS educational efforts which depend on the interest/dedication an enthusiasm of the personnel and appear to be without defined policy or administrative support. The Adult Correctional Facilities also appear to include some HIV/AIDS educational efforts again based on individual institutional interests and not policy. Clearly, the population of correctional facilities are at serious risk and in serious need for HIV/AIDS education and such should be appropriately addressed.

COUNSELING AND TESTING

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HIV disease has and will continue to affect many New Jerseyans regardless of race, color or creed. Many programs have developed with emphasis on both the medical and psychosocial management of those individuals infected with HIV. However, an integral element in determining the course of management of these individuals is in first identifying who is infected. Testing for HIV infection has become a newsworthy topic: who should be tested, when the testing should be done and how results should be handled, have all been topics explored by the medical and legal communities as well as the public at large. This report attempts to identify the major areas of concern and contains recommendations which the Task Force feels should be considered by policymakers.

RECOMMENDATIONS

A. Counseling

1. Training

Currently the state offers a three day course whose attendance is only mandatory for those counselors who are employed at state supported sites. In addition, the session on interviewing techniques is only mandatory for this group of individuals. There are no mandatory continuing education requirements.

A review of the state funded testing sites revealed a disparity in the percentage of individuals that chose confidential versus anonymous testing. This occurred at sites in neighboring counties. It was felt that this disparity was not due to the patient population but to the counseling received at the respective sites. Based on this, the Task Force makes the following recommendations:

- Mandatory HIV training for all who provide counseling. We are recommending that the DOH establish an HIV counseling certification program.
- Mandatory continuing education for all counselors.
- Counseling be made available in the primary language of the person being

counseled (e.g. braille, sign language, foreign language).

2. Dispensing of Condoms

This is currently performed at all CTS. The committee recommends the following:

- Continue dispensing male condoms at all testing sites emphasizing that this is *safer* sex not safe sex.
- Ensure the availability of male condoms at all correctional institutions (See Special Populations).

B. Testing

Confidential and anonymous testing are currently available through Department of Health (DOH) Counseling and Testing Sites (CTS). Anonymous testing is only available at the CTS. Confidential testing is also provided by individual physicians and at hospital centers. The pros and cons of both types of testing are as follows:

1. Confidential Testing

Pros: Identification of the HIV infected individual thus allows easier follow-up and expedites intervention, particularly if the client does not return for post-test results.

Cons: Fear of discrimination against the HIV infected individual in the workplace, housing, education, medical care and insurance. Inability to contact the HIV infected patient who does not return for post-test results.

2. Anonymous Testing

Pros: The ability to determine the incidence and prevalence of HIV in a particular area.

It maintains the patient's ability to choose which type of testing is preferred.

Cons: It only serves as an epidemiologic tool if there is no post-test follow-up.

Inability to provide medical and/or psychosocial care if there is no post-test follow-up.

Inability to educate the infected individual or notify any sexual contacts thus creating the potential for additional persons to become infected.

Statistics from the DOH indicate that a large percentage (62) of those individuals tested anonymously in the five highest volume sites returned for the tests and received follow-up care. Seventy two (72) percent of those individuals testing confidentially returned for post-test results. Since the availability of both types of testing serves the public by allowing choice in health care decision making the committee recommends the following:

3. Continue to encourage HIV testing. Maintain and expand both confidential and anonymous testing sites throughout the state.
4. Support the State Plan to offer voluntary testing during hospitalization with the following stipulations:

    - Publishing this plan in the New Jersey Register for public comment prior to its enactment.
    - Notification of the Insurance Commissioner of the recommendation and its enactment so that he may implement appropriate steps to ensure that the methods by which New Jersey insurance carriers determine premiums and accept/deny policies are not affected by this form of testing and that no discrimination results for those persons who choose this form of testing.

5. No mandatory testing under any circumstances

Mandatory testing was discussed in terms of its implementation as part of routine prenatal care, premarital testing, sex offenses and needle stick injuries. It was felt that there was no role for mandatory testing. The Centers for Disease Control (CDC) has published guidelines for the management of health care workers who sustain needle stick injuries, which the committee supports. Additionally, the Federal Department of Labor, OSHA has just adopted the Federal Rules in occupational exposure to blood borne pathogens. This will be adopted shortly by the State of New Jersey.

The committee felt that it would impinge upon individual civil rights to impose mandatory testing in any of the above circumstances. Additionally, testing of the sex offender should, at a minimum, be dependent upon his/her conviction. However, since trials generally do not occur in a timely fashion intervening at this time would not be beneficial to the victim and therefore does not justify the violation of individual rights. If the offender were to be tested, it was felt that the victim should also be tested.

C. Special Populations

1. State Psychiatric Hospitals
   There are clients that have tested positive for HIV. Some of these individuals are admitted from the state and county correctional systems. While testing is done with consent when requested or when medically indicated, precise numbers of those individuals that are positive are unknown. A number of issues arise with respect to this group of individuals as they are attended by health care workers and others who may be exposed to the virus. Additionally, client to client, client to visitor contact, and client to staff contact is or may be problematic. Currently, staff and clients receive training and condoms are available for all clients that are institutionalized. The Department of Human Services has never supported mandatory testing for clients that are health care workers; however, medical staff at the institutions have indicated that they believe all clients should be tested for HIV upon admission.

2. Developmental Centers and Community Residences for the Disabled
   To date, HIV infection has not had a major impact. The division has had three known cases of HIV infection. Two of the three clients reside in the community. The third resided in a developmental center until his death. Division clients are tested for HIV infection when in the clinical judgment of the physician there is medical evidence to support such testing. However, written informed consent must be obtained from the client or guardian if the client is a minor or is incompetent.
3. Correctional Institutions
   Some inmates currently receive training on safer sex methods but do not receive the tools to implement their knowledge. While sexual activity is currently against the Department of Corrections regulations, a revision of the law may be necessary.
4. Adolescents
   HIV infectivity in the adolescent population continues to rise at alarming rates. Adolescents are permitted to obtain HIV testing without parental consent if they are at least 12 years of age. Currently only one CTS has targeted this population.
5. Children
   HIV testing is conducted when clinically indicated or upon request of the parent and/or guardian. Prior to testing, the requesting physician generally discusses the rationale for obtaining the test to the parent or guardian. It is extremely unlikely that a child would be tested for HIV without consent of the parent or legal guardian. For those children in foster care, the Division of Youth and Family Services (DYFS) appoints a social worker who must give informed consent.

The committee recommends the following for the special populations group:

- Continue distribution of condoms at all development centers and

community residence for the disabled.

- Continue HIV testing upon request at these same facilities.
- Ensure availability of male condoms at all correctional institutions.
- Pursuant to the consent agreement entered into by the Department of Corrections and the Public Advocate, the committee recommends a provision of voluntary HIV testing to all inmates with an exploration of the possibility of providing anonymous testing.
- Incorporation of HIV testing and counseling at ALL centers where adolescents seek medical care.

