AIDS INFORMATION GUIDE

Parole Operations
April 1986

New York State
MARIO M. CUOMO
Governor

Division of Parole
RAMON J. RODRIGUEZ
Chairman

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INTRODUCTION

A Message From Chairman Rodriguez

The New York State Department of Correctional Services has at present one of the largest concentrations of AIDS sufferers in the country. The high incidence of AIDS among intravenous drug abusers and the frequency of drug abuse histories among releasees makes the Division of Parole's clientele a high risk group for AIDS. Given these facts, it is prudent to focus and clarify Division policy and procedure as it applies to the issue of AIDS.

We in the Division must recognize that persons with AIDS are suffering a devastating, often times fatal disease. In our work we must strike a balance between our legitimate concern for the safety and well-being of Division staff, our responsibility to provide community protection and our casework obligation to provide and broker services for releasees.

The inmate and releasee with AIDS or ARC present a special challenge to Division staff and we must be sensitive to their special needs for assistance, support and counseling. As we strive to provide service and supervision to this population, we must maintain respect for individual rights to privacy and confidentiality. While we must exercise particular caution in our work with people with AIDS or ARC, the challenge presented by these cases is not unfamiliar to us...the Division has a tradition of dealing with tough cases, and a history of innovation and success.

In our approach to working with people with AIDS or ARC, it is important that we remain flexible and incorporate into our methods the results of new discoveries about the causes and course of this disease and the needs of people who are suffering with it. In every instance, our efforts should be guided by concern and respect for the privacy and dignity of individuals with AIDS or ARC and by a concern for the safety and well-being of Division staff.

The material in this Information Guide reflects these efforts and has been put together to assist you in your work with inmates and releasees with AIDS or ARC. The guide is divided into nine Sections. Section I addresses general information on AIDS and includes facts about AIDS that establish the foundation for our approach to casework and supervision of inmates and releasees with AIDS. In most regards the policies and procedures that guide and direct the work of Parole staff are encompassing enough to direct our work with inmates and releasees with AIDS, requiring only clarification and application. Section II includes policies and procedures in five specific areas where a more direct focus is warranted. Section III, Questions and Answers on AIDS, takes a look at a broader range of operational procedures and how they might be applied in providing services or supervision in these cases.

Section IV, Service Needs of People With AIDS, highlights areas which must be addressed in discharge planning and supervision in order to meet the complex and varied needs of people with AIDS. This information is expanded in Section V, which describes services and resources available to Parole staff working with these difficult cases; in Section VI, which includes lists of Division of Parole Regional AIDS Liaisons and Parole Services Program Specialists; and in Section VII which provides information about working with the Social Security Administration to secure SSI and other financial assistance for which people with AIDS are eligible.

Section VIII of the Information Guide includes descriptive materials and guidelines on AIDS put out by the New York State Department of Health. Section IX contains numerous informative articles and reports on AIDS, addressing topics such as transmission of AIDS, HTLV-III antibody testing and AIDS in prisons.

As this AIDS Information Guide documents, we have initiated numerous activities to address issues related to parole supervision and casework with inmates and releasees with AIDS or ARC. Most of these initiatives build on a long-standing approach to Parole case work and service delivery. Of particular importance to the work that lies ahead is our designation of an AIDS Liaison in each of the five Regions who, along with the Regional Parole Services Program Specialist, will provide you with information and technical assistance on AIDS cases. A listing of the Regional AIDS Liaisons and Parole Services Program Specialists is included in Section VI.

April, 1986

ACKNOWLEDGMENTS

This AIDS Information Guide was made possible by the combined efforts of many people. Of prime importance has been the willingness of Parole Officers across the state to discuss openly their concerns and the problems they have experienced working with inmates and releasees with AIDS. These conversations have served to define the issues and frame the approaches described in this guide.

A large number of Division staff participated in many lively debates over the numerous issues covered in this document. Executive staff, Parole Commissioners, Central Office Operations staff, Regional Directors, Area Supervisors, Senior Parole Officers, Parole Officers, and union representatives must all be acknowledged for their role in strengthening the content of this Information Guide and contributing to the development of Division policy.

Agencies at all levels of New York State and local governments have focused on AIDS and related issues in the past year. As a result of Governor Cuomo's insightful leadership on AIDS in New York State, many agencies have been working together toward an effective statewide response to this crisis. As a result, we have been fortunate to be able to on draw the expertise and assistance of numerous sister agencies, including the New York State Department of Health, Division of Substance Abuse Services, Department of Correctional Services, AIDS Task Forces and AIDS Institute. In addition, the assistance of a variety of other organizations has been invaluable. These include the Social Security Administration, the New York City Department of Health, the Gay Men's Health Crisis, Urban Resources Inc., Beth Israel Hospital, and numerous physicians affiliated with hospitals delivering services and conducting research on AIDS.

Finally, this Information Guide was produced with good grace and a minimum of frenzy as a result of the efforts of Sandy Griesemer and Barbara Santora, who typed it, produced it and sweated the details.

Terri G. Wurmser

SECTION I - GENERAL INFORMATION ABOUT AIDS

Fear and misinformation about AIDS are pervasive, and while the threat of AIDS is serious, many of the fears expressed by the general public are unfounded. Facts about AIDS--what it is, who is at risk, how it is transmitted, risk reduction precautions--are now widely available through the efforts of the New York State Department of Health. The reader is directed to the AIDS - 100 Questions and Answers booklet recently published by the Department of Health and to the sampling of pamphlets and articles contained in this section for general information on AIDS.[1]

The following facts about AIDS are excerpted from AIDS - 100 Questions and Answers in order to establish the foundation for the Division's approach to casework and supervision of inmates and parolees with AIDS.

What is AIDS?

Acquired immune deficiency syndrome (AIDS) is a disease complex characterized by a collapse of the body's natural immunity against disease. Because of this failure of the immune system, patients with AIDS are vulnerable to one or more unusual infections or cancers that do not pose a threat to anyone whose immune system is working normally.

What causes AIDS?

Investigators have discovered a virus that is closely linked with AIDS. Different groups of researchers have given different names to the virus: human T-lymphotropic virus, type III (HTLV-III): lymphadenopathy associated virus (LAV); or AIDS-related virus (ARV). Infection with this virus does not always lead to AIDS, and researchers are investigating whether other co-factors may be necessary to trigger the disease. Preliminary studies show that most HTLV-III infected persons remain in good health; others may develop illness varying in severity from mild to extremely serious.

How contagious is AIDS?

Unlike most communicable diseases -- colds, flu, measles, etc. -- AIDS is not transmitted through sneezing, coughing, eating or drinking from common utensils, or merely being around an infected person for a long time. After five years of experience it is evident that casual contact with AIDS patients does not place others at risk. No cases have been found where AIDS has been transmitted through casual (non-sexual) contact to a household member, relative, co-worker or friend. Health workers and others who care for AIDS patients on a daily basis have not become ill.

How is AIDS transmitted?

AIDS is not an easily transmissible disease. All evidence indicates that AIDS is spread through sexual contact, needle sharing or less commonly through transfusions of blood or blood components. Direct blood-to-blood or semen-to-blood contact appears necessary to transmit the virus associated with AIDS. There is no evidence that AIDS can be transmitted through air, water, food or casual body contact.

[1] Copies of 100 Questions and Answers may be obtained from the Regional AIDS Liaison or by contacting the N.Y.S. Department of Health, AIDS Institute, at (518) 473-0641.

Can you get AIDS by touching someone who has it?

After five years of experience there is no indication that AIDS is spread through any form of casual contact, including handshakes, bumping together in crowds, contact sports, even casual kissing.

Are health care workers or other occupational groups at special risk for AIDS?

Health care workers and other occupational groups who come into contact with AIDS patients or specimens have not developed AIDS. Safety protocols have been developed for various occupational groups to minimize direct contact with blood and other body secretions. The Centers for Disease Control (CDC) is following some 1,700 health care workers who have been exposed to the body fluids of AIDS patients; many of these workers have had needle-stick injuries while treating AIDS patients. None of these workers has developed AIDS as a result of an occupational exposure. Two health care workers, who experienced needle-stick injuries and who deny any AIDS risk behaviors, have been found positive for HTVL-III, but neither has developed AIDS. CDC has noted that it is impossible to definitively determine that these two cases represent occupational exposures since there were no blood samples available for testing prior to the needle-stick injuries. The only documented case of a health care worker contracting AIDS has been reported in England following a needle-stick puncture which involved a major infusion of blood from an AIDS patient into her hand. All scientific studies to date suggest that the risk to health care workers and other occupational groups is small, or non-existent if they follow safety protocols to minimize direct exposure to blood and body fluids.

SECTION II - POLICIES AND PROCEDURES

1. Confidentiality

2. Coordination with the Department of Correctional Services

3. Discharge Planning

4. Report Status

5. Record Keeping

1. CONFIDENTIALITY

Background

The Division takes with utmost seriousness its obligation to provide counseling to inmates and parolees with AIDS or ARC about the risk of transmission and about their responsibility to others in this regard. Public Officer's Law, Article 6-A, entitled the Personal Privacy Protection Act, prohibits the disclosure by a state agency of any record, or information gained from it concerning a person without their permission.

Policy

In accordance with the Public Privacy Protection Act and in a manner consistent with the handling of all information covered by this act, Division staff are prohibited from divulging confidential medical information about any inmate or releasee with AIDS or ARC without first receiving written consent from the individual.

2. COORDINATION WITH THE DEPARTMENT OF CORRECTIONAL SERVICES

Background

The Division of Parole is committed to a cooperative relationship with the Department of Correctional Services (DOCS) in order to provide a smooth transition to community living for inmates. In accordance with Section 259-a of the Executive Law of New York State, DOCS makes available to the Division information about inmates under its jurisdiction for purposes of preparation of reports to the Board of Parole and supervision of inmates released on parole or conditional release.

Policy

Continuity of care and treatment, coordination of essential services and comprehensive release planning for inmates with AIDS/ARC will be ensured and facilitated by the formal and consistent exchange of medical information between DOCS and the Division. Institutional Parole Staff will provide DOCS Facility Health Services Units with Parole Board appearance dates and due dates for Medical Discharge Summaries for all inmates identified by DOCS as having AIDS/ARC; DOCS Facility Health Services Units will provide Institutional Parole Staff with Medical Discharge Summaries for purposes of Parole Board Summary Report preparation and discharge planning.

Procedure

1. DOCS will send to the Director of Parole Operations on a regular basis a listing of all inmates diagnosed as having AIDS and ARC.

2. The Division will forward to Senior Parole Officers in institutions a listing of all new AIDS/ARC cases and will provide DOCS with Parole Board dates for these inmates.

3. DOCS, through designated facility Health Units, will provide institutional Parole staff with a Medical Discharge Summary report according to the following time frame:

   Medical reports on initial appearance cases are to be forwarded to the Senior Parole Officer ten (10) days before the 1st day of the month in which the inmate appears before the Parole Board.

   Medical reports on reappearance cases are due sixty (60) days before the 1st day of the month in which the inmate appears before the Parole Board.

   Medical reports on CR's are due sixty (60) days before the CR date.

   The Medical Discharge Summary will include the following:

   A diagnosis of the inmate's condition.

The prognosis in light of the inmate's current medical condition, including limitations on living arrangement and employability where applicable.

A report indicating the inmate's acceptance of his condition and cooperation with respect to treatment.

Any follow-up medical treatment plan developed by the facility health services staff, the attending physician, or hospital or that needs to be developed by the Parole Officer.

If the Medical Discharge Summary form is not received by the due date, the Senior Parole Officer at the facility should seek to obtain the report by contacting the facility Health Services Director or Nurse Administrator. Assistance in obtaining delinquent reports should be sought, where needed, from the Area Supervisor or Regional Director via direct contact with the facility superintendent.

4. Attach the Medical Discharge Summary Report prepared by DOCS facility Health Services Units to the Parole Board Summary as an addendum, with significant elements summarized in the "Medical" sub-section of the Parole Board Summary; include in Section II of the Parole Board Summary under "Special Conditions Recommended" components of the discharge plan that link the inmate's medical condition with specific needs for follow-up medical care, housing, employment, financial assistance or counseling.

5. Institutional Parole Officer contact the DOCS facility Health Services Director or Nurse Administrator several days before the Parole Board appearance in order to ensure the currency of information on medical status obtained through the DOCS Medical Discharge Summary Report; reflect any significant change in medical status and consequent change in discharge plan in a written addendum to the Parole Board Summary.

6. Inmates with AIDS or ARC who are ambulatory will appear before the Parole Board in the customary manner. It is the responsibility of the Senior Parole Officer to confirm the status of inmates with AIDS or ARC the day of the Parole Board hearing and, in conjunction with DOCS and the Parole Board, to make adjustments in the schedule as required.

3. DISCHARGE PLANNING

Background

Many parolees with AIDS/ARC will be so debilitated by the disease that they will be unable to seek or maintain employment. Under these circumstances, individuals so disabled are eligible for various local, state and federal financial and public assistance programs. Supportive financial resources are essential in order to ensure continuity of care and treatment for parolees with serious medical disabilities. Submission of applications for SSI, Medicaid or local public assistance prior to discharge for inmates likely to be eligible for these programs upon release will reduce, and hopefully eliminate, the lag between release and receipt of financial assistance, thus eliminating disruption in supportive services.

Policy

A parolee with AIDS/ARC may be unable to work due to his medical condition. It is appropriate and necessary for Parole Officers to assist inmates to obtain, complete and submit, prior to discharge, application forms for financial and medical assistance through SSI, Medicaid and Home Relief, and to facilitate this application process in every way possible.

Advocacy on behalf of these individuals is an essential role of Parole Officers in both institutional and field assignments. Division staff must take an aggressive position with respect to program development in these cases. Parole Officers are responsible for initiating, on behalf of inmates and parolees, actions necessary to identify and secure services and resources required to expedite release and ensure continuity of services in the community.

Procedure

1. Institutional Parole Officer establish contact with the Social Security Administration's District Office or the County Department of Social Services; assist inmates who are diagnosed as having AIDS/ARC, who may be eligible for and who may require assistance of this sort to submit applications prior to discharge.

2. Institutional Parole Officer facilitate the exchange of necessary information with the Field Parole Officer, including having the inmate sign the necessary Release of Information forms in order to share medical information as necessary to obtain needed social services.

3. Field Parole Officer establish contact with County Department of Social Services and local Social Security Administration District Office in order to arrange for follow-up interviews as necessary following release.

(Note: See Section VII, Pre-release Procedure, Agreement Between DOP and Social Security Administration for filing SSI applications)

4. REPORT STATUS

Background

While existing policies and procedures allow for modification in report requirements (see Field Service Manual Item 9201.00 Arrival Procedures; 9202.00 Initial Interview; 9203.00 Supervision Contacts), some additional modification in Arrival Procedures, Office Report Status and Supervisory Contacts may be necessary for releasees with AIDS/ARC due to medical status as determined on a case-by-case basis.

The purpose of the Arrival Report and Initial Interview for releasees with AIDS/ARC is the same as for any new releasee -- that is, clarifying the rules of parole, establishing a casework relationship with the releasee, assessing immediate and long-range needs and establishing alternatives and plans for a parole program, including services to address identified needs. In the case of a releasee with a serious medical problem, such as AIDS, the importance of expedited needs assessment and assistance by the Parole Officer in obtaining services becomes paramount.

Likewise, ongoing supervisory contacts during the period of parole supervision, including office reports, home visits and collateral contacts, are intended to accomplish previously established objectives -- regular meetings with the releasee and an opportunity for private interviews through office reports, verificiation of residence and familiarity with family or living situations through home visits, and assurance that required or needed services are being received through collateral contacts with Social Services, medical or other community providers. Again, these contacts are central to the provision of good parole supervision and service. Especially in circumstances of extreme medical disability, assistance and counseling to the releasee and, family, as well as referral and advocacy for service delivery, may require greater initiative then would the ordinary case.

Policy

ARRIVAL REPORT: Inmates diagnosed by the Department of Correctional Services as having AIDS or ARC will not be required to make an Arrival Report to the Area Office following release. All such inmates will be directed by the Institutional Parole Officer to proceed to their assigned program upon release and to phone the Field Parole Officer within 24 hours of release to make reporting arrangements.

Procedure

1. Conference between Field Parole Officer and Senior Parole Officer prior to discharge to review information relative to current medical status and to establish a plan for telephone Arrival Report, Initial Interview and subsequent supervisory contacts.

2. Notice by Field Parole Officer to Institutional Parole Officer concerning any pre-arranged appointments for services or directions to the releasee in this regard.

3. Institutional Parole Officer discuss with releasee requirements for telephone contact following release, provide inmate with a copy of Arrival Notice (form 4028) which releasee is to mail to Area Field Office.

OFFICE REPORT: Office Reports will not be required across the board in these cases. The need for, and appropriateness of, Office Reports by releasees with AIDS or ARC will be determined on a case-by-case basis based on the releasee's medical status. Where the medical condition of the releasee is so fragile that office visits are impractical or ill-advised from a medical standpoint, alternative arrangements may be made in accordance with established policies and procedures. To the extent that a releasee is excused from making Office Reports due to a medical condition, other standard contacts with the releasee should be enhanced to ensure continuity of supervision and service.

Procedure

1. Conference between Field Parole Officer and Senior Parole Officer to establish a modified schedule of Office Reports, including Initial Interview, based on the releasee's medical status.

2. Notation in case file of any modification in report schedule and reason for change.

3. Provision for periodic review of report schedule to ensure changes in report status are made in keeping with changes in medical status.

HOME VISIT: Existing standards apply, with Parole Officers using discretion to ensure prudence in the conduct of these visits in keeping with the medical status of releasees with AIDS or ARC.

COLLATERAL CONTACTS: Contact with Community Health professionals and Social Services providers is critical to acquiring current information on medical status and the need for services, both of which will impact ongoing decisions concerning office reports and other supervisory contacts.

5. RECORD KEEPING

Background

For policy, procedures and development purposes and in response to external inquiries, it is necessary from time to time for the Division to ascertain the number of releasees diagnosed as having AIDS or ARC. For this reason, it is necessary that each Regional Director be able to provide a timely and accurate account of the number of releasees in each Area Office identified as having AIDS or ARC and the Parole Officers responsible for supervision of these cases.

Policy

Each Regional Director shall establish and maintain in the Regional Office an accurate account of releasees being supervised in each Area Office who have AIDS or ARC and the Parole Officer supervising each case. Additionally, each Regional Director shall ensure that, on a monthly basis, a numerical count of all AIDS and ARC cases, broken down by Area Office and Parole Officer responsible for supervision is forwarded to the Central Office Parole Services Program Specialist.

SECTION III - QUESTIONS AND ANSWERS ABOUT AIDS

1. Q: According to the prison grapevine, we have an inmate in population who has AIDS who has not been officially "diagnosed" as such by DOCS and added to their roster. Why aren't we being told and what should we do to find out?

   A. The prison grapevine cannot be relied on as being totally accurate, and with an issue as emotionally charged as this one, is likely to be greatly exaggerated. There have, however, been instances where an official diagnosis of AIDS only confirms that which has been suspected, but unofficial.

   There is no simple answer as to why this occurs. In part it is the result of less than perfect communication between DOCS and DOP; that situation should be greatly improved with the now regular exchange of information between our agencies on these cases. In part, suspicions of inaccurate reporting stem from the fact that people can only be diagnosed as having AIDS or ARC after a very specific set of medical circumstances have been satisfied--and great care must be taken not to misdiagnose, thereby leaving an individual permanently stigmatized by such an error. Finally, in some instances DOCS Health Services staff may not be aware of an inmate's illness and therefore cannot treat or report it.

   In order to uncover medical problems requiring treatment, all new DOCS admissions receive a medical evaluation upon arrival in the correctional system. In addition, DOCS is required to provide periodic follow up medical exams on all inmates. If test results indicate abnormal findings, the inmate is referred to a community hospital for a complete evaluation. All confirmed AIDS and ARC cases are placed in the facility infirmary or community hospital.

   DOCS facility Health Services staff are, by law, precluded from discussing a patient's medical diagnosis with anyone other than Health Services staff without the patient's permission. The Health Services Unit provides DOP with a list of all AIDS and ARC cases and medical summary information for purposes of discharge planning. This information provided to Parole should be treated with the utmost confidentiality as is required by law, and should not be disclosed without the permission of the patient to anyone other than Division of Parole or DOCS Health Services staff.

   No inmate identified as having a communicable disease, known to Health Services, remains in population untreated. Bear in mind, however, that inmates have the right to seek, or to refuse to seek, health care. Obviously DOCS lists of AIDS/ARC cases will not include inmates whom you suspect might be ill but who have not come forth for treatment.

   Questions about any such cases should be directed to the facility Health Services Director or Nurse Administrator for clarification. Bear in mind, however, that DOCS cannot provide information on cases that have not been diagnosed.

2. Q: I recently interviewed an inmate in population who looked pretty ill, and while he didn't say so directly, I got the feeling from his description that he may think he has early symptoms of AIDS. He hasn't elected to be seen by the Health Services Unit nor has he discussed this with any DOCS personnel. What should I do about this?

   A: In addition to counseling the inmate about the serious implications for himself and others with whom he has contact if he is in fact ill, you should urge him to seek medical attention and assist him to do so in any ways that are appropriate. At a point, however, if the inmate fails to contact medical staff and you have reason to believe he is ill, you have an obligation to discuss the situation with the DOCS facility Health Services Physician or Nurse Administrator.

   Keep in mind, however, that medical treatment cannot be imposed by force, and the DOCS Health Services staff can only treat inmates who come forth for such treatment.

3. Q: I'm not a Parole Officer, but I'm still worried about having contact with inmates or parolees with AIDS. Can I get AIDS by being near them or processing paperwork on them?

   A: No. AIDS is not transmitted through the air, food or water, or by touching any object handled, touched or breathed on by a person with AIDS. There is no indication that AIDS is spread through any form of casual contact. AIDS cannot be transmitted by a routine office contact with inmates or parolees with AIDS.

4. Q: If I am working with an inmate or parolee with AIDS, will my family be in danger of getting infected?

   A: AIDS is not an easily transmissible disease and there is no evidence that it can be transmitted through air, water, food or casual contact. Since you are personally not at risk of getting AIDS as a result of the routine contact you have with an inmate or parolee with the disease, your family suffers no risk of exposure or infection as a result.

   The largest study to date of AIDS patients and their families, undertaken by the Montefiore Center in New York City, has unearthed no evidence of transmission of the virus to household members who have shared household items and facilities and had close personal interaction with the patient. The study indicates that household contacts who are not sexual partners of, or born to, patients with AIDS are <u>at minimal or no risk</u> of infection with HTLV III. Copies of the Montefiore Study can be obtained by contacting the Regional AIDS Liaison.

5. Q: In preparation for a Pre-Board Summary, I will be interviewing an inmate who has AIDS and is in the prison infirmary. How do I know what precautions to take?

   A: Just as you would for any inmate being treated for a communicable illness, consult the DOCS facility Nurse Administrator to determine what, if any, precautions are advised for DOCS staff and Parole Officers. (Note: For epidemiological and medical purposes, AIDS is not classified as a communicable disease.)

6. Q: Can I conduct my Pre-Board Summary interview with an inmate with AIDS by telephone?

   A: There is no medical evidence to suggest that AIDS is transmitted through casual contact. In most instances these interviews can be safely conducted in a face-to-face contact; face-to-face interviews with these inmates shall be the expected standard. Where, however, facility medical staff recommend that face-to-face contact not take place, after consultation with the Senior Parole Officer, a telephone interview may be arranged.

   In all instances where deviation from the face-to-face interview procedure occurs, an entry shall be made in the inmate's case record stating the basis on which such a decision was rendered. Written notice of all such actions shall be forwarded to the Area Supervisor with a copy to the Parole Services Program Specialist.

7. Q: Inmates with AIDS who are scheduled to appear before the Parole Board are often not ambulatory and may not be present at a given facility on their Board date. What can these inmates expect with regard to Board action in their cases?

   A: An ambulatory inmate with AIDS who is in the facility infirmary should appear before the Parole Board in the Parole Board room if at all possible. A non-ambulatory inmate with AIDS who is in the facility infirmary will, if necessary, be visited by the Parole Board members in the infirmary. Institutional Parole staff are responsible for coordinating with Correction staff to insure that appropriate arrangements for these interviews are made.

   An inmate with AIDS who is in the community hospital and is unable to appear or be seen at the facility infirmary will, if an initial applicant, be postponed for no more than two months or earlier to determine the arrangements necessary to accomplish the Parole Board appearance. Once a determination has been made, arrangements should be implemented without delay. In most instances this will include an assignment of a special panel of the Parole Board to conduct the parole interview at the community hospital. In the event an inmate with AIDS is scheduled to return to the correctional facility and the medical condition indicates no emergent need to provide an on-site community hospital visit, the inmate will be scheduled for the next available Board at the facility of return.

In reappearance cases where the inmate is in a community hospital, the Board will direct an immediate and expeditious investigation with regard to the inmate's medical condition. As a rule, this period of investigation by the institutional Parole Officer should not exceed two to three weeks and should result in a report to the Board concerning the seriousness of the disability and the likelihood of return to the institutional setting. Based upon a case-by-case decision following review of this report, the Board will make a determination relative to the urgency attached to an on-site community hospital Board appearance. Where return to the facility by the inmate can be anticipated, the inmate will be seen at the next Board panel visit at the facility. Otherwise, a special panel will be assigned to conduct the parole interview at the community hospital.

It is the responsibility of the Senior Parole Officer at the institution to insure that all necessary information and reports are prepared for the Board in a timely and enhanced fashion in order to eliminate unnecessary delay in these cases. If there is a need to discuss plans for the Board interview in advance, Parole staff should contact the Executive Secretary to the Board of Parole to discuss the case.

8. Q: What should I do if an inmate with AIDS or ARC is transferred from my institution to another prison?

   A: The Parole Transfer Summary prepared in these cases should be "flagged" in order to alert the receiving Parole Office that the case requires special attention, similar to the manner in which cases involving T.B. or extreme suicidal tendencies are identified. All available information concerning the inmate's medical condition should be noted in the summary, as well as any immediate needs of the inmate which would have an impact on the receiving facility.

9. Q: An inmate with AIDS who is currently hospitalized is scheduled for parole/CR to a hospital program. He wants to be released to a hospital closer to home. Who's responsible for making hospital transfer arrangements and providing transportation?

   A: The Division of Parole is committed to taking the initiative in providing leadership to ensure the development of comprehensive release plans in these cases. Division staff bear bottom line responsibility for release planning. Parole staff must take the lead in coordinating the development of the release program and expedite the completion of program plans.

   Under these circumstances, an inmate would be released to an approved program in the same manner as any other inmate, that is, via the Community Preparation process. In completing the community preparation assignment, i.e., developing a hospital program, the field Parole Officer will need to identify appropriate community medical facilities, working in conjunction with community resources (e.g., AIDS Task Force) and institutional Parole and DOCS staff.

As with other releasees, DOCS is responsible for arranging transportation in accordance with the release plan and established procedures. Frequently, to facilitate a transfer of this sort, DOCS may grant a medical leave of absence to a community hospital or transfer the inmate to a correctional facility closer to his parole destination. Division Staff should explore arrangements of these sorts where deemed necessary with appropriate DOCS Staff (Health Services or Temporary Release).

(Note: In cases where an inmate has been granted a medical leave of absence, signing of the Certificate of Release to Parole Supervision (Form 3010), typically handled by the Parole Officer in the institution, will be the responsibility of the Parole Officer in the field.)

10. Q: I can't get a residence for an inmate with AIDS -- his family is afraid to let him come home. Can I refer him to a Parole Resource Center? How?

A: Under these circumstances and with the consent of the inmate, a clear statement of medical diagnosis and status with relevant back-up documentation (e.g., the DOCS Medical Discharge Summary) must accompany the PRC referral. In accordance with the contractual agreement between the Division and residential service providers, individuals having medical problems beyond the capacity of the program to address may be refused admission by the program. This may well be the case with releasees with AIDS who require intensive or specialized treatment.

Before resorting to a PRC program, however, you may find that by making counseling and information available to families you are able to dispell some of their fears and misconceptions. Resources to assist in this process can be identified through Regional AIDS Task Forces, as well as by DOCS Ministerial and Family Services.

11. Q: I'm trying to work out a release plan for an inmate with AIDS who was recently hospitalized. His condition seems to change rapidly and I'm having trouble assembling a suitable plan. Who can help me with this?

A: Release plans in these cases should be built on medical information provided by DOCS facility Health Services Units through Medical Discharge Summaries. These plans should be comprehensive enough to anticipate possible changes in medical status and should include alternatives for community-based hospital and outpatient care.

In addition to DOCS facility Health Services staff, Regional AIDS Task Forces and DOP Regional AIDS Liaisons are resources as you develop these plans.

12. Q: When I am assigned the Community Preparation investigation on an inmate with AIDS or ARC, how do I know if the inmate has been informed of the diagnosis, if he has accepted his medical condition and told people who need to know about it, especially lovers or roommates?

A: This information should be included in the Medical Discharge Summary form prepared by DOCS facility Health Services staff and forwarded to the institutional Parole Officer. This form addresses specifically whether the diagnosis is known by the patient and/or family. In addition, the institutional Parole Officer should discuss these issues with the inmate in the interview for the Parole Board Summary and in subsequent contacts. The fact that an inmate has AIDS, and other information pertinent to this condition, should be mentioned in the medical status section of the Parole Board Summary to which the Medical Discharge Summary is attached.

If the field Parole Officer responsible for the community preparation investigation does not feel that this report is explicit enough with respect to the circumstances of the inmate's medical status, he should contact the institutional Parole Officer responsible for the preparation of the Summary and ask to be provided with additional information. The field Parole Officer should not initiate direct contact with DOCS facility Health Services staff, rather should rely on the institutional Parole Officer's relationship with the facility's Health Services staff to obtain any needed information.

13. Q: I've been assigned the Community Preparation investigation on an inmate approaching release who has AIDS. Although the Parole Officer in the institution has counseled him about responsible behavior in light of his medical condition, he has not yet told the person with whom he plans to live that he has AIDS. Can I tell?

A: Inmates have a federally protected right to confidentiality, which prohibits the disclosure of medical information without the inmate's permission. Absent this permission, Parole staff may not disclose this information. Any person revealing information of this sort without the necessary release form signed by the inmate may be liable for violating these federally protected rights.

We should exhaust every resource to avoid these situations. While it may not be an easy task, Parole Officers must use all of their skills to provide counseling that enables inmates with AIDS or ARC to behave in a responsible manner with regard to their medical condition.

14. Q: Can I disapprove an inmate's residence plan if he refuses to tell the person with whom he will be living that he has AIDS or ARC?

A: An inmate with AIDS or ARC may choose to exercise his federally protected right to confidentiality by refusing to reveal his medical condition, even to a roommate. We cannot deny release based on the exercise of this right. While you can and should urge the inmate to disclose this information and explore alternatives with him, in the final analysis, a residence plan that is acceptable in all other respects cannot be rejected for this reason.

15. Q: I'm doing the Community Preparation investigation on an inmate with AIDS. The Parole Officer in the institution describes him as asymptomatic. He has an offer of employment. Should I tell his employer about his medical condition or disapprove his employment?

A: Again we are faced with the same issue of protected rights and confidentiality. Employment can be disapproved only if a relationship exists between the inmate's crime and the proposed job. Since AIDS is not transmitted by casual contact, and requires sexual intercourse or the sharing of needles or exchange of blood, legitimate employment is not likely to present an opportunity for transmission of the disease.

Therefore, a diagnosis of AIDS or ARC is not a basis to deny employment, and you are prohibited from disclosing this condition to an employer without the necessary release forms signed by the inmate.

16. Q: An inmate is conditionally released without prior notice to the receiving field office. A check of the releasee's case folder indicates that he was diagnosed as having AIDS. What resources are available to assist the Parole Officer in developing a program?

A: The institutional Parole Office should be contacted and all available data reviewed to determine whether a program was previously proposed or developed. If no such tentative plan exists, appropriate local resources should be utilized (e.g., Regional AIDS Task Forces and county social services departments).

17. Q: An inmate with AIDS who is being released has been assigned to my caseload. Should I keep him from coming into the office by putting him on non-report status?

A: The issue here is whether the parolee's medical condition is so fragile that he is incapable of reporting or whether he is so immune suppressed that reporting would endanger him. These are decisions which depend on an individual's current medical status, and should be made on a case-by-case basis based on medical status.

Parolees with AIDS or ARC may be excused from office reports in keeping with the provisions of Field Services Manual Item 9204.00, Caseloads in

Supervision. These decisions must be made in consultation between the Parole Officer and Senior Parole Officer, be based on current medical status, and be reflected in notes in the parolee's folder. As in any case where there is a dimunition of supervision contacts, alternative means to establish contact should be fully utilized.

All cases where a releasee is excused from office reports shall be reviewed monthly by the Senior Parole Officer to determine whether the basis for such a decision is still valid. Documentation of such periodic reviews shall be included in the releasee's case record.

Written notice shall be forwarded to the Area Supervisor with a copy to the Parole Services Program Specialist in all cases where a releasee with AIDS or ARC is excused from regular office reports, with periodic updates in keeping with the requirement for monthly review of such decisions.

18. Q: I have a couple parolees on my caseload who have been diagnosed as having AIDS, and another whom I suspect. Won't I be in danger of getting AIDS when I make home visits?

A: As stated previously, there is no indication that AIDS can be transmitted through any form of casual contact and routine home visits should not pose any risk. In these cases, Parole Officers are expected to meet all standards and requirements of supervision, with the exception already described concerning office reports. Prudence would dictate that in the absence of office reports, the purpose served by these contacts must be accomplished by other means, in particular home visits. As in all other situations, as dictated by the specific needs of the case, additional contacts should be made as are appropriate.

19. Q: In supervising a releasee in the community who has AIDS, how do I know what precautions are recommended based on the releasee's current medical status?

A: Field Parole Officers should obtain the written consent of the releasee in order to establish contact with community medical professionals treating the releasee. Information germane to the issues of supervision and casework would be: is the releasee able to travel; what medication(s) is the releasee taking; are there special services needed by the releasee; can the releasee work; what is the releasee's current medical status.

Obviously, as the releasee's condition changes, so will responses to these questions and the nature of parole casework and supervision. Regular ongoing contact with health providers will be necessary to ensure practices are consistent with current medical status.

20. Q: I was just told by a parolee on my caseload that he has AIDS, and that no one else knows. Who should I tell? Is there anything else I should do? Should he see a doctor?

A: Aside from discussing the case with the Senior Parole Officer or other appropriate Division staff, Parole Officers are precluded from revealing any individual's medical status to any other source without his written permission. While Part 24 of the State Sanitary Code provides for mandatory reporting of AIDS, reporting must be directly by the person identifying the condition (e.g., physician, lab, coroner) to the Commissioner of Health utilizing prescribed forms.

If the parolee is not seeing a doctor, the Parole Officer should help him locate a clinic and any other required medical support services. All parolees with AIDS should have plans in place for medical services, to insure these are available when needed. This plan should include having the parolee sign any release of information forms necessary to enable the Parole Officer to obtain medical status reports from any treating physician.

In a situation like this, one of the most important responses by the Parole Officer is to counsel the parolee about the seriousness of this medical condition and the importance of medical treatment and responsible behavior. The Parole Officer is in a critical position to provide direction to the parolee and will want to discuss with him the ways in which this illness may impact daily living. The Parole Officer will want to insure that the parolee is receiving necessary medical, financial and other related assistance and assist him towards this end.

21. Q: A parolee I supervise who has a history of IV drug use seems to be losing weight rapidly and complains of symptoms that sound like AIDS. I've directed him to see a doctor, and have even located a clinic that will see him, but he has resisted going. What alternatives do I have?

A: The steps described here are the appropriate ones to take, that is, to counsel the parolee to obtain medical treatment, to assist him by identifying community resources and to facilitate the process of obtaining these resources in every way possible (such as, contacting the clinic on behalf of the parolee or escorting him to the clinic).

It is important that we recognize resistance and denial as common reactions to life-threatening illness, reactions which often keep people from seeking needed medical treatment. These cases require patience and creativity to encourage the parolee to obtain the medical evaluation and assessment which seemed to be indicated. Ultimately, however, the Parole Officer has little recourse if the parolee refuses to seek medical treatment, even if AIDS is suspected. This disease is not classified as a communicable disease and is not quarantinable, nor is having AIDS a criminal activity. The Parole Officer's alternatives in this situation are to bring all resources to bear to encourage the parolee to seek the medical attention that seems to be indicated.

22. Q: A parolee I supervise who has AIDS has lost his residence and has no prospects for another. What can I do beside send him to a men's shelter?

A: A shelter, typically a congregate living situation with limited facilities for privacy or personal hygiene, is not an adequate or appropriate setting for individuals who are seriously ill or suseptible to infection and other communicable diseases. Shelter settings should be used only as temporary, last resort for parolees with AIDS, and intensive efforts to work with community resources to locate an appropriate residence should be a priority. Assistance in locating housing should be sought from the DOP AIDS Liaison or Parole Services Program Specialist before sending any parolee with AIDS to a men's shelter.

23. Q: Does the Division have money to help parolees with AIDS with the cost of housing or other expenses?

A: The Emergency Support Fund and Emergency Housing Funds established in each area office exist to assist parolees in need of housing, transportation and other assistance. Funds can be accessed in accordance with local area office procedures.

24. Q: The number of people exposed to AIDS seems to be increasing all the time, and a lot of parolees are at risk because of IV drug use. How do I protect myself in case a parolee I'm taking into custody has AIDS? What should I do if I am exposed to AIDS by a parolee who spits on me or bites me? What if I get stuck by a needle or cut by a razor while I'm searching someone?

A: Apprehending a parolee who has AIDS or ARC should be a well planned operation. Advance thought should be given to contingency plans in the event that any problems develop.

Extreme caution should be exercised when searching any releasee known or suspected to have a disease that can be transmitted by blood contact since hypodermic needles, knives, or other such objects capable of causing puncture wounds might be encountered.

Advance arrangements should be made with the institution that is expected to receive the releasee whenever possible. The location of hospitals in the area should be known in the event that medical treatment is needed for any parties involved.

At the conclusion of the operation the case record should be annotated to indicate what transpired. If any unusual event occurred or circumstances were encountered, an Unusual Incident Report should be prepared according to standing procedures.

25. Q: What special precautions should be taken when transporting a releasee who has AIDS or ARC?

A: Any time it is necessary to transport a releasee who has AIDS or ARC, the Parole Officer or Warrant Officer responsible for transporting the releasee should be informed that the individual has AIDS or ARC, just as they should be informed if an individual is suicidal, is epileptic, or had any other medical problem. Standard procedures should be followed in these cases as they would be with any other releasee being transported by staff.

26. Q: If I violate a parolee who is diagnosed as having AIDS or ARC, where do I take him once I have him in custody and what information can I share with the other law enforcement agency?

A: The Division has both a responsibility and a legal authority to advise local jurisdictions of a parolee's medical status, to the extent that such medical conditions may require special treatment or handling for the health and safety of the parolee, other inmates or Corrections staff.

Upon arrival at a local detention site, Parole Officers should advise Corrections staff of the parole violator's medical status in the same manner that a Parole Officer would provide information in the case of an individual suffering from a heart condition, diabetes, etc.

27. Q: What precautions should I take when collecting or testing urine samples from parolees? What should I do if I get splashed with urine?

A: Parole Officers should not collect urine samples from any parolee suspected or diagnosed as having AIDS. If urine testing is required in these cases, the parolee should be referred to a clinic for this purpose.

Under ordinary circumstances, disposable gloves and special clothing should be worn by anyone who takes urine specimens. It is also suggested to place the urine specimen cup inside a plastic bag in order to control spillage.

If for some reason an individual is splashed with urine, however, there is no reason for alarm as the HTLV III virus has not been isolated in urine and no cases of AIDS have ever been linked to urine. Soiled surfaces should be cleaned with disinfectants, such as household bleach (dilute one part bleach to ten parts water).

28. Q: Is protective clothing available if I should need it, and how do I get it?

A: Protective clothing (gowns, gloves and masks) have been made available to each area office. Area Supervisors are responsible for providing access to these garments.

29. Q: Shouldn't all parolees be required to be tested for AIDS?

A: The State of New York does not recommend or support mandatory HTLV-III antibody testing for any group or individual. The screening test indicates only the presence of antibodies to HTLV-III virus, not the presence of virus . The presence of antibodies in the blood means only that the person has been exposed to the virus at some time. It does not necessarily mean that the individual is carrying the virus and is capable of transmitting it to others. Most persons exposed to the HTLV-III virus will not develop AIDS.

