



COMMISSION ON HUMAN RIGHTS

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File of
NYC

WOMAN AND AIDS - A REPORT

by the NYC Commission on Human Rights'

AIDS Discrimination Unit

The Human Rights Law of the City of New York prohibits discrimination in the areas of housing, employment and public accommodation on the basis of an individual's handicap or disability. The NYC Commission on Human Rights has taken the position that it has jurisdiction over all complaints of AIDS and AIDS-related discrimination under the protection afforded by the present statutory provisions. Consequently, the NYC Commission on Human Rights accepts complaints from and offers assistance to:

- Persons with AIDS
- Persons with ARC (AIDS-Related Complex)
- Those who have tested HTLV-III antibody positive
- Members of a group considered to be at risk for AIDS
- Members, co-workers, spouses, mothers and/or friends of someone in the above four categories who believe they have been discriminated against because of their association with this individual.

The Commission received its first reported incident of AIDS discrimination in June 1983. Thereafter the AIDS Discrimination Unit was established to document and respond to complaints of AIDS-related discrimination. This report summarizes some of the complaints involving women, which were received by the unit from November 1983 through December 1986. With the exception of some few cases, where the facts surrounding the incident have been determined, these reports of discrimination must be considered allegations, meaning that a formal complaint was not filed or if it was it is still under investigation. In many cases, the Commission was able to settle the case through advocacy, and

resolve the problem to the satisfaction of the caller and the party charged with discrimination. In such instances, official findings of fact were not reached. (Most often in such cases, a formal investigation to determine the veracity of the allegations was unnecessary. Indeed, respondents were very open about having fired someone with AIDS, or evicted someone they suspected of having AIDS.) In other cases, formal complaints were never filed; again, the facts could not be determined. However, such a body of allegations possesses a merit of its own: it is a record of the experience of the callers.

Discrimination problems abound for the person with AIDS, but such problems also affect those in close proximity to an individual who has AIDS: the support person, care provider, family member, spouse or mother. An alarming number of incidents of discrimination have been reported by women who do not have AIDS but are involved in the care or support system of a person with AIDS .

AIDS and AIDS-related discrimination have had a devastating impact on women's lives in a multitude of ways which extend beyond medical issues. Between January and December of 1986, 11% of all AIDS-related discrimination complaints reported to the Commission were reported by women;

Employment	25%
Housing	15%
Public Accommodation	60%

An additional 5.5% of the total number of AIDS-related complaints were filed on behalf of children, and women were almost always the parties who filed complaints on behalf of the children.

A civil rights worker has to be innovative and responsive to adequately address the myriad problem situations affecting women with AIDS or women who are care takers of people with AIDS. It is the rule, rather than the exception, that a caller reports more than one problem when contacting the Commission. Many of these callers raise complicated legal issues and seek help in areas for which the territory is as yet uncharted with respect to discrimination law. And those who have AIDS often need assistance quickly and desperately.

Unfortunately, because of AIDS hysteria, many callers fear adverse publicity or other negative reprisals and are reluctant to file a formal complaint or leave their name or telephone number, making follow-up in these instances difficult or impossible.

The end result, or perhaps it is more factual to say the ongoing result since the situations addressed in this volume continue to plague women who have or deal with AIDS, is a foray into a new and compelling area of discrimination law. We hope

that others who concern themselves with the problems related to this tragic epidemic will also try to summarize and document what they have learned because problems which require revisions in law or policy can best be delineated when a greater number of people are involved.

The incidents related in the body of this report are summaries of individual and systemic complaints involving women. By systemic, it is meant that the problem is company- or industry-wide, that a tacit or written policy exists which would adversely affect any person with AIDS or perceived to have AIDS. This type of complaint is common and it is significant in that the number of people adversely affected by the practice may well be much higher than the actual number of reports received. For every report of systemic discrimination received, we estimate that scores of people with AIDS or perceived to have AIDS may be denied that service (or job, housing, etc.)

To assist the reader, the complaints have been grouped by category. (i.e. all hospital and health-related complaints are listed in one group, all employment discrimination complaints in another, etc.) Seeing these complaints in type-groups furthers an understanding of the similar and recurring nature of the problems.

**Statistics on AIDS and AIDS-Related
Complaints Involving Men, Women and Children
Received by NYC Commission on Human Rights
During
November 1983 - December 1986**

1983:	3
1984:	49
1985:	96
1986:	314

EMPLOYMENT DISCRIMINATION

OCT 84 EMPLOYMENT/PERCEIVED AIDS

A waitress called. She and her boyfriend, who worked in the same restaurant, were fired after their employer learned that her uncle had AIDS. We advised her that she could file a complaint but she wouldn't bring charges against her employer because she lived in the neighborhood where the restaurant was located and feared repercussions. Jurisdictional, but no complaint was filed.

SEP 85 EMPLOYMENT/PERCEIVED AIDS/HTLV-III

A mother from Staten Island called because she feared she would lose her job unless she could "prove" that she did not have AIDS by taking the HTLV-III test. Her boss knows that she has a son who is unmarried, in his 40's, and lives in Greenwich Village. He has concluded that her son must be gay, must have AIDS and therefore his mother must be an "AIDS carrier." She has been told that she must prove that she doesn't have AIDS or be fired. The mother called, not about the violation of her civil rights, but wanting only to know where she could get the test. As she said: "Where am I going to get another job at my age?" Jurisdictional but no complaint was filed.

SEP 85 EMPLOYMENT/PERCEIVED AIDS/HTLV-III

A woman from Brooklyn, whose boyfriend had died due to complications caused by AIDS, called with a problem. She had confided in a co-worker the cause of her obvious grief and soon thereafter no one in the office would speak to her. She called because she had just been told by the personnel director that she was being placed on "indefinite leave without pay" until she could "prove" that she doesn't have AIDS. He said he "had to" let her go because two other employees "threatened to quit and sue the company" if she was allowed to remain on the job. She called the Commission only to find out where she could "get the AIDS test." We explained that 1) before she considered taking the test for the HTLV-III antibody, she should be aware of the possible repercussions she might experience if she tested positive, 2) she represented no health risk to co-workers, and wouldn't even if she did have AIDS, and 3) her employer was violating her civil rights and she was entitled to file a complaint with the Commission to rectify the situation. We offered to speak directly to her employer to explain these facts. Jurisdictional, but no complaint was filed.

NOV 85 EMPLOYMENT/PERCEIVED AIDS

A heterosexual woman employed in a beauty shop was the victim of an unfortunate joke. Someone had written her a letter purporting to be a notice from the Board of Health advising her that she had come in contact with someone who had a venereal disease. Her boss intercepted the letter and interpreted it as meaning the woman had AIDS, although she was in no known risk group. The boss told her that she would have to leave work and was not to return until she had been "tested". Jurisdictional, but the woman did not file a complaint.

HOUSING DISCRIMINATION

AUG 84 HOUSING/ACTUAL AIDS/BIAS

A worker from the AIDS Medical Foundation contacted the Commission about a case with which she had become involved. A woman from a small town in Maryland called the Foundation for help on behalf of a man in her town who had contracted AIDS. She said that the town had mobilized to force him to move. She was so frightened of retaliation by her neighbors that she would not give the Foundation staff member to whom she spoke either her name or phone number. She wanted to obtain information about his rights so that she could secretly pass the information on to him. We provided the requested information.

OCT 84 HOUSING/ACTUAL AIDS

The wife of a man with AIDS called because her heat and hot water had been turned off by the landlord in an effort to drive the family out, due to fear of AIDS. She only wanted the services restored and did not have the time to devote to a discrimination complaint. We made several phone calls, suggested referrals and the situation was resolved. Jurisdictional.

NOV 85 HOUSING/ACTUAL AIDS

A woman called. She is the mother of an 18 month old baby and the child has AIDS. Her landlord is trying to evict her. The mother herself is not in good health and was scheduled to go into the hospital for an indeterminate stay. She'd arranged through a social worker for Red Cross volunteers to stay with her child while she was hospitalized but the landlord's harassment seemed to preclude this arrangement. He had previously ripped her mailbox out, causing her to have to go to the post office daily.

Now he had shut her electricity off. She couldn't see how the Red Cross worker could mind her baby in the dark. We advised her that we would intercede on her behalf. However, she then informed us that the landlord didn't even know her child had AIDS, and she feared his finding out. He only wanted her out so that he could give the apartment to a member of another racial group. We told her this was also jurisdictional and encouraged her to file a complaint on that basis. In the interim she had numerous other problems and we gave her advice and referrals. She was to come in the following day to file a race complaint but never did. Since she did not have a phone and hadn't yet given us her address, we could not re-contact her. Jurisdictional.

PUBLIC ACCOMMODATION DISCRIMINATION

Ambulances and Ambulettes

NOV 84 AMBULANCE/ACTUAL AIDS/PUBLIC ACCOMMODATION

A Red Cross worker called to report an incident involving an ambulance company. One of their home attendants called for an ambulance to transport her client, a woman with AIDS, to the hospital. The patient was having difficulty breathing. When the ambulance driver, who was described by the Red Cross worker as "very abusive," arrived, he refused to touch the patient, saying "this woman's contagious." Eventually the situation was resolved when another ambulance company transported the woman.

JAN 85 AMBULETTE/ACTUAL AIDS/CHILD/SYSTEMIC

A Red Cross social worker called to report an insurmountable problem regarding transportation. A 2 1/2 year old baby with AIDS needed regular transportation from Staten Island to Einstein Hospital in the Bronx for necessary treatment. Ambulette and taxi companies had refused to transport the baby because she has AIDS. And because Medicaid's expense ceiling is so low, the social worker has been unable to seek other modes of transportation. The end result is that the child has to be ferried to and from appointments by the Red Cross, tying up one of their few volunteer cars all day and thus cutting off service to others. Jurisdictional.

FEB 85 AMBULANCE/ACTUAL AIDS/PUBLIC ACCOMMODATION

The mother of a man with AIDS brought home "to die in peace" eventually had to call an ambulance for her son because he took a turn for the worse and couldn't breathe. When the Emergency Medical Technicians from the volunteer ambulance service arrived, they found out the man had AIDS and wouldn't transport him.

MAR 85 AMBULANCE/ACTUAL AIDS/PUBLIC ACCOMMODATION/SYSTEMIC

The guardian /social worker of a child with AIDS was repeatedly denied ambulance service for the child by several different companies and called to report the problem. We added this report to our growing file of ambulance and ambulance denials and notified the person that we should be called on if this happened again.

FUNERAL HOMES

Note: During most of the period covered by this report, the Commission's AIDS Discrimination Unit attempted to settle individual complaints of funeral home discrimination on a case by case basis. However, in July of 1986, the Commission charged three funeral homes with AIDS discrimination. These charges were not filed by an individual complainant, but by the Commission itself. They were based on widespread reports of discrimination against people with AIDS by the funeral homes charged.

One of the homes thus charged challenged the Commission's jurisdiction in court. The resulting decision, supported the Commission's jurisdiction to investigate such complaints. It further clarified three points: 1) that funeral homes are covered in the law's prohibition against discrimination in the area of "public accommodation;" 2) that people have rights not only in life, but also in death, and are entitled to be treated with dignity in both states; and 3) that family members and life partners may file complaints of AIDS discrimination on behalf of the deceased, despite the fact that they themselves do not have AIDS.

As a result of this decision and the Commission's continuing vigilance against funeral home discrimination, this problem has been severely curtailed.