CARE AND TREATMENT

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RECOMMENDATIONS RELATED TO EFFECTIVE TREATMENT FOR HIV-INFECTED INDIVIDUALS

Basic Premise: To be effective, treatment must be accessible.

"Accessibility" requires that care and treatment be *affordable*, located *within reach* of patients and their families, and that there be an adequate number of knowledgeable health care providers; including physicians, dentists, nurses, social workers, counselors and therapists who have adequate education and expertise to meet the needs of patients and families.

A. Affordability

Financing the treatment needed by individuals who are HIV-infected is a complex issue which has generated it's own set of fears: people are afraid that their health insurance will not cover this illness adequately; employers fear the rising cost of employee health insurance and may attribute that problem to HIV-related treatment; insurers are trying to minimize their risks related to HIV infection by excluding potentially-infected individuals; many people simply have no health insurance and no financial resources to pay for care; and health care providers fear they will have to absorb these costs of care at an ever increasing rate.

There are no simple solutions to the problems on which these fears are based, but recognition of the extent to which they impact upon New Jersey residents is a basic first step. Once that information is available, logical plans can be formulated to improve funding of treatment facilities, and appropriately regulate health care insurance related to HIV-infected individuals.

Thus the following initial recommendations related to treatment affordability are proposed:

1. Utilizing the skills of a health care economist, develop and implement a study of the treatment availability and gaps throughout New Jersey for

those at risk or HIV-infected in relation to payment for that treatment. (See reference no. 1)

2. Utilizing the data gathered in the first recommendation, develop funding solutions based on all payment methods and types of treatment facilities.

   Possible solutions may include greater encouragement of HMO-type care "packages", development of other forms of group practice, provision of higher reimbursement levels for HIV-related care, and altered regulations with respect to private insurance coverage.

B. Care Within Reach of Patients and Their Families

"Reach" can also be viewed broadly as both geographical and socio-cultural reach of patients and families. Sometimes problems associated with either aspect of "reach" are as simple as failure of communication and information dissemination. Sometimes the issues are more difficult to resolve, involving transportation networks or cumbersome regulatory structures. No matter what the problem there must be a resolution, or people will continue to go without treatment and the disease will continue to take its toll.

Care must also be within reach and reach out to those with special needs and difficulties accessing services: women and children, the incarcerated, the drug-dependent, adolescents, gay and lesbian individuals, those with physical and/or psychological impairment. Every recommendation of this Task Force is intended to encompass all people in need who are infected with and affected by HIV. Some recommendations specific to those special needs are proposed in the following pages, and further such specific recommendations will be made as the work of the Task Force continues.

Various means of education and creative design of services must be used to solve these problems. As initial steps to accomplish this the following recommendations are proposed:

1. Development of a comprehensive directory of services in New Jersey for HIV-infected/at risk individuals and their families. Such a project might also be logically carried out by the aforementioned health care economist. It could also be developed in conjunction with, or as an update of other guides, such as that produced by the N.J. Lesbian and Gay Coalition. *Comprehensive* is a key requirement. All services, in-patient, out-patient, community-based, home care, preventive, curative, drug-related, etc. must be included. Transportation, volunteer services, financial resources and the like are also vital. Access to all case management services is another necessary aspect of the guide's information. Services helpful to those with

special needs (such as treatment centers which include gynecological care and provide child care; resources for accessing rehabilitation counseling; hospice care for terminal situations; facilities with flexible schedules; "buddy" programs and special support services; those near transportation routes, or which assist with transportation; those which welcome teenagers; etc.) should be highlighted in the directory. And finally, it must be made readily available to all in need of information.

2. The red-tape barriers of eligibility requirements must be minimized. These are constant sources of confusion and deter use of treatment services.

   - The state must develop presumptive eligibility for all state-funded care of people with HIV infection.

   - State-funded care eligibility requirements must be revised to eliminate all age gaps for HIV-infected people and those at risk. Currently, for example, some children may go through a "no care zone" during which they are too old for payment under one program but too young for coverage under a school age or other program.

   - "Red-tape" regimented approaches to care must be re-organized to provide flexible appointment schedules, particularly for women with children. Appointments must be coordinated to meet the multiple needs of individuals on a "one-stop" basis. For example, women who need both medical and gynecological care, or a mother and child who both need treatment, or a drug-dependent individual in need of both medical examination and drug treatment follow-up. Multiple appointments at scattered locations or different times and dates only discourage people from seeking treatment. We must reorder priorities to encourage and assist.

3. Health care, under the best of circumstances is often confusing. For those experiencing the devastating problems associated with HIV infection, the confusion reaches impossible dimensions. Case management has been shown to be an effective means of helping patients and families sort through the system and their many needs to get the care required. New Jersey's ACCAP case management system is a particularly useful, cost-effective, and patient-sensitive model. Other models also exist, such as those developed in the Robert Wood Johnson/State Health Department AIDS demonstration projects. These comprehensive case management models must be a part of every delivery system for treatment of HIV

infection. Thus it is recommended that comprehensive case management be required in all state/federally-funded facilities treating HIV-infected individuals.

- There must also be adequate funding for case management via the ACCAP and other systems.

- Because of the efficacy of the ACCAP Model Waiver (Medicaid) not only in relation to case management, but in the use of a variety of alternative modes of care to maintain clients comfortably in the community, it is also recommended that this program's slot utilization be regularly re-evaluated for possible increase, and to assure enough slots for prompt admission into the program for all in need (and who meet the eligibility requirements).

- Care management and support also seems particularly necessary in relation to the incarcerated individual, not only within the prison system but after release as well. Adequate prevention, education, treatment and counseling must be provided to those in prison. For those who are HIV positive, it cannot stop there. Provision for follow-up after release is crucial to assure that care and treatment continue. Thus some form of care management and support is recommended for at least the first few months of the post-release period.

4. Geography, as was previously mentioned, also plays an important role in accessibility. Some areas of New Jersey are well served by public transportation, and some areas have little or none. Lack of public transportation make it virtually impossible for many people to obtain any screening, treatment, counseling and other necessary services. Red tape and lack of clear information also causes many to go without available alternative transportation methods. Therefore, any comprehensive state-wide treatment program must include development of adequate transportation, and it is recommended that:

   - The state must develop public transportation to comprehensive screening/ treatment facilities, as well as to long term care facilities for people at risk, or HIV-infected.

   - Transportation information systems must be provided to help patients and families utilize what is available.

5. Long term care remains a problem for HIV-infected individuals. To the greatest extent possible, such chronic care is being provided in the community in the form of home care, and for many this has been a successful method. However, there are and will always be people without home or family/caretaker resources to enable them to remain in a home care setting. For some, their care needs may progress to such an extent that round-the-clock help is necessary for safety and comfort. A long term care facility such as a nursing home is the logical alternative for these patients, and New Jersey has pioneered such a facility for people with AIDS. To date, though, the state has only one of these. More are needed to serve people throughout the state. Thus, the following is proposed:

   - Adequately determine the extent of additional need for institutional long term care for HIV-infected individuals. This may also be part of the data collection carried out by the health care economist suggested in the first recommendation.