For parolees who request it, testing can be obtained through regional HTLV-III antibody test sites that have been established by the State Health Department to provide testing and counseling for persons who wish to know if they have been exposed to the virus. Testing is free of charge at these sites, and strict confidentiality is maintained through use of a code system. Persons seeking the HTLV-III antibody test need not give a name, address or any other potentially identifying information. Private physicians also have been provided information about procedures for performing the test or arranging for their patients to obtain testing. For information on HTLV-III testing in New York City call (718) 485-8111; outside of New York City call (518) 473-0641.

30. Q: Should I be counseling parolees about safe sex and drug use as it relates to AIDS?

A: Counseling is an important part of a Parole Officer's job. Parolees who have a history of drug use may well be at risk of getting AIDS, and should be counseled about these issues. There are community resources available to you through the AIDS Task Forces to help you in this regard, either by providing direct counseling to parolees or by helping you to enhance your skills in this area.

31. Q: What resources are available within the Division to assist us and provide updated information on procedures related to inmates and parolees with AIDS?

A: Each region has designated an AIDS Liaison and a Parole Program Specialist who are available to provide technical assistance in difficult cases, and who are responsible for disseminating information about AIDS and resources programs available to assist people with AIDS. Lists of DOP Regional AIDS Liaisons and Parole Services Program Specialists are contained in Section VI of this manual; additional information about programs and resources can be found in Section V. This manual has been designed to be easily updated so new materials can be included as they are acquired.

SECTION IV - SERVICE NEEDS OF PEOPLE WITH AIDS

Parole casework with inmates and parolees with AIDS/ARC is not dissimilar from casework on behalf of other inmates or parolees with serious medical disabilities, although it often requires a degree more flexibility, ingenuity and tenacity. This section presents a general approach to casework with inmates and parolees with AIDS/ARC, with emphasis on the issues of continuity of care and coordination of services. These general casework guidelines must obviously be tailored to individual cases and local protocols.

The Regional AIDS Liaisons and Parole Services Program Specialist in each Region are available to provide special technical assistance to Division staff working with these cases and will be responsible for identifying resources and developing referral mechanisms to assist you in your work.

Discharge Planning

Appropriate discharge planning for inmates with AIDS/ARC is accomplished in part by coordination with the Health Services staff of the Department of Correctional Services (DOCS). The specific details of a discharge plan for an inmate with AIDS/ARC begins with a physician's assessment of the inmate's medical status and prognosis. The Medical Discharge Summary prepared by DOCS Health Services staff and made available to Division staff in the institution, describes the diagnosis, prognosis and aftercare services required by these inmates (see Section II, Policy on Coordination with the Department of Correctional Services.

If the goal of discharge planning is coordination of service and continuity of care and treatment, the challenge to Division is to overcome fragmentation and gaps in community-based service delivery systems. Development of discharge plans that are tailored to each inmate's unique circumstances and medical condition requires adequate lead time and careful planning. Close coordination between the Parole Officers in institutional and field assignments and with DOCS staff is essential, as is flexibility in planning and the development of contingency plans in anticipation of changes in medical status.

Discharge plans should address the following areas:

1. Medical Services

   .type and level of care required (hospital, out-patient, home care)
   .payment method for medical services (medicaid, private insurance)
   .special arrangements for hospital transfer

2. Financial Support

   .eligibility for SSI and other public benefit programs (e.g., home relief, food stamps)

3. Housing

4. Counseling

The following are activities that Parole Officers in institutional and field assignments must initiate in these cases:

Institutional Parole Officer

- o Track inmates with AIDS/ARC to ensure that Medical Discharge Summaries are developed and that the inmate's medical condition is addressed in discharge plans for all parolees and Conditional Releasees.

- o Obtain the Medical Discharge Summary from DOCS and facilitate the necessary information exchange between the institution's medical staff and field Parole staff.

- o In consultation with the field Parole Officer, assist the inmate who may be eligible for such programs, to initiate an application package for SSI or medicaid prior to discharge.

- o Obtain from the inmate, and make available to the field Parole Officer, signed release of information forms as necessary to share medical information with community service providers and others.

- o Apprise the field Parole Officer assigned to the community preparation investigation of any changes in medical status that affect the discharge plan.

Field Parole Officer

- o Establish contact with the local social services department and make arrangements for eligibility determination and assistance upon release as needed (food stamps, emergency public assistance, medicaid, home health aid services).

- o Arrange for community based medical services by identifying hospitals, clinics or physicians who can provide care and treatment and by facilitating exchange of medical information as necessary.

- o Identify housing resources and assist in the development of a residential plan that is adequate to the medical needs of the inmate with AIDS/ARC.

- o Assist families of inmates with AIDS/ARC by making referrals for counseling and other needed services.

Community Supervision

While most parolees currently known to have AIDS/ARC were first identified by DCCS while incarcerated, we can expect an increase in cases that will be identified by Parole Officers supervising releasees in the community.

Our approach to community supervision in these cases is not dissimilar to that in other cases where releasees suffer a serious medical condition or have severe problems requiring specialized services. Providing assistance to releasees to obtain medical care and treatment may be the primary focus of casework with these releasees and the Parole Officer's role in this regard is of critical importance.

We must anticipate the rapid change in medical status that frequently occurs with AIDS, where periods of relative health alternate with periods of acute infection and hospitalization. At the same time that the releasee's health is deteriorating, important support systems and financial resources may collapse or be exhausted. These circumstances will suggest additional important areas of casework and intervention, such as counseling with the releasee and/or family and assistance in obtaining social services, financial assistance or housing.

OVERVIEW OF PSYCHOLOGICAL ISSUES CONCERNING AIDS *

Prepared by Ken Wein, Ph.D. and Diego Lopez, C.S.W.

"As a psychiatrist at the Memorial Sloan-Kettering Cancer Center, I have the opportunity to interview, evaluate, and treat many patients with Kaposi's sarcoma (K.S.) and AIDS who are experiencing difficulties in coping with their illness. More than any other population of cancer patients, this one suffers a dramatic change in self-esteem, daily habits, and general life style in response to the onset of the illness.

"Psychological and social interventions are an integral part of treatment, for without adequate coping strategies and environmental supports, patients are easily lost from follow-up care."

Joseph Barbuto, M.D.
Psychiatry Service
Memorial Sloan-Kettering Cancer Center
(Letter reprinted from New York Times Magazine, March 27, 1983)

I. Social Isolation

- A. Withdrawal of social supports.
  - 1. Fear of mortality among friends, family.
  - 2. Helplessness; inability to effectuate change
    - a. Inability to "make patient feel better"
    - b. Unrealistic expectations among friends, family.
  - 3. Overidentification with patient
    - a. Friends are typically of same age, exhibit same lifestyle, interests, daily habits
    - b. Arousal of sense of vulnerability, fragility
  - 4. Fear of contagion
    - a. Conflicting, sometimes unscientific media reports
    - b. Difficulty separating appropriate and inappropriate anxiety
    - c. Hepatits B model
- B. Isolation among hospital patients
  - 1. Infection control precautions sometimes severe
  - 2. Occasional homophobic reactions among hospital staff

II. Alteration in Quality of Life

- A. Crisis, disruption, disorganization in thinking and daily habits.
- B. Experiencing "bankruptcy", boredom, isolation, social withdrawal
  - 1. Patients often too sick to work, too well to stay at home

*NOTE: these materials have been excerpted from training materials on AIDS developed by the Gay Men's Health Crisis, Inc.

2. Fatigue limits vocational, social participation

3. Medical restrictions
   a. Sexual practices limited, abstinence
   b. Social outlets withdrawn

4. View of self as leper in social, sexual void

III. Drop in Self-Esteem

A. Stigma of AIDS

1. AIDS as a sexually transmitted disease

2. Patients begin to feel guilty, dirty

B. Internal dialogue: "What did I do to deserve this?"

1. Surfacing of internalized homophobia
   a. "I have AIDS because I am gay"
   b. Bargaining -- "I'll go straight, if only I am cured"

2. Self-condemnation concerning "life in the fast lane"

C. View of self as toxic to others

IV. Intensity of Emotion

A. Obsessive cognitive (thinking) style

1. Absence of customary diversions, distractions, daily habits

2. Void filled by ruminative (obsessive, repetitive) thinking

B. Emotional vacillation

1. Anger, guilt, rage, depression, fear, easy tears

2. Fluctuations frequent within course of day

3. "Roller Coaster" effect
   a. Alternation between hopeful highs and helpless lows
   b. Rapid alternation due to changes in medical condition, doctor's reports, media, etc.

C. Anger

1. At lack of justice, righteousness in life

2. In response to realistic, concrete frustrations
   a. Demand for answers, effective treatments, comparative outcome data not satisfied

Dual Diagnosis: AIDS and Addiction

Larry Caputo

Acquired Immune Deficiency Syndrome, commonly known as AIDS, principally affects male homosexuals, intravenous drug abusers, and patients with hemophilia who are receiving factor VIII concentrate. The purpose of this article is to establish a framework for understanding the psychosocial impact of AIDS on those persons who are intravenous drug abusers. The article also explores the extent to which interventive social work roles and strategies toward comprehensive biopsychosocial services may be integrated into the health care system and ultimately implemented for use with this patient population.

Since the onset of the AIDS epidemic in 1981 through September 1984, University Hospital, the primary teaching hospital of the University of Medicine and Dentistry of New Jersey (UMDNJ), treated 124 patients for manifestations of this diagnostic entity. There was, however, a unique profile for the patients treated at UMDNJ: Of 124 patients, 98 had used intravenous drugs (heroin, cocaine); 80 were people of color (including a substantial number of women), and nearly all were in need of financial assistance. Fewer than ten men were identified as gay. This profile of patients—a profile of isolated, disenfranchised, and misunderstood people—creates implications far surpassing those for any other group at high risk of contracting AIDS. There was little sense of community among the drug abusers, even when there were common threads such as color, ethnicity, or an AIDS diagnosis. An attempt to form a group was a most difficult, but not impossible, task for the social worker.

One must also note that, in terms of the black and Hispanic communities, cultural aspects should be considered in attempting to deliver appropriate and needed services. There is a view that members of these populations are only impoverished versions of white, middle-class Americans. This perception has obscured the sociocultural aspects of observed differences in behavior, attitudes, and thinking. A social worker needs, therefore, to be aware of the African cultural base of the black population, as well as the specifics of the culture of each particular Latino population.

Because each individual is different, however, knowledge of culture, lifestyles, stress points, and the impact of external systems on each particular minority group must not negate the need to understand the individual and his or her special situation. In other words, this author does not believe that just because a person is a drug abuser and is diagnosed as having AIDS, there are no specific differences within the population.

IMPACT OF AIDS

The person with AIDS has many medical, social, and emotional complications that make the patient, family, and companions constantly vulnerable to crises. The way in which hospital personnel, patients, and families cope with these pressures affects not only adjustment but also the patients' survival.

The National Association of Social Workers, in a policy statement dated September 1984, suggested that the psychosocial impact of AIDS is similar to that of other life-threatening illnesses[1] Anxiety; depression; concern about body image, finances, and loss of control; and a confrontation with morality are among the feelings and critical issues faced by persons with AIDS. In addition, all individuals with AIDS and many of those closely associated with them have experienced extreme rejection and isolation due to the public's fear of contamination.

In April 1984, the nation's top public health officers announced their discovery that the essential agent causing AIDS was human T-Cell lymphotropic virus, or HTLV-III, adding that they were also certain that this virus would prove to be identical to one isolated by French scientists called lymphadenopathy-associated virus, or LAV.[2] These officials have further stated that there is no evidence to suggest that AIDS is aggressively contagious. According to the Centers for Disease Control in Atlanta, "airborne spread (as in outbreaks of influenza) and interpersonal spread through casual contact do not seem likely."[3]

DEMOGRAPHICS

Most persons with AIDS are in their thirties. About 60 percent are white. The majority of the remaining cases have been intravenous drug users, who are more likely to be younger and nonwhite. However, AIDS has been observed in all major ethnic groups of the U.S. population.[4]

My review of the psychosocial literature, thus far, reveals that most of it is written with a slant toward all risk groups except the one on which this article focuses, who may be the poorest.[5] To imply, however, that any high-risk group has adequate support

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[1] National Association of Social Workers, "Acquired Immune Deficiency Syndrome," NASW Public Social Policy Statement, Silver Spring, Md., September 1984.

[2] R. C. Gallo et al., "Isolation of Human T-Cell Leukemia Virus in Acquired Immune Deficiency Syndrome (AIDS)," *Science*, 220 (1983), pp. 865–867.

[3] Centers for Disease Control, as quoted by Gay Men's Health Crisis, Inc., *Medical Answers about AIDS* (New York: GMHC, June 1984).

[4] K. Mayer and H. F. Pizer, *The AIDS Fact Book* (New York: Bantam Books, 1983).

[5] See, for example, F. P. Siegal and M. Siegal, *AIDS: The Medical Mystery* (New York: Grove Press, 1983); and A. G. Fettner and W. A. Check, *The Truth about AIDS: Evolution of an Epidemic* (New York: Holt, Rinehart & Winston, 1984).

CCC Code: 0037-8046/85 $1.00

plishment of a defined change.[12] Encouraging verbalization, providing for ventilation of feelings, examining the pattern of relationships, exploring the secondary gains that the patient achieves by seemingly destructive behavior, and offering honest encouragement are also among other avenues by which the enabler role might be enacted.

CASE OF MR. P

Mr. P was a 29-year-old black male with a nine-year history of intravenous heroin abuse, who had recently been diagnosed as having AIDS. He was a person with several pervasive mental health problems, primarily poor self-image and a concomitant sense of powerlessness. Mr. P never graduated from high school. He knew, because of his color, history of drug abuse, and the AIDS diagnosis, that he had limited opportunities. Mr. P was being treated for pneumocystitis carinii pneumonia (PCP) and esophageal candidiasis, two diseases frequently seen in persons with AIDS. There was no evidence of a physiologic heroin dependence. Before hospitalization, Mr. P was living with his aunt. His aunt received welfare and took care of two young children, ages 6 and 4. She visited Mr. P in the hospital on a daily basis until the day she was informed that he had been diagnosed as having AIDS.

Intervention began, after the initial assessment, with the worker in the role of enabler. The worker encouraged Mr. P to be vocal and expressive. As trust between Mr. P and the worker developed, the patient requested information about AIDS, which dynamically moved the worker into the role as educator. Mr. P requested that the worker inform his aunt of his diagnosis. The worker, after informing the aunt, found that her knowledge about AIDS was limited. The worker began to provide a service to the aunt primarily in the role as educator. Simultaneously, the worker began the application process for public assistance for the patient.

The social worker was confronted with strong resistance to providing services to the person with AIDS, on the part of agency staff, anxiety or fear about the contagion factor, and often blind ignorance regarding the facts about AIDS. These reactions necessarily moved the worker into the dual role as educator and advocate.

While moving back and forth through the interventive roles in behalf of Mr. P, the worker learned that the patient's aunt had decided to stop visiting him in the hospital. The social worker learned further that the aunt was not going to allow Mr. P to return to his home after discharge. The worker, understanding the reality of housing for the patient, set up a meeting with the aunt. While proceeding to educate the entire family system about the contagion factor and offering precautions for care of the immunologically impaired person, the worker assumed the role of mediator and used specific techniques to bring about resolution of the conflict. Mr. P was discharged from the hospital two days later and returned to live with his aunt.

Mr. P then returned to the outpatient clinic for follow-up care by the clinic team. During the clinic visit, Mr. P informed the worker that he was interested in obtaining counseling for his substance abuse problem and other related problems. The worker, in the broker and enabler roles, supported Mr. P's decision to seek professional help and referred him to the appropriate agency.

SUPPORT FOR SUPPORTERS

The team of professionals who are intensely involved with gradually deteriorating AIDS patients are at risk for emotional distress. Staff, like patients, sometimes cope by using denial, but this is generally an unsatisfactory defense mechanism. Directors of these teams should encourage weekly group meetings in which cases are discussed and, more important, in which staff members can have an opportunity to discuss personal reactions. It is inevitable that providers working with AIDS patients will at times experience fear, frustration, anxiety, discomfort, and many other feelings as the AIDS crisis grows. Unless time is set aside to discuss these issues, symptoms of distress are likely to develop rapidly.[13]

WHAT CAN BE DONE

This article has attempted to address the unique psychosocial profile of the intravenous drug abuser with AIDS and has offered a methodological approach for integrating comprehensive biopsychosocial services into the health care system. Practitioners who adopt and adapt this approach to service delivery will require abilities in all roles so that they can select the most appropriate interventive role for each patient's situation. Failure, on the part of service providers, to be sensitized to the unique requirements and sociocultural attributes of this sociocultural patient population will result in minimal use of the services offered.[14] Service providers must identify what they know or, what is most important, what they do not know about the cultural lifestyles, addictive behavioral responses, and styles of defenses that are shared by most persons with AIDS.[15]

Social workers and other helping professionals must begin to take an active role in seeking solutions to the complex problems that AIDS presents to individuals and our society. Accurate information about AIDS, its treatment, and available medical, financial, and psychosocial resources should be widely disseminated to reduce phobia and stigmatization of those in high-risk groups.[16] We are now led to believe by health officials that AIDS in the United States apparently is being spread increasingly as a heterosexual venereal disease. For example, a New York study found that a surprisingly high number of sexually promiscuous heterosexual men had been exposed to the AIDS virus.[17] This author proposes that in a short time, no one will be talking about AIDS in terms of "high-risk" groups.

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[12] Grosser, "Community Development Programs Serving the Urban Poor."

[13] S. F. Morin and W. F. Batchelor, "Responding to the Psychological Crisis of AIDS," *Public Health Reports*, 99 (January–February 1984), p. 9.

[14] M. Delgado, "Culturally Specific Mental Health Program," in E. Mizio and A. J. Delaney, eds., *Training for Service Delivery to Minority Clients* (New York: Family Service Association of America, 1981), p. 121.

[15] S. O. Miller, "Reflections on the Dual Perspective," in Mizio and Delaney, eds., *Training for Service Delivery to Minority Clients*, p. 55.

[16] See NASW, "Acquired Immune Deficiency Syndrome," Policy Statement.

[17] "AIDS Exposure in Heterosexuals Is Seen Increasing," *Wall Street Journal*, April 18, 1985.

and treatment services is equivalent to saying that poverty in the United States is insignificant because it is even more egregious in certain underdeveloped countries. The mere suggestion, for example, that gay men (the largest affected group) have substantial medical, financial, and social supports angers the persons being served as well as many service providers.

ADDICTION AND AIDS

For purposes of this article, discussion focuses most often on substance abuse in its most chronic and "pathological" state. Depending on the substance, this may be manifested by intoxication throughout the day, inability to cut down or stop use, repeated efforts to control use through periods of temporary abstinence, continuation of substance use despite a serious physical disorder and the immunologic abnormalities that the individual knows are exacerbated by use of the substance, and need for daily use of the substance for adequate functioning.[6]

Frequently, individuals who develop substance abuse disorders may also have preexisting personality and affective disorders with concomitant impairment in social functioning. It is therefore necessary to determine that the social impairment associated with the diagnosis of substance abuse or dependence is actually due to the use of the substance.

A practitioner who is designated to deliver services to the chemically addicted AIDS population must be fully aware of the federal, state, and local regulations concerning treatment services. Workers should be aware of locally available treatment resources and usually should refer substance abusers to these specialized treatment centers and not attempt the treatment themselves, unless they have had formal training or experience in working with substance abusers, their companions, and families, as well as experience with the attitudes of society toward the treatment of such individuals.[7]

[6]American Psychiatric Association: *Diagnostic and Statistical Manual of Mental Disorders* (3d ed.: Washington, D.C.: APA, 1980), p. 165.

[7]R. Berkow, ed., *The Merck Manual of Diagnosis and Therapy*, Vol. 1 (14th ed.: Rahway, N.J.: Merck, Sharp and Dohme Research Laboratories, 1982), p. 937.

PRACTICE PERSPECTIVES

The interventive strategies set forth here assume the methodological social work commitment of person-situation interaction and are performed on a concurrent, ongoing basis. Workers may use this model to conceptualize their interventive roles while working, on an individual or group basis, with patients, families, companions, and outside agency personnel—the patient system.

A system may be described as a set of interrelated elements with a capacity for certain kinds of performance. The assumption is that a system is a complex adaptive organization of parts, which by its very nature continually generates, elaborates, and restructures patterns of meanings, action, and interaction. Within a system, something is continually going on, including a constant interchange with the environment across its boundary.[8] The following discussion focuses on five interventive roles from social work theory—educator, advocate, mediator, social broker, and enabler.

Educator. The social worker provides the person with AIDS with current information necessary for coping with the diagnosis. Secondarily, the worker may provide educational services to the patient's family, companions, hospital staff, and outside agency personnel with whom the patient system interrelates. Giving information implies supplying data, input, and knowledge that the patient or recipient is free to use or not.[9]

Advocate. The institutions with which a substance abuser with AIDS must deal are not always aware of the facts about AIDS, much less positively motivated toward handling the issues brought to them by the patient. As advocate, the social worker becomes the speaker for the patient by presenting and arguing the patient's cause when this is necessary to accomplish the objectives. The advocate in social work is not neutral but, like the advocate in law, is a partisan representative for the patient.[10] The advocate, after providing the education necessary for the patient to act responsibly, will argue, debate, bargain, negotiate, and manipulate the environment in behalf of the patient, to the extent that the patient is unable to do so.

Mediator. Mediation involves efforts to resolve disputes or conflicts that may exist between the patient and other persons or organizations—the patient system. If, for example, a patient has been left homeless because of the fear of contagion and the service contract has the goal of returning the patient back into his home, then the social worker may need to serve as mediator between the patient and fearful family members.

Social Broker. The primary objective is to steer the patient toward existing services that are aware of the facts about AIDS and can be of benefit. Its focus is on helping people use the system and negotiate its pathways. The essential benefit of this objective is connecting resource persons with the patient. Serving as a social broker requires a broad knowledge of community resources as well as a knowledge of the operating procedures of agencies so that effective connections can be made.

Enabler and Counselor. Assistance in the form of helping patients to do things that they can really do themselves is not assistance, nor is it enabling. Overhelping can lead patients to develop a sense of passivity, dependence, and helplessness. It can reinforce a sense of imminent decline. Patients should be encouraged to do as much as they can, taking into account medically prescribed limitations.[11] Workers should take the enabler role when their intervention activities are directed toward assisting patients to find the coping strengths and resources within themselves. The major distinguishing element of the enabler role is that change occurs because of the patient's efforts; the responsibility of the worker is to facilitate or enable the patient's accom-

[8]W. Buckley, *Sociology and the Modern Systems Theory* (Englewood Cliffs, N.J.: Prentice-Hall, 1971).

[9]B. J. Biddle and T. J. Edwin, *Role Theory: Concepts and Research* (New York: John Wiley & Sons, 1966).

[10]C. F. Grosser, "Community Development Programs Serving the Urban Poor," *Social Work*, 10 (July 1965), pp. 15–21.

[11]Gay Men's Health Crisis, Inc. (GMHC), New York, New York, is a not-for-profit corporation founded in January 1982 as a result of community concern about Acquired Immune Deficiency Syndrome (AIDS). Beyond its clinical services, GMHC provides a broad range of educational and informational materials to persons with AIDS, family members, companions, and service providers.

PSYCHOSOCIAL ISSUES WITH A.I.D.S. AND I.V. DRUG USERS

"At certain moments I find myself looking on my whole life as leading up to the present moment, the present being all I have to affirm. It's somehow undignified to speak of the past or to think about the future. I don't seriously occupy myself with the question in the 'here-and-now', lying on my bunk, and, under the influence of heroin, inviolable. That is one of the virtues of the drug, that it empties such questions of all anguish, transports them to another region, a painless theoretical region, a play region, surprising, fertile and unmoral. One is no longer grotesquely involved in the becoming. One simply is."

--Alexander Trocchi Cain's Book (1960)

"It seems that addicts in general find it difficult to tolerate prolonged interpersonal contacts when there is no means or running away from them... It is no accident that our patients refer to the world outside (of the U.S. Public Health Service Hospital in Lexington, Kentucky) as the 'street'; they cherish their mobility, the opportunity to escape difficult relationships, very highly."

---Psychiatrist in James Mills'
The Panic in Needle Park (1966)

"More than any other population of cancer patients, (Kaposi Sarcoma victims) suffer a dramatic change in self-esteem, daily habits, and general life style in response to the onset of the illness.
Psychological and social interventions are an integral part of treatment, for without adequate coping strategies and environmental supports, patients are easily lost from follow-up care."

--Joseph Barbuto, M.D.
Psychiatrist, Memorial Sloan-Kettering

Paul Kaiser, C.S.W. has been working in New York with A.I.D.S. patients who were I.V. drug users. What follows are his comments and observations concerning the impact of a diagnosis of A.I.D.S. for I.V. drug users. They are predicated upon the belief that the primary psychosocial aspect of addiction is that it serves as a defense against interanl, largely unconscious, intolerable feeling states. It may be helpful to think of the credo of an addict as something like, "WHENEVER POSSIBLE, AVOID FEELING. DO ANYTHING, CREATE ANY ACTIVITY, BUT KEEP TOO BUSY TO SIMPLY FEEL..."

I DENIAL

A. If I don't acknowledge something, it doesn't exist. e.g., addiction itself: "I could stop anytime if I really wanted to."

1. This is one of substance abusers' principal defenses. It is used overwhelmingly.

a. As a defense mechanism it is unconscious. It is not the same as lying, which is a conscious process.

b. As a defense mechanism it serves an important function. It can protect the self from overwhelming anxiety or a need for a more destructive defense; e.g. suicide.

2. The defense should be confronted only whenit is interfering with life functioning, such as getting needed medical attention.

B. The immediate effect of an AIDS diagnosis is a dramatically increased need for denial to defend against increased anxiety.

1. It is interesting to note in this context that Denial is also one of the recognized stages people go through in the process of dying. With many abusers, the entire process of dying takes place within this stage.

2. The acceptance of the AIDS diagnosis and its implications is a process. Typically, patients move back and forth through an infinite number of gradations of acceptance and denial.

II SELF ESTEEM/SELF IMAGE

A. Typically, this is exceedingly poor to begin with although this may be defended against with a presentation of grandiosity and omnipotence.

B. An AIDS diagnosis is a tremendous attack upon anyone's self esteem.

1. Typical reactions include:
I'm stupid
I've been betrayed
I'm being punished
I deserved this
I did this to myself

2. Listen for moralistic connotations in patients' responses. It is sometimes useful to point out that viruses do not have purposeful motivation.

III ADDICTOPHOBIA

A. Our atti tudes and feelings toward addicts.

1. Addicts present infantile, ego-syntonic neediness and demands for immediate gratification.

2. These are antithetical to prevailing attitudes regarding the value of delaying gratification. They therefore offend us and engender very strong negative emotional reactions.

B. Substance Abusers have these attitudes themselves, although they frequently manifest through the defensive measures erected against them. (see II Self Esteem)

C. The principal effect of an AIDS diagnosis is an exacerbation of the neediness and demandingness and, hence, the negative reactions on the parts of abusers and non abusers alike.

IV INTERPERSONAL RELATIONS

A. Addicts are generally highly active and interpersonally active, but in a socially encapsulated manner, associating almost exclusively with other substance abusers.

B. The effect of AIDS is further encapsulation.

1. Patients' withdrawal

a. Increased overt dependency and feelings of helplessness increase the need to avoid confronting (accepting) the AIDS condition.

b. Contact with others frequently leads to questions or reactions which threaten the denial.

2. Others' withdrawal

a. Other substance abusers identify with the AIDS patient.

b. This leads to fear and increases of feelings of vulnerability and anxiety. N.B. This, like all the other phenomena cited are applicable, usually to a lesser degree, to everyone; not just substance abusers. e.g. Note the difficulty many of us experience in visiting people in a hospital.

V AUTONOMY--ISSUES OF CONTROL AND DEPENDENCE

A. This is an extremely threatening area. Generally, all feelings of dependency or loss of control are to be avoided at all costs.

B. Addiction itself can be seen as an avoidance of acknowledging emotional dependency by making one's self physically dependent. (see VI-Externalization)

C. Effects of AIDS

1. Tremendous need to avoid acknowledging need for help.
e.g. medical appointments

2. Threat of loss of mobility.

a. This threatens entire life style (i.e., keep moving!) both literally and figuratively.

b. The threat of loss of mobility or an actual loss leads to increased anxiety which leads to an increased need for avoidance behavior which is restricted by the loss of mobility. (see VI)

VI NEED TO AVOID UNCOMFORTABLE FEELINGS--EXTERNALIZATION

A. Externalization, the principal defense of addiction, is the avoidance of internal conflict my means of creating conflict between the self and the environment.

B. AIDS increases the need for escape behavior as a means of avoiding the increase in anxiety due to the diagnosis.

C. An increase in self destructive or self punishing behavior may result for above reason as well as from an unconscious need for punishment. (see II Self Esteem)

D. Diagnosis may generate increase in rage.

1. Since this is another intolerable feeling it may result in a dramatic increase in angry acting-out behavior.

2. This is frequently directed at other substance abusers. e.g. continuing to share needles.

E. Increased possibility of mental deterioration.

1. This may be due directly to the disease; e.g. brain infection.

2. The increase in anxiety, rage, etc. may result in decompensation; that is, a breakdown of functioning due to inadequacy of former defenses to deal with increased anxiety.

VII ISSUES DIRECTLY RELATED TO THE MEDICAL MILIEU

A. Medical personnel seen as authoritarian. This threatens needs not to acknowledge or experience loss of control, helplessness or dependency.

B. Medical personnel seen as purveyors of bad news, therefore, to be avoided.

C. Medical milieu is seen as extension of society from which already feel alienated, rejected, and inadequate.

D. Most people feel some anxiety when dealing (usually under the pressure of symptoms) with doctors and medical settings. e.g. loss of dignity involved in undressing.

E. Medical personnel views of substance abusers. (see III Addictophobia)

1. Substance abusers frequently represent antithesis of medical beliefs and expectations.

a. Responsibility for self,caring for self.

b. Cooperative effort between staff and patient.

c. Acceptance of medical authority.

2. Doctors' difficulties in dealing with feelings of helplessness and impotence.

a. Substance abusers, frequently embodying Borderline and Narcissistic pathology, often communicate their feelings by inducing those feelings in others. That is, in an effort to help us understand what they are feeling, they "make" us feel helpless, angry, frustrated, rejected, and impotent.

b. AIDS itself, presents doctors with feelings of helplessness and defeat.

c. Patients with AIDS present doctors with issues around death and dying. (see IX Death and Dying)

d. For all of the above reasons it is very easy for a "negative contract" to be established in which the medical personnel do not communicate directly, honestly, or openly with the AIDS substance abuser patient and the patient encourages and accepts this.

VIII SOCIAL FUNCTIONING

A. Substance abusers, much more than any other AIDS patients, present a paucity of social support systems.

B. Patients may not recognize or may hesitate to suggest systems which do exist. e.g. family

IX DEATH AND DYING

A. Truly accepting one's own mortality or impending death is one of the most anxiety producing processes imaginable. We all utilize massive denial with this issue. e.g., not having a will.

B. Substance abusers, since they expose themselves to lethal practices daily, and because of their low tolerance for uncomfortable feelings, must utilize massive defenses against seeing, recognizing, or acknowledging mortality.

C. Substance abusers with AIDS are faced with an additional threat or insult to their fragile sense of self. The AIDS diagnosis stimulates the most terrifying, horrible feelings imaginable.

D. Most people with terminal illnesses react to their impending deaths in a manner more or less consistent with the way in which they've dealt with stress and crisis throughout their lives.

1. People who have a pattern of turning to others for support will be able to do this while dying.

2. People who typically have withdrawn into themselves when faced with an emotional crisis will likely repeat this approach.

3. As indicated above, substance abusers who characteristicaly use activity and anaesthetizing agents as a means of avoiding unpleasant feelings, will frequently repeat this pattern when faced with having AIDS.

ADDITIONAL STRATEGIES OF INTERVENTION*

1. **Listen actively and with concern.** A person can be made to feel important and deserving of help regardless of how trivial the problem may seem. Comments such as "hm, hm", "I see", and "go on", are useful in letting the client know we are listening. They encourage more talking and help build trust and rapport. We must also listen to ourselves internally.

2. **Encourage the open expression of feeling.** The worker's acceptance of a person's feelings often is the beginning of a healing process toward feeling better again. Crisis workers may want to role-model by using such expressions as: "If that happened to me, I think I'd be very angry."

3. **Treatment goals.** The goal is the establishment of a time-limited, accepting, open social relationship. Treatment is often just being with the client, listening to him or her, and understanding what he or she is saying. Sharing intense emotions helps to dilute their negative effects. Good empathetic listening skills are therefore critically important. Because crisis work with AIDS clients involves "being there", listening, and sharing, the best therapeutic style is the worker's own personality. Crisis workers are advised simply to be themselves, to trust themselves. Fabrications are inappropriate and easily detected by clients.

4. **Control issues.** Persons with AIDS tend to become passive recipients of medical treatment dictated by physicians and medical institutions. The medical establishment can be impersonal, frustrating, and lead to a sense of helplessness. Clients should therefore be encouraged to take as much of an active role in treatment as possible. They can participate in their treatment plan by learning about nutrition, stress management, relaxation skills, transcendental meditation, coping visual imagery, the "Simington Method", etc. Various self-help books focusing on these areas are available in bookstores.

5. **Be helpful, but don't "overhelp".** Assistance in the form of helping clients to do things that they can do themselves is <u>NOT</u> assistance. Overhelping can lead clients to develop a sense of passivity, dependency, helplessness. It can reinforce a sense of imminent decline. Clients should be encouraged to do as much as they can, taking into account medically prescribed limitations.

6. **Maximize the quality of the client's life.** Clients should be encouraged to participate in as many social, recreational, leisure, and occupational pursuits as possible, given their medical status. Discourage the frequently adopted role of the "professional patient," wherein clients spend all of their time in support groups, with crisis workers, therapists, and medical practitioners. Suggest that the client go to movies, theater, dinner parties, and the like. Link the

*NOTE: These materials have been excerpted from training materials on AIDS developed by the Gay Men's Health Crisis, Inc.

person to a social network; either restoration of old ties or the formation of new ones.

7. **Encourage the client to be vocal and expressive.** The significant others in clients' lives shrink away from the responsibility of discussing "heavy" issues. Clients are frequently told that they are being morose and depressing or that they are engaging in negative thinking when they initiate discussions involving their mortality. Don't assume that you can't or shouldn't talk about these issues with clients. It is important, however, that you let the client take the lead and allow him or her to guide you into these topics.

8. **Permit denial.** If the client is obviously utilizing the defense mechanism of denial, let it be, as long as his or her medical care is not compromised as a result. The failure to accept one's prognosis is usually not damaging. Denial reduces stress, keeps clients happy, intact, coping, and helps them to maintain a positive quality of life.

9. **Encourage participation in groups.** Group therapy is the treatment modality of choice for people with AIDS. Groups are safe and supportive place to discuss relevant issues and exchange information. They afford clients the opportunity to see examples of effective coping philosophies among other group participants. Further, group therapy always has a social component, thus reducing isolation.

10. **Reliability, consistency, and continuity.** The support offered by peer crisis workers must be reliable, consistent, and continuous. Since support primarily involves "being there", it is important that workers make commitments to themselves and to their clients to be available. Clients should be advised far in advance if workers plan to be out of town. Arrangements should be made for "back-ups." Additionally, clients should be followed-up on a regular basis to ensure continuity of care after they have been referred to other GMHC services.

11. **Help the person gain an understanding of the crisis.** Why me? What did I do to deserve such treatment? The crisis worker can help the individual see the many factors which contribute to a crisis situation, and thereby curtail self-blaming (i.e., homophobia, politics, bureaucracies, lack of medical knowledge).

12. **Assist by thinking of new ways of coping with problems.** Here it helps to discover how the person coped before the crisis. We can usually discover that coping abilities were stopped at some prior traumatic event or that they were appropriate until this current crisis, and client needs to be reminded of this.

13. **Help the client gradually accept reality.** Respond to the client's tendency to blame his or her problems on others. Client may want to be a victim. The crisis worker should explore with the client the consequences of such a role.

14. **Decision Counseling Techniques.**

- **What problem is to be solved?**
  Worker: What do you want help with now?

- **How is it to be solved?**
  Worker: What do you think would be most helpful?

- **Who should be involved in solving it?**
  Worker: Who else have you talked to about this problem who could be helpful?

Decision counseling also includes setting goals for the future and an alternative action plan to be used if the current plan fails or goals are not achieved. Crisis workers must have knowledge of the person's functional level and of his or her network of social attachments.

Used effectively, clients can:

- develop new problem-solving skills
- establish more stable emotional attachments
- improve social skills
- increase competence and satisfaction with life patterns
- cut away at any denial regarding death and help prepare themselves for dealing with new issues (i.e., mortality, legal affairs, etc.).

15. **Reinforce** the newly learned coping devices, and follow-up after the resolution of the crisis. Persons are not cut off in an abrupt manner. Check-in. Follow-up work can often be the occasion for reaching people who are unable to initiate help for themselves before an acute crisis occurs.

16. **Be sensitive to the client's social unit.** Clients do not live in a vacuum. They are surrounded by friends, family members, roommates, and lovers. It is not unusual for clients to experience as much stress from significant others as they do from the disease itself. Workers should obtain the client's permission to consult with these individuals, to strengthen the client's natural social supports, and to make referrals for significant others as needed.

17. **Allow time for an alliance to develop.** It takes time to establish trust and to cultivate an ongoing, accepting relationship. Be patient.

18. **Avoid statistics.** Statistics are not helpful. Discussions of mortality rates can lead to pessimism, self-defeatism, and helplessness. Further, overall statistical data is not relative for individual cases.

19. Maintain regular contact with the client's primary physician. It is not unusual for clients to misconstrue doctors' statements. Anxiety often interferes with listening and comprehension. It is critically important that workers obtain written permission from their clients to consult with physicians and hospitals concerning recommendations for diet, rest, leisure, work, sexual practices, etc.

20. Accept being used as a dartboard. Workers should recognize their need for a "thick skin." Clients will find many reasons to become angry, and they will often direct this anger at whatever or whoever is present. Workers should not personalize these attacks. When they occur, clients should be engaged in dialogue. We often direct the most anger toward the people we feel "safest" with.

21. Give yourself permission to experience discomfort. Workers should recognize, and refrain from, self-condemnation when they experience fear, anxiety, discomfort, or general self-consciousness with clients. Working with individuals who are facing a possible terminal illness is not easy. Remember that you are human and that it is natural to feel fragile, frightened. Workers are encouraged to participate in support services designed for them by GMHC.

EMOTIONAL STAGES OF THE DYING PATIENT *

(As per Dr. Elizabeth Kubler-Ross)

In general, stages overlap, coexist. Patients may fluctuate from stage to stage, even daily.

The following are defense mechanisms and are necessary for adequate coping.

1. First Stage: DENIAL AND ISOLATION

   - Most primitive but healthy (buffer)
   - "Not me, it can't be true"

   Allow patient his denial; it must be up to him to indicate readiness to deal with his mortality.

   Avoid judgment.

2. Second Stage: ANGER

   - "Why me?"
   - Displaced and projected. Expect being a dartboard.
   - Empathy most important here. Do not take it personally.

3. Third Stage: BARGAINING

   - Only effective briefly
   - Demands replaced with bargains
   - Often associated with quiet guilt

4. Fourth Stage: DEPRESSION

   - Numbness and stoicism, anger and rage replaced by a sense of great loss
   - Two types important to distinguish
     - Reactive depression
     - Preparatory grief
   - Allow patient to feel sad

5. Fifth Stage: ACCEPTANCE

   - Almost all patients who have sufficient time experience this stage
   - Neither depressed nor angry — void of feelings
   - How do we know if a patient is giving up too early?

*NOTE: These materials have been excerpted from training materials on AIDS developed by the Gay Men's Health Crisis, Inc.

b. Lack of effective governmental response
c. Victimization by medical establishment
d. Inability to retain control
e. Media hysteria
f. Abandonment by friends, family

V. Issue of Control

A. General sense of lack of control over disease, body, life

1. Reinforcement of passive, helpless patient role by medical establishment

2. Lack of effective treatment plan

B. Struggle to regain control

1. Scrambling from doctor to doctor for disconfirmation of diagnosis

2. Perceived sense of urgency to select treatment option

C. Relevance for counseling

VI. Denial

A. Defense mechanism

1. "Not me, it can't be true"

2. "I'll be the first to overcome this disease"

3. Denial as primitive but healthy buffer

B. Importance of denial in keeping patients intact

1. Helps patient to maintain positive quality of life

2. Allows patient to deny; patient must indicate readiness to deal directly, openly with prognosis

C. Denial to be challenged only when medical treatment is compromised

VII. Financial Stressors

A. Cost of treatment is exorbitant
1. Range: $50,000 to $100,000

2. Can reach one half million dollars

B. Importance of knowledge of third party reimbursement and government financial aid

LEGAL ASPECTS OF AIDS *

People with AIDS often must face issues besides the immediate questions of medical care and treatment. In the course of providing assistance to People with AIDS, GMHC has recognized that many of the problems it was seeing were legal in nature. The GMHC Legal Services Division, which operates in cooperation with the Pro Bono AIDS Panel of the Bar Association for Human Rights of Greater New York (BAHR-GNY), has been set up to provide free legal assistance to People with AIDS who cannot afford to retain a private lawyer.

