AIDS

Is There a Will to Meet the Challenge?

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Preface

This report completes the formal work of the Citizens Commission on AIDS for New York City and Northern New Jersey. Established in July 1987 by a consortium of 18 foundations, the Commission has sought to stimulate private sector leadership in responding to AIDS and to contribute a thoughtful, nonpartisan voice in the public sector.

AIDS is an immense and complex problem. The Commission approached its initial task by tackling separate elements of the problem. The Commission's four reports (and the four chapters of this final report) represent its analysis of: AIDS and the workplace, breaking the link between HIV and drug use, the health care and social service crisis, and education and prevention.

As the Commission comes to a close, the circle must be reassembled. No single part of the problem can be solved without addressing the others. AIDS policies for the workplace should reflect a review of health care benefits, and should ensure that appropriate education programs are provided. Parents who receive AIDS education in the workplace will be better able to discuss the subject with their children and are more likely to support AIDS education in their schools and community organizations. People who are educated about the link between drug use and HIV and the benefits of drug treatment are more likely to support expanded drug treatment facilities. Drug users need both drug treatment and links to medical care and HIV education if they are to protect themselves, their needle-sharing partners, and their sexual partners. Comprehensive medical and counseling services that meet the needs of clients with HIV/AIDS and their caregivers and families are closely linked to preventing HIV transmission.

The various elements of the HIV epidemic should not compete with each other for attention and funding. Nor should HIV compete with other social and medical problems. Only a wholehearted and holistic approach will contain the epidemic and remedy the underlying economic and social problems AIDS has so dramatically highlighted.

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Contents

Introduction

The AIDS epidemic continues its relentless course, with no end in sight. But AIDS is fading from public concern. When the Citizens Commission on AIDS was created three and a half years ago, AIDS was an unpopular cause. It is now rapidly becoming a "post-popular" cause, without ever having truly engaged widespread public support.

→ Since 1981, over 28,000 cases of AIDS have been reported in New York City and another 10,000 in New Jersey--more than were reported in the whole country in July 1987 when the Citizens Commission on AIDS was created. To put these numbers in terms of everyday experiences, consider that with its 24,000 seats, Madison Square Garden could not hold all the people in New York City who have been diagnosed with AIDS.

→ Cases of AIDS have been reported in every United Hospital Fund-designated neighborhood of New York City. AIDS has been reported in every county in New Jersey, with a sixfold increase in the hardest hit areas.

→ More than half of those diagnosed with AIDS have already died. There are at least 17,000 men, women, and children in New York City and New Jersey living with AIDS.

→ The true impact of the epidemic is not fully captured by statistics about AIDS, which is only the final stage in a spectrum of illness related to infection with the Human Immunodeficiency Virus (HIV).*

→ The numbers of people estimated to be ill with symptoms of HIV disease in New York and New Jersey would fill the 77,000 seats in Giants Stadium.

→ Even if there were to be no further transmission of HIV, the most conservative estimates of already infected people--150,000 to 200,000 in New York City and up to 50,000 in New Jersey--warn of the epidemic's future impact on individuals, families, the health care and social welfare systems, and the economy of the region.

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* In this report, the term "AIDS" (Acquired Immunodeficiency Syndrome) is sometimes used to refer to the spectrum of illness of HIV disease, of which AIDS is the most serious and final stage. In time, "HIV disease" may replace AIDS as the term most familiar to the public. However, "AIDS" is currently better known.

→ AIDS has hit hard at young adults, many of whom have children. An estimated 20,000 New York City children will be orphaned by AIDS by 1993. Most of these children are not themselves infected with HIV, and are therefore not eligible for many special services. Yet they have overwhelming needs for emotional support, stable homes, and health care, to say nothing of basic needs for food and shelter.

While these numbers are alarming in themselves, what is even more ominous is the apparent peak in public interest long before the region feels the full onslaught of the epidemic. Political leadership appears to be following the public mood rather than taking bold initiatives. With a few exceptions, leadership at all levels has been lacking. The public mood that the Citizens Commission confronted at its inception was a mixture of hysteria and confusion. As the Commission ends its work, the prevailing mood is apathy and hostility. Outside the most devastated communities, the epidemic seems hidden, happening to someone else, somewhere else. An invisible wall seems to separate those who are suffering from everyone else.

Ten Reasons to Care about AIDS

Why should people who are not at risk themselves--or who believe they are not at risk--care about those who are? Because:

→ **They may be wrong about their own risk.** In New York and New Jersey, the epicenter of the epidemic, any sexually active person, or any person who uses injectable drugs or "crack" cocaine, may be at risk.

→ **They may be wrong about their children's risk.** AIDS threatens a generation of adolescents and pre-teenagers whose experimentation with sex or drugs can now lead to HIV infection and death.

→ **AIDS is an epidemic.** More precisely, HIV/AIDS is a series of still unfolding epidemics, with different peaks and valleys among different populations, each with no end in sight.

→ **HIV transmission can be prevented.** Consistent, ongoing, supportive multicultural educational programs, linked to direct services, motivate and sustain safe behaviors.

→ **In the vast majority of cases AIDS is ultimately fatal.** There is no cure or vaccine, and no way to reverse HIV infection.

→ **Early medical treatment can help people who are already HIV-infected.** Lives can be prolonged and improved through early medical and psychosocial intervention and appropriate counseling.

→ **AIDS is decimating a generation of otherwise healthy adults in their most productive years.**

→ **AIDS threatens to overwhelm an already strained health care and social welfare system.** Society needs a health care system available to all who need it, when they need it, and for whatever reasons they need it.

→ **Deferring costs now will increase burdens later.** Failing to provide drug treatment and HIV-related services in community-based settings will lead to greater acute-care costs as more and more people fall ill.

→ **AIDS tests our humanity, decency, and dignity.** If we turn our backs, we dinminish ourselves and quite possibly jeopardize our futures.

LOOKING BACK, LOOKING AHEAD

The following statements summarize the principal events and trends from 1987-1990 and outline an agenda for policymakers and the public.

AIDS AND THE WORKPLACE

Positive Steps

- → The Citizens Commission's "Responding to AIDS: Ten Principles for the Workplace" and variants are endorsed by 580 corporations, unions, religious, and voluntary organizations; the "Ten Principles" are widely accepted as basic framework for personnel policy development on HIV disease
- → The Federal Americans with Disabilities Act (ADA), protects people with disabilities, including HIV infection and AIDS, from workplace discrimination
- → A series of legal decisions protects rights of employees with HIV/AIDS
- → Education materials are developed for varied workplace settings; trained staff in City, State, and voluntary agencies provide free or low-cost education in workplaces

Negative Signs

- → There is still no national commitment to recognizing impact of AIDS on the workplace
- → The majority of employers have failed to develop AIDS policies and education programs
- → There are few linkages between AIDS education providers and employers
- → Employment discrimination continues; people with low and moderate incomes lack access to legal services
- → The cost of health care continues to rise; some self-insured employers respond by limiting or capping AIDS coverage

Future Directions

- → Focus on special problems for small and mid-sized companies (cost of health care benefits, denial of relevance of problem to their workplaces, and lack of resources for education)
- → Educate employers, employees and advocates for implementation of ADA

- → Continue workplace training, including a component for managers who are often first to deal with AIDS issues
- → Review health care benefits packages to provide high-quality and cost-effective care to HIV-infected employees
- → Devote attention to problems and needs of caregivers (family members, care partners) who need flexible schedules and emotional support
- → Develop policies, education, and procedures that meet stringent standards of infection control and protect rights of HIV-infected health care workers

AIDS AND DRUG USE: BREAKING THE LINK

Positive Steps

- → Nineteen New York City Community Boards, six New Jersey cities, and two New Jersey Boards of Chosen Freeholders endorse Commission's four-point statement calling for expanded drug treatment
- → Federal funds are appropriated for reducing drug treatment waiting lists through the Anti-Drug Abuse Act of 1988, helping New Jersey double treatment slots (from 4,000 to 8,000) and helping New York State to add 8,480 treatment slots. Of these slots, approximately 5,396 are in New York City (bringing the City's publicly funded slots to 37,450)
- → Studies showed continued evidence of reduction in needle-sharing behavior by drug users
- → New York State establishes primary health care in some substance abuse treatment centers

Negative Signs

- → The majority of Community Boards and Freeholders fail to endorse the Commission's goals and in some cases even fail to respond to repeated requests for discussion
- → Community opposition to the siting of new drug treatment centers continues
- → National Drug Control Strategy fails to emphasize expansion of treatment and research
- → Congress fails to appropriate urgently needed treatment waiting list reduction funds for fiscal year 1991
- → Long waiting lists to enter treatment continue; there is no reliable estimate of potential demand if drug treatment were actually available
- → Crack worsens HIV epidemic by increasing risk of transmission through sexual activity and the use of heroin to counteract extreme euphoria

- → The lack of effective treatments for crack addiction, alternative treatments for heroin addiction and for polydrug use continues
- → The lack of drug treatment services for pregnant women and adolescents continues
- → The lack of outreach and effective education aimed at reducing risky sexual behavior by drug users continues
- → Tuberculosis, syphilis, and bacterial pneumonia emerge as public health threats among HIV-infected drug users
- → Controversies over needle exchange and bleach distribution distract from broader issues of treatment and education and constrain risk reduction efforts

Future Directions

- → Build national leadership to support greater funding of treatment slots to deal with a national emergency
- → Continue building community support for equitably sited drug treatment facilities
- → Fund research on treatments for drug addiction, especially crack
- → Develop new models for linking drug treatment with medical care and HIV/AIDS education
- → Continue outreach to drug users and their sexual partners
- → Supplement increased federal, state, and local funding (needed to cover the basic costs of expanded drug treatment and education) with increased private funding, especially in areas such as capital costs and the creation and evaluation of innovative treatment and education models
- → Establish independent monitoring of funding and accessibility of drug treatment so that accurate data on the number and location of slots are readily available

THE CRISIS IN AIDS CARE: A CALL TO ACTION

Positive Steps

- → A consensus develops on creation of continuum of community-based care to eliminate unnecessary and expensive hospitalizations. The consensus is outlined in series of reports in New York City by public and private groups analyzing the health care crisis and proposing specific actions (Citizens Commission on AIDS, New York City AIDS Task Force, Mayor's Task Force on AIDS, New York State 5-Year Plan, New York AIDS Coalition/Committee for AIDS Funding)
- → Housing is emphasized as critical need for persons with HIV/AIDS; community-based organizations demonstrate willingness to provide housing if they are given resources and technical assistance

- → Public health officials and AIDS service providers emphasize benefits of early medical intervention; Treatment Assessment Program (TAP) is created in New Jersey
- → Coalition building and advocacy leads to passage, by overwhelming margin, of federal Ryan White Comprehensive AIDS Resources Emergency (CARE) Act authorizing $875 million in emergency funds to hardest-hit cities and states
- → New York State's AIDS Institute undertakes initiatives providing enhanced rates for primary care and grants to community health centers and substance abuse centers, building a basis for long-term financing of these services
- → New York State Appellate Court affirms lower court decisions to halt Medicaid Utilization Thresholds (MUTs), which would have rationed Medicaid services for poor and disabled people
- → New York City creates HIV Health and Human Services Planning Council (as required to obtain federal funds under the CARE bill); New Jersey creates Citizens Advisory Board to develop plan
- → Federal AIDS Housing Opportunity Act authorizes funding for housing services for people with AIDS
- → Some new models are developed for long-term care in New York State
- → New York State enacts comprehensive HIV testing, informed consent, and confidentiality legislation
- → In New Jersey, Coalition of AIDS Service Providers (a network of CBOs) is created to respond to budget and policy issues

Negative Signs

- → New York City and New York State fail to implement fully their own plans and to act on recommendations of other groups
- → Congress fails to appropriate authorized level of funding under the CARE bill ($144 million new funds actually appropriated, of which New York City's share is approximately $16 million, Newark's is $1.6 million and Jersey City's is $875,000, with additional money available through competitive grants)
- → In New Jersey, crisis concerning Uncompensated Care Trust Fund jeopardizes provision of care to medically indigent people
- → Potential of early medical intervention fails to be realized for many HIV-infected people; New Jersey fails to provide adequate funds for TAP program
- → Budget deficits produce funding and personnel freezes or cuts while caseload increases
- → An atmosphere of competition for scarce resources develops between groups and between equally important elements (prevention and treatment, hospitals and community-based services)

- → Congress fails to appropriate funds for the Federal AIDS Housing Opportunity Act
- → Discrimination by health care workers emerges as serious problem in providing care
- → New York State refuses to require long-term care facilities to provide comprehensive care, including gynecological care and explicit HIV education
- → New York City and New Jersey fail to develop adequate plans for housing homeless people with HIV/AIDS; currently most services for homeless people in New York City are provided through the shelter system
- → New Jersey enacts weak confidentiality legislation which requires named reporting of people with HIV infection and significantly diminishes access to anonymous testing
- → New York State Court of Appeals upholds lower court's decision permitting insurers to use HIV antibody test to screen applicants for health as well as life insurance

Future Directions

- → Ensure access to health care, particularly for underinsured and uninsured populations
- → Develop service linkages to provide continuum of care between hospital-based and community-based systems and between drug treatment and medical care facilities
- → Enhance staff recruitment, retention and support at all levels of health care and social services
- → Integrate HIV/AIDS into broader agency missions and systems of medical care while assuring its distinctive focus
- → Involve representatives of all affected communities in planning and implementation of programs
- → Continue research on more effective therapies and making them available to all who might benefit
- → Review epidemiological, clinical, and resource utilization data of people with serious HIV-related illness to recommend policy changes concerning eligibility for entitlement programs and other social welfare programs
- → Expand public and private insurance coverage for promising investigational drugs and innovative therapies
- → Prepare for Medicare coverage as more and more PWAs live past the two-year eligibility requirement to qualify for Medicare
- → Develop supported housing alternatives
- → Enforce human rights statutes to prevent discrimination by health care and social service providers
- → Maintain access to anonymous testing in New York; expand availability of anonymous testing in New Jersey

PREVENTION AND EDUCATION: TEN MYTHS

Positive Steps

→ Citizens Commission on AIDS "Ten Myths" and education report are widely distributed

→ In New York City, Chancellor Joseph Fernandez takes the lead in improving AIDS/HIV education and proposes to make condoms available in schools

→ Many effective community-based education programs are continued and refined

→ Many gay men adopt safer sexual behavior

→ Adolescents as group at special risk because of sexual and drug-using behaviors are increasingly recognized

→ Multicultural programs and materials are being developed

→ Centers for Disease Control revises its standards on educational materials, allowing some exemptions for explicit targeted materials

Negative Signs

→ There are erratic and uncoordinated efforts for staff development and implementation of mandated curriculum in New York City and New Jersey

→ New York City and New Jersey rely heavily on federal funds for AIDS education and fail to provide additional state and local funds

→ There is growing concern that some gay men have relapsed to unsafe sexual practices

→ HIV/AIDS education programs are often unlinked to concrete services, especially for adolescents

→ Extensive and consistent AIDS prevention media campaigns have not been created to educate and sensitize public

Future Directions

→ Continue education and prevention efforts to motivate, sustain, and reinforce safer behaviors

→ Make special efforts to reach adolescents (including gay youth, youth of color, and school dropouts), homeless people, mentally disabled people, women, drug users, underserved ethnic groups, and other targeted populations

→ Encourage development of appropriate multicultural materials and programs

→ Provide adequate funding for these programs

Chapter 1

Responding to AIDS: Ten Principles for the Workplace

In September 1987 the Commission and its executive director met for the first time to discuss its 18-month agenda (the Commission was later extended to February 1991 so that the agenda could be completed). The Commission identified AIDS and the workplace as an area in which it could begin to work immediately. This topic was selected for several reasons: (1) there was a clear need, since several surveys had indicated that most businesses had not developed AIDS policies or education programs and since much HIV-related discrimination was experienced in the workplace; (2) there was already a body of legal, ethical, scientific, and managerial experience to draw upon; and (3) Commission members and staff were most familiar with workplace issues.

Ten Principles for the Workplace

The Commission ultimately chose to present its conclusions in "Responding to AIDS: Ten Principles for the Workplace," issued in February 1988 (see Appendix 1). This one-page document, supplemented by a 45-page report, became a model for subsequent Commission reports; that is, a brief statement or set of conclusions supported by a longer, more detailed and referenced discussion. The principles themselves were distilled from workplace presentations made to the Commission, staff interviews with experts in the field, and published material on the subject. It was not the content of the principles that was new but their presentation and the Commission's advocacy for these standards. The Ten Principles stressed nondiscrimination in employment decisions, the involvement of senior management and union leadership in setting and communicating AIDS policies, the importance of the workplace as a site for AIDS education, the legal and ethical standards for confidentiality of medical information, and the importance of infection control training and equipment in workplace settings where there is a potential risk of exposure to HIV. The specific points, the precise language, and the order of the Ten Principles were revised many times during their development. Outside readers, including corporate leaders, helped the Commission refine the statements.

The Commission decided that the Ten Principles would make a more powerful statement about nondiscrimination and the need for proactive planning and education if they were publicly endorsed by major corporations, unions, and religious and voluntary agencies. The Commission members began a vigorous

campaign to solicit endorsements. Initial contacts at the CEO level were usually followed by staff-level discussions; staff, in turn, presented their recommendations to the CEO. Many major companies were already following most of the principles yet were reluctant to say so publicly for fear of being labeled as having an "AIDS problem." Others had not even begun to think about the issue. A few were frankly hostile.

At several points during the six weeks of intensive discussions, it seemed as though the search for endorsers was going to fail. The Commission decided that a critical mass of 20 or 25 endorsers (other than those represented on the Commission) was needed to go public; otherwise, the idea would be dropped and the Ten Principles would be released without endorsements. The first employer to endorse the Ten Principles was the Girl Scouts of America; the first major corporation was IBM. In the last few days before the press conference, there was a frenzy of activity and by the deadline, a group of 30 endorsers was on board (see Appendix 2).