   - Promote the development of long term care beds needed, either via use of existing facilities, or via construction of another facility.

   - Develop adequate public transportation for access to all long term care facilities for HIV-infected individuals and their families.

   - Hospice care should also be available to people with AIDS who have reached the level of terminal care. Hospice services at home, as well as in-patient hospice care should be encouraged and developed if unavailable to clients in any particular community in New Jersey.

6. Treatment within "reach" of people's socio-cultural landscape includes care which is user-friendly. This ranges from care given in an attitude and atmosphere of acceptance, to care which is centralized and is, in essence, "one-stop-shopping." It is speculated that treatment centers which bring together several practitioners who have specifically chosen to care for the problems of HIV-infected individuals is one method to develop an accepting atmosphere. At the same time, it can provide for patients and families that centralized care which avoids traveling to many locations for each type of treatment needed, from medical to dental to counseling, and so on. Thus the following recommendations are made:

   - Stimulate development of alternative practice models, including multi-specialty group practice sites specifically related to care of HIV

infection.

- Consider reimbursement at higher levels for such care as one means of promoting this development.

- Encourage AIDS Resource Centers, consortia, and similar network models, as discussed in reference no.2 and as various communities are in the process of implementation. However, there must be safeguards to avoid unnecessary duplication of services, while promoting "real time" (prompt and regular) communication and coordination between service agencies.

C. Adequate Number of Knowledgeable Health Care Providers

While we are faced with a growing number of people at risk or HIV-infected in New Jersey, we are, at the same time, experiencing a loss of adequately prepared practitioners to treat these individuals. There is a crucial need to educate the next generation of infectious disease specialists, both adult and pediatric, as well as to develop adequate dental services and other specialties such as nursing and social work. In addition, the many general practitioners who are attempting to effectively treat their HIV-infected patients need on-going information and clinical updates to assist them in their work. Lack of such information may be one of the factors which causes some practitioners to be reluctant to treat this illness. The following recommendations are aimed both at increasing the supply of clinical specialists and providing adequate education resources for generalists.

1. To stimulate provider education it is urged that the State Medical Department disseminate the Academy of Medicine Practice Guide (Identification and Management of Asymptomatic HIV-Infected Persons in New Jersey: A Practical Protocol for New Jersey Clinicians) to all physicians and dentists in the state.

2. It is also advised that the state evaluate the causes for poor response to provider education programs, and develop new educational methods which may be more effective and better-received.

3. To expand and ensure sufficient health care professionals in the care and treatment of HIV infection, it is recommended that New Jersey create a state-funded program of practice fellowships for the treatment of those infected with and affected by HIV.

   One model for such a program is the HIV Clinical Scholars Program developed by the New York State Department of Health AIDS Institute.

It is suggested that the following fellowship allocation be used in New Jersey for each of the eight facilities in the state affiliated with a teaching program:

Physician	6 slots
Nurse	3 slots
Dentist	1 slot
Social Worker	3 slots

The cost per year for each site is estimated currently at $400,000.

While the New York model has been mentioned, it is also suggested that there be flexibility in the project design here in New Jersey to maximize creative and utilitarian thinking.

These recommendations related to treatment of the HIV-infected individual and family should be considered initial ones. There are many other problems which require exploration and resolution. However, these are most paramount and most frequently touch the lives of those who are infected. In addition, these are realistic recommendations which can be implemented fairly rapidly.

SUBSTANCE ABUSE

Task Force Members:

Julia Del C. Aleman, Chair
Marion Banzhaf
Thomas D. Farrell
Clement R. Ferdinando, Jr.
Alan Weiss

Ad Hoc Members:

Marcia Abramson
Frank Busichio
Tom O'Leary
Edith Springer
Jackie Mirkin
Lorhetta Nichols
Donna and Terry O'Connor

The transmission of HIV to intravenous drug users ("IDUs") has been well documented, in addition there is great concern with respect to transmission of HIV as it relates to the use of other substances. Sexual activities that take place under the influence of substances which are not used intravenously such as alcohol and crack, pose a great risk since judgment on safer sex tends to be impaired.

HIV prevention and education efforts among substance users in the state of New Jersey has been tried through a number of approaches: drug treatment programs, detoxification units, mobile health vans, literature distribution, outreach workers, HIV testing sites.

However, it seems that the above mentioned attempts have not made a significant impact in reducing the transmission of HIV among substance users in the state of New Jersey. Statistics show that HIV transmission among substance users in the state of New Jersey continues to increase.

The Substance Abuse Subcommittee of the Governor's AIDS Advisory Council would like to highlight a number of issues which reflect the inadequacies of the above mentioned efforts. Finally, the subcommittee will make recommendations that can serve as guidelines for the development of innovative programs that can effectively work with substance users in the face of HIV.

Facts and Findings

- According to data from the New Jersey State Department of Health Division of Alcoholism, Drug Abuse and Addiction Services the estimated number of intravenous drug users in the state of New Jersey is 50,000.

- The estimated number of non injecting illicit drug users (alcohol not included) is 650,000.

- There have been 11,402 AIDS cases reported from June 1981 through June 30, 1992. 67% are African - American or Latino (6,129 African - American or 54%; 1,529 Latino, or 13%). 59% of the cases are intravenous users (55% ivdus; 4% both ivdu and homosexual male). Of the 1,125 heterosexual transmission cases, which represent 10% of the total New Jersey cases, more than half are drug related. New Jersey has the highest percentage of AIDS cases in the IVDU transmission category of all the states in the U.S.

- The estimated number of funded drug treatment slots in New Jersey is 8,568, excluding alcoholism treatment. The number of substance users exceeds the number of drug treatment slots available.

- Many substance using individuals do not attend drug treatment programs, they might seek services from other social services agencies and/or institutions i.e. drop in centers, homeless shelters, etc.

- Anecdotal evidence from HIV positive substance users suggests that discharge planning from drug detox units is inadequate. In many instances referrals are not made to medical facilities or any other programs that can meet the needs of the HIV positive substance user

- Continuum of care is inadequate and sometimes non existent within the drug treatment facilities.

- There are no existing drug treatment programs in the state of New Jersey that accept HIV positive, pregnant, substance using women or HIV positive, substance using women with their children.

- Anecdotal evidence suggests that a number of alcohol and substance abuse counselors are not sensitive to issues related to sexuality, cultural and class differences. In addition, that some counselors tend to be homophobic, adictophobic and prejudice against people who use drugs.

RECOMMENDATIONS

A. Certification and re-certification of substance abuse and alcohol counselors should include extensive training around cultural and class differences and sexuality.

B. Active substance users should have access to a myriad of services, including HIV prevention and education.

C. Other models of care should be explored i.e. The Harm Reduction Model. The use of the non-traditional model of care has proven to be effective in reducing the transmission of the HIV among drug users.

D. The transmission of HIV among substance users should be treated as a public health issue and not as a moralistic issue, hence drug users.