This article profiles some of the typical legal problems GMHC has encountered and is equipped to handle, but is by no means exhaustive. These issues and other legal problems may arise requiring immediate legal intervention. It is important to remember that these issues are not confined to Persons with AIDS, however, the fact of being ill often brings some urgency that these legal concerns be addressed as soon as possible. Furthermore, the best time to deal with most of these problems, especially drafting of wills, is while a client is in relatively good health, and not while he or she is hospitalized, cricitally ill, or near death.

1. Wills

Wills are extremely important for everyone, but especially for gay men and lesbians who often create close ties with people who are not related by blood or marriage. Without a will, property passes by the laws of intestate succession to only close family members. In New York, for example, when a person dies without having a will, assuming he or she is not married and has no children, property then passes to his or her parents. If the parents have both predeceased the decedent, property then passes to brothers or sisters, then living, or if not living, to the brothers' or sisters' children. Going down this line of succession specified under New York law, if no close relatives are living at the time a person dies, distant relatives may be the only distributees entitled to inherit the person's property. Without a will, there is no provision whatsoever for the distribution of property to lovers, friends or other non-relatives. The only way to leave property to non-family members is by having a properly drafted and executed will. And with a will, a person may leave his or her property to whomever he or she wishes and in whatever amount, provided there is no surviving spouse. (There are some exceptions to this rule, where property is said to pass "outside" the will. Examples are apartments or houses owned as joint tenants with a right of survivorship, bank accounts held jointly or in trust for another, and some life insurance policies, pension funds and annuities.)

In addition to directing how property is to be inherited, a will often includes other important provisions, such as a designation of the person who will be responsible for the estate, known as the executor, instructions on funeral arrangements and body disposition, naming of

*NOTE: These materials have been excerpted from training materials on AIDS developed by the Gay Men's Health Crisis, Inc.

persons who are not to inherit any property, and instructions for the payment of debts, expenses of the estate and taxes, if any.

There are some special concerns drafting wills for people with AIDS. It is important that the client be competent to articulate what his or her wishes are and show no signs of undue influence from other persons. The Surrogate's Courts scrutinize these circumstances very closely, especially when someone dies within a short time after a will has been signed or when a person chooses to leave a significant portion of his or her estate to non-family members. For this reason, it is important to have the will prepared and signed at the very earliest time. On the other hand, our legal services program is ready and available to prepare wills in emergency situations for critically ill clients when necessary. This service, however, should be the exception rather than the rule.

Because of the particular concerns of our client population, wills should always be prepared by and signed under the supervision of an attorney. GMHC is, of course, available for this service.

2. Authorizing Other People to Act for You

A Power of Attorney (P.A.) is a legal document by which one person authorizes another to act for him or her. The P.A. will deal with virtually all transactions, including such day-to-day matters as paying bills. The P.A. can remain in effect even though the person who sign it becomes incapacitated, but the P.A. will become inoperative upon the signer's death. If it appears that the person you are helping may become too sick to manage his day-to-day affairs, and he has a close friend, lover, or relative he trusts to handle his affairs, you may want to suggest that a lawyer be consulted about a P.A.

In addition to a P.A. which deals with financial affairs, an individual may wish to sign another kind of P.A. that authorizes another person to make medical decisions for him and to have first priority in visitation rights in a hospital. This need arises because some hospital restrict medical decision making and/or visitation to family members when the patient is gravely ill. There is no guarantee that the hospital will honor such a document, but many hospitals will.

Finally, it is possible under Article 78 of the New York Mental Hygiene Law to designate in advance the person to act for you in the event that a court declares that you are "incompetent" (i.e., unable to make you own decisions).

3. Living Wills

A "living will" is not a will at all. It is a document that expresses your wishes about your right to be allowed to die if your condition is so serious that nothing can be done to help you, other than to sustain life through artificial means. Some states have passed laws that authorize living will, but New York is not one of them. If you have

strong feelings about this issue, you may want to draw up a living will anyway, in the hope that wishes will be followed.

4. Housing

Sharing Apartments

Most rental leases in New York have a provision that restricts occupancy of the rental apartment to the tenant(s) whose name is on the lease and certain members of the tenant's family. Violation of this restriction, without the landlord's permission, could result in eviction. This was a major problem for many people who wanted to share their apartment with a friend or lover, and was especially serious for people who were sick, and could no longer live alone.

During the Summer of 1983, the New York legislature responded to this problem by passing a law that allows anyone who lives in a rental unit to share his or her apartment with an additional person, regardless of what the lease says. This does not mean, however, that tenants now enjoy complete freedom to share their apartment with as many people as they wish. Moreover, notice to the landlord is required if there is an additional person, and that person is not given any right to remain in the apartment if the tenant moves out. It should be stressed that despite the fact that your lease gives you an interest in real property, it is not an interest which can be bequeathed in a will, i.e., my roommate Joe or Eileen cannot be designated as the person to stay in my wonderfully rent controlled apartment for the balance of my lease upon my death. The lease terminates upon death, even though the estate of a deceased person does have a right to stay in the apartment until matters are wound up.*

The new housing law is complicated and contains other important provisions that affect tenant rights, such as the right to sublet. If a Person with AIDS has housing questions, these could probably be resolved by a telephone call to GMHC Legal Services or during a General Consultation (see below).

Landlord-Tenant Actions

Summary proceedings in Landlord-Tenant Court, known by many people as "Dispossess Proceedings" urgently require immediate legal intervention. A client should be referred to Legal Services immediately if he or she has been served with papers from his or her landlord, in the mail, affixed to or under the front door of the apartment, or to someone who lives in the apartment. These papers are known as a "Notice of Petition" and "Petition", and must be responded to immediately to prevent an eviction from the apartment.

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* In this type of situation, its probably best to try to have the roommate included on the existing lease or to ask the landlord for a new lease for both the present tenant and the roommate. A landlord is not required under the law to honor these requests.

Summary proceedings usually involve one of two types of situations: (1) non-payment of rent, or (2) a claim by the landlord that a term or terms of the lease have been "substantially violated" by the tenant. Special care should be taken if a client is served with dispossess papers while he or she is in the hospital.

Legal Services can often respond to these cases effectively. Since landlords often serve papers improperly, i.e., without following the strict requirements of law, the case may be thrown out on technical grounds. We may also be able to negotiate and resolve the case with the landlord or the landlord's attorney. And, in cases where an eviction cannot be prevented, we can stall an eviction for weeks or months, giving the client precious time to find alternative housing. The important thing to remember is that we need to act very quickly.

5. AIDS Related Discrimination

The shocking fact is that there have been a number of complaints by Persons with AIDS and other people that they have been denied jobs, asked to leave their present job, refused treatment in dental and other health care facilities, refused entrance or requested toleave a restaurant or other public accomodation because of their illness or "perceived" illness. This brand of discrimination is absolutely illegal under various Federal, State and New York City laws.

With few exceptions, usually dealing with public employment, it is not illegal in New York and most other jurisdictions to discriminate against a person because of his or her sexual orientation. However, AIDS is considered a handicap or disability under the law, and it is illegal to discriminate against people having a handicap or disability. Moreover, even people who do not have AIDS but suffer AIDS related discrimination are protected under, at least, New York State law, because it is illegal to discriminate against someone who is though or "perceived" to have a handicap or disability. This is especially important because a number of people who have been discriminated against do not, in fact, have AIDS, but are thought to have AIDS primarily because they are Gay. In at least one case, a man was fired from a job just after he told his supervisor at work that a friend of his had just been diagnosed with AIDS.

The majority of our cases deal with AIDS related discrimination in the workplace, however, there have been a number of reports of discriminatory practices in areas of public accomodations (i.e., places and services open to the public at large such as restaurants, health facilities, funeral homes, ambulances), and housing. Protection against AIDS related discrimination extends to all situations involving employment, housing and public accomodation.

It is important to note that the cases we see and hear about may represent "the tip of the iceburg". For example, many employers may realize that it is illegal to fire an employee because he has AIDS, so they might give another reason for termination, such as misconduct, faltering productivity or too many absences from work. It is impor-

tant in all such cases to look beyond the obvious and try to see what really happened and why the person really lost his job. It is the responsibility of all of us to seek out and report all instances of discrimination, especially cases that are no so obvious on the surface. In this area, the law is on our side. It is equally important that persons document their suspected cases of discrimination from the outset and if unsure, to contact Legal Services for advice and instruction.

6. Liability for the Debts of Others

It is hardly news that medical care is expensive, and AIDS patients frequently run up very high medical bills in a short time. Hospitals often become quite concerned about how the bills will be paid if the patient has limited insurance coverage, and may look around for another person (usually a family member) to guarantee payment. Normally, a person is under no obligation to assume the debts of relatives who are not minor children. There is certainly no obligation on the part of a friend or a lover. While this may be a consideration in entering the hospital under normal circumstances, if an emergency health situation occurs, a public hospital is obligated under law to accept the patient.

During a personal health crisis, funds naturally become diverted from their normal course to payment for medical services. After a time, one's regular creditors may get impatient and the last thing one needs while being ill, is to be harassed by these impatient creditors. While this harassment may be annoying, it is not necessarily threatening since there are three ways to address the problem. First, some persons are "judgment proof". If an ill person has little or no physical assets, i.e., no real property and no source of income, then a creditor is left without anything he can attach to satisfy the debt owed to him. In this kind of situation the client is said to be "judgement proof", i.e., what few assets the person has such as clothing, furniture, most appliances, books, etc., he may keep without fear that a creditor may try to take them. Most people who do not have real property or large bank accounts are in fact judgment proof. There are very strict provisions in the law to govern this. The creditor may scream alot, but there is nothing he can do except go to court and get a judgment against the debtor which cannot be enforced. If the debtor is working, wages can be garnished, but under law, this can only be done in the amount of 10% of the paycheck. Second, the debtor may declare bankrupcty, which can discharge him or her from all debts under the law. The problem here for severely ill persons is that a bankruptcy follows one around for a period of ten years and a hospital may be discouraged from admitting someone if it finds out that he or she has taken this route in the past. Moroever, a person can only file a petition in bankruptcy once every six years. A third alternative, however, is that creditors can be approached by letter to settle the accounts of an individual by accepting a smaller amount of the debt and being satisfied with that smaller amount. The threat of bankruptcy looming on the horizon (which will probably cause the

creditor to receive nothing) sometimes convinces the creditor to accept $25.00 instead of the $200.00 that is owed.

7. Transfer of Assets

It is not uncommon to hear people say that if they become sick, they intend to give away their property and then get assistance from the government. Government programs that provide financial and medical assistance have rules about the transfer of assets. An improper transfer can result in disqualification for benefits. The rules are hard to understand, and are not uniform among all programs. If you or someone you know is thinking about transferring any property because of illness, check first with a lawyer or other person who is familiar with the rules.

8. General Consultation Services

GMHC offers a general legal consultation to every client of the agency who requests this service. Our main focus is one of prevention. Consequently, we encourage people to have a consultation with a lawyer so possible legal problems may be indentified and resolved before they become major problems. At a general consultation, a client may discuss with a lawyer whether or not it is important to have a Will done, or create a joint bank account, whether or not a client is able to pay his or her bills, and what to do if the client cannot, whether or not there is a potential problem concerning insurance coverage, or whether or not some attempt should be made with a landlord to add the client's lover, roommate or friend to his or her apartment lease. The emphasis, again, is to help the client put his or her affairs in order before an emergency arises. This preventive approach allows our legal staff to deliver legal service in competent, effective and not a time-hurried fashion. Accordingly, we ask all people working with GMHC to stress the importance of this general consultation service.

9. People Who Are Not U.S. Citizens

GMHC Legal Serivces has been attempting to help a number of people with AIDS who are undocumented workers (i.e., people from other countries who are in the United States without having a "green card", student visa or other authorization from the U.S. Department of Immigration and Naturalization to remain in the U.S.). The main problem here is not the fear of deportation, although deportation does remain as a possible concern. The main problem is that most undocumented workers are not eligible for any public benefits whatsoever. Volunteer lawyers working with GMHC Legal Services are trying to establish the legal basis for our undocumented clients to remain in this country, with the hope that these clients will then be eligible to receive public benefits. Thus far, this end is not in sight. It is important, however, to refer undocumented persons with AIDS to the legal services program, especially if they are in need of public benefits.

GMHC Legal Services

SECTION V - SERVICES AND INFORMATIONAL RESOURCES

To meet the growing needs of people with AIDS/ARC, existing traditional health and social services delivery systems have been supplemented with new programs and services. Many services are available to address the needs of New York State residents with regard to AIDS. Some services are designed specifically for persons with AIDS, others are geared for the general public as well as those in risk groups. These services range from information and referral, to medical and social services, to financial and legal assistance. Services are provided by many types of organizations, including government agencies, community based organizations, voluntary associations, hospitals and religious institutions.

The New York State Department of Health, AIDS Institute has funded regional AIDS Task Forces and community service organizations to provide education and outreach services for people with AIDS. (See listing of the Regional AIDS Task Forces at the end of this Section). The AIDS statewide hotline (1-800-462-1884) is the conduit linking the public with all AIDS programs. Each call to the toll-free number is answered by an operator who can make available informational materials on AIDS, can provide the numbers for regional hot lines operated by local organizations that will respond with information, referrals and direct services, and can activate informational tapes on AIDS and the HTLV III antibody test. Examples of educational materials about AIDS that have been developed by the New York State Department of Health are included in this Information Guide; additional copies can be obtained by contacting the DOP Regional AIDS Liaison or the Department of Health.

In addition to state initiatives, many local social services agencies have established special procedures to expedite financial assistance and services to persons with AIDS. At the federal level, the Social Security Administration has added AIDS to the impairment categories for which a presumptive disability decision can be made, thereby providing immediate financial relief to individuals so afflicted.

The following information and patient services are available to assist you in your efforts to work with inmates and parolees with AIDS.

Information Services

Agencies provide three major types of services to meet the demand for accurate information about AIDS: telephone hotlines, printed educational material, and speaker's bureaus. A list of New York State Regional AIDS Task Forces can be found at the end of this Section. Additional resources can be identified with the assistance of the Division of Parole Regional AIDS Liaisons and Parole Services Program Specialists.

Patient Services

Information services are largely designed to educate a broad spectrum of community members. Patient services, on the other hand, are primarily intended for those with AIDS or AIDS-related conditions. People with AIDS require a broad range of services including medical services, counseling/emotional support services, alcohol/drug rehabilitation services, religious support services, home care, financial assistance, housing assistance and legal aid.

For people in need of medical services for the diagnosis and treatment of AIDS and AIDS-related conditions, many physicians, hospitals and out-patient facilities provide comprehensive medical examinations. New York State has plans to create a system of 10 to 15 hospital-based AIDS centers that will provide hospital care, hospice care and home services. Coordinated health services for persons with AIDS are currently in place in many jurisdictions, particularly New York City, which treats the largest number of people with AIDS in the State. For further information about medical services for the diagnosis and treatment of AIDS, consult the Regional AIDS Task Force or the AIDS Liaison in your region.

For people in need of counseling and emotional support services, a variety of options are available. Most hospitals that treat patients with AIDS provide psycho-social support programs for patients and their families. Community based organizations, identifiable through the Regional AIDS Task Forces, have developed innovative approaches to providing psycho-social, practical and financial assistance to people with AIDS or AIDS related conditions and for those close to such patients. For further information about the range of available counseling and emotional support services, consult the Regional AIDS Task Force or the DOP AIDS Liaison in your region, as well as county social services departments.

For people in need of alcohol or drug rehabilitation services, many hospitals residential programs and half-way houses operate treatment programs. However, some non-hospital programs and drug treatment programs will not accept people with AIDS. For further information about available drug and alcohol services, consult the Regional AIDS Task Force or the DOP AIDS Liaison in your region.

Various agencies are available to help persons obtain home-care services. If the person with AIDS has medicaid, home-care can be obtained through county social services departments, many of which have special service units for people with AIDS. Arrangements for services are usually made a physician or social worker who is familiar with the patient's needs and may require coordination with DOCS facility Health Services staff. For further information about home-care services, consult the Regional AIDS Task Force, the County Department of Social Services or the DOP AIDS Liaison in your region.

For people in need of financial assistance, several avenues may be explored. Social Security benefits are available for those with AIDS who have been diagnosed as having an opportunistic infection and, in some cases, for those who do not have an opportunistic infection but are disabled. Medicaid coverage accompanies social security insurance benefits. Persons paying FICA or self-employment taxes are eligible for certain benefits. For further information consult the SSI Tele-Claims Service in your area, the Social Security Administration District Office AIDS Liaison or SSI representative in your area, or the DOP AIDS Liaison in your region (See phone listings for SSI Representatives and SSI Tele-Claims Services at the end of this Section).

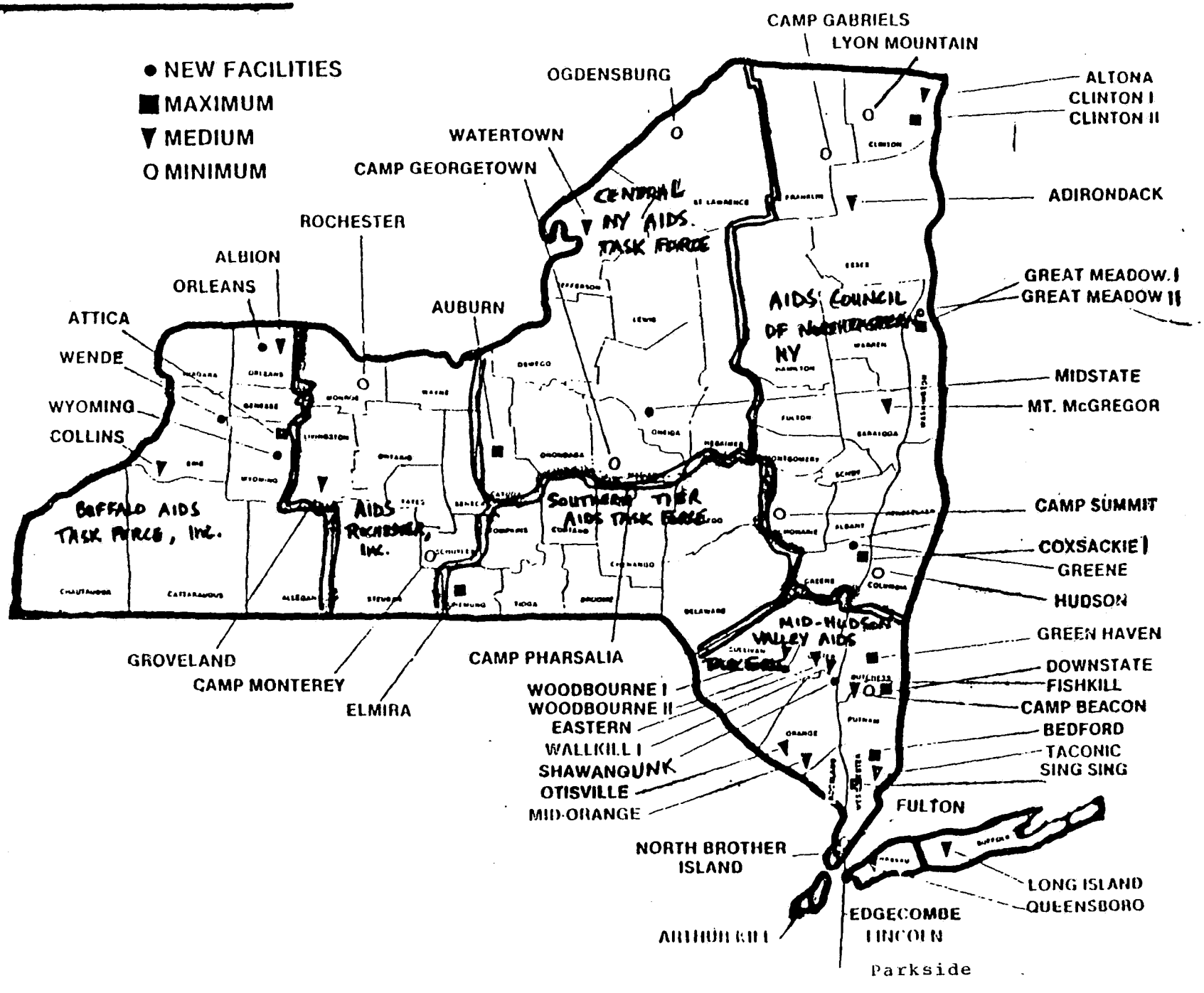
For people in need of housing assistance, local social service agencies and Regional AIDS Task Forces represent the best resources. Often, additional assistance can be obtained through local church or religious organizations.

Many legal issues--including wills, power-of-attorney, estate planning, hospital visitation rights and immigration--arise for people with AIDS. In addition, many people with AIDS/ARC are discriminated against. To address issues of discrimination, a person with AIDS can contact the NYS Division of Human Rights or federal agencies included in the listing at the end of this Section. For further information on where legal help is available, consult the Regional AIDS Task Force or the DOP AIDS Liaison in your region.

Footnote:

Portions of this material have been excerpted from AIDS - A Special Report on Acquired Immune Deficiency Syndrome, prepared for the NYC Schools by the NYC Department of Health, October, 1985

NYS AIDS Task Forces



NYS REGIONAL AIDS TASK FORCE

Region: **Metropolitan New York City**

Contractor: **Beth Israel Medical Center**

AIDS Coordinator: **Wendy Wilbert**
Beth Israel Medical Center
First Avenue at 16th Street
New York, New York 10003
(212) 420-4141

Counties Served: Metropolitan New York City (5 boroughs), primarily intravenous drug users

Services: **AIDS Hotline - (212) 420-4141**

information
referral
education
counseling
support groups
literature

NYS REGIONAL AIDS TASK FORCE

Region: Metropolitan New York City

Contractor: Gay Men's Health Crisis, Inc.

Director: Mr. Richard Dunne
Gay Men's Health Crisis, Inc.
Box 274
132 West 24th Street
New York, New York 10011
(212) 807-6664

Counties Served: Metropolitan New York City
(5 boroughs)

Services: AIDS Hotline - (212) 807-6655

crisis intervention
buddy program
recreation services
support and therapy groups
information, referral and advocacy
education
literature

NYS REGIONAL AIDS TASK FORCE

Region: New York City

Contractor: Urban Resource Institute

Director: Mr. Michael Bischoff
22 Chapel Street
Brooklyn, New York 11201
(718) 834-5340

Education Coordinator: Mr. Ron Davis
(718) 852-8042

Counties Served: Primarily serve minority communities in Brooklyn, specifically intravenous drug users

Services: AIDS Hotline - (718) 852-8045

health education
information
referral

NYS REGIONAL AIDS TASK FORCE

Region: **Long Island**

Contractor: **Long Island AIDS Project**

Director: **Ms. Jane Holmes**
Lond Island AIDS Project
School of Allied Health Professions
Health Sciences Center Level II
State University of New York
Stony Brook, New York 11794-8204
(516) 444-2403

Counties Served: Nassau, Suffolk

Services: **AIDS Hotline - (516) 444-AIDS**

visitation program
support group
counseling
information, referral and advocacy
education
literature

NYS REGIONAL AIDS TASK FORCE

Region: **Central New York**

Contractor: **Central New York AIDS Task Force**

Director: **Mr. Brad Cohen**
Box 1911
Syracuse, New York 13201
(315) 475-2430

Counties Served: Cayuga, Herkimer, Jefferson, Lewis, Madison, Oneida, Onondaga, Oswego, St. Lawrence

Services: **AIDS Hotline - (315) 475-AIDS**

buddy program
advocacy
support groups
family networks
in-service education programs, workshops
literature

NYS REGIONAL AIDS TASK FORCE

Region: Mid-Hudson Valley

Contractor: Mid-Hudson Valley AIDS Task Force

Director: Mr. John E. Egan
255 Grove Street
White Plains, New York 10601
(914) 997-5149

Counties Served: Dutchess, Orange, Putnam, Rockland, Sullivan
Ulster, Westchester

Services: AIDS Hotline - (914) 997-1614

education
advocacy/counseling (re: social services, health care, etc.)
support groups
buddy support program
literature

NYS REGIONAL AIDS TASK FORCE

Region: Northeastern Area

Contractor: AIDS Council of Northeastern New York

Director: Ms. Laurie Novick
332 Hudson Avenue
Albany, New York 12210
(518) 434-4686

Counties Served: Albany, Clinton, Columbia, Essex, Franklin, Fulton, Greene, Hamilton, Montgomery, Rensselaer, Saratoga, Schenectady, Schoharie, Warren, Washington

Services: AIDS Hotline - (518) 445-AIDS

hospital inservice programs
community forums
speakers bureau
literature
buddy program
support groups

NYS REGIONAL AIDS TASK FORCE

Region: **Rochester**

Contractor: **Rochester Area Task Force on AIDS - AIDS Rochester, Inc.**

Director: **Ms. Jackie Nudd**
133 Liberty Pole Way
Rochester, New York 14604
(716) 232-7181

Counties Served: Livingston, Monroe, Ontario, Schuyler, Seneca, Steuben, Wayne, Yates

Services: **AIDS Hotline - (716) 244-8640**

speakers bureau
crisis intervention
support groups
buddy program
health risk analysis
informal rap sessions
literature

NYS REGIONAL AIDS TASK FORCE

Region: **Southern Tier**

Contractor: **Southern Tier AIDS Task Force**

Director: **Ms. Charlene Ketchum**
c/o Opportunities for Broome, Inc.
P. O. Box 1492
Binghamton, New York 13902
(607) 723-6493

Counties Served: Broome, Chemung, Chenango, Cortland, Delaware, Otsego, Tioga, Tompkins

Services: **AIDS Hotline**

advocacy/counseling
referral
education

NYS REGIONAL AIDS TASK FORCE

Region: Western New York

Contractor: Buffalo AIDS Task Force, Inc.

Director: Ms. Valerie Eastman
P. O. Box 38
Bidwell Station
Buffalo, New York 14222
(716) 881-AIDS

Counties Served: Allegany, Erie, Cattaraugus, Chautauqua, Genesee, Niagara, Orleans, Wyoming

Services: AIDS Hotline - (716) 881-AIDS

advocacy
buddy program
education

NEW YORK STATE DEPARTMENT OF SOCIAL SERVICES
REGIONAL OFFICES

BUFFALO REGIONAL OFFICE

Buffalo Regional Office
NYS Department of Social Services
125 Main Street, 4th Floor
Buffalo, NY 14203

Contact: Ms. Karen Schimke
Director

Telephone No. 716/883-4093

Includes the following counties: Allegany, Cattaraugus, Chautauqua, Erie, Genesee, Niagara, Orleans, Wyoming.

WESTERN REGIONAL OFFICE

Western Regional Office
NYS Department of Social Services
259 Monroe Avenue, Monroe Square
Rochester, NY 14607

Contact: Mr. Jack Klump
Acting Director

Telephone No. 716/238-8200

Includes the following counties: Chemung, Livingston, Monroe, Ontario, Schuyler, Seneca, Steuben, Wayne, and Yates.

EASTERN REGIONAL OFFICE

Eastern Regional Office
NYS Department of Social Services
40 North Pearl Street/Annex
Albany, NY 12243

Contact: Mr. John O'Connor
Director

Telephone No. 518/473-1095
Toll Free No. 1-800-342-3715
Extension 31095

Includes the following counties: Albany, Broome, Cayuga, Chenango, Clinton, Columbia, Cortland, Delaware, Essex, Franklin, Fulton, Greene, Hamilton, Herkimer, Jefferson, Lewis, Madison, Montgomery, Oneida, Onondaga, Oswego, Otsego, Rensselaer, Saratoga, Schenectady, Schoharie, St. Lawrence, Tioga, Tompkins, Warren, and Washington.

METROPOLITAN REGIONAL OFFICE

Metropolitan Regional Office
NYS Department of Social Services
2 World Trade Center
29th Floor
New York, NY 10047

Contact: Mr. Fred Cantlo
Director

Telephone No. 212/488-3485
Toll Free No. 1-800-342-3715
No. NYC 488-3485

Includes the following counties: Dutchess, Nassau, Orange, Putnam, Rockland, Suffolk, Sullivan, Ulster, and Westchester.

LOCAL SOCIAL SERVICES DISTRICTS
(Commissioner's Name, Agency Address, and Agency Phone Numbers)

ALBANY COUNTY

Mr. James McCaffrey
112 State Street
6th Floor
Albany, New York 12207
Area Code 518
General No. - 447-7300

ALLEGANY COUNTY

Ms. Joan D. Habberfield
County Office Building
Belmont, New York 14813
Area Code 716
General No. - 268-7661

BROOME COUNTY

Mr. Joseph S. Sanfilippo
36-38 Main Street
Binghamton, New York 13905
Area Code 607
General No. - 772-2660

CATTARAUGUS COUNTY

Mr. Ronald B. Hackett
265 North Union Street
Olean, New York 14760
Area Code 716
General No. - 375-4011

CAYUGA COUNTY

Mr. Stefan R. Bandas
County Office Building
160 Genesee Street
Auburn, New York 13021
Area Code 315
General No. - 253-1011

CHAUTAUQUA COUNTY

Mr. Charles V. Fiorella
Hall R. Clothier Health and Social Services Building
Mayville, New York 14757
Area Code 716
General No. - 753-4421

CHEMUNG COUNTY

Mr. Raymond E. Fortier
Human Resource Center
425-447 Pennsylvania Avenue
Elmira, New York 14904-1795
Area Code 607
General No. - 335-4537

CHENANGO COUNTY

Mr. Stanley J. Kimiecik
County Office Building
Norwich, New York 13815
Area Code 607
General No. - 337-4537

CLINTON COUNTY

Mrs. Rose Pandozy
30 Durkee Street
(Mail - P.O. Box 990)
Plattsburgh, New York 12901
Area Code 518
General No. - 563-3300

COLUMBIA COUNTY

Mr. James R. Van Alstyne
610 State Street
Hudson, New York 12534
Area Code 518
General No. - 828-9411

CORTLAND COUNTY

Ms. Mary Ann Discenza
County Office Building
P.O. Box 5590
60 Central Avenue
Cortland, New York 13045-5590
Area Code 607
General No. - 753-9681

DELAWARE COUNTY

Mr. William R. Moon
126 Main Street
Delhi, New York 13753
Area Code 607
General No. - 746-2325

DUTCHESS COUNTY

Mr. John H. Battistoni
14 Academy Street
Poughkeepsie, New York 12601
Area Code 914
General No. - 431-5000

ERIE COUNTY

Mr. Fred J. Buscaglia
95 Franklin Street, 8th Floor
Buffalo, New York 14202
Area Code 716
General No. - 846-8850

ESSEX COUNTY

Mr. Walter P. Huchro
Court House
Elizabethtown, New York 12932
Area Code 518
General No. - 873-6301

FRANKLIN COUNTY

Mr. Orra A. Langdon
Court House
Malone, New York 12953
Area Code 518
General No. - 483-6767

FULTON COUNTY

Mr. Marcus Harazin
Fulton County Building
P.O. Box 549
Johnstown, New York 12095
Area Code 518
General No. - 762-4671

GENESEE COUNTY

Mr. Dale E. Crandall
3837 West Main Road
Batavia, New York 14020
Area Code 716
General No. - 344-2580

GREENE COUNTY

Mrs. Carol W. Wallace
465 Main Street
Catskill, New York 12414
Area Code 518
General No. - 943-3200

HAMILTON COUNTY

Mr. David G. Curry
Court House
Lake Pleasant, New York 12108
Area Code 518
General No. - 548-3462

HERKIMER COUNTY

Mr. Michael J. Bush
County Office Building
Box 231
Herkimer, New York 13350
Area Code 315
General No. - 867-1222

JEFFERSON COUNTY

Mrs. S. Jean Wagoner
175 Arsenal Street
Watertown, New York 13601
Area Code 315
General No. - 782-9030

LEWIS COUNTY

Mr. Dorrance Moshier
Utica Boulevard (P.O. Box 193)
Lowville, New York 13367
Area Code 315
General No. - 367-3536

LIVINGSTON COUNTY

Mr. W. Michael Woodhouse
Livingston County Campus
Building #3
Mt. Morris, New York 14510
Area Code 716
General No. 658-2801

MADISON COUNTY

Mr. James L. Covert
P.O. Box 637
Wampsville, New York 13163
Area Code 315
General No. - 366-2211

MONROE COUNTY

Mr. W. Burton Richardson
111 Westfall Road - Room 660
Rochester, New York 14620
Area Code 716
General No. - 442-4000

MONTGOMERY COUNTY

Mr. Robert L. Reidy
County Office Building
Fonda, New York 12068
Area Code 518
General No. - 853-4646

NASSAU COUNTY

Mr. Joseph D'Elia
County Seat Drive
Mineola, New York 11501
Area Code 516
General No. - 535-4817

NEW YORK CITY

Mr. George Gross
250 Church Street
Room 1500
New York, New York 10013
Area Code 212
General No. - 553-5997

NIAGARA COUNTY

Mr. Louis B. Scozzafava
100 Davison Road - P.O. Box 506
Lockport, New York 14094
Area Code 716
General No. - 439-6333

ONEIDA COUNTY

Mr. Richard N. DuRose
Oneida County Office Building
800 Park Avenue
Utica, New York 13501
Area Code 315
General No. - 798-5700

ONONDAGA COUNTY

Mr. Robert J. Stone
Onondaga County Civic Center
421 Montgomery Street
Syracuse, New York 13202
Area Code 315
General No. - 425-2222

ONTARIO COUNTY

Mr. Irwin Rockoff
120 North Main Street
Canandiagua, New York 14424
Area Code 716
General No. - 394-1440

ORANGE COUNTY

Ms. Gladys Burleigh
Acting Commissioner
Quarry Road, Box Z
Goshen, New York 10924
Area Code 914
General No. - 294-9361

ORLEANS COUNTY

Mrs. Patricia Hardenbrook
14016 Route 31 West
Albion, New York 14411
Area Code 716
General No. - 589-7004

OSWEGO COUNTY

Mr. Richard N. Nells
Spring Street
Mexico, New York 13114
Area Code 315
General No. - 963-7271

OTSEGO COUNTY

Mr. James L. Cary
County Office Building
197 Main Street
Cooperstown, New York 13326
Area Code 607
General No. - 547-4294

PUTNAM COUNTY

Mr. John W. Sweeney
110 Old Route 6 Center
Carmel, New York 10512
Area Code 914
General No. - 225-7040

RENSSELAER COUNTY

Mr. John R. Beaudoin
133 Bloomingrove Drive
Troy, New York 12180
Area Code 518
General No. - 283-2000

ROCKLAND COUNTY

Mr. Noah Weinberg
Building L
Sanatorium Road
Pomona, New York 10970
Area Code 914
General No. - 354-0200

ST. LAWRENCE COUNTY

Ms. Sharon K. Singh
Harold B. Smith County Office Bldg.
Judson Street
Canton, New York 13617
Area Code 315
General No. - 354-0200

SARATOGA COUNTY

Mr. Leo F. Ryan
County Complex
Ballston Spa, New York 12020
Area Code 518
General No. - 885-5381

SCHENECTADY COUNTY

Mr. Richard J. Staszak
487 Nott Street
Schenectady, New york 12308
Area Code 518
General No. - 382-3470

SCHOHARIE COUNTY

Mr. Gilbert L. Chichester
Schoharie, New York 12157
Area Code 518
General No. - 295-8134

SCHUYLER COUNTY

Ms. Kathryn R. Doolittle
County Office Building
P.O. Box 169
Watkins Glen, New York 14891
Area Code 607
General No. - 535-4965, 2780 & 2789

SENECA COUNTY

Ms. Helen M. Pawlikowski
2226 County House Road
Waterloo, New York 13165-9461
Area Code 315
General No. - 568-9854

STEUBEN COUNTY

Mr. James V. Murray
P.O. Box 631
Bath, New York 14810
Area Code 607
General No. - 776-7611

SUFFOLK COUNTY

Ms. Alice M. Amrhein
Box 2000, 10 Oval Drive
Hauppauge, New York 11788
Area Code 516
General No. - 348-4000

SULLIVAN COUNTY

Mrs. Muriel O'Connor
Infirmary Road
Box 231
Liberty, New York 12754
Area Code 914
General No. - 292-4900

TIOGA COUNTY

Mr. Raymond Case
P.O. Box 240
Owego, New York 13827
Area Code 607
General No. - 687-5000

TOMPKINS COUNTY

Ms. Mary Pat Dolan
108 East Green Street
Ithaca, New York 14850
Area Code 607
General No. - 274-5251

ULSTER COUNTY

Mr. Thomas W. Roach, Jr.
Ulster County Offic Building
268 R Clinton Avenue
P.O. Box 1800
Kingston, New York 12401
Area Code 914
General No. - 331-9300

WARREN COUNTY

Mr. Joseph P. Menaldino
Warren County Municipal Center
Lake George, New York 12845
Area Code 518
General No. - 761-6300

WASHINGTON COUNTY

Mr. Earl Costello
6 Church Street
Granville, New York 12832
Area Code 518
General No. - 632-5211 or 642-2800

WAYNE COUNTY

Ms. Rita B. Otterbein
22 William Street
P.O. Box 10
Lyons, New York 14489-0010
Area Code 315
Income Maintenance No. - 946-4881

WESTCHESTER COUNTY

Mr. John J. Allen
112 East Post Road
White Plains, New York 10601
Area Code 716
General No. - 285-5500

WYOMING COUNTY

Mrs. Lois V. Bowling
466 North Main Street
Warsaw, New York 14569
Area Code 716
General No. - 786-3111

YATES COUNTY

Mr. Paul E. Dickson
County Office Building
110 Court Street
Penn Yan, New York 14527
Area Code 315
General No. - 536-4451

Agency Contacts for Discrimination Complaints

1. New York City

   A. Commission on Human Rights
   52 Duane Street, New York, New York 10007
   Contacts: Keith O'Connor, Director, Patterns & Practice Division
   (212) 566-1826
   or Katy Taylor, Patterns & Practice Division
   (212) 566-5446

   B. Bureau of Labor Services
   Municipal Building, 1 Centre Street, Room 2400
   Contact: Esta Bigler, Assistant Director
   (212) 669-7412
   Industrial & Commercial Incentive Board
   (212) 566-0302

2. New York State

   A. Division of Human Rights - Administrative Office
   2 World Trade Center, Room 5308, NYC 10047
   Contact: Liz Abzug, Deputy Commissioner
   (212) 488-7626

   B. Division of Human Rights - Regional Offices

   Albany 12225-0063
   Alfred E. Smith State Office Building
   PO Box 7063
   25th Floor
   (518) 474-2705

   Binghamton 13901
   164 Hawley Street
   State Office Building
   (607) 773-7713

   Brooklyn 11201
   26 Court Street
   (718) 852-0313

Buffalo 14202
69 Delaware Avenue
(716) 847-3713

Hauppauge (Suffolk) 11787
State Office Building
Veterans Highway
(516) 360-6434

Hempstead (Nassau) 11550
175 Fulton Avenue
(516) 538-1360

Manhattan (Lower) 10007
270 Broadway (9th Floor)
(212) 587-5041

Manhattan (Upper) 10027
163 West 125th Street
(212) 678-2303

Rochester 14614
36 West Main Street
(716) 325-2367

Syracuse 13202
100 New Street
(315) 428-4633

White Plains 10603
30 Glenn Street
(914) 949-4394

C. Office of Employee Relations, P.O. Box 2133,
Albany, New York 12223

3. Federal (in New York)

A. Office of Federal Contract Compliance
Program
1515 Broadway, Room 3308,
New York City 10036
Contact: Louis Blumengarten
(212) 944-3400

B. Office of Federal Contract Compliance
Program - Regional Offices
Buffalo, New York 14202
Jackson Building
220 Delaware Avenue, Room 609
(716) 846-5065

Garden City, New York 11430
605 Stuart Avenue
Room 228

New York City, New York 10278
26 Federal Plaza
Room 36-116

C. Department of Education -
Office of Civil Rights
26 Federal Plaza, 33rd Floor
New York, New York 10278
(212) 264-5181

D. Health & Human Services -
Office of Civil Rights
26 Federal Plaza, Room 33-12
New York, New York 10278
(212) 264-3313

In addition to the above-listed agencies, individuals who believe they have been discriminated against due to their sex (but not sexual orientation or physical handicap) may wish to contact the Equal Employment Opportunity Commission. The EEOC'S New York District Office is located at 90 Church Street, Room 1301, New York City 10007 (212) 264-7161.