The announcement of the Ten Principles, dubbed a "Bill of Rights" in the press release, was reported in the *New York Times*, the *Wall Street Journal*, the *New York Post*, *New York Newsday*, and the *Los Angeles Times*, and was carried on the AP national wire service. These key stories resulted in a flood of phone calls and inquiries. By the fall of 1990--two and a half years after the report's release--the Commission had responded to several thousand inquiries from around the world. The Ten Principles, and a slightly revised version issued by the New England Corporate Consortium, have been endorsed by more than 580 employers across the nation and have become the "gold standard" for AIDS-in-the-workplace activities (see Appendix 3).

The Ten Principles have also contributed to government activities. For example, in July 1990 the City Council of Philadelphia mandated all businesses with more than three employees to provide AIDS education. The ordinance relies heavily on the Ten Principles. According to the ordinance, education programs should include current information about HIV transmission as well as the rights of employees who have been infected or who may be thought to have been infected with HIV. The City is required to notify all businesses concerning the provisions of the ordinance. The ordinance also provides for dissemination of educational materials through the Department of Health and sanctions in cases where employers fail to comply. As another example, an Assembly Joint Resolution was introduced in the New Jersey legislature encouraging all employers, including the State, to endorse and adhere to the Ten Principles.

Several national organizations have promoted the Ten Principles to their membership: among them, the National Leadership Coalition on AIDS, the National AIDS Network, the United Way of America, and the National Episcopal

AIDS Coalition. Most recently the Episcopal Diocese of Connecticut endorsed the Ten Principles and called on its 184 congregations to consider them by April 1991. The Diocese further resolved to bring the Ten Principles to the attention of the National Episcopal General Convention. The American Baptists also released the Ten Principles in a resource guide distributed to more than 2,000 of their clergy.

The Ten Principles have been distributed at dozens of meetings and reprinted in numerous articles in business magazines and newsletters, professional journals and AIDS publications, including "AIDS: A Report, the Human Immunodeficiency Virus Epidemic in New Jersey," issued by the New Jersey Department of Health in March 1989. In March 1990, at a conference for business leaders where President Bush was the featured speaker, Dr. Louis Sullivan, Secretary of Health and Human Services, cited the Ten Principles in his address, recommending them "...as an excellent guide in preventing discrimination on the job." At the Fifth International Conference on AIDS in Montreal, the Ten Principles were accepted as a poster presentation and were translated into French and Portuguese (a Spanish translation was part of the original report). The Commission was asked to present the Ten Principles at a World Health Organization consultation in 1988. In 1990 the Commission met with a delegation of Brazilian health officials and private sector leaders to discuss the Commission's workplace initiatives.

Phase V of the national campaign, "America Responds to AIDS," developed by Ogilvy & Mather with a grant from the Centers for Disease Control, will reprint the Ten Principles in a brochure intended to encourage employers to develop appropriate workplace policies and education programs. The National Leadership Coalition on AIDS has created a brochure on AIDS for small businesses in which the Ten Principles are featured.

In short, the Ten Principles have developed a life of their own and exemplify the "multiplier effect" the Commission's funders hoped the group would create. The National Leadership Coalition on AIDS has agreed to continue dissemination of the Ten Principles after the Citizens Commission ends its work.

Survey of Workplace Principle Endorsers

Along with responding to inquiries and promoting the Ten Principles, the Commission has followed up workplace issues in other ways. In the spring of 1990 it surveyed 300 endorsers of the Ten Principles to determine the impact on policy

development, education programs, and other areas, and to identify potential future problems in the workplace.*

The key findings of the survey are:

- 82% of the 114 respondents have AIDS policies.
- 87% of the respondents with AIDS policies report no difficulties implementing them.
- 94% of the employers with AIDS policies communicate the policy to their employees, usually in written form (83%), as part of the employee guidelines or in a company newsletter.
- 72% of the businesses that offer AIDS education to their employees have more than 1,000 employees.
- Two-thirds of the organizations with fewer than 100 employers are AIDS service providers. Of the remaining third, only 4% offer AIDS education programs for their employees.
- Ongoing seminars are rated the most effective component of the education programs.
- Free literature is the most common form of workplace education. It is always coupled with at least one other form of education, often a seminar or video.
- The majority of respondents say the primary obstacle to furthering AIDS education in the workplace is a lack of resources, such as staff, time, or money for materials.
- 32% of the respondents think that more media coverage would increase AIDS awareness at the worksite.
- 83% are involved in AIDS philanthropy within their community through presentations to community groups, distribution of written materials, or program sponsorship.
- Virtually all the respondents think that, over the next five years, their financial and time investment in AIDS will either remain at current levels or increase.
- 60% of all respondents predict the cost of health care will be the greatest AIDS-related problem in the next five years.

Small Business Leadership Forum

In July 1990, the Commission coordinated an innovative small business leadership forum in New Jersey in partnership with the National Leadership

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* An expanded discussion of the findings is reported in a separate paper available from the Commission: *Responding to AIDS: A Survey of the "Ten Principles" in Action in the Workplace.*

Coalition on AIDS, the New York Business Group on Health, local United Ways, the New Jersey Business and Industry Association, and several local small-business associations. The purpose of the conference was to examine the issues small business owners address as they develop AIDS policies and programs and to create a core group of leaders within the small business community who would continue AIDS initiatives in New Jersey. Seventy-three CEOs and business leaders, 25 of them from businesses with fewer than 100 employees, attended the conference. Congressman Donald Payne of the 10th Congressional District in New Jersey had agreed to present the luncheon address, but was unavoidably detained at the last minute; his speech was presented by an aide. The conference participants received a resource packet, enabling them to identify educational materials and speakers for their own AIDS workplace programs.

Along with educating participants, the conference had other rippling effects. Individual business owners and businesses associations representatives remained involved in AIDS issues after the conference was over. The New Jersey Business and Industry Association dedicated the President's Page of its August 1990 monthly magazine, which reaches 13,000 businesses, to a discussion of the conference. The Black Men's Health Project of Newark, a participating organization in the planning process, is developing a three-day health conference, which will include a segment devoted to AIDS. The Metro Newark Chamber of Commerce met with representatives of the conference planning committee to consider how they might address their membership on the issue of AIDS.

Finally, the National Leadership Coalition on AIDS will use the planning process as a model for further small-business AIDS programs, another demonstration of the success of the project.

Legal Developments

The Commission has followed AIDS-related legal issues in the workplace. The enactment of the federal Americans with Disabilities Act of 1990 (ADA) and some state laws have supported the creation of responsible workplace policies. New York State, New York City, and New Jersey all had strong disability discrimination statutes in place prior to the onset of the HIV epidemic. However, a recent survey of AIDS-related discrimination conducted by the American Civil Liberties Union AIDS Project reveals that approximately 57 percent of the discrimination complaints filed in New Jersey, and 38 percent of the complaints filed in New York State, were employment-related. Nationally 37 percent of filed discrimination complaints were employment-related, by far the most frequent type of discrimination reported.[1]

People with AIDS and HIV infection have generally prevailed in employment discrimination claims. These claims have been supported by the

Supreme Court of the United States, which held in the 1987 landmark case, School Board of Nassau County, Florida v. Arline,[2] that contagious diseases fall within the purview of the federal Rehabilitation Act's nondiscrimination provisions. This position was affirmed in a subsequent federal employment case in California, where a special education teacher with AIDS was allowed to return to the classroom.[3]

A recent survey of AIDS litigation revealed that the majority of employment disputes involve health care workers; workers who provide human services for children, such as teachers, foster parents, and day care workers; and food handlers. According to the survey, "Adverse employment decisions did not appear to be based on an assessment of the person's ability to do the job."[4] The ACLU reported that widespread fear of HIV transmission appeared to play a major role in adverse employment decisions. Other considerations that result in discriminatory practices included fear of productivity losses due to illnesses and hospitalizations; high health insurance costs; and fear that an entire business will become stigmatized by association with AIDS.[5]

When the Commission prepared its Ten Principles, concern about HIV transmission from patients to health care workers was (and remains) a major issue. The last of the Ten Principles addresses the need for stringent infection control education, and calls for appropriate equipment and procedures in workplaces where there may be a risk of HIV transmission. Now, an opposite concern has surfaced: concern about transmission from infected health care workers to patients. The tenth principle serves as a basis for protecting both patients and health care workers. Nevertheless, cases involving infected health care workers are likely to assume a significant role in AIDS litigation during the next few years.[6] Most recently, the New York State Division on Human Rights determined that the Westchester County Medical Center, which in 1986 withdrew an offer of employment to an HIV-positive pharmacist, violated the State Human Rights Law; the Commissioner of Human Rights ordered the hospital to pay $30,000 in compensatory damages and to offer employment to the pharmacist without job restrictions.[7] On the other hand, in a highly significant court decision, a federal appeals court upheld a hospital's dismissal of a nurse who refused to submit to HIV antibody testing to refute the hospital's suspicions that the nurse was infected.[8] Policies will need to be developed that both protect patients and protect infected health care workers who pose no threat to patients from stigmatization and discrimination.

The Challenges Ahead

In the last few years, corporate America has shown a greater willingness to address the issue of AIDS in the workplace. This trend has been greatly aided by outspoken leadership from such companies as Levi Straus, IBM, Digital Electronics, and a few others. A growing body of research (including the

Commission's report on its survey of the endorsers of the Ten Principles) documents the effectiveness and importance of workplace AIDS education programs in addressing employee concerns about AIDS. A study in the spring of 1990 by the New York Business Group on Health reports on the positive response by employees to the programs sponsored by their companies and the employees confidence in the information provided to them. The study concludes that: "...it is advantageous for employers to offer worksite AIDS education programs and that such programs will be appreciated and valued by employees...Workplace AIDS education should be an ongoing effort of repeat programs and updated information and should specifically address workplace attitudes."[9]

Undoubtedly, the presence of people with AIDS or HIV disease in the workforce has been a major motivation, perhaps the greatest one, for employers to address this issue. A recent study released in the fall of 1990 by Gay Men's Health Crisis and the New York Business Group on Health showed that in New York City 81 percent of the large corporations have reported employees with AIDS or AIDS-Related Complex (ARC), a term sometimes used to cover a spectrum of HIV disease that does not meet the criteria for AIDS.[10]

Smaller businesses, which employ the majority of workers, have lagged far behind in forming policies and educational programs. In the GMHC-New York Business Group on Health study, 54 percent of mid-sized companies had employees with AIDS or ARC, while only 10 percent of small businesses did. The denial and resistance to creating programs and polices in these small and mid-size businesses mirrors the earlier experience in bigger corporations, even though the impact of even a single employee with AIDS may actually be more severe in a small business. Because small companies have fewer resources to address the problem, overcoming inertia is even more difficult. Outreach to smaller businesses, especially through small business associations and innovative initiatives, is necessary to promote further planning and educational programs. A key element is linking small businesses with already existing low-cost or free "AIDS in the Workplace" trainers.

The prolonged life span and improved quality of life that is now available to many employees with AIDS or HIV infection, coupled with recent legal protections, will lead to more productive and longer working lives but will also create more need for flexibility in scheduling and other workplace accommodations. The cost of health care benefits and reimbursement for drugs and outpatient services will be major issues for employers, employees, and unions, particularly among smaller businesses that lack health care benefits or have inadequate coverage. In sum, the major focus of future AIDS workplace efforts should be expanding education and policy development to small businesses, sustaining and increasing the level of corporate America's response, and linking businesses to community-based education and services.

Endnotes

1. American Civil Liberties Union AIDS Project, Epidemic of Fear: A Survey of AIDS Discrimination in the 1980s and Policy Recommendations for the 1990s (1990), p. 141.

2. 480 U.S. 273, 107 S.Ct. 1123 (1987).

3. Chalk v. United States District Court, 840 F.2d 701 (9th Cir. 1988).

4. Lawrence O. Gostin, "The AIDS Litigation Project: A National Review of Court and Human Rights Commission Decisions, Part II: Discrimination," 263 Journal of the American Medical Association (April 18, 1990), p. 2086.

5. American Civil Liberties Union AIDS Project, Epidemic of Fear (1990), p. 23.

6. Leckelt v. Board of Commissioners of Hospital District No. 1, 909 F.2d 820 (5th Cir. 1990).

7. Doe v. A Medical Center, Nos. IB-E-D-116054-86 & IB-P-S-117683-87 (December 12, 1990) reported in the New York Law Journal (December 26, 1990).

8. Leckelt v. Board of Commissioners of Hospital District No. 1, et al., 909 F.2d 820 (5th Cir. 1990).

9. Judith Barr, Sc.D. and Leon Warshaw, M.D., "AIDS Education in the Workplace: What Employees Think," Report of a Study by the New York Business Group on Health (Spring 1990), p. 35.

10. Robin L. Miller, M.A., et. al., AIDS-Related Education and Training in the Workplace New York: Gay Men's Health Crisis and New York Business Group on Health (1990), p. 8.

Appendix 1

The Ten Principles for the Workplace

1. People with AIDS or HIV (Human Immunodeficiency Virus) infection are entitled to the same rights and opportunities as people with other serious or life-threatening illnesses.

2. Employment policies must, at a minimum, comply with federal, state, and local laws and regulations.

3. Employment policies should be based on the scientific and epidemiological evidence that people with AIDS or HIV infection do not pose a risk of transmission of the virus to coworkers through ordinary workplace content.

4. The highest levels of management and union leadership should unequivocally endorse nondiscriminatory employment policies and educational programs about AIDS.

5. Employers and unions should communicate their support of these policies to workers in simple, clear, and unambiguous terms.

6. Employers should provide employees with sensitive, accurate, and up-to-date education about risk reduction in their personal lives.

7. Employers have a duty to protect the confidentiality of employees' medical information.

8. To prevent work disruption and rejection by coworkers of an employee with AIDS or HIV infection, employers and unions should undertake education for all employees before such an incident occurs and as needed thereafter.

9. Employers should not require HIV screening as part of general pre-employment or workplace physical examinations.

10. In those special occupational settings where there may be a potential risk of exposure to HIV (for example, in health care, where workers may be exposed to blood or blood products), employers should provide specific, ongoing education and training, as well as the necessary equipment, to reinforce appropriate infection control procedures and ensure that they are implemented.

Appendix 2

The First 30 Endorsers of the Ten Principles

American Red Cross of Greater New York
American Telephone and Telegraph Company
A. Philip Randolph Institute
Archie Comics
Atlantic Industries
Atlantic Magazine
Chemical Bank
City of New York
Dow Jones & Company
Fund for the City of New York
Girl Scouts of the U.S.A.
Howard J. Rubenstein Associates
IBM Corporation
ITT Corporation
Johnson & Johnson
Lambda Legal Defense and Education Fund
Ms. Magazine
National Urban League
Newark Teachers Union
The Rockefeller Brothers Fund
The Salvation Army
Sassy Magazine
The Shubert Organization
Time, Inc.
Times Mirror Co.
United Federation of Teachers
United Jersey Banks
U.S. News & World Report
Warner Lambert Co.
Wildcat Services

Appendix 3
Current list of endorsers
(as of January 1, 1991: 404 Endorsements)

Corporations and Small Businesses

Abt Associates, Boston, MA
AEtna Life Insurance Company, Hartford, CT
Alan Emery Consulting, San Francisco, CA
Allstate Insurance Company
American Telephone and Telegraph Company
Archie Comics
Atlantic Industries
Atlantic Magazine
Backer Spielvogel Bates, Inc.
Bankers Trust Company
Ben & Jerry's Ice Cream, VT
Birch & Davis Associates, Inc., Silver Spring, MD
Burroughs Wellcome Company
Chemical Bank
Chevron Corporation
CIBA-GEIGY Corporation
Coastal Training Institute, Montgomery, AL
Digital Equipment Corporation, Concord, MA
Dow Jones & Company
Du Pont (E.I. du Pont de Nemours & Company, Inc.)
EduCare Associates, Inc.
Equicor Health Plan, Inc., Wichita, KS
The Equitable
Ethicon, Inc.
Franklin Research & Development Corporation
General Electric Company
Girard Video, Washington, DC
Glaxo Inc., Research Triangle Park, NC
Glick and Weintraub, P.C.
GOOD MONEY Publications, Inc.
HEM Industries, PA
Hoffmann-La Roche Inc.
Howard J. Rubenstein Associates
International Business Machines Corporation
ITT Corporation
Johnson & Johnson
League of Resident Theatres
Levi Strauss & Company
Levine, Huntley, Schmidt, and Beaver, Inc.
Lola Restaurant
The Mercantile and General Reinsurance Company Toronto, ON
Manhattan Plaza
Merck & Co., Inc.
Metropolitan Life Insurance Company
Midwest Title Guarantee Company of Florida
Miss Ruby's Cafe
Mobil Oil Corporation
Morgan Guaranty Trust Company of New York
Ms. Magazine
National Association of Public Television Stations
Norton Company
Ogilvy and Mather Advertising
Ortho Pharmaceutical Corporation
Pacific Bell
Philip Morris Management Corporation
Playboy Enterprises, Inc.
Polaroid Corporation, MA
Princeton Project Resources, Inc., Princeton, NJ
The Principal Financial Group, Des Moines, IA
Progressive Asset Management, San Francisco, CA
The Prudential Insurance Company
Sassy Magazine
Schering-Plough Corporation
The Shubert Organization
SmithKline Beckman Corporation
Squibb Corporation
Swing Shift
Synectic Development Systems, MA
Syntex Corporation
Time Inc.
Times Mirror Co.
Transamerica Life Companies
U.S. News & World Report
Union Carbide Corporation
United Jersey Banks
Warner Lambert Co.
Wells Fargo Bank
Whole Wheat 'n Wild Berrys Restaurant
WNET - Public Television
Xerox Corporation