LIVING WITH AIDS: SURVIVAL NEEDS

Task Force Members:

James Credle
Barry Moore
Suzanne Sblendoris
Jim Davis
Tom O'Leary

Addressing the survival needs of people living with AIDS ("PLWA") requires the following actions:

1. Identification of major needs areas, and evaluation of existing resources to meet the needs.

2. Increasing the sufficiency and availability of and the accessibility to all resources.

Few would argue that the survival needs addressed below are being met for all our citizens. For PLWAs these inadequacies are at times more devastating and affect all aspects of existence. AIDS patients are more vulnerable for many reasons, most significantly because the populations impacted have historically lived with discrimination. Further, AIDS often causes family and social support systems to erode, creating further dependence on a public support network. Often the remaining personal support network is fearful, lacking knowledge, and consequently unable and/or unwilling to provide required support.

The following areas of need are the most crucial to address to provide support to the PLWA:

1. INCOME SUPPORT

Too many people in our society fall below the poverty line and even with food stamps and other such entitlements do not reach this income level. While they may qualify for other entitlements such as Medicaid, the most often neglected areas are those of basic survival. Indeed this impacts on all areas addressed herein.

2. HOUSING

A full spectrum of housing options must be made available, including independent, assisted living/group homes, boarding homes, foster care, residential health care to skilled nursing care. The location housing restrictions should be waived to support caregivers' willingness to "take in family members requiring care."

3. FOOD, CLOTHING, TELEPHONES & BASIC APPLIANCES

Needs in this area are commonplace. No refrigerator or means for cooking food. No telephone to access support and assistance. No food because of lack of money and difficulty with getting food supplies. Food Banks are too few and are often depleted early each month. Meals on Wheels programs have long waiting lists and often can't deal with dietary restrictions and are too costly for some.

4. TRANSPORTATION

All required modes are not available and third party payment is often inadequate. Problems with transportation cause further isolation from available resources and the support of others.

5. HEALTH CARE AND MEDICATIONS

Gaps exist in the areas of gynecological services, intermediate/step-down care and Hospice programs. Some private physicians have not stayed knowledgeable of available treatments and/or do not consult with infectious disease specialists. Medications are not available to many because of the costs and inadequate third party coverage. Many young working people with AIDS have their health coverage terminated when they can no longer work and can't afford private insurance. There are time gaps before they may qualify for entitlements.

6. FOSTER CARE, CHILD CARE & RESPITE CARE

Some services exist but they are limited. The high incidence of AIDS among women in New Jersey has resulted in long term child problems, and role reversal with children caring for mothers and other family members.

RECOMMENDATIONS

Several New Jersey programs have begun to address some of the basic needs of PLWA. The AIDS Community Care Alternatives Program (ACCAP), the state Medicaid Waiver Program for AIDS patients, should be evaluated for its admission criteria and service package. Expansion in key areas such as respite and inclusion of HIV positive patients not yet diagnosed with AIDS would be beneficial. The AIDS Drug Distribution Program (ADDP) provides medication assistance and liberalization of eligibility would result in greater access to needed therapies and *future* health care cost savings.

The following recommendations address the needs identified earlier. Achievement of

these four goals would significantly impact on these survival needs.

A. Broaden the eligibility requirement for resources.

1. Reduce access delays due to application processing for resources;

   - Eliminate barriers based on physical location (*e.g.*, ineligibility for resources in community while hospitalized); and

   - Institute presumptive eligibility for all resources with indefinite time period.

2. Coordinate existing resources to prevent barriers, duplication and identify needs.

   - Improve communication among resource providers.

   - Develop centralized intake with database to reduce/eliminate data gatherings by various providers in a manner to assure confidentiality is maintained.

   - Create clearing house (information and referral) entity to identify and maintain data on all AIDS/HIV resources; and promulgate to all providers on regular schedule.

   - Create, maintain and distribute computerized statewide AIDS resource directory by county, updating monthly.

3. Enhance entitlement programs to provide funding to PLWA's so that no one falls below "poverty level," ensuring that all poverty needs are met including such items as adequate housing, furniture, appliances, telephone, etc.

4. Pilot a universal health insurance program with a single payor, publicly administered, available to all in need which provides comprehensive acute, long term care, preventive and community based services.

LEGISLATIVE INITIATIVES

Task Force Members

Joseph F. Suozzo, Esq., Chairman
Riki E. Jacobs, Esq., Vice Chairwoman
Lawrence Bembry
Channell M. McDevitt
Paul W. Armstrong, M.A., J.D., LL.M.
Council Chairman (Ex-Officio)
Patricia T. Leuzzi, Esq.
Robert S. Olick, M.A., J.D.
Diana Stager

The Legislative Subcommittee submits the following premise and recommendations for consideration by the Council as part of its first report to the Governor:

Basic Premise:

First, and foremost, the Task Force urges that the Council only support administrative and legislative initiatives addressing HIV/AIDS which are firmly rooted in public health concerns.

A. Developing Public Policy

Consistent with this foundational principle the Council must pursue the development of responsible public policy in keeping with public health concerns which acknowledge both the continuing development of medical knowledge about HIV/AIDS, and the complex societal issues posed by the deadly virus. As an example, the Task Force can not support governmental action which shifts the responsibility and task of the treatment and prevention of HIV/AIDS to the criminal justice system. Governmental action of this nature offers only the false promise of a quick-fix, and tricks the public into believing that the transmission of HIV/AIDS can be stopped by enacting criminal penalties rather than through statewide education and prevention.

B. Joint Bi-partisan Legislative Committee

The Task Force firmly believes that the establishment of a joint bi-partisan legislative committee to coordinate and develop a comprehensive legislative approach to deal with the complex public policy issues surrounding HIV/AIDS is warranted. This approach would be in keeping with successful legislative initiatives dealing with past statewide crises.

C. Coordinating State and Federal Initiatives

The Task Force recommends the establishment of ongoing and formal liaison with the federal government, and the National Commission on AIDS, as well as the efforts of our sister states.

D. Governmental Policy for the Treatment and Control of the HIV/AIDS Virus

In encouraging the development of public policy for New Jersey, the Task Force supports legislative and other governmental action which promotes treatment and control of the disease through:

1. broad-based education and prevention efforts;
2. voluntary testing, counselling and treatment; and
3. appropriate and intensive health care intervention, treatment and follow-up.

E. Current Opposition to Mandatory Testing

Importantly, the Task Force opposes mandatory testing at this time. Such efforts are not cost-effective, do not provide an effective means to control the disease, discourage presentation for testing and other interactions with the health care system, and misdirect scarce resources from broad-based public health efforts which offer the best means to control and prevent transmission of HIV.

Proposed HIV/AIDS Legislation - 1992 Session

SENATE

S-98 Senator Ewing - Requires persons being tested for venereal disease and marriage license applicants to submit to HIV testing.

S-182 Senator Zane - Requires marriage license applicants to submit to HIV testing.