Prisoners Legal Services Offices

New York City	105 Chambers Street New York, New York 10007 (212) 513-7373
Buffalo	487 Niagara Street Buffalo, New York 14201 (716) 856-2650
Ithaca	102 West State Street Ithaca, New York 14850 (607) 273-2283
Plattsburgh	22 Broad Street Plattsburgh, New York 12901 (518) 563-7300
Poughkeepsie	2 Catherine Street Poughkeepsie, New York 12601 (914) 473-3810

STATE OF NEW YORK
EXECUTIVE DEPARTMENT
DIVISION OF PAROLE
97 CENTRAL AVENUE
ALBANY, NEW YORK 12206

RAMON J. RODRIGUEZ
CHAIRMAN

EDWARD ELWIN
EXECUTIVE DIRECTOR

PAROLE SERVICES PROGRAM SPECIALIST

METRO I	MILTON BROWN	(212) 594-5800
METRO II	ALFRED F. ROSARIO	(212) 594-5800
CENTRAL ADIRONDACK	HAROLD CANNON	(518) 453-7496
WESTERN-SOUTHERN TIER	DON F. GAWRONSKI	(716) 847-7616
HUDSON VALLEY	EUGENE DOUGHERTY	(914) 485-7830
CENTRAL OFFICE	TERRI WURMSER	(518) 474-4788
CENTRAL OFFICE (NY)	BETTYE DEES	(212) 594-5800

REGIONAL AIDS LIAISONS

METRO I	ED GRAHAM SPO	(212) 594-5800
METRO II	ALAN PENSAK, SPO	(212) 594-5800
CENTRAL ADIRONDACK	PETE SILBERSTEIN, SPO	(518) 438-5956
WESTERN-SOUTHERN TIER	DONALD GAWRONSKI	(716) 847-7616
HUDSON VALLEY	MARGARET MENZIES, PO	(914) 452-0620

Prerelease Agreement - New York State Division
of Parole and the Social Security Administration

This Prerelease Agreement should not be confused with the Pre-Release Centers and programs operated by the Department of Correctional Services.

I. INTRODUCTION

The Social Security Administration (SSA) and the New York State Division of Parole (DOP) propose a Prerelease Agreement for inmates of State correctional facilities who are to be released to parole supervision. The difficulty of making suitable release arrangements for prisoners is exacerbated if the prisoner is suffering from a disability, particularly those suffering from AIDS. The purpose of the Prerelease Program is to provide a guarantee of financial help for those who are paroled to the community and to ensure that title XIX (Medicaid) eligibility is established as quickly as possible. Proper use of a prerelease procedure will facilitate release plan development and will ensure continuity of medical care upon release to the community.

Upon notification that a prisoner has been accepted for parole, or anticipation of a likely release decision by the Parole Board, the DOP will review the inmate's income, resources and disability for potential Supplemental Security Income (SSI) eligibility. SSA will provide the DOP with guidance in evaluating both medical and nonmedical criteria.

Those inmates whose income or resources exceed the SSI eligibility limits will be referred to the NYS Department of Social Services, Division of Medical Assistance for "Medicaid Only". Those inmates who appear to be SSI eligible will have an SSI application filed in accordance with the Prerelease Program procedures. In no case will a potential SSI applicant be considered for the program more than 90 days prior to the scheduled release date. This will allow social security sufficient lead time to make a medical determination prior to release.

This agreement is effective June 2, 1986.

NOTE: A liaison will be identified for each SSA District or Branch Office parallel to each institutional or area Parole Office for purposes of implementing this Prerelease Agreement.

II. THE APPLICATION PROCESS

A. New York State Division of Parole Responsibilities

The Parole Officer located at the correctional facility will identify prisoners who could benefit from the prerelease procedure according to the following guidelines:

1. The individual's release is imminent, i.e., could be released within 90 days.

2. The individual has a need for funds, i.e., meets the SSI income and resource limitation criteria.

3. The individual has a condition which can be considered as disabling under SSA's criteria.

Upon identification of an inmate who meets the basic criteria, the Parole Officer will prepare a packet to be forwarded to the parallel SSA district or branch office. The packet should contain the following completed forms:

1. SSA -3368 - Disability Report

2. SSA-3369 - Vocational Report - (Should not be completed if claimant never worked or had only one job in the 15-year period before he stopped working.)

3. (2) SSA-827s - Authorization to Release Medical Information to the Social Security Administration

4. SSA-8510 - Authorization to Obtain Personal Information

5. SSA-824 - Report on Individual with Mental Impairment (if applicable)

6. SSA-8000 - Application for Supplemental Security Income - (Completion of the SSI Application will vary according to prior agreement with the local social security office.)

Supplies of the above forms will be provided to the institutional parole offices for completion by Parole Officers. In addition, the Parole Officer should attach a copy of the New York State Department of Correctional Services Medical Discharge Summary Form or other summary of medical evidence. This will assist SSA in making disability determinations, especially presumptive disability determinations in certain cases.

Evidence from a medical source is required to determine the existence or severity of an impairment. Therefore, the Parole Officer will obtain and submit from the facility Health Services Staff all available medical evidence, including:

1. dates of current and prior periods of hospitalization;

2. medical history covering the past 12 months;

3. description of findings including orientation, coherence, emotional status, results of psychological tests, and current mental status examination results (for mental disability claims);

4. diagnosis;

5. course of condition during present hospitalization if applicable including changes in mental/physical status, adjustment to hospital routine, adjustment to work detail, personal adjustment, relationship with others;

6. prognosis;

7. recommendation for posthospitalization followup; i.e. medications, dosage and any other type of therapy; and

8. individual's ability to manage funds based upon a physician's determination.

For mental impairment cases, this information can be summarized on form SSA-824.

Social Security has developed a medical reference base for the determination of impairments that would preclude work activity. This Listing of Impairments provides sets of medical evidence, within the context of a particular disease or disorder, which must be considered before Social Security reaches a conclusion of disabled. Examples of specific evidence needed are dependent on the type of impairment, but may include such evidence as EKG's, blood tests, x-rays, pulmonary studies, psychological tests, etc. In order to properly evaluate AIDS, for example, the following specific information should be submitted if available:

. The onset and nature of all symptoms (e.g., fatigue, fever, anorexia, diarrhea, shortness of breath, etc.) should be quantified in terms of frequency, duration, precipitating factors, and mode of relief.

. Dates of treatment and any relevant testing should always be given, as well as the specific testing done (e.g., a diagnostic test showing immune deficiency or opportunistic infection).

. Treatment, response, and prognosis are also needed.

This list is not all inclusive, but is meant to serve as a guide.

The entire medical packet will be forwarded to the district or branch office (DO/BO) parallel to the correctional facility under cover of a transmittal letter provided to institutional parole offices by SSA. The transmittal letter will serve to provide basic identifying information on the prospective parolee (e.g., social security number) and provide the DO/BO with a Parole contact within the correctional facility. If the social security number is not known, or the inmate never had one, the Parole Officer should complete form SS-5 and submit proof of age and citizenship as appropriate.

B. SSA's Responsibilities

Upon receipt of prerelease packet, the DO/BO will initiate action to complete an SSI application if not already included in the inmate's packet by prior agreement. If no arrangement has been made for the Parole Officer to complete an application, the DO/BO will complete an SSI application within approximately two weeks in person at the correctional facility or by phone. In either case, the DO/BO may need to contact the institution's Parole Officer by phone to obtain additional information for purposes of determining eligibility.

If it appears that the inmate is ineligible for SSI based on technical reasons, i.e. excess income or resources, the district or branch office (DO/BO) will informally notify the Parole Officer by phone and process the denial immediately. A formal notice will also be sent to the inmate/claimant. If it appears that the inmate meets all technical requirements of SSI entitlement, the DO/BO will forward the medical file to the New York State Department of Disability Services (DDS) for a medical determination. Any unresolved technical issues will be developed concurrently.

III. PRERELEASE NOTIFICATION AND FOLLOWUP

A. SSA Responsibilities

In all situations where a medical determination has been made on a prerelease claim, an informal notice of the decision must be provided to the Institutional Parole Officer by phone or letter. If the decision is a denial, a formal notice will follow shortly and the facility may decide to appeal if appropriate.

Whenever potential eligibility for payments exists, e.g., the medical determination is an allowance, the DO/BO will provide informal notice by letter or phone to the Institutional Parole Officer and advise he/she that action on the claim will be delayed for 30 days pending release. At the end of 30 days the DO/BO will contact the facility and, if release is imminent, extend the period to include an additional week. If release does not occur or is not anticipated within this period, the DO/BO will take final action to disallow the claim.

In some cases (e.g. an allegation of total deafness, blindness, allegation of AIDS, etc.) the DO/BO or the NYS DDS will be able to make a presumptive disability decision. This permits SSA to make immediate SSI payments for three months upon release of a parolee even if DDS has not completed a final medical determination. The DO/BO will notify the insitutional Parole Officer by phone or letter if such a presumptive disability decision has been rendered. If the final DDS decision is a denial, the presumptive disability payments will not be considered an overpayment by SSA.

B. DOP Responsibilities

During the pendency of the claim, the Institutional Parole Officer should advise the DO/BO of any change in the anticipated release date or any change in circumstances of the inmate. At the time of application SSA will fully advise the inmate and the Parole Officer of all reporting responsibilities. SSA will provide DOP with a list of all DO/BOs parallel to correctional facilities and a contact person(s) within the DO/BO.

IV. ACTION UPON RELEASE

A. DOP Responsibilities

As soon as the inmate is released, the Institutional Parole Officer should notify the DO/BO of the release and the new address of the parolee. The Institutional Parole Officer should also advise the parolee of the need to contact the SSA DO/BO immediately upon release. The facility Parole Officer should notify the receiving Parole Office that the parolee is participating in the prerelease program so that contact with the new servicing DO/BO can be established by the Field Parole Office. SSA will supply Parole Officers with a listing of SSA offices and areas that they service.

B. SSA Responsibilities

Within a few days after notification of release is received, the DO/BO will transfer the file to the new servicing DO/BO with an annotation of the new address of the released prisoner. The DDS will be notified of the new address if a final medical determination has not been made.

If a favorable medical decision has been rendered, the servicing DO/BO will attempt to make contact with the parolee to verify current factors of entitlement in their new living arrangement. Upon successful completion of the verification process which may require third-party contacts, e.g., with a landlord to verify current rental agreement, payment will be initiated by making appropriate systems inputs. Payments should be received within 10 days-two weeks. The Parole Officer should be aware of this process and encourage the individual to make immediate contact with the DO/BO. It is not necessary to wait for SSA to contact the individual.

The Field Parole Officer should contact the SSA DO/BO in cases where the releasee is unable to report to the DO/BO in person in order to arrange for a SSA field representative to contact the releasee either by phone or home visit.

If problems arise in the adjudication of the individual's claim, the DO/BO may contact the Parole Officer for assistance.

DEPARTMENT OF HEALTH & HUMAN SERVICES

Social Security Administration

Refer to: SD2B4

Region II
Federal Building
26 Federal Plaza
New York NY 10278

NOTE: Each office does not have an AIDS Liaison

Social Security District Office AIDS Liasons

Manhattan

Office	Address	Liaison	Phone
Downtown	26 Federal Plaza	Gary Goodman	264-5263
Delancey Street	85 Delancey Street	Tony Russo	260-5525
Chinatown	231 Grand Street	Bob Tomasulo	226-3593
Midtown	1515 Broadway	Howard Pohl	944-4926
Murray Hill	475 Third Avenue	Shelly Banks	684-1771
Lenox Hill	133 E. 58 Street	Julian Friedkiss	752-1623
Uptown	55 W. 125 Street	Robert Windram	860-6153
North Harlem	101 W. 144 Street	Peter Gillard	283-4483
East Harlem	306 E. 111 Street	Hiram Durant	427-3113
Washington Heights	4292 Broadway	Bernadette Malenzie	923-2568

Staten Island

Staten Island	60 Bay Street	Evelyn Brown	(718)447-1677
New Dorp	2626 Hylan Boulevard	Don Labetti	(718)979-9748

Bronx

Office	Address	Liaison	Phone
South Bronx	880 River Avenue	Al Lefebvre	538-2540
Hunts Point	953 Southern Blvd.	" "	" "
Bronx Hub	390 E. 150 Street	" "	" "
North Bronx	2720 Jerome Avenue	Fred Maurin	933-7225
West Farms	2095 Southern Blvd.	" "	" "
Bronx River Pkwy.	3315 White Plains Rd.	" "	" "
East Bronx	1990 Westchester Ave.	Burt Cohen	822-5943
Baychester	4008 Boston Road	" "	" "

Brooklyn

Office	Address	Liaison	Phone
Avenue X	333 Avenue X	Alyce Furman	(718)627-3302
Boro Hall	248 Duffield Street	Ed Malone	(718)330-7623
Bay Ridge	6209 11 Avenue	" "	" "
Bed-Stuy	1360 Fulton	" "	" "
Bushwick	790 Broadway	Lynda Straker	(718)963-9451
Williamburgh	217 Havermeyer St.	" "	" "
Glendale	67-10 Myrtle Avenue	" "	" "
Cypress Hills	3386 Fulton Street	Horace Johnson	(718)827-3853
East New York	114 Pennsylvania	" "	" "
Canarsie	1329 Rockaway Pkwy.	" "	" "
Flatbush	2236 Nostrand Avenue	Josephine Laska	(718)859-0631
Kings Plaza	4123 Avenue U	" "	" "
Crown Heights	350 Troy Avenue	" "	" "

Queens

Office	Address	Liaison	Phone
Long Island City	29-28 41 Avenue	Tom Puleo	(718)937-7753
Astoria	21-77 31 Street	Art Rowe	(718)278-3797
Jackson Heights	77-14 Roosevelt Ave.	Juan Padilla	(718)899-1056
Jamaica	90-25 161 Street	Charles Silverstein	(718)990-1613
Fa. Rockaway	617 Beach 20 Street	John Remus	(718)337-5750
Flushing	136-65 37 Avenue	Carol Canizara	(718)539-5404

Nassau County

All Offices	222 Station Plaza N. Mineola, NY	Rick Berman	(516)747-3991

Suffolk County

All Offices	75 Oak Street Patchogue, NY	Pat Campagna	(516)475-6996

Westchester County

All Offices	55 Church Street White Plains, NY	Ronald Sobel	(914)683-1529

Erie County, NY

Buffalo	111 West Huron St.	Ed Driscoll	(716)846-4663

Rochester, NY

Rochester	100 State Street	Tom Ragonese	(716)263-6814

New Jersey

Office	Address	Liaison	Phone
Asbury Park	1200 Memorial Dr.	Kenneth Kukielka	(201)774-2752
Bricktown	530 Brick Blvd.	" "	" " "
Toms River	8 Robbin St.	" "	" " "
Atlantic City	Pacific & Penn. Ave.	Dennis Chornomaz	(609)347-8363
Wildwood	136 E. Spicer Ave.	" "	" " "
Bridgeton	149 W. Broad St.	Robert Rougeau	(609)455-2059
Camden	2101 Ferry Ave.	Sidney Bader	(609)962-8123
Glassboro	N. Delsea Dr.	" "	" " "
Mt. Holly	Rt. 38&Eayrestown Rd.	" "	" " "
Elizabeth	342 Westminster Ave.	Patricia Wilson	(201)353-3334
Plainfield	315 E. Front St.	" "	" " "
New Brunswick	52 Charles St.	William Easton	(201)828-5114
Raritan	US Hwy. 206 South	" "	" " "
Perth Amboy	336 Madison Ave.	Carol Shpiner	(201)826-1359
Trenton	402 E. State St.	John Gianiodis	(609)989-2030
East Orange	68 S. Harrison St.	Frank Costa	(201)675-5055
Hackensack	22 Sussex St.	Jean Pryor	(201)487-5049
Irvington	686 Nye Ave.	Kathy Brehm	(201)645-6029
Jersey City	861 Berge Ave.	William Babics	(201)645-6029
Montclair	396 Bloomfield Ave.	Robert Klein	(201)744-1268
Morristown	147 Speedwell Ave.	Len Greene	(201)539-2332
Newton	15 Rt. 206 North	" "	" " "
Newark	970 Broad St.	Charles McCall	(201)645-3247
Clinton Hill	193 Avon Ave.	" "	" " "
Passaic	30 River Dr.	Craig Murden	(201)470-8103
Paterson	60 Van Houten St.	Vera Porter	(201)279-1737
Ho-Ho-Kus	201 E. Fanklin	" "	" " "

Puerto Rico

Office	Address	Liaison	Phone
San Juan	1002 Munoz Rivera Ave.	Marie Serrano	(809)753-4228

Regional Coordinator	- 26 Federal Plaza Rm. 40-114	Jane Zanca	(212)264-7291

State Agency AIDS Liaisons
New York Region

New York
Office of Disability Determinations

Area	Liaison	Phone
Manhattan and Staten Island	Frank Giordano	(212)587-3081
Brooklyn	Tom Couteau	(212)587-3720
Bronx and Westchester	Guy Thom	(212)587-3209
Queens and Long Island	Richard Learned	(212)587-3519
Albany	Bill Smalenbach	(518)473-9285
Buffalo	Don Hull	(716)847-3923

New Jersey
Division of Disability Determinations

All Areas	Al Ward	(201)648-2432

Puerto Rico
Disability Determination Program

All Areas	June Mary Jimenez	(809)754-8925

Virgin Islands
Disability Programs Branch, SSA

All Areas	Roberto Caraballo	(809)774 7375

DEPARTMENT OF HEALTH & HUMAN SERVICES

Social Security Administration

Refer to:

Region II
Federal Building
26 Federal Plaza
New York NY 10278

Social Security Teleclaims Phone Numbers

New York

Manhattan, Bronx, Brooklyn, State Island, Rockland	(212) 264-3691
Queens, Nassau, Suffolk, Westchester	(212) 657-4451
Erie County	(716) 846-4705
Albany	(518) 472-7649
Auburn	(315) 252-3166
Batavia	(716) 343-0702
Binghamton	(607) 773-2850
Corning	(607) 936-3477
Dunkirk	(716) 366-7403
Elmira	(607) 734-4004
Geneva	(315) 789-1184
Glens Falls	(518) 793-7220
Gloversville	(518) 725-4222
Herkimer	(315) 866-6840
Hudson	(518) 828-9441
Ithaca	(607) 273-0977
Jamestown	(716) 484-0164
Kingston	(914) 338-7307
Monticello	(914) 794-2816
Newburgh	(914) 561-4707
Niagara Falls	(716) 297-2924
Ogdensburg	(315) 393-1653
Olean	(716) 372-1168
Oneonta	(607) 432-0905
Oswego	(315) 342-3632
Plattsburgh	(518) 561-8120
Poughkeepsie	(914) 452-3620
Ridgemont	(716) 225-4679
Rochester	(716) 263-6825
Rome	(315) 339-2455
Schenectady	(518) 382-1005
Syracuse	(315) 423-5159
Troy	(518) 271-6507
Utica	(315) 797-6197
Watertown	(315) 788-1749

New Jersey

Northern New Jersey	(201) 777-1528
Central and Southern New Jersey	(201) 727-7752

Puerto Rico

San Juan	(809) 753-5374
Mayaguez	(809) 832-5350

AN OVERVIEW OF SOCIAL SECURITY DISABILITY AND SUPPLEMENTAL SECURITY INCOME DISABILITY

The Social Security Administration has two disability benefit programs:

Social Security Disability Insurance

Social Security pays monthly disability benefits to:

1. Disabled workers under 65 and their families.

2. Unmarried people disabled before age 22 whose parent (or grandparent in certain circumstances) receives retirement or disability benefits or is deceased.

3. Disabled widows and widowers of workers who were insured at the time of death.

Disabled workers need Social Security credits. A disabled worker must have worked long enough and recently enough under Social Security to be insured. In 1985, workers earn credit for one-fourth year of coverage for each $410 in earnings, up to a maximum of a full year's credit for earnings of $1640 or more. (The amount of earnings required for these credits will gradually increase in future years.)

The years of work credit needed for disability insurance coverage depends on the applicant's age when he/she became disabled:

1. Before age 24 - credit is needed for 1 1/2 years of work in the 3-year period ending when disability starts.

2. Age 24 through 31 - credit is needed for having worked half the time between 21 and the time disability starts.

3. Age 31 or older - credit is needed for at least 5 years of work in the 10 years before disability starts.

Supplemental Security Income Disability

The SSI program pays monthly benefits to disabled people who have limited income and assets.

Income - An applicant may have some income and still qualify for SSI payments. Each case must be evaluated individually. Generally, the first $20 a month in income is not counted. Income above the first $20 (other than earnings) usually reduces the amount of the SSI payment.

The first $65 a month in earnings is not counted. The SSI payment is reduced by $1 for each $2 in earnings over $65 a month.

Resources - Resources are items an applicant owns such as real estate, personal property, savings and checking accounts, cash or stocks and bonds, life insurance, automobiles, burial plots or burial funds.

A single adult may be eligible for SSI with resources valued at up to $1,600. A couple may have resources valued at up to $2,400.

Citizenship - Applicants for SSI must be a citizen of the U.S. or a legal alien residing in the U.S.

How to File a Claim

Applications can be filed in several ways:

- Applicant can call the special telephone numbers attached. The local SSA office will then call the applicant back and take the claim over the telephone. SSA encourages applicants to take advantage of the "teleclaims" procedure in order to reduce their exposure to possible complicating infections.
- SSA field representatives can visit home-bound applicants who have no phone.
- For those who are hospitalized, the hospital social services staff can arrange for an SSA field representative to take the claim at the hospital.
- Or, applicants can apply in person at the local Social Security office.

Documents Needed

For Social Security Disability Insurance, the following documents are needed:

- Social Security card or a record of Social Security number.
- Proof of age for each person eligible (e.g. birth certificate).
- Copy of W-2 forms (tax returns if self-employed) for the past 2 years.
- Dates of military service.
- Dates of prior marriage if spouse is also filing.
- Claim number for any other benefits being received (or expected) because of disability .
- For disabled widows/widowers, worker's death certificate.

For Supplemental Security Income Disability, the following documents are needed:

- Social Security card and proof of age, as above.
- Information about income and assets: payroll slips, tax returns, bank books, insurance policies, auto registration, burial plot or burial fund records.
- Information about current residence: mortgage, lease, landlord's name.

IMPORTANT: Applicants should not delay filing if all of these documents are not available. The Social Security office can assist in obtaining the necessary records.

In addition to the above, the SSA disability interviewer will request the following:

- Names, addresses, and phone numbers of treating physicians and hospitals. Clinic numbers for outpatient clinic treatment are helpful.
- Vocational information for jobs performed during past 15 years (job duties, approximate dates worked, and approximate salary).

How Medical Reports Are Obtained

Medical evidence to support the disability claim is obtained by a state agency authorized to process SSA/SSI disability claims. In this region the state agencies are:

New York	:	Office of Disability Determinations Albany, Buffalo, New York City
New Jersey	:	Division of Disability Determinations Camden, Newark
Puerto Rico	:	Disability Determination Program San Juan

The state office will request medical reports directly from treating physicians and hospitals. Applicants can assist by asking treating physicians to submit reports promptly. Medical reports also can be sent by the appplicant to the local SSA office if he/she has such reports.

The medical evidence needed includes details of the medical history, current symptoms, current physical findings, and results of relevant diagnostic laboratory tests.

Criteria for Evaluating Disability

Those who meet the CDC definition of AIDS will be found disabled under SSA/SSI (if non-medical eligibility requirements are met). For those who do not meet the CDC definition (e.g. AIDS Related Complex), an individual evaluation is made based on the symptoms, physical findings, and laboratory findings. These are assessed in relation to SSA's full listing of medical criteria depending on the effects of the condition. Both physical and mental conditions are included in SSA's criteria. Vocational factors such as advanced age, lack of education, and lack of work skills may also be considered.

In general, benefits cannot be paid to anyone who is currently working. However, there are exceptions to this where earnings are very low or are subsidized. This can be explored with the local Social Security office.

When Benefits Start

Under Social Security Disability Insurance, monthly benefits start with the 6th full month of disability for workers and widows/widowers. There is no waiting period for those disabled before age 22 who are filing a claim on a parent's record.

Under Supplemental Security Income, benefits begin as soon as the claim is allowed. Applicants may also receive 3 months of benefits while awaiting the disability decision in some circumstances.

Other Benefits

Medicare insurance is available to those receiving Social Security Disability Insurance benefits after 24 months.

Medicaid is available to those who are eligible for Supplemental Security Income as well as those who are eligible for local assistance programs. Information about this can be obtained from local government agencies.

DEPARTMENT OF HEALTH & HUMAN SERVICES

Social Security Administration

Region II
Federal Building
26 Federal Plaza
New York NY 10278

Medical Evidence Needed for Disability Claims For Persons with AIDS/ARC

Physicians who treat persons with AIDS or ARC may receive a request for a medical report in support of a patient's claim for Social Security or SSI disability benefits. Below is the type of evidence which should be included in the medical reports.

1. Medical History

Details of the medical history should include:

- Presenting symptoms.
- Pertinent physical findings at onset.
- Clinical course to the present.
- Where there has been significant weight loss, the number of pounds lost and representative weights should be given, plus the period of time over which the weight was lost.
- Relevant DATES should always be given. (The onset date of disability can affect the amount of retroactive benefits due.)

2. Current Symptoms

Current symptoms (e.g. fatigue, fevers, night sweats, anorexia, diarrhea, cough, shortness of breath) should be quantified, where possible, in terms of:

- Frequency
- Duration
- Precipitating factors
- Mode of relief

3. Current Physical Findings

- Both positive and negative relevant findings should be reported.
- Findings such as lymphadenopathy, nodules, plaques, lumps, rashes, thrush, bruises, bleeding, skin ulcers, etc. should be described in terms of location and extent.
- Where CNS involvement has resulted, the relevant reflex, motor, or sensory abnormalities should be given.
- Where retinal involvement has occurred, fundoscopic findings and current visual acuity (with best correction) are needed.
- Current height and weight should be given.

4. Laboratory Testing

These should include:

- Diagnostic tests showing immune deficiency

- Lymphocyte subpopulation studies
- Lymphocyte transformation studies (if available)
- CBC with differential (esp. WBC and Hematocrit)
- ANA

- Diagnostic tests showing opportunistic infection involved, e.g.:

- Pathology report
- Bronchoscopy
- Endoscopy
- Chest x-ray
- Stool analysis
- Culture reports
- CSF analysis
- Platelet count
- Liver function studies
- Kidney function studies
- GI series
- Skeletal survey
- ECG
- CAT scan

- You may include a copy of the laboratory's report or cite the pertinent findings. It is especially important to give the specific gross and microscopic examination findings from pathology reports.

- For patients with ARC, any relevant test results should be given.

- DATES of testing should always be given.

5. Treatment and Response, Prognosis

- Specify current mode of treatment and response.
- Give dosages for any medications.
- For patients with ARC, give prognosis for current episode of illness.

DEPARTMENT OF HEALTH & HUMAN SERVICES

Social Security Administration

Region II
Federal Building
26 Federal Plaza
New York NY 10278

Medical Reports for Disability Claims of Persons with AIDS/ARC

When a person with AIDS/ARC files a claim for Social Security (SSA) or Supplemental Security Income (SSI) disability benefits, he/she will list the physicians and hospitals where treatment has been received. Medical reports will then be requested from these sources to document the claim for benefits. Requests for such medical evidence are made by the state agencies which process disability claims on behalf of SSA. The state agencies in this SSA region (New York, New Jersey, and Puerto Rico) are listed below.

Several different methods may be used to provide the medical evidence needed in support of a disability claim. Generally, a written request is sent to a treating physician with a questionnaire to be completed. In lieu of completing this questionnaire, a physician may call the phone number included with the request and provide evidence directly to a disability examiner or staff physician at the state agency. Another option is for the treating physician to call the toll-free number provided on the state agency request form and to dictate a report. Physicians may sometimes be called directly by the state agency and asked to provide a medical report over the telephone. This is done to expedite a claim, especially where there has been a delay in securing a written report or in obtaining the hospital record.

Transcriptions of phone reports are always sent to the physician for verification and signature.

The state agency will include the patient's signed permission for release of information with their requests for a report and with transcriptions of phone reports.

State Agencies

New York

Dept. of Social Services
Office of Disability Determinations

110 William Street
New York, NY 10038

P.O. Box 1993
Albany, NY 12201

P.O. Box 5030
Ellicott Station
Buffalo, NY 14205

Toll-free number (statewide): 1-800-556-6758

New Jersey

Dept. of Labor
Division of Disability Determinations

P.O. Box 649
Newark, NJ 07101

Toll-free numbers:

From NJ: 1-800-242-6708
Outside NJ: 1-800-526-1122

P.O. Box 431
Camden, NJ 08102-0431

Toll-free numbers:

From NJ and NY 1-800-582-7652
From Penn, Del, Md: 1-800-257-5279

Puerto Rico

Dept. of Social Services
Disability Determinations Program
Call Box 71301
San Juan, PR 00936

No toll-free number. Call phone number given on written request.

New York State Department of Health

A I D S
I N S T I T U T E

Vol. 3 No. 1 Newsletter **March 1986**

AIDS: The Public Health View

AIDS is a syndrome - the acquired loss of a person's natural defense to deal with disease agents. As one scientist has put it, for the immune deficient, "any bug will do." Accordingly, what is seen with the person suffering with AIDS is the depletion of the immune system's ability to protect, thus allowing the person to fall victim to pneumonia, other opportunistic infections or the relatively rare Kaposi's sarcoma.

Some months ago, scientists identified a particular virus, a retrovirus, associated with AIDS. The virus is referred to as HTLV-III (official U.S. name), or LAV (in France) or ARV (in California). It is important to note that this agent, while necessary to the development of AIDS, is not in and of itself the cause of the condition. From the public health perspective, AIDS is a host-specific disease. A person must have or create a vulnerability to the agent in order to become infected. This characteristic is important to keep in mind in searching for ways to control the AIDS epidemic.

With the identification of the associated virus, HTLV-III, and with the rapid development of a serum antibody test for that virus, we are learning a good deal more about AIDS. The antibody screening test is routinely applied to all donated blood in the country to prevent contaminated blood from entering the blood pool and from being used for transfusions. Hopefully, one important method of AIDS transmission has been halted, through contaminated blood products. The antibody screening test has enabled scientists to obtain general background information on the occurrence of the virus or its antibody in the general population. Tests conducted at blood banks on more than one million donation units have shown that approximately 0.8 percent of blood donors initially react positively to the antibody; but when the test is repeated, the positivity level drops to 0.2 percent. Further, a confirmatory test — specific for the virus — results in only 0.08 percent of the blood donors being confirmed as HTLV-III positive. Of those confirmed positive, 60-70 percent evidence no clinical illness of any sort; 20-30 percent may develop an AIDS-related condition of swollen lymph nodes, general weakening and weight loss but are not overtly ill; some 5-10 percent may actually develop clinical AIDS.

The epidemiological fingerprint of AIDS is of enormous interest and importance. Since the identification of this syndrome in our population in 1981, more than 6,000 cases in New York State and more than 16,000 cases in the nation have been identified and investigated. Although 200 new cases are diagnosed each month in New York State, a locked pattern of susceptibles has become apparent in the past five years.

AIDS provides a clear and concise pattern of movement. The disease is not transmissible to domestic and personal contacts even if household articles are shared (e.g., food, utensils, towels, toilets, etc.). AIDS is **not** transmissible to health care workers who interact with those afflicted. It **is** transmissible only by innoculation with shared and improperly cleaned injection apparatus or through sexual contact (primarily anal intercourse) or through intrauterine exposure of mother to child.

Long before we can hope to achieve general protection of the population through a vaccine or effective medical treatment, success in ending the AIDS epidemic—because of its epidemiologic picture—will come through application of exposure intervention. To this end, the Department of Health has launched a public education campaign focused on the unique modes of exposure for those at risk. Our goal, and the basis for all our public health activities, is to break the chain of virus transmission.

William Leavy
Executive Deputy Director
New York State Department of Health

AIDS International Conference Announced

The AIDS Institute and the Milbank Memorial Fund are co-sponsoring an international conference entitled "AIDS: Impact on Public Policy" to be held May 28-30, 1986, at the New York Hilton Hotel in New York City.

The AIDS epidemic has raised numerous social, ethical and legal questions. The extent of the social implications of AIDS surpasses any other disease in modern times. Because the private rights of individuals continue to be threatened by this health crisis, important policy issues have and continue to emerge in every area including education, health care, insurance and employment.

This conference will focus on current social, economic and policy issues surrounding the AIDS epidemic. The format of the conference will present an overview of the relationship between our current scientific knowledge and attendant social ramifications.

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New York Blood Center

The New York Blood Center is participating in a contract with the AIDS Institute to develop information and strategies to cope with the impact of screening blood donors for antibody to HTLV-III. This contract, initiated in January 1985, established a working group to provide guidance to the blood center and to American Red Cross blood centers in upstate New York. Sociological studies conducted in collaboration with the Department of Social Medicine and Health Policy, Harvard Medical School, are assisting the group to develop a counseling program and educational materials for donors who are antibody positive.

The Greater New York Blood Program, operated by the New York Blood Center, is the largest blood program in the world, providing more than a million units of blood products a year to patients cared for in 260 hospitals. It serves an area extending from the tip of Long Island to the northern border of Dutchess County and includes parts of northern New Jersey and the five boroughs of New York City.

The blood program accepts responsibility for providing the safest possible blood supply. When it was recognized that AIDS could be transmitted by blood transfusion, the blood program instituted a donor self-exclusion protocol whereby individuals at high risk for contracting AIDS could indicate, through a confidential response to a questionnaire that their donation should be used for research studies only, but not for transfusion. This effort preceded federal requirements that members of high risk groups not donate blood and has recently been recommended by the federal government for implementation by other blood centers across the country. As a result of this procedure, despite the high number of AIDS cases in the region, the New York area has a relatively low incidence of transfusion-transmitted AIDS.

But, no matter how effective this procedure was, combined with the marked cooperation of individuals in high risk groups agreeing not to donate blood, an element of risk remained as long as there was no way to test blood for the presence of AIDS virus. Thus, the announcement in 1984 was welcome news that a virus many believe to be the probable cause of AIDS, HTLV-III, had been identified and a screening test would be developed and commercially available. Simultaneously, however, the announcement raised new concerns. The test being developed was a test for antibody to the virus, not for the virus itself. Thus, a reactive test indicates that the individual has been exposed at some time, in some way, to the virus. It does not indicate the presence of the virus or whether or not the individual is infectious. It is not a test for AIDS.

AIDS Institute Contract

Recognizing that many questions would have to be addressed in a very short period of time, the AIDS Institute provided funds to the New York Blood Center to establish a working group to grapple with these issues. Comprising attending (treating) physicians, immunologists, research scientists, attorneys, nurses and social workers, the working group included representatives from city and state health departments, the American Red Cross and the gay community.

The first issue to be resolved was the definition of a positive test. Because of the low incidence of the virus in the general blood donor population, the probability of a high number of false positive reactions to the ELISA (enzyme-linked immunosorbent assay) screening test was anticipated. A false positive occurs when the donor's blood reacts with some other element in the screening medium. In order to ascertain, as far as possible, a true antibody response for HTLV-III, the sample is tested a second time. If the second screen is also reactive, the specimen is then tested by a different method known as Western blot. Only if the Western blot is positive will the donor be notified of a positive test for antibody to the HTLV-III virus.

The working group recognizes, however, the need for ongoing review of data in the field of screening for the presence of antibody to HTLV-III and for additional methods of testing to confirm the presence of antibody and/or virus. It will, therefore, conduct periodic reviews of the rapidly accumulating data in this field.

Donor Notification Program

In order to determine personal reactions reflecting the level of information and misinformation about the meaning of a positive test, a survey was designed by Jerry Avorn, M.D., Harvard Medical School. Among the encouraging findings of the donor attitude survey conducted by the blood program was the fact that more than 90 percent of the donors surveyed said that they wanted to be informed of their test results. Virtually all of the services to be offered—physician referral, hotline service, psychological counseling and behavior modification advice—were requested by antibody positive donors. Somewhat fewer individuals felt that they would want access to a lawyer with AIDS-related experience.

Almost all the participants believed the possibility that their blood would be found to carry the virus was zero or one in a million, but many felt that it was likely that this incidence was one in 10,000 in the general population.

Approximately 50 percent of those surveyed believed that a positive test result would mean that they probably had AIDS and 50 percent felt that this would mean they could probably give AIDS to their sexual partner. Nearly half of the respondents felt there was a possibility that the test result might be false positive.

Analysis is continuing on several other items in the 60-item questionnaire. Results of this survey were used in the design of a program for donors who are antibody positive. Future findings will enable modification of this program when appropriate.

Recognizing the implications of such information to the donor, the working group developed an information booklet for donors spelling out the best currently available information about the meaning of a positive test, including what it does and does not mean. The booklet reassures the individual that the positive antibody test does not mean the individual has AIDS and that data thus far indicate that the majority of people will not develop AIDS. The booklet stresses the need for common sense precautions in life style and the evolving nature of our knowledge about the antibody test.

To assure that each donor receives all relevant information, a videotape narrated by the author was prepared by the working group with support from the AIDS Institute. Specially trained nurse clinicians will meet with each donor and, after providing initial information, will watch the video with the donor. The nurse will then discuss the information presented and answer any questions the donor may have. Training, role playing and counseling for the nurse clinicians is conducted with the participation of Samuel Perry, M.D., psychiatrist, Cornell University Medical School.

All donors will be urged to see their private physicians or to contact a physician participating in the referral program. For this purpose, referral lists for both medical and psychosocial follow-up will be provided to all donors. Procedures will be modified as appropriate, based on initial experience with donor notification. Because the significance of test results is so uncertain, the Greater New York Blood Program will invite HTLV-III antibody positive individuals to participate in research projects designed to increase our information about the significance of a positive test and the need for and use of health care resources by HTLV-III positive individuals.

There are two additional avenues the New York Blood Center will pursue. The first is an evaluation of the knowledge, attitudes and beliefs of staff members working in various areas of the blood center concerning the HTLV-III antibody test. This information will be helpful in developing educational material. The second is the development of training materials for counseling HTLV-III positive donors. It is anticipated that the information and materials derived from these efforts will be used by health care workers in blood centers and other settings.

The AIDS Institute will make available all completed donor information materials, script, videotape and written materials.

Johanna Pindyck, M.D.
Director, Greater New York Blood Program
Senior Vice President, New York Blood Center

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AIDS Conference

Five major topics have been developed to address these issues.

Public Health and Private Rights: Health, Social, and Ethical Perspectives will focus on the role of government in balancing the need to protect public health and its concurrent obligation to protect populations at risk of social isolation and stigma. It will explore the issues of confidentiality, quarantine, mandatory screening, contact tracing and the social responsibility of individuals with the disease. *Speakers:* Thomas Vernon, M.D., Executive Director, Colorado Department of Health; Harvey Fineberg, M.D., Ph.D., Dean, Harvard School of Public Health. *Moderator:* Ronald Bayer, Ph.D., Associate for Policy Studies, The Hastings Center. *Panelists:* Dean Echenberg, M.D., Ph.D., Director, Bureau of Communicable Disease Control, Department of Public Health, City and County of San Francisco; James Childress, Ph.D., Kyle Professor of Religious Studies and Professor of Medical Education, University of Virginia; Alexander Capron, J.D., Norman Topping Professor of Law, Medicine, and Public Policy, The Law Center, University of Southern California.