Health & Medical Groups

Addiction Recovery Corporation
Waltham, MA
American College Health Association
American Hospital Association
American Indian Health Care Association
American Medical Association
American Nurses Association
American Pharmaceutical Association
American Psychological Association
American Public Health Association
American Red Cross/Greater Amarillo Chapter
American Red Cross in Greater New York
Association of American Medical Colleges
Association of State and Territorial Health Officials
Blue Care Network - Health Central, Lansing, MI
Blue Cross/Blue Shield Association
Chicago, IL
BRC Human Services Corporation
Cancer Care/New Jersey
Cancer Care/New York City
CIGNA Healthplan, Inc.
CIGNA Healthplan of Arizona
Clinton County Department of Public Health, NY
Colorado Department of Health
Cook County Hospital, Chicago, IL
DePaul Hospital, Milwaukee, WI
Group Health Association of America, Inc.
Washington, D.C.
Hartford Health Department, CT
Hospice of Hillsborough, Inc., FL
Howard Brown Memorial Clinic, Chicago, IL
Kaiser Permanente, Oakland, CA
Maurice Falk Medical Fund, Pittsburgh, PA
Miller Medical Group, TN
N.J. Chapter Society of Patient Representatives
The National Assembly of National Voluntary
Health and Social Welfare Organizations, Inc.
The National Foundation for Infectious Diseases
National Hemophilia Foundation
National Hospice Organization
Newark Beth Israel Medical Center
NOVA HealthCare Group, McLean, VA
Northeast Pediatric Associates, P.A., TX
Professional Nurse, Boston, MA
St. Clare's Hospital and Health Center
San Francisco Medical Society
Securities Operations Specialists, Inc.
Substance Abuse And Alcoholism Treatment Center,
Inc., Chicago, IL
Tennessee Department of Health and Environment
U.S. Conference of Local Health Officials
University of Medicine and Dentistry of New Jersey
University of Michigan Hospitals
University of New Mexico Hospital, NM
Whitman-Walker Clinic, Inc., Washington, DC

Local Governments

Battery Park City Authority
City of New York
Department of Human Services, Health Division
Town of Hamden, CT
U.S. Conference of Mayors
Union County Chosen Board of Freeholders
Union County, NJ

Religious Organizations

American Jewish Committee, New York Chapter
Associated Catholic Charities, LA
Catholic Charities, USA
Dominican Sisters of Newburgh, NY
East Shore Unitarian Universalist Church
Mentor, OH
Episcopal Diocese of Connecticut
First Existentialist Church of Atlanta
Ministerial Network on AIDS
Priests of the Sacred Heart, Houston, Texas
Union of American Hebrew Congregations
Unitarian Society, Fall River, MA
Unitarian Universalist Association
United Church Board for Homeland Ministries
Universalist Unitarian Church of Farmington, MI

Non Profit Organizations

A. Philip Randolph Institute
Association for a Better New York
The Association of the Bar of the City of New York
Better Business Bureau, NY
Cayuga County Action Program Seneca Office
The Center for Population Options
Washington, DC
Center for Constitutional Rights
Center for Women Policy Studies
East Harlem Block Nursery, Youth Action Program
Girl Scouts of the U.S.A.
Hopkins House Association, Inc., Alexandria, VA
Human Rights Campaign Fund
Institute of Disease Prevention in the Workplace
Albany, NY
Lower Manhattan Cultural Council
March of Dimes
The National Assembly of National Voluntary Health and Social Welfare Organizations, Inc.
National Coalition of Hispanic Health & Human Services
National Lesbian & Gay Task Force
National Urban League
Non-Traditional Employment for Women
North Central Texas Rehabilitation Agency
Northwest Action Against Rape
Public Responsibility in Medicine & Research
Sacramento Black Alcoholism Center, CA
The Salvation Army
Society for the Right to Die, New York, NY
United Way of America
United Way of Greater Dayton Area, OH
United Way of Greater Rochester
United Way of New York City
United Way of Northwest Georgia
United Way of San Joaquin County, Inc.
Wellness Council of Tucson, AZ
Wildcat Services
Women's Action Alliance

Unions

Actors' Equity Association
American Federation of Teachers
Association of Flight Attendants, AFL-CIO
Bridge and Tunnel Maintainers, Local 1931
California State Employees' Association
National AFL-CIO
New Jersey State AFL-CIO
New York State AFL-CIO
Newark Teachers Union
Service Employees International Union, AFL-CIO, CLC
United Federation of Teachers

Foundations

Fund for the City of New York
The Pettus Crowe Foundation
The Rockefeller Brothers Fund
United Hospital Fund

AIDS Groups

A.V.O.C., OH
Action AIDS, PA
AID, Atlanta, Inc.
AID for AIDS, NV
AIDS/ARC Services Division, CA
AIDS Action Committee, MA
AIDS Action Council, Washington, DC
AIDS Center for Queens County, NY
AIDS Community Services of Western New York
AIDS Comprehensive Family Care Program, NY
AIDS Council of Erie County, PA
AIDS Education Network, SC
AIDS Education Project, FL
AIDS Foundation, AZ
AIDS Foundation, IL
AIDS Help, Inc, FL
AIDS Interfaith Network, CA
AIDS Ministries Program, CT
AIDS National Interfaith Network

(AIDS Groups continued)

AIDS Pastoral Care Network, Chicago, IL
AIDS Prevention Project, WA
AIDS Professional Education Project, CA
AIDS Project, CA
AIDS Project, CA
AIDS Project, CT
AIDS Project, CT
AIDS Project, CT
AIDS Project, CT
AIDS Project, ME
AIDS Project, MO
AIDS Related Community Services, NY
AIDS Resource Center, NY
AIDS Response, TN
AIDS Response, CA
AIDS Service Association, FL
AIDS Services Foundation, CA
AIDS Services of Austin, TX
AIDS Southern Kentucky, KY
AIDS Support Group, WA
AIDS Support Program, OK
AIDS Task Force, GA
AIDS Task Force, NC
AIDS Task Force, WV
Alianza, DC
Aliveness Project, MN
All Saints AIDS Service Center, CA
American Foundation for AIDS Research (AmFAR)
American Red Cross/Chester Wallingford, PA
Among Friends, WI
Aquarius Management Corporation, NY
Association of PLWA, NM
Association of PWAs, GA
Athens AIDS Task Force, OH
Australian Federation of AIDS Organizations, Inc.
Bay Area Addiction, Research & Treatment, CA
Beach Area Community Health Center, CA
Body Positive, NY
Boston Department of Health & Hospitals, MA
Broadway Cares
Carolina AIDS Research & Education, SC
Cedar AIDS Support Systems, IA
Center One, FL
Center for Social Services, CA
Central Florida AIDS Unified Resources, FL
Central Valley AIDS Team, CA
Charleston AIDS Network, WV
Chattanooga CARES, TN
Chicken Soup Brigade, WA
Children's Quilt Project, CA
Coastal Bend AIDS Foundation, TX
Colorado AIDS Project, CO
Community Counseling Services for Sexual Minorities, WA
Community Health Project
Comprehensive AIDS Center, Northwestern University Medical School, Chicago, IL
Dallas Gay Alliance, TX
Damien Center, IN
Dayton Area AIDS Task Force, OH
Delaware County AIDS Network, PA
Design Industries Foundation for AIDS (DIFFA)
Diablo Valley AIDS Center, CA
Dorchester Counseling Center, MA
East L.A. Rape Hotline, CA
El Rincom Supportive Services, IL
Elisabeth Kubler-Ross Center, VA
ERASE, NC
Fenway Community Health Center, MA
Four State Community AIDS Project
Gay and Lesbian Aliance, NJ
Gay Men's AIDS Network, CA
Gay Men's Health Crisis, Inc.
GLCSC Voluntary Legal Services, CA
Good Samaritan Project, MO
Governor's Council for Sexual Minorities, PA
Grand Rapids AIDS Task Force, MI
H.A.C.E.R., TX

(AIDS Groups continued)

Haitian Coalition on AIDS, NY
Health Information Network, WA
Health Issues Taskforce of Cleveland, OH
Hispanic AIDS Forum, NY
Hispanic League Against AIDS, FL
Hospice Care of Broward County, FL
Human Health Organization, CA
Idaho AIDS Foundation, ID
Inland AIDS Project, CA
Instituto Familiar de la Raza-Latino AIDS Project San Francisco, CA
International Society for AIDS Education
John XXIII Commission for AIDS Ministry, CA
Justice Professional, NM
Kairos House, CA
Kansas AIDS Network, KS
Kansas City Free Health Clinic, MO
Kupona Network, IL
Lancaster AIDS Project, CA
LDS AIDS Project, CA
Lesbian and Gay Community Switchboard, AZ
Living Room, OH
Long Island Association for AIDS Care, NY
Los Barrios Unidos Community Clinic, TX
Madison AIDS Support Network, WI
Madison County AIDS Prevention Program, IL
Maine Health Foundation, ME
Metrolina AIDS Project, NC
MidCity Consortium to Combat AIDS, CA
Milwaukee AIDS Project, WI
Minnesota AIDS Project, MN
Minority AIDS Project, CA
Minority Task Force on AIDS, NY
Mobilization Against AIDS, CA
Momentum AIDS Outreach Program, NY
Monmouth-Ocean AIDS Information Group, NJ
Montgomery AIDS Outreach, AL
Mountain State AIDS Network, WV
National Association of Black & White Men Together, CA
National Catholic AIDS Network, NY
National Lawyers Guild AIDS Network
National Leadership Coalition on AIDS
Nebraska AIDS Project, NE
NECHAMA, CA
Nevada AIDS Foundation, NV
New Friends, CA
New Jersey Buddies, NJ
New Mexico AIDS Services, NM
Newark AIDS Consortium, Inc.
No AIDS Task Force, LA
North Jersey Community Research Initiative, NJ
Northeast Ohio Task Force on AIDS, OH
Northern Lights Alternative, NY
Northern Virginia AIDS Ministry, VA
Northwest AIDS Foundation, WA
Oak Lawn Counseling Center, TX
Open Arms, TX
Operation Concern, CA
Paz Y Liberacion, TX
People with AIDS Coalition, AZ
People with AIDS Coalition, FL
People with AIDS Coalition, NY
People with AIDS Coalition, TX
Philadelphia Community Health Alternatives, PA
Project AHEAD, CA
Rio Bravo Association, TX
Roanoke AIDS Project, VA
St. Louis Effort for AIDS, MO
Salud, DC
San Antonio AIDS Foundation, TX
San Diego AIDS Project, CA
San Francisco AIDS Foundation, CA
Santa Cruz AIDS Project, CA
Shanti, AZ
Shanti, CA
Shanti, CA
Shanti, OK
Shiprock Community Health Center, NM

(AIDS Groups continued)
Southwest AIDS Committee, TX
Spectrum, DC
Spokane AIDS Network, WA
Stop AIDS Resource Center, CA
Terrific, Inc., DC
Testing the Limits, NY
Tidewater AIDS Crisis Taskforce, VA
Topeka AIDS Project, KS
Traveler & Immigrants Aid of Chicago, IL
Triangle AIDS Network, TX
Tucson AIDS Project, AZ
Urban Indian Health and Human Services, NM
Upper Manhattan Task Force on AIDS
Venereal Disease Action Coalition, MO
Vida Latina, MI
Village Nursing Home AIDS Day Treatment, NY
WARN, CA
Washington Employers' AIDS Prevention Alliance
Wellness House, MI
Wellness Networks, MI
West Hollywood CARES, CA
West Side AIDS Project, NY
Western Reserve AIDS Foundation, OH
Willamette AIDS Council, OR
WNC AIDS Project, NC
Women's AIDS Network, CA

In July 1989 the New England Workplace Response to AIDS released a modified version of the Citizens Commission on AIDS' Ten Principles. Their version has been endorsed by additional business and service organizations in the New England region. For a list of these additional endorsers contact:
AIDS Action Committee of Massachusetts
131 Clarendon Street
Boston, MA 02116
1 (800) 669-0696

Chapter 2

AIDS and Drug Use: Breaking the Link

Released in September 1988, "AIDS and Drug Use: Breaking the Link" addressed the close relationship between drug use and HIV disease. Drug-related HIV infection now represents the fastest growing source of transmission in New York and New Jersey; yet programs developed to tackle drug use are dwarfed by the magnitude of the problem. The tragedy of this poorly addressed problem is not only the numbers of infected and ill drug users but also its impact on the sexual partners of drug users, including women who do not themselves use drugs, and on newborn infants born to HIV-infected mothers. As a result of the link between drug use and HIV infection, the bi-state region has the nation's highest rates of HIV disease among women and children.

The Commission's report called for significantly increasing opportunities for drug use treatment, with the ultimate goal of treatment on demand. The Commission stressed the importance of available treatment both as a compassionate measure to treat those who wish to be free of drugs and to prevent further HIV transmission among drug users, their sexual partners, and their children. The diverse treatment modalities were examined, as was research demonstrating that while drug users and their sexual partners are difficult to educate, they should not be considered unreachable. Several studies have shown that a large number of drug users (in many studies, the majority) report changes in their drug-using behavior to reduce their risk of contracting HIV. Usually the behavior involved reducing risk rather than eliminating it. However, more drug users reported changes in drug injection behavior than changes in sexual behavior. These trends continue, according to the National Research Council's report, AIDS: The Second Decade.[1]

The Commission also considered the ongoing controversies regarding risk reduction and concluded that distribution of bleach should be supported within the context of a comprehensive approach that primarily emphasizes drug treatment, education, and counseling, and that needle exchange programs should be evaluated.[2] Finally, the Commission attempted to engage community leaders, politicians, and health planners and providers as advocates for vastly expanded drug treatment.

The Commission developed a four-point policy statement calling for:

(1) the immediate provision of treatment for every drug user who wants it and expanded efforts to draw drug users into treatment;

(2) targeted AIDS education and services for all those at risk;

(3) equitable distribution of drug treatment facilities throughout our communities;

(4) increased federal, state, and local funding sufficient to cover the basic costs of expanded drug treatment and education, supplemented by increased private funding in areas such as capital costs and the creation and evaluation of innovative treatment and education models.

The Commission wrote to 32 mayors and the 25 Boards of Chosen Freeholders and County Executives of Northern and Central New Jersey, as well as the 59 Community Boards of New York City, asking them to support the statement. Several follow-up meetings were held to explain the Commission's purpose and to seek support for the goals outlined in the statement. To bring community, political, and professional leaders into the planning process, the Commission also solicited endorsements from community and professional leaders.

The Commission was moderately successful. Eighty-six individuals and groups--community, religious, professional, and political leaders, and governmental bodies--endorsed the four-point statement. These endorsers included the cities of Bayonne, Hoboken, Jersey City, Morristown, Newark, and Wayne; the Boards of Chosen Freeholders of Essex and Monmouth Counties; and 19 of New York City's 59 community boards.* New Jersey Senator Frank Lautenberg, former New York City Mayor Edward I. Koch, Mayor David N. Dinkins (then Manhattan Borough President) Brooklyn Borough President Howard Golden, and Bronx Borough President Fernando Ferrer also supported the statement.

Whether these endorsements and the advocacy of other groups has translated into vastly improved access to drug treatment is hard to determine. It has proved exceedingly difficult to obtain accurate information about the availability of drug treatment. Statistics are kept for various purposes and sometimes there are significant discrepancies between funding allocations and actual treatment slots available. The Commission recommends that the funding and accessibility of publicly supported drug treatment continue to be independently monitored. There is a need for an accurate and up-to-date accounting of the increased flow of drug treatment funding, as well as a mechanism to determine where slots may be opening.

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* The New York City Community Boards endorsing the four-point statement are: Community Boards 2, 4, and 5 of the Bronx; Community Boards 5, 6, 7, 8, 9, and 14 of Brooklyn; Community Boards 1, 2, 4, 5, 6, 9, and 12 of Manhattan; and Community Boards 1, 6, and 7 of Queens.

In general, because of increased federal funding, more people are in treatment now than in 1988; but the demand continues to exceed supply. The New Jersey State Department of Health estimates that 152,000 drug users, including 40,000 to 75,000 intravenous users of heroin and cocaine, need treatment.[3] An estimated 50 percent of the intravenous drug users in the state's urban areas are HIV-infected. When the Commission's report was released in 1988, the State Health Department estimated that its various drug treatment centers could accommodate about 4,000 intravenous drug users. With added federal funding, the state now supports 8,000 treatment slots. An additional 2,000 treatment slots are available at private, for-profit facilities. Despite the doubling of publicly funded treatment slots since 1988, as of September 1990, 2,200 drug users were on waiting lists at the state's outpatient drug-free or methadone maintenance clinics, or residential treatment centers. And those on waiting lists can wait up to six months to receive treatment. Treatment (and the education that accompanies it) are clearly important in preventing further HIV transmission. Several studies have demonstrated that individuals who enroll and stay in methadone maintenance programs have lower rates of HIV infection than drug users who have not sought treatment or who have not been able to obtain access to treatment.[4]

Waiting lists are only a partial measure of demand, since many clinics do not even keep waiting lists, and many drug users might well be motivated to seek treatment if it was more readily available. Moreover, treatment slots in one neighborhood cannot easily be filled by drug users from a geographically distant area. Transportation and fear of unfamiliar neighborhoods can be formidable barriers.

In 1988, the Commission reported that more than half of New York City's estimated 200,000 intravenous drug users were infected with HIV. At any given time, about 33,000 publicly funded drug treatment slots were available to assist these people. The New York State Department of Substance Abuse Services reports that, as of September 1990, 54,359 publicly funded drug treatment slots and 10,862 licensed, non-funded slots were available in New York State.[5] Of those totals, 38,411 publicly funded slots and 6,355 non-funded slots are in New York City. With $21 million in additional federal funding for drug treatment, the state has been able to add about 8,500 more slots since 1988. Of that number, 5,396 slots were added in New York City, 2,203 from federal waiting list reduction funds. In September 1990, approximately 3,100 people were on treatment waiting lists, a majority waiting for a slot in residential treatment. An additional 1,000 people were waiting to transfer to other levels of treatment services.