NOV 83 FUNERAL HOMES/ACTUAL AIDS/PUBLIC ACCOMMODATION

The Bronx mother of a young woman called. She couldn't find a funeral home to bury her daughter. Every one she called refused to deal with the body when they found out the death was due to complications caused by AIDS. The woman was bereft and did not want to press any charges; she just wanted her daughter "to have a decent burial." We were able to supply her with the names of a few funeral homes that will deal with AIDS-related deaths. We accepted a complaint against the first funeral home the woman contacted, but the woman later refused to pursue it.

MAY 85 FUNERAL HOMES/ACTUAL AIDS/PUBLIC ACCOMMODATION

We received an anonymous call from a woman in Queens. Her husband was near death due to AIDS complications and she was trying to quietly arrange for his burial, because she was terrified that her friends and neighbors would discover the reason her husband had died. She feared that she and her two children would be subjected to the hysteria and discrimination that she had seen on television. Her immediate problem was that she could not find a funeral home that would bury her husband. The only one that was willing to inter the body wanted several thousand additional dollars, money which she just did not have. We interceded and the situation was resolved. Jurisdictional.

JULY 86 FUNERAL HOME/ACTUAL AIDS/PUBLIC ACCOMMODATION

The mother of a man who had recently died due to AIDS complications called to report that a funeral home in Queens was charging her several hundred dollars extra for embalming her son's body and also was requiring her to purchase a special kit that was unnecessary. We contacted the director of the funeral home and the extra charges were dropped and he changed his policy in regard to dealing with bodies that had died due to AIDS complications. Jurisdictional.

AUGUST 86 FUNERAL HOME/ACTUAL AIDS/ PUBLIC ACCOMMODATION

A woman whose 7 year old nephew had died due to AIDS complications called. She had been unable to find a funeral home that would provide both embalming and viewing services. She had finally found one funeral home that had agreed to allow viewing but was requiring the mother to purchase a closed glass casket that costs an extra \$500. We contacted the funeral director and reminded him that the Commission had an agreement with the funeral association that he was part of-- that they would provide full services, including embalming and open casket viewing, to families and friends of people that had died due to AIDS related complications. Jurisdictional.

DEC 86 FUNERAL HOME/PERCEIVED AIDS/PUBLIC ACCOMMODATION

The mother of a man who had recently committed suicide called to complaint of a problem she'd had with a Manhattan funeral home. When her son died, he had been in a hospital. The hospital asked the family if he was gay and they replied that he was. As a "precaution" the hospital put the body in the "contaminated" section of the morgue. When the funeral home came for the remains, they found the body in the contaminated section and assumed that he had AIDS. The funeral director called the mother in and stated that he would not embalm the body. He said he was only willing "to stick him in a plastic bag" and said that he

would not provide an open casket ceremony under any circumstances. We accepted a complaint from the mother. Jurisdictional.

HOSPITALS

JUN 84 HOSPITAL/ACTUAL AIDS/INSURANCE/PUBLIC ACCOMMODATION

We were contacted by a husband and wife who both had AIDS. They stated that their health insurance policy only allowed them to consult certain oncologists and radiologists, all of whom offered them absolutely no treatment. The callers said that the health provider's position was that there is no effective treatment for AIDS and therefore they would not provide treatment, nor would they agree to cover expenses incurred for treatment outside the health care provider's closed network of doctors. CCHR has no jurisdiction over insurance matters and therefore we could not investigate. Instead we made referrals. The couple also reported that, when they were last in the hospital (a private Manhattan hospital) they were treated poorly and had a "constant battle" to have their rooms cleaned and their food trays brought into their rooms, rather than have them left on the floor outside their rooms. We encouraged them to call us should they experience abusive treatment during future hospital stays, since this is a jurisdictional issue and we have found such situations to be easily remedied through advocacy.

SEP 85 HOSPITAL/ACTUAL AIDS/PUBLIC ACCOMMODATION

A Red Cross home attendant called to report the poor treatment one of her clients was receiving in the Brooklyn Hospital to which she had been admitted with a bout of AIDS-related pneumonia. When our caller visited her client in the hospital, she found that she and her roommate, who also had AIDS, had not been cleaned in three days, their beds and clothing had not been changed or cleaned, and food trays were left in the hall. The Red Cross worker was so upset that she cleaned both women herself, made their beds and took their soiled clothing home to wash. She stated that the staff treated them like "lepers" and that when she complained to the administration, she was given "the run around." We called the hospital and they agreed to look into the matter and correct any problems and provide additional training for staff. Jurisdictional.

OCT 86 HOSPITAL/PERCEIVED AIDS/PUBLIC ACCOMMODATION

A woman called the Commission to complain about the behavior of a nurse at the emergency room of a private hospital. She accompanied her sister, who has AIDS, to the emergency room. The nurse who dealt with them asked her sister if she was using

drugs, and then turned to our caller and said "If we took your blood, you'd probably test seropositive, too." We called the hospital and spoke with the Patient Representative. They looked into the matter and the result was that an admonitory note was placed into the nurse's file. Jurisdictional.

SEP 86 HOSPITAL/PERCEIVED AIDS/PUBLIC ACCOMMODATION

A woman who works as a therapist with people who have AIDS called the Commission. She had gone to the eye infirmary of a private NYC hospital to obtain treatment for an eye injury. However, due to the fact that she works with people who have AIDS, she was perceived as having AIDS herself. Consequently she was treated to a battery of AIDS-related tests instead of receiving the treatment she sought. We accepted a complaint on the woman's behalf. Jurisdictional.

OTHER INSTANCES OF PUBLIC ACCOMMODATION DISCRIMINATION

NOV 83 FOSTER CARE/PERCEIVED AIDS/PUBLIC ACCOMMODATION

A woman who died from complications caused by AIDS left behind three small children. A social worker attempted to place the children in foster care, but had been unable to do so because they were perceived by potential care providers to have AIDS. Eventually their grandmother, who was very old, ill and nearly blind, was forced to take them. Jurisdictional, but no complaint was filed.

JAN 84 PUBLIC ACCOMMODATION/PERCEIVED AIDS

A Haitian woman, who is a health care community worker dealing with a Haitian clientele, called to document an incident. She went to the main post office in Brooklyn to mail a package to the AIDS Institute. When she presented the package at the counter, no one would touch it and the clerks refused to wait on her. Even after she spoke with a supervisor, they would not accept the package. She mailed the package from another post office and reported the incident to the Commission.

MAY 85 PSYCHOTHERAPY/PUBLIC ACCOMMODATION/ACTUAL AIDS

The Gay Men's Health Crisis buddy of a woman with AIDS called us about an incident which occurred in a large psychotherapy clinic in Brooklyn where his client had gone seeking treatment for depression related to her AIDS diagnosis. After waiting many months for her Medicaid benefits to clear, the woman went for an intake interview with a social worker. The social worker became

alarmed when she discovered that the woman had AIDS and dismissed her, claiming the clinic was unable to provide therapy for her and suggesting that she "leave by the back exit." When the GMHC buddy attempted to contact the director of the clinic, his calls were refused. He then notified state and city agencies about the incident and, through the combined efforts of several agencies including CCHR, the clinic director agreed to educate his staff about AIDS, acknowledging that there was "widespread trepidation about handling AIDS among staff." The woman no longer felt she could seek therapy at that clinic, however, and therapy was arranged elsewhere. Jurisdictional, but not complaint was filed.

MAY 85 PUBLIC ACCOMMODATION/PERCEIVED AIDS

The daughter of a woman with AIDS had been reporting to a local welfare office to pick up welfare checks to which her mother was entitled. She was told by a case worker that she could no longer come into the center because she might be "contaminated." The Gay Men's Health Crisis intervened on her behalf and the situation was resolved without our involvement. Jurisdictional, but no complaint was necessary.

SEP 84 PERCEIVED AIDS/BIAS

A lesbian tried to give blood at a blood center and was refused "because of AIDS" despite the lack of any logical connection between lesbians and AIDS. We alerted the City's AIDS Education Unit to the situation and the problem was resolved.

JAN 85 PERCEIVED AIDS/PROSTITUTES/BIAS/VIOLENCE

A church worker who deals with prostitutes in the course of her work called because she is concerned about the AIDS backlash which she sees affecting prostitutes, particularly streetworkers, who are vulnerable in their open environment to attacks by others. She said there had been increased arrests, harassment, violence and, consequently, a loss of income for those affected.

JUL 85 PERCEIVED AIDS/PROSTITUTES/BIAS/SYSTEMIC

A research reporter from a major magazine was doing a story on the impact of AIDS on prostitutes when he called the Commission. The prostitutes to whom he had spoken reported growing AIDS-related backlash against them in their personal and professional lives. They expressed frustration that they were being labeled a risk group when they are not, and said they are often the most informed of sexually active adults and are extremely careful about sexually transmitted diseases, including AIDS. They pointed out that condom use was standard practice in the industry long before AIDS and that the exchange of bodily fluids was often

minimal and that in fact they would make "excellent safe sex counselors." We referred the reporter to the AIDS Education Unit of the NYC Department of Health.

FEB 84 SCHOOL/PERCEIVED AIDS/CHILD

The mother of a teenage son, whose stepfather had died of complications caused by AIDS, called. Her son had been subjected to humiliation and abuse after the city-funded Catholic school program he had been attending expelled him because they perceived him to be an "AIDS carrier." Since that time, he became anti-social, depressed and had been arrested on petty charges. Now he was in a facility with "hardened criminals" and she feared she would "lose him". She wanted to sue the city, whom she saw as ultimately responsible. We made appropriate referrals. Not jurisdictional.

APR 85 SCHOOL/PERCEIVED AIDS/CHILDREN

A social worker, whose caseload included a man with AIDS, called to report that two of the man's three stepchildren (all of whom were stated to be "in excellent health") were being kept out of public school. One of the children, an eleven year old, attended a school where the officials discovered that her stepfather has AIDS; they immediately sent her home. The parents were told that she wouldn't be allowed to return because they "can't guarantee the safety of the rest of the children." To make matters worse, an official of the school called the officials of a school which another sibling attended (a ten year old) and alerted them to the health status of the stepfather. The officials at the second school then decided to bar that child from attending. A doctor who is part of the AIDS team which works with the stepfather wrote the schools to state that there is absolutely no reason that the children should not be allowed to attend school. We suggested that all parties contact the AIDS Education Unit of the NYC Department of Health. The social worker informed us that an AIDS Education speaker went to the schools to calm their fears and as a result the children are now back in school.

SEP 86 SCHOOL/PERCEIVED AIDS/HIV/CHILDREN

A woman whose sister recently died of AIDS-related causes called because her sister's sons were asked by the headmaster of their school to take the HIV antibody blood test before they were allowed to return to school. The headmaster was contacted by the Commission and the situation, a jurisdictional one, was resolved.

OCT 86 SCHOOL/PERCEIVED AIDS/DISMISSAL OF CHILD

The mother of a second grader in a private school called the Commission. Her sister had died of AIDS-related causes and the Director of her daughter's school found out. As a result, the child was immediately dismissed from the school. We accepted a complaint from the mother, on behalf of the daughter. The school has challenged the Commission's jurisdiction; however, the Commission found probable cause to credit the allegations of the complaint and the jurisdictional issue will have to be dealt with at a Public Hearing.