Research: International Cooperation and Competition will examine scientific cooperation in AIDS research and will evaluate how well the traditional international research protocols are working. This discussion will also focus on the scientific and public policy process that is determining the relative importance of competing and overlapping research domains. *Speaker:* James Wyngaarden, M.D., Director, National Institutes of Health. *Moderator:* LeRoy Walters, Ph.D., Director, Center for Bioethics, Kennedy Institute of Ethics. *Panelists:* John Seale, M.D., M.R.C.P., Venereologist, London, England; Morris Abram, J.D., Former Chairman of the President's Commission on the Study of Medical Ethics, Vice-Chairman, Civil

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AIDS Institute Funded Organizations

For referral or assistance, call the NYS AIDS Hotline toll free:

1-800-462-1884

Or contact your nearest local AIDS program:

Mid-Hudson Valley AIDS Task Force (Includes Westchester & Rockland)	**(914) 997-1614**
AIDS Council of Northeastern New York	**(518) 445-AIDS**
AIDS Rochester, Inc.	**(716) 244-8640**
Central NY AIDS Task Force	**(315) 475-AIDS**
Southern Tier AIDS Task Force	**(607) 723-6520**
Buffalo AIDS Task Force, Inc.	**(716) 881-AIDS**
Long Island AIDS Project	**(516) 444-AIDS**
Haitian Coalition (NYC)	**(718) 855-0972 or 0973**
Hemophilia Foundation (NYC)	**(212) 682-5510**
Beth Israel, AIDS Information for IV Substance Abusers (NYC)	**(212) 420-4141**
Gay Men's Health Crisis (NYC)	**(212) 807-6655**
Albert Einstein College of Medicine Pediatric AIDS Information	**(212) 430-3333**

If you have an AIDS related hospital problem call the New York State Patient Care Investigation Unit:

For New York City	**(212) 502-0874**
All others	**(518) 474-5013**
After business hours	**(collect) (518) 445-9989**

AIDS Conference

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Rights Commission; Andrew Moss, Ph.D., Epidemiologist, San Francisco General Hospital; Susan Zolla-Pazner, Ph.D., Co-Director of AIDS Center, Manhattan VA Medical Center, Associate Professor, New York University Medical Center.

Clinical Management: Treatment Modes and Impact on the Health Care System will include various disease management and treatment protocols for individuals with AIDS including long term care, community based vs. institutional management and the effects on health insurance. *Speakers:* David Axelrod, M.D., New York State Commissioner of Health; Mervyn Silverman, M.D., former Director of Health, City and County of San Francisco. *Moderator:* James Curran, M.D., M.P.H., Director, AIDS Branch, Centers for Disease Control. *Panelists:* Eric Sandstrom, M.D., Karolinska Institute, Stockholm, Sweden; Donald Abrams, M.D., Assistant Director, AIDS Activities, San Francisco General Hospital; Michael Adler, M.D., Middlesex Hospital Medical School, Department of Genito-Urinary Medicine, London, England; Sheldon Landesman, M.D., Associate Professor of Medicine, Director, AIDS Study Group, SUNY Downstate Medical Center.

Education and Communication: Enhancing Public Understanding and Fostering Disease Prevention will center around educational efforts to communicate the existing state of the art knowledge of AIDS. Topics will include risk reduction, control of media hysteria and public backlash. *Speakers:* Nathan Fain, Gay Men's Health Crisis Center, New York City and Robert Bazell, Science Correspondent, NBC News. *Moderator:* Virginia Apuzzo, Executive Deputy Director, New York State Consumer Protection Board. *Panelists:* Tony Whitehead, Terrence Higgins Trust, London, England; Michael Callen, Member, New York State AIDS Advisory Council, Member of People with AIDS Coalition, New York.

AIDS and Economics: An International Perspective will examine the impact of AIDS on the various national health systems and the allocation of resources for basic research, screening, prevention, education and treatment. *Speakers:* Rashi Fein, Ph.D., Professor, Economics of Medicine, Harvard Medical School and J. B. Brunet, M.D., Director, World Health Organization Collaborative Services in Western Europe. *Moderator:* Daniel M. Fox, Ph.D., Director, New York State Center for Assessing Health Services, Professor of Humanities in Medicine, State University of New York at Stony Brook. *Panelists:* Victor Fuchs, Ph.D., Professor of Economics, Stanford University; Fakary Assad, M.D., Director, Division of Communicable Diseases, World Health Organization, Geneva, Switzerland; Ann Scitovsky, Chief, Health Economics Department, Palo Alto Medical Foundation.

Keynote speakers for the conference: E. Donald Acheson, D.M., F.R.C.P., F.F.C.M., F.F.O.M., Chief Medical Officer, Department of Health and Social Security, London; Frederick Robbins, M.D., former president, National Institute of Medicine; Nathan Clumeck, M.D., Head, Division of Infectious Diseases, St. Pierre Hospital, Brussels, Belgium.

More than 1,000 international participants are expected from a variety of public health and public policy disciplines.

For further information regarding this conference, contact Ms. Sherry Chorost, Conference Coordinator, AIDS Institute (518) 473-0641.

A I D S

This newsletter is published quarterly by the AIDS Institute, New York State Department of Health, Albany, New York 12237.

Mario M. Cuomo
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Office of Public Health

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AIDS Institute

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STATE OF NEW YORK

DEPARTMENT OF HEALTH MEMORANDUM

SERIES - 84 - 97
DATE - 11/29/84

PUBLIC HEALTH SERIES: PH - 18, H - 61, NH - 43, HRF - 44, D&TC - 24, HMO - 8, Hospice - 20, HHA - 26

SUBJECT: Confidential and Identifying Patient Information

The publication of the names of AIDS patients in the news media represents a violation of patient privacy and a potential precedent for future breaches of privacy in AIDS cases and other reportable diseases. This has occurred even though State and Local Health Units have properly refused to release patient names.

To help stem the occurrence of such incidents, the Department of Health recommends that health officials observe the following practices:

1. All patient information derived from disease reporting should be treated as confidential. This concept dictates that any information pertaining to a particular case should be known only to the attending physician, to appropriately authorized personnel in the health care facility in which the patient is treated, and to the appropriate County or State Health authority.

2. Confidential information includes any information which can be used to identify an individual patient. Such information will vary with circumstances but may include such basic and seemingly innocuous data as age, sex, month of report, or date of death, particularly if the number of patients or the jurisdiction in which the disease occurs is small.

3. No identifying information about an AIDS patient should be given to individuals, representatives of the news media, or the public at large. As a guide, information given should be limited to that appearing in the Department of Health's AIDS Surveillance Monthly Update, which provides a numeric count by age, sex, county of residence, and diagnostic characteristics. Officials are especially cautioned against answering inquiries indicating that the questioner has some knowledge of a particular AIDS case and is merely seeking clarification or corroboration of seemingly harmless information.

The Department of Health recognizes that public health officials have a responsibility to alert the public to the presence of disease in the community. This responsibility does not extend, however, to the release of identifying or confidential patient information. When in doubt, officials are asked to consult with the appropriate Department of Health Regional/Area Office for guidance.

Dwight T. Janerich, DDS, MPH
Director, Division of Community
Health and Epidemiology

Office of Public Health

for Raymond D. Sweeney
Director, Office of Health Systems
Management

Distribution: Regional and Area Directors of Public Health
Area Offices of Health Systems Management
Hospital Infection Control Practioners
County and City Health Commissioners
County Public Health Directors
Hospital Administrators
County Nursing Services
District Health Offices
Article 28 Facilities
Medical Examiners
Funeral Directors
Laboratories

STATE OF NEW YORK

DEPARTMENT OF HEALTH MEMORANDUM

Series ·	83-88
Date ·	10/31/83

PUBLIC HEALTH SERIES: H-48, NH-36, HRF-36, D&TC-25, HMO-2, HHA-19, PH-16

SUBJECT:

Mandatory Reporting for Acquired Immune Deficiency Syndrome

The Public Health Council has approved an emergency amendment to the State Sanitary Code to provide for mandatory reporting of Acquired Immune Deficency Syndrome (AIDS). The purpose of this memorandum is to provide affected parties with instructions for reporting conditions of AIDS. Below is the text of the new Part 24 of the State Sanitary Code:

Section 24.1 All cases or suspected cases of Acquired Immune Deficiency Syndrome shall be reported to the Commissioner of Health by city, county and district health officers, physicians, hospital administrators, laboratories or persons in charge of state institutions. Pathologists, coroners and medical examiners or other persons determining from examination of a corpse, or from history of the event leading to death that at the time of death the individual was apparently affected with AIDS shall also make such report to the Commissioner. Reports shall be made in a manner and on forms prescribed by the Commissioner of Health. After receiving the report, the Commissioner may request the individual making the report to provide additional information as may be required for the epidemiologic analysis and study of Acquired Immune Deficiency Syndrome.

Section 24.2 Such reports and additional information shall be kept confidential, as required by Public Health Law Section 206 (1)(j).

Attached is the "Initial Case Report" form for use in reporting cases of AIDS to the New York State Department of Health. The initial report may use either a distinctive identification code or the patient's name. For each case of AIDS, information listed on the form should be called or mailed to The New York State Department of Health, P.O. Box 2073, Empire State Plaza Station, Albany, NY 12220 (phone 518-474-6730); or in New York City, by calling 212-566-3630/3624 or mailing the form to The New York City Department of Health, Box 44, Rm 609, 125 Worth Street, New York, New York 10013. Shortly, these forms will be on multi-part paper so that the reporting individual may retain the second copy for clinical files. Subsequently, personal patient-specific information will be requested on prescribed forms which will be used to collect more detailed epidemiologic and clinical information which will be protected by the safeguards of Public Health Law 206 (1)(j). Public Health Law 206 (1)(j) reads as follows:

(1) The Commissioner shall:

(j) cause to be made such scientific studies and research which have for their purpose the reduction of morbidity and mortality and the improvement of the quality of medical care through the conduction of medical audits within the state. In conducting such studies and research, the Commissioner is authorized to receive reports on forms prepared by him and the furnishing of such information to the Commissioner, or his authorized representatives, shall not subject any person, hospital, sanitarium, rest home, nursing home, or other person or agency furnishing such information to any action for damages or other relief. Such information when received by the Commissioner, or his authorized representatives, shall be kept confidential and shall be used solely for the purpose of medical or scientific research or the improvement of the quality of medical care through the conduction of medical audits. Such information shall not be admissible as evidence in any action of any kind in any court or before any other tribunal, board, agency, or person

This section of the Law limits the uses to which the personal data may be used and provides protections against lawsuits for the reporting person as well as the confidentiality of records accumulated through the study of AIDS. Thus, case reports and names are protected by law and cannot be released. Periodically, the Department will issue reports on epidemiological and clinical findings.

Initial report forms will be available from city/county health departments, or district/area/regional/central offices of the New York State Department of Health.

Curbing the Fear of AIDS

An important new study confirms that there is virtually no chance of acquiring AIDS through casual contact. The study discovered no such cases in households of AIDS patients. There is no justification, hence, for society to turn victims of AIDS into pariahs, forcing them out of jobs and apartments, refusing to provide them services or to let them, in the case of children, stay in school.

AIDS is a fearful disease, but it is extremely difficult to contract. In America it is spread almost exclusively by virus-laden blood or semen that gains direct access to the bloodstream. These routes include homosexual intercourse, the sharing of contaminated needles among drug addicts, injection of blood products before blood donors were given the new AIDS screening test, and passage in the womb from affected mothers to their fetuses.

The fear of more casual infection was aroused because the virus was occasionally detected in the saliva and tears of AIDS victims. That fear has now been firmly laid to rest by a survey in The New England Journal of Medicine of 101 people who live in the same house as an AIDS victim. The survey, conducted by Gerald Friedland of New York's Montefiore Medical Center and colleagues elsewhere, excluded people in known risk groups and also the sexual partners of AIDS patients. It focused on household members who shared bathrooms and kitchens with AIDS victims, regularly hugged and kissed them and helped them bathe, eat and dress. If the AIDS virus could be transmitted by casual contact, these housemates would show some sign of infection. None did.

AIDS is a lingering, lethal disease with many strange properties. No one was sure at first that it could not spread like wildfire. But as hospitals in New York and San Francisco began to fill with AIDS patients, nurses and physicians cared for them despite the evident risk. Their courage provided the first evidence that AIDS is not casually transmitted.

This record, confirmed by the new study, should set a clear limit on the fear of AIDS. Much remains to be learned about the disease, but there is now abundant evidence that no one need fear living or working with AIDS victims. No one need deny them comfort while they live, or abandon them when they are dying.

Government's obligation, meanwhile, is to avoid the secrecy in policy making that a judge found in the recent dispute over admitting AIDS victims to New York schools. He upheld the city's right to decide such questions on a case-by-case basis, but urged open discussion at every stage.

The AIDS epidemic will rise higher before it ebbs or is brought under control. Until then, Americans now know there is safety as well as humanity in treating its victims with understanding.

LACK OF TRANSMISSION OF HTLV-III/LAV INFECTION TO HOUSEHOLD CONTACTS OF PATIENTS WITH AIDS OR AIDS-RELATED COMPLEX WITH ORAL CANDIDIASIS

GERALD H. FRIEDLAND, M.D., BRIAN R. SALTZMAN, M.D., MARTHA F. ROGERS, M.D., PATRICIA A. KAHL, R.N., MARTIN L. LESSER, PH.D., MARGUERITE M. MAYERS, M.D., AND ROBERT S. KLEIN, M.D.

Abstract To determine the risk of transmission of human T-cell lymphotropic virus Type III/lymphadenopathy-associated virus (HTLV-III/LAV) to close but nonsexual contacts of patients with the acquired immunodeficiency syndrome (AIDS), we studied the nonsexual household contacts of patients with AIDS or the AIDS-related complex with oral candidiasis. Detailed interviews, physical examinations, and tests for serum antibody to HTLV-III/LAV were performed on 101 household contacts of 39 AIDS patients (68 children and 33 adults), all of whom had lived in the same household with an index patient for at least three months. These contacts had shared household items and facilities and had close personal interaction with the patient for a median of 22 months (range, 3 to 48) during the period of presumed infectivity.

Only 1 of 101 household contacts — a five-year-old child — had evidence of infection with the virus, which had probably been acquired perinatally rather than through horizontal transmission.

This study indicates that household contacts who are not sexual partners of, or born to, patients with AIDS are at minimal or no risk of infection with HTLV-III/LAV.
(N Engl J Med 1986; 314:344-9.)

SINCE the recognition of the epidemic of the acquired immunodeficiency syndrome (AIDS) in 1981, several populations have been described that are at increased risk of infection with the human T-cell lymphotropic virus Type III/lymphadenopathy-associated virus (HTLV-III/LAV) and disease due to it. These include homosexual men,[1] intravenous drug abusers,[2] and recipients of transfusions of blood and blood products.[3,4] In addition, transmission of HTLV-III/LAV infection to heterosexual partners of patients with AIDS[5] and children born to mothers with AIDS or in high-risk groups has been described.[6]

The major routes of transmission of HTLV-III/LAV infection have been well established. Bloodborne transmission is supported by the presence of AIDS and HTLV-III/LAV infection in transfusion recipients and hemophiliacs, as well as in intravenous drug abusers, among whom sharing of needles is common.[7] HTLV-III/LAV has been isolated from peripheral blood in both symptomatic and asymptomatic cases of infections.[8] Transmission also appears to occur by means of intimate sexual contact, both homosexual and heterosexual,[5,9] and the virus has been isolated from semen.[10] Isolation of HTLV-III/LAV from saliva has been accomplished,[10,11] but there is no direct evidence for transmission by means of this fluid. The risk of transmission by less intimate contact is believed to be low or nonexistent. In support of this view is the indirect evidence that AIDS has remained confined almost exclusively to the risk groups initially described, in which close to 95 percent of all cases occur.[12] Except for sexual partners and children born to infected mothers, none of the family members in more than 12,000 cases reported to the Centers for Disease Control (CDC) are known to have contracted AIDS (CDC: unpublished data). In addition, hospital workers in frequent contact with patients and patients' blood have been found to be seronegative for antibody to HTLV-III/LAV.[13] Finally, most children in whom AIDS has developed have belonged to an age group in which perinatal transmission has been strongly suggested.[12] Nonetheless, the possible risk of transmission of HTLV-III/LAV infection to close contacts of infected persons remains of great concern. To address this issue directly, we identified and studied a large number of close but nonsexual household contacts of patients with AIDS or the AIDS-related complex with oral candidiasis.

From the Division of Infectious Diseases, the Department of Medicine, and the Departments of Pediatrics, Biostatistics, and Epidemiology, Montefiore Medical Center, North Central Bronx Hospital, and Albert Einstein College of Medicine, Bronx, N.Y., and the AIDS Branch, Centers for Disease Control, Atlanta, Ga. Address reprint requests to Dr. Friedland at Montefiore Medical Center, 111 E. 210th St., Bronx, NY 10467.

Supported under a Cooperative Agreement (U62/CCU200741-01) with the Centers for Disease Control, and by a grant A0-208 with the New York State AIDS Institute. Dr. Saltzman was supported by a Training Grant (5-T32-AI-070183-06) from the National Institute of Allergy and Infectious Diseases.

METHODS

Definition of Index Patients and Household Contacts

AIDS was defined according to criteria established by the CDC.[14,15] In adults (persons over the age of 18), AIDS-related complex was defined as the presence of (1) unexplained generalized lymphadenopathy (at least one lymph node of more than 1 cm) involving two or more extrainguinal node-bearing areas and persisting for at least three months, or unexplained oral candidiasis, confirmed by microscopy, and (2) two laboratory abnormalities — a low absolute number of helper T cells (<408 cells per cubic millimeter) and a low T-helper/T-suppressor (T4/T8) ratio (<1.0).

A diagnosis of AIDS-related complex was made in children less than 13 years of age if at least one of the following major clinical criteria or at least three minor clinical criteria, plus at least one laboratory criterion, were all present for at least two months. The major clinical criteria were interstitial pneumonitis, parotid-gland enlargement, and oral candidiasis in the absence of antibiotic therapy. The minor criteria were recurrent bacterial infections, generalized lymphadenopathy, hepatomegaly, diarrhea, and failure to thrive. Laboratory criteria included an elevated concentration of one or more serum immunoglobulins, lymphopenia, a low absolute number of T lymphocytes, a low absolute number of T-helper lymphocytes, and a low T-helper/T-suppressor ratio (<1.0).

Household contacts were defined as persons who were not sexual partners but who lived in the same household as the AIDS patient for at least 3 months in the period starting 18 months before the

onset of symptoms in the patient and ending at the time of contact screening.

Subject Recruitment and Evaluation

Evaluation of household contacts began in October 1984 and was carried out through April 1985. Household contacts were derived from three populations: (1) available contacts of patients who had been cared for and died at our institution within one year before the initiation of the study, (2) contacts of living patients treated at our institution from October 1984 to April 1985, and (3) contacts of patients referred from other New York City medical institutions between October 1984 and April 1985. Beginning in October 1984, all living patients with AIDS who were treated at our institution were interviewed to determine the constellation of their households and families. With the patients' consent, eligible household members were invited to participate in the study. If the patients had died before the initiation of screening, their known household contacts were invited to participate. If household members had been referred from other institutions, the diagnosis of AIDS in the index case was confirmed by our review of the medical records.

After informed consent was obtained, each household member was screened by means of a detailed, standardized interview, a physical examination, and laboratory testing. The interview included recording of demographic variables and the medical history (including birth history for children), an assessment of possible risk factors for AIDS, a complete history of sexual activity and drug use, and a detailed assessment of the duration and type of household exposure to the patient with AIDS. Subjects 13 years of age and older were interviewed directly. The parents or guardians of subjects under 13 years were interviewed instead of the subjects themselves. Complete physical examinations were performed, with particular attention to the presence of lymphadenopathy, oral candidiasis, weight loss, and failure to thrive.

Laboratory Evaluation

Laboratory evaluation included complete blood count and measurement of immunoglobulins, T-cell subsets, and antibodies to HTLV-III/LAV by enzyme immunoassay. Complete blood counts were performed according to standard methods. Lymphopenia was defined as the presence of fewer than 1200 lymphocytes per cubic millimeter. IgG was measured by radial immunodiffusion (normal range, 564 to 1765 mg per deciliter for adults and 269 to 1641 for children). Serum and heparinized venous blood obtained from study participants were shipped overnight to the CDC, where studies of T-cell subsets, serologic testing for HTLV-III/LAV, and viral isolation were performed. T-cell subsets were measured in whole blood (children under two years) or in lymphocytes separated from whole blood by Ficoll–Hypaque gradient as previously described.[16] Absolute T-cell counts were calculated from percentages of T-cell subsets and lymphocyte counts (the normal range for absolute T4-cell counts was 408 to 1583 per cubic millimeter; the normal T4/T8 ratio was 1.0 to 4.0). Antibodies to HTLV-III/LAV were determined by an enzyme immunoassay (Abbott Laboratories, North Chicago). All serum samples were tested twice. A single positive result in any sample was confirmed with the Western blot assay.[17] Cultures for HTLV-III/LAV were performed as previously described.[18]

Statistical Analysis

Summary statistics for continuous-type variables (i.e., time intervals) are expressed in terms of medians, ranges, and quartiles. The term "interquartile range" refers to the range in which the middle 50 percent of the sample lies. We determined exact confidence intervals for the binomial proportions.

Results

From October 1984 to April 1985, 41 living patients with AIDS or the AIDS-related complex with oral candidiasis were available for interview and agreed to participate in the study. We identified 140 household contacts through this group, and 63 additional contacts of 12 patients who had died of AIDS from September 1983 through September 1984 at our institution. Thirty household contacts of seven patients were referred from other institutions. Of the 233 household contacts of 60 patients, 36 were sexual partners of index cases. Since sexual transmission of HTLV-III/LAV has been well documented, these subjects were evaluated separately and were not included in the present study. Eighty-nine (45 percent) of the remaining household contacts declined to participate in the study: 55 percent were "too busy" with work or school or "not interested" in the issue, or felt that screening was "unnecessary"; an additional 15 percent were "opposed to research," 16 percent could not be located, and 15 percent could not be screened because the index patient did not consent to participation of his or her family.

Thus, a total of 108 nonsexual household contacts of 41 patients were evaluated. Seven were excluded from analysis — three because of the presence of risk factors for AIDS (one intravenous drug abuser and two homosexual men), one because blood was not obtained, one because household contact lasted less than three months, and two because review of hospital records of the index case failed to confirm the diagnosis of AIDS. The remaining 101 household contacts of 39 patients constituted the study population. Of the 39 index patients, 37 had AIDS and two had AIDS-related complex with oral candidiasis. There were 27 males and 12 females. Twenty-eight patients were heterosexual intravenous drug abusers (72 percent), one patient was a homosexual intravenous drug abuser (3 percent), three patients were homosexual or bisexual (8 percent), three were sexual partners of persons known to belong to risk groups (8 percent), and four had no documented risk factor for AIDS (10 percent). None of the household contacts had sexual contact with a patient with AIDS or had any other risk factors for AIDS.

Of the 101 household contacts, 72 (71 percent) were Hispanic, 18 (18 percent) were black, 7 (7 percent) were white, and 4 (4 percent) were in other ethnic groups. Of 77 contacts reporting household income, 50 (65 percent) had an income below $10,000, 19 (25 percent) had incomes of $10,000 to $20,000, and 8 (10 percent) had incomes above $20,000; 80 percent of the study subjects belonged to households in which three or more people were supported by such incomes. The 33 adult contacts had completed a mean of 9.5 years of education (median, 10; range, 0 to 16). Forty-five of the contacts were male and 56 were female. Their mean age was 19.4 years (median, 13; range, 0.8 to 78). The 101 contacts included 68 children under the age of 18 (50 were the biologic children of AIDS patients, and 18 were not), 3 offspring over the age of 18, 10 siblings, 11 parents (2 fathers and 9 mothers), and 9 other relatives. Thirty-three of the contacts were older than 18 years, 47 were 6 to 18 years old, and 21 were less than 6 years of age at the time of screening.

Table 1. Months of Household Contact with Patients with AIDS among 101 Household Members.*

	Median	Range	Interquartile Range†
From January 1978	37	3–87	16–68
From 18 months before symptoms in patient	22	3–48	9–27
From onset of symptoms in patient	7	0–35	5–13
From diagnosis of AIDS in patient	1	0–21	0–6

*All intervals were calculated to time of evaluation of household member
†Range in which the middle 50 percent of the sample lies

Fifteen of these 21 were biologic children of index cases. Six of the 15 children were born to four mothers who contracted AIDS, and 3 others were born to mothers who had serum antibody to HTLV-III/LAV at the time of screening.

The 55 percent of household contacts who participated in the study were of geographic, ethnic, and socioeconomic backgrounds similar to those of the total household-contact population, but differed somewhat in age distribution. The screened population had an identical proportion of children 6 to 18 years old (47 percent) but a lower proportion of adults (33 vs. 41 percent) and a higher proportion of children under 6 years old (21 vs. 12 percent).

Duration of Household Contact

Two variables — the duration of household contact with the index patient, and the amount of time elapsed between initial exposure to the patient and the time of screening — were calculated for several periods.

Of the 101 household contacts, 94 lived with the index patient for at least three months while the patient was symptomatic or after AIDS or AIDS-related complex was diagnosed. Seven lived with the index patient for 3 months or longer during the period 18 months before the onset of symptoms but less than 3 months afterward. Only one contact lived with an index patient only during the 18-month period before the onset of symptoms. The total duration of the household exposure of the contacts to the patients was substantial (Table 1).

Among the 101 household contacts, a median of 31 months elapsed from the time of initial exposure to the patients during the period beginning 18 months before the onset of patients' symptoms to the time of screening (range, 3 to 54 months; interquartile range, 23 to 35).

Seventy-eight household members had their initial contact with a patient during the 18 months before the onset of symptoms. For this group, the median number of months elapsed from initial exposure to screening was 32 (range, 17 to 54; interquartile range, 26 to 38). Eighty-eight household members had initial or continuing contact with the patients after the onset of symptoms but before the diagnosis of AIDS or AIDS-related complex. For this group, the median number of months elapsed to the time of screening was 13 (range, 1 to 36; interquartile range, 8 to 19). Sixty-eight household members had initial or continuing contact with a patient after the diagnosis was established. For this group, the median number of months elapsed to the time of screening was 9 (range, 1 to 32; interquartile range, 3 to 19).

Types of Household Exposure

Among household members, there was substantial sharing of items and facilities with the patients, as well as considerable personal interaction (Table 2). After the diagnosis of AIDS was established, most types of household personal interactions with the index case were reduced substantially. However, a high percentage of household members assisted the patient with bathing, dressing, and eating. These activities were usually increased by parents, siblings, and older children of the patients.

Clinical and Laboratory Findings

No household contact had AIDS; one met the criteria for AIDS-related complex in children. Of the 101 household contacts, 99 (98 percent) were seronegative for HTLV-III/LAV antibodies by enzyme immunoassay and 100 (99 percent) were negative for antibody when Western blot assay was performed for confirmation (Table 3). Both household contacts with HTLV-III/LAV antibodies on immunoassay were children. One child, a two-year-old girl, was positive on enzyme immunoassay but negative on Western blot testing. She had no symptoms suggestive of HTLV-III/LAV

Table 2. Type of Contact with Patients with AIDS among 101 Household Members

Activity	Percentage of Members in Activity
Sharing of household items	
Razors	9
Toothbrushes	7
Nail clippers	42
Combs	51
Towels	37
Clothes	15
Eating utensils	25
Eating plates	46
Drinking glasses	48
Sharing of household facilities	
Bed	37
Toilet	90
Bath or shower	92
Kitchen	93
Washing items used by patients	
Dishes	65
Toilet	49
Bath	55
Clothes	38
Interacting with patient	
Helping to bathe	10
Helping to dress	16
Helping to eat	13
Shaking hands	21
Hugging	79
Kissing on cheek	83
Kissing on lips	17

Table 3. Antibodies to HTLV-III/LAV among Household Contacts of Patients with AIDS.

Contact Group (in Relation to Patient)	No. Screened	No. Positive (Percent)	
		Enzyme Immunoassay	Western Blot
Children <6 yr	21	2 (10)	1*(5)
Biologic offspring	15	2 (13)	1*(7)
Other	6	0	—
Children 6–18 yr	47	0	—
Adults	33	0	—
Parents	11		
Siblings	10		
Other	12		
Total	*101*	*2 (2)*	*1*(1)*

*Infection was probably acquired through perinatal transmission (see text).

infection. Her physical examination was normal, and she was in the 5th percentile for height and 37th percentile for weight. Her hematocrit, white-cell count, IgG concentration, T4/T8 ratio, and absolute T4-cell count were all within normal limits. A repeat specimen obtained eight months later was negative on enzyme immunoassay. Lymphocytes cultured at this second screening did not grow HTLV-III/LAV. Immunoassay testing of the child's mother was positive at 31 months after the child's birth but negative at 27 and at 35 months. Western blot testing of the mother's immunoassay-positive specimen was negative, and lymphocytes obtained from her at the same time as well as on a subsequent screening failed to grow virus. The child's father was given a diagnosis of AIDS in September 1984. There was no history of sexual abuse of the girl by her father.

The second child was the five-year-old daughter of two intravenous drug abusers. Her mother was given a diagnosis of AIDS in September 1984. The child was positive on enzyme immunoassay, which was confirmed by Western blot assay. Culture of her peripheral-blood lymphocytes for HTLV-III/LAV, however, was negative. She has been hospitalized three times since birth for bacterial pneumonia and was noted to have oral candidiasis at one year of age. At the time of screening (at the age of five years) the child had generalized lymphadenopathy without oral candidiasis and was in the 62nd percentile for height and 37th percentile for weight. Although the total white-cell and lymphocyte counts were normal, the percentage of T4 cells was low (33 percent) and the percentage of T8 cells high (56 percent), with a consequent T4/T8 ratio of 0.59. IgG was elevated, at 2800 mg per deciliter. On rescreening three months later, the child's T-cell ratio remained low (0.35), and her IgG was elevated (3000 mg per deciliter).

Immunologic testing of the household contacts gave the following results. Of 86 subjects in whom lymphocyte counts were performed, 79 had normal counts and 7 had lymphopenia. Of 94 in whom IgG was measured, 84 (90 percent) had normal levels, 9 had elevated levels (1560 to 2800 mg per deciliter), and 1 had a low level (90 mg per deciliter). Of 100 subjects in whom T-cell subsets were determined, 92 had a normal percentage of T4 cells and 6 had a low percentage; 4 of the 100 had low T4/T8 ratios — 3 because of an increase in the percentage of T8 cells alone and 1 because of both a decrease in T4 cells and an increase in T8 cells. Of 86 subjects in whom absolute T-cell counts were calculated, 83 (96 percent) had normal counts and 3 (4 percent) had low counts (168, 232, and 287 per cubic millimeter, respectively). These three patients had lymphopenia, which accounted for their low T4-cell counts, but had normal T4/T8 ratios and IgG levels. Only one subject, the five-year-old seropositive child, had more than a single immunologic abnormality.

Five additional children in the household-contact population were born after January 1, 1978, to three mothers in whom AIDS subsequently developed. None of the mothers had symptoms of AIDS at the time of delivery. The mean interval between delivery and the onset of symptoms in the mothers was 37 months (range, 16 to 55). The five children were negative for HTLV-III/LAV antibody and healthy, without any major physical or immunologic abnormalities. In addition, three healthy seronegative children under six years of age were born to two mothers who had antibody to HTLV-III/LAV on enzyme and Western blot assays but who did not have AIDS or AIDS-related complex. Two of the children were born 51 and 52 months before screening of the mother. One child was born seven months after her mother was documented as seropositive.

Discussion

In this study, despite prolonged and close contact with patients with AIDS or AIDS-related complex, 100 of 101 household contacts did not contract HTLV-III/LAV infection. The only contact who became infected was a five-year-old child whose mother had AIDS. This infection appeared to have been acquired by perinatal transmission, since the child had had signs and symptoms of HTLV-III/LAV infection since infancy. We interpreted the results of enzyme immunoassay of serum from a two-year-old child as being falsely positive, since the Western blot assay and a repeat enzyme immunoassay were negative. In addition, the child was clinically well and had no immunologic abnormalities. We conclude that nonsexual household contacts of patients with AIDS or AIDS-related complex with oral candidiasis are at minimal or no risk for horizontal transmission of HTLV-III/LAV infection (95 percent confidence interval, 0 to 2 percent).

We were able to screen the majority of household contacts of index patients. They were representative of the total household-contact population except for the larger proportion of children under the age of six — the group that might be expected to be at highest risk for horizontal transmission of HTLV-III/LAV within the household setting. We have no evidence

that persons who may have been ill or infected declined to participate in the study. Persons who belonged to risk groups and who did not choose to participate would have been removed from analysis by the study protocol. Thus, we believe that there was no discernible selection bias in the study population that might weaken our conclusions.

The precise period of infectivity of patients with AIDS is not known, but studies of transfusion recipients who contracted AIDS[4,19] clearly indicate that persons with HTLV-III/LAV may be infectious for months to years before the onset of symptoms. For this reason, we arbitrarily chose for study several periods of household exposure before the onset of symptoms of AIDS: from 1978, because this year represents the approximate beginning of the AIDS epidemic, and from 18 months before the onset of symptoms in the index case. The current state of knowledge suggests that a patient with AIDS is likely to be infectious during most or all of the latter period. Support for this view is derived from studies of transfusion-related AIDS in which continued carriage of virus in the blood of implicated donors, even those without symptoms, has been demonstrated over long periods, ranging from 12 to 52 months (mean, 28).[19] In the present study, household members had substantial household exposure to patients with AIDS during the period in which the patients were likely to be carrying virus and to be contagious. Periods of household exposure after the diagnosis of AIDS were briefer for several reasons, including early death or prolonged hospitalization of the index case, early screening of household contacts after the diagnosis of AIDS was documented, and fluidity and changes in household structure after diagnosis. Most of the families in this study were poor and lived in crowded conditions, which would be expected to facilitate horizontal transmission of infection. In addition, substantial sharing of household facilities and items likely to be soiled with body secretions took place during the period of presumed infectivity, as did the close personal interaction and affectionate behavior expected among family members.

Little information exists about the time of seroconversion after exposure to the virus. Limited information suggests that seroconversion occurs within one to four months. In one instance, in which a nurse was stuck with a needle from a patient with AIDS, seroconversion was documented 49 days after exposure.[20] In a longitudinal study of seronegative homosexual men, seroconversion was documented 19 to 56 days after the onset of an acute illness with lymphadenopathy.[21] In recently developed animal models, a similar time course from exposure to seroconversion was noted.[22,23] In the present study, a substantial amount of time elapsed between initial exposure to the patient in the household setting and the time of screening. On the basis of the limited data available, it appears that sufficient time had elapsed for seroconversion to have occurred in most subjects if there was a substantial risk. Follow-up of the household contacts will be necessary to confirm continuing seronegativity, but it is reasonable to assume that seroconversion will be unlikely in those with no further contact with the index cases.

False negative and false positive results on tests for antibody to HTLV-III/LAV are unlikely. Each enzyme immunoassay was repeated, and positive results were tested by Western blot assay and virus culture. Small numbers of household members had immunologic abnormalities that were minor and nonspecific and not associated with HTLV-III/LAV seropositivity. No patient had more than one independent abnormality, except the one HTLV-III/LAV–positive child. It is most likely that this child acquired the infection congenitally or during the perinatal period. However, it is interesting and important to note that she was the only infected child among six children born since 1978 to four women with AIDS and three children born to two HTLV-III/LAV–positive, asymptomatic mothers. The risk of infection with HTLV-III/LAV among children born to infected mothers is not known. These very preliminary findings suggest that it is not substantial; however, large-scale prospective studies are needed to address this issue properly.

Hepatitis B and HTLV-III/LAV infection are quite similar epidemiologically. The populations at greatest risk and the presumed routes of transmission are almost identical. Homosexual men, intravenous drug abusers, transfusion recipients, sexual partners of infected persons, and infants born of infected mothers all have increased rates of infection with both agents. Several studies have found apparent horizontal transmission of hepatitis B infection in households.[24,25] Therefore, despite the fact that HTLV-III/LAV, like hepatitis B, is present in saliva and blood, it is reassuring that horizontal transmission of HTLV-III/LAV appears to be minimal to nonexistent in the household setting.

This study has expanded and confirmed the findings of previous studies of small numbers of household contacts.[26] The absence of horizontal transmission of HTLV-III/LAV infection as determined in this study should serve to alleviate the fears and concerns of the growing number of household members and other close contacts of patients with AIDS, as well as the population at large. Established guidelines for controlling the spread of AIDS both within the hospital and outside it appear to be reasonable and safe. Families of patients appear to be at little or no risk of HTLV-III/LAV infection. This study supports the view that transmission of the infection requires injection of blood or blood products or intimate sexual contact, and that longstanding household exposure to patients with AIDS is associated with little or no risk of transmission of HTLV-III/LAV infection.

We are indebted to Harold Jaffe, M.D., James Curran, M.D., and Neal Steigbigel, M.D., for critically reviewing the manuscript; to

Ms. Cheryl Feiner, M.P.H., for performing computer analyses; to Ms. Bonnie Jones and Mr. Charles Schable for performing laboratory tests; and to Ms. Ingrid Symes and Ms. Leticia Vasquez for helping to prepare the manuscript.

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MEDICAL PROGRESS

NEW POSITIVE INOTROPIC AGENTS IN THE TREATMENT OF CONGESTIVE HEART FAILURE

Mechanisms of Action and Recent Clinical Developments

(Second of Two Parts)

Wilson S. Colucci, M.D., Richard F. Wright, M.D., and Eugene Braunwald, M.D.

Newer Phosphodiesterase Inhibitors

Among the most promising recent developments in positive inotropic agents has been the description of a class of drugs that have both potent positive inotropic and vasodilatory effects (Table 1). Initial reports have documented that these drugs do not inhibit sodium–potassium ATPase, nor are their inotropic effects diminished by reserpine-induced depletion of endogenous catecholamine stores, pretreatment with beta-adrenergic or alpha-adrenergic blockers, H_2 antagonists, agents that block prostaglandin synthesis, or drugs that selectively block the fast inward sodium channels. Hence, they are often referred to as "nonglycoside, non-sympathomimetic" positive inotropic agents. Although structurally dissimilar from one another and from the methylxanthines, these agents appear to inhibit phosphodiesterase F-III, the cyclic-AMP-specific cardiac phosphodiesterase, selectively and potently. A growing body of evidence supports the

From the Cardiovascular Division, Department of Medicine, Harvard Medical School, and Brigham and Women's Hospital, Boston. Address reprint requests to Dr. Colucci at the Cardiovascular Division, Department of Medicine, Brigham and Women's Hospital, 75 Francis St., Boston, MA 02115.

Supported in part by a training grant (HL-07049) from the National Institutes of Health. Dr. Colucci is a Clinician-Scientist of the American Heart Association.

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TRANSMISSION OF AIDS

The Case against Casual Contagion

THE epidemic of acquired immunodeficiency syndrome (AIDS) has become an epidemic of fear.[1] Although our understanding of the disease has been progressing rapidly, the new knowledge has often produced more public concern than relief. The identification of the etiologic agent as a virus — although of critical scientific importance — did little to quell the fears of either the medical community or the general population. Instead, people reacted to the fact that AIDS is caused by a virus with a hysteria reminiscent of another viral infection — the polio epidemic of the early 1950s.

As each new observation was announced, concern intensified. Isolation of the virus from semen explained the rapid spread of the disease in the sexually active male homosexual population but also aroused the fear of potential spread in the heterosexual population. The recognition of an asymptomatic-carrier state amplified the fear of sexual contagion in our society, and that fear was further intensified by reports of widespread transmission of the AIDS virus by heterosexual activity in Africa. The recognition that contaminated blood and blood products were the vectors for transmission of the virus to transfusion recipients and patients with hemophilia and that intravenous drug users acquired the infection by sharing needles raised the possibility that health care workers could be at similar risk from occupational exposure. Probably the most sensational information, and perhaps the most misleading, was that the virus had been isolated from saliva and then from tears. This suggested to the public that the disease might be spread by food handlers, by kissing or shaking hands, or even by contact with fomites. The media did little to dispel these notions; on the contrary, the public was led to believe that AIDS was a highly contagious disease.

The belief that the AIDS virus can be transmitted by casual contact has produced numerous political, legal, and ethical dilemmas. Responses have been varied, including calls for quarantine, mass screening of all potentially infected persons, expulsion from military service of all antibody-positive personnel, and exclusion of infected children from schools. In some cases refusal to care for AIDS patients has been condoned.

Throughout the epidemic, the Centers for Disease Control (CDC) has had a critical role in countering such reactions. Rational guidelines (based on the best available data on the modes of transmission) for preventing the transmission of the AIDS virus were developed and widely publicized early in the course of the epidemic.[2] However, the response of public officials has been erratic, and the public remains confused.

Where are we now, five years after the epidemic became evident? First of all, although the epidemic is still increasing at an alarming rate nationwide, there is some indication that the rate of increase is slowing in certain areas, such as New York City, and in San Francisco the number of new cases has actually been constant for the past year. This observation may reflect a slowing of the rate of viral acquisition. According to one recent epidemiologic survey in San Francisco, only 5 percent of seronegative homosexual men acquired evidence of infection between 1984 and 1985 (Moss AR: personal communication).