Providing adequate drug treatment services to women with HIV disease is a particularly urgent need in the New York/New Jersey region. The numbers of available beds should reflect the growing numbers of HIV-infected women who can benefit from drug treatment. In particular, services must be available to pregnant

women who use drugs; at present, very few facilities will accept pregnant women. Providers must be sufficiently flexible to meet the needs of women with children. There is also an urgent need for drug treatment designed for adolescents. These needs cannot be met solely by expanding existing centers; new centers must be created. The problems of local opposition to siting drug treatment centers and obtaining funds for capital development are serious ones that must be addressed in the future.

Impact of Crack

When the Commission issued its report in September 1988, the focus was mainly on intravenous drug users because HIV transmission is clearly related to sharing contaminated needles or works. With 340,000 heavy users of "crack" cocaine in New York City alone, the crack epidemic has become an increasing source of concern in HIV transmission. Crack increases risk of HIV infection indirectly in several ways. Its users, particularly young women, frequently resort to prostitution to obtain the drug or money to buy the drug. Crack results in a quick and extreme "high"; crack users frequently then turn to injected heroin to counteract the effect. Finally, there is some preliminary laboratory evidence that the chemical action of crack may impair the immune system. Much more research is needed to determine how to treat crack addiction and how to educate crack users about the risk of HIV.

Federal Drug Strategy

The Bush Administration's National Drug Control Strategy, prepared by William Bennett, focuses heavily on interdiction and police power to control drug use.[6] It stresses evaluating treatment strategies, noting the high rate of recidivism, and suggests that those who are unwilling to enter treatment voluntarily might be forced to do so. Although monitoring and evaluating programs should be a high priority, the Bennett strategy seems to focus on the poor examples rather than the successful ones. With Bennett's retirement, implementation of the drug control strategy falls to former Florida Governor Robert Martinez. So far there is no indication of a change of emphasis.

Federal funding to reduce waiting lists for drug treatment under the Anti-Drug Abuse Act of 1988 has enabled New Jersey to double its treatment slots and New York State to significantly increase theirs. Regrettably, Congress has not appropriated any funding in fiscal year 1991 for reducing treatment waiting lists.

A Cost-Effective Strategy

In 1988, the Commission emphasized the cost effectiveness of drug treatment on demand. Lifetime medical care costs of AIDS average $40,000 to

$75,000 (in 1988 dollars), according to several recent studies. The public is bearing an increasing burden of this care as coverage shifts from private insurers to Medicaid. Furthermore, these estimates assume a survival of 15 months from diagnosis. As survival time increases, medical costs, particularly of pharmaceuticals, can be expected to increase as well. By contrast, drug treatment averages $15,000 per year for residential care and $3,000 for ambulatory treatment. Deferring public investment in drug treatment will only create a much larger burden for the health care system and taxpayers in the future.

Endnotes

1. National Research Council, AIDS: The Second Decade (Washington: National Academy of Sciences, 1990), p. 89.

2. For an update on needle exchanges and other "harm reduction" efforts around the country see Health/PAC Bulletin, vol. 20, No. 3 (Fall 1990), 3-31.

3. Data on New Jersey was obtained through a personal conversation with Richard Schadl, Chief, Data Analysis and Epidemiology Section, New Jersey State Department of Health.

4. National Research Council, op. cit., pp. 90-91

5. Data on New York State was obtained through personal conversations with Dr. Frank McCorry and Terrence Jackson of the New York State Division of Substance Abuse Services.

6. National Drug Control Strategy (Washington: The White House, September, 1989).

Chapter 3

The Crisis in AIDS Care: A Call to Action

In March 1989 in New York City and in May 1989 in New Jersey, the Commission released "The Crisis in AIDS Care: A Call to Action," which documented the health care and social service needs of the region. This report presented the analysis of a bi-state group of consultants that examined the impact of HIV disease on the care delivery system. Similar to other planning documents, such as the report of the New York City AIDS Task Force, the Commission's report assessed care programs and policies in New York City and in New Jersey, particularly acute and long-term care programs, and their capacity to meet future needs. The Commission's special contribution was its examination and support of the contributions of community-based organizations that provide a broad range of support services. This community focus, the Commission argued, is essential, both as a cost-effective alternative to institutionalized care and as a more humane service delivery system.

The heart of the care report was contained in "Action Agendas" for New York City and New Jersey. These agendas promoted a continuum of HIV care including hospital-based and long-term care; community-based alternatives to maintain people in the community; housing to prevent homelessness and unnecessary hospitalization; early diagnosis and treatment; specialized programs to meet the needs of women, children, and adolescents; and nondiscrimination in the delivery of health care. Many essential recommendations have yet to be effectively addressed by state and local governments. As the Commission ends its work, it suggests the following action agenda:

1. In New York, the State and City should jointly appoint and empower a small, high-level body composed of key public officials and private sector leaders to mobilize and coordinate HIV initiatives. New Jersey should also create such a group.
2. To ensure the delivery of quality care in New York City hospitals, 1,800 new acute care beds should be added by 1994. New York State and New Jersey must address the pressing financial and personnel needs of urban hospitals.
3. New York City and State and New Jersey should fund and implement comprehensive ambulatory care programs for HIV disease, which should include primary care, early intervention, appropriate medications, administration and monitoring of treatments, and psychosocial services.

4. New York City and State and New Jersey should aggressively develop sufficient numbers of long-term care beds and supported housing units. Community-based organizations that are willing and able to provide residential care should be supported whenever possible.
5. To reflect the true impact of HIV disease among women, children, drug users, and poor people, a review of existing epidemiological, clinical, and resource utilization data should be undertaken to identify areas where eligibility for entitlements and services based on the CDC surveillance definition of AIDS is inadequate.
6. State Health Departments should develop and expand health care and professional training programs to meet the specialized needs of women, adolescents, and children.
7. HIV counseling and testing programs, including programs targeting women and newborns, should be available on a voluntary basis. Anonymous testing should be maintained. Counseling and testing should be linked to prevention and treatment services.
8. New York City and State and New Jersey should aggressively combat discrimination against people with HIV disease, especially in the provision of health care and social services.

AIDS Spending in New York City

Although public funding for AIDS has increased since 1987, it is totally inadequate to meet the vastly increased needs for services.* As a result, New York and New Jersey are actually losing ground in the battle against the epidemic.

Consider the pattern of funding and expenditures in New York City. In FY 91, total AIDS appropriations from all sources, including Medicaid, rose above $1.26 billion, a threefold increase since 1987. Currently, the Federal government provides just under one-third of all AIDS dollars in the City: the City and the State each contribute about one-quarter of the total and third-party insurers and philanthropic organizations provide the rest (see Figure 1, "Where the Money Comes From").

However, an enormous percentage of public monies is committed to mandated spending -- that is, spending dictated by law (see Figure 2, "Mandated Versus Non-Mandated Spending"). Of the almost $600 million dollars that flow

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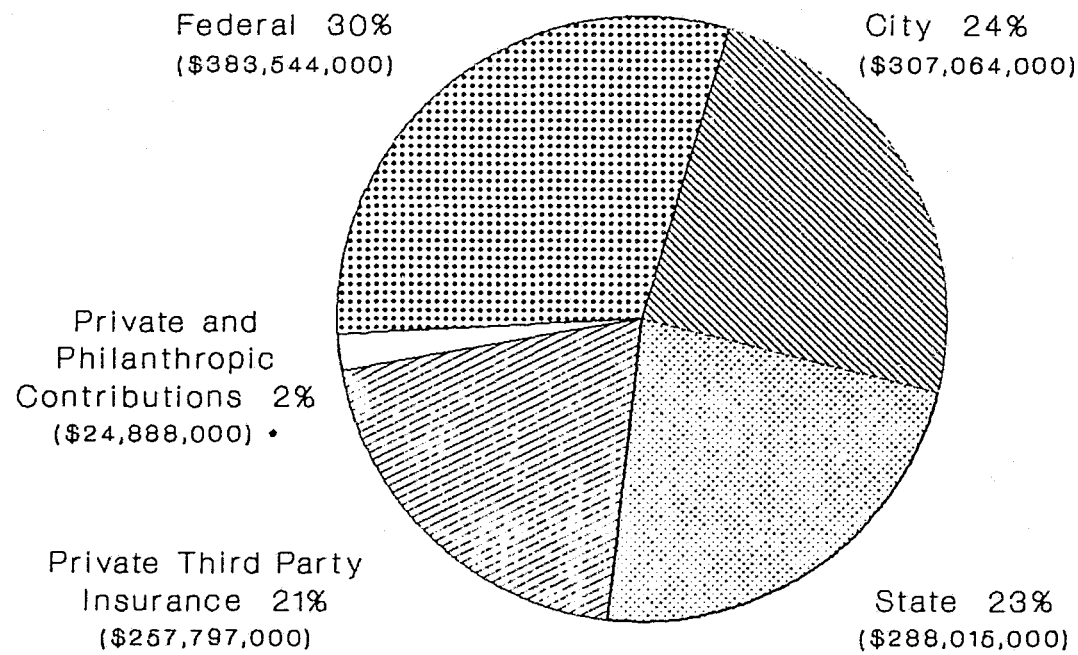
* This section and the accompanying charts are drawn from work originally prepared by the Citizens Commission staff for the New York City AIDS Fund 1991-92 Needs Assessment. For a copy of that document write to Len McNally, New York Community Trust, 2 Park Avenue, New York, NY 10016.

WHERE THE MONEY COMES FROM

Sources of Estimated AIDS Dollars in New York City - FY'91



Total Operating Funds - $1,261,308,000

Figure 1

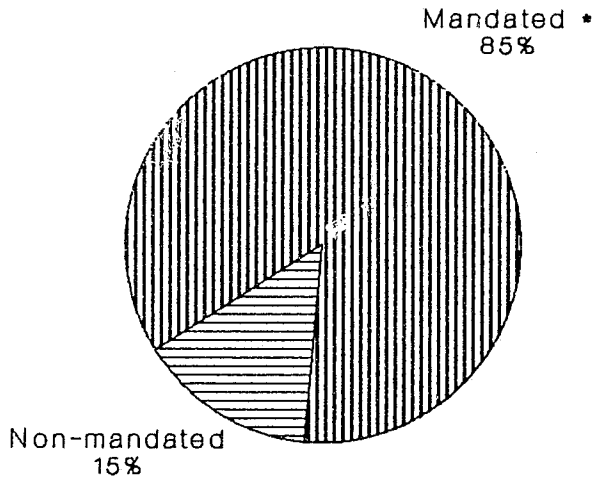
Source: NYC Office of Management & Budget, 6/90; Chart created by the Citizens Commission on AIDS, 11/90.

* Based on estimates from 14 major AIDS funders and service providers

MANDATED VS. NON-MANDATED $'s

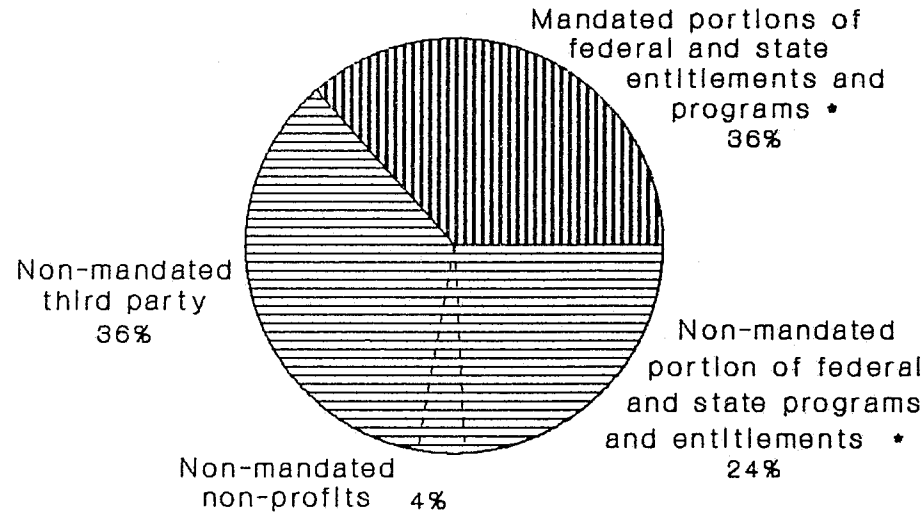
Estimated AIDS Expenditures in N.Y.C. - FY'91

(Total operating funds - $1,261,308,000)



Expenditures which flow through the NYC budget

($599,448,000)



Expenditures not included in the NYC budget

($661,860,000)

Figure 2

Data: NYC Office of Management and Budget, 6/90; NY AIDS Coalition; Nancy Klein, MR Strategic Services. Chart created by the Citizens Commission on AIDS, 11/90.

* includes Medicaid

through New York City's budget, 85 percent is allocated to mandated programs, including Medicaid. Federal and state entitlements and programs comprise 60 percent of the additional $661 million spent on AIDS that is not included in the New York City budget -- and the majority of those funds are also mandated. (The remaining monies come from philanthropy and third-party payers and are not mandated.)

Furthermore, many funded services and public benefits, including Medicaid, are available only to people with full-blown AIDS, as defined by the Centers for Disease Control. While individuals with full-blown AIDS have enormous needs for services, they represent only the tip of the iceberg. The CDC definition, developed for surveillance purposes, does not reflect the true medical and economic impact of HIV disease. Public agencies that use this definition can limit their responsibility for many of the epidemic's associated costs.

The private sector is equally averse to assuming the burden. The pressure on the public sector is increasing as payer distribution shifts increasingly from private insurance to Medicaid. This trend, termed "the Medicaidization of AIDS," has been documented by Jesse Green and Peter Arno. Because of Medicaid's low reimbursement rates, many private physicians are unwilling to accept Medicaid patients. Many people with AIDS are thus denied access to office-based primary care, which escalates the burden on public hospitals, community clinics, and emergency rooms.[1]

Another problem is that services have lagged far behind demand. Last year, community-based organizations had to deal with increased caseloads ranging from 30 to 60 percent while their budgets remained essentially flat. An especially troubling example of the overwhelming impact of AIDS came in October 1990, when the Gay Men's Health Crisis (GMHC) announced that increased demand and funding shortfalls had, for the first time in its nine-year history, forced it to limit its intake to the first 100 new clients every month. As New York City's oldest, largest, and probably best-funded AIDS service organization, GMHC's decision was widely viewed as an ominous sign.

Federal, state and local AIDS funds are largely targeted toward acute inpatient care. More than half the City money spent on AIDS goes to the Health and Hospitals Corporation (HHC), which runs the public hospital system. In the HHC system, 82 percent of the money goes to inpatient care; the figure is slightly higher (87 percent) in the voluntary system. Of expenditures not included in the City's budget, 62 percent are spent by third-party insurance or Medicaid payers and go to voluntary hospitals (see Figure 3, "Where the Money Goes" and Figure 4, "Where Medical Care is Delivered"). Clearly hospital care is an important and expensive component of medical care. Yet today, people with AIDS do not spend most of their time in the hospital -- according to City estimates, 80 percent of them

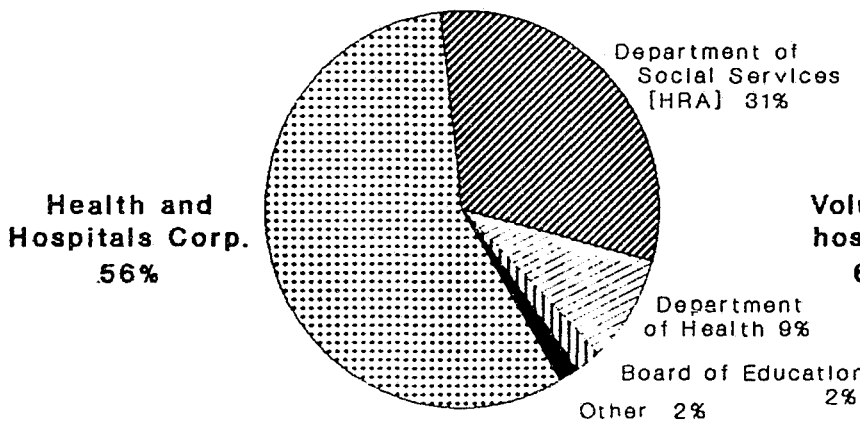
WHERE THE MONEY GOES

Est. AIDS Expenditures in N.Y.C. - FY'91

(Total operating funds - $1,261,308,000)

Expenditures which flow through the NYC budget

($599,448,000)



Expenditures not included in the NYC budget

($661,860,000)

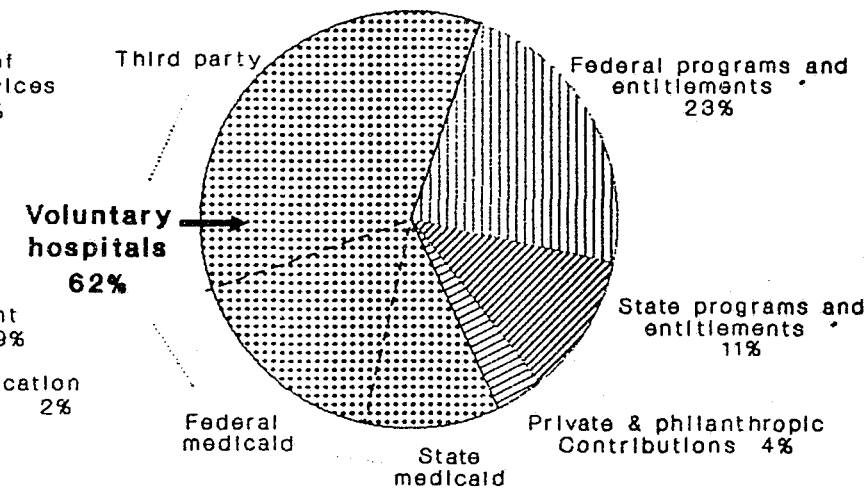


Figure 3

KEY POINTS:

- **Most of the NYC AIDS budget is devoted to hospital care and social services.**
- **Less than 10% goes to the DOH.**
- **Outside of the City budget, 2/3 of expenditures go toward hospital care.**

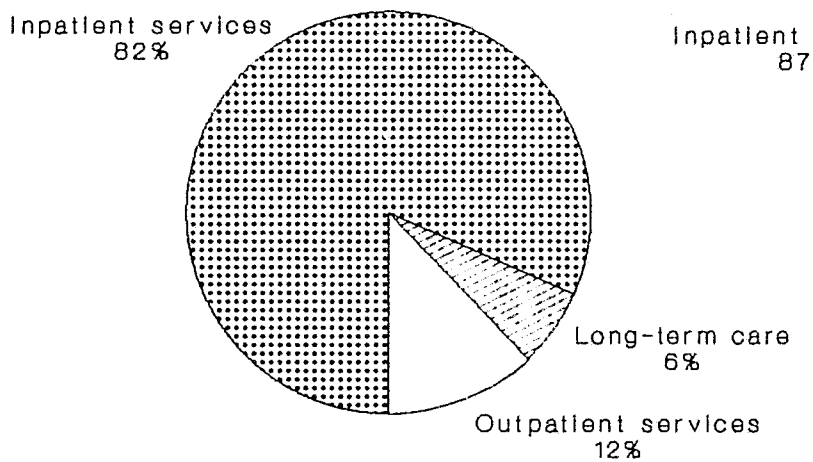
* Represents non-medicaid programs and entitlements, i.e. SSI (federal), ADAP (federal/state), AIDS Institute (state).