S-113 Senator Cardinale - Prohibits the instruction of sex education in the schools unless the following is stressed: abstinence from premarital sex; abstinence as the only completely reliable means of preventing the transmission of AIDS and STDs and of avoiding pregnancy; the failure rate of contraceptive devices such as condoms.

S-390 Senator Bassano - Establishes the New Jersey AIDS Viral Disease Tissue Research Bank. Appropriates $30,000.

S-308 Senator Connors - Requires the express written consent of a parent or guardian before a child may be permitted to enroll in the family life education program given by local school districts.

S-331 Senator Cardinale - Broadens the statutory definition of venereal disease to include infection with HIV.

S-878 Senators Cardinale and Scott - Prohibits condom distribution in state institutions.

ASSEMBLY

A-181 Assemblymen Kavanaugh and Penn - Requires that a person convicted of aggravated sexual assault or sexual assault be sentenced to a mandatory minimum term of 15 years if the person knew he or she was HIV infected at the time of the offense.

A-316 Assemblywoman Crecco - Requires that public school sex education courses stress abstinence from sexual activity as the only reliable means of preventing STDs and AIDS and of avoiding pregnancy. It also requires that AIDS prevention information stress the avoidance of IV drug use.

A-771 Assemblyman Felice - Requires the Department of Health to provide AZT or any other drug approved for the treatment of HIV and AIDS free of charge to emergency volunteer workers diagnosed with HIV as a result of job related exposure.

A-897 Assemblymen Stuhltrager and Catania - Requires that persons convicted of sexual assault, aggravated sexual assault, and aggravated criminal sexual contact submit to testing for STDs and HIV at the victim's request.

A-785 Assemblywoman Bush - Requires that a living organ donor be tested for HIV.

A-924 Assemblywoman Bush - A comprehensive bill which addresses the following: requires that anonymous testing be offered at all state funded counseling and testing sites; requires that anyone tested for HIV receive pre and post-test counseling with an exception for blood banks and life insurance companies; relieves persons required to report diagnosed cases of AIDS and HIV infection to the Department of Health of liability in any action for damages unless the person knowingly provided false information; provides that organizations which maintain records on behalf of third party payers adhere to confidentiality and disclosure provisions of the law; authorizes a physician to contact the sexual or needle sharing partner of an HIV infected person without the person's consent and without revealing any identifying information; relieves physicians from liability in any action arising from the failure to contact or from the contact if made in good faith; provides that a person's medical record can be disclosed for the purpose of conducting a prosecution for a crime only if the disclosure would be permitted under state law, court rule or common law, and the court finds that disclosure is warranted; provides that no HIV test shall be ordered without the written informed consent of the subject of the test or his or her authorized representative; provides that informed consent must include information about testing, AIDS and HIV infection, the benefits of early diagnosis and treatment, transmission and the availability of anonymous testing; directs the Commissioner of Health to prepare and distribute guidelines for the adoption of universal precautions; amends the law to authorize a minor to consent to HIV testing.

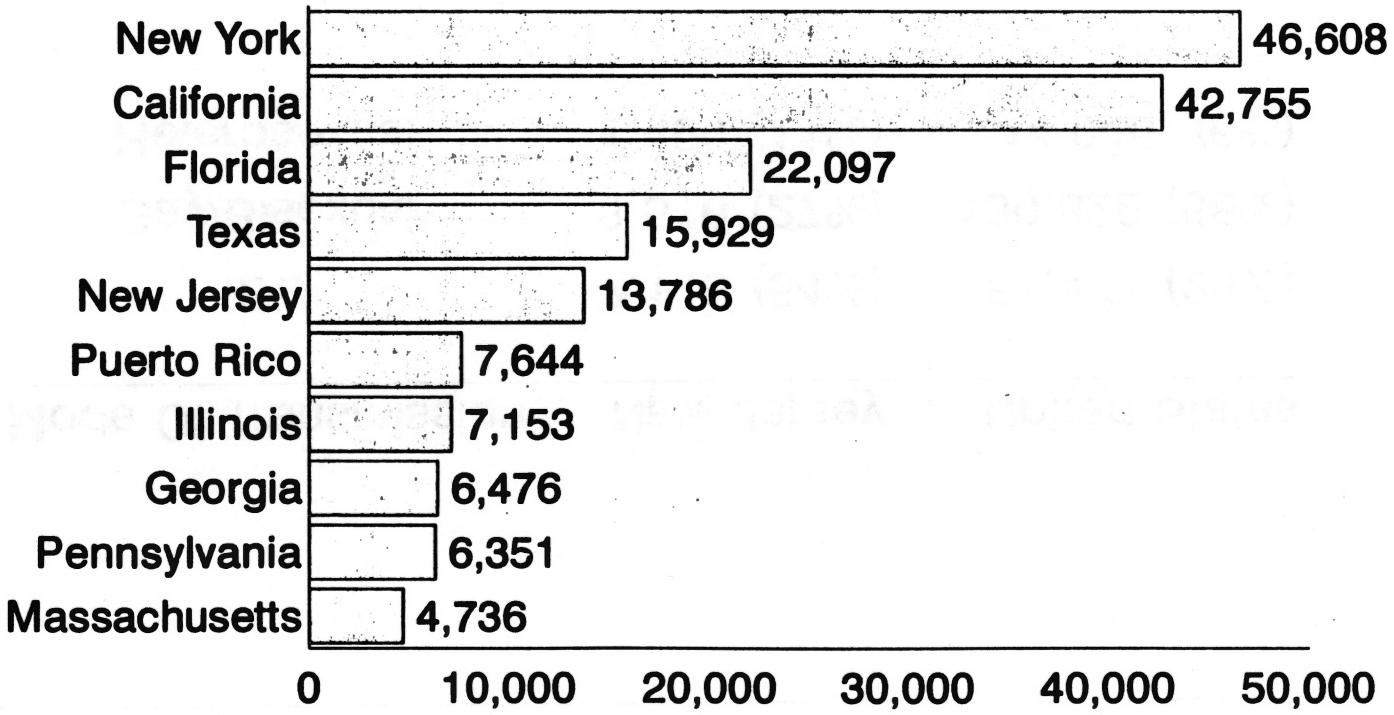
A-970 Assemblywoman Ogden - Requires the notification of emergency medical transportation services of a patient's HIV status.

A1027 Assemblymen Impreveduto and Kelly - Same as S-182.

A-1028 Assemblymen Impreveduto and Kelly - Same as S-98.

A-1246 Assemblyman Solomon - Amends the definition of attempted murder to include the knowing transmission of HIV without the knowing consent of the victim; includes causing death by infecting a person with the HIV virus as a result of an act committed without the knowing consent of the victim, by one who knows he/she is infected with HIV in the definition of murder; transmission of HIV is to be included as an aggravating factor in consideration of the death penalty, if the offense was committed by an actor who knew he or she was HIV infected.