Secondly, and surprisingly, the disease has remained confined largely to the high-risk groups (homosexual men, intravenous drug users, patients with hemophilia and persons who received transfusions before blood screening was introduced, and the offspring and sexual partners of members of these groups), and the distribution of cases among these groups has been remarkably constant throughout the epidemic. In only 5 percent of cases is the mode of transmission unknown. Thus, there is no evidence that the disease is spreading to other populations.

Thirdly, certain factors have been shown to potentiate the transmission of the AIDS virus in the high-risk groups. Very early in the epidemic, studies from the CDC demonstrated that the risk of spread in the homosexual male population correlated with the number of sexual partners.[2] This behavior accounted for the rapid dissemination of the disease throughout the country. Rectal receptive intercourse and the exchange of blood through the sharing of needles are activities that promote viral transmission. These activities may allow fluids containing infected cells to enter the circulation of the uninfected recipient.[3]

In addition, intrauterine spread or vertical transmission of the disease from mother to fetus is an

established mode of transmission.[2] The chance that an infected mother will transmit the virus to her unborn offspring may be as high as 50 percent. Unfortunately, clinical AIDS is much more likely to develop in an infected infant than in an infected adult. The virus has been isolated from breast milk, and breast feeding could represent another mode of transmission.

Furthermore, there seems to be no doubt that the disease can be spread by heterosexual sex. Although heterosexual transmission has been postulated as the predominant mode of transmission in equatorial Africa, studies conclusively documenting this remain to be published. That the virus can be transmitted from men to women during vaginal intercourse is supported by the fact that female prostitutes in Africa appear to be at extremely high risk of infection. According the the CDC (CDC AIDS program: personal communication), the total number of such cases in the United States in which heterosexual transmission has been implicated remains low — only 180 so far — and the disease in 152 of these cases was transmitted from a man to a woman. On the other hand, examples of sexual transmission from a woman to a man are more difficult to document; only 28 cases have been reported in the United States.

It is possible that the difference between the two sexes in the rate of transmission is due to the fact that there are more male intravenous drug users and bisexuals capable of transmitting the disease to women than there are infected women capable of transmitting the virus to men. Although it would appear that the potential for the future spread of this disease in the heterosexual community remains a serious problem, we still do not know the relative risk of spread of the virus through vaginal intercourse and are even less secure in our knowledge about transmission from women to men. To date there is no evidence that the disease is spread by oral intercourse or by kissing.

Finally, remarkably consistent current data indicate that occupational exposure to patients infected with the AIDS virus does not pose a serious risk to health care workers. Over 1750 health care workers with intense exposure to patients with AIDS have been studied for evidence of antibody to the AIDS virus.[4] Of the workers not otherwise members of high-risk groups (e.g., homosexual men or intravenous drug abusers), less than 0.1 percent were found to be antibody positive. In our institution (San Francisco General Hospital), more than 300 health care workers with intense and sustained exposure to patients with AIDS for nearly four years have been studied; all are antibody negative, with the exception of 14 of 50 homosexual male hospital workers (Gerberding JL: personal communication).

Can the disease be contracted by an accidental needle stick with a needle contaminated by blood from a patient with AIDS? Probably yes, but with an extremely low frequency (less than 0.5 percent). Only one documented case, in a British nurse who acquired the virus after actually receiving a microinjection of blood after an arterial puncture, has been reported.[5] Three additional cases of possible needle-stick transmission in the United States have been suggested but not proved.[6] One worker was not available for follow-up, and the other two denied high-risk activity; it is possible that in each of these three cases, acquisition of the virus could have been through one of the more well-described routes. In addition, over 660 subjects (including one who acquired hepatitis B) with needle sticks from infected needles have been studied and found not to have seroconverted.[7] The low frequency of transmission of the AIDS virus by accidental needle stick as compared with that of hepatitis B, in which 20 to 30 percent of those so exposed acquire the virus, may be due to the large differences in the concentrations of infectious particles in the blood (up to 10^{13} viral particles per milliliter for hepatitis B, as compared with 10^4 for AIDS).[3] One can therefore conclude that caring for AIDS patients, even when there is intensive exposure to contaminated secretions, is not a high-risk activity. Infection-control committees should therefore implement policies to minimize accidental needle sticks and develop infection-control procedures based on the current CDC recommendations.

The article by Friedland et al. in this issue offers strong supporting evidence that the AIDS virus is not transmitted by casual contact, even within a family unit in which there is intimate contact with infected persons.[8] Of 101 subjects tested who were living in a household with a documented carrrier of the AIDS virus, none acquired the virus, and it seems clear that the one antibody-positive subject was infected by vertical transmission in utero or at the time of birth. The implications of this study are strengthened by the fact that the infection-control procedures followed by many health care workers were obviously not employed in the families studied. The duration of exposure reported was certainly sufficient, and the interactions numerous enough, to provide every opportunity for the virus to be spread within the family if such transmission was likely. Other, smaller family studies have produced results consistent with those of Friedland et al. Only 1 of 35 household members associated with 14 seropositive Danish patients with hemophilia had serum antibody to the AIDS virus (human T-cell lymphotropic virus Type III [HTLV-III]). This person had engaged in vaginal, oral, and anal intercourse with one of the infected patients with hemophilia.[9] The failure of the virus to spread in the secretion-rich environment of the family may in part be explained by the very low isolation rate recently reported in samples of saliva.[10] Ho and his colleagues could isolate HTLV-III from only 1 of 83 saliva samples cultured from antibody-positive subjects, although the virus was detected in 28 of the 50 blood samples tested from the same population.[10] Others have confirmed these studies.[3]

The picture is therefore clear. The AIDS virus is spread sexually, by the injection of contaminated blood, and vertically from mother to fetus. Other modes of transmission are extremely rare. Persons at high risk of acquiring the virus are men who are homosexually and bisexually active, intravenous drug abusers, persons receiving infected blood products intravenously, and children born of infected mothers. At intermediate risk are persons, especially women, who engage in heterosexual sex with members of high-risk groups. Groups whose members are highly unlikely to acquire the virus (i.e., virtually no-risk groups) include health care workers caring for AIDS patients and anyone who has casual contact with persons infected with the AIDS virus, including food handlers, schoolchildren, co-workers, and family members. On the basis of these facts, the keys to preventing transmission of the virus are (1) the screening of all donated blood and (2) education and other attempts to modify risky sexual behavior and intravenous drug abuse.

It is now time for members of the medical profession, armed with this knowledge, to take a more active and influential role in quelling the hysteria over the casual transmission of AIDS. We need to support public and medical officials who oppose universal screening, quarantine, the exclusion of students from classrooms, and the removal of employees, including health care workers, from the work place.[7] The evidence presented by Friedland et al. is a powerful argument with which to counter the public's fear of casual contagion and should be used to thwart attempts to discriminate against persons in the so-called high-risk groups.

San Francisco General Hospital
San Francisco, CA 94110 MERLE A. SANDE, M.D.

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CORRESPONDENCE

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MYSTERIOUS CLUSTERS OF DEATHS IN HOSPITALS

To the Editor: There are serious flaws in using an epidemiologic study of the sort described by Buehler et al. (July 25 issue)[1] to aid a criminal investigation of possible murder.

First, Rothman[2] draws a parallel between John Snow's investigation of a cholera epidemic in London, which identified a guilty water pump, and the investigation by Buehler et al., which identified a guilty person. It hardly needs pointing out that people have more rights than pumps, particularly since the identities of Nurse A and Nurse B are about as well known to Canadians as the identity of the president of the United States. However, the comparison has an even more serious flaw. In Snow's investigation, the correct diagnosis of cholera was not an issue. In the study by Buehler et al., the cause of the deaths of most of the babies was — and is still — unknown. Police responsible for investigating a group of mysterious deaths had better be very certain which of those deaths involved murder and which did not, if they hope to identify a murderer by a study of the type conducted by John Snow or Buehler et al. Faulty identification of the number of murders would clearly send such an investigation in the wrong direction.

Second, it was not the mandate of Buehler et al. to establish the cause of death. However, the police and the Royal Commission of Inquiry concluded that at least some of the deaths were due to digoxin overdose. These include the deaths of some of the babies who were exhumed or whose tissues (which had been preserved at autopsy) were studied. In the studies of these babies, the forensic scientists of the Ontario Solicitor-General's office developed assays to detect digoxin in fixed or decomposed tissues. They found high levels of the agent, and the police and the Royal Commission of Inquiry decided that some of these babies had been murdered by an overdose of digoxin. This diagnosis was based principally on the digoxin assays. The only problem with this procedure was that the investigators had no control ("normal") values. Such values may be very difficult to obtain in a population of exhumed bodies, but in their absence, the situation is analogous to that in which a physician makes a diagnosis on the basis of a single laboratory test, without any knowledge of the normal values for that test. If this were ever to happen (unthinkable thought) and the diagnosis were wrong, it would be a prima facie case of malpractice. Digitalis is a biologic product, and the genes for its production exist. Who knows what organisms invade dead and decomposing tissues and what they might produce?

Third, epidemiology has come a long way since the days of Lister, Semmelweis, and Snow. In particular, we have learned how to evaluate diagnostic tests in terms of a number of characteristics — most notably, their sensitivity and specificity. Once these are known, Bayesian statistics can be used to develop statistical probabilities about whether a particular diagnostic test is likely to indicate the correct diagnosis. This approach was not really necessary in John Snow's case, but it would be highly desirable in the investigation of

Epidemiologic Notes and Reports 1985 Sept 27;34:575-578

Update: Evaluation of Human T-Lymphotropic Virus Type III/ Lymphadenopathy-Associated Virus Infection in Health-Care Personnel — United States

The occurrence of the acquired immunodeficiency syndrome (AIDS) in intravenous (IV) drug users, blood transfusion recipients, and persons with hemophilia indicates that parenteral transmission of human T-lymphotropic virus type III/lymphadenopathy-associated virus (HTLV-III LAV) occurs via infectious blood or blood products (*1*). Currently available practices have nearly eliminated these risks for transfusion recipients and persons with hemophilia (*2,3*). Because health-care personnel may be inadvertently exposed to the blood of AIDS patients, several studies have been conducted to determine the prevalence of HTLV-III LAV antibodies in health-care personnel who have cared for these patients (*4-10*). Combining published results with data reported to CDC shows that, to date, 1,758 health-care workers participating in such studies have been tested for antibodies to HTLV-III. Twenty-six (1.5%) were seropositive, and all but three of these persons belonged to groups recognized to be at increased risk for AIDS. Epidemiologic information is not available for one of these three health-care workers who was tested anonymously. Because of the high level of interest in these studies and in the potential for occupational transmission of HTLV-III/LAV through parenteral and mucosal routes, the case histories for these two health-care workers are reported below.

Patient 1. A female health-care worker was tested for serum antibodies to HTLV-III in November 1984 as part of a study of hospital personnel. She had sustained accidental needlestick injuries in November 1983 and March 1984 (12 months and 8 months before) while drawing blood from patients with AIDS. At the time of enrollment in the study, serum antibodies to HTLV-III were detected by enzyme immunoassay (EIA) and Western blot techniques. No serum obtained before or within 12 months after the needlesticks was available for testing. She was in good health until June 1984, when she developed mild but persistent lymphadenopathy, most marked in the axilla. Beginning in August 1984, she experienced intermittent diarrhea. When interviewed by a physician, the patient denied IV drug use or blood transfusions and reported being heterosexually monogamous since 1981. Her long-term sex partner denied homosexual activity, IV drug use, or other known risk factors when interviewed separately. Although repeatedly antibody negative by EIA and Western blot methods over an 8-month period, HTLV-III was recovered from his peripheral lymphocytes in April 1985 but could not be recovered from lymphocytes obtained several months later.

Patient 2. A male laboratory worker was discovered to be lymphopenic after he volunteered to be tested in conjunction with a study in April 1985. At that time, he had serum antibodies to HTLV-III by EIA and Western blot methods. No previous blood samples were available for testing. As part of his job, he processed platelets pooled from individual donors for transfusion. In December 1983, he sustained an accidental cut on the hand while processing blood from a patient with leukemia. He also sustained an accidental needlestick injury in August 1984 while processing a unit of pooled platelets. Both incidents resulted in parenteral exposure to blood from other persons. It is not known whether any of the individual platelet donors or the patient with leukemia had HTLV-III infection. The health-care worker is asymptomatic, although he had transient cervical lymphadenopathy during early 1985. HTLV-III was recovered from his peripheral blood lymphocytes in September 1985. During three independent interviews, he denied any homosexual activity, IV drug use, foreign travel, or blood transfusions. He described himself as heterosexual and was not aware that any of his approximately 12 lifetime sex partners had AIDS or were at increased risk for HTLV-III/LAV infection.

Reported by J Nadler, MD, S Landesman, MD, D Rechtman, MD, S Holman, MS, New York City, New York; J Groopman, MD, Boston, G Seage, MPH, Boston Dept of Health and Hospitals, G Grady, MD, Massachusetts Dept of Health, J Gerberding, MD, San Francisco, California; Environmental Epidemiology Br, Laboratory of Tumor Cell Biology, National Cancer Institute, National Institutes of Health; Hospital Infections Program, AIDS Br, Div of Viral Diseases, Center for Infectious Diseases, CDC

Editorial Note: These two health-care workers probably represent occupational transmission of HTLV-III/LAV due to parenteral exposure, although in neither was a preexposure serum sample available to date the onset of infection. Although not reported during investigations of these two cases, it is difficult to totally assure that additional risk factors for AIDS

were absent. For purposes of epidemiologic surveillance, a case of occupationally acquired HTLV-III/LAV infection should ideally include all the following features: a worker with no identifiable risk factors for AIDS whose serum, obtained within several days of the date of a possible occupational exposure, is negative for antibody to HTLV-III/LAV but whose follow-up serum, in absence of interim exposure to other risk factors, is positive for antibody to HTLV-III/LAV. The two cases reported here do not fully meet these ideal criteria. However, there is one published report from England of a nurse who developed HTLV-III/LAV antibody following an accidental needlestick injury (*11*). Her serum was negative for antibody to HTLV-III/LAV at the time of exposure. This nurse reportedly had none of the recognized risk factors for AIDS and was asymptomatic at the time the report was published.

The two cases reported here represent the only known evidence of probable occupational transmission of HTLV-III/LAV in the United States. This confirms that the risk of transmission of HTLV-III/LAV infection to health-care workers from patients is extremely low (*4-10*). HTLV-III/LAV infections appear to be much less transmissible through needlesticks than hepatitis B, nearly 26% of persons comparably exposed to a hepatitis B surface antigen-positive patient develop infection (*12*). Nonetheless, personnel should follow recommendations designed to minimize the risk of exposure to parenteral or mucosal (e.g., blood spatter on conjunctiva) contact with potentially infectious materials from patients with AIDS or suspected AIDS (*13,14*).

Epidemiologic studies of needlestick injuries in hospital personnel indicate that over 40% of the accidents are potentially preventable if recommended precautions are followed when handling used needles or other sharp objects (*6*). Educational programs to familiarize health-care workers with the basic practices in infection control are essential to the prevention of AIDS and other infections. Health-care workers and others should become familiar with and follow recommended precautions when handling specimens, secretions, and excretions from persons known to be infected with HTLV-III/LAV. Health-care personnel whose serum is positive for HTLV-III/LAV antibody should follow the precautions that have been published for health-care workers with AIDS (*15*).

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AIDS poses no dangers to co-workers in office settings

Two State employees are known to have had AIDS—acquired immune deficiency syndrome—and one has died from it, but both were members of identified high risk groups according to State officials. Neither posed dangers to their fellow workers.

According to the Department of Health, in the case of a co-worker with AIDS "There's no special handling required."

"Casual contact does not transmit AIDS. There has never been a case of AIDS that has been even suspected of being transmitted by a co-worker," says Frances Tarlton, spokeswoman for the Department.

The Department's policy is that if AIDS patients are well enough to work, they should do so, and neither proximity nor shared use of facilities such as drinking fountains and toilets are cause for concern, she said.

Dr. James O. Mason, Acting Assistant Secretary for Health in the U. S. Department of Health and Human Services, reiterates that "AIDS is a bloodborne, sexually transmitted disease that is *not* spread by casual contact."

He adds that "fear among people who are not at risk is unwarranted and counterproductive. People who are frightened of friends, co-workers and family members who may be at risk of AIDS are suffering unwarranted fear, and that fear doesn't produce any worthwhile outcomes. This is the fear we need to do away with."

Mason also says: "AIDS is not spread by the kind of nonsexual, person-to-person contact that occurs among workers, clients and consumers in such settings as offices, schools, factories and construction sites. Workers known to be infected with the AIDS virus should not be restricted from work on this account, nor should they be restricted from using telephones, office equipment, toilets, showers, eating facilities and water fountains. In the case of accidents in the work setting, equipment that is contaminated with blood or other body fluids from any worker, known to be infected or not, should be cleaned with soap and water or a detergent. A disinfectant or a fresh solution of household bleach . . . should be used to wipe the area after cleaning."

Mason's office offers additional pointers for three employee groups.

Health care workers should follow standard infection control precautions. They should use special care to avoid being cut with sharp items—needles or scalpels—which are potentially infective. They should dispose of such sharp items in puncture-resistant containers as close as possible to the area where they were used, and avoid extra handling of needles to recap or remove them from disposable syringes, or bend or break them on purpose before disposal. Where there is the possibility of exposure to blood or other body fluids, employees should take routine precautions. Gloves should be worn for handling items soiled with blood or equipment contaminated by blood or other body fluids. Gowns, masks and eye-coverings may be required for procedures involving more extensive contact with blood and other fluids, such as post mortem examinations, some dental procedures or endoscopic procedures involving use of equipment to look inside hollow organs such as the lungs or bladder. Those who get blood on their hands should wash them thoroughly and immediately. To minimize the need for mouth-to-mouth resuscitation, mouthpieces, resuscitation bags or other ventilating devices should be kept handy. Gloves should be worn for direct contact with mucous membranes or broken skin of patients, and employees with sores or skin infections that ooze should refrain from direct patient care.

Personal service workers, such as hairdressers, barbers and massage therapists, should follow principles of good hygiene. Instruments such as razors should either be disposed of or thoroughly cleaned and disinfected between clients. Workers with sores or skin infections which are oozing should not have direct contact with clients.

Food service workers should follow recommended standards of good personal hygiene and food sanitation. They should take care to avoid hand injuries when preparing food. In the event of injury, food contaminated with blood should be thrown out for both aesthetic and sanitary reasons. ★

Infection Control and Employee Health

William M. Valenti, MD

AIDS Update Part 2

The Acquired Immune Deficiency Syndrome (AIDS) continues to perplex health care providers. As our knowledge has increased, so has the number of questions, especially those related to infection control and employee health. Since the last time AIDS was reviewed in this column,[1] additional information has become available which elaborates on some of the infection control aspects of this disease.

THE ROLE OF HTLV-III

The human T-cell lymphotropic retrovirus (HTLV-III) appears to be the cause of AIDS.[2] Other names used for HTLV-III are lymphadenopathy-associated virus (LAV) and AIDS-associated retrovirus. So called co-factors may be necessary to initiate disease after an individual acquires HTLV-III infection. Agents such as cytomegalovirus, the Epstein-Barr virus and multiple exposures to HTLV-III have been suggested as possible cofactors. Only a relatively small percentage of individuals who acquire HTLV-III antibody eventually develop overt disease or "full-blown AIDS." Studies to date have shown that after 1 to 5 years of follow-up, 4% to 19% of seropositives developed AIDS.[3]

In addition, the spectrum of disease caused by HTLV-III appears to be broader than originally thought. An additional 25% of those with antibody may have developed AIDS-related diseases including neurological symptoms, fever, weight loss, diarrhea, oral candidiasis and lymphadenopathy during the follow-up period.[3]

The test for antibodies to HTLV-III has now been approved by the Food and Drug Administration for use in screening the nation's blood supply. The test, using the enzyme-linked immunosorbent assay (ELISA) method, has been shown to be both sensitive and specific.[4] When combined with the Western blot assay, antibody to HTLV-III was found in 100% of patients with AIDS, more than 80% of patients with AIDS-related complex and fewer than 1% of heterosexual controls.[3,5] The use of this test should allay the anxiety of both patients and personnel over the safety of blood products used for transfusion. The test is also being used for diagnostic purposes and as a result has brought with it another series of questions, concerns, and controversies regarding infection control. Antibodies to HTLV-III tell us that an individual has come in contact with the virus at some time in the past and that the exposure was significant enough to cause an antibody response. There has been speculation that individuals with HTLV-III antibody are viremic and are able to transmit the disease to others, but there are no data available yet to support this. When more specific testing is available, it should be possible to determine current infectivity vs. past infection, in a manner similar to hepatitis B testing. Until then, patients with HTLV-III antibody should be placed on precautions that include care with blood and needles as well as appropriate protective clothing when contact with body fluids is anticipated. Strategies for isolation precautions should also attempt to maintain patient confidentiality without compromising employee health.

Recently, the case definition for AIDS was revised and now incorporates the results of antibody testing to HTLV-III in the definition.[6] HTLV-III by itself does not fulfill the criteria for infection. However, the criteria for AIDS are met when antibody is present with certain associated diseases such as disseminated histoplasmosis, isosporiasis, bronchial or pulmonary candidiasis, non-Hodgkin's lymphoma or histologically confirmed Kaposi's sarcoma. In addition, patients are to be excluded if they have been

From the Department of Epidemiology, University of Rochester Medical Center, Rochester, New York.

Address reprint requests to William M. Valenti, MD, University of Rochester Medical Center, 601 Elmwood Avenue, Rochester, NY 14642.

tested for antibody to HTLV-III and have a negative test.[6]

RISK TO HEALTH CARE WORKERS

The evidence showing lack of transmission of HTLV-III to health care workers (HCWs) has been reassuring. Hirsch et al have published the preliminary results of follow-up of needle stick accidents in 30 HCWs from patients with AIDS. There were no HTLV-III antibody conversions in any of the employees who had antibody determinations done an average of 8 months after the accidents.[7] The Hospital Infections Branch of the Centers for Disease Control is continuing its prospective study of HCWs with parenteral exposures to the blood of persons with AIDS. To date, no HTLV-III antibody conversions have occurred in 261 employees who have been tested a mean of 241 days following the incidents (Eugene MacRae, MD, Centers for Disease Control; personal communication). A HCW in England developed HTLV-III antibody following what was reported as a needle stick from a patient with AIDS.[8] However, investigation of this incident has suggested that injection of blood also took place at the time of the needle puncture (Harold Jaffe, Centers for Disease Control; personal communication). Current isolation precautions seem to be adequate for the protection of employees.[9]

INFECTION CONTROL PRECAUTIONS

Hepatitis B continues to provide a good model for our understanding of AIDS since the agents of these two diseases are transmitted in similar fashion. Therefore, isolation precautions for persons with AIDS and AIDS-related complex should be similar to hepatitis B.[9] Some employee health and infection control practitioners have asked if isolation precautions should be instituted for patients in high-risk groups for AIDS. Infection control staff should follow the same process of problem solving that is used for patients with other suspected infectious diseases. It should be kept in mind that people at risk for AIDS may not be readily apparent, in the same way that persons who are carriers of hepatitis B surface antigen (HBsAg) are not always detected. Decisions related to the need for isolation precautions are best made on an individual basis after evaluating the patient for a history of such things as unexplained fevers, weight loss, diarrhea and lymphadenopathy.

Employees who have significant exposures to the blood of persons with AIDS should be handled according to the hospital's infection control policy for hepatitis B since some patients at high risk for AIDS will also be carriers of hepatitis B surface antigen (HBsAg). Employees may also be entered into the CDC's prospective follow-up study of employees with such exposures. (Additional information regarding this study can be obtained from the CDC's Hospital Infections Branch at 404-329-3406.) Some institutions have recommended that pregnant employees not have contact with patients with AIDS.[10] This is a controversial matter that should be thought out carefully so that infection control policies are equitable for all employees. Pregnancy does not increase the already remote chance of acquiring HTLV-III from patients.[11] It would seem reasonable then, not to restrict pregnant employees from caring for patients with AIDS, at least for infection control purposes. Since many people with AIDS shed cytomegalovirus (CMV),[12] some have proposed that pregnant women be restricted on that basis. Since nosocomial transmission of CMV from patients to personnel has not been shown to occur,[13] we do not restrict pregnant women from caring for CMV patients either. Those hospitals who restrict pregnant women from caring for patients with CMV should also consider the same restriction for patients with AIDS in order to be consistent and uniform in their approach to this disease.[11]

THE HEALTH CARE WORKER WITH AIDS

Another concern involves the HCW with AIDS or AIDS-related diseases. Some facilities have either restricted or attempted to restrict such employees from patient contact. We recently revised the guidelines for the care of patients with AIDS in our hospital, and it was decided that the matter of the employee with AIDS would be evaluated individually rather than trying to develop a strategy for all such situations. The Advisory Committee on Infections Within Hospitals of the American Hospital Association has approached this problem in a thoughtful manner that is consistent with the epidemiology of AIDS.[11] They note that many factors need to be considered when evaluating such employees including the nature of the employee's patient care responsibilities, results of continued follow-up of the employee and the advice of the hospital's legal counsel. As with the hepatitis B carrier,[14] it is not necessary to restrict all employees with AIDS from working in health care settings.[14] Using the hepatitis model, the transmission of HTLV-III from personnel to patients is remote to non-existent. The CDC employee health guideline recommends that employees with AIDS receive counseling about precautions to minimize the risk to others and that these employees wear gloves when involved in any procedures that involve trauma to tissues or direct contact with mucous membranes or non-intact skin.[14] The other important issue here is to addres restrictions for any infectious diseases that might be more easily transmitted from person-to-person (eg, pulmonary tuberculosis, herpes simplex or herpes zoster).

INFECTION CONTROL IN THE LABORATORY

Clinical and research laboratories will have special needs that should be considered in the hospital's overall approach to AIDS. Guidelines for laboratories that are currently available are worth reviewing.[14-16] While all were written before HTLV-III was proposed as the agent of AIDS, the recommendations are remarkably similar and appropriate, for the most part. The risk of acquiring AIDS in the course of laboratory work in no way approaches the risk of hepatitis B. However, laboratory workers should know that the specimens they are handling are potentially hazardous, in the same way we place patients on precautions for hospital staff with patient contact. If precautions for patients and their laboratory specimens are developed along the same lines, then it is not necessary for specimens to be labeled with the patient's diagnosis. Ideally, a biohazard label should be

sufficient since all labeled specimens should be processed using the same precautions. Since hepatitis B appears to be transmitted more easily than HTLV-III, it makes infection control sense to take the same (or more) precautions when handling specimens from patients with hepatitis B. The method of notifying the laboratory of these specimens has been a dilemma for many hospitals, where a variety of methods has been used. Laboratories in some hospitals keep lists of names of patients with AIDS and AIDS-related diseases. If this is the case, these lists should be kept out of public areas, and efforts should be taken to verify the names on the list and remove them if the diagnosis is ruled out or if the patient dies. This task usually becomes an infection control duty which can be cumbersome to manage. On the other hand, the available guidelines emphasize the importance of good technique rather than extraordinary precautions when processing specimens. These precautions include proper handling of needles and syringes, the need for minimizing aerosols, protective clothing as needed, the use of 1:10 household bleach for decontamination of blood spills and handwashing after handling specimens.[15,16]

SAFETY OF THE HEPATITIS B VACCINE

The safety of the hepatitis B vaccine has been one of the most heated controversies in medicine during the entire AIDS crisis. The major concern of vaccine contamination with HTLV-III appears to be settled by the recently published vaccine safety statement from the CDC.[17] The major points of the safety statement are that: 1) HTLV-III has been shown to be inactivated by the extensive vaccine manufacturing process; 2) no DNA sequences of HTLV-III have been detected in the vaccine; and 3) no excess HTLV-III antibody conversions have been detected in vaccinees when compared to controls. The vaccine appears to have been vindicated, but not all employees are aware of this safety report. Many HCWs are deferring vaccination because of unwarranted concerns over vaccine safety. Epidemiologically and intuitively, hepatitis B appears to be more transmissible than HTLV-III; at least one case report has demonstrated nosocomial transmission of hepatitis B in the absence of HTLV-III transmission.[18]

THE NEED FOR PLANNING

There are two elements of an infection control program related to AIDS. All health care facilities should have a policy in writing that follows the model described by the American Hospital Association.[11] An educational program for employees is also essential. Because of the diverse nature of HCWs, such programs should be tailored to each group specifically.[19] The epidemiology of AIDS may be changing in such a way that disease is no longer confined to the so-called high-risk areas but may emerge in small to medium-sized cities as well.[20] In addition, some persons with AIDS who acquire their disease in high-risk areas will continue to return home to be near family and friends and may also require hospitalization. Acute and extended care facilities that have not cared for persons with AIDS should not wait until the first patient is admitted before starting their planning. The time for this planning is now.[21]

Planning, writing policies and employee education are essential elements of infection control programs for AIDS. The role of infection control and employee health practitioners is central to these activities. It is essential then that we analyze available data carefully to help our employees put this disease into perspective so that they may continue to provide optimal care for persons with AIDS.

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NEW YORK STATE
DIVISION OF SUBSTANCE ABUSE SERVICES

SPECIAL BULLETIN 1-85: ACQUIRED IMMUNE DEFICIENCY SYNDROME (AIDS)

October 3, 1985

I. HTLV-III Blood Test

A virus known as HTLV-III (an abbreviation for Human T-Lymphotropic Virus-III) has been associated with AIDS - Acquired Immune Deficiency Syndrome. The HTLV-III virus is either the cause of AIDS or a contributing factor.

A person who has been exposed to the HTLV-III virus usually develops HTLV-III antibody to fight off the virus. The HTLV-III virus is probably transmitted during sexual activity that involves the exchange of body fluids (such as blood and semen), by sharing needles to inject drugs, or by receiving transfusions of blood or blood products containing the virus.

In March, the Federal government approved the use of a test to screen blood for the presence of antibodies to the Human T-Lymphotrophic Virus (HTLV-III). The HTLV-III test is being used to screen donated blood to make certain that blood containing the HTLV-III antibody is not used in transfusions. The test has recently also been made available to individuals in groups at high risk for AIDS, such as intravenous drug users. It is therefore extremely important that we understand the limitations of the test.

What the test results mean...

The HTLV-III blood test is NOT A TEST FOR AIDS. The test only indicates if a person has developed antibodies to the HTLV-III virus. The HTLV-III test:

- -- is NOT a test for AIDS;
- -- is NOT a test to predict if someone will get AIDS;
- -- is NOT a test to indicate if someone is immune to the HTLV-III virus;
- -- is NOT a test to determine if someone can transmit the HTLV-III virus to others.

Results of the HTLV-III blood test are inconclusive at the individual level and the test provides little medical information. A positive test result may cause unnecessary psychological distress, and, if not kept confidential, could lead to discrimination. A negative test result may cause an unwarranted sense of security. With these limitations in mind, clients should be discouraged from routinely seeking the HTLV-III test.

Availability of testing

Despite the severe limitations of the test, some clients will want to have their blood tested. It is therefore critical that programs prepare staff to deal with the predictable questions and psychological stress stemming from positive test results.

For those who insist on having the test done, the State Health Department has established regional counseling and testing centers upstate. The centers will provide information about the test; give each individual seeking the test a code number; draw blood and forward it to a State-designated laboratory for analysis; and, perhaps most importantly, provide post-test counseling. A code system is used to ensure the confidentiality of all test results. There is no charge for the test. Clients who want the test done should be referred to the centers listed below whenever practicable to make certain that adequate pre- and post-test counseling is provided.

More information about the HTLV-III antibody test and the services offered through regional testing centers may be obtained by calling the HTLV-III Test Representative at one of the following numbers:

Buffalo	(716) 847-4520
Rochester	(716) 423-8081
Syracuse	(315) 428-4736
Albany	(518) 457-7152
New Rochelle	(914) 632-4133, Ext. 439
Nassau County	(516) 535-2004
Suffolk County	(516) 348-2999

In New York City, the City Department of Health should be contacted regarding testing or questions about counseling antibody positive patients. The City Department of Health's AIDS Hotline number is (718) HTLV-III.

APPENDIX A

FACT SHEET ON AIDS AMONG IV DRUG USERS

• IV drug users—not just gay men—get AIDS. The majority of drug users tested in a recent study in New York City had already been exposed to the virus that is believed to cause AIDS. Researchers think they were exposed by sharing needles with other drug users. Drug users in other areas of the United States and in other countries have also been exposed.

• By February 4, 1985, 1,403 intravenous drug users had already gotten AIDS and 725 of these men and women had died of the disease.

• AIDS can be spread sexually from men to men, and from men to women or women to men. Some people who have had sex with IV drug abusers have themselves developed AIDS even though they had never used drugs intravenously.

• Researchers believe that some healthy people can be AIDS carriers. Whether or not an IV drug user is contagious for AIDS cannot be told by his physical appearance.

• At least 46 children of IV drug users have already gotten AIDS, presumably transmitted from their parents before or at birth. About 60% of children who have gotten AIDS have died of the disease.

• No one can assure you that you haven't already been exposed to the virus that causes AIDS, but you can reduce your risk of coming in contact with this virus in the future by doing the following:

I. Stop shooting drugs.

II. If you continue to shoot drugs:
   1. Don't share any needles, works, or cookers.
   2. Stop going to shooting galleries and renting works.
   3. Use your own clean equipment and don't share it with anyone.
   4. Be aware that some "new needles" are re-bagged. Inspect the packages and don't use re-bagged needles.

III. Don't enter into a sexual relationship with someone who has AIDS or who shoots drugs.

IV. If you have been having sex with a drug user, you may already have been exposed to the AIDS virus. This does not necessarily mean you will get AIDS since many people seem to have been exposed to the virus without developing the disease. You can help yourself and your partner, however, by encouraging your partner to stop using drugs and to enter drug treatment. This will reduce your chances and your partner's chances of being exposed to the virus again. You might also consider changes in your sexual habits. While it is possible that the virus can be spread by any type of sexual activity, certain changes in your sexual practices may reduce your chances of being exposed to AIDS. For example, you might:
   1. Use condoms during vaginal intercourse.
   2. Eliminate anal intercourse—this type of sex appears to be especially dangerous.
   3. Eliminate "rimming," or oral-anal contact.
   4. If you have oral sex, you can minimize your exposure by not having your partner come (ejaculate) in your mouth, or by not swallowing the ejaculate.

• If you want to get help to stop using drugs, the following groups are available to you:
[Local agencies should type in their recommendations here.]

From Marmor et al. (1984). The epidemic of acquired immunodeficiency syndrome (AIDS) and suggestions for its control in drug abusers. *Journal of Substance Abuse Treatment*, Vol. 1, No. 4, pp. 237-247, published by Pergamon Press Inc., Elmsford, NY 10523.

APPENDIX B

FACT SHEET FOR IV DRUG USERS WITH AIDS

You have been told that you have Acquired Immunodeficiency Syndrome, or AIDS. This disease is characterized by a weak immune system. The immune system is responsible for the protection of an individual against various infections and tumors. The following measures are strongly recommended.

- Refrain from the use of drugs immediately. This will protect you against other infections. It will also protect others from acquiring the disease from you, as AIDS is acquired from blood on contaminated needles, syringes and cookers.

- AIDS can also be sexually transmitted. If you have a steady sexual partner and your doctor advises that it is alright for you to continue to have sex, then protect your partner by:
  1. Using condoms during vaginal intercourse.
  2. Eliminating anal intercourse, as this type of sex appears to be especially dangerous.
  3. If you have oral sex, don't ejaculate in your partner's mouth.

- AIDS can be transmitted to children either during pregnancy or around the time of delivery. Therefore at any sign of illness in your children seek medical attention for them. If you are a woman this would *not* be a good time to become pregnant. If you are a man, it would *not* be a good time for your mate to become pregnant. Use a safe method of contraception as recommended by your doctor.

- Refrain from donating blood, sperm or any body fluid, tissues or organs.

- Toothbrushes, razors or other objects that could be contaminated with blood should not be shared.

- Since your immune system is weakened by AIDS, you are a likely victim for many infections. It is of the utmost importance that you be followed at a medical clinic even if you are feeling well. If you begin to feel unwell, seek medical attention immediately. Tell any doctor, nurse, or dentist you are seeing that you have AIDS, so that proper evaluation can be done, and precautions taken to prevent transmission of the disease to others.

- Many of the infections associated with AIDS require long-term treatment and follow-up. If you have been advised to take certain medications, do not stop using them unless you consult your physician.

- If you need help to stop using drugs, the following groups are available to you:

- If you need help with family counseling, personal counseling, housing, nursing care or home care, seek help from clinics, hospitals, social agencies, and mental health clinics.

From Marmor et al. (1984). The epidemic of acquired immunodeficiency syndrome (AIDS) and suggestions for its control in drug abusers. *Journal of Substance Abuse Treatment*, Vol. 1, No. 4, pp. 237-247, published by Pergamon Press Inc., Elmsford, NY 10523.

APPENDIX C

INFECTION CONTROL GUIDELINES FOR PERSONNEL OF DRUG TREATMENT CENTERS AND PRISONS

The following guidelines are suggested to minimize the risk of transmission of the AIDS virus to staff caring for persons with AIDS or at risk of AIDS, including all intravenous drug abusers.

- In administering health care, disposable needles and syringes should be used. Care should be taken to prevent needlestick injuries by the proper disposal of needles in designated plastic or metal containers, without recapping or clipping the needles.

- Persons drawing blood should wear gloves and use luer-lock syringes.

- Gloves need only be worn when handling blood, urine, sputum or fecal specimens.

- Gowns need only be worn when there is likelihood of soiling of clothes with body fluids.

- Masks need only be worn when there is risk of contact with aerosolized secretions such as suctioning of patients or high-speed drilling by dentists.

- Whenever possible disposable instruments should be used such as thermometers, tongue depressors etc.

- Soiled instruments or other objects should be bagged and labelled "contaminated" and processed in the appropriate manner.

- A label marked prominently with "Blood and Body Fluid Precautions" should be affixed to all blood and other specimens. This warning label should accompany the specimen through all phases of processing until ultimate disosal. Specimens should be placed in an impervious bag or container for transport.

- Any spills of body fluids should be cleaned using a freshly prepared (once daily) 10% solution of household bleach.

- Hands should always be washed, regardless of the use of gloves, after close patient contact such as after physical examination and when soiled with possibly infected bodily fluids.

- Laboratory workers should follow the same precautions recommended for processing specimens from patients known to be carriers of hepatitis B.

These guidelines are consistent with those approved by the American Hospital Association. For more detailed comprehensive guidelines which may be applicable to your particular situation or facility see: American Hospital Association (1984), A Hospitalwide Approach to AIDS. Recommendations of the Advisory Committee on Infections within Hospitals. *Infection Control*, 5, 242–248.

Accidental parenteral or mucous membrane exposures to blood from definite or suspected AIDS patients should be reported to your supervisor, your local Infection Control officer if one is available, or if not, to the CDC Hospital Infections Program at (404) 329-3406.

From Marmor et al. (1984). The epidemic of acquired immunodeficiency syndrome (AIDS) and suggestions for its control in drug abusers. *Journal of Substance Abuse Treatment*, Vol. 1, No. 4, pp. 237-247, published by Pergamon Press Inc., Elmsford, NY 10523.

Journal of Substance Abuse Treatment, Vol. 1, p. 237–247, 1984
Printed in the USA.

0740-5472/84 $3.00 + .00

ORIGINAL CONTRIBUTION

The Epidemic of Acquired Immunodeficiency Syndrome (AIDS) and Suggestions for its Control in Drug Abusers

MICHAEL MARMOR, PhD

New York University School of Medicine

DON C. DES JARLAIS, PhD

New York State Division of Substance Abuse Services

SAMUEL R. FRIEDMAN, PhD

Narcotic and Drug Research, Inc.

MARGARET LYDEN, MPH

New York University School of Medicine

WAFAA EL-SADR, MD

Manhattan Veteran's Administration Hospital and New York University Medical Center

Abstract— *Intravenous (IV) users of illicit drugs have accounted for 17% of AIDS cases seen in the United States. Previous research has shown that more than half of IV drug abusers entering a drug detoxification program in New York City had serologic evidence of exposure to the virus believed to cause AIDS. Spread of AIDS among drug abusers presumably occurs by transmission of the virus via shared needles, works, or drug-containing solutions. Secondary spread of AIDS from IV drug abusers to others may occur by venereal transmission or by perinatal transmission to infants. In this article, relevant characteristics of the AIDS epidemic are presented to assist the staff of drug treatment programs in their work with IV drug abusers. Suggestions regarding the education of drug treatment personnel and the dissemination of information about AIDS to drug abusers and their families are offered. Fact sheets on AIDS for drug treatment and prison staff, and for drug abusers with and without the disease are presented. Finally, possible approaches to the prevention of AIDS in drug users are discussed.*

Keywords— Acquired Immunodeficiency Syndrome, drug abuse, transmission, infectious diseases, prevention, AIDS

FROM THE TIME of the first recognition of the acquired immunodeficiency syndrome (AIDS) in spring 1981 through February 4, 1985, a total of 8,215 cases has been reported to the Centers for Disease Control (CDC) (CDC, AIDS Activity, Surveillance Section, personal communication, 1985). The epidemic continues to grow rapidly, with 3,688 cases reported to the CDC through the 45th week of 1984 compared

This work was supported in part by Grant DAO3574 from the National Institute on Drug Abuse; Grants CA33205, CA13343 and CA16087 from the National Cancer Institute, Grant ES00260 from the National Institute of Environmental Health Sciences; and the Kaplan Cancer Center of New York University Medical Center.