Source: NYC Office of Management and Budget, 6/9.
Chart created by the Citizens Commission on AIDS, 11/90.

WHERE MEDICAL CARE IS DELIVERED

Outpatient and Long Term Care vs. Inpatient Care

Health & Hospitals Corporation
($339,028,000)



Voluntary Hospitals
($463,041,000*)

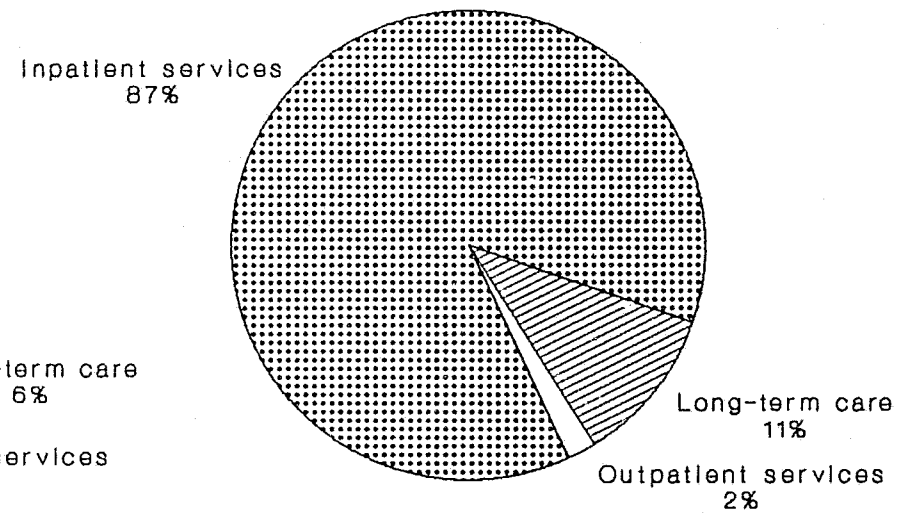


Figure 4

KEY POINTS:

- **More than 80% of all medical care is delivered in hospitals.**
- **Outpatient and long term care services account for less than 20% of medical care.**
- **Chart does not include the cost of private physician services.**

• Includes NYC Medicaid, monitored through DSS

Source: New York City Office of Management and Budget--6/90
Chart created by the Citizens Commission on AIDS--11/90.

are in the community at any given moment. Nevertheless, a significant number of PWAs stay in hospitals longer than necessary because of a lack of community-based services. The challenge is to provide an array of services so that people can be appropriately supported in their homes and communities, a challenge that has yet to be adequately addressed (see Figure 5, "Service Needs for People with AIDS/HIV Illness").

In the Summer of 1990, passage of the Ryan White Comprehensive AIDS Resources (CARE) Act raised great hopes that more federal funds would become available for community-based AIDS services. Unfortunately, Congress drastically reduced the appropriations available to fulfill the intent of this legislation. In the waning days of the 1990 session, just $350.5 million dollars -- down from the $875 million that Congress originally determined was needed to fight the epidemic in the nation's hardest-hit cities and to provide others with services -- were attached to the bill. Only $144 million represents new federal dollars. New York City is guaranteed $16 million in new funds, although it is eligible to compete for more money.

A further blow to funding came in the Fall of 1990 when the AIDS Institute lost $7.5 million held over from prior budget years because of a lag in implementation programs. In addition, the State temporarily froze about one third of the Health Department's budget for AIDS because of the State's financial crisis. Governor Cuomo's 1991 "State of the State" message promises no cuts in HIV-related funding. As welcome as this is, level funding means losing ground as caseloads increase and costs rise due to inflation.

Planning

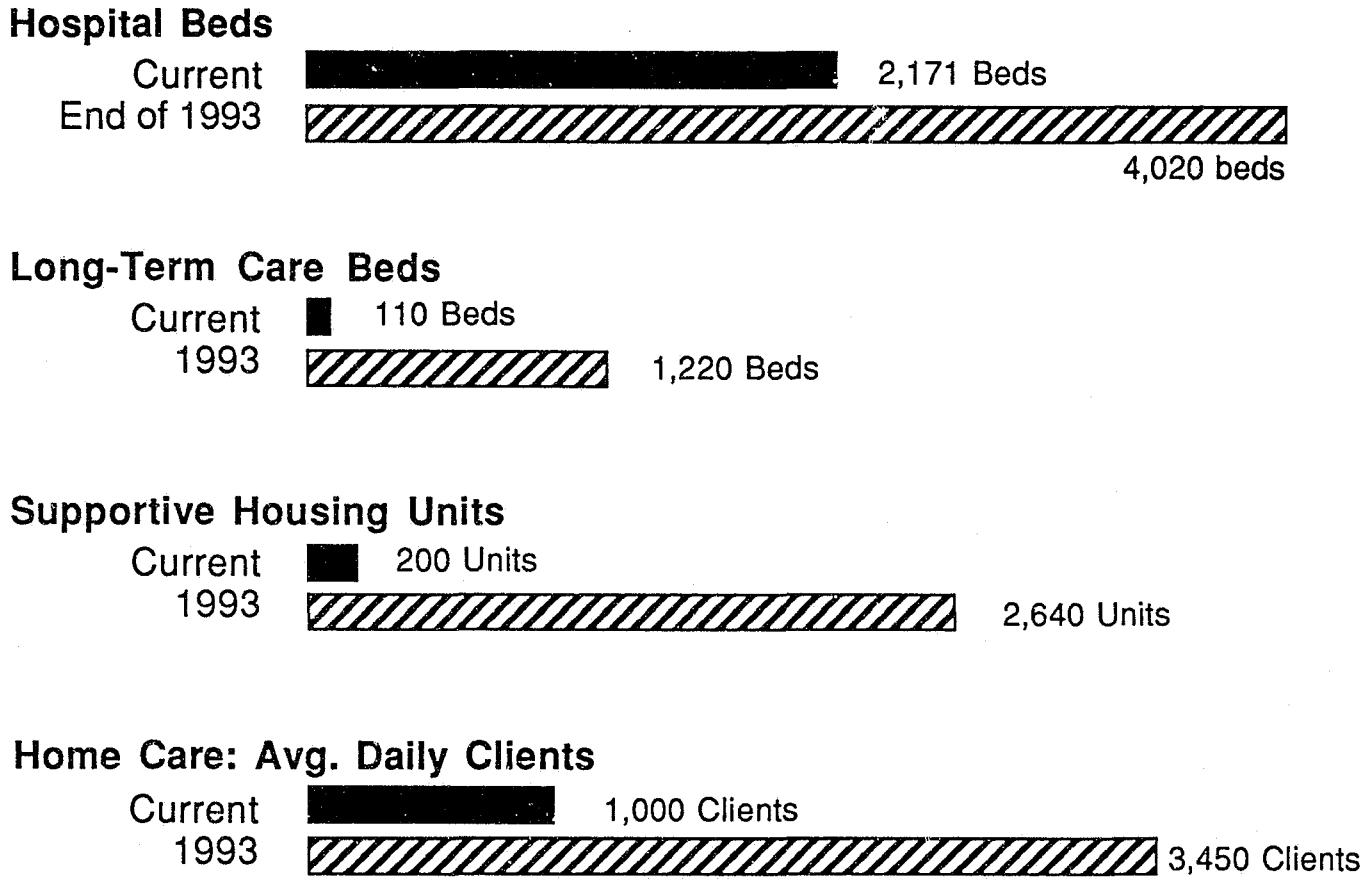
Successful management of the HIV epidemic requires comprehensive and coordinated planning and policies. While the need to plan seems obvious, especially in managing a complex, life-threatening, and costly epidemic, New York and New Jersey have yet to implement effective and coordinated public and private responses. However, there have been some noteworthy attempts.

To streamline the planning process and to mobilize and coordinate HIV initiatives in New York City, the Commission advocated the appointment of a small, high-level body of key public officials from both City and State and private sector leaders. Similarly, it called on the City and the State to negotiate -- with specific goals, timetables, and financing streams -- an action plan incorporating the diverse State and City planning documents. These recommendations are as valid today as they were two years ago.

During the past two years, planning documents have been prepared by the New York City AIDS Task Force, the New York City Interagency Task Force on

Service Needs for People with AIDS/HIV Illness

Current Capacity vs. Projected Need



If housing and long-term care are not provided, projections for hospital beds increase to 4,990 by the end of 1993.

Figure 5

Sources: NYC AIDS Task Force, July 1990; Greater NY Hospital Association, November 1990; Visiting Nurse Services of New York City.
Chart created by the Citizens Commission on AIDS
for New York City and Northern New Jersey, January 1991.

AIDS, the State of New York in its "5-Year Interagency Plan" (which is being updated), the Mayor's Task Force on AIDS (under Mayor Edward Koch), and the New York AIDS Coalition/Committee for AIDS Funding. Each of these reports presented useful strategies for meeting New York City's HIV-related needs but efforts to implement them have not brought together the parties that must be part of a coordinated plan. New York City and State have yet to integrate their programs for maximum effectiveness. And for the most part, the community-based organizations that try to reach most of the 250,000 people estimated to have HIV disease and the large number at risk have not been included as full partners in the planning process. The New York City AIDS Task Force, composed of key City and private sector agencies, came closest to developing a broad-based, coordinated approach. However, the Task Force was basically a City project, without significant State representation, and it lacked a mechanism to oversee or to develop a framework for implementing its ambitious report.

As in New York, the Commission called for a high-level panel of key public officials and private sector leaders in New Jersey. Until recently, HIV planning in New Jersey has been far less developed than in New York, mostly because the State did not consider comprehensive planning and coordination of its HIV-related programs as valuable. For example, under former Commissioner of Health Molly Joel Coye, the State Department of Health chose not to develop a long-term planning agenda for its programs, including those of the Division of AIDS Prevention and Control. Moreover, efforts by the various departments that assume, or should assume, a role in managing the epidemic have been largely uncoordinated. Department officials argued that resources devoted to planning are ill-spent because so many contingencies exist. Finally, the significant recommendations of the New Jersey Pediatric AIDS Advisory Committee, as well as the New Jersey Coalition of AIDS Service Providers, have yet to be adequately addressed.

Recent developments suggest this situation may be altered. On October 11, 1990, in his belated policy announcement on the State's HIV epidemic, Governor Jim Florio set forth his "10 principles" for managing the health crisis. Foremost among the Governor's recommendations are mandates to the Department of Health to produce a comprehensive plan within 90 days, and to form an interdepartmental task force to coordinate state HIV programs. The Health Department has also created a community panel to advise on the planning process. This is a significant first step that may result in a blueprint for the future. However, the State's willingness and financial ability to fund adequately its HIV programs are still to be demonstrated.

In response to legislative requirements of the CARE Act of 1990, the New York City's Mayor's Office has developed a planning council consisting of government officials, health care providers, and community-based organizations that

may at last tackle the need for broad-based, specific HIV planning. Similar planning efforts are underway in Newark and Jersey City. The CARE Act presents some important new opportunities for New York State and New Jersey to coordinate HIV policy and planning with local governments and community-based providers.

Hospital Care

At the time the Commission released its care report, New York City's hospitals were in gridlock. The AIDS census in hospitals was growing by more than one bed every day. There were more people with AIDS hospitalized each day at Bellevue Hospital, for example, than in the entire city of San Francisco. Occupancy levels were dangerously high; emergency rooms were overwhelmed; staffing shortages were critical; revenues were not matching costs. The Commission warned that prompt access to hospital care might be jeopardized for all New Yorkers, which could weaken the City's ability to attract and maintain businesses. To ease the pressures on hospital beds caused by HIV disease, in addition to substance abuse and psychiatric admissions, the Commission recommended that 2,200 beds, in addition to the 1,800 then used for people with AIDS, be added by 1994 for HIV disease alone. Likewise, it urged the State to develop procedures to recertify hospital beds taken out of service and to create and staff new beds before shortages created a full-blown emergency.

Although there are some signs that the crisis in hospital capacity has been easing, at least temporarily, there is no basis for complacency. New York has yet to come to grips with the health care crisis. Few new hospital beds have been added. Emergency rooms remain overcrowded and continue to provide most health care in lower-income communities. Greater New York Hospital Association (GNYHA) figures indicate that the average daily AIDS hospital census has increased at just under 6 percent in three of four quarterly reports since January 1990. While this rate of increase is lower than in previous years, overall occupancy continues to rise. From March 1987 to October 1990 the average daily census increased from 1,071 beds to 2,171 beds -- a 100 percent increase in hospital beds for people with AIDS and "suspected AIDS" over a period of less than four years.[2] GNYHA predicts that 3,700 - 3,800 hospital beds will be occupied by HIV patients by the first quarter of 1994.[3]

There are many factors at work, and no certainty about the balance between those that tend to decrease the need for hospital beds and those that increase it. There may be a plateauing of new AIDS cases, albeit at a very high level, in the most highly HIV-saturated communities. On the other hand, the course of the epidemic in other groups, notably women and adolescents, is unknown. Prevention efforts may have slowed incidence in some communities, but unless these programs are aggressively continued, there may be relapses in behavior and another wave of HIV infection.

Statistics based on CDC-defined cases of AIDS or "suspected AIDS" may underestimate severe and life-threatening HIV-related illness and tend to be under reported by physicians. Health planners also must consider recent increases in other diseases linked to HIV infection, but not included in the CDC's definition of AIDS, such as tuberculosis, syphilis, bacterial pneumonia, and endocarditis.

Many people with HIV infection are now being treated prophylactically with AZT, ddI, aerosolized pentamidine, bactrim, and other medications. These medications prolong life and have prevented progression to full-blown AIDS and life-threatening opportunistic infections. People who have access to early intervention may not need hospitalization as early or as often as in the early years of the epidemic. As the effectiveness of these drugs declines over time, however, increasing numbers of people will progress to more serious illnesses if new interventions are not developed. Newly diagnosed cases will also increase as more of the approximately 200,000 HIV-infected individuals progress to AIDS. To be prudent, the Commission continues to recommend the addition of 1,800 new hospital beds, with careful monitoring of resource utilization, so that the hospital system is prepared for future needs.

In general, New Jersey's hospitals have not experienced a shortage of hospital beds. However, HIV patients have been distributed inequitably in a few urban hospitals, such as University Hospital and St. Michael's Hospital in Newark, Jersey City Medical Center, and St. Joseph's Hospital and Medical Center in Paterson. United Hospitals Medical Center in Newark has cared for the majority of the pediatric cases. Acute care beds in urban areas must be sufficiently increased to meet local need. Many hospitals, especially urban institutions, also continue to suffer from inadequate financing. Recent uncertainty about the continuation of New Jersey's Uncompensated Care Trust Fund adds to the financial jeopardy of many hospitals. (The Fund is a surcharge on all hospital admissions that helps pay for indigent care.) Additionally, suburban hospitals must assume more responsibility to serve people with HIV disease. A proposal mandating all hospitals to share responsibilities has been before the State Legislature for several sessions. Hearings should be held to determine the most effective way to use the State's hospital resources.

Shortages in health care personnel of all types have chronically plagued New York and New Jersey. Shortages of all types of health care workers persist, particularly in municipal hospitals in poor communities. A new AIDS unit at Lincoln Medical and Mental Health Center in the Bronx has never been opened because of staff shortages.[4] The Commission's report advocated the immediate recruitment, training, and retention of health care workers, especially in minority communities. Except in some suburban New Jersey facilities, chronic staff shortages remain a serious problem. Innovative recruitment and training programs must be funded and supported by both states. New York State's new medical

fellowship program, which provides $1 million to support training in HIV care for physicians, nurse practitioners, and physician assistants is a useful, although limited, start. Unfortunately, implementation of this program may be jeopardized because of state budget cuts.

Early Diagnosis and Treatment

Commenting on the considerable advances in the development of new HIV-related drugs, including drugs for early intervention, the National Commission on AIDS declared that "scientific breakthroughs mean little unless the health care system can incorporate them and make them accessible to people in need." The Commission's care report was among the earliest to examine the impact of early intervention and to call for expanding ambulatory care to make medical care accessible. It has now been sixteen months since the clinical trial demonstrating the efficacy of early intervention in slowing down the progression of HIV disease was halted (August 1989). Yet there is much anecdotal evidence that the vast majority of people who could benefit form intervention are not receiving it. This is particularly true of the poor, hard-hit minority communities in New York and New Jersey.

It is now the standard of care to treat HIV-infected people with T-cell counts below 500 with AZT to prevent the progression to AIDS and with aerosolized pentamidine or bactrim to stave off pneumocystis carinii pneumonia. The standards may change as new drugs, such as ddI and ddC for treatment of HIV infection and other prophylaxes for opportunistic infections, are developed and refined. However, if the significant promises of early intervention are to be fulfilled, New Jersey and New York must expand outpatient and community-based health care immediately, despite tight budget constraints in both states. This need is urgent because the period before already infected people progress to serious illness is limited.