MAY 84 INSURANCE/ACTUAL AIDS

A social worker at Kings County Hospital called to report that one of her AIDS patients found that her group insurance policy was refusing to pay for her treatment and attempting to exclude her from coverage due to her diagnosis. Since insurance issues are not considered covered under the Human Rights Law umbrella term of "public accommodation", we referred her to the State Insurance Board, which regulates the insurance industry. No jurisdiction.

DEC 86 UNION/BENEFITS/ACTUAL AIDS

A woman called the Commission because her brother had died due to an AIDS-related condition and his death certificate listed "AIDS" as the cause of death. The problem was that her union would not provide her with the benefits they would provide any member's survivor upon death, because the death was AIDS-related. We spoke with the medical examiner's office and others and finally arranged that the specific opportunistic disease which resulted in his death would be listed on the certificate.



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REPORT OF THE NEW YORK CITY COMMISSION ON HUMAN RIGHTS AIDS DISCRIMINATION UNIT:

AIDS AND PEOPLE OF COLOR:

THE DISCRIMINATORY IMPACT

October 27, 1986

The New York City Commission on Human Rights has been dealing with the AIDS crisis since 1983 when an Hispanic grandmother from the Bronx contacted us. Her daughter had just died due to AIDS complications and had left behind three young children. The grandmother had been unable to find a single funeral home that would arrange a burial for her daughter nor had she been able to find anyone willing to help care for the children--no foster home, home care agency, family or friends would offer assistance. This is only one example of the discrimination brought on by the stigma associated with AIDS.

Most people believe that AIDS is a disease which primarily afflicts white, gay men. This assumption is not only incorrect, but dangerously misleading.

In New York City 53% of all persons with AIDS are Black or

Hispanic.¹ This figure is greater than the 45% population figure for Blacks and Hispanics in New York City. On the national level, the statistical gap is even wider: while Blacks comprise only 12% of the total population, more than 25% of those with AIDS in the United States are Black.² Similarly Hispanics, who comprise only 6% of our national population, represent 14% of all people with AIDS in the United States.³

The results of recent testing for antibodies to HIV (Human Immunodeficiency Virus, formerly known as either HTLV-III or LAV, and generally accepted as the cause of AIDS) among military recruits bolsters the statistically unbalanced picture for Black Americans: more than three times as many Black recruits test positive for HIV antibodies than do white recruits - 3.8 of every thousand Black recruits test positive, compared with only 1.0 out of every thousand white recruits.⁴

¹ New York City Health Department, AIDS Surveillance Update, August 27, 1986. Of the 7426 reported AIDS cases, 2262 (30%) are Black, 1689 (23%) are Hispanic, 3422 (46%) are White and 53 (1%) are Other (Native American, Asian etc.) or of unknown origin.

² Dr. Wayne Greaves, Chief of Infectious Diseases at Howard University Hospital--remarks at "AIDS and the Black Community" conference, July, 1986, Washington D.C. See also: "Where Is AIDS Going?", FOCUS, vol. 1 no. 1, December, 1985, p. 2

³ Id.

⁴ Centers for Disease Control, Morbidity and Mortality Weekly Report, July 4, 1986. Study based on 237,586 White recruits and 55,185 Black recruits from October, 1985 - March, 1986.

At a recent conference entitled "AIDS and the Black Community" sponsored by the National Coalition of Black Lesbians and Gays and partially funded by the Public Health Service, a number of startling statistics were presented. It was reported that, at a Zaire clinic specializing in the treatment of non-AIDS sexually transmitted diseases ("STDs"), to date 40% of the persons seeking medical attention for these non-AIDS related STDs tested positive for the HIV virus.⁵ It has been unofficially estimated that almost 50% of the sexually active adult population of Central Africa will contract the AIDS virus within the next 10 years.⁶ Current medical opinion based on studies done in the United States advises us that between 10-30% of all persons who test HIV positive (i.e. who contract the virus) will develop AIDS or AIDS related Complex (ARC). Thus this is a serious projection indeed.

Second, while the average life span of a white person with AIDS in the United States is two years, the average person of color with AIDS is expected to live only 19 weeks.⁷ Why? This

⁵ Telephone interview with Dr. Primm, Executive Director of Addiction Research and Treatment Cooperation (Brooklyn) and President of the Urban Resource Institute, August 27, 1986. Comments based on his conversation with African medical officials at World AIDS Conference, June, 1986, Paris, France.

⁶ Dr. B. Primm, *id.*; see also: J. Langone, "AIDS Update", *Discover*, September, 1986, which reports, "[a]n estimated 10,000 cases are now occurring every year in the AIDS belt across the continent's [Africa's] midsection, bringing the total to at least 50,000 since 1981..." at p. 32.

⁷ Dr. Wayne Greaves, *supra*,.

disparity is attributable to a number of factors. Because of poverty and lack of education, attributes which apply to a large sector of Black and Hispanic Americans, the vast majority of this population do not seek medical attention until they are acutely ill. Many who are underemployed or unemployed, do not have access to workplace-funded medical insurance and do not have a family doctor, relying instead on hospital emergency rooms for medical care. Consequently, many people of color are neither diagnosed nor treated for AIDS related conditions until the disease has run rampant in their bodies. Hence, an historical problem - the absence of proper medical care for racial and ethnic minorities and the poor - has critical implications in the AIDS epidemic. Furthermore, since heterosexual minorities do not identify themselves as being at risk for AIDS, they are unreached by efforts to educate the public about modes of AIDS transmission. The little information that does arrive in the daily media implies that one is safe if one is not a white, gay male or an intravenous drug user.

While there is still much to be learned, what we do know about AIDS is very important. All the scientific evidence states that AIDS is not spread by casual contact. The Centers for Disease Control have issued guidelines which clearly state that, except in certain well defined instances, caring for, or living or working with a person who has AIDS or who is HIV-positive

presents no health risk.⁸ AIDS is not transmitted by holding hands, sneezing, coughing, or sharing eating utensils or sanitary facilities. We also know how it is spread. AIDS is transmitted through blood (shared needles which have come into contact with HIV-contaminated blood), semen (unsafe sexual practices such as anal and/or vaginal intercourse without a condom), and from pregnant mother to unborn child.

The stigma connected with AIDS has combined with already existing prejudices in our society to produce widespread discrimination against those who have the disease as well as those associated with AIDS in any way. Thus people with AIDS, in addition to coping with a catastrophic illness, often face abandonment by family and friends, the loss of their jobs and health insurance and eviction from their homes. Many are denied needed services such as transportation by ambulance, or emergency medical and emotional care. The range of discrimination suffered by this group is phenomenal.

Additionally, there is an ever growing group of people who do not have AIDS but who are nevertheless targeted for AIDS related discrimination: those who are perceived to be an AIDS "risk". This group includes IV drug users, homosexuals, Haitians, people who test HIV positive and anyone who loves and

⁸ See, "Recommendations Regarding HTLV-III Transmission in the Workplace", Morbidity and Mortality Weekly Report, November 15, 1985.

cares for people with AIDS - the doctors, family members, spouses, lovers, children and friends of a person with AIDS.

To cite just one example of the AIDS backlash on an identifiable group, consider the devastating impact of AIDS related discrimination on Haitians. Despite the fact that Haitians have been removed from the list of AIDS risk groups, the stigmatization remains. Reports from Haitian community workers indicate that in some areas the unemployment rate for Haitians is twice that of other Black workers⁹. Why? Many Haitians feel this situation is directly attributable to AIDS. Particularly hard hit have been domestic workers, who are generally female and often undocumented. Haitian children have been beaten up (and in at least one case, shot) in school; Haitian store owners have gone bankrupt as their businesses failed; and Haitian families have been evicted from their homes. The problem of discrimination against this community is not new, but unfounded fears about AIDS have surely escalated the intensity of prejudice directed against Haitians. The same is true for the various groups now linked with AIDS in the public's consciousness as so called high risk groups (gays, IV drug users, prostitutes, etc.)

In response to the discrimination aspect of the AIDS epidemic, the New York City Commission on Human Rights has created an AIDS Discrimination Unit to provide assistance to

⁹ Leonard A. Eisener, Fair Employment Report (formerly Civil Rights Employment Reporter), December, 1983 at p.206.

persons with AIDS, persons assumed to have AIDS, those who test HIV positive and those who are feared because they are or are perceived to be members of an "at-risk" group. The Commission accepts these complaints under the Human Rights Law's prohibition against discrimination on the basis of physical handicap, in housing, employment and public accommodations. To date the Commission has received over 200 reports of discrimination related to AIDS. Many of these complaints set forth charges of systemic discrimination, for example where a company has a policy of refusing to deliver medical supplies to homebound AIDS patients, or where any employee suspected of having AIDS is immediately terminated. All indications are that AIDS related discrimination is widespread and growing.¹⁰

In New York City, IV drug users constitute the fastest growing percentage of the AIDS population, topping 36% of all metropolitan AIDS cases as of 7/30/86.¹¹ While drug users come in a wide variety of racial, ethnic, sexual and economic groups, it is unquestionable that Blacks and Hispanics comprise a

¹⁰ See: New York City Commission on Human Rights, Report on AIDS Discrimination, April, 1986 for summaries of cases.

¹¹ AIDS Surveillance Report, op. cit., shows that IV drug users comprised 32.4% of the first 2000 reported AIDS cases in New York City but grew to 36.8% of the last 2000 cases. See also, FOCUS, op. cit., reporting that in New York City the proportion of IV drug-related AIDS cases increased from 18% in 1981 to 33% in 1985.

disproportionately large percentage of IV drug users with AIDS.¹² In New York City today, IV drug users seeking entrance to a live-in therapeutic community, on the average must face a six month waiting list for admission.¹³ Complicating matters, some of these treatment centers refuse to accept persons with AIDS or ARC into their programs. Reports have come to the Commission that some drug treatment programs require potential residents to "prove" they do not have AIDS by testing HIV negative.

This group has few advocates, and little in the way of educational outreach tried thus far has proven successful. Because there is a high rate of illiteracy among drug users, audio/visual educational materials, street theatre and peer outreach efforts by former addicts need to be pursued in hopes of creating an effective means by which to educate this group about the risks of HIV transmission. It is not a simple task. The sexual partners of IV drug users (or partners of former users who even occasionally shared needles) must also be reached. The

¹² H.M. Ginzburg, Public Health Reports, April-May, 1984, study found that nearly 40% of the IV drug users with AIDS are Black. The August 18, 1986 New York City Health Department AIDS Surveillance Report shows that of the 2581 IV drug user AIDS cases in New York City, 912 (35%) are Hispanics.

¹³ Byron, "Women with AIDS," The Village Voice, September 24, 1985, p. 19. In a telephone conversation on September 4, 1986, Daniel Gallagher, Coordinator of Specialized Services, New York State Division of Substance Abuse Services, stated that although there are over 200 drug treatment programs in New York City, the average wait for entry into an in-patient (residential) treatment program is 4-6 months. A telephone call to Beth Israel Medical Center revealed that they run 23 outpatient drug treatment programs; however, the average wait for admission is one year.

message? Don't share needles, and use condoms when having sex or abstain from unsafe sexual practices.

Information about AIDS has reached some segments of the IV drug-using population. An unfortunate side effect of this information may be the growing use of CRACK. Reliance upon this dangerous but non-intravenous drug may well be that community's response to the fear of HIV transmission through shared needles. Drug dealers, capitalizing on the fear of AIDS, reportedly tout CRACK as the no-needle alternative (information to keep in mind when developing AIDS related or anti-CRACK educational materials).