The opinions expressed in this article do not necessarily reflect policy of the New York State Division of Substance Abuse Services or Narcotic and Drug Research, Inc.

Requests for reprints should be sent to Michael Marmor, Laboratory of Biostatistics and Epidemiology, Department of Environmental Medicine, New York University School of Medicine, 341 East 25th Street, 2nd Floor, New York, 10010-2598.

with 1,743 cases in the same period of 1983 (CDC, 1984a). The CDC has projected that approximately 9,600 new cases of AIDS will occur in 1985 (M. Morgan, CDC, personal communication). Despite the discovery of the probable cause of AIDS in 1983–1984 (Barré-Sinoussi, et al., 1983; Popovic, Sarngadharan, Read, & Gallo, 1984), neither an effective treatment nor a preventive vaccine have been developed to date.

After homosexual or bisexual men, the second largest AIDS risk group, accounting for 17% of cases, has been the population of intravenous users of illicit drugs (herein referred to as IV drug abusers) (CDC, 1984b). Although this portion of the epidemic had accounted for 1,403 cases of AIDS and 725 deaths as of February 4, 1985 (CDC, AIDS Activity, Surveillance Section, personal communication, 1985), it has received relatively little scientific or public attention. Yet the epidemic of AIDS among IV drug abusers is growing at least as rapidly as the AIDS epidemic as a whole, and it may be a critical bridge for sexual transmission of the epidemic from male and female drug abusers to the general population of nondrug abusers. AIDS is thus emerging as a critical problem for both drug abusers and for the public at large. In this article, we summarize information on AIDS relevant to the treatment and counseling of IV drug abusers and discuss possible approaches for prevention.

MEDICAL BACKGROUND

The CDC has defined AIDS as the presence of a reliably diagnosed disease that is at least moderately predictive of underlying cellular immunodeficiency in an individual with no known predisposing causes for immune deficiency (CDC, 1984b). Common diseases seen in AIDS patients include Kaposi's sarcoma, a form of cancer that was previously rare in the United States, and various opportunistic infections, the most frequent of which have been *Pneumocystis carinii* pneumonia, toxoplasmosis, and esophageal candidiasis (Greene & Slepian, 1984; Jaffe, Bregman & Selik, 1983; Selik, Haverkos, & Curran, 1984).

While some AIDS patients have denied prodromal symptoms, many have reported histories of nonspecific illnesses in the weeks or months preceding diagnosis. Such prodromal symptoms commonly have included persistent fevers, night sweats, fatigue or malaise, diarrhea, significant weight loss, and persistent unexplained lymphadenopathy. As many of these symptoms may be present in non-AIDS conditions and, in particular, in IV drug abusers without AIDS, clinical and laboratory evaluations are necessary to separate treatable non-AIDS illnesses from AIDS. Final diagnosis of CDC-AIDS will depend on diagnosis of a disease of immunosuppression as discussed above.

Viruses that appear to cause AIDS have now been identified by several research groups (Barré-Sinoussi et al., 1983; Levy et al., 1984; Popovic et al., 1984). These viruses—lymphadenopathy-associated virus (LAV) discovered in France, and human T-cell lymphotropic virus-III (HTLV-III) discovered in the United States—are thought to be identical or at least very closely related (Cheingsong-Popov et al., 1984). Evidence supporting the causal role of HTLV-III/LAV in AIDS is based on recent and rapid growth in prevalence of serum antibodies among members of AIDS risk groups (CDC, 1984c; Kalyanaraman et al., 1984), demonstration of seroconversion prior to disease onset (Feorino et al., 1984), high rates of seroprevalence of antigens or antibodies in persons with AIDS or at high risk of AIDS (Brun-Vezinet et al., 1984; Gallo et al., 1984; Kalyanaraman et al., 1984; Safai et al., 1984; Sarngadharan et al., 1984), immunologic abnormalities consistent with AIDS in IV drug abusers exposed to the virus (Des Jarlais et al., 1985), and in vitro cytotoxic effects of these viruses on T helper cells, the cells primarily affected by AIDS (Klatzman et al., 1984). Non-human primates inoculated with LAV or HTLV-III have developed immunologic signs consistent with those observed in humans with AIDS, but to date have not been diagnosed with diseases consistent with the CDC definition of AIDS (Alter et al., 1984; CDC, 1984d).

EPIDEMIOLOGICAL PATTERNS

The epidemiology of AIDS has been consistent with that expected of a disease caused by a blood-borne and venereally transmitted agent. Characteristics of the AIDS epidemic relevant to IV drug abusers are as follows.

1. Among drug abusers, AIDS appears to have been transmitted by small amounts of blood in shared needles, syringes, or cookers. We do not yet know how much sharing of works is needed to transmit the virus.

2. AIDS has been shown to be sexually transmitted from male IV drug abusers to females who do not use IV drugs (Harris et al., 1983; Masur et al., 1982; Pitchenik, Fischl, & Spira, 1983). Sexual transmission from AIDS-infected females to males has not been as well-established, but has been reported in at least one case in New York City (New York City Department of Health, 1984) and appears to occur commonly in AIDS in Africa (Piot et al., 1984; Van de Perre et al., 1984). Male-to-male transmission of AIDS has, of course, been common in the epidemic, and the dual presence of male homosexuality or bisexuality and IV

drug abuse in some individuals may have been the bridge for the AIDS virus between these two populations.

3. AIDS has occurred in at least 46 infants born to IV drug using women or men (CDC, AIDS Activity, Surveillance Section, personal communication, 1985; Oleske et al., 1983; Rubinstein et al., 1983). The mortality rate among pediatric cases of AIDS has been about 60% (New York City Department of Health, 1984). The specific mode of transmission of the virus from mother to infant has not been established, although it is thought to occur during pregnancy or at the time of delivery. As casual transmission of the virus to health care workers or families of AIDS cases has not been observed, the apparent father-to-infant cases of AIDS transmission probably represent indirect father-to-mother-to-infant processes. Transmission of pediatric AIDS from affected children to their siblings or to other family members was *not* observed in a recent study of this question (Zabala et al., 1984).

4. An asymptomatic carrier state for AIDS appears to exist (Laurence et al., 1984; Marmor, 1984). This hypothesis is supported, for example, by the presence of transfusion-associated AIDS cases, since blood donors who provided AIDS-contaminated blood were probably healthy at the time of donation or they would not have considered themselves or been considered by blood banks to be suitable donors (Curran et al., 1984). A carrier state for AIDS is also suggested by the occurrence of the disease in female sexual partners of asymptomatic IV drug abusers (Pitchenik, Fischl, & Spira, 1983).

5. Recent evidence indicates that the AIDS virus can be present in saliva and semen of infected persons who are clinically well (Groopman et al., 1984; Zagury et al., 1984). The ability of saliva to transmit the infection, however, is not known. The absence of AIDS cases with histories of contact limited to exchanges of saliva with members of AIDS risk groups argues strongly against efficient transmission of the disease by this route.

6. It is possible that repeated exposure to the AIDS virus or exposure to a large inoculum may be necessary for development of a full-blown case of the disease. This hypothesis is supported by the absence of AIDS among health care workers in the United States who have experienced "needle sticks" while caring for AIDS patients (CDC, 1984e). It is also possible that exposures to other agents (cofactors) in addition to HTLV-III/LAV may be necessary before a person will develop full-blown AIDS. Among IV drug abusers, such co-factors might be exposure to immunosuppressive drugs or exposure to infectious organisms other than HTLV-III/LAV on unsterile needles or in drug cutting media.

7. IV drug using cases of AIDS have been concentrated in the New York metropolitan area (Allen, 1984). Whereas 37% of male homosexual AIDS cases have occurred in New York or New Jersey, approximately 79% of IV drug using AIDS cases have occurred in these two states (CDC, AIDS Activity, Surveillance Section, personal communication, 1984). Although substantial numbers of IV drug addicts live in California, this state has accounted for only 2.1% of IV drug-using AIDS cases (but 29% of homosexual cases). The geographic localization of AIDS to the New York area may reflect a greater overlap between the homosexual and drug using communities in New York City than elsewhere, greater needle sharing in New York City, or lack of travel by potentially infectious New York area IV drug abusers to other cities. It seems unlikely that any of these factors would be strong enough to keep AIDS from spreading to IV drug abusers in other areas.

8. AIDS has occurred in substantial numbers of prisoners, especially in New York State correctional facilities (Hanrahan et al., 1984; Wormser et al., 1983). Prisoners investigated by Hanrahan et al. (1984) appeared to have contracted AIDS prior to incarceration as evidenced by reduced leukocyte counts at the time of imprisonment. AIDS in these prisoners was most probably attributable to drug abuse; 14 of 14 studied had used heroin and/or cocaine in New York City prior to imprisonment while none reported homosexual activity prior to imprisonment (2 of 14 reported homosexual activity while in prison).

9. AIDS among IV drug addicts has been associated with extremely high mortality rates. Most drug abusers with AIDS have developed severe opportunistic infections, whereas homosexual men with AIDS have been diagnosed more often with Kaposi's sarcoma (Des Jarlais et al., 1984). This difference in disease distributions may account for the longer survival of homosexual men with AIDS than drug addicts with AIDS. The median survival of AIDS patients with opportunistic infections in New York City was reported to be about 10 months, while AIDS patients presenting only with Kaposi's sarcoma at diagnosis had a median survival of 15 months (Rivin et al., 1984).

SEROEPIDEMIOLOGY

The above discussion relies largely on the epidemiology of AIDS using the CDC definition of the disease. A new phase of AIDS epidemiology has now emerged with the development of tests capable of detecting serum antibodies to the AIDS virus. While the prognostic implications of these tests for individuals are still uncertain, their epidemiologic importance is already clear. As in many other diseases, seroepidemiology has revealed that exposure to the virus is

more widespread than was previously realized and clinical expression of AIDS is more varied, ranging from apparently asymptomatic exposure to fatal illness.

To date, only limited data have been published on the seroepidemiology of AIDS in intravenous drug abusers. Of 86 IV drug abusers entering a drug detoxification program in New York City in 1984, 58% (50) had antibodies to the core protein of LAV (Spira et al., 1984). Seroprevalence rates among IV drug abusers did not differ by sex: 63% (19) of 30 female drug abusers were found to have antibodies to LAV, compared with 60% (28) of 49 male drug abusers (Marmor et al., 1985). A much lower seropositivity rate (1.5%) was found in Britain, where only one case of AIDS in an IV drug abuser (who was a male homosexual) had occurred by late 1983 (Cheinsong-Popov et al., 1984; McEvoy, 1984). In Zurich, Switzerland, 37 of 103 IV drug abusers (36%) participating in a hepatitis B vaccination program had HTLV-III/LAV antibodies (Schüpbach et al., 1985).

Controlling the Spread of AIDS among IV Drug Abusers

The finding that half or more of IV drug abusers entering detoxification programs in New York City have been exposed to HTLV-III/LAV, the putative causal agent of AIDS, raises serious issues concerning the control of AIDS in this population and in the population as a whole. At present, we do not know what proportion of otherwise healthy individuals with HTLV-III/LAV antibodies might be capable of infecting others with AIDS. Several researchers, however, have advised homosexual men to assume that persons with antibodies to HTLV-III/LAV are potentially contagious. The rapid and continued growth of the AIDS epidemic among intravenous drug abusers in New York City and the high rate of occurrence of HTLV-III/LAV antibodies in this population support the notion that many IV drug abusers have been capable of transmitting AIDS through needle sharing.

The prospects for "secondary" spread of AIDS from drug abusers to the general population must also be considered. The high prevalence of antibodies to HTLV-III/LAV found in female drug abusers in New York City raises the possibility of spread of the disease to nondrug-using male sexual partners via prostitution. It is not uncommon for female IV drug addicts to support their habits by engaging in prostitution. Surveys to determine the prevalence of HTLV-III/LAV among prostitutes in cities affected by AIDS have not yet been conducted, and are urgently needed.

To slow the spread of AIDS among IV drug abusers, it will be necessary to reduce intravenous drug abuse or to ensure that drug abusers do not share needles, cookers, or solutions containing drugs. Expansion of drug information and treatment programs could serve as primary measures for reducing IV drug use among persons already addicted. Increased self-referral to treatment programs might be expected if IV drug users were informed that AIDS infection is common among their peers, that infectivity cannot be determined by physical appearance, and that AIDS in drug abusers is often fatal. Since the prevalence of HTLV-III/LAV antibodies among drug abusers in New York City is so high, counselors and therapists of drug abusers in the New York area could advise their clients to consider all other IV drug abusers as potentially infectious for AIDS. As gradual spread of the epidemic to drug abusers in other states is to be expected, similar advice would be justified in other geographic locales. These same arguments directed at potential drug abusers and especially at high school students might help some individuals avoid intravenous drugs entirely. For those not yet using drugs, the AIDS epidemic may, in fact, be an extremely convincing deterrent. What better deterrent could there be than the information that a single sharing of a needle with a drug abuser may pose as much as a 50% chance of exposing a new drug user to AIDS?

Materials need to be developed to communicate information on the AIDS problem to intravenous drug abusers and those at risk of intravenous drug abuse. We have drafted "Fact Sheets" on AIDS for IV drug abusers, with and without the disease, that drug counselors may find to be of help (see Appendices A and B). Audiovisual materials including television public service messages aimed at current and potential IV drug abusers also need to be developed to communicate information about AIDS. Drug abusers who have contracted the disease might also be used to communicate information on AIDS. In our experience, some patients with AIDS have been very willing to talk about their disease and their feelings concerning drug abuse. Such patients have sometimes been able to communicate the hazards of IV drug abuse and the symptoms of AIDS and its various manifestations more effectively than physicians or other medical personnel. Most important, drug counselors and therapists need to be informed about AIDS so they can intelligently address the concerns of their staff and patients, and so they can use this information in their efforts to reduce drug abuse and encourage less risky practices among those continuing to use drugs.

How successful can AIDS information programs be in reducing the spread of the current epidemic? We recently conducted an interview study aimed at measuring the state of knowledge of AIDS among IV drug abusers. Preliminary analyses suggested that an extensive educational campaign could lead to considerable reduction in the sharing of works to inject

drugs. We doubt that education alone, however, could eliminate the sharing of works entirely. Furthermore, whether a considerable reduction in needle-sharing would have a substantial effect on the course of the AIDS epidemic would depend upon such factors as the rapidity with which information can be gotten to the populations at risk, the ability of drug abusers to act on that information, the percentage of IV drug users who have already been exposed to AIDS, the percentage exposed who will become infectious (capable of transmitting the virus), the length of the period of infectiousness, and whether multiple exposures to the virus are necessary for development of serious illness. Only limited data are available regarding each of these issues.

We doubt that educational programs alone will have a substantial impact on the rate of spread of the AIDS epidemic among IV drug abusers. If we are right, more vigorous control measures will be needed. One immediate measure that should be implemented is the provision of effective treatment for all who wish to stop injecting illicit drugs. Waiting lists for treatment programs in New York City and elsewhere attest to the fact that current programs are not adequate to meet demand.

A more extreme step that may be justified as an emergency measure for control of the AIDS epidemic is the elimination of controls over the sale of hypodermic syringes, or even free distribution of syringes. Development of inexpensive, single-use, non-reusable syringes would help reduce possible adverse side-effects of such programs (e.g., the possibility of inadvertently causing an increase in IV drug abuse). State supervised facilities where addicts may inject drugs are being discussed in the Netherlands and might be another alternative in the United States (Calonius, 1984). While these suggestions may seem extreme, they may also be appropriate given the potential consequences of further spread of AIDS. In any case, we hope our suggestions will encourage readers to think of other, perhaps more pragmatic ways to slow the spread of AIDS among IV drug abusers.

CONTROLLING THE SPREAD OF AIDS FROM DRUG ABUSERS TO OTHERS

As discussed above, sexual transmission of AIDS can occur. The diagnosis of AIDS in an individual thus may cause severe stress to his or her intimate relations. Tests to detect antibodies to the virus will soon be licensed by the Food and Drug Administration, but their primary immediate use will probably be in the protection of the nation's blood supply. Widespread use of serologic tests as adjuncts to counseling of drug abusers or their consorts will probably not be feasible for some time. Even when tests become available, they may cause as many problems as they solve because of the anxieties attached to AIDS and our lack of knowledge of the prognostic implications of a positive test result.

In the absence of serologic testing for the AIDS virus, it would seem advisable to inform drug abusers and sexual partners of drug abusers that their exposure to AIDS is unknown at present, but that continued IV drug use will increase the likelihood of exposure of both individuals. The cessation of drug use should be strongly encouraged. Use of condoms and other modifications to sexual habits also might be suggested as offering partial protection against AIDS to the male or female sexual partners of IV drug abusers. AIDS has occurred in infants of IV drug using men and women, but the data regarding horizontal transmission by casual contact to other family members including children are reassuring. Sharing of a domicile with an AIDS-infected individual does not in itself seem to increase the risk of contracting AIDS.

DEALING WITH AIDS OUTBREAKS IN TREATMENT CENTERS AND PRISONS

To date, about 70 cases of AIDS in New York City have been diagnosed in patients who were in drug treatment programs. As the epidemic is continuing to grow rapidly, treatment programs in the New York area and elsewhere can expect to see AIDS occur among their clients. As discussed above, substantial numbers of AIDS cases have occurred among prisoners, and this problem, too, can be expected to increase with time.

The severe morbidity and mortality associated with AIDS can make the occurrence of AIDS in treatment programs or prisons difficult for staff as well as for clients or inmates. Among staff, fear of contracting the disease will need to be addressed through education concerning the signs and symptoms, modes of transmission, and possible methods for prevention of AIDS. Specific guidelines for infection control in facilities treating AIDS patients and members of AIDS risk groups have been published and can serve as a resource (Advisory Committee on Infections Within Hospitals, 1984). Workshops to address these issues could be organized with the help of drug treatment agencies, public health agencies, medical centers, and private groups, such as the Gay Men's Health Crisis in New York City. In addition to transmitting facts about AIDS, such workshops could address staff attitudes towards patients with diseases carrying a poor prognosis. Staff members with little experience in this area may feel uncomfortable providing care and support to AIDS patients. The staff's own fear of contracting AIDS will no doubt surface in such workshops and will need to be

addressed. In this regard, workshops should emphasize that epidemiologic data indicate that health care workers are *not* at substantially increased risk of AIDS because of their contact with persons with AIDS or pre-AIDS. Despite the occurrence of more than 8,000 cases of AIDS in the United States and many more cases of undiagnosed AIDS, only 4 nurses who were not also members of AIDS risk groups have been reported to have developed the disease, and these persons lacked convincing evidence of job-related exposures to AIDS or pre-AIDS patients (Centers for Disease Control, 1983b). No cases of AIDS have been reported among physicians who were not also members of AIDS risk groups. A nurse in England developed a transient glandular-fever-type syndrome and HTLV-III/LAV antibodies following a needle stick with possible microinjection of blood, but later recovered (Needle stick transmission, 1984). Numerous needle stick incidents among nurses and physicians in the United States have yet to yield a documented case of AIDS, and a recent study of hospital employees showed no HTLV-III seroconversions among 33 persons with accidental exposures to HTLV-III and 52 other potentially high-risk hospital employees (Hirsch et al., 1985).

Despite the minimal occupational risk of AIDS, staff at drug treatment programs and prisons should be encouraged to reduce any potential risk of contracting AIDS by following the guidelines promulgated by the CDC for providing health care to these patients (CDC, 1983a). These guidelines are essentially the same as those for protection against hepatitis B. We have summarized recommendations most relevant to staff at drug programs and prisons in Appendix C. The AIDS virus does not appear to be easily transmitted and, like hepatitis B, can be effectively eliminated from contaminated surfaces by chemical disinfectants, such as a 10% solution of household bleach (Spire, 1984). Once staff in drug treatment programs and prisons are knowledgeable about AIDS and comfortable with their own feelings, these attitudes and information can be transmitted to clients or inmates.

Programs that successfully overcome their staff's potential fear of AIDS can perhaps benefit from improved morale and satisfaction gained from the provision of critical services in a compassionate way to individuals affected by the disease. After an initial AIDS manifestation has been treated, AIDS patients are often well enough to be released from hospitals, but not well enough to resume all previous activities. In addition to continuing medical care, AIDS patients will have a wide range of social, psychological and other needs. These may include counseling on death and dying, prevention of relapse to IV drug use, and counseling for spouse, family and other loved ones. Outpatients with AIDS may need additional help with provision of housing, health and disability benefits, and the everyday chores of living, such as grocery shopping.

CONCLUSIONS

We believe AIDS is an imminent problem for drug counselors and therapists in the New York City area and may develop into a problem in other areas soon. We would like to encourage the early education of staff and clients concerning AIDS. A brochure entitled "Facts on AIDS" and several other brochures on AIDS designed for homosexual and bisexual men, for the public, and for health care providers are available from the Public Health Service and may be requested in bulk from the Office of Public Affairs, Public Health Service, Room 725H, Hubert H. Humphrey Building, Washington, DC 20201. As a brochure for drug abusers does not yet exist, we suggest that the "Fact Sheet" (see Appendix A) or some modification of it be used. We have also prepared a Fact Sheet for drug abusers diagnosed with AIDS who should be informed about their condition and responsibilities to themselves and others (see Appendix B), and one for employees of drug treatment programs and prisons (see Appendix C). While AIDS poses a very severe threat to public health, we believe it also provides an opportunity for rewarding work with affected individuals and a unique situation that might encourage widespread reduction in IV drug abuse. We welcome the response of readers to our suggestions on how the drug treatment community might best respond to the challenges presented by the AIDS epidemic.

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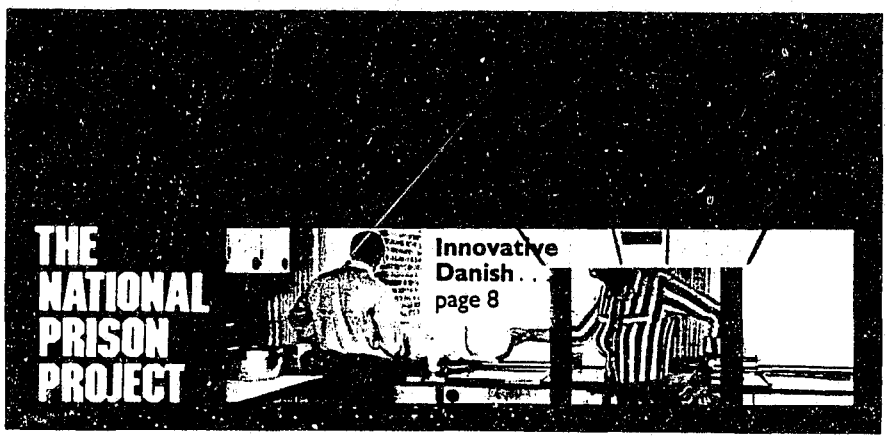

ISSN 0748-2655 NUMBER 6, WINTER 1985

NPP Gathers the Facts on AIDS in Prison

Urvashi Vaid

INSIDE . . .

This issue begins a two-part series on AIDS in prison. Starting on this page are the results of a state-by-state survey and, on page five, concerns about potential for abuse in current AIDS testing.

In early September of 1985, the National Prison Project initiated a survey of corrections departments around the country to determine the incidence of Acquired Immune Deficiency Syndrome (AIDS) in the nation's prisons. This article, the first of a series, reports on the results of the survey. The second article will appear in the Spring 1986 issue of the *JOURNAL* and will focus on the legal and political dimensions of the occurrence of AIDS in prison. The results of the survey are summarized on page four.

Methodology

A four-page questionnaire was developed to gather some basic factual information about AIDS in prison. The survey was co-authored by Urvashi Vaid and Dr. Ron Sable, assistant medical director for the Cook County Jail in Chicago. Dr. Sable also works with AIDS patients at the Cook County Hospital. He has been active in training correctional health care providers to develop an appropriate institutional response to AIDS.

The survey sought information in five general areas: epidemeological data; screening and medical care; institutional operations; and staff and inmate education. Specifically, data on the number of cases of AIDS and AIDS Related Complex (ARC) was sought by risk group, age, race and sex. The survey asked about procedures for intake screening for AIDS, the use of the HTLV-III antibody test, and general policies on the medical care and handling of diagnosed AIDS patients. Questions also covered the segregation of persons with AIDS and ARC, as well as their access to basic institutional programs. Finally, the survey sought information on the educational efforts of the departments, along with information about inmate and staff reaction.

Photo by Bill Powers Courtesy Frost Publishing Group

The survey was sent to the medical directors of all 50 state departments of corrections, as well as to the appropriate administrators of correctional institutions in the District of Columbia, Puerto Rico, the Virgin Islands and Guam. Twenty-six written surveys were returned. Follow-up phone calls to obtain basic statistical and factual information yielded 22 additional responses.[1] Two states (Maryland and Ohio) and the District of Columbia did not respond in any fashion. The statistical information reported on these states was gathered informally through press accounts and is marked as such.

The survey was developed in order to gather basic statistical information and to get a sense of how corrections departments are responding to this medical crisis, and to share this information with the many people and agencies who are concerned about this serious problem. It was not designed to obtain detailed information about particular systems, nor to anticipate all possible scenarios encountered in correctional settings. Protocols and policies on AIDS were requested and those obtained are available to the reader from the NPP.

Discussion

Information about the number of cases of AIDS gathered from all 50 states reveals that there have been 420 cases of AIDS diagnosed in the nation's prisons.[2] Since responses to the survey were obtained over a two and one-half month period (September to November, 1985), the precise number of cases reported will have changed overall as well as in particular states. The 420 figure reflects the number of cases diag-

—continued on next page

[1]Responses obtained solely by phone are indicated with a (*) on the chart.

[2]The number of cases of AIDS in the nation's jails is not reflected in this figure. A whole different range of problems is presented when considering jail inmates, many of whom are incarcerated for short periods of time.

"Prison systems around the country are striving to develop a balanced institutional response to this medical crisis."

nosed to date, and does not identify the number of persons with AIDS who are presently incarcerated. More than half of these 420 prisoners have died. It was difficult to determine the exact number of prisoners with AIDS who have died because some states did not provide the information, and in some instances, prisoners with AIDS may have died after release.

The 420 cases have been distributed among 24 states. Four states with no diagnosed AIDS cases reported that they had individuals who have tested positive on the HTLV-III antibody test, while 22 reported no cases at the time of the survey. The overwhelming majority of the 420 cases diagnosed to date (85%) have been found in the New York, New Jersey and Florida systems.

Although the survey sought data on the age, race, sex and risk group identity of prisoners with AIDS, the responses obtained were incomplete and therefore unreportable. The data received on the race of prisoners with AIDS indicates that black and Hispanic prisoners are heavily represented. Nationally, people of color account for over 39% of all the reported cases, as of November 11, 1985. The results obtained did indicate that intravenous (IV) drug users form the largest group of prison inmates with AIDS. According to the Assistant Commissioner for Health Services for the New York State Department of Correction, Dr. Raymond Broaddus, over 95% of the 231 prisoners with AIDS in New York were intravenous drug users.

Three major areas were generally explored in the survey: the identification and diagnosis of persons with AIDS and ARC; the medical and institutional treatment of prisoners with AIDS, ARC and of those prisoners with a positive antibody test; and the development and use of educational materials related to AIDS.

Only sixteen states reported the use of some form of intake screening specifically aimed at identifying persons at risk for AIDS or those with AIDS-associated symptoms. Screening methods used included complete physicals, complete blood count (CBC), skin tests to measure immune competence, and detailed questionnaires to identify members of high-risk groups. No state reported sole reliance on the Enzyme Linked Immuni-Sorbent Assay (ELISA) test, which measures the presence of antibodies to the HTLV-III virus, as a diagnostic tool. However, 60% (29) of the 48 states which responded to the survey indicated that they use the ELISA test in some fashion. Five others are developing policies governing its use. The most common usage was a means to confirm the diagnosis of AIDS where other symptoms were present. The second most typical usage of the test was on a case by case basis, as determined by the medical staff. New York and New Jersey do not use the ELISA test at all.

Some of the problems with using the HTLV-III test as a diagnostic tool are discussed in this issue of the *JOURNAL* by Dr. Robert Cohen, the medical director for Rikers Island Jail in New York City. The test was designed to protect the blood supply from possibly infected blood. The test was not designed to diagnose which persons who test positive for the antibody will develop the disease. The test cannot distinguish individuals who are carriers of the virus from those who have been exposed to it. In addition, the ELISA test when used on its own results in an extremely high number of false positives. The test also results in a high number of false negatives; in other words, individuals who test negative to the HTLV-III antibody have gone on to develop the disease.

Despite these fundamental problems with the HTLV-III antibody test, and without even discussing the additional problems posed by the need for confidentiality of test results or the discriminatory treatment of persons based on their test results,[3] prisoners and corrections professionals around the country are calling for a greatly expanded use of the test under the mistaken assumption that it somehow diagnoses AIDS. Two inmates in Alabama recently sued to obtain such testing. Inmates without AIDS in New York sought, among other things, to compel the state to examine all inmates and staff to insure that the disease had not spread.[4] The corrections officers' union in Michigan is seeking use of the HTLV-III test on all state inmates, while corrections officials in D.C. may seek the early release of a prisoner with AIDS on the grounds that they do not have the resources to properly treat him. So far only one state, Nevada, has used the test on a mass basis, to determine the antibody status of all inmates in the system, as well as of all new admissions. No information is available regarding what the state plans to do with persons testing positive or on the confidentiality of test results. However, Missouri also plans to use the test to screen all new admissions, and proposals to perform mandatory screening have been made in Delaware and Pennsylvania.

The use of the test to create more restrictive, indefinite housing for persons on the sole basis of their exposure to the HTLV-III virus poses massive legal and administrative problems. For one, there is no medical basis to justify such segregation on the basis of seropositivity. AIDS is not spread through casual contact, but only through the exchange of bodily fluids during sex or by the

[3]These issues will be addressed in Part 2 of this series.

[4]*LaRocca v. Dolsherm*, 467 NYS 2d 302, 120 Misc. 2d 697 (1983). The suit also sought to prevent the formation of a single prison where prisoners with AIDS were housed. The court denied injunctive relief.

The National Prison Project of the American Civil Liberties Union Foundation
1616 P Street, N.W. Washington, D.C. 20036 (202) 331-0500

medium of contaminated blood transmitted through needles. There is no evidence that the HTLV-III virus is airborne, exchanged through kissing, shaking hands or any other non-sexual interaction. The virus has not been isolated in human feces. Finally, only a small percentage of those testing positive on the ELISA go on to develop AIDS.[5] Indefinite confinement on the basis of antibody status alone would thus pose serious due process and Eighth Amendment problems. An additional logistical problem must be considered in reviewing any proposal to isolate all antibody positive persons. Leading medical experts estimate that between 1 to 2 million people in the U.S. have been exposed to the HTLV-III virus.[6] New York State estimates that over 60% of the approximately 36,000 inmates in its system have been needle-users.[7] Even if it were medically and legally defensible to segregate prisoners on the basis of antibody status alone, it would be physically impossible, given the overcrowded condition of most prison systems, to isolate such a large number of prison inmates, without the construction of new facilities designed solely to accomplish such isolation.

Segregation on the basis of a confirmed diagnosis of AIDS is the policy of 20 of the 42 states from whom information on this point was obtained (48%). Seven (17%) others are in the process of developing a policy and two (5%) indicated that they decide to segregate on a case by case basis. Only three states, Louisiana, Michigan and Minnesota, noted that they do not formally segregate prisoners with AIDS, while two others noted that they had been segregating prisoners with AIDS, but were planning to stop. Most states reported that persons with AIDS who are actively fighting an infection are sent to an outside hospital. Some reported that they house individuals in prison infirmaries.

The segregation of prisoners with AIDS has been justified primarily on the grounds that AIDS patients need to be protected from infections they might catch in general population, and from the wrath of other prisoners. The segregation of prisoners with AIDS has been challenged on constitutional grounds in one lawsuit to date, *Cordero v. Coughlin*, 607 F.Supp. 9 (S.D. N.Y. 1984). The prisoners argued that defendants' policy of segregating them resulted in a lack of social, rehabilitative and recreational activities which violated their First,

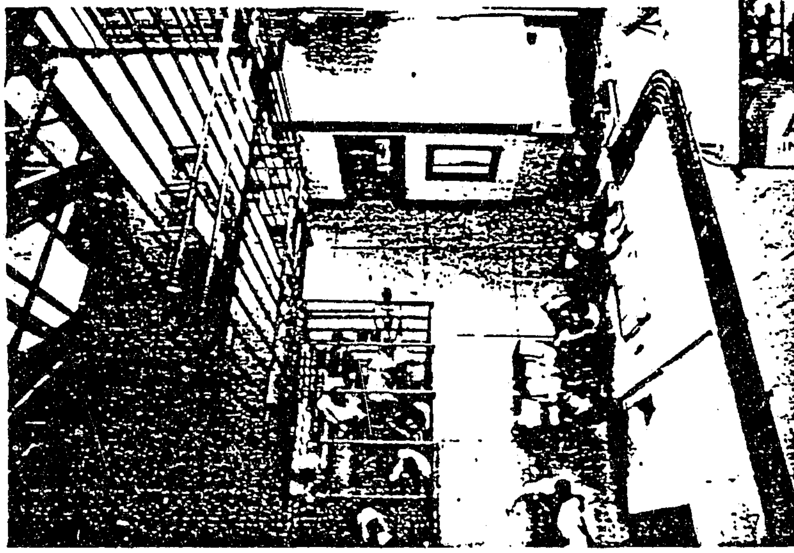

Photo by Bud Powers Courtesy [illegible] Publishing Group

Eighth and Fourteenth Amendment rights. The court rejected the Equal Protection claim after finding that the state had a legitimate objective " . . . to protect both victims and other prisoners from the tensions and harm that could result from the fears of other inmates." The court held, in part, that "[C]ertainly the separation of these inmates . . . bears a rational relation to this objective, at least until some better system is developed, and it is undisputed that defendants are changing their programs as they work to improve their ability to cope with the needs of prisoners with AIDS." *Id.*, at 10.

The court rejected the Fourteenth Amendment liberty interest claim on the basis of *Jewitt v. Helms*, 459 U.S. 460 (1983), and rejected the Eighth Amendment claim on the basis that no showing had been made that plaintiffs were denied adequate food, clothing, shelter, sanitation, medical care and safety. *Id.*, at 11. The court also rejected the First Amendment claim on the basis of *Jones v. North Carolina Prisoners Labor Union, Inc.*, 433 U.S. 119 (1977) and denied the claims raised under New York state law based on *Pennhurst State School and Hospital v. Halderman*, 465 U.S. 89 (1984).

The *Cordero* case makes it clear that while prisoners with AIDS who seek to remain in general population have an uphill fight, they could successfully challenge their confinement in such a status if conditions are violative of the Eighth Amendment. In other words, segregation of prisoners with AIDS must involve more than placement in an isolation cell for 24-hours a day. Comprehensive and detailed information about the conditions under which people with AIDS are confined was not sought in the survey. However, information concerning prisoners' access to visitation, law library, exercise, correspondence and vocational and educational programs was sought. Ten states provided information on these areas.[8] All ten allow some visitation with the AIDS patient; only one does not provide access to a law library or to exercise (Virginia); and three do not allow access to vocational and educational programs (Pennsylvania, South Carolina, Virginia). It should also be noted that at least one action seeking better medical treatment is being brought on behalf of prisoners with AIDS.[9]

The survey revealed that a significant number of states (20%—8 out of 40) from whom information was obtained isolate prisoners with the condition described as AIDS-Related Complex (ARC). Ten states (25%) have not had any diagnosed ARC cases, while 9 (23%) states reported they do not, or do not plan to, isolate persons with ARC. These states include Florida and New York. Of the eight who stated they do not segregate ARC patients, four segregate prisoners with AIDS. Seven states reported they are developing policies with regard to segregation and six reported that they do so on a case by case basis.

Ironically, the survey revealed that no consistent definition of AIDS Related Complex is used across the country. Of the 46 states from whom information

—continued on page 5

[5] "Update: Acquisition of AIDS in the San Francisco Cohort Study 1978-1985," *Morbidity and Mortality Weekly Report*, vol. 34, no. 38, p. 573 (1985).

[6] Cohen, Robert J., "AIDS: The Impending Quarantine," Health PAC Bulletin, p. . . . 1985.

[7] Conversation with Raymond Broaddus . . . 9 85.

[8] California, Connecticut, Illinois, Maine, Michigan, New York, North Carolina, Pennsylvania, South Carolina, Virginia.

[9] This action is being brought by a private attorney and Prisoners Legal Services of New York. Further details will be reported in the second article of this series.

	Date First AIDS Case Identified in System	Total Number of AIDS Cases in System Statewide to Date	Total Deaths from AIDS	Total Cases of ARC At Present	Use of ELISA (HTLV-III Antibody Test): Used	In Plasma Program	On High Risk Groups	On Symptomatic Individuals To Confirm Diagnosis	To Screen All Admissions	On All Inmates	Western Blot Used to Confirm	Are There Any Protocols for the Handling of Prisoners with AIDS?	Are (or will) prisoners With AIDS (be) Segregated From the General Population?	Are (or will) prisoners With ARC (be) Segregated From the General Population?	Have Security Staff Received Any Special AIDS Training?	Have the Medical/Nursing Staff Received Any Special AIDS Training?	Have Any Brochures, Handouts, Guidelines on AIDS Been Developed for Staff or Inmates?
Alabama*	0	P	0	0	C				C	C	Y	C	Y	U	U	U	Y
Alaska*	0	0	0	0				B				S	U	U	U	U	U
Arizona*	1/85	1	0	3		Y		B			Y	S	Y	U	Y	U	U
Arkansas	0	P	0	0		Y					Y	C	N/A	N/A	N	D	C
California	7/84	14	6	10				B				Y	Y	Y	Y	Y	Y
Colorado*	0	0	0	0				B	C	C		S	U	U	U	U	U
Connecticut	1984	7	3	12	Y							Y	Y	B	Y	Y	Y
Delaware*	3/85	1	1	0			B	B	C	C		C	Y	Y	U	U	U
D.C.	No answer yet																
Florida	1982	31**	7	K				Y				Y	Y	K	U	U	Y
Georgia	7/84	6**	2	6				Y				Y	Y	Y	Y	Y	Y
Hawaii*	0	0	0	0	C	C						C	C	C	C	C	C
Idaho	0	0	0	0			Y					N	N/A	N/A	Y	Y	Y
Illinois	11/84	1	1	1		N						Y	D	N	Y	Y	Y
Indiana*	10/85	2	0	0					Y			Y	E/I	U	Y	Y	U
Iowa*	U	0	0	0		Y		Y				U	N	U	Y	Y	N
Kansas	0	0	0	0		N						C	C	C	C	C	C
Kentucky*	5/84	1	0	1					Y			Y	Y/I	N/A	U	U	Y
Louisiana*	10/85	1	0	1			Y		Y			N	N	N	U	U	U
Maine	9/85	1	0	1					Y			Y	Y	Y	Y	Y	Y
Maryland**	U	0**															
Massachusetts	U	3	1	U		N						S	Y/I	N	U	U	Y
Michigan	8/84	2	1	1		N						Y	N	N	Y	Y	Y
Minnesota	0	0	0	0					Y			Y	N	N	Y	Y	Y
Mississippi	0	0	0	0		N						S	N/A	N/A	U	Y	Y
Missouri	9/85	P	0	K		Y		Y	D			Y	Y	Y/I	N	Y	Y
Montana	0	0	0	0	B							D	D	N/A	D	Y	Y
Nebraska*	U	0	0	0						D/C		C	U	U	U	U	U
Nevada*	0	P	0	0					Y	Y	Y	D	C	C	U	U	U
New Hampshire*	10/85	1^	1	1	U							Y	B	B	U	U	U
New Jersey*	1981	94	66	20	N							Y	U	B	U	U	U
New Mexico	0	0	0	0	C			D				C	C	C	D	D	Y
New York*	11/81	231	U	38	N							Y	Y	B	Y	Y	Y
North Carolina*	U	3	1	U				Y				C	D	U	U	U	Y
North Dakota	0	0	0	0	B							Y	U	U	Y	Y	Y
Ohio**	U	2**	U	U													
Oklahoma*	1985	0	0	2				Y				S	D	Y/I	U	U	U
Oregon*	0	P	0	1				Y				Y	E	E	U	U	U
Pennsylvania	10/84	4	0	2				Y				Y	Y	N	Y	Y	Y
Rhode Island	U	1	1	3				Y				Y	B	B	U	U	U
South Carolina	U	2	1	6				Y				Y	Y	B	Y	Y	Y
South Dakota*	0	0	0	0	N							N	N/A	N/A	U	U	U
Tennessee	0	0	0	0				B				C	C	C	N	N	N
Texas	8/83	9	4	U	Y							Y	Y	Y	Y	Y	Y
Utah	0	0	0	0	N							N	N/A	N/A	N	N	N
Vermont	0	0	0	0	N							N	N/A	N/A	N	N	N
Virginia	1/85	2	1	3	N							Y	Y	N	Y	Y	Y
Washington	0	0	0	0	N							C	C	C	Y	Y	Y
West Virginia	0	0	0	0				Y				C	Y	Y	N	N	N
Wisconsin	0	0	0	1	C		C	C				C	C	C	Y	Y	Y
Wyoming	0	0	0	0	N							N	N/A	N/A	N	N	N

—continued from page 3.
on this point was obtained, 35% (14) use no definition of ARC. Five percent (2) do not identify prisoners with ARC in any way. Only 20% (8) cited the Centers for Disease Control's definition as the one they use. The CDC defines ARC as the existence of any two clinical and two laboratory abnormalities from two separate lists of symptoms and tests which they have created. Another 20% identified ARC as a pre-AIDS condition marked by the presence of symptoms alone, while another 23% (9) defined ARC as being a positive HTLV-III test with some AIDS-associated symptoms.