Top 10 States: Cumulative AIDS Reports



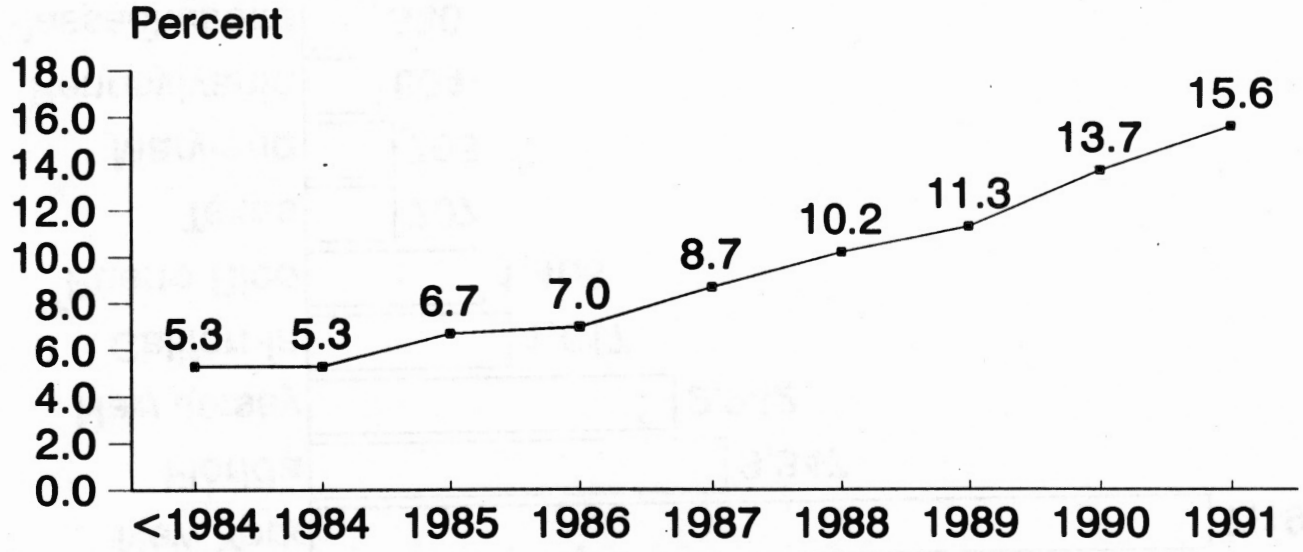
Data reported as of 6/30/92
(U.S. Total Cases = 230,179)

Cumulative AIDS Cases Among Adults In New Jersey by Mode Of Transmission

Mode Of Transmission	New Jersey	United States
IDU	7,145 (54%)	51,477 (23%)
Gay/Bisexual	3,510 (27%)	130,822 (58%)
Heterosexual	1,490 (11%)	14,045 (6%)

Data reported as of 6/30/92

HETEROSEXUAL CONTACT TRANSMISSION MODE AS PERCENT OF ADULT AIDS CASES BY YEAR OF DIAGNOSIS

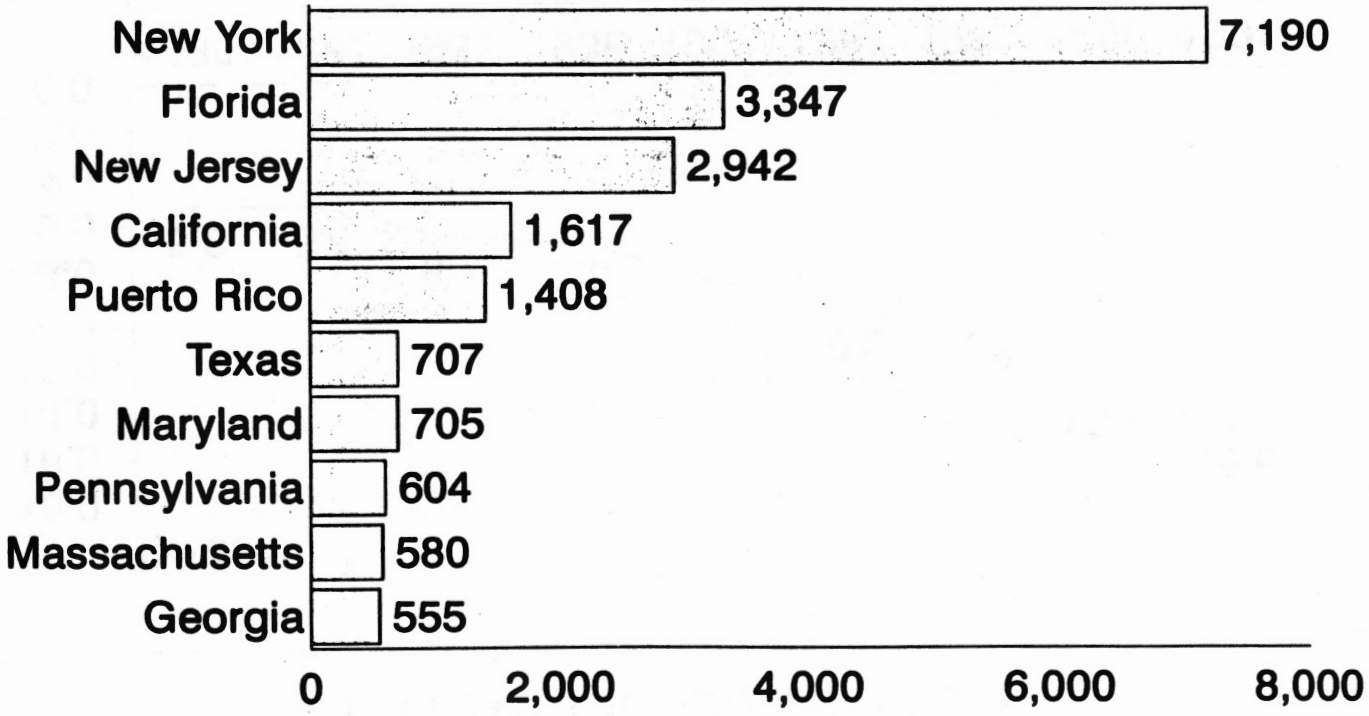


	<1984	1984	1985	1986	1987	1988	1989	1990	1991
Males	3.6	3.5	2.7	2.6	4.1	3.8	5.9	6.5	6.5
Females	15.4	16.7	23.6	25.0	25.7	33.2	30.2	36.9	42.7

Year of Diagnosis

Data reported as of 6/30/92

Top 10 States: Women Cumulative AIDS Reports



Data reported as of 6/30/92
(U.S. Women Cases = 24,323)

Cumulative AIDS Cases In New Jersey Among Women

	New Jersey	United States
Total	2,926 (22%)	24,323 (11%)
IDU	1,769 (60%)	12,113 (50%)
Heterosexual	961 (33%)	8,524 (35%)