Women also remain critically uninformed about AIDS. As of August 18, 1986, women constituted 10% (728) of the reported AIDS cases in New York City.¹⁴ Out of this total, 84% are women of color. While 55% of these women state that they have used IV drugs, 20% contracted AIDS through sexual activity with a partner in a risk group. Nationally the number of cases of women with AIDS reported to the Centers for Disease Control more than quadrupled from 280 in May of 1984 to 1,475 as of July 1986.¹⁵ It is projected that by 1991 AIDS will be the largest killer of women of childbearing age in New York City.

¹⁴ New York City Health Department, AIDS Surveillance Update, August 18, 1986.

¹⁵ C. Norwood, op. cit. at 49.

Unfortunately, it is virtually impossible for a woman to determine if her male sexual partner is in a risk group or is HIV positive. The stigma of a man's admission that he has engaged in homosexual activity and the difficulty in determining if a sexual partner has been an occasional IV drug user serve to make risk factor identification elusive. Therefore, use of condoms as a precaution is imperative for heterosexually active women. In addition, many men (recovered drug users, infrequent participants in homosexual activities, blood transfusion recipients, etc.) may truly be unaware that they are HIV carriers since it is currently estimated that 70-90% of those infected with HIV will not manifest any AIDS related diseases.¹⁶

Historically, women have often been blamed for the spread of sexually transmitted diseases.¹⁷ Both the media and leading researchers improperly lump together discussions of sexually active women, prostitutes and IV drug users - as though all sexually active women were prostitutes, all prostitutes were IV drug users, and all IV drug using women were prostitutes.¹⁸ Race and sex stereotyping about drug users, prostitutes, sexually active women and poor women only compounds the problem.

¹⁶ C. Langone, op. cit. at 29, reporting that the Centers for Disease Control (CDC) has estimated that 1-1.5 million people in the U.S. are infected with HIV but only 10-30% are likely to get AIDS.

¹⁷ Allan M. Brandt, No Magic Bullet: A Social History of Venereal Disease in the United States Since 1880, Oxford University Press, 1985.

¹⁸ For further discussion see: P. Maher and A. Tallmer, "The Typhoid Mary Debate", The Connection, September 2, 1985, p. 26.

Women in need of medical care are highly vulnerable to abuse, and issues of confidentiality and informed consent become quite serious. Women of color and poor women in general are subject to situations with far reaching complications when seeking medical help or prenatal care. It has been alleged that some of these women are routinely screened for HIV antibodies with neither their knowledge nor their consent. And talk of the mandatory sterilization of the HIV-positive women thus identified has made the rounds of "health committees" nationwide. Though no studies have been completed, if some researchers are correct, HIV positive women face an additional risk - if they become pregnant, the possibility that they could develop AIDS may increase.

The high rate of teenage pregnancy among minorities is irrefutable.¹⁹ This has tremendous implications regarding the spread of AIDS. Even if these young women use birth control methods such as the pill or a diaphragm and thus feel "safe" they remain at great risk for contracting AIDS. The HIV virus is

¹⁹ According to the New York City Health Department, there were 13,339 live births to young women under the age of 20 in 1984. Of this number, approximately 32% were born to Puerto Rican mothers and 56% were born to "non-white" (Black and Asian) mothers.

definitely known to spread through vaginal intercourse.²⁰ Use of condoms must be encouraged; AIDS education aimed at this segment of the population must be avidly undertaken. The virus is not willing to wait for the community's timely response; it is spreading now. To fail to address these issues is to see our children or our children's children die prematurely from the horrors of AIDS.

As AIDS spreads in the adult population, the impact on our next generation is already apparent. Between June 1981 and June 1986, 292 cases of children with AIDS (ages 0-12) were reported to the National Centers for Disease Control. Of this number 81% are Black or Hispanic (176 [60%] Black, 61 [21%] Hispanic). In New York City there are 139 children with AIDS - 92% are Black or Hispanic.²¹ Current estimates by the NYC Department of Health show that in 1986 alone, approximately 500 children will be born with HIV virus.

Some of these children will develop AIDS and die in infancy, but most will not. Problems abound for the child who is seen by

²⁰ C. Norwood, "AIDS Goes Straight", Us Magazine, August 25, 1986, p. 47, reporting that studies from the U.S., Europe, Africa and Haiti all confirm that AIDS can be spread by vaginal intercourse. Between 40-60% of wives or other long-term female sexual partners of men with AIDS have become infected with the HIV virus. The August 18, 1986 New York City Health Department's AIDS Surveillance Update reports that 151 females--representing 21% of the 728 women with AIDS in New York City--contracted the disease through sexual intercourse with male partners with AIDS.

²¹ New York City Health Department, AIDS Surveillance Update, August 18, 1986.

others as an AIDS risk. The Commission has received reports that even the healthy children of people with AIDS were denied housing, expelled from school and refused public services. What will become of children with AIDS or with the HIV virus? Will they be able to obtain foster care? Schooling? Day care? Or will unchecked fears of AIDS foster quarantine, tatoos and new leper colonies for this vulnerable segment of our society?

The vast majority of prison inmates are racial and ethnic minorities and 60% of the inmates in NY State prison facilities acknowledge a history of IV drug use.²² Here too AIDS is spreading at an alarming rate,²³ as these men and women have sexual relations and use IV drugs while incarcerated. In addition many inmates have spouses who, through conjugal visits and sexual relations after prisoners are released, are directly affected and placed at risk of contracting AIDS. While the Commission in no way advises against conjugal visits, it is obvious that prisoners and those who may be sexually active with prisoners must receive education about AIDS transmission and be encouraged to take appropriate precautions (e.g., insistence upon use of condoms).

²² According to the Director of Public Information at the New York State Department of Corrections, there are 38,000 inmates in New York State prison facilities. 51% are Black, 27% are Hispanic, and 22% are White and other.

²³ In 1985 there were approximately 30+ inmates with AIDS of any given time, while in 1986 that number has jumped to 50+ inmates with AIDS. Steven Del Giacco, Public Information Officer at the New York State Department of Corrections reports that in the New York State and City prisons and jails and the county jails there were 23 inmate deaths from AIDS in 1983, 68 AIDS related deaths in 1984 and 107 AIDS related deaths in 1985.

Of the 4,184 homosexually or bisexually active men who have been diagnosed with AIDS in New York City, 32% (1,339) are racial minorities, primarily Black and Hispanic. The continued assertion that AIDS only affects gay white men and other efforts to ignore the existence and needs of Black, Hispanic and Asian homosexuals--by the gay community as well as the Black, Hispanic and Asian communities--reinforces racial and sexual stereotypes. The AIDS statistics prove that these men do exist and, more urgently, that their needs are not being addressed.

Fears about sex, death and disease are deeply ingrained in our society. These fears readily combine with pre-existing prejudices about racial and ethnic minorities, homosexuals, immigrants, women and drug users. The resultant brew can be summed up in one sentence: AIDS does not discriminate, but people do. People with AIDS have been thrown out of their homes,²⁴ seen their healthy children barred from entering schools and obtaining day care services, lost their jobs, been denied ambulance service and essential medical attention, and been denied access to places of public accommodation, such as restaurants, stores, bars, hospitals and clinics.

²⁴ P. Souder, J. Smith and S. Altman, AIDS Shelter Project Final Report, January 15, 1986, concluded that there is a need for 644 units of housing for persons with AIDS in 1986 and that this need will rise to 2400 units of housing by 1990. The study also found that on any given day there are approximately 660 homeless people with AIDS in New York City. This situation is in large part a reflection of discrimination: when people with AIDS are denied access to nursing homes or evicted from their homes, they are left with nowhere to go.

It has been estimated that by 1991 there will be over 270,000 cases of AIDS nationally, resulting in 179,000 deaths. In New York City not only is AIDS the current leading cause of death for males aged 30-44, it is also the second leading cause of death for females aged 30-34.²⁵ Health officials, charting the progressive course of the disease, have predicted that there will be 40,000 AIDS cases within New York City by 1991 and that 30,000 of these people will die.²⁶ The majority of those who die in this manner will be men, women and children of color.

Prejudice against racial and ethnic minorities ("they're all on welfare"), homosexuals ("they're only fags"), immigrants ("they're taking our jobs away"), sexually active women ("she's a whore and deserves what she gets") and drug users ("they're nothing but junkies anyway") interferes with our ability to respond to AIDS as a health crisis. As the wife of one man with AIDS noted, "...the labeling of this disease [into risk group categories] has got to stop. When we're labeled, we're no longer people."²⁷ This stigmatization of AIDS as "their" disease diverts our attention away from the very real social, economic, discrimination and health issues which affect all of us.

²⁵ A. Kristal, "The Impact of AIDS in Patterns of Premature Death in New York City", 255 Journal of the American Medical Association, 2306 (1986).

²⁶ New York City Health Commissioner Dr. Stephen Joseph, as quoted in K. Altman, "40,000 AIDS cases seen in City by 1991", New York Times, July 31, 1986, p. A13.

²⁷ C. Norwood, op. cit. at 49.

Education combined with aggressive enforcement of our civil rights laws is an effective weapon against prejudice and discrimination. And knowing that we may ourselves be at risk for AIDS is a step toward prevention of the disease. Don't let anyone convince you that AIDS is someone else's problem. To support this myth is to assure the continued spread of AIDS and the HIV virus, while fueling the growing backlash against women and racial, ethnic and sexual minorities.

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Note: Copies of "NYC Commission on Human Rights Report on Discrimination Against People With AIDS, November 1983 - April 1986", are available upon request. This report details all accounts of AIDS and AIDS related discrimination reported to the Commission, and includes an analysis of the trends and special circumstances surrounding AIDS discrimination.



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THE AIDS DISCRIMINATION DIVISION
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NEW YORK CITY COMMISSION ON HUMAN RIGHTS

UPDATED REPORT

AIDS AND PEOPLE OF COLOR:
THE DISCRIMINATORY IMPACT

August, 1987

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Mayor

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Commissioner/Chairperson

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First Deputy Commissioner

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AIDS and People of Color: The Discriminatory Impact was first written in the summer of 1986. In part it was a reaction to the wealth of information and multiple issues raised at the "AIDS and the Black Community" conference held in Washington, D.C. in July, 1986 (a joint effort of the Public Health Service and the National Coalition of Black Lesbians and Gays). In the last year many others have written on the subject. This updated report attempts to incorporate new information on the topic.

AIDS continues to touch the lives of so many of us and continues to have a disproportionate impact on people of color. For this reason, the AIDS Discrimination Unit of the New York City Commission on Human Rights believes that the focus on AIDS and the minority communities must continue to be a priority.

There is indeed a second epidemic: it is one of fear, prejudice and discrimination. A grasp of the basic human rights issues permeating this epidemic is imperative if effective, culturally sensitive policy and educational materials are to be developed.

People of color, already burdened by a history of racism and economic disparity, have borne a tremendous share of the AIDS crisis. In the U.S., this has largely been due to the tragic inroads drug addiction has made into some, often poorer, minority communities. Drugs have been shown to be a symptom of the effects of urban poverty and oppression. This helps us to understand the higher incidence of intravenous drug use within

some Black and Hispanic¹ communities. But, as with most modes of HIV transmission, it is behavior - in this case the needle-sharing associated with intravenous drug use - **not one's race or ethnicity**, that is the operative risk factor. Unfortunately, people of color have at times suffered both indifference and stigmatization during the AIDS epidemic (e.g. as the "invisible" component of the gay community, or as the Afro-American or Haitian labelled "AIDS carrier" in the media).