For lower income people, Medicaid covers the costs of HIV-related drugs. Both New York and New Jersey also administer the federally-funded AIDS Drug Reimbursement Program for people above Medicaid income limits. The New York program, the preferred approach, reimburses an expanded number of HIV-related medications. Regrettably, New Jersey's program has failed to adjust its benefits as the science of HIV treatment has progressed. New Jersey reimburses only the costs of AZT, aerosolized pentamidine, and alpha interferon, although several other drugs are commonly prescribed to treat HIV infection and opportunistic infections.

Both states should assure that HIV drug programs remain a priority, even if federal support levels are modified in the future. Furthermore, the treatments available under these programs should reflect state-of-the-art care, not dated

approaches. For example, it is cruel not to reimburse the costs of alternatives to AZT as they become available, since many individuals cannot tolerate AZT. Finally, any drug reimbursement program is of little use to people with HIV disease unless the public and targeted communities are informed of available services.

The question of the management of early intervention care is a key issue. For example, in New York City there are currently about 11,000 people alive with AIDS; possibly another 50,000 who would benefit from early medical care and social services; and another 50,000 who should be closely monitored. These conservative estimates mean the majority of patients can't, and won't be served in the acute medical care system. Although under great strain, this system does provide care to people with AIDS, but it does little for families and extended social networks affected by HIV disease.

Along with covering HIV-related medications, New Jersey and New York must assure that primary care services are available to administer and monitor the course of treatments. Outpatient and community health programs have yet to meet that challenge fully. New York State provides enhanced Medicaid reimbursement rates to AIDS Designated Centers in return for a diverse range of HIV-related health care and supportive services, provided through outpatient clinics and the hospitals to which they are attached. (See Appendix 1 for profile on Bronx Lebanon Hospital.) Similarly, New Jersey offers comprehensive care to people at early stages of infection through the Treatment Assessment Program (TAP), which is limited to five hospital outpatient departments. (See Appendix 2 for profile on St. Joseph's Hospital and Medical Center in Paterson.)

As more and more people, encouraged by governmental agencies, medical practitioners, and AIDS activities, decide to be tested, waiting lists for treatment will grow. Community-based outpatient care must be sufficiently expanded in both states to serve the people who heed the positive "early intervention" message. And reimbursement rates must continue to reflect the actual costs of providing care. New York State has developed promising initiatives in this area.

In addition to supporting outpatient clinics, both states must re-examine their policies in order to increase the small numbers of independent, community-based physicians willing to provide primary care to Medicaid-eligible people. Poor people should not be consigned to overburdened hospital emergency rooms and outpatient clinics as their primary sources of routine medical care. New York State and New Jersey, which have among the lowest Medicaid reimbursement rates in the country for physician office visits, should study and implement proposals to increase these rates for physicians providing primary care to lower income communities or to require physicians to treat Medicaid patients as a prerequisite to being licensed.

New York and New Jersey should also assist needy people with HIV disease and other chronic, progressive diseases to maintain their private health insurance, which usually provides better coverage than Medicaid. This may be accomplished by enacting legislation authorizing state Medicaid programs to reimburse the costs of health insurance premiums. This is a cost-efficient approach, since the costs of premiums will almost always be less expensive than medical expenses reimbursed directly by Medicaid. Although the CARE Act permits states to use their funding to reimburse health insurance costs, funding is limited for new programs.

The 1990 provision of the federal Consolidated Omnibus Budget Reconciliation Act (COBRA) may also help retard the shift in financing from the private to the public sector by helping individuals who lose their jobs maintain their private group health insurance. The Act requires Medicaid payment of health care premiums and cost-sharing for enrollment under group health plans where cost-effective and offers states the option of federal medical assistance to qualified individuals.

Government officials should continue to promote the kinds of policies that most encourage targeted communities to seek access to the medical system and that make counseling and testing services readily available. Despite many studies in New York, Oregon, South Carolina, and California demonstrating that targeted communities -- including communities of color, gay men, and women -- were reluctant to be tested if named reporting was required, there are recurrent proposals for mandatory named reporting of HIV infection.

In January 1990, New Jersey enacted an HIV reporting and confidentiality law (P.L. 1989, c. 303), which mandated "identified" reporting of people with HIV infection and sharply curtailed anonymous testing. Following criticism by community-based groups and advocates, the State Senate amended this bill (S. 2329), requiring reporting of demographic information about people with HIV infection and maintaining anonymous testing. Unfortunately, the Assembly counterpart to this measure (A. 3948), which passed in January 1991, retains provisions for named reporting. The State Health Department prefers named reporting, purportedly to improve the delivery of health services. However, the Health Department has never explained how the collection of names improve service delivery, nor how past identified reporting has enhanced the care of people with AIDS and ARC. Therefore, the Commission urges the State Legislature to support the Senate bill, which maintains the option of anonymous testing and requires demographic reporting.

In New York State the 1988 HIV testing, informed consent, and confidentiality law (1988 Session Laws, C. 584; Article 27-F), codified anonymous testing at state-supported counseling and testing sites. However, mandatory reporting has remained a controversial issue. Former City Health Commissioner

Stephen Joseph called for renewed discussion of mandatory reporting in 1989 and several New York State medical societies have sued State Health Commissioner David Axelrod and the State Public Health Council to have HIV infection formally designated as a "communicable disease" or "sexually transmitted disease." Such a designation, which is a legal rather than a medical determination, would require mandatory reporting, permit HIV testing without informed consent, and might eliminate anonymous testing. Thus far the plaintiffs have been unsuccessful, but this case is now before the State Court of Appeals.[5] As an amicus curiae to this important case, the Commission hopes that the Court will affirm the determinations of State public health officials.

Long-term Care

HIV disease is a chronic and progressive condition punctuated by episodes of acute illness and relative well-being. Following hospitalizations to treat acute infections, many people are ready for hospital discharge yet still require intensive supportive care. Such care may appropriately be provided in skilled nursing facilities (SNFs) or health-related facilities (HRFs) or by home care workers supported by community-based organizations. Because few long-term care facilities have accepted people with HIV disease, and New York and New Jersey have not required them to do so, appropriate long-term care has been scarce. Although new facilities are now under various stages of development, long-term care beds are almost as difficult to find today as they were two years ago.

Moreover, programs that help individuals avoid inappropriate hospitalization are in short supply. For example, additional home health care personnel, including registered nurses, physical therapists, home health aides, and social workers, are needed to meet current needs. Recruitment of these professionals is often difficult because of low salaries, the reluctance of staff to enter crime-ridden neighborhoods, and lack of experience handling the special characteristics and needs of AIDS clients. Furthermore, delivering newly developed high-technology intravenous therapies presents several obstacles, such as inadequate Medicaid reimbursement rates (resulting in losses of $50 to $60 per visit) and the need for continuous laboratory monitoring, two hour nursing shifts, and twenty-four hour staff availability. Respite care, especially for pediatric patients, adult day care, and hospice care programs are also scarce. All patients need frequent assistance in accessing and processing claims for entitlements and other benefit programs. It is vital to develop these programs to relieve hospitals of patients ready to be discharged and to provide people with HIV disease more appropriate and compassionate care.

In New York City, there are only 66 beds for people with AIDS in HRFs and 44 beds in SNFs. The New York State Public Health Council has granted or is considering certificates of need for 930 HRF beds and an additional 1,005 SNF

beds.[6] Unfortunately, several new projects, sponsored by the Archdiocese of New York, have been mired by controversy because of disputes over the content of required risk reduction counseling; contraception for men and women, including condom and dental dam distribution; and the provision of gynecological care, including reproductive options counseling and access to abortion services, for women. AIDS organizations filed a federal lawsuit in November 1990 to require the New York State Department of Health to mandate that all facilities provide these services.[7] New Jersey has approximately 80 skilled nursing facility beds for people with AIDS; certificates of need for 150 new beds are being reviewed.

Developing sufficient numbers of long-term care beds must be a priority. Fear is hindering progress in this area -- community fears that people with HIV disease will downgrade neighborhoods and institutional fears that if HIV patients are admitted to existing facilities, other patients will leave or fail to come. Leadership has been lacking in hard-hit cities like Newark, where politicians have not cooperated with providers to locate sites suitable for development. Likewise, state regulators and human rights agencies have not required nursing homes to admit people with HIV disease nor have they sought redress under state human rights laws. Political and community leadership is urgently needed to promote the development of largely unmet long-term care services.

Housing

Housing advocates estimate that there are more than 10,000 HIV-infected homeless people in New York City. The New York City Task Force estimates were more conservative; it recommended that 2,640 housing units be created by 1993. Based on reports from case management programs, the New Jersey Health Department estimates that 10 percent of people living with AIDS are homeless -- approximately 400 individuals. If people with HIV disease are included, there may be up to 5,400 homeless HIV infected people in the state. Providing HIV-related housing is one of the most cost-effective uses of service funds because people who do not have adequate housing remain in hospitals longer than medically required.

In spite of these staggering numbers, very few housing programs have been developed. Non-medical housing has been as difficult to create as long-term care facilities. Housing may be provided through permanent and transitional room and board (known as congregate) facilities, private market scattered-site apartments, and publicly-supported apartments; rental subsidies to prevent for those who already have an apartment from becoming homeless is also appropriate. To promote a home-like setting and avoid fostering an "institutional" environment, congregate facilities should be small, housing a maximum of 50 people per site. Facilities should provide a private sleeping area (except by choice), private bath-rooms, common dining facilities, and access to secure refrigeration for medication, to cooking facilities, and to medical and social support services. In New York City

as of June 1990, there were approximately 65 beds for permanent or transitional housing, 133 units of private market scattered-site housing, and fewer than 50 residential units available in public housing stock. An additional 3,626 people receive rental assistance from the City Human Resources Administration.[8]

New York City has announced plans to increase housing services to people with AIDS. The Human Resources Administration has reported it will provide, by June 1991, an additional 370 scattered-site apartments, 500 publicly-supported apartments, 700 private sector apartments, and 2,400 rental assistance slots. The City's plan to expand the availability of housing for people with AIDS could be a major contribution to meeting residential needs. Housing advocates report, however, that the City has already fallen substantially behind in implementing these plans. The Human Resources Administration (HRA) is also developing plans to house 625 people with HIV-related illnesses in special shelters.[9] Expanding shelter programs for symptomatic HIV infected persons, however, fails to meet medically appropriate standards for this very vulnerable population. This policy may even be more expensive than scattersite housing.

Only a handful of housing programs exist in New Jersey, although the State Health Department reports it is working with the Department of Community Affairs to create new housing. These efforts are long overdue. The State should immediately begin working with and funding community groups to develop residential services, and to overcoming community resistance to siting.

New mechanisms to finance new residential programs for people with HIV disease must be developed. Creating such funding streams will require innovative planning and a commitment to providing services in all our communities. Unfounded fears and political timidity have prevented the New York State Legislature from passing legislation creating a new financing stream for HIV-related residential facilities.[10] On the federal level, the National Affordable Housing Act, which was enacted in the fall of 1990, authorizes $75 million in fiscal year 1991 and $157 million in fiscal year 1992 to provide a range of housing services including housing counseling and referral; development and operation of shelters and services; short-term rental assistance; rehabilitation of single-room occupancy (SRO) units; development of community residences; and other housing projects. (The HIV-related housing services contained in the National Affordable Housing Act were previously part of a separate proposal known as the AIDS Housing Opportunity Act.) However, Congress failed to appropriate any funding for HIV-related housing for fiscal year 1991.

Women, Children, and Adolescents

New York and New Jersey lead the nation in the numbers of women and children with HIV disease. As of November 30, 1990, New York and New Jersey

ranked first and second among the states in numbers of cumulative cases of CDC-reported AIDS among women; New York and New Jersey rank first and third in numbers of cumulative cases of CDC-reported AIDS among children. HIV disease among women and children is concentrated in poor, African-American and Latino communities in urban centers. In fact, New Jersey and New York have the highest overall AIDS death rates for women in the country; these rates are even higher for African-American women.[11] To meet the health needs of women and children, this region must implement programs to meet the specialized medical and social service needs of these groups.

The federal CDC definition of AIDS has been a serious barrier for women in need of services. Because women with HIV-related illnesses often do not display the same symptoms as gay men, even severely ill women may not be properly diagnosed.[12] Intractable gynecological infections are a particular problem. The failure to recognize the early symptoms of HIV in women is in part responsible for the lower survival rates among women from the time of AIDS diagnosis to death. The rigid diagnostic requirements of the definition has grave implications for women who cannot qualify for Medicaid, Supplemental Security Income (SSI), and other benefit programs as a result. This policy definition also denies federal funding to New York and New Jersey under legislative formulas based on diagnosed cases of AIDS. MFY Legal Services in New York City filed a federal lawsuit in October, 1990 against Health and Human Services Secretary Louis Sullivan to broaden the Social Security Administration's definition of AIDS for evaluating claims for disability benefits.[13] In addition, the Commission is developing a bi-state working group of policy makers and clinicians to examine existing epidemiological, clinical, and resource utilizations data in order to formulate policy recommendations. (This project will continue after the Commission formally ends.)

Concerned health care professionals and women's groups in New York and New Jersey have been calling for specialized training on women's medical requirements. While these programs are beginning to have an impact, Bronx Lebanon Hospital and University Hospital in Newark are among the few treatment centers with a clinic specializing in women's health care. The Health Departments in both states should begin funding new HIV clinics for women and families immediately. Additionally, sponsors of clinical trials of HIV-related drugs should include significantly greater numbers of women in their trials and should avoid excluding them from protocols unless there are scientifically valid reasons.

Support services must also reflect women's unique needs. Counseling is particularly important for considering whether or not to become pregnant and whether or not to have an abortion. Pregnant women and women with children also require legal services on custody and guardianship matters.

Policies and programs for women with children should support families of origin, keeping them together as long as possible. Newly created residential programs should be designed for families with children, with support services to maintain family structure. Likewise, foster care and other social welfare programs should not penalize extended family members caring for children of ill mothers. These family members should receive the same financial assistance for child care as foster parents, as long as they provide adequate care.

Two years ago, New York and New Jersey were seriously considering proposals to mandate "routine" screening of pregnant women and newborns. The proposals focus on women as vectors of HIV transmission and on the possibility of offering treatment to infected infants and inspired highly controversial and emotional debates. In 1989, the New Jersey State Health Department supported legislative action on routine screening with limited exceptions. Similarly, the New York State Health Department called for procedures to "unblind" hospital seroprevalence studies on newborns. Both states now advocate voluntary HIV testing for pregnant women with explicit informed consent. New York State established an Obstetrical Initiative in selected hospitals to offer counseling and testing, with referral to services, to women at high risk, especially those who have given birth without prenatal care. However, arguments for mandatory or routine screening continue to surface. At least until more definitive ways of identifying and more effective modes of treating HIV infected infants are found, voluntary policies should be promoted. Similar recommendations have been made by the Institute of Medicine and a working group from Johns Hopkins University and the Kennedy Institute of Ethics.[14]

Because of their unique needs and legal status, adolescents should be able to obtain access to prevention education, HIV testing and counseling, medical care, and psychosocial services on their own initiative, without requiring parental consent. While the assistance of a parent, guardian, or supportive adult should be encouraged, many adolescents whose behavior puts them at risk of acquiring HIV disease do not have a supportive family network. New York and New Jersey should develop comprehensive community-based HIV health and education programs for adolescents.[15]

Children, who have historically been under-represented in clinical trials, should have access to promising drugs. Access to trials should be ensured after Phase I/II studies have demonstrated safety and some drug activity in adults. An exception to this principle are seropositive but asymptomatic babies under 15 months in whom a positive HIV test may reflect the presence of maternal antibodies, not true infection. Perinatal transmission rates are now believed to range from 20 percent to 40 percent; therefore, most HIV-positive infants are not infected. Drug trials may offer benefit, but also risk; since noninfected children can obtain no benefit and may be harmed by participating in HIV drug studies, they

are generally not appropriate trial participants. Furthermore, to ensure the ethical acceptability of the informed consent process and the trial procedures, children not in the custody of their parents, and therefore especially vulnerable, should be provided advocates to make appropriate decisions for them.[16]

New York and New Jersey must be prepared to assist the tens of thousands of children who have been and will be orphaned because of the loss of their parents to HIV disease. Some of these children may themselves be infected with HIV and already symptomatic; others may be infected but asymptomatic; and still others -- probably the majority -- are uninfected. The vast majority of these children come from impoverished families. Dr. Pauline Thomas of the New York City Department of Health estimates that there will be 20,000 orphans by 1993. The New York City AIDS Task force estimated in 1989 that "over the next years a minimum of 60,000 to 70,000 children in New York City will lose at least one parent to AIDS."[17] The scope of this problem is likely to be similarly severe in New Jersey. Solutions must be developed soon to help these very vulnerable, at-risk children. (Carol Levine, the Commission's Executive Director, is undertaking a project on this subject after the Commission completes its work.)

Discrimination by Health Care Providers

In 1989 the Commission discussed widespread reports of discrimination by health care providers against people with HIV disease. Discriminatory practices unfortunately are as common today as when the Commission issued its earlier report.[18] These practices have recently been condemned by the National Commission on AIDS, which noted that a "shocking number of physicians [and dentists] are reluctant to take care of people living with HIV [disease]."[19] For example, although the HIV epidemic is entering its second decade, Gay Men's Health Crisis lists just 52 out of New York City's 25,000 physicians for client referral. There are only four dentists and five dental clinics on GMHC's referral list; however, a dental organization with 75 members does accept patients with HIV, but will not treat patients receiving Medicaid.