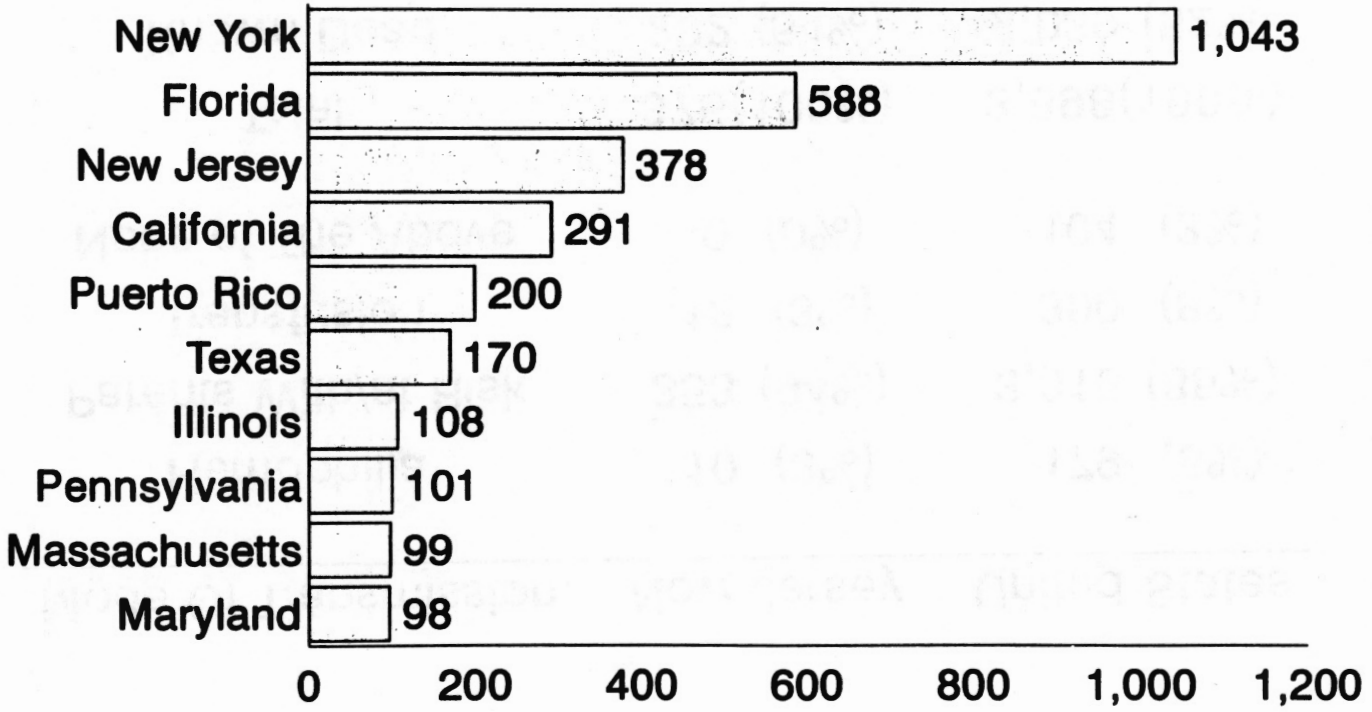
Data reported as of 6/30/92

Pediatric AIDS

- New Jersey ranks third nationally in cumulative pediatric cases reported, behind New York and Florida
- New Jersey ranks second to New York in cumulative pediatric cases per 100,000 population
- New Jersey seroprevalence rate in newborn testing is again second to New York with 500 per 100,000 births

Data reported as of 6/30/92

Top 10 States: Pediatric Cases Cumulative AIDS Reports



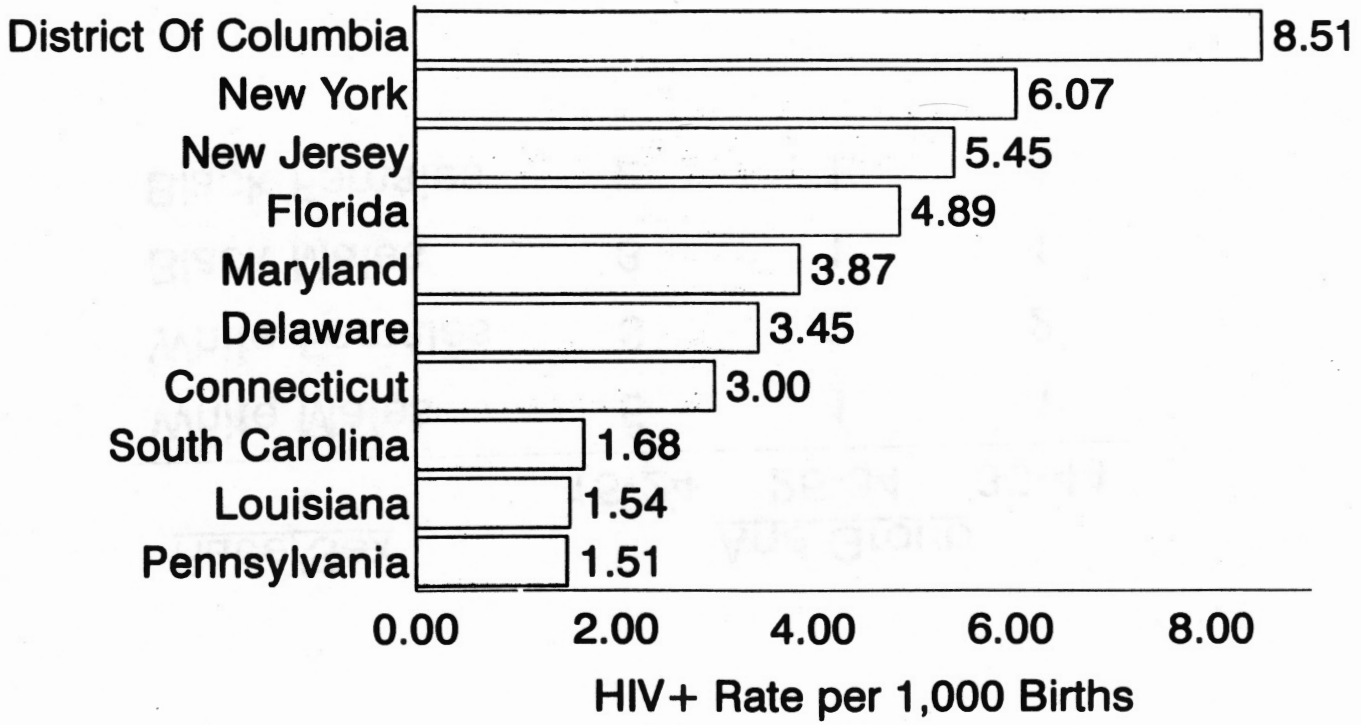
Data reported as of 6/30/92
(U.S. Pediatric Cases = 3,898)

Cumulative Pediatric AIDS Cases In New Jersey By Mode of Transmission

Mode Of Transmission	New Jersey	United States
Hemophilia	10 (3%)	179 (5%)
Parents With/at Risk	353 (94%)	3,315 (85%)
Transfusion	12 (3%)	300 (8%)
None of The Above	0 (0%)	104 (3%)
Total	375(100%)	3,898(100%)
Known Dead	202 (54%)	2,039 (52%)

Data reported as of 6/30/92

Top 10 States: Newborn HIV Seroprevalence



Data reported to CDC as of 5/1/92
From 39 States and D.C.