The issues, like the communities of people affected by AIDS, overlap. To enable the reader to obtain a clear understanding of the many separate, yet related aspects of the second epidemic of fear and prejudice, this report is broken into the following categories: women; IV drug users; prisoners; men who have sex with men; testing and stigma; children; and future projections. Human rights advocates and public health officials must meet the challenge of integrating these sometimes divergent concerns and communities in order to develop an effective response to AIDS and AIDS-related discrimination.

¹ For purposes of this report, the term Hispanic is being used to apply to Latino/a, Chicano/a and other Spanish-speaking communities.

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Introduction

The New York City Commission on Human Rights has been dealing with the AIDS crisis since 1983 when an Hispanic grandmother contacted the Commission. Her daughter had just died due to AIDS complications and had left behind several young children. The grandmother had been unable to find a single funeral home that would arrange a burial for her daughter nor had she been able to find anyone willing to help care for the children--no foster home, home care agency, family or friends would offer assistance. This is only one example of the discrimination brought on by the stigma associated with AIDS.

Many people continue to believe that AIDS is a disease which primarily afflicts white, gay men. This assumption is not only incorrect, but dangerously misleading.

In New York City, 55% of all persons with AIDS are Black or Hispanic.² This figure is greater than the 44% population figure for Blacks and Hispanics living in New York City.³ On the national level, the statistical gap is even wider: while Blacks comprise only 12% of the total population, more than 24%

² New York City Health Department, AIDS Surveillance Update, June 24, 1987. Of the 10589 reported AIDS cases, 3297 (31%) are Black, 2534 (24%) are Hispanic, 4694 (44%) are White and 64 (1%) are Other (Native American, Asian etc.) or of unknown origin.

³ Information from the 1980 census, New York City Health Department.

of those with AIDS in the United States are Black.⁴ Similarly Hispanics, who comprise only 6% of our national population, represent 14% of all people with AIDS in the United States.⁵

The results of recent testing for antibodies to HIV (Human Immunodeficiency Virus, formerly known as either HTLV-III or LAV, and generally accepted as at least a primary cause of AIDS) among applicants for military service reflect the disproportionate impact on Black Americans: more than three times as many Black applicants test positive for HIV antibodies than do white applicants - 3.9 of every thousand Black male and female applicants test positive, compared with only 0.9 out of every thousand white male and female applicants.⁶

Also startling are statistics that indicate that while the average life-span of a white person with AIDS in the United States is 18-24 months, the average person of color with AIDS is

⁴ Centers for Disease Control, AIDS Weekly Surveillance Report, United States AIDS Program, Center for Infectious Diseases, July 6, 1987. See also: R. Selik, et.al., "Relative Risks of AIDS for American Blacks and Hispanics," TP.88, poster presentation at Third International Conference on AIDS, June 1-5, 1987, Washington, D.C., see also: "Acquired Immune Deficiency Syndrome among Blacks and Hispanics--United States," Morbidity and Mortality Weekly Report, Vol. 35, No. 42, October 24, 1986.

⁵ Id.

⁶ D. Burke, et. al., "Human Immunodeficiency Virus Infections among Civilian Applicants for United States Military Service, October, 1985 to March, 1986," The New England Journal of Medicine, Vol. 317, No. 3, p.131, July 16, 1987. Study based on 306,061 recruits screened. See also: "Trends in Human Immunodeficiency Virus Infection Among Civilian Applicants for Military Service -- United States, October 1985-December 1986," Morbidity and Mortality Weekly Report, Vol. 36, No. 18, May 15, 1987.

expected to live only seven months.⁷ Why? This disparity is attributable to a number of factors. It has been suggested that Kaposi's Sarcoma, which strikes White people with AIDS much more frequently than Black and Hispanic persons with AIDS, and carries with it a more optimistic prognosis, accounts for some of the difference in life spans.

Another factor affecting the lifespans of these different groups may revolve around the higher percentage of intravenous drug users within the group of Black and Hispanic persons with AIDS. IV drug users may tend to put off seeking medical help longer than others. There are also sociological factors involved. One factor is that more Black and Hispanic persons are unemployed or underemployed than Whites. People in this situation may not have access to workplace-funded medical insurance. There may be no family doctor and people in such a situation may thus have to rely on hospital emergency rooms for medical care. Consequently many people of color are, for a variety of reasons, neither diagnosed nor treated for AIDS-related conditions until the disease reaches an advanced stage. Hence, an historical problem - the absence of proper medical care for racial and ethnic minorities and the poor - has critical implications in the AIDS epidemic.

⁷ Conversation of July 28, 1987, with Dr. Wayne Greaves, Chief of Infectious Diseases, Howard University Hospital.

Stigma and Designated Risk Groups

The stigma connected with AIDS has combined with already existing prejudices in our society to produce widespread discrimination against those who have the disease as well as those associated with AIDS in any way. Thus people with AIDS, in addition to coping with a catastrophic illness, often face abandonment by family and friends, the loss of their jobs and health insurance and eviction from their homes. Many are denied critical services such as transportation by ambulance, or emergency medical and emotional care. The range of discrimination suffered by this group is phenomenal.

Additionally, there is an ever growing group of people who do not have AIDS but who are nevertheless targeted for AIDS-related discrimination: those who are perceived to be "AIDS risks". This group includes IV drug users, homosexuals, prostitutes, Haitians, homeless men and women, the poor, racial and ethnic minorities, people who test HIV positive and anyone who loves and cares for people with AIDS - family members, health care workers, spouses, lovers, children and friends of the person with AIDS.

Initially, persons whose behavior put them at a risk for HIV infection were categorized on the basis of "risk group" rather than "risk behavior." Unfortunately risk definition based upon identity has caused confusion and discrimination. Persons who do not identify themselves as members of a "risk group" (i.e., men who participate in sexual activity with other men but do not identify as gay or homosexual, recovered IV drug users,

transfusion recipients, women who are infrequent participants in sexual activity with men, etc.) may not realize their past or intermittent behavior put them at risk of HIV infection and so may not respond to educational efforts or follow risk reduction guidelines. The World Health Organization and the New York City Health Department have revised their risk categories to more precisely reflect risk **behavior**. Unfortunately, the media has not responded accordingly. The original "risk group" categorization has led to stigmatization of those who either are members of or are perceived to be part of these "groups" (homosexuals, Haitians, prostitutes, etc.).

Too often in discussions of public policy related to AIDS, we hear that human rights and public health are in conflict. This creates a false dichotomy. In the midst of something as dire as an epidemic, drastic public health measures may be necessary. But where fundamental constitutional rights are at stake (liberty, freedom from unlawful searches [blood tests], privacy), public policies that intrude upon these rights must be shown to be sound (meaning that they are necessary to serve "compelling" governmental interests).⁸ Given the nature of the AIDS epidemic, good public health policy must consider civil

⁸ Public health measures may also be subject to constitutional challenge if they can be shown to be irrational. The key is whether the proposed policy actually does (or will) protect public health or safety. See generally: Closen, Connor, Kaufman and Wojcik, "AIDS: Testing Democracy", 19 John Marshall Law Review, 837, 892 (Summer, 1986); Merritt, "The Constitutional Balance Between Health and Liberty", AIDS: Public Health and Civil Liberties, A Hastings Center Report Special Supplement, December, 1986.

rights because the epidemic will be driven further underground if we don't protect these rights. Where widespread stigmatization and discrimination exist, all people, and especially those we most want to reach, are understandably reluctant to seek needed information, diagnosis and treatment. Public health officials, including Surgeon General Koop, have noted that the stigma and discrimination associated with AIDS are among the biggest impediments to implementation of an effective public health program to combat AIDS and HIV transmission. Public health and civil rights are natural and necessary allies in the fight against AIDS.

IV Drug Users

In New York City, IV drug users constitute 30% of all adult metropolitan AIDS cases as of June 24, 1987.⁹ (An additional 5% of adult metropolitan AIDS cases were men who both used IV drugs and had unprotected sex with other men.)¹⁰ While drug users come in a variety of racial, ethnic, sexual and economic groups, it is known that Blacks and Hispanics comprise a large percentage of IV drug users with AIDS. Current statistics indicate that 81% of all IV drug users with AIDS in the United States are Black or

⁹ NY City Health Department, AIDS Surveillance Update, June 24, 1987.

¹⁰ Id.

Hispanic.¹¹

New data suggests that the current case definition of AIDS used by the Federal Centers for Disease Control may not accurately reflect the prevalence of HIV infection among IV drug users.¹² Since 1981, IV drug user deaths in New York City have increased dramatically--an average of 30% each year.¹³ The New York City Health Department has conducted several investigations to study this trend and they have concluded that the increase in mortality among IV drug users is caused by HIV-related disease which does not qualify as AIDS under the CDC definition. They believe these severe manifestations of HIV infection are underestimated among IV drug users by a factor of 50 to 100%.¹⁴

¹¹ Centers for Disease Control, AIDS Weekly Surveillance Report, United States AIDS Program, Center for Infectious Diseases, July 6, 1987. Of the 6164 cases reported among IV drug users, 3126 (51%) are Black and 1827 (30%) are Hispanic.

¹² B. Truman, et. al., New York State Dept. of Health, "Surveillance for HIV-related disease that does not meet the CDC AIDS Case Definition: Upstate New York," WP.61, poster presentation at Third International Conference on AIDS. See also: S. Weiss, et. al., "Mortality, AIDS Incidence and Immunologic Abnormalities Among Intravenous Drug Abusers (IVDA) in New York City (NYC): A 5-Year Prospective Study," TP.87, poster presentation at Third International Conference on AIDS.

¹³ Joint Subcommittee on AIDS in the Criminal Justice System of the Committee on Corrections and Committee on Criminal Justice Operations and Budget of the Association of the Bar of New York, AIDS AND THE CRIMINAL JUSTICE SYSTEM: A PRELIMINARY REPORT AND RECOMMENDATIONS, June 12, 1987, pp. 8-9; See also, NYC Dept. of Health, "Increasing Mortality in Intravenous Drug Users: Its Relationship to the AIDS Epidemic in New York City", 5 City Health Information No. 13, 2-3 (Special AIDS Issue No. 4, August 13-27, 1986).

¹⁴ Conversation with Dr. Rand Stoneburner, New York City Health Department, July 30, 1987. See also: AIDS AND THE CRIMINAL JUSTICE SYSTEM: A PRELIMINARY REPORT AND RECOMMENDATIONS, op. cit.

Classification becomes an issue when attempting to obtain many social service benefits. In order to qualify for accelerated SSI and Medicaid payments, for example, individuals who are ill with HIV-related infections must meet the CDC case definition of AIDS. If an individual does not meet the CDC case definition of AIDS, he or she may wait up to two years to qualify for and obtain benefits. It is unlikely that a person who is too ill to work due to HIV-related illness will live through the waiting period.

There are an estimated 250,000 IV drug users in New York State, 200,000 of whom live in the New York City metropolitan area.¹⁵ Although there are over 200 drug treatment programs in New York City,¹⁶ the New York State Division of Substance Abuse Services reports there are 1,724 persons on the waiting list for residential, drug-free (non-methadone) treatment programs. There are 353 persons on the waiting list for methadone maintenance programs.¹⁷ IV drug users seeking treatment in NYC may wait from

¹⁵ Id. at 5.