Studies of the attitudes of medical students, physicians, and other health professionals continue to demonstrate a pervasive unwillingness to treat HIV disease. In a study of internal medical residents presented at the Sixth International Conference on AIDS, only 17 percent indicated a strong intent to provide AIDS care. Researchers found strong negative attitudes towards gay men and intravenous drug users among a majority of those not intending to treat HIV-infected people.[20]

The degree of provider bias has been documented in a study conducted by the New York City Commission on Human Rights.[21] The City Commission surveyed people with AIDS and AIDS service providers on the extent of

discrimination in the delivery of a diverse range of health care services. Among clients, 80 percent reported discriminatory practices in hospital care, 50 percent in medical services, 33 percent in ambulance services, 26 percent in drug rehabilitation, 23 percent in home care, 23 percent in government benefits, 17 percent in drug trials, and 12 percent in mental health. Service providers reported similarly high levels of biased care -- 84 percent reported discriminatory practices in hospital care, 91 percent in medical services, 61 percent in ambulance services, 33 percent in drug rehabilitation, 68 percent in home care, 51 percent in government benefits, 69 percent in long-term care, and 69 percent in child services.

The City Commission also studied HIV-related discrimination by clinics providing abortion services. In 1989 approximately 54 percent of the providers contacted refused to serve women who identified themselves as being HIV positive. A follow-up study conducted in 1990 yielded similar results -- 42 percent of the providers overcharged or refused to serve HIV-positive women.

The landmark Americans With Disabilities Act (ADA), which was enacted in the summer of 1990 and will become effective in 1992, explicitly defines the "professional office of a health care provider" as a public accommodation which is prohibited from discriminating against people with disabilities. New York and New Jersey should also enact legislation affirming that state human rights laws apply to the offices of individual medical practitioners. To strengthen the New York State and City laws, the Citizens Commission has been an amicus curiae in health care discrimination cases currently before New York State courts.

Federal, state, and city human rights enforcement agencies should be appropriately managed, funded, and staffed to permit prompt and thorough investigations, settlement negotiations, and prosecutions of discrimination complaints in all settings, but especially in the provision of health care. Staff need training to deal sensitively with cultural differences. Moreover, to prevent discrimination, all health care agencies should provide continuous and scientifically rigorous staff education on the needs of people with HIV disease and on the use of "universal precautions" to prevent occupational exposure to HIV. Although the CDC has recommend the routine use of universal precautions since 1987, some facilities are not yet providing continuous education and an adequate supply of protective equipment to guard against occupational exposure. Health care facilities must provide workers with sufficient education and equipment to ensure that precautions are routinely followed.

Summing Up

The crisis in AIDS care, documented by the Commission in 1989, continues two years later. Although there have been some promising developments, care is still fragmented, inadequately financed, and largely inaccessible to the poorest communities. The scope of the problem and the legacy of past neglect make large-scale changes difficult and costly; but the costs of continued neglect will be even higher and more damaging to our communities.

Endnotes

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3. Personal conversation with Ginnie Lupi, Greater New York Hospital Association.

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14. Leslie M. Hardy, ed., HIV Screening of Pregnant Women and Newborns (Washington: National Academy Press, 1991); Working Group on HIV Testing of Pregnant Women and Newborns, "HIV Infection, Pregnant Women, and Newborns," 264 Journal of the American Medical Association 2416 (November 14, 1990).

15. For a more complete report on adolescents, see "Illusions of Immortality: The Confrontation of Adolescence and AIDS," prepared by the Ad Hoc Committee on Adolescents and HIV for the New York State AIDS Advisory Council, January 1991.

16. For additional analysis about the conduct of clinical trials, see Carol Levine, Nancy Neveloff Dubler, and Robert J. Levine, "Building a New Consensus: Ethical Principles and Policies for Clinical Research on HIV/AIDS," IRB: A Review of Human Subjects Research (January/February, March/April 1991), pp. 1-16.

17. New York City AIDS Task Force Report, (July 1989), p. 60.

18. See Lawrence O. Gostin, "The AIDS Litigation Project, A National Review of Court and Human Rights Commission Decisions, Part II: Discrimination," Journal of the American Medical Association 263 (April 18, 1990), 2086, 2089..

19. National Commission on AIDS, "Report Number Three: Research, the Workforce and the HIV Epidemic in Rural America" (August 1990).

20. M. Cooke, B. Koenig, N. Beery, and S. Folkman, "Which Physicians Will Provide AIDS Care?" Sixth International Conference on AIDS (San Francisco, 1990), Vol. 3, p. 108.

21. New York City Commission on Human Rights, "The Extent and Impact of HIV-Related Discrimination in New York City" (May 1989), unpublished study.

Appendix 1

Bronx-Lebanon Hospital Center AIDS Program

The Bronx has among the highest concentrations of AIDS in the country. Figures on the cumulative incidence of CDC-defined AIDS cases released in June, 1990 for South Bronx communities within the Bronx-Lebanon Hospital service area are as follows: Hunts Point/Mott Haven, 1,047 per 100,000 adults; High-Bridge/Morrisania, 795 per 100,000 adults; Crotona/Tremont, 730 per 100,000 adults; and Fordham/Bronx Park, 420 per 100,000 adults.[1] In comparison, Manhattan, with the highest cumulative incidence rate of AIDS among New York City's five boroughs, has a rate of 873 per 100,000 adults; overall, the Bronx has a rate of 436 per 100,000 adults.

Yet health care services are a scarce commodity in the impoverished South Bronx. The Community Service Society recently documented the inadequate levels of primary care services available in these communities.[2] Also increasing the need for comprehensive HIV services are the estimated 20,000 intravenous drug users in the Bronx, concentrated primarily in the South Bronx, who are HIV infected. The Bronx-Lebanon AIDS Program was developed in response to these overwhelming statistics. Its patient population reflects the neighborhoods it serves -- predominantly poor African-American and Latino communities. Not surprisingly, the majority of Bronx-Lebanon's patients are Medicaid-eligible or uninsured.

Since the start of the HIV epidemic, Bronx-Lebanon has provided inpatient and outpatient services. In 1987, Bronx-Lebanon met New York State's criteria to become a Designated AIDS Center. In return for receiving enhanced reimbursement rates under Medicaid, Bronx-Lebanon provides an array of inpatient and outpatient services, including case-managed care. Currently, the hospital's daily average census for inpatient HIV care ranges between 100 and 120 patients. Overall, one-third of the hospital's inpatients are estimated to be HIV-infected. General inpatient beds are supplemented by a 22-bed dedicated AIDS unit. As of October 1990 the outpatient department had provided care to about 1,500 patients. During 1990 there were approximately 10,000 outpatient visits. As a site of the National Institutes of Health's Community Programs for Clinical Research in AIDS (CPCRA), Bronx-Lebanon also affords patients the opportunity to participate in several important clinical trials.

Staffing the outpatient AIDS Program are 2 physicians (full-time equivalents), 1.5 physician assistants and nurse practitioners, 6 case managers, 4

nurses, 3 research assistants, a psychiatrist and psychologist, and 0.6 house officers. Dr. Jerome Ernst, the program's medical director, reports an increasing need for additional physicians and nurses, but says it is difficult to fill positions, some of which have been vacant for years. In particular, the clinic has been unable to recruit more than one gynecologist. "The medical profession's attitude in caring for people with AIDS and minority communities must be changed," he explains.

The outpatient clinic and the City Health Department's testing and counseling program are located in the same building. Patients who test HIV-positive are referred to the infectious disease, or AIDS, clinic. As of October 1990, the clinic maintained a waiting list of about two weeks, an extremely short waiting period in comparison to other outpatient clinics in New York. In addition to the infectious disease clinic, HIV care is offered to several hundred patients in the general medical, ambulatory care clinics.

Few clinics in the country provide care to as many HIV-infected women as the Bronx-Lebanon's AIDS clinic. Almost 40 percent of its caseload in November 1990 were women. Currently there are equal numbers of males and females between the ages of 18 and 22 and Dr. Ernst expects the percentage of female HIV patients will increase. One clinic session exclusively for women is being developed. However, Dr. Ernst stresses that because of the high numbers of female patients, all staff are trained to meet the special needs of women. The pediatric AIDS clinic currently cares for more than 100 children.

Dr. Ernst regards community networking as a critical clinic activity. The clinic provides medical services to residents of Hope Project Return, an HRF run by Project Samaritan, and is working to establish links with the newly developed Woodycrest HRF. The clinic also links patients of the area's community health centers to its NIH drug protocols. A borough-wide committee has recently been formed under the leadership of Bronx-Lebanon social workers to address the special needs of children of people with AIDS; this group is planning a major conference on children's needs in April 1991.

Bronx-Lebanon is planning to add several new programs in 1991. A nursing home across from the hospital, scheduled to open in the summer, will care for 240 patients, half of whom will be people with HIV disease. Plans are underway to develop an AIDS day care center and to increase community networking with the Franklin Men's Shelter and with local storefront medical clinics. Because many residents in the South Bronx obtain services at these storefront clinics and "storefront" physicians could benefit from linkages to the hospital's training programs and services, Dr. Ernst called this plan vital.

For the future, Dr. Ernst hopes to convert one of Bronx-Lebanon Hospital's buildings into a specialized hospital to provide comprehensive HIV care.* Many medical and public health experts have been debating the benefits and liabilities of AIDS dedicated hospitals and this is a controversial proposal. Most recently, a committee of experts in New York publicly opposed the development of such facilities, arguing that "one-disease institutions may be stigmatized, neglected and unable to offer adequate care." In addition, the panel reported that it would be almost impossible to assemble in one facility the diverse resources required by people with HIV disease.[3] Dr. Ernst remains undaunted, asserting that the feasibility of this approach can be properly evaluated only by developing a model of specialized care in New York.

* Dr. Ernst emphasizes that his proposal to develop a specialized hospital for HIV care does not represent the current plans or policies of the Bronx-Lebanon Hospital Center.

Endnotes

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2. See, Community Service Society of New York, "Building Primary Health Care in New York City's Low-Income Communities" (1990).

3. David J. Rothman and Eileen A. Tynan, "Special Report: Advantages and Disadvantages of Special Hospitals for Patients with HIV Infection," 323 New England Journal of Medicine 764 (September 13, 1990).

Appendix 2

St. Joseph's Hospital and Medical Center, Paterson
The Comprehensive Care Center for HIV Infection

With a total of 527 reported AIDS cases, Paterson, a predominantly lower income urban center located in northern New Jersey, currently ranks third among New Jersey's cities, behind Newark and Jersey City. (The Bergen-Passaic Metropolitan Area has a total of 1,304 cases through October 1990). The Comprehensive Care Center for HIV Infection (CCC) at St. Joseph's Hospital and Medical Center is an "umbrella" medical facility designed to meet the broad range of medical and service needs that people with HIV disease need. Among New Jersey's care programs, the CCC probably comes closest to providing a continuum of HIV care.

St. Joseph's began treating people with AIDS in 1981 on an inpatient basis, providing continued outpatient care on discharge at the hospital's Family Health Center. The Infectious Disease, or AIDS, Clinic was not formally established until 1986, when the hospital obtained a start-up grant of $56,000 from the State Department of Health. Operating with an infectious disease specialist, a nurse coordinator, and a social worker, the clinic initially treated six to eight patients per day. To ensure that HIV care was part of the hospital's medical education program and to provide additional medical staffing, hospital residents from the internal medicine program rotated clinic duty every three months.

In 1987, St. Joseph's was designated as a Counseling and Testing Site. The following year, an inpatient AIDS unit and a dental clinic were established. Confidential HIV testing was offered in obstetrical clinics.

A pediatric outpatient disease clinic for HIV-positive children, affiliated with the Children's Hospital AIDS Program in Newark, was initiated with a grant from the Division of Child Health Services. A residence for HIV-positive children was also opened. Currently the pediatric clinic and residence operates on a $180,000 grant from the Division of Youth and Family Services. Pediatric case-management is funded by a $143,000 grant from the Division of Child Health Services.

In January 1990, St. Joseph's was selected as one of five hospital outpatient departments to receive a $250,000 state grant to develop a Treatment Assessment Program (TAP) site. Designed to treat people with asymptomatic HIV infection, TAP sites use a case management approach to care. The Infectious Disease Clinic

is also a site of the North Jersey Community Research Initiative, which sponsors clinical trials of HIV-related drugs.

The Infectious Disease Clinic and TAP program had 760 registered clients, 650 of whom were very active, as of November 1990. (During 1990, St. Joseph's average daily inpatient census for HIV disease was 15-20 patients, reaching a high of 40 patients in March.) Since January 1990, 300 new patients have been registered; 100 more are anticipated by the end of 1990. Medical Director Dr. Christine Reyelt described one major difficulty with the TAP program: "While TAP was designed for the asymptomatic population, most patients present significant medical need. Although initially asymptomatic, these patients are continued in the program as their HIV disease progresses."

While the intent of CCC, and other TAP sites, is to offer treatment to patients after they are notified of a positive HIV test result, there are waits of up to three months for treatment at the infectious disease, TAP, and gynecological clinics. Dr. Reyelt acknowledges that this lengthy waiting period, which is also common in overstressed clinics in nearby Jersey City and Newark, is too long. However, CCC was credited by staff as providing treatment earlier in the course of HIV infection, thereby avoiding inpatient care as long as possible.

Financial limitations have resulted in significant service gaps. Sister Fran Demarest, CCC's Administrative Director, noted that $250,000 provided under the TAP program is inadequate to meet the full range of adult needs. Aside from the growing waiting list, the AIDS clinic needs another full-time physician, a nurse, a social worker, and a data entry clerk. Also needed are a psychiatrist, a social work therapist, and a substance abuse counselor to handle the psychosocial and substance abuse needs of patients. CCC has found it particularly difficult to recruit new physicians.

CCC is working with the State Health Department to determine the actual costs of treatment and the feasibility of setting higher reimbursement rates under Medicaid. The level and timeliness of State reimbursement are critical since the majority of clinic patients are Medicaid-eligible or have their services charged to indigent care. While the hospital is reimbursed at the rate of $65 per patient visit, actual cost to the clinic is estimated to be closer to $125 per visit. Cash flow is also a major problem. Although indigent care is theoretically reimbursed by New Jersey's Uncompensated Care Trust Fund, payment from the State can take up to three years and is rarely in full.

CCC has recently been denied State funding to assist pregnant women who desire drug treatment services, despite the critical nature of these services. CCC is also seeking funding to provide drug use, alcohol, and HIV prevention counseling to parents of children enrolled at Head Start.

According to Sr. Demarest, comprehensive care enables clinics to develop services in an organized fashion, without duplication and fragmentation, and promotes the efficient use of staff. Although CCC is underfunded, understaffed, and seeks to provide more care than it can actually deliver, it offers a valuable framework for other community health programs developing a comprehensive set of services for people with HIV disease.

Chapter 4

AIDS Prevention and Education: Reframing the Message

Although prevention and education were high priorities for the Commission's from its inception, its report on the subject was the last to be issued. Each of the other three reports had included material about prevention and education but none had addressed the problem comprehensively. This agenda item was postponed partly because other areas were so urgent and it was difficult to work on several subjects at once, and partly because so much had already been written and said on the topic of education that the Commission struggled to find a fresh approach.

In this case, delay proved fortuitous. By the time the Commission finally focused intently on this issue--the fall of 1989--the health care crisis and the promise of early intervention had taken so much of the media and public attention that the Commission's warnings about complacency and the prevalence of what it called "Ten Myths about AIDS Education" struck the right note. The report was called "AIDS Prevention and Education: Reframing the Message," and emphasized the lessons that had been learned through the experiences of prevention programs. The report was released in late November, without a press conference, to coincide with World AIDS Day, which focused on youth that year.

The "Ten Myths" captured prevalent misconceptions about AIDS education and offered facts and recommendations to refute them (see Appendix 1). For example, Myth No. 1 is: "Continued AIDS public education is not necessary because everyone already knows how HIV is and is not transmitted." The facts are that: "Although the level of knowledge has increased, large numbers of people still believe that they can catch AIDS from drinking glasses, toilet seats, and casual contact." The recommendation is: "Public education about AIDS must remain a continuing priority."

The report also criticized the CDC's restrictive criteria on targeted educational materials, which required that materials developed for specific groups be "inoffensive to most educated adults *beyond that group* [emphasis added]." That standard has been somewhat relaxed, and the new guidelines permit exceptions if "the potential offensiveness...is outweighed by the potential effectiveness in communicating an important HIV prevention message."

The timing of the report's release and the direct appeal of the Ten Myths resulted in wide media coverage. In particular, radio stations around the country picked up the story and either reported it on their own or arranged interviews with the Commission. Media in the New York-New Jersey area serving African-American and Latino markets also carried the story. Other media followed up with stories about some of the AIDS education projects profiled in the report.

After issuing the report, the Commission prepared posters of several of the most important myths and distributed them to endorsers of the Commission's "Ten Principles" on AIDS and the workplace to display on employee bulletin boards. The posters were also offered to community-based organizations for their educational efforts.

The myths also led directly to a collaborative project to develop a bilingual calendar/resource guide for Upper Manhattan. Gwyland Winslow, a VISTA volunteer collecting material on AIDS for Community Board #9 in Manhattan, saw the myths and concluded that the educational message they presented would be ideal as a calendar in his community. Representatives from eight community-based organizations formed a coalition, coordinated by the Citizens Commission, to develop the project. With the support of grants from the Hunt Alternatives Fund, J. P. Morgan & Co., Incorporated, and the Metropolitan Life Foundation, 20,000 copies of the calendar/resource guide were printed and distributed throughout Upper Manhattan. The calendar features drawings by two students from P.S. 121 and lists more than 30 community health and AIDS-related services. Posters of the calendar cover will be distributed in New York City elementary schools.

Condom Distribution in New York City's High Schools

The most significant policy proposal for improving HIV/AIDS education and prevention has come from Joseph A. Fernandez, the Chancellor of the New York City public schools. If Chancellor Fernandez's proposal is approved, condoms will be distributed on request by male and female volunteers. Parental consent will not be required in all New York City high schools. This proposal, announced in December 1990, goes further than the original concept, proposed in September, which would have limited distribution to those high schools with health clinics. Each of the 120 high schools will design its own distribution plan. This program, if implemented, would be the most aggressive in the nation. The condom distribution program must be approved by the Board of Education; most members have supported the concept but some may not be willing to go as far as the Chancellor has proposed.