Provisional 1990 Ranking
HIV Related Causes of Death By Age Group/Race/Sex

Race/Sex	Age Group		
	15-24	25-34	35-44
White Males	5	1	1
White Females	6	2	2
Black Males	3	1	1
Black Females	2	1	1

Source : New Jersey Center for Health Statistics

Provisional 1990 Ranking
HIV Related Causes of Death By Age Group

Age Group	Rank
1-14	4
15-24	5
25-44	1
45-64	8
65+	--
Overall Rank	8

Source: New Jersey Center for Health Statistics

Reported AIDS Incidence and Relative Risk By Race/Ethnicity and Gender In New Jersey

Gender-Race/Ethncty	Rate/100,000 pop'n	Relative Risk
Males		
White, non-Hisp	146	1.0
Black, non-Hisp	1373	9.4
Hispanic	527	3.6
Females		
White, non-Hisp	23	1.0
Black, non-Hisp	458	20.1
Hispanic	122	5.3

Rates based on cummulative data as of 6/30/92

Pediatric AIDS Incidence and Relative Risk By Race/Ethnicity and Gender In New Jersey

Gender-Race/Ethncty	Rate/100,000 pop'n	Relative Risk
Males		
White, non-Hisp	6.3	1.0
Black, non-Hisp	83.0	13.2
Hispanic	49.0	7.8
Females		
White, non-Hisp	5.2	1.0
Black, non-Hisp	89.0	17.1
Hispanic	33.0	6.4

Rates based on cummulative data as of 6/30/92

Table B

Governor's Advisory Council On AIDS

1991-1992 Schedule Of Meetings

Location	Date
Richard J. Hughes Justice Complex 25 Market Street Trenton, New Jersey	December 16, 1991
Mary Roebling Building 20 West State Street Trenton, New Jersey	January 7, 1992
Department of Transportation 1035 Parkway Avenue Trenton, New Jersey	February 5, 1992
Department of Community Affairs 101 South Broad Street Trenton, New Jersey	March 4, 1992
Department of Transportation 1035 Parkway Avenue Trenton, New Jersey	April 1, 1992
Department of Labor John Fitch Plaza Trenton, New Jersey	May 5, 1992
New Jersey Bioethics Commission 742 Alexander Road Princeton, New Jersey	June 12, 1992
Department of Labor John Fitch Plaza Trenton, New Jersey	September 2, 1992

Table C

Governor's Advisory Council on AIDS

Public Hearing Witnesses

May 27, 1992

Rutgers University, Labor and Education Center
New Brunswick, New Jersey

Dr. Celso Bianco
New York Blood Center

Dr. Joel Leizer, President Elect
New Jersey Dental Association

Gilbert Baez
Raritan Bay Medical Center

Sandra Nilsson
Raritan Bay Medical Center

Alan Weiss
ACT-UP

Carl Sigmon
ACT-UP

Pat Buckley
MCOSS

Elizabeth Silvey
Hyacinth Foundation

Sandra Freeman
Office of Women & AIDS

Robert Liggon
Paterson Counseling

Nikki Ian
ACT-UP

Terri Leonard
Planned Parenthood/Middlesex

JoAnn Moffitt
CAPCO

Mary DeWaters
Middlesex County AIDS Coalition

Sharon Cherry
Private Citizen

John Mackin
ACT-UP
Hyacinth Foundation Hotline

Dan Piggon
ACT-UP

Katherine Neal
Rutgers University

STATE OF NEW JERSEY
EXECUTIVE DEPARTMENT

EXECUTIVE ORDER NO. 45

WHEREAS, the presence of Acquired Immune Deficiency Syndrome (AIDS) and Human Immunodeficiency Virus (HIV) present a serious public health concern for the State of New Jersey; and

WHEREAS, New Jersey ranks fifth in the nation with regard to the number of its citizens infected with AIDS since 1981; and

WHEREAS, the number of AIDS cases has been steadily increasing and in November of 1990, New Jersey reported its ten-thousandth AIDS case; and

WHEREAS, as many as forty-thousand New Jerseyans may be infected with HIV; and

WHEREAS, the human suffering caused by AIDS is of continuing concern to all New Jerseyans; and

WHEREAS, New Jersey's AIDS/HIV effort needs to be better coordinated to deliver critical services efficiently and cost effectively to its citizens.

NOW, THEREFORE, I, JIM FLORIO, Governor of the State of New Jersey, by virtue of the authority vested in me by the Constitution and laws of this State, do hereby ORDER and DIRECT:

1. There is hereby created a Governor's Advisory Council on AIDS, hereinafter referred to as the Advisory Council.

2. The Advisory Council shall consist of the Commissioner of Health or her designee; the Commissioner of Corrections or his designee; the Commissioner of Education or his designee; the Commissioner of Human Services or his designee; the Commissioner of Community Affairs or his designee; the Commissioner of Insurance or his designee; the Attorney General or his designee; the Public Advocate or his designee; the Chancellor of Higher Education or his designee; two members of the Senate to be appointed by the President

thereof, no more than one of whom shall be from the same political party; two members of the General Assembly to be appointed by the Speaker thereof, no more than one of whom shall be from the same political party; and no more than thirty-five public members to be appointed by the Governor. The public members shall consist of educators, labor representatives, health care providers, advocates and persons who have tested HIV positive. The public members shall serve at the pleasure of the Governor. All members of the Advisory Council shall serve without compensation.

3. The Governor shall designate a Chairperson and Vice Chairperson from among the public members of the Advisory Council.

4. Advisory Council vacancies shall be filled by the Governor for the remainder of the unexpired term.

5. It shall be the duty of the Governor's Advisory Council to:

a. Advise the Governor on policy relating to AIDS issues;

b. Monitor the Department of Health's implementation of its plan to fight AIDS in the 1990's;

c. Recommend legislation to the Governor;

d. Advise the Governor as to what measures need to be taken to coordinate State efforts concerning AIDS research and treatment;

e. Advise the executive branch concerning its relationship with voluntary agencies and private sector entities involved in AIDS-related activities, including funding sources for research; and

f. Prepare an annual report for the Governor on or before June 1 of each year, regarding its findings, and any recommendations it deems appropriate.

6. The Advisory Council shall receive administrative staff support from the Department of Health, but shall not obligate any funds of that Department or of any other department, office, division or agency of the State.

STATE OF NEW JERSEY
EXECUTIVE DEPARTMENT

7. This Order shall take effect immediately and shall terminate on June 2, 1994.

GIVEN, under my hand and seal this 24th day of Oct. in the Year of our Lord, one thousand nine hundred and ninety-one, and of the Independence of the United States, the two hundred and sixteenth.

Respectfully,

GOVERNOR

Attest:

ELIZABETH A. RYAN
Assistant Counsel

FILED

OCT 28 1991

JOAN HABERLE
SECRETARY OF STATE

A Publication of the Governor's Advisory Council on AIDS

December 1992