¹⁶ Telephone conversation, July 23, 1987, with Alan Kott, Assistant Deputy Director of Substance Abuse and Evaluation, New York State Division of Substance Abuse Services.

¹⁷ Id.

three weeks to six months before admission.¹⁸ Complicating matters, some of these treatment centers refuse to accept into their programs persons with AIDS or ARC or those who test HIV positive. Reports have come to the Commission that some drug treatment programs require potential residents to "prove" they do not have AIDS by testing HIV negative.

Women

AIDS is also a women's issue. It has a particularly devastating impact on women who have the disease themselves or who have children or other family members who have AIDS or live in communities beset by the disease, and who care for the people who are sick with the manifestations of HIV infection.

Women are most often the caretakers of the family and of the sick. Consequently, when a woman becomes ill or dies, particularly in poverty-stricken communities where women are often the economic base as well, the whole fabric of family and extended community can be shaken. Volunteerism is increasingly seen as the answer to the escalating cost of caring for those

¹⁸ In a telephone conversation on July 27, 1987, Bill Griffin, Regional Supervisor, Contract Management, NY State Division of Substance Abuse Services, stated that the average wait for entrance to a residential drug-free program was three weeks. In a telephone conversation on July 23, 1987, John Kemp, Director of New York State Division of Substance Abuse Services Brief Therapy Center, stated that in his personal experience, the waiting time for treatment in New York City varies from several weeks to three months or more. A telephone call to Beth Israel Medical Center revealed that they run 23 outpatient drug treatment programs. The wait for treatment in some of the programs is three to six months. (Telephone conversation with Frank King, Intake Coordinator, July, 1987)

with AIDS and ARC. However, the enormous burden this illness already places on those communities with the least support and resources to handle such a crisis must be recognized.

Women also remain critically uninformed about how to protect themselves from AIDS. As of June 24, 1987, women constituted 10.4% (1096) of the reported AIDS cases in New York City.¹⁹ Out of this total, 84% are women of color.²⁰ While 61% of these women state that they have used IV drugs, 22% contracted AIDS through sexual activity with a partner who was infected with the HIV virus (generally through IV drug use).²¹ Nationally the number of cases of women with AIDS reported to the Centers for Disease Control has increased more than fifteenfold from 162 in the end of 1983,²² to 2569 as of July, 1987.²³ It is projected that by 1991 AIDS will be the largest killer of women of childbearing age in New York City. According to the Centers for Disease Control, because of IV drug use and the incidence of HIV infection within some Black communities, statistically a Black woman is 13 times more likely to have AIDS than a White woman.

¹⁹ New York City Health Department, AIDS Surveillance Update, June 24, 1987.

²⁰ Id. This number includes: 560 Black women (51%), 352 Hispanic women (32%), and 4 women (1%) whose race is other or unknown.

²¹ Id.

²² Guinan and Hardy, "Epidemiology of AIDS in Women in the United States, 1981 Through 1986," Journal of the American Medical Association, Vol. 257, No. 15, pp.2039, 2040, April 17, 1987.

²³ AIDS Weekly Surveillance Report, op. cit.

For the same reasons (incidence of HIV infection within communities hard hit by intravenous drug use) an Hispanic woman is 11 times more likely to have AIDS than a White woman.²⁴

Unfortunately, it is difficult for a woman to determine if her male sexual partner is at risk or is HIV positive. The stigma of a man's admission that he is bisexual or has engaged in homosexual activity and the difficulty in determining if a sexual partner has been an occasional IV drug user serve to make risk factor identification elusive. Therefore use of condoms as a precaution is imperative for women whose partners may be at risk. In addition, many men (recovered drug users, infrequent participants in homosexual activities, blood transfusion recipients, etc.) may truly be unaware that they are HIV carriers since the majority of such persons may remain without symptoms of AIDS-related illness for months or years after infection.²⁵

Historically, women have often been blamed for the spread of sexually transmitted diseases.²⁶ Both the media and leading researchers improperly lump together discussions of sexually

²⁴ "Acquired Immune Deficiency Syndrome (AIDS) among Blacks and Hispanics--United States," Morbidity and Mortality Weekly Report, Vol. 35, No. 42, October 24, 1986. See also: Richard Goldstein, "AIDS and Race," Village Voice, Vol. XXXII, No. 10, March 10, 1987, p. 23.

²⁵See: "Provisional Public Health Service Inter-Agency Recommendations for Screening Donated Blood and Plasma for Antibody to the Virus Causing Acquired Immunodeficiency Syndrome," Morbidity and Mortality Weekly Report, Vol. 34, No. 5, **, 1985.

²⁶ Allan M. Brandt, No Magic Bullet: A Social History of Venereal Disease in the United States Since 1880, Oxford University Press, 1985.

active women, prostitutes and IV drug users -- as though all sexually active women are prostitutes, and all prostitutes are IV drug users. Race or sex stereotyping about drug users, prostitutes, sexually active women and poor women only compounds the problem.²⁷

Women in need of medical care or information regarding reproductive care are highly vulnerable to abuse, and issues of informed choice, confidentiality and informed consent at such a time become quite serious. Women of color and poor women in general are subject to situations with far reaching complications when seeking medical help or prenatal care. It has been alleged that in certain parts of the country women are routinely screened for HIV antibodies with neither their knowledge nor their consent. Talk of the mandatory sterilization of, or abortions for, the seropositive women thus identified has made the rounds of "health committees" nationwide. These recurring indications of disregard for the rights of women are quite alarming.

²⁷ For further discussion see: P. Alexander, "Prostitutes are being Scapegoated for Heterosexual AIDS", Sex Work, Cleis Press (1987), p.248; P. Maher and A. Tallmer, "The Typhoid Mary Debate", The Connection, September 2, 1985, p. 26. These articles point out that undue attention has been placed on prostitutes (sex industry workers) as a "risk group" for AIDS. At least in the U.S., this focus is misleading and stigmatizing. In almost all instances where a woman who had worked as a prostitute tests antibody positive, she has reported a recent history of intravenous drug use. Prostitutes that do not use intravenous drugs (estimated to be the vast majority [85-90%]) do not appear to be testing HIV antibody positive at a rate higher than other sexually active women. Interestingly, many studies indicate that most prostitutes routinely use condoms (and have for years) for all sexual contacts with customers. Intravenous drug use, certainly a significant risk behavior, is often eclipsed. Instead, the emphasis is inappropriately placed on prostitution.

Teenagers and Children

The high rates of pregnancy and sexually transmitted diseases among minority teenagers are irrefutable.²⁸ This has tremendous implications regarding the spread of AIDS. Even if these young women use birth control methods such as the pill or a diaphragm and thus feel "safe" they remain at risk for sexually transmitted diseases, including AIDS. Because the HIV virus is definitely known to spread to women through vaginal and anal intercourse, generalized use of condoms must be encouraged.²⁹ AIDS education aimed at young men and women has been undertaken by both the City and community groups; but it is likely that even greater efforts must be undertaken. The HIV virus is not willing to wait for the community's timely response; it is spreading now. In New York City today, AIDS is the fourth leading cause of death for young women from ages 15-24.³⁰ To fail to address these issues is to ensure that more children and teenagers will become infected and die of AIDS-related causes.

28 According to the New York City Health Department, there were 13,168 live births to young women under the age of 20 in 1986. Of this number, 6251 (47.5%) were Black, 5269 (40%) were Hispanic, 1504 (11.4%) were White and 144 (1%) were American Indian, Chinese, Filipino or "other non-white."

29 C. Everett Koop, Surgeon General's Report on Acquired Immune Deficiency Syndrome, October, 1986. See also: Constance Wofsy, Editorial, "Human Immunodeficiency Virus in Women," Journal of the American Medical Association, Vol. 257, No. 15, pp. 2074, 2076.

30 Telephone conversation with Dr. Singh, (July, 1987) New York City Health Department, Bureau of Health and Statistics Analysis.

As AIDS spreads in the adult population, the impact on our next generation is already apparent. Between June 1981 and July, 1987, 525 cases of children with AIDS (ages 0-12) were reported to the National Centers for Disease Control. Of this number 414 (79%) are children of color.³¹ In New York City there are 187 children known to have AIDS - 90% are Black or Hispanic.³² NYC Department of Health estimates indicate that in 1987 alone, approximately 1200 children may be born with HIV infection.³³ According to Centers for Disease Control figures, a Black child is 15 times more likely to be born with AIDS than a White child and an Hispanic child is 9 times more likely to be born with AIDS than a White child.³⁴

Some of these children will develop AIDS and die in infancy, but most will not. Problems abound for the child who is seen by others as an AIDS risk. The Commission has received reports that even the healthy children of people with AIDS were denied housing, expelled from school and refused public services. What will become of children with AIDS or children who have the HIV virus? Will they be able to obtain foster care? Finding foster

³¹ 280 (53%) are Black; 130 (25%) are Hispanic; and 4 (1%) are other or unknown. AIDS Weekly Surveillance Report, op.cit., July 6, 1987

³² 107 (57%) are Black; 62 (33%) are Hispanic; and 18 (10%) are White. New York City Health Department, AIDS Surveillance Update, June 24, 1987.

³³ Conversation with Dr. Polly Thomas, New York City Dep't of Health, August 4, 1987.

³⁴ "Acquired Immune Deficiency Syndrome (AIDS) Among Blacks and Hispanics--United States," Morbidity and Mortality Weekly Report, Vol. 35, No. 42, October 24, 1986.

care for any child is a difficult task; it is much more difficult for the child with AIDS. And what of schooling?³⁵ Will the City be able to continue to check the public's fears or will AIDS panic go on to foster quarantine, tattoos and confinement for this vulnerable segment of society?

The recent fire-bombing of a proposed home for "boarder babies" in New York's Queens County suggests that AIDS fear and racial bias may represent a growing problem in some communities. In New York City many children with AIDS, though not acutely ill, spend extended periods of time, in some cases their whole lives, in hospitals. Some are still too ill to go home, others have no home because their parents have died from AIDS. It has proven almost impossible to find foster placement for HIV-infected children.

Prisoners

The vast majority of prison inmates are racial and ethnic minorities and 60% of the inmates in New York State prison facilities acknowledge a history of IV drug use.³⁶ As of January 15, 1987, AIDS was the leading cause of death in New York State

³⁵ The City of New York successfully defended the rights of children with AIDS to attend public school. District 27 Community School Board v. Board of Education, 130 Misc. 2d 398, 502 N.Y.S. 2d 325 (Queens Co. 1986).

³⁶ According Steven Del Giacco, Public Information Director at the New York State Commission of Corrections, there are 40,000 inmates in New York State prison facilities. As of September, 1986, 50% are Black, 28% are Hispanic, and 22% are White and other. (Conversation of July, 1987)

prison facilities, causing more than 50% of the deaths.³⁷ Here too the HIV virus may be spreading³⁸ as these men and women have sexual relations and use IV drugs while incarcerated. In addition many inmates have spouses who, through conjugal visits or sexual relations after prisoners are released, are directly affected and placed at risk of contracting AIDS. While the Commission in no way advises against conjugal visits, it is obvious that prisoners and those who may be sexually active with prisoners must receive education about AIDS transmission and have access to condoms. NYC's Health Commissioner, Dr. Stephen Joseph, in an effort to stem the tide of HIV transmission within the prison system, has publicly called for the distribution of condoms to prisoners.