The Chancellor was convinced of the need for condom distribution because "New York City is leading the nation in adolescent AIDS cases." Even more compelling than the number of full-blown AIDS cases among adolescents is the fact

that the large number of AIDS cases among 20 to 29 year-olds reflects HIV infections acquired during adolescence. Moreover, the Chancellor pointed out, "People at any age have ready access to condoms at supermarkets and drugstores without the benefit of an educational or counseling component."[1]

Chancellor Fernandez's proposal is a courageous and forthright response to a crisis. Even if the plan is approved and funded, however, several obstacles must be overcome: the cost of condoms in an era of budget cuts, liability concerns, and, perhaps most formidable, student and school administrators' acceptance of the program. Unless the specific distribution plans are sensitive to teenagers' concerns, they will not be successful. Furthermore, while condoms are an important part of AIDS prevention programs, they are only effective within a context of social support and continuing education about risk reduction. The Chancellor has also proposed to update and improve AIDS education in the schools,[2] which is currently erratic. Earlier in the year the Chancellor's office distributed an AIDS information brochure to high school students. While the attempt to give information was certainly worthwhile, the brochure itself was poorly conceived. It failed to take advantage of the experiences of community-based organizations in dealing with adolescents and others at risk and instead sent only "fear" messages.

Recommendations for Continued Action

Several excellent HIV/AIDS educational campaigns, programs, and materials have been produced in the past year. Among them: "Me First! Medical Manifestations of HIV in Women," produced by the New Jersey Women and AIDS Network; a series of full-page advertisements called "Living with HIV: The Sooner You Take Control the Better," produced by a group of medical organizations and AIDS service providers; GMHC's program, "Keeping It Up," designed to prevent relapse in safer-sex behavior; and "House," safer sex interventions developed by coalitions of AIDS service providers that target gay men of color and incorporate education messages into the popular dance format of "voguing." These examples illustrate creativity, multicultural sensitivity, and community outreach. But much more must be done. The Commission's basic recommendations are still far from reality (see Appendix 2).

Endnotes

1. New York Times, December 3, 1990, p. A1.

2. Memo from Amina Abdur-Rahman, Deputy Chancellor for External Programs and Community Affairs, New York City Public Schools, December 6, 1990.

Appendix 1

Ten Myths About AIDS Education

Myth No. 1: Continued AIDS public education is not necessary because everyone already knows how HIV is and is not transmitted.

FACT: Although the level of knowledge has increased, large numbers of people still believe that they can catch AIDS from drinking glasses, toilet seats, and casual contact.

RECOMMENDATION: Public education about AIDS must remain a continuing priority.

Myth No. 2: Public service announcements have saturated the media with AIDS information.

FACT: Most AIDS campaigns conducted through public service announcements have had limited impact because they have been aired infrequently and erratically.

RECOMMENDATION: AIDS education campaigns should be aired during prime time and with the same exposure as commercial campaigns.

Myth No. 3: AIDS education for heterosexuals is not necessary because AIDS is not spreading beyond the gay or drug-using communities.

FACT: AIDS is spread through heterosexual as well as homosexual sex. The percentage of women who do not use drugs and are being infected heterosexually is increasing, as is the percentage of adolescents of both sexes.

RECOMMENDATION: Education and prevention programs should be aimed at heterosexuals, especially teenagers and drug users, in addition to gay and bisexual men.

Myth No. 4: AIDS education in schools is difficult to introduce because so many parents object.

FACT: All public opinion surveys show that the vast majority of parents support some form of AIDS (and sex) education in schools. The precise content of the education is more controversial.

RECOMMENDATION: All public and private schools should provide AIDS education from grades K-12, and should educate parents about the curriculum as well as about ways to discuss AIDS with their children. AIDS educators should meet with parents who object, to explain the curriculum and reduce fears.

Myth No. 5: If AIDS instruction is provided in the schools, adolescents do not need any additional education.

FACT: Even with the best curriculum and the most highly skilled teachers, AIDS education that is limited to the classroom cannot have the same impact as AIDS education that is repeated in many different settings outside the classroom.

RECOMMENDATION: Community-based organizations should be supported by public and private funds in providing AIDS education to adolescents.

Myth No. 6: Continued AIDS education for gay men is not necessary because they have all adopted "safer sex" practices.

FACT: Although gay men in general have substantially reduced risky behavior, some have been unable or unwilling to do so and others have difficulty in maintaining behavior change over long periods.

RECOMMENDATION: Targeted, explicit education for gay men that provides motivation for sustained behavior change should be continued and supported by public agencies as well as community-based groups.

Myth No. 7: AIDS education for drug users is a waste of time and money because they are unconcerned about their health and unable to change their behavior.

FACT: Concerned about AIDS and increasingly aware of the risks, many drug users have stopped sharing needles or are sharing less frequently, but their sexual behavior has been slower to change.

RECOMMENDATION: Targeted AIDS education for drug users should be expanded and supported by public funds. Special emphasis should be placed on changing sexual behavior because drug users continue to be the main source for the heterosexual transmission of HIV.

Myth No. 8: Continued AIDS education for blood donors is not necessary because everyone knows who should and should not donate blood.

FACT: Although the safety of the blood supply has dramatically increased since HIV antibody testing was introduced, two problems remain: (1) many people who are eligible to donate do not do so out of unfounded fear that they can contract AIDS in this way, and (2) some HIV-infected heterosexuals do not understand or acknowledge their risk and continue to donate blood.

RECOMMENDATION: Blood banks and those who organize workplace or community blood drives should develop more explicit information about behavioral risk, and easy, confidential ways for at-risk donors to exclude themselves.

Myth No. 9: If people are given accurate information, they will change their attitudes and behavior.

FACT: Knowledge alone does not lead to changes in attitude or behavior. Some people with high levels of knowledge continue to engage in risky behavior because they do not perceive themselves to be at risk. Some attitudes and behaviors are so deeply held that information alone will not change them.

RECOMMENDATION: Prevention programs should do more than provide information -- they should also give people skills and techniques to change attitudes and behavior.

Myth No. 10: Fear of death is the most effective motivator in changing behavior.

FACT: While a certain level of anxiety can heighten personal perceptions of risk, messages that stress fear alone are easily denied or screened out.

RECOMMENDATION: AIDS prevention messages should create a sense of personal risk, should emphasize the possibilities for protecting oneself and gaining control over the threat, and should reinforce the idea that AIDS is preventable. There is no advantage in creating a sense of inability to control the situation.

Appendix 2

Summary and Recommendations

The following general principles should guide AIDS education and prevention programs:

1. To be effective, educational efforts must contain several key elements:

   a. Educational messages should be accurate, consistent, cumulative, and long-term.

   b. Educational messages should be communicated through all appropriate media and through numerous forms of one-to-one and small group contact.

   c. Educational messages should be developed by and communicated by persons who are knowledgeable, credible to the audience, and sensitive to the emotional and cultural nuances of the information.

   d. Effective educational messages may arouse a certain level of fear; however, other approaches, including positive alternatives to risky behavior, social acceptability, and humor, are often more effective.

   e. Education and prevention programs targeted at specific populations should be linked to the provision of appropriate services.

2. Public education campaigns providing accurate, up-to-date, and clearly stated information about AIDS should be a continuing, coordinated, and high-priority effort.

3. The mass media have an important role to play in communicating basic information and in creating a social context in which targeted messages are more likely to be acceptable.

4. Targeted education campaigns for gay men should be continued and supported, so that those who have changed behavior can sustain those changes and those who have not can be motivated to change.

5. Drug users and their sexual partners are difficult populations to educate but they should not be considered "unreachable."

6. Efforts to change risky behavior to prevent further transmission of HIV face significant barriers.

7. Developmentally appropriate school-based AIDS education should be supported from kindergarten through higher education.

8. Educational programs should be evaluated for their effectiveness.

Based on these principles and recognizing that no single sector of society can bring about all the needed changes and that all sectors working in their respective arenas will support one another's efforts the Citizens Commission on AIDS makes the following recommendations:

A. GOVERNMENT

Public health authorities at the federal, state, and local levels have a responsibility to provide AIDS education. After a shaky and uncertain start, in which education was largely and successfully funded and conducted by organizations in the gay community, governmental agencies such as the New york State AIDS institute, the New York City Department of Health, and the New Jersey State Department of Health, and the federal Center for Disease Control, have now committed more substantial resources and energies to education.

Based on the experience of the past nine years, the future role of public health agencies should be to:

1. Continue to develop and fund general educational messages and programs.

2. Continue to fund community-based groups to develop their own targeted messages and programs.

3. Fund carefully designed social science research to learn more about (a) categories of individuals who engage in risky behavior but whose activities are largely hidden from society, such as bisexual men, and men of color who have sex with other men; (b) attitudes toward risk-taking, particularly among adolescents and those who continue to engage in risky behavior even after conventional educational efforts.

4. Stand firm against attempts to censor or restrict explicit information directed to specific groups such as gay men or drug users.

5. Establish AIDS Education Clearinghouses in New York and New Jersey, in collaboration with the private sector, to serve as resource centers for community-based organizations, service providers, the media, and the general public.

B. MASS MEDIA

The mass media, when used appropriately, can raise public awareness and knowledge about basic AIDS facts. Further, it can create a climate in which people with AIDS are treated compassionately and those at risk are motivated to seek more specific information and counseling about risk reduction. A very large gap between public perception and scientific knowledge about risk remains. While advertising and news media have reduced that information gap, particularly among better educated people, more needs to be done.

Advertising campaigns have been limited in effectiveness because their messages are inconsistent and apparently contradictory (for example, one message says that AIDS is hard to catch while another says that everyone is at risk). In addition, the messages appear for short durations, in time slots with limited audiences, and without the intensity of repetition that is essential for impact.

1. **AIDS prevention messages should be approached as a marketing problem: the expertise of the advertising and marketing community should be marshaled to contribute to this goal with the same energy and resources they would devote to selling a commercial product.**

2. **Local media outlets should work together to develop a comprehensive plan for presenting AIDS prevention messages to their audiences. The first step should be an inventory of what has already been presented to determine content, frequency, and intended audiences. The next step should be a focused discussion with AIDS prevention specialists to outline the major elements of an effective campaign. Finally, a series of messages targeted to particular audiences through particular media should be constructed, and a marketing plan for disseminating these messages should be implemented.**

3. **In addition to public service advertising, television programming should include references to AIDS and HIV disease prevention as part of story lines in ways that are compatible with the characters and plot. That is, the episode need not be principally about AIDS in order to have an AIDS prevention message built into it.**

4. **Minority media should be particularly encouraged to develop targeted AIDS prevention messages and programming for their audiences.**

C. WORKPLACES

Except when promoting the health benefits of specific products, the corporate role in public health education has been limited. But the business community cannot afford to remain aloof from AIDS prevention: the health of its

current and future workforces, and of their families and communities, as well as the added tax burdens that will inevitably accompany an expanded HIV epidemic, demand that it play a role.

1. **Businesses, in cooperation with unions where they exist, should provide HIV prevention education in their workplaces and encourage their employees to participate in community and school-based efforts.**

2. **Businesses can play an important role in AIDS prevention and education by providing financial support to the education efforts of national and community-based groups.**

3. **Businesses should provide HIV prevention education in their product inserts where it may be seen by individuals with no other access to AIDS education, such as low-income women. Examples are baby care and personal hygiene products.**

4. **Businesses that cater to minority markets (food producers, banks, and small neighborhood businesses) should support AIDS education for their customers.**

5. **Entrepreneurial efforts should be encouraged: one example is the development of novel ways to distribute condoms, promote their use, and make them more "user-friendly."**

D. EDUCATIONAL INSTITUTIONS

All institutions vested with the responsibility of educating young people -- public, private, and parochial schools, colleges and universities, and others -- should incorporate AIDS education into their programs. AIDS education should begin in kindergarten and continue through the 12th grade, with the most intense attention devoted to students in grades 7 through 12.

A scientifically accurate, developmentally appropriate curriculum is the first step. But a curriculum is only the beginning. Staff training is an immediate and pressing need in all jurisdictions. Teachers need special training to prepare themselves for dealing with a topic that is as sensitive for them as it is for their students. They also need thorough grounding in the facts of AIDS and advice on how to handle the emotions and questions that may arise.

1. **The New York City Board of Education should fund more aggressive attempts to train more staff in AIDS education, to introduce its curriculum citywide, and to evaluate the results.** While the Board has taken important first steps in these areas, the implementation of AIDS education still lags far behind the need.

2. **The New Jersey legislature should mandate AIDS education for students in grades K-12, and should provide adequate support to the New Jersey Department of Education to carry out that mandate. The Department of Education should work with local school districts to evaluate their AIDS instruction and to train staff in implementing their instruction guide.**

3. **Schools should take the lead in developing education programs aimed at parents.** Parents can benefit from AIDS education by learning what their children are learning and how to talk to them about the relationship among AIDS, sexual behavior, and drug use. Better-informed parents are likely to be more supportive of schools' efforts. An additional benefit is that many adults who engage in high-risk behavior may better appreciate their own risk.

4. **Colleges and universities in the New York-New Jersey area should provide AIDS education on a continuous basis.** AIDS education has been provided in many higher-education institutions; this should be continued and expanded, since new students enroll each year and others may need reinforcement to avoid high-risk behavior. The intensity of such efforts should not be diminished because of beliefs that a heterosexual epidemic is unlikely. While that may be so in terms of large populations, individual heterosexuals can be at high risk because of their behaviors. Moreover, most college populations include gay men at risk.

5. **Boards of Education should ensure that AIDS educational curricula and materials are appropriately developed and that instruction is provided in special and mainstreamed classes for students with visual, hearing, mental, and developmental disabilities.**

E. FOUNDATIONS

In recent years private foundations have begun to support AIDS education efforts to a greater extent, stimulated in part by groups like Funders Concerned about AIDS and the National AIDS Partnership's local groups in New York City and New Jersey. Private foundations should sustain and expand this involvement.

1. **Private foundations should place particular emphasis on programs that target hard-to-reach groups and that support efforts for which public funds are difficult to obtain.**

2. **Private foundations should fund innovative models and collaborative arrangements among groups with similar goals.**

3. **Private foundations should fund well-designed evaluation components or projects.**

4. **Private foundations should fund efforts to replicate or adapt successful models.**

F. COMMUNITIES

Communities, both large and small, are most effectively served by the sum of all these efforts by governments, mass media, businesses, unions, schools, and community-based groups. To determine whether a community is doing all it should for AIDS prevention, citizens can ask themselves the following questions:

1. Do all the schools in the community have AIDS education programs? If so, what is the curriculum? How are the teachers trained? Is the curriculum accurate and up to date? Does it provide for referrals or follow-up sessions for those who need more specific advice? Do the schools have sessions for parents?

2. Do the major community-based organizations, such as religious organizations, youth groups, social groups, and others, provide AIDS education to their members? Are there ways for individuals at high risk to be referred for further counseling and health care services without violating their privacy?

3. Are families involved in AIDS education? Are there sources for support and referrals for families who want assistance in this area?

4. Does the public health agency support and fund community-based AIDS education? What is its target audience? What is its message?

5. Do the major businesses and unions in the community provide AIDS education in the workplace? Can this education be opened to others in the community?

6. Is anonymous or confidential counseling and HIV antibody testing readily available in the community?

7. Are the medical professionals in the community trained to deal with AIDS and HIV infection? Do they routinely discuss sexual behavior and drug use with their patients in a respectful and sensitive way? Do they share their expertise with the community through educational programs?

8. Do the media that reach the community present AIDS prevention messages that are appropriate for the audience?

9. Does the local governmental body support educational programs and other interventions that may slow the spread of AIDS, such as support for drug treatment facilities?

10. Do local libraries have an up-to-date collection of audiovisual and written materials, in all appropriate languages and for all subgroups? Are there special materials for adolescents?

11. Are educational materials available in formats accessible to people with visual and hearing impairments? Are continuing, appropriately developed educational programs in place for people with mental retardation and other developmental disabilities?

12. Are there adequate drug treatment facilities in the community? Do drug treatment facilities provide AIDS education and counseling?

Chronology
Citizens Commission on AIDS

July 1987	Citizens Commission on AIDS formed. John Jacob and John Zuccotti, co-chairs.
September 1987	Carol Levine appointed Executive Director.
January 1988	Strategic planning session for the Commission.
February 1988	Release of the Commission's first report, "Responding to AIDS: Ten Principles for the Workplace." Thirty endorsers of the Ten Principles announced at the press conference.
June 1988	The Ten Principles for the Workplace presented to a World Health Organization consultation.
September 1988	Release of "AIDS and Drug Use: Breaking the Link." Eighty endorsers of the Commission's recommendations for expanded drug treatment and education for drug users. There are 137 endorsers of the Ten Principles.
March 1989	Release of the Commission's third report, "The Crisis in AIDS Care: A Call to Action."
May 1989	Release of New Jersey Action Agenda in conjunction with the release of "The Crisis in AIDS Care."
June 1989	The Ten Principles for the Workplace are presented in poster session at the V International AIDS Conference.
Summer 1989	Commission is instrumental in forming the first statewide coalition of AIDS service providers in New Jersey.
November 1989	Release of the Commission's fourth report, "AIDS Prevention and Education: Reframing the Message."
July 1990	Conference for small business in New Jersey on AIDS and the workplace.

November 1990	Over 400 endorsers of the Ten Principles, with an additional 180 endorsers of a revised version released by the New England Corporate Consortium on AIDS.
December 1990	In association with eight prominent AIDS service organizations 20,000 free 1991 calendar/AIDS community health resource guide are distributed in Upper Manhattan.
January 1991	The National Leadership Coalition on AIDS agrees to officially oversee the future distribution of the Ten Principles.
February 1991	Release of the Commission's final report, "AIDS: Is There a Will to Meet the Challenge?"

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