The final area surveyed was the development of training and educational materials on AIDS for staff and inmates. As the chart indicates, information was not obtained from all 48 responders on these points. However, the data gathered clearly reveals that the majority of corrections departments have developed training seminars for medical and security staff, and have distributed educational materials to inmates. The process of education is perhaps the key ingredient to the corrections community's response to the AIDS crisis. The educational brochures and fact-sheets gathered through the survey were reviewed and, while found to be technically accurate, varied greatly with respect to their specificity and their perspective. Prison systems concerned with needle-use as well as consensual and non-consensual sexual activity inside prisons must continue to develop and improve educational materials which specifically and vividly impress upon both inmates and staff the risks associated with certain behaviors. Information which discusses in detail the risk of sharing needles, defines casual contact concretely in the context of the prison environment and tackles tough questions about safe and unsafe sexual practices was not found among the educational materials received.

KEY

- ***Telephone response obtained**
- ****Information obtained from press reports**
- **A = case not confirmed but highly suspected to be AIDS**
- **B = determined on a case by case basis**
- **C = in the process of developing policy**
- **D = no, but plan to**
- **E = have been, but may not in the future**
- **I = housed in infirmary or hospital**
- **K = the ARC classification is not recognized by the system**
- **N = No**
- **N/A = not applicable**
- **P = have individuals with positive HTLV-3 antibody tests, but not confirmed AIDS diagnosis**
- **S = same protocol(s) used as for other infectious diseases**
- **U = information unavailable**

Conclusion

The diagnosis of AIDS among prison inmates has caused enormous concern among inmates, correctional officers and prison administrators. Although such concern is understandable given the serious nature of the disease, it is important to remember that while approximately 420 persons with AIDS have been diagnosed in the nation's prisons, there were over 452,372 prisoners incarcerated in state correctional systems, as of the middle of 1985.[10] Assuming that half of the 420 prisoners with AIDS have died, the approximately 200 cases of AIDS in prison represent less than .001% of the total national prison population in state correctional systems. Prison systems around the country are striving to develop a balanced institutional response to this medical crisis. National organizations such as the National Institute of Corrections (NIC) and the American Correctional Association are also working on the issue and will be releasing an "Issues and Practices Document" on AIDS in prison in early 1986. The next article in this series will discuss more specifically the legal, administrative and political problems that the incidence of AIDS in prison poses. ■

[10]Bureau of Justice Statistics, Mid-Year Report on Prisoners, 1985.

Courtesy Frost Publishing Group

This survey would not have been possible without the research and organizational skill of NPP law student intern Katy Baird, nor without the input and assistance of NPP law clerk Laurie Solomon.

Medical Expert Views Potential for Abuse in AIDS Screening

Robert L. Cohen, M.D.

At the present time there is no test for AIDS. The antibody test which is available, known as the ELISA test, was designed to screen donated blood for presence of antibodies to the HTLV-III virus, which is thought to cause AIDS.

The first published report of the virus now thought to be the cause of AIDS came from Barre-Sinoussi, et al., of France in 1983.[1] They called it Lymphadenopathy Associated Virus (LAV). In 1984, Dr. Robert Gallo of the National Cancer Institute reported finding the AIDS virus, which he labelled HTLV-III.[2] Dr. Gallo's prior research involved the rival causes of certain cancers, in the course of which he had identified a virus causing a human cancer and named it HTLV-I. Although LAV and HTLV-III seem to be identical and LAV was described 18 months earlier, Margaret Heckler, then Secretary of HHS, credited Gallo with the "discovery" of the AIDS virus.

The thesis that this virus is the causative agent of AIDS rests on several pieces of evidence. First, LAV/HTLV-III appears to be a new agent, not previously seen in the United States or Europe. Second, it specifically infects certain kinds of T-Cells and damages them, creating the T-Cell defect characteristic of patients with AIDS. Third, the virus is found in most patients with AIDS and has been found in asymptomatic individuals who have donated blood to individuals who later developed AIDS.

—continued on next page

[1]Barre-Sinoussi, F., Chermann, J., Rey, F., et al., "The Multiple Isolation of a T-Lymphotropic Retrovirus From a Patient At Risk for Acquired Immune Deficiency Syndrome," *Science*, Vol. 220:868-871, 1983.

[2]Gallo, R.C., Salahuddin, S.Z., Popovic, M., et al., "Frequent Detection and Isolation of Cytopathic Retroviruses From Patients With AIDS Or Risk of AIDS," *Science*, Vol 224:500-503, 1984

"At the present time there is no test for AIDS."

The official position of the Centers for Disease Control and the National Institutes of Health is that LAV/HTLV-III causes AIDS, and it does appear probable that most, though not all, individuals who have AIDS have been exposed to it. However the majority of individuals who have antibodies directed against LAV/HTLV-III do not have AIDS as defined by the CDC.

Dr. Gallo developed a simple assay for measuring the presence of antibody to the LAV/HLTV-III virus, using a technique called Enzyme Linked ImmuniSorbent Assay (ELISA). This test is now available as a commercially produced kit manufactured by several drug companies. Although this method is widely used, it gives false positive results with disturbing frequency. In two studies involving screening of donated blood during the period March through June in 1985 the following results were obtained:

1. In the first study, conducted by the FDA, an initial positive ELISA result was found in 9,629 out of 1,128,166 units of blood tested.

2. Of those 9,629 initially testing positive, 2,831 were found to be positive when the ELISA test was repeated. Thus 29% of those initially testing positive remained positive on further testing.

3. In another study conducted by 1,593,969 units of donated blood, repeated ELISA testing was positive for 3,209 units. When a sample of 2,552 of these repeatedly positive units was tested by the Western Blot test, a confirmatory test for presence of antibody to the LAV/HTLV-III antibody, 587 were labeled positive. Thus only 23% of those repeated testing positive were confirmed to actually be positive.

4. Combining the results of these two studies we see that a positive ELISA test when repeated is positive only 29% of the time, and that these repeatedly positive tests can be confirmed only 23% of the time. Out of 1,000 tests 290 would be positive on repeated ELISA testing, and 23% of these 290, or 67 would be confirmed as positive by the Western Blot test. Therefore 923, or 92% would be labeled falsely positive by a single ELISA test.

These studies of volunteer blood donors tested a population with a low prevalence of positive antibody. For the ELISA, as for other laboratory tests, the lower the prevalence of individuals with antibody present in the sample being tested, the higher the number of false positive tests. At the present time the prevalence of AIDS and of antibody to LAV/HTLV-III among prisoners is very low in most states, and false positive tests would be common if performed. Although a Western Blot test for confirmation could be performed on repeated positive ELISA tests, this test is at the present expensive and not completely reliable.[3]

The ELISA test not only has many false positive results, it also has false negative ones. In a study of 96 patients with AIDS, ARC, or at risk for AIDS, four had no detectable antibody to LAV/HTLV-III even though LAV/HLTV-III virus was grown from their blood.[4] This represents a detection failure rate greater than four percent among people who could potentially transmit the disease. At this rate, among the one to two million people exposed to date, 40,000-80,000 would escape detection.

The presence of antibody to HTLV-III does not provide that the HLTV—III virus is present; it just means that exposure has occurred. Additionally, more than two thirds of individuals who have been exposed to the HLTV-III virus show no evidence of AIDS or any AIDS related disease. There would be no difference in the treatment that any individual would receive based upon the results of this test. If virus were present then the individual has the potential to transmit the disease.

For these reasons, HTLV-III antibody testing should not be performed in prisons or jails. The diagnosis of AIDS or AIDS Related Complex is made by clinical evaluation, not by this test. We have found on Rikers Island that a combination of the White Blood Cell (WBC) count which is less than 3500 and an anergy screen which is negative to 4 antigens does identify individuals who have severely depressed T-cell ratios.

AIDS is not casually transmitted; it can only be spread in a jail or prison through sexual intimacy or sharing of needles. There is no reason to segregate inmates based upon the results of this test. Because intravenous drug use is a common experience for inmates prior to their incarceration, targeted educational efforts about the spread of AIDS through sharing of syringes can be very productive for this population. Similarly, education about safe practices should be provided to all inmates. Since consensual homosexual sex occurs in prisons and jails, just as it does everywhere in our society, condoms should be provided to help prevent the spread of AIDS within correctional facilities. ■

Dr. Cohen is the Director of the Montifiore Rikers Island Health Services in New York City.

[3] "Blood Banks Give HTLV-III Test Positive Appraisal at Five Months," JAMA, Vol. 254, No. 13, p. 1681.

[4] Salahuddin, S.Z., Markham, P.D.; Redfield, R.R., et al., "HTLV-III in Symptom-Free Seronegative Persons," *Lancet*, p. 1418-1420, 1984.

Expert Negotiation Brings New Approach to Prison Litigation in Hawaii

Ted Janger

The details of the Hawaii settlement and consent decree were reported in the Fall 1985 JOURNAL, "Hard Fought Settlement Reached in Hawaii Case," 5 NPP JOURNAL at 3.

When a legislature or bureaucracy fails to meet its Eighth Amendment obligations, it falls to the judiciary to determine the scope and meaning of the words "cruel and unusual punishment," and to formulate a remedy. Fiss, *The Forms of Justice*, 93 Harv. L.Rev. 1 (1978); Fletcher, *The Discretionary Constitution: Institutional Remedies and Judicial Legitimacy*, 91 Yale L.J. 635 (1982). That judges are well qualified to determine the meaning of constitutional values has deep roots within our jurisprudence, but once constitutional liability has been established, remedying the deficiency is often a process which carries judges well outside their accustomed role as settlers of disputes. Chayes, *The Role of the Judge in Public Law Litigation*, 89 Harv. L. Rev. 1281 (1976). As a result, prison reform litigation is sometimes criticized for turning judges into prison wardens.

Expert negotiation was developed as a child of necessity.

During the early years of prison litigation this criticism carried some weight. When the novel issues of liability for conditions of confinement first reach the courts, the judge and parties are forced to pick their way through previously

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February 1986

AIDS in Prisons and Jails: Issues and Options

Theodore M. Hammett

Acquired Immunodeficiency Syndrome (AIDS) has rapidly become one of the most difficult and complex public health issues facing the United States. Since AIDS was first identified in this country in 1981, over 17,000 Americans have developed the disease. The rapid increase in cases, particularly in the past 2 years, and the continued uncertainties as to the future course of the disease's spread have led the President to term AIDS "the Nation's number one health priority."

In the correctional context, dealing with the problem of AIDS may pose even more difficult problems since inmate populations may include high proportions of individuals in AIDS risk groups, particularly intravenous drug users. Correctional administrators must formulate policies that allow them to manage their institutions effectively, while dealing with a serious health problem that may cause fears among staff and inmates. Administrators face difficult decisions concerning prevention, housing, and the provision of medical care, decisions which are frequently complicated by legal and cost issues.

In response to urgent information needs expressed by corrections professionals, the National Institute of Justice and the American Correctional Association sponsored a study entitled *AIDS in Correctional Facilities: Issues and Options*. The study was based, in large part, on responses to a national mail questionnaire from all 50 State correctional departments, the Federal Bureau of Prisons, and 33 large city and county jail systems. The responses were received between November 1985 and January 1986.

From the Director

Acquired Immunodeficiency Syndrome (AIDS) represents a serious challenge for American correctional systems.

Recognizing that many inmate populations contain a high concentration of individuals at risk for the disease—primarily because of histories of intravenous drug use and, to a lesser degree, homosexual behavior—correctional administrators are concerned with developing effective policies to ensure the health and safety of both inmates and staff.

Often already coping with crowded institutions and limited budgets, they face difficult decisions regarding prevention, institutional management, and the identification and treatment of inmates with AIDS. These decisions are further complicated by a range of legal issues, the high costs of medical care, and the need to control fear and misinformation throughout the institution.

Recognizing the potential scope of these problems, many correctional administrators have expressed interest in receiving information that can help them in formulating policies on AIDS. To address this need, the National Institute of Justice and the American Correctional Association jointly sponsored the development of a report entitled *AIDS in Correctional Facilities: Issues and Options*.

Given the urgency of the need, the study was an intensive effort, conducted over a 4-month time period. In addition to the dedication of the project director, Theodore M. Hammett, the cooperation of the National Institute of Corrections, the Association of State Correctional Administrators, the Centers for Disease Control, and the American Correctional Association should be recognized.

This *Research in Brief* summarizes the major findings and conclusions of the full report. Like the full report, it is intended to be informational rather than prescriptive.

Certain principles, such as the importance of inmate and staff education on AIDS, are indisputable. Still, there are many other issues and policy questions that continue to spur debate both within and between the correctional and medical communities.

By outlining these debates and providing the most current information available, the National Institute of Justice and ACA hope that correctional administrators will be better equipped to deal with the problem of AIDS.

James K. Stewart
Director
National Institute of Justice

The study summarizes the latest medical information on AIDS, presents statistics on the incidence of AIDS in correctional facilities, and enumerates the key issues and options facing correctional administrators as they formulate policy responses to this complex problem. This Research in Brief summarizes the major findings and conclusions of that report.

Cause and transmission of AIDS

AIDS is a serious communicable disease that undermines the human body's ability to combat infections. In 1983 and 1984, the probable cause of AIDS—variously called human t-cell lymphotropic virus type III (HTLV-III) and lymphadenopathy-associated virus (LAV)—was identified. Thus far, most cases in the United States have been among homosexuals and intravenous drug abusers, with cases primarily concentrated in large metropolitan areas on the east and west coasts.

End-stage AIDS is almost always fatal. However, a range of milder forms of illness, sometimes called AIDS-Related Complex (ARC), may also appear among those infected with the AIDS virus.

Infection with HTLV-III is transmitted through contaminated blood and semen, primarily during sexual activity and needle-sharing related to intravenous drug abuse. The virus is difficult to transmit and there is absolutely no evidence of its transmission through casual contact, such as coughing, hugging, handshaking, sharing eating and drinking utensils, or using the same toilet facilities.

In 1985, a test was developed and made widely available to detect the presence of antibodies (evidence of the body's attempt to fight off an infection) to HTLV-III. While the test does not detect the presence of the virus itself, seropositivity (i.e, presence of antibodies) means that an individual has been infected with the AIDS virus at some time, although the body may have subsequently fought off the infection.

The likelihood that HTLV-III seropositivity means current infection with the virus is considered much greater for individuals in identified AIDS risk groups (e.g., homosexual or bisexual males, intravenous drug abusers). Nevertheless, seropositive individuals may never develop any symptoms, let alone develop end-stage AIDS.

Currently, the Centers for Disease Control (CDC) estimate that 5 to 6 percent of seropositive individuals will develop end-stage AIDS while another 25 percent will develop ARC. However, recent research suggests that the percentage of seropositive individuals who will develop AIDS may be somewhat higher. Moreover, CDC cautions that seropositive individuals may be able to transmit the infection to others, even if they never develop symptoms themselves. Exhibit 1 summarizes the relationships among exposure, infection, seropositivity, ARC, and AIDS.

AIDS in the correctional population

Responses to the study questionnaire reveal that, since 1981, there have been a cumulative total of 455 confirmed AIDS cases in 25 State and Federal prison systems. Twenty large city and county jail systems reported 311 cases of AIDS among inmates. These figures represent *cumulative* total cases since the responding jurisdictions began keeping records.

As of the period November 1985 to January 1986, there were 144 cases of

Exhibit 1

Relationships among exposure, infection, HTLV-III seropositivity, and development of ARC or AIDS

Stage	Meaning	Relationship to previous stage(s)
Exposure	Individual has contact with HTLV-III in a way that makes transmission possible (e.g., sexual contact or needle-sharing activity)	—
Infection	Individual is infected with HTLV-III. Infection may be permanent or body may successfully combat the virus.	Unknown, although multiple exposures probably increase the risk of infection
Seropositivity	Individual has antibodies to HTLV-III. Infection has occurred at some time in the past, but date of infection or whether individual remains infected cannot be determined.	CDC considers the HTLV-III antibody test a reliable indicator that infection has occurred at some time. Repeat and confirmatory testing increase reliability.
ARC	A combination of conditions that together give evidence of infection with AIDS virus.	About 25 percent of seropositive individuals will probably develop ARC (CDC estimate) This estimate is uncertain due to the lengthy incubation period.
AIDS	Illness characterized by one or more opportunistic infections at least moderately indicative of underlying cellular immunodeficiency	About 5 to 6 percent of seropositive individuals will probably develop AIDS. (CDC estimate). Recent studies place the fraction as high as one-third. Again, all estimates are uncertain due to the lengthy incubation period.

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AIDS among State and Federal inmates in 19 systems and 35 cases among city and county inmates in 11 systems.

No known AIDS cases have occurred among correctional staff as a result of contact with inmates. Questionnaire respondents reported nine cases of AIDS among current or former staff, but none of these individuals had been involved in an incident with an inmate in which transmission of the AIDS virus might have occurred. Indeed, most were known or suspected to have been in AIDS risk groups.

The distribution of AIDS cases across correctional systems is highly skewed (Exhibit 2). Fifty-one percent of the prison systems have had *no* cases and 80 percent have had fewer than four cases. Among responding city and county jail systems, 39 percent have had no cases and 70 percent have had fewer than four cases.

At the other extreme, two State prison systems and only one of the responding city and county jail systems have had more than 50 cases. The regional distribution is also highly uneven. Over 70 percent of the cases, both in State prison systems and in city and county jail systems, have occurred in the mid-Atlantic region, with all other parts of the United States contributing much smaller percentages.

The vast majority of correctional AIDS cases, particularly in jurisdictions with large numbers of cases, are believed to be associated with prior intravenous drug abuse. There is substantial debate, but little hard data, on the extent to which the AIDS virus is being transmitted within correctional institutions. The two primary means of transmission are prohibited behavior in all corrections systems. However, logic and common sense suggest that, even in the best-managed correctional facilities, there may be at least some transmission of the infection occurring among inmates.

Correctional policy issues and options

The major policy areas involved in the correctional response to AIDS are education and training; HTLV-III antibody testing; and medical, legal, and correctional management issues.

Exhibit 2

Distribution of cumulative total AIDS cases among inmates, by type of system

Range of total AIDS cases	State/Federal prison systems				City/county jail systems			
	n systems	%	n cases	%	n systems	%	n cases	%
0	26	51%	0	0%	13	39%	0	0%
1-3	15	29	24	5	10	30	16	5
4-10	5	10	30	7	7	21	43	14
11-25	2	4	42	9	1	3	12	4
26-50	1	2	33	7	1	3	40	13
51-100	1	2	95	21	0	0	0	0
> 100	1	2	231	51	1	3	200	64
TOTAL	51	100%	455	100%	33	99%[a]	311	100%

Source: NIJ-ACA questionnaire responses

[a] Due to rounding

Education and training

Because there is no vaccine or cure for the disease, education and training programs are the cornerstone of efforts to curb the spread of AIDS in prisons and jails, as well as in the population at large. Education and training programs also provide the opportunity to counteract misinformation, rumors, and fear concerning the disease. For example, the majority of systems responding to the questionnaire reported that inmates and staff worried about the possibility of contracting AIDS; many responses referred to fear of casual contact or types of contact not actually associated with transmission of the virus.

As a result, many correctional administrators feel strongly that education and training are not options but absolute requirements. Ninety-three percent of the responding jurisdictions currently offer or are developing AIDS educational programs for staff; 83 percent offer or are developing such programs for inmates.

Among respondents whose educational programs have operated for some time, the vast majority believe these programs to be effective in reducing the fears of staff and inmates. Several jurisdictions reported that timely educational efforts had successfully averted threatened job actions by correctional staff unions.

Experience suggests that training and education programs should be instituted before deep-seated fears have developed, and repeated periodically so that the latest medical information can be presented and new staff and inmates can be reached on a timely basis.

Effective education programs may include live presentations by training teams, printed materials, and videotapes. Program curricula and materials should be brief, clear, and straightforward and tailored to the particular knowledge gaps and concerns of the audience. They should discuss the means of transmission of the AIDS virus and emphasize everyone's responsibility to avoid behaviors known to be associated with transmission. They should also guard against encouraging a false sense of security in

any group. At the same time, programs should not create needless fear by advocating unnecessary precautionary measures.

HTLV-III antibody testing

There is substantial debate, both in corrections and in society at large, surrounding the uses of the HTLV-III antibody test and the meaning of the test results. The most controversial testing application in corrections is mass screening: the testing of all inmates or all new inmates, regardless of the presence of symptoms or other clinical indications.

Correctional policies on HTLV-III antibody testing. Only four State correctional systems (Nevada, Colorado, Iowa, and Missouri) have implemented or plan to implement mass screening programs for inmates; no city or county systems responding to the questionnaire have instituted or planned such programs. However, almost 90 percent of the responding jurisdictions do employ testing for more limited purposes. These include testing of risk-group members, testing in support of diagnoses of AIDS or ARC, testing in response to incidents in which the AIDS virus might have been transmitted, testing on inmate request, and testing carried out as part of anonymous epidemiological studies. Exhibit 3 summarizes study findings on correctional testing policies.

Mass screening: the debate. The debate over mass screening for antibody to HTLV-III in correctional institutions involves the following major questions:

- *Should correctional systems take steps not being taken in the community at large?*

Proponents of testing argue that rates of HTLV-III seropositivity are higher among inmates and that the virus is likely to be transmitted within institutions; they believe that screening is necessary to identify infectious individuals and to target prevention programs.

Opponents argue that there is no proof of higher rates of HTLV-III transmission in prison and therefore there is no legitimate reason to screen.

Exhibit 3

Summary of responding jurisdictions' HTLV-III antibody testing policies for inmates[a]

Policy category	State/Federal prison systems		City/county jail systems	
	n	%	n	%
• Mass screening (all or all new inmates)	4	8%	0	0%
• Screening of risk groups	2	4	7	21
• Testing *only* for diagnoses, incident response, or epidemiological studies	39	77	20	61
• Testing *only* on inmate request	1	2	1	3
• No testing	5	10	5	15
TOTAL	51	101%[b]	33	100%

[a]Includes actual and planned policies. This is a hierarchical categorization. That is, jurisdictions that do mass screening are placed in that category, regardless of whether they also do testing for other purposes; jurisdictions that do screening of all members of at least some risk groups, but no mass screening, are placed in the "screening of risk groups" category regardless of whether they also do testing for diagnosis, incident response, or epidemiology studies.

[b]Due to rounding.

- *What are the policy implications of identifying seropositive individuals?*

Proponents of screening argue that seropositive individuals must be identified so they can be given special supervision, counseling, and other programming.

Opponents argue that mass identification of seropositives would serve no purposes not better addressed by educational programs and would, in fact, create significant correctional management problems—particularly if large numbers of seropositives were identified and there was irresistible pressure to segregate them.

- *How would mass screening affect education and prevention programs?*

Proponents argue that screening is necessary to inform and target education and prevention programs.

Opponents argue that screening needlessly and misleadingly divides the inmate population into a stigmatized class and a "safe" class, thereby undermining the important educational message that everyone should be careful.

- *Is it possible to develop a reliable and confidential screening program?*

Proponents argue that the antibody test is reliable and that confidentiality of results can be maintained.

Opponents argue that the test results are often unreliable and that real and rumored results would inevitably become known to the inmate population and others outside the institution, potentially subjecting actual or supposed seropositives to threats and intimidation while in prison and to discrimination in housing, employment, and insurability after discharge.

- *What are the legal implications of screening?*

Proponents argue that mass screening is legal and proper and, in fact, that failure to conduct mass screening may result in serious legal liabilities.

Opponents point out that laws and policies requiring subjects' informed consent for HTLV-III antibody testing preclude mandatory mass screening and suggest that liability issues can be effectively managed.

- *What are the costs of mass screening?*

Proponents of screening argue that the test can be economically administered.

Opponents argue that when the costs of repeat and confirmatory tests and the costs of separate correctional programming for seropositives are included, the total price could become prohibitive, particularly for large systems and/or those likely to identify large numbers of seropositive inmates.

- *Will mass screening allay or inflame fears?*

Proponents argue that screening could help to calm the concerns of inmates and staff if it found low rates of seropositivity. Moreover, regardless of the seropositivity rates, failure to screen could cause serious public relations problems.

Opponents argue that mass screening will needlessly inflame fears, particularly if the seropositivity rate is found to be high.

- *Are there feasible alternatives to screening?*

Proponents argue that screening is the best method of obtaining the necessary information on HTLV-III seropositivity and transmission.

Opponents argue that there are better ways to identify high-risk individuals and diagnose AIDS and ARC that avoid the negative consequences of mass screening. These include astute medical surveillance and alternative laboratory work for diagnoses.

In addition, anonymous epidemiological studies may permit estimation of HTLV-III seropositivity and transmission rates while avoiding the correctional management and confidentiality problems of mass screening.

Implementation issues. Correctional administrators who decide to implement any mass or selective testing program face a range of issues, including when and where to administer the test, and whether testing should be voluntary, mandatory, or on request.

In 60 percent of the responding jurisdictions, all testing is either voluntary or on inmate request. In 15 percent of the jurisdictions, all testing is mandatory.

There are serious legal and ethical issues involving both whether inmates can be compelled to submit to testing and whether they have a right to testing on request. Laws in some jurisdictions (e.g., California and Wisconsin) prohibit HTLV-III antibody testing without the informed consent of the subject.

Those who oppose mandatory testing argue that, because of the potentially serious negative effects of testing (e.g., discrimination in housing, employment, insurability), medical ethics require that there be a right of refusal, regardless of law or policy.

Some also argue that correctional systems have an obligation to provide the test to any or all inmates who request it. However, if such testing is provided, many physicians believe that inmates should be fully and accurately informed of the potential personal and psychological effects of testing before they make any decisions and that those who are tested be counseled on the meaning and implications of the results.

Medical, legal, and correctional management issues

Correctional administrators responding to the challenging problem of AIDS in prisons and jails must balance medical considerations and medical advice against complex correctional management factors. Decisionmaking is further complicated by legal and cost concerns. The following section discusses these issues.

Medical issues. Perhaps the highest priority in the correctional response to AIDS is providing timely, professional, and compassionate medical care to inmates who become ill with the disease. As in society at large, prompt detection and diagnosis are needed to minimize spread of the disease and alleviate the suffering of patients.

Whether or not HTLV-III testing is used, appropriate diagnostic workups are necessary to identify immunosuppression, ARC, and AIDS. Also, certain tests may be able to detect early evidence of opportunistic infections typically seen in AIDS patients.

Careful surveillance and regular followup are extremely important for patients with AIDS, ARC, and HTLV-III seropositivity, since life-threatening symptoms can develop very quickly. Because AIDS patients experience serious psychological as well as physical problems, counseling and support systems involving correctional staff and family members are also considered important components of care.

Correctional management issues. Ironically, the medical treatment of AIDS patients may be the simplest issue confronting correctional administrators. Other questions—where to house and treat the inmate, how to prevent the spread of the disease, and how to pay for medical care—are likely to be even more difficult to resolve.

Housing policies. One of the most critical and difficult decisions for correctional administrators is where to house and treat inmates with AIDS, ARC, or HTLV-III seropositivity. Of course, medical considerations dictate many of these decisions. Most jurisdictions place inmates with confirmed diagnoses of AIDS in a medical facility either within the correctional system or in the community, although the duration of such hospitalization varies considerably.

Preventing the spread of AIDS within the prison and protecting affected inmates from intimidation and violence are important considerations. Other factors in treatment and housing decisions include availability and location of facilities able to provide appropriate care, costs of any new construction or renovations necessary to prepare special units, and staffing of any special AIDS units (correctional as well as medical).

Correctional administrators have a number of options concerning treatment and housing placements for inmates with AIDS, ARC, or HTLV-III seropositivity. The key options are the following:

1. maintaining inmates in the general population;

2. returning inmates to the general population when their illnesses are in remission;

3. administratively segregating inmates in a separate unit or relying on single-cell housing;

4. hospitalization; and

5. case-by-case determination of all housing and treatment decisions.

Exhibit 4 summarizes the housing policies of the responding systems. Two-thirds of the Federal and State systems, and 70 percent of responding city and county systems have written policies in place or in development for managing inmates with AIDS, ARC, and HTLV-III seropositivity.

Most jurisdictions hospitalize or administratively segregate at least some of the three AIDS-related inmate categories.

City and county jurisdictions are more likely to use segregation: 39 percent of responding city and county jail systems segregate all three AIDS-related inmate categories, as opposed to only 16 percent of State and Federal prison systems. Almost one-third of all responding systems have basic policies involving case-by-case determination of treatment and housing programs.

While Exhibit 4 indicates the wide variation in correctional policies on housing and treatment of inmates with AIDS, the four jurisdictions with almost 75 percent of the correctional AIDS cases (New York State, New York City, New Jersey, and Florida) all follow the same combination of policies:

1. medical segregation of AIDS patients, but no segregation of inmates with ARC or HTLV-III seropositivity;

2. careful evaluation and ongoing monitoring of inmates suspected of having ARC or AIDS;

3. no mass screening for antibody to HTLV-III; and

4. extensive staff and inmate educational programs.

All four of these systems report that equilibrium has been reached on the AIDS issue, with no widespread fear among staff or inmates regarding transmission of the virus within the institutions.

Precautionary measures. Correctional agencies have adopted a wide range of precautionary measures to control spread of AIDS within institutions; many are based on Centers for Disease Control guidelines for clinical staff.[1] The CDC guidelines advise clinical and laboratory staff "to use the same precautions when caring for patients with AIDS as those used for patients with hepatitis-B virus infection...Specifically, patient-care and laboratory personnel should take precautions to avoid direct contact of skin or mucous membranes with blood, blood products, excretions, secretions, and tissues of persons judged likely to have AIDS."

Several physicians interviewed for this study believe that, since the AIDS virus is less hardy and more difficult to transmit than the hepatitis-B virus, precautions designed to prevent transmission of hepatitis-B should more than suffice to prevent transmission of AIDS.

Some correctional agencies have instituted precautionary measures which go far beyond those recommended by CDC. Many of these measures are designed to limit exposure under extremely unusual circumstances or to prevent exposure through casual contact. However, all evidence indicates that AIDS cannot be transmitted by a single exposure of any kind or through casual contact. This is a major theme in most AIDS education programs.

Precautionary measures addressing very rare or casual modes of contact, even if implemented in a good faith effort to reduce the fears of staff and inmates, may ultimately increase those fears by encouraging the view that the disease is spread by the very sort of unusual or casual contacts they seek to prevent. Such a conflict between educational messages and practical measures may not only increase fear within the institution, but also may foster suspicion of the correctional

Exhibit 4

Summary of responding jurisdictions' housing policies[a] for inmates with AIDS, ARC, and HTLV-III seropositivity

Policy combination	State/Federal prison systems		City/county jail systems	
	n	%	n	%
• Segregate AIDS cases; ARC cases and seropositives maintained in general population	3	6%	3	9%
• Segregate AIDS and ARC cases; seropositives maintained in general population	10	20	3	9
• Segregate all categories	8	16	13	41
• No segregation of any categories	2	4	0	0
• No policy	8	16	1	3
• Combinations involving case-by-case determination	16	31	10	30
• Other policy combinations	4	8	3	9
TOTAL	51	101%[b]	33	101%[b]

[a]For the purposes of this categorization, segregation means that the *basic* policy is to hospitalize (either within or outside the correctional system) or to segregate administratively the particular category of inmate, regardless of whether these inmates are returned to the general population when their symptoms subside. Single-celling is also included in segregation.

[b]Due to rounding

[1]CDC, *Morbidity and Mortality Weekly Report* (*MMWR*) 1982, 31:577-580, see also *MMWR* 1985, 34:681-695.

system for, in effect, saying one thing about the transmission of AIDS but doing something else.

Notification and confidentiality. One of the most difficult and sensitive issues regarding AIDS in corrections is who receives information on the medical status of inmates with AIDS, ARC, or HTLV-III seropositivity. Decisions regarding who should receive HTLV-III antibody test results and who should be notified of AIDS or ARC diagnoses may be dictated by precise legal and policy standards such as requirements for written authorization to release test results or other medical records.

Two-thirds of State and Federal prison systems and 91 percent of responding city and county jail systems have general or specific confidentiality policies covering AIDS-related medical information.

Some argue that decisions regarding disclosure versus confidentiality of medical information in cases of AIDS or ARC should be based solely on legal requirements—that is, no information should be reported to anyone unless it is required by law. This position is based on the premise that correctional systems should bear no greater responsibility for notification than do institutions in the community at large.

Where law or policy allows any discretion, decisions regarding disclosure versus confidentiality invariably raise the question of which should take precedence: the inmate's right to have medical information kept confidential or the correctional system's perceived legal and moral responsibility to protect its staff and other inmates, as well as the public, from HTLV-III infection.

There are valid claims on both sides. On the one hand are arguments that correctional staff have a right to know when they are dealing with inmates who may be infectious or who have a serious communicable disease, and that other inmates, spouses, or sexual partners have a right to know who may be carrying a sexually transmitted disease. Notification to public health departments and inmates' former and/or subsequent correctional systems may also be considered important to facilitate treatment, prevention measures, and contact tracing. Such disclosures may also be designed to reduce or eliminate the correctional system's legal liability should a released or transferred inmate transmit AIDS to others.

On the other hand, the most compelling reason for maintaining confidentiality is that persons known to have AIDS, ARC, or HTLV-III seropositivity may suffer ostracism, threats, and possibly violent intimidation while in prison, and discrimination in employment, housing, and insurance availability after they are discharged.

Because of their rapid population turnover rates, jails face even more difficult policy decisions and logistical problems regarding disclosure and confidentiality of medical information.

The most notable study finding regarding disclosure is that a relatively small number of systems provide test results to inmates (31 percent of State and Federal systems and 52 percent of responding city and county systems). No State or Federal system and a small fraction of city-county systems (19 percent) disclose results to inmates *only*. Seventy percent of State and Federal systems and 61 percent of responding city and county systems provide results to medical staff.

No jurisdictions responding to the questionnaire specifically reported that spouses or sexual partners or previous correctional facilities of seropositive inmates are notified of test results.

Costs of care and associated services. Questionnaire responses showed that correctional systems are almost universally concerned about the costs of medical care and associated services for inmates with AIDS. Questions regarding range of costs elicited widely varying estimates, but all agreed that medical care for AIDS patients is extremely expensive, whether it is provided in a correctional medical facility, in another public medical facility, or in a hospital in the community, particularly because correctional inmates are ineligible for Medicaid reimbursement.

Correctional systems should plan on spending anywhere from $40,000 to over $600,000 for hospitalization and associated medical costs of caring for each inmate with AIDS.[2] The costs will vary depending on the amount of acute care required; they will also probably be higher if inmates are placed in hospitals in the community than if they are retained in correctional medical facilities or other public medical facilities.

To the figures for hospitalization and medical care must be added costs of ancillary services such as counseling, possible legal assistance, increased insurance (unless the system is self-insured), and funerals. Obviously, medical care and associated services for inmates with AIDS could have serious budgetary implications for correctional systems.

Legal issues. There is currently very little law specifically on correctional systems' policies regarding AIDS cases, though several cases have been filed in New York and other States. Otherwise, specific AIDS-related legal concerns remain largely hypothetical. Still, there is substantial caselaw on correctional medical care in general, which is important for administrators to consider in developing policies regarding AIDS.

Suits on the quality of correctional medical care[3] may be brought on the basis of Federal constitutional standards, State law, or common law. There are three constitutional principles relevant to correctional medical care.

First, under the eighth amendment, inmates are entitled to a safe, decent, and humane environment.[4] Second, in *Estelle v. Gamble*,[5] "deliberate indifference to serious medical need" was held to violate the eighth amendment protection against "cruel and unusual punishment." Finally, the constitutional guarantee of "equal protection of the laws" applies to correctional medical care cases, and particularly to

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[2]The low figure is from "Special Report: The AIDS Epidemic," *New England Journal of Medicine* 1985; 312:523; the high figure is based on 2 years at New York City's annual estimate of $300,000 for patients requiring acute care

[3]This discussion is based largely on the presentation of Clair Cripe, Esq., of the Federal Bureau of Prisons, at a meeting of Correctional Commissioners on AIDS, sponsored by the National Institute of Corrections, Atlanta, Georgia, November 6, 1985

[4]See, e.g., *Rhodes v. Chapman*, 452 U.S. 337 (1981)

[5]429 U.S. 97 (1976)

cases involving AIDS inmates, because of the segregation issues.

Medical care in correctional institutions is usually governed by the same State laws (e.g., medical practice and nursing practice acts) that apply to care in the community at large. Finally, in some States, correctional medical care may be subject to suits for common law torts such as negligence. Medical malpractice suits are also a possibility.

Existing caselaw on AIDS in correctional facilities falls into the following three major categories:

1. Equal protection. Cases filed by inmates alleging denial of equal protection based solely on the fact that they had AIDS (e.g., *Cordero v. Coughlin*).[6] This case was decided in favor of the correctional department.

2. Quality of care. Cases filed by inmates alleging inadequacies in medical care and associated services (e.g., *Storms v. Coughlin*).[7]

3. Failure to protect others from AIDS. Cases filed by inmates and potentially also by staff alleging inadequate protective measures and seeking additional steps such as mass screening of inmates and segregation of inmates with AIDS, ARC, or HTLV-III seropositivity (e.g., *Mtr La Rocca v. Dalsheim*).[8] The *La Rocca* case was decided in favor of the correctional department; other cases on these issues are still pending.

AIDS poses complex and difficult problems for correctional systems. The only certainty is that the problems will not disappear. Every correctional system should develop comprehensive policies and procedures for managing the AIDS problem in its institutions. The information provided here and in the full report can help correctional administrators consider the range of options available and the strengths and weaknesses of each.

Theodore M. Hammett was project director for Abt Associates, Inc., in the urgent 4-month study that led to this condensed report. To learn about availability of the full report, call the National Institute of Justice/NCJRS at 800–851–3420 and give the title and identifying number, NCJ 100126. (From Alaska, Maryland, and the Metropolitan Washington, D.C., area, call 301–251–5500.)

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[6] 607 F Supp 9 (S.D.N.Y., 1984)

[7] *Storms v. Coughlin* was filed in U.S. District Court for the Southern District of New York. Some of the issues may be mooted by new State regulations, but the plaintiff's attorney believes that there are a number of important quality-of-care issues to litigate. See also *Thagard v. County of Cook*, unreported opinion: No. 85 C 4429 (N.D. Ill., May 20, 1985).

[8] 120 Misc 2d 697 (N.Y. 1983). See also *Herring v. Keeney* (U.S.D.C., Oregon, filed September 17, 1985); *Sheppard v. Keeney* (U.S.D.C., Oregon, filed October 7, 1985); *Malport v. Keeney* (U.S.D.C., Oregon, filed October 11, 1985); *Telepo et al. v. Kean et al.* Civil Action 85-1742A (U.S.D.C., New Jersey, filed May 1985).

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