Men who are sexually active with other men

Of the 5,885 homosexually active men who have been diagnosed with AIDS in New York City, 35% (2,041) are racial minorities,

³⁷ Approximately half of the inmate AIDS cases in federal and state prisons occurred in NY State prison facilities. As of January 15, 1987, of the NY State prison cases, 335 (97%) are male, 12 (3%) are female; 46% are Hispanic, 39% are Black, and 14% are White. D. Morse, et. al., "AIDS in New York State Prison Inmates," THP.70, poster presentation at Third International Conference on AIDS.

³⁸ In 1985 there were approximately 30+ inmates with AIDS at any given time, while in 1986 that number jumped to 50+ inmates with AIDS. The upward trend has continued. In 1987 there are 80+ inmates with AIDS at any given time. Steven Del Giacco, Public Information Director at the New York State Commission of Corrections reports that in the New York State and City prisons and jails and the county jails there were 23 inmate deaths from AIDS in 1983, 68 AIDS-related deaths in 1984, 107 AIDS-related deaths in 1985 and 146 AIDS-related deaths in 1986. (Conversation of July, 1987)

primarily Blacks and Hispanics.³⁹ Of an additional 489 men who were both sexually active with other men and used intravenous drugs, 61% (296) are men of color.⁴⁰ Nationally, of Black and Hispanic men stricken with AIDS, over 50% are among men who were homosexually active.⁴¹ The continued assertion that AIDS only affects gay white men and other efforts to ignore the existence and needs of Black, Hispanic, Asian and Native American gay and bisexual men -- by the gay community as well as the Black, Hispanic, Asian and Native communities -- reinforces racial and sexual stereotypes. The AIDS statistics prove that these men do exist. It is likely that special educational efforts directed toward the needs of these men - and especially gay and bisexual minority teenagers - may be necessary.

The National AIDS Network head of Minority Affairs, Gilberto Gerald, described the dilemma facing Black and Hispanic people with AIDS:

Not only is homosexuality a taboo topic in both the Black and Hispanic communities, but intravenous drug users have no political constituency either. AIDS

³⁹ 1086 (18.5%) are Black, 910 (15.5%) are Hispanic, and 45 (1%) are other or unknown. New York City Health Department, AIDS Surveillance Update, June 24, 1987.

⁴⁰ Id. 166 (34%) are Black, 129 (26%) are Hispanic, and 1 (.2%) is other or unknown.

⁴¹ The New York Times reported that of the 764 Black male cases of AIDS per million Black and Hispanic population, 379 were "gay or bisexual men who are not intravenous drug users". Of the 730 Hispanic male cases of AIDS per million Black and Hispanic population, 389 were among gay or bisexual men who are not intravenous drug users. W. Schmidt, "High AIDS Rate Spurring Efforts for Minorities", New York Times, August 2, 1987, p. 1. Source: Dr. Roger Bakeman, Dept. of Psychology, Georgia State University, based on CDC data from April 6, 1987.

patients are a minority within a minority.⁴²

Like Black and Hispanic men generally, gay and bisexual men have historically been stereotyped as "oversexed" and "promiscuous". This is, of course, not true but the stigma remains and has been exacerbated by the AIDS epidemic. Stereotypes aside, it must be remembered that it is behavior, i.e. how you do what you do - safe or unsafe sex - rather than how many people you do it with, that is the actual risk factor.

The Scope of AIDS-related Discrimination

Fears about sex, death and disease are deeply ingrained in our society.⁴³ These fears readily combine with pre-existing prejudices against racial and ethnic minorities, homosexuals, immigrants, women and drug users. The resultant brew can be summed up in one sentence: **AIDS does not discriminate, but people do.** People with AIDS and even those simply "suspected" of having AIDS have been thrown out of their homes,⁴⁴ have seen their healthy children barred from entering schools and obtaining day

⁴² Id. at 27.

⁴³ Allan M. Brandt, "AIDS: From Social History to Social Policy", 14 Law, Medicine and Health Care 231 (December, 1986).

⁴⁴ The New York City Human Resources Administration's AIDS Management Unit currently estimates that they provide housing assistance to approximately 473 persons with AIDS (as of June, 1987). Patrick Hacker, Director of Supportive Housing for the AIDS Resource Center, confirms that inadequate housing and homelessness are serious and growing issues for people with AIDS. This situation is in large part a reflection of discrimination and stigma: when people with AIDS are denied access to nursing homes, evicted from their homes or shunned by family and friends, they are left with nowhere to go.

care services, have lost their jobs, have been denied ambulance service and essential medical attention, and have been denied access to places of public accommodation such as restaurants, stores, bars, hospitals and clinics. Since the early days of the AIDS crisis, significant headway has been made but the Commission continues to receive reports of problems encountered by people with AIDS in all these areas. For instance, while it may seem that children with AIDS or ARC can now enter New York City schools, this decision applies only to public schools. Recently the Commission encountered fierce determination on the part of one private school to bar a child whose aunt had AIDS from entering classes.

To cite just one example of the AIDS backlash on an identifiable group, consider the devastating impact of AIDS-related discrimination on Haitians. Despite the fact that Haitians have been removed from the CDC's list of AIDS risk groups, the stigma remains. Reports from Haitian community workers indicate that in some areas the unemployment rate for Haitians is twice that of other Black workers⁴⁵. Why? Many Haitians feel this situation is directly attributable to AIDS. Particularly hard hit have been domestic workers, who are generally female and often undocumented. Haitian children have been beaten up (and in at least one case, shot) in school; Haitian store owners have gone bankrupt as their businesses failed; and Haitian families have been evicted from their homes.

⁴⁵ Leonard A. Eisener, Fair Employment Report (formerly Civil Rights Employment Reporter), December, 1983 at p.206.

The problem of discrimination against this community is not new, but unfounded fears about AIDS have surely escalated the intensity of prejudice directed against Haitians. The same is true for the various groups (gays, IV drug users, prostitutes, etc.) now linked with AIDS in the public's consciousness.

The HIV Antibody Test

The HIV antibody test detects the presence of antibodies to Human Immunodeficiency Virus, an agent generally thought to cause AIDS. A positive test result does not mean an individual has AIDS or will get AIDS; it indicates exposure to a virus associated with the syndrome. Rather than rely on use of mandatory HIV antibody testing, New York City Health Commissioner Stephen Joseph has determined that at this time our most effective approach is a widespread program of effective AIDS prevention education combined with counseling-based HIV antibody testing as an option. As Commissioner Joseph stated in a recent public address:

Virtually all public health officials from areas of highest AIDS prevalence are agreed that forcing people to learn their serostatus when no treatment is available, and unless confidentiality can be assured, would be unwise and counterproductive.⁴⁶

Remarks by Commissioner Joseph entitled "Planning for AIDS in New York City" presented to the Association for a Better New York Community Council of Greater New York, April 21, 1987.

⁴⁶ Remarks by Commissioner Stephen Joseph entitled "Planning for AIDS in New York City" presented to the Association for a Better New York, Community Council of Greater New York, April 21, 1987.

Everyone is appropriately concerned about preventing further HIV transmission. However, calls for mandatory testing offer a false sense of security.⁴⁷ In the absence of a cure and vaccine, it is primarily behavioral changes (avoidance of high risk behavior) that will prevent further spread of the virus. Required testing of large segments of the population would be enormously costly - diverting large amounts of scarce funds and labor away from much needed education and drug treatment programs. At a recent national gathering of AIDS experts sponsored by the CDC, calls for mandatory HIV antibody testing were rejected as a counterproductive public health measure which may also lead to discrimination.⁴⁸

The issue of testing and subsequent stigmatization is not a new one among minority communities. In 1970, for example, a single, inexpensive and relatively reliable test for sickle cell hemoglobin became available.⁴⁹ Shortly thereafter, a number of states enacted sickle cell testing programs. Some were compulsory and none had specific confidentiality protections. Although well-intentioned, these programs and the attention they generated triggered a response of panic and discrimination. There was confusion over the difference between carrying the

⁴⁷ See: N. Hunter, "AIDS Prevention and Civil Liberties: The False Security of Mandatory Testing." American Civil Liberties Union, 1987.

⁴⁸ Public forum on proposed mandatory HIV antibody testing held in Atlanta, Georgia on February 28, 1987.

⁴⁹ Sickle cell anemia is a serious genetic blood disorder which primarily affects black people. It causes severe physical debilitation and often results in death at an early age.

trait and having the disease. Some airlines grounded all Black employees because of fears that a sickling crisis might occur if a plane de-pressurized; some insurance companies began charging higher premiums for sickle cell carriers; and the armed forces considered deferring enlistment of all carriers.⁵⁰

Any policy or program calling for required testing for the HIV antibody test and the subsequent exclusion or segregation in the event of a positive result must be evaluated in terms of its impact on people of color. In October, 1985, the federal government began testing applicants for military service. Since then testing in the military has been expanded to include active duty personnel and their dependents (in some circumstances). Reserve personnel are also being tested. In March, 1987, the Labor Department began testing applicants for the Job Corps. The State Department now tests all applicants for the Foreign Service. The federal government has announced plans to test all prisoners in federal prisons and immigrants.

Significant amounts of unemployment and underemployment among people of color and the soaring cost of higher education in the United States have led many minority youths to use the military and the Job Corps as a means of acquiring training, job skills, and employment.

All other things being equal, the military's policy will, by necessity, have a discriminatory impact upon poor people of color, given the

⁵⁰ P. Reilly, Genetics, Law and Social Policy (1977) at 74. This paragraph is quoted from N. Hunter, "AIDS Prevention and Civil Liberties: The False Security of Mandatory Testing", American Civil Liberties Union, 1987 at 18.

number of Black and Hispanic recruits. This disproportionate impact is, of course, further exacerbated by the fact that Black and Hispanic people have been exposed to HIV in far greater proportions than have white people. 51

The Department of Labor's testing of Job Corps applicants has a similar impact.

Job Corps is a federally funded job training program for economically disadvantaged persons between the ages of 16 and 21. A large proportion of Job Corps participants are people of color. For most Job Corps members, the program is the last available opportunity to obtain job skills and a realistic expectation of future employment.⁵²

Testing of prisoners also produces a disparate impact upon people of color, given the high proportion of minorities who are incarcerated. Wherever there exists a profession or an otherwise identifiable, formally-ordered segment of the population which is made up largely of minorities, mandatory testing of these groups will naturally take a heavy toll among minorities. Thusfar, the great proportion of those groups undergoing such testing do indeed have a high minority representation. A recent article in New York Newsday reported New York City and New Jersey Boxing Commission officials calling for widespread testing and exclusion of those testing HIV antibody positive among boxers.⁵³ Even forced testing of women arrested for prostitution has a disproportionate impact on minority communities because women of

⁵¹ Katherine Franke, "AIDS and Race," The Exchange, National Lawyer's Guild AIDS Network, Issue 4, May, 1987, p.4.

⁵² Id.

⁵³ W. Matthews, "Rubber Gloves for this Fight", New York Newsday, July 26, 1987, Sports 28.

color, while not comprising the majority of sex industry workers, are more likely to be arrested.

The NYC Commission on Human Rights' Response

In response to the discrimination aspect of the AIDS epidemic, the New York City Commission on Human Rights has created an AIDS Discrimination Unit to provide assistance to persons with AIDS, persons assumed to have AIDS, those who test HIV positive and those who are feared because they are or are perceived to be members of an "at-risk" group. The Commission accepts these complaints under the New York City Human Rights Law's prohibition against discrimination on the basis of physical handicap in housing, employment and public accommodations. As of June 30, 1987, the Commission had received over 750 reports of discrimination related to AIDS. Many of these complaints set forth charges of systemic discrimination, for example where a company has a policy of refusing to deliver medical supplies to homebound AIDS patients, or where any employee suspected of having AIDS is immediately terminated. All indications are that AIDS-related discrimination is widespread and growing.⁵⁴

The Commission's AIDS Discrimination Unit has received calls from the families of people with AIDS requesting assistance in their efforts to obtain necessary medical assistance and procedures for a relative with AIDS. AIDS Discrimination Unit staff have arranged for emergency service by ambulance, fought to

⁵⁴ See: New York City Commission on Human Rights, Updated Report on AIDS Discrimination, August, 1987 for summaries of cases.

obtain much-needed medical/dental care, insured access to funeral homes which denied services, and advised delivery personnel of the illegality and monetary repercussions of refusing to furnish services to persons with AIDS or those who associate with persons with AIDS. The Unit has interceded in a wide range of discrimination cases and many times obtained a positive result due to efforts to advocate on behalf of the person with AIDS. More recently the Commission launched an educational campaign to alert the public to the fact that AIDS-related discrimination is illegal and to counter the growing backlash against people with AIDS.

Projections for the Future

It has been estimated by the U.S. Public Health Service that by 1991, 3-4 million Americans will have become infected with HIV - about one in every 70 people. There will be over 270,000 cases of AIDS nationally, resulting in 179,000 deaths.⁵⁵

(Studies done in the United States indicate that within a six year period approximately 20-30% of all persons who test HIV positive will go on to develop AIDS and another 20-30% will develop AIDS Related Complex [ARC].) In New York City, AIDS is already the current leading cause of death for males aged 25-44 and for females aged 25-34. It is the third leading cause of

⁵⁵ C. Everett Koop, Surgeon General's Report on Acquired Immune Deficiency Syndrome, October, 1986.

death for females aged 35-44.⁵⁶ Health officials, charting the progressive course of the disease, have predicted that 43,000 AIDS cases will have been reported within New York City by 1991 and it is likely that 31,000 of these people will have died.⁵⁷ **The majority of those who die in this manner will be men, women and children of color.**

The World Health Organization estimates that there will be 500,000 to 3 million new AIDS cases between 1987 and 1991, in people who were already infected with HIV as of 1986. They report that 50 million to 100 million people will be infected with HIV worldwide by 1991.⁵⁸

AIDS is a global problem, a pandemic. The majority of those affected by AIDS and HIV infection are now and will continue to be people of color and the population of the third world. The discrimination and lack of resources which disparately affect the poor and people of color with AIDS in the United States are part of a global pattern of discrimination and lack of resources.⁵⁹ As Jonathan Mann, Director of the World Health Organization recently stated:

Fear and ignorance about AIDS continues to lead to tragedies: personal, family, and social. In some

⁵⁶ Conversation with Dr. Singh, New York City Health Department, July, 1987.

⁵⁷ Official projections, New York City Department of Health, July 28, 1987, based on cases diagnosed through December, 1986.

⁵⁸ World Health Organization, Special Programme on AIDS, "Strategies and Structure, Projected Needs," March, 1987, p. 18.

⁵⁹ See: Panos Dossier 1, AIDS and the Third World. (Revised and Updated Edition), The Panos Institute, March 1987.

circles, the HIV-infected are still divided by some into the "innocent" and, by implication, the "guilty" persons. Fortunately, other groups, such as the World Council of Churches, have issued eloquent pleas for understanding, for healing, and for compassion.

...

Inevitably and necessarily, the social debates about AIDS acquire a distinct political dimension. AIDS has become a touchstone for political beliefs. AIDS has unveiled thinly disguised prejudice about race, religion, social class, and nationality. As a result, we are witnessing a rising wave of stigmatization: against Westerners in Asia, against Africans in Europe, of homosexuals, of prostitutes, of hemophiliacs, of recipients of blood transfusions. AIDS, or more properly fears about AIDS, has become a direct threat to free travel between countries, and, more generally, to open international exchange and communication⁶⁰

Conclusion

Tremendous strides have been made over the last five years and we now know quite a bit about Acquired Immune Deficiency Syndrome. All the scientific evidence states that AIDS is not spread by casual contact. The National Centers for Disease Control have issued guidelines which clearly state that, except in certain well-defined instances, caring for, or living or working with a person who has AIDS or who is HIV-positive presents no health risk.⁶¹ AIDS is not transmitted by holding hands, sneezing, coughing, or sharing eating utensils or sanitary facilities. We also know how it is spread. AIDS is transmitted

⁶⁰ Jonathan Mann, "AIDS Epidemiology, Impact, Prevention and Control: The World Health Organization Perspective," paper presented at Third International Conference on AIDS.

⁶¹ See: "Recommendations Regarding HTLV-III Transmission in the Workplace", Morbidity and Mortality Weekly Report, November 15, 1985.

through blood-to-blood contact (such as shared needles which have come into contact with HIV-contaminated blood), blood-to-exposed mucous membrane contact (such as contact in a medical setting where the recommended precautions are not followed), semen-to-mucous membrane contact (unsafe sexual practices such as anal and/or vaginal intercourse without a condom with an HIV-infected partner), and from pregnant mother to unborn child.

Prejudice against racial and ethnic minorities ("they're all on welfare"), homosexuals ("they're only fags"), immigrants ("they're taking our jobs away"), sexually active women ("she's a whore and deserves what she gets") and drug users ("they're nothing but junkies anyway") interferes with our ability to respond to AIDS as a health crisis. As the wife of one man with AIDS noted, "...the labeling of this disease [into risk group categories] has got to stop. When we're labeled, we're no longer people."⁶² This stigmatization of AIDS as "their" disease diverts our attention away from the very real social, economic, discrimination and health issues which affect us all.

Education combined with aggressive enforcement of our civil rights laws is an effective weapon against prejudice and discrimination. Don't let anyone convince you that AIDS is someone else's problem. To support this myth is to assure the continued spread of both the HIV virus and the stigma associated with AIDS, while fueling the growing backlash against women and racial, ethnic and sexual minorities.

⁶² C. Norwood, "AIDS Goes Straight," Us Magazine, August 25, 1986, pp. 47, 49.

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Note: Copies of "NYC Commission on Human Rights Report on Discrimination Against People With AIDS, Update: January 1986 - June 1987", are available upon request. This report details representative accounts of AIDS and AIDS-related discrimination reported to the Commission, and includes an analysis of the trends and special circumstances surrounding AIDS discrimination.

APPENDIX: A BRIEF OVERVIEW OF SOME EDUCATIONAL OUTREACH EFFORTS
DIRECTED TOWARD MINORITY POPULATIONS WHICH HAVE BEEN
UNDERTAKEN BY THE NEW YORK CITY DEPARTMENT OF HEALTH
AND THE BOARD OF EDUCATION*:

Because AIDS is still thought to be a white, gay male disease, many people of color don't realize that they are at risk for AIDS. For this reason, many community groups and the New York City Department of Health's AIDS Education Unit have begun outreach efforts in minority communities.

The Department of Health works with many community groups to develop AIDS educational materials. Currently, the Department of Health provides some funding to the Haitian Coalition on AIDS, the Hispanic AIDS Forum, the Minority Task Force on AIDS and the Gay Men's Health Crisis for a variety of educational materials, including brochures in Creole, audiocassettes in Spanish and Creole, and a comic book. The Department of Health sponsors a weekly AIDS educational segment on the Gay Cable Network and has taken out ads in publications of the Hispanic, Black, and Haitian communities. Videos are also being prepared in both Spanish and English to be used in counseling IV drug users.

The City Department of Health's AIDS Education Unit currently has an outreach effort in nine primarily Hispanic and Black communities throughout the boroughs. These particular communities were targeted due to a high incidence of IV drug use. The focus has been to educate both IV drug users and all other community members about AIDS transmission. The AIDS Education

Unit attempts to reach IV drug users and those with whom they interact, including sexual partners, children, and other family members.

These programs have made strides in educating the public about AIDS facts and myths; however many more people need to be reached. Communication methods such as audio/visual educational materials, street theatre and, especially, peer outreach efforts by former addicts are some methods which have been used to good effect as a means by which to educate this group about the risks of HIV transmission. Creative ideas are necessary to reach this segment of the population, which has traditionally been underserved by organized health care and education.

The AIDS Education Unit is aware of the need to educate women about the special situations they face during the epidemic and has undertaken a number of programs designed to meet this need. The unit's emphasis is on reaching the entire community, including women. Women's risk of contracting AIDS from unprotected sexual encounters is discussed in general educational presentations. The unit also does outreach at places where large numbers of women can be reached, such as Head Start centers and WIC offices. The City also has pamphlets entitled "Women and AIDS," and "Children and AIDS." The City's AIDS Hotline conducts groups for women where their questions and concerns can be raised and addressed. Several community groups and agencies have also responded to this need, sponsoring educational forums and producing pamphlets which detail the risks women may face and provide suggestions on how they may protect themselves.

Special outreach efforts are now being directed at children and teenagers. It is presently part of the required curriculum of the New York City public high school system that students be given AIDS Education. A new film that the New York City Board of Education will show in New York City public high schools and some middle schools includes a discussion among five teenagers (three female and two male; several of whom are minority teenagers) about AIDS and risk reduction. The AIDS Education Unit also has a brochure for adolescents about AIDS. The entire brochure, including concept, design and graphics, was designed by adolescents.

The AIDS Education Unit also has a program for inmate education about AIDS in the city's correctional facility on Rikers Island, including the male, female, detoxification, and adolescent facilities, and in city correctional facilities in each borough. Starting August 1987, the AIDS Education Unit began distributing an inmate release packet, including condoms and AIDS education materials, to all released inmates on Rikers Island. And, in a new pilot project, condoms are now being distributed to inmates in the section of Rikers which houses gay men.

The work of the gay community in AIDS education shows the success that grassroots, culturally relevant educational campaigns can achieve. Many gay community groups have developed brochures, videos, comic books and other materials which discuss safer sex guidelines and the special needs of gay men. Studies in New York City and San Francisco have shown that many members

of the gay community have significantly changed their sexual behavior to incorporate risk reduction techniques; to a large degree, this behavioral change is a direct result of education. Although the efforts of gay community groups have been very effective in reaching many homosexually active men, still more work is needed to educate those men who are sexually active with other men, without the use of risk reduction-techniques. Educational efforts should emphasize reaching men of color and young and adolescent men. The New York City Department of Health is currently working on a brochure for men who are sexually active with other men.

The Office of Lesbian and Gay Health Concerns of the New York City Department of Health is now doing outreach to gay and bisexual men of color. They are providing education to men in bars, clubs, and on beaches.

In this section, we have only touched upon some of the many legitimate efforts which have been proposed by both City and community organizations to care for and protect the various segments of the public affected by AIDS. These programs need our full support to be implemented.

* The information in this appendix was provided by the New York City Board of Education and the following divisions within the New York City Department of Health: Division of AIDS Program Services, AIDS Education Unit, and Office of Lesbian and Gay Health Concerns.